

# Public Perspectives on Health Delivery System Reforms

## Key Findings<sup>1</sup>

- 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.

Policy experts and the majority of the American public seem to agree that there are serious problems with the health care system and that some form of fundamental change may be needed to ensure access to affordable, high quality care.<sup>2</sup> Policy experts point to the advantages of a restructured health care system built on a foundation of structured, accountable care systems where providers can work closely with patients, directing them to the most appropriate and effective prevention, treatment, and care management options. There is an emerging consensus in the policy community about the central importance of “aligning incentives” so that providers, payers, the research community, and consumers are all focused on identifying and learning to use the most effective health care. What consumers have to say about this alignment, however, may determine what kinds of structural changes to the health care delivery system are politically feasible.

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.<sup>3</sup>

- **A foundation built on** comprehensive care for patients of all ages, with an emphasis on disease prevention, health promotion, and shared decision-making. This includes the concept of “medical homes” where primary care providers take responsibility for coordinating care across providers and settings. Medical homes would be pivotal for the systematic application of:
- **Evidence-based care, based on clinical care research** (including preventive services, diagnostic and clinical treatments, drugs, devices, therapeutics, and care management protocols) and by methods and systems for disseminating this knowledge to providers

and consumers and 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 asking about how the American public views reforms to increase coverage, or pay for increased coverage, the subject here is, at the broadest level: “What do we know about the kind of health care system Americans want,” or, in a negative formulation, “What changes to the health care system might the American public say are unacceptable?”

Gauging support for anything having to do with health care is at least as risky as other areas of opinion research. Public opinion polls, surveys, structured town hall meetings, focus groups, and internet polls have identified underlying support for greater emphasis on primary care and preventive services, health promotion programs, shared decision-making, health information systems and other components of proposed health care system reforms. There is also evidence of concern about the quality and trustworthiness of health care products and health providers, and about health care information sources; about how medical information will be used, including questions about privacy and confidentiality of personal medical records; about consumers' capacity and willingness to take on greater responsibility for making health care decisions; and about how changes in health care delivery could affect choice of providers and treatment options.



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Public opinion research is imprecise and subjective. Results are subject to biases due to questions asked, question order, and to sample design. Respondents may be unrepresentative or they may not adequately represent the views of particular populations who may have a greater stake in the outcomes of policy changes. Questions that are posed with little or no context may yield ambiguous or meaningless responses. For consumers or potential consumers of health care, there are very different domains of interest revolving around health care in the abstract or in the here and now, particularly for people with serious health problems. The context provided for participants in qualitative and quantitative research can generate diametrically different pictures of public response to various components of health reform proposals. Perhaps most important, things change. Information gathered at one point in time may no longer reflect public views just a few months later, especially when major changes in the economy or political environment entirely refocus the public's attention.<sup>4</sup>

The limitations of opinion research and other sorts of input do not, however, render this information useless. Over the past several years a variety of initiatives have employed qualitative and quantitative combinations of techniques to explore what people have to say about health care in greater depth than polls can provide. There are sound studies that provide insights into aspects of public views and preferences about health care and how it is delivered, and a growing body of literature examining how behavioral and economic theory interact in the domain of health care. Piecing together the wide range of seemingly inconsistent findings may yield more than the sum of the parts. Developing a fuller understanding of values, preferences, concerns, and misconceptions about health care should not, however, be approached as a purely intellectual exercise. Rather, it is critical for policymakers as they shape legislation and seek support for change from the public. Better understanding of values and preferences could help policymakers

avoid potential problems both in designing, describing, and marketing reform proposals. History suggests that reform proposals can be derailed when interests groups are able to leverage evidence of public opposition to or concern about some sensitive issue or aspect of the reforms.<sup>5</sup>

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

A recent effort to understand Americans' attitudes about health care initiated by the U.S. Congress provides a useful starting point for discussing public views about health care and proposed delivery system reforms. The Medicare Prescription Drug Improvement and Modernization Act of 2003 (The Medicare Modernization Act) created the Citizens' Health Care Working Group and called on it to "engage in an informed national public debate to make choices about the services they want covered, what health care coverage they want, and how they are willing to pay for coverage."<sup>6</sup>

The Working Group began its exploration of public views about health care beginning in the spring of 2005, and completed its work in late 2006. In addition to information and views collected in hearings, town meetings, internet polls, other print polls, and written comments collected over more than a year, the Working Group also reviewed findings from more than 100 public opinion polls and surveys, along with a wide range of research and journalistic materials. Based on the public input it reviewed, the Working Group developed recommendations that included creating new programs to promote community-based and patient-centered care and to advance evidence-based practice, along with a systematic approach to integrating comparative effectiveness findings in the design of core benefits in a comprehensive universal health care system. These Working Group sessions were, in some respects, a precursor to the community meetings about health care reform conducted throughout the United States by the Presidential Transition Team in December 2008.

On average, people participating in the Working Group polls and meetings<sup>7</sup> were more educated than the population as a whole, and, by definition, more motivated to engage in conversations about health reform (some sessions lasting four hours or more). However the 18 month effort provided a unique opportunity to look across a wide variety of inputs, including meetings, polls, and secondary review of existing poll data. The input across all these sources was remarkably consistent, and also consistent with published research literature addressing public perceptions of and values regarding health care. The richness of the materials also provides context for interpreting other public opinion data and research, including several comprehensive state-based efforts to obtain public perspectives, and other public opinion and research studies addressing the three general components of reform discussed here.<sup>8</sup>

*The Report on Health Care Community Discussions* issued by the U.S. Department of Health and Human Services in March 2009 that summarizes the findings from the community meetings held by the Transition Team provides additional context, and additional evidence of the consistency of public views about health care.<sup>9</sup>

Working Group meetings always began with detailed discussions about health benefits and the services people thought should be provided, and how they thought that health care should be delivered. Across all the community meetings, and in the four sets of polls, there was strong support for a clearly defined, comprehensive benefits package. People at the meetings were strongly supportive of preventive services and wellness programs, which many thought should be part of any basic benefit package. More than 90 percent of poll respondents said that annual physicals and preventive care should be included in "basic" or "essential" services covered by health insurance.<sup>10</sup> There was also 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. The

Transition Team meetings drew particular attention to the importance of preventive care in keeping with the emphasis in President Obama's health reform proposal presented during the election campaign. A lack of emphasis on prevention was the third most often selected of the "top" concerns listed in the participant survey, after costs of health insurance and costs of health care services, which were named the top concern of 31 percent and 24 percent of respondents, respectively. One in five (20 percent) of survey respondents picked prevention as the biggest problem in the health system, compared to 13 percent whose top concern was difficulty finding health insurance due to a preexisting condition, and 12 percent who indicated that quality of care was their top concern among those listed.<sup>11</sup>

In open-ended discussions, people often talked about the need for health care to be more secure, stable, transparent, and easy to navigate. Meeting participants at both the Working Group and the Transition Team meetings in fact raised, in various ways, all of the issues addressed by the Institute of Medicine's domain of "patient-centered care," expressing concerns that health care needs to be "respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."<sup>12</sup> Meeting participants also raised specific concerns about being able to choose and maintain a stable, lasting relationship with a primary care provider. The Transition Team reported frequent pleas for changes that place a central focus on patients' needs. As articulated by one group, "We want a system that encourages engagement between people and their primary care providers: that is patient-centered, which means meeting people where they are, as they are, and giving them the services that actually improve their health."<sup>13</sup>

In the Working Group polls, respondents were asked what was "most important to them and their families when it comes to getting health care." Addressed this

way, the importance of patient-centered care was secondary to cost. About 1 in 10 chose "being able to get information about the quality of health services in order to make informed decisions about care for my family and me," while 5 percent stated that "having health care providers who are respectful and communicate well" was most important. For another 23 percent, the ability to choose a personal physician (17 percent), a specialist (4 percent) or hospital (1 percent) was most important. For almost everyone else, issues related to cost were the most important concern. Close to half of all poll respondents said that keeping down costs of premiums or out-of-pocket costs for visits, drugs or other supplies was most important.

Working Group sessions also focused on how the underlying problems with health care in the United States drive health care costs. At most of the sessions, participants talked about how complicated administrative arrangements waste resources. Meeting participants set out specific concepts of system changes, ranging from the elimination of private insurance to greater use of information technologies to streamline health care. There was support for various approaches to promote greater personal responsibility. At some sessions, participants stressed the importance of making information available to people that could help them better manage their health problems. There was also a lot of discussion—but not consensus—about providing incentives to get people to adopt healthier lifestyles.

In the larger context of the discussions, however, there was a consensus that there is enough money being spent on health care already, so that the real problem is how to reorganize spending and improve system efficiency.<sup>14,15</sup> Views about the need for system reforms help to explain a seeming contradiction between willingness to pay more for comprehensive, universal health coverage and reticence about individuals paying more, or accepting limits, on the health care. The overriding message to the Working Group was concern, and

at times, anger, about the lack of coverage for many, increasingly inadequate coverage for others, and the threat to access posed by increasingly unaffordable premiums and out-of-pocket costs even among those with "good" health insurance. In almost every meeting, and in the Working Group polls, a majority of participants said they would be willing to pay more to ensure that everyone has access to high-quality health care. This finding was consistent with other opinion research before and since these sessions.<sup>16</sup> Similar values again emerged in the Transition Team meetings in late 2008. Analysis of the group meeting reports found a set of principles for reform revolving around the concepts of fairness, patient-centered and choice-oriented care, a need for simple and efficient care that is easier to navigate, and a need for care to be more comprehensive and less fragmented.<sup>17</sup>

At the same time, people providing input to the Working Group on what sort of trade-offs they were willing to make to ensure affordable, high-quality care were not convinced that they should be asked to trade off benefits or services for universal coverage. Rather, many believed that savings from streamlined administration, more efficient treatment, and less fraud and abuse, along with healthier life styles, would yield enough savings to pay for universal coverage. Asked about priorities for public spending to accomplish their stated goal of comprehensive coverage, participants focused on expanding coverage first, but there was also strong support for investing in public health programs to prevent disease and promote healthy life styles. Broadly, people expressed support for spending on programs generally related to access to care, ranging from programs to protect the public in the event of epidemics or disasters to safety net programs and guaranteeing that there are enough health care providers, especially in inner-city and rural areas, and for funding programs that eliminate problems in access to care or quality of care for minorities. Funding health information technologies and biotechnology research generally ranked relatively low compared to access-related priorities.<sup>18</sup>

Other data consistent with the Working Group and Transition Team community meetings findings include a project conducted in Arizona during the same time-frame as the Working Group (late 2005) that used a group process methodology employing structured day-long dialogue sessions of about 40 consumers each to explore virtually the same issues as the Working Group meetings.<sup>19</sup> Like many providing input to the Working Group, people participating in these dialogue sessions were primarily concerned about cost and access to care. Nevertheless, the dialogue about what health care should be and how it should be delivered echoed the same themes—the need for stable, fairly comprehensive coverage and emphatic support for promoting preventive care and efforts to promote better health behaviors. The Oregon Health Values Survey conducted in late 2004 to provide input for the Oregon Health Policy Commission also found that respondents assigned the highest priority to preventive services among all the types of services that should be included in health coverage.<sup>20</sup> Like the other projects seeking out what people want in health care, the Oregon initiative found that while people expressed support for patient-centered concepts, including involvement in decision-making and having a system that is easy to navigate, affordability trumped other considerations.<sup>21</sup>

### Medical Homes

Public opinion surveys and polls also have found support for the concepts underlying the emerging construct of “medical homes.” Most Americans have a regular place or provider that they might identify as a medical home.<sup>22</sup> The 2008 Commonwealth Survey of Public Views of the Health Care System found that 91 percent of American adults believe it is important or very important to have one place or one doctor responsible for a person’s primary care and for coordinating that care.<sup>23</sup> There was also 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. Survey respondents

indicated support for better coordination of care, and for new systems and technology to improve care coordination, efficiency, and quality, as discussed below.<sup>24</sup>

A Harris Interactive poll commissioned by the Patient-Centered Primary Care Collaborative in fall 2008 asked respondents to consider a specific model of primary care medical homes as one part of health care reform proposals being debated in the 2008 presidential election campaign. Poll participants were given the following description:

The health care reform plan would also include support for a new primary care model, the Patient-Centered Medical Home. With Patient-Centered Medical Homes, consumers would choose a personal physician to coordinate all of a patient’s health needs and provide an individualized program of preventive care. This new primary care model features whole-person care, same-day appointments, better access to electronic health records that support enhanced quality and safety measures, and email consultations to strengthen the relationship between the patient and doctor.

When asked “if this health care reform plan included support for the Patient-Centered Medical Home, how would that affect your support of this plan?” about half of respondents indicated they would be more likely to support either presidential candidate’s health reform proposal if the medical home model were included.<sup>25</sup>

Broad support for primary care in general, or specific concepts of medical homes does not, however, entirely square with other documented concerns about getting health care. As with other aspects of health care delivery, there is a divide between general perceptions and personal experience. A survey conducted in March 2009, for example, 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. For example, 17 percent said they had to redo a test or procedure because the doctor did not have the earlier test results, 10 percent had to come back because a health professional did not have their medical information, and 9 percent had tried unsuccessfully to get two of their doctors to talk to each other.<sup>26</sup> While these rates may be of great concern from a policy perspective, they are not nearly as salient to people on a day to day basis.

A similar issue of perceptions versus experience is perhaps even more clear when it comes to obtaining preventive care or participating in programs offering preventive screenings or in health promotion activities such as weight loss programs, smoking cessation, exercise, and so forth. The 2007 EBRI Health Confidence Survey found, for example, that “employees’ comfort with wellness programs decreases sharply as the programs become more managed.”<sup>27</sup> The EBRI survey found 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 tied employees’ participation in wellness programs to lower insurance premiums.<sup>28</sup> Data from the 2008 Deloitte Survey of Health Care Consumers show 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.<sup>29</sup> The Deloitte survey report also noted that there appears to be a wide gap between reported interest in getting assistance in maintaining a healthy lifestyle and actually participating in programs designed to provide this assistance.<sup>30</sup>

Public support for preventive services or health promotion reflects personal values and preferences regarding health behavior in general (although not necessarily their own).<sup>31</sup> But this support is also tied to a belief that better health behaviors can reduce health care costs, and therefore make health coverage more affordable. For example, a national survey conducted in 2005 found that 48 percent of respondents strongly agreed, and another 32 percent agreed with the statement, “A greater emphasis from insurance providers on regular medical check-ups and preventive services would decrease health care costs for everyone.”<sup>32</sup>

In many of the Working Group meetings, participants voiced the belief that a greater focus on prevention, wellness, and education will reduce total health care costs over time. In some (e.g. community meetings in Indianapolis, Baton Rouge, La., and Sacramento, Calif.), participants decided, after active discussions, that greater emphasis on prevention and/or wellness was the most important step that could be taken to reduce the costs of health care in America.<sup>33</sup> Among participants expressing views about prevention and wellness, there were people who believed, 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.

The community meetings and dialogues also provide some insight into the danger of overstating support for restructuring primary care. Although there appears to be strong 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 offering incentives to guide personal behaviors. While Working Group meeting participants almost always said that some people should pay more for health coverage than

others, support for using health behaviors as a criterion in setting premiums was limited. Between 20 and 30 percent of participants in several meetings thought costs should be linked to health behaviors, but in the majority of sessions, fewer than 20 percent supported that policy.<sup>34, 35</sup>

In the abstract, core concepts such as coordination, communication, and continuity resonate very well with the public. But for people attending the Arizona dialogues, and participants attending Working Group sessions around the country, there were lingering reservations. 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.

Public views of ongoing efforts to improve the coordination, quality, and effectiveness of health care may offer some notes of caution for policymakers. In the Working Group polls (posted in 2006), about 1 in 5 respondents said that being able to pick their own personal physician (17 percent), specialist (4 percent), or hospital (1 percent) would be the single most important factor to them and their families if they were to have an opportunity to choose health care coverage.<sup>36</sup> More than one in three people responding to the Working Group’s Internet poll said they would be willing to pay a higher deductible in exchange for more choice of providers and services.<sup>37</sup> A survey conducted in October 2008 sponsored by the Partnership to Fight Chronic Disease found that people were most worried about coverage and cost issues, but about 1 in 10 respondents identified choice of doctors as their greatest or second most important worry.<sup>38</sup>

Medical homes are intended to foster strong relationships between primary care doctors and patients. This model gives primary doctors the lead role in guiding patients

to appropriate specialty care providers.<sup>39</sup> Systems that organize access to specialty care or diagnostic tests could look to some like “gatekeeping” (discussed below). 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). The 2008 EBRI Health Confidence Survey found that more than one-third of respondents were either “not too confident” or “not at all confident” about being able to have enough choice about who provides their medical care during the next 10 years.<sup>40</sup> But polls conducted in 2004 and 2006 found that support for universal health care reforms also could be undercut by limits on choice of doctors. While 62 percent of adults polled in 2004 said they supported a universal system (run by the government, supported by taxes, modeled on Medicare), 35 percent supported such reform if it meant limited choice of doctors.<sup>41</sup> A similar poll fielded in 2006 found that 56 percent would support universal health insurance, declining to 28 percent if it meant limited choice of doctors.<sup>42</sup>

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>43</sup> But when asked to consider provider choice in particular, most people think choice is still important. The 2008 Health Confidence 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” extremely important, 35 percent said it was very important, and another 11 percent said it

was important. In comparison, 63 percent said making health care more affordable was extremely important, 27 percent said it was very important, and 7 percent said it was important.<sup>44</sup>

### Effective, Evidence-Based Care

A variety of surveys and polls have shown that people are aware of, and concerned about, the effectiveness of medical care. A 2007 Harris Interactive/*Wall Street Journal* poll, for example, found that 83 percent of respondents said that, based on what they know or had heard, they were sometimes or often concerned about people being over-treated, and concerned about getting too many treatments or treatments that were more aggressive than was appropriate. Fifty percent were concerned that they personally had received too many treatments or overly aggressive treatment.<sup>45</sup> Other polls have also shown that between one-quarter and one-third of adults in the United States are concerned about unnecessary, inappropriate, or duplicative tests or treatments.<sup>46</sup> More than one-third of the Transition Team community discussions about quality of care surfaced concerns about the overuse of medical services, and 20 percent raised concerns about medical errors.<sup>47</sup>

The public is also generally supportive of medical and health-related research.<sup>48</sup> A 2005 survey sponsored by an alliance of health industry stakeholders, for example, reported that most Americans (70 percent) believed that “the health care services they receive are based on the best and most recent research available,” and 95 percent believed that they should be so. That survey also found general support for greater investment in research, with 70 percent saying it was very important, and another 26 percent saying it was important to invest in more research “to assure that there is a solid scientific base for health care.”<sup>49</sup>

Four separate polls fielded by or for the Working Group also showed some, but measured, support for greater use of effectiveness research in guiding health

policy. While participants were uncomfortable with limiting coverage of services overall, they expressed some support for limitations of coverage to services “with proven medical effectiveness.” Half of the Working Group’s Internet poll respondents either agreed (36 percent) or strongly agreed (14 percent) that health plans or insurers “should not pay for high-cost medical technologies or treatments that have not been proven to be safe and medically effective.” On the other hand, almost a quarter of all poll respondents disagreed (17 percent) or disagreed strongly (6 percent) with health plans/insurers not paying for unproven treatments. Close to one-third disagreed (21 percent) or strongly disagreed (11 percent) with insurers not paying for treatments or technologies—even if proven safe or effective—if less expensive but equally safe and effective alternatives are available.<sup>50</sup> A set of poll responses submitted by members of the Communication Workers of America showed somewhat lower levels of support for evidence-based restrictions on coverage than Working Group responses as a whole. Only 30 percent of the union members said they agreed or strongly agreed that plans should not pay for unproven technologies or treatments, while more than 40 percent said they were “neutral” on the subject.<sup>51</sup> There are a number of plausible explanations, but one that is consistent with the discussions in many of the community meetings would be that people who have relatively good employment-based health insurance may be more apprehensive about possible limits on coverage.

Similar evidence of support for the idea of coverage decisions being based on treatment effectiveness also appears in subsequent surveys. In a 2006 national survey respondents were asked “If a doctor recommends an expensive new drug or medical treatment, do you think insurance companies should pay for it only if it’s been proven to be more effective than other, less expensive treatments, or pay for it even if it has not been proven more effective than other, less expensive treatments.” A majority, 62 percent, said that the insurer should only pay for it if it’s

been proven to more effective, and 34 percent said the insurer should pay for it even if it has not been proven more effective.

<sup>52</sup> A similar question, focusing on prescription drugs, was included in a 2008 survey. Asked, “If a doctor recommends an expensive new drug, do you think insurance companies should always pay for it, or should they only pay for the new drug if it has been proven more effective than existing treatments,” 58 percent of respondents said that insurance companies should pay only after the drug was proven effective, while 38 percent said they should pay for it. 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>53</sup>

Other data show limited support for expanding comparative effectiveness research. A 2006 survey showed that around 60 percent of the population supported the establishment of an agency for comparative effectiveness.<sup>54</sup> However, the poll did not give detailed information about whether people would support effectiveness research if it limited their treatment options or affected the costs of treatment alternatives. Further, the program described in the survey would review only *new* technologies and drugs to compare them to available alternatives; the survey does not ask about broader application of comparative effectiveness research to the full range of existing drugs and technologies.<sup>55</sup> In December 2008, a revised question addressed the same topic more broadly. When asked about support for the creation of a new, independent federal scientific body to “decide whether approved new medical technologies 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 that “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>56</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>57</sup>

Tying effectiveness to consumer costs could raise similar concerns. “Value-based” systems provide financial incentives—lower premiums or coinsurance—to use more effective services, or enroll in health plans that are found to provide more effective care, based on “evidence-based” criteria that payers and providers agree upon. There are not many of these programs currently, and there is a great deal of variation among those that are in place.<sup>58</sup> National surveys cannot provide direct evidence regarding public views about satisfaction or experiences with these programs.<sup>59</sup> Available evidence regarding willingness to trade off cost versus access to particular medical treatment options provides only a limited perspective on values and preferences. A national poll conducted in 2007 asked respondents a set of questions about health care priorities. Respondents were asked to think about health care reform and specifically their own situation, then to pick which was the most important to them from a list. The responses suggest that some concept of “best medical treatment” is highly valued. Having coverage was picked most often (29 percent); “Having access to the best medical treatment” was next (24 percent). Improving quality and reducing

medical errors ranked third (17 percent), followed by lowering cost (14 percent), then maintaining choices (12 percent). A series of tradeoff questions then allowed respondents to indicate their preferences by choosing between two statements trading preferences. Significantly more 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 important 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>60</sup>

It is not obvious, 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. The 2006 Health Care in America Survey suggests that in the public’s view, “better” medical care is multidimensional, 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.<sup>61</sup> Most respondents (76 percent) rejected the notion that more expensive doctors provide better medical care. Just under half (47 percent) said they believe that expensive new drugs, treatments, and medical technology produce better results than older, less expensive alternatives, 43 percent did not believe this, and 10 percent said they did not know if they believed it.<sup>62</sup>

Other evidence suggests that “best” is not primarily an issue of clinical effectiveness. Some possible insights can be drawn from a series of *Wall Street Journal*/Harris Interactive surveys that asked whether people believe there are fair and reliable ways to assess care provided by medical groups. The surveys have found that respondents are generally favorable toward a variety of assessments such as data on patient satisfaction, providing recommended preventive services, indicators of appropriate management of chronic disease, and assessments by medical accrediting and professional boards. The

percent of people saying these methods of assessing quality are fair has also increased somewhat over time.<sup>63</sup> The assessment method or measure rated “fair” most frequently in the 2008 survey is patient satisfaction surveys (rated fair by 76 percent of respondents); the frequency of preventive screening tests is deemed fair by 69 percent, and medical tests that measure how well doctors are managing patients with chronic conditions by 68 percent.<sup>64</sup>

Support for “pay for performance” based on quality assessment, however, is limited in this same survey. Only 38 percent favored health insurance plans paying more to hospitals and medical groups which have been shown to provide better care and less to those that have not (the comparable figure in the 2006 survey was 33 percent). The 2006 version of this survey also asked respondents if they would be willing to pay more for insurance that covered them to go to hospitals and medical groups that have been shown to provide “superior medical care” based on the set of measures described in the survey. While the majority thought the measures were fair, only 14 percent said they would be willing to pay significantly more to be able to go to hospitals or medical groups deemed superior on a composite measure.<sup>65, 66</sup>

Data from surveys conducted earlier in this decade suggest that the public perceptions of “best treatment” may be as closely tied to choice (and coverage) of treatments as they are to assessments of quality based on measures accepted by the health care community. As noted above, there is some evidence that being able to get specialty care is very important to some people. Forty-two percent of respondents to a 2005 Harris Interactive poll said they would be very willing or somewhat willing to pay the full cost of a doctor’s visit (when the visit would not be covered by their insurance) in order to get specialized treatment or service from the doctor.<sup>67</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.<sup>68</sup>

Out-of-pocket cost, however, can focus public attention on treatment options. The 2008 EBRI Health Confidence Survey found that, among people who reported increased health costs in the past year, 63 percent said costs led them to talk to the doctor carefully about treatment options and costs.<sup>69</sup> The survey also found that more than half of all respondents reported that they often or always asked doctors about why tests were needed (74 percent), the risks of treatments or side effects of medications (66 percent), and about the success rates of treatment options (51 percent); just over a third (36 percent) reported asking about less costly treatment options or medication when visiting a doctor.<sup>70</sup>

While this does not necessarily indicate a growing appreciation of evidence-based medical decision-making, it does indicate that some consumers are focusing on the concepts underlying comparative effectiveness research.

### Health Information Technology

The concept of applying health information technology to increase health care efficiency and quality, like the concepts of evidence-based, well-coordinated, patient-based health care, scores highly in public opinion polls. But the gap between general views and particular concerns about health information is, again, worth considering.<sup>71</sup>

In the abstract, electronic health records and the use of information technology in doctors' offices have public support. The Democracy Corps poll cited earlier found that 16 percent of likely voters said they would be much more likely, and 33 percent somewhat more likely to vote for a candidate for Congress who advocated adopting electronic medical records to improve efficiency and cut costs.<sup>72</sup> The Commonwealth Fund 2008 survey found that almost 9 in 10 adults thought that it

is important, or very 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.<sup>73, 74</sup>

A national survey sponsored by the Markle Foundation in 2008 found that 79 percent of the public believe that using online patient health records would provide major benefits to individuals by helping them manage health care and health services. This survey focused on internet-based personal health records that could be used in a variety of ways. More than 8 in 10 thought that electronic records could improve individuals' and their families' ability to check for mistakes in their health records, track health-related expenses, avoid duplicate tests or procedures, keep doctors informed of their health status, move from doctor to doctor, manage the health of family members, or get treatments tailored to the user's health status.<sup>75</sup> But while people indicate general support for online electronic medical records, the majority of those surveyed said they were not interested in joining a free online personal health patient health record system. The most common reason was concern about privacy and confidentiality—an issue that also threatens support for practitioner/office-based electronic medical records systems.

EBRI surveys have consistently found that Americans have a generally favorable view of centrally-maintained electronic medical records systems that can be shared among providers, but that they also worry about the confidentiality of these systems. Although levels of confidence in the confidentiality of electronic medical records have increased somewhat since 2005, the 2008 Health Confidence survey found that 62 percent said they were not confident that the records would remain confidential.<sup>76</sup>

The Harris Interactive organization and *Wall Street Journal* conducted several different surveys that included questions about electronic medical records in 2005 and 2006. For example, a 2005 *Wall Street*

*Journal*/Harris Interactive survey reported that “while the majorities of online adults believe that electronic medical records have the potential to improve quality and cost-effectiveness of health care, an equally large percentage is concerned about potential privacy issues associated with the use of these records.” The survey also found that many express interest in communicating with physicians online, but they are unlikely to support paying for that service.<sup>77</sup>

In the 2007 *Wall Street Journal* poll administered by Harris Interactive, the focus was on the public's level of confidence that their physicians and other health care providers have a complete and accurate picture of their medical history, and how electronic information systems could address gaps in information. In that online poll, 60 percent of respondents believed that benefits outweighed the privacy risks of electronic medical records. The survey also found that 63 percent agreed or strongly agreed that electronic medical records can significantly reduce the frequency of medical errors, and 55 percent agreed or strongly agreed that the use of electronic medical records can significantly reduce health care costs. The percent agreeing that electronic medical records can reduce errors increased from a survey administered in 2006, but declined for the question about reducing costs (62 percent in 2006 compared to 55 percent in 2007). The percent agreeing (strongly or somewhat) that electronic medical records make it more difficult to ensure patients' privacy decreased from 61 percent in 2006 to 51 percent in 2007.<sup>78</sup>

Variations in responses in public opinion polls that address electronic medical records may point to the importance of both context and wording of the questions. For example, several of the Harris Interactive online surveys were conducted with input from a leading national expert on privacy issues, Dr. Alan Westin. In the 2006 survey developed with Dr. Westin, there was a series of questions addressing how people would want to be involved in a transition to an electronic records



system, what they would be able to do with these systems, and possible benefits and risks, including a set of questions explaining privacy law and regulation. Respondents were asked the following:

Supporters of the new patient electronic record system say that strong privacy and data security regulation will be applied. Critics worry that these will not be applied or will not be sufficient. Overall, do you feel that the expected benefits to patients and society of this patient electronic medical record system outweigh potential risks to privacy, or do you feel that the privacy risks outweigh the expected benefits?

The plurality, 42 percent, thought that privacy risks outweigh expected benefits, 29 percent that expected benefits outweigh potential risks, and 29 percent were not sure.<sup>79</sup>

Concern about how the public might respond to efforts to promote electronic medical records led the Institute of Medicine to ask Dr. Westin to design a survey to examine public views on privacy and health research. The survey was part of a larger project that included a review and analysis of previously published national surveys conducted since 1993. Like the previous survey conducted with Harris Interactive, the 2007 IOM survey found that the public had serious concerns about the security and confidentiality of personal health information in electronic records systems. More than half (58 percent) of survey respondents agreed with the statement, “The privacy of personal medical records and health information is not protected today by federal and state laws and organizational practices.”<sup>80</sup> In a presentation to the IOM in early 2008, Dr. Westin concluded that public concerns about health information privacy and security pose a “make-or-break” issue for the transition to an information-based, restructured health care system.<sup>81</sup> In an editorial piece discussing this survey and other public opinion data on electronic medical records, Humphrey Taylor, Chairman of the Harris Poll, emphasized, however, that because electronic medical records are not yet common, public opinion polls are not measuring what people

think about electronic health information systems *per se*. Rather, the surveys are picking up “public reactions to ideas and benefits they that never previously thought about, but which they view in the light of their general concerns about protection of the confidentiality and privacy of their sensitive medical information.”<sup>82</sup>

Lingering fears about confidentiality surfaced again in a 2008 Harris Interactive Survey, where, among respondents who had heard about medical records being lost or stolen, seven percent believed that they or a family member may have had their personal medical records lost or stolen. Respondents also believed that computerized medical records were far more likely to be stolen than paper records. While the poll may not provide an accurate estimate of the incidence of breaches of medical information, it does suggest that a lot of people believe that there are some potentially serious risks as well as benefits associated with electronic medical records.<sup>83</sup>

Concerns about electronic health information were evident yet again in a 2009 survey that 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 in this survey believed that the electronic systems would lead to reduced health costs. More than a third thought electronic health information would result in higher costs of care for their families and for the country.<sup>84</sup>

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

Although there is generalized support for proposed health care system reforms in public opinion data, there are also some reservations that cut across the different dimensions of proposed system reforms. The ways that messages about health care are conveyed to the public obviously affect perceptions. But, 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.<sup>85</sup> Both reflect people’s experiences as well as concerns about the future. Although Americans report barriers to care, problems with communication, lack of 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<sup>86</sup>, and worry about losing it. People want to know how reforms will affect them now as well as in the future.<sup>87</sup>

Context is critical in interpreting public opinion data regarding health plans in particular. 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 shared decision-making and care management. Growing concern about health care costs and access to care may also have increased the public’s willingness to look beyond concerns about care management. As costs or the threat of losing coverage altogether increase, people may be more willing to accept limits on provider choice. Data from the Community Tracking Survey show that among adults (age 18-64) with employer-sponsored health coverage, those saying they would be willing to accept a limited choice of physicians and hospitals to save money on out-of-pocket health costs increased from 51 to 59 percent from 2001 to 2003.<sup>88</sup>

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, at least in the initial polls. But unsatisfactory answers to consumers about their concerns could tarnish pro-

posed reforms even if there is general support for changing the health care system. In addressing these concerns, the policy community can turn to a variety of work examining how people have responded to previous efforts to restructure health care. This includes both direct evidence and work addressing centrally important concepts such as “trust” and “choice” that shape public perceptions of health care.

### Some Lessons From The Recent Past

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. Consistent with opinion data cited in the previous section, 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. A study of patients enrolled in a range of managed care plans in California conducted in the late 1990s found that most preferred to seek initial contact from primary care doctors for a set of medical problems, but about one in four also indicated that they thought that their primary care physician interfered with their ability to see specialists. Views about barriers to specialty care were highly correlated with actual experience getting referrals. The authors concluded, moreover, that the emphasis on specialty care that has shaped Americans’ health care values and preferences could undermine system reforms. “The challenge in the United States,” they suggested “is to create practice arrangements that promote a first-contact and coordinating role for primary care physicians without simultaneously casting primary care physicians in the role of rationer of specialty care.”<sup>89</sup>

An analysis of managed care backlash by Robert Blendon, Sc.D., and colleagues drew on a review of 20 national public

opinion data sets from 1995 and 1997, as well as a survey designed specially to explore views about the managed care field in late 1997. Consistent with other research, this analysis found that people were generally happy with their own health care, regardless of whether it was managed care or traditional coverage. There were also widespread concerns about managed care. Much of this concern centered on aspects of managed care that could limit access to or payment for care. More than half of the respondents to the 1997 survey (59 percent) thought managed care plans made it harder for people who are sick to see specialists, 51 percent said that managed care had decreased quality of care for people who are sick, and 55 percent of people enrolled in managed care said they were at least somewhat worried that if they were sick, their health plan would be more worried about saving money than about the best medical treatment. In their analysis of the survey results and previous survey findings, Blendon et al. suggested that two major factors might be driving public backlash against managed care. The first was a relatively high level of dissatisfaction based on actual experiences with managed care, including access to specialists, tests, and waiting times. Related to this was a fear, based on reports of rather rare but very serious problems, that people were not adequately protected from this sort of thing happening to them.<sup>90</sup>

Dramatic examples of people suffering very bad outcomes associated with managed care practices described by Blendon 10 years ago<sup>91</sup> may also remain in play. Even one major news story, such as a \$120 million judgment in 1999 against a health plan that denied coverage for certain aspects of treatment recommended for a cancer patient (who subsequently died), appeared to galvanize what a *Los Angeles Times* reporter labeled “public outrage against HMOs.”<sup>92</sup> 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>93</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>94</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. For policymakers, the goal is to help health providers and insurers decide on the best treatment, and align insurance and payment incentives accordingly. Decisions that reflect the best available evidence will deny payment for some treatment options.<sup>95</sup> A letter to the editor in *The New York Times* article reacting to provisions of both the Obama and McCain health care proposals that called for accelerated programs of comparative effectiveness research illustrates a view that the available evidence suggests may be common:

Apparently economists and both Senators Barack Obama and John McCain think that there are too many unnecessary expenses in our health care system. My question is, “Unnecessary” according to whom? A bean counter at some insurance company? An unapproachable government bureaucrat?

I’m sure that there are many high-cost and low-success-rate procedures that are statistically unnecessary, but if one of those procedures represents the only chance of survival for a friend or relative, it will seem very necessary to me.

There is no question that we spend a lot of money on health care in this country. Let’s not rule out the possibility that we are getting our money’s worth.<sup>96</sup>

Research on managed care 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<sup>97</sup> is associated with lower satisfaction with health care, including levels of trust in health providers.<sup>98</sup> 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.<sup>99</sup>

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<sup>100</sup>—have greater concerns about access to providers and the specialized treatment they need than healthier people.<sup>101</sup> 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. The National Working Group on Evidence-based Health Care, a consortium of patient and disease advocacy organizations convened by Mental Health America, 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>102</sup> Soon after the passage of the economic stimulus package in early 2009, which included substantial funding for comparative effectiveness research,<sup>103</sup> the Partnership to Improve Patient Care (formed in November 2008) announced plans to “amplify the voice of the partnership’s

diverse members, including 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>104</sup>

There is also evidence that not everyone wants the same choices, or wants to make a lot of choices at all when it comes to making decisions about the actual process of health care. Researchers investigating data from the 2002 General Social Survey found that there were great variations in preferences for participation in medical decision-making. Women were more likely than men to prefer a “patient-directed” approach<sup>105</sup> people who reported being in generally excellent health reported a preference for being more involved in seeking information to help direct their own health care, as did people with more education. Older patients (independent of health status) were more likely to state a preference for physician-directed care.<sup>106</sup>

Differences in experiences with health care could influence how people feel about potential changes to the way health care is delivered. The 2002 General Social Survey found that African-American and Hispanic respondents<sup>107</sup> were more likely to prefer that doctors decide about treatment than white respondents.<sup>108</sup> Data compiled for the National Healthcare Disparities Report, however, show that minorities are somewhat less satisfied with their interactions with health care providers.<sup>109,110</sup> Using data from the Medical Expenditure Panel Survey, the report presents scores on a composite measure that combines information on patient-provider communication reflecting whether providers listen carefully, respect what patients have to say, and spend enough time with patients. The 2004 data show a small but significant gap between black and white respondents, with 11.3 percent of blacks reporting poor communication, compared to 9.0 percent of whites, and higher for Hispanics than for non-Hispanic whites (12.2 percent compared to 8.7 percent).

Public opinion provides a somewhat different perspective on values and perceptions about health care than national panel surveys. In particular, available opinion data show that while minority populations are more likely to express concerns about general problems with access and quality of care, they too are generally happy with their own health care providers and the care they receive from them. Although it was conducted almost a decade ago, the Kaiser Family Foundation’s 1999 survey on this topic illustrates some important aspects of public perspectives. Whereas the survey found significant differences in perceptions of discrimination and disparate treatment of minorities among white, African American, and Latino respondents, respondents’ ratings of care actually received (including tests, treatments, and communication) were generally similar. Asked to assign an overall letter grade to their regular doctor or provider, 47 percent of white respondents, 48 percent of African Americans and 43 percent of Latinos awarded A’s (for “Excellent”); only 2 percent of each group gave their provider a D or F. On the issue of communication, one question was “Did the doctor or provider explain things in a way you could understand?” Among Respondents, 92 percent of white, 91 percent of African American, and 88 percent of Latino respondents said “yes.”<sup>111</sup> But when asked about their last visit to a doctor or health provider, white respondents were less likely to report that there were any tests or treatments that they felt they needed but did not get (11 percent), compared to 16 percent for African American, and 19 percent for Latino respondents.<sup>112</sup>

Differences in perceptions regarding access to appropriate treatment could be related to distinct differences in trust of health care providers and other groups involved in health care. The 1999 Kaiser survey data showed that about two-thirds of white respondents said they trusted doctors and other health care providers most (51 percent) or almost all (16 percent) of the time. The figure was just about half among African Americans (37 percent most of

the time and 17 percent almost all of the time) and Latinos (34 percent most, and 16 percent almost all of the time). African Americans and Latinos were, on the other hand, more likely to say they trusted Medicaid or Medicare to do what is best for patients than white respondents.<sup>113</sup> If these differences are still reflective of public perceptions, responses to health reform proposals that affect how providers interact with patients might be expected to vary across racial and ethnic lines.

### The Role Of Research In Advancing Reform

Several areas of research might help identify both potential pitfalls and possible directions for reform of the health care delivery system.

One category of potential work to support reform is relatively short-term, focused, work drawing on social marketing expertise. New research could provide very important insights on what people are most concerned about or perceive as risks associated with changes in how care is organized or delivered. The goal, however, could be to better understand how, based on these perceptions and concerns, to craft language or illustrations, or devise broader education strategies, that can either address these concerns or, at minimum, provide a basis for designing formats for informed, dispassionate public discussion.

This could involve qualitative research (e.g. focus groups) on values, preferences, and level of understanding of health care, as well as targeted surveys to anchor the focus group findings with representative, generalizable data. It could also include a new application of interactive game-based exercises, where people sort through evidence, options, etc. and tell researchers how their health care should be structured. The research could fill important gaps in understanding of consumer values and preferences related to coverage, treatment options, and choice of providers.

The upfront work required to build interactive exercises could also advance our understanding of how to present information about care integration, and use of comparative effectiveness research, etc. to consumer audiences, and gain insight into how individuals might view restructuring of care systems when presented with clear, unbiased information.

This type of methodology could be applied in different types of activities, e.g. having people design health care for the future in the abstract, based on medical or other needs, preferences, scientific evidence, or other criteria, while balancing competing goals (access, convenience, cost, etc.), or having people design the health care they want for themselves and their families, balancing access to particular types of providers and services with potentially limiting factors, including restrictions related to medical evidence or value or efficiency.

A second line of research could draw on an array of recent literature in behavioral economics and psychology as well as health services research. Economists and psychologists have focused the research communities' attention on limitations, or adverse consequences, of some aspects of consumer choices related to health insurance and health care.<sup>114</sup>

In principle, reforms focused on better care coordination and evidence-based practice could define better choice sets. Additional research could explore whether different reform models can reduce frustrations associated with choice, or help people make better health care decisions. The concept of managed consumerism, for example, is drawn from lessons learned from managed care backlash as well as from problems associated with market-based approaches. While managed care encountered resistance associated with constraints on "choice," consumer/market approaches emphasize choice and self management, but do not adequately protect more vulnerable populations.<sup>115</sup>

Additional work could lay out how managed consumerism, or other models of care that integrate choice, financial incentives, and quality oversight would—from the perspective of consumers—work in, or be models for, a reformed "high-performing" system.

Research on how different populations may deal with reforms emphasizing shared decision-making and health care self-management could also be useful for planning and evaluating system reforms over the longer term. For example, research has examined frustrations that Medicare beneficiaries face when trying to sort through choices among health plans, supplemental insurance coverage, and prescription drug plans options.<sup>116</sup> Research on insurance choices highlights the extent to which making choices based on complex technical information can be particularly problematic for elderly or disabled people. Choosing a plan can involve finding, if it exists, and analyzing, if the information is relevant and complete, complicated information on benefit design, out-of-pocket costs, formularies, etc. Problems sorting through treatment options may be even more difficult to the extent that these decisions often need to be made when people are experiencing health problems.

Understanding consumer perspectives on the use of comparative effectiveness research in other countries, including Canada, Australia, the United Kingdom, and the Netherlands, could also be instructive. For example, political scientists have applied the concept of agency theory in research on public views about the legitimacy of different approaches to national health reforms.<sup>117</sup> New work might explore the extent to which people accept or at least acquiesce to evidence-based limits on coverage administered by, for example, health plans versus public insurance systems. This work might also examine the factors that could increase the acceptability of agency in health care, e.g. if people are comfortable with structured choices if they believe the system will allow them flexibility when they need it, that the process for making choices is understand-

able and less anxiety-inducing than before, and they trust the criteria that are used to structure their choices. This research could also explore how Americans' limited trust in institutions, including insurers, government, and "science" in general affects views about health care.

## Conclusion

When it comes to health care, perhaps even more than many other areas of public policy, concerns about change are personal. 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.

What differences in preferences about interacting with health care providers might mean in terms of public reaction to proposals to restructure health care is not obvious. 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. 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?

Reforming health care ultimately comes down to the issue of trust. Many experts believe that 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?

Predicting how public opinion might affect the direction of health reform efforts, or possibly undermine major legislative reforms, is probably not sound practice. Evidence works somewhat differently in opinion research than in some other areas of social science research.

First, salient information is generated and disseminated very quickly. Second, a preponderance of evidence is not necessarily the deciding factor. Isolated incidents, whether true or not, can take on great importance. Third, more than one interpretation of public opinion data can be (at least in part) correct. Data can be, and often are, taken out of context to support a point.

The vagaries of public opinion pose difficult challenges to health service researchers who are committed to generating information and methods that can help policymakers fix the problems undermining health care in the United States. If history is a guide, the debate about health care reform will include many public discussions which begin with an "expert" declaring the "The American people do/do not want a health care system that... [fill in the blank]." Such pronouncements, if incorrect or biased, undermine the legitimacy of the field.

A more subtle threat comes from the misuse of research findings to influence public opinion. Polls consist of short responses to simplified statements about complicated issues. Policymakers want to explain changes in ways that will resonate with the public's values and preferences. There is a risk, however, that establishing support for reforms that the research community believes are crucial may lead to biased polling, just as biased polling has been used to feed opposition to reforms. The public may support reforms based on values and beliefs that are supported by sound research—health promotion and disease prevention have real benefits, care coordination and shared decision-making have benefits, health care can be delivered far more effectively. But support in polls does not mean that the public has the information it would need to make good choices about policy. If people believe that prevention and better health behaviors, comparative effectiveness research, and health information technology are great ideas because they will reduce health care costs sufficiently to pay for comprehensive universal coverage without any need for increased revenues, there is a problem. Research is not being used fairly—some of what research has determined, based on evidence, is being used to support reforms, while other research findings are being set aside, intentionally or not. To have a truly balanced debate about structural reforms, the public needs to know what the research community knows. If the goal is to have an evidence-based health care system, people need to understand and respect research on health care.

## Endnotes

- 1 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.
- 2 In a Gallup survey conducted in November 2008, 14 percent of respondents agreed that the U.S. health care system is in a state of crisis, 59 percent that it has major problems. Saad, L. “Americans Rate National and Personal Healthcare Differently.” Gallup, Inc., December 4, 2008. Also see [www.gallup.com/poll/112813/Americans-Rate-National-Personal-Healthcare-Differently.aspx?version=print](http://www.gallup.com/poll/112813/Americans-Rate-National-Personal-Healthcare-Differently.aspx?version=print). A *Washington Post*–*ABC News* poll conducted in early December 2008 found that 77 percent of respondents thought that President Obama should start right away to take major changes in the U.S. health care system. “Washington Post – ABC News Poll,” *The Washington Post*, December 2008. Also see [www.washingtonpost.com/wp-srv/politics/documents/postpoll\\_121508.html?sid=ST2008122001562&s\\_pos=list](http://www.washingtonpost.com/wp-srv/politics/documents/postpoll_121508.html?sid=ST2008122001562&s_pos=list).
- 3 Examples of reform concepts incorporating these three components in various ways include recommendations from Miller, M.E. “Report to the Congress: Reforming the Delivery System,” Medicare Payment Advisory Commission, Testimony before the U.S. Senate Committee on Finance, September 16, 2008. Also see [www.medpac.gov/documents/20080916\\_Sen%20Fin\\_testimony%20final.pdf](http://www.medpac.gov/documents/20080916_Sen%20Fin_testimony%20final.pdf); Shortell, S. and L. Casalino. “Accountable Care Systems for Comprehensive Healthcare Reform.” Unpublished paper prepared for a workshop on “Organization and Delivery of Care and Payment to Providers” Center for Advanced Study in the Behavioral Sciences, Stanford University, March 1 and 2, 2007; Davis, K. “Slowing the Growth of Health Care Costs—Learning from International Experience,” *The New England Journal of Medicine*, Vol. 359, No.17, October 23, 2008, pp. 1751-55.
- 4 The economic turmoil at the close of 2008 may in fact have focused attention on losing health coverage rather than on costs of health care. The Gallup annual “Health and Healthcare Poll” for 2008 showed that more Americans said the most urgent health problem facing this country at the present time was access to care (30 percent), followed by costs (25 percent). In the annual surveys conducted in 2006 and 2007, costs were identified as most urgent, followed by access. Jones, J. “Healthcare Access, Costs Are Top Health Concerns.” Gallup, Inc., December 1, 2008. Also see [www.gallup.com/poll/112516/Healthcare-Access-Cost-Top-Health-Concerns.aspx?version=print](http://www.gallup.com/poll/112516/Healthcare-Access-Cost-Top-Health-Concerns.aspx?version=print).
- 5 Blendon, R. et al. “Understanding The American Public’s Health Priorities: A 2006 Perspective,” *Health Affairs*, Web Exclusive, October 17, 2006, W508-W515; Jacobs, L. “1994 All Over Again? Public Opinion and Health Care,” *The New England Journal of Medicine*, Vol. 358, No.18, May 1, 2008, pp. 1881-83.
- 6 *Health Care that Works for All Americans: The Health Report to the American People*, Citizens’ Health Care Working Group, September 2006. Also see [govinfo.library.unt.edu/chc/healthreport3.pdf](http://govinfo.library.unt.edu/chc/healthreport3.pdf).
- 7 The Working Group and partner organizations, individual Working Group members and private groups conducted a total of 84 meetings attended by 6,650 people. An Internet poll posted by the Working Group received over 14,000 responses (including more than 600 paper polls mailed to the Working Group by organizations and individuals). And another 6,000 people provided input to four open-ended questions about health care in America online.
- 8 In addition to reviewing the background materials and data collected by the Working Group, the discussion here is based on additional review of surveys and polls conducted more recently, and others identified in the course of reviewing the literature and searching survey data sources. This includes public opinion data collected by or on behalf of organizations such as the Kaiser Family Foundation, Harvard University, *New York Times*, *USA Today*, *Los Angeles Times*, *Wall Street Journal*, Harris, Gallup, National Opinion Research Center, Employee Benefit Research Institute, Commonwealth Fund, and Center For Studying Health System Change Community Tracking surveys and polls, as well as other research surveys conducted for various organizations and published in the health services and public health literatures.
- 9 Altogether, 3,276 groups submitted meeting summary reports to the Presidential Transition Team via the Internet; along with the meeting reports, the groups provided individual participant surveys from more than 30,000 people who attended the sessions. The Transition Team provided brief guides to hosts and moderators of the sessions, as well as a participant guide. The report and supporting materials, including appendices on methodology, are available at [www.healthreform.gov](http://www.healthreform.gov).
- 10 “Appendix C: Online Health Care Poll,” *Health Care that Works for All Americans: Dialogue With the American People*, Citizens’ Health Care Working Group on Health, September 2006. Also see [http://govinfo.library.unt.edu/chc/recommendations/appendix\\_c.pdf](http://govinfo.library.unt.edu/chc/recommendations/appendix_c.pdf).
- 11 “Americans Speak on Health Reform: Report on Health Care Community Discussions,” U.S. Department of Health and Human Services, March 2009. Also see [www.healthreform.gov/reports](http://www.healthreform.gov/reports).
- 12 *Crossing the Quality Chasm: A New Health System For the 21<sup>st</sup> Century*, National Academy of Sciences, Institute of Medicine, March 2001.
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