



Curbing **HEALTH-CARE COSTS**

Are Citizens Ready to Wrestle with

TOUGH CHOICES?



PUBLIC AGENDA

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executive summary

What do Americans think about health-care spending?

In what way, if at all, do their initial thoughts and feelings change when they have the opportunity to deliberate over different approaches to controlling costs? Which changes to the health-care system will people most readily accept and which are likely to elicit resistance?

In an effort to inform policy and broaden the dialogue about controlling health-care costs, Public Agenda, in partnership with the Kettering Foundation, used an innovative qualitative methodology called Learning Curve Research with Americans aged 40-64 in 4 cities around the country. In this exploratory research, participants first engaged in open discussions about their views and experiences with the health-care system. Next, we presented the groups with key facts about the nation's health-care spending and listened as they asked questions and worked through what those facts meant. Participants then engaged in a facilitated deliberation, during which they considered and discussed three different approaches to getting health-care costs under control. Then in small surveys and one-on-one follow-up interviews, participants reflected on the deliberations and talked about their views.

Key observations

- **Even insured participants were deeply concerned about their personal health-care spending and the uneven quality of the care they receive.** They frequently identified insur-

ance and pharmaceutical companies as causes of rising costs. But they also blamed doctors and hospitals for greed, inefficiency, and overtreatment.

- **Participants were eager to talk about how much national spending has risen. Variations in spending and health outcomes across the country and internationally elicited considerable surprise.** But the facts alone were not enough. Participants needed time and discussion to make sense of this information. They raised urgent questions about why costs have increased while Americans' health has not improved.
- **Participants supported policies that would encourage providers to work together more effectively.** They also saw pros and cons in various approaches to payment reform under which insurers would pay physicians some variation of flat fees—per year or per care episode, for example—rather than for each service performed. They agreed that this could reduce overtreatment but raised concerns about whether it would lead physicians to skimp on care.
- **Participants wanted to see limits on what insurance companies, hospitals, and doctors can charge.** At the same time, they were divided over how much the federal government should be involved in health care.



- **The idea of shifting more costs to individuals was troubling to most participants.** While many acknowledged that paying more out of pocket could spur more judicious use of medical services, they were already chafing at the increased personal costs they've experienced in recent years. Participants worried that further cost sharing could lead people to avoid getting the care they need. They also noted the reasons that make it so difficult for patients to compare prices and shop around for medical services.
- **Overall, participants were ready to deliberate over the approaches to cost savings that experts and health-system leaders have proposed, are experimenting with, or are have already implemented.** They believed that other members of the public, as well as medical professionals and insurers could benefit from similar opportunities to deliberate.

Implications

- **For communication:** This research highlights the kinds of concerns and attitudes that Americans bring to conversations about health-care spending and cost control, and the places where they may lack enough information to understand the issues. Leaders who understand these nuances can communicate more effectively with members of the public about how reforms will affect patients and families.
- **For public engagement:** Throughout this project, we observed that citizens, when given the chance, can engage with the difficult choices that are necessary to address the nation's out-of-control health-care

spending. There are many ways to encourage better citizen dialogues on these issues, locally as well as on the state and national levels. More and better public dialogue and engagement, especially at a time when the country is going through rapid and unprecedented changes in how it provides and pays for health care, can help foster smoother transitions, better care, and sounder policy decisions.

- **For policy:** While the scale of this research is small, it provides clues about which approaches to cost savings Americans may be most willing to consider, embrace, or resist. Participants were intrigued by payment reform but raised concerns about how it would affect quality of care. Care coordination and electronic medical records held wide appeal. But increased cost sharing seemed to participants to be part of the problem, rather than part of the solution. And government price setting proved particularly contentious.
- **For future research:** The health-care system is changing. How will the public's views change along with it? Will payment reform affect patients' experiences of care—and thereby change their views on cost savings? Will increasing cost sharing cause people to make medical decisions in new ways? And what can we learn from the millions of Americans who are now able to purchase insurance on exchanges or who are newly eligible for Medicaid? Understanding their perspectives and experiences will be vital to helping the health system adapt in patient-centered, cost-effective ways.

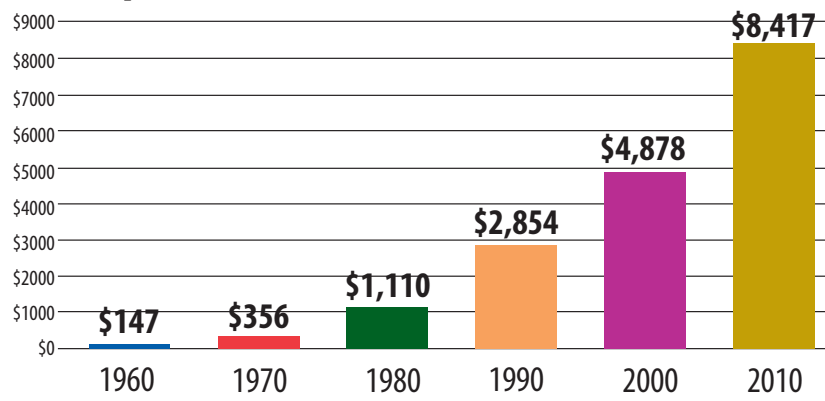
introduction



Rising health-care spending threatens American families as well as the nation’s economy. Spending has grown faster than the gross domestic product every year since at least 1970.¹ Health-care spending is projected to account for more of the nation’s debt than any other category of spending.²

Medicare’s trust fund for inpatient care could run out by 2024.³ Rising insurance premiums, deductibles, and co-payments are squeezing employers and individuals, and leaving 47.9 million Americans uninsured.⁴ Insurance companies and hospitals are under increasing scrutiny over

National Health Expenditures Per Capita, 1960-2010*



Source: Centers for Medicare and Medicaid Services
* Numbers not adjusted for inflation.

¹ Kaiser Family Foundation, “Costs: Visualizing Health Policy,” *JAMA* 308, no. 12 (2012).

² Bipartisan Policy Center, *A Bipartisan Rx for Patient-Centered Care and System-Wide Cost Containment*, ed. Pete V. Domenici, Tom Daschle, Bill Frist, and Alice M. Rivlin (Washington, DC: Bipartisan Policy Center, 2013).

³ Boards of Trustees of the Federal Hospital Insurance and Federal Supplementary Medical Insurance Trust Funds, *Annual Report* (Baltimore, MD: Centers for Medicare and Medicaid Services, 2012).

⁴ John Holahan and Megan McGrath, *Reversing the Trend? Understanding the Recent Increase in Health Insurance Coverage among the Nonelderly Population* (Washington, DC: The Urban Institute and the Kaiser Family Foundation, 2013).

what they charge and how they spend their profits.⁵

But despite all we pay—18 percent of GDP, 21 percent of all federal spending, and \$8,680 per person per year on average—American health outcomes are often worse than those in other industrialized countries.⁶ Where does this money go? Lack of coordination, poor care delivery, overtreatment, administrative complexity, and unfair pricing account for an estimated 20 percent of our health-care spending, according to Donald Berwick, former administrator of the Centers for Medicare and Medicaid Services.⁷

Providers, insurers, employers, and regulators are now experimenting with strategies to bring costs down. Some hospitals and medical professionals are exploring ways to coordinate and improve care delivery. Some insurers are changing the ways physicians are reimbursed. And some employers are testing insurance plans that cap costs and encourage employee wellness. The Affordable Care Act (ACA) is accelerating these and other cost-saving experiments. Health-care spending growth actually slowed somewhat in

2011, although it is unclear whether that resulted from the slow economy or from purposeful cost-saving efforts.⁸ But what does the public think about these efforts to get health-care costs under control?

Where is the public?

A common assumption is that insurance shields most Americans from the actual costs of their care, leaving them unconcerned about cost effectiveness. But polling data suggests that the public is deeply worried about health-care costs while also insufficiently informed about the changes to the health-care system that are already underway. Only 30 percent of Americans are confident that they can afford the care they need without suffering economic hardship.⁹ Immediately before enrollment began in the state and federal exchanges created under the ACA, 51 percent of the general public and 67 percent of the uninsured said they did not have enough information about the law to know how it would impact their families.¹⁰

⁵ Steven Brill, “Bitter Pill: Why Medical Bills Are Killing Us,” *Time*, March 4, 2013. Centers for Medicare & Medicaid Services, *Medicare Provider Charge Data* (Baltimore, MD: Department of Health and Human Services, 2013).

⁶ Micah Hartman et al., “National Health Spending in 2011: Overall Growth Remains Low, but Some Payers and Services Show Signs of Acceleration,” *Health Affairs* 32, no. 1 (2013).

⁷ Donald M. Berwick and A. D. Hackbarth, “Eliminating Waste in US Health Care,” *JAMA* 307, no. 14 (2012).

⁸ Hartman et al., “National Health Spending in 2011.”

⁹ Employee Benefit Research Institute, “2012 Health Confidence Survey: Americans Remain Confident about Health Care, Concerned about Costs, Following Supreme Court Decision,” *EBRI Notes* 33, no. 9 (2012).

¹⁰ Kaiser Family Foundation, *Kaiser Health Tracking Poll: September 2013* (Washington, DC: Kaiser Family Foundation, 2013).

Misinformation and confusion pose obstacles to progress. But efforts to control costs and to increase the value that Americans get for their health-care dollars will require engaging patients and families. It is important, therefore, that public perspectives be part of any conversation about health-system change. Americans need opportunities to come to terms with health-care spending, deliberate over the implications of potential solutions, wrestle with trade-offs, and develop informed judgments about the policies and practices they are willing to support. This research suggests that it is possible for Americans to do so. It sheds light on how to help people work through these issues and on the direction their thinking tends to go as they do so.

This research

Curbing Health-Care Costs summarizes a unique research project undertaken by Public Agenda, in collaboration with the Kettering Foundation, to learn more about what happens when Americans deliberate over approaches to controlling health-care costs. It clarifies the concerns and assumptions that citizens bring to the table on these tough choices and explores ways to help them engage more deeply with the problem. This exploratory study was designed to guide future research and to lay the groundwork for broader public engagement.

We used an innovative qualitative methodology called Learning Curve Research as a way to understand the starting points of Americans' thinking on health-care costs and to see how their perspectives and concerns evolved as they considered new information, deliberated over approaches to curbing costs, and considered each other's opinions. The cost-saving approaches that participants deliberated over were based on reforms that experts and leaders have proposed, are experimenting with, or have already implemented. These deliberations were not designed to achieve consensus among participants or to assess particular changes in participants' opinions about specific policies. The methodology is described in more detail at the end of this report.

In the following pages, we summarize our observations from this exploratory research and outline what we see as its main implications for public communication, public engagement, policy, and future research. We also asked experts in health care, public opinion, and communication for their reflections on this research. In particular, we asked them to elaborate on the implications of these findings for the changes that are happening in the health-care system right now and for efforts to engage members of the public more effectively and meaningfully on health-care costs. The report concludes with these expert commentaries.



what we heard

PUBLIC STARTING POINTS: Participants immediately expressed deep concern about their personal spending and the disorganization of the current system. They identified insurance and pharmaceutical companies as causes of rising costs, but felt that doctors and hospitals share the blame. Participants did not entirely trust the quality of care they receive from primary care physicians and public hospitals, leading them to grudgingly accept higher prices from specialists and better known hospitals. In each group, a few participants spontaneously raised single-payer government-provided insurance, which some found appealing but others viewed as unacceptable.

- **Participants voiced considerable concern that their personal costs are rising.**

Both insured and uninsured participants shared a sense of urgency and anxiety about their health-care costs. Many expressed a strong sense of injustice, commiserating with one another about shockingly high out-of-pocket costs and bills from insurers and providers. Those who were insured acutely felt the impact of high premiums and deductibles. A woman in Alabama described the toll of insurance costs on her income, “They’re taking so much out of your check that it’s almost like you’re working for nothing.”¹¹ And an Ohio man confided, “I’ve got three kids in college. A four thousand dollar deductible—that’s pushing the edge of the envelope.”

Participants also worried about costs for older family members, who they see struggling to afford prescriptions and copayments. A participant in Ohio told us about her

mother-in-law spending \$500 for 10 days worth of prescriptions. Another described watching his mother pay a \$65 co-pay for every doctor’s visit. “When you are on a fixed income, it will tear into your pocket,” he said.

Several insured participants had been uninsured within recent memory. A woman in Alabama remembered, “If it came to feeding your family or keeping a roof over their head, as opposed to having insurance, which one would you pick?” An uninsured man in New Jersey noted that he had a pocketful of prescriptions that he couldn’t afford to fill. Small business owners lamented the “astronomical” costs of buying insurance for their families and employees—and said they felt as though the insurance they could buy still required them to pay high out-of-pocket costs. A small business owner in New Jersey told the other focus group participants, “You pay all that money for health care, and then you’re still paying when you go to the doctor.”

¹¹ Quotations in this report have been minimally edited for clarity.

A New Jersey woman summed up the group's feelings about the system: "It's just one huge scam and I feel like we're all getting ripped off and something needs to be done."

- **Many shared personal stories about what they perceived to be disorganization and poor service in the health-care system.**

Participants in these groups expressed concerns about the service they receive from health-care providers, which many described as impersonal and inefficient. A woman told the Stamford group, "I think that they spend more time trying to figure out what kind of insurance you have before they actually get to treating you." A man in Ohio lamented the lack of personal interaction with doctors, who he said are either "trying to make the most money possible or just have too many patients." A woman in Alabama felt, "Most doctors just treat you like a number." Several participants also noted that it is very difficult for patients to understand their physicians, especially patients who are elderly or ill.

Not surprisingly, dissatisfaction was particularly acute for uninsured participants. As a man in Alabama confided to the other members of his group, "I'm going to public health care and it sucks. It's like they don't even really try to diagnose what's actually wrong with you." But even insured participants criticized the system as disorganized and uncoordinated. Many angrily shared stories of billing and service nightmares. A man in New Jersey told the harrowing story of his heart surgery. He said he was lying on the operating table when he asked the anesthesiologist if his services were covered by his insurance, to which the anesthesiologist reportedly replied, "Well, do you want me to do this or not?"

In fact, the anesthesiologist was out of network and the hospital took the man to court because he could not pay his bills. Another New Jersey man described going to a doctor for office visits that were covered but then getting a surgical operation from the same doctor only to find out afterwards that it was not covered. "Lucky for me, I was home on medical leave, so I could spend hours every day on the phone chasing people down. Otherwise, I'd be responsible for that out of pocket, which I'm sure happens to a lot of people."

Participants' concerns about disorganization and poor service are consistent with national polls, in which 71 percent of insured Americans say they are satisfied with health services they receive and 44 percent of uninsured Americans describe themselves as satisfied. But when they are dissatisfied, polls show that insured and uninsured people alike cite high costs, poor service delivery, and bad customer service.¹²

- **Participants often viewed insurance and pharmaceutical companies as greedy and as the culprits responsible for rising costs. But many felt that physicians and hospitals also share the blame. And some were angry about people who they believe take advantage of the system.**

The groups immediately and repeatedly blamed pharmaceutical and insurance companies for rising costs. A New Jersey man maintained, "Insurance companies can charge whatever they want. There's no incentive for them to lower their prices." The participants also cited cozy relationships between pharmaceutical companies and the federal government that they believe drive up prescription drug prices. A man in New Jersey said of pharmaceutical companies,

¹² Deloitte Center for Health Solutions, *2012 U.S. Survey of Health Care Consumers* (Washington, DC: Deloitte, 2012).

“They lobby here and they lobby there and they get special interests. That’s wrong.”

But participants had harsh words for hospitals and physicians as well. Emotions ran high as participants described physicians preying on patients in poor health, overdiagnosing nonexistent or minor conditions and milking their insurance. Polling shows that 61 percent of Americans have considerable trust in their own doctors, and that doctors in general are among the most highly trusted professionals.¹³ But participants in these groups told stories about the many doctors they had quit—perhaps before finding practitioners they could trust. An Ohio man explained, “Most people, life or death, would choose life, regardless of the cost. But that doesn’t give the doctor open season to request something that could’ve been done simpler.”

Doctors were specifically criticized for being too aggressive at the end of life. A man in Ohio noted that “my health is invaluable. But I’m not about to go into debt paying a bill if it’s going to keep me alive one extra second longer than when I would’ve died normally.” Participants also described high hospital charges for simple things like aspirin and Tylenol.[®]

Participants were well aware that pharmaceutical companies market aggressively to physicians, offering money, meals, trips, and other gifts to doctors who “push” brand name drugs despite side effects or cheaper generics. Many maintained that physicians receive “kickbacks” for prescribing drugs, a claim that no one in any group ever challenged. The threat of malpractice lawsuits was also cited as a factor leading doctors to overtest and overtreat. A New Jersey

woman said, “I’d have no blood left if I was going to listen to everything that they told me to do.”

Some participants were angry about people who they believe are free riders on the health-care system. Some felt that immigrants and Medicaid recipients benefit unfairly from government help or abuse the system while working people have trouble finding insurance or paying for care. A New Jersey woman said, “It seems like the people who don’t work get all the care they need. It seems crazy that people who go out to work are penalized. We are paying for everyone else.” However, a man in Alabama cautioned, “Elderly people need Medicare and some people need Medicaid. Some people are taking advantage of it but just taking it completely from people? You cannot do that.” Polls indeed show that 44 percent of Americans believe that people who receive welfare genuinely need it while 46 percent believe that welfare recipients are taking advantage of the system, a nearly even divide.¹⁴

- **Many participants mistrusted the quality of primary care physicians and public hospitals, leading them to grudgingly favor specialists and better known hospitals.**

Participants understood that health-care quality varies across doctors and hospitals. In particular, they mistrusted the quality of care that primary care physicians provide. One participant explained, “With the family doctor you get a generic diagnosis. I did not feel they were qualified enough. That was a waste of my copayment.” Participants also

¹³ AARP Research Center, *Americans’ Trust in Organizations and Individuals: An AARP Bulletin Survey* (Washington, DC: AARP, 2013). Frank Newport, *Congress Retains Low Honesty Rating, Nurses Have Highest Honesty Rating; Car Salespeople, Lowest* (Princeton NJ: Gallup, Inc., 2012).

¹⁴ Public Religion Research Institute, *2012 Pre-Election American Values Survey* (Washington, DC: Public Religion Research Institute, 2012).

complained that when primary care physicians refer them to specialists, the patient is responsible for two copays while both doctors get paid by insurers.

In every region where we conducted a focus group, participants cited certain hospitals as higher quality and others as falling short. For example, a man in Ohio described the Veterans Administration hospital as “like a zoo.” He felt that if Veterans Administration doctors “could make it on the outside, they wouldn’t be there.” A New Jersey woman complained about what she described as the “dirty” facilities at her local hospital. A woman in Alabama compared hospitals in Birmingham to those in other parts of the state. “I’m assuming that Birmingham’s going to be a little bit more expensive. I want that quality care. I want that specialist.”

These perceptions of uneven quality often translated into a feeling that specialists and renowned hospitals provide better care than primary care physicians or public hospitals. Group members described specialists as more qualified, advanced, and trusted than primary care physicians. It would be wrong to say that participants purposefully sought out more expensive care, especially given their concerns about their out-of-pocket spending. But some grudgingly felt that higher quality care from specialists and renowned hospitals justifiably costs more. A man in New Jersey said, “The guy that operated on my back deserves more money than the primary care guy who just writes prescriptions and refers you. The specialists had to go to school for much longer. It seems to be they are always on call.” But another participant objected, “I don’t think paying more means you should get better care. We should be working on getting that hospital up to standards no matter what area it is.”



- **In each group, a few participants spontaneously raised single-payer government-provided insurance. Some found it appealing but others viewed it as unacceptable.**

When the moderator asked participants about their ideal health-care system, several immediately brought up Canadian and European single-payer, universal insurance. An uninsured Alabama woman said, “We’re in the dark ages” compared to those countries. “We need to have national health care already,” she insisted. Polling from 2009 showed that 40 percent of respondents favored a single-payer system and 56 percent opposed it, with views roughly split along party lines.¹⁵

Those participants who favored single-payer noted that it might require tax increases but indicated that this trade-off would at least be worth considering. A man in Stamford noted that Canadian taxes are higher but said, “The question is a choice. Do you want health care for everyone? You’re going to pay for it.” Another man replied, “I’d just like to see our hard-earned tax monies go towards that rather than creating bombs and whatnot.” But other participants worried that what they described as “socialized health care” would lower quality, diminish patient choice, and lead to long waiting lists.

¹⁵ Public Religion Research Institute, *2012 Pre-Election American Values Survey*. Atul Gawande, “The Cost Conundrum,” *New Yorker*, June 1, 2009.

FACING THE FACTS: In the second part of the deliberative focus groups, moderators presented participants with information about health-care spending. Graphs and charts illustrated spending as a percentage of GDP and of the federal budget; per capita spending over time and in international comparisons; as well as price variation across the United States. The information elicited rich conversations and questions. It appeared that participants had not necessarily considered health-care spending in the aggregate as a national problem, but they were eager to learn.

- **The statistics that raise experts' concerns about health-care costs were new to almost all participants. As they made sense of the information together, participants raised questions and tried to figure out what was driving these trends.**

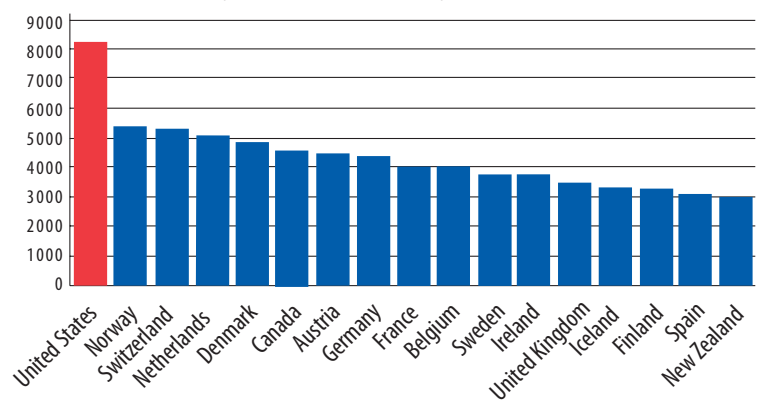
In pre-discussion surveys, more than 8 in 10 participants described themselves as concerned about rising costs, but only about a third strongly agreed that the country is spending more on health care than it can afford. When we presented them with information about health-care spending, all of them were surprised that it occupies such a large share of the federal budget or of the economy overall. Few realized the extent to which spending has risen for the nation overall. As participants worked through this information, they raised questions, engaged each other in lively conversations, and appeared to develop an increased sense of urgency about national health-care spending.

Participants were particularly surprised that prescription drugs account for a relatively small percentage of rising health-care costs. They were amazed that the federal government spends more on health care than on defense. International comparisons were more meaningful than one might have expected. Groups

were shocked by how much more the United States spends on health care relative to other industrialized countries and by our relatively low life expectancy. A woman in Stamford concluded, "It's not like our money is being used very cost effectively."

Participants were also struck by the rapid increase in health-care spending in their lifetimes. They cited a broad range of potential causes, many focusing initially on reasons why people might need more medical care because of poor nutrition, lack of exercise, pollution, and stress. They noted, as well, that costs are higher because people live longer and therefore use more medical services. But participants also made note of the proliferation of new diagnostic categories

Total Expenditure on Health Care Per Person, US Dollars, 2010



Source: Organisation for Economic Co-operation and Development


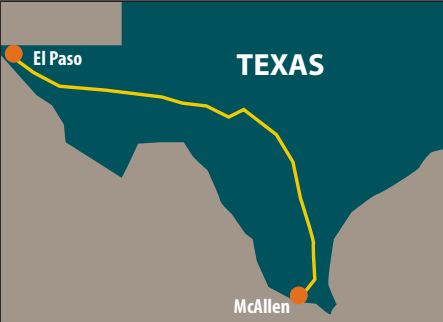

and of more and more expensive medical technologies. A New Jersey man described how medical supply drives demand. “Now, any ailment that you have, there is a pill for it.” One man in Ohio remarked that new technologies can be a blessing but another responded, “That machine will probably pay for itself in a year and a half” while hospitals continue to charge full price to use it.

Groups were especially engaged by a slide showing how much average Medicare spending per patient varies be-

tween El Paso and McAllen, Texas—a comparison described by Atul Gawande in his 2009 *New Yorker* article “The Cost Conundrum.”¹⁶ One New Jersey woman noted, “We’re trying to make sense out of it, and there’s no sense to be made.” But ultimately, in every group, someone concluded that doctors and hospitals in McAllen simply charge higher prices. As a man in New Jersey explained, “It looks like McAllen is actually just marking up their price. At the same time, they are not delivering the care that they’re supposed to. They’re giving shoddy care, and they charge more money.”

Health-Care Spending and Quality in Two Texas Towns*

El Paso and McAllen have similar demographics, similar population health, and a similar number of hospitals.

 <p>El Paso</p>	 <p>El Paso</p> <p>TEXAS</p> <p>McAllen</p>	 <p>McAllen</p>
<p>\$7,663</p>	<p>Average Annual Medicare Costs Per Enrollee, 2007</p>	<p>\$14,044</p>
<p>93.2</p>	<p>Centers for Medicare and Medicaid Services Hospital Quality Score out of 100</p>	<p>86.9</p>

Source: Centers for Medicare and Medicaid Services

*Numbers reached using the Dartmouth Atlas of Health Care

¹⁶ Atul Gawande, “The Cost Conundrum.”

WRESTLING WITH COST SAVINGS: Participants deliberated over three approaches to controlling costs. The approaches, in brief, were:

- **Approach A.** Increase consumer cost sharing, price transparency, and choice among insurance plans and health-care providers.
- **Approach B.** Reform physician payment and incentivize teamwork, care coordination, and use of electronic health records.
- **Approach C.** Regulate health-care prices and insurance markets, bring generic drugs to market sooner, and expand access to Medicare.

Participants weighed the approaches carefully, grappling with the benefits, trade-offs, and potential consequences of each. In general, they supported policies to encourage providers to work together more effectively. Many were intrigued by payment reform, but saw it as having both upsides and downsides. Moreover, they wanted to see limits on what insurance companies, doctors, and hospitals can charge, but struggled over how much the federal government should be involved in health care. While participants agreed that Americans need to take responsibility for their health, they worried that greater cost sharing would lead people to avoid seeking the care they need.

-
- **When participants considered payment reform, they felt that it could reduce over-treatment but raised concerns about whether it would lead physicians to skimp on patient care.**

Reforming the way physicians are paid is at the top of the agenda for many health-care policy experts, who believe that costs and usage are high largely because of the fee-for-service payment system, in which hospitals and physicians charge separately for every service they provide.¹⁷ But until the moderators explained it, participants in these focus groups were generally unaware of the fact that we pay for our health care by paying for each service separately.

Participants carefully weighed the pros and cons of payment reform—which generally calls for some varia-

tion of a flat fee—trying to figure out how it would change incentives in the health-care system and affect their care. They reasoned that charging flat fees per year or per episode of care for each patient would give them a sense of control because they could predict their out-of-pocket costs. They also felt that charging flat fees would prevent doctors from overtesting and overtreating just to make money. And they felt that doctors would be able to focus more on taking care of patients than on dealing with insurance companies.

However, participants were concerned that charging flat fees would lead doctors to skimp on care, in part because doctors are so accustomed to being paid generously. An Ohio woman wondered, “Are you really giving me the full scope of everything you would if you were charging for every little thing?” Several participants felt that doctors would sim-

¹⁷ Commonwealth Fund, *Confronting Costs: Stabilizing U.S. Health Spending While Moving toward a High Performance Health Care System*, ed. by Commission on a High Performance Health System (The Commonwealth Fund, 2013).

ply resist any cuts to their reimbursement. But others maintained that some doctors would continue to do their best no matter how much they get paid. For a woman in Alabama, “It just boils down to your personal integrity.” A man in the Alabama group agreed, “Some of them are doing it for the money, some of them do it because they care about human beings.” A man in Ohio described the trade-offs of price setting and charging flat fees: “You can skimp or you can gouge. Ultimately you want somebody that’s going to be able to be honest enough, upright enough, and cares enough to do what’s necessary to make sure that I’m healthy.”

Several participants were concerned that flat fees would have to reflect regional variations in the cost of living. They suggested that doctors, hospitals, and insurance companies collaborate to work out reasonable prices. A man in New Jersey said he liked the idea of paying doctors flat fees but noted, “I bet you the doctors won’t like it.” A New Jersey woman said that payment reform “sounds good to me but I don’t know if the doctors would agree. They’re used to a high rate now and they feel like they are able to demand that. It’s going to be really tough.” Survey research indeed shows that physicians have mixed views on whether and how to pursue payment reform.¹⁸

- **People were ambivalent about performance-based payment for physicians.**

Some health systems and insurers are already experimenting with “performance-based payment,” which means paying physicians based in part on patients’ health outcomes, recovery rates, or satisfaction. The idea of performance-

based payment sparked lively debate. Some participants reasoned that financial incentives would make doctors work harder. But given their prevailing view that doctors are already well paid and perhaps even greedy, many objected to performance-based payment. A New Jersey man argued, “I don’t think a doctor should get a bonus for doing his job.” A New Jersey woman found the idea of bonuses “incredibly offensive.”

Participants also worried that doctors would figure out how to game the system if their payments were based on performance. A woman in New Jersey insisted, “It would get out of hand. People would manipulate it.” Participants predicted that doctors would coerce patients into giving them higher satisfaction scores and push them out of the hospital too early if their payments were based on recovery time. They also worried that doctors would turn away sicker patients who were unlikely to earn them sufficient performance-based pay.

Several participants objected to performance-based payment because they felt it was unfair to hold doctors accountable for outcomes that might be out of their control. Several people compared performance-based pay for physicians to merit pay for teachers. A woman in New Jersey who was a teacher maintained that a doctor “shouldn’t be judged by my behavior.” She continued, “I don’t expect a bonus when my kids pass a test. The satisfaction that they were able to pass a test for me is enough.”

Many participants believed that payment reform would have to account for specialists’ expertise and egos. A man in New Jersey who favored payment reform

¹⁸ Amy M. Lischko, Anoop Raman, and Rosie Lau, *Physician Payment Reform: A Review and Update of the Models* (Waltham, MA: Massachusetts Medical Society, 2008); A. D. Federman, M. Woodward, and S. Keyhani, “Physicians’ Opinions about Reforming Reimbursement: Results of a National Survey,” *Archives of Internal Medicine* 170, no. 19 (2010).

cautioned, “I guess you need to make sure that specialists get more money than the primary care doctors.” They worried that payment reform would make specialists less motivated to provide quality care and would make talented students less motivated to become specialists. This is consistent both with participants’ higher regard for specialists and their general feeling of being at the mercy of doctors. For example, a man in Alabama specifically cited the Cleveland Clinic, and asked how its “top-of-the-line physicians” could ever accept the same reimbursement as “a doctor who works in rural Alabama.”

- **Helping medical professionals coordinate care elicited very positive responses. Several participants felt that being able to access their electronic medical records would give them better control over their health care.**

Many participants in these focus groups had experienced firsthand the problems caused by lack of coordination among doctors, nurses, and pharmacists. This is consistent with polls in which 47 percent of American adults surveyed had experienced failures of coordination, such as doctors not sharing information with other medical professionals or not informing patients about their test results.¹⁹

Participants believed that if doctors worked together to interpret test results and develop treatment plans, the quality of care could improve. The groups therefore strongly supported electronic medical records and other tools to help medical professionals coordinate care. They noted that electronic medical records could help avoid adverse drug interactions, reduce invasive and uncomfortable overtesting, and

save time. Concerns about privacy did not emerge strongly in these groups. Moreover, several participants wanted access to their own medical records so that they could understand their doctors’ instructions and better communicate with specialists or new physicians. A Stamford man said, “If I held my medical records, I’d be in control with my situation and be able to provide information to whoever needs said information.”

- **A key tension in the groups was over how and how much the federal government should be involved in health care.**

All participants shared the belief that something significant needs to happen to address the health-care spending problem. But their views on the proper place of the federal government in that solution were complex—and became a key point of tension in the deliberations.

Some roles for the federal government were uncontroversial even for self-described conservatives and free-market advocates in the focus groups. They favored limiting annual increases in insurance premiums, getting generic drugs to market more quickly, and restricting pharmaceutical companies’ marketing to physicians. But these self-described conservatives and free-market advocates found the idea of government price setting particularly objectionable. And they generally opposed giving all Americans the option of joining Medicare. This is consistent with polling from 2009 in which 82 percent of Democrats and only 53 percent of Republicans supported expanding Medicare to cover people between the ages of 55 and 64.²⁰

However, many participants maintained that only the federal government has the power to solve a problem as

¹⁹ Kristof Stremikis, Cathy Schoen, and Ashley-Kay Fryer, “A Call for Change: The 2011 Commonwealth Fund Survey of Public Views of the U.S. Health System,” *The Commonwealth Fund Issue Brief* 6 (2011).

²⁰ Kaiser Family Foundation, *Kaiser Health Tracking Poll: September 2009*.



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big as health-care spending. A woman in Ohio granted, “No one likes to think of government regulation of something so intimate as health care but I don’t see the market correcting itself.” A New Jersey interviewee said, “Do I want socialized medicine? Hell no, I don’t think that’s the answer. But there’s got to be some regulatory system.” He cautioned, “You’re going to come up against a million people that say no, but it’s going to be the ruination of this country. People cannot live the life they need to live if they’ve got to pay eight hundred dollars a month on a fixed income.”

But even those who favored a stronger role for government saw trade-offs and tensions in their own perspectives. An Alabama woman who described herself as very pro-government noted, “There’s an upside and a downside. You’d have to weigh the pros and cons.” Several participants specified that they were not ideologically opposed to government, but that they don’t trust our government to do a good job on something as difficult as health care. Specifically, participants worried that further government involvement would reduce the quality of care and increase patients’ waiting times. Participants also worried that government involvement would increase medical prices. Indeed, there is a lively debate among experts about whether expanded access to Medicare would in fact increase Medicare prices overall.²¹ But participants’ concerns tended to focus on issues of trust rather than economics. One New Jersey man said, “Once you put the government in charge of anything, it’s just going to run off with spending it. I don’t even trust the

government to send an important piece of mail. I certainly don’t want them in charge of my brain surgery.” Another warned, “Who’s watching the government?” These concerns are consistent with polls showing a long-term decline in trust in government from 1960 to 2013.²²

However, participants in these groups often seemed to be calling for some form of government action despite their apprehensions. For example, an Alabama woman who said she regarded any federal involvement in health care as tantamount to socialism nonetheless felt it was wrong that medical providers can charge different prices for the same service. Some participants acknowledged that their opinions on the government’s role in health care were not necessarily stable. A New Jersey woman who was insured by her husband’s employer and was cautious about government intervention felt that if she had to enroll in her own employer’s high-deductible plan, “My opinion is going to totally change. I might want the government to see how the insurance companies are run because I don’t want my job to dictate my deductible.”

- **Capping prices in particular provoked contention over the proper role of government.**

Medicare already determines the prices it will pay for medical services. But for some participants in these focus groups, government price capping was unacceptable. “I don’t think the government has any business in determining what a private company can pay” an Alabama woman insisted. An Ohio man described price setting as “like the nanny state. You’re not incentivizing the best and the brightest to become doctors. Let the market decide.”

²¹ Dana Goldman and Adam Leive, “Why ‘Medicare-for-All’ Is Not the Answer” (Health Affairs Blog, 2013).

²² Pew Research Center for the People & the Press, *Political Survey, January 2013* (Washington, DC: Pew Foundation, 2013).

However, some participants seemed to work through their feelings about price capping during the deliberation and moved towards measured support for it. An Ohio man explained that at first he disliked the idea because he was worried that it would limit doctors' ability to make money. "But then the more I thought about it I really don't feel why there's a reason why that couldn't work. I don't see why, when we have something that is causing the crisis, that there couldn't be some form of government regulation on some things."

For a few participants, government price capping seemed like a natural idea. An Alabama man felt, "You have to have some type of government involvement in whatever you do. I don't see anything wrong with regulating prices." A New Jersey man noted, "They set limits on everything else in this world. Why not health-care costs?" An Alabama man proposed a regulatory board that would oversee and set prices based on the different costs of living across the county. But he was clear that the board should include not only government representatives but also representatives from hospitals, doctors, and insurance companies.

- **The idea of shifting more costs to individuals was troubling to most participants. But many acknowledged that paying more out of pocket could spur more judicious use of medical services.**

Policy experts have proposed increased consumer cost sharing as a means to control health spending. But that shift is already underway. The percentage of insured people with deductibles has been rising. In 2006, only 52 percent

of insured workers had a deductible for single coverage but by 2012, 72 percent faced a deductible. Of those, 34 percent were enrolled in plans with deductibles over \$1000, including 14 percent with deductibles over \$2000.²³

Participants in these groups saw increased cost sharing as a part of the problem rather than as a solution. Many were already on high-deductible plans and described delaying or rationing their care as a result. A woman in Alabama said, "I put off as much as I can. I don't go unless it's just a dire emergency. You just doctor yourself." An Ohio man said, "Blood better be spurting out before I'm going to the doctor now." Participants with high-deductible plans said they felt like they had no insurance at all. A woman in New Jersey asked, "Why would you pay for insurance in the first place?" Meanwhile, participants noted that people with high deductibles may go to the doctor more than necessary once they meet their deductibles.

Nonetheless, several participants reported that increased out-of-pocket costs had already encouraged them to use health care more judiciously, though they were unhappy with the trade-offs. A man in Ohio with a high deductible said, "I don't necessarily like it, but there are pros and cons and trade-offs. It forces you to think, 'Do I really need to go to the doctor?'" A woman in Alabama explained that since her copayment had gone up, she hadn't gone to the emergency room for her migraines but instead treated them on her own. Another man in Ohio concluded, "I'm forced to become a more conscientious health-care consumer and shop for prices where perhaps I didn't care that much before."

As participants worked through the implications of increased cost sharing, several reasoned that high-deductible

²³ Kaiser Family Foundation and Health Research & Educational Trust, *Employer Health Benefits 2012 Annual Survey* (Washington, DC: Kaiser Family Foundation, 2012).

plans or other forms of cost sharing would only bend the cost curve if health-care services were more reasonably priced. A woman in the Ohio focus group pointed out, “If we could control the overall cost of this better and get it more reasonable then people could shoulder more of the expense because the cost would be down.”

- **Shopping around for health care seemed challenging to most participants, but the idea of more choice among insurance plans held some appeal.**

States, insurers and nonprofit organizations are promoting cost calculators and other price-transparency systems so that people can shop around for medical care.²⁴ The notion of price transparency seemed to hold some appeal, but focus group participants ultimately found the idea of shopping around for medical care disconcerting. A few had used their insurers’ cost calculators, called their insurance companies, or talked to their doctors’ staff to get prices—often as a reaction to shockingly high bills. Many participants said they had asked their doctors for less expensive or generic drugs, perhaps reacting to the prices they had paid for their prescriptions. But for other medical services, several participants noted that comparing prices is difficult because patients do not necessarily know in advance what combination of tests and treatments they will need. A woman in New Jersey who favored price transparency for what she called “chronic care issues” noted, “It’s not like when you go out to buy a car and you can price them at different dealerships. You break your leg, you don’t really shop around.”

Moreover, participants did not expect or even want their

doctors to have price information. In part, they were well aware that figuring out prices under their insurance plans is very difficult and they did not expect their doctors to be able to figure out prices either. But more important, because appointments tend to be short, participants wanted doctors focused on their care rather than on prices. An uninsured Alabama man felt that even for health-related questions, “You just feel like he ain’t have time to answer your little piddly questions, and you’re trying to get out of there because you just waited three hours to see him.” An Ohio man joked, “They can tell you what they’re going to be paid but they probably can’t tell you what you’re going to have to be paying.”

Even if price information were readily available, participants had difficulty imagining how comparing prices for medical procedures would work in the real world. A woman in New Jersey explained that if a doctor decides to perform a test, you’re not likely to leave the office to find a better price elsewhere. Others pointed out that shopping around presumes that patients have choices among practitioners, facilities, or procedures, which is not the case in every region.

By way of contrast, some participants wished they had more choice among insurance plans rather than being tied to the insurers and plans their employers chose. But a woman in Ohio worried that too much choice among insurance plans could be overwhelming. “Quite honestly, I don’t want to have to do all of that research. I am not going to be able to develop that kind of expertise.” This is consistent with national polls indicating that 80 percent of insured workers rank choice in health-care plans as extremely or very important, but only 36 percent are very or somewhat confident

²⁴ Catalyst for Payment Reform and Health Care Incentives Improvement Institute, *Report Card on State Price Transparency Laws* (Catalyst for Payment Reform and the Health Care Incentives Improvement Institute, 2013).

that they could choose the best available plan if they had more choice.²⁵

- **Participants agreed that citizens need to take personal responsibility for prevention. But they didn't believe that relying on people to change their lifestyles would substantially impact spending.**

The groups were universally concerned about unhealthy food, lack of exercise, and other lifestyle choices that lead to disease. They noted that reduced insurance premiums could be incentives to help people control their weight, blood pressure, and other risk factors. A man in Ohio who described himself as overweight felt that it was reasonable for him to pay more for his insurance. Even smokers felt they

should pay higher premiums and higher taxes on cigarettes.

But participants pointed out that their environments make unhealthy habits easy and healthy choices difficult. A woman in Ohio explained, "I understand I have to be responsible. However, I want to see that the media or the government are going to be equally participating and not just making the patient responsible." Overall, participants were keen to discuss what communities and individuals could do to promote better health, but they did not seem to think that prevention efforts alone could solve the health-care spending problem, especially since they believed that too many Americans are already in poor health. They thought prevention was a worthwhile goal, but understood that prevention alone would not do enough to bend the cost curve.

²⁵ Employee Benefit Research Institute, "Views on Employment-Based Health Benefits: Findings from the 2012 Health Confidence Survey," *EBRI Notes* 33, no. 12 (2012).



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PARTICIPANTS' REFLECTIONS: In surveys immediately following the deliberative focus groups, all participants reported enjoying the deliberations. When we interviewed them a few days later, they were still in the process of working through the information they had learned and the approaches they had considered. Many seemed to feel even more urgency about the need to get national health-care spending under control. They wondered what, if anything, they could do to help. But they were heartened by the conversations and believed that deliberative public conversations could be a valuable tool to help doctors, insurers, and patients design and implement better health-care policies.

- **The deliberations seemed to intensify most participants' sense of urgency about health-care costs.**

In follow-up interviews, participants reported that the focus groups made them realize that health-care spending is a significant and widely shared problem that affects all Americans, our government, and our economy. An Ohio woman reflected, "Bottom line, basically everyone had the same concerns: Quality health care, skyrocketing prices, and what can be done to ensure that people have what we consider quality health care."

Many described themselves as angry but eager for more information and more opportunities to engage. In post-deliberation surveys, 7 in 10 participants reported that they had learned things about health care that they did not know before. Only a third said they felt the same about health care as they did at the beginning of the deliberation. This does not mean that they had arrived at stable new opinions on health-care spending. Instead, participants continued to work out their views on the issue, recognizing that health care is a complex problem with no easy solutions.

- **Participants wondered what they could do to change the complex health-care system—or to protect themselves from it.**

- **They saw public deliberation as one potential way to make progress.**

A strong majority—about 7 in 10—of our participants reported in the follow-up survey that these types of conversations can help people like them make better decisions about health care. But for the nation as a whole, many participants, like a New Jersey woman, asked, "Now what?" A few participants reported scrutinizing their medical bills and spending more closely. But they generally felt disempowered to change the complicated and troubled health-care system. A woman in New Jersey admitted, "I don't know what's the right answer, but something has to change in America." A man in Ohio said, "I don't know when the country is going to wake up to the fact that we just can't afford everything. Some hard decisions are going to have to be made."

Yet many believed that further deliberation could raise public awareness and would constitute an important step towards constructive change. In follow-up interviews, several participants recommended that doctors, patients, hospital administrators, and policymakers should deliberate together. In follow-up surveys, a strong majority of participants felt that conversations like these can help our country make better decisions about health care.

- **Deliberating with a diverse group of fellow citizens helped participants realize that compromise is possible. They wondered why our leaders cannot find common ground.**

Participants did not reach consensus in these groups, nor did we encourage them to do so. However, in the surveys we conducted after the deliberations, all participants reported that they had at least a somewhat better understanding of viewpoints that were different from their own.

Many participants told us in follow-up interviews that the civility and quality of their deliberations provided

evidence that health-care leaders and policymakers could compromise. For instance, an Ohio man said, “There were some differences but I think ultimately everybody was willing to compromise. Now, why the government can’t come to that consensus, I have no idea.” An Alabama man asked, “If we can come up with an idea like that, why can’t the federal government, and doctors and hospitals and the people that represent them come up with the same idea and use it?” Similarly, a woman in New Jersey said, “At least this small group of citizens has an overall opinion even if we all can’t agree.” An Alabama woman said, “Hopefully, if people would speak up, we’d get some things solved.”

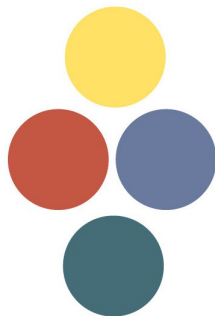
The Deliberative Process Observed in This Study



Public Starting Points

People arrive with individual views.

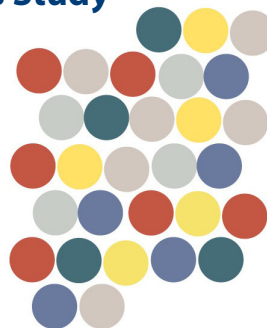
Participants began the conversation by discussing their ideal health-care system, which elicited strong concerns about problems in our current system.



Facing the Facts

Engaging the the bigger picture.

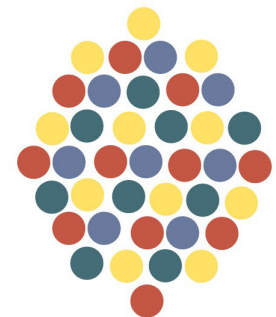
They were surprised to learn how much health-care spending has increased for the nation as a whole. National and international comparisons in spending and outcomes raised questions about whether this money is being spent wisely.



Deliberating over Policy Approaches

Options are considered.

Participants discussed the pros and cons of various approaches to curbing costs. They were enthusiastic about improving efficiency and coordination among practitioners and concerned about how payment reform would affect their own medical care.



Reflecting on the Deliberations

Thinking converges.

In surveys and follow-up interviews, participants reported more urgency about national health-care spending and saw public deliberation as one way to make progress.



implications

In preparation for this research, we conducted interviews with health-system executives, physicians, researchers, and foundation leaders. Several predicted that Americans would be unable or unwilling to engage with the issue of national health-care spending. Their predictions were consistent with the results of the 2008 National Issues Forums deliberations, which showed that even highly engaged citizens had difficulty confronting the trade-offs that would be involved in building a better health-care system.²⁶

The intervening years have witnessed an often-ugly debate about the Affordable Care Act, a close Supreme Court decision upholding the law, and a difficult path to implementation and enrollment marked by a government shutdown and technical difficulties with the federal health insurance exchange website. But that political drama, coupled with rising insurance premiums and deductibles, may have made some Americans more aware of, and willing to engage with, the health-care problems facing our nation.

Participants in this Learning Curve Research were both willing and able to discuss the complexity of the health-care system and to do so with an impressive degree of interest and thoughtfulness. They were open to hearing alternate viewpoints and were ready to weigh the pros and cons of a variety of cost-savings strategies.²⁷ Despite its modest size, we believe these findings are richly suggestive for future public communications, engagement, policy, and research.

For communication

This research highlights the kinds of concerns and attitudes that Americans bring to conversations about the nation's health-care spending crisis, and the places where they may lack enough information to understand its causes and to judge potential solutions. It demonstrates what happens when citizens have the chance to consider and work through information about trends and variations in spending and health outcomes. And it begins to indicate how they may weigh various policy approaches.

State and federal agencies, insurers, and employers are figuring out how to implement health-care reforms, cost-savings measures, and new ways of purchasing insurance. A more nuanced understanding of public perspectives can help them design policies that will work for patients and their families and communicate more clearly about pending change. For physicians, nurses, and other front-line professionals, understanding these public concerns will be crucial to implementing successful change.

For public engagement

If, as this research suggests, members of the public are ready to engage more thoughtfully on the challenge of health-care costs, then their perspectives can play a robust role in fostering better practices and policies to control costs and improve quality. This role includes participating in how insurance plans are designed, how medical providers deliver

²⁶ John Doble, Jared Bosk, and Samantha DuPont, "Coping with the Cost of Health Care: How Do We Pay for What We Need?," in *Outcomes of the 2008 National Issues Forums* (New York, NY, and Kettering, OH: Public Agenda/Kettering Foundation, 2009).

²⁷ A series of 40 community conversations convened by the Bush Foundation in 2012 also found members of the public (in this case Minnesotans) ready to engaged in nuanced discussions about health care. Bush Foundation, *Public Conversations and Public Solutions: Making Health and Health Care Better in Minnesota* (Saint Paul, MN: Bush Foundation and Citizens League, 2012).

care, and how policies encourage further change. Deliberative engagement in a range of settings could help advance this through local initiatives to improve health services.

For example, employers and unions who must deal with significant insurance and health costs could stand to gain significantly from understanding their employees' and members' views, educating them and working with them to use benefits and health care more effectively and efficiently. Community-based organizations and patient advocacy organizations would also be natural places to bring people together to engage with and deliberate over cost-savings practices and policies, from preventive medicine to better use of emergency rooms to Patient-Centered Medical Homes (PCMHs) and Accountable Care Organizations (ACOs).²⁸

Local and state officials in collaboration with community-based organizations could reach out to their constituents—not only to inform them about changes in the health-care system, but to give residents opportunities to share their views, deliberate, and influence policy decisions. This work can and should also inform federal lawmakers' and regulators' considerations and decisions, especially as the current federal role in the health-care system is not well understood and any changes to that role are controversial.

For policy

The research provides clues about the policies that Americans will most easily accept and those that are likely to elicit the most resistance. Coordinated care and electronic medical records held wide appeal. Payment reform was intriguing but raised concerns about whether quality would suffer. Government price setting was more contentious—and people do not necessarily understand how much the federal government is already involved in health care through Medicare, Medicaid, the military, and the FDA. The suspicions of

primary care that we found among our participants mean that Patient-Centered Medical Homes may need to consider how to gain patients' trust and respect. Finally, participants were quite dissatisfied with the poor service they so often receive in the health-care system. But some policymakers, insurers, and employers want patients to act more like savvy shoppers. If they want to achieve that goal, they will have to do a better job of treating patients like valued customers.

For future research

The health-care system is changing. How will public opinion change along with it? Payment reform is central to many reform efforts. But participants in our research had not encountered payment reform before; some did not seem to be aware that the current system is predominantly fee for service. Many worried about getting the right balance of benefits and trade-offs from payment reform. Future research should track changing public views on, and experiences with, different approaches to payment reform. And because payment reform is supposed to improve quality, future research should also assess how payment reform changes patients' experiences of care and views on cost savings.

Benefits are increasingly being designed to give Americans more financial responsibility and choice in health care. But our work suggests that citizens may not be fully ready to embrace these responsibilities. How will increased cost sharing affect when and how people seek care? How can insurance plans, hospitals, clinics, and medical professionals engage people in medical decision making that is better for their health and for their wallets? Finally, research on the perspectives and experiences of newly insured Americans who gain coverage under the ACA will be vital to helping actors across the health system adapt in patient-centered and cost-effective ways.

²⁸ The Affordable Care Act encourages the creation of Accountable Care Organizations—organizations of health-care providers that work to improve quality and control costs. Doctors and hospitals in ACOs stand to get paid more if they keep their patients healthy and out of the hospital. A Patient-Centered Medical Home is a provider in which primary care physicians coordinate care. PCMHs emphasize communication among physicians, patients, and families.

expert commentary

The following commentaries from experts in health care, public opinion, and communication offer further reflection on these findings and their implications.



Here is what consumers in other advanced industrial democracies need to understand about their health-care systems: practically nothing. From cradle to grave, their health-care needs are met nearly automatically by mechanisms that operate behind the scenes. No one has to worry about picking the “wrong” health insurance plan, or not being able to afford the cost of a serious illness or injury. There are no serious public debates about whether doctors make too much money, whether governments are in the pocket of the drug companies, or whether some people are “free riders.” It just never comes up, because these countries long ago reached a political consensus that health care is a human right, and that “social solidarity,” a term that most Americans have never heard, dictates that it be available on an equal basis to all.

The citizen groups convened by Public Agenda illuminate how Americans interpret their experience with an impossibly complex system that offers far less and demands far more of them as consumers than any other country’s.

- They (erroneously) blame high costs on insurance and pharmaceutical companies, whose prices they regularly see up close and personal whenever they write a premium check or pick up a prescription at the drugstore. But they accept the (equally erroneous) idea that high-powered specialists and prestigious hospitals, who are the true drivers of high costs in the United States, deserve their big bucks.

- Having experienced for themselves the disorganized care that our current system delivers, they like the idea of measures to coordinate care. This is perhaps the most encouraging finding from the entire exercise, because the

delivery system reforms built into the Affordable Care Act and the Health Information Technology incentives from the 2009 stimulus bill are already having a noticeable impact on

care coordination. I recently wrote an article on Patient-Centered Medical Homes and saw for myself how enthusiastically patients receive them.²⁹

- Somewhat surprisingly, given how Americans have been taught to value “cutting-edge” health care, consumers are beginning to recognize how providers can drive overuse of services in general and expensive technology in particular. But they don’t seem to have much of an idea how to address this problem.

I was asked to comment on how providers and insurers can use these findings to improve communication with consumers. That’s a worthy goal that I find myself in slight disagreement with. Clear language and transparent prices are fine and necessary, but the ultimate goal should be a health-care system that shields consumers from its underlying complexity as much as possible.

Absent the creation of a single-payer system, we are stuck with the patchwork mess we have now, which health reform will vastly improve in terms of access and affordability but simplify little if at all. So for the time being the focus should be on benefit designs that automatically push consumers towards higher quality, more cost-effective care. Tiered networks and reference pricing are promising starts. The price competition that we can already see developing on state insurance exchanges will, I hope, drive more innovation in this area.

Nancy Metcalf

Consumer Reports

Nancy Metcalf is a senior editor at Consumer Reports magazine who reports on health. She has answered thousands of consumers’ questions about health care and insurance in her “Ask Nancy” column.

²⁹ Nancy Metcalf, “A Doctor’s Office That’s All about You: More Than 25,000 Doctors Commit to Patient-Centered Care,” *Consumer Reports* (July 2013).

As is evident in this report, there are disconcerting contradictions and inconsistencies in Americans' views on health care that indicate the need for continued public information and deliberation. Several of these contradictions are worth noting, as they may hold a key for developing successful approaches to engaging the public in policies and practices that enable quality care and controlled cost.

As the report notes in its introduction, the current cost crisis is certainly not new, yet public consciousness and a sense of urgency have begun emerging only in the past five years. The reasons are many: unlike all other consumer services, the majority of health-care costs are indirect, handled through a third-party payer. Out-of-pocket costs were historically an issue only for the poor, uninsured, and underinsured. The rest of the nation remained fairly protected, and blissfully unaware. But those days have passed.

Many of the findings in this study ring true with our own at the American Institutes for Research and our Center for Patient and Consumer Engagement. Recent deliberations across the country that we conducted for the Agency for Healthcare Research and Quality found similar public interest in information, a variety of perspectives, and a desire for a place at the table as solutions are found and implemented. As in the deliberations we conducted, the study participants walked in with both misinformation and an individual, rather than a social, perspective on costs. It is no wonder that health consumers, who are informed more by direct marketing than science or policy analysis about health care, indicate in this study their belief that specialists

and renowned hospitals justifiably cost more. Our own 2010 study found that most consumers believed that more care, newer care, and more expensive care was better.³⁰ However, this study also shows the extent to which patients understand that doctors may order too many tests and treatments because they are financially motivated to do so.

Thomas Workman, PhD,
American Institutes for Research

Thomas Workman is the Principal Communication Researcher and Evaluator in the Health Program at the American Institutes for Research, where he leads its Center for Patient and Consumer Engagement.

There are many encouraging signs from this study, however, that need additional fostering. Our own experience echoes the experience in this study of witnessing a shift in perspective as participants become informed, an eagerness to learn more about the issue of health-care costs, and a sense of duty in "wrestling" with the complexities of health-care costs. These results, along with other similar findings, need to bolster the efforts now underway—funded by both federal agencies and private founda-

tions—to engage consumers and patients in cost payment reform at a variety of levels, ranging from cost-effectiveness conversations when deciding treatment with a doctor to engagement at clinics and hospitals considering new forms of payment systems, such as bundled payments. Critical to the effort is the need for consumers to demand that cost and quality remain on the table together. Accountable Care Organizations, Patient-Centered Medical Homes, and a variety of new models for care are seeking both reduced costs and increased quality, and many are committed to involving patients and consumers in their efforts as the ultimate end-users of their work. We can only hope that a similar spirit of engagement can be found in public policy settings. Our patients have much to add to those discussions.

³⁰ Kristin L. Carman et al., "Evidence That Consumers Are Skeptical about Evidence-Based Health Care," *Health Affairs* 29, no. 7 (2010).

Passage and implementation of the Affordable Care Act raises questions about how to achieve cost control, including how best to replace the current fee-for-service payment system and how to rethink what exactly our health insurance plans cover.

But beyond these important policy questions, this research raises concerns about some Americans' values related to health care. Persons in most developed countries are used to the idea that every member of society should have coverage and is entitled to access to health care. They do not understand, and frankly neither do I, why in the United States a sizeable minority of the population feels that health care is a privilege.

However, I believe that framing health-care coverage and access as an issue of right vs. privilege is misguided since it is clear that we do not all agree on that issue and will not easily resolve the debate. But, when presented with the data, I hope we can all agree that our performance on outcomes such as life expectancy is not as good as in many other countries. Try as many have in the past to say that our population is different, good data now show that that is not the explanation.

Most people in the United States do not realize that there is tremendous variation in health outcomes across the country; and in fact, where you live makes a difference. There is wider variation in health outcomes within the United States than across about 18 other developed countries. Our best states perform as well as the best countries but our worst

states perform more poorly than the poorest performing developed countries. When presented information on variation on health outcomes and spending within the United States and internationally, participants in Public Agenda's focus groups indeed reacted with surprise. But they also reacted with great interest, and began thinking and deliberating over why outcomes and costs vary so widely.

This indicates that Americans are ready to engage not only with the issue of rising health-care costs but also with questions about quality and outcomes.

It turns out that there is a strong relationship between state health outcomes and measures of social capital. This was pointed out by Robert Putnam nearly 15 years ago in his book, *Bowling Alone*.³¹ In states with high levels of social capital, as measured by responses to various survey questions and memberships in various organizations, people are more likely to trust and work with their neighbors. Those states may also be more likely to have a variety of state and local programs that benefit their entire populations. Putnam demonstrated not only that measures of social capital vary by state but also that the overall level of social capital in this country has been decreasing steadily for a few decades.

I would love to see public discourse begin to focus on how we might increase our levels of social capital. Indeed, more public discourse in general is likely to have a salubrious effect on our national and local levels of social capital. While this may seem distant from controlling health-care costs, I suspect there will ultimately be a strong relationship.

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³¹ Robert D. Putnam, *Bowling Alone: The Collapse and Revival of American Community* (New York: Simon & Schuster, 2000).

Though this study is small in scale, it leads to several far-reaching conclusions. I want to use my nickel to comment on one of them.

The study presented three strategies for health-care cost containment to average, older adult Americans (ages 40 to 64): make the public pay more for services; hold doctors and administrators responsible for reforms in efficiency; and/or, have the government control prices. Frankly, I am surprised by how clear-cut the implications of these discussions were. For a variety of reasons, the first and third strategies seem hopelessly impractical, leaving only the second for consideration. I have spelled out below the reasoning behind this conclusion.

In an era of stagnant wages and rising health-care costs, the public feels heavily burdened already. Being asked to pay even more for a system that functions so inefficiently will incite high levels of political resentment and won't do much to pressure the system into greater efficiency. The public is not equipped to choose among alternative plans, because it doesn't know how to evaluate the implications of each alternative. And average consumers are in no position to evaluate (let alone turn down) the advice of medical specialists.

Most important of all, the study reveals a staggering ignorance of how the system really works and how it got that way. In my more than 60 years of polling experience I am accustomed to seeing public lack of knowledge and information on issues. But even I am taken aback by the extent of public blindness and denial on this issue. I do not blame the public for its ignorance. Average Americans have played a scant role in shaping public policy in health care. From the

perspective of experts, the public has nothing to contribute to strategic policy thinking and has been effectively left out of the conversation. It will take a huge amount of time and effort to bring the public into the picture.

People's fears that government price controls inevitably means that doctors will provide less care is a compelling political argument. Wide ideological opposition to price controls strengthens the argument. Government-based price controls are dead on arrival.

As soon as one turns to reforming the delivery system—Strategy Two—powerful reasons for doing so immediately present themselves. The doctors themselves are deeply dissatisfied with the status quo. They are angry, demoralized, and resentful even

though they may benefit financially.

The lack of transparency in the system is its most bewildering feature. The system of employer coverage that hides costs from the public arose by accident in the early days of WWII. It is the source of many dysfunctions. An even greater (and less transparent) source of dysfunction is the federally mandated monopolistic role of the American Medical Association (AMA) in setting codes for pricing. Much of the lack of price sensitivity in the system can be tracked back to this source. The role of the AMA makes it easy to game some promising reforms, such as digital record keeping, with the perverse result that this innovation often adds to costs and confusion rather than reducing them.

My personal view is that public engagement is needed to bring about the necessary reforms. Effective public engagement is possible, but it will take a lot more research and experimentation to learn how to do it right.

Daniel Yankelovich

Public Agenda

Daniel Yankelovich is a public opinion pioneer and cofounder of Public Agenda.

learning curve research methodology

Public opinion generally isn't static. As people engage on complex issues and weigh trade-offs, their views tend to evolve. Learning Curve Research studies this evolution using a variety of methodologies. The current project involved extended deliberative focus groups.

For this project, Public Agenda convened 3 extended deliberative focus groups plus 1 pilot focus group, with a total of 44 Americans. Each participant had at least some recent contact with the health-care system as patients. Participants were 40 to 64 years old, with the expectation that this age group—as patients and potential caretakers of children or elderly parents—would have the broadest perspective on the health-care system. This is also a politically significant group that tends to vote at high rates. Participants were also recruited to represent a broad cross-section of the public in terms of gender, socioeconomic status, race/ethnicity, and health insurance status. Focus groups took place in professional focus group facilities and all participants were compensated for their time.

First, participants engaged in three-hour focus groups divided into three main parts:

- **Participants had a general conversation** about the health-care system, the quality of care they receive, and their experiences with costs.
- **Facilitators presented participants with information** about the nation's health-care costs, including cost and quality comparisons over time, across countries, and across different areas in the United States. Participants responded to the information, asked questions, and discussed it as a group. This information is available for download from our website.
- **After a short break, participants deliberated** over three approaches to addressing the nation's health-care cost problem using a choicework discussion guide developed by Public Agenda, available for download from their website. The policy approaches were based on a review of reforms and changes to the health-care system that leaders and experts have proposed, are experimenting with, or have already implemented. The choices are not meant to be exhaustive or comprehensive, but to provide a basis for deliberation and reflection. The discussion guide laid out a set of concrete practices and policies that could help address the health-care cost problem, including the advantages and trade-offs of each approach.

The choices, in brief, were:

- **Approach A.** *Give people more responsibility for their health and health care.* Participants discussed measures that were geared toward ensuring that people have more “skin in the game” through taxes on unhealthy lifestyle choices, high-deductible insurance plans, and copays, as well as more choice among insurance plans and health-care providers.
- **Approach B.** *Make sure doctors and hospitals work in smart, cost-effective ways.* Participants discussed the issues surrounding payment reform, including pay-for-performance and charging flat fees per patient or episode of care, as well as incentivizing providers to work in teams, coordinate care, and share electronic health records.
- **Approach C.** *Contain health-care costs by regulating prices.* In this approach, participants discussed the pros and cons of capping health-care prices, regulating insurance markets, bringing generic drugs to market sooner, and expanding access to Medicare. Before and after the group sessions, participants completed surveys that

assessed their awareness of and opinions about health-care costs, their issue knowledge, and their sense of efficacy to effectively deliberate with fellow citizens.

Finally, we conducted follow-up telephone interviews with all participants, within a week after the focus groups. The interviews explored what participants took away from the conversations and how they were thinking about the various approaches to reducing spending after they had the time to “sleep on” the issues and perhaps discuss them with others. These interviews also gave participants opportunities to reflect on the deliberative research process and to express views they may not have shared in the groups.

The deliberative focus groups were conducted in Secaucus, New Jersey; Montgomery, Alabama; and Cincinnati, Ohio. A pilot was conducted in Stamford, Connecticut, allowing us to test the choicework guide, graphs and charts on health-care costs, the moderators guide, and the surveys.

The graphs and choicework discussion starter Public Agenda used to facilitate the focus group discussions are available upon request from

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Public Agenda. *Citizens' Solutions Guide: Health Care.* New York, NY: Public Agenda, 2012.

The *Citizens' Solutions Guide* to health care arms voters with the knowledge they need to understand the challenges and choices Americans face. Public Agenda's *Citizens' Solutions Guides* are a series of nonpartisan resources to help members of the public think through difficult issues, weighing values, priorities, pros, cons, and trade-offs.

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Can members of the public participate in preventing and treating cancer? This chapter discusses opportunities for engaging the public in cancer control, including successful examples of community engagement strategies in Canada, the United Kingdom, and Indonesia.

<http://global.oup.com/academic/product/cancer-control-9780199550173>.

Doble, John, Jared Bosk, and Samantha DuPont. *Coping with the Cost of Health Care: How Do We Pay for What We Need?* New York, NY, and Kettering, OH: Public Agenda/Kettering Foundation, 2009.

The National Issues Forums, a nonpartisan nationwide network of public forums for the consideration of public policy issues, facilitated deliberative forums with more than 1,000 citizens in 40 states and the District of Columbia in 2008 to understand how citizens can cope with the rising cost of health care. This report discusses the outcomes of those forums. <http://www.publicagenda.org/media/public-thinking-about-coping-with-the-cost-of-health-care>.

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