
Fixing the Health-Care System:

What People See—and What They're Willing to Do—After Deliberating

THIS REPORT—PREPARED AT A TIME when the difficulty of achieving a broad consensus about what should be done about health-care reform is once again at center stage—is a summary of insights from hundreds of community forums convened over the course of almost four decades by the network of the National Issues Forums.

INTRODUCTION

The cost of health care to individuals, businesses, and government has soared over the past decades, and the system has faced unparalleled new challenges with the spread of COVID-19 nationwide. Recent opinion surveys suggest that the vast majority of Americans believe the system needs reform of some kind.¹ Leaders have offered a variety of proposals to hold down costs while ensuring that most Americans have medical insurance and access to appropriate care. Today, debates revolve around fundamental reforms such as “Medicare-for-All,” along with more limited proposals to curb drug prices, bar “surprise medical bills,” and require more price transparency. But change is hard to come by, so frustration remains high across the board.

Throughout this time, the nation’s leaders have sought to understand the public’s views in order to craft solutions and determine which proposals garner broad public support. Opinion researchers have conducted hundreds of surveys and focus groups. Elected officials and candidates have held town hall meetings and met with constituents.

Journalists have reported on individual patient experiences and leadership ideas for improving the health-care system. All are useful and informative.

Hundreds of Local Health-Care Forums

But this report summarizes a kind of public thinking that is often missing from the national stage: what Americans think when they weigh various options and deliberate about them with others. Since 1982, a national network of community-based groups has convened forums to give Americans the chance to do just that. Using issue guides created by the Kettering Foundation for the nonpartisan National Issues Forums Institute (NIFI), ordinary people have gathered in libraries, colleges, senior centers, and dozens of other public spaces to weigh options for what should be done on topics of shared concern. These local convenors host conversations, or “forums,” that last between 90 minutes and 2 hours. While the term “forum” may call to mind a panel of experts with lengthy presentations, NIFI forums allow people to think through and discuss complicated issues and ideas with others. Participants work with issue guides that present options for what might be done, along with their respective costs and trade-offs. These materials are carefully tested and reviewed to ensure that they are unbiased and understandable by nonexperts.

Since 1982, the National Issues Forums network has addressed reform of the nation’s health-care system seven times, including in online forums conducted in 2020, in the midst of the COVID-19 crisis. Working with NIF, the Kettering Foundation has prepared reports summarizing forum deliberations by drawing on observations, transcripts, moderator reports, and questionnaires returned by many participants.

NIF HEALTH CARE ISSUE GUIDES

YEAR	ISSUE GUIDE TITLE
1984	<i>The Soaring Cost of Health Care</i>
1992	<i>The Health-Care Crisis: Containing Costs, Expanding Coverage</i>
1994	<i>The Health-Care Cost Explosion: Why It's So Serious, What Should Be Done</i>
2003	<i>Examining Health Care: What's the Public's Prescription?</i>
2008	<i>Coping with the Cost of Health Care: How Do We Pay for What We Need?</i>
2015	<i>Health Care: How Can We Reduce Costs and Still Get the Care We Need?</i>
2020	<i>Health Care: How Can We Bring Costs Down While Getting the Care We Need?</i>

These reports capture the views of a diverse group of Americans who choose to participate in forums; they are not the result of scientific surveys of the American public. Rather, they offer indispensable insights into the ways in which people think about issues when they have an opportunity to weigh benefits and trade-offs—and perhaps most important—an opportunity to hear and learn from others.

Public Thinking: What We Learn from Forums Versus Surveys

The difference between what is gleaned from forums such as these and from surveys is instructive. Polls ask questions of random or representative samples of the public, but in most cases, these individuals have not had an opportunity to discuss alternative solutions with others nor to assess the costs and benefits of various courses of action. Surveys typically ask the public to respond to expert and legislative proposals or other leadership ideas for change.

Deliberative forums, on the other hand, can show:

- how typical Americans, using their own words and frames of reference, see problems in ways that differ from the ways policymakers see them
- what people say *after* looking at alternative solutions and weighing advantages and trade-offs with others
- what questions people have and how they think about the tensions among various courses of action

- what ideas they themselves propose and what responsibilities they believe the public has

Local deliberative forums can be engines for change. When people gather to talk about issues, they often agree to pursue the matter, taking action to improve their own communities.

Health-care reform has been a contentious, high-stakes issue for decades. Repeated policy debates have failed to generate broadly supported or widely understood policy solutions. For the most part, typical Americans have been on the sidelines. Yet at a time when productive public dialogue is conspicuously missing and when serious deliberation is vanishingly rare, the thoughtfulness and open-mindedness of NIF participants is reassuring. While forum participants rarely change their minds completely, many report “thinking differently” about the issue afterwards. Some say they’ve had second thoughts about ideas they initially supported. Many acknowledge that the challenge of fixing the health-care system is more complex and multifaceted than they had assumed.

Four Decades of Forums: Five Observations

This report offers five observations about what happens in health care forums—forums conducted over nearly 40 years including a series of 2020 deliberations that will continue throughout the year. They are:

1. Forum participants identify problems—and opportunities—that leaders miss. They offer detailed, “on-the-ground” reporting not easily available elsewhere.
2. Forums show that policy leaders and the public often talk past each other on health care. The risk of miscommunication is ever-present.
3. In forums, participants begin to recognize the tensions among various courses of action, and their conversations often reveal fault lines in proposals that otherwise draw broad support in polling, such as providing national health insurance to all.
4. When people deliberate in forums, they add nuance to their initial top-of-the-head responses, even on complex issues such as health care. They often temper their views or forge areas of common ground.
5. In deliberative forums, people often consider their own responsibilities for health care and think about what they themselves should do.

FOUR DECADES OF NIF FORUMS ON HEALTH CARE

1984 “The 1984 NIF forums revealed a citizenry that had more nuanced, and perhaps ambivalent, opinions on health care than did similar polls from the era. To be certain, some areas of common ground did appear to emerge out of the forums, but there are also points where forum participants appear torn, as if they are still working through the issue. The difference here can likely be attributed to the trade-offs and choice-work that are emphasized in NIF issue books and forums. **Proposals that sound great certainly lose some of their luster when their drawbacks must be seriously considered.**”²

1992 “People are universal in their belief that there has to be universal coverage. But when it comes down to the impact of changes, people are not willing to budge on the quality of care and their control over getting the doctor they want. It seems the country is yet a step away from facing up to the consequences. . . . I think **we’ve got to focus the public debate on the consequences of getting the things that we want.**”³

2008 “As forum participants deliberated, the comments illustrated why Americans think so much is wrong with our health-care system and point to the basic outlines of what the public would support in terms of changes and reform. At the same time, the forum results show how conflicted public thinking can be and suggest

how much ‘working through’ Americans need to do before reaching a stable, logically consistent public judgment about what a new health-care system would involve.”⁴

2016 “Underlying many of the comments about health-care costs was a generalized distrust of many institutions—often expressed as a frustration with “the system.” . . . No matter whether they thought of it as government, business, or a combination, participants repeatedly characterized the health-care system as distant and unresponsive. . . . But the broad criticism and even cynicism about the system did not [emerge] as a refusal to engage with efforts to improve health care or lower costs. **Many of those in the forums believed that individuals as patients, family members, and citizens needed to be more involved.**”⁵

2020 “Nearly everyone has personal experience of some sort with what they see as a complex, confusing, costly, and often distant health-care system. Almost everyone has a horror story either about themselves or about someone they know. But there is very little understanding of the kind of issues that the candidates are talking about. **The discussion of policy options is categorized by huge gaps in knowledge and a feeling that there is no credible source of information.**”⁶

FIVE KEY INSIGHTS FROM DELIBERATIVE FORUMS ON HEALTH CARE: 1984-2020

Forum participants identify problems—and opportunities—that leaders miss. They offer detailed, “on-the-ground” reporting not easily available elsewhere.

Like most public meetings, NIF forums begin with people describing the problems they see and how these problems affect them. Like leaders and experts, typical Americans talk about the cost of health care and worry about people who don't have insurance. They discuss the quality of care they and their families receive. In forums, people focus on the same health-care triumvirate that concerns leaders—cost, access, and quality.

Within minutes, however, participants begin pointing to aspects of the health-care system that receive minimal attention from leaders or that leaders assume most people don't want to discuss. Observations over multiple rounds of NIF health-care forums suggest that three of these “gaps” are particularly important:

- people's frustration with the convoluted, impenetrable, opaque nature of the system
- people's willingness to talk frankly about the need for a healthier American lifestyle
- people's readiness to talk about what happens—and what should be done—when patients approach death

It's too damn complicated

Over the years and throughout the country, NIF forum participants describe a health care system that is disjointed, chaotic, confusing, and convoluted. In 2020 forums, some commented that the COVID-19 crisis had exposed the system's weaknesses and lack of coordination. One participant said, “This discussion and current pandemic make me

think we need a consistent quality system for everyone. We shouldn't all have to think or worry about this so much.”

Not surprisingly, many complaints about complexity, confusion, and even possible deceitfulness revolve around costs. People from all walks of life are uncertain about their bills, what insurance covers, and the ways in which various insurance plans work or don't work together.

In the early 1990s, a California woman said, “Every month I have to look at all the bills and fill out all these things and figure out what I should pay and what the insurance company should pay and what Medicare should pay. And I get screaming angry. I don't even talk to my husband for a day.” By 2015, little had changed. An Arkansas woman asked why she couldn't use her medical drug plan in the hospital. “They just charge you [through] the nose for their drugs that are [the same] drugs that you have to take [normally], but . . . they charge you the cost . . . from their pharmacy at full price.” In an online forum in 2020, one woman said she was glad her employer chose her insurance plan because the policies are so dense and indecipherable.

And for years, forum participants have described the country's health-care system as an incomprehensible bazaar, where prices are stratospheric and ever-changing and even insured patients can be hapless bystanders wondering how to control their own costs and pay the sky-high bills they get.

In 2008, a Stamford, Connecticut, woman told this story: “When my daughter was hospitalized last year, . . . they sent me the bill, and I thought, ‘I don't have to pay this. I have insurance.’ Then, when I called the insurance, they said, ‘Oh, yeah. That changed last year.’ [So I had to pay much more than I thought].” In 2015, a Texas woman described bills she received after her husband's death: “My husband . . . had heart surgery, and then he died that night after. He had huge bills. . . . There were three doctors [who] would not accept what the insurance companies pay. . . . They said, ‘It's not enough.’ The insurance company says, ‘These are more

than what's reasonable and customary.' . . . I was caught in between that. [Finally, I asked my doctor what to do] and he said, 'Don't pay any money yourself. . . . They'll fight it out.'"

Participants have frequently reported feeling trapped into costly treatments, unable to judge whether they are needed or whether someone is just trying to make money. In the early 1990s, an Orange County woman said, "You don't really know going in what it's going to cost. You go to a doctor; they say you really ought to have this. You have absolutely no way of knowing [whether] it's a good idea or not." An Arizona man in a 2015 forum described the costs his family faced when his pregnant wife was involved in a minor traffic accident: "She was okay, but because she was pregnant, that meant the ambulance arrived. . . . That was three grand. That meant two nights in the hospital, plus the other care, plus the ultrasound, plus all the scans, plus—it just added on. She has health insurance, [but the] deductible was \$2,000. That means that I had to come up with \$2,000 in cash within a month of [the] accident. On top of that, . . . we were splitting it 80/20. The total bill for that accident was almost \$40,000, and she had no substantial injuries. This was just monitors."

The way we live

Leaders and experts often identify the American lifestyle as an important driver of high health-care costs. Yet many avoid offering policy ideas for improving unhealthy habits for fear of being accused of shaming patients or establishing a nanny state.

Forums, however, show repeatedly that Americans of all ages and backgrounds are quick to acknowledge that Americans' unhealthy choices—and their own—drive up health-care costs. This comment from a Wisconsin man in a 2015 forum is not atypical: "I'm a smoker who has friends [who] smoke, and they say, 'I smoke. It's my body. It's what I'm doing.' Well, we know somebody who got lung cancer, lost a lung, and now he's on disability. I am paying for it. It

is my problem." Another participant in a 2015 forum talked about her community: "Most of my family members who have died prematurely died from poor health practices—smoking, lack of exercise, bad food, cheap booze. And they died after extensive and costly health care. This is very common in my region."

In recent years, a "wellness" movement has gained traction in the US, but even in the 1980s, NIF participants were talking about prevention. In a 1984 forum, a New York man said, "It's far more sensible to build a fence of prevention around the edge of the cliff than it is to have a shiny new ambulance waiting at the bottom." And in 2020, in the midst of the pandemic, this focus on prevention continues. The prime goal may be ensuring health, but participants can be quick to tie prevention to reining in costs: "If fewer people are overweight, they are less likely to get diabetes, heart disease, etc. If they don't have these chronic diseases, they are hospitalized less [and] use less medicine, and the overall costs will go down."

People's willingness to acknowledge the dangers in the American lifestyle is an opening for decision-makers. Moreover, forums suggest that public thinking here is rarely simplistic, judgmental, or puritanical. A 2017 summary of NIF forums summarized the participants' deliberations on obesity. Some pointed to a lack of access to healthy food ("food deserts," or as one Arkansas participant put it, "food swamps"), cuts in school physical education programs, government subsidies of corn and therefore high-fructose corn syrup, and other factors. Some also differentiated between different causes of obesity. "Weight is tricky because a lot of people can control it, some cannot, and some choose to just 'let themselves go.' It would be very difficult to put all overweight people in the same category because their situations are very diverse," one participant said. In the end, participants were attracted to ideas like increasing physical education in schools but more

cautious about letting insurers charge more for overweight policyholders.

Death—we should talk about that

For most elected officials and health-care experts, policy discussions about end-of-life issues are off the table. The specter of being accused of advocating “rationing” or “death panels” makes these questions far too politically volatile for open discussion.

But participants in NIF forums, including those taking place during the pandemic, have repeatedly shown that they want and need to talk about end-of-life issues. Most speak from personal experience. Younger NIF participants describe experiences with grandparents or the families of friends. Many talk with considerable emotion about what happened when someone they loved died in the American health-care system. Some refer to the money spent on “heroic” end-of-life care, but their main concern is whether such care is compassionate and what the patient and the family want. Many described feeling a lack of control—the sense that what happens to their loved ones is on autopilot.

In forum after forum, across the years, participants described the costly, mechanistic care delivered to patients in the final months and days of life, with many broadly supportive of making options like hospice care better known and more widely used. “As each of my grandparents lay dying,” a younger participant said in 2015, “I saw firsthand how many resources were spent on what can only be considered futile care. Those resources did not increase their quality of life. Rather, they extended particularly painful periods of their lives, and I think ultimately resulted in less peaceful deaths.”

In a 2015 Arkansas forum, one participant talked about a friend’s mother who “had very serious Alzheimer’s and then came down with cancer. The doctors [wanted] to do chemo and radiation and put her through all kinds of misery. [My friend] said to me: ‘I don’t think we should be doing

that.’ I said, ‘No, you should not be doing that.’ I mean, obviously, why subject this poor woman to [all this]? It’s just going to be a punishment to her. Why was this being recommended? Somebody was going to make a lot of money.” In the same forum, another participant chimed in, “It would have been very nice if the doctor would have said, ‘Look, these things can be done, and if you want them done for your mother, we can do them, but I personally would recommend, given her condition with Alzheimer’s, that we don’t do that.’ But [the doctor] didn’t do that. He was pushing for it.”

As we will discuss later, only a handful of participants in forums over the years have called for government or insurance companies to take charge in this arena. Nearly all of them said that these decisions are personal, revolving around their own values and perspectives on life and death. There was a broad call to talk about these questions more openly. And many wanted far more candor from doctors and an effective way to avoid what they saw as the reflexive medical juggernaut set in motion when their loved ones neared the end.

2. Forums show that policy leaders and the public often talk past each other on health care. The risk of miscommunication is ever-present.

The fact that leaders and the public bring different outlooks to an issue is useful. Leaders and experts often focus on long-term, overarching, systemic problems with the US health-care system, while typical Americans generally talk about personal experiences and how policies affect them and their communities. Both perspectives are essential to solving problems.

But trouble can arise when leaders assume that the broader public shares their priorities, understands their ideas, and uses words the same way they do. For example, NIF observers have repeatedly noted differences in the way leaders and the public talk about “the cost of health care.” For

leaders and experts, “cost” generally refers to the combined costs paid by governments, employers, and individuals—the enormous sums the United States spends on health care overall. But in forums, people talk almost exclusively about their own costs—the co-pays, deductibles, and drug costs they pay from their own pockets. In fact, one important function of forums is to help average Americans confront the hidden health-care costs they pay in taxes, flattened wages, and the cost of goods and services. Still, most Americans don’t participate in deliberative forums, and assuming that leaders and the public are on the same wavelength when it comes to “health-care costs” is a recipe for misinterpretation.

For policymakers, this cross talk is dangerous. While some experts have pointed to “health-care costs” leveling off in recent years,⁷ participants in the 2020 NIF forums continue to see “high health-care costs” as painful, potentially ruinous, and ultimately unfair. A Jacksonville man recently said, “They are ripping us off. They are charging way too much, and we still aren’t getting great health care.”

Similar miscommunication problems arise for a whole range of leadership-named ideas, including “national health insurance,” “universal coverage,” “single payer,” “Medicare-for-All,” and curtailing “fee-for-service” payments. Over the years, NIF forums have repeatedly offered participants opportunities to deliberate on ideas such as “single payer” or “Medicare-for-All.” Issue guides provide explanations for how these proposals would work and what kinds of changes they would bring about. But this learning curve is steep for Americans already confused about how the current health-care system functions.

In forums over the years, some participants have assumed these proposals would operate as they do in veterans’ hospitals or in Great Britain, where the government operates health-care facilities and doctors and nurses are government employees. Participants who have spent time abroad bring inconsistent evidence to the table. In 2008, a Portland, Oregon, man talked about what he saw in Japan:

“Government health care was great. . . . Everyone was covered. Everyone got the same thing.” But that same year, a Charlotte man who had lived abroad had a warning: “The health-care system was terrible, terrible—condemned to mediocrity because of government regulation.”

In a 2015 Wisconsin forum, participants engaged in an extended and spirited back-and-forth on whether Medicare is a national single payer system or not. And since Medicare currently includes private plan options along with government-managed insurance, it’s hard to argue that their confusion wasn’t warranted.

Whether typical Americans understand and adopt leadership terminology is, fundamentally, a distraction. Far more crucial is whether they comprehend how proposed changes would affect them and whether they’re willing to accept the possible risks of change.

What we do know is that up to now, the political, expert, and journalistic debates on health-care reform have been exclusionary. People “in the know” talk among themselves and incorrectly assume the broader public is following along.

3. In forums, participants begin to recognize the tensions among various courses of action, and their conversations often reveal fault lines in proposals that otherwise draw broad support in polling, such as providing national health insurance to all.

Giving people 90 minutes or more to think through and discuss a complicated public issue is a rare and exceptional occurrence. And forums repeatedly show that, given this chance, participants begin accepting the reality that in health care—as in other issues—there is no perfect, risk-free, universally popular solution “if only” leaders would act.

Over the years, NIF forums have repeatedly raised the idea of a government-managed, single payer health-care system as an option for deliberation. And repeatedly, in forums across the country, participants have grappled with the same questions that bedevil and divide experts. How

much will it cost? How much government involvement do we want? Will a change like this imperil quality or limit people's choices? How will this work out for me and my community?

Many participants begin their deliberations with the conviction that the current US system is broken, so it's time to try a bold new approach. And since the 1980s, both polling and forums have shown a broad initial interest in some form of "national health insurance."⁸ In 2015, as just one example, a Texas man was enthusiastic: "We're talking about how much it costs and how poor the delivery system is . . . compared to all these other countries, and we're asking, 'What should we do?' . . . To me, the answer is rather obvious: If it's Switzerland that's so much better than we are, why don't we do what Switzerland does?"

But as the deliberation proceeds, others raise questions, many centering on concerns about more government involvement in health care. In 2015, one participant put it this way: "Any time the government gets involved, you're going to have a lot of waste. It's nobody's money anymore, so nobody feels responsible." Worries over the quality of care in countries with nationalized systems are also common. A Memphis man's 2008 anecdote about his father's experience in Spain is typical: "My father needs surgery. He goes to his government doctor, and the doctor says, 'Well, you're going to have to put your name on the waiting list, and it's going to take three months.' . . . Well, what did my father do? He went ahead, and he paid for his own surgery because he could've been dead in three months."

Often participants paint the idea as a political nonstarter regardless of its merits. In 2015, a forum participant in Texas said, "This country isn't going to do that in the way that these other countries have because it's a cultural thing. We could talk about this all day long. It's a political reality that it could never happen."

In 2020 health-care forums currently under way, issue guides juxtapose three options: a "Medicare-for-All" approach, an approach emphasizing individual responsibility, and a proposal to make improvements to the Affordable Care Act. But the key question in the NIF forums is not, as it might be in a survey, "Which approach do you endorse?"

Instead, participants are weighing the benefits of expanded insurance and lower out-of-pocket costs against the risks and possible trade-offs. For many, the "Medicare-for-All" idea offers the security, simplicity, and predictability they keenly want. But as deliberations proceed, concerns emerge: People might have to pay more in taxes, some participants suggest, or quality might go down. "Can our government do a better job?" a Florida participant asked. "I am not sure that the government has proved that they can run anything." Another participant acknowledged, "The effects are beyond my comprehension."

Similarly, many participants have applauded aspects of a market-based approach, especially the idea of requiring more transparency. But asking patients to make insurance decisions—including not to buy health insurance at all—and then live with the consequences no matter what, bothered many. A Topeka participant said, "I am not okay living in a system where people are dying because they chose not to make a good decision."

In the end, forum participants in 2020 seem to be struggling with the tension between their anger and dissatisfaction with the status quo and their fears about the results of broad and sweeping changes.

A Jacksonville, Florida, woman verbalized what can only be described as her process of weighing tensions and working through: "I don't know which of these options fits best. When I grew up, my mother couldn't afford health insurance so I watched my brother throwing up blood, but we couldn't get him help. I want everyone to be able to get health care

when they need it. I don't know how to do it; that is beyond my ability. But I do like the idea of not throwing everything out. The best approach is when you build slowly over time. The politicians would like to help, but when they get there, their hands are tied, too."

This woman's intricate thought process is not a rare occurrence in deliberative forums. In most forums, participants are neither repelled by nor won over by the options they weigh. And beneath the surface, the dilemmas they point to are the deep-seated tensions humans have wrestled with throughout history. How do we weigh fairness against freedom? How do we choose between freedom and security?

What is evident, however, is that once people start delving into seemingly popular ideas, they often have questions and second thoughts.

Some political and policy leaders have suggested that the COVID-19 crisis might be a watershed that would reshape Americans' views on health care. But a comparison of NIF forums conducted before and during the outbreak shows a remarkable consistency in the deliberations. For some participants, the pandemic underscores the need for universal, guaranteed coverage: "Yes, the pandemic has pushed me strongly in the direction of a single-payer system," one said. But others have found a different message in the crisis, as this exchange shows: "Would government do a better job? Not our current government, but I'm staying out of political talk!" one participant said. "You mean they cannot even get us all tested!" another added.

Forums thus serve two essential democratic policy-making purposes: (1) They alert leaders to areas where public opinion is still developing and not fully worked through, and (2) they give the lay public the chance to wrestle with the tensions and downsides of proposals that will impact their personal lives and communities.

4 ■ When people deliberate in forums, they add nuance to their initial top-of-the-head responses even on complex issues such as health care. They often temper their views or forge areas of common ground.

Most common responses to forums are comments to this effect: "This is more complicated than I thought." Forum deliberations on health care consistently show participants tempering initial reactions and ideas as they begin to recognize the complexity of the issues. With deliberation, simplistic answers tend to be marked as just that—simplistic.

The health-care issue provides numerous examples:

- **Doctors and hospitals:** Sharp criticism of doctors is a common starting point: "You never see a doctor driving a Ford or a Chevrolet," a Texas man said in 2015. But in forum after forum, deliberations will turn to the high cost of medical education and malpractice insurance and the participants' personal experiences with doctors and other medical professionals working hard to help them. In 2020, there seems to be a widespread sense among participants that the US system is massive, incredibly complicated, increasingly dysfunctional, and resistant to change, and that doctors and hospitals are caught up in it all. This is seen as a tragedy without a clear villain.
- **Employer Mandates:** Conversations about requiring employers to offer insurance coverage, initially very popular, often give way to concerns about how the proposal would affect small businesses and whether such a mandate could reduce salaries, increase prices, or lead to lay-offs.
- **Transparency:** Proposals for more transparency on doctor and hospital fees—almost universally endorsed in forum after forum—morph into considerations about how much "shopping around" and

price-comparing typical patients can really do. At a 2015 forum in Texas, one man said, “People don’t have time in emergency situations to research which hospital to go to.” Another man in the same forum responded, “Right, in those emergency situations, absolutely . . . [Do you say] ‘Hey, over in New Mexico, it’s a little cheaper. You guys have a price-match or anything?’ They’re not going to do it.”

- **The Age for Medicare Eligibility:** The idea of starting Medicare at 67 or 68 because people are living longer nowadays produces similarly nuanced exchanges. In Wisconsin, one participant in a 2015 forum said, “I think a lot of blue-collar people who have worked very hard physically, to think that they have to wait until age 67 to be on Medicare is a cruel thought.” From a 2015 forum in Texas, a woman made a similar point. “They’re thinking that instead of 65 you’re going to be healthy until you’re 75 or 70. That’s not necessarily true.”

Ironically, NIF forums suggest that politicians and policymakers searching for the KISS—“Keep It Simple Stupid”—approach to health care are misguided. Rather than being daunted by the process of weighing tensions and having second thoughts, most participants see the forum process as empowering and vital. At a 2015 forum, an Arizona participant summed up this view succinctly: “Everybody needs to participate in their health care.” And at a 2015 forum in California, one participant used the forum itself as an example of how public engagement in health-care decision-making should look:

Participant (with emotion): I can’t believe we didn’t have this conversation before we enacted Obamacare.

Moderator: Which conversation?

Participant (pointing to the whole room): This conversation, about the health-care system.

5 In deliberative forums, people often consider their own responsibilities for health care and think about what they themselves should do.

Elected officials and policymakers often feel obligated to solve problems so their constituents won’t have to worry about them—so that complexities and burdens are lifted off people’s shoulders. And NIF forums repeatedly show that people expect policymakers to do their best to set up systems that are practical, fair, and functional. But that doesn’t mean they expect government or health-care providers to act in every circumstance or to relieve Americans of all responsibility for their own health and health care.

Forums where people deliberate about what should happen in instances in which costly end-of-life measures are available but probably futile are a case in point. Virtually no participants wanted the government or health insurers or hospitals to make the decisions for them. And their main concern was not cost (as it is for policymakers), but rather the peace and dignity of their loved ones.

Many called for doctors and other medical professionals to be more candid and upfront about the prospects for recovery and the pain and discomfort “heroic care” sometimes produces. Even more to the point, many participants left the forums vowing to take action themselves. In a series of 2020 forums in Florida, several people strongly advocated for ideas like educating family members about their advance directive wishes so they could act as health-care surrogates.

In a 2015 forum, an Arizona participant said: “One of the questions here is, What are we going to do socially? I think we can start socially having this conversation. . . . We’re not going to be very good with our aged parents, relatives, and loved ones if we don’t have this conversation and make the conversation known to our children, heirs, and people younger than us. Let’s just be brave and go out and say something to somebody this week about where the line is.”

In a similar vein, forum participants often see an active role for themselves in tackling health-care costs, strongly supporting more transparency in doctor and hospital fees whether they are well insured or not and whether or not they will directly pay the bill. Similarly, discussions about lifestyle and substance abuse issues—and the health-care costs they generate—often transition into community conversations about local programs, schools, and what the participants could do individually and collectively to support and improve them.

DELIBERATIVE FORUMS: A SPACE TO LEARN, RECONSIDER, AND IDENTIFY COMMON GROUND FOR ACTION

In recent years, many Americans have expressed despair over the deeply polarizing turn in national politics. Many question the news media's credibility and even-handedness.⁹ Yet even within this context, deliberative forums show people grappling with new ideas and listening to each other carefully. Most seem open-minded. Many leave the forums reconsidering or adding nuance to their initial views. Perhaps the principal takeaway from the NIF health-care forums over nearly four decades is that inviting typical Americans to deliberate on health care produces feedback that is reasonable, thoughtful, and possibly easier to act on than what emerges from surveys and town hall meetings.

Especially when the nation seems to be divided into partisan camps, neither of which is inclined to talk across partisan differences, it is notable that, given the opportunity, many people are able to bridge that divide to engage in civil and productive conversations. It is both heartening and important to pay attention to what happens when people actually do gather to deliberate.

Notes

¹ <https://www.publicagenda.org/reports/taking-the-pulse-where-americans-agree-on-improving-health-care/>.

² Nicholas Felts, memorandum to Kettering Foundation research on deliberative politics working group, "Access, Affordability, and Quality: 30 Years of Making Tough Choices on Health Care in the National Issues Forums," Fall 2015.

³ David Mathews, "A Public Voice . . . '93: A Report from the National Issues Forums Fall & Winter 1992-1993." (Remarks at National Press Club, Washington, DC.)

⁴ Public Agenda. "Thinking about Coping with the Cost of Health Care: How Do We Pay for What We Need? Outcomes of the 2008 National Issues Forums." A Public Agenda report prepared for the Kettering Foundation, 2009.

⁵ "Citizens at Work: What Happens When Americans Wrestle with Tough Choices on Health Care and Economic Security and What That Says About How They Come to Grips with Difficult Decisions." Kettering Foundation, 2016.

⁶ John Immerwahr's field notes report (forthcoming).

⁷ See, for example, American Medical Association: <https://www.ama-assn.org/practice-management/economics/growth-health-spending-slows-post-aca-era>, and Brookings: <https://www.brookings.edu/testimonies/containing-health-care-costs-recent-progress-and-remaining-challenges>.

⁸ Nicholas Felts, 2015.

⁹ John Doble and Jean Johnson in collaboration with Paloma Dallas, "A House Divided? Reflections on the Public's Mood." Report to the Kettering Foundation, October 2017.

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The National Issues Forums (NIF) is a network of organizations that brings together citizens around the nation to talk about pressing social and political issues of the day. Thousands of community organizations, including schools, libraries, churches, civic groups, and others have sponsored forums designed to give people a public voice in the affairs of their communities and their nation.