

Health Care 2020

How Can We Bring Costs Down While Getting the Care We Need?

Observations from NIF Deliberative Forums

The network of the National Issues Forums has convened deliberative forums on a wide range of complex public issues (including health care) since the 1980s. This year, the NIF network has joined Public Agenda, USA TODAY, and the Kettering Foundation in an election year initiative called Hidden Common Ground. Combining Public Agenda's in-depth opinion research and special coverage from USA TODAY and America Amplified, a public radio network, the initiative will focus on key issues, examining where the public is truly divided and where common ground can be found. NIF's network of local organizations provides opportunities for people across the country to deliberate and exchange ideas through an array of organizations—libraries, civic associations, universities, community groups, and others. The first wave of these Hidden Common Ground forums, on divisiveness, has been completed, and a report is available at nifi.org.

THE COST, FAIRNESS, AND EFFECTIVENESS of the US health-care system has been a pressing public concern for decades. In the first half of 2020, Americans participated in forums to deliberate on the problem and possible solutions. The forums were convened by the nonpartisan network of the National Issues Forums (NIF). This report summarizes what we heard.

Between January and June 2020, the NIF network convened more than a dozen nonpartisan forums inviting everyday citizens to deliberate on the future of the health-care system in the United States. These forums took place in three ways:

- In early 2020, local convenors organized forums in a variety of community settings in cities and towns nationwide.
- As the COVID-19 pandemic took hold, convenors pivoted to holding forums via Zoom or other videoconferencing technology.
- Throughout the period, some convenors used the Common Ground for Action platform for online deliberation, which brings participants from different regions together to exchange views.

What unifies all these health-care forums—and NIF forums in general—is the emphasis on “choicework.” Participants weigh the advantages and disadvantages of three broad approaches to an issue and look at specific proposals with risks and trade-offs spelled out. They

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use nonpartisan issue guides prepared by the Kettering Foundation specifically for nonexperts. Forums typically last about two hours.

Although forum participants are by no means random and representative samples of the general public, the discussions still provide useful insights for understanding how people wrestle with the trade-offs raised by suggested solutions to the most challenging public issues in extremely difficult times. As one might expect, the spring 2020 forums were shaped by the greatest health crisis the country had experienced in a century. Yet, at a deeper level, in forums both before and after the pandemic began, many underlying concerns and priorities remain unchanged.

DELIBERATING ON HEALTH-CARE CHOICES

The issue guide for all forums presented three broad options:

Ensure health care for all. This option envisions providing health care for all Americans by incorporating them under a government-run national health-care plan, sometimes called “Medicare for All.”

Build on what we have. This approach centers on providing more coverage and containing costs by expanding Medicare, requiring healthy people to purchase insurance, and emphasizing prevention and living wills as ways to reduce health-care costs.

Let people make their own choices. This option emphasizes market forces and consumer choice. Insurance and medical prices should be made much more transparent, and individuals should be able to buy “no frills” plans if they wish.

In the NIF health-care forums, participants deliberated about these options one by one, weighing the

specific actions that could be taken and the trade-offs they might entail. The actions in the guide included ones that could be taken at the federal, state, and local level as well as actions individuals could take directly.

Many participants completed a post-forum questionnaire exploring their priorities and reactions to the forum. Several main insights emerged:

1. An Underlying Stability in Attitudes. *Although participants used different examples to describe problems and priorities in the US health-care system after the onset of the COVID-19 crisis, their underlying positions and priorities were largely unchanged.*

Since 1982, the NIF network has convened multiple rounds of nationwide forums on health care, and in 2020, the Kettering Foundation completed a review of the deliberations over the years. One of the most obvious takeaways from this review is that the main themes of the deliberations have been extremely consistent over time. Year after year, NIF participants have pointed to similar problems and concerns in their encounters with the American health-care system. While public opinion surveys have highlighted disagreements over specific policies, they have repeatedly shown a near consensus on many of the public’s concerns and goals for change.

Given that attitudes about health care are so consistent over time—and so widely shared—it is perhaps not surprising that we saw so much stability in the health-care deliberations both before and during the coronavirus pandemic. COVID-19 provided the forum participants with vivid examples of problems with the health-care system and made the need for change even more pressing. But while the examples changed, the areas of agreement and disagreement remained largely consistent.

2. Concern for Themselves and Compassion for Others. *In forum and after forum, participants voiced compassion for anyone facing problems in the health-care system. Even those with excellent health insurance could easily imagine themselves in similar circumstances as a result of a surprise illness, inadequate insurance coverage for astronomical bills, or an unanticipated loss of insurance coverage.*

What was most striking about the forums—before and during the COVID-19 outbreak—is that nearly every participant had a health-care horror story to tell either about themselves or about someone they knew personally. The realization, shared by so many participants, was that anyone can face a health crisis that may not be adequately covered even by the best insurance policies. A participant from Florida said:

This year has been a rough year for our family, for my husband and myself. We are fairly well off and on Medicare with a supplementary program. But the bills that you get after that are brutal. Even with all of that, the costs and the prescriptions are very expensive.

Other participants talked about loved ones with inadequate insurance or no coverage at all, describing the system as broken and inequitable. In the forums held in the midst of the pandemic, people expressed the same kind of discontent but with heightened urgency as we can see in these comments from online forums.

- “The pandemic has exposed the weaknesses in our health-care delivery system.”
- “The pandemic is underscoring that this is not a system. . . . [It’s exposing] inequities in care.”

During in-person forums, such concerns were greeted with nodding heads and murmurs of agreement. There

was an overriding sense of compassion for others, coupled with a worry that no one is really secure.

The participants’ sense that they may be at risk with even the best coverage made many of them skeptical of proposals to curb health-care costs by creating more consumer choice, including more “no frills” health insurance policies. While the idea of personal choice is generally popular with the public, applying this philosophy to health care struck many in the forums as extremely dangerous. Their concern was that healthy people will buy inadequate insurance and then be struck by an unexpected illness, forcing society to pay their expensive medical bills anyway. One online participant in a forum held before the COVID-19 outbreak said:

Reduced quality plans? Well, if the government allowed only good plans to be offered. . . . Otherwise, I’m afraid people (like me!) would go for the cheapest but find unexpected loopholes.

The COVID-19 crisis provided participants with a reminder that, as one online participant said, “Even younger healthy people are getting sick with this virus.” A Kansas participant articulated a concern that we heard repeatedly: “I am not OK living in a system where people are dying because they chose not to make a good decision about their health-care policy.”

3. A Complex Tragedy with No Clear Villains.

NIF participants were painfully aware of how complex the health-care system is and how limited their understanding of it is. Most resisted a simplistic urge to blame greedy actors and recognized that there is no magic solution.

Public opinion researchers often accuse the public of having a simplistic view of problems and an attraction

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to simplistic solutions. Snapshot polls often pick up people's top-of-the head responses, which may well be simplistic. This does *not* characterize how the forum participants approached the problems of health care once they began deliberating. Indeed, many were quite frank about their lack of understanding. A forum participant from Kansas said:

I don't understand how health care is delivered and how the changes being discussed would impact it. This category of medical care covers so much ground that I don't even know where we would start!

Confronted with a broken system, participants often saw plenty of blame to go around. Many criticized “big pharma,” often mentioning the outrageous price of EpiPens. It was also hard to find participants defending health insurance companies. What emerged, however, was not so much a clear sense of what is wrong, who is to blame, or what could be done to fix it. Instead, forum participants often came to a growing realization that this massive system is incredibly complicated, increasingly dysfunctional, and stubbornly resistant to change.

For example, forum participants often seemed to conclude that doctors are as much victims of the system as are their patients. A Florida forum member said:

I have a brother-in-law who is a physician. He struggled with the MBAs who came into the insurance industry and forced hospitals to discharge patients. He finally decided that private practice was not for him. The system is broken.

Many participants also suggested that hospitals are overwhelmed by uninsured people coming to emergency rooms for routine medical treatment.

As one hospital administrator in Kansas put it:

In the hospital where I work, some people come to the emergency room because they are cold and lonely. They know to say that they have chest pains so they will be seen and maybe get something to eat.

Politicians were often blamed for not being able to fix the system and being too cowardly to stand up to lobbyists, but few forum participants claimed that government was benefitting from the existing system. As a woman from Florida said, “The politicians would like to help, but when they get there, their hands are tied, too.” For many in the forums, the US has a tragically broken system without the comfort of a clear villain to blame.

Forum participants also struggled with a sense that there are no credible sources of information. For example, discussions of national health care invariably evoked conflicting anecdotal reports about health care in other countries. In a Kansas forum, one woman talked about the wonderful treatment her aunt had experienced in France, with four months in the hospital and no bill. Another woman in the same group countered by explaining that several relatives in Spain had terrible outcomes because their treatment was delayed by long waits for lab work. An online participant articulated a concern voiced in many forums:

That is what is so frustrating about our national discussions. Too many ideas but not enough information.

The United States is currently awash in contradictory views about the coronavirus; the NIF forums suggest that this is only a more extreme version of what was in place before the crisis.

4. Pragmatism and an Aversion to Radical Changes. *While ideological arguments about the role of government were evident in the NIF deliberations, participants were also deeply concerned about the practicality of making major changes to the health-care system.*

A sense of compassion clearly motivated many participants to call for change in a problematic health-care system. Still, this desire was often tempered by a realization of the overwhelming complexity of the system. The result was a broadly shared call for incremental change by building on what we have.

The interest in incremental change emerged most clearly in deliberations on “Medicare for All.” The idea of replacing our current patchwork system with a national, government-run approach to health care appealed to the compassion (and fear) shared by so many of the participants. A single payer system might be simpler and easier to understand than the confusing mess of multiple systems they now experience.

But talking about universal health care often plunged the participants into a familiar ideological argument about the efficacy of government programs. In an in-person forum held in Texas before the pandemic, a moderator described the argument in this way:

Those who had experiences of government-sponsored health-care programs—i.e., VA and Medicare—strongly supported “Medicare for All,” while others questioned the efficiency and effectiveness of governmental involvement in health-care issues.

In online forums convened in the midst of the pandemic, the argument was often rephrased in terms of the coronavirus, but again some participants said

the need for universal coverage was greater than ever, while others were even more skeptical about government’s competence and reliability. Here is a sampling:

- “I have strongly favored universal coverage; the need for it has been exposed for all to see.”
- First participant: “Would government do a better job? Not our current government. . . . But I’m staying out of political talk!”
Second participant: “You mean they cannot even get us all tested!”

But the idea of a bold transition to a completely different health-care system engages concerns that go beyond ideology. Even participants who supported universal coverage sometimes called for incremental changes. A woman in Florida captured a sentiment we often heard both before and during the COVID crisis:

I don’t know which of these options fits best. But 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 like the idea of throwing everything out. The best approach is when you build slowly over time.

5. A Different Conversation. *NIF participants often suggest their own ideas about the changes they want to see in the health-care system, but their language and priorities are quite different from what we hear from experts and leaders.*

One of the directions that participants most often wanted to discuss is almost taboo in leadership conversations—decisions about care at the end of life. Forum participants repeatedly called for a more sensible and compassionate approach to end-of-life medical care.

Most wanted franker discussions and more control for patients and their families.

While some participants talked of loved ones who could not get the care they needed, others told heart-breaking tales of family members who got painful and expensive care they did not want. A Florida moderator summarized the group's deliberation this way:

There was considerable discussion about the expense of end-of-life health care and emotional family realities. Several people strongly advocated making provisions for a durable power of attorney and a health-care surrogate who is not a family member. Others felt that by educating their family members about their advanced directive wishes, family members could serve as health-care surrogates.

Another topic that came up frequently in the forums was the need for healthier lifestyles among Americans and more emphasis on prevention. During the pandemic, a participant in an online forum echoed what was consistently heard earlier:

If [fewer] people are overweight, they are less likely to get diabetes, heart disease, etc. If they don't have chronic diseases, they are hospitalized less, use less medicine, and the overall costs will go down.

The idea of a public insurance system that people could buy into on a sliding scale also attracted a lot of interest from the participants presumably because it offers another option without destroying what is

already in place. Many participants seemed to accept that health care should be a shared financial responsibility—one in which individuals expect to contribute something to their own insurance and care.

Although the forums were rife with complaints, and sometimes sheer mystification, about high health-care costs, most participants did not seem to think that high-quality health care would be inexpensive or that prices would go down. A number of the participants filled out questionnaires after the forums and the responses here suggest a fairly realistic recognition that improving the US health-care system won't be cheap. The idea of adding dental and vision coverage to all insurance policies was also a fairly low priority. All in all, those responding to the questionnaire were more concerned with covering more people than with covering more categories of care.

As often occurs in the forums, participants do not necessarily coalesce around a single solution. Instead, they move away from simplistic or doctrinaire approaches and become more aware of the tensions and conflicts in complex policy choices. In these forums, participants often struggled to resolve the tension between their anger and dissatisfaction with the status quo and their fear of sweeping changes that might make a bad system worse. Most were looking for a way forward but in a different voice from what we often hear from elites.

In forum after forum, participants used the deliberations to explore the parameters for better policies, and they resisted the seduction of simplistic answers.

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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.