MAIN FINDINGS
Affordability was participants’ number one priority for health care. Unlike leaders, participants were not concerned about how much the government spends on health care, but they were angry about the costs they face.

In recent years, a majority of Americans, regardless of party identification, say making health care affordable to individuals and families should be the top health care priority for the president and Congress. This sentiment emerged immediately in our groups as people reflected on the health care system and their experiences with it. They shared stories about facing expensive medical bills, paying for pricey prescriptions and covering burdensome copays, premiums and deductibles. They were ardent and forthright about how the high cost of health care affected their lives and their families.

“The prices keep going up and our paycheck stays the same.”
Franklin County, MO; in her 30s; uninsured; Independent

“I fell into a trap. I couldn’t get Medicaid, but I couldn’t afford the Obamacare. So it was kind of a double-edged sword.”
Franklin County, MO; in his 50s; self-purchased health insurance; Republican

“My grandparents are retired and over half of their income goes to what Medicare can’t cover. My grandmother at 75 years old is looking for a part-time job to be able to cover Medicare copays. I think that’s absolutely ridiculous.”
Hamilton County, OH; in her 30s; Medicaid; Democrat

Experts and public officials often cite excessive government spending as a reason to reform the health care system. But surveys have found that more Americans are concerned about lowering the amount individuals pay for health care than decreasing how much the federal government spends on it over time. While some of our participants voiced concerns about waste and inefficiency, most viewed high health care spending by government as of little concern—or even as a sign of well-placed priorities—rather than as a fiscal red flag.

5 In some instances, quotations have been minimally edited for clarity.
Thus, when we presented focus group participants with information about how much their respective state governments and the federal government spend on health care, many were unconcerned about high levels of government spending. In fact, many viewed high spending favorably and were instead surprised by what they thought was a lower amount than they assumed. One man from Suffolk County, New York, went so far as to say that current federal government spending on health care is not enough:

“Only 20 percent of the federal budget? That’s a low number. It should be higher. That’s the problem. Health care should be a right, but then the 20 percent has to go up significantly.”

Suffolk County, NY; in his 40s; self-purchased health insurance; Democrat

In a similar vein, a respondent from Missouri added:

“Our defense spends $615 for a toilet. They can find a way to pay for health care.”

Franklin County, MO; in his 70s; self-purchased health insurance; Independent

One woman, also a political Independent from Franklin County, Missouri, said the government is already spending the taxpayers’ money, so it may as well spend that money on health care. An Independent from Suffolk County, New York, described health care as “such an important thing” that it merited public spending.

These findings are consistent with a 2018 Kaiser Family Foundation survey that showed very few Americans, regardless of political affiliation, support cuts to government health care programs—only 7 percent support such cuts for Medicare, and only 12 percent support such cuts for Medicaid.8

---

“Simplicity” was a recurring word in our groups. Needless complexity—including inconsistent and opaque billing practices, mysteriously shifting drug prices and arcane administrative procedures—was viewed as extremely aggravating by participants in our groups. Goals for health care in the United States, our participants agreed, should include a streamlined, transparent, easy-to-navigate system that does away with unpleasant surprise costs and red tape.

“The biggest thing I can tell you is they get these damn bills, and they’re all over the place. You’re talking about a dentist charging 110 bucks. Same dentist, $110 for you, $117 for you, $218 for you, $300 for you.”

Franklin County, MO; in his 70s; self-purchased health insurance; Independent

“I almost feel like I work in a doctor’s office. I’m emailing them, but you have to stay on top of them. You have to watch your bills as they come in so you reach that deductible. You have to be really organized in managing your own care.”

Suffolk County, NY; in his 50s; employer-sponsored health insurance; Republican

“My husband was in the hospital with some heart issues. They wanted to send him home on monitor for 30 days. And he said, ‘Well, what’s this going to cost me?’ And they couldn’t give him a price. So, he said, ‘Get a social worker, or someone, an insurance person in here to call my insurance company to find out what this is going to cost me out of pocket, because last time it happened it cost $10,000 because the insurance didn’t cover it.’ And all we got from the hospital was, ‘I don’t know, I don’t know, we can’t get you the information.’ So he left the hospital without the monitor.

Franklin County, MO; in her 40s; employer-sponsored health insurance; Independent
The desire for transparency is consistent with findings from a Public Agenda survey in which most Americans—63 percent—say there is not enough information about how much medical services cost.9

Participants often described health care costs as not just too high but irrational or suspect.

“I had a special pill they wanted me to take after my knee surgery, and when I went to pick it up it was $300. I called my doctor, I said, ‘Hey, I can’t afford that, and I’m paying all this insurance.’ He said, ‘Well, let me get back with you. Call me back.’ You know what that one pill cost after that? Three dollars and something. See, they playing games with these drugs.”

Hamilton County, OH; in her 60s; Medicaid; Independent

“All these drug companies are the ones setting the prices on all this stuff. And they just want to charge you whatever they think you’ll pay.”

Hamilton County, OH; in his 60s; employer-sponsored health insurance; Republican

Overall, participants were adamant about the frustrations of deciphering and navigating the health care system, particularly payment. Their exasperations were evident in how they described the system, using terms such as “nightmarish” or “makes no sense.” Tired of being given the runaround by insurers, hospitals and providers, participants called for a simpler, more efficient and transparent health care experience.

People viewed prices as out of control and were intrigued by the idea of states doing more to control prices. But they were unsure about value-based payment.

A 2017 survey from Public Agenda revealed that 68 percent of Americans think insurance companies are mostly interested in making money, rather than having patients’ best interests in mind. Thirty-eight percent of Americans think hospitals are mostly interested in making money, and 27 percent think that of doctors. We often heard similar sentiments in our focus groups.

“They charged me like $45 for a syringe. That’s why insurance is so high because they overprice everything and it just keeps on going up.”

Hamilton County, OH; in his 60s; employer-sponsored health insurance; Republican

“They have to inflate [Medicaid and Medicare costs]. The doctor has to inflate because they’re getting, like nothing from the insurance company. The doctor’s receptionist said, ‘He’s getting $35. This is why he’s charging you $200.’”

Suffolk County, NY; in her 60s; self-purchased health insurance; Democrat

“I got my arthroscopic surgery on my knee. I went to a surgery center and they charged my insurance company $32,000. And then six months later, it just so happened my husband had the same surgery. And because of convenience, he went to the hospital. And they charged $17,000. Same exact surgery.”

Franklin County, MO; in her 60s; self-purchased health insurance; Democrat

Participants in our Suffolk County, New York, group framed the problem in terms of excessive profit, motivated by greed and perverse incentives, though they were of varying views on the pros and cons of for-profit vs. nonprofit health care:

“The problem on the whole is because it’s all for-profit. Until the system becomes a not-for-profit, you’re going to have all these issues.”

Suffolk County, NY; in his 40s; self-purchased health insurance; Democrat

“Everyone needs to make some money. I mean, if they’re overcharging that’s one thing, but that’s what makes them better is that they’re for-profit.”

Suffolk County, NY; in his 50s; employer-sponsored health insurance; Republican

“It’s terrible that it is for-profit because it’s never going to change. It’s always going to be about money.”

Suffolk County, NY; in her 50s; Medicaid; Independent

“A lot of pharmaceutical companies do a lot of great work, and some have jerks like [Martin Shkreli]. But if it wasn’t for pharmaceutical companies, there would be a lot of cures that are not available today because they discovered them.”

Suffolk County, NY; in his 60s; Medicare; Independent

There was general agreement in these groups that more oversight is needed with respect to high prices. When we asked participants about states doing more to control how much hospitals and medical facilities can charge insurance companies—and briefly explained to participants the example of Maryland’s global payment system for hospitals—the notion generally elicited support.11

“One hundred percent better regulation is needed. There’s nobody watching. I went to the doctor the other day and she ran tests she didn’t have to.”

Suffolk County, NY; in her 50s; Medicaid; Independent

“If it’s Missouri people working for Missouri residents, then there’s a tighter ship there, and there’s accountability there. At least they’d have a vested interest in the people that they’re serving.”

Franklin County, MO; in her 40s; employer-sponsored health insurance; Independent

Insurers and providers are also increasingly experimenting with “value-based payment” as a strategy for controlling costs and incentivizing quality improvement. This means transitioning toward a system that rewards quality and outcomes of care rather than the quantity or volume of services provided. The only survey we are aware of that asks the general public about value-based payment found that, not surprisingly, most people are not familiar with the term or with terms such as “bundled payment.”

We explained the concept of value-based payment to participants and asked for their perspectives on paying providers based on quality and outcomes rather than on quantity or volume. Generally, people were not familiar with the concept and found it confusing. They had many questions about how it would work.

“TThere’s some merit to it, but I don’t think it’s as simple as that because some people need more care than other people.”

Franklin County, MO; in her 40s; employer-sponsored health insurance; Independent

“Well, it could work because the doctor could give you the best test the first time.”

Hamilton County, OH; in his 50s; self-purchased health insurance; Republican

“They’ll do the least possible to get the best outcome. I don’t think that’s good for anybody.”

Hamilton County, OH; in his 60s; employer-sponsored health insurance; Republican

Some participants likened value-based payment in health care to proposals that tie teachers’ pay to student outcomes, with one woman, an Independent from Hamilton County, Ohio, saying she had “a real issue” with such an approach. If value-based payment is to be adopted more widely, there is clearly a need to better engage members of the public on what it is and its pros and cons.


Everyone should have access to health care, according to participants. But they objected to the idea that people should be required to have coverage and were skeptical that the government could effectively run a single-payer system.

There was agreement among participants that everyone should have coverage or access to health care. A combination of fairness, compassion and pragmatism seemed to animate people’s views that no one should be denied access to affordable health care because of financial distress or preexisting conditions. An Independent from Suffolk County, New York, went so far as to say that health care is a “human right” that should be available to all.

“Everybody's entitled to have [health insurance]. So, the opportunity for insurance is welcoming.”
Franklin County, MO; in her 40s; employer-sponsored health insurance; Republican

“I would like for the poor people to get the same good care that somebody with a lot of money can.”
Franklin County, MO; in her 60s; self-purchased health insurance; Democrat

“I think it's a good thing that everyone is entitled to get insurance.”
Hamilton County, OH; in her 60s; Medicare; Independent

“I like that we take care of our poor people. That's important to me.”
Suffolk County, NY; in her 60s; self-purchased health insurance; Democrat

“In the past, if you couldn’t afford insurance, you went to welfare and they would help people out that needed extra help. And it seemed like that worked in the past with some of the people I knew.”
Hamilton County, OH; in his 60s; employer-sponsored health insurance; Republican

“Even before the Affordable Care Act, our governor had already put things in place with the Medicaid expansion and a couple other things to make sure that almost everybody got [coverage]. He seemed to care more about the people in this state getting coverage and expanding things like Medicaid. And that was an expense that helped everyone.”
Hamilton County, OH; in her 60s; Medicaid; Democrat
Participants often specifically mentioned the Affordable Care Act’s rules that people with preexisting conditions cannot be denied coverage and that people under age 26 can stay on their parents’ insurance—two elements of the ACA that survey research indicates are quite popular.16

One woman made the case that everyone should have coverage because it’s not fair to those who are paying for insurance to subsidize the uninsured, but she was unusual in making that connection between universal coverage, costs and fairness.

“Everyone should be insured because it’s not fair that I pay insurance and here’s somebody else going to the hospital to get all these good services. I think it’s good that we do have this thing where everybody is sharing the cost.”

Hamilton County, OH; in her 60s; Medicare; Independent

Generally, participants seemed to feel that all Americans should have health insurance—if they want it. While a few had no issue with the individual mandate, participants often expressed discomfort with the idea of being required by the government to purchase health insurance coverage, viewing it as an encroachment upon freedom and choice.17

“I do know a healthy young person that chooses not to have health insurance. Is she gambling? Maybe, but life’s definitely a gamble. You shouldn’t have to if you don’t want to. Freedom shouldn’t be penalized.”

Suffolk County, NY; in her 60s; self-purchased health insurance; Democrat

“I think the patient should have the choice, but with the understanding that with that choice comes personal responsibility.”

Franklin County, MO; in her 40s; employer-sponsored health insurance; Independent

“I don’t think somebody should be forced or demanded to have something that they don’t want.”

Hamilton County, OH; in his 30s; employer-sponsored health insurance; Independent

“Having health insurance should be a personal decision. It shouldn’t be demanded upon the company to provide that because some people could care less about it. As a business owner, I get penalized for that.”

Hamilton County, OH; in his 50s; self-purchased health insurance; Republican

---


17 After we completed these focus groups in September 2017, Congress passed the Tax Cuts and Jobs Act, which effectively repealed the ACA’s individual mandate starting in 2019.
Survey research indicates an ongoing split among the public over the government’s role in health care. In 2017, 56 percent of Americans said the federal government should be responsible for making sure all Americans have health care coverage—comparable to the 59 percent who said so in 2000.¹⁸

We asked participants about the idea of letting all Americans join Medicare or even replacing private insurance with Medicare. Some were intrigued, citing their satisfaction with how Medicare was currently running and noting that it could help businesses by relieving them of the responsibility of purchasing health care for their employees.

“From my experience so far with my husband, Medicare is working out just fine. Nobody told him he can’t go to any specific doctor. Everybody he looked at takes his insurance.”  
Suffolk County, NY; in her 50s; Medicaid; Independent

“I like the idea because it takes burdens off of companies.”  
Hamilton County, OH; in his 50s; self-purchased health insurance; Republican

But participants also expressed concerns about Medicare for All. Generally, their questions and concerns were more practical than ideological, including skepticism that the government could efficiently implement and administer the program. They often referenced what they’ve experienced with other government-run health programs or their perceptions of health care in other countries.

“The government manages veterans’ health care, they already manage the VA, and they’re not doing a stellar job. Why in the world would anybody think they can take on another program and do better?”  
Franklin County, MO; in her 40s; employer-sponsored health insurance; Independent

“If you go to a lot of these countries [with government-run health care], people die because they wait months because they can’t get a liver or the doctors aren’t getting enough pay.”  
Hamilton County, OH; in his 30s; employer-sponsored health insurance; Independent

“I’m Native American. My dad moved to Oklahoma because he would get free medical care [through the Indian Health Service]. But when he got really sick we had to move back here to Missouri, because they didn’t even have the doctors to take care of him. And that is government.”  
Franklin County, MO; in her 40s; employer-sponsored health insurance; Republican

“A lot of people from Canada come to the States, and they just pay cash to get medical care because they are on wait lists.”  
Franklin County, MO; in her 40s; employer-sponsored health insurance; Independent

The sentiments we heard in these groups are consistent with survey research. A Gallup survey found Americans were almost evenly split in their preferences for a government-run health care system versus a system based on private insurance.\textsuperscript{19} A Kaiser Family Foundation survey found that public support for a single-payer system or Medicare for All is malleable: a slim majority supports such programs, but when survey questions present the trade-offs that may be required, opposition outweighs support.\textsuperscript{20} Overall, the discomfort we heard among participants about government-run health care suggests that people need time to mull over the trade-offs before they come to a stable judgment on the topic.


Participants were angry at politicians and politics. They felt that the odds for progress would improve if politicians had the same frustrating, expensive insurance coverage that their constituents do.

People in these diverse, multipartisan groups were united in their frustration with politicians and their inability and unwillingness to tackle health care with integrity. Almost all of our participants viewed politicians as caring more about special interests than the public interest.

“I hate seeing health care as a political football being tossed around where we’re stuck in the middle of that.”
Suffolk County, NY; in his 50s; employer-sponsored health insurance; Republican

“I think the drug companies have more lobbyists in Washington than there are politicians.”
Suffolk County, NY; in his 60s; Medicare; Independent

“It’s all the lobbyists saying, ‘Wow, this pharmaceutical company will throw money towards you if you take care of us.’ And it’s not just pharmaceutical companies.”
Hamilton County, OH; in her 60s; employer-sponsored health insurance; Independent

“The personalities and the politics keep getting in the way. It’s more of a game to them.”
Hamilton County, OH; in her 60s; Medicaid; Democrat

Many firmly believed that members of Congress have excellent and free insurance—leaving politicians out of touch with the health care system that ordinary Americans experience.

“All those senators and congressmen have their own little pocketbook of health care that’s different. They don’t have the same insurance that the rest of us have. That’s one of my bigger grieves.”
Hamilton County, OH; in her 60s; employer-sponsored health insurance; Independent

“We have 70-, 80-year-old people in Congress who are completely out of touch.”
Suffolk County, NY; in his 40s; self-purchased health insurance; Democrat

“They don’t have to pay for their insurance.”
Hamilton County, OH; in his 60s; employer-sponsored health insurance; Republican
In every group, at least one participant raised the idea that politicians should be required to have the same health insurance as their constituents so that elected officials could experience firsthand the shortcomings of the current system. This suggestion inevitably elicited widespread and enthusiastic responses from fellow participants. Having the same insurance as their constituents, participants said, would compel lawmakers to act promptly and in the public interest.

“If you want a health care plan passed tomorrow, make sure every senator and representative gets the same damn plan, no exceptions, no exemptions.”
Franklin County, MO; in his 70s; self-purchased health insurance; Independent

“I have no power to solve the world’s issues. But if the people making the laws had to follow the same laws, our health care system would be different.”
Hamilton County, OH; in her 60s; employer-sponsored health insurance; Independent