
II. PARTICIPATION IN HEALTH CARE COMMUNITY DISCUSSIONS

A. Reasons for Signing Up and Participating

Over 9,000 Americans from every state and the District of Columbia signed up to host a Health Care Community Discussion in areas ranging from small country towns to major American cities (Map 1). Health Care Community Discussion leaders came from every walk of life – patients and their family members, religious leaders, first responders, doctors, nurses, and small business owners.

Some people indicated in their sign-up submissions why they were interested in taking the time and energy to host a Health Care Community Discussion. Illustrative examples include:

- Don from Ohio explained, “We can present...an honest appraisal of the health care crisis from [the] ‘boots on the ground.’ Too often, academics and policy makers do not know how the system really functions. Similar to the military, it often helps to have the generals see the actual conditions on the battlefield to appreciate the difficulty the foot soldiers experience.”
- Robert from Indiana highlighted, “Our neighbors include a broad and diverse cross-section of America. Within a few miles we have steel mills, inner cities, suburbs, and farms....We are theologically...and politically diverse....Our event will demonstrate...the level of understanding among Americans regarding the need for access [to health care] by all Americans, and ideas for achieving that goal.”
- Elizabeth from South Carolina noted that her community could “show everyone that even the true middle class is really struggling with this issue.”
- Carl from New Jersey wrote, “This would be a gathering of ordinary Americans, with an extraordinary passion for seeing their friends and neighbors (and possibly themselves, in some instances) have access to the high-quality health care that American ingenuity has developed, but which American political gridlock has so far prevented from being delivered to all those who need it.”

- Donna from Illinois signed up to host “a holiday health care chat...with friends and neighbors.” She explained, “We will bring together many members of the community to discuss solutions from their perspectives – not just the problems. We will invite patients, doctors, nurses, students, young and not-so-young people, business folks and friends. This will be a cross-section of our community offering ideas.”

B. Who Participated in Health Care Community Discussions

Health Care Community Discussion hosts submitted over 3,276 group reports to the Change.gov reporting Web site. Almost three-fourths of the reports (72%) could be categorized according to the majority of participants. Of these reports, over three-fourths were attended by a majority of everyday Americans, 16 percent were attended by a majority of health care providers, and 8 percent were attended by a majority of members of advocacy organizations.

Looking at participants from Health Care Community Discussions that submitted group reports, more people in Southern and Western, rural, and high-income communities participated in the Health Care Community Discussions relative to their population. About 63 percent of participants – nearly 20,000 – were in Health Care Community Discussions in the South and West. About 8 percent of participants attended town meetings in rural areas. A relatively low percentage of participants attended Health Care Community Discussions that occurred in low-income communities. (See Figure 1 and Appendix C for a detailed table on Survey respondents.)

Group reports also provided details on the participants of their Health Care Community Discussions:

- A Health Care Community Discussion in a suburb of Cincinnati, Ohio, self-reported that it consisted of six small business owners, three physicians (two self-employed), a nurse in a small medical office, a recently unemployed professional, an employed professional, a self-employed therapist, two secretaries, and an elementary school art teacher. The individuals ranged in age from 24 to 65.

- A North Plainfield, New Jersey, Health Care Community Discussion of 10 participants was comprised of grant writers, social science researchers, union officials, educators, and nurses.
- In Sioux City, Iowa, a group of 14 participants (9 men and 5 women) included three business executives, an engineer, two infectious disease physicians, a cardiologist, two emergency room physicians, a retired nurse, a radiologist, two family practice physicians, and a nurse practitioner specializing in wound care.
- A retired couple, a working couple, a small business owner, a professional, a teacher, a newly unemployed person (one week out of a job), and an individual who had been unemployed for over two months attended a Health Care Community Discussion in Redondo Beach, California.

C. Sample of the Health Care Community Discussions

The reports were far reaching in substance and style. Here, we include four illustrative Health Care Community Discussions. They provide a glimpse of the opinions and ideas about health reform that emerged from the thousands of Health Care Community Discussions. To read more of the group reports submitted by Health Care Community Discussions from across the country, please visit www.HealthReform.gov.

Longmont, Colorado Health Care Community Discussion

On December 29, 18 residents of Longmont, Colorado, gathered in a home to discuss the following questions: “What should a good health care policy include?” and “How do we get involved in bringing about a better system?” The Health Care Community Discussion host described the meeting as “a truly grassroots event in a small town in Colorado where the political spectrum is changing.”

One participant’s story illustrated the devastation often inflicted upon families by a broken health care system that forces many Americans to delay care. A single mother with two teenage sons, ages 17 and 15, had felt sick but continued working her two jobs to support her family. As described in

the group report, “When [the mother] ended up in the emergency room, tests showed that her heart was so damaged by a virus that it only function[ed] at 30% of capacity....Her heart function is now only 25%.” In addition to the mother’s heart condition, her eldest son was diagnosed with bone cancer only when he was admitted to the emergency room after suffering from leg pain for “months.” Consequentially, as described in the group report, “A family that had been self sufficient is now destitute with two members suffering from life threatening illnesses which could have been alleviated with early health care.” The Longmont group cited cost as the biggest problem in the health care system and remarked, “[I]ndividuals fail to seek services because they are afraid of costs.”

University of Central Florida (Orlando, Florida) Health Care Community Discussion ○○

On December 22, approximately 70 people attended a Health Care Community Discussion hosted by the Department of Public Administration within the College of Health and Public Affairs at the University of Central Florida’s Orlando campus. Participants included everyday Americans and representatives from social service and local government agencies, medical offices, and various academic disciplines. Attendees cited access to care as the most significant problem with our current system, particularly for children and the uninsured. Other problems identified during the Health Care Community Discussion included needing to cover the uninsured, affordability, disparities in the cost of care, the quality of practitioners, the need to improve efficiency and patient services through medical technology, and an inadequate focus on preventive care.

One attendee from Belle Isle, Florida, shared her story about the impact of the high costs of health care on her ability to keep her family healthy. Her family was denied insurance because she has a pre-existing condition and her husband has high blood pressure. She was unable to purchase an insurance plan for her one year-old daughter without an adult being on the same plan. As a result, she had to delay required immunizations for her infant daughter because each shot cost \$125. She further explained, “My husband’s employer provides health care coverage, but we cannot afford the \$1,200 monthly premiums. His \$48,000 salary did not qualify us for Medicaid. We do not consider ourselves poor, and we are conservatives living within our means. I believe that all Americans should receive basic coverage and medically necessary medications. American citizens should be able to visit their own doctor or locate a doctor where they do not have to pass the welfare line to be treated.”

The UCF Health Care Community Discussion was covered by a local NPR radio station (WMFE), a local television station (WESH, Channel 2 NBC News), the *Orlando Sentinel*, and the *UCF Newsroom*.⁷

Oakland, California Health Care Community Discussion

On December 30, a pastor from Oakland, California, hosted a Health Care Community Discussion to talk about “the health care system...how it can be better, and [how it can] provide care for all citizens.” She also organized the meeting to discuss how the then-incoming Administration should address the rising costs of prescription drugs and health care services. The meeting participants included “a doctor who has traveled to Cuba to observe their health care system, a teacher, a public health nurse, a pastor who works with mentally disabled offenders, a pastor who is also a hospice chaplain, a psychologist, and a pharmaceutical representative.”

Participants talked about their struggles with the cost of health care. A teacher with two children revealed that she cannot afford the more than \$1,000 per month it would cost to insure her children, leaving her to choose between providing food or health care for her family. The group also discussed their difficulties in choosing doctors because they felt there was “no informed way of making this decision.”

The attendees were not familiar with the types of preventive services Americans should receive, and they thought that “public policy should make it mandatory that employers and insurance companies inform the public.” The group brainstormed ways in which public policy could promote healthier lifestyles. Participants suggested that “schools should be required to have [physical education] five days a week [and] sports for all students” and that “there should be more affordable and free [health] centers where people can exercise.”

Rockland, Delaware Health Care Community Discussion

On December 19, a group of 7 individuals from the Wilmington, Delaware area met to discuss health care reform. The host outlined her motivation for holding a Health Care Community Discussion in her sign-up: “As we look toward policy and other changes in the health care system, I believe it is

important to first make sure everyone sees the problems more fully, with less blame, and with a sense of commitment of responsibility to assist in this change. As the local community group reconnects, they provide an important source not only of information and feedback...they also become an important source for change....My hope is that our small group Health Care Community Discussion will steer in this direction.”

The group met on a Friday evening and discussed problems people faced, including the inability to afford co-payments or insurance, medical mistakes, and inadequate quality of care. The group offered several recommendations, including providing affordable access to quality health care for all; prioritizing intervention at all levels, such as a greater focus on prevention; and openly acknowledging and addressing our “culture of unhealthy lifestyles and externalizing responsibility.” After reflecting on both positive and negative experiences with the health care system, the group decided they would commit to take action locally by encouraging and developing health related community projects that could “help reform self-care aspects of health care.”⁸

D. Articles on Health Care Community Discussions

Hundreds of local papers around the country announced and reported on area Health Care Community Discussions, including the following stories:

- *KSNW NBC 3* in Wichita, Kansas; the *Kennebec Journal* in Augusta, Maine; *KOB.com NBC 4* in Albuquerque, New Mexico; and numerous other media outlets across the country announced discussions in their community and encouraged area residents to get involved.⁹ *KSNW NBC 3* publicized an upcoming Health Care Community Discussion at the Metropolitan Coffee House in Hutchinson, Kansas, and the meeting moderator Bunny Czarnopys said that, “They’re looking for the stories of Kansans and input...The stories of Kansas aren’t unique to stories across the country but one of them may catch the attention of the health care policy transition team. It’s the grassroots movement that [has] made major changes in the US healthcare policy in the past.”¹⁰

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- The *Tuscaloosa News* in Tuscaloosa, Alabama, covered a Health Care Community Discussion attended by 50 residents at a local high school, where participants discussed treatment costs, the importance of education in living healthier lives, how to make benefits easier to obtain, and ensuring access to medical care in rural areas.¹¹
 - The *Alaska Journal of Commerce* wrote a story on an Anchorage, Alaska, gathering of over 150 participants at an area library. Attendees highlighted that their major concerns were the high costs of health care services and insurance, as well as the lack of emphasis on prevention. They also discussed that the shortage of health care providers at all levels contributed to rising costs, especially in rural Alaska, where residents may have to pay hundreds of dollars just to travel to the nearest community for care.¹²
 - The *Southern Utah Spectrum* covered a Health Care Community Discussion in St. George, Utah, where attendees ranged from retirees and health care professionals to the unemployed and uninsured. Participants highlighted problems with the health care system, including too many layers of complexity, no affordable universal coverage, difficulty accessing health care, and lack of funding for preventive care.¹³
 - The *Citizen-Times* in Asheville, North Carolina, reported on a potluck dinner discussion attended by 18 local residents. The group spent nearly two hours talking about “ways the new administration could make health care more affordable and easier to access.” Brian Moore, who attended the meeting, said, “The one thing people uniformly agree on is that the health care system is broken and needs to be revamped. If we don’t begin to take a more active role in our personal health and health care in this country, we only have ourselves to blame.”¹⁴
 - The *Reno Gazette-Journal* in Reno, Nevada, covered a Health Care Community Discussion attended by 125 people at the Grand Sierra Resort. Participants discussed preventive care, the cost of prescription drugs, availability of care, and problems with insurance companies. Dr. Richard Fleming, who attended the Health Care Community Discussion said, “We need a voice. We should have more public discussions as bills are being debated.”¹⁵

- The *Herald-Mail*, in Charles Town, West Virginia, reported on a local group that gathered at a coffee shop. The group drafted a nine-plank platform addressing issues such as the prohibitive cost of insurance and the lack of access to quality health care. One of the hosts, Karen Spurier, opened the meeting by stating, “Clearly our health care system needs to change. The question is how.”¹⁶
- The *Star Tribune* of Minneapolis-St. Paul, Minnesota, wrote about a business executive, Roger Vang, who hosted a Health Care Community Discussion. Vang initially looked at Change.gov to learn about the potential impact of health care reform on his company. He saw Senator Daschle’s call to host a Health Care Community Discussion and responded. Despite a severe snowstorm, dozens of people, including members from a local manufacturing group and the Chamber of Commerce, packed Vang’s company lunchroom to share their opinions on health care.¹⁷



Grosse Pointe, Michigan



Indianapolis, Indiana



Escondido, California



Bowie, Maryland