

Americans Speak on Health Reform: Report on Health Care Community Discussions



U.S. Department of Health and Human Services
March 2009



Helena, Montana



Cartersville, Georgia

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EXECUTIVE SUMMARY

In December 2008, the Presidential Transition Team invited Americans to host and participate in Health Care Community Discussions to talk about how to reform health care in America. Over 9,000 Americans in all 50 states and the District of Columbia signed up during the holiday season to host a Health Care Community Discussion and thousands more participated in these gatherings. Friends, family, neighbors, and co-workers, representing the views of both health care patients and providers, came together in homes, offices, coffee shops, fire houses, universities, and community centers with a common purpose: to discuss reforming the health care system.

After each Health Care Community Discussion, hosts were asked to fill out a Participant Survey and submit a group report to the Presidential Transition Team's Web site, www.change.gov ("Change.gov"), summarizing the group's main concerns and suggestions. Committed to bringing all Americans to the table, the Health Policy Transition Team and a group of dedicated volunteers read and analyzed, line-by-line, the 3,276 group reports submitted to Change.gov. This extensive and intense engagement of the public in policy development by the Federal government is unprecedented and historic, as is this study, which systematically analyzed the information generated by the Health Care Community Discussions.

One of the most striking results from this analysis was the lack of differences in the concerns and solutions identified by participants: Americans who participated in Health Care Community Discussions were generally united in what they felt was wrong with the system and the general direction on how to fix it. The Health Care Community Discussions focused on concerns about a "broken" health system, access to health insurance and services, rising premiums and drug costs, being "uninsurable," medical mistakes, and the system not being "for them." In 30,603 Participant Surveys, the top concerns were cost (55%), lack of emphasis on prevention (20%), pre-existing conditions limiting insurance access (13%), and concerns about the quality of care (12%). Participants told stories about people who are bankrupted by medical bills, who cannot afford to see a doctor when sick, and who wind up in emergency rooms because they have nowhere else to turn. These stories, and thousands of similar ones, affirm that we must fix America's broken health care system, and that we must fix it now.

Many of the Health Care Community Discussions focused on the aspirations for the health system, suggesting that its performance would improve if it adhered to guiding values or principles. Among the reports discussing system solutions, participants expressed support for a system that is fair (36%), patient-centered and choice-oriented (19%), simple and efficient (17%), and comprehensive (15%). The Health Care Community Discussions offered a wide range of specific suggestions for fixing the system, including making health insurance more accessible through a public plan, creating scorecards on quality and cost, improving the nutritional content of school lunches, implementing electronic medical records, and creating an AmeriCorps for health workers.

The Health Care Community Discussions are a first step in this Administration's commitment to an open and inclusive style of governance that allows all Americans to have a voice in our country's health reform efforts. This Administration recognizes that true reform comes from the grassroots up and promises that when Americans speak, the Administration will listen. These Health Care Community Discussions reflect the President's commitment to enlist the public in achieving a top priority: creating a health system that is affordable, accessible, and high-quality for all Americans.

HIGHLIGHTS

Concerns about the U.S. Health Care System: Health Care Community Discussion groups were asked to appraise the performance of the U.S. health care system through a Participant Survey and in their own words through group reports. Many commented that the system is “broken,” particularly with regard to the adequacy, affordability, and accessibility of health insurance coverage.

Health Care Costs: Among the group reports that focused on the cost of health care, 28 percent focused on health insurance premiums with another 28 percent worried about the overall cost of the system. The cost of health care to individuals and families was a topic of discussion in one-fourth of the cost discussions; prescription drug costs were mentioned in 21 percent of such reports. Examples of these concerns included:

- From Enid, Oklahoma: “I have worked hard all my life as a farmer and in the energy sector. I have spent my life's savings on [health care] and now I am refused care at our local hospital because I cannot pay. I may have to file [for] bankruptcy due to this.”

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- From Fayetteville, North Carolina: The group described “a single mother of two children [who] remarked that her choice had become as basic as health insurance or food for her family.”
 - From Yelm, Washington: “If the premium costs continue to increase at the current annual rate, it would eat up most of their retirement savings just to pay health insurance premiums before they qualify for Medicare. The rate of increase of insurance premiums is out of control and they feel powerless to correct the problem.”
 - From Houston, Texas: “How can you go out on a limb and start a new business when health care is a noose around your neck?”
 - From Fort Wayne, Indiana, describing a small business’s experience: “[They] had premiums jump from \$385 per month for three employees to more than \$2,800 in four years. They were forced to drop coverage and have lost two key employees because of it.”

Access to Health Care: Among the Health Care Community Discussion reports that focused on access problems, 37 percent expressed concern about being denied access to care due to pre-existing conditions and other non-financial barriers, 27 percent reported challenges obtaining access to services, 20 percent felt their coverage was inadequate (such as lacking preventive care and mental health coverage), 18 percent pointed to provider shortages, and 16 percent disparaged a system where health care for many Americans is only accessible through hospital emergency rooms. This is in addition to the large fraction of participants worried about the cost of health care and health insurance.

- From Kingston, Rhode Island: “The central health care issue of our time is *access* to affordable, high-quality primary care.”
- From Wisconsin Dells, Wisconsin: “My mother is epileptic; she has been all of her life. This is not a choice she made, this is a condition...but because of her condition she is denied coverage. It’s not that she is just not covered for her epilepsy issues, she is denied for all her health concerns, prevention included.”

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- From Missoula, Montana: “No mother should have to say her daughter is ‘uninsurable.’ We provide education to all children but not health care? It just doesn’t make sense to me.”
 - From Keene, Texas: “More people need to have proper medical care so they don’t run to the emergency room when they have a medical problem that is not an emergency.”

Quality: Most of the quality concerns were with the overall system (47%), although 36 percent of reports that mentioned quality focused on overuse of services and 20 percent discussed medical errors.

- From rural Kentucky: A group at a public library talked about “concerns that you are safer outside of the hospital than in it, unless you have an advocate who can make sure the proper care is being given to a loved one.”
- From Sedona, Arizona: “Medical testing and test interpretation is sloppy and often inaccurate.”
- From Albuquerque, New Mexico: “We’re finding it harder and harder to talk to our doctors, and we’re feeling that our day-to-day health concerns are being increasingly marginalized.”

System: A large percentage of the Health Care Community Discussion reports pointed to structural and systemic issues at the heart of the problems in the U.S. health care system. In 37 percent of the reports that focused on system problems, participants either praised or criticized the link between employment and health insurance. Additional common topics of discussion included concern about the system’s complexity (27%), trepidation that it espouses the wrong values and emphasis (such as a lack of focus on prevention or the health system’s market orientation) (29%), and its coverage gaps that result in a large number of uninsured (21%).

- From Nashville, Tennessee: “The system does not seem to have prevention and health as a goal. It seems to be about something else entirely.”
- From Michigan City, Indiana: “Many, many stories were offered about people who suffered through needless hospitalizations because they were unable to get the insulin or blood pressure medicine that

they needed, or because they had conditions that were not diagnosed early enough.”

- From Cambridge, Massachusetts: “[T]he biggest problem in paying bills was the fact that nobody seems to know what their health care should cost. Nobody could cite a situation where they understood their medical bill or knew whether the insurance company was providing proper coverage for rendered services.”
- From Boulder, Colorado: “I fell off a roof in September and was just terrified to go to the hospital. A few hours there and you owe \$2,700 – I don’t understand how they come up with these bills, I don’t understand them.”
- From Portland, Oregon: “We also felt strongly that the health care system in its current state is clearly NOT FOR US. It is not designed to benefit or help us. Who is it for? Who does it benefit? We suspect that the answer is big corporations, because none of us know any individuals who feel that the health care system really meets their needs. It’s bureaucratic, disempowering, overwhelming, confusing, and frustrating in more ways than we can list.”

Solutions to the Problems in the U.S. Health Care System: Thousands of Health Care Community Discussions offered suggestions on the values, roles, and policies that should guide the effort to reform the U.S. health care system.

Principles for a Reformed U.S. Health Care System: Many of the Health Care Community Discussions focused on their aspirations for the health system, suggesting that its performance would improve if it adhered to guiding values or principles. Among reports discussing such principles, participants wanted a system that is fair (36%), patient-centered and choice-oriented (19%), simple and efficient (17%), and comprehensive (15%).

- *Fair:* Participants seek an inclusive health system that does not exclude Americans who cannot afford it or cannot access it due to sickness or health risks. From Charleston, South Carolina: “The nation needs some form of universal health care. The failure to insure that every citizen has access to affordable health care is a major reason for the chaos and fragmentation of the delivery of health care in this

country, and goes a long way towards explaining why our country ranks below many others in the overall health and longevity of its citizens. It is also a source of severe financial distress for millions of families and individuals across the country.”

- *Patient-Centered and Choice-Oriented:* Participants placed a high value on choice and orienting the health system around patients. From Scituate, Rhode Island: “We want a system that encourages engagement between people and their primary care practices and other health providers; that is patient centered, which means meeting people where they are, as they are, and giving them services that actually improve their health.”
- *Simple and Efficient:* Many Health Care Community Discussion participants suggested that a simpler health system would both improve outcomes and efficiency. From Merrick, New York: “The amount of increased paperwork and need for doctors to hire people to take care of it was cited as wasteful, a result of our present insurance environment, and the feeling that the money spent on that be put where it can increase the quality of care for everyone. Paperwork needs to be streamlined because it becomes the focus of care instead of the patient.”
- *Comprehensive:* The specific type of coverage was as important to some participants as whether they received coverage at all. From Bristol, Virginia: “There was also general consensus that mental health cannot be separated from physical health and that some level of mental health care services should be available to all citizens.”

Roles in a Reformed U.S. Health Care System: Participants in Health Care Community Discussions frequently stressed the importance of collaboration in both fixing and operating the health system. The theme of “shared responsibility” was common. However, Health Care Community Discussion groups had differing views on whether the roles of the main actors in the health system – the government, private sector, businesses, and individuals – should expand or contract in a reformed health system.

- *Role of Government v. Market:* The debate among participants was less about whether government should have a role in a reformed health system and more about the size of that role. A number of “single-payer” advocates participated in Health Care Community Discussions. From Livermore, California:

“This group was almost strident in its belief that we should simply adopt a single-payer system similar to what is enjoyed in Canada and much of Europe and take the burden off of individual employers and corporations altogether.” Others expressed concerns about the approach. From St. Louis, Missouri: “[A] major concern with [a] public v. private plan was the quality of care received with a public plan.” This debate took place within as well as across groups. From Bristol, Virginia: “Many argued that the insurance industry should be completely removed from the health care delivery system, but others saw how they acted as ‘gatekeepers’ to control costs, and to offer affordable coverage to some employers.” Other groups supported a “hybrid” model that would include both types of plans.

- *Role of Businesses:* Health Care Community Discussion participants expressed varying views on the role of employers in a reformed system. From Staten Island, New York: “All feel that all employers should be required to offer some health care plan to employees...” From Hillsborough, California: “Employers should be involved in paying for health care, but not providing coverage; health care itself should not be linked to employment; [there should be] seamless ‘portability’ of health coverage.”
- *Role of Individuals:* Most participants in Health Care Community Discussions stressed that individuals should take a primary role in health reform by leading healthier lives. From Leesburg, Florida: “Educate and prepare people, particularly youth, to take responsibility for their own health thereby empowering them to make healthy choices...” Other groups talked about the role of individuals in financing the health care system, including a sliding scale, income-based contribution.

Specific Suggestions: Health Care Community Discussions recommended numerous different solutions. The solutions clustered around several themes related to reducing insurance and drug costs, using information to improve the quality and efficiency of health care, promoting education and healthy behavior, and strengthening the capacity of the health care system.

- *Health Insurance Exchange:* A number of groups suggested organizing health insurance choices for Americans through a purchasing pool or exchange. From Redondo Beach, California: “All individuals with employer-based package[s] seemed to like the idea of options to utilize [an] insurance exchange or public insurance, depending on the cost of the program(s).”

- *Reducing Prescription Drug Costs:* Health Care Community Discussion groups recommended aggressive actions to lower the prices of prescription drugs. From South Trail, Florida: The government needs to “negotiate reasonable pricing for drugs with the pharmaceutical manufacturers.” From Sebastopol, California: “Pharmaceutical costs should be standardized and decreased through a government acquisition program.” From Welaka, Florida: “All feel there must be an overhaul of drug company marketing techniques and drugs from other countries should be easier to obtain.”
- *Research, Standards, and Promoting High-Value Health Care:* Participants suggested different options for using the power of research and standards to improve quality and efficiency. From Littleton, Colorado: “Public policy can create a data base to compare providers and their costs for basic services. In this data base can be a listing of their filed complaints or some type of review (maybe similar to the Better Business Bureau) where consumers can know if they are seeing a quality provider or not (rather than relying on the insurance company to tell them who they get the best rates from). Providers would ultimately benefit because patients would migrate to those more efficient/better outcome providers.”
- *Simplification and Information Technology:* Harnessing 21st century tools like information technology to make the health system perform better emerged as a common theme in Health Care Community Discussions. From Springfield, Missouri: “Health records should be...made electronic and secure. This will promote coordination of care, enhanced quality, and create a safer patient environment.”
- *Education on Health and Wellness:* Participants recommended education as a critical element of health reform. From New York, New York: “We further believe that meaningful health care reform must include an emphasis on health education – throughout the life course – focusing on prevention and wellness. The goal is to teach people what they need to know to stay healthy and give them enough knowledge to make informed choices when they need medical care.”
- *Promoting Healthy Lifestyles:* A number of reports recommended coupling education with incentives to promote healthy lifestyles. From Larchmont, New York: “The group agrees that the country needs to treat obesity as an epidemic taking over the nation. Every dollar we spend putting apples in the hands of our youth will translate into hundreds of dollars saved in diabetes treatments, etc.” From Fort Worth, Texas: The government needs to “make neighborhoods safer so people can get out and walk; put

in sidewalks in all communities; have community facilities aimed at teaching healthy behaviors.”

- *Expanding Health System Capacity:* Policy makers should invest in expanding the health care workforce and primary care clinics, according to some Health Care Community Discussion participants. From Valley Village, California: “Create a ‘Health Corps’ or ‘AmeriCare’ (along the lines of the Peace Corps) not only providing new jobs but also creating a network of health care providers across the country that can deliver affordable care, conduct community outreach for education, prevention, and wellness, and flag emerging health problems as they arise.” From South Pasadena, California: “While there is a shortage of nurses in the country, we are a powerful enough force to effect change for the public good in a cost-effective way.”

Suggestions for Future Engagement: The Participant Survey solicited more than just concerns and policy solutions: it also asked how policy makers should reach out to Americans, and how Americans want to remain involved in health reform.

- *How to Develop the Health Reform Plan:* According to 30,603 participants, the most popular way to develop a plan for health care reform is more community meetings similar to the Health Care Community Discussions (37%), a White House Summit on Health Reform (21%), and surveys to solicit ideas on reform (18%).
- *How to Stay Engaged:* Most participants (38%) wanted more information on health reform solutions as a means for continuing participation in the health reform debate, and nearly one-third of respondents (31%) wanted more opportunities to discuss the issues. All types of communities expressed interest in such opportunities. Further, 18 percent of respondents wanted more background information on the problems to stay engaged and 13 percent wanted more stories about how the system affects real people. Interest in continuing to stay involved was strong. From Green Acres, Washington: “We are extremely encouraged that President-elect Obama is reaching out to all Americans rather than special interest groups to come up with a solution. More than ever, we are optimistic that this solution will be reached.”

Conclusion: President Obama has encouraged all Americans to have a direct say in the effort to reform the health system. Individuals who participated in the Health Care Community Discussions rose to this challenge. These Health Care Community Discussions brought together people in all 50 states and the District of Columbia from all walks of life – patients, doctors, business owners, and advocacy groups – who united around a common concern: the need to reform health care in America. The stories of hardships that emerged from the Health Care Community Discussions, and thousands of similar stories, affirm the need to reform America’s broken health care system. The Health Care Community Discussions represent two related Administration commitments: to an open, inclusive style of governance that engages Americans in the policy process and to health reform that is directly responsive to the problems Americans face, the stories they share, and the solutions they offer.



Rio Rancho, New Mexico



Accokeek, Maryland



Seattle, Washington



Visalia, California