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."

- 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."

- 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

I. OVERVIEW OF HEALTH CARE COMMUNITY DISCUSSIONS

A. Introduction

This past December, thousands of Americans in all 50 states and the District of Columbia answered a call from the Presidential Transition Team to host and attend Health Care Community Discussions. The Transition Team's motivation for these grassroots discussions was to engage Americans and hear directly about their health care experiences and ideas. An overwhelming response of over 9,000 Americans signed up on the Presidential Transition Team's Web site, www.change.gov ("Change.gov"), to host Health Care Community Discussions and thousands more participated in these gatherings. All over the country, friends, family, neighbors, and co-workers, representing views of both health care recipients and providers, came together for conversations in homes, offices, coffee shops, fire houses, universities, and community centers with a common purpose: to discuss reforming our health care system to provide quality, affordable health care for all Americans.

After each Health Care Community Discussion, hosts were asked to fill out a Participant Survey and submit a group report to the Health Policy Transition Team summarizing the group's main concerns and suggestions. Committed to bringing all Americans to the table, the Health Policy Transition Team, a team of dedicated volunteers, and some employees of the U.S. Department of Health and Human Services spent thousands of hours reading and analyzing, line-by-line, the 3,276 group reports submitted to Change.gov. This report summarizes these Health Care Community Discussion participants' views on the health care problems Americans face and the solutions they propose.

B. Motivation

This Administration has made clear that health reform is a top priority – and recognizes that few challenges we face are as complex and consequential as fixing our health care system. The potential of health care to extend and improve the lives of Americans is enormous and ever expanding: once life-threatening diseases are now curable, and conditions that once were devastating are now treatable. But to seize this potential, we must reform our flawed system that fails to deliver affordable, accessible, and

high-quality health care to all Americans. The system suffers from a number of problems: health care costs are skyrocketing; over forty-five million Americans have no health insurance; many Americans who have insurance lack quality and affordable care; and our investment in prevention and public health is inadequate and fails to prevent or manage the rapid spread of chronic diseases. In the current economic crisis, health reform is even more essential in order to get the economy back on track. President Obama has commented that "in order to fix our economic crisis, and rebuild our middle class, we need to fix our health care system too…it's clear that the time has come – right now – to solve this problem: to cut health care costs for families and businesses, and provide affordable, accessible health insurance for every American."

But to successfully reform our health care system, the President believes we must first fix the process itself. Health reform cannot be achieved through closed-door meetings and ideas from Washington players alone. Instead, the Administration is committed to an open and inclusive process that allows everyday Americans to have a voice and direct involvement in our country's health care reform efforts. The rationale is that, through their own experiences, Americans know what works, what does not, and what can be done to help all Americans have access to affordable, quality health care and to live longer, healthier lives.

In December 2008, the Presidential Transition Team sought to tap into this knowledge by encouraging all Americans to participate in Health Care Community Discussions. Explained by then President-elect Obama, "Providing quality affordable health care for all Americans is one of my top priorities for this country because our long-term fiscal prospects will have a hard time improving as long as sky-rocketing health care costs are holding us all down. Yet in order for us to reform our health care system, we must first begin reforming how government communicates with the American people. These Health Care Community Discussions are a great way for the American people to have a direct say in our health care reform efforts, and I encourage Americans to take part if they are able. I am looking forward to hearing back from you." The Transition Team asked hosts of the Health Care Community Discussion to submit the compiled results from a Participant Survey and submit a group report summarizing their stories, their discussion, and their ideas.

These Health Care Community Discussions, therefore, 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. This new approach may break the old barriers to forging a health system that is affordable, available, and high-quality for all Americans.

C. Logistics

The Health Care Community Discussions were designed as a grassroots-driven effort to engage Americans on health reform. After Senator Tom Daschle announced these Health Care Community Discussions at a Colorado Health Summit and encouraged all Americans to "share their ideas about what's broken and how to fix it," the Health Policy Transition Team launched a sign-up page on Change.gov where anyone interested in hosting an event could sign up. The Change.gov sign-up page highlighted then President-elect Obama's commitment to "health care reform that comes from the ground up" and noted "that's why this holiday season, we're asking you to give us the gift of your ideas and input." The Obama-Biden Transition Project Co-Chair John Podesta sent an e-mail to registered users of Change.gov encouraging them to help shape health reform by signing up to lead a Health Care Community Discussion. The homepage of Change.gov encouraged Americans to sign up as well. Numerous newspapers, news shows, and radio programs reported on the opportunity to host these community gatherings.

Beginning on December 13, 2008, the Transition Team e-mailed a Moderator Guide to people who signed up at Change.gov to moderate a Health Care Community Discussion.[1] The Guide offered suggestions for the planning of their event. This Guide outlined three possible goals for hosts:

1. "Engage in discussions with your friends and neighbors about health care reform and draft a group submission with your findings and conclusions. This will help the Transition Health Policy Team flesh out key issues around health care and give the Team fresh ideas about the best ways to promote the President-elect and Vice President-elect's vision of quality, affordable health care for all Americans;

2. Develop your group submission to the Transition Health Policy Team through a process that respects, empowers, and engages all attendees; and

3. Identify particularly poignant stories about health care from participants that can be used to help emphasize the need for health care reform in our country."

The Moderator Guide was only a reference for hosts, who ultimately decided how to structure their gatherings. The Transition Team welcomed different discussion formats – whether held at home as an informal gathering, at work with more structured break out sessions, or even online through blogs or chatrooms.

The Transition Team also e-mailed hosts a suggested Participant Guide to distribute to attendees at their Health Care Community Discussions.[2] The Guide summarized major problems with our current health care system and provided background information on the President's health care agenda to provide every American high-quality and affordable health care. The Participant Guide also included several discussion questions that could be used to facilitate the conversations.[3]

At the end of each Health Care Community Discussion, the Transition Team asked hosts to have attendees fill out a multiple-choice Participant Survey in the Participant Guide, which asked about the biggest problem in the health system, the best way for policy makers to develop a plan to address the health system's problems, and what additional input and information would best help people to continue to participate in the health reform effort.

The Transition Team encouraged Health Care Community Discussion hosts to report back on their Discussions by uploading a group report at the Change.gov reporting Web site. In addition to requesting a group report and Participant Survey responses, the Health Policy Transition Team encouraged hosts to upload a photo and/or video of their Health Care Community Discussion. The Transition Team encouraged Health Care Community Discussions to occur between December 15 and December 31, 2008, although reports submitted through January 4, 2009, were accepted and included in the analysis.[4]

D. Analysis

The response to the request to participate in this project was enormous. Roughly 9,131 Americans from every state signed up to host a Health Care Community Discussion. Of these sign-ups, 3,276 groups submitted Health Care Community Discussion reports through the reporting Web site on Change.gov, either by uploading documents or writing comments in a text box, that were used in this analysis.[5] In addition, Participant Survey data for about 30,603 attendees submitted by group hosts was logged and analyzed. This extensive and intense engagement of the public in policy development by the Federal government is unprecedented and historic.

The Health Policy Transition Team, volunteers and, after January 20, a small number of U.S. Department of Health and Human Services employees committed not just to read every response but also to assess, synthesize, and summarize the responses and present them to the President. This information is crucial to the President's commitment to engage all Americans in reforming our health care system to provide affordable, accessible, and high-quality health care for all Americans. To thoroughly and accurately synthesize the responses, beginning in December 2008, the Health Policy Transition Team consulted with the nation's leading health services researchers to develop an analytic strategy (see Appendix A).

Under the guidance of the experts, the trained volunteers read and "coded" each report using a software program designed for qualitative analysis. These codes, which were developed by the Health Policy Transition Team and qualitative research experts, provided an organized and comprehensive list of the topics participants discussed and the nature of those comments.[6] The codes also helped to identify the major themes or distinct, recurring ideas expressed across all of the reports. The results below describe the number of reports that contained the codes, as well as quotes and examples that illustrate the themes that emerged from the reports. Generally, the analysis focused on topics of discussion mentioned in more than one in ten group reports; numerous additional concerns and solutions were proposed and can be viewed in the reports that are posted at www.HealthReform.gov (see Appendix B for a description of the methodology).

These Health Care Community Discussions were not designed to be a scientific research study, with a pre-determined sampling strategy and structured focus groups (e.g., professional moderator,

set questions, and probes) or other structured components (e.g., specific methods used to force participants to make tradeoffs about possible solutions). Nor were these Health Care Community Discussions intended to produce a catalogue of existing and new ideas for reform: this report neither filters out solutions that may already be in the mix nor links solutions to the Administration's policy or existing programs. Instead, this grassroots undertaking gave anyone the chance to exchange ideas with family, friends, neighbors, or acquaintances in the way they considered best. As such, it resulted in discussion and debate on a wide range of topics of greatest interest to them.

Philadelphia, Pennsylvania

Lincoln, Nebraska

Golden, Colorado

Charles Town, West Virginia

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]

- 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 Point, Michigan

Indianapolis, Indiana

Escondido, California

Bowie, Maryland

III. CONCERNS ABOUT THE U.S. HEALTH CARE SYSTEM

A. Prioritization of Concerns

The Participant Survey asked participants, "What do you perceive is the biggest problem in the health system?" The response options included:

- Cost of health insurance;
- Cost of health care services;
- Difficulty finding health insurance due to pre-existing condition;
- Lack of emphasis on prevention and quality of health care; and
- Quality of care

Cost represented the primary concern for 55 percent of the approximately 30,000 Participant Survey respondents: 31 percent of respondents worried the most about the cost of health insurance, and 24 percent were most concerned about the cost of health care services. One in five respondents reported concern about a lack of emphasis on prevention. About 13 percent of participants worried about pre-existing conditions limiting access to health insurance, and 12 percent raised concerns about the quality of care (see Figure 2).

Participants' concerns about the health care system were strikingly similar across the nation. For example, 24 percent of respondents in the Midwest, the South, and the West and 25 percent in the Northeast said cost of health care services was the biggest problem. Thirty-one percent of large metropolitan areas, 29 percent of small cities, and 30 percent of rural participants said that cost of health insurance was the largest problem. Two slight differences did emerge. Participants in the West were more concerned about finding health insurance due to pre-existing conditions than those in the Northeast (Map 2). In addition, 32 percent of participants in communities with a per-capita income under $25,000 said that cost of

health insurance was the greatest problem, compared with only 29 percent of those in places with per-capita income between $25,000 and $44,000. Surprisingly, participants in communities with an average income above $45,000 expressed the same level of concern about health insurance costs as those in lower income communities (see Appendix Table 1). Similarly, people living in higher-than-average unemployment communities shared the same concerns as those in communities with lower-than-average unemployment rates (Map 3).

It was clear from the Participant Surveys that, throughout the country, the cost of both insurance and health care services was on everyone's mind. At over 90 percent of the meetings, at least one person chose cost of insurance as the biggest problem and at 85 percent of the meetings at least one person named cost of health services.

The Health Care Community Discussion group reports offered additional insight into participants' concerns. The majority of reports (52%) conveyed concern about the structure of the system – ranging from its misplaced emphasis on acute care versus prevention to its complexity. The second most-often discussed problem was cost (48%), followed closely by access concerns (43%) (see Figure 3). The nature of these concerns is detailed below.

B. Cost Concerns

Individuals and businesses from Maine to California expressed dread when considering the question of the cost of health care, health insurance, and the system. As a group in Kirksville, Missouri, explained, "The cost of health care continues to spiral out of control. To be available, care must be affordable. If other countries are providing excellent universal health care for less than half of what we spend per capita, something is wrong." Health Care Community Discussions highlighted how the rising cost of insurance premiums and deductibles, the cost of health care services with or without insurance, and the cost of prescription drugs can all overwhelm a family and stifle a business. Among 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. How much individuals and families pay for health care was a topic of discussion in one-fourth of the cost discussions; prescription drug costs were

mentioned in 21 percent of such reports. Additionally, many of these reports conveyed the frustration of Americans who believe that they spend significant financial resources on an opaque and inefficiently administered health care delivery system (16%) (see Figure 4).

Cost to Individuals

According to a number of Health Care Community Discussion reports, the rising cost of health insurance is driving down coverage, leaving people uninsured, preventing access to care, and creating financial hardship. Numerous groups discussed how participants are unable to obtain group insurance rates and face prohibitive costs for private individual insurance; yet, at the same time, such individuals are disqualified from government aid by Medicare's age requirements and Medicaid's low-income threshold. A self-employed yardman from San Antonio, Texas, offered his story as an example of how rising costs and high premiums place coverage out of reach for many Americans, leaving people uninsured. He stated, "I work very hard but there is no way I can buy insurance for my family. My wife has severe rheumatoid arthritis and has had to many times go without treatments because I cannot pay for health insurance. She is too sick to be able to work. With her so sick, it makes it very expensive to buy any health insurance. What is a working man supposed to do?" A Lawrence, Kansas Health Care Community Discussion at a university discussed that "a whole class of people, the 'near poor,' don't qualify for public programs, but don't have employer-based coverage and can't afford other coverage."

The Health Care Community Discussions also included input from farmers who cannot afford the cost of individual insurance. Nineteen people, including some farmers, traveled over icy roads and braved a wind chill factor of 23 degrees below zero to discuss health care at a Green Bay, Wisconsin, convention center. They reported that people are "[sending their] spouse to work in order to have coverage: this makes the family farm very hard to manage with one spouse gone." A report from Enid, Oklahoma, contained a farmer's testimonial, "I receive SSDI [Social Security Disability Insurance] for several disabilities. 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 bankruptcy due to this. But, I am told by DHS [Department of Human Services] I make too much money for Medicaid and have to wait 2 years for Medicare."

Numerous groups discussed the financial hardships they endured as a result of insurance costs and high premiums. In North Carolina, a group of providers and community leaders organized a Health Care Community Discussion at an office in Raleigh. A doctor who participated in this group elaborated, "I have a patient, a minister of a local church for over 25 years. When he developed diabetes and his wife had chronic back pain, he was unable to afford insurance despite having paid into it for all those years. By state law, [his insurance company] had to cover him, but the premium cost for him and his wife was almost $4,000 a month." A group from St. Joseph, Missouri, sent in a story of a participant: "Most of us are getting our letters from our insurance companies saying our unaffordable health care premiums are going up – Happy New Year! It happens every January without fail. My husband and I can lower our monthly bill if we would like to select the $7,500.00 deductible. We are a total self pay premium." A self-employed couple from New York City shared their experience with health insurance costs, "We are middle-aged – [he] is in his 50s and I'm in my 40s so we are a long way off from Medicare! ... Health insurance and Housing costs are now on par. Even worse: Our cost for coverage is just for two people (no kids) and does NOT include any kind of coverage for drugs. So if one of us gets into a situation with expensive drug treatment, it might very well take our life savings and our home."

Health Care Community Discussion participants who were between jobs or unemployed also described their own problems with insurance costs. A participant at an Asheville, North Carolina Health Care Community Discussion organized by a non-profit health organization shared his experience: "When I switched jobs, I had to buy family health insurance coverage on the private market for 6 months until I could buy into the plan at my new company. My monthly payment for a disaster plan (insurance with a $5,000 deductible) was more than my mortgage." People who lose their insurance when they lose their job can obtain coverage through the Consolidated Omnibus Budget Reconciliation Act (COBRA), which provides temporary continuation of health coverage at group rates for certain former employees, retirees, spouses, former spouses, and dependent children.[18] Yet, Health Care Community Discussion groups indicated the cost of COBRA has risen beyond the reach of those it intended to cover. For example, a group from the Bronx, New York, noted, "COBRA sounds like a good program. In reality though, if you lose your job and are unemployed, there is no way you can afford to pay for your health insurance under COBRA. Extending COBRA will solve nothing. Two of the youngest members of our group are unemployed and cannot afford any health insurance for

their families. The cost of continuing the medical plan under COBRA is $18,000 a year." A second report from a group of Americans who live part-time in Loreto Bay (Baja, California Sur), Mexico, relayed the story of a participant doctor's daughter: "At the age of 26, my daughter, despite excellent diabetes control and care, found she could not buy a personal policy nor afford the COBRA coverage when she was between jobs. The personal policy was refused and the COBRA was over $1,000/month. Luckily, she had no illness or accident during her uninsured time which could have cost her over $50,000 for one event, like the flu requiring intensive care time."[19]

The rising cost of insurance premiums has also affected retirees who have not yet qualified for Medicare. A Health Care Community Discussion in Yelm, Washington, passed on the story of one participant: "[She] retired early from a large company. The company provides a very good retiree health care plan with the company covering a significant percentage of the premium cost based on the retiree years of service. For the bills that [she] sees, the health care costs paid to providers have not increased in the past 2 years, but the premium costs have increased significantly…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. If health care insurance premiums continue to increase at more than 50% per year, they are considering dropping the good retiree health care plan to become uninsured until they qualify for Medicare."

For many Health Care Community Discussion participants, the high cost of health insurance is just the first barrier to health care.

Cost of Services

Obtaining health insurance does not necessarily guarantee affordable health care, according to Health Care Community Discussion participants. A number of participants were "underinsured": they had some type of insurance but still spend a significant share of their income on health care. A group of everyday Americans from Ballard, Washington, reported, "Our self-employed veterinarian and his librarian wife paid $700.00/month (average) for catastrophic coverage. They had to pay for everything 'out of hospital.' Needless to say, they avoided visiting the doctor. When the wife had a[n]

accident-injury walking her dog, their out of pocket expenses were over $12,000.00. If you include the cost of their insurance, in 2008 they spent more than 25% of their combined before tax income on health care costs. She did not get the recommended physical therapy until she became 65." Similarly, a participant at a Health Care Community Discussion in Greeley, Colorado, reported, "One thing I want to make very clear is that I have good insurance and still the bills are out of control. I am one of the lucky people because I had $40,000 in savings when this cancer started. My catastrophic limit is $5,000 per year out of pocket and co-pays and medications are not included in the limit. In the past 3 ½ years I have spent $38,000 out of pocket even with good insurance…" At a Health Care Community Discussion in West Memphis, Arkansas, a "retiree explains that they have to come out of retirement in order to afford health care services. They state [that] their insurance companies don't have a plan for retirees."

High health care costs, even for the insured, deterred some participants and their families and friends from seeking needed services. A group in San Antonio, Texas, shared the experience of a 26-year-old participant with a small child who needed to have his tonsils removed because of recurrent infections. They explained that "[the participant] has…health care through his work, but even with the insurance the cost of the surgery is $900 and he cannot afford to pay it. He has decided not to have the surgery." Many of the Health Care Community Discussion participants said that costs kept them away from needed preventive services. In Aptos, California, "an [older] woman reported that she cannot get [a] mammography as it costs several hundred dollars, even with a discount offered by a local hospital." A woman in Hawthorne, California, lost her four sisters to cancer and in an effort to find out her own cancer susceptibility, she paid $2,917 out of pocket for a genetic screening. Another woman in Hemet, California, described her frustration with test costs by pointing out, "Last year I had a couple of tests due to some pain that I was experiencing. Just the bladder test alone cost more than $3,000! This was just a simple diagnostic test done as an outpatient that took less than 45 minutes…Education and preventative health care are extremely important - but how can illness be determined if the tests are too expensive."

Health Care Community Discussion groups expressed a high level of concern for the uninsured who have to pay high health care costs with no insurance assistance and are forced to make difficult choices as a result. A gathering at a senior center in La Jolla, California, stated, "People who are uninsured pay a non-negotiated rate for health care services; this is often many times higher than the rate paid

by insured patients. This situation presents an almost insurmountable burden for unemployed people with no coverage." A report submitted from a group in Fayetteville, North Carolina, described "a single mother of two children [who] remarked that her choice had become as basic as health insurance or food for her family." These basic decisions underscore the effects of health care costs and the hard economic times faced by many of the Health Care Community Discussion participants.

Cost of Prescription Drugs

According to the Health Care Community Discussion participants, the cost of prescription drugs can also create constant financial difficulty. Participants stated that these costs have drastically increased in recent years. Seventy-eight participants attended a Health Care Community Discussion at a New Hampshire public library and reported, "A daughter of a participant has multiple sclerosis and had her medication increase $1,700 to $2,200/month in over 2 years – a 29 percent increase." For others, "a bottle of insulin costs $100 for what used to be $20." Having insurance does not guarantee the ability to obtain drugs prescribed by the doctor. As one participant from a Discussion meeting held in Ashley, Pennsylvania, noted, "My insurance doesn't cover the $185 [for the] medication the doctor prescribed for me and there is no generic so I just don't take it. I can't afford it."

The prescription drug coverage gap or "donut hole" in Medicare Part D emerged as a major theme from the Health Care Community Discussion reports. The donut hole is the Medicare drug coverage gap between what a policyholder has to pay and where insurance coverage stops – after the first $2,700 paid out, until expenses amount to over $4,000. A group of health care workers met in a dentist's office in Greensboro, North Carolina, where they reported the story of a 76 year-old woman who had to pay $900 out of pocket every thirty days just for her osteoporosis medicine during this donut hole period. According to Health Care Community Discussion participants, these prescription drug costs are prohibitive for many individuals.

Instead of foregoing medication, some Health Care Community Discussion attendees purchased drugs abroad. A participant from a Holly Park, California, gathering explained, "Insurance companies only paid for certain prescribed medications needed by my mother [a senior]. Some medicine was too expensive for her to pay and even for me to afford. We were forced to purchase cheaper

drugs from Canada." A home care and hospice group in Connecticut hosted a Health Care Community Discussion for their members. A participant shared the story of her father on Medicare who could get the equivalent of a 3-month supply of a prescription drug in Canada for the price of a one-month supply of the same drug in Connecticut.

For other participants, the cost of drugs forced them to skip treatments to make prescriptions last longer or take half the dosage by cutting their pills in half. In rural Virginia, a participant in Abingdon talked about how his "93 year old mother has to choose which medications to take every other day in order to make the prescription last two months, instead of one. Even with using this strategy her medications easily consume over half of her 1,000 dollar monthly income." Another example arose at a Health Care Community Discussion group in San Diego, California. A participant talked about how her "husband had a serious, pre-existing heart condition and was also diabetic. They were unable to secure any kind of insurance for him, and the monthly cost for his care was too much for them to manage. Because of this, her husband was only taking half of the daily medications that his condition required."

Cost to Business

The Health Care Community Discussion groups made clear that the high cost of health care does not fall on individuals alone. In our employer-based health care system, American businesses shoulder a significant burden. Many participants felt this burden adversely affected small business and generally made American business uncompetitive. A member of a Health Care Community Discussion group from a Houston, Texas house forum described his family's experience: "My son-in-law and daughter currently live in Spain because that's where he can run his own small business. He had a business here in Houston, with three employees, young men. He insured them and it was cheap. But then he wanted to have a child, and the cost of insurance went through the roof. He couldn't afford it for himself, much less his three employees. So he moved to Spain, where they take it for granted that health care is a right. He took my two grandchildren with him. This shows how our system is hamstringing our business development. How can you go out on a limb and start a new business when health care is a noose around your neck?"

Throughout the group reports, small business owners echoed this concern. A physicians group sponsored a Health Care Community Discussion at a club in Gurnee, Illinois. At this forum, a small business owner described the effects of health care on his business by stating, "My small firm, an LLC with two partners, pays in excess of $1,500 per month for adequate health care. I think that this is high, and as I chat with other small business owners, they have similar concerns. This $18,000 that we pay each year prevents us from adding new software, using more part-time researchers, and other company expenditures that will inject money into the economy."

This high cost forced some small business owners who participated in Health Care Community Discussions to drop their health insurance benefits. At a gathering held by health department employees in Ottawa County, Michigan, a small business owner elaborated, "I am the owner of a small IT company…and employ…3 people - all of which are single parents - and one of them is my son. The cost of employee health care is so great that I cannot afford to provide anything. Quotes obtained from the local companies who provide 'deals'…are, in some cases, greater than the employees' bi-weekly take home pay. Other quotes that are affordable don't provide the coverage needed." A second business owner from a gathering comprised of a doctor's practice and its clients in Fort Wayne, Indiana "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." Many of the reports cited this tension between retaining coverage and workers due to the high cost of health care.

A few participants also noted that costs affect large corporations in addition to small businesses. For example, a participant from a coffee shop gathering in Grapevine, Texas, described "the many disadvantages of the current employer-based health insurance system, including the fact that it is a major competitive disadvantage for American corporations and American workers whose jobs can be outsourced overseas."

System Costs

Although numerous groups focused on how they, as individuals or as a small business owner, coped with the cost of the health care delivery system in America, many participants also had comments about problems with the system as a whole and how it raised the cost of health care. Major themes

that emerged from the Health Care Community Discussion reports included concerns over inefficient administration and frustration with the lack of transparency within the system.

Some Health Care Community Discussion participants felt that the administration of the health care system often has multiple actors performing duplicative services. At a community center in Petrolia, California, a retired provider commented, "The back and forth between medical providers and insurance companies is a colossal waste of money." A discussant at a house meeting in Lenoir City, Tennessee, reiterated this concern, "Currently we have too many levels of bureaucracy in the billing and delivery of health care. Each facility and patient is required to provide data to each insurance entity. Billing is redundant." A Health Care Community Discussion forum in Chicago, Illinois, reported, "The majority felt that the current health insurance system is too cumbersome with far too much money being spent on advertising, marketing, profits and administrative costs related to having to conform to non-standardized regulations, billing practices, and forms imposed by having to deal with such a large number of different insurance companies."

Health Care Community Discussions expressed general frustration about the lack of transparency within the health care system. Repeatedly, group reports highlighted that they did not understand the reason why everything from prescription drugs to insurance premiums to hospital band-aids cost so much and often expressed that they wanted more information on the specific basis for costs. A participant from Axtell, Texas, spent eight days in the hospital for the birth of her son and received "a confusing and unexpected bill" of $34,000. Often participants could not predict how much their health services would cost. A participant in a Health Care Community Discussion conference call in Maumee, Ohio, stated, "I think it's ridiculous that when I'm planning a surgery…like a hysterectomy, for example, I cannot call the doctor's office who will perform the surgery NOR the hospital where the surgery will be performed and find out exactly how much it will cost, what my insurance will pay, and what my cost will be AHEAD of time!"

A Health Care Community Discussion participant in a small group in Prescott, Arizona, shared her son's story, describing how "[when he] broke his collarbone…the hospital referred us to the orthopedist on call, and they said I had to see the one who was on call, but he didn't take my insurance. I found an orthopedist who did take my insurance, but he refused to see us because he was not on call that

night. Then we kept getting bills from people we never heard of. We get bills for things we don't even know what they are for. My husband and I both work, and we had to borrow money from my parents to pay for my son's medical bill." Some groups noted that "Pay Now" signs at the doctor's office confused and threatened those who did not know if they could pay the cost.

Conclusion

Health Care Community Discussion participants concluded that the American health care system places an extraordinary cost on individual Americans and American business. The cost of insurance, the cost of drugs, and the cost of health care services directly affected many participants, forcing them to make difficult choices. Participants also reported that the system's lack of transparency and cumbersome administration raise the cost of services and heighten the stress and frustration associated with health care.

C. Access Concerns

Among the Health Care Community Discussion reports that focused on access problems, 37 percent conveyed concern about being denied access to care due to pre-existing conditions and other non-financial barriers to insurance; 27 percent reported challenges in access to care; 20 percent did not feel their coverage was adequate, 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 (see Figure 5). Most of the reported barriers to access are cost related, described in the previous section. A group in Bethesda, Maryland, stated, "Access to quality health care is determined by ability to pay rather than need." Many Health Care Community Discussion groups concluded that the large numbers of uninsured Americans drive access problems. The report from the Unitarian Universalist Congregation's Meetinghouse in Fort Wayne, Indiana, highlighted, "...the plain and simple truth that there are too many uninsured." A potluck gathering in Kingston, Rhode Island, agreed, stating, "The central health care issue of our time is *access* to affordable, high-quality primary care."

Pre-Existing Conditions

Numerous participants cited pre-existing conditions as a significant barrier to accessing adequate, affordable care. In Wisconsin Dells, Wisconsin, one man spoke about his mother's struggles to acquire insurance coverage. He said: "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. She is uninsurable. Yet I know of few people who are healthier or tougher. She takes excellent care of herself, but [is] still uninsurable."

Individuals also discussed the effect that being "uninsurable" has had on their lives. At a "coffee and talk" gathering in San Diego, California, one 61 year-old woman explained that she crosses the border into Tijuana, Mexico, to receive care because she "can't afford [insurance] due to pre-existing conditions." In West Lafayette, Indiana, at a "small gathering of friends and neighbors," another couple described their son's struggle to find employment with health insurance benefits because he had Hodgkin's Lymphoma at age 17. Now an adult, he "has trouble finding a job with insurance benefits, because of his previous disease, even though he has successfully recovered."

Other Health Care Community Discussion participants shared similar stories about insurance coverage denials due to conditions ranging from high blood pressure to asthma. In Birmingham, Alabama, insurance companies deemed one man uninsurable because he took medication to lower his cholesterol and high blood pressure. This man had sought out private insurance only after he was laid off and could not afford to pay $3,500 a month to insure his family under COBRA. In Missoula, Montana, a participant related her struggles to acquire insurance for herself and her four-year-old daughter. This piano teacher had "several health conditions, including asthma." After giving birth to her second daughter, she and her husband, who is a musician employed by a local music store, took a second mortgage on their home to cover their medical bills. At age 3, their daughter had open-heart surgery and, at age 4, "is now uninsurable." She lamented, "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." The Missoula group report further explained, "The family's household income is just above Montana's SCHIP [State Children's Health Insurance Program] income limit. They are now in a situation where

they will soon have to choose between paying health insurance or [their] mortgage."

Emergency Rooms

The shortages described above leave many Americans without a reliable primary care physician, which in turn leads more Americans to rely on emergency rooms for health care, even for non-urgent matters. At a local coffee shop in Keene, Texas, one individual described, "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."

Health Care Community Discussion participants agreed that emergency rooms often became a primary source of care for both uninsured and insured populations. When discussing uninsured populations, participants characterized emergency rooms as "the norm." At a home in Milwaukee, Wisconsin, attendees lamented, "If one has no health insurance, one does not go until problems are so bad they require a trip to the ER, which could have been avoided. In Wisconsin, care cannot be refused at an ER. So people wait and go to the ER, which is more expensive a service in general."

A school nurse in Prescott, Arizona, said she sees "so many kids at the school who have no insurance and just go to the ER for strep throat." Even insured participants spoke about having to use emergency rooms for non-urgent care because "people cannot get in to see their doctor." As a result, a group of psychiatrists in Tucson, Arizona, wrote, "Urgent Care and Emergency Room[s] [are] used for primary care or minor acute care. This also results in dangerously long waits for true serious urgencies/emergencies."

Comprehensive Coverage

Several participants who actually had insurance deemed it as inadequate and failing to cover additional "essential" services. A group at a local church in Bristol, Virginia, reported, "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." Further, the host of a Health Care Community Discussion in Port St. Lucie, Florida, recounted, "One attendee (ex-military) expressed

[that] particular attention should be paid to the uninsured with mental health problems, and she especially worried about all the servicemen and women serving in various parts of the world." A participant in Albany, California, discussed dental care, noting that "Dental care is not included as part of health insurance, but it is just as important. The mouth and teeth are essential parts of the body!"

About 5 percent of all group reports expressed concern regarding a woman's inability to obtain and/or afford preventive health care. A group of friends from Planned Parenthood in Denver, Colorado, remarked, "Overall our group would like to see more coverage for women's health care. Some of my friends have stopped using birth control because it is too expensive. They literally are making decisions about birth control and pap smears and filling up their gas tank or buying groceries. It is so sad that these days women cannot protect themselves the way they should be able to. Women's health care is very preventative and if my friends had access to those services it would be a lot less expensive in the long run." A North Dakota women's group held a Health Care Community Discussion and reiterated this point by bluntly stating, "Preventative health care is an important part of being healthy and lowering money spent on health care for citizens and the state. The primary preventative health care services should be covered and routine: birth control, breast and cervical cancer screenings, sexual treatment infection screening and treatment."

Lack of adequate insurance for long-term care was mentioned in a number of Health Care Community Discussions. A group of senior citizens in Zephyrhills, Florida, described their fear that "providing long-term care can bankrupt a couple leaving the surviving spouse with no resources left." In Mountain View, California, a participant at a house Health Care Community Discussion of friends and neighbors "was concerned that her long-term care policy cost has doubled and she was unable to get information on what the policy covered."

Many participants agreed that their insurance should more adequately cover preventive services and alternative medicine. A Health Care Community Discussion group in Chesapeake, Virginia, reported that their group had agreed it was "costly to pay out of pocket for preventive health screenings" and that there was often a "long wait time for preventive health care appointments with primary care providers (over six month wait period for well exam)." The Chesapeake group also felt that "[p]rimary [c]are [p]roviders have limited education in preventive health care delivery systems, such as the many types

of therapies: massage, physical, occupational, emotional, nutritional and non-invasive procedures."

Several groups expressed their desire for a comprehensive system in terms of outcomes rather than benefits. "Health care reform must include as a goal the elimination of racial/ethnic health care disparities," declared one Dayton, Ohio group. Participants often spoke about difficulties in navigating the health care system due to linguistic and cultural barriers. A Health Care Community Discussion organized by a San Francisco, California HIV/AIDS health organization, explained: "[A]ccess to health care is not the only major issue with our health care system. Once you acquire access, you may still have to deal with cultural incompetence or a lack of quality health care, particularly if you have linguistic barriers, are part of the transgender community, or experience health issues that require special knowledge or training (such as survivors of torture)." Participants at a Health Care Community Discussion in Devon, Pennsylvania, described linguistic and cultural barriers as often "subtle, subjective and [e]mbedded in care," further explaining that, "As our society becomes even more multi-cultural and diverse, however, these issues will only increase."

Health Care Provider Shortages

A high proportion of Health Care Community Discussions elevated the issue of shortages in human capital throughout the health care system. At a packed room in a local union hall in Bellingham, Washington, attendees reported, "We have a serious shortage of primary care providers – which includes physicians, nurse practitioners, and other qualified professionals." A participant in Albuquerque, New Mexico, spoke about the effects of provider shortages on the health care system. She said, "There are not enough nurses to cover the beds on hospital floors, and because of this, hospitals are unable to admit patients that need admitting. Also, there are a record number of doctors leaving the field because 1) they have to put in enormously long hours because of the shortage of doctors, and 2) the shortage causes a lack of consult backup needed to properly care for patients. As more doctors leave the field, the situation worsens."

Groups in rural regions frequently mentioned that shortages were exacerbated in their communities. An Oklahoma gathering discussed how the outpacing of physician retirements over new replacements resulted in "more and more rural citizens…being left with fewer and fewer health care options."

Rural participants also spoke to additional hurdles in accessing care, namely transportation. As expressed by a professor at A.T. Still University in Kirksville, Missouri, "Rural communities have unique health care issues [that] need to be addressed. Simply getting to the doctor or hospital can present difficulties due to the distance that needs to be traveled. When specialized care is needed, an office appointment may turn into a day-long affair."

According to some participants, the high cost of training has deterred people from entering the health care field, especially in lower-paid professions that focus on primary care. A Health Care Community Discussion at a home in Hackettstown, New Jersey, discussed how "the cost of med school and setting up a practice is monumental. Try to get these prices down, so that doctors don't have to spend years trying to pay off these loans, and so perhaps find it less immoral to bill insurance companies."

Other participants expressed particular concern over shortages in mental health professionals. At a meeting hosted by the National Association on Mental Health Illness (NAMI) in Indianapolis, Indiana, participants elaborated on the shortage of mental health care facilities in many communities, "For many people affected by mental illness…there are only a few Community Mental Health Centers, and even private psychiatrists are scarce in many areas of the country. State hospitals take those with the most severe problems and they, as well as the Community Mental Health Centers, are underfunded and often short of doctors. It is more a matter of finding any treatment at all than it is in making choices."

Some participants worried about the high cost of malpractice insurance driving out doctors and creating physician shortages in hospitals throughout the country. A group in Irvine, California, noted, "Litigation and [the] high cost of malpractice [have] created shortages of physicians in specialties such as obstetrics." A participant from Harrisburg, Pennsylvania, offered his opinion on the impact of malpractice, "We have more medical schools in PA, yet fewer doctors. Graduating doctors leave PA because it is not a friendly state to practice in."

People unable to find doctors that accept their insurance reported a different type of "shortage." At a library in Rutland, Vermont, discussants explained, "People with Medicaid don't have the same access to qualified providers or prescription care because many doctors won't accept patients with

Medicaid because of the timing of getting paid…." Similarly, physicians attending an Oklahoma State Medical Association forum in Oklahoma City, Oklahoma said, "Additionally, lower Medicare reimbursement rates and insurance red tape are causing more and more health care providers to stop accepting certain insurers and Medicare. As a result, even those with health insurance are facing more limited options in health care."

Conclusion

Overall, discussants across the country remarked that comprehensive reform means more than just increasing the number of insured people and decreasing costs. From guaranteeing eligibility for those with pre-existing conditions, to covering all essential medical services, to ensuring the adequate supply of health professionals and primary care or non-emergency settings, participants agreed that true reform must address the many obstacles to access that Americans face every day.

D. Quality Concerns

Many Health Care Community Discussion participants identified quality of care as a significant problem in our health care system. A common theme among participants was the concern that our health system did not provide high quality of care, relative to other nations, despite its high expense. A report from a conference call Health Care Community Discussion between four doctors, including a former Surgeon General, urged, "The U.S. Health System has to be reoriented toward maximizing health status indicators with an emphasis on improving health status in the most vulnerable populations." At a Health Care Community Discussion in Northampton, Massachusetts, the group noted, "While the US has by far the highest per capita cost for health care in the world, we fall near the bottom among developed nations for standard outcomes such as infant mortality and life expectancy." The issue of quality is linked to several other issues raised in the Health Care Community Discussions including high costs, poor access to care, and the system's lack of emphasis on wellness and prevention. Most of the quality concerns were expressed in general terms (47%), although 36 percent of reports that mentioned quality focused on overuse of services and 20 percent discussed medical errors (see Figure 6).

Medical Personnel Training, Performance, and Errors

A number of Health Care Community Discussion participants expressed several concerns about the lack of skill, knowledge, or effective use of skill and knowledge on the part of providers and facilities. While studies point to system breakdowns as the primary cause for concern, most Health Care Community Discussion reports that focused on the topic offered personal examples. At a Health Care Community Discussion at a home in Ellicott City, Maryland, one participant commented that the biggest problem with the health care system is, "There are providers that should not be in practice." Specific concerns raised in the reports included misdiagnosis, failure to correctly and quickly diagnose evident problems, and delays in diagnosis and subsequent treatment. A Health Care Community Discussion in Highland, Maryland, discussed these problems in the context of a 14 year-old girl who was incorrectly diagnosed with a cyst and an underactive thyroid instead of the accurate diagnosis, cancer. In another case, failure to provide correct medications led a mother in Santa Fe, New Mexico, to report "how her daughter was given seizure medication that had the side effects of causing seizures." A Health Care Community Discussion held in Sedona, Arizona, by an advocacy group that helps homebound and disabled individuals noted, "Medical testing and test interpretation is sloppy and often inaccurate." A participant at a neighborhood gathering in Bella Vista, Arizona, attended mostly by retirees, noted that "many times poor discharge planning resulted in people being rehospitalized."

The Health Care Community Discussions elicited numerous concerns about medical errors and hospital acquired infections. Participants at a local public library in rural Kentucky expressed "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." Another participant at a restaurant in Cincinnati, Ohio, described a situation where "in the process of surgery, the surgeon stretched and cut the nerve, the lung collapsed and when she told the doctor she couldn't breathe, he didn't even examine her." At a Health Care Community Discussion in a home in Newark, Delaware, a provider expressed concern that "doctors too often misdiagnose illnesses until it is too late, which only [drives] cost for treatment later on."

Some groups identified competence issues for specific populations. For example, a Health Care Community Discussion at a center for adults with severe disabilities in Palm Beach Gardens, Florida, noted, "When patients with disabilities are hospitalized, they often go without basic needs (food, hygiene, toileting, communication) unless a family member or friend can stay with the person." A gathering in Lincoln, Nebraska, also commented, "Nursing homes… often do not provide the ongoing physical therapy that is needed for maintenance of basic body functions…In other words, care is canned, not individualized."

Some Health Care Community Discussions linked concerns about competence to the lack of comprehensive training and compensation of hospital medical staff. In Westfield, New Jersey, a meeting organizer hosted a virtual meeting after snow derailed the planned Health Care Community Discussion at her home. Their report concluded, "In order to promote better health care outcomes, the compensation and training of both nurses and attendees (the people who interact most with patients) must be addressed." A second group of professionals who met for a last minute event in Woodbine, Georgia, concurred, "[the] quality of care is often minimal as hospitals try to keep costs down-i.e. hospital staff need further training / education."

Reasons for Quality Problems

Several Health Care Community Discussions reported that a lack of "humanized" care drives health quality problems. At a pot-luck lunch with seven retirees in Boise, Idaho, participants commented that patients are "herded like cattle through the doctor's office." Two board certified emergency physicians in Phoenix, Arizona, held an event with attendees ranging from "plumbers and climbers to an architect, several real estate or travel agents, engineers, nurses, internists, ED physicians, and several businessmen." Their group report stressed the importance of "chang[ing] medicine back to something based on humanism, with patients treated as human beings not numbers or sides of beef." A report from a "virtual" Health Care Community Discussion on an Albuquerque, New Mexico-based blog highlighted, "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."

Many groups felt that the amount of time doctors are able to spend with patients is inadequate and lowers quality of care. A Health Care Community Discussion in Fredericksburg, Virginia, described

this "cattle syndrome," saying, "Doctors are forced to see too many people in too short of time. [This] results in doctors treating symptoms without ever being able to counsel patients on root causes, healthy lifestyles, or alternative therapies. [They] cannot develop doctor-patient relationships that can really address health issues." A Health Care Community Discussion at a home in Rockwell, Texas, highlighted that, "many 'quality' issues really result from doctors spending inadequate amounts of time with patients. More time should be spent in diagnosis, counseling, and tailoring treatment to the individual patient with more negotiation of treatment between doctor and patients." Patients and providers at a Health Care Community Discussion at the George Washington University Institute for Spirituality and Health described the systemic effect: "Health care delivery suffers from fragmented, disjointed care because physicians don't have enough time to spend with patients – specifically in order to provide whole-patient centered care. Health care delivery should not be like a factory…Not being fully open to taking the time to discuss a patient's problem results in the administration of too many tests because physicians don't have the time to really explore patient's problems. This leads to errors because in their rush to get to the next patient, health care providers do not ask critical questions or think about proper tests; this leads to physician burnout and high turnover; and, finally, this leads to disgruntled patients whose needs are not met."

Some Health Care Community Discussion groups attributed quality problems to overworked and exhausted medical personnel. At a Muslim-American community center in the Garland, Texas area, participants reported, "It is observed that doctors have heavy workload due to shortage of doctors; therefore sometimes errors are made from their side, to overcome this shortage the H1B visa sponsorship program may be started as it was started for IT professionals and nurses." A participant from a Health Care Community Discussion group in Miami, Florida, complained, "[W]hen I called the phone rings and rings and nobody picks it up. There [is a] workers' shortage…" A group in San Francisco, California, met on the Sunday night before Christmas and argued that we "need more GPs/PCPs [general practitioners / primary care providers], so that they're not overworked and have more time to spend with patients."

Other participants blamed the short time dedicated to patient care on decisions motivated by profits and financial incentives. The report from a Health Care Community Discussion at the Kansas City Public Library raised concerns that "health care facilities have become 'for profit' institutions, with

emphasis on profitability, rather than on good quality care." A Health Care Community Discussion held in Palm Beach Gardens, Florida, discussed how "decisions as to what is paid for (medications, therapies, equipment) are made by the insurance companies or Medicaid (often people with no medical training)...not by the doctor and patient." In Newport News, Virginia, a physician at a gathering, which included several family doctors, nurse practitioners, a medical office accountant, and a medical office administrator, commented, "Such low pay for thoughtful medical care forces PCPs [primary care providers] to see more patients per hour but with less time we are quicker to send patients to specialists where they receive fragmented and expensive care." A small meeting at a home in South Orange, New Jersey, summed up their many concerns in this statement, "The problem of inadequate quality is driven by financial concerns which cause time limits, inadequate coordination of services, consumer demands for inappropriate services (which are all too often provided) and provider-driven fear of malpractice (excessive and duplicate tests and procedures)."

Overuse of Health Care

Health Care Community Discussions often commented on the overuse of harmful or ineffective services. A Sedona, Arizona group felt there was an overuse of "pharmaceuticals prescribed for symptom relief" rather than "diagnosis and treatment of underlying causes." A submission from a Springfield, New York gathering reported that a woman "talked about unsuccessful visits to the doctor in which the doctor was unable to diagnose the pain in her knee but was quick to write a prescription for the undiagnosed condition." Participants who met at the United Methodist Church in Red Hook, New York, worried about "instances ...where doctors pressured them to undergo surgery, without alternatives or a second opinion being provided." The report from a Health Care Community Discussion in Solana Beach, California, attended by 80 people, expressed concern about the "over medication of our society and too many tests with not enough results."

Several groups also commented on unnecessary care given at the end of life. One summary from a meeting at a home in Tucson, Arizona, attended by 26 people, noted that we "need a balance between giving comfort and heroic overcare." A Health Care Community Discussion from Hancock, Michigan, also noted that our health care system needs to "support much more palliative care, as well as hospice care."

Health Care Community Discussion groups cited several factors as causes of overuse of health care services. Malpractice liability was one commonly mentioned cause. A gathering of friends and family members in Camano Island, Washington, noted that the "response to illness is sometimes more costly because the provider is concerned about a negligence lawsuit and either prescribes unnecessary treatment or orders excessive tests to avoid possible litigation in the future." One senior, at a café in Ashland, Kentucky, noted, "Doctors who do certain things always seem to find those things when you go to them." Others mentioned the patient's responsibility for overuse. A group that met at a hospital in Nogales, Arizona, pointed out, "Health care is expensive, but this cost is made exorbitant by high patient expectations that 'everything should be done for them.'" A Glen Ridge, Florida gathering also discussed that another cause of duplication of care is the "lack of a medical record that goes with the patient."

Underuse and Fragmented Health Care

On the opposite end of the use spectrum, many participants reported that poor quality and outcomes resulted from the underuse of medically necessary care. A participant at a Health Care Community Discussion in Orange, Massachusetts, shared a story about a cancer survivor who fought "the system" for four months to receive approval for physical therapy because "radiation [had] left her arms very weak." She explained, "The wait further deteriorated her arms and should not have occurred, the treatment was a 'no brainer.' Red tape has no place in cases where it is clearly evident that medical treatment is required." Further, at a forum hosted by the Everest Institute in North Miami, Florida, one attendee described, "I heard of three different women who had untreated ovarian cysts that grew to the size of full term pregnancies before they were surgically removed. All had to be in imminent danger of death before the hospitals involved would authorize the surgery because none of the women had insurance and none could qualify for Medicaid."

Some Health Care Community Discussions highlighted how fragmentation can cause problems to fall through the cracks and lead to errors, duplication of services, and problematic prescribing. At a local restaurant in Gaithersburg, Maryland, one group noted, "Fragmentation and lack of continuity of care create opportunities for medical error and redundant diagnostic and treatment efforts and associated costs." Other groups discussed that highly specialized providers find it hard to see patients

as individual cases, sometimes leading to misdiagnosis, ineffective treatment, and unnecessary expenditures. Changes in insurance coverage were also cited as a source of fragmentation. A group of physicians at an open house community holiday party in Bethesda, Maryland, described, "[P]atients have to find new docs and employers have to find new plans yearly or bi-yearly as a means to cut costs which decreases quality due to poor continuity of care."

A few participants voiced concern over the inability of many clinicians to identify and properly handle mental health and substance abuse problems. Consequently, participants felt such problems are often neglected and exacerbated, sometimes with disastrous consequences for the patient and family. A Health Care Community Discussion group facilitated by a non-profit community health organization in Asheville, North Carolina, described, "Patients bear the burden of undiagnosed mental health and substance abuse. Behavioral health is usually separated from physical health." Participants perceived the lack of integrated benefits – including mental health, substance abuse, and dental health services – as having some relationship to the lack of attention to these issues among clinicians.

Conclusion

Health Care Community Discussion participants expressed significant concerns about their ability to obtain high-quality health care. They attributed medical errors and dehumanized care to a variety of factors, including provider shortages, a lack of training and compensation for health care workers, and decisions that are driven by profit-seeking rather than a commitment to quality. Participants cited over-treatment and duplication of services as concerns, yet also worried about the underuse of needed services. In short, discussants conveyed that they live in a fragmented health care system that does not always deliver quality care. Many participants expressed that this should not be the way the system operates. As participants in a city library gathering in Seattle, Washington, wrote, "Having to sacrifice quality to lower cost = fallacy."

E. System and Other Concerns

A large percentage of the Health Care Community Discussion reports pointed to structural and systemic issues as the heart of the problems in the U.S. health care system. The fact that most people get their health insurance on the job was both praised and criticized in 37 percent of the reports that focused on system problems. The perception that the system espouses the wrong values and orientation (such as a lack of focus on prevention or the health system's market orientation) nearly tied with concerns about its complexity as topics of discussion (29% and 27% respectively) (see Figure 7). Over one in five (21%) of the groups focusing on system problems discussed the gaps in the system and the uninsured.

Lack of Emphasis on Prevention

Many groups believed that the current health care system does not focus on health. A group of businesswomen in Apple Valley, California, described their belief that, "The 'Health care System' has more focus on being sick than healthy. It's really a 'Sickcare System.'" The Maine Medical Association held a gathering in Augusta, Maine, with 70 various professionals and expressed, "We have the best sick medicine care and not the best preventive care." A house meeting in Nashville, Tennessee, agreed that "The system does not seem to have prevention and health as a goal. It seems to be about something else entirely." A gathering in Happy Valley, Oregon, speculated on the reason for this, "For the most part, neither providers, patients, nor third parties have a financial incentive for health outcomes (wellness, prevention, etc.)." A Baltimore, Maryland gathering summarized their major concerns, "Preventive care services were not available to the individuals who were uninsured. However, some insured individuals had also not received all the required preventive services. Another problem with preventive services was also the cost; one guy said he was waiting to win the lottery before getting his screening tests. The Health Care Community Discussion revealed that most individuals did not even know what was required and therefore the decision was that education was very important." At a meeting sponsored by the South Dakota Issues Forums in Rapid City, South Dakota, a nurse stressed, "There needs to be a new paradigm shift from disease care to prevention."

Many groups tied the low emphasis on prevention to our high health care costs. A group in Kirksville, Missouri, felt, "There simply is no more pragmatic way to deal with the escalating cost of health care

than to shift emphasis from spectacular attempts to deal with very advanced disease to prevention of disease in the first place." Another submission from Michigan City, Indiana, reiterated these thoughts, "The group could go on for weeks about how much money the government and the public would save if everyone had access to preventative care. 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." A much smaller percentage of groups disagreed with this view and felt that preventive care would not help save any money at all. A group of participants at a meeting in San Fernando Valley, California, expressed this idea, suggesting that, "preventive care should be a priority, but is not cost effective. If we control diabetes, cholesterol, and blood pressure, people will live much longer and develop more serious diseases such as cancer and chronic lung disease. They will need more expensive medications and heart surgery, etc."

Various Health Care Community Discussions vocalized the sentiment that a healthy lifestyle is the key to prevention and prevention, in turn, decreases overwhelming and expensive doctor visits. In Littleton, Colorado, a local coffee shop gathering included participants with different backgrounds, including major insurance company employees, a private Medicaid contractor, parents of special needs children, and the self-employed. They all agreed, "There is no incentive to be healthy in our current system. People who are fat (1 out of 3 Americans) and smoke pay the same as those who make an effort to get preventive care, exercise, and lead a healthy lifestyle." A 20-year public school teacher at a dinner Health Care Community Discussion in Gardiner, New York, noted, "Parents…are so uneducated themselves about proper nutrition that they just pass their own poor eating and health behaviors on to their kids…"

Complexity and Lack of Transparency

The belief that America's health care system is too complex and not transparent emerged as a consensus at various Health Care Community Discussions. Groups reported frustration with the lack of information about the quality, cost, and coverage of services. Attendees at a gathering in North Miami, Florida, articulated that these frustrations stemmed from "[l]ack of consumer knowledge" and "not being able to trust what they are told." In particular "they didn't know how insurance worked

and they didn't know enough about their health to know what they could doctor themselves and what really needed professional attention." A Health Care Community Discussion with family and friends in St. Louis, Missouri, described how the system "is fragmented and lacks continuity; is difficult to access and is not user-friendly for patients and providers…its communication and documentation systems are chaotic." In Annapolis, Maryland, the group told the story of: "A widow who lost her husband unexpectedly after he was struck down by a brain tumor. She not only lost the family's primary breadwinner [and] her lifelong companion but was thrust into the confusing world of sorting through paperwork, analyzing bills and figuring out the process of dealing with hospitals and insurance companies."

Health Care Community Discussion groups voiced specific concern over the lack of knowledge regarding the cost of procedures. An employee gathering at a software company in Cambridge, Massachusetts, discussed this point, "[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." Participants at a Health Care Community Discussion at West Virginia University in Morgantown, West Virginia, echoed this frustration, "You know what it will cost you for a hamburger at McDonald's. We need to know what an office visit will cost, what a procedure will cost." A participant at a Health Care Community Discussion in Boulder, Colorado, shared a personal health care crisis to illustrate this point. He described, "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. I started crying just thinking I had to go to the hospital."

Ignorance about the services covered by their insurers as well as their costs surfaced. Some Health Care Community Discussion participants complained that there is no easily accessible information to let patients know what is or is not covered under their particular insurance plan. For example, a participant in Scottsdale, Arizona, claimed to have "incurred more than $1,000 of unexpected costs for unnecessary allergy testing, most of which was not included in her health plan. Had she known before she agreed to testing that it was not covered, she would not have agreed to the testing." Numerous Health Care Community Discussions concluded that a transparent health care system, where patients are always aware of costs and the coverage of services, should be a reform priority.

Residents at Asbury Methodist Village, a retirement community in Gaithersburg, Maryland, specifically complained about Medicare forms: "Insurance forms from Medicare and supplemental insurance are too complex and information is not verifiable by patient/family (e.g., list name of practice or use of partner's names as Service Provider, not doctor's name). Medicare relies on patients to verify information and notify of inaccuracies. Most of us simply look only at 'You May Be Billed' column. If costs are covered, no questions are raised." A doctor from Birmingham, Alabama, "mentioned that it took him 2 hours to figure out his mother's Medicare Part B. More regulations and red tape also make it more expensive for doctors to practice and encourages them to join larger practices instead of going to rural areas."

An overly complex payment process laden with paperwork has clogged the system according to many participants. During a Health Care Community Discussion at a school in York, Pennsylvania, participants discussed how "billing is so complex that it is a distraction from patient care. It wastes resources on the provider side with staff devoted solely to payments and keeping track of billing pitfalls to avoid denial of payment." Participants in Las Vegas, Nevada, also echoed this sentiment: "Paying medical bills is time-consuming and frustrating. Providers use different billing systems and terminology, so each bill needs to be reviewed to ensure the provider billed the correct insurance company, has correctly applied insurance payments and adjustments, and that the EOB [Explanation of Benefit] from the insurance company matches what the provider has submitted."

Health Insurance through Employment

Many Health Care Community Discussion participants were satisfied with the current employer-based insurance system. In Temple Hills, Maryland, they found, "The majority would like to stay with employer-based coverage only." Participants from a meeting in Red Lion, Pennsylvania felt, "The employer should still be the primary source of health insurance but the government should be more aggressive against the health insurance companies and regulate costs." At a breakfast meeting hosted by a health care technology company in Wayne, Pennsylvania, the participants "…also agreed… that eliminating employer-based coverage and converting to another system would be a cumbersome and complicated task. Conversely, some felt that the employer's role in employee health should actually increase; that employers should become more involved in wellness and prevention programs

because unhealthy staff lowers productivity."

Yet, numerous Health Care Community Discussions expressed concerns about an employer-based health care system. The "Harold Street Yes We Can Group" from Houston, Texas, felt that an employer-based system is an outdated model. They summarized, "It's based on a system developed by businesses post-WW II, as a means of competing for employees when wages were frozen. We are the only industrialized country that ties health insurance to employment." Another group in Green Bay, Wisconsin, agreed with this point, "All felt that coverage by health insurance should not be dependent on employment; it's exactly when one loses employment that he cannot afford to pay for health insurance." A bipartisan group from Doylestown, Pennsylvania, forcefully recommended, "Employer-based coverage should be abolished or available only as an elective chosen by both the employees and employer. It should not be the main source of coverage."

Several groups noted problems of an employer-based system when people lose their jobs. A diverse Health Care Community Discussion group in Tampa, Florida – including physicians, small business owners, retirees, and parents – were concerned that "if a person loses their job, they are penalized twice: first, in losing their job and then by losing their health insurance." A house meeting in Ann Arbor, Michigan, shared one family's personal struggle: "With the loss of her job, [she] also lost all these benefits. While COBRA was available, she was not in a position to afford paying $1,100 - $1,200 a month to continue to carry those benefits, so her family went without health, dental, and vision insurance for just over four months."

Other Health Care Community Discussions focused on how an employer-based system limits job mobility. A Madison, Wisconsin, gathering summarized that "one of the other problems with access is that it is so often tied to employment. Since it is now rare to remain with the same job for a lifetime, employers have little incentive to provide health care that covers pre-existing conditions or preventative care." A conference call Health Care Community Discussion held by a home care and hospice organization in Connecticut recommended, "Portability of health insurance should be a main goal because people change jobs often. The new health care system should allow people to access health care regardless of whether they are working."

Health Care as a "Business"

Several Health Care Community Discussions expressed concern that our system treats health care as a commodity rather than a public good. A local gathering in Kingston, Rhode Island, noted, "These problems are systemic problems. The concept of health care as a business rather than as a basic human right or public service for the greater good is at the root of many of these problems." The group report from an acupuncture class in Portland, Oregon, attributed the system problems to corporate medicine: "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."

The perception that insurance companies and accountants run the health care system – rather than doctors and nurses – emerged as a common theme among the Health Care Community Discussion reports. A group who met at a coffee shop on the South Side of Pittsburgh, Pennsylvania, articulated this point: "The consensus was that the source of these problems is that health care is a for-profit system in which decisions about the type and amount of care are made mostly by insurance companies rather than by patients and care-givers." Some participants felt this severely hindered the quality of care a patient receives when visiting a doctor. Attendees at a meeting in Hamilton, New Jersey echoed this sentiment. They reported, "The health care system and the care a patient receives is driven and controlled by the insurance companies, not the doctors. The doctors are held captive by the insurance companies."

Other Health Care Community Discussions highlighted concerns over lobbying, specifically how the lobbying of doctors and hospitals raises ethical issues. A participant at a Lafayette, Indiana gathering expressed this opinion, "One of our group spoke to the ethically questionable relationships among lobbyists, public policy makers and profit making health care companies, which he believes precludes decision-making in the best interests of the public."

Conclusion

A number of Health Care Community Discussion participants concluded that the problem with America's health care system cannot just be reduced to cost, access or quality; the system as a whole requires structural and large-scale reform. Overall, participants advocated for a new system that promotes wellness rather than just managing sickness; a system that is less complex and more transparent; and a system that does not leave them in fear of losing their insurance when they lose their job. Some participants further hoped for a system that treats health care as a public good rather than a market commodity.

Wakefield, Rhode Island

Iowa City, Iowa

Los Angeles, California


St. Louis, Missouri

IV. SOLUTIONS TO THE PROBLEMS IN THE U.S. HEALTH CARE SYSTEM

The Health Care Community Discussion groups did not pinpoint one specific problem with the American health care system, but rather described an array of cost, access, and other systematic problems. Each group also offered solutions in response to the central questions of health reform. In rebuilding this system, what values should be prioritized? What roles and responsibilities should each actor assume? What specific ideas should be tried or adopted? Finally, at the end of the day, what should this system look like? Health Care Community Discussion reports offered thousands of solutions, which were often similar, to these questions.

A. Principles for a Reformed U.S. Health Care System

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 and principles. Among reports discussing solutions, participants wanted a system that is fair (36%), patient-centered and choice-oriented (19%), simple and efficient (17%), and comprehensive (15%) (see Figure 8).

Fair

Fairness was a common theme among Health Care Community Discussions and motivated many to call for a health system that insures all Americans. A number of Health Care Community Discussion reports explained how the group came to this conclusion. For example, the moderator of a Health Care Community Discussion at the St. Louis University School of Medicine in St. Louis, Missouri, comprised of forty-five members of the community, noted, "One of the attendees stated strongly that health care should be a 'right' rather than a privilege. After a brief subsequent discussion, I asked for a show of hands. Virtually everyone present agreed that health care should be a right and equally available to all citizens of all ages." A Health Care Community Discussion at a hospital in Asheville, North Carolina, took a theoretical approach, "The fundamental policy question to be addressed is, 'Is health care a public right?' If health care is a right, then solutions to paying for health care will require a public solution. If not, then the market will only allow those who can afford care to access

it as is the case with other commodities." In Devon, Pennsylvania, "The group agreed unanimously that some type of a universal care model not only should be 'on the table' as a philosophical option, but should be the preferred model and starting point of discussion."

A commonly expressed recommendation among Health Care Community Discussion participants was to make health insurance inclusive of people with health problems or risks. As a report from North Brunswick, New Jersey, explained, "People who have the pre-existing conditions are the ones who need the insurance the most yet most of their time is spent fighting with the insurance company on what is covered and what is not covered. Tests, which are recommended by doctors, are not covered by the insurance company. This kind of power in the hands of the insurance company should be taken away. Any insurance carrier which provides coverage in the US (travelers, third party insurance companies, or local insurance companies) should be mandated to cover every pre-existing condition at the same premium."

For some participants, the principle of fairness was less about helping the uninsured than about preventing their own high costs or compromising their own health. A group of community leaders and non-profit workers from a Charleston, South Carolina Health Care Community Discussion explained how the uninsured affect health costs. They said, "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." One parent who attended a meeting hosted by a health organization in Arlington, Texas, explained, "If someone is sick, they should receive medical care, regardless of whether or not they can pay. If my daughter is in school and she's sitting next to someone who is ill, but whose parents don't have insurance so she's not receiving the care she needs, then my daughter could contract her illness. I don't want that. It's not the kids' fault. Everyone should be afforded health care."

Participants in Health Care Community Discussions had different interpretations of what "covering" all Americans means. Some reports advocated that everyone should have minimum catastrophic insurance to prevent bankruptcy related to unexpected health events. As a group of diverse community members who met at a home in Albany, Georgia, stated, "There should be basic universal coverage

for all or at least catastrophic coverage for all or a national pool." In San Jose, California, a group of friends and neighbors echoed this suggestion, "The delivery of that system should be through a universal health care baseline insurance program with options for individuals and/or employers to add increased benefits or lower deductibles at an additional affordable cost. Those who have existing coverage through employment or retirement should not be forced into the universal system. The coverage should be transportable and without regard to pre-existing conditions." Participants at a Health Care Community Discussion group in New York, New York, urged looking less at insurance when contemplating a fair and inclusive system and more at the content and quality of care. They advocated, "Insurance should not only be about getting access to treatment, but equally good treatment for all…In other words, it is not about minimum care but excellent care."

Patient-Centered and Choice-Oriented

Numerous Health Care Community Discussion groups believed that any reformed or new health care system should have the patients' needs as a central focus. A small group from North Scituate, Rhode Island, met at a home and described this demand, saying, "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." A group of community members who met in Pittsburgh, Pennsylvania, on a Saturday morning conveyed a similar sentiment. They noted, "The consensus was that the definition of 'preventive care' must be expanded to include not just routine medical screenings such as mammograms, but also, more broadly, a model of patient-centered care in which primary care and people's personal relationships with caregivers are encouraged and incentivized, as opposed to the current system that most profitably rewards specialized and catastrophic care."

Choice emerged as a strongly held value in the Health Care Community Discussion reports. For example, many participants wanted the ability to choose their own provider and felt current insurance networks forced them to choose providers in-network regardless of quality or personal preferences. A group that met at a library in Richmond, Virginia, explained, "In terms of public policy, we want the flexibility to choose physicians (including specialists) outside of our insurance plan or networks without paying a high cost. It was a unanimous decision that we should not continue to allow

health insurance companies to select our doctors." A gathering at a small apartment in New York City advocated a similar position, "People, the general public, does not want a choice of insurers, we want a choice of providers."

Groups also expressed that they wanted the option to upgrade from a basic plan to one that covers additional care. For instance, a group from rural Kunkletown, Pennsylvania, noted, "A choice of policies, and upgrades to the basic policy should be available so that individuals or employers who want more than the basic policy may purchase it at additional cost. Most people want a choice, and allowing insurers to offer different policies will cause them to compete, which should be beneficial. Upgrades and alternatives to a basic policy might include such things as lower co-pays, coverage of procedures not covered in the basic policy, access to a greater choice of providers, and/or extra services such as dental and vision."

Simple and Efficient

Many Health Care Community Discussion participants felt that a more user-friendly private and public health care delivery system would yield to greater efficiency. At a meeting at the Saint Louis University Medical School in St. Louis, Missouri, the participants agreed, "People need a few choices they can understand…." Local physicians gathered at a Huntsville, Alabama medical center for a Health Care Community Discussion reiterated this sentiment, "The system should be made less complex so that less educated patients are able to understand how to access good health care/ benefits." A participant from Trenton, New Jersey, relayed her father's experience to emphasize the importance of an easy-to-navigate system. She said, "We need to make the health care system more user-friendly. The health system is very difficult to navigate. Recently, my father (a retiree…) was informed that [his employer] was canceling health care benefits for retirees. It was very stressful for him to figure out what he needed to do in order to purchase health care insurance for himself and my mother. He talked to friends, health insurance salespeople, etc. and everyone told him something different. This is a lot to ask a 75-year-old person to do!"

Participants from a Health Care Community Discussion at a Baptist church in Sterling, Virginia, concurred that simplifying health care options improves outcomes. They concluded, "Looking at

the number of options health care plans offer, this group suggested that the plans be streamlined so that the everyday consumer can better understand the language, reduce the number of redundant options, and be held accountable to pay for services they have initially contracted to pay." In Merrick, New York, a group concluded, "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

Numerous reports urged policy makers to ensure that insurance is comprehensive enough to protect against catastrophic health care costs. A mix of health care professionals, health care technology employees, and health care consumers at a Health Care Community Discussion in Madison, Wisconsin, reported, "The middle class, however, often has insufficient coverage, high deductibles, high co-pays, and/or limited catastrophic coverage, leading to years of harassment by collection agencies and, in many cases, personal bankruptcy." A conversation in Longmont, Colorado, pointed out, "Medical savings accounts sound like a good idea, but with very high deductibles and still high premiums, they can only serve the wealthy."

About 11 percent of groups recommended improving the comprehensiveness of benefits covered by health insurance plans to include, for example, mental health coverage, dental care, alternative medicine, and vision care. A group of community members in Springfield, Virginia, elaborated on the need to cover mental health services, noting, "The medical community recognizes that mental health is largely dependent on biological processes. It is abhorrent that the United States stigmatizes and leaves out the mentally ill. Due to their conditions, the mentally ill find it difficult to maintain regular employment. It is time to stop making these people fend for themselves, often in the frigid doorways of inner cities, and to provide the medical treatment they need and deserve. With treatment, the mentally ill are more likely to end up working and paying taxes, as opposed to ending up in shelters and jails." Some participants, such as those at a Health Care Community Discussion in Stafford County, Virginia, recommended, "Alternative treatments (massage, acupuncture, chiropractic/body work, naturopathy, nutrition services) need to become part of [the] mainstream

medical community, and more of their costs covered by insurance" and urged that any health system should "include dental and vision care as part of basic coverage." In Southwest Durham, North Carolina, a group spoke about the potential impact of covering alternative medicine, saying that it "would drive costs down by allowing people to choose care that was not as intrusive as traditional western." Another group in Fairbanks, Alaska, also voiced their frustration over the inadequate coverage with alternative medicines by stating, "We want the freedom to continue to choose what alternative modalities we wish including naturopathic medicine, auryuvedic medicine, homeopathy, herbology, Chinese medicine."

B. Roles in a Reformed U.S. Health Care System

Participants discussed and reported on the roles different actors should play in a reformed health system. Groups recommended collaboration as a way to both improve patient care and achieve reform, and the theme of "shared responsibility" was common. However, 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 Health Care Community Discussions were designed to solicit ideas for policy makers; therefore, it is not surprising that virtually all participants believed that policy makers and government should have a role in shaping, financing, and delivering health care. Specific suggestions from Health Care Community Discussion reports primarily focused on how to change Federal programs to make the health care system more affordable, accessible, and high-quality (detailed in the next section). There were some skeptics. A group in Middletown, Virginia, reported, "The consensus of the group of 27 neighbors who attended the forum was that most of the problems with the health care system is a result of the complex tangle of Federal government regulations already on the books and that any additional interference would only make matters worse." This opinion was in the distinct minority.

The real debate was over the balance of government versus the market in insuring Americans. Supporters of a single-payer system submitted numerous reports, in part due to the encouragement by advocacy groups to participate in Health Care Community Discussions. Under most versions of a single-payer system, the government would replace private insurers in organizing, financing, and paying for health care. Its specifics, and arguments for and against it, are described below (see Single-Payer System box).

Some participants who did not fully embrace a single-payer system nevertheless expressed concern about the current and potentially expanded role of private insurers. In Emeryville, California, a group comprised of health care professionals and consumers agreed, "Insurance companies should not 'dictate' nor be the final say on medical procedures and treatment." A group in Bend, Oregon, stated, "Insurance companies must not be allowed to insure people capitalizing on health problems to reap enormous profits."

Conversely, a small number of participants expressed concern that a public plan without private insurers would reduce the quality provided by private plans. Participants who met at a Baptist church in St. Louis, Missouri, felt, "[A] major concern with [a] public v. private plan was the quality of care received with a public plan. Private [plan holders] all felt [they] received excellent care. With Private plans there is more to take advantage of for the costs you are paying." A group of health care professionals in Waco, Georgia, explained, "On the whole it was felt that market based forces, rather than government involvement, was the key to the best overall outcome. The idea of a menu driven selection offered through a coordinated commercial effort of several different entities, perhaps under the auspices of the federal government, allowing people to pick and choose the coverage they needed and could afford, taking advantage of the economies of scale to be provided by such a cafeteria style mechanism, might be a viable alternative."

Some groups were divided in their opinions about the role of government relative to the private market. On a Monday afternoon in 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 participants spoke about a system with roles for both public and private actors. Some saw the private market's role as an addition to a new public insurance plan. A small and "enthusiastic" group in New York City talked about a two-tiered system over a light supper. They noted, "In addition to this basic system, additional health care products and services (including private insurance) could be purchased by those who have the means and desire for such things. This would allow a free market health care system to exist alongside the basic federal program, as, in fact, exists in many countries which have national health care." A group in Eureka, California, elaborated, "A hybrid system, with single-payer for basic health care and private insurance for catastrophic coverage and those wanting 'Cadillac' coverage (e.g., no requirement for referrals to specialists) might assuage some of the 'free market' advocates as well as address some of the reported shortcomings of pure single-payer systems with respect to rare or very expensive conditions." A group of health care consumers and providers in Springfield, Missouri, suggested that public and private insurers operate side by side, saying, "Private insurance should continue to play a role as an alternative to federally financed or managed insurance programs. Some consumers will opt to pay more for more coverage." Some participants raised policy concerns about public and private plans being offered side-by-side, without more regulation of the private plans. They feared unfavorable risk selection, where the sickest would choose a public plan, making it more costly than the private plan.

A few Health Care Community Discussion participants believed state government should play a larger role in a future health care system by either supplementing or entirely replacing the federal system. Groups implied that this sentiment resulted from a distrust of national solutions and the success of the Children's Health Insurance Program (CHIP) and other state programs. For instance, one participant in Gurnee, Illinois, stated, "I'm much more in favor of health care being addressed at a state or local level (or even a regional level) than a national health care initiative. I'm skeptical of the federal government handling this in an efficient or cost effective manner." Other groups recommended a federal and state partnership and explained, "There was general agreement that health care reform needs to take place at the local level along with whatever programs, policies and funding mechanisms are implemented by the federal government." In Washington, D.C., a group that met with just a few days notice wrote, "First and foremost, participants believe the…Children's Health Insurance Program…works and should be preserved, fully funded, expanded, and indexed to inflation." Participants also recommended a number of other state programs as reform models.

Other Health Care Community Discussion groups praised certain aspects of the Department of Veterans' Affairs (VA) system as a model for the larger health care system. A Health Care Community Discussion held by the Commission on Aging in Ridgefield, Connecticut praised the VA's coverage of hearing aids, dentures, and eyeglasses and suggested using "the VA model to obtain national discounts and supply these appliances." A Redway, California group recommended that America should enact a "public health insurance/health care program similar to Medicare and Veterans Administration programs we already have." However, not all comments were positive. A veteran at an Apollo Beach, Florida Health Care Community Discussion "complained about the decreased access to the VA system at a time when many can no longer afford private health insurance."

Single-Payer System

Over one-quarter (27%) of the groups discussed the merits of a single-payer system, and the majority of those groups supported this idea. These groups argued that this radical change was a necessary step for reform. On a rainy Thursday night before Christmas, a group of over 50 consumers and health care providers met in Del Rey Oaks, California, and stated, "Most attendees agreed that single-payer universal health care would be the preferred delivery system, and many even offered to pay additional taxes to support a government-run health care program."

Some groups believed that Medicare should serve as the model for a single-payer system. For example, one group of retirees from New York, New York, wrote, "The group felt unanimously that U.S. citizens should be on Medicare from birth; and were in favor of single-payer insurance." Others referenced other countries' models, such as those in Canada, France, and the United Kingdom. As a Health Care Community Discussion group from Livermore, California, stated, "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." A number of participants voiced their support for H.R. 676, a single-payer health care bill sponsored by U.S. Representative John Conyers (D-MI). For example, the League of Women Voters in Ithaca, New York, reported, "The group unanimously agreed that John Conyers' H.R. 676, the single-payer legislation, was the appropriate solution to support at this time, not alternatives that fine-tune existing employer-based coverage."

On the other hand, a number of groups opposed the idea of a single-payer system, concerned that it would lower the quality of service and eliminate competition. A provider in Maquoketa, Iowa, wrote, "I don't think that a single-payer plan would be a good idea. I think some standardization is necessary, but I worry that a single-payer plan would eliminate competition." A small group in Welaka, Florida, discussed this debate, saying, "All did not agree about a single-payer Medicaid/ Medicare model for health care. Objections centered [on the] inability to get care when needed and rationing of access to tests, medical procedures and qualified doctors."

Role of Businesses

As discussed earlier in this report, Health Care Community Discussion participants expressed varying views on the role of employers in a reformed system.

Many groups articulated support and even expansion of the current employer-based health insurance system. A group that met in an apartment in Staten Island, New York, reported that, "All feel that all employers should be required to offer some health care plan to employees, that business incentives be given, and that tax free 'Flex Spending' should be available to everyone. There should also be open forums of employees to be able to give input and make decisions regarding their health care plans."

Other groups envisioned employers continuing to help finance health care coverage but playing less of a role in actually providing that coverage. A doctor in Hillsborough, California, hosted a group that argued, "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." Members of a book group in Seattle, Washington, turned their normal gathering into a Health Care Community Discussion. They envisioned employers still playing a financial role, even in a single-payer system, suggesting "Unlink health care insurance from employers. We shouldn't have to change our insurance and our doctors when we change jobs. But employers could be a source of funding for a single-payer system."

Still others envisioned employers playing a role in improving the health status and wellness of their workers. At a coffee shop Health Care Community Discussion in Baton Rouge, Louisiana, participants expressed, "Employers should promote a healthy work environment and preventive care." A participant at an El Sobrante, California Health Care Community Discussion expanded upon that idea and specifically suggested that public policy should "encourage more companies to incorporate a gym into their facilities so that employees may work out during lunch breaks or before/after work for minimal or no cost."

Role of Individuals

Health Care Community Discussions placed a strong emphasis on the role of average Americans in improving their own health and the health system at large. A significant portion of reports advocated for greater individual responsibility in eating right, exercising, and adopting other behaviors that prevent the onset of disease. Many Health Care Community Discussion participants suggested that education should always be a priority. As a group in Leesburg, Florida, explained, "Educate and prepare people, particularly youth, to take responsibility for their own health thereby empowering them to make healthy choices in areas such as nutrition, sexuality, use of substances including tobacco and alcohol, as well as emotional health. This also needs to include funding for educating parents on how to help their children set boundaries and make healthy choices from infants through the teen years."

A number of participants felt Americans should share the responsibility for healthy living, and this responsibility has been underemphasized. Members of a family medicine residency program in Washington, Pennsylvania, discussed the need for Americans to start practicing healthier behaviors by pressing that, "Individuals need to take more personal responsibility for their health. The health care system is being bankrupted by many things, but one of them is the fact that people are making daily choices that are poor for their health and then expect medical care to make everything all better. You cannot smoke or eat a poor diet or not exercise or abuse substances and expect to have good health." An Indiana group echoed these same thoughts, "Many Americans do not take great enough responsibility for their own health. There is a cultural expectation of medicine to be the 'quick fix.'"

Other groups talked about the role of individuals in financing the health care system. One suggestion was to calibrate individuals' financing of health care with an income-based sliding scale contribution structure. In Kissimmee, Florida, the Health Care Community Discussion host commented, "Everyone in my group voiced they did not want something for nothing but they wanted to be able to pay the cost based on their financial situation." Another group met in the rural town of Saylorsburg, Pennsylvania, and discussed the "overuse" of health care. They suggested, "Co-pays and other charges to individuals should be used to deter individuals from insisting on tests and other procedures which are not medically necessary." Still others discussed the need for individuals who can afford health insurance to purchase it.

C. Specific Suggestions

The Health Care Community Discussion groups provided a wealth of specific ideas in their reports. These ideas encompassed a wide range of topics including establishing health insurance exchanges, decreasing the cost of prescription drugs, developing methods to enhance and promote high-value health care, developing ways to upgrade and simplify information technology, improving health and wellness through education, encouraging healthy lifestyles, and expanding the health system's capacity.

Health Insurance Exchange

Some Health Care Community Discussions focused on how people access health insurance and supported the "establishment of a Federally-sponsored health insurance cooperative or insurance exchange that allows individuals to purchase affordable group coverage." A group from Redondo Beach, California, discussed health insurance exchanges and felt, "All individuals with employer based packages seemed to like the idea of options to utilize insurance exchange[s] or public insurance, depending on the cost of the program(s)." Participants in a Health Care Community Discussion in Potomac, Maryland, agreed, "The group seemed receptive to the idea of something like the Federal Government negotiating for rates and policy qualifications as it does within OPM [Office of Personnel Management] for Federal employees and offering the choice of those plans universally at cost."

Similarly, Health Care Community Discussion participants discussed the potential for small businesses to form coalitions to obtain purchasing power and reduce the cost of health care insurance for their employees. At a home gathering in Saylorsburg, Pennsylvania, the group reported, "There were a number of thoughts about what might be done to help contain costs. For one thing, small employers and individuals must be able to buy as part of a larger group and benefit from that group's purchasing power. A woman who is a realtor noted that she must pay a particularly high price for insurance because she has no large group in which to buy." Other groups found the complexity of insurance exchanges undesirable. As a group of consumers from Ithaca, New York, noted, "Getting health care through an insurance exchange would be too complicated; we want a simple system."

Reducing Prescription Drug Costs

As noted earlier, many Health Care Community Discussion participants viewed the high cost of prescription drugs as a major problem. A group in Pennsylvania, comprised of a broad cross-section of the community, wanted the government to more actively negotiate prices: "We recommend using the vast purchasing power of the Federal government to negotiate with pharmaceutical companies and with lobbyists over fee schedules to lower costs on drugs and tests and raise reimbursement for people-driven care." Attendees at a gathering in Sebastopol, California, stated that "pharmaceutical costs are too high and do not appear to be associated with reasonable research and development costs. Pharmaceutical costs should be standardized and decreased through a government acquisition program. Pharmaceutical companies have become too involved in directing health care."

Participants in a Health Care Community Discussion in South Trail, Florida, recommended reimportation of prescription drugs from other nations. They explained, "There is something wrong with a system that requires a prescription for a drug that costs upwards of $100 for a one-month supply that can be obtained from Canada for pennies on the dollar. The citizens of America are fed up with the exorbitant cost of purchasing drugs in the very same country where the research, development and manufacture of these medications occurs."

In debating other ways to reduce the cost of prescription drugs, many groups suggested that the government regulate the amount of pharmaceutical company advertisements. A Health Care

Community Discussion in Kent, Washington, argued the need to "stop advertising by drug companies [and] [u]se the savings to lower the cost of drugs. Participants agreed advertising incentives increased the cost of medicine." Another group in Welaka, Florida, echoed these thoughts, saying, "Most STRONGLY felt commercial advertising of most prescription drugs should be stopped. All strongly felt that there is a serious lack of ethics in the way drugs are pushed at Doctors. All feel there must be an overhaul of drug company marketing techniques and drugs from other countries should be easier to obtain." Some groups suggested limiting pharmaceutical representatives' influence as a way to control costs. In Millerton, Pennsylvania, participants agreed that "pharmaceutical companies should not be allowed to wine and dine the medical offices. Many medical offices have lunch brought in (paid by a pharmaceutical company) every day. Are the doctors prescribing medication because it is the best for the patient or because they are getting incentives from these companies?"

Research, Standards, and Promoting High-Value Health Care

Several Health Care Community Discussion reports discussed the importance of research, standards, and promoting high-value health care. Some groups discussed specific research programs that should be enhanced. A university health council in Wisconsin urged the "[i]nfusion of major research dollars into the National Institutes of Health, Centers for Disease Control, and the Environmental Protection Agency to understand the relationship between disease, environment, and behavior and develop/implement effective strategies to achieve healthy people in healthy communities."

Some Health Care Community Discussion groups discussed how high quality care requires better quality measures and more accountability from providers. A Chesapeake, Virginia group, who gathered to talk about improving care for individuals with intellectual disabilities, suggested, "A quality scorecard should be designed to measure: quality of service, timeliness of service, ability to listen to patient, knowledge of medical condition, pain management and cleanliness of medical facility and staff. The scorecard should be submitted to a neutral agency." In Del Mar, California, a group of both providers and consumers concurred, "...that it would be helpful if the government could figure out a way to provide some sort of rating system with objective information available that would aid consumers in determining the quality of a physician." In Mesa, Arizona, "A majority of [graduate health] students supported the idea of a public rating system for providers to promote

improved quality and efficiency in the system." A group meeting in Rutland, Vermont, commented favorably on Pennsylvania's rating system, saying, "In Pennsylvania, doctors are rated and that information is available for public consumption."

In addition to quality reporting, Health Care Community Discussions also recommended cost reporting. At a Colorado Discussion, participants stated, "[P]ublic policy can create a data base to compare providers and their costs for basic services. In this database 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."

Other Health Care Community Discussions recommended going a step further by having a public or independent organization produce such information and recommend what works best in health care. A Health Care Community Discussion in Harrisburg, Pennsylvania, sponsored by a Pennsylvania underwriting organization, suggested implementing a national cost containment council as a way to rate and better manage the health care system. Describing a similar initiative in Pennsylvania, the group explained, "It compares procedure frequency, cost, etc at most of the state's hospitals. It also lists general cost." A forum in Binghamton, New York, focused on disseminating best practices. This would, in their assessment, "Standardize care delivery from state to state and county to county… [e]specially interpretation of regulations and definitions of terminology. That being said, there must be some appreciation for local differences in terms of availability of service and allowance for creative ways to build long term care plans that include local services." A group in Solana Beach, California, declared, "We should consider taking health care out of politics by having the details of the system controlled by a National Health Care Board with Regional Health Care Boards in various parts of the country, similar to the Federal Reserve Board."

Some Health Care Community Discussion participants also thought that scaling back coverage of expensive procedures with limited benefits could be one avenue to pursue high-value care. A group in Sherman Village, California, met on a Saturday morning and highlighted, "While the concept of 'rationing' is anathema to most Americans, there nevertheless needs to be discussion around

and decisions about cost-benefit analysis: if an expensive procedure is likely to prolong life only for a short time, then perhaps the same health care dollars should be used on a patient who has a reasonable expectation of improvement or at least longevity." A group that met in Silver City, New Mexico, suggested, "[A] 600-gram preemie would receive all appropriate care whereas a 90-year-old cancer patient would receive appropriate palliative care but would likely not receive a bone marrow transplant."

According to roughly 11 percent of Health Care Community Discussion groups, reforming the medical malpractice system would promote high-value care and reduce costs. Some groups suggested tort reform to standardize award regulations and "no fault" compensation. At a meeting in Arlington Heights, Illinois, the group concluded, "Medical mal-practice should be managed like workman's compensation, i.e., fixed payment schedules for bad outcomes. Medical professionals, hospitals and pharmaceutical companies would contribute to a workers' compensation type system. Payouts would be based on fixed schedules." A participant at a meeting in Bellaire, Texas, felt that "the legal punishment system for suing doctors/hospitals needs to be overhauled, perhaps putting variable monetary caps on liability. Too many doctors are quitting because of insurance/litigation issues. An issue of 'fairness' needs to be established."

Simplification and Information Technology

As described in a previous section, Health Care Community Discussion participants felt that the current health care system is antiquated, which raises costs and lowers the quality of care. Many of the reports (15%) named information technology as a solution and some offered specific suggestions to address this issue. Participants who attended a forum in Prior Lake, Minnesota, recommended that the government: "Simplify medical records. Pass transactional regulations at the federal level to decrease records keeping and billing costs and develop a national standard for billing, coding and record keeping. Make medical records truly portable for patients. Make a national medical database available to providers to identify 'best practices' and 'medical trends.'"

Several forums supported national disease registries and electronic medical records. The attendees at a meeting in Visalia, California, felt a need to "establish a universal health care data base for

sharing of medical information between doctors. The group discussed how pharmacists have a similar system and that it is important for doctors to be able to pull up a name and see where, why and how a patient has been treated." Group reports suggested that this would ensure higher quality care by synthesizing patient medical history and prior testing, but cautioned that sufficient privacy measures must be undertaken. In Springfield, Missouri, a diverse gathering of health care providers and several uninsured individuals agreed, "Health records should be standardized, made electronic and secure. This will promote coordination of care, enhanced quality, and create a safer patient environment." In Aptos, California, a registered nurses' family gathering discussed how, "[r]equiring the use of electronic medical records should also do a great deal to promote quality health care, as long as confidentiality is protected." Another group from Lexington, Mississippi, agreed with the idea that "all clinics, hospitals, doctor offices, pharmacies and specialty centers" should be required to have electronic medical records. EMRs [electronic medical records] can prevent duplication of services and prescriptions for conflicting medications." A group in New Jersey suggested a "Smart Card" to "track use of medical care … (similar to today's Veteran's Administration system)." Another group in Colorado Springs, Colorado, expressed, "We were impressed by the way the Veteran's Administration already serves as a successful model, by sharing a patient's medical information between its facilities all across the country. For example, an older veteran we know recently was given a CD of all his current VA medical records that he was able to take with him when he moved to another state and applied there for medical care. The VA is a system already in place that could show us how this sharing can work successfully."

Participants also suggested that an online and standardized billing system would help alleviate high health care costs by eliminating unnecessary variation and confusion. At a gathering in Cheyenne, Wyoming, a group of health care providers, consumers, and community leaders agreed that there is a need to "reduce the cost of health care administration [and create a] uniform billing system; electronic claims processing; standardized health insurance industry forms and physician credential; [and] smart card technology."

Education on Health and Wellness

Many Health Care Community Discussions emphasized the importance of education on health and wellness. Discussants believed that health reform should raise awareness about health and the health care system, support media campaigns, and train people with chronic illnesses to better manage their own care. Over one-quarter of the 3,276 reports (27%) suggested education as a health reform priority.

Roughly 12 percent of Health Care Community Discussion group reports suggested enlisting the public education system to help with disease prevention and promote healthier lifestyles. Comments centered on an underlying assumption that if people have the tools to live a healthy life, they will utilize costly medical care more appropriately. A group of 45 attendees at a Saint Louis University gathering in St. Louis, Missouri, emphasized preventive health care in schools. The group concluded, "Education about the benefits of diet, lifestyle and related approaches needs to start early – as early as grade school. Following this comment, several people spoke about the importance of the public school system as a place where such education should begin and where good habits should be formed." A meeting moderated by a physician and attended by 150 Tallahassee, Florida residents also reported, "The participants suggested promoting healthier lifestyles by stressing this subject in the public school system, including teaching healthy eating habits, exercise, encouraging walking/biking and consuming healthy foods."

Health Care Community Discussion groups also suggested that education on health and wellness should not be limited to children. A pharmacist in Pinole, California, strongly advocated, "Public policy can promote healthier lifestyles by educating the public on disease prevention by providing workshops and seminars on health-related issues, promoting proper diet and exercise, and alerting the public on the health risks involved with obesity, smoking, alcohol-consumption, and other disease-causing factors." Discussants at a home in New York, New York, also felt as though this was an important aspect to health care reform, noting: "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."

In addition to school- and workshop-based education, various groups advocated for promoting healthier lifestyles through public ad campaigns and bans on "unhealthy" habits. A group of health care consumers in Arlington, Virginia, felt a need to "develop an effective health literacy campaign aimed at all segments of the population, especially parents and children. Obesity and diabetes are major areas of concern." Likewise, in Glenwood, Colorado, participants sought to "make available free of charge to all parents information, in many formats and easily accessible, on the effects of poor lifestyle choices in food, thought and exercise and how they control what they bring into the house and what their children watch on TV."

Several Health Care Community Discussion groups recommended targeting education on health and wellness where it may be especially beneficial. In Geneva, Illinois, a group of friends recommended implementing one Illinois program on a national scale: "Healthy Families Illinois and similar home-visiting programs…provide voluntary 'parent-coaching' to moms and dads of very young, at-risk kids – everything from helping parents learn how to better foster their children's optimum growth and development, to helping them track down community-based health services they might not know about otherwise." A Health Care Community Discussion group in Napa, California, felt as though "every hospital should have community outreach teams that teach chronically ill patients how to self manage to avoid future emergency room trips."

Other Policies to Promote Healthy Lifestyles

Numerous Health Care Community Discussion participants recommended reaching beyond education to use policy tools to promote healthy lifestyles. In particular, groups focused on the role of healthy food and exercise in reducing obesity and preventable chronic diseases. Suggestions included providing healthier food in institutions, improving the clarity of nutrition labels, eliminating agriculture tax subsidies for unhealthy products, taxing unhealthy products, and promoting physical fitness.

Health Care Community Discussion participants frequently recommended promoting access to healthy food; it was a topic of discussion in 13 percent of groups. A group of 31 people in York, Pennsylvania, elaborated, "We discussed the school lunch program and agreed that it fails miserably in providing nutrition and instilling proper eating habits. School lunches should be part of the learning curriculum, and not for profit." Similarly, Americans meeting in Oaxaca, Mexico, agreed,

"Unhealthy foods should be removed from institutions such as schools, prisons, medical facilities, etc." A home gathering in Larchmont, New York, reported, "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." In addition to schools, discussants suggested that faith-based and social service organizations need to play a role in reforming health care. A group from Long Beach, California, stated, "Food Pantries/Food Banks - churches can provide healthy food to communities that need fresh produce and other dietary needs in place of cheap fast food."

Some participants also provided national-level food policy recommendations. At a meeting in Boston, Massachusetts, a group of co-workers felt a need to "mandate transparent and simple-to-read and understand food labeling (include visual health rating on each product label, include markings of organic and genetically modified foods, include listing of all artificial ingredients, etc.)." Targeting agriculture subsidies was raised at a Health Care Community Discussion held in a St. Louis, Missouri restaurant: "Public policy can promote healthier lifestyles by eliminating agricultural subsidies to unhealthy crops (such as tobacco, sugar and starchy grains), increasing agricultural subsidies to healthy food crops (such as vegetables and fruits), taxing unhealthy food ingredients (such as sugar and high fructose corn syrup), promote the practice of eating unprocessed foods, promote healthy nutrition beyond the standard food pyramid, promote exercise in the workplace and homes and schools, and promote the idea that people are responsible for their health."

Numerous Health Care Community Discussion reports suggested financial incentives for healthy behaviors and for the use of proven prevention methods. Although there was no consensus on who should receive incentives (such as employers, employees, providers, or consumers) or the type of incentive (such as tax breaks, payment incentives, lower insurance premiums/deductibles, gifts, or awards), the Health Care Community Discussions addressing this point believed that groups and individuals should be rewarded for promoting health and preventing disease. A group from Warrenton, Virginia, suggested, "The Government can offer tax deductions for healthy lifestyle choices such as health club memberships. The tax laws could be changed to 'help' health clubs and employer benefits such as sick days with pay and relaxation and recreation days off with pay. Employers could be offered incentives to create offices close to employees' homes. This promotes more healthy lifestyles."

Participants at a home in Glastonbury, Connecticut, considered changes to the health insurance system, recommending, "the new financing system will need to build in incentives that promote prevention for people across the lifespan: e.g., no co pays for preventive services; premium or co pay discounts for consumers who get the required screenings, vaccinations, and other preventive services."

Some Health Care Community Discussions recommended financial disincentives for unhealthy behaviors. In particular, some of these groups noted that since we already have "sin taxes," such as taxes on cigarettes, policy makers could simply make these financial disincentives greater or applicable to more areas, such as unhealthy foods. Participants at a meeting in a café in Staten Island, New York, suggested that "taxes could be raised on certain items like tobacco and sugar saturated items. The revenue raised should be used exclusively to combat these addictions, as well as to prevent, intervene, and treat the diseases they cause." A similar idea was proposed at the Health Care Community Discussion held at a home in Lenoir City, Tennessee, where participants stated that we "need to consider taxation on unhealthy foods as well as tobacco, alcohol. Consider a 'medical' tax on foods and substances that are known to impair health or are known carcinogens. Proceeds could be targeted for associated treatments or research efforts."

However, other groups expressed concern about the use of financial disincentives. A group in Grand Rapids, Michigan, noted that "Good health should be rewarded, but poor health should not be punished by health cost or discrimination." Participants at a Topeka, Kansas, Health Care Community Discussion held at a local public library thought that: "The poor often have diet and stress they cannot control… [and] should not be punished for what they cannot control" and were also concerned about "possible discrimination against individuals with special health care needs and disabilities that cannot be address[ed] through prevention activities." A Governor's Island, New York, Health Care Community Discussion attended by health care and pharmaceutical consultants acknowledged the possible criticisms of financial disincentives and recommended that "Rewarding patients who lead healthier lives is more effective than punishing patients who engage in unhealthy habits (ie, healthier people pay lower premiums will be more effective v. making smokers pay higher premiums)." Others cautioned against penalizing people for problems out of their control (e.g., triggered by genetics or the environment).

A number of Health Care Community Discussion groups encouraged the promotion of physical fitness. A group of friends in Salt Lake City, Utah, suggested, "Require mandatory physical education in schools. Physical education and health classes should be required beginning in preschool and continuing through high school and perhaps college." Participants at a health care brunch in Rockaway, New York, supported "[requiring] physical education 5 days a week in the public schools." Recommendations extended to communities as well. In Fort Worth, Texas, discussants agreed that we need 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

Delivering high-quality, affordable care to all Americans requires new insurance options, financing, and – as many Health Care Community Discussion participants noted – greater health system capacity. Reports suggested shortages in the number and types of our nation's health care providers. Groups recommended finding ways to train more providers, to encourage them to practice in underserved areas, to expand the roles of existing providers, and to support additional community-based services.

A number of groups suggested making professional training more affordable. At a Health Care Community Discussion in Cary, Illinois, participants urged policy makers to, "Improve access to medical schools. Medical schools are so expensive that our group believes that only those in middle/upper middle class families actually aspire, and become doctors. Thus the pool of competition is decreased. Also people from more depressed areas who might be happy to work in their childhood neighborhoods, are not as likely to become doctors." A Health Care Community Discussion in Sacramento, California, with participants of all ages, commented, "One solution would be for the government to pay for medical school, as they do in France, so that more doctors will choose Family Practice."

Some groups suggested that a program should be established to provide tuition reimbursement for community service work. A Health Care Community Discussion held by a long-term care county agency in Binghamton, New York, favored this idea, "[Creating] a 'Teach for America' in the health professions. College graduates could work in community health programs to pay back loans. They

could work as aides in nursing homes and home care." A group in the San Fernando Valley, California, also advocated this approach: "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." A state psychological association held a Health Care Community Discussion in Albany, New York, and suggested, "[o]rganizing psychologists for pro bono mental health services, such as the 'Give an Hour' program for members of the military and their families."

Nurses, pharmacists, and other providers who participated in the Health Care Community Discussions advocated for expanding their roles to expand primary care capacity. As articulated by a Health Care Community Discussion hosted by a chronically ill nurse in South Pasadena, California, "While doctors are a critical part of the health care system, and provide the diagnosis, treatment, and specialized knowledge that helps save lives, nurses are at the backbone of the broader health care safety net. Nurses carry their skills and knowledge wherever they go – whether into the schools, libraries, churches, mosques, parks, or neighborhoods. 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." A pharmacist from El Sobrante, California, pleaded, "Please, please, as a pharmacist I ask you to engage the profession of pharmacy more in helping to promote safe, effective use of medications and minimize over-spending on medications for the entire health care system. Please use pharmacists as a very accessible entry point for many patients." A Health Care Community Discussion group comprised of providers in Santa Fe, New Mexico, agreed with this sentiment, "Remove barriers to practice for professional providers, such as CNMs, NPs, PAs [Certified Nurse Midwives, Nurse Practitioners, and Physician Assistants], nutritionists, dental hygienists, and acupuncturists."

Other methods of increasing capacity suggested by the Health Care Community Discussion groups included providing additional free or low-cost clinics and increasing funding for social services that target underserved areas. At a meeting in Kirksville, Missouri, participants suggested building on existing clinics, noting: "Currently one of the most effective approaches to providing universal care is that of community health centers designed to provide care for the underserved. Many of these, including our Northeast Community Health Council, are delivering quality services in a highly cost

effective manner. Rather than attempting to shift the underserved en bloc into other systems, it would be more effective to selectively build on what is already in place." A group in Valley Village, California, favored the "Creation of a widespread network of free or low-cost community clinics staffed by paid professionals and volunteers and funded by government funds, employer contributions, and private donations." A group in Wailuku, Hawaii, also advocated for "more community health clinics." Participants in Bethesda, Maryland, recommended a similar idea, saying, "Hospitals should have clinics attached to them or there should be free-standing clinics (e.g., there are currently such clinics in Boston and elsewhere that are available on a walk-in basis to diagnose minor illnesses at a low cost and either treat or recommend specialty or hospital services if necessary)."

D. Relationships between Concerns and Solutions

One of the most striking results from the analysis described in this report was the lack of differences in the concerns and solutions across the country: 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. No significant differences were found in the results when looking at the groups' locations by rurality, region, average income, and unemployment. As such, the information from the Health Care Community Discussions is relevant to policy makers at the local, state, and national level.

That said, some patterns emerged in the detailed analysis of the Health Care Community Discussion reports. The analysis team separately analyzed reports that were from Health Care Community Discussions where a majority of attendees were from provider groups or advocacy groups, and compared them to groups where a majority of attendees were interested citizens. Provider groups were more likely to express concerns on a number of topics. Specifically, they were more concerned about provider shortages, the lack of a "system," inadequate research, payment rates, medical malpractice, the inefficiency of the system, and the inadequate treatment of mental health (see Figure 9).

A different pattern emerged in the comparison of topics of interest to advocacy groups and typical Americans. Health Care Community Discussions where the majority of attendees were from advocacy groups were more interested in access than average Americans and much more interested in women's

health and comprehensive coverage. (Planned Parenthood, among other advocacy groups, recommended that its members participate in Health Care Community Discussions.) (see Figure 10).

Relationships also emerged between perceived problems of Health Care Community Discussion participants and their solutions. For example, groups that expressed concern about accessing health insurance due to pre-existing conditions, the cost of prescription drugs, and the uninsured were also concerned that a health system includes for-profit providers and insurers. Health Care Community Discussion groups that raised problems with the employer-based health care system were more likely to support a single-payer system than others. And, those groups where the cost of the entire health system was at issue were significantly more likely to support education and prevention as solutions.

E. Suggestions for Future Engagement

The Health Care Community Discussion Participant Survey solicited more than just concerns and policy solutions: it asked how policy makers should reach out to them, and what they need to do to remain involved in health reform. To help summarize the participants' thoughts on the "next steps" of the health care reform process, the Participant Survey asked, "What do you think is the best way for policy makers to develop a plan to address the health system problems?" The possible responses were:

- Community meetings like these;
- Traditional town hall meetings;
- Surveys that solicit ideas on reform;
- A White House Summit on Health Reform; and
- Congressional hearings on C-SPAN.

Among participants, the most popular way to develop a plan for health care reform is more community meetings similar to the Health Care Community Discussions. Thirty-seven percent of respondents named this as the best way for policy makers to develop a reform plan, and at over 90 percent of meetings at least one person supported this idea (see Figure 11). Participants in rural communities were slightly less likely to prefer this approach (34% support), probably due to the physical challenge of convening Health Care Community Discussion groups (Map 4). These survey results are a promising indication that participants had positive experiences at the Health Care Community Discussions.

Over one in five (21%) of the 30,603 survey respondents supported the idea of a White House Summit on Health Reform. This idea was more popular in the Midwest and the West (22%) compared to those in the Northeast (17%). Surveys to solicit ideas on health reform were supported by 18 percent of respondents. Participants in rural communities (22%) and the Northeast (20%) were more likely than other participants to prefer surveys. One in ten participants chose C-SPAN hearings as the best way to develop a plan for health care reform.

Comments on how policy makers should develop health reform plans included:

- In Gardiner, New York, a dinner gathering among friends and family concluded, "Most felt that the best way for policy makers to develop a plan to address the health system problems is through traditional town hall meetings and communications campaigns targeted to people who are uneducated about health, wellness and prevention."

- In Tallahassee, Florida, a Prison Reform/Human Rights/Family Support advocacy group encouraged "traditional town hall meetings" and "community meetings like these whereby our government involves its people in discussions about what is best for our country."

- At a local restaurant in Aurora, Illinois, one group felt that "community meetings, town hall meetings [and] keeping in touch with the people, the average citizens, will give the people cause for hope. Each person will begin to believe that they can help make a difference."

- In Syracuse, New York, at a town hall meeting in a local church, participants agreed: "Local citizen participation in health planning is very important."

- Groups in San Bernardino, California and Watkinsville, Georgia advocated for "seeking grassroots input" and "keep[ing] the general public involved."

Many groups provided additional comments on having the opportunity to share their thoughts and concerns with the Obama health policy team.

- In Green Acres, Washington, participants reported, "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."

- In Aurora, Colorado, participants at a Health Care Community Discussion organized by a community based organization "had a wonderful and meaningful discussion on health care. Everyone was engaged and appreciative to be part of the global discussions being held across the nation."

- One group, led by a pediatrician in Tampa, Florida, said, "Thank you very much for giving us the opportunity to let our voices be heard. We are hopeful things really are going to be done differently in Washington D.C. and America from now on."

- In Riverhead, New York, a Health Care Community Discussion host shared that participants "were all engaged and encouraged by the fact that this team actually solicited input from the populace."

In addition to asking about what policy makers should do, the Participant Survey asked, "After this discussion, what additional input and information would best help you to continue to participate in this great debate?" The possible answers were:

- More background information on problems in the health system;

- More information on solutions for health reform;

- More stories on how the system affects real people; and

- More opportunities to discuss the issues.

Most participants (38%) wanted more information on health reform solutions as a means for continuing participation and 31 percent of respondents wanted more opportunities to discuss the issues (see Figure 12). Those in Health Care Community Discussion groups in the West (40%), rural areas (41%), and areas with per-capita income above $45,000 (41%) were particularly interested in information about solutions (Map 5). The level of interest in opportunities to discuss the issues was constant across different types of communities. More background information on problems and more stories about how the system affects real people were selected by 18 percent and 13 percent of respondents, respectively.

Lastly, Health Care Community Discussion participants' recommendations on how to proceed with health reform related to their own concerns and interests. Among the 30,603 survey respondents, participants more interested in quality than cost were more interested in Congressional hearings and stories and less interested in community discussions like the ones that they had participated in. People who were most interested in receiving more information on solutions were less interested in opportunities to discuss the issues. Those who most wanted a White House Summit on Health Reform were the least interested in C-SPAN hearings.

Overland Park, Kansas

Pompano Beach, Florida

San Jose, California

V. CONCLUSION

President Obama has encouraged all Americans to have a direct say in our health reform efforts, and individuals participating in 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 were united around a common concern: the need to reform health care in America. Participants told stories about personal bankruptcies caused by medical bills, Americans without insurance who cannot afford to see a doctor when they are sick, and people winding up in emergency rooms because they have nowhere else to turn. These stories, and thousands of similar ones, affirm the urgency of reforming our health care system. Americans are demanding that we finally address our health care challenges.

These Health Care Community Discussions are the 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.

Denton, Texas

APPENDICES

A. Analysis Team

This project was led by Jennifer Cannistra, an analyst on the Presidential Transition Team and subsequently in the newly created Office of Health Reform. Jeanne M. Lambrew, former Deputy Director of the Office of Health Reform, also guided the project. Advice and assistance on analysis of the survey questions were provided by the Cecil G. Sheps Center for Health Services Research at the University of North Carolina at Chapel Hill, under the leadership of Thomas Ricketts, Ph.D. Two preeminent qualitative researchers, Kelly Devers and her team at Virginia Commonwealth University and Shoshanna Sofaer at Baruch College School of Public Affairs, provided guidance on this project.

Sarah B. Fenn: Sarah served as the state legal Voter Protection Director for the Obama campaign in Indiana, Kentucky, and New Hampshire and as campaign field staff in Iowa, Idaho, Texas, and Florida. She holds a J.D. from the University of California, Davis School of Law and a B.A. from the University of California, Los Angeles (UCLA) and is admitted to the California Bar.

Tim Granholm: Tim is a recent graduate of Indiana University and an Obama campaign veteran. Since completing his volunteer position with the Presidential Transition Team, he has joined the U.S. Department of Health and Human Services.

Aida Dargahi: Aida was the Field Organizer at the University of Nevada, Las Vegas during the 2008 presidential election; she interned with Obama for America during the presidential primaries. Before joining the Obama campaign, Aida was completing her bachelor's degree in Political Science.

Jason F. Cunningham: Jason holds a B.A. from Union College and a J.D. from Suffolk University Law School. Jason served in the Obama campaign as the Deputy Political Director in New Hampshire and is admitted to the Massachusetts Bar.

Randy P. Silang: Randy was a field organizer for the Obama campaign in Jacksonville, Florida. He has a background in industrial engineering and management consulting and plans to pursue a Masters in

Public Policy degree at George Washington University in the fall.

Doug Taylor: Doug has over ten years of experience working in the technology and finance sectors, where he has developed and honed both his analytical and managerial skills. He is originally from California and holds a degree in Mathematical Economics from Pomona College.

Juliana Herman: Juliana is a graduate of the University of Pennsylvania with a double major in Political Science and American History. Most recently, she served as the Voterfile Manager for the Pennsylvania Campaign for Change, handling the voter targeting and database management for the Obama Campaign in Pennsylvania.

Matthew Lackey: Matthew Lackey is the Senior Political Strategist for the AFL-CIO. He has spent over six years using mathematical analysis and programming to optimize systems and programs for the private sector, international competitions, and progressive causes.

Kelly J. Devers, Ph.D.: Dr. Devers is an Associate Professor at Virginia Commonwealth University, Departments of Health Administration and Family Medicine. She is an expert in qualitative and mixed methods research and their use in health services and policy research.

Minha F. Husaini: Minha served as the National Muslim American Outreach Coordinator for the Research and Religious Affairs Departments at Obama for America in Chicago. She holds a Masters degree from the University of Southern California School of Policy, Planning, and Development.

Chrissi Johnson: Chrissi began her involvement with the campaign as a volunteer while attending graduate school at the University of Iowa; she then served as a member of the Missouri Research Team for the Obama campaign beginning in June 2008. She holds a Masters in Counseling and Rehabilitation in Higher Education from the University of Iowa, Iowa City and B.A.s in Journalism and Spanish from the University of St. Thomas, St. Paul, Minnesota.

Thomas Ricketts, Ph.D.: Dr. Ricketts is a Professor of Health Policy at the University of North Carolina at Chapel Hill Gillings School of Global Public Health and Managing Director of the American Academy

of Surgeons Health Policy Research Institute. His work has focused on access to health care and the supply of health care professionals.

Jennifer King: Jennifer is a Ph.D. student in the Department of Health Policy and Management at the University of North Carolina at Chapel Hill and a researcher at the Cecil G. Sheps Center for Health Services Research. She conducts research on access to care and insurance coverage and previously worked in the Health Policy Center at the Urban Institute in Washington, D.C.

Shoshanna Sofaer, Ph.D.: Dr. Sofaer is the Robert P. Luciano Professor of Health Care Policy at the School of Public Affairs, Baruch College. Dr. Sofaer is an expert on the use of qualitative and mixed research methods in health policy and health services research who frequently provides consultation and training to other researchers on this topic.

Eben A. Weitzman, Ph.D.: Dr. Weitzman is an Associate Professor in the Graduate Programs in Dispute Resolution, and in the Public Policy Ph.D. Program, both at the University of Massachusetts, Boston; he received his Ph.D. in social and organizational psychology from Columbia University. In 1995, he co-authored one of the first texts on computer assisted qualitative data analysis with the late Mathew Miles, and continues to write and teach about qualitative research methods for use in a wide range of areas including health care services and public policy development.

Karen W. Frazier: Karen is a Research Associate with the American Institutes of Research. She has extensive experience with qualitative data collection and analysis, project management, and related training activities in health services and policy research. She has a Bachelor's degree from the University of North Carolina at Chapel Hill and a Master's degree from the University of Virginia.

Kate Albright-Hanna: After graduating from Georgetown's School of Foreign Service, Kate worked at NBC News and then at CNN as a documentary producer. She joined the Obama campaign as director of video in the new media department, and then continued as the content lead during the Presidential Transition.

Andrew Sigle: Andrew's professional background is as an executive in the telecommunications industry in both the United States and Europe. He has undergraduate degrees in engineering and economics from the University of Illinois at Urbana and an M.B.A. from the University of Chicago's Graduate School of Business.

Anna Perng: Prior to joining the Obama Campaign for Change and the Presidential Transition Team, Anna was Development Officer for Community Legal Services of Philadelphia. She received her B.A. from Swarthmore College in 2003.

Kacy Rohn: Kacy graduated from Dickinson College in 2008 with a B.A. in Political Science. After graduating, she was selected as an Obama Organizing Fellow and then worked as a Field Organizer in Cumberland County, Pennsylvania for the general election.

Betsy Dexter: Betsy is originally from Owensboro, Kentucky and graduated from the University of Kentucky in 2002 with a B.S. in Communications.

Emeline Davis: Emeline is a Producer of Reality Television for such shows as Hell's Kitchen, Paradise Hotel, and Hit Me Baby One More Time. She holds an M.B.A. from Columbia University and a B.A. from Lawrence University.

Meredith Rahn-Oakes: Meredith is a recent high school graduate taking a year off before beginning at Georgetown University in the fall. She worked on the Obama campaign in Philadelphia, as a member of the Women's Vote Team.

Travis Moore: Travis manages the advocacy efforts of the Better World Campaign and UN Foundation, supporting the work of the UN and UN programs. He has also worked for Senator Tom Daschle and Representative Henry Waxman and holds an M.A. in contemporary European Politics from the University of Bath (UK).

Robin T. Kelley, Ph.D.: Dr. Kelley is an adjunct at Georgetown University in the Edmund A. Walsh School of Foreign Service. In addition to working on the report, she conducted a local Health Care Community Discussion in Washington, D.C. among resource limited residents. She graduated from

University of Maryland with her Ph.D. in Public and Community Health in 2002 and from Columbia University with her M.S.S.W. and Vassar College with her B.A. in English.

Ramy Eid: Ramy is an attorney primarily in government, former Deputy Attorney General for the State of New Jersey, and Assistant Corporation Counsel for the City of Newark, New Jersey. He holds a B.A. from the University of Massachusetts at Amherst and a J.D. from Seton Hall University School of Law.

B. Methodology

The Health Policy Transition Team's review of Health Care Community Discussion reports consisted of three parts: an analysis of group reports submitted by hosts to Change.gov; an analysis of individual Participant Surveys submitted by hosts to Change.gov; and an analysis of the host sign-ups and participants. The Transition Team received approximately 4,100 Health Care Community Discussion group reports through the reporting Web site on Change.gov, either from uploaded documents or comments in a text box. These submissions were screened by Health Policy Transition Team members and volunteers to determine if they were a group report from a Health Care Community Discussion. The review team determined that approximately 825 documents were not group reports.[20] As such, the Health Policy Transition Team and the trained volunteers read through and analyzed 3,276 Health Care Community Discussion group reports submitted to Change.gov.

With guidance from qualitative research experts, trained volunteers systematically labeled or "coded" sections of text in each of the group submissions using Atlas.ti, a computer software program designed to analyze written documents. These codes provided an organized and comprehensive list of the topics participants discussed and the nature of those comments, which helped to identify major themes or distinct and recurring ideas expressed across all of the reports. The Health Policy Transition Team and qualitative research experts developed 95 manual codes to apply to various words and ideas in the group submissions.[21] These codes, the critical ingredient in qualitative analysis, were generated by reviewing the topics in the Participant Guide and by reviewing a large sample of the group summaries to identify responses to those topics as well as other comments, ideas, and solutions. These codes were organized into six categories:

1. Biggest problem (including costs, access, quality, and problems with the overall system);

2. Other major problems or major concerns (such as unhealthy behaviors, shortages of key providers, and lack of information);

3. Impact of problems on various groups (such as state government, small businesses, providers, patients, families, the uninsured, and hospitals);

4. Hopes and visions for a reformed health system (such as less complex/simpler, comprehensive coverage, emphasis on wellness/prevention, and patient-centered);

5. Roles and responsibilities of various groups moving ahead (such as consumers, patients, employers, doctors, churches, businesses, hospitals, insurers, government, and schools); and

6. Specific suggestions or recommendations (such as Health IT, wellness education, public health improvement, and building (or not building) on the experiences of other states or countries).

After entering these codes and all of the Health Care Community Discussion group reports into Atlas.ti, the Health Policy Transition Team and trained volunteers read through thousands of Health Care Community Discussion group submissions on computers and applied codes to relevant sentences or paragraphs by highlighting the relevant text and selecting the applicable code. For example, a paragraph that discussed the shortages of hospitals and doctors in rural areas would be coded with "Access To: Hospitals, Doctors, Rural Concerns, Shortages." In addition, group reports were coded to identify whether the majority of a meeting's participants were everyday Americans, providers, or members of an advocacy group.

In addition to manually coding each document, the reviewing team also used the "autocode" feature of Atlas.ti, which searches for words, variations of words, or phrases and then applies the relevant autocode. The Health Policy Transition Team and a team of volunteer qualitative researchers helped develop "autocodes" to systematically capture themes. The autocodes covered a single-payer system, veterans, women's health, mental health, and malpractice. For example, several group submissions

discussed veteran's care. An Atlas.ti autocode searched for the word "veteran" and then placed the appropriate code on the sentence or paragraph where the words appeared.

After the thousands of group reports were read, analyzed, and coded, the reviewing team ran searches by codes and code combinations in the Atlas.ti database to view the written text from the group reports associated with a particular comment or idea in order to identify the major themes. The software also has the ability to conduct simple counts, cross-tabulations, and export data to Excel or other software like SAS to conduct basic descriptive statistics (e.g., correlations) to better understand the major themes discussed by group participants and the range of views expressed. For example, the coding system gives a count of the number of times Health Care Community Discussion group reports highlighted that the biggest problem of our current health care system is cost, access, quality, or the nature of the overall system. The coding system also allowed the team to assess whether there were systemic differences in perspective or opinion based on group characteristics or where the Health Care Community Discussions took place.

The code information was then exported from Atlas.ti and analyzed by the volunteer team, including volunteer qualitative research experts. The volunteers compared the coding results by region, population type, per capita income, and unemployment and looked for trends and differences between the percentages of responses of each code for each of the above categories.[22] For example, the group compared the percent of reports from the Northeast that mentioned "Suggestion_Education" to the percent of reports from the South, West and Midwest that said "Suggestion_Education." They also compared the percentages within a code by region, population type, income, and unemployment. For example, within the Southern Region, the researchers looked at what code had the highest percentage of documents coded with that response and whether that was the same code for each region, population type, income bracket, and unemployment bracket. The researchers also looked for correlations between codes to identify trends and interactions. For instance, the researchers analyzed the values and solution categories to determine if there was a correlation between the "Values_Prevention" code and the "Suggestion_Education" code. The researchers asked: Was a report more likely to mention education as a solution if they mentioned prevention as a key value for the health care system?

The Health Policy Transition Team also received Participant Survey responses uploaded by hosts through the reporting Web site on Change.gov. After eliminating outlier responses, 30,603 responses were used in the analysis.[23] Following the same procedure as the code analysis, the researchers analyzed the participant responses by region, population type, income, and unemployment. The results of the Participant Survey analysis were then compared to the results of the code analysis. The team looked for similarities and differences between the two analyses because the code analysis was conducted on the reports from open-ended, group discussions and allowed for multiple codes in a single category, and the Participant Survey responses were limited to one response per participant per question.

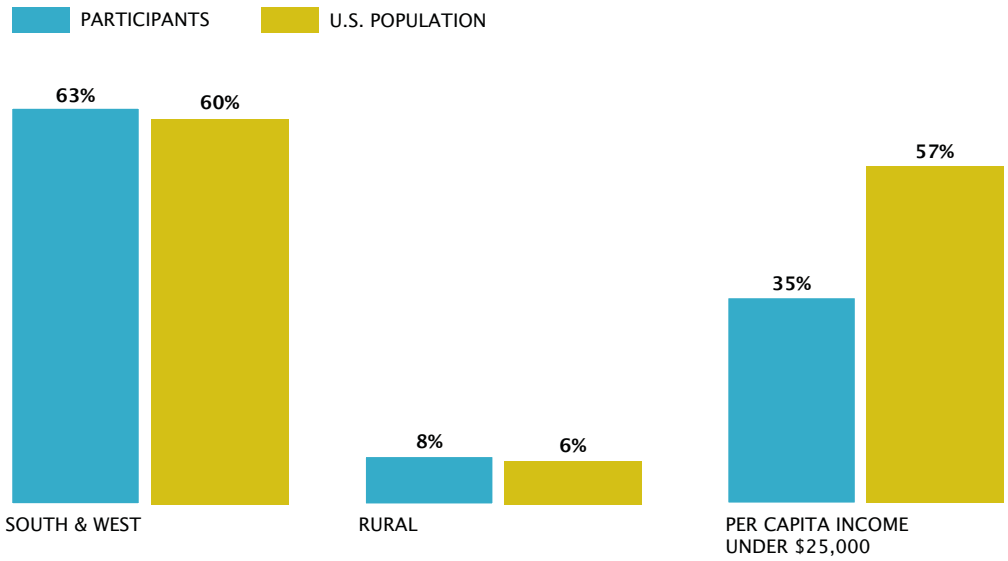
The Participant Survey and Health Care Community Discussion reports are distinct but complementary sources of information about the views of the public who chose to participate in this forum. The individual survey permits each participant who responded to express his or her opinions. The group reports capture the results of a dialogue among individuals and permit the expression of more complex points of views and differences of opinion on issues. For example, the Participant Survey addressed the issue of the "biggest problem" and permitted respondents to pick one item. In contrast, the "biggest problem" discussion in the groups generated responses on multiple problems and included responses not in the Survey response categories (e.g., underlying system structure or values) and responses on the interactions among those problems (e.g., because there is no real system or a system that prioritizes sickness instead of wellness or prevention, health care is costly and the system impersonal and hard to navigate). The other Participant Survey questions focused on other important topics related to the process of moving forward on health care reform, including how people would like to participate and what kinds of information would help them participate. Health Care Community Discussion reports also provided complementary information on these subjects.

The Health Policy Transition Team and qualitative research experts also analyzed the diversity of the people who signed up to be hosts and the participants who submitted Participant Surveys. Using the same categories as the code and Participant Survey response analysis, the researchers looked at the regional distribution, population type distribution, per capita income distribution, and unemployment rate distribution of the hosts and participants.

The quotes used in the report were edited to correct spelling, grammatical mistakes and for format; brackets were used to add language for clarity.

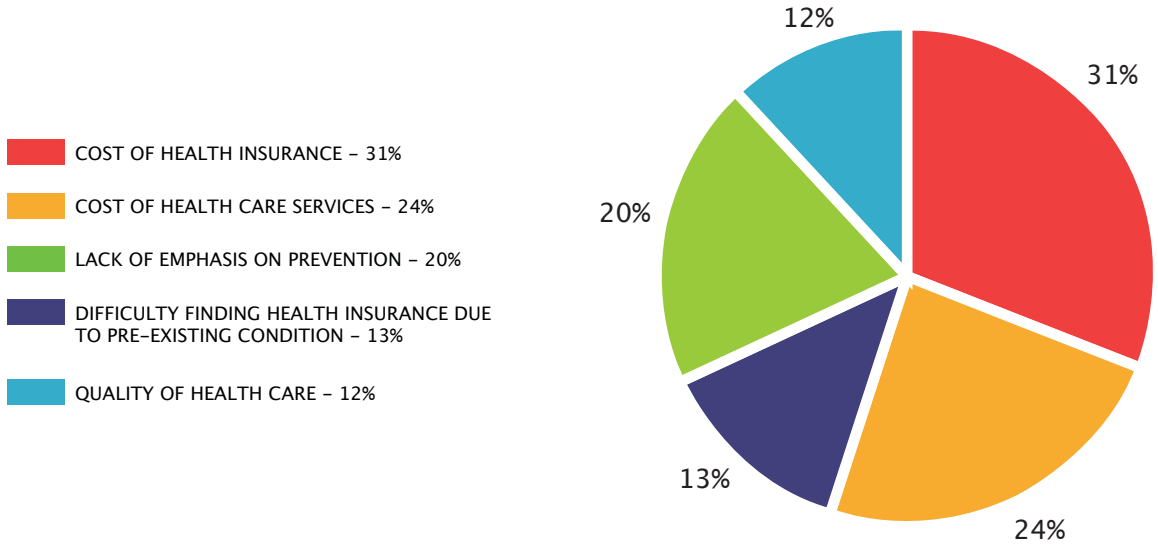
C. Figures, Tables, and Maps

FIGURE 1: PROFILE OF HEALTH CARE COMMUNITY DISCUSSION PARTICIPANTS



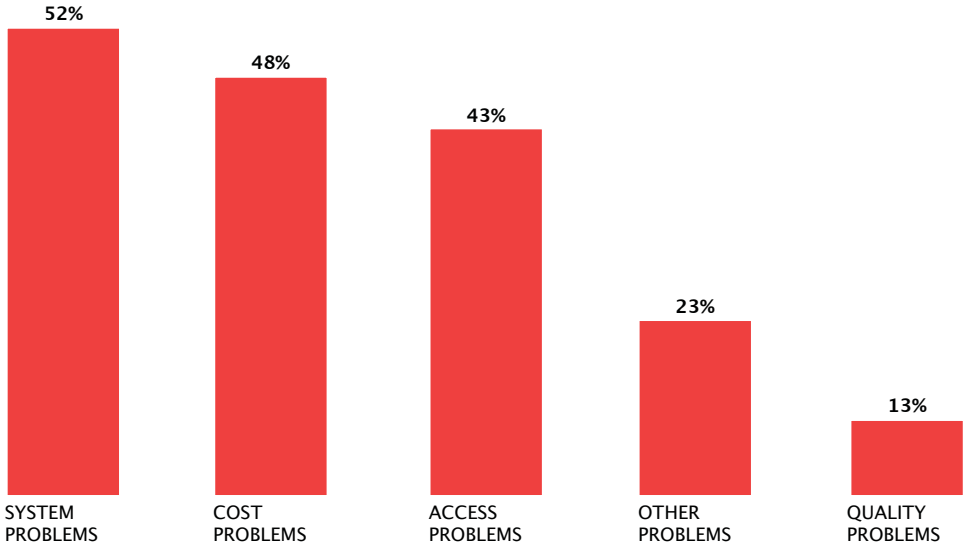
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 30,603 survey respondents.

FIGURE 2: TOP CONCERNS OF HEALTH CARE COMMUNITY DISCUSSION PARTICIPANTS



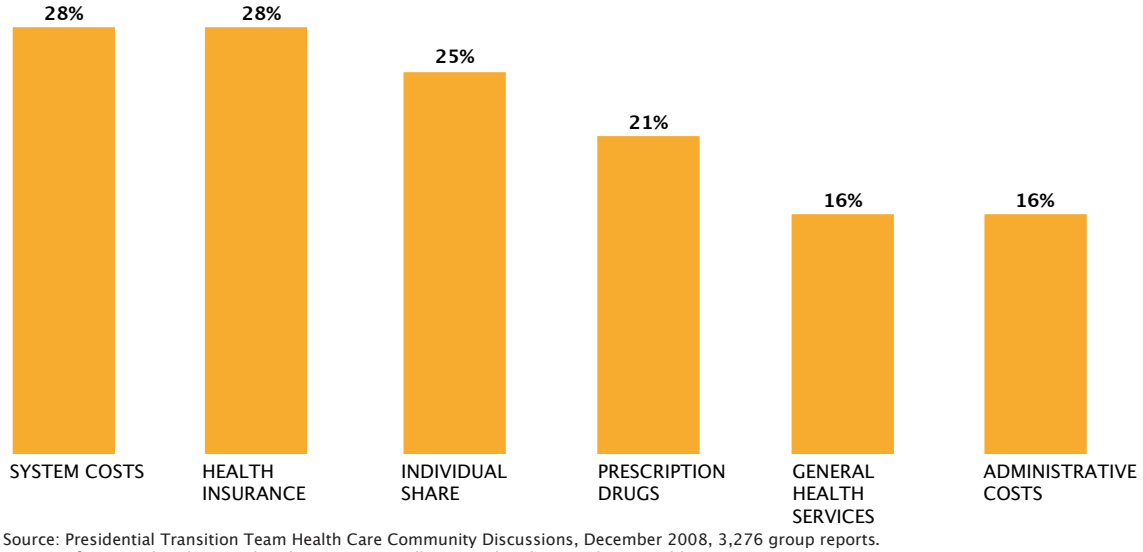
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 30,603 survey respondents.

FIGURE 3: OVERALL CONCERNS OF HEALTH CARE COMMUNITY DISCUSSION GROUPS



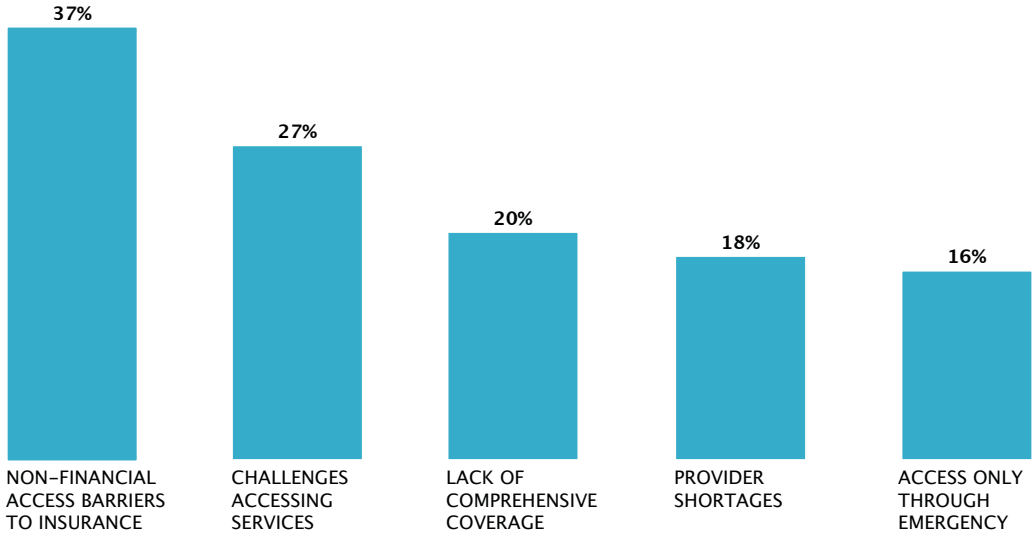
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports.
Note: The sum of each topic exceeds 100 percent because some groups discussed more than one topic.

FIGURE 4: TYPES OF COST CONCERNS OF HEALTH CARE COMMUNITY DISCUSSION GROUPS



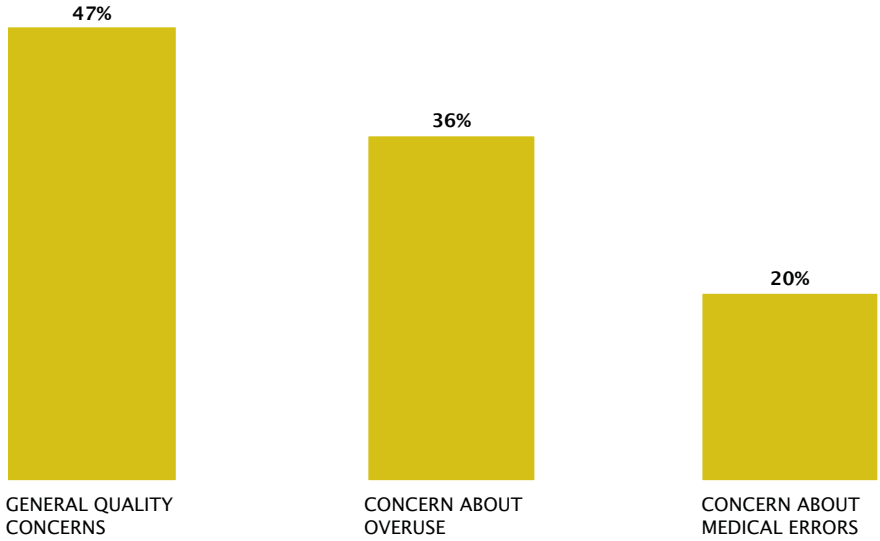
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports.
Percent of groups that discussed each topic among all groups that discussed cost problems.
Note: The sum of each topic exceeds 100 percent because some groups discussed more than one topic.

FIGURE 5: TYPES OF ACCESS CONCERNS OF HEALTH CARE COMMUNITY DISCUSSION GROUPS



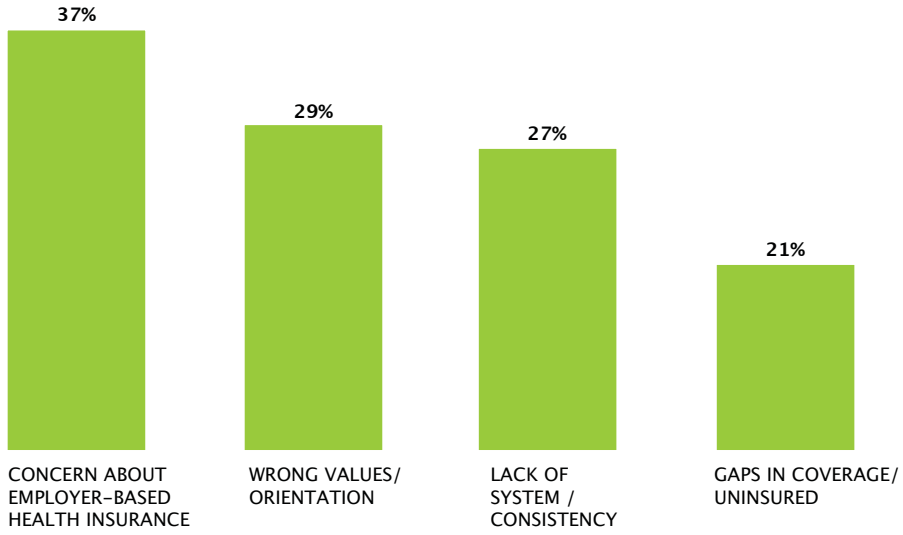
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports.
Percent of groups that discussed each topic among all groups that discussed access problems.
Note: The sum of each topic exceeds 100 percent because some groups discussed more than one topic.

FIGURE 6: TYPES OF QUALITY CONCERNS OF HEALTH CARE COMMUNITY DISCUSSION GROUPS



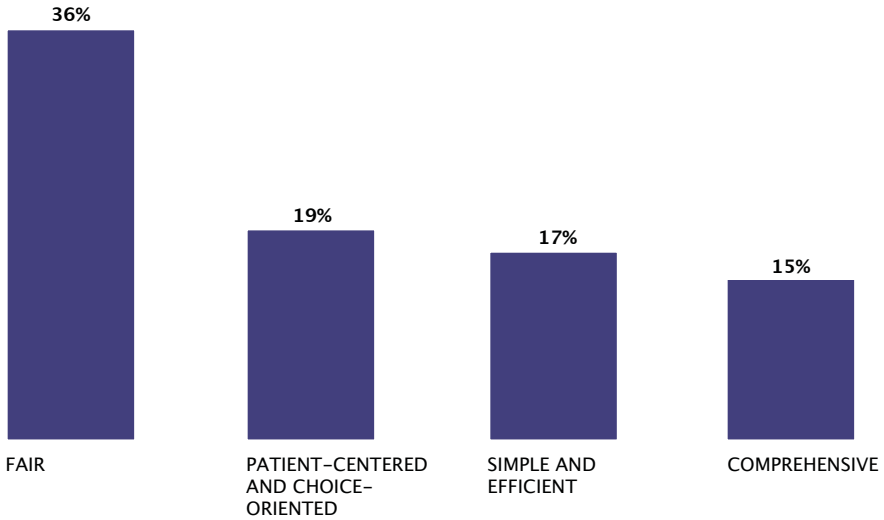
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports.
Percent of groups that discussed each topic among all groups that discussed quality problems.
Note: The sum of each topic exceeds 100 percent because some groups discussed more than one topic.

FIGURE 7: TYPES OF SYSTEM CONCERNS OF HEALTH CARE COMMUNITY DISCUSSION GROUPS



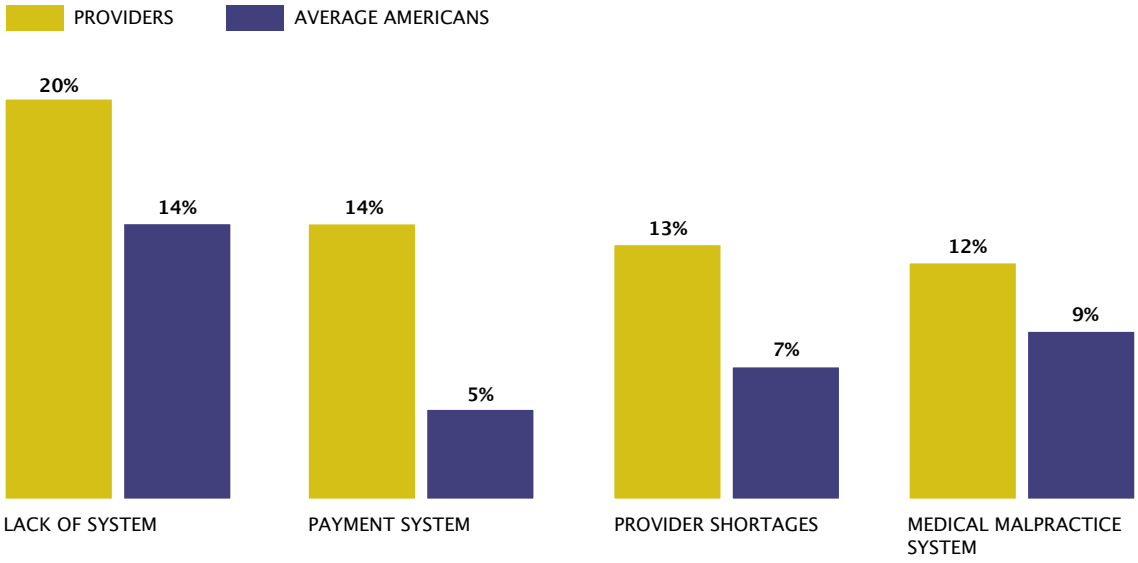
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports.
Percent of groups that discussed each topic among all groups that discussed system problems.
Note: The sum of each topic exceeds 100 percent because some groups discussed more than one topic.

FIGURE 8: VALUES FOR THE SYSTEM FROM HEALTH CARE COMMUNITY DISCUSSION GROUPS



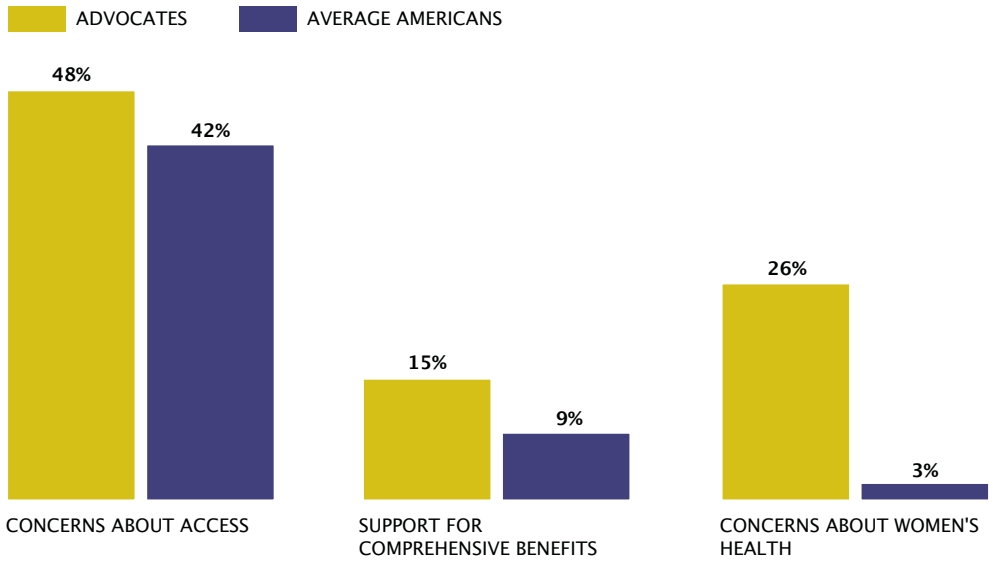
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports.
Percent of groups that discussed each topic among all groups that discussed solutions.

FIGURE 9: CONCERNS OF PROVIDERS COMPARED TO AVERAGE AMERICANS



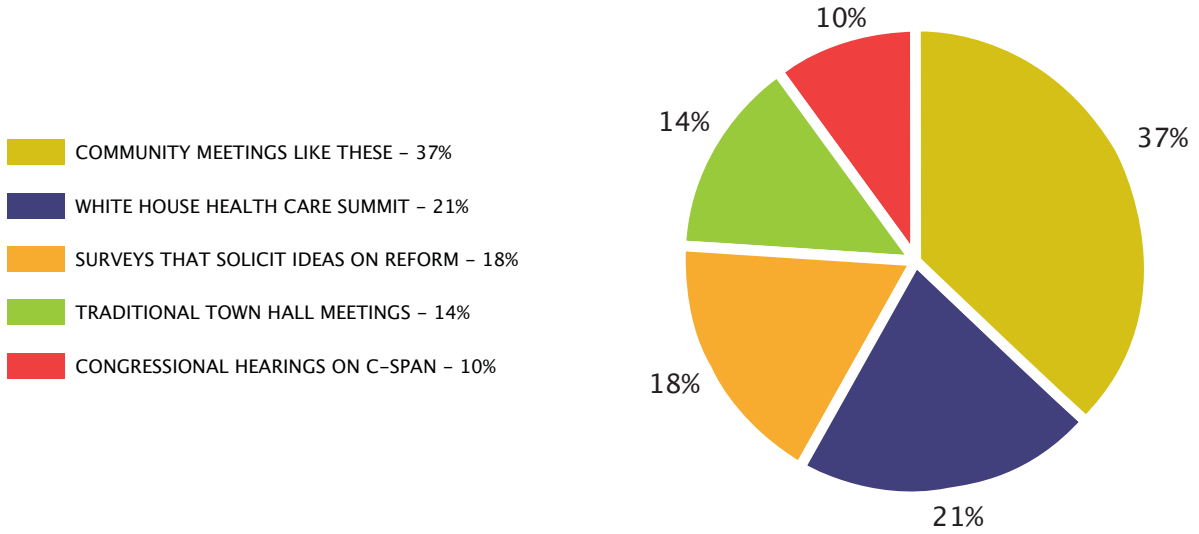
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports. Based on 2,448 (72%) reports where a majority of participants were from an advocacy group (8%), provider group (16%), or citizen group (76%).

FIGURE 10: CONCERNS OF ADVOCATES COMPARED TO AVERAGE AMERICANS



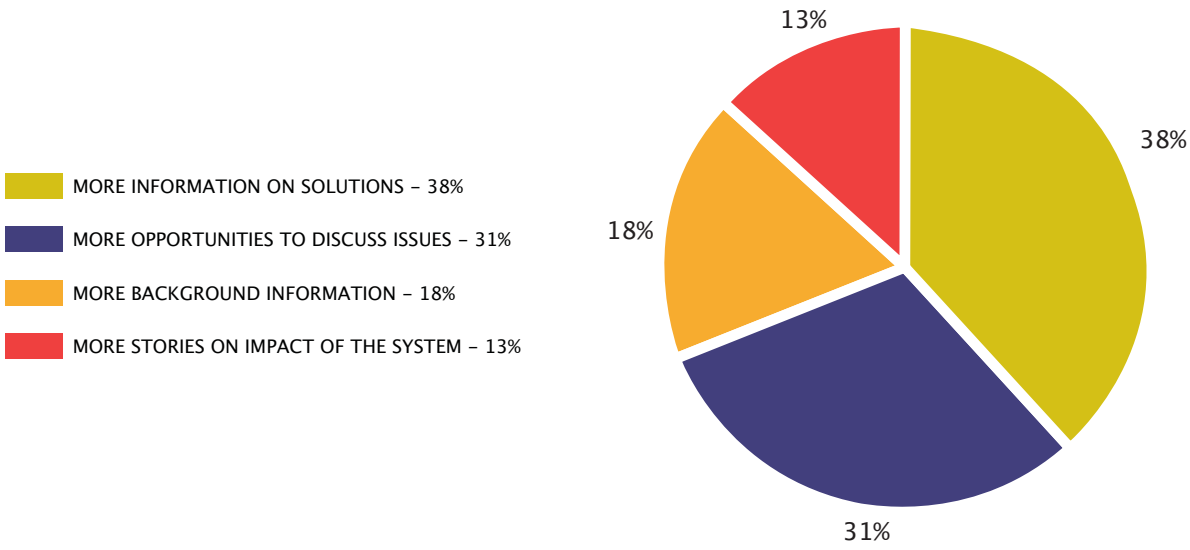
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 3,276 group reports. Based on 2,448 (72%) reports where a majority of participants were from an advocacy group (8%), provider group (16%), or citizen group (76%).

FIGURE 11: HOW POLICY MAKERS SHOULD GET PUBLIC INPUT ON HEALTH REFORM



Source: Presidential Transition Team Health Care Community Discussions, December 2008, 30,603 survey respondents.

FIGURE 12: HOW PEOPLE WANT TO STAY ENGAGED IN HEALTH REFORM



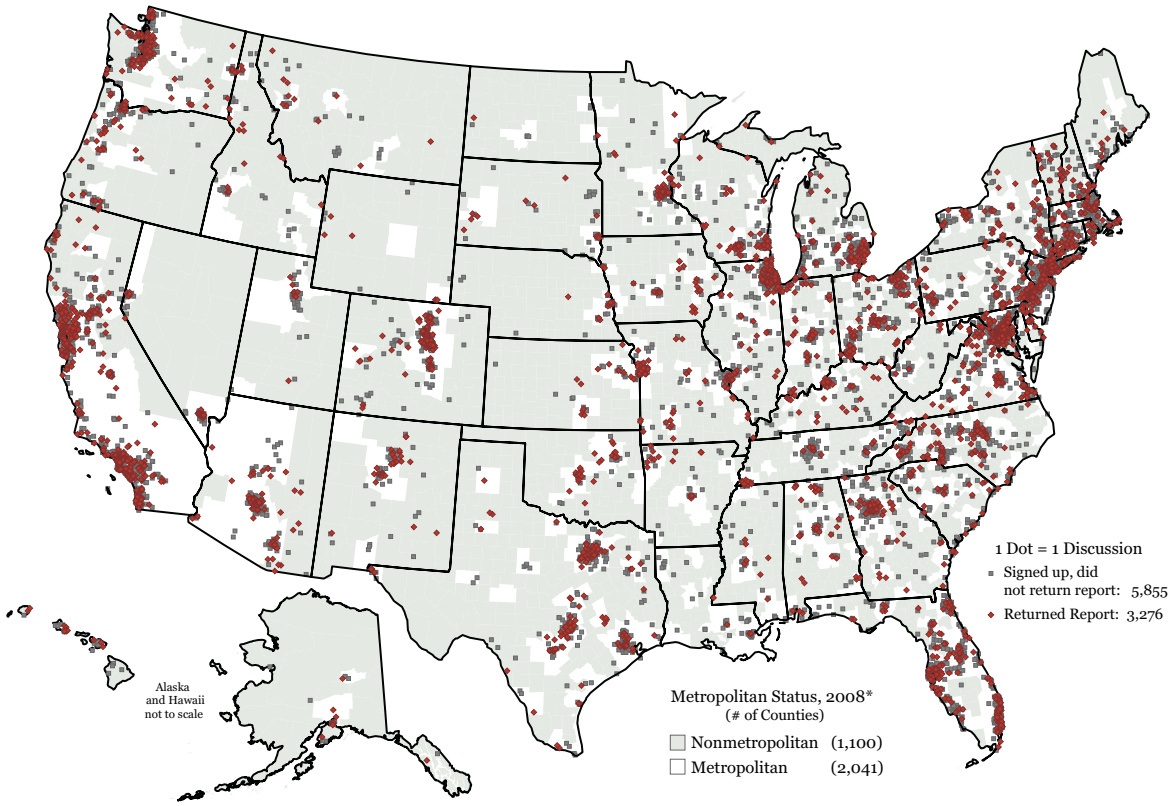
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 30,603 survey respondents.

TABLE 1: DETAILS FROM HEALTH CARE COMMUNITY DISCUSSION PARTICIPANT SURVEY

		COST OF HEALTH INSURANCE	COST OF HEALTH CARE SERVICES	DIFFICULTY FINDING HEALTH INSURANCE DUE TO PRE-EXISTING CONDITION	LACK OF EMPHASIS ON PREVEN-TION	QUALITY OF HEALTH CARE	COMMU-NITY MEETINGS LIKE THESE	TRADI-TIONAL TOWN HALL MEETINGS	SURVEYS THAT SOLICIT IDEAS ON REFORM	A WHITE HOUSE HEALTH CARE SUMMIT	CONGRE-SSIONAL HEARINGS ON C-SPAN	MORE BACKGROUND INFORMATION ON PROBLEMS IN THE HEALTH SYSTEM	MORE INFORMATION ON SOLUTIONS ON HEALTH REFORM	MORE STORIES ON HOW THE SYSTEM AFFECTS REAL PEOPLE	MORE OPPORTUNITIES TO DISCUSS THE ISSUES
REGION	TOTALS														
MIDWEST	5,728	1972	1462	719	1222	634	2,184	780	957	1268	493	908	2162	636	1788
		33%	24%	12%	20%	11%	39%	14%	17%	22%	9%	17%	39%	12%	33%
NORTHEAST	5,465	1,849	1,399	621	1,075	741	1,983	798	1,094	950	611	1,027	1,928	654	1,664
		33%	25%	11%	19%	13%	36%	15%	20%	17%	11%	19.48%	37%	12%	32%
SOUTH	9,359	2,982	2,438	1,325	1,882	1,357	3,487	1,299	1,577	1,894	916	1,723	3,221	1,308	2,662
		30%	24%	13%	19%	14%	38%	14%	17%	21%	10%	19.33%	36%	14.67%	30%
WEST	10,051	3,260	2,591	1,647	2,196	1,306	3,598	1,477	1,761	2,150	975	1,433	3,687	1,146	2,927
		30%	24%	15%	20%	12%	36%	15%	18%	22%	10%	16%	40%	12.47%	32%
TOTALS	30,603	10,083	7,890	4,312	6,375	4,038	11,252	4,354	5,389	6,262	2,995	5,091	10,998	3,744	9,041
		31%	24%	13%	20%	12%	37%	14%	18%	21%	10%	18%	38%	13%	31%
POPULATION TYPE	TOTALS														
METRO	25,986	8,595	6,636	3,579	5,373	3,482	9,614	3,667	4,505	5,409	2,479	4,412	9,328	3,238	7,642
		31%	24%	13%	19%	13%	37%	14.28%	18%	21%	10%	18%	38%	13%	31%
MICRO	2,256	678	636	316	485	258	881	351	394	446	251	355	774	265	679
		29%	27%	13%	20%	11%	38%	15.11%	17%	19%	11%	17%	37%	13%	33%
RURAL	2,360	790	618	417	517	302	757	336	490	407	265	324	896	241	720
		30%	23%	16%	20%	11%	34%	14.90%	22%	18%	12%	15%	41%	11%	33%
TOTALS	30,603	10,063	7,890	4,312	6,375	4,042	11,252	4,354	5,389	6,262	2,995	5,091	10,998	3,744	9,041
		31%	24%	13%	20%	12%	37%	14%	18%	21%	10%	18%	38%	13%	31%
PER CAPITA INCOME	TOTALS														
UNDER 25K	10,592	3,550	2,677	1,309	2,181	1,428	4,038	1,526	1,960	2,089	1,119	1,776	3,594	1,274	3,255
		32%	24%	12%	20%	13%	38%	14%	18%	19%	10%	18%	36%	13%	33%
25 - 44K	15,138	4,800	4,004	2,307	3,219	2,015	5,394	2,193	2,624	3,132	1,457	2,475	5,483	1,972	4,340
		29%	24%	14%	20%	12%	36%	15%	18%	21%	10%	17%	38%	14%	30%
45K +	4,872	1,713	1,209	696	975	599	1,820	635	805	1,041	419	840	1,921	498	1,446
		33%	23%	13%	19%	12%	39%	13%	17%	22%	9%	18%	41%	11%	31%
TOTALS	30,603	10,063	7,890	4,312	6,375	4,042	11,252	4,354	5,389	6,262	2,995	5,091	10,998	3,744	9,041
		31%	24%	13%	20%	12%	37%	14%	18%	21%	10%	18%	38%	13%	31%

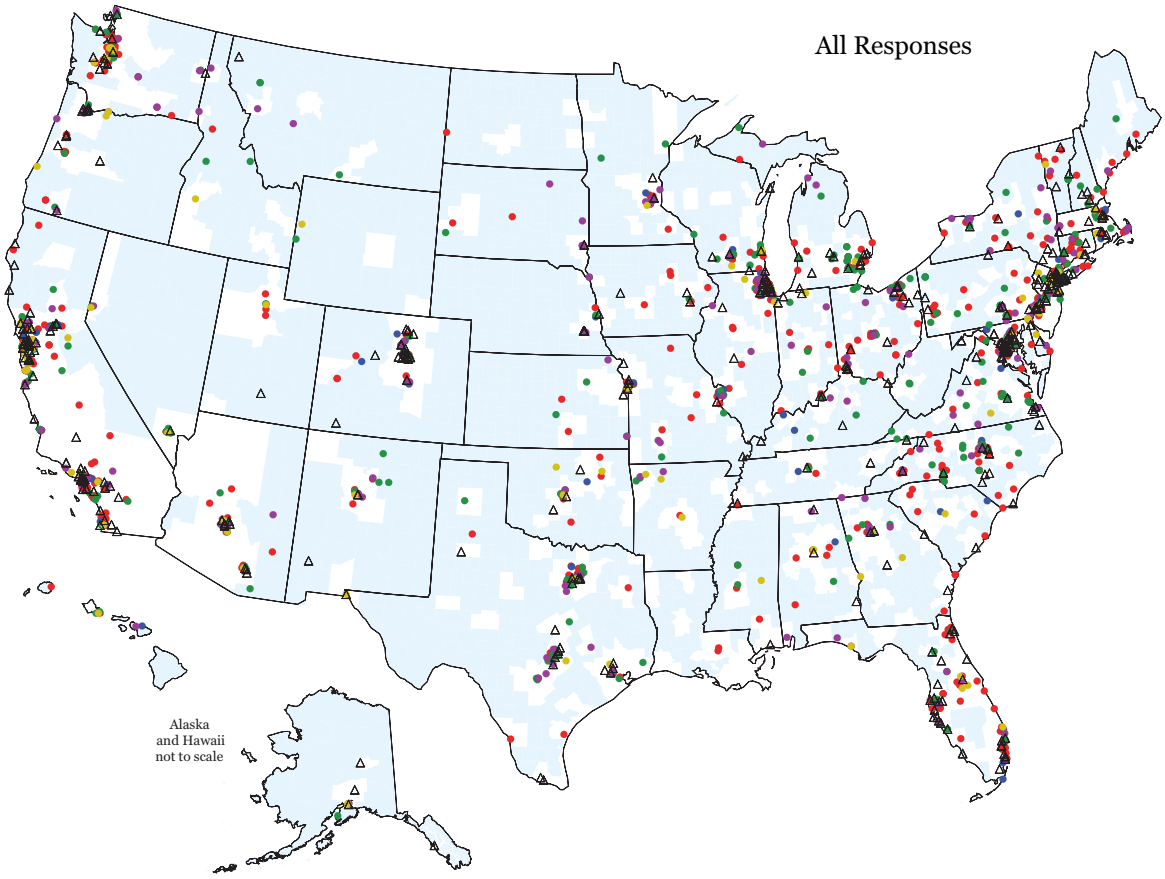
Source: Presidential Transition Team Health Care Community Discussions, December 2008, 30,603 survey respondents.

MAP 1: HEALTH CARE COMMUNITY DISCUSSION SIGN-UPS AND REPORTS,
Location and Metropolitan Status, December 2008



Produced By: The Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.
Sources: ZIP Code Boundaries: Nielsen Claritas PopFacts data set, 2008. Dots are randomly placed within ZIP Code Boundaries;
*Core Based Statistical Areas: US Census Bureau, 2008. Nonmetropolitan counties include micropolitan and counties outside of CBSAs.

MAP 2: BIGGEST PROBLEM IN THE HEALTH SYSTEM BY RURAL / URBAN AREA,
Results of Health Care Community Discussion Participant Surveys, December 2008



WHAT DO YOU PERCIEVE IS THE BIGGEST PROBLEM IN THE HEALTH SYSTEM? (# OF SITES)

- COST OF HEALTH INSURANCE **(610)**
- COST OF HEALTH CARE SERVICES **(298)**
- DIFFICULTY FINDING HEALTH INSURANCE DUE TO A PRE-EXISTING CONDITION **(62)**
- LACK OF EMPHASIS ON PREVENTION **(207)**
- QUALITY OF HEALTH CARE **(94)**
- TWO OR MORE OF THE ABOVE **(389)**

METROPOLITAN STATUS 2008* (# OF COUNTIES)

- Metropolitan (1,100)
- Nonmetropolitan (2,041)

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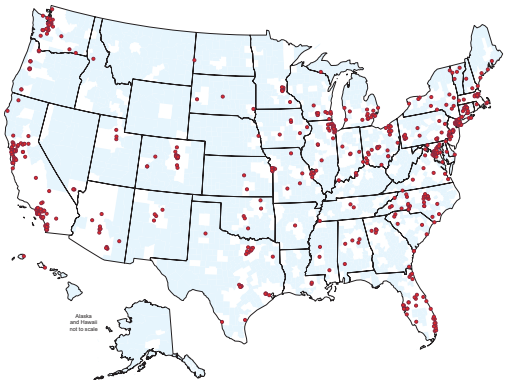
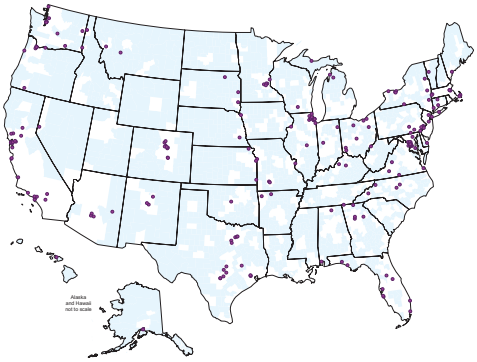
Produced By: The Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.
*Core Based Statistical Areas Source: US Census Bureau, 2008. Nonmetropolitan counties include micropolitan and counties outside of CBSAs.

MAP 2: (continued) BIGGEST PROBLEM IN THE HEALTH SYSTEM BY RURAL / URBAN AREA,
Results of Health Care Community Discussion Participant Surveys, December 2008

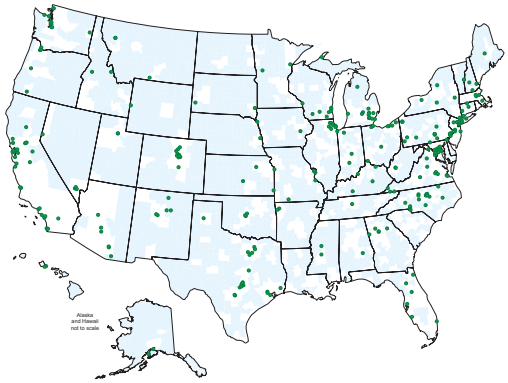
Cost of Health Insurance



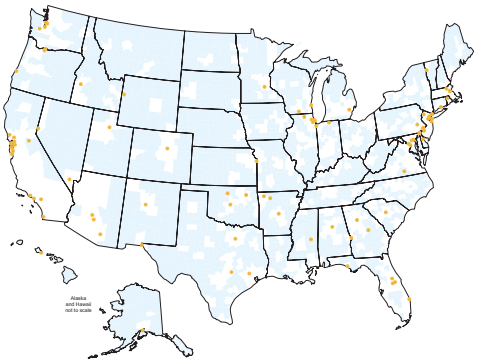
Lack of Emphasis on Prevention



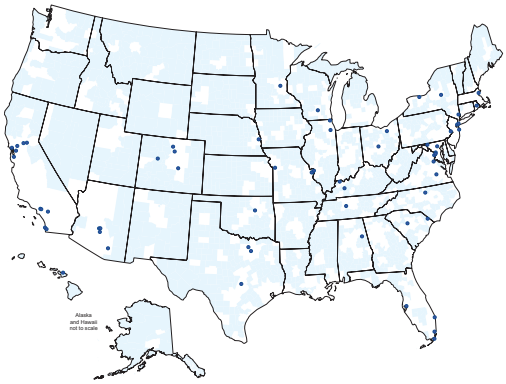
Cost of Health Care Services



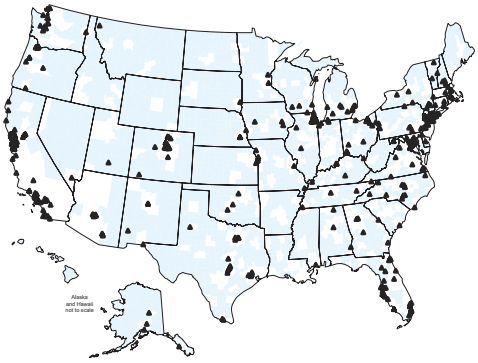
Quality of Health Care



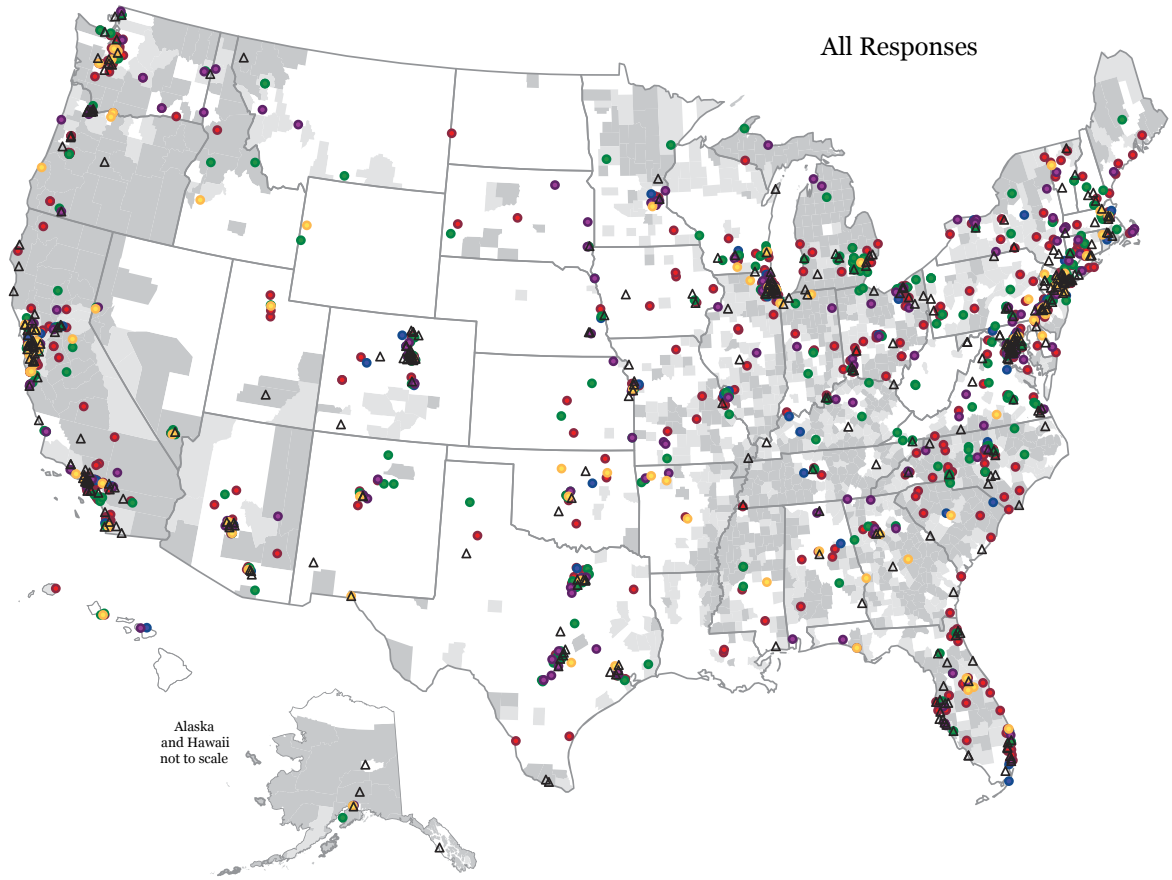
Difficulty Finding Health Insurance Due to a Pre-Existing Condition



Two or More Most Common Answers



MAP 3: BIGGEST PROBLEM IN THE HEALTH SYSTEM BY UNEMPLOYMENT RATE,
Results of Health Care Community Discussion Participant Surveys, December 2008



WHAT DO YOU PERCEIVE IS THE BIGGEST PROBLEM IN THE HEALTH SYSTEM? (# OF SITES)

- COST OF HEALTH INSURANCE **(610)**
- COST OF HEALTH CARE SERVICES **(298)**
- DIFFICULTY FINDING HEALTH INSURANCE DUE TO A PRE-EXISTING CONDITION **(62)**
- LACK OF EMPHASIS ON PREVENTION **(207)**
- QUALITY OF HEALTH CARE **(94)**
- TWO OR MORE OF THE ABOVE **(389)**
- TIED WITH ONE OR MORE ANSWERS **(300)**
- TIED WITH ONE OR MORE ANSWERS **(274)**
- TIED WITH ONE OR MORE ANSWERS **(111)**
- TIED WITH ONE OR MORE ANSWERS **(200)**
- TIED WITH ONE OR MORE ANSWERS **(112)**

UNEMPLOYMENT RATE, DECEMBER 2008*
(# OF COUNTIES)

- 8.7% to 24.6% (816)
- 7.2% to 8.6% (603)
- LOWER THAN 7.2% (1,722) (NATIONAL AVERAGE)

Solid circles indicate that the majority of respondents at the site preceived this as the biggest problem in the health system.
Open triangles indicate a tie between one or more problems (no plurality).

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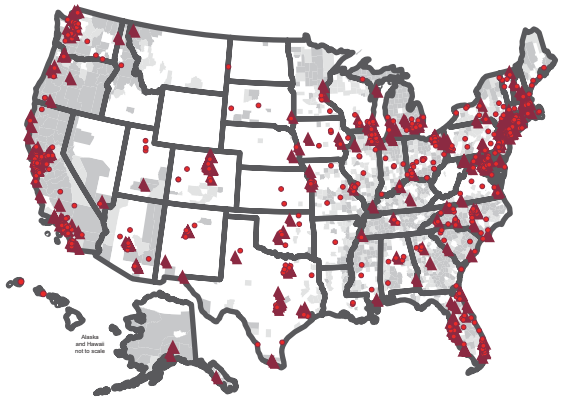
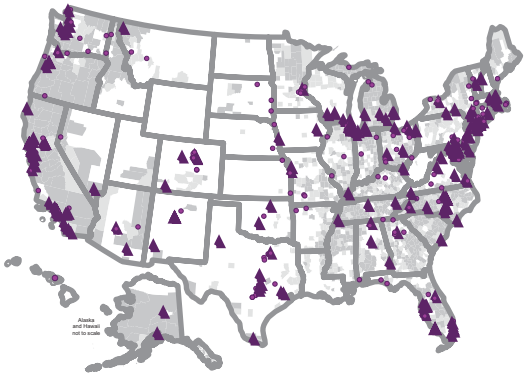
Produced By: The Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.
Source: Bureau of Labor Statistics, Local Area Unemployment Statistics, ftp://ftp.bls.gov/pub.time.series/la/la.txt, accessed 2 /18/09.
*Note: Data are preliminary unadjusted county unemployment rates from December 2008 for 50 US states and District of Columbia. Mean county unemployment rate was 7.15% (N=3,140).

MAP 3: (continued) BIGGEST PROBLEM IN THE HEALTH SYSTEM BY UNEMPLOYMENT RATE,
Results of Health Care Community Discussion Participant Surveys, December 2008

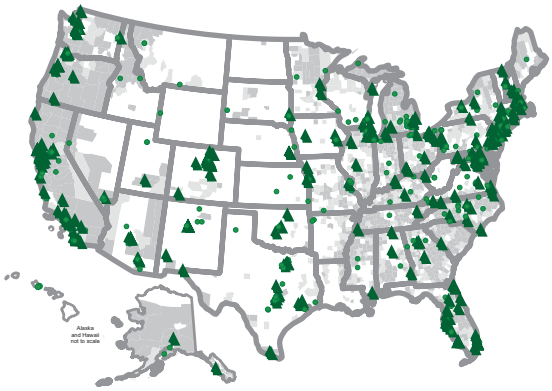
Cost of Health Insurance



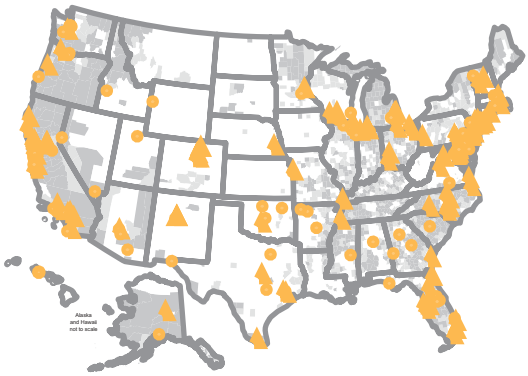
Lack of Emphasis on Prevention



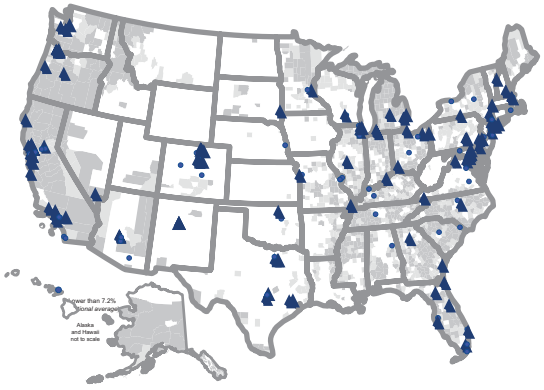
Cost of Health Care Services



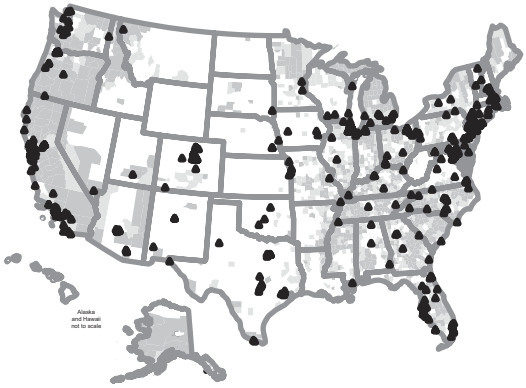
Quality of Health Care



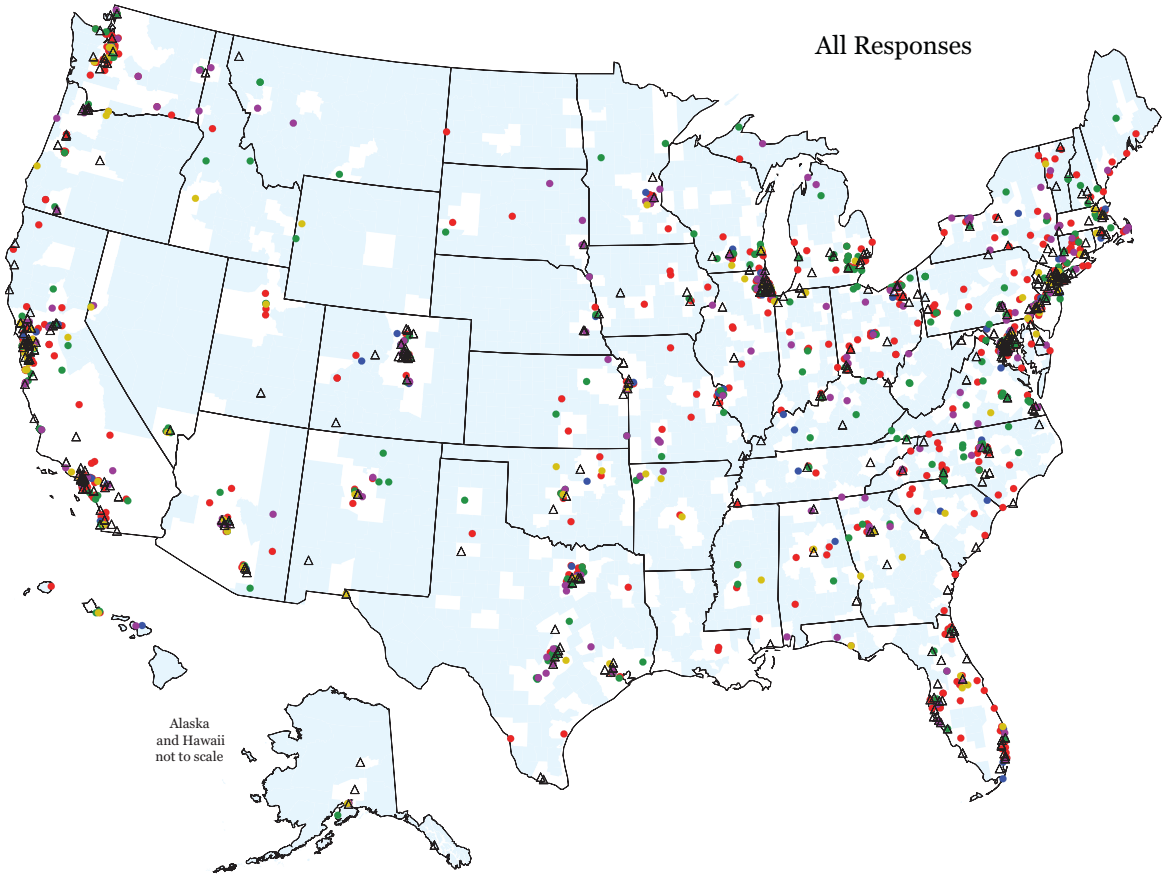
Difficulty Finding Health Insurance Due to a Pre-Existing Condition



Two or More Most Common Answers



MAP 4: HOW POLICY MAKERS SHOULD GET POLICY / INPUT ON HEALTH REFORM,
Results of Health Care Community Discussion Participant Surveys, December 2008



WHAT DO YOU THINK IS THE BEST WAY FOR POLICY MAKERS TO DEVELOP A PLAN TO ADDRESS THE HEALTH SYSTEM PROBLEMS? (# OF SITES)

- COMMUNITY MEETINGS LIKE THESE **(895)**
- TRADITIONAL TOWN HALL MEETINGS **(50)**
- SURVEYS THAT SOLICIT IDEAS ON REFORM **(134)**
- A WHITE HOUSE HEALTH CARE SUMMIT **(196)**
- CONGRESSIONAL HEARINGS ON C-SPAN **(84)**
- TWO OR MORE OF THE ABOVE **(301)**

METROPOLITAN STATUS 2008* (# OF COUNTIES)

- Metropolitan (1,100)
- Nonmetropolitan (2,041)

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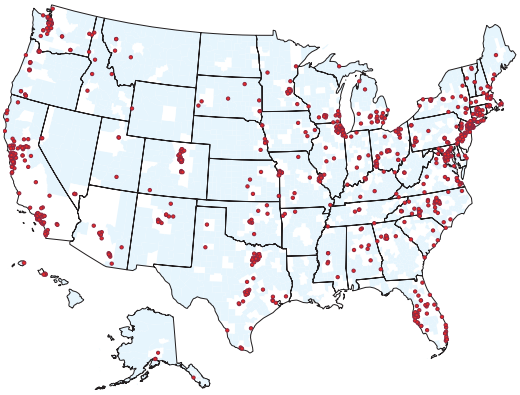
FOR HEALTH SERVICES RESEARCH

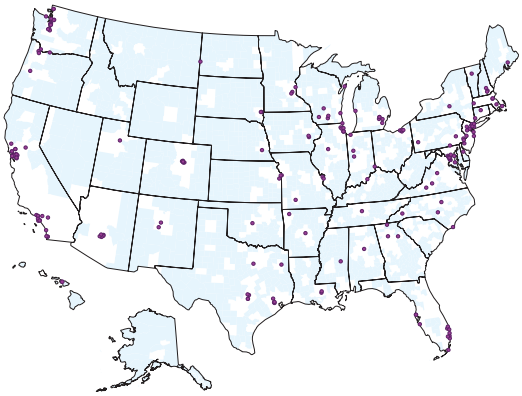
Produced By: The Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.
*Core Based Statistical Areas Source: US Census Bureau, 2008. Nonmetropolitan counties include micropolitan and counties outside of CBSAs.

MAP 4: (continued) HOW POLICY MAKERS SHOULD GET POLICY / INPUT ON HEALTH REFORM,
Results of Health Care Community Discussion Participant Surveys, December 2008

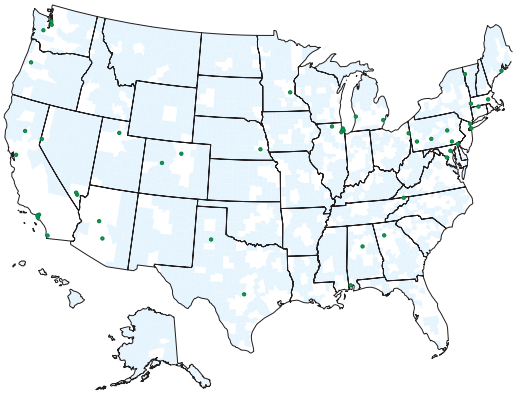
Community Meetings Like These



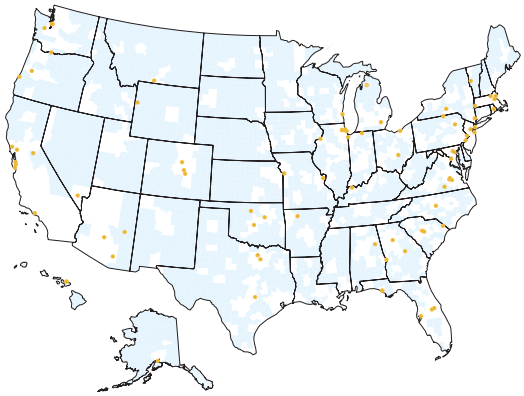
A White House Health Care Summit



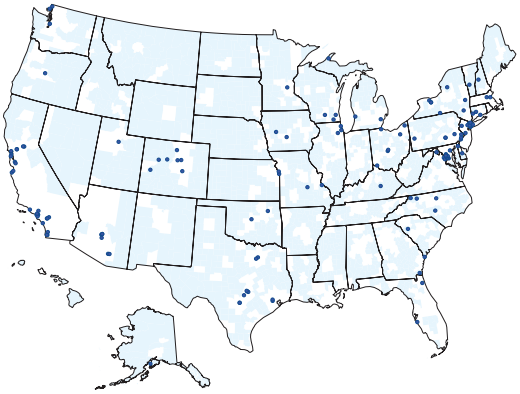
Traditional Town Hall Meetings



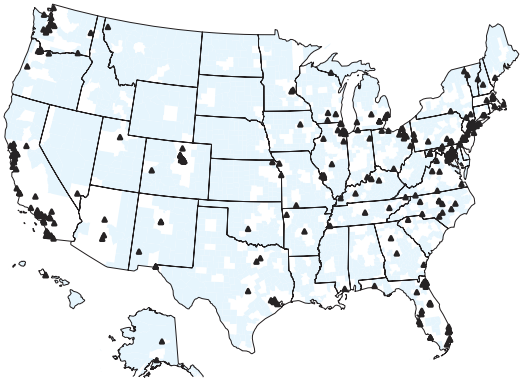
Congressional Hearings on C-SPAN



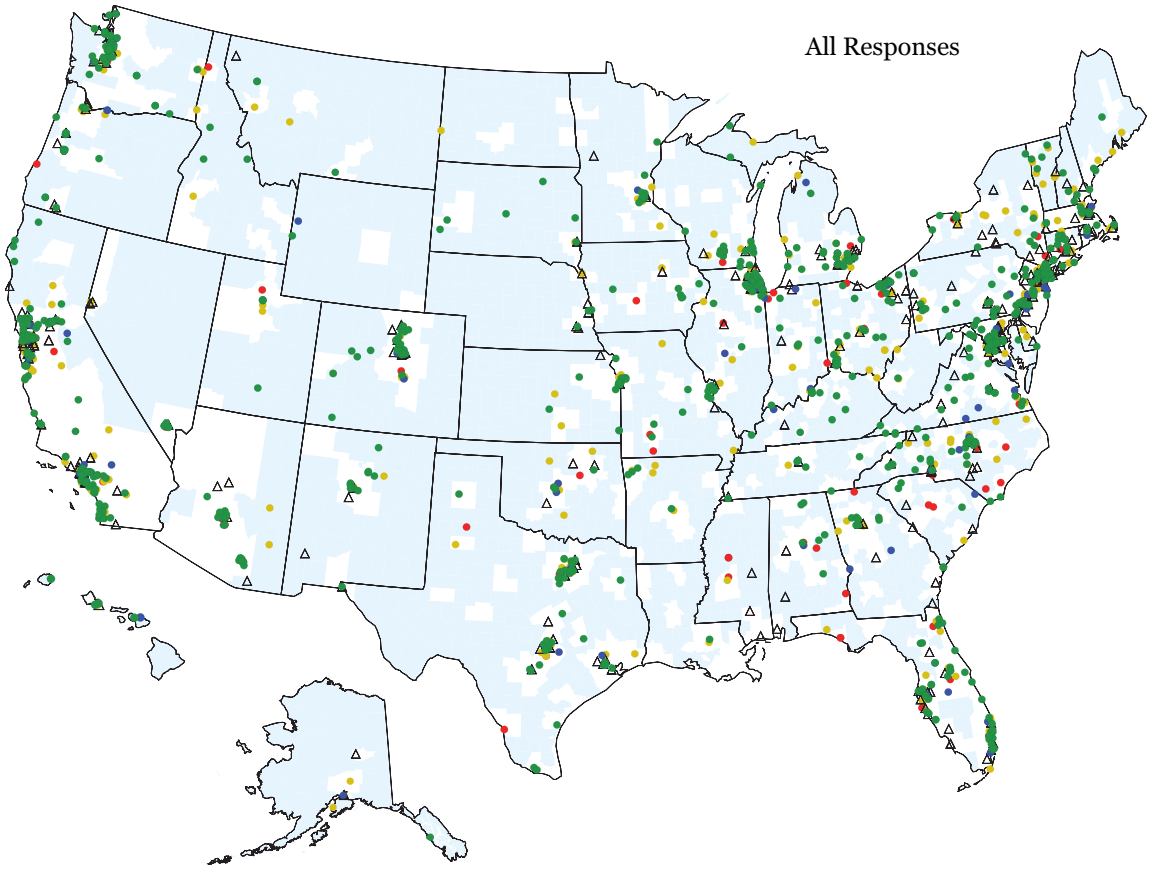
Surveys that Solicit Ideas on Reform



Two or More Most Common Answers



MAP 5: HOW PEOPLE WANT TO STAY ENGAGED IN HEALTH REFORM,
Results of Health Care Community Discussion Participant Surveys, December 2008



AFTER THIS DISCUSSION, WHAT ADDITIONAL INPUT AND INFORMATION WOULD BEST HELP YOU TO CONTINUE TO PARTICIPATE IN THIS GREAT DEBATE? (# OF SITES)

- MORE BACKGROUND INFORMATION ON PROBLEMS IN THE HEALTH CARE SYSTEM **(104)**
- MORE INFORMATION ON SOLUTIONS FOR HEALTH REFORM **(777)**
- MORE STORIES ON HOW THE SYSTEM AFFECTS REAL PEOPLE **(89)**
- MORE OPPORTUNITIES TO DISCUSS THE ISSUES **(380)**
- TWO OR MORE OF THE ABOVE **(310)**

METROPOLITAN STATUS 2008* (# OF COUNTIES)

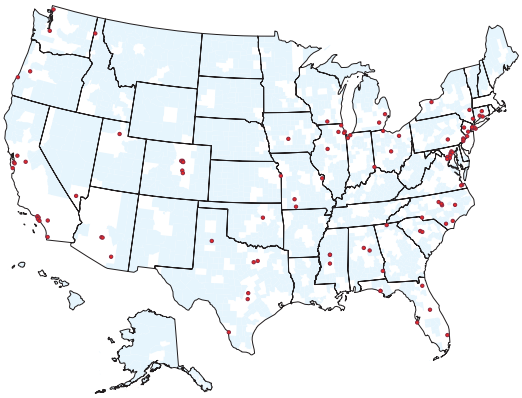
- Metropolitan (1,100)
- Nonmetropolitan (2,041)

UNC THE CECIL G. SHEPS CENTER FOR HEALTH SERVICES RESEARCH

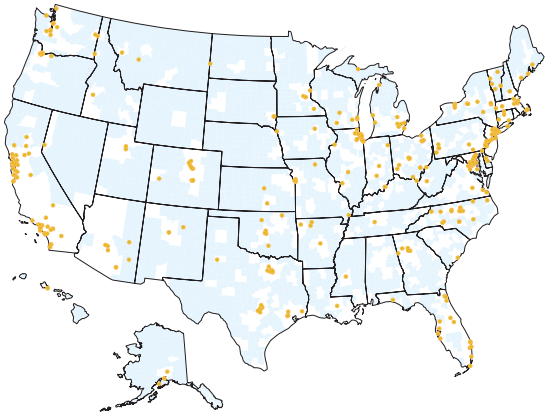
Produced By: The Cecil G. Sheps Center for Health Services Research, University of North Carolina at Chapel Hill.
Sources: ZIP Code Boundaries: Nielsen Claritas PopFacts data set, 2008. Dots are randomly placed within ZIP Code Boundaries;
*Core Based Statistical Areas: US Census Bureau, 2008. Nonmetropolitan counties include micropolitan and counties outside of CBSAs.

MAP 5: (continued) HOW PEOPLE WANT TO STAY ENGAGED IN HEALTH REFORM,
Results of Health Care Community Discussion Participant Surveys, December 2008

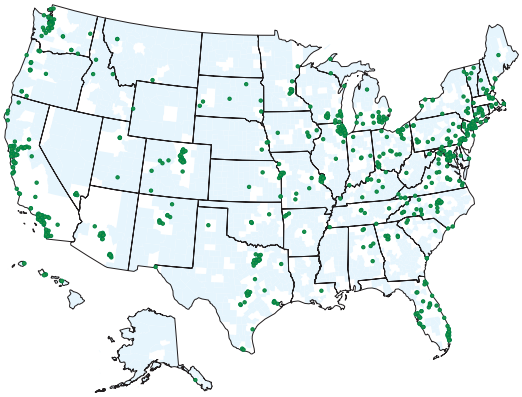
More Background Information on Problems in the Health System



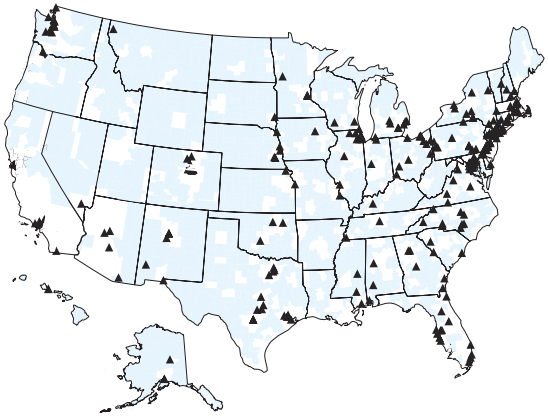
More Opportunities to Discuss the Issues



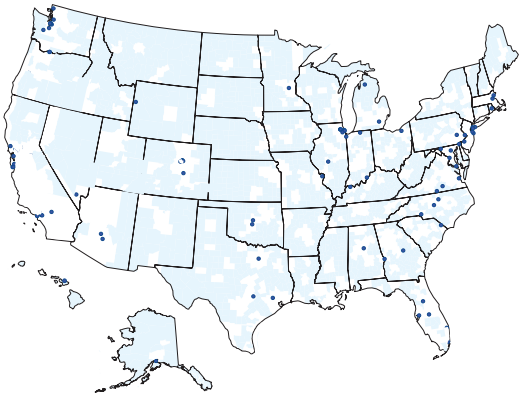
More Information on Solutions for Health Reform



Two or More Most Common Answers



More Stories on How the System Affects Real People



NOTES

1 The Moderator Guide is available at the HHS Web site hosting this report, http://www.HealthReform.gov.

2 The Participant Guide is available at the HHS Web site hosting this report, http://www.HealthReform.gov.

3 The questions included: 1) Briefly, from your own experience, what do you perceive is the biggest problem in the health system? 2) How do you choose a doctor or hospital? What are your sources of information? How should public policy promote quality health care providers? 3) Have you or your family members ever experienced difficulty paying medical bills? What do you think policy makers can do to address this problem? 4) In addition to employer-based coverage, would you like the option to purchase a private plan through an insurance-exchange or a public plan like Medicare? 5) Do you know how much you or your employer pays for health insurance? What should an employer's role be in a reformed health care system? 6) Below are examples of the types of preventive services Americans should receive. Have you gotten the prevention you should have? If not, how can public policy help? 7) How can public policy promote healthier lifestyles?

4 The Presidential Transition Team sent an e-mail to individuals who had signed up to host a Health Care Community Discussion informing them of the January 4, 2009 deadline.

5 All of the Health Care Community Discussion group reports are available on the HHS Web site hosting this report, http://www.HealthReform.gov.

6 A full list of these codes is available on the HHS Web site hosting this report, http://www.HealthReform.gov.

7 *See* "Obama Transition Team Holds Health Care Meeting At UCF: President-Elect Wants Citizens' Opinions On Health Care Reform," *WESH Channel 2 NBC News* (December 21, 2008), *available at* http://www.wesh.com/news/18331750/detail.html?rss=orl&psp=news; Luis Zaragoza, "UCF to host forum aimed at getting public comment on health care problems, solutions," *Orlando Sentinel* (December 19, 2008), *available at* http://blogs.orlandosentinel.com/news_education_edblog/2008/12/ucf-to-host-hea.html; and Zenaida Gonzalez Kotala, "Residents Share Health Care Nightmares at Obama-Inspired UCF Health Care Meeting," *UCF Newsroom* (December 22, 2008), *available at* http://news.ucf.edu/UCFnews/index?page=article&id=0024004102082b6ee011e4c7dabcc007c12&subject_id=0024004102975ad83011b2b83251c0c35.

8 The group reports for all four Health Care Community Discussion spotlights are available at the HHS Web site hosting this report, http://www.HealthReform.gov.

9 *See, e.g.*, Gadi Schwartz and Joshua Panas, "Group Wants Input on Healthcare for Obama," *KOB.com NBC 4* (December 29, 2008), *available at* http://kob.com/article/stories/S722177.shtml?cat=516; "Health Care Listening Session on Tuesday," *Kennebec Journal* (December 28, 2008), *available at* http://kennebecjournal.mainetoday.com/news/local/5755698.html; "Obama Asks for Kansans Input," *KSNW NBC 3* (December 29, 2008), *available at* http://www.ksn.com/news/local/36851034.html.

10 "Obama Asks for Kansans Input," *KSNW NBC 3* (December 29, 2008), *available at* http://www.ksn.com/news/local/36851034.html.

11 Jason Morton, "Community, professionals voice concerns over health care," *Tuscaloosa News* (December 31, 2008), *available at* http://www.tuscaloosanews.com/article/20081231/NEWS/812300237/1005/LIVING?Title=Community__professionals_voice_concerns_over_health_care.

12 Margaret Bauman, "Residents Say Biggest Health Care Problem is System," *Alaska Journal of Commerce* (January 16, 2009), *available at* http://www.alaskajournal.com/stories/011609/hea_20090116028.shtml.

13 Patrice St. Germain, "Reform of nation's health care discussed," *The Southern Utah Spectrum* (December 24, 2008), *available at* http://www.thespectrum.com/article/20081224/NEWS01/812240334.

14 Nanci Bompey, "Community Gets Involved in Health Care Reform," *Asheville Citizen-Times* (January 5, 2009), *available at* http://www.citizen-times.com/apps/pbcs.dll/article?AID=2009901050316.

15 Frank X. Mullen, Jr., "Northern Nevadans Weigh In on National Health Care Reform," *Reno Gazette-Journal* (January 4, 2009), *available at* http://www.rgj.com/article/20090104/NEWS/901040336/1321.

16 Kate S. Alexander, "Group Eyes Big Changes in Health Care," *The Herald-Mail* (December 29, 2008), *available at* http://www.herald-mail.com/?cmd=displaystory&story_id=213289&format=html.

17 Jim Adams, "An Invitation to Fix Health Care System Gets Crowds," *Star Tribune* (January 11, 2009), *available at* http://www.startribune.com/local/north/37395759.html.

18 United States Department of Labor, "FAQs About COBRA Continuation Health Coverage," http://www.dol.gov/ebsa/faqs/faq_consumer_cobra.HTML.

19 The American Recovery and Reinvestment Act included a time-limited tax credit equal to 65 percent of the premium for COBRA coverage for people who recently lost their job and insurance.

20 The team developed "exclusion categories" to eliminate submissions that either did not pertain to the goals of the project or were not compatible with the analytical software. The "exclusion categories" were:
(1) Individual Comment: The submission contained an individual's personal comments on health care ("I think that…") and was not a group report from a Health Care Community Discussion.
(2) Off Topic: The submission contained comments unrelated to health care or to a Health Care Community Discussion. This category included submissions with statements such as "did not have event" or "the event was cancelled."
(3) Policy Paper Not Associated With a Health Care Community Discussion: The submission was a policy white paper, a

group's Legislative agenda, or a policy paper not associated with the occurrence of a Health Care Community Discussion.
(4) Corrupt or Duplicative File: The submission was a corrupt file, unreadable, or was a second submission with a photo or survey results.
(5) Unconvertible PDF Files: PDF documents that were unable to be converted to text documents and thus unable to be analyzed by the software.

21 A full list of the 95 codes is available on the HHS Web site hosting this report, http://www.HealthReform.gov.

22 The analysis by region, population type, per capita income, and unemployment was done based on whether a document had a code or did not have a code. The number of times a code appeared in a single document was not taken into account, as the goal of the analysis was to compare unique documents to each other.

23 Three "exclusion" categories were used to eliminate survey outliers: (1) large differences in the total number of responses for each of the three questions from the same host; (2) single responses that indicated a group of 300 or more; and (3) the same repeated response for all questions. Tens of thousands of survey responses were eliminated as a result.

U.S. Department of Health and Human Services

March 2009