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

#### A. Prioritization of Concerns

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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

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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**

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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**

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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."

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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.<sup>18</sup> 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

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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.”<sup>19</sup>

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**

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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]

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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

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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**

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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

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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**

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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?”

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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**

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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

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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

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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**

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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**

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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

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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**

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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**

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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

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[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

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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**

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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.”

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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 medical 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**

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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**

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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).

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## Medical Personnel Training, Performance, and Errors

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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.”

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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**

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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

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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

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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**

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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.”

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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**

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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

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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**

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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

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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

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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

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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**

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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 “[I]ack of consumer knowledge” and “not being able to trust what they are told.” In particular “they didn’t know how insurance worked

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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.

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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**

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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

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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.”

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## Health Care as a “Business”

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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

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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