

# Community Meeting Discussion Guide

## It's time to do something about Health Care



www.citizenshealthcare.gov

#### The Citizens' Health Care Working Group

#### **Our Mission:**

Provide for a nationwide public debate about improving the health care system to provide every American with the ability to obtain quality, affordable health care coverage.

Develop an action plan for Congress and the President to consider as they work to make health care that works for all Americans.

## We Need Your Help to Make HEALTH CARE THAT WORKS FOR ALL AMERICANS

ur health care system offers excellent care to many Americans but it faces many challenges. Many of us can't get health care that we need. One in seven of us has no health insurance. Others have limited coverage that may not include some important services or may require high out-of-pocket payments before coverage kicks in. The health care we do get varies in quality. And everyone knows that health care costs are a major concern for families, employers, and government.

The Citizens' Health Care Working Group was formed to host a national conversation about our health care system. We want to start the discussion now. Please read this booklet and get comfortable with the key facts and issues. Then join the discussion.

#### WHO WE ARE. WHAT WE ARE DOING.

In 2003, Congress passed a law saying: "In order to improve the health care system, the American public must engage in an informed national public debate to make choices about the services they want covered, what health care coverage they want, and how they are willing to pay for coverage." That law created the Citizens' Health Care Working Group and we were appointed to it February 28, 2005. We plan to submit our recommendations to the President and Congress at the end of September 2006.

Congress is asking us to work with you to answer four questions<sup>1</sup>:

- What health care benefits and services should be provided?
- How does the American public want health care delivered?
- How should health care coverage be financed?
- What tradeoffs are the American public willing to make in either benefits or financing to ensure access to affordable, high quality health care coverage and services?

#### HERE'S WHAT WE'VE DONE SO FAR.

We issued "The Health Report to the American People," which provides information on the current health care system in this country. The report serves as a starting point for this guide and our conversation with you.

We held hearings in several communities across the country and heard from many experts. We went to Arlington, Virginia; Jackson, Mississippi; Salt Lake City, Utah; Houston, Texas; Boston, Massachusetts; and Portland, Oregon.

The report and transcripts from these meetings are available on our website: www.citizenshealthcare.gov.

#### NOW WE WANT TO HEAR FROM YOU.

Your participation in this meeting is important. What you tell us will help us make recommendations to the President and Congress.

## INTRODUCTION: HEALTH CARE AND HEALTH INSURANCE IN AMERICA

Every American needs health care services—for routine check-ups and preventive care, for treating chronic conditions, for receiving urgent care for serious injuries or illnesses, and for helping us live comfortably in our last days of life. In general, our need for health care increases as

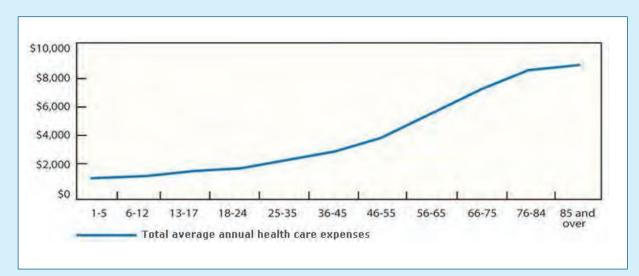
we age, but we are all at risk for needing critical and expensive care.

We get our care in a system that is large and complex. Health services are provided by doctors, nurses, and other health care professionals in an array of settings, such as hospitals, doctors' offices, long term care and rehabilitation facilities, and at home. We use a lot of pre-

## Our need for health services and the need for insurance to cover the costs of this care vary a lot and change over the course of our lives.

- In any given year, close to 50% of all health care spending pays for the care received by only 5% of the population. Any of us can experience illnesses or injuries that require serious medical attention at any time. These unexpected events can be very expensive. Hospital charges alone can top \$100,000 for these cases.
- In 2004, almost half of all people in the United States had a chronic condition that ranged from mild to severe. Health care for people with chronic diseases
- accounts for 75% of our total health care costs. Managing these illnesses can be expensive. For example, in 2002, people with diabetes spent, on average, \$13,243 on health care bills.
- As we age, our health care needs increase, beginning around age 55. On average, half of all the money spent on our health care will be for care we get after we turn 65. Health care costs for people ages 76 to 84 average about \$8,000 every year, almost eight times as much as for children between 1 and 5 years old.

#### Most Health Care is Used as We Get Older



Source: U.S. Department of Health and Human Services and Agency for Healthcare Research and Quality, *Medical Expenditure Panel Survey, 2002.* 

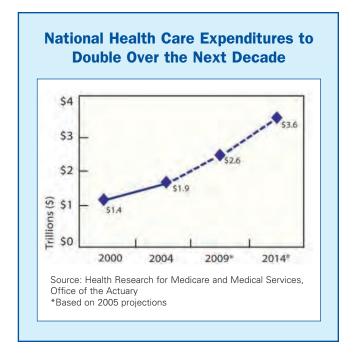
scription drugs, diagnostic tests, medical supplies and medical equipment. Some of these services are very expensive, but we also use many low-priced services and drugs. Our health care system also supports medical research. How well our health care system meets our needs for care and the costs associated with delivery of this care are subjects of much debate.

Most Americans have either private or public insurance that covers—that is, pays for—some or all of their health care needs. People with higher incomes are more likely to have comprehensive health insurance coverage. But more than 1 in 7 Americans—almost 46 million—do not have any health insurance. Most are members of working families. Many can't afford to buy health insurance. Some uninsured people can afford to buy health insurance, but choose not to do so.

Any change we make that affects costs, access to care, or quality may affect this system in ways that are difficult to predict.

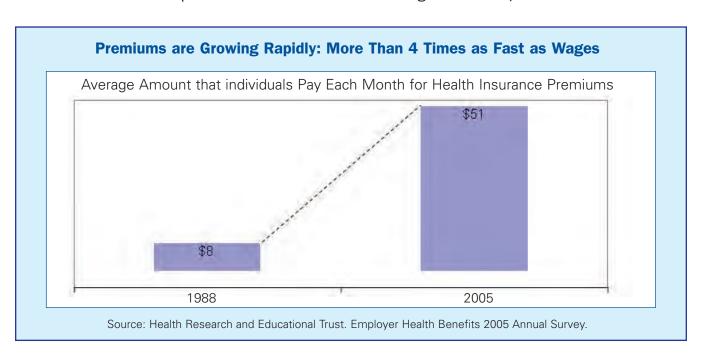
**Cost** is what is paid for health care and related expenditures. We ALL pay one way or the other, in employer contributions, in health insurance premiums, in taxes, or directly out of pocket.

In 2004, America spent \$1.9 trillion on health care. The total amount spent on our health care



system, including money spent on research, education and facilities, was about \$6,300 for each person in America. In ten years this amount is expected to rise to \$11,000 per person, based on projections made in 2005. In 1960 we spent about a nickel out of every dollar we earned on health care in the United States. Since then, that percentage has tripled.

Today, Medicare and Medicaid spending account for almost 20 cents out of every dollar that the federal government spends. If trends of the last



20 years continue, Medicare and Medicaid spending will account for 36 cents out of every dollar the federal government spends by 2040.

Many factors contribute to higher health costs in the United States, including how we use technology and the prices of the health care services we use. Inefficiency also contributes to higher costs. We pay for health care in a very complicated way. Complex billing and paperwork result in high administrative costs in the United States and can be frustrating for patients, doctors, hospitals, and insurance companies.

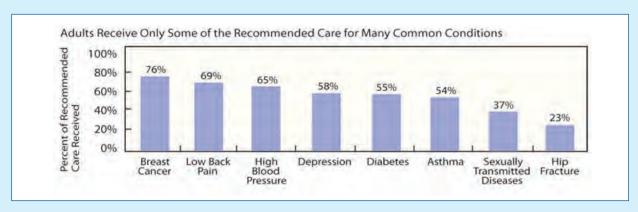
Higher health care costs mean insurers have to charge higher premiums. This makes employers less able and less likely to offer adequate coverage that employees can afford. As a result, fewer businesses are offering health insurance to their employees. The percentage of companies doing so has dropped from 69 percent in 2000 to 60 percent in 2005.

**Quality** refers to the kind of care you get – the right care in the right place at the right time, safe care, respectful of your wishes – in a way that's right for you and your family.

#### The quality of the health services we are getting often falls short of the mark.

Problems with the health services we use can consist of either too little or too much care.

#### **Adults Receive Only Some of the Recommended Care**



Medical errors are a very serious form of poor quality. An estimated 44,000 to 98,000 Americans die every year as a result of medical errors. This is more than the number of people who die from car accidents, or breast cancer, or AIDS. Serious medical errors can result in very long hospital stays and tens of thousands of dollars in added costs.

Some medical services are used much more frequently in some areas of the United States compared to other regions of the country. This disparity may be due to the overuse of some types of care. A recent poll found that half of all adults are somewhat or very concerned about being overtreated when they are sick or need medical care.

Despite spending more per person on health care than other developed countries, improvements in our health status as a nation are not consistently better and are sometimes worse. For example, the United States has seen an increase in the death rate from asthma in recent years, while death rates for asthma have declined or stayed the same in Canada, the United Kingdom, Australia, and New Zealand.

**Access** involves whether care is available, affordable, accessible, and appropriate. Health care coverage, whether it's private insurance – or a public program like Medicare or Medicaid – helps make the care we need more affordable, but does not always guarantee that we will have access to the appropriate care at the right time and the right place.

Health insurance is a major factor in access to care in America. The most important source of health insurance is employer-sponsored "group" coverage. Sixty-three percent of Americans under age 65 have health insurance through their workplace; some have coverage through

other private insurance or public programs; close to 17 percent have no health insurance coverage at all.

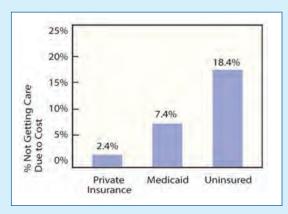
But, coverage provided through employment is getting less common and more costly.

- In 2004, just about all large companies offered their employees health insurance. But only half of the smallest companies (with fewer than 10 employees) did.
- Premiums faced by employers that do offer coverage are rising. Many employers are asking their employees to pay more of the premium out of pocket.

## Access to health care depends on where we live and who we are.

- Some areas of the United States do not have enough health care providers to serve everyone's needs. The availability of services varies from region to region, state to state, and from one community to another. There are special challenges in rural areas.
- More than 15% of Americans report not having a regular place to go when they need health care.

## **Costs Pose Barriers to Care for the Uninsured**



Source: Centers for Disease Control and Preventiion, National Center for Health Statstics, 2005. \*People under age 65 in 2003.

- There are pervasive differences in access to care across racial, ethnic and economic lines. Hispanics, African Americans, American Indians, and Asian Americans all are more likely than non-Hispanic whites to have problems accessing care. People with very low incomes have less access to care than other Americans.
- About half of uninsured adults with chronic health conditions go without recommended health care or medicines because of cost.
- Even when care is available, people can have problems getting through the health care system.

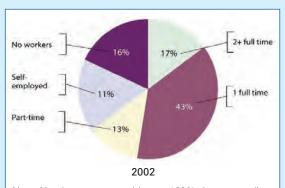
## Those without coverage often don't get the care they need.

- Uninsured Americans are nearly eight times more likely than people with private insurance to skip health care because they can't afford it.
- Delaying needed care can lead to more serious illnesses that need to be treated in an emergency room or the hospital. This can sometimes cost more than the cost of treating the original problem.

## Almost 46 million Americans have no health insurance.

- Most of those without coverage are workers and their families, and most have incomes above the poverty line. Even so, many people can't afford to buy the health insurance made available to them.
- There are some people, particularly young adults, without insurance who in principle could afford to buy it, but who choose not to do so.
- Millions more have insurance that provides only limited coverage, which leaves them at risk for high medical costs.

## Most Uninsured People Are In Households with at Least One Person Who Works



Note: Numbers may not add up to 100% due to rounding. Source: Economic Research Initiative on the Uninsured, 2005.

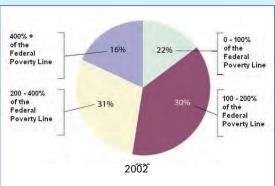
Because of the link between employment and coverage, sometimes when Americans need coverage the most, they don't have it. Often a severe illness may force workers out of work, losing coverage and the income that allows them to afford care at the same time.

The way that costs, quality and access affect each other makes the choices we face about improving our health care system tough. There are trade-offs to weigh in every decision we make.

States, communities, and large health care systems are attempting to deal with the interrelated health system issues of cost, quality, and access. In hearings around the country, we heard about both private and public sector programs.

Some programs we learned about are focused on controlling health care costs and improving the cost effectiveness and quality of health care.

## Most Uninsured People Have Incomes Above the Poverty Line



Note: Numbers may not add up to 100% due to rounding. Source: Economic Research Initiative on the Uninsured, 2005.

Federal poverty guidelines are issued annually by the U.S. Department of Health and Human Services and are used to determine financial eligibility for certain programs, such as Head Start, Food Stamps, and the National School Lunch Program. They also enter into determining eligibility for Medicaid. Poverty guidelines vary by family size and are frequently expressed in multiples of the federal poverty line. In 2002, as cited in the above chart, this was \$18,100 for a four person family; in 2006, the comparable figure is \$20,000.

#### Examples:

- Communities are trying to improve access to care in doctors' offices or clinics or expanding health insurance coverage to a greater number of people.
- Some payers are focusing on improving efficiency by offering rewards to providers for delivering appropriate, cost-efficient, and high-quality services.
- Electronic health information systems are being used to help prevent medical errors and identify appropriate care.
- Some programs are intended to more effectively deal with managing chronic illnesses.
- Some programs focus on the special needs of people at the end of life.
- A growing number of employers as well as private and public organizations are sponsoring programs designed to prevent illness and help people adopt healthier life styles.
- On page 13 of this guide we identify additional strategies that focus in particular on rising health care costs.

Many of these are new, so we don't know yet whether they will be effective. Some were

designed to work in particular places, so we don't know whether the programs would fit, or work successfully, in other locations or settings. Nevertheless, they represent important examples of the types of initiatives we must learn from to arrive at measures to improve the larger health care system.

Over time, more efficient ways of operating health care organizations, as well as general improvements in our health, could ease some of the upward cost pressure on our health care system, but our review of the evidence reinforces our conclusion that we need to address the entire health care system, not just specific problems in cost, quality, or access, no matter how urgent they may seem from our different perspectives. No single initiative that we have reviewed can provide all the answers to our health care system's problems. That's why we want to engage you in this discussion.

The mission of the Citizens' Health Care Working Group is to listen to you and to use what we hear to develop proposals that will help achieve "Health Care that Works for All Americans." We need your ideas about where we go from here.

Let's begin the discussion!

#### **AMERICAN VALUES**

Before we begin discussing ways to improve our health care system, we want to hear from you about the core values we should use to decide the shape of health care in the future.

As a starting point, we want to know what guiding principles or values you believe should be at the core of our health care system. What does *health care that works* for all Americans mean to you?

## **BENEFITS AND SERVICES**

The first thing Congress asked us to explore is:

What health care benefits and services should be provided?

In the United States, health insurance often covers both predictable and unpredictable kinds of health care. Some health problems—for example, injuries from car accidents or having a premature baby-do not occur very often but can cost hundreds of thousands of dollars when Just like homeowners' insurance, they do. when a lot of people buy health insurance, the costs for these rare, expensive events are spread out over the large group of people who bought policies. This reduces the cost to the unlucky few who actually need the help in a given year. In this way, health insurance is a transfer of money from those who don't get sick or injured this year to those who do.

But a lot of our health care needs are routine and predictable, like annual physical exams, or medicines to treat chronic diseases. When people know they will need certain services, they may think of insurance as a prepayment, like a service contract. But if people decide to buy health insurance only when they know they are likely to need it, policies can become expensive because everyone who is insured is using a lot of health care. At the same time, when healthy people choose not to buy health insurance they are not protected against large unpredictable expenses.

Currently in the United States, what mostly determines whether you have health insurance is whether you fall into one of several categories of people that are covered. These categories include, for example, employees of organizations that offer health insurance, people aged 65 or over and others eligible for Medicare, and people who qualify for the Medicaid program in the state in which they

#### **Key Facts on Benefits & Services**

- Our need for health services and the need for insurance to cover care vary a lot and change over the course of a lifetime, increasing with age.
- In 2004 almost half of all people in the United States had a chronic condition.
   Managing these illnesses can be expensive. Health care for people with chronic diseases accounts for 75% of our total health care costs.
- Generally, insurance coverage is based on being in a particular group (for example, employees, people who are elderly or cannot work because of disability, or people with very low incomes). Most people under age 65 receive insurance benefits from their employers. Others purchase insurance, although this may be expensive. Medicare is the national program for people age 65 or older and some younger people with disabilities. Medicaid provides assistance to people who meet criteria based on income, assets, and, in most states high medical expenses.
- Although most people have health insurance that pays part of the cost of getting healthcare, more than 1 in 7 Americans—almost 46 million—do not have any health insurance benefits.

live. If you do not fall into one of these or other categories of covered persons, you will have to purchase health insurance yourself, something that many find difficult to afford, if it is available at all. It could be possible to redesign the health care system so that every individual is covered. However, since personal, employer, and government resources are limited, decisions would need to be made about what services would and would not be covered and how much consumers would have to pay out of pocket for covered services.

There are hundreds of insurance benefit plans, with a wide variety of benefits. Some plans are very comprehensive and cover a lot of health care services; others are very limited. One health plan that many people view as "typical" now covers these types of benefits, many of which are subject to copayments and deductibles:

- Preventive Care—screenings, routine physicals, influenza and pneumonia immunizations, well child care, limited dental care
- Physicians' Care—inpatient services, outpatient surgery, related tests, home and office visits, medical emergency care
- Chiropractic Care
- Maternity Care
- Prescription Drugs
- Hospital/Facility Care—inpatient and outpatient services
- Physical, Occupational, and Speech Therapy
- Mental Health and Substance Abuse—inpatient and outpatient facility and professional care

We want to talk about the kind of insurance benefits you think are most important for you and for all Americans to have.

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## **GETTING HEALTH CARE**

## The next question Congress asked us to probe is: How does the American public want health care delivered?

Getting the health care that we want involves two seemingly simple concepts: getting the care—access—and getting good care—quality. Also, we like having the ability to make *choices* about the care we get.

ethnicity, and income. Reasons for these disparities are varied, reflecting differences in education and insurance coverage as well as communication problems and discrimination.

#### Access

An important part of access is being able to find a health care provider and being able to go to them when needed. Not all parts of the country have the same health care resources, and racial and ethnic minorities and people with lower incomes have more problems getting health care. Access also involves getting to the right kind of providers, like primary care professionals, specialists, dentists, and mental health providers, and to the right kind of care, such as home care and personal care. Out-of-pocket costs can also cause problems for some people.

For people facing a serious health problem or a chronic condition, it can be hard to get care, and the American health care system can be complicated, hard to navigate and inefficient.

#### Quality

The amount of health care services Americans use varies a lot across different parts of the country, often without a corresponding difference in health outcome. Evidence shows that much of the care some people receive is not always the "right" care.

When it comes to getting the right care, there is consistent evidence of a difference in the quality of care and health outcomes related to race,

#### **Key Facts on Getting Health Care**

- About half of Americans say they are "extremely" or "very" satisfied with the health care they have received in the last two years.
- More than 15% of Americans report not having a regular place to go when they need health care.
- There are differences in access to care across racial, ethnic, and economic lines:
  - Hispanics had worse access than non-Hispanic whites in almost 90% of access measures.
  - African-Americans had worse access in 50% of access measures.
  - Asians had worse access in over 40% of the measures used.
  - People below the poverty line had worse access to care in all the measures used.
- Not everyone who should receive certain services does. On average, adults get only 55% of the recommended care for many common conditions.

African Americans, Asian Americans, American Indians, Alaskan Natives, and Hispanic Americans routinely receive lower quality of care than white, non-Hispanic Americans. People in households with incomes below the poverty level receive lower quality of care than people with higher incomes.

#### Choice

Choice includes the ability to choose your health insurance coverage, a primary care doctor, a specialist, or a hospital. It also involves making choices about the types of tests and treatments that we get.

Some Americans can choose among several health plans and, often, can select their own doctors or hospital. Getting and understanding the information needed to make these choices can be difficult because of the complexity of the information, the challenges of communicating it in an easy-to-understand way, and the difficult circumstances under which many of these choices need to be made. Efforts are underway to address these problems.

We want to hear from you about what is important to you when you look for care, how involved you want to be in making decisions about your care and the information you use or would like to use in making choices about care.

We would like to hear about what you have learned from your experiences with health care and what they have told you about where improvements can be made.

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## **FINANCING**

#### The next question Congress asked us to address is:

How should health care coverage be financed?

We all pay for our growing health care bill through insurance premiums, taxes (income, payroll, property, or sales), foregone wage increases, or increased prices for goods or services.

Health care bills are paid through:

- a. Private insurance. This is most often sponsored by employers. Both employers and employees get tax breaks for a portion of the cost of insurance.
- b. Public programs like Medicare and Medicaid. This is the second largest source of coverage. Medicare is funded mainly through payroll taxes, federal general revenues and beneficiary premiums; Medicaid is funded through federal and state taxes.
- c. *Individuals and families*. Most people pay a portion of their insurance premium plus other out-of-pocket expenses, like deductibles and co-payments.

It is sometimes difficult to sort out private spending and public spending for health care. For example, both public programs and private insurance end up paying the costs for the uninsured who cannot pay for their health care. Employer health coverage is subsidized through the federal tax system because workers do not have to pay taxes on compensation received as employer-provided health care benefits, and premiums paid by employers that are part of an employee's compensation are exempt from payroll taxes as well as income taxes. But, no matter who pays the bill, the bills are going up for all of us—families, employers, states, and the federal government.

#### **Key Facts on Financing**

- In 2004, America's total cost for health care was \$1.9 trillion. That's about \$6,300 for each person in America. In ten years this amount is expected to rise to \$11,000 per person.
- In 1960 we spent 5¢ out of every dollar we earned on health care.
   Today we spend about 15¢.
- If current trends continue, by 2040, we will spend 36¢ out of every Federal dollar on Medicare and Medicaid.
- While most large firms offer health insurance to their employees, the percent of firms of all sizes offering health benefits to their employees fell from 69% in 2000, to 60% in 2005.
- Federal tax policy encourages businesses to offer health coverage to their employees. Employers and employees both receive tax benefits related to employer-provided health insurance. The way these policies work is estimated to have cost the government \$145 billion in tax revenue in 2004.

There are a number of efforts to reduce rising health care costs. Some of these may also improve health care quality.

- Both private and public programs have tried to place limits on the prices they pay to providers.
- Some programs such as Medicaid have also sought to limit who qualifies for benefits to reduce public spending.
- Some private health insurers and some public programs provide financial incentives to doctors who provide efficient, high quality care.
- Others limit coverage for high-cost technologies that haven't been proven to be safe, or limit the types of care they will cover.
- Some employers provide incentives to employees for healthy behaviors, or infor-

- mation on the cost of care and the quality of available care.
- Some hospitals, doctors and health systems are developing health information systems that improve their ability to diagnose, treat and monitor care.
- Individuals may also play a role in holding costs down by adopting healthy behaviors like exercise and good nutrition, and becoming more active in their own health care decisions.

We want to know what you think of the cost of health care and the way we pay for health care now. We will talk about whether we have the ability as a country to allow health care costs to grow at the current rate. We want your ideas on how we can work together to pay for the system we want.

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## TRADEOFFS AND OPTIONS

#### The final question Congress asked us to pursue is:

What tradeoffs are the American public willing to make in either benefits or financing to ensure access to affordable, high quality health care coverage and services?

Woven through our discussion today are the interrelated issues of cost, quality, and access. As a nation, we face hard choices as we try to slow the growth of health care costs, improve quality, and expand access to care. We need to know what changes you are willing to make as individuals and as a country to ensure that health care works for everyone.

First, we want to hear your priorities for investing in health care in America. Remember that if public spending on health care is increased, this may limit how much can be invested in other national needs such as education or defense.

Here are some ideas to consider:

- Has our health care system struck the right balance between prevention and treatment?
- Given that we have to set priorities, are we spending too much, about the right amount, or not enough on things like:
  - Guaranteeing that there are enough health care providers, especially in areas such as inner cities and rural areas
  - Investing in public health programs to prevent disease, promote healthy lifestyles, and protect the public in the event of epidemics or disasters
  - Guaranteeing that all Americans have health insurance
  - Funding the development of computerized health information to improve the quality and efficiency of health care

- Funding programs that help eliminate problems in access to or quality of care for minorities
- Funding biomedical and technological research that can lead to advancements in the treatment and prevention of disease
- Guaranteeing that all Americans get health care when they need it, through public "safety net" programs (if they can not afford it)
- Preserving Medicare and Medicaid
- If you believe it is important to ensure access to affordable, high quality health care coverage and services for all Americans, what do you think we should do? For example, should we:
  - Offer uninsured Americans income tax deductions, credits, or other financial assistance to help them purchase private health insurance on their own?
  - Expand state government programs for low-income people, such as Medicaid and the State Children's Health Insurance Program (SCHIP), to provide coverage for more people without health insurance?
  - Rely on free market competition among doctors, hospitals, other health care providers, and insurance companies rather than having government define benefits and set prices?
  - Open up enrollment in national federal programs like Medicare or the federal employees' health benefit program?

- Expand current tax incentives for employers and their employees to encourage employers to offer insurance to more workers and families?
- Require businesses to offer health insurance to their employees?
- Expand neighborhood health clinics?
- Create a national health insurance program, financed by taxpayers, in which all Americans would get their insurance?
- Require that all Americans enroll in basic health care coverage, either public or private?
- Increase flexibility afforded states in how they use federal funds for state programs—such as Medicaid and SCHIP to maximize coverage?

What are you willing to do to help make health care work for all Americans? Some believe that fixing the health care system will require

tradeoffs from everyone – e.g. hospitals, employers, insurers, consumers, government agencies. What could be done – and by whom? By "tradeoff" we mean reducing or eliminating something to get more of something else. Examples of tradeoffs that individuals might make include:

- Paying more so that others could get insurance.
- Limiting insurance coverage to only high medical bills, while paying directly out of pocket for more services.
- Using generic prescriptions to keep costs down.
- Waiting longer for medical care that is not urgent.
- Foregoing wage increases in order to keep or get health insurance benefits.

We're looking for your guidance on what you think it will take for us as a country to reach this goal.

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#### WHAT HAPPENS NEXT?

## Thank you for taking part in this meeting. We will carefully consider what you told us.

Once we have heard from you and others, we will develop recommendations on ways to improve our health care system. We will ask for public comments on these draft recommendations during the summer of 2006. In September of 2006, we plan to submit final recommendations to the President and Congress.

You have a continuing role in this process. We can't visit every community, but we want to hear from as many people across the country as possible. There are a variety of ways you can help us.

#### What you can do to stay involved.

Urge your friends, family members, colleagues, and neighbors to get involved. Show them our website: www.citizenshealthcare.gov.

Encourage them to answer the questions on our website or to participate in a meeting in their part of the country.

Host a meeting in your home, business, organization, or community and report your conclusions to us. We have toolkits to help on our website.

Later this year, read our recommendations and give us your feedback on them. Talk to your congressional representatives about your ideas. Together we can make health care work for all Americans.



Participants at the first Citizens' Health Care Working Group Community Meeting: Kansas City, Missouri, January 17, 2006

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#### Citizens' Health Care Working Group