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Citizen's Health Care Working Group Recommendations to the President September 25, 2006

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PATRICIA MARYLAND: My name is Patricia Maryland.

I'm chairperson of the Citizen's Health Care Working Group.

I'd like to introduce some of the other members that are in attendance today of our group, and I'll ask them to stand as I call their name. Dottie Bazos. Monte Cullen.

[misspelled?] Therese Hughes. Catherine McLaughlin. Rosie Perez. Deb Stern. [misspelled?] And Chris Wright.

[misspelled?]. Following this brief presentation, the Working Group members will be available to answer any specific questions that you might have from the report in our recommendations.

We're very excited about being here today to unveil our final recommendations following 18 months of work, of meetings and discussions with Americans from all walks of life throughout the nation. Our Working Group has been unique from day one. We were created by an act of Congress as a result of bi-partisan legislation authored by two senators, Senator Orrin Hatch and Senator Ron Wyden, a Republican and a Democrat who were frustrated by the continued gridlock on health care in Washington. The job of this group, comprised of a diverse subset of Americans, was to go out and listen to the American people and to bring back to Washington ideas from the people on how to change the nation's health care system, and how to break that gridlock.

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Initially, our job was to listen to what the public had to say. Here is a small sampling of what we heard as we traveled across America.

[VIDEO PLAYS]

Now our job is to report back to the president and to the U.S. Congress on what we learned. We heard remarkable consensus across the nation. It didn't matter what city we were in, urban or rural, large or small, the East or the West coast, North or South. It didn't matter if the person was young or old, employed or unemployed, sick or healthy, educated or not, Hispanic, African-American or Caucasian. We heard a consistent theme over and over again at our community meetings and from those that participated on our Internet survey.

What is even more remarkable is the consistency of our findings with recent national polling. No matter how we sliced or diced the results, we kept hearing the same theme and call to action. Americans want a health care system where everyone has access to high-quality care. They want a health care system where no one is impoverished by high health care costs. Americans believe that everyone should contribute and there should be no free riders. Americans believe that everyone needs to take personal responsibility for their health care, but should not be unfairly penalized for their ill health. They also believe their system should

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be simpler to navigate and should be community based. Americans believe that we should be able to improve and streamline our health care system to become much more efficient, and finally Americans believe that we can do better when it comes to caring for individuals at the end of life.

We know that there will be some individuals who may not agree with these findings. They may say that we did not hear from enough people, or that we heard from the wrong people, but I can tell you that there was common ground, and a common call for action. The American people want a health care system that is fair, affordable and available to all Americans. This message was loud and clear. As stated earlier this sentiment is remarkably similar to the results that we see in national polls when the subject is health care. We heard many interesting and innovative ideas, and it was those ideas that helped us to develop a set of steps to achieve our long term goal that all Americans have affordable health care by 2012.

Americans want the gridlock to end in Washington, and they want the president and Congress to move ahead. I would like to now introduce Catherine McLaughlin. Catherine will discuss how we obtained the views of the American public, and how we formed our recommendations. Catherine.

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CATHERINE MCLAUGHLIN: Thank you, Pat. Good morning, everyone. I'm glad to see you here on Monday morning trying to find out what we heard from Americans all over the country and how we went about doing our job.

It was about 18 months ago that Senators Wyden and Hatch gave us, literally, our marching orders. They said, "We want you to go all over the country and listen to people all over the country." As Pat said, North, South, West, East, urban, rural, everywhere, and so we immediately knew that we were going to be tired 18 months later, but we also knew that we were going to be excited about listening to so many people.

They wanted us to engage in an informed dialogue with the American people about the health care system, so the first thing that we did was hold hearings in six different cities across the country, where we asked health policy experts, health care professionals, business owners, union representatives, local community organizers of public programs and private health care programs to come and tell us what they knew about the health care system. What they knew about national programs, regional, local programs. What problems they experienced so that we could then use that information to educate the American public about our current health care system.

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At the same time, we had gotten data from federal surveys. Many of you are familiar with them, the current population survey and other surveys to give us more information about the health care system. We put this all together in the health report to the American public, which was posted on our Web site, almost exactly a year ago today, so that we did that first piece of saying, American public, this is what we know about the health care system. How many dollars are spent, where those dollars come from, what they buy, where they go? Then we started engaging in hearing from them.

We then went and had community meeting in almost 40 states. We ended up over the next eight months with 98 community meetings, over 7,000 participants at those meetings. You saw pictures at some of those meetings. You heard voices from some of those participants. I know the members of the Working Group here, one of us was at all of those meetings, and we sit there and go, "I remember that participant. I remember that comment." You saw that they sat around tables and they talked to each other. They talked to each other about health care, their own personal experience, their own understanding of the system, and their own ideas of how to improve it. Then we had them actually vote on these electronic keypads, so that we had an actual quantity of record of what their opinions were.

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Senators Wyden and Hatch asked us, "Please also use the Internet. Reach out beyond going and talking to people. There are people who won't come to community meetings. There are going to be people in parts of the country where you can't go, and therefore, can't go to community meetings." So we established an online poll on our Web site that contains some of the very questions that we were asking in these 98 community meetings, and we had also, the ability for them to vote on the same questions and give us information. We had over 14,000 responses to that poll.

In the sections of our Web site that allowed them to express comments, concerns, open ended questions, and blogs. Our staff was very active in getting blogs to try to reach out to the younger population. I have a teenage son. He would never go to community meetings, but blogs? Absolutely, I'll participate in blogs, so we had all of these avenues that we tried to advertise widely. We had partners who would try to advertise what was up there. We ended up getting over 6,000 commentaries from individuals to complement the more, yes, no, this is what I prefer of the 14,000, to add text, to add richness to what we were hearing.

We also had one event that combined these two elements, in what was called, "A high-tech version of an old fashion Town Hall meeting," in which in one night in March, believe it or not, in March, in the Midwest, all Big Ten

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universities participated, as well as 12 schools of public health. There were over 700 people at 22 campuses, connected via satellite at the same time, communicating with each other through email and through telephones, debating the same questions that we had in the community meetings. That was another way for us to reach out and try to get a lot of people to participate. We even ended up getting 100 undergraduate students at Purdue University participating. So we had gotten people from all ages, as Pat said, from all parts of the country.

The Working Group members also engaged in a lot of conversations. We talked to our friends, our family, our neighbors, our colleagues. Some of us went – my mother is in a life care community. I went and talked to 80 senior citizens at a life care community. We really reached out and then we would bring back to our meetings what we were hearing from as many people as we possibly could.

As Pat said we also were looking this whole time at national polls, because we wanted to ground what we heard within a broader context. So we collected over 100 national polls conducted by ABC News, *The Wall Street Journal*, *The New York Times*, *The Washington Post*, polls by Gallup, by Harris, by Zogby. We really went for any of these public opinion polls and to the degree possible, picked questions that were close to the questions we were asking, so that we had some

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way of comparing what we were hearing to what they were getting in these random samples all across the country.

We posted our interim recommendations at the beginning of the summer. We then had a 90-day public comment period. During that public comment period we helped to get more community meetings, meetings that had over 700 participants where we had gotten feedback on our recommendations themselves.

We also received over 7,000 comments online, or written. We had gotten handwritten letters that people would send us. People say, "I don't have access to the Internet. I don't have information, but I went to that meeting in Detroit, or I went to that meeting in Kansas City. I went to that meeting in LA, and I wanted to make sure you knew how I felt about it." We ended up with over 8,000 comments on our interim recommendations from individuals, as well as over 100 informal comments from organized institutions and organizations. All of these are posted on our Web site. I can't possibly summarize all of them for you today, but about three-quarters of them were favorable about our interim recommendations.

What did we do with all of this information? We brought these things all together, and we said, all right, here is the summary of over 35,000 responses that we received from these different methods. We actually had over 35,000

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responses. Our staff has been very, very busy. That's a lot of work, especially when some of the handwritten ones went on for pages and pages.

My 86-year-old mother laments the fact that her grandchildren don't know how to write letters anymore. [LAUGH] Well, we heard from some people who wrote us really long stories about their own personal experience in the health care system. These were from health care providers. These were from business owners. These were from patients. These were from people all over. We combine that with a national poll data that our staff summarized for us, as well as expert opinion. The experts we heard from in the hearings and over the eight months after those hearings solicited and unsolicited, expert opinions came flooding in. We looked at all of them, not surprisingly there was a diversity of opinions. There was a range of views about our current health care system, as well as about where we should go next and how we should get there. This shouldn't be a surprise. I can't get my family to agree on what movie to see tonight, so why would we expect America to agree, 35,000 people to agree, on something so personal as health care?

But what was a surprise to us was the congruence of several basic ideas. As Pat mentioned, we were stunned that no matter where the meeting was held, no matter whether it was online, no matter whether it was 100 undergrads in a

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class at Purdue, 18, 19 years of age, or people in a life care community, the average age was 87. They revealed that to me. They were very proud of it. I didn't have to ask, "How old are you?" About 70-, 80-, 90-percent would agree to the same preference, the same view.

When we then looked at the national polls, they found the same thing. So we found this convergence of these three systems, these three sources of information. That's what we then used our platform for deliberations. The Working Group sat down and said, "All right, what are the common themes? What are the values that we're hearing from the American public over and over and over?" That's what we used to produce our interim recommendations. I then mentioned that we heard from thousands and thousands of people about our interim recommendations. The overwhelming majority agreed with them. Again, we had gotten people who disagreed. We read all of them. The staff presented all of them to us, unvarnished. We saw the actual words that they gave us, and we sat down and had a whole series of very, very long, long meetings to incorporate all those comments and come up with our final recommendations.

I now turn this over to another Working Group member, Dottie Bazos, who is going to summarize what those recommendations are.

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DOROTHY BAZOS: Thank you, Catherine. For one moment I invite you to think about health care system based on the following principles, principles that were developed through a dialogue with the American people.

Think about a health system in which we agree that health and health care are fundamental to everyone's well being and security. Think about a health care system in which health is a shared social responsibility, in which all Americans have access to a guaranteed set of core benefits and services. Benefits are portable and independent of an individual's health and financial circumstances. Think about a health system that is designed to use our private and public resources most efficiently, most effectively.

Good morning. I'm Dottie Bazos, a member of the Citizen's Health Care Working Group. I'm from Concord, New Hampshire. My job is to quickly outline for you the recommendations that the Citizen's Working Group would like to bring before Congress and the President. These recommendations reflect these principles and values that I just read that are from the American public. The recommendations might be very much easier for you to understand should you use the lens of your own personal experience with our health care system.

First, we're proposing one broad recommendation and five additional recommendations that fit together to pave the

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way for accomplishing our central goal, which is to establish public policy that all Americans have affordable health care. Americans want a health care system that works for everyone. Ninety four-percent of all the participants at our community meetings agreed with this sentiment. Eighty-percent of the people who responded to us online strongly agree with this sentiment. These views, as Catherine said, are consistent with national polls, and we heard this message loud and clear, and time and time again.

The overwhelming majority of Americans who we talked to want health care system change to begin now. Thus, we are recommending immediate action that public policy establishing that all Americans have affordable health care, be enacted now in 2007. This public policy be fully implemented by the target date of 2012. So let's talk about all of the recommendations.

First, our recommendations fit together as three strategic steps to get to our goal. Step one calls for immediate action to improve security and access. First, we want to guarantee financial protection against very high health care costs. This recommendation calls for creating a program that could be implemented in the short term that would provide a basic level of financial protection to everyone. This recommendation calls for a universality as everyone would be required to have protection against high

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health care costs, and it is a first step towards developing in our nation, the foundation for providing core benefits to all Americans. Most importantly, this recommendation will provide peace of mind to you, to your family, and to your neighbors, and to all Americans by eliminating the real fear of financial ruin from high medical costs.

Concurrently, we also want to foster the development of integrated community health networks. Think about a community based system where you, your family, and your neighbors can go to get coordinated high quality health care locally. That's what Americans really want. That's what they are interested in. This recommendation focuses on immediate efforts to address gaps in access and to provide a medical home to more local residents. The goal is to foster local collaborations so health care providers will be able to work together more effectively and more efficiently. These networks will be laboratories for improving the effectiveness and efficiency of health care delivery in communities. This recommendation will begin to fix the delivery system, which is a plea that was often made from Americans as we went across the United States listening to them.

Step two is, in effect, the core of our recommendations. This recommendation identifies the need to define, implement and continuously update based on science and best practices, core benefits and services, for all

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Americans. It is clear from the public that this task is going to be very difficult and will require a transparent process in which consumers, you and I, play a vital role. It is also clear that in the absence of unlimited resources, tough choices will have to be made, and Americans at the table told us they would make those tough choices, if we had a fair and equitable system for everyone. We also know that there was a lot of good work going on in this area, in states, in the federal government and in the private sector. There is work to build on, and we believe that carefully constructed benefits and services can make health care more effective, more efficient, and will also help control health care costs for the nation, something that we are all worried about.

Step three focuses on building a better, more efficient health care system for all of us. Wouldn't it be comforting to know that the care that you and your family receive is based on best evidence of medical practice? Wouldn't it be comforting to be able to understand your options for treatments and what works best in medicine? Picture for a moment a health care system in which everyone, including frail elders and the dying are treated with respect and dignity, having their choices about care delivery honored even at the end of their lives.

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These are only some of the aspects of quality that people told us that they really care about. Thus, recommendation five focuses on advancing the pace of the work to build a health care system that works better for everyone by promoting efforts to improve quality of care and efficiency.

There is a lot of evidence that with the right tools and incentives, health care can be improved and waste in our system, largely eliminated. Some health care systems are already beginning to do this work. They've reduced cost by managing chronic conditions better, by implementing informed, shared patient decision making, by reducing patient injuries and redesigning systems of care so they reduce the need to redo tests and procedures when you go from one doctor to another.

Putting these improvements into place on a system-wide scale is going to take time and a great deal of effort. Doing it better means that we have to invest in health care delivery research. We have to restructure organizations and training programs and invest in health information technologies. The federal government is a dominate purchaser of health care, and it is uniquely well positioned to provide leadership in these areas, and we need to support this work.

Our last recommendation focuses on an especially difficult, often expensive aspect of health care that reveals

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some of the most serious problems with quality and efficiency in our health care system, and that is end-of-life care. We recommend that end-of-life care be fundamentally restructured so that people of all ages have increased access to the services they need in the place where they want to get those services.

For example, if you want to die at home, you should be able to die at home, well supported by your family and your community, not in pain, not struggling, but having a death with dignity. End-of-life issues are difficult, painful and complicated. There are no quick or easy fixes. It is clear that some of the efforts and resources used to extend a person's life may be only of limited value, and that what is done to or for a patient is often not what the patient or his family desires. We recommend that we intensify efforts to develop best medical practices to improve care for the dying. This recommendation seeks to better define, communicate and make available at individual family, community and society levels the support needed and wanted in one's last days.

So that sums up the recommendations, but before I turn the microphone over to Pat, I just want to remind us that the question of importance today is not whether we have in these recommendations developed the perfect answer for health system reform. The question is whether we as a nation

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have the political will to listen to the public, and to change a system that is clearly broken. The question is whether we can get to a time when all Americans have affordable health care.

Thank you for your time.

PATRICIA MARYLAND: Thank you, Dottie, Catherine.

Now what are the next steps? Today we are making available our recommendations with an executive summary and the full report. This information is also available online at www.citizenshealthcare.gov. Once the president receives the Working Group report, he has 45 days to submit to Congress a report which provides additional views and comments, as well as his recommendations for appropriate legislation and administrative action. Once Congress receives the report from the president, five congressional committees with a jurisdiction over health are required to hold hearings. I'll end on that note and invite for each of the members of the Working Group to entertain any questions that you might have. Again, Rosie Perez, Chris Wright, Therese Hughes, Deb Stern.

[END RECORDING]

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