CITIZEN DIALOGUES ON COVERING THE UNINSURED

A Report to the Robert Wood Johnson Foundation

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Citizen Dialogues on Covering the Uninsured

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Executive Summary

Introduction:

This report describes the results of a pilot series of dialogues on how to address the problem of the uninsured in the United States. Viewpoint Learning conducted three intense, daylong dialogues in Spring 2004, each one comprised of 30-40 participants randomly selected to be representative of the general population. Sponsored by the Robert Wood Johnson Foundation, these ChoiceDialogues™ – conducted in San Diego, Philadelphia and Atlanta – were designed to assess whether the public's views on what to do about the uninsured change when people engage the issue in serious and well-informed dialogue with their fellow citizens – and if so, how.

Our experience shows a huge gap on a wide variety of public policy issues between expert views (based on a close attention to and detailed knowledge of the issue) and public views (where attention is casual, information is sketchy and deeply held values are paramount). History has also demonstrated – sometimes painfully – that to be sustainable, major policy changes must be based not only on technical expertise but also on the public's deeply held values. The purpose of ChoiceDialogues is to reveal these values by examining how people's views evolve as they come to terms with difficult tradeoffs, and to help bridge the gap between the expert's technical perspective and the citizen's values-based perspective.

The ChoiceDialogues on covering the uninsured were conducted with several key purposes in mind:

- To provide an in-depth understanding of how Americans' values and priorities shape their approach to health care and the uninsured and how they reconcile conflicting priorities when difficult tradeoffs must be made
- To reveal promising opportunities and likely challenges for leaders and policy makers as they work to craft effective solutions that the public will support;
- To experiment with a more effective way of giving average citizens – not special interest groups, experts or advocates – a voice in shaping important decisions that affect their lives.

The dialogues were organized around a tested workbook format that laid out four possible approaches to the issue: two solutions that provided increased but not universal coverage (one through expanding existing government programs and the other through tax credits), and two that provided universal coverage (one building on the employer-based system and the other building on Medicare). These scenarios were designed as starting points only; participants were encouraged to build on them, combine them and create new options.

General Findings:

While the small number of dialogues means that the findings must be interpreted with caution, the initial results are striking and suggestive. As they engaged in extended dialogue, three diverse groups of citizens in very different parts of the country showed consistent shifts in their thinking and arrived at markedly similar conclusions. These included:

- Strong demand for **universal access to affordable health coverage**
- Consistent support for **a two-tiered health care system**, where affordable basic coverage would be universally available, with enhanced coverage available to those willing to pay for it
- Stipulation that **coverage** be **provided by a combination of private and public sector activity**, with each providing checks and balances on the other
- Willingness to **give up some degree of personal privacy** to achieve an equitable and efficient system
- Willingness to **pay more in taxes, premiums and co-pays, IF strong accountability measures are put in place**

As they worked through the issues over the course of the day, participants rejected the two scenarios that would have covered some but not all of the uninsured, and they showed strong and increasing support for the scenarios that provided universal coverage, even though these involved significant tradeoffs and costs to citizens. Rather than opting for one universal coverage scenario or the other, however, all three groups went on to combine elements from both into a system of checks and balances.

How values shaped citizens' conclusions. As detailed in the report, participants' conclusions were shaped by a handful of core values, which were constant across all three dialogues. These values shed an important light not only on participants' priorities, but also on how and why they reached the specific conclusions they did. Any proposal that aims to address the problem of the uninsured must take these underlying values into account.

<u>Universal coverage.</u>

- **Key value: We are in this together.** As they learned from the prepared materials and listened to each other's experiences, participants gained a much fuller understanding of the extent of the health coverage crisis. In the process, they made an important shift from seeing lack of insurance as a personal difficulty, affecting only the uninsured themselves, to seeing it as a national problem that affects everyone and that everyone must work together to address. This sense that everyone suffers on some level from the irrationality of the current system led participants to support solutions that cover everyone over partial or piecemeal approaches.

<u>What sort of universal system?</u> Once participants agreed that universal coverage was the goal, they turned to the question of what that system should look like– who should be covered, what should be included, who should be responsible and how to pay for it. Three key values shaped this part of the day's dialogue:

- **Key value: Fairness.** Most Americans contribute to the nation through work and/or taxes, and everyone – including the indigent and the unemployed – deserves access to health care. Health care coverage should be tied to individuals, not to specific jobs or living situations, and while the cost of coverage and care should be linked to people's ability to pay, everyone should pay *something*.
- **Key value: Personal responsibility.** Individuals bear a large responsibility for their own health. They should be given tools to keep themselves healthy, through public education and information and a focus on wellness. If individuals choose to smoke, drink or otherwise damage their health, then they should pay more for coverage.
- **Key value: Choice.** People should not be forced into one-size-fits-all coverage: they should be able to choose among providers and approaches to treatment. However, since offering everyone unlimited options may be too expensive, it would be better to make sure that everyone has access to the basics and make enhanced services available to those who choose to pay more for them. This allows people to exercise personal choice while making sure that no one falls through the cracks.

Participants agreed that universal access to basic health care, with supplemental coverage available to those willing to pay for it, was the most acceptable way of achieving universal coverage.

Blend of Public and Private Sector Roles. Once participants agreed on the kind of universal system they wanted to see, they turned their attention to who should administer it.

- **Key value: Checks and balances.** Both the private and the public sector have distinct strengths; at the same time participants trusted neither to create and implement a fair and efficient solution on its own. Instead, they saw a partnership-based approach, designed with appropriate checks and balances, as the best way to combine the innovativeness of the private sector with the oversight and economy of scale that government can offer.

Willingness to make sacrifices. Participants agreed that the health care system they wanted to see would require them to make some sacrifices, both financial and in terms of personal privacy. Things that are truly important – like health care – are worth paying for, through taxes, reduced wages, higher prices or reduced choice. Increased personal accountability means that people will have to allow broader access to their personal health information and closer scrutiny of their lifestyles. This is acceptable if it will result in greater efficiency and quality of care.

- **Key condition: Accountability. Participants were willing to make such sacrifices ONLY if there are clear lines of accountability on the part of providers, insurers and governments.** In particular, they wanted third-party verification that money is being spent wisely, that costs are being kept down and that quality of care is being maintained.

This pilot project was designed to engage regular citizens in working through the important decisions that must be made to resolve the problem of the uninsured, and to provide policy-makers with insights into the sorts of reforms citizens would be prepared to support and the conditions for that support. Such insight will be key to any successful reform of health care. While experts and stakeholders provide essential technical input, any sustainable solution

must also reflect citizens' values, beliefs and priorities. Polls and focus groups were not designed to provide this sort of insight on issues where people have not yet made up their minds. In fact polls and focus groups can be highly misleading on such issues — the ill-fated Clinton health care plan is just one cautionary tale. ChoiceDialogues have been developed to fill this gap, enabling representative groups of citizens to work through the issues and to make up their minds.

This project has provided an important initial outline of citizens' values and priorities on health care reform and covering the uninsured – an outline that can inform future efforts to craft workable solutions that the public will be willing to support. These initial findings need to be further tested, elaborated and deepened through research and civic engagement at both the state and national levels. In the end it is this citizen input on values, coupled with the best technical input from health care experts, that will be key in devising sustainable reforms to cover the tens of millions of Americans who are uninsured today.

Citizen Dialogues on Covering the Uninsured

A Report to the Robert Wood Johnson Foundation

I. Introduction

America's health care problem is threatening to turn into a health care crisis. Rising health insurance premiums, combined with the dramatic increase in health care costs overall, have forced many Americans into the ranks of the uninsured. More than 44 million Americans, most from working families, went without health insurance in the last year. The nation is paying a steep price for having so many uninsured – lost wages and productivity, higher health care costs, and poorer health outcomes overall.

In a pilot series of specialized ChoiceWork Dialogues [ChoiceDialogues™], Viewpoint Learning brought together representative samples of citizens to discuss health care and possible ways of addressing the problem of the uninsured. In these intense 8-hour sessions – funded by the Robert Wood Johnson Foundation – participants were asked to consider four alternative choices for covering the uninsured and to come to terms with some of the difficult decisions and tradeoffs involved. The ChoiceDialogue methodology differs from more traditional polls and focus groups in that it is designed to help participants move past their initial top of mind response to a more stable and well-considered judgment – a judgment that takes tradeoffs and consequences into account and meshes with core values. (For a more complete discussion of the methodology, see Appendix A.)

These dialogues on covering the uninsured were conducted with several key purposes in mind:

- To provide an in-depth understanding of how Americans' values and priorities shape their approach to health care and the uninsured and how they reconcile conflicting priorities when difficult tradeoffs must be made;
- To reveal promising opportunities and likely challenges for leaders and policy makers as they work to craft effective solutions that the public will support;
- To experiment with a way of giving average citizens – not special interest groups, experts or advocates – a voice in shaping important decisions that affect their lives and to lay the groundwork for more intensive inquiry with a larger sample.

As participants worked together to craft a vision for the country's health care, all three groups raised similar concerns and arrived at notably consistent conclusions – in particular a clarion call for universal access to health coverage in the United States. This report summarizes how participants – people representing a wide range of backgrounds and political beliefs – reached their conclusions, outlining the shared themes, the common ground, and the key values that informed citizens' views.

The conclusions that can be drawn from a small pilot project of this kind are necessarily limited; however, these initial results provide a remarkably clear and consistent view of public values and attitudes, as well as raising some important questions for future investigation. Information of this kind will be essential to any sustainable reform of the nation's health care system – history (most notably the demise of the 1992 Clinton health care plan) has shown us

that a solution that is well-conceived from a technical perspective will nonetheless founder if it does not mesh with citizens' key values. The findings that follow suggest several areas of opportunity for moving forward with meaningful reform that citizens will be prepared to support, and the conditions for that support.

II. ChoiceDialogue on Health Care and the Uninsured

Viewpoint Learning conducted a series of three day-long ChoiceDialogues – one each in San Diego, Philadelphia and Atlanta – with 30 to 40 participants in each. A cross section of participants was randomly recruited from across each city, and each group represented a wide range of socio-economic circumstance, ethnic backgrounds, and political leanings. In all three sessions, citizens spent the morning crafting a vision for covering the uninsured and in the afternoon did the difficult work of determining priorities, appropriate steps and acceptable tradeoffs.

As a framework for their discussion, participants used a specially designed workbook, constructed around four distinct values-based scenarios. The scenarios were developed in consultation with a health care experts from the Robert Wood Johnson Foundation and elsewhere, and they were designed to represent – from a citizen's perspective – a wide range of choices currently under discussion. These four scenarios served as a starting point only: participants were welcome to combine them or create new options:

- **Expand Existing Programs.** The first scenario is to leave current systems in place but to expand Medicaid and S-CHIP to include more of the lowest-income adults and children. The federal and state governments will increase access to these programs as much as possible without damaging the employer-based system. This will reduce the number of uninsured by about 20% (or about 9 million people).
- **Health Insurance Tax Credits for Working Americans.** Under this scenario, all working families, self-employed individuals and people who are temporarily unemployed who enroll in health insurance either through an employer or by purchasing it directly will receive a tax credit. This credit will help offset the cost of the coverage and other health care expenses. This approach means that every working family will receive some government help paying for private insurance. This will reduce the number of uninsured by about 64% (or about 30 million people).
- **Restructure the employer-based system** This scenario builds on the current employer-based system to provide health insurance to everyone under 65. People will get their insurance either directly through their employer or from health insurance pools called "exchanges" that can offer a variety of health plans. Every exchange will be required to include at least one zero-premium plan for anyone not covered by an employer.
- **Medicare for All.** In the fourth scenario, the Medicare system currently in place will expand to cover all citizens regardless of age or income, not just those over 65, the disabled, and people with end-stage renal disease. People will deal with Medicare instead of a private insurance company to pay for their basic health care needs (as people covered under Medicare do now). Employers and private insurance companies will no longer provide basic health care coverage, but could offer policies to supplement Medicare's basic health coverage.

III. General Findings

Where they started:

Participants connected with the issue at once. Many had personal experience with being uninsured and they spoke movingly of the hardship it had brought them and their families. Those who had good insurance were grateful for it, although often their gratitude was tempered by anxiety that increases in the cost of premiums and prescription drugs might make it unaffordable for them in the future. In addition, several participants nearing retirement or with pre-existing conditions felt trapped in unsatisfactory jobs and living situations because leaving meant losing coverage. At all three dialogues, participants criticized the waste and emphasis on profit they saw in the current health care system.

I'm really concerned about rising costs. My employer keeps raising my co-pay and I don't know how long I can keep up. [Philadelphia]

I considered staying with an abusive husband – because the insurance was good. [Atlanta]

It seems that [health care] is more about profitability and less about care. [San Diego]

For all their awareness on a personal level, most participants were surprised by how widespread the problem was. Many said they had had no idea there were as many as 43 million uninsured[1] or that most were in working families.

By the end of the morning, participants concluded that something is seriously wrong with the current system, and that major changes must be made.

A. TOP PRIORITY: UNIVERSAL COVERAGE

In all three dialogues, participants determined that their top priority was to ensure that all Americans and legal immigrants have access to affordable health coverage, and they rejected solutions that did not achieve that end.

I think everyone in the country should have access to good health care. I think it's morally reprehensible that some do not. [San Diego]

We are in this together

Participants reached this conclusion through a gradual expansion of perspective. As they learned more about each others' experiences with health care and insurance, they started to see the issue through the eyes of others – the insured, the uninsured and the under-insured. In the process, many saw aspects of the insurance question that simply had never occurred to them before, and all (insured and uninsured alike) got a much more complete sense of the reasons that people lack health insurance and of the challenges they face as a result – not as abstract statistics but as very real stories told by their fellow citizens.

On a very basic level, participants saw this as unfair – an injustice that needed to be set right. At first, they focused on how the cost of being uninsured affected the uninsured themselves: time spent and wages lost waiting for care at emergency rooms or low-cost clinics, having to

[1] The participants' workbook cited 2003 figures.

choose between paying for health care and meeting other basic expenses, putting off care until minor ailments become far more difficult and expensive to treat.

> *Let's say we're going home today and my shoulder's bothering me and I don't have health care so I'm not going to go to the doctor…. Well if all of a sudden the pain starts going down my arm and as I'm driving I veer off the road and kill a family in a minivan, what's the root cause of that? [Philadelphia]*

They soon realized, however, that that lack of insurance affects far more than the individuals themselves, and they began to examine the way that that cost was being shouldered by everyone in the room. Participants quickly grasped the way that caring for the uninsured drives up health costs for everyone, and they were dismayed that the current system ends up spending health care dollars on expensive emergency care rather than less costly preventive measures. Several participants made connections between a lack of affordable health care and costs to the broader economy and society as a whole – ranging from increased cost of doing business and loss of productivity to a declining quality of life.

Their increased understanding of the irrationality and inefficiency of the current system led participants to see health insurance as far more than an individual problem – it is a national problem that requires a national commitment to solve. This shift to a more community-based perspective led participants to support solutions that cover everyone over partial or piecemeal approaches, and it was central to participants' later thinking about what sort of system they wanted to see.

The decisiveness of participants' shift in favor of universal access to coverage can be seen in their before and after rankings of the choices.[2] Participants rejected the first two scenarios, both of which aimed to reduce but not eliminate the number of uninsured.

- Choice 1 (Expand Existing Programs). This choice fared the worst in all three groups, beginning the day with the lowest ranking across the board (averaging 5.3 points out of 10). Participants saw this as a "status quo" choice, and given their early agreement

[2] In each of the dialogues, participants were surveyed twice, once at the beginning of the day and again at the end. They were asked to rate their response to each choice independently on a scale of 1 to 10, 10 being totally positive and 1 being totally negative. In addition, at the end of the day participants were allowed to include a conditional statement along with the rating: for example, one participant rated "Expand the Employer-Based System" as a 10, given the condition that "Small businesses are protected with a sliding scale."

Quantitative results are expressed in terms of *means* and *shifts*.

- **Means:** The initial mean for each scenario indicates participants' average rating of the choice in the morning; the final mean represents participants' average rating of the same scenario at the end of the dialogue.
- **Shifts:** The "shifts" measure how widespread opinion change is within the group, as well as the direction of that change, by comparing individual participants' ratings of each scenario at the beginning and the end of the day. For example, if 25% of participants rate a scenario higher at the end of the day than they did at the beginning, and 5% of participants rate it lower, the net shift would be +20.

Charts describing the quantitative results can be found in Appendix B.

that the status quo was unacceptable, they rejected this choice out of hand. At the end of the day, this scenario's average rating was down to 3.9, with a net shift of - 43 [57% of participants rated it lower at the end of the day than they did at the beginning, while only 14% of participants rated it higher].

- Choice 2 (Health Insurance Tax Credits). This option was the most popular of the four at the beginning of the day, with an initial rating of 6.6 out of 10. In part, this was because at first glance participants felt this choice could fix the problem with the least disruption to the existing system. However, as they examined the scenario more closely, participants realized that it would still leave many people uninsured, and their support evaporated. At the end of the day this choice was down to 4.7, with a negative shift of - 49.

By comparison, participant support for the scenarios that involved universal coverage increased over the course of the day, even though each entailed significant tradeoffs and costs to citizens in the form of increased taxes, reduced wages, higher prices or reduced choice.

- Choice 3 (Expand the Employer-Based System). This option went up over the course of the day, rising from 6.4 in the morning to 7.1 at the end of the day, with a net shift of +14. Participants found it appealing because of its grounding in the employer-based system, which was familiar and which dovetailed with their belief that work is the primary way that people "earn" the social benefits they receive. The only exception to this trend was the Atlanta dialogue, where participants' support dropped, in large part because they saw this scenario as too complicated to lead to any workable solution.
- Choice 4 (Medicare for All). All three groups shifted in favor of this scenario, which rose from an average morning rating of 6.0 to a final rating of 7.3, with a +23 point net shift. Participants found the simplicity of this choice especially appealing, and many had had positive experience with Medicare. Those with the strongest reservations about this choice did not disagree with the goal of universal coverage but rather with handing the nation's health care over to what they regarded as a wasteful and untrustworthy government bureaucracy.

Once the groups had established that universal coverage was their goal, they embarked on a complex and wide-ranging exploration of how to get there. Importantly, this conversation was not so much a technical or ideologically driven comparison of the two universal coverage scenarios as an attempt to envision a system that would mesh with their core values. Accordingly, they mixed and matched elements from both scenarios to create a new vision of a system they would be prepared to support, and then worked together to sort through the difficult tradeoffs and costs that would need to be addressed to realize that vision.

B. A UNIVERSAL SYSTEM

First, participants began to come to grips with exactly what universal coverage means – who should be covered, what should be included, who should be responsible and how to pay for it. Three key values shaped this portion of the day's discussion: fairness, personal responsibility and choice.

Fairness

Participants spent a great deal of time discussing what would constitute a more equitable health care system, and they arrived at the following common ground:

> *We all agreed that everybody should be covered by the plan. No one thought that non-working Americans, or homeless people, should have to fend for themselves. [San Diego]*

Cover all Americans. Participants agreed that Americans and legal immigrants who work, pay taxes and contribute to society should have access to decent, affordable health care. They were surprised and shaken by the fact that most of the uninsured live in families with at least one full-time worker. Participants also agreed that it made sense for the unemployed and the homeless to have access to affordable basic coverage. However, some participants drew the line at providing coverage to illegal immigrants, arguing that they do not deserve such benefits. This question was not firmly settled in the groups where it was raised, but the prevailing feeling was that illegal immigrants should receive care only in emergencies.

> *I'm a survivor of a very serious illness, and now I am in the insurance trap…. I'm in an HMO and thankful to be, [but] I can never get insurance anywhere else because of my pre-existing condition. I can't leave this state, I can't retire anywhere else. [Atlanta]*
>
> *When you are born you get a Social Security card. It should be the same with health care. When you are born, you get coverage. [San Diego]*

Portability. Participants felt the current system was failing to keep pace with the increased mobility of American society. Older participants who had held the same job for decades spoke appreciatively of the benefits and pension plans that they had received, seeing that stability as a major contributor to their quality of life. However, younger participants, who tended to have (and to expect) higher job turnover, described a very different situation. Several told of having been trapped in a job or living situation because they feared losing benefits if they left, and many more had struggled to afford COBRA or other stop-gap coverage between jobs. This state of affairs led participants to believe that it is time to think about insurance in a new way. Many participants advocated tying coverage to the individual, not the employer. They envisioned "cradle-to-grave" coverage linked to a single identification number, along the lines of Social Security (whether that coverage was provided through government or the employer-based system).

> *There should be universal care, but there should be a cost for it, and the cost should be according to your income and ability to pay. No free rides. [Philadelphia]*

No free ride. All Americans deserve coverage, but everyone also needs to pull his weight. Participants believed strongly that the cost of coverage and care should be linked to people's ability to pay. There was support across the board for sliding scale mechanisms, but there was also strong consensus that everybody must pay *something*, even if only a token amount. Participants often noted that this would help control costs by discouraging unnecessary use of services, but it was also an expression of the deep-seated belief that entitlements encourage dependency.

Personal responsibility

The concern with "no free ride" led participants to emphasize that individuals bear a crucial (perhaps the most crucial) responsibility for maintaining their own personal health. This became a major discussion point in every dialogue.

Education and Prevention: In all dialogues participants emphasized the importance of education and prevention — moving from an emphasis on treating sickness to one of promoting wellness. Participants recognized that many Americans have poor health habits, and they felt that a great deal could and should be done to improve those habits, especially among the young. In part, people saw this as a smart economic move, feeling that investing up front in a healthier population would be more cost-effective than treating preventable diseases after the fact. More fundamentally, they felt it was in keeping with American values to help people help themselves and to take greater control over their own lives. Participants viewed giving people the tools and information they need to become healthier as a central responsibility of any decent health care system.

Incentives/Consequences for Healthy Behavior: This raised the question of where to draw the line between encouraging healthy behavior and enforcing it. Most participants saw unhealthy behaviors like smoking, drinking and overeating as matters of personal choice, but they were unwilling to restrict adults' ability to choose their way of life. At the same time, they felt it was unfair to ask people who take good care of themselves to pay for the more expensive care used by people who choose to damage their own health. As a result they overwhelmingly opted for a system of incentives and consequences, where people who engage in healthy behaviors would get some kind of financial break while those who do not would pay more. Even those who described themselves as smokers, or overweight or out of shape agreed that it was fair for them to pay more for health care if they did not take care of themselves. Interestingly, this idea was raised independently in all three dialogues, even though it appears nowhere in the workbook.

> *There should be incentives so if a guy like me doesn't want to exercise, doesn't want to eat right that's my choice. But if you choose to not smoke or to lose weight you get a payback, cash or discount. You are rewarded for what you're doing to help yourself and the system. [Philadelphia]*

Many participants cited the car and life insurance industries as models, and several people suggested a health care equivalent of the "good driver discount." Under this arrangement, people who remain healthy, meet certain health goals (quitting smoking, losing weight), or make only limited and judicious use of the health care system could get a rebate.

While most participants supported such models, they also expressed concern about who would be the arbiter of good behavior: "who would play God," as one woman put it. This theme became especially important later in the dialogue when participants turned to the question of the roles of the public and private sector.

> *I think Americans are very motivated by rebates – car rebates, tax rebates – how about a health rebate? They could review your use of the system and you get a rebate if you use it minimally. That's an incentive to stay healthy, take care of yourself and not use the resources. [San Diego]*

Choice

Participants were wary of one-size-fits-all solutions. They wanted to be able to choose the health care options that would work best for their families – and in particular, they wanted to be able to choose their own providers. They also saw choice and competition as one of the great strengths of the U.S. health care system: participants expressed pride in the quality of care available in the U.S., and they agreed that this country offers the best health care in the world to those who can afford it. They wanted to maintain this tradition of high quality health care and medical innovation while making its benefits available to everyone.

> *I am very concerned about being able to keep the doctor of my choice. [San Diego]*

> *We would like to see a very basic level of coverage you can take with you from job to job. [Atlanta]*
>
> *As tough as it is, I'm willing to pay for what I want… It's worth it to me to get good health care. [Atlanta]*

A two-tier solution: However, as they considered the matter, participants began to come to grips with the fact that allowing every American unlimited choice of providers and services was likely to be prohibitively expensive. When it came to making a tradeoff, most participants felt restricting choice somewhat was much better than leaving people without access to affordable insurance. Many found the HMO model acceptable and felt that HMO-type plans would likely be an inevitable result of expanding coverage.

As they explored this possibility, every group wound up leaning towards some kind of two-tiered health insurance system that would make basic coverage available to all citizens at an affordable price, with enhanced coverage available to those who wish to pay for it. Some envisioned making "basic" coverage completely portable, while employers could offer supplemental plans and enhanced coverage. As participants saw it, a two-tier system would make it much easier to achieve universal coverage. In addition, it would introduce choice into the equation in a fundamental way, allowing individuals to decide how important health insurance is for them and to assume responsibility for their own health, while making sure that everyone has access to the basics.

What does "basic" mean? Every group wrestled hard with the question of exactly what should (and should not) be considered "basic" health care, though all ultimately agreed that hospital care, medically necessary procedures and preventive medicine should be included. Services that were not deemed "basic" (for most participants this included elective and cosmetic surgery, second opinions and private rooms) came under the heading of "pay more/get more" – something that should be available to those who want to pay for it, but not part of the standard package. However, between the extremes of life saving care and elective cosmetic surgery, participants struggled with the question of what, specifically, they would be willing to include in or exclude from an affordable "basic" plan. The question was not fully resolved, and is a key point to investigate further.

C. WHO SHOULD RUN IT?

As they worked through the question of what their health care should encompass, participants turned to the question of who should administer it. Their mistrust of both the public and the

private sector was such that they were unwilling to be trapped in a system controlled by one or the other. Instead, they worked to create a blended approach that combined the best aspects of both.

Who to trust?

Participants' mistrust of both the private sector and government ran deep.

Most participants did not trust the private sector, with its focus on profit, to create a system that would be fair and accessible to all Americans. Participants were especially angry at the drug companies, which they saw as all too willing to exploit American consumers in the name of profit. In general they were concerned that the private sector would be more concerned with the bottom line than with the needs of patients.

At the same time, suspicion of government ran deep in all three groups. Many saw government as a fiscal black hole sucking in tax dollars, and they felt that waste, bureaucracy, corruption and inefficiency were rampant. Placing the nation's health care more fully in government hands, many felt, would result in a system that was cumbersome, intrusive and wasteful.

> *I have a problem with the private sector, because if [health care] is in their hands they're only going to be responsible to themselves or their CEO's, and I just don't trust them. [Philadelphia]*

> *We've got a problem in this country that starts with the Federal government taking our money and not being accountable. No business in the world could operate the way the Federal government does. Our government is guilty of fraud, they're guilty of theft, as far as I'm concerned. [Atlanta]*

Checks and balances

Because participants did not trust either the private or the public sector to run an effective and fair health care system alone, they turned instead to a checks-and-balances model that would allow them blend the best aspects of both sectors.

Participants felt that government's positive strengths lay in its ability to provide services fairly to all regardless of their ability to pay, its powerful regulatory authority to protect the public interest and its economies of scale. Participants felt that rigorous government oversight would be essential to protect citizens from the excesses of a profit-driven system and to keep the neediest from falling through the cracks. Many participants also hoped that government could use its huge purchasing clout to negotiate better prices for drugs and health services, thereby controlling costs.

At the same time, participants valued private sector efficiency, flexibility and responsiveness – and hoped that incorporating these into a universal coverage system would help counteract government's tendency toward the cumbersome, the inflexible and the wasteful. Most felt that competition and the drive for profit did a great deal to stimulate innovation and deserved credit for making U.S. health care the most technologically sophisticated in the world, and they hoped that substantial private sector involvement would help maintain the excellent quality of care now available (although not affordable to all).

The precise balance between public and private sector roles that participants envisioned varied from group to group. More research will be required to determine the reasons for those

differences and what balance between public and private roles would be more broadly acceptable.

D. PAYING FOR IT

Providing more coverage for more people requires either doing more with what is currently being spent, or spending more. As participants took in the fact that the U.S. spends over $1.5 trillion a year on health care, their first response was to argue that such an astronomical sum ought to be enough to provide decent care for everyone – it needs only to be spent more wisely. Accordingly, participants' first impulse was to pay for programs by cutting out waste, fraud and abuse.

Efficiency

Participants cited many instances of waste and inefficiency they had seen first-hand, including having to enter identical information on multiple forms, lack of coordination among providers and duplicative tests. They had several suggestions for improving efficiency, including:

- Smart cards and other information sharing mechanisms that could give providers nationwide access to an individual's medical information. This approach would also cut down on duplicative tests and procedures and on mistakes.
- A regional benefit matrix that would outline the cost of services in a given market, thereby rationalizing and standardizing costs. As participants envisioned it, this matrix could either be prescriptive or could serve as a guideline for consumers (one participant compared it to the Kelley Blue Book).
- Incentives for healthy behavior to cut down on use of the system
- Coordinated teams of providers (including physicians, physicians' assistants and nurses) that would be available 24 hours, making more efficient use of medical resources while providing more integrated care.

Additional funding

However, participants soon came to realize that measures like these would probably not do the job alone, and that they themselves would also have to pay something to create a more universal health care system. Overall, they showed a striking willingness to do so <u>if</u> certain conditions were met. They seriously discussed a wide range of possible funding mechanisms, including:

- <u>Taxes.</u> Participants discussed income taxes, payroll taxes and sales taxes as three possible ways of paying for health coverage. Each had its proponents arguing that it was fairest, but the overall consensus was that increased taxes of some kind were necessary and inevitable.
- <u>Premiums and co-pays.</u> Participants imagined that premiums and co-pays would continue to be a part of any universal system, though they wanted to keep these costs low. They advocated setting rates by means of a sliding scale keyed to income – the wealthy would pay more, the poor less, but everyone would pay something

- An expanded role for individual supplemental insurance. This concept was explored most thoroughly in Philadelphia, where participants envisioned universal access to a minimal government-sponsored package, while additional features would be available through the private market to people who want to pay for them.

Accountability

However, before they would pay more for any system of universal coverage, participants demanded much stronger accountability and transparency on the part of providers, insurers and governments. As they saw it, such accountability is sorely lacking in the current system: the government, providers and drug companies are raking in money hand over fist, with little accountability or transparency.

> *I think we need to address the issue of cost at the source: the hospital, the doctors, insurance companies, the ads for prescription drugs on TV – it's ridiculous! [San Diego]*

Participants wanted mechanisms that would allow them to follow the money and protect quality of care. Mechanisms they suggested included:

- Watchdog groups and medical oversight boards to provide credible third-party verification that costs are being reined in and quality of care is being maintained;
- Citizen oversight boards to keep tabs on how public money is spent;
- Performance ratings for providers, determined by both medical evaluators and patients;
- Clearer medical billing practices and explanation of benefits, so that consumers know what they should be getting, what they are getting and where their money goes;
- Easier public access to information about insurers, providers and government agencies, presented in a form that is clear and easy to follow.

> *When you [elected officials] try to get votes by promising to get health insurance, you have to go one step further and say "this is the way we're going to pay for it." Don't just say we're going to eliminate waste – be specific about how you're going to raise that money. If you're going to raise taxes, tell us. That will give people a choice. [Atlanta]*

Participants clearly stated that they would be willing to pay for health insurance reform only if such mechanisms were in place, and they called on decision-makers to be more straightforward with the public about what needs to be done and how much it will cost.

Implications for privacy

Several of the specific suggestions raised by participants raised potential privacy concerns – in particular, ideas like "smart cards" or allowing more intensive scrutiny of potentially unhealthy lifestyle choices like smoking or alcohol use. Interestingly, most participants concluded that this was a reasonable tradeoff to make, seeing it as connected to their willingness to assume more personal responsibility for their health – loss of privacy was, in a sense, how they

> *You can't expect things to be administered effectively if you're not willing to give up your medical history, your financial history [Atlanta]*
>
> *So it's Big Brother time. So what? We're there anyhow! [San Diego]*

could be held accountable for their exercise of that responsibility. Most were also willing to make their medical information and their personal behavior more easily available if it would increase efficiency and ease of access to care. While many participants also felt that they had little privacy left to lose, the question of what sorts of safeguards they would require or what sorts of information sharing they would find unacceptably intrusive was not fully explored.

IV: Other Findings

A. Social Capital

> *What surprised me was how much we agreed. I had thought that one of the reasons we're in this situation was that we all had wildly different ideas. [San Diego]*
>
> *An important thing I learned today is that it's not just about me and my health situation. It's about so many people in so many situations. [Atlanta]*

Participants were surprised and pleased at the amount of common ground they discovered – far more than what media presentations on the issue had led them to expect. Most saw the day as an important and unusual learning experience and felt that they had accomplished something valuable and worthy of being heard. They were particularly impressed with the quality of the conversation – that groups of people from such diverse backgrounds could work together and make real progress on such a difficult issue. As they learned from each other's experience, they also underwent an important shift in perspective, moving from a highly individual point of view to a more communal perspective – and with it a more collective sense of responsibility for doing something to address the issue. They clearly had come to realize that there were no easy answers, but they also saw possibilities they had not seen before.

B. Key Values

Participants' core values were constant across all three sessions, and these values shaped their responses to everything that was said or learned throughout the day. As outlined earlier, the values most important to participants' thinking about health insurance were:

- "We are in this together"
- Fairness
- Personal responsibility
- Choice
- Checks and balances
- Accountability

Contrast with Canada: Many participants pointed to Canada and Western European nations' health care systems as examples to be emulated; at the same time, American participants' key values differed significantly from those of people in nations that already have national health care. This can be clearly seen when comparing these ChoiceDialogue results to a 2002 series of dialogues Viewpoint Learning conducted in Canada on reforming that nation's health care system. Key distinctions between Canadian and American approaches to health care coverage – and how they defined their core values – are outlined in the table below:

U.S.	Canada
Two-tier coverage[3] allows flexibility and choice	Two-tier coverage is unfair: everyone should receive equal treatment
Co-pays and premiums for basic services are acceptable	Co-pays and premiums for basic services are unacceptable (OK only for "extras" like private rooms and 2nd opinions)
People getting a "free ride" penalize the majority who work hard and play by the rules	Fees for basic services penalize the needy by barring them from necessary care
Medical care should be allocated according to need and ability to pay	Medical care should be allocated solely according to need
Personal responsibility enforced by penalizing unhealthy behaviors (all pay, but those who make unhealthy choices pay more)	Personal responsibility enforced by social norms and promoting wellness
Health care is an essential commodity	Health care is a basic right

These differences may stem from the way that health care has been delivered in the U.S. over the last half-century, which has accustomed Americans to paying out of pocket for health care and established a strong link between health care and employment.[4] Whatever their historical grounding, however, these distinctive values shape Americans' current expectations and priorities, and any sustainable reform at this time will need to reflect them.

C. The role of information

These dialogues demonstrate that when members of the public engage with difficult policy issues, technical information is necessary but not sufficient to their reaching stable judgment. Participants in these dialogues did make use of information as they made up their minds, but their path to stable judgment drew far more heavily on values, emotions, deeply held beliefs and the reactions of their fellow citizens. Over the course of the day, certain pieces of information resonated particularly strongly with participants' core values and became important touchstones for their learning process. In particular,

[3] "Two-tier coverage" = basic universal coverage with enhancements available for an additional fee

[4] This was true to such an extent that even participants advocating single-payer models found it difficult to envision an American health care system that was not in some way employer-based.

- 43 million uninsured, and not all unemployed. Participants repeatedly said they had had no idea that there were so many uninsured Americans, and they were dismayed to learn that most come from households with at least one full-time worker. These two facts resonated with (and offended) participants' sense of fairness and their strong belief that people who work and contribute to society deserve access to decent health care.

- First in spending/18th in outcomes. Many people were astounded to learn that the U.S. spends over $1.5 trillion per year on health care. The participants' workbook included a table (reproduced at right) comparing per capita health spending with overall health outcomes in developed nations. On this chart, the U.S. ranks first in per capital health spending, but 18th in terms of health outcomes. Participants found this statistic especially shocking, since it challenged their belief that U.S. health care is the best in the world. This was not only a blow to national pride, but reinforced their sense that we can and must get better value for our health care dollars, and that the current system is not good enough

	Health Outcomes	Per Capita Spending
Japan	1	15
Sweden	1	16
Iceland	2	9
Norway	3	7
Italy	4	14
Canada	5	4
United Kingdom	9	19
France	12	12
United States	18	1

OECD Health at a Glance 2001

At the same time, some facts did not resonate or were rejected because they came into conflict with core values. These included:

- Public health argument. Most participants were far more concerned with the financial cost of having a large number of low-income uninsured people than with the public health cost. This attitude was especially pronounced when the conversation turned to illegal immigrants: for most participants, resentment of "outsiders" trying to take advantage of the system far outweighed the public health value of providing such immigrants with health care services.

- Partial fixes. Although solutions that led to less than full coverage were significantly less costly than universal coverage scenarios, participants saw such solutions as false economy. As they had framed it based on their values, the problem was that any American is uninsured. They wanted a solution that solved that problem once and for all.

V. Conclusion

While this pilot series of dialogues revealed great deal of common ground, its small scope necessarily means that some important questions cannot be resolved. Key issues that need further investigation include:

- What do Americans feel should be included under "basic" coverage, given the tradeoff with higher costs?
- What does the public see as the best mix of roles and responsibilities for the public and the private sector?
- How tightly are American visions of health care tied to an employer-based framework?
- To what extent do regional differences affect how citizens approach the question of health coverage?

This pilot project was designed to engage regular citizens in working through the important decisions that must be made to resolve the problem of the uninsured, and to provide policy-makers with insights into the sorts of reforms citizens would be prepared to support and the conditions for that support. Such insight will be key to any successful reform of health care. While experts and stakeholders provide essential technical input, any sustainable solution must also reflect citizens' values, beliefs and priorities. Polls and focus groups were not designed to provide this sort of insight on issues where people have not yet made up their minds. In fact polls and focus groups can be highly misleading on such issues — the ill-fated Clinton health care plan is just one cautionary tale. ChoiceDialogues have been developed to fill this gap, enabling representative groups of citizens to work through the issues and to make up their minds.

This project has provided an important initial outline of citizens' values and priorities on health care reform and covering the uninsured – an outline that can inform future efforts to craft workable solutions that the public will be willing to support. These initial findings need to be further tested, elaborated and deepened through research and civic engagement at both the state and national levels. In the end it is this citizen input on values, coupled with the best technical input from health care experts, that will be key in devising sustainable reforms to cover the tens of millions of Americans who are uninsured today.

APPENDIX A

ChoiceDialogue Methodology

ChoiceDialogue: The Methodology

Viewpoint Learning's ChoiceDialogue methodology differs from polls and focus groups in its **purpose, advance preparation, and depth of inquiry**.

- **Purpose.** ChoiceDialogues are designed to do what polls and focus groups cannot do and were never developed to do. While polls and focus groups provide an accurate snapshot of people's current thinking, ChoiceDialogues are designed to predict the future direction of people's views on important issues where they have not completely made up their minds, or where changed circumstances create new challenges that need to be recognized and addressed. Under these conditions (which apply to most major issues), people's top-of-mind opinions are highly unstable, and polls and focus groups can be very misleading. ChoiceDialogues enable people to develop their own fully worked-through views on such issues (in dialogue with their peers) even if they previously have not given it much thought. By engaging representative samples of the population in this way, ChoiceDialogues provide unique insight into how people's views change as they learn, and can be used to identify areas of potential public support where leaders can successfully implement policies consonant with people's core values.
- **Advance Preparation.** ChoiceDialogues require highly trained facilitators and (above all) the preparation of special workbooks that brief people on the issues. These workbooks formulate a manageable number of research-based scenarios, which are presented as a series of values-based choices, and they lay out the pros and cons of each scenario in a manner that allows participants to work though how they really think and feel about each one. This tested workbook format enables people to absorb and apply complex information quickly.
- **Depth of Inquiry**. Polls and focus groups avoid changing people's minds, while ChoiceDialogues are designed to explore how and why people's minds change as they learn. While little or no learning on the part of the participants occurs in the course of conducting a poll or focus group, ChoiceDialogues are characterized by a huge amount of learning. ChoiceDialogues are day-long, highly structured dialogues – 24 times as long as the average poll and 4 times as long as the average focus group. Typically, participants spend the morning familiarizing themselves with the scenarios and their pros and cons and developing (in dialogue with each other) their vision of what they would like to have happen in the future. They spend the afternoons testing their preferences against the hard and often painful tradeoffs they would need to make to realize their values. To encourage learning, the ChoiceDialogue methodology is based on dialogue rather than debate — this is how public opinion really forms, by people talking with friends, neighbors and co-workers. These 8-hour sessions allow intense social learning, and both quantitative and qualitative measures are used to determine how and why people's views change as they learn.

APPENDIX A

ChoiceDialogue Methodology

Steps in a ChoiceDialogue Project

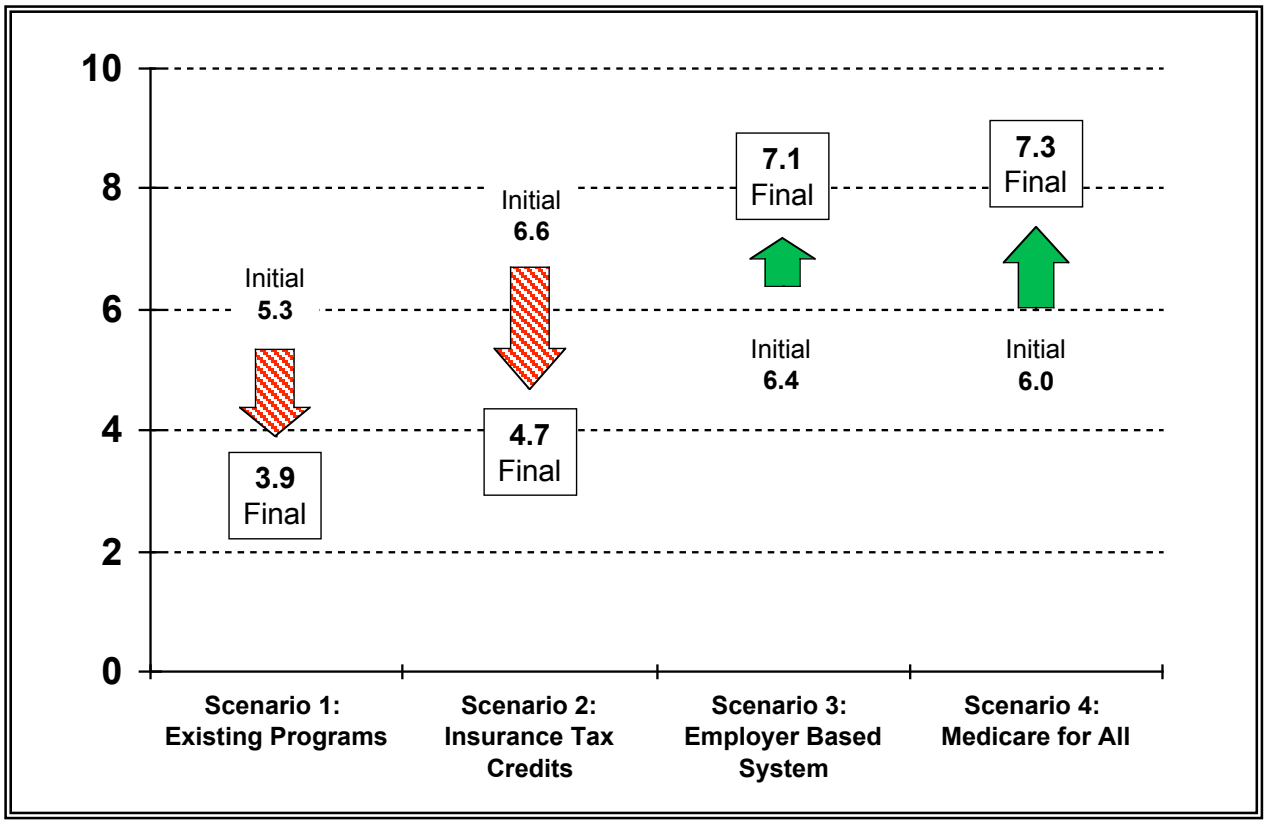
1) Archival analysis of polls (or conducting a special one) and other research to provide a baseline reading on what stage of development public opinion has reached;
2) The identification of critical choices and choice scenarios on the issue and their most important pros and cons;
3) A series of one-day dialogue sessions with representative cross-sections of stakeholders. Each dialogue involves about 40 participants, lasts one full day and is videotaped. A typical one-day session includes the following:
    - Initial orientation (including the purpose of the dialogue and the use to be made of the results, the nature of dialogue and ground-rules for the session, introduction of the focal issues and some basic facts about them);
    - Introduction of the choice scenarios on the specific focal issue, and a questionnaire to measure participants' initial views;
    - Dialogue among participants (in smaller groups and in plenary) on the likely good and bad results that would occur as a consequence of each choice if it were adopted, and constructing a vision of the future they would prefer to see;
    - A second, more intensive round of dialogue among the participants (again both in smaller groups and in plenary) working through the concrete choices and tradeoffs they would make or support to realize their vision;
    - Concluding comments from each participant on how their views have changed in the course of the day (and why), and a questionnaire designed to measure those changes.
4) An analysis of how people's positions evolve during the dialogues. We take before and after readings on how and to what extent people's positions have shifted on each choice as a result of the dialogue. (Some of the shifts are huge). This analysis is both quantitative and qualitative.
5) A briefing to leaders to make sense of the results. The briefing summarizes what matters most to people on the issue, how positions are likely to evolve as surface opinion matures into more considered judgment, and the opportunities for leadership this creates.

APPENDIX B

Quantitative Findings

In each of the dialogues, participants were surveyed twice, once at the beginning of the day and again at the end. They were asked to rate their response to each choice independently on a scale of 1 to 10, 10 being "totally positive" and 1 being "totally negative." These results were tabulated to determine both the average rating of each scenario and how each individual changed his or her views over the course of the day.

COVERING THE UNINSURED
Initial/Final Means
All Sessions

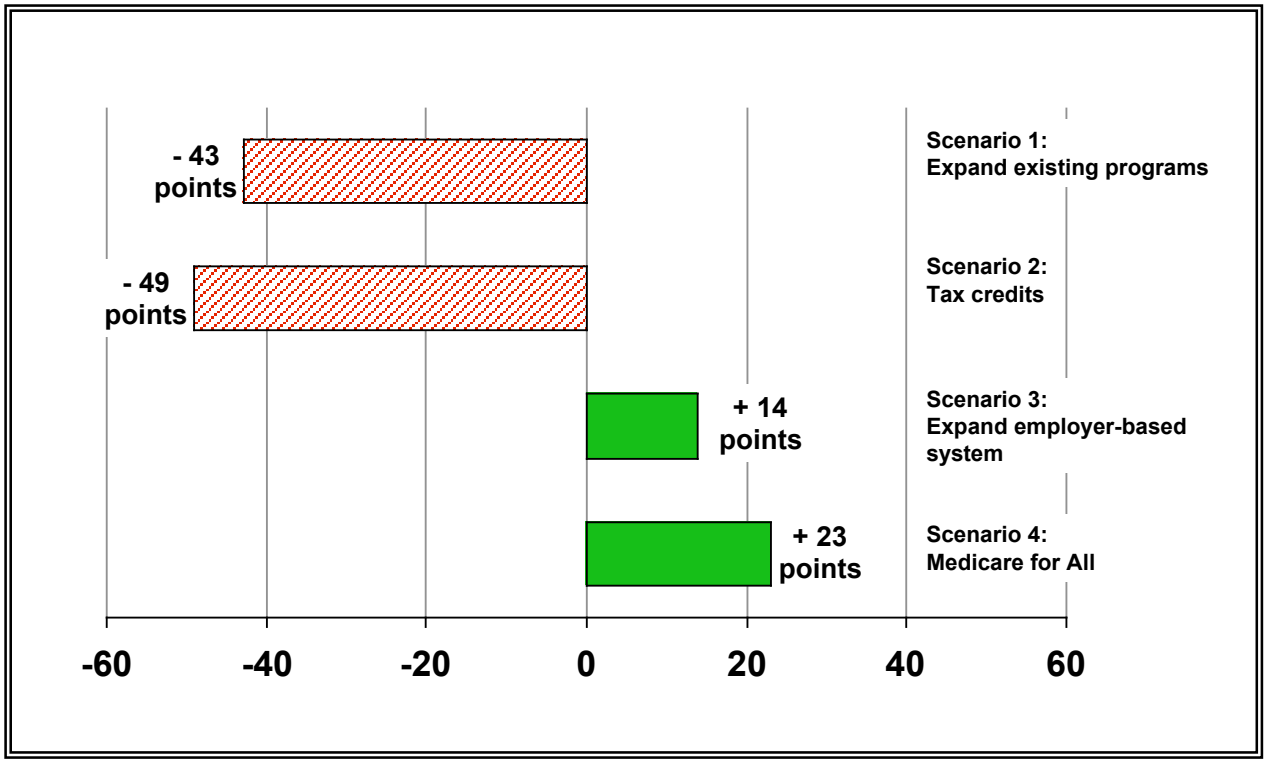


Means: The initial mean for each scenario indicates participants' average rating of the choice in the morning; the final mean represents participants' average rating of the same scenario at the end of the dialogue. The arrows indicate the direction of the change in mean, moving from initial to final.

APPENDIX B

Quantitative Findings

COVERING THE UNINSURED
Net Opinion Shifts
All Sessions



Shifts: The "shifts" measure how widespread opinion change is within the group, as well as the direction of that change, by comparing individual participants' ratings of each scenario at the beginning and the end of the day. These are expressed in terms of net shifts.

For example, if 50% of participants rate a scenario higher at the end of the day than they did at the beginning, and 15% rate it lower, then that scenario has a +50 positive shift and a -15 negative shift, making a net shift of +35.

In the chart above, the bar indicates the size and direction of the net shift for each choice. Net shifts of less than 10 points are not considered meaningful.