

Voices for Health Care: Public engagement to advance significant health care reform

Progress Report: December 2008



Project Sponsor: W.K. Kellogg Foundation

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Progress Report

Around the country, there is growing agreement that the American health care system is in trouble. Skyrocketing costs, a reeling economy, a growing number of uninsured and under-insured, and deteriorating health outcomes have pushed the issue of health care reform onto the front burner. Significant health care reform will depend on a combination of political will, technical expertise and public support. Success will depend on the engagement of both leaders and the public.

Project design and methodology

Voices for Health Care was designed to engage first leaders and then the public in three states (Ohio, Mississippi and Kansas) in working through alternatives for health care reform. Its objectives included:

- Identifying health care reforms to lower costs and improve access that both leaders and the public will support

- Defining the roles of employers, the public sector and individuals in such a system
- Revealing potential roadblocks and conditions for support
- Creating a roadmap which leaders and others can use to move these health care reforms forward.
- Developing a growing culture of and capacity for dialogue and civic engagement in each state where this work is conducted.

In all of these efforts, we have worked closely with local partners — state health care advocacy groups, and in two states these groups in turn brought in non-partisan policy institutes as co-conveners. Brief descriptions of our partner organizations can be found on the following page.

In all three states, the focus from the beginning was on building momentum, with each activity leading naturally to the next. In each state the sequence was:

1. A **Strategic Dialogue**, in which health care, political, civic and business leaders worked together to create several scenarios for reform to test with the public in *Choice-Dialogues*. These sessions built ownership for the subsequent phases of the project and began to build momentum around broadening the engagement efforts.
2. Three daylong **Choice-Dialogues** (in different locations around the state) in which randomly selected, representative samples of the public explored what sort of health care system they wanted to see in the future, grappling with the difficult choices and tradeoffs involved. Participants identified what sort of solutions they would be willing to support and under what conditions to improve health care in their state.¹

¹ A description of Choice-Dialogue methodology can be found in Appendix A.

3. An **Interactive Briefing** with leaders in each state, including many who had participated in the Strategic Dialogue as well as others from business, government, health care and other sectors. The discussion in these sessions focused not only on the substance of the findings but also on ways to build on the results, reach out to other leaders, and continue to engage the public.

The remaining elements (currently ongoing) focus on “scaling up” the dialogue to engage a broader cross section of the public. These efforts encourage people to grapple with the difficult choices involved using a variety of structured face-to-face and electronic methods. Just as important, they allow leaders in each state to develop and deepen local institutional capacity for dialogue and public engagement – around health care as well as other challenges facing their state.

4. Based on the Choice-Dialogue findings, we developed a “**Meeting-in-a-Box**” kit that enables leaders, advocates and others to conduct 2.5 hour, highly structured **community conversations** around health care reform. The kit includes feedback mechanisms that can be used to measure results and build a list of interested citizens who can continue to be engaged on the issue over time. Our local partners recruited local facilitators who we trained in the use of the Meeting-in-a-Box kit, and community conversations are now underway in each state.

5. **Online Dialogue.** We are currently conducting an Online Dialogue, which includes participants from each of the target states and from across the country. Through Online Dialogue many more citizens have had an opportunity to engage in a dialogue on health care reform online and to contribute their views, further

VOICES FOR HEALTH CARE PROJECT PARTNERS

The Kansas Health Consumer Coalition (KHCC)



KHCC is a statewide health advocacy organization whose mission is to advocate for affordable, accessible, and quality health care in Kansas. Launched in 2004, KHCC has substantial relationships with the Kansas Health Policy Authority (KHPA), which was created to provide recommendations to the Legislature and

the Governor related to health policy. Through its participation on several KHPA advisory councils KHCC has provided substantive policy recommendations to KHPA. KHCC has also forged strong collaborative relationships with key stakeholder groups throughout the state and has been instrumental in creating and strengthening several partner coalitions, including the Kansas Faith Alliance for Health Reform, Alliance of Health Advocates, and Kansans for Better Health.

The Mississippi Health Advocacy Program (MHAP)



MHAP strives to be a strong, effective voice for improved health care for all throughout the state of Mississippi, especially those whose health is threatened by poverty, racism, malnutrition and violence. MHAP will work with communities to identify health needs and formulate strategies for change, and will research, analyze, propose and promote policies that will enhance the health status of every person, regardless of financial status.

Universal Health Care Action Network of Ohio (UHCAN Ohio)



UHCAN Ohio is a statewide consumer advocacy organization promoting access to high quality, affordable, accessible health care for all Ohioans, through public education, consumer engagement, coalition building, and public policy. As one of twelve grantees of the Robert Wood Johnson Foundation "Consumer Voices for Coverage" initiative, we are building Ohio Consumers for Health Coverage, a united consumer voice with the goal of achieving health care for all that is effective, efficient, safe, timely,

patient-centered and equitable. UHCAN Ohio also provides leadership in state and local efforts involving hospital charity care accountability, expansion of primary care medical homes, special needs plans for people with disabilities, promotion of safe, effective, affordable prescription drugs, and other initiatives to improve quality and cost effectiveness of health care to improve outcomes.

- developing awareness of and interest in possible reforms.
6. Outreach through local **communications** and media activities that heighten public awareness of these efforts and create ‘buzz’ around the need for reform and the specific approaches identified by the public and leaders. Thus far, we have had TV, print, radio and online coverage in numerous markets including Kansas, Ohio, Mississippi, South Carolina and California.
7. **Invitation-only conference** to be held in Washington D.C., December 8-9. The conference will review project research, compare results across the states, and discuss the implications for national health care reform. It will identify the greatest obstacles and success factors involved in building the public support essential to sustainable health care reform. And it will distill key lessons about the role and potential of civic engagement in state- and national-level policy reform efforts and identify possible next steps.

The relationship among these steps is outlined in the flowchart on page 8.

Focus on state-level reform

Many Americans view health care reform as a national issue - too big and complex to be addressed at a state level. But states have long taken the lead on important issues (e.g. labor laws, climate change, education); often these state level efforts become the blueprint for national action. While national health care reform will certainly be on the table in the coming years, many state leaders feel it is important to act now, not wait for a national effort that may be years in coming. In addition, these state-by-state conversations can help to establish common ground and a foundation for a national conversation.

Strengthening local project partners

- Building institutional capacity for dialogue and civic engagement in each of the target states is a crucial aspect of this project. The project is designed to enable local partners in each state to:
- Strengthen and broaden their links with both leaders and the public to advance reform efforts
 - Use the Community Conversations as a tangible tool to reach out to a wide range of local organizations and the broader public
 - Build a more extensive database of people who want to be part of an ongoing dialogue on this issue
 - Position their organizations as leaders in creating a more thoughtful conversation around issues of health care reform
 - Create and test a model that they and others can apply to a range of important state issues.

Most of all, it is designed to ensure that the benefits of this effort can extend beyond this project.

Project results

Step 1: Strategic dialogues

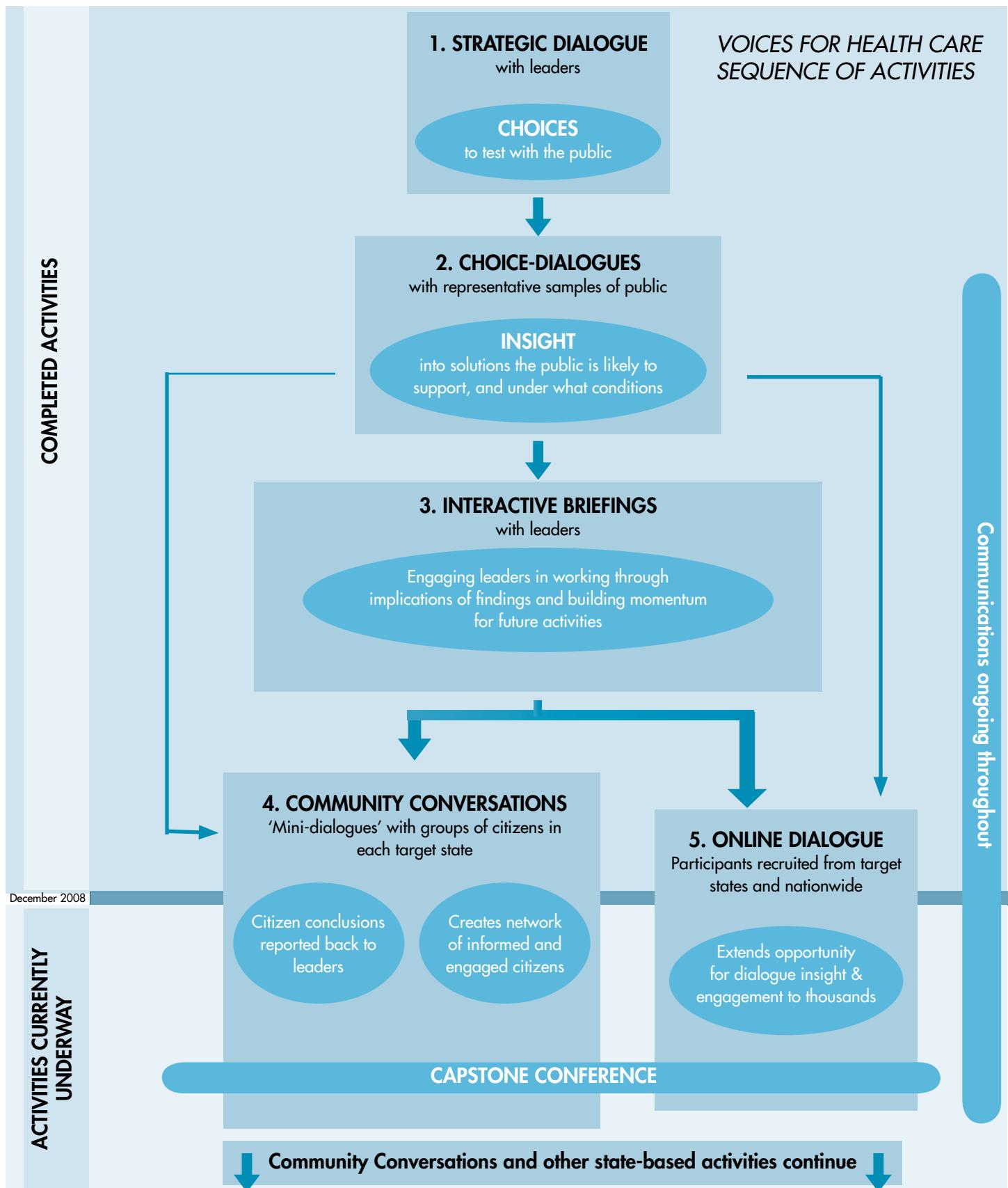
In November 2007 and January 2008, Viewpoint Learning conducted Strategic Dialogues in each of the target states. Each Strategic Dialogue brought together a mix of 30-40 leaders representing health care, state government, business, universities and civic and faith organizations to compare notes on the changes and trends that have shaped the current health care situation in their state, and to develop a range of choices or scenarios for reform they would be prepared to support and would like to see tested with the public in the next step of this project.

Strategic Dialogue participants in each state arrived at surprisingly similar conclusions about the roots of the problem and the range of possible solutions that

I think it's important how we frame this as we move forward – if we continue to focus [just] on the acute care/medical care system we are defeating ourselves. We have to start changing people's perception about what the health care system is all about – to ... get off our typical stuck in the mud [idea] that there's only one way to do things. There are lots of ways to do things.

Strategic Dialogue participant (Ohio)





would be required to address it. In each session, participants drew a picture of an increasingly fragile health care system and identified a common set of key problems:

- Rising costs
- Growing fragmentation and inefficiency
- Growing number of uninsured and underinsured
- Shrinking access to care
- Poor lifestyle choices
- A medical system focused far more on treating illness than promoting health
- A growing - and alarming - gap between the haves and have-nots

Across the board, these leaders indicated a shared desire for real change moving beyond incremental reform. Many talked about framing the issue not just as “health care” reform – focused primarily on the issues of access, cost and coverage – but instead thinking more broadly about true “health reform,” and how to take bold steps to create a healthier public. While a wide variety of ideas and perspectives were raised, a number of important common themes were repeated at all three sessions:

• Universal or near-universal coverage.

All dialogues established as a goal providing universal or near-universal health coverage in the state. This was something all participants believed was extremely important, although there were differing thoughts on how to accomplish it, what ought to be covered and what the proper roles were for the public and private sectors. But across all groups, leaders envisioned a system in which every person in the state gets some form of coverage and care regardless of age, income, employment, or health status.

The most interesting thing I heard was the support for a single payer system. I think people who are interested in politics think that's not going anywhere politically - but it seems like there was a lot more support than I ever would have thought.

Strategic Dialogue participant (Mississippi)

• Encouraging and rewarding personal responsibility. Participants in all three strategic dialogues said that there was a significant role to be played at the individual level and that the system must encourage healthier behavior through education and rewards for those who make healthy life style choices.

• Dealing with rising costs. Participants also considered how to address the high cost of coverage and care, though they differed in their focus. Kansas and Ohio participants focused on easing the burden on businesses through cost-sharing. Mississippi participants – in a state where the employer-based system covers less of the population – focused more on reducing costs. Many supported adopting evidence-based medicine protocols that would give priority to treatments most likely to have good outcomes.

Once these basic themes had been surfaced, the Strategic Dialogue participants pulled them together into a number of specific ideas for reform that they felt should be developed into scenarios and tested with the public. We expected that the three target states, facing such different circumstances,

would arrive at different sets of ideas. To our surprise, however, all three Strategic Dialogue groups arrived at very similar conclusions. These ideas formed the basis for four values-based scenarios that citizen participants considered in the subsequent Choice-Dialogues:

1. **Shared responsibility**
2. **Increasing personal responsibility**
3. **Public health insurance for all**
4. **A coordinated wellness system**

The complete text of the Choice-Dialogue scenarios can be found in the sidebar on page 10.

Leaders participating in the Strategic Dialogues were impressed by the wide range of perspectives at the table, the shared sense of urgency among people from different sectors, and the variety of expertise and experience represented. They appreciated the opportunity to move beyond short-term and incremental fixes to consider a long-term coordinated

This is a state that values personal responsibility, but I think we all define personal responsibility in a different way.... The thing that we should keep in mind is that there are large regional differences [in this state]. Rural versus urban, and many more issues – those all should be blended together instead of doing them regionally.

Strategic Dialogue participant (Kansas)

It was refreshing to have the opportunity to have a bunch of different folks at the table and to listen to everybody's input. That was very, very welcome.

Strategic Dialogue participant (Ohio)

vision for health care reform. Most were especially struck by the level of agreement about the need for significant reform and the core values all parties shared: they had not expected they would find so much common ground on what needed to be and what could be done. Participants ended the day with a growing sense of what might be possible, interest in what the Choice-Dialogues would reveal about the public's attitude toward the reforms they had just discussed, and interest in the project and its prospects.

Step 2: Choice-Dialogues

In March and April 2008 Viewpoint Learning conducted nine Choice-Dialogues on health care reform in Kansas, Mississippi and Ohio (three in each state). These dialogues were designed to explore public views on health care reform and the tradeoffs the public is (and is not) willing to make to achieve a better system. Each session was conducted with a randomly selected representative sample of 30-40 residents of the area. The total sample of nearly 300 people was extremely diverse, including participants from a wide range of backgrounds, incomes, education levels and political orientations.

As a starting point for discussion, participants used a special workbook, constructed around four distinct

FOUR SCENARIOS

1. SHARED RESPONSIBILITY

This approach requires employers, the government, insurers and health care providers to share responsibility for fixing holes in the current employer-based insurance system. Employers will have to provide health insurance for their employees or else pay a tax to help fund coverage for those who do not have employer-provided insurance. Insurance companies will have limits placed on their profits; and doctors and hospitals will pay new fees to subsidize coverage. People who do not get insurance through their employers will be able to get health coverage at group rates from a statewide "insurance clearinghouse." Government-funded health care will be expanded to cover more of the lowest income children and families. Together these reforms will build on the current system to significantly reduce the number of uninsured in [State].

2. INCREASING PERSONAL RESPONSIBILITY

In this choice, every [State resident] will be required by law to have at a minimum a high-deductible health insurance plan – a plan that covers both extraordinary medical expenses that cause financial hardship and basic preventive care. If people don't get health insurance from their employers, they will have to buy it themselves. The state will require that all insurers offer at least one low-cost high-deductible plan. For low-income people who can't afford insurance and whose employers don't provide it, the state will contribute to the cost. To pay for this, people who have the most generous employer provided benefits will pay income tax on their benefits. How much people pay for health insurance will depend on whether they are avoiding unhealthy habits and taking steps to stay healthy. The state will provide more information to help people choose hospitals and doctors and will develop new health education programs for all [State residents].

3. PUBLIC HEALTH INSURANCE FOR ALL

In this approach, all [State residents] will get comprehensive insurance through a statewide agency that acts as a single insurance company for all [State residents] under 65. The plan will cover basic preventive care, all medically necessary doctor visits, drugs, hospital stays and tests. All current health care providers in the state will be included in the new system, but they will not be employed by the state and people will be able to choose which providers they use. The new state agency will establish uniform standards for quality care, and an independent commission of doctors will make decisions about what treatments are most effective and will be covered. Employers and individuals will no longer pay health insurance premiums; instead, this coverage will be funded by an income tax on individuals and companies that is used only for health care. Individuals and employers will be able to purchase supplemental coverage for any services not included in the comprehensive plan

4. A COORDINATED WELLNESS SYSTEM

As in scenario #3, all [State residents] will get their insurance through a statewide agency. But in this choice, [State residents] will get all of their health care in a more coordinated way that emphasizes wellness and prevention. Instead of seeing a doctor only when sick, everyone will either choose or be assigned a "medical home" — a primary health care provider who is part of a larger network of providers and specialists. The primary provider (either a doctor or a nurse-practitioner) will provide basic medical care, preventive care and health counseling, decide when a specialist's care is needed and arrange that care. All [State residents] will also have a medical ID card that carries their medical history so that both primary care providers and specialists will have instant access to a patient's medical history. This will allow them to make better decisions about care and avoid duplication and mistakes.

approaches (or scenarios) for health care reform in their state. These scenarios were based on leaders' conclusions in the Strategic Dialogues (see above), translated into the language of citizens and designed to highlight the key values and trade-offs. These scenarios provided a *starting point only* – participants were free to adapt and combine them as they saw fit. As they worked through the scenarios, participants were asked to consider health care reform in light of three key questions: 1) how people should get their insurance, 2) how to make people healthier, and 3) who pays and how.

In all nine Choice-Dialogues, across three states and a wide range of specific local circumstances, participants followed very similar steps and reached a strikingly consistent set of conclusions. The following findings represent common ground across all nine dialogues.²



WHERE THEY STARTED

The health care system is in trouble

- High – and rising – costs for coverage, care, and prescription drugs. Employers can't afford to offer coverage; employees can't afford their share of premiums
- Growing number of uninsured and underinsured people
- People risk losing coverage if they lose/change jobs or get sick
- Not enough doctors, not enough nurses - especially in poor and rural areas
- Insurance and drug companies rake in profits; insurers turn away people in need
- The system is costing more and delivering less

93% agree: the U.S. health care system is in a state of crisis/has major problems.

². A more extensive writeup of the Choice-Dialogue findings appears in Appendix B.

**SOMETHING HAS TO
CHANGE!**

We are all affected by the health care crisis

It's affecting everyone in this room, insured and uninsured alike. The uninsured aren't who we thought they were: most people without insurance are working.

We are already paying – a LOT – to care for people who don't have insurance

We need to cover everyone!

89% agree: it is 'absolutely essential' or 'very important' to cover everyone in the state

98% agree that people must not be denied coverage because of a pre-existing condition or dropped from coverage when they get sick.

**HOW CAN WE COVER
EVERYONE?**

The employer-based system?

Pros

- It works for a lot of us - we don't want to change it and end up with something worse
- Offers choice and competition

BUT

- Doesn't cover everyone (e.g. part time workers, the self-employed)
- Fewer employers can afford to offer coverage; fewer employees can afford to pay their part.
- Companies would be more competitive if they didn't have to fund health care cost

CAN THE STATE DO BETTER?

We have some big concerns about a state-run system!

- *Restrictions on choice*
- *People who don't work, illegal immigrants, 'freeloaders'*
- *Cost*
- *Big government running health care*

A STATE-RUN SYSTEM? THINKING THROUGH THE CONCERNs

What about restrictions on choice of providers, treatments or plans?

Unlimited choice for everyone would be impractical and costly.

What kind of limits on treatments and providers can we accept?

→ *Choice of providers?*

People MUST be able to choose their own primary care provider

→ *Evidence-based medicine?*

- Want to focus on treatments that work - doctors and scientists should decide what's covered, not insurance companies

Evidence-based medicine OK only if patients and their doctors can appeal decisions and get second opinions

→ *Allow buy-up with a two-tier system?*

State provides basic coverage; employers offer supplemental (or people buy it themselves)

- Rewards hard work
- Preserves choice
- Protects people with good benefits from ending up with something worse
- Encourages employers to stay in the game and compete for employees
- How do we define "basic"?
 - No one should go without treatment because they can't pay
 - BUT we can't provide everything for everyone – people have to take some responsibility

More research needed to clarify how people balance these two values

What about people who don't work or illegal immigrants?

No 'freeloaders' - people need an incentive to work

But does it really make sense to leave people out?

- Most uninsured people do work
- Uninsured people cost the system more because they put off needed treatment
- People with communicable diseases must be treated or everyone suffers
- If everyone living in the state pays in, then all (citizens or not) should get the benefit

It's more important to cover everyone and keep costs down than to penalize the 'undeserving'

cont'd

**A STATE-RUN SYSTEM?
THINKING THROUGH THE
CONCERNS (cont'd)**

What about cost?

- We're already paying for the uninsured as it is
- A state system may cost less overall because of its greater bargaining power, and because less money is spent on marketing, overhead and profit

What about big government running health care?

Can the state do better than what we have now?

- Government is the only entity that can realistically cover everyone regardless of circumstance
- Health care dollars go to treatment, not profit

A state-run system may be inefficient, but it's better than what we have now - as long as there is strong oversight and watchdogs to protect against inefficiency and waste

80% support switching to a publicly run health insurance program paid for by taxes; only 18% support staying with the current employer-based system.

Includes strong majorities of conservatives as well as liberals, plus all age and income groups

**COVERING EVERYONE
ISN'T ENOUGH - WE NEED
A SYSTEM THAT MAKES
PEOPLE HEALTHIER**

Steps to improve wellness

- Improve preventive care
- Comprehensive care for children
- Encourage healthy behavior
 - Start with health education
 - Address systemic barriers to healthy behavior (high cost of fresh produce, lack of safe places to walk or bicycle)
 - Should we penalize unhealthy behaviors?
- Get employers involved: e.g. require employers to give time off for medical checkups, give them incentives to offer wellness programs etc.

It's better to offer incentives for 'good' behavior than to punish people for 'bad.'

cont'd

**COVERING EVERYONE
ISN'T ENOUGH - WE NEED
A SYSTEM THAT MAKES
PEOPLE HEALTHIER (cont'd)**

Steps to improve how care is delivered

- Medical ID cards. Must include measures to protect privacy – but advantages (better quality and continuity of care, efficiency, prevent abuse of system) outweigh privacy concerns.
- Use other health care providers like nurse practitioners to handle routine care.
- Better coordination of care. Interest in the idea of a “medical home,” IF people can choose their primary provider and appeal decisions about care.
- State incentives to increase the number of providers

HOW DO WE PAY FOR IT?

**We're paying now for a system that doesn't meet our needs;
let's pay for one that does**

More money will likely be needed beyond what we are paying now - everyone must do their part to pay for a system that works

Employers

- Tax corporate profits
- May offer supplemental coverage to employees

Individuals

- Co-pays/deductibles scaled to income
- Taxes. The wealthy pay their share, but everyone pays something
 - Income taxes
 - Sales taxes
 - “Sin taxes” on tobacco, alcohol and gambling

Will accept tax increases ONLY if the money is earmarked for health care and the system provides a clear and transparent accounting of how dollars are being spent.



Step 3: Interactive Briefings

A few weeks after the conclusion of each set of Choice-Dialogues, Viewpoint Learning conducted **Interactive Briefings** for leaders in that state. Many of the leaders at the Interactive Briefing had participated in the Strategic Dialogues; others were new to the project, including many from sectors other than health care. These larger more diverse sessions began with an overview of the Choice-Dialogue findings and what they revealed about public priorities for health care reform.

Leaders were encouraged by the amount of common ground identified by Choice-Dialogue participants, their thoughtfulness and their willingness to confront difficult choices. In particular they were surprised at citizens' openness to a public system, their strong support for preventive care, their support for electronic record keeping, and their broad-based willingness to pay for a system that provides everyone with access to care.

Leaders recognized that serious obstacles remain – including lack of resources and significant legislative and political barriers to change. Still, the fact that such diverse groups had reached strong conclusions led even the skeptics to conclude that they had more leeway than they had previously thought to engage their constituencies, colleagues and organizations in a tough-minded conversation about potential reform. The broad range of leaders present at the Interactive Briefings underscored this point for many: engaging with leaders from other sectors who unexpectedly shared urgency and commitment to the issue added to many participants' sense of momentum and possibility at the end of the session.

The Interactive Briefings also helped broaden interest in the Community Conversations that were soon to get underway (see next section). Leaders were given an overview of the Community

COMMUNITY CONVERSATIONS: ONE STATE'S EXPERIENCE

Kansas Health Care Coalition report on Community Conversation outcomes

- KHCC staff was able to easily recruit 23 facilitators from around the state; the ease with which KHCC staff located these individuals is a direct result of KHCC's existing, strong relationships with organizations and individuals working on a variety of health-related issues.
- The Community Conversations provided an invaluable conduit for KHCC staff to engage health consumers throughout the state in unprecedented discussions about important health reform issues.
- Allowed KHCC to increase its knowledge of existing organizations and networks dedicated to similar health reform issues.
- Increased public awareness about KHCC's mission and work.
- Helped KHCC further establish solid working relationships with diverse organizations throughout the state.
- The Community Conversations resulted in an increase in KHCC membership.
- These new KHCC members have since expressed a vivid interest in other KHCC activities and have become involved with KHCC, including writing letters to the editor on important health issues to their local newspapers and providing input related to KHCC's advocacy priorities.
- Since the Community Conversations began, KHCC has been contacted by numerous organizations and individuals throughout Kansas requesting presentations from KHCC related to health policy and the 2008 legislative session.
- KHCC staff now feels confident that they have connected with a strong and dedicated network of Kansans personally invested in health reform issues and eager to become involved in addressing policy issues as the 2009 Legislative Session approaches.
- KHCC's grassroots outreach has been strengthened

Conversation effort and were invited to convene conversations through their organizations. In addition, several signed up to be trained to lead these conversations themselves.

Step 4: Community Conversations

Shortly after the Interactive Briefing, local project partners, working with Viewpoint Learning, launched a series of Community Conversations on health care in their state. These conversations are currently ongoing in all three states. Using Viewpoint Learning's "**Meeting-in-a-Box**" kit (including background materials, worksheets, leader's guide, and a feedback

mechanism), Community Conversations allow leaders, their representatives and a range of local organizations at all levels to conduct a highly structured 2-3 hour dialogue session in which people engage with key issues and begin to work through the choices themselves. Participants' conclusions are collected and the results reported to leaders.

These mini dialogues replace top-down models of "informing and educating the public" with two-way dialogue in which citizens become partners in solving problems. They can also help advocacy groups engage the public and other stakeholders in a dialogue-based

conversation – one that is more likely to lead to real learning and to common ground.

The Voices for Health Care Community Conversation kit draws on the materials and conclusions of the Choice-Dialogues. The materials are simplified and streamlined to fit the shorter time frame, and also to distill the key insights and the points that resonated most powerfully in that state's Choice-Dialogues.

All these materials have been tested and then further refined based on feedback from test dialogue participants and from local partners in each state. The resulting materials are targeted as directly as possible to the specific needs and conditions of each state. In each state, conversation participants are asked to consider two key questions:

1. How can we improve health outcomes?
2. Given our answer to the first question, how can we control costs?

Viewpoint Learning conducted a training session in each state for people interested in leading or convening Community Conversations. Participants were recruited by local partners and included leaders from the Strategic Dialogues and Interactive Briefings, along with other health care advocates, academics, community leaders, health care providers and faith leaders. Participants were taken through the Community Conversation process and worked through how to use the kit and lead dialogues themselves. To date, we have trained more than 60 people as Community Conversation leaders, and additional training sessions are being planned.

Thus far, hundreds of people have participated in Community Conversations, which are ongoing in all three states.

Our local partners report other tangible benefits, including wider awareness of their organizations and increased visibility and credibility as a state leader on health

reform. In addition, they report that the Community Conversations have allowed them to connect with affinity groups (service organizations, faith-based groups, unions, etc.) that do not have health care as a primary focus. This allows our partners to tap into and develop a growing network of energized citizens who are interested and engaged in the question of health care reform.

Step 5: Online Dialogue

In November 2008, Voices for Health Care launched a national “online dialogue.” Online Dialogue enables hundreds (and potentially thousands) of people to participate in an electronic dialogue with others who hold very different worldviews. More than the usual online forum or chat room, Online Dialogue is a process that finds common ground and reveals new ways forward.

The Voices for Health Care Online Dialogue is currently underway. It is open to all Americans. Special effort has been made to recruit participants in the target states, through each state's advocacy partners and building on the lists of participants in all the previous elements of this project. In addition, participants were invited to attend using advertising and outreach through websites, affinity groups, health care blogs and social networking sites like Facebook.

The Online Dialogue has two phases:

1. **“Choice-Book”:** The first phase of the dialogue asks participants to complete an online “Choice-Book” that draws on material from our Choice-Dialogues. This process takes about 30 minutes to complete, can be done any time day or night, and can be completed in several sittings if time is an issue. The Choice-Book walks participants through a series of scenarios (based on the Choice-Dialogue scenarios), provides background information, and pros and cons of each scenario.

As they go, participants respond to each scenario and complete a brief questionnaire on their values and priorities; at the end of the Choice-Book phase, each participant receives a customized report outlining how his or her responses compare to the aggregate of participants.

2. **“Dialogue Groups”:** Participants who complete the Choice-Book also have the opportunity to participate in a weeklong “small group dialogue.” These online dialogue groups will be active in December. Participants will work in small groups to identify and discuss the issues that they believe need to be part of health care reform and search for common ground. Those who sign up will be “randomized” into groups so that each group includes a diverse range of members. Participants will be able to post and read comments in their group any time day or night; they will also be able to use daily summaries from a moderator to keep track of what is being discussed. While only registered group participants will be able to post in each online group the conversation will be visible to those in other groups. The groups' conclusions will be compiled and made available to all participants and included in the project's final report.



Communications/press

Since the beginning of the project, our partner organizations and we have conducted considerable outreach through local communications and media activities. These activities have aimed to heighten public awareness of these efforts and create ‘buzz’ around the need for reform and the specific approaches identified by the public and leaders.

Thus far, we have had TV, print, radio and online coverage in numerous markets including Kansas (Wichita, Topeka, Garden City Kansas City), Ohio, Mississippi (Tupelo and Jackson), South Carolina and California. In addition, our visibility on social networking sites has extended beyond the individuals who signed up to participate in the Voices for Health Care Online Dialogue; our presence on Facebook has driven web traffic to the Voices for Health Care website, and the Facebook application linking people to the Choice-Book has been downloaded thousands of times. This

Voices for Health Care has shown that when given the opportunity for civic engagement, Mississippians favor policies that actively address the state's poor health care outcomes. This is an innovative avenue for Mississippians to bridge the disconnect between public opinion and public policy by making their voices heard.

**Roy Mitchell, MHAP
Program Director**

suggests a wider community of individuals who – while not actively engaged at the moment – are aware of the project and have the potential for more active involvement at a later date.

Next Steps

The formal activities of Voices for Health Care will continue at least into the first quarter of 2009. Remaining work on the project will include:

- Completing the Online Dialogue
- Ongoing Community Conversations
- A **stakeholder dialogue** in Kansas, bringing together citizen participants from the Choice-Dialogues with civic and elected leaders. Stakeholder Dialogue participants take the citizens' conclusions from the Choice-Dialogues as their starting point and work to build on them and further develop a set of practical steps and action plans to move toward a common ground vision defined by leaders and citizens.
- Additional Community Conversation trainings and additional briefings in Mississippi and Ohio
- Further communications efforts
- A final report on the entire project.

Voices for Health Care has demonstrated that it is possible to engage leaders and the public in a more thoughtful two-way conversation about significant health care reform. And it has demonstrated that the public is open to real change in their health care system once they have worked through the implications and consequences. However it will require a sustained effort on the part of leaders to continue to engage the public, move them along the learning curve, and foster broad-based consideration of the hard choices and tradeoffs necessary to bring about a better future for health care.

Real health care reform cannot happen without effective consumer engagement involving diverse consumers. For many years, consumer advocates have sought ways to reach out beyond our ranks of committed activists and engage ordinary people in shaping health care reform. The Voices for Health Care project has given us a set of tools - including the "community conversations" – that involve participants in dialogue (not debate) on values and trade-offs and encourage people with diverse viewpoints and experiences to find common ground - and enable us to share diverse consumer views with decision-makers.

Cathy Levine, Executive Director, UHCAN Ohio

CHOICE-DIALOGUE: THE METHODOLOGY

Choice-Dialogue methodology differs from polls and focus groups in its purpose, advance preparation, and depth of inquiry.

PURPOSE

Choice-Dialogues 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, Choice-Dialogues are designed to predict the future direction of people's views on important issues where they have not completely 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. Choice-Dialogues 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, Choice-Dialogues 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

Choice-Dialogues 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 Choice-Dialogues 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, Choice-Dialogues are characterized by a huge amount of learning. Choice-Dialogues 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 Choice-Dialogue 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.

CHOICE-DIALOGUES - DETAILED FINDINGS

Choice-Dialogues™ were developed by Viewpoint Learning to engage representative samples of the public in working through their views on complex, gridlock issues. Dialogue participants come to understand the pros and cons of various choices, struggle with the necessary trade-offs of each, and come to a considered judgment – all in the course of a single eight-hour day. When conducted with a representative sample, Choice-Dialogues provide both a basis for anticipating how the broader public will resolve issues once they have the opportunity to come to grips with them, and insight on how best to lead such a learning process on a larger scale. As a research tool, Choice-Dialogue represents an important means of hearing the thoughtful voice of the unorganized public, uncovering the public's underlying values and assumptions and developing a deeper understanding of the solutions they would be willing to support and the conditions for that support.

In March and April 2008 Viewpoint Learning conducted nine Choice-Dialogues on health care reform in Kansas, Mississippi and Ohio. These dialogues were designed to explore public views on health care reform and the tradeoffs the public is (and is not) willing to make to achieve a better system. Three sessions were conducted in each state, each with a randomly selected representative sample of 30-40 residents of the area. The total sample of nearly 300 people was extremely diverse, including participants from a wide range of backgrounds, incomes, education levels and political orientations.

As a starting point for discussion, participants used a special workbook, constructed around four distinct approaches (or scenarios) for health care reform in their state. These scenarios were based on leaders' conclusions in the Strategic Dialogues, translated into a citizen framework designed to highlight the key values. [Scenario text can be found on page 10 of the main report]. These scenarios provided a starting point only – participants were free to adapt and combine them as they saw fit. As they worked through the issues, participants were asked to consider health care reform in light of three key questions: 1) how people should get their insurance, 2) how to make people healthier, and 3) who pays and how.

In all nine Choice-Dialogues, across three states and a wide range of specific local circumstances, participants followed very similar steps and reached a strikingly consistent set of conclusions. Except where otherwise noted, the following findings represent common ground across all nine dialogues.

Where they started: Participants entered the room deeply troubled about the state of health care system – and many were acutely and personally affected by it. Top concerns included:

- High – and rising – costs for coverage, care, and prescription drugs. 63% of participants said they were "very concerned" about health care costs they were facing now or in the future.
- Number of uninsured and underinsured – this was felt especially acutely in places where many people were without insurance and could speak about the effect on themselves and their families.
- Growing insecurity. Even those who had insurance did not feel secure. Many participants worried that they would lose their coverage if they lost or changed jobs, or if they became seriously ill.
- Anger at excess profits being reaped by insurance companies, drug companies and hospitals, and at insurers' willingness to turn away people in need.
- A shortage of doctors. This was felt especially intensely in poorer and more rural areas. Some people simply couldn't find a provider when they got sick, and so had to do without.

Many people felt frustrated and powerless in the face of a system that is costing more and delivering less. 93% said the US health care system is either in a state of crisis or has major problems. And they strongly agreed that something has to change.

Over the course of the day, each group worked through a consistent series of steps as they worked to come up with a system that would solve these problems and result in better care for everyone in their state.

We need to cover everybody. At the outset, many participants focused on their individual struggles with finding and affording quality care. But as they began to work through the issues, everyone – insured and uninsured alike – began to see their individual problems are part of a much larger picture. People described outrageous bills they had received from doctors or hospitals; uninsured people described their struggles to get and pay for much-needed care; business owners described rising premiums preventing them from hiring to forcing them or stop offering coverage altogether; doctors and nurses described the struggles of trying to provide uncompensated care. These stories did a great deal to bring home that the insurance crisis is not an isolated problem or one that only affects deadbeats or the destitute: most people without insurance work, pay taxes and play by the rules. And as they learned more from each other about how the health care system works, participants realized that they all were already paying dearly to care for the uninsured. Fixing that was a matter of justice as well as economics. At the end of the day, 89% agreed that covering everyone in the state was ‘absolutely essential’ or ‘very important.’

- In particular, participants agreed that it was not right for people to be denied coverage or care because of a pre-existing condition, or to be dropped from coverage when they get sick. Any new health care system must provide coverage that cannot be taken away. 98% said this was ‘absolutely essential’ or ‘very important.’

The employer-based system may not be the way. How to cover everyone? Many participants who had good employer-provided coverage were wary of changing it, and many others valued the choice and competition offered by a private employer-based system.

Even so, few believed that the current employer-based system is up to the job of providing coverage for everyone in the state. Too many people fall through the cracks (part time workers, the self-employed), and rising costs mean that fewer employers are able to offer it and that fewer employees are able to pay their part. Participants worried about the effect on businesses large and small – 57% felt that companies in their state would be more competitive if they didn’t have to fund health care costs.

Can the state do better? Participants then considered whether the state could do better at addressing some of the problems facing the current system. They agreed quickly that the state was better equipped to do some things. In particular they supported:

- *Stricter regulation of insurers.* Participants in all states supported a stronger state role in regulating insurers – capping profits and requiring insurers to cover all applicants even if they get sick or have a pre-existing condition. They rejected the counter-argument that insurers would leave the state if such regulations were imposed. 86% of participants supported capping insurer profits, and more than half (59%) supported it strongly.
- *State incentives to increase the number of providers* – including hiring incentives as well as scholarships to attract more students into the pipeline. This was especially important to participants in rural and medically underserved areas, where many participants felt the provider shortage very acutely.

Working through concerns about a state-run health care system. Going beyond this, many participants began to see some advantages to a state-run health care system – it could cover everyone regardless of circumstance, and it would not be driven by profit. It would ensure that coverage was non-revocable and completely portable, and it would have greater bargaining power with drug companies, doctors and hospitals.

But many participants had to work through major concerns. These were especially acute for participants with good coverage, many of whom were reluctant to change the system if it meant they could wind up with something worse.

What about restrictions on choice? This was a serious obstacle for many, especially in Ohio and Kansas. People did not want to hand over all decisions about their care to a state bureaucracy, especially one that did not allow them to choose their own doctor. Participants in these states concluded that any public system would have to allow people to choose their own provider and allow for second opinions. (Mississippi participants were less concerned about provider choice: so much of the state was medically underserved that Mississippians’ top priority was simply to make sure people could get to a doctor at all.)

What should be covered and who will decide? This raised the question of what treatments should be covered – and participants quickly realized that unlimited choice would be impractical and costly. Most felt that some kind of limits would have to be set.

- *Evidence based medicine.* Most agreed that decisions about what will be covered should be made by doctors and scientists based on what is likely to lead to good health outcomes, rather than by insurance companies focusing on the bottom line. 57% supported covering only treatments that have been proven effective.

But as they considered what this would mean for them personally, a serious trust issue surfaced – if care had to be limited, they wanted to make sure someone they trust and who knows them imposed these limits. While most indicated they would accept their doctors' decision about appropriate treatment, they were not so willing to accept decisions made by a faceless medical review board. Three out of four (77%) felt that the doctor's judgment should prevail in decisions about treatment. To balance these two priorities, participants agreed that any evidence-based protocol must provide a means for patients and their doctors to appeal decisions and get second opinions.

- *Allow-buy-up with a two-tier system.* Participants in all states expressed interest in a two-tier health insurance system in which the state would provide basic coverage to everyone while employers could offer supplemental coverage to employees (or individuals could purchase it themselves). Proponents said that such a system would reward hard work, preserve choice and provide some assurance that those currently enjoying good benefits would not end up with something worse. In addition, it would encourage employers to stay in the game and compete for employees by offering supplemental benefits.

However, participants differed about what exactly "basic" coverage should include. Some wanted a fairly comprehensive package of benefits like those found in a current HMO or managed care plan; these participants emphasized that no one should have to go without treatment because they are unable to pay. Others, concerned about costs, preferred a stripped down version that includes preventive medicine and protection against catastrophic illness or injury. More research will be needed to see how people balance these competing values.

What about paying for people who don't work or for illegal immigrants? This was a concern for some, especially at first. Many objected to paying to cover "freeloaders" and wanted to make sure that people have a strong incentive to work. But as they discussed it further, they concluded that leaving people out of the system was penny-wise but pound foolish. Not only is the cost of treating the uninsured passed on to everyone else, having large numbers of uninsured people in the system increases costs in the long run, since people without coverage tend to delay treatment until minor ailments are serious and more costly to treat (something many participants confirmed from personal experience). In addition, several participants noted that they did not want uninsured people delaying treatment of communicable diseases that could harm public health. Most ultimately concluded that if the system was set up in such a way that everyone living in the state pays in, then they would support all state residents (citizens or not) getting the benefit.

Interestingly, half of participants (50%) agreed that a state-run system would be bureaucratic and inefficient – but they did not see this as sufficient cause to reject such a system. They had too many stories of the inefficiency (and sometimes cruelty) of the current system for this argument to gain much traction. At the end of the day, 80% of participants supported switching to a publicly run health insurance program paid for by taxes; only 18% supported staying with an employer-based system. This included majorities of conservatives as well as liberals, plus all age, education and income groups, and insurance status.

Making people healthier. Participants agreed that expanding access to health care was not enough by itself – they wanted a system that would make people healthier. They began by focusing on steps to improve wellness.

- *Improve preventive care.* Participants overwhelmingly supported improving access to preventive care like screenings, vaccinations, and disease management. 97% of participants supported putting more resources into preventive care, and 70% supported it strongly. This was the first and most important step to making people healthier.
- *Comprehensive care for children.* Participants emphasized that good care, especially preventive care, is especially important for children – it will pay off in improved health throughout the child's entire life. Participants agreed that all children must receive

comprehensive care, even if the state-provided baseline for adults is something less. This was consistently one of participants' top priorities: 76% rated it as "absolutely essential."

- *Better health education.* Participants wanted to make sure that both children and adults have the tools and knowledge they need to make healthier choices.
- *Encourage healthy behavior.* 90% of participants supported encouraging healthy behaviors like quitting smoking, exercising, and getting screenings (64% strongly support). They agreed that while education is a key first step it is not enough in itself. It is also crucial to address systemic obstacles that make it more difficult for people to engage in healthy behaviors (high cost of fresh produce, lack of safe places to walk or bicycle). Participants struggled, however, with how stringently people should be held accountable for their own health choices. Some people (for example smokers) said that since they chose to engage in an unhealthy activity they should be asked to pay a premium for that choice. However, many others were uncomfortable with this idea; they wondered who would sit in judgment and were concerned that people would too easily be scapegoated for things that were not truly under their control. As a rule, participants preferred offering incentives for 'good' behavior to penalizing people for 'bad.'
 - Mississippi participants took this one step further, suggesting sin taxes to discourage unhealthy behaviors like smoking, drinking and gambling. In particular, many said that Mississippi's tobacco tax should be raised. Not only would this bring in revenue, it would also lower the smoking rate.
- *Get employers into the game.* Participants suggested requiring employers to give employees time off for medical checkups, as well as incentives for employers to provide wellness programs or subsidize gym memberships for their workers.

Participants also agreed on several concrete steps to improve how care is delivered:

- *Medical ID cards.* Participants were intrigued by the idea of medical ID cards that give providers access to a patient's medical history. Participants in Mississippi were especially supportive, given the number of people (including participants) whose medical records had been lost in the aftermath of Hurricane Katrina. Participants in all states felt that the cards would improve quality and continuity of care, would help make the system simpler and more efficient and would prevent people from abusing the system. They agreed that privacy must be protected, but even those most concerned about privacy concluded that the benefits of medical ID cards outweighed their drawbacks. As one participant in Kansas noted, if insurers have to cover everyone regardless of health status, one key drawback of having one's medical history more accessible simply vanishes. At the end of the day, an overwhelming 97% of participants supported using medical IDs and similar technology to improve record-keeping and coordinate care, with two thirds (66%) strongly supporting.
- *Use other health care providers like nurse practitioners to handle routine care.* 83% of participants felt that these professionals could handle most minor complaints as well as an M.D. Some supported this idea out of desire to reduce costs, others (especially in rural areas) supported it as a way of increasing access in places with few providers.
- *Better coordination of care.* Participants, especially in Kansas and Ohio, supported the idea of a "medical home" provided that people would be able to choose their primary provider and appeal decisions about care. Many felt that today's system focused more on treating disease than treating the person: a more cooperative, patient-centered approach among medical professionals would improve patient care. Mississippi participants supported this idea as well, though as already noted, the need for care was so great in many parts of the state that reorganizing a non-existent system was not an especially high priority.

Everyone pays. Participants then turned to the question of who should pay for a better health care system, and how. They recognized that they ultimately pay no matter what – through taxes, wages, the cost of goods and services, insurance premiums, the cost of care and so forth – and that they were already paying for a system that did not meet their needs.

While some believed that a public system would cost less overall because of the bargaining power of the state, getting profit out of the system and a healthier population, others doubted that they personally would end up paying less. Most agreed that some additional

revenue would probably be needed – and that everyone in the state has a stake in a better health care system and should make a contribution to paying for it.

- *Employers.* Participants supported a tax on corporate profits; they also hoped employers would offer supplemental coverage to employees.
- *Co-pays/deductibles scaled to income.* Participants agreed that individuals have to bear some of the cost of their own care, for example through co-pays or deductibles. However, it was important that these payments be scaled to income: most participants (63%) felt that high out-of-pocket costs discourage people from getting needed care, and they wanted to make sure that care is not out of the reach of the poor.
- *Taxes.* Most participants supported some combination of income taxes and sales taxes so that the wealthy pay their fair share, but the poor pay something. As noted above, they also wanted employers to play a role in paying for coverage through a tax on corporate profits. Participants also suggested a role for “sin taxes” on tobacco, alcohol and gambling. However, they would only pay more taxes if the money was earmarked for health care and the system provides a clear and transparent accounting of how dollars are being spent. By the end of the day, 79% of participants said they would be willing to pay higher taxes so that everyone can have health insurance.

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