Citizens' Health Care Working Group
Washington, DC
Public Meeting
Wednesday, October 5, 2005

Attendees

Members

Randy Johnson, Chair
Catherine McLaughlin, Vice Chair
Frank Baumeister, MD
Dorothy Bazos
Montye Conlan
Richard Frank
Joe Hansen
Therese Hughes
Brent James, MD
Patricia Maryland
Rosario Perez
Aaron Shirley, MD
Deborah Stehr
Christine Wright

Staff

George Grob, Executive Director
Andy Rock
Caroline Taplin
Connie Smith
Jessica Federer
Margretta Kennedy
Carolyn Dell

Also Present:

Jack Molnar, consultant

The chairperson, Randy Johnson, opened the public meeting at 10:45 a.m.

Questions for the American People

The executive director, George Grob, led a discussion about the questions that would be used for the public. This discussion was framed by proposing several questions for the Working Group to consider:

- What is the primary purpose of the questions?

  - Get input from the American public on the 4 questions in our legislative charge;
  - Flow from the report and obtain input on key issues raised in the report;
  - Identify core concerns, problems as the basis for framing recommendations;
  - Ascertain fundamental values regarding health care and the health care system, e.g., role of business, government, individuals; access to basic and essential services;
  - Ascertain the American public's position on specific policy/recommendation areas; such as tax code changes, specific approaches to cover the uninsured, pay for performance, technology;
  - Special issues; e.g., end of life care, long term care, mental illness, drug treatment;
  - Other.

- Should the questions focus on personal or policy preferences; what does the American public want for themselves vs. what do they want for America?

- How specific should questions be; do we ask broad, global, or value questions about "what should be" or do we ask more specific, detailed, or logistical questions about "how to change/fix the system"?

- Can we have a basic questionnaire and subsets of key questions for different venues; e.g., community meetings, on-line, telephone, National survey, mail?

- What process does the Working Group wish to pursue to develop questions? Work as a committee of the whole? What will be the role of consultants and staff?

The proposed schedule showed having the questions for the community meetings finalized by December 1, including pre-testing. Schedules for other venues; e.g., closed-ended questions for telephone, specific questions for focus groups, to be determined.

Discussion

Rosie Perez – If we focused on a couple issues, the rest would shake out. I think initially, we're going to get the personal stories and maybe later we'll be able to probe on more focused areas.

Catherine McLaughlin – Regarding the option of major policy choices (tax code changes, etc.): until the American public is better educated and knows what the unintended consequences would be, it might be unproductive and not where we should seek feedback. We're required to get feedback from the public on the recommendations; we should focus on the higher level questions when we get closer to that stage.

Dottie Bazos – I'd prefer to start with the contextual framework first. We need to consider the Oregon documents and consider the types of questions and trade offs that they present. We need to consider whether to use questions that have already been tested for validity and reliability in the field. That can be expensive; if we are using new questions, we'll have to test them.

George Grob – We'll eventually need to reach some closed-ended questions, although not necessarily for the first couple of months. By sampling and analyzing responses to the open ended questions, we'll be able to determine what we need for closed ended questions. We also have a number of logistical questions that have to be addressed.

Joe Hansen – What do you do with responses that are personal or interest group perspectives that are skewed?

George Grob – Eventually, we'll do a randomized poll as a comparison; and the community meetings enable us to do outreach on certain issues.

(There was a general discussion regarding several suggested or possible demographic questions that ought to be asked in the different sets of core questions that would be asked. Race/ethnicity was added; it was agreed that asking for education made it unnecessary to also request income and might be considered less personal. A question on chronic illness or disability was discussed and not agreed to; as results from self-declared disabilities could vary widely and be ambiguous. It was also decided to make the demographic questions optional rather than "no bypass" because people might not answer the questions at all. It was also agreed to include age, but in ranges, rather than by asking for birth date. Whether or not an individual had insurance was also agreed to.)

Richard Frank – We're not going to learn anything about who the American public looks like from this process; this will simply aid us in interpretation and diagnosis. I suggest we have only enough of demographic questions so we can see and say whether we have a good mix of types of people so we can say something about that.

Questions for Community Meetings

Richard Frank – First: what are the questions we can ask that will give us information we can't get anywhere else? We need to start by putting on the table all the surveys and random samples that are being done. We don't need to duplicate those. Second, what are the questions that people are well placed to answer? At least for the first round, ask people about things that they know about; e.g., ask people about their experiences with doctors; what things have broken down for you; what has worked well.

Catherine McLaughlin – I agree; let's not reinvent the wheel. But a lot of the surveys are not "informed" surveys. We may want to ask some of these questions after we inform the public. Are we going to ask the public about moving forward or only about the past? We may need the past to get to the future that they want. And do you ask those questions of the same people or different groups?

Richard Frank – Both; we'd do it with the same people or in a staged fashion.

Therese Hughes – Personal stories are important to understand the concerns, values, issues and what's important to them.

Catherine McLaughlin – Should we hold some community meetings first not with the key pad meetings but just open forums?

George Grob – There are some very easy open ended community meetings we can hold if we can get the rooms; using staff time and members and having an open mike format that focuses on certain topics either at the participants' tables first or to the entire group. How we structure the 12 meetings is a different matter; those need to have clear up or down votes and opinions. Therese's perspective leads to open ended questions.

Joe Hansen – You can't look forward without looking back. You have to ask people what they expect. We wouldn't be here if there was not a fear, not only among this group, but in the country, of what's happening to health care.

Richard Frank – We can probably come up with categories. Round one can be priorities; round two can emphasize trade offs. Forcing everyone to do the same thing in all 12 sites seems like undo emphasis on forcing uniformity.

George Grob –The legitimacy of the 12 is in handling them all in roughly the same manner. They can all begin in having an information section and an opinion gathering component. So we couldn't tailor the questions different at each meeting.

Richard Frank – Try and get representatives from the area, gather their opinions. By forcing uniformity, you don't give people the voice they need.

Montye Conlan – It seems there is a way of juggling the qualitative and quantitative elements.

Catherine McLaughlin – The demonstration in Maine by America Speaks resulted in the participants rebelling against the questions/options that were being posed.

Aaron Shirley – How should we use that experience?

Catherine McLaughlin – The sponsors of the Maine public opinion day, the governor's office, were disappointed because, by the end of the day, the participants expressed a clear preference for universal health insurance and the Governor's office didn't want to hear that. So you need to be careful what questions you pose.

George Grob – I'm hearing that everyone wants to talk about values rather than policy options, at least for a while. But for coming up with questions; different approaches being proposed are having broad open questions versus focusing on values. We've heard from everyone and I believe what we've heard is that we begin with open ended questions for the signature meetings.

Joe Hansen – As Aaron Shirley said, "if we're really going to listen then we need to listen whether we like it or not." If we predetermine the results then we may get into trouble.

Jack Molnar – We need to listen people's concerns, give them a chance to tell us what they think should be done, and then, and using the technology allowing the participants to vote on what

we've identified as the things we've heard from them. The 2 Signature Meetings through America*Speaks*, and 10 Standardized Meetings through the Public Forum Institute, are intended to be designed to obtain random groups of participants.

Richard Frank – We need agreement among the Working Group about what process we'll have to address issues related to how we will conduct the community meetings.

Frank Baumeister – Has America*Speaks* and the Public Forum Institute dealt with health issues? The American Health Decisions has done nothing but health, since 1982. They've developed an approach and done this over many years. Dr. Michael Garland is an experienced specialist. I'd think that they would be a great resource in this effort.

George Grob – The Public Forum Institute (PFI), helped out in Oregon.

Aaron Shirley – The group that did the community meetings in Oregon were very clear and understood how to conduct these sessions.

Montye Conlan – Is there some way to have some space between having the qualitative sessions and then being able to develop the more targeted questions since different topics might come up at different sites?

George Grob – We have the opportunity now to have the more classic open mike sessions. These are relatively cheap to do. Let's keep our other inquiries open-ended for now while we start with these meetings. We need to sit back and listen for a while before we close up the questions. We can't keep them open forever. I will set up a combined meeting with America Speaks and PFI and Michael Garland from Oregon, and as many members as can meet, within two weeks, if possible, in order to come to closure with the contractors over what they need to do to prepare the Discussion Guide to be used at the community meetings.

Richard Frank – Regarding the 12, even though the process could be the same, the substance could be different at these meetings so that they could reflect the local area. As soon as you've decided not to go everywhere, the groups you meet with won't be representative of the larger area or region.

Discussion Regarding Content of Questions

The Working Group engaged in a brainstorming session to identify topic areas they felt would need to be addressed during future deliberations. Topics suggested were:

- Health information technology (HIT)
- Electronic medical records
- Controlling the use of medical technology/innovations
- Coverage of preventive health services
- End of life care
- Health care as a right

- Categorical eligibility versus universal coverage
- Compliance with evidence-based practice guidelines
- Mental health coverage
- Dental health coverage
- Coverage of nontraditional medical care
- Entitlement to a basic health care package
- Insurance only for big ticket items
- Undocumented aliens
- The homeless
- Tax deductibility
- Tax increases to pay for coverage/services/infrastructure
- Requiring everyone to purchase insurance
- Addressing the system as a whole
- Health care literacy
- Consolidation of public programs
- Coverage of basic and essential services for all
- Portability of coverage
- Roll of employment-based insurance
- Overuse of health care services
- Uneven distribution of health care capacity
- De facto discrimination
- Nationwide equity for health care
- Direct to consumer advertising of health care services
- Culturally competent and linguistically appropriate services
- Complexity of information
- Communication, autonomy, and responsibility – expectations of individuals
- Rationing
- Individual insurance mandate
- Community or individual rates
- Hard to serve areas
- Tracking use of health care services
- Hospices
- Long term care
- Profiteering
- Insurance benefits gaps
- Safety net
- Inefficiencies in switching plans
- Non-medical services for the disabled

(This list was further discussed and revised by the Working Group at its meeting in Baltimore, November 15, 2005 and is reflected in the Minutes from that meeting.)

Staff summarized media interest and the audience expected for the press conference scheduled for Thursday, October 6, 2005. The event would be webcast on the Kaiser site.

The meeting closed at 4:00 p.m., with a brief discussion regarding what would be the next steps. These included planning how to advance informal community meetings.