CITIZENS' HEALTH CARE WORKING GROUP

HEALTH CARE THAT WORKS FOR ALL AMERICANS

Meeting Summary

April 11-12, 2005
Rockville, Maryland

Welcome

Randy Johnson, Chair of the Citizens' Health Care Working Group, welcomed all participants. All members of the Working Group were present for both meeting days; a list of the Working Group Members is attached. Dr. James participated in Tuesday's meeting using audio conferencing.

Members were sworn in as a working group. Mr. Johnson introduced Senator Orrin Hatch (R-Utah) and Senator Ron Wyden (D-Oregon).

Perspective From the Senate

Senator Hatch welcomed everyone in the group and indicated he was delighted to be invited to speak. He also thanked Senator Wyden for coming to him with the idea of forming this Working Group. Senator Hatch explained that rising costs may mean that over the next few years the country may not be able to offer good health care to its citizens. He touched on some of the current problems of the health care system, including the increasing costs of prescription drugs and health care insurance, mounting levels of Medicaid paperwork, and the issue of defensive medicine.

Senator Wyden commended Senator Hatch for his involvement in legislation over the past 20 years that has improved the country's health care—the children's health initiative, generic drug initiatives, and community health centers. He went on to compare the challenge facing the group's members to hikers in the Himalayas, trying to find a path through decades of frozen debates. Senator Wyden remarked that this effort was different. This citizen-centered inquiry and solution-seeking effort has never been done before. In the fall, the American people will for the first time get a report summarizing where health care dollars are spent. This will be the first step of the process. Then there will be community meetings and other forms of citizen input, leading to recommendations.. These avenues will lead to public involvement and political accountability. He hoped that the group would have a citizens' roadmap at the end of the process that will help Congress write a law to provide health care for all Americans and that the President will sign it.

Participant Discussion

Mr. Johnson asked Senator Wyden to elaborate on what he meant by describing where the health care dollar goes. The Senator replied that it would be helpful if the breakdown of each dollar could be split in various ways such as Medicare, Veterans Administration, Medicaid, children, insurance companies, etc. This will help identify places in the system where there is inefficiency and duplication.

Catherine McLaughlin, Ph.D., Vice Chair of the Citizens' Health Care Working Group, asked if the expectation is for the group to develop specific recommendations or a global set of recommendations. Senator Hatch responded that both need to be provided. It is important to have global recommendations, but practical solutions are needed as well. If the report contains only general concepts, it will make the job of Congress very difficult. Senator Wyden added that it is important to give people enough information so they can understand choices and tradeoffs. For example, if one wants a particular kind of service, is one willing to give up something else? In his view, the key is to give people information so they can make good choices. If one were to draw a line down the center of a sheet of paper and place what the group would ideally want people to have on the left hand side and the amount of the $1.8 trillion currently spent annually on health care on the right hand side, this would help people clarify their health care and spending choices and take an active role in this area.

Overview of Legislative Requirements

Mr. Johnson introduced the staff who have been working with the group: Larry Patton, liaison to the Working Group from the Agency for Healthcare Research and Quality (AHRQ); Ken Cohen; Andy Rock; and Caroline Taplin. He also introduced Michael O'Grady, who will represent Secretary Michael Leavitt on the Working Group.

Mr. Johnson reviewed the congressional charge for the Working Group, including the approach to upcoming hearings, items to include in *The Health Report to the American People*, topics for community meetings, development of the final recommendations to Congress and the President, and congressional hearings. He presented a timetable for accomplishing the tasks and a logistical roadmap that prioritized the tasks. He explained that the group's objective for this meeting was to identify a preliminary list of major issues facing the U.S. health care system from the Working Group's perspective. The group should also identify initiatives designed to deal with some of the major issues.

Major Working Group Issues

Members of the Working Group introduced themselves and commented on what they thought were the major health care issues faced by the American citizen today. Dr. McLaughlin consolidated some of the issues discussed by the group. She noted that many of the issues can be grouped in the following categories cited in the statute:

- Cost
- Access
- Quality

In addition, several overarching issues were discussed by the group. This preliminary set of issues identified by the members included the following:

Cost Issues

- Uncompensated care
  - Inequitable distribution
- Pharmaceutical costs
- Rising premiums and copayments
- Efficiency
- Information technology
- Direct-to-consumer drug advertising
- Educating consumers about where health dollars come from and where they go
- Pressure on State budgets

Access Issues

- Disparities/vulnerable populations
  - Urban/rural locations
  - Race and ethnic minorities
  - Insurance coverage (or lack thereof)
  - Poverty
  - Undocumented individuals
- Availability of providers
  - Physicians
  - Nurses
  - Mental health providers
  - Other health care providers (e.g., nurse practitioners)
- Payment issues (e.g., inadequate reimbursement in public programs)
- Medicaid categorical eligibility
  - Bureaucratic barriers
- Language and cultural barriers
- Insurance coverage
  - Fragmentation
  - Availability of risk-bearing organizations
- Underinsurance

Quality Issues

- Holistic health care
- Patient/provider relationship
- Information technology
- Information availability
- Medical errors
- Prevention
- Incentive structure

Overarching Issues

- Data needed for decisionmaking by policymakers, providers, and consumers
- Personal responsibility
  - Financial contribution

    - Taking charge of personal health care
- Link between economic cycle and Medicaid spending
- Lack of an integrated health care system

Dr. McLaughlin observed that all of the Working Group's eight mandated topics were included in one way or another in the above list.

Richard Frank thought the group could probably benefit from reading some background documentation. He suggested that a shared set of reports from the Medicare Payment Advisory Commission, the Kaiser Foundation fact sheets, and other documents that could address some of the group's questions be made available to the members. These materials could be provided ahead of time before each meeting. The Working Group agreed that this would be a good idea.

Current Initiatives That Address the Issues

Mr. Johnson led the group in a discussion of some of the current initiatives that address the issues that the group brought forward. He emphasized that it is not important to have all the answers at this point, but the group should begin to develop some thoughts on successful initiatives. After a short discussion, the group developed the following list of initiatives:

- Use of health promoters with minority populations
- Family support systems—respite care (funded through Medicaid)
- Heuga Center program for the management of multiple sclerosis
- Medicaid waivers to allow flexibility in implementing State programs
- Children's Hospital Informatics Program (CHIP)
- The work of Robert Master, M.D., using Medicaid as a way to help patients with HIV and end-stage renal disease decrease their hospital admissions
- Cash and counseling program (this is particularly effective in rural areas)
- The Mississippi Medicaid program, which implemented a disease management program 2 years ago that was built around community nurses being available to patients with diagnoses of diabetes, hypertension, or asthma
- Patient, nurse, and physician teleconferences where practitioners speak on a particular topic and then open up the forum for questions and answers (Q&As)
- The public-private partnership built around the Los Angeles County Medicaid Demonstration Waiver
- Healthy Community Access Programs
- Health Information Technology
- A push for the measurement, transparency, and disclosure of health outcomes using national standards and risk-adjusted data to identify superior providers and disease management strategies that work
- The Bridges to Excellence and Leapfrog initiatives
- Pay-for-performance initiatives
- The New York State model for report cards

Perspective From the AHRQ Director

Carolyn Clancy, M.D., Director of AHRQ reviewed AHRQ's mission, which is "to improve the quality, safety, efficiency, and effectiveness of health care for all Americans." AHRQ's research focus is different than that of other agencies. While the National Institutes of Health supports biomedical research and the Centers for Disease Control and Prevention supports research that is focused on the community, AHRQ's research focuses on effectiveness and what works. AHRQ's research is patient-centered rather than disease-specific. AHRQ's mission also includes the production and use of evidence-based information. Dr. Clancy gave an overview of the 2004 *National Healthcare Quality Report* and *National Healthcare Disparities Report* and Agency products and priorities. She thanked all members for their participation on the Working Group.

Hearings: Content and Structure

Mr. Johnson gave a general overview of the hearings, which would serve as a starting point to discuss what the group would like to accomplish through the hearings and what structure is needed to achieve the identified goals. He noted that the hearings would build consensus around key issues and also provide input for *The Health Report to the American People*. The hearings,, would involve a variety of stakeholders, including citizens, patients, providers, purchasers, and regulators. The hearings would also involve expert groups of policymakers, researchers, and consultants. He added that the locations for the hearings should include some geographical diversity as long as it is feasible.

Mr. Johnson remarked that one of the advantages of this group is that it will have an opportunity to hear directly from the American people. He noted that if the group begins discussing potential approaches too soon, it would be perceived as already having developed its own ideas and solutions to the issues. When the hearings are conducted, the group will hear about the issues and perhaps some of the initiatives developed to address these issues. Because of this, group members might have to decide how close they want get to potential solutions—not necessarily the group's solutions, but digested ideas from reading materials and experts. The general idea is to gather information through the hearings to create a report that would educate the American people in a transparent way and show the "hydraulics" of the health care system. This could help citizens understand the costs and tradeoffs in the system. Dr. McLaughlin added that the report will also list local and State initiatives as a means to provide some accounting on current efforts.

Participants agreed that it is important to provide a national perspective through the hearings, but there is also a need for presenting the local perspective as well. It is important to have the hearings in various settings. Aaron Shirley, M.D., suggested that Mississippi would be a suitable site to have a hearing. Having a hearing in that State could be strategic because the group would have the opportunity to see several initiatives that are addressing issues discussed by the group related to access, patient education, and reduction in costs. It would also help the group to hear from those "in the trenches"—practitioners and those delivering care directly to individuals.

Therese Hughes suggested that it would be helpful to have experts address the group and inform members on the inner workings of the health care system today. This would help bring all members up to speed.

The group agreed on a broad outline for the Washington, DC, meeting to be held May 11–13, 2005. The schedule would be as follows:

Day 1 Morning: Educational Forum for group members
Afternoon: Working Group meeting

Day 2 Hearings on the uninsured and one of the eight mandated topics to be selected by staff. The meetings will be interactive with ample opportunity for dialogue. One topic would be discussed in the morning and the other in the afternoon.

Day 3 Working Group meeting

On the first day, the group would receive a primer on the health care system. This would enable members to develop a good foundation on the system. The forum would include presentations as well as Q&A sessions. The primer will be followed by a Working Group meeting. The second day would focus on hearings, and the third day would allow the subcommittee to have further discussion on the previous days' topics and also discuss subsequent hearings. There was general agreement by the group that it would be helpful to avoid having long periods of expert testimony on any one topic. Rather, it would be helpful to intersperse Working Group meetings and hearings, or have hearings on different topics if they are to last all day.

Dr. McLaughlin pointed out that the details on speakers and logistics would be delegated to a subcommittee and the group's staff. The group agreed to this and also gave the subcommittee some flexibility in scheduling testimony Days 1-3 based on the availability of speakers..

Dr. Frank noted that, because the topic of the uninsured is so broad, addressing it initially could help the group cover a large number of topics that were mandated.

Mr. Patton suggested including a format for the hearing where there would be a 30-minute presentation followed by Q&As, something very similar to the Government Accountability Office (GAO) conference. This would be instructional and allow the basic questions as well as the more sophisticated ones to be answered. The group agreed and adopted his recommendation.

The Health Report to the American People

Dr. McLaughlin gave an overview of *The Health Report to the American People*. The report would include an analysis of cost/utilization and coverage/payment data as well a synthesis of the extant literature. The synthesis would include summaries of reports and feedback from experts in the field on specific initiatives and reports to provide a critical combined analysis of the evidence. The report would also include insight and information provided by the hearings

about innovations and initiatives that are taking place but are not in the public press or published literature.

Dissemination of the report would take place through multiple venues, including the group's Web site; stakeholder sites; national/local newspapers, television, and radio; and professional and trade journals. The idea would be to ensure that the report is disseminated as broadly as possible so many people could read it and give the Working Group feedback.

The information in the report would be presented at various levels of complexity. There would be a full report (with multiple tables and data) on the group's Web site as well as shorter summaries targeted for community meeting, print, and radio usage. These short summaries would list major points and provide summaries of the most illustrative data. The approach would help to reach as many individuals as possible.

The report will be the starting point for discussions. A revised report with recommendations would be developed using feedback obtained from the community meetings, Internet, and other venues. Dr. McLaughlin noted that a subcommittee will be created, and staff hired, to begin work on the report. The subcommittee will obtain feedback from the Working Group on data and information to be included. The report's outline will be based on the list of statutes that need to be covered. The plan is to have a working draft of the report by the end of August 2005 to be circulated to the Working Group and a revised version completed by October 2005.

Legal and Ethical Requirements and Logistics

Mr. Patton gave a presentation on the legal, administrative, and ethical issues governing the Working Group. He walked participants through the Federal Advisory Committee Act, also known as FACA or the "Government in the Sunshine Act." He pointed out the following legal requirements:

- There needs to be 15 days' advance public notice of a meeting, and the location must be accessible to disabled individuals.
- At a minimum, there needs to be written public input for every meeting. It is recommended that this be done electronically so all comments can be made available for public review.
- Any documents prepared for the Working Group need to be made available publicly and posted on the group's Web site. All documents need to be retained for the duration of the advisory committee. This includes e-mails to staff or all group members.
- E-mails to the group as a whole need to "cc" the staff so they can be saved as part of the public record.
- There needs to be a designated Federal official at every meeting to make sure the interests of the Government are maintained.
- The group is required to maintain detailed minutes of every group meeting. The Chair needs to certify the minutes within 90 days after each meeting. Alternatively, the group may decide to post a version of the transcript on its Web site.

- Closed meetings are not allowed except to protect trade secrets, or confidential commercial information, or to hold administrative working sessions. Subcommittees, however, do not need to meet publicly as long as their work is discussed during a public meeting of the Working Group.
- Group decisions cannot be made by private telephone calls or private e-mails. If decisions are to be made through telephone calls or e-mails, they need to be open to the public.

Mr. Patton discussed the ethics, conflict of interest, and financial disclosure obligations of the group. He indicated that the Senate's ethic rules apply to non-detailed staff, but there are fewer restrictions for group members. Group members can chose to adopt commonsense rules and ethics guidelines.

Mr. Patton noted that if a member has a rate of pay that is above 120 percent of the GS-15 level, he or she must provide a financial disclosure form. Also, individuals who work more than 60 days a year on committee business need to provide a financial disclosure form. Usually, this will include only the Chair, Vice Chair, and Executive Directors. He also reviewed the process for reimbursement, explaining that it takes approximately 10 days to be reimbursed after the signed forms are received.

After the presentation, the group agreed on the following:

- In lieu of minutes, the group will post a copy of the transcript online. Members will have a chance to review the summary and correct typographical errors before it is posted. A small summary of action points (two pages or so) will also be developed.
- The group will use a salary scale comparable to that of GAO or the Executive Branch for new staff hires, except for consultants.
- Committee members will be paid for 1 day for preparation/travel for each group meeting.
- Members will be paid on a prorated hourly basis for self-reported hours of subcommittee work. For some people, this may trigger the 60-day financial disclosure requirement.

Structure for Future Meetings

The group discussed issues about using technology to facilitate attendance at the meetings, scheduling of future meetings, forming subcommittees, and disclosure of proceedings after the meetings. The group agreed to the following next steps:

- Dotty Bazos, and Patricia Maryland will join Dr. McLaughlin and Mr. Johnson as members of the Hearings Subcommittee.

- Dr. McLaughlin will approach members to join the Reports Subcommittee.

- Mr. Johnson also mentioned that there is the potential of creating a General Communications Subcommittee. Dr. McLaughlin reported that she has been working with several members to develop a Web site that is easy to navigate and user-friendly.

She presented some preliminary templates for the Web site. She also encouraged all members to provide feedback on the Web site in the next few days. The site will be publicized to the general public during the summer.

- Dr. Bazos suggested—and the group agreed—that future committee meetings should be scheduled so that they are predictable (scheduled on a certain day of each month, for example).

- The group agreed that it would be best to have face-to-face meetings, but members may also attend meetings through other methods (telephone, two-way interactive video, etc.) if necessary. Dr. Frank noted that face-to-face meetings would be helpful in the beginning for members to get to know each other on a personal level.

- Brent James, M.D. commented that he had been contacted by external parties to talk about the committee's discussions. He asked if there were any limitations on talking to external parties. Mr. Johnson suggested that a good response to inquires would be "we are in the process of being established and there will be information on the Web site that you will be able to access. You will also be able to submit information through the Web site."

Mr. Johnson thanked everyone for their hard work and ideas and wished all safe and pleasant travel.

Citizens' Health Care Working Group

Chair

Randall L. Johnson	Naperville, Illinois

Vice Chair

Catherine G. McLaughlin	Ann Arbor, Michigan

Members

Frank J. Baumeister, Jr.	Portland, Oregon
Dorothy A. Bazos	Concord, New Hampshire
Montye S. Conlan	Ormond Beach, Florida
Richard G. Frank	Boston, Massachusetts
Joseph T. Hansen	Washington, D.C.
Therese A. Hughes	Newbury Park, California
Brent C. James	Salt Lake City, Utah
Patricia A. Maryland	Carmel, Indiana
Rosario Perez	Houston, Texas
Aaron Shirley	Jackson, Mississippi
Deborah R. Stehr	Lake View, Iowa
Christine L. Wright	Sioux Falls, South Dakota
Michael O. Leavitt	Secretary, U.S. Department of Health and Human Services
Michael J. O'Grady	Secretary Leavitt's Representative

HHS Personnel Present

Carolyn Clancy
Larry Patton
Kenneth Cohen
Andrew Rock
Caroline Taplin

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