

U.S. Cochrane Center Consumer Coalition
Report of the First Meeting
Wednesday, July 16, 2003 – Thursday, July 17, 2003
Cosmos Club, Washington, DC

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Overview and Goal of the Meeting

The US Cochrane Center (USCC) proposed a meeting to bring together representatives of consumer advocacy groups focused on issues relevant to health care in the United States—a “Consumer Coalition.” The criteria for seeking out and inviting groups were: first, a demonstrated interest in and connection to consumers of health care; and, second, an interest in the principles and practices of evidence-based health care and how these might relate to consumers. Within this framework, diverse representation of healthcare populations and advocacy groups was sought. The goal of bringing these groups together was to discuss ways in which the USCC and advocacy groups might collaborate effectively on projects designed to communicate concepts of evidence-based health care to consumers in the general population. Anticipated outcomes included the following:

- Conceptualization and articulation of specific initiatives for future action;
- Development of an implementation plan for these initiatives;
- Appointment of individuals to working groups with specific charges.

Wednesday, July 16

Participants arrived in the evening for the opening session, which took place during a working dinner. (See agenda attachment 1.) Kay Dickersin (KD) opened the meeting and welcomed all those attending, then outlined briefly the background and rationale for the proposed Consumer Coalition. Nancy Owens (NO) spoke next, and provided a brief introduction to The Cochrane Collaboration, *The Cochrane Library*, and the role of the USCC in the organization. Susan Kaplan (SK) then spoke about the goals of the meeting and of the Consumer Coalition as envisioned by the USCC.

Following dinner, Kayla Kirsch (KK) and Laurie Durnell (LD) introduced themselves as the facilitators and outlined their roles in the meeting. They pointed out informational posters placed around the room describing goals for the meeting, ground rules and “givens.” (See attachment 2.) Participants were then asked to introduce themselves and their organizations; to discuss their organizations’ goals and challenges; to describe a way in which they hoped to use evidence-based health care in future work; and to share a guiding principle or piece of wisdom that would be useful to the subsequent discussion. Introductions and discussion occupied the remainder of the evening.

Thursday, July 17

Welcome and Overview of the Day

LD welcomed meeting participants and walked through an overview of the day’s activities. Agenda items included mutual education (information sharing), finding synergies, developing projects, and next steps. LD reiterated the importance of *listening*, articulated by the group as desirable on Wednesday night, and she encouraged listening to presentations as the means of

identifying ideas and opportunities for coalition building. She also stressed the need for the Consumer Coalition to organize quickly, to learn by doing, and to establish relationships among Coalition members. LD outlined plans for the day in which breakout groups would develop ideas for joint projects and identify challenges, leading ultimately to project selection. She then described the process for building a Coalition infrastructure once projects are selected.

KK took the floor next, and talked about process issues, such as identifying opportunities and thinking expansively as a preliminary strategy. Subsequent steps would enable groups to focus on specific ideas and to solidify planning. She described the people involved in planning and attending the meeting: facilitators, design team, resource people, USCC staff, and participants. Next she outlined ground rules for the meeting: shared airtime for all participants; a welcoming attitude to all ideas, leaving behind personal agendas for "big hat" thinking; the importance of each participant speaking his/her own truth; and full participation in all aspects of the meeting.

The outline below provides a narrative of the meeting events, which may have deviated from the formal agenda.

1. Growing the Consumer Coalition: Common Ground

For the first session, the participants were asked to define common themes from Wednesday night's introductory meeting. These were listed as follows:

- Evidence leads to quality health care, but it is also important to be concerned with the quality of evidence.
- Evidence has been used as authority, as opposed to truth. What constitutes evidence is critical.
- We need to find and to evaluate ways of communicating evidence to consumers.
- Giving people the appropriate knowledge is essential but not sufficient to change behavior. Patient values determine how information is used. It is vital to understand what those values are, and how they affect information use.
- The Consumer Coalition needs a definition of evidence-based health care (EBHC) to lay the foundation for future discussion and planning. The broad spectrum of perspectives and expectations makes it difficult to envision coming together as a Coalition. It might be more effective for the group to divide and focus work in two broad areas: lack of evidence and misuse of evidence.
- There is a need to build skills in critical thinking and healthcare literacy in community members as groundwork for use of EBHC. For consumer education to have an impact, there

is a need to educate healthcare providers and policymakers, so that they are able to listen to consumers.

- Sustaining efforts and building on ideas to effect change are important for each of the target audiences.
- Developing appropriate messages for each of the target audiences, possibly specialized segments of the population, and not assuming consistent levels of literacy or understanding, is important to success.

KD defined EBHC as a combination of using the best available research evidence and incorporating patient values with clinician expertise and values to broaden decision-making. This produced several questions. First, what does “best available research” mean? KD described the HRT research before the Women’s Health Initiative as comprising good observational studies, but observed that research using this design is not the best approach to determining efficacy. She stressed the importance of using the right research design to generate evidence.

This led to another question: Should practice depend on the available evidence, regardless of its presumed reliability? In other words, do you use what’s out there, or do you wait until better evidence comes along? This question was reframed as, “Is some evidence better than no evidence?”

This led to discussion of identification of the appropriate research design. The group viewed this as a methodological issue, and that the general public may not be able to judge the quality of available information. Trudy Lieberman (TL) pointed out that even though the public may not be qualified to evaluate the quality of evidence, there are information intermediaries who can assume this role. This sparked further discussion about how consumers get information and misinformation; how much information they can absorb based on their critical thinking skills and training; and ways to reach underserved populations.

The consensus was that establishing partnerships among consumers, clinicians, and researchers is important. It is a formidable task, but it is important to move forward and to keep goals simple. If nothing more, we can give consumers the tools that they need to apply EBHC concepts in personal healthcare decisions

2. Stories from the Field: Frontrunner Presentations

This portion of the meeting focused on four presentations of ongoing work that could inform the direction of the Consumer Coalition’s efforts.

2.1 Christine Brunswick (CB): National Breast Cancer Coalition (NBCC)—Project LEAD

CB explained that Project LEAD was developed in recognition of the importance of training credible and informed consumers. The project’s goal is to ensure that individuals are able to

participate in healthcare decision making in a meaningful way. Project LEAD is a four-day, intensive training course in scientific concepts and critical thinking. To date, the course has produced 1000+ advocates, and now runs a journal club for graduates. Project LEAD is focused on ensuring that people have *agency* as well as information. The Project LEAD concept has also been expanded into other topic areas, including a Clinical Trials Program for graduates that is designed to increase their involvement in trial design and approval. Another related project is the Quality Care Initiative, which introduces concepts of EBHC and quality care in the community. The program is expanding geographically, and an international Project LEAD is in development. Overall, the aims of Project LEAD and related initiatives are to build the credibility of consumers and to empower them to participate fully in healthcare decision-making.

2.1.1 Questions and comments

A. What are the results of these programs?

Serving as an equal partner with scientists and clinicians in the decision-making process represents one major accomplishment. Project LEAD and similar programs have changed the paradigm of the relationship between providers and patients. For example, Cindy Pearson (CP) cited the Department of Defense Breast Cancer Research Program, in which consumers participate in research funding decisions and take the lead on policy-making committees.

CP emphasized that the strength of consumer involvement is that informed consumers ask *why* research is being done, or done in a particular way. This type of consumer involvement in the grant funding process has also improved the credibility of funding applicants. The National Cancer Institute (NCI) is now copying initiatives pioneered by NBCC. This indicates changes in thinking at an institutional level. Advocates help to make trial design more appropriate and appealing to consumers, which increases study participation.

B. Who teaches the courses? Who attends the courses? Who pays for them?

Courses are free, although participants pay (or get scholarships) for their travel and lodging. Courses are taught by scientists, based around a core faculty that works with NBCC to design and refine course structure.

C. What are the implications for the USCC Consumer Coalition?

- Established training courses like this one could be enhanced by addition of technological resources that could exponentially increase involvement.
- This is an example that it can be done!
- Questions were raised as to whether only certain types of people can be trained, or whether anyone can benefit. Is mass training or targeted training preferable? Participants are self-

selected, even within the NBCC membership. The intimate nature of the classroom setting is integral to Project LEAD's success, so "mass" training would have to be structured similarly. Perhaps the Consumer Coalition should consider two levels of training, with training of the trainers offered as well.

- The Robert Wood Johnson Foundation has invested in video conferencing technology. What about using something similar for journal clubs?
- There is a similar training course on health sciences research run by Academy Health, funded by the Agency for Healthcare Research and Quality (AHRQ).
- Questions were raised as to how to motivate the average consumer to attend training such as Project LEAD. The answer is that people who attend are self-motivated. It is two-way education (teacher and student) with a long-term commitment on both sides. Personal passion is what drives the program. To maintain this focus, the NBCC is developing a web-based continuum of education for graduates.
- Group discussion generated ideas for Coalition training: satellite training; train the trainers; video conferencing; mass training by geographic region; and training for policymakers.
- One participant suggested "Mini-Med" seminars for communities. Participants would invest a few hours and gain an improved understanding of quality in health care.
- Perhaps different types of programs should be developed, one for motivated people, one for the general public.

2.2 Roger Bernier (RB) and Sallie Bernard (SB): Consumer Involvement in Vaccine Safety Evaluation

SB described the rationale for Safe Minds: to involve a diverse group of stakeholders in issues related to vaccine safety and to inform decision makers about the variety of available perspectives. In SB's experience, "unfriendly" advocacy groups (i.e., those who are critical of available research) are likely to have fewer opportunities for involvement and to find the experience negative.

RB next described the project from his perspective as Centers for Disease Control and Prevention (CDC) staff. It is an effort funded by the CDC to engage stakeholders in a positive way which brings together representatives from vaccine manufacturers, public health administration, the CDC, the Food and Drug Administration (FDA), pro-vaccine and vaccine concern groups, and other constituencies. This coalition selected a steering committee, which has made recommendations on future actions and the advisability of establishing relationships with policymakers, such as the National Vaccine Advisory Committee (NVAC) and the Department of Health and Human Services (DHHS). The diversity of viewpoints involved in the group's formative stages caused a number of

political disagreements among participants. As a result, some groups—pro-vaccine groups and vaccine manufacturers— have chosen not to participate in the project.

Lessons that have been learned from this project include:

- Establishing meaningful consumer participation in decision making is difficult but achievable as long as participation is considered safe. Consumer representation is in vogue today, but it is not necessarily the “real thing.”
- It is possible to work productively with people whose views are different from, or even diametrically opposed to, one’s own. RB and SB represent opposite ends of the spectrum, but they have succeeded in working together.
- Having an advocate within the relevant government agency is critical to the success of a consumer organization.
- If a particular issue is controversial, coalition building becomes difficult.

RB talked about the similarities between the vaccine project and the USCC Consumer Coalition initiative. He reiterated the importance of creating partnerships among consumers, researchers, and practitioners. These are projects targeted to getting information to people, which can then lead to greater involvement in the decision-making process. He also commented that strategies are not right or wrong, but situational. Any successful project involves defining a goal and then developing a strategy to achieve that goal.

A participant remarked that CDC research is sometimes perceived by consumers as “dead on arrival.” RB responded that this perception is probably not because of the quality of the research, but because of relationship problems. To trust research, people need relationships with the researchers. For this reason, RB chose policy analysis as an area where the public could actively participate by bringing their values, perspectives, and expertise to the table.

Why is public participation in policy making so hard to attain? Concepts of the public vary according to political perspective, which affects degrees of power sharing along the political continuum. It is also difficult to get people to agree to participate when the overall goal is to change perspectives or behavior.

The USCC Consumer Coalition is also in the position of trying to improve relationships. Perhaps the best way to improve EBHC is to focus on the relationships among the players. The project cannot only focus on provision of resources and education; knowledge about resources and methods doesn’t guarantee use.

2.2.1 Questions and comments

- One participant questioned the CDC’s description of relationships and communication.

- Another participant restated the importance of relationships, particularly willingness to share power with those of opposing views.
- Another participant stated that lack of research is the issue in vaccinology, and yet public policy is taking precedence. Could or would the CDC acknowledge “wrongdoing” by not waiting for long-term studies before declaring vaccines safe? This would increase public trust. However, liability issues may prevent such acknowledgement.
- The USCC Consumer Coalition should target health issues appropriate for public contributions.
- Potential barriers to effective collaboration include: the perception of the public as ignorant and unable to participate meaningfully; the perception that liability is involved in admissions of error; and the perception that government agencies are resistant to consumer participation.
- The research community needs to define questions and priorities based upon a variety of perspectives, including those of consumers.
- Patient expertise and values are the bottom line. Empowerment is an important model to consider to ensure effective participation; programs need to provide resources and tools.
- Should the USCC consider a conference focusing on EBHC from the consumer perspective? Consumer participation can prove beneficial to the entire research establishment.

2.3 Hilda Bastian (HB): Consumer participation in The Cochrane Collaboration and Hot Topics

HB talked about The Cochrane Collaboration’s institutional focus on consumer participation: the reasons for it, the initiatives to achieve it, and the barriers encountered. Her points included:

- The risks and benefits of interaction among different communities.
- The principles put forth by Archie Cochrane and used to formulate Collaboration policy: *No survey without service and the importance of giving back to the community.*
- The aspirations of The Cochrane Collaboration are clear: Everything it does, it does with consumers. Everything it produces, it produces for consumers.
- The various roles of consumers in the Collaboration were described.
- The density of information and science in Cochrane Collaboration systematic reviews and the importance of finding ways to make *The Cochrane Library* usable by consumers.

HB provided a preview of the new Cochrane-affiliated website focused on consumers and evidence. The ensuing discussion touched on the following related issues:

- The importance of usable, accessible information and its key role in consumer involvement.
- The need to educate people about “good” as opposed to “bad” research.

- The availability of training in The Cochrane Collaboration specifically targeted to consumers.
- The need to gauge the community's interest in understanding and interpreting the volume of information available.
- The need for broad informational initiatives directed at consumers, with synopses of Cochrane systematic reviews as an example of such an initiative.
- The assumption that users of reviews have a minimum level of knowledge.
- The unanswered question of what consumers can get out of the available evidence.

Hilda suggested a few joint advocacy issues: scientific literacy; evidence-based content in the media; access to drug company research; trials registration.

2.3.1 Questions and comments

- How many hits have there been on the Cochrane-affiliated consumer website? Hilda estimated 1-2 hits per minute.
- Access to information is a barrier that the website attempts to rectify, but barriers to access (i.e., access to computers) remain.
- Monitoring the media's reporting of health information in the media is needed, particularly in countries with unrestricted access to *The Cochrane Library*.
- We should identify issues that are relevant mainly to people in the community, as opposed to issues that are important mainly to clinicians.
- Is follow up with professional societies undertaken to monitor changes in guidelines? No, primarily because resources are not available to do so.
- Research indicates that many users of the consumer website audience are clinicians. This was initially of concern to the website developers, but they now see the value of producing summaries for overburdened doctors.
- Trial registration was discussed, and reasons for not reporting research results were presented. The conclusion was that results from potentially useful but unreported trials will not be available until registration of all clinical trials is mandatory.

2.3.2 Implications and opportunities for USCC Consumer Coalition

- This website could serve as an information source for many constituencies.
- Links from Coalition member websites to this consumer website would be useful.
- There are a number of opportunities for getting people involved in testing the website and providing feedback.
- Cochrane material can be used as a basis for media coverage of health information.

2.4 Trudy Lieberman (TL): Rocky Mountain Course on Evidence-based Health Care

Academics, physicians, policymakers, and journalists attend the annual Rocky Mountain Workshop on EBHC. TL first commented briefly on the barriers journalists face in using and reporting on EBHC, including commercial pressures and editorial constraints. At the Rocky Mountain workshop participants are divided into small groups, mainly by profession and area of specialty (e.g. physicians, journalists, policy-makers). Groups undertake assessment of evidence in the context of learning the hierarchy of evidence, which TL described as an effective learning experience. One session involves profession mixed groups where participants undertook an exercise examining HRT. This systematic evaluation was an illuminating process.

Another workshop focused on how journalists can get the evidence out to readers, and incorporate underlying concepts of epidemiology into their articles. Groups examined use of anecdotes in media coverage, and how to resolve the tension between the need for an accurate presentation with the preference for human interest. Ms. Lieberman asked those assembled how conflicts of interest should be disclosed to reporters so that this information is conveyed to readers. Unfortunately, editors often consider this type of information as expendable. To summarize, the Rocky Mountain Workshop was effective because of the small group, problem-based format.

2.4.1 Questions and comments

- Has there been an assessment of the post- EBHC workshop reporting of journalists to evaluate changes in content or style? No.
- Had TL ever written a story to share information on the hierarchy of evidence? No, but this would be an interesting topic. "Canned news" produced by proponents of medical interventions and passed off as "real news" reporting was discussed.
- The good reputation of *Consumer Reports (CR)* was noted as a model for The Cochrane Collaboration and its work: What did it take to establish that reputation and did TL see something equivalent for healthcare in the future? TL replied that rigid standards and little margin for error or sloppiness contributed to the reputation that *CR* holds. She was of the opinion that it would be difficult to start something similar today because standards have declined throughout American society. There has been internal discussion at *CR* about providing healthcare information, but so far this has not happened. TL stated that there is a strong sense of unquestioning trust in doctors in the US, and more questioning needs to happen in order to make acceptance of EBHC widespread.
- The concept of EBHC is counterintuitive in the US. There is a common perception that we have the best healthcare system in the world that is based on best evidence.

- The public needs to think collaboratively and in terms of social insurance principles. Pervasive self-interest is a big barrier to cooperation.
- One participant mentioned the Carter Center's Journals Program as an example of the training available to healthcare journalists. Has this improved the quality of reporting?

3. Envisioning Success: 2008

The group was asked to imagine that they were in the year 2008, with five years of the Consumer Coalition behind them, and to reflect on the goals and successes achieved. What were some of the things they were proud to have accomplished?

- *The Cochrane Library* is free for everybody.
- The Cochrane Collaboration has established and developed relationships with scientists, who are now willing to tell the whole story, to talk about what works and what doesn't—and to put it in journals.
- Changes have taken place in the pharmaceutical industry.
- The Cochrane Collaboration has become a household name.
- The media comes to The Cochrane Collaboration first for information.
- Consumers also come to Cochrane first. It is a *Consumer Reports* for health care.
- Evidence-based research is the name of the game, and the Cochrane reviews and trials registers are comprehensive.
- The media focuses on summaries instead of breakthroughs to provide the big picture.
- The Cochrane Collaboration and evidence are "cool."
- People ask questions about the treatments that their doctors recommend. They are active participants in their own health care, across all levels of society.
- Providers are practicing EBHC, using *The Cochrane Library*, and providing *The Cochrane Library* to people who need access. Funding is now available to support research and increase awareness of results.
- Community-based (and evidence-based) efforts are established to reach out to people who have no direct access to health care.
- Healthcare professionals wear buttons saying, "Ask me about the evidence." Evidence has become a marketing and promotional tool. Slogans sell healthcare services as evidence-based to attract business.
- Doctors and patients are working together to find the evidence before deciding on treatment.

3.1.1 Specific objectives to achieve goals

Building on these ideas, the group was asked to make specific proposals about what they could do as a Coalition to achieve these goals. The following ideas were offered:

- Set up an infrastructure with operational processes.
- Target advocacy groups to get the issue of EBHC addressed in the entertainment sector.
- Develop and promote a website. Build access to pharmaceutical research into website development.
- Propose legislation requiring publication of trial information and results.
- Identify and analyze gaps in the evidence and develop a research agenda.
- Identify key legislative topics than can be advanced through sympathetic legislators.
- Develop a public education campaign about EBHC.
- Coordinate a consensus conference on EBHC involving insurers, the research community, consumers, and healthcare providers. Provide constituents with a toolkit on EBHC.
- Identify the stakeholders in public education.
- Get pharmaceutical companies in a race to full disclosure—CERES (related to environmental disclosure) can be used as a model. Companies like General Motors have been convinced that it's in their best interest to appear to be environmentally responsible. Identify a likely target that will brand itself as an industry leader and convince others to follow.
- Identify organizations trying to define quality care and to influence those coalitions on the importance of EBHC in order to drive public policy.
- Fund inserts to consumer group newsletters detailing information from CC that is of interest to consumers.
- Work with The Cochrane Collaboration to define standards for EBHC.
- Expand the Consumer Coalition membership by inviting quality people to the table.
- Start a leadership project ('the race to disclosure') pushed forward by pacesetting journalists.

The facilitators then asked if there are gaps in this list that need filling? What does this list say about the vision of the USCC Consumer Coalition? These questions sparked a discussion that raised the topics described below.

- KD said that the funder that supported this meeting wants consumers to feel on firmer ground in evaluating healthcare information and using EBHC tools to achieve (and demand) good quality of care.

- It is important to clearly state the Consumer Coalition's vision: *Support consumers to understand, demand, and influence evidence to achieve good quality of care in the public interest.*
- Who is the consumer? The USCC Consumer Coalition might also include as members employers who should be using EBHC to make better health insurance purchasing decisions.
- Participants should have no preconceived notions but should want to make a difference.
- What about including an aim for more advocacy, rather than education? For example, we could aim to get consumers on policymaking committees to influence production of evidence.

The group then spent time framing and grouping some of the identified targets into representative groups, for example education, consensus conferences, policymaking, identifying gaps, and communication. This process identified some gaps in the list of targets, namely the *context of evidence and relationships*.

- How do we improve relationships and the context in which evidence is produced and evaluated? If we do not address prerequisites for the use of evidence, other initiatives will be hampered. It is crucial to establish trust in the evidence itself.
- How do we create clusters of peers (payer/provider/patient) who are working together?
- Brand loyalty is important, including establishing standards and a reputation for being impartial. Again, *Consumer Reports* was used as a model.

Most of the participants want this to be a Consumer Coalition without industry involvement. One participant asserted that the group would have no credibility with the media if industry were involved. The consensus was that this is a Consumer Coalition. Specific projects might involve relationship building with industry, but this should be situational. The point was raised that there are consumer groups that are fronts for industry. Consideration needs to be given about whether this should be a factor in selecting groups that are part of the infrastructure of this Consumer Coalition.

4. Establishing criteria for project selection by the Consumer Coalition

Projects selected by the Consumer Coalition should be synergistic, potentially high impact, focus on common issues, useful of our resources, doable, well-timed, and clearly needed by consumers. The group spent some time determining which issues they would choose to prioritize as their top three projects. Before a vote was finalized, one participant spoke of the need to have a venue to articulate what was not being said in the meeting, in order to ensure that all points of view were being heard. The group took some time to address this point, and identified the following concerns:

- Are we a coalition of consumers or of trade associations that speak for consumers?
- What about outreach?

- More focus is needed on broader health issues (less focus on breast cancer).
- What can we learn from other established organizations?

This was followed by a debate about whether to develop projects directly or follow the model of first defining a mission and creating an infrastructure for coalition development. The group decided to devote resources to simultaneously projects and development of the Coalition as a whole. The groups then spent about 40 minutes in breakout sessions discussing five chosen topics.

5. Reports from Breakout Groups

5.1 Define Standards and Decision Tool (Joyce, Trudy)

This group focused primarily on a strategy for developing and implementing a decision tool for evaluating evidence. They identified the following steps: identify framework, design tool, design dissemination strategy. Input would come from: The Cochrane Collaboration, Agency for Healthcare Research and Quality, Institute of Medicine, assorted consumer groups. The anticipated outcome would be a decision tool with a dissemination strategy

5.2 Building on the website (Cindy, Leyla, Rebecca, Hilda)

This breakout team has a goal of targeting millions of people who will know they can find useful, trustworthy information through HB's website, *informedhealthonline*. The website's constituents are journalists, consumer organizations, health groups, healthcare professional organizations, and other websites. Promoting the website can be done by linking, e-mail alerts, and "hooks" to get people interested. The website development team is interested in soliciting Coalition and other US-based organizations for participation in "Hot Topics" and quarterly evidence reviews. The team also discussed cross-connections to NIH and PubMed sites. They aspire to create links with WebMD and sites of other medical and professional organizations. Further planning for the website will involve focus groups to get feedback on new presentation styles. Canadian focus groups are in progress, and Hilda is interested in US feedback also. The group described the possibility of attaining funding for dissemination, enhancements, and translations. They brainstormed potential funders. Long term plans included establishing connections to people without immediate web access and advocacy efforts to get internet access in underserved health populations.

5.3 Mission statement (Maryann, Christine)

The breakout group worked on defining the goal of this Coalition. Proposed mission statements were discussed extensively by the meeting participants. Comments and amendments to these included the following:

- Promote high quality health care for everyone, informed by the best available evidence.

- Empower consumers by providing universal access to and understanding of evidence-based health care.
- Encourage people to use the best available research when they make healthcare decisions.
- Demonstrate how to evaluate available research and reach conclusions about the benefits and risks of healthcare interventions.

5.4 Infrastructure (Ngina, Mark, Joy, Susan K, Marlene)

The infrastructure breakout group agreed with the organizational circles diagram laid out by KK (See Attachment 3.) The group envisions the Consumer Coalition as involving primarily grassroots advocacy groups, committed to EBHC with a diverse membership representing the most vulnerable consumers. The work of expanding the Coalition's membership falls to the **Planning Committee**, consisting of a convenor, the USCC Consumer Coalition Coordinator, and five other members. The Planning Committee will also be responsible for refining the mission statement and generating tasks for the Working Groups. **Working Groups** will focus on carrying out specific tasks and projects identified by the Coalition. (See Attachment 4.) Working Groups might broaden participation to involve people from industry and other stakeholders. Special **Task Forces** may be created to address certain issues. The breakout group suggested that there should be one Planning Committee member for each Working Group, quarterly conference calls, and an annual meeting.

The breakout group recommended that the Consumer Coalition's goals include continued efforts to build membership and to seek funding. The group articulated a preference not to invite industry-sponsored consumer groups to participate, except as Working Group members.

The infrastructure breakout group suggested that the Planning Committee be drawn from participants who attended this meeting and recommended that committee membership be limited to one person per organization/constituency. The Planning Committee will set the agenda for 2004, and initiate contact with working groups. Each member of the Planning Committee will be responsible for one Working Group.

Candidates for the Planning Committee: Trudy Lieberman, Leyla McCurdy

In the absence of sufficient volunteers to fill the Planning Committee, four people volunteered to act as "temporary advisors": Ngina Lythcott, Joy Simha, Sallie Bernard, Marlene McCarthy.

5.5 Identifying gaps in research (Roger, Sallie, Susan D.)

The group identified problems with this topic, primarily managing the task of creating a comprehensive list of gaps, which requires time and focused effort. As an alternative, the group suggested interim steps to meet this goal. (1) *The Cochrane Library* should be examined for gaps. (2) Gaps in consumer and evidence-based information should be identified. (3) People can be

assigned to examine the DHHS 2010 Healthy People Initiative to identify gaps in healthcare research. (4) Consumer groups and experts in different fields can be surveyed to identify their perception of gaps. SB and RB are committed to working on this project; KD and Susan Dimock (SD) may get involved as well. Potential constituents for this information are researchers, including those working with The Cochrane Collaboration.

With time running out, the participants decided to halt feedback from the breakout groups and move on to Next Steps.

6. Next Steps

The US Cochrane Center Coordinator will create a meeting report, including graphic reductions of the charts that KK and LD prepared over the course of the day's discussions. Following this, the USCC will coordinate a conference call for the Planning Committee to undertake further work on the mission statement.

KD thanked everyone for coming, participating, engaging, and agreeing to stay involved. She also thanked KK and LD for facilitating the meeting.

The meeting ended at 4:35 pm.