

**US Cochrane Center Consumer Coalition Meeting Report**  
**Second Annual Meeting**  
**Tuesday, August 3 – Wednesday, August 4, 2004**  
**Cosmos Club, Washington, DC**

**Background**

Participants at the first annual meeting, held July 16-17, 2003, explored whether consumers had a common understanding of evidence-based health care (EBHC) and considered how advocates could incorporate EBHC concepts and information into their outreach, education, and policy-making activities. The discussions raised many issues that could not be fully addressed in a single meeting. However, participants identified common ground upon which to build a coalition. A start was made at defining the mission and infrastructure of the Coalition, and exploring initial projects. Further development of these tasks was delegated to a volunteer Steering Committee. Committee members (Sallie Bernard, Trudy Lieberman, Ngina Lythcott, Joy Simha, and Carlos Ugarte) participated in several conference calls between March and July, 2004<sup>1</sup> and developed recommendations for consideration during the second annual meeting.

**Overview**

The second annual US Cochrane Center Consumer Coalition meeting was held August 3-4, 2004 at the Cosmos Club in Washington, DC. Six new organizations were included in the second meeting.<sup>2</sup> In addition to health advocates, participants included a liaison to the Cochrane Consumer Network, Liz Whamond, and an epidemiologist, Roger Bernier (Centers for Disease Control and Prevention), who participated in the first annual meeting because of a special assignment to engage the public on issues related to vaccine safety and policy. Other participants included two US Cochrane Center staff members, one guest speaker, and two guest presenters.

The meeting further considered how evidence could be used and improved to empower consumers individually and collectively. The group determined that, to develop effective strategies, it is necessary to take into account the diverse needs of populations, gaps in existing evidence, and the financial conflicts that can drive the way primary research is prioritized, conducted, and reported. Consequently, the Coalition selected projects that would not only facilitate consumers' use of EBHC information but would also improve the quality, quantity, and relevance of that information.

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<sup>1</sup> Five committee conference calls and 2 additional sub-committee calls were held during that period. Leyla McCurdy participated in the first conference call but was unable to continue on the Steering Committee due to other commitments.

<sup>2</sup> Some organizations sent different representatives from the 2003 meeting so that (aside from staff and guests) there were 9 people who had not previously been involved.

## **Summary**

Following is a summary of the meeting, which corresponds to the order in which topics were addressed during the meeting.

Tuesday, August 3

### **Welcome/introduction**

After a brief welcome and overview of the purpose and agenda of the meeting, participants introduced themselves and their organizations by describing the extent to which they used EBHC in their advocacy work, and the obstacles that made the use of EBHC information more difficult or complex.

### **Issues identified in introductions – obstacles and challenges to increased use of EBHC:**

- 'Evidence' isn't reliable – The quantity and quality of evidence is compromised by commercial interests (e.g. advertising, media hype, conflicts of interests in the scientific and medical communities) and political biases. Primary research designs are too often flawed – more guidelines about how to conduct research are needed.
- Research is often misrepresented when it is reported – not enough information about adverse effects skews conclusions and hinders informed decision-making. This is especially a problem for healthy people making decisions about prevention.
- Gaps in evidence – Primary research has often neglected certain populations, conditions or diseases. Some existing evidence is outdated or irrelevant to particular populations.
- Evidence is biased toward pharmaceutical interventions since pharmaceutical products are studied much more extensively than complementary and alternative health interventions, creating a bias in knowledge at the end.
- Gaps in health care – access to health care based on reliable evidence is essential.
- Gaps in practice – Where there is evidence, clinicians may not be using it. Standards/guidelines based on evidence need to be developed and applied.
- System-wide integrated approaches involving providers, consumers, and government may work better (e.g. SOSrx – National Consumers League)
- Consumer access and understanding (i.e. ability to evaluate research) is limited – need outreach to communities in appropriate language and cultural context. Evidence should be translated and disseminated in ways that are accessible and meaningful to consumers.
- Need to determine why evidence doesn't change consumers' behavior. Are media and authoritative messages over-powering evidence that contradicts sales pitches? What belief systems influence consumer understanding and behavior?
- Practitioners may not take environmental factors into account and therefore are providing treatment in lieu of addressing environmental triggers (e.g. asthma in children).

## **Steering Committee recommendations**

After introductions, Steering Committee members led discussions about the proposed mission statement, infrastructure, and initial projects<sup>3</sup>. Following a lengthy discussion of the mission statement, several participants (Maureen Corry, Adrienne Dern, and Jodi Sperber) volunteered to distil everyone's suggestions into a concise statement with revised definitions for further consideration on the following day.

There were also a number of comments about the infrastructure proposal and it was agreed that the Steering Committee would revise the proposal and resubmit it to members after the meeting. One of the primary issues discussed was how to expand the Coalition. Participants agreed that it was desirable to include as many advocacy organizations as possible; however a determination needs to be made as to who will be eligible to participate in making decisions about the Coalition.

Three proposed projects and a fourth project suggested by Ngina Lythcott, the 'Think' Committee were discussed in preparation for selecting initial projects on the following day.

## **Tips on developing a media strategy**

At the conclusion of dinner, Steering Committee member, Trudy Lieberman, introduced health care journalist and Association of Health Care Journalists (AHCJ) board member, Andrew Holtz, who provided some tips on developing an effective media strategy. His main points included:

- Media coverage is not an end in and of itself but instead should be part of an overall strategy that incorporates whatever means of communications (e.g. Internet, community outreach) are most likely to accomplish goals taking into account the resources of the organization.
- Consider the audience to which your message is aimed towards (e.g. large segment of consumers vs. a small group of policymakers who have the power to effect specific change).
- Build relationships with journalists – be available when they need information. Remember that journalists are independent; don't count on journalists to tell your story uncritically or the way that you want them to tell it. There is, however, a natural affinity between advocates and journalists who both seek the facts.
- Press releases aren't that helpful to journalists especially those who specialize in health care. It would be useful if consumers could translate EBHC for those journalists (and the public) who aren't familiar with it using simple and accessible terminology and messages (one message for TV and only a couple for print media).
- In response to questions/comments about journalists' reluctance to identify funding sources and other sources of bias when reporting on medical research, Andrew and Trudy indicated that the AHCJ is attempting to educate its members and set standards for its organization and journalists to abide by. Advocates should also ask journalists probing questions to highlight conflict of interest issues.

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<sup>3</sup> Ngina Lythcott led the discussion about the mission statement; Joy Simha and Carlos Ugarte led the discussion about infrastructure, and Sallie Bernard expanded upon the proposed projects.

## Meeting Report (cont'd)

Wednesday, August 4

### **Consumer participation in the Cochrane Collaboration- the Cochrane Consumer Network (CCNet)**

Maryann Napoli presented an overview of the CCNet including its composition, structure, and various roles for consumers in the Cochrane Collaboration. Liz Whamond provided additional information and described the Consumer Program at the upcoming annual Cochrane Collaboration Colloquium to be held in Ottawa, Canada, October 1 - 6.

The presentation and subsequent discussion identified ways to make systematic reviews more relevant and useful to consumers:

- Encourage more consumer input into selecting and framing questions for review.
- Critique protocols to ensure that research will produce useful information – e.g. exclude research that doesn't include sufficient follow up time to evaluate a particular intervention.
- Make summaries more accessible and consumer friendly:
  - Consider health literacy, language and culture
  - Include population studied, serious adverse events, overall mortality, absolute risk, and specific intervention (e.g. not just the name of the herb but the specific brand)
- Persevere post-publication to address issues not incorporated into the review process.
- Encourage Wiley (publisher of *The Cochrane Library*) to give full-text access to consumers.
- Explore whether consumers are currently using *The Cochrane Library* and/or summaries and if so, how they access, understand, and use the information.

### **Developing and promoting a credible and visible image**

Guest facilitator, Chrissy Faessen, introduced herself and Joanne Howes by describing how their firm (DDB Bass & Howes) assists advocacy groups to promote their issues and image. She posed a number of questions to help participants refine the mission, vision, and identity of the Coalition and analyze the most effective way to brand an issue or the Coalition.

Chrissy raised the following points:

- Branding is important to strengthen the message and make it more likely to be well received.
- Group needs to decide whether to create a powerful brand for the Coalition (e.g. similar to Consumer Reports 'You can trust us for objective information') or for an issue (e.g. evidence-based decision-making). In either event, the message must be clear and concisely articulated in order to rise above the clutter and noise in the marketplace.
- Branding an issue is less time-consuming and costly than branding a Coalition.
- Regardless of whether we choose to brand the Coalition or the issue, the following tasks must be undertaken:
  - Define the target audience
  - Define/refine goals
  - Evaluate our position in the marketplace

## Meeting Report (cont'd)

- Identify obstacles, allies, and enemies
- Create a personality for the Coalition
- Describe what success looks like

Discussion of the above indicated that the following issues also need to be resolved:

- To what extent does the Coalition want to be identified with the Cochrane Collaboration?
- What resources does the Coalition most want to make available to consumers (e.g. Cochrane, other EBHC sources)?
- Is there a concept of EBHC that will unite members of the Coalition and be useful to consumers?
- What is the main goal of the Coalition? To give consumers tools to ask questions?
- To what extent does the Coalition want to include scientists, journalists, providers, and community outreach workers in their targeted population(s)?
- Is there a slogan or name that would capture consumers' interest? Ann Fonfa suggested: 'Evidence informs choices – look it up'

Because there wasn't enough time to explore all these (and additional) issues, the Steering Committee will continue the process of developing a brand, consider additional consultation with Chrissy and Joanne, and make recommendations to the Coalition.

Joanne Howes pointed out that (because EBHC is being used by many people to mean different things) the Coalition should find a way to make EBHC its own issue in order to effectively communicate the Coalition's message(s).

### Further consideration of mission and vision statements

The revised mission statement and definitions were discussed during a working lunch. Alternative versions of the mission statement and vision statements were also considered.

#### Revised mission statement:

The mission of the US Cochrane Center Consumer Coalition is to promote the health of populations and the quality of individual health care by empowering consumers, public health policy makers, and health care providers to make informed decisions based on the best current evidence through research, education, and advocacy.

#### Definitions

Consumer: Any individual who interacts with and/or is impacted by formal and informal systems of public health or individual health care. Such individuals represent a diverse array of characteristics including age, race, culture, language, gender, sexual orientation, disability status, geographic location, socioeconomic status and/or national origin.

Best current evidence: The most recent, relevant, and comprehensive review of research relating to prevention, screening, diagnosis, and treatment, performed in a scientifically and ethically sound manner.

## **Meeting Report** (cont'd)

### Alternative mission statements:

The mission of the US Cochrane Center Consumer Coalition is to promote the health of populations and the quality of individual health care by empowering consumers to make informed decisions based on the best current evidence.

Or

The mission of the US Cochrane Center Consumer Coalition is to improve decision-making about health.

### Proposed vision statement:

All consumers, policy makers and providers will use evidence in making health decisions.

Alternative vision statement: Health care will be based on a collaborative decision-making process between practitioners and consumers, which takes into account the best research evidence, clinical expertise, and patient values. Existing gaps in research relevant to various diseases and populations will be filled.

It was agreed that the vision should describe a state of being – describing what success looks like.

In order to move on to necessary actions steps – selecting additional Steering Committee members and initiating projects - it was decided that the Steering Committee should give further consideration to the various proposed mission vision statements, and definitions, and make recommendations to the Coalition.

## **Steering Committee elections**

Participants agreed with the Steering Committee's recommendation that 3 openings should be filled. One original member, Ngina Lythcott, stood down to begin staggering terms. Ngina and 2 new members, Zobeida Bonilla and Jodi Sperber, were nominated and elected to serve 3-year terms.

All Steering Committee members with their term expirations are listed below:

Joy Simha, Young Survival Coalition, '05  
Carlos Ugarte, National Council of La Raza, '05

Sallie Bernard, Safe Minds, '06  
Trudy Lieberman, Center of Consumer Health Choices, Consumers Union, '06

Zobeida Bonilla, Our Bodies Ourselves, Latina Health Initiative, '07  
Ngina Lythcott, Black Women's Health Imperative, '07  
Jodi Sperber, National Coalition for Lesbian, Gay, Bisexual and Transgender Health, '07

## **Meeting Report (cont'd)**

### **Preparation for implementing projects**

The group took a vote to see how much interest there was in each project:

Planning Committee for March 3, 2005 Workshop - 5

Committee to Develop Web-based Course for Consumers - 3

Research Committee - 4

'Think' Committee - 2

All four committees met and devised initial plans to accomplish projects. The 'Think' Committee delegated their issues of concern to the other 3 committees and their members joined the Research Committee.

### **Committees reported to the Coalition**

The meeting concluded after committee reports with thanks to the participants and plans to pursue the projects underway.

### **Next steps**

- Steering Committee will revise mission statement and infrastructure proposal based on input during the meeting. Will also further consider how to develop the Coalition's identity per recommendations from Chrissy Faessen and Joanne Howes.
- Project Committees will follow up on steps outlined in their initial discussions, hold conference calls to continue their work, and provide progress reports at an interim to be determined by the Steering Committee.
- Coalition Coordinator (and other US Cochrane Center staff) will work with the committees to develop timelines, identify resources, and achieve goals.