

United States Cochrane Center (USCC) Consumer Coalition
Meeting Minutes
September 7 - 8, 2005
Sheraton Columbia Hotel, Columbia MD.

This meeting was recorded by AT&T teleconference services.

Present at the meeting:

Members of the USCC Consumer Coalition:

Annette Bar-Cohen (AB)	Director of Programs, National Breast Cancer Coalition (for Carolina Hinestrosa)
Zobeida Bonilla (ZB)	Our Bodies Ourselves; Latina Health Initiative Program Manager
Ann Fonfa (AF)	President, The Annie Appleseed Project
Ngina Lycott (NL)	Breast Cancer Liaison, Black Women's Health Imperative
Maryann Napoli (MN)	Co-founder and Associate Director, Center for Medical Consumers
Cindy Pearson (CP)	Executive Director, National Women's Health Network
Barbara Warren (BW)	Director, Organizational Development, Planning & Research, LGBT Community Center

Affiliated with The Cochrane Collaboration:

Laura Coe (LC)	USCC Coordinator
Christine Costantino (CC)	USCC Web Developer
Kay Dickersin (KD)	Director, USCC
Elizabeth McCurdy (EM)	USCC Consumer Coalition Coordinator
Project Office member	Agency for Healthcare Research and Quality
Jane White (JW)	National Sales Manager, John Wiley & Sons, Inc.

Participating via telephone:

Affiliated with the USCC Consumer Coalition:

Rebecca Burkholder (RB)	Director of Health Policy, National Consumers League
Joy Simha (JS)	Co-founder, Young Survival Coalition
Musa Mayer (MM)	Web course consultant, breast cancer advocate, writer

Apologies:

Members of the USCC Consumer Coaliton:

Sallie Bernard (SB)	Co-founder and Executive Director, SafeMinds
Katherine Browne (KB)	Managing Director, Consumer-Purchaser Disclosure Project, National Partnership for Women & Families
Maureen Corry (MC)	Executive Director, Maternity Center Association
Merrill Goozner (MG)	Director, Integrity in Science, Center for Science in the Public Interest
Trudy Lieberman (TL)	Director, Center of Consumer Health Choices, Consumers Union
Marlene McCarthy (MM)	Rhode Island Breast Cancer Coalition
Leyla McCurdy (LM)	Senior Director Health & Environment Programs, National Environmental Education & Training Foundation

Wednesday, September 7, 2005

- 1. Welcome and overview** 9:00 am - 9:35 am
Elizabeth McCurdy

After welcoming members, EM reviewed the meeting agenda (see Appendix A, Agenda).

- 2. Review of the web course on evidence-based healthcare for consumer advocates**
9:35 am - 3:00 pm
Zobeida Bonilla, Kay Dickersin

A draft of the web course contents was completed by the Web Course Committee (Zobeida Bonilla, Jane Nadel, Jodi Sperber, Carlos Ugarte, Liz Whamond) on September 7, 2004. This document defined the parameters of this course, and has served as a guide for further development.

KD noted that the course (What is Evidence-based Healthcare and Why is it Important?") is designed for consumer advocates and when completed will be available to them free of charge. The six proposed modules are:

- Module 1 - Introduction to Evidence-based Healthcare (EBHC) concepts
- Module 2 - ASK: the importance of research questions in EBHC
- Module 3 - ALIGN: research design, bias and levels of evidence
- Module 4 - ACQUIRE: search techniques and assessing risks and benefits
- Module 5 - APPRAISE: critical appraisal and early access to interventions

Module 6 - APPLY: making better decisions for EBHC

Modules 1 and 2 have been developed with both audio and visual components, while 3 - 6 are in outline form.

Members reviewed modules 1 and 2 during the meeting, and provided both oral and written feedback. Feedback was positive and suggested changes will be reflected in future revisions to these modules.

3. Review mission, vision statements and bylaws 3:15 pm - 4:15 pm
Steering Committee (SB, ZB, NL, TL, JS)

EM highlighted modifications to this document suggested by Brown General Counsel. Members made additional revisions, and voted to approve the document.

4. Steering Committee elections 4:15 pm - 5:15 pm
Steering Committee (SB, ZB, NL, TL, JS)

There were three open positions on the Steering Committee, one for 2005 - 2007 and two for 2005 - 2008. One application for the term 2005 - 2007 was received and reviewed.

Voting by anonymous written ballot filled the following two positions:

- BW for 2005 - 2007
- JS was nominated to serve from 2005 - 2008. Acceptance of this nomination is pending.

Action: EM will contact members to solicit nominations to fill any open positions.

5. Adjourn 5:15 pm

The meeting adjourned at 5:15 pm, followed by a reception and dinner at 6:15 pm.

Thursday, September 8, 2005

Review of Coalition Projects 8:00 am - 12:45 pm

1. Plain Language summaries 8:00 am - 9:30 am
Maryann Napoli

The Cochrane Consumer Network (CCNet) has funding to develop plain language summaries for Cochrane Complementary and Alternative Medicine (CAM) reviews, and is facilitating the writing of summaries for other reviews. Members have been invited to join MN and AF who are already participating in this project.

Action: MN will facilitate the inclusion of members who are interested in this project.

2. National license to *The Cochrane Library* 9:30 - 10:30 am
Kay Dickersin, Jane White, Barbara Warren

2.1 What is a systematic review?
Kay Dickersin

Members decided to bypass this presentation.

2.2 Overview of *The Cochrane Library*
Jane White

JW presented an overview of *The Library* and provided members with searching hints and tips. John Wiley provides regular tutorials via WebEx, and members can call Denine Tilery at 201-748-6647 to get more information or schedule a session.

BW brought members up to date on the National License Initiative. Members again thanked Wiley for their free year long subscriptions to *The Library* they received in August. BW encouraged members to utilize *The Library* as a means to understand its utility for consumers and assess the potential benefit of a national license. Anticipating future usage by their constituents, members would like to track use and assess satisfaction levels.

Action: EM and BW will proposed a methodology (eg. a survey) to track constituent use of, and satisfaction with, The Library.

Action: EM will forward Wiley tutorial information to members.

3. Prioritizing topics for Cochrane systematic reviews? 10:30 - 11:15 am
Barbara Warren

The original focus of the “prioritizing topics” project, as defined at the 2005 Annual Meeting, was to develop the top ten priority topics for Cochrane systematic reviews from a consumer perspective. Members discussed changing this initiative to re-prioritize, or comment on, existing priority topics within Cochrane Review Groups. KD proposed that members might also want to look at existing Cochrane reviews in their field of interest, and identify research gaps. A number of members are especially interested in focusing on gaps in the representation of special populations (eg. minorities, women and LGBT populations).

KD suggested that coordination with CCNet would serve to engage The Collaboration and help define the parameters and support for this project.

Action: MN agreed to review this project with CCNet representatives at the Colloquium in October.

Action: Members agreed to look at Cochrane reviews in their field of interest, identify evident gaps, and forward this information to MN prior to the Colloquium.

4. Membership expansion
Elizabeth McCurdy

Members reviewed a list of potential new members submitted by EM.

5. A new name for the Coalition?
Ngina Lythcott

NL led a discussion of key concepts (eg. EBHC, consumer, advocacy, Coalition) that might be included in a new name for the Coalition.

MN proposed “Consumers United for Evidence-based Healthcare (CUE)”, as a new name. Members approved this name and would like to adopt it pending notification of the entire Coalition.

Action: EM will forward this proposed name to all members for final approval.

6. The Coalition: past, present and future

NL led a discussion of Coalition accomplishments and helped members define future

priorities. High priority projects include finishing and piloting the web course, developing a web site, and membership expansion.

The Research Committee will disband and members will be encouraged to join other projects.

7. The Cochrane Colloquium- Melbourne, Australia

KD discussed the benefit of attending the Colloquium. She has requested approval from AHRQ to use unexpended funds to support US consumer travel expenses. We anticipate that the application process will be administered by Colloquium staff.

8. Adjourn

The meeting adjourned at 2:30 pm.

Appendix A
USCC Consumer Coalition Meeting
Sheraton Columbia Hotel
September 7 - 8, 2005

AGENDA

This meeting is funded by a generous grant from AHRQ

Wednesday, September 7

- 8:30 am** **Registration and continental breakfast**
- 9:30 am** **Welcome and overview**
Elizabeth McCurdy
- 9:35 am** **Review of the web course** (breaks as needed)
Zobeida Bonilla, Kay Dickersin, Musa Mayer (by phone)
- Module I - INTRODUCTION: What is evidence-based healthcare and why is it important?
- Module II - ASK: Research questions in evidence-based healthcare
- Module III - ALIGN: Understanding basic healthcare research design
- 12:45 pm** **Lunch**
- 1:30 pm Module IV - ACQUIRE: Learning effective search techniques
- Module V - APPRAISE: Critically appraising the research you find
- Module VI - APPLY: Making healthcare decisions
- 3:00 pm** **Break**
- 3:15 pm** **Review mission, vision statements and bylaws**
Steering Committee
- 4:15 pm** **Steering Committee elections**
Steering Committee
- 5:15 pm** **Adjourn**
- 5:30 pm** **Reception and dinner**

