

United States Cochrane Center (USCC) Consumer Coalition
Annual Meeting Minutes
March 30 and April 1, 2005
Brown University, Providence R.I.

Present:

Sallie Bernard (SB)	Co-founder and Executive Director, SafeMinds
Roger Bernier (RB)	Associate Director for Science, National Immunization Program, Centers for Disease Control
Rebecca Burkholder (RB)	Director of Health Policy, National Consumers League
Laura Coe	USCC Coordinator
Kay Dickersin	USCC Director
Ann Fonfa (AF)	President, The Annie Appleseed Project
Ngina Lythcott (NL)	Black Women's Health Imperative; Vice Dean and Dean of Students Columbia University
Marlene McCarthy (MM)	Rhode Island Breast Cancer Coalition
Elizabeth McCurdy (EM)	USCC Consumer Coalition Coordinator
Maryann Napoli (MN)	Co-founder and Associate Director, Center for Medical Consumers
Carol Sakala (CS)	Maternity Center Association
Joy Simha (JS)	Co-founder and Board Member Young Survival Coalition
Barbara Warren (BW)	Director Organizational Development, Planning & Research; The Lesbian, Gay, Bisexual & Transgender Community Center

Guests:

Janet Wale (JW)	Cochrane Consumer Network (CCNet)
Liz Whamond (LW)	CCNet

Apologies:

Zobeida Bonilla (ZB)	Latina Health Initiative, Our Bodies Ourselves
Katherine Browne (KB)	Managing Director, Consumer-Purchaser Disclosure Project, National Partnership for Women & Families
Maureen Corry (MC)	Executive Director, Maternity Center Association
Carolina Hinestrosa (CH)	Executive Vice President for Programs and Planning, National Breast Cancer Coalition
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
Leyla McCurdy (LM)	Senior Director Health & Environment Programs, National Environmental Education & Training Foundation
Cindy Pearson (CP)	Executive Director, National Women's Health Network

Wednesday, March 30, 2005

1 Preparation for conference and annual meeting

4:10 pm - 5:30 pm

1.1 Welcome and introductions

After welcoming members, EM reviewed the annual meeting agenda.

1.2 Overview: Agenda for the conference

JS gave a brief overview of the conference agenda to be held the following day. Attendees from the Joint Meeting of the USCC Advisory Board and The Cochrane Collaboration Steering Group (CCSG) and invited guests, will join the conference throughout the day.

2. Dress rehearsal for March 31: PowerPoint presentations

4:30 pm - 5:30 pm

Coalition members revised PowerPoint presentations to be shown the following day at the session "EBHC and consumer advocacy in the United States." The presentations will highlight:

- > Each members' constituency;
- > Areas where they believe the Collaboration can play a supportive role;
- > Areas where they believe improvement in the access to and availability of EBHC information is needed;
- > Areas where EBHC information is utilized within each member organization.

3. Reception and Coalition dinner

6:00 pm

Attendees at the Joint Meeting of the USCC Advisory Board and the Cochrane Collaboration Steering Group Meeting and invited guests, joined members of the Coalition at the Hope Club for a reception and dinner. During the dinner, those present were asked to give an example of where a Cochrane systematic review has informed policy or practice within their sphere of influence.

Friday, April 1, 2005

1. Welcome and Review of Conference Highlights

8:30 am - 9:00 am

Members agreed that the conference was a great success. The stated objective and aims of the conference were successfully met.

2. Looking ahead: the Coalition in 2008

9:00 am - 10:00 am

This portion of the meeting focused on developing new projects that will forward the mission, vision and goals of the Coalition. New projects include:

2.1. Priority topics for Cochrane systemic reviews from a consumer perspective

Members believe they have been given a clear directive from the Cochrane leadership at the March 31, 2005 meeting to develop a list of top priority research questions for systematic reviews from a consumer perspective. EM noted that although Cochrane review groups may already have priority topic lists, consumer priorities need to be represented.

2.1.1 Developing priority topics: a survey

Members discussed developing a survey to gather information for priority topics. This survey might include demographic information and background information on the understanding and utilization of EBHC information. AF suggested using Pew data to help highlight what healthcare topics consumers are interested in. EM suggested that final list should be concerned with 'high impact' issues, to maximize the effectiveness, dissemination and use of any resulting systematic reviews. The benefits of a survey include education, outreach, expansion of Coalition membership and engagement of each members constituency base.

Action: SB, BW offered to develop a survey, and report to the Coalition by May 1, 2005.

Action: EM, KD, and LC will facilitate this process by:

- 1. Providing information on processes for identifying priority topics, and refining the final list.*
- 2. Providing guidelines for stating priority topics as EBHC questions*

2.1.2 Preparation for a survey

Members stated that their constituents need to be familiar with *The Library* in order for the survey to bear meaningful data. The abstracts and synopses are currently freely available, but access to the full reviews is by subscription only. Full reviews can provide important information that is not in the abstract or the synopses.

Action: *KD will try to obtain free access to The Library for members and their constituents for one year.*

Action: *Members will educate themselves and their constituents about The Library and EBHC.*

Action: *EM, KD, and LC will facilitate this process by providing members with:*

- 1. Information on the Collaboration and The Library, in a form suitable for distribution (e.g. a brochure);*
- 2. A step-by-step guide to searching The Library;*
- 3. Information on EBHC concepts and skills, and readily available tutorials for members and their constituents;*
- 4. An update on the Coalition web course (“Evidence-based healthcare and critical appraisal for consumer advocates”) by May 1, 2005.*

2.2 Name change for the Coalition

The Coalition is supported by the USCC via an AHRQ grant. Members would like to see a new name that reflects their vision and mission statements rather than the supportive structure. RB asked whether the Coalition would like to focus on a specific component of EBHC (eg. evidence vs. patient preference vs. decision making) and whether this should be factored into a new name. This discussion brought forth issues surrounding the definition and scope of EBHC, and the responsibilities of the Coalition within the AHRQ grant.

Action: *NL and AF to work on a name change for the Coalition, and forward their thoughts to members within 30 days.*

Action: *EM and KD will forward the contact information for DDB & Howes (representatives from this business attended the 2004 annual meeting and they have offered continuing assistance to the Coalition)*

Action: *EM will forward definitions of EBM and EBHC and highlight the components that are included in evidence-based decision making (eg. patient preference, evidence, clinical expertise.)*

Action: *EM will forward a summary of the AHRQ grant which defines in part the relationship between the USCC and the Coalition.*

2.3 A national (US) subscription to The Library

A national subscription to *The Library* will forward the mission and vision of the Coalition.

Action: *BW and MM to investigate obtaining national access to The Cochrane Library.*

Action: *EM, KD, and LC will facilitate this process by researching the appropriate mechanism for obtaining national access, providing contacts, and highlighting barriers the might be encountered.*

2.4 Increasing Coalition membership

NL proposed doubling membership within the year. Members read membership

guidelines from the 2004 annual meeting report. EM provided a list of potential members that was reviewed.

Action: NL to identify health advocacy groups within the Latino, Asian, Pacific Islander, Native American, and Latin American populations. AF to help NL in the development of a potential list of new advocacy groups. They will report back to the Coalition within 30 days.

Action: EM will facilitate the process by providing:

1. a list of potential advocacy groups they have gathered already
2. background information on the Coalition in a form suitable for distribution to new members (e.g. a brochure.)

2.5 Pilot project with CCNet: CAM synopses

Members would like all Cochrane systematic reviews to have synopses. JW explained that the CCNet is involved in preparing synopses for Cochrane complementary and alternative medicine (CAM) reviews.

Action: AF, JW and LC to work on this project and report to the Coalition within 30 days.

3. Mission and Vision Statements: Final Revisions

10:00 am - 11:00 am

3.1 Section 2. Mission Statement

The mission statements that were prepared during the 2004 annual meeting were reviewed. Members adopted the following:

“The mission of the US Cochrane Center Consumer Coalition is to promote the health of populations and the quality of individual health 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.”

3.2 Section 2. Vision statement

The vision statements that were prepared during the 2004 annual meeting were reviewed. Members adopted the following:

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

3.3 Section 3. Objectives

Members changed the title of Section 3 to:

Section 3. Goals

A statement needs to be added to Section 3 which will reflect the goal of communication to providers and policy makers.

Action: MM agreed to work on this additional statement and report back to the Coalition within 30 days.

3.4 Section 4. Definitions: Best Current Evidence

Members agreed it is important to add to the definition of Best Current evidence by including a reference or statement on rehabilitation and/or quality of life issues. There was no specific action taken on this item.

3.5 Section 4. Definitions: Evidence-Based Health Care

Members changed “physician to provider” The definition now reads:

“Evidence-Based Health Care: Health care based on a collaborative decision-making process between providers and consumers, which takes into account the best research evidence, clinical expertise, and patient values”

4. Committee Breakout Groups

11:15 pm - 1:00 pm

We reviewed the existing committees (workshop, web course, research, steering).
The following items were discussed:

4.1 Workshop Committee (JS, MN, RB, LM, AF)

This committee was formed to organize the conference on March 31, 2005. It was agreed that the Workshop Committee will disband following the conference. Members extended their thanks.

4.2 Web Course Committee (ZB)

The Web Course Committee will continue to oversee the development of the web course entitled “Evidence-based healthcare and critical appraisal for consumer advocates”.

Action: EM, KD, and LC to develop the material produced by the Committee into a web course format. They will report back to the committee by May 1, 2005.

4.3 Steering Committee (SB, TL, ZB, NL, JS)

The Steering Committee will focus on developing an agenda for the next meeting in Fall, 2005. Baltimore was a suggested location due to the re-location of the USCC to Johns Hopkins in September.

Action: EM, KD, and LC will facilitate the selection of a meeting date and location, and development of

the agenda.

4.4 Research Committee (SB, NL, CP, MG,MC)

This committee agreed to remain intact, and to focus on the identification of research gaps.

Action: *EM, KD, and LC will facilitate the identification of gaps by providing research and development support.*