

Consumers United for Evidence-based Healthcare (CUE)

2006 Annual Meeting Minutes

21 September 2006

Hilton Alexandria Mark Center Hotel

Alexandria, Virginia

1. Executive summary

This report summarizes the 2006 Annual Consumers United for Evidence-based Healthcare (CUE) Meeting which convened on September 21, 2006 in Alexandria, Va. The meeting's goals were to provide critical appraisal education and training, promote professional development, and foster collaboration among consumer organizations and the research community.

The 25 meeting participants and observers heard from the keynote speaker, Dr. Alejandro Jadad of the Centre for Global eHealth Innovation, lobbyist Dr. Ramón Castellblanch, and current CUE members. Topics included: what is evidence-based healthcare (EBHC)?, practical applications of EBHC, and how consumer advocates might use EBHC in their advocacy efforts. The agenda included a keynote address, plenary sessions, panel discussion, and open forum (see Appendix A). The meeting also provided an opportunity to welcome the nine new CUE member organizations in attendance (see Appendix B).

Recurrent themes were finding ways to make systematic reviews more accessible to consumers, increasing awareness about EBHC and CUE, and securing financial support and partnerships to continue the growth and development of CUE.

2. Welcome and introductions

The meeting began with a welcome from **Joy Simha**, *CUE member, CUE Steering Committee Co-chair, and representative of the Young Survival Coalition*. She provided a history of CUE and summary of its relationship to its scientific partner, the United States Cochrane Center (USCC). Ms. Simha noted the importance of consumer involvement with the research community. Highlights from her welcome are as follows.

Consumers need access to high quality health information and critical appraisal tools

Consumers are bombarded with healthcare information from the print media, TV, radio, Internet and their healthcare providers. Interpreting the accuracy and validity of information is often difficult, as reports can be conflicting and evidence may seem to change over time. Consumers and consumer advocates need the tools to interpret, analyze, and understand this influx of information.

Consumers are key stakeholders in health and healthcare decision making

Consumers help raise funds for health research, advocate for local and federal legislative changes, and are directly affected by healthcare program and policy decisions. For these reasons and others, consumers request a seat at the decision-making table. The increased attention to “participatory research” demonstrates a recognition of consumers as contributing stakeholders.

Ms. Simha concluded her welcome with a brief summary of current CUE projects, an overview of the day's agenda, and expressed appreciation to the meeting's sponsor, the Agency for Healthcare Research and Quality (AHRQ).

All meeting participants and observers introduced themselves, their organizations, and provided examples of how they currently use EBHC in their work. Attendees hailed from consumer advocacy organizations, research institutions, and a government agency (see Appendix C for the participant and speaker list).

Kay Dickersin, PhD, Director of the USCC, next provided a history of CUE and overview of the Cochrane Collaboration. Dr. Dickersin encouraged CUE members to become involved in the activities of the Cochrane Collaboration, CUE's scientific partner.

Barbara Warren, PsyD, CUE member, CUE Steering Committee Co-chair, and representative of the National Coalition for Lesbian, Gay, Bisexual and Transgender Health followed with a screening of two of three videos currently in development by her group. Dr. Warren attended the XIII Cochrane Colloquium in Melbourne Australia and interviewed conference participants from around the world about EBHC and its benefits to consumers and to providers. Dr. Warren plans to create a third video that will introduce viewers to the Cochrane Collaboration and EBHC. With additional funding, CUE hopes to produce a video that will highlight CUE and United States consumers, consumer advocates, and researchers.

3. Keynote Address: Consumers, evidence and the health system

We were pleased to welcome **Alejandro Jadad, MD Dphil FRCPC, Chief Innovator and Founder, Centre for Global eHealth Innovation**, to present the keynote address: *Consumers, evidence and the health system: A review from the age of the Internet and Web 2.0*.

Dr. Jadad was introduced to EBHC as a medical student in his native country of Columbia, talking about drug use to a group of school children. He discussed his growing involvement in EBHC and how he used evidence-based research to help his father, who had cancer, make treatment decisions.

Dr. Jadad defined EBHC as “the explicit, judicious and conscientious consideration of current best evidence from clinical care research to guide clinical decisions or the delivery of health services.” He noted that there are many competing interests in healthcare, including industry, media, government, health professionals, managers, the public, and researchers. Current weaknesses in the system include the unsustainable drug development process, weak and clinically irrelevant research, and the “myths” of informed consent, equipoise and shared decision-making.

He posed the question, “How can we protect us from bias?” and discussed the following biases and problems:

- Manipulation by omission;
- Manipulation by commission;
- Creating a self-fulfilling prophesy;
- Difficult to resist; and
- Personal bias.

Dr. Jadad suggested searching *The Cochrane Library*, [EBM Online](#), [Bandolier](#), The Center for Reviews and Dissemination, and [BMJ Online](#) as EBHC resources. Patients are self-organizing (for example AIDS activists in the 1980s) and can and will force significant changes in the direction of healthcare decision-making, but he wondered how we can get people interested in EBHC and if we are “missing a good chance.” Dr. Jadad presented Web 2.0, an example of e-communication, and noted that we are being tuned out by the younger generation, e.g., myspace.com and the online You Tube. The new multi-tasking M-generation must be engaged by new approaches and Dr. Jadad challenged the group to find new means of communicating with consumers.

4. Developing evidence-based healthcare in California

Ramón Castellblanch, *PhD, MPP, Associate Professor, Health Education, San Francisco State and volunteer lobbyist, Senior Action Network (SAN), California* provided an example of how EBHC has been applied in a practical sense (i.e. through legislation).

Dr. Castellblanch described his experience as a volunteer lobbyist for Senior Action Network (SAN), a grassroots senior advocacy group, working to introduce EBHC policies to the California state legislature. Using the examples of California Senate Bill 1727, defeated in the Assembly Health Committee in 2002 and the Assembly Bill 2326, defeated by one vote at the last hour during the final vote in 2004, Dr. Castellblanch discussed strategies that did not work (e.g. high-lighting the cost aspect of implementing the policy) and those that did (e.g., emphasizing the safety aspects of the evidence-based policy on prescription drugs and building a coalition of labor, consumer and senior groups to support the bills).

Groups that lobbied against these EBHC bills included pharma-related groups, insurers and certain mental health consumer organizations. Individual assembly members also were able to mobilize their constituencies in opposition to the bills. Concerns of supporters, which also had to be overcome, included excluding coverage of drugs in mental health, designation of a credible entity to provide information on safety and effectiveness of the prescription drugs, and ensuring that the issues of liability and conflict-of-interest were resolved.

Dr. Castellblanch concluded by noting that the process of using EBHC to develop and implement policy in the state of California (and in the federal government as well) is a long and arduous but ultimately worthwhile process. Lessons learned along the way lead to further development and refinement of the policy, evolution of partnerships with supporters, and eventually to the passage and implementation of the legislation.

5 The past, present, and future: An overview of CUE committees and projects

Marianne Hamilton, *MPA, USCC Consumer Coordinator*, chaired the session on ongoing CUE activities and proposals for new projects.

5.1 Supporting outreach activities and a national subscription to The Cochrane Library

Dr. Barbara Warren spoke about CUE outreach activities and strategies for obtaining a national subscription to *The Cochrane Library*. She stated that, in order to advocate for a national subscription, CUE needs information on how *The Cochrane Library* is currently being used and by whom. Consumers and consumer advocates should be educated about this resource and trained to critically appraise evidence-based health literature. Systematic reviews available on *The Cochrane Library* should be available in plain language summaries. Dr. Warren shared her experience of partner-building with John Wiley & Sons (the publisher of *The Cochrane Library*). A representative from John Wiley & Sons has made presentations on *The Cochrane Library* for Dr. Warren's staff and colleagues as well as the organization she represents. All CUE members were encouraged to invite representatives of John Wiley & Sons to their organizations' events.

5.2 Participating in developing Cochrane plain language summaries

Maryann Napoli, *CUE member and representative of the Center for Medical Consumers* provided information on how CUE members can serve as consumer reviewers to the Cochrane's systematic reviews and participate in writing plain language summaries for the published reviews. She encouraged CUE members to subscribe to Consumers Digest, an international e-discussion for consumers where Cochrane review groups routinely advertise for consumer reviewers. To subscribe via the World Wide Web, visit <http://lists.cochrane.org/mailman/listinfo/consumers> or, via email, send a message with subject or body 'help' to consumers-request@lists.cochrane.org.

5.3 Proposal for new projects and discussion

The group discussed ways to disseminate its distance education course on EBHC for consumer advocates. One idea was to provide links from the member organizations' websites to

the USCC website. Additionally, members discussed providing presentations at their organizations' conferences on EBHC, Cochrane, the distance-education course and CUE. One proposed project was the compilation of the online course into a book, possibly in collaboration with CUE member organization, *Our Bodies Ourselves*.

Further discussion focused on fund-raising strategies, potential partnerships with the scientific community, and how CUE members can stay actively involved (despite busy work schedules) on CUE projects throughout the year. Potential solutions were to attend, or encourage co-workers to attend, the educational opportunities supported by the USCC. These opportunities include scholarships to the Rocky Mountain Workshop on Evidence-based Healthcare and the annual Cochrane Colloquium.

5.4 Distance education course on EBHC for consumer advocates

Dr. Kay Dickersin reported on a CUE and USCC collaboration, the distance education course on EBHC for consumer advocates. This free, web-based course is being developed to help consumer advocates understand EBHC and to find, critically appraise, and use source information to inform health care decision making. Dr. Dickersin presented the first module, encouraged the members to review and evaluate all six modules, and shared goals for the course. CUE members discussed advertising the course at their organizations' websites and conferences.

6. Panel Discussion on how incorporate evidence into your organization's advocacy efforts.

The goal of the panel discussion was to provide examples of how some of CUE member organizations are currently using EBHC in their advocacy efforts. A brief summary follows.

6.1 *Our Bodies Ourselves* Evidence-based Information and Advocacy

Zobeida Bonilla, PhD, CUE member and Steering Committee member and representative of *Our Bodies Ourselves* provided participants with a brief history of *Our Bodies Ourselves*, an overview of its program areas, and explanation of its use of evidence-based health information.

The organization, *Our Bodies Ourselves* grew from a group of women's discussion about their experiences with doctors and health. This initial discussion led them to research specific health topics, to look for evidence in the published literature, and to put their knowledge into an accessible form that "can be shared with others and that can serve as a model for women who want to learn about themselves, communicate their findings with doctors, and challenge the medical establishment to change and improve the care that women receive."

The organization was founded on evidence and the beliefs that:

- Women, as informed health consumers, are catalysts for social change;
- Women can become their own health experts, particularly through discussing issues of health and sexuality with each other;
- Health consumers have a right to know about controversies surrounding medical practices and about where consensus among medical experts may be forming;
- Women comprise the largest segment of health workers, health consumers, and health decision-makers for their families and communities, but are under-represented in positions of influence and policy making;
- A pathology/disease approach to normal life events (birthing, menopause, aging, death) is not an effective way in which to consider health or structure a health system.

The impact of *Our Bodies Ourselves* and its publications continues to evolve. Now, new publications are directed to specific audiences, such as Latinas, and attempt to address the social, political, and economic contexts specific to different populations. As an example of the organization's impact, women's groups from around the world have organized to produce their own versions of *Our Bodies Ourselves* books incorporating evidence with their own experiences.

6.2 Research, access, influence: Evidence and the National Breast Cancer Coalition Fund

Annette Bar-Cohen, *CUE member and representative of the National Breast Cancer Coalition Fund*, highlighted the NBCCF's mission to end breast cancer through the power of grassroots advocacy in public policy, science, and education. To do so, the NBCCF has built its foundation on the use of evidence as demonstrated in the organization's responses to public inquiries, legislative work, and initiatives. The NBCCF uses evidence to:

- Focus its mission
- Craft position statements
- Respond to breaking news
- Answer public inquiries
- Set legislative priorities
- Develop the Clinical Trials Initiative, Quality Care Initiative, and educational programs

The NBCCF has based its positions on the evidence even when these positions are controversial (i.e. "there is no scientific evidence from randomized trials that breast self exam saves lives or enables women to detect breast cancer at earlier stages. In addition, there are some data that show that breast self exams greatly increases the number of benign lumps detected, resulting in increased anxiety, physician visits and unnecessary biopsies.") Ms. Bar-Cohen informed the audience that although standing by the evidence "is not always fun" it helps define

and direct the organization.

6.3 Center for Science in the Public Interest

Merrill Goozner, *CUE member and representative of the Center for Science in the Public Interest* spoke about the quality of evidence in the medical literature and how to identify conflicts of interest. A journalist, Mr. Goozner provided examples of how healthcare information, about Amgen's Epogen, statins, and VIOXX, has been marketed to the detriment of the public

Mr. Goozner spoke about the relationship between medical journals and pharmaceutical companies and encouraged the audience to ask themselves: Who's saying that? And who's paying them to say it?

Merrill Goozner's health-related articles, can be viewed on his blog at:
<http://www.gooznews.com/>.

7. Summary of open forum

Chaired by CUE Steering Committee Co-chair Barbara Warren (on behalf of Co-chair Joy Simha), this open forum allowed the meeting's participants and observers to engage in general discussion about EBHC, their own organizations' experiences, and their general impressions of the day's speakers and topics. Many CUE members (including the representatives from the TMJ Association and the National Center for Transgender Equality) shared how evidence, or lack there of, has shaped their topic areas. It was also an opportunity for new members to ask questions about the coalition. Additional discussion centered on fund-raising strategies, potential partnerships and resources, and the future role this coalition might play in healthcare development, communication, and policy.

Appendix A: 2006 Annual Meeting Participant and Speaker List

Participants and Speakers

Natanya Alon National Partnership for Women & Families	Simon Aronoff National Center for Transgender Equality
Annette Bar-Cohen National Breast Cancer Coalition	Zobeida E. Bonilla Our Bodies Ourselves
Ramón Castellblanch - Guest speaker San Francisco State	Terrie Cowley The TMJ Association, Ltd.
Kathleen DeBold Mautner Project, the National Lesbian Health Organization	Kay Dickersin US Cochrane Center
Ann Fonfa Annie Appleseed Project	Merrill Goozner Center for Science in the Public Interest
Marianne Hamilton US Cochrane Center	Alejandro Jadad - Keynote speaker Centre for Global eHealth Innovation
Barbara Loe Fisher National Vaccine Information Center	Julie Kosteas National Council on Aging
Maryann Napoli Center for Medical Consumers	Cindy Pearson National Women's Health Network
Joy Simha Young Survival Coalition	Barbara E. Warren National Coalition for LGBT Health

Observers

Margaret Coopey Agency for Healthcare Research and Quality	Christine Costantino US Cochrane Center
Alaina K. Fournier Agency for Healthcare Research and Quality	Marian D. James Agency for Healthcare Research and Quality
Karsten Juhl Jørgensen The Nordic Cochrane Centre	Kelly Manos US Cochrane Center
Roberta Scherer US Cochrane Center	