Preparing, maintaining and promoting the accessibility of systematic reviews of the effects of healthcare interventions
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### Abbreviations used in USCC Annual Report

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<th>Abbreviation</th>
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<tr>
<td>AHRQ</td>
<td>Agency for Healthcare Research and Quality</td>
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<td>ARCHIE</td>
<td>Cochrane Contact Database</td>
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<td>ARVO</td>
<td>Association for Research in Vision and Ophthalmology</td>
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<tr>
<td>CAM</td>
<td>Complementary and Alternative Medicine Field</td>
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<tr>
<td>CCNet</td>
<td>Cochrane Consumers Network and Field</td>
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<tr>
<td>CCSG</td>
<td>Cochrane Collaboration Steering Group</td>
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<tr>
<td>CENTRAL</td>
<td>Cochrane Central Registry of Controlled Trials</td>
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<tr>
<td>CEVG</td>
<td>Cochrane Eyes and Vision Group</td>
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<tr>
<td>CEVG@US</td>
<td>Cochrane Eyes and Vision Group, US Satellite</td>
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<td>CRG</td>
<td>Collaborative Review Group</td>
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<td>CUE</td>
<td>Consumers United for Evidence-based Healthcare</td>
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<td>EBHC</td>
<td>Evidence-based healthcare</td>
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<td>Master List</td>
<td>Master List of Journals Being Searched</td>
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<tr>
<td>NEI</td>
<td>National Eye Institute</td>
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<tr>
<td>PaPaS</td>
<td>Pain, Palliative and Supportive Care Group</td>
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<tr>
<td>RCT</td>
<td>Randomized controlled trial</td>
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<tr>
<td>STDMG</td>
<td>Cochrane Screening and Diagnostic Tests Methods Group</td>
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<tr>
<td>UCSF</td>
<td>University of California San Francisco</td>
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<td>USCC</td>
<td>United States Cochrane Center</td>
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<td>WHO</td>
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1. Introduction

The United States Cochrane Center (USCC) was established in December 2002 when the New England Cochrane Center Boston Office, the New England Cochrane Center Providence Office, and the San Francisco Cochrane Center merged to form a single registered entity with a central office and two branches. The central office is the first point of contact for the work of The Cochrane Collaboration in the United States and is responsible for fulfilling the Center’s core functions. The central office of the USCC is at the Johns Hopkins Bloomberg School of Public Health in Baltimore, Md.; the Center Director is Professor Kay Dickersin.

2. Mission

The overall mission of the USCC is to further the Collaboration's goal of making systematic reviews of research evidence on the effects of healthcare widely available.

3. Responsibilities of the USCC

The core functions of the USCC are to provide support to Cochrane entities with a coordinating base in the US or one of the countries for which the USCC is the reference center; support new Collaborative review groups (CRGs), fields, and methods groups interested in registering with the Collaboration; and support individuals who seek information about the work of the Collaboration.

The USCC shares the same core responsibilities with other Cochrane Centers:

- To promote and represent The Cochrane Collaboration;
- To serve as a source of information about The Cochrane Collaboration;
- To provide or facilitate training and support for review authors, editors, handsearchers, and other contributors to The Cochrane Collaboration;
- To support regional editorial bases of Review Groups, Methods Groups and Fields/Networks by assisting in finding funding and mediating conflicts, either between Cochrane entities or between individuals and entities;
- To contribute to improving the quality of Cochrane Reviews by performing, supporting or promoting methodological research;
- To promote accessibility to The Cochrane Library to healthcare professionals, patients; and others, e.g., by pursuing national subscriptions and translations where necessary; and
- To handsearch general healthcare journals in the linguistic area of the Center and to submit the search results to the Collaboration’s trial database.
In fulfilling these core functions, Centers are required to

- Ensure effective and efficient communication and mediation between Center members and members of other entities for which the Center is a reference center;
- Maintain their details in the Cochrane Contact Database (ARCHIE);
- Maintain a description of the Center’s activities in The Cochrane Library (Center Module) at least on an annual basis;
- Ensure sustainability and continuity of the Center’s program of work; and
- Produce a strategic/business plan with targets, and an annual report which reports progress against these targets.

In addition to its core obligations, the USCC has had unique functions that advance The Cochrane Collaboration’s mission. From 1994 - 2005, the USCC had responsibility for coordination of the Cochrane Central Registry of Controlled Trials (CENTRAL), and associated functions. Since 2006, the USCC has continued to develop, update, and maintain the Master List of Journals Being Searched (Master List), which includes 2,309 unique journals that have been or are being handsearched by members of The Cochrane Collaboration.

The USCC’s major unique functions at this time are to

- Coordinate and support Consumers United for Evidence-based Healthcare (CUE), a coalition of US healthcare consumer advocacy groups;
- Monitor an online handsearching course;
- Monitor an online course on evidence-based healthcare (EBHC); and
- Contribute to hosting the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations, to be held in Keystone, Colorado October 18-22, 2010.

4. **Funded projects**

4.1 **Agency for Healthcare Research and Quality (AHRQ) large conference grant (2007 - 2010)**

In 2007, the USCC was awarded a 3-year grant from AHRQ to conduct a series of conferences to increase US involvement in and contributions to The Cochrane Collaboration. The complete conference series includes three US Cochrane Contributors’ Conferences, three meetings of US contributors at the annual Cochrane Colloquium, three training workshops titled Evidence-based Healthcare (EBHC) and Critical Appraisal of the Healthcare Literature (for consumers) at the annual Cochrane Colloquium, and three training workshops titled Train the
Trainers in EBHC and Critical Appraisal at the annual Cochrane Colloquium. As a result of USCC conferences and workshops, a critical mass of US-based clinicians, educators, researchers, policymakers and consumers have been trained to prepare and use the essential elements of EBHC. This critical mass has increased our effectiveness in dissemination of information about EBHC and about The Cochrane Collaboration.

The conference series in 2009 included a US Contributors’ Conference, Stakeholder Summit on Using Quality Systematic Reviews to Inform Evidence-based Guidelines (see Section 6.3.1 and Appendix A); a US Contributors’ Meeting at the 17th Cochrane Colloquium in Singapore (see Sections 6.4.2 and Appendix B); and two workshops Train the Trainers in EBHC and How to Ask an Answerable Question for Healthcare and Health Research— for consumers (see Section 6.2.1). A complete list of workshops and courses is included in Appendix C. Evaluation is an essential part of the USCC’s conference and workshop education plan and is used for forward planning of conferences and workshops.

Planning for the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations to be held in Keystone, Colorado was well underway in 2009. Kay Dickersin and Hannah Rothstein, of the Campbell Collaboration, were appointed Co-chairs of the Scientific Program Committee, and in 2009 formed a Planning Committee to develop the program, topics and speakers for the daily plenary sessions. USCC staff also participated in the monthly Colloquium Organizing Committee teleconferences.

4.2 Agency for Healthcare Research and Quality (AHRQ) small conference grant (2007 - 2008)

CUE has continued to foster the growth of a critical mass of consumer advocacy organizations committed to integrating critical appraisal and the concepts of EBHC into their work. During 2009, we completed followup work (analyzing evaluations, preparing and posting conference report) related to the 2008 Annual CUE Membership Meeting, July 23, 2008 in Washington, DC, funded by AHRQ (see Appendix D).

4.3 Agency for Healthcare Research and Quality (AHRQ) large conference grant (2009 - 2012)

On September 30, 2009, the USCC was awarded a 3-year conference grant to host two membership conferences and a major Summit in conjunction with CUE. The overall program objective is to host a series of in-person and online conferences, workshops, and meetings related to translating research into practice and policy, with a focus on methodological and technical...
issues of major importance in the field of health services research. During the time period September 30, 2009 - December 31, 2009, we hosted CUE Steering Committee teleconferences, and appointed planning committees for the 2010 CUE Annual Membership Meeting and the 2010 CUE Advocacy Summit, to be held October 17, 2010. These meetings will be held immediately preceding the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations in Keystone, Colorado. CUE conferences and workshops will contribute to a critical mass of US-based consumers trained to prepare and use the essential elements of EBHC and to work effectively with clinicians, educators, researchers, and policymakers to promote the use of EBHC.

4.4 The Cochrane Collaboration Prioritisation Fund grant (2007 - 2009)

We received an award in 2007 from the Cochrane Collaboration Prioritisation Fund to work on the Evidence-based Priority-Setting for New Systematic Reviews and Clinical Trials.

The overall goal of this project was to test a method for prioritizing clinical questions in eyes and vision that need to be addressed by Cochrane systematic reviews. We used the 2005 American Academy of Ophthalmology Preferred Practice Patterns on the management of primary open angle glaucoma to derive 45 answerable clinical questions that could be addressed by randomized controlled trials (RCTs) and systematic reviews of RCTs. Between April and September 2008, we used a two-round Delphi survey asking members of the American Glaucoma Society to prioritize the questions for research that would inform good patient care. The results of this project have been written up and a manuscript accepted for publication in 2010. (Li T, Ervin A, Scherer R, Jampel H, Dickersin K. Setting priorities for comparative effectiveness research: A case study using primary open-angle glaucoma. Ophthalmology. In Press).

4.5 National Eye Institute (NEI) contract (2002 - 2009)

The Cochrane Eyes and Vision Group, US Satellite (CEVG@US), based at the USCC, was awarded a 7-year contract in 2002 from the NEI to build a critical mass of US-based vision researchers and practitioners who are trained to prepare and use systematic reviews. CEVG@US held two workshops in 2009 on how to complete a systematic review (see Appendix C). Sections 6.8 and 7.1 provide additional information on the activities of CEVG@US.
4.6 Blue Shield of California Foundation

We received a grant from the Blue Shield of California Foundation to enable course developers Kay Dickersin and Musa Mayer to enhance the online course *Understanding Evidence-based Healthcare: A Foundation for Action*. The project goal is to make the course more directly applicable to practicing doctors and researchers by adding a new targeted module and new introductions to existing modules that address the modules’ relevance to healthcare providers.

5. San Francisco Branch of the USCC

The San Francisco Branch of the USCC, based at the University of California, San Francisco, (UCSF) supports the HIV/AIDS CRG and helps manage conflicts of interest within The Cochrane Collaboration. The Branch advises on management of Cochrane’s electronic Criticism Management System as it has transitioned to Wiley InterScience, Inc., the publisher of *The Cochrane Library*, and to *The Cochrane Library* Editor-in-chief. The Branch actively promotes The Cochrane Collaboration in the western United States.

In 2009, Lisa Bero was a Center representative on The Cochrane Collaboration Steering Group (CCSG), a member of the CCSG Executive Group, and the CCSG representative to the Cochrane Collaboration Feedback Management Advisory Group. She is the Abstract Committee Chair for the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations in Keystone, Colorado. Dr. Bero is also the Cochrane Collaboration representative to the World Health Organization (WHO) for the Collaboration’s application to be a non-governmental organization in official relations with WHO. Dr. Bero will be on sabbatical from September 21, 2009 - March 22, 2010 at WHO.

Dr. Bero has worked on two systematic reviews underway in 2009: (1) for the Effective Practice and Organisation of Care Group, “Effect of outpatient pharmacists' non-dispensing roles on patient outcomes and prescribing patterns” by Nkansah N, Mostovetsky O, Yu C, Cheng T, Beney J, Bond CM, Bero L. Cochrane Database of Systematic Reviews 1997, Issue 4. Art. No.: CD000336. DOI: 10.1002/14651858.CD000336 (Update) and for the Methodology Review Group, “Pharmaceutical industry sponsorship and research outcomes” by Lisa Bero, Joel Lexchin, Bryan Sandlund, Sergio Sismondo (Protocol) (see Appendix E for Dr. Bero and Dr. Rennie’s presentations and papers).
6. Progress report on targets for 01/01/09 to 12/31/09

Based on the USCC mission and responsibilities, performance targets, objectives and activities were developed to guide the work of the USCC in 2009. This section summarizes the achievements related to 2009 performance targets (see Appendix F for USCC Performance Targets for January 1, 2009 - December 31, 2009).

6.1 Coordinate, maintain, and regularly update the Master List of Journals Being Searched (Master List)

6.1.1 Coordinate, maintain, and regularly update the Master List

The USCC coordinates the Master List, which as of January 18, 2010 includes 2,406 unique journals and 367 conference proceedings that are handsearched by members of The Cochrane Collaboration to identify controlled trials. The Master List database is maintained through continuous updating which occurs whenever an entity notifies the USCC of a new search, completion of a search, or discontinuation of a search. To keep the Master List current, the USCC conducts an annual Master List update survey, which asks the coordinators of all registered handsearches to provide updated information about their handsearch activities via email. Due to a lack of funding, beginning in 2010, the USCC will no longer coordinate the Master List.

6.2 Provide training and support for reviewers, review group coordinators, trial search coordinators, editors, handsearchers, consumers, those responsible for training activities, and others (review group coordinators were renamed “managing editors” in 2009).

6.2.1 Develop and facilitate Cochrane training workshops and courses

The USCC developed and presented training workshops on the following topics in 2009: “How to perform a Cochrane systematic review,” “Evidence-based occupational therapy,” “Evidence-based ophthalmology,” “How to ask an answerable question for health care and health research,” and “Train the trainers in evidence-based healthcare” (see Appendix C for details).

In addition to these training workshops, the USCC continues to monitor, revise, and develop web-based distance education courses. Following are courses that were available in 2009.
• **Handsearching: Identifying and Classifying Controlled Trial Reports:** This course was developed in 2003 and revised in 2004 and 2005. In 2006, the course was transferred to the Johns Hopkins Bloomberg School of Public Health WebCT platform where it has remained.

A tracking system allows us to monitor registrant “visits” to the course. As of December 10, 2009, 720 individuals had registered for the course, representing a wide cross-section of countries (e.g., Brazil, Norway, Thailand, India and Iran) and diverse professions (e.g., clinicians, informaticians, epidemiologists, nurses, librarians, lawyers, and consumers). The mean number of visits to the training website by the 713 registrants was 43, (range, 0 to 754; median = 9). Of those who accessed the course at least once, the mean number of visits was 72 (median = 44). Sixty-two students have completed the course and passed the online “test” which consists of handsearching an online version of a vision science journal. An additional 59 students are in the process of taking the test.

• **Understanding Evidence-based Healthcare: A Foundation for Action:** This course is designed to help consumer advocates understand the fundamentals of EBHC concepts and skills. It has been available free of charge since September 2007 when it was first launched. It is accessible from the USCC and CUE webpages and has been widely accessed by consumers, healthcare providers, researchers, policymakers and students in healthcare disciplines ([http://apps1.jhsph.edu/cochrane/CUEwebcourse.htm](http://apps1.jhsph.edu/cochrane/CUEwebcourse.htm)). As of April 12, 2010, 2,614 individuals had enrolled in the course. During calendar year 2009 alone, 989 people registered for the online course.

Course objectives are to provide consumer advocates with the tools they need to
- Successfully navigate the world of medical information;
- Critically appraise research studies;
- Influence the creation of responsible public policy in healthcare; and
- Help the people they serve to make healthcare choices based on the best available evidence.

The course comprises 5.5 hours of audio lectures with slides, presented in six modules, viewable in 10 - 15 minute segments. Hosted by the Johns Hopkins Bloomberg School of Public Health, the course has a single lecturer, consumer advocate Musa Mayer.

In 2009, work was underway to enhance the online course to make it more directly applicable to practicing doctors and researchers. A new module and revised introductions to existing modules were created to highlight the course’s relevance to practicing healthcare providers.
• Translating Critical Appraisal of a Manuscript into Meaningful Peer Review: The course, comprising 12 didactic lectures, is expected to launch in 2010.

The target audience for the course are clinicians who wish to learn more about serving as a peer reviewer for biomedical journals. The course’s learning objectives include increasing participants’ understanding of available evidence regarding the effectiveness and utility of the peer review process, different types of clinical research questions and appropriate designs for studying them, strengths and limitations of various study designs, measures used to test association between exposures and outcomes, how to apply critical appraisal to manuscripts submitted for peer review, and how to provide meaningful feedback to authors and editors that they can use to improve manuscript quality.

6.2.2 Make available on the worldwide web and elsewhere guides for Cochrane procedures

Training and supporting review authors, trials search coordinators, managing editors, handsearchers and consumer advocates are core functions of the USCC. Training materials are regularly reviewed and modified to ensure that they are accurate, current and useful. The following guides, handbooks, other documents, and Internet links are accessible on the USCC website:

• EBHC and general information including primers, articles, books, and related organizations;
• Cochrane Collaboration background documents including The Cochrane Policy Manual and the Cochrane Handbook for Systematic Reviews of Interventions, and access to The Cochrane Library;
• A full range of resources for reviewers including Cochrane documents (Cochrane Handbook for Systematic Review Interventions, RevMan homepage, and GRADEpro software) and outside resources such as the NHS Centre for Reviews and Dissemination’s Undertaking Systematic Reviews of Research on Effectiveness;
• Handsearcher resources (e.g., Handsearcher Training Manual and Handsearch Training Resource, Capetown Colloquium 2000);
• The Master List of Journals and Conference Proceedings Being Searched as well as forms to use to register a new search for a journal or conference; and
• Trials search coordinator resources including the Guide for Trials Search Coordinators.
Information about the following online training programs is also available:

- Online handsearching course; and
- Online course oriented to consumers, *Understanding Evidence-based Healthcare: A Foundation for Action*.

The following meeting reports and podcasts of presentations are accessible:

- Current and past USCC Annual Reports, CUE Annual Meeting and Conference Reports, US Contributors' Meeting and Conference Reports and many USCC workshop agendas and/or abstracts;
- Podcasts of 2009 USCC Conference, *Stakeholder Summit on using Quality Systematic Reviews to Inform Evidence-based Guidelines*; and

USCC staff regularly review and update website resource pages, ensuring that all links are active (see Section 6.3.6).

6.2.3 Provide ongoing support and training through individual contact, email discussion lists, and directories

USCC staff communicate regularly with members of various Cochrane entities and provide review authors with ongoing support and training through mentoring and methodological consultation. With support from the NEI, the Center provides US-based authors working on Cochrane systematic reviews related to eyes and vision with a methodologist who prepares materials for and works with authors via email, telephone and in-person consultation. Twenty-five review authors received technical assistance from USCC staff in 2009 (see Section 6.2.1 for additional training and support information).

6.2.4 Maintain online distance education course for consumer advocates, *Understanding Evidence-based Healthcare: A Foundation for Action*

On September 15, 2007, the USCC, in conjunction with CUE, launched *Understanding Evidence-based Healthcare: A Foundation for Action*, an online course available free of charge. This course was developed to help consumer advocates understand EBHC and to find, critically appraise, and use source information to inform their healthcare decision making. The course continues to be offered free of charge and as of April 12, 2010, 2,614 individuals had enrolled in the course.
6.2.5 Plan and implement changes to consumer online distance education course to appeal to healthcare providers

Work continued on enhancements to the 5.5 hour consumer online course, *Understanding Evidence-based Healthcare: A Foundation for Action* oriented to practicing healthcare providers. A new module has been recorded, in addition to introductions to each module by a prominent physician, highlighting the direct application of the course to the medical community. The course will be available in 2010. Blue Shield of California Foundation has provided support for this project.

6.3 Promote awareness of The Cochrane Collaboration and access to Cochrane products

6.3.1 Plan and host a US Contributors’ Conference

The USCC hosted the US Contributors’ Conference, *Stakeholder Summit on Using Quality Systematic Reviews to Inform Evidence-based Guidelines*, held June 4-5, 2009 in Baltimore, Maryland (see Appendix A). The conference theme was selected in response to requests for information about the best uses of systematic reviews in clinical practice guideline development and how to assess the quality of the evidence. The conference aimed to provide a forum for exchange between systematic reviewers and guideline developers, particularly on methodological aspects of the work. Major conference goals were to contribute to increased production of high quality systematic reviews that are responsive to the needs of user communities, and to enhance professional society adoption and application of these reviews to inform evidence-based guidelines.

The Conference Planning Committee designed a program that addressed current key issues for North American systematic reviewers, methodologists, guidelines developers, clinicians, consumers, policy makers, and researchers. Speakers were invited to address topics that included standards for systematic reviews from both the reviewer and user perspectives, current challenges in “grading” evidence for guideline development and strategies to make guidelines “actionable.” Presentations by reviewer-guidelines developer teams that have previously worked together highlighted effective strategies and ongoing challenges.

The conference agenda incorporated plenary sessions, panel discussions, and workshops. Speakers and participants included representatives of The Cochrane Collaboration, AHRQ’s evidence-based practice centers, educational and research institutions, government agencies, advocacy organizations, professional societies, and public and private organizations.
Throughout the two days of the conference two recurrent themes emerged, 1) guidelines developers, who are often unfamiliar with the process of performing a systematic review, are seeking standards for systematic reviews, and 2) there is a lack of available evidence on vital clinical questions. Speakers and audience members also emphasized the need for ongoing orientation and education in systematic review processes and EBHC for guidelines development teams, increased transparency of documentation and procedures reporting in the work of all parties, explicit assessment of gaps in the evidence, and careful reporting of and attention to conflicts of interest. Different systems to grade evidence were proposed and lively exchanges ensued between individuals using an established system and those using a self-designed hybrid system. Issues of quality of evidence, strength of recommendation and clinical judgement were raised in a number of presentations and discussion sessions. Concerns were voiced as to whether existing systematic reviews cover the many pressing clinical questions which guidelines must address.

Following the conference, podcasts of all presentations were uploaded and a conference report posted onto the USCC website for the convenience of individuals unable to attend the conference. Feedback from the conference evaluation indicated that the meeting met participants’ expectations, and was useful in crystallizing critical issues for advancing the production and use of clinical evidence.

6.3.2 Ensure that individuals (including the media and consumers) and institutions within the region served by the USCC are aware of The Cochrane Collaboration and the USCC and understand its products and functions; highlight Cochrane activities in presentations and reports to health professionals, consumers, and others whenever relevant

Promoting awareness within the US of The Cochrane Collaboration is an important role of the USCC. USCC staff make presentations about the Collaboration to relevant audiences to increase understanding of what the Collaboration can provide and to build stronger partnerships with the media and healthcare consumers. In 2009, USCC staff participated in conferences, meetings, and workshops and made presentations highlighting EBHC, The Cochrane Collaboration, Cochrane activities, and consumer advocacy and The Cochrane Library (see Appendix E for USCC staff presentations).
6.3.3 Work to ensure that *The Cochrane Library* is made available and accessible to regional institutions, government agencies, professional organizations and others

Promotional materials for *The Cochrane Library* are distributed to all workshop and meeting participants. To increase the availability and accessibility of *The Cochrane Library* in the US, John Wiley and Sons, Inc. continues to provide free 30-day access to all participants in USCC-sponsored workshops. The USCC also encourages institutions, organizations and colleagues to expand subscriptions to Cochrane products. In addition, all CUE member organizations continue to receive a free subscription to *The Cochrane Library*.

Additional examples of access to *The Cochrane Library* include: (1) the state of Wyoming offers free access to *The Cochrane Library* to its residents; and free online access to the public is offered as follows: (2) the National Institute of Child Health and Human Diseases provides the complete text of Cochrane reviews produced by the Cochrane Neonatal Review Group; (3) MEDLINE provides abstracts of Cochrane systematic reviews; and (4) the Cochrane Collaboration and Wiley Interscience provide Cochrane review abstracts via their webpages.

6.3.4 Encourage the news media to use *The Cochrane Library*, provided free of charge through John Wiley and Sons, Inc.

Interactions with the media include personal contacts by telephone, email, and at meetings. In 2009, we received contact about more than two dozen stories related directly to Cochrane reviews or to evidence-based healthcare or comparative effectiveness research. For example, Pam Louwagie, a reporter at the *Minneapolis Star Tribune*, inquired about Cochrane reviews on methods to prevent falls in older people. She wrote a three-part series on falls in nursing homes, published November 19th and 20th, 2009 in the *Minneapolis Star*. Sharon Begley wrote a Newsweek Web Exclusive titled, *A Science Fact Check: “Meet the Cochrane Collaboration, A group of scientists who are verifying the latest research in their spare time.”* We also contact reporters when we see an article indicating they may not be aware of relevant information in *The Cochrane Library*. For example, in 2009 we contacted Kelly Brewington, a medical reporter at the *Baltimore Sun* to let her know how *The Cochrane Library* might have been useful and to alert her to Wiley’s policy of complementary subscriptions for journalists.

6.3.5 Work with physicians, consumers, government and others to identify ways in which Cochrane reviews can better meet their needs

The USCC is committed to identifying ways that Cochrane reviews can meet the needs of physicians, consumers, government and other constituencies. We do this in several ways,
including one-on-one contact (for example by telephone), presentations at professional conferences, and hosting of conferences by the USCC. In 2009, Janie Gordon, Kay Dickersin and Roberta Scherer had numerous telephone contacts with interested persons; Kay Dickersin presented the Cochrane Collaboration at a variety of conference (see Appendix E); and we hosted several conferences and workshops aimed at disseminating information about the Cochrane Collaboration in the context of professional practice and consumer needs. For example, we hosted the 2009 US Contributors’ Conference, *Stakeholder Summit on Using Quality Systematic Reviews to Inform Evidence-based Guidelines*. A major conference goal was to contribute to increased production of high quality systematic reviews that are responsive to the needs of user communities, and to enhance professional society adoption and application of these reviews to inform evidence-based guidelines. Our attendees included physicians, consumers, government representatives, systematic reviewers, and guidelines developers who worked throughout the meeting to explore ways to enhance the relevance of systematic reviews to pressing needs of user communities (see Section 6.3.1). A Wiley representative attended the meeting and made demonstrations of *The Cochrane Library* available to attendees.

The USCC actively encourages CUE members to participate in Cochrane review groups to integrate a consumer perspective not only into the Plain Language Summary but into all aspects of review group activities, including priority setting for systematic review production. To help consumers prepare for this role we offer educational programs such as our online course *Understanding Evidence-based Healthcare: A Foundation for Action*, and workshops such as *How to Ask an Answerable Question for Healthcare and Health Research— for consumers* offered at the Singapore Colloquium. Didactic sessions were also included at the *2009 Annual CUE Membership Meeting* held in Washington, DC, September 3, 2009 (see Sections 6.2.1 and 6.7.1).

6.3.6 Ensure interest, relevance and accuracy of the USCC’s website

The USCC continues to expand its presence on the Internet. Continued maintenance and development of the USCC web presence increases visibility of The Cochrane Collaboration, the USCC and CUE. In 2009, USCC staff made improvements to both the USCC and CUE webpages to facilitate easy navigation for visitors to the site and to increase interest and relevance.

Specific improvements follow:
- Added podcasts from our conferences for ready access to presentations;
- Fewer “clicks” to get to information;
- Continuous monitoring to provide information updates;
• Regular checking for broken links;
• Easier access to The Cochrane Collaboration features;
• Updated EBHC resources;
• Updated listings of workshops, conferences, meetings, announcements and news; and
• Updated posting of conference reports.

6.4 Perform USCC administrative functions

6.4.1 Perform handsearching of US medical journals and conference proceedings

In 2009, a total of 48 journal-years (from US medical journals and conference proceedings) were handsearched by the USCC, resulting in the identification of 772 RCT reports and 170 controlled clinical trial reports. In 2009, a total of 1,582 RCT reports and 617 controlled clinical trial reports (includes trials identified the previous year and sent for medical subject heading (MeSH) indexing if the article or abstract was not already MeSH indexed) were submitted to Cochrane’s CENTRAL Register of Controlled Trials.

6.4.2 Participate in annual Collaboration meetings at the 2009 Cochrane Colloquium and midyear meetings

The USCC hosted a US Contributors’ Meeting at the XVII Colloquium in Singapore, October 12, 2009, which was attended by 33 US contributors. Attendees reported on the work of their entity (Center, CRG, Field, Methods Group, CUE) and Lisa Bero gave a CCSG report. US contributors discussed upcoming Cochrane training programs in the US, outreach and dissemination efforts, and funding opportunities and barriers. Of special note was discussion of plans for the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations in Keystone, Colorado (see Appendix B for meeting minutes).

In addition to the US Contributors’ Meeting, USCC staff participated in the following Center-related meetings during the 2009 Colloquium:

• Meet the Entities exchange;
• Cochrane Center staff meeting where staff from all Cochrane Centers and Branches met to exchange information and ideas and to hear CCSG and Center Director updates;
• Cochrane Consumers Network and Field (CCNet) meetings;
• Cochrane Center Directors meeting;
• Colloquium Policy Advisory Group meeting; and
• Colloquium 2009 debriefing session.
6.4.3 Perform general Center administrative functions

The USCC performed general Center administrative functions:

- Performed comprehensive maintenance and updates of the US Cochrane Center Contact Directory. USCC staff added contacts from workshops and meetings, The Cochrane Library, ARCHIE, and other sources to update the Directory, which includes names, postal and email addresses, phone numbers, and other relevant information;

- Completed and submitted to the Cochrane Secretariat documentation regarding the Center’s activities, including the Center’s module and bi-annual monitoring report. The module continues to be updated quarterly, or as needed. This Annual Report describes the USCC’s progress on 2009 targets (see Appendix F) and presents targets for 2010 (see Appendix H); and

- Responded to inquiries from healthcare professionals, consumers, journalists, and others about the USCC, The Cochrane Collaboration, The Cochrane Library, CUE and EBHC.

6.5 Seek and obtain funding support for USCC activities

6.5.1 Continue working with funders to support USCC activities.

AHRQ (Grant No. R13 HS016868) provided support to the USCC in 2009 for the US Contributors’ Conference, Stakeholder Summit on Using Quality Systematic Reviews to Inform Evidence-based Guidelines, held June 4 - 5, 2009 in Baltimore, Maryland. AHRQ also awarded the USCC a three-year grant in 2009 (R13 HS017668) to host a series of in-person and online conferences and meetings for consumer advocates and others related to translating research into practice and policy, with a focus on methodological and technical issues of major importance in the field of health services research.

Additional support to the Center in 2009 was provided by NEI through a contract for a project which aims to develop a critical mass of US-based vision researchers and practitioners trained in preparing and using systematic reviews and to increase awareness of EBHC in eyes and vision.

Blue Shield of California Foundation provided support to enhance and extend the Johns Hopkins online course, Understanding Evidence-based Healthcare: A Foundation for Action, to appeal directly to practicing doctors and clinical researchers.
6.5.2 Work with USCC branches and US-based entities to identify sources of funding and to leverage combined efforts to obtain funding.

The USCC works with all Cochrane US-based entities to identify potential funding sources and to leverage our combined efforts. US contributors discuss upcoming opportunities at a special meeting at the annual Cochrane Colloquium and throughout the year as opportunities arise.

6.6 Conduct and disseminate research

6.6.1 Conduct methodological research on issues of importance to systematic reviews, reporting biases, trials registers, and evidence-based healthcare.

A core objective of the USCC is to conduct methodological research related to systematic reviews, trials registers, and meta-analysis. To date, a modest program is ongoing with studies funded in targeted subject areas (e.g., eyes and vision, trials of the drug gabapentin) and on broadly applicable methodologic topics.

6.6.1.1 Evidence-based Priority-Setting for New Systematic Reviews and Clinical Trials Project

The overall objective of the Evidence-based Priority-Setting for New Systematic Reviews and Clinical Trials Project, funded by The Cochrane Collaboration Prioritisation Fund, is to test a framework for setting priorities for randomized controlled trials and systematic reviews related to interventions for primary open angle glaucoma and ocular hypertension. We translated guideline statements into answerable clinical questions and asked clinicians to rank the importance of each question. We then examined existing evidence, summarized in reliable systematic reviews, to identify remaining evidence gaps. This framework, if successful, could subsequently be applied to setting research priorities in other health fields (see Section 4.4). Tianjing Li presented preliminary results at the 2008 Cochrane Colloquium. A manuscript describing the study findings has been accepted for publication in Ophthalmology. Results were also reported at the Sixth International Congress on Peer Review and Biomedical Publication, held in September 2009 at Vancouver, Canada and the 30th Society for Clinical Trials Annual Meeting (see Appendix E).
6.6.1.2 How well do clinicians understand clinical trials and clinical trial registration? (CEVG@US)

In 2006, the Association for Research in Vision and Ophthalmology (ARVO) announced that any investigator submitting a 2007 abstract describing a controlled clinical trial must have registered that trial with an appropriate trials register. This provided an opportunity to examine how well clinicians understand clinical trials and clinical trial registration. For 2007 abstracts, all those describing an RCT or providing registration information were identified. Information on study participants, intervention, sample size, and primary outcome was abstracted and compared to similar information abstracted from clinicaltrials.gov. Results were reported at the Sixth International Congress on Peer Review and Biomedical Publication, held in September 2009 at Vancouver, Canada (see Appendix E).

6.6.1.3 Commercial relationships, funding and full publication of randomized controlled trials initially reported in conference abstracts (CEVG@US)

We aim to assess the concordance of reported commercial conflicts of interest and publication of randomized controlled trials initially presented as conference abstracts at ARVO meetings. Abstracts describing RCTs that were presented at ARVO meetings in 2001, 2002, and 2003 have been identified. We extracted data from each abstract, including “author commercial interest” (as defined by ARVO), study funding, and direction of results of primary outcome. Commercial relationships and funding sources were not mutually exclusive. Using PubMed (latest search March 2009) and direct author contact, we identified full reports associated with included abstracts. Preliminary results for 2001 include identification of 130 abstracts with results reported for a primary outcome. Sixty-nine (53%) had been published in full. Abstracts noting commercial relationships had a higher full publication rate when the primary outcome result favored the experimental group. Further research is needed to explore this association. This work was presented at the Sixth International Congress on Peer Review and Biomedical Publication, held in September 2009 at Vancouver, Canada (see Appendix E).

6.6.1.4 Survey of systematic reviews and meta-analyses in glaucoma (CEVG@US)

We aim to identify and characterize published systematic reviews relevant to glaucoma to further the Evidence-based Priority-Setting for New Systematic Reviews and Clinical Trials Project, and to identify authors of non-Cochrane reviews interested in converting their reviews to the Cochrane format. In collaboration with information specialists at the William H. Welch Medical Library at Johns Hopkins University, Drs. Tianjing Li and Roberta Scherer searched
PubMed, *The Cochrane Library*, and EMBASE up to September 2009 to identify eyes and vision systematic reviews.

To date, we have identified over 600 systematic reviews on eyes and vision topics, and have classified them by publication date, condition, and type of research question addressed (e.g., etiology, prevention, diagnosis, or intervention). For intervention reviews, we have begun to abstract research question (study population, interventions being compared, and outcomes), databases searched, search date, criteria for including studies into the systematic review, risk of bias assessment, analytic methods, and funding sources (Li T, Dickersin K, Scherer R. Re: Registering systematic reviews. *CMAJ*. 2010 Jan 12;182(1):13-14. Available at: http://www.cmaj.ca/cgi/eletters/182/1/13#324055).

### 6.6.1.5 Develop an open access study-based eyes and vision trials register (E-Trials) (CEVG@US)

We aim to develop a study-based eyes and vision trials register, rather than a citation-based register, to assist systematic reviewers and other investigators. Dr. Tianjing Li and Ms. Elizabeth Ssemmanda began development of the study-based register by reviewing existing study-based specialized registers from other Cochrane review groups. The next steps include design of the database, development of a procedures manual, and execution of the database design in a Filemaker Pro database. No significant work on this project was completed in 2009; work will be restarted in 2010.

### 6.6.1.6 A study of internal company documents and publications to identify reporting and other biases in clinical trials of gabapentin for off-label indications

We aim to determine the extent and nature of reporting biases in clinical trials of gabapentin related to four off-label indications: migraine prophylaxis, bipolar disorders, neuropathic pain and nociceptive pain. We compared internal company documents of trials related to gabapentin, which became public consequent to litigation against Pfizer, with published reports of the corresponding trials. We looked for discrepancies on primary and secondary outcomes in the trial protocol and publication. With Dr. Swaroop Vedula as the lead author, results from this project were published in the *New England Journal of Medicine* in 2009 (see Appendix E).

In a second study, we examined several internal company documents including trial protocols, internal reports, publications, emails and internal memos to identify the details of a publication strategy. In the context of a publication strategy, reporting biases constitute a potent mix because they serve to distort the scientific evidence available to the public. Such distortion is
associated with severe consequences in the case of trials related to off-label uses of drugs because trial publications are frequently the only source of trial data available to the public. Findings from this study have been presented at the Sixth International Congress on Peer Review and Biomedical Publication, held in September 2009 at Vancouver, Canada (see Appendix E).

6.7 Facilitate the development and growth of the USCC’s consumer coalition, Consumers United for Evidence-based Healthcare (CUE)

6.7.1 Support CUE infrastructure and functions

As the scientist partner of CUE, the USCC convened monthly CUE Steering Committee teleconferences, supported a one-day CUE Annual Meeting, and a half-day face-to-face Steering Committee meeting in 2009, despite a lack of funding for these meetings. The USCC also encouraged CUE member organizations to develop and implement collaborative projects and to disseminate CUE’s EBHC resources to their membership.

CUE 2009 projects included

- Maintaining Understanding Evidence-based Healthcare: A Foundation for Action, a free of charge online course on EBHC for consumer advocates;
- Continuing to encourage members of CUE’s member organizations to register in the online EBHC course;
- Teaching consumers about evidence and how to use it in making healthcare decisions;
- Recruiting new CUE member organizations;
- Adding information about EBHC, CUE, and the USCC to CUE member organizations’ agendas, meetings, workshops, newsletters, and websites;
- Establishing new relationships and working with existing consumer organization partners to increase dissemination of EBHC;
- Disseminating EBHC through presentations including a workshop entitled: How to ask an answerable question for health care and health research: A workshop for consumers, XVII Cochrane Colloquium: October 12, 2009 in Singapore;
- Identifying new potential funding sources; and
- Increasing participation of CUE members on advisory committees, peer review panels, and EBHC listservs.

The 2009 Annual CUE Membership Meeting, September 3, 2009, was hosted by the US Cochrane Center (see agenda in Appendix G and report in Appendix I). The goal was to bring CUE’s leadership and membership together to engage in a forum on current trends and
challenges in EBHC and to discuss administrative matters relevant to the coalition. Several CUE members presented some of their current projects, including strategies for improvement in quality measures in Medicaid-covered maternity services, the quality of care delivered in retail-based health clinics, the evidence for making hospitals safer, and organizing the grassroots to assure that women’s health issues are included in all new healthcare programs and policies. A legislative update on healthcare reform was provided by a staff member from Maryland Senator Barbara Mikulski’s office. Jean Slutsky, AHRQ, highlighted the importance of consumer participation in AHRQ programs, specifically in comparative effectiveness research. A representative from the Foundation for Informed Decision Making spoke about the process of shared decision making and available disease-specific tools. The meeting provided a forum for CUE members with different advocacy priorities to come together to discuss their work, address common concerns and learn from one another. Recurrent themes included strengthening the CUE infrastructure, obtaining reliable funding for infrastructure and proposed projects, and building upon the coalition’s momentum.

Planning for the CUE Advocacy Summit, *Advocacy in the Era of Evidence: An International Summit for Consumer Advocates*, scheduled for October 17, 2010, began in 2009. Because the summit immediately precedes the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations, in Keystone, Colorado, it presents a unique opportunity to bring together an international group of evidence-based consumer advocates and their scientist partners. We are planning for 100 attendees.

The Summit will lay the groundwork for partnerships among consumer advocacy groups throughout the United States and globally, as well as new consumer-scientist partnerships. We envision that this Summit, by convening CUE members and those engaged in systematic reviews, will lead to increased participation by attendees in Cochrane activities.

6.7.2 Strengthen the ties between CUE and The Cochrane Collaboration Consumer Network (CCNet)

With the support of the USCC, CUE members have strengthened ties with CCNet by collaborating on activities and projects that address common goals. In 2009, CUE members

- Interacted with their peers at the 17th Cochrane Colloquium in Singapore, participating in a workshop with CCNet members, *How to ask an answerable question for health care and health research— for consumers*, and CCNet business meetings and educational sessions;
- Participated in the CCNet moderated e-mail list;


• Participated in CCNet’s Geographical Centres Advisory Group (Barbara Warren, CUE Co-chair, and Maryann Napoli);
• Participated in CC Colloquium Stipends Committee (Maryann Napoli);
• Participated in the CCNet External Review of Consumers in the Cochrane Collaboration (John Santa, CUE Steering Committee member, Barbara Warren, Kay Dickersin, and Janie Gordon); and
• Promoted US consumer involvement with The Cochrane Collaboration.

Ann Fonfa, CUE member and representative of The Annie Appleseed Project, has actively participated with the Adverse Effects Methods Group. Maryann Napoli, CUE and CCNet member and Associate Director of the Center for Medical Consumers, has participated for many years in The Cochrane Collaboration as a consumer peer reviewer. Maureen Corry, CUE Steering Committee member and Executive Director of Childbirth Connection and Barbara Warren, CUE Co-chair and Executive Board Member of the National Coalition for LGBT Health have both served as peer reviewers for Cochrane reviews.

6.8 Work collaboratively with the CEVG@US satellite office

6.8.1 Share materials and resources related to educational projects

See Section 7.1 for details regarding the activities of the CEVG@US and Section 6.2.1 for collaborative educational projects.

6.8.2 Collaborate with CEVG@US on research projects

See Section 7.1 for details regarding the activities of the CEVG@US and Sections 6.6.1.2, 6.6.1.3, 6.6.1.4, and 6.6.1.5 for collaborative research projects.

6.9 Contribute to the Planning of the 2010 Cochrane Colloquium

6.9.1 Contribute USCC staff time toward the planning process

Kay Dickersin, Roberta Scherer, Janie Gordon and Lesia Green have been involved in the Colloquium planning process. USCC staff actively disseminated information about the upcoming Colloquium and devoted time on the agenda at the US Contributors Meeting, Singapore Colloquium, to an update and discussion. Throughout the year, Kay Dickersin, Roberta Scherer, and Janie Gordon participated in monthly Colloquium Organizing Committee teleconferences.
The USCC sought and obtained funding to cover expenses for Colloquium speakers and to cover Colloquium registration fees for consumers.

The USCC played an active role in the development of the scientific program of the Joint Colloquium of the Cochrane and Campbell Collaborations. The program supports the Colloquium theme “Bringing Evidence-Based Decision Making to New Heights.” Kay Dickersin, USCC Director, and Hannah Rothstein, Campbell representative, serve as Co-chairs of the Colloquium Scientific Committee. Lisa Bero, Director, USCC, San Francisco Branch, is Chair of the Abstract Committee and Karen Robinson, US contributor, is Chair of the Workshop Committee. The Scientific Committee began its meetings in Spring, 2009.

7. US-based Cochrane review groups

7.1 Eyes and Vision CRG - US Satellite (CEVG@US)

The CEVG registered with The Cochrane Collaboration in April 1997. The editorial base is located at the London School of Hygiene and Tropical Medicine, in London, England; the Coordinating Editor is Richard Wormald, FRCS, FRCOphth, a consultant ophthalmologist. CEVG@US members serve as CEVG Editors: Kay Dickersin has been an Editor since the group’s inception, and Roberta Scherer also serves as an Editor. Ann Ervin serves as an Internal Referee.

On April 22, 2002, the NEI of the National Institutes of Health funded the CEVG@US (first at Brown University and beginning October 1, 2005 at Johns Hopkins Bloomberg School of Public Health) to develop a critical mass of US-based individuals who would contribute to the CEVG@US. The mission of the CEVG is to prepare systematic reviews of interventions used to prevent or treat eye diseases and/or visual impairment and to offer workshops on how to complete a systematic review. CEVG@US also oversees and coordinates handsearching training, open to The Cochrane Collaboration and others, as well as handsearching efforts for the CEVG (see Section 6.2.1).

The CEVG@US satellite hosts the CEVG website (http://eyes.cochrane.org) and has collaborated with the editorial base in the development of short and long-term priorities for improving site navigation and layout. The website includes links from vision-based organizations (including the Association of Vision Science Librarians, the Institute of Ophthalmology, and the American Academy of Ophthalmology), a site map for improved navigation, and a listserv to encourage interested individuals to sign up to receive email notification of newly-published Cochrane titles, protocols, updates and reviews.
For Issues 1 - 4, 2009 of *The Cochrane Library*, CEVG submitted 14 new protocols, 15 new reviews, and 14 review updates. CEVG@US contributed 4 new protocols, 6 new reviews, and 2 review updates to Issues 1-4, 2009. Issue 1, 2010, contains 78 completed reviews and 53 protocols of reviews in progress from CEVG. Of those, CEVG@US has contributed 22 completed reviews and 20 protocols.

CEVG currently has 509 authors/co-authors of reviews, protocols or assigned titles from 21 countries around the world. CEVG@US has approximately 114 US authors and also collaborates with authors from other countries on reviews.

### 7.2 HIV/AIDS CRG

The Cochrane HIV/AIDS Group is an international network of healthcare professionals, researchers, and consumers working to prepare and maintain systematic reviews on the prevention, treatment and care of HIV infection and AIDS. With its editorial base at the UCSF, and with a satellite editorial base at the South African Cochrane Centre in Cape Town, the Cochrane HIV/AIDS Group was officially registered with the Cochrane Collaboration in March 1997.

The Cochrane HIV/AIDS Group's mission is to conduct systematic reviews of interventions in the four following areas of HIV/AIDS research: Behavioral, Social, and Policy Prevention; Biomedical Prevention; Therapeutics, Diagnostics, and Prognostics; and Health Services and Care. The Cochrane HIV/AIDS Group is an affiliate of The Cochrane Collaboration, the International AIDS Society, UCSF Global Health Sciences, and the UCSF AIDS Research Institute.

For Issues 1-4, 2009 of *The Cochrane Library*, the HIV/AIDS Review Group submitted 7 new protocols, 10 new reviews, and 2 review updates. Issue 1, 2010 contains 61 completed/published reviews and 42 published protocols of reviews in progress from the HIV/AIDS Review Group. We currently have 399 authors/co-authors of reviews, protocols or assigned titles from 38 countries around the world. Seventeen new review titles were registered in 2009.

### 7.3 Neonatal CRG

The Neonatal Group, registered in April 1993, is currently located at the University of Vermont and is funded through a contract with the National Institute of Child Health and Human
Development. Funding covers major editorial as well as administrative needs. Although now US-based, the Neonatal Group has benefitted from strong support in Canada, Australia, and the UK.

For Issues 1 - 4, 2009 of *The Cochrane Library*, the Neonatal Review Group submitted 21 new protocols, 7 new reviews, and 25 review updates. Issue 1, 2010 contains 258 completed reviews and 77 protocols of reviews in progress from the Neonatal Review Group. We currently have 547 authors/co-authors of reviews, protocols or assigned titles from 37 countries around the world. Eighteen new review titles were registered in 2009.

7.4 Prostatic Diseases and Urologic Cancers CRG

The Department of Veterans Affairs Coordinating Center is the administrative center for the Prostatic Diseases and Urologic Cancers Group and the Prostatic Diseases and Urologic Malignancies subgroups. The primary aim of the Department of Veterans Affairs Coordinating Center of the Prostatic Diseases and Urologic Cancers Group is to prepare, maintain, and disseminate systematic reviews of randomized controlled trials of interventions for benign prostatic diseases and urologic cancers.

In 2009, systematic reviews were conducted by collaborators from relevant disciplines including urology, oncology, and internal medicine with technical support, as needed, provided by experts in biostatistics, consumer groups and pharmaceutical companies. Dr. Wilt served as the overall Coordinating Editor, but divided his responsibilities with Dr. Mike Shelley. Rod MacDonald was the Feedback Editor, Jim Tacklind the Managing Editor, and Indy Rutks the Trials Search Coordinator. Malcolm Mason, of Cardiff, Wales, served as the Coordinator of the Urologic Malignancies subgroup.

The Prostatic Diseases and Urologic Cancers CRG contacted and worked with individuals and other prostate disease organizations throughout the United States and Europe to develop and assist with Cochrane reviews and perform handsearches for trials relevant for reviews. These organizations included Blue Cross Blue Shield, Prostate Trials Office, National Institute for Health Research Centre for Reviews and Dissemination, European Organization for Research and Treatment of Cancer, and Prostate Cancer Trialists’ Collaborative Group. The CRG worked closely with the Cochrane Cancer Network and other Cochrane entities for technical and administrative support.

A specialized registry of RCTs in prostatic diseases and urologic malignancies was developed and submitted for inclusion in *The Cochrane Library*. The specialized registry contains
approximately 4,183 references to date (as of 11/08). As of December 31, 2009, we had 30 published Cochrane reviews and 29 published titles and protocols.

7.5 Pain, Palliative, and Supportive Care, Pain and Headache Pain section (PaPaS) CRG

PaPaS was registered with the Collaboration in 1998. It focuses on reviews for the prevention and treatment of pain, end-of-life palliative care, and the support of patients, families, and caregivers. PaPaS covers four main topics: acute pain, chronic pain (both related and unrelated to cancer), palliative care, and supportive care.

Four editors for the group are based in the US. Ewan McNicol, of the Tufts Medical Center in Boston, Massachusetts, is the Editor for pain reviews and supports some authors on behalf of PaPaS. Doug McCrory and Rebecca Gray are Editors focusing on the Headache Pain section of the group's scope and Amy Abernethy is an Editor for Palliative Care; all three are based at the Duke University Center for Clinical Health Policy Research in Durham, North Carolina. Art Lipman, an Editor for Palliative Care, is at the University of Utah Health Sciences Center and Kenneth Jackson, also an Editor for Palliative Care, is based at Pacific University.

At the end of 2009, there were over 700 active members of the PaPaS CRG, 35 were consumers and 19 were from developing countries. During 2009, the PaPaS CRG published 35 new protocols, 27 new reviews, 7 updates and registered 22 titles. In January 2010, 13 new protocols, 6 new reviews and 3 updated reviews were in the editorial process. The specialized register contained 35,804 studies.

There are several changes anticipated for the PaPaS CRG in 2010. After April 2010, the editorial base will primarily be located at the Churchill Hospital in Oxford, England. The headache scope, which is managed from Duke University, will be managed by the Oxford office.

8. US-based Cochrane fields

8.1 Complementary and Alternative Medicine (CAM) Field

The CAM Field was established in 1996 to meet the growing need for evidence-based research in complementary and alternative medicine. The field is dedicated to producing systematic reviews of RCTs in areas such as acupuncture, massage, chiropracty, herbal medicine, and homeopathy. The field is based at the University of Maryland, School of Medicine, in Baltimore, Maryland. Brian Berman is Field Coordinator, Susan Wieland is Field Methodologist,
and Eric Manheimer is Field Administrator. The CAM Field's work is supported by a grant from the US National Institutes of Health, Center for Complementary and Alternative Medicine.

The CAM Field was active in identifying, reviewing, and disseminating evidence on CAM therapies and staff dedicated much of their effort to preparing Cochrane reviews. For example, Eric Manheimer co-authored two systematic reviews that were published in *The Cochrane Library*, Issue 1, 2009, and was the lead author of a systematic review that was published in *The Cochrane Library*, Issue 1, 2010. The CAM Field also contributes to the development of the database of CAM-related reviews by awarding a bursary each year to Cochrane reviews for which substantial progress has already been made and whose completion has been stalled due to a lack of funding. In addition, the CAM Field contributes to review preparation by hosting training workshops for CAM review authors, writing articles and book chapters about systematic reviews in CAM, and working with international research scholars at the CAM Field base who are undertaking fellowships or sabbaticals with a focus on systematic reviews. Finally, the field facilitates Cochrane CAM review preparation by responding on an *ad hoc* basis to requests for peer-review authors, from Cochrane review group coordinators. The field also maintains a register of CAM trials, which it submits regularly to CENTRAL, as well as a “Topic List” of all CAM-related Cochrane reviews and protocols. As of Issue 1, 2010 of *The Cochrane Library*, the register of trials includes 36,256 reports of CAM trials. The Topic List includes 384 CAM-related Cochrane reviews and 225 CAM-related protocols. The field's National Institutes of Health funding partially supports work on CAM Field-related projects that are undertaken at the Thomas Chalmers Center, based at the Children's Hospital in Ontario.

The CAM Field dedicates extensive effort to disseminating Cochrane reviews to the CAM research and practice communities as well as to the general public. The field's column in the journal *Explore*, for example, is designed to promote awareness of The Cochrane Collaboration and to improve CAM practitioners’ and researchers’ understanding of randomized trial and systematic review methodology. The field works in collaboration with CCNet to effectively and efficiently communicate the message of Cochrane CAM reviews to the general public, by producing streamlined and simplified summary overviews in lay language. Thirty of these summary overviews have been prepared so far, and they are now available on the CAM Field website ([http://www.compmed.umm.edu/integrative/cochrane_consumer.asp](http://www.compmed.umm.edu/integrative/cochrane_consumer.asp)), organized according to the therapeutic area, healthcare condition, and treatment. The CAM Field staff also collaborated with the Norwegian branch of the Nordic Cochrane Center to communicate the message of Cochrane reviews to the general public, through the creation of Summary of Findings tables/Plain Language Summaries (SoF/PLS) of CAM-related Cochrane reviews. Nine of these summaries have been prepared so far, and they are now available on the CAM Field website ([http://www.compmed.umm.edu/integrative/cochrane-plainlang.asp](http://www.compmed.umm.edu/integrative/cochrane-plainlang.asp)). Beginning with the
July/August 2009 issue of the journal *Alternative Therapies in Health and Medicine*, the CAM Field launched a new column called *Cochrane CAM Reviews: Summaries of Findings*. The purpose of this column is to highlight some of the recent ‘Summary of Findings’ tables of CAM-related Cochrane reviews. For the first column, we focused on the Cochrane review “The effect of probiotics on preventing necrotizing enterocolitis in premature babies.”

### 8.2 Behavioral Medicine

The Cochrane Behavioral Medicine Field was officially registered with The Cochrane Collaboration in 2006. The goal of this field is to increase and improve the evidence-base of behavioral medicine interventions through the facilitation of collaborations between behavioral medicine society affiliates and Cochrane review group affiliates. The field focuses on interventions that improve health outcomes through behavioral mechanisms alone or in combination with other therapies. These types of interventions are performed by many types of practitioners (e.g., physicians, psychologists, psychiatrists, nurses, nutritionists) in a variety of settings for many of the conditions covered by Cochrane review groups.

Initial field activities have included developing a website (www.cochranebehavmed.org) with a searchable database of behavioral medicine-specific citations (RCTs, systematic reviews), providing resources for systematic review authors and others, conducting a survey to join the field, and a survey to submit descriptions of work-in-progress for the database. The Behavioral Medicine Field also sent out a bi-weekly *Behavioral Medicine Alert*, a digest of recent behavioral medicine citations (which reached more than 200 individuals), and quarterly Update emails. The field hosted an international meeting of behavioral medicine professionals to discuss prioritization of systematic review topics, and initiation of and author involvement in a Cochrane systematic review. The field had an Advisory Board composed of 14 individuals representing seven different countries.

In 2009, the Convenor, Karina Davidson PhD, and Trials Search Co-ordinator, Louise Falzon, were not able to identify funding sources to maintain the field at Columbia University Medical Center in New York City. They began a series of discussions with interested parties to identify a new Convenor and a new base.

### 9. US-based Cochrane methods groups

#### 9.1 Cochrane Screening and Diagnostic Tests Methods Group (SDTMG)

The SDTMG began working on the development and implementation of methods for
systematic reviews of screening and diagnostic tests in the 1990s. The group led the initiative to include diagnostic accuracy reviews in The Cochrane Library and worked on the development of the consensus approaches and the necessary infrastructure for launching this part of the Library in October 2007. A central piece of this effort was the development of the Cochrane Handbook for Diagnostic Test Accuracy Reviews, which is currently in the final stages of editing. Members of SDTMG were instrumental in the formation of Regional Support Units for diagnostic accuracy reviews, which provide methodologic support and guidance to investigators in CRGs and Centers. The Cochrane SDTMG is co-convened by Constantine Gatsonis of Brown University, Providence, RI, USA; Petra Macaskill of the University of Sydney, Australia; Roger Harbord of Bristol University, UK; and Mariska Leeflang of the Academic Medical Center, University of Amsterdam, Netherlands.

10. Performance targets

See Appendix H for the USCC performance targets for 2010.

11. USCC contact information, current

11.1 USCC, Baltimore, MD

Director, USCC: Kay Dickersin, PhD

Contact Person: Janie Gordon, ScM
Coordinator, USCC
Johns Hopkins Bloomberg School of Public Health
615 N. Wolfe Street, Room E6012
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Web page: http://www.cochrane.us

11.2 San Francisco Branch

Co-Directors: Lisa Bero, PhD
Drummond Rennie, MD

Contact Person: Erika Campbell, BA
Administrator, San Francisco Branch of the USCC  
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3333 California Street  
San Francisco, California, USA 94118  
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Fax: +1-415-502-8227  
Email: campbelle@pharmacy.ucsf.edu  
Web page: http://www.ucsf.edu/sfcc

12. Full and part-time staff at the USCC Offices in 2009

Director: Kay Dickersin, PhD
Co-Directors, San Francisco Branch: Lisa Bero, PhD  
Drummond Rennie, MD
Associate Director: Roberta W. Scherer, PhD
Coordinators: Janie Gordon, ScM  
Erika Campbell, BA (San Francisco Branch)
Consumer Coalition Coordinator: Janie Gordon, ScM
Methodologists: Ann Ervin, MPH, PhD  
(Project Director, CEVG@US)  
Tianjing Li, MD  
Kristina Lindsley, MS  
Satyanarayana (Swaroop) Vedula, MD
Handsearchers: Karen Chang, MHS  
Kristina Lindsley, MS  
Sam Luo  
Srona Sengupta
Master List Processors: Lisa Lassiter, BS  
Roberta Scherer, PhD
Web Developer Lesia Green
13. **Sources of funding and support**

13.1 **Contracts and grants**

13.1.1 USCC - National Eye Institute (NEI)

Source: National Eye Institute  
Title: Support for US Activities of the CEVG within The Cochrane Collaboration  
PI: Kay Dickersin, PhD  
Dates: April 22, 2002 - April 3, 2009  
Specific Aims: To develop a critical mass of US-based vision researchers and practitioners who are trained in preparing and using systematic reviews

13.1.2 USCC - Agency for Healthcare Research and Quality

13.1.2.1
Source: Agency for Healthcare Research and Quality  
Title: Training for US Cochrane Contributors and Others  
PI: Kay Dickersin, PhD  
Dates: June 1, 2007 - May 31, 2010  
Specific Aims: To conduct a series of educational conferences to increase involvement in The Cochrane Collaboration

13.1.2.2
Source: Agency for Healthcare Research and Quality  
Title: Translating Research into Practice and Policy  
PI: Kay Dickersin, PhD  
Dates: September 30, 2009 - September 29, 2012  
Specific Aims: To host a series of conferences for Consumers United for Evidence-based Healthcare (CUE), related to translating research into practice and policy, with a focus on methodological and technical issues of major importance in the field of health services research. The target audience is health consumer advocacy groups.
13.1.2.3
Source: Blue Shield of California Foundation
Title: Enhancement of the online course, “Understanding Evidence-based Healthcare: A Foundation for Action,” for use by practicing doctors and researchers
PI: Kay Dickersin, PhD
Dates: June 1, 2009 - January 1, 2011
Specific Aims: To enhance online course for doctors and clinical researchers.

13.1.4 USCC San Francisco Branch

The USCC San Francisco Branch had no contracts or grants in 2009.

14. Acknowledgments

The USCC staff thanks everyone who has contributed to the success of the Center. Funders have provided support to allow the Center to carry out the activities reported for 2009. Special thanks go to individuals who have contributed their time and expertise serving as a member of the USCC Advisory Group, as faculty for one of our training programs, as an investigator on a project, or as a consumer advocate involved in CUE. Each contribution is recognized and much appreciated.
Appendix A

US Cochrane Center Stakeholder Summit on Using Quality Systematic Reviews to Inform Evidence-based Guidelines
Baltimore, Maryland
June 4 -5, 2009

June 4

11:00 am - 5:00 pm  Registration

1:00 - 1:15 pm  Welcome and introductions - Kay Dickersin - Director, US Cochrane Center

1:15 - 2:30 pm  Standards for systematic reviews: Part 1 - Internal needs and perspectives from the guidelines producers

Chair: Steve Phurrough - Agency for Healthcare Research and Quality

Cystic Fibrosis Foundation guidelines: Starting from scratch - Karen Robinson - Johns Hopkins School of Medicine

From systematic review to clinical practice guideline: The Kaiser Permanente perspective - Marguerite Koster - Kaiser Permanente

Systematic reviews ≠ guidelines: Translation needs and challenges - Martha Faraday - American Urological Association (Consultant)

Discussion

2:30 - 3:00 pm  Break

3:00 - 5:00 pm  Standards for systematic reviews: Part 2 - Meeting external standards

Chair: Cheryl Dennison - Johns Hopkins University School of Nursing

Performance measures related to guidelines - Mark Antman - American Medical Association
Case study: Screening new methadone patients for cardiac risk: When are practice recommendations ready for prime time? **Marc Gourevitch** - New York University School of Medicine

The Institute of Medicine’s report, *Conflict of Interest in Medical Research, Education, and Practice*: Advice on conflict of interest to guidelines producers. **Robert Krughoff** - Consumer CHECK-BOOK/Center for the Study of Services

Discussion

### June 5

7:00 - 8:00 am  Registration  
Breakfast on your own

8:30 - 9:30 am  **Plenary - Thorny problems for guidelines developers**

Chair: **Milo Puhan** - Johns Hopkins Bloomberg School of Public Health

Is there a benefit to standardizing methods for grading the evidence and making recommendations -- If so, is GRADE "the one"? - **Yngve Falck-Ytter** - Case Western Reserve University School of Medicine


Discussion

9:30 - 11:30 am  **Panel: Collaborations between systematic reviewers and guideline developers**

Chair: **Susan Norris** - Oregon Health and Science University
Using Quality Systematic Reviews to Inform Evidence-based Guidelines (cont’d)

9:30 - 10:20 am  Evolution of the National Kidney Foundation - Tufts Evidence Review Team collaboration in developing kidney disease guidelines - Garabed Eknoyan - Baylor College of Medicine and Ethan Balk - Tufts Medical Center
Discussion

10:20 - 10:40 am  Break

10:40 - 11:30 am  Diagnosis and treatment of low back pain: A joint clinical practice guideline from the American College of Physicians and the American Pain Society - Amir Qaseem - American College of Physicians and Roger Chou - Oregon Health and Science University
Discussion

11:30 am - 1:00 pm  Lunch on your own

1:00 - 2:15 pm  Panel: Ensuring a better interface between systematic reviews and guidelines

Chair: Roger Herdman - Institute of Medicine

What have we learned about the quality of the underlying evidence from the National Guideline Clearinghouse - Vivian Coates - ECRI Institute and Mary Nix - Agency for Healthcare Research and Quality

Transparency of guidelines --- What do we mean and how do we get there? - Jeffrey Harris - Kaiser Federation Care Management Institute

The American Urological Association guidelines: How we identified a workable process - Heddy Hubbard - American Urological Association
Discussion
Using Quality Systematic Reviews to Inform Evidence-based Guidelines (cont’d)

2:15 - 3:20 pm  Breakout Workshops

GRADE Profiler: How to make it work for you - **Yngve Falck-Ytter** - Case Western Reserve University School of Medicine and **Nancy Santesso** - McMaster University (Edinburgh Hall - 5th floor)

Options for formal consensus processes: The steps to success - **Catherine MacLean** - WellPoint, Inc. (Chapter Room - 4th floor)

Getting physicians on-board with guideline development - **Henry Jampel** - Johns Hopkins School of Medicine (Doric Room - 4th floor)

Incorporating systematic reviews into practice guidelines - **Karen Robinson** - Johns Hopkins School of Medicine and **Roberta Scherer** - Johns Hopkins Bloomberg School of Public Health (Mirror Room - 5th floor)

3:20 - 3:30 pm  Break

3:30 - 4:30 pm  Panel: Ensuring the guideline is a trusted source

Chair: **Kay Dickersin** - US Cochrane Center

What is a meaningful consumer voice? - **Carol Matyka** - National Breast Cancer Coalition

US government approaches to guidelines: Experience of the US Preventive Services Task Force and QUERI - **David Atkins** - United States Department of Veterans Affairs
G-I-N: An international initiative to promote systematic development of clinical practice guidelines - Jako Burgers - Harvard School of Public Health and Dutch Institute for Healthcare Improvement CBO

Discussion

4:30 - 4:45 pm  Evaluation and adjournment
Appendix B

Minutes
US Contributors’ Meeting
XVII Cochrane Colloquium, Singapore
Suntec Conference Center, Room 203
Monday, October 12, 2009, 7:30 – 9:00

1. **Welcome and introductions:** Kay Dickersin, US Cochrane Center (USCC) Director, welcomed everyone to the meeting. The attendees introduced themselves and briefly described ongoing activities.

2. **What’s happening in the US:** The US-based groups presented current news, as follows:

   - **United States Cochrane Center (USCC):** Kay Dickersin reported that the USCC presented a conference, “Stakeholder Summit on Using Quality Systematic Reviews to Inform Evidence-based Guidelines” on June 4-5, 2009. In addition, the USCC presented 2 workshops, one in January and one in July, on how to complete Cochrane systematic reviews. The USCC will be presenting two workshops at the Singapore Colloquium.

   - **USCC San Francisco Branch:** During the past year Lisa Bero, Director of USCC, San Francisco Branch, presented information on the Cochrane Collaboration on 11 separate occasions. While the presentations were mostly to groups in the San Francisco area, she also had presentations at the NIH and the Environmental Protection Agency (EPA). The EPA was especially interested in how Cochrane methodology could be applied to systematic reviews of environmental studies.

   - **North American training opportunities:** Roberta Scherer, USCC Associate Director, reported that the USCC has available a free online course, “Understanding Evidence based Health Care” that, while originally developed for consumer advocates, is available and has been found useful by other groups of individuals. In addition, the USCC is expecting will launch a free online course on peer review in the near future. Another training opportunity reported by Lisa Bero of the San Francisco Branch is the incipient course on critical appraisal emphasizing assessment of bias in drug studies; this course is designed as five 30-minute segments on U-Tube and will provide continuing medical education credit.

   - **Pain, Palliative, & Supportive Care Review Group/Headache Section:** No longer located in the US.

   - **Prostatic Diseases and Urological Cancers Review Group:** No one present from the group.

   - **Eyes and Vision Review Group Satellite:** Roberta Scherer reported that funding from the National Eye Institute (NEI) ended this year for the US satellite of the Eyes and Vision Group (CEVG@US), and that an application has been submitted to NEI for continued funding. The group has been awarded a challenge grant from the American Recovery and Reinvestment Act to investigate meta-analytic methods using indirect comparisons. In addition, CEVG@US is collaborating with the Johns Hopkins Evidence-based Practice Center on a series of systematic reviews on glaucoma.
• **Neonatal Review Group:** Roger Soll, Coordinating Editor of the Neonatal Group, commented that the Neonatal Group is actively involved in coordinating the update of approximately 260 reviews.

• **HIV/AIDS Review Group:** Tara Horvath, Assistant Managing Editor for the HIV/AIDS Group, described the collaborative activities of the HIV/AIDS review group in San Francisco and the South African Cochrane Centre satellite. The HIV/AIDS group sponsors a mentoring program for new authors, who are mainly from sub-Saharan Africa. They are also active in applying GRADE appraisals to studies of interventions to prevent mother to child transmission of HIV for the World Health Organization (WHO).

• **Complementary Medicine Field:** Susan Wieland reported on the Complementary Medicine Field for Director Brian Berman. With 2 more years of funding from a 5 year grant from the National Center on Complementary and Alternative Medicine, the Complementary Medicine Field has supported a working group to identify and translate trials from the Chinese biomedical literature and two reviews on acupuncture this year. The Complementary Medicine Field also provided funds for completion of 2 additional systematic reviews on complementary medicine, written numerous journal articles, provided training about the Cochrane Collaboration, and worked with CCNet on plain language summaries and the Nordic Cochrane Center on the application of GRADE.

• **Behavioral Medicine Field** - No longer in existence.

• **Screening and Diagnostic Tests Methods Group** - No one present from the group.

• **Justice Health Field (proposed)** - Catherine Gallagher, co-convener of the proposed Justice Health Field, reported that there will be an exploratory meeting of the field at the Singapore Colloquium. This third exploratory meeting will provide an overview of the proposed module and follows 2 exploratory meetings held previously in Orlando. The aim of the Justice Health Field is to promote reviews on healthcare for prisoners or other institutionalized persons. This goal encompasses a population of over 8 million persons and children, who carry a disproportionate burden of disease because of the institutional setting. The Justice Health Field expects to collaborate with the Campbell Criminal Justice group and currently has funding from the Agency for Health Care Research and Quality (AHRQ) through a conference grant and through review support.

• **Consumers United for Evidence-based Healthcare (CUE):** As reported by Barbara Warren, the USCC received funding for CUE through a conference grant from AHRQ. During this past year, CUE members have collaborated with CCNet on plain language summaries, and been active in health care reform issues. The 2010 Colloquium in the US is especially important for CUE as it is currently reaching out to increase advocacy group membership US-wide.

• **Cochrane GI annual presentations at Digestive Disease Week:** Ron Koretz noted that the contract for the Cochrane GI annual presentation at the Digestive Disease Week was terminated this year. He does not expect it to be picked up in the future due to financial constraints.
2. **Cochrane Collaboration Steering Group (CCSG):** Lisa Bero described CCSG reports and activities of special interest to the US. Analyses by Wiley show that the US is one of the primary users of *The Cochrane Library*. There is the possibility of group funding support through the Cochrane Opportunity Fund, which will be released later this year and will target proposals for projects related to the Collaboration’s strategic objectives. The CCSG is looking for ways to increase consumer involvement, including a request to CCNet to develop a consumer participation plan and a half day brainstorming session at the mid-year Center Directors meeting in New Zealand. Lisa also reported the ongoing plans for a collaboration between the Cochrane Collaboration and WHO; the Cochrane Collaboration hopes to have a seat on the World Health Assembly, the governing body of WHO. This development is especially important to the US because of the link between WHO and the Pan American Health Organization (PAHO). PAHO initiated Cochrane systematic review training for the US-Mexico border group this past year.

4. **Funding: Successes, challenges & future plans:** Various individuals reported on funding successes, as follows:
   - Roger Soll continues to receive support from the National Institute of Child Health and Human Development (NICHD) for the Neonatal Group. For this support, the Neonatal Group publishes all their systematic reviews on the NICHD website.
   - Susan Norris was approached and is funded by the Centers for Disease Control and Prevention (CDC) to investigate conflict of interest in systematic reviews.
   - The CDC also has “AIDS relief” funds, and is reported to be approaching the HIV/AIDS group.
   - It was noted that some individuals at the CDC are interested in forming a satellite for the Public Health Group and closer alliances with Cochrane generally.

   The ensuing discussion revolved around ways to increase funding. Rich Rosenfeld suggested that persons who are leaders in a clinical organization or society with a journal might try to negotiate with the journal publisher for funding for one or more persons to attend the Colloquium in exchange for submission of a systematic review by these individuals, thus providing a source of increased citations for the journal.

5. **2010 Colloquium in Keystone, Colorado:** Robert (Bob) Dellavalle, Paula Marchionda and Vicky Koehler

   Bob Dellavalle described plans for the 2010 Cochrane Colloquium to be held in Keystone, Colorado. Keystone is a winter ski resort and a summer holiday resort, and has adequate facilities for handling a large conference, especially during the fall season. Attendance by North American participants is expected to be high due to the location. Attendees are encouraged to be aware of the possibility of altitude sickness, since the elevation at Keystone is about 9,500 ft. Steps to deal with this potential problem include suggesting participants plan a preliminary stay at Denver. In fact, the CCSG will hold the first day of their meeting in Denver, and other groups are planning pre-conference meetings. It was suggested that specific recommendations to prevent or mitigate altitude sickness should be provided to conference participants (e.g., avoiding alcohol use during the first few days at high altitude, taking preventive medications such as carbonic anhydrase inhibitors).
The 2010 Colloquium, a joint colloquium with the Campbell Collaboration, has the theme “Bringing Evidence-Based Decision-Making to New Heights.” As a joint meeting, the colloquium will provide a unique opportunity for networking. Committees will be co-chaired by members of both the Cochrane and Campbell Collaborations. Persons named to head committees to date are as follows: Scientific Program: Kay Dickersin and Hannah Rothstein; Abstract Committee: Lisa Bero; Workshop Committee: Karen Robinson and Terri Petite; and Stipend Committee: Maryann Napoli and Jini Henderson. Bob distributed the working organizational chart to those attending the meeting and encouraged anyone who is interested to help either to contact Bob directly or participate in the local organizing committee monthly telephone calls. These monthly telephone calls use Elluminate (sponsored by PAHO) and anyone could join the call. The Stipend Committee especially could use help.

Based on previous colloquia, the estimated budget for the Keystone Colloquium will be about one million dollars. Past colloquium organizers have found that the majority of required funds come from participant registration, but start-up money is raised locally. The University of Colorado has provided seed money and Bob has also applied to AHRQ for conference funding. The contract with the Keystone Resort is through a memorandum of understanding between the venue and the University of Colorado, meaning that the University currently has undertaken financial responsibility. Bob requested that anyone with suggestions for additional funding sources contact him with details.

Bob announced that postcards describing the meeting and important dates would be available during the entire Singapore Colloquium at an exhibit table. He also said that he would show a video of Keystone at the final plenary and asked all US Singapore Colloquium attendees to participate by wearing cowboy hats at the final plenary.

Discussion about the 2010 Colloquium began with a question by Rich Rosenfeld about plans to publicize the Colloquium within the US, especially among clinicians. He suggested that perhaps one plenary could focus on “How can Cochrane be an asset to your [clinical] society?” Michael Borenstein commented that we should think about other ways to publicize the Colloquium as well, e.g., mailings to individuals already involved in Cochrane. Other suggestions included blast emails, announcements in journals, and memos or blurbs to send to organizations to include with their mailings. There was general consensus with Bob Dellavalle’s suggestion that a Public Relations Committee should be in contact with the various organizations to make sure the Colloquium is placed on the appropriate calendars. Ben Djulbevojic commented that it would be useful to highlight the relevance of Cochrane to the organization in the blurb, for example with links to guideline or guideline development. Marguerite Koster, Kaiser Permanente, then suggested that perhaps medical societies could fund specific Cochrane reviews needed to inform guidelines and that perhaps the Colloquium could have a workshop on building partnerships highlighting known successes.

6. Outreach/Issues/Announcements

- **Guidelines International Network (G-I-N):** Rich Rosenfeld described the opportunities for Cochrane involvement at the upcoming G-I-N Annual Meeting to be held August 25 -28, 2010 in Chicago, Illinois. G-I-N is an international non-profit organization that was started in 2002, and currently is comprised of 96 organizations from various countries. Rich noted that there are synergies between the goals of G-I-N
and Cochrane. He voiced the opinion that Cochrane should be a presence at the G-I-N meeting and asked for specific suggestions as to how to facilitate Cochrane involvement. Areas of possible involvement for Cochrane include consumer representation, education, panel participation, searching for trials, implementation and understanding of reviews. Rich noted that there will be a panel at the G-I-N meeting on external peer review of Cochrane for guideline development.

- **Bureaucratic hurdles faced by reviewers when submitting Cochrane protocols:** Ambuj Kumar reported that he was involved in a situation in which he had prepared a Cochrane protocol, only to be told that the title had been transferred to a different Cochrane group. He was unsure of whom to contact and lamented the bureaucratic hurdles faced by potential Cochrane review authors. Roger Soll commented that this type of situation has been a problem in the past, but he expects to see a change in the “culture” with the appointment of David Tovey, Editor-in-chief of *The Cochrane Library*. Roger went on to say that this type of issue is expected to receive high priority by the Editor. In addition, Ambuj was instructed to contact the USCC in cases like this as it is the responsibility of Centers to advocate for individuals within their reference area.

It was also suggested that the various review groups find some way to thank the external peer reviewers. Currently they receive no recognition. Further, there is a real need to involve “new” physicians.

- **Cochrane response to comparative effectiveness research (CER):** Not discussed due to time constraints.
Appendix C

USCC Training Workshops and Courses 2009

Workshops and courses in 2009 included:

1. *Completing a Cochrane systematic review workshop.* This workshop was offered twice: January 15 - 17, 2009 in Ft. Lauderdale, Florida, and July 22 - 24, 2009 in Baltimore, Maryland (Kay Dickersin, Roberta Scherer, and Ann-Margret Ervin).


5. *Train the trainers of evidence-based healthcare workshops.* XVII Cochrane Colloquium: October 14, 2009 in Singapore. (Roberta Scherer, US Cochrane Center, Joseph Mathew, South Asian Cochrane Centre, Taryn Young, South African Cochrane Center, and Phil Wiffen, UK Cochrane Centre.)
Appendix D

Report

Consumers United for Evidence-based Healthcare (CUE)

**July 23, 2008 Annual CUE Membership Meeting**

U. S. Cochrane Center

23 July 2008

Nitze Building
1740 Massachusetts Ave., N.W.
Washington, D.C.

*This meeting was sponsored by the Agency for Healthcare Research and Quality (Grant No. R13 HS017397).*
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   Appendix F: Evaluation Survey Instrument
1. **Overview**

This report summarizes the 2008 Annual Membership Meeting for Consumers United for Evidence-Based Healthcare (CUE), hosted by the US Cochrane Center (USCC). A planning committee (see Appendix B, Planning Committee) was appointed to set meeting goals and objectives. The meeting objectives were to bring together CUE’s leadership and membership to discuss programmatic and administrative matters relevant to the membership and the Coalition as a whole, and to learn about topical issues related to evidence-based healthcare (EBHC). Members heard presentations from outside individuals and groups working on problems related to the CUE mission, namely, a journalist-author writing about “over treatment”; a representative from the Institute of Medicine’s (IOM) Communications Collaborative, associated with the Roundtable on Evidence-based Medicine; the Director of ClinicalTrials.gov; legislative staff associated with a congressional initiative related to comparative effectiveness; and the Director of the South Asian Cochrane Network, from Vellore, India (see Appendix C, Speakers). In addition, a panel of selected CUE members shared their organizations’ experiences with EBHC and how they have interacted with the Cochrane Collaboration.

Continuing challenges include finding ways to increase awareness of CUE in the consumer and health professional communities, increase awareness and use of EBHC, and obtain financial support to continue the growth and development of the work of CUE in the United States.

2. **CUE membership meeting agenda** (see Appendix A, Conference Program)

2.1 **Introduction of CUE member organizations - Sallie Bernard**, Co-Chair CUE Steering Committee

The meeting began with introductions of CUE members and USCC staff. Using two PowerPoint slides per organization (see Appendix D, CUE Organizations’ PowerPoint Presentations), each representative briefly summarized his/her organization’s mission, constituency, and ways in which it uses EBHC. CUE Steering Committee Co-Chair Sallie Bernard made comments on behalf of organizations not represented at the meeting. In addition to CUE members’ presentations, guest Mayri Sagady-Leslie spoke briefly about her organization, the Coalition for Improving Maternity Services.

2.2 **CUE annual report - Barbara Warren**, Co-chair CUE Steering Committee

2.2.1 **A call to action**

CUE Steering Committee Co-chair Barbara Warren welcomed the attendees. She summarized CUE’s major accomplishments since the 2007 annual meeting (see Appendix E,
CUE Accomplishments 2007 - 08. She challenged the group to consider how CUE could best engage consumer advocates in the important work to be done over the next year or two, given limited resources.

Warren outlined the success to date of the CUE online consumer course: *Understanding Evidence-Based Healthcare (EBHC): A Foundation for Action*. She noted that the 6-module online course was launched September 15, 2007. At 10 months since launch, approximately 1,000 people have enrolled in the course. It was noted that one goal is to have a better feedback mechanism for the course, so CUE could get information on enrolles and how they apply what they have learned in their work. Warren noted that groups beyond consumers (nurses, physicians, etc.) have expressed interest in the course and in the possibility of earning professional continuing education credit. She also noted the need for greater outreach about the course to increase dissemination.

Warren reviewed dissemination activities, including the CUE Advocacy Summit: *Understanding EBHC: A Foundation for Action* held July 17, 2007. She reported that at the 2007 Cochrane Colloquium in São Paulo, Brazil, she and Kay Dickersin (KD) and Janet Wale (representing the Cochrane Consumer Network or CCNet) presented a workshop “Developing a Local Coalition of Consumer Advocates”. She also noted that she and KD made a roundtable presentation about the online course at the American Public Health Association Annual Meeting, Washington, D.C., November 2007. It was also noted that CUE Steering Committee member Maureen Corry would join KD in discussing the Cochrane Collaboration and EBHC as part of the National Healthcare Policy Forum (Congressional Briefing) session, July 25, 2008.

The CUE video, created by Barbara Warren, was shown and much appreciation was expressed to Barbara Warren and Rich Davis for their excellent and important contribution to CUE.

Warren concluded with an appeal to all to help identify funding support to enable CUE to continue and expand its work.

### 2.3 Current hot issues and developments in EBHC

#### 2.3.1 How failure to practice EBHC makes us sicker - Shannon Brownlee

Schwartz Senior Fellow, New America Foundation and author of *Overtreated: Why Too Much Medicine is Making Americans Sicker and Poorer*

Ms. Brownlee began by talking about geographic variation in the frequency of medical tests and surgical procedures. Using Medicare claims data in the 1970s, investigators identified geographical variations for several procedures in Vermont and Maine. Further investigation
revealed there was little evidence to inform physicians’ judgments, and that often procedures were done with the potential for little or no patient benefit and for actual harm to the patient.

Ms. Brownlee identified “informed” patient choice as a major patient rights issue. She cited data that suggest patients, when fully informed of the risks/trade-offs of health procedures/medications, tend to make choices that are more conservative than their physicians’ recommendations. This suggests patients may be consenting to treatments that, given full information, they might have declined. Ms. Brownlee illustrated this point by citing the tradeoffs between mastectomy versus lumpectomy for women with breast cancer. This illustration resonated with many of the meeting attendees who commented that women are generally not fully informed about the benefits versus harms of these alternative treatment.

A lively discussion period followed. Ms. Brownlee responded to the question: Do you see a change in the “more is better” attitude, as far as the delivery of medical care goes? She noted that as baby boomers make health care decisions for aging parents they are seeing first-hand that more is not always better, especially in end of life care. She noted that consumers often believe that more tests and procedures than necessary are ordered, to increase physician revenue.

A point was made that there is a fine line between advocating for consumers’ rights and totally destroying patients’ trust in their healthcare providers. Consumer Reports held focus groups in which participants identified other people’s physicians as the problem; not their own physician. This illustrated that people may not understand the inherent potential harms associated with health care and that informed patient choice is needed. The importance of EBHC and tools to find reliable evidence should be incorporated into medical education.

A question was asked regarding how to change existing medical practices when the evidence clearly indicates these practices are not optimal (eg, increased use of Caesarean section and the associated premature birth/respiratory problems). Ms. Brownlee said that she would continue to write about these issues. She noted that CUE has an important role to play in disseminating this information to consumers.

Challenges associated with the pharmaceutical industry were outlined, including the stance on comparative effectiveness.

2.3.2 Legislation on a new institute for comparative effectiveness – Kavita Patel, Deputy Director, Health Subcommittee of Senator Edward M. Kennedy

Dr. Patel explained that while comparative effectiveness is becoming the new buzz phrase on Capitol Hill, it is a concept that goes back to the Clinton Administration’s work on health care. She categorized those on Capitol Hill into one of three categories: either they support
comparative effectiveness because they believe it will contain costs; they are against it because it is an attempt to establish “cookbook medicine” that will take decision-making on behalf of a patient’s best interest out of the hands of physicians; or they are agnostic and don’t understand comparative effectiveness.

She noted there is a drive for legislation that will establish a new institute for clinical effectiveness, which will mean more systematic reviews and randomized clinical trials (RCTs) to build the evidence-base for healthcare services. At this point in time, no one knows whether there will be a new federal agency, or in what existing agency the institute may be placed. Senator Kennedy’s office is working on language to ensure that any institute will go beyond comparing Drug A to Drug B, and will set priorities for effectiveness research. Kennedy wants to ensure funding for research innovation (such as health services research) and dissemination of findings to both healthcare providers and consumers. The consumer voice in policy development will be essential, as it will build political will across jurisdictions. She asked: Will holding spots for consumers on committees be the best way to ensure consumer representation? Kennedy’s office is open to ideas on strategies to include consumers in policy decisions.

Senators Baucus and Conrad have proposed that the comparative effectiveness institute would be a public-private entity. PhARMA’s is concerned that this institute would dictate payment decisions and is lobbying against cost-effectiveness as a component of comparative effectiveness. Conversely, the insurance industry views comparative effectiveness as a means to reduce their costs. Patel asked: How do we ensure consumer voices are heard along with corporate interests?

A discussion period followed. A CUE member suggested that consumer groups prepare the “patient education” materials that are distributed by health agencies. A point was made that any legislation should include RCTs and systematic reviews on interventions beyond drugs, biologics, and devices. For example, procedures such as preventive care, surgery or radiation, behavior change, systems change, physical therapy, screening, and other interventions are important both in terms of costs and existing health concerns. CUE members further recommended including legislative language creating a funding stream to allow meaningful contributions from consumer organizations such as CUE.

Dr. Patel was asked about policies such as the Medicare Modernization Act that forbid use of comparative effectiveness in Medicare/Medicaid reimbursement decision-making and about the Drug Effectiveness Review Project (DERP). She answered that drug comparisons are easier to address than questions about best practices. State Medicaid Agencies are able to use DERP’s systematic reviews in local decision-making in part because they do not address issues of cost in their reports.
The last question was: Is there any hope for a legislative effort that would restrict the pharmaceutical industry’s funding of medical education? Patel noted that work is underway on The Sunshine Act, which addresses transparency in medical education and medical research funding. State-level legislation is also beginning to address this issue.

2.3.3 IOM Roundtable on Evidence-Based Medicine’s Communication Collaborative - Gail Shearer, Director Health Policy Analysis, Consumers Union & CUE Member

Gail Shearer began by noting there is much confusion about the meaning of comparative effectiveness research and evidence-based medicine. Such confusion plays into hands of opponents of comparative effectiveness/evidence-based medicine, who paint it as an insurance industry-led movement aiming to ration medical care. Educating the public about comparative effectiveness requires carefully constructed messages that connect with consumers and the general public. She noted that the healthcare reform disaster of the ‘90s speaks to how essential effective communications will be in gaining public support.

Shearer explained that the IOM Roundtable has a shared vision of a healthcare system that draws on best evidence to provide care most appropriate to each patient. The IOM Roundtable participants represent diverse interests, including representatives of academic research, industry, and government, all sharing the common goal of increasing evidence-based practice. Their goal is that by 2020, 90% of medical decisions will be supported by evidence. The Roundtable’s Learning Healthcare System series of reports is an excellent resource supporting the benefits of incorporating evidence based medicine into healthcare practice.

She noted that Jim Guest, President of Consumers Union, is Chair of the IOM Evidence-based Medicine Roundtable’s Communication Collaborative, and the Working Group Chair is Kristin Carman of the American Institutes for Research. The Collaborative is focused on three key strategies to advance the case for EBHC: advance communications, facilitate public engagement, and develop platforms. Overall, their goal is to develop language that will be appropriate for discussing concepts of EBHC with the lay public.

Key questions raised by the Communications Collaborative regarding a new institute for comparative effectiveness include: What will the organizational structure look like? How will the organization be able to engage stakeholders while still avoiding conflicts of interest? Will cost effectiveness be addressed? How will it succeed when so many earlier efforts failed? How will an institute be funded?

In the discussion period, CUE members voiced concern about the lack of “true” consumer voices on IOM and other review panels. The common practice of designating a member’s spouse
or a scientist who has breast cancer as consumers was mentioned. Ms. Shearer noted that the
inclusion of stakeholders takes time. She explained that the IOM tends to engage the medical
community; through its work with the Communication Collaborative it is trying to engage the
public. The Communication Collaborative is addressing effective communication, not policy.

2.3.4 Expansion of ClinicalTrials.gov to include information on clinical trial results -
Deborah A. Zarin, Director, ClinicalTrials.gov, Lister National Center for Biomedical
Communications, National Library of Medicine

Dr. Zarin presented updates to ClinicalTrials.gov. Currently, 59,000 studies are in the
database, of which 15% are observational, 50% are US-based, and 30% are industry supported.
The FDAAA 801 (Food and Drug Administration Amendments Act) requiring basic result
reporting, enacted Sept 27, 2007, expands the existing legislation to require that Phase II – IV
and medical and device trials with at least one US site must register the trial and information on
key protocol items. The expansion applies to trials of drugs, biologics, and devices approved for
marketing in the U.S and completed on or after Sept 27, 2007. The results reporting component
of clinicaltrials.gov must be up and running by Sept 27, 2008, and will be available at
http://prsinfo.clinicaltrials.gov/. CUE members recommended that the public have access to full
protocols for all clinical trials, not just the types of trial and key data items outlined in the
legislation. As of Sept 27, 2009 adverse events reports will be required. The legislation also
requires serious and frequent adverse event reporting. Results will be due within 12 months of
completion of primary outcome data collection, with penalties associated with non-compliance.
Dr. Zarin provided meeting attendees with a tour of the ClinicalTrials.gov website and mockups
of proposed results tables. Public comments are welcomed.

During the discussion period, Dr. Zarin responded to the question: Is there a way for
consumers to determine if a sponsor is failing to report a primary outcome? Zarin noted that the
system has a tracking method to determine if outcome measures have changed since trial
registration. In response to another question she noted that there is no way to know what
proportion of clinical trials will be captured in this database, since there is currently no way to
know about all initiated trials for certain.

Dr. Zarin confirmed that the results database is intended for those who know how to read the
medical literature. The mock up is currently available and anyone can sign up for updates to the
site.

2.4 Getting the most from The Cochrane Library: Demonstration - Kay Dickersin,
Director, U.S. Cochrane Center

Kay Dickersin demonstrated how to navigate within The Cochrane Library.
2.5 Campaign for national license to *The Cochrane Library*: Experience in India - Prathap Tharyan, Director South Asian Cochrane Network

The South Asian Cochrane Network (SCAN) is the newest Cochrane Center. SCAN seeks to increase awareness of *The Cochrane Library*, train people in the region to conduct systematic reviews, increase the use of evidence in medicine in South Asia, increase the demand for high quality research, and create a sustainable network to continue SCAN. SCAN’s mission includes preparing quality systematic reviews that will assist people in making well informed healthcare decisions.

With these goals in mind, Dr. Tharyan negotiated with Wiley publishers to offer India an initial national subscription to *The Cochrane Library*, free of charge in 2006-2007, to create demand among users. Use of *The Cochrane Library* in India went up 700%, primarily from full text downloads. This large increase in demand was used as leverage to obtain funding for a national license.

Dr. Tharyan presented an example of how nationwide awareness of the results of a systematic review on primaquine led to a change in India’s national malaria-prevention policy. He noted that India is now anxiously awaiting the development of a national clinical trials registry.

2.6 Panel discussion. CUE members’ experience in dissemination and incorporating evidence into advocacy

2.6.1 Requiring CUE’s online course as a prerequisite for quality care Project LEAD - Annette Bar-Cohen, National Breast Cancer Coalition (NBCC)

Ms. Bar Cohen stated that evidence is the foundation for NBCC’s work and helps inform its policies and responses to breaking health news, public queries, and setting legislative priorities.

She explained that Project LEAD provides basic science training to consumer advocates, including training in research design, epidemiology, clinical medicine, and advocacy skills. Since 1995, the program has graduated more than 1,300 participants. Participants must first complete the CUE online course to be admitted to Quality Care Project LEAD, a more training program focusing on health systems change.

Ms. Bar-Cohen discussed the NBCC’s Quality Care Initiative, which aims to increase access to and improve the quality of breast cancer care for everyone. The initiative is guided by NBCC’s patient-centered, evidence-based vision of quality care, which includes six overlapping core values: access, information, choice, respect, accountability and improvement. To implement
these core values, NBCC is educating breast cancer patients, advocates, and the public at large, working to influence health care providers to embrace and implement NBCC's vision of quality care, and influencing policymakers to create a national health care system that reflects NBCC's vision and establish other policies that nurture and protect quality breast cancer care.

### 2.6.2 Evidence-based complementary and alternative cancer therapies - Ann Fonfa, Annie Appleseed Project

Ms. Fonfa spoke about the first evidence-based complementary and alternative medicine for cancer conference held in January 2008, and sponsored by Annie Appleseed. She reported there were 165 attendees, more than 20 speakers and over 16 exhibitors. Meeting results, speakers’ bios and agenda are available at the Annie Appleseed Project’s website [http://www.annieappleseedproject.org/evcamforadc.html](http://www.annieappleseedproject.org/evcamforadc.html).

### 2.7 CUE projects: updates & future directions

#### 2.7.1 Campaign for national license to The Cochrane Library in the US - Prathap Tharyan, Director, South Asian Cochrane Network; Kay Dickersin, Director, U.S. Cochrane Center

Dr. Dickersin asked whether the US Cochrane Center should sponsor a petition for a national license to *The Cochrane Library*. Currently, Canada and the EU have web-based petitions for national licenses. She noted that the US has the largest number of people accessing *The Cochrane Library*, and the second largest number of individuals contributing to systematic reviews, yet we have no national license.

From experience at US-sponsored workshops, it appears that most medical institutions and the National Institutes of Health already have access to *The Cochrane Library*. However, it’s difficult to know the accessibility of Cochrane full-text reviews for certain, since Ovid bundles Cochrane with its other offerings. Most practicing doctors don’t have ties to medical libraries, although they may be able to get access through medical societies. It was noted that the plain language summary and review abstracts are probably most helpful to practicing physicians, and these are available free online. The state of Wyoming provides free access to *The Cochrane Library* to all of its residents. Initially, Representative (Charlie) Scott and librarians were alerted to the importance of systematic reviews and *The Cochrane Library* through an initiative for policy makers, funded by the Milbank Memorial Fund, and including educational opportunities through the Rocky Mountain Workshop on Evidence-based Healthcare. The small population of Wyoming made the subscription cost, which is calculated on a per person rate, comparatively low. NCI is making access to *The Library* available to all members of CancerPlanet.
It was noted that at $0.10 per person, the annual subscription cost for a U.S. national license would be $3.5 million per annum.

Members requested more information about current use of The Cochrane Library in the US, to determine demand. A free trial period of access was also suggested as a way to create interest among consumers and other decision makers. A key question was, who would utilize full access to systematic reviews the most, and how would we “sell” this need to Congress in order to secure funding? A member raised questions as to whether the “average” American would be able to navigate and understand the information in The Library. Would access to the full text be of practical added value to the abstracts and plain language summaries currently available for free to the general public? It might not be necessary to make the case that the average person on the street would use it, but perhaps making the case for expanded access for consumer organizations would be justification enough for a national license. Additional plain language summaries are needed, regardless, for decision makers of all types (The Evidence Informed Policy Network was mentioned for comparison.)

Other suggestions included advocating for librarian access to The Cochrane Library, which might be well-received in Congress. Public libraries were mentioned as an untapped resource that could be an access point for a national subscription.

2.8 Open forum. Looking ahead: Goals for upcoming year

The primary CUE goals for the upcoming year are to secure funding for infrastructure support and to expand membership and the reach of CUE. Current funding expires September 2008. The need to maintain CUE’s membership criteria that limit industry funding of applicant organizations was emphasized. A member noted that the website Guidestar.com is a good source to view funding sources of consumer groups.

KD reported that she is working on resubmission of a large conference grant to Agency for Healthcare Research and Quality (AHRQ), due to the Agency on August 12, 2008. She noted the application’s proposal regarding proposed CUE meetings. To take advantage of the 2010 Cochrane Colloquium being in Keystone, Colorado, a major CUE conference is proposed to precede the Colloquium. Smaller membership meetings in Washington D.C. are proposed for 2009 and 2011. She thanked CUE members for their excellent letters of support, which effectively outlined CUE’s dissemination and outreach activities.

KD has received numerous requests for recommendations of CUE advocates to serve on advisory committees. She asked whether the CUE membership was interested in the USCC and CUE serving as a clearinghouse for scientists/policy makers looking for informed consumer advocate representatives. There was cautious support for the activity, with CUE members
expressing concern that recommended advocates should have completed the online training course and be knowledgeable about evidence-based healthcare.

2.9 Summary of CUE member evaluations

Twenty-one organizational representatives registered and 18 attended the 2008 CUE Membership Meeting, coordinated by the USCC and sponsored by the AHRQ. Participants were asked to complete a detailed evaluation form (see Appendix F, Evaluation Survey Instrument).

The evaluation scores and comments indicate that respondents were positive (scoring excellent or very good) about the meeting’s presenters, content, and organization. Twelve respondents returned the evaluation, although not all questions were answered by all respondents. Of the 12 respondents who answered the question, 100% (12/12) noted the CUE Meeting met their expectations. Suggestions primarily focused on improving time management of the meeting and allocating more time for discussion.

The survey instrument consisted of questions measured on a five-point Likert scale (excellent was scored as 5 and poor was scored as 1) on quality of the sessions and quality of the presentations by speaker. Open-ended comments were also solicited.
CUE Annual Membership Meeting, 23 July 2008 (cont’d)

Appendix A

Program Agenda
Consumers United for Evidence-based Healthcare (CUE)

2008 Annual Membership Meeting
July 23, 2008
Washington, D.C.
Johns Hopkins University School of Advanced International Studies

7:30 am - 8:30 am  Registration and continental breakfast

8:30 am - 8:45 am  Welcoming remarks  Janie Gordon, Kay Dickersin, Barbara Warren, Sallie Bernard

8:45 am - 9:15 am  Introduction of new and current member organizations  Sallie Bernard

We ask all members to introduce themselves and their organization’s mission and evidence-based healthcare (EBHC) focus.

9:15 am - 9:45 am  CUE 2007 Report  Barbara Warren
Accomplishments for the year including demonstrations of three new videos
Challenges ahead!

9:45 am - 10:00 am  Discussion and feedback from group

10:00 am - 10:15 am  Break

10:15 am - 11:30 am  Current hot issues and developments in EBHC

How failure to practice EBHC makes us sicker and poorer  Shannon Brownlee, Schwartz Senior Fellow, New America Foundation and author of Over-treated: Why Too Much Medicine is Making Americans Sicker and Poorer

Legislation on a new Institute for Comparative Effectiveness  Kavita Patel, Deputy Director, Health Subcommittee of Senator Edward M. Kennedy
IOM Roundtable on Evidence-Based Medicine’s Communications Collaborative  Gail Shearer, Director Health Policy Analysis, Consumers Union & CUE Member

Expansion of ClinicalTrials.gov to include information on clinical trial results  Deborah A. Zarin, Director ClinicalTrials.gov, Lister National Center for Biomedical Communications, National Library of Medicine

11:30 am - 11:45 am  Discussion

11:45 am - 12:30 pm  Getting the most from The Cochrane Library: Demonstration  Kay Dickersin

12:30 pm - 1:15 pm  Lunch and Speaker

Campaign for National License to The Cochrane Library: Experience in India  Prathap Tharyan, Director South Asian Cochrane Network

1:15 pm - 2:15 pm  Panel Discussion: CUE members’ experience in dissemination and incorporating evidence into advocacy

Requiring CUE’s online course as a prerequisite for Quality Care: Project LEAD  Annette Bar-Cohen, National Breast Cancer Coalition

Evidence-based Complementary and Alternative Cancer Therapies  Ann Fonfa, Annie Appleseed Project

2:15 pm - 2:30 pm  Break

2:30 pm - 3:30 pm  CUE projects: updates & future directions

Campaign for National License to The Cochrane Library in the U.S.  Prathap Tharyan, Director, South Asian Cochrane Network and Kay Dickersin, Director, U.S. Cochrane Center
CUE online course update; Dissemination of ebhc; educating ourselves educating others  Kay Dickersin, Director, U.S. Cochrane Center

3:30 pm - 4:15 pm  Open Forum Looking Ahead: Goals for upcoming year

4:15 pm - 4:30 pm  Wrap Up and Adjourn
Appendix B

Planning Committee Members
Consumers United for Evidence-based Healthcare (CUE)
2008 Annual Membership Meeting
July 23, 2007
Washington, DC

Sallie Bernard
Rebecca Burkholder
Maureen Corry
Kay Dickersin
Janie Gordon
Ngina Lythcott
Jennifer Sweeney
Barbra Warren
Kiki Zeldes
Appendix C

Speaker List

Consumers United for Evidence-based Healthcare (CUE)
2008 Annual Membership Meeting
July 23, 2007
Washington, DC

Ms. Annette Bar-Cohen
National Breast Cancer Coalition
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abar-cohen@stopbreastcancer.org

Ms. Sallie Bernard
Safe Minds
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Ms. Shannon Brownlee
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Dr. Kay Dickersin
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Dr. Kavita Patel
Health subcommittee of Senator Edward M. Kennedy
Health, Education, Labor and Pensions
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Dr. Prathap Tharyan
South Asian Cochrane Network & Center
Advanced Centre for Research & Training in
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Dr. Barbara Warren
National Coalition for LGBT Health
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barbaraw@gaycenter.org

Dr. Deborah Zarin
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Appendix D
CUE Organizations' Powerpoint Presentations

 Consumers United for Evidence-based Healthcare

CUE Member-O rganizations

- The Annie Appleseed Project
- Black Women's Health Imperative
- Center for Medical Consumers
- Center for Science in the Public Interest
- Childbirth Connection
- Citizens for Health
- Citizens Health Alliance for Truth
- Consumers Union
- Faces and Voices for Recovery
- Lamaze International
- Medcar Project, the National Lesbian Health Organization
- National Breast Cancer Coalition
- National Center for Transgender Equality
- National Coalition for Lesbian, Gay, Bisexual, Transgender Health
- National Consumers League
- National Council on Aging
- National Environmental Education Foundation
- National Mental Health Consumers' Self-Help Clearinghouse
- National Partnership for Women and Families
- National Vaccine Information Center
- National Women's Health Network
- Our Bodies Ourselves
- Safe Minds
- TMJ Association, Ltd.
- Young Survival Coalition
Annie Appleseed Project

Mission Statement:
To provide information, education, advocacy and awareness for people with cancer about complementary, alternative medicine (CAM), and other issues.

Annie Appleseed Project

Constituency:
- Those with cancer questions and access to the Internet
- Just under 2 million people accessed our site in the last 12 months. They come from every state and many other countries.

Evidence-based healthcare applications:
- Evidence lacking in CAM
  - Most studies/reviews end with "need studies"
  - Mistrust, Misunderstanding, Misuse
- We advocate for studies on natural substances but are often told since they cannot be patented, they are not researched. This is changing.
Black Women’s Health Imperative

Mission:

Founded in 1983, Black Women’s Health Imperative (Imperative) promotes optimum health for Black women across the life span—physically, mentally and spiritually.

Constituency:

Broad-based constituency of 19.5 million Black women and girls and other women of color living in the U.S.

Evidence-based healthcare applications:

- We provide health education to Black women.
- We provide advocacy and influence public policy that impacts the health of Black women.
- We form coalitions with community-based organizations.
- We offer Black women culturally appropriate tools and information to be informed and empowered healthcare consumers.
Center for Medical Consumers

**Mission:**

To help people look for and understand the research supporting their doctor's treatment recommendations.

Our advocacy work in Albany and Washington centers on the reduction of hospital-acquired infections and medical errors and improving the FDA's drug safety and drug promotion standards.

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Center for Medical Consumers

**Constituency:**

- Our monthly articles provide a critical appraisal of the latest studies. We concentrate on medical interventions aimed at healthy people (e.g., screening tests, drugs for bone loss);
- Our articles appear in the country's largest electronic information services (Gale Group, EBSCO, Lexis/Nexis, ProQuest) that are used by private and public libraries;
- Our Web site gets about 40,000 visits a month;

**Evidence-based healthcare applications:**

- Evidence-based advocacy: hospital patient safety, FDA watchdogs, deceptive prescription drug advertising, etc.
Cherab Foundation

Mission Statement:

- We are a world-wide nonprofit organization working to improve the communication skills, education, and advocacy of the verbal disabled, all those with speech and language delays or impairments. Our area of emphasis is verbal apraxia, a severe, neurologically-based communication disorder that used to be rare in children but has been on the rise within the past two decades.
- We are committed to assisting with the development of new therapeutic approaches, preventions and cures to neurologically-based speech disorders that affect all ages with a focus on children.
- We bring together families, affected individuals, and medical, research, speech, and educational professionals.

CHERAB Foundation

Evidence-based healthcare applications:

1. We educate the rights of the verbal disabled to families, affected individuals, schools, policy makers and the public.
2. We currently are seeking research funds through various sources to validate our group’s anecdotal findings for fish oil and vitamin E as a treatment for apraxia and other communication impairments.
3. As a grassroots organization we work with other organizations to raise awareness about various communication impairments and their impact on the individual and society when not addressed or when misdiagnosed.
Childbirth Connection

Mission Statement:
Childbirth Connection is a national not-for-profit organization founded in 1918 as Maternity Center Association. Our mission is to improve the quality of maternity care through research, education, advocacy and policy. Childbirth Connection promotes safe, effective and satisfying evidence-based maternity care for all women and their families.

Childbirth Connection

Constituency: Women and health professionals

Evidence-based healthcare applications:

- Childbirth Connection launched our long-term national program to promote evidence-based maternity care in 1999.
- Our award-winning website provides evidence-based information and resources for women and health professionals to help them make informed maternity care decisions. The website provides access to the electronic version (2000) of the renowned "Guide to Effective Care in Pregnancy and Childbirth".
- Childbirth Connection has commissioned systematic and narrative reviews and pioneering national Listening to Mothers surveys to illuminate women's childbirth experiences and clarify evidence-practice gaps. Accompanying media outreach campaigns help publicize results and products.
- The organization is the long-term North American sponsor of the Consumer Panel of the Cochrane Collaboration Pregnancy and Childbirth Group, which involves consumers as referees to strengthen the quality of systematic reviews.
- Childbirth Connection also works to build awareness of maternity care quality issues among federal and state policy makers.
Consumer Reports

- Consumers Union, the publisher of Consumer Reports, is a powerful consumer organization and social change agent.
- CU has a long history of giving people the expert, unbiased facts they need to make informed decisions in the consumer marketplace.
- Our mission since 1936 ... An expert, independent, nonprofit organization, whose mission is to work for a fair, just, and safe marketplace for all consumers.
- What we do: test, inform and protect.

Our Health-Care Mission

- To build on CU's unique strengths and trusted reputation to help consumers make better-informed health-care decisions and influence health-care reform.
- We believe that through a combination of evidence-based information and community action, we can make high-quality, safe and affordable healthcare a reality for many more Americans.
- Because Consumer Reports is without commercial agendas or advertiser influence, we are in a unique position to provide this information.
- Our areas of focus over the next 3 years are Health-Care Reform, Patient Safety, Evidence-based Medicine, Provider Ratings, Doctor-Patient Relationships, and Healthy Living Guidance.
Consumer Reports Health

- Our goal is to become the source that more consumers turn to first when making health-care decisions, because our information is evidence-based, relevant, and transparent.
- In June 2008, we launched a new consumer health website **ConsumerReportsHealth.org** as the platform for our work.
- In June 2008, we also announced the **Consumer Reports Health Ratings Center**, led by Dr. John Santa, to develop unique research and ratings to guide consumers.
- In July 2008, we began the next phase of **Consumer Reports Best Buy Drugs**, supported by a major new AG grant.
- We have developed a community of citizen-advocates who work with us to achieve reform in the healthcare arena.
- With them, we can increase CU’s impact with policy makers, ultimately securing passage of laws & regulations that provide needed consumer protections.

Faces & Voices of Recovery

**Mission:**

Faces & Voices of Recovery is committed to organizing and mobilizing the millions of Americans in long-term recovery from alcohol and other drug addiction, our families, friends, and allies to speak with one voice. Our organization is dedicated to changing public perceptions of recovery, promoting effective public policy in Washington and in all 50 states, and demonstrating that recovery is working for millions of Americans. It is our collective strength that will ensure our success and it is our mission to bring the power and proof of recovery to everyone in America.
Faces & Voices of Recovery

Constituency:
People in recovery from addiction to alcohol and other drugs, families, friends and allies

Evidence-based healthcare applications:
Getting out information about pathways to recovery; involvement of individuals and families who are using this information in developing policy and programs

Lamaze International

Mission Statement:
- The mission of Lamaze International is to promote, support and protect normal birth through education and advocacy.
- The Lamaze Institute for Normal Birth is a vehicle for advocacy, information and coalition building to advance the Lamaze International mission to promote, support and protect normal birth through education and advocacy.
National Breast Cancer Coalition

Mission:
To eradicate breast cancer
Primary goals:
- **RESEARCH**: increase funding and accountability, and foster innovative research with high, meaningful impact
- **ACCESS**: to high quality health care and breast cancer clinical trials for all women
- **INFLUENCE**: expand influence of well-trained advocates throughout breast cancer decision-making process

National Breast Cancer Coalition

Constituency:
Hundreds of grassroots organizations, thousands of individuals, breast cancer survivors, stakeholders in breast cancer community

Evidence-based healthcare applications:
- Training Programs - basis for Project LEAD® courses
- Beyond the Headlines, Positions: basis for critical analyses, position papers, response to research in the news, literature and controversies
- Clinical Trials Initiatives: Criteria for clinical trials, industry, research partnerships
- Legislative Agenda: Basis for support or lack of support for legislation
National Center for Transgender Equality

Constituency: Transgender people in the United States, LGBT advocates and allies, members of Congress and other elected officials

Evidence-based healthcare applications: We have used evidence-based healthcare/medicine in the Washington State Medicaid case and we look forward to using it more in the future.

National Coalition for Lesbian, Gay, Bisexual and Transgender Health

Mission:
The National Coalition for LGBT Health is committed to improving the health and well being of lesbian, gay, bisexual and transgender individuals and communities through public education, coalition building and advocacy that focuses on research, policy, education and training.
National Coalition for Lesbian, Gay, Bisexual and Transgender Health

Evidence-based medicine is critical to insuring that the needs of the lesbian, gay, bisexual and transgender communities for relevant, sensitive and effective health care are developed and disseminated to providers and consumers. For example:

- HIV/AIDS is still the most critical health care issue facing gay, bisexual and other men who sex with men;
- Lesbians still have significantly higher rates of breast cancer than heterosexual women;
- Transsexual men and women need effective hormone therapy and gender reassignment surgeries;
- As more and more gay and lesbian couples are seeking to have children, LGBT sensitive reproductive healthcare is becoming a growing area of need.

National Consumers League

**Mission Statement**

- Our mission is to protect and promote economic justice for consumers and workers in the U.S. and abroad. Represent consumers on marketplace & workplace issues.
- Founded in 1899, NCL is the oldest consumer organization in the U.S.
National Consumers League

Health Policy

- Carried out through: education projects, general advocacy, forums
- Focus on:
  - Safe use of medications – SOS Rx, medication reconciliation, adherence, OTCs, communication, DTC
  - Quality of health care
  - National health reform/coverage

National Environmental Education Foundation

Mission:

The National Environmental Education Foundation is a private, non-profit organization committed to advancing environmental knowledge among health professionals in order to improve health care and public health, with a special emphasis on protecting children and other populations disproportionately impacted by environmental pollutants. Through the development of national agendas, trainings, curriculum integration, and strategic partnerships, NEFF facilitates the integration of environmental health into health care provider education and practice.
National Environmental Education Foundation

Constituency:
Our constituents are health professional organizations, healthcare providers, public health organizations and the general public.

Evidence-based healthcare applications:
We use evidence-based healthcare information in developing all our tools, resources and trainings.

National Partnership for Women & Families

Mission Statement:
- Founded in 1971 as the Women's Legal Defense Fund, the National Partnership for Women & Families is a leader on issues that affect women and families—issues like increasing access to quality, affordable health care; ensuring equal opportunity and fair treatment in the workplace; and helping Americans balance their work and family responsibilities.
Americans for Quality Health Care: a Project of the National Partnership for Women & Families

Constituency:
We represent consumers and workers. Our Americans for Quality Health Care (AQHC) initiative is engaging consumer advocates in activities to improve health care quality. The AQHC project is also working to provide consumers with performance information about their health care providers so that they can make educated health care decisions.

Evidence-based health care applications:
Advocacy and Public Education: The consumer groups we work with advocate for increased use of EBM as a way to improve health care quality; they also use EBM to raise their constituents' awareness about informed decision-making and better self-management of their health.

Mission Statement:
- Oldest and largest consumer organization advocating the institution of vaccine safety and informed consent protections in the mass vaccination system
- We have been dedicated to the prevention of vaccine injuries and deaths through public education and to defending the informed consent ethic since 1982.

National Vaccine Information Center
National Vaccine Information Center

Evidence-based healthcare applications:

- Independent clearinghouse for information on diseases and vaccines, NVIC does not promote the use of vaccines and does not advise against the use of vaccines. We support the availability of all preventive health care options, including vaccination, and the right of consumers to make educated, voluntary health care choices.

- NVIC has provided information about diseases and vaccines to hundreds of thousands of parents, health care providers and other individuals who have contacted our organization during the past three decades.

National Women's Health Network

Mission Statement:

- Founded in 1975 to give women a greater voice within the healthcare system.
- Our mission is to improve the health of all women by developing and promoting a critical analysis of health issues in order to affect policy and support consumer decision-making.
National Women's Health Network

Constituency:
NW NHN is a membership-based organization supported by thousands of individuals and organizations nationwide.

Evidence-based healthcare applications:
- Fact sheets, position papers, outside resources, and a newsletter to support individual decision-making by providing evidence-based information.
- Menopause & Aging Program is working to promote women's access to accurate health information from sources free from financial conflicts of interest, as well as products, services & resources that are backed up by solid evidence showing effectiveness for use during mid-life & late-life.

Our Bodies Ourselves

Our Bodies Ourselves (OBOS), also known as the Boston Women's Health Book Collective, is best known for the publications Our Bodies, Ourselves and Nuestras Cuerpos, Nuestras Vidas.

Mission:
Our mission is to empower women with information about health, sexuality, and reproduction.

We work in and for the public interest, promote equality between women and men, and build bridges among social justice movements.
Constituency:
- Women's health groups, community-based groups, community health centers, hospitals, women's health programs, women's resource centers in college campuses
- Women around the world through the OBOS Global Network
- Individuals who read our books and visit our website

Evidence-based healthcare applications:
- Latina Health Initiative - In addition to Nuestra Cuerpos Nuestra Vida (NCNV), the organization has produced Promotors de Salud, a training guide for community health workers based on NCNV and Janeway to Parenthood, De Camino a la Maternidad, a booklet about childbirth.
- Global Translation/Adaptation Program - A Russian edition of Our Bodies, Ourselves has just been published and Nepal, Russia, and Turkey are developing culturally adapted translations. Upcoming projects include adaptations for East Africa, India, and Jordan.
- Public Voice and Action - Our organization is a voice in policy advocacy and educational efforts on women's health. We have reached a wide audience with our feminist and consumer perspective on such issues as breast implants, direct-to-consumer advertising, prescription drugs, and Domino and genetics.

Safe Minds

Mission:
- SafeMinds seeks to prevent and find effective treatments for the disabling conditions of autism spectrum disorder caused by early life exposures to man-made sources of mercury, the second most toxic substance on earth.
- Our mission is achieved through scientific research, public awareness, and advocacy in the public policy and legal arenas.
Safe Minds

Constituency:
- Families, individuals with autism, scientists, clinicians, and policymakers who understand that environmental factors play a role in autism causality

Evidence-based healthcare applications:
- We advocate for funding clinical research that we hope can provide evidence for treatment approaches.
- We are partnering with other groups in making the case that the underlying mechanisms of autism are treatable and recovery is possible.
- With other groups, we are trying to identify ways to determine the effectiveness of complex, individualized treatment regimens using alternate approaches to the RCT, such as large clinical databases.

The Young Survival Coalition

Mission:
The Young Survival Coalition's mission is to increase the quantity and quality of life for young women affected by breast cancer.
The Young Survival Coalition

Constituency:
- 24,000 in our network
- Constituents are breast cancer survivors, professionals and friends and family who care about young women affected by breast cancer

Evidence-based healthcare applications:
We try to encourage our constituents to make their decisions based upon available evidence. We seek to educate them about what information constitutes evidence. Our website is a premier resource of information available to young women and they can ask our resource link coordinator questions and communicate with each other on our bulletin boards.
Appendix E
CUE Accomplishments 2007-08

Education and Training for Consumer Advocacy Groups

- *Understanding Evidence-based Healthcare: A Foundation for Action*, launched on September 15, 2007 and offered free of charge.
- As of November 15, 2007, enrollment is open to any interested individual and almost 1000 have enrolled in the course as of July 2008.

Dissemination

- *Developing A Local Consumer Coalition Of Consumer Advocacy Groups*
  Kay Dickersin, Barbara Warren with Janet Wale (CCNet) International Cochrane Colloquium, São Paulo Brazil October, 2007
- *Access To Evidence-based Healthcare Information: Web-based Training For Consumers And Providers*
Healthcare Policy

On July 25, Maureen Corry will speak on behalf of CUE at the National Health Policy Forum’s session “Introduction to the Cochrane Collaboration and Fundamentals of Evidence-based Health”, the first in a series for Congressional staff on “Everything You Always Wanted to Know about Comparative Effectiveness but Were Afraid to Ask”.

CUE Annual Membership Meeting, 23 July 2008 (cont’d)
## Appendix F

**Program Evaluation**

Consumers United for Evidence-based Healthcare (CUE)

2008 Annual Membership Meeting

July 23, 2007

Washington, DC

### Introduction of new and current member organizations

Check here if you did not attend this session □

OR Circle the best answer for each item.

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### CUE 2007 Report

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Current hot issues and developments in EBHC

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B. Quality of presentation by speaker

Shannon Brownlee
How failure to practice *EBHC makes us sicker and poorer*

Kavita Patel
Legislation on a new Institute for Comparative Effectiveness

Gail Shearer
IOM Roundtable on Evidence-Based Medicine’s Communications Collaborative

Deborah A. Zarin
Expansion of ClinicalTrials.gov to include information on clinical trial results

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Getting the most from *The Cochrane Library*: Demonstration

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B. Quality of presentation by speaker

Kay Dickersin

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### Campaign for National License to *The Cochrane Library*: Experience in India

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### Panel Discussion: CUE members’ experience in dissemination and incorporating evidence into advocacy

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CUE Annual Membership Meeting, 23 July 2008 (cont’d)

CUE projects: updates & future directions

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Open Forum Looking Ahead: Goals for upcoming year

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**Overall Evaluation**

1. The program was presented without evident commercial bias or influence.
   - ( )₀ No
   - ( )₁ Yes
   - ( )₂ Not Certain

2. The program met my expectations
   - ( )₀ No
   - ( )₁ Yes
   - ( )₂ Not Certain

3. Please provide comments or suggestions: ____________________________________________________________
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Appendix E

USCC and San Francisco Branch Presentations and Papers 2009

Kay Dickersin’s presentations


Kay Dickersin’s papers

Journal Articles


Monographs

Editorials, Book Reviews, and Letters


Roberta Scherer’s presentations


Roberta Scherer’s papers


Tianjing Li presentations
1. Challenges in Peer Reviewing Evidence-Based Clinical Practice Guidelines: Do We Know the Degree to Which the Guidelines Reflect Underlying Evidence? Presented at the Sixth International Congress on Peer Review and Biomedical Publication. September 10-12, 2009, Vancouver, Canada.
Isabel Rodríguez-Barraquer presentations

Swaroop Vedula presentations

San Francisco Branch

Lisa Bero’s presentations
1. Invited Speaker. Evaluating Systematic Reviews and The Cochrane Collaboration. Alcohol Research Group, Berkeley, CA (Jan 20)

2. Invited Speaker: “Tainted evidence on drugs” International Cochrane Symposium. Evidence-based Medicine and Systematic Reviews: Challenges and Opportunities. Copenhagen, Denmark (April 22)

Lisa Bero’s papers


**Drummond Rennie’s papers**


2. **Rennie, D.** Integrity in scientific publishing. *Health Services Research* (Accepted for publication).
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<td>1. Target:</td>
<td>Coordinate, maintain, and update the Master List of Journals Being Searched (Master List)</td>
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<tr>
<td>1.1 Objective:</td>
<td>Coordinate, maintain, and regularly update the Master List</td>
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<td>2. Target:</td>
<td>Provide training and support for reviewers, review group coordinators (RGCs), trial search coordinators (TSCs), editors, handsearchers, consumers, those responsible for training activities, and others</td>
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<td>2.1 Objective:</td>
<td>Develop and facilitate Cochrane training workshops and courses</td>
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<td>Make available on the worldwide web and elsewhere guides for Cochrane procedures</td>
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<td>Provide ongoing support and training through individual contact, email discussion lists, and directories</td>
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<td>2.4 Objective:</td>
<td>Maintain online distance education course for consumer advocates, <em>Understanding Evidence-based Healthcare: A Foundation for Action</em></td>
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<td>2.5 Objective:</td>
<td>Plan and implement necessary changes to consumer online distance education course, to appeal to an audience of health professionals and students</td>
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<td>3. Target:</td>
<td>Promote awareness of the Cochrane Collaboration and access to Cochrane products</td>
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<td>Plan and host a US Contributors’ Conference</td>
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<td>3.2 Objective:</td>
<td>Ensure that individuals (including the media and consumers) and institutions within the region served by the USCC are aware of the Cochrane Collaboration and the USCC and understand its products and functions; highlight Cochrane activities in presentations and</td>
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reports to health professionals, consumers, and others whenever relevant

3.3 Objective: Work to ensure that The Cochrane Library is made available and accessible to regional institutions, government agencies, professional organizations, and others

3.4 Objective: Encourage the news media to use The Cochrane Library, provided free of charge through John Wiley and Sons, Inc.

3.5 Objective: Work with physicians, consumers, government, and others to identify ways in which Cochrane reviews can better meet their needs

3.6 Objective: Ensure interest, relevance, and accuracy of the USCC’s website

4. Target: Perform USCC administrative functions

4.1 Objective: Perform handsearching of US medical journals and conference proceedings

4.2 Objective: Participate in annual Collaboration meetings at the 2009 Cochrane Colloquium and midyear meetings

4.3 Objective: Perform general Center administrative functions

5. Target: Seek and obtain funding support for USCC activities

5.1 Objective: Continue working with funders to support USCC activities

5.2 Objective: Work with USCC branches and US-based entities to identify sources of funding and to leverage combined efforts to obtain funding
6. Target: **Conduct and disseminate research**

6.1 **Objective:** Conduct methodological research on issues of importance to systematic reviews, reporting biases, trials registers, and evidence-based healthcare

7. Target: **Facilitate the development and growth of the USCC’s consumer coalition, Consumers United for Evidence-based Healthcare (CUE)**

7.1 **Objective:** Support CUE infrastructure and functions

7.2 **Objective:** Strengthen the ties between CUE and the Cochrane Collaboration Consumer Network (CCNet)

7.3 **Objective:** Increase CUE membership

8. Target: **Work collaboratively with the CEVG@US satellite office**

8.1 **Objective:** Share materials and resources related to educational projects

8.2 **Objective:** Collaborate with CEVG@US on research projects

9. Target: **Contribute to the planning of the 2010 Cochrane Colloquium**

9.1 **Objective:** Through the Scientific Committee, organize the scientific program

9.2 **Objective:** Contribute USCC staff time toward the planning process
Appendix G

CUE Annual Membership Meeting Agenda
National Partnership for Women and Families Office
Washington, DC
September 3, 2009; 8:30 am - 5:00 pm

8:00 am - 8:30 am  Registration and continental breakfast

8:30 am - 8:35 am  Recognition of life’s work of Carolina Hinestrosa, Executive Vice President, National Breast Cancer Coalition
Kay Dickersin, Director, US Cochrane Center

8:35 am - 8:40 am  Welcoming remarks
Sally Bernard and Barbara Warren, Co-chairs, CUE
Kay Dickersin and Janie Gordon, US Cochrane Center

8:40 am - 9:00 am  Introduction of member organizations
Barbara Warren

We ask all members to introduce themselves and their organization’s mission.

9:00 am - 9:30 am  CUE 2008/2009 report and discussion
Sally Bernard

What consumer advocates need to know about health care reform

9:30 am - 9:50 am  Legislative update: What to expect when Congress returns
Mona Shah, Health Legislative Assistant, Senator Barbara Mikulski (Md)

9:50 am - 10:15 am  Discussion

10:15 am - 10:30 am  Break

How to get your priorities into legislation

10:30 am - 10:45 am  Being counted
Rebecca Fox, Executive Director, National Coalition for LGBT Health
### 10:45 am - 11:00 am
**Medicaid quality improvement**
Maureen Corry, Executive Director, Childbirth Connection

### 11:00 am - 11:15 am
**Discussion**

### Evidence in practice

#### 11:15 am - 11:30 am
**What is the evidence on care delivered in retail clinics?**
Rebecca Burkholder, Vice President, Health Policy, National Consumers League

#### 11:30 am - 11:45 am
**The evidence for making hospitals safer**
John Santa, Director of the Health Ratings Center, Consumer Reports

#### 11:45 am - 12:00 pm
**Discussion**

#### 12:00 pm - 1:00 pm
**Lunch**
*Call - in lunch discussion: What consumers can learn from new models for building advocacy and leadership in the 21st century - Back to the grassroots!*  
David Wellstone, Board Co-chair, Wellstone Action

### Current hot issues and developments in healthcare

#### 1:00 pm - 1:20 pm
**Where is the consumer in comparative effectiveness research?**
Jean Slutsky, Director, Center for Outcomes and Evidence, AHRQ

#### 1:20 pm - 1:40 pm
**Shared decision making: How to make it work for you**
Lyn Paget, Director of Communications, Foundation for Informed Decision Making

#### 1:40 pm - 2:00 pm
**Discussion**

#### 2:00 pm - 2:15 pm
**Advocacy in action**

#### 2:15 pm - 2:30 pm
**Raising Women’s Voices for the health care we need**
Cindy Pearson, Executive Director, National Women’s Health Network

#### 2:30 pm - 3:00 pm
**Discussion**

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X:\Cochrane\03 Centers\USCC\3 Reports\Annual Rpt\2009\Annual Report\G Agenda CUE Annual Membership Meeting 2009.wpd

August 28, 2009
Page 2 of 3
2:30 pm - 2:45 pm    **Break**

2:45 pm - 3:00 pm    **Finding the evidence: Demonstration of *The Cochrane Library*, other sources**  
Kay Dickersin and Janie Gordon

3:00 pm - 4:00 pm    **CUE projects: updates & future directions**

- Building membership - ideas and priorities for expansion
- CUE online course update
- Playing a key role in health care policy
- Dissemination
- Looking ahead: Goals for upcoming year
- Future directions

4:00 pm - 4:15 pm    **Steering Committee election**

4:15 pm - 4:30 pm    **Wrap-up and evaluation**
Appendix H

United States Cochrane Center
Performance Targets for January 1 - December 31, 2010

1. Target: Update the Master List of Journals Being Searched (Master List) as registration forms are received.

1.1 Objective: Update the Master List of Journals Being Searched (Master List) as registration forms are received

2. Target: Provide training and support for reviewers, managing editors, trial search coordinators (TSCs), editors, handsearchers, consumers, those responsible for training activities, and others

2.1 Objective: Develop and facilitate Cochrane training workshops and courses

2.2 Objective: Make available on the worldwide web and elsewhere guides for Cochrane procedures

2.3 Objective: Provide ongoing support and training through individual contact, email discussion lists, and directories

2.4 Objective: Maintain online distance education course for consumer advocates, Understanding Evidence-based Healthcare: A Foundation for Action

2.5 Objective: Launch updated version of online course Understanding Evidence-based Healthcare: A Foundation for Action

2.6 Objective: Launch new version of online course Understanding Evidence-based Healthcare: A Foundation for Action, for healthcare providers and researchers

2.7 Objective: Maintain online distance education course for handsearchers: Handsearching: Identifying and Classifying Controlled Trial Reports
3. Target: Promote awareness of the Cochrane Collaboration and access to Cochrane products

3.1 Objective: Ensure that individuals (including the media and consumers) and institutions within the region served by the USCC are aware of the Cochrane Collaboration and the USCC and understand its products and functions; highlight Cochrane activities in presentations and reports to health professionals, consumers, and others whenever relevant.

3.2 Objective: Work to ensure that The Cochrane Library is made available and accessible to regional institutions, government agencies, professional organizations, and others.

3.3 Objective: Encourage the news media to use The Cochrane Library, provided free of charge through John Wiley and Sons, Inc.

3.4 Objective: Work with physicians, consumers, government, and others to identify ways in which Cochrane reviews can better meet their needs.

3.5 Objective: Ensure interest, relevance, and accuracy of the USCC’s website.

3.6 Objective: Plan and host US contributors’ meeting, to be held in conjunction with the 2010 Joint Cochrane and Campbell Colloquium.

4. Target: Perform USCC administrative functions

4.1 Objective: Perform handsearching of US medical journals and conference proceedings.

4.2 Objective: Participate in annual Collaboration meetings at the 2010 Cochrane Colloquium and midyear meetings.

4.3 Objective: Perform general Center administrative functions.

5. Target: Seek and obtain funding support for USCC activities

5.1 Objective: Continue working with funders to support USCC activities.
5.2 **Objective:** Work with USCC branches and US-based entities to identify sources of funding and to leverage combined efforts to obtain funding

6. **Target:** Conduct and disseminate research

6.1 **Objective:** Conduct methodological research on issues of importance to systematic reviews, reporting biases, trials registers, and evidence-based healthcare

7. **Target:** Facilitate the development and growth of the USCC’s consumer coalition, Consumers United for Evidence-based Healthcare (CUE)

7.1 **Objective:** Support CUE infrastructure and functions

7.2 **Objective:** Strengthen the ties between CUE and the Cochrane Collaboration Consumer Network (CCNet)

7.3 **Objective:** Increase CUE membership

7.4 **Objective:** Increase partnerships among scientists, policymakers and others with CUE members through providing a “clearinghouse” for those seeking consumer partners

7.5 **Objective:** Sponsor the 2010 Advocacy Summit, Advocacy in the Era of Evidence: An International Summit for Consumer Advocates, in conjunction with the 2010 Joint Colloquium of the Cochrane and Campbell Collaborations

8. **Target:** Work collaboratively with the CEVG@US Satellite office

8.1 **Objective:** Share materials and resources related to educational projects

8.2 **Objective:** Collaborate with CEVG@US on research projects
9. **Target:** Contribute to the success of the 2010 Cochrane Colloquium

**9.1 Objective:** Plan and contribute to scientific portion of 2010 Joint Colloquium of the Cochrane and Campbell Collaborations at Keystone, Colorado

**9.2 Objective:** Contribute USCC staff time and resources toward the planning process