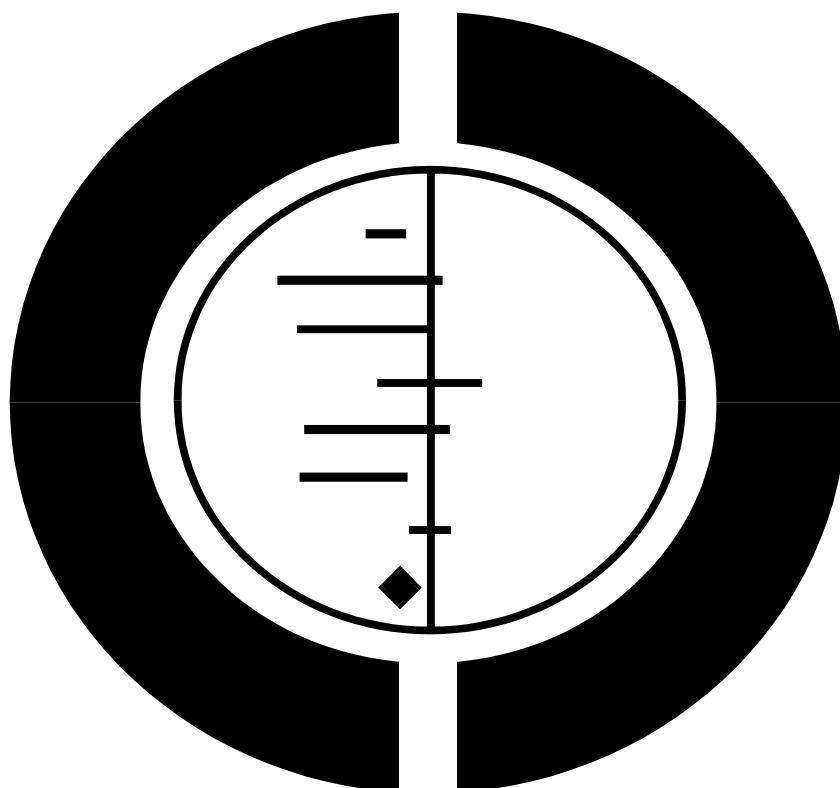


United States Cochrane Center

Combined Annual Report

January 1, 2007 - December 31, 2007, and

January 1, 2008 - December 31, 2008.



The Cochrane Collaboration

Preparing, maintaining and

promoting the accessibility of systematic reviews

of the effects of healthcare interventions

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(ii) Abbreviations used in USCC Annual Report

Abbreviation	Full Name
AAO	American Academy of Ophthalmology
AHRQ	Agency for Healthcare Research and Quality
ARCHIE	Cochrane Contact Database
ARVO	Association for Research in Vision and Ophthalmology
CAM	Complementary and Alternative Medicine Field
CCNet	Cochrane Consumers Network and Field
CCSG	Cochrane Collaboration Steering Group
CCT	Controlled clinical trial
CENTRAL	Cochrane Central Registry of Controlled Trials
CEVG	Cochrane Eyes and Vision Group
CEVG@US	Cochrane Eyes and Vision Group, US Satellite
CRG	Cochrane Review Group
CUE	Consumers United for Evidence-based Healthcare
EBHC	Evidence-based healthcare
Master List	Master List of Journals Being Searched
NEI	National Eye Institute
PaPas	Pain, Palliative and Supportive Care Group
RCT	Randomized controlled trial
UCSF	University of California San Francisco
USCC	United States Cochrane Center

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 University 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. A specific objective is to coordinate and support Consumers United for Evidence-based Healthcare (CUE).

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 Cochrane 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
- 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;
- 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 more than 2,600 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

- develop and support CUE, a coalition of US healthcare consumer advocacy groups;
- monitor an online handsearching course.

4. Funded projects

4.1 Agency for Healthcare Research and Quality (AHRQ) conference grant (2002 - 2007)

In 2002, the USCC was awarded a 5-year grant from AHRQ to conduct a series of conferences to increase US involvement in and contribution to The Cochrane Collaboration. The complete conference series included two large US Cochrane Contributors' Conferences, a series of smaller hands-on training workshops, and development and launch of a web-based distance education course for consumer advocates offered free of charge and with unrestricted use. As a

result of the 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 evidence-based healthcare (EBHC). This critical mass has increased our effectiveness in dissemination of information about EBHC and The Cochrane Collaboration.

In 2007, activities included a series of hands-on training workshops, and the final launch of a web-based distance education course on EBHC for consumer advocates. A complete list of educational programs is included in Appendix A.

The AHRQ grant also funded the creation and support of a coalition of healthcare consumer advocacy groups. The goal of CUE, founded in 2003, is 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. CUE meets annually to further its aims to build a coalition of health advocacy organizations who

- incorporate evidence-based methods into their work;
- educate constituencies about evidence methods and interpretation;
- encourage dissemination of evidence-based findings.

This grant supported the *CUE Advocacy Summit, Understanding Evidence-based Healthcare: A Foundation for Action* held July 17, 2007, which was attended by more than 100 consumer advocates (see Section 6.8.1 and Appendix B). The summit was preceded by the *2007 Annual CUE Membership Meeting*, July 16, 2007 in Washington, D.C. (see Section 6.8.1 and Appendix C). In addition a consumer online course on EBHC was created (see Section 6.3.2) and several workshops were held for consumers (see Appendix A).

CUE representatives have played an increasing role in The Cochrane Collaboration: members of networks, fields, and review groups, peer reviewers, and developers of plain language summaries.

4.2 Agency for Healthcare Research and Quality large conference grant (2007 - 2010)

The conference series in 2007 - 2008 included an US Contributors' Conference, *Priority Setting for Systematic Reviews* (see Section 6.4.1 and Appendix D), US Contributors' Meetings at Cochrane Colloquia (see Sections 6.5.2 and Appendices E and F), a workshop *Train the Trainers in EBHC and Critical Appraisal* (see Section 6.3.2 and Appendix A). Evaluation is an essential part of the USCC's conference and workshop education plan; evaluation results will be considered in the planning process for the 2009 conference and workshops.

4.3 Agency for Healthcare Research and Quality 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. The CUE Steering Committee has monthly teleconferences and meets annually to further its aims to build an effective coalition of health advocacy organizations. This grant supported the *2008 Annual CUE Membership Meeting*, July 23, 2008 in Washington, D.C. (see Section 6.8.1 and Appendix G).

4.4 The Cochrane Collaboration Prioritisation Fund

The Cochrane Eyes and Vision Group, US Satellite (CEVG@US) was awarded funds by The Cochrane Collaboration Prioritisation Fund to work on the Evidence-based Priority-setting for New Systematic Reviews and Clinical Trials Project, which will test a framework for setting priorities for randomized controlled trials (RCT) and systematic reviews related to interventions for primary open angle glaucoma, ocular hypertension, and angle closure glaucoma. This framework, if successful, could subsequently be applied to setting research priorities in health fields other than vision science. In 2007, CEVG@US derived clinical questions based on recommendations presented in the American Academy of Ophthalmology (AAO) guidelines for primary open angle glaucoma, documented the evidence cited in the guidelines, and described the strength of the recommendations. CEVG@US next obtained a prioritized list of the restated clinical questions, through a Delphi survey of American Glaucoma Society members. To date, two rounds of online Delphi survey have been completed, in which participants are asked to rank the importance of having the answer to each of the restated clinical questions to provide effective patient care. The survey results will be used to establish a list of priorities.

4.5 National Eye Institute (NEI) contract

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 2007, and two workshops in 2008 on how to complete a systematic review. Sections 6.3.3 and 7.1 provide additional information on the activities of CEVG@US.

5. San Francisco Branch of the USCC

The San Francisco Branch of the USCC, based at the University of California, San Francisco (UCSF), has been involved in transitioning the development and management of Cochrane's electronic Criticism Management System to Wiley InterScience, Inc., the new publisher of *The Cochrane Library*. The Branch supports the HIV/AIDS CRG and is involved in the management of conflicts of interest within The Cochrane Collaboration. The Branch is also active in promoting The Cochrane Collaboration in the Western United States. In 2007, Lisa Bero was a member of the Scientific Programme Committee, for the 15th Cochrane Colloquium in São Paulo, Brazil. In 2008, Dr. Bero was a member of the Search Committee for Editor in Chief for *The Cochrane Library*. She also participated in two systematic reviews underway in 2008: the Effective Practice and Organisation of Care Group – Pharmacy interventions, and the Methodology Review Group – Association of funding and research outcomes. see Appendix H for presentations and papers. Additional training was provided to students in the health professions (see below).

Meta-analysis and Cochrane Collaboration Training provided by UCSF 2007 - 2008

Academic Year and Quarter	Course Number	Course Title	Nature of Contribution	Hours/Quarter of Instruction	Total Students Enrolled
Spring 2007	SPSS 205 Univ of CA. San Diego	Pharmacy Informatics	School of Pharmacy Video Conference Lecture	3	100
Summer 2007	IDS112	EBM Intersession	School of Medicine Lecture	1	115
Fall 2007	SciMeth117	Scientific Methods: Foundations in Scientific Inquiry	School of Dentistry Lecture	1	80
Winter 2007	Epi180.12	Intro to Clinical Research	School of Medicine Lecture	1	40
Spring 2008	SPSS 205 Univ of CA. San Diego	Pharmacy Informatics	School of Pharmacy Video Conference Lecture	3	100
Summer 2008	DPH 210	Dentistry / Research Methods	School of Dentistry Lecture	2	30
Summer 2008	Intersession #1	Policy/Ethics/EBM 3 rd yr. medical students	School of Medicine Lecture	1.5	110

Academic Year and Quarter	Course Number	Course Title	Nature of Contribution	Hours/Quarter of Instruction	Total Students Enrolled
Fall 2008	SciMeth 117	Scientific Methods: Foundations in Scientific Inquiry	School of Dentistry Lecture	2	112

6. Progress report on targets for 01/01/07 to 12/31/08

Based on the USCC mission and responsibilities, performance targets, objectives and activities were developed to guide the work of the USCC in 2007 and 2008. This section summarizes the achievements related to 2007 and 2008 performance targets (see Appendix I for USCC Performance Targets for January 1, 2007 - December 31, 2008).

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

The USCC coordinates the *Master List*, which includes 2,209 unique journals and 323 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, through which the coordinators of all registered handsearches are asked to provide updated information about their handsearch activities via email. The annual *Master List* update survey resulted in responses from 89% (56/63) and 94% (58/62) of Cochrane entities with registered searches in 2007 and 2008, respectively.

6.2 Work with National Library of Medicine to ensure that randomized trials included on MEDLINE are appropriately indexed as publication type [PT] RANDOMIZED CONTROLLED TRIAL (RCT) (MEDLINE Retagging Project), pending receipt of funding.

6.2.1 Perform electronic search for randomized controlled trials on MEDLINE, and submit the results to the National Library of Medicine.

The USCC did not receive the necessary funding to achieve Targets 6.2 & 6.2.1.

6.3 Provide training and support for reviewers, review group coordinators, trial search coordinators, editors, handsearchers, consumers, and others responsible for training activities.

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

Training and supporting review authors, trials search coordinators, review group coordinators, 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:

- 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*
- Trials search coordinator resources including the *Guide for Trials Search Coordinators*
- Handsearcher resources (e.g., *Handsearcher Training Manual* and *Handsearch Training Resource, Capetown Colloquium 2000*)
- Online handsearching course
- Master List of Journals Being Searched and of Conference proceedings as well as forms to use to register a new search for a journal or conference
- Online course oriented to consumers, *Understanding Evidence-based Healthcare: A Foundation for Action*
- Reports and documents including 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
- Podcast of 2008 USCC Conference, *Priority Setting for Systematic Reviews*
- Cochrane Collaboration background documents including *The Cochrane Policy Manual* and the *Cochrane Handbook for Systematic Reviews of Interventions*, and access to *The Cochrane Library*

- Evidence-based healthcare and general information including primers, articles, books, and organizations.

The USCC strives to make resources readily accessible to affiliated groups and individuals. In 2007, USCC staff completed a comprehensive review of its website resource pages, ensuring that all links were active, updating all pages and their contents (see Section 6.4.5).

6.3.2 Develop and facilitate Cochrane training workshops and courses.

The USCC developed and presented a number of training workshops in 2007 and 2008 (see Appendix A).

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 2007 and 2008.

- *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 through 2007 and 2008. As of October 2008, 571 individuals have 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).

A tracking system allows us to monitor registrant “visits” to the course. As of October 24, 2008, the mean number of visits to the training website by all registrants is 40, (range, 0 to 754; median = 7) for all 571 students. Of those who accessed the course at least once, the mean number of visits is 67 (median = 41). Sixty students have completed the course and taken the online “test” which consists of handsearching an online version of a vision science journal. An additional 50 students are in the process of taking the test.

- *Understanding Evidence-based Healthcare: A Foundation for Action*, a free of charge online course designed to help consumer advocates understand the fundamentals of evidence-based healthcare concepts and skills (<http://apps1.jhsph.edu/cochrane/CUEwebcourse.htm>).

Course objectives are to provide consumer advocates with the tools they need to

- successfully navigate the world of medical informatio;

- critically appraise research studies;
- influence the creation of responsible public policy in healthcare;
- 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.

The course was launched September 15, 2007. As of September 1, 2008, 1,160 people had obtained a User ID (24% of whom are from outside the US), 855 had registered for the course, and 200 had completed all six modules (38% of those completing Module 1). Of the 855 enrolled, 41% consider themselves consumer or health advocates, and 50% work on evidence-based healthcare. Sixty-four percent were taking the course for personal growth, 14% as part of an educational course, and 10% as work-related training. Eighty-five percent of those completing all six modules gave the course the highest possible ranking (excellent), and 38% said that the content was new or unfamiliar. Confidence had grown most for the topics of systematic reviews, The Cochrane Collaboration, and evidence-based healthcare.

- *Translating Critical Appraisal of a Manuscript into Meaningful Peer Review*: Development of this course began in 2004 and has continued through 2008, with an expected launch mid-2009. The course will include didactic lectures and a hands-on module where participants can write and receive faculty feedback for the manuscript critiques they prepare.

The web-based course will replace an existing in-person workshop provided through 2005. The target audience for the course includes clinicians who wish to learn more about serving as a peer reviewer for biomedical journals. The course 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. When it is completely web-based, the course will include three modules: two didactic modules comprising approximately 12 lectures, and one hands-on module comprising development of two manuscript critiques by the participants, group discussion, and feedback from the faculty.

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

USCC staff communicates regularly with members of various Cochrane entities and provides 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. Thirteen review authors received technical assistance from USCC staff in 2007, and 19 in 2008. The USCC offers a quiet space and one-on-one support for review authors who wish to spend mini-sabbaticals to work on their reviews. In 2008, one author, Dr. Prithvi Sankar, Assistant Professor of Clinical Ophthalmology, Scheie Eye Institute, visited the CEVG@US office for assistance with his systematic review, *Medical interventions for treating chronic primary angle glaucoma* (see Section 6.3.2 for additional training and support information).

6.4 Promote awareness of The Cochrane Collaboration and access to Cochrane products.

6.4.1 Plan and host the US Contributors' Conference

The USCC hosted the US Contributors' Conference, *Priority Setting for Systematic Reviews* July 10 - 11, 2008 in Baltimore, Maryland (see agenda in Appendix D). The conference theme was selected in response to a global need to set priorities for systematic reviews, so as to conserve resources and ensure that systematic reviews address important questions. Numerous groups and individuals are currently engaged in conducting systematic reviews to assess intervention effectiveness, and among them a variety of priority setting systems are used. The conference aimed to provide a forum for learning about approaches in use around the world, and for discussion and debate on the issues raised. An important goal was to bring together participants from a cross-section of involved groups to explore areas for collaboration and strategies for minimization of unnecessary duplication of effort.

The Conference Planning Committee designed a program that would be of interest to North American clinicians, researchers, policy makers and consumers. Speakers from the US, UK and Canada were invited to address different methods to prioritize systematic reviews, problems in priority setting and potential solutions, case studies of methodology for prioritizing systematic reviews and cross-group cooperation in priority setting. The conference agenda included plenary sessions, panel discussions, and debates. Speakers and participants included representatives of

The Cochrane Collaboration, educational and research institutions, government agencies, advocacy organizations, and journals, as well as public and private organizations.

The opening plenary provided a springboard for discussion by highlighting recommendations from the recent Institute of Medicine Report *Knowing What Works in Health Care: A Roadmap for the Nation*. Throughout the two days of the conference, several recurrent themes emerged: there is more than one effective prioritization system; more research is needed on current systems including testing of all new systems; and stakeholders (including patients and clinicians) must be identified and integrally involved in all prioritization schemes. Prioritization issues cover topic selection, how best to use existing systematic reviews, and the tradeoffs between updating reviews versus taking on new topics. There was widespread support for development of a registry of systematic reviews, perhaps by recasting the content already available in *The Cochrane Library*.

Questions remain as to the ideal tension needed to limit unnecessary duplication while allowing duplication that is both necessary and productive. It was noted that by combining the best of centralized and decentralized systems, we would be well-positioned to leverage highly trained and experienced contributors and to meet both our scientific and practical goals. The challenge is how to create such a system.

Following the conference, podcasts of all presentations were uploaded onto the USCC website for the convenience of individuals unable to attend the conference. Feedback from the conference evaluation indicates that presentations and the meeting overall met participants' expectations and helped crystallize critical issues in priority setting for systematic reviews.

6.4.2 Ensure that individuals (including the media and consumers) and institutions within the region served by the USCC are aware of all aspects of The Cochrane Collaboration and the USCC; highlight Cochrane activities in presentations and reports to health professionals, consumers, and others whenever relevant.

Promoting awareness of The Cochrane Collaboration is a central USCC objective. To achieve this objective, USCC staff make presentations about the Collaboration to key audiences to increase understanding of what the CC can provide and to build stronger partnerships with the media and healthcare consumers. In 2007 & 2008, USCC staff participated in programs and made presentations highlighting Cochrane activities, including EBHC and The Cochrane Collaboration, consumer advocacy and access to online healthcare information, and the need for a global clinical trials registration system. USCC staff presentations are listed in Appendix H.

The Cochrane Library is highlighted in USCC staff presentations, workshops, and meetings. 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; (2) the National Institute of Child Health and Human Diseases provides the complete text of Cochrane reviews produced by the Cochrane Neonatal Review Group to all; (3) MEDLINE provides abstracts of Cochrane systematic reviews to all; and (4) the Cochrane Collaboration and Wiley Interscience, the company's online publishing platform for professionals in the sciences, technology, and medicine, provide abstracts via their webpages to all.

6.4.3 Encourage 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. Some contacts have resulted in media highlighting Cochrane reviews. For example, in 2008, Ms. Christine Brophy, Research Editor at *Boardroom Inc./Daily Health News* requested information about the Cochrane Systematic Review, *Cranberries for Preventing Urinary Tract Infection*. The USCC provided her with a copy of the full systematic review. An article appeared soon after in *Bottom Line's Daily Health News*, September 18, 2008, entitled *Cranberries Keep Bacteria from Digging In*.

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

The USCC is committed to increasing consumer involvement in Cochrane activities and increasing consumer awareness of Cochrane products. In addition to developing an online course targeted to consumer advocates, *Understanding Evidence-based Healthcare: A Foundation for Action*, other consumer-centered activities in 2007 and 2008 were conducted:

- The *2007 Annual CUE Membership Meeting* was held in Washington, D.C. on July 16, 2007, followed by the first national *CUE Advocacy Summit: Understanding Evidence-based Healthcare: A Foundation for Action* held July 17, 2007 and attended by more than 90

consumer advocates. The CUE Steering Committee elected to open the meeting to the public as a way to broaden the discussion about EBHC between consumer advocates and other stakeholders. The goals of the advocacy conference were to build a critical mass of US-based consumer advocates trained to prepare and use the essential elements of EBHC and to increase collaboration between consumer advocacy organizations, Cochrane Collaboration contributors, the USCC, CUE, policymakers, clinicians, government, and payers;

- The *2008 Annual CUE Membership Meeting* was held in Washington, D.C. on July 23, 2008. The meeting goals were to provide professional development on EBHC and to promote collaboration between consumer organizations and the research, government and legislative communities; and
- The Cochrane Collaboration and CUE participated in the National Health Policy Forum, *Exploring Comparative Effectiveness: Fundamentals of Evidence-Based Health and Introduction to The Cochrane Collaboration*, in Washington, D.C. on July 25, 2008. The forum provided an opportunity for Congressional staff to hear from Kay Dickersin, Director, USCC; Maureen P. Corry, Executive Director, Childbirth Connection and CUE representative; Lorne A. Becker, Co-chair, Cochrane Collaboration Steering Group; Roger F. Soll, Editor, Cochrane Neonatal Review Group; and Prathap Tharyan, Director, South Asian Cochrane Network and Centre.

6.4.5 Maintain and expand the USCC's web presence.

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. In 2008, USCC staff redesigned the website and made improvements to facilitate easy navigation for visitors to the site.

Specific improvements follow:

- Launch of a redesigned site (similar to www.Cochrane.org site) November 2008
- Addition of podcasting for ready access to conference presentations
- Addition of funding support information
- Improvement to the CUE homepage
- Continuous monitoring to provide information updates
- Periodic check of links to resource sites for continued validity
- Addition of new reports and images/photos

- Incorporation of a standard registration template for workshop and conference registration

6.5 Perform USCC administrative functions

6.5.1 Perform handsearching of US medical journals and conference proceedings

In 2007, a total of 29 journal-years (from US medical journals and conference proceedings) was handsearched by the USCC resulting in the identification of 409 RCTs and 222 controlled clinical trials (CCTs). In 2008, a total of 62 journal-years (from US medical journals and conference proceedings) was handsearched by the USCC resulting in the identification of 827 RCTs and 244 CCTs, of which 1,086 RCTs and 459 CCTs had not been indexed in MEDLINE with either RCT or CONTROLLED CLINICAL TRIAL (CCT) as the publication type.

6.5.2 Participate in annual meetings at Cochrane Colloquia in 2007 (São Paulo) and 2008 (Freiburg)

The USCC hosted US Contributors' Meetings at the XV Colloquium in São Paulo, Brazil, (October 26, 2007) and at the XVI Colloquium in Freiburg, Germany (October 5, 2008). Attendees reported on the work of their entity (Center, CRG, Field, or Methods Group) and heard from representatives of The Cochrane Collaboration Steering Group (CCSG). The CCSG report was given by Dr. Lisa Bero (CCSG member) in 2007 and by Dr. Lorne Becker (CCSG co-chair) in 2008. US contributors discussed upcoming Cochrane training activities in the US, outreach and dissemination efforts, and funding opportunities and barriers (see Appendices E & F for meeting minutes).

In addition to the US Contributors' Meeting, USCC staff participated in the following Center-related meetings during the Colloquia of both years:

- Meet the Entities exchange (2007 and 2008)
- Cochrane Center Staff Meeting (2007 and 2008) where staff from all of the Cochrane Centers met to exchange information and ideas and to hear CCSG and Center Director updates
- Cochrane Consumers Network and Field (CCNet) Meetings (2007 & 2008)
- Cochrane Center Directors' Meetings, held on
 - October 23, 2007 (São Paulo)
 - October 3, 2008 (Freiburg)

In addition, Kay Dickersin served on both the Workshop and Scientific Committees for the 2007 São Paulo Colloquium. Dr. Dickersin also participated in the mid-year Center Directors' meeting in Vellore, India, in April 2008.

6.5.3 Perform general Center administrative functions

The USCC performed general Center administrative functions:

- Initiated a comprehensive review and update of the US Cochrane Contact Directory
USCC staff used information from workshops and meetings, *The Cochrane Library*, ARCHIE, and other sources to update the Directory, which includes names, postal and email addresses, and other information
- Completed and submitted required 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 reports the USCC's progress on 2007 and 2008 targets (see Appendix I) and presents targets for 2009 (see Appendix J)
- Responded to inquiries from healthcare professionals, consumers, journalists, and others about the USCC, The Cochrane Collaboration, *The Cochrane Library*, CUE and EBHC

6.6 Seek and obtain funding support for USCC activities

6.6.1 Seek funding for the continuation of the MEDLINE Retagging Project to ensure that all controlled trials on MEDLINE are indexed appropriately on MEDLINE and included in CENTRAL.

The USCC used available funds to continue the MEDLINE Retagging Project through December 2006. Attempts to generate income for this project were unsuccessful and it will be discontinued.

6.6.2 Continue working with funders to support USCC activities.

In 2007, the Agency for Healthcare Research and Quality (Grant No.R13HS13368-04) provided support to the USCC for the July 17, 2007 *CUE Advocacy Summit: Understanding Evidence-based Healthcare: A Foundation for Action*. Additional funds from the John M. Eisenberg Clinical Decisions and Communications Science Center and Kaiser Permanente Institute for Health Policy also provided support for the summit. In addition, the Agency for

Healthcare Research and Quality provided support for the *2007 Annual CUE Membership Meeting*, July 16, 2007.

The Agency for Healthcare Research and Quality (Grant No.R13 HS016868-01) provided support to the USCC in 2008 for the US Contributors' Conference, *Priority Setting for Systematic Reviews*, July 10 - 11, 2008. The Kaiser Permanente Institute for Health Policy contributed to this conference as well. The Agency for Healthcare Research and Quality (Grant No. R13 HS017397) provided support for the *2008 Annual CUE Membership Meeting*, July 23, 2008, which addressed translating evidence into quality care and getting the message out to your constituency.

Additional support for the Center for 2007 - 2008 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 evidence-based healthcare in eyes and vision.

6.6.3 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; we are in regular contact with them about potential funding sources.

6.7 Conduct and disseminate research

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

A core objective of the USCC is to conduct methodological research in systematic reviews, trials registers, and meta-analysis. To date, targeted research funding has not been obtained, and a modest program is ongoing.

6.7.1.1 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 prioritization grant, is to test a framework for setting priorities for randomized controlled trials and systematic reviews related to interventions for primary open angle glaucoma, ocular hypertension, and angle closure glaucoma.

This framework, if successful, could subsequently be applied to setting research priorities in other health fields (see Section 4.4 for complete details). Tianjing Li presented preliminary results at the 2008 Cochrane Colloquium (see Appendix K).

6.7.1.2 Classify Cochrane Eyes and Vision Group (CEVG) reviews and randomized trials in eyes and vision by disease and intervention

The objectives of the CEVG trials coding project are to select and apply suitable coding systems for diseases and interventions used in eyes and vision so that trials and systematic reviews can be accessed by authors, practitioners, guideline writers and others seeking evidence. This pilot project involved selection of a coding system to test using published CEVG reviews and a sample of trial reports in the CEVG register of controlled trials. Barbara Hawkins, PhD and Stephen Gichuhi, MD, MBA, MSc conducted the pilot project by independently applying codes from the International Classification of Diseases, Version 10 and the World Health Organization's beta test version of the International Classification of Health Interventions to a random sample of eyes and vision trials in the CEVG trials register and 43 CEVG systematic reviews in *The Cochrane Library*. Inter-observer agreement was found to be satisfactory for the systematic reviews using International Classification of Diseases, Version 10 coding, but not for International Classification of Health Interventions coding, due to the small number of codes applicable to interventions for eyes and vision. Dr. Hawkins coded a 10% sample (981 entries) of all titles and abstracts in the CEVG trials specialized trial register using both coding systems. Dr. Hawkins presented summary findings and an evaluation of the methods used in the pilot study at the 2007 meeting of the Society for Clinical Trials in Montreal, QC. (see Appendix L).

6.7.1.3 How well do clinicians understand clinical trials and clinical trial registration?

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 at an appropriate trials register. This provided an opportunity to examine how well clinicians understand clinical trials and clinical trial registration. The 2007 ARVO program abstracts (n = 6,044) were handsearched and all abstracts describing randomized controlled trials and controlled clinical trials (174 and 73, respectively) were identified.

All 2007 abstracts for which the author had entered information in the space allocated for trial registration (n = 258) were also identified. Upon inspection, only about half of registered abstracts described the results of a RCT or CCT (124/258; 48%). Slightly more than half (53%; 92/174) of all abstracts identified as a RCT report had a trial register name in the registration box. Compared with RCTs with no trial register information, RCTs with a trial register name

recorded in the information box were more often multi-center trials that evaluated pharmaceutical interventions compared with diagnostic or other types of interventions. These results were presented at the 2008 ARVO meeting (see Appendix M) and the 2008 Society for Clinical Trials meeting.

6.7.1.4 Correspondence between abstracts and full publications

Systematic reviewers have long questioned whether RCT results reported in abstracts should be included in systematic reviews. Only 60% of all RCTs reported in abstracts reach full publication and reporting biases exist such that negative results are less likely to be published in full. The goal of this study is to assess the concordance of RCT data reported in conference abstracts with the subsequent full length reports to estimate the reliability of abstract data. Abstracts describing RCTs that were presented at the Association for Research in Vision and Ophthalmology meetings in 2001, 2002, 2003, and 2004 have been identified. We are currently identifying the corresponding full length reports using PubMed, the Cochrane Central Register of Controlled Trials (which contains the CEVG specialized register), EMBASE, Web of Science, SCOPUS, and LILACS (for studies published by groups from Latin America and the Caribbean). The abstract and full length report will be considered to be a match if the study question, interventions, and study population are the same or very similar and at least one author is noted on both the abstract and full length report. Authors of RCTs for which no full length report is identified will be contacted and asked whether the results have been published and if so, where they are published. We will then assess the qualitative and quantitative concordance of data between abstracts of RCTs and their full length reports.

6.7.1.5 Survey of systematic reviews and meta-analyses in glaucoma

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. Roberta Scherer and Tianjing Li searched PubMed, *The Cochrane Library*, The Cochrane Database of Systematic Reviews, the Database of Abstracts of Reviews of Effects, the Health Technology Assessment Database, and the NHS Economic Evaluation Database in November 2006, and searched EmBase in March 2007. Inclusion criteria included a clearly formulated research question, explicit methods to identify primary studies, and predetermined inclusion and exclusion criteria; exclusion criteria were evaluation of only animal or *in vitro* studies. All systematic reviews were classified by eye condition and year of publication. All reviews of glaucoma were assessed for methodologic rigor

using a modified version of the Critical Appraisal Skills Programme instrument for systematic reviews. Results were presented at ARVO in May 2007 (see Appendix N) and at the 15th Cochrane Colloquium in October 2007.

6.7.1.6 Develop an open access study-based eyes and vision trials register (E-Trials)

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 Ssemanda began development of the study-based register by reviewing existing study-based specialized registers from other Cochrane Review Groups. The next steps included the design of the database, development of a procedure manual, and execution of the database design in a Microsoft Access database. Assembly of existing citation-based eye trials databases involved importing four overlapping datasets: the existing CEVG register, the 10% random sample of the CEVG register with subject matter codes previously described (see Section 6.7.1.2), a study-based dataset of eye trials that included information on trial participant demographics, and all additional MEDLINE fields not already included in the MEDLINE-indexed trials in the CEVG specialized register.

The final database was examined to assess the number of publications per year, the publication types (randomized clinical trial/controlled clinical trial), United States Public Health Service funding, the number of US first authors and the eye MeSH pathology terms using the MEDLINE index codes. Information about the types of eye conditions being tested in RCTs was obtained using the codes applied in the 10% random sample of the CEVG specialized register used to test coding strategies (see 6.7.1.2). Dr. Frederick Ferris presented these data as a part of the Jackson Memorial Lecture during the American Academy of Ophthalmology's 2008 Annual Meeting (November 9, 2008) and Ms. Ssemanda presented a poster on this work at the 16th Cochrane Colloquium, October 3 - 7, 2008 (see Appendix O).

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

6.8.1 Continue development of CUE infrastructure and functions.

As the scientist partner of CUE, the USCC convened regular CUE Steering Committee teleconferences, supported CUE Annual Meetings in 2007 and 2008, and coordinated the July 17, 2007 *CUE Advocacy Summit: Understanding Evidence-based Healthcare: A Foundation for Action*. The USCC also encouraged CUE member organizations to develop and implement collaborative projects and to disseminate CUE's EBHC resources to their membership.

CUE 2007 and 2008 projects were

- developing and launching *Understanding Evidence-based Healthcare: A Foundation for Action*, an online course on EBHC for consumer advocates;
- recruiting new CUE member organizations;
- increasing the number of registrants for the online EBHC course;
- teaching consumers about evidence and how to use it in making healthcare decisions;
- 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 partners to increase dissemination of EBHC;
- disseminating EBHC through presentations including a workshop entitled *Developing a Local Coalition of Consumer Advocates* at the 2007 Cochrane Colloquium in São Paulo, Brazil and a presentation about the online course at the American Public Health Association Annual Meeting, Washington, D.C., November 2007;
- producing a video about CUE and EBHC, now posted on the CUE website <http://apps1.jhsph.edu/cochrane/NSvideopage2.htm>.

In 2007, quarterly teleconferences of the CUE Steering Committee were held and in 2008 the frequency was increased to monthly. This regular contact has helped CUE respond more effectively to opportunities to strengthen consumer understanding and use of EBHC.

The *2007 Annual CUE Membership Meeting*, July 16, 2007, was hosted by the US Cochrane Center (see Agenda in Appendix C). The goal was to bring together CUE's leadership and membership to discuss programmatic and administrative matters relevant to the coalition. Selected CUE members were invited to present examples of their organizations' experiences with evidence-based healthcare and how they have interacted with The Cochrane Collaboration. The meeting provided a forum for CUE members from throughout the nation to come together to discuss their work and address common questions. Recurrent themes included strengthening the CUE infrastructure, obtaining reliable funding for infrastructure and proposed projects, and maintaining the momentum of the coalition.

Continuing challenges include how to increase awareness of the Coalition in the consumer and health professional communities, build on the potential of new relationships forged during the Advocacy Summit and elsewhere, increase awareness and use of evidence-based healthcare, and obtain financial support to continue the growth and development of the work of CUE in the United States.

On July 17, 2007, CUE and the US Cochrane Center hosted the inaugural *CUE Advocacy Summit: Understanding Evidence-based Healthcare: A Foundation for Action* (see Agenda in Appendix B, Section 6.4.4 and Section 6.6.2).

The one-day summit included plenary sessions, the launch of a distance-education course for consumer advocates, and workshops designed to provide practical training for consumer advocates on how to access and apply EBHC to their advocacy and educational efforts. “*Understanding Evidence-based Healthcare: A Foundation for Action*” was selected as the summit name as it reflected the following overall objectives:

- Build a critical mass of US-based consumer advocates trained to prepare and use the essential elements of EBHC
- Increase collaboration between consumer advocacy organizations, Cochrane Collaboration contributors, the USCC, CUE, policymakers, clinicians, government, and payers
- Provide training on EBHC and critical appraisal of the healthcare literature for consumer advocates
- Provide a forum for communication on incorporating evidence into advocacy activities
- Contribute to improving the quality of healthcare through cooperative efforts to produce and use clinical evidence
- Increase awareness of, involvement in, and contribution to the principles of EBHC between US consumers

Speakers and participants were affiliated with nonprofit organizations (45%), government agencies (15%), the private sector (10%), the media (2%), and educational and research institutions (28%). One-hundred three people registered and 93 attended, coming from 15 states, the District of Columbia, and Canada. Speakers presented on topics including new methods being used and tested to educate consumers and consumer advocates about EBHC, consumers’ understanding of EBHC, and ways in which evidence is developed, interpreted, and applied. Recurring themes included the individual’s need to become involved in healthcare decision-making, the move to EBHC by policymakers, what EBHC means for consumer advocates, and the many opportunities for consumer advocates to have a voice in ongoing programs. Based on personal and survey feedback, the conference achieved the stated objectives.

On July 23, 2008, the *Annual CUE Membership Meeting* was hosted by the US Cochrane Center in Washington, D.C. (see Agenda in Appendix G). The meeting objectives were to bring together CUE’s leadership and membership to discuss organizational and administrative matters relevant to the membership and the Coalition as a whole, and to learn about topical issues related to evidence-based healthcare. Members heard presentations from external experts working on

policy issues important to CUE members, namely, a journalist-author writing about “over treatment”; a representative from the Institute of Medicine’s Communications Collaborative, associated with the Roundtable on Evidence-based Medicine; the Director of ClinicalTrials.gov; a legislative staff member associated with a congressional initiative on comparative effectiveness research; and the Director of the South Asian Cochrane Network, from Vellore, India. In addition, a panel of CUE members shared their own experiences with EBHC and how they have interacted with The Cochrane Collaboration.

Continuing challenges include increasing awareness of CUE in the consumer and health professional communities, increasing understanding and use of EBHC, and obtaining the necessary financial support for projects that address CUE’s mission.

6.8.2 Continue to develop and test an online distance education course for consumer advocates (2007); Monitor and revise an online distance education course for consumer advocates (2008)

As noted elsewhere, on September 15, 2007, CUE and the USCC 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. (Details of the course and course participants are provided in Section 6.3.2.).

A colorful heavy stock “postcard” was created to help disseminate information about the course. Cards were distributed at the XVI Colloquium in Freiburg and have been made available to CUE members for distribution to their membership.

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

With the support of the USCC, CUE members are working to strengthen ties with CCNet by collaborating on activities and projects that achieve mutual goals. CUE members

- interact with their peers at Cochrane Colloquia and participate in the CCNet moderated e-mail list;
- participate in CCNet’s Geographical Centres Advisory Group (Barbara Warren and Maryann Napoli);
- promote US consumer involvement with The Cochrane Collaboration.

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. Ann Fonfa, CUE member and representative of The Annie Appleseed Project, has actively participated with the Adverse Effects Methods Group. While at the 2007 Colloquium in São Paulo, Barbara Warren, CUE Co-chair and representative of the National Coalition for Lesbian, Gay, Bisexual, and Transgender Health, and her colleague Richard Davis began work on a video about CCNet; they interviewed and filmed CCNet members who described how they work with advocates to improve health care in communities around the world. In addition, the team created a video about The Cochrane Collaboration based on a series of interviews conducted in 2006. One other video was created and posted on The Cochrane Collaboration website in 2008: a six minute piece about CUE, featuring interviews with CUE members about their work within The Cochrane Collaboration and how they incorporate evidence-based healthcare in their advocacy work (see <http://www.cochrane.org/consumers/happenings.htm>).

6.9 Work collaboratively with the CEVG@US satellite office

6.9.1 Share materials and resources related to educational projects

See Section 7.1 for details regarding the activities of the CEVG@US and Section 6.3.2 for collaborative educational projects.

6.9.2 Collaborate with CEVG@US on research projects.

See Section 7.1 for details regarding the activities of the CEVG@US and Section 6.7 for collaborative research projects.

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 serves as a Methodological Editor.

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 in the US (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.

In 2007, the CEVG@US provided assistance to authors working on Cochrane reviews, facilitating publication of eight protocols, four reviews, and one update of a review. In 2008, the CEVG@US provided assistance to authors working on Cochrane reviews, facilitating publication of eight protocols, three reviews, and five updates.

CEVG@US oversees and coordinates handsearching training, open to The Cochrane Collaboration and others, as well as handsearching efforts for the CEVG.

The CEVG@US satellite hosts the CEVG website (<http://www.cochraneeyes.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.

7.2 HIV/AIDS CRG

The Cochrane HIV/AIDS Group is an international network of healthcare professionals, researchers, and consumers working to prepare, maintain, and disseminate systematic reviews on the prevention and treatment of HIV infection and AIDS. An affiliate of the International AIDS Society, University of California, San Francisco Global Health Sciences, and the University of California, San Francisco AIDS Research Institute, the Cochrane HIV/AIDS Group was officially registered in March 1997. Its editorial base is at the University of California, San Francisco, with a satellite editorial base in Cape Town at the South African Cochrane Centre. In addition, the Cochrane Sexually Transmitted Diseases Group, based in Porto Alegre, Brasil, functions as a satellite of the HIV/AIDS Group, while it prepares for its reestablishment as an independent entity. The HIV/AIDS Group's mission is to conduct systematic reviews of randomized controlled trials and other rigorous controlled studies 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.

7.3 Neonatal CRG

The Neonatal Group, registered in April 1993, currently is 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. For Issues 1 - 4, 2007 and Issues 1 - 4, 2008 of *The Cochrane Library*, the Neonatal Review Group submitted 24 new protocols, 28 new reviews, and 82 review updates. As of Issue 4, 2008, the Neonatal Group has completed 249 reviews. Although now US-based, the Neonatal Group has benefitted from strong support in Canada, Australia and the UK.

7.4 Prostatic Diseases and Urologic Cancers CRG

The primary aim of the Department of Veterans Affairs Coordinating Center of the Prostatic Diseases and Urologic Malignancies Group is to prepare, maintain, and disseminate systematic reviews of randomized controlled trials of interventions for benign prostatic diseases and urologic cancers. They serve as the administrative center for both the Prostatic Diseases and Urologic Malignancies subgroups. Systematic reviews will be conducted by collaborators from relevant disciplines including urology, oncology, and internal medicine and technical support will be provided by experts in biostatistics, consumer groups and pharmaceutical companies. Dr. Wilt serves as the overall coordinating editor, Rod MacDonald is the group coordinator, Jim Tacklind is the assistant group coordinator, and Indy Rutks is the trials search coordinator. Malcolm Mason and Mike Shelley of Cardiff, Wales, serve as the editor and coordinator, respectively, of the Urologic Malignancies subgroup.

The Cochrane Review Group in Prostatic Diseases and Urologic Malignancies has contacted and is working 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 include Blue Cross Blue Shield, the Prostate Trials Office, the National Institute for Health Research Centre for Reviews and Dissemination, the European Organization for Research and Treatment of Cancer and the Prostate Cancer Trialists' Collaborative Group. The Cochrane Review Group in Prostatic Diseases and Urologic Malignancies works 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 has been developed and submitted for inclusion in *The Cochrane Library*. The registry will be updated with assistance from the USCC. The Cochrane Review Group in Prostatic Diseases and Urologic Malignancies' specialized registry contains approximately 4183 references to date (as of 11/08). As of 11/08 they have: 28 published reviews in *The Cochrane Library*, 20 reviews in progress, five completed reviews published in peer-reviewed journals, 12

completed reviews not affiliated with Cochrane published in peer-reviewed journals, and 10 completed technology assessments.

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. While the editorial base is located at the Churchill Hospital in Oxford, England, two editors are based in the US. Ewan McNicol, of the Tufts/New England Medical Center in Boston, Massachusetts, is the lead editor for the pain reviews, and Doug McCrory, of the Duke University Center for Clinical Health Policy Research in Durham, North Carolina, is the lead editor for the headache pain reviews. By the beginning of 2007, there were 490 active members of this group, two of whom were consumers and 13 of whom were from developing countries. During 2007, the PaPas CRG published eight new protocols, eight new reviews, and registered 22 titles. As of September 2008, three new published protocols, five new reviews and three updated reviews were in the editorial process for 2008. The specialized register contained 30,200 studies. More information about PaPas can be found on its website at: <http://www.jr2.ox.ac.uk/cochrane/>.

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, chiropractic, herbal medicine, and homeopathy. The field is based at the University of Maryland, School of Medicine in Baltimore, Maryland. Brian Berman is Field Coordinator 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 has been active in identifying, reviewing, and disseminating evidence on CAM therapies and staff dedicate much of their effort to preparing Cochrane reviews. For example, Eric Manheimer has co-authored two systematic reviews that will be published in *The Cochrane Library* in early 2009. 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 they submit regularly to CENTRAL. 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 further 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 the awareness of The Cochrane Collaboration and to improve the understanding of randomized trial and systematic review methodology by CAM practitioners and researchers. 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.

8.2 Primary Health Care Field

The Primary Health Care Field transitioned from US-based leadership January 19, 2007.

8.3 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 is based in New York, at the Columbia College of Physicians and Surgeons, and convened by Karina Davidson, PhD; Louise Falzon is the trials search coordinator. The Advisory Board is composed of 14 individuals representing seven different countries.

This 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.

Recent field activities include 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 sends out the bi-weekly Behavioral Medicine Alert, a digest of recent behavioral medicine citations (currently reaching 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.

9. US-based Cochrane methods groups

9.1 Cochrane Screening and Diagnostic Tests Methods Group

The Cochrane Screening and Diagnostic Tests Methods Group is a fully operational group dedicated to the development and implementation of methods for systematic reviews of screening and diagnostic tests. Work continued on supporting the development of the Handbook, statistical software, and infrastructure for the Cochrane Diagnostic Reviews. The group held training and scientific sessions at the annual Cochrane Colloquia in Freiburg (2008). The Cochrane Screening and Diagnostic Tests Methods Group 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 J for the USCC performance targets for 2009.

11. USCC contact information, current

11.1 USCC, Baltimore, MD

Director, USCC: Kay Dickersin, PhD

Contact Person: Janie Gordon, ScM
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Johns Hopkins Bloomberg School of Public Health
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11.2 San Francisco Branch

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

Contact Person: Erika Campbell
Administrator, San Francisco Branch of the USCC
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Web page: <http://www.ucsf.edu/sfcc>

12. Full and part-time staff at the USCC Offices in 2007 and 2008

Director:	Kay Dickersin, PhD
Co-Directors, San Francisco Branch:	Lisa Bero, PhD Drummond Rennie, MD
Associate Director:	Roberta W. Scherer, PhD

Coordinators:	Kelly S. Manos, MAS (from 03/2006 to 11/2008) Janie Gordon, ScM (from 3/3/2008 to present) Erika Campbell (San Francisco Branch)
Consumer Coalition Coordinator:	Marianne Hamilton, MPA (through August 2007) Janie Gordon, ScM (March 2008 - present)
Systematic Review authors:	Stephen Gichuhi, MD, MSc Tianjing Li, MD Kristina Lindsley, MS Satyanarayana Vedula, MD
Handsearchers:	Cindy Chen Derek Ng Isabel Rodriguez-Barraquer Bonnie Swenor
<i>Master List</i> Processors:	Arisha Ashraf (from 11/06 to 10/07) Lisa Lassiter Roberta Scherer, PhD

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
Funding:	\$5,381,920
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: September 30, 2002 - September 29, 2007
Funding: \$2,383,838
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: Training for US Cochrane Contributors and Others
PI: Kay Dickersin, PhD
Dates: June 1, 2007 - May 31, 2010
Funding: \$300,000
Specific Aims: To conduct a series of educational conferences to increase involvement in The Cochrane Collaboration

13.1.2.3

Source: Agency for Healthcare Research and Quality
Title: Translating Evidence to Quality Care: getting the Message to Your Constituency
PI: Kay Dickersin, PhD
Dates: September 30, 2007 - September 29, 2008
Funding: \$43,117
Specific Aims: To conduct an educational conference for health consumer advocacy groups to facilitate translation of research into practice and policy.

13.1.3 Kaiser Permanente Institute for Health Policy

Source: Kaiser Permanente Institute for Health Policy
Title: USCC Conference: *Priority Setting for Systematic Reviews*
PI: Kay Dickersin, PhD
Dates: July 10 - 11, 2008
Funding: \$5,000
Specific Aims: To support the USCC Conference *Priority Setting for Systematic Reviews*.

13.1.4 USCC San Francisco Branch

The USCC San Francisco Branch had no contracts or grants in 2007 - 2008.

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 2007 and 2008. Special thanks go to individuals who have contributed their time and expertise as a member of the USCC Advisory Group (see Appendix P), faculty for one of our training programs, an investigator on a project, or as a consumer advocate involved in CUE. Each contribution is recognized and very much appreciated.

Appendix A

USCC Training Workshops and Courses 2007 - 2008

Workshops and courses in 2007 included:

1. *Completing a Cochrane systematic review.* This workshop was offered twice: January 26 - 28, 2007 in Sarasota, Florida, and July 18 - 20, 2007 in Baltimore, Maryland. (Kay Dickersin, Roberta Scherer, and Ann Ervin);
2. *Evidence-based healthcare, occupational therapy, and the Cochrane Collaboration.* One half day workshop for the American Occupational Therapy Association Annual Conference: April 19, 2007 in St. Louis, Missouri. (Roberta Scherer and Sue Doyle, US Contributor);
3. *Using systematic reviews to inform practice.* Workshop for Association for Research in Vision and Ophthalmology: May 9, 2007 in Ft. Lauderdale, Florida. (Kay Dickersin);
4. *How to critically appraise an article about intervention effectiveness.* Workshop at the CUE sponsored Advocacy Summit: Understanding Evidence-based Healthcare: A Foundation for Action: July 17, 2007 in Washington, DC. (Roberta Scherer);
5. *Evidence-based healthcare: A workshop on finding, synthesizing, and applying clinical evidence.* One day workshop for MedChi, the Maryland State Medical Association: September 7, 2008 in Baltimore, Maryland. (Kay Dickersin, Roberta Scherer, Ann Ervin, Steven Goodman, Karen Robinson, and others);
6. *Developing a local coalition of consumer advocacy groups.* XV Cochrane Colloquium, workshop for consumer advocates: October 24, 2007 in São Paulo, Brazil. (Kay Dickersin, Barbara Warren of Consumers United for Evidence-based Healthcare (CUE) and Janet Wale of Cochrane Consumers Network and Field (CCNet);
7. *Train the trainers.* XV Cochrane Colloquium, workshop for health professionals: October 26, 2007 in São Paulo, Brazil. (Roberta Scherer, Charles Wisonge of the South African Cochrane Center, and Denise O'Connor of the Australasian Cochrane Center); and
8. *Handsearching.* XV Cochrane Colloquium, workshop for health professionals: October 27, 2007 in São Paulo, Brazil. (Roberta Scherer and Susan Wieland).

Workshops and courses in 2008 included:

1. *Diabetic Retinopathy Clinical Research Network evidence-based healthcare workshop.* One half day workshop for Diabetic Retinopathy Clinical Research Network: January 25, 2008 in Tampa, Florida. (Roberta Scherer and Ann Ervin);
2. *Pediatric Eye Disease Investigator Group evidence-based healthcare workshop.* One half day workshop for Pediatric Eye Disease Investigators Group: February 9, 2008 in Tampa, Florida. (Kay Dickersin, Roberta Scherer, Ann Ervin, and others);
3. *Evidence-based occupational therapy: Finding, synthesizing and applying clinical evidence.* One half day workshop for the American Occupational Therapy Association Annual Conference: April 11, 2008 in Long Beach, California. (Roberta Scherer and Sue Doyle, US Contributor);
4. *Completing a Cochrane systematic review.* This workshop was offered twice: March 14 - 16, 2008 in Ft. Lauderdale, Florida; July 16 - 18, 2008 in Baltimore, Maryland. (Kay Dickersin, Roberta Scherer, Ann Ervin, Roger Soll of the Cochrane Neonatal Review Group, and others);
5. *The Cochrane Collaboration and The Cochrane Library.* One-half day workshop for Society for Clinical Trials: May 18, 2008 in St. Louis, Missouri. (Roberta Scherer, Ann Ervin, Kay Dickersin, Barbara Hawkins, and David Sackett);
6. *How to handsearch paper and electronic journals and conference proceedings to identify articles eligible for the Cochrane Central Register of Controlled Trials.* XVI Cochrane Colloquium. Workshop for health professionals: October 5, 2008 in Freiburg, Germany. (Roberta Scherer and Ruth Mitchell of the Cochrane Renal Group);
7. *Assessment of Understanding Evidence-based Healthcare: A Foundation for Action, an online course for consumer advocates.* Workshop for health professionals and consumers: October 6, 2008 in Freiburg, Germany. (Kay Dickersin and Musa Mayer);
8. *Consumers speak out! What do we want results reporting to look like?* XVI Cochrane Colloquium, workshop for health professionals and consumers: October 7, 2008 in Freiburg, Germany. (Kay Dickersin, Janet Wale CCNet, and Davina Ghersi of the Cochrane Breast Cancer Review Group); and

9. *Train the trainers of evidence-based healthcare*. XVI Cochrane Colloquium, workshop for health professionals: October 7, 2008 in Freiburg, Germany. (Roberta Scherer and Swaroop Vedula).

Appendix B

Consumers United for Evidence-based Healthcare (CUE) Advocacy Summit

Understanding Evidence-based Healthcare: A Foundation for Action

July 17, 2007

Washington, DC

Program Agenda

- 7:00 - 8:00 am **Registration and continental breakfast**
- 8:00 - 9:00 am **Pre-conference workshop:** *Introduction to Consumers United for Evidence-based Healthcare (CUE)*
- Facilitators:**
Joy Simha, Young Survival Coalition,* CUE Steering Committee Co-chair
Barbara Warren, National Coalition for Lesbian, Gay, Bisexual and Transgender Health,* CUE Steering Committee Co-chair
Marianne Hamilton, United States Cochrane Center
- 9:00 - 9:15 am **Welcoming remarks**
Joy Simha and Barbara Warren, CUE Steering Committee Co-chairs
Kay Dickersin, United States Cochrane Center
- 9:15 - 9:45 am **Keynote address:** *Questions Are the Answer: Get More Involved With Your Health Care PSA campaign*
- Speaker:** Jean Slutsky, Agency for Healthcare Research and Quality
- 9:45 - 10:20 am **Presentation:** *Understanding Evidence-based Healthcare - A Foundation for Action*
- Facilitators:**
Musa Mayer, Patient Advocate, AdvancedBC.org
Kay Dickersin, United States Cochrane Center
- 10:20 - 10:40 am **Open discussion**
- 10:40 - 11:00 am **Break**
- 11:00 - 12:15 pm **Panel:** *Evidence-based Healthcare: The Building Blocks*
- Co-chairs:**
Ngina Lythcott, Black Women's Health Imperative*
Michael McGinnis, Institute of Medicine, EBM Roundtable
- What do consumers think about evidence-based healthcare?*
Kristin Carman, American Institutes for Research
- Evidence synthesis: Many sources, many interpretations? The Cochrane Collaboration, Evidence-based Practice Centers, and others*
Mark Grant, Blue Cross Blue Shield Association

What do guidelines really mean? Translation to coverage decisions
Tara Larson, North Carolina Department of Health

12:15 - 1:30 pm **Lunch presentation:** *Getting the evidence out to the public, Consumer Reports Best Buy Drugs*

Speaker: Jim Guest, Consumers Union*

Discussant:

David H. Hickam, John M. Eisenberg Clinical Decisions and Communications Science Center

1:30 - 3:00 pm **Simultaneous workshops session I**

Workshop A. How to translate evidence for consumers

Facilitators:

Annette Bar-Cohen, National Breast Cancer Coalition*
Sandy Robinson, John M. Eisenberg Clinical Decisions and Communications Science Center

Workshop B. How to incorporate EBHC into your organization's mission

Facilitators:

Sallie Bernard, SafeMinds*
Don Steinwachs, Johns Hopkins University

Workshop C. How to critically appraise a systematic review

Facilitators:

Cindy Pearson, National Women's Health Network*
Eric Bass, Johns Hopkins Evidence-based Practice Center

3:00 - 3:15 pm **Break**

3:15 - 4:45 pm **Simultaneous workshops session II**

Workshop D. Internet evidence-based resources

Facilitators:

Barbara Warren, National Lesbian, Gay, Bisexual, and Transgender Health Coalition
Claire Twose, Johns Hopkins University

Workshop E. Focusing the message to different settings and cultures

Facilitators:

Zobeida Bonilla, Our Bodies Ourselves*
Cathy Gordon, John M. Eisenberg Clinical Decisions and Communications Science Center

Workshop F. How to critically appraise an article about intervention effectiveness

Facilitators:

Maryann Napoli, Center for Medical Consumers*
Roberta Scherer, Johns Hopkins University

4:45 - 5:00 pm **Evaluation and adjourn**
Joy Simha, Young Survival Coalition

* CUE member-organization

Appendix C

Annual CUE Membership Meeting

July 16, 2007
Washington, DC

Program Agenda

- 1:00 - 1:05 pm **Welcome:** Steering Committee Co-Chairs
- 1:05 - 1:30 pm **Introduction of CUE member organizations**
Facilitator: Marianne Hamilton, US Cochrane Center
- 1:30 - 2:00 pm **CUE Annual Report:**
Presenter:
Joy Simha, Young Survival Coalition
- 2:00 - 2:45 pm **Panel:** How CUE members have incorporated EBHC into their work
Chair: Sallie Bernard, SafeMinds
Panel Members:
Maureen Corry, Childbirth Connection
John Otto, National Center for Transgender Equality
Merrill Goozner, Center for Science in the Public Interest
- 2:45 - 3:00 pm **Break**
- 3:00 - 3:15 pm **An overview of CUE committees and projects**
Chair: Ngina Lythcott, Black Women's Health Imperative
- 3:15 - 3:45 pm **Dissemination: Spreading the message about CUE**
Facilitator: Tara Montgomery, Consumers Union
- 3:45 - 4:15 pm **CUE and the Cochrane Collaboration**
Chair: Marianne Hamilton, US Cochrane Center
Panel Members:
Ann Fonfa, The Annie Appleseed Project
Maryann Napoli, The Center for Medical Consumers
Barbara Warren, The National Coalition for Lesbian, Gay, Bisexual
and Transgender Health
- 4:15 - 4:45 pm **Open forum: Looking ahead**
Facilitator: Kay Dickersin, US Cochrane Center
- 4:45 - 5:30 pm **CUE administration** (Steering Committee elections, membership)
Facilitator: Zobeida Bonilla, Our Bodies Ourselves
- 5:30 - 5:45 pm **Evaluations and adjourn**

Appendix D

US Cochrane Center presents
Priority Setting for Systematic Reviews
July 10-11, 2008

July 10	Topic
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	Plenary: The Institute of Medicine's (IOM's) rationale and principles for prioritizing systematic reviews Chair: Kay Dickersin - Director, US Cochrane Center Speaker: Hal Sox - Editor, Annals of Internal Medicine Discussant: Prioritizing Evidence Syntheses - Sharon Straus - University of Calgary, Canada
2:30 - 3:00 pm	Break
3:00 - 5:00 pm	Methods to Prioritize Systematic Reviews: Case Studies I Chair: Steve Goodman - Johns Hopkins Oncology Biostatistics AHRQ's Effective Health Care Program - Evelyn Whitlock - Kaiser Permanente, Oregon The UK's National Health Service R&D and Department of Health Programmes - Martin Burton - Oxford Radcliffe Hospitals NHS Trust The Cochrane Collaboration - Lorne Becker - Co-Chair, Cochrane Collaboration Steering Group Canada's Approach: Canadian Institutes of Health Research - Ian Graham - Canadian Institutes of Health Research

5:00 - 6:30 pm Reception

July 11

7:00 - 8:00 am Registration

8:30 - 10:00 am Plenary debate: Models of priority setting for systematic reviews of clinical effectiveness

Chair: **Lisa Bero** - University of California San Francisco

Let 1000 flowers bloom: Support for the current "system" -
Doug McCrory - Duke University Medical School

Both prioritization and review production should be
centralized - **Gail Wilensky** - Project Hope

Discussant: How can we leverage the best of these two
models? A hybrid model of centralized priority setting - **Sally
Morton** - Research Triangle Institute

10:00 - 10:15 am Break

10:15 am - 12:00 pm Panel: Knotty problems related to review prioritization

Chair: **Nananda Col** - Maine Medical Center

Meaningful engagement of decision makers in priority-setting-
Sean Tunis - Center for Medical Technology Policy

Considering adverse effects in prioritising reviews - **Andrew
Herxheimer** - Cochrane Collaboration Adverse Effects
Methods Group

A mid flight correction: setting priorities - **David Moher** -
University of Ottawa

	Incorporating systematic reviews into other systematic reviews: Can we save time and be valid? - Evelyn Whitlock - Kaiser Permanente, Oregon
12:00 - 1:00 pm	Lunch
1:00 - 2:15 pm	Methods to Prioritize Systematic Reviews: Case Studies II
	Chair: Luis Gabriel Cuervo - Pan American Health Organization
	Drug Effectiveness Review Project - Alison Little - Oregon Health & Science University
	The James Lind Alliance and I - Lester Firkins - James Lind Alliance
	Centers for Disease Control & Prevention Community Guide - Shawna Mercer - Centers for Disease Control and Prevention
2:15 - 2:30 pm	Break
2:30 - 3:30 pm	Open Discussion: Working together or working apart: Cross-group cooperation in priority setting
	Chair: Eric Bass - Johns Hopkins University Department of General Internal Medicine
	Jean Slutsky - Agency for Healthcare Research and Quality
	Lisa Bero - University of California San Francisco
3:30 - 3:45 pm	Evaluation and adjourn

Appendix E



Minutes
US Contributors' Meeting
XV Cochrane Colloquium, São Paulo
Friday, October 26, 2007, 18:00 – 19:00
Port Elizabeth Room

1. Welcome and introductions:

Bobbi Scherer, US Cochrane Center (USCC) Associate Director, welcomed everyone to the meeting. The attendees introduced themselves and briefly described ongoing activities.

2. What's happening in the US:

- Ron Koretz, Editor for the Hepato-Biliary Group, reported that for the past four years he has facilitated a successful Cochrane Symposium at the annual Digestive Diseases Week meeting. He reported that this year was remarkably successful in that the number of participants overflowed the available room and monitors were set up for those unable to enter the meeting room. He also reported that a satellite Cochrane symposium at the Association of Liver Diseases was less successful.
- Complementary and Alternative Medicine (CAM) Field - Eric Manheimer reported that five years of funding (\$2.1 million) was awarded by the National Center for Complementary and Alternative Medicine (NCCAM) to the University of Maryland for Brian Berman, CAM field Coordinating Editor. The project provides funding for some Cochrane reviews, a bursary for CAM reviews, continued development of the CAM trials register, and dissemination of Cochrane reviews through columns in the journals *Explore* and *Journal of Complementary and Alternative Medicine*.
- Barbara Warren, Co-Chair of the USCC-sponsored coalition of consumer advocacy groups, Consumers United for Evidence-based Healthcare (CUE), reported a successful year for CUE, with two major initiatives. First, CUE and the USCC launched a distance education course on evidence-based healthcare and critical appraisal for consumer advocates hosted by the Johns Hopkins Bloomberg School of Public Health. Second, CUE and the USCC coordinated a conference for consumer health advocacy groups. The CUE Advocacy Summit was held in Washington, D.C. with over 100 participants and speakers representing government, consumer advocacy groups, journalism, and policymaking. In addition, Barbara Warren and Richard Davis reported that they have produced a video about CUE that will be used on the USCC, Cochrane, and other web sites to disseminate information about the organization. They also were filming participants at the São Paulo Colloquium for another video, this one about the Cochrane Consumer Network (CCNet). Finally, Barbara and Kay received support from Wiley to present *The Cochrane Library* and CUE's online course at the American Public Health Association meeting in Washington, D.C., 6 November, 2007. Barbara itemized CUE's current projects, including recruiting new member-organizations to CUE, establishing

relationships with policy makers, and lobbying for a national subscription to *The Cochrane Library*.

- Lisa Bero, Co-Director of the San Francisco Branch of the USCC reported receiving funding of \$200,000 for five years from the Flight Attendant Medical Research Institute, for interventions with policymakers and critical appraisal related to tobacco use. This funding will allow the Branch to continue methodological studies in the field of tobacco use. Lisa also reported that the HIV Cochrane Review Group has been supporting the Sexually Transmitted Diseases Review Group, pending a move to a permanent location, probably Brazil.
- Louise Falcon reported for the Behavioral Medicine Field. Funding is minimal at this time, but there has been progress in attracting authors and in building the trials register. These activities are supported by the group's website, which provides information about the Behavioral Medicine Field and also provides free access to the group's trials register.
- Maryann Napoli, CUE and CCNet member, commented on the successful CUE Advocacy Summit meeting. Maryann reported that as a member of CCNet, she is trying to increase the participation of US consumers in the preparation of plain language summaries. She also reported that CCNet aims to provide funds to bring more consumers to the Colloquium, but they have not been able to meet this goal.
- Tianjing Li, from the Cochrane Eyes and Vision Group, US Satellite (CEVG@US) reported that the group received one of the prioritization awards from the Cochrane Collaboration. The CEVG group will identify priority topics using guidelines prepared by the American Academy of Ophthalmology. CEVG@US also sponsored two successful systematic review workshops in 2007, one in Florida and one in Baltimore. Planned activities for the next year include two 2 ½ - day workshops on conducting systematic reviews and two half-day workshops on evidence-based healthcare; the latter to be held in conjunction with ophthalmology research network meetings. Other activities include support for US-based review authors and handsearching the US vision science literature. CEVG also supports an online handsearching course, which is free and available to anyone. In process is a second online course, this one on peer review of the biomedical literature.
- Prostatic Diseases and Urologic Cancers Group - No representative present
- Becky Gray from the Pain, Palliative, and Supportive Care Group, Headache Satellite reported that the group is operating on reserves until new funding is obtained. She also reported on her activities as the IMS support person in the US. She described the anticipated rollout of RevMan 5, including the addition of two new tables, the summary of findings table and the risk of bias table. She also indicated that she is available for any group with questions about the new RevMan version or any other IMS problems.

- Primary Health Care Field - No representative present.
- Screening and Diagnostic Test Methods Group - No representative present.
- Skin Group - No representative present
- Neonatal Group - No representative present
- US Cochrane Center - Bobbi Scherer reported that the main activities of the US Cochrane Center in the past year were the launch of the distance education course for consumer advocates on evidence-based healthcare and the CUE Advocacy Summit, as described by Barbara Warren. Other activities included two workshops on evidence-based health care and various presentations on Cochrane and evidence-based healthcare, as well as usual activities associated with the Masterlist of Journals Being Handsearched. Kay Dickersin reported that the Boston Branch of the USCC has closed.
- Susan Norris, from the Oregon Evidence Based Practice Center reported that work continues on the Drug Effectiveness Review Project (DERP), which aims to compare the effectiveness and safety of different drugs within pharmaceutical classes. As such, DERP makes frequent use of *The Cochrane Library*. DERP comparative effectiveness reviews complement the work of the Cochrane Collaboration.
- Randy Elder, Director of the group at the Centers for Disease Control (CDC) producing the Guide to Community Preventive Services (Community Guide), reported increased support at the CDC for the Community Guide group. He indicated that the Community Guide group is investigating a possible collaboration with the Cochrane Public Health Field.
- Ida Sim, Associate Professor at the University of California, San Francisco, and active in implementing the WHO Trials Registration Portal, reported on progress relating to trial registration. This includes a new US law mandating results reporting for trials of drugs newly approved by the Food and Drug Administration. Currently, there is an opportunity to give feedback on this law. Ida challenged the group to ask "What is Cochrane's voice?" and asked whether the USCC could post information about the relevant legislation on the USCC website.

3. Cochrane Steering Group news

Lisa Bero briefly summarized Cochrane Collaboration Steering Group (CCSG) discussions and decisions made at the Colloquium. Of obvious interest is the planning and implementation of RevMan 5, with the addition of the new tables, ways to incorporate figures into the text, and attention to non-intervention review types (e. g., diagnostic accuracy and methodological reviews). Simultaneously, an updated version of the Handbook of Systematic Reviews of Interventions has been developed and is available for comment. The Handbook will be published as a paperback book, as well as be available

free online; it is expected to be available soon. Cochrane Opportunity Funding proposals are again available and due in November. The CCSG also plans to present a request for proposals to fund development of the "new CENTRAL." This project will fund development of an internal group to create a database combining study and citation-based specialized registers. Those partnering with an external group will be preferred. Other news includes a formal association with the Guidelines International Network (G-I-N), last year's review of CCSG and CCSG's response, the upcoming review of the Collaboration by Jeremy Grimshaw, and the decision to renew the contract with Wiley for another five years. Venues for the next colloquia are as follows: Freiburg, 3-7 October, 2008; Singapore, 11-15 October 2009; and Keystone, Colorado, 18-22 October, 2010.

Appendix F



Minutes
US Contributors' Meeting
XVI Cochrane Colloquium, Freiburg
Sunday, October 5, 2008, 7:30 – 9:00 a.m.
Konzerthaus - Runder Saal Meetings

1. Welcome and introductions:

Kay Dickersin, US Cochrane Center (USCC) Director, welcomed everyone. The attendees introduced themselves and briefly described ongoing Cochrane activities.

2. 2010 Colloquium in Keystone Colorado: Robert Dellavalle

Robert Dellavalle presented a slide show on the upcoming 2010 Colloquium, "Taking evidence-based decision making to new heights." He reported that current Committee Chairs are Kay Dickersin - Scientific Committee and Lisa Bero - Abstract Committee. He asked for volunteers to serve as committee chairs and members. He noted the next planning committee conference call would be Oct 16, 2008 at 2pm and provided call-in details. Dellavalle asked volunteers to contact him at robert.dellavalle@uchsc.edu.

3. What's happening in the US:

- USCC - Kay Dickersin reported on US Cochrane participation in "Everything You Always Wanted to Know about Comparative Effectiveness but Were Afraid to Ask," a half day session for congressional staffers in Washington DC, hosted by the National Health Policy Forum, July 25, 2008. Presenters at the session, Introduction to the Cochrane Collaboration and Evidence-based Healthcare, included Kay Dickersin, Director USCC; Lorne Becker, Co-Chair, Cochrane Steering Group; Roger Soll, Coordinating Editor, Neonatal Group; Maureen Corry, Childbirth Connection and Consumers United for Evidence-based Healthcare (CUE); and Prathap Tharyan, Director, South Asian Cochrane Center.

The USCC sponsored a conference on Priority Setting for Systematic Reviews, July 10 -11, 2008 in Baltimore, Maryland. In Spring 2009, the USCC is planning to sponsor a conference on *Performing Systematic Reviews of Diagnostic Tests*.

- San Francisco (SF) Branch - Lisa Bero reported receiving funding for research and workshops for pediatricians, journalists, and consumers on how to critique evidence. She noted that the SF Branch was also helping the USCC to expand CUE membership.
- CUE and Cochrane Collaboration Consumer Network (CCNet) - Maryann Napoli, of the Center for Medical Consumers, reported that CUE was launched by the USCC four years ago. It currently has 26 member organizations, the majority of which are disease-specific health advocacy groups. She explained that CUE member organizations cannot receive the majority of their funding from commercial sources. She highlighted the free online course created by the USCC in conjunction with CUE, *Understanding Evidence-based Healthcare: A Foundation for*

Action. Consumer health advocates, undergraduate and graduate students, and health professionals have enrolled in the course. Ms. Napoli highlighted the work of CUE Co-chair Barbara Warren and her colleague Richard Davis, who have produced two videos: *What is the Cochrane Collaboration?* and *What is CUE?* They also have completed a “first cut” of a video about CCNet. Ms. Napoli noted that CUE has a critical need for funding.

- Cochrane Eyes and Vision Review Group, US Satellite (CEVG@US) - Bobbi Scherer reported on training activities sponsored by CEVG@US. In 2007, two workshops were offered on how to do a systematic review. While these workshops gave priority to Cochrane Eyes and Vision Review Group authors, other Cochrane authors also enrolled. CEVG supports an online handsearching course which is offered free of charge and is open to all. Planned activities for the next year include two 2 ½ day workshops on conducting systematic reviews. Other activities include support for US-based review authors and handsearching the US vision science literature. A second online course on peer review of the biomedical literature is under development.

Tianjing Li noted that CEVG@US received a Cochrane Collaboration 2007 Prioritization Fund Award, “Using practice guidelines to determine review priorities: a pilot project.” The study tests a system for setting research priorities, using glaucoma and the American Academy of Ophthalmology Preferred Practice Patterns as a model. She noted also that CEVG@US has been recruiting new authors for CEVG priority topics. Work is progressing on the Study-based Eyes and Vision Group Trial Register. Graduate student Elizabeth Ssemanda has merged four existing databases into one and is in the process of cleaning up the database. Dr. Li explained that the CEVG@US satellite receives funding from the National Eye Institute, at the NIH. USCC-based methodologists have been helping clinical authors prepare reviews. Dr. Li noted that two 2007-8 workshops on evidence-based ophthalmology were conducted, one for the Diabetic Retinopathy Clinical Research Network (DRCNet), and one for the Pediatric Eye Disease Investigator Group (PEDIG).

- HIV/AIDS Review Group - Lisa Bero reported that the HIV/AIDS Review Group has been working closely with the STD satellite in Brazil, and new reviewers in South Africa. They have mentored South African authors who are doing systematic reviews, pairing an experienced U.S. author with a new South African author. George Rutherford received two funding awards for work in South Africa: a Fogarty grant to work with systematic review authors and a grant from the Robert Wood Johnson Foundation to disseminate reviews to policymakers. The HIV/AIDS Review Group is working with the Cochrane Effective Practice and Organisation of Care (EPOC) Review Group to disseminate systematic review results in a one page easy-to-understand format.
- Neonatal Review Group - Roger Soll reported that the editorial base of the Neonatal Review Group has moved from McMaster University to University of Vermont. The Neonatal Group has produced over 260 reviews. Getting new people involved and updating this large number of reviews is a large task. They are hiring a core methodologist and a new Trial Search Coordinator (TSC).

- Pain, Palliative and Supportive Care (PaPaS) Review Group, Headache Section - Janie Gordon reported on behalf of Doug McCrory and Rebecca Gray. The Headache Section continues to operate, but at a very low level due to insufficient funds. They have stopped registering new titles, and are focusing almost exclusively on moving along the highest priority reviews already in the pipeline.
- Hepato-Biliary Review Group - Janie Gordon reported on behalf of Ronald Koretz (Editor). The Hepato-Biliary Review Group continues to present a successful Cochrane Symposium at the annual Digestive Disease Week (DDW) meeting. They will present the next symposium in Chicago in 2009, which will be the sixth consecutive year for the symposium.
- Complementary Medicine Field - Susan Wieland reported on behalf of Eric Manheimer and Brian Berman. She noted that the Complementary Medicine Field is funded by a 5-year grant from The National Center for Complementary and Alternative Medicine at NIH. They are working to develop systematic reviews using the Chinese literature.

4. Cochrane Steering Group (CCSG) Update

Lorne Becker noted strong US representation on the Steering Committee (Lorne Becker, Lisa Bero, and Roger Soll). He reported there were outstanding candidates for the new Editor-In-Chief position for *The Cochrane Library* and that the position should be filled within a few weeks. He noted the changes made in RevMan 5 and the subsequent improvement in how systematic reviews look. Dr. Becker spoke of the impressive partnership between the CC and Wiley to improve interfaces (e.g., Summary of Findings and Risk of Bias tables). He reported that the first diagnostic test accuracy reviews will appear in 2008 Issue 4. There are about 30 additional diagnostic reviews in the pipeline. An RFP is being written to solicit bidders to develop CENTRAL. He reported that Cochrane and Wiley are working well together and that *The Cochrane Library* is generating profits for both parties.

Dr. Becker noted that the CCSG has been focusing on knowledge translation. They recently devoted 1 ½ days to discussion of the underlying principles of knowledge translation and potential partnerships. The linking of electronic health records and Cochrane was discussed by Pekka Mustonen, who presented information about Duodecim Medical Publications in a plenary session. This represents an excellent opportunity! He also noted development of new journal outlets, such as *Evidence-based Child Health*, a source of reports of Cochrane reviews.

5. Dissemination of information about the Cochrane Collaboration and Cochrane products in the U.S.

Dr. Dickersin noted the importance and challenge of getting information/reviews to health practitioners, consumers, and other decision makers. New software exists that can scan medical records, identify diagnoses/treatments for which Cochrane systematic reviews exist, and provide a pop-up note and link to the relevant review. This system is being used by Duodecim in Finland. It was suggested that Cochrane seek funds from Wiley to develop more decision maker-friendly products.

It was noted that Cochrane stories need to be more widely disseminated. One such story came from Marguerite Koster at Sunday 5 October plenary. Ms. Koster reported that when Kaiser Permanente is developing medical guidelines, the first step is to turn to *The Cochrane Library*. Maryann Napoli noted that she writes about Cochrane reviews for the public. The importance of reaching health journalists was emphasized. For example, Cochrane reviews can be used to set the context for stories about new study results. Journalists can get free access to *The Cochrane Library*, but more needs to be done to disseminate this information and to get reporters to use *The Cochrane Library*. Lisa Bero pointed out that Wiley promotes dissemination by issuing press releases on reviews that are “newsworthy”, before each issue of *The Library* comes out. This provides reporters with an early (embargoed) look at upcoming reviews. Podcasts that highlight selected reviews are also available.

We need to be proactive and respond to inaccuracies in the press by pointing out when there is a Cochrane systematic review that reaches a different conclusion. We should use the opportunity to explain the strengths of a systematic review compared to a single study. A suggestion was made to read and monitor influential health blogs, responding to comments with data from Cochrane. Two specific *NYTimes* health reporters/bloggers were mentioned: Gina Kolata, and Tara Parker Pope. *The Duke Health News Review* screens people to determine whether they are eligible to be “independent sources” for comments on health related news. If eligible, they can be called upon to comment on news stories. Cochrane authors could apply to become “independent sources.”

Journalists should be notified now about the 2010 Cochrane Colloquium in Keystone, Colorado, so that they can plan to attend.

Kay Dickersin reported on new developments for the online course *Understanding Evidence-based Healthcare: A Foundation for Action*. She noted that the US Cochrane Center has applied for a grant to provide a new “front-end” for clinicians. There is discussion about doing a new front-end for journalists as well. A suggestion was made to investigate a role for the online course in medical school curricula. Dr. Dickersin reported that she and Musa Mayer are developing a new module on the process of drug approval.

Offering continuing medical education (CME) credits for the online course was discussed. Providing CME was noted as a source of credibility for the course. Different opinions were voiced as to whether physicians would pay for credits when there are so many opportunities available for free credit. The American Academy of Family Physicians is very supportive of evidence-based medicine; Lorne Becker believes that it may be worth pursuing whether CME could be provided through the Academy.

Some professional societies award CME credit for reading articles. Some journals, such as the *American Family Physician* (official journal of the American Academy of Family Physicians), have a “Cochrane Corner” which provides CME. It was suggested that Wiley could contract with specialty organizations to provide access to a limited number of reviews which could be used in this manner.

Kay Dickersin noted that the USCC could make slides available to be used in talks about Cochrane, and, depending upon available funds, USCC staff may also be available to make a presentation at professional society meetings.

6. Funding: Successes, Challenges & Future Plans

Kay Dickersin reported that the USCC currently has funding from the Agency for Healthcare Research and Quality (AHRQ) to host annual conferences. Funding from the National Eye Institute supports increasing involvement of US-based ophthalmologists and optometrists in using evidence-based healthcare and in contributing to Cochrane reviews. She noted the USCC has just completed a 1-year grant supporting CUE, and that a proposal to support CUE activities for 3 years has been submitted.

Appendix G

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

Program Agenda

- 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 *Overtreated: 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

CCNet participation Barbara Warren, National Coalition for Lesbian, Gay, Bisexual and Transgender Health

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

2008 CUE Annual Membership Meeting – Agenda (cont'd)

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 H

USCC and San Francisco Branch Presentations and Papers 2007 - 2008

Kay Dickersin's presentations (2007)

1. How the US Cochrane Center can help you. Department of Surgery Retreat on Clinical Trials and Outcomes Research. Department of Surgery, Johns Hopkins School of Medicine, Baltimore, Md. January 6, 2007.
2. Flawed Evidence: A challenge to evidence-based healthcare. Dean's Lecture. Johns Hopkins Bloomberg School of Public Health. Baltimore, Md. January 10, 2007.
3. Flawed evidence: A challenge to evidence-based healthcare. Essex South District Winter Meeting. Massachusetts Medical Society. Beverly, Ma. January 17, 2007
4. Evidence and its synthesis in current practice (panel). Judging the Evidence: Standards for Determining Clinical Effectiveness. Institute of Medicine Roundtable on Evidence-based Healthcare. Washington DC. Feb 5, 2007.
5. *The Cochrane Library* and rapid research on the web. Annual Meeting of the Maryland Chapter of the American College of Physicians. Ellicott City, Md. February 9, 2007.
6. The Cochrane Collaboration in the US: Strategies for success and the challenges ahead. Maternal and Child Health Systematic Reviews. Tulane School of Public Health and Tropical Medicine. New Orleans, La. March 1, 2007.
7. Evidence-based healthcare: What is it and what do we need to get it? Annual Advocacy Training Conference. National Breast Cancer Coalition. Arlington, Va. April 29, 2007.
8. The WHO International Clinical Trials Registry Platform. 2nd Annual Forum on Clinical Trial Registries and Results Databases. Center for Business Intelligence (CBI). Washington, DC. May 1, 2007.
9. Using systematic reviews to inform practice. ARVO Special Interest Group. Fort Lauderdale, Fl. May 9, 2007.
10. Key role of the Cochrane Collaboration in quality and safety. 2007 Summer Institute on Evidence-based Practice. Quality and Safety. San Antonio, Tx. July 12, 2007.
11. Introducing *Understanding Evidence-based Healthcare: A Foundation for Action*. Consumers United for Evidence-based Healthcare, Consumers United for Evidence-based Healthcare (CUE) Advocacy Summit. Washington, DC. July 17, 2007.
12. The US Cochrane Center's new online course for consumer advocates: Understanding Evidence-based Healthcare: A Foundation for Action. Rocky Mountain Workshop on Evidence-based Healthcare. Colorado Springs, Co. Aug 5, 2007.
13. Clinical trials. The National Breast Cancer Coalition's Project LEAD Institute. San Diego, Ca. August 22, 2007.
14. Systematic reviews and meta-analysis. The National Breast Cancer Coalition's Project LEAD Institute. San Diego, Ca. August 23, 2007.

15. Screening. The National Breast Cancer Coalition's Project LEAD Institute. San Diego, Ca. August 23, 2007.
16. Systematic reviews in epidemiology: Why are we so far behind? Reading and Writing Review Articles in Occupational Epidemiology. Lo-Skolen, Helsingør, Denmark, August 28, 2007.
17. Critical appraisal of the healthcare literature. Evidence-based Healthcare: A Workshop on Finding, Synthesizing, and Applying Clinical Evidence. MedChi, The Maryland State Medical Society, Baltimore, Md. September 7, 2007.
18. History of Evidence-based Healthcare and Methods Used to Summarize the Evidence Making More Effective Use of Research. Reforming States & The Milbank Memorial Fund. Washington, DC. September 19, 2007.
19. Systematic reviews and meta-analysis: A primer. Annual Biostatistics Conference. Glaxo Smith Kline. Collegeville, Pa. September 26, 2007.
20. Evidence-based healthcare: What is it and what do we need to get it? Medicine in Action: A Special Course in Advanced Medical Writing. Johns Hopkins University. Baltimore, Md. October 2, 2007.
21. Reporting on the risks and benefits of clinical trials (publicly and freely available tele-seminar). Foundation for American Communications (FACS). Washington, DC. October 3, 2007.
22. Consensus vs evidence: What is most helpful to the practitioner? World Ophthalmology Leaders Forum in Education. Guidelines for Developing Guidelines. New Orleans, La. November 12, 2007.
23. The value and limits of evidence. National Breast Cancer Coalition Quality Care LEAD. Washington, DC. November 15, 2007.
24. Cancer findings and the Cochrane Collaboration. LunchLearnLink Seminar Series. Cancer Prevention and Control. Johns Hopkins Bloomberg School of Public Health. Baltimore, Md. December 13, 2007.

Kay Dickersin's presentations (2008)

1. Evidence-Based Healthcare Forum "Advancing the Evidence of Experience: Practical Issues for Patient/Consumer Inclusion." Clear Messages: Importance of Information Sharing, Translation and Dissemination. Mental Health America. Washington DC March 6, 2008.
2. The 2nd South Asian Regional symposium on Evidence Informed Health Care. Clinical Trials Registration and Results Reporting: The CONSORT guidelines and Beyond. Vellore, Tamil Nadu, India. April 9, 2008.
3. National Breast Cancer Coalition Annual Advocacy Training Conference - Beyond Ribbons to Revolutions. Breast Cancer Research: Expectations Versus Reality. National Breast Cancer Coalition Fund. Washington, DC. April 26-29, 2008.

4. York Hospital Department of Obstetrics and Gynecology conference Series. Stop DUB: Findings that give women options and give doctors a secure evidence base. York Hospital Grand Rounds. York, Pa. May 14, 2008.
5. National Health Policy Forum. Introduction to the Cochrane Collaboration and Fundamentals of Evidence-based Health. The George Washington University, Washington, DC. July 25, 2008.
6. The Rocky Mountain Workshop on how to practice evidence-based health care. University of Colorado. Salt Lake City, Ut. July 26-31, 2008.
7. The Expert Panel to Evaluate What Works Clearinghouse. United States Department of Education. Washington DC. September 11, 2008.
8. Data and Safety Monitoring Boards: Skills Building Workshop. Basic Structure and Function of DSMBs. Johns Hopkins Medical Institution. Baltimore, Md. September 29, 2008.
9. The 16th Cochrane Colloquium, Evidence in the ear of globalization. Consumers speak out! What do we want results reporting to look like? Frieberg, Germany. October 3-7, 2008.
10. Sixth Sino - US Symposium on Medicine in the 21st Century. Johns Hopkins University School of Medicine. Baltimore, Md. October 10-11, 2008.
11. Academy 2008 Anaheim. American Academy of Optometry. Anaheim, Ca. October 22-25, 2008.

Roberta Scherer's presentations (2007)

1. Evidence-based health care and the Cochrane Collaboration. Grand Rounds for Internal Medicine house staff at the University of Maryland School of Medicine. Baltimore, Md, March 2, 2007.
2. The Cochrane Collaboration approach to evidence-based decision making. Advisory Board meeting of the Center for Alternatives to Animal Testing. Baltimore, Md, June 14, 2007.
3. Evidence-based healthcare and the Cochrane Collaboration. First International Forum towards Evidence-based Toxicology. Cernobbio, Italy. October 16, 2007.

San Francisco Branch

Lisa Bero's presentations (2007)

1. The Cochrane Collaboration: Minimizing Influence of Commercial Organizations. Beyond the Evidence Symposium. Amsterdam, Netherlands. April 18, 2007 (Invited Speaker).

2. The Methods and Uses of Systematic Reviews and Why some Statins appear more efficacious than others. Making More Effective Use of Evidence-Based Research. A meeting sponsored by the Reforming States Group and Milbank Memorial Fund. Washington, DC. September 18 – 19, 2007 (Invited Speaker). Dr. Bero also served as a small group discussion leader for this meeting of members of the judicial, legislative and executive branches of state government.
3. Spinning your trial results: What is the future of traditional journals? Special session of XV Cochrane Colloquium. São Paulo, Brazil. October 24, 2007 (Invited Speaker).

Lisa Bero's presentations (2008)

1. Systematic reviews, meta-analysis and the Cochrane Collaboration. Division of General Pediatrics, Fellowship Seminar, University of California. San Francisco, California. July 16, 2008 (Invited Speaker).
2. Meta-analysis and the Cochrane Collaboration. Division of General Pediatrics Research Seminar, University of California. San Francisco, California. July 16, 2008 (Invited Speaker).

Lisa Bero's papers (2007)

1. Yank, V. Rennie, D, and **Bero, L.** Financial ties and concordance between results and conclusions in meta-analyses: retrospective cohort. *BMJ* 335: 1202-1205, 2007.

Appendix I

United States Cochrane Center Performance Targets for January 1, 2007 - December 31, 2008

- 1. Target:** **Coordinate, maintain, and update the Master List of Journals Being Searched (Master List).**
- 1.1 Objective:** Coordinate, maintain, and regularly update the Master List.
- 2. Target:** **Work with National Library of Medicine (NLM) to ensure that randomized trials included on MEDLINE are appropriately indexed as publication type [PT] RANDOMIZED CONTROLLED TRIAL (RCT) (MEDLINE Retagging Project), *pending receipt of funding*. (2007 only)**
- 2.1 Objective:** Perform electronic search for randomized controlled trials (RCTs) on MEDLINE, and submit the results to NLM. (2007 only)
- 3. Target:** **Provide training and support for reviewers, review group coordinators (RGCs), trial search coordinators (TSCs), editors, handsearchers, consumers, and others responsible for training activities.**
- 3.1 Objective:** Make available on the worldwide web and elsewhere guides for Cochrane procedures.
- 3.2 Objective:** Develop and facilitate Cochrane training workshops and courses.
- 3.3 Objective:** Provide ongoing support and training through individual contact, email discussion lists, and directories.
- 4. Target:** **Promote awareness of the Cochrane Collaboration and access to Cochrane products.**
- 4.1 Objective:** Plan and host the US Contributors' Conference (2008 only)

USCC 2007 and 2008 Performance Targets (cont'd)

- 4.2 Objective:** Ensure that individuals (including the media and consumers) and institutions within the region served by USCC are aware of all aspects of the Cochrane Collaboration and the USCC; highlight Cochrane activities in presentations and reports to health professionals, consumers, and others whenever relevant.
- 4.3 Objective:** Work to ensure that *The Cochrane Library* is made available and accessible to regional institutions, government agencies, professional organizations, and others.
- 4.4 Objective:** Encourage the news media to use *The Cochrane Library*, provided free of charge through John Wiley and Sons, Inc.
- 4.5 Objective:** Work with physicians, consumers, government, and others to identify ways in which Cochrane reviews can better meet their needs.
- 4.6 Objective:** Maintain and expand the USCC's web presence.
- 5. Target:** **Perform USCC administrative functions.**
- 5.1 Objective** Perform handsearching of US medical journals and conference proceedings.
- 5.2 Objective:** Participate in annual Collaboration meetings at the 2007 and 2008 Cochrane Colloquium and midyear meetings.
- 5.3 Objective:** Perform general Center administrative functions.
- 6. Target:** **Seek and obtain funding support for USCC activities**
- 6.1 Objective:** Continue working with funders to support USCC activities.
- 6.2 Objective:** Work with USCC branches and US-based entities to identify sources of funding and to leverage combined efforts to obtain funding.

7. Target: Conduct and disseminate research

7.1 Objective: Conduct methodological research on issues of importance to systematic reviews, trials registers, and evidence-based healthcare.

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

8.1 Objective: Support CUE infrastructure and functions.

8.2 Objective Provide an online distance education course for consumer advocates.

8.3 Objective Strengthen the ties between CUE and the Cochrane Collaboration Consumer Network (CCNet).

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

9.1 Objective: Share materials and resources related to educational projects.

9.2 Objective: Collaborate with CEVG@US on research projects.

Appendix J

United States Cochrane Center Performance Targets for January 1 - December 31, 2009

- 1. Target:** **Coordinate, maintain, and update the Master List of Journals Being Searched (Master List).**
- 1.1 Objective** Coordinate, maintain, and regularly update the Master List.
- 2. Target:** **Provide training and support for reviewers, review group coordinators (RGCs), 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:** Plan and implement necessary changes to consumer online distance education course, to appeal to an audience of health professionals and students
- 3. Target:** **Promote awareness of the Cochrane Collaboration and access to Cochrane products.**
- 3.1 Objective:** Plan and host a US Contributors' Conference
- 3.2 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

USCC 2009 Performance Targets (cont'd)

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 K

Evidence-based priority-setting for new systematic reviews: a case study for primary open-angle glaucoma

T. Li¹, K. Dickersin¹, E. Ssemanda¹, R. Scherer¹, A. Ervin¹.

¹*Cochrane Eyes and Vision Group US Project, Johns Hopkins Bloomberg School of Public Health*

Background:

It is essential to prioritize systematic reviews, to ensure that important clinical questions are addressed. Practice guidelines reflect the community's clinical questions and may provide a starting point for prioritization.

Objective:

As part of the Cochrane prioritization project, we are testing a framework to prioritize clinical questions related to management of primary open-angle glaucoma (POAG), which can then be addressed by Cochrane reviews.

Methods:

Using an iterative process and the input of multiple individuals, we restated each recommendation in the 2005 American Academy of Ophthalmology guideline on the management of POAG as an answerable clinical question. To identify the available evidence for each question, we searched *The Cochrane Library*, PubMed and EMBASE for systematic reviews, and the Cochrane CENTRAL Register of Controlled Trials for RCTs. We are asking international experts in the field to rank the importance of the clinical questions using an online Delphi survey conducted between April and August 2008, without informing them of the available evidence for each question. The survey is undergoing the ethics review and approval process.

Results:

We derived 45 clinical questions from the guideline. We identified 35 systematic reviews and over 400 potentially eligible RCTs pertaining to one or more clinical questions specified (*see* Table). We have encountered challenges in determining how best to: derive questions from clinical recommendations; decide the relevance of an RCT to a question without doing a systematic review; ask clinicians about the importance of a topic in a way that is meaningful to them; and incorporate information about the available evidence when we ask clinicians about prioritization of reviews.

We will present the ranking of questions based on the results of the Delphi survey.

Conclusions:

In testing a possible process for prioritizing systematic reviews using guidelines, we have encountered some challenges and are investigating solutions.

Conflicts of interest statement:

This project is supported by The Cochrane Collaboration Opportunities Fund and National Institutes of Health contract NO1-EY-2-1003, USA.

Table. Examples of five statements in the AAO* POAG† guidelines, restated clinical questions, and systematic reviews identified.

Statements in the AAO POAG guidelines	Restated clinical questions	Cochrane systematic reviews‡ (clinical question(s) addressed)	Non-Cochrane systematic reviews‡ (clinical question(s) addressed)
<p>The IOP§ can be lowered by medical treatment, or by laser, filtering, or cyclodestructive surgery (alone or in combination). The choice of initial therapy depends on numerous considerations, and discussion of treatment with the patient should include appropriate options. [A: III] In many instances, topical medications constitute effective initial therapy. 56 [A:I]</p>	<p>A. Is medical therapy an effective initial treatment in lowering IOP in patients with POAG? B. What is the effect of discussion of treatment options on the choice of initial therapy?</p>	<p>1 (A, C-G) 2 (C-G)</p>	<p>1 (C) 2 (C) 3 (C) 4 (C, D) 5 (C, D) 6 (C, D, F) 7 (C, D, F) 8 (C, D, E, F) 9 (C, G)</p>
<p>The prostaglandin analogs and the beta adrenergic antagonists are the most frequently used eye drops for lowering IOP in patients with glaucoma.</p>	<p>C. Are prostaglandin analog eye-drops effective in lowering IOP in patients with POAG? D. Are beta-adrenergic antagonist eye-drops effective in lowering IOP in patients with POAG?</p>		<p>10 (D) 11 (D)</p>
<p>Agents less frequently used include alpha₂ adrenergic agonists, topical and oral carbonic anhydrase inhibitors, and parasympathomimetics.</p>	<p>E. Are alpha₂ adrenergic agonist eye-drops effective in lowering IOP in patients with POAG? F. Are topical and oral carbonic anhydrase inhibitors effective in lowering IOP inpatients with POAG? G. Are parasympathomimetic eye-drops effective in lowering IOP in patients with POAG?</p>		

* American Academy of Ophthalmology

† Primary open angle glaucoma

‡ 2 Cochrane and 11 non-Cochrane systematic reviews pertaining to one or more clinical questions were identified

§ Intraocular pressure

Appendix L

CODING OF CLINICAL TRIALS AND SYSTEMATIC REVIEWS IN THE COCHRANE LIBRARY USING INTERNATIONAL STANDARDS

Stephen Gichuhi, Barbara S. Hawkins, Kay Dickersin
U.S. Cochrane Center and Eyes and Vision Group,
The Johns Hopkins University, Baltimore, Maryland

Registers and databases of reports of clinical trials and systematic reviews are invaluable resources for clinical trialists, health professionals, and consumers. However, their utility in retrieval of information about a particular health condition and/or intervention is limited by variations in terminology used by different medical specialties and researchers. Coding clinical trials and systematic reviews using international coding standards in common use may improve access to and translation of evidence to practice. WHO's International Classification of Diseases (ICD-10) is used internationally across research and clinical settings and presents a good option. The International Classification of Health Interventions (ICHI) is in beta testing prior to public release and would add additional indexing information.

The Cochrane Library currently includes 4,539 systematic reviews and review protocols and over 470,000 citations to controlled trials. *The Library* is searched using textwords and MeSH. A project is underway within the Cochrane Eyes and Vision Group (CEVG) to tag vision-related systematic reviews and over 7,000 clinical trials available to the public on *The Cochrane Library*, with ICD codes for (a) the disease entity(ties) addressed and (b) the intervention(s) evaluated. We present the results of the pilot study.

In our pilot study, two independent reviewers completed coding for 43 CEVG systematic reviews published in *The Cochrane Library*. Inter-observer agreement using ICD-10 was 81.4%. ICHI was suboptimal for coding of individual medications.

In the next phase of piloting, we will code a subset of trials and compare search results using the current MeSH and textword approach versus the new ICD coding.

Support by NIH contract NO1-EY-2-1003, National Eye Institute, National Institutes of Health.

Appendix M

Abstract - Registration of Randomized Controlled Trials

Authors: Roberta W. Scherer, PhD¹; Pamela C. Sieving, MA, MS², Ann Ervin PhD¹; Kay Dickersin, PhD¹. ¹Johns Hopkins Bloomberg School of Public Health, Baltimore, Md; ² National Institutes of Health Library

Title: Registration of Randomized Controlled Trials presented at ARVO in 2007

Purpose: Starting in 2007, ARVO required that abstracts reporting controlled clinical trials note the place of trial registration and the trial registration number. Our purpose was to determine (1) whether randomized controlled trials (RCTs) accepted for presentation at the 2007 ARVO meeting had been registered in a clinical trial registry, and (2) if all abstracts that included trial registration information were indeed controlled clinical trials.

Methods: We hand searched the 2007 ARVO program abstracts (n = 6,044) to identify all those describing RCTs. We also reviewed all 2007 abstracts where the author had entered information in the space allocated for trial registration (n=258). We determined the proportion of abstracts describing RCTs that had been registered prior to submission, and abstracted trial registration information. We also examined all abstracts where authors included registration information, and classified the study design, some of them RCTs and some of them non-RCTs.

Results: We classified 2.9% (173/6044) of all abstracts as describing an RCT. This proportion was lower than the proportion of abstracts classified as an RCT for abstracts submitted to ARVO in the previous three years (2006, 3.6% (219/5920); 2005, 3.6% (212/5732), and 2004, 3.4% (189/5610)). Only 62% (107/173) of RCTs had been registered before submission, with the majority (88/107) registered at clinicaltrials.gov or the International Standard Randomized Controlled Trials Number. Other entries included the EudraCT trials register (n = 2), regulatory agencies (n=3), ethics committees (n=3), and other (n = 11). Authors of 39% (66/173) of RCTs did not provide any trial registration information.

Authors of an additional 151 non-RCT abstracts provided a response in the space allocated for trial registration information. Three of these entries were a statement that registration was not required due to study design. Of the remaining 148 abstracts, 18 described a controlled clinical trial, 96 described an uncontrolled clinical trial, 22 described a case control study, and 12 we classified as other, including animal studies (n=5), laboratory experiments (n=4), image evaluation with no human involvement (n=2), and a simulation experiment (n=1).

Conclusions: The proportion of accepted abstracts describing RCTs decreased in 2007 compared with that of previous years, perhaps indicating that registration was a barrier for submission or acceptance. Nearly 40% of authors did not adhere to the requirement to register RCTs before submission to the 2007 ARVO meeting.

Appendix N

Identification of Systematic Reviews in Vision Research

Tianjing Li, MD, Roberta Scherer, PhD, Claire Twose,
Blair Anton, Kay Dickersin, MA, PhD
Cochrane Eyes and Vision Group,
The Johns Hopkins University, Baltimore, Maryland

Purpose: To identify and characterize published systematic reviews relevant to eyes and vision in major medical bibliographic databases.

Methods:

Search strategy: We developed a search strategy using keywords and terms from controlled vocabularies in the Unified Medical Language System thesaurus tool. We combined topical terms with terms related to systematic review methodology. We searched PubMed and the Cochrane Database of Systematic Reviews, the Database of Abstracts of Reviews of Effects, the Health Technology Assessment Database and the NHS Economic Evaluation Database in *The Cochrane Library* in November 2006.

Eligibility: We included systematic reviews, defined as full text review articles using a systematic methodology that included a clearly formulated research question, explicit methods to identify the primary studies, and predetermined inclusion and exclusion criteria. We included reviews with and without meta-analyses of the primary studies. Systematic reviews were eligible if they related to the etiology, epidemiology, prevention, diagnosis, therapeutic intervention, practice patterns, economic evaluation, or health care utilization of eye diseases or visual impairment in humans. We excluded systematic reviews that evaluated only animal or *in vitro* studies.

Analyses: We reviewed the citations identified, determined final eligibility, and eliminated duplicates. We classified the records by eye condition studied.

Results: Our search identified 2,707 distinct records, of which 321 were eligible. The number of systematic reviews increased more than 10-fold from 1992 (n = 4) to 2005 (n = 57) (see figure). A substantial proportion (41.1%; 132/321) concerned common aging eye conditions: 17.1% (55/321) on glaucoma, 11.2% (36/321) on age-related macular degeneration, 9.6% (31/321) on cataract, and 5.9% (19/321) on diabetic eye disease. Other topics with 7 or more reviews were low vision (10/321), refractive surgery (8/321) vision screening (7/321) and retinoblastoma (7/321).

Conclusions: Our results revealed an increase in the application of systematic review methodology to assess the evidence in the eyes and vision literature in recent years. Enormous challenges remain, however, with many ocular conditions areas for which an evidence-based approach has not been used.

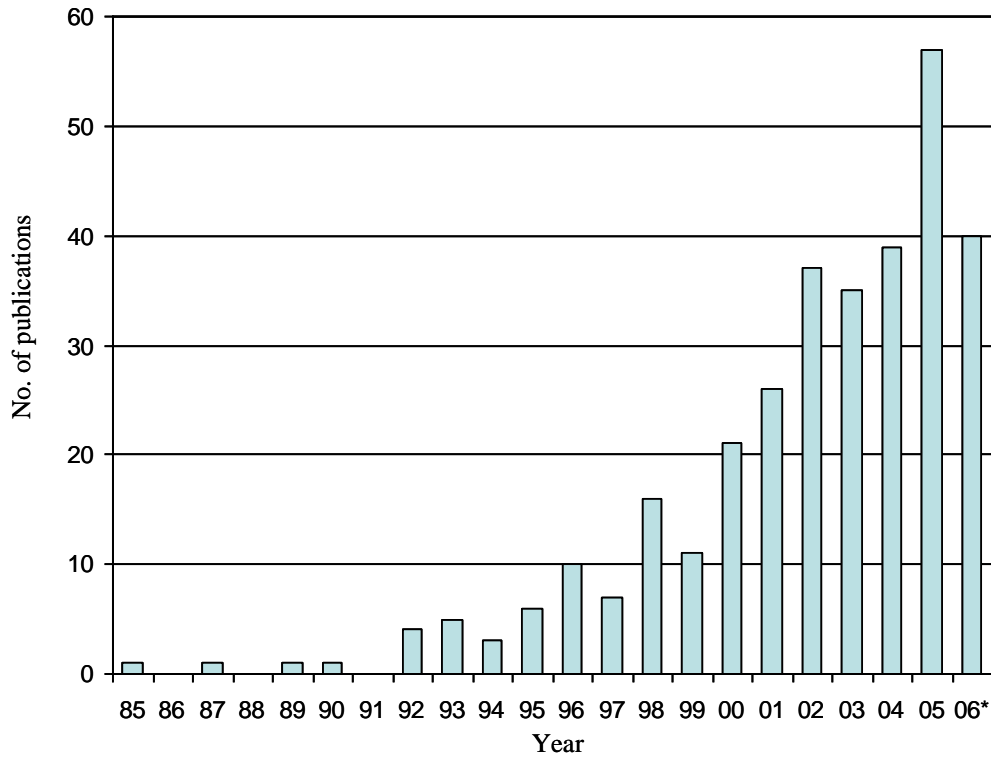


Figure 1. Number of eyes and vision systematic reviews by year of publication.
 * Partial year

Supported by NIH contract NO1-EY-2-1003, National Eye Institute, National Institutes of Health

Appendix O

The E-trials Project: First Steps in the Development of a Study-based Eyes and Vision Trials Database

E. Ssemanda¹, K. Dickersin¹, T. Li¹, R. Scherer¹, A. Ervin¹, B. Hawkins¹.

¹*Cochrane Eyes and Vision Group US Project, Johns Hopkins Bloomberg School of Public Health, Baltimore, MD 21205*

Background:

A comprehensive study-based database of clinical trials in eyes and vision would make it possible to provide usable research evidence to clinicians, policymakers, researchers, and consumers. The first step in creating a study-based database is to assemble all available vision science trial reports.

Objectives:

Our initial objective was to develop and use a Procedures Manual to build a study-based database of eyes and vision trial reports by integrating three existing datasets, and incorporating a fourth newly created dataset. Our long-term goal is to convert the report-based to a study-based register, and populate database fields with trial characteristics used in performing systematic reviews.

Methods:

We developed the "E-trials" database by importing four datasets as comma-delimited files into a Microsoft (MS) Access database. The first three datasets are: 1) a ProCite file containing the Cochrane Eyes and Vision Group (CEVG) specialized register (CEVG-SR), 2) a MS Excel file containing a 10% random sample of the CEVG-SR trial reports with International Classification of Diseases (ICD-10) and International Compendium of Health Indicators (ICHI) codes, and 3) a MS Excel file characterizing trial reports in eight ophthalmology journals. We created the fourth dataset, a ProCite file of the subset of the CEVG-SR trial reports indexed in MEDLINE, using six software programs to retrieve and import information from 42 MEDLINE fields. We plan to identify reports contributing to single studies, and to evaluate studies to populate fields describing trial characteristics.

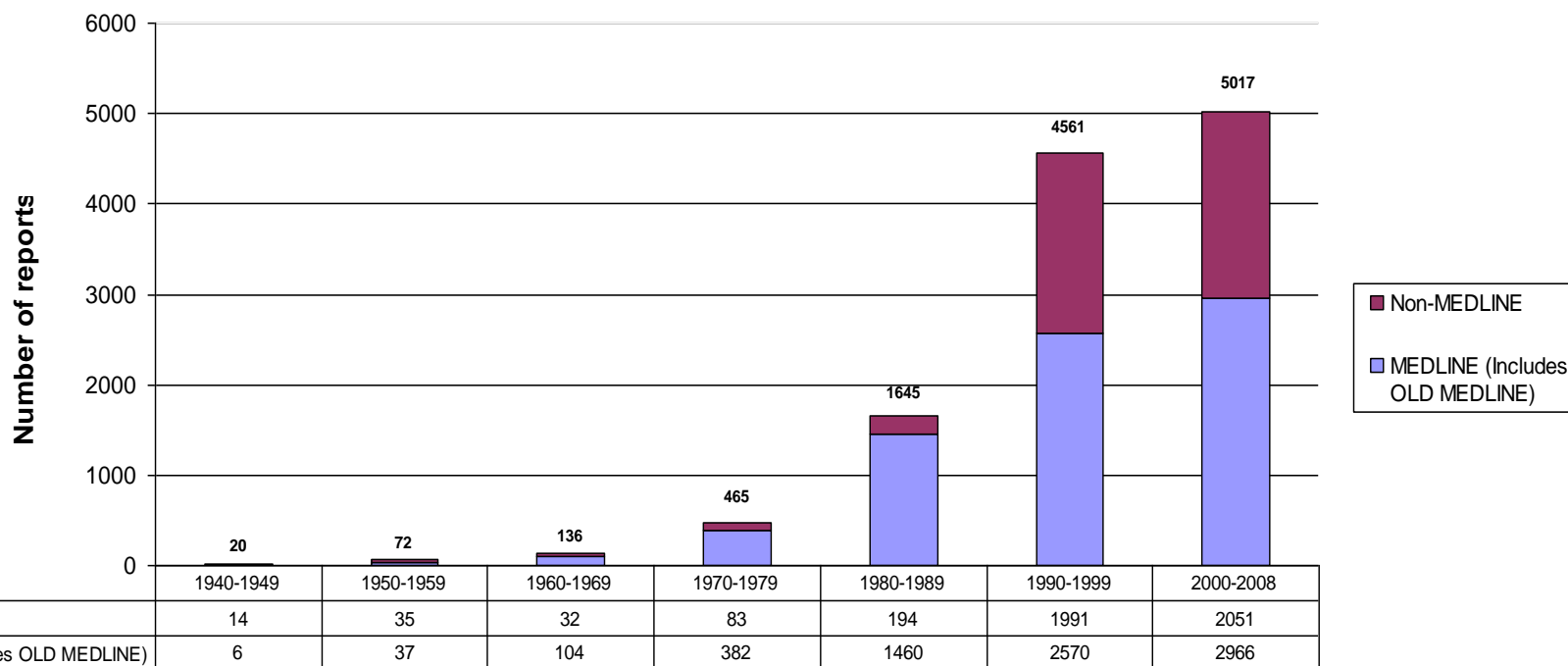
Results:

Considerable planning, in the form of a Procedures Manual, was undertaken prior to the construction of the database. Overall, the integration of datasets went smoothly. Of 11,925 trial reports in the CEVG-SR, 7,525 (63.1%) were indexed in MEDLINE. We estimated that 1785/11,925 (15%) are conference abstracts. In the subset for MEDLINE-indexed reports, 5,749 (76.4%) were indexed as publication type [PT] RCT and 887 (11.8%) were indexed as PT CCT. The proportion of reports that are MEDLINE-indexed has decreased over time and this could be due in part to alterations in MEDLINE's conference abstract policy.

Conclusions:

The first step of developing our study-based register is complete and we are able to analyze information about trial reports.

Figure. Number of reports in E-trials database by decade and MEDLINE indexing



Number of reports in E-trials by decade

Appendix P

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