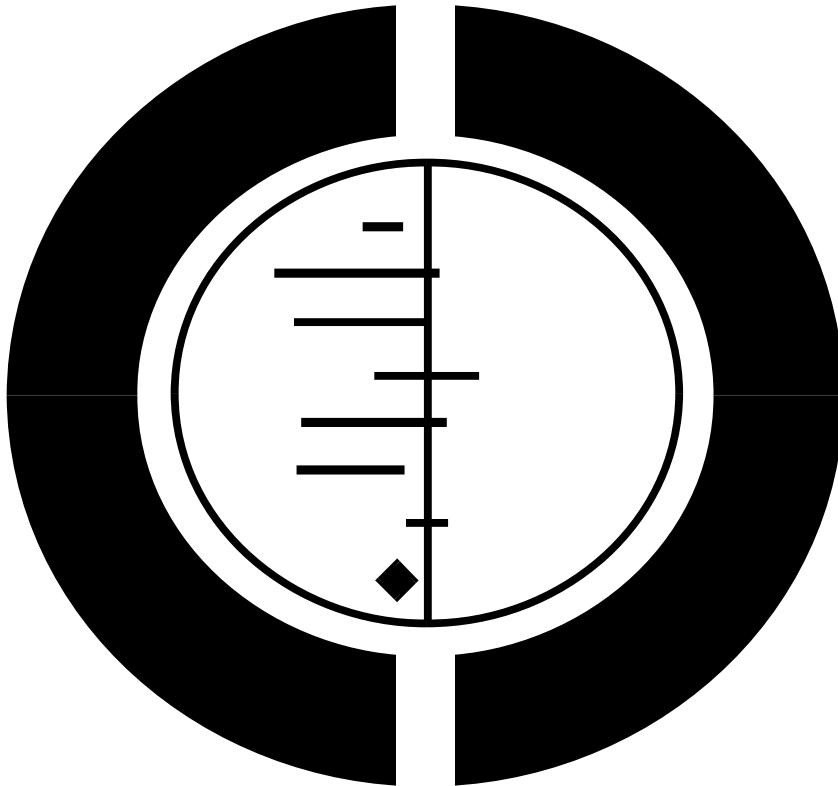


UNITED STATES
COCHRANE CENTER

ANNUAL REPORT
2005

United States Cochrane Center



Annual Report January 1, 2005 - December 31, 2005

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
AHCJ	Association of Health Care Journalists
AHRQ	Agency for Healthcare Research and Quality
AVSL	Association of Vision Science Librarians
CAM	Complementary and Alternative Medicine Field
CCAG	Cochrane CENTRAL Advisory Group
CCNet	Cochrane Consumers Network
CCSG	Cochrane Collaboration Steering Group
CCT	Controlled clinical trial
CCTR	Cochrane Controlled Trials Register
CDR	Cochrane diagnostic reviews
CENTRAL	The Cochrane Central Register of Controlled Trials
CEVG	Cochrane Eyes and Vision Group
CEVG@US	Cochrane Eyes and Vision Group, US Satellite
CMP	CENTRAL Management Plan
CRG	Collaborative review group
CTAG	CENTRAL and Trials Registers Advisory Group
CUE	Consumers United for Evidence-based Healthcare
EPC	Evidence-based practice center
HSSS	Highly sensitive search strategy
IMSG	Information Management System Group
Master List	Master List of Journals Being Searched
MeSH	Medical subject heading
NEI	National Eye Institute

NIH	National Institutes of Health
NLM	National Library of Medicine
PaPas	Pain, Palliative and Supportive Care Group
RCT	Randomized controlled trial
RevMan	Review Manager
RGC	Review group coordinator
SR	Systematic review
TSC	Trials search coordinator
UCSF	University of California, San Francisco
UKCC	United Kingdom Cochrane Centre
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.

In September 2005, the central office of the USCC moved from Brown University in Providence, Rhode Island to the Johns Hopkins University Bloomberg School of Public Health in Baltimore, Maryland. The move occurred because the USCC Center Director assumed full-time responsibility as Professor and Director of the Center for Clinical Trials. The status of the Boston and San Francisco Branches of the USCC remains unchanged.

2. Mission

The overall mission of the USCC is to further the Collaboration's goal of making widely available systematic reviews of evidence from randomized controlled trials of the effects of health care. Since 1994, the USCC (with origins as the Baltimore Cochrane Center) has had as its specific objective to help Cochrane collaborators to prepare systematic reviews by coordinating the development of a comprehensive central database of reports of randomized and controlled clinical trials (The Cochrane Central Register of Controlled Trials [CENTRAL]).

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:

- Ensure effective and efficient communication between the Center and members of other entities within the Cochrane Collaboration;
- Contribute to maintaining the Center's Contact Directory;
- Create and maintain a Center module, updated at least once annually;
- Ensure the sustainability and continuity of Center projects to forward the objectives of the Collaboration;
- Produce a strategic plan with targets and an annual report that reports on progress in meeting these targets;

- Serve as an information source about the Cochrane Collaboration and support people who want to become involved, including authors, handsearchers, consumers, and others;
- Provide and facilitate training and support for authors, editors, coordinators, handsearchers, and other contributors;
- Support CRG editorial bases, methods groups and fields/networks located in countries for which the Center is the reference center and where deemed appropriate by Center needs and resources;
- Promote accessibility to *The Cochrane Library* to healthcare professionals, consumers, the media and others;
- Handsearch general healthcare journals from the region and promote handsearching activities in the reference countries; and
- Submit handsearch results to CENTRAL.

In addition to the Center's core obligations, the USCC has had a unique function that advances the Cochrane Collaboration's mission. The Center coordinates the development of CENTRAL, the most comprehensive database of clinical trial reports in the world; it provides a major source of evidence for Cochrane reviews. CENTRAL is published quarterly in *The Cochrane Library*. The USCC is responsible for developing, updating, and maintaining the CENTRAL database, which includes:

- Acting as the central clearinghouse for trial reports identified by the Collaboration through CENTRAL, MEDLINE, and other sources by:
 - Monitoring, collecting, and processing results of individual or group electronic searches of the specialist and general healthcare literature;
 - Monitoring, collecting, and processing results of individual or group handsearches of the specialist and general healthcare literature;
 - Coordinating the *Master List of Journals Being Searched*, which includes over 2,800 journals being handsearched by members of the Cochrane Collaboration; and
 - Identifying quality checked citations for the National Library of Medicine (NLM) for retagging in MEDLINE as RANDOMIZED CONTROLLED TRIAL (RCT) [publication type] or CONTROLLED CLINICAL TRIAL (CCT) [publication type].
- Convening the Cochrane CENTRAL Advisory Group (CCAG), which requires preparation of meeting agendas, minutes, and other relevant documentation;
- Assuming tasks and responsibilities as needed by the CRGs and as assigned by the CCAG; and
- Supporting trials search coordinators (TSCs) and others who maintain specialized registers of trials to offer training, advice and guidance.

With funding support from Brown University, the NLM, and other sources ending, the USCC completed coordination of CENTRAL through Issue 2, 2006 of *The Cochrane Library* (last data submitted by December 31, 2005).

4. Funded projects

With the USCC relocating to Johns Hopkins University in September 2005, requests were submitted to the Agency for Healthcare Research and Quality (AHRQ) and the National Eye Institute (NEI) to transfer the funding from Brown University to Johns Hopkins University. Both requests were approved.

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

The USCC was awarded a 5-year conference grant in 2002 from AHRQ to conduct a series of conferences to increase and improve US involvement in and contribution to the Cochrane Collaboration. The conference series includes two US Contributors' Conferences, a series of smaller hands-on training workshops, and development of a web-based distance education module on evidence-based healthcare for consumer advocates. An essential part of the conference and workshop educational plan is critical evaluation. All conference and workshop participants are asked to evaluate the sessions which are modified to improve the educational goals. The result of the conferences and workshops will be a critical mass of US-based clinicians, educators, researchers, policymakers and consumers trained to prepare and use the essential elements of evidence-based healthcare.

4.1.1 USCC Consumer Coalition

The AHRQ grant has supported an annual meeting dedicated to the creation and support of a coalition of healthcare consumer advocacy groups. The goal of the consumer coalition, founded in 2003, is to foster the growth of a critical mass of consumer organizations committed to integrating critical appraisal and the concepts of evidence-based healthcare into their work. Named "Consumers United for Evidence-based Health Care (CUE)" in 2005, the coalition meets annually to further its aims to build a coalition of health advocacy organizations that:

- Incorporates evidence-based methods into their work;
- Educates its constituencies about evidence methods and interpretation;
- Encourages dissemination of evidence-based findings; and
- Develops a distance education course on evidence-based healthcare for consumer advocates for unrestricted use.

4.2 National Eye Institute (NEI) contract

In 2002, the USCC was awarded a 7-year contract by the NEI to build a critical mass of US-based vision professionals who are trained in preparing and using systematic reviews. In 2005, the US Satellite of the Cochrane Eyes and Vision Review Group (CEVG@US) based at the USCC, held two workshops on how to perform a systematic review. Section 8.1 provides additional information on the activities of the CEVG@US.

4.3 National Library of Medicine (NLM) grants

The Center was funded for 10 years (1994-2004) by the NLM to identify and re-tag controlled trial reports in MEDLINE. In 2005, the Cochrane Collaboration Steering Group (CCSG) provided funds for this project, which will continue until the funds are expended. Detailed information on the MEDLINE Retagging Project is provided in Sections 7.1.1 and 7.2.1.

5. Boston Branch of the USCC

The Boston Branch of the USCC is part of the Center for Clinical Evidence Synthesis in the Institute for Clinical Research and Health Policy Studies, Tufts-New England Medical Center, Boston. Dr. Joseph Lau, Branch Director, directs CCES and its AHRQ Evidence-based practice center (EPC).

The Boston Branch of the USCC has had a special focus on methods research and training in evidence synthesis. Through formal and informal training opportunities, the Branch educates the Tufts University-wide community and affiliated hospitals throughout New England about the Cochrane Collaboration. Branch faculty regularly teach courses on meta-analysis, introducing students and fellows to *The Cochrane Library* and the work of the Cochrane Collaboration. Dr. Lau also teaches a course on evidence-based nutrition, an increasingly important topic for clinical medicine and public health policy. The Branch provides unique opportunities to individuals interested in gaining evidence synthesis skills and practical training beyond a single course through a mentorship program for those interested in publishing reviews, including in *The Cochrane Library*, thus continuing to increase the pool of likely future reviewers available to CRGs. In 2005, Dr. Lau presented the Cochrane Collaboration at international conferences on evidence-based healthcare held in Taipei, Taiwan, and Tokyo, Japan and at a series of conferences in the US.

6. San Francisco Branch of the USCC

The San Francisco Branch of the USCC 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 also supports the HIV/AIDS CRG and is involved in the debate on conflicts of interest within the Cochrane Collaboration. The San Francisco Branch is based at the University of California, San Francisco.

7. Progress report on targets for 01/01/05 to 12/31/05

Based on the USCC mission and responsibilities, a series of performance targets, objectives and activities were developed to guide the work of the USCC in 2005. This section summarizes the achievements related to each 2005 performance target, (see Appendix A for USCC Performance Targets for January 1, 2005 - December 31, 2005).

7.1 Target: Coordinate the development and maintenance of The Cochrane Central Register of Controlled Trials (CENTRAL)

Kay Dickersin and the Center she has directed (the USCC 2002-present, the New England Cochrane Center, Providence Office (1998-2002) and the Baltimore Cochrane Center (1993-1998) have coordinated development and maintenance of CENTRAL since 1994. This role will cease in 2006. In the Fall of 2005, a request was submitted to publisher John Wiley and Sons, Inc. and the Cochrane Secretariat to continue funding the coordination of CENTRAL, once Update Software relinquished its role in March 2006. Our goal was to sustain and expand the USCC role to include development of a study-based register and streamlined processing. The request for funding was denied and the USCC will continue to be responsible for the maintenance of CENTRAL only through *Issue 2*, 2006 (publication date April, 2006).

7.1.1 Perform and compile results of literature searches (MEDLINE search, handsearch, and specialized register submissions)

In 2005, the USCC coordinated the following activities related to CENTRAL:

- *Search for and import citations from electronic search of MEDLINE:* The USCC conducts an annual electronic search of MEDLINE using phases I and II of the Cochrane Highly Sensitive Search Strategy (HSSS) to identify new controlled trials not already tagged as publication type [PT] CONTROLLED CLINICAL TRIAL (CCT) or RANDOMIZED CONTROLLED TRIAL (RCT). To allow for the time lag for indexing articles by NLM indexers, the 2004 MEDLINE search was completed during the Summer of 2005. After a quality control check that involved assurance that no submitted article would have both tags, 1563 records were submitted for retagging to the NLM, (see 7.2.1 and Appendix B for Electronic Search Submissions to NLM in 2005). These citations are readily accessible and identifiable as CONTROLLED CLINICAL TRIAL (CCT [PT]) or RANDOMIZED CONTROLLED TRIAL (RCT [PT]) on MEDLINE and can be imported directly into CENTRAL .
- *Receive and process results of handsearching journals:* Citations identified by individual handsearching of journals and conference proceedings also are submitted quarterly for processing. In 2005, the USCC processed 9,854 handsearch submissions for *The Cochrane Library*.
- *Receive and process specialized registers:* Each CRG is responsible for developing a subject-specific specialized register of studies potentially eligible to be included in systematic reviews. Cochrane fields may also develop registers, although not required. The USCC receives and processes updated specialized register submissions which are checked against pre-agreed publishing standards. Processed registers subsequently are submitted

to *The Cochrane Library* publisher. In 2005, the USCC processed 558,349 citations from specialized registers for *The Cochrane Library*.

The *Specialized Register and Handsearch Results Log* documenting specialized register and handsearch submissions processed for CENTRAL in 2005 is available on the USCC website (www.cochrane.us).

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

The USCC coordinates the Master List of Journals Being Searched (Master List), which includes approximately 2,800 journals and 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 mailing, 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 e-mailing conducted in March 2005 resulted in responses from 47 of 78 Cochrane entities with registered searches.

7.1.3 Serve as coordinating group for the CENTRAL Advisory Group (CCAG) activities.

Since 1998, the Director of the USCC has served as the convener of the CCAG. Reporting to the Steering Group, the CCAG and accordingly USCC staff have had responsibility for planning, convening and taking minutes for all conference calls and in-person meetings of the group. Meeting minutes were made publicly available. In addition to meetings and teleconferences, the USCC maintained the listserv for the group to communicate regularly via an email discussion list. USCC staff also prepared and disseminated CENTRAL and CCAG related materials.

As of October 2005, the CCAG was disbanded, while the CENTRAL Vision Group prepares a study proposing next steps in the development of CENTRAL.

7.1.4 In collaboration with the CCAG, review group coordinators (RGCs), the Informational Management System Group (IMSG), TSCs, the United Kingdom Cochrane Centre (UKCC), Update Software and John Wiley and Sons, prepare for development of the “new CENTRAL”

In 2005, the USCC continued to pilot test development of a study-based trials register to enhance the current report-based CENTRAL. USCC activities related to this task began in 2004 and continued in 2005, and included:

- Further testing of a study-based CENTRAL register using Oracle 9.2;

- Testing of populating the database by downloading trial records from MEDLINE;
- Testing data extraction from existing specialized registers using a CENTRAL submission from the Cochrane Eyes and Vision Group (CEVG);
- Revising the remit for a proposed CENTRAL and Trials Registers Advisory Group (CTAG), which was circulated to CCAG, IMSG, and the TSCs, and based on feedback obtained in 2004; and
- Evaluating feedback from a questionnaire used to obtain information from TSCs for CCAG regarding data fields included in their specialized registers.

Also in 2005, and related to the maintenance of CENTRAL, USCC staff:

- Continued work on a project to index conference abstracts in CENTRAL using Medical Subject Headings (MeSH), to assess the feasibility of applying MeSH to all CENTRAL records;
- Updated the web-based TSC resources page and content to include answers to additional questions posed by TSCs related to organizing their submissions to CENTRAL;
- Updated the CENTRAL Management Plan (CMP) web page, to provide several download options, including:
 - Allowing formatting of all forms in PDF or RTF; and
 - Providing information separated by chapters, sections and forms.

Results of these activities were used to inform the CCSG of the feasibility of converting CENTRAL from a citation-based to a study-based register.

7.2 Target: Work with the National Library of Medicine (NLM) to ensure that controlled trials included in MEDLINE are appropriately indexed as publication type CONTROLLED CLINICAL TRIAL (CCT) and RANDOMIZED CONTROLLED TRIAL (RCT) (“MEDLINE Retagging Project”).

7.2.1 Receive, process, and quality check submissions of handsearch results from Cochrane entities, perform electronic search on MEDLINE, and submit the results to NLM.

The USCC submitted a total of 2,933 citations to NLM for retagging in 2005. Of these, 1,370 new citations were identified through handsearching by other Cochrane entities, including 1,126 RCT records and 244 CCT records. In addition, the USCC identified 1,050 new RCT records and 513 new CCT records from its annual electronic search of MEDLINE to identify newly added RCTs and CCTs that remained unindexed as such, using phases I and II of the Cochrane highly sensitive search strategy (HSSS) (see Appendix C for a detailed summary).

7.3. Target: Provide training and support for reviewers, review group coordinators (RGCs), trial search coordinators (TSCs), editors, handsearchers, and consumers. In addition, provide training and support for others responsible for training activities.

7.3.1 Maintain, revise, and distribute on the Worldwide Web and elsewhere guides for Cochrane procedures

Training and supporting reviewers, TSCs, RGCs, and handsearchers are core functions of the USCC. Training materials are continuously reviewed and modified to ensure that they are accurate, current and useful. The following guides, handbooks, and documents are freely accessible on the USCC website and are regularly updated:

- The CMP, edited by USCC staff, documents procedures for contributing to, updating, maintaining, and managing the CENTRAL register. Sections 2 and 3, the *Guide for Submission of Specialized Registers to CENTRAL* and the *Guide for Submission of Handsearch Results to CENTRAL*, provide instructions and include forms used by TSCs to submit citations identified by electronic and handsearches of the healthcare literature on a specific disease or topic. Minor revisions were made to both sections in February 2005. Minor revisions also were drafted for Sections 4 and 5, *Coding of Records in CENTRAL* and *Correction of Records and Work Performed by the USCC in the Development and Management of CENTRAL* and Section 7, *Searching CENTRAL*.
- *Cochrane Handsearcher Training Manual*, produced by USCC staff, introduces Cochrane guidelines for identifying RCTs and CCTs, provides practice exercises for individuals interested in becoming handsearchers, and provides a knowledge assessment test. It may be accessed online at the USCC website www.cochrane.us and on the Cochrane Collaboration website at www.cochrane.org.
- *Guide for Trial Search Coordinators* introduces new TSCs to procedures involved in coordinating CENTRAL submissions.
- *Specialized Register and Handsearch Results Log*, produced by USCC staff, is a cumulative report providing information about quarterly specialized register and handsearch submissions to CENTRAL.
- *Summary of Specialized Registers and Handsearch Submissions Results*, produced by USCC staff, summarizes the types of problems encountered in processing records for CENTRAL.

The USCC continuously searches for ways to make resources easily accessible to affiliated groups and individuals. For example, as noted above, the USCC staff created special resource

pages for TSCs, reviewers, handsearchers, consumers, and newcomers to the Cochrane Collaboration in 2004 and updated the resources page and content in 2005.

7.3.2 Develop and facilitate Cochrane training workshops and courses

The USCC developed and presented the following training workshops in 2005:

- *Translating Critical Appraisal of a Manuscript into a Meaningful Peer Review*: Brown Medical School, January 22, 2005 in Providence, RI. (Kay Dickersin and Suzanne Brodney-Folse of the USCC, and others);
- *Completing a Cochrane Systematic Review*: Two 3-day workshops: February 26-28, 2005 in Sarasota, Florida and July 21-23, 2005 in Providence, RI. (Kay Dickersin, Suzanne Brodney-Folse, Joyce Coutu, Satyanarayana Vedula, and Roberta Scherer of the USCC, and others);
- *The Cochrane Collaboration: What is it, how does it relate to evidence-based healthcare, and how can I access its output?* Association for Health Care Journalists, April 3, 2005 in Durham/Chapel Hill, NC. (Kay Dickersin of the USCC, Doug McCrory of the Pain Group, and others);
- *Developing Evidence-based Guidelines*: Cystic Fibrosis Foundation, August 17-18, 2005 in Columbia, Md. (Kay Dickersin of the USCC, Karen Robinson, and others);
- *Review of the Distance Education Program for Consumers on Evidence-based Healthcare*: CUE Meeting, September 7, 2005 in Columbia, Md. (Kay Dickersin of the USCC, and others);
- *Evidence-based healthcare and critical appraisal for consumer advocates*; North American Health Science Librarians, September 17, 2005 in Providence, RI. (Laura Coe of the USCC);
- *Train the Trainers: Techniques for Training Systematic Reviewers*: 13th Annual Cochrane Colloquium, October 23, 2005 in Melbourne, Australia. (Satyanarayana Vedula of the USCC and others);
- *Using ProCite for Creating and Submitting Trial Databases to CENTRAL*: 13th Annual Cochrane Colloquium, October 23, 2005 in Melbourne, Australia. (Susan Wieland of the USCC, Eric Manheimer of the Complementary and Alternative Medicine Field, and Gail Higgins of the Cochrane Renal Review Group);

- *Critical Appraisal Skills for Consumer Advocates: Assessing a New Online Course*: 13th Annual Cochrane Colloquium, October 24, 2005, in Melbourne, Australia. (Kay Dickersin of the USCC, and Maryann Napoli of CUE and the Cochrane Consumers Network (CCNet));
- *Determining Study Design Classification of Potential Trial Reports Using MEDLINE Abstracts as Examples*: 13th Annual Cochrane Colloquium, October 25, 2005 in Melbourne, Australia. (Susan Wieland of the USCC and Anette Bluemle of the German Cochrane Center).

In addition to these training workshops, web-based distance education courses were revised or under development in 2005:

- *Handsearching: Identifying and Classifying Controlled Trial Reports*: This course was developed in 2003 and revised in 2004 and 2005. Version 2 was released in February 2005 and updated in October, 2005. Approximately 174 individuals registered for the course in 2005, representing a cross-section of countries (e.g., South Korea, Peru, Russia, and Saudi Arabia) and professions (e.g., clinicians, librarians, medical writers, epidemiologists, and nurses) (see Appendix D for a description of the Handsearching distance education course).
- *Translating Critical Appraisal of a Manuscript into Meaningful Peer Review*: Development of this course began in 2004 and continued in 2005. It will replace the in-person workshop of the same name. It includes didactic lectures and a hands-on module where participants can write and receive faculty feedback for the manuscript critiques they prepare (see Appendix E for the course overview).
- *Critical appraisal skills for consumers: understanding the evidence using an online course on Evidence-based Healthcare for Consumer Advocates*: The USCC consumer coalition, CUE, formed a committee to design a web-based course for consumers in August 2004 and developed a draft outline of a course designed to educate consumers about ways to search for, evaluate, use and improve healthcare evidence. In 2005, the USCC engaged Musa Mayer, M.S., M.F.A., an author, consumer advocate and breast cancer survivor, to assist in developing the course modules, completing drafts of three of six planned modules (see Appendix F for the course abstract).

7.3.3 Provide ongoing support and training through individual contacts, email discussion lists, and directories

USCC staff communicate regularly with TSCs from various Cochrane entities. The TSC email listserv was maintained by the USCC through October 2005 when it was turned over to the German Cochrane Center. The TSC email listserv provided a critical communication link with

TSCs regarding CENTRAL submission queries, reminding TSCs of upcoming deadlines and meeting dates, and posting other information that may be relevant to TSC training and support. The *TSC Directory* was updated regularly by USCC staff until October 2005.

USCC staff provides reviewers 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 assistant, based in Providence and later in Baltimore, who prepares materials for and works with authors via email, telephone and in-person consultation. Approximately 27 review authors received technical assistance from USCC staff in 2005, (see Appendix G for a list of review topics and authors). 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 2005, five review authors spent time at the USCC working with staff on their reviews. Three additional review authors also spent time at the USCC offices working on their reviews as part of a “Finishing School” that is offered by the USCC.

7.4 Target: Promote awareness of the Cochrane Collaboration and access to Cochrane products.

7.4.1 Ensure that individuals (including 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 and consumers, whenever relevant

Promoting awareness of the Cochrane Collaboration is a critical USCC objective. USCC staff make presentations about the Collaboration to key audiences to provide greater understanding of and access to *The Cochrane Library*, and to build stronger partnerships with the media and healthcare consumers. In 2005, USCC staff participated in programs and made presentations highlighting Cochrane activities, including evidence-based healthcare and the Cochrane Collaboration, consumer advocacy and access to online healthcare information, and the need for a global clinical trials register. Presentations are listed in Appendix H.

Of note, Kay Dickersin was invited to participate in a workshop about web-based learning at the May 2005 Society for Clinical Trials Meeting in Portland, Oregon. She presented the USCC’s experience in converting the paper-based Handsearcher Training manual to a Web-based course. In addition, Dr. Drummond Rennie, San Francisco Branch Co-Director, was an invited speaker at Plenary Session III: *Mandatory Clinical Trial Registration - Where Do We Stand?* which Dr. Dickersin chaired.

7.4.2 Cochrane Collaboration Mid-Year Meetings, Providence, RI

The USCC hosted the Cochrane Collaboration mid-year meetings March 29-April 4, 2005. The mid-year meetings provided an opportunity to foster one-on-one interactions between members of the CCSG, Cochrane Center Directors, and the USCC Advisory Board, representing leaders in US healthcare. The Center Directors' Meeting was held on days 1 and 2, and the CCSG Meeting on days 5 and 6. The CUE Conference was held on days 2 - 4 (see 7.4.6 for a detailed description of the CUE meeting). The following meetings were held:

7.4.2.1 Center Directors' Meeting, March 29, 2005

Minutes of this meeting are circulated internally. Attending were representatives from the following Cochrane Centers: Germany, IberoAmerican, US Providence, US San Francisco, Canada, China, Italy, Dutch, Brazilian, South African, UK. Also in attendance were Nick Royle (Secretariat) and Deborah Pentesco-Gilbert (John Wiley and sons, Inc.).

7.4.2.2 Consumers United for Evidence-based Healthcare (CUE) Conference, March 30-31 and April 1, 2005

The meeting report is accessible from the home-page of the USCC website, www.cochrane.us, under "Meeting and Conference Reports."

7.4.2.3 Joint Meeting of the Cochrane Collaboration Steering Group (CCSG), Center Directors and USCC Advisory Board, March 31, 2005

On day 3, a joint conference of the Cochrane Collaboration Steering Group, Center Directors and the USCC Advisory board was held. Joint aims of the conference were for the USCC Advisory Board to learn more about the Cochrane Collaboration and products and to discuss how other Cochrane Centers use their Advisory Boards. The agenda for the Joint Conference is presented in Appendix I.

7.4.2.4 Joint Meeting of the CCSG, Center Directors, and CUE, March 31, 2005

The second joint conference hosted at the Cochrane midyear meetings was "Developing alliances: Evidence-based healthcare in the US," (see Appendix J for agenda). The conference was designed to create alliances between US-based consumer advocacy groups and global leaders in evidence-based healthcare, promoting the missions of both CUE and the Collaboration. The goals of the conference were to provide education and foster further development of CUE.

To increase skills related to understanding the work of the Cochrane Collaboration and its relationship to evidence-based healthcare, the morning session of the meeting was dedicated to

oral presentations by Cochrane leaders on topics related to evidence-based health care, critical appraisal, the Cochrane Collaboration, and *The Cochrane Library*. In the afternoon, CUE members presented to the Cochrane leaders information about their organizations and provided ideas about how to make Cochrane reviews consumer-friendly. This was followed by discussion on barriers to access and use of Cochrane reviews by consumer advocates.

7.4.2.5 CCSG Meeting, April 2-3, 2005

CCSG meeting minutes are posted electronically on www.cochrane.org.

7.4.3 Work to ensure that *The Cochrane Library* is made available and accessible to all regional institutions and government agencies

In 2005, access to *The Cochrane Library* continued to be available free of charge for all CUE members representing advocacy organizations. In addition, to increase the availability and accessibility of *The Cochrane Library* in the US, John Wiley and Sons continues to provide free 30-day access to all USCC-sponsored workshop participants.

The state of Wyoming offers free access to *The Cochrane Library* to its residents. The National Institute of Child Health and Human Diseases provides the complete text of Cochrane reviews produced by the Cochrane Neonatal Review Group. Abstracts of Cochrane systematic reviews are available on MEDLINE, and freely available via the Cochrane Collaboration and Wiley Interscience web pages. The American Academy of Ophthalmology, a US-based organization, provides a link to *The Cochrane Library* on its website.

7.4.4 Encourage institutions and colleagues (e.g., National Institutes of Health (NIH), professional review organizations, health departments, university libraries) to expand subscriptions to Cochrane products

Presentation of *The Cochrane Library* is a regular feature of USCC staff presentations on evidence-based healthcare, the Cochrane Collaboration, and related topics. In 2005, the USCC Director made presentations highlighting *The Cochrane Library* for the Cystic Fibrosis Foundation, the International Association for Dental Research, the Johns Hopkins Department of Ophthalmology, and the American Gastroenterological Association, while the Project Coordinator, Ms. Coe presented the Cochrane Collaboration to the North American Health Sciences Librarians.

7.4.5 Encourage news media to subscribe to and use *The Cochrane Library*

Andrew Holtz, one of the directors of the Association of Health Care Journalists (AHCJ) and member of the USCC Advisory Board, successfully proposed that two workshops on the Cochrane Collaboration and *The Cochrane Library* be offered at the annual AHCJ conference in

April 2005. The 3-hour sessions began with presentations by Kay Dickersin, Douglas McCrory (Editor, Pain, Palliative and Supportive Care Cochrane Review Group), and Jessie Gruman (President, Center for the Advancement of Health and USCC Advisory Board member), followed by hands-on training from Julia Lampam (Publicity and Exhibitions Manager, Wiley Interscience) on using *The Cochrane Library*. Over 40 participants attended the workshops which were extremely successful and generated considerable interest in the systematic reviews and *The Cochrane Library* as a media resource. Mr. Holtz also brokered with Wiley, the publisher of *The Cochrane Library*, for free access for members of the association.

Jessie Gruman began a pilot program in early 2004 writing stories, similar to press releases, on newly published Cochrane reviews for the Center's Health Behavior News Service. The partnership began in earnest with the October 2004 issue of *The Cochrane Library*, with stories produced from each new issue of *The Cochrane Library* (released quarterly). From October 2004 to June 2005, the News Service disseminated 39 stories based on Cochrane reviews (not including the pilot study). This has resulted in 766 verified clips in newspapers, broadcast media, newsletters, magazines and Web sites. Cochrane stories were used by the Wall Street Journal, New York Times, Washington Post, Times of London, Dallas Morning News, Arizona Republic, Detroit News, Foxnews.com and ABC's "Good Morning America." The only other comparable data available is the frequency of mentions of Cochrane (either generally or reference to a specific review) in English language newspapers indexed on Lexis-Nexis from 1993-2003. In that study 362 Cochrane mentions were found: 64 in 2000, 60 in 2001, 68 in 2002 and 71 in 2003. These latter data are based on all types of media, including non-English language media, and thus the two sets are not strictly comparable. Nevertheless, the 2004-5 numbers almost certainly represent a sizable increase, which is probably due, at least in part, to the dissemination activities of the Center for the Advancement of Health.

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

In 2005, USCC staff performed outreach activities to schools of medicine and public health, hospitals, and government agencies on how Cochrane reviews promote evidence-based healthcare. In 2005 Kay Dickersin presented talks about the Cochrane Collaboration, systematic reviews, or evidence-based healthcare at the Symposium on Systematic Reviews in Dental and Craniofacial Research for the International Association for Dental Research, the Annual Meeting of the Pediatric Academic Societies, Digestive Diseases Week of the American Gastroenterological Association, and the American Academy of Optometry. Suzanne Brodney-Folse presented talks at the Retina Journal Club and the Center for Gerontology and Health Care Research at Brown University in 2005 (see Appendix H).

The USCC is committed to increasing consumer involvement in Cochrane activities and increasing consumer awareness of Cochrane products. In addition to developing a web-based

workshop for consumer advocates, a number of other consumer-focused activities were undertaken in 2005:

- The Third Annual USCC Consumer Coalition meeting was held in Providence, RI, on March 30 and April 1, 2005, in conjunction with the mid-year meetings of the Cochrane Collaboration (see also 7.4.1). Participants elected to work on projects that would facilitate consumers' use of evidence-based healthcare information and that would improve the quality, quantity and relevance of that information. Three groups were established to work on (1) the web-based course on evidence-based healthcare, (2) research issues, and (3) development of a strategic plan for the group (see Appendix K for the meeting agenda).
- Four sessions at the US Cochrane Contributors' Meeting, held in Melbourne, Australia from 22-26 October, 2005, focused on consumer needs and involvement in the Cochrane Collaboration (see the meeting agenda in Appendix M for details).

7.4.7 Act as facilitators, when requested, to aid in the listing and indexing of Cochrane reviews and other products in electronic publications and databases (e.g., indexing of Cochrane reviews in MEDLINE)

No requests for these services were made in 2005.

7.4.8 Maintain and expand the USCC's web presence

Continued maintenance and development of a USCC web presence increases visibility of the Cochrane Collaboration. Toward this end, a number of improvements were made to the USCC website in 2005:

- Replaced navigation graphics with text for accessibility and search engine optimization;
- Added "Newcomers" link to webpage;
- Added USCC brochures to USCC webpage;
- Updated the link to *The Cochrane Library*;
- Uploaded all downloadable forms to PDF format;
- Completed TSC Resource Page update with links to the Cochrane TSC Guide, submission forms, frequently asked questions, and other helpful links; and
- Reviewed other Cochrane websites in planning for website redesign.

7.5 Target: Perform USCC administrative functions

7.5.1 Perform handsearching of US medical journals and conference proceedings

A total of 34 journal-years (from US medical journals and conference proceedings) were handsearched by the USCC, resulting in the identification of 936 new reports of RCTs and 438 new reports of CCTs for CENTRAL inclusion (see Appendix N for details).

7.5.2 Participate in annual meetings at the 2005 Cochrane Colloquium in Melbourne

The USCC hosted the 26 October 2005 US Contributors' Meeting in Melbourne, Australia. The conference was attended by approximately 40 participants from across the US. Topics covered at the meeting included North American training opportunities, dissemination efforts in the US to increase understanding and use of *The Cochrane Library*, developing Cochrane in the US and beyond, funding efforts and plans, and upcoming USCC events.

In addition to the US Contributors' Meeting, USCC staff participated in several other Center-related meetings at the Colloquium:

- Meet the Entities exchange;
- Cochrane Center Staff Meeting on October 25, 2005, where staff from the 12 Cochrane Centers met to exchange information and ideas.
- Cochrane Center Directors' Meeting, held on October 22, 2005, included discussion on strategic planning for Center Directors, identifying strategies to establish stable funding for Center activities, raising awareness of *The Cochrane Library* and how to use it, and identifying and developing responses to the needs of developing countries. Kay Dickersin served as Co-Chair of this group for 2003-2005.

The USCC provided funds for four CUE members to attend the 13th Annual Cochrane Colloquium in Melbourne from October 22-26, 2005. The USCC also offered a workshop entitled *Critical Appraisal Skills for Consumer Advocates: Assessing a New Online Course*, which was attended by 13 individuals.

In addition, Kay Dickersin has served as a member of the Thomas C. Chalmers Award Selection Committee since its inception in 1995. The prize is awarded to the best oral paper and poster presented at the Cochrane Colloquium which addresses a methodological issue related to systematic reviews that demonstrates: originality of thought, high quality science, interpretation of the relevance of the issue to advancing methodology of systematic reviews, and clarity of presentation (oral or poster). This award was administered through the USCC from 1995 to 2005.

Kay Dickersin participated in the mid-year CCSG meeting, in her role as Co-Publication Arbiter.

7.5.3 Perform general Center administrative functions

In 2005, the USCC performed administrative functions, as follows:

- Updated all documents related to the move of the Center from Brown University to the Johns Hopkins Bloomberg School of Public Health, including:
 - Brochures describing the USCC;
 - Information on the USCC website;
 - Contact information in the USCC module; and
 - Contact information in ARCHIE, the Cochrane Collaboration contact database.
- Updated the US Cochrane Contact Directory: USCC staff used information from meeting attendance, *The Cochrane Library*, and other sources to update the USCC Contact Directory, which lists names, postal and email addresses.
- Updated the USCC Handbook to incorporate new and modify existing procedures. In 2005, the USCC CENTRAL Coordinator revised sections related to CCAG, and TSCs functions, as well as CENTRAL funding.
- Completed and submitted required documentation regarding the Center's activities, including the Center's module and annual monitoring report. The module continues to be updated quarterly, or as needed. This Annual Report lists the USCC's progress on 2005 targets and presents targets for 2006 (see Appendix O).
- Responded to all queries related to the Cochrane Collaboration throughout the year.

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

7.6.1 Continue working with other funding agencies (e.g., Agency for Healthcare Research and Quality, Milbank Memorial Foundation fund) that have contributed funding to the Baltimore Cochrane Center or NECC in the past, as well as the Cochrane Steering Group

The Milbank Memorial Fund provided support for the USCC Advisory Board meeting in March 2005, held in conjunction with the Cochrane Center Directors' and CCSG meetings. The USCC continues to maintain close relationships with the organizations represented by the members of the Advisory Board and continuously evaluates potential funding opportunities (see Appendix P for current list of USCC Advisory Board members). The USCC also worked closely with AHRQ and the NEI to ensure that mutual project goals were realized. The Center looks

forward to forging new relationships with the Centers for Disease Control and Prevention and Centers for Medicare and Medicaid Services by offering training workshops in 2006. These collaborations may result in the emergence of funding opportunities within these organizations once they gain a better understanding of the work of the USCC.

7.6.2 Ensure continuation of AHRQ funding

In 2005, the USCC continued to receive support from AHRQ through its conference grant. A continuation application for Year 04 of the Brown University AHRQ Large Conference Grant No. R13 HS13368-04 entitled "Training for US Cochrane Contributors and Others" was submitted in June 2005 and approved in September 2005. The Year 03 Annual Progress Report for the above grant was completed and submitted to AHRQ in June 2005.

7.6.3 Ensure continuation of NEI funding for programs to increase awareness of and involvement in evidence-based healthcare research among US eyes and vision specialists

A progress report on the activities of CEVG@US was submitted to NEI in April 2005 in fulfillment of the terms of a 7-year contract with that agency. The request to transfer funds from Brown University to the Johns Hopkins University served as the second semi-annual report. The aims of this contract are to develop a critical mass of US-based vision researchers and practitioners trained in preparing and using systematic reviews, as well as to increase awareness of evidence-based healthcare in vision-related healthcare as well as general healthcare.

7.6.4 Continue to identify new sources of funding for the ongoing development and for the development of the "new CENTRAL":

With the decision not to continue coordinating CENTRAL, the USCC will not seek additional funding for CENTRAL activities (see section 7.1).

7.6.5 Work with other Cochrane Centers in the US to identify sources of funding and to leverage our combined efforts to obtain funding

Identification of funding for US Centers is an ongoing task.

7.7. Target: Conduct research

7.7.1 Conduct methodological research in systematic reviews, trials registers, and meta-analysis

A core objective of the USCC is to conduct methodological research in systematic reviews, trials registers, and meta-analysis. Lack of funding specifically for research, and the need to

fulfill obligations related to current grants and contracts, limits the resources available to systematically develop a program of research. Presentations from research activities in 2005 included:

- Kay Dickersin and Susan Wieland presented “Insufficient Reporting and Indexing of Exposures Limit MEDLINE Searches for Observational Studies,” a poster, at the Society for Epidemiological Research-CESB Meeting. Toronto, Canada. June 27-30, 2005;
- Kay Dickersin and Yuan-I Min presented “Rate of full publication and time to publication,” a poster, at the Society for Epidemiological Research-CESB Meeting in Toronto, Canada. June 27-30, 2005;
- Roberta Scherer and Eric von Elm presented “Do clinical trials get published after presentation at biomedical meetings? A systematic review of follow-up studies.” 2005 Peer Review Congress, Chicago, Illinois, September 18, 2005;
- Kay Dickersin, Roberta Scherer, Yuan-I Min and Aynur Unalp-Arida presented “How does prior publication affect full publication of completed clinical trials?,” a poster, at the 2005 Peer Review Congress, Chicago, IL, September 17, 2005.
- Kay Dickersin, Roberta Scherer, Yuan-I Min and Aynur Unalp-Arida presented “Is publication bias associated with journal impact factor?,” a poster, at the 2005 Peer Review Congress, Chicago, IL, September 17, 2005;
- Kay Dickersin and Catherine Mansell presented “Rethinking publication bias: Developing a schema for classifying editorial discussion” at the 2005 Peer Review Congress, Chicago, IL, September 17, 2005;
- Roberta Scherer, Susan Brodney-Folse, and Christine Costantino co-authored “Identifying and classifying controlled trial reports: Development of a web-based course to teach handsearching,” a poster, at the 13th Annual Cochrane Colloquium in Melbourne; October, 2005.

The following manuscript was published in 2005:

- Wieland, S, Dickersin, K. Selective exposure reporting and MEDLINE indexing limited the search sensitivity for observational studies of the adverse effects of oral contraceptives. *J Clin Epidemiol.* 2005;58:560-567.

8. Update on US-based Cochrane Review Groups

8.1 Cochrane Eyes and Vision Group-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, UK and 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 provided funding to develop a critical mass of US-based individuals who would contribute to the CEVG in the US ("CEVG@US"). Roberta Scherer, PhD was awarded a subcontract from the NEI award to oversee and coordinate handsearching efforts for the CEVG@US. On October 1, 2005, the CEVG@US Project relocated from Brown University to The Johns Hopkins Bloomberg School of Public Health.

The CEVG prepares systematic reviews of interventions used to prevent or treat eye diseases and/or visual impairment. In 2005, the CEVG@US registered four review titles, submitted two protocols, published four protocols, and submitted two reviews which had at least one US author and published one update of a review. About 60% of all CEVG reviews are from the UK with Brazil and the USA producing the second and third largest number of reviews, respectively.

A web-based version of the handsearcher training course was released in 2003 to the public free of charge, and was revised in 2004 for extensive pilot testing. Version 2 of the online handsearcher course was released in February 2005 and updated in October 2005. Electronic and hand searches in 2005 identified 937 RCTs and 436 CCTs. These trials were submitted for inclusion in the CEVG specialized register, which contained 8,579 reports as of September 2, 2005. Citations to these trials were published in *Issue 1, 2006 of The Cochrane Library*.

The CEVG@US satellite has responsibility for hosting 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. Changes include new links from vision-based organizations (including the Association of Vision Science Librarians, the Institute for Ophthalmology, and the American Academy of Ophthalmology) to the website, 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.

The CEVG@US initiated a study in 2005 to identify the "unanswered research questions" or evidence gaps in the treatment of eye diseases to ensure that practice guidelines are unbiased and evidence-based. The objectives of the study are to describe the level of evidence used in formulating professional practice guidelines for the treatment of eye disease, document the availability of the highest level of evidence to support these guidelines, and identify the research

questions that still need to be addressed to allow unbiased decisions about treatments for eye disease. The study will result in a priority list of research questions to be addressed by Cochrane systematic reviews and/or new trials.

8.2 HIV/AIDS CRG

The Cochrane HIV/AIDS CRG was officially registered in March 1997, and has its editorial base at the University of California, San Francisco and a satellite editorial base at the South African Cochrane Centre, Cape Town. The Group's mission is to conduct systematic reviews of RCTs and other rigorous controlled studies with clinical, serologic, behavioral, economic and other outcomes on the prevention and treatment of HIV infection and AIDS. An affiliate of the International AIDS Society, the UCSF Institute for Global Health, and the UCSF AIDS Research Institute, the HIV/AIDS group is an international network of health care professionals, researchers, and consumers working to prepare, maintain, and disseminate systematic reviews on the prevention and treatment of HIV infection and AIDS.

The HIV/AIDS group produces systematic reviews in the four following areas of HIV/AIDS: Behavioral, Social, and Policy Prevention; Biomedical Prevention; Therapeutics, Diagnostics, and Prognostics; and Health Services and is in the process of re-establishing the Cochrane STD Group.

8.3 Prostatic Diseases and Urologic Cancers CRG

The Prostatic Diseases and Urologic Cancers CRG, registered on December 23, 1996, is dedicated to producing reviews of the best available evidence for interventions in the prevention, treatment and rehabilitation of benign and malignant prostate conditions (benign prostatic hyperplasia, prostate cancer, prostatitis) and urologic cancers (bladder, renal, testicular, penile, and urethral). Located at the Department of Veterans Affairs Medical Center in Minneapolis, Minnesota, the Group had 68 active members, including two consumers, in 2005. Seventeen members were from developing countries. Over the course of the year, this CRG published three new protocols, two new reviews, and listed nine review titles. Fifteen protocols and two reviews were in editorial process. To date, Prostatic Diseases and Urologic Cancers CRG has published 24 reviews and 13 protocols. The group's specialized register contained 3,227 studies. Information about the Prostatic Diseases and Urologic Cancers CRG can be obtained from the Review Group Coordinator, Roderick McDonald, at roderick.macdonald@med.va.gov.

8.4 Pain, Palliative, and Supportive Care CRG, Pain section (PaPas)

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 five 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. Dan Carr of the New England Medical Center in Boston, Massachusetts, is lead editor for the pain reviews, and Doug McCrory of the Duke University Center for Clinical Health Policy Research is lead editor for the headache pain reviews. In 2005, there were 512 active members of this group, five of whom were consumers and 14 of whom were from developing countries. In 2005, the PaPas CRG published eight new protocols, ten new reviews, and one substantive update to a review; 24 titles were registered. Seven draft protocols and five draft reviews were in the editorial process. The specialized register contained 26,143 studies. More information about PaPas can be found on its website, <http://www.jr2.ox.ac.uk/cochrane>.

9. Update on US-based Cochrane Fields

9.1 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 (CAM). 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 Field Administrator. The CAM Field's work is currently supported by a grant from the US NIH Center for Complementary and Alternative Medicine, awarded in 2003.

The CAM Field has been active in identifying, reviewing, and disseminating evidence on CAM therapies. The CAM Field staff dedicates much effort to preparing Cochrane reviews. For example Brian Berman and Eric Manheimer each co-authored a systematic review that was published on *The Cochrane Library* in the past year. The CAM Field also contributes to the development of the database of CAM-related reviews by awarding a bursary each year to authors of 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 reviewers; writing articles and book chapters about systematic reviews in CAM; and working with international research scholars at the CAM Field base, undertaking fellowships or sabbaticals with a focus on systematic reviews. Finally, the CAM Field facilitates Cochrane CAM review preparation by responding, on an *ad hoc* basis, to requests for peer reviewers from Coordinators of CRGs. The Field also maintains a register of CAM trials, which they submit regularly to CENTRAL. The Field's NIH 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 also dedicates extensive effort to further disseminating Cochrane CAM reviews to the CAM research and practice communities, as well as to the general public. The Field's columns in the journals *Explore* and the *Journal of Alternative and Complementary Medicine*, for example, are designed to promote the awareness of the Cochrane Collaboration and

to improve the understanding of randomized trial and systematic review methodology among CAM practitioners and researchers. The Field also works in collaboration with the Cochrane Consumer Network to effectively and efficiently communicate the message of Cochrane CAM Reviews to the general public, by producing streamlined and simplified summary overviews of these CAM-related reviews in lay language.

9.2 Health Care of Older People Field

The Health Care of Older People Field was re-established in August 2005. Leadership is shared by David J Stott and Peter Langhorne at the University of Glasgow, Gil Ramirez at Charles R Drew University of Medicine and Science, and Shelley de la Vega at the University of the Philippines. Field coordination is provided by David J Stott at the University of Glasgow. The Field is committed to improving the safety and effectiveness of care provided to aging men and women throughout the world by disseminating relevant Cochrane findings to users of such information: consumers, physicians, nurses, therapists, social workers, insurers, including public health officials and organizations that advocate on behalf of older adults.

9.3 Primary Health Care Field

The Primary Health Care Field was registered with the Cochrane Collaboration in 1993, with the aim of improving the safety and effectiveness of care provided by primary care practitioners by disseminating relevant Cochrane information to clinicians, consumers, and other interested parties. The scope of interests in the Primary Health Care Field includes the organization and provision of preventive and treatment services for both acute and chronic conditions within the community setting. The group works to ensure representation of primary care practice in Cochrane reviews, disseminate findings of Cochrane reviews to the primary care audience, and identify potential authors for systematic reviews of primary care-related topics. Additionally, the Field collects reports of RCTs and CCTs relevant to primary care for their specialized register.

9.4 Possible Behavioral Medicine Field

The application for the Cochrane Behavioral Medicine Field was completed and submitted to the Cochrane Collaboration in 2005. The goal of this Cochrane field is to increase and improve the evidence-base of behavioral medicine interventions through the facilitation of collaborations between behavioral medicine society affiliates and CRG affiliates. It is based in New York, at the Columbia College of Physicians and Surgeons, and convened by Karina Davidson, PhD. Other core staff include Kimberlee J. Trudeau, Ph.D., Field Administrator and Louise Falzon, TSC. 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, etc.) in a variety of settings for many of the conditions covered by CRGs.

Recent Field activities include the development of a website (www.cochranebehavmed.org) with a searchable database of behavioral medicine-specific citations (RCTs, systematic reviews), resources for systematic reviewers and others, a survey to join the Field, a survey to submit descriptions of work-in-progress for the database; the weekly *Behavioral Medicine Alert*, a digest of recent behavioral medicine citations; monthly *Update* emails (currently reaching over 160 individuals); systematic review-related workshops at Columbia University; and involvement of two volunteer hand searchers.

10. Update on US-based Methods Groups

10.1. Cochrane Screening and Diagnostic Tests Methods Group

The Cochrane Screening and Diagnostic Tests Methods Group is a fully operational Group dedicated to evaluating evidence of the reliability and validity of screening and diagnostic tests. In 2005, work continued on development of a Handbook, design of software that will be incorporated into RevMan, and development of the infrastructure for implementation of the Cochrane Diagnostic Reviews Handbook (CDR initiative). The steering group of the CDR initiative held regular conference calls through the year and met in person in Providence, RI in April 2005. Sessions to train reviewers in conducting reviews of diagnostic accuracy were held at the Melbourne Colloquium in October 2005. The Cochrane Screening and Diagnostic Tests Methods Group is co-convened by Constantine Gatsonis of Brown University and Jon Deeks of Oxford University.

11. Performance Targets

See Appendix O for the USCC performance targets for 2006.

12. USCC Contact Information, 2005

12.1. USCC, Baltimore, MD

Director, USCC: Kay Dickersin, PhD

Contact Person: Laura Coe, MPH
Coordinator, USCC
Brown University (to September 30, 2005)
Johns Hopkins Bloomberg School of Public Health (October 2005 - December 2005)
615 N. Wolfe Street, Box W5010
Baltimore, Maryland, USA 21205
Telephone: +1-410-502-4640
Fax: +1-410-502-4621
Email: uscc@jhsph.edu
Web page: <http://www.cochrane.us>

12.2. Boston Branch

Director: Joseph Lau, MD

Contact Person: Deirdre DeVine, MLitt
Coordinator, Boston Branch of the USCC
Division of Clinical Care Research
New England Medical Center, NEMC#63
750 Washington St
Boston, Massachusetts, USA 02111
Telephone: +1-617-636-5133
Fax: +1-617-636-8023
Email: ddevine1@tufts-nemc.org

12.3. 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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Suite 420
3333 California Street
San Francisco, California, USA 94118
Telephone: +1-415-476-4958
Fax: +1-415-502-8227
Email: campbelle@pharmacy.uscf.edu
Web page: <http://www.uscf.edu/sfcc>

13. Full and part-time staff at the USCC Offices in 2005

Director:	Kay Dickersin, PhD
Director, Boston Branch:	Joseph Lau, MD
Co-Directors, San Francisco Branch:	Lisa Bero, PhD Drummond Rennie, MD
Associate Director:	Suzanne Brodney-Folse, PhD (to 09/01/05) Roberta W. Scherer, PhD (from 10/01/05 to present)
Associate Director, Boston Branch:	Alexia Antczak-Bouckoms, DMD, Dsc
Coordinators:	Laura Coe, MPH Deirdre DeVine (Boston Branch) Erika Campbell (San Francisco Branch)
Coordinator, CENTRAL-Related Activities:	Elena Glatman, MA
CUE Coordinator:	Elizabeth McCurdy (01/03/05 to 9/30/05)

Systematic Reviewers: Joyce Coutu (3/10/03 to 9/01/05)
Tianjing Li
Swaroop Vedula

Handsearchers: 24 students (Providence)
2 students (Baltimore)

Specialized Register and *Master List*
Processors: Arisha Ashraf

Workshop Trainers: Laura Coe (Providence)
Kay Dickersin (Providence, Baltimore)
Suzanne Brodney-Folse (Providence)
Roberta W. Scherer (Baltimore)
Swaroop Vedula (Providence, Baltimore)
Susan Wieland, MPH (Providence)

14. Sources of funding and support

14.1. Contracts and grants

14.1.1 USCC Providence - 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

14.1.2 USCC Providence - Agency for Healthcare Research and Quality (AHRQ)

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

14.1.3 USCC Providence -Cochrane Collaboration Steering Group

Source: Cochrane Collaboration
Title: MEDLINE Retagging Project
PI: Kay Dickersin, PhD
Dates: January 1, 2005 - December 31, 2005
Funding: \$35,815
Specific Aims: To conduct and coordinate hand and electronic searches of health related literature to identify reports of RCTs and CCTs that are not already indexed as such on MEDLINE. The yield of searches is processed by the USCC and sent to NLM for indexing as PT RANDOMIZED CONTROLLED TRIAL or CONTROLLED CLINICAL TRIAL

14.1.4 USCC San Francisco Branch - None**14.1.5 USCC Boston Branch - None****14.2 Brown University Core Funding**

PI: Kay Dickersin
Dates: July 1, 2005 - September 30, 2005
Brown Ref: GIP Account
Funding: \$40,000
Specific Aims: To support personnel efforts and expenses of USCC

15. Acknowledgments

The USCC staff would like to thank 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 2005. Special thanks go to Dan Fox and other individuals who have contributed their time and expertise to the Advisory Group; faculty for one of our training programs; investigator on projects; consumer advocates involved in CUE; and members of the CCAG, the Cochrane TSCs, and contributors to CENTRAL. Each contribution is recognized and very much appreciated.

Appendix A

United States Cochrane Center Performance Targets for January 1, 2005 - December 31, 2005

- 1. Target:** Coordinate the development and maintenance of the Cochrane Central Register of Controlled Trials (CENTRAL)
- 1.1 Objective:** Perform and compile results of literature searches (MEDLINE search, handsearch results, and specialized register submissions).
- Action Items:**
- Receive and process submissions of handsearch results from Cochrane entities and submit to CENTRAL publisher [Anticipated Completion Date (ACD): Quarterly];
 - Receive and process submissions of specialized registers (SRs) from Cochrane entities and submit to CENTRAL publisher (ACD: Quarterly);
 - Perform quality control on electronic search results before submission to CENTRAL (ACD: 10/05);
 - Produce and disseminate on the US Cochrane Center web site a list of all SRs and handsearch submissions processed for CENTRAL (ACD: Quarterly).
- 1.2 Objective:** Coordinate, maintain, and regularly update the *Master List of Journals Being Searched (Master List)*.
- Action Items:**
- Maintain *Master List* through annual update mailing (ACD: Annually in March).
- 1.3 Objective:** Serve as coordinating group for the CENTRAL Advisory Group (CCAG) activities. This involves planning meetings and phone calls, preparing and distributing summary and transcribed minutes, maintaining the CCAG email discussion list, and preparing and disseminating CENTRAL and CCAG related materials.
- Action Items:**
- Convene annual meeting of CCAG at the 2005 Cochrane Colloquium (ACD: 10/05);
 - Distribute to the CCAG list the final minutes for the 2005 Colloquium meeting of the CCAG (ACD: 12/05);
 - Convene and produce minutes for CCAG conference calls (ACD: 1-2 times annually);

Performance Targets for January 1 - December 31, 2005 (cont'd)

- Produce documents required for CCAG reporting to Steering Group (ACD: Twice annually) ;
- Decide on how to proceed with stored paper copies of old handsearch results to facilitate retrieval of lost records (ACD: Ongoing).

1.4 Objective:

In collaboration with the CCAG, Collaborative Review Group (CRG) Coordinators, the Information Management System Group (IMSG), Trials Search Coordinators (TSCs), the United Kingdom Cochrane Center (UKCC), Update Software and Wiley InterScience, prepare for the development of the “new CENTRAL”.

Action Items:

- Pilot tests are required of the following processes:
 - EMBASE and LILACS downloads (ACD: 6/05),
 - repopulating SRs with “clean” data (ACD: Ongoing).
- Develop survey to TSCs to learn which fields are included in their SRs;
- Decide upon a final set of fields to include in CENTRAL for the new generation of *The Cochrane Library* software (ACD: Ongoing - being discussed by CCAG);
- Develop systems for record coding on CENTRAL to enable searching specifically for records not yet included in any Review Group’s SR (ACD: To be determined by CCAG);
- Develop systems for insuring upload to CENTRAL of the 755 remaining lost handsearch results (ACD: Ongoing);
- Develop plans to register unpublished trials on CENTRAL or elsewhere (ACD: To be determined by CCAG);
- Work with Update Software and CCAG to locate 755 remaining lost records (ACD: 9/05);
- > • Develop systems and rules for publishing references of ongoing and unpublished trials (ACD: To be determined by CCAG);
- Create a database list of updated journal names (each journal with its own table of information) (ACD: Ongoing);
- Establish systems for quality checking handsearch submissions from non-English language journals (ACD: Ongoing).

Performance Targets for January 1 - December 31, 2005 (cont'd)

2. Target: Work with National Library of Medicine (NLM) to ensure that controlled trials included on MEDLINE are appropriately indexed as publication type CONTROLLED CLINICAL TRIAL (CCT) or RANDOMIZED CONTROLLED TRIAL (RCT) (MEDLINE Retagging Project).

2.1 Objective: Receive, process, and quality check submissions of handsearch results from Cochrane entities, perform electronic search on MEDLINE, and submit the results to NLM.

- Action Items:**
- Complete the 2004 search of MEDLINE using Phases I and II of the Cochrane Highly Sensitive Search Strategy (HSSS) (ACD: 7/05);
 - Review search results and identify unindexed reports of RCTs and CCTs (ACD: 9/05);
 - Complete quality control of the results from electronic search (ACD: 10/05);
 - Quality check handsearch results and submit for MEDLINE retagging (ACD: Once each year);
 - Submit file of unindexed reports of RCTs and CCTs to NLM for retagging (ACD: Ongoing);
 - Phase I, 2001 - 2004 titles without abstracts to identify potential trials (ACD: Ongoing).

3. Target: Provide training and support for reviewers, Review Group Coordinators (RGCs), Trial Search Coordinators (TSCs), editors, handsearchers, and consumers. In addition, provide training and support for others responsible for training activities.

3.1 Objective: Maintain, revise and distribute on the worldwide web and elsewhere guides for Cochrane procedures.

- Action Items:**
- Distribute and maintain on the web and elsewhere a *Guide for Submission of Specialized Registers to CENTRAL*, to assist RGCs/TSCs and others in submitting their specialized registers to CENTRAL (ACD: Ongoing);
 - Distribute and maintain on the web and elsewhere a *Guide for Submission of Handsearch Results to CENTRAL*, to assist RGCs/TSCs and others in submitting their handsearch results to CENTRAL (ACD: Ongoing);
 - Revise as needed, distribute and maintain the *CENTRAL Management Plan* (ACD: Ongoing);

Performance Targets for January 1 - December 31, 2005 (cont'd)

- Revise as needed, *Locating and Selecting Studies*, Chapter Five of the *Cochrane Reviewer's Handbook* (ACD: Ongoing);
- Maintain help file for TSCs at <http://www.cochrane.us> (ACD: Ongoing).

3.2 Objective: Develop and facilitate Cochrane training workshops and courses.

- Action Items:**
- Provide register and handsearch submission training for TSCs, RGCs, and others, at the 2005 Colloquium and other opportunities, as requested (ACD: 10/05);
 - Develop and facilitate one workshop at the Colloquium on handsearching the healthcare literature for trial reports (ACD: 10/05);
 - Develop and facilitate one workshop at the 2005 Colloquium on train-the-trainer (ACD: 10/05);
 - Maintain a web-based distance education handsearching course (ACD: Ongoing);
 - Maintain the permissions for the Cochrane Handsearcher Training Manual (ACD: Ongoing);
 - Develop and maintain a web-based distance education peer review course (ACD: Ongoing);
 - Develop and maintain a web-based distance education consumer course (ACD: Ongoing);
 - Through both the dissemination of the Handsearcher Training Manual and the provision of the handsearching workshops, train 50 individuals to handsearch the medical literature (ACD: 12/05);
 - Facilitate one workshop in peer review for 2005 (ACD: 4/05);
 - Facilitate two systematic review training workshops for 2005 (ACD: 7/05);
 - Provide one critical appraisal for healthcare professionals workshop (ACD: 10/05);
 - Develop and facilitate one workshop with US consumer advocates on ways to disseminate information on evidence-based healthcare to consumers of healthcare in the US (ACD: 9/05).

Performance Targets for January 1 - December 31, 2005 (cont'd)

- 3.3 Objective:** Provide ongoing support and training through individual contacts, email discussion lists, and directories.
- Action Items:**
- Support communication on the development and maintenance of CENTRAL through maintenance of TSCS' e-mail discussion list (ACD: Ongoing);
 - Support communication and collaboration among TSCS and Centers through the updating and regular distribution of *The Cochrane Collaboration Directory of Trial Search Coordinators (TSCS) and Contact People at Centers* (ACD: Ongoing);
 - Provide mentoring and methodological consultation to individual Cochrane collaborators throughout the year (ACD: Ongoing);
 - Train health professionals, the media, and consumers to use *The Cochrane Library* (ACD: Ongoing).
- 4. Target:** **Promote awareness of The Cochrane Collaboration and access to Cochrane products.**
- 4.1 Objective:** Ensure that individuals (including 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 and consumers, whenever relevant.
- Action Items:**
- Make international and national or local presentations about The Cochrane Collaboration and distribute informational materials to interested parties (ACD: 9/05);
 - Conduct a one-day conference for policy makers on The Cochrane Collaboration and evidence-based healthcare in conjunction with the Cochrane leadership mid-year meetings (3/05).
- 4.2 Objective:** Work to ensure that *The Cochrane Library* is made available and accessible to all regional institutions and government agencies.
- Action Items:**
- Participate in conference calls with the North American Cochrane Center Group of Wiley InterScience (Wiley) as needed (ACD: Ongoing);
 - Promote *The Cochrane Library* in presentations, workshops, meetings and distribute promotional materials to participants (ACD: Ongoing).
- 4.3 Objective:** Encourage institutions and colleagues [e.g., National Institutes of Health (NIH), professional review organizations, health departments, university libraries] to expand subscriptions to Cochrane products.

Performance Targets for January 1 - December 31, 2005 (cont'd)

- Action Items:**
- Negotiate with Wiley free trial access for the members of the USCC Consumer Coalition (ACD: Ongoing).
- 4.4 Objective:** Encourage news media to subscribe to and use *The Cochrane Library*.
- Action Items:**
- Log media contacts (ACD: Ongoing);
 - Monitor media mentions of The Cochrane Collaboration in English language news sources (ACD: Ongoing).
- 4.5 Objective:** Work with physicians, consumers, government, and others to identify ways in which Cochrane reviews can better meet their needs.
- Action Items:**
- Address this topic at meetings, workshops and presentations to gather information (ACD: Ongoing).
- 4.6 Objective:** Act as facilitators, when requested, to aid in the listing and indexing of Cochrane reviews and other products in electronic publications and databases (e.g., indexing of Cochrane reviews in MEDLINE).
- Action Items:**
- Provide assistance to facilitate the process of indexing, if needed (ACD: Ongoing).
- 4.7 Objective:** Maintain and expand the USCC's web presence.
- Action Items:**
- Track hits to the site (ACD: Ongoing);
 - Develop strategies to improve layout, format, navigation and overall design (ACD: Ongoing);
 - Update and revise content (ACD: Ongoing).
- 5. Target:** **Perform USCC administrative functions.**
- 5.1 Objective:** Perform handsearching of US medical journals and conference proceedings.
- Action Item**
- Search 50 journal-years and perform a quality check on search results (ACD: Ongoing).
- 5.2 Objective:** Participate in annual meetings at the 2005 Melbourne Colloquium **(The ACD for all Action Items listed below is 10/05).**
- Action Items:**
- Host US Cochrane Contributors' meeting;

Performance Targets for January 1 - December 31, 2005 (cont'd)

- Participate the Meet the Entities exchange;
- Participate in the Cochrane Center Staff meeting;
- Participate in the Center Director meeting;
- Participate in the Steering Group meeting (as requested);
- Administer the Thomas C. Chalmers, MD Award.

5.3 Objective: Perform general Center administrative functions.

- Action Items:**
- Develop and maintain a US Cochrane contributors' database of postal and email addresses and update twice yearly (ACD: Ongoing);
 - Host the mid-year meetings of the Steering Group and Center Directors' Meetings at Brown University in Providence, Rhode Island (ACD: 3/05);
 - Participate in mid-year Steering Group and Center Directors' Meetings (ACD: 3/05);
 - Monitor and respond to all requests for information about The Cochrane Collaboration and Cochrane related products (ACD: Ongoing);
 - Maintain up-to-date USCC Task List (ACD: Ongoing);
 - Revise and reformat USCC Handbook (ACD: Ongoing);
 - Hold a USCC Advisory Board meeting (ACD: 3/05);

6. Target: **Seek and obtain funding support for USCC activities.**

6.1 Objective: Ensure continuation of the MEDLINE Retagging Project funding from NLM to ensure that all controlled trials on MEDLINE are indexed appropriately on MEDLINE and included in CENTRAL.

- Action Items:**
- Submit a request for funding to the CCSG to continue the MEDLINE Retagging Project (ACD: 9/05).

6.2 Objective: Continue working with other funding agencies (e.g., Agency for Healthcare Research and Quality, Milbank Memorial Fund) that have contributed funding to the Baltimore Cochrane Center or NECC in the past, as well as the Cochrane Steering Group.

Performance Targets for January 1 - December 31, 2005 (cont'd)

- Action Items:**
- Raise funds for consumers to attend the 2005 Cochrane Colloquium (ACD: 9/05).
- 6.3 Objective:** Ensure continuation of AHRQ funding.
- Action Items:**
- Submit continuation application to AHRQ (ACD: 7/05);
 - Provide documentation and reports to AHRQ as required (ACD: Ongoing).
- 6.4 Objective:** Ensure continuation of NEI funding for programs to increase awareness of and involvement in evidence-based healthcare research among US eyes and vision specialists.
- Action Items:**
- Provide documentation and reports to NEI as required (ACD: 5/05 and 10/05, twice a year).
- 6.5 Objective:** Continue to identify new sources of funding for the continuation of CENTRAL and development of the “new CENTRAL”.
- Action Items:**
- Submit a request to CCSG for funding (ACD: 9/05).
- 6.6 Objective:** Work with other Cochrane Centers in the US to identify sources of funding and to leverage our combined efforts to obtain funding.
- Action Items:** Provide grant writing assistance and informal training to US contributors and entity members, as needed (ACD: Ongoing).
- 7. Target:** **Conduct research**
- 7.1 Objective:** Conduct methodological research in systematic reviews, trials registers, and meta-analysis.
- Action Items:**
- Submit poster presentations to the 2005 Cochrane Colloquium (ACD: 10/05);
 - Submit papers for publication describing research and other work related to The Cochrane Collaboration (ACD: Ongoing);
 - Develop protocol for a project that compares handsearching the paper version of a journal with the online version of the same journal (ACD: Ongoing).
-

Appendix B

Submissions to NLM in 2005 (reports published in 1966-2004)

Cochrane Group	RCTs	CCTs	TOTAL
Hand Search Results			
Airways Group	14	4	18
Australasian Cochrane Center	0	0	0
Breast Cancer Group	14	3	17
Canadian Cochrane Center	0	0	0
Cancer Network	0	0	0
Colorectal Cancer Group	0	0	0
Cystic Fibrosis and Genetic Disorders Group	0	0	0
Depression, Anxiety and Neurosis Group	16	28	44
Dutch Cochrane Center	0	0	0
Eyes and Vision Group	84	79	163
German Cochrane Center	128	88	216
Gynecology	5	0	5
Gynaecological Cancer	12	2	14
Health promotion	11	2	13
Hepato-Biliary Group	6	2	8
Inflammatory Bowel Disease Group	16	0	16
Neonatal Group	60	23	83
Neurological Network	0	0	0
Neuromuscular Disease Group	0	0	0
Nordic Cochrane Center	0	0	0
Peripheral Vascular Disease Group	0	0	0
Rehabilitation and Related Therapies Field	5	1	6
Skin Group	0	0	0
UK Cochrane Center	738	7	745
US Cochrane Center	0	0	0
Vaccines	17	5	22
Total Hand Search	1,126	244	1,370
Electronic Search Results			
US Cochrane Center			
Total Electronic Search	1,050	513	1,563
Total Submission	2,176	757	2,933

Appendix C
1994–2005 MEDLINE Retagging Submissions to The National Library of Medicine (NLM)

Publication and Search Type	Year of Submission to NLM ¹												
	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	Totals
RCTs²													
Handsearch	115	6,904	6,045	4,131	1,225	2,472	3,635	4,878	1,219	400	305	1,126	32,455
Electronic Search	19,496	5,502	345	4,685	973	853	540	669	1,263	1,280	1,357	1,050	38,013
CCTs³													
Handsearch	144	2,939	2,453	1,922	928	1,497	1,682	1,342	906	146	110	244	14,313
Electronic Search	2	8,611	18,243	5,781	3,129	1,268	524	364	413	580	670	513	40,098
Totals													
Handsearch	259	9,843	8,498	6,053	2,154	3,969	5,317	6,220	2,125	546	415	1,370	46,768
Electronic Search	19,498	14,113	18,588	10,466	4,102	2,121	1,064	1,033	1,676	1,860	2,027	1,563	78,111
Total Submitted by USCC⁴	19,757	23,956	27,086	16,519	6,256	6,090	6,381	7,253	3,801	2,406	2,442	2,933	124,879

¹ Includes citations identified through searches received in the first round of submissions January 1 - X 31, 2005.

² RCT = RANDOMIZED CONTROLLED TRIAL [Publication Type]

³ CCT = CONTROLLED CLINICAL TRIAL [Publication Type]

⁴ USCC = United States Cochrane Center

Appendix D

Description of Web-based Course Handsearching - Identifying and Classifying Controlled Trial Reports

A. Team Members:

- Faculty (Kay Dickersin, Roberta Scherer)
- Project Manager (Suzanne Brodney Folse (to September 2005), Roberta Scherer (from October 2005 to present))
- Instructional Designer (Bryce Myers, Dan Schwartz)
- Web Developer (Maggie Friedfeld (to September 2004), Sue Baumes, Christine Costantino)
- Administrator/Coordinator (Joyce Coutu)
- Administrative Assistant (Darlene Wood, Heidi Kelleher)
- Handsearching Experts (Susan Wieland, Elena Glatman, Swaroop Vedula, Roberta Scherer)
- Research/Content Assistant (Arisha Ashraf)
- Student/Staff Reviewers for Pilot Study

B. Syllabus

This course is divided into modules. The approximate time it will take to complete each part of the course is noted after the module title.

B.1. Module 1: Why is Handsearching Important? (15 minutes)

Describes the rationale for the creation of the Cochrane Collaboration and the development of the Cochrane CENTRAL Register of Controlled Trials ("CENTRAL" for short), the Cochrane Collaboration's source of trial reports, and introduces the Cochrane Collaboration classifications of trials eligible for inclusion in CENTRAL.

B.2. Module 2: Steps to Successful Handsearching (1 hour total. Each step with corresponding quiz, 10 minutes each)

Describes where in journal articles the information needed for identification and classification of trial reports may be found, and outlines the step-by-step decision making necessary in identification and classification for trial reports eligible for CENTRAL.

B.3. Assessments

Assessments are intended for users who have read through both course modules and have successfully completed the quizzes within them.

Self-Assessment with Abstract Examples (90 minutes)

Provides a self-assessment exercise in identifying and classifying trial reports eligible for CENTRAL from abstracts.

Handsearching - Identifying and Classifying Controlled Trial Reports (cont'd)

B.3.1 Self-Assessment with Journal Article Examples (2 hours)

Provides a self-assessment exercise in identifying and classifying trial reports eligible for CENTRAL from full-text examples.

B.3.2 Handsearching Test (6-12 hours)

Tests the trainees ability to identify and classify trial reports eligible for CENTRAL by handsearching a full issue of a journal.

B.4. Glossary & Resources

Defines terms relevant to the course modules and includes references to websites for additional information and study. Entries derived from:

- Cooper, Harris M. and Hedges, Larry V., (Eds). *The Handbook of Research Synthesis*. New York: Russell Sage Foundation, 1994.
 - Last, John M., *A Dictionary of Epidemiology*. 2nd Edition, New York: Oxford University Press, 1988.
 - Meinert, Curtis L., *Clinical Trials Design, Conduct, and Analysis*. New York: Oxford University Press, 1986.
 - *The Cochrane Reviewers' Handbook*, v. 4.2.5, May 2005.
<http://www.cochrane.org/resources/handbook/index.htm>
-

Appendix E

Description of Web-based Course Translating Critical Appraisal of a Manuscript into Meaningful Peer Review

A web-based version of the Cochrane Eyes and Vision Group's review course is under development and will be launched for pilot testing in Spring 2007. The web-based course will replace the in-person workshop we offered through 2005. We would like to test the effectiveness of the course in the context of a randomized trial and will consider seeking funding, after the web-based course has been pilot-tested and revised. The target audience for the course includes ophthalmologists, optometrists, and other vision practitioners 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.

The activities proposed for the web-based course are similar to those used for the in-person workshop. Both require the participant to read the original submission of the two manuscripts, write the manuscript critiques with comments for the editor and author, and discuss the critiques and recommendations in a small group setting. The course will also incorporate material to assist students using online learning for the first time. Students will be provided with instructions to configure their computers, navigate within the Training Management System (TRAMS) platform, obtain and submit assignments online, and participate in online discussions.

The web-based course includes 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 faculty.

Appendix F

Description of Web-based course

Critical appraisal skills for consumers: Understanding the evidence using an online course on Evidence-based Healthcare for Consumer Advocates

Facilitator(s): Kay Dickersin, Maryann Napoli, Musa Mayer, and Marianne Hamilton

Consumers are bombarded with healthcare information from the print media, TV, radio, Internet and from their doctors. Interpreting the accuracy and validity of information is often difficult, as reports can be conflicting and evidence may seem to change over time. The United States Cochrane Center (USCC) and Consumers United for Evidence-based Healthcare (CUE) have developed a web-based course on evidence-based healthcare and critical appraisal skills for consumer advocates.

The course will introduce a web-based course for consumer advocates on evidence-based healthcare and critical appraisal skills that will be offered free-of-charge. The workshop will be an opportunity for the USCC and CUE to obtain feedback from Cochrane contributors.

Consumers are bombarded with healthcare information from the print media, TV, radio, internet and from their doctors. Interpreting the accuracy and validity of information is often difficult, as reports can be conflicting and evidence may seem to change over time. The United States Cochrane Center (USCC) and Consumers United for Evidence-based Healthcare (CUE) have developed a web-based course on evidence-based healthcare and critical appraisal skills for consumer advocates. At the conclusion of the online course, participants will be able to:

1. Understand what evidence-based healthcare is and how they can use it to inform their own healthcare decisions;
 2. Find reliable sources of evidence-based information;
 3. Critically appraise information found in clinical guidelines, healthcare web sites, the lay news media, and journal articles (primary research and systematic reviews).
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Appendix G

Methodological Support Provided to Review Authors by the US Cochrane Center, 2005

This table lists the reviewers who requested technical or other assistance with the preparation of his or her Cochrane systematic review.

Reviewer	Review Title
Len Levin, MD, PhD <i>University of Wisconsin</i>	Drug treatment for giant cell arteritis
Eydie Miller-Ellis, MD <i>Scheie Eye Institute, University of Pennsylvania</i>	Interventions for acute angle closure glaucoma
Adla Angelina, MD <i>University of Colorado at Denver Health Sciences Center</i>	Autologous serum for xerophthalmia/dry eyes
Kanchan Ramchand, MD <i>Massachusetts Eye and Ear Infirmary</i>	Surgical interventions for simple retinal detachments
Dayse Figueiredo Sena, MD <i>Massachusetts Eye and Ear Infirmary</i>	Neuroprotection for treatment and prevention of glaucoma
Aravind Reddy <i>United Kingdom</i>	Iridectomy for narrow angles for prevention of primary angle closure glaucoma
Kate Shotten <i>Royal Victoria Infirmary</i>	Conventional occlusion versus pharmacologic penalization for amblyopia
Simon Law, MD <i>University of California, Los Angeles</i>	Acupuncture for glaucoma
Kimberly Miller <i>Brown University</i>	Interventions for blepharitis
Rajesh Shetty, MD <i>Mayo Clinic, Jacksonville</i>	Peripheral iridotomy for pigmentary glaucoma
Prithvi Sankar, MD <i>Scheie Eye Institute, University of Pennsylvania</i>	Interventions for chronic angle closure glaucoma
Gina Sleilati, MD <i>Henry Ford Hospital, Department of Endocrinology and Metabolism</i>	Blood pressure control in the management of diabetic retinopathy

Methodological Support Provided to Review Authors, 2005 (cont'd)

Reviewer	Review Title
Donald Grover, MD <i>University of Rochester Eye Institute</i>	Intravitreal steroids for macular edema in diabetes
Howard Savage, MD <i>George Washington University</i>	Medical interventions for traumatic hyphema
Magda Krzystolik, MD <i>Brown University</i>	Anti VegF for age-related macular degeneration
Xuanping Zhang, PhD <i>Oregon State University</i>	Interventions for screening for diabetic retinopathy
Arthur Geltzer, MD <i>Brown University</i>	Surgical implantation of steroids with antiangiogenic characteristics for treating exudative macular degeneration
Suzanne Brodney Folse, PhD <i>USCC</i>	Corticosteroids for treating optic neuritis
Milan Mathew, MD, MPH <i>Brown University</i>	Antioxidant supplementation for preventing and slowing the progression of age-related cataract
Roy Chuck, MD <i>Wilmer Eye Institute, Johns Hopkins School of Medicine</i>	Topical corticosteroids as adjunctive therapy for bacterial keratitis
Don Minckler, MD <i>University of California Irvine</i>	Aqueous shunts for glaucoma
Usha Reddy Magda Krzystolik, MD <i>Brown University</i>	Interferon for age-related macular degeneration
Aileen Antonia-Santos, MD, PhD <i>Michigan State University</i>	Interventions for stimulus deprivation amblyopia
David Friedman, MD, MPH <i>Wilmer Eye Institute, Johns Hopkins School of Medicine</i>	Lens extraction versus laser peripheral iridotomy for angle closure glaucoma
Charles Wilkinson, MD <i>Greater Baltimore Medical Center</i>	Interventions for asymptomatic retinal lattice breaks and lattice degeneration for preventing retinal detachment

Methodological Support Provided to Review Authors, 2005 (cont'd)

Reviewer	Review Title
Eric Manheimer, MS <i>University of Maryland School of Medicine</i>	Surgery for non-arteritic anterior ischemic optic neuropathy
Kirk Wilhelmus, MD <i>Cullen Eye Institute, Baylor College of Medicine</i>	Interventions for herpes simplex virus epithelial keratitis

Review author mini sabbaticals, 2005

This table lists the names of individuals who spent time at the US Cochrane Center working on his or her review.

Reviewer	Review Title
Jeffrey Walline, OD, PhD and Donald Mutti, OD, PhD <i>Ohio State University College of Optometry</i>	Interventions for slowing myopia progression in children
Aileen Antonia-Santos, MD, PhD <i>Michigan State University</i>	Interventions for stimulus deprivation amblyopia
Usha Reddy <i>Brown University</i>	Interferon for age-related macular degeneration
Vimal Kapoor <i>Dalhousie University Faculty of Medicine</i>	Interventions for preventing ophthalmia neonatorum

Appendix H

USCC Staff Presentations January 1, 2005 to December 31, 2005

Kay Dickersin's presentations

1. The ethics of research in advocacy. Sarah Lawrence Health Advocates in Research Conference. Bronxville, N.Y. January 13-14, 2005.
2. Towards global registration of clinical trials. European Clinical Research Infrastructure Network. Brussels, Belgium. February 14, 2005.
3. Clinical trial design and small studies: A coordinating center perspective. Uterine Leiomyoma. Food and Drug Administration/National Institutes of Health. Washington, DC. February 25, 2005.
4. The systematic review as a research tool. Symposium on Systematic Reviews in Dental and Craniofacial Research. International Association for Dental Research. Baltimore, Md. March 12, 2005.
5. Getting the big picture. Association of Health Care Journalists. 6th National Conference. Chapel Hill, NC. April 3, 2005.
6. Why we need uniform, comprehensive, registration of clinical trials. Annual Meeting of the Pediatric Academic Societies. Washington, DC. May 15, 2005.
7. The basic science of systematic reviews. Cochrane Symposium. American Gastroenterological Association. Digestive Diseases Week. Chicago, Ill. May 16, 2005.
8. Epidemiology methods: Screening. Project LEAD: Refresher and What's New in the Field. National Breast Cancer Coalition Annual Advocacy Conference. Washington, DC. May 21, 2005.
9. Why we need a comprehensive register of clinical trials. Breast Cancer Research: Your Tax Dollars – Who Benefits? National Breast Cancer Coalition Annual Advocacy Conference. Washington, DC. May 21, 2005.
10. Constructing an Internet training course for multicenter clinical trials (workshop). 26th Annual Meeting of the Society for Clinical Trials. Portland, Or. May 22, 2005.
11. Forum on making/influencing public policy. 26th Annual Meeting of the Society for Clinical Trials. Portland, Or. May 24, 2005.
12. How do we investigate the effect of a risk factor on breast cancer? Era of Hope. Department of Defense Breast Cancer Research Program Meeting. Philadelphia, Pa. June 9, 2005.
13. Rationale for updating QUOROM. Presentation to QUOROM Group. Ottawa, Canada. June 2, 2005.
14. The Cochrane Collaboration. Evidence-based medicine: What is it, and what can it do for you? Medicine and the Media. Bethesda, Md. June 26, 2005.
15. Clinical trials registration: Overdue and still elusive. Bloomberg School of Public Health Johns Hopkins University. Baltimore, Md. July 1, 2005.
16. Clinical trials registration: Overdue and still elusive. Rocky Mountain Workshop on Evidence-based Healthcare. Keystone, Co. August 2, 2005.

17. A little bit about evidence, including some stuff that maybe you didn't know you should ask. Rocky Mountain Workshop on Evidence-based Healthcare. Keystone, Co. August 2, 2005.
18. The Cochrane Collaboration and Cochrane reviews. Workshop on Developing Evidence-based Guidelines. The Cystic Fibrosis Foundation. Columbia, Md. August 18, 2005.
19. Rethinking publication bias: Developing a schema for classifying editorial discussion. International Congress on Peer Review and Biomedical Publication. Chicago, Ill. Sept 17, 2005.
20. How does prior publication affect full publication of completed clinical trials? 2005 Peer Review Congress, Chicago, Il, September 17, 2005
21. Supporting the review process with study-based registers. A vision for the Cochrane Collaboration. XIII Cochrane Colloquium. Melbourne Australia. October 26, 2005.
22. Developing evidence-based guidelines in vision care: Can the promise become the practice? Monroe J. Hirsch Memorial Research Symposium. American Academy of Optometry. San Diego, Ca. December 11, 2005.

Roberta Scherer's presentations

1. Do clinical trials get published after presentation at biomedical meetings? A systematic review of follow-up studies. 2005 Peer Review Congress, Chicago, Illinois, September 18, 2005.

Suzanne Brodney Folse's presentations

1. Critical appraisal of a Cochrane systematic review and randomized trial. Retina Journal Club. Rhode Island Hospital and Brown Medical School, Providence, RI. January 13 and 27, 2005.
2. The Cochrane Collaboration: What is it? How can its work be useful to you? Center for Gerontology and Health Care Research. Brown University. Providence, RI. January 18, 2005.

Laura Coe's presentations

1. Evidence-based Healthcare and Critical Appraisal for Consumer Advocates presented at a one day meeting, "Evidence-based healthcare and critical appraisal for consumer advocates" for the North American Health Sciences Librarians, Providence, RI, September 27, 2005.

Posters

1. Wieland S, Dickersin K. Insufficient Reporting and Indexing of Exposures Limit MEDLINE Searches for Observational Studies Society for Epidemiological Research-CESB Meeting. Toronto, Canada. June 27-30, 2005.
2. Min Y-I, Dickersin K. Rate of full publication and time to publication. Society for Epidemiological Research-CESB Meeting. Toronto, Canada. June 27-30, 2005.
3. Min Y-I, Unalp-Arida A, Scherer R, Dickersin K. Is publication bias associated with journal

- impact factor? 2005 Peer Review Congress, Chicago, Il, September 17, 2005.
4. Min Y-I, Unalp-Arida A, Scherer R, Dickersin K. How does prior publication affect full publication of completed clinical trials? 2005 Peer Review Congress, Chicago, Il, September 17, 2005
 5. Scherer R, Brodney Folse S, Costantino C. Training handsearchers: going from a paper to a web-based course. In: Proceedings of the 13th Cochrane Colloquium, Melbourne, Australia, October 25, 2005.
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Appendix I

Joint Meeting of the Steering Group, Center Directors and the USCC Advisory Board

Brown University, Providence, Rhode Island

March 30-31, 2005

Agenda

Wednesday, March 30th

6:00 pm **Reception**-The Ballroom at the Hope Club (directions attached)

7:00 pm **Dinner**

Welcome

Kay Dickersin, Director, US Cochrane Center

Purpose of the meeting

Daniel M. Fox, President, Milbank Memorial Fund

Introductions of participants: Each participant should be prepared to offer one example of his or her experience of the use of a systematic review to inform policy or practice.

James Neilson, Chair, Steering Group

Thursday, March 31st

7:30 am **Continental Breakfast**- McKinney Room at the Watson Institute, Brown University (directions attached)

8:30 am Who uses Cochrane Reviews? How do leaders of the Collaboration convert demand for reviews into funding?

10:30 am **Break**

10:45 am How do Cochrane Centers use advisory groups and other stakeholders to stimulate the use of reviews to inform policy and practice and to leverage funding for core support?

12:00 pm **Lunch:** Discussion continues

1:00 pm What strategies to promote Cochrane have been most effective and how can these strategies be adapted to circumstances in other countries?

Joint Meeting of the Steering Group, Center Directors and the USCC Advisory Board (cont'd)

2:15 pm What have US reviewers and members of the USCC Advisory Board learned from this meeting?

3:00 pm Summary and next steps

Adjourn



Appendix J

**United States Cochrane Center Consumer Coalition Conference
Creating Alliances: Consumers and Evidence-based Healthcare
Brown University, Providence, RI
March 30 - April 1, 2005**

AGENDA

Wednesday, March 30, 2005

- 4:00 pm** **Registration** - The Library at the Watson Institute, Brown University (directions attached)
- 4:10 pm** **Preparation for conference and annual meeting**
Facilitator: Ngina Lythcott
- 4:10 pm** *Welcome and introductions* - Elizabeth McCurdy
4:15 pm *Overview: agenda for the conference* - Joy Simha
- 4:30 pm** **Dress rehearsal for March 31: PowerPoint presentations**
- 5:30 pm** **Adjourn**
- 6:00 pm** **Reception** - Hope Club, Brown University (directions attached)
- 7:00 pm** **Dinner** - Hope Club

Thursday, March 31, 2005

- 7:30 am** **Registration and continental breakfast** - The Library at the Watson Institute (directions enclosed)
- 8:30 am** **Getting to know the details: The Cochrane Collaboration**
Facilitator: Sallie Bernard
- 8:35 am** *Whirlwind tour of the Collaboration and its history* - Jim Neilson
- 8:50 am** *The Collaboration and consumers: past, present...*
Liz Whamond - how the CCNet has evolved
- 9:05 am** *The Collaboration and Consumers: ...and future*
Janet Wale - summaries for Cochrane reviews

- 9:15 am** *Discussion*
- 9:30 am** **Mini workshop on evidence-based healthcare (EBHC)**
Facilitator: Ann Fonfa
- 9:35 am** *EBHC: an overview*
Sally Green
- 9:55 am** *EBHC and critical appraisal: an example*
Rob Scholten
- 10:15 am** *Discussion*
- 10:30 am** **Break**
- 10:45 am** **Navigating *The Cochrane Library*: a hands on tutorial - Computer Information Systems Building - Room 265, Brown University (directions enclosed)**
Facilitator: Joy Simha
- Deborah Pentesco-Gilbert
 Jordi Pardo
- 11:45 am** *Discussion*
- 12:00 pm** **Lunch**
- 12:45 pm** **EBHC and consumer advocacy in the United States - Joukowsky Forum Room at the Watson Institute (2 minute presentations by Consumer Coalition members, discussion at the end)**
Welcome: Joy Simha
Facilitator: Elizabeth McCurdy
- 12:50 pm** *Sallie Bernard*
Co-founder and Executive Director, SafeMinds
- Zobeida Bonilla*
 Program Manager, Latina Health Initiative, Our Bodies Ourselves
- Rebecca Burkholder*

Director of Health Policy, National Consumers League

Carol Sakala
Maternity Center Association

Ann Fonfa
Founder, The Annie Appleseed Project

Annette Bar-Cohen
National Breast Cancer Coalition

Ngina Lythcott
Breast Cancer Liaison, National Black Women's Health Imperative; Vice Dean
and Dean of Students, Columbia University, Mailman School of Public Health

Marlene McCarthy
Co-founder and Chair, Rhode Island Breast Cancer Coalition

Maryann Napoli
Associate Director and Co-founder, Center for Medical Consumers

Barbara Warren
National Association for Gay, Bisexual and Transgender Health

Joy Simha
Co-founder, Young Survival Coalition

- 1:30 pm** *Discussion*
- 2:00 pm** **Break**
- 2:10 pm** **What consumers need from *The Cochrane Library*: where we are today**
(Each talk will be 15 minutes with discussion at the end)
Facilitator: Rebecca Burkholder
- 2:15 pm** *Cochrane reviews can be made more accessible*
Maryann Napoli
- 2:30 pm** *What the lay media really needs from *The Cochrane Library**
Avery Comarow

Creating Alliances: Consumers and Evidence-based Healthcare (cont'd)

2:45 pm *Consumer Reports and Health - will Cochrane be able to contribute?*
Ronni Sandroff

3:00 pm *Discussion*

3:25 pm **Break**

3:40 pm **Dream big: future alliances for consumers**
Facilitator: Elizabeth McCurdy

3:45 pm *Ensuring the perspective of people of color in EBHC*
Ngina Lythcott

4:00 pm *Our Bodies Ourselves: evidence-based from the start*
Zobeida Bonilla

4:15 pm *Productive consumer-partnerships*
Sallie Bernard
Roger Bernier

4:30 pm *Discussion*

5:00 pm **Adjourn**

5:30 pm **Consumer Coalition Dinner** – Adesso (directions attached)

Friday, April 1, 2005

8:00 am **Continental Breakfast** - McKinney Conference Room at the Watson
Institute (directions attached)

9:00 am **US Consumer Coalition Annual Meeting** - McKinney Conference Room
at the Watson Institute (a separate agenda contains the details of this
meeting)

1:30 pm **Close**



Appendix K

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

Present:

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

Guests:

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

Apologies:

Zobeida Bonilla (ZB)	Latina Health Initiative, Our Bodies Ourselves
Katherine Browne (KB)	Managing Director, Consumer-Purchaser Disclosure Project, National Partnership for Women & Families
Maureen Corry (MC)	Executive Director, Maternity Center Association
Carolina Hinestrosa (CH)	Executive Vice President for Programs and Planning, National Breast Cancer Coalition
Merrill Goozner (MG)	Director, Integrity In Science, Center for Science in the Public Interest
Trudy Lieberman (TL)	Director, Center of Consumer Health Choices, Consumers Union
Leyla McCurdy (LM)	Senior Director Health & Environment Programs, National Environmental Education & Training Foundation
Cindy Pearson (CP)	Executive Director, National Women's Health Network

Wednesday, March 30, 2005

1 Preparation for conference and annual meeting

4:10 pm - 5:30 pm

1.1 Welcome and introductions

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

1.2 Overview: Agenda for the conference

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

2. Dress rehearsal for March 31: PowerPoint presentations

4:30 pm - 5:30 pm

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

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

3. Reception and Coalition dinner

6:00 pm

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

Friday, April 1, 2005

1. Welcome and Review of Conference Highlights

8:30 am - 9:00 am

Members agreed that the conference was a great success. The stated objective and aims of the conference were successfully met (see Appendix C for evaluations).

2. Looking ahead: the Coalition in 2008

9:00 am - 10:00 am

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

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

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

2.1.1 Developing priority topics: a survey

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

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

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

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

2.1.2 Preparation for a survey

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

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

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

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

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

2.2 Name change for the Coalition

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

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

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

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

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

2.3 A national (US) subscription to The Library

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

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

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

2.4 Increasing Coalition membership

NL proposed doubling membership within the year. Members read membership guidelines from the 2004 annual meeting report (see Appendix D Bylaws). EM provided a list of potential members that was reviewed.

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

Action: EM will facilitate the process by providing:

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

2.5 Pilot project with CCNet: CAM synopses

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

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

3. Mission and Vision Statements: Final Revisions (see Appendix D)

10:00 am - 11:00 am

3.1 Section 2. Mission Statement

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

“The mission of the US Cochrane Center Consumer Coalition is to promote the health of populations and the quality of individual health by empowering consumers, public health policy makers, and health care providers to make informed decisions based on the best current evidence through research, education, and advocacy.”

3.2 Section 2. Vision statement

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

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

3.3 Section 3. Objectives

Members changed the title of Section 3 to:

Section 3. Goals

A statement needs to be added to Section 3 which will reflect the goal of communication

to providers and policy makers.

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

3.4 Section 4. Definitions: Best Current Evidence

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

3.5 Section 4. Definitions: Evidence-Based Health Care

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

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

4. Committee Breakout Groups

11:15 pm - 1:00 pm

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

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

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

4.2 Web Course Committee (ZB)

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

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

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

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

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

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

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

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



Appendix L

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

This meeting was recorded by AT&T teleconference services.

Present at the meeting:

Members of the USCC Consumer Coalition:

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

Affiliated with The Cochrane Collaboration:

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

Participating via telephone:

Affiliated with the USCC Consumer Coalition:

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

Apologies:

Members of the USCC Consumer Coaliton:

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

Wednesday, September 7, 2005

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

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

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

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

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

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

Module 6 - APPLY: making better decisions for EBHC

Modules 1 and 2 have been developed with both audio and visual components, while 3 - 6 are in outline form (see Appendix C, web course overview).

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

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

EM highlighted modifications to this document suggested by Brown General Counsel. Members made additional revisions, and voted to approve the document (see Appendix E, US Cochrane Center Consumer Coalition; Organizational Principles and Operating Structure).

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

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

Voting by anonymous written ballot filled the following two positions:

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

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

5. Adjourn 5:15 pm

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

Thursday, September 8, 2005

Review of Coalition Projects (see Appendix F, overview) 8:00 am - 12:45 pm

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

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

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

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

2.1 What is a systematic review?
Kay Dickersin

Members decided to bypass this presentation.

2.2 Overview of *The Cochrane Library*
Jane White

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

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

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

Action: EM will forward Wiley tutorial information to members.

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

Barbara Warren

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

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

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

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

4. Membership expansion

Elizabeth McCurdy

Members reviewed a list of potential new members submitted by EM. Suggestions are reflected in the revised document (see Appendix I).

5. A new name for the Coalition?

Ngina Lythcott

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

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

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

6. The Coalition: past, present and future

NL led a discussion of Coalition accomplishments and helped members define future priorities (see Appendix J, PowerPoint slides). High priority projects include finishing and piloting the web course, developing a web site, and membership expansion.

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

7. The Cochrane Colloquium- Melbourne, Australia

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

8. Adjourn

The meeting adjourned at 2:30 pm.



Appendix M

Agenda for US Contributors' Meeting XIII Cochrane Colloquium, Melbourne

Wednesday, October 26, 7:30 – 9:30 a.m.

Room: Howqua 2

7:30-7:40 Welcome and introductions (Kay Dickersin)

7:40-7:50 What's happening in the US (All)

- USCC relocation
- Consumers United for Evidence-based healthcare (CUE)
- Behavioral Medicine Field
- US Contributors' Meeting 2006
- Newly elected Steering Group members
- Healthcare of Older People Field

7:50-8:00 North American training opportunities (Roberta Scherer)

- CEVG
- AHRQ

8:00-8:15 Outreach: Dissemination of Cochrane in the US

- Increasing understanding of and use of *The Cochrane Library*

8:15-8:25 Developing Cochrane Collaboration interaction in the US and beyond (Douglas McCrory)

- Recruitment and increasing Cochrane involvement in the US
- Satellites—new opportunities?
- Websites

8:25-8:45 Funding: Successes, challenges, and future plans

- Reports from US contributors'

8:45-9:00 Cochrane Steering Group news (Lorne Becker)

9:00-9:15 Center news

- USCC (Kay Dickersin)
- San Francisco branch (Drummond Rennie)
- Boston branch

US Contributors' Meeting Agenda (cont'd)

9:15-9:25 Upcoming events (Kay Dickersin)

- April 2006 US Contributors' meeting
 - Location & topics

9:25-9:30 Any other business (Kay Dickersin)

Appendix N

RCTs and CCTs Identified by USCC in 2005

name	year	searched	RCT	CCT
American Journal of Ophthalmology	1974	03-Jan-05	1	2
Archives of Ophthalmology	2004	03-Jan-05	23	5
American Journal of Ophthalmology	1951	03-Jan-05	0	4
American Journal of Ophthalmology	1952	04-Jan-05	0	4
American Journal of Ophthalmology	1965	17-Jan-05	1	5
American Journal of Ophthalmology	1953	24-Jan-05	0	6
Ophthalmology	2004	25-Jan-05	39	4
American Journal of Ophthalmology	2004	08-Feb-05	32	0
American Journal of Ophthalmology	1955	16-Feb-05	1	7
American Journal of Ophthalmology	1956	17-Feb-05	0	2
American Journal of Ophthalmology	1970	18-Feb-05	3	1
American Journal of Ophthalmology	1971	18-Feb-05	3	5
American Journal of Ophthalmology	1969	02-Mar-05	2	4
American Journal of Ophthalmology	1954	17-Mar-05	0	7
American Academy of Optometry	2004	31-Mar-05	39	41
Journal of the American Optometric Association	1992	06-Apr-05	5	3
American Journal of Ophthalmology	1967	08-Apr-05	5	3
American Journal of Ophthalmology	1968	08-Apr-05	0	5
Association for Research in Vision and Ophthalmology	2000	25-Apr-05	146	47
Association for Research in Vision and Ophthalmology	2005	07-Jun-05	214	117
Association for Research in Vision and Ophthalmology	2003	25-Jul-05	212	66
American Journal of Ophthalmology	1964	25-Jul-05	3	2
American Glaucoma Society	2005	26-Jul-05	9	2
American Glaucoma Society	2004	26-Jul-05	9	2
American Glaucoma Society	1999	27-Jul-05	7	1
American Glaucoma Society	2002	27-Jul-05	5	1
American Glaucoma Society	1997	27-Jul-05	7	0
American Glaucoma Society	2000	27-Jul-05	7	1
American Glaucoma Society	2003	27-Jul-05	9	1
American Glaucoma Society	2001	27-Jul-05	6	3
American Journal of Ophthalmology	1960	09-Aug-05	0	6
American Journal of Ophthalmology	1963	02-Dec-05	1	2
Association for Research in Vision and Ophthalmology	2002	20-Dec-05	149	79
Total trials identified			937	436

Appendix O

United States Cochrane Center Performance Targets for January 1 - December 31, 2006

- 1. Target:** Coordinate activities for the Cochrane Central Register of Controlled Trials (CENTRAL) for *The Cochrane Library, Issue 1 2006*
- 1.1 Objective:** Perform and compile results of literature searches (MEDLINE search, handsearch results, and specialized register submissions).
- 1.2 Objective:** Coordinate, maintain, and regularly update the Master List of Journals Being Searched (Master List).
- 2. Target:** Work with National Library of Medicine (NLM) to ensure that controlled trials included on MEDLINE are appropriately indexed as publication type CONTROLLED CLINICAL TRIAL (CCT) or RANDOMIZED CONTROLLED TRIAL (RCT) (MEDLINE Retagging Project).
- 2.1 Objective:** Receive, process, and quality check submissions of handsearch results from Cochrane entities, perform electronic search on MEDLINE, and submit the results to NLM.
- 3. Target:** Provide training and support for reviewers, review group coordinators (RGCs), trial search coordinators (TSCs), editors, handsearchers, consumers and others responsible for Cochrane 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 bi-annual US contributors' conference.
- 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 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.
- 5.3 Objective:** Participate in annual meetings at the 2006 Cochrane Colloquium
- 5.4 Objective:** Perform general Center administrative functions
- 6. Target:** **Seek and obtain funding support for USCC activities**
- 6.1 Objective:** Seek funding for continuation of the MEDLINE Retagging Project to ensure that all controlled trials on MEDLINE are indexed appropriately on MEDLINE and included in CENTRAL.
- 6.2 Objective:** Continue working with funders to support USCC activities.
- 6.3 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 methodologic 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:** Continue development of CUE infrastructure and functions
- 8.2 Objective** Continue to develop and test an online distance education course for consumer
- 8.3 Objective** Strengthen the ties between CUE and the Cochrane Collaboration Consumer Network (CCNet).

USCC 2006 Performance Targets (cont'd)

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 P

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