

U. S. Cochrane Center Report

Consumers United for Evidence-based Healthcare (CUE)

Advocacy Summit

“Understanding Evidence-based Healthcare: A Foundation for Action”

17 July 2007

Willard InterContinental Hotel

Washington, DC

This conference was sponsored by the Agency for Healthcare Research and Quality (Grant No. R13HS13368-04) and the John M. Eisenberg Clinical Decisions and Communications Science Center. A contribution to the meeting was also made by the Kaiser Permanente Institute for Health Policy.

Table of Contents

1. Overview..... 3

2. Keynote address: Questions are the answer: Get more involved with your healthcare - A PSA campaign. 4

3. Summary of plenary and panel sessions. 4

 3.1. Understanding Evidence-based Healthcare: A Foundation for Action. 4

 3.2. Panel: Evidence-based healthcare: The building blocks. 5

 3.2.1. What do consumers think about evidence-based healthcare?. 5

 3.2.2. Evidence synthesis: Many sources, many interpretations? The Cochrane Collaboration, evidence-based practice centers, and others.. 6

 3.2.3. What do guidelines really mean? Translation to coverage decisions.. 6

 3.3. Getting the evidence out to the public, Consumer Reports Best Buy Drugs.. 7

4. Workshops. 8

 4.1. Pre-conference Workshop: Introduction to Consumers United for Evidence-based Healthcare. 8

 4.2. Simultaneous workshops session I. 9

 4.2.1. How to translate evidence for consumers.. 9

 4.2.2. How to incorporate EBHC into your organization’s mission. 10

 4.2.3. How to critically appraise a systematic review... 12

 4.3. Simultaneous workshops session II. 13

 4.3.1. Internet evidence-based resources... 13

 4.3.2. Focusing the message to different settings and cultures... 14

 4.3.3. How to critically appraise an article about intervention effectiveness.. 15

5. Summary of participant evaluations. 15

6. Appendices.....

 Appendix A: Conference program.....

 Appendix B: Conference planning committee members.....

 Appendix C: Conference invited speakers.

 Appendix D: Evaluation survey instrument..

1. Overview

On July 17, 2007 CUE and the US Cochrane Center (USCC) hosted the inaugural Consumers United for Evidence-based Healthcare (CUE) Advocacy Summit, “Understanding Evidence-based Healthcare: A Foundation for Action” (see Appendix A for conference program). The CUE Steering Committee elected to open the meeting to the public as a way to broaden the discussion about evidence-based healthcare (EBHC) among consumer advocates and other stakeholders. The Summit was sponsored by Agency for Healthcare Research and Quality (AHRQ) and the John M. Eisenberg Clinical Decisions and Communications Science Center, with a contribution from the Kaiser Permanente Institute for Health Policy. These groups assisted the CUE Steering Committee and the USCC in planning the conference (see Appendix B).

The one-day Summit included plenary sessions, the launching of a distance-education course for consumer advocates, and workshops designed to provide practical training for consumer advocates on how to access and apply EBHC to their advocacy and educational efforts. “Understanding Evidence-based Healthcare: A Foundation for Action,” was chosen as the title of the summit to reflect the overall objectives, which were to:

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

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

Continuing challenges for CUE and the USCC include increasing awareness of the Cochrane Collaboration and Cochrane systematic reviews in the consumer and health professional communities, building on the potential of new relationships forged during the Summit, increasing awareness and use of EBHC, and obtaining financial support to continue the growth and development of the work of CUE in the United States.

2. Keynote address: Questions are the answer: Get more involved with your healthcare - A PSA campaign. Jean Slutsky, PA, MSPH, *Director, Center for Outcomes and Evidence, Agency for Healthcare Research and Quality (AHRQ).*

In her address, *Questions are the answer: Get more involved with your health care PSA campaign*, Ms. Slutsky provided an overview of AHRQ's mission and the patient-wide campaign to discuss "what is a consumer and what is a patient?" She described AHRQ's efforts to encourage consumers to become actively involved in their own healthcare, specifically, AHRQ's Public Service Announcement (PSA) campaign designed to motivate consumers to ask questions of their healthcare providers. The "Patient Involvement Campaign" was designed in collaboration with the Advertising Council for TV, radio, print, and websites. It includes a video, a "Question builder" feature on the agency's website www.ahrq.gov/questionsaretheanswer, and accompanying materials for distribution.

The PSA was developed with consumer input obtained through at-home interviews and focus groups with the objectives to identify the healthcare facts and materials that are most motivating to consumers and to identify opportunities to educate the public. Through this process, AHRQ discovered that respondents were less concerned with medical error and more concerned with other healthcare issues such as insurance, access, doctor issues, and prescription drugs. Additionally, respondents voiced frustration with the nature of doctor visits that allow too little time to ask questions.

Ms. Slutsky concluded her presentation with a presentation of the "Questions are the Answer" PSA video and corresponding booklet, posters, and brochure. She then opened the floor for discussion and questions.

3. Summary of plenary and panel sessions

3.1. Understanding Evidence-based Healthcare: A Foundation for Action. **Musa Mayer, MS.** *Patient Advocate, Author, and Founder of AdvancedBC.org*; and **Kay Dickersin, PhD, MA.** *Director, United States Cochrane Center, and Director and Professor, Center for Clinical Trials, Johns Hopkins Bloomberg School of Public Health.*

Ms. Mayer and Dr. Dickersin outlined the newly developed online course for consumer advocates about EBHC. Dr. Dickersin began by providing an introduction to the course including

its objectives and target audience. The course utilizes a variety of teaching tools including key concepts and real-world examples. Ms. Mayer displayed portions of Modules One, Three, and Five while reading the accompanying script. Each module is designed to allow participants to learn through both visual and aural means.

Dr. Dickersin outlined the next steps for launching the course, anticipated on August 1, 2007. Interested participants will register through the USCC website. Dr. Dickersin requested that the first group registering for the course commit to completing within three months and providing feedback to the course developers. Future goals include developing an updated version 2.0, based on the input of early users. Dr. Dickersin thanked CUE and the members of the Cochrane Collaboration Consumer Network (CCNet) for their input into the development of this pilot program.

3.2. Panel: Evidence-based healthcare: The building blocks

Co-Chairs: **Ngina Lythcott**, DrPH, MPH. *Associate Dean, Boston University School of Public Health and Breast Cancer Liaison for the Black Women's Health Imperative*; and **Michael McGinnis**, MD, MPP. *Senior Scholar, Institute of Medicine, National Academy of Science, Roundtable on Evidence-based Medicine.*

3.2.1. What do consumers think about evidence-based healthcare?

Kristin Carman, PhD. *Principal Research Scientist, American Institutes for Research*

Dr. Carman presented the results of consumer interviews and focus groups on a communication toolkit, "Explaining evidence-based health care to your workforce." The toolkit, funded by California Health Care Foundation, was designed for employers and unions and used off-the-shelf or adapted written materials highlighting practical tips for communication about healthcare.

Initially, the researchers identified consumers' knowledge about EBHC and topics of concern, using literature review and website searches. Next, they conducted 10 telephone interviews with experts, 15 key stakeholder interviews with information intermediaries representing unions and employees, and four focus groups (two union and two non-union). Four additional focus groups are planned, as well as a survey to assess consumer attitudes about EBHC. To date, the investigators have identified five themes voiced by focus group and interview participants: comprehension, relevance, trust, discomfort, and overload.

The ultimate goal of the project is to build the Toolkit. This will require assessing and understanding employers and unions actions to communicate EBHC concepts; the desired topics and components of the Toolkit; and consumers' understanding of the different components of EBHC.

3.2.2. Evidence synthesis: Many sources, many interpretations? The Cochrane Collaboration, evidence-based practice centers, and others.

Mark Grant, MD, MPH. *Senior Scientist, Technology Evaluation Center, Blue Cross Blue Shield Association.*

Dr. Grant presented a systematic review of the effectiveness of viscosupplements to relieve pain from knee osteoarthritis at 12 weeks. He identified and compared five systematic reviews already published on the topic, examining the patients treated, the intervention, the comparison (e.g., placebo), and the study outcomes for each study covered in each review.

He compared the reviews on quality, exploration of between-trial variability, synthesis methods, potential publication bias, and uncertainty in combined effects.

Dr. Grant suggested that three critical issues must be considered when performing a review: clinically meaningful evidence of benefit, bias understanding, and explicitness about degree of uncertainty. Synthesizing evidence from reviews requires a critical appraisal of both reviews and the primary literature and understanding the sources of uncertainty. He concluded that decision-makers must critically examine syntheses of available research.

3.2.3. What do guidelines really mean? Translation to coverage decisions.

Tara Larson, MA, EdS. *Assistant Director, Division of Medical Assistance, North Carolina Department of Health and Human Services.*

Ms. Larson described the implementation of the Evidence-based Medicine Principles for Clinical Policy in the North Carolina Medicaid program. Implementing this program caused a large shift in both practice and policy development in the state. Prior to the program, health care coverage had been structured using practice standards established by major health insurance carriers and Medicare, with providers lobbying for coverage based on their practices, and legislators pushing for coverage based on financial impact and local constituents.

Key components of the policy included identifying the audience (internal staff, external agencies, providers, and consumers), educating the audience on evidence-based practice, and involving stakeholders in the process. To structure clinical coverage policies to reflect decisions based on current evidence-based practices in the health care industry, the group defined a topic of coverage, identified relevant evidence, and enumerated required steps for the coverage policy determination process (e.g., what resources will be accessed and used).

A formal presentation of a draft policy is made to the Physician's Advisory Group, a group of practicing physicians and practitioners, who assess clinical aspects and provide advise on the impact of the policy from a day-to-day operations standpoint. Questions and concerns are answered using "hard evidence."

Other factors to consider while developing policy include the need to retrain existing staff on EBHC techniques, possibly reclassifying positions and salaries or recruiting new staff with different skill sets, and committing resources to making the changes. In addition, the impact on providers must be considered as coverage changes could impact revenue. Ms. Larson concluded by describing the reality that, as a public agency, issues to consider include legislative issues, cost, recipient education, and the time and effort required to base coverage on the evidence.

3.3. Getting the evidence out to the public, Consumer Reports Best Buy Drugs.

James Guest, JD. *President and CEO, Consumers Union*; **David H. Hickam**, MD, MPH. *Director, John M. Eisenberg Clinical Decisions and Communications Science Center.*

Mr. Guest explained that the organization Consumers Union has a variety of programs for educating consumers about various healthcare programs and services, including:

- The Best Buy Drugs Program, which combines evidence on drugs overlaid with price information presented in a simple fashion for its readership;
- A publication on diabetes drugs, released July 16, 2007 includes a press release and information on AHRQ, Consumers Union, etc.;
- Partnerships with libraries (for example, an Aging Network in Minnesota), enlisting physicians to provide information to patients, and pharmacists to include a pamphlet in prescriptions;
- MEDCO, a pharmacy benefits package;
- Terascon, an informational product for physicians on PDAs; and
- Magazines with “health letter” Consumer Reports.

Consumers Union communication programs include focus groups to discuss EBHC, blogs, and community groups. Consumers Union “activists” (350,000 people) participate in activities such as sending emails to Congress.

The Best Buy Drugs program, created to make evidence about comparative effectiveness available to consumers, uses brochures designed for consumers, clinicians, and policymakers. The goal is to use scientific evidence, translated into understandable and useable information, to facilitate informed healthcare decisions by consumers. Program challenges are in summarizing information and in learning how consumers put evidence to use. Program successes are in including evidence of benefit and harm and indicating when evidence is inconclusive. This technique makes information “actionable” for patient and provider. Information is ordered by key dimension (e.g. strength of evidence); by summarizing and interpreting information through context, highlighting, and “framing”; by use of examples and narratives; and by considering the level of “numeracy” in consumers.

4. Workshops

Seven workshops were offered to conference attendees. A pre-conference workshop aimed to provide a basic introduction to CUE for those individuals with no or little experience with the coalition. Two sessions of three simultaneous workshops each were offered in the afternoon to provide practical training on how to apply EBHC to advocacy efforts.

4.1. Pre-conference Workshop: Introduction to Consumers United for Evidence-based Healthcare.

Marianne Hamilton, MPA. *Consumer Coordinator, United States Cochrane Center, Johns Hopkins Bloomberg School of Public Health*; and **Barbara Warren**, PsyD. *Director, Organizational Development, Planning & Research of the Lesbian, Gay, Bisexual & Transgender Community Center and Executive Committee member of the National Coalition for Lesbian, Gay, Bisexual and Transgender Health*

Ms. Hamilton provided participants with an overview of the history and mission of CUE and background on the organizations comprising its membership. She emphasized CUE's diverse membership with regard to the health topics and constituencies represented. Additionally, she explained how the USCC, through funding from AHRQ, continues to support the development and infrastructure of this coalition.

Dr. Warren provided participants with an overview of the evolution of CUE. She spoke of CUE's unique structure and role, emphasizing membership of grassroots organizations. Dr. Warren explained that CUE and the member organizations are dedicated to promoting the access and understanding of EBHC. Projects, such as the newly developed online course for consumer advocates, are important because consumers and advocates can become overwhelmed by the availability of information. CUE is committed to addressing a variety of topics relevant to consumers including bias in research, improving communication between healthcare providers and consumers, and access to easily understandable health information.

Continuing challenges of CUE include increasing awareness of the coalition, maintaining its independence and integrity while continuing to grow in membership, visibility, and impact. As healthcare continues to evolve, CUE is dedicated to ensuring that decisions and treatments are evidence-based and that consumers play an active part in health-related decision making.

CUE members participating from the floor echoed Dr. Warren's comments, and included Ngina Lythcott, Sallie Bernard, Cynthia Pearson, Zobeida Bonilla, Maryann Napoli, Barbara Lo Fisher, and Ann Fonfa.

4.2. Simultaneous workshops session I

4.2.1. How to translate evidence for consumers.

Facilitators: **Annette Bar-Cohen**, MA, MPH. *Director of Programs, National Breast Cancer Coalition*; and **Sandra Robinson**, MSPH. *Information Products Manager, John M. Eisenberg Clinical Decisions and Communications Science Center.*

Ms. Bar-Cohen discussed the use of evidence in advocacy and public policy, using evidence from breast self exam (BSE) trials and the National Breast Cancer Coalition (NBCC) as an example of an evidence-based advocacy organization. The organization provides NBCC's analysis of BSE research and NBCC's position on various topics through a series of position papers available online.

Ms. Bar-Cohen also discussed the NBCC's Clinical Trials Initiative, Quality Care Initiative, and how the organization is using evidence to develop legislative priorities. She concluded by describing the education and training programs offered by the NBCC and noted that "standing by the evidence is not always fun" in that NBCC can take the unpopular position. She believes that the NBCC position keeps the scientific community "honest" and keeps the public informed.

Ms. Robinson discussed the John M. Eisenberg Clinical Decisions and Communications Science Center (Eisenberg Center), a multi-disciplinary team funded by AHRQ. The Center's goals and mission are to:

- Make evidence about comparative effectiveness accessible to consumers, clinicians, and policymakers;
- Promote evidence-based decision-making and informed choice; and
- Create print and website decision aids.

The Eisenberg Center prepares comparative effectiveness reports, which are evidence-based and audience focused, with report presentation modified by testing and review. Ms. Robinson explained that evidence on effectiveness, safety, and costs are considered in developing the comparative effectiveness reports in addition to translation of the evidence to a format useful for treatment decisions. Audience characteristics are taken into account when reports are developed and include literacy, health literacy, age, culture, and perceived threats. Special attention is paid to framing the question (e.g., differences in perception of 20% mortality vs 80% survival) and tailoring and targeting the information for the intended audience (consumers, clinicians, or policy-makers). Testing draft versions of reports with consumers identified several themes. Consumers want:

- Established and trusted sources of information;
- Familiar language used in the reports;

- Reports of comprehensive information for management of chronic conditions;
- Reports of information on both short- and long-term effects of drugs/treatments;
- Information in the reports to be congruent with the patients' own experiences; and
- The information to be current.

The Eisenberg Center also learned that effectiveness is the most important factor in affecting a consumer's choice of drugs/treatment, and this is followed by safety and cost.

Reviewer comments are solicited from organizations representing or providing information to the primary audiences. Each report includes key sections designed to assist the audience in sorting out the information presented, including a short summary of key findings, information about benefits and risks, and considerations for decision-making. Challenges include changing context, the scope of the Eisenberg Center's Effectiveness Reports, presenting complex information, health literacy, and competing information.

A number of factors determine the topics selected, including the burden of the condition, availability of studies on the topic, and costs associated with the condition. Research topics may be suggested by anyone by mail or online (see AHRQ's website). There are a number of opportunities for consumers to participate in the Effective Care Program.

4.2.2. How to incorporate EBHC into your organization's mission

Facilitators: *Sallie Bernard, Executive Director and Co-Founder, Autism Speaks and SafeMinds; and Donald Steinwachs, PhD, MS, Professor and Director, Health Services Research and Development Center, Johns Hopkins Bloomberg School of Public Health.*

Ms. Bernard discussed how the two consumer groups, Autism Speaks and SafeMinds, focus on research and advocacy for people and families affected by autism spectrum disorders. Autism Speaks is the largest non-profit organization focusing on research, treatment and advocacy while SafeMinds is a small organization focusing on the role of mercury in autism causation. Incorporating EBHC into the organizations has been done through a four stage process. First is the realization that target populations can improve their health-related outcomes using an evidence-based approach. Second is obtaining evidence that demonstrates better outcomes through better healthcare practices. Next, the identified evidence is evaluated and a set of recommendations or guidelines is created. Consumer involvement is especially important during this stage to represent the interests of constituencies. Finally, the assessment is disseminated to the wider public with evaluations written to communicate effectively to professionals, consumers, payers, and policymakers.

Autism Speaks (formerly Cure Autism Now) was founded on the philosophy that autism is treatable and that a cure is attainable. Taking a cue from the AIDS and Alzheimer's disease activists, Autism Speaks uses a proactive approach to advocate for increasing clinical research in

treating autism. EBHC is embedded in the strategic plan of both Autism Speaks and SafeMinds, with the goal of making treatment advances through sound science. The two groups have partnered with other autism and environmental organizations, clinicians and academic researchers to build the research field and generate evidence by supporting and participating in conferences, clinical trials and other research, and by translating research findings into formats that can be understood by families. Recent efforts include working for passage of the Combating Autism Act 2006, which provides approximately \$1 billion over five years for autism research, treatment, screening and training for physicians to enter the field.

Dr. Steinwachs discussed the researcher's perspective, using mental health care quality as an example. The Schizophrenia Patient Outcomes Research Team (PORT), funded by the National Institute of Mental Health and the Agency for Healthcare Policy and Research (now AHRQ), showed that less than half of mental health care patients receive evidence-based treatment. Barriers to use of EBHC include physicians' training, attitudes, beliefs and experiences; organizational/practice constraints; payment limitations; community resources and availability of treatments; and patients' understanding of EBHC. Dr. Steinwachs presented data showing that barriers with both physicians and consumers/patients are significant and slow the adoption of EBHC.

Dr. Steinwachs, a member of the Institute of Medicine's (IOM) Evidence-based Medicine Roundtable, stated that a goal of the Roundtable is that by 2020 90% of clinical decisions will reflect the best available evidence. The IOM roundtable charter proposes "The Learning Healthcare System," designed to generate and apply best evidence for the collaborative health care choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in healthcare.

A consumer Internet education program for mental health quality was developed with funding from the National Institute of Mental Health with the objective to empower people with severe mental disorders to be aware of and ask for treatments that are evidence-based. The interactive website structure provides feedback messages tailored to user responses based on schizophrenia treatment recommendations. Optional video clips demonstrate ways patients can initiate conversations with clinicians about their concerns.

Dr. Steinwachs concluded that patients/consumers have critical roles in the adoption and success of EBHC. They must create the demand for EBHC services and demand generation of better evidence. In addition, they must be willing to make their own data available for analysis in a learning healthcare organization.

4.2.3. How to critically appraise a systematic review.

Facilitators: Cindy Pearson. *Executive Director, National Women's Health Network;* and **Eric Bass, MD, MPH.** *Director, Evidence-Based Practice Center, and Professor of Medicine, John Hopkins School of Medicine.*

Dr. Bass focused on one example in his presentation, a report about the widespread use of multivitamins and mineral supplements and emerging reports on adverse effects. The National Institutes of Health requested a report on the evidence that used a systematic approach, had a rigorous methods section, avoided financial conflict of interest, and incorporated peer review. Dr. Bass stated that his “insider’s view” of the purpose of the report was to review the efficacy of single/paired nutrient supplements and the efficacy and safety of multivitamins. He identified seven steps for a critical appraisal:

- Define questions and establish eligibility criteria;
- Search literature;
- Review citation to identify eligible studies;
- Extract data;
- Evaluate study quality;
- Synthesize evidence; and
- Submit for peer review.

Dr. Bass described how AHRQ’s Evidence-based Practice Centers (EPC) conduct systematic reviews and challenges faced by reviewers, including potential conflict of interests.

Challenges in formulating the review included developing questions precise enough to focus on the specific issues, given the focus on prevention of chronic disease in healthy adults. Chronic diseases targeted in his review included cancer, cardiovascular disease, and diabetes. The EPC team graded the overall strength of the evidence by rating quantity, quality, and consistency of evidence using the instrument developed by the Grade Working Group. Forty-four potentially relevant articles were found, but only a few chronic diseases were addressed in them. Populations and vitamin/mineral combinations differed among studies, so the reviewers did not combine their findings quantitatively. The report was peer reviewed with early input by technical experts. The draft report was reviewed by nine experts and revised to include responses to reviewers’ comments.

Ms. Pearson reported on the ramifications of a critically appraised systematic review on women’s health and practice. Manufacturers of Premarin, an estrogen plus progestin pharmaceutical, requested from the Food and Drug Administration (FDA) an addition to the label stating that Premarin “prevents cardiovascular disease”. The FDA held an open meeting to discuss the systematic review of observational studies prepared by the drug company. Experts in this field presented the review to FDA, and emphasized the consistency, comprehensiveness, and the strength of evidence.

At the meeting, Ms. Pearson presented her assessment of the review, strongly arguing that the FDA should not permit the label change at this time because of the potential for selection bias in observational studies and that randomized controlled trials should be the level of evidence required for FDA approval.

As a result of her appraisal, Ms. Pearson went before Congress to testify that more research needed to be done, leading to initiation of the Women's Health Initiative (WHI), a randomized trial which ultimately showed increased risk of stroke with estrogen and an increased breast cancer, endometrial cancer, and pulmonary embolism with estrogen/progesterone combination.

4.3. Simultaneous workshops session II

4.3.1. Internet evidence-based resources.

Facilitators: **Barbara Warren**, PsyD. *Director, Organizational Development, Planning & Research of the Lesbian, Gay, Bisexual & Transgender Community Center and Executive Committee member of the National Coalition for Lesbian, Gay, Bisexual and Transgender Health;* and **Claire Twose**, MLIS. *Association Director, Public Health and Basic Science Liaison Services, Welch Medical Library, Johns Hopkins University.*

Ms. Twose and Dr. Warren discussed how to search the Internet for EBHC sources, and gave tips on how to make the best use of general search engines. They demonstrated some Internet sites showing how to use and evaluate evidence.

Ms. Twose showed how to conduct a search by breaking the question into components and using synonyms for the search terms. The databases and other sources are selected and the question is translated into a database query. This is an iterative process, using advanced features such as a controlled vocabulary (subject headings, key words, thesaurus or MeSH terms), Boolean searching (and, or, not) and wildcards, creating a search history and combining searches, and conducting "view search"/manual field searching.

General sources for searching were demonstrated by Ms. Twose while Dr. Warren led the discussion of real life examples. Sources reviewed included:

- *The Cochrane Library;*
- Center for Review and Dissemination (York, UK);
- PubMed;
- TRIP (Trip Database - For Evidence Based Medicine);
- AHRQ;
- National Library of Medicine (NLM) Gateway;
- MedlinePlus; and
- General search engines (Google, Google Scholar and www.scirus.com).

Sites for education about using and evaluating evidence include:

- Doing a systematic review: <http://www.york.ac.uk/inst/crd/report4.htm>
- The Cochrane Reviewers Handbook: <http://www.cochrane.org/resources/handbook/>
- User's Guides to the Medical Literature: http://www.cche.net/principles/content_all.asp
- EBM Toolkits for appraising the evidence: <http://www.med.ualberta.ca/ebm/ebm.htm>

4.3.2. Focusing the message to different settings and cultures.

Facilitators: **Zobeida Bonilla**, PhD, MPH. *Latina Health Initiative Program Manager, Our Bodies Ourselves*; and **Cathy Gordon**, MPH. *Research Associate, John M. Eisenberg Clinical Decisions and Communications Science Center.*

Dr. Bonilla and Ms. Gordon discussed the challenges faced by organizations trying to obtain evidence-based information when their groups are not represented and/or are limited by low health literacy or other barriers.

Dr. Bonilla raised issues about the importance of who is producing the evidence. She discussed the Boston Women's Health Book Collective (BWHBC), and their push for evidence through the book, *Our Bodies Ourselves (OBOS)*. *OBOS* focuses on women's issues such as sexuality, reproductive health and women's health throughout the life cycle. These topics were initially controversial in the US, and *OBOS*'s message is not always welcomed across the world in different cultures.

Dr. Bonilla discussed how the *OBOS* message could be targeted to a specific population. Settings, cultures and ethnicity, age groups, language groups, and interest groups must be considered when developing the message. A new audience might not benefit from a direct or literal translation, since health education and information priorities in a particular culture may be different. Also, sufficient evidence may not be available for a particular group, culture or setting.

Ms. Gordon proposed that to engage consumers, the affected population should be identified, community-based recruitment and qualitative research should be used, and the message should be shaped for the consumer. Within a community, it is important to identify condition-specific populations and groups with special needs (e.g., groups with higher prevalence of a condition or where there are disparities in health outcomes) and to extend outreach to a broad cross-section of the community and organizations which are serving the identified groups of interest.

Ms. Gordon presented the Oregon Health & Science University "Project EQUALED," where minority patients' experiences with health care providers was explored using focus groups to learn about consumers' experiences and information needs for health care decision-making.

Focus group moderators were recruited and trained from within the targeted focus group to increase the cultural and/or gender congruence between moderator and focus group participants and provide access to community contacts for focus group sites.

Multiple rounds of testing provided feedback on the summary guides from consumers for comprehension and resonance with their experiences. Preferences regarding design, color, layout and use of photography were solicited, missing information identified, and reading level adjusted for a broad audience. Challenges include the description of concepts such as clinical trials, EBHC and finding and reaching the appropriate target audience.

4.3.3. How to critically appraise an article about intervention effectiveness.

Facilitators: **Maryann Napoli**, *Associate Director, Center for Medical Consumers*; and **Roberta Scherer**, PhD. *Associate Director, United States Cochrane Center, and Associate Scientist, Johns Hopkins Bloomberg School of Public Health.*

During this workshop, Dr. Scherer presented key concepts in critical appraisal of an article about intervention effectiveness. Ms. Napoli led discussion of critical appraisal concepts, using examples from the current literature. Concepts included:

- Information source: is it a published study, a drug company or university-generated press release, or a presentation at a conference, and who paid for the study;
- Type of information: what is the risk and what is the benefit (decrease in risk) and does it apply to the reader. How does the risk compare to other known risks?;
- Outcomes: surrogate and true outcomes of interest. Fosamax to prevent bone loss was presented as an example of use of a surrogate outcome, with bone fracture is the outcome of interest;
- Relative risk and absolute risk: example of cholesterol-lowering drugs; risk assessment and the applicability of risk to the reader.

5. Summary of participant evaluations

Ninety-three individuals attended the 2007 Annual Consumers United for Evidence-based Healthcare (CUE) Meeting. Participants were encouraged to provide a written evaluation of the meeting.

The survey instrument (see Appendix D) largely consisted of questions measured on a five-point Likert scale. Open-ended comments were also solicited. The evaluation scores and comments show that respondents were generally supportive of the meeting's presenters, content, and organization. Forty-five participants returned the evaluation, and not all questions were answered by all respondents. Most respondents (86%; 36/44) believed the program met their expectations. Suggestions focused on time/space management and a desire for more information and networking. A number of respondents would have liked to have seen PowerPoint slides or

printouts of the speaker's presentations. These suggestions will be taken into account when planning future meetings.

Appendix A

Consumers United for Evidence-based Healthcare (CUE) Advocacy Summit
Understanding Evidence-based Healthcare: A Foundation for Action
July 17, 2007
Washington, DC

Conference Program

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

- 12:15 - 1:30 pm **Lunch presentation:** Getting the evidence out to the public, Consumer Reports Best Buy Drugs
Speaker:
Jim Guest, Consumers Union*
Discussant:
David H. Hickam, John M. Eisenberg Clinical Decisions and Communications Science Center
- 1:30 - 3:00 pm **Simultaneous workshops session I**
- Workshop A.** How to translate evidence for consumers
Facilitators:
Annette Bar-Cohen, National Breast Cancer Coalition*
Sandy Robinson, John M. Eisenberg Clinical Decisions and Communications Science Center
- Workshop B.** How to incorporate EBHC into your organization's mission
Facilitators:
Sallie Bernard, SafeMinds*
Don Steinwachs, Johns Hopkins University
- Workshop C.** How to critically appraise a systematic review
Facilitators:
Cindy Pearson, National Women's Health Network*
Eric Bass, Johns Hopkins Evidence-based Practice Center
- 3:00 - 3:15 pm **Break**
- 3:15 - 4:45 pm **Simultaneous workshops session II**
- Workshop D.** Internet evidence-based resources
Facilitators:
Barbara Warren, National Lesbian, Gay, Bisexual, and Transgender Health Coalition*
Claire Twose, Johns Hopkins University
- Workshop E.** Focusing the message to different settings and cultures
Facilitators:
Zobeida Bonilla, Our Bodies Ourselves*
Cathy Gordon, John M. Eisenberg Clinical Decisions and Communications Science Center
- Workshop F.** How to critically appraise an article about intervention effectiveness
Facilitators:
Maryann Napoli, Center for Medical Consumers*
Roberta Scherer, Johns Hopkins University
- 4:45 - 5:00 pm **Evaluation and adjourn**
Joy Simha, Young Survival Coalition*

* CUE member-organization

Appendix B

Consumers United for Evidence-based Healthcare (CUE) Advocacy Summit
Understanding Evidence-based Healthcare: A Foundation for Action

July 17, 2007

Washington, DC

Planning Committee Members

Sallie Bernard
Zobeida Bonilla
Kay Dickersin
Marianne Hamilton
Ngina Lythcott
Joy Simha
Barbra Warren

**APPENDIX C: Consumers United for Evidence-based
Healthcare (CUE) Advocacy Summit**
Understanding Evidence-based Healthcare: A Foundation for Action
July 17, 2007, Washington, DC
Speaker List

Annette Bar-Cohen, MA, MPH
National Breast Cancer Coalition
1101 17th Street NW, Suite 1300
Washington, DC 20036
202-973-0597
abar-cohen@stopbreastcancer.org

Eric Bass, MD, MPH
Johns Hopkins University
1830 East Monument Street, Rm 8068
Baltimore, MD 21210
410-955-9871
ebass@jhmi.edu

Sallie Bernard
SafeMinds
254 Trickum Creek Road
Tyrone, GA 30290
970-544-3466
sbernard@safeminds.org

Zobeida Bonilla, PhD, MPH
Our Bodies Ourselves
4 Plympton Street
Boston, MA 02118
781-504-3959
zobeida@bwhbc.org

Kristin Carman, PhD
American Institutes for Research
1050 Thomas Jefferson, NW
Washington, DC 20007
202-403-5090
kcarman@air.org

Kay Dickersin, PhD, MA
US Cochrane Center
Johns Hopkins Bloomberg School of Public
Health
615 N Wolfe Street, MSC 5010
Baltimore, MD 21205
410-502-4421
kdickers@jhsph.edu

Mark Grant, MD, MPH
Blue Cross Blue Shield Association
225 North Michigan Avenue
Chicago, IL 60601
312-297-6216
mark.grant@bcbsa.com

Cathy Gordon, MPH
John M. Eisenberg Clinical Decisions and
Communications Science Center
Oregon Health & Science University
3710 SW Veterans Hospital Road, HSRD
Portland, OR 97239
503-273-5305
gordonc@ohsu.edu

James Guest, JD
Consumers Union
101 Truman Avenue
Yonkers, NY 10703
914-378-2200
jguest@consumer.org

Marianne Hamilton, MPA
US Cochrane Center
Johns Hopkins Bloomberg School of Public
Health
615 N Wolfe Street, MSC 5010
Baltimore, MD 21205
410-502-4641
mhamilto@jhsph.edu

David Hickam, MD, MPH
John M. Eisenberg Clinical Decisions and
Communications Science Center
Oregon Health & Science University
3710 SW Veterans Hospital Road, HSRD
Portland, OR 97239
503-721-7817
hickam@ohsu.edu

Tara Larson, MA, EdS
North Carolina Department of Health and
Human Services
2501 Mail Service Center
Raleigh, NC 27699
919-855-4265
tara.larson@ncmail.net

Speaker List (cont'd)

Ngina Lythcott, DrPH, MPH
Black Women's Health Imperative
1420 K Street, NW, Suite 1000
Washington, DC 20005
617-638-4151
lythcott@bu.edu

Musa Mayer, MS
AdvancedBC.org
250 West 82nd Street, Apt. 42
New York, NY 10024
212-580-2622
musa@echonyc.com

Michael McGinnis, MD, MPP
Institute of Medicine of the National
Academies, Roundtable on Evidence-Based
Medicine
500 Fifth Street NW
Washington, DC 20001
202-334-3963
mcginnis@nas.edu

Maryann Napoli
Center for Medical Consumers
239 Thompson Street
New York, NY 10012
212-674-7105
mnapoli2@ix.netcom.com

Cindy Pearson
National Women's Health Network
514 Tenth Street, NW, Suite 400
Washington, DC 20004
202-347-1140
cpearson@nwhn.org

Sandra Robinson, MSPH
John M. Eisenberg Clinical Decisions and
Communications Science Center
Oregon Health & Science University
3710 SW Veterans Hospital Road, HSRD
Portland, OR 97239
503-220-8262
robinssa@ohsu.edu

Roberta Scherer, PhD
US Cochrane Center
Johns Hopkins Bloomberg School of Public
Health
615 N Wolfe Street, MSC 5010
Baltimore, MD 21205
410-502-4636
rscherer@jhsph.edu

Joy Simha
Young Survival Coalition
61 Broadway, Suite 2235
New York, NY 10006
201-251-9047
jsimha@vasuchari.com

Jean Slutsky, PA, MSPH
Agency for Healthcare Research and
Quality
540 Gaither Road
Rockville, MD 20850
301-427-1600
jean.slutsky@ahrq.gov

Donald Steinwachs, PhD, MS
Johns Hopkins Bloomberg School of Public
Health
624 North Broadway
Baltimore, MD 21205
410-955-6562
dsteinwa@jhsph.edu

Claire Twose, MLIS
Welch Medical Library, Johns Hopkins
University
1900 East Monument Street
Baltimore, MD 21205
410-502-0490
ctwose@jhmi.edu

Barbara Warren, PsyD
National Coalition for LGBT Health
1407 S St, NW
Washington, DC 20009
212-620-7310
barbaraw@gaycenter.org

APPENDIX D: Consumers United for Evidence-based Healthcare (CUE) Advocacy Summit
Understanding Evidence-based Healthcare: A Foundation for Action
 July 17, 2007
 Washington, DC
Program Evaluation

Pre-conference Workshop: Introduction to Consumers United for Evidence-based Healthcare (CUE)

Objectives:

- Introduce CUE, its member organizations, history, and mission; and
- Provide a context of the importance of CUE for advocates and researchers.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Objectives were met	5	4	3	2	1
B. Quality of presentation by speaker					
Joy Simha	5	4	3	2	1
Barbara Warren	5	4	3	2	1
Marianne Hamilton	5	4	3	2	1

Keynote address: "Questions Are the Answer: Get More Involved With Your Health Care"
 PSA campaign

Objectives:

- Describe AHRQ's PSA campaign and its relevance for consumers and consumer advocates.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1
B. Quality of presentation by speaker					
Jean Slutsky	5	4	3	2	1

Summit evaluation (cont'd)

Presentation: Understanding Evidence-based Healthcare: A Foundation for Action
Objectives:

- Present portions of a distance-education course on evidence-based healthcare for consumer advocates; and
- Discuss the course as presented.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1
B. Quality of presentation by speaker					
Musa Mayer	5	4	3	2	1
Kay Dickersin	5	4	3	2	1

Panel Discussion: Evidence-based Healthcare: The Building Blocks
Objectives:

- Describe research on consumers' experiences with evidence-based healthcare
- Describe sources and interpretations of evidence; and
- Provide an example of the application of evidence-based healthcare.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1
B. Quality of presentation by speaker					
Panel member - Kristin Carman	5	4	3	2	1
Panel member - Mark Grant	5	4	3	2	1
Panel member - Tara Larson	5	4	3	2	1

Summit evaluation (cont'd)

Lunch Presentation: Getting the evidence out to the public, Consumer Reports
Best Buy Drugs

Objectives:

- Describe the efforts of the Consumers Union to make healthcare evidence accessible to consumers; and
- Discuss other translation of evidence practices.

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Objectives were met	5	4	3	2	1
B. Quality of presentation by speaker					
Jim Guest	5	4	3	2	1
David Hickam	5	4	3	2	1

Simultaneous Workshops - Session One

Workshop A. How to translate evidence for consumers

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions were answered to satisfaction	5	4	3	2	1

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

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions were answered to satisfaction	5	4	3	2	1

Workshop C. How to critically appraise a systematic review

Check here if you did not attend this session

Summit evaluation (cont'd)

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions were answered to satisfaction	5	4	3	2	1

Simultaneous Workshops - Session Two

Workshop D. Internet evidence-based resources

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions were answered to satisfaction	5	4	3	2	1

Workshop E. Focusing the message to different settings and cultures

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions were answered to satisfaction	5	4	3	2	1

Workshop F. How to critically appraise an article about intervention

Check here if you did not attend this session

OR Circle the best answer for each item.

	Excellent	Very Good	Good	Fair	Poor
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions were answered to satisfaction	5	4	3	2	1

Overall Evaluation