

#### **United States Cochrane Center**

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Preparing, maintaining and promoting the accessibility of systematic reviews of the effects of health care interventions

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## A Letter to President-Elect Barack Obama and Senator Tom Daschle, Secretary-Designate for Health and Human Services (HHS)

December 17, 2008

**RE:** Importance of the Consumer Voice in Evidence-Based Health Care for Better Health Outcomes

Dear President-Elect Obama and Senator Daschle:

Health care reform will appropriately be a priority for the new administration. Our organization, Consumers United for Evidence-based Healthcare (CUE), supports incorporation of evidence-based health care (EBHC) principles into health care policy. Consumer participation in EBHC fosters informed decisions and is essential for achieving better health outcomes and optimal use of our health care dollars.

CUE (<a href="http://apps1.jhsph.edu/cochrane/uscccc.htm">http://apps1.jhsph.edu/cochrane/uscccc.htm</a>) is a project of the Johns Hopkins University-based U.S. Cochrane Center (<a href="http://uscc.cochrane.org/en/index.html">http://uscc.cochrane.org/en/index.html</a>), which is part of The Cochrane Collaboration. The Cochrane Collaboration is an international not-for-profit and independent organization dedicated to making up-to-date, accurate information about the effects of health care readily available worldwide. A coalition of 26 consumer organizations, CUE is the only broad-based coalition in the United States representing the consumer perspective by articulating how evidence-based health care can promote better informed health care decisions, better patient outcomes and a better health care delivery system.

Evidence-based health care has been defined by The Cochrane Collaboration as follows (http://www.cochrane.org/docs/ebm.htm):

"Evidence-based health care is the conscientious use of current best evidence in making decisions about the care of individual patients or the delivery of health services. Current best evidence is up-to-date information from relevant, valid research about the effects of different forms of health care, the potential for harm from exposure to particular agents, the accuracy of diagnostic tests, and the predictive power of prognostic factors. Evidence-based clinical practice is an approach to decision-making in which the clinician uses the best evidence available, in consultation with the patient, to decide upon the option which suits that patient best. Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating

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individual clinical expertise with the best available external clinical evidence from systematic research".

CUE endorses and promotes this view of EBHC. Our goal is to educate consumers and professionals about EBHC through grassroots outreach and dissemination. We think it is critical that consumers consider EBHC a positive tool to promote good health on both an individual patient and societal level. Utilizing treatments that sound science has found to be safe and effective makes good sense. The purpose of EBHC is not to deny patients access to coverage or specific interventions or to impose rules from the top down, but to help patients themselves, in consultation with their health care provider, identify the best approach for their situation. We have created an online course (<a href="http://apps1.jhsph.edu/cochrane/CUEwebcourse.htm">http://apps1.jhsph.edu/cochrane/CUEwebcourse.htm</a>) to educate consumers and professionals on understanding, evaluating, and incorporating evidence into their health care decisions.

To increase the use of EBHC we support the creation of an institute for comparative effectiveness. We encourage the U.S. government to obtain a national subscription to *The Cochrane Library*, a regularly updated collection of evidence-based medicine databases, which includes systematic reviews of health care interventions that are produced and disseminated by The Cochrane Collaboration.

Health care reform will never achieve its promise unless consumers are empowered with the tools to access, understand, and apply the evidence. Educated consumers can be an effective counterweight to industry marketing campaigns that try to sell treatments the same way detergents are sold, leading to efforts that at best are ineffective and at worst are harmful.

We strongly assert that as health care policy is debated, the evidence-based consumer voice needs to be at the table participating alongside other key stakeholders. We request that CUE be represented in any committees, panels, and other relevant workgroups on comparative effectiveness and evidence-based health care created by your administration. We look forward to your leadership to ensure that the needs and perspectives of consumers are well represented in your administration.

Sallie Bernard Barbara E. Warren

Sincerely,

Kay Dickersin, PhD

Director, USCC

Sallie Bernard SafeMinds

CUE Steering Committee Co-Chair

Barbara Warren, PhD

The National Coalition for LGBT Health CUE Steering Committee Co-Chair

Attachments:

List of CUE member organizations; Understanding Evidence-based Healthcare course description Distribution:

Janie Gordon, USCC; Cochrane files 1.2.15, 3.19.5.1.4, 3.19.5.1.1.4

#### Consumers United for Evidence-based Healthcare (CUE)

#### 2008 Member Organizations

- Annie Appleseed Project http://www.annieappleseedproject.org/
- Black Women's Health Imperative <a href="http://www.blackwomenshealth.org/">http://www.blackwomenshealth.org/</a>
- Center for Medical Consumers http://www.medicalconsumers.org/
- Center for Science in the Public Interest <a href="http://www.cspinet.org/">http://www.cspinet.org/</a>
- Cherab Foundation http://www.cherab.org/
- Childbirth Connection http://www.childbirthconnection.org/
- Citizens for Health <a href="http://www.citizens.org/">http://www.citizens.org/</a>
- Citizens Health Alliance for Truth http://www.chatdc.org/
- Consumers Union http://www.consumersunion.org/
- Faces and Voices of Recovery <a href="http://www.facesandvoicesofrecovery.org/">http://www.facesandvoicesofrecovery.org/</a>
- Lamaze International <a href="http://www.lamaze.org/">http://www.lamaze.org/</a>
- Mautner Project, the National Lesbian Health Organization http://www.mautnerproject.org
- National Breast Cancer Coalition http://www.natlbcc.org/
- National Center for Transgender Equality http://www.nctequality.org/
- National Coalition for Lesbian, Gay, Bisexual and Transgender Health <a href="http://www.lgbthealth.net/">http://www.lgbthealth.net/</a>
- National Consumers League <a href="http://www.nclnet.org/">http://www.nclnet.org/</a>
- National Council on Aging http://www.ncoa.org/
- National Environmental Education & Training Foundation <u>www.neetf.org/</u>
- National Mental Health Consumers' Self-Help Clearinghouse www.mhselfhelp.org/
- National Partnership for Women & Families www.nationalpartnership.org/
- National Vaccine Information Center <u>www.909shot.com/</u>
- National Women's Health Network www.nwhn.org/
- Our Bodies Ourselves http://www.ourbodiesourselves.org/
- Rhode Island Breast Cancer Coalition www.breastcancerri.org/
- SafeMinds www.safeminds.org/
- TMJ Association, Ltd. www.tmj.org/
- Young Survival Coalition www.youngsurvival.org/



# Understanding Evidence-based Healthcare: A Foundation for Action

An online course

www.cochrane.us

Understanding Evidence-based Healthcare: A Foundation for Action was created by the United States Cochrane Center as part of a project undertaken by Consumers United for Evidence-based Healthcare (CUE). It was designed to help users understand the fundamentals of evidence-based healthcare concepts and skills.

**Course Description:** We illustrate the key concepts with compelling real-world examples, using clear, concise, and scientifically accurate language. The course, with over 5+ hours of lecture and slides, has been used by individual learners, doctoral programs, medical residencies, and consumer advocacy programs. Over 1,000 individuals have enrolled.

### Registration is open and free of charge!

Register Today at: www.cochrane.us

For more information contact: USCC@jhsph.edu



# **Course Description**

Six modules: (Run times are an estimate only)

**Module 1:** INTRO: What is evidence-based healthcare and why is it

important? (45 minutes)

**Module 2:** ASK: The importance of research questions in evidence-

based healthcare. (40 minutes)

**Module 3:** ALIGN: Research design, bias and levels of evidence (1)

hour)

**Module 4:** ACQUIRE: Searching for healthcare information. Assessing

harms and benefits. (1 hour 10 minutes)

**Module 5:** APPRAISE: Behind the numbers: Understanding healthcare

statistics. Science, speed, and the search for best

evidence. (1 hour 20 minutes)

**Module 6:** APPLY: Critical appraisal and making better decisions for

evidence-based healthcare. Determining

causality. (1 hour)

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The Johns Hopkins School of Public Health.

(See website for specific contributions.)