

Appendix 1
AGENDA
Consumers United for Evidence-based Healthcare (CUE)
Advocacy in the Era of Evidence: An International Summit for Consumer Advocates
October 17, 2010
Keystone, Colorado
Arapahoe Room

8:00 – 8:30 a.m.

Pre-conference orientation to CUE

Maureen Corry, Executive Director, Childbirth Connection, Co-Chair, CUE Steering Committee

John Santa, Director, Health Ratings Center, Consumers Union, Co-Chair CUE Steering Committee

8:45 – 9:00 a.m.

Welcome

Maureen Corry, Co-Chair CUE Steering Committee

John Santa, Co-Chair CUE Steering Committee

Janet Wale, Cochrane Consumer Network

Kay Dickersin, Director, US Cochrane Center

9:00 – 9:15 a.m.

Consumers as leaders in evidence-based healthcare

Session Co-Chairs: Kay Dickersin, Barbara Warren

Advocacy in the era of evidence

Patricia Schroeder, former member of US House of Representatives

9:15 – 9:45 a.m.

Keynote Address: How do we fight to get the consumer voice front and center in healthcare decision making: The vision ahead

Cornelius Baker, National Black Gay Men's Advocacy Coalition and AED Center on AIDS & Community Health

9:45 – 10:00 a.m.

Discussion

10:00 – 10:45 a.m.

Panel Discussion: Consumer engagement and partnerships

Session Co-Chairs: Rebecca Burkholder, John Santa

How can citizens and consumer advocates join with scientists to create a better future?

The Agency for Healthcare Research and Quality (AHRQ) Community Forum

Jean Slutsky, Director, Center for Outcomes and Evidence, AHRQ

Understanding enough about statistics to ask the right questions

Steve Goodman, Johns Hopkins Medical Institutions

Consumer involvement in Guidelines International Network (G-I-N)

Richard Rosenfeld, Chairperson, Guideline Development Task Force, American Academy of Otolaryngology - Head and Neck Surgery

10:45 – 11:15 a.m.

Discussion

11:15 – 11:30 a.m.

Break

11:30 a.m. – 1:00 pm

Workshops (see next page)

1:00 – 2:00 p.m.

Working Lunch

Session Co-Chairs: Maureen Corry, Alessandro Liberati

Luncheon Keynote: Communicating evidence: Lessons learned from USPSTF's recommendations on screening young women for breast cancer

Ned Calonge, Chair, U.S. Preventive Services Task Force

2:00 – 3:30 p.m.

Workshops (see next page)

3:30 – 3:45 p.m.

Break

3:45 – 4:45 p.m.

Panel Discussion: Global Consumer Action

Session Co-Chairs: Sallie Bernard, Gerd Antes

CCNet: Consumer action in the Cochrane Collaboration

Janet Wale, Cochrane Consumer Network, Australia

Demand for Information

Claudia Cattivera, Directora, Contenido y Programación, Pacientes Online

Raising Women's Voices for the Healthcare We Need

Cynthia Pearson, Executive Director, National Women's Health Network

Results of survey of consumer involvement in systematic reviews: Challenges and opportunities

Julia Kreis, Harkness/Bosch Fellow

4:45 – 5:15 p.m.

Discussion

5:15 – 5:30 p.m.

Consumer Call to Action!

Maureen Corry, Co-Chair, CUE Steering Committee

John Santa, Co-Chair, CUE Steering Committee

5:45 – 7:00 p.m.

Reception, Edgewater Café

Workshops

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Each workshop will be offered twice, first at 11:30 am and at 1:45 pm. Participants should register for two workshops. All workshops will include a brief presentation and the majority of the time will be devoted to discussion.

Workshop A: Critical appraisal of the evidence: How to ask an answerable question
Silverhawk Room

Scientist: Mark Helfand, Oregon Health and Sciences University
Consumer: Cathy Gordon, Oregon Health and Sciences University

If consumers are going to contribute to prioritizing comparative effectiveness research, they need to know how to ask a question that can be answered by a single research study. In addition, they need to be able to read the health literature critically, including assessment of whether the researchers asked an appropriate question and chose an appropriate design for answering it. We will make a short didactic presentation and spend the majority of our workshop time reviewing and discussing examples from the health literature.

Workshop B: Critical appraisal of the evidence: What do the statistics tell us about the truth?
Windwood Room

Scientist: Steve Goodman, Johns Hopkins Medical Institutions
Consumer: Cynthia Pearson, National Women's Health Network

What do published results tell us about the chance that the conclusions are correct? This workshop will examine critical appraisal of published research with a particular focus on how the statistical evidence is presented and interpreted. We will examine the meaning of statistical significance, P-values, confidence intervals, and other statistical measures in terms of what they tell us about the chance that the conclusions are true. These issues will be illustrated with examples from published papers. Combined lecture and discussion format.

Workshop C: Critical appraisal of the evidence: A technology assessment case study
Sunburst Room

Scientist: Naomi Aronson, Blue Cross Blue Shield Technology Evaluation Center
Consumer: Vicki Tosher, Colorado Breast Cancer Coalition

What does it entail to critically appraise the available evidence on the effectiveness of a technology? We will present a case study on partial breast irradiation (eg, Mammosite and other techniques) after breast conserving surgery for how Blue Cross Blue Shield Technology Evaluation Center performs its assessments. We will examine how to identify the available evidence, potential biases in the existing studies, and how they are addressed in the review. Combined lecture and discussion format.

Workshop D: Clinical practice guidelines: Do they contribute to good quality care?

Silverwood Room

Scientist: Marguerite Koster, Kaiser Permanente Southern California
Consumer: John Santa, Consumers Union

This workshop will provide an overview of evidence-based clinical practice guideline development based on case examples of current guideline-based quality improvement efforts of consumer and health care organizations. Workshop participants will engage in a collaborative learning exercise designed to simulate consumer involvement in the development of guideline recommendations for a health issue of international interest, and generate discussion about the opportunities for and barriers to consumer involvement in evidence-based health care decision making.

Workshop E: Who is a consumer and who gets to decide?

Foxfire Room

Consumer: Barbara Warren, National Coalition for LGBT Health
Consumer: Janet Wale, CCNet

What does it entail to be in a “consumer role” as a participant and advocate within a consumer organization, and how does that differ from being in a personal consumer role as a patient on one’s own behalf, or from being in a provider or researcher role? What are the different functions and responsibilities of being a consumer representing other consumers, what skills do you need and what are some of the ethical, advocacy and other challenges of being a consumer/advocate versus a personal patient versus in a professional role? Presentation/discussion format with vignettes/exercise in resolving consumer ethical dilemmas.

Workshop F: Levels of evidence, benefits of each & when & how to use different kinds of evidence

Sundrift Room

Scientist: Prathap Tharyan, South Asian Cochrane Network & Centre
Consumer: Sallie Bernard, SafeMinds

We often hear about different levels of evidence for assessing whether an intervention is effective or has safety concerns. What does this mean? When do we really need randomized evidence and when is evidence from observational studies acceptable? If randomized trials exist but they have not been conducted in our population of interest (eg, a population with multiple co-morbidities, a poorly nourished population), or if no randomized trials have been conducted, is it acceptable to assess an intervention’s effectiveness using observational evidence?