

Report  
**CUE - Consumers United for Evidence-based Healthcare**  
**2011 Annual Membership Meeting**  
12 August 2011  
Johns Hopkins University Carey School of Business  
Washington, DC

*This meeting was sponsored by the Agency for Healthcare Research and Quality (AHRQ)  
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## Table of Contents

1.	Overview .....	3
2.	Keynote address .....	4
2.1	PCORI - The need for educated consumers .....	4
3.	Panel - The IOM Committee's Report on Clinical Practice Guidelines .....	5
3.1	Clinical Practice Guidelines We Can Trust .....	5
3.2	Clinical Practice Guidelines Evolution at the American College of Cardiology ..	6
3.3	Consumers and Guidelines: Lessons Learned, Opportunities Ahead .....	7
4.	Presentations .....	7
4.1	Communicating about Evidence .....	7
4.2	Transparency in Consumer Advocacy Organization Funding: The Case of Health Advocacy Organizations .....	8
4.3	PubMed Health and Consumer Summaries of Systematic Reviews .....	8
4.4	Meta-analysis in the Toolbox for Pharmaceutical Regulation .....	9
5.	Workshops .....	9
5.1	Serving on a Guidelines Panel .....	9
5.2	Effectively Representing the Advocate Perspective in Advisory Settings .....	10
5.3	Promoting Evidence-based Health Care in Accountable Care Organizations ...	11
6.	Summary of participant evaluations .....	11
7.	Appendices .....	13

## 1. Overview

The Consumers United for Evidence-based Healthcare (CUE) Annual Membership Meeting was the highlight of 2011. The goal of the Meeting was to build consumer leadership in evidence-based healthcare (EBHC) and comparative effectiveness research (CER) through CUE. We convened 40 consumer advocates, their science and policy partners, and others interested in working to include the public in evidence-based decision-making on August 12, 2011 in Washington, DC. This is a 62% increase over the 2010 Membership Meeting attendance. Attendees came from 7 states and the District of Columbia.

CUE members on the Planning Committee identified the plenary and workshop topics and recommended speakers and facilitators (see Appendix 1 for the agenda). Plenary sessions included “PCORI - The Need for Educated Consumers,” “Communicating about Evidence,” “Transparency in Consumer Advocacy Organization Funding,” The Institute of Medicine (IOM) Committee’s Report on Clinical Practice Guidelines,” and “PubMed Health and Consumer Summaries of Systematic Reviews.” Workshop sessions included “Serving on a Guidelines Panel,” “Effectively Representing the Advocate Perspective in Advisory Settings,” and “Promoting Evidence-based Health Care in Accountable Care Organizations.” In addition to receiving access to outstanding education and speakers, participants networked with and learned from each other.

The Planning Committee comprised CUE members and US Cochrane Center (USCC) staff and engaged in meeting preparations and post-meeting activities. Pre-meeting preparations in July and August included finalizing registrations and travel arrangements for attendees, and preparing meeting materials (eg, signage, nametags and conference folders that included the agenda, speaker biographical sketches, participant list, evaluation form, brochures about CUE, the Cochrane Collaboration, *The Cochrane Library* and the Affordable Care Act. Much effort went into surveying meeting attendees about workshop choice and assigning them to one of the three workshops available at the meeting. Post-meeting activities included collating meeting evaluations, drafting the meeting report, posting podcasts of the plenary sessions on the USCC website, processing reimbursements to scholarship recipients for travel-related expenses, and sending thank you letters to speakers and funders.

We were able to supplement the funds provided by the Agency for Healthcare Research and Quality (AHRQ), with additional funds allowing us to provide breakfast, snacks, beverages, and lunch to participants.

The annual meeting contributed to building a strong and sustainable network of informed consumer advocates who would not otherwise have had reason or funding to come together for

in-person meetings. The meeting evaluations and post-meeting communication with participants provided support for our conclusion that the knowledge and experience gained at the meeting contributed to consumer leadership in EBHC advocacy.

Participants were encouraged to provide a written evaluation of the meeting and were given a survey instrument largely consisting of questions measured on a five-point Likert scale. Open-ended comments were also solicited. The evaluation scores and comments show that respondents were overwhelmingly supportive of the meeting's presenters, content, and organization. Twenty-four participants returned the evaluation, and not all questions were answered by all respondents. Of the respondents who rated the statement "The program met my expectations," 100% responded "yes" (18/18).

A summary of the day was expressed by one participant in his/her evaluation:

"I always appreciate the level of engagement at CUE meetings. Participants come ready for discussion - to teach and learn. The day was very well facilitated with plenty of breaks and time to network."

## **2. Keynote address**

### **2.1 PCORI - The need for educated consumers**

**Lawrence Becker, PCORI (Patient-Centered Outcomes Research Institute)  
Board of Governors, and Director, Strategic Partnerships and Alliances,  
Xerox Corporation**

Lawrence Becker, as a member of the PCORI Board of Governors, gave CUE members an overview of The Patient-Centered Outcomes Research Institute (PCORI). PCORI "helps people make informed health care decisions – and improves health care delivery and outcomes – by producing and promoting high integrity, evidence-based information that comes from research guided by patients, caregivers and the broader health care community."

The PCORI Board, comprising a diverse group of individuals, convenes "Town Hall" meetings around the country as it seeks public input. PCORI's core duties are to:

- Establish national research priorities;
- Establish and carry out a research project agenda;
- Develop and update methodologic standards;
- Provide a peer review process with the core purpose of including consumers in the process; and
- Disseminate research findings.

Patients do not necessarily have the information they need to make well-informed healthcare decisions. PCORI promises to:

- Understand the choices patients face;
- Align methods and data with patient needs; and
- Provide patients and providers with information for better decision-making.

PCORI is working to establish initial national research priorities, informed by:

- Stakeholder engagement;
- Landscape reviews;
- Pilot projects;
- Conference grants;
- Methodology Committee report; and
- Extensive public comment.

The PCORI Methodology Committee aims to synthesize and establish confidence in available information about comparative effectiveness methods. There will be eight Tier 1 pilot projects with the Request for Applications issued in September, 2011. Mr. Becker urged audience members to request being added to the PCORI mailing list.

### **3. Panel - The IOM Committee's Report on Clinical Practice Guidelines**

#### **3.1 Clinical Practice Guidelines We Can Trust**

**John Santa, Director, Consumer Reports Health Ratings Center**

A large number of clinical practice guidelines (CPGs) of varying quality exist. For example, there are over 450 guidelines concerning high blood pressure. Dr. Santa proffered that some are excellent, and some are no more than advertisements disguised as guidelines. In an effort to improve the quality of CPGs and spearheaded by AHRQ, The IOM convened a committee that produced the report, *Clinical Practice Guidelines We Can Trust* (released March 23, 2011). Dr. Santa served as one of two consumers on the committee that produced the report.

Dr. Santa reported on the six characteristics necessary for guidelines to be considered trustworthy. He also outlined the eight standards that should be followed during the guideline development process (<http://us.cochrane.org/clinical-practice-guidelines-we-can-trust-john-santa> includes these lists). He highlighted several areas of the committee's effort, such as in-depth discussion concerning potential conflicts of interest (COI). Dr. Santa suggested that consumers who are involved in guideline development can be helpful by questioning COI. The report states that funders should have no role in guideline development; training is necessary for guideline developers; the guidelines process should begin with systematic reviews; consumers should be involved; and the process should be transparent and open for comment by the public.

Six weeks following the release of the report, 150 people attended an open meeting to discuss it. Dr. Santa said that this is a strong show of support among guideline developers to “get it right.” Concerning the report’s increased role for consumers, one guideline developer expressed to Dr. Santa that s/he had less than positive experiences with consumers on their guidelines panels, while others expressed positive experiences. Dr. Santa also noted, however, positive partnerships such as that between CUE members who have been trained and have served on guidelines development panels and the American Academy of Otolaryngology. The implications for CUE are to provide trained consumers who will positively impact this process of developing clinical practice guidelines we can trust.

### **3.2 Clinical Practice Guidelines Evolution at the American College of Cardiology Janet Wright, Senior Vice President for Science and Quality, American College of Cardiology**

The American College of Cardiology (ACC) has been developing clinical practice guidelines for 27 years. Dr. Wright described herself as a “rabid fan” of consumer involvement in this process. She spoke to the group about the potential impact of the IOM standards on ACC/AHA (American Heart Association) guideline development.

Responding to the IOM call for transparency, Dr. Wright explained that The ACC and the AHA receive no funding for guideline development. Each guideline requires approximately \$1,000,000 to complete. All funding sources are publicly accessible on their website. Concerning conflict of interest, the ACC has in place a system to handle relationships with industry (RWI), with disclosure of individual’s relationships required in advance, at every meeting and conference call, and published on their website. More detail about the ACC’s RWI policy is in the complete slidecast of Dr. Wright’s presentation, found on the CUE website at <http://us.cochrane.org/clinical-practice-guidelines-evolution-american-college-cardiology-janet-wright>.

Reporting on the potential impact of Standard 3 of the IOM report (multidisciplinary guideline development group composition), Dr. Wright noted that patients and consumers are the missing link for the ACC because they are not yet included on their guidelines writing committees. The reason for this lack of consumer involvement is due to: a lack of knowledge about consumers trained in EBHC; the burden and expense of training consumers; a perception that consumer involvement will delay guideline development; and the potential for introduction of bias contradictory to the evidence adjudication process, especially with lack of evidence. Dr. Wright reported that the ACC has had some negative experiences with consumers in the past.

Prior to being invited to speak at this meeting, Dr. Wright had been unaware of CUE, and is looking forward to improving the ACC guideline development process by working with CUE to include educated consumers in their efforts.

**3.3 Consumers and Guidelines: Lessons Learned, Opportunities Ahead**  
**Richard Rosenfeld, Chairperson, Guideline Development Task Force, American Academy of Otolaryngology - Head and Neck Surgery (AAO-HNS)**

Dr. Rosenfeld explained that clinical practice guidelines (CPGs) have a profound effect on health care: they drive quality measures, health policy, the questions doctors ask, and the way doctors get certified and re-certified. Therefore, CPGs should be developed by a multi-disciplinary and balanced group, meaning consumers should be involved from the beginning. Historically, this has not been the case, but the AAO-HNS has been including consumers from the beginning (the last six years). Both consumers and clinicians have to be accountable and balanced, and the same requirements must apply to both.

He highlighted the recent formation of G-I-N NA (Guidelines International Network, North America), which brings a regional influence to the guidelines development process. The G-I-N NA meeting will take place in New York within the year. Dr. Rosenfeld hopes to work closely with CUE to develop a link between North American guideline developers and consumers. He warned that the issue of consumer involvement cannot be a haphazard process left to chance. The process of consumer involvement in guidelines development needs to be intentional and involve the educated consumer. Dr. Rosenfeld emphasized that, indeed, the educated consumer can be the best member of a guideline group.

**4. Presentations**

**4.1 Communicating about Evidence**  
**Chuck Alston, Senior Vice President, Director of Public Affairs at MSL Washington**

As a person involved in communications with the public about health and medical issues, Chuck Alston presented his suggestions for communicating with consumers about evidence-based healthcare. Mr. Alston cited various sources that exposed consumer skepticism about popular health policy terms, including the term *evidence-based medicine*. Consumers hear the word “evidence” and interpret it as “impersonal, one size fits all.” Mr. Alston recommends that to overcome this negative perception of evidence and evidence-based medicine, care should be taken in presenting these terms. It should be clearly communicated that scientific evidence is only one component of evidence-based medicine, the other parts being the patient preferences and values, and clinical expertise of the clinician.

Mr. Alston’s results with focus groups show that the most effective message for patients about evidence, guidelines, or recommended care should include mention of three points: that national experts created the guidelines; they are based on scientific evidence; and they are not binding.

#### **4.2 Transparency in Consumer Advocacy Organization Funding: The Case of Health Advocacy Organizations**

**Sheila Rothman, Mailman School of Public Health, Columbia University**

Health advocacy organizations (HAO) were established in the first decades of the 20<sup>th</sup> century and were organized by concerned citizens to improve the health of their communities. They were funded by philanthropists and their mission was equated with the public interest.

Dr. Rothman posited that industry is attracted to health advocacy organizations because of their effectiveness and the ability to put a “face” on the disease or disorder. As a result, pharmaceutical companies donate to health advocacy organizations. Key in this relationship is the need for transparency on the part of the HAOs. Using data from the Eli Lilly Grant Registry and comparing it to information on HAO websites, Dr. Rothstein determined that of the 181 HAOs listed on the registry as having received grants from Eli Lilly, only 25% acknowledged on their website Eli Lilly as a funder, only 10% mentioned the purpose of the grant, and none of the HAOs mentioned the amount of the grant. Dr. Rothstein challenges HAOs to disclose funding sources on their websites, and said that “sunshine is the best disinfectant.”

During the subsequent discussion period, a member of the audience suggested that in addition to disclosing organizations that they fund, pharmaceutical companies should also be required to disclose the organizations they have declined to fund.

#### **4.3 PubMed Health and Consumer Summaries of Systematic Reviews**

**Hilda Bastian, Pubmed Health, NCBI (National Library of Medicine, NIH)**

Ms. Bastian is spearheading the re-development of PubMed Health into a website that will focusing on comparative effectiveness research. Since this website will rely on summaries of systematic reviews, Ms. Bastian outlined the elements of a good consumer summary. She emphasized that summaries should aim to be written in plain language and include contextual information which may not be in the review. It should also be relatively short while being accurate. To illustrate, she provided an example of a Cochrane Plain Language Summary with a SMOG factor (Simple Measure of Gobbledygook - a readability formula that estimates the years of education needed to understand a piece of writing) of less than 12.

PubMed Health will include review summaries from a growing list of contributors, including The Cochrane Collaboration, AHRQ, IQWiG (Institute for Quality and Efficiency in Health Care - Germany), NICE (National Institute for Health and Clinical Excellence - United Kingdom) and more. Plans exist for expanding PubMed Health to also include a “reading room” of online resources.



#### **4.4 Meta-analysis in the Toolbox for Pharmaceutical Regulation**

**George Rochester, Lead Statistician, Food and Drug Administration (FDA)**

The use of meta-analysis for pharmaceutical safety evaluations is well-established, but meta-analysis has not been used as the evidentiary framework for efficacy. Dr. Rochester emphasized that meta-analysis is just one tool the FDA uses to determine drug safety; others include its Critical Path, Safe Use, Adverse Event Reporting System and Vaccine Adverse Event Reporting System. He also explained that the FDA is developing guidance on the use of meta-analysis.

Sources of information signaling safety issues come from the sponsor's development program, conjectures from experts, scientific publications, regulatory actions outside of the US, and advocacy groups. For common adverse events, individual randomized-controlled trials (RCTs) may provide adequate information. For rare adverse events, however, RCTs may not provide enough follow-up or large enough populations, and meta-analysis of RCTs and/or observational studies may be required. Consumers can get information from FDA "pink sheets," PDUFA (Prescription Drug User Fee Act) and MDUFA (Medical Device User Fee Act) websites. Consumers should consider volunteering to serve on FDA advisory groups.

### **5. Workshops**

#### **5.1 Serving on a Guidelines Panel**

**Peter Robertson, Analyst, Research & Quality Improvement, American Academy of Otolaryngology - Head and Neck Surgery (AAO-HNS)**  
**Barbara Warren, National Coalition for LGBT Health**

Dr. Warren shared her experience as a consumer on a Clinical Practice Guidelines Development Panel concerning Sudden Hearing Loss with the AAO-HNS. She emphasized the success of the process which brought a diverse group of clinicians and consumers together and enabled them to come to a consensus.

Mr. Robertson described the history of the AAO-HNS Guideline Development Taskforce and explained that while practice guidelines use the results of systematic reviews as a basis for recommendations, they do not present sufficient information to provide reviews of the available evidence. Guidelines contain key statements that are action-oriented prescriptions of specific behavior from a clinician. The AAO-HNS uses a pragmatic, transparent process to develop guidelines which are evidence-based. He presented an overview of that process and emphasized that consumers and clinicians have equal voices in this process. At the AAO-HNS, consumers and clinicians receive the same training to prepare them to develop guidelines. Mr. Robertson welcomed invited CUE members to become active participants with them in the guidelines development effort.

**5.2 Effectively Representing the Advocate Perspective in Advisory Settings**  
**Annette Bar-Cohen, Executive Director of the Center for National Breast Cancer Coalition (NBCC) Advocacy Training**  
**Jennifer Sweeney, Director, Americans for Quality Health Care, National Partnership for Women and Families**

In her efforts with Aligning Forces for Quality, Jennifer Sweeney works with consumer advocates, patients and families to address healthcare quality issues within their communities. These individuals need to be effective in order to impact the issues within groups containing clinicians and policy makers. Consumers often want to share their personal health story, which helps others understand the patient point of view, but the sharing must be limited to be effective. The big picture is most important, and the personal story can support that.

Ms. Sweeney recommended that the consumer advocate should align with like-minded stakeholders in the group because they can help the advocate learn the ropes. The advocate should interact with his/her constituency regularly and get feedback. The advocate should remind decision makers that s/he is responsive to a constituency. It is important to prepare for the stakeholder meetings by studying all background materials and asking for support in order to learn about the interests of the other people at the table.

Giving thought to the scope of work needed with a group is very important - make sure the advocate role is clearly defined. Advocates can never prepare enough - someone else will always know more than the advocate. Usually there is a staff liaison who can answer questions - the advocate should ask for the agenda, research materials and website links to help them prepare.

Understanding the decision-making process is also important. Although advocates may be angry with good reason, that anger must be tempered in order to be successful in a multi-stakeholder group. The advocate message needs to be received positively by the other stakeholders. Consider: What's in it for me (WIIFM)? What's going to appeal to this other person? What will help us find common ground? The process is one of negotiation.

Annette Bar-Cohen explained that educated consumers need to be at the table whenever meaningful health decisions are made. That means 1) finding the tables and securing the seats; 2) figuring out what an educated consumer is for the setting and identifying one or more candidates; and 3) defining decisions where it is important to have meaningful input.

The NBCC considers the following to be criteria for an advocate who truly represents the patient advocacy perspective on an advisory group. S/he must be part of a patient-led, patient-centered organization; responsible and accountable to a patient constituency; must be personally affected by the disease or condition; and must be knowledgeable, trained, prepared and confident

in his/her ability to participate in the decision-making process of science and medicine.

### **5.3 Promoting Evidence-based Health Care in Accountable Care Organizations** **Kirsten Sloan, National Partnership for Women and Families** **Kate Ryan, National Women's Health Network**

Kirsten Sloan works with the Campaign for Better Care, whose goals are to ensure that the new models of healthcare (resulting from the Affordable Care Act - ACA) are really patient-centered, and to create a movement among older persons with chronic conditions (and their caregivers) to engage them in the new ACA models of care. One of these new models is the Accountable Care Organization (ACO). ACOs are groups of doctors, hospitals, and other health care providers, who come together voluntarily to give coordinated high quality care to the Medicare patients they serve. ACOs create incentives for health care providers to work together to treat an individual patient across care settings – including doctor's offices, hospitals, and long-term care facilities. Currently, patients have no regulated care management. This lack of management is characterized by uncoordinated care, lack of chronic care management, poor communication, and duplicate tests. The ACO, if done correctly, is a potential solution to this dilemma.

Kate Ryan explained that any entity applying to be an ACO will have to define the processes by which they will promote evidence-based healthcare. To demonstrate incorporation of EBHC, ACOs should: describe the evidence-based guidelines it will follow or establish; describe how it will implement these guidelines; and describe how it will demonstrate that it is following these guidelines.

## **6. Summary of participant evaluations**

The goal of CUE's annual meeting was to contribute to building a strong and sustainable network of informed consumer advocates who would not otherwise have had reason or funding to come together for in-person meetings. The meeting evaluations and post-meeting communication with participants provided support for our conclusion that the knowledge and experience gained at the meeting contributed to consumer leadership in EBHC advocacy.

Forty individuals attended the 2011 CUE Annual Membership Meeting. Participants were encouraged to provide a written evaluation of the meeting and were given a survey instrument (see Appendix 2) that largely consisted of questions measured on a five-point Likert scale. Open-ended comments were also solicited. Twenty-three participants returned the evaluation, and not all questions were answered by all respondents. The evaluation scores and comments show that respondents were overwhelmingly positive about the meeting presenters, content, and organization. All respondents to the question (18/18) reported that the program met their expectations. A number of suggestions focused on a desire for more time to cover the many

topics and for a room with better acoustics. All suggestions will be taken into account when planning future meetings.

## 7. **Appendices**

- Appendix 1 - Program Agenda
  - Appendix 2 - Evaluation Survey Instrument
  - Appendix 3 - Evaluation Quantitative Summary
  - Appendix 4 - Evaluation Comments
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## Appendix 1

Consumers United for Evidence-based Healthcare (CUE)

### **2011 Annual Membership Meeting**

August 12, 2011; 8:30 am - 4:30 pm

Johns Hopkins University Carey Business School

1625 Massachusetts Ave. NW

Washington, DC 20036

### **Program Agenda**

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8:30 am - 8:45 am	<b>Registration &amp; Continental Breakfast</b>
8:45 am - 9:30 am	<b>Welcoming remarks and Steering Committee Report</b> <i>Rebecca Burkholder</i> , Co-chair, CUE, Vice President of Health Policy, National Consumers League <i>John Santa</i> , Co-chair, CUE, Director, Consumer Reports Health Ratings Center <i>Kay Dickersin</i> , Director, US Cochrane Center, Director, Center for Clinical Trials, Johns Hopkins Bloomberg School of Public Health  <b>New CUE video</b> <i>John Santa</i> , CUE Co-chair; Director, Consumer Reports Health Ratings Center  <b>CUE's Role in Developing Trained Consumer Advocates</b> <i>Kay Dickersin</i> , US Cochrane Center
9:30 am - 9:50 am	<b>Keynote: PCORI - The Need for Educated Consumers</b> <i>Lawrence Becker</i> , PCORI (Patient-Centered Outcomes Research Institute) Board of Governors, and Director, Strategic Partnerships and Alliances, Xerox Corporation
9:50 am - 10:10 am	<b>Discussion</b>
10:10 am - 10:25 am	<b>Break</b>

## Appendix 1

### 2011 CUE Annual Membership Meeting – Agenda (cont'd)

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- 10:25 am - 11:05 am      **Panel - The IOM Committee's Report on Clinical Practice Guidelines**
- Clinical Practice Guidelines We Can Trust**  
                                 *John Santa*, Director, Consumer Reports Health Ratings Center
- Clinical Practice Guidelines Evolution at the American College of Cardiology**  
                                 *Janet Wright*, Senior Vice President for Science and Quality, American College of Cardiology
- Consumers and Guidelines: Lessons Learned, Opportunities Ahead**      *Richard Rosenfeld*, Chairperson, Guideline Development Task Force, American Academy of Otolaryngology - Head and Neck Surgery
- 11:05 am - 11:25 am      **Discussion**
- 11:25 am - 11:45 am      **Communicating about Evidence**  
*Chuck Alston*, Senior Vice President, Director of Public Affairs at MSL Washington
- 11:45 am - 12:00 pm      **Discussion**
- 12:00 pm - 1:10 pm      **Lunch/Networking Time/CUE business meeting**
- 1:10 pm - 1:25 pm      **Transparency in Consumer Advocacy Organization Funding: The Case of Health Advocacy Organizations**  
*Sheila Rothman*, Mailman School of Public Health, Columbia University
- 1:25 pm - 1:35 pm      **Discussion**
- 1:35 pm - 1:50 pm      **PubMed Health and Consumer Summaries of Systematic Reviews**  
*Hilda Bastian*, Pubmed Health, NCBI (National Library of Medicine, NIH)
- 1:50 pm - 2:00 pm      **Discussion**
- 2:00 pm - 2:15 pm      **Break**

## Appendix 1

### 2011 CUE Annual Membership Meeting – Agenda (cont'd)

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2:15 pm - 3:30 pm

**Workshops** (see *Workshop Descriptions*, page 4)

**Workshop A (room 201): Serving on a Guidelines Panel**

*Peter Robertson*, Analyst, Research & Quality Improvement,  
American Academy of Otolaryngology - Head and Neck  
Surgery

*Barbara Warren*, National Coalition for LGBT Health

**Workshop B (room 117): Effectively Representing the  
Advocate Perspective in Advisory Settings**

*Annette Bar-Cohen*, Executive Director of the Center for National  
Breast Cancer Coalition (NBCC) Advocacy Training

*Jennifer Sweeney*, Director, Americans for Quality Health Care,  
National Partnership for Women and Families

**Workshop C (room 202): Promoting Evidence-based Health  
Care in Accountable Care Organizations**

*Kirsten Sloan*, National Partnership for Women and Families

*Kate Ryan*, National Women's Health Network

3:30 pm - 3:40 pm

**Break**

3:40 pm - 4:00 pm

**Meta-analysis in the Toolbox for Pharmaceutical Regulation**

*George Rochester*, Lead Statistician, FDA

4:00 pm - 4:15 pm

**Discussion**

4:15 pm

**Evaluation**



**CUE Annual Membership Meeting  
August 12, 2011  
Workshop Descriptions**

**Workshop A: Serving on a Guideline Panel**

*Peter Robertson*, Analyst, Research & Quality Improvement, American Academy of Otolaryngology -  
Head and Neck Surgery  
*Barbara Warren*, National Coalition for LGBT Health

This workshop will provide an overview of the American Academy of Otolaryngology-Head and Neck Surgery clinical practice guideline development work. Participants will gain an understanding of the guideline development process and what to expect as a guideline development group participant. The consumers role in guideline development will also be discussed.

**Workshop B: Effectively Representing the Advocate Perspective in Advisory Settings**

*Annette Bar-Cohen*, Executive Director of the Center for NBCC Advocacy Training.  
*Jennifer Sweeney*, Director, Americans for Quality Health Care, National Partnership for Women and Families

This Workshop will outline best practices in representing the advocate perspective in advisory settings. Drawing from personal experiences, as well as from NBCC and NPWF curricula and trainings, Bar-Cohen and Sweeney will offer strategies to advocate effectively for patient and consumer interests, ways to prepare for meetings, resources to tap into to enhance content knowledge, and specific techniques to ensure your message is heard by the stakeholders.

**Workshop C: Promoting Evidence-based Health Care in Accountable Care Organizations**

*Kirsten Sloan*, National Partnership for Women and Families  
*Kate Ryan*, National Women's Health Network

This workshop will provide an overview of Accountable Care Organizations (ACO) and give participants a chance to discuss the model as well as generate ideas for how to promote evidence-based practices within ACOs. The new health reform law is encouraging the creation of ACOs, new health care entities that will coordinate the care of Medicare beneficiaries with the dual goals of improving the quality of health care and lowering health care costs. The workshop will explore how increased use of evidence-based medicine could help an ACO achieve those goals.



2011 Annual Membership Meeting  
August 12, 2011  
**Evaluation**

### 1. New CUE video

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of video</b>					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
<b>B. Quality of presentation by speaker</b>					
John Santa	5	4	3	2	1

### 2. CUE's Role in Developing Trained Consumer Advocates

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
<b>B. Quality of presentation by speaker</b>					
Kay Dickersin	5	4	3	2	1

### 3. Keynote: PCORI - The Need for Educated Consumers

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Lawrence Becker	5	4	3	2	1

## Appendix 2

2011 Evaluation - Annual Membership Meeting (cont'd)

### 4. Panel Discussion - The IOM Committee's Report on Clinical Practice Guidelines

John Santa  
Janet Wright  
Richard Rosenfeld

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Panel member - John Santa	5	4	3	2	1
Panel member - Janet Wright	5	4	3	2	1
Panel member - Richard Rosenfeld	5	4	3	2	1

### 5. Communicating about Evidence

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Chuck Alston	5	4	3	2	1

### 6. Transparency in Consumer Advocacy Organization Funding: The Case of Health Advocacy Organizations

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Sheila Rothman	5	4	3	2	1

## Appendix 2

2011 Evaluation - Annual Membership Meeting (cont'd)

### 7. PubMed Health and Consumer Summaries of Systematic Reviews

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Hilda Bastian	5	4	3	2	1

### Workshop A: Serving on a Guidelines Panel

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Peter Robertson	5	4	3	2	1
Barbara Warren	5	4	3	2	1

### Workshop B: Effectively Representing the Advocate Perspective in Advisory Settings

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Annette Bar-Cohen	5	4	3	2	1
Jennifer Sweeney	5	4	3	2	1

## Appendix 2

2011 Evaluation - Annual Membership Meeting (cont'd)

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### Workshop C: What do Accountable Care Organizations (ACOs) have to do with evidence?

I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
Kirsten Sloan	5	4	3	2	1
Kate Ryan	5	4	3	2	1

### 9. How Safety Data Are Included in the FDA Approval and Post-approval Process

	Excellent	Very Good	Good	Fair	Poor
<b>A. Quality of session</b>					
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
<b>B. Quality of presentation by speaker</b>					
George Rochester	5	4	3	2	1

### Overall Evaluation

	Yes	No	Not Certain
1. The program was presented without evident commercial bias or influence.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. The program met my expectations	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Please provide comments or suggestions: _____			
_____			
_____			
_____			
_____			
_____			