Report

CUE - Consumers United for Evidence-based Healthcare
2012 Annual Membership Meeting

June 8, 2012

Johns Hopkins University Carey School of Business

Washington, DC

This meeting was sponsored by the Agency for Healthcare Research and Quality (AHRQ)
(Grant # 1R13 HS017668-01A)

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A. Executive Summary

The high point of this year was the gathering of CUE members, researchers, policymakers and funders at the 2012 CUE Annual Membership Meeting in Washington DC (see Appendix 1 for Agenda). CUE consumer advocates networked, listened to and gave presentations, and participated in lively discussions, all with the aim of building the leadership capacity of CUE members concerning evidence-based healthcare (EBHC). The day was focused on the role and effect of the educated consumer in comparative effectiveness research (CER). Consumer advocates spent a high-energy day interacting with one another and with policy and science partners. The 34 participants (not including four USCC staff who were present) hailed from eight states and the District of Columbia.

CUE Planning Committee members began in January to identify topics and speakers. The Committee chose a panel format for three topics. These panels included both CUE members and outside speakers, allowing for a rich exchange of ideas from various viewpoints. For example, the first panel, *Strengths and Challenges to Engaging Consumers in Research*, included funder/researcher Dr. Lori Frank (Patient-Centered Outcomes Research Institute - PCORI), CUE member Kate Ryan (National Women's Health Network), and researcher Dr. C. Daniel Mullins (University of Maryland) (see Appendix 1 for composition of all three panels). Each of the three panels (and all presentations) was followed by a 15 - 30 minute discussion period with the audience. Additional panel sessions were *Effecting Change Through Consumer Advocacy* and *The Role of CUE Members with the FDA.*

Four individual presentations were made by policy partners (*The Sentinel Initiative* by Gregory Daniel of The Brookings Institution; *How We Know Consumers Are Making a Difference* by Anton Gunn of the US Department of Health and Human Services), a funder (*How Can CUE Contribute to AHRQ's Effective healthcare Program?* by Jean Slutsky of AHRQ), and a CUE member (*The Journey from Outside to Inside CUE: What Can We Do Better?* by Lorraine Johnson of LymeDisease.org).

CUE members divided into four groups to participate in the Roundtable Discussion: *Disseminating CUE to Member Organization Constituencies and Measuring the Impact of Our Work.* Members of the Steering Committee facilitated each group. The information shared within the smaller groups will help the Steering Committee and USCC staff to address the needs of CUE membership in the coming year (see Appendix 2 - Roundtable Summary).

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 (see Appendices 3, 4 and 5) and post-meeting communication with participants provided support for our conclusion that the knowledge and experience gained at the meeting contributes to consumer leadership in EBHC advocacy.

B. Detailed Report of Annual Meeting

1. Panel: Strengths and Challenges to Engaging Consumers in Research

1.1 PCORI's Engagement of Consumers and Patients

Lori Frank, PCORI (Patient-Centered Outcomes Research Institute)
Director, Engagement Research

Dr. Lori Frank introduced CUE members to the PCORI Methodology Committee's recently released research on methodological practices (*Our Questions, Our Decisions: Standards for Patient-centered Outcomes Research)*. The committee's research aim was to:

- Define the best methodological practices;
- Identify gaps in methods knowledge; and
- Prioritize methodological areas of focus.

Approximately 250 research articles concerning patient-engagement was found in the searched literature. Researchers found that there were very few studies in engagement; these studies were qualitative in study design and vague in method. No studies were found on comparative studies in patient engagement. This paucity of patient engagement studies signaled the necessity of the research that the PCORI Methodology Committee was carrying out.

The research culminated with *Our Questions, Our Decisions: Standards for Patient-centered Outcomes Research*, which listed six standards for patient-centeredness and engagement. The report lists ways to involve patients and consumers in every step of a research study, from identifying a research question that consumers care about to disseminating study results to the general public.

These standards for patient-centeredness and engagement are intended to ensure mutual benefit exchanged between study participants and researchers. Trust, transparency, co-learning, reciprocal relationships, and honesty were noted as key features which established the best practice of patient engagement in research. In the question and answer session following the talk, a CUE member noted how these new standards were changing the norm of consumer

engagement from passive to active.

1.2 Insight from CUE - Who Counts as a Consumer?
Kate Ryan, National Women's Health Network, CUE Steering Committee

Often, even with individuals well-versed in consumer advocacy, the terms "patient" and "consumer" are used interchangeably. Kate Ryan outlined her views on the differences in meaning for CUE members, all the while highlighting an important point: being a patient is equivalent to being a consumer of healthcare, but is not sufficient enough to become a consumer representative. Several CUE members expressed appreciation of the distinction; in the question and answer session, CUE member Jennifer Sweeney offered a helpful online resource for those who wished to learn more (http://www.nationalpartnership.org/site/PageServer?pagename=qcn_ToolBox_ConsumerEngagement).

Ms. Ryan emphasized the importance of consumer representatives being given a voice in healthcare research. They bring a different perspective to the table and serve as watchdogs of the healthcare industry in order to protect consumer interests. Consumer representatives are often individuals without medical training, but they are still expected to understand detailed health-related information. This, Ms. Ryan notes, is why being a consumer of healthcare is not sufficient to become a consumer representative. It is not a role in which one simply represents that individual's perspective, but rather the community's perspective is important. Therefore, it is necessary to have ties to a consumer advocacy group and vital to have no conflicts of interests, either financial or intellectual.

1.3 Input from Hard-to-Reach Consumers
C. Daniel Mullins, Professor, Pharmaceutical Health Services Research Department, University of Maryland

For consumer engagement to be a reality, "hard-to-reach" consumers must be involved. These are consumers who are not typically represented in research; examples include minorities, individuals with under-privileged socio-economic backgrounds, the elderly, and non-English language speakers. Dr. Mullins pointed out that consumers must be met in a culturally- and emotionally-sensitive manner. Researchers must be empathetic and responsive to participant values. For instance, a discussion of experimental treatment options with a person who has been given a cancer diagnosis should occur when the patient is emotionally ready.

Dr. Mullins identified alternative solutions for hard-to-reach individuals who are not receptive to researchers. He recognized community leaders as exerting influence concerning

community participation in research; these leaders can range from tribal leaders to the soccer mom on the block. Dr. Mullins strongly believes that research needs to be more patient-friendly, that researchers should not just tell participants, "I'm going to draw your blood," but explain why drawing their blood is necessary for a study.

Dr. Mullins introduced the "Ten-Step Process for Conducting Comparative Effectiveness Research," and he emphasized how study participants should be involved in every step. For topic solicitation, individuals should give broad input into topics that are important to them. To frame the question, ask individuals to rephrase the research question to make it more understandable. Traditionally, consumers have only been involved in the last three steps (reviewing results, translation, and dissemination) of the process, but Dr. Mullins emphasized that consumers should be thoroughly involved in every step.

2. Panel: Effecting Change Through Consumer Advocacy

2.1 Being an Effective Consumer Advocate
Jennifer Sweeney, Director, Americans for Quality Health Care, National Partnership for Women & Families, CUE Steering Committee

As a consumer advocate who has had 7 years of experience serving on advisory boards and panels, Jennifer Sweeney offered CUE members advice based on what she has learned. First, she noted how personal stories often make a big impact, but also stressed the importance of stepping back and connecting your personal story to the bigger picture. Ms. Sweeney suggested aligning with like-minded stakeholders who can amplify your voice on advisory boards. Staying connected with your constituents is also crucial in balancing the power dynamics in stakeholder meetings. As opposed to stakeholders who promote industry interests, consumer advocates can connect with their community.

Although power dynamics in stakeholder meetings can be a struggle for consumer advocates, Ms. Sweeney drew attention to the significance of understanding the other stakeholders' viewpoints. She told CUE members that "it [was] impossible to advocate on behalf of my organization" without having "a good sense of where the other stakeholders were coming from". If the discussion at a multi-stakeholder meeting is inaccessible for consumer advocates, Ms. Sweeney recommends pausing the discussion to ask for support.

Ms. Sweeney stressed the need for balance between advocacy and partnership. As opposed to seeing other stakeholders with an "enemy perspective," it is much more rewarding to see them with a "partnership perspective". She advised CUE organizations to encourage their members to serve on advisory boards and panels, to put the consumer voice front and center.

2.2 How Consumer Input Changed Things
Judy Norsigian, Executive Director, Our Bodies Ourselves

Ms. Norsigian, co-author of the groundbreaking book on women's healthcare, *Our Bodies Ourselves* (*OBOS*) (4.5 million copies in print), and founder of the organization by the same name, asked the assembled group to celebrate with her the 40th anniversary of the book's publication. She shared with the group that a key to success in advocacy is the proper selection of allies. She emphasized that often consumer advocates must struggle against large corporations or groups with large amounts of financial resources, and the consumer advocate can strengthen their position by creating strong partnerships with like-minded groups.

After 40 years of advocacy work, *OBOS* continues to advocate for evidence-based policy regarding women's health. *OBOS* is currently advocating for accountability and evidence-based information in the field of assisted reproductive therapies (ARTs). There is a lack of evidence showing long-term effects of egg donation on donors and inadequate informed consent provided to the donors. *OBOS* has collaborated in drafting a letter for fertility clinics, informing them of the existence of the Infertility Family Research Registry (IFRR) and asking them to encourage their patients to join the registry, which will be used for research into long-term effects of fertility practices.

She noted that efforts to provide evidence-based healthcare information to legislators has failed to produce sound public policy. She urged CUE members to consider how they link to other groups and resources to reach consumers and policymakers with the best information available.

3. How We Know Consumers Are Making a Difference
Anton Gunn, Director of External Affairs, US Department of Health and Human Services

Beginning January 2014, insurance plans resulting from the Affordable Care Act (ACA) will be available for purchase. Mr. Gunn described the biggest hurdle he faces in his position: most people do not know details about the ACA and the information they do have is incorrect. Since nearly 40 million Americans will be able to purchase new healthcare insurance in 2014, Mr. Gunn emphasized how critical it is to have networks engaged to share correct information about the ACA and increase its credibility.

He explained that the easiest way to interest citizens in the changes soon to occur in healthcare is to relate the ACA to their personal situation.

- Do you know anyone who is uninsured?
- Do you know anyone whose insurance was dropped because of premium increases or the

inability to afford co-pays?
- Do you know anyone who has needed mental health services but can't afford them?
- Do you fear losing your health insurance?

The ACA is aimed at solving these problems. He urged the groups represented at the meeting to become involved in outreach to consumers to educate them about the advantages to all Americans of the ACA.

4. How Can CUE Contribute to AHRQ's Effective Healthcare Program?
Jean Slutsky, Director, Center for Outcomes and Evidence (COE), Agency for Healthcare Research and Quality (AHRQ)

Ms. Slutsky shared her experience from the early days of Comparative Effectiveness Research (CER). In 2003, as a result of the Medicare Modernization Act, AHRQ was given the mandate to establish a program of CER that was inclusionary (with input from practicing clinicians, not just researchers), would translate findings and disseminate them to the point of clinical use, and keep those findings up-to-date. A key component of this approach to research is that it must be user-driven and be useful to those working directly with patients.

Ms. Slutsky described how they began, organizing town hall meetings of 600-700 people, seeking input on how best to obtain meaningful input not only from clinicians, but also from consumers, throughout the research process. Stakeholder panels that included consumers, device makers, clinicians and researchers showed the value of convening diverse groups of people to give input about the research agenda. These panels deliberated about what research questions were important to ask and how those questions should be prioritized. She explained this process highlighted the different points of view between clinicians and patients, and how important it is to identify these differences.

CUE, which also began in 2003, has been a valuable resource to AHRQ throughout the development of CER. Ms. Slutsky recalled CUE member participation in helping them to refine their research agenda, including defining research questions, research outcomes, and governance of patient registries. She looks forward to continued collaboration with CUE and its member organizations.

5. The Journey from Outside to Inside CUE: What Can We Do Better?
Lorraine Johnson, Executive Director, LymeDisease.org, CUE Steering Committee

Ms. Johnson described her journey of association with CUE as one of transformation -

personal, organizational and ultimately societal. She gave an overview of evidence-based medicine and explained that evidence alone is never enough - that values and perspectives matter. One must consider evidence gaps, the quality of the evidence and uncertainty. Miles Law was used to illustrate the importance of perspective when considering values - "Where you stand depends on where you sit."

Ms. Johnson's role as an advocate for a controversial disease propelled her to search for consumer organizations interested in evidence-based healthcare. This search proved difficult. She eventually discovered The Cochrane Collaboration and became a contributor to systematic reviews. Through attendance at the Cochrane Colloquium in 2010, she discovered CUE and attended the Consumer Summit in Keystone that year. CUE was a consumer organization that was serious about evidence-based healthcare and she embraced it. That was the start of lessons she learned about CUE:

- CUE receives no pharmaceutical funding.
- CUE is a learning community.
- CUE member organizations have diverse interests which lead to a rich dialogue.
- Patient groups don't speak with one voice and come from different perspectives.

In spite of many differences among CUE member organizations, there is a common focus on evidence-based healthcare and the importance of keeping funding from industry in check. Ms. Johnson proceeded to highlight a few differences between an individual patient and the prepared consumer advocate: the individual represents one's own interest versus that of a constituency; the individual may defer to authority versus speaking with a strong voice; and the individual is in danger of experiencing tokenism versus true partnership.

Ms. Johnson sees CUE as a "change agent" for society, starting with change in the individual who is exposed to CUE. That individual change can lead to change in that person's organization, which can eventually lead to a societal change. She quoted Frances Hasselbein of the Girl Scouts of America, "Culture does not change because we desire to change it. Culture changes when the organizations are transformed." She summarized by saying, "CUE excels at being an agent for this type of transformation."

6. Roundtable Discussion: Disseminating CUE to Member Organization Constituencies and Measuring the Impact of Our Work

The audience divided into three groups, each led by a Steering Committee member. Two questions were asked:

1. Why is your organization a member of CUE?

2. Based on what you have heard here today, what could CUE do to help you become more effective in your work?

Members outlined two principal reasons for CUE membership; 1. to learn about and promote evidence-based healthcare, and 2. to learn from, network, and join forces with other consumer advocacy organizations to influence health care reform.

Four themes emerged concerning how CUE can help.

1. Educate the public about evidence-based healthcare
2. Increase membership involvement in CUE work
3. Draft a long-term plan
4. Increase training opportunities

A detailed listing of suggestions can be seen in Appendix 2 - Roundtable Summary.

7. The Sentinel Initiative

Gregory Daniel, Fellow and Managing Director, Engelberg Center for Health Care Reform, The Brookings Institution

Dr. Daniel explained that all medical products have some risk and should be monitored throughout the product's life cycle for possible harm. Food and Drug Administration (FDA) pre-approval testing uses a relatively small test population, which is unlikely to expose rare adverse events related to a medical product. Once a product has been approved by the FDA and is broadly used, detection of rare adverse events associated with that product is more likely due to product use by a much larger population. A research structure and access to data are needed to monitor the medical products used in this larger population over time.

The FDA uses the AERS (Adverse Event Reporting System) and relies on the medical literature to monitor medical products. These can be slow to accumulate the needed information to produce a timely decision by the FDA concerning a product. However, a large body of untapped information exists in the form of medical claims data that result from routine medical care, ie, pharmacy claims data, diagnosis codes, procedure codes and limited demographic data. Although these data are not perfect, they can add to the toolbox of the FDA in tracking product safety.

In 2007, the FDA established a public-private partnership to deal with the issue of medical claims data with The Brookings Institution as the convening group. The Sentinel Initiative, a project to build a national electronic system for monitoring the post-marketing safety

of FDA approved drugs and other products, was formed as a result of this collaboration. Sentinel includes 17 data partners, including Wellpoint, Kaiser, United Health, and Humana.

Since every Sentinel partner collects medical data differently, a common data model was developed called the Mini-Sentinel Distributed Database, which allows the partners to format their data so that it will be usable by all. The process of information-gathering begins when the FDA develops a safety question. Then the Coordinating Center creates a SAS code in response. That code is then applied by the 17 partners to their respective databases of standardized data. The results are then sent back to the Coordinating Center which compiles them for the FDA. The FDA uses these results as one of several tools to make decisions concerning medical products.

Dr. Daniel explained that they have included consumer organizations in Sentinel meetings. They have concluded that there is a difference between "patient" and "consumer" and that there is a range of sophistication within patient and consumer groups. Sentinel welcomes consumer input and is navigating how to improve meaningful consumer involvement**.**

8. Panel: The Role of CUE Members with the FDA

8.1 Why I Fight to Improve the FDA, and You Should, Too
Diana Zuckerman, President, National Research Center for Women and Families

The National Research Center for Women and Families, a "thinktank" that provides research information to the public, would like to encourage other consumer organizations to become involved in the issue of medical device safety and the FDA approval process. Dr. Zuckerman began by explaining the classification system for medical devices: Class I: low risk such as bandaids (no FDA approval necessary); Class II: moderate risk such as contact lenses, joint replacements and some cardiac devices (need to be "substantially equivalent" to other devices already on the market, no clinical trials necessary); and Class III: high risk devices such as pacemakers and artificial hearts (clinical trials required, must be proven "reasonably" safe and effective).

The GAO found that the FDA approved 90% of 13,000 new medical devices between 2003 - 2007. Fifteen percent of all medical devices are recalled. In 2009, 4556 deaths due to medical devices occurred, which was a 60% increase compared to deaths in 2006.

Dr. Zuckerman urges that to improve medical device safety, the FDA should require that clinical trials be conducted on devices prior to their approval; inspections of facilities producing devices should always take place, and post-marketing studies should be conducted on devices. Medical device data should become part of the Sentinel Initiative.

As a result of the increasing number of medical devices coming to market, the increasing number of harms associated with medical devices, and the inadequate infrastructure to assess the safety and efficacy of these devices, Dr. Zuckerman urges CUE members to become involved in influencing the improvement of medical device safety and regulation.

8.2 Update on the FDA Safety and Innovation Act
Elizabeth Jungman, Senior Health Policy Advisor, Senate Committee on Health, Education, Labor and Pensions (HELP)

Ms. Jungman encouraged consumer advocates to understand the substance and process of legislation surrounding the 2012 FDA Safety and Innovation Act (FDASIA). Possible changes in this Act include:

- the re-authorization of the user-fee agreement,
- an increase of medical device user fees,
- drug shortage provisions,
- drug approval provisions, and
- rules pertaining to conflict of interest.

Ms. Jungman described the current atmosphere regarding 2012 FDASIA and explained that educated consumer voices can have a meaningful impact on legislators in their deliberations. She urged CUE members to seek out lawmakers who share their opinion and also those who do not share their opinion regarding FDASIA to open a dialogue on this issue.

9. 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 an in-person meeting. 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.

Thirty-four individuals (not including 4 USCC staff who were present) attended the 2012 CUE Annual Membership Meeting. Participants were encouraged to provide a written evaluation of the meeting and were given a survey instrument (see Appendix 3) that largely consisted of questions measured on a five-point Likert scale. Open-ended comments were also solicited. Twenty-two participants returned the evaluation, and not all questions were answered by all respondents. The evaluation scores and comments (see Appendices 4 and 5) show that respondents were overwhelmingly positive about the meeting presenters, content, and organization. One respondent suggested lengthening the meeting to 2 days to allow for more networking. All suggestions will be taken into account when planning future meetings.

C. Appendices

Appendix 1 - Program Agenda
Appendix 2 - Roundtable Summary
Appendix 3 - Evaluation Survey Instrument
Appendix 4 - Evaluation Quantitative Summary
Appendix 5 - Evaluation Comments

Consumers United for Evidence-based Healthcare (CUE)
2012 Annual Membership Meeting
June 8, 2012; 8:30 am - 4:45 pm
Johns Hopkins University Carey Business School
1625 Massachusetts Ave. NW
Washington, DC 20036
Program Agenda

8:30 am - 8:45 am **Registration & Continental Breakfast**

8:45 am - 9:15 am **Welcoming remarks and Steering Committee Report**
Rebecca Burkholder, Co-chair, CUE, Vice President of Health Policy, National Consumers League
John Santa, Co-chair, CUE, Director, Consumer Reports Health Ratings Center
Kay Dickersin, Director, US Cochrane Center, Director, Center for Clinical Trials, Johns Hopkins Bloomberg School of Public Health

What's New in CUE
Nancy Fitton, CUE Coordinator

CUE's Communication and Partnerships
Kay Dickersin, US Cochrane Center

9:15 am - 10:15 am **Panel: Strengths and Challenges to Engaging Consumers in Research**

PCORI's Engagement of Consumers and Patients
Lori Frank, PCORI (Patient-Centered Outcomes Research Institute) Director, Engagement Research

Insight from CUE - Who Counts as a Consumer?
Kate Ryan, National Women's Health Network, CUE

Input from Hard to Reach Consumers
C. Daniel Mullins, Professor, Pharmaceutical Health Services Research Department, University of Maryland

10:15 am - 10:45 am **Discussion**

10:45 am - 11:00 am **Break**

2012 CUE Annual Membership Meeting – Agenda (cont'd)

11:00 am - 11:30 am **Panel - Effecting Change Through Consumer Advocacy**

Being an Effective Consumer Advocate
Jennifer Sweeney, CUE Steering Committee, Director, Americans for Quality Health Care, National Partnership for Women & Families

How Consumer Input Changed Things
Judy Norsigian, Executive Director, Our Bodies Ourselves

11:30 am - 11:45 am **Discussion**

11:45 am - 12:00 pm **How We Know Consumers Are Making a Difference**
Anton Gunn - Director of External Affairs, US Department of Health and Human Services

12:00 am - 12:15 pm **Discussion**

12:15 pm - 1:15 pm **Lunch/Networking Time/CUE business meeting**

1:15 pm - 1:30 pm **How Can CUE Contribute to AHRQ's Effective Healthcare Program?**
Jean Slutsky, Director, Center for Outcomes and Evidence (COE), Agency for Healthcare Research and Quality (AHRQ)

1:30 pm - 1:45 pm **Discussion**

1:45 pm - 2:00 pm **The Journey from Outside to Inside CUE: What Can We do Better?**
Lorraine Johnson, CUE Steering Committee, Executive Director, LymeDisease.org

2:00 pm - 2:15 pm **Discussion**

2:15 pm - 2:30 pm **Break**

2:30 pm - 3:15 pm **Roundtable Discussion - Disseminating CUE to Member Organization Constituencies and Measuring the Impact of Our Work**

3:15 pm - 3:30 pm **The Sentinel Initiative**
Gregory Daniel, Fellow and Managing Director, Engelberg Center for Health Care Reform, The Brookings Institution

2012 CUE Annual Membership Meeting – Agenda (cont'd)

3:30 pm - 3:45 pm **Discussion**

3:45 pm - 4:15 pm **Panel: The Role of CUE Members with the FDA**

Diana Zuckerman, President, National Research Center for Women and Families

Elizabeth Jungman, Senior Health Policy Advisor, Senate Committee on Health, Education, Labor and Pensions (HELP)

4:15 pm - 4:30 pm **Discussion**

4:30 pm **Evaluation**

Appendix 2
Summary of Roundtable Discussion
Disseminating CUE to Member Organization Constituencies
and Measuring the Impact of Our Work
2012 CUE Annual Membership Meeting

A roundtable exercise was conducted at the CUE Annual Meeting. The audience was divided into three groups, each one led by a Steering Committee member. Two questions were asked:

1. Why is your organization a member of CUE?
2. Based on what you have heard here today, what could CUE do to help you become more effective in your work?

Following is a summary of group responses.

1. Why are you a member of CUE?

1.1 To learn about and promote evidence-based healthcare (EBHC)

- To access and promote evidence on complementary medicine
- To be able to identify and then critique the gaps and holes in existing evidence
- EBHC is critical for older people. Want to get the word (health promotion, self-management) out to the community
- Understand the contribution about evidence-based healthcare that CUE makes to consumers who serve on committees

1.2 To learn from, network, and join forces with other consumer advocacy organizations to influence health care reform

- Access to evidence to support ACA provisions, for political advocacy purposes and for consumer education
- To leverage the limited power of smaller organizations by joining forces with each other to advocate for and to influence health care research and reform
- CUE is a good match for work on FDA and prescription drug issues
- To enhance information and skills through shared resources and networking
- To promote two-way learning
- Another resource for our organization's work
- Access to other consumer groups
- Networking: I have ambivalence about what most people consider evidence (eg, mammography and self-exam for African American women). I like the 2 -way learning community aspects of the networking in CUE.

2. What could CUE do to help you become more effective in your work?

2.1 Educate the public about evidence-based healthcare

- CUE could present a universal message to the public about the benefits and the

limitations of evidence, and about the appropriate use of evidence in health care and the need for total transparency
- CUE needs to develop more educational materials at 6th grade reading levels and for older adults
- CUE could develop a coordinated public campaign that is co-sponsored with allies

2.2 Increase membership involvement in CUE work

- CUE needs to encourage and offer opportunities for more active engagement in its work to the membership.
- CUE could create working groups around similar interests of member organizations and then facilitate collaborative activities to implement objectives to achieve the goals
- More direct involvement of the CUE membership in planning CUE activities and events, maybe time to expand the steering group or create subcommittees.
- Consumers can contribute to the regulation of devices. For example, although consumers serve on advisory committees for devices, they do not have a vote (by law). In cases where patient representatives are included, they always vote to approve.

2.3 Draft a long-term plan

- CUE needs to be more proactive and have a longer term plan for its goals and objectives, a plan to get ahead of the curve and not just react to events in health care

2.4 Increase training opportunities

- How to negotiate, work with advisory groups where consumer is the lone voice of the non-health professional.
- How to be more effective, establish authority on advisory groups
- Need for courses. Need to better understand how to come into the room not "ballsy" but not passive
- Get consumers to open up to the group they are serving with, and then progress can be made
- How can members of my organization become involved in systematic reviews? We have people and topics. How does that happen?
- Develop a Project LEAD, CUE style, for all consumer advocates, ie generalize Project LEAD.
- Would like to see CUE involved more in patient-reported outcomes.
- Inform them about PCORI training.

CONSUMERS UNITED FOR EVIDENCE-BASED HEALTHCARE

2012 Annual Membership Meeting
June 8, 2012
Evaluation

1. Panel - Strengths and Challenges to Engaging Consumers in Research

☐ I did not attend this session

	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
B. Quality of presentation by speaker					
Lori Frank	5	4	3	2	1
Kate Ryan	5	4	3	2	1
C. Daniel Mullins	5	4	3	2	1

2. Panel - Effecting Change Through Consumer Advocacy

☐ I did not attend this session

	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
B. Quality of presentation by speaker					
Panel member - Jennifer Sweeney	5	4	3	2	1
Panel member - Judy Norsigian	5	4	3	2	1

3. How We Know Consumers Are Making a Difference

☐ I did not attend this session

	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 were answered to satisfaction	5	4	3	2	1
B. Quality of presentation by speaker					
Anton Gunn	5	4	3	2	1

4. How Can CUE Contribute to AHRQ's Effective Healthcare Program?

☐ I did not attend this session

	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 were answered to satisfaction	5	4	3	2	1
B. Quality of presentation by speaker					
Jean Slutsky	5	4	3	2	1

5. The Journey from Outside to Inside CUE: What Can We do Better?

☐ I did not attend this session

	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 were answered to satisfaction	5	4	3	2	1
B. Quality of presentation by speaker					
Lorraine Johnson	5	4	3	2	1

6. Roundtable Discussion - Disseminating CUE to Member Organization Constituencies and Measuring the Impact of Our Work

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Relevant content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Topic was covered to satisfaction	5	4	3	2	1

7. The Sentinel Initiative

☐ I did not attend this session

	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 were answered to satisfaction	5	4	3	2	1
B. Quality of presentation by speaker					
Gregory Daniel	5	4	3	2	1

8. Panel - The Role of CUE Members with the FDA

☐ I did not attend this session

	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 were answered to satisfaction	5	4	3	2	1
B. Quality of presentation by speaker					
Diana Zuckerman	5	4	3	2	1
Elizabeth Jungman	5	4	3	2	1

Overall Evaluation

	Yes	No	Not Certain
1. The program was presented without evident commercial bias or influence.	☐	☐	☐
2. The program met my expectations	☐	☐	☐

3. Please provide comments or suggestions: _____

Appendix 4 – Evaluation Quantitative Summary
CUE 2011 Annual Membership Meeting
June 8, 2012

Responses are based on a 5-point Likert Scale, 1 (poor) to 5 (excellent).

1. Panel - Strengths and Challenges to Engaging Consumers in Research	Responses	Average	SD	median	min	max
A. Quality of session						
Informative content	18	4.33	0.91	5	2	5
Adequate time allotted	18	4.33	0.77	4	3	5
Questions answered to satisfaction	18	4.39	0.78	5	3	5
2. Panel - Effecting Change Through Consumer Advocacy						
A. Quality of session						
Informative content	18	4.11	1.02	4	2	5
Adequate time allotted	17	4.00	1.06	4	2	5
Questions answered to satisfaction	17	3.82	1.01	4	2	5
3. How We Know Consumers Are Making a Difference						
A. Quality of session						
Informative content	18	4.33	0.91	5	2	5
Adequate time allotted	17	4.35	0.79	5	3	5
Questions answered to satisfaction	17	4.47	0.87	5	2	5
4. How Can CUE Contribute to AHRQ's Effective Healthcare Program?						
A. Quality of session						
Informative content	17	4.29	0.77	4	3	5
Adequate time allotted	17	4.53	0.62	5	3	5
Questions answered to satisfaction	17	4.35	0.70	4	3	5
5. The Journey from Outside to Inside CUE: What Can We do Better?						
A. Quality of session						
Informative content	18	4.28	0.75	4	3	5
Adequate time allotted	18	4.50	0.71	5	3	5
Questions answered to satisfaction	17	4.47	0.72	5	3	5
6. Roundtable Discussion - Disseminating CUE to Member Organization Constituencies and Measuring the Impact of Our Work						
A. Quality of session						
Relevant content	13	4.46	0.78	5	3	5
Adequate time allotted	13	4.15	1.21	4.5	1	5
Topic was covered to satisfaction	12	4.17	1.03	4	2	5
7. The Sentinel Initiative						
A. Quality of session						
Informative content	13	4.31	0.85	4.5	3	5
Adequate time allotted	13	4.15	1.07	4.5	2	5

Questions answered to satisfaction	12	4.00	1.04	4	2	5
8. Panel - The Role of CUE Members with the FDA						
A. Quality of session						
Informative content	11	4.73	0.65	5	3	5
Adequate time allotted	10	4.50	0.85	5	3	5
Questions answered to satisfaction	9	4.67	0.71	5	3	5
Overall Evaluation						
1. The program was presented without evident commercial bias or influence.	16	1.00	0.00	1	1	1
2. The program met my expectations.	15	Yes = 13 No = 1 Not Certain = 1				

Appendix 5
2012 CUE Annual Membership Meeting
Evaluation Comments

- Excellent presentations great opportunity to meet others
- Great speakers - audience was informed, smart, interested. What a good day!
- Very good, thank you
- Program very informative in many areas. Exceeded expectations
- Need comments section on evaluation form after each session
- Need check box on evaluation form for CUE member, Funder or Other
- Moderators must limit the audience "Questions" to some up front time frame. The same people spoke repeatedly with extensive comments before even attempting to ask a question. They used Q & A as an opportunity to pitch their organizations.
- We needed a discussion of metrics around success of these patient engagement efforts.
- Great networking, great presentations
- Better than expected. Great food; great packets of information, more time for networking needed - longer meeting needed, ie, 1.5 - 2 days
- Excellent panels on engagement. Right balance of speakers and time for questions
- Fabulous meeting