Report
**CUE- Consumers United for Evidence-based Healthcare**
**2014 Annual Membership Meeting**
July 25, 2014
Barbara Jordan Conference Center
Kaiser Family Foundation
Washington, DC

## A. Executive Summary

CUE celebrated its 11th anniversary on July 25, 2014 at the CUE Annual Membership Meeting in Washington DC (see Appendix A for Membership List). The gathering of CUE advocates was stimulating according to many personal reports and subsequent discussions by the Steering Committee (the Planning Committee for the event). CUE members, researchers, policymakers and funders networked, listened to and gave presentations, and participated in lively discussions, all with the aim of building the leadership capacity of consumer advocates generally, and CUE members specifically, in the area of evidence-based healthcare (EBHC). Thirty-five people attended.

Preparations for the meeting began in January 2014 as CUE Planning Committee members elected to follow a mixed format of individual speakers (n=4) and panels (n=4). Individual speakers and panels were allotted a 15 to 30 minute discussion period, involving questions posed by members of the audience from a microphone on the floor. This format was in response to past evaluation requests asking for more time for audience participation, and allowed maximum interaction of the audience with the speakers while staying within a scheduled time frame and keeping the questions focused.

Panels included both CUE members and outside speakers, allowing for a rich exchange of ideas from various viewpoints (see Appendix B for Agenda). The first panel of the day, **Patient Privacy and Making Data Available**, included ***Ms. Deven McGraw***, a partner with Manatt, Phelps & Phillips, LLP and Leader of the PCORNet Data Privacy Group; ***Dr. Nancy Kass***, Deputy Director for Public Health in the Berman Institute of Bioethics, Johns Hopkins Bloomberg School of Public Health; and ***Dr. Peter Doshi***, University of Maryland School of Pharmacy and Associate Editor, *The BMJ*. The other three panel topics were ***Advocacy and Conflicts of Interest – Why CUE Cares; How Can FDA Serve Patients Better?***, *and* ***How Can We Use Social Media to our Advantage?*** Individual speakers included ***Ms. Jean Slutsky***, Chief Engagement and Dissemination Officer, Patient Centered Outcomes Research Institute (PCORI), who spoke on **Patient Engagement at the Patient Centered Outcomes Research Institute**; ***Mr. Bill Vaughan***, Steering Committee, CUE, who spoke on **Cutting Edge Issues for CUE in 2014-2015**; ***Mr. Andrew Cray***, Policy Analyst, LGBT Research and Communications Center for American Progress, who spoke on **The Impact of Consumer Movements on the Affordable Care Act;** and ***Dr. Mark Helfand***, Oregon Health and Science University and PCORI's Methodology Committee, who spoke on **PCORI's Incorporation of Patient Stories into Methodology Standards – A Potential Role for CUE?** Audio slidecasts of all presentations and discussion periods are posted on the CUE website at: http://us.cochrane.org/2014-cue-annual-membership-meeting-presentations.

We were able to supplement the funds provided by the Agency for Healthcare Research and Quality (AHRQ), to allow breakfast, snacks, beverages, and lunch to be served to participants.

The development of a strong and sustainable network of informed consumer advocates continues to be the goal of the CUE Annual Membership Meeting. The strong and ever-growing clearinghouse

function of CUE was highlighted in a report of the many CUE members who have answered the call to serve as consumer representatives on guidelines panels, advisory boards, workshops and in other capacities. Invitations that come to CUE and are distributed to the membership are considered CUE clearinghouse activities. In addition, invitations to CUE members to partner with other organizations because they are a member of CUE are also considered clearinghouse activities.

Post-meeting discussions with the CUE Steering Committee highlighted the excellent roster of speakers. The Committee felt that opportunities to get to know participants may have been greater in past years, since we did not host a focused lunch discussion in 2014.

The meeting evaluations and post-meeting communication with participants provide strong 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**

The meeting began with a **welcome and introductions, hosted by the CUE co-chairs, *Lorraine Johnson*** and ***Ngina Lythcott*. *Emily Little***, CUE Coordinator, CUE presented an update of CUE accomplishments in 2014.

**1. Patient privacy and making data available** *(Lorraine Johnson, Moderator)*

Patient privacy remains one of the top reasons why data sharing needs to be regulated. However, when does regulation become too inflexible and detrimental to progress? To address this, CUE member organizations heard from individuals who have struggled with this problem and who have designed original solutions.

**1.1 The paradox in HIPAA (and how we can fix it)** *Deven McGraw*, Partner, Manatt, Phelps & Phillips, LLP

HIPAA governs how clinical and administrative data can be accessed or disclosed for educational purposes. However, HIPAA's provisions allow identifiable information to be used with few constraints for internal operational purposes, while stringently regulating data usage that is primarily concerned with sharing generalized knowledge through research. This arrangement creates disincentives to engage in data analysis that contributes to a learning health care system. Ms. McGraw further suggested that HIPAA should be modified so that its regulations can more directly address privacy and confidentiality risks.

The presentation reviewed the definitions of Protected Health Information, and data that are subject to HIPAA regulations. Both HIPAA and the Common Rule define 'research' as having the goal of producing generalizable information to be shared externally. Under both regulations, participation in "research" requires consent or a formal waiver of consent. "Operations", on the other hand, refers to internal administrative uses of patient data associated with the business of being in healthcare not subject to HIPAA regulations. Ms. McGraw referred to an emerging view that a data analysis will fall under HIPAA regulations if the analysis will be shared for research purposes, but not if the analysis is for internal use only. Ms. McGraw cautioned that this interpretation could discourage researchers from sharing their results, thus impeding research progress.

The Health IT Policy Committee (HITECH) within the Department of Health and Human Services has written some guidance on how to implement the Common Rule, allowing the use of clinical data for evaluations of safety, quality and effectiveness to be treated as operations. Ms. McGraw sat on this committee as a consumer. The committee's recommendations acknowledge that further work is

needed to determine whether analysis of electronic health record (EHR) data should be treated under more robust rules.

**1.2 When is the learning healthcare system "clinical care" and when is it "research"?** *Nancy Kass*, Professor, Johns Hopkins Bloomberg School of Public Health in the Berman Institute of Bioethics

As a researcher, Dr. Kass and her project team asked themselves how they could engage their patients in a mutually beneficial manner. The older framework for patient protection in research involved ethical oversight, which was not applicable to clinical care settings. The distinction between research and clinical care lies in primary intent. The primary intent of clinical care is to provide the best care possible to the patient at hand, whereas the intent of research is to produce generalized knowledge through data collection.

This model, called the "distinctions paradigm", fails in the current ethical landscape. The distinctions paradigm penalizes low-risk research with the same supervision requirements as high-risk research, and therefore serves as a deterrent for low-risk research. Moreover, clinical care and research are not mutually exclusive in terms of benefit. Research does not merely help further research, but also carries over into the clinical care setting by providing a systemized collection of data from which evidence-based healthcare can be utilized.

The motivation behind the distinctions paradigm is to protect and educate patients, which it ultimately does not provide guarantees in practice. To remedy this, Dr. Kass introduced the "integrated paradigm". This model incentivizes learning while prioritizing the protection of participants' rights. Dr. Kass and her project team considered seven obligations:

- Respect patients;
- Respect clinical judgment;
- Provide each patient with the best care possible;
- Avoid risks unrelated to clinical care;
- Conduct learning activities; and
- Contribute to the general improvement of clinical care.

There must be transparency, accountability and engagement involved if this framework is to work. Dr. Kass believes that the key ideas underpinning the integrated paradigm are its commitment to continuous learning and its commitment to preserving patients' rights.

**1.3 Who wants my data and what are they going to do with it?** *Peter Doshi*, Assistant Professor, University of Maryland School of Pharmacy; Associate Editor, the *BMJ*

Peter Doshi described the dissemination of data in three steps: collecting data in clinical trials, evidence synthesis, and clinical decision-making. The data culled from trials is used to create systematic reviews and clinical practice guidelines, and the information is used as tools by health care providers. This process only works however, if data are shared. Data sharing has ethical benefits, such as the patient's expectation that his or her data will contribute to scientific knowledge, and scientific benefits, such as third party criticism and extension of knowledge.

Dr. Doshi noted that many pharmaceutical groups agree that data sharing is a public good. However, there are also drawbacks to data sharing that may infringe on patient privacy. The risk of patient identification when data is disseminated, for example, may be high. This likelihood is a reason given by some pharmaceutical groups (PhRMA, EFPIA) for not releasing data to third parties, despite their concurrently voiced dedication to data dissemination. Dr. Doshi encouraged CUE members to

submit comments on a draft by the FDA regarding informed consent information sheets, so that there can be greater pressure on entities to specify how a patient's participation in a research study will contribute to general knowledge, rather than being kept by a single pharmaceutical company or group of companies.

**2. PCORI's incorporation of the patient stories into methodology standards- a potential role for CUE?** *(Kay Dickersin, Moderator)*

*Mark Helfand*, Professor, Oregon Health & Science University

Dr. Helfand is on the Methodology Committee for PCORI. He began by discussing the history of PCORI and comparative effectiveness, which evolved from the need to generate research findings relevant to patients and caregivers. The mismatch between what patients want to know and the questions that research addresses led to PCORI using patient feedback as a springboard for new research. What is the role of methodology in this? Dr. Helfand pointed to the example of anti-arrhythmia drugs where early studies had strong theoretical underpinnings, and showed promising results from observational studies, but subsequent randomized controlled trials (RCTs) showed that these drugs were actually harmful and dangerous. The investigators behind the observational studies were trained, qualified senior investigators who nevertheless were in error about the drug's effectiveness. The problem, Dr. Helfand proposed, was the methodology. While RCTs are the best study design for demonstrating cause and effect, there needed to be a way to raise the bar for informative observational studies, without dismissing them altogether.

The Methodology Committee of PCORI has suggested asking patient- and caregiver-informed questions while maintaining a high standard for research methodology. Patient stories proved especially useful in creating well-formed patient questions and outcomes that inform methodology. The stories used in the PCORI methods standards were culled from HealthTalkOnline, PCORI, and the Informed Medical Decisions Foundation. A number of CUE members served as peer reviewers. Dr. Helfand will be part of a team developing HealthTalkOnline here in the United States.

**3. The impact of consumer movements on the Affordable Care Act** *(Barbara Warren, Moderator)*

*Andrew Cray*, Policy Analyst, LGBT Research and Communications, Center for American Progress

Andrew Cray explored the crucial role of consumer movements in shaping healthcare policy under the 2009 Affordable Care Act (ACA). Even though the dust has mostly settled in Congress and health reform has been signed into law, significant opportunities to guide implementation efforts remain. Using the LGBT community as a case study, Mr. Cray tracked the role of consumer advocates in identifying ways to improve population health, establishing an evidence base for prioritizing community-driven health needs, and providing outreach and education about coverage options.

Mr. Cray highlighted the isolation that members of the LGBT population felt, owing to their lack of health care coverage. This was particularly problematic because there was very little research that targeted and identified their health needs. The initiative Out2Enroll was created to change this pattern and to connect LGBT members with the new coverage options that the ACA offered. Community outreach encompassed grassroots meetings, town halls, public service announcements, and online resources.

The success of the Out2Enroll program was demonstrated by the policy changes in government that specifically addressed the LGBT community. The initiative sparked a wider discussion about healthcare coverage for long-ignored minorities and what the government's role is in rectifying this wrong.

**4. Horizon scanning: What is in the future for patient engagement?** *(Ngina Lythcott, Moderator)*
PCORI has a long history of working with patients and consumer advocates on many levels, from requesting their prioritized research questions to consulting them on the application review processes. Maintaining a high level of patient engagement in research remains a top priority of CUE member organizations.

**Patient Engagement at the Patient Centered Outcomes Research Institutes** *Jean Slutsky*, Keynote speaker, Chief Engagement and Dissemination Officer, Patient-Centered Outcomes Research Institute

The relevance of an institute such as PCORI is undeniable, given the gap that still exists between what is prioritized by patients and what is prioritized by researchers. PCORI addresses this by using research questions motived by patient need, and translating research findings so that they are applicable to patients and their caregivers.

One of the unique ways that PCORI differentiates itself from other research is its dedication to stakeholder engagement. This includes stakeholder involvement in topic selection, merit review, study implementation and data evaluation. The type of research that PCORI favors is likely to improve clinical practice, and the topics that PCORI chooses for research focus on chronic or understudied illnesses.

Ms. Slutsky explained the process of merit review of research applications to PCORI, which emphasizes the criterion for patient-centeredness and patient engagement. Applications are peer-reviewed by a mix of scientists, stakeholders and patients. The differing perspectives of the stakeholders asked to evaluate each application contribute to a rigorous and exhaustive review. PCORI will be re-evaluated in 2017 to determine whether the organization will be continued through legislation and government funding.

**5. Advocacy and conflicts of interest- why CUE cares** *(Helen Haskell, Moderator)*
Advocacy and conflicts of interest are intricately linked because they influence how and what research is carried out, and the potential influence on patient decision-making.

**5.1 What is gained and what is lost by drawing the line about when we believe there is conflict of interest? Recent dust-ups.** *Charles Ornstein*, Senior Reporter, ProPublica

Charles Ornstein, a Pulitzer-Prize winning journalist, has immersed himself in the decades-long discussion about conflicts of interest in medicine. Recently, pharmaceutical companies have had to start disclosing their payments to doctors publicly. Universal disclosure will begin in Fall 2014 when the Physician Payment Sunshine Act takes full effect. This Act has drawn attention to the largest payment recipients, those with blemished medical histories, and lax policy enforcement at teaching hospitals. In addition, the recent release of prescribing patterns by Medicare's drug program allows researchers and the public to see for the first time whether the top prescribers of brand-name products have financial relationships with their makers.

Mr. Ornstein is concerned about the lack of response from the public regarding the strong ties that pharmaceutical companies and caregivers have. A doctor's conflict of interest does not seem to be affecting the patient-doctor relationship/If a patient's doctor is receiving large sums from pharmaceutical companies and regularly prescribes drugs from those companies, Mr. Ornstein believes that the patient has the right to confront the matter. ProPublica has created user-friendly tools for the public that can look up the extent and nature of a financial relationship between pharmaceutical firms and doctors, called Dollars for Docs and Prescriber Check-up. Moreover, Mr. Ornstein and his team have created a checklist of questions that patients can ask their doctors if they feel worried about compromised quality of care.

**5.2 How Consumer Reports tackles issues of conflict of interest** *Doris Peter*, Director, Health Ratings Center, *Consumer Reports*

The Health Ratings Center at Consumer Reports gathers and translates data for consumers to help them make healthcare decisions. Dr. Peters focuses on the quality of medical devices, drugs, hospitals and health plans. An explosion of data and technology in the past years has widened the scope and work of the Health Ratings Center. It remains first and foremost a consumer-centric resource, and this model flourishes because of the trust that *Consumer Reports* has built with its strict conflict of interest policies. For instance, payments and advertisements are not accepted from drug manufacturers and hospitals, which makes *Consumer Reports* different from other ratings systems. Individuals working *Consumer Reports* are not allowed to have conflicts of interest with the companies that they are rating, in case their relationship introduces bias.

**5.3 Complications: When patients want treatment despite lack of good evidence** *Barbara Warren*, Steering Committee, CUE; Director, LGBT Health Services at Mount Sinai Beth Israel/Mount Sinai Health System; National Coalition for LGBT Health

How should clinicians address patients who seek care that is not evidence-based? Barbara Warren uses the example of off-label hormone therapy use by some transgender individuals, despite the lack of evidence supporting its safety and efficacy. Dr. Warren discussed the tension inherent in her role as an advocate between obtaining immediate treatment for patients versus an evidence-based approach.

In the guideline panels that Dr. Warren has served on, conflicts of interest have arisen regarding what an individual has personally experienced and what the evidence shows. There are unique viewpoints that individuals with and without the disease can bring to guideline panels, and there can be friction when the evidence is at odds with strongly held personal views. If patients want a particular type of care, the existing evidence can seem irrelevant.

**5.4 Systemic Conflicts of Interest: Academic Institutions** *Ngina Lythcott*, Co-chair, CUE; Liaison, Black Women's Health Imperative

Ngina Lythcott expressed concern that conflict of interest is inherent in academic institutions. Part of the funding of academic institutions comes from indirect cost recovery, which takes a percentage of grant money that researchers are given. The percentage can be 60% or more, and can comprise one third of a university's budget.

Another potential conflict of interest in academic institutions is the tenure process. Faculty members are awarded tenure if their research funding and publication impact is high, among other considerations. This becomes problematic when funding and publications are associated with a focus on supporting mainstream ideas. Evaluation of faculty members, ranking mainstream ideas over creative, unorthodox thinking is potentially problematic.

**5.5 Intellectual conflicts of interest and consumer engagement** *Lorraine Johnson*, Co-chair, CUE; CEO, Lymedisease.org

Intellectual conflicts of interest potentially relevant to clinical practice guidelines include panel members' desire for professional recognition, the panel's wish to be consistent with previously stated positions, and reimbursement incentives. These conflicts, according to Ms. Johnson, can significantly impact the quality of work that a guidelines panel produces. By compromising the integrity of a guideline, these conflicts of interest further compromise the type of care that a patient receives or that a caregiver provides.

The Institute of Medicine (IOM) recommends that a guidelines panel should include a variety of viewpoints to minimize the influence of bias. Another approach is to make the work of the guidelines transparent, for example by publishing the discourse.

**How can FDA serve patients better? (***Kate Ryan, Moderator)*
The FDA has a large impact on the way that consumers and patients are protected from evidence-poor drugs or devices. Ms. Ryan praised the ways in which evidence-based practices are followed within the FDA, but believes there are still opportunities for improvement.

**6.1 Patient-reported outcomes and patient preferences in the accelerated approval of devices**
*Bill Maisel*, Deputy Director and Chief Scientist, Center for Devices and Radiological Health (CDRH), U.S. Food and Drug Administration (no slidecast available for this talk, per the presenter's request).

Strengthening clinical trial standards, determining the right premarket-postmarket balance, and considering patient preferences are some of tasks of the CDRH. To maintain a patient-centric model, the CDRH focuses on evidence, value, and market access. The CDRH also seeks to strike a balance between ensuring that a trial has included sufficient patients followed for a long enough duration to "prove" a device's safety and making sure the trial is completed in a timely fashion. The Medical Devices Patient-Reported Outcomes of the CDRH contributes to meeting the Center's goals by evaluating patients' priorities and therefore what the CDRH needs to focus on.

Pre-market and post-market data on medical devices should be linked. This problem has been partially addressed with an emphasis on post-market surveillance and the use of registries. Moreover, there is a Draft Guidance for industry and FDA staff which discusses quicker pre-market approval for medical devices that are intended for life-threatening illnesses. It was issued on April 2014, and continues to be open for comments and suggestions on the FDA website.

**6.2 Changes needed in the FDA approval process**
*Diana Zuckerman*, President, National Center for Health Research and Cancer Prevention and Treatment Fund

The general standard for FDA drug approval has required at least two clinical trials, with particular attention on short-term safety and proof of efficacy. In the past few years, faster drug approvals have proliferated to match consumer demand. The standard for approving these drugs is significantly lower: one clinical trial, fewer participants, and less representation of women and people of color. These faster drug approvals require more extensive post-market surveillance, presumably to compensate for the shorter pre-market regulation. However, high quality conclusive studies on fast-tracked drugs still take years to appear post-approval, perhaps as much as a decade.

Medical devices, on the other hand, have a vastly different approval process. Low-risk medical devices are not regulated by the FDA, whereas moderate- to high-risk devices are. High-risk devices are subject to clinical trials and post-market surveillance, while moderate-risk devices only need to prove substantial equivalence to devices already on the market. Ms. Zuckerman cited a recent study with the following statistics on high-risk medical devices:

- 27% of clinical trials are randomized;
- 14% are single-blind or double-blind studies;
- Approximately 40% had an active control group; and
- The median total number of patients is 308

Moreover, when changes are made to devices post-approval, no clinical trials are necessary in assessing the revised device. This also poses a problem for post-market surveillance studies, which would follow a medical device without accounting for the changes that it has undergone.

The FDA has recently proposed an expedited pathway for high-risk medical devices. Dr. Zuckerman expressed concern that this project would bring about further lowering of quality standards, and she advocated for more clinical trials for medical devices that could potentially spot manufacturing or design flaws.

**7. Cutting edge issues for CUE in 2014-15** *(Ann Fonfa, Moderator)*

Looking forward, CUE must adapt to and anticipate the changing environment of consumer advocacy. The issues that Bill Vaughan raised are essential topics of discourse if CUE is to remain relevant.

**Cutting edge issues for CUE and what should we do about them? The case for more advocacy**
*Bill Vaughan*, Steering Committee, CUE; Board of Directors, National Committee to Preserve Social Security and Medicare

With humor and candor, Bill Vaughan described new challenges facing CUE member organizations: the drive for ever-faster drug and device approvals; a continuing financial crisis that will threaten health care and the Federal health agencies; a Congress where many are skeptical of science; and a Supreme Court that is drifting toward the freedom of corporations to say anything they want about their products, regardless of the quality of the evidence.

Mr. Vaughan suggested that one way to overcome these obstacles is to become more involved as a proactive, vocal proponent of evidence-based healthcare. A good opportunity for CUE member organizations to join together is coming up with the Prescription Drug User Fee Act (PDUFA) renewal. Some relevant issues to champion include better post-marketing studies and instituting better mechanisms to take ineffective drugs off the market. This is a pivotal moment in which Congress could reframe PDUFA to facilitate the approval of drug applications in favor of pharmaceutical companies. Alternatively, CUE members could use evidence-based practices to advocate for maintaining patient protections.

There are not just external obstacles facing advancement of CUE, but internal obstacles as well. Mr. Vaughan stressed the importance of joining together for maximal impact on public policy, and acknowledges the work that the Steering Committee could undertake to facilitate this. Given CUE's lack of resources dedicated to congressional action, Mr. Vaughan urged for collaborations with experienced organizations like the National Center for Health Research.

**8. How can we use social media to our advantage?** *(Emily Little, Moderator)*
CUE is looking to expand the influence of social media in reaching more consumer and patient advocacy organizations. Member organizations are curious as well on how to best utilize this tool to reach and mobilize the maximum audience.

**8.1 Everything you need to know about blogs, Twitter, PubMed Commons** *Hilda Bastian*, Blogs at Scientific American ('Absolutely Maybe') and 'Statistically Funny'. Works on PubMed Health and PubMed Commons at the National Institutes of Health.

As a blogger and editor of PubMed, Hilda Bastian has had extensive experience regarding the usefulness of social media in raising awareness and reaching a large audience. She focused on Twitter and Facebook as potential vehicles of social change.

Blogging takes a large commitment if it is to be effective. It is a tool of self-expression, more personal than the other social media platforms. The practice of regularly writing for an audience is also helpful in becoming a better writer; the quality of the writing in the blog will directly correlate with the sense of gratification and positive feedback from readers.

Ms. Bastian talked about being sure to understand the etiquette associated with Twitter, for example acknowledging the source of your tweet. Although you are given 140 characters in a tweet, Ms. Bastian suggested that taking up the entire allotted limit is excessively verbose on Twitter. This may seem daunting, because much of the information that CUE member organizations want to share cannot be fit in such a small amount of space. However, Ms. Bastian defended the short character limits because tweets can link to articles or webpages, and it also imposes the good practice of communicating a concept as simply as possible. A popular example of implementing social movement through Twitter is the hashtag. A hashtag creates an internal link within Twitter that connects you with other users who have used the same hashtag. Creating an effective hashtag can be difficult, but a successful hashtag creates a community of spirited advocates with whom you can share and collect information.

**8.2 Increasing CUE Facebook and Twitter activity** *Helen Haskell*, Steering Committee, CUE; President, Mothers Against Medical Error; President, Consumers Advancing Patient Safety

In 2000, Helen Haskell lost a child to a serious medical error. The Internet at that time was not as useful of a tool as it is today in as a change agent, but as social media platforms proliferated, so did the patient safety movement. Ms. Haskell's journey through the world of social media contained lessons for CUE's presence on Facebook and Twitter.

The immediacy with which relevant information can spread through these platforms is a boon for activism. Ms. Haskell observed that Twitter is a quick way to meaningfully and regularly connect with an organization's audience. Twitter is also democratic, given every user is trying to express a thought in only 140 characters.

Currently, there is an incredible amount of information on evidence-based healthcare online. There are podcasts, videos, Twitter feeds, and Facebook pages dedicated to EBHC. Ms. Haskell commented that now is the time for CUE and its member organizations to actively participate in this network of like-minded activists, to educate individual consumers, and connect with other advocacy organizations.

**C. Summary of Participant Evaluations**

The 2014 CUE Annual Meeting brought together a diverse group of informed consumer advocates, comprising scientists, consumers, patients, and policy partners, for a day of high level discussion and shared learning. Post-meeting participant evaluations provided feedback on the knowledge gained as well as the overall experience of those attending.

USCC staff members encouraged the 35 individuals who attended the Meeting to complete a written evaluation of their experience. Each individual was given a survey instrument (see Appendix C) consisting mainly of questions measured on a five-point Likert scale.

Fourteen participants returned the evaluation, although not all questions were answered by all respondents. All speakers at the meeting were rated positively. Evaluation scores and comments revealed that respondents were overwhelmingly positive about most sessions; mean respondent scores greater than '4' on a scale of 1 to 5, where 5 was the highest score, were considered to be 'positive'. The only session in which mean scores fell below '4' was during the final session entitled 'How can we use social media to

our advantage?' Responses for this session highlighted the need to improve content, allotted time, and discussion portion of this session in particular.
Open-ended comments were given by five respondents, all of which indicated overall satisfaction. Participants expressed an appreciation for time allocated to network with other advocates during the lunch hour and the diversity among speakers. Suggestions included a need to have more opportunities for commenting and coordinating among the organizations. All feedback will be considered when planning future meetings.