Report
Consumers United for Evidence-based Healthcare (CUE)
Leading the Way in Patient Engagement
2016 CUE Annual Membership Meeting
July 29, 2016
8:30 am - 5:00 pm
Barbara Jordan Conference Center
Kaiser Family Foundation
1330 G St. NW, Washington DC 20005

A. Executive Summary

The goal of the CUE Annual Membership Meeting continues to be the development of a strong and sustainable network of informed consumer advocates. Post-meeting discussions with the CUE Steering Committee highlighted the excellent roster of speakers and participants. 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.

CUE hosted its 13th CUE Annual Membership Meeting entitled, "Leading the Way in Patient Engagement", on July 29, 2016 in Washington, D.C. (see Appendix A for Membership List). CUE members, researchers, policymakers and funders networked, listened to and gave presentations, facilitated and attended workshops, and participated in lively discussions, all with the aim of building the leadership capacity of consumer advocates in the area of evidence-based healthcare (EBHC). Thirty-eight people attended the event.

Preparations for the meeting began in January 2016 as CUE Planning Committee members elected to follow a format that took participants through all the stages of EBHC, from research to implementation and policy formation. This format was in response to past evaluation requests asking for more time and opportunity for audience participation. The event comprised three Keynote presentations, two panel sessions (3-4 speakers each), and three simultaneous workshop sessions. Each Keynote speaker was allotted between 30-45 minutes, followed by a 30 minute discussion period, as with the panel sessions. Each speaker within a panel was allotted 12 to 15 minutes for his or her presentation, and overall a panel was allotted a 30 minute discussion period, involving questions posed by members of the audience from a microphone on the floor. Each workshop session was led by one health professionals and one consumer and lasted for 45 minutes. The conference structure 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 and perspectives (see Appendix B for Agenda). The first panel topic of the day, *Changing the research paradigm: Engaging patients,* included **Dr. Kate Smith**, Professor in the Department of Health, Behavior, and Society at the Johns Hopkins Bloomberg School of Public Health; and **Dr. Peter Doshi**, Assistant Professor of Pharmaceutical Health Services Research at the University of Maryland School of Pharmacy and Associate Editor of *The BMJ*. Panelists for the second panel topic, *The good, the bad, and the ugly: Empowering patients to implement research evidence*, included **Ms. Vivian Coates**, Vice President for Information Services and Health Technology Assessment as the Emergency Care Research Institute (ECRI) National Guideline Clearinghouse; **Dr. Richard Rosenfeld,** Program Director of

Otolaryngology at SUNY Downstate Medical Center; and **Ms. Allison Zieve**, Director of the Litigation Group at Public Citizen.

Ms. Hilda Bastian, editor of PubMed Health, **Dr. Lori Frank**, Program Director of Evaluation and Analysis at the Patient-Centered Outcomes Research Institute (PCORI), and **Dr. Robert Califf**, Commissioner the Food and Drug Administration (FDA) served as Keynote speakers. Full speaker biosketches can be found in Appendix C. Audio slidecasts of all presentations and discussion periods are posted on the CUE YouTube page at
https://www.youtube.com/channel/UChL0coVlLNb9uH5dOwN5iAQ

The leaders of Workshop A, entitled, "*Critical appraisal and public commenting techniques"*, included **Ms**. **Suchi Iyer,** Health Science Administrator at the Agency for Healthcare Research and Quality (AHRQ) and **Dr. Barbara Warren**, CUE Steering Committee member and consumer representative of the National LGBT Cancer Network. **Ms**. **Amanda Borsky,** Dissimination and Implementation Advisor at the AHRQ also assisted with the preparation of this workshop. Workshop B, titled "*The secrets of being successful as an advisory panel member*", was led by **Mr. Tom Getchius**, Director of Clinical Practice at the American Academy of Neurology and **Ms. Lisa Geng,** Executive Director of the Cherab Foundation. **Dr. Richard Rosenfeld,** Program Director of Otolaryngology at SUNY Downstate Medical Center led Workshop C, entitled "*Notes from a veteran guidelines panel member*". His consumer counterpart had a conflict and could not serve as a leader for this workshop.

It is because of the R13 Large Conference Grant provided by the Agency for Healthcare Research and Quality (AHRQ), that this Annual Meeting was able to take place. We were able to supplement the funds provided by AHRQ to allow breakfast, snacks, beverages, and lunch to be served to participants.

B. Detailed Report of Annual Meeting

To begin the meeting, Ngina Lythcott, CUE Steering Committee co-chair and Kay Dickersin, Professor of Epidemiology and Johns Hopkins University, provided a brief welcome and introductions, including new members that had joined CUE since the last annual meeting. Dr. Dickersin also announced that CUE Staff would be "Live Tweeting" the event on Twitter, and that participants could contribute to the feed by using the hashtag #CUEMtg2016.

 For the benefit of new members and guests at the Meeting, Reva Datar, CUE Coordinator, started her presentation with a brief overview of CUE's mission and activities. She provided a tour of the CUE website, including online courses, EBHC resources, and the set of instructional "short-shorts" (3-4 minute videos) for serving on an advisory panel. She then presented an update of CUE accomplishments since the 2015 CUE Annual Membership Meeting. This included acknowledgement of the renewed support received from AHRQ for CUE conferences in the form of a R13 Large Conference Grant for 2015-2018. Ms. Datar also provided an update on CUE's latest partnerships with health professional societies through CUE's Clearinghouse. 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. CUE

members were encouraged to answer calls to serve as consumer representatives on guidelines panels, advisory boards, workshops and in other capacities.

Introduction of Keynote I:
Jane Chang, MPH (moderator), CUE Steering Committee, National Environmental Education Foundation

Ms. Chang first thanked Ms. Hilda Bastian for serving as the Meeting's first Keynote speaker. She described her experience with Twitter and acknowledged the importance of learning more about it so that consumers can use it as a tool to strengthen their advocacy efforts.

Keynote Presentation I: "The Great Debate: How Twitter has changed community discussions of controversial healthcare topics"
Hilda Bastian, Editor, PubMed Health

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

Ms. Bastian began by introducing social media as a transformative technology which affords the opportunity for "mass self-communication strategies," useful for activism although all manner of communication can be amplified through social media. She explained that social media platforms differ based on how they are best used and that people may choose one or multiple platforms based on personal preference and intention.

Twitter stands out as an instrument for communication with strangers and people one does not directly know. It is best used as a personal broadcast medium, which is why it's the platform favored by many journalists. Twitter users tend to be younger, more urban, ethnically diverse, and to represent more of a gender balance than users of other social media. Twitter's interface permits one quickly and easily to broadcast thoughts and observations frequently and throughout the day.

Social media users, evidence-based health care, and science come together on Twitter in a variety of ways. Like other platforms, Twitter can act as a bridge between the scientific community and public at large, allowing the combatting of conspiracy theories and misinformation, and the creation of "spirals of trust" with credible information. Twitter enables the sharing of scientific studies and the promotion of debate about scientific research findings. Spirited discussions often arise around claims made by researchers on Twitter, especially when findings are seen by some to be exaggerated or spurious. Live Twitter chats hosted by doctors and other experts are a way for credible, timely information to be disseminated to social media users who are on Twitter. In addition, "Live Tweeting" from conferences has emerged as a way for scientific research and discourse to be exposed to the public at large. Prominent figures in the science world are able to disseminate credible information to their followers on a regular basis, via links to legitimate studies, infographics, or otherwise.

Introduction of Panel I: Changing the Research Paradigm: Engaging Patients

Ngina Lythcott, DrPH (Chair), CUE Steering Committee Co-chair; Black Women's Health Imperative

Dr. Lythcott introduced herself and her organization, the Black Women's Health Imperative. She introduced the panel topic and the first speaker, Dr. Kate Smith of the Johns Hopkins Bloomberg School of Public Health.

What patients can tell researchers: Healthtalk in the US
Kate Smith, PhD, MA, Professor in the Department of Health, Behavior, and Society at the Johns Hopkins Bloomberg School of Public Health

Dr. Smith began her talk by introducing the topic of health experiences research, which involves intentionally and systematically interviewing patients to gather in-depth qualitative information about their experience of illness. The Health Experiences Research Network (HERN), launched in 2014, is a partnership between University of Wisconsin, Johns Hopkins University, Oregon Health & Science University, and Yale University.

HERN collects the qualitative interviews and disseminates them using the established and rigorous DIPEx (Databases of Individual Patient Experiences) methodology developed at Oxford University over a decade ago, for collecting and producing patient narratives that are interpretive, descriptive, and holistic. Dr. Smith explained that the qualitative approach adopted by HERN provides a scientifically rigorous and humanistic model for conducting research that prioritizes the perspectives and experiences of the patient, rather than assuming that researchers and clinicians know what needs to be known, or how people's stories are best told.

HERN seeks to describe the widest possible range of individual experiences from the patient's point of view, and lets people speak for themselves about issues that emerge as critical to the conditions in question.

The healthexperiencesusa.org website is a vehicle through which people's stories are being distilled and presented so as inform patients, advocates, clinicians and researchers about what matters most to the people who matter most. The first HERN module, on depression among young adults, launched in July. Dr. Smith showed excerpts from the module and announced that more modules are planned for the coming year.

The gain to be realized by research transparency
Peter Doshi, PhD, Assistant Professor of Pharmaceutical Health Services Research at the University of Maryland School of Pharmacy and Associate Editor of The BMJ.

Dr. Doshi began his talk by introducing, broadly, what would result from greater research transparency. The gain from research transparency will be the ability to figure out what the research enterprise is actually doing, as healthcare professions and consumers currently do not really know. Greater transparency would allow the data from scientific studies to speak for themselves, rather than the current status quo in which possessors of the data explain its significance in filtered, truncated, and possibly biased publications.

Dr. Doshi introduced several examples from clinical trials that have led him to believe that increased research transparency will result in finding out that many studies are untrustworthy, and that much experimental research may be unethical. Dr. Doshi argued that a true commitment to research transparency requires those who fund independent researchers to commit to a program of "research on research" that ultimately enables system-level changes, as needed.

Introduction of Keynote II:
Paul Brown (moderator), CUE Steering Committee; National Center for Health Research

Mr. Brown introduced Dr. Lori Frank, the Program Director of Evaluation and Analysis at the Patient-Centered Outcomes Research Institute (PCORI).

Keynote Presentation II: "How does the US compare to international patient engagement efforts? INVOLVE, the James Lind Alliance, and Testing Treatments Interactive"
Lori Frank, PhD, Program Director of Evaluation and Analysis, PCORI

Interest in engaging patients in research has expanded greatly in the US since the 2010 creation of the comparative effectiveness non-profit, the Patient-Centered Outcomes Research Institute (PCORI). A requirement for PCORI funding is inclusion of patients and/or other relevant stakeholders in the research project. With nearly $1.5 billion in research funds expended to date, the number of US-based research partnerships between patients and researchers is growing. What has the substantial US investment in patient-centered research and engagement yielded, and how does that compare with engagement in research in other countries?

Patients are part of research teams in over 500 PCORI projects, and in addition PCORI has established more than 30 "Patient-Powered Research Networks" and "Clinical Data Research Networks," each with patient research partners as part of research teams. PCORI is influencing how others approach clinical research, further increasing US-based patient engagement in research. As exciting as these recent developments are, many international efforts predate PCORI. For example, INVOLVE and the James Lind Alliance in the UK have supported public engagement in research and research prioritization for more than a decade. The Canadian government's Strategy for Patient-Oriented Research has established public involvement mechanisms for research. The UK and Canada provide particularly instructive examples of consumer engagement in research funding prioritization and research-based policy formulation, at both the national and health-system levels.

The investment in PCORI has ignited a shift in the conduct of health services research in the US but successful models globally provide an opportunity for strengthening US-based research engagement.

Introduction of Panel Discussion II: The Good, the Bad, and the Ugly: Empowering Patients to Implement Research Evidence
Barbara Warren, Psy.D (chair), CUE Steering Committee; National LGBT Cancer Network

Dr. Warren introduced herself and the panel's title and theme before introducing the first speaker, Vivian Coates.

Variation in how clinical practice guidelines include the consumer perspective
Vivian Coates, MBA, Vice President for Information Services and Health Technology Assessment at the ECRI National Guideline Clearinghouse

Ms. Coates discussed the existing variation in how clinical practice guidelines include the patient perspective. She began by explaining that the ECRI Institute, a nonprofit health services research organization, has spent 25 years conducting health technology assessment and forecasting comparative-effectiveness. ECRI also provides methodology and implementation support to guideline developers.

She drew on the ECRI Institute's extensive experience in appraising guidelines to provide insights into the wide variation seen across guidelines from different developers. AGREE II, the most widely used international tool to assess the quality and reporting of practice guidelines, is used by the ECRI Institute to determine the level of patient involvement in existing clinical practice guidelines. Based on reported findings, her research showed that most guideline developers do not score above a 1 on a 1-7 scale, with a seven representing the highest level of consumer involvement and a one representing the lowest. She noted that not all guideline developers report their methods for patient engagement or how patient engagement contributed to the final recommendations.

Ms. Coates also reported that guideline developers with more guideline experience were found to be significantly better at seeking consumer input from the target population. She went on to present specific examples from the National Guideline Clearinghouse of different approaches used to facilitate consumer engagement.

How professional societies (and G-I-N NA) can step up their game
Richard Rosenfeld, MD, MPH, Program Director of Otolaryngology at SUNY Downstate Medical Center

Dr. Rosenfeld began his talk by asserting that consumer and patient engagement in clinical practice guidelines is no longer just an aspirational standard put forth by the Institute of Medicine, but an integral part of ensuring relevance, balance, and trustworthiness of the final product. Professional medical societies that develop guidelines should, and must, reach out to relevant consumer and advocacy groups to obtain two or more representatives for their guideline development groups.

The presentation went on to describe the American Academy of Otolaryngology-Head and Neck Surgery Foundation's approach, which fully integrates patient and consumer representatives into guideline development, including a plain language summary and patient-friendly implementation materials. The importance of strong leadership, group facilitation, and communication skills was emphasized, and Dr. Rosenfeld noted that these elements should produce an inviting environment that avoids intimidation and promotes full participation of consumers and patients in group discussions, exchanges, and writing assignments.

Basing regulation of commercial speech about pharmaceuticals on scientific evidence
Allison Zieve, JD, Director of the Litigation Group at Public Citizen

Ms. Zieve first provided a brief history of the pharmaceutical industry and its conflicts with the Food and Drug Administration (FDA) regarding marketing rights. At least since the 1990s, pharmaceutical companies have been pushing back against the FDA restrictions that bar companies from marketing

products for uses not approved by the agency. After only small initial success has the industry recently stepped up its efforts, filing lawsuits and introducing bills in Congress seeking to allow industry promotion of unapproved uses.

The industry's position is that, as long as statements made in promoting products is truthful, it is protected by the First Amendment and cannot be barred by the FDA. Ms. Zieve asserted that the industry's position fails to acknowledge that, in the field of health and science, a truthful statement can often be misleading. The positon also disregards entirely the history of drug regulation in the United States, which developed in response to real-world situations that highlighted the need for an objective decision-maker to assess safety and effectiveness of each use of a drug, before the drug is marketed for that use.

If accepted, the industry position would grant a drug manufacturer the presumptive ability to market a drug for any use as soon as it receives FDA approval for a single use, with the burden on the FDA to prove that the marketing is deceptive or that the drug is unsafe or ineffective for the additional use. And the position leads to the even more dangerous conclusion that, as long as selling a product is otherwise unlawful, a manufacturer could market the product (say, chocolate or plant food) as a drug, with no approval at all, even if the substance has not been approved by the FDA as a new drug for any use. To summarize, Ms. Zieve stated her position that the industry argument threatens the regulatory process for ensuring that prescription drugs are safe and effective.

Breakout Workshop Session

Workshop A: Critical Appraisal and Public Commenting Techniques
Health professional: Suchi Iyer, PhD, Health Science Administrator at the Agency for Healthcare Research and Qualtiy (AHRQ) and Amanda Borsky, DrPH, MPP, Dissemination and Implementation Advisor at AHRQ

Consumer: Barbara Warren, PsyD, CUE Steering Committee; National LGBT Cancer Network

The purpose of this session was to provide suggestions and techniques for how to provide effective public comments, especially for The Agency for Healthcare Research and Quality (AHRQ), Evidence-based Practice Center (EPC) systematic reviews. The session began by providing a didactic overview of:

• The AHRQ EPC program
• EPC methods
• PICOTS and critical appraisal in the EPCs
• Stakeholder engagement in the EPCs
• Public comment process in the EPCs
• Examples and critique of public comments in the EPCs

Each of these items was then open to discussion with participants. Session attendees were interested in using the information to provide guidance and feedback to their members on how to improve the effectiveness of public comments.

Workshop B: The secrets of being successful as an advisory panel member

Health professional: Tom Getchius, Director, American Academy of Neurology

Consumer: Lisa Geng, Executive Director, The CHERAB Foundation

The purpose of this hands-on workshop was to help participants be successful as advisory panel members.

Mr. Getchius and Ms. Geng first asked participants if they had ever felt intimidated to be involved with an advisory panel. They then asked for participants to describe why they felt this way and what could have been done differently to overcome these feelings. The discussion aimed to build confidence among participants and to encourage them to participate and impact positive change in areas of evidence-based healthcare that are important to them. Other topics addressed included: 1) developing an "elevator pitch" for a specific cause that would resonate with a panel; 2) motivating an advisory panel to take action; and 3) learning about evidence-based healthcare to become a convincing consumer advocate.

Discussion and shared experiences highlighted how participants were able to share their views while keeping the advisory panel engaged and provide them insight to improve research, treatment, prevention, and cures.

Workshop C: Notes from a veteran guidelines panel member
Richard Rosenfeld, MD, MPH, Program Director of Otolaryngology at SUNY Downstate Medical Center

The purpose of this workshop was to introduce the perspective of a healthcare professional with extensive experience working on guidelines panels with consumers. Topics covered include:

•   Definition and examples of clinical practice guidelines
•   The makeup of clinical practice guidelines teams: titles and roles
•   Key components of high-quality and trustworthy guidelines
•   Conflict of interest
•   Guideline development group processes
•   Anatomy of guideline statements

This workshop introduced a detailed explanation of the guidelines development team structure and the process. Standards for trustworthy guidelines will be emphasized. The role of the consumer in each step of the guidelines development process will be covered.

Introduction of Keynote III:
Kay Dickersin, PhD, Professor at the Department of Epidemiology at Johns Hopkins University

Dr. Dickersin introduced Dr. Robert Califf, the FDA's Commissioner of Food and Drugs. She noted his experience leading several landmark clinical trials and his service leading major initiatives aimed at improving methods and infrastructure for clinical research. Dr. Dickersin also highlighted the growing support for patient involvement at the FDA and encouraged participants to write their questions down on notecards that were provided to them during Dr. Califf's talks in case he did not have time to answer all questions in the subsequent 30 minute discussion period.

Keynote Presentation III: "The importance of meaningful patient participation in FDA decision-making"
Robert Califf, MD, MACC, Commissioner of the Food and Drug Administration (FDA)

Dr. Califf began his talk by describing meaningful patient participation in the drugs and devices research and development process, to which he is deeply committed, including his career previous to working at the FDA. He emphasized the FDA's mandate to make decisions based on sound evidence, and mentioned that he found it odd that in 2016 the issue of patient involvement in the FDA process and evidence generation system was still controversial.

Numerous initiatives exist at the FDA which are designed to incorporate the patient perspective for drug and device development. The ultimate goal is to understand patient experiences and preferences to improve patient health. The FDA Patient Representative Program began in the 1990s and it allows patients to take an active role on FDA Advisory Committees in conversations regulatory decision-making. This program has been involved in 30 meetings since January of this year, alone. An outgrowth of this program, the FDA Patient Network, broadens opportunities for patient engagement using email newsletters, a website, webinars, and social media. Since the passage of the Food and Drug Administration Safety and Innovation Act (FDASIA) in 2012 numerous other patient engagement initiatives have begun. The Patient-Focused Drug Development Initiative was created in order to more systematically obtain the patient perspective on diseases and treatments, and 19 of 25 disease-specific meetings have been convened so far which systematically gather patient input on conditions and treatment options. Patient perspective informs understanding of the context for the assessment of risk-benefit and decision making for new drugs.

On the devices side, the Center for Devices and Radiological Health (CDRH) has adopted measures to increase patient engagement as well. The Patient Preferences Initiative has the purpose of gathering patient perspectives on product benefits and tolerance of risks before the CDRH can approve a device. Furthermore the Patient Engagement Advisory Committee has been convened to advise CDRH on including patient participation throughout the lifecycle of the product and to evaluate new approaches to integrating patient input in regulatory decision-making. The use of patient perspective data has grown considerably in the past decade, with 50% of premarket approvals received in 2015 including such data.

Other patient engagement initiatives at the FDA include the FDA/European Medicine Agency Patient Engagement Cluster, a working group focusing on stronger collaboration on patient involvement issues between the two regulatory agencies. Finally, the Patient Advocate Collaborative, a product FDASIA, is an external stakeholder group which provides ongoing advice about input and monitoring of patient participation in regulatory processes and policy development.

Meaningful patient engagement has been expanded at the FDA and continues to grow, and to flourish, challenges must be overcome. Dr. Califf noted that patients need to be educated about trial design, the regulatory framework, and practical and legal limitations for sponsors, among other things, while clinicians must understand divisions within patient communities and different agendas and objectives among patient organizations in order to effectively engage patients.

C.   Summary of Recommendations Made in Presentations

Table 1: Recommendations and Resources provided by CUE Annual Meeting Speakers

Title of Talk	Speaker	Recommendations for CUE	Resources for Consumer Advocates
The great debate: How Twitter has changed community discussions of controversial healthcare topics	Hilda Bastian	• CUE members should get involved on Twitter • CUE members should create Twitter accounts for their organizations	Soba et al., "Pinterest thinking" http://www.ncbi.nlm.nih.gov/pubmed/26814029
What patients can tell researchers: Healthtalk in the US	Kate Smith	N/A	Homepage for DIPEx: www.healthtalk.org Homepage for Health Experiences USA: www.healthexperiencesusa.org
The gain to be realized by research transparency	Peter Doshi	N/A	N/A
How does the US compare to international patient engagement efforts? INVOLVE, the James Lind Alliance, and Testing Treatments Interactive	Lori Frank	• FDA- Patient Focused Drug Development Initiative: CUE members should be notified of meetings and get involved • CUE members can get involved with PCORI as merit reviewers	PCORI Methodology Standards INVOLVE COMET HTAI James Lind Alliance Cochrane Strategies for patient-oriented learning: Canadian Institutes of Health Research National Health Council: Valuing Patient Perspectives AHRQ

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Variation in how clinical practice guidelines include the consumer perspective	Vivian Coates	N/A	[NICE Factsheet 3: How individual patients and carers can get involved](#)
How professional societies (and G-I-N NA) can step up their game	Rich Rosenfeld	• CUE members should be aware of the G-I-N (NA) EGAPPS III meeting March 20-21, 2017 at the New York Academy of Medicine.	[Institute of Medicine: Clinical Practice Guidelines We Can Trust](#) [G-I-N PUBLIC's Toolkit on Patient and Public Involvement in Guidelines](#)
Basing regulation of commercial speech about pharmaceuticals on scientific evidence	Allison Zieve	N/A	N/A
Meaningful patient participation in FDA decision-making	Robert Califf	• Use FDA Patient Network to participate in FDA Advisory Panels	[FDA Patient Network](#) [CDRH Patient Preferences Initiative](#)

D. Summary of Conference Participant Evaluations

The 2016 CUE Annual Meeting brought together a diverse group of 38 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 participants' overall experience.

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

Thirty-three of 38 participants returned the evaluation, although not all respondents answered all questions. 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'. Mean scores

did not fall below '4' for any of the presentations. The two highest scoring presentations were, "How professional societies (and G-I-N NA) can step up their game" (Rosenfeld) and "What patients can tell researchers: Healthtalk in the US" (Smith).

Open-ended comments were given by 20 respondents, most of which indicated overall satisfaction. Participants expressed an appreciation for the discussion format, networking opportunities, and several of the speakers. Suggestions given to improve future conferences included more pre-planning of the breakout workshops by soliciting attendees' suggestions for content, as well as including workshops for participants with varied levels of experience and background knowledge. All feedback will be considered when planning future meetings.

Table 3: 2016 CUE Annual Meeting Evaluations – Short Answer

Respondent	Comment
1	"The program exceeded my expectations. This day allowed for high quality discussion and networking. I would allow for more small group discussions throughout the day."
2	"Allow more time for workshop. Please figure out the microphone so everyone knows how to use them."
7	"Hats off for getting Califf to attend!"
8	"Great discussion and excellent time management. I appreciate that breaks were never rushed and allowed for lots of informal decisions."
9	In regards to Workshop B: "The focus was changed which added to the workshop's usefulness."
10	In regards to Panel II: "Variable session quality"
12	"Conference center facility feedback -- I find it absolutely unbelievable that the screens are so high in the room - they could be lowered significantly! Hard on my neck to look at the screens." In regards to Keynote II: "Needs work - DoD has a great program that includes advocates at all levels."
13	"Great conference!"
14	In regards to Panel I: "Could have used more presentation time."
16	In regards to Keynote III: "A true bureaucrat - non-committal answers to everything."
17	In regards to Keynote I: "Interesting topic and speaker. Still not clear what the added value to EBHC is of Twitter."

	In regards to Keynote II: "Would be good to understand how the topics were determined - not clear." In regards to Workshop A: "Relatively entry level workshops - might consider having one that is more advanced." In regards to Keynote III: "Great discussion." "Several very informative seminars. Good networking. Perhaps a more advanced track."
18	In regards to Allison Zieve: "Loved it." "Prep needed for framework for Workshop B. It was quite unstructured and unhelpful. PCORI was not helpful because it was too broad and non-specific."
20	"The meeting was very long. Shorten lunch to 45min. Perhaps end at 4p and have a networking reception at the end of the day. I would have really appreciated having sodas available." In regards to Keynote I: "Too long" In regards to Peter Doshi: "Very good but his presentation didn't focus on patient engagement." In regards to Workshop B: "It would have been helpful to include key points/highlights from CUE's "Understanding Evidence-based healthcare" course." In regards to Keynote III: "Dr. Califf went through his slides very quickly."
22	"I love coming to this meeting every year, very informative and eye opening, thought provoking sessions!"
25	Regarding Keynote I: "Still don't understand why Twitter is important… or why it is valuable." Regarding Workshop B: "This was a disaster! No one seemed to know the secrets. Fortunately there were some others in the know who would offer some secrets!" "Excellent speakers. Great discussion sessions. Nice conversations during breaks. Love this conference!"
28	"Workshops could be more interactive."
29	Regarding Keynote I: "Would have liked more specific takeaway actions." Regarding Peter Doshi: "Great!"
31	"Great!"

32	"For the breakout sessions it may be helpful in the future to get prior input on what people want as an outcome or at least more substantive content."
33	"Good pairing/balance of panels and discussions."

E.   Summary of Breakout Workshop Evaluations

Conference participants this year were given the option of attending one of three breakout workshop sessions during the afternoon. Evaluative questions related to those workshops were included on the overall conference evaluation forms. Questions about the workshops were similar to those about the panels and Keynote speakers, including quality of the session (informative content, adequate time allotted, questions answered to satisfaction) and quality of the presentation by the speaker(s). Quality was evaluated on a rating scale between 1 and 5 with '1' signifying very poor quality and '5' signifying extremely good quality. Thirty-three of 38 registrants completed overall evaluations, although participants were only able to evaluate the workshop which they attended. Seven participants left written comments about the workshop sessions.

Quality of sessions was mixed overall, with quality sections in the workshops receiving scores which ranged from '2.7' – '4.3' and the speaker presentations receiving scores which ranged from '3' – '4.3'. Based on short-answer responses and evaluation scores, participants rated Workshop A, "Critical Appraisal and Public Commenting Techniques" (Suchi, Borskey, Warren) the highest in general, with Workshop B, "The secrets of being successful as an advisory panel member" (Getchius, Geng), receiving lower scores. Based on received comments, participants suggested that in the future, more preparation go into workshop presentation content, that they have subject matter based on participants' suggestions, and that they allow for varying levels of prior knowledge.