Report

CUE - Consumers United for Evidence-based Healthcare

2013 Annual Membership Meeting

July 26, 2013

Barbara Jordan Conference Center

Kaiser Family Foundation

Washington, DC

This meeting was sponsored by the Agency for Healthcare Research and Quality (AHRQ)
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A. Executive Summary

The 10th anniversary of CUE was celebrated on July 26, 2013 at the CUE Annual Membership Meeting in Washington DC. The gathering of CUE advocates was energizing and stimulating according to many personal reports and discussions subsequently by the Steering Committee (the Planning Committee for the event). The day began by reviewing goals that were generated at the first CUE meeting in 2003 (see Appendix 1), and looking forward to an exciting future for CUE. 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). Forty-two people were in attendance (27 CUE members, 9 speakers, 3 staff, 2 guests and 1 funder).

Preparations for the meeting began in January 2013 as CUE Planning Committee members elected to follow a panel format for four topics, each followed by a 30-minute discussion period. This format was in response to evaluation requests in 2012 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. The 30-minute discussion period comprised 15 minutes of answering moderator selected questions submitted on index cards, followed by 15 minutes of questions from a microphone on the floor.

Panels included both CUE members and outside speakers, allowing for a rich exchange of ideas from various viewpoints. To illustrate the diversity of the panels, the first panel of the day, *CUE in Partnership*, included Ms. Marguerite Koster, Practice Leader of the Technology Assessment & Guidelines Unit within the Southern California Permanente Medical Group, Kaiser Permanente Southern California and member of the Guidelines International Network North America (G-I-N NA) Steering Group, Dr. Lisa Simpson, President of AcademyHealth, and CUE member Dr. John Santa, Director of Consumer Reports Health Ratings Center. The remaining panel topics were *PCORI: A Grand Challenge Met Head-On, Open Access to Clinical Trial Data,* and *Where Do We Get Our Information?* (see Appendix 2). In addition to the panels, a fifteen-minute segment of the documentary film, *How to Survive a Plague*, was screened and subsequently discussed by Tim Horn, HIV Project Director, Treatment Action Group (TAG).

Attendance by both new and long-term members of CUE provided an invigorating atmosphere for the consumer advocates who would not otherwise have had reason or funding to come together for in-person meetings. The development of a 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 served as consumer representatives on guidelines panels, advisory boards, workshops and in other capacities (see Appendix 3). There are two types of clearinghouse activities. In the first, a general request for a consumer representative is sent to the USCC and is distributed to the entire membership as a request for volunteers. The second type of clearinghouse activity is when an invitation is sent by an organization directly to the CUE member, because they are a member of CUE, requesting him or her to partner. This occurs for example when an organization has worked with a particular CUE member and would like them to participate on another project.

Post-meeting discussion with the CUE Steering Committee highlighted the wonderful new space and excellent roster of speakers. The Committee felt that opportunities to get to know participants may have been greater in the past, given a focused lunch discussion. In addition, while submitting questions on index cards had the advantage of decreasing the time taken for commentary (as opposed to questions) from the floor, it also decreased opportunities for learning about one another.

The meeting evaluations (see Appendices 4, 5 and 6) 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.

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

B. Detailed Report of Annual Meeting

1. Panel: CUE in Partnership

1.1 Guidelines International Network North America (G-I-N NA)

Marguerite Koster, G-I-N NA Steering Group, Practice Leader, Technology Assessment & Guidelines Unit, Kaiser Permanente Southern California

Marguerite Koster explained the mission of Guidelines International Network, G-I-N (a group of over 90 organizations from 43 countries spanning 5 continents), to lead, strengthen and support collaboration in clinical practice guideline development, adaptation, and implementation. Ms. Koster reported that over 400 unique guidelines could be found for hypertension alone, although only one guideline is likely necessary. She summarized the motivation and rationale for creating G-I-N: to have consistent evidence-based guidelines worldwide. There was a strong emphasis throughout the presentation that G-I-N wants to facilitate collaboration with guidelines producers developing clinical practice guidelines, rather than wasting resources with numerous, conflicting guidelines.

In an attempt to broaden the circle of collaborators in G-I-N, the network launched the G-I-N Patient and Public Involvement Working Group (G-I-N Public). It connects caregivers and patients for a dialogue on guideline development, provides regular and comprehensive news updates, and reaches a wide audience on a Wiki website. Ms. Koster noted that "consumer involvement… has really been critical" during conferences and the guideline development phase. This appreciation of consumer involvement has manifested itself through G-I-N's vocal support of CUE's efforts.

Ms. Koster encourages a mutual relationship between CUE members and G-I-N North America (G-I-N NA). There are immediate opportunities for partnerships, such as creating a webinar of CUE member involvement in guideline development. For the long-term, G-I-N NA seeks to combine forces with CUE to match guideline developers with consumers and to increase consumer representation at G-I-N NA conferences.

1.2 Vision for partnerships on grants: What is needed

Lisa Simpson, President and CEO, AcademyHealth

As the president and CEO of AcademyHealth, Dr. Lisa Simpson was able to offer insight on how her diverse organization disseminates and encourages health services research. CUE is a partner on an AcademyHealth grant to PCORI, and the goal of this session was to describe how CUE and other consumer organizations might be partners on grants with AcademyHealth.

AcademyHealth proactively encourages an emphasis on the role that patients and consumers play in health services research through its consumer-patient research roundtables and advisory boards. To encourage consumer involvement, consumer stipends are available for AcademyHealth's annual research conference, which drew more than 2700 individuals this past year. During the question and answer session, Ms. Simpson affirmed that the rules of engagement at stakeholder meetings must be re-defined when pharmaceutical stakeholders are involved.

One CUE member participated in the AcademyHealth Electronic Data Management (EDM) Workshop in June, 2013 and four CUE members attended the AcademyHealth EDM Forum Stakeholder Symposium in June, 2012.

1.3 Advice for CUE partnerships for the next decade

John Santa, Director, Consumers Reports Health Ratings Center

John Santa expressed his appreciation, as a physician, for exposure to the consumer perspective since joining CUE and serving on the CUE Steering Committee. From his background in partnerships with organizations, from National Geographic to Wikipedia, Dr. Santa shared valuable insights about the best way to circulate healthcare information.

Dr. Santa had a few suggestions. If significant impact is sought, consumer organizations should not disseminate information independently. A single consumer advocacy organization cannot gain enough traction for change without partnerships. Forging partnerships increases dissemination, however, it comes with sacrifices and compromise. When Consumer Reports reached out to Wikipedia as a channel for healthcare information, they had to sacrifice a degree of independence in order to access a larger audience.

Consumer Reports has been successful in engaging a wide audience with up-to-date, relevant, evidence-based healthcare, and Dr. Santa encouraged adoption of a similar model for CUE and other consumer advocacy organizations. The way that consumer organizations publicize information today needs to be revamped, according to Dr. Santa. For example, consumer organizations overwhelmingly push "what to do" rather than "what to avoid", because proactive advice is better received.

Dr. Santa referenced the Choosing Wisely campaign, developed by Consumer Reports as a good model for lessons learned. Important lessons are: 1) go where the people are with your message (eg, social media); 2) talk about what they are talking about (eg, The Choosing Wisely campaign was reported in Vogue magazine); 3) be willing to get tough when the message is important (focus on safety rather than benefits); and 4) use empathetic stories to engage the audience.

2. Panel: PCORI: A Grand Challenge Met Head-On

2.1 My vision for PCORI

Sue Sheridan, Director of Patient Engagement, PCORI

Sue Sheridan's vision for PCORI involves a large, diverse, and educated community of patients and caregivers who are involved in every level of research. PCORI elicits and receives feedback from patient and consumer populations, which then contributes to determining research funding, priority groups and most importantly, dissemination. Research is not useful unless it is disseminated openly in an accessible way, and PCORI works with consumer groups to identify which venues are most effective. Recently, a patient-powered research network was launched by PCORI to better guide research efforts toward questions that patients have prioritized as meaningful. PCORI also plans to offer webinars for patients and consumers in how to craft a good comparative effectiveness research question.

2.2 A CUE member as peer reviewer

Ann Fonfa, President, Annie Appleseed Project

In 2012, Ms. Fonfa volunteered as a PCORI reviewer in the first group of consumers to serve in that role. At that time, there was no mentorship program, but Ms. Fonfa was an experienced reviewer through her work with the Department of Defense Breast Cancer Program.

Although there is general consensus among organizations about the importance of patient involvement, Ms. Fonfa pointed out the need for *early* patient involvement. When patients are involved early-on in research studies, researchers can better grasp the different priorities of patients and caregivers and account for them.

Ms. Fonfa applauded PCORI's new initiatives, noting that she was excited about the addition of complementary medicine to the topics they will cover. Yet there are consistent gaps in research, such as exclusion of the impact of health behavior on health outcomes.

2.3 The PCORI mentorship program for patient merit reviewers

Jim Hulbert, Contracts Administrator, PCORI

Fifty percent of the merit reviewers for PCORI are non-scientist stakeholders. Jim Hulbert explained PCORI's new mentorship program, which includes patient representatives from all 50 states. The program was created to help PCORI reviewers produce higher quality reviews.

The mentors' role is to assist in training development, provide weekly updates to PCORI and to identify strong patient merit reviewers. Mentors also provide ongoing support during traditionally non-working hours, such as weekends. As a result of the program, mentees report overall higher confidence in developing reviews. The reviews themselves were also judged to be stronger and well-articulated. The mentorship program has helped this diverse group to level the playing field, benefitting everyone involved.

At least five CUE members have served as PCORI patient/consumer reviewers.

2.4 Views of a PCORI grantee: Using patient-reported outcomes data to improve patient and clinician understanding and use
Claire Snyder, Associate Professor of Medicine, Johns Hopkins Medical Institutions.

Claire Snyder received one of the first PCORI grant awards. Her approach from the time the study was conceived was to include stakeholders (including patients) in planning and implementation and Dr. Snyder's research team has considered stakeholder input a priority. It has not been easy however, because patient-reported outcomes have been inconsistently reported. There was no reliable model on which Dr. Snyder and her team were able to model their own patient-reported outcomes.

In order to address this issue, Dr. Snyder and her investigative team have included key stakeholders as collaborators on research questions, study design, study conduct and implementation. This allows for rewarding discussions and effective dissemination. Most of the stakeholder members have multiple roles, such as one stakeholder who has both a patient and nursing perspective. Although Dr. Snyder's investigative team has found solutions to the problems it encountered, the lack of a widely-accepted model for reporting patient-reported outcomes highlights a hole in current research.

3. *How to Survive a Plague* - Screening & discussion
Tim Horn, Treatment Action Group (TAG)

Following a 15-minute screening of the documentary film, *How to Survive a Plague*, Tim Horn explained what had been effective in AIDS activism, resulting in changes to the Food and Drug Administration (FDA) regulatory paradigm. In the early years of the HIV/AIDS epidemic, those who were dying from HIV/AIDS demanded that the FDA accelerate HIV/AIDS drug approval. A balance needed to be struck between achieving reliable evidence and the rapid approval of new drugs for fatal conditions. The problems that the Treatment Action Group (TAG) faced, such as high drug prices and a lack of a national plan to combat HIV/AIDS, are reminiscent of problems which face many disease-specific patient organizations today.

One of the biggest factors that Mr. Horn credited to a falling death toll from HIV/AIDS was widespread self-education by AIDS activists about clinical trials and evidence-based healthcare. Those who were more knowledgeable were able to critically analyze results and determine if researchers' conclusions were based on reliable evidence. Patient populations also looked to other models of infectious disease to understand how HIV/AIDS could similarly be treated. Clinical trials for treatment of HIV/AIDS at that time focused on mono-therapy regimens, yet Mr. Horn noted that tuberculosis and other diseases showed that combination treatments were more effective. As a result, the HIV/AIDS patient population demanded clinical trials that tested a combination of drugs, and this proved a beneficial approach.

Mr. Horn stressed the importance of education of advocates about research, and that consumer advocates always should remember that they represent consumers and patients, not other stakeholders. He cautioned advocates against blurring the division between hype and hope, and he believes this can be avoided by critical thinking based on the evidence.

4. Panel: Open access to clinical trial data

4.1 New rules about clinical trial data

Peter Doshi, Postdoctoral Fellow in Comparative Effectiveness Research, Johns Hopkins University Medical School

Dr. Doshi began by highlighting several well-known drugs and explaining that each one had a story behind it, a story about the data and when it became public. To illustrate the data traditionally released from drug trials, Dr.Doshi used an iceberg. A small tip is seen above water and represents data available to the public, to other researchers and systematic reviewers; the majority of the iceberg is underwater and represents data that is kept from the public eye. This discrepancy between revealed and unrevealed data makes a large difference in what could be known about the effectiveness and safety of a drug. Today, there is a global debate about how much of that submerged iceberg should be disclosed. Dr. Doshi, in agreement with the AllTrials Campaign, supports the policy that all trials, past and present, should be registered and the full methods and the results reported. Dr. Doshi applauded CUE for being a signatory on the AllTrials petition (which urges release of all trial data for public access), and for displaying the AllTrials link on the CUE homepage.

The European Medicines Agency has both reactive and proactive data release policies for full clinical trial data disclosure, though the proactive policy has recently been challenged in court. Dr. Doshi used Celebrex as an example of a drug that had its advertised effectiveness compromised once all the trial data was published. Originally published data supported Celebrex over other drugs for arthritis treatment; yet, unpublished data and data from at later follow-up times showed that Celebrex had the same number of complications as the comparison drugs, and there were many discrepancies between the published and unpublished trial results.

4.2 Open access to genome data

Steven Salzberg, Director, Center for Computational Biology

Steven Salzberg is a strong advocate of open science, which he said many scientists resist. There has been a change, however, with increasing numbers of scientists supporting the open science movement. This movement encompasses three areas: free software, open data and open publishing. New software, for example, is developed to assist in DNA sequence analysis and the huge amount of data generated. By making software freely available to scientists, progress can be more rapid.

A cultural shift in the genomics world began to occur shortly after 2001, when publicly-funded genome researchers started releasing their data publicly on a daily basis. As soon as the data were generated, they were deposited in GenBank, a public access repository. This was motivated, in part, by a fear that a privately-held company would begin to patent their own data. Thousands of genome sequences have since been identified and made public under this open data model, from bacteria to mammals, although some scientists and groups have failed to comply (eg, the Centers for Disease Control and Prevention for influenza viruses). A more transparent data sharing model would likely improve the influenza vaccine, but not enough data has been openly provided for this to happen.

4.3 Federal initiatives

Kate Ryan, Senior Program Coordinator, National Women's Health Network

Ms. Ryan explained that ClinicalTrials.gov is an important step in the open data movement, but that several loopholes in the legislation exist. The two largest problems with ClinicalTrials.gov are: (1) registration exemptions and (2) results reporting exemptions. The requirements differ for trial registration and results reporting, which is why more than 121,000 trials have been registered while only 4,700 trial results have been reported. Phase I trials conducted outside the FDA paradigm are not covered by the law and do not have to be registered. Ms. Ryan said that the results reporting requires only that data used to support an application for approval of a drug or device by the FDA, though rule-making has not yet clarified whether off-label uses are covered. This means that data from trials not included as part of the application (showing that a drug is ineffective or harmful) are not required to be reported. This lapse in reporting could result in future attempts at developing this drug and could harm trial participants, since the original harms were never reported.

Ms. Ryan worked with Representative (now Senator) Edward Markey's office to develop the TEST Act: the Trial and Experimental Studies Transparency Act. The purpose of the TEST Act is to close the loopholes in ClinicalTrials.gov. All trials concerning humans would have to be registered (whether in- or outside of the United States). It requires that all results need to be registered whether or not the trial is included in an FDA application. However, the Act does not address the issue of enforcement. Ideally, meaningful financial penalties would result for non-compliance.

CUE sent a letter to Rep. Markey in support of the TEST Act in April, 2013. The TEST Act has been introduced into both houses of Congress and Ms. Ryan will keep us informed of the progress of this bill.

5. Panel: Where do we get our information?

5.1 Using social networking sites to find out what is important to patients

Sally Okun, Vice President of Advocacy, Policy & Patient Safety, PatientsLikeMe

What does it mean to an ALS (amyotrophic lateral sclerosis) patient to be able to brush his teeth without help for an additional six months or for an MS (multiple sclerosis) patient to walk for an extra year before having to use a wheelchair? These are the kinds of questions that are often not considered in clinical outcomes when clinical trials are designed. But these are the kinds of questions patients ask their clinicians and each other. What will this experience be like, what lies ahead for me? These types of questions might never be answered because data are not being captured in a systematic way that allows for understanding and analysis.

Patientslikeme is a for-profit online community of over 200,000 patients who are experiencing a variety of health conditions. Patient members can record their experiences and put information into their profile, tracking their own experience and sharing that experience with others. There are many other health-related sites for people like this, but there is little available

where patients and researchers can longitudinally track the patient experience.

The organizers of patientslikeme have studied, among other things, the burden of disease, the treatment risks and the off-label utilization of certain drugs. For example, they looked at amitriptylene off-label use in ALS patients. These patients regularly use amitriptylene, which was approved in the 1960's to treat depression. A side-effect of amitriptylene is dry mouth, so many ALS patients use it to treat excess oral secretions.

Within the patientslikeme community, 2000 conditions are represented and 3.3 million "private" messages are exchanged annually. Between 5% and 10% of newly diagnosed ALS and MS patients join, with 7000 ALS patients and 30,000 MS patients as members of the online community. Many patients register for the group at the time of their diagnosis, creating an opportunity to study their experience throughout the course of their disease.

Patientslikeme has learned that recording health data gives people the opportunity to exchange insights in a way that matters. For instance, the organizers of patientslikeme found that HIV/AIDS patients took more interest in their lab values and were more adherent in their treatment regimes because fellow patients on the site encouraged adherence to treatment.

The patientslikeme model can speed up the collection of information that is helpful to patients on a practical level and at a lower cost. For example, the organizers learned in 6-8 months that lithium did not appear to slow progression of ALS in patientslikeme members. They published the information and let their community know before the NIH had recruited their first patient for a trial to study this.. Although the patientslikeme approach does not follow conventional guidelines for high quality outcomes research, it provides important information that should be summarized and disseminated. Patientslikeme contributed lab data, symptom data, and functional status data for a few thousand dollars; the preliminary findings were confirmed by an NIH study (which cost millions of dollars).

Ms. Okun challenged CUE organizations to partner with them by getting their patient groups involved in patientslikeme, which will lead to more diversity in the online community.

5.2 Health care consumer information sources: lessons for advocates from two new national studies

Carol Sakala, Director of Programs, Childbirth Connection

Dr. Sakala explained that where consumers get their healthcare information depends on their condition. Childbirth Connection, which is 95 years old and a long-time member of CUE, has conducted three "Listening to Mothers" surveys in the last decade. Dr. Sakala hopes that CUE organizations will think about how they might conduct a similar investigation with their own constituencies.

Their most recent survey, conducted in 2011-2012 and reported in June 2013, revealed that information sources have multiple dimensions - some are valued and trusted more than others. For example, the most trusted source of pregnancy and childbirth information for those surveyed

is the maternity care provider, compared with the least trusted which is represented by commercial websites focused on pregnancy and childbirth issues. Childbirth education classes and the mother's health plan rated second and third in trustworthiness, respectively.

It is important to know where consumers stand on the various information sources. The three surveys they have conducted have allowed them to follow trends over the years and also add new topics that emerge. The information gleaned from these surveys allows them to target their efforts and tailor their information in the manner that will be most effective, meeting the consumer on their ground and in ways they are most likely to receive.

6. Summary of Participant Evaluations

The goal of the 2013 CUE 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-nine individuals (including 27 CUE members, 9 speakers, 2 guests and 1 funder but not including 3 USCC staff who were present) attended the 2013 CUE Annual Membership Meeting. Participants were encouraged to provide a written evaluation of the meeting and were given a survey instrument (see Appendix 4) that largely consisted of questions measured on a five-point Likert scale.

Open-ended comments were also solicited. Twenty-five participants returned the evaluation, and not all questions were answered by all respondents. The evaluation scores and comments (see Appendices 5 and 6) show that respondents were overwhelmingly positive about the meeting presenters, content, and organization. All mean respondent scores were greater than "4" on a scale of 1 to 5, where 5 was the highest score. There was no single panel or talk that was clearly "most popular, although the "open access to data" session was noted in a subsequent Steering Committee teleconference to be one of the meeting highlights. The Steering Committee also remarked in the teleconference that opportunities to get to know participants may have been greater in the past, given a focused lunch discussion. In addition, while submitting questions on index cards had the advantage of decreasing the time taken for commentary (as opposed to questions) from the floor, it also decreased opportunities for learning about one another. Suggestions will be taken into account when planning future meetings.

Audio slidecasts of all presentations and discussion periods are posted on the CUE website at http://us.cochrane.org/2013-cue-annual-membership-meeting-presentations.

Appendices

Appendix 1
2003 Goals for CUE

Appendix 2

Program Agenda
2013 Annual Membership Meeting
Consumers United for Evidence-based Healthcare (CUE)
July 26, 2013
Washington DC 20005

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

8:45 am - 9:15 am **Welcoming remarks and Steering Committee Report**
Rebecca Burkholder, retiring Co-chair, CUE, Vice President of Health Policy, National Consumers League
Lorraine Johnson, Co-chair, CUE, CEO, Lymedisease.org
Ngina Lythcott, incoming Co-chair, CUE, Black Women's Health Imperative

What's New in CUE
Nancy Fitton, CUE Coordinator

CUE's 10th anniversary: Celebrating our accomplishments, anticipating the next 10 years.
Kay Dickersin, Director, US Cochrane Center, Professor, Johns Hopkins Bloomberg School of Public Health

9:15 am - 10:00 am **Panel: CUE in Partnership**
- Moderator, *Kate Ryan*, Senior Program Coordinator, National Women's Health Network

Guidelines International Network North America (G-I-N NA)
Marguerite Koster, G-I-N NA Steering Group, Practice Leader, Technology Assessment & Guidelines Unit, Kaiser Permanente Southern California

Vision for partnerships on grants: What is needed
Lisa Simpson, President and CEO, AcademyHealth

Advice for CUE partnerships for the next decade
John Santa, Director, Consumers Reports Health Ratings Center

10:10 am - 10:30 am **Discussion**

10:30 am - 10:45 am **Break**

10:45 am - 11:25 pm **Panel: PCORI: A Grand Challenge Met Head-On**
- Moderator, *Ngina Lythcott*, Black Women's Health Imperative

My vision for PCORI
Sue Sheridan, Director of Patient Engagement, PCORI

A CUE member as peer reviewer
Ann Fonfa, President, Annie Appleseed Project

The PCORI mentorship program for patient merit reviewers
Jim Hulbert, Contracts Administrator, PCORI

Views of a PCORI grantee: Using patient-reported outcomes data to improve patient and clinician understanding and use
Claire Snyder, Associate Professor of Medicine, Johns Hopkins Medical Institutions.

11:25 pm - 12:00 pm **Discussion**

12:00 pm - 1:00 pm **Lunch/Networking Time**

1:00 pm - 1:15 pm ***How to Survive a Plague*** **viewing**
Barbara Warren, National Coalition for LGBT Health

1:15 pm - 1:30 pm ***How to Survive a Plague***
Tim Horn, Treatment Action Group (TAG)

1:30 pm - 2:00 pm **Discussion**

2:00 pm - 2:45 pm **Panel: Open access to clinical trial data**
- Moderator, *Diana Zuckerman*, President, National Research Center for Women & Families

New rules about clinical trial data
Peter Doshi, Postdoctoral Fellow in Comparative Effectiveness Research, Johns Hopkins University Medical School

Open access to genome data
Steven Salzberg, Director, Center for Computational Biology

Federal initiatives

Kate Ryan, Senior Program Coordinator, National Women's Health Network

2:45 pm - 3:15 pm **Discussion**

3:15 pm - 3:30 pm **Break**

3:30 pm - 4:00 pm **Panel: Where do we get our information?**

Using social networking sites to find out what is important to patients
Sally Okun, Vice President of Advocacy, Policy & Patient Safety, PatientsLikeMe

Health Care Consumer Information Sources: Lessons for Advocates from Two New National Studies
Carol Sakala, Director of Programs, Childbirth Connection

4:00 pm - 4:30 pm **Discussion**

4:30 pm - 4:40 pm **Evaluation**

4:45 pm **Adjourn**

Appendix 3
CUE Clearinghouse Activities
2007 – 2013
(as of 09-23-2013)

Organizations come to CUE in search of prepared consumers to serve in various capacities. This chart documents CUE members who have fulfilled these requests.

Date	Requesting Organization	Project	CUE Member Participant	Representing CUE Member Organization
2007	American College of Obstetricians and Gynecologists	Comments on ACOG policy statement on providing care in out-of-hospital births	Joy Simha Ann Fonfa Maryann Napoli Amy Romano Linda Golodner Barbara Loe Fisher Cynthia Pearson Zobeida Bonilla	Young Survivors Coalition Annie Appleseed Project Center for Medical Consumers Lamaze International National Consumers League National Vaccine Information Center National Women's Health Network Our Bodies Ourselves
2008	Institute for Clinical and Economic Review	Appraisal document of brachytherapy and proton beam therapy for treatment of clinically localized, low-risk prostate cancer	David Most	Annie Appleseed Project
2008	National Quality Policy Forum	Workshop	Maureen Corry	Childbirth Connection
2008 to 2009	Johns Hopkins University Evidence-based Practice Center (EPC)	Consumer health informatics peer reviewer	Maryann Napoli Musa Mayer	Center for Medical Consumers Patient Advocate
September, 2008	Council for Training in Evidence-Based Behavioral Practice	Advisory Board	Maryann Napoli	Center for Medical Consumers
October, 2008	American Academy of Otolaryngology – Head and Neck Surgery	Hoarseness Guideline	Terrie Cowley	TMJ
2009	American Academy of Otolaryngology – Head and Neck Surgery	Tonsillectomy Guideline	Mary Ellen Higgins Mannix	Pulse of Pennsylvania
2009	Center for Medical Technology Policy	Patient Consumer Advisory Committee	Maureen Corry Jennifer Sweeney	Childbirth Connection National Partnership for Women and Families
2009	Center for Medical Technology Policy	Complementary and Integrative Medicine Stakeholder Symposium	Ann Fonfa	Annie Appleseed Project
2009	Cochrane Collaboration	Complementary medicine and adverse effects review	Ann Fonfa	Annie Appleseed Project
2009	Cochrane Collaboration	Steering Committee of Cochrane Consumer Network	Barbara Warren	National Coalition of LGBT Health
2009	Cochrane Collaboration	Adverse Effects Methods Group	Ann Fonfa	Annie Appleseed Project

Date	Requesting Organization	Project	CUE Member Participant	Representing CUE Member Organization
2009	Cochrane Collaboration	Haematological Malignancies Review Group	Maryann Napoli	Center for Medical Consumers
2009	Cochrane Collaboration	Pregnancy and Childbirth Review Group	Maureen Corry Carol Sakala	Childbirth Connection
2009	Cochrane Collaboration	Hypertension Review Group and Vaccines Field	Maryann Napoli	Center for Medical Consumers
2009	Cochrane Collaboration	Oral Health Review Group	Joan Wilentz	TMJ
2009	G-I-N	Steering Committee of Patient and Public Involvement Group	Carol Sakala	Childbirth Connection
2009	John M. Eisenberg Center at Oregon Health & Science University	Summary guide review on core-needle biopsy for breast abnormalities	Joy Simha Ngine Lythcott	Young Survival Coalition Black Women's Health Initiative
2009	John M. Eisenberg Center at Oregon Health & Science University	Summary guide review on treating cholesterol with combination therapy	Rebecca Burkholder	National Consumers League
2009	*Medical Decision Making (MDM)*	Notification of upcoming issue on risk communication (MDM journal editor request)	CUE members	CUE
May, 2009	Johns Hopkins University Evidence-based Practice Center	Evidence report on "Comparative Effectiveness and Safety of Diabetes Medications for Adults with Type 2 Diabetes: Update."	Janice Harris (tried to get a patient to also participate)	Black Women's Health Initiative
February, 2010	AHRQ	Consumers for Effective Health Care Program's Stakeholder Group	Carol McDaid Barbara Warren Linda Harmon Theresa Cowley	Faces and Voices of Recovery Coalition for LGBT Health Lamaze International TMJ
May, 2010	AHRQ	Speaker at Directors' Meeting for AHRQ's Evidence-Based Practice Centers	Jennifer Sweeney	National Partnership for Women and Families
2010	Cochrane Collaboration Steering Group	Advisory Committee	John Santa	Consumers Union
2010	Johns Hopkins University, Dr.P.H. Jonathon Weiner	Stakeholders Advisory Committee	John Santa	Consumers Union
2010 to 2011	American Cancer Society	Practice Improvement in Cervical Screening and Management Guideline	Abbe Herzig	Consumers Union

Date	Requesting Organization	Project	CUE Member Participant	Representing CUE Member Organization
2011	American Academy of Otolaryngology - Head and Neck Surgery Foundation	Sudden Hearing Loss Clinical Practice Guideline	Peg Ford Barbara Warren	Ovarian Cancer Advocacy Alliance National Coalition for LGBT Health
2011	American Academy of Otolaryngology - Head and Neck Surgery Foundation	Improving Voice Outcomes after Thyroid Surgery Clinical Practice Guideline	Brenda Seals Barbara Warren	Native American Cancer Research National Coalition for LGBT Health
2011	Evidence-Based Guidelines and Clinical Statements American College of Chest Physicians	Lung Cancer Guideline	Maryann Napoli	Center for Medical Consumers
2012	FDA	FDA Patient Representative Program	Kat Werner	Young Survival Coalition
January, 2012	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Tympanostomy Tubes in Children Guideline	Helen Haskell	Mothers Against Medical Error
January, 2012	PCORI	Merit Review	Kat Werner	Young Survival Coalition
January, 2012	Diagnostic Errors in Medicine Conference	Planning Call	Judy Norsigian Nancy Fitton	Our Bodies Ourselves CUE
February, 2012	PCORI	National Patient and Stakeholder Dialogue Washington DC	Nancy Fitton	CUE
March, 2012	PCORI	Patient-Centeredness Work Group Baltimore, Maryland	Kay Dickersin Lorraine Johnson John Santa	CUE Lymedisease.org Consumer Reports
April, 2012	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Bell's Palsy Guideline	Bill Vaughan	National Committee for the Preservation of Social Security and Medicare
June, 2012	American College of Chest Physicians	Cough Guideline	Terrie Cowley	TMJ Association
June, 2012	AcademyHealth	Electronic Data Management (EDM) Forum Orlando, Florida	Nancy Fitton Julie Kosteas Sarah Ruiz Princetta Scott	CUE National Council on Aging National Council on Aging Annie Appleseed Project
July, 2012	PCORI	Electronic Data Management Workshop Palo Alto, California	Sallie Bernard Sandy Walsh	Safeminds CABCO- California Breast Cancer Organizations
July, 2012	Center for Medical Technology Policy (CMTP)	Bioethics Focus Group, Learning Healthcare System Baltimore, Maryland	Bill Vaughan	National Committee to Preserve Social Security and Medicare

Date	Requesting Organization	Project	CUE Member Participant	Representing CUE Member Organization
August, 2012	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Tympanostomy Guideline Review	Sandy Walsh	CABCO- California Breast Cancer Organizations
August-December, 2012	Center for Advancing Health	Comparative Effectiveness Research Interviews	Judy Norsigian Gail Hunt John Santa Bill Vaughan Maureen Corry Arthur Levin Richard Birkel	Our Bodies Ourselves National Alliance for Caregiving Consumer Reports National Committee to Preserve Social Security and Medicine Childbirth Connection Center for Medical Consumers National Council on Aging
September, 2012	American College of Chest Physicians	Pulmonary Arterial Hypertension	Unfulfilled to date	--
September, 2012	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Acute Otitis Externa Guideline	Helen Haskell	Mothers Against Medical Error
October, 2012	PCORI	Transforming Patient-Centered Research: Building Partnerships and Promising Models Workshop, Washington DC	Lorraine Johnson	Lymedisease.org
November, 2012	Diagnostic Errors in Medicine Conference	Consumer Speaker	Helen Haskell	Mothers Against Medical Error
November 26-27, 2012	PCORI / IOM	Large Simple Trials and Knowledge Generation in a Learning Health System Workshop Washington DC	Kate Ryan	National Women's Health Network

Date	Requesting Organization	Project	CUE Member Participant	Representing CUE Member Organization
December, 2012	Guidelines International Network North America	Inaugural Conference New York, New York	Bailey, Kim	Families USA
			Canin, Beverly	Breast Cancer Options
			Elmer, Joan	SHARE/National Breast Cancer Coalition
			Foglia, Mary Helen	SHARE/National Breast Cancer Coalition
			Ford, Peg	Ovarian Cancer Advocacy Alliance
			Gibson, Rosemary	Mothers Against Medical Error
			Grant, Anne	SHARE/National Breast Cancer Coalition
			Hunt, Gail	National Alliance for Caregiving
			Hynes-Kadish, Kathy	SHARE/National Breast Cancer Coalition
			Napoli, Maryann	Center for Medical Consumers
			Nemiroff, Hope	Breast Cancer Options
			Santa, John	Consumer Reports
			Traver, Amy	Families USA
			Vanamee, Eva	Safeminds
			Walsh, Sandy	CABCO - California Breast Cancer Organizations
			Whamond, Liz	Cochrane Consumer Network
			Zuckerman, Diana	National Research Center for Women and Families
January, 2013	American Academy of Orthopedic Surgeons	Surgical Management of Osteoarthritis of the Knee Guideline (survey)	All CUE organization representaitves	All CUE organizations
January, 2013	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Bell's Palsy Guideline Review	Mary Helen Foglia	SHARE/National Breast Cancer Coalition

Date	Requesting Organization	Project	CUE Member Participant	Representing CUE Member Organization
January, 2013	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Bell's Palsy Guideline Review	Bill Vaughan	National Committee to Preserve Social Security and Medicare
January, 2013	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Tinnitus Guideline	Liz Whamond	Cochrane Consumer Network (CCNet)
February, 2013	PCORI / NIH	Multiple Chronic Conditions Conference Washington DC	Terrie Cowley	TMJ Association
July, 2013	American Academy of Otolaryngology – Head and Neck Surgery Foundation	Allergic Rhinitis Guideline	TBD	TBD
July, 2013	Blue Cross Blue Shield Association	Medical Advisory Panel consumer & patient representative	TBD	TBD
July, 2013	Guidelines International Network North America	Consumer representative to Steering Group	Peg Ford	Ovarian Cancer Advocacy Alliance
July 29, 2013	PCORI / IOM	Dissemination and Implementation Roundtable Washington DC	Kate Ryan	National Women's Health Network
August, 2013	Guidelines International Network	Global Conference San Francisco, California	Jenifer Holloman Sandy Walsh Pamela Cocks	Homebirth Summit CETF CABCO Lymedisease.org

Appendix 4
2013 CUE Annual Membership Meeting
Evaluation Survey Instrument

2013 Annual Membership Meeting
July 26, 2013
Evaluation

1. Please select one of the following:

☐ I am a guest or speaker (not a CUE member)

☐ I am attending on behalf of a CUE member organization

☐ I am staff

2. Panel - CUE in Partnership

☐ 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					
Marguerite Koster	5	4	3	2	1
John Santa	5	4	3	2	1
Lisa Simpson	5	4	3	2	1

3. Panel - PCORI

☐ 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					
Sue Sheridan	5	4	3	2	1
Ann Fonfa	5	4	3	2	1
Jim Hulbert	5	4	3	2	1
Claire Snyder	5	4	3	2	1

4. How to Survive a Plague

☐ 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					
Tim Horn	5	4	3	2	1

5. Panel: Open access to clinical trial data

☐ 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					
Peter Doshi	5	4	3	2	1
Steven Salzberg	5	4	3	2	1
Kate Ryan	5	4	3	2	1

6. Panel: Where do we get our information?

☐ 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					
Sally Okun	5	4	3	2	1
Carol Sakala	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 5
Evaluation Quantitative Summary
2013 CUE Annual Membership Meeting
July 26, 2013

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

	# of Responses	Average	SD	median	min	max
Total evaluations submitted	25					
1. Panel - CUE in Partnership						
A. Quality of session						
Informative content	21	4.38	0.59	4	3	5
Adequate time allotted	21	4.10	0.77	4	3	5
Questions answered to satisfaction	21	4.24	0.70	4	3	5
2. Panel - PCORI						
A. Quality of session						
Informative content	21	4.05	0.97	4	2	5
Adequate time allotted	21	4.00	0.84	4	3	5
Questions answered to satisfaction	21	4.17	0.76	4	3	5
3. How to Survive a Plague						
A. Quality of session						
Informative content	25	4.60	0.71	5	3	5
Adequate time allotted	25	4.56	0.65	5	3	5
Questions answered to satisfaction	25	4.68	0.63	5	3	5

Appendix 5 – Evaluation Quantitative Summary

	# of Responses	Average	SD	median	min	max
4. Panel - Open access to clinical trial data						
A. Quality of session						
Informative content	24	4.75	0.53	5	3	5
Adequate time allotted	25	4.48	0.71	5	3	5
Questions answered to satisfaction	24	4.65	0.56	5	3	5
5. Panel - Where Do We Get Our Information?						
A. Quality of session						
Informative content	18	4.50	0.51	4.5	4	5
Adequate time allotted	18	4.50	0.51	4.5	4	5
Questions answered to satisfaction	18	4.39	0.61	4	3	5
Overall Evaluation						
1. The program was presented without evident commercial bias or influence.	24	23 yes	1 not certain			
2. The program met my expectations.	24	24 yes				

Appendix 6
2013 CUE Annual Membership Meeting
Evaluation Comments

Overall

- Excellent program!
- Exceeded my expectations. This was an extremely high-level meeting – thanks so much.
- Great conference. Love to meet everyone and find out what other organizations are doing. I always learn a lot and am proud to be part of such an outstanding group, CUE.
- Very enjoyable discussions. Congrats!
- Where is FDA? They really took it on the chin but didn't get to respond in real time.
- I don't think it would have been out of place to have someone from a PhRMA on Panel 5 [Panel – Open Access to Clinical Trials].
- Excellent sessions - great presentations, lively discussions, diverse topics of current importance/relevance addressed.
- Great program. Wonderful to hear from this engaged group.
- Really liked all afternoon sessions.
- Seemed to be a strong element of frustration with conventional research/researchers. Room was beautiful - but really cold!
- The PCORI presentations felt more like ads for PCORI than substantive content.
- Really informative and dynamic meeting and great networking.
- Great!!

Panel – PCORI

- *My vision for PCORI*
  Too long
- *Quality of session*
  Maybe more time for speakers

Appendix 6
2013 CUE Annual Membership Meeting
Evaluation Comments

How to Survive a Plague

- Too long
- Too much introduction. Needed more on how AIDS campaign can be applied to breast cancer and other time-sensitive "plagues".
- Wow – wish we could have watched the whole movie!

Panel – Open Access to Clinical Trials

- *Steven Salzberg*
  Wonderful!
  So great
- *Peter Doshi*
  So great