

Agenda

Cutting edge issues for CUE over the next 365 days
Consumers United for Evidence-based Healthcare (CUE)
2014 Annual Membership Meeting
July 25, 2014; 8:30 am - 5:00 pm
Barbara Jordan Conference Center
Kaiser Family Foundation
1330 G Street NW, Washington DC 20005

- 7:30 am - 8:30 am **Registration & continental breakfast**
- 8:30 am - 9:30 am **Welcome and introductions**
Lorraine Johnson, Co-chair, CUE; CEO, Lymedisease.org
Ngina Lythcott, Co-chair, CUE; Liaison, Black Women’s Health Imperative
Emily Little, Coordinator, CUE; Senior Research Program Coordinator, Johns Hopkins University School of Medicine
Kay Dickersin, Director, US Cochrane Center; Professor, Johns Hopkins Bloomberg School of Public Health
- 9:30 am - 10:15 am **Patient privacy and making data available**
Chair: *Lorraine Johnson*, Co-chair, CUE; CEO, Lymedisease.org
- The paradox in HIPAA (and how we can fix it)**
Panelist: *Deven McGraw*, Partner, Manatt, Phelps & Phillips, LLP
- When is the learning healthcare system “clinical care” and when is it “research”?**
Panelist: *Nancy Kass*, Professor, Johns Hopkins Bloomberg School of Public Health and Deputy Director for Public Health in the Berman Institute of Bioethics
- Who wants my data and what are they going to do with it?**
Panelist: *Peter Doshi*, Assistant Professor, University of Maryland School of Pharmacy; Associate Editor, The BMJ (formerly, British Medical Journal)
- 10:15 am – 10:45 am **Discussion**
- 10:45 am – 11:00 am **Break**
- 11:00 am - 11:15 am **PCORI’s incorporation of the patient stories into methodology standards – a potential role for CUE?**
Chair: *Kay Dickersin*, Director, US Cochrane Center; Professor, Johns Hopkins Bloomberg School of Public Health
Speaker: *Mark Helfand*, Professor, Oregon Health & Science University
- 11:15 am – 11:30 am **Discussion**

- 11:30 am – 11:45 am **The impact of consumer movements on the Affordable Care Act**
Chair: **Barbara Warren**, Steering Committee, CUE; Director, LGBT Health Services at Mount Sinai Beth Israel/Mount Sinai Health System; National Coalition for LGBT Health
Speaker: **Andrew Cray**, Policy Analyst, LGBT Research and Communications Center for American Progress
- 11:45 am – 12:00 pm **Discussion**
- 12:00 pm - 1:00 pm **Lunch/networking time**
- 1:00 pm- 1:15 pm **Horizon scanning: What is in the future for patient engagement**
Chair: **Ngina Lythcott**, Co-chair, CUE; Liaison, Black Women’s Health Imperative
- Patient Engagement at the Patient Centered Outcomes Research Institutes**
Speaker: **Jean Slutsky**, Chief Engagement and Dissemination Officer, Patient-Centered Outcomes Research Institute
- 1:15 pm - 1:30 pm **Discussion**
- 1:30 pm - 2:05 pm **Advocacy and conflicts of interest – Why CUE cares**
Chair: **Helen Haskell**, Steering Committee, CUE; President, Mothers Against Medical Error; President, Consumers Advancing Patient Safety
- What is gained and what is lost by drawing the line about when we believe there is conflict of interest? Recent dust-ups.**
Speaker: **Charles Ornstein**, Senior Reporter, ProPublica
- Conflicts of Interest and their influence on consumer engagement**
Panelist: **Doris Peter**, Director, Health Ratings Center, Consumer Reports
Panelist: **Barbara Warren**, Steering Committee, CUE; Director, LGBT Health Services at Mount Sinai Beth Israel/Mount Sinai Health System; National Coalition for LGBT Health
Panelist: **Ngina Lythcott**, Co-chair, CUE; Liaison, Black Women’s Health Imperative
Panelist: **Lorraine Johnson**, Co-chair, CUE; CEO, Lymedisease.org
- 2:05 pm – 2:30 pm **Discussion**

- 2:30 pm – 3:00 pm **How can FDA serve patients better?**
Chair: **Kate Ryan**, Steering Committee, CUE; Program Coordinator, National Women's Health Network
- Patient-reported outcomes and patient preferences in the accelerated approval of devices**
Speaker: **Bill Maisel**, Deputy Director and Chief Scientist, Center for Devices and Radiological Health, U.S. Food and Drug Administration
- Changes needed in the FDA device approval process**
Prepared Response: **Diana Zuckerman**, President, National Center for Health Research and Cancer Prevention and Treatment Fund
- 3:00 pm – 3:15 pm **Discussion**
- 3:15 pm – 3:30 pm **Break**
- 3:30 pm – 3:45 pm **Cutting edge issues for CUE in 2014-15**
Chair: **Ann Fonfa**, Member, CUE; President, Annie Appleseed Project
Speaker: **Bill Vaughan**, Steering Committee, CUE; Board of Directors, National Committee to Preserve Social Security and Medicare
- 3:45 pm – 4:00 pm **Discussion**
- 4:00 pm – 4:30 pm **How can we use social media to our advantage?**
Chair: **Emily Little**, @United4Evidence
CUE Coordinator; Senior Research Program Coordinator, Johns Hopkins University School of Medicine
- Everything you need to know about blogs, Twitter, PubMed Commons**
Panelist: **Hilda Bastian**, @hildabast
Blogs at Scientific American ('Absolutely Maybe') and 'Statistically Funny'. Works on PubMed Health and PubMed Commons at the National Institutes of Health.
- Increasing CUE Facebook and Twitter activity**
Panelist: **Helen Haskell**, @hhas
Steering Committee, CUE; President, Mothers Against Medical Error; President, Consumers Advancing Patient Safety
- 4:30 pm – 4:45 pm **Discussion**
- 4:45 pm - 5:00 pm **Evaluation**
- 5:00 pm **Adjourn**