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*, @hhask  
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**