

Agenda
Consumers United for Evidence-based Healthcare (CUE)
Integration of the Consumer Voice: From Research to Policy
2015 CUE Annual Membership Meeting
8:30 am - 5:00 pm
Villers Conference Center
Families USA Headquarters
1201 New York Avenue NW, Washington DC 20005

- 7:30 am - 8:30 am **Registration & continental breakfast**
- 8:30 am - 9:00 am **Welcome and introductions**
Lorraine Johnson, Co-chair, CUE; CEO, Lymedisease.org
Ngina Lythcott, Co-chair, CUE; Liaison, Black Women’s Health Imperative
Reva Datar, Coordinator, CUE; Senior Research Program Coordinator, Johns Hopkins University Bloomberg School of Public Health
Kay Dickersin, Director, Cochrane United States; Professor, Johns Hopkins Bloomberg School of Public Health
- 9:00 am – 10:00 am **Ensuring that research is rigorous and reducing waste**
Chair: *Coco Jervis*, Program Director, National Women’s Health Network
- What makes a research study “good”?**
Panelist: *Steven Goodman*, Associate Dean of Clinical and Translational Research; Professor, Stanford School of Medicine; chief of the Division of Epidemiology in Health Research & Policy; co-founder of the Meta-research innovation Center at Stanford (METRICS)
- Novel data sources for use in intervention studies**
Panelist: *Mike Lauer*, Director of the Division of Cardiovascular Sciences at the National Heart, Lung, and Blood Institute (NHLBI) at the National Institutes of Health (NIH)
- Patient-powered research registries: Hype or hope?**
Panelist: *Lorraine Johnson*, Co-chair, CUE; CEO of Lymedisease.org
- What the law requires versus what is actually being done at ClinicalTrials.gov**
Panelist: *Deborah Zarin*, Director of ClinicalTrials.gov
- 10:00 am – 10:30 am **Discussion**
- 10:30 am – 10:45 am **Break**
- 10:45 am - 11:30 am **What is needed for consumers to truly engage in research?**
Chair: *Jane Chang*, Engagement Officer of Health and Environment Program, National Environmental Education Foundation

How CUE can more systematically engage lay journalists

Panelist: **Peter Doshi**, Assistant Professor of Pharmaceutical Health Services Research, University of Maryland School of Pharmacy; Associate Editor, *The BMJ*

Has PCORI's requirement to engage patients in research worked?

Panelist: **Lee-Lee Ellis**, Doctoral Graduate of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health

How AHRQ will fulfill the Affordable Care Act directive on dissemination and implementation of PCOR findings

Panelist: **Stephanie Chang**, Director of Evidence-based Practice Center Program, Agency for Healthcare Research and Quality

11:30 am – 12:00 pm **Discussion**

12:00 pm - 12:45 pm **Lunch/ Networking**

12:45 pm- 1:00 pm **“Precision medicine”: What should patients and consumer advocates expect?**

Chair: **Kay Dickersin**, Director, Cochrane United States; Professor, Johns Hopkins Bloomberg School of Public Health

Excerpt from “Emperor of All Maladies” PBS Special

Keynote Speaker: **Lori Wilson**, Surgical Oncologist, Howard University Hospital

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

1:30 pm – 2:15 pm **Consumers partnering to develop clinical practice guidelines**

Chair: **Caitlin Morris**, Steering Committee, CUE; Program Director for Health System Transformation, Families USA

Engaging patients to prioritize Kaiser Permanente's clinical practice guidelines

Panelist: **Wendy Bennett**, Associate Professor of Medicine, Johns Hopkins School of Medicine

How can we ensure that guidelines panels truly engage consumers?

Panelist: **Marguerite Koster**, Chair of Guidelines International Network (G-I-N) North America; Practice Leader, Evidence-based Medicine Services Unite, Kaiser Permanente

Consumer involvement in clinical practice guidelines: The view from G-I-N PUBLIC

Panelist: **Carol Sakala**, Director, Childbirth Connection Programs of the National Partnership for Women & Families

2:15 pm – 2:30 pm **Film Screening of CUE's 'short-shorts' for serving on an advisory panel**

Chair: **Ngina Lythcott**, Co-chair, CUE; Liaison, Black Women's Health Imperative

2:30 pm – 3:00 pm **Discussion**

- 3:00 pm – 3:15 pm **Break**
- 3:15 pm – 4:15 pm **Evidence-based federal policy: Is Congress letting it happen as it should?**
Chair: **Barbara Warren**, Steering Committee, CUE; Director of LGBT Programs and Policies in the Office for Diversity and Inclusion of the Mount Sinai Health System, NYC.
- US Department of Agriculture (USDA): An evidence-based approach to dietary guidelines**
Panelist: **Maureen Spill**, Nutritionist of Center of Policy and Promotion, US Department of Agriculture
- USDA: Politics and evidence**
Panelist: **Jessica Black**, Director of Kids' Safe and Healthful Foods, Pew Charitable Trusts
- EPA/IRIS: An evidence-based approach for environmental health hazards**
Panelist: **Vince Cogliano**, Director, Integrated Risk Information System (IRIS) Program, Environmental Protection Agency (EPA)
- The Food and Drug Administration (FDA): 21st Century Cures. What CUE needs to know and actions to take**
Paul Brown, Steering Committee, CUE; Government Relations Manager, National Center for Health Research
- 4:15 pm – 4:45 pm **Discussion**
- 4:45 pm - 5:00 pm **Closing remarks and Evaluation**
- 5:00 pm **Adjourn**