2016 CUE Annual Meeting

The 2016 CUE Annual Meeting took place July 29, 2016 at the Barbara Jordan Conference Center in Washington, DC

Registration and Introductions

Registration desk is open! #CUEmtg16 pic.twitter.com/qYhq4n2s6t

And we begin! Intro by Ngina Lycott. What would it mean to our work if CUE had organizations that cover all priority populations #CUEmtg16
Welcome to #CUEmtg2016! Thank you Barbara Jordan Conference Center and Kaiser Family Foundation for hosting us. pic.twitter.com/fJZMzFy2FL
#CUEmtg2016 would not be possible without support from #AHRQ and our steering committee! Thank you! pic.twitter.com/PfPD32lDT1

CUE @UNITED4EVIDENCE · 2 YEARS AGO

Since 2003, CUE provides a professional society-type setting for consumer advocates; serving as a focal point for educ & sharing #CUEmtg16

CUE @United4Evidence · 2 YEARS AGO

Great speakers 13th annual CUE mtg @#CUEmtg16

Barbara Warren @bwarrenpsyd · 2 YEARS AGO

Cherab Foundation proud to represent and present at the CUE conference #CUEmtg16

Cherab Lisa Geng @TheLateTalker · 2 YEARS AGO
Patient Engagement is key! #CUEmtg16

Reva Datar introduces CUE and the many resources on its website us.cochrane.org/CUE #CUEmtg16

Keynote I: The great debate: How Twitter has changed community discussions of controversial healthcare topics

Hearing about how twitter has changed community discussions of controversial healthcare topics at #CUEmtg16

Hilda Bastian says tweets can keep us up to date with the evidence #CUEmtg16
Morning keynote by @hildabast ! #Twitter & evidence-based health. #metaanalyses #CUEmtg16 pic.twitter.com/bTwjmbswG4

@UScochrane

Symplur.com is a good source for Twitter chats #CUEmtg16
@hildabast creating consumer Twitter activists for evidence-based healthcare @United4Evidence #CUEmtg16 pic.twitter.com/pMTVcDuNYQ

@richard_davis @RIDAVIO 2 YEARS AGO

Julie Childers @jkchilders

@hildabast: Counteract "merchants of doubt" with "virtual spirals of trust" #CUEmtg16

@jkchilders 2 YEARS AGO

Ginger Skinner @Ginger_Skinner

When it comes to cyber-bullying, women of color are most vulnerable population on the Internet. @hildabast at @United4Evidence #CUEmtg16

@Ginger_Skinner 2 YEARS AGO

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HT @hildabast: Think about when to use an organizational voice and when to use a personal voice. Always acknowledge your source! #CUEmtg16

@United4Evidence 2 YEARS AGO
Panel 1: Changing the research paradigm: Engaging patients

Prof. Kate Smith from @JohnsHopkinsSPH: What patients can tell researchers through health experiences research. #Healthtalk #CUEmtg16
Interesting talk on Patient voices. A movement? What patients can tell researchers! #CUEmtg16 #healthtalk pic.twitter.com/QouGtpdXuo

Prof. Smith: "Tell me your story...we are moving from 'voice' to 'voices'" #CUEmtg16 @HealthTalk @UScochrane

Link to website from current presentation at #CUEmtg16 for anyone following along: healthtalk.org/peoples-experi...
Here's Healthtalk Online US #CUEMtg16 1st module young people & depression #QualResearchFTW! healthexperiencesusa.org/depressionModu... pic.twitter.com/DmET0Srsxz

HILDA BASTIAN @HILDABAST  ·  2 YEARS AGO

Barbara Warren
@bwarrenpsyd

Kate Smith from Hopkins on how patient experience helps research @health_talk.org #CUEmtg16

2 YEARS AGO
Next up, Dr. Peter Doshi on the Big Gain from Research Transparency. What can we learn from Transparency? #CUEmtg16 pic.twitter.com/D4U5bolnPw

USAPatientNetwork @Patient_Network

We agree that if we want to conduct research that matters to patients, we must understand what they care about. #CUEmtg16 @United4Evidence
Presentation by Peter Doshi: a single trial report, in two different forms #CUEmtg16 @United4Evidence pic.twitter.com/aNJapETq9P
Hmm would you have enrolled? Purpose (not in consent form!) wasn't proving that new drug is more effective #CUEmtg16 pic.twitter.com/Hec5xZvKnZ

@UNITED4EVIDENCE · 2 YEARS AGO

Peter Doshi asks, "how would a patient feel if s/he had participated in a trial shown to have had distorted reporting"? #CUEmtg16

@UScochrane · 2 YEARS AGO
Non-inferiority trials: Peter Doshi's definitely not a fan! #CUEmtg16 My explainer: statistically-funny.blogspot.com/2012/08/drugs--... pic.twitter.com/YY7ljKCviK

@HILDABAST · 2 YEARS AGO
We need more divers. We only know what's above the water line. #CUEmtg16
pic.twitter.com/fyqgFlYrZp

Keynote II: How does the US compare to international patient engagement efforts? INVOLVE, the James Lind Alliance, and Testing Treatments Interactive

Thank you Jane and @NEEFusa for the great introduction to the social media session this morning! #CUEmtg16 twitter.com/NEEFusa/status...
Keynote 2: Dr. Lori Frank on how the US is doing with #patient #engagement in research #pcori #CUEmtg16 pic.twitter.com/Tc8Lyj5PB8

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Hilda Bastian
@hildabast

Hearing about @PCORI Elizabeth Harrison fellowships:
businessnetworkingorangecounty.com/elizabeth-harr... #CUEmtg16

@hildabast - 2 YEARS AGO

CUE @United4Evidence

For ref: International Perspectives on Patient Engagement: Results from the 2011 Commonwealth Fund Survey #CUEmtg16 commonwealthfund.org/publications/i...

@United4Evidence - 2 YEARS AGO
#PCORI conceptual model for #PCOR. Importance of evaluating patient perspective, co-learning, transparency #CUEmtg16 pic.twitter.com/zX7QgUpOwn

Cochrane US
UScochrane

Involve, ICHOM, HTAi, PCORI, FDA, COMET, EMA have patient focused projects. #CUEmtg16

James Lind Alliance highlighted by Lori Frank as a way to get engaged in priority setting #CUEmtg16 https://t.co/whScmmx9Oi

Lori Frank reports how patients have been involved in some (though not all) of EMA committees #CUEmtg16 https://t.co/htKcvrdZ4l
Panel II: The good, the bad, and the ugly: Empowering patients to implement research evidence

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Vivian Coates from @ECRI_Institute discusses how clinical practice guidelines include the consumer perspective. UK doing the best?

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Of possible interest: "Clinical Practice #Guidelines We Can Trust" nationalacademies.org/hmd/Reports/20... #CUEmtg16 #CPG #guidelines #IOM

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Dr Rosenfeld: Clinical practice guidelines should optimize care, be informed by #systematicreviews #CUEmtg16

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Dr. Rosenfeld presents a few examples of decision grids and guidelines developed w/ consumers and patients entnet.org/content/clinic... #CUEmtg16

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@United4Evidence

Perfect summary of a problem brought up by the current panel. Thanks @hildabast @CUEmtg16 twitter.com/hildabast/stat...

2 YEARS AGO
Allison Zieve of @Public_Citizen worried about bills that would weaken FDA standards. We agree #patientsafety should be priority #CUEmtg16

Question from audience: What does/would patient's involvement in #FDA's guidance for industry look like? #CUEmtg16

Refresher on #PICOTS. Thank you Dr. Suchitra Iyer from #AHRQ. Setting the stage for what to look for. #CUEmtg16 pic.twitter.com/HsIHi1yOms
Dr. Iyer: Opportunities for Stakeholder Input in #AHRQ reviews. @AHRQNews #CUEmtg16 pic.twitter.com/YPJ3WFAcEC

Keynote III: The importance of meaningful patient participation in FDA decision-making

Dr. Califf: "@US_FDA plays a significant role in the Nation's counterterrorism capability" (i.e., emerging public health threats) #CUEmtg16
Final keynote by Dr. Robert Califf: Meaningful Patient Participation in @US_FDA Decision Making at #CUEmtg16 pic.twitter.com/uUlrm2dX5U

@CUE UNITED4EVIDENCE - 2 YEARS AGO

Julie Childers
@jkchilders

Delighted to be hearing talk by Dr. Robert Califf, FDA Commissioner. #CUEmtg16
#patientparticipation

2 YEARS AGO
A definition of #regulatory decision making. @US_FDA @UScochrane #CUEmtg16 pic.twitter.com/jdKtY2wewD
FDA's roster of patient-focused drug development meetings: Califf, FDA Commissioner #CUEmtg16 pic.twitter.com/YtpLMqNsMN

HILDA BASTIAN @HILDABAST · 2 YEARS AGO

CUE @United4Evidence

Dr. Robert Califf " @US_FDA is all about making decisions" so how do we make these decisions more #evidence #informed? #CUEmtg16

2 YEARS AGO
The Essential Role of the Patient Voice

- The presence of patients as part of the process of evaluating drugs and medical devices is critical.
- Patients have a direct stake in the review process.
- And should have a role in all phases of product development.
- They are in a unique position to provide essential insights to help with FDA’s mission.
- From patients, we can:
  - Learn more about the what it is like to live with a disease or condition;
  - Understand more about the adequacy of treatment options;
  - Discover opportunities to develop new and more effective treatments and responses to disease; and
  - Design a more effective benefit-risk framework to better evaluate the safety and effectiveness of medical products.

Value added through patient engagement #CUEmtg16 pic.twitter.com/9EJZKelbXO

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Dr. Califf: "It's not just speed... it's high quality clinical trials" @US_FDA #CUEmtg16

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"CUE represents many conditions...rather than a condition-based organization, we are a knowledge-based organization" Kay Dickersin #CUEmtg16

CUE @United4Evidence

Thank Dr. Robert Califf, @US_FDA Commissioner, for being our final keynote at #CUEmtg16 and leading a great Q&A!
This concludes #CUEmtg2016! Don't hesitate to let us know if you know organizations that may be interested in CUE and evidence-based health!