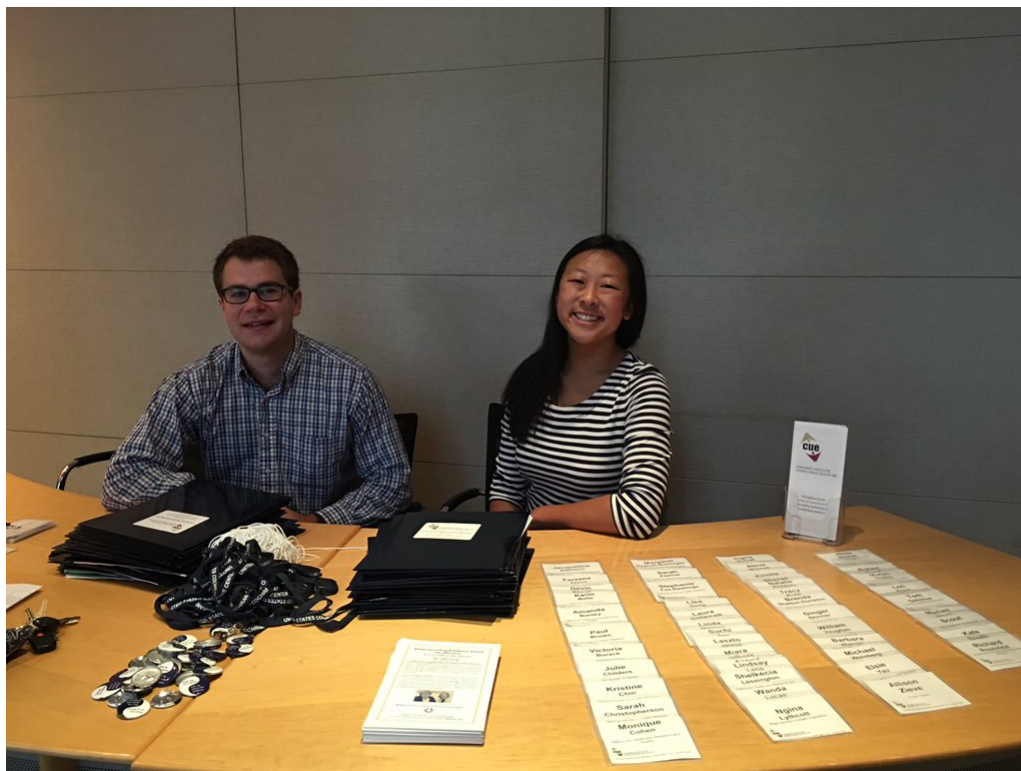


by CUE Cochrane USA a year ago

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](https://twitter.com/qYhq4n2s6t)

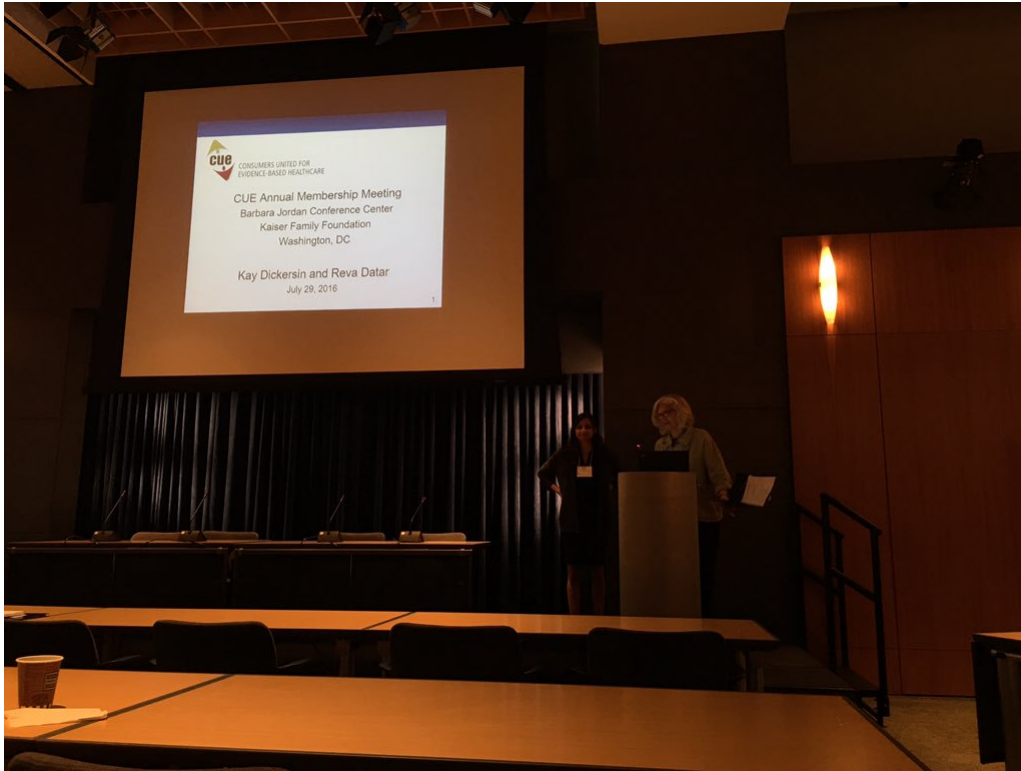
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And we begin! Intro by Ngina Lycott. What would it mean to our work if CUE had organizations that cover all priority populations [#CUEmtg16](https://twitter.com/CUEmtg16)

 2 YEARS AGO



Welcome to #CUEmtg2016! Thank you Barbara Jordan Conference Center and Kaiser Family Foundation for hosting us. pic.twitter.com/fJZMzFy2FL

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#CUEmtg2016 would not be possible without support from #AHRQ and our steering committee! Thank you! pic.twitter.com/PfPD32IDT1

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

 2 YEARS AGO



Barbara Warren

@bwarrenpsyd

Great speakers 13th annual CUE mtg @#CUEmtg16

 2 YEARS AGO

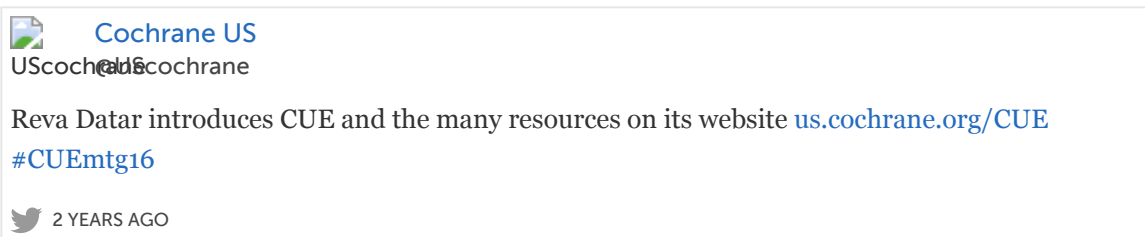
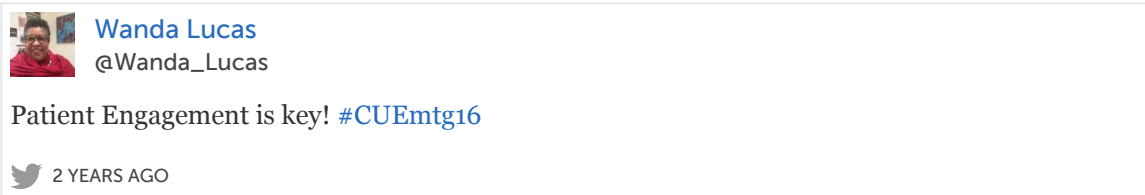


Cherab Lisa Geng

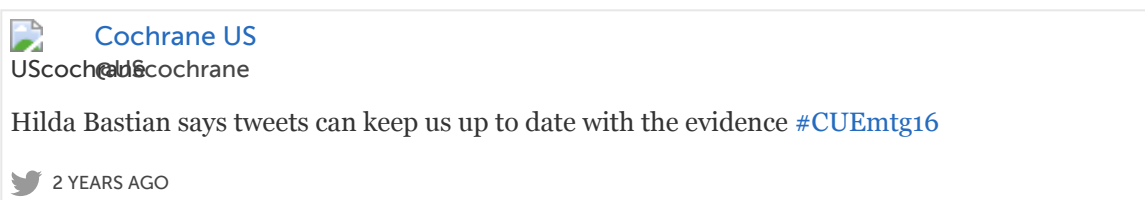
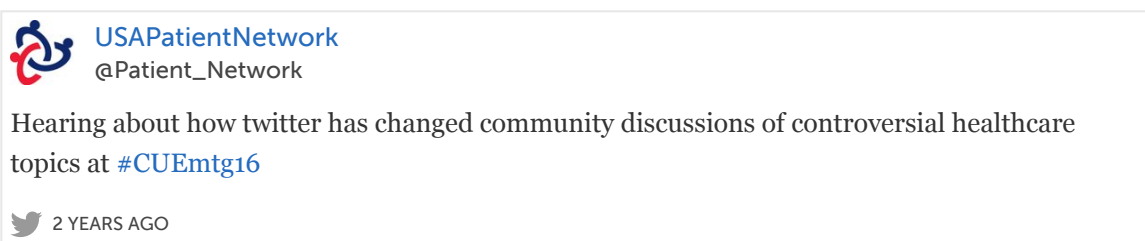
@TheLateTalker

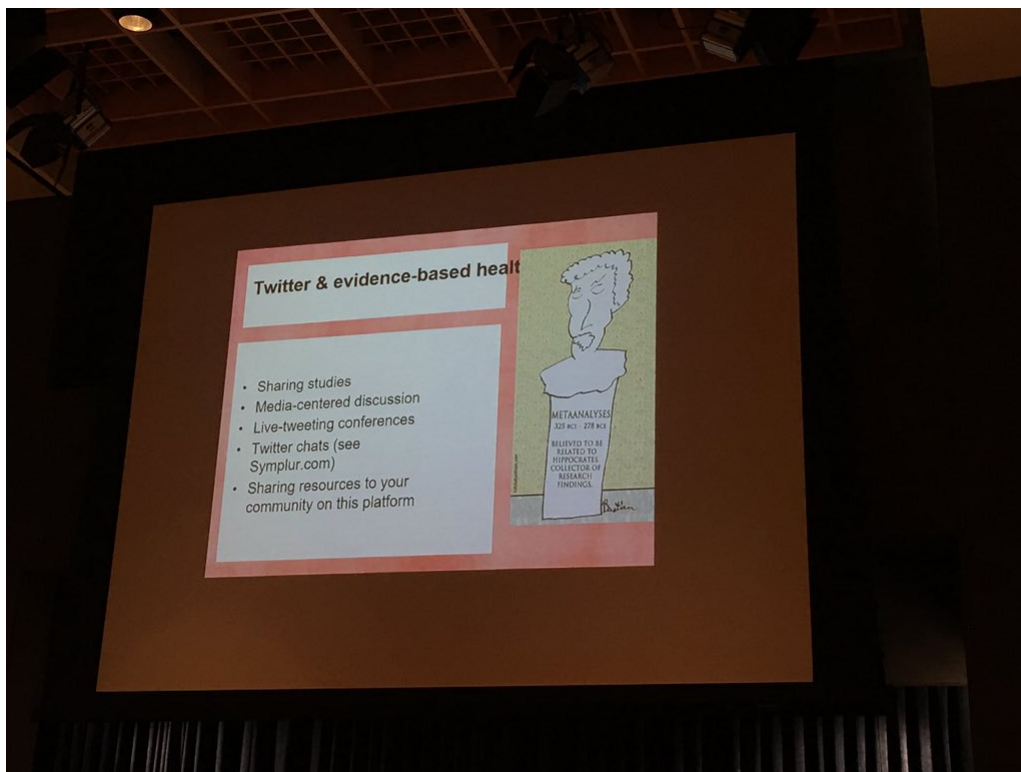
Cherab Foundation proud to represent and present at the CUE conference #CUEmtg16

 2 YEARS AGO



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





Morning keynote by @hildabast ! #Twitter & evidence-based health. #metaanalyses #CUEmtg16
pic.twitter.com/bTwjmbswG4

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Cochrane US

UScochrane

[Symplur.com](https://www.symplur.com) is a good source for Twitter chats #CUEmtg16



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[@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](#)

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](#)

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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](#)

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[@hildabast](#) on social media and where Twitter fits in for health evidence consumer organizations
[#CUEmtg16](#) [pic.twitter.com/4yqlh5aVEt](#)

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Panel 1: Changing the research paradigm: Engaging patients



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Prof. Kate Smith from [@JohnsHopkinsSPH](#): What patients can tell researchers through health experiences research. [#Healthtalk](#) [#CUEmtg16](#)

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Interesting talk on Patient voices. A movement? What patients can tell researchers! #CUEmtg16
[#healthtalk pic.twitter.com/QouGtpdXuo](https://pic.twitter.com/QouGtpdXuo)

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Prof. Smith: "Tell me your story...we are moving from 'voice' to 'voices'" #CUEmtg16
[@HealthTalk](https://twitter.com/HealthTalk) [@UScochrane](https://twitter.com/UScochrane)

2 YEARS AGO



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Link to website from current presentation at #CUEmtg16 for anyone following along:
healthtalk.org/peoples-experi...

2 YEARS AGO



Here's Healthtalk Online US [#CUEmtg16](#) 1st module young people & depression
[#QualResearchFTW!](#) healthexperiencesusa.org/depressionModu... pic.twitter.com/DmET0Srsxz

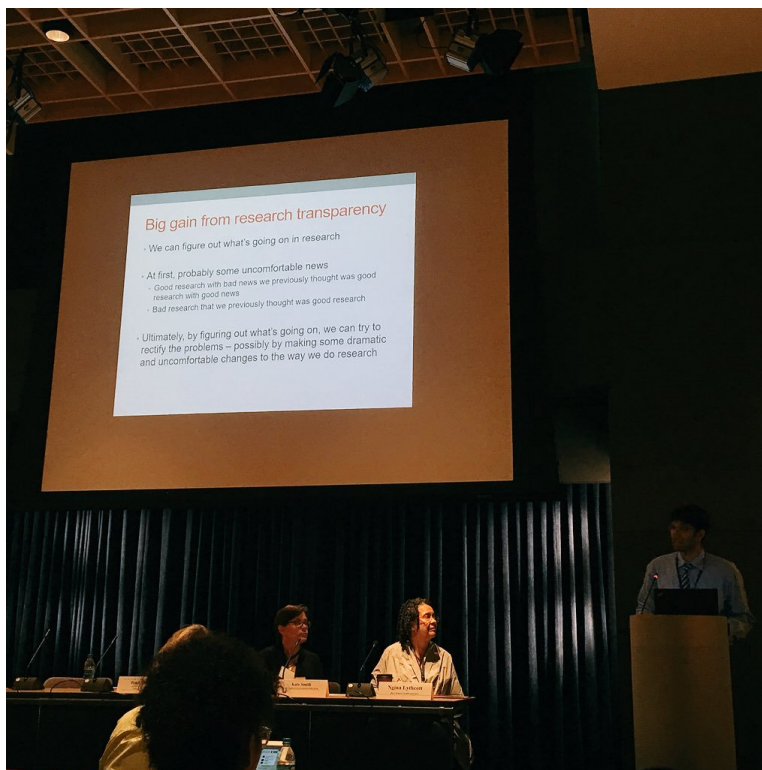
HILDA BASTIAN @HILDABAST · 2 YEARS AGO



Barbara Warren
 @bwarrenpsyd

Kate Smith from Hopkins on how patient experience helps research [@health talk.org](http://healthtalk.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](#)

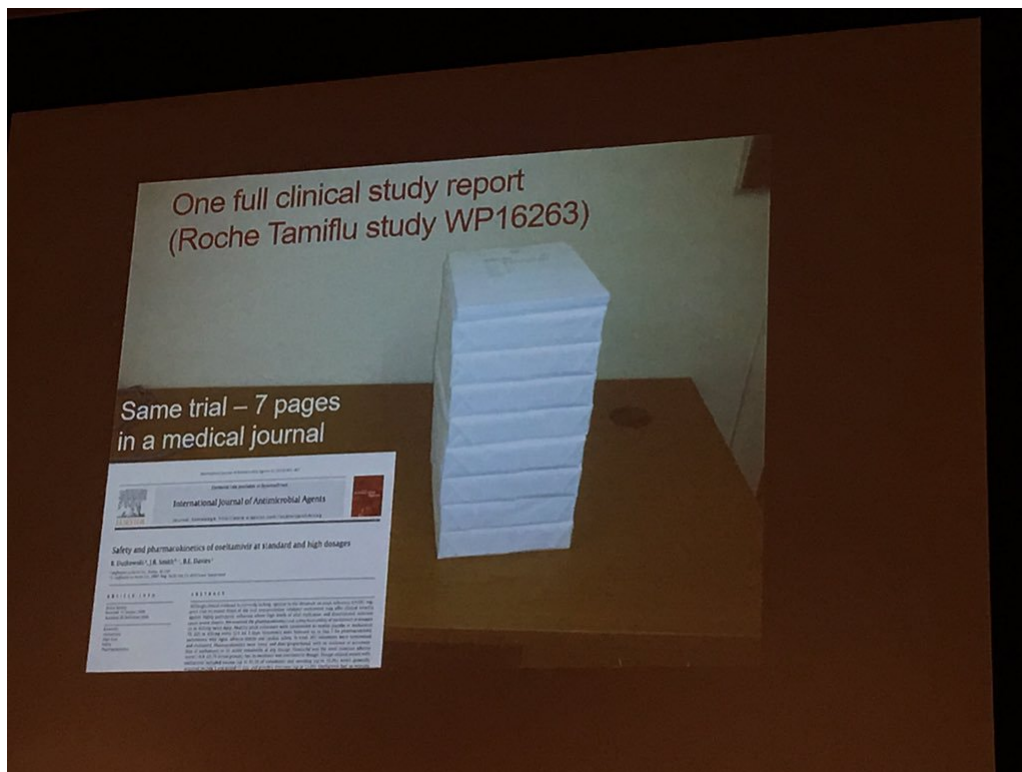
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USAPatientNetwork
@Patient_Network

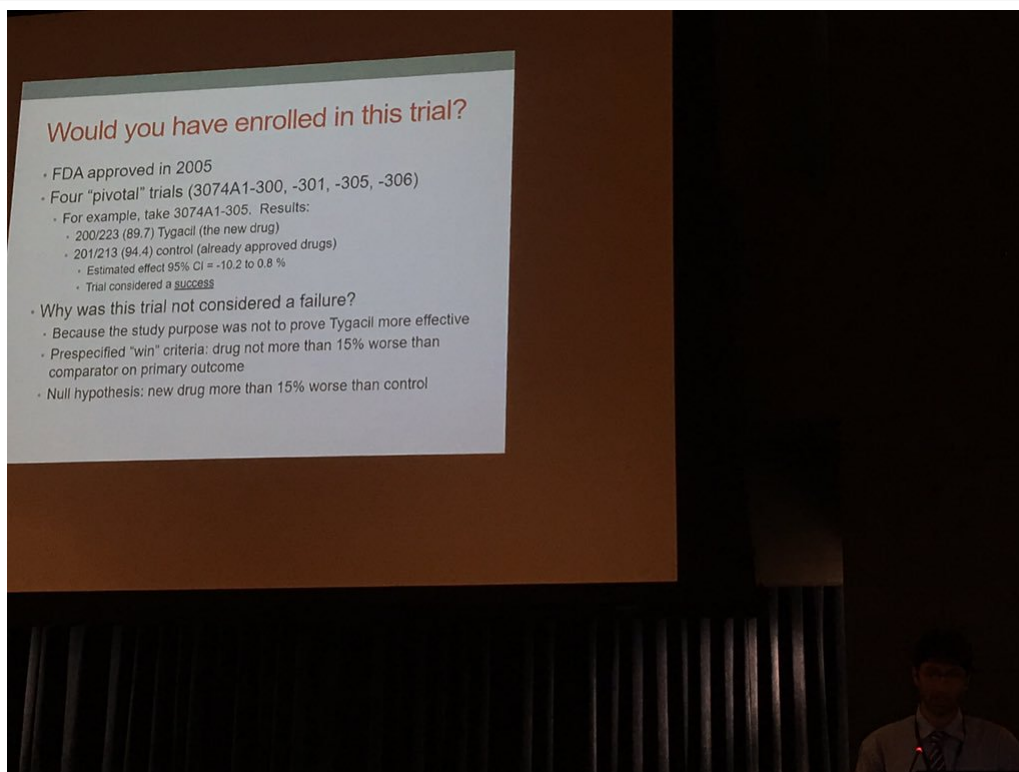
We agree that if we want to conduct research that matters to patients, we must understand what they care about. [#CUEmtg16](#) [@United4Evidence](#)

 2 YEARS AGO



Presentation by Peter Doshi: a single trial report, in two different forms [#CUEmtg16](#)
[@United4Evidence](#) [pic.twitter.com/aNJapETq9P](#)

JIMMY LE @JTOANLE · 2 YEARS AGO



Hmm would you have enrolled? Purpose (not in consent form!) wasn't proving that new drug is more effective [#CUEmtg16](#) pic.twitter.com/Hec5xZvKnZ

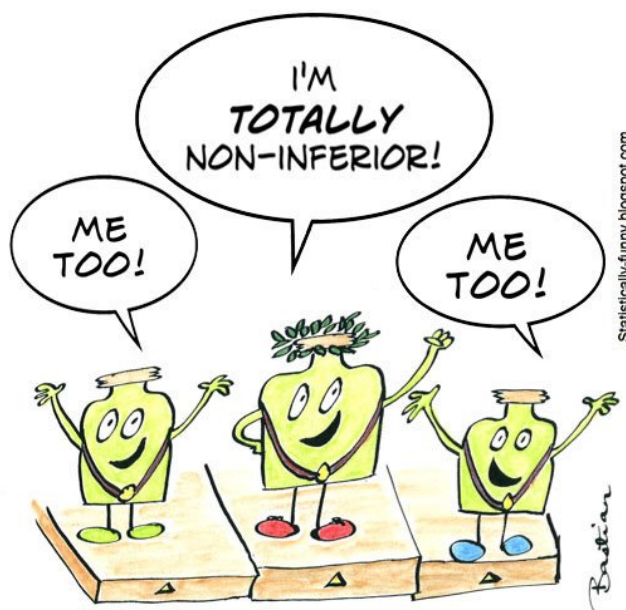
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Cochrane US
UScochrane

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

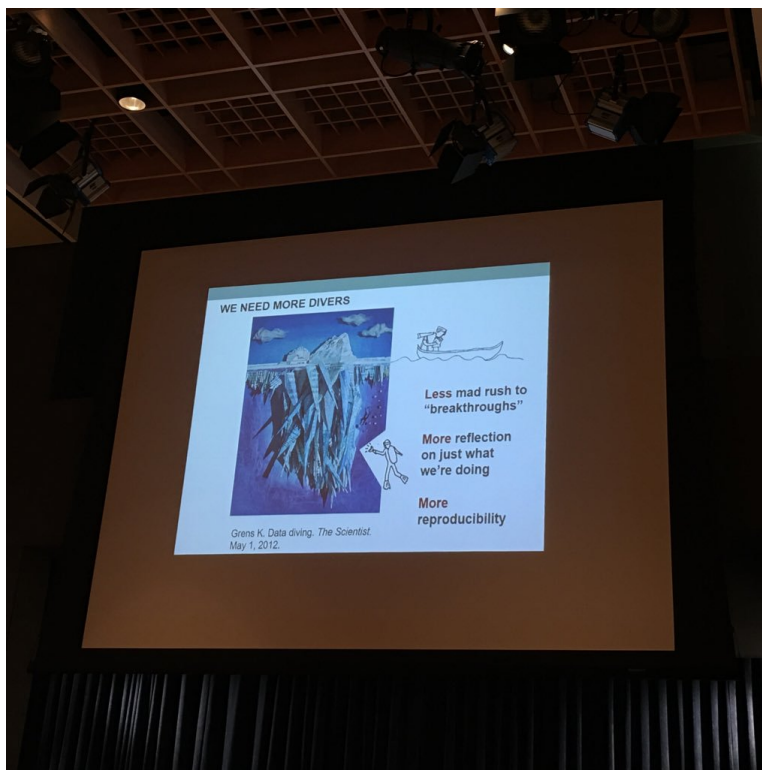
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**HARRY SCORES RECORD-BREAKING
8TH PERSONAL 'NO WORSE'
AT THE PHARMA OLYMPICS!**

Non-inferiority trials: Peter Doshi's definitely not a fan! #CUEmtg16 My explainer: statistically-funny.blogspot.com/2012/08/drugs-... pic.twitter.com/YY7lJCviK

 HILDA BASTIAN @HILDABAST · 2 YEARS AGO



We need more divers. We only know what's above the water line. #CUEmtg16
pic.twitter.com/fyqgFIYrZp

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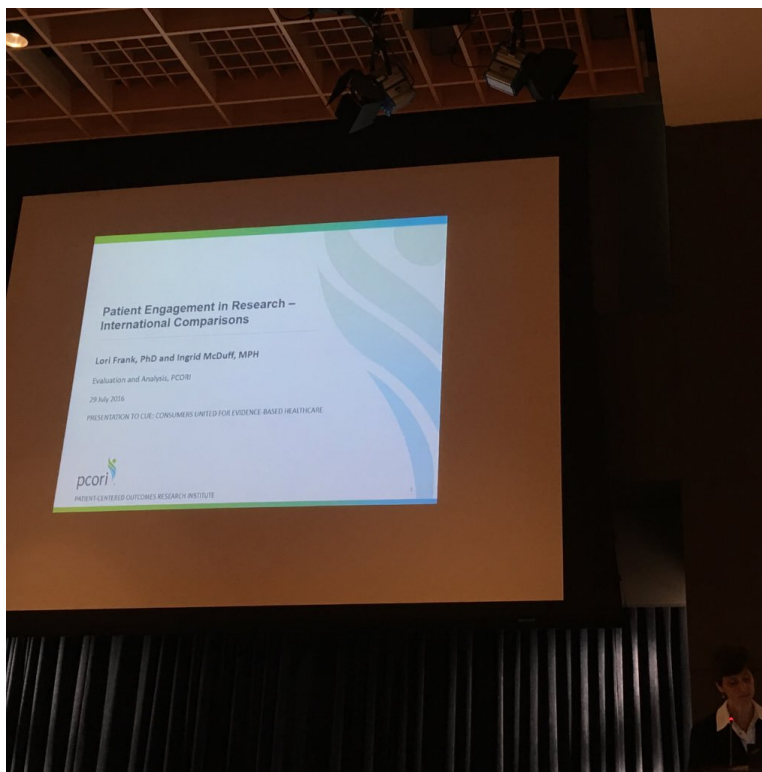
Keynote II: How does the US compare to international patient engagement efforts? INVOLVE, the James Lind Alliance, and Testing Treatments Interactive



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Thank you Jane and @NEEFusa for the great introduction to the social media session this morning! #CUEmtg16 twitter.com/NEEFusa/status...

 2 YEARS AGO



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](#)

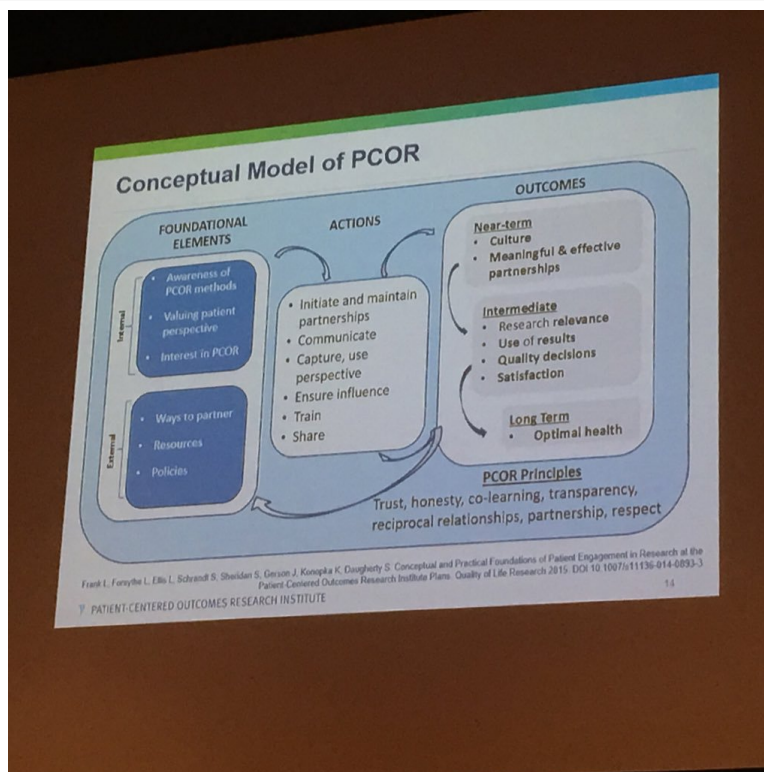
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For ref: International Perspectives on Patient Engagement: Results from the 2011 Commonwealth Fund Survey [#CUEmtg16](#) commonwealthfund.org/publications/i...

 2 YEARS AGO



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

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Cochrane US
UScochrane

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

2 YEARS AGO

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

James Lind Alliance highlighted by Lori Frank as a way to get engaged in priority setting #CUEmtg16 pic.twitter.com/whScmmx9Oi

COCHRANE US @USCOCHRANE · 2 YEARS AGO

Lori Frank reports how patients have been involved in some (though not all) of EMA committees #CUEmtg16 <https://t.co/htKcverdZ4l>

Lori Frank reports how patients have been involved in some (though not all) of EMA committees #CUEmtg16 pic.twitter.com/htKcverdZ4l

COCHRANE US @USCOCHRANE · 2 YEARS AGO

 **Cochrane US**
UScochrane@UScochrane

What is dissemination? Are we incorporating medical education as a dissemination means?
[#CUEmtg16](#)

 2 YEARS AGO

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?

 2 YEARS AGO

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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](#)

 2 YEARS AGO

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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](#)

 2 YEARS AGO

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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](#)

2 YEARS AGO

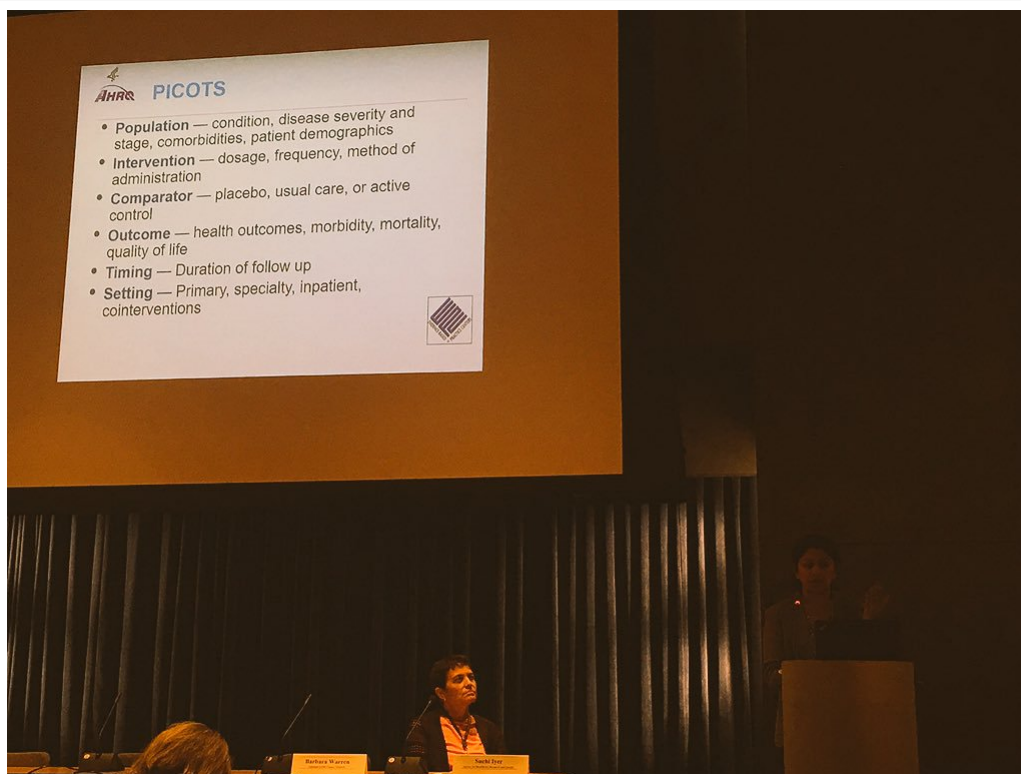


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Question from audience: What does/would patient's involvement in [#FDA](#)'s guidance for industry look like? [#CUEmtg16](#)

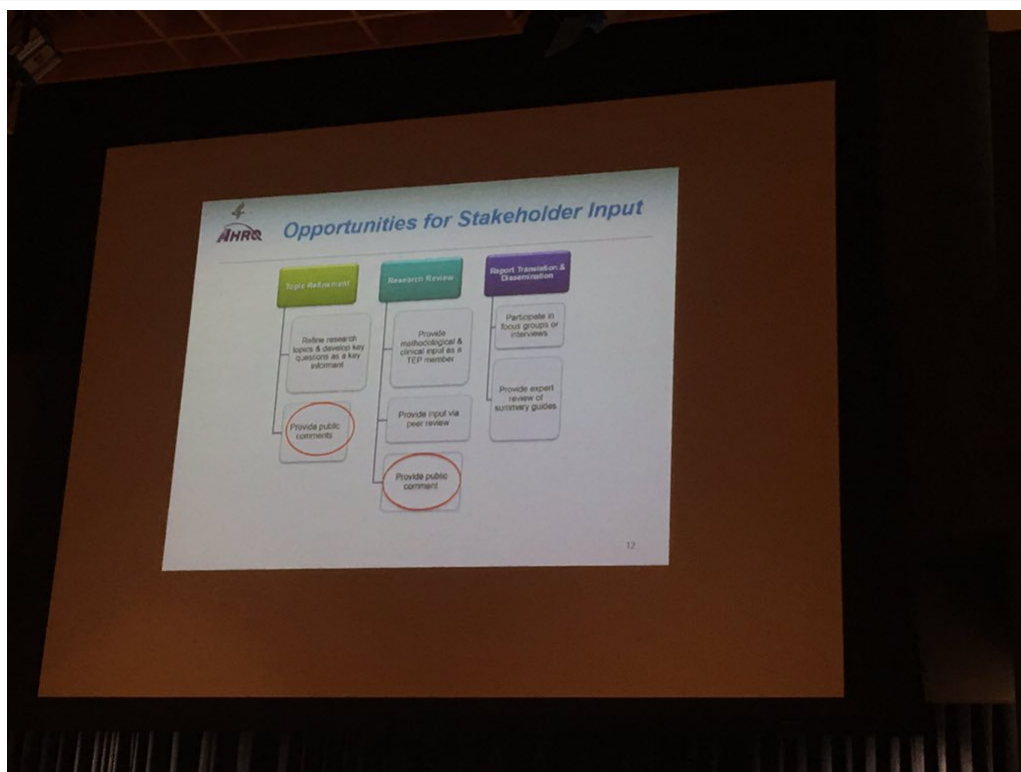
2 YEARS AGO

Breakout workshop session



Refresher on [#PICOTS](#). Thank you Dr. Suchitra Iyer from [#AHRQ](#). Setting the stage for what to look for. [#CUEmtg16](#) [pic.twitter.com/HsIH1yOms](#)

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Dr. Iyer: Opportunities for Stakeholder Input in #AHRQ reviews. @AHRQNews #CUEmtg16
pic.twitter.com/YPJ3WFAcEC

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



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Dr. Califf: "@US_FDA plays a significant role in the Nation's counterterrorism capability" (i.e., emerging public health threats) #CUEmtg16

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Final keynote by Dr. Robert Califf: Meaningful Patient Participation in @US_FDA Decision Making at #CUEmtg16 pic.twitter.com/uUlrm2X5U

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Julie Childers
@jkchilders

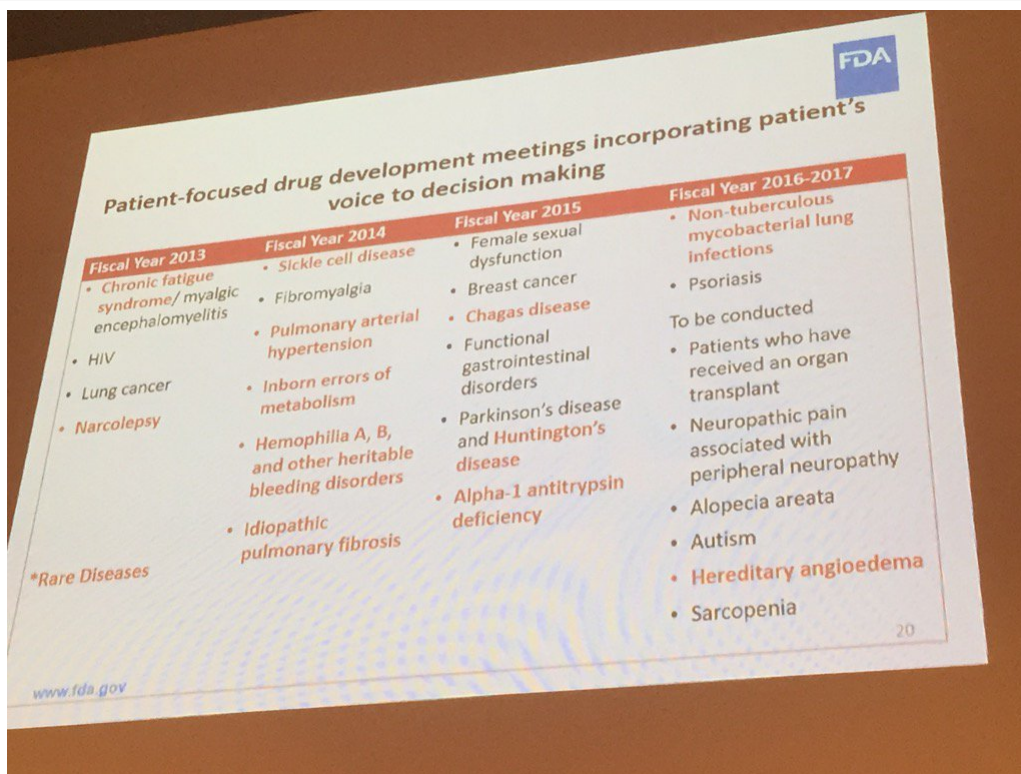
Delighted to be hearing talk by Dr. Robert Califf, FDA Commissioner. #CUEmtg16
#patientparticipation

 2 YEARS AGO



A definition of [#regulatory](#) decision making. [@US_FDA](#) [@UScochrane](#) [#CUEmtg16](#)
pic.twitter.com/jdKtY2wewD

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Fiscal Year 2013	Fiscal Year 2014	Fiscal Year 2015	Fiscal Year 2016-2017
- Chronic fatigue syndrome/ myalgic encephalomyelitis - HIV - Lung cancer - Narcolepsy	- Sickle cell disease - Fibromyalgia - Pulmonary arterial hypertension - Inborn errors of metabolism - Hemophilia A, B, and other heritable bleeding disorders - Idiopathic pulmonary fibrosis	- Female sexual dysfunction - Breast cancer - Chagas disease - Functional gastrointestinal disorders - Parkinson's disease and Huntington's disease - Alpha-1 antitrypsin deficiency	- Non-tuberculous mycobacterial lung infections - Psoriasis To be conducted - Patients who have received an organ transplant - Neuropathic pain associated with peripheral neuropathy - Alopecia areata - Autism - Hereditary angioedema - Sarcopenia

*Rare Diseases

www.fda.gov

20

FDA's roster of patient-focused drug development meetings: Califf, FDA Commissioner [#CUEmtg16](#)
[pic.twitter.com/YtpLMqNsMN](https://twitter.com/YtpLMqNsMN)

 HILDA BASTIAN @HILDABAST · 2 YEARS AGO

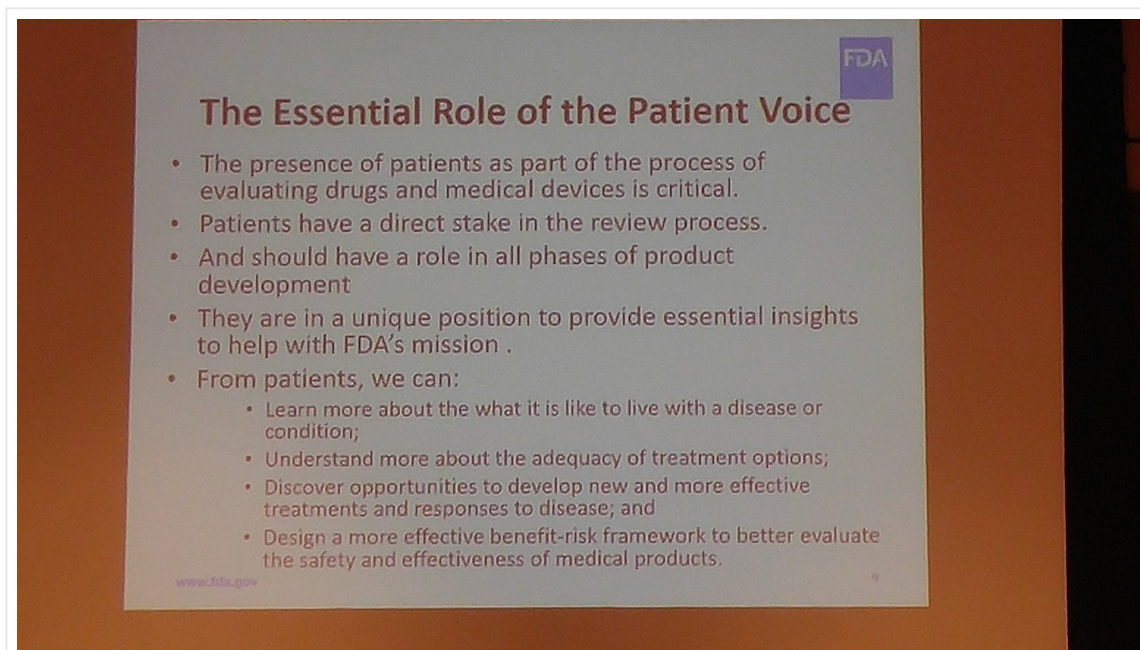


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Dr. Robert Califf " [@US_FDA](#) is all about making decisions" so how do we make these decisions more [#evidence](#) [#informed](#)? [#CUEmtg16](#)

 2 YEARS AGO



Value added through patient engagement [#CUEmtg16](#) pic.twitter.com/9EJZKelbXO

 CHERAB LISA GENG @THELATETALKER · 2 YEARS AGO



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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](#)

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Thank Dr. Robert Califf, [@US_FDA](#) Commissioner, for being our final keynote at [#CUEmtg16](#) and leading a great Q&A!

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This concludes #CUEmtg2016! Don't hesitate to let us know if you know organizations that may be interested in CUE and evidence-based health!



2 YEARS AGO