

by CUE Cochrane USA · a year ago

2017 CUE Summit

The 2017 CUE Summit on "Leveraging the Power of Patient & Consumer Advocacy to Transform Healthcare" took place on March 19, 2017 at the National Academy of Medicine in New York City.

Registration and Introduction



Registration desk is open. Come by if you have any questions! [#CUESummit17](#)
pic.twitter.com/dc4xfBn7Rp

 CUE @UNITED4EVIDENCE · A YEAR AGO



Arturo Durazo
@adurazo2

Now happening: Summit on leveraging the power of patient and consumer advocacy!
[#CUESummit17](#)

 A YEAR AGO



Surrounded by amazing leaders who harness patient and consumer advocacy into transforming research and clinical care! #CUESummit17 pic.twitter.com/3K06FUaoOm

 ARTURO DURAZO @ADURAZO2 · A YEAR AGO



Getting up early on a Sunday morning is worth it to get to advocate for patients! #CUESummit17 pic.twitter.com/Kv7WQahR2O

 JEN HORONJEFF @JHORONJEFF · A YEAR AGO



Leveraging the Power of Patient and Consumer Advocacy to Transform Healthcare [#CUESummit17](#)
pic.twitter.com/7rdEVmrrye

 CUE @UNITED4EVIDENCE · A YEAR AGO



Sanford Jeames; DHA
@JeamesSailor

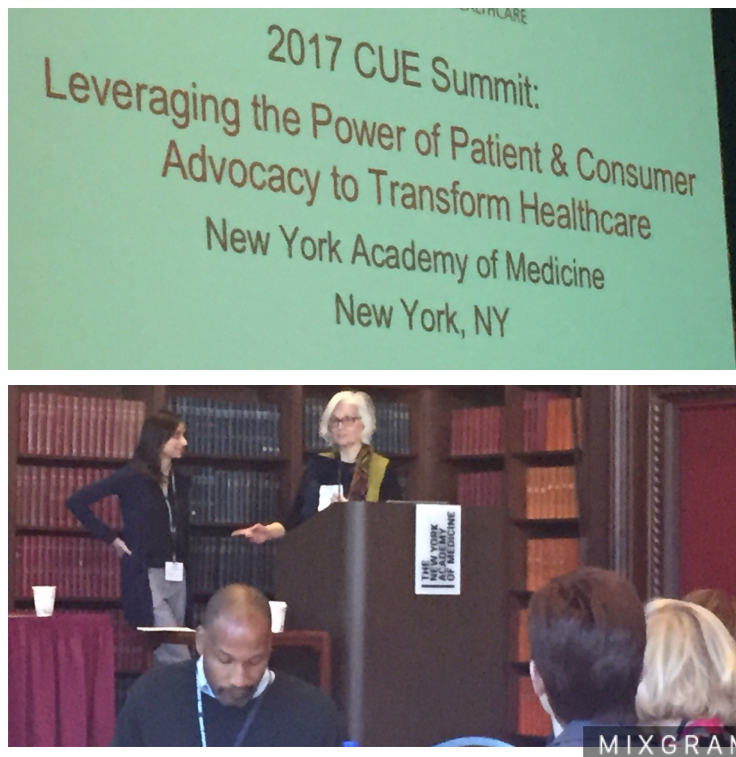
[@MightyCasey](#) [@SterlingHIT](#) [@United4Evidence](#) Great way to start the morning among powerful advocates. [#CUESummit17](#) [#Advocacy](#)

 A YEAR AGO



What a great start to #cuesummit17 pic.twitter.com/pC849FiDD0

 TOM GETCHIUS @THOMASGETCHIUS · A YEAR AGO



Now open: Summit on leveraging the power of patient and consumer advocacy! [#CUESummit17](#)
[@KayDickersin](#) [pic.twitter.com/eOvPxhFcLC](#)

ARTURO DURAZO [@ADURAZO2](#) · A YEAR AGO



Sandra Zelman Lewis
[@SandraZLewis](#)

Excited for today's CUE Summit [@United4Evidence](#) [#CUESummit17](#) [#LivingGuidelines](#)

A YEAR AGO



Sally Crowe
[@sally_crowe](#)

Very happy to be part of this summit today! [#CUESummit17](#) [twitter.com/united4evidenc...](#)

A YEAR AGO



Casey Quinlan
[@MightyCasey](#)

[@JeamesSailor](#) [@SterlingHIT](#) [@United4Evidence](#) They hit BOTH my high/hot spots in welcome: black activists *and* LGBTQ activists! [#CUESummit17](#)

A YEAR AGO



Nueva Vida participating at [#cuesummit17](#). Impressive presenters. pic.twitter.com/sxs9SMCEel

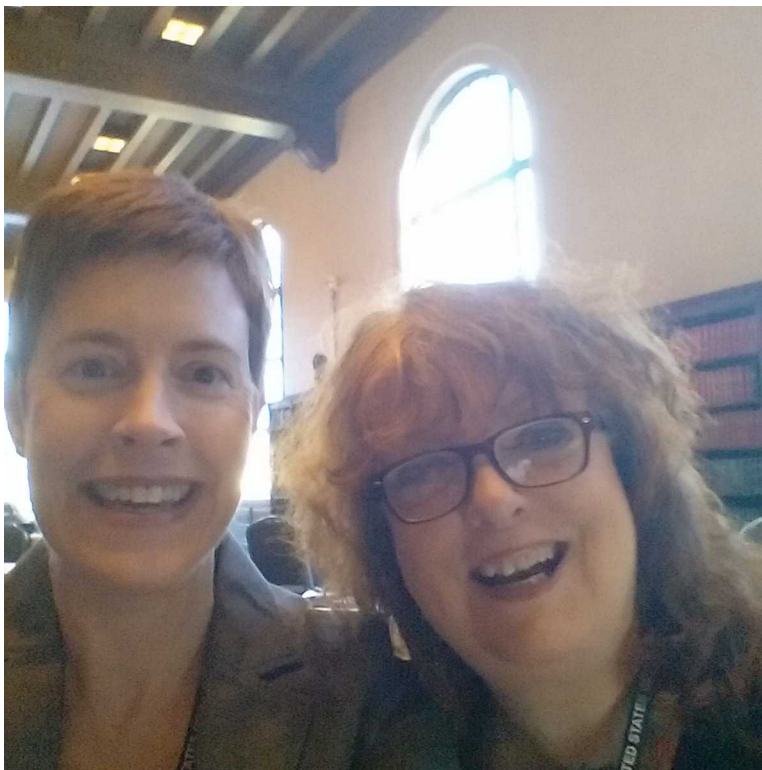
 NUEVA VIDA @NUEVA_VIDA · A YEAR AGO



CUE
@United4Evidence

What is [#CUE](#)? We are a national coalition of over 40 [#health](#) advocacy organizations promoting [#evidence](#)-based health care. [#CUESummit17](#)

 A YEAR AGO



All smiles as @MightyCasey and I start our Sunday morning at #CUESummit17 in NYC w/ @yogileana @JeamesSailor @hhask pic.twitter.com/j3aoAP8EGp

 MARY ANNE STERLING @STERLINGHIT · A YEAR AGO



Mikala_Edwards
@MK_PinkGal

Very excited and honored to be a part of @United4Evidence summit gaining momentum for my advocacy work #cuesummit17 #youngsurvivor #bc

 A YEAR AGO



CUE
@United4Evidence

"A lot of the richness comes from meeting each other to form partnerships and collaborations" @nlythcott #CUESummit17

 A YEAR AGO



Sally Crowe
@sally_crowe

#CUESummit17 First up today is @VinayPrasad82 who is talking about the politics of consumer advocacy - strap in the for the ride!

 A YEAR AGO



I can't think of a better way to start off spring break than w/ a conference on [#evidence-based](#) [#healthcare](#) [#CUESummit17](#) [@United4Evidence](#) [pic.twitter.com/SNxcvqBwZw](#)

JIMMY LE [@JTOANLE](#) · A YEAR AGO



Annie Appleseed
[@AnnieAppleseed](#)

[#CueSummit17](#) Attending the 3rd annual CUE Summit Consumers United for Evidence-based Healthcare New York City is... [fb.me/8rvEovGqx](#)

A YEAR AGO



Surrounded by books and consumer advocates at [#cuesummit17](#) in NYC. [@MightyCasey](#) [@hhask](#) [@yogileana](#) [@JeamesSailor](#) pic.twitter.com/OpgtvTuVKu

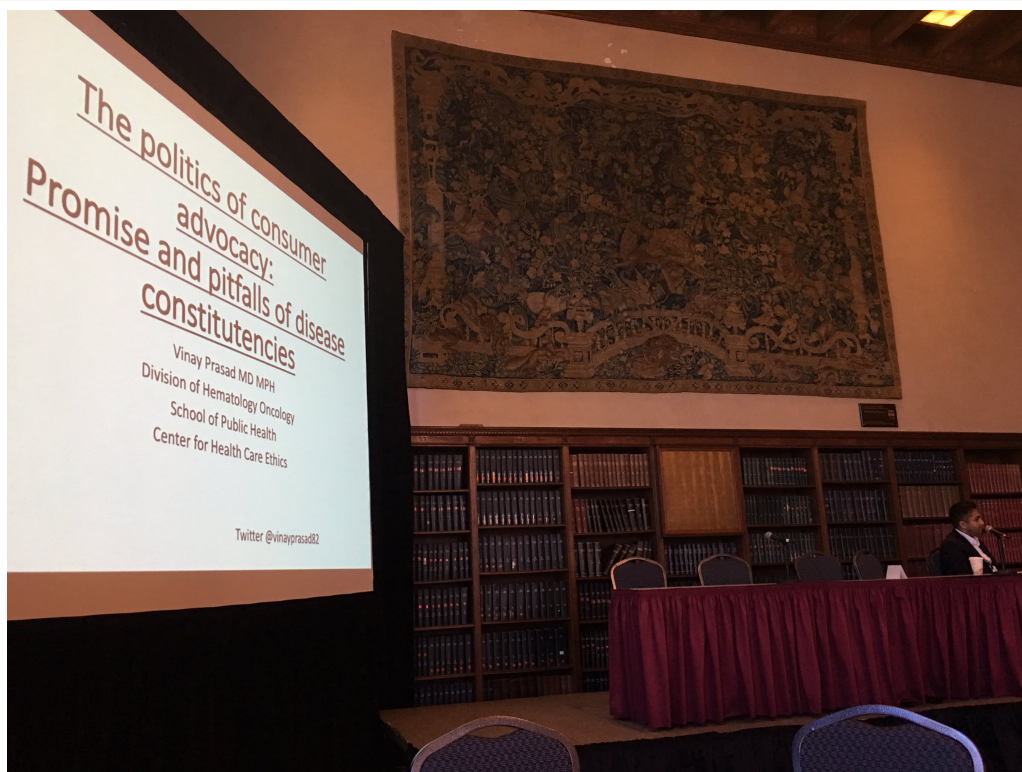
 MARY ANNE STERLING [@STERLINGHIT](#) · A YEAR AGO



@United4Evidence @KayDickersin Very excited this morning for #CUESummit17. Great sharing 2 take place. #advocacy pic.twitter.com/weudNdlVJr

 SANFORD JEAMES; DHA @JEAMESSAILOR · A YEAR AGO

KEYNOTE 1: The politics of consumer advocacy: The promise and pitfalls of disease constituencies *Vinay Prasad, Assistant Professor of Medicine at the Oregon Health and Sciences University*



Up first, Dr. [@VinayPrasad82](#): "The politics of [#consumer](#) advocacy: Promise and pitfalls of disease constituencies" [#CUESummit17](#) pic.twitter.com/gcsFDYIls

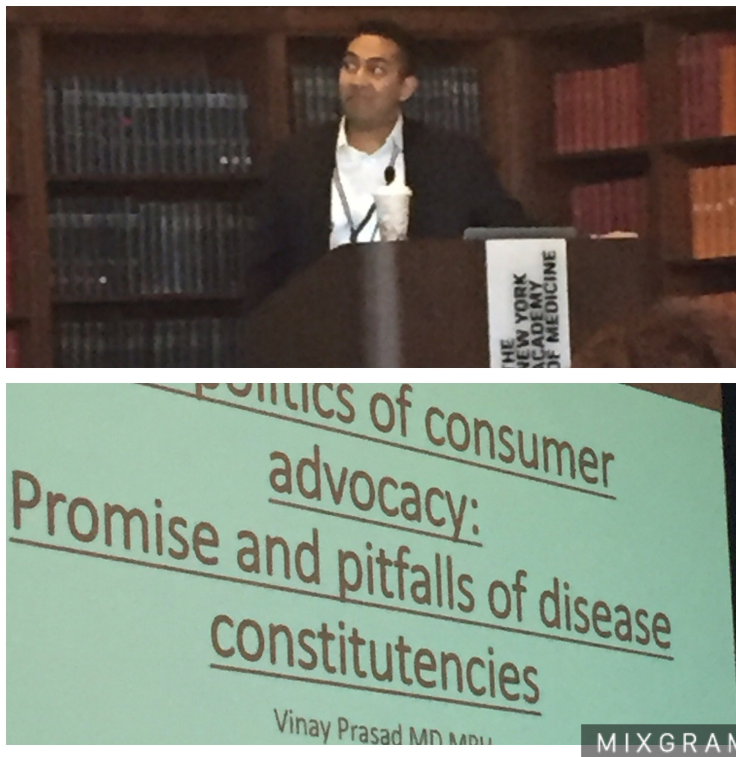
CUE [@UNITED4EVIDENCE](#) · A YEAR AGO



Sanford Jeames; DHA
[@JeamesSailor](#)

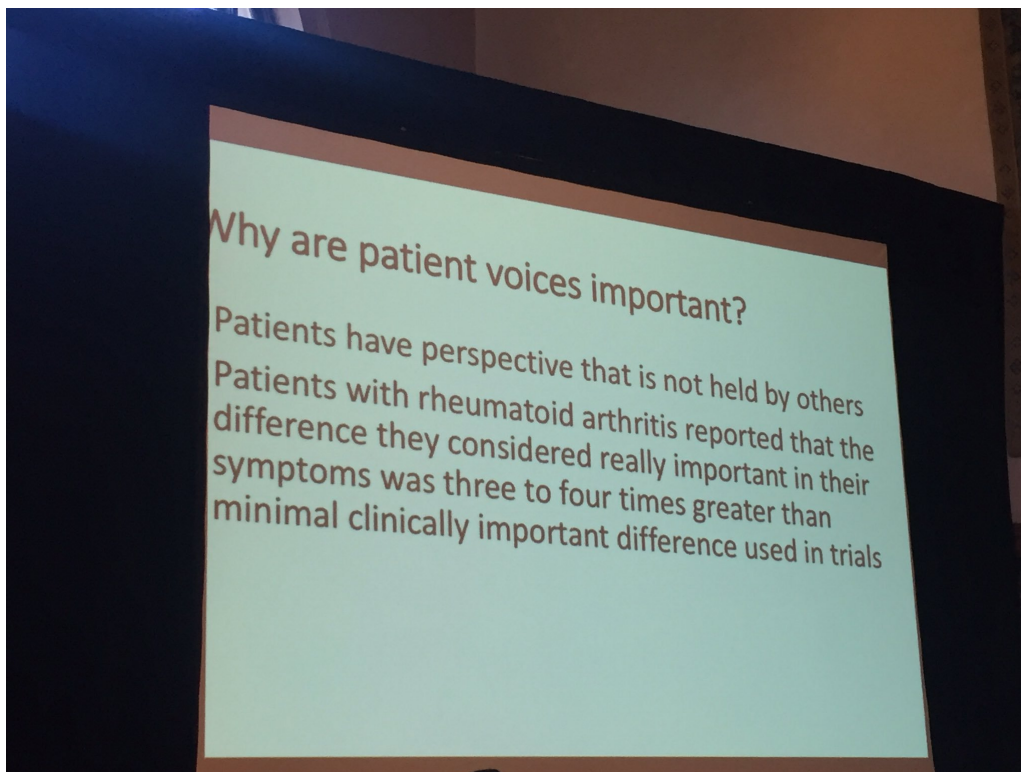
[@United4Evidence](#) [@MightyCasey](#) [@SterlingHIT](#) What a great way to begin the [#CUESummit17](#) with opening discussion on consumer advocacy [#Changes](#)

A YEAR AGO



Dr. [@VinayPrasad82](#) on opportunity and challenge of consumer advocacy. [#CUESummit17](#)
pic.twitter.com/N8VGy2ii1S

 ARTURO DURAZO [@ADURAZO2](#) · A YEAR AGO



Why is [#patientvoice](#) so important? Because [#patientpriorities](#) may differ from clinicians/researchers [@VinayPrasad82](#) [#CUESummit17](#) [pic.twitter.com/UNa0loPH5y](#)

JEN HORONJEFF [@JHORONJEFF](#) · A YEAR AGO



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[@United4Evidence](#)

Why are patient voices important? "Patients have [#perspective](#) that is not held by others." [@VinayPrasad82](#) [#CUESummit17](#)

A YEAR AGO



Sanford Jeames; DHA

[@JeamesSailor](#)

[@United4Evidence](#) [@MightyCasey](#) [@VinayPrasad82](#) Do cancer drugs really work well in real world situations? Results say NO! [#CUESummit17](#) [#CBPR](#)

A YEAR AGO



Sally Crowe

[@sally_crowe](#)

[#CUESummit17](#) [@VinayPrasad82](#) we need pragmatic trials, with 'real world' populations to assess impact 4 new cancer drugs.

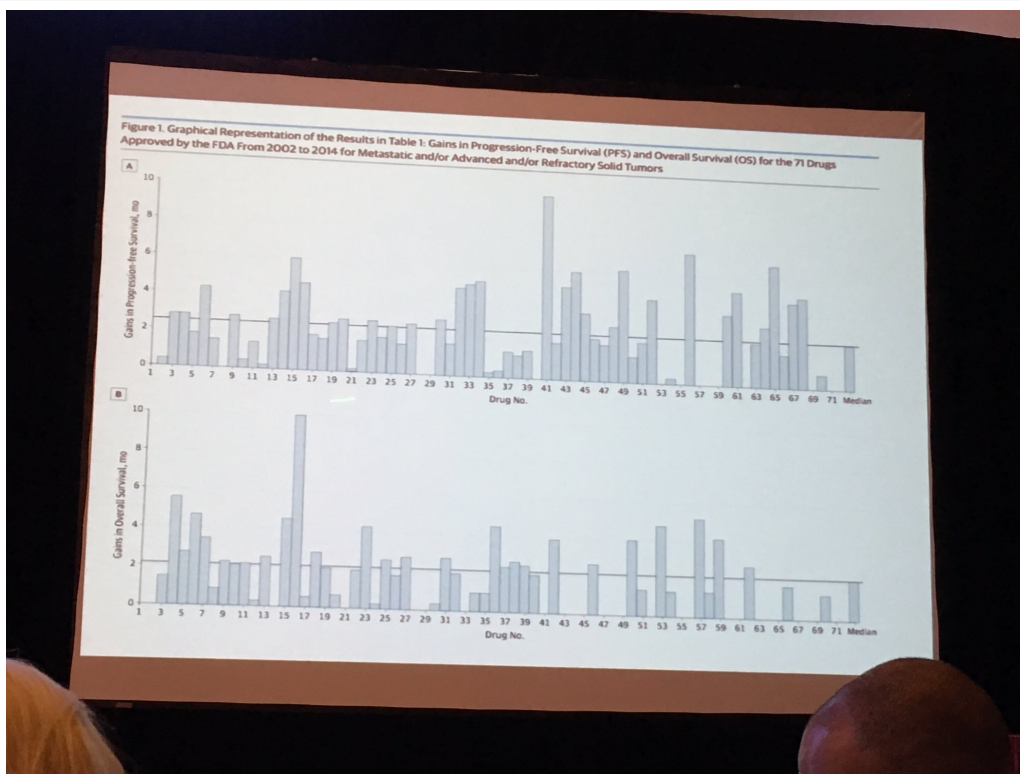
A YEAR AGO



Jen Horonjeff
@jhoronjeff

"We are extrapolating [#clinicaltrials](#) results of younger healthier ppl to older cancer populations." [@VinayPrasad82](#) [#cuesummit17](#)

A YEAR AGO



V Prasad: of cancer drugs approved by FDA between 2002 & 2014, they increased progression free survival only 2.1 mos on avg [#CUESummit17](#) [pic.twitter.com/BRoBqEKzyX](#)

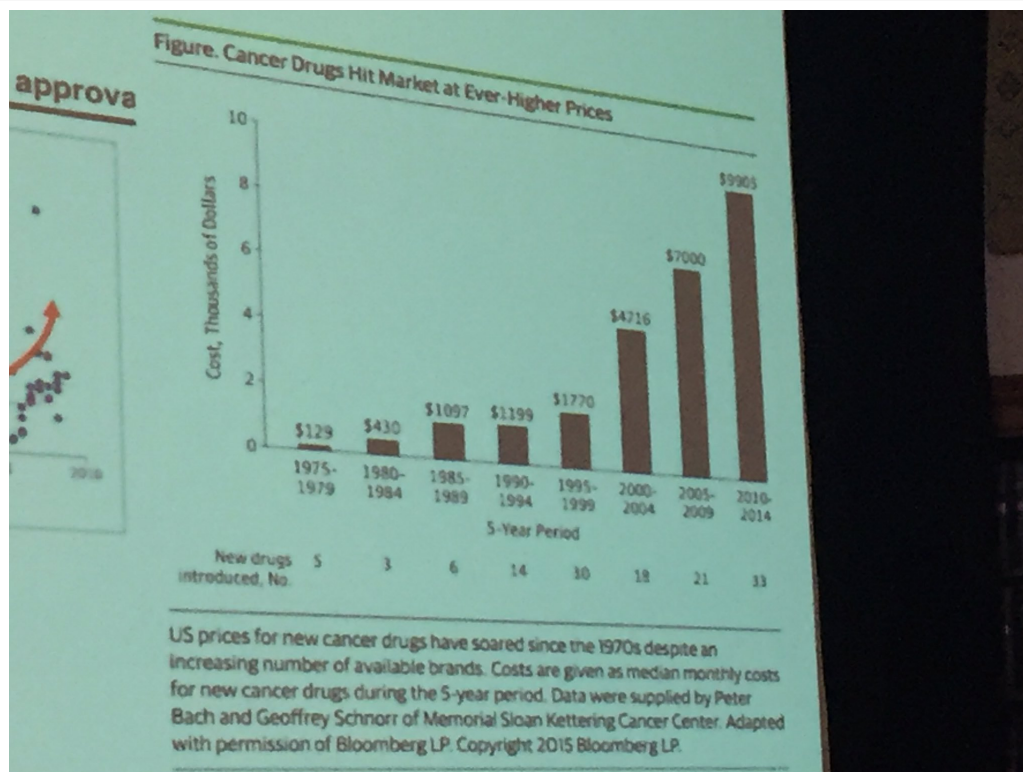
KAY DICKERSIN @KAYDICKERSIN · A YEAR AGO



Casey Quinlan
@MightyCasey

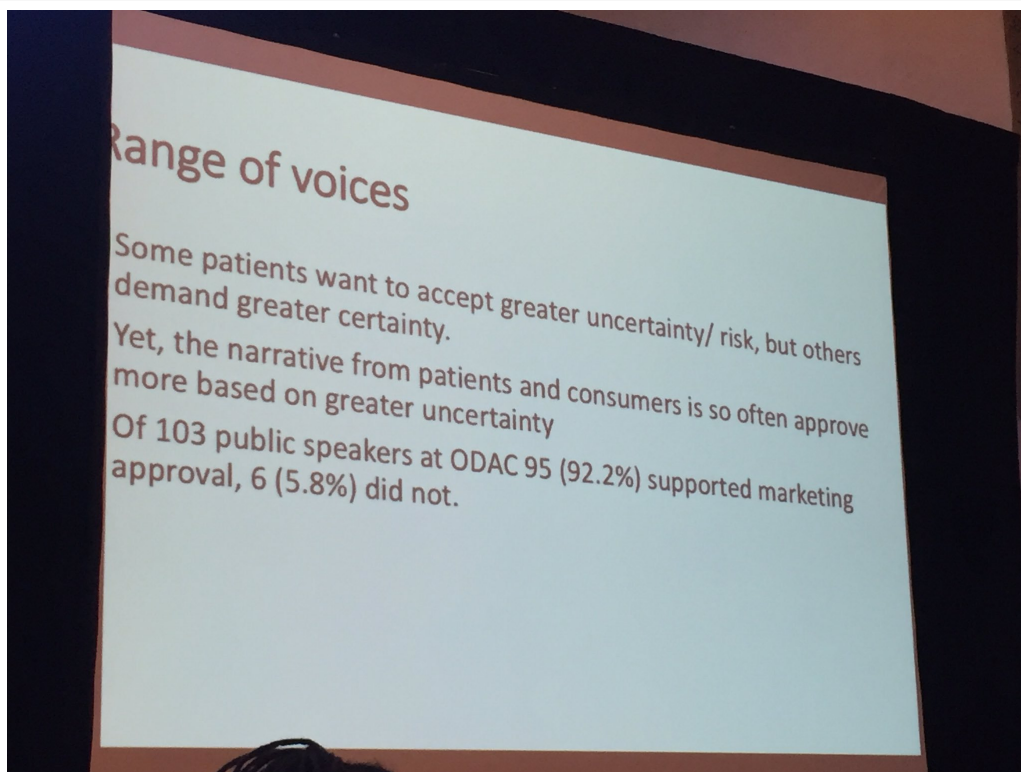
+1 RT [@sally_crowe](#): [@VinayPrasad82](#) we need pragmatic trials, with 'real world' populations to assess impact 4 new cancer drugs. [#cuesummit17](#)

A YEAR AGO



Cost of one month of cancer treatment over time. Yikes! #CUESummit17
pic.twitter.com/ByoTI67bHa

JEN HORONJEFF @JHORONJEFF · A YEAR AGO



Narrative in media is that patients want to approve more Rx with less certainty. But the numbers tell a different story. [#CUESummit17](#) [pic.twitter.com/S3JgpAWOfz](https://twitter.com/S3JgpAWOfz)

JEN HORONJEFF @JHORONJEFF · A YEAR AGO



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@United4Evidence

How well do cancer drugs work in the real world? What outcomes matter to patients? Pts covered by [@VinayPrasad82](#)'s talk today @ [#CUESummit17](#)

A YEAR AGO



Casey Quinlan
@MightyCasey

Hearing [@VinayPrasad82](#) break down *exactly* why I push back on DTC [#pharma](#) ads for cancer drugs w/"weeks median survival" [#s4pm](#) [#cuesummit17](#)

A YEAR AGO



Casey Quinlan
@MightyCasey

Millions (billions?) of \$\$ spent on DTC [#pharma](#) TV ads for Opdivo, Keytruda, for ... weeks, maybe months, median survival? Pfui [#cuesummit17](#)

A YEAR AGO

**Arturo Durazo**

@adurazo2

Widen scope of FDA approvals: When approving Tx, connect clinical efficacy & consumer requested standards. [#CUESummit17](#) [@VinayPrasad82](#)



A YEAR AGO

**Sanford Jeames; DHA**

@JeamesSailor

[@United4Evidence](#) [@MightyCasey](#) [@SterlingHIT](#) [@VinayPrasad82](#) Great question raised here. Can patients demand better evidence? [#CUESummit17](#)



A YEAR AGO

**Casey Quinlan**

@MightyCasey

"All the people who have died, died." Channeling Jim Carroll in pointing out who DOES NOT get to speak on [#cancer](#) drug approval [#cuesummit17](#)



A YEAR AGO

**CUE**

@United4Evidence

At drug advisory mtgs, who's voices are missing? Those who've died & those who've suffered significant toxicity. [@VinayPrasad82](#) [#CUESummit17](#)



A YEAR AGO

**Sally Crowe**

@sally_crowe

[#CUESummit17](#) who is not speaking at drug advisory meetings? Skewed towards +ve conclusions by analysis of who is speaking - [@VinayPrasad82](#)



A YEAR AGO

**Casey Quinlan**

@MightyCasey

Calling out [#pharma](#) support for patient advocacy orgs doesn't address root issue: med-industrial complex protecting \$3.4T/year. [#cuesummit17](#)



A YEAR AGO

Representativeness
Public speakers at ODAC

Table 2. Characteristics of 103 Public Speakers at the 28 Oncologic Drugs Advisory Committee Meetings

Characteristic	No. (%)
Speakers with the cancer in question	46 (44.7)
Speakers who received the drug in question	32 (31.1)
Speakers who represented an organization	58 (56.3)
Speakers who were principal investigators in seminal trials	2 (1.9)
Speakers who disclosed a financial association ^a	31 (30.1)
Speakers with a financial association that was not disclosed	2 (1.9)
Speakers whose financial association was through an organization ^b	20 (19.4)

^a Travel fees (n = 11), organization financially supported by the company in question (n = 18), and both organizational support and travel fees (n = 2).

^b Caring for Carcinoid Foundation (n = 2), Facing Our Risk of Cancer Empowered (FORCE) (n = 2), Sarcoma Foundation of America (n = 2), Aveo Nurse Steering Committee (n = 1), Aveo Nurse Steering Committee and Aveo's Inspire Program (n = 1), Avon Foundation Breast Cancer Crusade (n = 1), breastcancer.org (n = 1), Cancer Support Community (n = 1), Lung Cancer Alliance (n = 1), Musella Foundation for Brain Tumor Research and Information, Inc (n = 1), MyLifeLine.org (n = 1), National Brain Tumor Society (n = 1), National Organization for Rare Disorders (n = 1), Ovarian Cancer National Alliance (n = 1), Programs and Services of the Cancer Support Community (n = 1), Research Advocacy Network (n = 1), and Uniting Against Lung Cancer (n = 1).

"Who is not represented at these @US_FDA meetings? Patients who have died or do not want to travel to advocate" @VinayPrasad82 #cuesummit17 pic.twitter.com/M20B9soPuY

 JEN HORONJEFF @JHORONJEFF · A YEAR AGO



Kay Dickersin
@KayDickersin

V Prasad: if FDA uses lower efficacy stds, then we are unlikely to learn more w time. Unfair to those who want more info! #CUESummit17

 A YEAR AGO



Arturo Durazo
@adurazo2

When drugmakers fund patient advocates, there is silent discussion about Tx costs.
#CUESummit17 @VinayPrasad82

 A YEAR AGO



Sally Crowe
@sally_crowe

#CUESummit17 call from @VinayPrasad82 for more representation at drug advisory meetings via use of film/online so less well can contribute

 A YEAR AGO



Casey Quinlan
@MightyCasey

Agree w/ @VinayPrasad82 that patient orgs co-opted by #pharma \$\$ are d-bags (my term, not his) for NOT CALLING OUT DRUG PRICING #cuesummit17

A YEAR AGO



Mary Anne Sterling
@SterlingHIT

"We need video diaries from #patients participating in clinical drug trials" --@VinayPrasad82 #CUESummit17

A YEAR AGO



Casey Quinlan
@MightyCasey

Holla @CureForward RT @SterlingHIT: "We need video diaries fm #patients participating in drug #clinicaltrials" --@VinayPrasad82 #CUESummit17

A YEAR AGO



#cuesummit17 one of the signs of a great talk--a line at the microphone!
pic.twitter.com/hZ1d4RKDMh

TOM GETCHIUS @THOMASGETCHIUS · A YEAR AGO

**Sally Crowe**

@sally_crowe

#CUESummit17 so interesting - Q & A for @VinayPrasad82 a long line of people with questions get up, is this an American or a Vinay thing?!



A YEAR AGO

**CUE**

@United4Evidence

How do we address problem of #omission & #commission? Ensure 1) range of opinions, 2) #representativeness, and 3) #transparency #CUESummit17



A YEAR AGO

**Casey Quinlan**

@MightyCasey

Calling out patients/orgs for taking #pharma support \$\$ misses point that PATIENTS HAVE TO PAY BILLS, TOO. #rattyboxers #s4pm #cuesummit17



A YEAR AGO

**Kay Dickersin**

@KayDickersin

Amy Verstappen says we need better consumer training about how to avoid conflict of interest #CUESummit17



A YEAR AGO

**Sally Crowe**

@sally_crowe

#CUESummit17 Conflict of Interest a early issue here - can @United4Evidence & others address this in training and support for consumers?



A YEAR AGO

**Jimmy Le**

@jtoanle

Dr @VinayPrasad82: are cancer trials measuring the outcomes important to patients? Representing patients with cancer? #cuesummit17



A YEAR AGO



The Q&A line for @VinayPrasad82 at #CUESummit17 pic.twitter.com/F5o8H1yKU0

 CUE @UNITED4EVIDENCE · A YEAR AGO



Casey Quinlan
@MightyCasey

Once again for cheap seats: US med-industrial complex = \$3.4T/year revenue machine. THAT'S what's driving the train. [#hcpt](#) [#cuesummit17](#)

 A YEAR AGO



Dr. Vinay Prasad "The politics of consumer advocacy: The promise & pitfalls of disease constituencies" [#CUESummit17](https://pic.twitter.com/oqgdWh1pPN) pic.twitter.com/oqgdWh1pPN

JANICE TUFT [@HASSANAH2017](#) · A YEAR AGO



Sally Crowe
[@sally_crowe](#)

[#CUESummit17](#) This article may be of interest to [@United4Evidence](#) participants - given current discussion on COI [@SDenegri](#) [@JeremyTaylorNV](#) [twitter.com/jeremytaylornv...](https://twitter.com/jeremytaylornv)

A YEAR AGO



Casey Quinlan
[@MightyCasey](#)

[@sally_crowe](#) [@VinayPrasad82](#) Totes a Vinay thing - he's Keith Richards when it comes to economics + evidence in oncology => [#cuesummit17](#)

A YEAR AGO



CUE
[@United4Evidence](#)

Why are trials not representative? Frailer people not interested? Companies not interested? Probably the latter [@VinayPrasad82](#) [#CUESummit17](#)

A YEAR AGO

**CUE**

@United4Evidence

Thanks for sharing @sally_crowe! #CUESummit17 [twitter.com/sally_crowe/st...](https://twitter.com/sally_crowe/status/911111111111111111)



A YEAR AGO

**Arturo Durazo**

@adurazo2

Closer examination of how patient/carer decision aids are created needed. Current aids many times misleading. #CUESummit17



A YEAR AGO

**Casey Quinlan**

@MightyCasey

@JeamesSailor @VinayPrasad82 @United4Evidence @SterlingHIT That's the \$3.4 trillion-with-a-T (per year) question, innit? #CueSummit17 #CBPR



A YEAR AGO

**Mikala Edwards**

@MK_PinkGal

@VinayPrasad82 said it best - we need real consumer voices, "overall survival isn't the gold standard." #patient #represent #CUESummit17



A YEAR AGO

**Sanford Jeames; DHA**

@JeamesSailor

@KayDickersin @jhoronjeff Great question about standards. However, labs R not real world settings. Ppl R not rats in lab. #CUESummit17 #CBPR



A YEAR AGO

**CUE**

@United4Evidence

Overall survival isn't necessarily the gold standard in #cancertrials @VinayPrasad82 #CUESummit17 [twitter.com/MK_PinkGal/sta...](https://twitter.com/MK_PinkGal/status/911111111111111111)



A YEAR AGO



Arturo Durazo

@adurazo2

Best gift of today, transform core thoughts from cancer survivor to cancer victor! Thank you,
[@MzDesNY](#) [#CUESummit17](#)



A YEAR AGO



Sanford Jeames; DHA

@JeamesSailor

[@sally_crowe](#) [@jhoronjeff](#) [@United4Evidence](#) The bigger question needs 2 B methods of turnover 4 advocates. Need new voices. [#CUESummit17](#)



A YEAR AGO



Jen Horonjeff

@jhoronjeff

[@JeamesSailor](#) [@KayDickersin](#) Absolutely. Need to find balance between trial evidence, RWE and access! [#cuesummit17](#)



A YEAR AGO



CUE

@United4Evidence

Cancer [#survivor](#) to cancer [#victor](#) [#CUESummit17](#) [twitter.com/adurazo2/statu...](https://twitter.com/adurazo2/status/911111111111111111)



A YEAR AGO



CUE

@United4Evidence

"What you hear at the microphone is very powerful in ways that are not easy to identify."
[@VinayPrasad82](#) [#CUESummit17](#)



A YEAR AGO



Sally Crowe

@sally_crowe

[#CUESummit17](#) interesting distinction about use of words re evidence discussions e.g. 'low quality evidence' do we mean this doesn't work?



A YEAR AGO

**Sanford Jeames; DHA**

@JeamesSailor

@MightyCasey @CureForward @SterlingHIT @VinayPrasad82 Diaries R effective, but who funds this? #CBPR not funded equally. #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

@JeamesSailor @sally_crowe I wouldn't say "turnover" but totally agree we need more voices, more diversity/representativeness #cuesummit17



A YEAR AGO

**Mary Anne Sterling**

@SterlingHIT

Plain language and #health literacy are early winners in discussion w/ @VinayPrasad82 at #CUESummit17 in NYC.



A YEAR AGO

**Sanford Jeames; DHA**

@JeamesSailor

@jhoronjeff @KayDickersin I'm firm believer that evidenced based practice can B achieved w/ further inclusion of lifestyles. #CUESummit17



A YEAR AGO

**Jimmy Le**

@jtoanle

"Getting people's voices to be heard is not easy" @VinayPrasad82 #CUESummit17



A YEAR AGO

**Sally Crowe**

@sally_crowe

#CUESummit17 Plea for more inclusion of voices not usually heard at drug advisory meetings - is it methods, culture or resource issue?



A YEAR AGO

**Casey Quinlan**

@MightyCasey

@JeamesSailor @CureForward @SterlingHIT @VinayPrasad82 EGGZACKLY. Back to "who funds this," often #pharma \$\$ only \$\$ on table. #CUESummit17



A YEAR AGO

**CUE**

@United4Evidence

From the audience: when you have rare disorders, there is less studies, less evidence. How do we collect what pts are saying? #CUESummit17



A YEAR AGO

**Sanford Jeames; DHA**

@JeamesSailor

@jtoanle @VinayPrasad82 @MightyCasey @SterlingHIT Patient voices can B heard by going 2 the people. 2 much fear 2 engage. #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"Need scale of how likely would someone rec a Rx - from I'd give to my kids to I wouldn't give to worst enemy!" Great comment! #cuesummit17



A YEAR AGO



Patients care about clinical outcomes, not surrogate markers. Patients care about surrogates bc MDs told them to [@VinayPrasad82](#) [#CUESummit17](#) [pic.twitter.com/3mO3AcMAyd](#)

BRANDYN LAU [@LAUZEETWEET](#) · A YEAR AGO



Jen Horonjeff
[@jhoronjeff](#)

[@jtoanle](#) [@VinayPrasad82](#) not easy but can't give up innovating new approaches!
[#cuesummit17](#)

A YEAR AGO



Arturo Durazo
[@adurazo2](#)

1st Q&A reminds me of Vioxx fiasco. Have new guidelines been examined? R leading methods to test efficacy used? [#cuesummit17](#) [@VinayPrasad82](#)

A YEAR AGO



John Santa says we need to support consumer orgs that put their foot (feet?) down and say "stop the bad behavior" [#CUESummit17](#) pic.twitter.com/muDGN0wk0t

KAY DICKERSIN @KAYDICKERSIN · A YEAR AGO



Jen Horonjeff
@jhoronjeff

@jtoanle @VinayPrasad82 yes, I think there are interesting [#healthIT](#) startups that are integrating this approach. Exciting! [#cuesummit17](#)

A YEAR AGO



Jimmy Le
@jtoanle

I can't think of a better way to summarize: "patients care about clinical [#outcomes](#), not surrogate markers" @VinayPrasad82 [#CUESummit17](#) twitter.com/LauzeeTweet/st...

A YEAR AGO

PANEL 1: Have we made a difference? Progress in patient/consumer engagement in healthcare decision-making



Next up, a panel on "Clinical practice guidelines: did we make a difference?" [#cpg #CUESummit17](#)
pic.twitter.com/aKi2MzZhLS

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Arturo Durazo
 @adurazo2

Now: Panel on how patient/consumer engagement has made a difference in healthcare decision-making. [#CUESummit17](#)

A YEAR AGO



Arturo Durazo
 @adurazo2

[@SandraZLewis](#) now affirming how patients/consumers meaningfully contribute to healthcare decision-making! [#CUESummit17](#)

A YEAR AGO



Sanford Jeames; DHA
 @JeamesSailor

[@United4Evidence](#) [@KayDickersin](#) Did consumers contribute 2 guidelines 4 decisions. YES! Can we improve more 2 clinical practice [#CUESummit17](#)

A YEAR AGO



Arturo Durazo

@adurazo2

Poorly written recommendations lead to confusion. This buffered by patient/consumer partnership! #CUESummit17 @SandraZLewis

A YEAR AGO

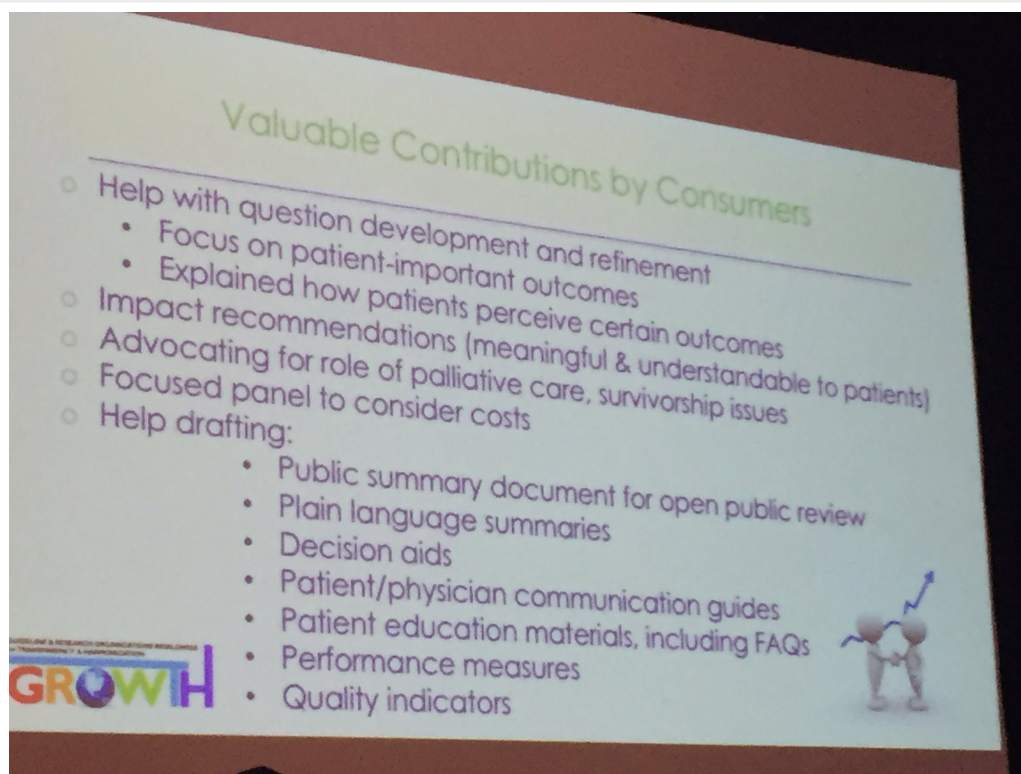


CUE

@United4Evidence

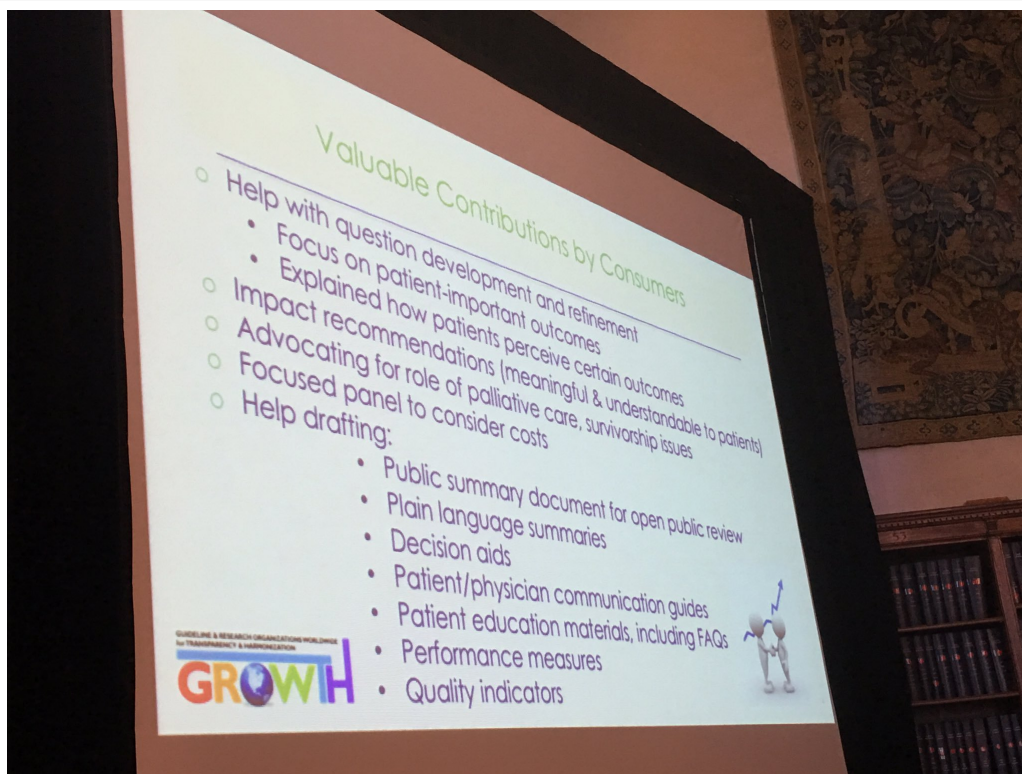
S. Lewis: Do consumer contributions make a positive difference? YES @GrowthEvidence @DoctorEvidence #CUESummit17 @SandraZelmanLew

A YEAR AGO



How valuable are #consumerinsights/#patientpriorities? Super valuable! #CUESummit17
pic.twitter.com/526cgOXz8z

JEN HORONJEFF @JHORONJEFF · A YEAR AGO



The valuable contributions that consumers contribute. A preview of the survey results by [@SandraZelmanLew](#) #CUESummit17 [pic.twitter.com/18UgqHeMky](#)

 CUE @UNITED4EVIDENCE · A YEAR AGO



Sandy Zelman Lewis #cuesummit17 Consumers do make a difference ! pic.twitter.com/5R8qfqp72t

 NUEVA VIDA @NUEVA_VIDA · A YEAR AGO



Casey Quinlan
@MightyCasey

Translation: "OMG, trial subjects are actual human beings? WHO KNEW?" #citizenscience
#cuesummit17

 A YEAR AGO



Arturo Durazo
@adurazo2

Yes, more plain language summaries! Clinical research blinds with dazzling science. Consumers should't need a science degree. #CUESummit17

 A YEAR AGO



Mikala_Edwards
@MK_PinkGal

Consumers need the real facts in plain language. Overall survival is NOT = to QOL
#informedDecisions #patientchoice #CUESummit17 twitter.com/united4evidenc...

 A YEAR AGO

**CUE**

@United4Evidence

Consumers make important impacts on guideline panels: welcoming discussions, better q's & lang, greater awareness @SandraZLewis #CUESummit17



A YEAR AGO

**Annie Appleseed**

@AnnieAppleseed

#CueSummit17 slides from a talk by Sandra Zelman Lewis.



A YEAR AGO

**Arturo Durazo**

@adurazo2

Maryann Napoli, Ctr for Medical Consumers, reflects on her on contributions as a public representative. #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

Thank you @SandraZelmanLew for bringing attention to the value of #PatientExperience! #cuesummit17 twitter.com/jhoronjeff/sta...



A YEAR AGO

**Casey Quinlan**

@MightyCasey

Incidentalomas, anyone? Overscreening leads to overtreatment, but med-industrial complex mints coin off both. #rightcare #s4pm #cuesummit17



A YEAR AGO

**Sanford Jeames; DHA**

@JeamesSailor

@United4Evidence @KayDickersin @MightyCasey @SterlingHIT Great question raised? Will assessment of work reveal results? #CUESummit17 #Self



A YEAR AGO



Sally Crowe
@sally_crowe

#CUESummit17 does patient/consumer engagement make a difference in healthcare decision making? Differing panel views for the ensuing debate

A YEAR AGO



Arturo Durazo
@adurazo2

Bill Vaughan, Ntnl Committee to Preserve Social Security & Medicare, continues to confirm how patients/consumers influence! #CUESummit17

A YEAR AGO



Bill Vaughan says that the way to preserve MEDICARE and social security is to stop doing stupid stuff!! #CUESummit17 pic.twitter.com/PknSSkQqaz

KAY DICKERSIN @KAYDICKERSIN · A YEAR AGO



Mary Anne Sterling
@SterlingHIT

Save #Medicare by "stop doing stupid stuff". Awesome quote from #CUESummit17 panelist Bill Vaughan.

A YEAR AGO



Cherab Lisa Geng

@TheLateTalker

Accepting pts video input Also can use a survey to collect input for those that can't travel due to health, financial reasons [#CUESummit17](#) [twitter.com/United4Evidenc...](#)



A YEAR AGO



Jen Horonjeff

@jhoronjeff

"We can save transferring cost to ppl who are on Medicaid/Medicare if we quit doing stupid stuff!" Bill Vaughan 🙏🙏 [#CUESummit17](#)



A YEAR AGO



CUE

@United4Evidence

Role of [#advocates](#) on [#panels](#) has changed. Now we have a [#voice](#) and can make an [#impact](#). [#CUESummit17](#)



A YEAR AGO



Jen Horonjeff

@jhoronjeff

I think Bill already won the [#CUESummit17](#) with that one! [twitter.com/sterlinghit/st...](#)



A YEAR AGO



Kay Dickersin

@KayDickersin

Bill Vaughn says that patients talking about different stuff from doctors! How do we get doctors to see what is impt to pts? [#CUESummit17](#)



A YEAR AGO



Sanford Jeames; DHA

@JeamesSailor

[@United4Evidence](#) [@KayDickersin](#) [@SterlingHIT](#) Great point raised at [#CUESummit17](#) if enough talk goes into drug cost 4 approval. [#Reality](#) [#cost](#)



A YEAR AGO



Mary Anne Sterling
@SterlingHIT

Psychological issues are "black hole" for most MDs. --Bill Vaughan #CUESummit17

A YEAR AGO



Arturo Durazo
@adurazo2

Doctors knows body, but patients' internal process is absent. More psychosocial lens in patient-doctor mtng. #CUESummit17

A YEAR AGO



Christine □□□
@Christine4Trump

#SundayMorning #UnitedNYCHalf #BasketballIn4Words #4WordGreatIdeas #PoliticsNation #GorkaMustGo #CNNSOTU #CUESummit17 #ThisWeek twitter.com/TEN_GOP/status...

A YEAR AGO



Suzie Siegel
@SuzieSiegel

Many #sarcoma patients get help from drugs used off-label. I got remission from #leiomyosarcoma via Gemzar + Taxotere. #CUESummit17

A YEAR AGO



Suzie Siegel
@SuzieSiegel

In 2003 in TX, I was lucky that Blue Cross covered my off-label chemo. Medicare would not have. There's your savings for you. #CUESummit17

A YEAR AGO



Mikala_Edwards
@MK_PinkGal

Bill Vaughan: When focused on how to shift #Medicare w/o putting cost of people: "stop doing stupid stuff" #CUESummit17 #patientfirst

A YEAR AGO



Casey Quinlan
@MightyCasey

Bill Vaughan @NCPSSM is my brother from another mother based on his willingness to call bulls**t on eminence-based bulls**t #cuesummit17



A YEAR AGO



CUE
@United4Evidence

Bill Vaughn: Human as a group can fight the tsunami of darkness #CUESummit17



A YEAR AGO



Suzie Siegel
@SuzieSiegel

Rare diseases have a harder time getting the same amount of evidence. Which patient voices do we listen to? #CUESummit17



A YEAR AGO



Jen Horonjeff
@jhoronjeff

Bill Vaughan remarks Drs don't always care about lack of evidence, they keep doing it. See @TheAtlantic #cuesummit17 theatlantic.com/health/archive...



A YEAR AGO



CUE
@United4Evidence

"We got to think of science as not what it was, but as what it can be!" @SandraZLewis #CUESummit17



A YEAR AGO



Casey Quinlan
@MightyCasey

+1 RT @SuzieSiegel: Rare diseases have a harder time getting the same amount of evidence. Which patient voices do we listen to? #CUESummit17



A YEAR AGO

**Arturo Durazo**

@adurazo2

@United4Evidence Vaughan's alert a terrific sum! Must be vigilant against anti-intellectualism threatening advancement. #CUESummit17



A YEAR AGO

**CUE**

@United4Evidence

Bringing consumers up to speed w/ guidelines development, a mission for #CUE.
@SandraZLewis #CUESummit17



A YEAR AGO

**CUE**

@United4Evidence

We are moving in the right direction! @SandraZLewis #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"As guideline developers, we need to do a better job telling clinicians that the patient reps are EQUALS in discussion" 🙏🏻 #CUESummit17



A YEAR AGO

**Jimmy Le**

@jtoanle

Patients values and preferences should be represented in guidelines @DoctorEvidence
@SandraZLewis #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"Values and priorities of patients should be considered and written into guidelines"
@SandraZelmanLew #cuesummit17



A YEAR AGO



Casey Quinlan
@MightyCasey

OMFG!! @DrSusanLove IN DA HOUSE! I think I just plotzed. Meeting personal hero IRL = high "total geek-out" potential. #bcsn #cuesummit17



A YEAR AGO



Casey Quinlan
@MightyCasey

@KayDickersin If we could end \$1T/year of waste in med-industrial complex, now THAT would free up some MONEY => #rightcare #cuesummit17



A YEAR AGO



Casey Quinlan
@MightyCasey

@TuftsB @VinayPrasad82 @MLIWI Absolutely. The whole \$3.4 trillion-with-a-T enchilada. #hcpt #rightcare #CUESummit17



A YEAR AGO



Laura Logie, Nueva Vida's Director of Research, at #cuesummit17 pic.twitter.com/VUgwATc0Qb



NUEVA VIDA @NUEVA_VIDA · A YEAR AGO



Suzie Siegel
@SuzieSiegel

@sally_crowe a small amount to print brochures, for ex. He talks about evidence but can't prove his accusations against people. #CUESummit17



A YEAR AGO



Sanford Jeames; DHA

@JeamesSailor

@Deadline2020 @United4Evidence Expanded info about pt advocacy presented by Anne Cohen. #ProjectLead is lead N science tng #CUESummit17

A YEAR AGO



Health Advocate

@healthadvoc_ca

More independence/transparency needed to combat problematic industry sponsored patient advocacy groups: sciencedaily.com/releases/2017/... #CUESummit17

A YEAR AGO



Suzie Siegel

@SuzieSiegel

@jhoronjeff Should drs listen "only" to pts who advocate what dr believes to be best evidence-based med? #CUESummit17

A YEAR AGO

#CUESummit17 END CORP CORRUPTION STOP WASTE FRAUD ABUSE N #HEALTHCARE
#GOVERNMENT HEALTHCARE = HUMAN RIGHT JUSTICE 4 ALL AGES INDICT \$CRIMES
pic.twitter.com/5ghk7ZLgZl

MIRANDA C. BELL @TRUTHSEARCH1957 · A YEAR AGO

**Suzie Siegel**

@SuzieSiegel

@jtoanle No! It makes a difference to me & others whether our cancer is progressing or staying stable. #CUESummit17



A YEAR AGO

**Suzie Siegel**

@SuzieSiegel

@jtoanle Prasad's career is based on his criticism. He isn't desperately searching for ways to heal people. #CUESummit17



A YEAR AGO

**Arturo Durazo**

@adurazo2

Wikipedia is not a reliable source! Double-check source of medical & Tx information.

#CUESummit17



A YEAR AGO

**CUE**

@United4Evidence

We are screening the resources for serving on advisory panel videos at #CUESummit17 consumersunited.org/resources-serv...



A YEAR AGO

**CUE**

@United4Evidence

Don't hesitate to let us know if you have other feedback or suggestions regarding the videos

#CUESummit17



A YEAR AGO

**Sally Crowe**

@sally_crowe

#CUESummit17 discussing & evaluating new @United4Evidence videos 2 assist with interactions on committees - grt feedback from participants



A YEAR AGO



MissionaryBLMM
@MissionaryBLMM

#SundayMorning #SundayBrunch #CUESummit17 #cue17 #cuexpo2017 #UnitedNYCHalf
#AMJoy #COYS #SayItWithStickers #AllLivesMatter #AllSoulsMatter
[twitter.com/MissionaryBLMM...](https://twitter.com/MissionaryBLMM)



A YEAR AGO



Casey Quinlan
@MightyCasey

Too much eminence-based, not EVIDENCE-based, medicine. On a loop. People/patients know more than given credit for. #CUESummit17 #s4pm



A YEAR AGO



Jen Horonjeff
@jhoronjeff

How do we handle that patient advocates often coming from higher education and SES than the communities we "represent"? #CUESummit17



A YEAR AGO



Do we actually solve the problem or do we just say we do it ? Great question posed by S. Jeames at
#CUESummit17 pic.twitter.com/6aizsjDDdh



CUE @UNITED4EVIDENCE · A YEAR AGO



Arturo Durazo

@adurazo2

Bulk of clinical research doesn't address practical questions faced by patients, caregivers & clinicians. ~Prof. @JeamesSailor #CUESummit17



A YEAR AGO

KEYNOTE II: How PCORI "priority populations" are engaging in research implementation *Sanford Jeames, Adjunct Professor at Huston-Tillotson University*



CUE

@United4Evidence

S. Jeames: It's not research if the population you are trying to help are not involved. We need to talk to patients. #pcori #CUESummit17



A YEAR AGO



Jen Horonjeff

@jhoronjeff

"If you're asking a research question and already know the answer, it's not research"

@JeamesSailor #CUESummit17



A YEAR AGO



CUE

@United4Evidence

.@JeamesSailor: Talking about patients is not the same as talking with patients. #CUESummit17



A YEAR AGO



Arturo Durazo

@adurazo2

Talk with patients than talk to! ~Prof. @JeamesSailor #CUESummit17



A YEAR AGO



CUE

@United4Evidence

#research #patientvoice #CUESummit17 @JeamesSailor twitter.com/jhoronjeff/sta...



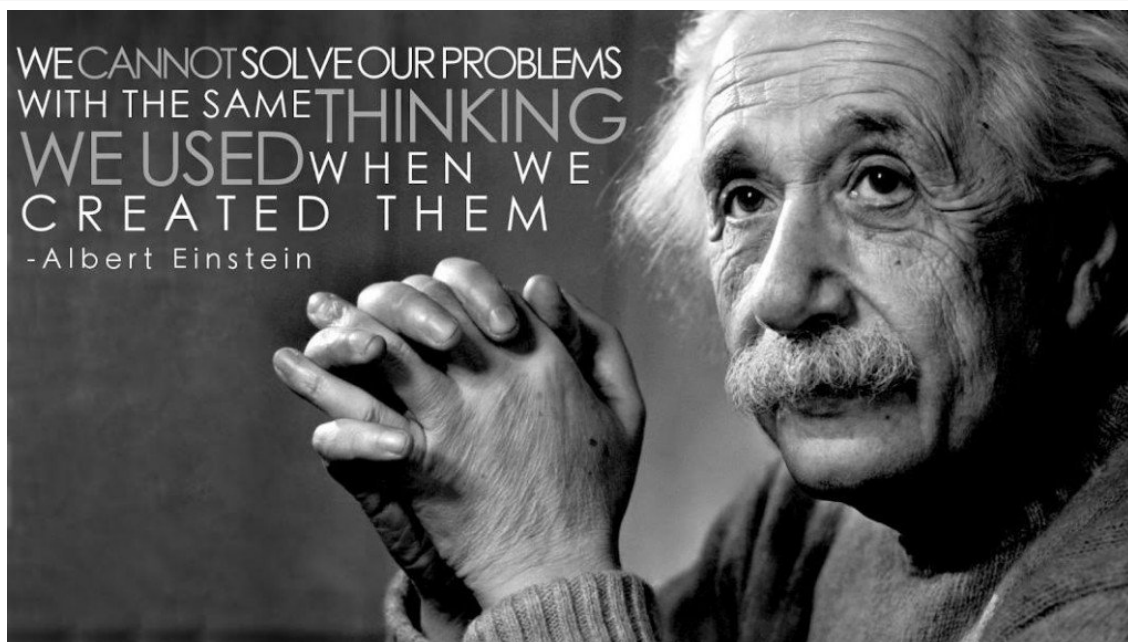
A YEAR AGO



Jen Horonjeff
@jhoronjeff

"If we don't talk to the patients about those questions, it's not research"-@[JeamesSailor](#). I'd say not MEANINGFUL research! #CUESummit17 [twitter.com/jhoronjeff/sta...](https://twitter.com/jhoronjeff/status/944444444444444444)

A YEAR AGO



Favorite quote of vibrant speaker Dr. Sanford E. Jeames #CUESummit17
pic.twitter.com/72OhY1lSkQ

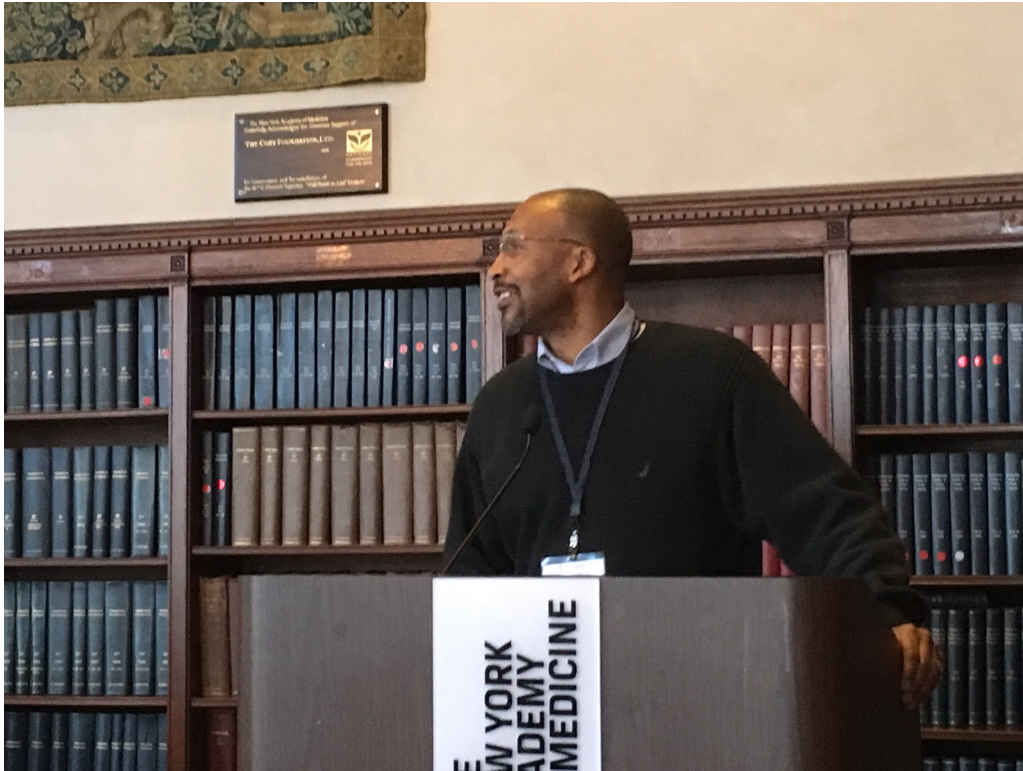
CHERAB LISA GENG @THELATETALKER · A YEAR AGO



Arturo Durazo
@adurazo2

Prof @[JeamesSailor](#) covers PCORI priority pops: LGBTQIA, women, minority, uninsured, underinsured, faith-based, & CBOs #CUESummit17

A YEAR AGO



It is not research if we aren't including priority populations in the conversation (not just talking about them) [@JeamesSailor](#) [#CUESummit17](#) [pic.twitter.com/Y9IFrvBrYt](#)

 KAY DICKERSIN [@KAYDICKERSIN](#) · A YEAR AGO



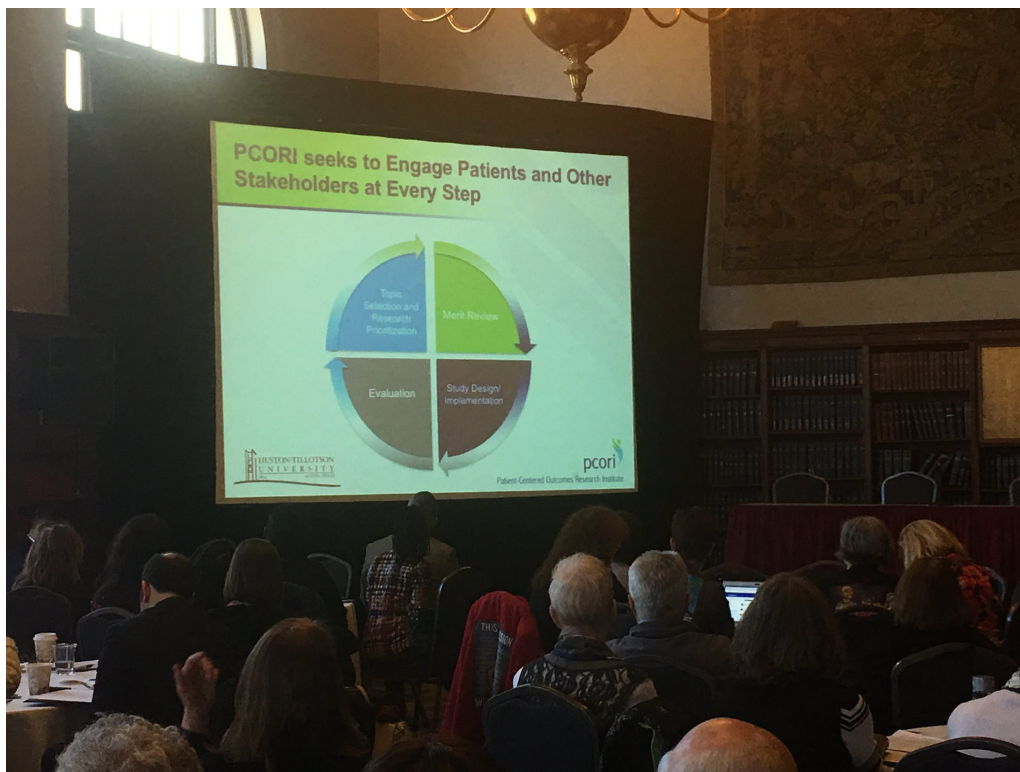
A reminder of [#PCORI](#) priority populations at [#CUESummit17](#) pic.twitter.com/eQM1b4qTdF

 CUE @UNITED4EVIDENCE · A YEAR AGO



If members of the affected population aren't in the conversation, it's NOT research [@JeamesSailor](#)
[#CUESummit17](#) [@elliottthaut](#) [@AdilHaiderMD](#) [pic.twitter.com/RV2mzexY7U](#)

 BRANDYN LAU [@LAUZEETWEET](#) · A YEAR AGO



#PCORI and #engagement at every step #CUESummit17 pic.twitter.com/87CT3fZm7h

JIMMY LE @JTOANLE · A YEAR AGO



Casey Quinlan
@MightyCasey

PPRNs and CDRNs are unsung heroes of patient reported outcomes AND community based clinical research. #CUESummit17 HT @PCORnetwork

A YEAR AGO



Jen Horonjeff
@jhoronjeff

"Let's include more people in research dev & input that HAVE NEVER DONE IT BEFORE!"
@JeamesSailor YES! 🙏🙏🙏 Make more accessible #CUESummit17

A YEAR AGO



CUE
@United4Evidence

Why do we do it? Collaboration and Dissemination. We need to listen and work with other people. @JeamesSailor #CUESummit17

A YEAR AGO



Jimmy Le
@jtoanle

"Research should change clinical practice." [@JeamesSailor](#) [#CUESummit17](#)



A YEAR AGO



Jimmy Le
@jtoanle

What can we do? Learn more, encourage people, and share what we found. [@JeamesSailor](#)
[#CUESummit17](#) [#pcori](#)



A YEAR AGO



Always one of the smartest guys in any room he's in. HT [@JeamesSailor](#) [#CUESummit17](#)
pic.twitter.com/wpZb19QjiY



CASEY QUINLAN [@MIGHTYCASEY](#) · A YEAR AGO

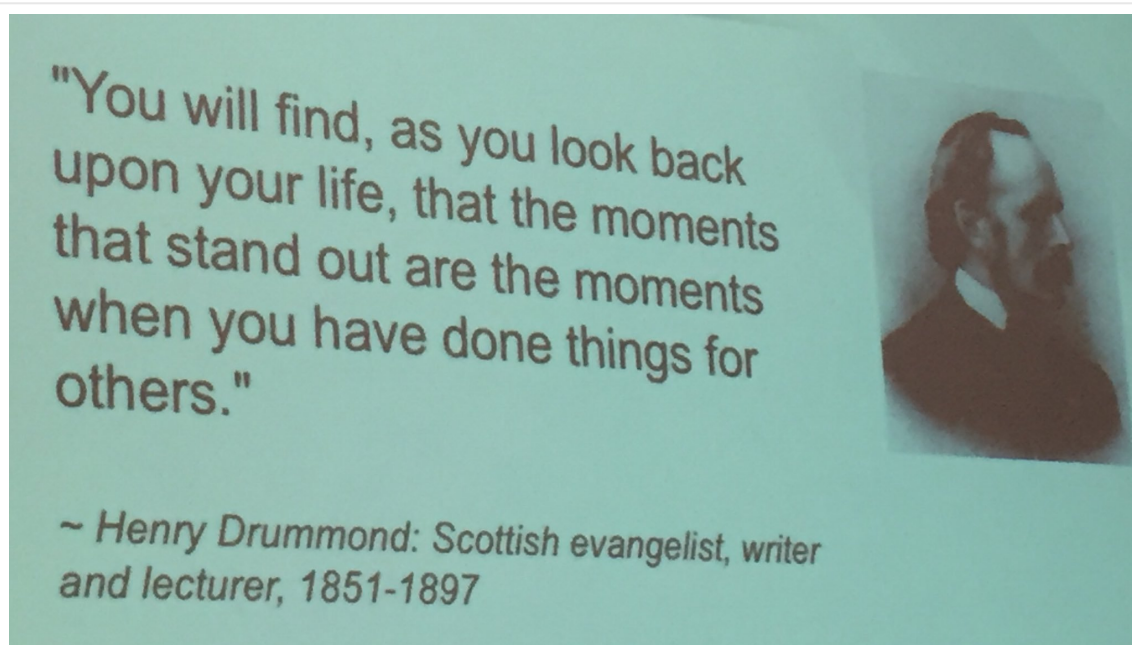


Mikala_Edwards
@MK_PinkGal

[@JeamesSailor](#) "If u r doing research and the group you are focused on is not part of the convo...it's NOT research!" [#CUESummit17](#) [#diversity](#)



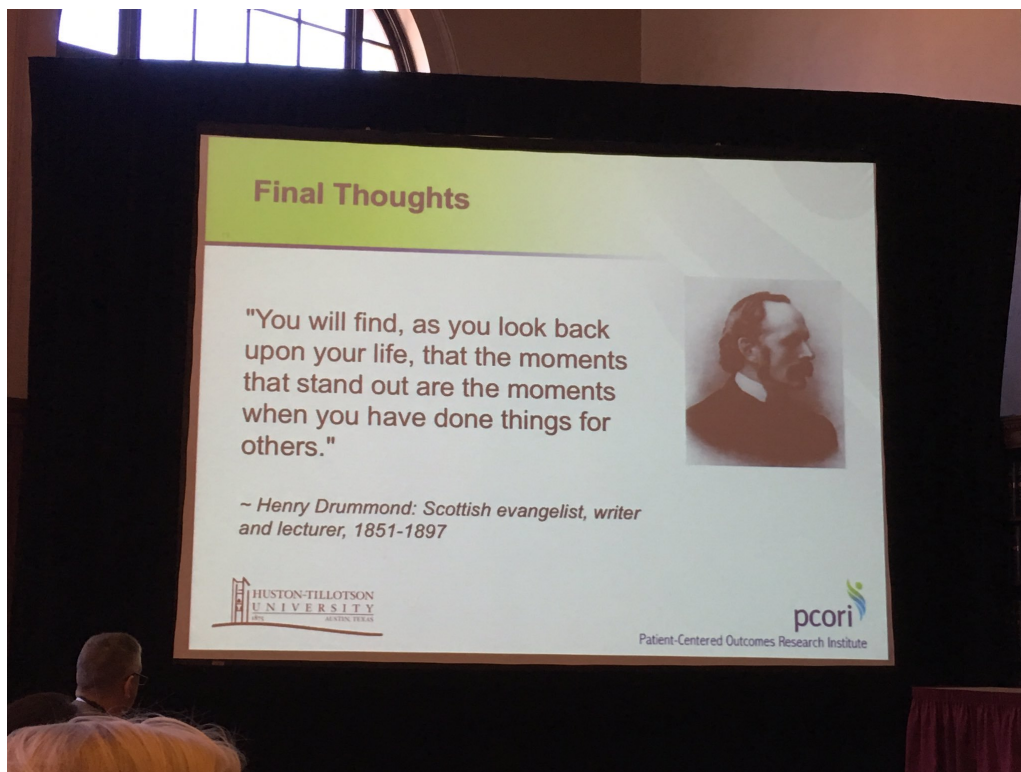
A YEAR AGO



A reminder and challenge to us all - let's all make more moments stand out (aka, help others)!

#CUESummit17 @JeamesSailor pic.twitter.com/xeTbkfc0Ef

JEN HORONJEFF @JHORONJEFF · A YEAR AGO



A good reminder to us all from Sanford Jeames [@JeamesSailor](https://twitter.com/JeamesSailor) #CUESummit17 pic.twitter.com/ncD1M2ccbr

KAY DICKERSIN @KAYDICKERSIN · A YEAR AGO

**CUE**

@United4Evidence

"We are powerful as advocates because we are at the table." [@JeamesSailor](#) [#pcori](#)
[#CUESummit17](#)



A YEAR AGO

**CUE**

@United4Evidence

"If we don't have diverse populations in a trial, it is a failed trial & a waste of time."
[@JeamesSailor](#) [#CUESummit17](#) [#clinicaltrials](#) [#pcori](#)



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

I hear myself say this multiple times a day. [#CUESummit17](#) [twitter.com/united4evidenc...](#)



A YEAR AGO

**CUE**

@United4Evidence

We have to stress to our [#funders](#) that we NEED more [#inclusion](#). We have to expand the conversation. [@JeamesSailor](#) [#CUESummit17](#)



A YEAR AGO

**Christine** □□□

@Christine4Trump

[#SundayMorning](#) [#UnitedNYCHalf](#) [#BasketballIn4Words](#) [#4WordGreatIdeas](#) [#PoliticsNation](#)
[#GorkaMustGo](#) [#CNNSOTU](#) [#CUESummit17](#) [#ThisWeek](#) [twitter.com/Italians4Trump...](#)



A YEAR AGO

**Sally Crowe**

@sally_crowe

[#CUESummit17](#) Do patients and clinicians research priorities really matter? -
[tinyurl.com/m5259qa](#)



A YEAR AGO



Another [#queue](#) for the [#q&a](#) at the [#CUESummit17](#) [@JeamesSailor](#) [pic.twitter.com/JqZaaC9ov0](#)

 CUE [@UNITED4EVIDENCE](#) · A YEAR AGO



Casey Quinlan
[@MightyCasey](#)

“Make America Sick Again!” [@MightyCasey](#) [medium.com/@mightycasey/m...](#) Hey [@VinayPrasad82](#) here's post I mentioned [#CUESummit17](#)

 A YEAR AGO



Casey Quinlan
[@MightyCasey](#)

Hey [@JeamesSailor](#) here's [@CureForward](#) post w/shout out. [cureforward.com/blog/general/c...](#) [#cuesummit17](#)

 A YEAR AGO



Kay Dickersin
[@KayDickersin](#)

Sanford James says patient navigators should be in the community not the hospital [@JeamesSailor](#) [#CUESummit17](#)

 A YEAR AGO



Jimmy Le
@jtoanle

"Talking about patients is NOT the same as talking with patients" @JeamesSailor
[#CUESummit17](#) twitter.com/united4evidenc...



A YEAR AGO



Sally Crowe
@sally_crowe

[#CUESummit17](#) current debate about patient driven research tinyurl.com/m5259qa
[@United4Evidence](#) [@JeamesSailor](#)



A YEAR AGO



Jen Horonjeff
@jhoronjeff

"Why aren't patients being compensated for their involvement?" "Systematic barriers"-
[@JeamesSailor](#) [#CUESummit17](#)



A YEAR AGO



Jen Horonjeff
@jhoronjeff

It's 2017, time to change the system where patients are valued for their expertise!!
[#CUESummit17](#) twitter.com/jhoronjeff/sta...



A YEAR AGO



Sally Crowe
@sally_crowe

[#CUESummit17](#) so an interesting observation about the "supplicatory" nature of the discussion -
more about rights & ed to participate?



A YEAR AGO



Jen Horonjeff
@jhoronjeff

TRUTH! We must get here! "Researchers need to understand their communities better, and use
virtual tools to do so"-[@SterlingHIT](#) [#CUESummit17](#)



A YEAR AGO

**Arturo Durazo**

@adurazo2

@gregggonzales Thank you for joining #CUESummit17 I'm looking forward to your talk, and inspiring words I'm sure!



A YEAR AGO

**Casey Quinlan**

@MightyCasey

Short history of slice of genomic medicine in #cancer, advocacy, cross community collaboration: cureforward.com/blog/precision... #s4pm #cuesummit17



A YEAR AGO

**Mikala_Edwards**

@MK_PinkGal

"As advocates we need to learn not only how to bring conversation skills to the table but CONFRONTATION skills" #CUESummit17 #Beheard



A YEAR AGO

**Rylee Ownbey**

@rownbey

An awesome read on #blendedlearning and the role of #edtech in our classrooms #cue17 #CUESummit17 #aste17 #UCET17 #edtechteam #akedchat twitter.com/rownbey/status...



A YEAR AGO



Laura Logie, Director of Research at Nueva Vida presenting in a few minutes so [#CUESummit17](https://pic.twitter.com/AwCbJvsGgP)

NUEVA VIDA @NUEVA_VIDA · A YEAR AGO



[@United4Evidence](https://twitter.com/United4Evidence) [@KayDickersin](https://twitter.com/KayDickersin) I'm honored to have been part of great summit here in [#NYC](https://twitter.com/nycc). [#CUESummit17](https://pic.twitter.com/mlyOZeQRP2) [#advocacy](https://twitter.com/advocacy)

SANFORD JEAMES; DHA @JEAMESSAILOR · A YEAR AGO

PANEL II: Let's start over: How to achieve patient engagement in research implementation



Gregg Gonsalves of Yale begins the 2nd panel session with a discussion abt what success looks like in research implementation [#CUESummit17 pic.twitter.com/SlegJJDPm5](https://pic.twitter.com/SlegJJDPm5)

CUE @UNITED4EVIDENCE · A YEAR AGO



Arturo Durazo
@adurazo2

[@gregggonsalves](https://twitter.com/gregggonsalves) Reminding us that Tx and delivery reform is not a passive process! Reflections about ACT-UP mass movement. [#CUESummit17](https://twitter.com/CUESummit17)

A YEAR AGO



Casey Quinlan
@MightyCasey

Patient communities - all of HUMANITY - owes [@actuporg](https://twitter.com/actuporg) so much. Silence = death for ALL OF US. [#cuesummit17](https://twitter.com/cuesummit17)

A YEAR AGO



Arturo Durazo
@adurazo2

[@gregggonsalves](https://twitter.com/gregggonsalves) ACT-UP mass movement successfully led way to expanded access of Tx. [#CUESummit17](https://twitter.com/CUESummit17)

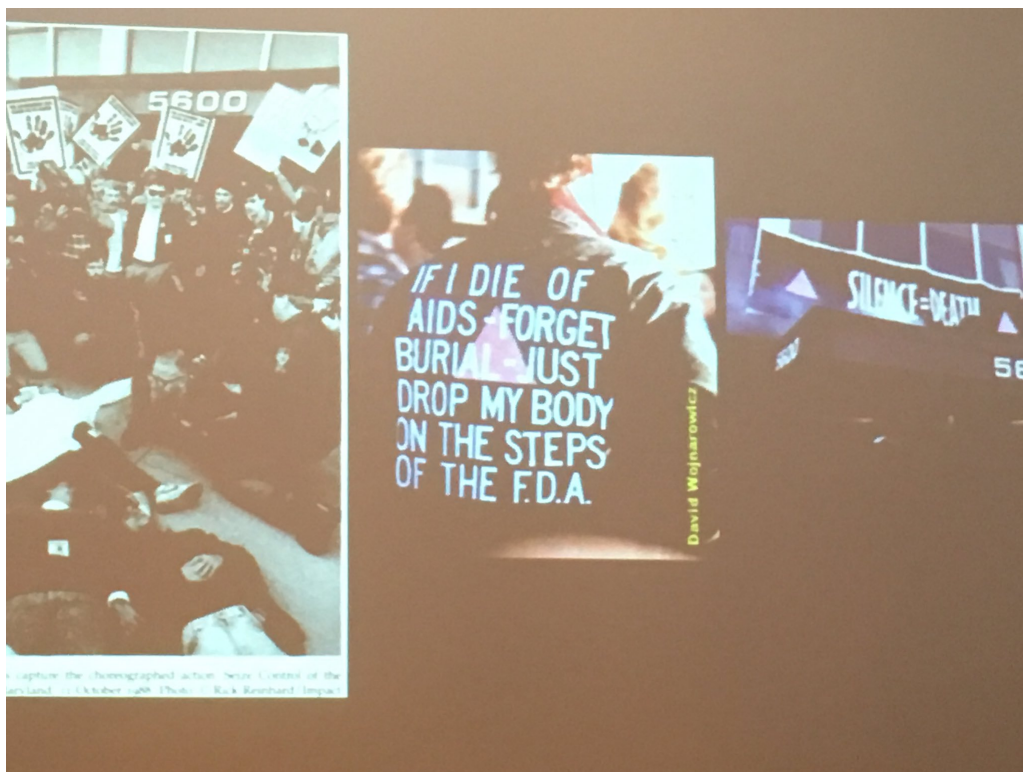
A YEAR AGO



Jen Horonjeff
@jhoronjeff

"We don't need Right to Try laws, we already have them"-@greggongsalves recounts how @actupny & HIV/AIDS advos paved the way #CUESummit17

A YEAR AGO



Remembering the early AIDS movement --decreasing time to approval did not lead to clinical benefits. @greggongsalves #CUESummit17 pic.twitter.com/QxUHXSBXhp

KAY DICKERSIN @KAYDICKERSIN · A YEAR AGO



CUE
@United4Evidence

Mentality such as "any drug is better than no drug" and "new drug is better than old drug" could be detrimental to healthcare #CUESummit17

A YEAR AGO



Arturo Durazo
@adurazo2

@greggongsalves MD & PhD not necessary to promote Tx & care research reform!
#CUESummit17

A YEAR AGO



Casey Quinlan

@MightyCasey

+100000000 >> RT @adurazo2: @greggongsalves MD & PhD not necessary to promote Tx & care research reform! #CUESummit17



A YEAR AGO



Jen Horonjeff

@jhoronjeff

"I'm not a scientist, but I and my friends taught ourselves-because it was life and death"
@greggongsalves #CUESummit17 #ActUp



A YEAR AGO



Arturo Durazo

@adurazo2

@LaLaPhD from @nueva_vida Covers what patient engagement looks like to marginalized communities. #CUESummit17



A YEAR AGO



CUE

@United4Evidence

Experiences from the AIDS epidemic and tuberculosis shows that research could be enhanced through independent funding #CUESummit17



A YEAR AGO



Sanford Jeames; DHA

@JeamesSailor

@adurazo2 @United4Evidence @KayDickersin Thx for YOUR inspiration. We all win together, especially patients! #CUESummit17 #CBPR #advocacy



A YEAR AGO



Jen Horonjeff

@jhoronjeff

"As an acad researcher, I sat in my ivory tower assuming pt groups would excited to participate in my genius research"-@LaLaPhD #CUESummit17



A YEAR AGO

**Mary Anne Sterling**

@SterlingHIT

"Nothing about me without me". Great start to the presentation by Laura Logie of @nueva_vida. #CUESummit17



A YEAR AGO

**Arturo Durazo**

@adurazo2

Inspired by @LaLaPhD Let's rethink term, Hard-To-Reach. Excluded-Partners is a better illustration. Engage w/trust bldg. #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"Researchers should not be asking patients to come sit at their table, they should go to sit at the patients' table" @LaLaPhD #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"Decades of mistrust keeps marginalized communities from participating in research" @LaLaPhD #CUESummit17



A YEAR AGO

**Casey Quinlan**

@MightyCasey

RT @jhoronjeff: "Decades of mistrust keeps marginalized communities from participating in research" @LaLaPhD #CUESummit17



A YEAR AGO

**Mary Anne Sterling**

@SterlingHIT

Vulnerable populations don't like the word "research". And language barriers impede participation in health research. @LaLaPhD #CUESummit17



A YEAR AGO



Casey Quinlan

@MightyCasey

"Researchers should not be asking patients to come sit at their table, they should go to sit at the patients' table" @LaLaPhD #CUESummit17

A YEAR AGO



CUE

@United4Evidence

Barriers and challenges to successful patient engagement (@LaLaPhD): 1) mistrust, 2) language, 3) #socialdeterminants of health #CUESummit17

A YEAR AGO



Mary Anne Sterling

@SterlingHIT

Social determinants of health = low enrollment in research implementation. --@LaLaPhD #CUESummit17

A YEAR AGO



CUE

@United4Evidence

What else is missing? The research gaps, i.e. the who, the how, and the when @LaLaPhD #CUESummit17

A YEAR AGO



Jimmy Le

@jtoanle

.@LaLaPhD: Researchers shouldn't be asking patients to come sit at their table...they should go sit at the patients' table #cuesummit17

A YEAR AGO



Alison Cameron

@allyc375

@adurazo2 @LaLaPhD I collated definitions of "hard to reach". My faves were "service resistant" & "chronically uninformed" 🤖 #CUESummit17

A YEAR AGO



Casey Quinlan
@MightyCasey

Too much research is privilege (academic medicine) inviting privilege (white folks, mostly male) to participate. [#fail](#) [#cuesummit17](#)

A YEAR AGO



Alison Cameron
@allyc375

[@adurazo2](#) [@LaLaPhD](#) TY - that makes me less nervous about my US debut at [@StanfordMedX](#) Ed next month! [#CUESummit17](#)

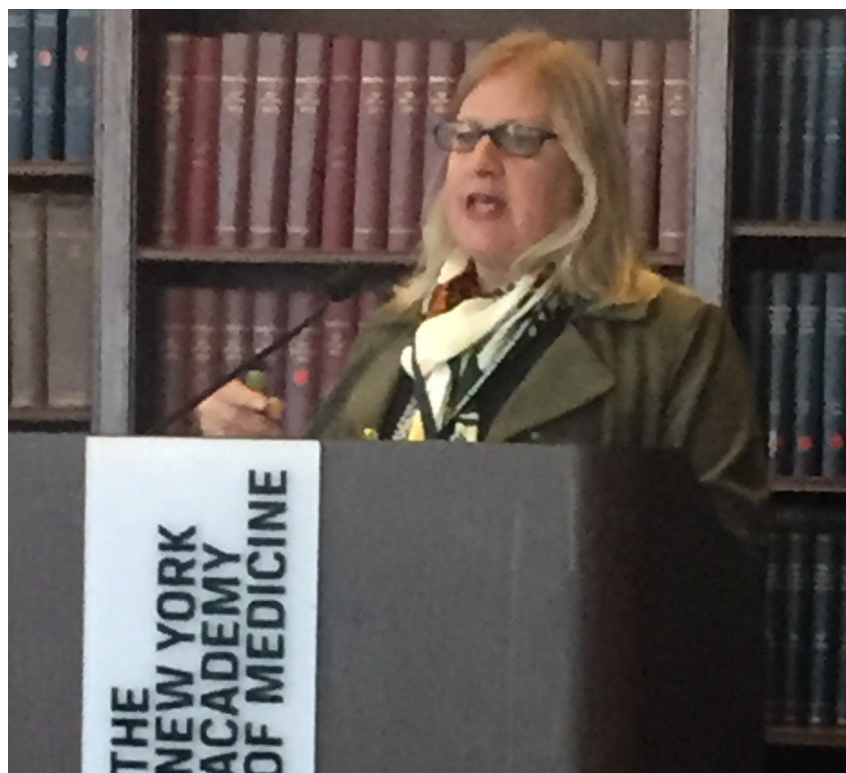
A YEAR AGO



CUE
@United4Evidence

Framework for enhancing clinical practice guidelines through continuous patient engagement onlinelibrary.wiley.com/doi/10.1111/he... [#cuesummit17](#)

A YEAR AGO



Dr. Laura Logie, Nueva Vida's Research Director, presenting at [#CUESummit17](#)
pic.twitter.com/G3hNpLLS74

NUEVA VIDA @NUEVA_VIDA · A YEAR AGO



Mary Anne Sterling
@SterlingHIT

Family members of health research participants should be welcomed at the table. [@LaLaPhD](#)
[#CUESummit17](#)

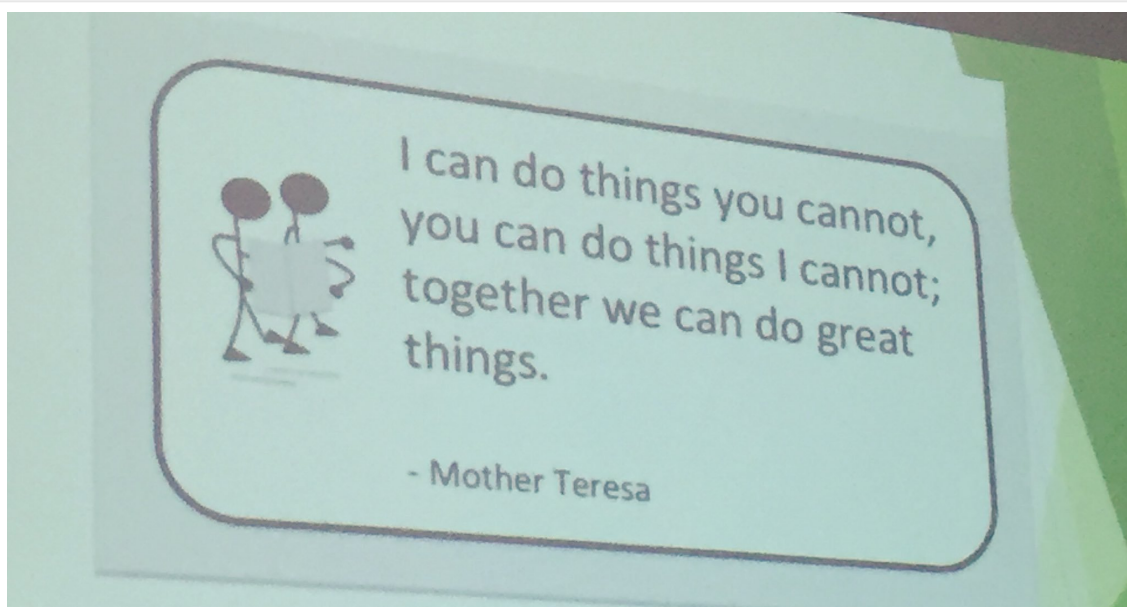
A YEAR AGO



Zahra Hashir
@Zahra0343

Bill Vaughan says that the way to preserve MEDICARE and social security is to stop doing stupid stuff bit.ly/2naQVrn [#CUESummit17](#)

A YEAR AGO



Collaboration! Cooperation! Respecting each others' expertise and value! [#CUESummit17](#)
pic.twitter.com/6NOCQL3WVn

JEN HORONJEFF @JHORONJEFF · A YEAR AGO



Casey Quinlan
@MightyCasey

Proof that Harvard has "bag of dicks" history? Kicked Carl Sagan to the curb for being "populist." [#Science](#) must be ACCESSIBLE. [#cuesummit17](#)

A YEAR AGO

**Arturo Durazo**

@adurazo2

@JSlutskyPCORI Sagan Effect can cost a researcher's position. Quality research should have diverse presentations! #CUESummit17



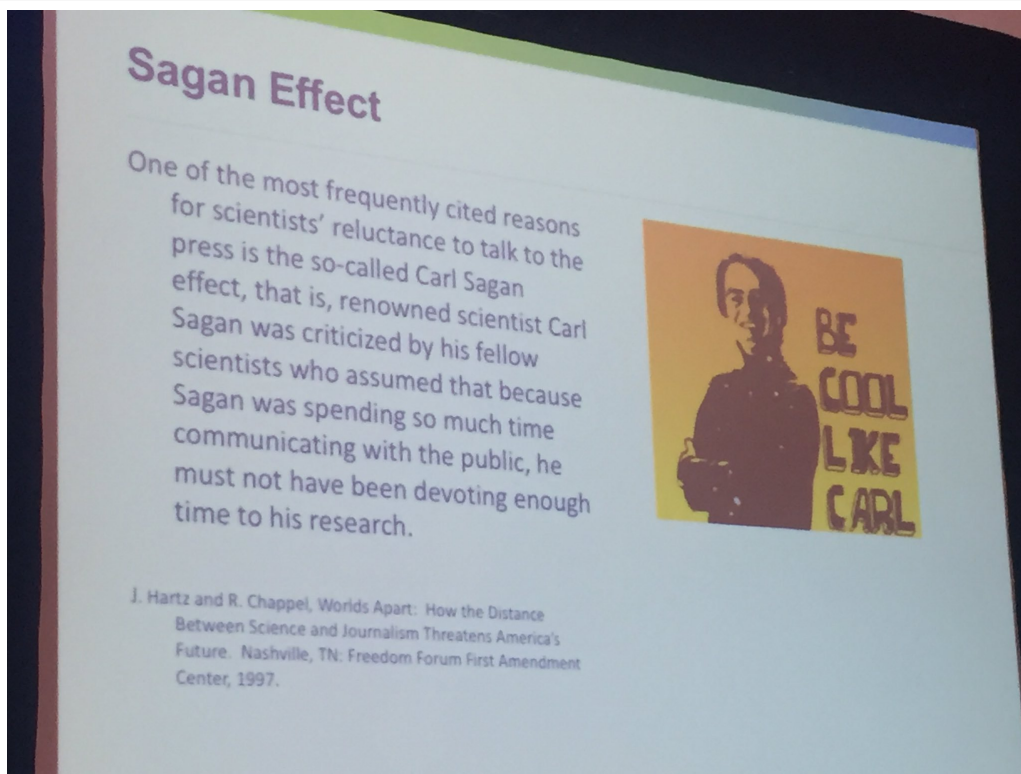
A YEAR AGO



Speed the implementation of patient-centered outcome research. #CUESummit17 @PCORnetwork
pic.twitter.com/mPrfpOaNA8



JANICE TUFTE @HASSANAH2017 · A YEAR AGO



Carl Sagan accused of being a populist because he spent time explaining research in ways public could understand. [pic.twitter.com/D7Nm3r3LiQ](https://twitter.com/D7Nm3r3LiQ)

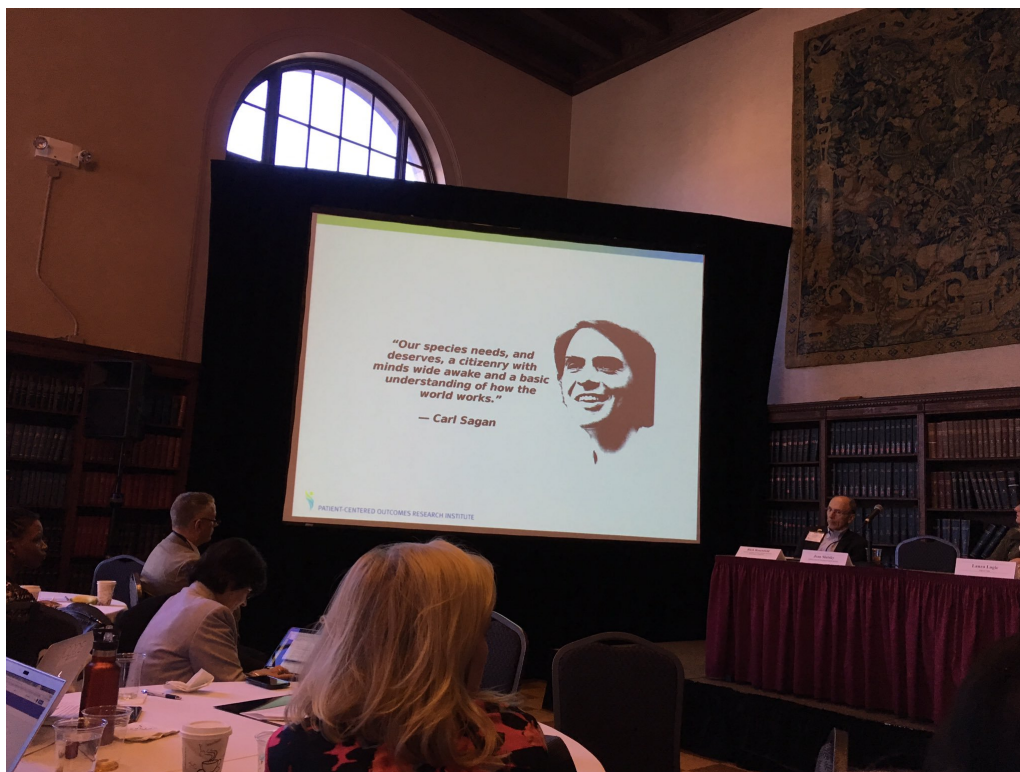
JEN HORONJEFF @JHORONJEFF · A YEAR AGO



Casey Quinlan
@MightyCasey

"Our species needs, and deserves, a citizenry w/minds wide awake + a basic understanding of how the world works." Carl Sagan [#cuesummit17](https://twitter.com/cuesummit17)

A YEAR AGO



Jean Slutsky points out that Carl Sagan was ignored by scientists because he communicated science to the public [#CUESummit17](#) pic.twitter.com/oiwMPLqVa5

 KAY DICKERSIN @KAYDICKERSIN · A YEAR AGO



CUE

@United4Evidence

Reminding the audience about the Sagan effect [@JSlutskyPCORI](#) [#CUESummit17](#)
twitter.com/KayDickersin/s...

 A YEAR AGO



Arturo Durazo

@adurazo2

[@JSlutskyPCORI](#) [#CUESummit17](#)

 A YEAR AGO



CUE

@United4Evidence

[#PCORI](#) negotiates with top tier journals to help promote open and public access to published research [@JSlutskyPCORI](#) [#CUESummit17](#)

 A YEAR AGO



Sally Crowe
@sally_crowe

#CUESummit17 great to hear how @PCORI are developing strategies and partnerships for more patient centred outcome research Jean Slutsky

A YEAR AGO



Mary Anne Sterling
@SterlingHIT

PCORI's @JSlutskyPCORI discussing how increased partnership among stakeholders leads to speedier implementation of PCOR. @PCORI #CUESummit17

A YEAR AGO



vlugzee.com #MCILIV #TOTSOU #teachersmatter #SaudiArabia #SampJuve #UnitedNYCHalf
#SundayMorning #BMGFCB #CUESummit17 #FCBCLive pic.twitter.com/dKjz5LK8a7

VLUGZEE @VLUGZEE · A YEAR AGO



couragesings
@couragesings

Next time, will #cuesummit17 self-accredit as #PatientsIncluded according to the charter?
patientsincluded.org/conferences/

A YEAR AGO

**CUE**

@United4Evidence

Great question: How do we take this righteous indignation that creates advocates & hone it to what we need at the table? [#cuesummit17](#)



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"How do patient advocates maintain righteous indignation while working with people they are politely raging against?" [#CUESummit17](#)



A YEAR AGO

**Sally Crowe**

@sally_crowe

[#CUESummit17](#) We are now considering the concept of 'riotous indignation' and how this can be used and channeled in public involvement



A YEAR AGO

**CUE**

@United4Evidence

"You can have a [#hypothesis](#) but at the end, you need [#evidence](#)." [@gregggonsalves](#)
[#CUESummit17](#)



A YEAR AGO

**Alison Cameron**

@allyc375

[@jhoronjeff](#) I had a lot of support & training to help me channel the anger constructively. Doesn't always work! [#CUESummit17](#)



A YEAR AGO

**CUE**

@United4Evidence

Q&A [@TheLateTalker](#) how do we give voice to the patients with few research on their disease?
[#CUESummit17](#)



A YEAR AGO



Jimmy Le
@jtoanle

#United4Evidence #CUESummit17 [twitter.com/United4Evidenc...](https://twitter.com/United4Evidence)



A YEAR AGO



CUE
@United4Evidence

Some reading on Real-World Evidence — What Is It and What Can It Tell Us? — NEJM
nejm.org/doi/full/10.10... #CUESummit17



A YEAR AGO



@sally_crowe @jhoronjeff Lack of meaningful roles for us can make the anger leak out sideways.
#CUESummit17 pic.twitter.com/2y2BgTDpKw



ALISON CAMERON @ALLYC375 · A YEAR AGO

KEYNOTE III: If it works in the UK will it work in the US? Sally Crowe, Crowe Associates Ltd, Cochrane Consumer Network



Alison Cameron
@allyc375

@sally_crowe I did Community Organising training with London Citizens. Helped me accept even embrace the anger #CUESummit17



A YEAR AGO



Casey Quinlan
@MightyCasey

What @NC4HR dude was talking up (training in DC): usapatientnetwork.org/workshops #cuesummit17



A YEAR AGO



CUE
@United4Evidence

R. Rosenfeld: #Altruism as one of the reasons people get involved in guidelines and advisory panel but not the only reason. #CUESummit17



A YEAR AGO



CUE
@United4Evidence

#PCORI METHODOLOGY 101 Training For Patients and Stakeholders Training Booklet & Resource Guide pcori.org/sites/default/... #CUESummit17



A YEAR AGO



Rasu Shrestha MD MBA
@RasuShrestha

@MK_PinkGal @DrSusanLove Advocacy at it's finest. #bcsn #CUESummit17



A YEAR AGO



Rasu Shrestha MD MBA
@RasuShrestha

@SandraZLewis @United4Evidence @GuidelinesNA True. Many patients are also researchers. Huge trove of knowledge. #CUESummit17



A YEAR AGO

**Rasu Shrestha MD MBA**

@RasuShrestha

@KayDickersin @lyubovlytvyn @JeamesSailor So darn true. Worth remembering.... every single day. #CUEsummit17



A YEAR AGO

**Joan Hanson**

@mrsjoanhanson

#CUESummit17 [twitter.com/vlopezcusd/sta...](https://twitter.com/vlopezcusd/status/871111111111111111)



A YEAR AGO

**Dan Robotham**

@djrobotham

Most people ignore most research because most research ignores most people? #CUESummit17 @LindAlliance #research @NIHRINVOLVE [twitter.com/adurazo2/statu...](https://twitter.com/adurazo2/status/871111111111111111)



A YEAR AGO

**Sally Crowe**

@sally_crowe

#EGAPPS3 #CUESummit17 Terrific summary of outcomes that matter to people on dialysis, health care professionals and where there is consensus [twitter.com/ajkdonline/sta...](https://twitter.com/ajkdonline/status/871111111111111111)



A YEAR AGO

**Touch for Care**

@KlaraVanZuijdam

@SterlingHIT @nickisnpdx @MightyCasey @hhask @yogileana @ReginaHolliday they r awesome 💖😊 #TheWalkingGallery #CUESummit17



A YEAR AGO

**Nick Adkins**

@nickisnpdx

@SterlingHIT @ReginaHolliday @MightyCasey @hhask @yogileana those r awesome! 🍊 #thewalkinggallery #CUESummit17 #GSD



A YEAR AGO

KEYNOTE Consumer engagement: goals for the next decade *Susan Love, Dr. Susan Love Research Foundation*



The legendary @DrSusanLove is here at #CUESummit17 representing #breastcancer #advocacy
pic.twitter.com/OrPtGbiCSK

 MIKALA_EDWARDS @MK_PINKGAL · A YEAR AGO



Elin Silveous
 @ElinSilveous

The public needs access to NNT (Number Needed To Treat) in order to makes
 #InformedDecisions & weigh benefits, risks, costs. #CUESummit17
twitter.com/united4evidenc...

 A YEAR AGO



Sanford Jeames; DHA
 @JeamesSailor

@jhoronjeff @LaLaPhD Great pt 2 change research. Go to communities & listen & learn.
 #CUESummit17 #CBPR #advocacy

 A YEAR AGO



Elin Silveous
 @ElinSilveous

Empowering consumers? Respectfully, how? Thank you. #CUESummit17
twitter.com/jtoanle/status...

 A YEAR AGO



Elin Silveous

@ElinSilveous

Key concept: Public. Reflects healthcare consumers, caregivers, patients, providers, corporations. #CUESummit17 [twitter.com/adurazo2/statu...](https://twitter.com/adurazo2/status/948484848484848484)

A YEAR AGO

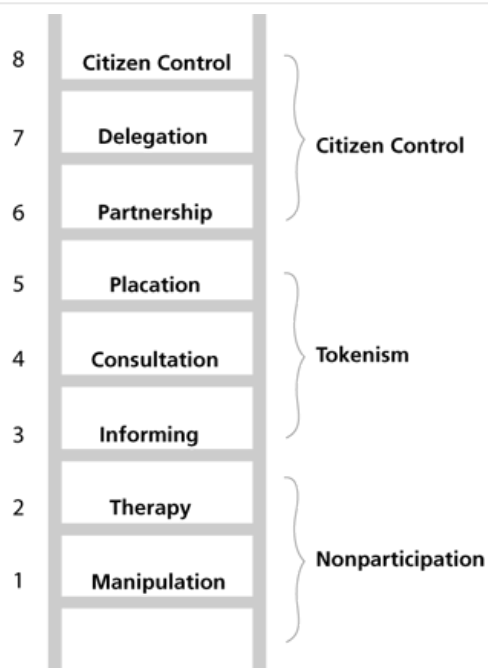


couragesings

@couragesings

Must give plug for #patientsincluded for journals to #cuesummit17. Would be amazing if more journals signed on patientsincluded.org/journals/

A YEAR AGO



Arnstein's Ladder (1969)
Degrees of Citizen Participation

.@ePatientDave @United4Evidence @sally_crowe @SterlingHIT Holds up well after so many years. Some pts don't want to be involved #CUESummit17 pic.twitter.com/f6D7IUOMfy

ANNETTE MCKINNON @ANETTO · A YEAR AGO



Annette McKinnon

@anetto

.@SterlingHIT @DrSusanLove @ArmyofWomen The person who sets the questions controls answers. Don't get answers for Q's not asked #CUESummit17

A YEAR AGO

**Nottingham Eczema**

@eczemasupport

@sally_crowe thanks for all your gr8 tweets from #CUESummit17 Really appreciated



A YEAR AGO

**Kay Dickersin**

@KayDickersin

John Santa suggests more use of "open notes" will help us make progress in understanding what's. Important to patients #CUESummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

"The idea that EMR is a data goldmine is bologna! It's for billing only." @DrSusanLove #CUESummit17



A YEAR AGO

**Kay Dickersin**

@KayDickersin

Free text q's capture more than closed ended q's about "collateral damage" of treatment. New software can analyze. @DrSusanLove #CUESummit17



A YEAR AGO

**Casey Quinlan**

@MightyCasey

Another issue w/research study surveys is WACK prediction of how long it takes a person/patient to fill 'em out! #cuesummit17



A YEAR AGO

**Jen Horonjeff**

@jhoronjeff

Amazing work by @DrSusanLove abt collateral damage in metastatic breast cancer. Thank you for respecting #patientexperience #CUESummit17



A YEAR AGO



Cristy St John
@CristyStJohn

#Medical Surveys may be too outdated- free text alt option2 offer nuance. Quality of #life often equated w/ #Health outcomes #CUESummit17

A YEAR AGO



Casey Quinlan
@MightyCasey

"The difference between a patient and a researcher is a diagnosis" - @DrSusanLove #cancer #cuesummit17

A YEAR AGO



Cristy St John
@CristyStJohn

#research often studies #patients who die & not long-term #survivors & why- historical #data important What is it we don't know? #CUESummit17

A YEAR AGO



Cristy St John
@CristyStJohn

Precision #medicine next step may be figuring out collateral damage/ side-effects of #disease treatment when selecting methods #CUESummit17

A YEAR AGO



Mary Anne Sterling
@SterlingHIT

#PrecisionMedicine may include predicting collateral damage of #breastcancer treatment. @DrSusanLove #CUESummit17 @ArmyofWomen

A YEAR AGO



Arturo Durazo
@adurazo2

@DrSusanLove Defines "collateral damage" as long-term effects of cancer experience than immediate effects of cancer Tx. #CUESummit17

A YEAR AGO



Cristy St John
@CristyStJohn

[#clinical](#) understanding quality of life w/non life-threatening diagnosis can be vastly different to Pt exp&impact daily living [#CUESummit17](#)

A YEAR AGO



Arturo Durazo
@adurazo2

Inspired by [@DrSusanLove](#): Cancer experience more than Dx progress & Tx outcome. Capture how it fully impacts life beyond Dx. [#CUESummit17](#)

A YEAR AGO



Mary Anne Sterling
@SterlingHIT

Metastatic Collateral Damage Project designed to crowd source life impact data from [#patients](#). [@DrSusanLove](#) [#CUESummit17](#) [@ArmyofWomen](#)

A YEAR AGO



Casey Quinlan
@MightyCasey

Financial toxicity goes deeper than just "you don't have enough for extras." Often means "can't pay rent, lose housing." [#cuesummit17](#)

A YEAR AGO



Arturo Durazo
@adurazo2

[@DrSusanLove](#) Tx improvements followed by long-term survivorship means need for closer look at what improves quality of life. [#CUESummit17](#)

A YEAR AGO



The difference between a doctor and a patient is a diagnosis [@DrSusanLove](#) [#CUESummit17](#)
pic.twitter.com/abLqIJhx3F

 BRANDYN LAU [@LAUZEETWEET](#) · A YEAR AGO



Sandra Zelman Lewis
[@SandraZLewis](#)

Dr. Susan Love: The difference between a researcher and a patient is a diagnosis.
[#CUESummit17](#) [@United4Evidence](#) [#EGAPPS3](#) [@GuidelinesNA](#)

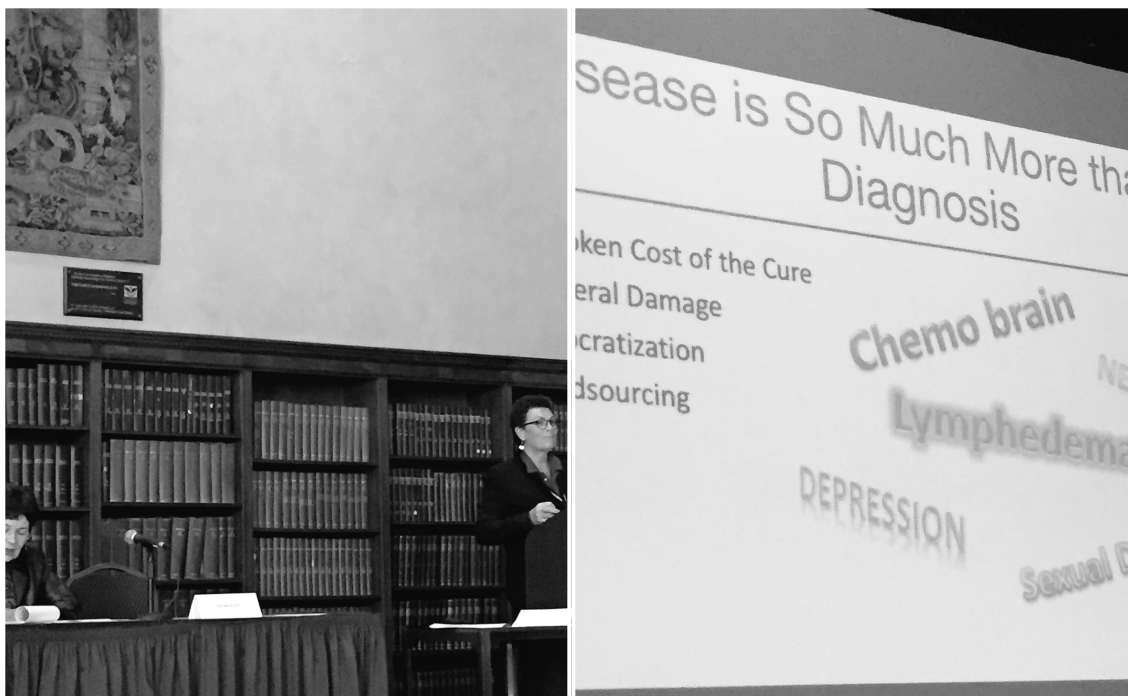
 A YEAR AGO



Mary Anne Sterling
[@SterlingHIT](#)

Keynoter [@DrSusanLove](#) discussing Health of Women (HOW) Study at [#CUESummit17](#) in NYC.
[@ArmyofWomen](#)

 A YEAR AGO



Difference btwn [#patients](#) & [#clinicians](#) is impact of diagnosis- understanding collateral damage of [#disease](#) [#CUESummit17](#) [#qualityoflife](#)
[pic.twitter.com/1MGmFLDhHQ](https://t.co/1MGmFLDhHQ)<https://t.co/1MGmFLDhHQ>[pic.twitter.com/1MGmFLDhHQ](https://t.co/1MGmFLDhHQ)

CRISTY ST JOHN @CRISTYSTJOHN · A YEAR AGO



Jimmy Le
@jtoanle

Side effect vs. collateral dmg. While we're successful at keeping ppl alive, we need to also addr. collateral dmg [@DrSusanLove](#) [#CUESummit17](#)

A YEAR AGO



Jen Horonjeff
@jhoronjeff

"Difference between patient & researcher is a diagnosis-don't know what it's like till live it"
[@DrSusanLove](#) [#patientexperience](#) [#CUESummit17](#)

A YEAR AGO



Arturo Durazo
@adurazo2

[@DrSusanLove](#) Not enough to claim success with primary, clinical outcomes. More to be done to reduce long-term, Tx effects. [#CUESummit17](#)

A YEAR AGO



The 2017 CUE Summit has come to an end. Thank you all for making this a very successful and informative conference [#CUESummit17](https://twitter.com/MaVniO3Ro7) [pic.twitter.com/MaVniO3Ro7](https://twitter.com/MaVniO3Ro7)

 CUE @UNITED4EVIDENCE · A YEAR AGO