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

@adurazo2

Now happening: Summit on leveraging the power of patient and consumer advocacy! #CUESummit17
Surrounded by amazing leaders who harness patient and consumer advocacy into transforming research and clinical care! #CUESummit17 pic.twitter.com/3K06FUaoOm

Getting up early on a Sunday morning is worth it to get to advocate for patients! #CUESummit17 pic.twitter.com/Kv7WQahR2O
Leveraging the Power of Patient and Consumer Advocacy to Transform Healthcare #CUESummit17
pic.twitter.com/7rdEVmrrye

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

Sandra Zelman Lewis
@SandraZLewis

Excited for today’s CUE Summit @United4Evidence #CUEsummit17 #LivingGuidelines

Sally Crowe
@sally_crowe

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

Casey Quinlan
@MightyCasey

@JeamesSailor @SterlingHIT @United4Evidence They hit BOTH my high/hot spots in welcome: black activists *and* LGBTQ activists! #CUESummit17
Nueva Vida participating at #cuesummit17. Impressive presenters. pic.twitter.com/sxs9SMCEeI

CUE @United4Evidence
What is #CUE? We are a national coalition of over 40 #health advocacy organizations promoting #evidence-based health care. #CUESummit17
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

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

MK_PinkGal @MK_PinkGal - A YEAR AGO

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

CUE @United4Evidence - A YEAR AGO

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

sally_crowe @sally_crowe - 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

@JTOANLE · A YEAR AGO

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

@AnnieAppleseed · A YEAR AGO
Surrounded by books and consumer advocates at #cuesummit17 in NYC. @MightyCasey @hhask @yogileana @JamesSailor pic.twitter.com/OgvtTuVKu

MARY ANNE STERLING @STERLINGHIT - 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/gcsFDFYIIIs

@United4Evidence @MightyCasey @SterlingHIT What a great way to begin the #CUESummit17 with opening discussion on consumer advocacy #Changes
Dr. @VinayPrasad82 on opportunity and challenge of consumer advocacy. #CUESummit17
pic.twitter.com/N8VGy2ii1S
Why is patientvoice so important? Because patientpriorities may differ from clinicians/researchers. Patients have perspective that is not held by others. Patients with rheumatoid arthritis reported that the difference they considered really important in their symptoms was three to four times greater than minimal clinically important difference used in trials.

@JHORONJEFF · A YEAR AGO

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

@United4Evidence · 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
"We are extrapolating #clinicaltrials results of younger healthier ppl to older cancer populations." @VinayPrasad82 #cuesummit17

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

+1 RT @sally_crowe: @VinayPrasad82 we need pragmatic trials, with 'real world' populations to assess impact 4 new cancer drugs. #cuesummit17
Cost of one month of cancer treatment over time. Yikes! #CUESummit17 pic.twitter.com/ByoTI67bHa
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

@JHORONJEFF · A YEAR AGO

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

CUE @United4Evidence

A YEAR AGO

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

Casey Quinlan @MightyCasey

A YEAR AGO

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

Casey Quinlan @MightyCasey

A YEAR AGO
Arturo Durazo
@adurazo2

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

Sanford Jeames; DHA
@JeamesSailor

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

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

CUE
@United4Evidence

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

Sally Crowe
@sally_crowe

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

Casey Quinlan
@MightyCasey

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

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

Arturo Durazo
@adurazo2

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

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
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

Mary Anne Sterling
@SterlingHIT

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

Casey Quinlan
@MightyCasey

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

#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 an 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

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
Dr. Vinay Prasad “The politics of consumer advocacy: The promise & pitfalls of disease constituencies” #CUESummit17 pic.twitter.com/oqgdWh1pPN

Sally Crowe
@sally_crowe

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

Casey Quinlan
@MightyCasey

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

CUE
@United4Evidence

Why are trials not representative? Frailer people not interested? Companies not interested? Probably the latter @VinayPrasad82 #CUESummit17
CUE @United4Evidence

Thanks for sharing @sally_crowe! #CUESummit17 twitter.com/sally_crowe/stra...

Arturo Durazo @adurazo2

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

Casey Quinlan @MightyCasey

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

Mikala_Edwards @MK_PinkGal

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

Sanford Jeames; DHA @JeamesSailor

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

CUE @United4Evidence

Overall survival isn't necessarily the gold standard in cancertials @VinayPrasad82 #CUESummit17 twitter.com/MK_PinkGal/sta...
Arturo Durazo
@adurazo2

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

Sanford Jeames; DHA
@JeamesSailor

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

Jen Horonjeff
@jhoronjeff

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

CUE
@United4Evidence

Cancer #survivor to cancer #victor #CUESummit17 twitter.com/adurazo2/statu...

CUE
@United4Evidence

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

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?
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
@MightyCasey

A YEAR AGO

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

@United4Evidence

A YEAR AGO

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

@JeamesSailor

A YEAR AGO

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

@jhoronjeff

A YEAR AGO

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

@LAUZETWEET · A YEAR AGO

@jhoronjeff

@jtoanle @VinayPrasad82 not easy but can’t give up innovating new approaches! #cuesummit17

@jhoronjeff · 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

@adurazo2 · 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/muDgnowk0t

Jen Horonjeff
@jhoronjeff
@jtoanle @VinayPrasad82 yes, I think there are interesting #healthIT startups that are integrating this approach. Exciting! #cuesummit17

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...

 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

Arturo Durazo
@adurazo2

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

Arturo Durazo
@adurazo2

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

Sanford Jeames; DHA
@JeamesSailor

@United4Evidence @KayDickersin Did consumers contribute 2 guidelines 4 decisions. YES! Can we improve more 2 clinical practice #CUESummit17
Arturo Durazo
@adurazo2

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

CUE
@United4Evidence

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

JEN HORONJEFF @JHORONJEFF

How valuable are #consumerinsights/#patientpriorities? Super valuable! #CUESummit17 pic.twitter.com/526cgOXz8z
The valuable contributions that consumers contribute. A preview of the survey results by @SandraZelmanLew #CUESummit17 pic.twitter.com/18UgqHeMky
Sandy Zelman Lewis #cuesummit17 Consumers do make a difference! pic.twitter.com/5R8qfgp72t

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

Arturo Durazo @adurazo2
Yes, more plain language summaries! Clinical research blinds with dazzling science. Consumers shouldn't need a science degree. #CUESummit17

Mikala_Edwards @MK_PinkGal
Consumers need the real facts in plain language. Overall survival is NOT = to QOL #informedDecisions #patientchoice #CUESummit17 twitter.com/united4evidenc...
Consumers make important impacts on guideline panels: welcoming discussions, better q’s & lang, greater awareness @SandraZLewis #CUESummit17

#CueSummit17 slides from a talk by Sandra Zelman Lewis.

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

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

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

@United4Evidence @KayDickersin @MightyCasey @SterlingHIT Great question raised? Will assessment of work reveal results? #CUESummit17 #Self
#CUESummit17 does patient/consumer engagement make a difference in healthcare decision making? Differing panel views for the ensuing debate

Arturo Durazo
@adurazo2

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

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

Mary Anne Sterling
@SterlingHIT

Save #Medicare by "stop doing stupid stuff". Awesome quote from #CUESummit17 panelist Bill Vaughan.
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/United4Evidence...

Jen Horonjeff
@jhoronjeff

"We can save transferring cost to ppl who are on Medicaid/Medicare if we quit doing stupid stuff!" Bill Vaughan 🗣️⋯ #CUESummit17

CUE
@United4Evidence

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

Jen Horonjeff
@jhoronjeff

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

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

Sanford Jeames; DHA
@JeamesSailor

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

CUE @United4Evidence

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

CUE @United4Evidence

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

Jen Horonjeff @jhoronjeff

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

Jimmy Le @jtoanle

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

Jen Horonjeff @jhoronjeff

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

OMFG!! @DrSusanLove IN DA HOUSE! I think I just plotzed. Meeting personal hero IRL = high "total geek-out" potential. #bsm #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 to assist with interactions on committees - great feedback from participants

A YEAR AGO
MissionaryBLMM
@MissionaryBLMM

#SundayMorning #SundayBrunch #CUESummit17 #cue17 #cuexpo2017 #UnitedNYCHalf
#AMJoy #COYS #SayItWithStickers #AllLivesMatter #AllSoulsMatter
twitter.com/MissionaryBLMM...

Casey Quinlan
@MightyCasey

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

Jen Horonjeff
@jhoronjeff

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

CUE
@UNITED4EVIDENCE

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

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
"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...

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

Prof @JeamesSailor covers PCORI priority pops: LGBTQIA, women, minority, uninsured, underinsured, faith-based, & CBOs #CUESummit17
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
A reminder of #PCORI priority populations at #CUESummit17 pic.twitter.com/eQM1b4qTdF
If members of the affected population aren't in the conversation, it's NOT research @JeamesSailor #CUESummit17 @elliotthaut @AdilHaiderMD pic.twitter.com/RV2mzexY7U
#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 @PCORNnetwork

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

CASEY QUINLAN @MIGHTYCASEY

Always one if the smartest guys in any room he's in. HT @JeamesSailor #CUESummit17 pic.twitter.com/wpZb19QjiY

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
"You will find, as you look back upon your life, that the moments that stand out are the moments when you have done things for others."

~ Henry Drummond: Scottish evangelist, writer and lecturer, 1851-1897

A reminder and challenge to us all - let's all make more moments stand out (aka, help others)!
#CUESummit17 @JeamesSailor pic.twitter.com/xeTbkfc0Ef

A good reminder to us all from Sanford Jeames @JeamesSailor #CUESummit17 pic.twitter.com/ncD1M2ccbr
"We are powerful as advocates because we are at the table." @JeamesSailor #pcori #CUESummit17

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

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

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

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

#CUESummit17 Do patients and clinicians research priorities really matter? - tinyurl.com/m5259qa
Another #queue for the #q&a at the #CUESummit17 @JeamesSailor pic.twitter.com/JqZaaC9ov0

Casey Quinlan
@MightyCasey

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

Casey Quinlan
@MightyCasey

Hey @JeamesSailor here’s @CureForward post w/shout out. cureforward.com/blog/general/c... #cuesummit17

Kay Dickersin
@KayDickersin

Sanford James says patient navigators should be in the community not the hospital @JeamesSailor #CUESummit17
Jimmy Le
@jtoanle

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

Sally Crowe
@sally_crowe

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

Jen Horonjeff
@jhoronjeff

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

Jen Horonjeff
@jhoronjeff

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

Sally Crowe
@sally_crowe

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

Jen Horonjeff
@jhoronjeff

TRUTH! We must get here! "Researchers need to understand their communities better, and use virtual tools to do so"-@SterlingHIT #CUESummit17
Arturo Durazo
@adurazo2
@greggconsalves 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...
Laura Logie, Director of Research at Nueva Vida presenting in a few minutes so #CUESummit17 pic.twitter.com/AwCbJvsGgP

@United4Evidence @KayDickersin I'm honored to have been part of great summit here in #NYC. #CUESummit17 #advocacy pic.twitter.com/mlyOZeQRP2

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 about what success looks like in research implementation #CUESummit17 pic.twitter.com/SlegJJDPM5

Arturo Durazo
@adurazo2
@gregggonsalves Reminding us that Tx and delivery reform is not a passive process! Reflections about ACT-UP mass movement. #CUESummit17

Casey Quinlan
@MightyCasey
Patient communities - all of HUMANITY - owes @actuporg so much. Silence = death for ALL OF US. #cuesummit17

Arturo Durazo
@adurazo2
@gregggonsalves ACT-UP mass movement successfully led way to expanded access of Tx. #CUESummit17
"We don’t need Right to Try laws, we already have them" - @gregggonsalves recounts how @actupny & HIV/AIDS advos paved the way #CUESummit17

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

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

@gregggonsalves MD & PhD not necessary to promote Tx & care research reform! #CUESummit17
Casey Quinlan
@MightyCasey

+100000000 >> RT @adurazo2: @gregggonsalves 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" @gregggonsalves #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

Arturo Durazo  
@adurazo2

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

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

Jen Horonjeff  
@jhoronjeff

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

Casey Quinlan  
@MightyCasey

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

Mary Anne Sterling  
@SterlingHIT

Vulnerable populations don't like the word "research". And language barriers impede participation in health research. @LaLaPhD #CUESummit17
"Researchers should not be asking patients to come sit at their table, they should go to sit at the patients' table" @LaLaPhD #CUESummit17

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

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

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

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

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

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

Alison Cameron
@allyc375

@aduraz02 @LaLaPhD TY - that makes me less nervous about my US debut at @StanfordMedX Ed next month! #CUESummit17

CUE
@United4Evidence

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

Dr. Laura Logie, Nueva Vida’s Research Director, presenting at #CUESummit17 pic.twitter.com/G3hNplLS74

NUEVA VIDA @NUEVA_VIDA - A YEAR AGO
Family members of health research participants should be welcomed at the table. @LaLaPhD #CUESummit17

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

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

Proof that Harvard has "bag of dicks" history? Kicked Carl Sagan to the curb for being "populist." #Science must be ACCESSIBLE. #cuesummit17
Arturo Durazo
@adurazo2

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

A YEAR AGO

JANICE TUFTE
@HASSANAH2017

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

A YEAR AGO
Carl Sagan accused of being a populist because he spent time explaining research in ways public could understand. □ #CUESummit17 pic.twitter.com/D7Nmxr3LiQ

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

CUE @United4Evidence
Reminding the audience about the Sagan effect @JSlutskyPCORI #CUESummit17 twitter.com/KayDickersin/s...

Arturo Durazo @adurazo2
@JSlutskyPCORI #CUESummit17

CUE @United4Evidence
#PCORI negotiates with top tier journals to help promote open and public access to published research @JSlutskyPCORI #CUESummit17
Sally Crowe
@sally_crowe

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

Mary Anne Sterling
@SterlingHIT

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

couragesings
@couragesings

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

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

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

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

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

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

@jhoronjeff I had a lot of support & training to help me channel the anger constructively. Doesn’t always work! #CUEsummit17

Q&A @TheLateTalker how do we give voice to the patients with few research on their disease? #CUESummit17
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. #bcsm #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

Joan Hanson
@mrsjoanhanson

#CUESummit17 twitter.com/vlopezusd/stat...

Dan Robotham
@djrobotham

Most people ignore most research because most research ignores most people? #CUESummit17 @LindAlliance #research @NIHRINVOLVE twitter.com/adurazo2/statu...

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/statu...

Touch for Care
@KlaraVanZuijdam

@SterlingHIT @nickisnpdx @MightyCasey @hhask @yogileana @ReginaHolliday they r awsome 😍😊#TheWalkingGallery #CUESummit17

Nick Adkins
@nickisnpdx

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

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

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...

Sanford Jeames; DHA
@JeamesSailor

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

Elin Silveous
@ElinSilveous

Empowering consumers? Respectfully, how? Thank you. #CUESummit17
twitter.com/jtoanle/status...
Key concept: Public. Reflects healthcare consumers, caregivers, patients, providers, corporations. #CUESummit17 twitter.com/adurazo2/statu...

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

@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

@SterlingHIT @DrSusanLove @ArmyofWomen The person who sets the questions controls answers. Don’t get answers for Q’s not asked #CUESummit17
Nottingham Eczema @eczemasupport
@sally_crowe thanks for all your gr8 tweets from #CUESummit17 Really appreciated

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

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

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

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

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

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

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

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

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

Precision Medicine may include predicting collateral damage of breastcancer treatment. @DrSusanLove CUESummit17 ArmyofWomen

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

Arturo Durazo  
@adurazo2

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

Mary Anne Sterling  
@SterlingHIT

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

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

Arturo Durazo  
@adurazo2

@DrSusanLove Tx improvements followed by long-term survivorship means need for closer look at what improves quality of life. #CUESummit17
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 between patients & clinicians is impact of diagnosis - understanding collateral damage of disease #CUESummit17 #qualityoflife
pic.twitter.com/1MGmFLDhHQ
https://t.co/1MGmFLDhHQ

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

Jen Horonjeff
@jhoronjeff

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

Arturo Durazo
@adurazo2

@DrSusanLove Not enough to claim success with primary, clinical outcomes. More to be done to reduce long-term, Tx effects. #CUESummit17
The 2017 CUE Summit has come to an end. Thank you all for making this a very successful and informative conference #CUESummit17 pic.twitter.com/MaVniO3Ro7