

by CUE Cochrane USA a few seconds ago

Who is making recommendations for my healthcare?



Barbara Warren
@bwarrenpsyd

talking to Reva about Twitter chatting on Thursday about LGBT consumer engagement
[@United4Evidence](#)

2 YEARS AGO

Who is making recommendations for my healthcare?
Thursday, March 17, 2016 12:00PM-1:00PM EST

Featuring Dr. Barbara Warren
LGBT Healthcare Advocate

[@United4Evidence](#)
[#AskCUE](#)

We welcome you to our [#AskCUE](#) Twitter Chat on consumer involvement in guidelines this THURSDAY, 3/17/16 @ 12PM EST pic.twitter.com/RmkOaM6J6A

CUE @UNITED4EVIDENCE @SysRevMeta · · 2 YEARS AGO



Barbara Warren
@bwarrenpsyd

hoping for a good conversation [@United4Evidence](#)

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

Tweeting about LGBT inclusion in guideline development

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

[@United4Evidence](#) The national association of LGBT Community Centers, Center
Link#AskCUE

2 YEARS AGO



Intro to SRMA 2016

@SysRevMeta

The Intro to [#SysRevMeta](#) team will be participating in the [#AskCUE](#) TwitterChat hosted by [@United4Evidence](#) tmrw. Who's making healthcare rec?

2 YEARS AGO

LUNCHBREAK! Join us at noon EST with Dr. Barbara Warren and [@United4Evidence](#) and [#AskCuefb.me/7Nllz4zqU](#)

CENTERLINK LGBT @CENTERLINK · 2 YEARS AGO



LGBT HealthLink

@LGBTHealthLink

Happening RIGHT NOW! [#AskCue](#) [#LGBTWellness](#) [twitter.com/United4Evidenc...](https://twitter.com/United4Evidence)

2 YEARS AGO



LGBT HealthLink

@LGBTHealthLink

[@United4Evidence](#) [@LGBTHealthLink](#) would like to thank Dr. Warren for her long standing support our our communities! [#AskCue](#) [#LGBTWellness](#)

2 YEARS AGO



Barbara Warren

@bwarrenpsyd

[@United4Evidence](#) [@nlythcott](#) [@CenterLink](#) Guidelines 4 healthcare providers to update evidence based clinical intereventions [#AskCue](#)

2 YEARS AGO

**CUE**

@United4Evidence

We are discussing what different stakeholders can do to involve [@PCORI](#) [#PriorityPopulations](#) (bit.ly/1pqc52b) in health recs [#AskCUE](#)



2 YEARS AGO

**CUE**

@United4Evidence

We are discussing what different stakeholders can do to involve [@PCORI](#) [#PriorityPopulations](#) (bit.ly/1pqc52b) in health recs [#AskCUE](#)



2 YEARS AGO

**CUE**

@United4Evidence

To start things off, we ask [@bwarrenpsyd](#) : Are [#LGBT](#) grps well represented in current healthcare guidelines? [#AskCUE](#) [@CenterLink](#)



2 YEARS AGO

**Barbara Warren**

@bwarrenpsyd

[@United4Evidence](#) [@CenterLink](#) No they are not except HIV related [#AskCue](#) [@CenterLink](#)



2 YEARS AGO

**CUE**

@United4Evidence

Q2. Is there a way that I can participate in the making of medical guidelines? [#askcue](#) [@bwarrenpsyd](#) twitter.com/nlythcott/stat...



2 YEARS AGO

**Barbara Warren**

@bwarrenpsyd

[@United4Evidence](#) Yes contact CUE to find out how [#AskCue](#) [@CenterLink](#)



2 YEARS AGO



Bill Vaughan
@Bill6440

@United4Evidence @bwarrenpsyd Is it true that seniors are badly under-represented in clinical trials? #AskCUE

2 YEARS AGO



Jimmy Le
@jtoanle

Excited to be participating in another #AskCUE Twitter chat with @United4Evidence and @bwarrenpsyd

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

@Bill6440 @United4Evidence seniors, POC, LGBT etc.#AskCue @CenterLink

2 YEARS AGO



Marguerite Koster
@MargueriteK_LA

IOM-Clinical recommendations based on a systematic evidence review and assessment of benefits & harms of alternative care options #askCUE

2 YEARS AGO



Ngina
@nlythcott

@United4Evidence @PCORI So medical guidelines are important. Are you saying patients can participate in setting them? #askcue

2 YEARS AGO



Bill Vaughan
@Bill6440

@United4Evidence What can be done to stop the gross under-representation of seniors in trials? #AskCUE

2 YEARS AGO

**Elvira Mitraka**

@lv_ra

With the recent push for [#OpenAccess](#) to biomedical data, shouldn't pts have [#OpenAccess](#) to guideline dev reports? [#AskCUE](#) [@GuidelinesNA](#)



2 YEARS AGO

**CUE**

@United4Evidence

A.2 [@nlythcott](#) [@CenterLink](#) Check out our Clearinghouse! bit.ly/1Vgonnr [#AskCUE](#)



2 YEARS AGO

**Bill Vaughan**

@Bill6440

[@United4Evidence](#) If we don't test new drugs well on seniors, can the dosages Drs prescribe them be wrong or harmful? [#AskCUE](#)



2 YEARS AGO

**Jimmy Le**

@jtoanle

What can guideline groups do more to reach out to consumer groups like LGBT populations ? [#AskCue](#) [@bwarrenpsyd](#) [@United4Evidence](#)



2 YEARS AGO

**Barbara Warren**

@bwarrenpsyd

[@SysRevMeta](#) [@CenterLink](#) [@hivguidelines](#) CenterLink and CUE project to engage and train LGBTs to join guideline panels [#AskCue](#) [@CenterLink](#)



2 YEARS AGO

**Marguerite Koster**

@MargueriteK_LA

[@United4Evidence](#) Guidelines-recommendations based on systematic evidence review & benefits/harms of alternative care options. [#askCUE](#)



2 YEARS AGO



Cochrane US
@UScochrane

[@jtoanle](#) [@bwarrenpsyd](#) [@United4Evidence](#) [#AskCUE](#) Medics say consumers need more education to serve on guidelines panels. What does this mean?



@SysRevMeta · 2 YEARS AGO



emclears
@emclears

[@United4Evidence](#) How many consumers usually contribute to a given guideline? [#AskCUE](#)



2 YEARS AGO



Barbara Warren
@bwarrenpsyd

[@UScochrane](#) [@jtoanle](#) [@United4Evidence](#) CUE helps Guideline panels 2 learn how to effectively engage educated consumers [#AskCue](#) [@CenterLink](#)



2 YEARS AGO



Ngina
@nlythcott

[@Bill6440](#) [@United4Evidence](#) This is so important. Those of us over 55 are often told we're not eligible for trials. [#askcue](#)



2 YEARS AGO



CUE
@United4Evidence

[@AnnieAppleseed](#) [@CenterLink](#) On Twitter.. Just use the [#AskCUE](#) to ask your questions or give responses!



2 YEARS AGO



Cochrane US
@UScochrane

[@lv_ra](#) [@GuidelinesNA](#) [#AskCUE](#) Great point! Many guidelines are open only to members. And of course who is on the panel?



2 YEARS AGO



Cochrane US
@UScochrane

@LGBTHealthLink @United4Evidence #AskCUE who decides when a change is needed?

2 YEARS AGO



Bill Vaughan
@Bill6440

@United4Evidence Is there info on how to get the doctors on these panels to listen to me, an ordinary, no-fancy-degrees patients? #AskCUE

2 YEARS AGO



Ngina
@nlythcott

Too often people of color are under represented in clinical trials and so the research outcomes may not pertain to us at all. #askcue

2 YEARS AGO



LGBT HealthLink
@LGBTHealthLink

#AskCue A:6 YES!! LGBT patients should be participating! Speaking up for ourselves!
[twitter.com/United4Evidenc...](https://twitter.com/United4Evidence)

2 YEARS AGO



Jimmy Le
@jtoanle

Great question #AskCue @United4Evidence [twitter.com/emclears/statu...](https://twitter.com/emclears/status)

2 YEARS AGO



Cochrane US
@UScochrane

@Bill6440 @United4Evidence #AskCUE Could we extrapolate from studies of how to everyone in the room noticed, (young, old, women, LGBT)?

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

@United4Evidence Yes again CUE provides training to consumers on how to serve effectively and be heard #ASKCUE @CenterLink

2 YEARS AGO



Ngina
@nlythcott

@jtoanle @bwarrenpsyd @United4Evidence I think that sometimes we need to reach out to them. #askcue

2 YEARS AGO



LGBT HealthLink
@LGBTHealthLink

#AskCue A;7 Identify an LGBT Comm Ctr near you to include consumer groups. lgbtcenters.org [twitter.com/United4Evidenc...](https://twitter.com/United4Evidence)

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

@United4Evidence @hivguidelines We recommend 2 per panel and guideline developers in the know concur #AskCue @CenterLink @hivguidelines

2 YEARS AGO



Jimmy Le
@jtoanle

Very true! #AskCUE twitter.com/nlythcott/stat...


2 YEARS AGO




Helen Haskell
@hhask


.@United4Evidence: Children are another underrepresented group. Where can parents go to find out about contributing to guidelines? #askcue

2 YEARS AGO


 **Barbara Warren**
@bwarrenpsyd


@jtoanle @United4Evidence Concur with open access. Only closed because guideline develop often not funded #Askcue @CenterLink

 2 YEARS AGO


 **Ngina**
@nlythcott


@UScochrane @Bill6440 @United4Evidence Sometimes,too often the health needs of priority populations have more variables at issue. #askcue

 2 YEARS AGO


 **Marguerite Koster**
@MargueriteK_LA


@United4Evidence @UScochrane @jtoanle @bwarrenpsyd Take the CUE training to participate in guideline panels #askCUE

 2 YEARS AGO


 **CUE**
@United4Evidence


See our website for more information about CUE's #clearinghouse functions #AskCUE twitter.com/UScochrane/sta...

 2 YEARS AGO


 **Elvira Mitraka**
@lv_ra

Are medical informatics being used to assess how well guidelines include diff #PriorityPopulations in their panels? #AskCUE @mnx @AHRQNews

 2 YEARS AGO

 **Nicole Fusco**
@napcat87

@hask @United4Evidence Such an important point! Children are often excluded from research entirely. #askcue

 2 YEARS AGO



KT
@kttlk

[@United4Evidence](#) What are guideline developers doing to address the needs of elderly pts with #MCCs? [@MargueriteK_LA](#) [@GuidelinesNA](#) #AskCUE

2 YEARS AGO



Bill Vaughan
@Bill6440

[@United4Evidence](#) Took course. Fascinating examples. Eye opening. Fun really. #AskCUE

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

[@UScochrane](#) [@nlythcott](#) [@jtoanle](#) [@United4Evidence](#) why want t CUE project w/ CenterLink & other LGBT orgs.#askcue [@CenterLink](#) [@hivguidelines](#)

2 YEARS AGO



Ngina
@nlythcott

[@jtoanle](#) [@United4Evidence](#) remember that critical mass is almost always important. Two at a minimum.#askcue

2 YEARS AGO



Helen Haskell
@hhask

[@Bill6440](#), I think patients can just ask the obvious questions that arise. Sometimes they are the only ones willing to ask #askcue

2 YEARS AGO



Helen Haskell
@hhask

[@Bill6440](#), I think patients can just ask the obvious questions that arise. Sometimes they are the only ones willing to ask #askcue

2 YEARS AGO



Cochrane US
@UScochrane

@Bill6440 @United4Evidence What else is needed? what is not there that could be? #AskCUE



2 YEARS AGO



Barbara Warren
@bwarrenpsyd

@United4Evidence guideline developers need \$ to pay to dev. - charge for reports.Govt funding help #askcue @CenterLink @hivguidelines



2 YEARS AGO



Cochrane US
@UScochrane

@nlythcott @jtoanle @United4Evidence Why is this? to feel empowered? #AskCUE



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Intro to SRMA 2016
@SysRevMeta

Of possible interest: extra resources & free courses @UScochrane @United4Evidence #AskCUE
us.cochrane.org/CUE twitter.com/UScochrane/sta...



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Intro to SRMA 2016
@SysRevMeta

Of possible interest: extra resources & free courses @UScochrane @United4Evidence #AskCUE
us.cochrane.org/CUE twitter.com/UScochrane/sta...



2 YEARS AGO



Nicole Fusco
@napcat87

@United4Evidence @bwarrenpsyd How do we better involve patients with rare diseases in guideline development? #askcue



2 YEARS AGO

**KT**
@kttlk

[@United4Evidence](#) Ppl w rare/severe dzs often prefer [#CAM](#). R guideline grps more/less willing 2 hv proCAM pt on panels? [#AskCUE](#) [@CochraneCAM](#)

2 YEARS AGO

**Intro to SRMA 2016**
@SysRevMeta

How can we help make [#systematicreviews](#) more accessible and available for [#guidelines](#) developers and [#patients](#)? [@United4Evidence](#) [#AskCUE](#)

2 YEARS AGO

**Barbara Warren**
@bwarrenpsyd

[@United4Evidence](#) [@Bill6440](#) Guidelines often done by specialty med orgs and don't use best practice = multi disciplinary panelists [#askcue](#)

2 YEARS AGO

**Barbara Warren**
@bwarrenpsyd

[@napcat87](#) [@United4Evidence](#) CUE currently RECRUITING new rare disease consumer groups JOIN US NOW to get active [#askcue](#)

2 YEARS AGO

**Cochrane US**
@UScochrane

[@bwarrenpsyd](#) [@United4Evidence](#) [@Bill6440](#) [#AskCUE](#) I love "Nothing about us, without us"

2 YEARS AGO

**Bill Vaughan**
@Bill6440

[@United4Evidence](#) KHN today reports correlation between Rx's for brands and mfgers payments to docs. We need Evidence based guidelines![#AskCUE](#)

2 YEARS AGO



emclears
@emclears

[@United4Evidence](#) [#askCUE](#) How can guideline developers better reach out to consumers for involvement?

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

[@United4Evidence](#) LGBTconsumers. PLEASE contact CUE 2 join us. We can get you active in our work [#askcue](#) [@CenterLink](#) [@hivguidelines](#)

2 YEARS AGO



CUE
@United4Evidence

[@SysRevMeta](#) [@hildabast](#) Checkout [@cochranecollab](#) for up-to-date and free systematic reviews!

@SysRevMeta · 2 YEARS AGO



Barbara Warren
@bwarrenpsyd

[@UScochrane](#) [@United4Evidence](#) [@Bill6440](#) gay men missing from guidelines on anal cancer tx [#askcue](#) [@CenterLink](#)

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

[@UScochrane](#) [@United4Evidence](#) [@Bill6440](#) Transgender consumers not asked to be on new Trans hormone guideline updates [#askcue](#) [@CenterLink](#)

2 YEARS AGO



Barbara Warren
@bwarrenpsyd


[@United4Evidence](#) [@nlythcott](#) [@GuidelinesNA](#) CUE works with guideline developers to learn best practices 2 engage educated consumers [#askcue](#)

2 YEARS AGO


 **Bill Vaughan**
@Bill6440


[@United4Evidence](#) Do folks think supporting Shared Decision Making is likely to promote Evidence-based care? #AskCUE

 2 YEARS AGO


 **Cochrane US**
@UScochrane


[@Bill6440](#) [@United4Evidence](#) Unconflicted EB guidelines! #AskCUE

 2 YEARS AGO


 **Barbara Warren**
@bwarrenpsyd


[@UScochrane](#) [@United4Evidence](#) [@Bill6440](#) [@CenterLink](#) No consumers. Endo Society "afraid" of consumers. Need education #askCue [@CenterLink](#)

 2 YEARS AGO


 **Marguerite Koster**
@MargueriteK_LA


[@United4Evidence](#) [@kltk](#) [@GuidelinesNA](#) Ongoing webinars, conference workshops etc. Join GIN NA LinkedIn group and raise issues! #AskCUE

 @SysRevMeta · 2 YEARS AGO


 **Nicole Fusco**
@napcat87

[@United4Evidence](#) [@bwarrenpsyd](#) Should inclusion be different for disabled patients? Can we involve them as well as their caretakers? #askcue

 2 YEARS AGO

 **Barbara Warren**
@bwarrenpsyd

[@napcat87](#) [@United4Evidence](#) If we can find disability consumer groups to join CUE . LGBT disability groups ? Ideas how? #askcue [@CenterLink](#)

 2 YEARS AGO



Ngina
@nlythcott

@UScochrane @kltlk @United4Evidence @MargueriteK_LA @GuidelinesNA
Coalitions/collaborations of ultra informed consumers might work. #askcue

2 YEARS AGO



Marguerite Koster
@MargueriteK_LA

@nlythcott @UScochrane @kltlk @United4Evidence @GuidelinesNA Yes - exactly my thoughts.
One person can't rep all groups. #AskCUE

2 YEARS AGO



Barbara Warren
@bwarrenpsyd

@nlythcott @UScochrane @United4Evidence @Bill6440 @CenterLink Please visit
us.cochrane.org/CUE today to find out how to join us #askcue

2 YEARS AGO



Ngina
@nlythcott

@UScochrane @kltlk @United4Evidence @MargueriteK_LA @GuidelinesNA Did I say that
(smile). #askcue

2 YEARS AGO



Nicole Fusco
@napcat87

@United4Evidence @bwarrenpsyd @CenterLink A lot of disabled patients work at state run
workshops. Maybe we can start there? #askcue


2 YEARS AGO




Marguerite Koster
@MargueriteK_LA


@United4Evidence @kltlk @GuidelinesNA GIN NA wants to hear from consumers. Pls suggest
topics for webinars via LinkedIn group #AskCUE

2 YEARS AGO


 **Ngina**
@nlythcott


@UScochrane @kltlk @United4Evidence @MargueriteK_LA @GuidelinesNA and trusted.
#askcue

 2 YEARS AGO


 **Cochrane US**
@UScochrane


@MargueriteK_LA @United4Evidence @kltlk @GuidelinesNA #AskCUE what is next webinar
and when?

 2 YEARS AGO


 **LGBT HealthLink**
@LGBTHealthLink


Thank you for having us! #AskCue #LGBTWellness [twitter.com/United4Evidenc...](https://twitter.com/United4Evidence)

 2 YEARS AGO


 **Cochrane US**
@UScochrane


#AskCUE Thank you Barbara Warren!!!!

 2 YEARS AGO


 **CUE**
@United4Evidence

And don't forget to checkout our website @ us.cochrane.org/CUE If you're a consumer or
guideline dev, we hope you get involved! #AskCUE

 2 YEARS AGO

 **Bill Vaughan**
@Bill6440

@UScochrane @United4Evidence The exams of false leads are super! More are needed to warn
us against cutting scientific corners#AskCUE

 2 YEARS AGO