Who is making recommendations for my healthcare?

by CUE Cochrane USA a few seconds ago

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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/7NIlz4zqU

2 YEARS AGO

Happening RIGHT NOW! #AskCue #LGBTWellness twitter.com/United4Evidenc...

2 YEARS AGO

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

2 YEARS AGO

@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
Who is making recommendations for my healthcare?

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

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

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

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

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

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

With the recent push for #OpenAccess to biomedical data, shouldn’t pts have #OpenAccess to guideline dev reports? #AskCUE @GuidelinesNA

CUE
@United4Evidence

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

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

Jimmy Le
@jtoanle

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

Barbara Warren
@bwarrenpsyd

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

Marguerite Koster
@MargueriteK_LA

@United4Evidence Guidelines-recommendations based on systematic evidence review & benefits/harms of alternative care options. #askCUE
Who is making recommendations for my healthcare?

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 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
Who is making recommendations for my healthcare?

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

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

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

#AskCue A: YES!! LGBT patients should be participating! Speaking up for ourselves! twitter.com/United4Evidence...

Great question #AskCue @United4Evidence twitter.com/emclears/status...

@Bill6440 @United4Evidence #AskCUE Could we extrapolate from studies of how to everyone in the room noticed, (young, old, women, LGBT)?
Who is making recommendations for my healthcare?

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/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
Who is making recommendations for my healthcare?

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

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

2 YEARS AGO
@United4Evidence What are guideline developers doing to address the needs of elderly pts with #MCCs? @MargueriteK_LA @GuidelinesNA AskCUE

@United4Evidence Took course. Fascinating examples. Eye opening. Fun really. AskCUE

@UScochrane @nlythcott @jtoanle @United4Evidence why want t CUE project w/ CenterLink & other LGBT orgs. AskCUE @CenterLink @hivguidelines

@jtoanle @United4Evidence remember that critical mass is almost always important. Two at a minimum. AskCUE

@Bill6440, I think patients can just ask the obvious questions that arise. Sometimes they are the only ones willing to ask AskCUE
Who is making recommendations for my healthcare?

- **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 empoered? #AskCUE
  - 2 YEARS AGO

- **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

- **Intro to SRMA 2016**
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  - 2 YEARS AGO

- **Nicole Fusco**
  - @napcat87
  - @United4Evidence @bwarrenpsyd How do we better involve patients with rare diseases in guideline development? #askcue
  - 2 YEARS AGO
Who is making recommendations for my healthcare?

KT @kiltk
@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 Rxs for brands and mfgers payments to docs. We need Evidence based guidelines! #AskCUE
2 YEARS AGO
Who is making recommendations for my healthcare?

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

@United4Evidence LGBT consumers. PLEASE contact CUE to join us. We can get you active in our work #askcue @CenterLink @hivguidelines

@SysRevMeta @hildabast Checkout @cochranecollab for up-to-date and free systematic reviews!

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

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

@United4Evidence @nlythcott @GuidelinesNA CUE works with guideline developers to learn best practices to engage educated consumers #askcue
Who is making recommendations for my healthcare?

Bill Vaughan
@Bill6440

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

Cochrane US
@UScochrane

@Bill6440 @United4Evidence Unconflicted EB guidelines! #AskCUE

Barbara Warren
@bwarrenpsyd

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

Marguerite Koster
@MargueriteK_LA

@United4Evidence @kltlk @GuidelinesNA Ongoing webinars, conference workshops etc. Join GIN NA LinkedIn group and raise issues! #AskCUE

Nicole Fusco
@napcat87

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

Barbara Warren
@bwarrenpsyd

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

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 examps of false leads are super! More are needed to warn us against cutting scientific corners#AskCUE

2 YEARS AGO