

# THE CUE QUARTERLY

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CONSUMERS UNITED FOR  
EVIDENCE-BASED HEALTHCARE

## THE CUE QUARTERLY

A quarterly newsletter brought to you by Consumers United for Evidence-based Healthcare

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May 2017

### [2017 CUE Advocacy Summit: Leveraging the Power of Patient & Consumer Advocacy to Transform Healthcare](#)

CUE held its third Consumer Advocacy Summit on March 19, 2017 at the New York Academy of Medicine. The Summit was held in conjunction with the Guidelines International Network North America's Evidence-Based Guidelines Affecting Policy, Practice and Stakeholders (E-GAPPS III) conference. The Summit focused on the expansion of patient-centered outcomes research and clinical comparative effectiveness research, and the demand for more consumer engagement in research implementation practices.

Click [here](#) to access the 2017 CUE Summit Presentations

# Clearinghouse

## Clearinghouse Opportunities

1. **Making GRADE the Irresistible Choice (MAGIC Project)** is a research group that uses GRADE methodology to create trustworthy guidelines and have worked extensively with the Cochrane Collaboration and G-I-N. They are seeking a consumer representative to serve on a primary care (urology-related) guideline. This guideline is considering whether prescription of alpha blockers for ureteric stones patients would be useful. The ideal consumer representative would be a patient with lived experience of suspected ureteric stones or their caregiver, if they feel they can speak to the values of the patients for whom the guideline would be developed. The total time commitment is approximately 7-10 hours.
2. **MAGIC Project** is also seeking a consumer to serve on a Prostate-Specific Antigen (PSA) screening guideline. Ideal patients are those who are eligible for screening but have not been screened or those who have been screened but are considering their options, and do not have financial or intellectual conflicts related to PSA screening. Panel members who are strongly affiliated with a position related to the guideline topic are not eligible. The total time commitment for this guideline is approximately 7-10 hours.

*If interested, please contact Kolade Fapohunda ([kfapohu1@jhu.edu](mailto:kfapohu1@jhu.edu)) or Genie Han ([ghan14@jhu.edu](mailto:ghan14@jhu.edu)) if possible. The application form is attached [here](#).*

## Featured CUE Members



*Terry Kungel, MBA, Director of the **Maine Coalition to Fight Prostate Cancer** and Chair of the CUE Steering Committee, currently serves on several committees, applying evidence-based healthcare to serve his community.*

Implementing Evidence-based Healthcare (EBHC) as a Consumer: Terry serves as a patient representative, special government employee for the FDA, a consumer reviewer for the Congressionally Directed Medic program, a merit reviewer for the Patient-Centered Outcomes Research Institute, and as a participant for the National Comprehensive Cancer Network (NCCN). Most recently, Terry advocated for the application of NCCN's guidelines for MRI-based prostate cancer biopsies. He previously served on an The American Society of Clinical Oncology (ASCO) Guideline Committee addressing prostate cancer survivors. Terry looks forward as a consumer representative on future CUE Clearinghouse requests and we thank him for his many contributions to the implementation of evidence-based healthcare and his continued support for CUE!



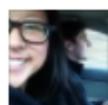
*Yanling Yu, PhD, founder of **Washington Advocates for Patient Safety**, serves her community by promoting the use of evidence-based healthcare (EBHC) in patient-centered care and patient safety.*

Dr. Yu serves on several state- and nationwide advisory committees including the Washington State Medical Assurance Commission, the FDA Pulmonary-Allergy Drugs Advisory Committee, and the University of Washington's Team Strategies and Tools to Enhance Performance and Patient Safety (TeamSTEPPS) training program.

By participating in CUE's Clearinghouse, Dr. Yu was selected to serve as a consumer representative on the College of Emergency Physicians' (ACEP) Clinical Guideline Development Panel. In this capacity, Dr. Yu will review and comment on draft critical questions and on draft guideline text. Over the course of one year, she will work on developing guidelines for several different topics including opioid use, headache, and community-acquired pneumonia. Dr. Yu was selected for this position because of her knowledge regarding EBHC and development methodology. We thank Dr. Yu for all her contributions to patient safety through the application of EBHC.

*If you or someone in your organization has participated in CUE's Clearinghouse or research implementation projects as a consumer representative, please contact Kolade Fapohunda ([kfapohu1@jhu.edu](mailto:kfapohu1@jhu.edu)) or Genie Ghan ([ghan14@jhu.edu](mailto:ghan14@jhu.edu)) to share your accomplishments.*

**RECENT ACTIVITY**



**Genie Han** shared a link.

Yesterday at 3:10pm

Hi everyone! I'm excited to share our 2017 Meeting Presentations with you

...every one interested to share our 2017 meeting recommendations with you all. You can find them on the homepage of [www.consumersunited.org](http://www.consumersunited.org), or you can click here for the direct link to Youtube: <https://www.youtube.com/playlist...>

Feel free to share these presentations on social media and with your constituents!



## Welcome to CUE | CUE

CUE is a national coalition of health and consumer advocacy organizations committed to empowering consumers to make the best use of evidence-based healthcare.

[CONSUMERSUNITED.ORG](http://CONSUMERSUNITED.ORG)

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### Top Stories from CUE Facebook Group

#### Pharmaceutical Marketing for Rare Diseases

##### 5.24.17 (The JAMA Network)

"The US Food and Drug Administration (FDA) draws a distinction between direct-to-consumer advertising drug products, which it regulates, and advertisements intended to create disease awareness, which it does not. Posted by: Michael Weinberg, Association for the Protection of Cancer Patients

#### Congress Totally Ignored Trump's Cuts to NIH Funding

Congress totally ignored Trump's cuts to NIH funding

### 5.1.17 (The Atlantic)

"With the release of their budget agreement for 2017, lawmakers have demonstrated how little they care about the administration's plans for NIH. The omnibus, which spells out funding between now and the end of this year, allocates an additional \$2 billion to the agency".

Posted by: Jimmy Le, US Cochrane

Strategies To Address The Challenges Of Outcomes-Based Pricing Agreements For Pharmaceuticals

### 4.4.17 (Health Affairs Blog)

"With major reforms of U.S. health policy likely in the coming years, the future of the health care system is uncertain. It is highly likely, however, that the increasing focus on a value-based, rather than volume-based, system will continue."

Posted by: Kay Dickersin, US Cochrane

The pollution of health news: Time to drain the swamp

### 3.15.17 (Healthnewsreview)

"The flow of healthcare and research news to the public can be contaminated at various points along a stream of information."

Posted by: Gary Schwitzer, HealthNewsReview.org

INSPIRE Research Portal

### 3.15.17 (Patient Advisory Network)

"This portal is an online library of resources designed for patients and researchers partnering on **patient outcomes research (PCOR)**, healthcare studies that actively engage patients in the research process from start to finish."

Posted by: Kay Dickersin, US Cochrane

For more top stories, please visit our Facebook.

## Education & Training





## Featured Resource

### Series III: Scenarios exploring the interpersonal dynamics of advisory panel participation

CUE has created a series of short vignettes based on real experiences from professionals and patients on advisory panels. These videos portray real-life scenarios and situations likely to be encountered by professional guideline developers and consumer advocates as they collaborate on advisory panels. The scenarios depict preparing for the panel as a consumer, effectively moderating the panel as a Chair, and ensuring that diverse voices are heard, understood, and respected. To test your knowledge, click [here](#) to access the Self-tests for Series III.

Feedback is welcome! [CUE@jhu.edu](mailto:CUE@jhu.edu)

CUE-Consumers United for Evidence-based Healthcare

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