

# 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 (CUE)

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### Clearinghouse Opportunities

1. **The College of American Pathologists (CAP)** is seeking a patient or patient advocate for a new clinical practice guideline (CPG) on **Checkpoint Inhibitor Testing in Body Sites Other Than Lung**. An ideal representative would be a **patient or patient advocate who has been diagnosed with a skin, kidney, or GI cancers who have been or are being treated with the drug pembrolizumab or other immune checkpoint inhibitors**. The duration of this project is approximately 18 months (kick-off on **March 1, 2018**) for development and dissemination of this evidence-based guideline.

*If interested, please contact Kolade Fapohunda ([kfapohu1@jhu.edu](mailto:kfapohu1@jhu.edu)) as soon as possible. The application form is attached here.*

### Featured CUE Members





***John James, PhD, Founder of Patient Safety America***

Evidence-based knowledge of healthcare is at the core of Dr. James' advocacy. Research shows that patients often provide valuable insights in their care. To foster that inclusivity, I am advocating for improvements in informed consent and patient rights through Centers for Medicare & Medicaid Services (CMS). As a member of the Patient Safety Standing Committee of the National Quality Forum (NQF), I use evidence to evaluate the worth of proposed measures of healthcare. As the Houston co-leader of the Right Care Alliance, I am forming teams that will better inform the public of the evidence behind risks of pharmaceuticals. I am currently writing an op-ed for *Consumer Safety* (an online resource on health safety-related news) on the dangers of drugs with the Food and Drug Administration's "black box" warning. I am also writing a journal article that connects the high cost of U.S. medical care with harm to patients through denial of access and emotional stress associated with devastating medical bills.



***Brenda Shelton-Dunston, MPH, Executive Director at Black Women's Health Alliance Philadelphia***

The Black Women's Health Alliance (BWHA) is a non-profit, community-based health and human services organization that was founded in 1983. The mission is to improve healthcare outcomes and eliminate and/or reduce health disparities experienced by women of African Ancestry, other women of color, and their families through advocacy, education, research and support activities, programs and services.

BWHA has a longstanding history of conducting evidence-based programs and services in partnership with community based organizations, churches, schools, universities, governmental entities, foundations, businesses, etc. Programs such as Prime Time Sister Circle Program (PTSC) in which an evidenced-based facilitator/expert directed wellness program that targets and improves the lifestyle of women of color and Supporting Our Sisters (SOS) Parenting Leadership Program which works with at risk, high risk and hard to reach pregnant and parenting women, teens, fathers, their

WORKS WITH AT RISK, HIGH RISK AND HARD TO REACH PREGNANT AND PARENTING WOMEN, TEENS, FATHERS, OTHER CHILDREN AND OTHER CAREGIVERS. We thank BWA for their continual contributions to their local community and CUE.

*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 (kfafohu1@jhu.edu) or Genie Han (ghan14@jhu.edu) to share your accomplishments.*

## Social Media

### Top Stories from CUE Facebook Group

[Doctors have decades of experience fighting “fake news.” Here’s how they win](#)

**1.24.18 (Vox)**

"Some lessons from the health community's long battle with misinformation..."

Posted by: Kay Dickersin, Cochrane United States

[Know Your Chances: Understanding Health Statistics](#)

**1.23.18 (PubMed Health)**

"Pop quiz:

A study in a major medical journal reports that a new drug can shrink liver tumors. What is the most important additional information you would want to know?

- How much the tumors shrink
- Whether people feel better or live longer. Perhaps an easy question (answer is B), but it makes an important difference between surrogate outcomes (like in A) and patient outcomes (like in B).

"Unfortunately, we have many examples of cancer drugs that shrink tumors but do not extend life (some even shorten it)", according to Drs. Steven Woloshin, Lisa Schwartz, and H Gilbert Welch in their free medical statistics text, "Know Your Chances".

Posted by: Genie Han, Consumers United for Evidence-based Healthcare

[Reluctance to share innovations means lost opportunities for life sciences firms, Johns Hopkins experts write](#)

**1.24.18 (HUB)**

"Sharing and the flip side, reluctance to share, is everywhere! We need to demand it as stockholders and the public more generally! But who will pay? We already work 24/7 so we all need to see more investment in sharing and transparency...."

Posted by: Kay Dickersin, Cochrane United States

[The Catalogue of Bias in health research](#)

**1.19.18 (Catalogue of Bias)**

"An ongoing collaboration to define all of the biases affecting health research and provide examples, preventive steps and educational resources"

Posted by: Helen Haskell, National Patient Safety Foundation

[Nerve Pain Med Prescriptions Triple Amid Opioid Crisis](#)

**1.19.18 (the Fix)**

"Combination of... increased... prescribed to patients with... and... diagnosis... which...

"Gabapentinoids are increasingly prescribed to patients with opioids and benzodiazepines, which increases the risk of respiratory depression and death."

Posted by: Jimmy Le, Cochrane United States

[Nothing Protects Black Women From Dying in Pregnancy and Childbirth](#)

### **1.19.18 (ProPublica)**

"Not education. Not income. Not even being an expert on racial disparities in health care."

Posted by: Michael Weinberg, Cochrane United States

**For more top stories, please visit our Facebook & Twitter!**

### **Education & Training**

[Introduction to CUE Resources and Clearinghouse](#)

CUE recommends that you watch this introductory video before exploring our educational resources on our website ([www.consumersunited.org](http://www.consumersunited.org)). This video introduces CUE educational resources and the Clearinghouse, and provides helpful information on CUE website navigation.

[How to communicate effectively on an advisory panel](#)

CUE has created a video about communication strategies on an advisory panel, based on a Twitter Chat co-hosted with Dr. John Santa of OpenNotes (previously Director of the Health Ratings Center at Consumer Reports). This video provides strategies based on real experiences from patients participating on advisory panels, such as how to ensure the consumer view is being heard and how to introduce conflict tactfully.

Feedback is welcome! [kfapohu1@jhu.edu](mailto:kfapohu1@jhu.edu)

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