

Lay Summary of Final Report

2017 CUE International Consumer Advocacy Summit:
Leveraging the Power of Patient & Consumer Advocacy to Transform Healthcare
Consumers United for Evidence-based Healthcare (CUE)
March 19, 2017
7:30 am–5:00 pm
New York Academy of Medicine
1216 5th Avenue, New York, NY 10029

On March 19, 2017, CUE hosted its 3rd International Consumer Advocacy Summit, “[Leveraging the Power of Patient & Consumer Advocacy to Transform Healthcare](#)”. The 2017 CUE Summit combined a summit of consumers who are not members of CUE, as well as CUE members. To facilitate bidirectional communication and collaboration between consumers and all healthcare stakeholders, the CUE Summit was held back-to-back with the Evidence-based Guidelines Affecting Policy, Practice, and Stakeholders (E-GAPPS III) conference at the New York Academy of Medicine in New York City. The summit was also held in conjunction with the CUE Annual Membership Meeting, typically held in Washington, DC, which we believe encouraged and provided for a highly diverse and enthusiastic audience. The presentations equipped advocates with valuable knowledge and generated lively discussion. Post-meeting communication with CUE Steering Committee members indicate that they left the meeting with renewed focus and evidence-based healthcare (EBHC)-specific goals in their consumer advocacy leadership. Sixty-two individuals attended the event.

Speakers addressed assigned topics and made recommendations for CUE, which will be addressed in 2018 (see Table 1). Audio slidecasts of all presentations are posted on the CUE YouTube page at <https://www.youtube.com/channel/UChL0coVILNb9uH5dOwN5iAQ>. The audience live-tweeted the meeting with the #CUESummit17 hashtag; the Storify summary of the Summit is available at <https://storify.com/United4Evidence/2017-cue-summit>. For more in-depth summaries of keynote and panel presentations, please refer to CUE’s website: <http://consumersunited.org/conferences/cue-meeting-reports>.

A contract for the Summit was awarded by PCORI (Contract # EAIN-2654). The Agency for Healthcare Research and Quality (AHRQ) provided funds for the CUE Annual Meeting (Grant # R13 4134401, held in conjunction with the Summit).

Table 1: Recommendations to consumer advocates by CUE Summit Speakers

Title of Talk	Speaker	Recommendations for CUE	Resources Recommended for Consumer Advocates
The politics of consumer advocacy: The promise and pitfalls of disease constituencies	Vinay Prasad (Assistant Professor of Medicine, Oregon Health and Sciences University)	<ul style="list-style-type: none">● Include hard-to-reach populations, such as rural communities or reluctant patients, in FDA panels● Use patient “video diaries” of their experiences as trial participants● Have 100% transparency in patient advocate funding● Remove board members taking funds from the pharmaceutical industry	Ending Medical Reversal by Vinay Prasad and Adam Cifu

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Yes, patients/consumers have made a difference	Sandra Zelman Lewis (Chief Guidelines Officer, Doctor Evidence)	<ul style="list-style-type: none"> Continue the involvement of patients in guideline panels for the benefit of all stakeholders Coordinate with guideline developers to improve processes for maximizing the patient stakeholders' ability to meaningfully contribute 	GROWTH Evidence G-I-N PUBLIC
I have no idea whether public representatives like me have made much of a difference	Maryann Napoli (Retired Associate Director, Center for Medical Consumers)	<ul style="list-style-type: none"> Follow-up with the recommendations created from advisory board participation, in order to assess the patient/consumer stakeholder impact Read media publications based on advisory board recommendations, to evaluate what public impact the recommendations had 	N/A
Maybe, patients/consumers have made a difference	Bill Vaughan (Board of Directors, National Committee to Preserve Social Security and Medicare)	<ul style="list-style-type: none"> Connect with constituents through social media 	Twitter Facebook
How PCORI "priority populations" are engaging in research implementation	Sanford Jeames (Adjunct Professor, Huston-Tillotson University)	<ul style="list-style-type: none"> Promote the inclusion of educated but inexperienced advocates on advisory boards Promote stakeholder diversity in regards to race, gender, sexual orientation, and socioeconomic status on advisory boards 	Advocates in Science and Health American Association for Cancer Research American Society for Clinical Oncology PCORI Patient Protection and Affordable Care Act Research Advocacy Network
What does success look like?	Gregg Gonsalves (Research Scholar in Law, Yale University)	<ul style="list-style-type: none"> Divest from pharmaceutical funding, or at least be transparent about funding sources Be educated about the 21st Century Cures Act and the consequences it could have for the FDA 	Rescuing Accelerated Drug Approval: Moving Beyond the Status Quo
What does patient engagement look like to marginalized communities?	Laura Logie (Director of Research, Nueva Vida)	<ul style="list-style-type: none"> Demand more research on best methods for consumer engagement Encourage researchers to have a "pre-engagement" phase with the patient population, where researchers can learn more about the community they intend to study 	Estoy Contigo: Compartiendo el Camino

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		<ul style="list-style-type: none"> Employ community engagement workers to bridge cultural and linguistic gaps 	
<p>Do increased partnerships among stakeholders lead to speedier implementation of patient-centered outcomes research (PCOR)?</p>	<p>Jean Slutsky (Chief Engagement and Dissemination Officer, PCORI)</p>	<ul style="list-style-type: none"> Become involved in PCORI to help determine important research questions and disseminate findings Take advantage of PCORI’s accelerated timeline for research publications and check their content regularly 	<p>Patient-Centered Outcomes Research Translation Center</p> <p>PCORI’s Process for Peer Review of Primary Research and Public Release of Research Findings</p>
<p>If it works in the UK will it work in the US?</p>	<p>Sally Crowe (Director, Crow Associates Ltd.)</p>	<ul style="list-style-type: none"> Learn how to communicate effectively with hard-to-reach populations; this includes a framework for advocacy training education Learn how to communicate with stakeholders (researchers, clinicians, etc.) to better promote their views 	<p>Association for Medical Research Charities</p> <p>Evidently Cochrane</p> <p>INVOLVE</p> <p>National Institute for Health Research</p> <p>James Lind Alliance</p> <p>Patient and Public Involvement Toolkit</p> <p>Patient Research Ambassador Initiative</p> <p>Research Involvement and Engagement</p>
<p>Consumer engagement: goals for the next decade</p>	<p>Susan Love (Chief Visionary Officer, Dr. Susan Love Research Foundation)</p>	<ul style="list-style-type: none"> Participate in the PCORI model of patient engagement so that processes ranging from research topic selection to outcomes selection prioritize the patient experience Appraise the long-term effects of interventions (“collateral damage”) rather than focusing on solely short-term complications (“side effects”) 	<p>BreastCancer.org</p> <p>Dr. Susan Love Research Foundation</p> <p>Health of Women (HOW) Study</p> <p>Metastatic Breast Cancer Collateral Damage Project</p> <p>National Breast Cancer Coalition</p> <p>Young Survival Coalition</p>