

2018 CUE Annual Membership Meeting: How do We Assess the "Value" of Health Care, Given the Evidence?

Consumers United for Evidence-based Healthcare (CUE) July 13, 2018 8:30 am–4:45 pm Henry J. Kaiser Family Foundation Barbara Jordan Conference Center 1330 G Street NW, Washington, DC 20005

A. Executive Summary

The goal of the CUE Annual Membership Meeting is the development and maintenance of a strong and sustainable network of informed consumer advocates.

On July 13, 2018, CUE hosted its 15th Annual Membership Meeting, "How do We Assess the 'Value' of Health Care, Given the Evidence?", on Friday, July 13, 2018 in Washington, D.C. (see Appendix A for Membership List). CUE members, researchers, and policymakers networked, listened to and gave presentations, facilitated and attended workshops, and participated in lively discussions, all with the aim of building the leadership capacity of consumer advocates in the area of evidence-based healthcare (EBHC).

The CUE Planning Committee's preparations for the July 2018 meeting began in December 2017 as Committee members selected the theme to be using evidence to assess the value of health care, in response to interests of CUE members. Consumer discussants for each session were a new addition to the conference. The event comprised three keynote presentations, one panel session with three speakers each, three workshops, and a "film screening" of one of CUE's educational videos on communication strategies for advisory panel participation. Each keynote speaker was allotted 15 or 30 minutes, each followed by a 5 minute consumer discussant and 30 minute discussion period. Each panel speaker was allotted 15 minutes each for his or her presentation with a 5 minute consumer discussant and 30 minute discussion period following the session. Discussion sessions allowed members of the audience to pose questions to specific speakers from a microphone on the floor. The conference structure provided optimal time for conference participants and consumers to interact with the speakers and ask focused questions while staying within a scheduled time frame.

Keynote speakers were selected on the basis of their work on and insight into consumer advocacy (see Appendix B for Agenda). Dr. Trent Haywood (Chief Medical Officer at Blue Cross Blue Shield Association); Dr. Gerard Anderson (Professor at Johns Hopkins Bloomberg School of Public Health); and Ms. Cindy Pearson (Executive Director of the National Women's Health Network) served as keynote speakers. Dr. Scott Zeger (Professor at Johns Hopkins Bloomberg School of Public Health) was scheduled to serve as a keynote speaker but was replaced by Dr. Gerard Anderson due to a personal reason. Consumer discussants for keynote speakers included Bill Vaughan (National Committee to Preserve Social Security and Medicare); Dr. Janice Bowie (transitioning CUE faculty); and Terry Kungel (Executive Director of Maine Coalition to Fight Prostate Cancer). Full speaker biosketches can be found in Appendix C.

The panel session included federal and state policymakers and researchers, allowing for a rich exchange of ideas and perspectives. The panel session's topic, "'Value' that is disparities-sensitive", included Dr. Eliseo Pérez-Stable (Director at the National Institute on Minority Health and Health Disparities at the National Institutes of Health); Dr. Krisda Chaiyachati (Assistant Professor at University of Pennsylvania); and Dr. LaQuandra Nesbitt (Director at the District of Columbia Department of Health). The consumer discussant was Brenda Shelton-Dunston (Executive Director of Black Women's Health Alliance).

The workshops provided three interactive options for participants to engage and learn in a small group setting. The facilitators for Workshop A, titled, "How to search for information on the internet", included Lori Rosman (Public Health Informationist at Johns Hopkins Medical Institutions) and Stella Seal (Associate Director of Health System and Community Services at Johns Hopkins Medical Institutions). Workshop B, titled "Health economics 101 related to 'value'", was facilitated by Dr. Darrell Gaskin (Professor at Johns Hopkins Bloomberg School of Public Health; Director of Johns Hopkins Center for Health Disparities Solutions). Workshop C, titled, "'Value' in drug prices: What are the challenges?" was facilitated by Dr. Gerard Anderson.

We had several ways of learning whether presentations equipped advocates with valuable knowledge. First, meeting evaluations (see Section D) indicate that the selection of speakers was well-tailored to the specific interests and concerns of consumer advocates (Appendix B for Agenda and speakers). Second, post-meeting communication with Steering Committee members and meeting attendees indicate that they left the meeting with renewed focus and evidence-based healthcare (EBHC)-specific goals in their consumer advocacy leadership. Thirty-five stakeholders attended the event (6 CUE staff, 20 CUE member organization representatives, 9 presenters).

Audio slidecasts of all presentations are posted on the CUE YouTube page at: https://www.youtube.com/channel/UChL0coVILNb9uH5dOwN5iAQ.

It is because of the R13 Large Conference Grant (Grant # R13 4134401) provided by the Agency for Healthcare Research and Quality (AHRQ), that this Annual Meeting was able to take place. We were able to supplement the funds provided by AHRQ to allow breakfast, snacks, beverages, and lunch to be served to participants.

B. Detailed Report of CUE Summit

To begin the meeting, Dr. Kay Dickersin, Professor of Epidemiology at Johns Hopkins University, provided a brief welcome and introduction to CUE and meeting hosts. Genie Han, CUE Coordinator, introduced the new CUE Steering Committee member, Tammy Boyd of the Black Women's Health Imperative. Ms. Han also announced that CUE staff would be "Live Tweeting" the event on Twitter, and that participants could contribute to the feed by using the hashtag #2018CUE (see Appendix D for Wakelet summary).

Dr. Janice Bowie and Dr. Elliott Tolbert, the transitioning Johns Hopkins faculty leadership for CUE, introduced themselves to CUE members and discussed their academic interests in consumer engagement in research. They expressed excitement for CUE's capacity to effect meaningful change in the education and empowerment of consumers. Next, Terry Kungel, the Steering Committee co-chair, announced that the Steering Committee has approved a new policy for continued CUE membership standards. These standards will strengthen the CUE membership by implementing a yearlong probationary status if a CUE member organization does not fulfill a minimum set of requirements (see Appendix E for details).

Introduction of Keynote Presentation I:

Sandy Finestone (moderator), CUE Steering Committee; President, Association of Cancer Patient Educators

Sandy Finestone introduced Dr. Trent Haywood as the first keynote presentation of the day.

Keynote Presentation I: Insurance coverage with evidence development

Trent Haywood, MD, JD, Chief Medical Officer, Blue Cross Blue Shield

Dr. Haywood's background as the Deputy Chief Medical Officer for Medicare and Medicaid at the Centers for Medicare and Medicaid Services (CMS) laid the groundwork for his perspective on evaluating an evolving evidence base. In unique situations where evidence for an intervention is promising but does not yet meet the evidentiary standard, CMS had the opportunity to provide interim coverage for patients as evidence continued to develop.

Dr. Haywood acknowledged the risks in using preliminary information for coverage but clarified that individuals balance trade-offs in their healthcare decision-making process, particularly with the rise of precision medicine. Dr. Haywood spoke about how insurers like Blue Cross Blue Shield are interested in maximizing the value of healthcare relative to the cost to the patient and consumer but require an understanding of patient and consumer values for successful implementation. With the increasing involvement of the patient and consumer voice in healthcare and availability of online information, a "consumer scientist" role (i.e., scientific information is more accessible to modern-day consumers) is taking shape where patients and consumers are now making judgments alongside clinicians in evaluating the evidence base.

Discussant for Keynote Presentation I:

Bill Vaughan, National Committee to Preserve Social Security and Medicare

Mr. Vaughan further discussed the idea of "consumer scientists," explaining that the average consumer normally lacks the level of health literacy to be actively involved in his or her medical decision-making. He challenged audience members to develop resources to address this need.

Introduction of Panel I: "Value" that is disparities-sensitive

Ann Fonfa (moderator), CUE Steering Committee; President, Annie Appleseed Project

Ms. Fonfa introduced panel members and noted their federal and state policy contributions aimed at improving the health of patients and consumers. Due to a state emergency, Dr. Nesbitt's presentation was moved to the start of the panel.

Public health approaches to eliminate disparities in infectious disease

LaQuandra Nesbitt, Director, District of Columbia Department of Health

Dr. Nesbitt provided several experiences implementing value-conscious health policy in the District of Columbia. A disproportionate number of new HIV cases diagnosed in the District of Columbia are clustered in communities with low socioeconomic statuses. To prevent new HIV infections, the District of Columbia Department of Health began a treatment program that includes education and outreach to affected individuals. Dr. Nesbitt additionally examined the District's current strategies to eliminate hepatitis C among residents; similar to HIV, hepatitis C incidence predominantly occurs in District communities with low socioeconomic statuses. This focus on state-level preventative measures aims to reduce the overall future cost burden for the District and for patients.

How affordability affects health disparities

Eliseo Pérez-Stable, Director, National Institute on Minority Health and Health Disparities, National Institutes of Health

Dr. Pérez-Stable began by explaining the history of the National Institute on Minority Health and Health Disparities (NIMHD), an institute at the National Institutes of Health that oversees funding for minority health research. Health disparities research does not just focus on race and ethnicity groups, but also rural populations and any other group that experiences a worse health outcome compared to a reference. Dr. Pérez-Stable presented several evidence-based policy strategies that NIMHD considers reducing healthcare disparities, including: expanding access to healthcare (e.g., having a primary care clinician); looking to public health approaches; coordinating healthcare, especially for uneducated or high need individuals who lack the resources to navigate options; and utilizing a patient-centered medical care model that emphasizes communication and cultural competency.

The Affordable Care Act (ACA) aimed to minimize health disparities by increasing insurance coverage and thereby access to healthcare, especially for Latino populations. However, health disparities persist with prescription medication and specialty care and procedure affordability. Strategies to reduce cost include limitations on molecule modifications to create a new drug with a higher price but not higher value; new indications for existing drugs; publicly-available lists of affordable essential medications; and policy to facilitate cost reduction of existing drugs when a similar but new drug comes to market. Further recommendations from the National Academies of Sciences, Engineering, and Medicine to mitigate the cost burden for consumers and patients include implementing a code of conduct for industry, transparency protocols, and federal price negotiation.

When value is the only goal in healthcare: Unintended racial disparities

Krisda H. Chaiyachati, Assistant Professor, University of Pennsylvania

Dr. Chaiyachati posed a scenario for the audience: Imagine two men or women, equal in every way but of different races, who enter a hospital for the same treatment and condition but one receives a lesser quality of healthcare or experiences a worse outcome. Research demonstrates that this phenomenon of health disparity exists and moreover, is particularly stark when comparing black and white population groups. He suggested that multiple forces impact health care outcomes: the environment (e.g., where they live), the hospital (e.g., how clinicians in the hospital treat patients), and the individual choices of the patient.

Dr. Chaiyachati's research focuses on measuring the quality of healthcare received based on the price that an individual is paying for that healthcare, and how it differs in regard to race. Healthcare quality improvement programs, such as public reporting of hospital quality measures, have actually widened heathcare disparities between minorities and whites. As an example, Dr. Chaiyachati found that Medicare's Hospital Readmissions Reduction Program, which penalizes hospitals with higher than expected readmissions rates, was compounding health disparities by withdrawing funding from safety net hospitals that serve black patients with an already-higher baseline level of readmissions rates. An additional finding was that hospitals that spend more money on community needs see lower readmission rates, thereby making the case for hospitals to financially invest in the communities they serve to minimize health disparities.

Discussant for Panel I:

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

Ms. Shelton-Dunston contextualized the panel's discussion with how her organization, which serves minority women of color, addresses the role of social determinants of healthcare in health disparities. She observed that the panelists' presentations expressed a light at the end of the tunnel in regard to improving health disparities and healthcare value.

Introduction of Keynote Presentation II:

Tammy Boyd, MPH (moderator), CUE Steering Committee; Director of Health Policy and Legislative Affairs, Black Women's Health Imperative

Keynote Presentation II: How do we measure value in health care?

Gerard Anderson, Professor, Johns Hopkins Bloomberg School of Public Health

Dr. Anderson opened his presentation with an intriguing question about value: What are your priorities when it comes to your health? The different priorities held by different groups (e.g., countries, disease groups) helps to explain the complicated nature of the U.S. healthcare system today. Dr. Anderson utilized an example of a high needs (e.g., uses the healthcare system more often) individual with chronic illness and explained that her priority may not be more healthcare but being more involved in her community; therefore, a healthcare system designed to provide more for chronic illness patients may not be meeting her needs.

This uncoordinated healthcare system ultimately decreases the value that individuals receive from their healthcare. Dr. Anderson noted that of a peer-reviewed literature search for articles published between May 31, 2008 and June 10, 2014 about successful healthcare programs designed to help high needs populations, only half of the programs remained active. Although these programs were improving healthcare quality, they were unsuccessful in improving patient satisfaction. Dr. Anderson advocated for an investment in social services to improve the value of U.S. healthcare, in regard to patient satisfaction and spending.

Discussant for Keynote Presentation II:

Janice Bowie, Professor, Johns Hopkins Bloomberg School of Public Health

Dr. Bowie elaborated on the complex perspective that Dr. Anderson presented on how individuals perceive value, by highlighting the lack of social services in the United States. This inability to meet American social care needs leads to poorer health outcomes despite an expensive healthcare system.

Workshop A: How to search on the internet for information about healthcare value and cost Lori Rosman, Public Health Informationist, Johns Hopkins Medical Institutions
Stella Seal, Associate Director, Health System and Community Services, Johns Hopkins Medical Institutions

Ms. Rosman and Ms. Seal shared their knowledge of internet databases covering healthcare treatment and drug information and related costs, and recommended optimal search strategies to identify relevant information. The workshop consisted of interactive exercises that walked participants through the search process.

Workshop participants first learned how to assess credibility of resources using Health on the Net Foundation (HON), site domains, and website traffic data (e.g., last updated date). Once credibility of a source is established, participants were encouraged to further research the evidence base of a source by searching for guidelines and evidence reports from Trip Database; Agency for Healthcare Research and Quality's Evidence Practice Centers; and the National Institute for Health and Care Excellence.

CUE member organization constituents (i.e., patients and consumers) also use healthcare and drug costs in their medical decision-making. Resources that compile this data include Guroo, Agency for Healthcare Research and Quality's Healthcare Cost and Utilization Project, and GoodRx. Ms. Rosman and Ms. Seal ended the workshop with a primer on keywords and Google search limits.

A handout with the resources and tips from the workshop was given to all meeting participants. The handout is available on the CUE website: http://consumersunited.org/sites/default/files/inline-files/CUE_Resources_Handout_13July2018.pdf.

Workshop B: Health economics 101 related to "value"

Darrell Gaskin, Professor, Johns Hopkins Bloomberg School of Public Health; Director, Johns Hopkins Center for Health Disparities Solutions

Dr. Gaskin provided an introduction to health economics for workshop participants in his interactive presentation. Dr. Gaskin used practical examples from the United States healthcare system to apply economics principles, and challenged participants to theorize on why healthcare spending in the United States is so high.

Unlike in a traditional market with buyers and sellers, the United States healthcare market has many agents with different incentives: buyers (patients), sellers (providers), payers (patients, insurance companies), and regulators (government, professional health organizations). Dr. Gaskin explored each of these roles and their potential to solve the United States healthcare spending problem. Healthcare providers and insurers do not have a fundamental financial interest in decreased healthcare spending. Although patients do have a financial interest as buyers, they are the least informed agent and cannot effectively negotiate when sick (e.g., when demand for healthcare is high). Dr. Gaskin discussed with workshop participants about healthcare sponsors having the potential to negotiate healthcare spending, so long as consumers place pressure on them to do so.

Workshop C: "Value" in drug prices: What are the challenges?

Gerard Anderson, Professor, Johns Hopkins Bloomberg School of Public Health

Dr. Anderson utilized an informal roundtable discussion format to generate participant-led conversation about healthcare quality and value. CUE member organization representatives were familiar with the financial barriers that patients face when accessing drugs. Dr. Anderson discussed how the issue of non-accessibility are not just restricted to individual patients, but state governments as well. There are several United States-specific practices that potentially explain the high cost of prescription drugs; one example is the fast proliferation of new and expensive prescription drugs in the marketplace.

Building upon healthcare interactions shared by participants, Dr. Anderson moderated a discussion on how CUE member organizations may be able to combat high prescription drug costs. A potential solution is for CUE member organizations to mobilize and support policy that would implement a higher evidence threshold for market entry of new prescription drugs.

Introduction of Keynote Presentation III:

Ann Fonfa (moderator), CUE Steering Committee; President, Annie Appleseed Project

Ms. Fonfa introduced Ms. Pearson, highlighting the contributions that Ms. Pearson has made to advancing patient and consumer advocacy and to CUE.

Keynote Presentation III: Consumer groups and perceived conflicts of interest

Cindy Pearson, Executive Director, National Women's Health Network

Ms. Pearson examined the historic role that patients and consumers have played in influencing health policy changes, such as demanding transparency in prescription drugs and advocating for FDA procedural changes during the AIDS epidemic. These activist movements underpinned the success of the early national breast cancer awareness marches and campaigns, which helped to form the National Women's Health Network.

Grassroots activism soon became a target for industry interests who would appropriate these movements into marketing campaigns. Ms. Pearson provided examples of patient and consumer health advocacy campaigns and organizations that were outwardly similar to historic patient- and consumer-driven health activism but were actually initiated by industry interests. The lack of transparency on the financial ties of patient and consumer health advocacy campaigns muddies an individual's ability to discern potential bias. For individuals interested in funding transparency, Ms. Pearson recommended the recently released database "Pre\$cription For Power" from Kaiser Health News that allows individuals to explore the funding of patient and consumer health advocacy organizations. She noted that current research does not imply most organizations do receive industry funding, but the organizations that do receive industry funding receive a large amount. Industry funding may be viewed as compromising the message of patient and consumer health advocacy organizations.

Discussant for Keynote Presentation III:

Terry Kungel, co-chair, CUE Steering Committee; President, Maine Coalition to Fight Prostate Cancer

Mr. Kungel acknowledged the importance of Ms. Pearson's call for transparency, and noted that CUE membership requirements state that member organizations must report their funding and receive less than 50% of funding from industry. He discussed "gray" areas of concern, such as in-kind donations and how that may or may not influence a health or health advocacy organization's message.

C. Summary of Recommendations Made in Presentations

2018 CUE Annual Meeting speakers and workshop hosts made recommendations for CUE, which will be addressed in 2018 (see Tables 1 and 2).

Table 1: Recommendations to consumer advocates by 2018 CUE Annual Meeting Speakers

Title of Talk	Speaker	Recommendations for CUE	Resources Recommended for Consumer Advocates
Insurance	Trent Haywood, MD,	Encourage patients and consumers to	N/A
coverage with	JD, Chief Medical	be upfront with clinicians and insurers	
evidence	Officer, Blue Cross Blue	about their values and priorities during	
development	Shield	healthcare decision-making.	

Title of Talk	Speaker	Recommendations for CUE	Resources Recommended for Consumer Advocates
How affordability affects health disparities	Eliseo Pérez-Stable, Director, National Institute on Minority Health and Health Disparities, National Institutes of Health	 Advocate for federal policies that aim to minimize health disparities, such as policies that expand access to healthcare, improve healthcare coordination, and emphasize patient-centered medical care; Provide a resource for your constituency that lists affordable essential medications to avoid high prescription drug costs. 	CDC Health Insurance Coverage Data "Making Medicines Affordable: A National Imperative", National Academies of Sciences, Engineering, and Medicine
When value is the only goal in healthcare: Unintended racial disparities	Krisda H. Chaiyachati, Assistant Professor, University of Pennsylvania	 Support hospital investment in surrounding communities to minimize health disparities; Observe long-term impact of healthcare quality improvement programs for unintended consequences on health disparities. 	"Mapping Life Expectancy", Robert Wood Johnson Foundation Centers for Medicare & Medicaid Services' Readmissions Reduction Program "Time for Value-Based Payment Models to Adopt a Disparities-Sensitive Frame Shift"
Public Health Approaches to Eliminate Disparities in Infectious Disease	LaQuandra Nesbitt, Director, District of Columbia Department of Health	Advocate for cost-effective preventative healthcare programs that are aimed at reducing health disparities.	90/90/90/50 Plan: Ending the HIV Epidemic in the District of Columbia
How do we measure value in health care?	Gerard Anderson, Professor, Johns Hopkins Bloomberg School of Public Health	 Advocate for an investment in social services rather than in medical spending, to improve patient satisfaction and healthcare value. 	N/A
Consumer groups and perceived conflicts of interest	Cindy Pearson, Executive Director, National Women's Health Network	 Research the funding sources of consumer and patient health advocacy organizations and campaigns to assess potential bias; Advocate for health policy changes to address industry funding transparency; Be transparent about your organization's funding sources. 	Pre\$cription for Power PharmedOut Patients and Consumers Coalition

Table 2: Recommendations to consumer advocates by 2018 CUE Annual Meeting Workshop Hosts

Title of Workshop	Workshop Host(s)	Recommendations for CUE	Resources Recommended for Consumer Advocates
How to search on the internet for information about healthcare value and cost	Lori Rosman, Public Health Informationist, Johns Hopkins Medical Institutions Stella Seal, Associate Director, Health System and Community Services, Johns Hopkins Medical Institutions	Take advantage of free online account creation in publicly available databases to create personalized searches for healthcare value and other health-related information;	"Consumer Health Information FAQs"
Health economics 101 related to "value"	Darrell Gaskin, Professor, Johns Hopkins Bloomberg School of Public Health; Director, Johns Hopkins Center for Health Disparities Solutions	Provide information and guidance to your organization's constituency so that they may make an informed decision about their health insurance plans.	N/A
"Value" in drug prices: What are the challenges?	Gerard Anderson, Professor, Johns Hopkins Bloomberg School of Public Health	Provide information and guidance to your organization's constituency about how to advocate for better access to pharmaceuticals.	N/A

D. Summary of Conference Participant Evaluations

Participant evaluations and surveys provided feedback on the knowledge gained by participating in the Annual Membership Meeting as well as the participants' overall experience at the conference.

Each registrant was given an evaluation instrument (see Appendix E) in the folder received at the time of in-person registration, consisting mainly of questions measured on a five-point Likert scale. The evaluation instrument recorded scores for each speaker and session on a scale of 1 to 5 where 5 was the highest score. Mean respondent scores greater than '4' were considered to be 'positive'. Open-ended, short answer comments were also sought (see Appendix F).

Seventeen of twenty-seven attendees returned the evaluation; not all respondents answered all questions. Mean scores did not fall below '4' for any of the presentations. All speakers at the meeting were rated positively. Evaluation scores revealed that respondents were overwhelmingly positive about most sessions. Consumer discussants and workshops were all favorably rated (i.e., mean scores did not fall below '4') as well.

Open-ended comments were given by 10 out of 20 respondents, most of which were positive (see Tables 3 and 4). Participants expressed appreciation for the topic selection, networking opportunities, and energetic Q&A sessions. Suggestions referred to specific speakers or sessions, and requested increased discussion time. All feedback will be considered when planning future meetings.

Table 3: 2018 CUE Annual Meeting Evaluation—Text Response: Anticipated impact of meeting on respondents' work [Paraphrased]

Respondent	Comment
7	Made me think more about patient populations besides my own.
9	Enforce my motivation and expand our emphasis on evidence-based research and info.
12	Networking opportunities, resources, ideas for working with fellow activists
13	Understand the healthcare industry better, the problems and improvements being made.
18	Foundational knowledge re: health equity/disparities will be important in informing best practices.
19	There was some new and very useful information presented in the workshop with regards to seeking out and judging health information; this is useful in considering how the public sees and utilizes free healthcare resources.

Table 4: 2018 CUE Annual Meeting Evaluation—Text Response: Comments and Suggestions for Next Meeting [Paraphrased]

Respondent	Comment	
5	Excellent diversity in all panels. [Address] implicit bias/institutional racism in evidence-based care [and address] equity.	
7	Eye opening experience.	
12	[In regard to Workshop A:] Handouts were fabulous; thank you!	
13	It was nice to hear that the disparities of healthcare among minorities is improving and happy to see [that] CUE is trying to help.	

Respondent	Comment	
15	Good discussion on value, cost, sources of evidence. Good diversity of perspectives. Keep the level of speakers as high as this one. Good mix of academics, insurers, advocates.	
16	[In regard to Workshop C:] I would have liked him to tell us what we need to know. [In regard to meeting overall:] I liked the discussion time allotted. We need more economics and equity.	
19	I thought the conference was very well put together. I look forward to next year! One possible thing is that timing will always be an issue, but perhaps one fewer session would allow every other session an extra half hour for discussion or extended presentations.	
20	Construction noise next door was intrusive.	