2019 CUE Annual Membership Meeting: Applying Evidence and Action to Eliminate Health Disparities in Priority Populations

Consumers United for Evidence-based Healthcare (CUE)
June 21, 2019
8:00 am–3:30 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 June 21, 2019, CUE hosted its 16th Annual Membership Meeting, "Applying Evidence and Action to Eliminate Health Disparities in Priority Populations", 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 2019 meeting began in December 2018 as Committee members selected the theme to be sourcing and applying evidence to eliminate health disparities, in response to interests of CUE members. The event comprised two keynote presentations, two panel sessions, and two workshops. Each keynote speaker was allotted 15 or 30 minutes, each followed by a 5 minute consumer discussant and 20 minute discussion period. Each panel speaker was allotted 15 minutes each for her presentation with a 5 minute consumer discussant and 20 minute discussion period following the session. Discussion sessions allowed members of the audience to pose questions to specific speakers from a microphone. 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 health disparities and consumer advocacy (see Appendix B for Agenda). Dr. Cara James (Director, Office of Minority Health, Centers for Medicare & Medicaid Services) and Commander Karen Chaves (Director, National Healthcare Quality and Disparities Report Program, Agency for Healthcare Research and Quality) served as keynote speakers. Consumer discussants for keynote speakers included Tammy Boyd (Director of Health Policy, Black Women's Health Imperative) and Dr. Elliott Tolbert (CUE faculty). Full speaker biosketches can be found in Appendix C.

The first panel session allowed for a rich exchange of ideas and perspectives from federal policy and research. The panel session's topic, *"'State of the Union': A report on priority population health"*, included Dr. Chidinma Ibe (Assistant Professor of Medicine, Johns Hopkins Center for Health Equity) and Ms. Mia Keeys (Health Policy Advisor to Congresswoman Robin Kelly [D-IL]). Ms. Lisa Lang (Assistant Director, Health Services Research Information, National Library of Medicine) was slated to serve as a panelist but could not attend due to a last-minute emergency. The consumer discussant was Helen Haskell (President, Mothers Against Medical Error).

The workshops provided two interactive options for participants to engage and learn in a small group setting. Workshop I, titled, *"*Rules of engagement: Consumer engagement in guidelines*"*, was facilitated by Dr. Lorraine Nnacheta (Associate Guideline Advisor, American Heart Association/American College of Cardiology). Workshop II, titled *"*Communication strategies that work: Innovation in dissemination*"*, was facilitated by Ms. Jane Chang (Program Officer, Dissemination and Implementation, Patient-Centered Outcomes Research Institute [PCORI]).

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, Appendix C for biosketches). 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. Forty-three stakeholders attended the event (three 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/playlist?list=PLoNq5zvuX8j3OV5gSURA3bMHFtBuiHUTe.

It is because of the R13 Large Conference Grant (Grant # R13 HS26675-01) 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. Janice Bowie, Professor of Health, Behavior, and Society at Johns Hopkins University, provided a brief welcome and introduction to CUE and meeting hosts. Dr. Elliott Tolbert, Research Associate at Johns Hopkins University, highlighted CUE successes from the past year, such as CUE Clearinghouse matches and new funding sources. Genie Han, CUE Coordinator, briefly presented available CUE educational resources and how to access them. 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 #2019CUE (see Appendix D for Wakelet summary).

Introduction of Keynote Presentation I: Achieving health equity through increased understanding, sustainable solutions, and collective actions
Melissa Potter (moderator), Director of Patient Engagement and Outreach, LymeDisease.org

Melissa Potter introduced Dr. Cara James as the first keynote presentation of the day.

Keynote Presentation I: Achieving health equity through increased understanding, sustainable solutions, and collective actions
Cara James, PhD, Director, Office of Minority Health, Centers for Medicare & Medicaid Services

Dr. James opened the first keynote presentation by discussing the Centers for Medicare & Medicaid Services' (CMS) Office of Minority Services' health equity framework: (1) increase understanding and awareness of disparities, (2) develop sustainable solutions, and (3) take collective action. A recent report from CMS highlighted the racial and ethnic disparities that exist in Medical Advantage beneficiaries. For example, Hispanic beneficiaries received worse cares than White beneficiaries on 15 of the 35 CMS measures of patient experience and clinical care. CMS provides tools for the public to access more data on health and healthcare disparities, such as the Mapping Medicare Disparities (MMD) Tool.

In addition to race and ethnicity, there are other social risk factors for health and healthcare disparities including rurality and language. Dr. James noted that data gaps exist for certain risk factors, such as sexual orientation and gender identity. One of the six steps outlined in the CMS Equity Plan for Improving Quality in Medicare seeks to address this and other data gaps, by expanding the collection of standardized data. For example, CMS has proposed to collect standardized data on social determinants of health (e.g., preferred language, health literacy) from post-acute care providers.

In the following question-and-answer session, Dr. James addressed a wide variety of issues specific to meaningful consumer engagement, such as the importance of avoiding jargon and providing consumers with orientation materials. Dr. James also identified several health equity research areas that are gaining more attention: rurality, maternal mortality, polysubstance abuse, value-based care, and diabetes.

Discussant for Keynote Presentation I: Achieving health equity through increased understanding, sustainable solutions, and collective actions
Tammy Boyd, MPH, Director of Health Policy, Black Women's Health Imperative
Janice Bowie, PhD, MPH, Professor, Johns Hopkins Bloomberg School of Public Health

Ms. Boyd and Dr. Bowie jointly commented on Dr. James' presentation and guided the subsequent discussion. Dr. Bowie suggested that CUE member organizations should contribute to CMS policy and research through online comments or in-person listening sessions.

Introduction of Panel I: "State of the Union": A report on priority population health
Brenda Shelton-Dunston (moderator), MPH, Executive Director, Philadelphia Black Women's Health Alliance

Ms. Shelton-Dunston introduced panel members Dr. Chidinma Ibe and Ms. Mia Keeys.

Using stakeholder-engaged research to advance health equity: The RICH LIFE Project
Chidinma Ibe, PhD, Assistant Professor of Medicine, Johns Hopkins Center for Health Equity

Meaningful stakeholder engagement requires significant time commitment and effort from both the researcher and the stakeholder. Engagement may also take place at several different steps in the research process; for example, consumer stakeholder may be involved in developing measurement instruments and also in translating research findings to the community. Dr. Ibe presented lessons in stakeholder engagement from the Johns Hopkins Center for Health Equity's RICH LIFE Project (Reducing Inequities in Care of Hypertension: Lifestyle Improvement for Everyone), a patient-centered research study that has engaged health system leaders and community-based organization (CBO) stakeholders. Dr. Ibe noted four key principles of patient-centered outcomes research (PCOR):

1. Reciprocal relationships (e.g., Advisory Board co-leadership by a CBO and a researcher);
2. Co-learning (e.g., co-presentations at conferences by consumers and health system leaders);
3. Partnership (e.g., encouraging regular, frequent communication); and
4. Transparency (e.g., soliciting stakeholder feedback during each meeting).

It was especially important to acknowledge how researcher-consumer and researcher-health system leader dynamics were different, and to customize engagement accordingly. For example, Dr. Ibe recommended ceding control of discussions to consumer stakeholders during meetings, whereas health system leaders may benefit from health equity training opportunities.

Health policy and equity: A historical analysis
Mia Keeys, Health Policy Advisor to Congresswoman Robin Kelly (D-IL)

Ms. Keeys began her presentation by reflecting on how factors such as access to a hospital, environmental hazards, and grocery store proximity affected her quality of life and health outcomes when growing up. Health is determined not just by the summation of individual decisions, but also where individuals work and play. She encouraged audience members to recall how they were impacted by social determinants of health, and to use both scientific evidence and personal experience to influence health policymakers.

Starting with the 19th century Indian Removal Act, Ms. Keeys provided a timeline of United States health policy milestones that have shaped the policies that exist today. The most significant health policy milestone in the 21st century, the Affordable Care Act (ACA), expanded access to care and protected individuals with pre-existing health conditions. Ms. Keeys stressed that health policy should not only address the current state of health, but anticipate and address what will come in the future.

Discussant for Panel I: "State of the Union": A report on priority population health
Helen Haskell, President, Mothers Against Medical Error

Ms. Haskell is an experienced consumer stakeholder with a background on patient safety. Using both the RICH LIFE Project and health equity-promoting policy as examples, Ms. Haskell discussed the role of implicit bias as a barrier to receiving quality medical care.

Workshop I: Rules of engagement: Consumer engagement in guidelines
Lorraine Nnacheta, PhD, Associate Guideline Advisor, American Heart Association/American College of Cardiology

Dr. Nnacheta held an interactive roundtable discussion with CUE member organizations on the facilitators and barriers of consumer engagement in guidelines. Although the movement to include consumer stakeholders in guideline panels is growing, many health professional societies do not adopt this practice because of financial and time constraints. In her past and current roles with health professional societies, Dr. Nnacheta has used the CUE Clearinghouse to involve consumers in roles such as peer review and guideline panel participation. Meaningful consumer engagement requires training for both the panel chair and consumer stakeholder and an environment where all stakeholders feel comfortable contributing.

Consumer stakeholders are important to translate evidence synthesis into clinical change. When a guideline is prepared, it must be disseminated to patients to promote shared decision-making. Consumers can facilitate this by developing patient education resources such as one-page summaries in lay language.

Workshop II: Communication strategies that work: Innovation in dissemination
Jane Chang, Program Officer, Dissemination and Implementation, Patient-Centered Outcomes Research Institute (PCORI)

PCORI prioritizes dissemination of research findings so that end-users may receive health evidence in a timely manner. End-users include consumers, insurers, policymakers, and medical providers. Effective dissemination also promotes quicker uptake of research findings, which may translate into improved health outcomes.

PCORI utilizes a variety of dissemination methods. For example, PCORI produces two different research abstracts at the termination of every project: one for a public audience, and one for a professional audience. This ensures that end-users receive relevant information in an appropriate format. Ms. Chang notes that it can be difficult, for consumers and medical providers alike, to distill a systematic review into its main results and strength of evidence; PCORI aims to rectify this by translating findings into one-page evidence updates. Moreover, PCORI encourages open-access publication to ensure that a broader audience can access research findings.

Introduction of Keynote Presentation II: Developing evidence for eliminating health disparities at AHRQ
Ann Fonfa (moderator), CUE Steering Committee; President, Annie Appleseed Project

Ms. Fonfa introduced Commander Chaves, who directs the National Healthcare Quality and Disparities Report Program at the Agency for Healthcare Research and Quality.

Keynote Presentation II: Developing evidence for eliminating health disparities at AHRQ
Karen Chaves, Director, National Healthcare Quality and Disparities Report Program, Center for Quality Improvement and Patient Safety, Agency for Healthcare Research and Quality (AHRQ)

Cmdr. Chaves presented a three-pronged approach to addressing health disparities at AHRQ: (1) developing evidence; (2) synthesizing evidence; and (3) disseminating evidence; this framework is similar to that of the Centers for Medicare & Medicaid Services' health equity framework. Each step of this approach involves innovative techniques and strategic partnerships. For example, AHRQ has partnered with PCORI to create an unprecedented data platform combining data from several federal agencies; this evidence development provides researchers with the resources to study community-level social determinants of health.

AHRQ also funds the United States Preventive Task Force (USPSTF) and Evidence-based Practice Centers (EPC) to synthesize existing evidence on health disparities. Since 1998, USPSTF has operated as an independent all-volunteer group that develops recommendations for healthcare decision-making and identifies evidence gaps in research. USPSTF recommended that additional research is needed before recommending routine screening of social determinants of health in primary care settings. Specifically, there needs to be additional research on an accurate screening tool settings, a clear pathway for addressing identified social determinants, and evidence that accurate screening can improve health outcomes.

The final step of AHRQ's approach to addressing health disparities is dissemination. AHRQ is mandated by Congress to publish an annual National Healthcare Quality and Disparities Report, which summarizes research findings from federal health agencies and national data sources. The report additionally presents trends in health disparities over time.

Looking ahead, AHRQ is exploring innovative methods to improve health services research, such as data visualization tools and machine learning. Cmdr. Chaves encouraged CUE members to explore tools on the AHRQ website, including databases (e.g., State Snapshots) and evidence synthesis (e.g., EPC Reports).

Discussant for Keynote Presentation II: Developing evidence for eliminating health disparities at AHRQ
Elliott Tolbert, Research Associate, Johns Hopkins University

CUE member organizations rely on AHRQ as a reliable source of evidence in informing research priorities and policy. Dr. Tolbert thanked Cmdr. Chaves for her comprehensive overview of AHRQ's work in identifying and addressing health disparities in the United States.

Introduction of Panel II: Meaningful research engagement with priority populations
Janice Bowie (moderator), PhD, MPH, Professor, Johns Hopkins Bloomberg School of Public Health

Dr. Bowie noted the diversity of representation throughout the 2019 CUE Annual Meeting presentations before introducing the final panel of the day.

Research applications of centering Black mothers
Joia Crear-Perry, MD, FACOG, President, National Birth Equity Collaborative

Dr. Crear-Perry presented a sobering picture of maternal mortality in the United States. Maternal mortality rates have increased in the United States, and furthermore the gap in maternal mortality rates between black and white women has also increased. This surprising and unfortunate trend persists despite the fact that the United States is one of the highest health care spenders as percentage of GDP.

There needs to be a concerted effort by advocacy organizations, medical professionals, and policymakers to address the issue of maternal mortality and reduce the disparity in maternal mortality rates. Dr. Crear-Perry terms this as "birth equity", and believes that the disparity originates from the history of reproductive injustice in the United States. Dr. Crear-Perry highlighted successful consumer advocacy-driven partnerships and initiatives in promoting birth equity, such as the Mothers' Voices Driving Birth Equity and the New York City Standards for Respectful Care at Birth.

Engaging LGBT older adults in health research
Porsha Hall, MA, MPH, Director of Program Quality and Innovation, SAGE

The aging lesbian, gay, bisexual and transgender (LGBT) population is an under-researched group for two key reasons: they are disinclined to participate in research due to stigma and discrimination, and even when they do participate, they are rarely asked about sexual orientation and gender identity. Advocacy organizations and health professionals agree that the under-researched nature of LGBT older adults poses a health problem. For example, LGBT older adults are twice as more likely than heterosexual older adults to live alone, which may aggravate social isolation and worsen chronic conditions.

Ms. Hall suggests that the solution is to engage health advocacy organizations, such as SAGE, as research partners. Consumer health advocacy organizations ("consumer organizations"), particularly community-based ones, develop trust by directly serving their constituents. Researchers who partner with consumer organizations can therefore leverage the organization's established relationships to conduct patient-centered, community-relevant research. Consumer organizations are also equipped to effectively disseminate research findings. Ms. Hall notes that for LGBT older adults, Twitter is not an effective communication channel. Instead, SAGE uses targeted Facebook ads and flyers with diverse representation to attract interest.

Meaningful engagement in research: Learnings from PCORI's portfolio
Lisa Stewart, MA, Senior Engagement Officer, Public and Patient Engagement, Patient-Centered Outcomes Research Institute

PCORI is unique because they require all research studies to actively engage the stakeholders that the study is intended to benefit. Ms. Stewart notified CUE members that PCORI is currently conducting a scientific study on stakeholder engagement in their funded projects, with results projected in 2020. This study will help clarify what conditions are necessary for successful engagement practices.

In regard to priority population engagement in research, Ms. Stewart contends that it is mostly the same as non-priority population engagement—except that priority populations have a mistrust of research. One way that PCORI seeks to address this mistrust is by building learning networks between researchers and patients. For example, PCORI's Asthma Evidence to Action Network is an in-person meeting of patient partners and principal investigators involved in PCORI-funded asthma studies. Nine of the approximately thirty asthma studies are exclusively focused on improving health outcomes for African-Americans and Hispanics; Ms. Stewart added that the incidence of asthma is higher in African-American and Hispanic populations. Ms. Stewart encouraged CUE member organizations to access PCORI's engagement framework to further explore their possible involvement in PCORI-funded projects.

Discussant for Panel II: Meaningful research engagement with priority populations
Shaunice Wall, Linda Golodner Food Safety and Nutrition Fellow, National Consumers League

Ms. Wall discussed the importance of consumer engagement in research and policy while acknowledging that marginalized populations are justifiably wary of being engaged due to a history of mistreatment.

C. Summary of Recommendations Made in Presentations

2019 CUE Annual Meeting speakers and workshop hosts made recommendations for CUE, which will be addressed in 2020 (see Tables 1 and 2).

Table 1: Recommendations to consumer advocates by 2019 CUE Annual Meeting Speakers

Title of Talk	Speaker	Recommendations for CUE	Resources Recommended for Consumer Advocates
Achieving health equity through increased understanding, sustainable solutions, and collective actions	*Cara James, PhD, Director, Office of Minority Health, Centers for Medicare & Medicaid Services*	• Explore tools from the Centers for Medicare & Medicaid Services to develop evidence-based health equity perspectives; • Provide public comments on Notices of Proposed Rule Making (NPRM) for Centers for Medicare & Medicaid Services programs to ensure inclusion of the consumer voice.	Mapping Medicare Disparities (MMD) Tool CMS Equity Plan for Improving Quality in Medicine From Coverage to Care (C2C) Resources Chronic Care Management Resource CMS Office of Minority Health

Title of Talk	Speaker	Recommendations for CUE	Resources Recommended for Consumer Advocates
Using stakeholder-engaged research to advance health equity: The RICH LIFE project	*Chidinma Ibe, Assistant Professor of Medicine, Johns Hopkins Center for Health Equity*	• Participate in research (e.g., PCORI-funded studies) as consumer stakeholders and assert reciprocal relationships, co-learning, partnership, and transparency; • Ensure that consumer stakeholders are provided the space to provide feedback and contribute to discussions during meetings.	PCORI Engagement Resources
Health policy and equity: A historical analysis	*Mia Keeys, Health Policy Advisor to Congresswoman Robin Kelly (D-IL)*	• Use both personal experience and scientific evidence to convey an impactful perspective about health policy, especially when speaking to health policymakers.	N/A
Developing evidence for eliminating health disparities at AHRQ	*Karen Chaves, Director, National Healthcare Quality and Disparities Report Program, Center for Quality Improvement and Patient Safety, Agency for Healthcare Research and Quality (AHRQ)*	• Utilize tools and reports developed by AHRQ to develop an evidence-based understanding of health equity in the United States and identify evidence gaps.	Healthcare Cost and Utilization Project (HCUP) Medical Expenditure Panel Survey U.S. Preventive Services Task Force (USPSTF) Evidence-based Practice Center (EPC) Pathways to Prevention (P2P) Achieving Health Equity in Preventative Services: A Systematic Review National Healthcare Quality and Disparities Reports AHRQ State Snapshots
Research applications of centering Black mothers	*Joia Crear-Perry, President, National Birth Equity Collaborative*	• Familiarize yourself with the historical background of health inequity so that your organization can address its root causes.	Mothers' Voices Driving Birth Equity Birth Equity Index NYC Standards for Respectful Care at Birth

Title of Talk	Speaker	Recommendations for CUE	Resources Recommended for Consumer Advocates
			Setting the Standard for Holistic Care of and for Black Women
Engaging LGBT older adults in health research	*Porsha Hall, Director of Program Quality and Innovation, SAGE*	• Emphasize your organization's close relationship with its constituency so that researchers understand the value of partnering with your organization; • Acknowledge the barriers to engagement that exist if your organization serves a marginalized group, and develop creative methods to address them.	National Resource Center on LGBT Aging
Meaningful engagement in research: Learnings from PCORI's portfolio	*Lisa Stewart, Senior Engagement Officer, Public and Patient Engagement, PCORI*	• Recognize that priority populations have a mistrust of researchers that must be transparently addressed; • Participate in PCORI-funded projects, particularly those that address disparities, to involve the patient voice in equity-promoting research.	Asthma Evidence to Action Network PCORI Engagement Rubric

Table 2: Recommendations to consumer advocates by 2019 CUE Annual Meeting Workshop Hosts

Title of Workshop	Workshop Host(s)	Recommendations for CUE	Resources Recommended for Consumer Advocates
Rules of engagement: Consumer engagement in guidelines	*Lorraine Nnacheta, Associate Guideline Advisor, American Heart Association/American College of Cardiology*	• Take advantage of free evidence-based healthcare and advisory panel engagement trainings for consumer stakeholders; • Participate in clinical practice guideline panels to ensure the relevance of the guideline to patients.	CUE Education & Training
Communication strategies that work: Innovation in dissemination	*Jane Chang, Program Officer, Dissemination and Implementation, Patient-Centered Outcomes Research Institute (PCORI)*	• Develop a plan for dissemination of research findings to communities-of-interest by engaging community members.	PCORI Dissemination and Implementation Framework PCORI Evidence Maps

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.

Twenty-eight of 43 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 were all favorably rated (i.e., mean scores did not fall below '4') as well.

Open-ended comments were given by 22 out of 28 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 time management, and requested increased discussion time. All feedback will be considered when planning future meetings.

Table 3: 2019 CUE Annual Meeting Evaluation—Text Response: Anticipated impact of meeting on respondents' work [Paraphrased]

Respondent	Comment
1	Greater ability to network and incorporate consumer ideas into upcoming guideline discussions with my organization
2	Not sure yet
7	Not sure - more aware of other large consumer organizations
9	Greater awareness and hopefully, more emphasis on issues of health equity in orgs, community groups, and CUE organizations
10	Incredibly informational. Networking and so many resources (online and human!)
13	This will guide how I design and conduct research studies, as well as how I report the results. This will also affect how I speak to physicians
17	Great speakers. Got me thinking
18	I will continue to keep these issues in mind as I go into the medical field to address health disparities
20	Focus group information will be implemented with consumer dissemination of information
21	Continue to push in the areas we are strong and make improvements on the humanizing efforts to our constituents
23	This meeting opened my eyes regarding addressing my own potential bias as a researcher

24	It's helpful to get the names of organizations/people we could reach when we have further questions, or need a fuller perspective on a topic discussed
26	Presentations were revelatory to informing my research on maternal health
28	Refreshing to see so many committed individuals to move the ball further

Table 4: 2019 CUE Annual Meeting Evaluation—Text Response: Comments and Suggestions for Next Meeting [Paraphrased]

Respondent	Comment
1	Loved the conference. Excellent speakers, venue, and atmosphere. Loved the diversity of the panel as well
4	Love seeing so many women of color on the panels!! More of this please!!
6	Moderators needed to keep to time
7	Small breakout groups based on similar organizations/fields; time for discussions with consumer participants
7	[For Mia Keeys] Dynamic and great use of slides, focused on what participants should take away
7	[For Workshop I] Would prefer more discussion time
9	Not to pack the agenda; may need to change the day of the week to maximize participation
10	Great space, great food, great participation
13	More time for discussions
15	Longer day to allow for more discussion. Continue to bring diverse perspectives! (Loved the diversity)
17	Make moderators, speakers, and discussants stick to time allotment
18	This conference provided various insightful and diverse perspectives on health disparities! The speakers were really great and their presentations were interesting. In the future, I would provide more time for the workshops so that they can be more interactive
19	Wanted to learn more about structural/institutional racism, equity, legacy of racism/medical mistrust
20	Excellent conference!

Respondent	Comment
21	Timing - I think the information shared today was invaluable and I think added time would be beneficial (maybe only 10 min break outside of lunch) to allow more time for questions/discussion following the presentations
22	I think there was not enough time for discussions, which were the most interesting part of the day
23	More perspective from consumer advocates
24	Time-keeping needs improvement; thanks for the take-away materials
26	More time for questions
28	Full day; start later

CONSUMERS UNITED FOR EVIDENCE-BASED HEALTHCARE

2019 Member Organizations

Annie Appleseed Project 7319 Serrano Terrace Delray Beach, FL 33446-2215 www.annieappleseedproject.org Representative: Ann Fonfa, President (CUE Steering Committee) Email: annieappleseedpr@aol.com	**Association of Cancer Patient Educators** 18025 Sky Park Circle, Suite A Irvine, CA 92614 www.hopewellnesscenter.vpweb.com Representative: Sandra Finestone, Executive Director (CUE Steering Committee) Email: sandyfinestone@aol.com
Black Women's Health Alliance 1324 W. Clearfield Street Philadelphia, PA 19132 www.pbwha.org Representative: Brenda Shelton-Dunston, Executive Director (CUE Steering Committee) Email: bsdunston@blackwomenshealthproject.org	**Black Women's Health Imperative** 55 M Street SE, Suite 940 Washington, DC 20003 www.bwhi.org Representative: Tammy Boyd, Director of Health Policy and Legislative Affairs (CUE Steering Committee) Email: tboyd@bwhi.org
California Breast Cancer Organizations (CABCO) Phone: 530-304-2746 Representative: Sandy Walsh, President Email: sawalsh@prodigy.net	**Celiac Disease Foundation** 20350 Ventura Boulevard, Suite 240 Woodland Hills, CA 91364 www.celiac.org Representative: Marilyn G. Geller, CEO Email: marilyn.geller@celiac.org

2019 Member Organizations

Center for Science in the Public Interest 1220 L Street NW, Suite 300 Washington, D.C. 20005 www.cspinet.org Representative: Caitlin Dow, Senior Nutrition Scientist Email: cdow@cspinet.org	**Centering Healthcare Institute** 89 South Street, Suite 404 Boston, MA 02111 www.centeringhealthcare.org Representative: Angie Truesdale, CEO Email: atruesdale@centeringhealthcare.org
Cherab Foundation P.O. Box 8524 Port St. Lucie, FL 34952-8524 www.cherabfoundation.org Representative: Lisa Geng, President Email: lisa@cherab.org	**Children With Diabetes Foundation** 8216 Princeton-Glendale Road, PMB 200 West Chester, OH 25069-1675 www.cwdfoundation.org Representative: Sonia Chritton, Vice President, Research Email: sonia@soniachritton.com
Connecticut Center for Patient Safety 857 Post Road, Suite 220 Fairfield, CT 06824 www.CTCPS.org Representative: Lisa Freeman, Executive Director Email: lisa.freeman@ctcps.org	**Consumers Union** 101 Truman Avenue Yonkers, NY 10703 www.consumersunion.org Representative: Chuck Bell, Programs Director, Advocacy Email: cbell@consumer.org
Faces and Voices of Recovery 10 G Street NE, Suite 600 Washington, D.C. 20002 www.facesandvoicesofrecovery.org Representative: Deborah Garrett, Senior Project Coordinator Email: dgarrett@facesandvoicesofrecovery.org	**Families USA** 1201 New York Avenue NW, Suite 1100 Washington, D.C. 20005 www.familiesusa.org Representative: TBD

2019 Member Organizations

Hepatitis B Initiative of Washington, D.C. 1725 I Street NW, Suite 300 Washington, D.C. 20006 www.hbi-dc.org Representative: Jane Pan, Executive Director (CUE Advisory Board) Email: janepan@hbi-dc.org	**Homebirth Summit Consumer Engagement Task Force** BC Women's Hospital Shaughnessy Building 4500 Oak Street, Room E416A Vancouver, BC V6H 2N1, Canada www.homebirthsummit.org Representative: Lynsey Hamilton Email: lynsey.hamilton@ubc.ca
Lamaze International 2025 M Street NW, Suite 800 Washington, D.C. 20036 www.lamazeinternational.org Representative: Jeanne Mendelson, Chief Operations Manager Email: jmendelson@lamaze.org	**LymeDisease.org** (formerly California Lyme Disease Association) P.O. Box 716 San Ramon, CA 94583 www.lymedisease.org Representative: Lorraine Johnson, Executive Director (CUE Steering Committee) Email: lorrainejohnson@outlook.com
Maine Coalition to Fight Prostate Cancer 60 Western Avenue, Suite 254 Augusta, ME 04330 www.mcfpc.org Representative: Terry Kungel, President Email: tkungel@hughes.net	**MedShadow Foundation** 17 W. 67th Street, #PH-A New York, NY 10023 www.medshadow.org Representative: Suzzane Robotti, President Email: su@medshadow.org
Mothers Against Medical Error www.mamemomsonline.org/Home_Page.html Representative: Helen Haskell, President (CUE Steering Committee) Email: haskell.helen@gmail.com	**National Alliance for Caregiving** 4720 Montgomery Lane, Suite 205 Bethesda, MD 20814 www.caregiving.org Representative: Grace Whiting, President and CEO Email: grace@caregiving.org

2019 Member Organizations

National Breast Cancer Coalition 1101 17th Street NW, Suite 1300 Washington, D.C. 20036 www.stopbreastcancer.org Representative: Annette Bar-Cohen, Consultant Email: anat@bar-cohen.com	**National Center for Health Research** 1001 Connecticut Avenue NW, Suite 1100 Washington D.C. 20036 www.center4research.org Representative: Jack Mitchell, Director of Government Relations Email: jm@center4research.org
National Center for Transgender Equality 1133 19th Street NW, Suite 302 Washington, D.C. 20036 www.transequality.org Representative: Harper Jean Tobin, Policy Counsel Email: hjtobin@nctequality.org	**National Committee to Preserve Social Security and Medicare** 10 G Street NE, Suite 600 Washington, D.C. 20002 www.ncpssm.org Representative: William K. Vaughan, Member, Board of Directors (CUE Steering Committee) Email: wkvjee@hotmail.com
National Consumers League 1701 K Street NW, Suite 1200 Washington, D.C. 20006 www.nclnet.org Representative: Nissa Shaffi, Health Policy & Programs Associate email: nissas@nclnet.org	**National Council on Aging** 251 18th Street South, Suite 500 Arlington, VA 22202 www.ncoa.org Representative: TBD
National Environmental Education Foundation 4301 Connecticut Avenue NW, Suite 160 Washington, D.C. 20008 www.neefusa.org Representative: Vernessa Perry, Program Officer, Health & Wellness Email: vperry@neefusa.org	**National Mental Health Consumers' Self-Help Clearinghouse** 1211 Chestnut Street, Suite 1100 Philadelphia, PA 19107 http://mhselfhelp.org Representative: Susan Rogers, Executive Director Email: susan.rogers.advocacy@gmail.com

2019 Member Organizations

National Partnership for Women & Families 1875 Connecticut Avenue NW, Suite 650 Washington, D.C. 20009-5728 www.nationalpartnership.org Representative: Sarah Coombs, Health Policy Analyst Email: scoombs@nationalpartnership.org	**National Women's Health Network** 1413 K Street NW, 4th floor Washington, D.C. 20005 www.nwhn.org Representative: Sarah Christopherson, Policy Advocacy Director Email: schristopherson@nwhn.org
Nueva Vida 206 N. Washington Street, Suite 300 Alexandria, VA 22314 www.nueva-vida.org Representative: Laura Logie, Director of Research (CUE Advisory Board) Email: research@nueva-vida.org	**Our Bodies Ourselves** 5 Upland Road, Suite 3 Cambridge, MA 02140 www.ourbodiesourselves.org Representative: Judy Norsigian Email: judynorsigian@gmail.com
Ovarian Cancer Alliance of San Diego 1032 Isabella Avenue Coronado, CA 92118 www.ocaofsd.org Representative: Peg Ford, Founder and Chair Email: pegford2@hotmail.com	**Patient Safety America** www.patientsafetyamerica.com Representative: John T. James, CEO Email: john.t.james@earthlink.net
Philadelphia Ujima Drexel University College of Medicine 2900 Queen Lane, Room 239 Philadelphia, PA 19129 www.philadelphiaujima.com Representative: Ana Nuñez Email: ana.nunez@drexelmed.edu	**Rhode Island Breast Cancer Coalition** 2 Shoppers Park Coventry, RI 02816 www.breastcancerri.org Representative: TBD
SCAD Alliance P.O Box 4300 Alexandria, VA 22314 www.scadalliance.org Representative: Katherine Leon, Chair, Board of Directors Email: katherine.leon@scadalliance.org	**SafeMinds** 100 West Road, Suite 300 Baltimore, MD 21204 www.safeminds.org Representative: Jackie Lombardo, Board Member Email: jlombardo@safeminds.org

2019 Member Organizations

VHL Alliance 1208 VFW Parkway, Suite 303 Boston, MA 02132 www.vhl.org Representative: Ilene Sussman, Executive Director (ext. 4) Email: ilene.sussman@vhl.org	**TMJ Association** P.O. Box 26770 Milwaukee, WI 53226 www.tmj.org Representative: Terrie Cowley, Executive Director Email: info@tmj.org
Young Survival Coalition 61 Broadway Street, Suite 2235 New York, NY 10006 www.youngsurvival.org Representative: Stacy Lewis Email: slewis@youngsurvival.org	**Washington Advocates for Patient Safety** 3941 NE 158th Lane, Seattle, WA 98155 www.washingtonadvocatesforpatientsafety.org Representative: Yanling Yu, President Email: yy8@uw.edu

Agenda

Consumers United for Evidence-based Healthcare (CUE)
Annual Membership Meeting
Applying Evidence and Action to Eliminate Health Disparities in Priority Populations
Friday, June 21, 2019
8:00 am to 3:30 pm
Henry J. Kaiser Family Foundation, Washington DC 20005

8:00 am–8:30 am	**Registration & continental breakfast**
8:30 am–9:00 am	**Welcome and introductions** Janice Bowie, Professor, Johns Hopkins Bloomberg School of Public Health Genie Han, Coordinator, CUE; Senior Research Program Coordinator, Johns Hopkins Bloomberg School of Public Health
9:00 am–9:30 am	**Keynote I: Achieving health equity through increased understanding, sustainable solutions, and collective actions** Speaker: Cara James, Director, Office of Minority Health, Center for Medicare & Medicaid Services Moderator: Melissa Potter, Director of Patient Engagement & Outreach, LymeDisease.org
9:30 am–9:35 am	**Discussant:** Tammy Boyd, Director of Health Policy, Black Women's Health Imperative
9:35 am–9:55 am	**Discussion**
9:55 am–10:10 am	***Networking Break***
10:10 am–10:55 am	**Panel I: "State of the Union": A report on priority population health** Chair: Brenda Shelton-Dunston, Executive Director, Black Women's Health Alliance **Using stakeholder-engaged research to advance health equity: The RICH LIFE project** Panelist: Chidinma Ibe, Assistant Professor of Medicine, Johns Hopkins Center for Health Equity **Health policy and equity: A historical analysis** Panelist: Mia Keeys, Health Policy Advisor to Congresswoman Robin Kelly (D-IL)
10:55 am–11:00 am	**Discussant:** Helen Haskell, Mothers Against Medical Error
11:00 am–11:20 am	**Discussion**

11:20 am–12:05 pm	**Workshop I: Rules of engagement: Consumer engagement in guidelines** Lorraine Nnacheta, Associate Guideline Advisor, American Heart Association/American College of Cardiology **Workshop II: Communication strategies that work: Innovation in dissemination** Jane Chang, Program Officer, Dissemination and Implementation, Patient-Centered Outcomes Research Institute (PCORI)
12:05 pm–1:10 pm	**Lunch**
1:10 pm–1:25 pm	**Keynote II: Developing evidence for eliminating health disparities at AHRQ** Speaker: Karen Chaves, Director, National Healthcare Quality and Disparities Report Program, Center for Quality Improvement and Patient Safety, Agency for Healthcare Research and Quality (AHRQ) Moderator: Laura Logie, Director of Research, Nueva Vida
1:25 pm–1:30 pm	**Discussant:** Elliott Tolbert, Associate Scientist, Johns Hopkins Bloomberg School of Public Health
1:30 pm–1:50 pm	**Discussion**
1:50 pm–2:00 pm	***Networking Break***
2:00 pm–2:45 pm	**Panel II: Meaningful research engagement with priority populations** Chair: Janice Bowie, Johns Hopkins Bloomberg School of Public Health **Research applications of centering Black mothers** Panelist: Joia Crear-Perry, President, National Birth Equity Collaborative **Engaging LGBT older adults in health research** Panelist: Porsha Hall, Director of Program Quality and Innovation, Services & Advocacy for Gay, Lesbian, Bisexual & Transgender Elders (SAGE) **Meaningful engagement in research: Learnings from PCORI's portfolio** Panelist: Lisa Stewart, Senior Engagement Officer, Public and Patient Engagement, PCORI
2:45 pm–2:50 pm	**Discussant:** Shaunice Wall, Linda Golodner Food Safety and Nutrition Fellow, National Consumers League
2:50 pm–3:10 pm	**Discussion**
3:10 pm–3:30 pm	Closing remarks and **Evaluation**
3:30 pm	***Adjourn***

Biographical Sketches
Alphabetical by Last Name
Consumers United for Evidence-based Healthcare (CUE)
Annual Membership Meeting
Applying Evidence and Action to Eliminate Health Disparities in Priority Populations
Friday, June 21, 2019
8:00 am to 3:30 pm
Henry J. Kaiser Family Foundation, Washington DC 20005

* Keynote
† Panelist
§ Workshop host

§**Jane Chang, MPH**, is a Program Officer for the Dissemination and Implementation team at the Patient-Centered Outcomes Research Institute (PCORI). She plays a key role in developing and managing activities and initiatives around translation, public reporting, and targeted dissemination of PCORI-funded research findings. Before joining PCORI, Jane managed the Climate for Health program at ecoAmerica, where she worked on engaging national health leaders and institutions in order to elevate climate change as a visible health priority, build climate literacy, and collaborate for collective impact. Previously, she also led the National Environmental Education Foundation's environmental health programs, striving to improve the public's health through advanced environmental health knowledge, with an emphasis on children and underserved populations. Jane also spent several years as a part-time faculty member in Prevention and Community Health at George Washington University's Milken Institute School of Public Health. She received a BS in biology from the University of Maryland, Baltimore County and an MPH in community-oriented primary care from George Washington University.

†§**Joia Adele Crear-Perry, MD, FACOG,** is a thought leader around racism as a root cause of health inequities, Speaker, Trainer, Advocate, Policy Expert, and fighter for justice – is the Founder and President of the National Birth Equity Collaborative.

Recently, she addressed the United Nations Office of the High Commissioner for Human Rights to urge a human rights framework to improve maternal mortality. Previously, she served as the Executive Director of the Birthing Project, Director of Women's and Children's Services at Jefferson Community Healthcare Center and as the Director of Clinical Services for the City of New Orleans Health Department where she was responsible for four facilities that provided health care for the homeless, pediatric, WIC, and gynecologic services within the New Orleans clinical service area. Dr. Crear-Perry has been celebrated for her work to improve the availability and utilization of affordable health care for New Orleans' citizens post the Hurricane Katrina disaster of 2005. Currently, her focus has expanded nationally and internationally as it relates to Maternal and Child Health. Joia is most known for her work to remove Race as a risk factor for illness like premature birth and replacing it with Racism.

After receiving her bachelor's trainings at Princeton University and Xavier University, Dr. Crear-Perry completed her medical degree at Louisiana State University and her residency in Obstetrics and Gynecology at Tulane University's School of Medicine. She was also recognized as a Fellow of the American College of Obstetrics and Gynecology.

She is married to Dr. Andre Perry and has three children: Jade, Carlos, and Robeson. Her love is her family; health equity is her passion; maternal and child health are her callings.

†**Porsha Hall, MA, MPH**, is a health gerontologist and researcher who holds over 15 years of experience designing programs and initiatives to improve the health outcomes among marginalized groups of older adults. She is currently employed as the Director of Program Quality and Innovation at SAGE where she leads the design, implementation, and management of comprehensive strategies for measuring the effectiveness of SAGE's programs and services. She is pursuing a Doctorate in Health Education at Teachers College, Columbia University, and she holds a MPH in Community Health Education from Hunter College and a MA in Gerontology from Georgia State University.

*__CDR Karen Ho Chaves, MHS,__ is the Director of the National Healthcare Quality and Disparities Report Program at the Agency for Healthcare Research and Quality (AHRQ). Previously she was a Public Affairs Advisor at the Substance Abuse and Mental Health Services Administration (SAMHSA). She has been a United States Public Health Service Commissioned Corps officer since 2009 and is the Planning Section Chief of the USPHS Regional Incident Support Team for the National Capital Region (RIST-NCR). She is the Co-Chair of the Healthy Minds Initiative of the Asian Pacific American Officers Committee. She has served as the Health Policy Advisor at the White House Initiative on Asian Americans and Pacific Islanders. Prior to her federal service, she worked as a community advocate with the NICOS Chinese Health Coalition in San Francisco, California. Commander Chaves received her Master of Health Science in Health Policy at the Johns Hopkins School of Public Health and B.A. at University of California, Berkeley.

†**Chidinma Ibe, PhD,** is the Associate Director for Stakeholder Engagement at the Johns Hopkins Center for Health Equity and an Assistant Professor of Medicine in the Division of General Internal Medicine, at the Johns Hopkins University School of Medicine. She holds a joint appointment in the Department of Health, Behavior and Society at the Johns Hopkins Bloomberg School of Public Health. Dr. Ibe collaborates with patients, community members, and health system leaders to develop and evaluate community-based solutions for reducing hypertension disparities.

[*]**Cara V. James, PhD,** is the Director of the Centers for Medicare & Medicaid Services (CMS) Office of Minority Health (OMH), and co-chair of the CMS Rural Health Council. She is a nationally recognized expert in health disparities, health equity, and improving health outcomes for vulnerable populations. As the Director of the CMS OMH, Dr. James leads CMS's efforts to meet the unique needs of minority and underserved populations. Under her leadership, CMS OMH developed the first CMS Equity Plan to Improve Quality in Medicare, created an ongoing initiative to help individuals understand their coverage and connect to care, and strengthened the quality and increased the collection and reporting of demographic data. Dr. James is a member of the National Academy of Medicine (NAM) Roundtable on the Promotion of Health Equity and the Elimination of Health Disparities. Dr. James received her Ph.D. in Health Policy from Harvard University.

[†]**Mia Keeys, MA,** serves as the Policy Director of the Congressional Black Caucus Health Braintrust and as Health Policy Advisor to Congresswoman Robin Kelly (D-IL). Previously, Mia has been a Kaiser Family Foundation Barbara Jordan Health Policy Scholar; a Fellow for the City of Philadelphia in the Deputy Mayor's Office for Health and Opportunity; an HIV/AIDS researcher in South Africa; and a U.S. Fulbright Fellow to Indonesia, where she lived and worked for three years. The National Minority Quality Forum recognizes Mia as a 40 Under 40 Leader in Minority Health. The National Academy of Medicine featured Mia's children's book on health equity in their national exhibit, "Visualizing Health Equity".

Mia holds Bachelor of Arts degrees in English and Psychology from Cheyney University, and a Master of Arts degree in Medical Sociology from Vanderbilt University, where she was a Robert Wood Johnson Foundation Health Policy Fellow through Meharry Medical College. She is currently a doctoral student at The Milken Institute School of Public Health at The George Washington University. Mia is also a creative non-fiction writer, with training from the University of Oxford in the United Kingdom. She is originally from Philadelphia, PA.

[§]**Lorraine Nnacheta, MPH, DrPH,** received both her Master of Public Health and Doctor of Public Health degrees from Walden University in 2013 and 2019, respectively. She has over 15 years of progressive experience in various facets of the healthcare industry. Early work as an oncological clinical coordinator at Washington Hospital Center's Cancer Institute provided a strong background in understanding the consumer's perspective regarding participating in clinical trials and comprehending their treatment options. Work in health policy and research at both the Foundation for AIDS Research (amfAR) and the National Alliance of State and Territorial AIDS Directors (NASTAD) further encouraged an understanding of the role of consumer advocacy in the development of health policies and guidelines. Over the last 5.5 years at the American Academy of Otolaryngology, Head and Neck Surgery Foundation (AAO-HNSF), Dr. Nnacheta worked with various multi-disciplinary specialty organizations, and AAO-HNSF members, to develop numerous clinical practice guidelines, with topics ranging from Hoarseness (Dysphonia) and Allergic Rhinitis, to Tonsillectomy in Children and Meniere's Disease. Dr. Nnacheta currently serves as an Associate Guideline Advisor at the American Heart Association, where she oversees the development of various guideline products in the field of cardiology.

[†]**Lisa Stewart, MA,** is a Senior Engagement Officer at the Patient-Centered Outcomes Research Institute (PCORI). Her work involves monitoring engagement practices on PCORI-funded studies, exploring the influence and impacts of engagement on research, and promoting promising engagement practices through resource and curriculum development. Before joining PCORI, Lisa led patient and stakeholder teams as a co-investigator on patient-centered research studies. She began working in health systems as a patient/family navigator in pediatric care, working with families of children with complex medical conditions and serving as a consumer representative on quality improvement teams. She co-led Children's National Health System's Patient and Family Advisory Council and its Community Advisory Board, Clinical and Translational Science Institute.

2019 CUE Annual Membership Meeting

32 Items

Photos, tweets, and more from the 2019 CUE Annual Membership Meeting on June 21, 2019!

CUE
@United4Evidence

SAVE THE DATE: the CUE Annual Meeting will take place at the Barbara Jordan Conference Center in Washington DC, on Friday, June 21st! Huge thanks to @KaiserFamFound for the space, and @AHRQNews for funding! #2019CUE #EBHC #patientcentered

9:18 PM - Mar 8, 2019

See CUE's other Tweets

CUE @United4Evidence · May 2, 2019

#CUE2019 Annual meeting will be on Friday, June 21, 2019 @ Washington DC! CUE members, register today!: jhsph.co1.qualtrics.com/jfe/form/SV_4Z...

CUE
@United4Evidence

ONE MORE WEEK until #CUE2019! Looking forward to seeing everyone in DC at @KaiserFamFound! #EBHC #healthequity @BWHAphilly @NCPSSM @blkwomenshealth @Lymenews @hhask

6:43 PM - Jun 14, 2019

See CUE's other Tweets

HBI-DC
@HBIDC

Looking forward to attending #CUE2019 2019 CUE Annual Membership Meeting by @United4Evidence Applying Evidence and Action to Eliminate Health Disparities in Priority Populations

♡ 3 5:22 PM - Jun 19, 2019

See HBI-DC's other Tweets

HBI-DC
@HBIDC

#2019CUE @United4Evidence CUE Meeting is about to start

♡ 3 12:21 PM - Jun 21, 2019

See HBI-DC's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE CUE starting its annual meeting on Eliminating Health Disparities—can't wait!

♡ 2 12:34 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

The 2019 CUE Annual Membership Meeting has commenced! #2019CUE

♡ 3 12:49 PM - Jun 21, 2019

See CUE's other Tweets

Chidinma Ibe
@ChidinmaIbePhD

Great point made by Dr. Cara James at the #2019CUE Annual Meeting about how to build the business case for health disparities research...including the reality that moral persuasion is not enough. @United4Evidence

♡ 7 1:02 PM - Jun 21, 2019

See Chidinma Ibe's other Tweets

CUE
@United4Evidence

#2019CUE twitter.com/United4Evidenc...

> **CUE** @United4Evidence
> Dr. Cara James says Data matters because it helps with policy making. Ex: exempting of sickle cell patients from opioid use restriction using data that compares pain crisis to hospice patients

♡ 1 1:18 PM - Jun 21, 2019

See CUE's other Tweets

CUE
@United4Evidence

Dr. Bowie asks, Is there a role for consumers in CMS? Dr James responded that consumers can play a major role. However, she mentioned that it is helpful when consumers come in prepared. Also, diverse patients group are needed as same people tend to participate in CMS. #2019CUE

♡ 2 1:28 PM - Jun 21, 2019

See CUE's other Tweets

JH Health Equity
@JHhealthequity

Ditto the excitement! We're so pleased @JHhealthequity's @ChidinmaIbePhD will share successful approaches from the RICH Life Project when partnering with #healthsystems in Maryland + Pennsylvania. #HealthEquityVoices twitter.com/United4Evidenc…

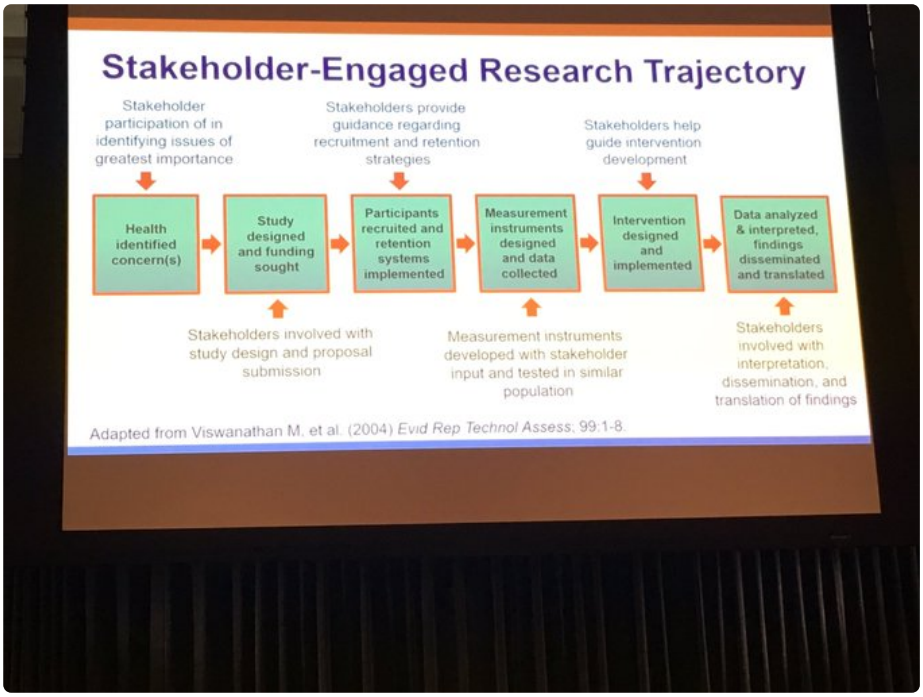
> **CUE** @United4Evidence
> So excited for the Annual Membership Meeting! #EBHC #healthdisparities #healthequity #2019CUE twitter.com/HBIDC/status/1…

♡ 8 1:36 PM - Jun 21, 2019

See JH Health Equity's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE great slide from Dr. Chidinma Ibe on where stakeholders can be involved in research



♡ 11 2:27 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

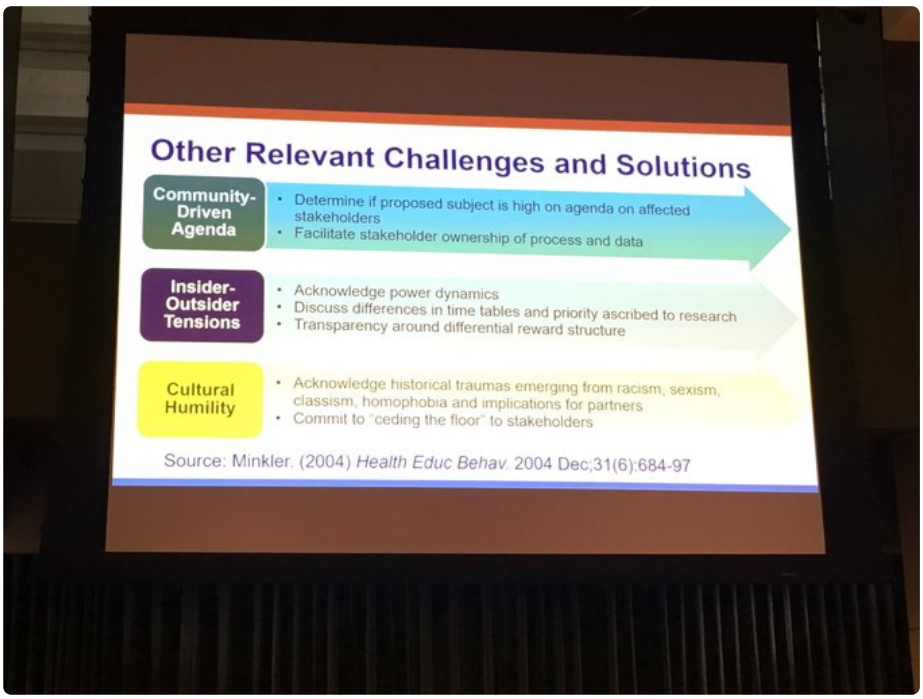
Dr. Ibe gives an overview of the RICH Life project (Reducing Inequities in Care of Hypertension: Lifestyle Improvement for Everyone) , a team that attempts to compare standard clinical performance and education for providers and staff to a more comprehensive approach #2019CUE

♡ 1 2:41 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

Challenges in stakeholder engagement abound! #2019CUE

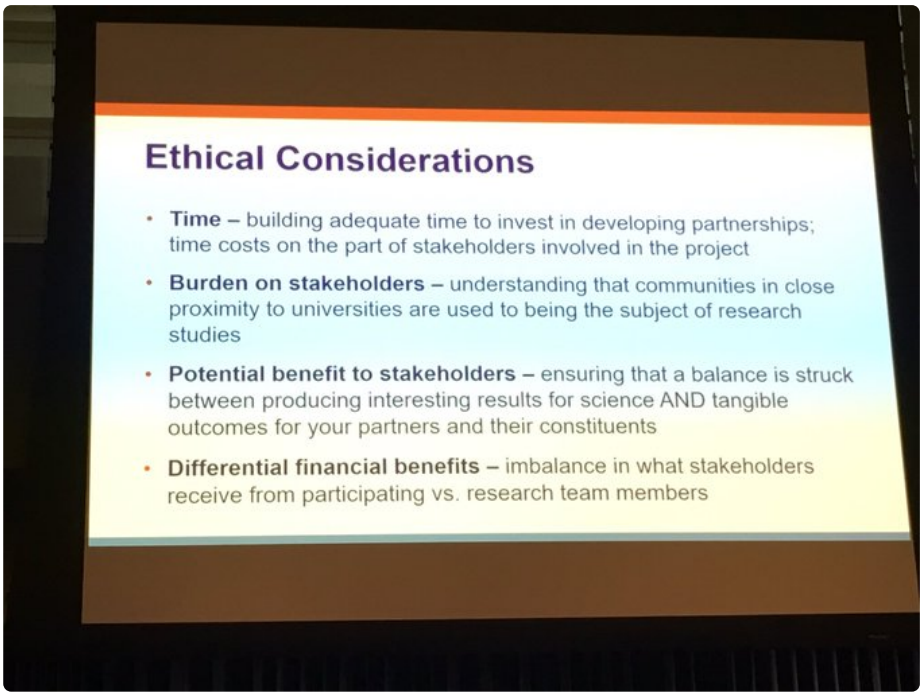


♡ 3 2:46 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

Kay Dickersin
@KayDickersin

Lots is forgotten about the burden put on stakeholders to participate! Resources needs more thought. #2019CUE



♡ 4 2:49 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

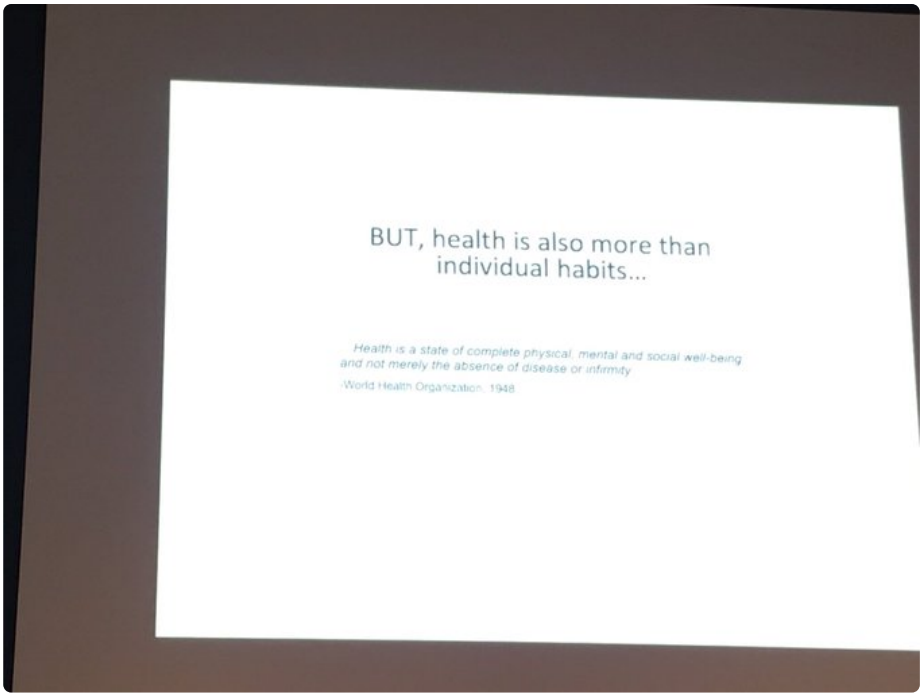
#2019CUE

2:49 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

Mia Keeys says that social determinants of health are more than the items usually on the list. Tell your story and translate it to policy. Did you walk to get your groceries? Did you have access to good food? Where did you get health care? Who decided this? #2019CUE

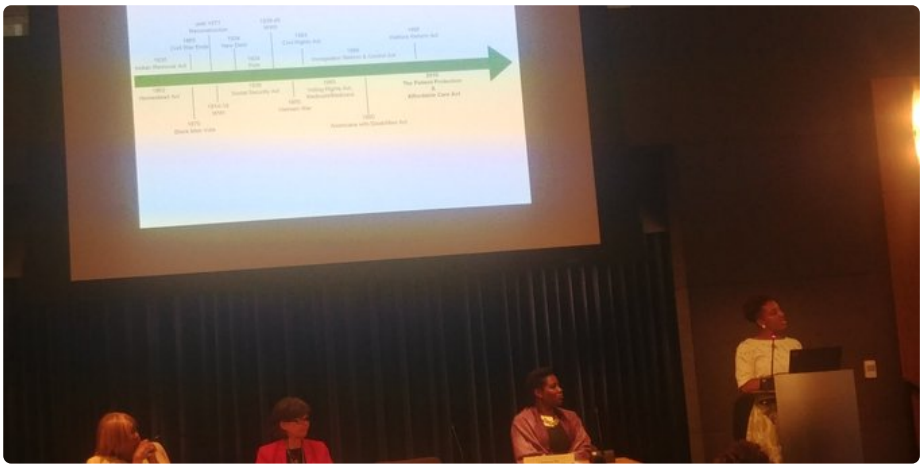


2 3:08 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

Mia Keyes highlights the importance of policy and how policies from the past still affects our lives today. #2019CUE

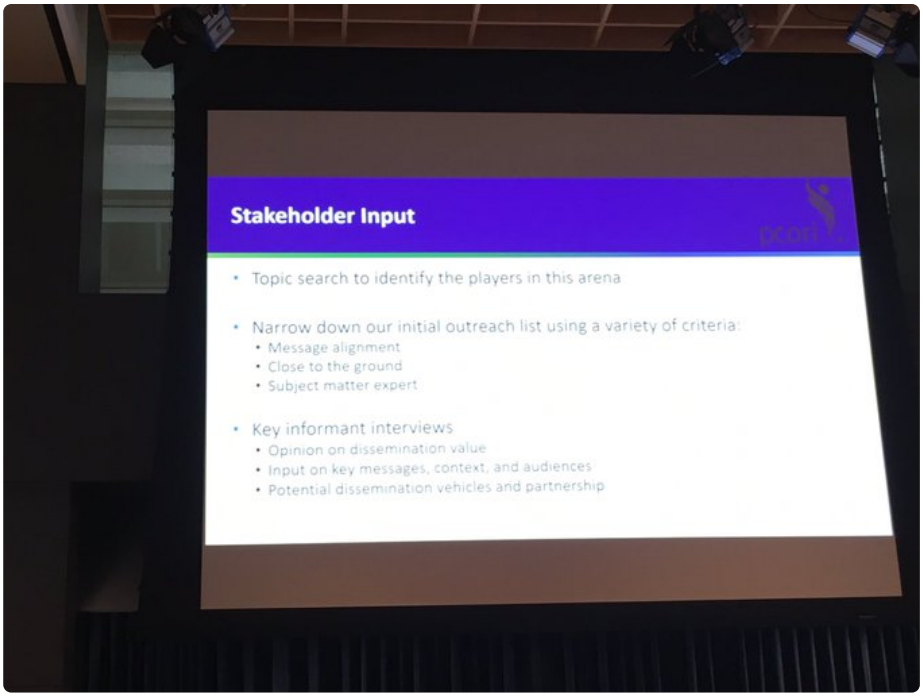


♡ 1 3:22 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

Jane Chang talks about how best to disseminate research results to get evidence into practice more quickly. #2019CUE

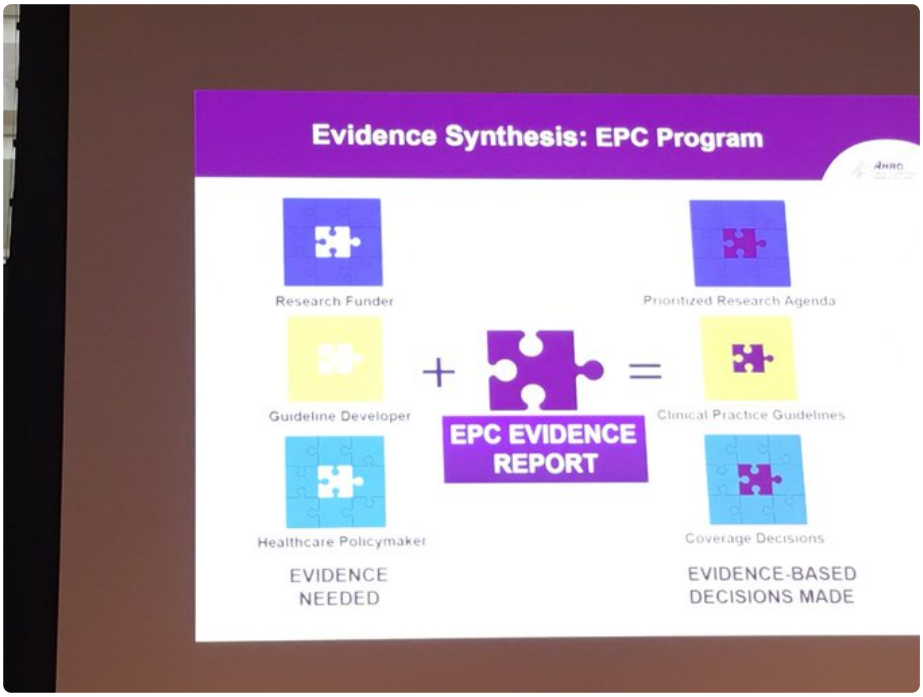


♡ 3 3:53 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE CMDR Karen Chavas reports how evidence (from the EPCs) fits into guidelines.



5:26 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

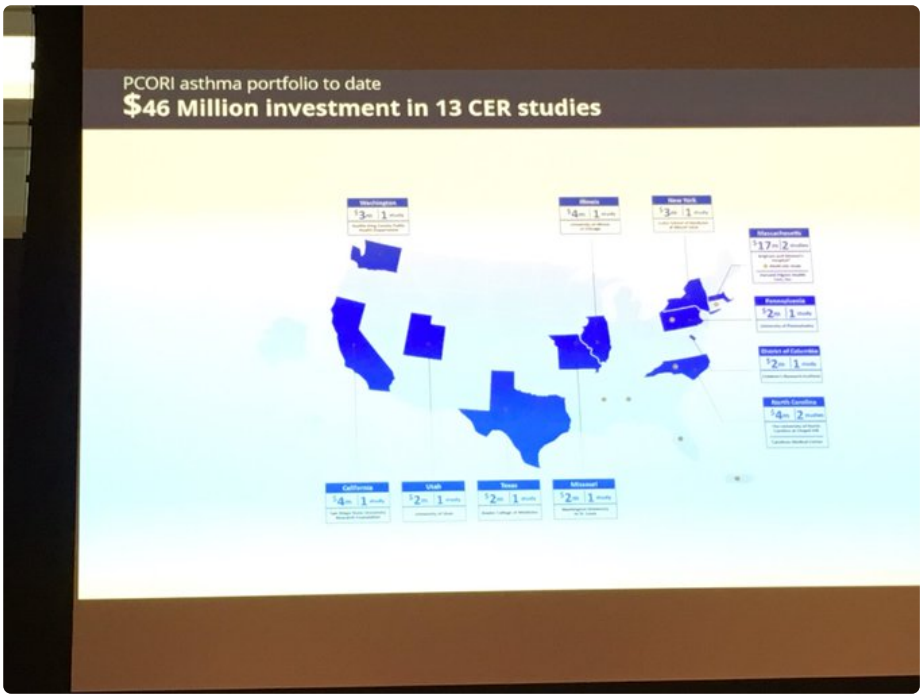
Lisa Stewart, senior engagement officer at PCORI, talks about how @PCORI engages stakeholders in its research. #2019CUE

1 6:16 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE PCORI funds $43m in asthma! About 13 studies. Rationale:10 people die from asthma every day in the US.



1 6:21 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

Different experiences, different perspectives. This is why minorities' perspectives are necessary in healthcare decision making-Lisa Stewart #2019CUE

6:30 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE Asthma: life is complex and there is A LOT going on. Consumers must be engaged in the research!! Picture on left is a cockroach in the spacer.

6:30 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

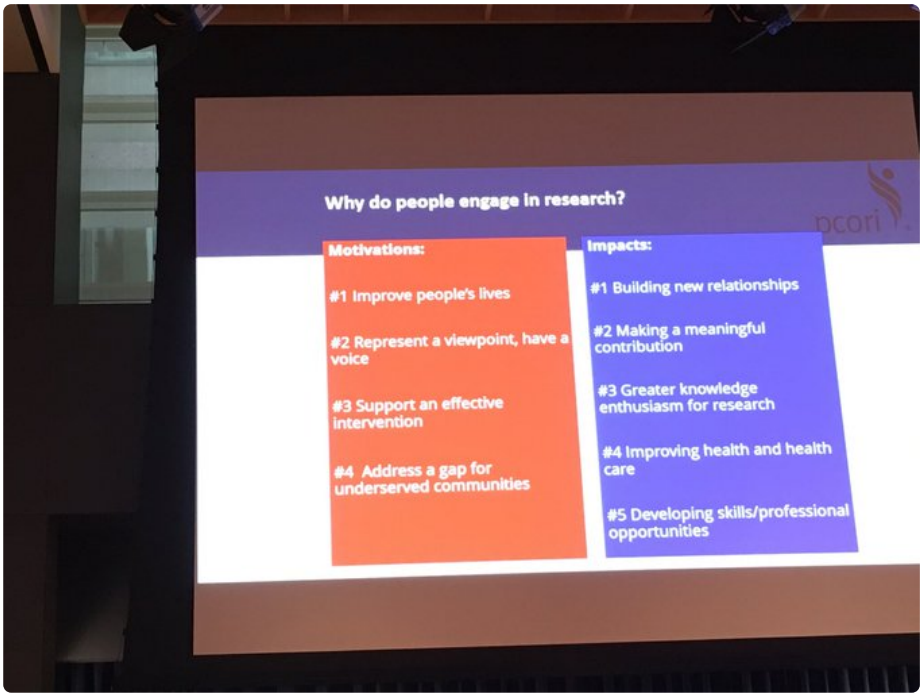
Different experiences, different perspectives. This is why minorities' perspectives are necessary in healthcare decision making-Lisa Stewart #2019CUE

6:30 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE many reasons to become engaged!



6:31 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

Porsha Hall gives a talk about the aging LGBT population and lack of research on this minority groups. The SAGE org. addresses some of the issues encoubtered by the LGBT comminity. #2019CUE

6:43 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

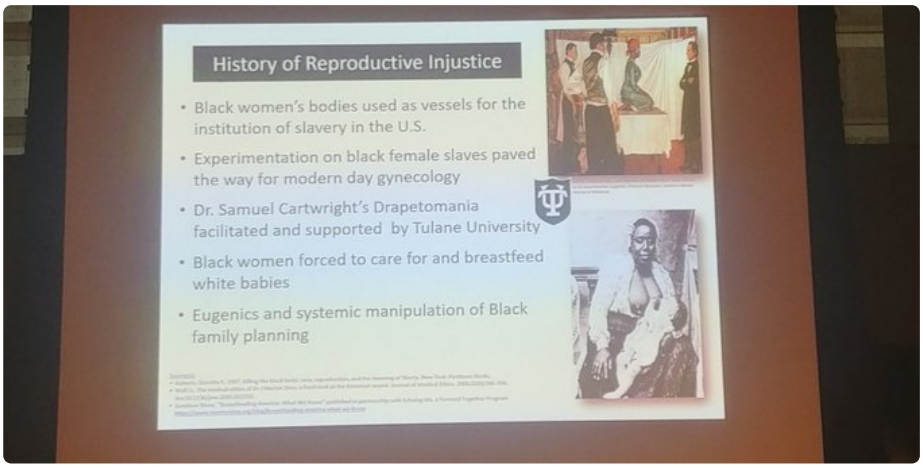
#2019CUE each person engages in research for a different reason,shares results differently, prefers different incentives.

♡ 2 6:49 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

CUE
@United4Evidence

The history of reproductive justice. #2019CUE

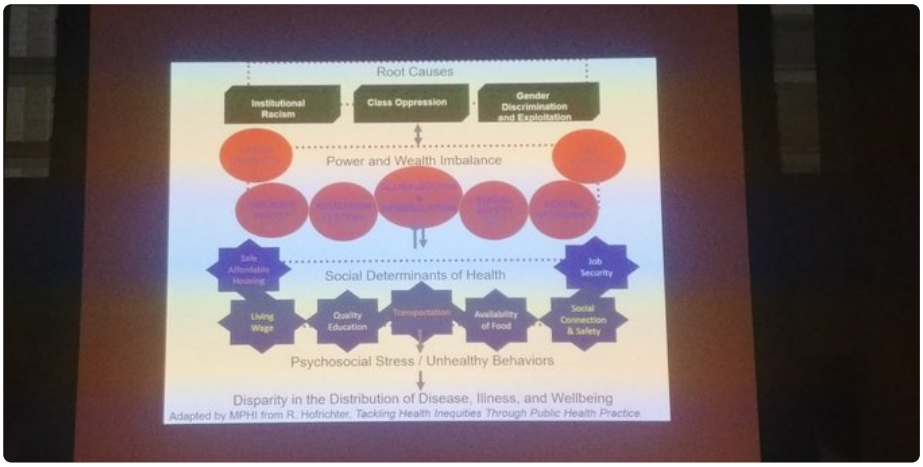


♡ 6:56 PM - Jun 21, 2019

See CUE's other Tweets

CUE
@United4Evidence

#2019CUE how did we get here?

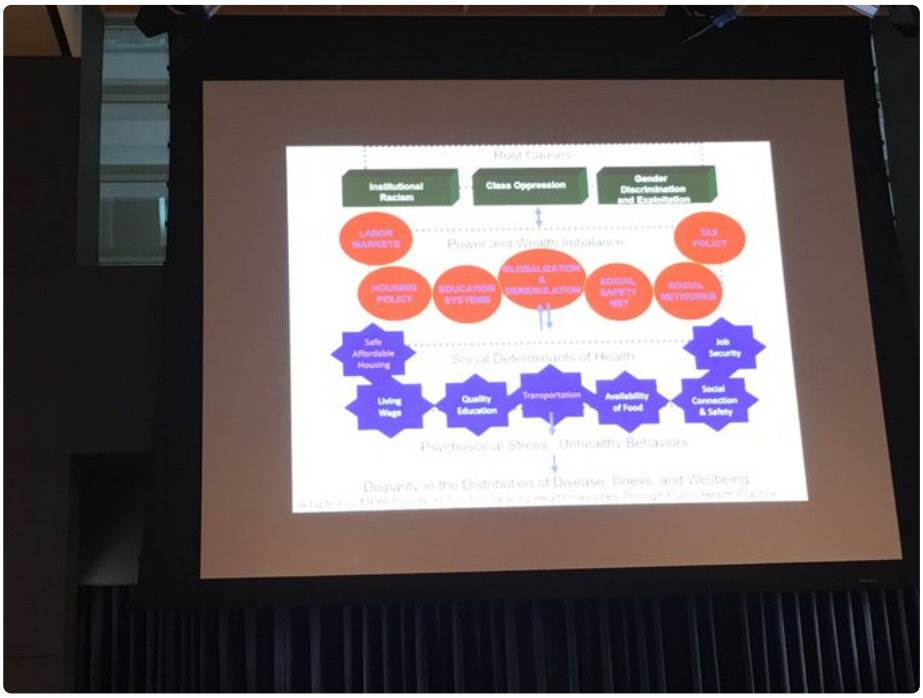


7:01 PM - Jun 21, 2019

See CUE's other Tweets

Kay Dickersin
@KayDickersin

#2019CUE Julia Crear-Perry presents a compelling case of reasons to achieve equity.



7:03 PM - Jun 21, 2019

See Kay Dickersin's other Tweets

Chidinma Ibe @ChidinmaIbePhD · Jun 21, 2019

Thank you so much for a wonderful conference, @United4Evidence. It was an honor to be a panelist at #2019CUE. Stakeholder-engaged research is but one way to restore justice in the research enterprise, which has been used to reinforce devastating, harmful racist ideologies. twitter.com/JHhealthequity…

> **JH Health Equity** @JHhealthequity
> Ditto the excitement! We're so pleased @JHhealthequity's @ChidinmaIbePhD will share successful approaches from the RICH Life Project when partnering with #healthsystems in Maryland + Pennsylvania. #HealthEquityVoices twitter.com/United4Evidenc…

Chidinma Ibe
@ChidinmaIbePhD

I am grateful for the opportunity to represent @JHhealthequity and the #RICHLIFE Project! Special shout-out to @LisaCooperMD, one of the study's Co-PIs, and @nataliespicyn, one of our wonderful partners! 🙌🏾

♡ 5 9:54 PM - Jun 21, 2019

See Chidinma Ibe's other Tweets

CUE
@United4Evidence

Missed #2019CUE? Here are some photos from our Annual Membership Meeting (and check back for mtg slidecasts)! Thank you SO much to our amazing funders, speakers, attendees & Steering Committee! #EBHC #healthequity @CMSGov @BWHAphilly @hhask @AHRQNews

♡ 2 5:01 PM - Jun 24, 2019

See CUE's other Tweets

CONSUMERS UNITED FOR EVIDENCE-BASED HEALTHCARE

2019 CUE Annual Membership Meeting
June 21, 2019
Evaluation

Please **DO NOT SEPARATE pages of this evaluation

1. Please select one of the following:

☐ I am a guest or a speaker (not a CUE member)

☐ I am attending on behalf of a CUE member organization

☐ I am Johns Hopkins staff

2. Achieving health equity through increased understanding, sustainable solutions, and collective actions

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate presentation time allotted	5	4	3	2	1
Adequate discussion time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by speaker					
Cara James	5	4	3	2	1
C. Quality of presentation by discussant					
Tammy Boyd	5	4	3	2	1

3. "State of the Union": A report on priority population health

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate presentation time allotted	5	4	3	2	1
Adequate discussion time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by speaker					
Chidinma Ibe	5	4	3	2	1
~~Lisa Lang~~	~~5~~	~~4~~	~~3~~	~~2~~	~~1~~
Mia Keeys	5	4	3	2	1
D. Quality of presentation by discussant					
Helen Haskell	5	4	3	2	1

4. Breakout Workshop Session

Workshop I: Rules of engagement: Consumer engagement in guidelines

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by workshop host					
Lorraine Nnacheta	5	4	3	2	1

Workshop II: Communication strategies that work: Innovation in dissemination

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by workshop host					
Jane Chang	5	4	3	2	1

Workshop III: Identifying funding opportunities

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by workshop host					
Joia Crear-Perry	5	4	3	2	1

5.

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate presentation time allotted	5	4	3	2	1
Adequate discussion time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by speaker					
Karen Chaves	5	4	3	2	1
C. Quality of presentation by discussant					
Elliott Tolbert	5	4	3	2	1

6. Meaningful research engagement with priority populations

☐ I did not attend this session

	Excellent	Very Good	Good	Fair	Poor
A. Quality of session					
Informative content	5	4	3	2	1
Adequate presentation time allotted	5	4	3	2	1
Adequate discussion time allotted	5	4	3	2	1
Questions answered to satisfaction	5	4	3	2	1
Overall	5	4	3	2	1
B. Quality of presentation by speaker					
Joia Crear-Perry	5	4	3	2	1
Porsha Hall	5	4	3	2	1
Lisa Stewart	5	4	3	2	1
E. Quality of presentation by discussant					
Shaunice Wall	5	4	3	2	1

Overall Evaluation

	Yes	No	Not Certain
1. The program was presented without evident commercial bias or influence.	☐	☐	☐
2. The program met my expectations.	☐	☐	☐
3. Moderators kept sessions on time.	☐	☐	☐

4. What impact, if any, do you think this meeting will have on your work? _____

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5. Please provide comments or suggestions for future conferences: _____

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