

PI: <b>DICKERSIN, KAY</b>	Title: AHRQ Conference Grant Program (R13)	
Received: 04/30/2015	FOA: PA13-017	Council: 01/2016
Competition ID: FORMS-C	FOA Title: AHRQ CONFERENCE GRANT PROGRAM (R13)	
<b>1 R13 HS024461-01</b>	Dual:	Accession Number: 3817871
IPF: 4134401	Organization: JOHNS HOPKINS UNIVERSITY	
Former Number:	Department: CLINICAL TRIALS	
IRG/SRG: HEOR	AIDS: N	Expedited: N
Subtotal Direct Costs (excludes consortium F&A) Year 1: 35,000 Year 2: 34,999 Year 3: 34,999	Animals: N Humans: N Clinical Trial: N Current HS Code: 10 HESC: N	New Investigator: N Early Stage Investigator: N
<i>Senior/Key Personnel:</i>		
<i>Organization:</i>		
<i>Role Category:</i>		
Kay Dickersin	Johns Hopkins University	PD/PI

*Appendices*

m-7\_phs\_researchplan\_appendi

*Additions for Review*

Supplemental Material

Dickersin email

No additional sources sought.

Updated Pages

Dickersin composite budget

Applicant was given the opportunity to provide a composite budget detailing additional funding requested. Applicant email indicates no other outside funding sources have been contacted.

APPLICATION FOR FEDERAL ASSISTANCE  
**SF 424 (R&R)**

<b>3. DATE RECEIVED BY STATE</b>		<b>State Application Identifier</b> MD: Maryland
<b>1. TYPE OF SUBMISSION*</b>		<b>4.a. Federal Identifier</b>
<input type="radio"/> Pre-application <input checked="" type="radio"/> Application <input type="radio"/> Changed/Corrected Application		<b>b. Agency Routing Number</b>
<b>2. DATE SUBMITTED</b> 2015-04-30	<b>Application Identifier</b> 00071953	<b>c. Previous Grants.gov Tracking Number</b>
<b>5. APPLICANT INFORMATION</b>		<b>Organizational DUNS*:</b> 001910777
Legal Name*: Johns Hopkins University Department: CLINICAL TRIALS Division: BLOOMBERG SCHOOL OF PUBLIC HEA Street1*: Bloomberg School of Public Health Street2: 615 N. Wolfe Street, Suite W1600 City*: Baltimore County: State*: MD: Maryland Province: Country*: USA: UNITED STATES ZIP / Postal Code*: 21205-2103		
Person to be contacted on matters involving this application Prefix:      First Name*: Anthony      Middle Name: Edward      Last Name*: Jenkins      Suffix: Position/Title: Sr. Grants & Contracts Associate Street1*: 615 N Wolfe St W1600 Street2: 615 N Wolfe St W1600 City*: Baltimore County: State*: MD: Maryland Province: Country*: USA: UNITED STATES ZIP / Postal Code*: 21205-2103 Phone Number*: 4106141856      Fax Number: 4109550258      Email: ajenki29@johnshopkins.edu		
<b>6. EMPLOYER IDENTIFICATION NUMBER (EIN) or (TIN)*</b>		1520595110A5
<b>7. TYPE OF APPLICANT*</b>		O: Private Institution of Higher Education
Other (Specify): <input checked="" type="radio"/> <b>Small Business Organization Type</b> <input type="radio"/> Women Owned <input type="radio"/> Socially and Economically Disadvantaged		
<b>8. TYPE OF APPLICATION*</b>		If Revision, mark appropriate box(es).
<input checked="" type="radio"/> New <input type="radio"/> Resubmission <input type="radio"/> Renewal <input type="radio"/> Continuation <input type="radio"/> Revision		<input type="radio"/> A. Increase Award <input type="radio"/> B. Decrease Award <input type="radio"/> C. Increase Duration <input type="radio"/> D. Decrease Duration <input type="radio"/> E. Other (specify) :
<b>Is this application being submitted to other agencies?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No      What other Agencies?		
<b>9. NAME OF FEDERAL AGENCY*</b> AGENCY FOR HEALTHCARE		<b>10. CATALOG OF FEDERAL DOMESTIC ASSISTANCE NUMBER</b> 93226 TITLE: AHRQ Conference Grant Program (R13)
<b>11. DESCRIPTIVE TITLE OF APPLICANT'S PROJECT*</b> AHRQ Conference Grant Program (R13)		
<b>12. PROPOSED PROJECT</b>		<b>13. CONGRESSIONAL DISTRICTS OF APPLICANT</b>
Start Date* 04/01/2016	Ending Date* 03/31/2019	MD-007

**14. PROJECT DIRECTOR/PRINCIPAL INVESTIGATOR CONTACT INFORMATION**

Prefix: First Name\*: Kay Middle Name: Last Name\*: Dickersin Suffix:  
 Position/Title: Professor  
 Organization Name\*: Johns Hopkins University  
 Department: CLINICAL TRIALS  
 Division: BLOOMBERG SCHOOL OF PUBLIC HEA  
 Street1\*: 625 Wolfe St  
 Street2:  
 City\*: Baltimore  
 County:  
 State\*: MD: Maryland  
 Province:  
 Country\*: USA: UNITED STATES  
 ZIP / Postal Code\*: 21205-2103  
 Phone Number\*: 4105024421 Fax Number: Email\*: kdicker3@johnshopkins.edu

**15. ESTIMATED PROJECT FUNDING**

a. Total Federal Funds Requested\* \$104,997.81  
 b. Total Non-Federal Funds\* \$0.00  
 c. Total Federal & Non-Federal Funds\* \$104,997.81  
 d. Estimated Program Income\* \$0.00

**16. IS APPLICATION SUBJECT TO REVIEW BY STATE EXECUTIVE ORDER 12372 PROCESS?\***

- a. YES  THIS PREAPPLICATION/APPLICATION WAS MADE AVAILABLE TO THE STATE EXECUTIVE ORDER 12372 PROCESS FOR REVIEW ON:  
 DATE:  
 b. NO  PROGRAM IS NOT COVERED BY E.O. 12372; OR  
 PROGRAM HAS NOT BEEN SELECTED BY STATE FOR REVIEW

**17. By signing this application, I certify (1) to the statements contained in the list of certifications\* and (2) that the statements herein are true, complete and accurate to the best of my knowledge. I also provide the required assurances \* and agree to comply with any resulting terms if I accept an award. I am aware that any false, fictitious, or fraudulent statements or claims may subject me to criminal, civil, or administrative penalties. (U.S. Code, Title 18, Section 1001)**

I agree\*

\* The list of certifications and assurances, or an Internet site where you may obtain this list, is contained in the announcement or agency specific instructions.

**18. SFLL or OTHER EXPLANATORY DOCUMENTATION**

File Name:

**19. AUTHORIZED REPRESENTATIVE**

Prefix: First Name\*: Jennifer Middle Name: Last Name\*: Hopkins Suffix:  
 Position/Title\*: Grants Associate  
 Organization Name\*: Johns Hopkins University  
 Department: ASSOC DEAN RESEARCH/PERSONNEL  
 Division:  
 Street1\*:  
 Street2: 615 N Wolfe St W1600  
 City\*: Baltimore  
 County:  
 State\*: MD: Maryland  
 Province:  
 Country\*: USA: UNITED STATES  
 ZIP / Postal Code\*: 21205-2103  
 Phone Number\*: 4105020093 Fax Number: 4109550258 Email\*: jtrento1@johnshopkins.edu

**Signature of Authorized Representative\***

Hopkins, Jennifer

**Date Signed\***

04/30/2015

**20. PRE-APPLICATION** File Name:**21. COVER LETTER ATTACHMENT** File Name: M-9\_RRSF424\_Cover\_Letter.pdf

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**Appendix**

*Number of Attachments in Appendix: 1*

## Project/Performance Site Location(s)

### Project/Performance Site Primary Location

I am submitting an application as an individual, and not on behalf of a company, state, local or tribal government, academia, or other type of organization.

Organization Name: Johns Hopkins University  
Duns Number: 001910777  
Street1\*: Bloomberg School of Public Health  
Street2: 615 N. Wolfe Street, Suite W1600  
City\*: Baltimore  
County:  
State\*: MD: Maryland  
Province:  
Country\*: USA: UNITED STATES  
Zip / Postal Code\*: 21205-2103  
Project/Performance Site Congressional District\*: MD-007

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File Name

### Additional Location(s)

## RESEARCH & RELATED Other Project Information

<b>1. Are Human Subjects Involved?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No	
1.a. If YES to Human Subjects Is the Project Exempt from Federal regulations? <input type="radio"/> Yes <input type="radio"/> No If YES, check appropriate exemption number:        — 1 — 2 — 3 — 4 — 5 — 6 If NO, is the IRB review Pending? <input type="radio"/> Yes <input type="radio"/> No IRB Approval Date: Human Subject Assurance Number	
<b>2. Are Vertebrate Animals Used?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No	
2.a. If YES to Vertebrate Animals Is the IACUC review Pending? <input type="radio"/> Yes <input type="radio"/> No IACUC Approval Date: Animal Welfare Assurance Number	
<b>3. Is proprietary/privileged information included in the application?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No	
<b>4.a. Does this project have an actual or potential impact - positive or negative - on the environment?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No	
4.b. If yes, please explain: 4.c. If this project has an actual or potential impact on the environment, has an exemption been authorized or an environmental assessment (EA) or environmental impact statement (EIS) been performed? <input type="radio"/> Yes <input type="radio"/> No 4.d. If yes, please explain:	
<b>5. Is the research performance site designated, or eligible to be designated, as a historic place?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No	
5.a. If yes, please explain:	
<b>6. Does this project involve activities outside the United States or partnership with international collaborators?*</b> <input type="radio"/> Yes <input checked="" type="radio"/> No	
6.a. If yes, identify countries: 6.b. Optional Explanation:	
<b>7. Project Summary/Abstract*</b>	Filename M-4_Project_Summary.pdf
<b>8. Project Narrative*</b>	M-3_Narrative.pdf
<b>9. Bibliography &amp; References Cited</b>	M-12_Bibliography_and_References_Cit d.pdf
<b>10. Facilities &amp; Other Resources</b>	M-8_Facilities.pdf
<b>11. Equipment</b>	

## Abstract

*Our objective is to host a series of in-person conferences in 2016, 2017, and 2018, in which evidence-based information and tools are summarized, communicated and used by patient and consumer organizations and individuals with the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services.*

Consumers United for Evidence-based Healthcare (CUE), founded in 2003 and supported by AHRQ since its start, will host the proposed annual meetings to build capacity among consumer health groups; present opportunities for consumers' scientist partners to learn more about them; and establish relationship-building opportunities among stakeholders. CUE's accomplishments since its founding have made the group an recognized leader in consumer and patient engagement in evidence-based healthcare (EBHC). The United States Cochrane Center (USCC) will provide the lead scientific partnership and staffing to coordinate the meeting.

We are requesting a project period of 3 years to support the same conferences on an annual basis, sponsored by CUE, a permanently sponsoring organization. Our proposal includes in 2016, 2017, and 2018: (1) Monthly CUE Steering Group teleconferences; (2) three CUE Steering Group Meetings in Washington, DC; (3) three day-long Annual CUE Membership Meetings in Washington, DC; (4) three workshops presented at the annual Cochrane Colloquia.

The target audience will be health consumer groups interested integrating in their advocacy activities into EBHC. The day-long Membership Meeting will comprise didactic sessions, workshops, and discussion, with networking time set aside. Conference materials will be disseminated via slide casts of plenary sessions onto the CUE website and social networking tools (e.g., live tweeting during the event), both engaging external audiences. Consumer target groups include the many priority populations with which CUE engages. Dissemination and implementation will be assessed twice annually by survey.

We aim to (1) build on CUE's established momentum to extend the capacity of US-based consumer advocates; (2) increase collaboration and partnerships among the growing number of CUE member organizations and healthcare scientists; (3) provide online and in-person education on up-to-date topic areas related to EBHC; (4) provide a forum for communication and methodological consultation on how to incorporate research evidence into consumer activities; (5) contribute to improving the quality of healthcare; and (6) increase awareness of, involvement in, and contribution to the principles of EBHC among US consumers.

## **Narrative Summary**

*Our objective is to host a series of in-person conferences in 2016, 2017, and 2018, in which research findings and evidence-based information and tools are summarized, communicated and used by consumer organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services.* With the demand for consumer engagement in research increasing, Consumers United for Evidence-Based Healthcare's (CUE's) leadership will contribute uniquely to the public health sector, with an increased understanding among all stakeholder groups of patient-important issues, informed advocacy, and scientist-consumer partnerships.

## **Facilities & Other Resources**

### **Department of Epidemiology**

Established in 1919, the Department of Epidemiology is located in the Johns Hopkins Bloomberg School of Public Health, and has had a longstanding commitment to high quality education and research. Dr. David Celantano is Department Chair. The Department is organized into the following nine programs: Aging, Cancer, Cardiovascular Disease, Clinical, Clinical Trials, General, Human Genetics, Infectious Disease; and Occupational and Environmental Epidemiology.

The Department of Epidemiology has 754 primary faculty members, over 200 students and 262 full-time staff. Epidemiology faculty members offer more than 76 courses in the School of Public Health, and publish more than 230 research articles per year in peer-reviewed journals. The Department administers approximately 273 projects; a large fraction of these are NIH grants and multi-center collaborative studies. The Department occupies several locations throughout the Johns Hopkins East Baltimore Campus.

All faculty have an office that includes state of the art computing, Internet, and email programs as well as office and data analysis software as needed. Faculty offices are situated to provide efficient communication.

### **The Center for Clinical Trials**

The Center for Clinical Trials (CCT) was founded in 1990 as a collaborative effort of faculty from the Johns Hopkins School of Medicine and the Bloomberg School of Public Health. Its main function is to serve as the hub of academic activities related to clinical trials in the Department of Epidemiology. Collectively, the faculty have as their core purpose guiding and inspiring research, scholarship and intellectual engagement, in the Johns Hopkins Community and globally, in the areas of clinical trials and evidence-based healthcare. Faculty in the Center participate in teaching and research collaborations locally, nationally, and worldwide. Dr. Kay Dickersin, Professor of Epidemiology, was appointed Director of the Center for Clinical Trials in 2005.

The clinical trials concentration in the Department of Epidemiology's doctoral program is overseen by the CCT. Educational offerings include formal courses, seminars, journal clubs, and "hands-on" experience for students interested in clinical trials.

Faculty in the Center for Clinical Trials are involved in numerous research projects. All have leadership experience in the coordination, design, conduct and analysis of large, multicenter, randomized clinical trials. All have also conducted methodological research related to clinical trials and systematic reviews. A core groups of CCT faculty have also served in key roles in the area of evidence-based healthcare, including the Agency for Healthcare Research and Quality (AHCPR/AHRQ) guidelines projects, the Patient Outcomes Research Teams (PORTs), and Evidence-based Practice Centers (EPCs). The US Cochrane Center and Cochrane Eyes and Vision Group Satellite are located in the CCT. Research projects have

been funded by various agencies within the National Institutes of Health, AHRQ, the American Lung Association, Robert Wood Johnson Foundation, and commercial organizations.

Faculty in the Center have an excellent history in meeting contract objectives within both time and cost schedules. There is no record of cost overruns or non-delivery of contracted goods/ services on any of the contracts or grants administered by the Center.

Faculty and staff associated with the Center for Clinical Trials conduct research across two locations, Wolfe Street (5,521 square feet) and Ann Street (9,382 square feet). Within the Wolfe Street space, the Cochrane Collaboration group occupies 1,251 square feet. Photocopying facilities available to the Cochrane staff include a large office copier “in house” and the Department of Epidemiology’s two copiers.

### **The United States Cochrane Center**

The United States Cochrane Center (USCC) is based in the CCT, one of 14 international centers that support the Cochrane Collaboration, an international not-for-profit organization that aims to help people make well-informed decisions about healthcare. It produces and disseminates systematic reviews of healthcare interventions and promotes the search for evidence in the form of clinical trials and other studies of interventions. Cochrane reviews are regularly updated and available electronically on *The Cochrane Library*, published by John Wiley and Sons. The USCC was awarded a large conference grant (08/03/07-12/31/10) from AHRQ to fund the development of training and support programs to increase awareness and involvement of clinicians, researchers, and consumers in the work of the Cochrane Collaboration. The USCC was also most recently awarded a large 3-year conference grant (08/12 – 12/15) to support the Annual Membership Meeting and a workshop series related to Consumers United for Evidence-based Healthcare (CUE). The grant provided a 50% CUE Coordinator, two Annual Membership Meetings for members and one Consumer Summit.

Cochrane Eyes and Vision Group (CEVG) is one of 52 Cochrane review groups, and aims to prepare, maintain and promote access to systematic reviews of interventions used to prevent or treat eye diseases and/or visual impairment, and interventions that help people adjust to visual impairment. CEVG members are coordinated and supported by the editorial base at the London School of Hygiene & Tropical Medicine in London, UK, as well as the US satellite base at Johns Hopkins (CEVG@US). CEVG@US is funded by the National Eye Institute of the National Institutes of Health. The overall objective of the CEVG@US is to develop a critical mass of US-based vision researchers and practitioners who are trained in preparing and using systematic reviews in the practice of evidence-based healthcare.

### **William H. Welch Medical Library**

The William H. Welch Medical Library provides resources that support teaching, research, and patient care at the Johns Hopkins Medical Institutions. Since 2001, Welch has been organizing library services around the all-digital collection of the future, creating state-of-the-art interfaces to these collections and redefining the role of librarians who support the digital collection. WelchWeb at [welch.jhu.edu](http://welch.jhu.edu) provides online access to a rich array of electronic informational resources, including more than 300 databases, 3600 online journals, and 500 e-

books. The Welch Library offers liaison services and classes on basic computing applications, including searching on-line databases and scientific writing. The print collection contains more than 400,000 volumes and subscriptions to 1,100 journals.

A number of “touchdown suites”, [welch.jhu.edu/about/will\\_touchdown.pdf](http://welch.jhu.edu/about/will_touchdown.pdf), are being created in locations such as Oncology and the Population Center ([poplibrary.jhmi.edu](http://poplibrary.jhmi.edu)) to provide a range of library services and digital resources supporting teaching research and patient care.

The Welch library also operates satellite libraries. The largest, the Lilienfield Library in the Bloomberg School of Public Health is the primary resource for information in public health, management science and social services. Other satellite libraries are located in the Meyer Building and the School of Nursing.

Located in the Welch Library, the Institute of the History of Medicine houses a collection of 50,000 volumes and 80 current journals. It is one of the most comprehensive collections of secondary literature in the history of medicine.

## RESEARCH &amp; RELATED Senior/Key Person Profile (Expanded)

PROFILE - Project Director/Principal Investigator				
Prefix:	First Name*: Kay	Middle Name	Last Name*: Dickersin	Suffix:
Position/Title*:	Professor			
Organization Name*:	Johns Hopkins University			
Department:	EPIDEMIOLOGY			
Division:	BLOOMBERG SCHOOL OF PUBLIC HE			
Street1*:	625 Wolfe St			
Street2:				
City*:	Baltimore			
County:				
State*:	MD: Maryland			
Province:				
Country*:	USA: UNITED STATES			
Zip / Postal Code*:	21205-2103			
Phone Number*:	4105024421	Fax Number:	E-Mail*: kdicker3@johnshopkins.edu	
Credential, e.g., agency login: KDICKER3				
Project Role*: PD/PI			Other Project Role Category:	
Degree Type: Doctor of Philosophy			Degree Year: 1989	
Attach Biographical Sketch*:			File Name	
Attach Current & Pending Support:			ID-00001709_BN-1_BIOSKETCH pdf	

Principal Investigator/Program Director (Last, First, Middle): Dickersin. Kay

**BIOGRAPHICAL SKETCH**

Provide the following information for the key personnel and other significant contributors in the order listed on Form Page 2.  
Follow this format for each person. **DO NOT EXCEED FOUR PAGES.**

NAME Kay Dickersin, Ph.D.		POSITION TITLE Professor	
eRA COMMONS USER NAME kdicker3			
EDUCATION/TRAINING (Begin with baccalaureate or other initial professional education, such as			
INSTITUTION AND LOCATION	DEGREE (if applicable)	YEAR(s)	FIELD OF STUDY
University of California, Berkeley	BA	June 1974	Zoology
University of California, Berkeley	MA	Dec.1975	Zoology (cell biology)
Johns Hopkins School of Hygiene and Public Health, Baltimore	Ph.D.	May 1989	Epidemiology

**A. Personal Statement**

I founded Consumers United for Evidence-based Healthcare (CUE), a partnership with health and consumer advocacy organizations, in 2003. The organization is organized around the concept that consumer groups would benefit from a focal point for educational networking and dissemination of information, if they are to have meaningful impact on comparative effectiveness research (CER) and evidence-based healthcare. Funding from AHRQ has made CUE's impressive growth possible. My work with CUE nicely aligns with my longstanding interests in and contributions to both CER and public engagement in CER. I have worked for many years to develop educational programs for consumers partnering in the research process, including development 15 years ago of the original curriculum for the National Breast Cancer Coalition's Project LEAD. More recently, I co-developed an online course for consumer advocates, Understanding Evidence-based Healthcare, funded by AHRQ. My research spans both the practicalities of conducting CER and the methodological challenges. I have served on the Institute of Medicine's Committees on Comparative Effectiveness Research Prioritization, Reviewing Evidence to Identify Highly Effective Clinical Services, and the Committee on Standards for Systematic Reviews of Comparative Effectiveness Research, all of which emphasized the importance of consumer engagement in the CER process.

**B. Positions and Honors****Faculty positions:**

1989 – 1992	Assistant Professor, Department of Ophthalmology, University of Maryland (UMAB) School of Medicine; joint appointment Department of Epidemiology & Preventive Medicine
1992 – 1998	Assistant Professor (1992-1996); Associate Professor (1996-1998), Department of Epidemiology & Preventive Medicine, University of Maryland School of Medicine; joint appointment Department of Ophthalmology
1993 – present	Director, Baltimore Cochrane Center (1991-1998); Co-Director, New England Cochrane Center (1998-2003); Director, U S Cochrane Center (2003-present)
1998 – 2005	Associate Professor (1998-2002); Professor (2002-2005), Medical Science, Department of Community Health, Brown University
2005 - present	Professor, Department Epidemiology, Johns Hopkins Bloomberg School of Public Health

Principal Investigator/Program Director (Last, First, Middle): Dickersin. Kay

**Editorial positions (selected):**

Editorial Advisory Board *BMJ* (2006 – 2012)  
 Advisory Group *Trials* (2005 – present)  
 Associate Editor *Clinical Trials, J Society Clinical Trials* (2003 – 2012); *Controlled Clinical Trials* (1992-1999)  
 Epidemiology Advisor *BioMed Central* (2001 – present)  
 Associate Editor *Health Expectations* (1997- present)  
 Associate Editor *BMC Women's Midlife Health* (2013 – present).

**Federal advisory committees (selected):**

1994- 2000 National Cancer Advisory Board (NCAB) (appointed by President Clinton).  
 1997- 2012 National Cancer Institute, PDQ Screening and Prevention Advisory Committee  
 2004– 2010 Task Force on Community Services, Centers for Disease Control and Prevention

**HONORS/AFFILIATIONS (MEMBERSHIP OR LEADERSHIP POSITIONS)**

1999 Elected to membership, American Epidemiological Society.  
 2006 Elected to membership, Society for Research Synthesis Methods.  
 2007 Elected to membership, Institute of Medicine.  
 2011 Elected Fellow, Society for Clinical Trials.  
 2013 Valkhov Chair, Radboud University Medical Center, Nijmegen, Netherlands.

**Awards**

1971 Howard Hughes Fellowship in Medical Research, Harvard Medical School.  
 1980 - 1981 Public Health Traineeship, Johns Hopkins University, School of Hygiene and Public Health.  
 1981 Selected for Student Workshop, Society for Epidemiology Research.  
 1993 - 1997 Frohlich Fellowship, New York Academy of Sciences.  
 1994 "Woman of Excellence," National Association of Women Business Owners, Baltimore Regional Chapter.  
 1995 Ellen Barnett Memorial Award, Susan G. Komen Foundation Race for the Cure.  
 1996 Women's Hall of Fame, Baltimore City Commission for Women.  
 1998, 2006 "Maryland's Top 100 Women," Daily Record.  
 1998 MAMM magazine's "50 Who Made a Difference."  
 2000 "Exceptional Advocate," National Breast Cancer Coalition.  
 2007 "Contributions and Enduring Commitment to the Eradication of Cancer," American Assoc. Cancer Research.  
 2009, 2013 Johns Hopkins Bloomberg Sch. Public Health Student Assembly, Advising, Mentoring, Teaching Recognition Award (AMTRA).  
 2014 Ingram Olkin Award, from the Society for Research Synthesis Methods for lifetime contributions to the field.

**Named lectureships**

1995 Archie Cochrane Memorial Lecture, Society for Social Medicine, UK.  
 2010 Ruysch Lecture Academic Medical Center of the University of Amsterdam. Amsterdam, The Netherlands.  
 2013 Valkhof Lecture. Radboud University Nijmegen Medical Centre. Nijmegen, The Netherlands.  
 2013 EQUATOR Lecture. Chicago, Illinois.

Principal Investigator/Program Director (Last, First, Middle): Dickersin. Kay

**C. Selected peer-reviewed publications****Publications most relevant to the current application****Journal articles**

1. **Dickersin K**, Schnaper L. Reinventing medical research. In: Moss K (ed). *Man-Made Medicine: Women's Health, Public Policy and Reform*. Durham: Duke University Press, 1996.
2. Wells J, Marshall P, Crawley B, **Dickersin K**. Newspaper reporting of screening mammography. *Ann Intern Med* 135:1029-1037, 2001.
3. **Dickersin K**, Braun L, Mead M, Millikan R, Wu AM, Pietenpol J, Troyan S, Anderson B, Visco F. Development and implementation of a science training course for breast cancer activists: Project LEAD (Leadership, Education and Advocacy Development). *Health Expectations* 4:213-220, 2001.
4. Andejaski Y, Bisceglia IT, **Dickersin K**, Johnson JE, Robinson SI, Smith HS, Visco FM, Rich I. Quantitative impact of including consumers in the scientific review of breast cancer research proposals. *J Womens Health Gender Based Med* 11:379-388, 2002.
5. Andejaski Y, Breslau ES, Hart E, Lythcott N, Alexander L, Rich I, Bisceglia I, Smith HS, Visco FM, and **the US Army Medical Research and Materiel Command Fiscal Year 1995 Breast Cancer Research Program Integration Panel**. Benefits and drawbacks of including consumer reviewers in the scientific merit review of breast cancer research. *J Womens Health Gender Based Med* 11:119-136, 2002.
6. **Dickersin K**, Munro MG, Clark MA, et al, the STOP-DUB (Surgical Treatments Outcomes Project for Dysfunctional Uterine Bleeding) Research Group. Results of a randomized trial comparing hysterectomy and endometrial ablation for dysfunctional uterine bleeding. *Obstet Gynecol* 110:1279-89, 2007.
7. Gibbons MC, Wilson RF, Samal L, Lehmann CU, **Dickersin K**, Lehmann HP et al. Impact of Consumer Health Informatics Applications. *Evidence Report/Technology Assessment* Number 188; 2009.
8. Frick KF, Clark MA, Steinwachs DM, Langenberg P, Stoval D, Munro MG, **Dickersin K**, and The STOP DUB Research Group. Financial and quality-of-life burden of dysfunctional uterine bleeding among women agreeing to obtain surgical treatment. *Women's Health Issues*. 19:70-78, 2009.
9. Li T, Vedula S, Scherer R, **Dickersin K**. What comparative research is needed? A framework for using guidelines and systematic reviews to identify evidence gaps and research priorities. *Ann Intern Med* 156:367-377, 2012.
10. Kreis J, Puhan MA, Schünemann HJ, **Dickersin K**. Consumer involvement in systematic reviews of comparative effectiveness research. *Health Expect* doi: 10.1111/j.1369-7625.2011.00722.x. [Epub ahead of print], 2012.
11. Li T, Hutfless S, Scharfstein DO, Daniels MJ, Hogan JW, Little RJ, Roy JA, Law AH, Dickersin K. Standards should be applied in the prevention and handling of missing data for patient-centered outcomes research: a systematic review and expert consensus. *J Clin Epidemiol*. 2014; 7(1):15-32. doi: 10.1016/j.jclinepi.2013.08.013. PMID: 24262770.
12. Chan AW, Tetzlaff JM, Altman DG, Laupacis A, Gøtzsche PC, Krleža-Jeric K, Hróbjartsson A, Mann H, **Dickersin K**, Berlin JA, Doré CJ, Parulekar WR, Summerskill WS, Groves T, Schulz KF, Sox HC, Rockhold FW, Rennie D, Moher D. SPIRIT 2013 statement: Defining standard protocol items for clinical trials. *Ann Intern Med*. 158:200-7, 2013.

**Book Chapters/Monographs**

13. **Committee on Reviewing Evidence to Identify Highly Effective Clinical Services**. Institute of Medicine. *Knowing What Works in Health Care. A Roadmap for the Nation*. Washington, DC: The National Academies Press, 2008.
14. **Committee on Comparative Effectiveness Research Prioritization**. Institute of Medicine. *Initial Priorities for Comparative Effectiveness Research*. Washington, DC: The National Academies Press, 2009.
15. **Committee on Standards for Systematic Reviews of Comparative Effectiveness Research**. Eden J, Levit L, Berg A, Morton S (eds). *Finding What Works in Health Care: Standards for Systematic Reviews*. Institute of Medicine of the National Academies. Washington, DC: National Academies Press, 2011.

Principal Investigator/Program Director (Last, First, Middle): Dickersin. Kay

#### **D. Ongoing Research Support (most relevant)**

##### **Cochrane Eyes and Vision Group, Coordinating Resource Center**

U01EY020522 K. Dickersin (PI) 2010 – 2017

NIH/National Eye Institute

The major goal of this project is to develop a critical mass of U.S.-based vision researchers and practitioners who are trained in preparing and using systematic reviews.

##### **Consumers United for Evidence-based Healthcare: Building Capacity and Engagement**

R13HS021596 K. Dickersin (PI) 2013-2016

AHRQ

CUE, Consumers United for Evidence-based Healthcare, and The United States Cochrane Center (USCC) will host a series of in-person and online meetings in 2013, 2014, and 2015, related to comparative effectiveness, health information technology (health IT), patient safety, and other emerging areas. Our aim is to build capacity within health consumer advocacy groups; to educate and inform; and to establish relationship-building opportunities among stakeholders.

##### **Integrating Multiple Data Sources for Meta-analysis to Improve Patient-centered Outcomes**

No number assigned K. Dickersin (PI) 2013-2015

PCORI

We will explore the reliability and validity of incorporating data from multiple data sources for two specific cases and to produce open access guidance about using multiple data sources, which can be added to by others, for those producing systematic reviews of PCOR.

#### **Completed Research Support (most relevant)**

##### **Conference Grant for Consumers United for Evidence-based Health Care**

R13HS17688-01A1 K. Dickersin (PI) 2009-2012

AHRQ

The United States Cochrane Center (USCC) will host 3 annual membership meetings and a 2010 Consumer Summit for health consumer advocacy groups interested in integrating understanding and interpretation of evidence-based healthcare (EBHC) into their advocacy activities.

##### **The US Cochrane Center.**

AHRQ K. Dickersin (PI) 2007 - 2010.

The aim of the project is to facilitate stronger interactions and communication among groups producing systematic reviews, and collaborations on a research agenda for translating of research into policy and practice.

## RESEARCH & RELATED BUDGET - SECTION A & B, Budget Period 1

ORGANIZATIONAL DUNS\*: 001910777

**Budget Type\*:**     Project     Subaward/Consortium

**Enter name of Organization:** Johns Hopkins University

**Start Date\*:** 04-01-2016

**End Date\*:** 03-31-2017

**Budget Period:** 1

<b>A. Senior/Key Person</b>												
Prefix	First Name*	Middle Name	Last Name*	Suffix	Project Role*	Base Salary (\$)	Calendar Months	Academic Months	Summer Months	Requested Salary (\$)*	Fringe Benefits (\$)*	Funds Requested (\$)*
1.	Kay		Dickersin		PD/PI							
<b>Total Funds Requested for all Senior Key Persons in the attached file</b>												
<b>Additional Senior Key Persons:</b> File Name:											<b>Total Senior/Key Person</b>	

<b>B. Other Personnel</b>											
Number of Personnel*	Project Role*	Calendar Months	Academic Months	Summer Months	Requested Salary (\$)*	Fringe Benefits*	Funds Requested (\$)*				
0	Post Doctoral Associates	0	0	0	0.00	0.00	0.00				
0	Graduate Students	0	0	0	0.00	0.00	0.00				
0	Undergraduate Students	0	0	0	0.00	0.00	0.00				
0	Secretarial/Clerical	0	0	0	0.00	0.00	0.00				
2	Other	3	0	0							
0	Other Professionals	0	0	0	0.00	0.00	0.00				
0	Allocated Admin Support	0	0	0	0.00	0.00	0.00				
<b>2</b>	<b>Total Number Other Personnel</b>						<b>Total Other Personnel</b>				
							<b>Total Salary, Wages and Fringe Benefits (A+B)</b>		<b>21,162.58</b>		

RESEARCH & RELATED Budget {A-B} (Funds Requested)

## RESEARCH & RELATED BUDGET - SECTION C, D, & E, Budget Period 1

**ORGANIZATIONAL DUNS\*:** 001910777

**Budget Type\*:**     Project     Subaward/Consortium

**Organization:** Johns Hopkins University

**Start Date\*:** 04-01-2016

**End Date\*:** 03-31-2017

**Budget Period:** 1

<b>C. Equipment Description</b>	
List items and dollar amount for each item exceeding \$5,000	
<b>Equipment Item</b>	<b>Funds Requested (\$)*</b>
<b>Total funds requested for all equipment listed in the attached file</b>	
<b>Total Equipment</b>	
<b>Additional Equipment:</b> File Name:	

	<b>Funds Requested (\$)*</b>
1. Domestic Travel Costs ( Incl. Canada, Mexico, and U.S. Possessions)	8,374.00
2. Foreign Travel Costs	0.00
<b>Total Travel Cost</b>	<b>8,374.00</b>

	<b>Funds Requested (\$)*</b>
<b>E. Participant/Trainee Support Costs</b>	
1. Tuition/Fees/Health Insurance	0.00
2. Stipends	0.00
3. Travel	0.00
4. Subsistence	0.00
5. Other: Other	0.00
<b>0 Number of Participants/Trainees</b>	<b>Total Participant Trainee Support Costs</b>
	<b>0.00</b>

RESEARCH & RELATED Budget {C-E} (Funds Requested)

**RESEARCH & RELATED BUDGET - SECTIONS F-K, Budget Period 1****ORGANIZATIONAL DUNS\*:** 001910777**Budget Type\*:**  Project  Subaward/Consortium**Organization:** Johns Hopkins University**Start Date\*:** 04-01-2016**End Date\*:** 03-31-2017**Budget Period:** 1

<b>F. Other Direct Costs</b>	<b>Funds Requested (\$)*</b>
1. Materials and Supplies	553.00
2. Publication Costs	0.00
3. Consultant Services	0.00
4. ADP/Computer Services	0.00
5. Subawards/Consortium/Contractual Costs	0.00
6. Equipment or Facility Rental/User Fees	0.00
7. Alterations and Renovations	0.00
8. Other Direct Costs	4,910.00
9. All Other Costs	0.00
<b>Total Other Direct Costs</b>	<b>5,463.00</b>

<b>G. Direct Costs</b>	<b>Funds Requested (\$)*</b>
<b>Total Direct Costs (A thru F)</b>	<b>34,999.58</b>

<b>H. Indirect Costs</b>			
<b>Indirect Cost Type</b>	<b>Indirect Cost Rate (%)</b>	<b>Indirect Cost Base (\$)</b>	<b>Funds Requested (\$)*</b>
1. MTDC	0	34,999.58	0.00
<b>Total Indirect Costs</b>			<b>0.00</b>
<b>Cognizant Federal Agency</b>	US Department of Health and Human Services, Steven Zuraf (301)		
(Agency Name, POC Name, and POC Phone Number)	492-4855		

<b>I. Total Direct and Indirect Costs</b>	<b>Funds Requested (\$)*</b>
<b>Total Direct and Indirect Institutional Costs (G + H)</b>	<b>34,999.58</b>

<b>J. Fee</b>	<b>Funds Requested (\$)*</b>
	<b>0.00</b>

<b>K. Budget Justification*</b>
File Name: M-6_S2S_Budget_Justification.pdf (Only attach one file.)

RESEARCH &amp; RELATED Budget {F-K} (Funds Requested)

## RESEARCH & RELATED BUDGET - SECTION A & B, Budget Period 2

ORGANIZATIONAL DUNS\*: 001910777

**Budget Type\*:**     Project     Subaward/Consortium

**Enter name of Organization:** Johns Hopkins University

**Start Date\*:** 04-01-2017

**End Date\*:** 03-31-2018

**Budget Period:** 2

<b>A. Senior/Key Person</b>												
Prefix	First Name*	Middle Name	Last Name*	Suffix	Project Role*	Base Salary (\$)	Calendar Months	Academic Months	Summer Months	Requested Salary (\$)*	Fringe Benefits (\$)*	Funds Requested (\$)*
1.	Kay		Dickersin		PD/PI							
<b>Total Funds Requested for all Senior Key Persons in the attached file</b>												
<b>Additional Senior Key Persons:</b> File Name:											<b>Total Senior/Key Person</b>	

<b>B. Other Personnel</b>											
Number of Personnel*	Project Role*	Calendar Months	Academic Months	Summer Months	Requested Salary (\$)*	Fringe Benefits*	Funds Requested (\$)*				
0	Post Doctoral Associates	0	0	0	0.00	0.00	0.00				
0	Graduate Students	0	0	0	0.00	0.00	0.00				
0	Undergraduate Students	0	0	0	0.00	0.00	0.00				
0	Secretarial/Clerical	0	0	0	0.00	0.00	0.00				
2	Other	3	0	0							
0	Other Professionals	0	0	0	0.00	0.00	0.00				
0	Allocated Admin Support	0	0	0	0.00	0.00	0.00				
<b>2</b>	<b>Total Number Other Personnel</b>						<b>Total Other Personnel</b>				
							<b>Total Salary, Wages and Fringe Benefits (A+B)</b>		<b>21,406.05</b>		

RESEARCH & RELATED Budget {A-B} (Funds Requested)

**RESEARCH & RELATED BUDGET - SECTION C, D, & E, Budget Period 2**

ORGANIZATIONAL DUNS\*: 001910777

Budget Type\*:  Project  Subaward/Consortium

Organization: Johns Hopkins University

Start Date\*: 04-01-2017

End Date\*: 03-31-2018

Budget Period: 2

<b>C. Equipment Description</b>	
List items and dollar amount for each item exceeding \$5,000	
<b>Equipment Item</b>	<b>Funds Requested (\$)*</b>
<b>Total funds requested for all equipment listed in the attached file</b>	
<b>Total Equipment</b>	
<b>Additional Equipment:</b>	File Name:

<b>D. Travel</b>	<b>Funds Requested (\$)*</b>
1. Domestic Travel Costs ( Incl. Canada, Mexico, and U.S. Possessions)	8,374.00
2. Foreign Travel Costs	0.00
<b>Total Travel Cost</b>	<b>8,374.00</b>

<b>E. Participant/Trainee Support Costs</b>	<b>Funds Requested (\$)*</b>
1. Tuition/Fees/Health Insurance	0.00
2. Stipends	0.00
3. Travel	0.00
4. Subsistence	0.00
5. Other: Other	0.00
<b>0 Number of Participants/Trainees</b>	<b>Total Participant Trainee Support Costs 0.00</b>

RESEARCH &amp; RELATED Budget {C-E} (Funds Requested)

**RESEARCH & RELATED BUDGET - SECTIONS F-K, Budget Period 2****ORGANIZATIONAL DUNS\*:** 001910777**Budget Type\*:**  Project  Subaward/Consortium**Organization:** Johns Hopkins University**Start Date\*:** 04-01-2017**End Date\*:** 03-31-2018**Budget Period:** 2

<b>F. Other Direct Costs</b>	<b>Funds Requested (\$)*</b>
1. Materials and Supplies	609.00
2. Publication Costs	0.00
3. Consultant Services	0.00
4. ADP/Computer Services	0.00
5. Subawards/Consortium/Contractual Costs	0.00
6. Equipment or Facility Rental/User Fees	0.00
7. Alterations and Renovations	0.00
8. Other Direct Costs	4,610.00
9. All Other Costs	0.00
<b>Total Other Direct Costs</b>	<b>5,219.00</b>

<b>G. Direct Costs</b>	<b>Funds Requested (\$)*</b>
<b>Total Direct Costs (A thru F)</b>	<b>34,999.05</b>

<b>H. Indirect Costs</b>			
<b>Indirect Cost Type</b>	<b>Indirect Cost Rate (%)</b>	<b>Indirect Cost Base (\$)</b>	<b>Funds Requested (\$)*</b>
1. MTDC	0	34,999.05	0.00
<b>Total Indirect Costs</b>			<b>0.00</b>
<b>Cognizant Federal Agency</b>	US Department of Health and Human Services, Steven Zuraf (301)		
(Agency Name, POC Name, and POC Phone Number)	492-4855		

<b>I. Total Direct and Indirect Costs</b>	<b>Funds Requested (\$)*</b>
<b>Total Direct and Indirect Institutional Costs (G + H)</b>	<b>34,999.05</b>

<b>J. Fee</b>	<b>Funds Requested (\$)*</b>
	<b>0.00</b>

<b>K. Budget Justification*</b>
File Name: M-6_S2S_Budget_Justification.pdf (Only attach one file.)

RESEARCH &amp; RELATED Budget {F-K} (Funds Requested)

## RESEARCH & RELATED BUDGET - SECTION A & B, Budget Period 3

ORGANIZATIONAL DUNS\*: 001910777

**Budget Type\*:**     Project     Subaward/Consortium

**Enter name of Organization:** Johns Hopkins University

**Start Date\*:** 04-01-2018

**End Date\*:** 03-31-2019

**Budget Period:** 3

**A. Senior/Key Person**

Prefix	First Name*	Middle Name	Last Name*	Suffix	Project Role*	Base Salary (\$)	Calendar Months	Academic Months	Summer Months	Requested Salary (\$)*	Fringe Benefits (\$)*	Funds Requested (\$)*
1.	Kay		Dickersin		PD/PI							
<b>Total Funds Requested for all Senior Key Persons in the attached file</b>												
<b>Additional Senior Key Persons:</b> File Name:											<b>Total Senior/Key Person</b>	

**B. Other Personnel**

Number of Personnel*	Project Role*	Calendar Months	Academic Months	Summer Months	Requested Salary (\$)*	Fringe Benefits*	Funds Requested (\$)*	
0	Post Doctoral Associates	0	0	0	0.00	0.00	0.00	
0	Graduate Students	0	0	0	0.00	0.00	0.00	
0	Undergraduate Students	0	0	0	0.00	0.00	0.00	
0	Secretarial/Clerical	0	0	0	0.00	0.00	0.00	
2	Other	3	0	0				
0	Other Professionals	0	0	0	0.00	0.00	0.00	
0	Allocated Admin Support	0	0	0	0.00	0.00	0.00	
<b>2</b>	<b>Total Number Other Personnel</b>					<b>Total Other Personnel</b>		
							<b>Total Salary, Wages and Fringe Benefits (A+B)</b>	<b>21,653.18</b>

RESEARCH & RELATED Budget {A-B} (Funds Requested)

**RESEARCH & RELATED BUDGET - SECTION C, D, & E, Budget Period 3**

ORGANIZATIONAL DUNS\*: 001910777

Budget Type\*:  Project  Subaward/Consortium

Organization: Johns Hopkins University

Start Date\*: 04-01-2018

End Date\*: 03-31-2019

Budget Period: 3

**C. Equipment Description**

List items and dollar amount for each item exceeding \$5,000

<b>Equipment Item</b>	<b>Funds Requested (\$)*</b>
-----------------------	------------------------------

**Total funds requested for all equipment listed in the attached file****Total Equipment****Additional Equipment:** File Name:**D. Travel****Funds Requested (\$)\***

1. Domestic Travel Costs ( Incl. Canada, Mexico, and U.S. Possessions)	8,374.00
2. Foreign Travel Costs	0.00
<b>Total Travel Cost</b>	<b>8,374.00</b>

**E. Participant/Trainee Support Costs****Funds Requested (\$)\***

1. Tuition/Fees/Health Insurance	0.00
2. Stipends	0.00
3. Travel	0.00
4. Subsistence	0.00
5. Other: Other	0.00
<b>0 Number of Participants/Trainees</b>	<b>Total Participant Trainee Support Costs</b>
	<b>0.00</b>

RESEARCH &amp; RELATED Budget {C-E} (Funds Requested)

**RESEARCH & RELATED BUDGET - SECTIONS F-K, Budget Period 3****ORGANIZATIONAL DUNS\*:** 001910777**Budget Type\*:**  Project  Subaward/Consortium**Organization:** Johns Hopkins University**Start Date\*:** 04-01-2018**End Date\*:** 03-31-2019**Budget Period:** 3

<b>F. Other Direct Costs</b>	<b>Funds Requested (\$)*</b>
1. Materials and Supplies	462.00
2. Publication Costs	0.00
3. Consultant Services	0.00
4. ADP/Computer Services	0.00
5. Subawards/Consortium/Contractual Costs	0.00
6. Equipment or Facility Rental/User Fees	0.00
7. Alterations and Renovations	0.00
8. Other Direct Costs	4,510.00
9. All Other Costs	0.00
<b>Total Other Direct Costs</b>	<b>4,972.00</b>

<b>G. Direct Costs</b>	<b>Funds Requested (\$)*</b>
<b>Total Direct Costs (A thru F)</b>	<b>34,999.18</b>

<b>H. Indirect Costs</b>			
<b>Indirect Cost Type</b>	<b>Indirect Cost Rate (%)</b>	<b>Indirect Cost Base (\$)</b>	<b>Funds Requested (\$)*</b>
1. MTDC	0	34,999.18	0.00
<b>Total Indirect Costs</b>			<b>0.00</b>
<b>Cognizant Federal Agency</b>	US Department of Health and Human Services, Steven Zuraf (301)		
(Agency Name, POC Name, and POC Phone Number)	492-4855		

<b>I. Total Direct and Indirect Costs</b>	<b>Funds Requested (\$)*</b>
<b>Total Direct and Indirect Institutional Costs (G + H)</b>	<b>34,999.18</b>

<b>J. Fee</b>	<b>Funds Requested (\$)*</b>
	<b>0.00</b>

<b>K. Budget Justification*</b>
File Name: M-6_S2S_Budget_Justification.pdf (Only attach one file.)

RESEARCH &amp; RELATED Budget {F-K} (Funds Requested)

## Budget Justification

**A. Overview.** Salaries include a 2% annual increase, consistent with annual salary pool increases. Fringe benefits are included at federally negotiated rates, which is 34.5% for faculty and staff. This conference grant application does not include indirect costs, per federal guidelines. Resources requested for the project include those for: (1) development of education and meeting materials; (2) coordination of the meeting proposed, and (3) center administration related to personnel, Center operations, and grants management, *for functions not already provided by the University*. Not all costs associated with this meeting are included in our application. We will apply for funds from other agencies to expand the 2017 Annual meeting to a Summit, if warranted.

### B. Budget items

Task	Year 01	Year 02	Year 03
<b>Meetings</b>			
CUE Annual Membership Meeting	July 2016	July 2017	July 2018
CUE Steering Group Meeting	July 2016	July 2017	July 2018
CUE Steering Group teleconferences	2016 (monthly)	2017 (monthly)	2018 (monthly)
<b>Workshops</b>			
In-person, annual Cochrane Colloquium	October 2016	October 2017	October 2018

#### B.1. Personnel

**Kay Dickersin, MA, PhD, Principal Investigator** <sup>(b) (6)</sup> **FTE Years 01-03.** Dr. Dickersin will assume the major responsibility for scientific direction and oversight for the project. She will work with the Planning Committees to finalize the agendas and speakers for the annual CUE membership meetings in 2016, 2017, and 2018. Dr. Dickersin will also oversee the meetings and participate as faculty and will speak at or co-convene a workshop. She will contribute substantially to the content of the educational materials, drawing from her teaching and research experience, such as teaching medical under-graduates, postgraduates, and doctoral students, and designing and teaching a science curriculum for consumers. She will be responsible for oversight of the study budget, personnel, and communications with the Agency for Healthcare Research and Quality (AHRQ) Project Office. Dr. Dickersin, as US Cochrane Center Director was the original convenor of CUE and has held this role since 2003. The USCC has been the recipient of various conference grants from AHRQ to support CUE and its educational and dissemination activities. Dr. Dickersin and the USCC have launched a highly successful online course on evidence-based healthcare, with an FDA module launched in February, 2012. They have also guided conferences and workshops for health professionals and

consumer advocates on understanding and applying evidence-based healthcare, using systematic reviews, and critical appraisal of the literature. CUE and the USCC successfully convened two international Summits for consumers and consumer advocates in 2007 and 2010.

**Reva Datar, MPH, Consumer Coordinator,** (b) (6) **FTE Years 01-03.** Ms. Datar will have responsibility for day-to-day coordination and implementation of the project and supervision of Project staff associated with curriculum development and meeting planning. She will be involved with all aspects of the educational programs including development and implementation of course content for the educational workshops and planning and coordinating sessions for the meetings. In addition, she will assist with recruitment of course speakers/faculty, as well as contribute to the educational workshops. Ms. Datar will oversee the practicalities of the educational workshops and conferences, including conference planning and working with local hosts. She will have responsibility for administrative aspects of the project including coordination of all project activities and internal and external meetings, tracking the project time lines, monitoring product quality, monitoring the study budget, and preparation of study reports. Ms. Datar will be responsible for negotiating contracts for space and hospitality-related contracts. She will ensure high quality follow-up communication among the meeting's attendees. We will build on the successful coordination and implementation of the well-received previous annual CUE meetings as well as other educational courses which we have coordinated in the past.

**James Heyward, Web Developer** (b) (6) **FTE Years 01-03.** Mr. Heyward will assist with electronic communication, including the web pages and social media. He will oversee preparation of electronic meeting registration, announcements, brochures, and other materials that will be posted to our website. Mr. Heyward will have the day-to-day responsibility for all web-based dissemination and web-based communication with collaborators and the public regarding the conference and CUE Steering Committee activities. This includes designing, establishing, and updating the meetings website, online registration, linking of the registration system to participant databases, and maintenance of the meeting contact database for product dissemination, advertisement, and other communication.

## B.2 Non-Personnel

Items included relate to supplies, travel, meeting expenses, and other items identified as essential to operation of the meeting. Nearly all of the non-personnel budget relate to meeting expenses, including travel for staff and speakers to the meeting. As discussed in the Conference Plan, we have proposed funds for:

- [Three] one-day CUE Annual Membership Meetings, relating to translating research into practice and policy for consumers, with a focus on methodological and technical issues of major importance to consumer advocates in the field of

health services research and interventions. The meetings will take place in Washington DC (2016, [2017], 2018) and will be open to membership, potential members, and partners. If funding is granted by other funding agencies, we would like to expand the 2017 membership conference into a consumer Summit, similar to Summits hosted in 2007 and 2010;

- Three one-day annual CUE Steering Committee meetings, relating to operational matters for the Coalition to be held in conjunction with the CUE annual Membership Meetings (2016 , 2017, 2018);
- Three workshops, on each year in 2016, 2017, and 2018 for consumer advocates, to be held in conjunction with the Cochrane Colloquium.

### B.2.1 Travel

Below is a table describing the proposed meeting, location, number of speakers, Steering Committee members, and USCC Staff. No travel expenses are being requested for Federal employees.

<b>Date</b>	<b>Meeting</b>	<b>Proposed Location</b>	<b>Number</b>
07/16	CUE Annual Membership Meeting	Washington, DC	2 CUE speakers 3 USCC Staff
07/16	CUE Steering Committee Meeting	Washington, DC	7 Steering Committee members 2 USCC Staff
10/16	Cochrane Colloquium	TBA	1 CUE Coordinator
7/17	CUE Annual Membership Meeting	Washington, DC	2 CUE speakers 3 USCC Staff
7/17	CUE Steering Committee Meeting	Washington, DC	7 Steering Committee members 2 USCC Staff
10/17	Cochrane Colloquium	TBA	1 CUE Coordinator
7/18	CUE Annual Membership Meeting	Washington, DC	2 CUE speakers 3 USCC Staff
7/18	CUE Steering Committee Meeting	Washington, DC	7 Steering Committee members 2 USCC Staff
10/18	Cochrane Colloquium	TBA	1 CUE Coordinator

We have included travel expenses for the PI/Consumer Coordinator, USCC staff, members for the CUE Steering Committee, and travel scholarships for CUE members that otherwise could not, due to financial constraints, attend the annual meeting.

Four of the CUE Steering Committee members live outside of Washington, D.C. We estimate trip costs for these members attending two days of meetings in Washington, D.C. at \$1,051 per person for those traveling by air (two individuals) and staying two nights, and at \$551 for those CUE Steering Committee members traveling by train (two individuals) and staying one night. We estimate that costs for participants that will be attending the one-day Annual CUE Membership Meeting only at \$813.

Travel Item	Two Day (attendance at Steering Committee Meeting and CUE Annual Membership Meeting)		One Day (attendance at CUE Annual Membership Meeting only)
Travel	Airfare: \$500	Train: \$200	\$500
Lodging	\$400	\$200	\$200
Ground Transportation	\$75	\$75	\$75
Per diem	\$76	\$76	\$38
<b>TOTAL</b>	<b>\$1051</b>	<b>\$551</b>	<b>\$813</b>

Since Washington, D.C. is considered local travel for USCC staff members, travel costs are adjusted by replacing airfare costs with those for mileage, tolls, and parking. For two USCC staff attending both days of meetings, travel cost is estimated at \$350 per person; costs for one staff member attending only the CUE Annual Membership Meeting is \$50 per person.

### B.2.2 Supplies

**Meeting Supplies.** Supplies directly related to support of the meeting include those needed for word processing, correspondence, and educational materials (e.g., binders, folders, stationary, plain bond, envelopes, filing and mailing supplies, and labels). Printer, fax and toner supplies are included. Based on our experience from prior meetings, we estimate meeting supply costs at \$503, \$559, and \$412 in Years 01, 02, and 03, respectively.

### B.2.3 Meeting

The following is a description of the projected expenses for conducting the annual membership meeting and Steering Committee meeting. Based on past experience, we anticipate a meeting room cost of \$1,500 for one day in Years 01, 02, and 03. Based on our most recent meeting, we anticipate audiovisual charges of \$1,000 for Years 01 and 02 and a charge of \$750 for Year 03. This includes on-site technical support, audio visual rentals, cabling for Internet access, set-up charges, microphones, podcasting, etc. AV costs will be monitored for increases and decreases in Year 01 and expenses not covered in subsequent years will be sought from other funders. Speaker fees are included at \$300 per speaker for three speakers in Year 01 and for two speakers in Years 02 and 03.

#### **B.2.4 Other Expenses**

**Postage & Delivery.** While we anticipate that much of our communication with registrants will be accomplished electronically, we will still have need for periodic mailings to advertise conferences and to speakers/faculty for review of presentation materials and other draft documents. Materials to be shipped include meeting announcements, registration materials, and advance shipment of educational materials to training sites. Based on experience from prior conferences and workshops, we estimate postage and delivery expenses at \$50 for Years 01, 02, and 03.

**Graphic Services and Duplication.** We will prepare all documents and reports for meeting and interim communication and distribute them as needed. Examples of documents include articles, meeting proceedings; educational and presentation materials; meeting materials; memoranda relating to project operations; status reports as requested by AHRQ and others. We will utilize the in-house Johns Hopkins Bloomberg School of Public Health Copy Center for graphics and reproduction services. Based on our experience from prior meetings, we estimate graphics and reproduction costs at \$550 in Years 01 and 02, and at \$450 in Year 03 (decreasing costs because we depend on pre-existing materials, such as banners).

**Phone and Conference Calls.** Because face-to-face meetings will be relatively infrequent, telephone and fax communication will be critical. Expenses related to long distance phone communication are estimated at \$960 for Years 01, 02, and 03. This covers telephone handsets and monthly service and 15 conference calls per year for the CUE Annual Meeting planning and monthly Steering Committee calls.

**RESEARCH & RELATED BUDGET - Cumulative Budget**

	Totals (\$)	
Section A, Senior/Key Person		
Section B, Other Personnel		
Total Number Other Personnel	6	
Total Salary, Wages and Fringe Benefits (A+B)		64,221.81
Section C, Equipment		0.00
Section D, Travel		25,122.00
1. Domestic	25,122.00	
2. Foreign	0.00	
Section E, Participant/Trainee Support Costs		0.00
1. Tuition/Fees/Health Insurance	0.00	
2. Stipends	0.00	
3. Travel	0.00	
4. Subsistence	0.00	
5. Other	0.00	
6. Number of Participants/Trainees	0	
Section F, Other Direct Costs		15,654.00
1. Materials and Supplies	1,624.00	
2. Publication Costs	0.00	
3. Consultant Services	0.00	
4. ADP/Computer Services	0.00	
5. Subawards/Consortium/Contractual Costs	0.00	
6. Equipment or Facility Rental/User Fees	0.00	
7. Alterations and Renovations	0.00	
8. Other 1	14,030.00	
9. Other 2		
10. Other 3		
Section G, Direct Costs (A thru F)		104,997.81
Section H, Indirect Costs		0.00
Section I, Total Direct and Indirect Costs (G + H)		104,997.81
Section J, Fee		0.00

## PHS 398 Cover Page Supplement

OMB Number: 0925-0001

### 1. Project Director / Principal Investigator (PD/PI)

Prefix:

First Name\*: Kay

Middle Name:

Last Name\*: Dickersin

Suffix:

### 2. Human Subjects

Clinical Trial?  No  Yes

Agency-Defined Phase III Clinical Trial?\*  No  Yes

### 3. Permission Statement\*

If this application does not result in an award, is the Government permitted to disclose the title of your proposed project, and the name, address, telephone number and e-mail address of the official signing for the applicant organization, to organizations that may be interested in contacting you for further information (e.g., possible collaborations, investment)?

Yes  No

### 4. Program Income\*

Is program income anticipated during the periods for which the grant support is requested?  Yes  No

If you checked "yes" above (indicating that program income is anticipated), then use the format below to reflect the amount and source(s). Otherwise, leave this section blank.

Budget Period*	Anticipated Amount (\$)*	Source(s)*
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....
.....	.....	.....

## PHS 398 Cover Page Supplement

### 5. Human Embryonic Stem Cells

Does the proposed project involve human embryonic stem cells?\*  No  Yes

If the proposed project involves human embryonic stem cells, list below the registration number of the specific cell line(s) from the following list: [http://grants.nih.gov/stem\\_cells/registry/current.htm](http://grants.nih.gov/stem_cells/registry/current.htm). Or, if a specific stem cell line cannot be referenced at this time, please check the box indicating that one from the registry will be used:

Cell Line(s):  Specific stem cell line cannot be referenced at this time. One from the registry will be used.

### 6. Inventions and Patents (For renewal applications only)

Inventions and Patents\*:  Yes  No

If the answer is "Yes" then please answer the following:

Previously Reported\*:  Yes  No

### 7. Change of Investigator / Change of Institution Questions

Change of principal investigator / program director

Name of former principal investigator / program director:

Prefix:

First Name\*:

Middle Name:

Last Name\*:

Suffix:

Change of Grantee Institution

Name of former institution\*:

## PHS 398 Research Plan

Please attach applicable sections of the research plan, below.

OMB Number: 0925-0001

1. Introduction to Application (for RESUBMISSION or REVISION only)	
2. Specific Aims	M-10_PHS_ResearchPlan_SpecificAims.pdf
3. Research Strategy*	M-5_PHS_ResearchPlan_ResearchStrategy.pdf
4. Progress Report Publication List	
<b>Human Subjects Sections</b>	
5. Protection of Human Subjects	
6. Inclusion of Women and Minorities	
7. Inclusion of Children	
<b>Other Research Plan Sections</b>	
8. Vertebrate Animals	
9. Select Agent Research	
10. Multiple PD/PI Leadership Plan	
11. Consortium/Contractual Arrangements	
12. Letters of Support	M-11_PHS_ResearchPlan_LettersOfSupport.pdf
13. Resource Sharing Plan(s)	
<b>Appendix (if applicable)</b>	
14. Appendix	M-7_PHS_ResearchPlan_Appendix.pdf

## Specific Aims

*Our objective is to host a series of in-person conferences in 2016, 2017, and 2018, in which research findings and evidence-based information and tools are summarized, communicated and used by organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services.*

Consumers United for Evidence-based Healthcare (CUE), founded in 2003 and supported by the Agency for Healthcare Research and Quality (AHRQ) since its start, will host the proposed annual meetings. CUE's accomplishments since its founding have made the group a recognized leader in consumer and patient engagement in evidence-based healthcare (EBHC). The United States Cochrane Center (USCC) will provide lead scientific partnership and staffing to coordinate the meeting.

Our goal is to complement and promote AHRQ's core research, dissemination, and implementation activities by providing a mechanism for consumers to build capacity from within and to develop partnerships with Agency stakeholders and others to improve the quality, safety, efficiency, and effectiveness of healthcare for all Americans. The conferences are "dissemination and implementation conferences". The target audience will be CUE and health consumer groups interested integrating in their consumer health activities with EBHC goals.

The specific aims of our proposal are to:

1. Build on CUE's established momentum to extend the capacity of US-based consumer advocates educated to use and communicate essential elements of EBHC; and
2. Increase collaboration and partnerships among the growing number of CUE member organizations and healthcare societies and scientists.

To build capacity (Aim 1), the CUE annual meeting will comprise didactic sessions, workshops, and discussion, with networking time set aside (see Table 1). The workshops will serve as opportunities to test out new educational ideas and promote CUE to non-member attendees. Information and available tools will also be communicated to CUE members throughout the year and the CUE annual meetings as well as the consumer workshops will provide access to up-to-date information and opinion leaders who can serve as potential partners to the attending consumer organizations (see Appendices B, E, F, G for evidence of capacity-building using our methods).

Using proven methods, we will increase collaboration and partnerships (Aim 2), in part by providing access to key opinion leaders at our conferences with ample time for discussion and networking. In addition, we provide a "Clearinghouse" service to potential partners between the meetings, filling requests for consumer partners for committees and other engagement opportunities (see Appendices A, C, D, I, J for partnerships established using our methods).

Dissemination and implementation of information means that the CUE organization as a whole and CUE member groups individually will not only communicate the material received but that they will also put the information to use in their practice, to improve the outcomes, quality, access to, and utilization of healthcare services (see Table 2). The extent of dissemination and implementation will be assessed twice annually by survey (see Appendix H). Conference materials will be disseminated beyond the participants attending the event via uploaded videos and slide casts of plenary sessions onto the CUE website, utilizing social networking tools (e.g., live tweeting during the event), to engage external audiences. CUE members and conference attendees can share conference and other resources with their constituents, spanning the many priority populations (low income groups; racial and ethnic minority groups; women; the elderly; individuals with special health care needs; and individuals living in the inner-city; rural and frontier areas) with which CUE engages.

## Research Strategy (Conference Plan)

### A. Significance

Educated patients and consumers are needed as participants in the research and policy-setting process for evidence-based healthcare (EBHC) and health services research, now more than ever before. We believe that **dissemination and implementation conferences will contribute a great deal to fulfilling this need** by summarizing and communicating research findings and evidence-based information and tools, with the goal that consumer organizations will use the information to improve the outcomes, quality, access to, and cost and utilization of health care services. We also believe our proposed conferences will hold consumer groups to develop partnerships with stakeholder organizations and build their capacity to participate in research activities and use the results of health services research. Our conference focus is mainly EBHC and comparative effectiveness, and we also cover health information technology, patient safety, understanding data about prevention and care management, value, healthcare innovations and emerging areas.

CUE is a national coalition of 36 health and consumer organizations working toward a common mission: to promote the health of populations and the quality of individual healthcare by empowering consumers, health policymakers, and healthcare providers to make informed decisions based on the best current evidence through research, education, and advocacy. United by a common interest in integrating, understanding, and interpreting EBHC into their advocacy activities, CUE member-organizations work to strengthen the voice of consumers and provide leadership in healthcare research (see [here](#) for list of members). CUE reaches out to potential members on an ongoing basis, with special efforts dedicated to attracting priority populations.

CUE activities from the start have had the support of AHRQ. CUE provides networking and learning opportunities for educated consumer advocates who participate at the highest level of involvement in research, clinical practice guidelines, and policy development, and who communicate effectively with their constituencies about the evidence and its importance in high quality health care. CUE provides a central hub for consumer health advocacy groups to exchange information, network, and learn about relevant up-to-date developments and evaluation of evidence. CUE is well-positioned to build on this strong foundation to meet the ever-increasing needs for educated consumer advocates now and for the future. A video describing CUE can be viewed [here](#).

CUE's Annual Membership Meeting is the centerpiece of the learning, networking and dissemination activities that patients and consumers in the group undertake. The conferences, organized by a Steering Committee, provide education, networking and visibility for CUE, resulting in consumer/decision-maker partnerships that will further the goals of effective healthcare programs at AHRQ and worldwide. Continuing our series of conferences and meetings will allow us to build capacity and strengthen CUE and its member organizations to serve in the new patient-centered health services paradigm.

### B. Innovation

CUE challenges existing paradigms: it is a coalition of consumer advocacy organizations crossing disease boundaries, encompassing multiple populations and priority populations, and includes a range of organizations from small grassroots to larger, widely-recognized groups. CUE conferences provide a unique opportunity for consumer advocates, scientists, funders, and policy partners to learn and network among one another. As a result of these unique collaborations among stakeholders, CUE believes that the discourse surrounding current issues in evidence-based healthcare will significantly improve and that changes in clinical research and practice will greatly benefit.

#### B.1 Advancing consumer knowledge in evidence-based healthcare

With the US Cochrane Center as its host, CUE has access to resources it would not otherwise have. For example, CUE members are given a free subscription to *The Cochrane Library*. While CUE member organizations are vitally interested in being part of a professional network of consumer organizations, each organization has a separate mission and is not in a position to take on the unique mission of CUE, nor in a position to provide educational opportunities and real-time exposure to developments in the health services

field. Thus, hosting of CUE by the USCC presents a unique opportunity for educational support and links to other stakeholder groups with whom CUE members can partner.

A policy unique to CUE is that member organizations may not be dominated by pharmaceutical companies, providers, or any other commercial vested interest, or in any way that could cause the organization to compromise or be viewed as possibly compromising its commitments to consumers.

## **B.2 Social networking and other innovative online materials**

CUE provides a forum for communication and methodological consultation to consumers (Aim 4), and this effort encompasses social networking projects. The [CUE Facebook Group](#) is a platform for the exchange of ideas and resources about EBHC aimed at a broad audience. Announcements are also posted on this site, for example, the opportunity to serve as a consumer liaison to the FDA or as a grant peer reviewer, and to attend public webinars.

CUE is actively engaged on [Twitter](#) (Twitter Handle: @United4Evidence) and regularly tweets and retweets during conferences. In February 2015, CUE hosted a Twitter Chat, featuring Sir Ian Chalmers, entitled "[What does evidence-based healthcare mean to you?](#)" In addition, many CUE members have joined the Cochrane Consumer Network, through which they join a listserv and obtain access to internal Cochrane communication, including opportunities to serve as a peer reviewer for Cochrane reviews.

## **B.3 Improving upon past conferences**

To our knowledge, CUE is the only organization of its kind that serves as a coalition for healthcare-oriented consumer advocacy groups in the US. Our proposed Annual Membership Meetings will continue to utilize methods that have worked well at such conferences in the past 3 years and will change those methods that do not work so well, to provide new and innovative approaches for engaging and informing conference participants.

The format of our conference panels, which include both CUE members and outside speakers, has been well received by participants and will remain part of our proposed plans. We will also retain long discussion periods, and time for networking. Changes will include holding at least two breakout workshops at each conference so as to allow participants to have an opportunity to receive hands-on experience in EBHC-related topics; holding a Live-Tweeting event during each conference, to provide both participants and non-participants with an unprecedented platform to stay informed with conference proceedings and conference discussions; and placing a greater emphasis on priority populations and diversity among speakers.

## **C. Approach: 3-year conference plan**

### **C.1 Focus**

CUE works to support and further AHRQ's mission to improve the quality, safety, efficiency and effectiveness of healthcare for all Americans. CUE conferences summarize and communicate research findings and evidence-based information and tools at conferences. CUE works to ensure that this information is used by organizations and individuals that have the capability to use evidence-based information to improve the outcomes, access to, and utilization of health care services. The conferences address issues related to AHRQ priority populations (i.e., low income groups; racial and ethnic minority groups; women; children; the elderly; individuals with special health care needs; and individuals living in inner-city, rural, and frontier areas.

### **C.2 Format**

We are requesting a project period of 3 years to support the same conferences on an annual basis, sponsored by CUE, a permanently sponsoring organization. Our proposal includes in 2016, 2017, and 2018:

1. Monthly CUE Steering Group teleconferences;
2. Three CUE Steering Group Meetings in Washington, DC;
3. Three day-long Annual CUE Membership Meetings in Washington, DC;
4. Three workshops presented at the annual Cochrane Colloquia.

Note that we will apply to other funders to expand the 2017 CUE Membership meeting to a CUE Summit, similar to Summits hosted in 2007 and 2010. While we will plan for an Annual meeting, regardless, we may be able to expand this conference into a larger event that is open to the public and that aims to bring the patient and consumer communities together with other stakeholders (Appendix A).

The format of CUE conferences typically includes: exposure to emerging areas of interest, and research related to EBHC through plenary sessions; exposure to key players in the research and decision-making world; educational workshops, including opportunities to hone critical appraisal skills; a period of discussion following each presentation; and networking time. Our format affords our members the opportunity for two-way learning with scientists and policymakers, as well contact with other consumer advocates; for being part of the dissemination process and learning how other groups translate new information into action; and for asking questions and expressing their opinions to presenters.

Our annual one-day conference is typically held in summer of each year, with the in-person CUE Steering Committee held the day before. Both are held in Washington, DC. CUE Steering Committee teleconferences are the third Wednesday of each month. The Cochrane Colloquia are typically held in September or October of each year. The infrastructure provided by Johns Hopkins Bloomberg School of Public Health and the US Cochrane Center adds to the resource-rich environment of venues available to support the proposed conferences and meetings.

In terms of AHRQ's defined Priority Populations, we commit to ensuring the representation of women, minorities, and special populations as speakers, chairs, and attendees at our conferences so that topics of concern to these groups in particular are covered and so that CUE membership includes advocacy groups that are concerned with health issues focused on these priority populations.

A top priority of our conferences is entry and synthesis of evaluation data immediately following each meeting. We schedule a "debrief" and discussion of the evaluations soon after the meeting, and discuss changes to the next meetings as a result of the feedback we receive.

### **C.3 Steering Committee meetings and planned teleconferences**

We will rely on the counsel and assistance of our CUE Steering Committee in planning for our Annual Membership meetings. Members of this group have continued generously to provide their expertise to the planning of the proposed CUE conferences and workshops and to serve as speakers when appropriate. Current members of the Steering Committee are: Ngina Lythcott (Co-Chair), Lorraine Johnson (Co-Chair), Paul Brown, Rebecca Burkholder, Caitlin Morris, Helen Haskell, William Vaughan, and Barbara Warren. The CUE Steering Committee will provide overall direction, policy and program development and management of CUE projects. The CUE Steering Committee conducts business by monthly teleconferences, e-mail and other means. Meeting attendees will discuss the operational matters of CUE including ongoing projects, policy changes, funding, proposed partnerships, and strategies for strengthening and sustaining the work of the Coalition. In addition, the Committee will meet in person once each year at the time of the CUE Annual Membership meeting.

### **C.4 Details about the proposed conferences**

The conferences and workshops are designed to address Specific Aims 1-6, in that they build on CUE's momentum, provide an opportunity to establish partnerships, provide education, provide a forum for communication and consultation, lead to improving the quality of care, and increase awareness of EBHC.

#### **C.4.1 CUE Annual Membership Meetings (2016, 2017, 2018)**

The objectives of the Annual Membership Meeting are to provide education and training on research and methodology that promotes the inclusion of consumer advocates in scientific research, and also to address programmatic and administrative matters pertaining to CUE. Additionally, the meeting will serve to strengthen the infrastructure and sustainability of CUE. Each panel discussion in the agenda will include a CUE member that will present his or her experiences incorporating evidence into advocacy activities, stimulating discussion and providing a consumer perspective. Registration will remain free of charge. We suggest the following agenda for 2016, recognizing that we may need to add and subtract sessions. We are not providing agendas for 2017 and 2018, so as to keep the agenda up-to-date and unique.

**Table 1- 2016 Consumers United for Evidence-based Healthcare (CUE)  
DRAFT Annual Meeting Agenda  
Leading the Way in Patient Engagement**

**Keynote 1: The Great Debate: How Twitter has become a citizens' forum for discussing controversial topics in healthcare** -- Charles Ornstein, ProPublica

**Panel I: Changing the research paradigm: Engaging patients**

*Chair: Coco Jervis, Program Director, National Women's Health Network USA*

- The promise of PCORNet – Lorraine Johnson, CUE Steering Committee Co-Chair, LymeDisease.org
- What patients can tell researchers: Healthtalk in the US - Rachel Grob, University of Wisconsin
- The gain to be realized by research transparency – Peter Doshi, University of Maryland School of Pharmacy

**Keynote 2: Is the US falling behind internationally in patient engagement? INVOLVE, the James Lind Alliance, and Testing Treatments Interactive**

Sally Crowe, Director, Crowe Associates Ltd

**Panel II: The good, the bad, and the ugly: Empowering patients to implement research evidence**

*Chair: Barbara Warren, Steering Committee, CUE; Director, LGBT Health Services at Beth Israel/Mt. Sinai Health System; National Coalition for LGBT Health*

- Variation in clinical practice guidelines- Vivian Coates, National Guidelines Clearinghouse
- How professional societies (and G-I-N NA) can step up their game - Rich Rosenfeld, Guidelines International Network, North America, USA
- Notes from a veteran guidelines panel member: Bill Vaughan, National Committee to Preserve Social Security and Medicare

**Breakout Workshop Session**

**Workshop A: Critical appraisal and public commenting techniques:** Stephanie Chan, AHRQ and TBN consumer partner

**Workshop B: The secrets of being successful as an advisory panel member:** Marguerite Koster, President, G-I-N NA and TBN consumer partner

**Panel III: Priority populations: A reach or reality?**

*Chair: Ngina Lythcott, Black Women's Health Imperative*

- National Healthcare Disparities Report: Let's see how far we've come – Veronica Soileau, Health Scientist Administrator, AHRQ
- Missing the Mark: Targeting priority populations for health equity and social justice in the US – Al Richmond, Community-Campus Partnerships for Health

**C.4.2 Workshops at the Cochrane Colloquium**

To better disseminate information about EBHC and CUE, and to maintain a strong connection with prolific and engaged scientific partners, we will also offer an in-person workshop at the annual Cochrane Colloquia. In the past, Colloquium workshops have discussed "How to ask an answerable question in healthcare research" and "Selecting patient-centered outcomes for research". These workshops benefit potential CUE audiences because they are opportunities to engage with international consumers, to understand learning trouble spots, and to derive benefits for both the teachers and participants. Knowledge gained will be brought to educational programs developed for CUE. Future workshop topics may include a discussion of the drug approval process, how guidelines are developed and used, and reliable resources for finding out about health. Participating in the Cochrane Colloquium benefits CUE in the following ways:

- CUE is viewed within Cochrane and internationally as a successful consumer model to emulate;
- Cochrane provides opportunities for exposing CUE to international and US leadership;
- Cochrane provides opportunities for consumers, and specifically CUE members, to influence evidence syntheses and to hone their skills.

## C.5 Logistical arrangements

Co-sponsorship will be sought for support of speakers, consumer stipends, and other needs not met by the budget proposed in this application. In the past, we have secured co-funding by the Kaiser Permanente Institute for Health Policy, Blue Cross Blue Shield, and others to help support conference costs.

Speakers for all three annual meetings will be selected based on a number of considerations. Our primary consideration is to have an interesting program that will increase the participants' knowledge and strengthen the field overall. We want to foster both debate and collaboration and aim to include a diverse roster, in terms of specialty, constituency, gender, and ethnicity/race. Past speakers have included both highly regarded, well-known figures in EBHC and health services research, and also newcomers, who stimulate new ideas and fresh directions. The Steering Committee use evaluation materials from previous annual meetings as a starting point in developing each year's agenda. They will help identify presenters as well as provide feedback on draft conference materials.

## C.6 Evaluation and description of most recent conference and workshop

For each session within the proposed conferences, we collect formal written evaluations using a Likert scale instrument. Summaries of evaluation results are disseminated to the faculty and the Steering Committee. The most recent Annual Membership Meeting took place in 2014 and Steering Committee members elected to follow a mixed format of individual speakers and panels. Participant evaluations provided support for our conclusion that the knowledge and experience gained at the meeting contributed to consumer leadership in EBHC advocacy. Participants expressed an appreciation for time allocated to network with other advocates and the diversity among speakers, and suggested that we create even more opportunities for commenting and coordinating among the organizations (see 2014 evaluations [here](#)).

The most recent CUE workshop at the Cochrane Colloquium also took place in 2014 and was entitled, "Ensuring that patient-centered outcomes are included in research" (Appendix B). The workshop provided attendees with hands-on experience suggesting outcomes that should be examined in Cochrane systematic reviews. Evaluations of this workshop were overall positive, with one participant noting that it was 'the best workshop' at the event and most comments were similarly positive. Suggestions included allowing a patient/consumer to help facilitate the workshop and for workshop leaders to provide more examples of patient-centered outcomes in research (Appendix C).

## D. Dissemination

We recognize that true dissemination goes well beyond simply putting information "out there" and instead involves a strategy for seeing that what is disseminated has an impact on both conference participants and non-participants.

### D.1 Publicizing the conferences

As in the past, we will publicly post all conference announcements on our website and we will send formal announcements to CUE members via email. We will follow-up individually by telephone calls with CUE members from whom we do not get a response. As noted earlier, we will also employ new social media techniques to engage with CUE members and interested participants. In addition, CUE will schedule regular posts on both of its social media platforms (Facebook and Twitter) announcing the conference and registration instructions beginning at least two months prior to the event. This will be followed up with a Live-Tweeting event that will be held during the conference itself and that we will advertise for in the weeks leading up to each conference.

### D.2 Dissemination of conference and meeting materials

The products of the conferences will have the potential to inform future research, policy, practice, training of health services researchers, and enhance AHRQ's collaborative relationships. The following products are expected as a result of the planned conferences and will be used and disseminated among member groups and beyond in innovative, high-impact ways:

- Meeting Reports: Posted on the USCC/CUE [website](#) and disseminated to meeting participants and CUE members via email. Links to reports will be regularly posted on CUE social media platforms (Facebook, Twitter);

- Slidecasts of presentations (PowerPoint presentations plus audio) from the annual Membership meetings posted on the CUE website (see [here](#)). All materials are placed on the website in perpetuity. Links to slidecasts will be regularly posted on CUE social media interfaces (Facebook, Twitter);
- Conference handouts: These include the CUE brochure, handouts with summaries of and links to CUE resources and short-courses, and any handouts or tools provided by collaborating organizations during workshops or breakout sessions. Conference handouts will be distributed to all participants and each participant is welcome to take extra copies to disseminate to their own constituents that could not participate in the event.
- Live-Tweeting Storify Summary: A summary of all posts and contributions made during the Live-Tweeting event will be posted on the CUE website and shared on CUE social media platforms (Facebook and Twitter). A PDF version of the Storify Summary will also be attached to our CUE Quarterly Survey which will be disseminated via email and post (to those consumers without internet access).

CUE representatives disseminate what they learn at conferences to constituents in their organizations. Good outreach dissemination will be demonstrated if CUE member websites reflect knowledge about EBHC; if their annual membership or other meetings host sessions devoted to EBHC; if their membership attends CUE, Cochrane, or other EBHC conferences; and if the CUE member organizations offer educational courses about EBHC. Evidence of the reach of our conferences comes from new requests, partnerships, and initiatives.

## **E. Evidence of impact**

Although developing formal mechanisms to assess the impact of conferences is difficult under the best of circumstances, we have evaluated the impact of CUE's conferences and activities via semi-annual, in-depth surveys of CUE member organizations (Appendix D).

Based on the most recent semi-annual surveys we received for 2014 (85% response rate), our member groups reach over 200,000 consumers by way of dissemination to their own constituencies. Most member organizations also contribute to a range of healthcare-related committee(s), board(s), panel(s), or review team(s) as well (Appendix E). This indicates a broader scope of influence for CUE and an expansive pool of potential members. Furthermore, almost 70% of respondents already advertise the CUE website and its resources on their own websites. CUE has established a strong and diverse following on social media in recent months, having gained over 90 Twitter followers in the past six months alone (206 Followers as of April 20<sup>th</sup>, 2015), and having 260 members on its Facebook Group page. CUE ensures that its membership is informed and made aware of opportunities to communicate with healthcare professionals and policy-makers. For example, CUE members shared comments on the IOM's "Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk" document, published in January 2015.

In addition, since 2007, the CUE Clearinghouse has successfully matched patient/consumer participants with health professional groups for 75 distinct projects (e.g., surveys, engagements to speak or attend conferences, review groups, and clinical practice guideline advisory panels). The number of Clearinghouse requests pertaining to advisory panel projects has increased in recent years; between 2007 and 2012, CUE received 12 requests for patient/consumer participants to sit on advisory panels. From 2012 to 2014, the Clearinghouse received 18 such requests. In 2014 alone, CUE successfully matched eight consumers with professional partner organizations that are engaged in research implementation: two surveys; two conference/webinars, and four advisory panels (Appendix F).

## **F. Conclusions**

CUE is a unique organization in the United States and indeed the world. In 12 years, it has grown from a few organizations working together on EBHC, to a stable, sustainable organization in its own right. Its initial start-up support and the development of the online course was piggybacked onto a large conference grant awarded to the USCC by AHRQ. Currently, it is supported by a 3-year large conference grant for \$150,000. Each grant we apply for and receive that supports CUE's work contributes to a stable infrastructure, and allows us to apply for additional resources and bolster CUE's capacity generally.

## References

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4. Whitlock, E. P., Lopez, S. A., Chang, S., Helfand, M., Eder, M., & Floyd, N. (2010). AHRQ series paper 3: Identifying, selecting, and refining topics for comparative effectiveness systematic reviews: AHRQ and the effective health-care program. *J Clin Epidemiol* 63(5): 491–501.
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April 15, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Kay,

As a Co-Chair of the Steering Committee for Consumers United for Evidence-based Healthcare's (CUE), I agree to enthusiastically lend my support to your application to the Agency for Healthcare Research and Quality (AHRQ) for a 3-year large conference grant. The preceding funds afforded to you by AHRQ has allowed CUE to grow substantially, establishing a reputation for quality educational offerings for consumer advocates.

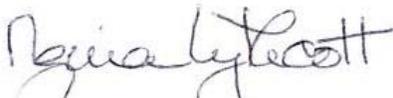
My experience as a [REDACTED] has provided me with a strong interest in empowering consumers by informing them about evidence-based healthcare and all that it entails. I have served as the Breast Cancer Liaison for the Black Women's Health Imperative (BWHI) for over 15 years. I represent BWHI as a member of the Department of Defense, the Breast Cancer Research Program Integration Panel, and for CUE. I also serve as a Board member of Breast Cancer Action.

As a founding member of CUE, I played a major role in the conception, development, and implementation of many of CUE's conferences, their two Summits, informational videos, and short courses. CUE has a comprehensive educational resource bank, which includes the widely successful short course, *Understanding Evidence-based Healthcare: A Foundation for Action*, 15 minute lectures by world-class leaders presenting at CUE's conferences, and a host of web-based links and tools pertaining to evidence-based healthcare. All of CUE's online courses and other resources are offered free of charge to the public.

The effects of the high level training, the dissemination of evidence-based resources and information, and the long term commitment to consumer engagement by CUE are far-reaching. I am continuously amazed by CUE-educated consumers as they are responsible, well-prepared participants in guideline and advisory panels. It is important that CUE provides consumers and patients with the necessary resources and forums to become more effective contributors as well.

I wish you the best of luck with your grant application and foresee important gains to be made if it is funded, in terms of patient and consumer engagement at the stage of research implementation and impact.

Sincerely,



Ngina Lythcott, RN, MSW, Dr.PH



April 27, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Dr. Dickersin,

As a CUE Steering Committee member, I give my enthusiastic support to Consumers United for Evidence-based Healthcare (CUE), as you apply for a 3-year large conference grant from the Agency for Healthcare Research and Quality (AHRQ). The funding afforded to you to date has allowed CUE to grow in size and influence, with a reputation of quality educational offerings and the unique position of having members with minimal industry influence.

Your proposal aims to host a series of in-person conferences in 2016, 2017, and 2018, in which research findings and evidence-based information and tools are summarized, communicated and used by organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services. These conferences will serve to build capacity among consumer health groups and present opportunities for consumers and scientists to establish partnerships with one another.

As Program Director for Health System Transformation at Families USA, I have an invested interest in improving healthcare delivery and quality through evidence-based medicine, care coordination, patient-centered outcomes research, health information technology (HIT), and quality measurement. These interests align strongly with those of CUE, as we work together to promote patient and consumer advocacy in healthcare research and implementation. With this conference grant, CUE will continue to work to improve the quality, safety, efficiency, and effectiveness of healthcare for all American consumers.

Through CUE, we have been able to partner with other CUE member organizations in such activities as co-leading workshops and presentations at CUE meetings, planning the CUE Summit and Annual Meeting agendas, and reviewing the online course, *Understanding Evidence-based Healthcare*, among other activities. CUE has a comprehensive educational resource bank, which includes the widely successful short course, *Understanding Evidence-based Healthcare: A Foundation for Action*, 15 minute lectures by world-class leaders presenting at CUE's conferences, and a host of web-based links and tools pertaining to evidence-based healthcare. All of CUE's online courses and other resources are offered free of charge to the public, allowing CUE's influence to extend beyond that of just conferences and workshops alone.

I look forward to a continued partnership with CUE and wish you success with your grant application!

Sincerely,

A handwritten signature in black ink, appearing to read "C. Morris", is written over a light gray rectangular background.

Caitlin Morris  
CUE Steering Committee

[FamiliesUSA.org](http://FamiliesUSA.org)

1201 New York Avenue, NW, Suite 1100  
Washington, DC 20005

main 202-628-3030 / fax 202-347-2417



April 15, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Kay,

I am writing to express my enthusiastic support for your application to the Agency for Healthcare Research and Quality (AHRQ) for a Conference Grant Program Award. I am pleased to serve in partnership with the CUE Steering Committee for Consumers United for Evidence-based Healthcare's (CUE's) dissemination and implementation conference series project. Together we form the conference Planning Committee. Your proposal aims to host a series of conferences in which research findings and evidence-based information and tools are summarized, communicated and used by organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services.

I understand that you are planning to apply to funding agencies for grants that will allow you to expand the Year 02 CUE Annual Meeting into a CUE Summit, open to the public. This is wonderful. I have participated in CUE Summits before, and they are informative and stimulating events. Your plans to partner with the Guidelines International Network/North America (G-I-N/NA) on the Summit is a great idea, one we have explored earlier this year with the G-I-N and G-I-N/NA leadership, where it met with a favorable response. I know that this application is only for support of the Annual Meeting, but I commit to partnering with CUE whether the 2017 meeting expands to a Summit or remains an Annual Meeting.

As the current Chair of G-I-N/NA, I have worked extensively with CUE over the past few years. As partners in the push for consumer involvement in guideline development and better healthcare, CUE and G-I-N/NA have supported each other in their efforts. I have attended many of CUE's Annual Meetings and International Summits during which I was given the opportunity to speak to CUE members about G-I-N/NA and the importance of consumer involvement in guideline development and other forms of research implementation. CUE has similarly contributed tremendously to G-I-N/NA webinars and conferences, most recently attending our Evidence-Based Guidelines Affecting Policy, Practice and Stakeholders Conference on March 2-3, 2015. CUE was able to recruit 20 consumer participants to attend this conference, which provided a rich source for our discussions and breakout sessions that may have otherwise gone untapped.

I am impressed by CUE-educated consumers as they are responsible, well-prepared contributors to guideline and advisory panels. CUE has a comprehensive educational resource bank, including the widely successful short course, *Understanding Evidence-based Healthcare: A Foundation for Action*, short videos of presentations by world-class leaders at CUE's past conferences, and a host of web-based links and tools pertaining to evidence-based healthcare. All of CUE's online courses and other resources are offered free of charge. The effects of the high-level training and long term commitment to consumer engagement by CUE are far-reaching and its aim to expand this level of education to the practice of guideline development is definitely a step in the right direction.

I wish you the best of luck with your grant application and foresee important gains to be made if it is funded, in terms of patient and consumer engagement at the stage of research implementation and impact.

Sincerely,



Marguerite A. Koster, MA, MFT  
Chair, Guidelines International Network/North America



lymedisease.org

Advocacy, Education and Research

April 27<sup>th</sup>, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Dr. Dickersin,

As co-chair of the CUE Steering Committee, I offer my enthusiastic support of the US Cochrane Center and Consumers United for Evidence-based Healthcare (CUE), as you apply for a 3-year large conference grant from the Agency for Healthcare Research and Quality (AHRQ). The funding afforded to you to date has allowed CUE to grow in size and influence, with a reputation of quality educational offerings and the unique position of having members with minimal industry influence. As Chief Executive Officer of LymeDisease.org, a CUE member organization, I have seen first-hand the great impact CUE has had on my organization's internal thinking, our work with other organizations, and the information we distribute to those in our community.

LymeDisease.org brings a large constituency and a dedication to promoting a central voice for Lyme patients across the nation through advocacy, education, and research. In turn, CUE has allowed us to partner with other CUE member organizations in such activities as co-leading workshops and presentations at CUE meetings and conferences, planning the CUE Summit and Annual Meeting agendas, and reviewing the online course, *Understanding Evidence-based Healthcare*, among other resources and tools developed by CUE.

Our involvement with CUE has provided my organization with an enhanced understanding of the needs of different patient groups involved in evidence-based healthcare. Watching the approaches of different groups and recognizing a common theme shared by organizations that are trying to responsibly give voice to patients in a manner that can be heard and that is consonant with evidence based approaches has expanded our way of looking at the world. It is, in a sense, a form of education by immersion.

The core of what CUE is accomplishing is a culture change that occurs by educating the patient voice in the principles of evidence based healthcare and placing that educated voice in the heart of the vital discussions taking place in panels, in presentations, and at policy making forums that are shaping healthcare today. I wish you success with your grant application!

Sincerely,

Lorraine Johnson  
Co-chair, CUE Steering Committee





**NATIONAL CENTER FOR  
HEALTH RESEARCH**  
The Voice For Prevention, Treatment And Policy

April 23, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Kay,

I am writing to show my enthusiastic support to your application to the Agency for Healthcare Research and Quality (AHRQ) for a 3-year large conference grant. As the Consumers United for Evidence-based Healthcare (CUE) representative for the National Center for Health Research (NCHR) and a CUE Steering Committee member, I have an invested interest in ensuring that all consumers understand and can implement findings from research for evidence-based healthcare.

I have had 20 years of organizing experience, including working on consumer health issues, with the National Center for Health Research (NCHR), US PIRG and the Progressive Leadership Alliance of Nevada (PLAN). As the Government Relations Manager for NCHR, I have reached out to other nonprofit organizations and helped to organize their policy positions on health care issues for the Patient, Consumer, and Public Health Coalition.

The effects of the high level training, the dissemination of evidence-based resources and information, and the long term commitment to consumer engagement by CUE are far-reaching. It is important that CUE provides consumers and patients with the necessary resources and forums to become more effective contributors as well. To help to achieve this goal, CUE has a comprehensive educational resource bank, which includes the widely successful short course, *Understanding Evidence-based Healthcare: A Foundation for Action*, 15 minute lectures by world-class leaders presenting at CUE's conferences. CUE also has a host of web-based links and tools pertaining to evidence-based healthcare. All of CUE's online courses and other resources are offered free of charge to the public, allowing CUE's influence to extend beyond that of just conferences and workshops alone.

I wish you the best of luck with your grant application and foresee important gains to be made if it is funded.

Sincerely,

A handwritten signature in black ink that reads "Paul R. Brown".

Paul Brown  
National Center for Health Research



April 17, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Dr. Dickersin,

As a CUE Steering Committee member, I offer my enthusiastic support of the US Cochrane Center and CUE – Consumers United for Evidence-based Healthcare, as you apply for a 3-year large conference grant from the Agency for Healthcare Research and Quality. The funding afforded to you to date has allowed CUE to grow in size and influence, with a reputation of quality educational offerings and the unique position of having members with minimal industry influence.

Your proposal aims to host a series of in-person conferences in 2016, 2017, and 2018, in which research findings and evidence-based information and tools are summarized, communicated and used by organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services. These conferences will serve to build capacity among consumer health groups and present opportunities for consumers and scientists to establish partnerships with one another.

The National Consumers League (NCL) brings a dedication to promoting social and economic justice for consumers and workers. The participation of each CUE member organization serves to enrich the activities of CUE, and in particular, NCL brings its experience as the nation's oldest consumer organization and ability to bring diverse stakeholders together to work on issues of common interest.

In turn, CUE has allowed us to partner with other CUE member organizations in such activities as co-leading workshops and presentations at CUE meetings and other member's organizational meetings, drafting testimony to the IOM on essential benefits, planning the CUE Summit and Annual Meeting agendas, introducing CUE to the Patient-Centered Outcomes Research Institute, and reviewing the online course, *Understanding Evidence-based Healthcare*, among other activities.

I look forward to a continued partnership with CUE as we are on the cusp of seeing the highest level of consumer involvement in healthcare and healthcare research that there has ever been in the United States.

Sincerely,

Sincerely,

A handwritten signature in black ink that reads "Rebecca Burkholder". The signature is written in a cursive, flowing style.

Rebecca Burkholder, JD  
National Consumers League  
CUE Steering Committee



Barbara E. Warren, Psy.D.  
Director, LGBT Programs and Policies  
Office of Diversity and Inclusion, Mount Sinai Health System  
Office: Mount Sinai Beth Israel 10 Union Square East, Suite 2K-03  
New York, New York 10003  
Phone: [212-844-6389](tel:212-844-6389)  
Cell:  
[Bwarren@chpnet.org](mailto:Bwarren@chpnet.org)

April 27, 2015

Kay Dickersin, MA, PhD  
Director, the United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Kay,

I am writing to express my support for Consumers United for Evidence-based Healthcare's (CUE's) 3-year large conference grant application from the Agency for Healthcare Research and Quality (AHRQ). CUE has grown substantially in size and influence, and has been awarded funds from AHRQ since its conception. These funds have helped CUE to establish a reputation of quality educational offerings and the unique position of having members with minimal industry influence.

Your proposal aims to host a series of in-person conferences in 2016, 2017, and 2018, in which research findings and evidence-based information and tools are summarized, communicated and used by organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services. These conferences will serve to build capacity among consumer health groups and present opportunities for consumers and scientists to establish partnerships with one another.

As a Steering Committee member and co-founder of CUE, I played a major role in the conception, development, and implementation of many of CUE's conferences, their two Summits, informational videos, and short courses. CUE has a comprehensive educational resource bank, which includes the widely successful short course, *Understanding Evidence-based Healthcare: A Foundation for Action*, 15 minute lectures by world-class leaders presenting at CUE's conferences, and a host of web-based links and tools pertaining to evidence-based healthcare. All of CUE's online courses and other resources are offered free of charge. My organization strongly encourages all consumer advocates to take advantage of these resources.

As Director for LGBT Health Services at Mount Sinai Beth Israel/Mount Sinai Health System in New York City, I have an invested interest in promoting the patient voice in evidence-based healthcare, particularly those of priority populations like LGBTs. I have extensive experience in training consumer organizations and patients in understanding and using evidence-based healthcare in shared decision making and on how to participate effectively as a consumer in guideline development and other forms of research implementation.

I sincerely hope your application is approved and that we can continue working to establish the consumer voice in evidence-based healthcare through our work with CUE.

Sincerely,

Barbara Warren  
CUE Steering Committee

April 15, 2015

Kay Dickersin, MA, PhD  
Director  
The United States Cochrane Center  
Department of Epidemiology  
Johns Hopkins Bloomberg School of Public Health  
615 North Wolfe Street, Mail Room W5010  
Baltimore, MD 21205 USA

Dear Kay,

I am writing to express my support for Consumers United for Evidence-based Healthcare's (CUE's) 3-year large conference grant application from the Agency for Healthcare Research and Quality (AHRQ).

Your proposal aims to host a series of in-person conferences in 2016, 2017, and 2018, in which research findings and evidence-based information and tools are summarized, communicated and used by organizations and individuals that have the capability to use the information to improve the outcomes, quality, access to, and utilization of healthcare services. These conferences will serve to build capacity among consumer health groups and present opportunities for consumers and scientists to establish partnerships with one another.

I currently serve as a representative to CUE for the National Committee to Preserve Social Security and Medicare. CUE has a comprehensive educational resource bank, which includes the widely successful short course, *Understanding Evidence-based Healthcare: A Foundation for Action*, 15 minute lectures by world-class leaders presenting at CUE's conferences, and a host of web-based links and tools pertaining to evidence-based healthcare. My organization strongly encourages all consumer advocates to take advantage of these resources. All of CUE's online courses and other resources are offered free of charge.

From working with CUE, I know that the effects of the high level training and long term commitment to consumer engagement already provided by CUE are far-reaching. The partnerships that CUE provides between consumers and patients with professional groups that are convening advisory panels, through its Clearinghouse, are vital to the advancement of healthcare and ensuring an impact of evidence-based healthcare and patient-centered research.

I also have extensive experience in working with consumer advocacy groups. I currently volunteer for the Virginia Insurance Counseling and Advocacy Program (Virginia's SHIP program) and previously was a health government affairs representative for Consumers Union (the independent, non-profit publishers of *Consumer Reports*) and have worked as Director of Government Relations for Families USA, a national health advocacy organization that is another member of CUE. In the past, I have been deeply involved in health policy, having worked for thirty-six years for various members of the House of Representatives' Ways and Means Committee and as Health Subcommittee Staff Director for the Minority.

I hope we get this grant application because of the important gains to be realized in terms of patient and consumer engagement at the stage of research implementation and impact.

Sincerely,

William K. Vaughan  
Vice Chair, Board of Directors  
National Committee to Preserve Social Security & Medicare