

Eugene Washington PCORI Engagement Award Program

Engagement Awardee Lunch and Learn:
Engagement in Practice - Success Stories
Across PCORI-funded Projects

June 9, 2021



Agenda



Introduction

Awardee Presentations

- Megan Morris, PhD, MPH
 - [University of Colorado Denver](#)
- Kemi Doll, MD, MS
 - [University of Washington](#)

Q&A

Wrap-Up

Housekeeping



- This webinar is available to the public and is being recorded.
- The slides and webinar recording will be made available on PCORI's website following the webinar.
- Attendees are in listen-only mode.
- To learn more about the awardees presenting in this webinar and their Eugene Washington PCORI Engagement Award projects, click [here](https://www.pcori.org/events/2021/engagement-awardee-lunch-and-learn-engagement-practice-success-stories-across-pcori):

[https://www.pcori.org/events/2021/engagement-awardee-lunch-and-learn-engagement-practice-success-stories-across-pcori.](https://www.pcori.org/events/2021/engagement-awardee-lunch-and-learn-engagement-practice-success-stories-across-pcori)

Welcome



Eugene Washington PCORI Engagement Award Program Background



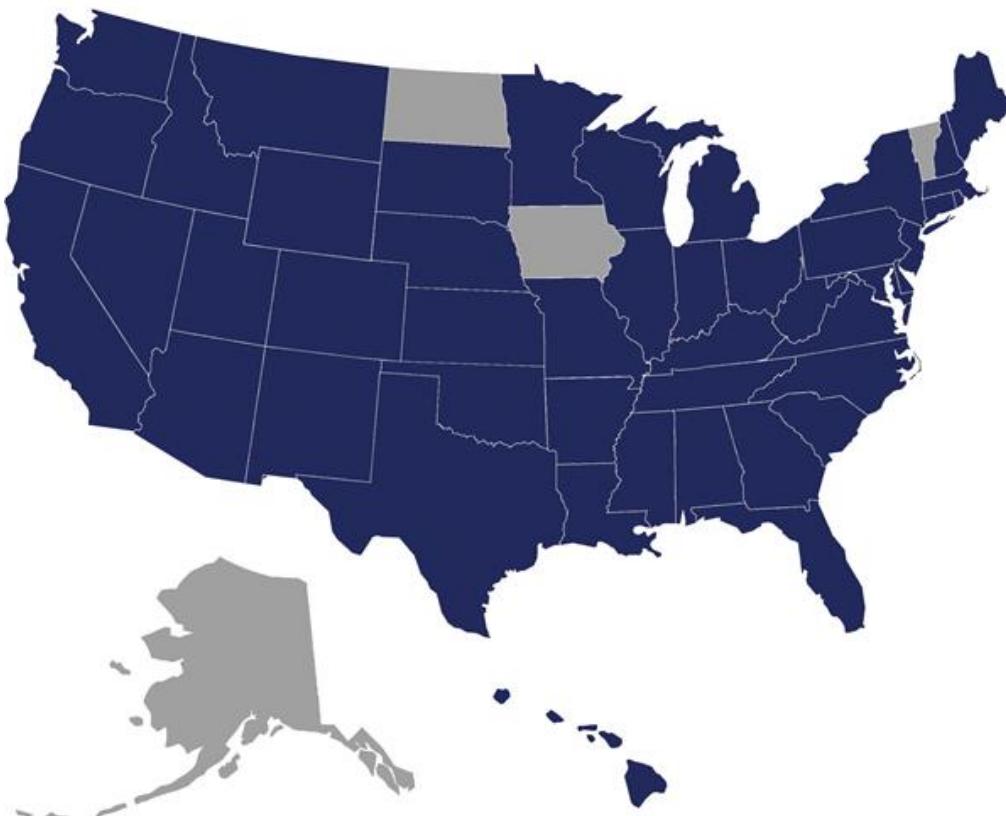
- Support projects to build a community of patients and other stakeholders equipped to participate as partners in patient-centered outcomes research/comparative clinical effectiveness research (PCOR/CER), as well as serve as channels to disseminate PCORI-funded study results
- Funding for projects and conferences, NOT research



Building a National Network for PCOR



- Approximately \$118.6 million awarded since 2014, creating an expansive network of individuals, communities and organizations interested in and able to participate in PCOR/CER



Engagement in Practice



- Exploring key aspects in successfully moving research forward with a focus on stakeholder engagement
- Learning objectives:
 - Identify examples of how engagement strategies utilized in research support projects, such as Engagement Awards, complement and impact strategies applied within PCOR/CER studies
 - Describe the range of ways awardees and partners work together in PCORI-funded projects from building capacity for research within Engagement Awards to successfully moving forward in conducting research studies
 - Learn how engagement strategies have been adapted to engage stakeholders safely in a virtual setting given the evolving context around the COVID-19 pandemic

Advancing Healthcare Equity for Patients with Disabilities

Research and Engagement Award

Megan Morris, PhD, MPH, CCC-SLP

University of Colorado
Anschutz Medical
Campus



Acknowledgement and Disclaimer



- These studies were funded through a Patient- Centered Outcomes Research Institute® (PCORI) Research Award and Eugene Washington PCORI Engagement Award (12754-UCD, AD-2019C1-15642).
- The statements presented in this presentation are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI), its Board of Governors, or Methodology Committee.

Disability in the US

1 in 4
adults live
with a
disability



Significant Health and Healthcare Disparities



2.7x



3x



6x



54% v. 83%



1 in 3



3x

Engaging with Stakeholders: 2014



- Engaged with Partnerships for Improving Patient Care (PIPC)
 - Consortium of disability advocacy organizations
- Travelled to DC to meet with PIPC multiple times
- Multiple listening sessions to discuss their priorities
 - Developed research questions based on their priorities and aligned with PCORI's mission and priorities

Timeline



- 2014
 - Submitted first proposal for **Research Award**
- 2017
 - Resubmitted proposal for **Research Award**
 - Submitted for the **Engagement Award**
- 2018
 - Resubmitted proposal for **Research Award**
 - Resubmitted for the **Engagement Award**
- 2019
 - Resubmitted **Research Award**
 - Started **Engagement Award**
- 2020
 - Started **Research Award**

Engagement Award: Learning Collaborative to Address Disability Equity in Healthcare



- **Objectives:** The long-term goal is to develop and implement Learning Collaborative to Address Disability Equity in Healthcare (LEADERs), a sustainable learning collaborative.
 - Develop a national advisory committee of key stakeholders
 - Engage key stakeholders to understand their priorities for PCOR to address disability healthcare disparities
 - Develop a sustainable infrastructure for engaging and disseminating research findings to the LEADERs

Research Award: INTERACT Trial



- **Study Objective:**
 - Compare the effectiveness and implementation of 2 interventions to increase primary care providers' use of evidence-based communication strategies, improving the quality of their communication with patients with communication disabilities.
 - 8 primary care sites across 4 sites in the US
 - Focus is on communication disabilities (14% of US population)
 - Hearing
 - Speech
 - Language
 - Voice

Engagement Award

- Increased interest in the Learning Collaborative
 - Began meeting weekly
 - Put together website of resources
- In-person meeting reimagined
 - Virtual meeting of 80 people over two days
- COVID-19 Enhancement
 - Expand the Learning Collaborative
 - Engage Stakeholders to understand effects of COVID-19 on care for persons with disabilities

Research Award

- Delayed timeline
- Additional qualitative work to understand adaptations to interventions for a post-COVID world

Benefits of Both Mechanisms: Planning



Engagement Award -> Research Award

- Help with identifying and modifying research questions
- Help with letters of support for application (strengthened application)
- Identify Advisory Board members
- Method to continually engage stakeholders while waiting for Research Award funding

Benefits of Both Mechanisms: Conducting



Engagement Award -> Research Award

- Develop engagement strategies
- Allow us to quickly incorporate COVID-19 related modifications
- Understanding what are challenges on the “front lines”

Benefits of Both Mechanisms: Dissemination



Research Award -> Engagement Award

- Tools and results will be immediately disseminated

Lessons Learned



- Engage Stakeholders early and often
- Be persistent in engagement and funding
- Listen and be flexible to what the stakeholders need
- Be honest and upfront with research process

Engagement Award

- Instrumental in engaging a wide range of stakeholders
- Provided a foundation for both a Research Award and future collaborations

Research Award

- Application was strengthened by Engagement Award support
- Active communication between the Research project and the Engagement Award

Thank you!

PCORI for funding of both awards
Courtney Clyatt and Mari Kimura

PIPC
University of Colorado team
Advisory Committees

Contact information:

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References



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Seeking Black Women's Voices in Endometrial Cancer Research via Deliberate Community Engagement

Research and Engagement Award

Kemi Doll, MD, MS

University of Washington



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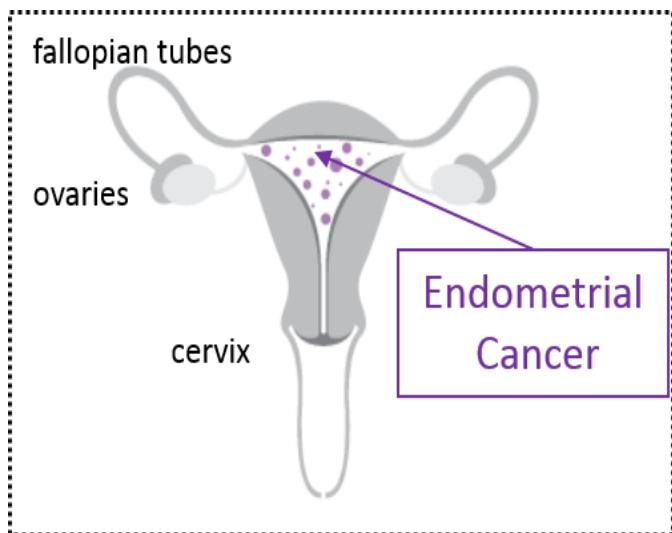
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Engagement

Seeking Black Women's
Voices in Endometrial
Cancer Research via
Deliberate Community
Engagement



Endometrial Cancer



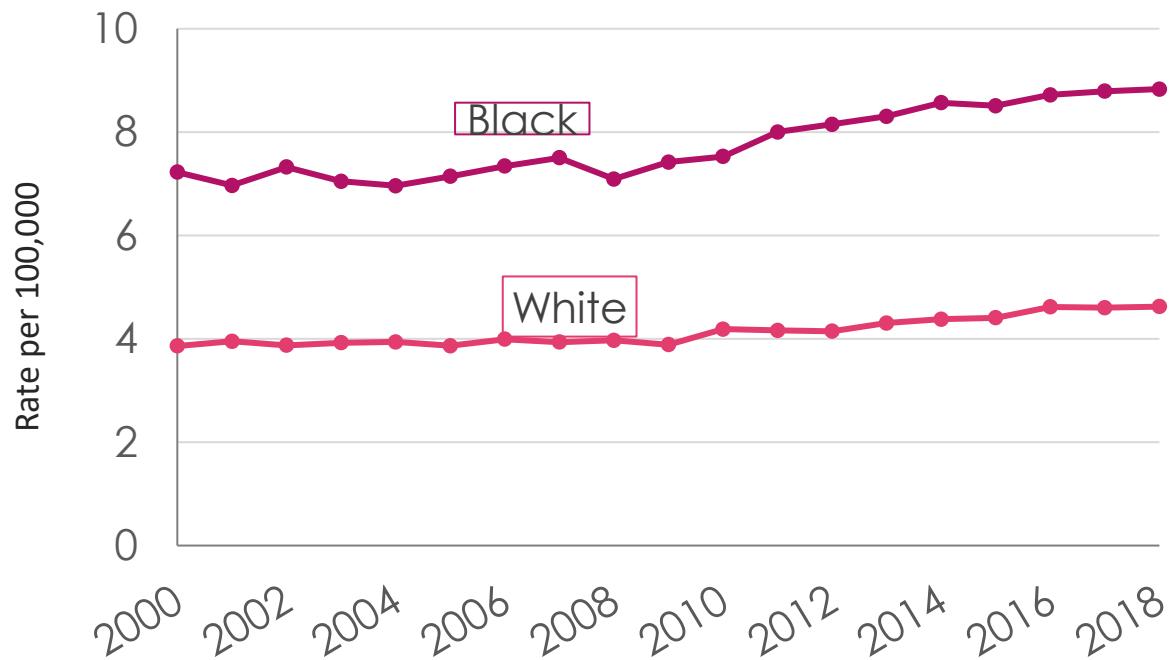
63,000 cases/ year

Lifetime risk in US: 3%

1 in 37 women by age 80

5-year survival: 81%

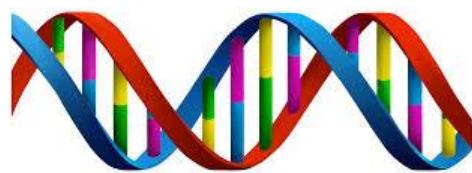
US Endometrial Cancer Statistics by Race/Ethnicity: Mortality



Data from: SEER cancer statistics review 1975-2018, Available at: seer.cancer.gov

Endometrial cancer disparities: a race-conscious critique of the literature

Kemi M. Doll, MD, MS; Cyndy R. Snyder, PhD; Chandra L. Ford, PhD, MPH, MLIS



How has knowledge about Black women with EC been constructed?

Race defined as a biological/genetic entity



1995...1996.....2004..2005.....2015 2016
Observational studies documenting surgical disparities

No work to address repeated documented treatment inequity



Assumptions that healthcare environments represent 'color-blind'



Absence of the Black woman's voice

Doll KM, Snyder C, Ford CL. *AJOG*. Sept 2017.

Eugene Washington PCORI Engagement Award December 2017-2019



ecana

Endometrial Cancer
Action Network for
African-Americans

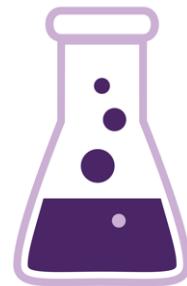
<https://ecanawomen.org>



COMMUNITY



EDUCATION



RESEARCH

Eugene Washington PCORI Engagement Award December 2017-2019



Objective 1

Create ECANA: a formal organization of patients, caregivers, clinicians, and researchers to facilitate PCOR in EC

Objective 2

Build a website for patients that will provide PCOR training, solicit research priorities, and link researchers to patient partners

Objective 3

Update and adapt published research priorities in EC to include the input of African-American women affected by the disease

Eugene Washington PCORI Engagement Award December 2017-2019



1



Community Education Research News & Events About [Donate](#)

WHO WE ARE

ECANA: Endometrial Cancer Action Network for African-Americans

We are a group of women who have come together to create support, community, and empowerment for any African-American woman affected by endometrial cancer. We are patients, doctors, survivors, community advocates, and professional leaders all committed to one purpose: to support Black women affected by endometrial cancer.



OUR STORIES

Early Detection Will Save Your Life - with Jurline



"The Life You Save Is Going to Be Your Own!"
Join Jurline, endometrial cancer survivor and ECANA Ambassador, as she describes the life-saving benefits of early detection in her diagnosis journey.

ECANA: We Have a Voice - with Lisa



Lisa describes the feeling of finding a safety net among the ECANA community. She reminds us that it is imperative that Black EC survivors have a voice in the cancer and medical communities.

My Health Has to Come First - With Heide



Join Heide - attendee at ECANA's Conference for Community, Education, and Research Training - as she shares her journey from putting her health second, to putting it first. She shares the benefits of putting your health before other.

<https://ecanawomen.org>

- ▼ [How was I diagnosed with Endometrial Cancer?](#)
- ▼ [How will/did the doctor determine if I have Endometrial Cancer?](#)
- ▼ [How do I know what Stage and Grade of Endometrial Cancer I have?](#)
- ▼ [What is the treatment for Endometrial Cancer?](#)
- ▼ [What are the goals of treatment?](#)
- ▼ [How do I know if treatment is working?](#)

LEARN THE LINGO

vaginal ultrasound

endometrial cancer

stage

grade

Eugene Washington PCORI Engagement Award December 2017-2019



ECANA Conference Training for Community, Education, and Research



March 15th – 16th, 2019 Honolulu, HI
SGO Annual Meeting on Women's Cancer
<https://ecanawomen.org/ecanaconference>

Research

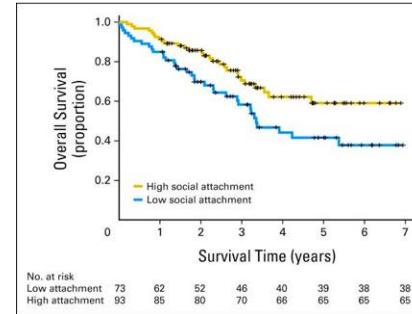
Social Interventions for
Support during Treatment
for Endometrial Cancer
and Recurrence
(The SISTER Study)



Social Isolation and Endometrial Cancer



- *Social isolation is associated with poor quality of life and lower overall survival in patients with cancer.*
- *There are several evidenced-based peer support strategies that decrease social isolation and improve treatment adherence.*
- *Current practice at comprehensive cancer centers is widely variable with regard to social support interventions.*



Lutgendorf SK, et al. JCO. 2012;30(23)



Table 1: Frequency and Variation of NCI Comprehensive Cancer Centers Offering Social Support Services (n=50)

	Any Cancer	Gynecologic Cancer
Self-directed written support information	14%	0%
Link to external written support	68%	34%
Support Groups		
Internal or Affiliate	26%	14%
Local, non-affiliate	86%	32%
1:1 Peer Support	22%	8%

Social Isolation and Endometrial Cancer



Evidenced-based peer support strategies have yet to be adapted and compared among Black women with EC, a growing high-need demographic.

"It also was very difficult, looking back, even thinking that now, how lonely I felt at times...the fact that I'm alone and I'm dealing with this."

– Adrienne, EC Survivor

Improving support for Black women with EC undergoing active treatment was identified as a priority area of research by the Endometrial Cancer Action Network for African Americans (ECANA)

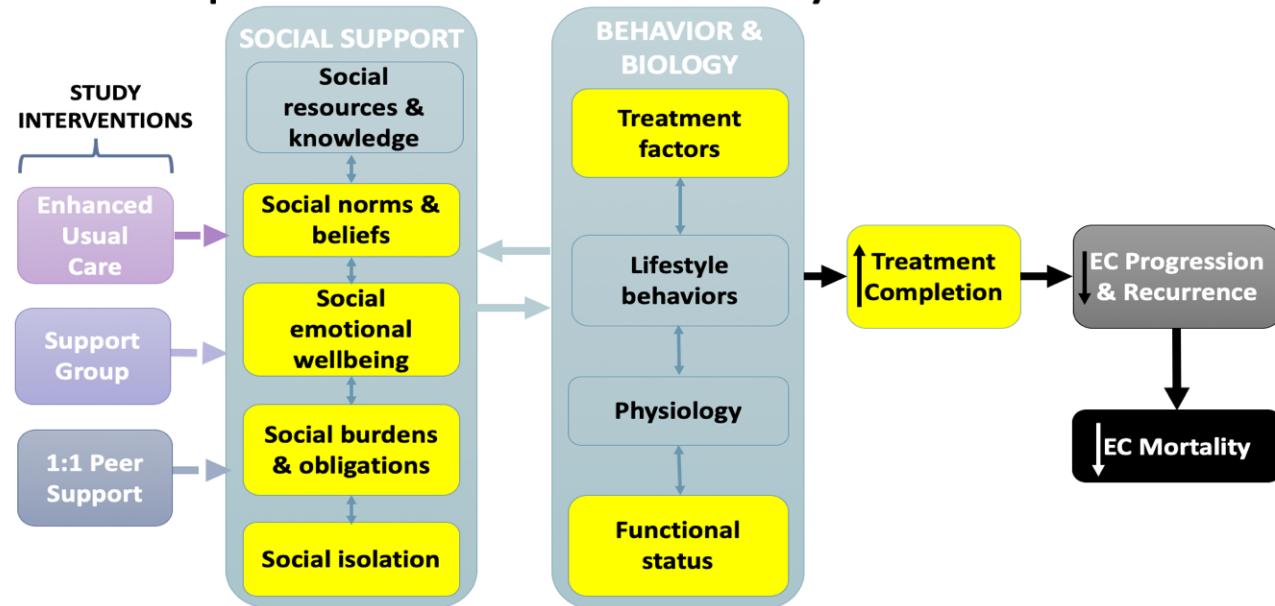
"What I would like to see and what I would have liked to have had is someone who's been through it already to be with me."

– Jurline, EC Survivor

Social Isolation and Endometrial Cancer



Figure 2: Conceptual Framework of the SISTER Study



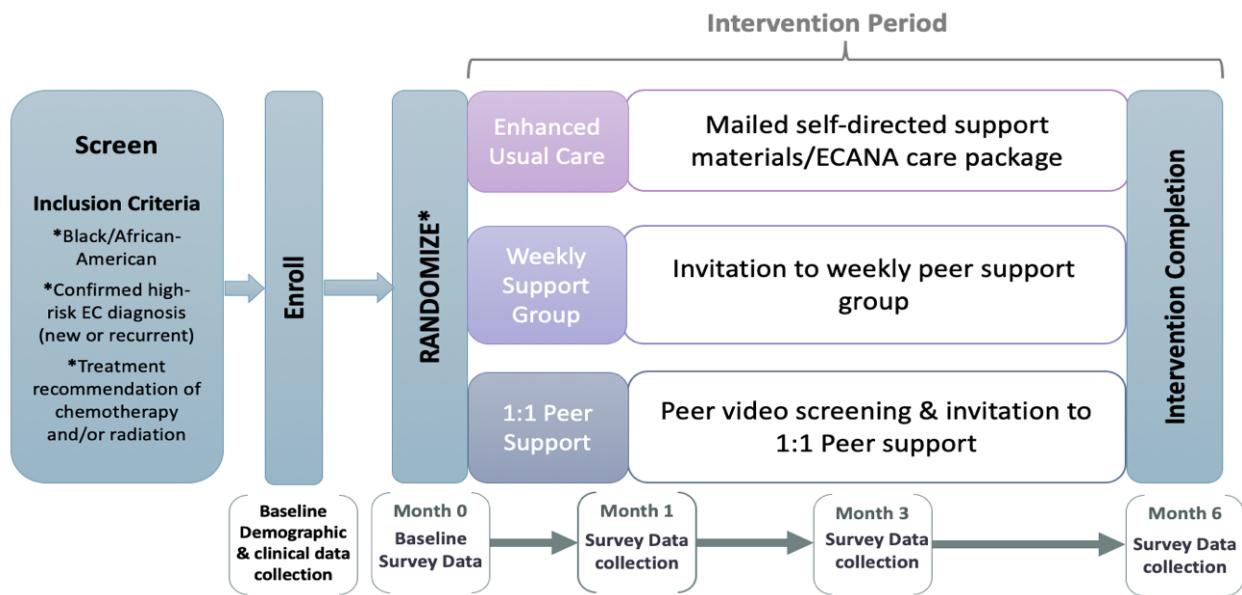
Note: Highlight indicates measured by The SISTER Study

Adapted from Kroenke CH et al. A conceptual model of social networks and mechanisms of cancer mortality, and potential strategies to improve survival. *Transl Behav Med.* 2018;8(4):629-642.

SISTER Study Goals and Design: 2021-2025



National Multi-Center Randomized Controlled Trial



SISTER STUDY SITES	
★	Primary research institution
★	Collaborative site
★	Clinical site – community
★	Clinical site – academic

Primary Outcome: Treatment Completion (Relative Dose)

Secondary Outcome: Social Isolation (Social Provisions Scale -24)

Reflections



Benefits to PCORI Support



A funding organization that 'gets' it.

- Funding to start from scratch
- Engagement-focused development incubator
- Flexibility of strong relationships and shared goals
- Tiered funding support matches professional development

Engagement Strategies are Durable



What got us here, keeps us going!

- Centering engagement principles—co-learning, shared power, and trust
- Facilitating growth & development of patient partners
- Leading with patient-centeredness, always
- Expanded view of power and trust with larger projects, teams, and funding
- Coaching/training new partners and collaborators to engagement culture

The SISTER Study – Organizational Chart



Data Coordinating Center (DCC)

Director: Bryan Comstock, MS
Lead Biostatistician: Sarah Monsell, MS

Intervention Coordinating Center (ICC)

Director: Kemi Doll, MD MS
Project Manager: Liz Sage, MPH

Stakeholder Coordinating Center (SCC)

Co-Directors: Danielle Lavallee PharmD, PhD,
Bridgette Hempstead
Project Manager: Julianna Alson, MPH

SISTERS SITES
Director: Liz Sage, MPH

University of North Carolina - REX
Site PI: Leslie Clark, MD

University of North Carolina – Chapel Hill
Site PI: Vickie Bae-Jump, MD, PhD

University Medical Center – New Orleans
Site PI: Navya Nair, MD, MPH

Johns Hopkins University
Site PI: Anna Beavis, MD, MPH

University of Chicago
Site PI: Nita Lee, MD, MPH

New York Presbyterian - Weill Cornell Medicine
Site PI: Ella Chapman-Davis, MD

NY Presbyterian – Brooklyn Methodist Hospital
Site PI: Ella Chapman-Davis, MD

University of South Alabama Health
Site PI: Rod Rocconi, MD, FACOG

U. of Washington/Seattle Cancer Care Alliance
Site PI: Kemi Doll, MD, MS

University of Arkansas for Medical Sciences
Site PI: Heather Williams, MD, MS

SISTERS PEER SUPPORTERS
Director: Adrienne Moore

Jurline Reddeaux, MSW

Jacquelyn Mbayo

Sheila Johnson

Martha Jean Williams

Margie Willis

Miche'al Hopkins

4 Additional TBD

External Advisory Board (EAB)

Wui-Jin Koh, MD
Monica McLemore, RN, PhD, FAAN
Joa Crear-Perry, MD, FACOG
Liz Swisher, MD
Scott Ramsey, MD, PhD
Abdulrahman Sinno, MD
Carol Brown, MD, PhD
Laurel Rice, MD
Michael Birrer, MD, PhD

Advocate Advisory Board (AAB)

Anissa Foster

Lisa Barr

Juanita Thomas

TBD Site Representative survivors or caregivers*

Lessons Learned



The relationships are the bedrock. Everything else can shift.

Meaningful engagement will never be wasted effort.

You can be learning and leading at the same time.

Each award application is a tool to create the content, relationship, and organizational structure you will need to do the work.

Contact Information



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Q&A and Wrap-Up



- Feel free to ask questions by typing into the Questions pane on the Control Panel.
- Recording and slides will be posted on the event page after the webinar.

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Thank You!

