

# Eugene Washington PCORI Engagement Award Program

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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](#)

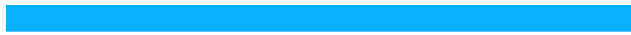
Q&A

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>.

# Welcome



# Eugene Washington PCORI Engagement Award Program Background

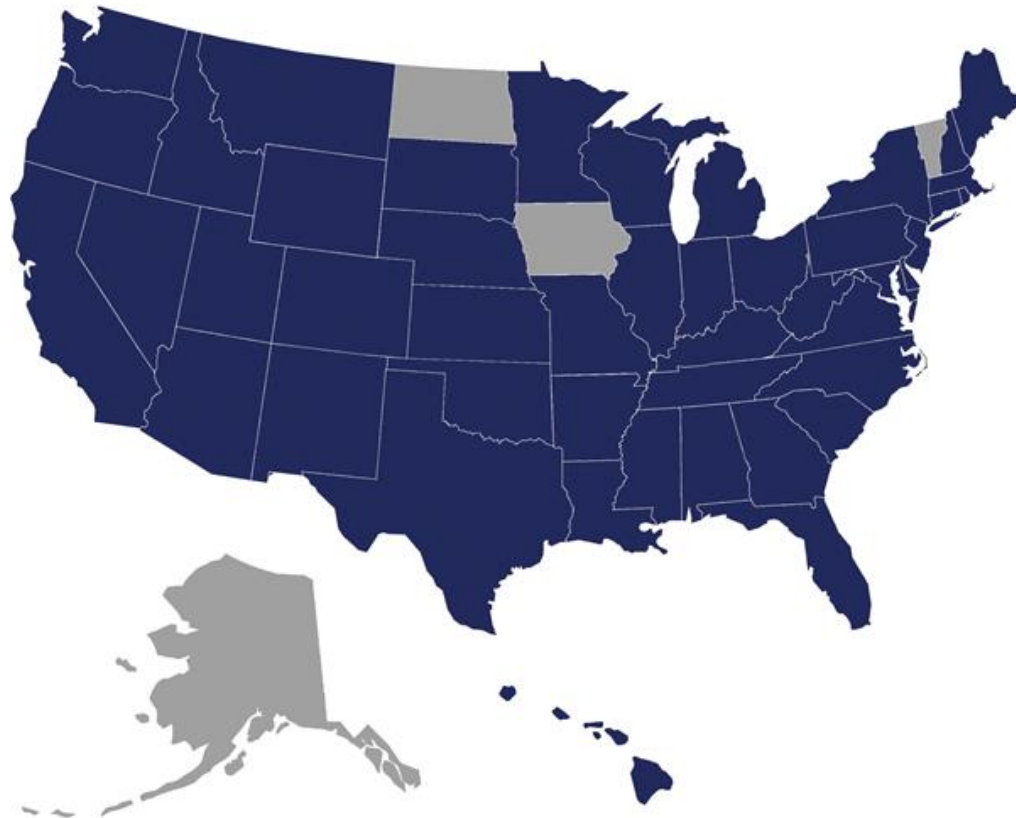


- Support projects to build a community of patients and other stakeholders equipped to participate as partners in patient-centered outcomes research/comparative clinical effectiveness research (PCOR/CER), as well as serve as channels to disseminate PCORI-funded study results
- Funding for projects and 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

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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 reimaged
  - 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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[megan.a.morris@cuanschutz.edu](mailto:megan.a.morris@cuanschutz.edu)

# References

- <https://www.cms.gov/files/document/federaldatadisability508.pdf>
- Gleason J, Ross W, Fossi A, Blonsky H, Tobias J, Stephens M. (2021) <https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051>
- <https://www.healthaffairs.org/doi/10.1377/hblog20210325.480382/full/>
- Iezzoni L. Eliminating health and healthcare disparities among the growing population of people with disabilities. *Health Affairs*. 2011 30(10)
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- Bartlett G, Blais R, Tamblyn R, Clermont RJ, MacGibbon B. Impact of patient communication problems on the risk of preventable adverse events in acute care settings. *CMAJ* 2008;178:1555-62.

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

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Research and Engagement Award

Kemi Doll, MD, MS

University of Washington

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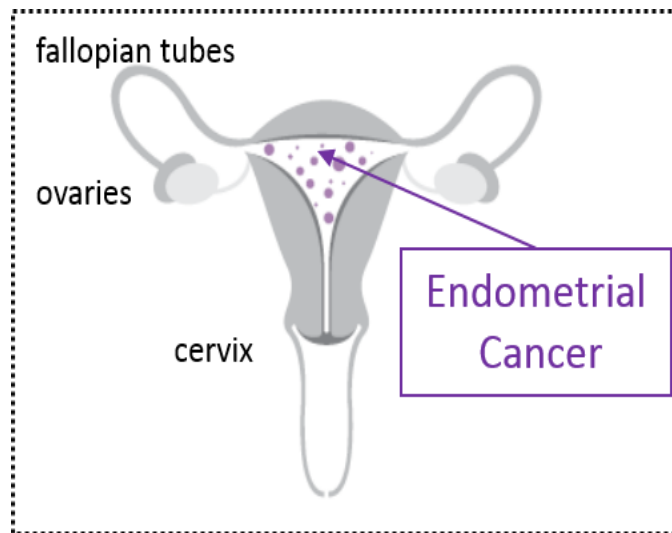
# Engagement

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



# Endometrial Cancer



63,000 cases/ year

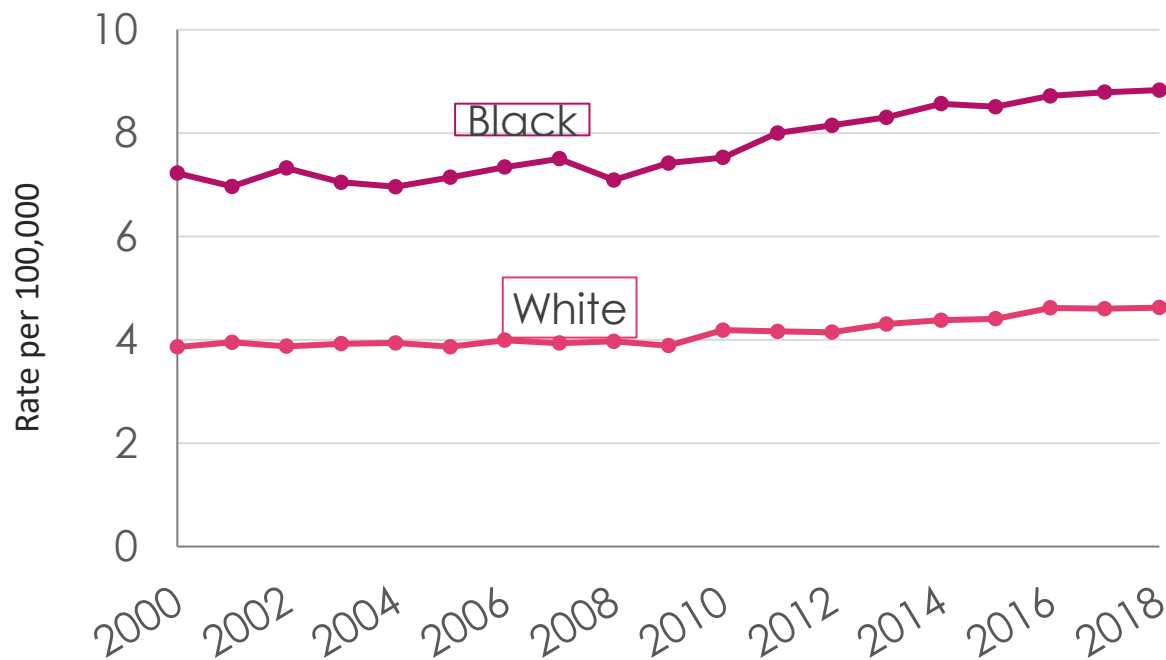
Lifetime risk in US: 3%

1 in 37 women by age 80

5-year survival: 81%

# Endometrial Cancer

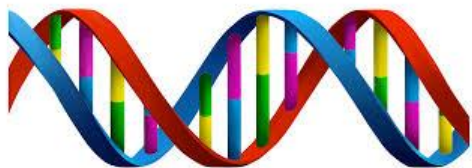
## US Endometrial Cancer Statistics by Race/Ethnicity: Mortality



Data from: SEER cancer statistics review 1975-2018, Available at: [seer.cancer.gov](https://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

Assumptions that healthcare environments represent 'color-blind'



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

No work to address repeated documented treatment inequity



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



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: the health and well-being of 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 15<sup>th</sup> – 16<sup>th</sup>, 2019 Honolulu, HI  
SGO Annual Meeting on Women's Cancer  
<https://ecanawomen.org/ecanaconference>

# Research

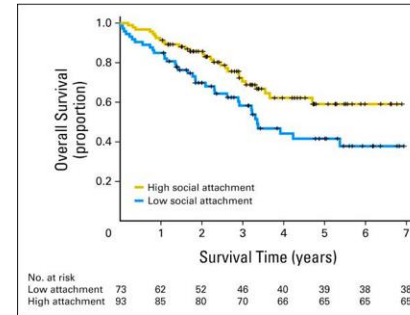
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Social Interventions for  
Support during Treatment  
for Endometrial Cancer  
and Recurrence  
**(The SISTER Study)**



# 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

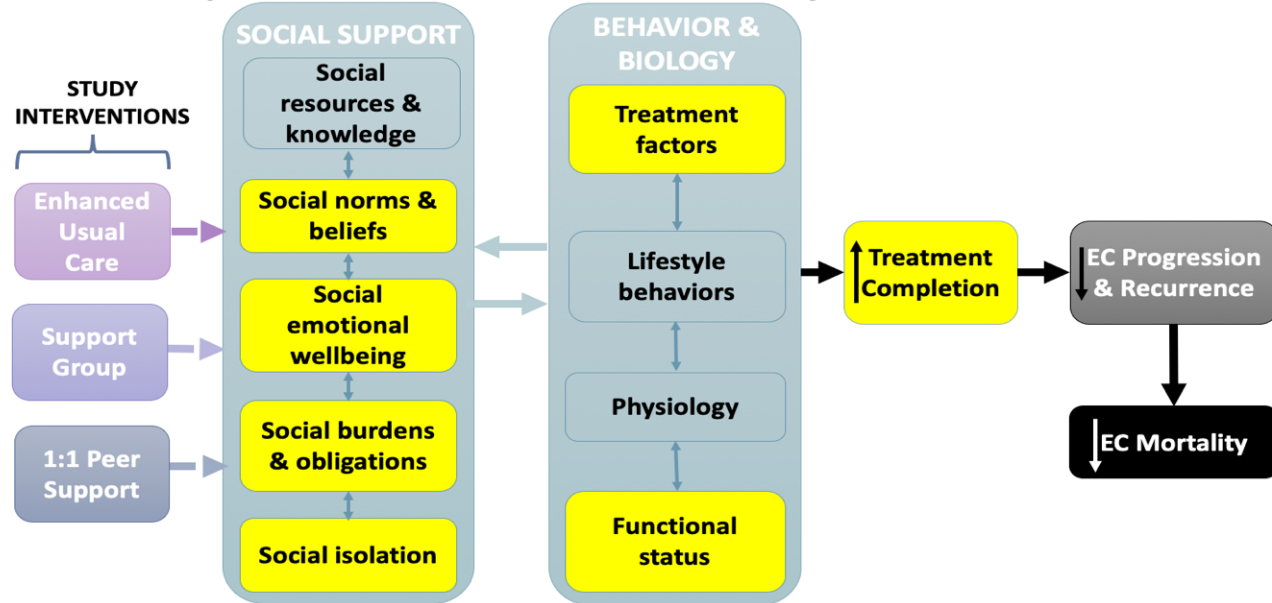
*Improving support for Black women with EC undergoing active treatment **was identified as a priority area of research** by the Endometrial Cancer Action Network for African Americans (ECANA)*

*"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

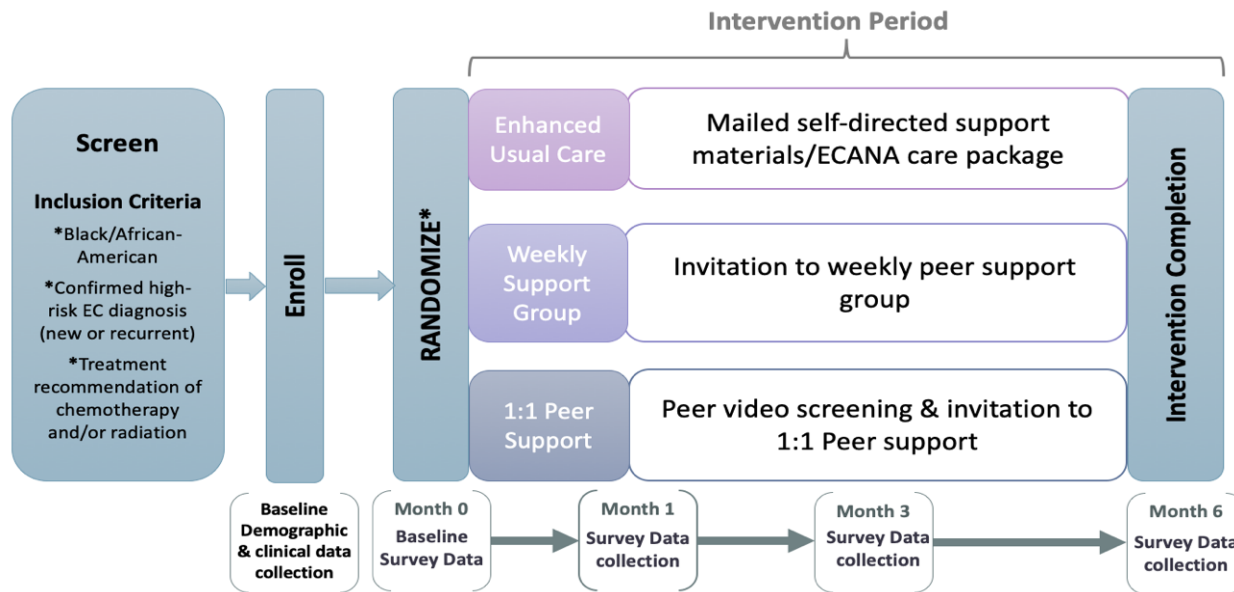


Note: Highlight indicates measured by The SISTER Study

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

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# Benefits to PCORI Support

## **A funding organization that 'gets' it.**

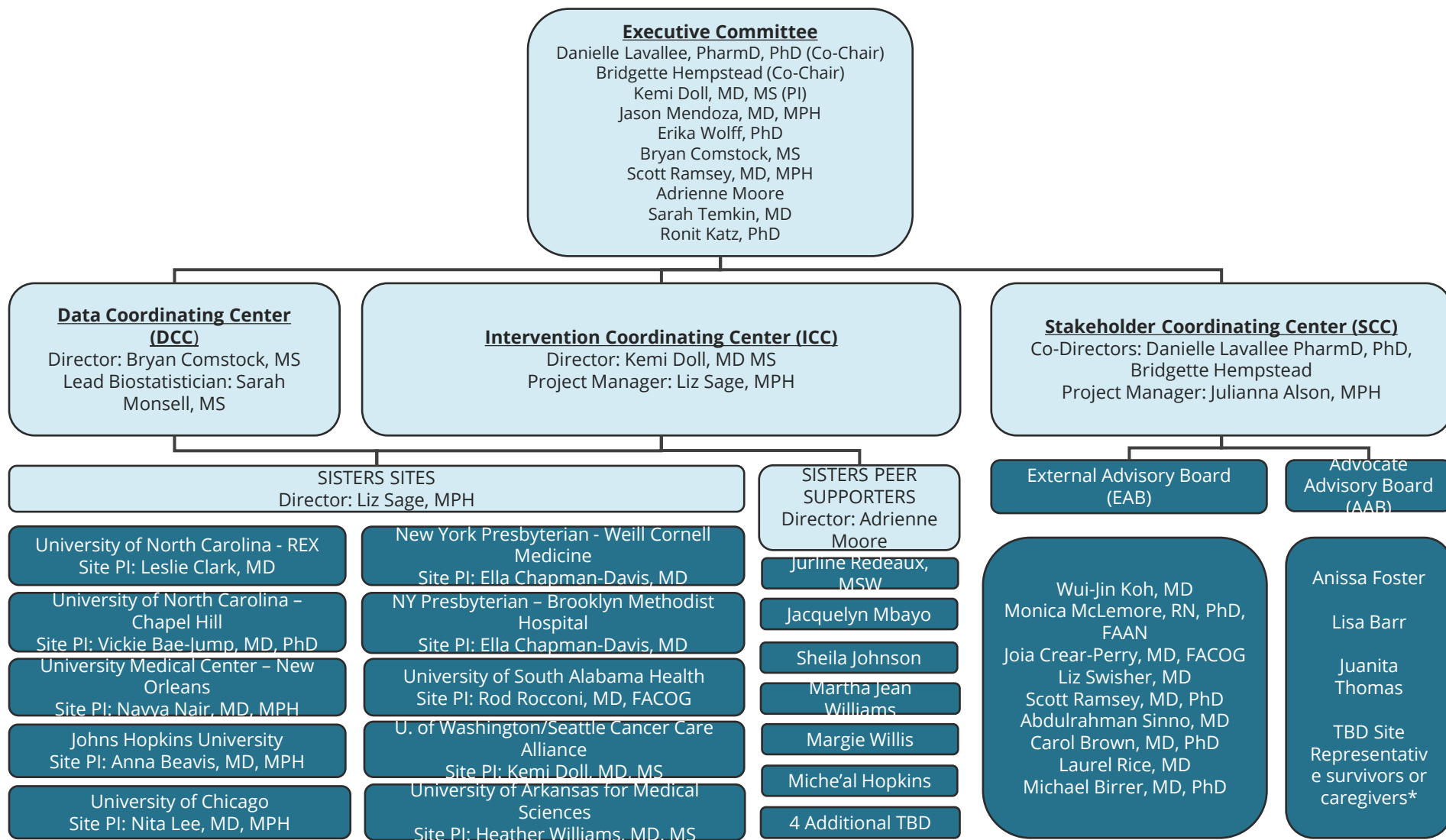
- Funding to start from scratch
- Engagement-focused development incubator
- Flexibility of strong relationships and shared goals
- Tiered funding support matches professional development

# 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



# 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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Visit: <https://www.pcori.org/engagement/eugene-washington-pcori-engagement-awards>

# Thank You!

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