

# 6TH ANNUAL VALUE IN CANCER CARE SUMMIT 2019




## A Patient-Centered Approach to Cancer Equity: Building a Bridge of Engagement



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- Founder of The Endometrial Cancer Action Network for African Americans (ECANA)
- Health services researcher in both the University of Washington School of Medicine and School of Public Health

# A Patient-Centered Approach to Cancer Equity: Building a Bridge of Engagement



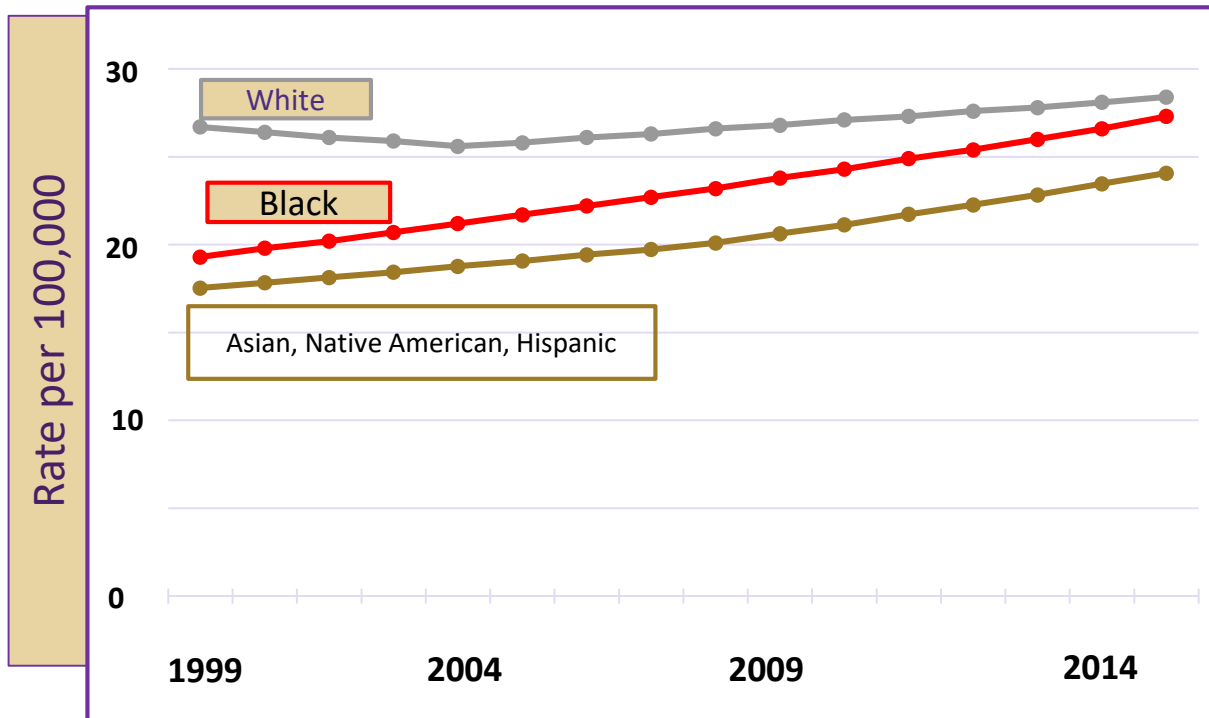
Kemi M. Doll, MD MSCR  
Division of Gynecologic Oncology  
Value in Cancer Care Summit  
May 13<sup>th</sup>, 2019

UNIVERSITY *of* WASHINGTON

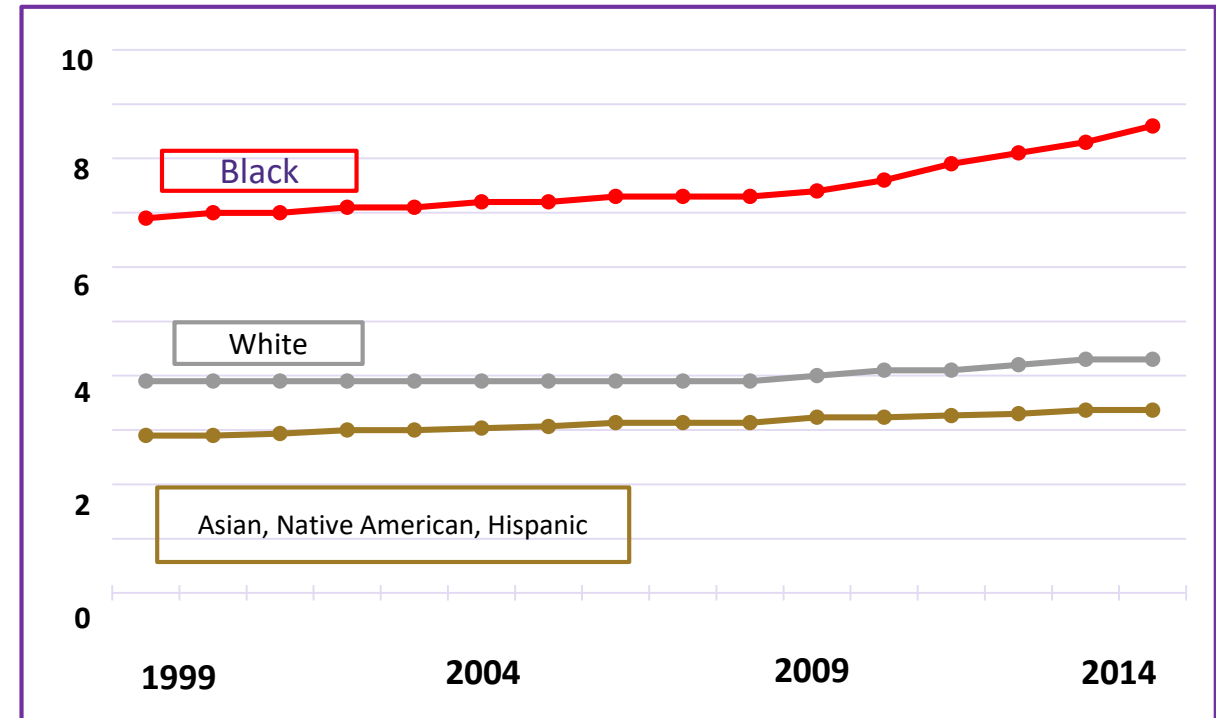


# US Endometrial Cancer Statistics by Race/Ethnicity

## Incidence

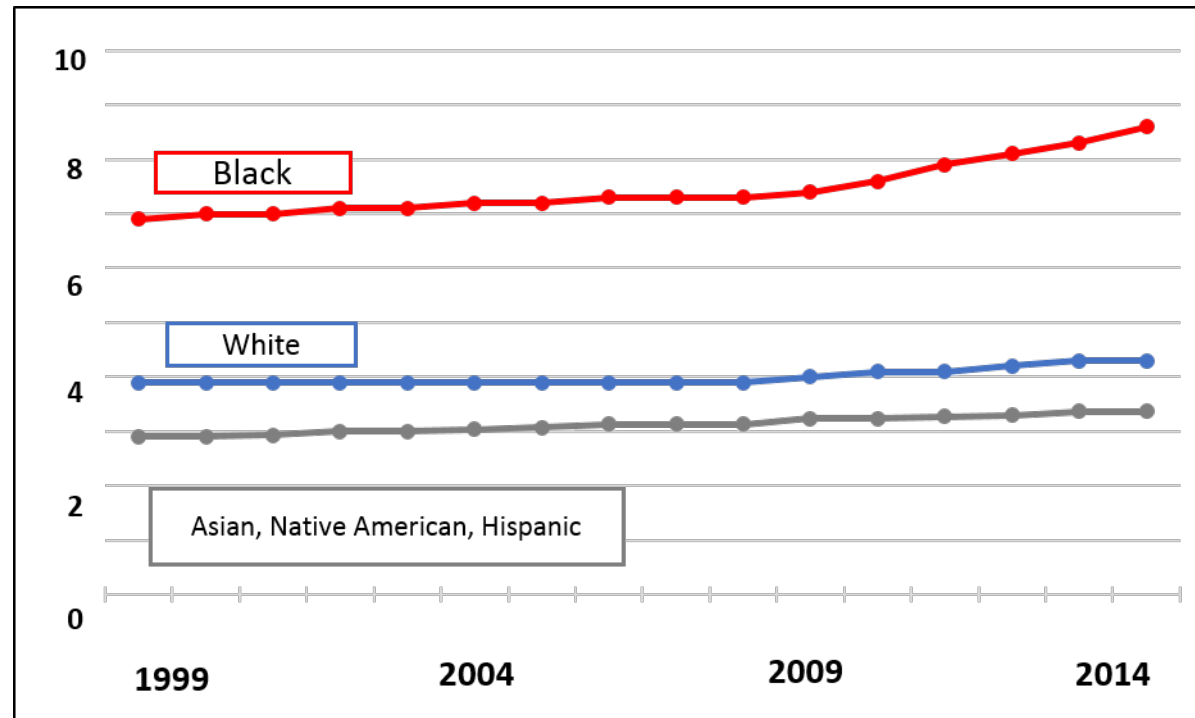


## Mortality



SEER cancer statistics review 1975-2014; Available at [seer.cancer.gov](http://seer.cancer.gov)

## Endometrial Cancer US Mortality Rates by Race/Ethnicity 1999-2014



Rate per 100,000

The Black-White mortality gap in endometrial cancer is **one of the largest** in all of cancer care in the US.

Rank	Cancer	Black:White Mortality Rate Ratio
1	Stomach	2.3
2	Multiple Myeloma	2.3
3	Uterine (Endometrial)	2.0 (1.6-2.9)
4	Cervix	1.8
5	Breast	1.4
6	Colorectal	1.3

DeSantis et al, *CA: A Cancer Journal for Clinicians*, 2019  
 \*Cote et al, *Cancer Epidemiol Biomarkers Prev*, 2015

Lack of a visible community of Black EC survivors is a major barrier to patient-research partnership.



# ecana

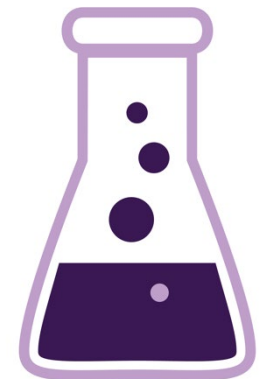
Endometrial Cancer  
Action Network for  
African-Americans



COMMUNITY



EDUCATION



RESEARCH

Funded PCORI Engagement Award, PCORI Conference Award,  
ITHS Community Engagement Award, and **Generous Donors!**



# Our Mission

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ECANA is a sustainable infrastructure for personal empowerment to better health - through **knowledge, community building, and action** - for African-American women affected by endometrial cancer. ECANA will promote **transparent, equity-directed patient-centered research** to reduce racial disparities in endometrial cancer through project development, training patient advisors, and public promotion of research efforts.



# ECANA Steering Group Summit March 2018

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## Lessons Learned:

- *Radical transparency*
- *Community ties come before research engagement*
- *Interest must be bi-directional*



<https://ecanawomen.org>



Community

Education

Research

News & Events

About

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## 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 – improving the lives of Black women affected by this disease. On this



<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?**

<https://ecanawomen.org>

## LEARN THE LINGO

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vaginal ultrasound

endometrial cancer

stage

grade

## Wellness Corner



Articles, resources, and tips to thrive throughout your journey with Endometrial Cancer



**Have a Partner, Be a Partner**


***Have a partner...***

Whether you are the most outgoing and

## Our Stories

Category

**Information is Power - with Adrienne**



Watch this video to hear Adrienne,

**I Got a Second Opinion - with Margie**




Watch this video to hear Margie, ECANA

**Find Your Peace, Find Your Doctor - with Margie**



Watch this video to hear Margie from the

**Receiving the Diagnosis - with Adrienne**



Watch this video to hear Adrienne from the ECANA

## Research & Advocacy: Get involved, help to solve!

A Seat at the Research Table

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Article Spotlight

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ECANA Community Survey

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**In this section,** you can learn about the latest research on endometrial cancer and racial disparities, hear from investigators in the field, learn about what it's like to be involved with research partnership, and get involved yourself.

**Come back soon** to take the *ECANA Research Survey*, which we will use to establish priorities for endometrial cancer research.

If you are an investigator, a patient involved with a research partnership, or interested in getting involved, please [contact us](#) - we would love to hear from you!



August 20, 2018

## **A Seat at the Research Table: Martha Jean Williams**

*As a community member, involvement in research can mean many different things.  
Ms. Martha Jean*

## **"Endometrial carcinoma recurrence according to race and ethnicity": Q&A with Dr. Ashley Felix**



*September 11, 2018*

Dr. Ashley Felix is an Assistant Professor at the Ohio State University College of Public Health. Her research focusing on identifying which factors put people at risk for different endometrial cancer subtypes, and what we can do about these factors. She also researches the molecular mechanisms of these relationships. Her work has specifically focused on women diagnosed with aggressive endometrial cancer, which is characterized by racial disparities.

## ***ECANA attends the PCORI Annual Conference***

*October, 2018*

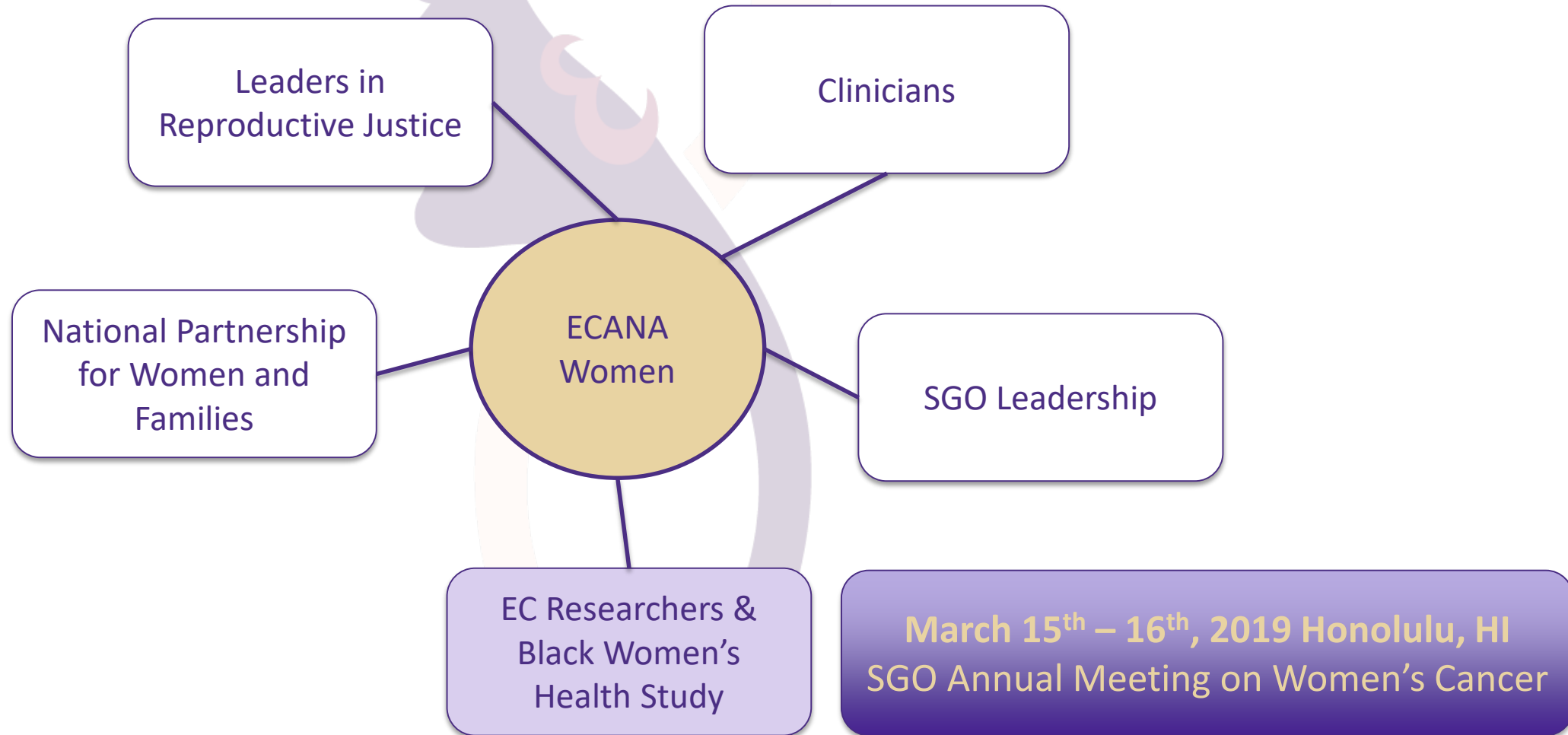
Two of ECANA's patient advisor steering group members – Margie and Adrienne – were awarded an opportunity attend the Patient Centered Outcomes Research Institute (PCORI) national conference in October. The team is so grateful for their strong representation and awareness-raising of ECANA, and for gleaning so many critical lessons that will propel ECANA into meaningful engagement and research partnership as we grown. Read on for reflections from Adrienne and Margie about their time there!



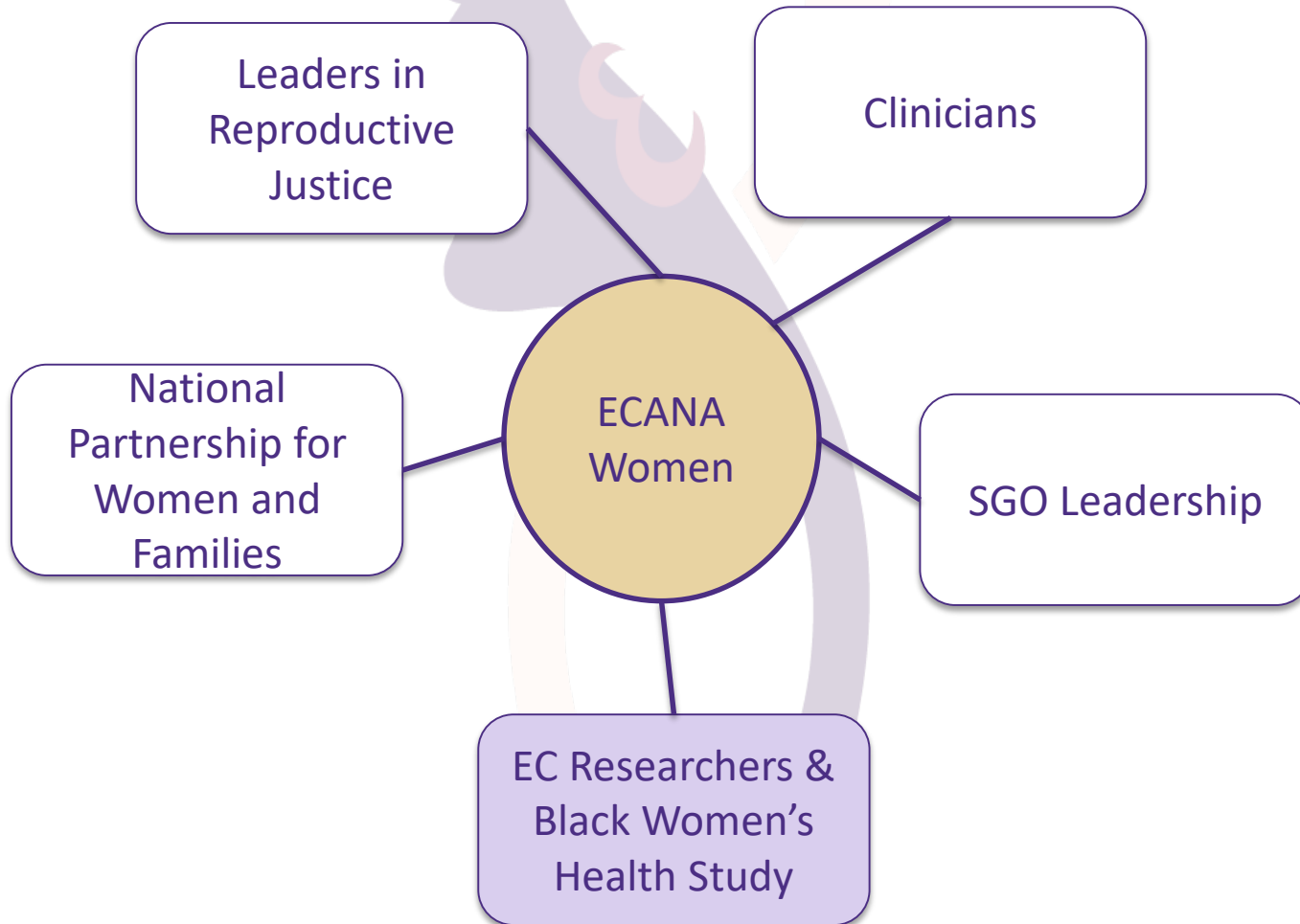
**We put research engagement in concert with education, awareness, and advocacy work.**



# ECANA Conference for Community, Education, and Research Training



# ECANA Conference for Community, Education, and Research Training

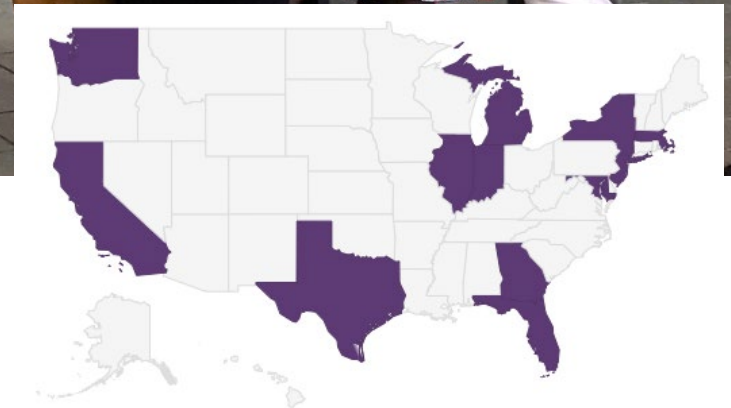


Effective recruitment was grounded in the strength of the steering group connections and the power of social media.

# ECANA Conference for Community, Education, and Research Training



March 15<sup>th</sup> – 16<sup>th</sup>, 2019 Honolulu, HI  
SGO Annual Meeting on Women's Cancer

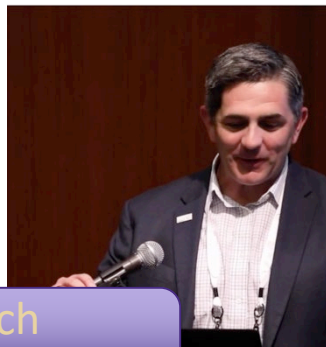


# ECANA Conference for Community, Education, and Research Training

EC Education



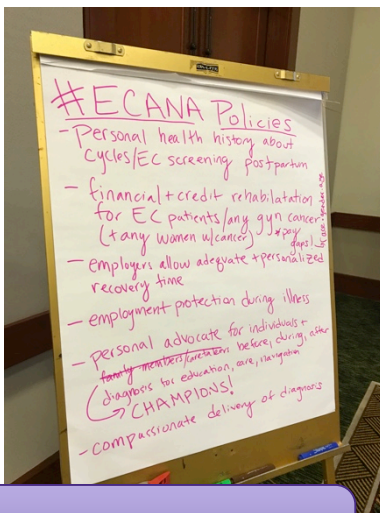
Research Presentations



RJ Training



Advocacy Work



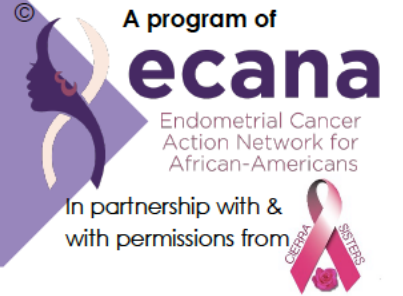
Wellness workshops




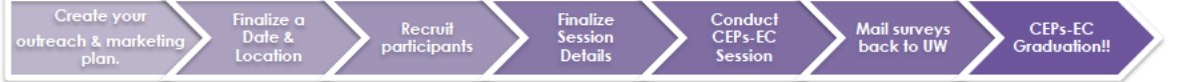
# ECANA Conference for Community, Education, and Research Training



COMMUNITY EMPOWERMENT PARTNERS  
FOR ENDOMETRIAL CANCER  
(CEPs<sup>®</sup>-EC)



 A Guide to Unlocking Your Own CEPs-EC Session



Participants gained immediately actionable skills that will build experience for future research partnership.



We created a support community for BOTH cancer survivorship and research engagement.



# A Patient-Centered Approach to Cancer Equity: Building a Bridge of Engagement

- Engagement of underserved populations in cancer research requires **meaningful community** at every stage: *initiation, recruitment, and sustainability*.
- Research engagement should happen **in concert with community education and advocacy outreach**.
- Participation should be **resource-independent** for the community/patient of interest.

# Thank You!

Email: [kdoll@uw.edu](mailto:kdoll@uw.edu)

Website: <https://ecanawomen.org>

Follow on twitter / IG : @KemiDoll, @ecanawomen,  
#ECANA2019



# ecana

**Endometrial Cancer Action  
Network for African-Americans**