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

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• Gynecologic Oncologist at the University of Washington and Seattle Cancer Care Alliance
• 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 13th, 2019
US Endometrial Cancer Statistics by Race/Ethnicity

### Incidence

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>1999 Rate per 100,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>10</td>
</tr>
<tr>
<td>Black</td>
<td>20</td>
</tr>
<tr>
<td>Asian, Native American, Hispanic</td>
<td>30</td>
</tr>
</tbody>
</table>

### Mortality

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>1999 Mortality Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black</td>
<td>0</td>
</tr>
<tr>
<td>White</td>
<td>2</td>
</tr>
<tr>
<td>Asian, Native American, Hispanic</td>
<td>4</td>
</tr>
</tbody>
</table>

SEER cancer statistics review 1975-2014; Available at seer.cancer.gov
Endometrial Cancer
US Mortality Rates by Race/Ethnicity
1999-2014

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

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.
Funded PCORI Engagement Award, PCORI Conference Award, ITHS Community Engagement Award, and Generous Donors!
Our Mission

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.
Lessons Learned:

- Radical transparency
- Community ties come before research engagement
- Interest must be bi-directional
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
<table>
<thead>
<tr>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>How was I diagnosed with Endometrial Cancer?</td>
</tr>
<tr>
<td>How will/did the doctor determine if I have Endometrial Cancer?</td>
</tr>
<tr>
<td>How do I know what Stage and Grade of Endometrial Cancer I have?</td>
</tr>
<tr>
<td>What is the treatment for Endometrial Cancer?</td>
</tr>
<tr>
<td>What are the goals of treatment?</td>
</tr>
<tr>
<td>How do I know if treatment is working?</td>
</tr>
</tbody>
</table>
LEARN THE LINGO

vaginal ultrasound  endometrial cancer

stage  grade
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 outsole and
Research & Advocacy: Get involved, help to solve!

- A Seat at the Research Table
- Article Spotlight
- ECANA Community Survey

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!
A Seat at the Research Table: Martha Jean Williams

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

- Leaders in Reproductive Justice
- Clinicians
- National Partnership for Women and Families
- EC Researchers & Black Women’s Health Study
- SGO Leadership

March 15th – 16th, 2019 Honolulu, HI
SGO Annual Meeting on Women’s Cancer
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 15th – 16th, 2019 Honolulu, HI
SGO Annual Meeting on Women’s Cancer

National Partnership for Women and Families
ECANA Conference for Community, Education, and Research Training
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!

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Website: https://ecanawomen.org

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