



eCana

Endometrial Cancer
Action Network for
African-Americans

National Conference for Community, Education, and Research Training **Public Report**

March 15th – 16th, 2019

in Honolulu, Hawaii

at the Society for Gynecologic Oncology's
Annual Meeting on Women's Cancer

Acknowledgements

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Cierra Sisters, Inc. donated journals for each ECANA Ambassador.

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Hey Sister, Inc. (Regena Hammock) donated ECANA t-shirts for each attendee.

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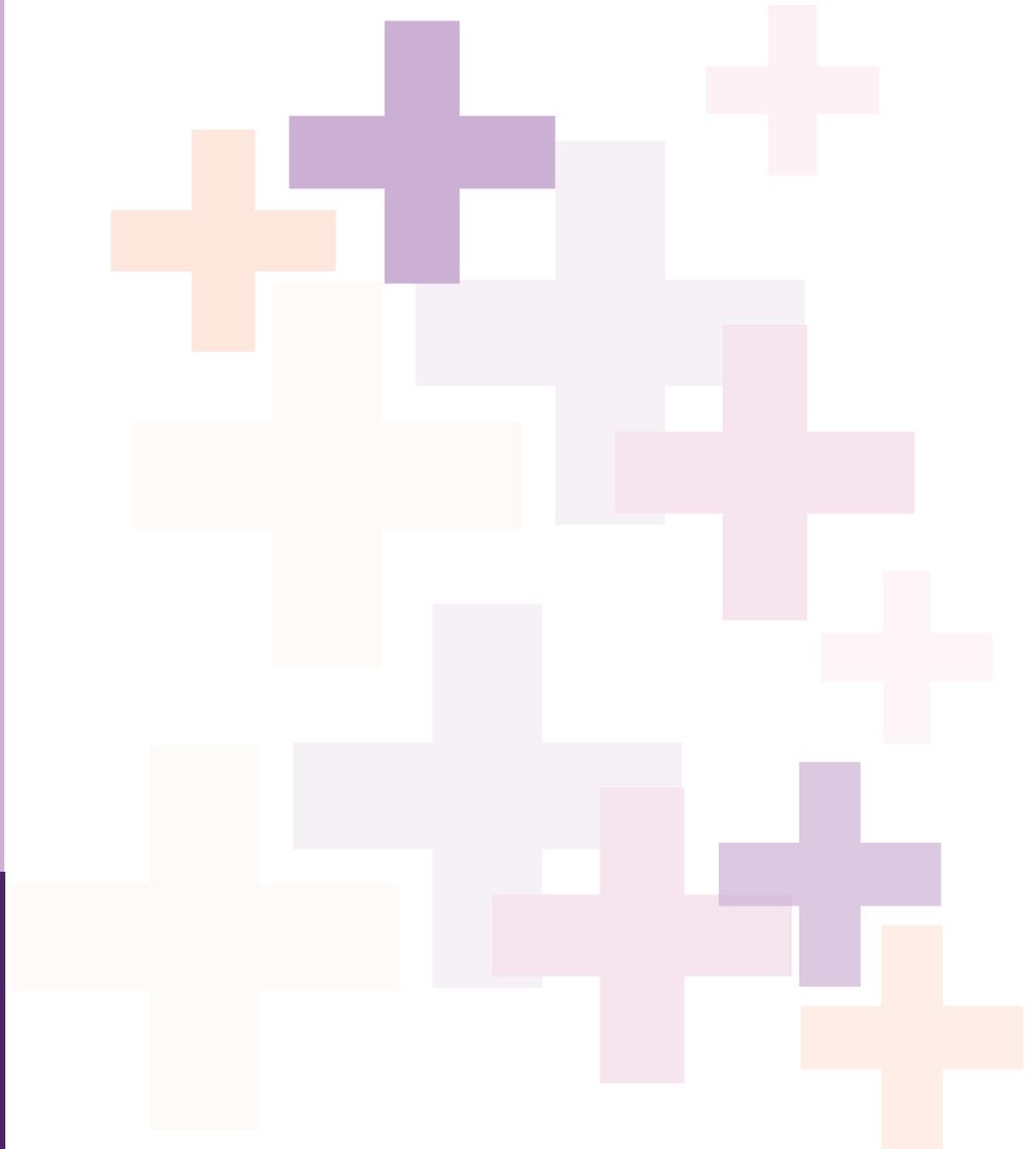
Our generous and valued individual donors.

Thank you!

You can find our conference highlight video at ecanawomen.org/ecanaconference and the Our Stories segment of our website - a video series documenting women's experience at the conference and with endometrial cancer - at ecanawomen.org/community/stories.

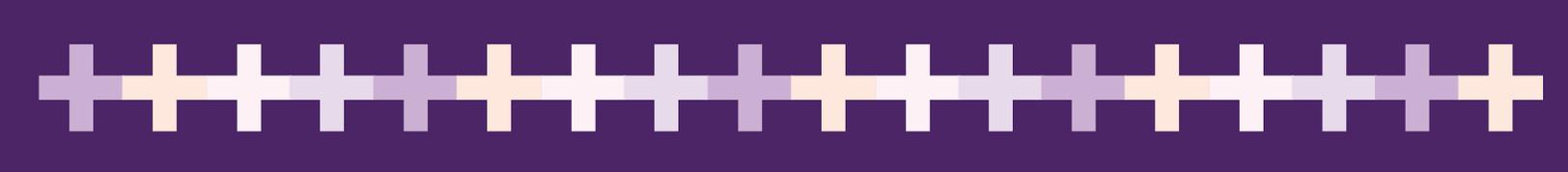
TABLE OF CONTENTS

I. About ECANA	2
II. The Conference	4
II. Team & Setting	5
IV. Conference Activities	8
Table talk highlights and future potential research work	16
V. Summary	17



The Endometrial Cancer Action Network for African-Americans (ECANA)
University of Washington, School of Medicine
Seattle, WA
December, 2019





I. About ecana

Endometrial cancer is a cancer of the inner lining, or inner wall, of the uterus. *It is the most common gynecologic cancer in the United States and affects 1 in 37 women by age 80. Endometrial cancer also harbors one of the worst racial inequities in all of US cancers. Black women with endometrial cancer have a 90% higher 5-year mortality risk than White women, and all other groups of women in this country.* Despite these statistics, there was a conspicuous absence of both a visible community of Black women survivors, and advocacy efforts focused on Black women – until now.

The Endometrial Cancer Action Network for African-Americans (ECANA) was founded in December of 2017 after an initial grant awarded from the **Patient-Centered Outcomes Research Institute (PCORI)**. The founding group who wrote and submitted the grant consisted of **Dr. Kemi Doll, Ms. Margie Willis, Ms. Liz Sage, and Ms. Bridgette Hempstead.** **ECANA** was created by a multi-stakeholder group from inception and this power sharing model continues to be the guiding force behind our growth.

ECANA is a sustainable infrastructure for personal empowerment to better health - through knowledge, community building, and action - for African-Americans at risk and those already affected by endometrial cancer. **ECANA** promotes 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. To serve this mission, we pursue the following 4 strategies:

- 1. Support community building among African-American women with endometrial cancer by creating a means of connection via a national website and local ambassadors*
- 2. Create responsive, accessible, engaging educational content as a resource for African-American women affected by endometrial cancer*
- 3. Build a presence in peer-reviewed literature and academic spaces via direct, deliberate, and equitable collaboration with endometrial cancer researchers*
- 4. Advocate for clinical and research evidence-based guidelines that optimize outcomes for African-American women with endometrial cancer*

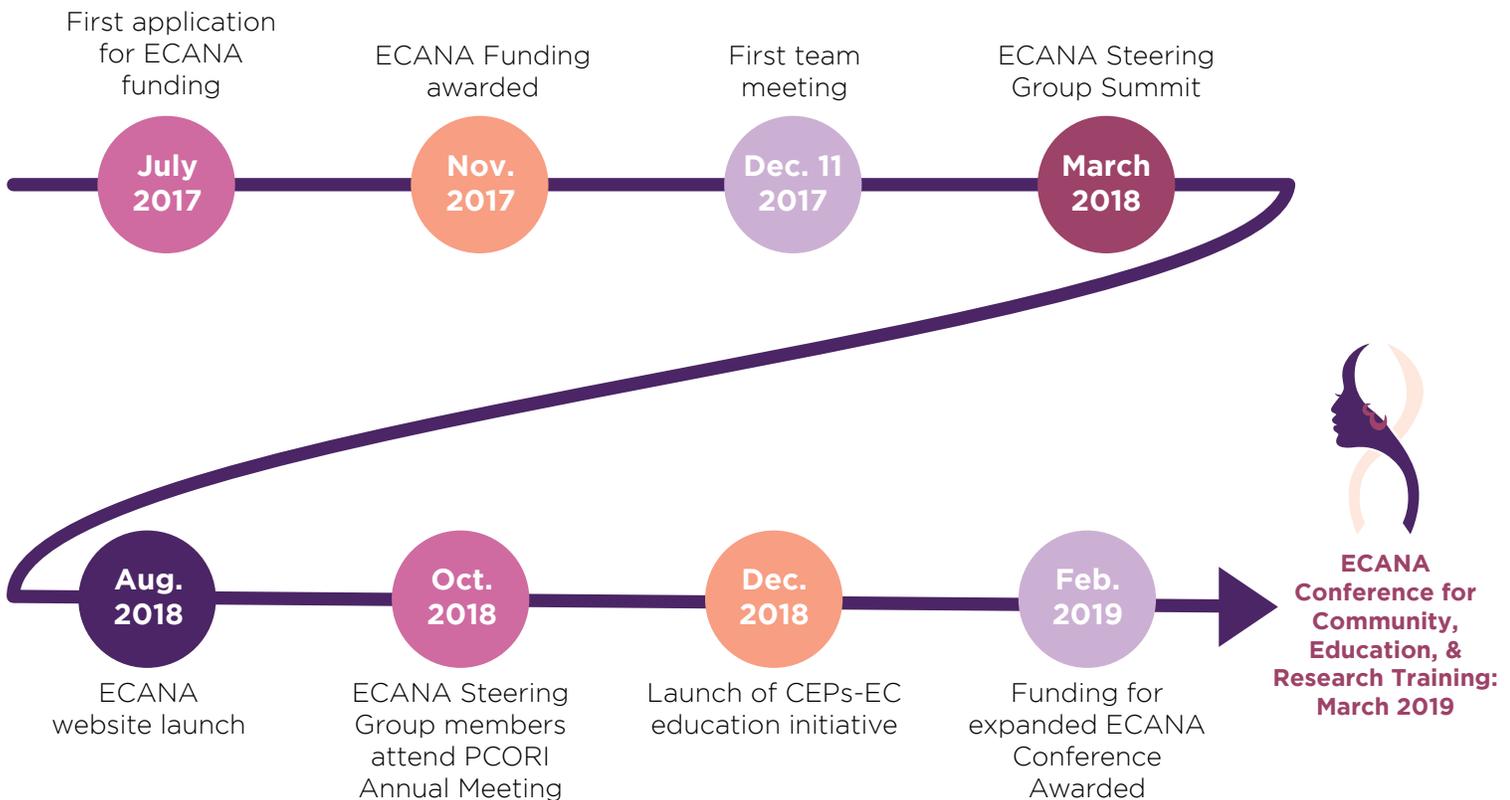
To execute these strategies with integrity, rigor, and respect we adhere to the following values:

- We center the voices, values, and needs of African-American women with endometrial cancer.
- We communicate clear personal and group intentions and maintain fidelity to them.
- We have transparency in process and power.
- We cultivate creativity and ‘thinking outside the box’.
- We approaching inevitable challenges as opportunities and focus energy on solutions, not barriers.

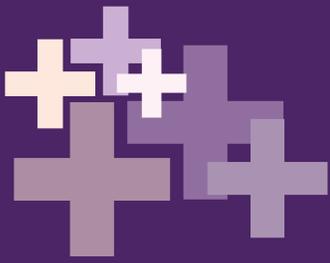
Our steering group is comprised of **Dr. Kemi Doll**, three Patient Advisors – **Ms. Margie Willis**, **Ms. Martha Jean Williams**, and **Ms. Adrienne Moore** – all Black women who have had endometrial cancer; one Community Advisor – **Ms. Bridgette Hempstead**, founder and CEO of Cierra Sisters, Inc. – a support group for African-American women with cancer in greater Puget Sound area; two research staff members – **Liz Sage** and **Julianna Alson**; a generalist Obstetrician Gynecologist – **Dr. Tracy Irwin**; and a patient-centered outcomes research advisor – **Dr. Danielle Lavallee**.

Since our founding in December of 2017, we held an in-person **Steering Group Summit** in New Orleans, LA in March of 2018, launched our **ecanawomen.org** website in August 2018, and executed a national peer-education training program (**Community Empowerment Partners – ECANA**) from March to November of 2019.

OUR JOURNEY SO FAR



From inception, one of our goals was to hold a national public conference that centers the perspectives, priorities, and needs of Black women with endometrial cancer. The **2019 ECANA Conference on Community, Education, and Research** was the realization of that goal. In this report, we detail our process, the event, and key lessons learned, with the goal of spreading actionable knowledge and strategy for building authentic patient-centered community and engagement with marginalized groups.



II. The Conference

As it was originally conceived, the national public conference had a stated focus on identifying research priorities and pathways for research partnerships that engage Black women with endometrial cancer. This goal aligned with the priorities of PCORI and our leadership. However, we learned with open and transparent dialogue among our multi-stakeholder group that we had to be particularly attentive to community-building and education among Black women with endometrial cancer. This pre-partnership work was deemed vital to the success of any research prioritization or collaboration efforts. With our attention on these elements, we set a goal to build a strong foundation of trust, empowerment, and a supportive community of endometrial cancer patient partners. In short, we needed to create a “home” for our survivor network, to provide support in their future efforts to navigate research partnerships. Ultimately, this would ensure our actions toward the stated organizational goals were cohesive, effective, and sustainable.

As a result of curiosity and co-learning in monthly steering group meetings and regular one-on-one calls with our patient and community partners, we identified and clarified the significant barriers to meaningful work between patients and researchers in this field:

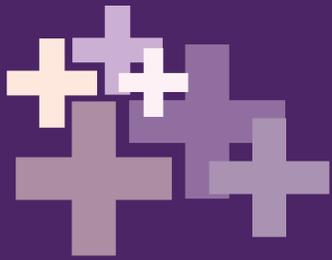
- 1)** the known history of abuse and exploitation of Black women in clinical reproductive health care which generates earned mistrust of research and exacerbates the unequal power dynamics between Black women with endometrial cancer and researchers;
- 2)** silence, stigma, and lack of knowledge about endometrial cancer among Black women;
- 3)** a lack of awareness of these first two barriers among endometrial cancer researchers resulting in a “colorblind” approach to endometrial cancer research; and
- 4)** absence of a shared framework among patients/survivors and researchers of how endometrial cancer fits in the spectrum of reproductive health.

In response to this information from our needs assessment, we adapted the focus of ECANA’s short-term activities, and, accordingly, the goals of our national conference.

We planned for the ECANA Conference for Community, Education, and Research Training to take a holistic approach to partnership building. Specifically, we sought to:

1. Address the partnership barriers for each stakeholder group;
2. Build trusting community and deepen endometrial cancer knowledge among patient partners;
3. Initiate patient-researcher partnerships from several regions of the country.

To create a meaningful experience for participants and reach these goals, the ECANA steering group knew we had to bring on the right team and find a space that could help us both build internally and begin to expand in visibility. In the next section, we describe these elements of the conference.



III. Team & Setting

Our team started from the solid foundation of ECANA’s Steering Group, and set out to expand our group in each of our stakeholder areas, as well as bring on team members who had the skills, motivation, and value-alignment to help us bridge the previously mentioned gaps.

Stakeholder Group	Role(s)
ECANA Steering Group	All: Recruit, screen, and invite additional Black women EC survivors to conference; oversee development and implementation of conference logistics and activities; develop and disseminate conference report; Doll: Facilitate EC educational module; moderate EC researcher, advocacy, and RJ sessions; Hempstead & Moore: Facilitate peer education session. Willis & Williams: Facilitate wellness workshops.
EC Patient Partners	Attend all conference activities: undergo training in peer education, PCOR, and research-partnerships, participate in Table Talks with EC researchers; build support network for EC patient partners.
EC Researchers	Present to other conference attendees on ongoing and future work, and partnership opportunities; listen and learn from patient partners about what is needed from researchers to establish meaningful partnerships; generate collaborative ideas for future study in EC
EC Advocacy	Develop and facilitate conference activities around policy and advocacy.
Reproductive Justice Facilitators	With ECANA Steering Group, develop a session on the intersection of RJ, and EC among Black women, and successful partnership in research and advocacy. Facilitate Table Talks between EC researchers and ECANA patient partners.

A. ECANA Ambassadors

While we began with the term “**patient partner**” we evolved over the course of the meeting to refer to these individuals as **ECANA Ambassadors**. We refer to them this way in the remainder of this report.



To meet our goal of creating a network of trusting and knowledgeable Black women with EC, we recruited individuals with a high level of commitment to ECANA’s mission. Our steering group mutually agreed on criteria for bringing a new ECANA Ambassador on board. Criteria included: having had endometrial cancer and identifying as Black or African-American; interest in promoting education, advocacy, research partnership, and/or community-building around EC; agreement with a focus on Black women specifically; and a willingness to participate with ECANA to do peer education when they returned home after the conference. The ECANA patient partner steering group members recruited all participants and conducted all screening phone calls with anyone identified as a potential fit, and were empowered to make the initial screening judgements for participation.

Over the course of two months, we recruited, screened, and booked travel for 10 new ECANA Ambassadors representing each region of the country. These new members, in addition to our steering group’s original patient partner members, totaled 13 women representing 12 states.



We want to note that many ECANA Ambassadors we reached out to had already attempted some form of education or advocacy in their own community – ranging from public talks, to social events, to their own smaller advocacy organizations. This was confirmatory evidence of the interest in advocacy and community engagement among Black women with endometrial cancer, and highlighted the incredible value and resource that had been previously untapped in this arena.

B. EC Researchers

Endometrial cancer researchers were obvious critical stakeholders of interest for this effort. We recruited four research leaders. They represented clinical, translational, outcomes, and epidemiologic research efforts. Some of these individuals were already in the ECANA clinician network, and others were recruited through previous professional work with Dr. Doll. In addition, we invited a representative from the **Black Women’s Health Study** (BWHS). The BWHS is a large, ongoing prospective study that collects data on Black women’s health through a group of 59,000 enrolled participants. In our recruitment process we detailed the scope and goals of the conference and asked each researcher to explicitly endorse their willingness to be learners of the endometrial cancer experience from our Ambassadors and participate in Reproductive Justice education (see below).

C. Reproductive Justice Leaders

In direct response to the gap that we uncovered during our needs assessment with steering group members, we prioritized addressing endometrial cancer as a reproductive life event. The Reproductive Justice framework was an appealing one to bridge this gap. Reproductive Justice is a movement that promotes “*the human right to maintain personal bodily autonomy, have children, not have children, and parent the children we have in safe and sustainable communities.*” Its roots and framework have an explicit lens of racial equity.



While this movement has primarily focused on Black women during reproductive events and reproductive years, **ECANA** recognizes that these reproductive events influence a woman's experience of the peri-menopausal and menopausal years as well. In addition, we recognize that for endometrial cancer, in particular, the symptoms are experienced as reproductive symptoms, and not cancer symptoms. *The purpose of these trainings was to situate the problem of endometrial cancer racial inequity within the advocacy, research, and experiential lens of reproductive justice.* Therefore, we invited two leaders from the reproductive justice movement – **Dr. Monica McLemore** and **Dr. Joia Crear-Perry**, as stakeholders. Their role was to provide reproductive justice education and training to both our ECANA ambassadors and our endometrial cancer researchers.

D. Advocacy Leaders

To address the need for increased endometrial cancer awareness and advocacy, we solicited the participation of the **National Partnership for Women and Families** (NPWF), a non-profit, non-partisan health advocacy organization based in Washington, DC. Our purpose with an advocacy organization as a stakeholder was two-fold:

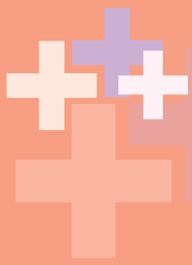
1) to learn from their expertise regarding positioning endometrial cancer as a women's health issue and methods for local and national advocacy and **2)** to expose such a well-positioned organization to the problem of racial inequity in endometrial cancer and the significant opportunity of advocacy within this space.

Their directive was to both participate in the conference and develop and lead training on health policy and advocacy.

E. Setting

The Society for Gynecologic Oncology is the nation's largest professional society of gynecologic oncologists. The immediate-past president, at the time of the conference (**Dr. Carol Brown**), and current president (**Dr. Laurel Rice**) served as members of the **ECANA steering group** and were our liaison to collaboration with the larger organization. **The Annual Meeting on Women's Cancer** is the preeminent meeting of researchers and clinicians in gynecologic oncology and draws an annual audience of over 2,000 with national and international participants. This convening of endometrial cancer researchers allowed for a natural space in which to engage these stakeholders. Additionally, it provided a mechanism to highlight the existence and activities of ECANA, making Black women with endometrial cancer literally visible in this research community. **ECANA Ambassadors** were given sponsored registration and could attend all SGO activities. Co-locating our meeting also created cost-efficiency by sharing space, audiovisual equipment, and the group accommodation rates through SGO's generous partnership. This represented an expansion of this supportive partnership, which was initiated at the **2018 ECANA Steering Group Summit**, held at SGO's 49th Annual Meeting the year prior.





IV. Conference Activities



We developed a multi-faceted, patient-centered, and highly interactive experience for all attendees that was driven by the ideas and priorities of our steering group.



Conference Agenda

Friday, March 15th - Day 1

Time	Activities
7:00-7:30	Arrival & Community Empowerment Partners-Endometrial Cancer pre-questionnaire
7:30-8:45	Opening & Welcome
9:00-9:15	Address from SGO President
9:15-10:00	EC Educational Module
10:15-12:30	Community-Building Workshops
12:30-1:15	Lunch
1:30-3:00	Reproductive Justice Training for ECANA Women
3:15-5:15	Community Empowerment Partners-Endometrial Cancer Training
5:15-5:30	Wrap up

Saturday, March 16th - Day 2

Time	Activities
8:00-8:20	Group Photo
8:30-9:15	SGO Research Panel
9:45-10:30	Patient Centered Outcomes Research Overview
10:45-11:30	Advocacy for ECANA Women // Reproductive Justice Workshop for Researchers
11:45-12:30	Research Presentations
12:30-1:30	Lunch Table Talks
1:45-5:15	Community Empowerment Partners-Endometrial Cancer Training
5:15-5:30	Wrap-up/Next-steps/Goodbye

i. Opening and welcome

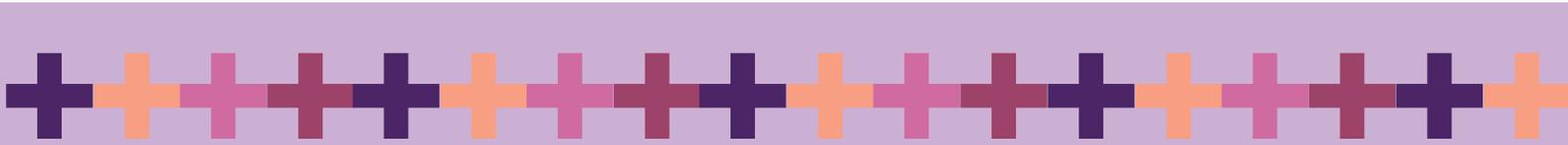
Our day began with **Dr. Kemi Doll** giving a warm welcome and setting the tone for transparency and intention for the two day conference. We told the story of the creation of ECANA, the rationale behind our values and goals, and how the current conference fit into this larger vision. This story-telling included an emphasis on the shared power model of the ECANA Steering group and highlighted accomplishments of our non-University staff members. This demonstrated the importance of community input and how ECANA centers these contributions. By setting the stage through modeling direct communication and by setting ground rules and intentions for our time together, we established a safe, nurturing, and motivating learning environment. At the conclusion of this welcome address, Dr. Doll invited all members to introduce themselves and include any aspect of their story they felt comfortable with sharing, along with their hopes for the conference. Attendees shared vulnerably. Many expressed that parts of themselves felt seen for the first time even through the invitation to the conference. We deliberately allowed one hour for this process as it was critical to begin the relationship building and trust work that would be needed for future activities. Not more than two hours into day one of the conference, the new ECANA Ambassadors requested a contact list so they could stay in touch. The ECANA team encouraged social media posting and created hashtags (**#ecanawomen #ECANA2019**) for participants to use.

ii. EC education

Dr. Doll facilitated a session reviewing the basics of endometrial cancer, racial disparities in EC, and how ECANA fits into this context. This addressed a primary need we identified from our patient partners on the steering group – that all ECANA Ambassadors need to be able to understand endometrial cancer from a clinical perspective. As ECANA, we also felt it important that all members understood the nature and degree of racial disparity in this condition and how ECANA was positioned to advocate for change. This session included information on reproductive anatomy, the biology of cancer, the specifics of endometrial cancer symptoms and treatment as well as easy-to-understand summaries of current research efforts.

iii. Community-building workshops

ECANA Steering Group Community and Patient Advisors conceived, developed and executed their own community-building sessions on topics about life after EC. In the months leading up to the conference, the steering group identified their topics, and developed session goals, agendas, and materials with support from UW staff and feedback from one another during steering group meetings. By featuring these sessions early on the first day, led by our ECANA steering group members, we set the tone of having their voices central to the work and demonstrating co-leadership in action. These sessions also directly served our mission of creating a meaningful and strong community. They were open to only the ECANA Ambassadors and our steering group members to facilitate honest dialogue.



Sessions included:

You Have the “Write to Heal”: **Ms. Adrienne Moore** led a workshop on writing, with a conversation about writing as a healing modality. Participants were prompted to write about their cancer experience. After a quiet half hour of writing, some volunteers shared their pieces with loving support from the other attendees.

Keep on Grooving: **Ms. Margie Willis** led a movement workshop for wellness, which included a talk on the health benefits of an active lifestyle, an active chair yoga session, and activity goal setting for each woman. As an ongoing feature of the conference, she provided guidance for breathing exercises during breaks between sessions on both days.

Relationships After endometrial cancer & in endometrial cancer Advocacy: **Ms. Martha Jean Williams** and **Ms. Bridgette Hempstead** presented to the group about their journeys navigating relationships with friends and loved ones after diagnosis. They highlighted lessons for self-care and boundary-setting in both personal lives, and as survivors engaging in academic or organizational partnerships.

Other wellness and community-building activities emerged organically throughout the conference including Ms. Hempstead leading the group in song, group outings for dinners, planning for meet-ups after the conference, and exchange of contact information.

Reproductive Justice Trainings

Before the conference, **Dr. Monica McLemore** and **Dr. Joia Crear-Perry** worked closely with **Dr. Doll** to develop the workshop based on input she relayed from steering group meetings. Their training with the ECANA Ambassadors consisted of a 90-minute session where they taught about the history and current action of Reproductive Justice, held space for women to share their reproductive life experiences, and demonstrated the power of this story-telling when moving forward with research and advocacy work. The session was dynamic, with lively conversation and sobering stories of racism perpetuated on multiple levels. This directly allowed for the integration of story-telling, empowerment, and learning.



The Reproductive Justice training for the endometrial cancer researchers had a different focus and therefore a different execution. In a small group format, the researchers met with our trainers at a round table. After an opening video about the social construction of race, there was open dialogue about how race functions in biomedical research, including frank discussion of the benefits of the narrow biological definition in grant applications and funding. By establishing a common goal of decreasing mortality among Black women with EC, the group was able to engage in listening and co-learning around what it means to consider RJ in endometrial cancer research and what system disruption looks like for an endometrial cancer researcher.

iv. Community Empowerment Partners Endometrial Cancer

Our Community Advisor Steering Group member, Bridgette Hempstead, is the **founder and CEO of Cierra Sisters Inc.**, a support group for African-American women with cancer in greater Puget Sound area. Ms. Hempstead developed a breast cancer peer education curriculum for Black women – in the tradition of ‘*each one teach one*’ – that Cierra Sisters, Inc. had been implementing for over 20 years. In 2016, the tool was formalized and re-named as **Community Empowerment Partners**© (CEPs©).

In a recent evaluation of the program – in collaboration with **Fred Hutchinson Cancer Research Center** – the program was found effective in increasing knowledge and intention to talk with friends and family about breast health. As part of our goal of building an empowered, nationwide community of Black women with EC, we chose this curriculum as our training tool to transfer valuable peer education skills to the conference attendees. Prior to the conference, we secured additional grant funding to support the adaptation of the original breast cancer program to endometrial cancer and conduct the Community Empowerment Partners training at the meeting.

Ms. Hempstead and **Ms. Moore** served as the community leaders of this project. Their expertise in peer and health education, community health programs, and lived experience with cancer was critical to the success of this component. In the months leading up to the conference, they, alongside **Dr. Doll** and the **UW research staff**, adapted the training materials and surveys. Ms. Moore and Ms. Hempstead spent time practicing the toolkit curriculum to train the peer educators, clarifying clinical questions with Dr. Doll for appropriate wording, and revising slides and talking points as needed. The adaptation process was iterative and collaborative to create the **Community Empowerment Partners for Endometrial Cancer (CEPs-EC) program**.

The conference training consisted of **two sessions** – 2 hours on Day 1, and 3 hours on Day 2. On **Day 1**, Ms. Moore and Ms. Hempstead taught the education curriculum to the ECANA Ambassadors, going through the prepared slides and modeling community-based teaching. Participant questions were recorded and used as data to refine the clarity of the slides and script going forward.

On **Day 2**, the 2nd half of the training included marketing and outreach modules to prepare trained community empowerment partners to recruit participants for their own sessions, role-playing tasks, and the graduation ceremony. To facilitate different types of learners, we incorporated break-out sessions, role-playing with educational points, and traditional didactics.



During the marketing and outreach module, attendees shared their experiences with different kinds of community outreach and event coordination. We reviewed as a group the timeline of activities after the conference to include national support phone calls, and small group coaching assignments to support their progress. After refining the training materials from their feedback, each trained ECANA Ambassador received mailed materials from the UW team to use for their home sessions.



At the end of the second day, we had a very joyful graduation ceremony! Each trained community empowerment partner received a certificate to designate them a certified Community Empowerment Partner for Endometrial Cancer, and a key to symbolize that they have the key to lift up their community through education.

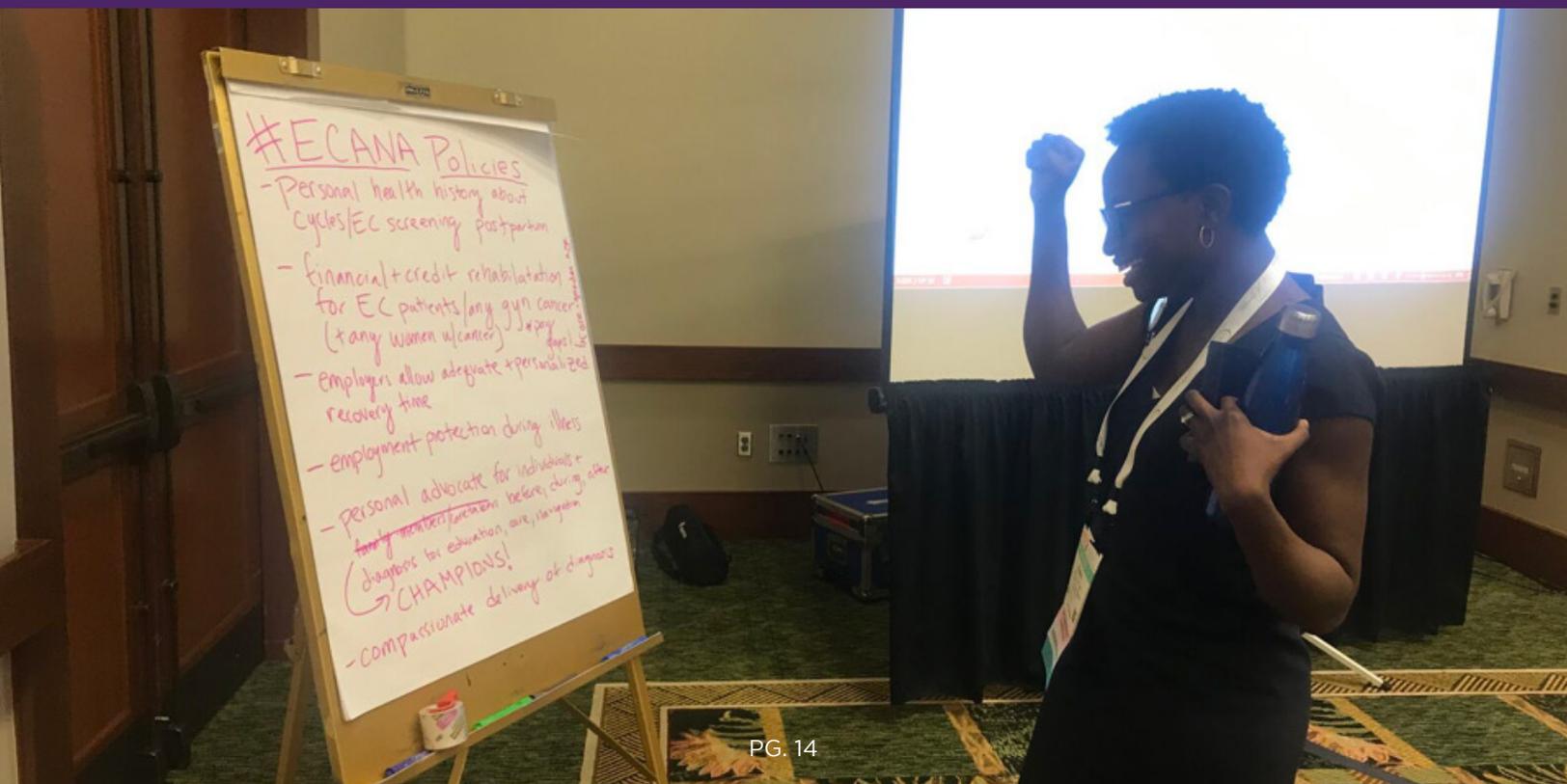


v. Advocacy Sessions

Sarah Coombs, representing NPWF, lead a powerful advocacy training and policy writing exercise. She described NPWF's role in policy advocacy and examples of policy change initiatives in maternal health. She then facilitated breakout sessions in which participants developed policy recommendations related to their experiences as endometrial cancer survivors. The ECANA Ambassadors had well-thought-out ideas for policy initiatives that made the conversation vibrant and productive. The report-out from these sessions was rich with inspirational ideas. This session laid the groundwork for ECANA's future work in local and national advocacy and was a natural extension of the Reproductive Justice framework which appreciates the influence of policy on health. It also contributed to energy and knowledge necessary for patient partners to advocate, network, and raise visibility in their own communities.

+ ECANA policy agenda

- Robust collection of personal health history about menstrual cycles and EC screening
- Financial aid and credit rehabilitation for gynecologic cancer patients (any women with cancer)
- Employers to allow adequate and personalized recovery time
- Employment protection during illness
- Funded personal advocate for individuals before, during, and after diagnosis for education, care, and navigation
- Medical provider training for compassionate delivery of diagnosis



vi. Research Presentations and Training

On Day 2, all participants attended an SGO research panel, moderated by Dr. Kemi Doll, focused on challenges in cancer care delivery. This was followed by a patient-centered outcomes research (PCOR) training for our patient partners, led by Dr. Doll. The training was adapted from materials developed by PCORI. The main teaching points included definitions of research, phases of research studies, the goal of clinical research, and the definitions of patient-partnership. The attendees learned of several levels of engagement with examples of each, and were asked to consider what roles they could envision themselves in. The training included a discussion on patient compensation and expectations for a trustworthy relationship, which include:

- + Reciprocal relationships
- + Co-learning
- + Partnership
- + Trust
- + Transparency
- + Honesty

After the advocacy training, the morning wrapped up with short presentations from 4 endometrial cancer researchers:

Rod Rocconi, MD:

Molecular and genetic determinants of racial disparity: A time to act

Leslie R. Boyd, MD:

Endometrial Cancer Care In NYC: The Impact Of Public Hospitals

Ashley Felix, PhD:

Early detection of recurrent disease using non-invasive methods

Victoria Bae-Jump, MD, PhD:

Targeting Metabolism in Endometrial Cancer Treatment.

Kim Bertrand of the Black Women's Health Study, provided a unique perspective on research for patient participants and the endometrial cancer researchers. Her contributions throughout the conference added to the patient participants feeling that they were a part of something larger. It also gave a window into what research can look like when it is focused on specifically on Black women's health - as ECANA aims to do within endometrial cancer research. Finally, Dr. Bertrand provided an honest look into the internal challenges facing the Black Women's Health Study to meaningfully engage and be led by Black women's voices. The transparency contributed to patient partners' understanding the current research landscape and to a feeling that their voices truly matter in re-shaping this landscape.

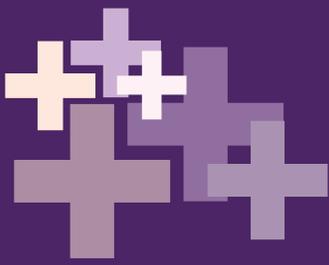
After this ECANA Research session, the investigators and conference attendees had lunch together. All ECANA partners had the chance to follow up directly with researchers to learn more and ask questions about their work as well as brainstorm interesting ideas moving forward.



Table talk highlights and future potential research work

- Discussion of obesity as risk factor for recurrence, as well as age and the need to identify common predictors of recurrence among Black women
- Provider communication: how to better understand and communicate what the patient experience of treatment will be like; the importance of a positive outlook
- Why do Black women have more fibroids?
- Discussion of the mental health and non-clinical burdens of cancer – specifically around coping skills and the self-sufficiency of Black women as a barrier to receiving needed support
- How to recruit Black women into clinical trials – not at the time of diagnosis, as it is too overwhelming
- Discussion of community education around complex clinical terms





V. Summary

The ECANA Conference for Community, Education and Research Training had a strong positive impact for all attendees, and well beyond the walls of our conference. We created a national network of ECANA Ambassadors who are trained in peer education and patient-centered outcomes research. Each committed to holding an educational event in their home community over the course of 2019. We also successfully trained endometrial cancer researchers in core tenets of Reproductive Justice. We saw the effectiveness and benefits of this training shine during the meaningful conversations the researchers engaged in about race and racism in discussions with patients.

Lessons learned

Lessons from this conference are rich with value not only for patient-centered outcomes research in, but for any work in community engagement, community, health equity, and reproductive health.

Achievement of our conference goals required engaging Black women with endometrial cancer in the planning of this two-day event. Given the historical context of exploitation and neglect of Black women by the health care providers and researchers – especially in reproductive health – we approached the setting of our event, a national meeting of clinicians and researchers, with care and intention. Ultimately, we believe we were successful, but there were a number of challenges and lessons learned along the way.

+ Participant Recruitment

Successful recruitment hinged on initial consensus among the Steering Group about the values and qualities of appropriate attendee candidates. Yet, the recruited attendees were not homogenous. Diverse lived experiences of the women in the room contributed to a stronger, more inclusive program. In addition, outreach via social media and the outward facing website was much more successful than outreach via clinicians.

The success of our steering group's outreach efforts cannot be overemphasized. We were able to identify women who were already independently conducting outreach, education, and advocacy about endometrial cancer individually. By taking this route, we identified attendees that already have a baseline level of comfort with many of the skills required for success as ECANA Ambassadors: storytelling, outreach, and advocacy. Warm outreach messages from a steering group member were critical to establishing ECANA as a community that is welcoming, safe, and valuable to each participant.

Our website, an initial significant investment of ECANA time and resources, worked both directly and indirectly to support recruitment. One of ECANA Ambassadors was recruited directly through the website portal.

In addition, many of our members reported visiting the website to gather more information before committing to attend the conference. It was repeatedly mentioned as the ‘push’ needed to trust our new organization enough to make a 2-day trip with strangers. **It was vital to have this outward-facing web presence that was written by and for survivors.**

+ Financial Barriers

We set as a primary goal that participants would not face financial barriers to attend. This was critical to not recapitulate the ongoing inequity in the patient advocacy and patient-research partnership space where volunteer time and self-funding activities is common.

A number of financial constraints posed challenges for engagement with Black women with endometrial cancer. Because of funding requirements, we had to exclude anyone who needed financial support in order for a support person or caregiver to travel with them. Though additional financial resources could have aided this, we required participants with a high capacity for mobility and sustained active engagement over the course of two full days. We acknowledge that this created barriers for Black women with some forms of disability mobility limitation, or cognitive limitations who may have been interested in participating.

Another financial barrier involved reimbursing patient partners for expenses related to travel. Many university systems of reimbursement are not set up for the optimal schedule of payment for individuals who are not staff or faculty, and this posed financial risk that jeopardized attendance for some of our attendees. The project team was able to work closely with our institution’s Travel Office to find flexible solutions that were satisfactory for our partners as well.

+ Relationship and Trust-Building

Building meaningful relationship and trust started at the recruitment phase and was the most important factor that supported the success of the conference. Even with no financial barriers, potential candidates were looking for trustworthiness and clear intentions before committing to sign up. Being prepared for this through carefully constructed community-centered language in all of our promotional materials, and establishing our ideal attendee’s qualities allowed this to occur.

Addressing power dynamics head on – with transparency of process and acknowledgement of prior mistreatment – resulted in stronger relationships that quickly formed and enriched conference discussion as well as engagement after the conference. One manifestation of this was deliberately creating space for participants to share and engage with each other before facilitated interaction. Building relationships among ECANA Ambassadors prior to activities involving researchers also allowed trust and cohesion within a shared identity and empowered Ambassadors to ask questions and share more openly with researchers.



+ Time and Resources

Despite expanding our initially planned 1-day conference into a 2-day event, by securing an additional grant, we could have used more time. Our attendees provided feedback that they would have liked more time for several of the sessions – Reproductive Justice and research training in particular. Yet, none identified a component they would omit. As a planning team, we would have liked more time for rest between sessions and opportunities for attendees to debrief, including our invited speakers.

One excellent use of resources was frequent and consistent provision of healthy food and drink options. We note that catering can be an afterthought in conference planning, but when planning an ambitious agenda for new participants we found these brief times to eat, rest, and socialize critical to ongoing relationship-building. In addition, several of our most valuable take home points from the participants came during these informal conversations.

+ Key Factors for building patient-researcher relationships in marginalized communities.

- A community of support - that patients have ownership of - must exist first.
- Deliberate creation of a power sharing environment must occur, allowing for meaningful interaction and conversation among patients and researchers.
- Relationship-building should start with the PCOR principles of trustworthiness and respect to intentionally depart from histories of exploitation and encourage meaningful patient participation.



Engagement of Black women into endometrial cancer research was both possible and realized with the ECANA conference. Since the conference, ECANA members have been placed as patient advisors on research studies, have completed peer education in their own communities, and have initiated partnerships with sister advocacy organizations. These successes were a result of deliberate investment of time, skill, and money to address the absence of these very women in EC work. Both the intention and the work are required for success. We hope this conference report sheds light on our processes for the purpose of inspiring replication and innovation on our methods so that we continue to bring marginalized voices into the considerable opportunity that patient engagement offers to the health and wellbeing of all.