

Gynecologic Research and Cancer Equity: Progress, Process and Future Opportunities

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November 9th, 2024

I have no financial
conflicts of interest
to disclose.

Objectives

1. Introduce The GRACE Center mission, vision, and values.
2. Review GRACE Center research studies.
3. Discuss future horizons and collaboration opportunities.

The GRACE Center

— GYNECOLOGIC RESEARCH AND CANCER EQUITY —

www.gracecenteruw.com



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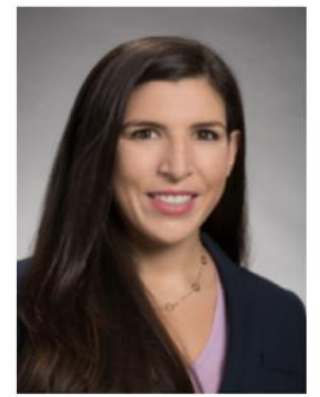
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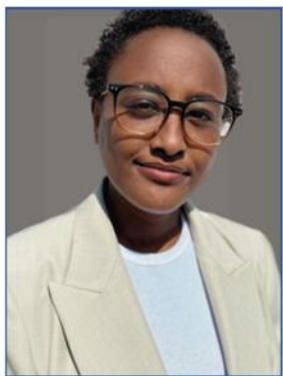
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The GRACE Center

— GYNECOLOGIC RESEARCH AND CANCER EQUITY —



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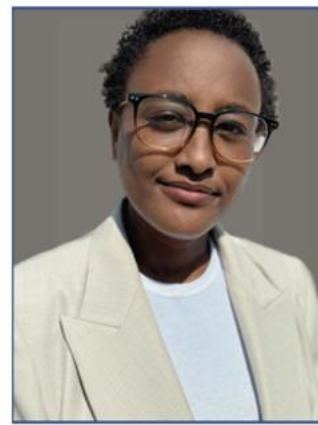


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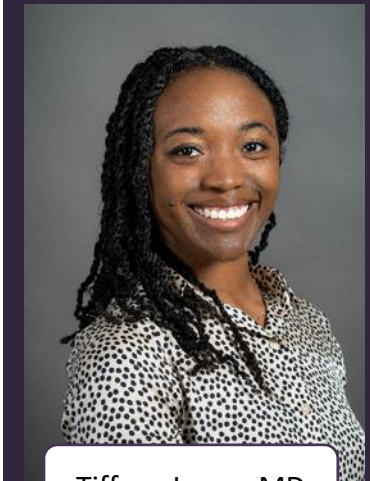
Minerva Orellana, PhD



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The GRACE Center

GYNECOLOGIC RESEARCH AND CANCER EQUITY



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Junior Faculty Mentees



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THE GRACE CENTER: MISSION



The Mission of The GRACE Center is to act to investigate and ameliorate causes of disproportionate suffering from benign and oncologic gynecologic health conditions, so that all people may live full and healthy reproductive lives.

We believe that gynecologic health spans the lifetime and is intimately linked with gynecologic cancers that affect individuals later in life.

Our goal is to unite these perspectives to deepen our understanding of the science of gynecologic cancers through transdisciplinary approaches, grounded in the perspectives of marginalized people with lived experience.

THE GRACE CENTER: WORK



Through our work:

- We seek to create **catalytic conversations** that deepen awareness and create **new connections** that facilitate understanding of gynecologic equity issues in the U.S.
- We seek to be a **possibility model** of centering the margins, inclusive leadership, and meaningful impact using research and research partnership as our tools.
- We seek to support the **emergence of more scholars** of gynecologic health equity, through opportunities for students, trainees, staff, and faculty members.

THE GRACE CENTER: VALUES



At the GRACE Center, we value **kindness, warm community, high quality work, curiosity, growth and radical innovation.**

At the GRACE Center, we acknowledge that we function in racist, sexist, ableist, transphobic, and homophobic systems and we choose to use our work to combat these moral failings to improve the conditions of gynecologic health for marginalized populations.

We value **balance and joy** – and ultimately, believe each one of us can make this world a better place. At the GRACE Center, we give each other grace.

The GRACE Center: 5 Year Vision Intentions (2023)

NARRATIVE Shifts

OPPORTUNITY for
purpose-aligned staff

Equity Methods
EXPLAINED

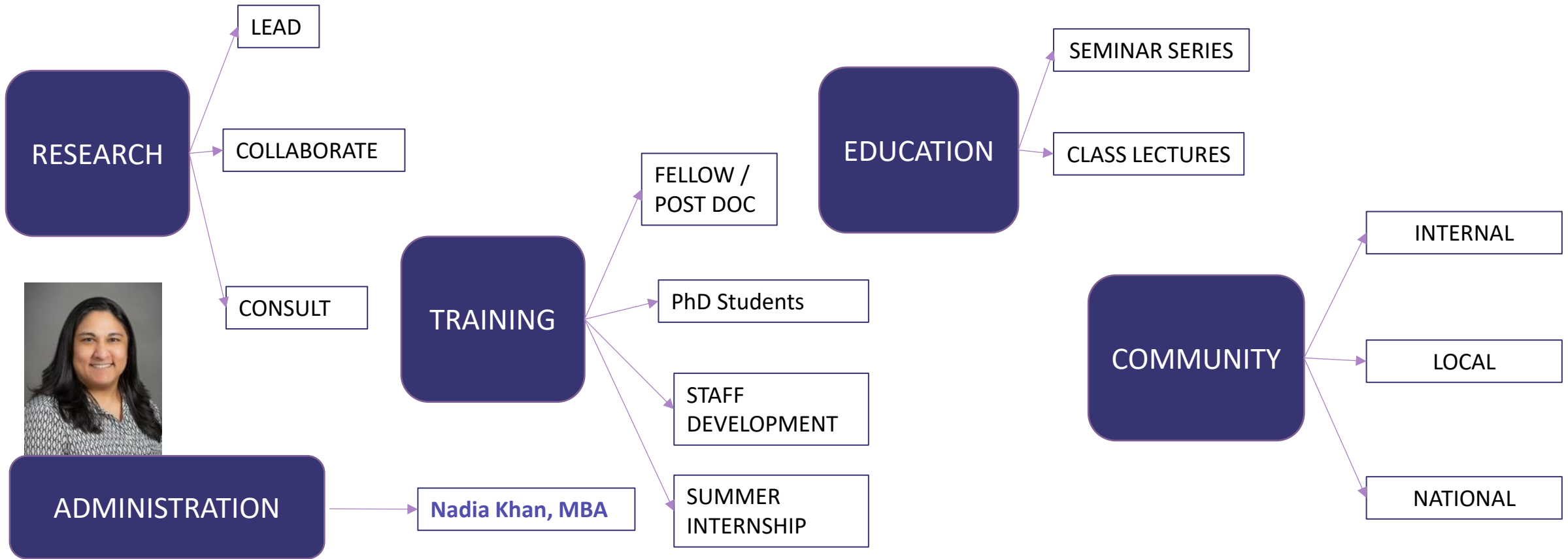
Center of Qualitative and
Community Engagement
EXPERTISE

Facilitating 'hardly had'
CONVERSATIONS

GYN Health Equity HOME

Example of organized &
aligned academic
MULTI-MISSION

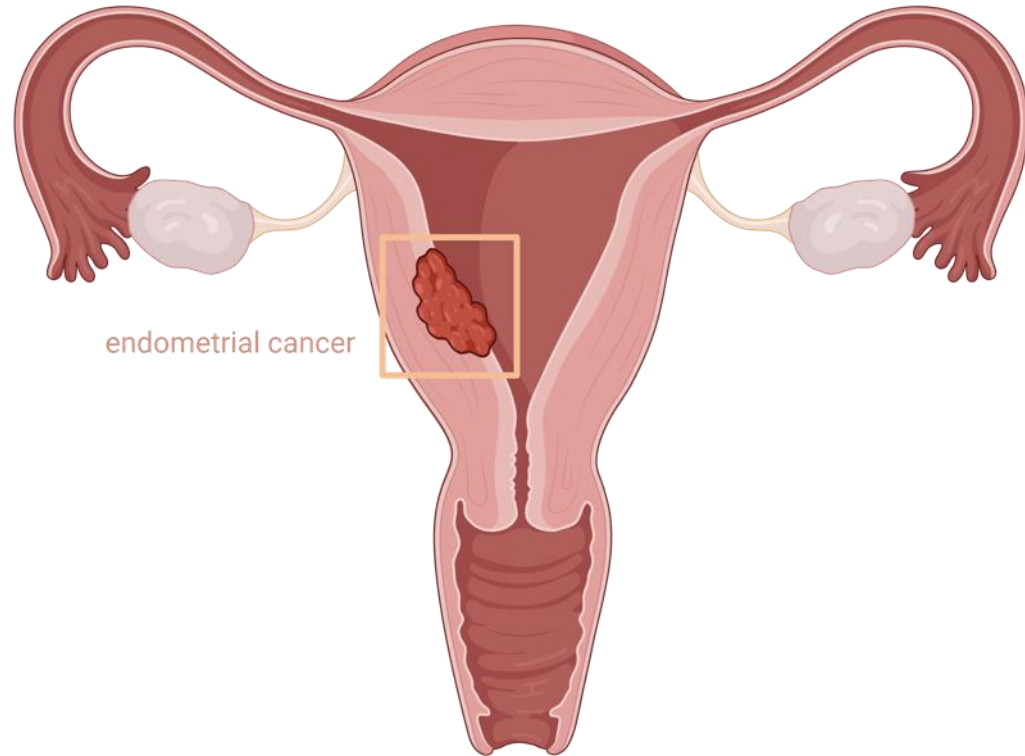
The GRACE Center: 5 Year Vision Structure



Objectives

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- 2. Review GRACE Center research studies.**
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Endometrial Cancer



66,000 cases/ year

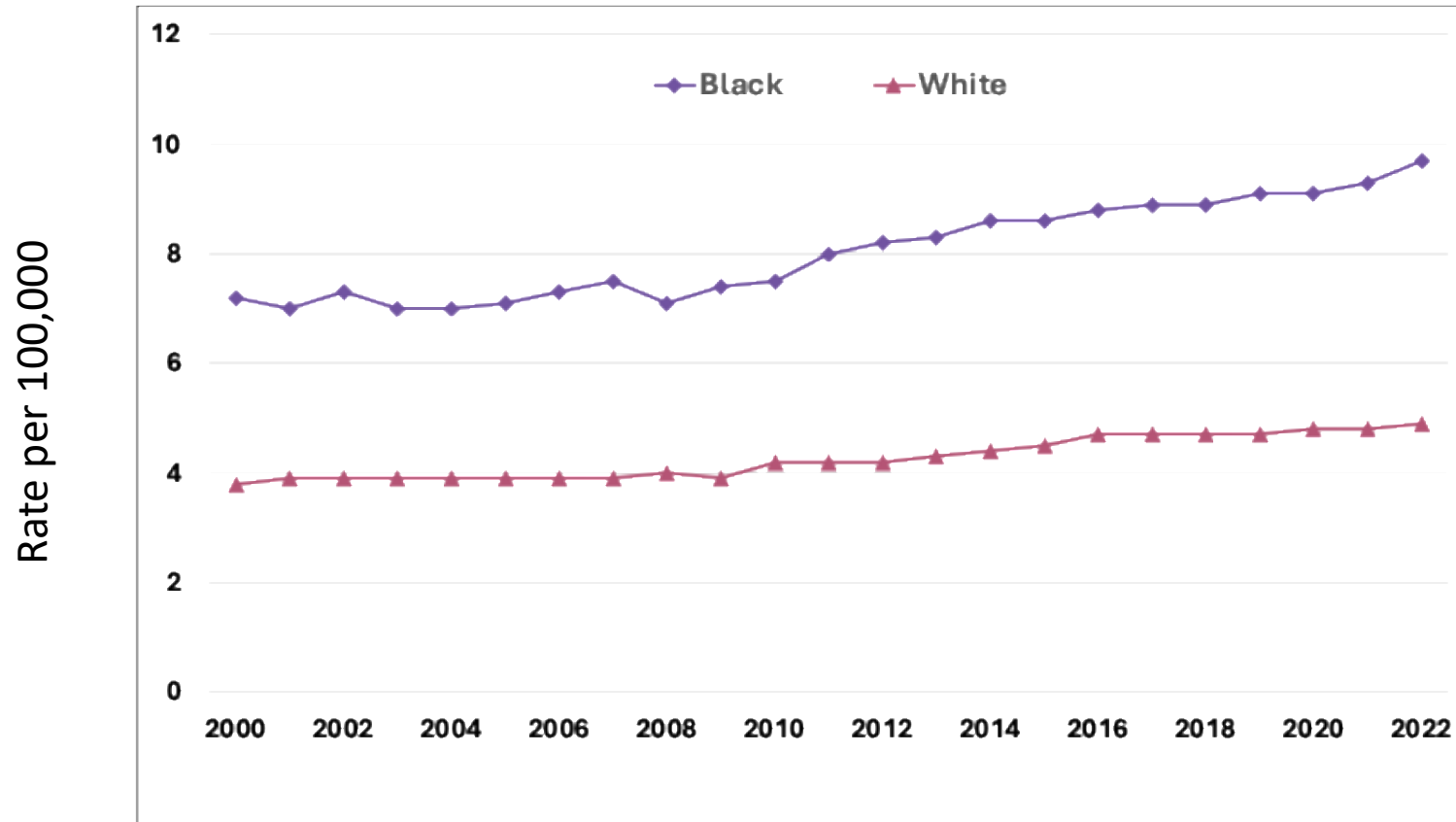
Lifetime risk in US: 3%

1 in 32 women by age 80

5-year survival: 80%

Giaquinto AN et al. *CA Cancer J Clin*, 2022.
<https://seer.cancer.gov/statfacts/>

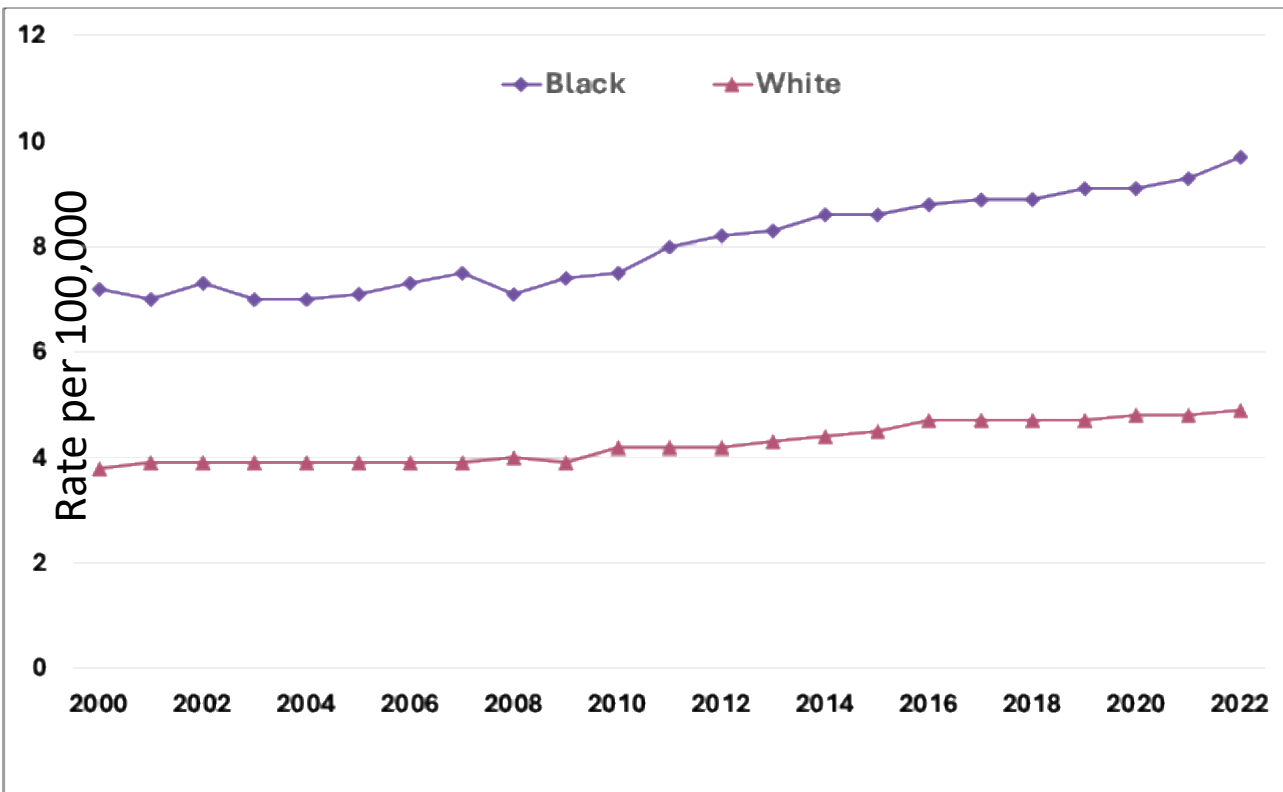
US Uterine Cancer Statistics by Race/Ethnicity: Mortality



For Black women, uterine cancer mortality has >> ovarian cancer mortality since 2005.

Guiaquinto, et al. *Obstetrics & Gynecology*. 2022.

Uterine Cancer
US Mortality Rates by Race/Ethnicity 1999-2018



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	2.2
3	Uterine (Endometrial)	2.0 (1.2-2.8)
4	Cervix	1.7
5	Breast	1.4
6	Colorectal	1.3

Giaquinto et al, *CA: A Cancer Journal for Clinicians*, 2022
Clarke et al, *JAMA Oncology*, 2022

US Black women and Endometrial Cancer

- Non-endometrioid histology is on the rise for everyone, and most strikingly in Black women.
Cote et al. Cancer Epi Biom 2015; Clarke et al. JCO 2019

- Mortality rates are the highest among Black women, after adjustment for stage and histology, with **40-60% unexplained**.
Doll et al AJOG 2019; Karia et al Gyn Onc 2023

- **Young Black women under 50** are more likely to have high-grade histology (*30% non-endometrioid*)
Mukerjee et al. Gyn Onc 2018

- Black vs. White EC molecular profile differences largely follow known differences in histologic subtype
Wilhite et al. Gyn Onc 2022; Whelan et al. Gyn Onc 2023

Black women's reproductive health



Obstetrics and Maternal-Fetal Medicine

Higher rates of

- Preterm Labor
- Low Birth Weight infants
- Maternal mortality



Gynecologic Care

Higher rates of

- Fibroids
- Irregular cycles
- Infertility
- Premenopausal Hysterectomy



Gynecologic Cancers





Higher mortality in

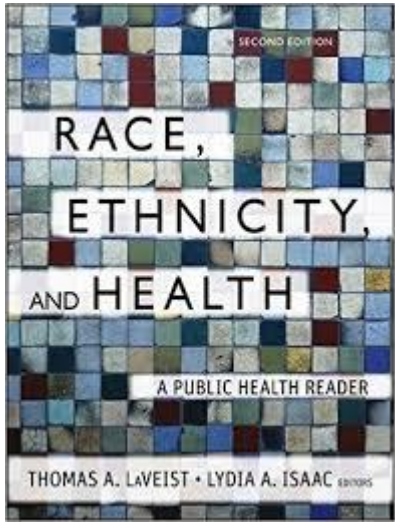
- Ovarian cancer
- Cervical cancer
- **Endometrial cancer**

Eichelberger, Doll, Ekpo & Zerden. Black Lives Matter: Claiming a Space for Evidence-Based Outrage in Obstetrics and Gynecology. AJPH. Oct 2016.

Disclosure: I have a perspective

"Fundamental Causes" of Social Inequalities in Mortality: A Test of the Theory*

Phelan, Jo C ; Link, Bruce G ; Diez-Roux, Ana ; Kawachi, Ichiro ; Levin, Bruce . *Journal of Health and Social Behavior* 45.3 (Sep 2004): 265-85.



Critical Race Theory, Race Equity, and Public Health: Toward Antiracism Praxis

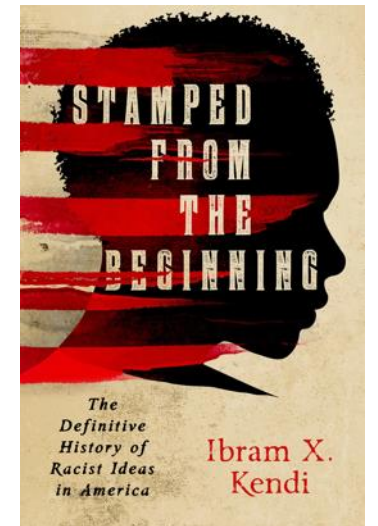
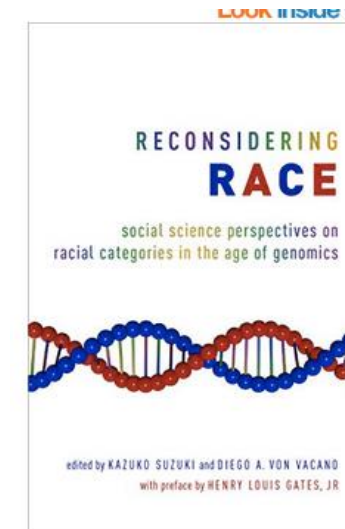
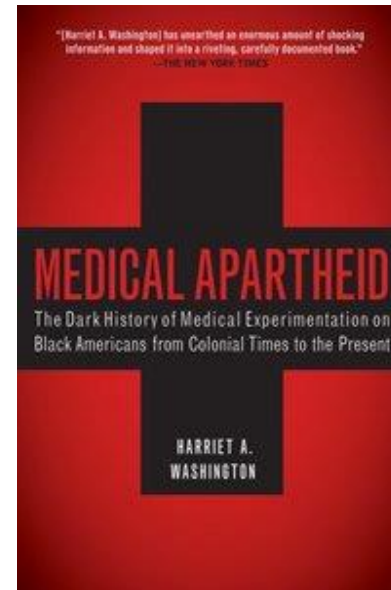
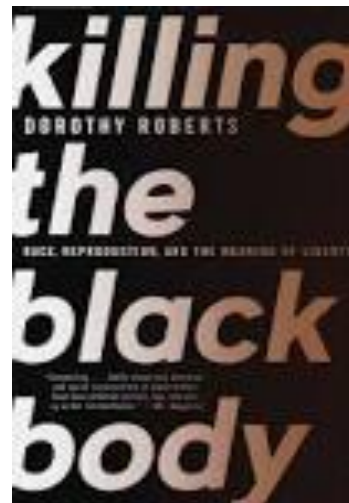
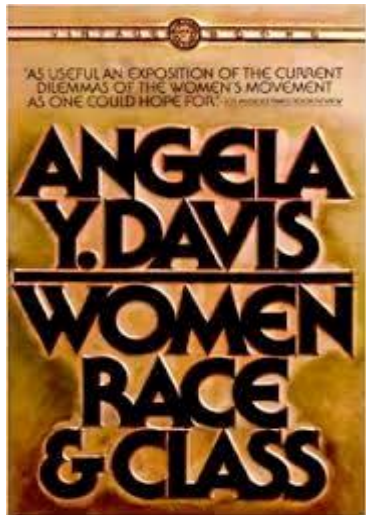
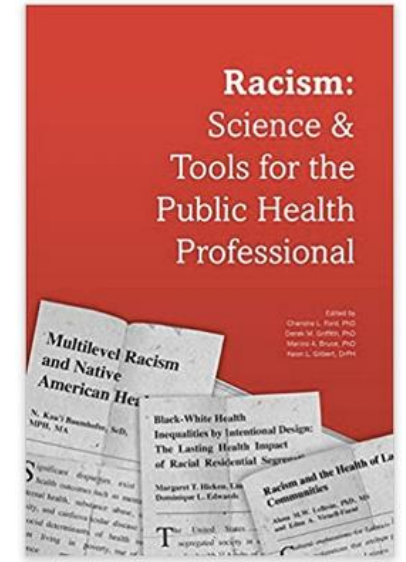
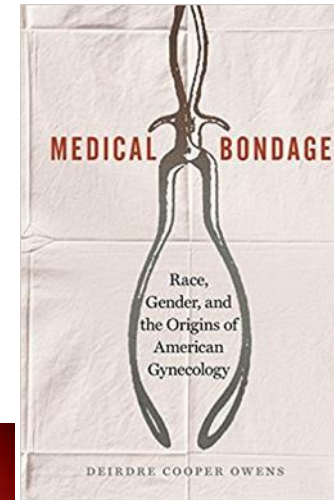
Racial scholars argue that racism produces rates of

Chandra L. Ford, PhD, and Collins O. Airhihenbuwa, PhD

Methods for the Scientific Study of Discrimination and Health: An Ecosocial Approach

The scientific study of

Nancy Krieger, PhD



@KemiDoll

Public Health Critical Race Praxis
(Ford & Airhehenbuwa)

Racism is **omnipresent in society** and active in the daily lives of people of color.

Racial biases **inform the nature of research questions** and *a priori* assumptions driving research.

Research efforts are EQUITY oriented.

How has knowledge about Black women with EC been constructed?

Fundamental Cause Theory
(Link & Phelan)

The link between SES and mortality persists over time due to differential access to key flexible resources (knowledge, money, power, prestige, and social connections).

Differences in health outcomes **based on social position in a society** arise in the context of the treatability of a given condition.

What are the modifiable factors that contribute to the Black-White mortality gap in EC?

The Ecosocial Theory of Disease Distribution
(Krieger)

Embodiment: How we, as humans, 'literally **biologically embody exposures** arising from our societal and ecological context, thereby producing population rates and distribution of disease.'

How does the social environment influence biologic differences in histology and outcomes?

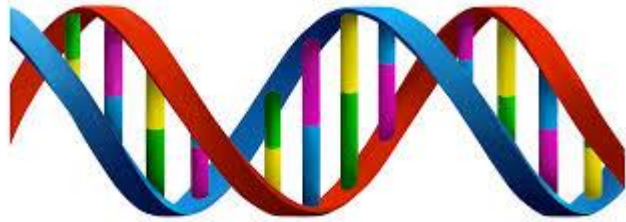
Doll, KM. Investigating Black-White disparities in gynecologic oncology: Theories, conceptual models, and applications. *Gynecologic Oncology*. April 2018.

EARLY STUDIES: 2016 - 2020



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?

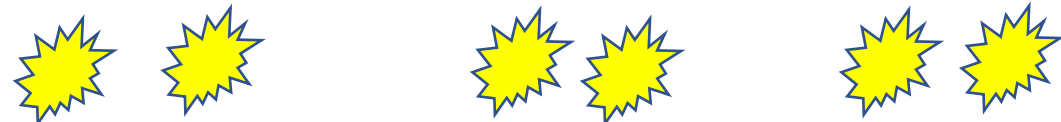
Race defined as a biological/genetic entity



Assumptions that healthcare environments represent 'color-blind' spaces



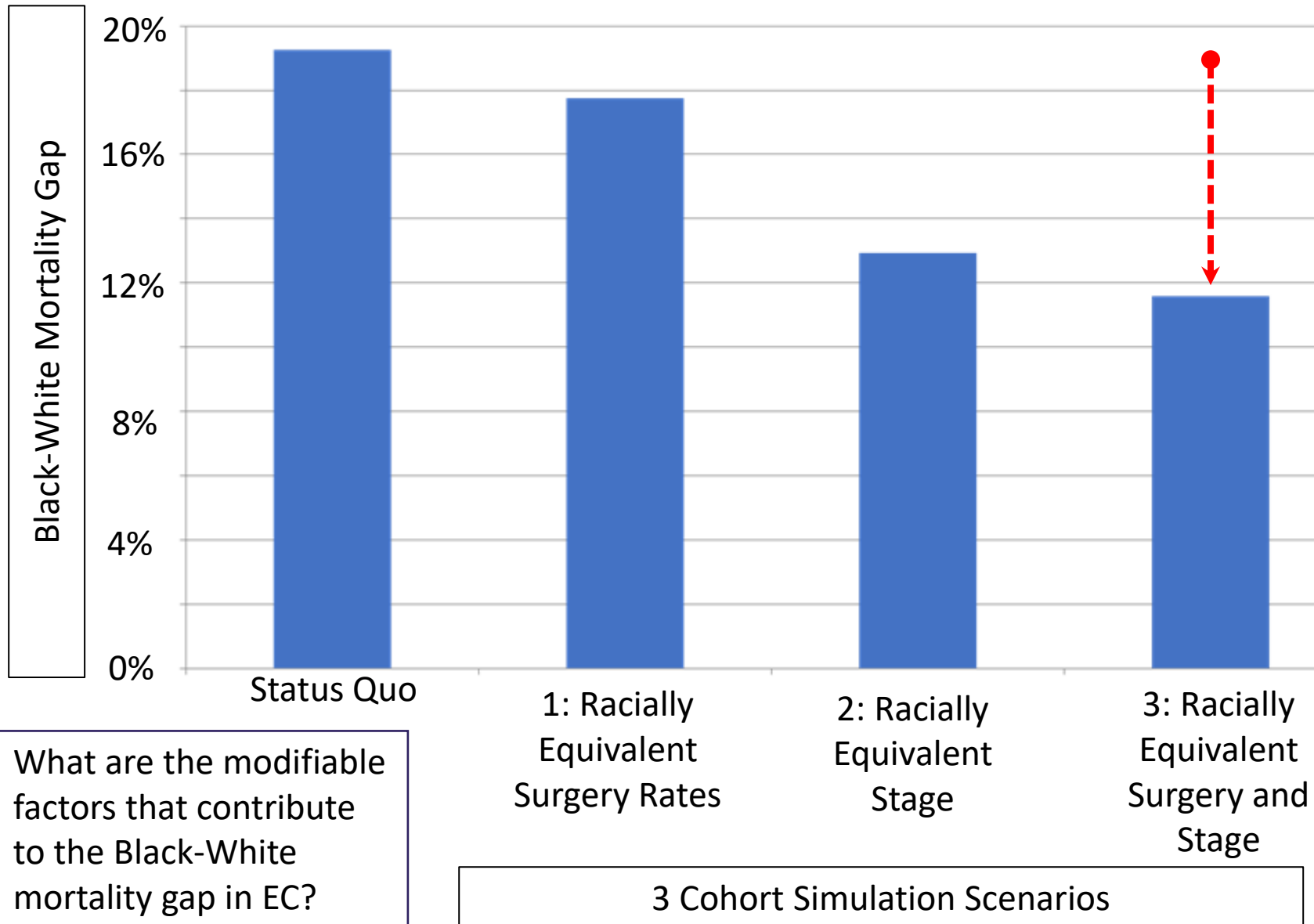
Absence of the Black woman's voice



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

No work to address repeated documented treatment inequity

Preliminary work: Cohort Simulation



What are the modifiable factors that contribute to the Black-White mortality gap in EC?

Data Source:
SEER 18-Registry
EC Cases 2004 - 2009
Base Population **N= 34,580**

Absolute 5-year mortality gap:
19.3% → 11.6%

40% of Black-White mortality gap is attributable to stage at diagnosis and surgery rates

Doll KM, Winn AN, & Goff BA. *AJOG*. March 2017.

Context: Black women's reproductive health

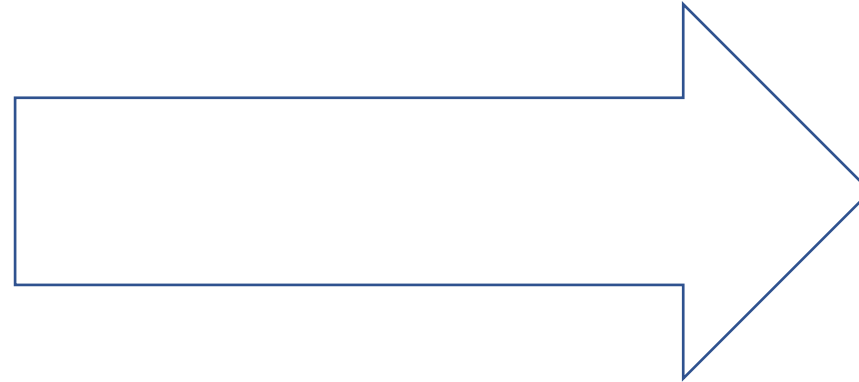


Gynecologic Care

Higher rates of

- **Fibroids**
- **Irregular cycles**

cause abnormal bleeding in young black women

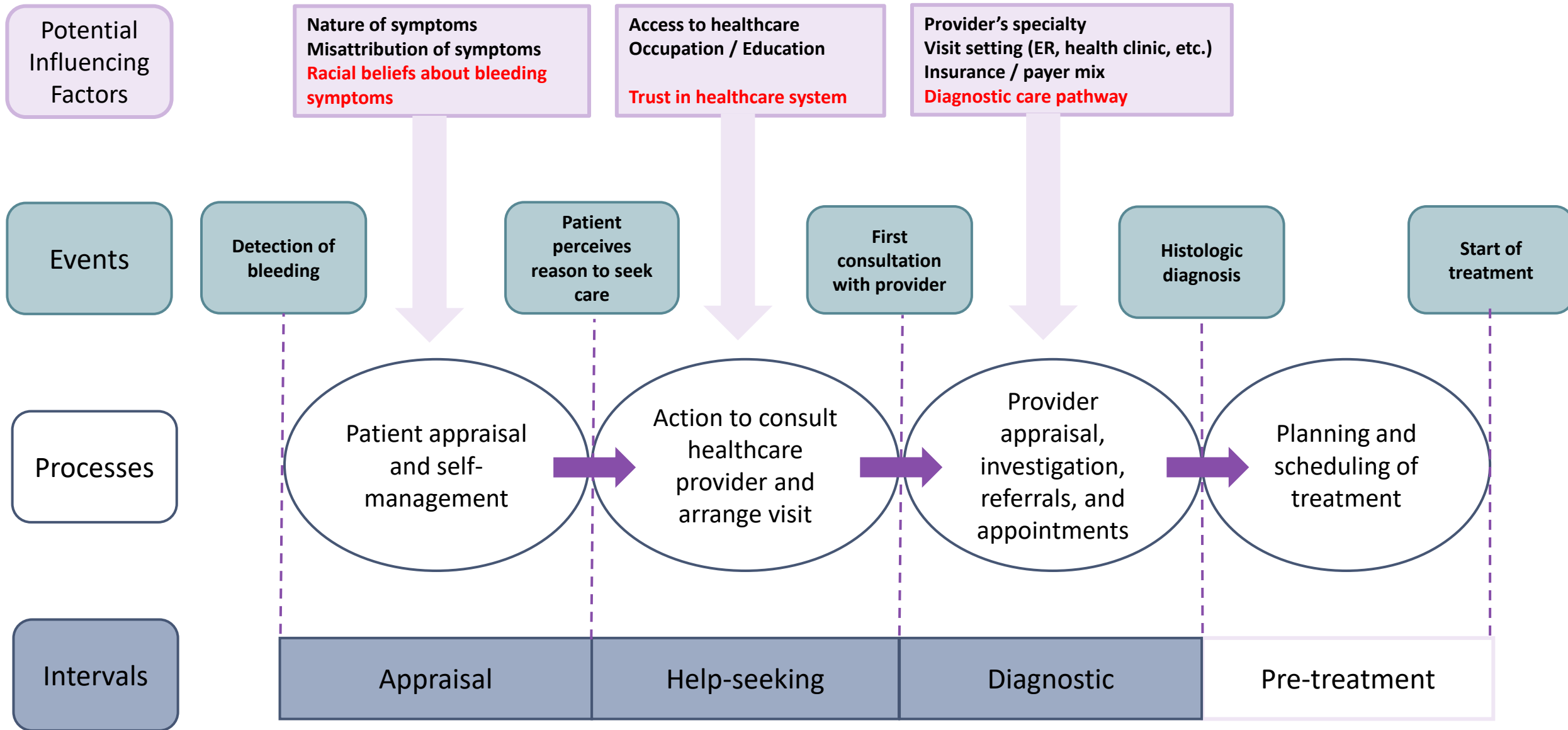


Gynecologic Cancers

Results in **normalcy** of abnormal bleeding in older black women

- **Endometrial cancer**

We may have a RACIALIZED view of the primary symptom of endometrial cancer



Application of The Andersen Model of Total Patient Delay

Appraisal Interval: Normalizing Delay

Community-Engaged Qualitative Study

N=32 Black and White women with EC

Semi-structured interviews (1-2 hours) on experience of menopause, symptom onset, and diagnosis

"I was just surprised. Just surprised. Not alarmed, because it wasn't heavy at all. Very light. But it was there. And I'm like, 'Is that blood?'Because it was nothing compared to what I'd been used to since I was in my 20s. Nothing."

Black women expressed multiple factors associated with delay

- Nature of symptoms: **not new, bothersome, painful**
- Misattribution of symptoms: **fibroids, irregular cycles**
- Cue to action: **personal waiting period, symptom severity**
- Symptom disclosure: **misaligned with patient risk**



Julianna Alson, MPH



Liz Sage, MPH

Appraisal Interval: Overlapping Vulnerability

Overlapping Vulnerability + Underlying Risk

Areas of Vulnerability	Contributor	Black Women Vulnerability
Experiential: Knowledge	Knowledge about menopause and the menopausal transition.	↑
	Endometrial Cancer knowledge	↑
Experiential: Prior Negative Reproductive Healthcare Experience	Racist microaggressions and explicit race-based discrimination	↑
	Experiences with obesity and fat shaming	↑
Medical: Prior or Concurrent GYN Conditions	Gynecologic conditions (e.g., polyps and fibroids)	↑
	History of very heavy periods / abnormal uterine bleeding.	↑
	Non Gyn comorbid health conditions or procedures	↓
Structural: Access to quality healthcare provider relationship	Providers' responses are vague, reassuring, or otherwise minimize risk.	↑
Epidemiological: Underlying Histologic Risk	Population rate of aggressive histologic subtypes.	↑

Appraisal Interval: Overlapping Vulnerability

Overlapping **Vulnerability** and Underlying **Risk** of EC Care Delay

Areas of Vulnerability	Contributor	Black Women Vulnerability	White women vulnerability
Experiential: Knowledge	Knowledge about menopause and the menopausal transition.	↑	↓
	Endometrial Cancer knowledge	↑	↑
Experiential: Prior Negative Reproductive Healthcare Experience	Racist microaggressions and explicit race-based discrimination	↑	—
	Experiences with obesity and fat shaming	↑	↑
Medical: Prior or Concurrent GYN Conditions	Gynecologic conditions (e.g., polyps and fibroids)	↑	Moderate
	History of very heavy periods / abnormal uterine bleeding.	↑	↓
	Non Gyn comorbid health conditions or procedures	↓	Moderate
Structural: Access to quality healthcare provider relationship	Providers' responses are vague, reassuring, or otherwise minimize risk.	↑	Moderate
Epidemiological: Underlying Histologic Risk	Population rate of aggressive histologic subtypes.	↑	↓

Native / Indigenous people?

Trans, Queer, and Gender Non-Binary Individuals?

Immigrants, refugees, and/or low English proficiency?

...And more

Diagnostic Interval: Care Delivery Omissions

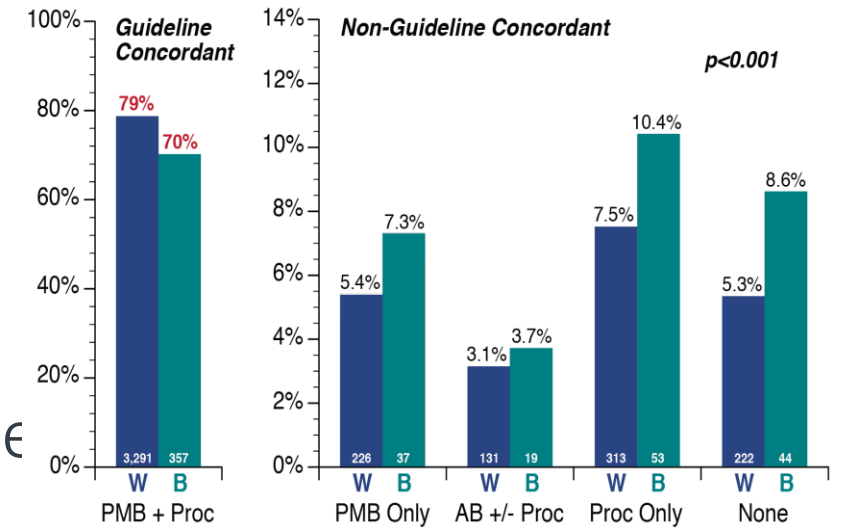
SEER-Medicare Study

EC Cases 2000-2011 (N=4,354 (W), 537 (B))

Identified symptoms (bleeding) and procedures (TVUS, biopsy, D&C) prior to diagnosis

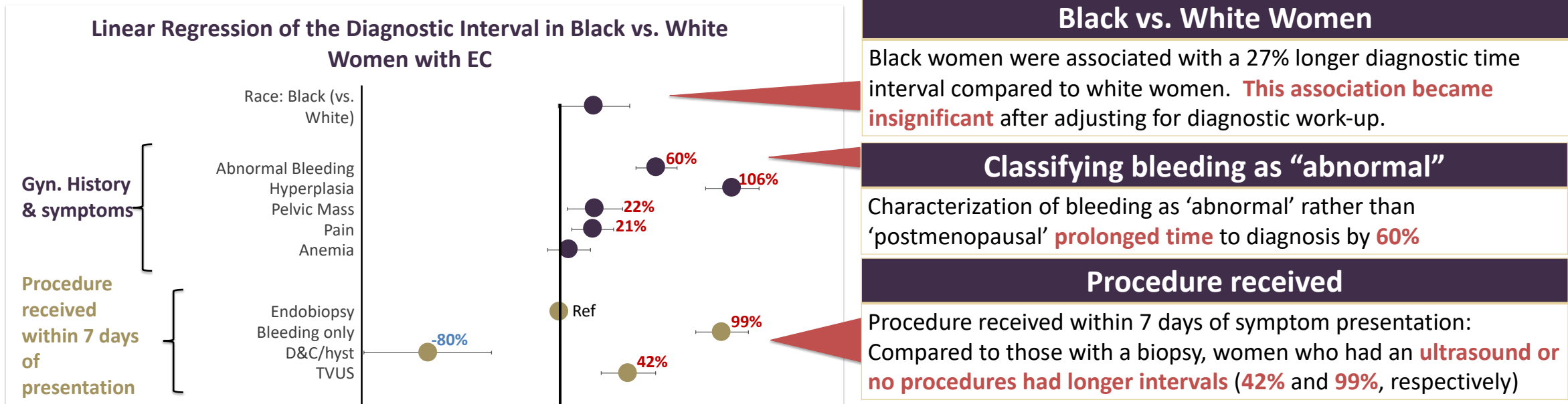
Black women with **aRR 1.12 – 1.74** for non-guideline adherent work up

Non-guideline pathways associated with **aOR 2.3-2.5** with Stage 3-4 disease



Liz Sage, MPH

Influencing Factors on Diagnostic Interval among Women with EC



Median days: 28 days (1 – 110)

Black women had **27% longer time** from bleeding to diagnosis.

This was **explained** by 1) bleeding classification and 2) lack of prompt biopsy, TVUS or D&C.

Overall **time was NOT related to stage at diagnosis**, as the time intervals were *relatively narrow*.

Diagnostic Interval: Provider Survey



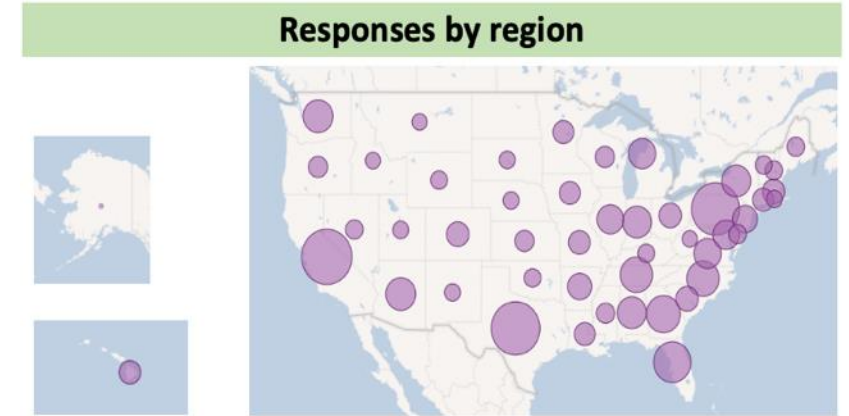
Li Sage, MPH

How are Peri-menopausal Reproductive Symptoms Assessed by First Line Providers?

Demonstrated overall moderate (6/10) EC knowledge

Indicated **non-guideline adherent management choices** from **10 to up to 39%** in response to EC symptoms

Within guideline choices, preferred **TVUS > biopsy**



Provider Characteristics	N (%)
Fam Med, IM, or EM	252 (47.5%)
No University Affiliation	350 (73%)
NP (vs MD)	195 (37%)

Estimated Performance of Transvaginal Ultrasonography for Evaluation of Postmenopausal Bleeding in a Simulated Cohort of Black and White Women in the US

Study: Quality of the Guidelines

Kemi M. Doll, MD, MS; Sarah S. Romano, MPH; Erica E. Marsh, MD; Whitney R. Robinson, PhD

	Black	White	Absolute Difference	Relative Black : White
Sensitivity	47.5%	87.9%	40.4%	84% more sensitive test for White women
NPV	91.7%	97.0%	5.3%	2-fold increase in number of false negative results
AUC	0.57	0.73		Overall nearly 30% better performance among White women

Table. **Race Comparison** of Performance of TVUS ET **4MM** thresholds for identifying endometrial cancer among a simulated cohort with postmenopausal bleeding

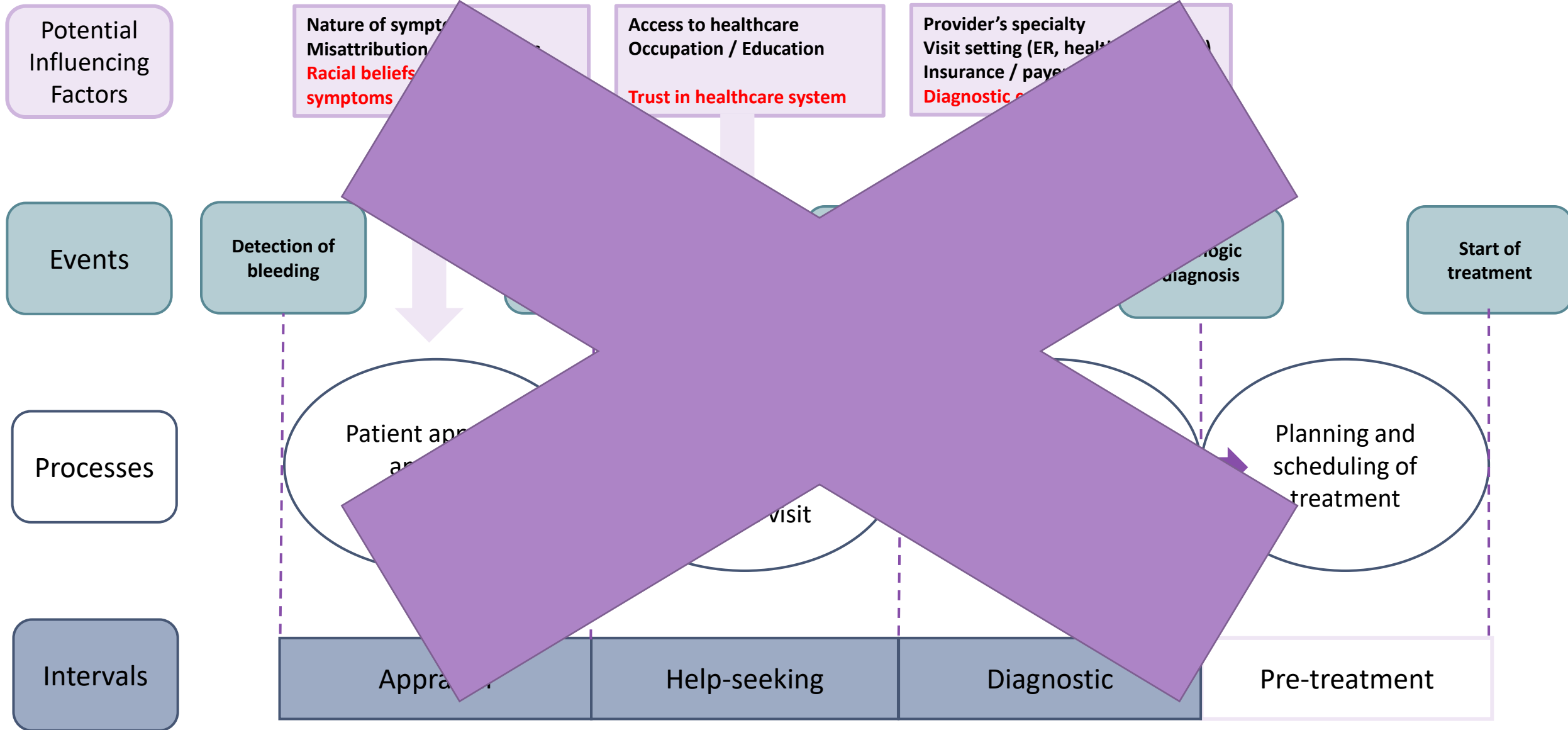
Study: Quality of the Guidelines

Guidelines that emphasize TVUS are based on a paradigm of a low-risk population, high accuracy of the test, and low consequences in the setting of a false negative.

None of these assumptions apply to U.S. Black women at risk for EC.

Our clinical algorithm has **built in racial inequity** in effectiveness which likely contributes to delayed diagnoses.

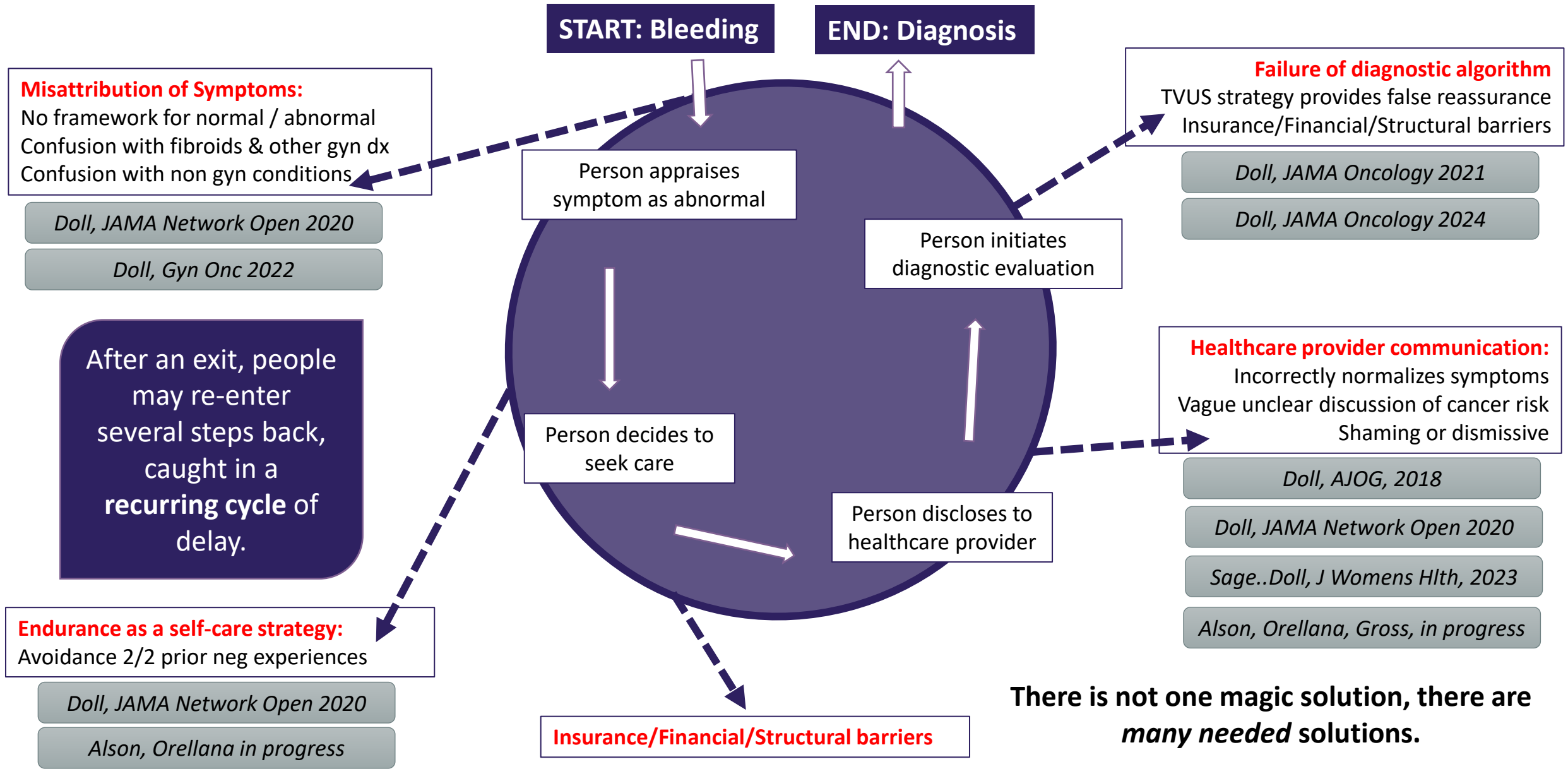
Doll, Romano, Marsh & Robinson. *JAMA Oncology*. July 2021;7(8):1158-1165



Application of The Andersen Model of Total Patient Delay

Overlapping **Vulnerability** and Underlying **Risk** of EC Care Delay

Overlapping Vulnerability + Underlying Risk = EC Care Delay





ecana

Endometrial Cancer
Action Network for
African-Americans

<https://ecanawomen.org>



COMMUNITY



EDUCATION



Adrienne Moore, RT, Me-BA



RESEARCH **JW** Medicine

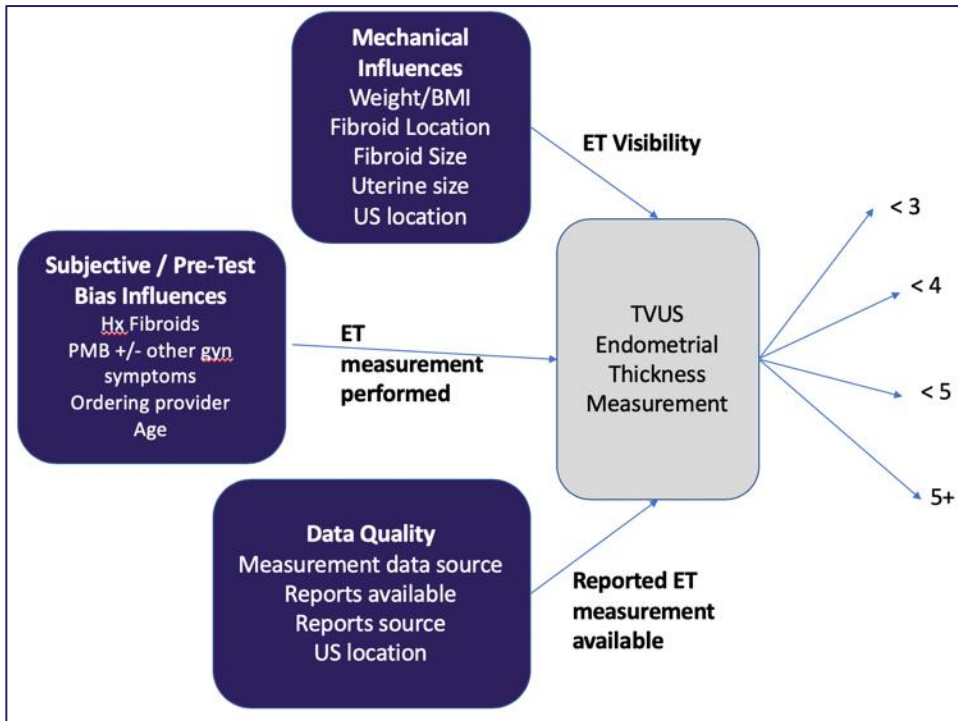
Originally Funded by PCORI, UW ITHS, generous donors
--> Now Independent 501©3 Non-profit

GRACE Center 2024 At A Glance: Projects

Current Projects (Leading)	Current Projects (Collaborating)	Mentored Work
The SISTER Study (Social Interventions for Support in Treatment of Endometrial Cancer and Recurrence) – DOLL	Racial Differences in Hysterectomy: A Multilevel Investigation – ROBINSON, Duke (R01)	Unblinding the Disparities Within: Evaluation of Gynecologic Cancer Clinical Trials using a Health Equity Lens - OLULORO
GUIDE-EC : Guidelines for Ultrasound in early Detection of Endometrial Cancer - DOLL	ITHS Community Engagement Core: Preclinical Research Engagement – KO, UW (U54)	Low English Proficiency (LEP) and Delays in Gynecologic Oncology care - GROSS
Dissemination Tool of Biopsy-First Early Detection of EC: GUIDES BY US - DOLL	TP53 in Endometrial Cancer Development and Racial Disparities – RISQUES & DOLL (CCSG Pilot)	Improving Labor and Birth experiences of Bisexual Women of Color - WILLIAMS
Designing Novel Mechanisms for Acceptability of Blood and Tissue Based Research among Black women with high-risk endometrial cancer (ACTS) - DOLL	Multilevel Determinants of Racial Disparities in Receipt of Guideline-concordant Endometrial Cancer Treatment (R01, PI: Felix, OHSU)	Immunosenescence in Endometrial Cancer - JONES
ROSES : Roles of Social Change in Engagement Science- DOLL	The Carolina Endometrial Cancer Study (Collab, PI: Olshan/Nichols)	<p style="text-align: right;">Under Review</p> Observing and Understanding Racial Hypervigilance on the SISTER Study (OUR SISTER) NCI R01 Feb 2024 / Nov 2024 The SISTER Extension Study – PCORI LTFU June 2024

Guidelines for Ultrasound In the Detection of Early Endometrial Cancer (GUIDE-EC Study)

Goal: To inform guideline change through development of a risk-based approach to evaluating symptomatic Black women via 3,500 Black women cohort.



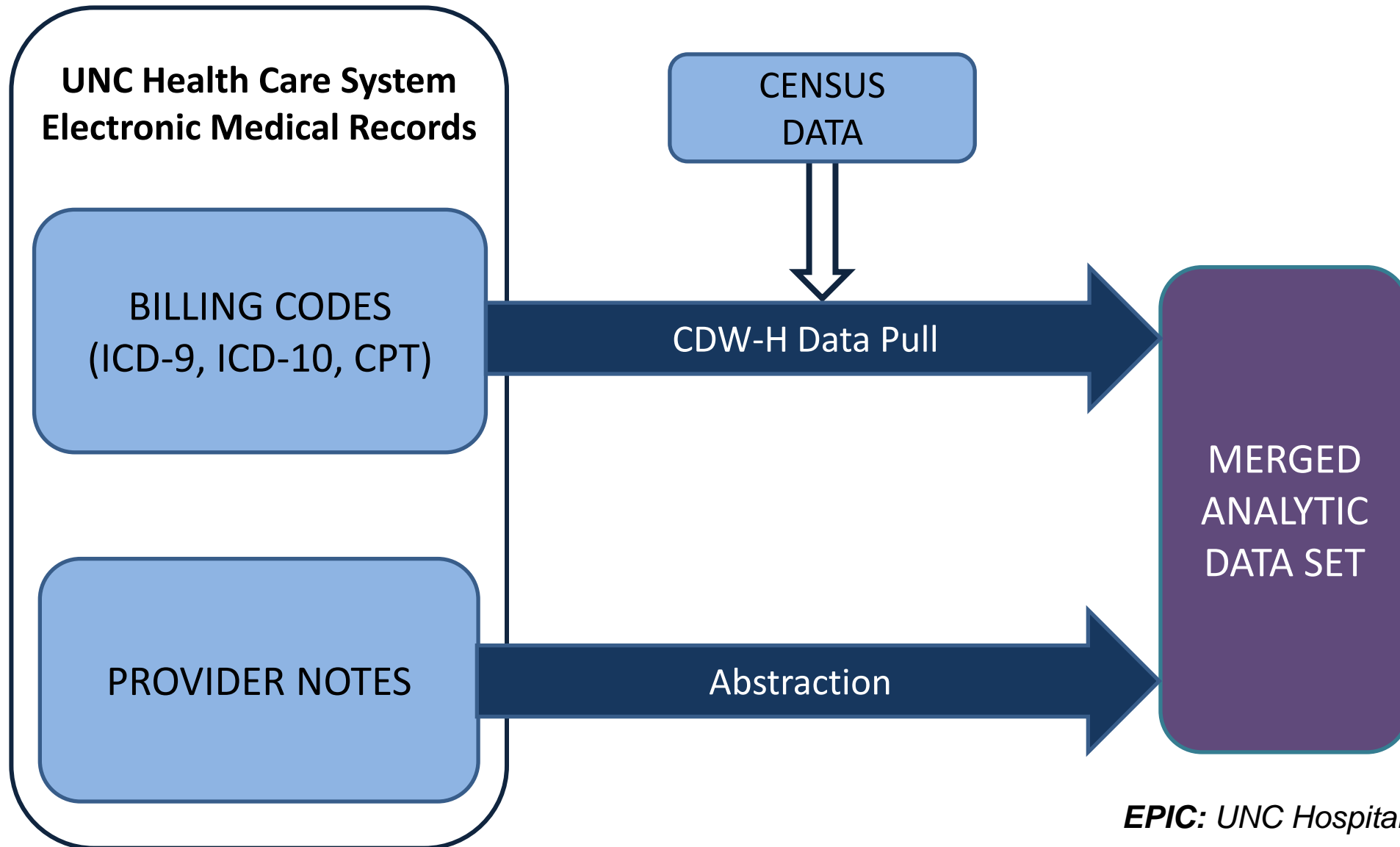
Whitney Robinson, PhD
Social Epidemiology
Duke University



Erica Marsh, MD MSCI
Reproductive Endocrinology
U of Michigan

Kuni Foundation Discovery Award; 2021-2024

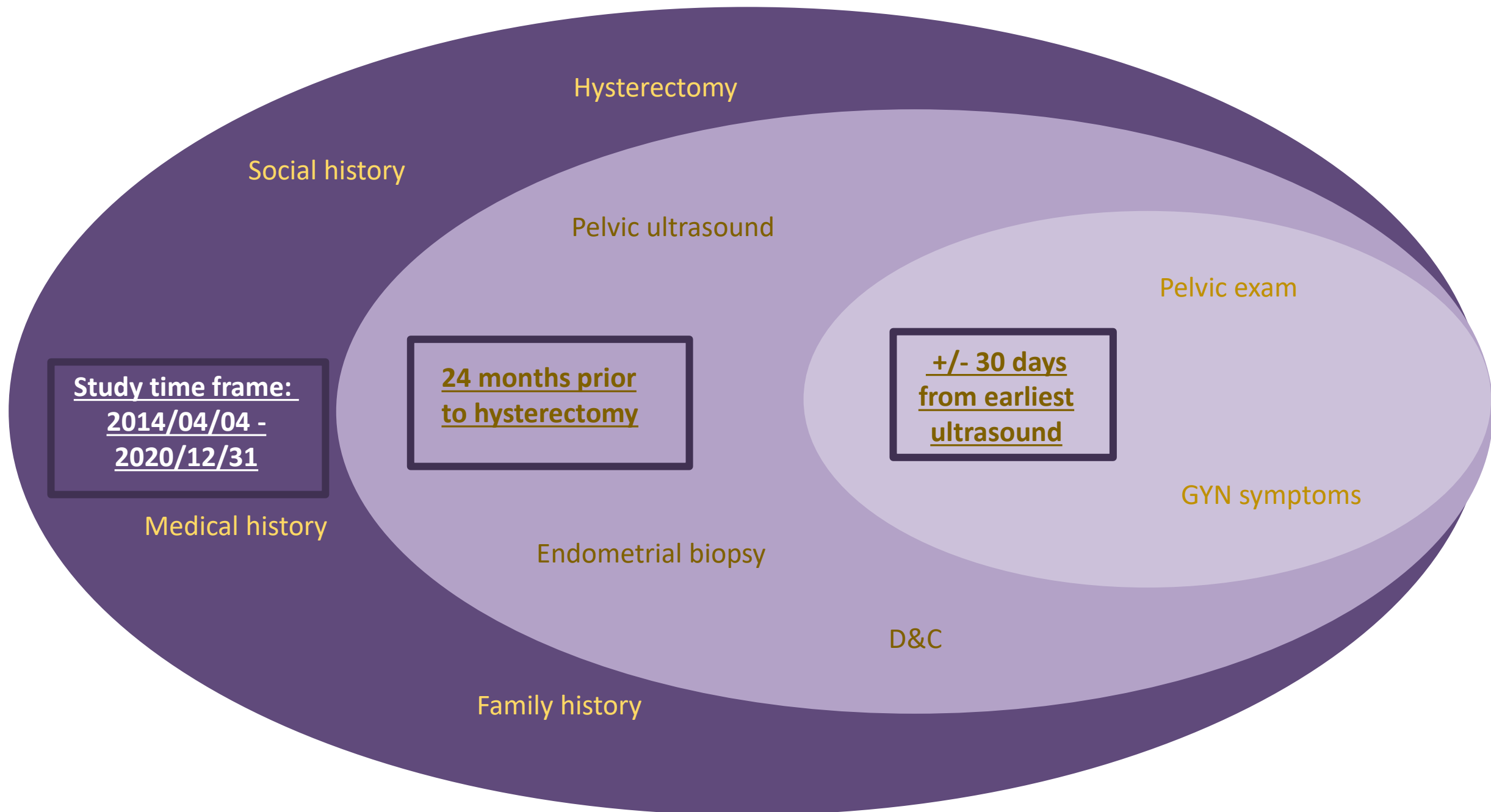
Data collection



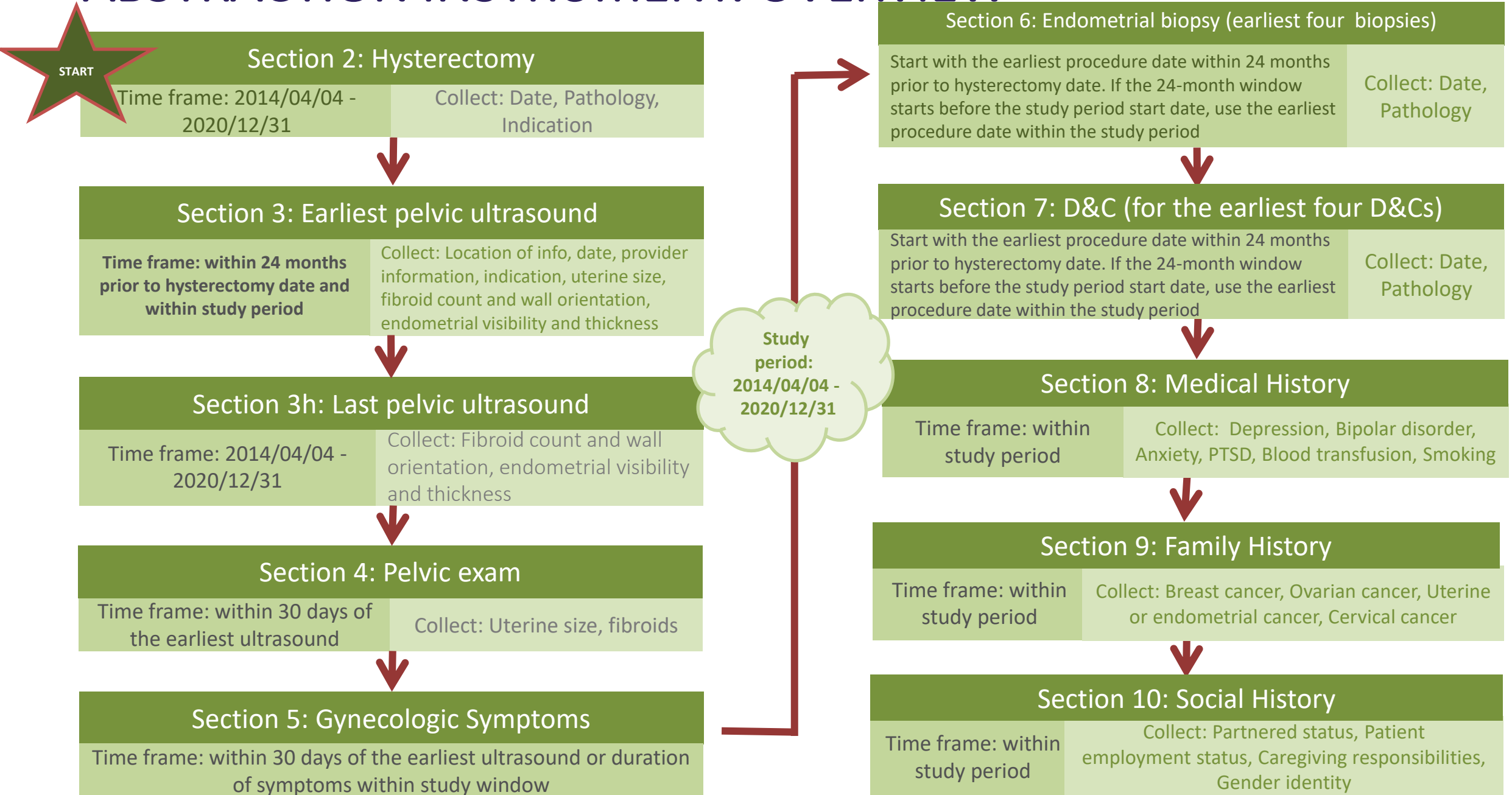
Legend:

***EPIC:** UNC Hospitals electronic medical record*

***CDW-H:** Carolina Data Warehouse for Health (search query engine for EPIC)*



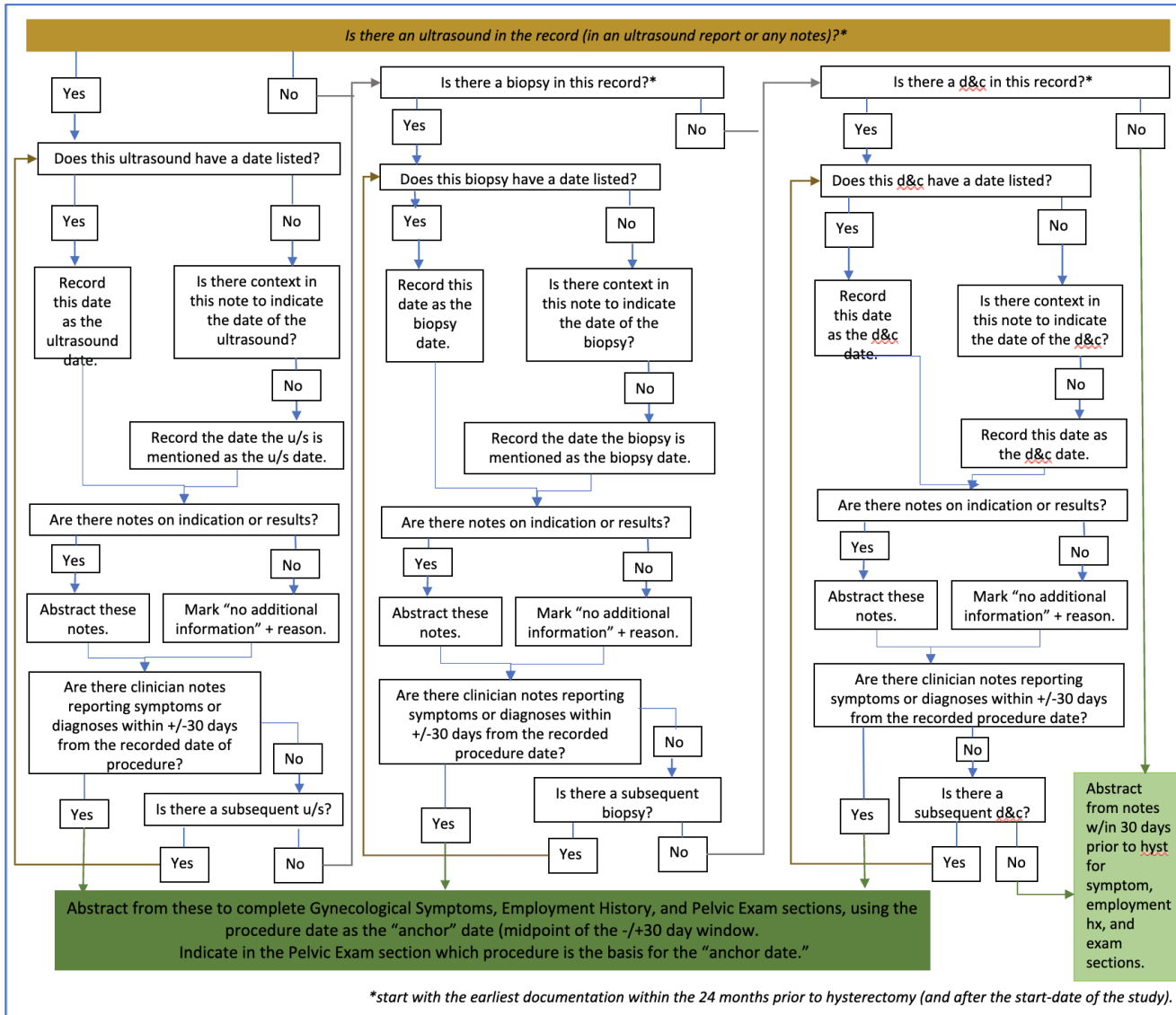
ABSTRACTION INSTRUMENT: OVERVIEW



Abstraction Process & Quality Control

- 4 professionally trained abstractors with > 20+ years combined experience
- 30 page Abstraction Protocol with live updates/auditing
- 3 Levels of QC:
 - 5% records chosen at random for double abstraction
 - Computer based comparison of all entries
 - Discrepancies flagged and categorized (ie. Typo vs. error vs difference in interpretation)
 - Study team and/or clinician review to resolve
 - Abstractor-generated questions → PI + Study team review
 - Triggers direct clinical record by clinician if needed
- Included direct Epic records, scanned records from OSHs, and telephone and nursing notes

Example Abstraction Flowchart tool



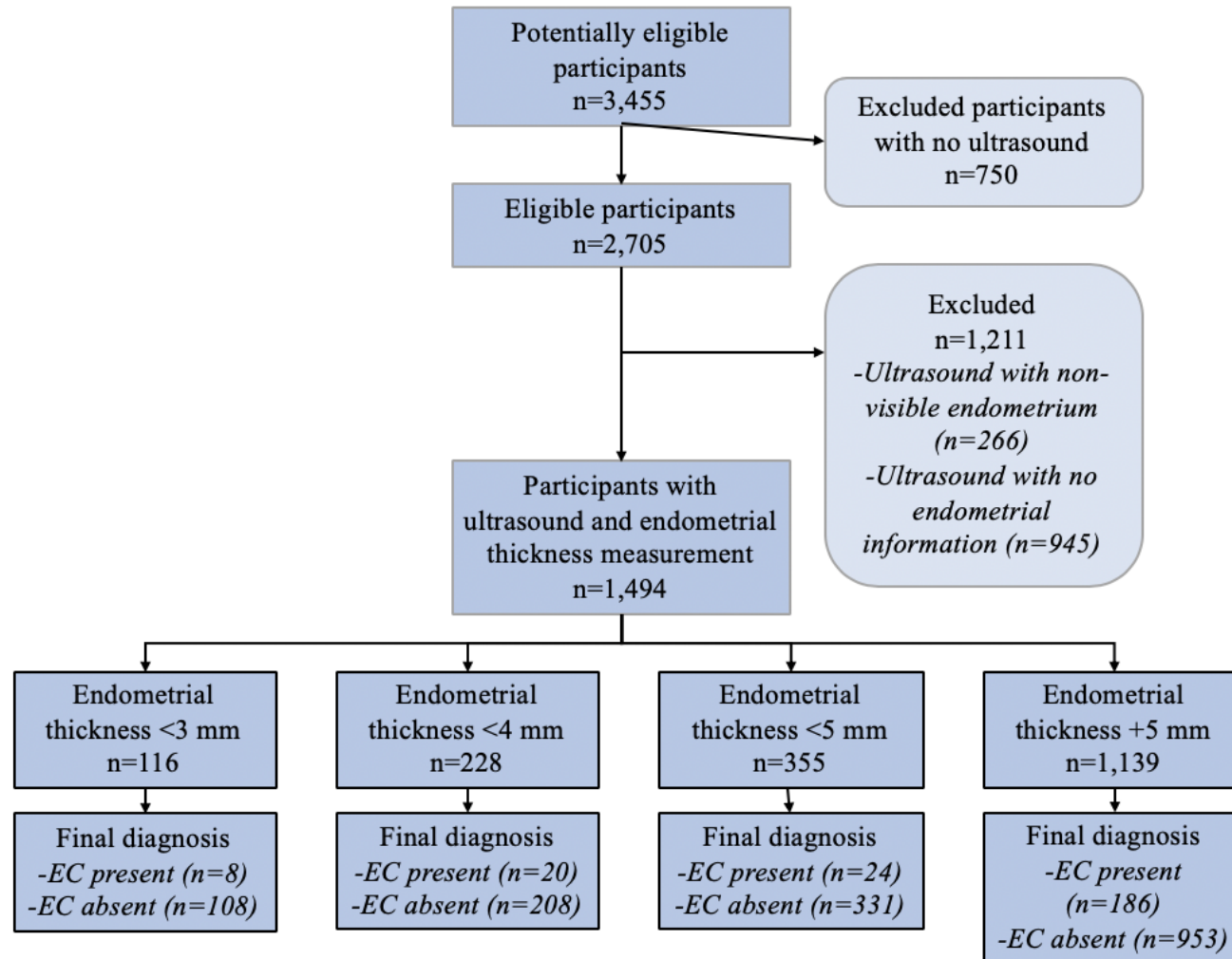
Julianna Alson, MPH
SENIOR PROJECT MANAGER



Patrice Williams, B.S
RESEARCH COORDINATOR

Data Abstraction: August 2021 – August 2022

eFigure 1. Flowchart of inclusion and exclusion of patient cases from the GUIDE-EC full sample.



Endometrial Thickness as Diagnostic Triage for Endometrial Cancer Among Black Individuals

Kemi M. Doll, MD, MSCR; Mindy Pike, PhD; Julianna Alson, MPH; Patrice Williams, BA; Erin Carey, MD, MSCR; Til Stürmer, MD, PhD; Mollie Wood, PhD, MPH; Erica E. Marsh, MD, MSCI; Ronit Katz, DPhil; Whitney R. Robinson, PhD



Julianna Alson, MPH



Patrice Williams, B.S



Mindy Pike, PhD

Table 3. Sensitivity, Specificity, and False-Negative Probability of Endometrial Cancer by Endometrial Thickness Thresholds in the 1494 Participants

Endometrial thickness threshold, mm	No. of patients		Sensitivity, % (95% CI)	Specificity, % (95% CI)	False-negative probability, % (95% CI)
	Endometrial cancer (n = 210)	No endometrial cancer (n = 1284)			
Threshold: 3 mm					
<3	8	108	96.2 (92.6-98.3)	8.4 (7.0-10.1)	3.8 (1.7-7.4)
≥3	202	1176			
Threshold: 4 mm					
<4	20	208	90.5 (85.7-94.1)	16.2 (14.2-18.3)	9.5 (5.9-14.3)
≥4	190	1076			
Threshold: 5 mm					
<5	24	331	88.6 (83.5-92.5)	25.8 (23.4-28.3)	11.4 (7.5-16.5)
≥5	186	953			

Endometrial Thickness as Diagnostic Triage for Endometrial Cancer Among Black Individuals

Kemi M. Doll, MD, MSCR; Mindy Pike, PhD; Julianna Alson, MPH; Patrice Williams, BA; Erin Carey, MD, MSCR; Til Stürmer, MD, PhD; Mollie Wood, PhD, MPH; Erica E. Marsh, MD, MSCI; Ronit Katz, DPhil; Whitney R. Robinson, PhD



Julianna Alson, MPH

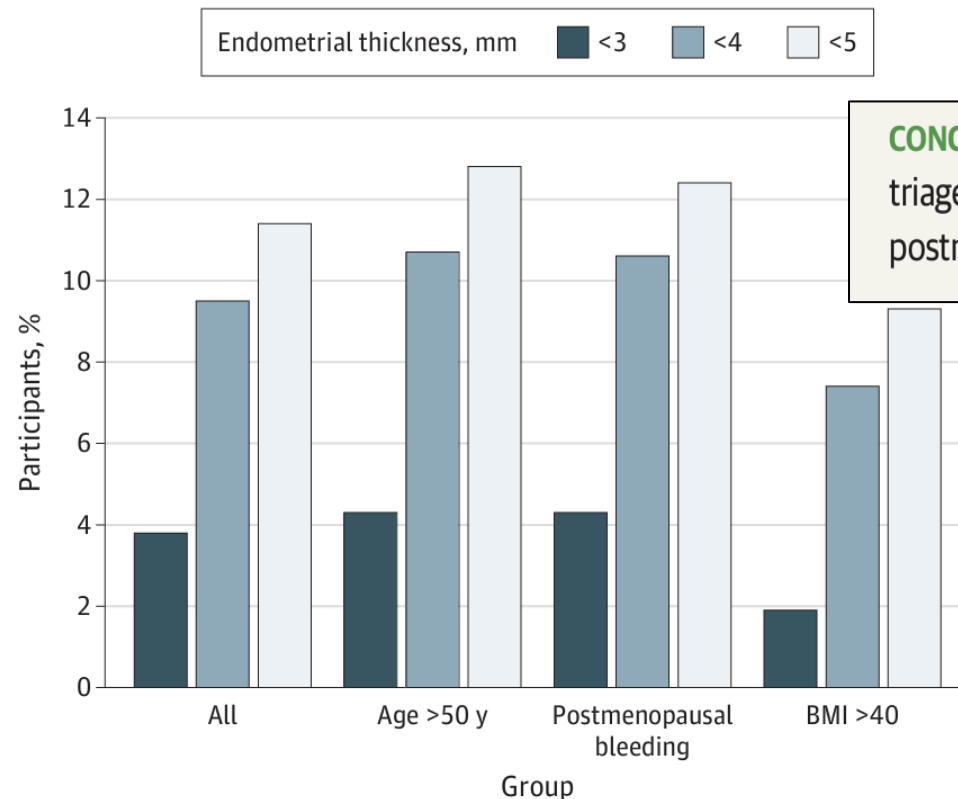


Patrice Williams, B.S



Mindy Pike, PhD

Figure. False-Negative Probability of Endometrial Thickness Measurement for Endometrial Cancer Diagnostic Triage Among Black Individuals



CONCLUSION AND RELEVANCE These findings suggest that the transvaginal ultrasonography triage strategy is not reliable among Black adults at risk for EC. In the presence of postmenopausal bleeding, tissue sampling is strongly recommended.

Aim 2 Paper in Progress:
Identifying people at high risk for suboptimal diagnostic pathway.

JOIN US IN A DIALOGUE TO IMPROVE HEALTH CARE FOR BLACK WOMEN!

This is a dialogue about your gynecologic healthcare experiences as Black Women. We can improve healthcare and survival among Black women. Join us for a group discussion.

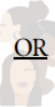
WHY PARTICIPATE

- Endometrial (uterine) cancer is the most common gynecologic cancer in the United States - more common than cervical and ovarian cancer.
- Black women are almost twice as likely to die from endometrial cancer compared with white women in the U.S. This is partly because Black women are more likely to be diagnosed later. Earlier diagnosis may lead to better outcomes!

TO PARTICIPATE YOU MUST BE A:

Black or African-American Woman with one of the following criteria:

35-49 years of age
Experience with bleeding that is of concern to you*



50 years of age or older

*Concerning bleeding can include heavy periods lasting more than 7 days, irregularly timed cycles, spotting in-between periods, requiring transfusions or medications to manage your menstrual cycle

HOW DO I PARTICIPATE?

Visit the link below to take a survey to see if you are eligible, and feel free to share!

WWW.EPOCHTRIBE.COM



scan to open link

Assistance with the survey is available, follow instructions at the link. The focus groups will take place in Durham & Charlotte in June 2023. If you're selected, we will contact you with the time and location. Focus group participants will be provided with a \$100 gift card.

FOCUS GROUPS ON BIOPSY & US EXPERIENCES



Durham Arts Council
Age 35 – 49
10 participants



Julianna Alson, MPH



Patrice Williams, B.S



Pauline's Tea Room - Charlotte
Age 50+
8 Participants



Virtual
Age 50+
7 participants

GUIDE EC FOCUS GROUPS - RESULTS



Julianna Alson, MPH



Patrice Williams, BS

Components and prerequisites of a successful risk-based provider discussion about biopsy

**Patient is empowered to make a risk-informed choice that will maximize chances of early EC detection*

Acknowledgment of
medical racism

Race concordant
medical care

Ample opportunities
to ask questions

Personalized care recommendations

Description of the full range of possible
pain/discomfort experiences

Detailed, lay-oriented health education

Racial disparities
in EC and
ultrasound utility

Physical risks of
waiting for biopsy

Emotional
benefits of
choosing biopsy

Procedure
mechanisms and
logistics

GUIDE EC PROVIDER INTERVIEWS

Semi-structured interview with 12 providers (OBGYN, IM, FAM MED, ED)



Maya Gross, MD MPH



Minerva Orellana, PhD

Perceptions of Racial Disparities in outcomes for EC

Uncertainty in specifics of guidelines

Skepticism in ability to tailor diagnostic evaluation

Apathy/disinterest in addressing this issue

Barriers/facilitators to biopsy-first

Facilitators

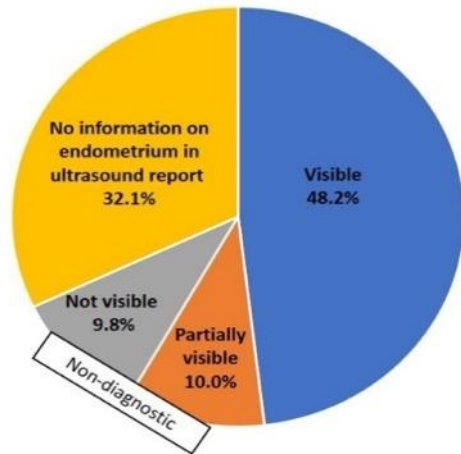
- Clinical decision-making support
- Education/dissemination of new recommendations
- Increased proportion of providers performing EMB

Barriers

- Acceptability of same-day biopsy to patients
- Pain management
- Lack of provider ability to perform EMB
- System/resource barriers

GUIDElineS for endometrial cancer detection: BiopsY vs. UltraSound (*GUIDES BY US*)

Goal: Develop & disseminate
multi-media toolkit and interactive decision aid for Black women
and gender expansive individuals with symptoms of EC



Define risk factors for NON-DIAGNOSTIC ultrasound results.

Convene focus groups to elicit barriers and facilitators to 'biopsy-first' approach: Black women + Gender expansive individuals

Create and test a public facing educational toolkit

AACR Victoria's Secret Global Fund; 2023 - 2026



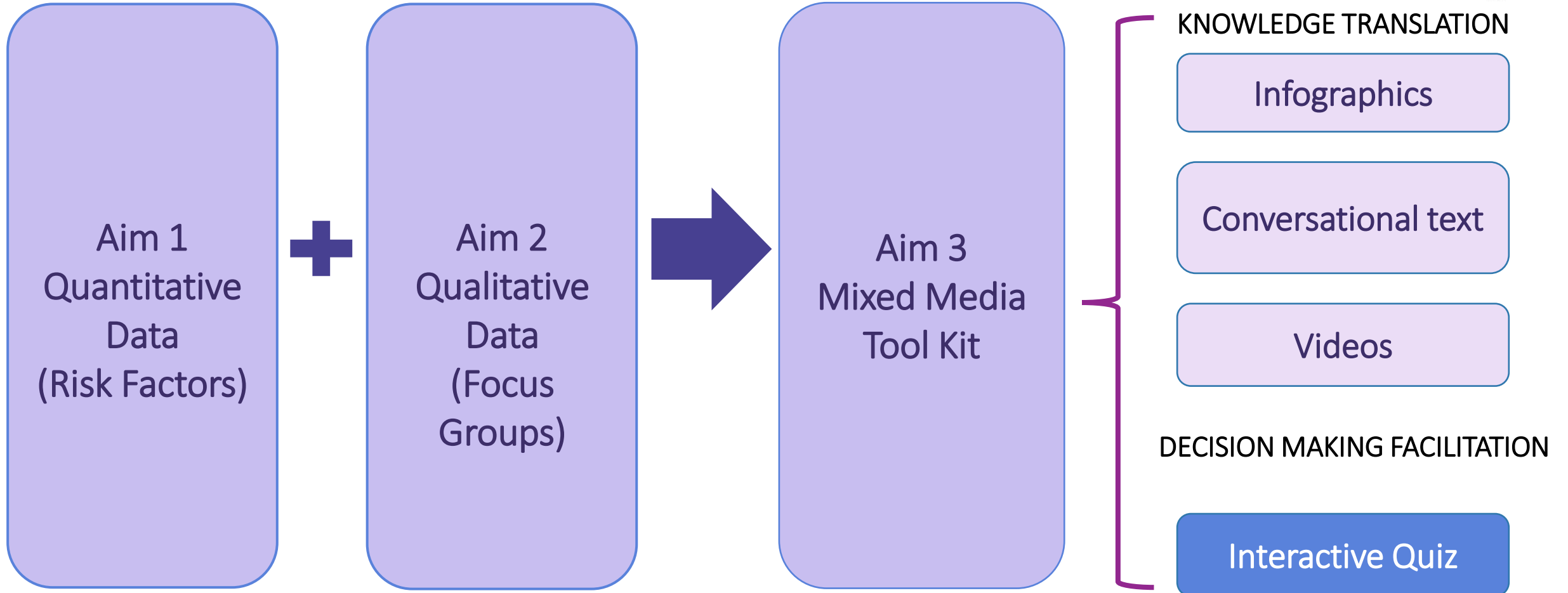
GUIDES BY US: DEVELOPMENT OF A MIXED MEDIA TOOLKIT



Patrice Williams, B.S

Minerva Orellana, PhD

Adrienne Moore, RT, MEd, BA



GE FOCUS GROUP AMERICAN PUBLIC HEALTH ASSOCIATION ABSTRACT - ACCEPTED



Minerva Orellana, PhD

APHA 2024 Annual Meeting

Speakers' Corner

Presentation Details

Please note: All live events are scheduled for Eastern Time

Abstract Title: Incorporating black gender expansive voices in endometrial cancer public health messaging

Abstract ID: 549032

Part of Session: 5079.0: [Transgender and Gender Diverse People's Health](#)

Date/Time: **Wednesday, October 30, 2024: 10:30 a.m.-12:00 p.m.** in Duluth Room

Session Type: Oral

Program: [LGBTQ Health Caucus](#)

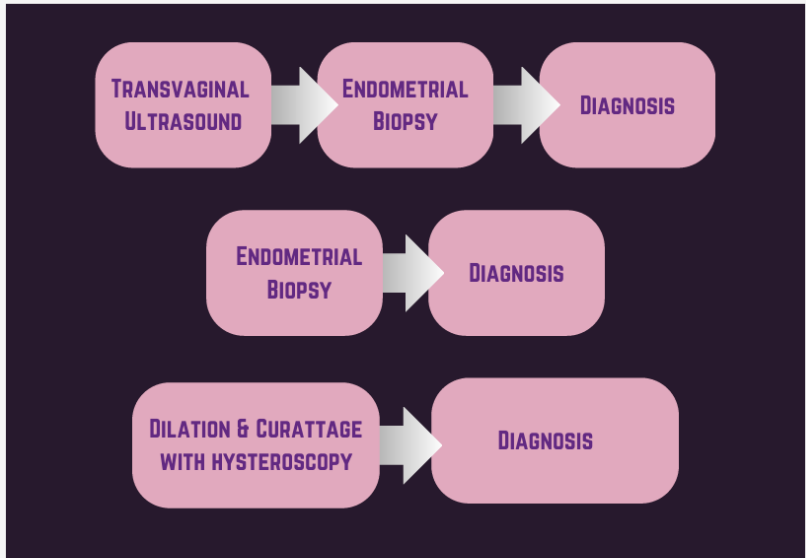
The GRACE Center
 GYNECOLOGIC RESEARCH AND CANCER EQUITY

**INTRODUCING
 GUIDES BY US**

We will be providing community inspired information around endometrial cancer along with resources for doctor's visit because early detection saves lives.

www.gracecenteruw.com @GUIDESByUs

@guidesbyus



Public health awareness campaign launched September 2024 across social media

Endometrial Cancer Symptoms

POSTMENOPAUSAL BLEEDING
 'Postmenopausal bleeding' is bleeding that happens after you have stopped bleeding for around or more than 12 months during menopause. Though you may have stopped bleeding, you can still experience menopausal symptoms such as hot flashes and difficulties sleeping. Studies have noted that menopausal symptoms can last up to ten years in Black people.

VERY HEAVY ABNORMAL UTERINE BLEEDING
 For younger women or anyone with a uterus, who have not entered menopause, EC most often presents as new ongoing very heavy bleeding that is different from your routine cycle.

OTHER SYMPTOMS
 Other EC symptoms can include pelvic or abdominal pain, new fatigue, light-headedness, and urinary symptoms, such as urinary frequency, incontinence, and/or retention.

www.gracecenteruw.com @GUIDESByUs

American College of Obstetricians and Gynecologists guidelines recommends three

Data suggests that most providers prefer starting with a transvaginal ultrasound. However, a transvaginal ultrasound might not be as good in Black women or people with a uterus or anyone over the age of 60.



The GRACE Center
 GYNECOLOGIC RESEARCH AND CANCER EQUITY

**LET'S LEARN ABOUT
 ENDOMETRIAL
 CANCER**



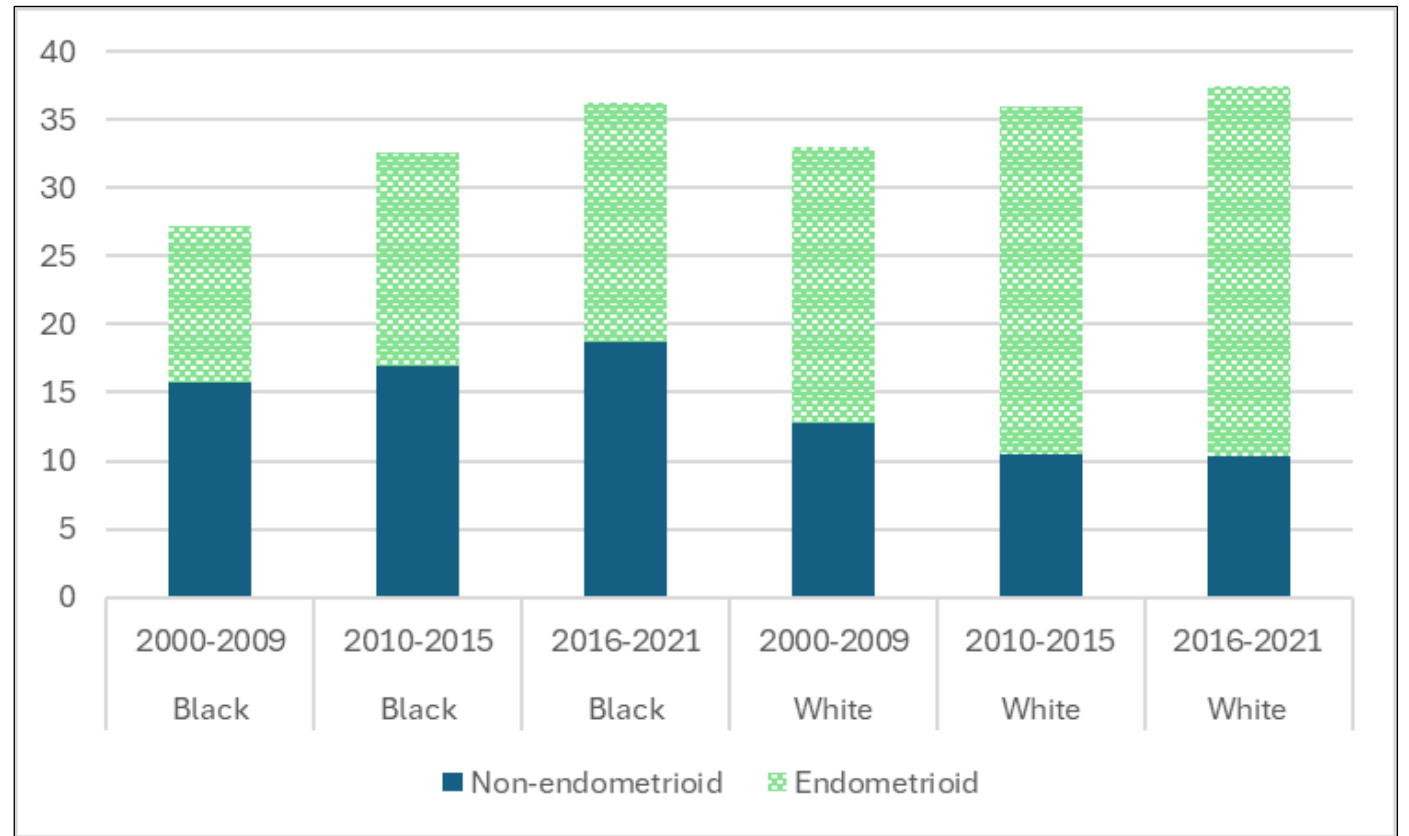
Minerva Orellana, PhD



Leah Franklin, MPH
 UW Medicine

'Narrowing', or *Eliminating* the Mortality Gap?

Not all endometrial cancer is created equal.
Over half of Black women diagnosed with EC have high-risk histology type.

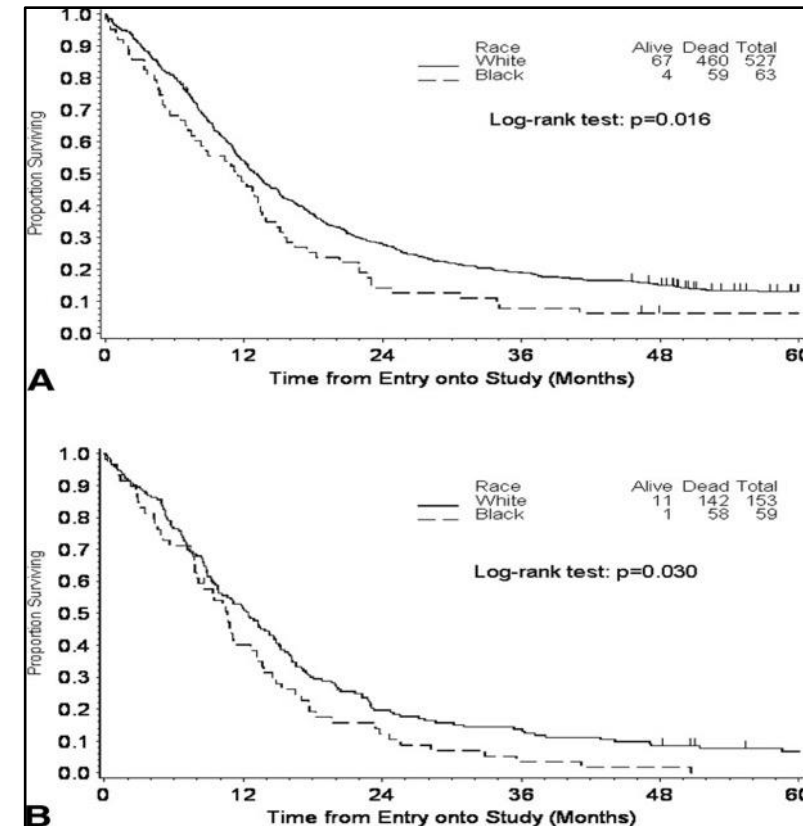


Age-adjusted rates per 100,000 from SEER cancer registry.

'Narrowing', or *Eliminating* the Mortality Gap?

Survival is more than access to care. Black women have lower survival on clinical trials and with guideline-concordant treatment.

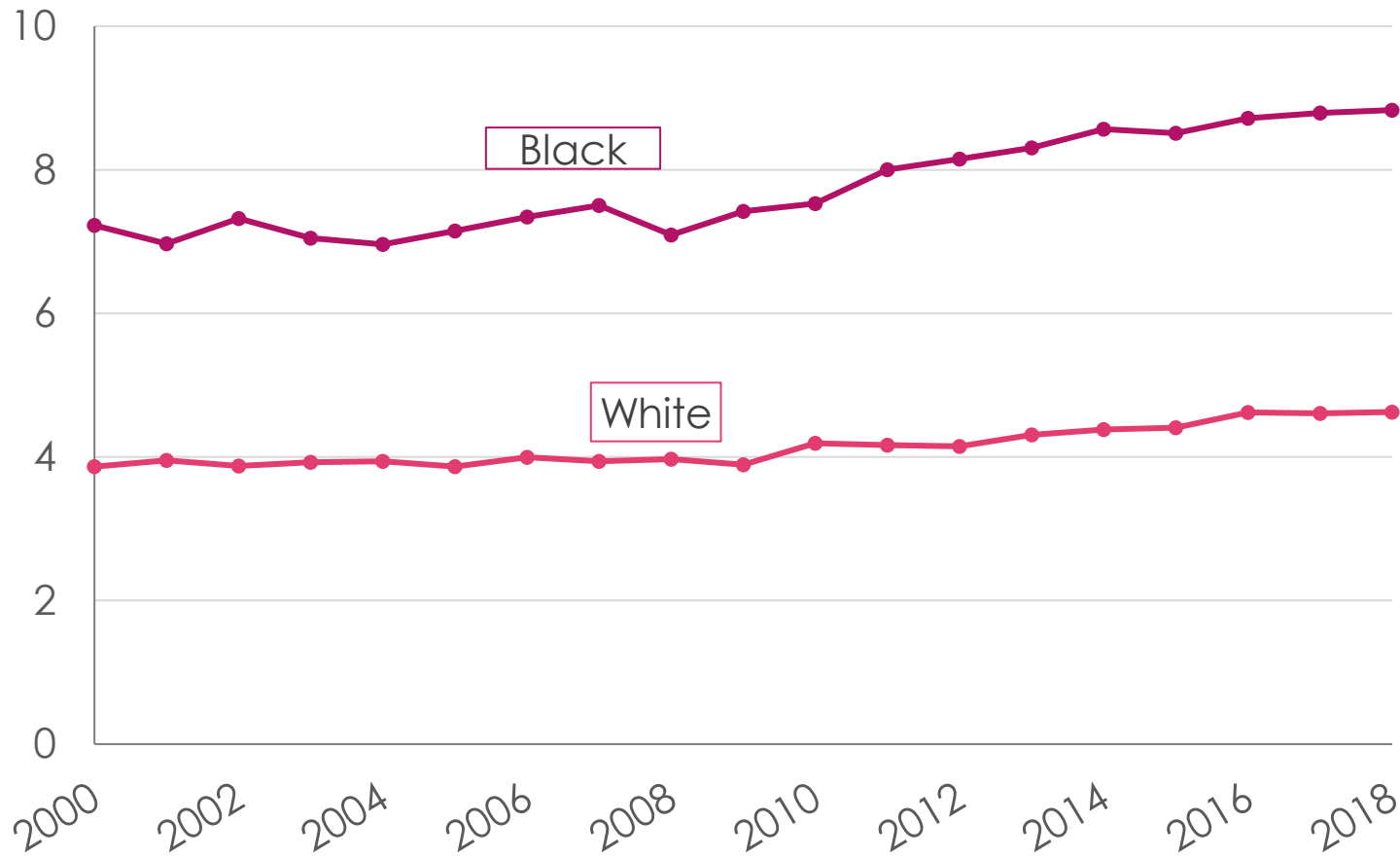
Racial disparity in survival among patients with advanced/recurrent endometrial adenocarcinoma on GOG/NRG Clinical Trials



Maxwell et al. *Cancer*. 2006

The Ecosocial Theory of Disease Distribution

Endometrial Cancer
US Mortality Rates by Race/Ethnicity 1999-2018

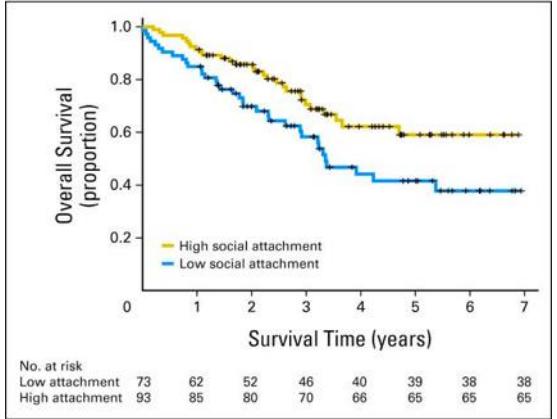


Social Isolation & Endometrial Cancer

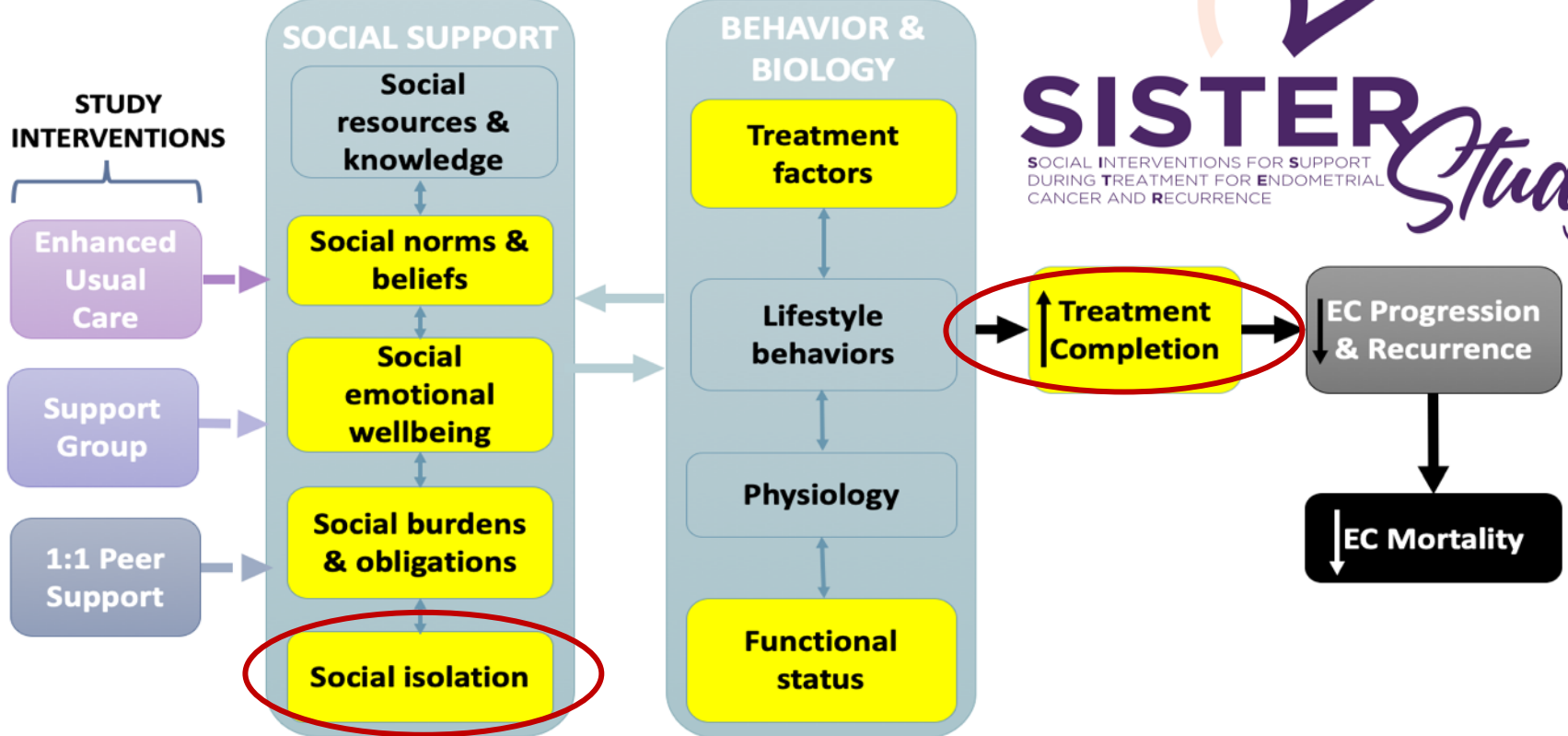


SISTER Study
 SOCIAL INTERVENTIONS FOR SUPPORT DURING TREATMENT FOR ENDOMETRIAL CANCER AND RECURRENCE

Figure 2: Conceptual Framework of the SISTER Study



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

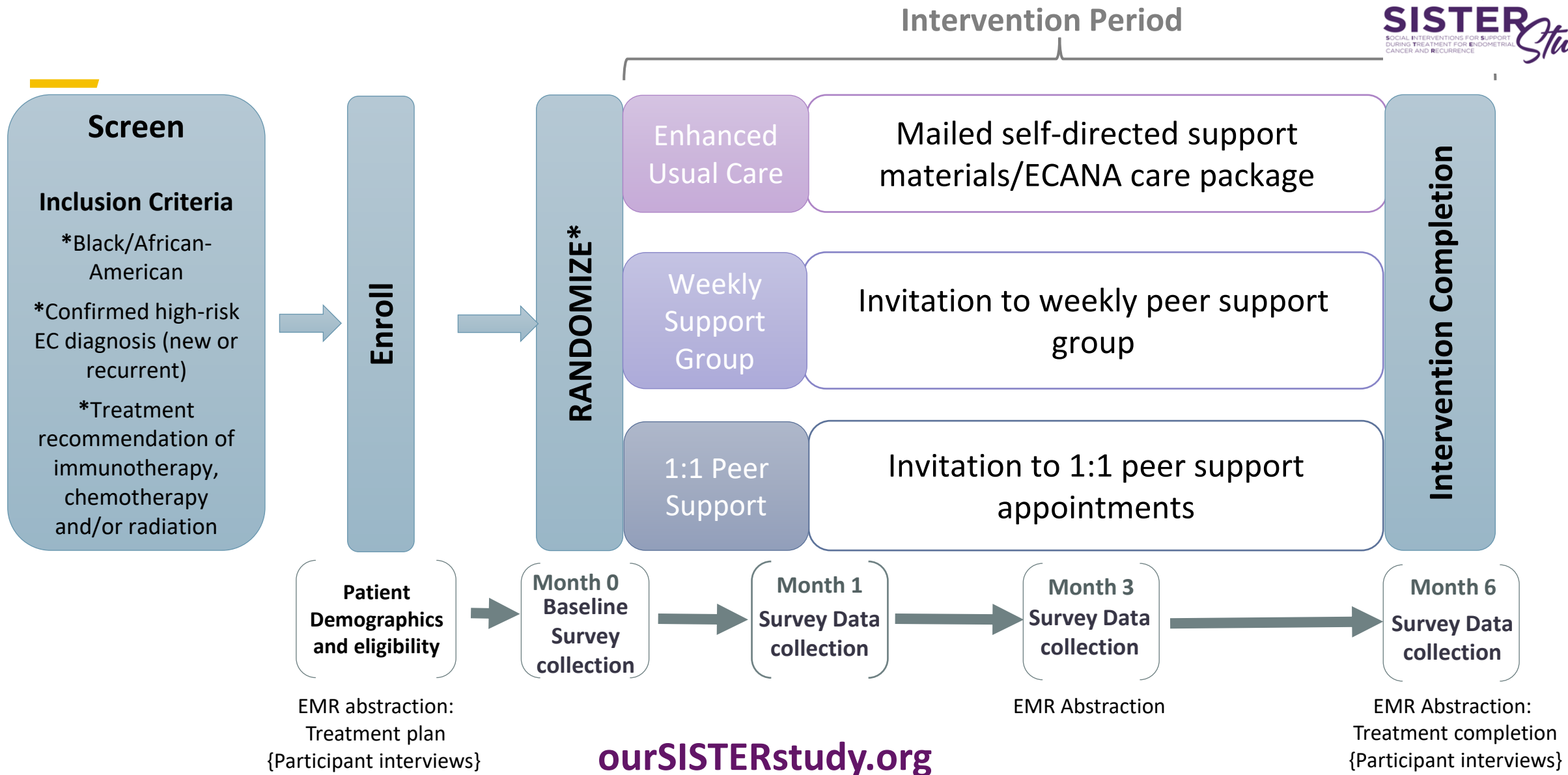


Note: Highlight indicates measured by The SISTER Study

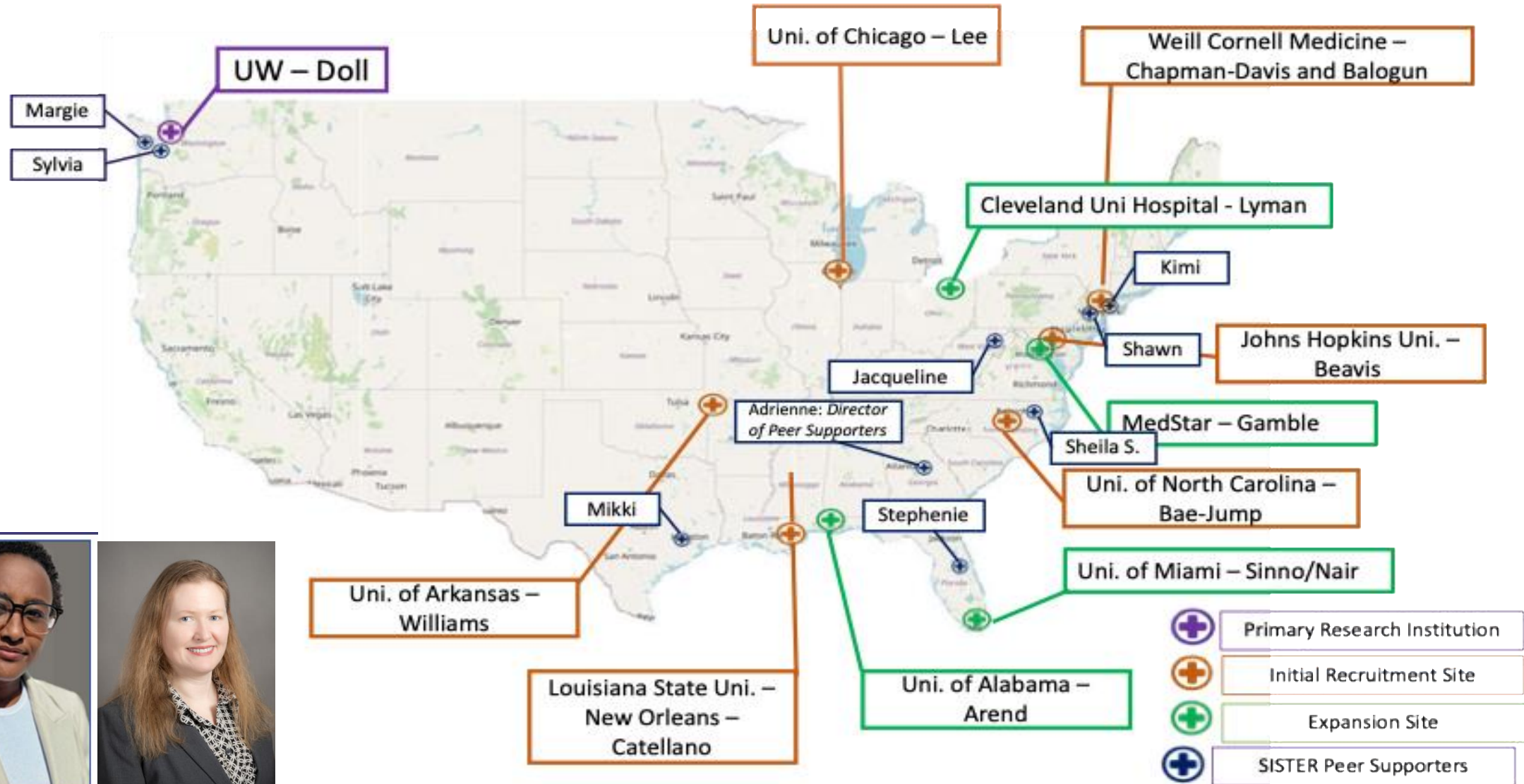
Social isolation is lethal in cancer treatment.

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 Design: 2021 - 2025



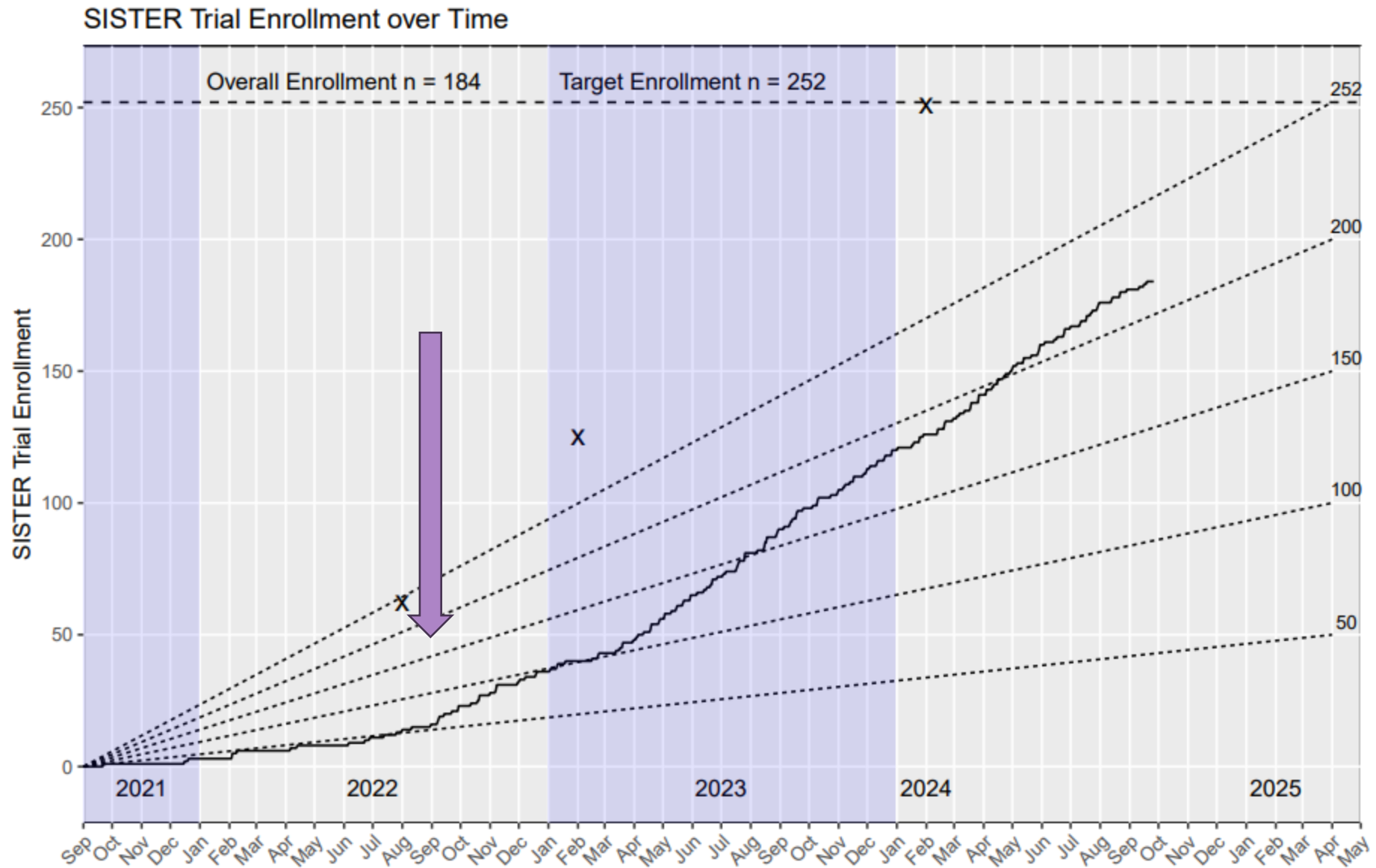
13 SISTER Study sites



Beza Tadess, MPH



Lisa Johnson PhD



Lesson: Do NOT try to launch a (non-COVID) multi-site randomized trial during a pandemic.

SISTER enrollments



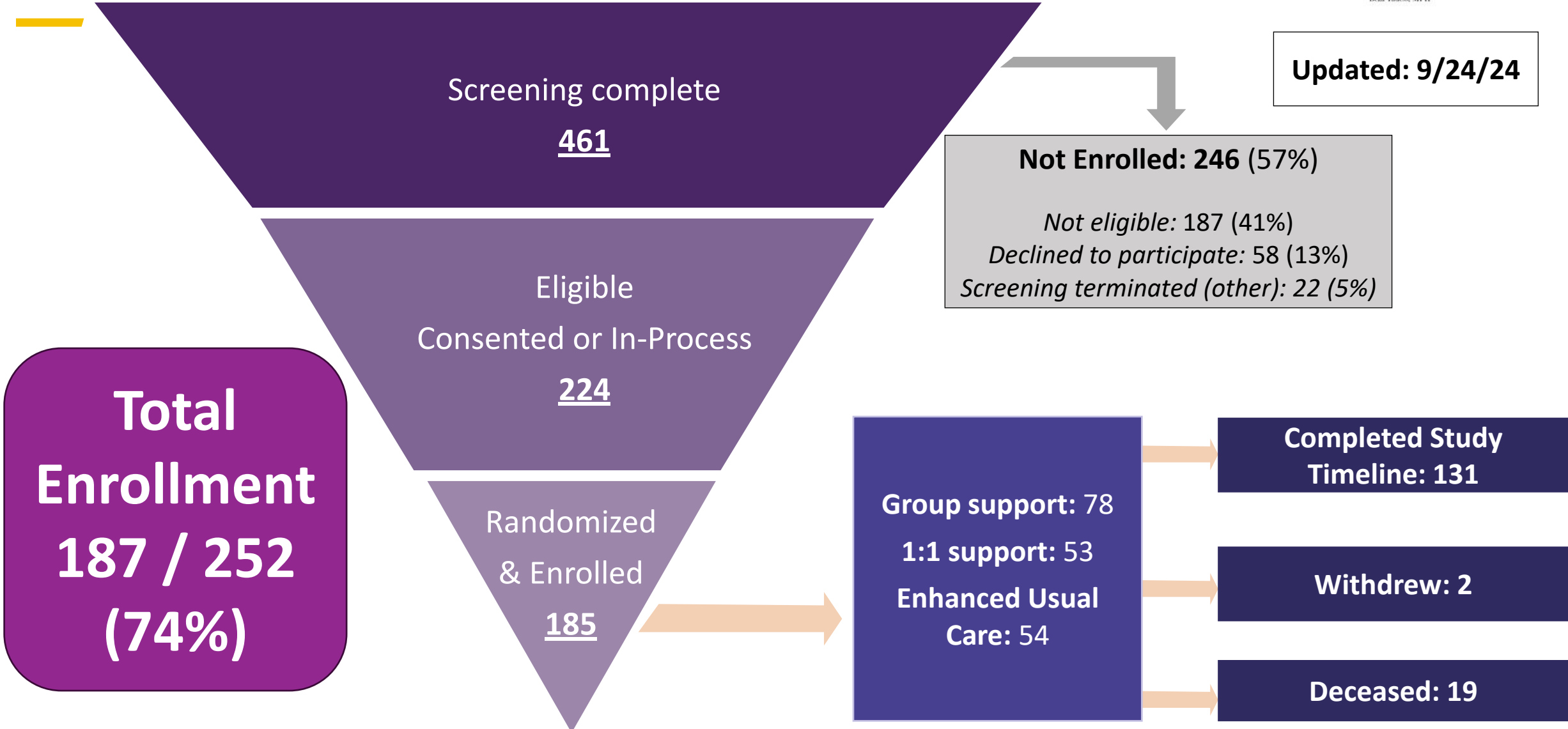
Julianna Alson, MPH

Leah Franklin, MPH

Beza Tadess, MPH

Patrice Williams, BS

Updated: 9/24/24



SISTER is more than a trial...It's a community



Leah Franklin, MPH



Julianna Alson, MPH



SISTER Study team - April 2024

Advisory Council for Translational Science (ACTS)

We are still recruiting for our ACTS survey which will allow us to re-imagine research involving blood and tissue collection for our community! If you or someone you know is eligible and has not already completed the survey, we invite you to [complete this paid survey](#).

Endometrial Cancer Research in the Black Community: Designing the studies YOU value

We aim to re-imagine how we do research that involves bodily samples, like blood, hair, and other tissue samples. We want to find out how to make this kind of sample collection process better for our community so our data can be included in important research!

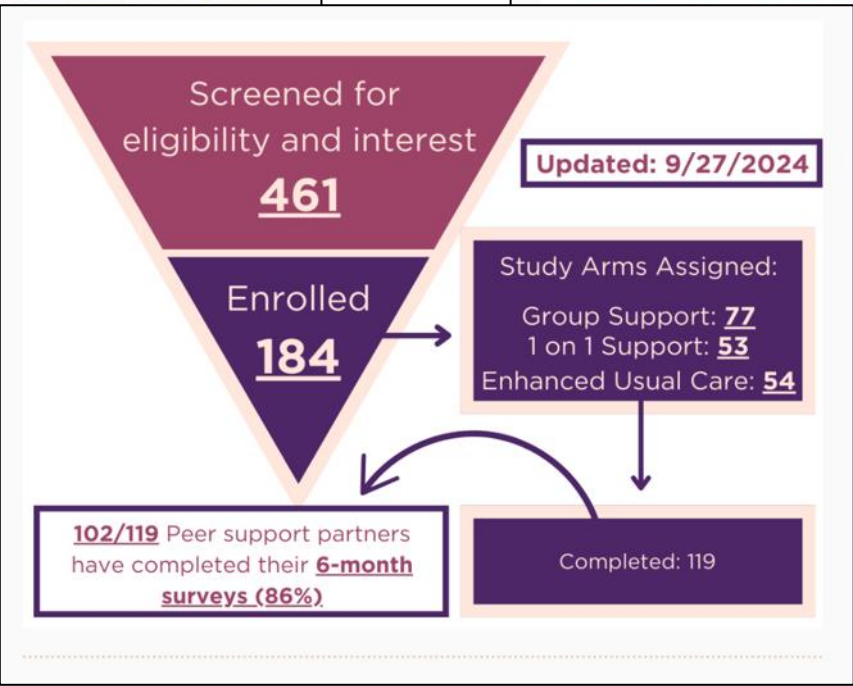
Hello Ms. <<First Name>>,

Welcome to the first quarterly edition of the SISTER Study newsletter!

Thank you again for finishing the SISTER study. We cannot thank you enough for your great contributions to science that will impact the lives of Black women with Endometrial Cancer (EC). Thank you again.

SISTER Updates

We have enrolled **184** participants in the SISTER Study! We are on track for our target enrollment. **Amazing** job team!



through endometrial cancer to complete a 15 minute survey!

participate?

an or of African descent

ancer

English without translation

participate?

Black women who have

resentation of Black endometrial cancer

ated for your participation.

ologist and health equity researcher, University of Washington and co-leader (Principal Investigator) of the Black Action Network for African American Women's Health (BAAWH) during Treatment for Endometrial Cancer (TEC) study and is dedicated to improving the lives of Black women diagnosed with endometrial cancer, so that we can all thrive!

sted?

see

tinyurl.com/surveyACTS

Self-Care!

We are starting another new segment: Self-Care with the SISTER Team! Here we learn how members of the team are taking time for themselves. At the GRACE Center, we believe we cannot do our best work without building in regular self-care.

This quarter, Nadia Khan, our fantastic new Administrative Director shares with us what she does to relax and keep herself balanced!

The Art of Rest with Nadia Khan

Intentionality

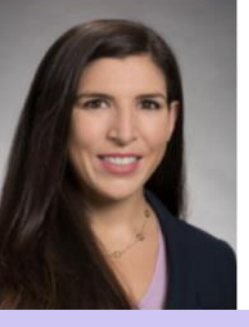
The foundation of my self-care routine is the intentional cultivation of rest. When we talk about rest, it is important to distinguish it from sleep. While adequate sleep is unquestionably essential for our physical and mental health, the kind of rest I am referring to is intentionally scheduling time to unwind, decompress, and recharge while awake. Typically, my rest routine spans from Friday evening through Saturday morning, marking the transition from the workweek to a slower, more relaxed pace.

Relaxing Activities vs. Draining Activities

During my rest period, I deliberately refrain from engaging in tasks that feel taxing or draining. Instead, I opt for restorative activities that allow me to disconnect from work and personal responsibilities.

Carve Out Time For

SISTER is a Hybrid Effectiveness-Implementation Trial Type I



Participant Interviews

45 at baseline
45 at completion (6mo)

Baseline
38 complete

6-months
3 complete

Peer Supporter Interviews

Post-training, 50% enrollment, 100% enrollment

Post-training
Complete (n=8)

50% enrollment
Complete (N=9)

100% enrollment
Not yet started

Peer Supporter Session Notes

Collected throughout study

Ongoing data collection

Recruiter interviews

Begin interviews at 25% enrollment

3/10 complete

Healthcare team interviews

50% enrollment

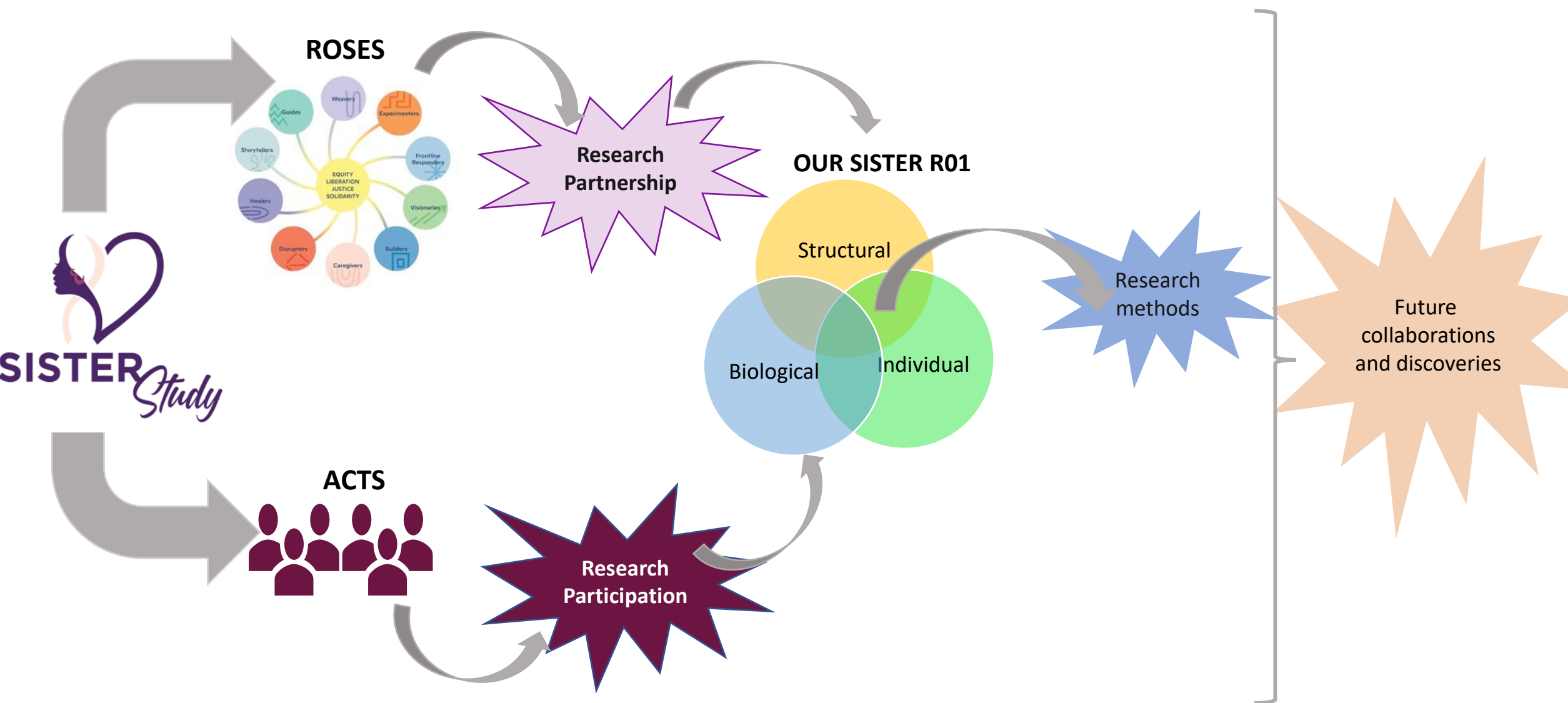
Not yet started – interview guide to be developed early 2025

Stakeholder interviews

After all participants have completed the study

Not yet started

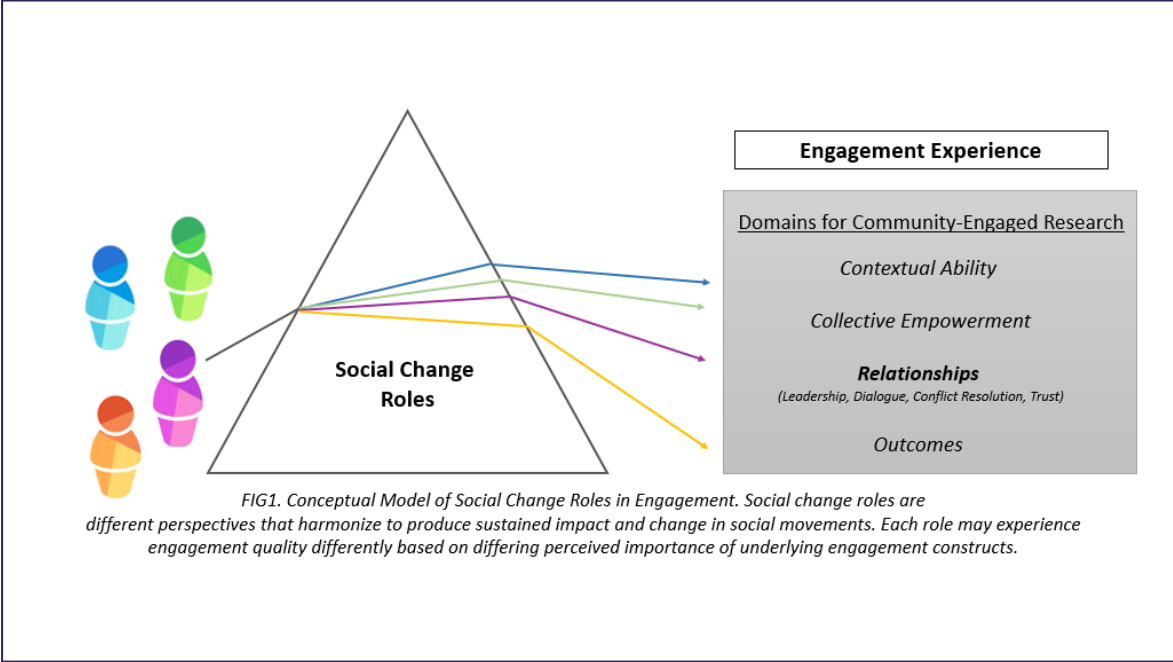
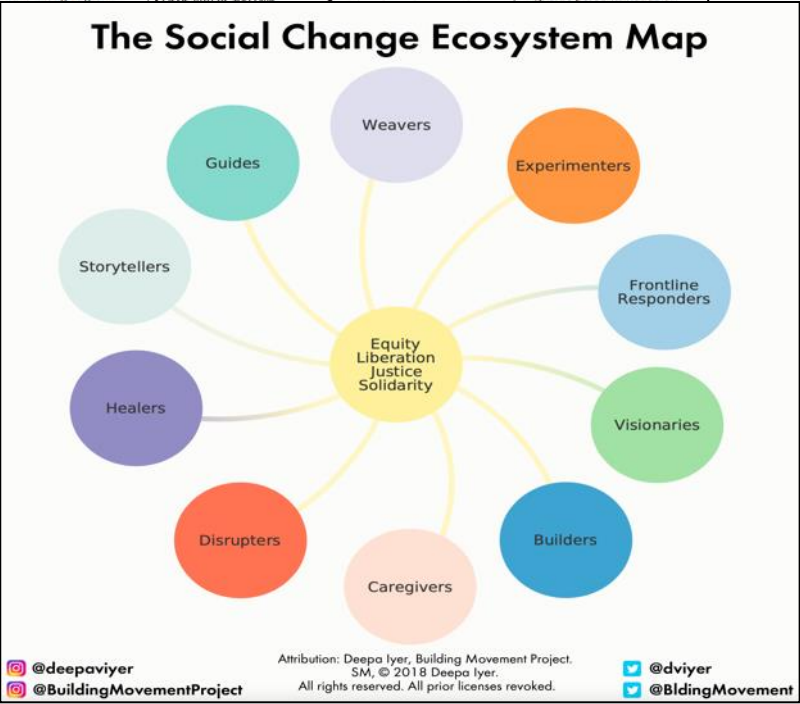
The SISTER Study: A Seed for Future Discovery & Survival



Roles of Social Change in Engagement Science (ROSES Study)

Goal: Create reproducible structures to guide research partnerships in creating a balance of needed perspectives and supporting long-term successful community engagement

<p>Ineffective</p> <ul style="list-style-type: none"> • Naive citizen: Does not realise the powerholders and institutions serve elite interests • Super-patriot: Blind obedience to powerholders and country 	<ul style="list-style-type: none"> • Promotes positive, widely-held values e.g democracy, freedom, justice, non-violence • Grounded in centre of society • Protects against charges of 'extremism' 	<ul style="list-style-type: none"> • Uses official channels to make change • Uses variety of means: lobbying, legal action, elections • Monitors success to assure enforcement, expand success and guard against backlash 	<p>Ineffective</p> <ul style="list-style-type: none"> • Promotes minor reforms • Co-optation: identifies more with official powerholders than grass roots • Limited by hierarchical/patriarchal structure • Does not advocate paradigm shifts
<p>CITIZEN REFORMER</p>			
<p>REBEL CHANGE AGENT</p>			
<p>Ineffective</p> <ul style="list-style-type: none"> • Self-identifies as 'being on the fringe' • 'Any means necessary', including violence and property destruction • Acts from strong negative emotion • Anti any r • Per move 	<ul style="list-style-type: none"> • Protests: Says "NO!" to violation of positive values 	<ul style="list-style-type: none"> • Uses people power: educates, convinces & involves majority of citizens 	<p>Ineffective</p> <ul style="list-style-type: none"> • Utopian: promotes visions of perfectionism disconnected from current movement needs • Dogmatic: advocates single approach while ignoring others • Ignores personal needs of



Leah Franklin, MPH



Patrice Williams, BS

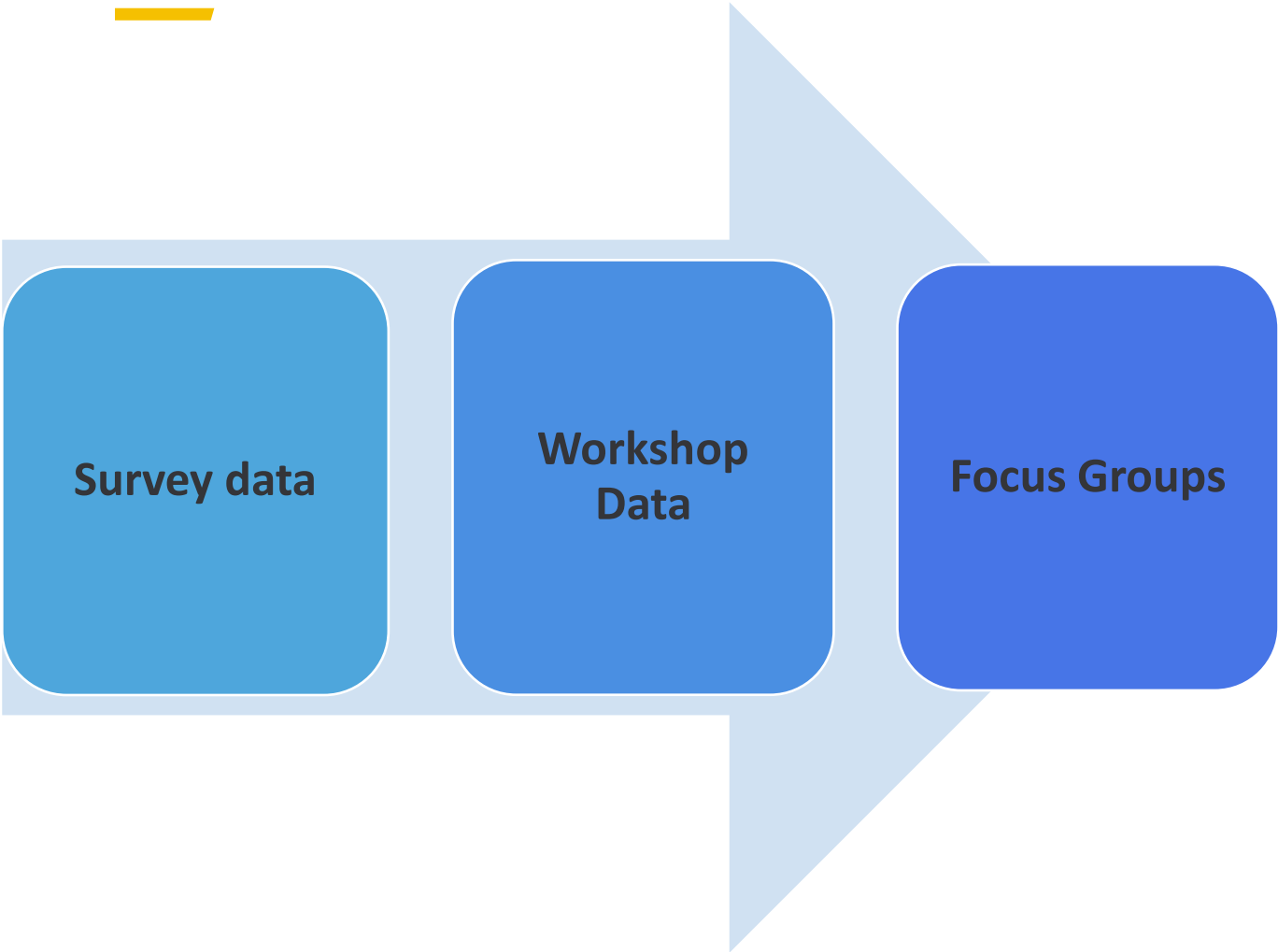


Julianna Alson, MPH

PCORI Science of Engagement #2022C2-28908; 2024 - 2027

CONFIDENTIAL – DO NOT DISTRIBUTE

GOAL: CREATE A FRAMEWORK TO GUIDE OTHER TEAMS



Social Role:
Rebel

	Green	Grey	Green	White	White	Green
Yellow	Green	Grey	Green	White	Yellow	Green
Yellow	Green	Grey	Green	Red	Yellow	Green
<i>Change Commitment</i>	<i>Change Efficacy</i>		<i>Power Sharing</i>	<i>Sustainability</i>	<i>Communication</i>	<i>Co-Learning & Input</i>



Social Role:
Helper

Green	White	Grey	White	Green	Green	White
Green	Yellow	Grey	White	Green	Green	Yellow
Green	Yellow	Grey	Red	Green	Green	Yellow
<i>Change Commitment</i>	<i>Change Efficacy</i>		<i>Power Sharing</i>	<i>Sustainability</i>	<i>Communication</i>	<i>Co-Learning & Input</i>

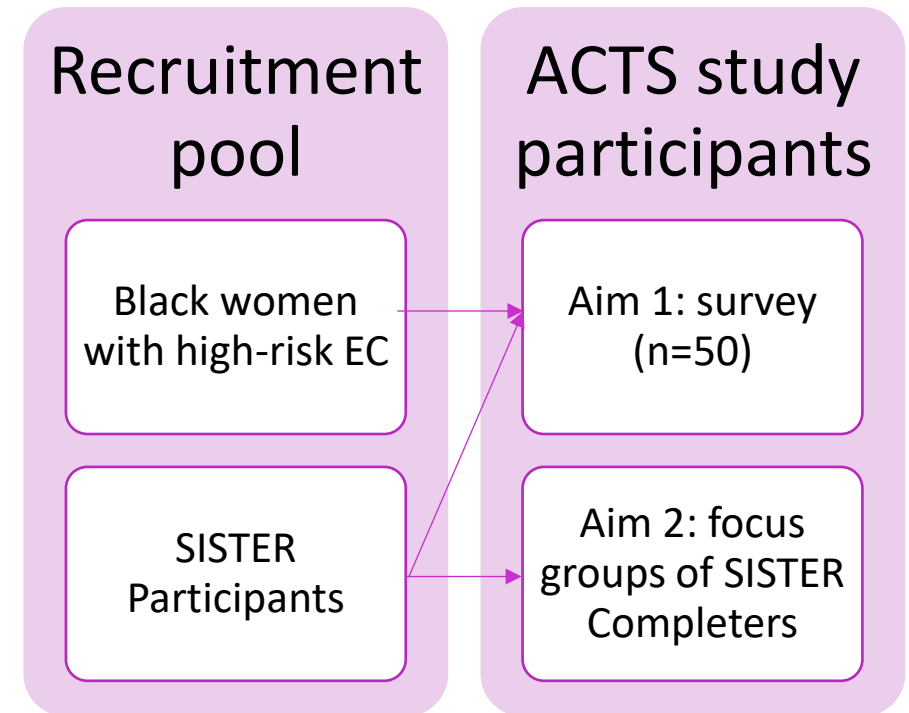
Advisory Council for Translational Science (ACTS)



Goals:

To determine best **recruitment approaches** and **data sharing practices** that optimize acceptability and participation in biospecimen research among Black women with EC.

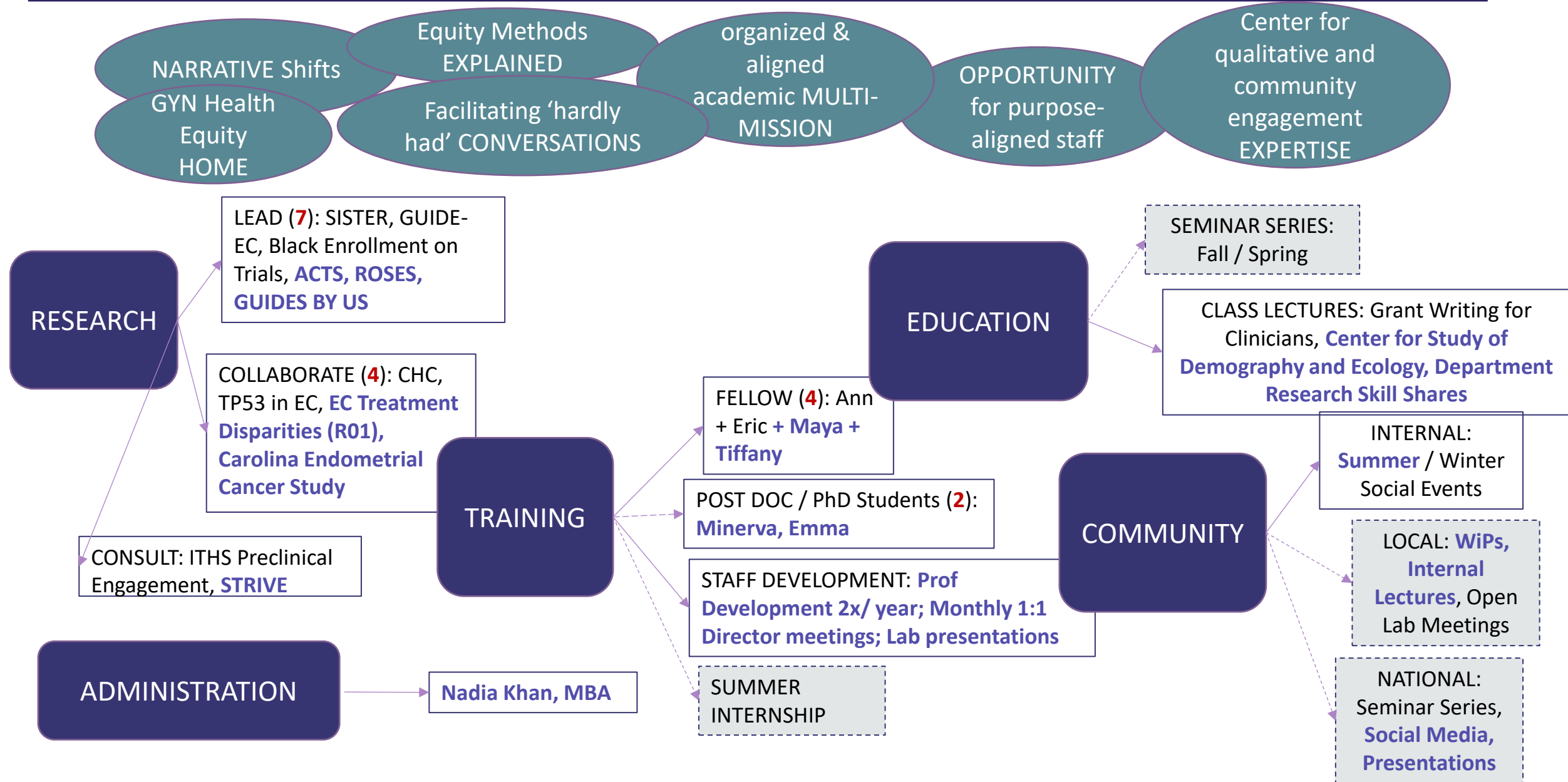
Recruit and convene an **Advisory Council** to oversee all translational research efforts.



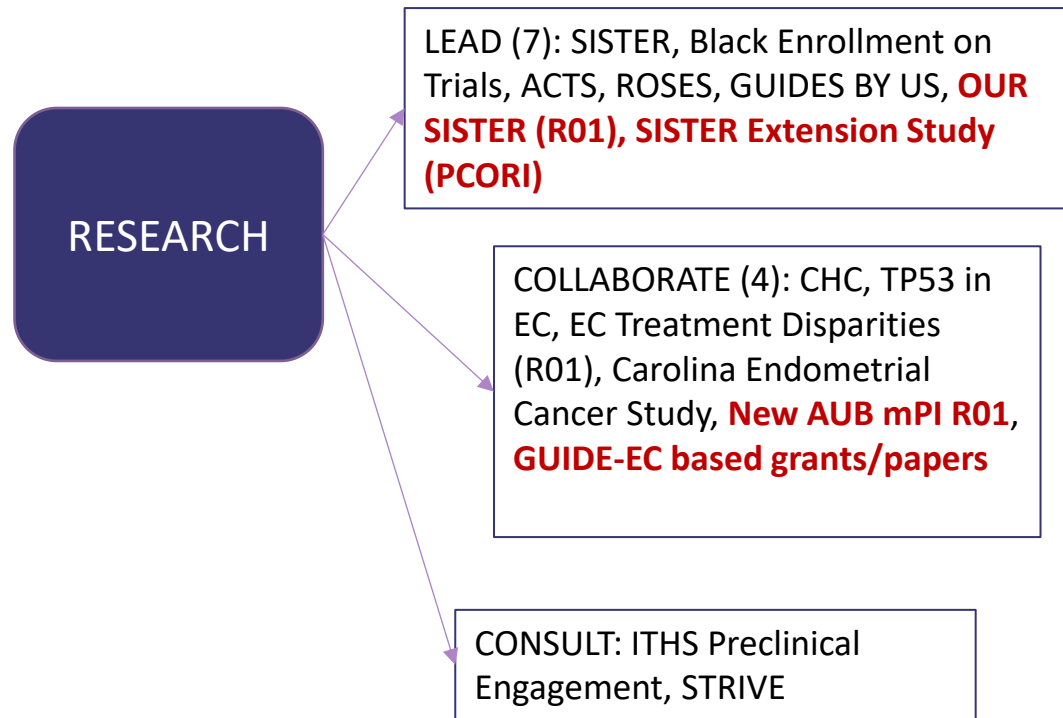
Objectives

1. Introduce The GRACE Center mission, vision, and values.
2. Review GRACE Center research studies.
3. Discuss future horizons and collaboration opportunities.

The GRACE Center: 2023-24 Progress



The GRACE Center: Looking Ahead...



OUR SISTER (R01)

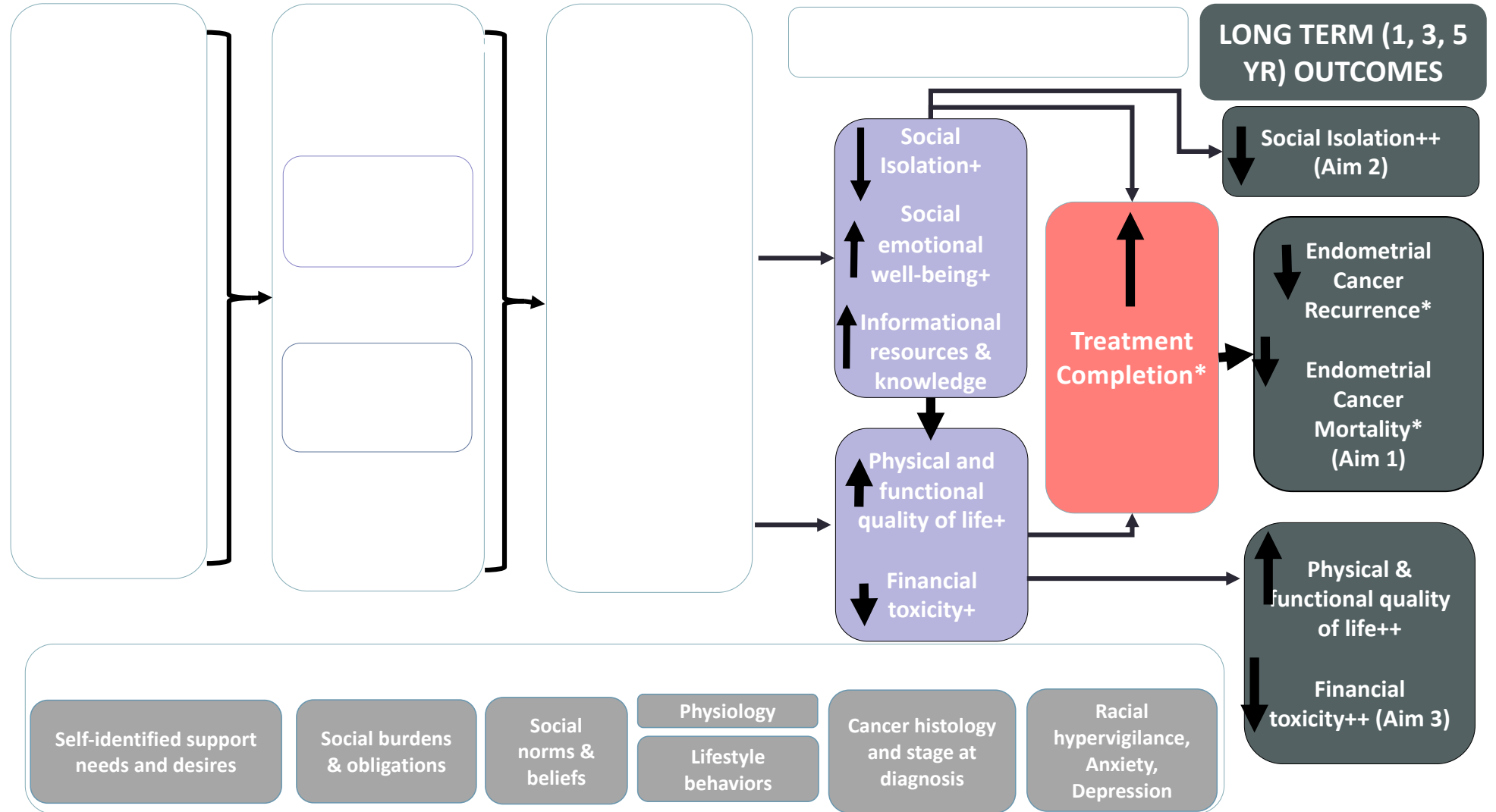
- Structural: 5 years funding for SISTER Team. Building biorepository for future EC questions.
- Research: Advancing study of embodiment of racism and concept of racial hypervigilance

SISTER Extension Study (PCORI)

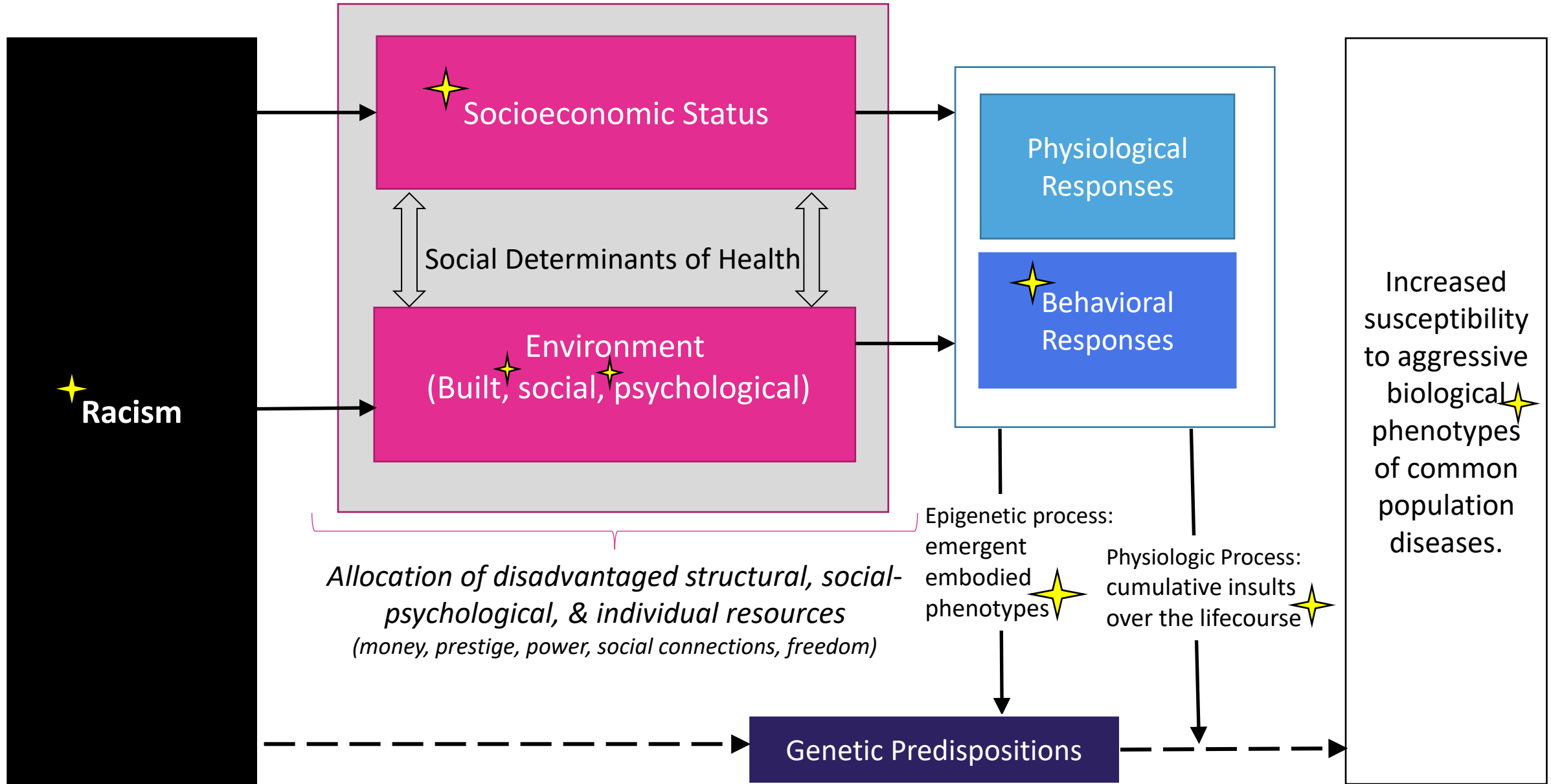
- Structural: 5 years funding for SISTER Team. Continued database of survey, treatment, and interview data for future studies.
- Research: understand social support 'cliff', long term QoL issues for survivors, how new treatment landscape is affecting survival

On the horizon: SISTER – Long Term Follow Up Study

5 Year Extension grant submitted September 2024.



Conceptual Model of Racism as a Fundamental Cause That Contributes to Poor Disease Outcomes



On the horizon: Observing and Understanding Racial Hypervigilance on the SISTER Study (OUR SISTER)

- Goal: Understanding how exposure to structural racism influences individual hypervigilance (stress) and EC poor prognostic tumor features.
- Goal: Build a biorepository of **tissue, blood, and other biospecimens** from the SISTER cohort for this study and future research.

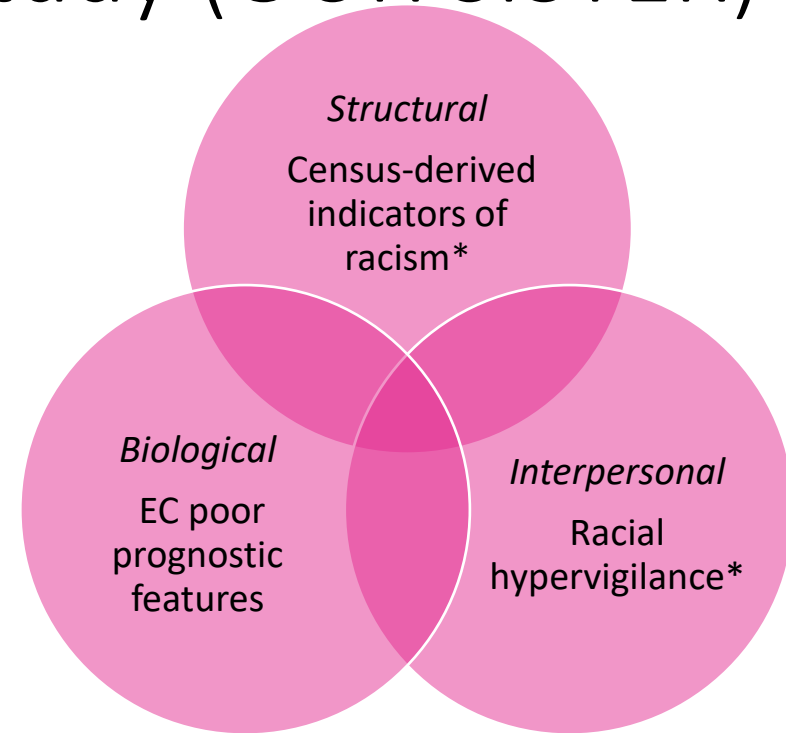
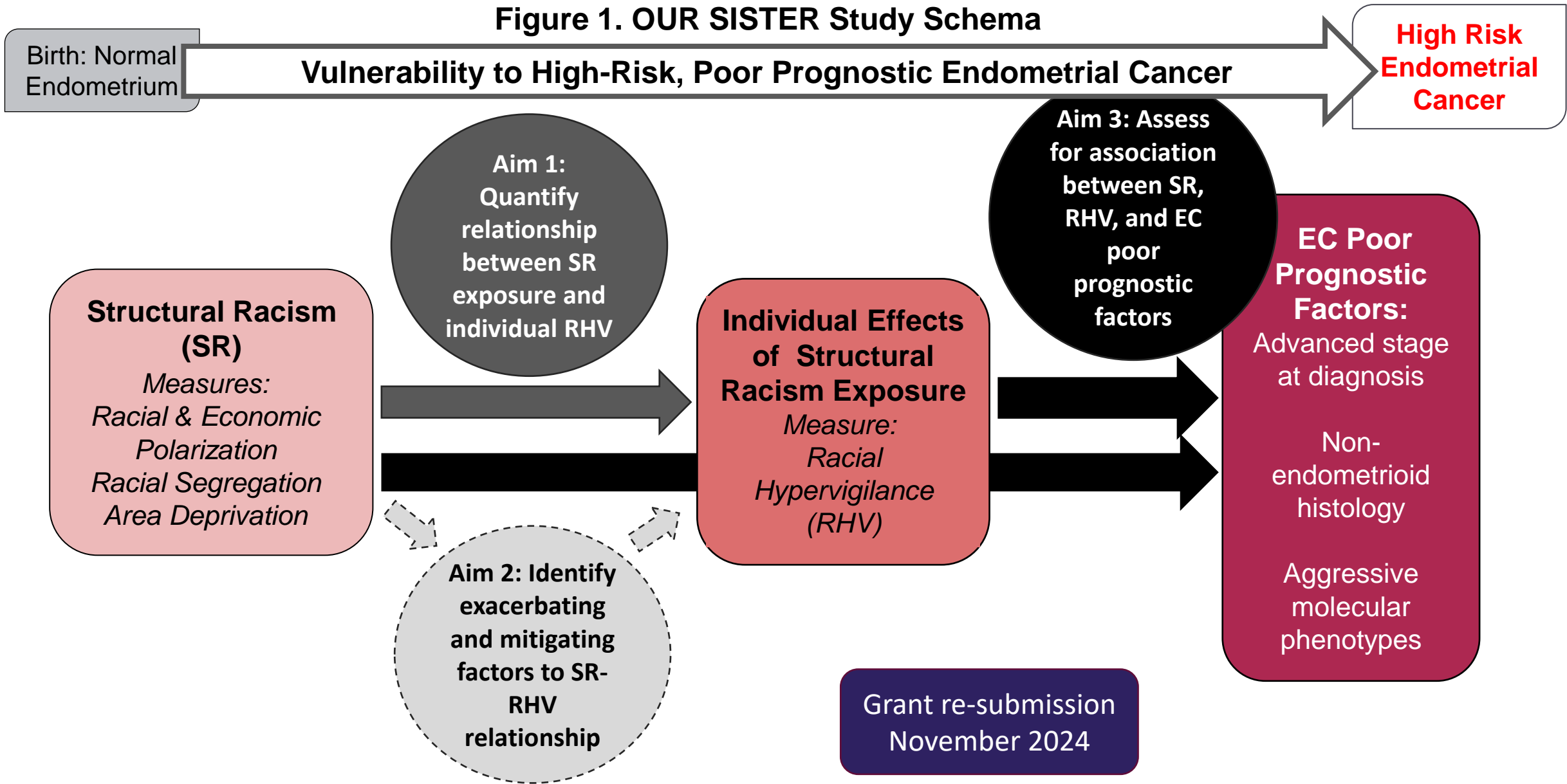


Figure 1. OUR SISTER Study Schema



GUIDE EC: Opportunity for ANCILLARY STUDIES

- 3,500 Black individuals who underwent hysterectomy over 6+ years
- 10 hospitals + 100s outpatient clinics
- 1400 possible data points per case entry
- Detailed gynecologic symptoms up to 24 months prior to surgery
- General medical & social history including mental health
- Detailed ultrasound quality and measurement data
 - fibroid location, fibroid size
- MRI, D&Cs

Next Step: Develop data access and proposal process

The GRACE Center: Narrative Shifts...



Why Are More Black Women Dying From the Most Common Reproductive Cancer?

There are a couple theories.



ROSA FURNEAUX
Bio



#IWishIKnew

“Every gynecologist should brief their patients on uterine cancer symptoms both pre- and post-menopause.”

– Rebecca L.



Aminatou Sow @aminatou · Jan 24
Hey Twitter! Exactly a year ago I had a total abdominal hysterectomy with a bilateral salpingo-oophorectomy. That means a removal of the uterus, cervix, fallopian tubes, and ovaries. The whole sink!
20 181 1.8K

Aminatou Sow @aminatou · Jan 24
The good news: I don't have endometrial cancer right now!
The meh news: Menopause is a beast! Being a cancer survivor is hard in its own ways.
9 11 838

Aminatou Sow @aminatou · Jan 24
Your chances of surviving endometrial cancer might depend on your race unfortunately. This is the same cancer that took Gwen Ifill away from us. Black women have a 55-percent higher mortality rate after diagnosis than other groups of women
3 62 405

Aminatou Sow @aminatou · Jan 24
One of the few people in the country studying this is Dr @KemiDoll. Her research focuses on disparities in uterine cancer [endometrial cancer is the most common type of uterine cancer]
1 24 374

One Type Of Cancer Is Killing Black Women At Record-High Rates

White women are less likely to die from the same condition.



GOODMORNINGAMERICA.COM

Studies show endometrial cancer is more aggressive for Black women

Dr. Kemi Doll is committed to eliminating the racial mortality gap in endometrial cancer thro...

ABNORMAL VAGINAL BLEEDING? SEE A DOCTOR

TRENDS IN RATES	SEE A HEALTHCARE PROVIDER IF BLEEDING
<ul style="list-style-type: none"> NEW CASES ↑12%* DEATHS ↑21%** BLACK WOMEN 2X MORE LIKELY TO DIE 	<ul style="list-style-type: none"> ✓ AFTER MENOPAUSE ✓ BETWEEN PERIODS ✓ AFTER SEX

UTERUS

*or Registries (NPCR) and the National Cancer Institute's (NCI) Surveillance, Epidemiology and End Results (SEER) Program. **Deaths from CDC's National Center for Health Statistics National Vital Statistics System. WWW.CDC.GOV

Awareness is rising...

RED DAB? RED FLAG



Endometrial cancer is a cancer of the womb that disproportionately affects Black women. In fact, Black women are nearly twice as likely to die from endometrial cancer than other women. And it can't usually be detected by a routine Pap smear, so knowing what to look for can be key to getting treated. *Red Dab? Red Flag* aims to make Black

women aware that if they experience any unusual spotting or a red dab of blood, it could be a sign of endometrial cancer and to talk to their doctor, sooner.



[Transcript](#) ▾

[View video on YouTube](#) ↗

Watch Shawn's Powerful Patient Story

www.RedDabRedFlag.com

September
Gynecologic
Cancer
Awareness
Month
2022



[Transcript](#) ▾

[View video on YouTube](#) ↗

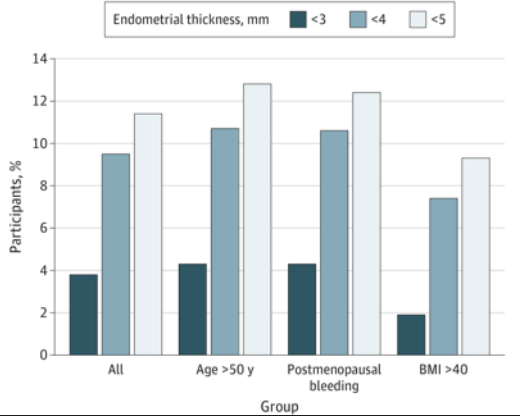
Watch Dr Doll's Message to Black Women

Endometrial Thickness as Diagnostic Triage for Endometrial Cancer Among Black Individuals

Kemi M. Doll, MD, MSCR; Mindy Pike, PhD; Julianna Alson, MPH; Patrice Williams, BA; Erin Carey, MD, MSCR; Til Stürmer, MD, PhD; Mollie Wood, PhD, MPH; Erica E. Marsh, MD, MSCI; Ronit Katz, DPhil; Whitney R. Robinson, PhD

CONCLUSION AND RELEVANCE These findings suggest that the transvaginal ultrasound triage strategy is not reliable among Black adults at risk for EC. In the presence of postmenopausal bleeding, tissue sampling is strongly recommended.

Figure. False-Negative Probability of Endometrial Thickness Measurement for Endometrial Cancer Diagnostic Triage Among Black Individuals



Editor's note: UW Today will be publishing issues Monday through Thursday for July and August. We will resume our normal publication schedule in September.



Ultrasounds may not find endometrial cancer in Black patients

Endometrial cancer is the most common type of gynecological cancer in the United States. It is becoming increasingly prevalent, especially among Black people, who are more likely to receive a late-stage diagnosis. A study led by UW researchers and published in JAMA Oncology found that a common diagnostic strategy can fail to catch endometrial cancer 4% to 11% of the time in Black patients.

WOMEN'S HEALTH

Common endometrial cancer test is less effective for Black women, research shows

New study suggests the test may be missing cancers among Black patients more often.

Ultrasound May Be Unreliable in Spotting Endometrial Cancer in Black Women



Fact-Checked Learn more about our fact check policy





With more money and more attention pouring into EC, it's critical we have INFORMED and ENGAGED voices in the public sphere.

Chemical Hair Relaxers and EC

- Use > 4 times in 12 mo prior to study enrollment → HR 2.55

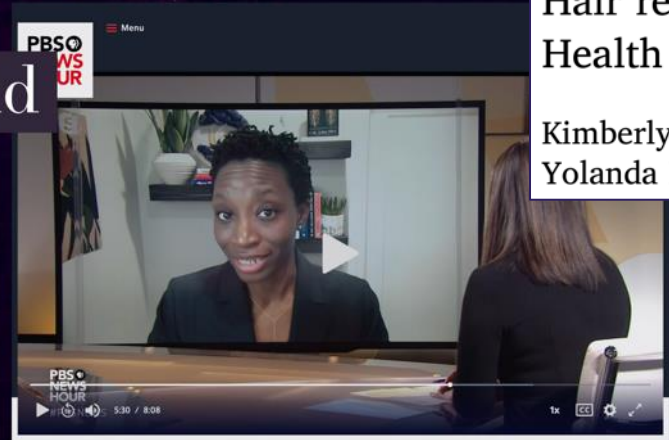
Use of Straighteners and Other Hair Products and Incident Uterine Cancer

Che-Jung Chang, PhD ¹, Katie M. O'Brien, PhD,¹ Alexander P. Keil, PhD,² Symielle A. Gaston, PhD,¹ Chandra L. Jackson, PhD,^{1,3} Dale P. Sandler, PhD,¹ Alexandra J. White, PhD, MSPH ^{1,*}

Hair straighteners and uterine cancer

Several women diagnosed with uterine cancer are now suing L'Oréal and other cosmetic companies after a recent study tied the illness to chemical hair straightening products. Dr. Kemi Doll joined Amna Nawaz to discuss the study and the concerns it has raised.

PBS News Hour



Hair relaxer use and risk of uterine cancer in the Black Women's Health Study

Kimberly A. Bertrand^{a,b,*,1}, Lauren Delp^a, Patricia F. Coogan^a, Yvette C. Cozier^{a,c}, Yolanda M. Lenzy^{d,e}, Lynn Rosenberg^a, Julie R. Palmer^{a,b}

Postmenopausal women:

- HR 1.6 for moderate and heavy use
- HR 1.71 for > 20 years of use
- HR 1.85 for >5-6 times per year

How does our emphasis on obesity cloud our innovation in exploring environmental risk factors in North America, among Black women, and variation by other marginalized status?

Early Stage At Diagnosis

GUIDES projects follow up analyses
Multi-level Intervention Execution
GUIDES By US - Dissemination

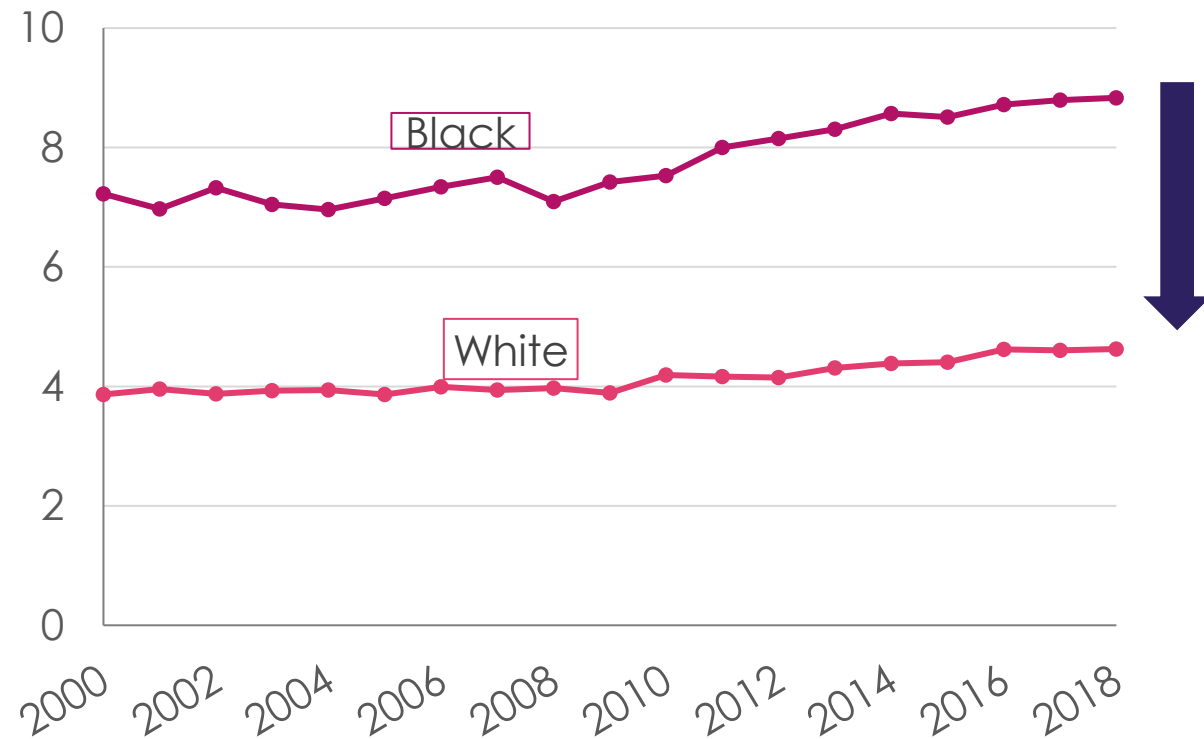
Embodiment and Outcomes

Racism, Deprivation, and EC Histology
(OUR SISTER)
Social Support and Survival (The SISTER Study)

Comm Engagement & Trial Methods

Acceptability of Blood and Tissue Based Research
(ACTS)
Roles of Social Change in Engagement Science (ROSES)

Goal: Close the Gap



Lesson: Start anywhere, just be sure to start.

ORIGINAL STUDY

Detection of Gynecologic Cancers in Indigent Women in an Urban Inner-City Hospital

Kemi M. Doll, MD,*† Roman Puliaev, MD,* Julie Chor, MD, MPH,*† Alicia Roston, MPH,*
Urjeet A. Patel, MD,*† and Ashlesha Patel, MD, MPH*†

Objective: Access to care is a major concern for impoverished urban communities in the United States, whereas early detection of gynecologic malignancies significantly influences ultimate survival. Our goal was to compare the stage at detection of common gynecologic cancers at an urban county hospital with national estimates, and to describe the demographic and socioeconomic characteristics of this population.

Methods: All new patients presenting to the John H. Stroger, Jr. Hospital of Cook County gynecologic oncology clinic from January 1, 2008, to December 31, 2009, were reviewed under an institutional review board–approved protocol. Patients receiving primary treatment at the institution during these dates were included for analysis. We used χ^2 tests to compare the institution's stage distributions to national estimates.

Results: Two hundred nineteen patients met inclusion criteria over the 2-year study period. Racial and ethnic minorities represented 72.5% of the population. Of the 219 patients, 56.1% (123/219) were uninsured and 37.9% (83/219) were covered by Medicaid or Medicare. We identified 97 (43.9%) cervical, 95 (43%) uterine, and 29 (13.1%) ovarian cancers, including 2 synchronous primaries. Compared to the National Cancer Data Base, women with uterine cancer at our institution were significantly more likely to present with later-stage disease ($P < 0.05$), whereas cervical cancer and ovarian cancer stage distributions did not differ significantly.

Conclusions: Compared to national trends, women with uterine cancer presenting to an urban tertiary care public hospital have significantly more advanced disease, whereas those with cervical cancer do not. Nationally funded cervical cancer screening is successful but does not address all barriers to accessing gynecologic cancer care. Promotion of public education of endometrial cancer symptoms may be a vital need to impoverished communities with limited access to care.

Key Words: Uterine cancer, Cervix cancer, Minority health, Early detection of cancer

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The epidemiology of gynecologic cancer is reported. Both cervical and uterine cancer are common and often present with advanced disease. This is reflected in national databases where the incidence of patients with stage I disease is more common for cervical cancer and nearly 70% for uterine cancer. Prognosis is excellent for the patients who are often cured by surgery and avoid lengthy and costly adjuvant therapies that have significant impact on quality of life.²

Disparities exist, however, in cancer presentation, treatment, and survival. It is known that significant cancer care

“...Nationally funded cervical cancer screening is successful but does not address all barriers of gynecologic cancer care. **Promotion of public education of endometrial cancer symptoms may be a vital need to impoverished communities with limited access to care.**”

My resident research project,
submitted April 9 2012!



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THANK YOU



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