Community-Based Participatory Research: *The What & The How*

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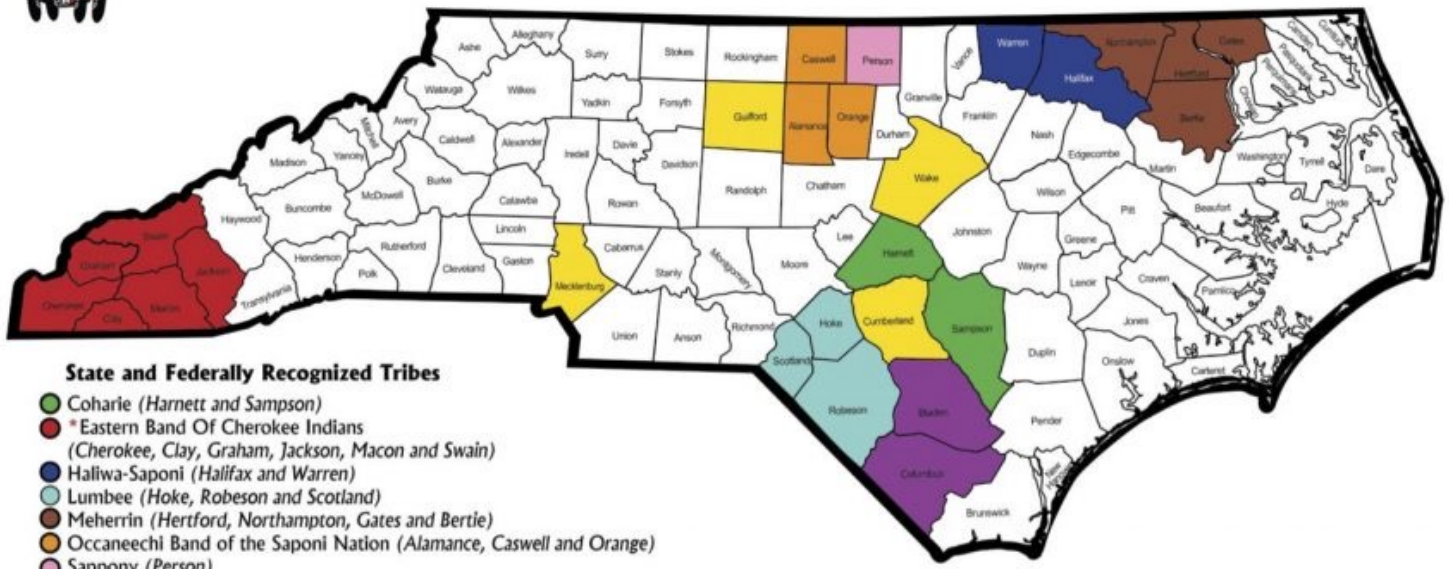
12 April 2024

N.C. Commission of Indian Affairs

N.C. Tribal and Urban Communities

NC DOA Department of Administration



State and Federally Recognized Tribes

- Coharie *(Harnett and Sampson)*
- *Eastern Band Of Cherokee Indians
  (Cherokee, Clay, Graham, Jackson, Macon and Swain)
- Haliwa-Saponi *(Halifax and Warren)*
- Lumbee *(Hoke, Robeson and Scotland)*
- Meherrin *(Hertford, Northampton, Gates and Bertie)*
- Occaneechi Band of the Saponi Nation *(Alamance, Caswell and Orange)*
- Sappony *(Person)*
- Waccamaw Siouan *(Bladen and Columbus)*

* *Federally Recognized*

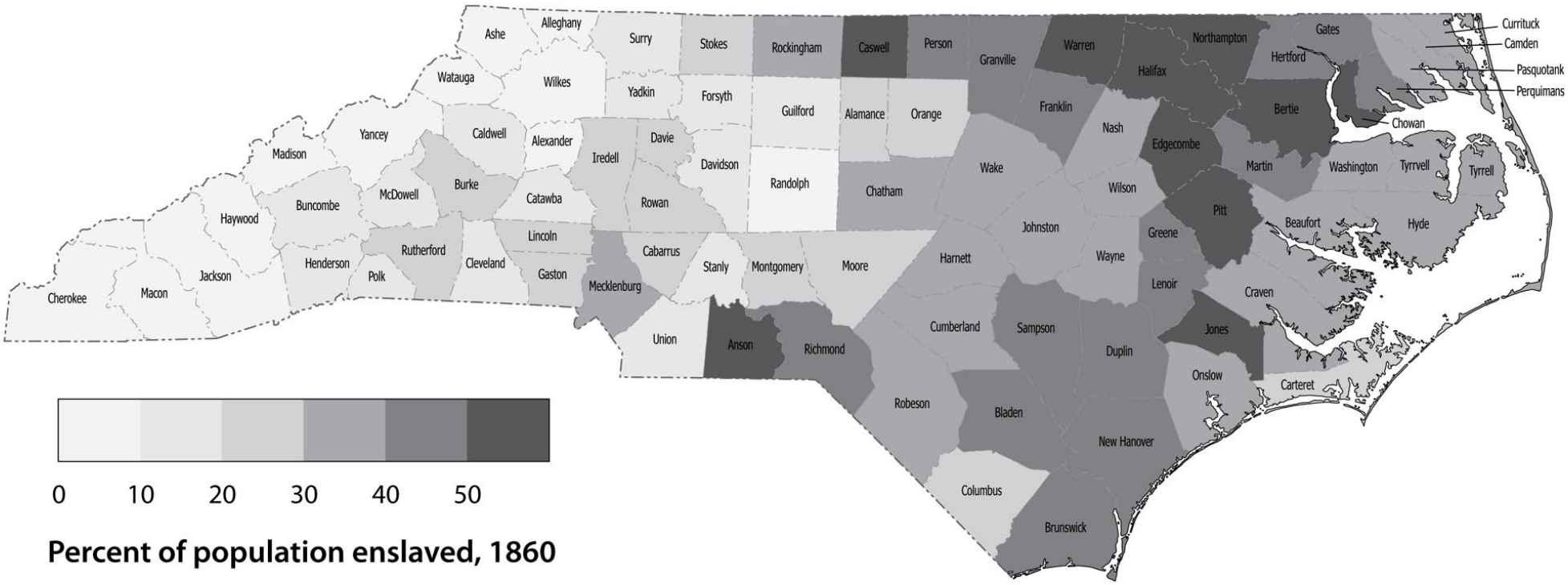
Urban Indian Organizations
(Holding membership on the NC Commission of Indian Affairs):
Cumberland County Association for Indian People
Guilford Native American Association
Metrolina Native American Association
Triangle Native American Society

Areas in Color indicate counties where the eight Recognized Tribes of North Carolina reside.

Counties in yellow (Mecklenburg, Guilford, Cumberland and Wake) Location of American Indian Associations

Map published by the North Carolina Commission of Indian Affairs.

2020

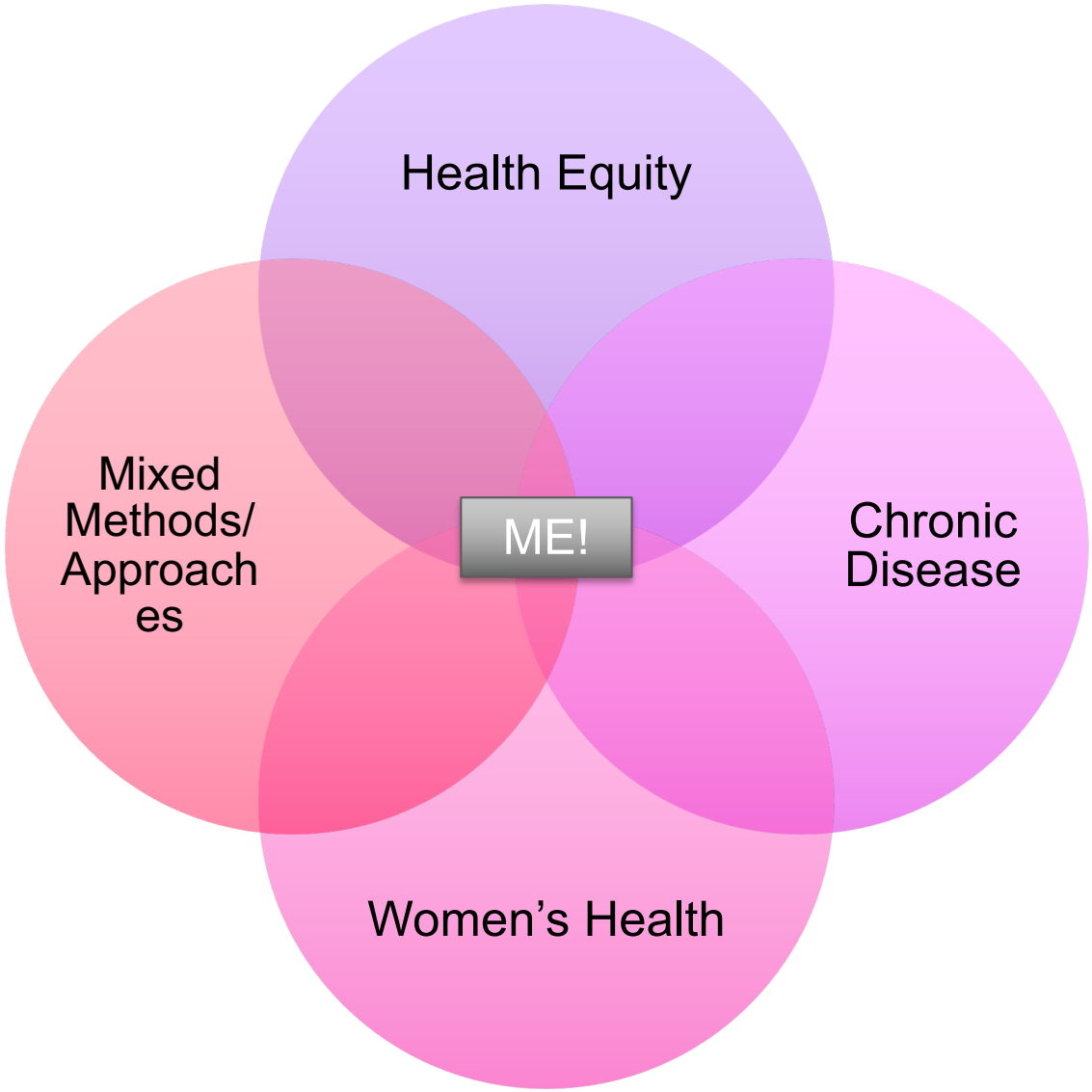


Map of Enslaved Populations in North Carolina

Civil War Era NC

What You Should Know About Me

- Black mama to a 5-year-old, eldest sister of 3, & mother has lupus
- Member of a 20-year-old community-medical-academic partnership for 12+ years
- Frameworks/approaches that guide my work: anti-racism, reproductive justice, womanism, CBPR, health equity


Health Equity
Mixed Methods/ Approaches
ME!
Chronic Disease
Women's Health

Defining Community-Based Participatory Research (CBPR)

"A collaborative process that equitably involves all partners in the research process and recognizes the unique strengths that each brings. CBPR begins with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities."

SOURCE: Definition developed and adopted by the Kellogg Community Health Scholars Program based upon Israel, B. A., Schulz, A. J., Parker, E., Becker, A. B. (1998). Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Ann Rev Public Health*, *19*, 173-202.

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CBPR Principles

1) Recognizes community as a unit of identity.
2) Builds on strengths and resources within the community.
3) Facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
4) Fosters co-learning and capacity building among all partners.
5) Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6) Focuses on the local relevance of public health problems and on ecological perspectives that attend to the multiple determinants of health.
7) Involves systems development using a cyclical and iterative process.
8) Disseminates results to all partners and involves them in the wider dissemination of results.
9) Involves a long-term process and commitment to sustainability.
10) Openly addresses issues of race, ethnicity, racism, and social class, and embodies "cultural humility."
11) Works to ensure research rigor and validity but also seeks to "broaden the bandwidth of validity" with respect to research relevance.

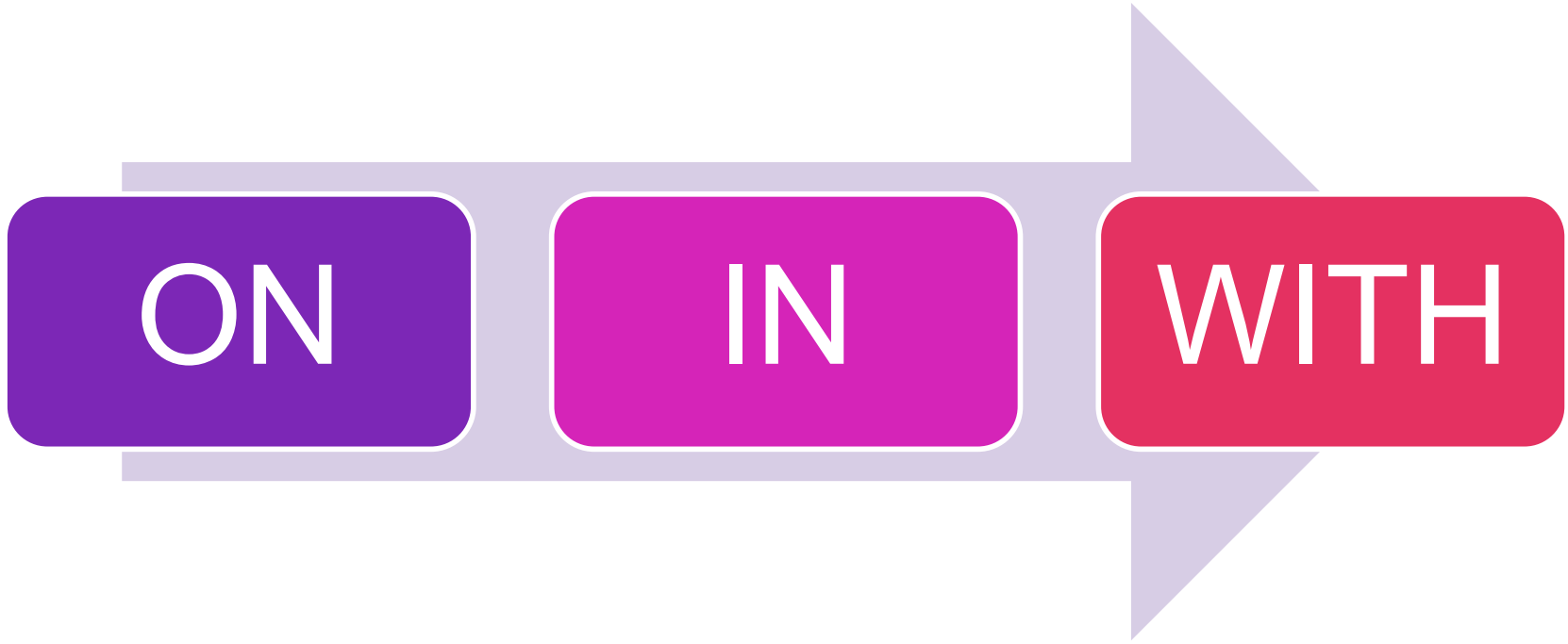
Barbara Israel, DrPH

Meredith Minkler, DrPH

Nina Wallerstein, DrPH

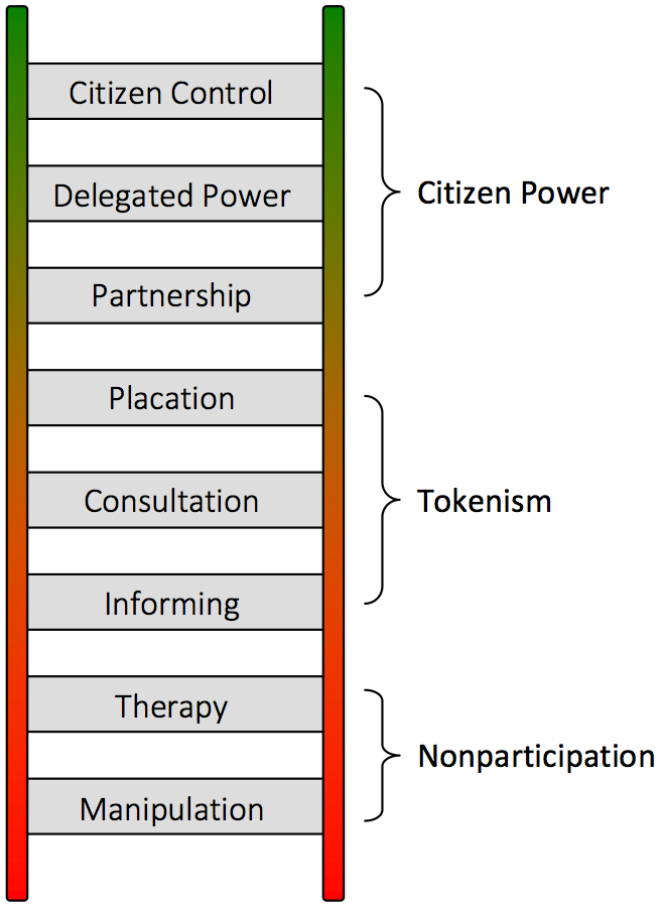
SOURCE: Israel, B. A., Schulz, A. J., Parker, E., Becker, A. B. (1998). Review of Community-Based Research: Assessing Partnership Approaches to Improve Public Health. *Ann Rev Public Health*, *19*, 173-202.; Minkler, M. and Wallerstein, N. eds. (2008). Community-based participatory research for health: From process to outcomes (2nd edition). San Francisco, CA : Jossey-Bass.

Community-Engaged Research Continuum



SOURCE: Courtesy of Nina Wallerstein, DrPH, NM CARES Health Disparities Center, 2011

Arnstein's Ladder of Citizen Participation



Increased levels of decision-making power

The "powerful" have continued right to decide, but "powerless" can advise

"Educate" or "cure" the "powerless"

SOURCE: Arnstein, S. R. (1969). A ladder of citizen participation. *Journal of the American Planning Association, 35*(4), 216-224.

SOURCE:
https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf

IAP2 SPECTRUM OF PUBLIC PARTICIPATION

Add to Chat:
Where do your community partnerships fall?

	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
GOAL	To provide balanced and objective information in a timely manner.	To obtain feedback on analysis, issues, alternatives and decisions.	To work with the public to make sure that concerns and aspirations are considered and understood.	To partner with the public in each aspect of the decision-making.	To place final decision-making in the hands of the public.
PROMISE	"We will keep you informed"	"We will listen to and acknowledge your concerns."	"We will work with you to ensure your concerns and aspirations are directly reflected in the decisions made."	"We will look to you for advice and innovation and incorporate this in decisions as much as possible."	"We will implement what you decide."


Who is at the table?

Ways to have a more equitable table

Collaborate with people that represent the groups you hope to interact with:

- Community partners
- Students / Interns
- Colleagues (in & outside of your discipline)

Approaching New Partnerships

1

Be Authentic & Transparent

- You as yourself is good enough!
- Will gain respect & trust if transparent upfront about intentions

2

Have a Plan for Project Role

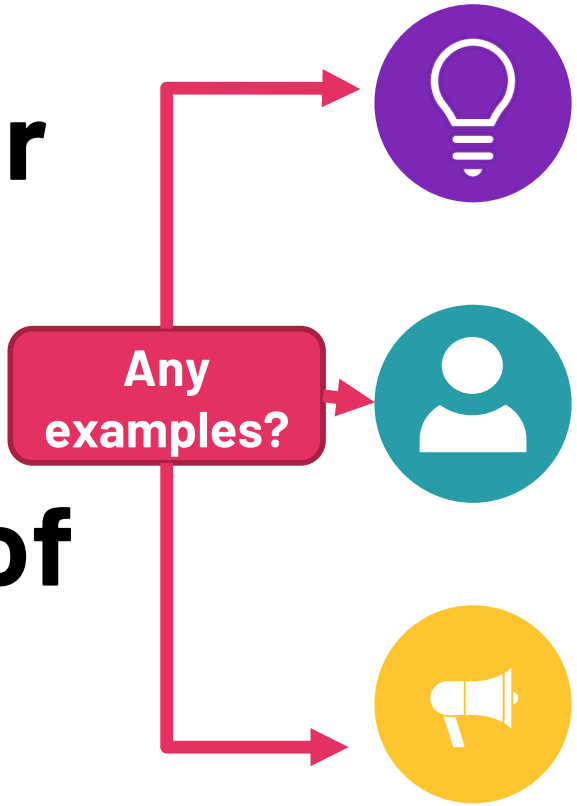
- Have idea of how to include partner… but with flexibility
- Ask partner how they'd like to be involved
- Give them a NO option (& respect that decision)

3

Develop Partnership

- Informal 1st meeting
- Attend events/meetings in community
- Make sure the relationship is reciprocal
- Show the $$$!

Involve Your Table Members Every Step of the Way



Idea Development

From establishing research question to crafting a grant proposal or IRB application

Data Collection AND Analysis

Assist with interviews/focus groups & get hands dirty with analysis

Dissemination & Wrap-Up

Push team to disseminate outside of typical pathways for your field

Leveling Participant-Interviewer Power Differentials through Place & Interaction

SOURCE: Black KZ, Faustin YF. How community-based participatory research can thrive in virtual spaces: Connecting through photovoice. Human Organization. 2022 Aug;81(3):240-247. doi: 10.17730/1938-3525-81.3.240.

1

Engage participants in a way that aligns with their comfort level.

- You can ask participants for their preferred way to engage in the project.
- This added level of choice could also mitigate barriers to participating for some people.

2

Consider who may be left out of your project based on the engagement method you use.

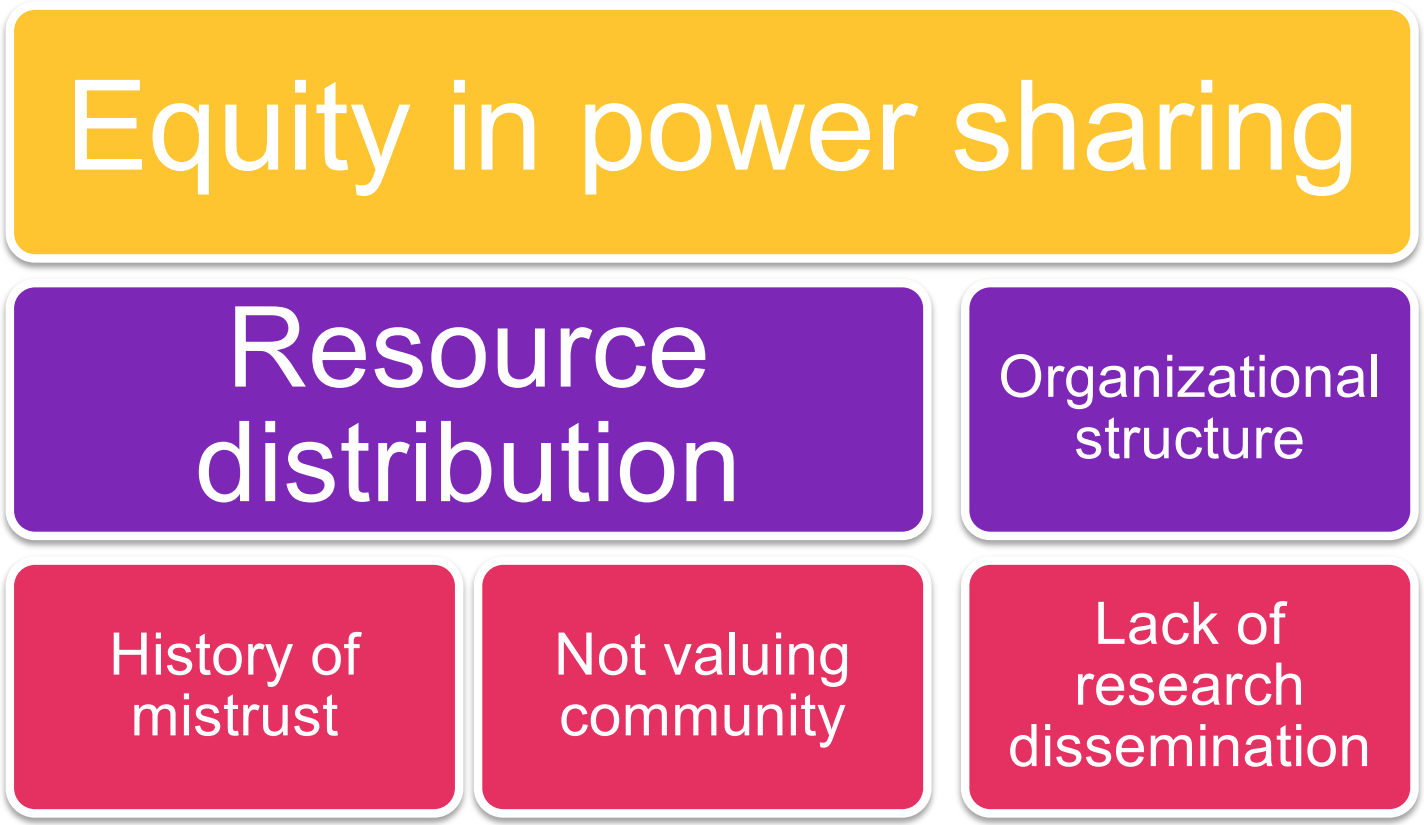
- Think through how requirements of your project may unnecessarily limit who can participate.
- You can note this as a limitation or determine ways to overcome participation barriers.

3

Be flexible with meeting times.

- Focus on scheduling sessions that work best for the participants. Garner participants' input on scheduling sessions, which will optimize their ability to attend the sessions.

Challenges for Community-Academic Partnerships



Equitable Participant Incentives

- You are being paid for your time, AND so should participants & partners
- Ask your partners what they believe is an equitable and meaningful incentive
- Write it in your grant (+ some)
- Ensure the participants receive incentive in a timely manner
- If payment is monetary, pay in cash whenever possible
- Make sure incentive is in line with the times (i.e., inflation)

SOURCE: Black KZ, Yongue Hardy C, De Marco M, Ammerman AS, Corbie-Smith G, Council B, Ellis D, Eng E, Harris B, Jackson M, Jean-Baptiste J, Kearney W, Legerton M, Parker D, Wynn M, Lightfoot A. Beyond incentives for involvement to compensation for consultants: Increasing equity in CBPR approaches. Progress in Community Health Partnerships: Research, Education, and Action. 2013 Fall;7(3):263-270. doi: 10.1353/cpr.2013.0040.

Examples from the Field

Greensboro Health Disparities Collective (GHDC)
Exploring Racism & Systemic Inequities through Students' Memories (ERASISM)

The Formation of the Greensboro Health Disparities Collaborative

- Partnership Project recruited researchers from the UNC School of Public Health to secure a planning grant from Moses Cone-Wesley Long Community Health Foundation
- GHDC formed in 2003
- CBPR planning process: September 2003-May 2005

GHDC's Mission

Our mission is to establish structures and processes that respond to, empower, and facilitate communities in defining and resolving issues related to disparities in health.

Making It Work... for 2 decades!

Full Value Contract

By-Laws

2-Day Racial Equity Training

Membership Fee

Monthly Meetings

Family Dynamics

Accountability for Cancer Care through Undoing Racism & Equity (ACCURE)

Principal Investigators

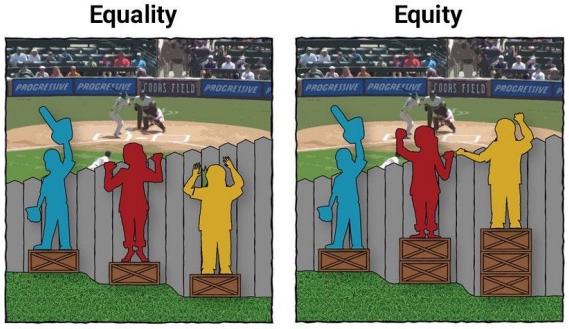
- Eugenia Eng, DrPH *(UNC Gillings School of Global Public Health)*
- Samuel Cykert, MD *(UNC School of Medicine)*

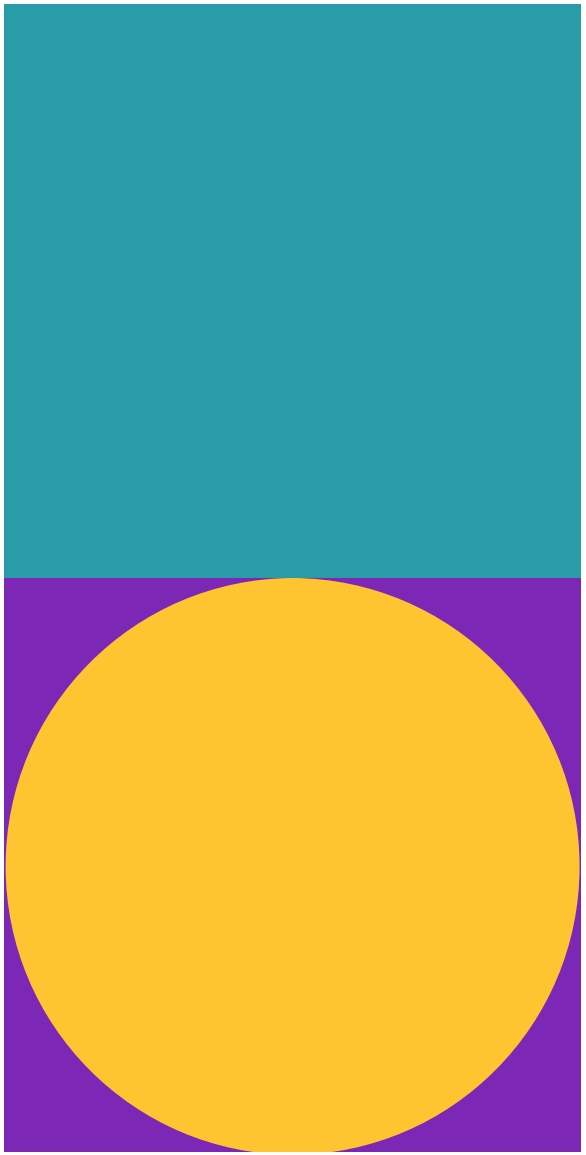
Project Aim

- Examine how institutional biases in the cancer care system can be changed to reduce racial inequities in the quality & completion of breast & lung cancer care

Funder

- National Cancer Institute (R01)





ACCURE: Power Analysis of Cancer Care System

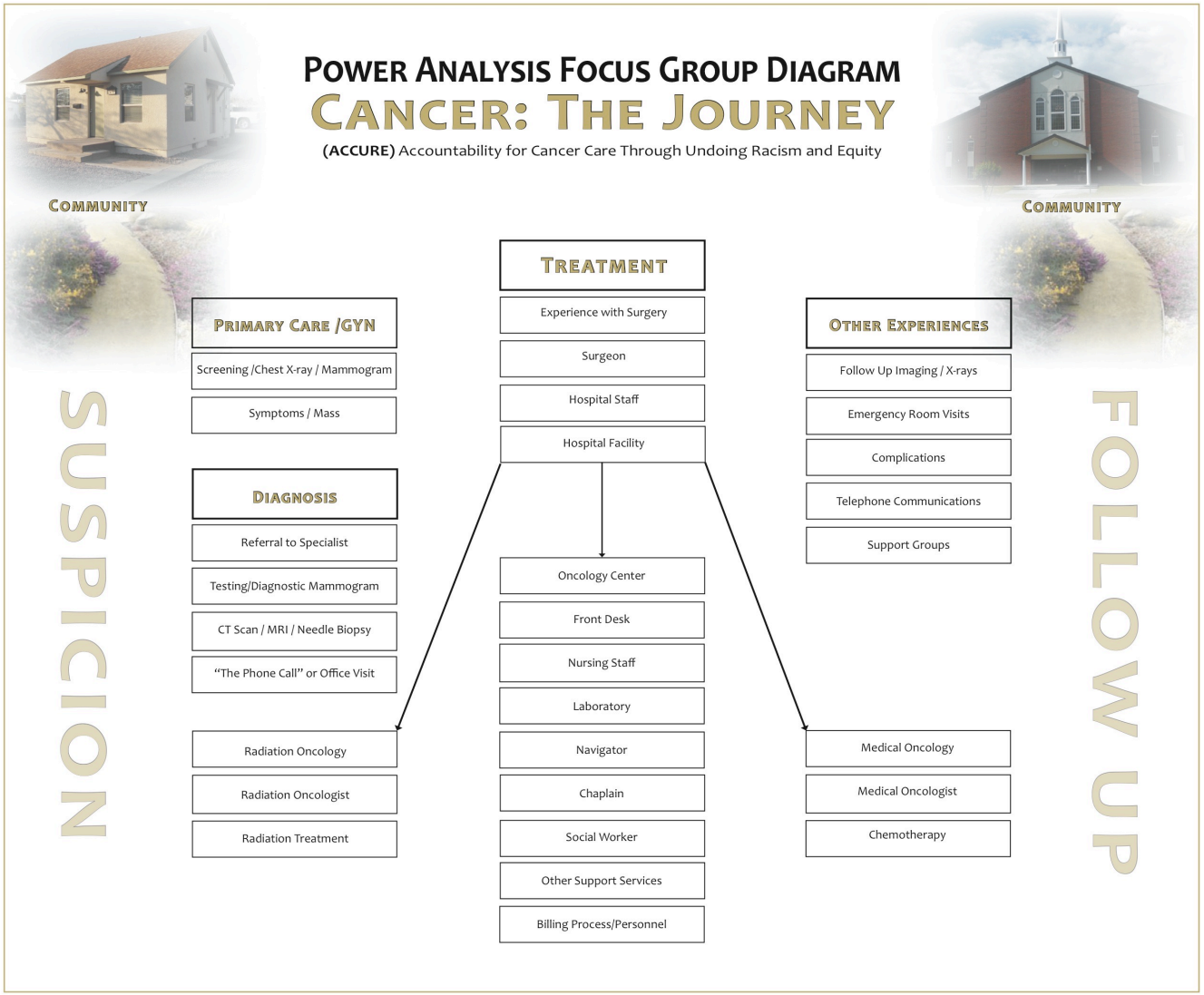
- **STUDY POPULATION:** Stage 1-2 breast & lung cancer patients; received care at 1 of 2 cancer centers; completed treatment ≤12 months
- **DATA COLLECTION:** 8 focus groups (4 at each center); by race & cancer type; N=27 patients
- **DATA ANALYSIS:** Community-guided process; teams of community members & academics

Analysis of Power & Authority

Challenges participants to analyze the structures of power & privilege that hinder equity

SOURCE: www.racialequityinstitute.com

Cancer Journey Map



SOURCE: Schaal JC, MD, Lightfoot AF, Black KZ, et al. Community-guided focus group analysis on cancer disparities. Progress in Community Health Partnerships: Research, Education, and Action. 2016 Spring;10(1):159-167. doi: 10.1353/cpr.2016.0013.

How We Used CBPR & Equity Approaches for our Analysis Process

- Enlisted 16 Volunteers from GHDC
- Provided training in qualitative analysis
- Developed paired coding process to ensure diverse perspectives
- Brought emerging findings to Greensboro Health Disparities Collaborative for further refinement and application of findings to Power Analysis

Partnership Involvement

- **Community Partners:** Elizabeth Biddle, Pat Chamings, Sheryl Coley, Carol Cothern, Kay Doost, Chris Goettsch, August Elliott, Rhonda Enoch, Lilli Mann, Neda Padilla, Kristen Werner, Turner Wiley

- **Academic Partners:** Stephanie Baker, Kristin Black, Eugenia Eng, Keon Gilbert, Danielle Harris, Janet Jeon, Deanna LaMotte, Alexandra Lightfoot, Mary S. Mouw, Kathryn Stein, Emily Waters, Michael Yonas, Christina Yongue

- **Medical Partners:** Barbara Akins, Karen Foley, LaSonja Little, Linda Robertson, Jennifer Schaal

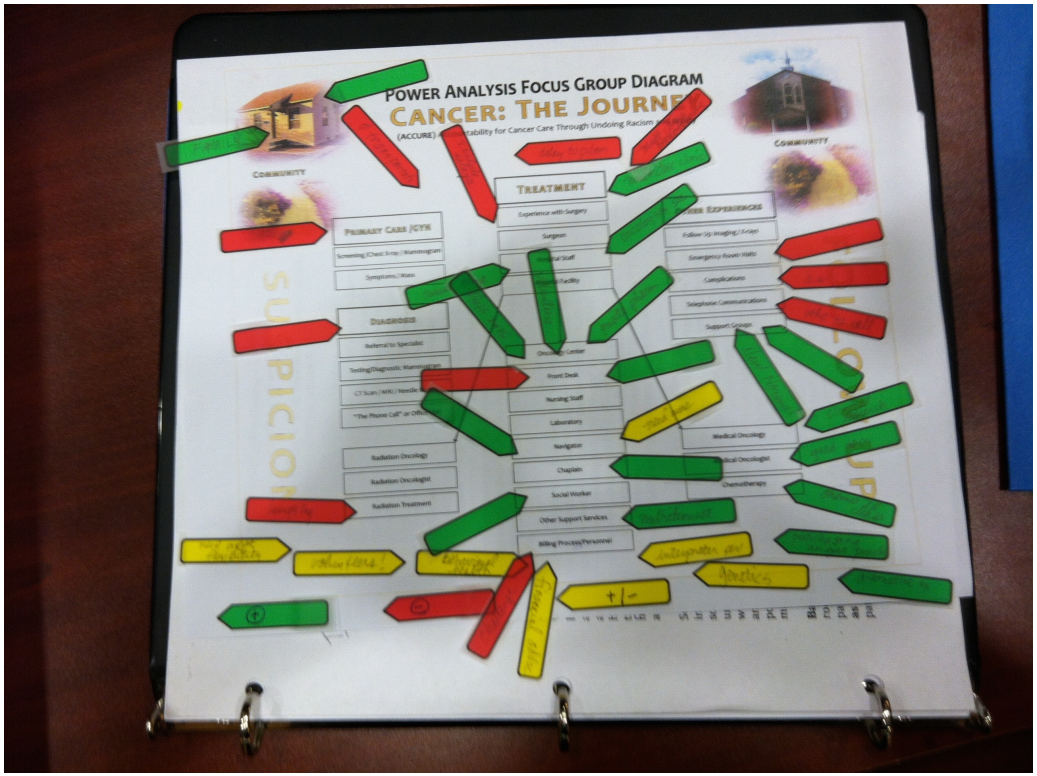
- **Greensboro Health Disparities Collaborative:** Broader membership provided feedback and input to strengthen interpretation and analysis at multiple points

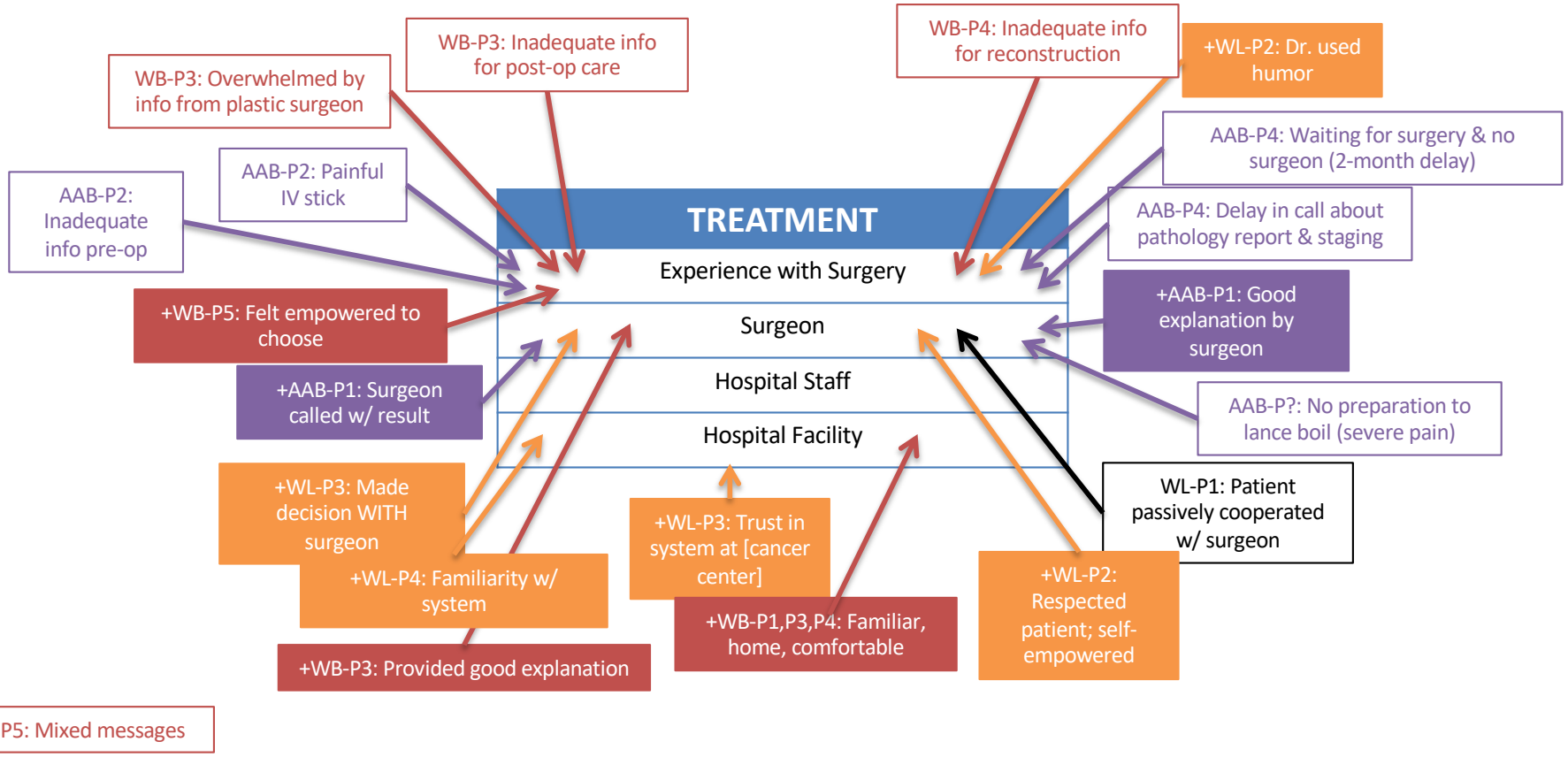
SOURCE: Schaal JC, MD, Lightfoot AF, Black KZ, et al. Community-guided focus group analysis on cancer disparities. Progress in Community Health Partnerships: Research, Education, and Action. 2016 Spring;10(1):159-167. doi: 10.1353/cpr.2016.0013.

Process: Using Power Analysis as a Tool in Qualitative Analysis

- Team of community and academic members reviewed transcripts for “pressure points”
- Analyzed pressure points by cancer type, race, and cancer center site
- Attributed the pressure points to relevant sections in the cancer journey diagram
- Discussed pressure point analysis with Greensboro Health Disparities Collaborative to inform development of Healthcare Equity Training

Mapping Patients' Experiences on Cancer Journey Diagram





Mapping Patients' Experiences on Cancer Journey Diagram

SOURCE: Black KZ, Lightfoot AF, Schaal JC, et al. '*It's like you don't have a roadmap really*': Using an antiracism framework to analyze patients' encounters in the cancer system. Ethnicity & Health. 2018 Dec 13;1-21. doi: 10.1080/13557858.2018.1557114.

Analysis of Power & Authority Themes

Where do you see structure in the themes?

1

Fear was disempowering & discouraged continuation of care

2

Uncertainty & lack of information were disempowering & hindered care

3

Trust in the medical team was crucial to continuing care

4

Communication was empowering when providers shared information & were also good listeners

5

Navigating complex, impersonal healthcare systems was often confusing, overwhelming, & disempowering

6

In these impersonal systems, small interpersonal interactions were enormously important in helping patients feel cared for or disregarded

Analysis of Power & Authority Themes

Where do you see structure in the themes?

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ACCURE: Power Analysis Results

Diagnosis

- Diagnosis delivered routinely via phone

Disconnects in communication with staff

Course of Treatment

- Lack of info & uncertainty of what to expect is stressful

Delays in scheduling surgery & other procedures

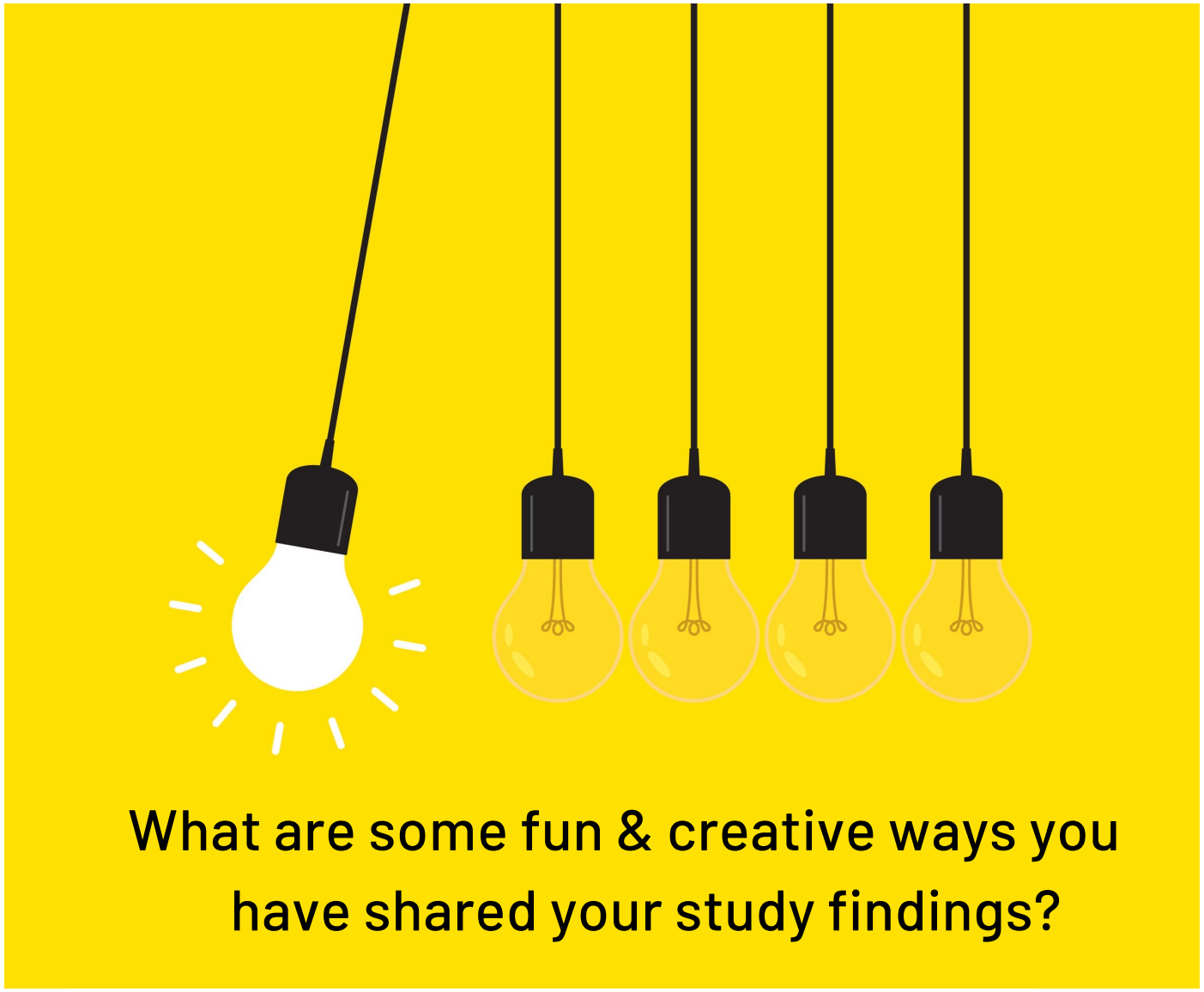
Daily Grind

- Navigating complex system is over-whelming & disempowering

Experiencing micro-aggressions

When Treatment Ends

- Strong support initially received dissipated once treatment ended


What are some fun & creative ways you have shared your study findings?

Ways to Share Findings

The Other Side of Through: Young Breast Cancer Survivors' Spectrum of Sexual and Reproductive Health Needs

Qualitative Health Research
2020, Vol. 30(13) 2019–2032

DOI: 10.1177/1049732320929649
journals.sagepub.com/home/qhr
SAGE

Kristin Z. Black[1], Eugenia Eng[2], Jennifer C. Schaal[3], La-Shell Johnson[2], Hazel B. Nichols[2], Katrina R. Ellis[4], and Diane L. Rowley[2]

Opinion

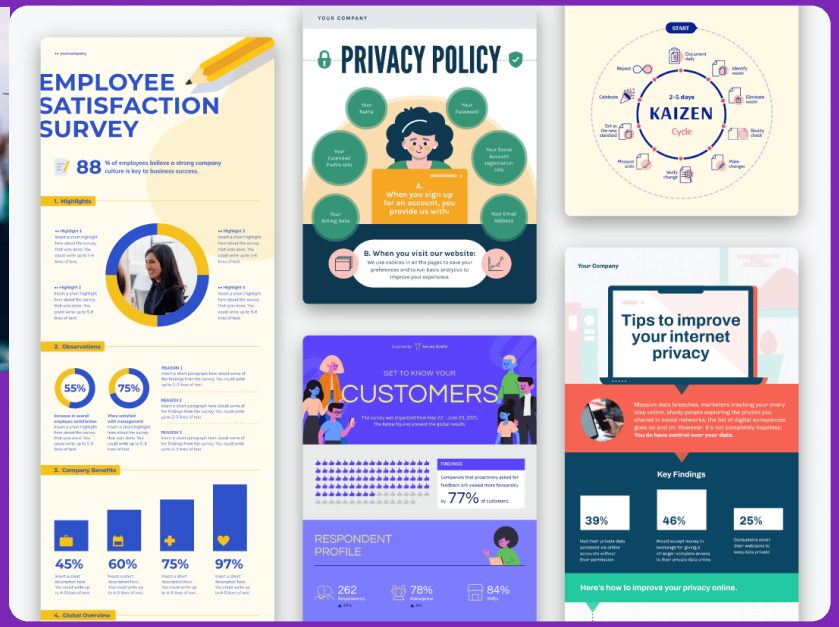
IN MY OPINION

Schools need adequate staffing, not silver bullets, to restore quality

By Walt Hellman
Special to the Argus

How long will Oregon be a state that sets ambitious education improvement goals while simultaneously reducing teachers' ability to deliver basic education?

an average of 40 in Hillsboro high schools and Oregon can't afford to keep its schools open all year. Tragically, for these 20 years, Oregon's educational and political leaders have not focused people's attention on the important need for replacement funding and increased



Exploring Racism and Systemic Inequities through Students' Memories (ERASISM)

Principal Investigators

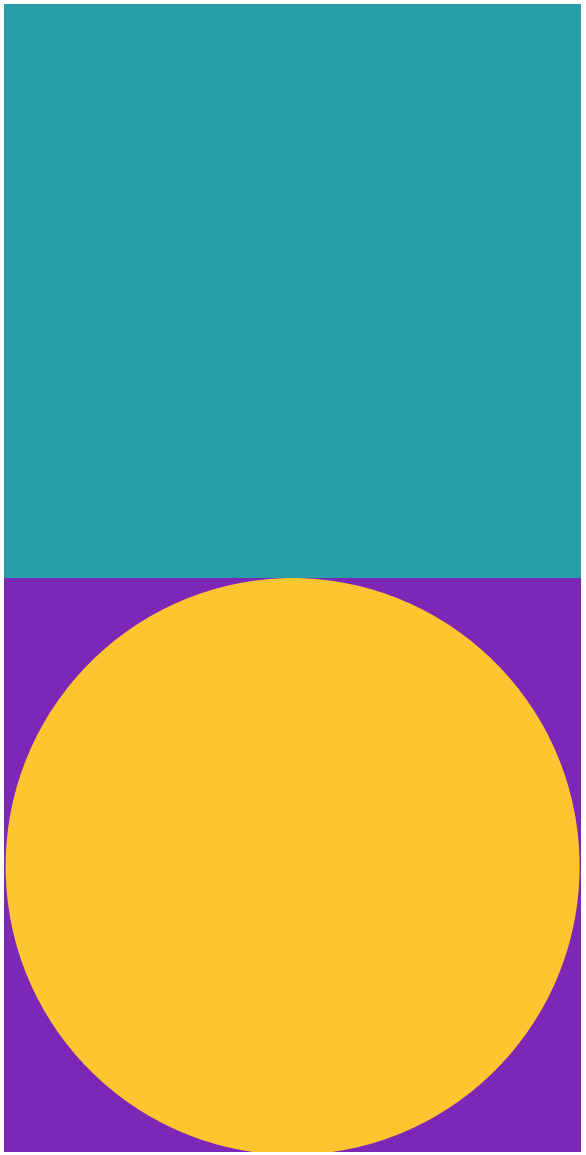
- Kristin Black, PhD, MPH; Tamra Church, MAEd, MCHES®

Project Aim

- Learn about students' experiences with overt and covert racism on East Carolina University's (ECU) campus

Funders

- ECU Department of Health Education & Promotion; ECU College of Health and Human Performance



ERASISM: Photovoice Project

- **STUDY POPULATION:** Undergraduate BIPOC students in College of Health & Human Performance at East Carolina University
- **DATA COLLECTION:** 5 sessions; 2 groups; N=7
- **DATA ANALYSIS:** Sort & Sift, Think & Shift®

Deciding on What to Share

For the ERASISM project, we:

Gathered all pics & provided quote options for each pic

Had the students vote on 10 favorite pics & choose quotes for each pic

Created photo exhibit only sharing what the students approved of

Dear ECU

In my short time during my freshman year at ECU I faced a lot more racism than I thought I would. I heard the constant use of the n-word by my white peers. Whether it was singing a song or referring to other people. These same people got hostile or defensive when asked not to use the slur and couldn't understand why they couldn't say it. I was also excluded from events purely based on my race or the people we were hanging out with weren't "into black people". The class of 2024 needs to do better.

- Student '24

Traveling Photo Exhibit

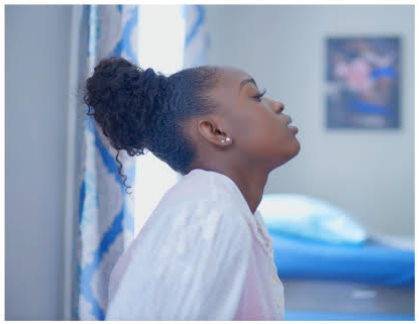
STUDYING WHILE BLACK

Balancing Racism & Academia

BLACK WOMEN'S RESISTANCE TO RACISM: FROM BIRTHING TO LIVING

RECLAIMING POWER

THE BLACK MATERNAL HEALTH CRISIS


Join Assistant Professor of Dance, Keshia Wall, & Associate Professor of Public Health Studies, Stephanie Baker, as they debut their collaborative documentary-dance short film about the Black maternal health crisis.

Youth Empowered Advocating for Health

YEAH's Mission:

- Leadership/skills curriculum
- Advocacy training
- Opportunities

Community and Church Forums Goals:

- Present photovoice findings
- Galvanize community participation and social action
- Break silence around HIV and racism
- Gain support for YEAH objectives
- Over 120+ people participated!

Engaging Participants & Partners at End of Project

Member checking session

Hold group or individual meeting to share preliminary findings & acquire their perspective

Co-presentations

Invite them to serve as co-presenters for any presentation & present to their network

Official thank you (but not goodbye)

Send an official thank you note to express your gratitude & stay in touch about future opportunities

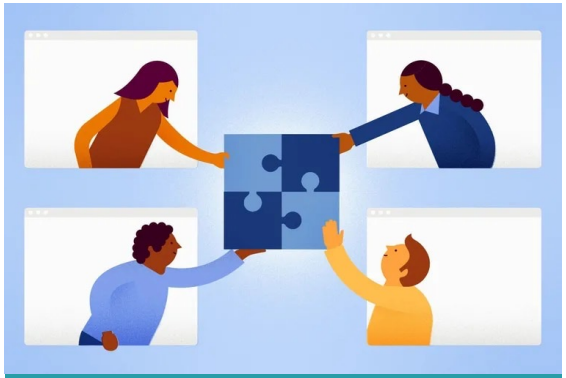
If nothing else, I hope you learned that...

Engage in Community Partnerships

Community members are invaluable partners in research & they should be paid for their contributions

Center Equity

You should study equity &/or practice it in your research



This Work Takes Time

Integrating equitable practices into your research is a long distance walk, not a sprint

Q & A

Any & all questions are welcome!

It's so lovely to co-learn with all of you!

Thank you for listening.

Kristin Z. Black

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Mat. & Child Health
Health Behavior

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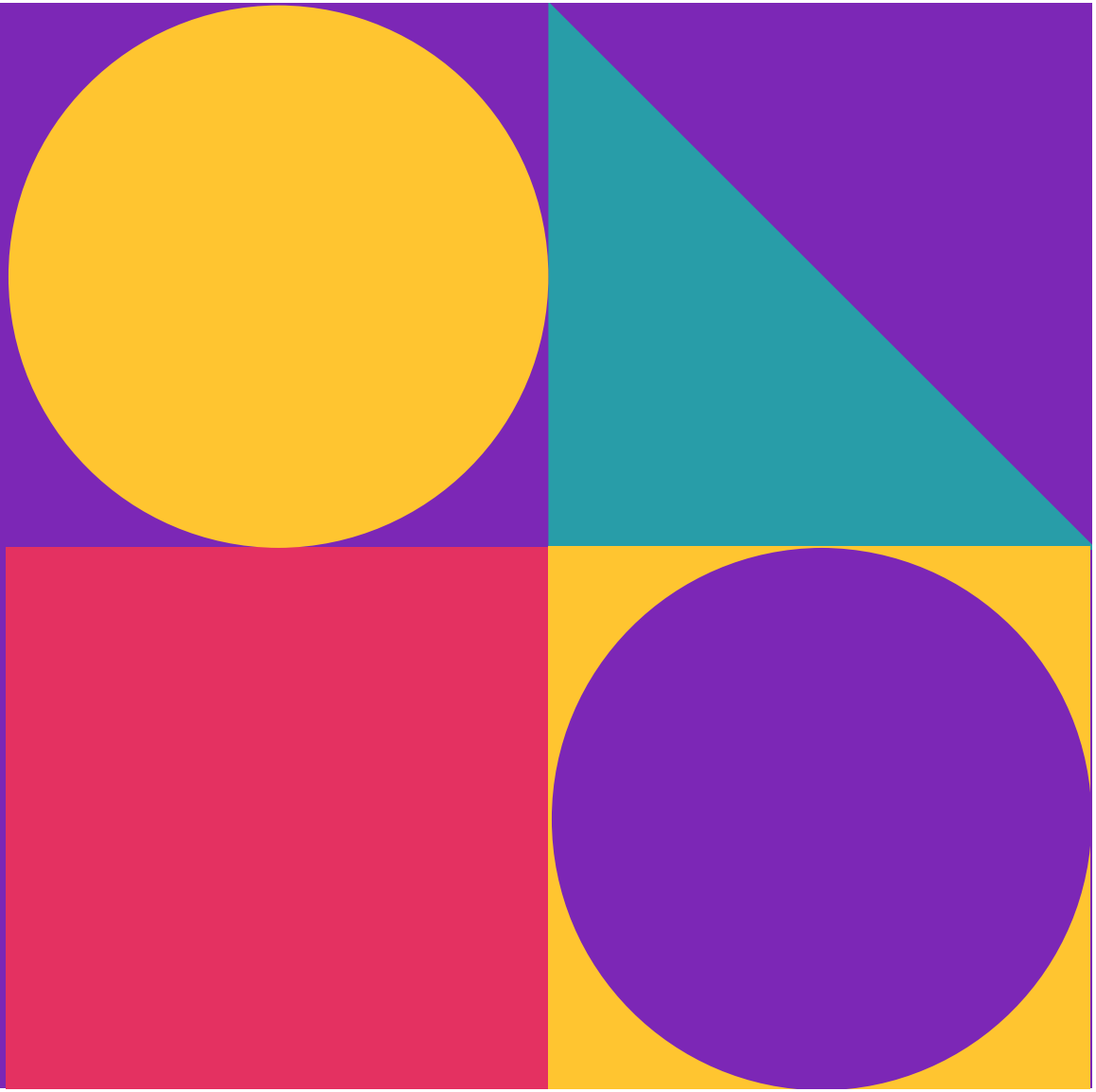
@drkristinzblack

EXTRA SLIDES



Equitable Participant Incentives (Examples)

ACCURE:	•**Participants:** $15 gift card for 90 min •**Community Interviewers**: $10 per interview
Dissertation:	•**Participants:** $25 cash for 1st & $35 cash for 2nd session •**Advisory Board:** volunteered time
ROKTRC:	•**Participants:** $30 debit card for 1.5-2 hrs (4 sessions total)
MAPPS-MH:	•**Participants:** $30 debit card for 60 min (2 sessions total) •**Advisory Board:** $150 check/DD for 60-90 min (5 mtgs total)

At first glance…

Overwhelmingly positive comments

Patients valued their interactions with staff and described them as *'welcoming'* and *'like old friends'* who *'knew their names'*.

(Black & White breast & lung cancer patients)

"So…between the cancer center, the therapist that they have there…the smallest person, even the greeters when you come in the door…they go above and beyond their job. Because I think you have to be a special kind of person to work there, you just can't be like a regular doctor's office, because they are compassionate, they understand people are going through some serious stuff, mentally, physically, and emotionally."

(Black lung cancer patient)

SOURCE: Black KZ, Lightfoot AF, Schaal JC, et al. '*It's like you don't have a roadmap really*': Using an antiracism framework to analyze patients' encounters in the cancer system. Ethnicity & Health. 2018 Dec 13;1-21. doi: 10.1080/13557858.2018.1557114.

Racial Differences in Care

“Cause I had a boil to come up…the provider said ‘let me take a look at it’ and then the next thing I knew he asked for something and he immediately lanced it. He didn’t prepare me. He didn’t tell me what he was doing. Nothing. And I had to actually literally grab my pants because I was getting ready to cold cock him…That’s how bad it was.”

(Black breast cancer patient)

Racial Differences in Care

“I could get food down more and better than I had. But…there was another woman that told me about the mints and the… Lemonheads…up there at the chemo place. And when I come in there for my treatment…I would grab a handful and throw them in my purse. There was this one lady up there at that desk, she knew I was coming. Every time I came she would move ‘em…And I asked her where’s the Lemonheads at? {imitating lady at front desk} ‘Oh, they haven’t put any out today.’ … She was at the front desk on floor three….I went back to where the chemo people were, they always had their Lemonheads out, so I grabbed a handful of them…But for her to move them Lemonheads that really like, just took me…”

(Black breast cancer patient)

ACCURE RCT Findings:
Rates for Treatment Complete

	2007-2012	2013-2017	
	Retrospective	Control	Intervention
Black, Breast & Lung	79.8%	83.1%	88.4%
White, Breast & Lung	87.3%	90.1%	89.5%

Eugenia Eng, DrPH

Samuel Cykert, MD

SOURCE: Cykert S, Eng E, Manning MA, Robertson LB, Heron DE, Jones NS, Schaal JC, Lightfoot A, Zhou H, Yongue C, Gizlice Z. A multi-faceted intervention aimed at black-white disparities in the treatment of early stage cancers: The ACCURE Pragmatic Quality Improvement trial. Journal of the National Medical Association. 2019 Mar 28.

ACCURE: Products & Lessons Learned

Key Takeaways:

① Antiracism framework as a tool to critically examine systems

② Vital to work in collaboration with communities to conduct health equity-centered research