Advancing NIH Research on the Health of Women: A 2021 Conference

The Urgent Need for Cross-cutting Race-Conscious Approaches to Cancer Disparities Research

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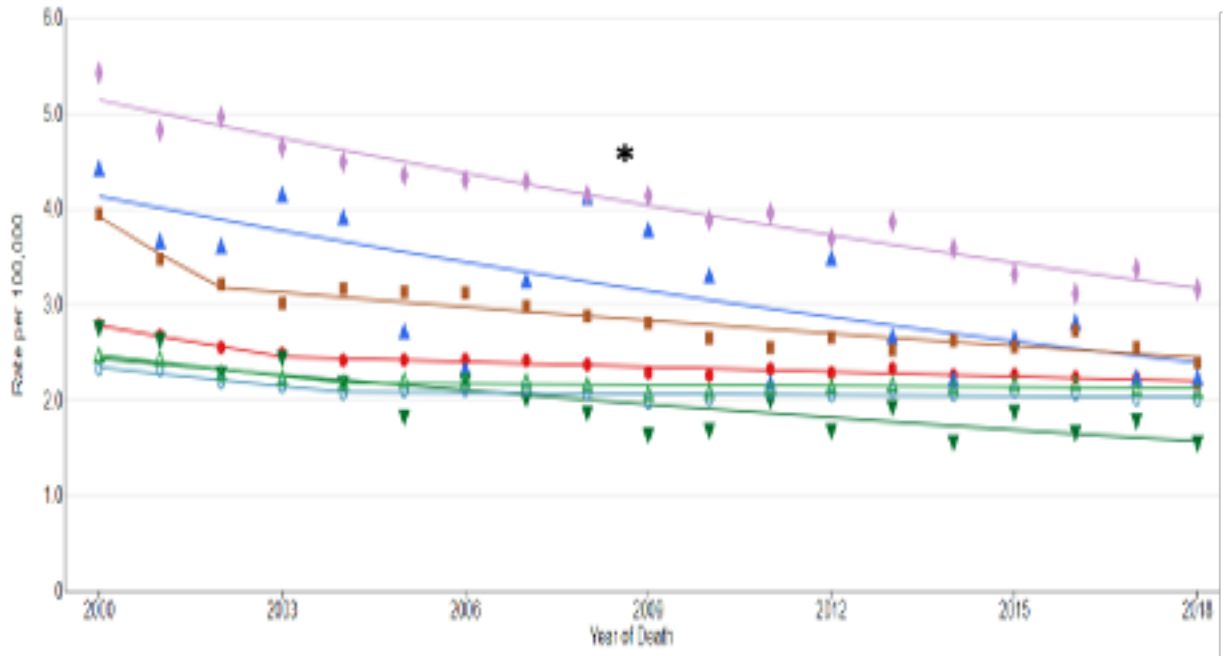
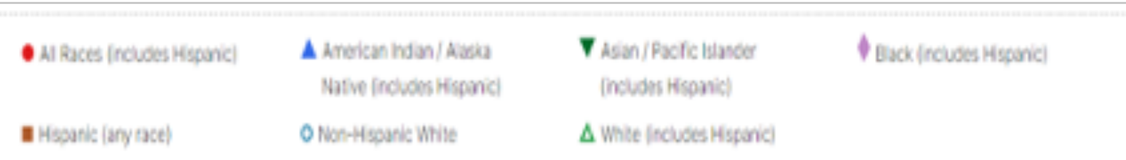
#HealthOfWomen2021

Disparities in Cervical Cancer Mortality by Race/Ethnicity in the US

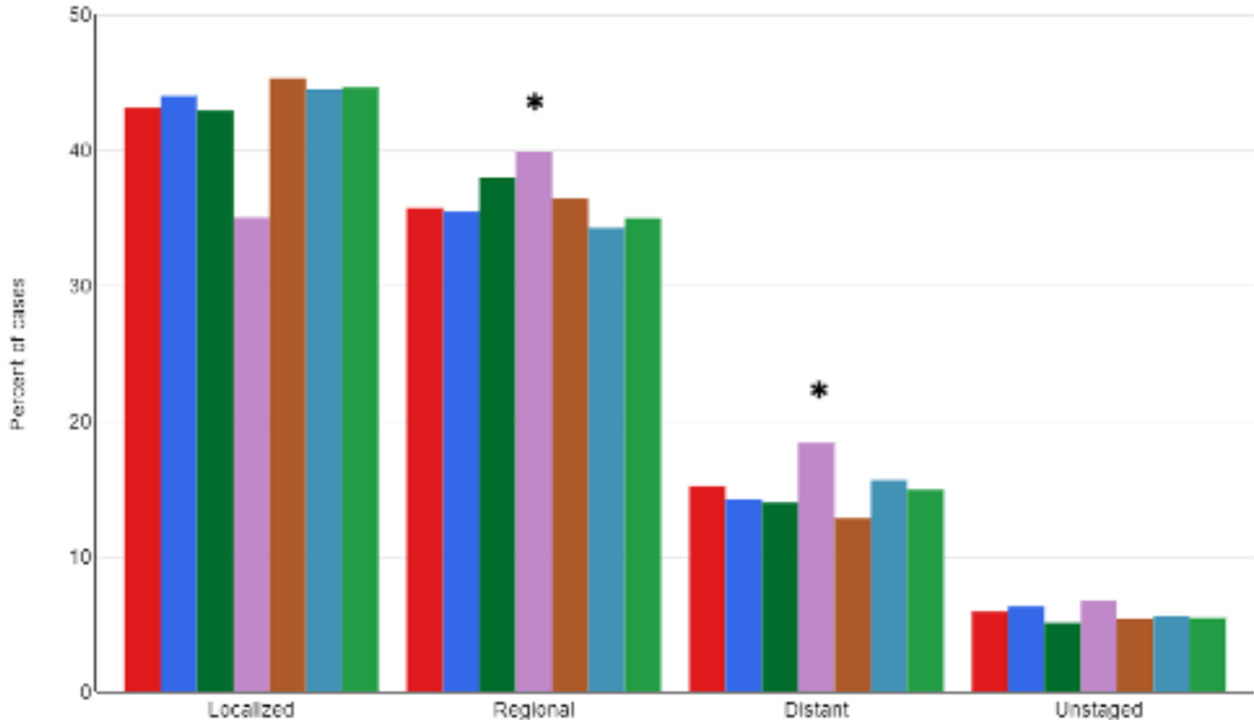
Mortality





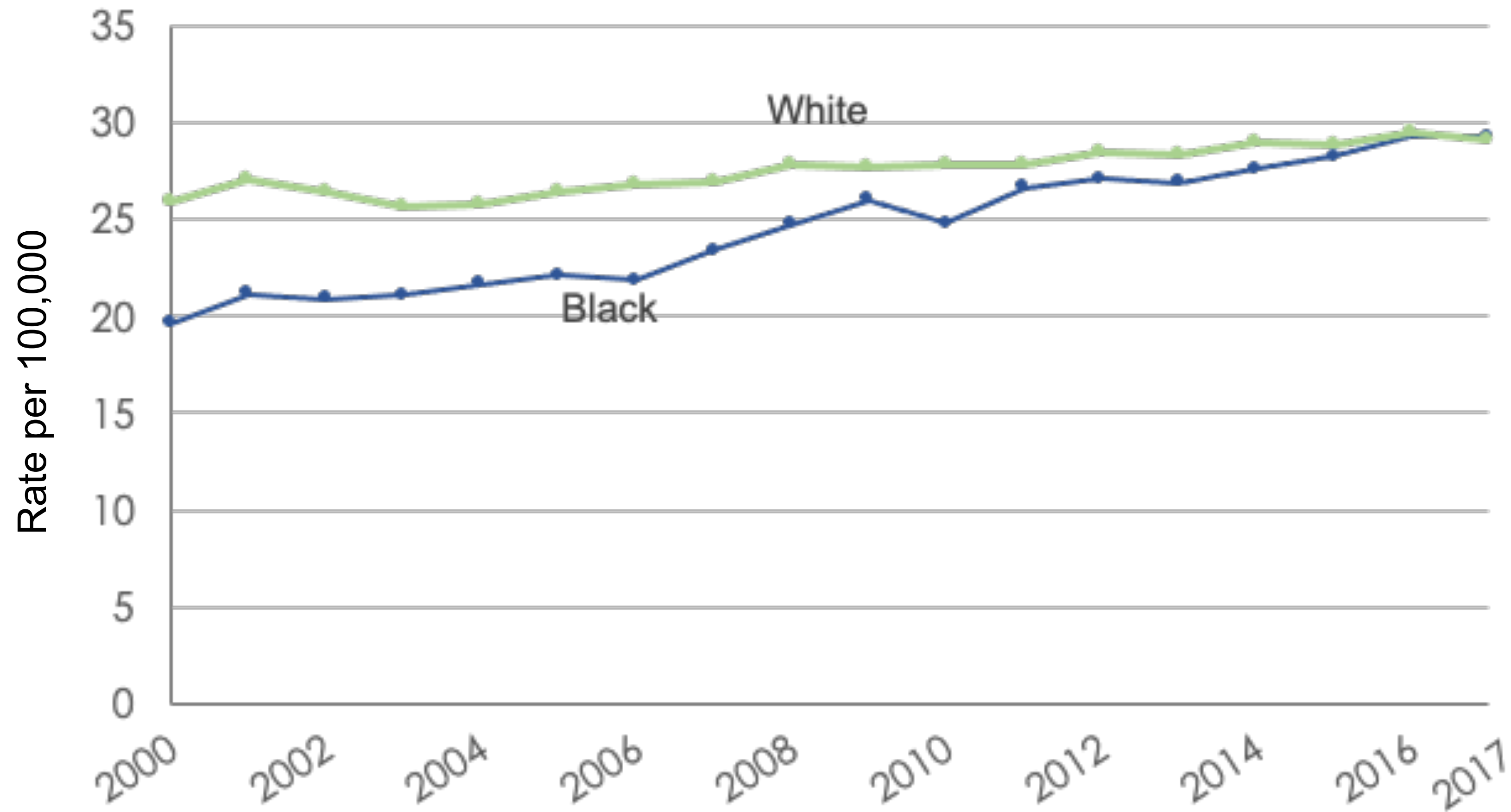
SEER Reference

Stage Distribution



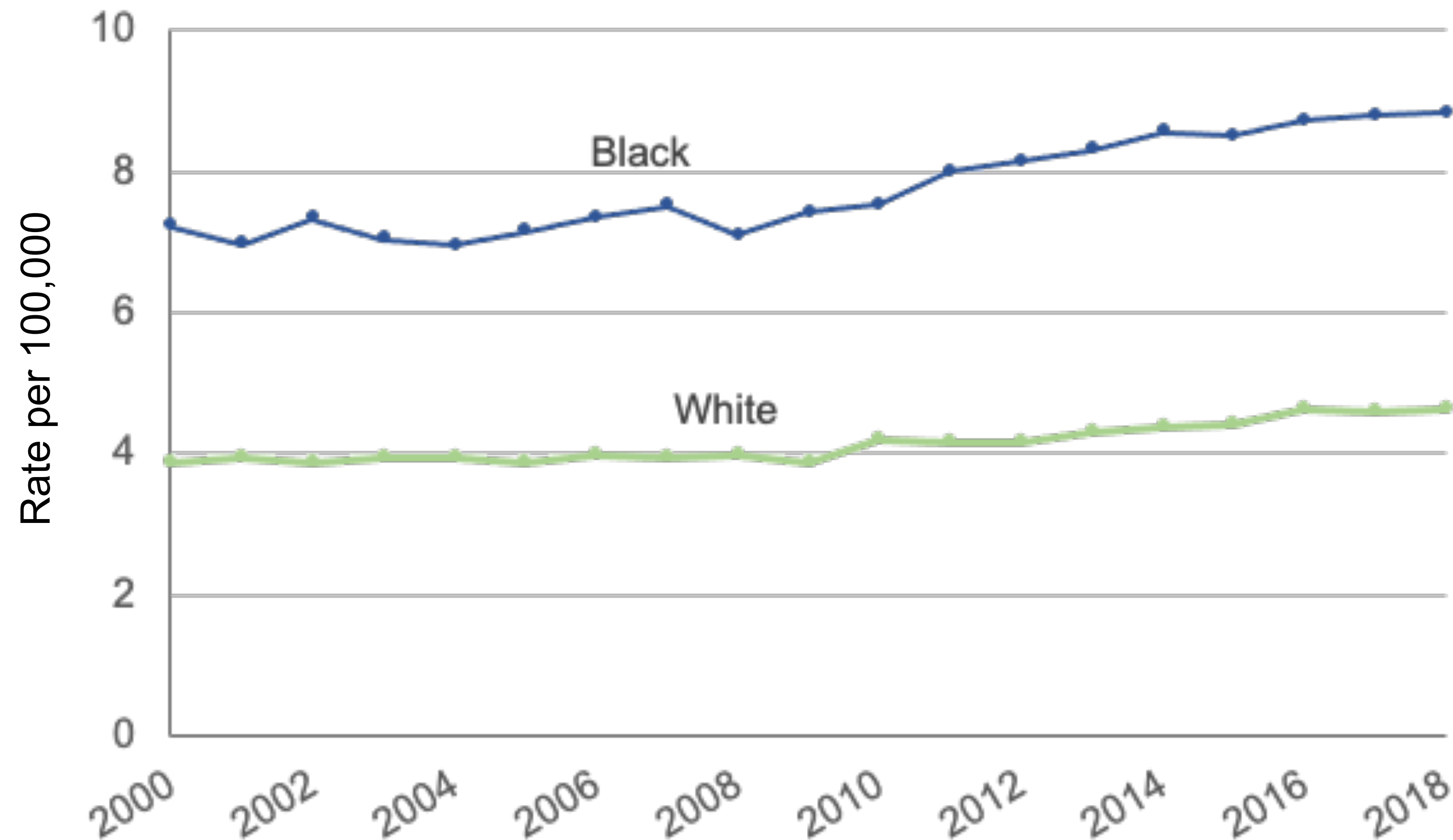
SEER Reference

US Endometrial Cancer Statistics by Race/Ethnicity: Incidence



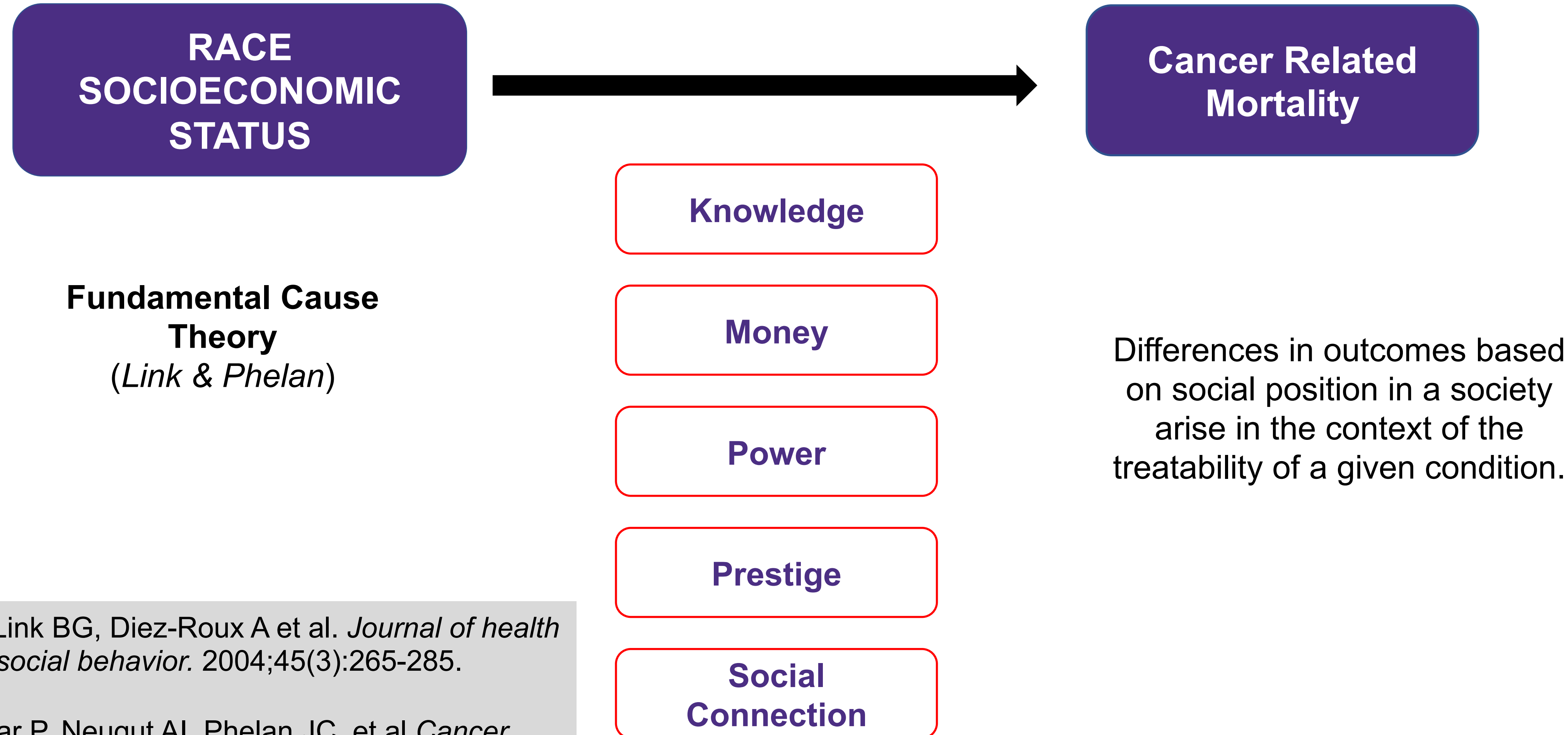
Data from: SEER cancer statistics review 1975-2018, Available at: seer.cancer.gov

US Endometrial Cancer Statistics by Race/Ethnicity: Mortality



Data from: SEER cancer statistics review 1975-2018, Available at: seer.cancer.gov

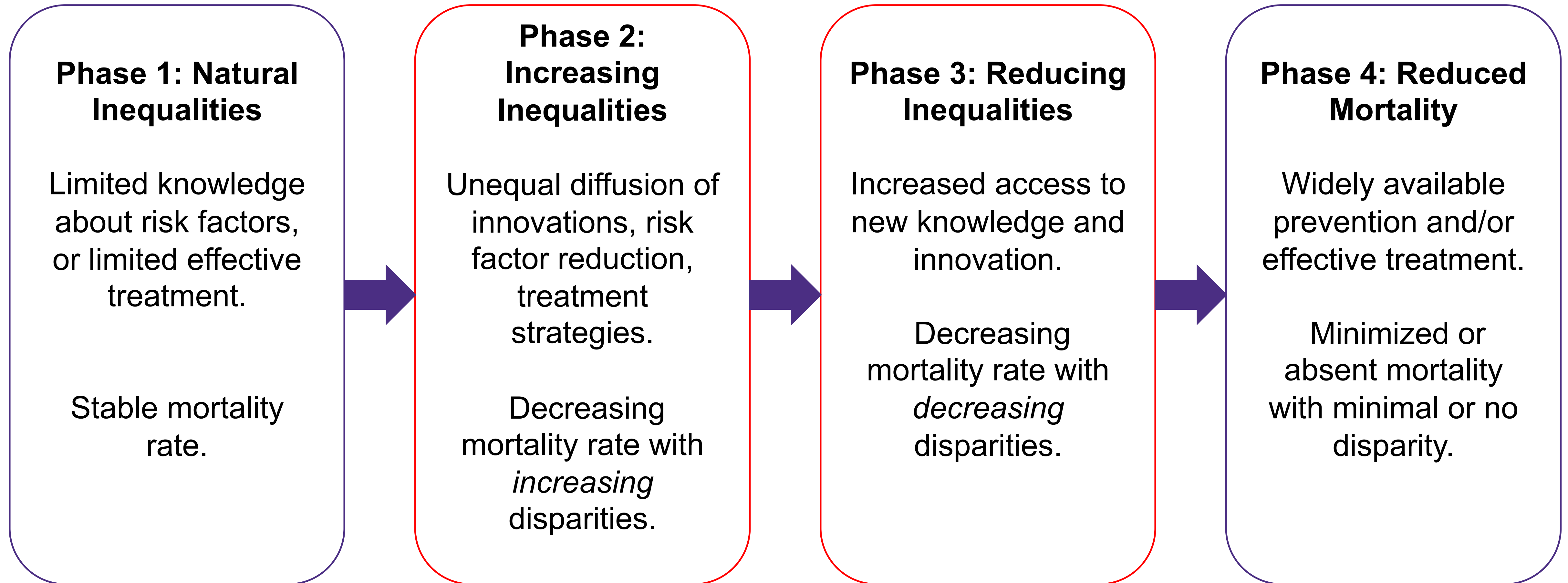
Racial disparities in cancer outcomes are the default outcome of our current biomedical research and healthcare delivery systems.



Phelan JC, Link BG, Diez-Roux A et al. *Journal of health and social behavior.* 2004;45(3):265-285.

Tehranifar P, Neugut AI, Phelan JC, et al.*Cancer Epidemiol Biomarkers Prev.* 2009;18(10):2701-2708.

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



Doll, KM. Investigating Black-White disparities in gynecologic oncology: Theories, conceptual models, and applications. *Gynecologic Oncology.* 2018 Apr;149(1):78-83

Treatability increases because of federally funded biomedical research.

Phase 1: Natural Inequalities

Limited knowledge about risk factors, or limited effective treatment.

Stable mortality rate.

NIH lead discovery of Innovations, Risk factors, and Treatments…

….WITHOUT an equity lens

Tolerance of predominantly White trial participants
Absence of equity science expertise
Narrow definitions of success

Phase 2: Increasing Inequalities

Unequal diffusion of innovations, risk factor reduction, treatment strategies.

Decreasing mortality rate with *increasing* disparities.

Example
Endometrial Cancer

Disparities persist because of the disproportionate lack of federally funded equity research.

Phase 2: Increasing Inequalities

Unequal diffusion of innovations, risk factor reduction, treatment strategies.

Decreasing mortality rate with *increasing* disparities.

Underfunding
Exclusion of Black & URM Researchers
Misaligned incentives
Poor research design and execution

Targeted, specific innovation to adapt the status quo by disrupting key flexible resources (knowledge, money, prestige, power, and social connections)

Phase 3: Reducing Inequalities

Increased access to new knowledge and innovation.

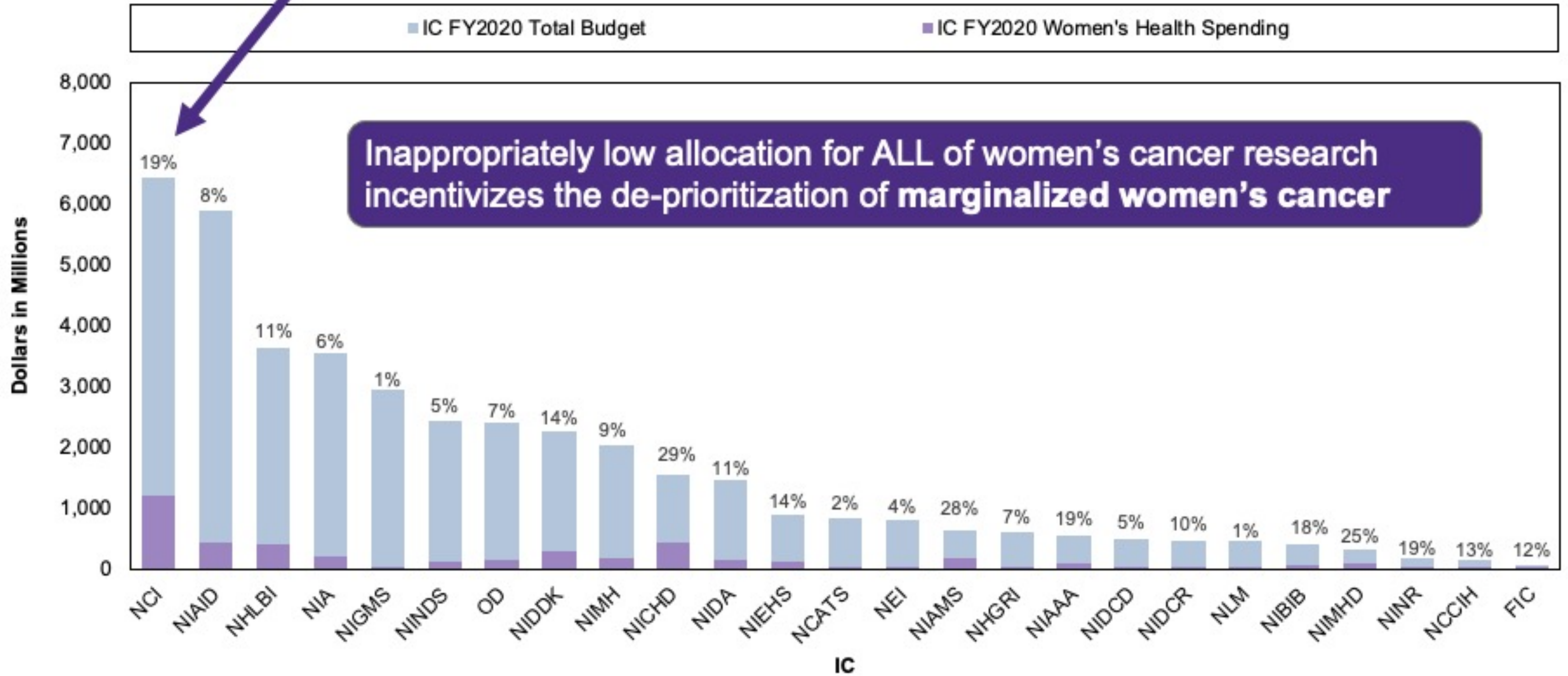
Decreasing mortality rate with *decreasing* disparities.

<u>Example</u>
Cervical Cancer

Our Default Approach is Not Working

- Inappropriately low funding allocated

IC Total Budget and Percentage Women's Health Research Spending, FY2020



Sources:
1. Women's health spending data derived from NIH RCDC data system frozen file.
2. IC total budget excludes buildings and facilities (B&F) costs; data derived from NIH Office of Budget "Appropriations History by Institute/Center" file, https://officeofbudget.od.nih.gov/approp_hist.html.

Our Default Approach is Not Working

- Inappropriately low funding allocation
- Systematic underfunding and exclusion of Black & Underrepresented Minoritized researchers

"The cluster with the lowest award rate (7.5%) is characterized by the words **ovary, fertility, and reproductive…**"

Currently, it makes more sense for Black and URM cancer researches to **AVOID women's health and disparities research** than to

SCIENCE ADVANCES | RESEARCH ARTICLE

SCIENTIFIC COMMUNITY

Topic choice contributes to the lower rate of NIH awards to African-American/black scientists

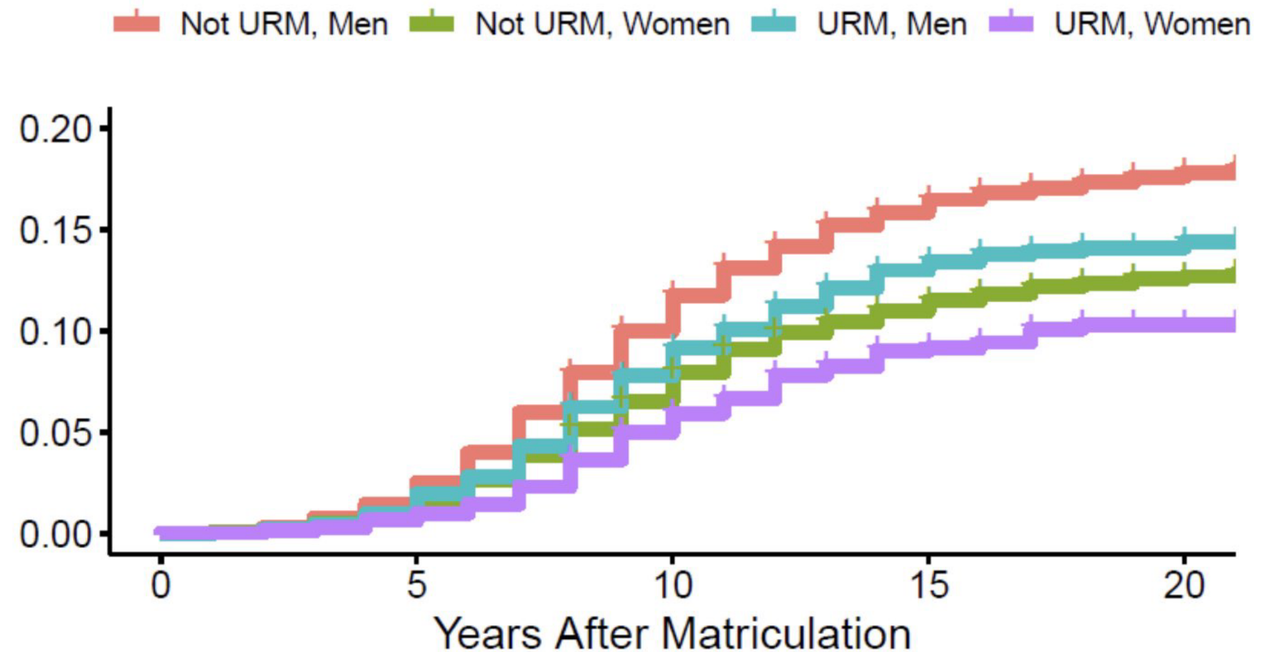
Travis A. Hoppe[1,2], Aviva Litovitz[1,2], Kristine A. Willis[3]*, Rebecca A. Meseroll[1,2], Matthew J. Perkins[1,2], B. Ian Hutchins[1,2], Alison F. Davis[4], Michael S. Lauer[5], Hannah A. Valantine[4], James M. Anderson[2], George M. Santangelo[1,2†]

Fig. 1 Funding gap between AA/B and WH scientists at each stage of the R01 application and review process.

Arrows on the left indicate the number of AA/B and WH R01 applicants in FY 2011–2015. The total number of applicants with a reported race/ethnicity is 45,998. Rocket charts depict the number of applications that were submitted, discussed, and funded per applicant. Comparative rates of discussion, funding of discussed applications, and overall funding rates are presented on the top right (**$P < 0.01$).

Time to first R01 award according to URM status and gender among K awardees

Members of the group with the worst gynecologic cancer outcomes are currently the **LEAST likely to be supported** in an NIH-funded research award.



Number

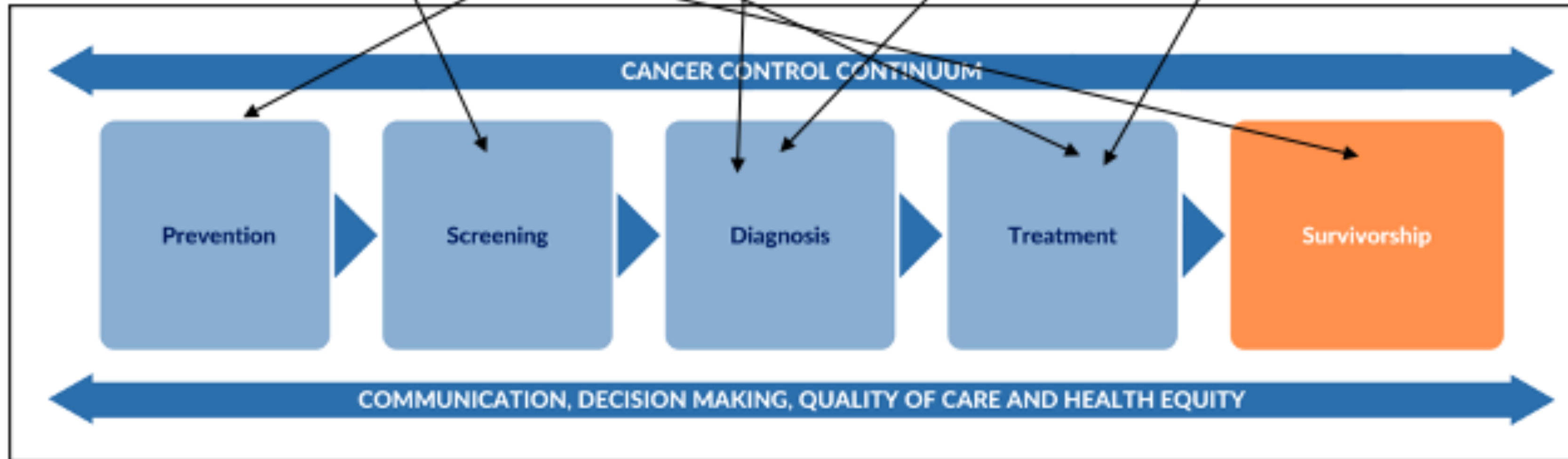
Not URM, Men	15922	15688	12478	7069	2818
Not URM, Women	14059	13927	11124	6120	2339
URM, Men	1888	1869	1489	811	302
URM, Women	2108	2094	1635	787	269

Source: https://nexus.od.nih.gov/all/2021/07/27/further-demographic-analyses-of-nih-r01-grant-outcomes-of-t32-postdoctoral-participants/

Our Default Approach is Not Working

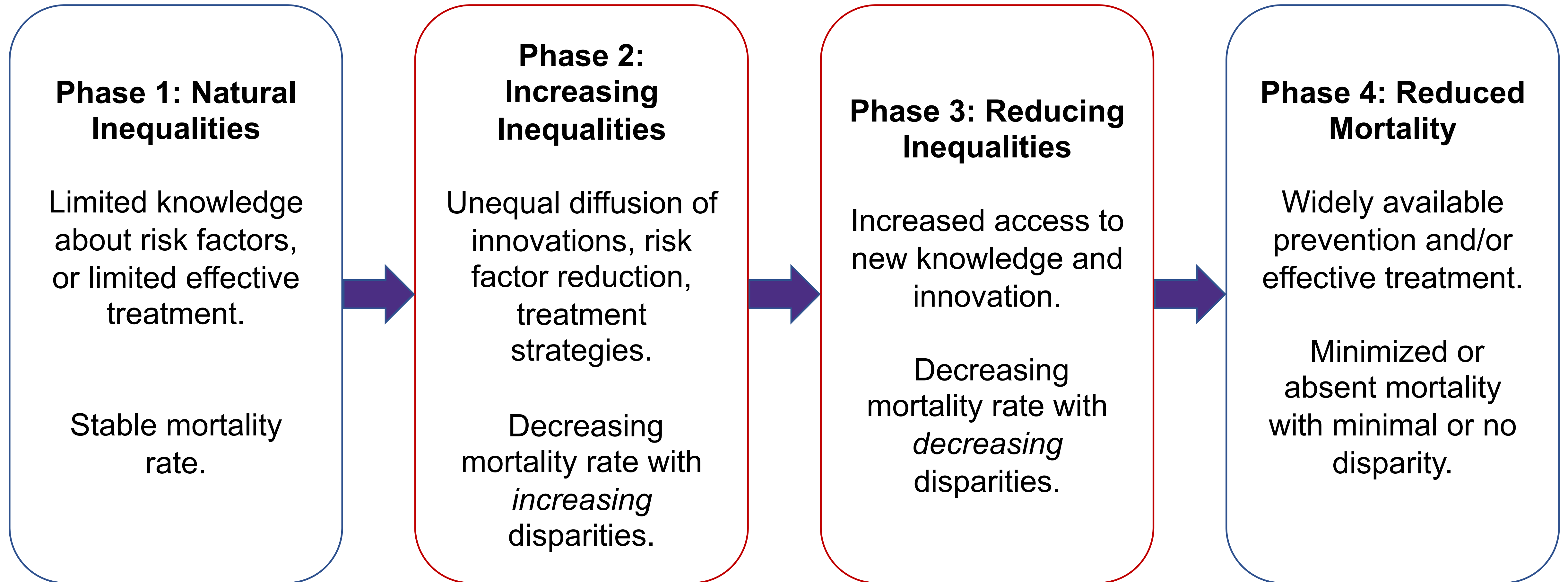
- Inappropriately low funding allocation for women's health
- Systematic underfunding and exclusion of Black & Underrepresented Minoritized researchers
- Systematic underfunding and exclusion of racism research

Racism operates at ALL levels across societal structures and environments.



There should be as many RFAs, study sections, and opportunities for funding as there are connections between upstream / downstream factors and the cancer care continuum.

How do we DISRUPT this process on behalf of improving the lives of all people with gynecologic cancers?



Doll, KM. Investigating Black-White disparities in gynecologic oncology: Theories, conceptual models, and applications. *Gynecologic Oncology.* 2018 Apr;149(1):78-83

A Race-Conscious Approach to Women's Cancer Research

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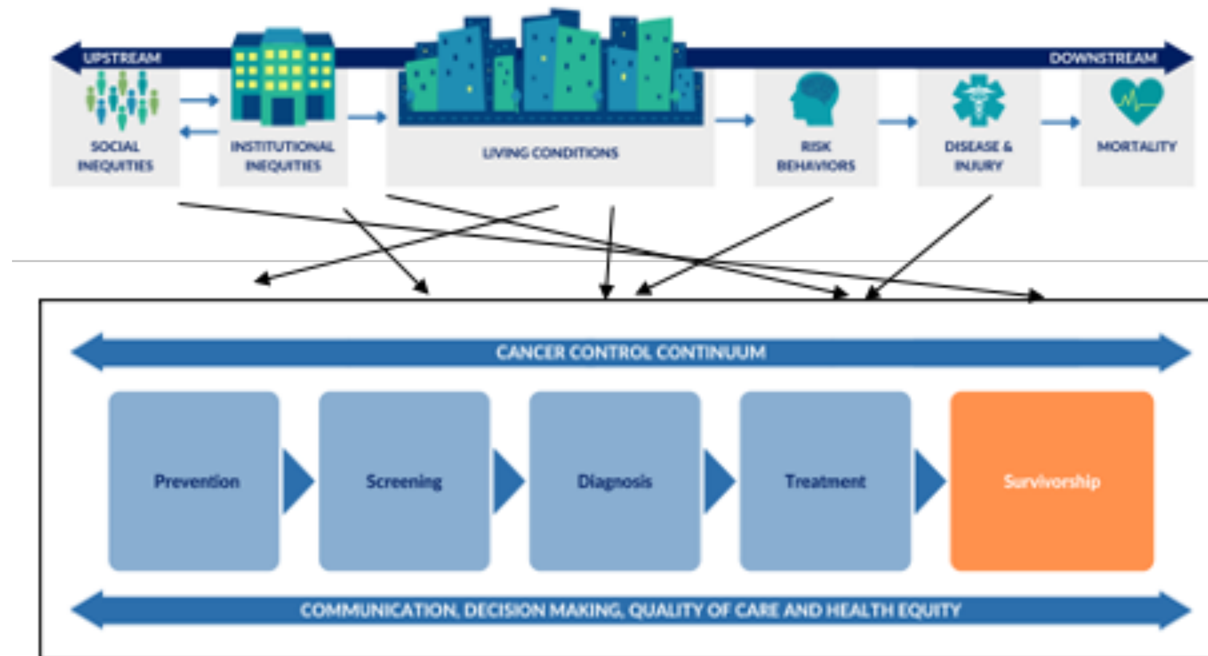
1. Embrace cross-cutting approaches that acknowledge the power and complexities of how racism influences health

- *Early detection in the setting of social and physical environments?*
- *Clinical trial design in the setting of racist funding processes?*
- *Treatment environment as a mediator of treatment completion?*
- *Survivorship in the setting of the value of Black labor?*



2. Align funding to incentivize the study of unjust creation, dissemination and delivery of cancer research knowledge

- Use disciplinary self-critique to disrupt the current pattern of *colorblind innovation* that creates and exacerbates ongoing inequities

Systematic Review

PUBLIC HEALTH *Reports*

Naming Institutionalized Racism in the Public Health Literature: A Systematic Literature Review

Public Health Reports
2018, Vol. 133(3) 240-249
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DOI: 10.1177/0033354918760574
journals.sagepub.com/home/phr

Rachel R. Hardeman, PhD, MPH[1], Katy A. Murphy, RN, MPH[1], J'Mag Karbeah, MPH[1,2], and Katy Backes Kozhimannil, PhD, MPA[1]

3. Prioritize equity research grounded in theories and frameworks that undergird race, gender, and health.

- Example: Intersectional Frameworks for Research Participation – Andrea Gilmore-Bykovkyi PhD, RN

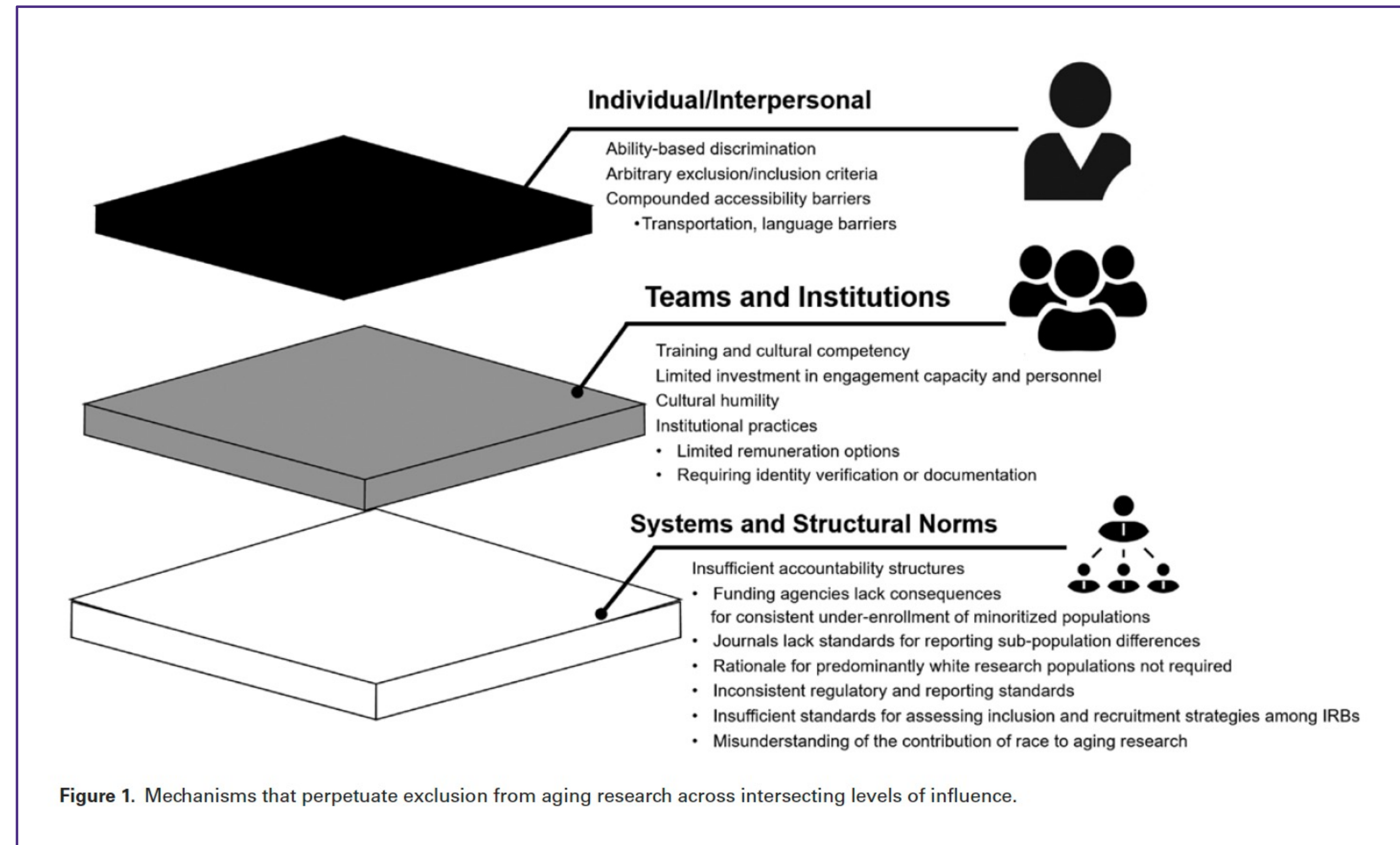
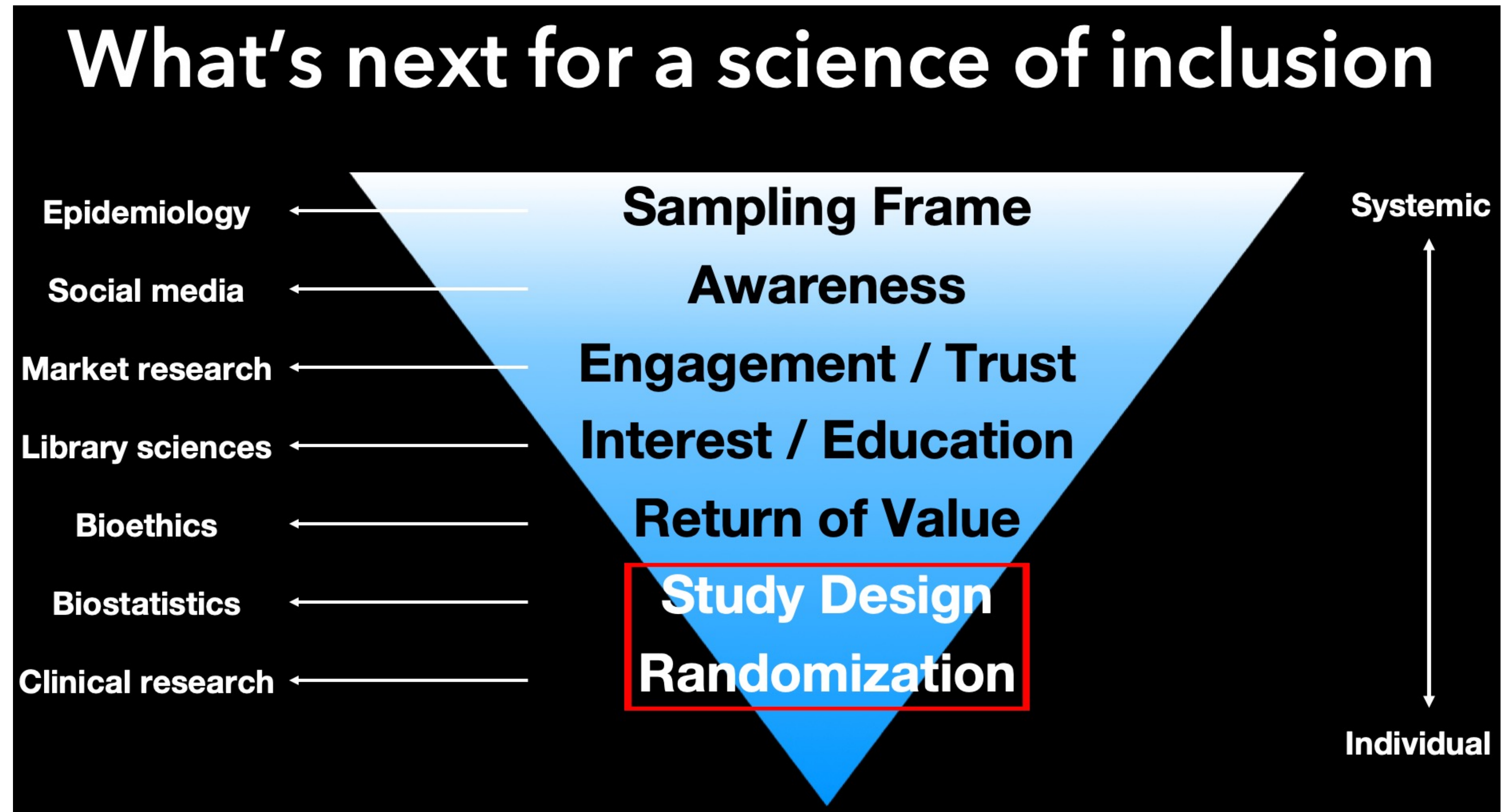


Figure 1. Mechanisms that perpetuate exclusion from aging research across intersecting levels of influence.

Gilmore-Bykovskyi A, Croff R, Glover C et al. Toward Intersectional Frameworks of Research Justice and Participation. *The Gerontologist.* July 2021

4. Prioritize equity research grounded in theories that undergird race, gender, and health.

- Example: Inclusion Science for Recruitment of Marginalized Populations into Clinical Trials – Jonathan Jackson PhD



Used with permission from Dr. Jackson

5. Embrace a goal of NIH-funded research as a tool to disrupt the default outcome of marginalized women as the secondary priority.

- Redefine innovation in cancer research to be equity-conscious
- Redefine high-risk, high-reward in cancer equity research
  - Community engagement, support, and co-leadership
- Fund Black Scientists[1]
- White is not the default human[2] – divest from the ‘control’ group fallacy
- Fund cancer equity research with more money – divest from the scarcity myth

1. Stevens, KR et al. Fund Black Scientists. *Cell* 2021 Feb 4;184(3):561-565
2. Stephanie Bray & Monica McLemore. *Frontiers in Public Health* 2021 May 24; 9:675788

A Race-Conscious Approach to Women's Cancer Research

1. Recognize that the default structure of cancer research **creates** and **exacerbates** cancer inequities for marginalized women
2. Embrace **cross-cutting approaches** that acknowledge the power and complexities of how racism influences health
3. Align funding to incentivize the study of the **unjust creation, dissemination and delivery** of cancer research knowledge.
4. Prioritize equity research **grounded in theories** on how race, gender, and health operate in our society.
5. Embrace a **goal** of NIH-funded research as **a tool to disrupt the default outcome** of marginalized women as the secondary priority.

Suggested RFA Solicitations for Gynecologic Cancer Equity

- *Quantitative and Qualitative Evaluation of Bias and Exclusion in Biomedical Cancer Research*
- *Development of multi-level Approaches to Equitable Representation of Marginalized Populations in Cancer Clinical Trials*
- *Impact of structural and interpersonal racism on outcomes in the cancer care continuum*
- *Life course approaches to evaluate gynecolgic cancer disparities among Black and Native women*
- *Interdisciplinary structural interventions to overcome expected inequity in clinical trial participation*

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Thank you!

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