"Black Bodies, Black Health: Centering Humanistic and Social Scientific Research to Identify Strategies for Disrupting Structural Racism as a Determinant of Health and Well-being"

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In December of 2021, a medical illustration of a Black fetus went viral, spawning multiple news articles and public discussions across social media among doctors and the general public.[1] The reaction was due to the rarity of medical representations of Black bodies as generalized figures for humanity, and the discussion highlighted the normalization of Whiteness within medical fields, even at the indiscriminate level of the images used in anatomy textbooks. One doctor created a Twitter poll asking others, "Have you ever seen a dark-skinned Black baby inside a pregnant mother illustrated in a medical text?"[2] Ninety-six percent of the nearly 4,000 plus respondents said no, and this was not an aberration limited to this Twitter sample. Less than 4 percent of medical texts feature illustrations of non-White bodies, as one study performed by researchers at the University of Pennsylvania has shown (Adelekun et. al 2021). This base-level of representation, or more accurately the lack thereof, has implications for who and what we see as normative, what is characterized as well and unwell, which bodies we value and which we do not. One Twitter commentator summarized the consequences of this aptly by saying, "Most of modern medicine doesn't consider anything but White men's anatomy and physiology, even

[1] Aliyah [@Liyahsworld_xo]. (2021, December 2). *I've literally never seen a black foetus illustrated, ever.* [Tweet]. Twitter. https://twitter.com/Liyahsworld_xo/status/1466463156386021385?s=20.
[2] Dr. Raven the Science Maven [@ravenscimaven]. (2021, December 3). *Have you ever seen a dark-skinned Black baby inside a pregnant mother illustrated in medical texts? Poll in the thread.* [Tweet]. Twitter. https://twitter.com/ravenscimaven/status/1466836756406300672?s=20.

today. Its structural racism that's so baked into the systems that often not even people embedded in them realize the harm they're propagating."[3]

Black Bodies, Black Health (BBBH), a one-year research project supported by the Robert Wood Johnson Foundation (RWJF), centered humanistic and social scientific fields to identify strategies needed to disrupt structural racism as a determinant of health and well-being. The project focused on articulating the racialization processes by which White bodies have become naturalized and Black bodies have been made invisible as figures of human health and well-being, and the consequences of such processes of representation. The ultimate goal was to identify various approaches foundations and related funding organizations can take to target, catalyze, and support research that focuses, both in theory and method, on disrupting a broader cultural imagination of disease that signifies Black/minority bodies as sites of disorder. The representation of Black bodies as unwell is both the result of deeply entrenched historical processes and modern discourses that has consequences for how systems and structures engage and respond to disease in ways that serve to undermine the wellbeing of Black and non-White patients.

The Historical Roots of Contemporary Health Inequity

The fact that it was Chidiebere Ibe's illustration of a Black fetus that sparked a viral conversation about the medical field's devaluation of Black bodies in the United States, is apt given the historical treatment of Black motherhood. As the 20th century dawned, so did a

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[3] Cosmic Whore-er [@liquidfox1]. (2021, December 3). *Have you ever seen a dark-skinned Black baby inside a pregnant mother illustrated in medical texts? Poll in the thread.* [Tweet]. Twitter. https://twitter.com/liquidfox1/status/1466911126390665217?s=20.

fledgling eugenics movement that aimed to mitigate societal ills (crime, poverty, and immoral acts such as promiscuity) through selective breeding. While eugenics has been discredited and most recognize the harm of designating groups as 'fit' and 'unfit', this underlying logic has continued, both insidiously and at times directly, to inform the treatment of Black mothers (Dikötter 1998). The early 20th century saw the emergence of the birth control movement. There was initially great opposition to birth control among early 20th century conservatives, but that was neutralized in part by a wider discourse that framed birth control as a means of controlling Black women's fertility, whether its use was voluntary or compulsory (McDaniel 1996; Davis 1981; Roberts 1997).

As the 20th Century continued, so did these efforts to control Black women's fertility. The massive assault on Black women's bodies has been described as the "New Jane Crow" to highlight the lack of discourse about, and the historical trajectory of, the oppression of Black women in particular (Jones and Seabrook 2017). There were many reasons for sterilizations, including population control as connected to stereotypes of Black motherhood, U.S. welfare discourse, as well as practice for medical students at local universities (Ko 2016, Thomas 1998). U.S. doctors routinely refused to deliver the babies of Black women and Medicaid recipients who had already borne two or more children unless they consented to sterilization, whereas under a concurrent practice, White and middle-class mothers who had not had 'enough' children by a given age were *refused* sterilization (Davis 1981).[4][5][1]

[4] Doctors followed a rubric known as the 'rule of 120,' in which the product of a mother's age and number of births had to equal or exceed 120 before they could be considered for sterilization. For more, see Deardorff 2014.

Black women only received legal protection from coercive sterilization after the fallout resulting from the notorious 1973 sterilization of Minnie Lee Relf, a 14-year-old Black girl in Mississippi who was first administered Depo Provera, and was subsequently surgically sterilized, after social workers noticed that boys were hanging around her house and feared Minnie might become pregnant while her family received benefits (Nelson 2003). Because these procedures—which Relf and her impoverished and illiterate parents were not fully informed of—had been paid for with federal funds, President Nixon hurriedly banned the use of such funds for the sterilization of minors and the informed consent guidelines that we consider standard today were established.

While this change sought to protect Americans from unethical treatment by requiring their consent, the practice and utility of Blacks as subjects in medical experimentation has long been exploited. Beginning in 1932, the U.S. Public Health Service recruited 662 poor rural Black sharecroppers in Macon County, Alabama, for the benefit of exploring the untreated course of syphilis, which at the time was referred to as 'bad blood' (Brandt 1978, Brown 2017). Black sharecroppers were lied to and recruited because they were seen as expendable. They were informed that they would receive treatment for 'bad blood' and free health care if they consented to the study. As of 1955, it was recorded that 30% of the participants died from the study (Brandt 1978). When penicillin was made available as an option for treating syphilis, it was denied to participants in the study (Brandt 1978). This study shockingly went on until 1972 and spanned the Jim Crow period into the Civil Rights Movement.

About eighteen years after the start of the Tuskegee syphilis study, Johns Hopkins University used the cells of Henrietta Lacks, a Black rural tobacco farmer from Virginia to create the polio vaccine, making advancements in disease research that led to the expansion of the biomedical industry (Skloot 2010). Henrietta Lacks' human cell line, referred to as HELA, was

the world's first immortal cell line to live indefinitely outside of the body and it is now bought and sold to laboratories across the nation. Cells from the cancerous tumor within her cervix were cut out months before she died from cervical cancer in 1951 without her knowledge or consent (Skloot 2010). While Lacks' cells were looked at as remarkable and prolific, as a Black woman she was treated as disposable and garnering her consent was unnecessary.

These well-known and egregious historical examples of the indiscriminate use of Black bodies and their body parts to find cures for diseases and vaccinations, has imprints on contemporary health disparities that have not been fully appreciated. Blacks were viewed as expendable, explicitly devalued, and deemed not worthy of being consulted for consent, informed of risk, and more. Denying Blacks' full humanity enabled their harsh and brutal treatment, and racism justified this intentional harm of Black life. Even today many doctors and nurses believe that Black patients have higher pain tolerance than Whites. We speak often of the deep suspicion that still characterizes the engagement of Blacks with the medical establishment today, but we do not reflect often on the practices within the American healthcare system that continue to normalize Whiteness and thereby characterize Black bodies as unwell.

The Path Forward

The deleterious effects of experiencing racism on the individual level are increasingly understood and damning—from shortened life expectancy to premature birth, racial discrimination kills (Chae et. al 2020, Braveman et. al 2021). Yet the impacts of structural racism, while acknowledged, are less understood (Gee and Ford 2011). There is a renewed call to focus on racism and abandon race, that is, to track and disrupt racial disparities but not reify differences amongst racial groups (Braveman and Dominguez 2021). While this work of envisioning disruption is not often the domain of health experts, it is the intellectual strength of

the humanities and social sciences. The Black Bodies, Black Health (BBBH) project brought together cross-disciplinary groups of experts to explore and unpack structural racism in service of creating equitable health outcomes, centering humanistic and social scientific approaches. We recognized and valued the different lens that each field brought to the study of health inequity and racism.

Humanistic scholars think about the development of age-old conceptions of race that ground population health disparities. They examine histories of this way of thinking as well as the systems that produce, reinforce, and reify this pattern of thought. Humanists make connections between the representation of health and well-being as racialized, represented in cultural forms, medical discourse, narratives of individual behavior, and emphasize the ways in which all of these contribute to both the imagination and the development of disease. The cultural representation of disease, from news media to public commentary, influences how systems and structures respond. When the origin of disease is culturally represented and understood in the public mind as rooted in individual reckless behavior, resolution requires individuals taking personal responsibility. Whereas, when the origin of disease is understood to be in the mind – deviation rooted in susceptibility, it is understood culturally as a public health challenge, which requires state investment and public sympathy. Using this lens we can see, for example, how locating the challenges of the crack epidemic as a problem of individual behavior rooted in recklessness, led to a different public response than the opioid crisis. The race of the users, predominately Black in the case of crack and often White, in the case of opioids, humanists and many others argue had everything to do with the way systems were mobilized or not to respond.

Social scientists focus often on how health disparities and differential treatment are embedded in structures and systems in the present, highlighting how an emphasis on personal

responsibility misses the systems and structures that influence and shape human behavior or differentially condition the response of the medical establishment to treat it. In contrast, a biomedical approach emphasizes physiological factors often exclusively, then aggregates to describe patterns and disparities across groups, which has led to a focus on interventions in individual behavior and typing of racial/ethnic groups as well or unwell, e.g., Black women and obesity. Physiological factors and health outcomes, however, cannot be understood absent the structural conditions that give rise to disparities across groups. We need to understand the connection between behavior and physiological outcomes, but we cannot treat behavior as the sole site of intervention. BBBH drew on the intellectual strength of the humanities and social sciences to focus on racism and envision disruption, identifying avenues for exploration and change to grapple with the structural roots of racial disparities. This strong interdisciplinary focus informed our recommendations regarding how funding programs can best intervene in supporting scholarship that aims to disrupt structural racism and increase health equity.

Insights and Research Directions

The interdisciplinary approach of Black Bodies, Black Health was exemplified in the research specialties of the project's primary investigators, a sociologist (Branch) and a literary and cultural critic and psychoanalyst (Stephens). The BBBH Steering Committee covered a range of areas of expertise including public health, family medicine, sociology and psychology, and queer and cultural studies. This group identified key lines of inquiry and illustrated the kinds of frameworks that would inform the seed grantees and shape the research insights that emerged from BBBH. For example, psychologist Luis Rivera (Rutgers-Newark) argues that precisely because the impact of structural racism is often insidious, one missing research approach is the investigation of the role of implicit bias in health inequities. He asks, how does implicit bias at

the level of where people live impact Black Americans who reside in these areas? What are the best approaches for reducing the harm of implicit bias at the level of context and environment?

Perry Halkitis, Dean of the School of Public Health at Rutgers, has led the charge in arguing for a definition of racism as a public health crisis, impacting the advancement of medicine and the policies, systems, and organizational structures that, by their very nature, perpetuate discrimination. Shawna Hudson, Professor and Research Division Chief in the Department of Family Medicine and Community Health at the Rutgers Robert Wood Johnson Medical School, recommends research that engages more fully with the science of implementation, which "engages process, actors, and actions in context and seeks to promote the adoption and integration of evidence-based practices, interventions and policies into routine health care and public health settings." As she continues: "Implementation science differs from intervention research in that it focuses testing and understanding the strategies used to implement evidence-based practices, rather than on intervention effectiveness. As we work to disrupt structural racism, we need to encourage action-based and participatory scientific practices that incorporate iterative, plan-do-study-act cycles to help us to understand and operationalize impactful interventions and processes in action."

Dawne Mouzon, a sociologist (Rutgers-New Brunswick) whose research seeks to identify and explain risk and protective factors for the physical and mental health of populations of African descent, notes a pattern in Robert Wood Johnson Foundation awards between 2005 and 2007 that focus on cultural competency interventions, such as teaching health care providers "cultural shortcuts" of race/ethnic minority groups and often implicitly identifying "culture" as the main cause of health behavior and outcomes. She draws attention instead to research on a new concept, structural competency, which emerged in 2014 from the work of Jonathan Metzl, M.D., Ph.D. (a physician, psychiatrist, and sociologist) and Helena Hansen, M.D. (a

psychiatrist). Structural competency focuses on clinical skills but identifies institutional factors and policies that shape health inequities, while offering a theoretically informed framework to design health care interventions that seek to improve both health and health care outcomes for marginalized patients. For Mouzon, the shift from cultural competency to structural competency is analogous to the recognition that structural racism, rather than interpersonal racism, is a stronger root cause of health and social inequities, and therefore a funding focus on structural competency interventions would chart an important new research direction.

Carlos Decena, a cultural and queer studies scholar in Latino and Caribbean Studies, draws from his experience with the cultural politics of HIV/AIDS to emphasize the need to stay alert to the nuances of the politics of representation when addressing all issues concerned with illness and the way it is discussed. At the nexus between humanities-based research and the questions of Blackness and health lies, he argues, both biological and population-based factors implicated in addressing health challenges as well as the materiality of the meaning-making practices of representation developed around those very problems. In other words, while remaining centered in the experience of health and illness in Black communities, he urges us also to attend substantively to how these experiences are represented, since representation often shapes the questions asked, the evidence gathered, and the solutions proposed.

From the fall of 2021 through fall 2022, an interdisciplinary team of Rutgers researchers and thought leaders, informed by a broader array of disciplinary approaches in the humanities, identified frameworks in the human and social sciences that would be productive directions for research. Through seed projects, workshops to develop a shared understanding of "race" and "disruption," and a conference with national experts on race and health equity research, BBBH identified an exciting set of research directions to think with in regard to future funding of

research, directions that can have a disruptive impact on our understanding of the impacts of structural racism on health outcomes.

Mapping Health Inequity: Project Scope and Structure

BBBH began by offering seed grants to incentivize humanists, social scientists, and biomedical researchers across Rutgers to engage in interdisciplinary work to explore and unpack structural racism in service of creating equitable health outcomes. External experts not only attended the August BBBH conference, but also, provided one-on-one feedback on position papers developed by the seed grantees. Drawing on existing research and taking a local frame grounded in New Jersey, grantees were asked to envision the work of disruption of structural racism, reimagining systems drawing from a range of fields and theoretical approaches. We were especially interested in two types of projects—humanities projects that drew the connections, historically and conceptually, between how understandings of race have directly and negatively impacted health treatments and outcomes in the United States; and social scientific or biomedical research projects that foregrounded the humanistic assumptions or implications of their work, were grounded in New Jersey, and focused on linking research in the following subject areas to broader questions of health and well-being: schools/education; poverty; child welfare; environmental justice; work/labor; housing; law enforcement, criminal justice and penal reform, all of which we envision as the structural underpinnings of health inequities.

The seed grant program had four aims: 1) to identify Rutgers faculty members whose scholarship and expertise were tied to one of the dimensions of structural racism impacting health that we aimed to explore; 2) to spur the intentional translation of field-specific knowledge and cutting-edge research on vexing questions into digestible insights for the benefit of the general public; 3) to encourage the engagement of community members in producing knowledge

on both the impact of structural racism and its solutions, incorporating humanistic and social scientific methods such as storytelling, ethnography, community curation and digital archiving; 4) to develop a position paper that outlines the research promise, avenues for interdisciplinary exploration as well as possible policy solutions or interventions to reduce structural racism in their respective area. Fifteen Rutgers faculty (representing Rutgers Biomedical and Health Sciences, New Brunswick, Newark, and Camden) were awarded seed grants and paired with an external expert, a researcher who was not in their field to promote cross-disciplinary exchange and deepen their insights. We identified four distinct clusters: Black Bodies, Physician Education, Environmental Racism, and The Carceral State that reflected the intellectual domains of the seed grantees projects.

The Black Bodies research cluster embodies and encompasses the overarching themes of the BBBH project. These projects, led by BBBH co-lead Anna Branch and her research project manager, Candace King, delve into the dynamics of performance and health. In particular, they consider how Black health and wellbeing are impacted while at work. In both projects, work is considered in both the professional and physiological context. For example, Yana Rodgers, professor in the Department of Labor Studies and Employment Relations and faculty director of the Center for Women and Work, along with members of her research team, Debra Lancaster and Sarah Small, examine the occupational crowding of Black workers into frontline industries during the pandemic. As their study finds, Black women were at a higher risk for exposure to COVID-19 due to occupational segregation. Unlike Black workers, White workers in New Jersey were able to withdraw from frontline industries at the onset of the pandemic, especially in healthcare support services. As a result, Rodgers and her team conclude, Black workers are occupationally crowded to the benefit of not only White wages, but also White health. The Black Bodies research cluster also included Peter Economou, Assistant Professor of Applied

Psychology and Director of Organizational Psychology Programs, and his research team members Alexander Gamble and Tori Glascock. Their research aims to better understand the health consequences of race-related stress (RRS) and its overall impact on Black bodies, including physiological and psychological. In particular, their study examines Black student-athletes' experiences of RRS while attending both predominantly white institutions (PWI's) and historically black colleges and universities (HBCU's). In some instances, structural racism is painted as a problem that is only *seen*, not *felt*. Both projects speak to the physiological impact of structural health disparities on Black Bodies. More concretely, both projects clearly outline the processes by which structural racism produces tangible harm in Black communities. Both the occupational and athletic arenas speak to the notion of Black performance and how Black workers and athletes are adversely affected as a result.

As previously discussed, the relationship between Black patients and the medical establishment has been quite contentious in the United States, evidenced by deep distrust in the initial response to Covid-19 vaccinations. Medical doctors shape conceptions about the body, as well as notions of harm and cure. The projects in the Physician Education research cluster, led by BBBH co-lead Michelle Stephens and Shawna Hudson, consider the relationship between patient and practitioner. For example, Pamela Brug, a medical doctor at Rutgers Robert Wood Johnson Medical School, and Juana Hutchinson Colas, an Associate Professor of Obstetrics and Gynecology, study how socioeconomic factors, such as race, ethnicity, age, sex, and gender, create compounding effects that impact the decisions patients make about their health and create a divide between patient and physician. Similarly, Johanna Schoen, professor of History, observes a related issue in her study of Black and Hispanic mothers whose children were admitted to the Neonatal Intensive Care Unit. As Schoen reports, there was a technical language barrier between the clinician and their parents which not only affected how they understood the

medical process, but also, alienated them from the physician. This technical oversight is also present in other areas of healthcare. Alexandria Bauer, Assistant Research Professor in the Center of Alcohol and Substance Abuse Studies and Applied Psychology, found this divide in the mental health sector as well. Bauer found that there were social judgements that often created a rift between mental health patients and physicians. Such stigmas, Bauer notes, have adverse effects that lead to misdiagnoses because the provider either underestimates or overexaggerates their symptoms.

Societal institutions such as the medical field and higher education are key determinants in Black health. The projects in the Physician Education research cluster confront the structural challenges within medical institutions that perpetuate Black harm. Similarly, the projects in the Carceral State research cluster, led by Dawne Mouzon, Luis Rivera, and Perry Halkitis, undertake a critical examination of the criminal justice system as a total institution. The criminal justice system has a profound impact on the health and wellbeing of people who are incarcerated as well as their families and the effects persist after release from institutionalization. These projects tackle the physiological effects of mass incarceration and police exposure. Take for instance, Lauren Lyons, a doctoral student in the Department of Philosophy, whose study unearths the longstanding effects of the criminal legal system well beyond the prison cell. Lyons connects both pre-determinants and post-effects of health from incarceration. She points out that Black people with chronic diseases and serious mental illnesses are disproportionately likely to be incarcerated, and those without may even be subjected to those traumas both during and post incarceration. Lori Hoggard, an Assistant Professor of Psychology, delved into the physiological effects of incarceration in her investigation of how police exposure is biologically embedded in a sample of African American men residing in New Jersey. African Americans are also nearly four times more likely than White Americans to be killed by police officers and are significantly more

likely than White Americans to be killed while unarmed, and significantly more likely to be the targets of non-lethal police force (e.g., taser, pepper spray). Given these facts, Hoggard views racial inequities in policing as a linchpin of racial inequities in health. Ann Bagchi, an Associate Professor in the Rutgers Business School, along with her research team members Dwight Peavy and Anna Rivera, take this approach further as they target the implicit bias within law enforcement. In addressing the stigmas that police officers harbor towards Black men and women through structural-level reforms, Bagchi and her team believe there is an opportunity to enhance equity within New Jersey's criminal justice system. However, Maxine Davis, an Assistant Professor in the School of Social Work, offers another move to address the structural racist underpinnings of policing. In her study of Intimate Partner Violence/Domestic Violence (IPV/DV), Davis re-envisions the resources necessary to overcome the systemic factors that increase risk of harm. Her recommendation draws on the strengths of Black community members' creativity rather than the use of problem centered approaches to address the social issue of IPV.

In the Physician Education and Carceral State clusters, seed grantees tackle the issue of implicit bias that perpetuates health disparities from a number of angles. The projects in the fourth and final research cluster, Environmental Racism, led by Carlos Decena, are no different. All spaces are not created equal, as studies have shown that standards of living vary by zip code, and where we live impacts how we live. These projects explore how the environment, including considerations of climate as well as other factors of space, impact health and wellbeing. A study on Black women and Breast Cancer screening led by Mei Fu, Senior Associate Dean of Nursing Research and Professor at the Rutgers–Camden (School of Nursing), and Wanda Williams, an Associate Professor of Nursing at the University of North Carolina, Greensboro (formerly of Rutgers–Camden), unveils the structural challenges that lead to health inequity. Fu, the principal

investigator of the project, and Williams uncovered place-based structural and racial determinants such as transport and childcare needs that impede Black women's access to adequate care. Fu and Williams offer a unique approach to measuring the environmental factors that perpetuate health disparities. In the same vein, Anita Bakshi, an Assistant Professor of Teaching in the Department of Landscape Architecture, advocates for researchers to consider how individual stories can help to explicate the structural roots of racial disparities and health outcomes. For example, in her study of The Ramapough Turtle Clan, Bakshi writes that The Ramapough already have knowledges about their community health and its relation to the pollution of their land. Rachel Devlin, an Associate Professor of History, also argues for more scholarly consideration of the personal history of the people native to a region. In her study of "Cancer Alley," the "chemical corridor" stretching along the Mississippi River from Baton Rouge to New Orleans, Devlin highlights the storytelling of Amos Favorite, a pollution activist. She envisions his stories as valuable historical, numerical, local, and statistical data that researchers can rely on to highlight Black experiences of living with toxic pollution.

Together, the four BBBH research clusters helped us to identify three primary challenges in the study of Black Health: 1) Studying Race: What does it mean to adequately address and attend to race within health disparities? How does race as a body of measurement, of difference, show up structurally? 2) Documenting Harm: Harm is not a "one-time" or "one-size" instance. How do we identify, catalog, and address harm in a way that not only addresses the shortcomings of the structure, but also provides specific reprieve to those affected? 3) Limitations of Researchers: Instances of gatekeeping prohibit certain research from being conducted and published and there are certain barriers to doing the work (i.e., money and time). What do researchers, and especially researchers of color, up and down the academic pipeline, need to carry out their work?

Project Findings and Initial Recommendations

The introduction to the Culture of Health Series' edited anthology, *Necessary Conversations: Understanding Racism as a Barrier to Achieving Health Equity*, begins with the plight of Jackson, Mississippi, whose residents were devastated by March 2020's record-breaking floods. This climate tragedy left inhabitants, who are predominantly Black, without safe drinking water. Two years later, Jackson is still facing a dry well from the city officials' negligence, with the Justice Department issuing a warning that "an imminent and substantial endangerment to human health exists" (Harris et. al 2022). As the nearly three yearlong battle for clean water conveys, the health inequities within Black communities like Jackson are not only pervasive, but persistent. The Black Bodies, Black Health External Expert Conference held on August 16-18, 2022 represented an effort to unpack the compounding effects that lead to inequity and to help envision a path forward to develop an ecosystem tailored to advance racial and health equity. As Robert Wood Johnson Foundation (RWJF) Chief Science Officer and Vice President of Research-Evaluation-Learning Alonzo Plough asserts in *Necessary Conversations*, "a Culture of Health is impossible without a full-bore commitment to racial equity" (xi). With this commitment in mind, seed grantees met one-on-one with external experts and their research cluster as a whole to discuss challenges and offer recommendations for agencies and foundations invested in furthering research impact in race and health equity.

General Recommendations from Cross Cluster Insights

- ***An annual Black Bodies, Black Health convening and/or active BBBH working group:*** A majority of seed grantees and external experts expressed the value of a forum, such as

BBBH and a strong interest in returning to develop their projects, while engaging with public actors on the issue of health inequity.

- ***Meeting among community and other local actors in New Jersey:*** Many felt that inviting government officials, community organizers and educators, and health physicians to the conversation might help them to benefit more directly from research that envisions anew what the future could be.
- ***Fund projects that would not only serve a scholarly purpose, but also support researchers***: There is a need for funding opportunities that are process-oriented (e.g., creating space for researchers' thinking and thinking together), that can support research projects in the early stages of conceptualization and development.

Specific Research Cluster Recommendations and Insights

Black Bodies

For the researchers working and dialoguing together in this cluster, systemic challenges to their research included: the lack of shared language in the study of Black bodies; insufficient attention paid to how race shows up structurally; and the inadequacy of systems for Black workers that have been set up to support wellbeing. Research findings included evidence of systemic oppression within athletic systems and the long-term deleterious effects of those systems on Black student athletes, including physiological markers of stress. Findings also revealed the negative effects of occupational crowding of Black workers into frontline industries during the pandemic.

To ameliorate these research and socio-historical challenges researchers called for increased funding for critical thinking spaces, that is, funding for more spaces and convenings to

think about the historical and cultural processes that produce our narratives about the Black body, and to create further opportunities for collaboration across disciplines. Researchers also argued more specifically for better financial support and comprehensive health training for athletic departments, entailing infrastructures in which athletic departments engage in educational experiences and self-reflection on how their actions and words may aid in the oppression and commodification of Black student-athletes. They also recommended funding for more targeted efforts to collect community survey data on the experiences of Black workers in essential jobs, gauging their health risks and the extent to which workplace supports alleviate those risks, including in collective bargaining, in education and training programs, and in stronger care infrastructures.

The Black Bodies research cluster focused on health inequities that occur at the margins and intersections of social identity. Black Bodies cluster participants agreed that "health" is *experienced* in a myriad of ways as it relates to harm or cure, therefore when addressing health, they argued that we must attend to the intersections of Black identity (i.e., class, sexuality, faith, etc.). To examine these theoretical ideas in practice, participants were interested in developing shared language across disciplines and breaking down silos across fields such as Economics, Biostatistics, Public Health, and Sociology. For example, Social and Behavioral Sciences (Economics and Sociology) widely use "time use surveys" to highlight the unequal burden that women bear for the second shift in the home using real time information on the activities of men and women to document gender inequality. Public Health/Biostatistics researchers widely use "ecological measurement assessment" to gather real-time information on health behavior. Economist Yana Rodgers and external expert Stephanie Cook had an enlightening conversation when they realized the potential of linking these two data forms in future data collection strategies to make the structural impact of health inequity more visible. The discovery of such

methodological affinities across disciplines might offer useful frameworks for understanding health at the margins.

The participants reflected on a number of barriers and blind spots that researchers face while carrying out their work, one of which includes gatekeeping and funding. Creating funding incentives for scholars to carry out interdisciplinary work on health disparities is crucial, as field stretching innovations are not often encouraged on the tenure track and beyond. Critical insights into our understanding of the impact of racism on health at the structural and system level, occur when we invest and spend time in dialogue to understand our disciplinary lanes and purposefully push the boundaries. More opportunities for disciplines to engage with one another in the interest of disrupting health disparities across multiple domains would be immensely beneficial for the field. As disciplines come together to address pressing issues, we can better engage public actors, organizations, and health practitioners to collectively advance change.

Physician Education

Researchers found that certain systemic challenges set the context for the inadequate education of physicians and health care professionals in understanding the relationships between racism and health care equity. Minority access to proper healthcare, sub-par care received by many members of ethnic minority populations, barriers for minorities to seeking healthcare as a profession, and "one-size fits all" and colorblind approaches to care, all negatively impacted patients of color and their relationships to the medical and health care industry.

Researchers called strongly for comprehensive training for healthcare providers to recognize the non-monolithic nature of the populations that they serve. They also called for increased support for Black clinicians on the pathway and retention pipeline into the medical field—beginning in elementary school, well before traditional high school and college prep

programs. Such initiatives would show communities that the health care and public health work opportunities and center on making other clinical tracks, beyond the M.D., visible as options for Black youth (e.g., Nursing, Physician Assistants, Social Work, Behavioral Health, etc.). Researchers also felt that there was a strong need for community engagement and participatory action-based research. We should be addressing community, patient and healthcare system research needs by advancing research designs that move beyond traditional approaches currently valued in many fields (i.e., hypothesis driven and RCT studies).

Overall, the participants in the Physician Education research cluster recommended shifting the discussion of and research approaches to health care in the United States from the purely biomedical to the biopsychosocial. Such an approach will require that providers, particularly medical providers, attend to the psychological, psychosocial, social, and structural factors that shape help in the delivery of service. Attending to health in this manner will in turn empower patients to speak openly about their life experiences, including the experiences of systemic racism that adversely affect their health and well-being. In order to enact change in the health disparities noted across populations that are marginalized and oppressed, there must be ongoing and consistent training for providers during their disciplinary studies, including but not limited to open and clear conversations about implicit biases and serotype threat.

It was also suggested that there must be an ongoing effort to create avenues for racial minorities to pursue healthcare as a profession. This not only requires addressing the economic disparities faced by members of racial minority groups, but also, shifting the sensibilities and assumptions of the health professions, particularly medicine, to the paradigm reviewed above that disparages the Black body. With regard to research, efforts must be undertaken to develop and test interventions that support health equity. It was clear that there is a substantive body of literature on health disparities across race. While documenting these disparities has been key, it

is imperative that the dialogue shift to enacting health inequity. This entails studies that move beyond the overly simplistic delineation of disparities across demographic states, including but not limited to race.

The Carceral State

For the researchers in this cluster, systemic challenges included Black hypervisibility in the criminal justice system and in fatal encounters with police, the direct and indirect consequences of the criminal legal system on incarcerated people and their families (such as the interruption of education, the strain on family networks, and destabilizing housing), and a policymaking process that inflicts trauma and stress on the wider community.

To address these challenges and based on their studies, researchers recommended more effective training for police officers to mitigate implicit bias within the criminal justice system, building better data to avoid overreliance on racial statistics and the reification of differences between racial groups, and investing in community empowerment models so that affected communities have a voice in the process, with creative community designed and led solutions that offer specific interventions as opposed to "one-size" approaches. Funding research studies that explore other systems of social support (i.e., the provisions of housing, food, healthcare, etc. to disrupt the root causes of crime and structural injustice/racism) was determined to be key, in addition to funding for research that evaluates policy to address the need for racial impact assessments for all new and existing legislation. Research must be prioritized that evaluates specific interventions (i.e., policies, programs, practices) that have the potential to counteract the harms of structural racism and improve health, well-being, and equity outcomes.

This research cluster engaged in a lively discussion about how funding agencies should change their funding priorities. For example, for community-based participatory research, they should expand their notion of who is a "legitimate researcher" (such as funding community members/organizations to collect their own big data because they are experts in their own right). Research should be done "Not about us without us," a key phrase used to justify the need for true community partnership. Participants also shared the need for funding projects that allow space for thinking, amplifying the need above for developing funding opportunities that are process-oriented (e.g., collaborative development), as opposed to fully developed research projects. Participants shared the ethos that it was "necessary to yield creative disruption." Research is not just science, it also about other types of production as well. Most participants acknowledged that this is also a constraint in their own disciplines and institutions (i.e., the thinking process is not prioritized in terms of tenure and/or promotion). One external expert called for the funding of future "thought leaders" and encouraged more "thought leadership systems."

Environmental Racism

In the research area of environmental racism, especially as pertaining to communities and women of color, systemic challenges include: the healthcare barriers related to place-based structural and racial determinants; as well as a lack of support by major national agencies that currently do not support, for example, breast self-examination (BSE); uncomfortable mammogram procedures that induce pain and tenderness coupled with some Black women patients, who found their technicians to be unpleasant and uncaring, can discourage preventive screenings. The lack of forums for community stories to be told and heard compounds the physical harm and illnesses community members live with.

To address and disrupt these challenges, researchers recommended mitigating environmental barriers to healthcare access by meeting needs and alleviating hardships, such as transportation, childcare, and extending hours of mammogram screening on evenings and weekends for Black and minority women. Researchers described the need for ongoing education and encouragement of breast self-examinations among Black women. Expanding the definition of data would allow researchers to look for "measurements" in atypical patient accounts that fall outside of those provided by the medical establishment and agencies like the CDC, such as native storytelling. Research that prioritizes local voices, how local and community stories can help to explicate the structural roots of racial disparities and health outcomes, would be an important new direction in health disparities research.

The discussion of The Ramapough Lunaape Nation Turtle Clan's projects in particular, concerning their resignifications of food sovereignty and relationship to land in the context of environmental degradation, offered an opportunity for a wide-ranging discussion of cultural politics and expressive praxis in relation to shifting views and political work in health in indigenous and Black communities. A dimension of the "public-facing" nature of this work was demonstrated in how the researchers accompanied The Turtle Clan's efforts to generate alternative histories, representations, and claims related to their lands and how they link land contamination to the illnesses they experience. While it remains important to question and challenge the power-laden interactions shaping the research encounter, the conversation generated by this project put a stronger emphasis on the value that research can have in producing resources for communities actively engaged in cultural struggle. Thus, what is being reimagined here is not just research as "public-facing" work but the function of research in community. Rejecting an extractive ethos, work of this kind instead turns into the production artifacts that the community can mobilize in their efforts to raise awareness and combat

environmental degradation. Interaction with the grantees, their mentors, and members of other clusters brought attention to the possibility that what we are incubating, collectively, is a different way to imagine the function of research.

Insights from the Research Process

BBBH began with a simple question on research process: What would we learn from bringing humanists, social scientists, and biomedical researchers to the table to explore, unpack, and disrupt structural racism in service of creating equitable health outcomes? What would a just racial future require to remediate the imprints of the past in the structures of our present? The structure of interaction around these research questions, framings, findings, and next steps was, itself, an original creation emerging from this process. In most grant/grantee settings, funds are disbursed with the expectation of a product and perhaps some "check points" with program officers. The fact that this process was structured with a "heavier hand," so to speak, with seed grantees required to be in substantive engagement with the leaders of the project, with external experts, and with each other, created something of much greater value.

In the three-day August conference, for example, the question of "tenderness" in the treatment of Black women in breast cancer screening encounters produced a conversation that extended far beyond the feedback the seed grantee received. Together, the participants of the cluster conversation touched on questions of the clinical encounter itself, how it is embedded (or not) in communities of care, how Black women experience the biomedical encounter as alienating both as racialized and classed subjects in Camden, New Jersey, and how we factor in the "local" in thinking about race and health. As the discussion spread over the two days of the meeting, the cluster came back to these points with additional insights and questions for the researchers, and many noted just how rare it is to have research in progress treated in this way.

Other key insights emerged from the process overall. One constant topic over the course of this research process was how to study race in a way that moves away from reifying race. Reimagining race at the individual level (interpersonal perceptions of race and experiences with racism), and at a structural level (involving both racist systems and histories) revealed the power of research questions and approaches in which these two factors are not held as mutually exclusive. To reimagine race, one cannot isolate the individual from the places and communities in which they live and work. Places are imbued with systems, including those that are racist and racializing, but they are also imbued with racist individuals from high status groups who create, maintain, and protect the systems. How do you deploy race and disrupt racism without simultaneously reifying race in both individuals and systems? One important outcome of the BBBH project has been this understanding of the necessary intersection between individuals and places, and its broader implications for health inequities. To reimagine race and its effect on Black bodies and Black health, scholarship and research should adopt intersectional approaches.

Another topic emerged as grantees grappled with the operationalization and measurement of race, particularly in some of their disciplines. What are we talking about when we refer to race, racism, and even systemic racism? How does one measure race and racism today when the demography of the United States is changing so rapidly? Most individuals are comfortable with identifying with prevailing racial categories, but do these racial categories "accurately" represent the individuals who fall into them? How do we disrupt these long-standing categories that often hinder our understanding of Black bodies and Black health? These questions are particularly significant in the carceral state, where justice-involved individuals are often seen through a racialized lens (i.e., the racialization of bodies), undermining the basic humanity of these same individuals. How do we measure race in the carceral state to achieve a just future?

Community was another theme that often came up in cluster discussions. What roles do community and the community play, if any, in the effect of the carceral state on Black bodies and Black health? Do communities that are affected by system racism understand that racism is a key barrier to leveraging their strengths to problem solve? Clearly communities need to be engaged, but how do we move a community from cohesion to mobilization to effect change in the carceral state? How does a community make the case of race and racism to policymakers, and influence equitable policy? Should communities hold the carceral state accountable or responsible? The carceral state is supposed to be a space of rehabilitation, but one sense emerging from this project is that this is less possible when community involvement and initiatives are not encouraged.

Over the course of two workshops and a conference with external experts, the BBBH leads, steering committee, and seed grantees came to a shared internal understanding of the goals, challenges and possibilities of our work together. Overall, an important takeaway of the BBBH experience was the value of this kind of intellectual stewardship as crucial to the "incubation" of research on racialized health disparities.

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Appendix

The first BBBH workshop focused on developing a shared vocabulary of race across fields and the second identified themes and introduced field vexing questions that emerged from the respective seed projects. The workshops were followed by an external expert conference that aimed to tell a crosscutting story of the BBBH project privileging four factors: the centering of the black body; tracing the history of cultural representations of the Black body in European and American culture; defining structural racism as itself a public health issue; and mapping the geographical determinants of race and health outcomes as a question of value. We used a graphical illustrator to visually capture key ideas in real time. The graphical illustrations recorded by our sketch effect artist, Joe Watkins, and generated from these convenings are included in this appendix.

The first illustration captures the seed grantees' descriptions and discussions of their conceptualizations of their projects. A continuous point of discussion in the second workshop, and throughout the BBBH project, was the conceptualization of disruption. What does disruption mean and how useful is the word disruption? The unresolved tension between reimagining and reifying race emerged as central to the goal of disruption.

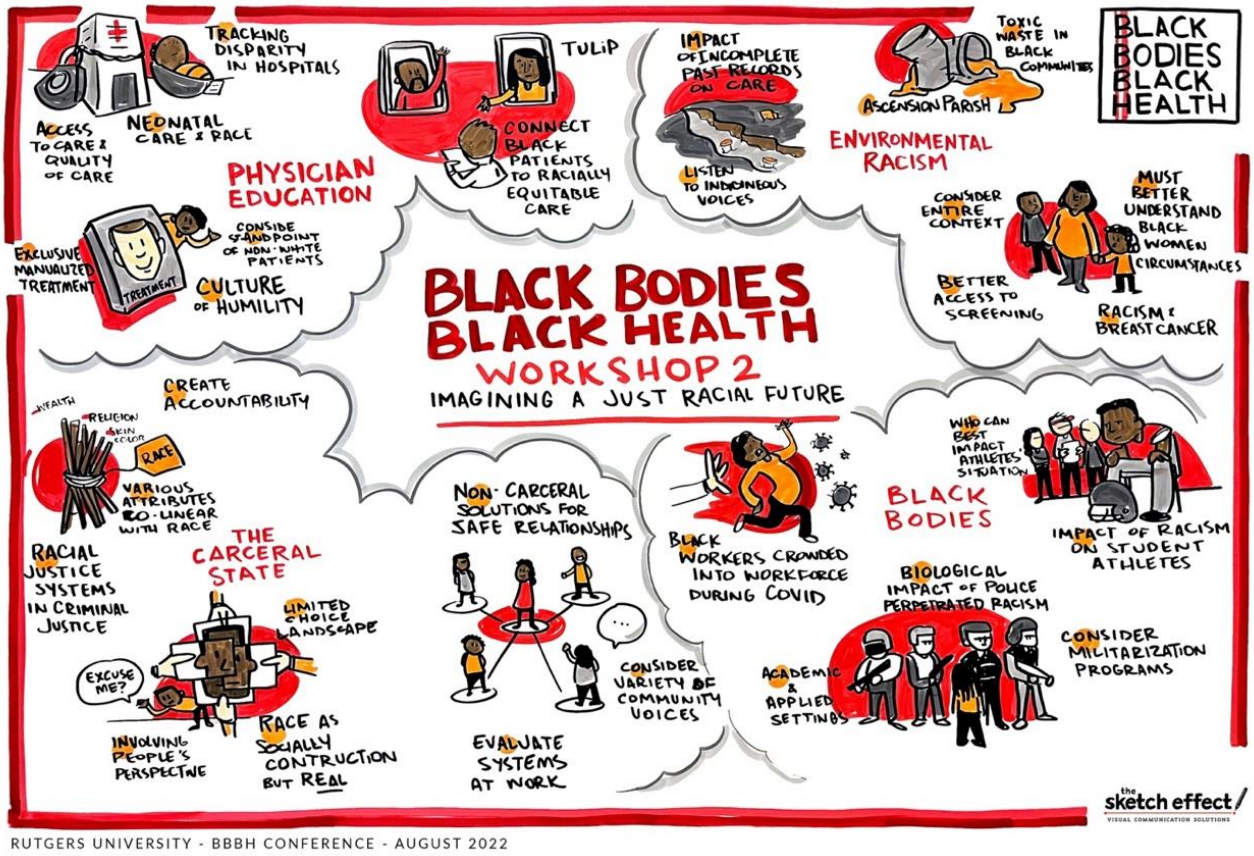

Figure 1. Second BBBH Workshop on disruption[2]

The remaining graphical illustrations were generated from four prompting talks held as part of the external expert conference. They highlight takeaways from the opening address by project co-leads Drs. Anna Branch and Michelle Stephens, a presidential keynote by Rutgers President Dr. Jonathan S. Holloway, a presentation on the narrative origins of the disparate treatment of Black bodies by Associate Professor of English, Dr. Patricia Akhimie, and a presentation on how

[2] The graphical illustrator from the BBBH external expert workshop used a video recording to create this image.

racism and structural racism undermine the public health by Dean of the School of Public Health, Dr. Perry Halkitis.

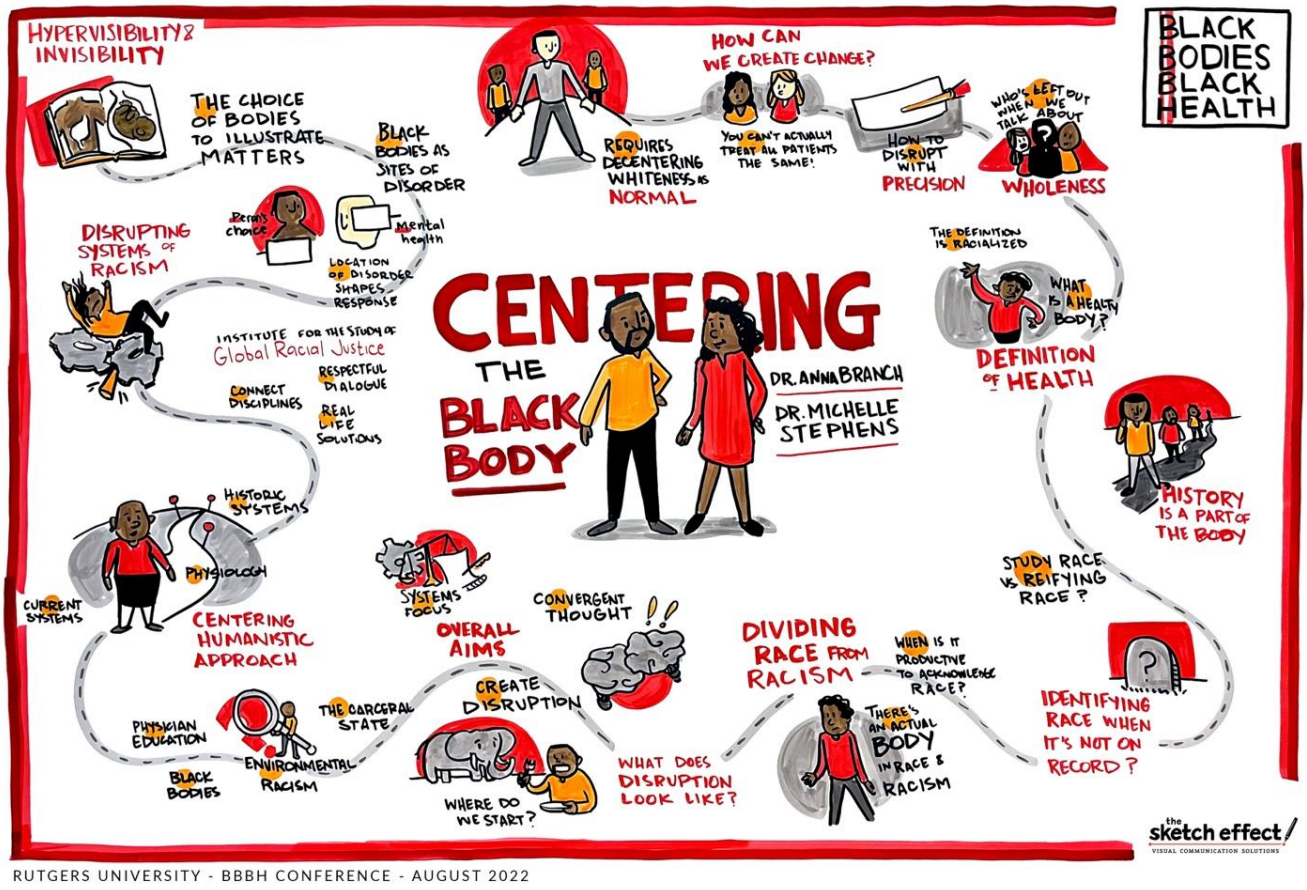

Figure 2. Drs. Branch and Stephens opening prompting talk at external expert conference

Figure 3. Prompting talk by Dr. Patricia Akhimie

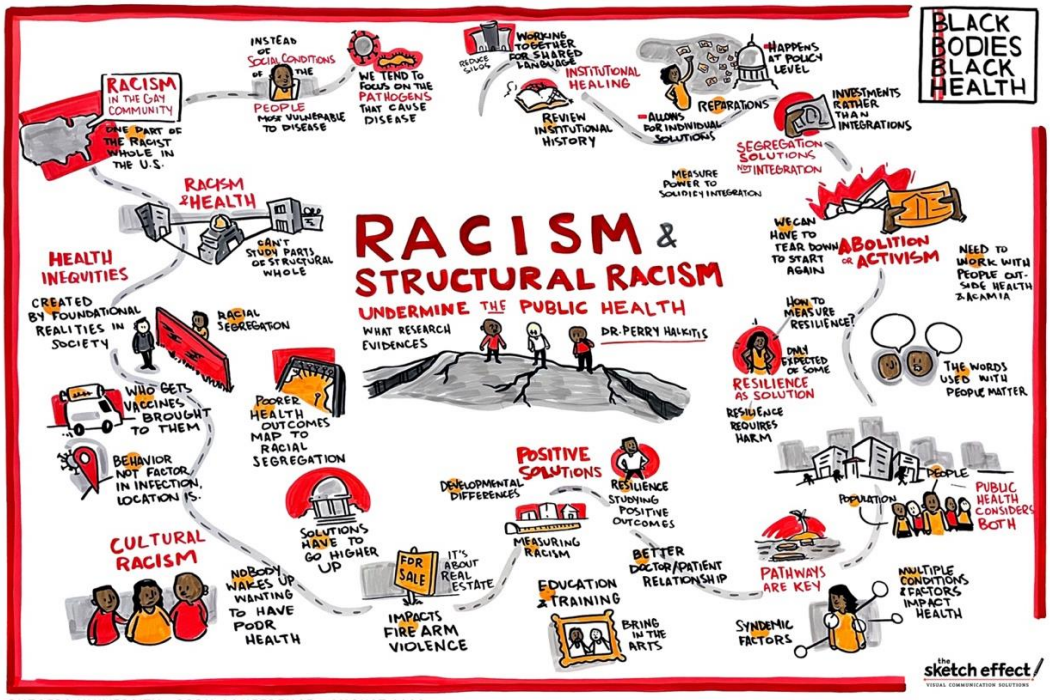

Figure 4. Prompting talk by Dean Perry Halkitis

Figure 5. Presidential keynote by Dr. Jonathan S. Holloway

All prompting talks including the presidential keynote at the BBBH Conference were recorded and publicly available for viewing on demand on the ISGRJ website. To access the full conversation, please review the following link on our YouTube page:

https://www.youtube.com/watch?v=2584YapyiHg