

Addressing Anti-Black Racism A Bioethics Call to Action

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THE PROBLEM

The United States is a deeply and increasingly <u>unequal nation</u>:

- Economic inequality was more pronounced at the beginning of 2020 than 50 years ago, with wealth concentration levels not seen in almost a century.
- A <u>2017 United Nations report</u> found that the U.S. had the highest incarceration rate in the world and the highest youth poverty rate among <u>Organisation for Economic</u> <u>Cooperation and Development nations.</u>
- Health inequalities in the U.S. are among the largest in the world.

These inequalities disproportionately affect Black and brown people:

- Black women in America are three times more likely than White women to <u>die</u> in pregnancy or childbirth.
- Young Black people are nine times more likely to be <u>victims of homicide</u> compared to their White counterparts.
- Middle-aged Black Americans are 50 percent more likely than White Americans to have high blood pressure and other chronic health conditions.
- Each of these grim statistics has persisted or worsened during the <u>Covid pandemic</u>, which has disproportionately infected and killed the nation's Black, Latinx, and Indigenous people.

Racism, not race, is a fundamental cause of these inequities.

BIOETHICS MUST ACT TO ADDRESS ANTI-BLACK RACISM

In the face of persistent and worsening injustices and suffering caused by racism, bioethics scholars, researchers, educators, and practitioners must act. Why bioethics?

- Anti-Black racism and its effects are a bioethics issue:
 - Anti-Black racism poses a serious threat to individual and public health, is a barrier to the delivery of quality health care, and is an impediment to scientific research—it affects the areas of human activity around which the field of bioethics has coalesced.

- Yet over its 50-year history, bioethics as a field has remained largely silent on issues of racial injustice.
- The existence of such stark inequities and health disparities caused by racism is an *ethical* problem: it violates tenets of social contractarian thinking, impedes the marginalized from fully reaping societal benefits despite bearing social burden, undercuts the principle of beneficence, and is deeply unjust.
- Bioethics includes among its founding principles a commitment to justice, and bioethicists understand the ways in which health and justice are connected.
 - Yet, for 50 years, bioethics has focused primarily on injustices that occur in individual health decisions and access to health care. The field has paid insufficient attention to epistemological and structural racial injustices in medicine and society and to the scholars working on these issues, even though research shows that these justice-related problems have a larger influence on the health and well-being of individuals and communities.

Bioethicists have the skills:

- Bioethics is arguably one of the most disciplinary-rich fields and is well-suited to tackle complex, multifaceted problems.
- The <u>skills bioethicists possess</u> in, for example, conflict resolution, mediation, negotiation, facilitating public engagement, and policy analysis can help foster agreement on better public health and policy strategies for addressing health inequities.
- Bioethicists have been working on these issues:
 - Black and brown bioethicists have worked on these issues for <u>decades</u>, developing evidence, expertise, and insights.
 - Yet for too long, bioethics as a field has disregarded the voices of Black and brown bioethicists. They have not been included or credited with writing, for decades, on topics that identify structural racism as a primary driver of health inequities.

Bioethics has influence:

- Bioethics is at the <u>nexus of and has influence in</u> many <u>disciplines</u> that directly impact health equity, including medicine, nursing, law, science, public health, and health policy.
- Bioethics has significant and growing influence on many of the factors that directly impact health equity: the development of policy, the conduct of research, the training of health care providers, and the delivery of health care.

WHAT MUST BE DONE?

Despite a recent shift in bioethics toward examining the social determinants of health, including racism—a shift that the Covid-19 pandemic glaringly brought to the fore—bioethics must do more. Bold and lasting change is needed.

Bioethics leaders, researchers, scholars, and educators must:

• Listen:

- Open spaces to bioethicists and other scholars of color and respect how Black bioethicists choose to engage in this work.
 - Bioethics cannot proceed without some in the field taking a step back and allowing Black bioethicists to contribute without feeling pressured to be the spokespersons for all minority issues.
- Become familiar with voices in the field that, for too long, have been marginalized or <u>ignored</u>. Acknowledge the historical importance to the field of bioethics of work of bioethicists of color addressing issues of racism. (Scholarship led by bioethics scholars regarding race and racism is not new!)

Learn:

- Read research and scholarship that explicates and illustrates the connection between justice and health, including historical explorations of structural racism.
- Understand the harm that is anti-Black racism and the connection between racism and human health and well-being. Do the ethical work of explaining why racism is wrong.
- Understand that structural racism exists in and impacts the field of bioethics.
- Read, cite, and teach the work of scholars of color as a standard practice.
- Commit to changing the field of bioethics:
 - Gather data on the racial and ethnic composition of people working in the field of bioethics, and <u>develop metrics</u> to measure improvement and success, including the numbers of Black people and other minorities in the field, especially in leadership positions.
 - Train, mentor, promote, and <u>elevate bioethicists of color</u>, including to leadership positions in the field.
 - Invest in the success of bioethicists of color through mentorship, scholarships, and fellowships at the undergraduate, graduate, postdoctoral, and assistant professor levels.
 - Use the field's social and cultural capital in medicine, public health, and policy to help remediate racial and ethnic health inequities.
 - Advocate for policies to address inequalities, such as universal health insurance, significantly increased minimum wage, and universal social assistance programs like paid family leave.

CHANGE IN BIOETHICS SCHOLARSHIP AND EDUCATION

- Change the focus of bioethics scholarship and education:
 - Put minoritized people at the center of bioethics scholarship.
 - E.g.: Prioritize Black people, Black women, and other traditionally marginalized persons the norm in bioethical analyses.
 - Engage with and learn from <u>Black activists</u>.

- Move beyond a focus on individuals to investigate structures and systems, investigating racism-related topics that impact health, such as:
 - Mass incarceration
 - Maternal mortality
 - Bias, discrimination, and anti-Black racism in health care settings.
- Give due consideration to the causal role of <u>structural racism</u> and its accumulating effects on the health and well-being of people of color.
- Commit to the inclusion and engagement in scholarship and education of bioethicists of color who have written on topics that identify structural racism as a primary driver of health inequities.
- Commit to the integration and application of interdisciplinary scholarship, frameworks, and methodologies from justice-orientated fields.
- Work to operationalize racial justice in the same way that bioethics has worked to operationalize respect for autonomy through the mechanism of informed consent. For instance, ask such questions as:
 - What is racism? What is anti-Black racism? Why is racism wrong, ethically?
 - The connections between racism and the stifling of human health and wellbeing, and the ethical implications of these connections, need to be explicit in bioethical analyses.
 - What are apt responses to racism, including anti-Black racism? For instance, which forms of individual conduct, political activism, public policy, or institutional reform aimed at countering racism and its effects are justified, permissible, or praiseworthy.
- Begin scholarship with a commitment to being responsible to the communities that will be affected by the findings and analyses.
 - Add community and stakeholder voices and involvement to inform bioethics research priorities.
- Prioritize anti-Black racism as a central concern in bioethics scholarship, including in bioethics encyclopedias and other reference works.
- Expand ethics education to include the history of racism, from colonial times to the present.

CHANGE IN HEALTH CARE AND EDUCATION

Because bioethics has influence and involvement in health care and medical education, the field has opportunities to identify and address anti-Black racism in the delivery health care and the education of health practitioners.

- Health care providers have a fiduciary obligation to "do no harm," yet too often fail to recognize the harm that can be done by racism in medicine. <u>Bioethics can</u>:
 - Help providers and institutions acknowledge the role of medicine's racist past and present in harming Black people.

- Help providers and students understand that while the cycle of anti-Black racism may have originated in the past, every clinical encounter is an opportunity for repair.
- Advocate for revisions of professional codes of ethics and other policies to squarely face the reality that racism impacts health care and health outcomes.
- Help health care providers recognize how individual treatment decisions are influenced by racism.
- Advocate for policies and practices that increase the number of Black and brown health care providers.
 - Facilitate patients' opportunities and requests to be cared for by clinicians who share their race.
- Work to change aspects of medical education that assume White bodies are the norm.
- Help hold professional organizations, including the American Medical Association and the U.S. Centers for Disease Control and Prevention, <u>accountable</u> for their recent commitments to addressing racism in clinical and public health.
- Apply analytic and practical <u>skills</u> developed in bioethics, for example, conflict resolution, mediation, negotiation, facilitating public engagement, and policy analysis, to help foster agreement on public health and policy strategies to address health inequities.
- Reframe the question, Why don't Black people trust medicine?
 - This question suggests that there is something inherently wrong with Black people, rather than something inherently wrong with the systemic conditions that perpetuate adverse health and quality-of-life risks and outcomes among Black people. <u>Deemphasize blame</u>: asking why Black people mistrust medicine blames and shames those most affected by health inequities.
 - Instead, help institutions, providers, and students understand that the <u>real</u>
 <u>problem</u> is the history in the U.S. of structural and scientific racism demonstrates
 a lack of respect for Black bodies.
 - Acknowledge that health care institutions have played a role in this history and therefore in fostering mistrust.
 - Acknowledge that hesitancy and mistrust from Black patients are a normal response to this history.
 - Reframe the language of mistrust/distrust and focus on institutional trustworthiness.
 - Emphasize connections between trust and societal change. Absent concerted efforts to bring about a more just society, efforts at building trust in health care will not succeed.
 - <u>Ask instead</u>: In what ways is biomedicine failing Black people? How can we work together to transform systems of research and care to better meet Black patients' needs? How can medicine help eliminate racism?
- Focus community engagement not on the needs of biomedicine, but on understanding the priorities, needs, and values of different communities through sustained, nontransactional relationships.

CHANGE IN HEALTH-RELATED RESEARCH

Because bioethics has influence and involvement in a range of different kinds of health-related research, the field has opportunities to identify and address anti-Black racism in the design and conduct of research. For example:

- Acknowledge that structural racism and related power imbalances have greatly contributed to <u>the marginalization and exclusion</u> of Black scholars within health equity and other health-related research.
- Support the inclusion of Black researchers <u>in positions of power</u> throughout each phase of the research process, including in decisions about funding and research priorities, as well as the conduct of the research itself, because inclusion:
 - Improves the research (the lived experiences of Black researchers can be invaluable in shaping health-related research, starting with the questions bioethicists seek to answer in their work).
 - Addresses mistrust by increasing the visibility of trusted sources among Black populations.
 - Directly addresses anti-Black racism within the research enterprise itself.
- When designing studies, consider:
 - o Gathering community and stakeholder perspectives to focus research questions.
 - Addressing the root causes of health inequity (including, structural anti-Black racism) rather than its symptoms (such as medical mistrust).
 - <u>Center Black people</u>, including <u>Black women</u>, and avoid examinations that compare and contrast vulnerable populations to the experiences and outcomes of White populations.
 - Supporting the use of <u>empirical methods using an antiracist lens</u> to describe, clarify, and understand intersectional experiences of stigma and amplify the promotion of change.

ATTTRIBUTES NEEDED FOR CHANGE

- Courage:
 - Beyond technical expertise this work will require a kind of courage that Stephen Sodeke, a senior Black bioethicist, describes as moral courage to engender real change. <u>Bioethicists</u> must move from being silent allies to upholding and uplifting the values of justice and respect for all persons.
- Internal transformation:
 - As Alice Walker reminds us, "We will be really misled if we think we can change society without changing ourselves." To <u>transform the field of bioethics</u>, "we must do the inner work needed to cultivate an antiracism ethos and to generate the collective social and political will within the field to address the systemic issues surrounding racism and health."
- Solidarity:

 The formation and dissemination of this special report was and remains a call for solidarity among bioethicists. It is <u>a calling</u> for non-Black bioethicists to bear witness to and amplify the work of Black scholars.