

Addressing Anti-Black Racism in Bioethics: *Responding to the Call*

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In the 1962 essay “As Much Truth as One Can Bear,” a manifesto written to literary artists about their role during times of social and political upheaval, the novelist, playwright, and social critic James Baldwin declared, “We are the generation that must throw everything into the endeavor to remake America into what we say we want it to be. Without this endeavor, we will perish.... Not everything that is faced can be changed; but nothing can be changed until it is faced.”¹ Baldwin’s plea still speaks to us. For those of us in the field of bioethics who recognize that racism continues to affect every aspect of our collective life, including our work in the field, it is every bit as relevant now as it was six decades ago, before bioethics had begun.²

As an academic field concerned with health and health care issues, particularly the influence of structures, policies, practices, and norms on conditions that unfairly advantage some and disadvantage others throughout society,³ bioethics has a moral and ethical responsibility to respond to the long-standing intergenerational challenges that racism has posed to the overall health and well-being of Black, Indigenous, Latinx, and other people of color.⁴ Bioethics is arguably one of the most disciplinary-rich fields, comprising scholars with pedagogical and methodological expertise in many areas critical to advancing equity in health and health care—including medicine, nursing, law, science and technology, public health, health policy, theology, philosophy, and other humanities.⁵ Bioethicists are therefore uniquely positioned to lead antiracism efforts and shape the contours of dis-

course and practice,⁶ yet the field has largely remained silent on issues of racial injustice.⁷ Such silence is deafening and represents a systemic failure to face the challenge that Baldwin so prophetically described. Beyond technical expertise, however, this work will require a kind of disposition that Stephen Sodeke describes as moral courage to engender real change.⁸ As social activist, writer, and poet Alice Walker reminds us, “We will be really misled if we think we can change society without changing ourselves.”⁹ If we bioethicists seek to transform the field of bioethics, we must do the inner work needed to cultivate an antiracism ethos¹⁰ and to generate the collective social and political will within the field to address the systemic issues surrounding racism and health.

To highlight this persistent problem, a plenary session at the 2019 annual meeting of the American Society for Bioethics and Humanities brought long-standing issues of racism and health justice to the ASBH national stage.¹¹ The session was organized and supported by The Hastings Center as part of its fiftieth anniversary celebration and as an element in an antiracism initiative it had begun,¹² in collaboration with the ASBH Race & Culture/Ethnicity (RACE) affinity group. The RACE affinity group was founded in 1999 by Claretta Y. Dupree to enhance opportunities for collaboration, mutual support, networking, and mentoring among Black scholars working in bioethics and health care. The session, titled “What Does Justice Require of Bioethics? Moving Our Field Forward,” featured an address by Mary T. Bassett, with remarks offered by Marion Danis and one of us, Virginia A. Brown. Bassett challenged bioethics to address injustices in mass incarceration and maternal mortality and other well-documented health inequities that disproportionately burden communities of color.¹³

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Bassett, Danis, and Brown collectively called on bioethicists to redress several oversights in the field's work:

- lack of attention to the ethical and moral obligation to address structural racism;¹⁴
- lack of due consideration to the role of structural racism and its accumulating effects on the health and well-being of people of color;
- lack of inclusion, engagement, and ethically appropriate crediting¹⁵ of bioethicists of color who have historically written on topics that identify structural racism as a primary driver of health inequities; and
- lack of integration and application of interdisciplinary scholarship, frameworks, and methodologies from justice-orientated fields to inform a braver, bolder, and broader bioethics—one that specializes in examining, critiquing, and addressing the intrapersonal, interpersonal, institutional, and structural forces that drive unequal patterns of disadvantage among minoritized populations.

This 2019 plenary session and its call to action echoed similar calls by prominent Black scholars, tracing back to the early 1970s, that expressed the moral and professional urgency of both addressing racism within the field of bioethics and treating it as an issue for the work of bioethics. Well-documented examples of such antiracist progress on a national stage include Patricia A. King's 1974 appointment to and her work on the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, the commission widely recognized for producing *The Belmont Report*.¹⁶ This report, finally demanded in the wake of the U.S. Public Health Service Syphilis Study at Tuskegee, defined ethical guidelines for research with human subjects. Twenty-two years later, Vanessa Northington Gamble would lead the movement for the presidential apology for the "longest nontherapeutic experiment on human beings" when she successfully chaired the Tuskegee Syphilis Study Legacy Committee.¹⁷ The work of the legacy committee resulted in a formal apology, proffered by then President Clinton, for the betrayal by the United States Public Health Services. It also led to the establishment of the National Center for Bioethics in Research and Health Care at Tuskegee University.¹⁸ In 1999, Marian Gray Secundy was appointed as the director of this center, making her the first Black American to direct a federally funded bioethics center in the United States.¹⁹ These remarkable contributions and accomplishments undoubtedly influenced the direction of bioethics, yet this work remains largely unrecognized within a field

whose discourse, practice, and priorities are dominated by White-majority thought.

In July 2005, in perhaps one of the first organized efforts to strengthen the network of Black bioethicists and develop a concrete action plan to advance bioethical issues, Tuskegee University's National Center for Bioethics in Research and Health Care convened and sponsored a meeting, "Creating a Black Agenda in Bioethics," on the university's historic campus.²⁰ The majority of the attendees at this invitation-only meeting were either nationally recognized or emerging bioethics scholars committed to advancing a social justice agenda. Under the leadership of

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There is a critical need to address the structural and systemic forces that perpetuate a nondiverse bioethics workforce and that otherwise prevent the identification, recruitment, retention, recognition, and advancement of Black bioethicists.

Gamble, who had succeeded Secundy as director of this bioethics center in 2004, approximately thirty-five scholars²¹ engaged in collective and interactive dialogue around the following questions: (a) “What are the current topics and areas that Black bioethicists are tackling? What are we missing?” (b) “How can Black bioethicists become more visible in the multiple discussions and activities around bioethics that are relative to the Black community?” (c) “How do we nurture and support Black bioethicists?”²²

The meeting highlighted the unique role of Black bioethicists in working to transform the field of bioethics and to aid in the struggle against racism. Indeed, many of the same issues and tensions that we grapple with today as Black bioethicists engaged in social justice work in historically White institutions and spaces were highlighted by the scholars attending this historic meeting: lack of diverse perspectives and topics in mainstream bioethics, narrow disciplinary focus and methodology, liberal color-blindness, lack of community voice and involvement to inform bioethics priorities, and the embeddedness and pervasiveness of structural racism in the field of bioethics.

A Call to Transform Bioethics

In this special report, *A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue*, which tries once again, almost sixteen years after the Tuskegee meeting, to create an agenda to address anti-Black racism, we bring that historic gathering of predominately Black bioethicists to the forefront for several reasons. First, we wish to emphasize that scholarship led by bioethics scholars regarding race and racism is not new,²³ even though the work regarding race and racism in bioethics, led primarily by Black bioethicists, has often been made invisible by systems and structures (for example, through a lack of funding or a lack of recognition as “scholarly”) that deemed this type of scholarship as “ancillary to the real work of bioethics,” as one of the essays in this report notes.²⁴ Second, to point out this history is to highlight the ongoing need for spaces and structures in which Black bioethicists who are addressing issues of racial injustice can engage in dialogue, scholarly collaboration, and mentorship efforts.²⁵ Third, the intergenerational connectedness of Black scholars in bioethics necessitates attention to those

voices that preceded us as we reimagine the critical work of dismantling anti-Black racism in bioethics.

Inspired by the unrecognized and undocumented scholarship, achievements, and efforts of Black scholars working in the field of bioethics, an independent antiracism task force of diverse U.S. scholars (see the text box) whose work prioritizes underrepresented issues within bioethics such as racial and social justice was collaboratively established in June 2020. The goal of this task force is to interrogate the field of bioethics’ moral responsibility to respond to continued racial and health inequities and to bear witness to the long-standing health, health care, and social injustices, including those exacerbated by the Covid-19 pandemic, ongoing political tribalism, societal and institutional racism, and state-sanctioned violence against Black people in the United States. While the intersections of racism and health inequities have been central to the scholarship of many of us working in bioethics,²⁶ it was clear, after several meetings of the task force, that more attention is owed to confronting anti-Black racism and the ways in which this embedded and embodied form of racism threatens the actualization of justice in health and health care, not only for Black people and other minoritized groups but for all people.²⁷ Such work, we argue, is essential for achieving the goals of bioethics.

Furthermore, beyond justice in health and health care, there is a critical need to address the structural and systemic forces that continue to perpetuate a nondiverse bioethics workforce and that otherwise prevent the identification, recruitment, retention, recognition, and advancement of Black bioethicists. Bioethics must also critically interrogate its long-standing role in perpetuating the structural injustice toward Black scholars that limits the field’s growth through failing to embrace the full breadth of talent, expertise, and perspectives²⁸ needed to move the field forward in its responsibility to social justice.

The set of articles, essays, and commentaries assembled by the task force aligns with the initiatives, declarations, and efforts to address the adverse and cumulative effects of structural racism specifically against Black people.²⁹ Arguably, the premature death and disease disproportionately impacting Black Americans and the well-documented association of such death and illness with racism—some of which is highlighted in this special report—are issues

that have not gained due academic visibility or prominence in the field of bioethics. Thus, in this critical moment in United States history, we reckon with anti-Black racism and the lack of prioritization of social and racial justice in the field by gathering behind social justice issues specifically affecting the health and well-being of Black people. The focus on anti-Black racism and its personal and structural adverse effects is not meant to ignore other forms of racism or other lived experiences of racism; it was selected by our diverse task force with the intention of centering and honoring Black voices and scholars in the ongoing struggle for liberation.

In this report, we seek to elevate the voices of established Black scholars, emerging Black scholars, and other scholars who work on relevant underrepresented topics in bioethics. The voices included are intergenerational and interdisciplinary—a direct response to the national push for and moral and professional responsibility of those working in bioethics to make the field more equitable, more diverse, and more inclusive. We also attempt to pay homage to and demonstrate respect for the many Black scholars who preceded us. These scholars were often systematically excluded from mainstream bioethics when their scholarship emphasized racism and health. We aim to build on the foundational and insightful work of those influential scholars by introducing their scholarship to a new generation of bioethicists. Finally, we strive to underscore the urgency for reimagining a braver, bolder, and broader bioethics that prioritizes social justice.

Structure and Summary of Contributions

Structurally, this special report contains five major sections representing different approaches to scholarship, including theoretical, empirical, and narrative forms. The first section highlights two target articles focused on anti-Black racism and health care settings, with each article accompanied by two commentaries. The second section includes four essays thematically centered around anti-Black racism and health equity research and practice. Section three features four essays that explore anti-Black racism and bioethics. The next section consists of four essays framing a braver, bolder, and broader bioethics. We conclude with a powerful tribute to the late Marian Gray Secundy, a bioethics luminary, friend, colleague, role model, and mentor, and a tie that binds together many bioethics scholars who prioritize social justice in their scholarship and *praxis*.

Anti-Black Racism and Health Care Settings

Leading national health organizations recently declared racism a serious threat to the public's health, a barrier to the delivery of quality health care, and an impediment

to scientific research.³⁰ This section speaks to the importance of confronting anti-Black racism in health care and contending with its harmful effects. In the article “Is Trust Enough? Anti-Black Racism and the Perception of Black Vaccine ‘Hesitancy,’” Yolonda Wilson maintains that the question, “Why don’t Black people trust?”—a question that has long been raised to understand and explain fundamental differences in health and health care outcomes—is misguided.³¹ It suggests, argues Wilson, 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.³² Wilson offers a Black feminist analysis of racial injustice in medicine to emphasize the role that health care institutions have played in fostering a climate of distrust for Black people. An accompanying commentary by Shameka Poetry Thomas uses a reproductive justice and narrative medicine lens to further support the notion that merely focusing on the question, “Why don’t Black people trust?” is not only fundamentally flawed but also blames and shames those most affected by health inequities.³³ Thomas argues that the United States health system’s dark history of structural and scientific racism demonstrates a lack of respect for Black bodies, and particularly for Black women in the context of reproductive health care. Thomas emphasizes the utilization of analytical approaches, such as narrative medicine, to center Black women’s lived experiences to foster health justice. The second commentary, by Jennifer Elyse James, also asserts that the question, “Why don’t Black people trust?” is insufficient.³⁴ James describes the ways in which a Black feminist approach to knowledge production can facilitate the centering of community perspectives and lead to better questions. She calls for a radical reimagining and deeper integration of Black feminist bioethics into bioethics scholarship to move toward eliminating racism as a harmful determinant of health.

In the second article, “Anti-Black Racism as a Chronic Condition,” Nneka Sederstrom and Tamika Lasege argue that the embodied experience of anti-Black racism continues to harm communities of color.³⁵ They frame their essay by emphasizing the fiduciary obligation of health care providers to “do no harm” and offer several strategies to promote equitable health outcomes among Black people, including systematic efforts to address anti-Black racism in health care by acknowledging the role of medicine’s racist culture and practices in harming Black people. In a commentary, Elizabeth P. Clayborne, drawing on her physician’s perspective on anti-Black racism in medicine, maintains that both subtle and overt forms of systemic racism plague the educational systems and scientific metrics of medicine in the United States.³⁶ She proposes a multipronged approach to decenter Whiteness in medicine,

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beginning with an imperative to increase the diversity of physicians and providers. Finally, Nia Johnson, focusing especially on women and infants, reckons with the moral stakes surrounding increased mortality for Black Americans and argues that health care institutions should facilitate patients' opportunities to be cared for by clinicians who share their race.³⁷ Johnson acknowledges that racial concordance may be an imperfect approach, but she contends that the mortality risks faced by Black Americans in health care settings warrant seemingly radical solutions.

Anti-Black Racism and Health Equity Research and Practice

According to the U.S. Centers for Disease Control and Prevention, health equity is achieved when every person has the opportunity to "attain his/her/their full health potential" and no one is "disadvantaged from achieving this potential because of social position or other socially determined circumstances."³⁸ In "Now You Are Part of the Solution: Bioethicists' Contribution in Addressing Racialized Health Inequity," Jelani Kerr argues that bioethicists are uniquely positioned to shape the contours of discourse in the population health zeitgeist.³⁹ Kerr highlights how neoliberalist policies in the United States promote inequality and unfavorable health outcomes that are exacerbated among racial and ethnic minorities, as this policy approach is often coupled with various forms of institutional racism. He challenges the field of bioethics to expand its limited purview and use its social and cultural capital in medicine, public health, and policy to help remediate racial and ethnic inequities.

While health equity research is intended to improve the overall health and well-being of minoritized populations, Alicia L. Best contends, in "Anti-Black Racism and Power: Centering Black Scholars to Achieve Health Equity," that anti-Black racism and power imbalances manifest at every phase of the scientific research process, contributing to the marginalization and exclusion of Black scholars within the research enterprise.⁴⁰ She emphasizes the importance of centering Black scholars in funding, conducting, and implementing health equity research to combat the way power has been used as a central component of anti-Black racism.

Building on this need to center Black researchers in the research process, the commentary by Alana Gunn underscores the importance of respectfully engaging research participants, who often experience intersectional marginalization and stigma because of their social identities.⁴¹ Gunn explores qualitative interviewing as a justice-centered praxis, providing spaces for women to name their experiences of oppression, reconstruct the meanings they attach to these experiences, and channel their stories of navigating harm to promote the health of others.

The section concludes with Keisha S. Ray highlighting some of the major health organizations' commitments to addressing anti-Black racism and their policies meant to advance health equity.⁴² Ray argues that, in light of the historical lack of action by these organizations in this area, bioethicists bear a collective responsibility to maintain a level of accountability for those organizations as they seek to fulfill their new commitments.

Anti-Black Racism in Bioethics

Charlene Galarneau and Patrick T. Smith begin this section by considering the way anti-Black racism is addressed across the four editions of the *Encyclopedia of Bioethics*.⁴³ As with all such reference works, this collection reflects value judgments, held by those who shape and develop a field, about which issues are most important to address and the appropriate ways to address them. In turn, such reference works can become the lens by which those working in the field begin to understand it. In "Speaking Volumes: The *Encyclopedia of Bioethics* on Racism," Galarneau and Smith conclude that the subject of racism is obscured in the *Encyclopedia of Bioethics* by its historical inattention to African American approaches to bioethics, to racism as a bioethics issue, and specifically to racism as a matter of justice.

In an essay, Nicole M. Overstreet advances the argument that understanding the ethics that the United States practices—rather than focusing on what it preaches—offers a more dynamic path for informing and transforming a field seeking to reckon with anti-Black racism.⁴⁴ She draws on state consequentialism from a United States-centric lens as a potential starting point for examining how the United States prioritizes its own social, political, and economic in-

terests to the detriment of the very principles that are at the heart of bioethics.

In another essay, Joanne C. Suarez draws on her lived experiences as an Afro-Latina navigating the field of bioethics to introduce a Latinx bioethics perspective and highlight the importance of a collective effort between Blacks and Latinos in the United States to address anti-Black racism.⁴⁵ Her essay concludes with reflections to move toward a more inclusive and racially equitable bioethics.

Mali Collins argues that the “getting back to normal” rhetoric, two years into the Covid-19 pandemic, misaligns with the lived experiences and realities of Black people contending with anti-Black racism.⁴⁶ She raises important questions for health care providers, bioethicists, and those who practice antiracist work concerning their role in taking a stance against medical negligence and violence toward Black people. Overall, she emphasizes that the cycle of anti-Black racism may have originated in the past, but every intimate encounter—systemic, institutional, or interpersonal—is an opportunity to lay a different future for the medical care of Black people and the field of bioethics.

Braver, Bolder, Broader Bioethics

To begin this section, Jennifer McCurdy challenges bioethicists to consider divergent conceptions and experiences of the health care landscape by engaging with Katherine McKittrick’s work *Demonic Grounds: Black Women and the Cartographies of Struggle*.⁴⁷ McCurdy applies McKittrick’s Black geographies to the physical spaces of health care (hospital, intensive care ward, or birthing room) and the discursive space of bioethics journals and texts, and she recommends that bioethics embrace a more expansive capacity for difference.

Further recognizing the effects of racism on the health and well-being of Black women, April Mack’s essay argues that womanism, a social theory focused on the embodied lives of Black women, can be useful to bioethics when considering health care ethics during times of a pandemic.⁴⁸ Mack further contends that an understanding of womanism as a correlative to the Black Lives Matter clarion call can create an ethical narrative in bioethics that can exist beyond pandemics.

Acknowledging the importance of incorporating the experiences of those who began this fight for change, Elizabeth Bogdan-Lovis, Karen Kelly-Blake, and Wendy Jiang draw from the professional histories of four senior Black bioethics scholars to thematically examine how best to recalibrate bioethics to meet the needs of a modern world—to imagine a braver, broader, and better bioethics, with social justice centrally positioned and poised to address anti-Black racism.⁴⁹ This essay highlights the courage these Black scholars had in walking boldly into the world

of bioethics that was, and still is, dominated by White-majority thought dictating policy and approach.

Finally, through interviews with three community activists, Gwendolyn Wallace emphasizes the importance of engaging Black activists in bioethics work and of considering how the field of bioethics might be expanded with the integration of abolitionist perspectives and praxis.⁵⁰ Wallace also explores what will be lost if bioethicists fail to center the voices of those community activists committed to Black liberation in their work.

Tributes to Dr. Marian Gray Secundy

As the first director of the National Center for Bioethics in Research and Health Care and throughout every aspect of her life, Marian Gray Secundy pioneered early conversations and scholarship in bioethics on racial justice and anti-Blackness.⁵¹ A passionate advocate for health equity, a visionary scholar, and a skilled community advocate, Secundy harnessed the energies of other scholars and community members alike to bring attention to and find resolutions for addressing health and health care inequities. During her more than thirty-five-year career, she devoted herself to teaching, mentoring, and promoting social and health justice. In honor of this legacy, this special report offers a tribute by Stephen Sodeke, Faith E. Fletcher, Virginia A. Brown, John R. Stone, Cynthia B. Wilson, Tené Hamilton Franklin, Charmaine D. M. Royal, and Vence L. Bonham, which includes short remembrances in which several of these authors describe their association with Secundy to celebrate and honor her as a leader, friend, scholar, advocate, and teacher in bioethics, one whose story has just begun to receive the recognition it so richly deserves.⁵²

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Disclaimer

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As a member of the task force, Vence L. Bonham Jr. is serving in his personal capacity.

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20. See the transcript where Gamble poses and responds to "Why Isn't There Usually a Black Ethicist in the House?" and discusses the "Creating a Black Agenda in Bioethics" meeting in Tuskegee, AL, J. Moreno et al., presentation transcript, Center for American Progress, October 3, 2005, <https://cdn.americanprogress.org/wp-content/uploads/kf/051003%20MORENO%20BOOK.PDF>; see the discussion by Gamble addressing the lack of racial and ethnic diversity in bioethics and the impetus for organizing the "Creating a Black Agenda in Bioethics" meeting in S. M. Wolf and J. P. Kahn, "Bioethics Matures: The Field Faces the Future," *Hastings Center Report* 35, no. 4 (2005): 22-24; Faith E. Fletcher discusses her experience as a graduate student attending "Creating a Black Agenda in Bioethics" in the archived report: "Creating a Black Agenda in Bioethics," *Michigan State University Medical Humanities Report* 27, no. 1 (2005).

21. Note that this list of participants, provided by Stephen Sodeke, reflects participants documented from one of the meeting activities. Participants included professionals from a range of disciplines including, but not limited to, bioethics, history, public health, genetics, law, medicine, nursing, medical humanities, and theology as well

as community members and students: Vanessa Gamble (conference organizer), Stephen Sodeke, Michelle Yeboah, Carlton Haywood, Dorothy Roberts, Vence L. Bonham Jr., Michele Goodwin, Annette Dula, Charmaine Royal, Rueben Warren, Cynthia Wilson, Harriet Washington, Anne Simpson, Lawrence Prograis, John Stone, Isaac Mwase, Leonard Ortmann, Connie Price, Gregory Gray, Gloria Ramsey, Pamela Foster, Faith Fletcher, Timothy Banks, Walter Bowie, Valerie Wilson, LaVera Crawley, Yvonne Maddox, Albert Mosley, Freeman Suber, Darryl Roberts, Frances Krouse, Angela Prudhomme, Sherine Jennels, Muhjah Shakir, Bryan Lindsey, and Peter Paris.

22. Dorothy Roberts raised these questions in her presentation “Toward a Black Agenda in Bioethics,” at the “Toward a Black Agenda in Bioethics” meeting at Tuskegee University National Center for Bioethics in Research and Health Care in Tuskegee, Alabama, July 17-19, 2005.

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24. L. Bogdan-Lovis, K. Kelly-Blake, and W. Jiang, “On the Shoulders of Giants: A Reckoning with Social Justice,” in *A Critical Moment in Bioethics: Reckoning with Anti-Black Racism through Intergenerational Dialogue*, ed. F. E. Fletcher et al., special report, *Hastings Center Report* 52, no. 2 (2022): S72-S78, at S77.

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