Is Race-Based Medicine Good for Us?: African American Approaches to Race, Biomedicine, and Equality

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## I. Introduction: The Political Context

Public discourse on race-specific medicine typically erects a wall between the scientific use of race as a biological category and the ideological battle over race as a social identity. Scientists often address the potential for these therapeutics to reinforce a damaging understanding of "race" with precautions for using them rather than questioning their very development. For example, Esteban Gonzalez Burchard, an associate professor of medicine and biopharmaceutical sciences at the University of California, San Francisco, states, "We do see racial differences between populations and shouldn't just close our eyes. Unfortunately, race is a politically charged topic, and there will be evildoers. But the fear should not outweigh the benefit of looking."1 Although it is recognized that ideology influences the social meaning of race, it is usually assumed that there is a separate, prior scientific understanding of race that is not contaminated by politics.

I am interested, however, in the intersection of science and the politics of race in the public debate about race-based pharmaceuticals, especially among African Americans. As the field of science and technology studies has shown, not only are scientific discoveries (such as new genomic findings) shaped by their interaction with pre-existing ideologies and structures of power (such as racism and racial inequality), but new forms of science and power emerge *simultaneously*.<sup>2</sup> The scientific debate about race-based pharmaceuticals is occurring in the context of an equally heated battle over approaches to racial equality. Colorblindness and race consciousness compete as major schemes for determining the proper treatment of race in social policy.<sup>3</sup> In the political arena, advocacy for colorblind policies is often based on the assertion that racism has ceased to be the cause of social inequities while raceconscious policies are promoted as a necessary means for remedying persistent institutional racism.

In June 2007, the United States Supreme Court spotlighted this contest in its 5-4 decision striking down race-conscious plans to desegregate elementary schools in Seattle and Jefferson County, Kentucky.<sup>4</sup> The Court adopted the position that the Constitution requires the government to be colorblind by paying no explicit attention to race in policymaking. As Chief Justice John Roberts concluded, "The way to stop discrimination on the basis of race is to stop discriminating on the basis of race."<sup>5</sup> Thus, race consciousness is decreasing in government social policy at the very

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moment it is increasing in biomedicine. At the same time, the new racial biopolitics foregrounds the tension vexing attempts to develop an antiracist agenda that directly confronts the very real impact of systemic racism without reifying race as a natural division of human beings.

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"Is race-based medicine good for us?" is at once a medical and political question, and the answer depends on one's approach to achieving racial equality. There is no consensus among African Americans on this question. On one hand, some African American scholars, scientists, and advocates have criticized race-based medicine as a scientifically flawed and commercially corrupted misuse of biomedical research on health inequities that threatens to reinforce dangerous biological understandings of race.<sup>6</sup> On the other hand, others have supported racial therapeutics precisely to redress past discrimination and fulfill longstanding demands for science to attend to the health needs of African Americans. For example, the Association of Black Cardiologists co-sponsored the trial to test the efficacy of BiDil in treating heart failure in African Americans, and the National Medical Association and some members of the Black Congressional Caucus supported the drug's approval by the Food and Drug Administration (FDA).7

In this article, I present a preliminary framework for my larger research project investigating in greater depth how African Americans answer the question, "Is race-based medicine good for us?"8 How are black scientists, advocates, and consumers in particular navigating the competing interests of African Americans both in race-conscious inclusion in technological advances and in opposing the dangerous consequences of biological definitions of race? I present three prevailing approaches to race consciousness that appear to influence people's evaluation of these technologies: conservative colorblindness, identity politics, and the rejection of "race." My goal here is to explore how these three political perspectives might produce different evaluations of the validity of race-based medicine. This theoretical project provides a useful foundation both for studying empirically African Americans' perspectives on racial therapeutics and for establishing ethical guidelines for their development that place racial justice at the center.

I conclude by proposing an alternative approach necessary to address the implications of race-based biotechnologies in the current political context. At

the turn of the 21st century, a new system of punitive neoliberal governance aggressively increases economic and social insecurity in poor black communities while denying the state's responsibility for causing it or obligation to address it. I argue that race-based medicine helps to promote a biological explanation for racial inequities that obscures their sociopolitical causes and requires

individualized and market-based solutions rather than social change. By making black people's subordinated status seem natural, this view provides a ready logic for the staggering disenfranchisement of black citizens, as well as the perfect complement to colorblind social policies.

## II. Three Competing Approaches to Race-Based Medicine and Equality

Race does not predetermine a single perspective held by African Americans on racial medicine any more than it predetermines their personality traits. Indeed, the debate about the validity and ethics of race-specific drugs is as intense among African Americans as between other groups. In Hegemony and Socialist *Strategy*, Ernesto Laclau and Chantal Mouffe criticize the Marxist politics of representation that treats the working class as historically predestined to be actors for social change.9 They contrast the strategy of representing this given role to potential activists with a politics of articulation that requires agents to engage in political activism by creating ideological common ground on which to build alliances. Similarly, the lack of consensus among African Americans shows that their historical position as victims of racial oppression does not dictate a particular perspective on race-based medicine. Rather, African Americans are actively articulating political approaches to race-based medicine that reflect their divergent interests and understandings of racial justice.

### A. Conservative Colorblindness

According to conservative colorblind ideology, the gaps between black and white health, welfare, and status are products of unbiased market operations, not social injustice. Because racism no longer impedes blacks' progress, many conservatives argue, there is no need for social policies to take race into account. If systemic racism is nonexistent, then colorblindness requires some explanation for the startling racial disparities that continue to mark every socioeconomic, health, and political indicator. This is why some conservative proponents of social colorblindness eagerly embrace genetic explanations of health disparities as well as racial medicine.<sup>10</sup>

Sally Satel, a resident scholar at the American Enterprise Institute, explicitly distinguishes between colorblindness in social policy and in medicine. "It is evident that disease is not colorblind, and therefore doctors should not be either," she writes in her *New York Times Magazine* cover article, "I Am a Racial Profiling Doctor." "As citizens, we can celebrate our

genetic similarity as evidence of our spiritual kinship. As doctors and patients, though, we must realize that it is not in patients' best interests to deny the reality of differences."<sup>11</sup> Not surprisingly, Satel embraced BiDil as proof of a genetic explanation for racial disparities in illness and responses to treatment. In "Race and Medicine Can Mix Without Prejudice: How the Story of BiDil Illuminates the Future of

Medicine," Satel reiterates the distinction between the social and biological meaning of race: "Social race is the phenomenon constructionists have in mind — the idea that an individual himself and society's perception of him influences the ethnic or racial group with which he is identified. Biological race, however, is what BiDil's developers are concerned with — that is, race as ancestry."<sup>12</sup>

According to this view, racial difference is real at the molecular level but should be overlooked in the political sphere. It turns the social construction of race on its head: race is biologically real, but merely constructed in society.<sup>13</sup> Because race matters biologically, doctors and researchers cannot be colorblind, but colorblindness is acceptable, even preferable, with regard to social policies.

Claims that new genomic research demonstrates racial differences work to diffuse accusations of racism on the part of colorblind proponents. Indeed, conservative believers in genetic racial distinctions charge their critics with relying on political ideology rather than on science.<sup>14</sup> They take the position of righteous underdog, bravely battling political correctness with unadulterated scientific truth. In this ingenious twist of political logic, the critics of biological race become the racists. Conservative colorblindness holds that race is a natural category that became politicized only in the last few decades as a result of post-civil rights identity politics. This ignores the history of racial classifications as a political system of governance that has been traced to the 15th century when Spanish and Portuguese royalty described southern Africans as subhuman to justify enslaving them.<sup>15</sup> The very origin of "race" to accommodate European, and later American, imperialism and slavery is the quintessential example of the use of science to achieve political ends.

Some black conservatives may support a colorblind approach to social policy along with its acceptance of a biological understanding of race. The California Racial Privacy Initiative, for example, which was

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> defeated by voters in 2004, barred the state from using any racial classifications in its data collection and record keeping except "otherwise lawful classification of medical research subjects and patients."<sup>16</sup> Its most vocal supporter was black conservative activist and former University of California Regent Ward Connerly, also an architect of the abolition of affirmative action in California state education, employment, and contracting. This initiative would have limited the government's ability to identify, monitor, and correct social inequities based on race while permitting the very type of racial classification that may reinforce a biological meaning of race.

> Many black conservatives who support a colorblind approach to social policy, however, do not rely on biological explanations of racial disparities. Manhattan Institute senior fellow John McWhorter, for example, points to a "culture of victimhood" rather than biological difference to explain blacks' persistent social disadvantage.<sup>17</sup> Far from viewing this as a problem inherent in African Americans, McWhorter argues blacks can change this culture by rejecting the irresponsibility and violence created by civil rights social programs. Similarly, the reason conservative Supreme Court Justice Clarence Thomas opposes affirmative action is not a belief that blacks are inherently inferior. To the contrary, he promotes individual will and self-reliance

as the antidotes to racial discrimination.<sup>18</sup> Nevertheless, the colorblind approach of black conservatives like Connerly, McWhorter, and Thomas is conducive to alliances with conservatives like Entine and Satel who explicitly endorse genetic explanations for racial disparities. Conversely, it will be interesting to see if genetic theories of racial difference held by some conservatives cause fissures in conservative advocacy of colorblind social policies.

#### **B.** Identity Politics

At the other end of the mainstream political spectrum from conservative colorblindness, identity politics also provides a platform to promote race-based medicine. Unlike colorblind conservatives, however, some proponents of identity politics support affirmative action in social programs as well as race consciousness in biomedical research. variable risks reinforcing biological definitions of race that have historically legitimized racial inequalities. Forcing genetic findings from biomedical research into social categories of race threatens to make these categories seem genetically determined.23 These federal programs are critical to investigating the reasons for race-based disparities and to developing programs that effectively address them. Federal funding requirements, however, can easily be interpreted to treat "races" not only as social groupings but as biologically distinct populations whose health status and responses to therapies vary for genetic reasons inherent in each group. When I asked a scientist who studied genetic contributions to hypertensive heart disease why she reported her findings according to the race of research subjects, she responded that this racial classification was a condition of receiving federal funding for her research.24

I argue that race-based medicine helps to promote a biological explanation for racial inequities that obscures their sociopolitical causes and requires individualized and market-based solutions rather than social change. By making black people's subordinated status seem natural, this view provides a ready logic for the staggering disenfranchisement of black citizens, as well as the perfect complement to colorblind social policies.

Claims about justice in scientific research have shifted from protecting socially disadvantaged subjects from unethical practices toward promoting access to clinical trials.<sup>19</sup> Group-based demands for increased participation in biomedical research create a dilemma between including individuals on the basis of their racialized identities and contesting racial categories.<sup>20</sup> In response to these demands, the federal government has institutionalized the scientific use of racial categories to ensure greater participation of minorities in clinical research and to address health inequities. The NIH Revitalization Act of 1993 mandates the inclusion of women and minorities as subjects in federally funded clinical research and the reporting of research findings according to racial categories.<sup>21</sup> Other federal programs, such as the Department of Health and Human Services "Healthy People 2010" initiative, encourage race-based research to eliminate health disparities among racial and ethnic groups.<sup>22</sup>

Race consciousness in federal funding guidelines creates a perplexing paradox. While designed to correct historic discrimination against people of color, requiring that biomedical researchers use race as a

Identity politics is often expressed as a fight among racial and ethnic groups for a piece of the pie of dwindling state resources. Supporting a pharmaceutical marketed specifically to blacks is an expedient way for black politicians and organizations to stake a claim to scientific advances for their constituents. In December 2005, the National Association for the Advancement of Colored People (NAACP) announced its partnership with Nitromed, the pharmaceutical company that markets BiDil, "to implement measures to narrow health care disparities that exist between African Americans and Caucasians."25 As part of this alliance, NitroMed promised the NAACP a three-year \$1.5 million grant; the NAACP has subsequently vigorously promoted BiDil as a life-saving drug for African Americans.<sup>26</sup> NitroMed's Chief Executive Officer, Dr. Michael Loberg, described one of the partnership's chief aims as "together with the NAACP,...doing our part to remove all barriers to access of BiDil."27

When I stated at an April 2006 MIT conference on race-based therapeutics that there was no consensus among African Americans on the benefits of these pharmaceuticals, Juan Cofield, president of the NAACP New England Area Conference, stood up in the audience and emotionally objected. He argued that support for BiDil by his organization, the National Medical Association, and the Association of Black Cardiologists demonstrated a clear consensus in favor of race-specific medicine. He castigated me for jeopardizing black lives by raising any criticism of the drug.

As law professor Rene Bowser observes, "After years of studying differences between Blacks and Whites, there is little evidence that such research has paid positive dividends to Blacks."28 To some African Americans, BiDil may seem like the first tangible sign of recognition of persistent health inequities and progress in addressing them. At the FDA hearing on NitroMed's application to market BiDil, black cardiologists and members of Congress testified that approving BiDil would help the agency make amends for America's racist history of medical maltreatment and demonstrate its concern for black people's health.<sup>29</sup> Representative Donna Christian-Christensen of the Black Congressional Caucus, for example, portrayed FDA approval as a remedy for medical wrongs against African Americans "for whom treatment has been denied and deferred for

...is valid, but, under present circumstances, impractical."<sup>33</sup> According to this view, the urgent crisis of African American heart disease must take precedence over political objections to using race as a biomedical category; indeed, these objections are seen as a form of racial discrimination on grounds that they block African Americans' access to a "life-saving drug."

#### C. Absolutist Anti-Race

A less mainstream strain of black political thought rejects the use of "race" embraced by identity politics. Black political theorists Anthony Appiah and Paul Gilroy, for example, argue that "race" is an obsolete relic of racist domination unsuited for contemporary opposition to racism.<sup>34</sup> They link the current recognition of race to its historical roots in a racist hierarchy that ranked whites as superior to others. British sociologist Paul Gilroy chaired Yale University's African American Studies department, and his writings have influenced U.S. black political thought. Gilroy's excavation of contemporary racism's colonial origins effectively underlines a key premise of race that is critical to understanding its relationship to racism: "For me, 'race' refers primarily to an impersonal, discur-

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400 years.<sup>30</sup> Similarly, despite acknowledging that "race lacks any true biologic definition," Keith Ferdinand, the chief science officer of the Association of Black Cardiologists, supports BiDil as a "life-saving drug" that addresses "evidence of racial and ethnic differences in cardiac care in the United States which may significantly affect health outcomes.<sup>31</sup>

"Should a drug be withheld simply because it may play into a racist agenda?" asks a guest editorial in the *Chicago Defender*.<sup>32</sup> The black supporters of BiDil argue that the benefits of a therapy that specifically caters to blacks' medical needs outweigh any detrimental messages it generates about race. Gary Puckrein, executive director of the National Minority Health Month Foundation, states that "concern about the medical and scientific validity of the concept of race sive arrangement, the brutal result of the raciological ordering of the world, not its cause."<sup>35</sup> In other words, race is a concept that was invented to legitimize racism, not a natural distinction among human beings that can produce racism if not handled properly.

Gilroy's observation explains why it is insufficient to attempt to contain the racist *consequences* of racial therapeutics. The belief in inherent racial differences that underlies and is reinforced by race-based medicine is itself a dangerous misrepresentation of humanity. Gilroy advocates instead that we "detonate the historic lore that brings the virtual realities of 'race' to such dismal and destructive life."<sup>36</sup> In his 2000 book *Against Race: Imagining Political Culture Beyond the Color Line*, Gilroy predicted that advances in genomic research would eventually and unintentionally discredit the idea of "specifically *racial* differences" and facilitate the development of a "postracial humanism" because genetics would render race a useless way of classifying people.<sup>37</sup> Writing before the advent of race-based medicine, he observed, "At the smaller than microscopic scales that open up the body for scrutiny today, 'race' becomes less meaningful, compelling, or salient to the basic tasks of healing and protecting ourselves."<sup>38</sup> Perhaps even Gilroy underestimated the tenacity of race-thinking he so sharply condemned.

Gilroy aims to contest the belief that race remains a necessary category for identity and to replace it with a cosmopolitan vision of planetary humanism. Recognizing the oppressive effects of racism, Gilroy nevertheless advocates abolishing all forms of racethinking. Although Gilroy's "postracial" vision rests on an important insight about the problem with racial classifications, it limits the use of racial categories to identify, measure, and challenge the consequences of racism. This approach ignores the need for researchers to use race as a political category in order to investigate the effects of racial inequities on African Americans' health. It is also naïve to believe that genetic science will inevitably overcome the political investment in racial classifications. Rather, race serves as an organizing principle for the collection, analysis, and reporting of genetic data.<sup>39</sup> We must therefore affirmatively scrutinize the persistent use of race in biomedical research and products.

# III. Toward a Social Justice Approach for a Neoliberal Age

Science historian Evelynn Hammonds observes, "[T]he appeal of a story that links race to medical and scientific progress is in the way in which it naturalizes the social order in a racially stratified society such as ours."40 Explaining racial inequality in biological terms rather than in terms of white political privilege has profoundly shaped science in America for three centuries, beginning with the scientific defense of slavery.<sup>41</sup> Besides resuscitating the fallacy that biological races have scientific validity, racial medicine has tremendous potential to affect the direction of state efforts to address health disparities, and racial inequality more broadly, by diverting attention from the structural causes of racial inequities toward genetic explanations and technological solutions.42 The public may think that race-based medicine shifts responsibility for addressing disease from the government to the individual by suggesting that health disparities are a result of genetic variation rather than inequitable social structures and access to health care.

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Why not pursue both race-based medicine and social approaches to health inequities, full steam ahead? One reason is that funding for developing racial pharmacogenomics will cut into resources available for social strategies. More importantly, racespecific therapeutics may reduce the public's willingness to change social conditions that impair African Americans' health. As Troy Duster astutely observed in *Backdoor to Eugenics*, characterizing a disease as a "genetic disorder" directs us to address it through genetic screening, genetically tailored therapies, and technologies geared toward preventing the genetic problem, rather than investigating the links between disadvantage and illness and increasing access to health care.<sup>43</sup> Placing the responsibility for ending health disparities on individual health decisions or on taking race-based medications will weaken the sense of societal obligation to fix systemic inequities.

It is critical to place race-based medicine into a political trend that extends beyond issues of health. This diversion of attention from social causes and solutions reinforces privatization, the hallmark of the neoliberal state that pervades every aspect of public policy.44 In the wake of globalization, the United States has led industrialized and developing nations in drastically cutting social welfare programs while promoting the free market conditions conducive to capital accumulation. Critical to this process of state restructuring is the transfer of social services from the welfare state to the private realm of the market, family, and individual while advancing private sector interests in the market economy. Rather than providing needed resources to families, the state promotes private remedies, such as marriage and adoption, for the economic consequences of its disinvestment in these communities.

At the same time that the state is dismantling the social safety net, it has intensified its punitive intervention in communities of color. Neoliberalism does not entail a unidimensional shrinking of government; it equally depends on the brutal, even barbaric, deprivation of freedoms to the nation's most marginalized residents. Surveying the Bush Administration's disastrous response to Hurricane Katrina, Henry Giroux observes that the neglect of its victims "revealed the emergence of a new kind of politics, one in which entire populations are now considered disposable, an unnecessary burden on state coffers, and consigned to fend for themselves."<sup>45</sup> Welfare is no longer a system of aid, but rather a system of behavior modification that attempts to regulate the sexual, marital, and childbearing decisions of poor unmarried mothers by placing conditions on the receipt of state assistance.<sup>46</sup> Meanwhile, the U.S. prison population has grown to proportions unprecedented in the history of Western democracies by locking up astounding numbers of young black men.<sup>47</sup> The racial disparity in the foster care population mirrors that of the prison system.<sup>48</sup>

In other words, at the turn of the 21st century, a new system of punitive governance aggressively increases economic and social insecurity in poor black communities while obscuring the state's responsibility for causing it or obligation to address it. My past work highlighted how attributing social inequities to the childbearing of poor minority women, justifying state reproductive regulation, is a critical component of this punitive trend away from state support for families and communities.49 Race-based medicine plays a similar role. Its marketing helps to promote the view that inequities resulting from neoliberal policies are actually caused by natural differences between blacks and whites. Like marriage and adoption in welfare policy. racial therapeutics places the burden on individuals for curing their unequal status. The genetic explanation of racial disparities provides a ready logic for the staggering disenfranchisement of black citizens, as well as the perfect complement to colorblind policies implementing the claim that racism has ceased to be the cause of their disempowered status.

The biologization of race seems acceptable today precisely because prior forms of overt racial violence are now institutionalized and therefore invisible to many Americans. Scientists, pundits, and entrepreneurs can disassociate their promotion of inherent racial classifications from prior explicitly racist and eugenic incarnations because racial inequality no longer relies on overt white supremacy. At the same time, a renewed belief in inherent racial differences provides an alternative explanation for persistent gross inequities in blacks' health and welfare despite the end of de jure discrimination. Thus, the growing popularity of a genetic definition of race helps to legitimate a new coercive politics of race at a time when the United States claims to have moved beyond violent enforcement of racial hierarchies.

It is highly unlikely that there is a consensus among African Americans in favor of race-based medicine. The history of their victimization by medical practitioners and researchers makes many blacks justly skeptical of the faith that scientific discoveries inevitably represent progress or that they will always be used to improve people's – especially black people's – lives.<sup>50</sup> Black people's experience of exploitation and insistence on an ethics of racial justice make this perspective essential in the broader society's deliberations about race-based medicine. A tradition of black protest has tied personal problems, such as poor health, unemployment, and a criminal record, to deeper institutional flaws. Contemporary critical race scholars tend to reject colorblind solutions to racial inequality, recognizing that only aggressive, race-conscious remedies can reverse the centuries-old institutionalized white privilege and nonwhite disadvantage.<sup>51</sup> At the same time, they have contributed significantly to the view of race as a political invention by demonstrating law's crucial role in creating and defining racial categories.52

Despite the allegiance of some African Americans to a conservative colorblindness or identity politics that embrace race-based medicine or rejection of race that discounts black solidarity, radical black politics holds promise for constructing a formidable challenge to the use of racial genetics in the neoliberal agenda. Moreover, recognizing the relationship between neoliberalism and a new biopolitics of race opens opportunities for building alliances between antiracist, disability rights and economic, reproductive, and environmental justice movements for social change.

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