

# Epistemic Trafficking: On the Concept of Race-Specific Medicine

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**I**N JUNE 2005, THE U.S. FOOD AND DRUG ADMINISTRATION (FDA) announced its approval of the drug BiDil, designed to treat heart disease in patients who self-identify as African-American exclusively and, with this decision, “race-specific” medicine was established as the FDA became the first regulatory body to approve a medication for therapeutic use in a specific racial group. Manufactured by the pharmaceutical corporation NitroMed, BiDil is comprised of two generic drugs, isosorbide dinitrate and hydralazine, which had been commonly prescribed to treat heart failure prior to the creation of BiDil as a “two-in-one” pill (Kahn, “Race” W1). The composition of BiDil is not novel and thus cannot be conceived of as a medical breakthrough. Further, the scientific conduct that paved the way for the FDA’s approval of BiDil for use in African-American populations was particularly suspect: the clinical trials conducted by NitroMed to test the effectiveness of BiDil on patients predisposed to heart disease were accessible only to African-American participants (Kahn, “Ethnic Drugs”). By carrying out the trials in this manner, NitroMed was able to guarantee its desired outcome. Unless the drug proved to be ineffective in treating heart disease—an outcome that was extremely unlikely, considering the longstanding proven effectiveness of both isosorbide dinitrate and

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hydralazine as separate therapies—it was inevitable that the results of the trials would indicate the successful creation of a race-specific drug since the only participants in the trial were African-American and BiDil was known to be effective in treating heart disease in humans generally. Thus, NitroMed was able to produce results proving the effectiveness of BiDil in African-American populations. As Jonathan Kahn notes:

The trial investigators themselves concede that BiDil will work in people regardless of race. Without a comparison population, the investigators cannot even claim that the drug works *differently* in African Americans. The only responsible scientific claim that can be made on the basis of these trials is that BiDil works in *some people who have heart failure*—period. (“Ethnic Drugs” C3)

For the moment, I will bracket the most obvious objection to NitroMed’s dubious practices: the accusation of essentialism. Although this is inestimably important, it remains a secondary consideration until I contend with the social and political implications of the FDA’s approval of BiDil. Thus, rather than putting forth questions concerning the criteria employed by NitroMed for inclusion in their constructed category of “African-Americanness” (recognizing the absurdity of any mode of thinking that puts forth a conception of racial purity), I periodize the emergence of race-specific medicine and draw attention to the particular discursive constructions through which this practice produces meaning.

The problem of race-specific medicine emerges from within a broader framework of a conjuncture in which biopower produces value through the transformation of biology into information at the molecular level. This particular form of power interpellates individuals as biocitizens or health consumers (Roberts) through discourses of risk and responsibility; biopower possesses the generative capacity to produce new forms of what is understood as the common sense of the truth of the biological, thus ensuring a smooth transition to this new form of biopolitics as the calculated management of the productive capacities of molecular forms of life following the revolution in the life sciences industry.

The contemporary biopolitical moment is one in which the life sciences and capitalism are equally interested in, and working together to forge, newly profitable futures for human life through new conceptions of therapeutic specificity as well as new forms of corporate management and intervention; race-specific medicine is but one iteration of this tendency. My discussion of BiDil seeks to reframe the disparity in incidence of heart

disease—a problem that is too often moralized and technologized—as a social and political problem by focusing on the ways in which science and technology produce material shifts that become intelligible through narratives and social discourses that appear as inevitable discoveries rather than as components of larger political projects. These narratives and discourses often emphasize theoretical and technical complexity, which functions to dissociate science from the social. I draw attention to the way in which BiDil appears as a naturalized, dehistoricized object; as Barthes might say, its contingency is removed so that it is received as a complete and rational practice that reflects truth and necessity.

I read the emergence of race-specific medicine as another troubling iteration of a pervasive tendency through which social problems are culturalized, geneticized, and technologized. This paper focuses on the ways in which the institutional authority of science inscribes what is received as a true description of a biological basis for race and how this knowledge gets taken up, informing public policy and the distribution of resources in complicated ways. While heart disease disproportionately afflicts African-Americans, there is no genetic basis for these rates of disease (Winkleby et al.). Instead, these higher rates of heart disease reflect the disproportionate access to material resources for racialized people in the U.S. Heart disease is a disease of poverty that could most effectively be treated through structural change, but, instead, BiDil works to reify race as biology, which serves a number of political imperatives, including the maintenance of systemic racist practices in the U.S. (Roberts). The geneticization of race is symptomatic of a larger tendency in the logic of the personalized medicine industry in the context of neoliberalism. The production of BiDil, then, can be read as another iteration of the narrative within which responsibility for health is framed as belonging to the individual, thus absolving the state of responsibility. As I discuss in this paper, BiDil helps to establish the concept of individual risk and responsibility (in the place of state responsibility for health) as the conceptual ground upon which the personalized medicine industry might flourish.

Data produced by scientific studies is often presented as banal and is not usually understood as an illicit object likely to be disseminated through the mode of circulation known as trafficking. However, the particular form of trafficking through which data gets translated into information and information into knowledge—which in turn gets marshaled to do political work—is a process that has not yet received enough critical attention from humanities scholars. This article focuses on the ways in which science produces a particular form of narrative that is employed to

explain and shape the political organization of social life. While science is a conceptually hermetic practice that relies almost entirely on metaphor in its construction of transmissible narratives for popular consumption (especially the more abstract sciences such as molecular biology, which cannot think itself or function without the use of metaphors), technological products are often put forth as the only possible solutions for problems that are historical, social, and economic in nature. My analysis is attentive to both the micro-production of scientific knowledge in the lab as well as the function of the scientific object as a nexus of truth-power.

This paper discusses NitroMed's production and marketing of BiDil as the world's first race-specific drug, arguing that BiDil must be understood as the launch of a new racial project born on the terrain of genomics. I explore the practices of ordering and classification that take place within NitroMed's production of a genetically determined need, drawing attention to a new dominant ideology bolstered by scientific research and statistical measurement: an emergent form of what I call *epistemic trafficking*. The concept of traffic is crucial to this analysis because it illuminates the double movement of race-based medicine: racialized scientific knowledge is disseminated evenly and yet it produces a decisively uneven distribution of material resources. This paper examines the epistemic trafficking performed by the production of BiDil through a modification of Michael Omi and Howard Winant's concept of the "racial project" as a form of social organization based on an essentialist understanding of race that works to distribute resources "along racial lines" (56).

I argue that BiDil should be understood to form part of a larger political paradigm within which social inequalities get displaced onto science as a separate and apolitical sphere. Scientific discourse, in turn, represents these inequalities as naturalized biological categories that are understood as inevitable. I focus on the practice of epistemic trafficking and the way in which its ability to biologize social problems quickly ushers these problems out of what is understood to be the political realm and into a scientific practice that is rendered opaque and illegible as a result of its complexity and the expertise required to critically engage with its claims. I draw attention to the questions that cannot be asked and criticisms that cannot be conceptualized from within this epistemic paradigm in which one particularly shortsighted technological solution is put forth as the correct and necessary panacea to treat a problem that is historical, social, and economic in nature. The dominant ideological (and financial) investment in genetic determinism ensures that particular questions concerning class,

structural racism, and health cannot be asked from within the conceptual space opened up by the approval of BiDiI.

While race-based medicine has received criticism from numerous quarters, two key elements are consistently missing in analyses of the problems of race-based medicine. First, the focus on the supposed materiality (at the level of DNA) of racial difference<sup>1</sup> elides social factors contributing to disease, including unequal access to health care, education, housing, and nutrition. Second, and perhaps even more significantly, a lack of close critical attention to the discourse and conditions of scientific production prevents us from recognizing drug research itself as a site in which systemic racist practices and beliefs are articulated. In order to reorient the debate away from a critical analysis of the narratives constructed by genomics as puppet of big pharma—a crucial site of debate, to be sure—I turn instead to the animating logic of the institutions that construct scientific facts prior to their circulation.

Extending the critique put forth by Bruno Latour and Steve Woolgar in *Laboratory Life*, I draw attention to the fact that the daily tasks of the laboratory, including data collection and analysis, are carried out largely by white Americans, that is, those who have a stake in the racial hegemony their research supports. The consequences of a disproportionately low number of African-American scientists participating in pharmacological research produces not only a deficit in the biomedical imaginary but also an insidious racial project that eludes recognition as such because it is trafficked by the authoritative discourse of science. While existing criticisms of race-based medicine contest genomics' ideas concerning what constitutes race, I argue that the emergence of race-based medicine is symptomatic of a meta-epistemic problem. Although it has been widely acknowledged that scientific research is a white practice, the humanities have not yet begun to grapple with the material and ideological consequences of the fact that scientific knowledge is itself racialized.

1. References to the concept of race throughout this paper should be understood as references to the socially constructed concept of race rather than as contributions to the racial projects that seek to reify the category of race. Through my discussion of race as social construct, however, I wish to emphasize (rather than minimize) the fact that the lived experience of racialized people and the oppression perpetrated in the name of race is informed by scientific ideas concerning what constitutes race and how these ideas are taken up. I want to acknowledge, then, that race persists both as a category for biological research (based on phenotype) and as a category in social and political life for racialized people, in which case phenotype is understood to reflect genotype. Inequalities have historically been and continue to be legitimized on the basis of this fallacious conception of an indisputable biological racial identity.

The concept of traffic does not designate the circulation of a single idea or set of meanings within a specific target audience and in service of a specific set of interests; rather, it denotes the circulation of a complicated set of signs producing multiple and internally contradictory ideological implications. Crucially, the traffickers of these signs cannot predict or control the narratives in which these signs will become imbricated once consumed by their recipients. To traffic a set of ideas that have been encoded in a material object is, in a sense, to relinquish control over the ideas. It becomes impossible to guarantee the interpretive reception of these ideas once they have been trafficked. When a set of ideas is trafficked by the FDA—a regulatory institution understood to make decisions on the basis of scientific data in isolation from political and economic interests—and particularly when these ideas offer official pronouncements on the biological validity of a category in the name of which enormous violence has been and continues to be perpetrated, it becomes particularly important to examine the ways in which these ideas get disseminated and understood as sacrosanct. Narratives of scientific fact remain disproportionately influential in the contested epistemic space of North America in the twenty-first century.

The process of epistemic trafficking that was carried out by the FDA when it approved BiDil for use by African-Americans only effectively reified the concept of race as biology. The material and ideological consequences of this particular form of trafficking are dire, and yet this knowledge has been circulated freely and has been enormously influential. The FDA's approval carried the weight of science behind it, and, as a result, this decision is framed as indisputable and as a reflection of a biological truth supported by data and facts. The decision to approve BiDil for use in racialized populations is encoded as a humanitarian decision made to benefit a population that suffers disproportionately from heart disease, rather than a political decision intertwined with capitalist imperatives. In this way, the carrying out of a savvy business plan—constructing a niche market to ensure strong sales for a new product entering an already saturated market of drugs designed to treat heart disease—does not merely produce profit for NitroMed but also alters Americans' understanding of race. It is this epistemic shift that has deleterious political, material, cultural, and social effects for racialized people in the U.S. What's worse is that the knowledge trafficked by NitroMed and backed up by the FDA—that there is indeed a biological basis for racial categories—constructed a narrative about racial difference that was not only accepted without much resistance but that

was actually welcomed by the dominant ideology of systemic racism in the U.S. As has been shown, this narrative is not easily reversed.

### The Discursive Construction of Race-Specific Medicine

As Kahn suggests, the approval of BiDil ushered in a new era for Big Pharma: what is known today as pharmacogenomics, or “personalized medicine.” Prior to BiDil, pharmaceuticals did not produce drugs for specific populations but instead focused on the development of drugs that would be prescribed widely to the general population, even creating the conceptual space for these drugs where markets did not already exist.<sup>2</sup> Although the paradigm which preceded pharmacogenomics understood that a wider target population for the drug would produce a larger profit, the new paradigm responds to rising costs of conducting clinical trials because testing on a single population reduces the number of confounding variables that must be accounted for in the trials. As Kahn notes, the cost of conducting clinical trials with drugs for which pharmaceuticals seek approval for the general population can be prohibitively high, within the range of \$700 to \$900 million per drug and stretching over a period of up to fifteen years (“Exploiting Race” 741). Producing a drug that is targeted toward a specific population reduces the number of variables that need to be taken into account during the trial stage, thus reducing both the cost of the trials and the amount of time required to bring the drug to market. Although BiDil lacked general population approval, it was brought to market quickly and inexpensively, and its approval automatically generated a niche market protected by patent until 2020 (Kahn, “Exploiting Race”). It thus was instantly profitable as its early profits weren’t subsumed in a \$900 million debt incurred by broader trials.

The FDA’s approval of BiDil for use in African-Americans suffering from heart disease trafficked a pernicious idea of race as a clearly demarcated biological category supported by science and thus also a natural and inevitable one. This narration of race as a necessary (rather than contingent) category for analysis has particularly deleterious effects when trafficked outside the realm of biological research. Capitalism continually requires new markets in order to expand, and as Donna Haraway notes, capitalism in the U.S. feeds off of what it considers to be natural in order to continue

<sup>2</sup> For example, as Ethan Watters demonstrates, the pharmaceutical giant Glaxo-SmithKline was able to alter Japanese cultural narratives concerning illness and health and the normal and the pathological in order to construct a market in that country for its antidepressant selective serotonin reuptake inhibitor (SSRI) drug Paxil.

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to accumulate wealth (214). BiDil works to naturalize the category of race; a high incidence of heart disease in a racialized population in the U.S. is naturalized as a matter of genetics, thereby creating a patent-protected market (Kahn, “Exploiting Race”). Kahn suggests that the FDA’s approval of BiDil had the effect of biologizing race in insidious ways, such that inequalities that persist along racial lines were justified scientifically. While I agree with Kahn, I also want to note that an equally disastrous result could potentially follow from the assertion that there is no biological basis for race, such that existing measures put in place to counteract the material effects of racism might begin to be perceived as unwarranted.

Recent genetics research, including that carried out as part of the HGP, has shown that “humans are overwhelmingly genetically identical; racial ancestry accounts for a very tiny sliver of human genetic diversity; genetic population structure is more variable within than between populations; and human genetic variation is fundamentally clinal rather than discrete” (Koenig, Lee, and Richardson 8). These research results, however, should not be uncritically welcomed as the beginning of the end of oppression perpetrated toward racialized people. The danger of scientific data that diminishes a biological basis for racial categories is that this data becomes available to be taken up as justification for what the neoliberal colour-blind ideology imagines as a “postracial” era. Irrespective of whether or not a greater amount of genetic variation exists within any particular racial category than between racial categories, racialized people throughout the world continue to be oppressed. Of additional concern is that policies implemented to counteract the past and present oppression of racialized people, such as affirmative action policies in the U.S., could potentially be de-legitimized by scientific findings which suggest that there is no genetic basis for the category of race. In an era and context that continues to value scientific findings over all other explanations, we need to be attentive not only to the questionable explanatory power of these findings but also to the ways in which these findings function discursively beyond themselves when re-deployed and re-encoded within a broader political economic frame.

But how can BiDil be considered the first pharmacogenomic drug if there is no genetic basis for the selection of race as a variable? The trait of “African-Americanness” was selected not due to some common genetic characteristic shared by research subjects within this group but, rather, because many research subjects who self-identified as African-American responded well to BiDil during the first general population clinical trial for the drug, which was rejected by the FDA in 1996 (Kahn, “Exploiting Race”).



The variable of race was selected following this initial rejection by the FDA in a post hoc interpretation of research findings—in the sense that the variable of interest was defined after the results had been established—which is a further indication of the contingency of this knowledge. Race was selected from eighteen possible variables measured in the study, including “age, race, cardiovascular history, and clinical conditions (such as left ventricular ejection fraction)” (NitroMed in Kahn, “Exploiting Race” 744). The category of race as employed by this study, then, does not describe a common genetic characteristic or other biological feature that rendered this population more likely to benefit therapeutically from BiDil. Indeed, the developers of BiDil have publicly admitted that they do not understand why BiDil works to prevent heart failure in many research subjects who self-identify as African-American: “the mechanism of action by which it appears to have a beneficial effect on heart failure patients is unknown” (Kahn, “Exploiting Race” 742).

Despite this acknowledgement, the selection of race as a variable in this study has produced social and political implications on a scale that is simply unparalleled by other possible research variables (including age, cardiovascular history, and clinical conditions). The scale of the material and epistemological reverberations of this choice of variable underscores the way that this seemingly apolitical decision is not understood as contingent but, rather, as deliberate and necessary, as though race was the only possible research variable for the study. The selection of race as variable was trafficked as an assertion that race remains the single most important biological marker of difference of relevance to today’s medical breakthroughs, when it instead functioned as a cost-saving measure that has never been proven medically significant. It is imagined that decisions made concerning the design of studies are specifically not contingent—that there are no other possible designs for a study—and that a study is designed for a specific end: to maximize therapeutic benefit for a population, rather than to maximize profit. When race gets chosen (or even defined) as a biologically and/or medically meaningful trait, this act is understood by the public as one of necessity rather than one of contingency.

Research subjects in the BiDil trial who self-identified as African-American found themselves grouped together as participants in the trial not as a result of a genetic commonality but instead because many of these people received therapeutic benefit from BiDil. In the absence of any data pointing toward a biological basis for this grouping, it is likely that a number of other characteristics apart from “African-Americanness” are also shared by many of the research subjects within this group, including less

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“medically significant” characteristics, such as clinical conditions and living conditions. Both of the latter characteristics are known determinants of health, but it is also likely that this group of research subjects shares other characteristics that do not function as direct determinants of health. Indeed, while NitroMed has been unable to provide any scientific data supporting its hypothesis of a shared genetic trait that determines heart disease, a number of studies provide data that links heart disease to class. These studies suggest “links between hierarchies of social advantage and health” (Braveman et al. 196); in other words, annual income and access to resources (including education, health care, and nutrition) are inversely proportional to higher rates of incidence of hypertension and heart disease (American Heart Association). This pattern in which the distribution of health reflects the capitalist distribution of wealth is shown to be pervasive in the U.S. As Paula Braveman et al. write: “Those with the lowest income and who were least educated were consistently least healthy, but for most indicators, even groups with intermediate income and education levels were less healthy than the wealthiest and most educated” (194). While no *genetic* correlation has been found between racial difference and incidence of hypertension and heart disease, the dominant ideological (and financial) investment in genetic determinism ensures that particular questions concerning class, structural racism, and health cannot be asked from within the conceptual space opened up by the approval of BiDiI. More specifically, the attempt to biologize race distracts public attention from the crucial question in light of this data: Why do a disproportionately large number of people who self-identify as African-American live in social conditions that frequently lead to the development of hypertension and heart disease?

### **Narration as Scientific Method**

As Haraway has persuasively argued, scientific laboratories produce narratives of epistemological and material power (255). More specifically, the field of biology as a practice of ordering and classification produces meaning that is disproportionately influential both socially and politically. Biological research produces knowledge through modes of comparison that begin with the isolation of a single research variable, and, for this reason, the practice requires tools for categorization and comparison. In short, biology names and hierarchizes difference for the purpose of this research, and the name, hierarchical position, and significance, often understood through metaphor, get taken up in the social world untranslated. As a result, these crude differentiations often have deleterious social and political effects.

Particularly within the contemporary context of the rapidly expanding social impact of a pharmaceutical ideology of “personalized medicine,” what seems essential is a rigorous interrogation of the interests served by particular research questions that lead to active research on race-specific medicine in the first place. What barriers are being introduced to limit access to the rationale (and rationality) and practices behind the inestimable power and influence in imagining the landscape of medical research, health, and welfare for Americans? In what ways are scientific research practices themselves and the very structures through which scientific knowledge is created relics of a not-so-distant past when scientific research was the profession of the white male alone? If these barriers persist today, and they undoubtedly do, then the facts and data that emerge as research outcomes and their broader social and political implications must be scrutinized with a renewed sense of urgency. Further, these research results should be understood as products of institutions created to ensure the impossibility of weakening or dismantling the tenure of white privilege at a structural level.

Science Studies scholars, including C.P. Snow, Thomas Kuhn, Karl Popper, Paul Feyerabend, and Bruno Latour and Steve Woolgar, were among the first to question the purported objectivity of the knowledge and facts that had hitherto been uncritically accepted as indisputable results of an infallible scientific method. While the limitations to the length of this paper prohibit an extended consideration of the multiple relevant insights put forth by each of the aforementioned scholars, I will briefly discuss Latour and Woolgar’s critical examination of the everyday functioning of scientific research in the laboratory as an introduction to my own position on the construction of facts and statistics produced to legitimate the marketing of BiDil as the first race-specific drug.

In order to write *Laboratory Life: The Construction of Scientific Facts*, Latour and Woolgar undertook an anthropological study of the culture of the laboratory and the practices and conditions under which science produces knowledge and facts from the position of “inside outsiders” or “outsiders” (non-scientists) parachuted into this environment as observers. While their study has yielded innumerable insights informing current research in the field, their arguments have been met with a great deal of controversy, to the extent that they have been employed as ammunition in an ongoing debate over the validity of concepts such as objectivity, reason, and progress that culminated in the “Science Wars” of the 1990s. Latour and Woolgar’s insight posed the construction of fact and value at the site of the laboratory as not only inextricable from, but also a reflection of, a

particular set of interests arising out of a particular social and political context. Through an interrogation of the actual practices of scientists conducting research in a laboratory setting, Latour and Woolgar draw our attention toward the particular ways in which “the daily activities of working scientists lead to the construction of facts” (40).

When *Laboratory Life* was first published in 1979, Latour and Woolgar’s scrutiny of what were then perceived as the daily banalities of lab work was received with great suspicion: this study constituted an unprecedented shift as the critical attention that had previously been directed toward those holding positions of power was suddenly directed toward those perceived as laboratory technicians (since the technicians’ work had been understood as generative merely of research results and data, mechanically producing information rather than shaping the content of this data). By directing critical attention toward the processes through which scientific facts are produced, Latour and Woolgar intend to dispel beliefs concerning the purported infallibility of science and the truths it puts forth by contextualizing “scientific activity as just one social arena in which knowledge is constructed” (31). As such, they subject science to the same close scrutiny that is directed toward other social arenas out of which knowledge is produced.

Latour and Woolgar’s study remains influential today and offers a valuable lens through which to approach critically the machinery that underlies genomics and big pharma as mechanisms that contribute to the administration of the inequities that are inherent in the fractured social body required by capitalism in order to ensure its own reproduction. One of the most relevant insights offered by Latour and Woolgar to a discussion of BiDiI is their characterization of scientific research as a struggle to bring order and reason to an unwieldy collection of observations and data which chronically resist tidy, linear, and intelligible classification according to existing schema. Latour and Woolgar contend that research outcomes and the decisions made by scientists in order to reach specific outcomes must be understood as having arisen out of a practice that takes as its task the construction of “an ordered account out of a disordered array of observations” (34) or, in other words, the construction of a linear narrative as part of the practice of epistemic trafficking.

### **Inside the Laboratory of a Racial Project**

This characteristic defining feature of scientific inquiry—the organization and classification of diverse and divergent data, objects, and experiences—is also a defining feature of the racial project described by Omi and

Winant. The definition of the concept of race put forth by Omi and Winant describes with precision the particular way in which race is invoked by NitroMed: “race is a concept which signifies and symbolizes social conflicts and interests by referring to different types of human bodies” (55). NitroMed’s creation of BiDil as the world’s first race-specific drug must be understood as the launch of a novel racial project born on the terrain of genomics, yet the influence of this project extends well beyond this particular terrain. Omi and Winant define a racial project as that which “is simultaneously an interpretation, representation, or explanation of racial dynamics, and an effort to reorganize and redistribute resources along racial lines” (56). When the scientific practices described by Latour and Woolgar are employed by a racial project, a particular type of ordering and classification ensues. I will now turn to a discussion of how NitroMed both constructs “what race *means* in a particular discursive practice and the ways in which both social structures and everyday experiences are racially *organized*, based upon that meaning” through the development and marketing of BiDil (Omi and Winant 56).

A survey of the scholarship surrounding the production and reception of BiDil suggests a surprising failure on the part of commentators and critics to explicitly address the character of the interests driving the creation of a race-specific drug, both at the level of the researchers themselves as well as that of the pharmaceutical corporation NitroMed. Perhaps in reaction to a perceived discursive saturation following the debates of the “Science Wars,” it seems that the pendulum has begun to swing in the opposite direction: away from science as a site of critique. Oddly enough, many critics of NitroMed as the creators of the first race-specific drug (thus potentially ushering in yet another precedent and rationalization for continued unequal treatment on the basis of neat-and-tidy categorizations into units of racial difference) have been so fixated on the potential ramifications of race-based medicine that the production of the very facts or findings put forth to legitimate the race-specificity of BiDil has not been adequately assessed. An explicit critique of the actual conditions in which the scientific facts are produced is absent in the critical work addressing the development of BiDil. These conditions reflect not only corporate interests but also a cultural prejudice that is mentioned by several critics but which is not given sustained critical attention.

As I touched on earlier, Kahn emphasizes the contingency of the production of scientific objects and knowledge (as do many Science Studies scholars), showing that race was selected because it was a pre-existing, ready-to-hand category through which a trial could be conducted in the

least expensive manner possible, thereby maximizing profit for NitroMed as a biotech start-up that couldn't afford to finance the costs of bringing the drug to market through the larger trials that had previously been required by the FDA. The important point here is that while structural racism in the U.S. cannot be excised from this discussion, it is counterproductive to place too much emphasis on a conspiratorial analysis of the selection of race as research variable. This would be counterproductive because a dismissal of this process as racist prevents us from analyzing the form and processes through which scientific knowledge gets constructed, which are more complicated than merely an articulation of racism.

### **Ideological Investment in the Concept of Genetic Determinism**

As Steven Epstein argues, the genomic sciences employ the concept of racial difference in a manner that is both inconsistent and paradoxical, oscillating between two extremes: either denying the validity of any purported genetic basis for racial difference or strategically invoking racial difference as biological fact in order to support a pharmaceutical industry that depends upon the construction of new, race-specific markets in order to create profit for shareholders (223). Indeed, racial difference is invoked by genomics only strategically; the same science that produces data that entirely discredits the belief that there could be a genetic basis for racial difference also frequently reifies race as a non-negotiable biological marker of difference, but only when it is profitable to do so. Further, Epstein demonstrates, in a polemic directed against many authors who suggest that it must be acknowledged that there is at least *some* biological basis for race-based medicine through references to diseases such as sickle-cell anemia which are commonly understood to afflict African-Americans at a higher prevalence rate than other groups in the U.S., that “there is no such thing as a racially specific and exclusive disease” (212). Epstein shows that while a higher prevalence rate for sickle-cell anemia is found within populations whose ancestry can be traced back to Africa, if any categorization is made to facilitate more effective treatment for this disease, it must be made on the basis of geographic origin rather than on race (212). Arguing that sickle-cell anemia afflicts white populations in Africa with the same prevalence rate as is found in black populations, Epstein insists that if there is a biological basis for any method of differentiation between populations genetically, it will fall along the lines of geographic origin rather than race as phenotype. Of course, the NitroMed trial selected its

variable of self-identified African-Americanness precisely because this category of race can be neither genetically nor phenotypically defined.

Echoing Robert Schwartz's charge of racial profiling in genomics, Epstein draws attention to the spurious logic animating race-based medicine through an articulation of the highly problematic practice of "the use of group-based probabilities to make judgements about individual cases" (215). The fundamental problem at the root of this classificatory project emerges once again: no such thing as racial purity exists, and for this reason such attempts at grouping are flawed and highly suspect from the outset. Celeste Condit attributes this seemingly insatiable desire to categorize humans into groups based on this concept of racial difference reified by genetics to a Western tendency to understand the world through the lens of a "mind/body dualism" (246). She explains: "it is easier to imagine human biological difference as a product of different genes than as a product of different cultures, even though cultures produce the patterns of environmental toxins, nourishment, and stimuli that lead bodies to develop and decay in different ways" (246). I cannot endorse Condit's argument, however, considering her failure to indict systemic racism and the inequality inherent to capitalism as political-economic system. Condit's contention too closely resembles a neo-conservative discourse within which blaming the victim becomes a common practice through which the dominant race and class is alleviated of guilt and responsibility for their production and maintenance of the living conditions that would "lead bodies to develop and decay in different ways" (246).

I contend that the arguments put forth by these critics have reached a stalemate of sorts, in which the polemics orbit about what is posited as the central issue: whether or not there is any genetic basis for race-based medicine. This question alone takes the production of scientific fact by genetics for granted through its languishing within the bounds of a tired debate concerning whether or not the 0.012 percent of genetic variation between "racial categories" is substantial enough to potentially result in therapeutic advances for disease particular to what is named racial difference. While this sustained attention to the question of the critical import of genetic difference between races is problematic in the sense that this focus elides unacknowledged factors contributing to disease including unequal access to health care, education, housing, nutrition, etc., I suggest that a lack of close critical attention to the discourse and conditions of scientific production prevents us from recognizing drug research itself as a site in which systemic racist practices and beliefs are articulated.

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and beliefs are  
articulated.



A scientific indictment of class as a primary determinant of health—especially congestive heart failure—would undercut neoliberal capitalist political ideology in untenable ways. It becomes imperative, then, that the higher incidence of congestive heart failure experienced by people who self-identify as African-American is understood as biological rather than social in origin and cause. If this incidence of disease is understood as a symptom of a much larger structure within which class determines health, then the dominant ideological investment in the concept of genetic determinism becomes more clearly legible. This differential in incidence of disease is technologized and biologized in order to justify further investment in genetics research—for as long as genomic determination of disease remains not quite fully mapped or understood, then the public’s hope for a technological fix to health problems remains ignited. The alternative—an admission that genetics works together with environmental factors in the determination of disease—would provide an unwanted scientific call for a redistribution of public spending and resources such that material inequalities that determine disease would be ameliorated. The knowledge trafficked by the approval of BiDil is not embedded within a complicated narrative that acknowledges that cost-saving decisions on the part of NitroMed has produced a contingent and ideologically-suspect form of knowledge, but instead the knowledge is understood as a discovery or unearthing of some essential information, and the category of race gets reified.

### **On the Production of Racialized Knowledge**

In order to reorient the debate away from a critical analysis of the narratives constructed by genomics as puppet of big pharma—a crucial site of debate, to be sure, but also one that has dominated critical work at the expense of other untapped sites of intervention—it is necessary to take one step back and attempt to understand the animating logic of the institutions that work to construct scientific facts in the first place. As Amri Johnson reports, less than 1 percent of tenured scientists working out of the National Institutes of Health (NIH) in the United States self-identify as African-American (12). This shameful number speaks to a stubborn set of barriers that should be understood as being maintained today, in large part, through the reproduction of a dominant ideology of colorblindness, which maintains white privilege in a particularly insidious manner. Further, as Ruth Müller suggests, the patriarchal history of science in the West is problematically bound up with conceptions of objectivity in science in the sense that all potential scientific researchers apart from “the

bourgeois white man” have been excluded from the laboratory based on the assumption that their subject positions rendered them excessively “socially and emotionally bound, attached and tied” to contribute to the discovery of objective fact (3).

These insights invite an analysis of the structural barriers limiting participation in the scientific production of knowledge with consideration given to the following two points. First, the fact that the daily tasks of the laboratory, including data collection and analysis, are carried out largely by white Americans: those who have a stake in the racial hegemony their research supports. Second, the fact that the consequences of such a disproportionately low number of African-American and other racialized scientists contributing to the production of an institutional body possessing such enormous influence and capital as the NIH are dire and have not yet been fully recognized as such.

The consequences of this systemic exclusion are multifarious, but the particular consequence I wish to discuss is the deficit in the biomedical imaginary. I do not only contend that a deficit in African-American scientists will inevitably lead to an inadequate representation of African-American interests (as silenced by the dominant voice of science as pawn of white privilege) but also that the types of questions asked, the limits to inquiry, the potential of discovery, and the concepts employed with which to understand and visualize the problems at hand are in themselves intrinsically representative of the white privilege that continues to structure the institution out of which this research arises. While the first consideration I mention lends itself to empirical investigation in a certain sense, the second consideration is abstract and conceptual, which could potentially account for the fact that it has largely escaped the attention of critics.

As Kahn suggests, the production of BiDil was a strategic endeavour from its very conception, carried out in the interest of securing substantial profit for NitroMed. Because NitroMed held a patent for a race-specific drug, it became increasingly desirable to obtain FDA approval for a race-specific indication in order to create the potential for new race-specific markets that would inevitably generate increased profits. In order to take advantage of its patent, NitroMed needed to construct a deficiency in the existing landscape of therapies in order to sell BiDil as a breakthrough miraculously appearing “just in time” to fill the artificial need constructed as therapeutic gap. This was not a tremendously difficult undertaking for NitroMed as a great deal of research indicating a disparity in rates of affliction by particular diseases according to “racial difference” already existed and was thus available for NitroMed to draw from (Kahn “Getting

the Numbers Right” 475). As Kahn suggests, NitroMed found its “golden ticket” in a single statistic published in several leading scientific journals in 2001 and 2002 indicating a 2:1 ratio between racial groups’ afflictions with heart disease (“Getting the Numbers Right” 475). This statistic showed that the mortality rate of African-Americans afflicted by heart disease was twice as high as the mortality rate of other groups in the U.S. as defined by racial categorization. NitroMed pounced on this statistic, viewing it as the ideal infallible alibi that would allow the corporation to carry out its business plan under the guise of a “therapeutic solution” to an emerging epidemic. As Kahn contends, within the drug development and marketing team at NitroMed, “the statistic was being used to rationalize a search for race-based biological differences” as the necessary precursor to the attainment of a larger and more insidious goal: that of “reconceptualizing race in biological terms” (“Getting the Numbers Right” 477).

As Dana Tagaki so persuasively argued in the context of the debate over Asian-American admissions in *The Retreat from Race: Asian-American Admissions and Racial Politics*, statistics are too often accepted at face value without subjecting to critical analysis the ways in which data is collected and facts are constructed. Tagaki provides a critique of the lack of critical attention directed toward the rhetoric and discourses that present statistics as truth through a variety of different methods, arguing that we are drawn instead to the perceived stability and intelligibility of empirical facts. The FDA approval of BiDil and the subsequent debate over race-based medicine should be understood as yet another instance in which the debate “pivoted not on the facts per se but on the interpretations of the facts” (Tagaki 11). NitroMed’s strategic interpretation of the 2:1 ratio statistic indicating that the disparity in mortality from heart disease falls along the lines of racial difference was bolstered with dubious genetic evidence supporting a biological basis for the increased mortality rate. As Kahn contends, the research that resulted in the release of the 2:1 ratio statistic did not cite a cause for this disparity in mortality rates. Indeed, it would be impossible to determine a single cause for the increased mortality rate, especially considering the highly contested status of any purported genetic basis for categorization on the basis of race in the first place. NitroMed managed to mobilize this statistic to construct a deficiency in the pharmaceutical market by suggesting that the creation of a drug designed to the specifications of this niche—the particular susceptibility of African-Americans to heart disease—was not only possible, but necessary, and urgently needed.

## Inclusion as Commodification

In *Inclusion: The Politics of Difference in Medical Research*, Epstein argues that the institutionalization of the concept of inclusion in medical research can cause more harm than good. In an exemplary operation of Barthes's ex-nomination, medical researchers had considered the white male research subject to be the normative standard in trials, and the research results obtained testing done on these subjects to be the baseline from which norms for populations constructed as deviant from this white male standard (for example, racialized groups, women, children, etc.) would be compared. These deviant groups were understood to be essentially different from the normative standard, and tailored treatment plans for these groups were developed accordingly (but always in relation to the standard). During the 1980s, advocates for these groups did the important work of lobbying to extend the right of participating in clinical trials as research subjects extended to these previously excluded groups, arguing that these groups could not be receiving the best possible medical treatment if their treatments were always a derivative form of a standard from which they might fundamentally differ. Inclusion in the testing phase was understood as purely beneficial,<sup>3</sup> as it was equated with the ability to develop the best possible treatment. Epstein argues, however, that the biopolitical paradigm of inclusion works to biologize and essentialize difference as defined by researchers, and that, as a result, the category of research subjects seeking inclusion is often permitted to participate in a trial for the purposes of profit creation rather than therapeutic benefit to patients.

Demonstrating that the U.S. has proven itself quite capable of producing scientific theories and data to justify racist practices, policies, and ideologies throughout its history (including the use of craniometry to lend legitimacy to practices of slavery in the U.S.), Troy Duster argues that the financial incentive to biologize race continues to increase, and not merely in potential profits through the sale of race-specific pharmaceuticals (495). Echoing Angela Davis's argument that the American prison industrial complex depends on the continued imprisonment of racialized people to remain profitable, Duster suggests that genetic research on inherited traits of "criminality" and genetic research on racial categories

<sup>3</sup> Marginalized identities were prohibited from participating in clinical trials as research subjects during the 1980s (and thus also excluded from the therapeutic benefit that sometimes attends this participation) following a shameful history of exploitation. The most infamous study of this kind in recent U.S. history is the Tuskegee Syphilis Experiment, which continued to be conducted even after the Declaration of Helsinki was established in 1964 with the aim of preventing the exploitation of research subjects by requiring informed consent.

The channels through which scientific discourse is trafficked are worth scrutinizing to assess their role in propagating these ideas.

will converge, thus lending scientific justification to this racist practice (495). Duster writes:

[T]he next decade will witness an outburst of behavioral genetics research, buttressed by the molecular reinscription of race tying crime to biological processes, and then correlating those biological processes to race. It is not beyond conjecture that it will be an African-American who will lead the charge, fully supported by the Pioneer Fund or some equivalent well-funded, conservative think tank or funding source (495).

Of course not all scientific knowledge produced is ideologically identical to its funding source, but when science is employed as a tool to justify racist practices, it becomes particularly harmful. The channels through which scientific discourse is trafficked are worth scrutinizing to assess their role in propagating these ideas. Even minor changes to news media reporting practices, educational institutions' teaching, and artistic and pop cultural engagements with scientific discourse would alter the ways in which this knowledge gets taken up. If details concerning the conditions under which the research was conducted could be provided, pointing to the contingency (rather than inevitability) of this knowledge, it could become possible to alter conceptions of science, and, as a result, science might begin to be interpreted as a narrative developed within a particular context rather than as authoritative, infallible truth.

The deleterious effects resulting from the epistemic trafficking enacted by the FDA's approval of BiDil are undeniable. First, race is understood as a natural, biological category rather than a social one, which works to legitimize social and political acts of racism. Second, heart disease gets constructed as a race-specific genetic pathology rather than a disease that is produced by poverty and inadequate access to resources that maintain health. Third, the conditions under which knowledge is produced get effaced; a disproportionately white group of scientists selects a cost-effective research variable of African-Americanness without taking into account the social and political implications of this selection of variable, and this decision gets affirmed and transformed into indisputable fact by the knowledge-constructing agency with an enormous amount of political power in our science-revering society: the FDA.

I hope to have demonstrated how the spectacle of a pharmaceutical panacea being ushered in by the FDA to address such a pronounced articulation of insidious and pervasive structures of inequality endemic to social life throughout the U.S. worked to obscure systemic causes of this disparity in mortality rates. The scandal of race-based medicine has

garnered such a frenzy of attention that more long-standing and seemingly banal causes of higher rates of heart disease in particular populations—including systemic racism resulting in poverty, lack of access to adequate living conditions, health care, nutrition, education, etc.—are not addressed, and thus potential solutions to these urgent problems are not yet being imagined.

Biological discourse trafficked through the approval of BiDil perpetuates this narrative of cause and effect that limits our understanding of the mechanisms at work in the development, treatment, and prevention of disease. This narrative is a normative one in that it maps disease onto an as yet unidentified genetic trait and prescribes a pharmaceutical solution for this alleged pathology, also moralizing the question of access to the drug: suggesting that once therapeutic benefit has been proven, denying patients access to this drug would do violence. Discursive constructions trafficked through scientific narratives do not merely produce a stratified set of treatment options; they also produce profound material, economic, cultural, and legal implications outside the realm of health care.

## Works Cited

- Braveman, Paula, Catherine Cubbin, Susan Egerter, David R. Williams, and Elsie Pamuk. "Socioeconomic Disparities in Health in the United States: What the Patterns Tell Us." *American Journal of Public Health* 100.4 (2010): 186–96.
- Condit, Celeste. "How Culture and Science Make Race 'Genetic': Motives and Strategies for Discrete Categorization of the Continuous and Heterogeneous." *Literature and Medicine* 26.1 (2007): 240–68.
- Conen, David, Robert Glynn, Paul Ridker, Julie E. Buring, and Michelle A. Albert. "Socioeconomic Status, Blood Pressure Progression, and Incident Hypertension in a Prospective Cohort of Female Health Professionals." *European Heart Journal* 30.11 (2009): 1378–84.
- Davis, Angela Y. "Sick and Tired of Being Sick and Tired: The Politics of Black Women's Health." *The Black Women's Health Book*. Ed. Evelyn C. White. Seattle: Seal Press, 1990.
- Epstein, Steven. *Inclusion: The Politics of Difference in Medical Research*. Chicago: University of Chicago Press, 2007.
- Haraway, Donna. "Race: Universal Donors in a Vampire Culture." *Modest\_Witness @Second\_Millennium FemaleMan@\_Meets\_OncoMouse™: Feminism and Technoscience*. New York: Routledge, 1997. 213–66.

- Johnson, Amri. "Where Are the Black Scientists?" *Scientist* 19.21 (2005): 11–13.
- Kahn, Jonathan. "Getting the Numbers Right: Statistical Mischief and Racial Profiling in Heart Failure Research." *Perspectives in Biology and Medicine* 46.4 (2003): 473–83.
- . "How a Drug Becomes 'Ethnic': Law, Commerce, and the Production of Racial Categories in Medicine." *Yale Journal of Policy, Health, and Ethics*. 2004: 1–46.
- . "Ethnic Drugs." *Hastings Center Report* 35.1 (2005): C3.
- . "Race, Pharmacogenomics, and Marketing: Putting BiDil in Context." *The American Journal of Bioethics* 6.5 (2006): W1–W5.
- . "Patenting Race." *Nature Biotechnology* 24.11 (2006): 1349–51.
- . "Exploiting Race in Drug Development: BiDil's Interim Model of Pharmacogenomics." *Social Studies of Science* 38.5 (2008): 737–58.
- Koenig, Barbara A., Sandra Soo-Jin Lee, and Sarah S. Richardson. "Introduction: Race and Genetics in a Genomic Age." *Revisiting Race in a Genomic Age*. Eds. Barbara A. Koenig, Sandra Soo-Jin Lee, and Sarah S. Richardson. New Brunswick: Rutgers UP, 2008. 1–20.
- Latour, Bruno, and Steve Woolgar. *Laboratory Life: The Construction of Scientific Facts*. Princeton: Princeton UP, 1986.
- Müller, Ruth. "Bound to Nothing but Science Itself? Academic Life Science Careers and the Nomadic Disposable Research Scientist." Unpublished article.
- Omi, Michael, and Howard Winant. *Racial Formation in the United States: From the 1960s to the 1990s*. 2nd ed. New York: Routledge, 1994.
- Roberts, Dorothy. "Race and the New Biocitizen." *What's the Use of Race? Modern Governance and the Biology of Difference*. Eds. Ian Whitmarsh and David S. Jones. Cambridge: MIT Press, 2010. 259–76.
- Stepan, Nancy Leys, and Sander L. Gilman. "Appropriating the Idioms of Science: The Rejection of Scientific Racism." *The "Racial" Economy of Science: Toward a Democratic Future*. Ed. Sandra Harding. Bloomington: Indiana UP, 1993.
- Tagaki, Dana Y. *Retreat from Race: Asian-American Admissions and Racial Politics*. New Brunswick: Rutgers UP, 1992.
- Winkleby, M. A., D. E. Jatulis, E. Frank, and S. P. Fortmann. "Socioeconomic Status and Health: How Education, Income, and Occupation Contribute to Risk Factors for Cardiovascular Disease." *American Journal of Public Health* 82.6 (1992): 816–20.