Biomedical Ambiguity

Race, Asthma, and the Contested Meaning of Genetic Research in the Caribbean

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imagine their alternatives.[11] With the plural uses of these anomalies, cultural values are simultaneously experienced, made real, and questioned. Throughout, this work looks to the uses of diagnostics, of pharmaceuticals, of disease, of food, to find such anomalous objects, to see the ways biomedical categories are simultaneously questioned and effected. I explore categories and things (including scientific, technological, capitalist, and medical ones) as made and used in mutually inconsistent ways.

Part of this plurality is ambivalence: I became interested in the ways that biomedical practices such as genomic research, pharmaceuticalization of health, and the link between race and disease were simultaneously valued and critiqued within the logics I encountered. Geneticists, Bajan families, medical practitioners, and state officials all expressed conflicting evaluations and conceptualizations of the practices in which they were involved: for example, internationalism could be a source of pride and bitterness, biomedical categories could be laughed at and utilized, and medical identities could be contradictory. These moments of ambiguity and reflexivity seemed to be critical to the creation and implementation of biomedical meanings of "race" and "asthma." These contradictions are not simple reflections of political economies (whether of institutions, knowledge, or affect). I mean here to search out what James Boon (1998: 65) calls "resonant details," moments of irony, of anomaly, of surprising connections and reversals by which meaning is made. My argument is that the ambivalent interpretation of processes like pharmaceuticalization and biomedicalization found among those engaging in them—officials, physicians, patients—is central to both their entrenchment and instability.

This is an exploration of the biomedical vernacular: the ways genetics, asthma, race, nation, and environment are used culturally, and the mutual extremes and excesses that make such meanings contradictory. The relationship of such vernaculars (including those of officials) to official discourses (including anthropology's) is a vexing problem. I mean here to give an account of the ways discourses determine political economies, mute alternatives, the way identities are made of such categories, while being attentive to the way people are not fixed within these logics, that categories include the possibility of their negation, that cultures, families, individuals, and communities reflect on their categories in excesses that cannot be contained in any analytic approach. This book is an attempt to oscillate between these contradictory emphases rather than choose one or blend them into a consistent whole.

Chapter 1

Contestations of Race

Race is a thorny topic in American biomedicine today. As Morris Foster and Richard Sharp (2002) have argued, the Human Genome Project created interest in new applications of the relationship between genetic predispositions and race. A growing body of research attempts to link racial disparities in the prevalence and severity of diseases—for example, cancer, heart disease, asthma—with genetic propensities. The genetic basis for response to medication—including genes involved in drug-metabolizing enzymes and chemotherapeutics—has been similarly differentiated by racial categories. The Food and Drug Administration (FDA) has recently approved a heart medication, BiDil, that is the first pharmaceutical produced for and marketable to a particular racial group (see Kahn 2004 for a subtle discussion of the development of BiDil). The approval of BiDil, as with other projects based on purported biological differences between races conducted by the pharmaceutical and biotechnology industries and NIH-sponsored academic teams, has resulted in contentions over whether biological races exist, and if so, whether such categorization is medically relevant.[1] The contested field of race in bioscience is exacerbated by the increasing trend toward international biomedical research. As the FDA, NIH, and the pharmaceutical industry attempt to incorporate the results of this research, new links are being made between racial groups in the United States and populations in

Japan, the Middle East, Africa, and Latin America. The multiplicity of race is constitutive of this extension of biomedical work.

Race as Biological

Critics have argued that biological meanings of race should not be used in medical research. Many note the often-cited conclusion that greater genetic variation exists within groups than between them (Jenny Reardon (2005: 35) traces this datum, now found by many studies, to biologist Richard Lewontin). Craig Venter, the founder of the company that led the private sector's role in sequencing the human genome, uses this conclusion to argue against the use of race in clinical trials, in favor of an individualized approach (Haga and Venter 2003). Shields et al. (2005) argue that more precise ways of defining populations to study disease are available that obviate the need for self-identified race as a proxy for biological connections in biomedicine. Others point to the problems resulting from correlations of race with disease. Lee et al. (2001) and others (Duster 2003; Foster 2003) argue that the one-to-one association of sickle cell anemia with black race resulted in discriminatory mandatory testing policies and underdiagnosis of white patients with the disease.[2] The potential for discrimination in medical care has also been raised with the current heart medication research: two health care industry consultants found evidence that physicians incorrectly interpreted the research to mean that black patients should not be prescribed the heart medication angiotensin-converting enzyme (ACE) inhibitors (Masoudi and Havranek 2001). Biomedical researchers have responded to these critiques of the use of biological race in medicine by arguing for the necessity of accounting for all of the causes, genetic or otherwise, in the disparities in disease prevalence and severity between different races.

Such debates, in the *Journal of the American Medical Association, Nature,* the *New England Journal of Medicine, Lancet,* and other medical and scientific journals, often draw on studies by population geneticists who categorize races on the basis of genetic frequencies. In this research on genetic diversity, groups are selected as racially distinct, and differences in genetic frequency are studied. Population geneticists, as Reardon (2005) has shown, disagree on how best to categorize race. Determining the race of the population being studied is one such source of dispute (Rosenberg et al. 2002: 298): for example, self-reporting is contrasted with inferring ancestry through genotyping. Additionally, these projects usually involve populations from different countries, and which categories are applicable, particularly in the case of Caucasian, is disputed. Population geneticists also disagree

over the genes to be used, with some advocating particularly informative genetic markers and others arguing for randomly selected genes. Such categories rely on concepts of purity in an imagined past, as populations are measured according to an admixture of race-specific genes—for example, the amount of European genes in African Americans (Esteban et al. 1998; Graves 2001: 201–3). These posited distinct histories are also considered significant for study design, as more "recently admixed populations" are understood to provide different kinds of information than do groups considered more genetically distinct (Esteban et al. 1998). One of the generally accepted conclusions of this research is that Africa has the largest amount of genetic variability, due to the history of the human population.

Population genetic research on human diversity is variably incorporated into discussions about the use of race in biomedicine. There is a discourse arguing for the integration of geographic ancestry research into biomedical diagnostics of race and disease (anthropologist Duana Fullwiley is tracking the inclusion of a particular technology to conduct such research). These geneticists debate whether races that are distinguishable by particular genetic markers would be distinguishable by biomedically relevant genes (on this debate, see, e.g., Jorde et al. 2001; Wilson et al. 2001; Romualdi et al. 2002). But most agree on employing evolutionary history and population genetics in current biomedical research. Mark Shriver is an anthropologist whose research purports to correlate skin color and self-identification with genetic admixture of European, African, and other sources of ancestry; he uses his research to try to locate biological bases for differences in disease prevalence between races (Gower et al. 2003). Genaissance is a biotechnology company working on pharmacogenomics that particularly advocates such analysis. In an article in *Science* comparing genetic variability between populations labeled Hispanic Latino, African American, and Caucasian, Genaissance researchers argued for the use of self-reporting of race for genomic medicine, concluding, "Our observations demonstrate the necessity of understanding patterns of human genomic evolution if genomic variability is to be used as a tool in human health research" (Stephens et al. 2001: 492).

However, such use of genetic diversity research in biomedical disputes over race is rare. In my experience, researchers working on the genetics of diseases and the pharmacogenetics of drug responses employ racial distinctions largely independent of studies on genetic ancestry and diversity. Some of the results of such research are deployed: the datum that Africans have the greatest genetic variability is frequently used in support of genetic research on people of African descent as being particularly informative. But biomedical research and genetic diversity projects have differing

perspectives on the purpose and method of defining races. One biomedical researcher explained to me the difficulties that Genaissance was having in attracting interest among pharmaceutical companies with its population history approach. Genetic diversity research involves categorizing human populations by geographic areas and specific genetic loci chosen for their correlation with these areas; such focused designations of race, geographic origin, and genetic markers are of little use to most medical researchers and of less use to practitioners. In medical research, the genetic history of a population analyzed by human diversity geneticists is at times invoked, but this operates as a kind of atemporal history used to speculate about results rather than as an organic variable that produces new research questions. Instead, biomedical research primarily examines differentiation in medically relevant genes between races identified through more traditional means. These researchers most often use a utilitarian definition, based on the racial meanings employed in the census, geographic site of research, physical appearance, or the participants' own identification on a questionnaire. This production of race-disease links draws on historical, medical, and scientific meanings of race. The categories deployed—such as Asian, African American, Caucasian—emerge out of this historical complexity, informing the current biomedical use of the genetics of populations. The anthropological interest, then, is to find not the meaning of race in biosciences, but rather the techniques by which race can have so many meanings in bioscience. Race gains its facility as a relational discourse in exchange with other meanings and categories. Biological meanings of race draw from social, cultural, and economic ones.

The Medicine of Race, Blood, Disease

As Waltraud Ernst (1999b) points out, the ambiguities and contradictions in ideas of race have historically been a source of the concept's strength within science. Historian Nancy Stepan (1982) shows that the science of race in the nineteenth century created hierarchies of, variably, Africans, Mediterraneans, Jews, Caucasians, Asiatic, gypsies, and other groups. Racial theories were also used to constitute political legitimacy of nation-states as Western Europe was divided into the racial types of Celts and Anglo-Saxons, Gauls and Franks, Germans and Slavs (Augstein 1999).[3] This relational character of racial classification—its ability to integrate divergent, sometimes contradictory contents—has been foundational to its extensive scientific and medical use.[4] Race in this sense has a valued polysemy. This variability was belied by highly precise and technological measurements in the nineteenth-century

science of race; for example, skull measurements were used to give exact numbers on intellect, moral worth, capacity for civilization, level of spirituality, cultural complexity, technological sophistication, and so on. The result was a science that examines visibly physical characteristics as constituting historical trajectories of biologically distinguishable populations. Race was in the blood in this nineteenth-century science, carrying taboos of mixing and association with disease in perspectives on immigrants, populations in the colonies, and those considered black in the United States (see Banton 2000; Foucault 2003; and Khan 2004).[5] The particular content of each classification—which groups were included—has been less stable than this emphasis on precise measurements of a characteristic carrying multiple associations.

In the twentieth-century United States, the scientific link between blood, race, and disease became genetic. In the 1920s and 1930s, the genetics of race was mutually constituted with the genetics of disease. Daniel Kevles (1995) shows that racial distinctions were considered significant to human genetics from the inception of the field. Racially mixed populations were valued as genetically variable, taking the (conceptual) place of hybrids made in controlled experiments (193). This mixing relied on the idea of pure groups, whether as abstract ideal populations or as in existence somewhere (i.e., the races prior to or unaffected by hybridization). The scientific interest in the genetics of racial subgroups helped generate the emerging human genetics. For example, in Kevles's account, the genetics of blood groups (worked out in 1911) became an object of extensive research only in the 1930s through the differentiation of races by blood group frequency (195). Race was positioned with twin and family studies as sources of particular genetic knowledge:

> In 1931 [...Lancelot] Hogben called for the establishment of what amounted to a multi-part human genetic research program: twin studies to sort out the relative roles of heredity and environment; measurements of variability within hybrid populations to test for "race"-specific characters; pedigree investigations, especially from medical records, for determining the genetic basis of disease; and surveys of consanguinity, to decide whether certain diseases or physical traits might be the product of homozygous recessives. (198)

This type of a diagnostics of race reframed former meanings, geneticizing the blood-race links, pure races, and the associations of disease and race.[6]

In the United States, the clearest association of blood, race, disease, and genetics in the early twentieth century was sickle cell anemia. Keith Wailoo

(1997: 134–61) shows the ways that Mendelian genetics was used in the 1920s to shape the meaning of sickle cell anemia as a "potential disease" within "negro blood." Such links made between diseases, races, blood, and heredity were implicated in brutal practices toward particular populations, as Wailoo, Kevles, and others have documented, including in immigrant sterilization and other eugenics programs (Kevles 1995), medical discrimination (Wailoo 1997), and in the Tuskegee study on syphilis (see Jones 1981).

In the 1940s, the association of race research with Nazism resulted in changes in science in the United States. In her historical analysis of race in twentieth-century science, Reardon (2005) shows that new moral and political stances were taken in opposition to the association of racial distinctions with moral and mental hierarchies. Population geneticists distinguished their work from political implications that were no longer tenable in the climate of the United States. Reardon points out that these shifts did not include a widespread rejection of a biological basis for racial distinctions, but instead geneticists and anthropologists attempted to delineate more precisely the biological meaning of race. The genetic links of blood, race, and disease became an explicit object of evaluation in this process. Debates about the biological basis for race in the middle of the century emphasized the moral meaning of these methodological quandaries of racial categorization.

Moral Analytics

In 1962, Frank Livingstone (1962: 279) made his much-cited comment, "There are no races, there are only clines." In the discussion that followed this statement over the next two years in the pages of *Current Anthropology,* the moral, ontological, and strategic meanings of race were explicitly placed in opposition.

This discussion continued anthropological arguments over the physiological basis for race going back to the late nineteenth century.[7] Franz Boas radically destabilized contemporary concepts of race as a linguistic, cultural, and even physiological entity with his research on language; cultural change; and changes in body shape among immigrants toward U.S. norms. He wrote:

> Added to this is the failure to see that the many different constitutional types composing a race cannot be considered as absolutely permanent, but that the physiological and psychological reactions of the body are in a constant state of flux according to the outer and inner circumstances in which the organism finds itself. (Boas 1983: 255)

Faye Harrison (1995: 54) notes that Boas was not alone in conducting such research critiquing the science of race that linked mental and physiological characteristics; his work was complemented by that of other anthropological researchers. Boas's students subsequently took up such positions. Ashley Montagu's anthropologically influential work, *Man's Most Dangerous Myth* (1997), similarly extended critiques of the biological, intellectual, linguistic, and cultural characteristics grouped under the term "race."[8]

Theodosius Dobzhansky (1962) responded to Livingstone's statement by arguing that the quandary was a problem of nomenclature. For Dobzhansky, racial classifications were analytic designations, distinct from the ontological existence of races (which was indisputable): "There is nothing arbitrary about whether race differences do or do not exist, but whether races should or should not be named, and if they should, how many should be recognized, is a matter of convenience and hence of judgment" (280). Dobzhansky's framing restricted arguments against the use of race to whether particular terminologies should (morally, socially, occasionally scientifically) be employed.[9] When Livingstone responded to this formulation (1963), he emphasized the historical and cultural meanings that, he maintained, infused this proposed ontology. He drew attention to the socially significant types of racial classifications that were consistently made: "It is curious that we haven't yet discovered the valid races of Europe although perhaps more is known about these populations than any others. But the implication remains that if we keep collecting data, we will someday discover how many races there are in Europe. I don't believe it" (200). This positioning of race as an ontological, epistemological, or nomenclatural problem was taken up in subsequent anthropological encounters. Two years later, a series of responses between geneticists and anthropologists in *Current Anthropology* extended the discussion between Livingstone and Dobzhansky. C. L. Brace (1964) offered support of Livingstone's perspective. Carleton Coon (1964: 314), whose work on race brought considerable criticism from Montagu (see Montagu 1963a), argued that boundaries between races did not need to be arbitrary if "one considers the existence of racially intermediate zones as separate categories." Earl Count (1964: 315) argued that "'trait' varies in meaning under atomistic, typological, populational, processural, configurational thinking." At stake here was the question of the significance of race as a methodological tool, a physical reality, and a scientific designation.

This moral and epistemological contestation over the scientific uses of race is today integral to debates in biomedicine. One could trace the issue of racial physiological classification schemas as epistemological or ontological at least to Georges-Louis Leclerc de Buffon and Carolus von Linnaeus.

What is particular to the discussion above is the explicit interweaving of scientific, political, and medical meanings, by which moral claims could be made. Dobzhansky (1962: 280) ended his response to Livingstone by invoking the morality of the debate: "To say that mankind has no races plays into hands of race bigots, and this is least of all desirable when the 'scientific' racism attempts to rear its ugly head." In Livingstone's response, he also positioned the dispute morally, although differently: he argued that the high frequency of diseases such as sickle cell anemia among Turks, Africans, Indians, and others had a different explanation (natural selection) than other traits that are shared through historical links, making racial classification inextricable from its former associations (1963: 199–200). Today, biomedical approaches to race and health similarly emphasize the moral meanings of race as an epistemology and ontology. This ethical significance takes the form of medical need, social redress, and political implementation.

Urgent Science

The science of race and disease has produced a wealth of literature correlating race with disparities in disease prevalence, diagnosis, treatment, and mortality and morbidity rates (Graves 2001; Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care 2002; Good et al. 2002). For instance, African Americans have higher mortality rates for tuberculosis, diabetes, pneumonia, ulcers, and heart disease (Graves 2001). Researchers have shown disparities in health insurance, health care delivery and availability, and exposure to hazardous waste and environmental toxins (Graves 2001; Smedley et al. 2003). African Americans and Hispanic populations have been found to have higher rates of asthma in the United States, with considerably higher morbidity and mortality rates (NCHS n.d.; Nsieh-Jefferson 2003).

These disparities give a moral significance to genetic research on race and disease. The geneticists I talked with frame their projects in terms of intervention on such disparities, through the localization of particular genetic predisposition to disease or to discern medications that are particularly effective among minorities (see Shields et al. 2005 for a multidisciplinary discussion of this framing). Including racial or ethnic groups in genetics research is often thought to be important both by geneticists and by individuals considered representative of ethnic communities (e.g., see Reardon's 2005 discussion of the Genomic Research in African American Pedigrees project (G-RAP) designed by Howard University geneticists and biostatisticians, intended to create a linkage map of African American genomes).[10]

Medical markets are also critical to this gene-race-disease research. Such research combines the moral agenda of redressing disparities with the economic value of having access to genomic databases, biological samples, patients, and medication target populations. This market and moral interest gives gene-race-disease research an urgency. Regulatory, commercial, and research institutions in this context create a fractured approach to race.

In the United States, this contestation occurs primarily through government and private institutions interested in categorizing populations for medical intervention, such as the NIH, FDA, and pharmaceutical industry. In recent years, each of these institutions has contended with conflicting approaches to racial categories. These spaces of public ambiguity have opened through increasing emphasis by the social sciences on race as socially constructed; increasing pressures to address minority disparities in health; and the move to conduct biomedical research in countries outside the United States and Western Europe, resulting in the quandary of how to make populations of resource-poor countries representative of U.S. and U.K. populations.

NIH on Race

Ambiguities in the biomedical uses of race are highly visible in NIH practices. Since 1993, with the Revitalization Act, the NIH has had a policy advocating the inclusion of "women and members of racial and ethnic groups" in clinical research (see Reardon 2005). Sandra Lee, Joanna Mountain, and Barbara Koenig (2001: 42)[11] note that the NIH uses the racial classification scheme of the Office of Management and Budget (OMB), also used by the U.S. Census Bureau (see also Shields et al. 2005). However, the OMB (as these authors point out) considers race and ethnicity categories sociocultural constructs, in accordance with the suggestions of the American Anthropological Association. The result of these policies has been a diversity of views of race and ethnicity in NIH-funded research. Owing to the policy of considering race a social cultural construct, researchers applying for NIH funding almost ubiquitously use the term "ethnicity" instead of "race." Ethnicity in this sense usually involves self-identification on a questionnaire as one of the U.S. census populations, and the uses of this identification in research vary from biological to social meanings in NIH-funded projects (Lee et al. 2001; on the radical variation in methods of determining race in biomedical research, see Shanawani et al. 2006). Contradictory meanings of race are thereby incorporated into policy and practice. The National Human Genome Research Institute's Haplotype Map (Hapmap)

project, for example, is a collaborative effort that collected genotype information from three populations taken to be representative of different ethnicities—ninety individuals in Utah, ninety in East Asia, and ninety in West Africa—in an attempt to identify large blocs of genetic markers that can be used to facilitate biomedical research. Medical genetic researchers use this database to analyze their data—for example, excluding particular individuals from their analysis because they are genetically shown to be "of non-European ancestry" based on genotypic comparison with the Hapmap data (see, e.g., Wellcome Trust Case Control Consortium 2007). As a result of these contingencies of practice, ethnicity often becomes a biological entity with medical relevance in medical literature. These uses of "race" and "ethnicity" operate distinctly from the evolutionary history of genetic diversity research. Instead, self-identification by questionnaire is taken to more or less represent biological differences between populations, and the disputed question is whether a particular disease is influenced by such differentiation.

FDA on Race

This contradictory set of approaches to race is also found in medical regulation. In 1998, the FDA began requiring pharmaceutical companies to submit analyses of safety and effectiveness in "racial subgroups" for all new drug applications (Temple 2002). In 2003, the FDA issued a document entitled "Guidance for Industry: Collection of Race and Ethnicity Data in Clinical Trials." These principles are not legal responsibilities, but they are highly influential in the collaborative process between the pharmaceutical industry and FDA of getting drugs to market. The document is specifically designed to account for the changes occurring as a result of the trend of clinical trials being conducted in other (generally poor) countries through contract research organizations (see Petryna 2005 for an exploration of this phenomenon). Given the FDA's role of regulating medicines for U.S. consumption, this shift has caused concerns at the FDA over whether these populations are ethnically representative of U.S. populations.

In the Guidance document, the FDA reiterates the OMB's stance on race:

> The OMB stated that its race and ethnicity categories were non-anthropologic (in other words, not scientifically based) designations but, instead, were categories that described the sociocultural constructs of our society. (Food and Drug Administration 2003)

The document goes on to list various physiological and biological racial distinctions that are considered medically relevant:

> For example, in the US, Whites are more likely than persons of Asian and African heritage to have abnormally low levels of an important enzyme (CYP2D6) that metabolizes drugs belonging to a variety of therapeutic areas, such as antidepressants, antipsychotics, and beta blockers.... Additionally, after using some drugs in the psychotherapeutic class, slower enzyme metabolism (CYP2C19) has been observed in persons in the US of Asian descent as compared to Whites and Blacks.

In contemporary federal approaches to biomedicine, race holds these contradictory roles as socially constructed, not scientifically based, but differentiable by genetic research into drug responses.

The Guidance recommends that companies conducting clinical trials use the OMB list for collecting race information: American Indian or Alaska Native; Asian; black or African American; Native Hawaiian or Other Pacific Islander; and white. To accommodate the trend toward clinical trials in other countries, the FDA suggests that "more detailed categorizations of race and ethnicity" can be used—for example, European, Middle Eastern, or North African for white; or Indian or Japanese for Asian. Race is thereby positioned variably as geographic, biological, and social. The Guidance notes that "if sponsors choose to use more detailed characterizations of race and ethnicity, it is important for analytical purposes that the data trace back to the recommended categories described below." These categories are identical to the previous list (above) except in place of "Black or African American," is written "Black, of African Heritage." Here, the FDA contends with the biomedical vagaries of race/ethnicity. Race in this regulatory framework becomes variably cultural, biological, and medical, often in mutually exclusive forms.

This multiplicity has resulted in institutional friction. In March of 2003, the pharmaceutical industry trade organization PhRMA issued a response to the FDA Guidance. Their response focuses particularly on the discrepancies of race as cultural and as biological:

> It is stated that the OMB race and ethnicity categories were not scientifically based designations but instead, were categories describing the sociocultural construct of society in the USA. In the next paragraph, OMB categories are proposed as appropriate for evaluation of the influence of intrinsic factors, such as genetic factors. (PhRMA 2003)

The response identifies several categorical problems with the Guidance. PhRMA argues that some populations remain ambiguously categorized (e.g., Laplanders, Maori) and some racial groups are too broad (e.g., Asian). The response refers to the category white as "US-centric," not mapping well onto the more commonly internationally used "Caucasian," which includes the people of northern India. In contrast to this taxonomy, PhRMA repeatedly posits the need for scientifically based race and ethnicity categories.

These ambiguities and contestations reveal the ways race and ethnicity are being posited in biomedical practice through particular projects. In contrast to genetic variability research, the categories of race and ethnicity in biomedicine are being shaped by the sites chosen by contract research organizations for clinical trial markets; FDA understandings of pharmacogenetic research; and NIH-sponsored explorations of genetics of disease. As such research extends into various countries, new links are made between disease populations.

This contingency in practice has resulted in the varied use of racial categories and disease. Biomedical research has attempted to differentiate several genetic predispositions by racial prevalence. For example, genetic precursors to type II diabetes and to osteoporosis have been associated with racial categories, as have various genes involved in drug metabolism. Pharmacogenetic studies have found that Asians and Africans have an allelic variant in the gene encoding glucose-6-phosphate dehydrogenase that affects reaction to the antimalarial primaquine, in addition to other drugs (Lowitt and Shear 2001; Omenn and Motulsky 2003); approximately 50 percent of Caucasians compared with 80 percent of Egyptian peoples are reported to have a variant of the *N*-acetyltransferase-2 (NAT-2) gene that can cause an accumulation of toxic levels of isoniazid, a drug used to treat tuberculosis (Lowitt and Shear 2001); several polymorphisms of genes coding for the cytochrome p450 (CYP450) proteins are differentially correlated with being Asian, African, or Caucasian (Rusnak et al. 2001); and the FDA has approved a glaucoma drug that is marketable as being more effective in black patients (Lee et al. 2001). These statistics and research practices are producing new groupings of international populations.

Hyperdiagnostics of Race

The moral and market dimensions of race-disease links create a pressure to stabilize concepts like race for medical intervention. This creates a kind of expedient pragmatics to the biology of race that considers skin color, self-identification, parental ethnicity, and geographic ancestry (inferred or stated) each as diagnostic of race. The precise differences between these criteria for identifying race are not viewed as important to discern, in the need to treat people. The pressure exerted by markets and the sense of moral urgency is not to become consistent but to become efficacious, and in the case of race science, multiple forms of race identification used expediently produce results.

Biomedicine, then, like other approaches, treats race as *simultaneously* biological, medical, geographic, and socially constructed. But unlike other approaches, this allowance of a vague grouping along inexact lines collapses once results are found—for example, at the point where one needs to consider Japanese as representative or not representative of U.S. populations in order to sell pharmaceuticals or to develop medical routines. When this expedient approach to race combines with the diagnostic technologies of biomedicine, the result is a hyperspecific measurement of the highly variable object of race: e.g., 50 percent of Caucasians with the NAT-2 gene, and percentage of genetic Hispanic admixture. This radical precision of measurement applied to a constantly shifting category is a kind of hyperdiagnostics of race.

This strange quality of race in bioscience today is illuminated by Michel Foucault's work. In *The Order of Things* (1994a), Foucault argues that the table became the organizing tool of knowledge in the seventeenth and eighteenth centuries. Linnaeus's classificatory system as a table was a set of identities and differences by which all objects could be placed into a grid. Beings represented in this table lacked a history, or had a history without movement.[12] The physical characteristics that were used to calculate difference and similarity were independent of their historical trajectories or significance. Instead of locating functional or historical links or divergences, according to Foucault, the table offered the name: the name signified the identities and differences with other objects in the table—that is, it placed the being in the grid.

The critical insight that Foucault offers is that this form of knowledge had a contradictory function: it was both a self-consciously constructed tool—Linnaeus created the "Method" reflexively to organize beings—and a signifier of ontology, since all beings only existed within the table (i.e., through representation). Therefore, representation, which was analyzed for efficacy, parity, and direction by discourse, was also a frame that contained all things within it. As Foucault puts it:

> [To make use of signs] is an attempt to discover the arbitrary language that will authorize the deployment of nature within its space, the final terms of its

> analysis and the laws of its composition. It is no longer the task of knowledge to dig out the ancient Word from the unknown places where it may be hidden; its job now is to fabricate a language, and to fabricate it well—so that, as an instrument of analysis and combination, it will really be the language of calculation. (1994a: 62–63)

In this practice, representation takes on the qualities (simultaneously) of reflexive falsehoods (or approximations/models) and direct truths.

The uses of race in bioscience today carry this same uneasy quality: racial categories are posed as ontological because they are genetic, strategic because they are a step toward obviating their use, and socially constructed. And, like Foucault's table, they are taken to depict reality: the table can be used for diagnosis, medical intervention, and genealogy.

Stabilizing Contingency in Heart Research

BiDil illustrates this approach. BiDil is a combination of two previously available heart medications that was originally developed by a company called Medco Research. After failing to get approval by the FDA, the drug was subsequently picked up by the company NitroMed working with the Association of Black Cardiologists (Kahn 2004). In 2005, NitroMed got approval from the FDA to market the product specifically for the treatment of black patients. Jonathan Kahn (2004) has tracked the interplay of legal and commercial practices by which this pharmaceutical "became ethnic." His detailed analysis examines the way racial categorization is often added retrospectively in medical science. The primary incentives for this development of BiDil were the widespread biomedical conclusions that 1) black patients have higher levels of heart failure than other populations and 2) black patients respond poorly to two major classes of heart medications—beta blockers and ACE inhibitors—in comparison with white patients (Exner et al. 2001; see Kahn 2004 for a critique and qualification of both of these claims). The literature that reaches these conclusions illustrates the significance of race for biomedical researchers. As medical outcomes are differentiated by race, the causes of the outcomes are open to interpretation: genetic, physiological, economic, and access to medical care are all noted as potential causes of disease disparities. An interaction of these factors is usually posited. Hence, the biological becomes one of several aspects of race. With this formulation it becomes unnecessary to precisely define race or the contribution of genes to health: biological race can be substituted for social race because outcomes are the only area considered relevant.

The other primary function of race in the research on heart conditions is as a proxy. Researchers speak repeatedly of the use of race for biomedical research as an intermediate step to finding particular genetic populations—that is, toward eradicating the necessity of using race in biomedicine. Race is referred to as a "place holder" or a "surrogate marker." It becomes a strategic practice, rather than an ontological entity, reminiscent of the arguments in *Current Anthropology* discussed earlier. The significant point is that the concept of race as a tool becomes a necessary step toward future research: the direction of biomedicine is invoked as requiring such a proxy.[13] In this sense, attention in biomedicine is directed toward the future, which will obviate the problematics of current techniques but only through their contemporary utilization.

The anthropological question amid the discussion of potential and the future of genetic medicine then is, what is occurring in this contemporary utilization? To see the effects, and uses, and critiques of racial categories we need to listen to the ways researchers, practitioners, and families are taking up particular findings.

Asthma, Race, and Genetics

The genetics of asthma and asthma medication response is a large and varied field of research. Geneticists view asthma as a multifactorial disease, caused by several genes in interaction with the environment, resulting in studies focusing on various genetic loci and environmental factors. Race is a critical component of much of this research. Several epidemiological studies have made the case that African Americans have a slightly higher prevalence of asthma than Caucasians, and a much higher morbidity and mortality rate (Lang and Polansky 1994; Eisner et al. 2000; Miller 2000; Rona 2000). According to the Centers for Disease Control and Prevention (CDC), African Americans are three times more likely to be hospitalized or die from asthma (NCHS n.d.). Some studies have found that African Americans and Hispanics are more likely to have asthma after controlling for income and other socioeconomic indicators (Eisner et al. 2000; Rona 2000). Asthma thus follows other conditions in exhibiting disparities in prevalence and severity by race/ethnicity. And, as with other medical conditions, biological meanings of race are used to account for these disparities in ways that affect the meaning of the disease. The search for the genetic predisposition to asthma among black populations is a search for explanations other than the economic or medical-access conditions shared by these populations.

Gene-environment research thereby gives new meaning to concepts of environment, disparities in asthma severity, and race (see, e.g., Barnes et al. 2001; Hall 2001; Xu et al. 2001; Ahmadi and Goldstein 2002; Fenech and Hall 2002; Morahan et al. 2002; Shapiro and Owen 2002). The Collaborative Study on Genetics of Asthma (CSGA), which has included research teams from Johns Hopkins University, University of Chicago, University of Maryland, University of Minnesota, and four other universities, has reported different asthma susceptibility loci among African American, Hispanic, and European American populations (Barnes et al. 2001; Shapiro and Owen 2002). The University of California at San Francisco (UCSF) Genetics of Asthma in Latin Americans Study focuses on Latino and African American asthmatics. In the case of response to asthma medications, a variant in a gene ($\beta 2$ adrenergic receptor; $\beta 2$ AR) thought to increase the severity of asthma and decrease the response to a type of medication ($\beta 2$ agonists) is reported to exist in 37 percent of Caucasians in contrast to 49 percent of African Americans (Omenn and Motulsky 2003). A gene reported to influence response to another asthma medication (antileukotriene modifiers) has also been differentiated by racial group, and the genetic variations in CYP450-metabolizing genes that are differentiated by racial prevalence as discussed earlier affect response to asthma drugs too (Fenech and Hall 2002). These projects give shape to "race" and "asthma" and "environment" by formulating their interaction.

The Barbados Asthma Genetics Study

The Barbados Asthma Genetics Study is heralded by the team as having produced the largest database of asthmatics of African descent. The researchers have reported evidence of chromosome linkage with asthma and correlated this with African Americans, as part of the CSGA. Barbados is thereby brought into the genetics of asthma as a population considered representative of African Americans.

From the team's perspective, the perceived heterogeneity of the causes of asthma necessitates the focus on particular populations. The various possible environmental and genetic factors require studies attentive to the specificity of geographic area, climate, household behavior, and biological predispositions. Part of this specificity, for the research team, is a focus on race/ethnicity: the complexity of asthma—involving interactions of multiple genes and environmental factors—requires distinguishing effects such as racial/ethnic differentiation. As one article by the team puts it, "Because it is possible that different genes, as well as environmental exposures, influence asthma and asthma associated phenotypes in individuals of different ethnic backgrounds, three ethnic groups (African Americans, European Americans, and Hispanics) were ascertained in this study" (Xu et al. 2001: 1438). For the genetics team, this inclusion of race responds to a moral need to explain ethnic disparities of asthma.

The team members noted a similar prevalence, severity, and use of emergency departments for asthma by African Americans and Barbadians and contrasted these figures with those for Caucasians or the general U.S. population. In discussions, they considered ignoring race/ethnicity to allow research on Caucasians to be falsely representative of all populations. The group valued the genetics studies in Barbados partially as contrastive with other asthma genetics projects that do not include populations of African descent and thereby ignore diversity.[14] One member of the team described her research goals as focusing on the genetics of diseases that disproportionately affect minorities. Studies of genetic-environment interactions and race are thereby given a valence of morality as filling social and medical gaps: for the researchers, the genetics of asthma and race provides an important redress to a lack of research on populations who bear the larger burden of disease.

This interpretation gives new significance to genetic predisposition, environment, and race, through their interaction. As a gene-environment study, the project design was contrasted on one side with genetic susceptibility studies that fail to account for gene-environment interactions, such as the reciprocal influence of immune-response gene expression and allergen exposure. On the other side, the study design was posed against purely environmental studies that were considered more susceptible to factors that complicate results, such as age and socioeconomic status. As independent from these factors, genes are interpreted to be more stable and thereby more reliable in assigning causality. "Environment" is newly configured in this framing. The study has concluded that Barbadians have a high sensitivity to tropical mites, which is interpreted to be involved in asthma. The study's focus on a tropical country was contrasted with the focus of asthma research on developed countries: for the team, the Barbados research is a corrective to research that treats environments in developed countries as representative of the general asthmatic experience. The particularities of the Barbadian environment give a valence of social justice to the research as a step toward interventions particular to each environment. For example, a geneticist involved in the CSGA suggested that genetic predisposition might be part of the reaction to cockroach antigen that causes a high asthma prevalence and severity in urban areas such as Harlem (Lester et al.

2001). Here, race as a biological factor must morally be accounted for in studying the asthma experience among urban African Americans. In these extensions of gene-environment analyses, biological race interacts with social problems like urban housing disparities or conditions in developing countries.

But what occurs for the families, practitioners, officials, and researchers involved in these studies? How do these biomedical concepts get taken up in diverse ways, interacting with discourses of public health, family responsibility, ethnic identity, medical categories? The use and creation of biomedical categories occurs through such multiple interactions, producing unexpected meanings and practices. Biomedical categories, like goods in Boon's reading (1999: 299), "go crazy, or are already so 'foundationally.'"[15] They are created contradictorily and used compulsively. In this cultural life, excesses produce strange new objects, like the hyperdiagnostics of race, or, as we will see, estimates of asthma prevalence in a single population ranging from 18 percent to 80 percent. Attending to these moments of excess allows us to see researchers, practitioners, and patients as more than objects caught in institutional matrices. These individuals and communities interpret discursive formations such as the environment, race, and disease in diverse and often ambivalent ways that create their efficacy and allow them to be relevant to those involved.

Chapter 2

The Nation as Biomedical Site

Barbados as Genetic Site

Barbados is a center of international genetics-of-disease research. The various studies have been conducted by academic and industry research teams based in the United Kingdom and United States, including, in particular, teams from Johns Hopkins University and State University of New York (SUNY) Stony Brook. The current research includes searching for genetic propensity for cancers, asthma, acute lung injury, obstructive sleep apnea, asthma severity, and dengue fever (two studies, one American, one British). Previous genetic research in Barbados examined glaucoma. All of this research is premised on race. Biomedical research categorizes Caribbean populations as Afro-Caribbean, biologically equivalent to African American, in contrast to European, Caucasian, or other similar ethnic/racial distinctions. Researchers look for biological processes or genetic predispositions that characterize black populations. Studies have correlated Afro-Caribbean peoples as black with particular genetic predispositions for disease (Spencer et al. 2000; Kousta et al. 2001; Nemesure et al. 2003) or with a biological propensity for obesity, skin disease, and other conditions (Pomerleau et al. 1999; Dunwell and Rose 2003; Westermann et al. 2003).

Within this science of race in the Caribbean, Barbados is specifically chosen primarily because of the market mechanics of the state: the