The Meanings of "Race" in the New Genomics: Implications for Health Disparities Research

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> *The challenge is then to analyze the causes of racism while avoiding the implication that race exists.*
>
> —Steven Miles, 1993

> *A foolish consistency is the hobgoblin of little minds, adored by little statesmen and philosophers and divines.*
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> —Ralph Waldo Emerson, "Self-Reliance," 1841

Eliminating the well-documented health disparities found within the United States population is a laudable public policy goal. Social justice demands that we understand the sources of health inequality in order to eliminate them. A central dilemma is: To what extent are health disparities the result of unequal distribution of resources, and thus a consequence of varied socioeconomic status (or blatant racism), and to what extent are

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§ The authors gratefully acknowledge the financial support of The Greenwall Foundation, SmithKline Beecham Corporation, the Department of Energy (Ethical, Legal, and Social Implications [ELSI] Program), and the National Human Genome Research Institute (ELSI Program). Thomas Denberg generously provided comments on an earlier draft of the manuscript. Lorraine Caron, Sara Tobin, and LaVera Crawley from the Stanford Center for Biomedical Ethics also reviewed sections of the manuscript and offered helpful advice. Finally we wish to thank the editors of the *Yale Journal of Health Policy, Law, and Ethics* for their invitation to participate in a stimulating conference launching the new *Journal*, and for their patience and careful editorial assistance.

inequities in health status the result of inherent characteristics of individuals defined as ethnically or racially different? How we conceptualize and talk about race when we ask these questions has profound moral consequences.

Prior to the Human Genome Project (HGP), scientific efforts to understand the nature of biological differences were unsophisticated. The new technologies for genomic analysis will likely transform our thinking about human disease and difference, offering the promise of in-depth studies of disease incidence and its variations across human populations. In her opening remarks at a meeting of the President's Cancer Panel, which focused on health disparities in cancer treatment in the United States, Dr. Karen Antman noted that racial differences in cancer rates have been reported for decades, "but for the first time, science now has the opportunity to quantify such differences genetically."[1] Will the light refracted through the prism of genomic knowledge illuminate straightforward explanations of disease etiology, offering simple solutions to health inequalities? Or are there consequences, currently hidden in the shadows, that require our attention?

Protesting that their genes are being singled out as "mutant," individuals of Ashkenazi Jewish descent fear being targeted for genetic testing for breast cancer.[2] They ask, might not targeted testing lead ultimately to stigmatization and discrimination? The genetic variation in question, BRCA-1, is believed to be more prevalent among Ashkenazi Jewish women and has resulted in the identification of this population as "high risk." Researchers report that the frequency of BRCA-1 mutations in the general population is 1 in 1666,[3] compared to 1 in 107[4] among Jewish women of Eastern European origin. No one has a definitive explanation for this higher incidence among Ashkenazi Jewish women, although geneticists hypothesize a "founder's effect." Discord among Jewish groups has become pronounced, as the benefits and risks associated with targeted genetic testing and research are considered. While many scientists of Ashkenazi Jewish descent have supported testing as critical to the prevention and treatment of unsuspecting women who carry the breast cancer gene mutations, others, fearful of the potential harm of stigmatization, have discouraged participation. The issue is further complicated by the fact that breast cancer can neither be definitively cured, even if diagnosed early, nor prevented with certainty, although drastic measures, such as surgical removal of the breasts, are possible.

Increasing ability to detect genetic mutations linked to disease susceptibility has not been paralleled by therapeutic discoveries. This disjuncture has contributed to the conflict about population-based testing

and disagreement about the calculus of the largely unknown risks and benefits to individuals and populations. Knowing one has a BRCA mutation does not mean that one will ultimately develop cancer. Individuals must interpret complex, uncertain information to make sense of their cancer risk, and are often confused as to how to make sense of genetic information. The additional burden of contemplating the ramifications of targeted testing of their community, including the possibility of categorical discrimination and prejudice, is a daunting challenge. The mutations found most commonly among those of Ashkenazi ancestry were identified by chance. Blood stored for other purposes, notably screening for Tay Sachs, a heritable disease, was available for research. Other mutations in the BRCA-1 and BRCA-2 genes are specific to certain groups, generally isolated populations such as those in Iceland or Finland. How will knowledge that common diseases are associated with socially identifiable populations affect the treatment of those individuals? But more importantly, how will an increasingly sophisticated knowledge of molecular genetics affect our understanding of the nature of "difference" among human groups?

The discovery of genetic mutations associated with breast cancer has been heralded as one of the initial, and most dramatic successes of the HGP.[5] For the first time a common adult onset disorder was linked with a genetic abnormality. Ironically, this discovery also reveals a potentially dangerous, although unintended, consequence of genomic technology—the association of disease with an identifiable human population, in this instance, Ashkenazi Jews. Unfortunately, the lessons of history provide strong evidence that scientific research on the relationship of "race" to disease may have negative outcomes, in spite of good intentions. Sickle cell anemia provides the best-studied example. Indeed, it was the first "racialized" disease.[6] The association of sickle cell anemia with the black "race" was complete, a one-to-one correspondence; it took decades to recognize that the illness was not a marker of race. Treatment initiatives, in particular mandated screening programs, reflected existing social bias and prejudice.[7] Given the consequences of twentieth century Nazi racial science, individuals of Ashkenazi descent have particular reason to fear the notion that they are somehow biologically distinct. As we discuss in detail below, there is widespread agreement that *Homo sapiens* consist of a single population; that biologically distinct races do not exist. Will the tools of the new genomics, allowing us to map biological variation precisely, reinforce the idea that the human population can be divided into discrete biological entities? What policies might avert this end?

I. MEDICINE THROUGH A GENOMIC PRISM

Recent announcements celebrating the completion of the full sequencing of the human genome trumpeted the emergence of a "new genomic medicine."[8] Having the full human gene sequence available will quicken the pace of genetic discovery, and many believe it will transform all domains of medicine, including our understanding of the etiology of illness (and the meaning of health), disease prevention, diagnostics, treatment, and the development of targeted drugs, through the emergence of pharmacogenomics.[9] Indeed, for the foreseeable future, our scientific investigations—and basic understanding—of disease and illness will be conducted within a genomic paradigm.

The high-throughput genetic technologies now available, including high-speed sequencing machines and micro-array technologies, allow scientists to correlate specific genetic mutations with disease (or other "traits") much faster than in the past. We believe that the advent of genomic medicine has coincided with a resurrection of a genetic epistemology of difference among human groups that is predicated on the existence of "race," through which populations are conceptualized as having inherent, immutable biological differences. Three social and scientific trends have refocused attention on the meaning and significance of difference at the level of biology.

The first is the U.S. government's health disparities initiative—the national public health goal of eliminating health inequality among racially and ethnically identified populations by the year 2010.[10] The second is the recent announcement of the earlier than anticipated completion of the HGP. This joint public and private effort has produced expectations that gene-sequencing research will lead to important discoveries, such as solutions for diabetes, cancer, and other major diseases. It has also created a paradox. Public announcements of the genome have highlighted the news that human beings from throughout the world share a virtually identical genome; proclamations about the mapping and sequencing of the genome included conspicuous attention to the fact that human beings share 99.9% of their DNA.[11] The cover of *Science*, announcing the completion of the HGP, included an array of human faces of all ages—young and old—and individuals of varying phenotypes: African, Asian, etc. Hence the paradox. Although the political message of the unity of the human species was highlighted, the third force contributing to the salience of race in genomic medicine is the increasing body of genetic research focused on variation among populations. Although the vast majority of the human population shares the same genes, it is the minute differences

between individuals and among groups that researchers focus on as they seek to explain the incidence and severity of disease at the molecular level, through the examination of single nucleotide polymorphisms, or SNPs.

In light of these trends, it is of critical importance to examine the deployment of the race concept in health disparities research as the tools of the new genomic medicine come into widespread use. Increased funding for health-related genomics research, including the creation of new DNA repositories to serve as resources for genetic analyses, presents an opportunity to consider how existing understandings of racial and ethnic difference might shape the trajectory of research and the form of health care policies. We approach the issues from the broad disciplinary perspective of anthropology, including anthropological genetics, cultural anthropology, and medical anthropology.

In this paper we provide a strong critique of the continued use of race as a legitimate scientific variable. We offer an historical analysis of how the concept of race has changed in the United States and discuss the reification of race in health research. We discuss how genetic technology has been deployed in "proving" racial identity, and describe the consequences of locating human identity in the genes. The implications of the continued use of race in the new genomic medicine—in particular the creation of racialized diseases—is highlighted. We warn about the consequences of a shift toward population-based care, including targeted genetic screening for racially identified "at-risk" groups, including the potential for stigmatization and discrimination. A less commonly identified hazard is the epistemological turn towards genetic reductionism. We suggest that the application of a näive genetic determinism will not only reinforce the idea that discrete human races exist, but will divert attention from the complex environmental, behavioral, and social factors contributing to an excess burden of illness among certain segments of the diverse U.S. population. The intersection of the genomics revolution with the health disparities initiative should serve as a catalyst to a long overdue public policy debate about the appropriate use of the race concept in biomedical research and clinical practice.

II. INTERROGATING THE CONCEPT OF "RACE"

Why have we enclosed race in "scare quotes?" The power of race, or racial thinking, is derived from the supposition that race is biological and hence, immutable—inextricable from the essential character of individuals. Historically, race has been identified through physiological characteristics such as skull size, skin color, facial features, and other qualities readily available for scrutiny by the passing observer. The first

classificatory system dividing human beings into distinct races is credited to French naturalist Georges-Louis Leclerc (Comte de Buffon) in 1749.[12] Slightly later, in the eighteenth century, botanist Carolus Linnaeus identified four racial groups: americanus, asiaticus, africanus, and europeaeus.

Racial Classification of *Homo Sapiens*, Carolus Linneaus *Systema Naturae*, 1758

***Americanus rubescus* (Americans red)**—reddish, obstinate, and regulated by custom
***Europaeus albus* (Europeans white)**—white, gentle, and governed by law
***Asiaticus luridus* (Asians yellow)**—sallow, severe, and ruled by opinion
***Afer niger* (Africans black)**—black, crafty, and governed by caprice

His classificatory scheme is an amalgam of physical features and behavioral traits that reflect the social attitudes and political relations of the times, although presented in seemingly neutral, scientific terms. These racial distinctions arrange groups in a hierarchical fashion that reflect particular social values. This results in an ideology of race that is used to explain, predict, and control social behavior. Historians point out that the concept of immutable, biologically based human races developed in concert with western exploration and colonialism, providing a scientific justification for economic exploitation and practices such as slavery.[13] Prior to that time, the idea of distinct human sub-species whose differences were attributed to biology did not exist. The Greek term "barbarian," for example, reflects a hierarchical ranking according to one's closeness to civilization, and particularly to language, not a biologically based scheme.

When considering the relationship of "race" to health, one needs to pay attention to the conceptual underpinnings of race and racial thinking, not simply the terminology used. Other deployments of racial concepts elide social, behavioral, and environmental factors that contribute to the onset of disease. The conceptual problem—conflating biology with group identity—is not solved simply by a change in vocabulary. Emerging historically in response to the anthropological critique of race and racial thinking, the concept of "ethnicity" emphasizes the cultural, socioeconomic, religious, and political qualities of human groups, including language, diet, dress, customs, kinship systems, and historical or territorial identity.[14] In contrast to race, ethnicity has been conceptualized as socially articulated, reflecting common political interests and perspectives of individuals.[15] However, the appropriation of ethnicity in

health research often belies this distinction. Ethnicity, as well as "culture," has been used as a surrogate for biological difference in epidemiological and health services research. We argue that this confusion in terminology is potentially dangerous and requires serious attention. How we define difference has moral consequences.

A recent edition of *Webster's Medical Dictionary* defines race as, "a division of mankind possessing traits that are transmissible by descent and sufficient to characterize it as a distinct human type."[16] This usage of the term race reflects an outmoded concept that attempts to convey biological difference among human population groups as the defining feature of seemingly distinct human sub-populations. The definition is unfortunately characteristic of the careless approach to definition found within much of biomedical discourse and writing. A definition found in a key dictionary of epidemiology reflects a similar bias, defining race as ". . .persons who are relatively homogenous with respect to biological inheritance (see also ethnic group)."[17] By contrast, the fields of physical or biological anthropology and population genetics have long held that the idea that distinct human races exist is scientifically incorrect, as well as harmful.

The widely accepted consensus among evolutionary biologists and genetic anthropologists is that biologically identifiable human races do not exist; *Homo sapiens* constitute a single species, and have been so since their evolution in Africa and throughout their migration around the world.[18] Population genetics provides the best evidence for this conclusion: The genetic variation within a socially recognized human population is greater than the genetic variation between population groups.

In evolutionary biology the idea of race, although rarely used because of its fundamental ambiguity, is considered a synonym for subspecies. The term subspecies refers to a geographically circumscribed, genetically differentiated population. As Alan Templeton describes in a recent review in the *American Anthropologist*:

> Genetic surveys and the analyses of DNA haplotype trees show that human 'races' are not distinct lineages, and that this is not due to recent admixture; human "races" are not and never were "pure." Instead, human evolution has been and is characterized by many locally differentiated populations coexisting at any given time, but with sufficient genetic contact to make all of humanity a single lineage sharing a common evolutionary fate.[19]

Of course this does not mean that human populations long exposed to climatic variation or geographic isolation have not acquired health-related biological differences. Clearly such features exist, generally the result of

random events, such as genetic drift or population bottlenecks. The point is that meaningful genetic and biological differences do not always map clearly onto social categories of human difference, whether defined as race, ethnicity, or culture. Population geneticists use the concept of "clinal variation"—which specifies deviation across a geographic gradient—when analyzing meaningful sub-divisions of *Homo sapiens*. Sometimes genetically meaningful population differences correlate with social categories of difference; the populations of Iceland and parts of Finland provide examples. However, in a population as diverse as the United States this is often not the case. The political categories of difference used in much health research, for example "Hispanic," are biologically and genetically meaningless.

Before proceeding, we need to make one point clear. Arguing against the legitimacy of race as a category in biomedical research is not meant to suggest that the social category of race is not real, or that race as a key dimension of stratified societies does not exist. On the contrary, racial divisions have been a defining feature; some would say the defining feature, of U.S. history. Race is socially, not biologically, meaningful; it is "real" because we have acted as if certain people, at certain points in time, were inferior based on innate or "essentialized" characteristics.

Our preferred language when discussing human populations that have been categorized by race is to describe them as "racialized" groups. Although we use words like race and ethnicity in this paper, in general we prefer to use the race concept as an adjective rather than a noun. This terminology allows us to grant legitimacy to the social aspects of race while at the same time calling into question the idea that distinct human races exist. It also recognizes that who is defined as racially and ethnically different changes over time, a point to which we return below.

Terminology matters. We will argue against using race as a biological category in health research. However, we do not deny that health status varies among U.S. racialized populations. Genetic and biological differences should be studied directly, not through the distorting lens of a previous era's racial thinking. There may, however, be one exception in health disparities research. Studies of the health effects of racism *per se* may be one arena where using traditional political categories of race is justified.[20]

III. Elimination of Health Disparities as a National Priority

The National Institutes of Health (NIH), following the political leadership of the Surgeon General David Satcher, published the nation's blueprint for improved health in *Healthy People 2010*.[21] A main objective of

the plan is the elimination of glaring health disparities among segments of the population, particularly those identified as members of minority racial and/or ethnic groups. The report states that current information about the biological and genetic characteristics of African Americans, Hispanics, American Indians, Alaska Natives, Asians, Native Hawaiians, and Pacific Islanders does not explain the health disparities experienced by these groups compared with the white, non-Hispanic population in the United States. Although *Healthy People 2010* posits that these disparities are the result of complex interactions among genetic variation, environmental factors, and specific health behaviors, nonetheless, the categories of difference used to define the U.S. population are primarily racial categories—as opposed to other measures such as socioeconomic status, environment, or behavior.

Leaving aside for a moment the question of terminology, the statistics included in the report are alarming. Death rates due to heart disease and all cancers are more than 40% and 30% higher, respectively, for African Americans than for whites; for prostate cancer, it is more than double that for whites. African-American women have a higher death rate from breast cancer despite having a mammography-screening rate that is nearly the same as the rate for women identified as white. Hispanics living in the United States are almost twice as likely to die from diabetes than are non-Hispanic whites. Hispanics also have higher rates of high blood pressure and obesity than non-Hispanic whites. African Americans, American Indians, and Alaska Natives have an infant mortality rate almost double that for whites.

Asians and Pacific Islanders, on average, are reported as being one of the healthiest population groups in the United States. However, when this broad census category is divided into its many sub-populations, disparities for specific groups are quite marked. Women of Vietnamese origin, for example, suffer from cervical cancer at nearly five times the rate of white women. The case of Asian Americans, as with other groups, reflects the multiple terms, such as race, ethnicity, and national origin, used to describe American populations. Although unclear, it appears that Asian and Pacific Islanders are being treated as a single racial group. What remains consistent, however, is a comparison to an implicit category of "whiteness," that while tacitly evoked in each comparison, is left largely undefined. In addition, the nature of the relationship between racialized identity and disease is left unexplained. Categorizing individuals according to race labels, which are then associated with incidence of disease, conflates many complex factors that might contribute to disease in a population.

As with other government agencies, the NIH makes use of the racial classification scheme mandated by the Office of Management and Budget (OMB). This scheme is familiar to most of us because it is used by the U.S. Census Bureau. The passage of the NIH Revitalization Act of 1993 required that NIH-funded research projects include human subjects who are women as well as members of minority groups.[22] While these regulations were intended to correct the historical exclusion of women and minorities from participation in clinical trials, one unintended effect of the legislation has been the uncritical inclusion of one or two populations—often defined according to census categories unrelated to health outcomes—into a research design without adequate rationale for anticipated differences between populations. Such practices reinforce notions of racial difference and often come at the expense of a more nuanced study of the similarities among groups and the differences within broadly defined racial groups.

A critical review of the use of race is necessary in light of its profound effect on the production of medical knowledge. Statistics describing health differences between whites and racialized populations, such as those published in *Healthy People 2010,* are the result of epidemiological research that focuses on race as a category of inherent distinction. This research, in turn, establishes the agenda for progress in improving health status and determines the measures of success in achieving the NIH goals. The racial taxonomy used by epidemiologists impacts directly on the research design of studies examining the biological basis of difference among groups, initiating a trajectory of inquiry that is uncritical of the relationships among racialized groups, genetic characteristics, and environment.

IV. THE MUTABILITY OF RACIAL CATEGORIES

The taxonomy of race used in health research is primarily political. To understand fully the historical mutability of categories of race, we will discuss the evolution of census categories in the United States. Through comparison with categories used by other nations, the problematic nature of race as a scientific variable becomes evident. The U.S. Census Bureau has collected information on race since the first census in 1790. Historically, the Census Bureau has used widely varying principles and criteria in classifying the population, including national origin, tribal affiliation and membership, and physical characteristics. During the nineteenth century, African Americans were identified through a calculus based on percentage of African "blood." The term *mulatto* was used to describe an individual born of one black and one white parent. Although it was largely abandoned at the beginning of the twentieth century, other

terms measuring descent such as, *quadroon* and *octoroon,* were used to refer to individuals with one-quarter and one-eighth black ancestry, respectively. In the 1920s the United States extended this racial paradigm by instituting the infamous "one-drop rule" by which individuals with even one ancestor of African origin were classified as black. This framework of identifying race focused on lineage and implicitly defined "whiteness" by a standard of genetic "purity," despite physiological markers that may give the appearance of whiteness or blackness. This rule, although no longer embraced officially by the government, reflects a belief in the biological basis for group differences that continues to characterize racial thinking in the United States.

During the twentieth century, twenty-six different schemes were used to categorize racial difference in the U.S. population.[23] Certain groups, such as Jews who at one time were defined as non-white, were "de-racialized" later in the century. Since 1977, the federal government has sought to standardize data on race and ethnicity among all of its agencies through the OMB's issuance of the Statistical Policy Directive Number 15, "Race and Ethnic Standards for Federal Statistics and Administrative Reporting." In these standards, four racial categories were established: American Indian or Alaskan Native, Asian or Pacific Islander, black, and white. In addition, an "ethnicity" category was codified indentifying individuals as of "Hispanic origin" or "Not of Hispanic origin." The OMB guidelines stipulate that Hispanics may be of any racial category, although in practice, many who self-define as Hispanic check "other" when answering the race question, reflecting widespread confusion about the meaning of terms such as race and ethnicity.[24]

In 1997, in preparation for the 2000 census, the OMB revised these racial and ethnic categories, citing that they no longer reflect the diversity of the population. The reconsideration of these categories emerged in large part due to lobbying efforts by various groups seeking to broaden the choices available to respondents. As a result, the category of "Native Hawaiian or Other Pacific Islander" was added to the existing four as well as the choice of "Some Other Race." In addition, the ethnicity category was modified to "Hispanic or Latino" and "Not Hispanic or Latino." Although testimony presented in public and congressional hearings indicated a strong desire to include the option of "multiracial" among the census categories, the OMB decided against this, but allows respondents to choose more than one of the existing racial categories in identifying themselves.[25] These new standards on racial and ethnic categorization were used in the 2000 Census and are effective immediately for data collection by federal agencies, including the NIH. The categories on the actual census

questionnaire included a wide range of different groups that are then collapsed into the five racial groups and two ethnicities. These are listed below:

U.S. Census Categories, 2000

❑ White	❑ Black, African-American or Negro	❑ American Indian or Alaska Native	❑ Asian Indian
❑ Chinese			❑ Korean
❑ Vietnamese		❑ Japanese	❑ Samoan
❑ Other Pacific Islander	❑ Filipino	❑ Gaumanian or Chamorro	
	❑ Native Hawaiian		
	❑ Other Asian	❑ Some Other Race	

A separate question asks respondents for their ethnicity. The choices are Mexican, Mexican American or Chicano; Puerto Rican; Cuban; and other. The taxonomy that emerges from this multi-tiered approach to defining difference is not readily apparent. Recognizing the plurality and diversity among populations identified as Hispanic or Latino, the OMB designated these as ethnic or social categories in which groups share common cultural history, practices, and/or beliefs. Quite similarly, the category of Asian American consists of no less than twenty-five different populations of diverse origins. What makes Asian Americans a "race" and Latinos and Hispanics an "ethnic group" is difficult to determine.

The racial categories used by the census reflect terms of group identity that have emerged historically from the shared social and political experience of particular immigrant groups, which in turn have been influenced significantly by the historical immigration policies of the U.S. government. In light of this, the use of a racial taxonomy in the arena of biological research is particularly problematic. The designation of these terms as "racial," and their adoption and use in scientific research sponsored by federal agencies such as the NIH, threatens to reconstitute these groups according to assumptions of biological connections that are not valid.

When the U.S. Census Bureau's racial categories are compared to those employed by other nation-states, the arbitrariness and historical contingency of racial taxonomies becomes evident. The table below shows the 2001 Canadian Census Bureau categories. Of note is the fact that Canada does not explicitly highlight the historical concept of race by asking a "race" question, nonetheless, the category seems to be implicit. As a catalog of the "visible minority population" in Canada, these categories reflect a potpourri of terms indicating skin color, nationality, regional and territorial identity, ethnicity, and political sovereignty (as in the category of

Canadian Census Categories, 2001

- ❑ White
- ❑ Filipino
- ❑ West Asian (Afghan, Iranian)
- ❑ Chinese
- ❑ Latin American
- ❑ Southeast Asian (Cambodian, Indonesian, Laotian, Vietnamese)
- ❑ South Asian (East Indian, Pakistani, Sri Lankan)
- ❑ Japanese
- ❑ Korean
- ❑ Black
- ❑ Arab
- ❑ Aboriginal (North American Indian, Metis, Inuit)

"aboriginal").[26] As is the case with the U.S. Census, one's identity is not easily determined. How should an individual of Japanese descent who was born in Brazil and carries Brazilian citizenship describe herself? Is she a Latin American or Japanese? Knowing the reasons behind such questions might greatly influence how one "chooses" to identify oneself. The answer may change depending on the purpose of the question, for example: to determine the immigration rates of specific populations, to calculate the number of foreign residents in a particular district, or to assess the incidence of genetically related disease among a population. Of interest is the fact that the Canadian sub-group known to express a unique array of rare genetic illness (due to a founder effect)—French Canadians in Quebec—is not included. Identification of this group by primary language spoken further complicates the classification dilemma when the social goal is amelioration of health status.

The absence of a universal taxonomy of race is further documented by examining the census categories utilized by the United Kingdom. Whereas "Asian" in the United States includes a broad range of populations with origins throughout the Asian continent, in the United Kingdom the term is limited to those from the Indian subcontinent. In the United States, the categorization of these individuals depends on their historical location. Early in the twentieth century, individuals whose origins were South Asian were categorically identified as "Hindu," regardless of whether they actually subscribed to the Hindu religion. This was incongruous for many groups and the policy changed to classify individuals from the Indian subcontinent as "white," in spite of the large phenotypic variation in skin color dependent on distance from the equator found throughout the world.

More recently, South Asians in the United States were added to the long laundry list of groups that constitute the category of Asian American. The table below indicates that, in contrast to the conventional wisdom on race in the United States, Chinese in the United Kingdom are not

considered Asian, but rather are combined in a separate racial category with all "other" racial groups. While this categorization scheme may be the result of the small numbers of Chinese and other groups in the United Kingdom, combining all other non-identified populations with Chinese further reveals the lack of scientific rigor in the classification of race.

United Kingdom Census Categories, 2001

- ❑ White (British, Irish, Other White)
- ❑ Black or Black British (Black Carribean, Black African, Other Black)
- ❑ Mixed (White and Black Caribbean, White and Black African, White and Asian, and Other Mixed)
- ❑ Chinese or Other Ethnic Group (Chinese, Other Ethnic Groups)
- ❑ Asian or Asian British (Indian, Pakistani, Bangladeshi, Other Asian)

In defining systems of classification, Bowker and Star identify three properties.[27] The first is that there are "consistent, unique classificatory principles in operation."[28] The principles establish the rules of order as in, for example, genealogical descent. In the case of racial categorization, it is difficult to identify what rules are operative as they are often varied, inconsistent, and context specific. Physical appearance, geographic origin, language, and birthplace are just a few of the criteria used to determine racial identity. Despite its ubiquity, race has yet to be explicitly defined. The second property of a classification system according to Bowker and Star is that the "categories be mutually exclusive."[29] The principles must be sufficiently specific so that entities may not be put in more than one category. The reality of human diversity confounds this second criterion, as the generally disguised presupposition of "racial purity" is fundamental to racial classification. Since *Homo sapiens* consist of a single species, genetic purity is a myth. The exclusionary social functions of race exist in sharp contrast to the porosity of group boundaries, leaving this classification system ill-equipped to address the reality of biological difference across the human population, which is continuous, rather than divided into discrete segments. Finally, the third criterion is that a classification system must be complete and able to absorb even those entities not yet identified.

The historical mutability of racial categories—as illustrated by the Census Bureaus in the United States and abroad—and the inconsistent use of terms in both defining and describing race indicate that a classification system based on race is inevitably historically contingent. The possibility of it ever becoming a rigorous system with scientific utility is questionable. This does not mean that racial categorization is an unimportant factor in

studying the cause of health disparities throughout the world. Rather, the ever-changing taxonomy of race is a reminder that any research utilizing the concept of race and/or ethnicity must include an interrogation of the economic, political, and cultural factors that inform the struggle over how these categories are defined and used.[30] In the new genomic medicine, the uncritical use of racial and ethnic categories by those interested in biological difference often distorts the relationship between genetics, disease, and group difference.

V. THE USE OF GENETIC TECHNOLOGY IN ASCRIBING IDENTITY

The promise of genomic medicine is improved health. Perhaps medicines will be developed that target diseases found more frequently in people with a particular ancestry, or genetic epidemiological research carried out with an isolated population will identify a biological marker for schizophrenia. But might there be other consequences of the genomics prism? Will the reductionist paradigm transform, and perhaps "geneticize" our understanding of identity? The rapid production of genetic information through collaborations such as the HGP and the concomitant rise of gene mapping technologies suggest a need to reexamine current models of human identity. Genetic epidemiological studies often compare populations defined by social categories of racial and ethnic difference. Results indicating significant genetic variation may continue a cycle of reaffirming patterns that are built *a priori* into the research design. This conundrum, while not unique to genomics research, is further complicated by the current trajectory of studies that attempt to locate race or ethnic identity in the genes. The technically optimistic believe that genetic "evidence" may definitively identify individuals as belonging to certain groups. We remain skeptical of such claims. That categories of race and ethnicity are always historically constructed and context driven suggests a need to carefully consider the consequences of using genetics to define ethnic or racial identity.

A. DNA Testing: Proof of Native-American Ancestry?

The eagerness to use genetic technology and research in determining race and ethnicity has resulted in a renewed faith that genetics will be able to reveal who and what we are. Recently, House Bill 809 was presented to the Vermont legislature by state representative, Fred Maslack, which stipulated that results from genetic testing would be accepted as definitive "proof" of Native-American ancestry.[31] The genetic criteria that would be used in making this determination were not explained nor were the

potential uses for the genetic test described.[32] While the bill stipulated that this would be offered to individuals on a voluntary basis, one cannot contemplate the deployment of a genetic standard of race without considering the potentially discriminative and prejudicial ways this might be used, setting aside for the moment whether such testing could ever be "accurate" or what accuracy would mean. Given that humans have developed socially meaningful mechanisms for determining group membership, the central question is: Why is genetic testing necessary? If an individual has lived in a Native-American community, has adopted the history and cultural practices and beliefs of her tribe, and is embedded in a nexus of social relationships that recognize her as a member, then what does a "negative" genetic test mean for her and perhaps, more importantly, to the group as whole? By supplanting history and experience with a standard of relatedness measured by genetic similarity, human cultural identity is relegated to a simplistic biological standard.

B. The "Kenniwick Man" Controversy

The use of genetic testing in this arena is justified by racialist thinking and serves to reify archaic concepts of race, attempting to "reveal" truths about identity through genealogy. Another example is provided by the "Kenniwick Man" controversy in which 9,000 year old skeletal remains were declared the property of a consortium of Native-American tribes—an illustration of the power of racial politics in the United States. The Kenniwick Man is of great interest to geneticists, evolutionary biologists, and anthropologists in challenging theories of human migration to the Americas. Attempts to reconstruct the skull of Kenniwick Man led several scholars to conclude it seemed more similar to that of modern Europeans than of Native Americans. This resulted in speculation that the original settlers of North America were not groups from Asia as originally postulated, but were individuals of European origin. Headlines that declared Kenniwick Man as "white" reflect not only the careless shorthand used by the media in interpreting scientific data, but the need to assign race in the quest to determine the evolution of human species.[33] It was concluded that DNA testing of the remains might fail to prove a link to modern Native-American tribes although archeological evidence seemed to confirm that Kenniwick Man resided in a human group that may have included ancestors of more recent Native Americans. The debate remains murky, illustrating the problematics of proving ancestry. Most recently some anthropologists have determined that Kenniwick Man has more in common with the Ainu of Japan than with Northern Siberians or Native Americans. The tug-of-war over Kenniwick Man was resolved by the

existence of the Native American Graves Protection and Repatriation Act (NAGPRA)[34] which stipulates that property—including human remains taken from tribal lands—be returned to Native Americans to be disposed of as they wish.[35] Upon his return, Kenniwick Man will be reburied at an unidentified location on Native American territories. The existence of this legal agreement was convenient in dissipating this potentially explosive issue and allowed resolution despite the ambiguity of scientific evidence in determining the racial identity of Kenniwick Man.

C. The Role of Genetics in Defining African-American Identity

It would be misleading to claim that the search for identity through genetic testing has only been proposed by those residing outside of the groups in question. Reconstructing genealogy has been of great interest to African Americans seeking to locate their ancestral homelands, lost through the social disruptions of slavery. Genes are gaining increasing attention as an alternate way to reveal connections between contemporary African Americans and current populations in Africa. Recently, a geneticist from Howard University advertised the service of DNA analysis for African Americans who wanted to determine their pre-slavery heritage by locating their point of origin in Africa. Through a website entitled, African Ancestry, Rick Kittles urged African Americans to send in blood samples as a means of examining their "genetic makeup and developing a genetic fingerprint."[36] Although he abandoned his original plan of selling his services to interested individuals for $300 per test due to mounting public and scientific criticism, Kittles' endeavors represent a general embrace of genetics as a medium through which validation of identity may be achieved. Of concern are the potential negative consequences of locating African-American identity in the realm of genetics. These concerns are not fore-grounded, indeed they remain unaddressed. This is surprising given the warnings of scholars like Patricia King, who writes, "in a racist society that incorporates beliefs about the inherent inferiority of African Americans in contrast with the superior status of whites, any attention to the question of differences that may exist is likely to be pursued in a manner that burdens rather than benefits African Americans."[37]

D. African Burial Project

The African Burial Project is conducting similar genetic analyses with skeletal remains of long-deceased slaves, seeking to use genetics as a positive force in historical explication. Having received over $5 million from the U.S. General Services Administration and Congress, the African

Burial Project attempts to match DNA extracted from skeletal remains found in 1992 at an urban construction site in the United States with genetic samples of populations all across Africa and the Caribbean.[38] Michael L. Blakey, the director of the project, has explained that the outcome of the DNA database created and the genetic analysis of samples could "help restore the specifics of identity that were deliberately damaged by slaveholders in order to make enslaved Africans seem less human."[39] Blakey has indicated that upon the completion of the burial project, the DNA database will be made available to individuals in search of their African heritage.

The tests utilized in the African Burial Project have analyzed mitochondrial and Y-chromosome DNA that is passed down essentially unchanged through generations from mother to child and father to son, respectively. Results from such testing are limited in that each reveals only half of the lineage story. In addition, by attempting to locate similarities between the DNA of contemporary African Americans and modern Africans, the Kittles and Blakey projects implicitly adhere to the "one-drop rule" of racial categorization by ignoring the potentially significant degree of admixture between populations. The suggestion that identity is defined primarily by origins in Africa, rather than through social group membership based on shared historical experience, supports an ideal of genetic purity. Identity is "geneticized."

A reverse example can be found in the recent "discovery" that the youngest son of Sally Hemings, Eston Hemings-Jefferson was fathered by Thomas Jefferson.[40] Despite a long history of folk narrative that confirmed these family relations, the Hemings-Jefferson relationship became "fact" only when genetic evidence was marshaled.[41] What is interesting is how the genetic information affected the current racialized identities of the living progeny of the Hemings-Jefferson union. Besides validating the beliefs of some who had long believed that Jefferson was their distant relative, the news did little to change their lives in meaningful ways, nor has it changed their conceptions of their identities or how others define them. The Monticello Association, a private organization of some 700 descendents of Jefferson and his wife, Martha, continue to dispute claims by Hemings' descendents that they be included in the group, or be allowed burial in the cemetery at Monticello.[42]

The story of proving one's lineage based on discovery of a genetic forefather is a powerful theme within the broader discourse on racial difference. Denial of the inevitable interaction among human populations is necessary to the story of race, an idea that is contingent on notions of biological purity for the maintenance of group boundaries. To

acknowledge the constant admixture between groups and intra-population genetic variation would render the concept of race meaningless.

E. Testing for Race/Ethnicity

Through probabilistic techniques, genetic testing of continental ancestry is technically possible. Other research efforts seek to identify genetic markers that are highly correlated, not only with populations residing in (or with origins from) geographic areas that have been racially categorized, but also with phenotypic features associated with race.[43] A particular trajectory of genetic research is reflected in linkage and association studies that attempt to detect racial and ethnic differences in cases that are physically ambiguous. An example is the effort to determine genetic linkages of individuals of mixed descent. Using statistical procedures, one such study has claimed that 70-90% of ancestry information could be "extracted" even when "admixture" had occurred up to ten generations before.[44] The implications of this line of research are far reaching. The use of genetic technologies in directly determining race and ethnicity not only redirects identity from the social domain into the physical substrates of the body, but also, more importantly, shifts the power of defining who and what humans are into the arena of biomedicine. Testing for race/ethnicity may be justified as a means of improving the health status of minority populations, for example by targeting disease prevention programs to individuals from certain groups. This approach, however, reinforces the idea that disease results from essential characteristics within the individual.

VI. GENETIC DETERMINISM AND REDUCTIONISM

The powerful tools of molecular discovery, in concert with the promise of molecular medicine, represent a dominant cultural discourse on science and health. An unintended byproduct of the genomics revolution is a näive, almost religious faith in the power of genetics. The gene has become a powerful cultural icon;[45] genetic explanations have a pride of place in the popular imagination. Of course geneticists are well aware that genes act in concert with the environment, and that a full understanding of the genetic component of common illnesses requires sophisticated, multi-factorial research. Nonetheless, the paradigm of genetic reductionism may powerfully affect health disparities research by placing undue emphasis on genetics at the expense of other explanatory mechanisms, moving attention—and funding for research—away from features of the social and political environment that lead to ill health.

Genetic reductionism reflects a trend favoring an integrated theory of knowledge production that begins with faith in one particular approach to the scientific endeavor. In his most recent book, *Consilience*, Edward O. Wilson argues for a "unity of knowledge" that transgresses disciplinarity.[46] Heralding the advent of the Enlightenment era of scientific discovery, Wilson states, "Reductionism, given its unbroken string of successes during the next three centuries, may seem today the obvious best way to have constructed knowledge of the physical world, but it was not so easy to grasp at the dawn of science."[47] The opposition between culture and science is one that Wilson critiques by discussing the role of epigenetic rules. He argues that while genes are the fundamental basis for human behavior, cultural factors may influence the selection and hence, survival of particular genes. Wilson treats culture as mechanistic. Just as ethnicity is relegated to a static list of attributes associated with particular groups, culture has been relegated to mental or cognitive constructs that are unchanging and essentializing.[48] In Wilson's reductionist model of knowledge production, culture is subsumed within a genetic epistemology. Reductionist science leads to a particular approach to health research, and a particular, similarly decontextualized, approach to ethnic or cultural identity.

Alternatives to a reductionist understanding of ethnic or racialized identity allow a different approach to health research. Recent work in the social sciences on race and ethnicity has emphasized notions of "situational ethnicity,"[49] in which identity is dependent on the specific contexts in which individuals find themselves. In addition, the concept of "plastic ethnicity"[50] highlights individual and group agency as opposed to structural inscriptions of identity. The significance of such theories for health disparities research is an understanding that racial and ethnic identities—including health-related beliefs—take on different qualities and cannot be treated as stable entities even within an individual life course. We possess "multiple identities;"[51] one's gender, religion, nationality, or age may take on lesser or greater importance at different times and in different places, contributing to a number of cultural identities.

Reductionist research that locates ethnic identity in genetic variation confounds the notion of malleable identity. The implication of such research is that self-identity may be supplanted by a genetically based identification of individuals and groups. The result of such a shift in which identity is no longer a product of self-definition, but rather, is ascribed by science, has serious implications for how race and ethnicity will be conceived. Critical to this shift in identity politics is the explanatory power of genetic discourse in its "appearance and allure of specificity"[52] in

classifying individual identity.

VII. THE REIFICATION OF RACE IN HEALTH RESEARCH

Historically, race, genetics, and disease have been inextricably linked, producing a calculus of risk that implicates race with relative health status. Racialized groups have been associated with particular diseases. Sometimes these associations are accurate and sometimes they reflect underlying social prejudice. It is against this backdrop that investigations into health inequalities in the United States play out. Troy Duster, a sociologist who has examined these associations, has identified this process as the "prism of heritability" in which disease is uncritically linked to individuals because of racial assignment and categorically disassociated from other populations.[53] He cautions that race-based etiological theories may become hegemonic, effectively eliminating explanations of illness that take account of environmental or behavior factors associated with social class. Melbourne Tapper has studied this process with respect to the identification and management of sickle cell anemia in colonial Africa.[54] Tapper reveals that the political project of colonialism was further justified by the dominant discourse on race that identified sickle cell anemia as a "black disease" and contributed to a definition of "whiteness" that was predicated on the notion of invulnerability and health. Similarly, in the United States, prejudicial attitudes toward African Americans and immigrants from the Mediterranean region fueled racial rhetoric around sickle cell anemia and thalassemia. In the twentieth century, the association of race with disease was utilized by those who were politically opposed to miscegenation and immigration of people from southern Europe.

Given this history, particular caution must be employed when using the race concept in health-related research. Some have argued that the concept should be abandoned, based on the overwhelming scientific evidence that human races do not exist. Others argue for retaining the term, but limiting its application to the social, as opposed to the biological, realm. Recently, the American Anthropological Association, the official professional organization of physical, biological, social, and cultural anthropologists and archeologists in the United States, released a statement emphasizing the social and historical construction of race. Reflecting a general consensus among social scientists, physical and biological scientists and other scholars, the statement contended that race could not be considered a valid biological classification:

> The "racial" worldview was invented to assign some groups to perpetual

> low status, while others were permitted access to privilege, power, and wealth. The tragedy in the U.S. has been that the policies and practices stemming from this worldview succeeded all too well in constructing unequal populations among Europeans, Native Americans, and peoples of African descent. Given what we know about the capacity of normal humans to achieve and function within any culture, we conclude that present-day inequalities between so-called "racial" groups are not consequences of their biological inheritance but products of historical and contemporary social, economic, educational, and political circumstances.[55]

Despite such proclamations, race continues to be used erroneously, even harmfully, as a scientific variable, particularly in biomedical research designed to explain health behavior. Its use is ubiquitous; from 1910 to 1990, race was used in 64% of articles appearing in the *American Journal of Epidemiology*.[56] One author suggests that historians will find our current terminology to be inherently racist, rather than scientifically useful.[57] A review of biomedical literature claiming links between race and disease reveals that researchers rarely describe their racial and ethnic measurement or classification methods. In a review of articles published in *Health Services Research*, Williams noted, "Terms used for race are seldom defined and race is frequently employed in a routine and uncritical manner to represent ill-defined social and cultural factors."[58] Lack of precision—näively conflating biology and culture—makes it impossible to tease out the causes of health disparities between economically disadvantaged racialized populations and more privileged groups.

The lack of consistency in the use of terminology for concepts of race, ethnicity, ancestry, and culture is manifest in the wide variance in terms used to identify individual and group identities.[59] Terms such as white, Caucasian, Anglo, and European are routinely used interchangeably to refer to certain groups; whereas black, colored, Negro, and African American are used to refer to comparison groups.[60] And white-black comparisons are straightforward in contrast to the confused use of terms like Hispanic and Asian. Fundamental ambiguity in the concept of race obscures the role that genetic variation plays in our current understanding of disease. Socially defined notions of race are treated as legitimate biological variables; race itself is often used as a proxy for disease risk. Epidemiological studies employ race as shorthand for social and environmental factors that are associated with particular racialized groups.[61] When treated in this way, race is understood to have some contributory effect to particular conditions and diseases, but in a very imprecise way. For example, reports that black smokers are ten times more

likely to develop *helicobactor pylori* infection—a cause of duodenal ulcers—than white smokers,[62] treats skin color as an independent variable, and thus circumvents an explicit engagement with the complex interaction of social, environmental, and perhaps, biological factors that may have produced the statistically significant findings.

Research utilizing race serves to "naturalize" the boundaries dividing human populations, making it appear that the differences found reflect laws of nature.[63] In fact, the use of race and ethnicity in biomedical research is problematic because it is caught in a tautology, both informed by, and reproducing, "racialized truths."[64] We assume that racial differences exist, and then proceed to find them. While the scientific validity of racial distinctions between human populations has long since been disputed, the cultural logic of stratifying populations by race/ethnicity exerts a powerful pull—it is a highly ritualized scientific practice enshrined in law and government regulation.

A. Race, Smoking, and Nicotine Metabolism

Recent research on smoking and nicotine metabolism illustrates the implications of the reification of the race concept in health research. The use of tobacco is singled out as a leading health indicator in the *Healthy People 2010* vision statement. According to the report, adolescent rates of cigarette smoking have increased in the 1990s among white, African-American, and Hispanic high school students after years of declining rates during the 1970s and 1980s. A central goal of the *Healthy People 2010* mission is to decrease the rate of tobacco use through prevention programs and to focus research on treatment programs for existing smokers.

Epidemiological and behavioral research on cigarette smoking has clearly identified sociodemographic variation in smoking rates. "Race" is highlighted as a significant predictor of smoking behavior, yet its exact salience is difficult to tease out. Studies indicate that although a larger proportion of blacks[65] than whites smoke, several differences in tobacco use exist between these groups. Blacks consume fewer cigarettes[66] and begin smoking later in life than whites.[67] Blacks smoke cigarettes higher in tar and nicotine[68] and are specifically targeted by the tobacco industry as potential consumers.[69] Smoking among African Americans has been associated with a higher incidence of lung cancer, cardiovascular disease, low birth weight, and infant mortality.[70]

Research on a genetic basis for differences between African Americans and non-Hispanic European Caucasians has focused on differences in the metabolism of tobacco. The logic of such studies is founded on the notion

that racial groups may have distinct genetic characteristics that result in different biochemical processes such as variations in nicotine metabolism.[71] Recently it has been reported that racial and ethnic differences may exist in the serum cotinine levels of cigarette smokers.[72] Levels of cotinine, a metabolite of nicotine, indicate relative exposure to tobacco smoke. In this study, sponsored by the National Center for Chronic Disease Prevention and Health Promotion, non-Hispanic black smokers had significantly higher levels of serum cotinine than either white or Mexican-American smokers despite reporting to have smoked the same number of cigarettes a day. The study concluded that these differences may explain why blacks find it harder to quit and are more likely to experience higher rates of lung cancer than white smokers. The authors suggest that biological differences may account for the differential health status of certain groups. Studies like this contribute to a trajectory of research that links race and genetics to disease. However, by assuming a tight link between nicotine metabolism and race, researchers may overlook other biological or environmental mechanisms that could explain the elevated cotinine. They also rule out racism on the part of physicians as an explanation of excess cancer deaths among blacks. A recent study found racial differences in referral for potentially curative surgery among patients diagnosed with early-stage lung cancer associated with smoking.[73]

Research on the relative incidence of disease among racialized groups reflects a paradigm of inquiry that presumes racial differences exist. "Race biology," as described by Gary King, reflects current sociopolitical beliefs, values, and agendas regarding racial differences and is "predisposed to and rewarded for investigating 'inherent differences' rather than commonality."[74] Research findings—such as differences in nicotine metabolism—provide the promise of drug therapies based on presumed genetic differences between racialized groups. Such targeted medicines are a hallmark of the new genomic medicine.

B. Race and Pharmacogenomics

The emergence of the field of pharmacogenomics is based on the promise of individually tailored drugs; therapeutics will be tailored to the unique genetic makeup of specific populations. Those more likely, or less likely, to respond to a particular medicine, or those likely to have a severe adverse event, will be identified through genomic analysis. Pharmaceutical companies believe that such tests, and the medicines based on them, will be an important feature of health care in the future; intense and highly competitive research is underway.

Pharmacogenomics creates drugs for individuals by matching

medicines to patients' personal genetic codes.[75] However, in practice, research targets variation within pre-defined racialized groups, not individuals. According to a recent article in the *Washington Post,* "[r]ace influences which people are genetically predisposed to lack various enzymes needed to break down medications. Without those enzymes, the medication can have either a heightened or lessened effect."[76] In this case, race is identified as the independent variable that explains the necessary presence or absence of a biochemical agent that aids the metabolism of the drug. The use of the word "lack" redirects focus from the limitations of synthetic pharmacopoeia to the biological shortcomings associated with particular racialized groups. Who will be defined as "normal?" Racial thinking, or the belief that race is defined by biological differences between groups of individuals, informs the search for genetically tailored therapeutics intended to compensate for deviations from an unstated standard of genomic normality.

Although the idea of individually tailored therapy is the goal, it appears likely that products will actually be targeted according to race. One can only speculate on the cultural impact of the commercialization of drugs for racialized populations and the decision by pharmaceutical companies to bring to market therapeutics created for a certain group of consumers. The Food and Drug Administration (FDA) recently approved a new glaucoma drug, Travatan, which is marketed as, "the first glaucoma drug to demonstrate greater effectiveness in black patients."[77] Close reading of the FDA-approved package insert discloses that "[i]t is not known at this time whether this difference [in efficacy] is attributed to race or to heavily pigmented irides."[78] This turn toward a population-based approach to health care product marketing raises the possibility that drug development will build upon and strengthen current notions of racial difference. Health disparities do exist; individuals who self-identify as black are more likely to suffer from glaucoma-related blindness. But will medicines targeted by race alleviate those differences in health outcomes or disguise other explanations of disparities, such as lack of access to routine preventive eye care? The danger is that more and more diseases will be "racialized," and at the same time, the idea that racial differences exist and are inherent is reinforced. Careful policy guidelines on the marketing of medicines (and other health care products) to racially defined groups are needed. These guidelines must pay attention to language in order to avoid the suggestion that biologically distinct human races exist. One policy suggestion is to insist on neutral words such as "ancestry" when discussing population-level genetic variation, avoiding potentially misleading terms.

Pharmacogenomics research is the study of the genetic basis for differential drug responses between individuals. Identifying those genetic differences depends upon access to research databases that reflect a wide range of difference across the human population. Genetic variations, called SNPs, provide the raw material for research. SNPs occur at the rate of one in approximately 300 base pairs. The promise of SNPs research is the discovery of genes involved in human disease, such as asthma, diabetes, heart disease, schizophrenia, and cancer. (At the molecular level, sickle cell anemia is the result of a variant SNP.) SNPs are believed to play a major role in how humans respond to environmental insults such as bacteria, viruses, toxins, and chemicals (e.g. nicotine), including drugs and other therapies. The NIH, as well as private companies, have set up databases including a "representative" sample of human DNA. Because these databases must reflect the human population, how researchers conceptualize the racial or ethnic background of blood samples reveals a great deal about existing taxonomies of race.

Initially, databases were set up reflecting known social categories of difference. The Coriell Cell Repository, for example, includes cell lines—called "human variation panels"—from an amalgam of people, including such conceptually distinct categories as African American, Caribbean, Greek, Caucasian, Chinese, South American (Andes), and Southwestern American Indian.[79] Recognizing the issues we have identified in this paper, the NIH took a very different tact in setting up its "DNA Polymorphism Discovery Resource."[80] Established in 1998, samples were collected from 450 male and female U.S. citizens, apparently with the intention of reflecting the country's diversity. In order to avoid the creation of a database that could be mined and studied for difference by race, individual samples are not identified racially, rather, continental origin for the entire panel is presented.

DNA Polymorphism Discovery Resource

Population Group	Proportion of Admixture	Number of Individuals	Number of Genomes by Continent			
			Europe	Africa	America	Asia
European American	0.01	120	119	1	0	0
African American	0.17	120	20	100	0	0
Mexican American	0.39	60	36	5	19	0
Native American	0.05	30	2	0	28	0
Asian American	0.10	120	12	0	0	108
Totals		450	189	106	47	108

It remains to be seen whether this strategy will overcome the strong tendency of researchers who wish to stratify their samples according to "traditional" categories of race. It is, however, an example of a rare public

policy choice—a decision to avoid the imposition of categories of difference that do not adequately reflect actual genetic variation in the human population.[81]

VIII. TARGETED POPULATION-BASED RESEARCH AND SERVICES: AVOIDING SOCIAL HARMS

The association of the BRCA-1 mutation with Ashkenazi Jews is merely one of many correlations that have been, and continue to be, drawn between a disease and a racially identified population. The search for genetic variation in concert with categories of race threatens to perpetuate the racialization of disease. Two major strategies for discovering the relationship between human disease and variations in genetic polymorphisms have become standard. The first is a search for polymorphisms through sequencing in which any variation in gene sequences from a reference sequence is by definition identified as a new polymorphism. The second is a population genetics approach in which variation is detected within and between "identified" populations. Biomedical research focused on discovering associations between allelic frequencies and the occurrence of disease produces probability statements. For most common diseases, a particular genotype does not cause a specific disease in the same manner that genes determine blood type. Rather, genes are one factor among many that contribute to illness and are best understood in terms of statistical risk assessment. While genetic testing may be able to determine the presence or absence of genes or gene complexes, it cannot determine whether associated diseases and disorders will result; testing provides a set of probabilities only.

As noted in our discussion of pharmacogenomics research, the use of race in the identification of genomic materials is the critical initial step in the chain of knowledge production that results in correlations between racialized groups and risk of disease. Racial or ethnic labeling of an individual DNA donor by cell repositories and independent researchers may affect the health and welfare not only of that individual, but of the group with which that individual has been identified. Correlations that are derived from racial categorization of genomic materials used in research may result in policies regarding targeted genetic screening. Such recommendations have been made for various populations, including Europeans/Caucasians for cystic fibrosis testing, African Americans for sickle cell anemia, and Southeast Asians for beta-thalasaemia. A potential benefit of such targeted testing is the early identification of disease—or pregnancy termination depending on the timing of testing—in individuals who may not have been tested without being identified as belonging to a

particular population.

However, the conflation of race with risk of disease has negative implications for both the identified population and for society at large. Public health benefits are not the only outcome. Stigma and discrimination is a risk associated with the diagnosis of disease for any individual, particularly if curative measures are not available. While genetic markers are not definitive predictors of the onset of complex, common diseases, as opposed to rare Mendelian single-gene disorders, their value in determining relative risk is important in the delivery of health care. Insurance companies and managed care organizations, in particular, have economic stakes in controlling the potential costs of "high risk" clients.[82] In addition, social prejudice could arise in the identification of correlations between genes and disease. The calculus of risk may result in social consequences for individuals in the anticipation that they will fall ill.[83]

However, harm may extend beyond the individual at risk for a particular disease. When racially identified genetic markers are associated with illness, "race" itself becomes the surrogate risk factor. The potential harms associated with targeted genetic testing befall socially identifiable groups. The categorization of individuals according to race erases the individual specificity of genetic signatures. Associations become interpreted as causative relationships and race emerges as the salient scientific variable in the reporting of research findings.

Consequences are twofold: First, "race" itself becomes a source of stigma. Breast cancer becomes a "Jewish disease," and Jews become associated with high rates of cancer. Second, ideas of genetic reductionism are reinforced. The elision of economic factors such as poverty, employment, and unequal access to resources that are manifested in differences in nutrition, housing, and access to healthcare are subsumed within a genetics discourse that reifies notions of physiological difference. Ironically, such racial thinking renders the effects of racism on the relative health status of groups of individuals invisible. By pursuing targeted population testing in the shift to a genomic approach to healthcare, significant non-genetic factors will be left unaddressed. In addition, racially targeted programs may result in the neglect of individuals not identified with "at-risk" populations who may be afflicted with the diseases in question.

A. Protecting Identified Populations from Harms

If the potential harms of racially targeted testing extend beyond the individual to entire social groups, does our current, individually focused system for protecting human subjects in research (or requiring informed

consent for clinical services) provide adequate protection? Institutional review boards (IRBs) were created to provide mechanisms for oversight against potential risks to human subjects. Presently, IRBs are limited in their ability to evaluate future social harms that may arise from interpretation of research findings, such as genetic research targeted to racially identified populations. Their legislative mandate is protecting *individual* research participants and assuring informed consent.

Current oversight mechanisms do not address potential harms to communities with which individual human subjects are identified. For example, IRBs are not charged with the responsibility of assessing the risk of discrimination and stigmatization to identified populations from research that attempts to link genetic markers to disease and racialized groups. However, acknowledgement of such harms has fueled a growing debate over whether individuals, alone, should consent to research participation, or whether others who subscribe (or are ascribed membership) to the same racialized group should also participate in this process since they will share in the consequences of the research. As a result of these debates, increasing attention has been placed on the role of racial and ethnic communities in creating effective oversight measures in genetic research. The continued use of racial categories in the new genomic medicine may lead to the reevaluation of the established informed consent process that solely involves individual human subjects. What should be the role of groups as gatekeepers for research? How can we determine the need for public fora to consider the fears, desires, and perspectives of communities?[84]

Several scholars have argued that IRBs should implement new mechanisms that supplement individual consent with group permission.[85] In July 1999, the National Institute of General Medicine Sciences (NIGMS) conducted a workshop to address the ethical implications of identifying genetic materials with racial and ethnic populations in the Human Genetic Cell Repository created through a contract with the Coriell Institute. A key set of recommendations developed through the workshop was the creation of special "Oversight Groups for Populations-Based Samples" (OGPBS) for each racially and/or ethnically based community. These groups would presumably assure that samples would be acquired with the consent of the communities from which samples are collected, and with attention paid to the implications of future research.[86]

In September 2000, the NIGMS held the first "Community Consultation on the Responsible Collection and Use of Samples for Genetic Research" in which approximately sixty participants from a broad range of identified populations were invited to provide input on the best

approaches to minimize risks to communities. Central to the discussions among the participants was the ambiguous definition of racial and ethnic populations. In addition, participants of the NIGMS sponsored community consultation meeting debated the need for community consent *vs.* community consultation. Such discussions were in concert with a philosophical argument that charging groups—as opposed to individuals—with the moral authority to bestow informed consent is conceptually flawed and logistically confusing. In dispute are the assumptions that: 1) there exists a singular, self-evident social body that represents a particular individual human subject; 2) this social body has the moral authority to "speak" for all members of a particular group; and 3) consent from representatives of this social body absolves researchers of responsibility for prospective harms. Despite these challenges to the notion of group consent, there has been widespread support for the need for consultation and participation of communities in the research process. In developing culturally appropriate mechanisms to protect both individuals and communities, it is critical to acknowledge that individual decisions are inherently social decisions in which the collective is already deeply embedded. An anthropological approach that begins with the notion of "local moral worlds"[87] will be helpful in attempting to make meaningful the perspectives, beliefs, and actions of individuals within the context of a social group.

IX. Abandoning Race, Re-Crafting the Language of Difference: Implications for Health Care Research and Policy

In order to meet the vital policy goal of eliminating health disparities among diverse U.S. populations, it is critical to distinguish between biological and sociocultural contributions to the increased morbidity, mortality, and truncated access to services experienced by minority populations and the poor.[88] This can only be accomplished through careful attention to our categorization of "difference" in the conduct of research, in clinical and public health practice settings, and in our national health policy. A simplistic use of the category of race as a proxy for difference will inevitably limit the utility of information obtained through the study of the very real genetic variation that exists among U.S. populations with ancestry from all parts of the world. That variation, already well documented, will be fore-grounded as the use of genetic technologies expands. Increasingly, health-disparities research—both clinical and epidemiologic—will include comparisons that focus on variation at the level of DNA. We expect that emerging genomic technologies and the use of DNA repositories will play a large role in medical research in the future, thereby reinforcing the

notion that DNA is the primary factor underlying health differences between individuals.

We have argued that the way human difference is conceptualized and used in health-disparities research has profound moral consequences—that potential ill effects abound. Yet readers have undoubtedly noticed the seemingly inconsistent use of the term "race" in our analysis. On the one hand, we have highlighted the historical contingency and lack of scientific specificity of the concept. On the other hand, we have made clear that health disparities occur more often among racialized populations. Race does not exist, but racialized groups do, and the effects of this racialization are real. As Emerson suggests, "A foolish consistency is the hobgoblin of little minds...."[89] It is imperative *not* to think and talk about race in the simplistic, one-dimensional way characteristic of other scientific "variables." Rather, we must use extreme care and caution when invoking categories of difference in biomedicine, moving between concepts depending on the context and the purpose of the research. In health care, we are convinced it is legitimate to use traditional categories of racial difference only when engaged in studies of the pernicious effects of racism itself. When searching for the causes of health inequality, we must carefully tailor our approach to the demands of a specific research question, not simply follow conventional rituals of population stratification. Doing so will not only avoid reinforcing the destructive notion that biological races exist, it will also lead to a fuller understanding of health disparities. Of course this will require change in law and government regulation, as well as the way we think about race.

A. The Dangers of Genetic Reductionism

The prism of genetic reductionism yields dangers throughout health care. The effects are subtle and not easily remedied by top-down regulatory change. One potent implication of the conflation of genotype with phenotype in the new genomic medicine is a reconceptualization of disease etiology. By adopting a genetics-based explanatory model of illness, genes—rather than symptoms—become the critical way in which illness is identified. This may result in a shift in how disease is defined, which inevitably affects treatment and prevention strategies. Geneticists are engaged in research that links single genes, or more often, gene complexes, to particular diseases and/or conditions. While these genetic characteristics do not, in and of themselves, indicate the inevitability of the onset of illness, they are portrayed as of primary significance in determining one's risk of developing a particular disease. Despite the complex interplay of environmental and genetic factors in the eventual

onset of disease, increasing emphasis has been placed on the existence of "genetic markers" for disease. Such genetic reductionism undermines the lived experience of patients while privileging genetic signatures characterized by the presence or absence of "good" and "bad" genes. As a result, health will be measured less by one's condition in the present, and more through a calculus of risk for disease in the future.[90]

From such speculation, new definitions of healthy and unhealthy populations may emerge. Implicit to this new understanding of disease is a shifting boundary between normality and abnormality. Relying on a comparative and relational framework, the standard of health may be based on a human genome that is free of mutation. However, the labeling of genes as dysfunctional is complex and highly contextual, and has often been linked—without justification—to racialized populations. As mentioned previously, the now classic morality tale of sickle cell trait illustrates this point. The protective effect of the trait for individuals residing in areas where malaria is endemic is clear. In the United States, however, sickle cell trait serves no benefit in protecting against a disease that no longer poses a substantial threat. Rather, its deleterious effects for individuals who carry two copies of the altered gene have transformed a gene that is highly functional in malaria-ridden areas to a dangerous and dysfunctional mutation. The assignment of normality and abnormality is contingent on changing environmental conditions. As one of the first molecular diseases, sickle cell anemia clearly reveals the racialization of illness. The disease was believed to be confined to a particular racialized group, and race became the salient factor in explaining its etiology; from the outset of scientific and medical investigation it was identified as a "black disease."[91]

Our research paradigms and public policies must work to avoid the racialization of new diseases, with the associated stigmatization of populations. The legacy of mistrust created by the abuse of African-American subjects in medical research, symbolized by the Tuskegee syphilis study, serves as an ironic brake on genetics research. Black participants in the large-scale National Health and Nutrition Examination Survey (NHANES) were less likely than whites to allow their blood or other specimens to be stored for future research, regardless of guarantees of anonymity and privacy.[92] Fear of stigmatization overrides confidence in medical progress. The potential benefit of studying gene-environment interaction in human populations with varied ancestry may be lost.

A further consequence of over-reliance on the paradigm of genetic reductionism is the erasure of etiological explanations of critical importance in accounting for health disparities: environment, social

structure, poverty, or interactions among complex factors. When disease is "located" within the individual, strategies to ameliorate ill health tend to be similarly focused. The social dimensions of health and disease are ignored, or at best paid lip-service only. Resources—both governmental and private—flow to projects that embrace genomics and offer the possibility of products marketed to individuals who are encouraged to take responsibility for their own health. We do not dispute the promise of this scientific approach, rather we wish to point out how the light cast by genomics leaves alternative explanations of ill health in the shadows.

A final consequence of the genomic prism is the potential "rebiologization" of race as a conceptual category. Throughout the twentieth century, scholars, particularly anthropologists, have fought against the "essential" explanations of racial difference inherent in western thought since the time of Linneaus. In previous eras fundamental biological difference was assumed, but could not be directly assessed through genetic studies. The powerful technologies developed in support of the HGP are transformative, allowing the precise study of difference at the DNA level. We believe that caution is indicated in projects that employ powerful genetic technologies to study social categories of human difference. A possible, although not inevitable, outcome of the popular efforts to "prove" identity or origin through genetic research is that racial difference will once again be located in biology. Even research that focuses on disease etiology, as opposed to ethnic classification, has the potential for harm. It is possible, for example, that genetic research on breast cancer that targets individuals of Ashkenazi descent will have dual consequences: stigmatizing the population through the creation of a new racialized disease, while at the same time contributing to the idea that this population is somehow biologically distinct, that it constitutes a separate "race." We need to consider if alternative approaches to research design might avoid these dilemmas.

B. Avoiding Racial Classification Through "Individualized" Research and Practice

An alternative to the use of racial categories in health-related genomics research is a disciplined focus on patterns of genetic variation that are not influenced by prior racial categorization of individual research subjects or patients. SNPs research could utilize powerful genomic technologies to identify genetic signatures that are then classified according to similarity or difference, and correlated with health outcomes. In this way, variation at the genetic level might dictate new categories for making meaningful comparisons across human populations based on molecular difference. This relies on the ability to sample and make

comparisons within large populations. To achieve this, it is critical that we dispense with *a priori* racial classifications. Such a shift in methodology saves us from the tautological quandary of searching for differences in places where they are expected, thus reifying the idea of racial difference and ignoring the true range of genetic variation across the human population. In the same way, clinical policies and public health interventions that do not rely on racial or ethnic classification can be developed. Examples include existing newborn screening programs that are not targeted by socially defined racial categories, but examine genetic variation directly. Testing only people who are identified as black for sickle cell disease reinforces the racialization of disease and misses a significant proportion of cases. Given the current climate of research and policy, such strategies will not always be easy to implement. It is difficult to disabuse researchers, pharmaceutical companies, and public health managers of the idea that one must always classify by race.

C. Refining the Language of Race in Health Care Policy

The intersection of the genomics revolution with the health-disparities initiative provides an opportunity to refine our language. Prompted by the HGP, Joseph Graves, Jr., an evolutionary biologist, has called for a "Manhattan Project" on how we use the concept of race in the United States.[93] In fact, journal editors and editorial boards in a number of fields have recognized the need to re-examine the ritualistic use of racial and ethnic classifications in biomedical publications. Holding scientists accountable for their use of racial categories and racialized populations in their research is a promising intervention. Often populations are stratified into racialized groups in a research design without any rationale for why differences might be expected. In response to the lack of precision and potential danger of careless use of concepts such as race and ethnicity, the *British Medical Journal* took an early stand, issuing a statement in 1996.[94] More recently, *Pediatrics* issued guidelines requiring that authors explain why they chose to stratify research samples as they did, rather than rely on formulaic use of racial or ethnic categories.[95] *Nature Genetics* has also issued editorial guidelines, stating that there is no justification to use race as a proxy for genetic variation:

> The laudable objective to find means to improve the health conditions for...specific populations must not be compromised by the use of race or ethnicity as pseudo-biological variables. *Nature Genetics* will therefore require that authors explain why they make use of particular ethnic groups or populations, and how classification was achieved.[96]

We support these editorial policies and hope that such moves will lead to a critical re-examination of the meaning of race in health research and a heightened understanding of how racial classifications influence the production of medical knowledge.

The NIH held a conference in June 2000, called "Higher Levels of Analysis," which developed consensus recommendations including a call for a comprehensive re-examination of how foundational concepts like race, ethnicity, culture, and social class are measured and implemented in biomedical research.[97] One problem is that current practices of identification based on OMB directive 15 are governed by legal statute, and change would require legislative action. Whenever a researcher submits a proposal involving work with human subjects to the NIH, he or she must demonstrate that participants will be recruited to represent the diverse U.S. population, using census categories as descriptors of difference. The fact that these categories are primarily political, and may not be meaningful for a particular project, has been ignored. Ironically, the original intent of the legislation was to improve the health care of American minority populations, by requiring that women and minorities be included in all clinical trials funded by the NIH, unless the researcher could adequately explain why certain populations were excluded from research. This laudable policy goal has the unintended effect of discouraging researchers from using more subtle distinctions. It also conveys the idea that these concepts are scientifically meaningful, in spite of significant evidence of conceptual confusion in their implementation in health research.[98] Robert Hahn of the Centers for Disease Control and Prevention has participated in federal efforts to re-craft our classifications of race in the health arena, including the NIH conference mentioned above.[99] In spite of the recognized need, barriers to change are significant. Another irony is that governmental efforts to protect racialized populations from the potentially stigmatizing consequences of genetic research may play into the notion of bounded, biologically distinct groups. Care needs to be taken in how community consultation is carried out or how group consent is implemented.

Another key focus for policy discussion is the marketing of drugs, medical devices, or genetic tests to specific populations. The glaucoma drug Travatan provides an example of a targeted therapeutic agent. One scenario that must be addressed is the possibility that genetic tests will be marketed to socially identifiable groups based on variations in rates of certain mutations across the human population. This is already a well-established policy dilemma in genetic testing for a number of conditions. For example, over 900 discrete mutations in the gene associated with cystic

fibrosis have been identified, and specific mutations are found at different rates in individuals grouped according to ancestry from different continents. For example, delta 508, the first mutation identified, is more common among individuals of Northern European origin and is found less frequently among individuals whose origin is Asia. When screening tests are created, which collection of mutations should be included? Should targeted tests be developed or is it feasible to test all groups for all mutations? These are the dilemmas facing clinical laboratories that develop and conduct genetic tests.[100] Using a test known to have been developed with geographically limited genetic data is potentially harmful, yet creating specific tests for socially identifiable populations could intensify community harms if carelessly done. Attention to the language of difference used in FDA-approved package inserts for drugs and devices, and in educational materials, must be part of our "Manhattan Project."

We have emphasized that it is not enough simply to substitute a more "politically correct term"—such as ethnicity or culture—and continue to make use of an archaic race concept. The scientific evidence is clear that genetic variation does not neatly map onto socially meaningful groups. What alternatives exist to using the word race? When considering the health effects of racism, we prefer the term "racialized" group or population, to emphasize that the concept of race is historically contingent. How we speak is a direct reflection of how we think; the language of race is a non-trivial policy issue. Great care must be taken, particularly in the highly charged domain of human genetics research. In order to avoid the erroneous assumption that human races exist, one policy-making body has made a conscious decision to avoid use of the word race when discussing biological difference or genetic variation. Instead, the Secretary's Advisory Committee on Genetic Testing has used the concept of "ethno-cultural groups" when referring to human populations that might be adversely affected by genetic testing.[101]

D. The Dilemma of Difference

Finally, we recognize that a major challenge to eliminating the careless use of "race" in health research stems from a disjuncture between the goals of scientific investigation and those of public policy. Good science precludes the näive use of race. Yet, the policy goal of eliminating health disparities among racially and ethnically identified populations significantly influences how health research is designed and conducted. When alternative approaches to *a priori* racial categorization of human subjects are employed, research results must be reinterpreted in terms of political categories in order to determine progress towards the realization

of the public health goal of reducing inequality. If researchers are to be held accountable for their use of race, we must develop policies that allow both scientific and policy goals to be met, using the social and political concept of race, or of racialized groups, only when salient.

Debates about the significance of race in the new genetics are in this way no different than those about public policies like affirmative action. Calling attention to race in order to ameliorate inequality has the unintended effect of perpetuating the social divisions one wishes to eliminate. Legal scholar Martha Minow has called this the "dilemma of difference."[102] Minow asks: When does treating people differently lead to the goal of equal treatment and opportunity, and when does it stigmatize or hinder them when differences are ignored? It is imperative not to conduct research in a way that conveys the idea that biologically distinct human races exist. At the same time, real health inequalities must be remedied; genuine genetic variation across the human population must be better understood. A close examination of the historical practices of racial classification reveals the complexity that has plagued the deployment of race since the concept entered modern discourse. The racialization of human groups, historically linked to the maintenance of rigid, hierarchical boundaries rooted in unequal access to resources and opportunities, stands in direct opposition to the social justice goals of *Healthy People 2010.* The advent of the HGP, and the development of genetic technologies, provide great opportunity for reducing health inequalities. Achieving that goal requires careful attention to the moral significance of "race" in health-disparities research.

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101. Co-author Koenig serves on this committee, which is charged with recommending mechanisms to improve the oversight of genetic testing in the United States. *See also* the SACGT's report to Surgeon General David Satcher, *at* http://www4.od.nih.gov/oba/sacgt/gtsecondary.pdf (last visited May 2, 2001).

102. MARTHA MINOW, MAKING ALL THE DIFFERENCE: INCLUSION, EXCLUSION, AND AMERICAN LAW (1990).