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Race and Health Care:
Problems with Using Race to Classify, Assess, and Treat Patients

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Race and Health Care:
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Abstract

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Though racial classifications may serve as a mechanism for identifying and correcting disparities among various groups, using such classifications in a clinical setting to detect and treat patient needs can be problematic. This report explores how medical professionals and researchers use race in health care for purposes of data collection, risk assessment, and diagnosis and treatment options. Using mixed race individuals as an example, it then discusses some of the problems associated with using race to group individuals, assess risk, and inform patient care. Finally, it discusses how certain components of personalized medicine, such as genetic testing, Electronic Health Records, and Rapid Learning Systems could help address some of the concerns that arise from the application of race in a health care setting.

Table of Contents

Chapter 1: Introduction

In February of 2010, the Cardiovascular Specialists of Texas held the "Know Your Heart 2010" seminar at a medical center in Austin, Texas. In order to educate participants about cardiovascular disease, "the nation's number one killer," the seminar boasted several presentations on health concerns related to heart disease and screening and diagnostic measures that can help detect patients' health risks. The conference's website encouraged patients to "discover how lifestyle and genetics influence [their] risk for heart disease and stroke,"[1] and was advertised to Chinese, African Americans, Asians, Indians, Hispanics, and Caucasians. Potential participants were promised that "a physician from each ethnicity will answer patient questions" so they could "address issues regarding primary prevention that may be unique to specific ethnicities."[2] A local news station began their story on the seminar by saying, "Black, white, Asian—with every race comes different issues when it comes to heart health," and reported that, "doctors organized break out sessions within the seminar based on race."[3]

While the seminar and news report were undoubtedly well intended, a few things about the event and the subsequent news coverage bothered me. First, whether they knew it or not, the promoters of the seminar mistakenly confused race, ethnicity, and genetics. Though often used interchangeably, there are important distinctions among the three terms that the seminar failed to make. In doing so, the organizers unknowingly added to the confusion surrounding how a patient's race plays into his or her health and further promoted the idea of race as a biological construct rather than a social one. Furthermore, the broad categories of the seminar's racial and ethnic groupings were also troublesome, as they did not take into account the extent of genetic variation that exists even among individuals with similar geographic origin. Additionally, they seemed to imply that the

physician had to be the same or similar race or ethnicity as the patients in order to understand specific clinical issues for someone of that ethnicity.

Most selfishly, I was troubled by this question: which break out session would I have attended? As an individual with an Asian father and Caucasian mother, in which room would I have learned about the issues unique to my specific ethnicity? If I had gone to the room with the Caucasian doctor addressing a Caucasian audience, would I have missed a vital piece of information about my health that the Asian doctor discussed with the Asian audience? Probably not, but the "dilemma" I face as a multiracial individual raises questions about how relevant racial and ethnic identifiers are when it comes to health care. In particular, how can medical professionals and researchers assess an individual's medical history and future health risks without using race as an indicator of an individual's underlying genetics?

Though it may not have a single, definitive answer, this paper aims to address the aforementioned question. It will first explore some of the ways in which race plays a role in health care, particularly for purposes of data collection, risk assessment, and diagnosis and treatment options. Next, it will examine various problems associated with using race in a health care setting, particularly from the standpoint of mixed race individuals. Finally, it will discuss how specific components of personalized medicine could help alleviate some of the concerns about the application of race in a health care setting.

WHAT IS RACE?

In order to examine how race is used in health care, it is first necessary to discuss what is meant by "race." The word "race" does not have just one definition; it has taken on multiple meanings and purposes since its inception. Given that it appears to have numerous definitions and interpretations, what is it *really*? Popular ideas about race are

based on scientific formulations from the 19th and early 20th centuries that took external characteristics, such as skin color, facial features, and body shape and size, into account when determining racial categories.[4] These categories were based on social constructions of race that presumed externally visible traits indicate all other traits of an individual or population. Even though these categories do not have a biological basis, their application as evidence in support of racist doctrines is not uncommon. In the United States specifically, "an entire social structure and system of relations evolved based on race."[5] For example, the belief that blacks were racially inferior to whites served as a critical component in the justification of slavery. Though definitions of race and its boundaries were not initially clear, restriction of rights based on race became a growing part of the American legal landscape. Ultimately, access to "resources necessary for a decent life" depended on "which side of the color line one fell."[6] Oftentimes, this meant that non-white individuals were dealt the worse hand. The effects of this discrimination are still observable in modern society, particularly in the ways that people's attitudes have been shaped toward the concept of race and the assumptions they make about what another person's race reveals about her.

From a scientific standpoint, the reality is that race does not have legitimate roots in biology or genetics. After the completion of the Human Genome Project, which is the most comprehensive study of human DNA to date, the project's scientists ruled conclusively that:

> DNA studies do not indicate that separate classifiable subspecies (races) exist within modern humans. While different genes for physical traits such as skin and hair color can be identified between individuals, no consistent patterns of genes across the human genome exist to distinguish one race from another. There also is no genetic basis for divisions of human ethnicity. People who have lived in the same geographic region for many generations may have some alleles in common

> but no allele will be found in all members of one population and in no members of any other.[7]

In other words, there is no "Hispanic" or "Asian" or "African-American" gene.[8] Still, some argue that underlying biology can be inferred based on racial categories. However, groups that may be similar physically can have drastic variations genetically. For example, sub-Saharan Africans and Australian Aborigines may have similar skin coloring due to adaptation to the sun, but their genetic makeup is rather different.[9] Thus, traits that result from natural selection may not be the best mechanism for determining group membership as they may "imply genetic relatedness where, in fact, little exists." [10]

The presence of convincing evidence supporting a connection between biology and race is not entirely absent. In particular, the difficulties minorities face in finding unrelated stem cell donors illustrate this point.[11] Human Leukocyte Antigens (HLA) are groups of proteins on the surface of cells that play a role in the body's immune response to foreign materials. Because they vary from person to person, HLA tests are required prior to organ transplantations to ensure a match between the donor and recipient.[12] Studies have found unique antigens exist in specific groups, particularly African Americans and Asian Americans, which may be why minorities face difficulties in finding unrelated stem cell donors.[13] However, the presence of a specific HLA halotype may indicate the individual's point of geographic origin, but it does not necessarily reveal how she would be grouped racially. Thus, the distinction between "race" and "ethnic origin" is also important.

Though the term "ethnicity" is often associated with "minority issues" and "race relations," most scholars agree that it is centered around the idea that ethnicity is related to the "classification of people and group relationships" between groups that consider themselves "culturally distinctive."[14] The Census also states that ethnic origin and race

are considered separate concepts in federal statistics and therefore distinguish between ethnicity and race with its questions. Specifically, respondents are asked to indicate their origin in the question of Hispanic origin, but are also asked to answer the question on race because people of Hispanic, Latino, or Spanish origin "may be of any race."[15]

As the findings from the Human Genome Project indicate, science does appear to support the idea that genetic analysis can reveal a person's geographic origin, but does not necessarily reveal externally visible traits, such as skin color. Genetic differences do exist between groups, but how the groups are divided depends on which genes are examined. Moreover, approximately 90 percent of genetic variation occurs within a given population, whereas roughly 10 percent of genetic variation distinguishes groups.[16] Simply put, though human groups can be distinguished, people with different geographical origins are barely more different from each other than those from within the same geographical population.[17] Furthermore, an individual's geographic origin does not guarantee the presence of a specific genetic variant.

Though the difference between race and ethnicity may seem like an inconsequential matter of semantics, the significance is relevant when it comes to determining risk for particular diseases. Though some researchers suggest that the genetic variants that identify the geographic origin of people's ancestry are mostly irrelevant when it comes to examining traits relevant in health, the common heritage to which ethnicity often refers can, in some cases, be an indicator that individuals are at a higher risk of developing certain heritable diseases. For example, the frequency of Tay Sachs disease in Ashkenazi Jews of Eastern European descent is higher than in most other populations. However, all Ashkenazi Jews are not necessarily classified as white, just as all people classified as white would not be at risk for Tay Sachs.[18] Thus, it would not make sense for medical professionals to use racial categories as a means of assessing a

patient's risk of having Tay Sachs. Furthermore, heritable diseases like Tay Sachs, Thalessemia, and Sickle Cell Anemia are typically monogenic, meaning that a single gene alteration results in the manifestation of the disease.[19] However, most diseases are not monogenic. Common diseases like hypertension and diabetes (which are sometimes considered "race-related" because they occur more frequently in minority populations) are typically classified as complex or multifactorial disorders. In other words, they result from changes in several genes that work in combination with other social and environmental factors.[20] Complex disorders often occur in families, but there is not a distinct pattern of inheritance that allows for easy determination of a person's risk of inheriting or passing on the disorder.[21] In fact, the tendency for complex diseases to be inherited is low compared to monogenic disorders.[22] That being the case, simply using a person's race to suggest that she may be at a higher risk for developing certain diseases is misleading and further emphasizes the falsehood that race is connected to biology.

Still, some people point to data showing differences in health statistics across races and conclude that certain individuals are at a higher risk of developing particular diseases or conditions for biological reasons. For example, data show that significant differences exist in the life expectancy rates for blacks versus whites in the United States.[23] While some causes of death are known contributors to the higher mortality rates among blacks (e.g., circulatory diseases, cancer, diabetes, injuries, and homicide), the explanations for the racial discrepancies are not entirely clear.[24] Some may believe this health disparity exists because of a genetic predisposition to developing certain diseases, such as diabetes. However, genetics alone is not a strong argument for the higher incidence rates of diabetes in minority populations. In fact, a study conducted in the late 1990s indicates that socioeconomic status plays a critical role in some of the specific causes of death that contribute to the higher mortality rate among blacks.[25] A

substantially larger number of black families in the United States live below the poverty line as compared to white families. A 2008 survey conducted by the U.S. Census Bureau reveals approximately 21.2 percent of black families live below the poverty line, versus 7.2 percent of white families.[26] Because poorer areas commonly have more barriers in gaining access to health care and fewer opportunities for health education, screening, and disease prevention than higher income areas, they may experience worse health outcomes.

Why does any of this matter? A human classification system based on racial groupings has resulted in people using race as rationale to falsely link physical characteristics with behavioral characteristics, rank-order humans hierarchically, and create inequalities between established groupings.[27] There is growing evidence suggesting that the race of patients has a significant impact on the type of medical treatment they receive. Though reasons are not entirely clear, the consistency of disparate treatment by race suggests that unconscious biases may influence how a medical professional treats a patient.[28] For example, recent studies show that minorities, specifically black and Hispanic patients, are likely to encounter longer wait periods in the ER than their white counterparts.[29] It is not likely that this discrepancy in treatment is due to differences in genetic makeup. Rather, it is more likely that it represents a difference in treatment locations and the quality of health care a patient receives in a crowded, urban hospital versus a more "elite" hospital in a nicer part of town. More specifically, it may speak to the idea that continuing health disparities are a result of "prejudice, stereotypic, and racial/ethnic biases on the part of health care providers."[30]

Chapter 2: Race and Health Care

Asking how race is used in health care is a broad question that does not likely have a single, definitive answer. Regardless, there are specific examples of how race is used in medicine that indicate its presence is not far-removed from daily medical practices. Through formal measures, such as in textbooks or in the classroom setting, and informal measures, such as conversations with colleagues or during patient rounds, medical students are taught to include racial identifiers in the opening line of oral and written case presentations.[31] Traditionally, medical students learn to present patients by age, race, and gender (e.g., "The patient is a 42 year-old Hispanic male"). At present, some medical schools are reexamining this approach in order to "diminish the role of physician bias and stereotyping in the persistence of health care disparities."[32] Still, the practice begs the question: what purpose does the racial identification component of the patient description serve? Some of the main purposes may include data collection for health statistics reporting; health risk assessment to screen for certain diseases or illness; and in some cases, selection of treatment protocol.

DATA COLLECTION/HEALTH STATISTICS

Collecting data on individuals' race or ethnicity is common practice in a number of areas. The collection of data on race in the United States began as a means of identifying and eliminating potential disparities that occur across different groups with respect to housing, employment, and "other areas of civic life."[33] The U.S. Census Bureau cites several reasons for collecting data on race, including for federal programs, making policy decisions, legislative redistricting principles, promoting equal employment opportunities, and assessing racial disparities in health and environmental risks.[34] It is

worth noting, however, that the Census states that the inclusion of racial categories is not meant to "define race biologically, anthropologically, or genetically."[35] Still, some argue that the collection of racial data for public health research should be abandoned and replaced with more "meaningful" variables that provide more information about the social conditions that affect health (e.g., place of residence).[36]

Other studies have shown that racial labeling, even for purposes of better diagnosing and treating patients, can reinforce stereotyping and false assumptions about a patient's health status.[37] Often, stereotyping on the part of medical professionals results in racial and ethnic minorities receiving unequal medical attention, even when other variables (e.g., age, insurance status, income, severity of conditions) are similar.[38]

The American Academy of Pediatrics (AAP) suggests that without careful definitions and analysis of race and ethnicity in public health surveillance, researchers and policymakers may falsely label race and ethnicity as "biological contributors to illness."[39] Thus, the AAP recommends researchers use data collected on race and ethnicity only if the terms are carefully designed and the reasons for their use are fully explained.[40] Other guidelines for the use of race and ethnicity in health-related research suggest that any resulting publications should clearly state how individuals included in the data were placed in a racial category. Beyond that, the publications should not use any "stigmatizing or misleading" language and should refrain from using race to indicate any sort of genetic variation exists among racially grouped populations.[41]

Advocates for the continued collection of data on race and ethnicity believe that disposing of the practice altogether would result in the elimination of important data regarding the inequalities that exist between racial groups.[42] Their argument makes a valid point: completely eliminating the use of race as a variable in the collection of health statistics for the sake of racial ideology may come at the expense of identifying and

rectifying the social and economic factors (e.g., poverty and discrimination) that result in health disparities. However, it is worth emphasizing that in collecting and reporting on such data, researchers must be careful not to perpetuate the misconception that observed health disparities exist as a result of "racial genetics."

RISK ASSESSMENT

A number of diseases or illnesses, such as high blood pressure, heart disease, diabetes, osteoporosis, and several different types of cancer, include race on their list of risk factors. What they do not specify, however, is why. As previously discussed, blacks are considered to have a higher risk for developing diabetes, but that may be due more to social reasons than genetic ones. However, without explanations as to why race is considered a risk factor, people appear to assume it is for genetically influenced reasons. As such, the misunderstanding of race as an indicator of genetic factors influencing disease development is perpetuated.

Osteoporosis, a disease that makes bones weak and more likely to break, is particularly common among people age 65 and older; it is twice as common in women as it is in men.[43] Aside from gender and age, race is also cited as risk factor in developing osteoporosis. In particular, several organizations state that being white or of Southeast Asian descent increases an individual's risk of osteoporosis (though blacks and Hispanics also have a significant risk).[44] In order to assess an individual's risk of osteoporosis, medical professionals often administer bone marrow density (BMD) tests.[45] As its name suggests, the test measures an individual's bone marrow density and compares it to established norms or standards to produce the patient's T-score and Z-score. The Z-score is of particular interest in this case because it represents the number of standard

deviations above or below the expected average for someone of a similar age, sex, weight, and ***ethnic or racial origin***.[46] As pointed out earlier, there are considerable genetic variations even among similarly classified individuals (e.g., "White" or "Asian"). Thus, to compare scores across such broad categories of race and ethnic origin (seemingly under the guise of genetic similarities) seems somewhat illogical.

Several cancers also list race and/or ethnicity among the risk factors that increase an individual's chance of developing different cancer types. The National Cancer Institute (NCI) has a Breast Cancer Risk Assessment Tool posted on its website that allows medical professionals (and anyone else who happens across the website) to estimate a woman's five year and lifetime risk of developing breast cancer.[47] One of the "risk calculator" inputs asks for a woman's race or ethnicity in order to compute her likelihood of acquiring the disease. Though it is unclear how the projection is weighted exactly, the test illustrates that a woman's race is somehow factored into the equation. Breast cancer research does in fact show that the rates of developing and dying from the disease vary among racial and ethnic groups. Overall, white, non-Hispanic women have the highest incidence rate of breast cancer, though the incidence rate among women ages 40-50 is higher for black women. Additionally, black women are more likely to die from the disease. One theory as to why this is the case suggests that black women have more aggressive tumors.[48] However, social and environmental factors may play a bigger role in the observed differences. Specifically, access to care and/or when health care is sought affects when the patient is diagnosed. White patients who tend to have better access to treatment may receive treatment at an earlier, more "curable" stage. Additionally, more frequent screening means they are more likely to be treated for both false positives and non-aggressive tumors.[49]

The Siteman Cancer Center (Siteman) in St. Louis, Missouri goes a step further with its online risk assessment tool. The section of its website entitled *Your Disease Risk* allows an individual to approximate his risk of developing "five of the most important diseases in the United States and get personalized tips for preventing them."[50] *Your Disease Risk* states that its risk calculator model was developed over a period of ten years by "world-renowned experts" and combines the latest scientific evidence on disease risk into one tool so that individuals can calculate their risk for diabetes, heart disease, osteoporosis, stroke, and 12 different types of cancer. The mention of the celebrated experts and scientific evidence gives the impression that race was included as a risk factor because it has a scientific or biological component, even though it is likely that social circumstances related to racial categories more strongly influence the development of the diseases. Not every risk assessment questionnaire includes a question about race or ethnicity, but it is not always clear what purpose the question serves when it does appear. Still, to its credit, the Siteman calculator is more specific than the NCI Breast Cancer Risk Assessment Tool in that it allows a person to obtain more details on the factors that make up his individual risk profile. In some instances, the calculator results make no mention of what role the selected race or ethnicity plays in an individual's risk results. In other cases, the questionnaire results include the selected race among the list of factors that increase or decrease a person's risk. For example, selecting "African American" when filling out the prostate cancer risk assessment questionnaire informs a male that he has an increased risk of prostate cancer. The tool gives the following explanation:

> Being Asian lowers your risk of prostate cancer. Asian men have lower rates of prostate cancer than other men. Although scientists aren't sure why, one possibility is that Asian men eat foods that are linked to lower risk. Or they may have hormone levels that lower their risk of the disease.

> On the other hand, being African-American raises your risk of prostate cancer. African-American men have the highest rates of prostate cancer in the world. Although scientists aren't sure why, one possibility is that African-American men have hormone levels that are linked to higher risk. As a group, African-American men also eat foods that increase their risk of disease.[51]

Though the explanation mentions that differing diets, which are often affected by social factors, may play a role in the varied risk rates, it also implies that there is a biological basis for different risk levels due to race. While science and medicine should not completely dismiss the thought of a common genetic trait having an effect on a person's disease risk, researchers should be careful not to associate exceptionally broad categories of race with specific biological traits.

DIAGNOSIS/TREATMENT

The presence of race in health care extends beyond risk assessment practices. Recent forays into the world of race-based medicine have sparked much controversy regarding the connection between race and genetic biology. A prominent example of race-based medicine is the development of BiDil, a medicine approved by the U.S. Food and Drug Administration (FDA) in 2005 for the treatment of heart failure in self-identified African-Americans. The FDA's decision has had significant scientific and policy implications that have had a negative social impact on the perception of the relationship between race and genetics.

The FDA called the approval of BiDil a step toward the delivery of personalized medicine, but the science behind the purported difference in treatment outcomes for blacks is somewhat questionable. The African American Heart Failure Trial (A-HeFT), the major clinical trial upon which the approval of BiDil was based, tested the drug only on black patients.[52] Without a comparative study demonstrating that the drug is better

than existing treatments for the indicated group and that it is not better than existing treatments for non-indicated groups, conclusions about BiDil's heightened efficacy in black patients seem imprecise. Furthermore, A-HeFT did not include any type of genetic testing in order to identify common genetic or biological traits among the participants that might account for the supposed difference in treatment outcomes.[53] Additionally, the trial used self-identified race as a surrogate for genetic markers, despite the fact that the Human Genome Project concluded that there are not consistent patterns of genes across the human genome to distinguish one race from another.[54] The acceptance of self-identified race as a proxy for genetic information unscientifically endorses a biological model of race[55] and compromises the integrity of genetics-based research, which could result in negative social consequences regarding the public perception of race and genetics. Without scientifically sound genetic evidence, it does not seem prudent to consider BiDil a step toward personalized medicine, which aims to tailor treatments to individuals based on their genetic profiles, not their placement in a socially constructed category of race. Though some diseases may occur more frequently in some races than in others, it is not possible for race as it is recognized clinically and culturally to provide definitive evidence that a particular genetic variant is present.[56] For that reason, race is not a sufficient surrogate for choosing a treatment; the only way to know whether or not a patient has a particular genetic variant that will cause them to respond a certain way to a medication is to test him for it.[57]

Some say that the motives behind the development of BiDil as a race-specific drug are also questionable. They argue that BiDil was not initially designed as a race- or gene-specific drug. However, BiDil did not initially meet the FDA's statistical standards for market approval for general use in patients with heart failure. Critics believe that, with the drug patent about to expire, the drug manufacturers needed a new strategy to protect

the drug and get it to the market. As a result, they contend BiDil was reconceived as a race-specific drug so that the company would then have a longer period of intellectual property control over the drug.[58] That being the case, BiDil's market presence as a race-specific drug seems even more dubious.

Aside from the disputed science behind BiDil's approval, the FDA's decision also carried damaging social consequences. The focus on biological differences as an important cause of racial disparities diverts attention away from social factors that contribute to observed differences in health and health outcomes.[59] Additionally, the FDA has traditionally generalized data from clinical trials conducted with only white patients when approving drugs for use by all populations. Failure to do so in this case carries an underlying message that black bodies are not representative of the whole population because they are too different from other bodies.[60] This message not only exacerbates the social division between races, but further propagates the mistaken idea that different races have significant biological differences as well.

Interestingly, BiDil has experienced such poor commercial success that the drug manufacturer (NitroMed) suspended its marketing activities and laid off most of its employees.[61] Though it is still available on the market, its future is uncertain. Presumably, labeling it as a race-specific medicine has had a negative impact on people's perceptions of BiDil. Its lack of commercial success suggests that the public and physicians do not appear to be interested in race-based drugs.[62] However, it should be pointed out that the safety and health benefits of BiDil are not in question; it has served as a lifesaving therapy for many of the patients who use it. Unfortunately, the race-specific label limits the number of patients to whom doctors can prescribe the lifesaving therapy without it being considered an "off-label" use.

Chapter 3: The Case of Mixed Race

As mentioned during the previous discussion entitled "What is Race?", no such thing as "pure race" exists, so it stands to reason that everyone is, to some degree, "multiracial" or of "mixed race." However, for the purposes of this discussion, the terms "multiracial," "mixed race," and "mixed heritage" refer to individuals with parents who are classified as being from two distinct racial or ethnic categories. Mixed heritage individuals described by such a definition provide an excellent example of some of the problems associated with relying on race to classify individuals, assess risk, or inform patient care.

Racial identification, either on the part of the individual or by an external actor (e.g., a medical professional) is an area of concern, particularly in terms of the reliability of using race to assess health risk. For example, an individual who has one black parent and one Hispanic parent may self-identify as only one or the other. If she identifies as black and does not think to share the racial or ethnic identities of both of her parents with the medical professionals administering care, how comprehensive will the patient assessment be? Or, if a patient has one Asian parent and one white parent, but a medical professional identifies her as Hispanic, what effects does that external misidentification have on the adequacy, accuracy, and equitability of the physician's assessment of the patient? Furthermore, patients do not inform health care professionals that they believe they have disease X, thus allowing the clinician to then administer exams to confirm that diagnosis. Instead, patients present a list of symptoms to their physician, and then expect a diagnosis and treatment. While most physicians will follow proper medical protocol in assessing and diagnosing a patient, her beliefs and biases, however well-meaning they may be, could influence the type of treatment the patient receives. Thus, if the physician

believes the Asian/White patient to be Hispanic, the physician's perceptions about Hispanics in the health care setting may subconsciously influence her assessment and care of the patient.

Beyond issues of racial identification and classification, people have different "health beliefs, practices, and interpretations of their experiences with the health care system."[63] A series of interviews with mixed Asian/White participants reveals that individuals who are grouped together in the same broad racial category (e.g., Asian) still have varied health practices and interpretations of their experiences with the health care system based on the extent to which they have experienced racial discrimination, their SES, the amount of exposure or awareness they have of alternative medicines, and how long they have lived in the U.S.[64] Ultimately, the way they view each of those factors depends on the way they view themselves. For example, the adoption of alternative healing traditions is more common in individuals who more closely identify with their Asian heritage. That in mind, could the conceptualization of health and health care change based on which parent is which race? More specifically, if women are the stewards of health care seeking behaviors within the home,[65] how do the racial/ethnic classification and cultural influences of the mother affect mixed race individuals' approach to health care, if at all? While many of these questions may not have quantifiable answers, the sheer number of questions illustrates the confusion that can arise when applying broad racial categories in a health care setting.

The health risk assessment tools discussed previously are also problematic for mixed race individuals. For example, the Z-score of the bone density test compares a woman's score to the scores of other women categorized as the same race. However, medical professionals do not analyze the results of a woman who is Asian and white twice to compare it to the norms from the different racial groups.[66] Nor is there a way to

"weight" the test results in order to account for the woman's multiple genetic contributions.[67] Consequently, how meaningful is the analysis of her test results? Or, how arbitrary is the racial comparison for all women? The use of race in this manner also introduces potential problems related to a woman's reimbursement for treatment through insurance. Treatment for osteoporosis usually begins when a woman is "2.5 standard deviations from the norm for young women of her race."[68] Because the norms of Asian women are lower than the norms of white women, test results could classify the bone density of a woman who is both Asian and white "abnormal" depending on her racial categorization.[69] Thus, the measurements used for Z-score analysis are challenging not only in terms of risk assessment and determining if treatment is necessary, but also in terms of acquiring insurance coverage for treatment.

The online risk assessment tools discussed earlier pose a similar dilemma for mixed heritage individuals. The input options for "race/ethnicity" usually include five choices of race or ethnicity: white, African American, Hispanic, Asian or Pacific Islander, and American Indian or Alaskan Native. However, individuals who are of mixed heritage and do not self-identify with just one racial or ethnic classification do not have options from which they can choose. In some cases, the options "other" or "unknown" are available, but that particular option appears to serve more as a placeholder than an actual variable contributing to the risk assessment profile. Furthermore, risk assessment tests that include race or ethnicity as a factor raise an interesting question: If certain ethnicities are genetically predisposed to certain health conditions, what effects does being of mixed heritage have on the resulting health risk? Supposing that there are certain groups that are genetically predisposed to certain health conditions, how does that risk change when an individual's parents are from separately categorized groups? For example, if there is a biological component to prostate cancer as

the Siteman risk assessment tool suggests, would a man with an African American parent and an Asian parent be more or less at risk because of the different genetic contributions from each parent? Of course, if there is a biological component to prostate cancer, the only way to know if it is present in a man is to test him for the presence of the biomarker in question.

In general, the absence of options for multiethnic or multiracial individuals reveals part of the problem in using race as a risk assessment tool: it neglects to account for the extent of genetic variation that underlies the concept of race. Thus, not only does it disregard a number of people who do not fit neatly into any of the given categories, but it may also misgauge the genetic contributions of individuals who do select a specific race or ethnicity with which they identify socially.

The number of questions that arise regarding mixed race individuals in a health care setting also points to the fact that the amount of research available on multiracial individuals' health risks is limited. A review of literature from several leading health research organizations geared toward examining minority groups, such as the Institute of Medicine's (IOM) group for "Select Populations and Health Disparities" and the National Institutes of Health's (NIH) National Center on Minority Health and Health Disparities (NCMHD), reveals that there is little to no research available on health care and health concerns for self-identified mixed heritage individuals. While the FDA does recommend that researchers allow clinical trial participants to designate themselves as multiracial,[70] it appears to do little else to encourage the participation of self-identified multiracial participants in drug studies.

Prior to a 2000 study, it appears that no other research was conducted on multiracial individuals and their physical health.[71] The study conducted in 2000 reveals that among the participants, multiracial respondents reported the poorest health, while

Caucasians reported the best health. However, it also indicates that a possible explanation for the poor health of multiracial individuals could be due to lower socioeconomic status, not simply genetic factors. Above all else, the study points out how little is known about the health status of multiracial individuals and the need for further research. However, the discussion of mixed heritage individuals here is not simply to say that more research is needed on this specific segment of the population in order to provide them the best health care possible. Rather, mixed heritage individuals illustrate the idea that using race as a proxy for genetics in health care (and in general) is quite arbitrary.

The 2000 Census marked the first time individuals had the option to "mark one or more" race; the resulting data reveal that nearly 7-million individuals self-identified as multiple races.[72] Another study projects that individuals who self-identify as mixed race will make up 21 percent of the population by 2050.[73] The growing number of individuals who self-identify as multiracial indicates that the "traditional" methods of grouping people according to race need reassessment. Similarly, the manner in which medical professionals consider race to inform patient care needs reassessment. Nonetheless, inclusion of the option to mark one or more on the Census does not mean that mixed heritage individuals are a new "phenomenon." Recalling the idea that nobody is purely one race, it stands to reason that doctors have been treating "mixed heritage" patients for quite some time now. In some respects, that illustrates the notion that the actual "race" of an individual is irrelevant; the only way to treat the patient is to treat the patient.

Chapter 4: Addressing the Issue

The use of race in health care does not simply point to the need to reassess how patient care is informed, but also highlights the need for discourse regarding the social constructs regarding race. Thus, while the options in this section focus on health care issues, it is also important to keep in mind that in general, there are many other issues that arise from society's use of race as a significant identifier and fundamental classification system. In many respects, the problem at hand is an American Studies issue that deals with reassessing the overall use of race as a meaningful descriptor or means of classifying populations. In terms of health care, however, the use of race by medical professionals and public health researchers needs reassessment so that patients are cared for based on individual needs, not statistics. While this may seem like a lofty goal, there are some emerging health innovations and technologies that could help this type of personalized care system become a reality for the U.S.

The U.S. Congress describes personalized medicine as the "application of genomic and molecular data to better target the delivery of health care, facilitate the discovery and clinical testing of new products, and help determine a patient's predisposition to a particular disease or condition."[74] The overall goal is to help patients and physicians identify and develop the best line of treatment for the patient's "genetic and environmental profile."[75] This could include approaches that deliver more specific diagnoses (e.g., genetic screening programs) or that allow medical professionals to prescribe the type and dose of medication with the greatest efficacy for a particular group of patients (i.e., the application of pharmacogenetics). A promising aspect of personalized medicine is that it recognizes the level of variation across individuals is not only vast, but plays an important part in health and illness. Specifically, it recognizes that the "natural

variations found in our genes could influence our risk of developing a certain disease as well as how our bodies respond to that disease."[76] However, more than an individual's genotype affects his health; the environment in which he lives can also affect his development of disease and response to treatment. Under ideal circumstances, personalized medicine takes both the social and genetic variables into account in order to determine which treatments are the best suited for which subpopulations. Additionally, it could be useful in terms of discovering which groups of patients are more likely to develop certain diseases and, subsequently, the medical, social, and environmental responses that could help "delay onset of a disease or reduce its impact."[77] Eventually, personalized medicine could be a way to tailor health care to individuals without relying on racial classifications.

GENETIC TESTING

Genetic testing is a central component of personalized medicine. There is little debate that genetic factors influence several common diseases. As such, research to identify genetic determinants that play a role in development of particular diseases has swelled in recent years. Genetic testing encompasses a number of different tests, though the main purpose of this type of testing is to look for changes in a person's genes or the proteins those genes are meant to create. Individuals can undergo genetic testing to confirm a diagnosis if signs or symptoms of genetic disease are present; determine if they have a higher chance of getting a disease before symptoms appear; assess if they are at risk for a certain genetic condition; or determine if they are carriers of a gene alteration for a particular inherited disorder.

As mentioned previously, complex disorders have a number of contributing factors that make it difficult to determine an individual's risk of developing or passing on these disorders. It also makes these disorders challenging to study and treat because a lot of the contributing factors causing complex disorders are still unidentified. However, advances in genomics cause researchers to believe that they will soon be able to identify most of the major contributing genes for many complex disorders.[78] Identification of single nucleotide polymorphisms (SNPs), the most common type of genetic variation found in the human genome, have proven useful in detecting numerous biomarkers that have the potential to signal the presence of normal or abnormal processes of a condition or disease. [79] During the last ten to fifteen years, researchers have identified over 10 million SNPs, and SNP analysis has been applied heavily to human disease genetics, pharmacogenetics, and reproduction.[80] Fundamentally, SNP analysis involves identifying and mapping SNPs onto a known genome, scanning the genome sequence for the presence or absence of SNPs, and linking the genome to a specific characteristic.

Companies now offer direct to consumer (DTC) genetic testing so individuals can have their DNA genotyped to scan for particular SNPs. 23andMe is a "retail DNA testing service" that allows an individual to order a kit (for $429) containing a tube they spit into, then send to the 23andMe lab for analysis.[81] Analyzed reports include information on the individual's carrier status, disease risk, drug response, genetic traits, and other "cutting-edge research."[82] Though there are questions surrounding the accuracy, privacy, and security of such companies, this type of genetic testing does show promise in terms of health risk assessment as well as drug discovery and development for targeted populations based on the presence or absence of genetic or biological features, not their racial categorization.

A newer type of genetic testing is pharmacogenetic testing, which looks at a person's genes to determine how his body would break down certain drugs. Pharmacogenomic biomarkers, which are genetic variants that can predict an individual's response and outcome to a particular drug,[83] hold promise for the future of personalized medicine and physicians' ability to prescribe the "right drug to the right patient."[84] While this may sound similar to BiDil in the sense that pharmacogenetics involves targeting certain medications toward certain populations, there is one fundamental difference: pharmacogenetics looks for the presence of specific genetic or biological biomarkers in an individual, not simply at the color of his skin. Thus, rather than using broad racial categories as "stand-ins" that falsely represent an individual's biological underpinnings, pharmacogenetics can actually assess a patient for specific biomarkers that indicate how a person will respond to a given therapy.

GENETIC TESTING POLICY

While genetic testing offers many promises, it also hosts a number of concerns. Public policy issues such as regulation of clinical trials, intellectual property rights, and privacy concerns stand in the way of genetic testing and personalized medicine's further development and public acceptance.[85] However, successful attempts by policymakers to review and address such concerns in order to remove some of the impediments to the progress of genetic testing have been minimal.

In 2000, the government established the Healthy People 2010 program, which is the third iteration of the program based on the 1979 Surgeon General's Report, *Healthy People*. One of the objectives included in Healthy People 2010 is to eliminate health disparities observed in different groups of the U.S. population. A substantial portion of

the funds earmarked for this purpose have gone to initiatives designed to identify the role of genetics in health disparities.[86] However, the midcourse review of the program does not mention specific findings in the area of genetics and health disparities, so progress in this area is unclear.

In 2006, The Genomics and Personalized Medicine Act (GMPA), or S.3882, was introduced by then-Senator Barack Obama. The original bill, intended to "secure the promise of personalized medicine for all Americans by expanding and accelerating genomics research,"[87] included specific information related to the issue of "genetic variation and the rationale for using racial and ethnic categories in pharmacogenomic research."[88] It created a Personalized Medicine Interagency Working Group (IWG) tasked with addressing the following questions:[89]

- What constitutes racial and ethnic difference in regards to genetic variation research?
- How are individuals classified as members of a particular racial or ethnic group?
- What should be the standards for evaluating claims of race-based therapeutics?
- What effect will guidelines related to the use of racial and ethnic categories have on health disparities among minority populations?

However, when the bill was later revised and reintroduced as S.976, the entire section on "Race, Genomics, and Health" was completely omitted. Regrettably, this resulted in a lost opportunity on the part of Congress to "provide clarity and leadership"[90] on issues related to race and genetics in a health care setting. Without leadership on these specific issues, public concerns about the scientific validity and ethical responsibility of personalized medicine remain unabated.

Privacy and Security

One of the most pressing issues related to the development and implementation of mechanisms that support personalized medicine is the issue of keeping an individual's personal health information private and secure. In the case of genetic testing, privacy and security is a somewhat bifurcated issue. On one hand, concerns are centered around who should be privy to the genetic information revealed about an individual from genetic testing. On the other hand, concerns are related to how genetic information is kept secure, what people can do with the information once they get it, and what protections individuals have should their information no longer be secure. Because the surge of genetic testing is somewhat recent, there is not an overflow of policy related to the security of genetic information. The only existing laws that specifically mention genetic information are the Health Insurance Portability and Accountability Act of 1996, which prohibits health plans from using genetic information to deny or limit eligibility for coverage or increase premiums,[91] and the Genetic Information Nondiscrimination Act (GINA) of 2008, which prohibits insurance companies and employers from discriminating against individuals based on genetic information.[92] However, there are still several areas of discrimination that these laws do not cover. For example, while GINA provides some protection for individuals once their information gets "out there," it does not appear to do much to prevent it from getting "out there" in the first place. Additional policy addressing privacy concerns is essential as the popularity of genetic testing increases.

Accuracy

The accuracy of genetic tests, particularly the DTC tests, is also questionable. Currently, there is no federal regulation of most genetic tests, which means there is no

government agency assessing the clinical relevance of information supplied to physicians and patients as a result of genetic tests.[93] This may be of particular concern for individuals who use DTC genetic tests since there is no guarantee regarding legitimacy of how and by whom their tests are interpreted. As these tests become more "mainstream," the FDA needs to consider ways in which it can regulate the genetic testing industry in order to protect consumers.

Medical Education

For purposes of ensuring proper administration and accuracy of genetic tests, medical professionals need appropriate education and training regarding when and how to administer genetic tests. Because genetic testing is still in its beginning stages, primary care physicians may have little training in genetics and may not be well equipped to integrate genetics services into clinical care.[94] Though genetic testing may be best integrated into medical practice through technology and expert knowledge, it is still important to determine the general role physicians will play in genetic testing and the extent to which they are the appropriate gatekeepers for patients' genetic information. Enhanced genetics training as a part of the core curriculum in medical and postgraduate medical programs, continuing education in genetics, and the creation of clinical guidelines for genetics services could increase genetics knowledge among medical professionals.[95] In order to make sure physicians possess knowledge of basic genetics and genetic tests, it may also be helpful to have genetics requirements on physician licensure examinations,[96] or offer a course of study that allows doctors to be certified as genetic specialists.

Genetic counselors who counsel patients regarding the results of their genetic tests are not currently required to be state licensed or certified in order to practice as or claim the title of genetic counselors.[97] However, some do receive certification from the American Board of Genetic Counselors. In order to ensure patients receive accurate information and adequate support from genetic counselors, states could create certification processes that require all counselors to be certified by the American Board of Genetic Counseling or American Board of Medical Genetics.[98]

For all medical professionals, genetic competency training, exams, and certification processes should discuss race, ethnicity, and genetics, particularly regarding the lack of a genetic basis for race.

Access

Access to health care resources is another concern related to genetic testing. As long as extreme social inequities exist along with limited guarantees of access and care, access to beneficial health services will continue to be a problem. Though personalized medicine promises improved health care for all patients, questions about *who* has access to care are still important. Even in a perfect world where the implementation of personalized medicine is fully realized and the contributing genetic factors to every disease affecting mankind are known, what difference will it make if access to such care is cost prohibitive? If the same groups of people still do and do not have access to health care, will it widen the gap between the two groups? In other words, will the healthy get healthier and the sick get sicker? Though it does not seem likely that personalized medicine would worsen the health disparities observed among minorities, it is important

to consider how social factors, such as low SES, may serve as barriers in accessing these types of emerging health technologies.

Research

There is also little research in the area of social genetics and the "non-biological" effects of having and knowing one's genetic information. For example, if an individual discovers he has a genetic abnormality or biomarker that suggests he is at a higher risk for developing a specific disease, it does not necessarily indicate that he will ever develop that disease. However, knowing that the possibility exists could prove extremely stressful. In that event, does the stress of knowing a genetic abnormality is present outweigh the risk of not knowing? The way in which predictive genetic test results affect the "personal responsibility and psychological well-being"[99] of an individual requires further study. Additionally, the social implications that will result if genetic testing research indicates a common gene variant is present in a significant percentage of an ethnic group deserve attention. Will findings of that nature further complicate ideas about race, ethnicity, and health care in the U.S.?

Attributing differences to genetics has important social implications that researchers and policy makers must not overlook. Excess promotion of the idea that the increased rates of certain health conditions in minorities are due to genetic factors carries with it a subtext that implies their bodies are biologically "inferior" to their white counterparts.[100] While that is not necessarily the intent of policies that support genetic research in hopes of decreasing observed health disparities, it is an unfortunate by-product that may further separate people into socially constructed racial categories. Increased support for programs like the National Human Genome Research Institute's

Ethical, Legal, and Social Implications (ELSI) Research Program would allow researchers to better examine the future challenges of genomic research and genetic testing.

ELECTRONIC HEALTH RECORDS AND RAPID LEARNING SYSTEMS

Electronic Health Records (EHR) are also valuable tools for developing a functional personalized medicine system. The most commonly used definition of EHRs comes from the Health Information Management Systems Society, which states:

> The Electronic Health Record (EHR) is a longitudinal electronic record of patient health information generated by one or more encounters in any care delivery setting. Included in this information are patient demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports. The EHR automates and streamlines the clinician's workflow. The EHR has the ability to generate a complete record of a clinical patient encounter, as well as supporting other care-related activities directly or indirectly via interface—including evidence-based decision support, quality management, and outcomes reporting.[101]

As such, using EHR databases is a mechanism by which the U.S. could quickly gain more information on best practices in the clinical setting.[102] This sort of rapid learning system may be a way to seamlessly link biomedicine, research, and clinical care to allow for the "collection and analysis of information on clinical outcomes of large populations"[103] in a more timely manner. They also allow for the quick development of "new evidence for daily medical practice and policy" and may be a way to "increase the value of health care."[104]

An attractive component of EHRs is their ability to capture clinical data and provide information on billing data, trends of effective treatments, adverse reactions, and efficacy of medications in patients with co-morbidities.[105] In essence, an EHR facilitates

the one-time collection of data for multiple uses. Thus, the implementation of EHRs is a mechanism for aligning hospitals and physicians so that they can coordinate patient care. Many believe the interoperability of such systems is an important step toward providing higher quality care and services for patients who may visit a number of medical providers as they seek different forms of treatment.[106] Additionally, EHR databases provide a platform for collaborative research and have the potential to increase the United States' research capacity.[107]

As discussed previously, minorities and special needs populations are often underrepresented in clinical trials seeking FDA market approval. EHR databases offer the opportunity to document the health care received by all patients and subsequently identify the successes and failures of current care in both the clinical setting and various areas of health care research. What is most intriguing about the possibilities of a rapid learning health system is the potential it offers in answering the question, "What about patients like me?"[108] Studies show that patients are now more interested in information about other patients similar to themselves, not whole population statistics.[109] A database of patient profiles would allow physicians to access information about the health experience and outcomes for patients based on similarities more significant than racial classification, especially with the inclusion of genetic information in EHR databases.[110] Additionally, the increasing attention on genetics-based medicine means that new drugs will require evaluation in specific subpopulations over long periods of time. A rapid learning health system using EHRs may provide a new, less expensive, more coordinated avenue for observing the long-term efficacy of genetic-based therapies. While EHRs are not replacements for clinical trials, they offer research capabilities that medical professionals and researchers can use to gain a real-time understanding of treatment outcomes for millions of patients.

A current project of the National Cancer Institute is the BIG Health Consortium, which launched in 2008 as a "partnership comprised of all the key stakeholders in healthcare."[111] The group aims to build a new organizational framework to demonstrate that rapid learning systems are feasible, beneficial, and can make the practice of personalized medicine a reality.[112] The BIG Health Consortium believes linking different life science and health care sectors through an interactive and integrated platform can help develop predictive models that enhance the type of care patients receive.[113] Developing an "ecosystem" that contains the health information of large numbers of patients means that medical professionals and researchers may be able to access a wealth of information to help answer the "patients like me" question. In effect, patients can be grouped based on the presentation of similar symptoms or disease features, which may prove more meaningful in treating their condition than their designated race.

Another area of interest that moves the focus away from socially constructed external identifiers (i.e., race) and closer to the individual is the development of patient-input health data programs. Programs such as PatientsLikeMe, Keas, Google Health, and Microsoft Health Vault allow patients to participate in electronic health platforms so that they can organize and understand their own health information.[114] Through better understanding of their personal health needs and concerns, patients may be able to take a more active role and make more informed decisions in regards to their own health care. For example, PatientsLikeMe is a platform that allows patients to connect with other people who have similar experiences with life-changing conditions. The website hosts several different disease communities through which individuals can link up with other patients based on gender, age, treatments, symptoms, and length of time since diagnosis. The program ultimately aims to provide a more effective means of capturing and sharing

disease information that could help patients, medical professionals, and industry organizations treat the disease more successfully.[115]

Keas is another online health platform that health technology experts believe promises great capabilities in combining Web and database technologies to provide personalized health education for its users.[116] After filling out a brief questionnaire, users are directed to a "Wellness Home Page" that allows individuals to input health information, create health goals, enroll in health plans, and find health communities that give users the option to connect with other members who have similar health concerns. In addition to allowing a user to input as much personal health data as she chooses, the site asks for specific data about the user's basic health information, health interests, medical history, and family history. Interestingly enough, while Keas asks for detailed information to help build a user's profile (e.g., the user's last Hemoglobin A1c value), there is one piece of information that it does not appear to solicit in any of its background or health data sections: the user's race. This makes a telling statement about the relevance of race in the context of medical and family history. Specifically, whether or not an individual and her parents have a history of breast cancer, colon cancer, or heart disease (all of which are subjects Keas addresses) is more relevant than the color of her skin. This sort of information is also gathered in a clinical setting, but in light of the research revealing some physicians' tendencies to stereotype due to racial biases, it would be interesting to see what type of health-related information Keas provides in the absence of a visual encounter. Though Keas is not a diagnostic tool, it can provide health care plans tailored to an individual's needs based on her medical specifications, not perceptions of her race.

Ultimately, interactive online platforms could serve as a useful tool in moving beyond an individual's exterior and exploring more of the common genetic, social, and

environmental factors that contribute to a particular disease's development. However, if patients have concerns that their data will be mishandled or their privacy is at stake, they may be hesitant to participate in certain activities, such as donation of tissue or blood samples or disclosure of medical history, that help build things like rapid learning systems. [117]

ELECTRONIC HEALTH RECORDS POLICY

Government support of EHR systems recently increased with the American Recovery and Reinvestment Act of 2009 (ARRA). Specifically, $19.2 billion was allocated for the Health Information Technology for Economic and Clinical Health Act (HITECH Act) to support the adoption and meaningful use of EHR.[118] The promise of government funding to help cover the costs of implementing an EHR system will likely result in an increase in the number of doctor offices and hospitals that utilize these types of records. However, resistance on the part of some medical professionals and public concerns related to privacy stand as hurdles to the full adoption of EHR. More support of these policies and a clearer understanding on the part of the public regarding how it will benefit from implementation of EHR systems is crucial for the successful application of such systems in the U.S.

Meaningful Use of Electronic Health Records

In order to qualify for federal incentive funds for EHR adoption, eligible providers must meet HHS standards for "meaningful use" of certified EHRs. Among the criteria considered as a part of the "meaningful use" definition, providers must record demographics, including preferred language, insurance type, gender, race, ethnicity, and

date of birth for at least 80 percent of patients.[119] Though it may be necessary to collect and report this information for purposes of "track[ing] key clinical conditions,"[120] race and ethnicity codes should follow federal guidelines used by the Census Bureau. Thus, patients should have the option to "mark one or more" race and/or ethnicity when providing their demographic information. Though this does not entirely address the idea that most people are actually more than one race or ethnicity, it does allow for data collection that is more reflective of patients' racial and ethnic backgrounds. Additionally, if more self-identified "mixed race" individuals are represented in the data collected by EHRs, health professionals and medical researchers can perform more research on multiracial health issues. Furthermore, if health records data indicate the number of self-identified multiracial individuals is growing, they may also demonstrate the need to reassess traditional methods for grouping individuals by race and ethnicity.

While they may serve as a helpful tool in the coordination and provision of high quality health services, it is still important to keep in mind that EHRs are not an easy answer or quick fix to the overall lack of consistency and quality observed in the U.S.'s current health care system.[121] In reality, providing high quality health care, which seeks to "diagnose, treat, and improve the physical and mental-well-being" of individuals in a manner that is "safe, timely, patient centered, efficient, and equitable,"[122] is a major concern for the U.S. The Agency for Healthcare Research and Quality's (AHRQ) National Healthcare Quality Report for 2009 reveals that overall, the U.S.'s system of health care is "suboptimal"; it does not provide services efficiently and evenly across populations.[123] In fact, the AHRQ reports that the median for the receipt of needed services was only 58 percent in 2009. Moreover, patient safety is still a huge issue when examining health care performance. With approximately 200,000 deaths per year caused

by medical error,[124] it seems unlikely that something like the implementation of EHRs alone will correct these patient safety issues.

Chapter 5: Conclusion

For a long period of time, the U.S. medical care sytem has used race and ethnicity as important demographic categories. However, this surveillance practice is, for the most part, unique to the United States,[125] which causes one to wonder why so much attention is paid to individuals' race and ethnicity, particularly in the health care setting. Some argue that race has a history of being a "powerful predictor"[126] of disease and therefore has a place in health care. However, if racial and ethnic identifiers were truly strong predictors of disease, the same increased disease rates should occur in similar populations outside of the U.S. as well.[127] Simply put, if the elevated rates of diabetes, high blood pressure, and prostate and breast cancer in blacks in the U.S. strongly depend on genetic factors, then individuals with African ancestry living outside of the U.S. should also show increased rates of these conditions. Instead, the rates are far lower. [128] In fact, when examined globally rather than just in the U.S., health disparities do not come together in specific population regions or fall along racial or ethnic lines; rather, they cluster in impoverished areas.[129] However, some still argue that Mexican Americans or individuals with African ancestry have genetic predispositions that make them more vulnerable to developing these diseases when they live in the more sedentary, junk food dominated U.S.[130] Still, assumptions of genetic predispositions based on race or ethnicity do little to accurately unearth a patient's true propensity for developing a particular disease or illness.

Addressing the manner in which race is approached is not a light-hearted undertaking. The effects of eliminating or reducing the use of race in health care practices require extensive examination. While decreasing the social dependence on race in identifying and classifying individuals is ideal, it is important to consider whether or not doing so could achieve the opposite of the intended results. In other words, could it

ultimately have a disparate impact on certain subpopulations? For example, would the absence of race and ethnicity classifications affect the way in which data are collected and ultimately result in the misrepresentation of barriers to access that currently exist for different groups?

The bottom line is that each individual patient has unique needs, and ultimately, the only way to know if someone has a particular condition is to test him or her for it. Though genetic testing and research may help identify the biomarkers or other genetic variants for which clinicians should test, researchers, medical professionals, policymakers, and the general public must be careful not to overemphasize the role of genetic research in eliminating health disparities. Otherwise, the excitement surrounding the promise of genetic research may result in unrealistic expectations of how quickly this type of research can produce applicable results.[131] For most disease states, discovering the genetic biomarkers that identify a patient's risk for developing that disease, grouping patients by treatment outcome, revealing treatment response, or predicting adverse drug reactions is still a distant reality.[132] Though geneticists have made much progress in studying how genes may contribute to some of the diseases associated with health disparities, research is still necessary in terms of looking at how genes interact with the environment to produce certain results. However, overemphasis of genetic solutions as a panacea for health disparities may cause scientists to overlook or ignore the social and environmental factors that also play a role in incongruent health outcomes observed across races. Furthermore, if research and funding initiatives rely too heavily on genetics to explain disease-related differences among subpopulations, researchers could not only miss important explanatory factors, but inadvertently contribute to racial stereotyping as well.[133] Nonetheless, genetic testing does allow researchers and medical professionals the

possibility of analyzing a patient's actual genes instead of making assumptions about "what lies beneath" based on externally visible characteristics.

Ultimately, the use of race in health care presents a number of concerns which serve as reminders that collectively, people must reexamine the social value given to the concept of race in society's every day practices. In terms of healthcare delivery, it seems as though a better method for treating patients involves a personalized approach that focuses on the individual and does not utilize antiquated concepts of race when assessing risk and determining patient care. Still, personalized medicine by way of genetic testing and EHRs is only a small part of an improved health care picture. Addressing health disparities that exist across demographic groups also requires more coordinated community and individual effort in order to implement health education, prevention, and screening programs for groups more commonly affected by particular diseases or health conditions.

Community-based programs have demonstrated that collaboration among local citizens, business leaders, and governments creates the opportunity to address serious health issues within a particular community.[134] Such programs "act as a reality check of what is doable and practical: They can provide an actual model of what works; they help identify promising practices in key areas; and they can provide lessons about how to address political issues."[135] Furthermore, successful programs tend to focus on "root causes, rather than symptoms"[136] and allow citizens to educate themselves on and develop strategies to address problems based on major health concerns affecting their communities, regardless of racial or ethnic groupings. Additionally, newly designed community programs could include educational components that discuss race as an inaccurate stand-in for underlying genetic composition and make it clear that increased incidences of disease among particular races do not imply racial causation. This would

help shift the focus back to the root biological and social causes of disease and illness rather than allowing an external identifier such as race to become a simple explanation for differences seen across groups. Also, community programs that are less dependent on medical interventions and more focused on prevention and management of chronic conditions may help address some of the observed disparities.

While altering a centuries-old concept of race and overhauling current medical practices are no easy feats, policy supporting practices that better assess the genetic, social, and environmental factors contributing to a patient's health status will help address some of the disparities that result from current health care practices and procedures. Furthermore, continued advances in health innovations and technology may allow medical professionals to better address individuals' specific health care needs through more targeted health care delivery practices, race notwithstanding. Such scientific and medical innovations, along with constant efforts to eliminate health disparities (racial, ethnic, and otherwise) at the community, state, and federal level, may help make higher-quality health care more attainable in the Nation's near future. Although there is still much work to be done to minimize the U.S.'s application of race as an important descriptor and/or assessor, it is promising that several people and organizations have opened up a dialogue regarding ways to diminish the influence of race in health care settings.

It will be interesting to see if any changes are made before Austin's next "Know Your Heart" seminar in 2011. Will the organizers once again separate attendees into groups based on race and ethnicity, or will they recognize that race, ethnicity, and genetics should not be used interchangeably? Will they instead work to make sure that people are educated on all of the potential lifestyle and genetic risk factors, irrespective of their designated race or ethnicity? It is still important to acknowledge that no two

people are alike (even if they are grouped in the same racial or ethnic category), so differences among people and groups cannot be completely ignored. However, while those differences may be celebrated and honored, it is even more important to make sure that all individuals, regardless of race or ethnicity, are treated equally—after all, were all men not created that way?

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