THEMES AND DEBATES

The right to identity: Implications of using subjectively-assigned race in US healthcare

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Abstract

In the US, so-called race descriptors have historically been used to ensure control over enslaved and immigrant groups and classes. This paper examines historical, clinical, statistical, and human rights implications for subjectively-assigned race in US healthcare.

When compared to other patient descriptors such as age and sex, race is far inferior in terms of method of acquisition, accuracy, precision, and clinical importance. Examination of current US government documents soliciting race reveals categories inconsistent with existing federal guidelines, thereby confounding data at the origin of collection. Subjective and inaccurate labeling can endanger patients who are subjected to race-based disease diagnoses and/or treatments when a more complete ancestry is not elucidated.

As an aggregated collection of ethnic groups, racial categories are intrinsically open to statistical confusion, and complete ancestral data should be collected for analysis. The inaccuracies inherent in racial categories can result in study design bias, decreased data quality, and possible corrupted conclusions.

The subjective assigning of a person's race – "race-labeling" or "medical race-profiling" – is properly a human rights issue, as the right to accurately define one's individual or group ancestral heritage is a fundamental right supported by the United Nations Universal Declaration of Human Rights.

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Introduction

Designating an individual's "race" remains mostly an unexamined impressionistic endeavor in modern US society, as both mass and academic media routinely ascribe one race to multiethnic/multiracial individuals.[*] For example, both US President Barack Obama and actor Halle Berry are race-labeled as "black," "African-American," or "Negro,"[2] thus ignoring other significant social and biological ancestral contributions to their development as human beings.

Our studies in New Orleans examining subjectively-assigned versus self-reported patient race in US healthcare resulted in significant differences in aggregated (monoracial) versus dis-aggregated (multiracial/multiethnic) results.[3] Therefore, the historical, clinical, statistical, and human rights implications for assigned race ("race-labeling" or "medical race-profiling") in US healthcare are examined in this paper.

Brief outline of US race history pertaining to healthcare

Historical US government race descriptor use

The US government's use of the race concept was formalized in the 1787 Constitution, Article I, Section 2, which stipulated that the population of the states "shall be determined by adding to the whole Number of free Persons… and … three-fifths of all other Persons." This proviso ensured that "other persons" (a euphemism for slaves of full or partial African ancestry) were counted as 60% of "free persons" (of European ancestry). In the same section,

[*] "Race" in this article refers to the categories specified by the US government in the 1997 revisions of the 1977 United States OMB Statistical Policy Directive No. 15, Race and Ethnic Standards for Federal Statistics and Administrative Reporting.[1]

"Indians [Native Americans] not taxed" were completely excluded from being counted as persons.[4]

US government race descriptors figured in the initial 1790 census and were expanded in 1890 to five arbitrary groups: white, black, mulatto, Chinese, and Indian (Native American).[5] The "one-drop rule" (persons of mixed parentage were placed in the race or color classification of the non-white parent) was initially used to justify enslaving individuals who were of part-African ancestry. It was formalized into law by the Supreme Court in Plessy v. Ferguson in 1896,[6] and subsequently incorporated into state anti-miscegenation laws that made "race-mixing" a crime.

Starting with the 1960 census, individuals were allowed to choose one race from four pre-determined categories. In this process of self-identification, they were forced to self-deny other ancestral contributions. The one-drop rule had simply changed form from subjective labeling by a census taker to a limited forced self-identification. Forced self-denial of complete and true identity likely had psychological repercussions for those affected.

The 1990 census allowed residents to choose multi-ancestral backgrounds, as an "other race" classification could be listed instead of the preset categories. The US population responded emphatically by writing in more than 300 other "races" (which were really mostly ethnicities or other ancestral groupings).[7]

Because of the overwhelming response to the 1990 census, the US government definition of "race" was changed in the 1997 Federal Register and for the first time provided for self-identification to five predetermined categories with the ability to choose multiple categories. Thus, a "multiracial" status was finally allowed to be officially documented in the 2000 edition of the census. Despite state miscegenation laws being ruled unconstitutional by the Supreme Court in Loving v. Virginia in 1967,[8] the federal government allowed "bureaucratic anti-miscegenation" for an additional 33 years, during which multiracial/multiethnic individuals could not officially record their true ancestral status.

The 2000 US census reflected the 1997 change, allowing individuals to select from more than one pre-determined group and to choose race groupings in categories other than those delineated by the government. This new freedom instantly created fifty-seven categories of race-mixing.[9]

Current US government race confusion

Erroneous race-labeling within government institutions.

US governmental agencies claiming adherence to the 1997 Federal Register race changes still utilize several versions of race tabulation which are contradictory to and/or wrong by their own definitions, and which introduce selection bias and other systematic errors into human population ancestry.

The largest error is introduced by the US Department of Health & Human Services (DHHS) Applicant Background Survey form (OMB number 0990-0208). Despite being officially informed of their error in 2002,[10] the DHHS has continued to define "white race" as "a person having origins in any of the original peoples of Europe, the Middle East, or North America."[11]

Needless to say, those indigenous ("original") to North America are Native Americans – not "whites" – an error that simultaneously misclassifies Native American as well as white applicant data and thus systematically underestimates Native Americans and overestimates whites. Possibly the most egregious example of government race confusion involves applicants to the Indian Health Service, the branch of the DHHS responsible for Native American health, which solicited employees who could record as Native American in two categories (the erroneous "white" and "American Indian"),[12] thereby diluting the numerical impact of Native Americans as a cohesive group of indigenous ethnicities.

It is important to note that all applicants for health- and non-health-related DHHS government jobs complete the OMB 0990-0208 form, and governmental healthcare agencies such as the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) have had their personnel data corrupted by the same error in race categories.

Also concerning is the routine and cavalier way in which race is conjoined with ethnicity in reference to human disease when the two terms are com-

pletely different concepts – race assumes a natural or inherited disposition of a massive "ideal" population, while ethnicity includes cultural characteristics and all its complexities (customs, diets, geography, history, language, xenophobia stresses, etc.). An example is the use of the term "Hispanic," sometimes as a racial category that is compared to whites and blacks and at other times as an isolated ethnic group. As an ethnic group, Hispanics may belong to black, white, Asian, and/or Native American "races" separately or simultaneously.

In addition, the 2000 and 2010 US censuses divided residents into only two ethnic categories: "Spanish/Hispanic/Latino" and "not Spanish/Hispanic/Latino."[2,13] However, the term "Hispanic" is an imperfect macro-linguistic grouping and does not represent a distinct ethnic group; ethnic groups should have much more in common than language. The "Hispanic" concept spans over 430 million people, hundreds of ethnicities and languages, and includes all "races." According to contemporary US census policy, "not Hispanic or Latino" is a meaningful categorization for the rest of the world's several thousand ethnic groups.

Furthermore, the Hispanic/Latino concept leaves some large populations ancestrally stranded. While 175 million Brazilians view themselves as Latin (Latino) in Latin America, they are not necessarily of Spanish or "Hispanic" origin. Finally, those of combined Hispanic and non-Hispanic ancestry (e.g., an individual who is the progeny of a Puerto Rican parent and a Persian parent) are currently forced to choose only one ethnic descriptor, thereby self-denying the other.

New standards not implemented in the Medical, Epidemiology, and Public Health (MEPH) community

Despite the US government changing the way it collects race data, much of the US MEPH establishment has not done so; contemporary studies utilizing race often do not allow self-identification of race and/or do not offer multiracial/multiethnic options.

Although race-labeling is deeply ingrained into the culture of US medicine, it can be argued that the use of race is even more profound in the epidemiology and public health culture, from which local and national health policies are produced. Many epidemiologic studies still use subjectively-labeled race consisting of three to five groups while understating geographic, socioeconomic, nutritional, or other environmental risk factors for disease. Yet genetic associations are invariably and prominently hypothesized when differences are found between the assigned race groups. The CDC's Epidemiology Intelligence Service (EIS) training program still uses the pre-1997 model of race in some investigations. This trend occurs at the highest levels; the CDC Directors of the Epidemiology Program Office and EIS subjectively and erroneously race-profiled their own physician EIS officers.[10]

Patient descriptor validity

Age, race, and sex have long been used as patient descriptors in the US. On hospital rounds and in medical documents, patients are typically presented using these three descriptors in an ordered cadence prefacing the chief medical complaint, such as "Mr./Ms. X is a [age] year-old [race] [sex]."

It is useful to compare the clinical and governmental use and validity of these three descriptors in the MEPH communities in the US, with special attention paid to race vis-à-vis age and sex, in regards to method of acquisition, accuracy, precision (reproducibility), and importance (Table 1). Importance is defined here as how critical each descriptor is to formulating a differential diagnosis and its potential to impact standard-of-care medical treatment.

Age

Method of acquisition: Objective. Age data is solicited from the individual and is not estimated unless the individual and family members cannot provide the information.

Accuracy: High. Age can be defined in very exact terms, as birth certificates typically note the year, month, day, hour, and minute of birth. Exceptions may be for individuals from countries or regions with poor or nonexistent birth registration.

Precision: High. Identical age data may usually be obtained by consulting the patient or existing medical records.

Table 1: Comparison of age, race, and sex descriptors in MEPH studies

	Method of acquisition	Accuracy	Precision	Importance
Age	objective	high	high	essential
Sex	subjective or objective	high	high	important
Race	subjective	low	low	trivial

Importance: Essential. Age is essential when formulating differential diagnoses for both infectious and non-infectious diseases. Additionally, standard-of-care treatments may differ by age group for the same clinical entity. The existence of adult and pediatric specialties and subspecialties is testimony to significant diagnostic and treatment differences by age.

Sex

Method of acquisition: Subjective or objective. The sex of a patient is usually not asked, but subjectively observed and documented by health care workers and administrative staff. This observer bias may sometimes be offset by health insurance/administrative forms in which patients have an opportunity to self-identify sex, thereby correcting any subjective sex errors.

Accuracy: High. The presence of a Y chromosome is extremely accurate in identifying individuals who consider themselves and are seen as males. Exceptions may occur when the observer's judgment is not confirmed by the patient, such as with transgender and intersex individuals. Without this patient self-reporting, the resulting sex inaccuracy might affect some individuals, but population statistics may not be appreciably affected. An exception to this assumption is when a study targets physically and/or behaviorally androgynous or transgender individuals.

Precision: High. Reproducible sex data can usually be obtained by consulting the patient or the medical record (with the same gender caveat in "Accuracy" above).

Importance: Important. By virtue of anatomic and hormonal differences, sex may be critical when formulating differential diagnosis lists for both infectious and non-infectious disease. Accordingly, the Institute of Medicine recommends "womb to tomb" research on health differences between the sexes.[14] Many disease conditions are sex-specific, e.g., epididymitis in males or endometriosis in females. Current standard-of-care treatments do not routinely differ by sex, but an overview of current research reveals that sex differences may influence optimal treatment regimens.[15]

In addition, it is important to document if individuals are transgender or intersex, as this may contribute to their medical diagnoses and subsequent treatments. Indeed, the concept and term "gender" may prove to be more accurate and preferable than "sex" in future MEPH studies.

Race

Method of acquisition: Subjective. Patients are routinely subjectively assigned a race when they enter a healthcare setting in the US, under the assumption that an individual's race is patently obvious.

In every healthcare encounter, race is assigned twice – initially by a healthcare administrator (HA), often an aide or secretary, and later by a medical doctor (MD), with the MD using his own personal algorithm in the age, race, and sex descriptive triad in the patient history. Often these race assignments are not linked, i.e., the MD does not check the HA designation but rather assigns a race independently. In a hospital setting, patients may also fill in the race section on medical or insurance forms, but the choices are usually an exclusive three, four, or five race categories that restrict true self-identification of ancestry.

Epidemiology and public health investigations in the US often assign exclusive categories for sex and

race, but there may be no insurance/administrative form corroboration for subjective errors of gender and ethnicity.

Accuracy: Low. The concept of "race" as applied to human groups is by definition subjective and inaccurate. The Oxford English Dictionary records eight distinct definitions of the noun "race," and within the most relevant noun (Noun 6), the definition diverged from "the offspring … of a person" to "mankind."[16] Most anthropologists and scientists studying the use of race groups agree that the concept is subjectively defined and of poor practical scientific use.[17]

Racial identities involving one choice from a limited menu are routinely assigned to patients regardless of potential multiracial or multiethnic contributions to their ancestry. In the US, patients of part-African ancestry are routinely labeled only as "black," a practice derived from the "one-drop rule" (the "hypo-descent rule" in anthropological terminology), in which multiracial or multiethnic individuals are placed in a race category of darkest skin complexion and/or lowest status.[18] This practice, in conjunction with pre-1997 restrictive Directive 15 race categories – which stated, "the category which most closely reflects the individual's recognition in his community should be used for purposes of reporting on persons who are of mixed racial and/or ethnic origins"[19] – prevents the true expression of the ancestral makeup of patients and populations.

Precision: Low. Differing race data may be encountered when examining subjective observations in the medical record. Race data can also differ even if it has been self-identified; studies asking for patients to choose one of four categories will receive only that data, while those seeking a comprehensive ancestral background can obtain multiple category data.

Reproducibility is lowest for multiethnic or multiracial individuals, a considerable and increasing portion of the US population. Individuals with light or medium complexions are sometimes labeled by one HA or MD as "white" and by another as "black."[3] Although official reproducibility by restricted government categories may appear to be high for many multiracial individuals, since their ancestral representation is incomplete and therefore inaccurate, the claimed high reproducibility is contrived and reflects a systematic denial of part of their ancestry.

In addition, some multiethnic or multiracial individuals may be unaware of their status unless carefully questioned; the co-discoverer of DNA structure, James Watson, was found to have 16 times the number of genes considered to be of African origin then the average "white" European has.[20,21]

Importance: Trivial. Once a complete patient history – including socioeconomic class, occupation, nutritional, geographic, and ancestral histories – is elicited, a race classification is irrelevant. When ancestral history is limited or omitted, race-profiling is rarely helpful and can actually harm the patient if diagnosis and treatment are erroneously based on race-based disease assumptions.[22,23]

Two popular medical examples used to justify race-labeling in US healthcare are sickle cell anemia and hypertension. Hemoglobinopathies associated with sickling are both genetically and geographically diverse: sickle cell trait prevalence has been measured in the "Old World," from 0% to up to 45% in Africa, up to 25% in part of Saudi Arabia, up to 38% in part of India, up to 32% in parts of Greece, and is present in significant percentages in Sicily, Turkey, and Israel. Experts have shown that sickle cell gene frequencies do not follow race groupings but rather geographic zones (or clines) mirroring historically higher malaria frequencies.[24] In the "New World" of the US, sickle cell trait has been measured in 8% of "blacks," 0.5% of "Hispanics," and 0.2% of "whites."

Hypertension has often been presented as separate "black" and "white" diseases in the US, but hypertension is a rare condition in many African peoples.[25]

Race as a statistical confounder

By popular definition and use in the US MEPH literature, "races" are actually aggregated data sets of multiple smaller collectives such as ethnic groups. Therefore, current race groupings present as inherent confounders illustrative of Simpson's paradox, which describes statistical inaccuracy that may occur when analyzing aggregated data. Simpson's paradox stipulates that it is possible for data sets to

reach opposite statistically significant conclusions, depending on whether aggregated data (e.g., race) or distinct data (e.g., ethnicity or more exact smaller ancestral groupings) is analyzed.[26]

An example of Simpson's paradox involving race is presented in Table 2, in which hypothetical race Z is comprised of 800 individuals, 400 each from ethnic groups X and Y. Table 2a shows the response of individuals of race Z to treatments A and B; treatment A is statistically better than B at $p < 0.005$. However, when race Z is divided into ethnic groups X and Y (Table 2b and 2c), incredibly, treatment B is statistically better than A in both groups X and Y at $p < 0.05$.

For races made up of more than two ethnic groups, the mathematics will be more complicated but still includes the same potential confounding effect from aggregating smaller distinct groups, which can lead to either Type I or II error in hypothesis testing.

Human rights and race

The subjective labeling of a person's race ("race-labeling" or "medical race-profiling") is properly a human rights issue, as the right to accurately define one's ancestral heritage is a fundamental individual as well collective (e.g., ethnic group) right. Subjective race or ethnic labeling violates the United Nations Universal Declaration of Human Rights – particularly Articles 1, 3, 6, 12, and 22 – of which the US was a principal (signatory state) sponsor.[27] Although the US Department of Justice banned routine race-profiling in all 70 US government agencies with law enforcement powers in 2003,[28] the decision does not address medical race-profiling in the MEPH community.

Empowering and subsequent exercising the right to one's identity can help ensure accurate self-referenced ancestral documentation. This requires education and leadership from authorities that has so far been found lacking. This paper does not intend to single out President Barack Obama, who represents an important example of human diversity in the history of the US. However, he marked only "Black, African American, or Negro" in the 2010 US census,[29] which would not be accurate by a recent study[3] or his own biography.[30] Apparently, the

Table 2: Simpson's paradox: Analysis by aggregated data provides incorrect estimates of efficacy

a. Analysis by race Z (N= 800), which is comprised of ethnic groups X and Y
Treatment A is more effective than Treatment B ($p<.005$)

	Response	No Response	Response Rate
Treatment A	200	200	200/400 = 50%
Treatment B	160	240	160/400 = 40%

b. Analysis by ethnic group X (N=400)
Treatment B is more effective than Treatment A ($p<.05$)

	Response	No Response	Response Rate
Treatment A	180	120	180/300 = 60%
Treatment B	70	30	70/100 = 70%

c. Analysis by ethnic group Y (N=400)
Treatment B is more effective than Treatment A ($p<.05$)

	Response	No Response	Response Rate
Treatment A	20	80	20/100 = 20%
Treatment B	90	210	90/300 = 30%

Adapted from Heydtmann.[26]

US census remains so authoritative a sociopolitical document that Mr. Obama did not acknowledge his 50% European heritage. This is emblematic of a nation still facing a "race question" 46 years after equal legal rights (from anti-miscegenation laws) were legislated. Inaccuracies derived from census categories are perpetuated within families; for example, President Obama's daughters' multiple "race"/ethnicities could be hidden when confronted by simple ancestral questions. However, our recent experience in New Orleans with mostly lower class and often disempowered individuals showed they were willing and eager to represent their true ancestral contributions.

Discussion

Although the social sciences have rejected race as a social construct that is nearly useless in scientific endeavors, undefined race descriptors remain in use in the US MEPH community, with scientific

studies assuming them to be as intuitively obvious and useful as age or sex. However, recent research finds race validity at a level (59% incomplete and therefore erroneous)[3] that would preclude it from being scientifically helpful in evaluating individual patients or human populations. As the accuracy and precision of race are low, the importance of race is trivial. The use of race can even be detrimental in medicine, as patients may be harmed if inaccurately-assigned race is then utilized for diagnostic or therapeutic purposes.[22,23]

The concept and use of "race" artificially simplifies the complex nature of human ancestry and the often ignored numerous environmental interactions.[31] Race assumptions can lead down the wrong diagnostic path by acting as a false marker for other variables that differ within a race. For example, among "black" people, diet and rates of hypertension differ between East Africans and African–Americans, and sickle cell gene frequency differs between West and South Africans.[24,25] Additionally, a "black" or "white" cohort in one study may not be equivalent to similarly named cohorts in other studies. It follows that subjective race usage may lead to inherent study design bias and increased confounding and ultimately to erroneous conclusions based on race.

The definitive reference works of evolutionary and clinical human genetics overwhelmingly define genetic differences in terms of ethnic or even smaller groups (micro-ethnicities, tribes, clans, and greater family groups).[32,33] Specific gene frequency maps are shown to follow geography (in "clines") more accurately than races or even ethnic groups. For example, a gene frequency map of sickle cell anemia reveals higher density over specific areas of Europe, Africa, and Asia where endemic *P. falciparum* malaria engendered a survival advantage of sickle gene carriage.

Thousands of studies over the last century have been carried out in the US using subjective race-labeling, with many postulating causal genetic inferences from aggregated race data, often to the exclusion of dynamic environmental factors not elicited (e.g., social class, nutrition, exposure to toxins, stress effects of xenophobia). Because of the way the US MEPH systems have acquired and used race

data – contrasted by much of the rest of the scientific world's research on humanity – race has been subjectively extracted so pervasively in the US that health and policy specialists use it with little thought as to comparative accuracy or consequences. Nevertheless, the scientific futility of race-labeling in medicine is slowly being recognized,[34,35] and its abandonment will eventually enable MEPH research to be more rigorous and attentive to the populations it endeavors to study.

Within the next decades, "racial genetics" will be rendered obsolete, as wealthy societies will provide complete personal genetic data in a digitalized format. This development will remove any doubts about the lack of value in continuing to make poor and possibly dangerous assumptions about massive groups of people (e.g., their race) when a patient's individual DNA is readily available for analysis.[36] However, a predictable future danger is that the demonstrably inexact practice of race-labeling will be perpetuated in many resource-poor human populations because of lack of access to personal digitalized genetic data.

There will be some who are concerned that dropping the hypo-descent rule for US government healthcare statistics will lead to less minority group representation, reduced benefits, and worse health outcomes. This historically compelling argument requires renewed reflection for three reasons: (1) healthcare outcomes follow class lines – the poor in society will predictably die sooner than the rich no matter what race they are assigned; (2) healthcare equity projects are doomed to failure without equitable redistribution of wealth,[37] which, judging by US political history, has not and will never come by race allocation; and (3) continued research on false race premises will continue to corrupt scientific work. Indeed, class is so important for healthcare outcomes that while more educated classes predictably live longer, the life expectancy for "least-educated" (defined as lacking a high school diploma) whites has contracted 3 (for men) to 5 (for women) years between 1990 and 2008. In the same time period, "least-educated" black men gained lifespan while black women in the same category actually gained enough lifespan to surpass that of "least-educated" white women.[38]

However, scientific research on the social implications of race can still be beneficial, especially when determining the quantitative effects of xenophobic stressors (e.g., racism) on human health, in areas such as healthcare access, clinical decision-making, and health disparities research.[39] These lines of research remain unfortunately necessary as racial prejudice has been demonstrated to be constant and possibly increasing in the US.[40,41] This need not involve investigating race as a monolithic category but instead utilizing ethnic or smaller ancestral groups transparently aggregated to larger population models (up to and including transparently defined race), potentially giving a more nuanced view to the very real negative effects of xenophobia on health.[42,43]

Initially, race-labeling functioned as a means of explicit social and scientific apartheid, and was articulated prominently in US law.[44] However, 162 years after ex-slave Frederick Douglass eloquently destroyed American racial hypocrisy,[45] the US MEPH community is still engaged in race-labeling. Although all Douglass could rely on was his incisive wit to describe that intellectual hypocrisy with "scorching irony," "biting ridicule," and "withering sarcasm," we now have hard data to show that race-labeling is scientific hypocrisy as well.[3]

In modern times, race-labeling is not simply an anachronism that damages the quality of the science behind population research, it is representative of the poverty of official philosophy and its policy of institutional disrespect for certain individuals. It is also likely that continued race-labeling serves to perpetuate racial taxonomies in the US, which contributes to one of the mechanisms driving unequal medical care and worse patient outcomes – medical racism.[46] Clinically, subjective race-labeling is an arrogance which alienates the very individuals that physicians and public health professionals are sworn to serve, and should be abandoned.

A proposed solution to obtaining relevant identity and ancestral information in the social history section of the medical history is to ask two questions that would obtain the best information about social stressors and biological ancestry: (1) "What is your complete ancestral background back at least until your grandparental generation?" and (2) "What is your perception of how society looks at ("labels or profiles") somebody with your appearance and culture and how has this perception affected your life?"

New research has shown that ethnogenetic layering in the US can lead to new insights into genetic variation and human health.[47] And in his last work, Stephen Jay Gould indicated that because *Homo sapiens* stayed in Africa so long during its evolution, the genetic diversity of modern Africans (and its diaspora) surpasses that of all other "races" put together.[48] These works provide additional impetus for the MEPH community to cease assuming it knows so much about populations and individuals to continue subjectively race-labeling them.

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