Recalibrating the Use of Race in Medical Research

Race was originally introduced in US medical curricula in 1790 by Benjamin Rush, who asserted that blackness was a particular kind of leprosy. In 1857 Josh Nott characterized slaves as a biologically appropriate phenotype for hard labor under trying conditions. In the 1870s, the Jim Crow era of race exclusion from most societal venues reinforced medical segregation. This sordid history, although painful to recite, is the underpinnings of race in medicine, including its use in medical research.

Race as a variable in medical research has long been a contentious issue. It is widely accepted that race is an indistinct construct that is not always measured accurately and standardized. In 1999, the Human Genome Project emphasized race as nonbiological with no basis in the genetic code. What, then, does race define?

Race is a poor surrogate of social constructs and even more so, if not abjectly, of biology. Differences observed in research studies between “races” may result from the multifarious consequences of long-entrenched and continuously transformed racism. As the crisis of coronavirus disease 2019 has revealed once again, long-standing effects of racism have tremendous effects on the propagation of inequalities and injustice at all levels, including health and health care. Racism, tragically, remains a chronic and acute problem of modern societies, and the persist in medical research. But the imperfectness of race as a tool is problematic.

One school of thought asserts that because race (and ethnicity) is so weakly measured and even more poorly analyzed and reported, efforts should focus on trying to strengthen measurement, analysis, and reporting. A series of initiatives, including self-identification, especially in clinical trials and registries and in specifications of requirements for publicly funded research, ensured that more attention would be given toward obtaining more data on racial minority populations. However, empirical evaluations show that race information can be fragmented, inconsistent, and eventually not very usable.

The medical literature that uses or discusses race is vast, but is it really informative? On December 21, 2020, a search of PubMed with “race OR ethnicity” yielded 518,842 items, whereas one with focused terms such as “African American” and “Hispanic OR Latino” yielded 44,674 and 61,933 items, respectively. However, a recent evaluation4 of a random sample of 1000 Cochrane systematic reviews on various medical interventions showed that only 14 (1.4%) had proposed to perform race- or ethnicity-based subgroup analyses for treatment effects. Only 1 of those 14 analyses was completed but yielded noninformative results. Despite the poor performance of race as a measure, numerous passionate, burgeoning health professionals, many of whom are underrepresented in medicine, have been attracted to biomedical research, lured by life experiences to study with enthusiasm the interrelation of race and ethnicity with social and biological factors. Their work should go forward.

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use of race in medical research and practice is now being bandished as a surrogate for racism. Eradicating racism should be a moral imperative in medicine.

However, is any progress addressing inequities possible if race as a measure is banned? Is there still some room for using race variables? How much would be lost if these variables were eliminated? Is there a better tool in research and policy efforts? Are there some situations in which race variables remain valuable? What strategy would generate research that diminishes rather than increases inequalities and injustice? The time has come to recalibrate the use of race in medical research.

A second school of thought argues that race is a painful historical relic and lost cause. With this approach, race as a measure should be abandoned, and efforts should be diverted toward finding variables that are more robust and informative, both for the biological constructs (eg, genetic ancestry) and the sociologic ones (eg, discrimination, deprivation, socioeconomic status) for which race has failed to provide useful, reproducible insights. Does scientific theory support this approach?

On the frontiers of biology, the rapid advent of genetics has transformed the concept of ancestry. A spectrum of genetic granularity through whole-genome sequencing makes the surrogate of traditional races potentially obsolete. However, genetics, despite its tremendous accuracy of measurement and massive information, has been sluggish in making much progress in yielding useful medical tools for everyday practice and for improving patient and population outcomes that
matter to many. If anything, genetics may be contributing to worsen- ing inequalities, especially when most generic architecture databases overrepresent people of European ancestry (88% of genomewide data had European ancestry as of 2018), when genomics tools are too expensive to use for race-based research, and when both biological scientists and social scientists default to White as a refer-

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tice; and future research investigations.

For past investigations, a large amount of research involving race variables has been, in hindsight, pedestrian and arguably lies among the greater waste of spurious, nonusable biomedical evidence. However, there are examples for which race variables have become part of the norm of accepted medical knowledge and practice. This applies to both therapeutics (incorporation of race to identify clinically meaningful treatment effect modification for various interventions, as in hypertension or heart failure) and other clinical tools (incorporation of race to improve diagnosis or prognosis in, for example, calculation of kidney function or pulmonary function). Expert specialty medical societies and methodologists should jointly systematically reexamine evidence involving race labeling in research on race, ethnicity, and health. Am J Public Health. 1998;88(9):1303-1307. doi:10.2105/AJPH.88.9.1303


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