Perils of Race-Based Norms in Cognitive Testing
The Case of Former NFL Players

The landmark National Football League (NFL) Players’ Concussion Injury Litigation case, which brought to public attention the high prevalence of neurodegenerative disorders among former players, has now exposed a major weakness in the field of neuropsychology: the use of race-adjusted norms as a crude proxy for lifelong social experience. Under the settlement agreement, retired NFL players who undergo cognitive testing and meet criteria for neurodegenerative disorders may be eligible for substantial monetary awards. In a new class action lawsuit filed on August 25, 2020, Kevin Henry and Najeh Davenport, 2 retired players who were diagnosed as having dementia but later denied benefits, accused the NFL of systematically discriminating against Black players filing dementia-related settlement claims. The plaintiffs allege that the NFL has “repeatedly insisted that applicants’ scores must be race normed by using separate Black and White reference populations—a position that greatly reduces Black players’ chances of success.” In this Viewpoint, we explain the practice and perils of using race-adjusted norms and propose a new approach that could replace the current standard.

To determine cognitive impairment, neuropsychologists compare a patient’s test performance to their estimated baseline cognitive abilities. These estimations are derived from the test performance of healthy individuals (normative standards). Normative standards adjust for demographic factors known to relate to performance (usually age, sex, and education) by either comparing the patient only to individuals who are similar demographically or by statistically adjusting the standard based on the associations of these factors with test performance in the normative sample. The practice of adjusting for race as an additional demographic factor was developed to reduce harms that can result from the overidentification of cognitive impairment among Black individuals and other marginalized racial/ethnic groups, including overpathologizing and overtreating. However, in many clinical situations, false negatives cause even greater harm, such as when needed services are deemed unnecessary. In the case of the NFL evaluations, the new lawsuit alleges that race norms are being misused to systematically make it more difficult for Black players to qualify for their rightful compensation. This case is reminiscent of a damaging, century-long history of assuming that differences on intelligence tests (IQ) are primarily inherited and then using this false assumption to legitimize unequal distribution of resources by social class.

In accordance with the specific neuropsychological test protocol laid out by the settlement agreement, the neuropsychologist must classify estimated baseline cognitive abilities as above average, average, or below average using 1 of 3 models: (1) demographics (including race), (2) an irregular word reading test, or (3) a combination. This classification benchmarks the level of cognitive impairment needed to qualify for a settlement award. Current cognitive abilities are measured using a battery of cognitive tests, a subset of which may be further adjusted for race using the Heaton norms, which “correct” for Black race based on a sample from San Diego, California, matched to the 1990 census on age, educational level, and socioeconomic status. When race is used at either step in this process, the assumption is that a Black player started at a lower cognitive baseline. Therefore, a Black player with the same cognitive scores as a White player is assumed to have experienced less cognitive impairment. This policy has consequences for the approximately 70% of NFL players who identify as Black.

Among the scientific community, it is now widely recognized that race/ethnicity represents a crude proxy for lifelong social experiences, and biologically based racial differences in IQ have been debunked. The Human Genome Project has taught us that human beings are 99.9% similar at the DNA level, and the remaining 0.1% does not vary according to sociopolitically defined race categories such as Black or White. Black individuals and other marginalized race/ethnic groups in the US have experienced social and economic disparities that have well-documented associations with poor cognitive outcomes. Adjusting cognitive test performance for social determinants of brain health, such as education quality, significantly reduces variance explained by race. For example, past studies have found that early-life experiences, disparate educational quality, socioeconomic status, perceived discrimination, experiences of segregation, and neighborhood disadvantage each can have significant effects on cognitive health.

A more scientifically sound alternative to race norms would be regression-based normative approaches that explicitly measure and adjust for social determinants of brain health. Importantly, such adjustments would address the substantial heterogeneity within race/ethnic groups. We must identify the critical factors that explain baseline cognition and that can be measured reliably at scale (Table). Investments must be made to study how these factors and their interactions predict cognitive test performance in a diverse group of individuals.

To maximize the value of this work for broad clinical and research applications, tests should be selected that accurately measure cognitive abilities across diverse populations and that are efficient to administer at scale. In accordance with the open science initiative, researchers working on neuropsychological norm development should make data and algorithms publicly available so...
Table. Measurable Social Determinants of Brain Health for New Normative Approaches

<table>
<thead>
<tr>
<th>Domain</th>
<th>Characteristic</th>
</tr>
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<tbody>
<tr>
<td>Nativity and acculturation</td>
<td>Country of origin, age of immigration, reason for immigration, familiarity with testing environment</td>
</tr>
<tr>
<td>Language</td>
<td>Primary language, English language proficiency, multilingualism</td>
</tr>
<tr>
<td>Education</td>
<td>Total years of education, parents' total years of education, education quality, school characteristics, country of education</td>
</tr>
<tr>
<td>Literacy</td>
<td>Ability to read/write/count and health literacy</td>
</tr>
<tr>
<td>Psychosocial stress</td>
<td>Perceived discrimination, early-life adversity, stereotype threat</td>
</tr>
<tr>
<td>Occupation^</td>
<td>Occupational complexity and prestige, occupational stability, occupational stress</td>
</tr>
<tr>
<td>Economic and financial status^</td>
<td>Household income, financial strain, housing and food security, access to health care</td>
</tr>
<tr>
<td>Residential characteristics^</td>
<td>Urban/rural residence, neighborhood characteristics, social cohesion</td>
</tr>
</tbody>
</table>

^ Measured at midlife and current.
^ Measured at childhood, midlife, and current.

that limitations are transparent, data can be combined across samples, and new approaches can be accelerated.

Even with the best norms, the diagnosis of cognitive disorders should not be decided based on a plug-and-play formula of cognitive test scores. Rather, diagnosis should be based on expert clinical judgment following a comprehensive evaluation of clinical history, changes in the patient’s function, neurological examination findings, laboratory findings, and social context. Furthermore, changes in personality and behavior that are very commonly part of the dementia syndromes that follow repeated head trauma are often not captured on standard cognitive testing yet can be far more disabling for patients and troubling for caregivers than deficits in cognition.

In the US, a long history of structural racism and discrimination practices, including unequal distribution of resources, has disfavored Black individuals and led to enduring socioeconomic and health inequities. The use of race norms to determine monetary compensation perpetuates this problem. Perhaps most dangerously, their use may be misunderstood by some scientists, clinicians, and the public as evidence that race is a scientific entity. Advances in the inclusion of diverse populations in research and the measurement of social determinants of brain health provide new opportunities for a precision medicine approach to normative standard adjustments.

ARTICLE INFORMATION

Published Online: December 21, 2020. doi:10.1001/jamaneurol.2020.4763

Conflict of Interest Disclosures: Dr Possin reports grants from ClearView Healthcare Partners and Vanguard outside the submitted work. No other disclosures were reported.

Additional Contributions: Breton Asken, PhD; Katrin Casaletto, PhD; Aimee Kao, MD, PhD; Sergio Lanata, MD; Bruce Miller, MD; and Gil Rabinovici, MD, Memory and Aging Center, Department of Neurology, University of California, San Francisco, provided revision of the manuscript for intellectual content. These individuals did not receive compensation.

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