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October 16, 2020

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The Honorable Richard E. Neal  
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1102 Longworth House Office Building  
Washington, D.C. 20515

The Honorable Kevin Brady  
Ranking Member  
House Ways and Means Committee  
1139 Longworth House Office Building  
Washington, DC 20515

Dear Chairman Neal and Ranking Member Brady:

On behalf of the American Psychiatric Association (APA), the national medical specialty association representing over 38,500 psychiatric physicians, I want to thank you for conducting the hearing on May 27 on *'The Disproportionate Impact of COVID-19 on Communities of Color.'* The APA appreciates the Committee's continued work on this critically important matter. We also would like to thank you for the opportunity to provide feedback on the misuse and misapplication of race and ethnicity in clinical algorithms and research, an important issue that impacts the delivery of health care including care for patients with mental illness and substance use disorders. Please find the APA's answers (in italic text) to your [request for information questions](#) (in bold text) below.

**1.To what extent is it necessary that health and health related organizations address the misuse of race and ethnicity in clinical algorithms and research? What role should patients and communities play?**

*Clinical algorithms and research are becoming more common in health care since they have the potential to improve care by providing the right care, to the right person at the right time. However, concerns are growing regarding how these algorithms are created and how they are used to determine who receives care. As we leverage the advances in science and medicine, we must be careful and cognizant that we do not inadvertently exacerbate inequities in care, particularly for vulnerable populations. For example, a study by Obermeyer et al.<sup>1</sup> detected bias in the health cost based algorithm used by Optum, a health services company, to predict and rank which patients would benefit the most from additional care designed to help them adhere to their prescribed medication protocols or out of the hospital. The study looked at more than 6,000 self-identified Blacks and nearly 44,000 self-identified Whites. Although the algorithm excluded race, it used "cost" as a screen for high risk patients. Since cost is not a "race-blind" metric, the algorithm incorrectly concluded that the Black patients must be healthier since they spend less on health care. What was not taken into consideration was that Black patients access health care less, and therefore spend less.*

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<sup>1</sup> Obermeyer, Z., Powers, B., Vogeli, C., & Mullainathan, S. (2019). Dissecting racial bias in an algorithm used to manage the health of populations. *Science*, 366(6464), 447-453.

Further, a recent article, “Hidden in Plain Sight – Reconsidering the Use of Race Correction in Clinical Algorithms,” by Vyas et al.,<sup>2</sup> aggregated different physician specialty race adjusted algorithms to illustrate where implicit racial bias lies and to demonstrate the dangers of such practices, “given their potential to perpetuate or even amplify race-based health inequities.” From cardiology to oncology, the article found that algorithms used to direct care plans or predict outcomes are inherently biased regardless of intention.

If health and health related organizations support the goal “to create a more healthy, equitable, and inclusive society,”<sup>3</sup> then it is imperative that they address the misuse of race and ethnicity in clinical algorithms and research. We must ensure that information on race and ethnicity is systematically collected via patient self-report (not inference by a staff member or health care provider). It is also important that health organizations collect data on social determinants of health (e.g. education, job status, housing status, etc.) as opposed to relying solely on race to serve as a proxy.

In addition, we need to assess our algorithms and consider whether they are truly appropriate. There are many ways in which racial prejudice is baked into clinical algorithms (e.g., eGFR calculations, PFTs, etc.), potentially exacerbating health inequities. When race and ethnicity are used in research, especially when they are the central focus of research (like disparities research), we need to ensure that researchers explicitly explain the context in which these variables are being used and the mechanism through which race and ethnicity are related to the outcome being investigated.

Furthermore, research that focuses on race and ethnicity should ensure that the team of researchers includes those who have disparities expertise and/or lived experience. Health equity should be a focus of the research agenda and be supported as a fundamental organizing principle of research across agencies such as the National Institutes of Health (NIH), Patient Centered Outcomes Research Institute (PCORI), and other research organizations and funders. For example, NIH requires reporting on clinical research enrollment with a limited set of race (and ethnicity) categories, which may need expansion via consultations with patients, communities, others with diversity expertise and lived experience, and also should include social determinants of health factors.

Patients and communities should play a central role in this discussion because “a treatment selection system will likely work best if it is implemented in the context of joint decision-making between the patient and provider, rather than because the ‘computer says so.’”<sup>4</sup> Unequal treatment is not entirely explained by socioeconomic status, insurance coverage, stage or severity of disease, comorbidities, type and availability of health care services, and patient preferences. Overall, clinicians and scientists must distinguish between the use of race in descriptive statistics, where it plays a vital role in epidemiologic analyses, and in prescriptive clinical guidelines, where it can exacerbate inequities.

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<sup>2</sup> Vyas, D. A., Eisenstein, L. G., & Jones, D. S. (2020). Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *The New England Journal of Medicine*, 289(9), 874-882.

<sup>3</sup> Dawes, D. E. (2020). *The Political Determinants of Health*. Johns Hopkins University Press. P.18

<sup>4</sup> DeRubeis, R. J. (2019). The history, current status, and possible future of precision mental health. *Behaviour research and therapy*, 123, 103506.

*It is important that clinical trials, particularly large Phase III clinical trials, have diverse racial and ethnic composition so that we can come to understand the efficacy and safety of treatments across diverse populations. Similarly, it is important to develop biomarkers in diverse populations and understand the limits of applicability of these biomarkers to particular populations. Institutions and funding agencies should incentivize or require investigators to include patients and communities in the early phases of development of research projects to ensure that the research questions are meaningful to diverse communities frequently underrepresented in mental health research. In addition, it should be apparent that recruitment and other study procedures are likely to be acceptable to diverse study participants. Increasing the diversity of and methods for data collection will require participation and collaboration of the federal government, state governments, health plan and insurers, providers, purchasers, and consumers.*

**2. What have been the most effective strategies that you or your organization have used to correct the misuse of race and ethnicity in clinical algorithms and research, if any? What have been the challenges and barriers to advancing those strategies?**

*The APA through its Division of Diversity and Health Equity and Division of Education has produced Continuing Medical Education modules (e.g., Cultural Formulation Interview, toolkits (e.g., Stress & Trauma Toolkit for Treating Indigenous People in a Changing Political and Social Environment), fact sheets (e.g., Mental Health Disparities: Diverse Populations) and other educational content specifically for use in treating diverse and vulnerable populations. These educational resources can enable our members to be culturally competent psychiatrists as they serve the needs of evolving, diverse, underrepresented and underserved patient populations in order to end disparities in mental health care.*

*Several studies involving our APA members have emerged in the context of the COVID-19 pandemic that focus on race and ethnicity. In one positive example, an APA member's institution created a diverse team of researchers that included: 1) those affected by COVID-19 (e.g. front-line providers who cared for patients with COVID-19); 2) those with expertise on disparities; and 3) those with lived experience. This approach was successful in producing a substantial modification to a paper, that initially did not benefit from such diverse characteristics among the authors, adding diversity of perspective ultimately resulted in a substantially different interpretation and discussion of findings.<sup>5,6</sup> In order to alleviate implicit bias, this type of approach should be more widespread.*

*Another APA member was involved with the examination of the impact of race on treatment in two settings, an adolescent inpatient psychiatry unit and a consultation-liaison service. In both cases, the more deeply the team examined the issues, the more complicated the inference and the intervention. Below is a summary of the examination of the "case studies" from this study which are being prepared for publication.*

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<sup>5</sup> Golestaneh, Ladan et. al. *The Association of Race and COVID-19 mortality*. EClinicalMedicine. 2020 Aug;25:100455. doi: 10.1016/j.eclinm.2020.100455. Epub 2020 Jul 15.

<sup>6</sup> Linas, Benjamin P. and Cunningham, Chinazo O. *COVID-19 Disparities: A Call for Equity in Health Outcomes and Clinical Research*. Clinical Infectious Diseases. <https://doi.org/10.1093/cid/ciaa1460>. Published: 29 September 2020.

- *Differential restraint use by race: There is limited literature that suggests racial biases related to the application of physical restraints.<sup>7</sup> The adolescent psychiatry unit explored whether there was a different rate of the application of physical restraints by race. Most of the units have very low rates of restraint use. This unit has a slightly higher rate of restraint use because it uses brief periods of restraint to handle aggressive, often autism spectrum disorder (ASD), adolescents. Researchers found that there was a higher rate of restraint use for African American patients than Caucasian patients. However, the rate of assaults by patients on staff was higher among African American patients than Caucasian patients. Accounting for the differential rate of assault eliminated the apparent difference in restraint use by race. Therefore, the question to answer was, “Why did African American patients assault staff more than Caucasian patients?” For example, are staff developing closer or more supportive relationships with the Caucasian than African American patients? Are staff de-escalating aggression more effectively in Caucasian than African American patients?*
- *Differential prescription of antipsychotics by race: There is limited and somewhat unclear literature suggesting that African American patients with psychosis are more likely to receive adjunctive medications and less likely to receive newer antipsychotics than Caucasian patients.<sup>8,9</sup> At the institution’s Consultation-Liaison Program, they studied the relative rate of antipsychotic and antidepressant prescription by race. Researchers found that for African Americans, the rate of antipsychotic prescription was higher and the rate of antidepressant prescription was lower than for Caucasians. However, they also found the rate of psychotic disorders was higher and the rate of mood disorders was lower in the African Americans relative to the Caucasians. Adjusting for the diagnostic difference eliminated the impact of race on prescribing pattern.*

*The complex question to answer in the aforementioned case study is: “is there a racial bias in how clinicians are making psychiatric diagnoses?” This is an enormously challenging question to answer in clinical settings. One would need to have a “gold standard,” a diagnosis made by a trained reliable and culturally competent rater using a structured diagnostic interview, against which to compare the clinical diagnoses made by clinicians.*

*It is likely that there are multiple ways that race is influencing mental health care. The case study highlights the challenges we face in understanding the potential misuse of race and ethnicity in clinical algorithms and research, and the challenges to correct them. In this case study, our member concluded that these effects are probably not gross misapplication of psychopharmacology or misuse of restraints. The outstanding question our member identified, is whether there could be ways that race might subtly influence interactions with clinical staff. This*

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<sup>7</sup> Schnitzer K, Merideth F, Macias-Konstantopoulos W, Hayden D, Shtasel D, Bird S. *Disparities in Care: The Role of Race on the Utilization of Physical Restraints in the Emergency Setting*. Acad Emerg Med. 2020 Jul 20. doi: 10.1111/acem.14092. Epub ahead of print. PMID: 32691509.

<sup>8</sup> Puyat JH, Daw JR, Cunningham CM, Law MR, Wong ST, Greyson DL, Morgan SG. Racial and ethnic disparities in the use of antipsychotic medication: a systematic review and meta-analysis. *Soc Psychiatry Psychiatr Epidemiol*. 2013 Dec;48(12):1861-72. doi: 10.1007/s00127-013-0753-4. Epub 2013 Aug 14. PMID: 23942793.

<sup>9</sup> Mallinger JB, Lamberti SJ. Racial differences in the use of adjunctive psychotropic medications for patients with schizophrenia. *J Ment Health Policy Econ*. 2007 Mar;10(1):15-22. PMID: 17417044.

*in turn likely influences the clinical impressions of patients developed by staff and undermines the staff's ability to provide appropriate care.*

*The challenges and barriers to advancing strategies pertaining to racial equity concerns in clinical algorithms and related health outcomes are rooted in our “history of political and legal precedent that have baked into our systems the discriminatory standards, practices, and beliefs we observe or experience today.”<sup>10</sup> When we address the political determinants of health, we can then dismantle the social determinants of health and in turn improve mental health disparities.*

### **3. What strategies would you propose to build consensus and widely used guidelines that could be adopted broadly across the clinical and research community to end the misuse of race and ethnicity in clinical algorithms and research?**

*The foundation for a strategy to build consensus and widely used guidelines that could be adopted broadly across the clinical and research community to end the misuse of race and ethnicity in clinical algorithms and research is to learn, process and understand how they relate to the history of race and racism in our country. Currently, “many of these race-adjusted algorithms guide decisions in ways that direct more attention or resources to white patients than to members of racial and ethnic minorities,”<sup>11</sup> which can lead to minorities being systematically misdiagnosed and undertreated. When developing or applying clinical algorithms with race as a factor, Kaplan & Bennet<sup>12</sup> noted that physicians should ask three questions:*

- 1) Is the need for race correction based on robust evidence and statistical analyses (e.g., with consideration of internal and external validity, potential confounders, and bias)?*
- 2) Is there a plausible causal mechanism for the racial difference that justifies the race correction?*
- 3) Would implementing this race correction relieve or exacerbate health inequities?*

*It is critical to provide research opportunities for those who are most affected by racism. This should happen at the funding level, the medical school or health system level, and the research team level. We recommend establishing incentives to encourage this to happen within organizations. These types of strategies are described in the attached Linas & Cunningham<sup>13</sup> commentary. Also, more support is needed at all levels for research on health disparities, social determinants of health and health equity. The analysis that NIH recently conducted looking at funding disparities at NIH's research project R01 is an example of current funding gaps.<sup>14</sup>*

*We also recommend a strategy that includes the input of patients on race/ethnicity and social determinants of health factors. As mentioned previously, NIH requires reporting on clinical research enrollment with a limited set of race and ethnicity categories, which **we recommend be***

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<sup>10</sup> Dawes, D. E. (2020). *The Political Determinants of Health*. Johns Hopkins University Press. P.19

<sup>11</sup> Vyas, D. A., Eisenstein, L. G., & Jones, D. S. (2020). Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *The New England Journal of Medicine*, 289(9), 874-882.

<sup>12</sup> Kaplan, J. B., & Bennett, T. (2003). Use of race and ethnicity in biomedical publication. *JAMA*, 289(20), 2709-2716.

<sup>13</sup> Linas, Benjamin P. and Cunningham, Chinazo O. *COVID-19 Disparities: A Call for Equity in Health Outcomes and Clinical Research*. *Clinical Infectious Diseases*. <https://doi.org/10.1093/cid/ciaa1460>. Published: 29 September 2020.

<sup>14</sup> National Institutes of Health. (9 Oct. 2019). *Research topic contributes to persistent gap in NIH research grants to black scientists*. Available: <https://www.nih.gov/news-events/news-releases/research-topic-contributes-persistent-gap-nih-research-grants-black-scientists>

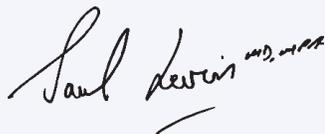
**expanded to include consultations with patients and communities.** In addition, NIH should work towards inclusion of social determinants of health factors. The list of factors should be informed by patients, communities, and others with diversity expertise and lived experience.

APA further recommends **that funders and institutions/organizations conducting clinical research partner with researchers and leaders in surrounding communities**, like PCORI's focus on patient-centeredness and the use of consumer advisory boards. An example of a partnership with leaders in their surrounding communities to enhance the diversity of participants in clinical research includes Yale's Cultural Ambassadors Program.<sup>15</sup> This program has been extremely successful in dramatically increasing the representation of Black and Indigenous People of Color (BIPOC) in large numbers of clinical trials. The Cultural Ambassadors program was developed by the Yale Center for Clinical Investigation (the Yale CTSA). This model has been adopted by other universities (e.g. Duke) and led to partnerships with the U.S. Food and Drug Administration (FDA) and Pfizer on strategies to enhance the diversity of clinical trials recruitment.

Finally, ignoring racial bias, bigotry, and maltreatment of BIPOCs in favor of a homogenized view of race, if continued, will compound the flaws of clinical algorithms and research that could otherwise benefit the health of racial and ethnic minorities. Today, "many of these race-adjusted algorithms guide decisions in ways that direct more attention or resources to white patients than to members of racial and ethnic minorities,"<sup>16</sup> which can lead to racial and ethnic minorities being systematically misdiagnosed and untreated.

Shining a light on disparities as well as understanding their impact, as your Committee is attempting to do, can contribute to building the kind of consensus that ultimately diminishes bias in clinical algorithms and research. We thank you for the opportunity to submit these comments for consideration, and for your leadership and focus on the issue of racial bias in medicine. Please let us know how we can assist in your efforts to alleviate racial bias and misuse of racial data in health research. If you have any questions, please contact Michelle Greenhalgh at [mgreenhalgh@psych.org](mailto:mgreenhalgh@psych.org) / 202.459.9708.

Sincerely,



Saul Levin, MD, MPA, FRCP-E, FRCPsych  
CEO and Medical Director

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<sup>15</sup> Yale Center for Clinical Investigation. *Yale Cultural Ambassadors: A Unique Community Partnership*. Available: <https://medicine.yale.edu/ycci/events/summit/2018summit/speakers/ambassadors/>.

<sup>16</sup> Vyas, D. A., Eisenstein, L. G., & Jones, D. S. (2020). Hidden in plain sight—reconsidering the use of race correction in clinical algorithms. *The New England Journal of Medicine*, 289(9), 874-882.

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## MEDICINE AND SOCIETY

Debra Malina, Ph.D., Editor

## Hidden in Plain Sight — Reconsidering the Use of Race Correction in Clinical Algorithms

Darshali A. Vyas, M.D., Leo G. Eisenstein, M.D., and David S. Jones, M.D., Ph.D.

Physicians still lack consensus on the meaning of race. When the *Journal* took up the topic in 2003 with a debate about the role of race in medicine, one side argued that racial and ethnic categories reflected underlying population genetics and could be clinically useful.<sup>1</sup> Others held that any small benefit was outweighed by potential harms that arose from the long, rotten history of racism in medicine.<sup>2</sup> Weighing the two sides, the accompanying Perspective article concluded that though the concept of race was “fraught with sensitivities and fueled by past abuses and the potential for future abuses,” race-based medicine still had potential: “it seems unwise to abandon the practice of recording race when we have barely begun to understand the architecture of the human genome.”<sup>3</sup>

The next year, a randomized trial showed that a combination of hydralazine and isosorbide dinitrate reduced mortality due to heart failure among patients who identified themselves as black. The Food and Drug Administration granted a race-specific indication for that product, BiDil, in 2005.<sup>4</sup> Even though BiDil’s ultimate commercial failure cast doubt on race-based medicine, it did not lay the approach to rest. Prominent geneticists have repeatedly called on physicians to take race seriously,<sup>5,6</sup> while distinguished social scientists vehemently contest these calls.<sup>7,8</sup>

Our understanding of race and human genetics has advanced considerably since 2003, yet these insights have not led to clear guidelines on the use of race in medicine. The result is ongoing conflict between the latest insights from population genetics and the clinical implementation of race. For example, despite mounting evidence that race is not a reliable proxy for genetic difference, the belief that it is has become embedded, sometimes insidiously, within medical practice. One

subtle insertion of race into medicine involves diagnostic algorithms and practice guidelines that adjust or “correct” their outputs on the basis of a patient’s race or ethnicity. Physicians use these algorithms to individualize risk assessment and guide clinical decisions. By embedding race into the basic data and decisions of health care, these algorithms propagate race-based medicine. Many of these race-adjusted algorithms guide decisions in ways that may direct more attention or resources to white patients than to members of racial and ethnic minorities.

To illustrate the potential dangers of such practices, we have compiled a partial list of race-adjusted algorithms (Table 1). We explore several of them in detail here. Given their potential to perpetuate or even amplify race-based health inequities, they merit thorough scrutiny.

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### CARDIOLOGY

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The American Heart Association (AHA) Get with the Guidelines–Heart Failure Risk Score predicts the risk of death in patients admitted to the hospital.<sup>9</sup> It assigns three additional points to any patient identified as “nonblack,” thereby categorizing all black patients as being at lower risk. The AHA does not provide a rationale for this adjustment. Clinicians are advised to use this risk score to guide decisions about referral to cardiology and allocation of health care resources. Since “black” is equated with lower risk, following the guidelines could direct care away from black patients. A 2019 study found that race may influence decisions in heart-failure management, with measurable consequences: black and Latinx patients who presented to a Boston emergency department with heart failure were less likely than white patients to be admitted to the cardiology service.<sup>24</sup>

Cardiac surgeons also consider race. The Society of Thoracic Surgeons produces elaborate calculators to estimate the risk of death and other complications during surgery.<sup>10</sup> The calculators include race and ethnicity because of observed differences in surgical outcomes among racial and ethnic groups; the authors acknowledge that the mechanism underlying these differences is not known. An isolated coronary artery bypass in a low-risk white patient carries an estimated risk of death of 0.492%. Changing the race to “black/African American” increases the risk by nearly 20%, to 0.586%. Changing to any other race or ethnicity does not increase the estimated risk of death as compared with a white patient, but it does change the risk of renal failure, stroke, or prolonged ventilation. When used preoperatively to assess risk, these calculations could steer minority patients, deemed to be at higher risk, away from surgery.

NEPHROLOGY

Since it is cumbersome to measure kidney function directly, researchers have developed equations that determine the estimated glomerular filtration rate (eGFR) from an accessible measure, the serum creatinine level. These algorithms result in higher reported eGFR values (which suggest better kidney function) for anyone identified as black.<sup>11,25</sup> The algorithm developers justified these outcomes with evidence of higher average serum creatinine concentrations among black people than among white people. Explanations that have been given for this finding include the notion that black people release more creatinine into their blood at baseline, in part because they are reportedly more muscular.<sup>11,25</sup> Analyses have cast doubt on this claim,<sup>26</sup> but the “race-corrected” eGFR remains the standard. Proponents of the equations have acknowledged that race adjustment “is problematic because race is a social rather than a biological construct” but warn that ending race adjustment of eGFR might lead to overdiagnosis and overtreatment of black patients.<sup>27</sup> Conversely, race adjustments that yield higher estimates of kidney function in black patients might delay their referral for specialist care or transplantation and lead to worse outcomes, while black people already have higher rates of end-stage kidney disease and death due to kidney failure than the overall population.<sup>25</sup>

As long as uncertainty persists about the cause of racial differences in serum creatinine levels, we should favor practices that may alleviate health inequities over those that may exacerbate them.

Similar adjustment practices affect kidney transplantation. The Kidney Donor Risk Index (KDRI), implemented by the national Kidney Allocation System in 2014, uses donor characteristics, including race, to predict the risk that a kidney graft will fail.<sup>12</sup> The race adjustment is based on an empirical finding that black donors’ kidneys perform worse than nonblack donors’ kidneys, regardless of the recipient’s race.<sup>28</sup> The developers of the KDRI do not provide possible explanations for this difference.<sup>12</sup> If the potential donor is identified as black, the KDRI returns a higher risk of graft failure, marking the candidate as a less suitable donor. Meanwhile, black patients in the United States still have longer wait times for kidney transplants than nonblack patients.<sup>29</sup> Since black patients are more likely to receive kidneys from black donors, anything that reduces the likelihood of donation from black people could contribute to the wait-time disparity.<sup>29</sup> Use of the KDRI may do just that. Mindful of this limitation of the KDRI, some observers have proposed replacing “the vagaries associated with inclusion of a variable termed ‘race’” with a more specific, ancestry-associated risk factor, such as *APOL1* genotype.<sup>28</sup>

OBSTETRICS

The Vaginal Birth after Cesarean (VBAC) algorithm predicts the risk posed by a trial of labor for someone who has previously undergone cesarean section. It predicts a lower likelihood of success for anyone identified as African American or Hispanic.<sup>13</sup> The study used to produce the algorithm found that other variables, such as marital status and insurance type, also correlated with VBAC success.<sup>14</sup> Those variables, however, were not incorporated into the algorithm. The health benefits of successful vaginal deliveries are well known, including lower rates of surgical complications, faster recovery time, and fewer complications during subsequent pregnancies. Nonwhite U.S. women continue to have higher rates of cesarean section than white U.S. women. Use of a calculator that lowers the estimate of VBAC success for people of color could exacerbate these disparities. This dynamic is particularly

**Table 1. Examples of Race Correction in Clinical Medicine.\***

Tool and Clinical Utility	Input Variables	Use of Race	Equity Concern
<p><b>Cardiology</b></p> <p>The American Heart Association's Get with the Guidelines–Heart Failure<sup>9</sup> (<a href="https://www.mdcalc.com/gwtg-heart-failure-risk-score">https://www.mdcalc.com/gwtg-heart-failure-risk-score</a>)</p> <p><i>Predicts in-hospital mortality in patients with acute heart failure. Clinicians are advised to use this risk stratification to guide decisions regarding initiating medical therapy.</i></p>	<p>Systolic blood pressure Blood urea nitrogen Sodium Age Heart rate History of COPD Race: black or nonblack</p>	<p>Adds 3 points to the risk score if the patient is identified as nonblack. This addition increases the estimated probability of death (higher scores predict higher mortality).</p>	<p>The original study envisioned using this score to “increase the use of recommended medical therapy in high-risk patients and reduce resource utilization in those at low risk.”<sup>9</sup> The race correction regards black patients as lower risk and may raise the threshold for using clinical resources for black patients.</p>
<p><b>Cardiac surgery</b></p> <p>The Society of Thoracic Surgeons Short Term Risk Calculator<sup>10</sup> (<a href="http://riskcalc.sts.org/stswebriskcalc/calculate">http://riskcalc.sts.org/stswebriskcalc/calculate</a>)</p> <p><i>Calculates a patient's risks of complications and death with the most common cardiac surgeries. Considers &gt;60 variables, some of which are listed here.</i></p>	<p>Operation type Age and sex Race: black/African American, Asian, American Indian/Alaskan Native, Native Hawaiian/Pacific Islander, or “Hispanic, Latino or Spanish ethnicity”; white race is the default setting. BMI</p>	<p>The risk score for operative mortality and major complications increases (in some cases, by 20%) if a patient is identified as black. Identification as another non-white race or ethnicity does not increase the risk score for death, but it does change the risk score for major complications such as renal failure, stroke, and prolonged ventilation.</p>	<p>When used preoperatively to assess a patient's risk, these calculations could steer minority patients, deemed higher risk, away from these procedures.</p>
<p><b>Nephrology</b></p> <p>Estimated glomerular filtration rate (eGFR) MDRD and CKD-EPI equations<sup>11</sup> (<a href="https://ukidney.com/nephrology-resources/egfr-calculator">https://ukidney.com/nephrology-resources/egfr-calculator</a>)</p> <p><i>Estimates glomerular filtration rate on the basis of a measurement of serum creatinine.</i></p>	<p>Serum creatinine Age and sex Race: black vs. white or other</p>	<p>The MDRD equation reports a higher eGFR (by a factor of 1.210) if the patient is identified as black. This adjustment is similar in magnitude to the correction for sex (0.742 if female).  The CKD-EPI equation (which included a larger number of black patients in the study population), proposes a more modest race correction (by a factor of 1.159) if the patient is identified as black. This correction is larger than the correction for sex (1.018 if female).</p>	<p>Both equations report higher eGFR values (given the same creatinine measurement) for patients identified as black, suggesting better kidney function. These higher eGFR values may delay referral to specialist care or listing for kidney transplantation.</p>
<p>Organ Procurement and Transplantation Network: Kidney Donor Risk Index (KDRI)<sup>12</sup> (<a href="https://optn.transplant.hrsa.gov/resources/allocation-calculators/kdri-calculator/">https://optn.transplant.hrsa.gov/resources/allocation-calculators/kdri-calculator/</a>)</p> <p><i>Estimates predicted risk of donor kidney graft failure, which is used to predict viability of potential kidney donor.</i><sup>†</sup></p>	<p>Age Hypertension, diabetes Serum creatinine level Cause of death (e.g., cerebrovascular accident) Donation after cardiac death Hepatitis C Height and weight HLA matching Cold ischemia En bloc transplantation Double kidney transplantation Race: African American</p>	<p>Increases the predicted risk of kidney graft failure if the potential donor is identified as African American (coefficient, 0.179), a risk adjustment intermediate between those for hypertension (0.126) and diabetes (0.130) and that for elevated creatinine (0.209–0.220).</p>	<p>Use of this tool may reduce the pool of African-American kidney donors in the United States. Since African-American patients are more likely to receive kidneys from African-American donors, by reducing the pool of available kidneys, the KDRI could exacerbate this racial inequity in access to kidneys for transplantation.</p>

<p><b>Obstetrics</b></p> <p>Vaginal Birth after Cesarean (VBAC) Risk Calculator<sup>13,14</sup> (<a href="https://mfmunetwork.bsc.gwu.edu/PublicBSC/MFMU/VGBirthCalc/vagbirth.html">https://mfmunetwork.bsc.gwu.edu/PublicBSC/MFMU/VGBirthCalc/vagbirth.html</a>)</p> <p><i>Estimates the probability of successful vaginal birth after prior cesarean section. Clinicians can use this estimate to counsel people who have to decide whether to attempt a trial of labor rather than undergo a repeat cesarean section.</i></p>	<p>Age BMI Prior vaginal delivery Prior VBAC Recurring indication for cesarean section African-American race Hispanic ethnicity</p>	<p>The African-American and Hispanic correction factors subtract from the estimated success rate for any person identified as black or Hispanic. The decrement for black (0.671) or Hispanic (0.680) is almost as large as the benefit from prior vaginal delivery (0.888) or prior VBAC (1.003).</p>	<p>The VBAC score predicts a lower chance of success if the person is identified as black or Hispanic. These lower estimates may dissuade clinicians from offering trials of labor to people of color.</p>
<p><b>Urology</b></p> <p>STONE Score<sup>15,16</sup></p> <p><i>Predicts the risk of a ureteral stone in patients who present with flank pain</i></p> <p>Urinary tract infection (UTI) calculator<sup>17</sup> (<a href="https://utical.pitt.edu/">https://utical.pitt.edu/</a>)</p> <p><i>Estimates the risk of UTI in children 2–23 mo of age to guide decisions about when to pursue urine testing for definitive diagnosis</i></p>	<p>Sex Acute onset of pain Race: black or nonblack Nausea or vomiting Hematuria Age &lt;12 months Maximum temperature &gt;39°C Race: Describes self as black (fully or partially) Female or uncircumcised male Other fever source</p>	<p>Produces a score on a 13-point scale, with a higher score indicating a higher risk of a ureteral stone; 3 points are added for nonblack race. This adjustment is the same magnitude as for hematuria.</p> <p>Assigns a lower likelihood of UTI if the child is black (i.e., reports a roughly 2.5-times increased risk in patients who do not describe themselves as black).</p>	<p>By systematically reporting lower risk for black patients than for all nonblack patients, this calculator may steer clinicians away from aggressive evaluations of black patients.</p> <p>By systematically reporting lower risk for black children than for all nonblack children, this calculator may deter clinicians from pursuing definitive diagnostic testing for black children presenting with symptoms of UTI.</p>
<p><b>Oncology</b></p> <p>Rectal Cancer Survival Calculator<sup>18</sup> (<a href="http://www3.mdanderson.org/app/medcalc/index.cfm?pagename=rectumcancer">http://www3.mdanderson.org/app/medcalc/index.cfm?pagename=rectumcancer</a>)</p> <p><i>Estimates conditional survival 1–5 yr after diagnosis with rectal cancer</i></p> <p>National Cancer Institute Breast Cancer Risk Assessment Tool (<a href="https://bcrisktool.cancer.gov/calculator.html">https://bcrisktool.cancer.gov/calculator.html</a>)</p> <p><i>Estimates 5-yr and lifetime risk of developing breast cancer, for women without prior history of breast cancer, DCIS, or LCIS.</i></p>	<p>Age and sex Race: white, black, other Grade Stage Surgical history Current age, age at menarche, and age at first live birth First-degree relatives with breast cancer Prior benign biopsies, atypical biopsies Race/ethnicity: white, African American, Hispanic/Latina, Asian American, American Indian/Alaska Native, unknown</p>	<p>White patients are assigned a regression coefficient of 1, with higher coefficients (depending on stage) assigned to black patients (1.18–1.72).</p> <p>The calculator returns lower risk estimates for women who are African American, Hispanic/Latina, or Asian American (e.g., Chinese).</p>	<p>The calculator predicts that black patients will have shorter cancer-specific survival from rectal cancer than white patients. Clinicians might be more or less likely to offer interventions to patients with lower predicted survival rates.</p> <p>Though the model is intended to help conceptualize risk and guide screening decisions, it may inappropriately discourage more aggressive screening among some groups of nonwhite women.</p>

**Table 1. (Continued.)**

Tool and Clinical Utility	Input Variables	Use of Race	Equity Concern
<p>Breast Cancer Surveillance Consortium Risk Calculator<sup>19</sup> (<a href="https://tools.bccsc-ccc.org/BC5yearRisk/calculator.htm">https://tools.bccsc-ccc.org/BC5yearRisk/calculator.htm</a>)</p> <p><i>Estimates 5- and 10-yr risk of developing breast cancer in women with no previous diagnosis of breast cancer, DCIS, prior breast augmentation, or prior mastectomy</i></p>	<p>Age Race/ethnicity: white, black, Asian, Native American, other/multiple races, unknown BIRADS breast density score First-degree relative with breast cancer Pathology results from prior biopsies</p>	<p>The coefficients rank the race/ethnicity categories in the following descending order of risk: white, American Indian, black, Hispanic, Asian.</p>	<p>Returns lower risk estimates for all nonwhite race/ethnicity categories, potentially reducing the likelihood of close surveillance in these patients.</p>
<p><b>Endocrinology</b></p> <p>Osteoporosis Risk SCORE (Simple Calculated Osteoporosis Risk Estimation)<sup>20</sup> (<a href="https://www.mdapp.co/osteoporosis-risk-score-calculator-316/">https://www.mdapp.co/osteoporosis-risk-score-calculator-316/</a>)</p> <p><i>Determines whether a woman is at low, moderate, or high risk for low bone density in order to guide decisions about screening with DXA scan</i></p>	<p>Rheumatoid arthritis History of fracture Age Estrogen use Weight Race: black or not black</p>	<p>Assigns 5 additional points (maximum score of 50, indicating highest risk) if the patient is identified as nonblack</p>	<p>By systematically lowering the estimated risk of osteoporosis in black patients, SCORE may discourage clinicians from pursuing further evaluation (e.g., DXA scan) in black patients, potentially delaying diagnosis and intervention.</p>
<p>Fracture Risk Assessment Tool (FRAX)<sup>21</sup> (<a href="https://www.sheffield.ac.uk/FRAX/tool.aspx">https://www.sheffield.ac.uk/FRAX/tool.aspx</a>)</p> <p><i>Estimates 10-yr risk of a hip fracture or other major osteoporotic fracture on the basis of patient demographics and risk-factor profile. Calculators are country-specific.<sup>‡</sup></i></p>	<p>Age and sex Weight and height Previous fracture Parent who had a hip fracture Current smoking Glucocorticoid use Rheumatoid arthritis Secondary osteoporosis Alcohol use, <math>\geq 3</math> drinks per day Femoral neck bone mineral density</p>	<p>The U.S. calculator returns a lower fracture risk if a female patient is identified as black (by a factor of 0.43), Asian (0.50), or Hispanic (0.53). Estimates are not provided for Native American patients or for multiracial patients.</p>	<p>The calculator reports 10-yr risk of major osteoporotic fracture for black women as less than half that for white women with identical risk factors. For Asian and Hispanic women, risk is estimated at about half that for white women. This lower risk reported for nonwhite women may delay intervention with osteoporosis therapy.</p>
<p><b>Pulmonology</b></p> <p>Pulmonary-function tests<sup>22</sup></p> <p><i>Uses spirometry to measure lung volume and the rate of flow through airways in order to diagnose and monitor pulmonary disease</i></p>	<p>Age and sex Height Race/ethnicity</p>	<p>In the U.S., spirometers use correction factors for persons labeled as black (10–15%) or Asian (4–6%).</p>	<p>Inaccurate estimates of lung function may result in the misclassification of disease severity and impairment for racial/ethnic minorities (e.g., in asthma and COPD).<sup>23</sup></p>

\* BIRADS denotes Breast Imaging Reporting and Data System, BMI body-mass index (the weight in kilograms divided by the square of the height in meters), CKD-EPI Chronic Kidney Disease Epidemiology Collaboration, COPD chronic obstructive pulmonary disease, DCIS ductal carcinoma in situ, DXA dual-energy x-ray absorptiometry, LCIS lobular carcinoma in situ, and MDRD Modification of Diet in Renal Disease study.

† The current calculator uses Ethnicity/Race, with the following options: American Indian or Alaska Native, Asian, Black or African American, Hispanic/Latino, Native Hawaiian or Other Pacific Islander, White, and Multiracial.

‡ Three countries' calculators are further subcategorized by race, ethnicity, or location: China (Mainland China, Hong Kong), Singapore (Chinese, Malay, Indian), and the United States (Caucasian, black, Hispanic, Asian).

troubling because black people already have higher rates of maternal mortality.<sup>30</sup>

UROLOGY

The STONE score predicts the likelihood of kidney stones in patients who present to the emergency department with flank pain. The “origin/race” factor adds 3 points (of a possible 13) for a patient identified as “nonblack.”<sup>15</sup> By assigning a lower score to black patients, the STONE algorithm may steer clinicians away from thorough evaluation for kidney stones in black patients. The developers of the algorithm did not suggest why black patients would be less likely to have a kidney stone. An effort to externally validate the STONE score determined that the origin/race variable was not actually predictive of the risk of kidney stones.<sup>16</sup> In a parallel development, a new model for predicting urinary tract infection (UTI) in children similarly assigns lower risk to children identified as “fully or partially black.”<sup>17</sup> This tool echoes UTI testing guidelines released by the American Academy of Pediatrics in 2011 that were recently criticized for categorizing black children as low risk.<sup>31</sup>

ASSESSMENT

Similar examples can be found throughout medicine. Some algorithm developers offer no explanation of why racial or ethnic differences might exist. Others offer rationales, but when these are traced to their origins, they lead to outdated, suspect racial science or to biased data.<sup>22,30,31</sup> In the cases discussed here, researchers followed a defensible empirical logic. They examined data sets of clinical outcomes and patient characteristics and then performed regression analyses to identify which patient factors correlated significantly with the relevant outcomes. Since minority patients routinely have different health outcomes from white patients, race and ethnicity often correlated with the outcome of interest. Researchers then decided that it was appropriate — even essential — to adjust for race in their model.

These decisions are the crux of the problem. When compiling descriptive statistics, it may be appropriate to record data by race and ethnicity and to study their associations. But if race does appear to correlate with clinical outcomes, does

that justify its inclusion in diagnostic or predictive tools? The answer should depend on how race is understood to affect the outcome.<sup>30</sup> Arriving at such an understanding is not a simple matter: relationships between race and health reflect enmeshed social and biologic pathways.<sup>32</sup> Epidemiologists continue to debate how to responsibly make causal inferences based on race.<sup>33</sup> Given this complexity, it is insufficient to translate a data signal into a race adjustment without determining what race might represent in the particular context. Most race corrections implicitly, if not explicitly, operate on the assumption that genetic difference tracks reliably with race. If the empirical differences seen between racial groups were actually due to genetic differences, then race adjustment might be justified: different coefficients for different bodies.

Such situations, however, are exceedingly unlikely. Studies of the genetic structure of human populations continue to find more variation within racial groups than between them.<sup>34,35</sup> Moreover, the racial differences found in large data sets most likely often reflect effects of racism — that is, the experience of being black in America rather than being black itself — such as toxic stress and its physiological consequences.<sup>32</sup> In such cases, race adjustment would do nothing to address the cause of the disparity. Instead, if adjustments deter clinicians from offering clinical services to certain patients, they risk baking inequity into the system.

This risk was demonstrated in 2019 when researchers revealed algorithmic bias in medical artificial intelligence.<sup>36</sup> A widely used clinical tool took past health care costs into consideration in predicting clinical risk. Since the health care system has spent more money, on average, on white patients than on black patients, the tool returned higher risk scores for white patients than for black patients. These scores may well have led to more referrals for white patients to specialty services, perpetuating both spending discrepancies and race bias in health care.

A second problem arises from the ways in which racial and ethnic categories are operationalized. Clinicians and medical researchers typically use the categories recommended by the Office of Management and Budget: five races and two ethnicities. But these categories are unreliable proxies for genetic differences and fail to capture the complexity of patients’ racial and

ethnic backgrounds.<sup>34,35</sup> Race correction therefore forces clinicians into absurdly reductionistic exercises. For example, should a physician use a double correction in the VBAC calculator for a pregnant person from the Dominican Republic who identifies as black and Hispanic? Should eGFR be race-adjusted for a patient with a white mother and a black father? Guidelines are silent on such issues — an indication of their inadequacy.

Researchers are aware of this dangerous terrain. The Society of Thoracic Surgeons acknowledged concerns raised by clinicians and policymakers “that inclusion of SES factors in risk models may ‘adjust away’ disparities in quality of care.” Nonetheless, it proceeded to consider “all preoperative factors that are independently and significantly associated with outcomes”: “Race has an empiric association with outcomes and has the potential to confound the interpretation of a hospital’s outcomes, although we do not know the underlying mechanism (e.g., genetic factors, differential effectiveness of certain medications, rates of certain associated diseases such as diabetes and hypertension, and potentially [socioeconomic status] for some outcomes such as readmission).”<sup>10</sup> This decision reflects a default assumption in medicine: it is acceptable to use race adjustment even without understanding what race represents in a given context.

To be clear, we do not believe that physicians should ignore race. Doing so would blind us to the ways in which race and racism structure our society.<sup>37-39</sup> However, when clinicians insert race into their tools, they risk interpreting racial disparities as immutable facts rather than as injustices that require intervention. Researchers and clinicians must distinguish between the use of race in descriptive statistics, where it plays a vital role in epidemiologic analyses, and in prescriptive clinical guidelines, where it can exacerbate inequities.

This problem is not unique to medicine. The criminal justice system, for instance, uses recidivism-prediction tools to guide decisions about bond amounts and prison sentences. One tool, COMPAS (Correctional Offender Management Profiling for Alternative Sanctions), while not using race per se, uses many factors that correlate with race and returns higher risk scores for black defendants.<sup>40</sup> The tool’s creators explained that their design simply reflected empirical data.<sup>41</sup>

But if the underlying data reflect racist social structures, then their use in predictive tools cements racism into practice and policy. When these tools influence high-stakes decisions, whether in the clinic or the courtroom, they propagate inequity into our future.

In 2003, Kaplan and Bennet asked researchers to exercise caution when they invoked race in medical research: whenever researchers publish a finding based on race or ethnicity, they should follow seven guidelines, including justifying their use of race and ethnicity, describing how subjects were assigned to each category, and carefully considering other factors — especially socioeconomic status — that might affect the results.<sup>42</sup> We propose an adaptation of these guidelines to evaluate race correction in clinical settings. When developing or applying clinical algorithms, physicians should ask three questions: Is the need for race correction based on robust evidence and statistical analyses (e.g., with consideration of internal and external validity, potential confounders, and bias)? Is there a plausible causal mechanism for the racial difference that justifies the race correction? And would implementing this race correction relieve or exacerbate health inequities?

If doctors and clinical educators rigorously analyze algorithms that include race correction, they can judge, with fresh eyes, whether the use of race or ethnicity is appropriate. In many cases, this appraisal will require further research into the complex interactions among ancestry, race, racism, socioeconomic status, and environment. Much of the burden of this work falls on the researchers who propose race adjustment and on the institutions (e.g., professional societies, clinical laboratories) that endorse and implement clinical algorithms. But clinicians can be thoughtful and deliberate users. They can discern whether the correction is likely to relieve or exacerbate inequities. If the latter, then clinicians should examine whether the correction is warranted. Some tools, including eGFR and the VBAC calculator, have already been challenged; clinicians have advocated successfully for their institutions to remove the adjustment for race.<sup>43,44</sup> Other algorithms may succumb to similar scrutiny.<sup>45</sup> A full reckoning will require medical specialties to critically appraise their tools and revise them when indicated.

Our understanding of race has advanced considerably in the past two decades. The clinical

tools we use daily should reflect these new insights to remain scientifically rigorous. Equally important is the project of making medicine a more antiracist field.<sup>46</sup> This involves revisiting how clinicians conceptualize race to begin with. One step in this process is reconsidering race correction in order to ensure that our clinical practices do not perpetuate the very inequities we aim to repair.

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# COVID-19 Disparities: A call for equity in health outcomes and clinical research

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COVID-19 is a mirror, forcing the United States to stare at its reflection. The reflection we see is a society wrenched by disparity and social unrest. The statistics are well-known-- Black, Latinx, and other non-white individuals account for 60% of COVID-19 deaths,<sup>1</sup> though they constitute 40% of the population.<sup>2</sup> A recent CDC analysis identified racial disparities in COVID-19 outcomes in 92% of hotspot counties in the U.S.<sup>3</sup>

When COVID-19 disparities emerged, a debate followed. Some suggested that COVID-19 differences in outcomes could reflect characteristics of the virus or the host that make people of color at high risk for poor outcomes. Others were skeptical, and instead pointed to structural racism, which increases the prevalence of co-morbidities among Black and Latinx people with COVID-19, and also impacts their ability to physically distance and seek care.

This issue of *Clinical Infectious Diseases* provides a quantitative analysis to answer questions about the role of race and racism in determining COVID-19 outcomes.

Researchers employed electronic health records to study COVID-19 outcomes. In a retrospective cohort of hospitalized patients with COVID-19, they employed multi-variable regression modeling to determine demographic and clinical factors associated with mortality after admission for COVID-19. If there is a genetic or physiologic reason that COVID-19 is a more serious infection among Black or Latinx people than white people, then race or ethnicity should be an independent predictor of mortality. If, however, race or ethnicity are social constructs that confound true underlying relationships between comorbid conditions, access to care, and COVID-19 death, then race or ethnicity should cease to be a significant predictor of death when adjusted for comorbid conditions and access to care.

The analysis includes 379 individuals; 14% were Black, 30% Latinx, and 50% white. Ninety-nine percent had health insurance, with 40% having public insurance alone. The paper's primary finding is that once individuals are hospitalized and the analysis is adjusted for co-morbidities, race and ethnicity do not predict COVID-19 death. In other words, COVID-19

disparities are not about genes, enzymes, or physiologic mechanisms. Disparities in COVID-19 death are the result of structural racism.

This paper is important. First, its findings contribute to the national discussion about disparities. Black and Latinx people do not die from COVID-19 due to physiology or biology. They die from COVID-19 because of racism. Disparities in COVID-19 death are a manifestation of racism.

Yet, as powerful as that finding is, it is only the first level of interpreting the work. The paper has an added dimension of impact. Beyond its findings, its very existence and the context in which the research occurs, catalyzes discussion about the U.S. healthcare system.

The analysis employs data from a large not-for-profit hospital network that includes several globally leading research institutions, a rich network of philanthropic donors, and one of the largest National Institute of Health (NIH) funding bases in the nation.<sup>4</sup> The COVID-19 population within that network included 50% Black and Latinx patients, with a majority of commercial payers. More than 99% had health insurance. In comparison, many hospitals overwhelmed by COVID-19 are caring for more than 80% of Black and Latinx patients with COVID, are working entirely with Medicaid or un-reimbursed care, and have little or no NIH funding or resources to conduct research.

The narrative of this paper does not really belong to this study team. It is the lived experience of thousands of health care providers and patients who do not have time or resources to conduct research, largely because the same structural racism that results in COVID-19 mortality in Black and Latinx communities also leads to safety-net hospitals struggling to survive, with limited capacity for conducting research. It is the study team's privilege to have electronic health records, informatics, supported research time, and statistical resources. We must acknowledge that privilege is established and maintained by the same system of disparate reimbursements and unequal care that generated COVID-19 disparities in the first place.

Once we open the box to examine privilege, we should be comprehensive and honest about all voices in the conversation, including our own. Dr. Linas is a white male physician working at a major university. Dr. Cunningham is a woman of color also working at a major academic medical center. We both work at safety-net hospitals that care for majority Medicaid populations, but we bring only our perspectives. Yet again, many of those who lived the COVID-19 disparity as health care providers or patients are absent. Lack of resources and support exclude them from researching their patients' experiences and telling their stories.

What is the call to action? How can we translate these observations into constructive change? We can do so by demanding equity in the distribution of Federal research funding. Currently, federal agencies grant research funds through a careful system of equality. Investigators propose projects, which are peer-reviewed, considering significance, innovation, investigators, and approach. The system is not perfect, but it effectively ensures that important concepts, rigorous approaches, and strong investigative teams attain funding. It is also a system that concentrates resources among a subset of investigators and institutions. This process purports to focus on delivering the best science. What this process does not deliver is equitable distribution of resources that ensures that stakeholders have a voice designing research and sharing insight from lived experiences.

Before COVID-19, we might have considered the tradeoff between "best science" and "equitable distribution of resources," and decided that NIH funding should solely focus on "best science." However, the best science requires diverse voices and participation. Science that systematically excludes broad segments of our healthcare system is not generalizable, does not always focus on the most relevant questions, and lacks adequate perspective to formulate the best hypotheses. In other words, science that is exclusive is not the "best science." The time has come for funders to include equity into decision-making about research. Federal funding agencies should require established research institutions to partner with community and safety-net hospitals, and they should support those partnerships with dedicated funding. Funding agencies should ensure that enrollment targets include

representation of women and people of color, and studies not meeting demographic enrollment goals will be terminated, similar to studies not reaching overall recruitment milestones. In short, it is time to evolve beyond equality, and attain equity in research funding processes. Inclusion matters, not only because it is the right thing to do, but also because it is essential to delivering the best science.

To be clear, none of this discussion about privilege casts a shadow on the outstanding individuals who conducted the aforementioned study. In fact, quite the opposite. These researchers should be applauded for leveraging resources to highlight disparity and seek solutions. This is exactly the kind of project needed to destabilize the status quo and affect change. Therefore, the paper is a fascinating and powerful microcosm of the very dynamics it seeks to investigate. We can all learn profound lessons from this work--by reading the results and by engaging directly with its complicated perspective on our social fabric. Ultimately, working at all levels to attain equity is necessary to move us all forward.

Neither author has any potential conflicts to disclose.

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## Cultural Formulation Interview

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### Description

As technological advances lead to an ever-increasingly interconnected and globalized society, the treatment of mental illness and preservation of mental health has become an international and cross-cultural practice. The phenomenology of mental illness, therapeutic alliance between physicians and patients, and benefits of treatment are profoundly affected by various cultural aspects. Recognizing that new approaches are necessary to effectively treat an increasingly diverse population and that cultural considerations apply to all patients, DSM-5 includes the Cultural Formulation Interview (CFI). The CFI is a set of questions designed to integrate and operationalize culture into mental health assessment and treatment in order to optimize patient outcomes. It operates from the viewpoint that culture is multi-dimensional, individualized, and applicable to any clinical encounter regardless of the demographic characteristic of the patient or the clinical setting. The goals of this PLM will be to increase awareness of the impact of culture on the practice of psychiatry and to describe current research in cultural psychiatry. This CFI PLM will provide information on the CFI's development, utility, and implementation into regular clinical practice.

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 <https://education.psychiatry.org/FileUploads/iconSampleQuestion.png>

## Learning Objectives

- Understand the basis of the impact of culture on the practice of psychiatry
- Learn the foundational basics of the DSM-5 Cultural Formulation Interview
- Identify and appreciate situated aspects of culture beyond typically categorized fields such as ethnicities, languages, sexual orientation, military service, etc

## Target Audience

Psychiatrists

## Estimated Time to Complete

Estimated Duration: 1 hour  
Release Date: November 30, 2018  
End Date: November 30, 2021

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### Program Presenters

- Michael Hann, MD, Director, Healthcare Business, US Naval Hospital Yokusuka, Japan. *Reports no financial relationships with commercial interests.*
- Roberto Lewis-Fernandez, MD, Professor of Clinical Psychiatry, Columbia College of Physicians and Surgeons. *Disclosure: Honoraria from American Psychiatric Publishing, Inc.*
- Ravi DeSilva, MD, Unit Chief, Inpatient Psychiatry, New York-Presbyterian Hospital, Asst. Professor of Psychiatry, Columbia University Irving Medical Center. *Disclosure: Guidepoint Consulting AristaMD*

### Program Planners

- Ranna Parekh, MD, Director of Division Diversity and Health Equity, American Psychiatric Association. *Reports no financial relationships with commercial interests.*
- Sejal Patel, Senior Program Manager, American Psychiatric Association. *Reports no financial relationships with commercial interests.*
- Vabren Watts, PhD, Deputy Director of Division Diversity and Health Equity, American Psychiatric Association. *Reports no financial relationships with commercial interests.*

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- Internet Connection: 1 Mbps or higher

Minimum Requirements:

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**Tag(s)** Cultural Psychiatry, Question-Based Learning, CME, Participation (COP)

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# Mental Health Disparities: Diverse Populations

## Mental Health in U.S.

- Approximately 18% of US adults have a diagnosable mental disorder in a given year, and approximately 4% of adults have a serious mental illness.<sup>1</sup>
- Mental and behavioral disorders are among the leading causes of disability in the U.S., accounting for 13.6% of all years of life lost to disability and premature death.<sup>2</sup>
- Mental disorders are among the top most costly health conditions for adults 18 to 64 in the U.S., along with cancer and trauma-related disorders.<sup>3</sup>
- An estimated 43% of people with any mental illness receive mental health treatment/counseling.<sup>4</sup>

## Increasingly Diverse Population

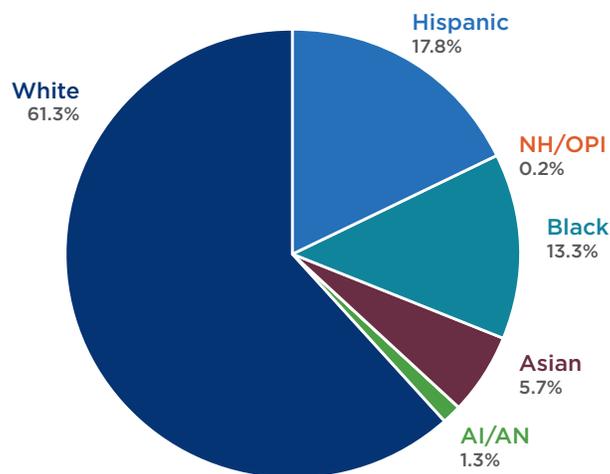
The U.S. population is continuing to become more diverse. By 2044, more than half of all Americans are projected to belong to a minority group (any group other than non-Hispanic White alone).<sup>5</sup>

## Mental Health, Diverse Populations and Disparities

Most racial/ethnic minority groups overall have similar—or in some cases, fewer—mental disorders than whites. However, the consequences of mental illness in minorities may be long lasting.

- Ethnic/racial minorities often bear a disproportionately high burden of disability resulting from mental disorders.
- Although rates of depression are lower in blacks (24.6%) and Hispanics (19.6%) than in whites (34.7%), depression in blacks and Hispanics is likely to be more persistent.<sup>6</sup>

## US Population, 2016



Source: US Census. Quick Facts: Population Estimates 2016. [www.psychiatry.org/psychiatrists/practice/professional-interests/disaster-and-trauma](http://www.psychiatry.org/psychiatrists/practice/professional-interests/disaster-and-trauma) (Notes: AI/AN – American Indian/Alaska Native, NH/OPI – Native Hawaiian/Other Pacific Islander)

- People who identify as being two or more races (24.9%) are most likely to report any mental illness within the past year than any other race/ethnic group, followed by American Indian/Alaska Natives (22.7%), white (19%), and black (16.8%).
- American Indians/Alaskan Natives report higher rates of posttraumatic stress disorder and alcohol dependence than any other ethnic/racial group.
- White Americans are more likely to die by suicide than people of other ethnic/racial groups.

- Mental health problems are common among people in the criminal justice system, which has a disproportionate representation of racial/ethnic minorities. Approximately 50% to 75% of youth in the juvenile justice system meet criteria for a mental health disorder.<sup>7</sup>
- Racial/ethnic minority youth with behavioral health issues are more readily referred to the juvenile justice system than to specialty primary care, compared with white youth. Minorities are also more likely to end up in the juvenile justice system due to harsh disciplinary suspension and expulsion practices in schools.<sup>8</sup>
- Lack of cultural understanding by health care providers may contribute to underdiagnosis and/or misdiagnosis of mental illness in people from racially/ethnically diverse populations. Factors that contribute to these kinds of misdiagnoses include language differences between patient and provider, stigma of mental illness among minority groups, and cultural presentation of symptoms.

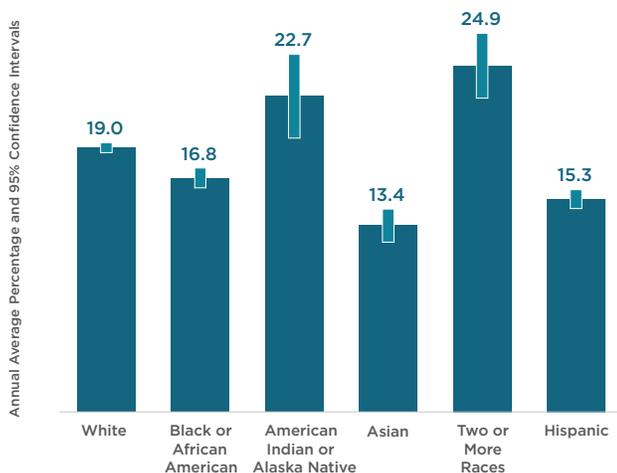
## Disparities in Mental Health Service Use

People from racial/ethnic minority groups are less likely to receive mental health care. For example, in 2015, among adults with any mental illness, 48% of whites received mental health services, compared with 31% of blacks and Hispanics, and 22% of Asians.<sup>9</sup>

There are differences in the types of services (outpatient, prescription, inpatient) used more frequently by people of different ethnic/racial groups. Adults identifying as two or more races, whites, and American Indian/Alaska Natives were more likely to receive outpatient mental health services and more likely to use prescription psychiatric medication than other racial/ethnic groups. Inpatient mental health services were used more frequently by black adults and those reporting two or more races. Asians are less likely to use mental health services than any other race/ethnic group.<sup>10</sup>

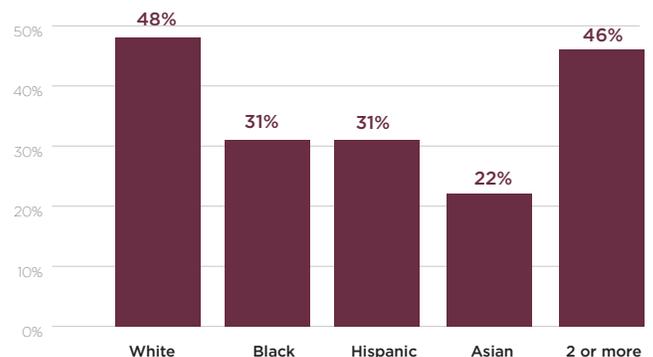
Among all racial/ethnic groups, except American Indian/Alaska Native, women are much more likely to receive mental health services than men.<sup>10</sup>

### Any Mental Illness in the Past Year among Adults, by Race/Ethnicity, 2008-2012



Source: Substance Abuse and Mental Health Service Administration, *Racial/Ethnic Differences in Mental Health Service Use among Adults, 2015*

### Among People with Any Mental Illness, Percent Receiving Services, 2015



Source: Substance Abuse and Mental Health Services Administration, *National Survey on Drug Use and Health, 2008-2015*

## Barriers to Care

Factors affecting access to treatment by members of diverse ethnic/racial groups may include:

- Lack of insurance, underinsurance
- Mental illness stigma, often greater among minority populations
- Lack of diversity among mental health care providers
- Lack of culturally competent providers
- Language barriers
- Distrust in the health care system
- Inadequate support for mental health service in safety net settings (uninsured, Medicaid, Health Insurance Coverage other vulnerable patients)

**To learn about best practices for treating diverse populations and to get answers to your questions by leading psychiatrists, please visit APA's Cultural Competency webpage at <https://www.psychiatry.org/psychiatrists/cultural-competency>.**

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## Footnotes

- <sup>1</sup> National Institute of Mental Health. Any Mental Illness Among US Adults. [www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-among-us-adults.shtml](http://www.nimh.nih.gov/health/statistics/prevalence/any-mental-illness-among-us-adults.shtml)
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- <sup>10</sup> Substance Abuse and Mental Health Services Administration. Racial/Ethnic Differences in Mental Health Service Use among Adults. 2015.

**This resource was prepared by the Division of Diversity and Health Equity and Division of Communications, and reviewed by the Council on Minority Mental Health and Health Disparities.**

# Stress & Trauma Toolkit

## for Treating **Indigenous People** in a Changing Political and Social Environment

Indigenous populations in the United States are diverse in languages, cultures, and histories. As a result, varying experiences and responses to historical traumas have emerged in the present in these populations. Historical trauma has been defined as “cumulative emotional and psychological wounding, over the lifespan and across generations, emanating from massive group trauma experiences.”

Witnessing or being directly involved in violent struggles carries risks, both physical and psychological, which can be passed on to the next generation. For Indigenous peoples, land dispossession, forced relocation, epidemics, and forced assimilation and sterilization are just some examples of the collective losses they have experienced over time.

Unfortunately, these losses continue even today in disputes such as those at Standing Rock that perpetuate stressors on Indigenous people. Indigenous populations have demonstrated strengths of resiliency by continuing their cultures, language, subsistence lifestyles, spirituality, and ceremonies. Indigenous peoples have also used activism as a way of life to collectively come together and resist oppression and land and water dispossession. The Standing Rock Dakota Access Pipeline protests in 2016, has raised awareness in mainstream America of the historical oppression, forced relocation, and land dispossession experienced by Indigenous people for centuries.

However, other responses to intergenerational traumas in Indigenous populations may include substance abuse, depression, anxiety, low self-esteem, anger, and suicidal thinking.

### Clinical Vignette

#### Miles, 24 years old

Miles is a 24-year-old Mescalero Apache man with a history of depression and post-traumatic stress disorder (PTSD) who was referred for evaluation of suicidal ideation by the counselor at his college. He was assessed by the behavioral health counselor and referred to the psychiatrist in an Indian Health Service clinic in the large southwestern city where Miles is living. Miles described feeling very down, isolated, and is having trouble concentrating in his college art classes. He attends a college that specifically teaches Indigenous studies, and he has a good peer and family support system. With a history of feeling hopeless and worthless, Miles has contemplated recklessly running into traffic, because “no one would miss me.”

Miles grew up on his home Indigenous nation. He is very connected to living there. Miles participated in community cultural events and ceremonies and immersed himself in athletics in high school. He was a well-known cross-country runner. Miles was ambivalent about attending college off his Indigenous nation; he was not sure he would be able to leave the support of the rural reservation life. However, his parents strongly encouraged him to attend college in an urban setting because of its focus on Indigenous studies.

In a patient history interview with the psychiatrist, Miles explained that he spent three months at the Standing Rock encampment in 2016, where he assisted in maintaining the camp and helped produce articles and videos for social media. Miles felt very accepted and valued during his stay at the encampment. There were many Indigenous youth with similar backgrounds. However, police forcibly broke up the

encampment and removed protestors—including Miles— spraying them with fire hoses and arresting them. Since returning from the encampment six months ago, Miles has been hyper-vigilant and irritable, with feelings of hopelessness and a lingering sense of not belonging.

Miles has attempted to engage with other college students who had been at the camp to increase his sense of belonging, which has helped. But he also has felt singled out by his white professors and suspects this is because of his activism. Miles feels his professors are unsure he is committed to his studies and are not sure how to engage him. While he is a bright student, he feels the teachers also feel threatened by him.

Miles is fearful of being arrested again; seeing law enforcement officers in the city where he attends college triggers these fears and hypervigilance. Miles is considering dropping out of college and returning to his home reservation because he feels overwhelmed by the pressures of living in the city and the triggers from law enforcement.

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## Factors that Put Indigenous Peoples at Risk for Mental Health Problems

**Historical trauma:** The psychological effects of forced relocation, assimilation, and other traumas inflicted on Indigenous peoples linger today. Indigenous peoples are confronting the trauma, learning the accurate history, and reconnecting with Indigenous spiritual practices and culture to assist the healing journey—but continuing discrimination and ongoing trauma hinder that progress.

**Intergenerational Trauma:** The intergenerational and unconscious grief from the historical trauma experienced by Indigenous peoples is passed from generation to generation due to forced relocation, land dispossession, and loss of spiritual practices, language and culture. If not addressed and identified accurately, depression, anxiety, PTSD, and substance use can be outward manifestations of the intergenerational trauma and unresolved historical grief.

**Racism, racial bias, and discrimination:** Racial and ethnic minority populations, including Indigenous peoples, often experience negative social factors such as bias and discrimination that contribute to poor physical and mental health.

- Institutional racism and social determinants of mental health: Institutional racism worsens social determinants of health and mental health, including access to quality education, safe housing, gainful employment, appropriate health care, and a clean environment.
- Low socioeconomic status (SES): Indigenous peoples tend to have disproportionately low socioeconomic status, as determined by education, income, and occupation. Low SES has been significantly associated with a higher risk for mental illness.

**Geographic challenges:** Many Indigenous people live in urban centers. They may have relocated to these areas for economic opportunities, but in the process may lose the cultural strength that comes from connection to the land. This may contribute to limited resources in terms of health care, mental health, education, and employment.

**Difficulties integrating traditional and modern lifestyle:** Indigenous persons may struggle to achieve a comfortable balance between tribal traditions and the demands of contemporary life.

**Lack of culturally appropriate diagnoses and treatments:** Diagnoses such as PTSD have been found to be relevant, but inadequate for capturing the scope of responses to historical trauma experienced by Indigenous peoples. The literature has identified a need to develop appropriate culturally based trauma theory and interventions for Indigenous peoples.

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## Suggested Assessment and Treatment Recommendations

1. Please see [Suggested Assessment and Treatment Recommendations for Marginalized Populations](#)

2. **Avoid stereotypes and create a welcoming environment** that acknowledges and respects the impact of complex histories and traumas of Indigenous peoples. Providers should recognize their own biases towards Indigenous peoples and acknowledge where they are in their own learning and awareness of Indigenous culture and experience. Providers who maintain openness and curiosity about patients with whom they work can achieve cultural agility and sensitivity.

3. **Encourage patients to reconnect with their culture and community** to reinforce identity, resilience, and self-esteem. This can prevent and protect against symptoms of mental illness, especially substance use issues, depression, and PTSD.

4. **Use cultural practices as primary and adjunctive treatment modalities.** Talking circles and drumming circles may be useful as primary treatment modalities or secondary to other treatments. Indigenous peoples have strong connections to this way of healing and connecting to their culture and transmitting Indigenous knowledge. Providers may employ culturally appropriate activities like these with

guidance from Indigenous providers. Other ideas to consider are to integrate Indigenous art and aesthetics that are part of the local Indigenous nations in office settings. Providers who regularly treat Indigenous people should consider becoming familiar with local customs and acknowledge traditions of the APA's Privacy Policy, including the use of cookies. [Read Our Privacy Policy](#)

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## Resources

APA Mental Health Facts for American Indian/Alaska Natives. 2017 <https://www.psychiatry.org/File%20Library/Psychiatrists/Cultural-Competency/Mental-Health-Disparities/Mental-Health-Facts-for-American-Indian-Alaska-Natives.pdf>

APA CME Module: Cultural Competence Curriculum, "Providing Culturally Competent Care to Indigenous Peoples: American Indian/Alaska Native/Native Hawaiian." 2016.

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## More Patient Populations:

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- Samra Sahlu, M.D.

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## About the Toolkit

**Disclaimer:** This toolkit is intended to provide general medical advice or recommendations. Each clinician is responsible for using his or her own medical judgement as to how to best diagnose and treat patients.

This introductory guide offers an array of topics that will be essential in understanding how to work with special populations experiencing stress and trauma in today's changing political environment. It provides basic information to raise awareness of the needs of special population patients and strategies to incorporate in care in psychiatric practices. This toolkit does not represent official APA policy, but offers a perspective from physicians that work with this community on a regular basis. The objective of this toolkit is to help a broader range of psychiatrists become familiar with best practices for treating special populations experiencing stress and trauma. Psychiatrists can consult Resources & References section on each page for further reading.

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