INSTITUTE FOR HEALING AND JUSTICE IN MEDICINE
THE HUB

Dear Chairman Neal: October 16th, 2020

On behalf of the Institute for Healing & Justice in Medicine (IHJM), we are writing in response to your Request For Information regarding the misuse of race in clinical diagnostic algorithms and, more broadly, throughout the healthcare sector. We appreciate your attention to this critical health equity issue and hope that our comments and research will prove useful to you in addressing it.

The IHJM is a diverse organization of over 100 students, physicians, and researchers founded in early 2020 to prioritize equity and justice while reimagining clinical practice, education, and research. We serve as an interdisciplinary, centralized hub for social justice and community activism in medicine that can be appreciated by, contributed to by, and accessible to people of all backgrounds. Our virtual events have been viewed by thousands of healthcare workers, students, researchers, and community members dedicated to learning about and working towards a goal of just, equitable, and antiracist medicine.

In May 2020, we released a comprehensive report and policy brief directly addressing the historical and contemporary misuse of race in the practice of medicine, including in race-based diagnostic algorithms and treatment planning. We encourage examining these materials as foundational background information for your continued work on these topics. This letter was written by students, faculty, and researchers from our national working group dedicated to addressing the misuse of race in clinical algorithms.

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?

Race is a dynamic sociopolitical category, not a static biological or genetic characteristic. There are greater genetic differences within racial categories than there are between races. Delineations between races are dynamic and specific to time and location due to shifting social beliefs and prejudices. Therefore, race is not a meaningful proxy for genetic alleles or family history, though the medical field has persistently misused race as such. The misuse of race and ethnicity in clinical algorithms actively causes harm. For example, race-based adjustments in kidney function calculations artificially inflate estimates of glomerular filtration rate (GFR) for Black patients, delaying treatment, referral to specialty care, and life-saving kidney transplants. This is especially damaging given that Black people are more than three times as likely to develop end-stage renal disease, and wait twice as long for kidney transplants, when compared to white people. Similarly, race is misused in the American Heart Association's "Get With The Guidelines–Heart Failure" in-hospital death risk score. Black patients with heart failure are systematically, by race alone, categorized as having lower risk for in-hospital death, even when presenting with the exact same clinical characteristics as white patients. Like other misuses of race as biology, there is scant evidence-based rationale for this adjustment, but potentially serious consequences for Black patients.

The flawed science behind race-based medicine does not only impact hospital tools regarding kidneys and hearts: it is pervasive across medicine and impacts medical practice in every specialty and for every human organ. It is imperative that clinical algorithms misusing race are abolished.

Finally, it matters who is at the table when these decisions are made. Many of our institutions have failed to include patient voices in decision-making. We call for authentic collaboration with the patients and communities we serve to design antiracist systems of care. It is necessary to integrate patient communities into leadership and implementation of changes in order to achieve equitable outcomes. Additionally, the voices of healthcare workers and students of color, along with professional medical organizations primarily serving physicians of color, should be prioritized, given these individuals' and groups' unique vantage point as both providers and receivers of this care.

Institute for Healing and Justice in Medicine
2018 Oxford St #1190 • Berkeley, CA • 94704
instituteforhealingandjustice.org Email: info@instituteforhealingandjustice.org

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?

Our coalition has assisted in the removal of race corrections in eGFR calculations at a number of individual institutions spanning the contiguous United States. Diverse institutions, including the Massachusetts General Hospital, Brigham and Women's Hospital, Beth Israel Deaconess Medical Center, UW Health and University of Wisconsin School of Medicine and Public Health, University of Washington, Vanderbilt University Medical Center, Zuckerberg San Francisco General Hospital, University of Nebraska Medical Center, and hospitals affiliated with the Warren Alpert Medical School at Brown University, have publicly announced their elimination of race-based eGFR calculations in lieu of varied alternatives, such as considering body surface area, muscle mass, or nutrition status, and implementing cystatin-C.

Strategies that have been effective in removing the race-based adjustment in eGFR calculations across institutions include critical appraisal of published eGFR studies, engagement of multiple institutional stakeholders in discussions, and grounding arguments for the elimination of race-based calculations in scientific and sociological research. Cystatin C, a superior marker for kidney function compared to current creatinine-based measures, does not require the use of race and could be an evidence-based and effective national strategy. Several institutions have already replaced creatinine-based GFR estimations with cystatin C-based calculations, and more have expressed interest in doing so. However, critical barriers to the widespread use of cystatin C persist, including the lack of standardization of cystatin C assays across institutions, accessibility of the test, and cost. Federal infrastructure and funding could be a vital factor in alleviating these barriers, as described in our response to the next question.

A barrier encountered at multiple institutions has been hesitation by physicians to remove race correction without direct evidence that it adds harm. However, a recent study found that 33.4% of Black patients were reclassified to a more severe chronic kidney disease stage when the race variable was removed from the CKD-EPI equation, alluding to potential underestimation of the severity of chronic kidney disease in Black patients when race correction is used. Additionally, international studies have found that addition of the race correction factor makes eGFR, in fact, less precise, when compared to the gold standard test (iohexol). Such evidence supports the removal of race correction from eGFR calculation. Beyond the clear need to address racism, additional direct evidence of harm in other clinical algorithms would support the case for removing race-based adjustments.

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?

First and foremost, the IHJM believes problems due to race-based medicine do not indicate race-blindness as the answer. We advocate for a race-conscious, structurally competent approach to diagnostic algorithms and clinical research alike, as recently discussed by our colleagues in *The Lancet*. More broadly, we propose a multilevel strategy which spans policy and governmental action, professional medical societies, research, the healthcare workforce and education:

1. Policy and Governmental Action: The federal government should declare racism a public health crisis and use this framework to devise and fund policy solutions that recognize and address racism, rather than race, as the sole driver of racial health inequity. The Ways and Means Committee can support legislation, such as H.R.8178, and appropriate funding for this framework, which can then guide genuine and substantive change toward equity and the repair of centuries of harm. Additionally, to support the universal use of cystatin C for estimating kidney function, we

recommend 1) calling on the National Institute of Standards & Technology to identify a traceable standard for cystatin C (as was previously done for creatinine), and 2) directing the appropriate federal agencies to provide infrastructure and funding the infrastructure necessary to scale-up the number of laboratories performing this test and others that would obviate the use of race in clinical algorithms.

2. Professional Medical Societies: This is a crucial lever for short-term reform. Specialty medical societies are the primary creators and purveyors of clinical practice guidelines, driven by expert recommendations and literature review from their clinician membership. To change clinical and research guidelines that misuse race and ethnicity, we recommend that the House Ways & Means Committee call upon the American Medical Association, the National Medical Association, other organized medicine societies, especially those representing the special interests of diverse racial and ethnic groups, and relevant specialty societies to urgently convene an interdisciplinary working group charged to address race-based medicine across specialties. Importantly, experts in the sociological and medical anthropological study of race and racism must be included to provide crucial context on the history of medical racism and clarify distinctions between race, ethnicity, and genetic ancestry. Without their expertise, revised guidelines risk reifying inequity, harm, and racial essentialism.
3. Research: Racism as a driver of health disparities is largely ignored in medical research and federal funding streams. As such, flawed research designs -- such as the small studies that led to the creation of race-based eGFR equations -- continue to perpetuate the notion that racial and ethnic disparities in health are due to race, rather than to racism. Medical and social science experts have painstakingly defined rigorous standards for publishing on racial and ethnic disparities in health that should be followed by researchers, reviewers, research journal editors, and federal research funding sources like the AHRQ and NIH. Ensuring that researchers define race in their experimental design, name racism as a driver of health inequities, and avoid attributing racial disparities in health to biological differences will lay the foundation to move beyond race-based medicine.
4. Health Workforce and Education: Race-based medicine is deeply ingrained in clinical education and reinforced through protocols and standards in clinical practice. As a result, licensed health professionals have nearly universally been taught (explicitly and implicitly) that there is a biological basis for race, which informs their clinical decision-making. In addition to eliminating the use of race in the clinical guidelines mentioned above, two initial steps in addressing pedagogy include (1) requiring clinical licensure boards to eliminate false insinuations of race as a biological risk factor in their licensing examinations and (2) ensuring healthcare providers and trainees receive teaching about the history of racism in medicine and structural racism, both as dedicated lessons and integrated throughout the curriculum. The IHJM concurs with the joint AMA/AHA/ANA response to the recent Executive Order eliminating such trainings. These steps will ensure current and future providers have a more nuanced understanding of the role of race in medical practice and research.

We have outlined herein the position of the Institute for Healing & Justice in Medicine on how the federal government can help address the misuse of race and ethnicity in clinical algorithms and in medicine at large. We hope that the recommendations and references provided are useful to the U.S. House Ways & Means Committee in preparation for future action and conversation. We are grateful for this opportunity to partner with the Committee in addressing these pressing health equity issues, promoting antiracism within the U.S. healthcare system, and preventing the misuse of race in the future of medicine.

Signed,
The Institute for Healing & Justice in Medicine