AMA
AMERICAN MEDICAL
ASSOCIATION

JAMES L. MADARA, MD
EXECUTIVE VICE PRESIDENT, CEO

ama-assn.org
t (312) 464-5000

September 25, 2020

The Honorable Richard E. Neal
Chairman
Committee on Ways and Means
U.S. House of Representatives
1102 Longworth House Office Building
Washington, DC 20515

Dear Chairman Neal:

On behalf of the American Medical Association (AMA) and its physician and medical student members, I am responding to your recent letter regarding the study about the use of race correction in clinical algorithms that was published in the *New England Journal of Medicine* (NEJM) on June 17, 2020. I share your concerns about the implications of this study on health inequities and disparities in health outcomes for minoritized and marginalized communities. The AMA has long recognized that racial and ethnic health inequities are an unjust and major public health reality in the United States. Understanding that race is a social and political construct and not a risk factor for disease and death, the AMA has publicly acknowledged that racism impacts public health and is a barrier to effective medical diagnosis and treatment.

Advancing equity in health requires the understanding and acceptance of the harmful impacts of historical and contemporary racism on our individual and collective ability to strive for and achieve a reality in which we all have the resources, conditions, opportunities, and power to thrive and achieve optimal health. The AMA remains strongly committed to achieving these goals and addressing such issues is a top priority for our organization, as detailed further below.

1. Please update the Committee on AMA's efforts to educate its members and raise awareness about health inequities affecting Black, Latinx, Indigenous, and other communities of color?

Over the past two decades, the AMA has spent considerable time, effort, and resources to better educate its members and raise awareness about health inequities affecting marginalized and minoritized communities. Below is a brief overview of select, notable actions taken by the AMA in the early part of the 2000s:

- 2003–AMA served as a key collaborator and author of the landmark *publication, Unequal Treatment,* which highlighted that racial bias towards their patients exists among and within physicians.
- 2004–AMA established the Commission to End Health Care Disparities, along with the National Medical Association (NMA) and the National Medical Hispanic Association, convening a coalition of more than 50 state medical associations, medical specialty societies, and other health professional organizations working collaboratively to eliminate disparities in health care.

- 2008–AMA issued an apology to the NMA for allowing the exclusion of Black physicians for over 100 years.

Over the last several years, the AMA continued to work to further educate the membership and raise awareness about health inequities. At its Annual Meeting in June 2018, the AMA adopted policy directing the organization to develop "an organizational unit, e.g., a Center or its equivalent, to facilitate, coordinate, initiate, and track AMA health equity activities." At the same meeting, the AMA adopted policy stating that "health equity," defined as optimal health for all, is a goal toward which the AMA will work to achieve by advocating for health care access, research and data collection, promoting equity in care, increasing health workforce diversity, influencing determinants of health, and voicing and modeling commitment to health equity. Subsequently, in April 2019, the AMA hired its inaugural Chief Health Equity Officer and Group Vice President, Aletha Maybank, MD, MPH and established the AMA Center for Health Equity (CHE).

In addition to creating the CHE, the AMA House of Delegates (HOD) continued its long-standing commitment to adopting policies focused on health equity and rooting out discrimination. More specifically, in 2019, the HOD adopted a strong anti-discrimination policy that states, "AMA maintains a position of zero tolerance toward racially or culturally based disparities in care; encourages individuals to report physicians to local medical societies where racial or ethnic discrimination is suspected; and will continue to support physician cultural awareness initiatives and related consumer education activities." This policy is one of many adopted by the AMA House of Delegates related to anti-discrimination. Furthermore, in 2020, the AMA Board of Trustees acknowledged racism is an urgent threat to public health, the advancement of health equity, and a barrier to excellence in the delivery of health care and pledged to dismantle racism across the entire health care system.

The AMA provides a wealth of health equity resources to help educate staff about the importance of these issues. Early in 2020, equity content was added to an internal AMA website, which includes learning modules on equity; a reading list of classic and contemporary texts and articles on various equity-related subjects; and videos/documentaries to aid individual and business unit study of equity issues.

Throughout the coronavirus pandemic, the AMA has viewed equity as an accelerant that focuses and prioritizes health practitioners' practice-wide goals to deliver high-level, comprehensive, equitable care to all, with thoughtful consideration of the myriad lived experiences of patients. To that end, the AMA created an equity in COVID-19 resource webpage for physician members and staff.

The AMA has also focused on COVID-19 in various speaking engagements across the country to educate physicians, practices, and policymakers and raise awareness about health inequities affecting Black, Latinx, Indigenous, and other communities of color. These efforts have included, but not been limited to, the following:

- On April 7, 2020, the *New York Times* published an op-ed written by Dr. Maybank on the significance of race and ethnicity data in combating COVID-19. In addition to receiving widespread attention, it contributed greatly to the national conversation on the disparate impact of the pandemic on minoritized and marginalized communities.

- On April 14, 2020, via Apple TV+, Dr. Maybank spoke with international syndicate host Oprah Winfrey, during a special presentation entitled, "Oprah Talks COVID-19-The Deadly Impact On Black America." During this in-depth conversation, Dr. Maybank discussed the detrimental impact the COVID-19 pandemic is having on Black people across the country.
- In April 2020, the CHE, in collaboration with the AMA's Marketing and Member Experience business unit, launched a YouTube-based conversation platform called "Prioritizing Health Equity." This regular series of conversations focuses on the experiences of marginalized and minoritized physicians, public health leaders, and medical students during the COVID-19 pandemic.

One of the AMA's critical concerns related to COVID-19 is the dearth of publicly available disaggregated data on the number of positive cases, hospitalizations, and mortality by race and ethnicity. Without these data, it is difficult to make sound decisions on resource allocation and to glean an overall understanding of how the virus is impacting various communities. As a result, on April 3, 2020, the AMA sent a letter to the Secretary of the U.S. Department of Health and Human Services (HHS), Alex Azar, urging the agency to collect, analyze, and distribute to the public explicit, comprehensive, standardized data on race, ethnicity, and patients' preferred spoken and written language related to testing status, hospitalization, and mortality stemming from COVID-19, noting the need to work with state and local public health offices and clinical data registries, where possible, to minimize the data collection burden for front-line clinicians, and to ensure that data collection efforts prioritize cultural sensitivity and patient privacy. The following physician and public health organizations signed onto this letter: the NMA, the National Hispanic Medical Association, the National Council on Asian Pacific Islander Physicians, the Association of American Indian Physicians, the American Academy of Family Physicians, the American Academy of Pediatrics, and the American College of Obstetricians and Gynecologists. The AMA also signed onto a letter in April with the American Hospital Association and American Nurses Association making a similar request of HHS. The AMA also continues to update its webpage monitoring which states are tracking COVID-19 by race and ethnicity to serve as a resource for physicians and health equity advocates to highlight the ongoing inequities at the state level.

The combination of the *New York Times* Op-Ed and April 3rd letter to HHS served as a catalyst for the AMA to support H.R. 6585, the Equitable Data Collection and Disclosure on COVID-19 Act. Introduced by Representative Robin Kelly (D-IL), the legislation, among other things, requires the Centers for Disease Control and Prevention (CDC) and the Centers for Medicare & Medicaid Services (CMS) to publish and update daily on the CDC website data on COVID-19 testing, treatment, and outcomes disaggregated by race, ethnicity, and other demographic characteristics.

The AMA also highlighted the plight of American Indians and Alaska Natives in a May 27, 2020 letter to HHS. This communication highlighted how critical funding allocated via the Coronavirus Aid, Relief, and Economic Security (CARES) Act to combat the coronavirus pandemic was not being distributed to these communities in a timely fashion. As a result, AMA pressed HHS to expeditiously address the distribution of testing funding, Indian Health Services funding, and provider relief funding.

In addition, the AMA submitted a written statement for the record to the House Ways and Means Committee for its May 27, 2020 hearing on "The Disproportionate Impact of COVID-19 on Communities of Color," and AMA's Immediate Past President Patrice Harris, MD, MA testified on June 23, 2020, at the House Budget Committee's hearing regarding "Health and Wealth Inequality in America: How COVID-19 Makes Clear the Need for Change."

The AMA is also involved in educational efforts, strategic planning, and development of external partnerships to address health inequities. For example, the AMA is working closely with West Side United (WSU), which is a social impact investment pact looking to take a solid step forward toward closing the life expectancy gap between "the Loop" and Chicago's Westside neighborhoods by invigorating economic growth and improving educational outcomes. During the pandemic, AMA continues to work very closely with WSU and Chicago's mayoral Racial Equity Response Teams to find and identify ways to impute missing race and ethnicity data.

The AMA also worked to establish a COVID-19 Latinx Task Force which is a national group comprised of over 40 organizations. The mission of the COVID-19 Latinx Task Force is to strategically articulate, bridge, and connect Latinx/Hispanic serving organizations, as well as build a repository and collective effort that provides authoritative public health information, resources, and leadership to Latinx communities, by delivering timely, life-saving information and health access during COVID-19, and beyond.

The AMA's efforts to educate its members and raise awareness about health inequities affecting Black, Latinx, Indigenous, and other communities of color extend to the AMA Foundation (AMAF) and Improving Health Outcomes initiative, as well. The AMAF's Community Health Program is designed to further increase health equity and improve health outcomes by creating a cohort of community-based organizations throughout the country to help prevent and manage Type 2 diabetes and/or hypertension for marginalized and historically disinvested communities. In 2019, the AMAF awarded $494,200 in grants to physician-led, community health organizations serving our most historically underserved populations. The program expanded to 11 cohort sites in California, Iowa, Missouri, Texas, New Jersey, New York, Georgia, North Carolina and Colorado. This effort positively impacts more than 6,500 patients while collaborating with local food pantries, farms, shelters, senior citizen residences, churches, and hospitals.

Additionally, AMA's Improving Health Outcomes initiative advanced the Health Equity Learning Project (HELP) to improve blood pressure control rates for Blacks with hypertension by testing a clinical protocol to improve physician-prescribing or antihypertensive medications according to clinical guidelines. HELP also supported initiatives to improve medication adherence and increase the use of self-measured blood pressure among Black patients.

Finally, the AMA has highlighted numerous equity issues through its advocacy to the federal government—including to federal agencies that do not traditionally address health care policy—on matters not related to COVID-19 or specifically about race. For example, following the AMA's declaration against violence against transgender people, we advocated for federal law enforcement agencies to identify and implement strategies to address the epidemic of violence against the transgender community, especially the amplified physical dangers faced by transgender people (especially women) of color. We have also strongly opposed policies that would stand in the way of optimal health for all, such as those that would allow federal grantees such as housing providers, Head Start programs, adoption agencies, and community health centers to refuse services to individuals based on their real or perceived sexual orientation or gender identity.

This intersectional approach to policy is critical and the AMA aims to apply an equity lens to all policies we evaluate, including those that may not at first glance appear related to equity. For example, the AMA has frequently highlighted the need for privacy and non-discrimination protections in draft legislation and proposed regulations related to data collection, use, and reporting. While data, innovation, and automation can be powerful tools to address inequities, "the language of 'progress' is too easily weaponized against

those who suffer most under oppressive systems, however sanitized."[1] In sum, the AMA recognizes the need to evaluate policy with an eye toward unintended consequences and avoidable harm, using an equity lens to evaluate potential outcomes, particularly for those that stand to be most harmed. As outlined above, the AMA is well-positioned to develop creative, evidence-based solutions, and is committed to serve as a thought-leader within and an example to the health care community that equity must be pervasive across and within policies.

2. What strategies is the AMA undertaking to review and reevaluate the use of race and ethnicity in clinical algorithms? How will the AMA work to support, encourage, and coordinate with other specialty organizations that are also conducting a reevaluation?

Following publication in the *NEJM* of "Hidden in Plain Sight: Reconsidering the Use of Race Correction in Clinical Algorithms," AMA reached out to the American College of Cardiology and the leadership of its National Cardiovascular Data Registry, the American College of Obstetrics and Gynecology, and the Society of Thoracic Surgery (STS) and the leadership of the STS Database to gauge their interest in convening a work group to address the issues raised by the *NEJM* article's authors. We are in active discussions with these groups and are extending similar outreach to additional organizations. AMA looks forward to supporting, encouraging, and coordinating its efforts with these organizations.

3. While reevaluating and ending the misuse of race/ethnicity in these algorithms could take some time, what guidance can the AMA issue quickly to redirect clinicians' use of these algorithms? How will the AMA inform clinicians of the impact of these algorithms on racial health inequities? What guidance would the AMA offer on how this should be communicated to patients?

In June 2018, the AMA adopted policy on health care augmented intelligence (AI), much of which is powered by algorithms.[2] This policy outlines that the AMA will leverage its ongoing engagement in digital health and other priority areas for improving patient outcomes and physicians' professional satisfaction by helping set priorities for health care AI. First and foremost, the policy supports the use of AI systems where those systems advance the quadruple aim of health care. Specifically, AI systems should: 1) enhance the patient experience of care and outcomes; 2) improve population health; 3) reduce overall costs for the health care system; and 4) support the professional satisfaction of physicians and the health care team. The policy further provides that the AMA will promote the development of thoughtfully designed, high-quality, clinically validated health care AI that:

- is designed and evaluated in keeping with best practices in user-centered design, particularly for physicians and other members of the health care team;
- is transparent;
- conforms to leading standards for reproducibility;
- identifies and takes steps to address bias and avoids introducing or exacerbating health care disparities, including when testing or deploying new AI tools on vulnerable populations; and
- safeguards patients' and other individuals' privacy interests and preserves the security and integrity of personal information.

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[1] Benjamin, Ruha. *Race After Technology* (p. 8). Wiley. Kindle Edition.
[2] https://www.ama-assn.org/system/files/2019-08/ai-2018-board-policy-summary.pdf

Furthermore, it is necessary for appropriate professional and governmental oversight to ensure safe, effective, and equitable use of and access to health care AI applications and systems. The use of AI applications in clinical settings raises a number of new and novel questions and concerns for patients and physicians, and introduces a level of risk to the health and wellbeing of our patients in ways that may not apply to AI deployed in non-health care settings. The AMA was an early and trusted advocate within the medical community for ensuring that AI systems identify and take steps to address bias, avoid introducing or exacerbating health care disparities, and safeguard people's privacy interests. This HOD policy was widely publicized within the health care community and among technology developers and policy makers, with the hope that they will guide clinicians seeking to adopt tools powered by algorithms and developers who design them. It may also serve as a useful resource when evaluating clinical algorithms that utilize race and ethnicity—for example, do such algorithms enhance patient care and outcomes or do they exacerbate health care inequities?

The AMA would posit, as do Vyas, Eisenstein, and Stone in the *NEJM* article, that "race is a poor proxy for genetics," and recognizes that some clinicians and researchers may unknowingly or unintentionally conflate "race" with "racism." In other words, the AMA is mindful that the myriad effects of racism, rather than race, are responsible for differences in health status and outcomes often attributed to race. The AMA agrees with the authors that now is a good time to *reconsider* the use of race and ethnicity data, empowered by the near universal adoption of electronic health record (EHR) systems, access to hundreds of thousands, if not millions, of patient records in clinical registries, and advances in computing power and statistical methods. The AMA is also mindful of advances in scholarship (e.g., public health, critical race theory, and social epidemiology) which call for a shift from thinking of race as a risk factor to a deeper understanding of racism as a determinant of health. Thoughtful reconsideration must include an examination of the underlying social conditions that contribute to health outcomes, including how systemic racism has created and shaped such social conditions; failure to address and remedy social risk factors will hinder efforts to reduce and eliminate the health inequities long associated with *racism* and *discrimination*—not race.

While this review is underway, it will also be important to be mindful of the unintended consequences of not using existing clinical risk calculators and to warn against providing patients with non-evidence based subjective estimates of risk.

Progress towards reducing inequities, in health care specifically, requires accurate measurement of such disparities, at baseline and over time. Access to reliable valid longitudinal data, and analysis of such data, are critically dependent on development, testing, adoption, and implementation of common standards for collection of such data. This all includes gathering clinical consensus to establish the appropriate method for integration within certified electronic health record technology (CEHRT) platforms. Many such standards are only now being developed. One standard development effort is the GRAVITY project in which the AMA is working closely with organizations such as HL-7 to develop and ballot (i.e., vet specifications prior to publishing) data standards related to housing insecurity and limited access to transportation. This is an iterative, collaborative, and complex multi-year process. Given the number of data elements to be standardized and knowing the pace at which standards are typically developed, it is unlikely that this will happen quickly.

As standards continue to be developed and refined, there are likely ways to utilize existing technology to better disaggregate race and ethnicity data. For example, for EHR technology to be certified by ONC, an EHR must recognize up to 900+ codes (the CDC value set). However, CEHRT is only tested to report on six aggregated race and ethnicity categories (American Indian or Alaska Native; Asian; Black or African

American; Native Hawaiian or Other Pacific Islander; White; and Hispanic or Latino).[3] EHR vendors can typically import the full CDC value set upon a clinician's request, but the federal government should research this topic and potentially encourage such functionality to be made available in baseline EHRs. It will, however, be critical that the federal government study the impact of requiring the full CDC value set as not to negatively affect EHR usability. Any requirements that could add additional burden to the use of EHRs (e.g., requiring individuals to scroll through 900+ codes rather than using a search functionality) must be coordinated with physicians and other EHR end users.

In the meantime, the AMA can develop and disseminate via its various far-reaching communications channels and on its learning platforms the information and educational content physicians need to best care for their patients while these issues are being addressed.

The AMA also expects that physicians will turn to their usual trusted sources of clinical information in their field, most commonly their specialty societies. The AMA already has formal agreements with several of the societies to jointly develop educational content and can reach out to them for this purpose. Through the societies and the AMA, physician awareness can be increased as to the strengths and limitations of clinical algorithms, how they can be best applied to patient care, and how to communicate nuanced information to patients. As specialty societies and physicians caring for patients focus on risk assessment of individuals, important contributions will be made by the public health community as it continues to focus on measuring risk at the population health level using instruments such as community health needs assessments. Social epidemiologists will be focusing on measuring health inequities (e.g., excess deaths, mortality rate ratios). Estimates of individual, community and population level risk will all benefit when they no longer use race and ethnicity data as proxies for the actual contributors to risk such as racism, health inequities, and social risk factors.

4. What remedies should be implemented to ensure appropriate care for patients who have not received it because of the clinical algorithms? What role could the federal government play in this implementation? What role should the AMA play in the implementation?

Patients have a fundamental right to know the risk, benefit, indications, and alternatives, including to not proceed, of any health care intervention that they are considering. Physicians have a fundamental obligation to ensure their patient's consent to care is well-informed. Additionally, as medicine grapples with questions of whether and how to best inform individuals of the use of AI and machine learning tools in their care delivery, we note that the AMA's Privacy Principles[4] state that individuals should have the right to know whether their data will be used to develop and/or train machines or algorithms. The opportunity to participate in data collection for these purposes must be on an opt-in basis. We encourage Congress to adopt these concepts into any forthcoming federal privacy legislation.

To ensure appropriate care for patients who may not have received it, perhaps because health care decisions were based at least in part on the output of a clinical algorithm, their clinical status and therapeutic options can be reviewed and revised as appropriate during their follow-up evaluation and management visits. If *risk calculators are used, clinicians could adopt an approach similar to the example* given by the authors of the NEJM article for coronary bypass surgery, changing what is entered for race and ethnicity into the algorithm, and discussing with the patient any observed differences in

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[3] https://www.healthit.gov/test-method/demographics
[4] https://www.ama-assn.org/press-center/press-releases/ama-issues-new-principles-restore-trust-data-privacy

absolute risk that might be based on race. In most clinical situations, what matters most to patients, their families, and physicians is the absolute risk of any proposed intervention.

In terms of the federal government's role, it could:

- Fund research to identify and evaluate the factors (e.g., SDOH) for which race and ethnicity currently serve as proxies in clinical algorithms.
- Incentivize through funding and by other means testing of such data elements across the health information ecosystem. Work related to SDOH should go through multiple rounds of development testing and production pilot use prior to adoption as national standards.
- Review its use of algorithms to ensure that (1) they are not inappropriately using race as a proxy for other factors (e.g., racism); and (2) any algorithms utilized by the federal government, regardless of who developed them, do not inadvertently further exacerbate inequities.
- Support initiatives led by specialty society clinical registry stewards with statisticians, geneticists, patients, and others:

  - To determine if removal of race and ethnicity from clinical algorithms, and inclusion of the data elements for which race and ethnicity are thought to be proxies (e.g., SDOH) increase or decrease the predictive accuracy of clinical algorithms. This should be an iterative process as new data elements are defined and implemented.
  - Examine the relative contribution of recent vs. legacy patient data to the predictive power of clinical algorithms in order to determine how often algorithms should be updated and at what time/age legacy data are no longer fit for use in such algorithms.

- Fund pilot studies in high priority areas (e.g., cardiovascular disease, renal disease, obstetrical care) to identify high-risk individuals and test interventions to reduce the modifiable contributors to heightened risk, accompanied by rigorous evaluation of the effectiveness of such pilots.

The AMA welcomes the opportunity to work with Congress, the national medical specialty societies, and others to address these important issues. At its core, rectifying the clinical algorithms and guidelines is a process best left to the specialty societies via a process of careful data analysis and periodic reevaluation.

5. Considering the unique experience of Black, Indigenous, and Latinx scholars, have a leading and vital perspective on these issues and the proposed solutions, despite being underrepresented in medicine. How is AMA supporting diversity in the discussions and strategy development relating to health equity?

In May 2020, the AMA's CHE hired a Director of Health Equity Strategic Data Use and Research, who brings experience in quantitative data analysis, social epidemiology, and sociology. In addition, the AMA plans to review use of its Physician Masterfile in published research, as well as in preparing manuscripts that set research agendas connecting structural drivers, physician data, and public health outcomes.

The CHE also leads the AMA collection of emerging practices on health and racial equity strategic programs and policies related to COVID-19. The collection of these practices is meant to support broader dissemination of best practices, innovation, and network development all within the larger goal of advancing health equity. The AMA will maintain the collection on its website. Post-COVID-19, the AMA will use the information to inform "after-action" conversations on planning and policy development.

In the spring of 2020, the AMA led a research effort to better understand the experiences of racially minoritized and marginalized physicians amid COVID-19. Internally, the AMA is using these insights to better support these physicians. Externally, the AMA is working to disseminate these findings with scholars and clinicians to provide insights on the experiences of these physicians via scholarly manuscripts. Our goal is for these insights to help us better understand the unique needs of and opportunities to better serve minoritized and marginalized physicians.
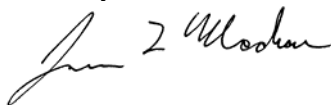
Developed in response to the COVID-19 threat, the Equity COVID-19 Resource Page consists of articles, commentaries, resource lists, etc., produced by world health and public health leaders relating to the pandemic. Not only are AMA utilization analytics demonstrating their usefulness for physician-members, this tool is also serving the general public. In addition, the Health Equity Resource Center for COVID-19 serves as a clearinghouse of sorts to ensure that communications have an equity lens and take into consideration structural issues that contribute to, and could exacerbate, existing inequities.

In consultation with the National Council of Asian Pacific Islander Physicians, during Asian American Pacific Islander Heritage Month (May 2020), the AMA released a public statement denouncing racism and xenophobia, particularly as it impacts Asian Americans and Asian-presenting persons in America. This document also publicly leverages a fuller report arguing for the discrete data disaggregation of Asian American and Pacific Islander health outcomes, which was presented to the AMA Board of Trustees in March 2020. A public version of the report is also available on the AMA website.

Conclusion

This letter provides only a snapshot of initiatives and advocacy activities underway at the AMA to address health inequities and disparities in health outcomes. The AMA applauds your leadership on this issue and looks forward to working with you and your congressional colleagues as we strive to improve the health of all of our citizens.

Sincerely,

James L. Madara, MD