POLICY STATEMENT Organizational Principles to Guide and Define the Child Health Care System and/or Improve the Health of all Children



# Eliminating Race-Based Medicine

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Race-based medicine has been pervasively interwoven into the fabric of health care delivery in the United States for more than 400 years. Race is a historically derived social construct that has no place as a biologic proxy. In addition to valid measures of social determinants of health, the effects of racism require consideration in clinical decision-making tools in ways that are evidence informed and not inappropriately conflated with the limiting phenotype of race categorization. This policy statement addresses the elimination of race-based medicine as part of a broader commitment to dismantle the structural and systemic inequities that lead to racial health disparities.

In an address at the annual meeting of the Medical Committee for Human Rights in March of 1966, Dr Martin Luther King, Jr. said, "Of all the forms of inequality, injustice in health care is the most shocking and inhumane." This oft cited quote presaged by nearly 4 decades the comprehensive and incontrovertible evidence documented in the Institute of Medicine's *Unequal Treatment* report that pervasive systemic inequities and historic structural barriers contribute directly to disparities disproportionately experienced by people of color in the health care system.<sup>2</sup> Race has been historically embedded into the foundations of health care in the United States for more than 400 years.<sup>3</sup> Race is a social, not a biologic, construct, and the use of race as a proxy for factors such as genetic ancestry is scientifically flawed.<sup>4,5</sup> Pediatricians may be unaware of this construct conflation. This policy statement specifically addresses race-based medicine, characterized as the misuse of race as a corrective or risk-adjusting variable in clinical algorithms or practice guidelines. The historic roots of race-based medicine and current reconsiderations are also discussed.

The role of race and racism in medicine has been vigorously debated. 6-11 Recognition of the determinative contribution of bias, whether implicit or explicit, to disparate and deleterious outcomes in a variety of settings, for a range of conditions, has been well chronicled.  $^{12-20}$  Further, perceptions of physiologic differences based solely on racial phenotypes have long been intertwined and persist in the practice and teaching of medicine. 21,22 A 2016 study of White

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To cite: Wright JL, Davis WS, Joseph MM, et al. Eliminating Race-Based Medicine. Pediatrics. 2022;150(1):e2022057998 medical students and residents demonstrated that endorsement of false beliefs about the way in which Black people experience pain was associated with lower pain score assessments and inaccurate treatment recommendations for Black patients compared to White patients in mock clinical scenarios. <sup>23,24</sup>

Beginning in the late 16<sup>th</sup> and early 17<sup>th</sup> centuries, race and racism became the primary mechanism through which enslaved Africans, their descendants, and other people of color were systematically subjected to subordination and marginalization in the United States. The evolution of modern medicine, in this context, has not been immune from the historical influence of inequitable societal attitudes and an unjust belief in the validity of human hierarchy. Phenotypic difference was intentionally used by the colonists and their descendants to justify the institution of slavery, the seizure of native lands, and the establishment of political and economic advantage. Flawed science and unfounded evidence further fueled the codified existence of race-based medicine in many places across the health care landscape. Eliminating race-based medicine and moving toward raceconscious medicine<sup>25</sup> is an essential step on the journey to equitable health care and outcomes.

#### **Background**

In 2019, the American Academy of Pediatrics (AAP) policy statement "The Impact of Racism on Child and Adolescent Health" directly named racism as a social determinant of health and called out the fallacy of racial biology. <sup>26</sup> The statement definitively emphasized that racebased medicine serves to "solidify the permanence of race, reinforce the notions of racial superiority, and justify differential treatment on the

basis of phenotypic differences." In 2020, the AAP Annual Leadership Forum passed a resolution, "Prohibit the Use of Race-Based Medicine," through which "the Academy shall end the practice of using race as a proxy for biology or genetics in all their education events and literature, and ... require [that] race be explicitly characterized as a social construct when describing risk factors for disease with all presentations at AAP-sponsored conferences."27 In 2021, the AAP Board of Directors and Executive Committee published a perspective reiterating the organization's high prioritization of and focused intent to operationalize the elimination of race-based medicine.28

One of the steps that the AAP has already undertaken to address racebased medicine was retirement of "Urinary Tract Infection: Clinical Practice Guideline for the Diagnosis and Management of the Initial Urinary Tract Infection (UTI) in Febrile Infants and Children 2 to 24 Months."29,30 The guideline came under scrutiny when Kowalsky et al questioned the systematic differential care recommended for Black or non-White children.<sup>31</sup> The inclusion of race as a decisionmaking factor in the clinical algorithm was based on a theoretical lower risk of UTI for children of color. Review of the guideline's cited references reveals that not only is the risk theoretical, but it is based on a blood group antigen-linked uroepithelial cell adherence hypothesis that the study authors state "requires additional study to substantiate or refute."32,33 Further examination of the literature regarding the adherence hypothesis finds some evidence for blood group phenotyping as a potential biomarker for UTI risk but nothing specifically aligning this risk with subjective racial identification.<sup>34</sup> In this case, race was inappropriately

inserted as default biologic proxy in lieu of incompletely explained epidemiologic observation. The just approach is to confer equitable care to all young children regardless of race.

### The Historic Roots of Race-Based Medicine

The origins of race-based medicine in the United States date back to the precolonial period and range from unproven hypothetical assumptions to outright cruel and inhumane practices. For example, Alabama physician J. Marion Sims, widely considered the father of modern gynecology, notoriously performed experimental vesico-vaginal fistula repair procedures on unanesthetized enslaved women.<sup>35</sup> He did so despite the availability and widespread use of ether, which he did employ with his White patients.<sup>3</sup> Sims' justification for this abusive practice was aligned with the broadly held belief in the medical community that, because of their thicker skin, Black people differentially experienced pain and were, therefore, more tolerant of surgical procedures, a concept espoused and published in 1851 by Sims' contemporary and fellow enslaver, Louisiana physician Samuel Cartwright. 36,37

Another such example lies in the roots of race-based lung function assessment, which can be traced back to founding father Thomas Jefferson, considered an enlightened intellectual of the era. Jefferson wrote in his influential 1781 treatise "Notes on the State of Virginia" about differences in lung capacity between the enslaved and White colonists. 24,38 He remarked on the dysfunction of the pulmonary apparatus in Black individuals and that "among the real distinctions which nature has made is a lack of lung capacity."24 Completely speculative, yet widely accepted, Jefferson's assertion remained

empirically unchallenged until the second half of the 19th century when Cartwright, drawing directly from Jefferson's unfounded hypothesis, performed rudimentary experiments using the enslaved on his plantation as subjects.<sup>39</sup> Cartwright concluded and published that lung capacity in Black individuals was 20% deficient and went on to further theorize that, because small lungs prevent Blacks from inhaling enough air that "forced labor is a way to vitalize the blood and correct the problem."36,40 This pseudoscience served to reinforce the practice of slavery and to perversely justify its necessity to help the enslaved.

# False Equivalency and Flawed Science: The Case for Eliminating Race-Based Medicine

Although the blatant philosophical and cognitively dissonant iustifications for slavery and the conditions of the enslaved are stunning, what is even more remarkable is how so much of this framework has persisted for hundreds of years in the form of race-based medicine. Despite growing acceptance of the false equivalency of race as a biologic proxy, there are numerous examples throughout the 21<sup>st</sup> century practice of medicine in which the attempted application of race correction or race adjustment factors have manifest in differential approaches to disease management and disparate outcomes. 41 Race assignment is not an independent proxy for genetic difference. However, there is recognition that differential lived experiences, particularly those that contribute to adversity, can impact physiologic and developmental mechanisms and, therefore, must be carefully accounted for in the transformative unwinding of racebased medicine. 42-45

A unifying definition for epigenetic events is the structural adaptation

of chromosomal regions so as to register, signal, or perpetuate altered activity states.46 Epigenetic induced changes of activity state can lead to combinations of genes that produce differential developmental outcomes. 46 Basic science work on the intergenerational elaboration of stress has elucidated that disruptive biological, physiologic, and neurodevelopmental mechanisms can manifest in utero and may persist in subsequent generational cohorts of the initially exposed. 47,48 The transmission of toxic stress across generations may sow the seeds of chronic disease development and contribute to the physiologic weathering described in some populations of color. 49,50,51 In other words, the impact of the trauma experienced by the enslaved and their descendants may be epigenetically embedded in ways yet to be completely understood. 52,53

Further, transparency regarding the truth behind the intensity of ancestral admixture in the preemancipation United States is required. Recent analysis of genotype array data from more than 50 000 US research participants reveals an overrepresentation of women of African descent in the gene pool than would otherwise be expected based on the slave ship manifests that documented the forcible transatlantic exile of 12 million Africans known as the Middle Passage.<sup>54</sup> The biases in the gene pool toward enslaved African women and European men can, in part, be attributed to the well-documented sexual exploitation of enslaved women by their enslavers. 55-58 This overrepresentation, despite the relatively smaller proportion of women in the Middle Passage, points to this sordid practice as an accelerator of genetic admixture<sup>53,59,60</sup> and deflates any assertion that binary stratification based on the phenotypic presence of melanin, ie, the "one drop rule" 61,62 or "blood quantum rule," has any

legitimate scientific validity as an independent biologic proxy measure.<sup>22</sup> This history regarding admixing helps explain why social terms such as race are less precise and do not always reliably match with genetics.

Race, as a social construct, does not represent shared genetic ancestry. It is, instead, a way of categorizing people on the basis of physical characteristics and geographic ancestry. The United States Census identifies 5 racial categories: White, Black, Asian, American Indian and Alaska Native, and Native Hawaiian and Pacific Islander. These racial categories, however, are not universal, because they vary between societies and have changed over time. Therefore, careful consideration of anthropologic, ecologic, economic, historic, and social science contributions is necessary if we are to unravel the complex milieu that constitutes the socially determined factors that frame health status and their attendant outcomes. An interdisciplinary approach that rigorously acknowledges the longstanding effects of intergenerationally transmitted trauma and the role that structural racism and differential lived experiences play in conferring risk and resilience is a necessary framework for future exploration aimed at the promise of equitable care delivery. 64-67

# Race-Based Guidelines Across the Medical Landscape

In addition to the aforementioned and now retired UTI clinical practice guideline, <sup>28–31</sup> there are several examples of race-based clinical algorithms or practice guidelines currently undergoing reexamination and reconsideration that deserve mention.

# Staging of Chronic Kidney Disease

The most mature efforts to reconsider race correction as part of

clinical disease management have occurred in the calculation of estimated glomerular filtration rate (eGFR) in the assessment of renal function and the staging of chronic kidney disease (CKD).<sup>68-71</sup> Race as an independent variable was originally introduced into eGFR calculation on the basis of the unsubstantiated notion that the higher average serum creatinine concentrations seen in Black people is a result of more muscle mass.<sup>72</sup> The effective risk of this race adjustment is that Black patients with advanced clinical disease may experience delays in being referred to specialty care or transplantation on the basis of race assignment and eGFR calculation alone. Recent analysis of developmental data sets that have omitted race in eGFR calculation demonstrate that more accurate disease staging with smaller differences between Black and non-Black patients is possible.<sup>73</sup> Also, Black adults with CKD will be identified younger and at relatively earlier stages of disease. 74,75 A small but growing number of health systems across the country have already officially eliminated the race modifier from eGFR calculation.<sup>76</sup>

### Lung Function Assessment

Racialization of the use of spirometry in the assessment of lung function has a long, tortuous history, as previously described. 23,36,38,39,40,77,78 The unsubstantiated assertions of deficient lung capacity in Black individuals by slave-holding medical professionals in the late 18th and early 19th centuries<sup>36,37,40</sup> persist today in the race norming that is programmed into spirometers.<sup>79,80</sup> In the United States, spirometers apply correction factors of 10% to 15% for individuals labeled Black and 4% to 6% for people labeled Asian.<sup>76,81</sup> Predictive reference equations have also been established for people from Hispanic backgrounds.82 The ubiquitous application of pulmonary function

testing (PFT) for respiratory illnesses like asthma and chronic obstructive pulmonary disease, conditions in which populations of color are clinically disproportionately represented, provide ample opportunity for thoughtful exploration to examine the validity of race and ethnic correction in use of the spirometer.

There is recognition that race does not adequately capture the interplay of individual and population-based exposures rooted in the social determinants that may influence lung health, nor does it begin to approximate ancestral contributions in the context of genetic admixture. Investigators have posited that more granular incorporation of ancestry into normative PFT equations may improve lung function estimates.83 A recent study found that explicit inclusion of measures of adverse exposure reduce the effect size of race categorization and blunt the potential for inaccuracy of pathology detection on the basis of race-specific prediction alone.84 Omitting the use of race in PFT is motivating researchers to creatively search for a better understanding of the etiologies of lung health disparities.85,86 The scientific community is now critically working to unwind the race-based evolution of lung function assessment.

# Atherosclerotic Cardiovascular Disease Risk

In 2020, the American Heart Association (AHA) issued an organizational declaration that structural racism is a fundamental driver of health disparities.<sup>87</sup> In its call to action, the AHA went on to further state that the task of dismantling racism requires advocating for policies and practices that eliminate inequities in health care with a commitment to internally examine and correct its own shortcomings.<sup>86</sup> The role of race as part of the calculation of atherosclerotic cardiovascular disease

(ASCVD) risk has been identified as a reappraisal opportunity.

Based on practice guidelines developed and published by the American College of Cardiology and the AHA in 2013, the ASCVD Risk Estimator uses pooled race and sexspecific cohorts as the methodology through which to estimate 10-year susceptibility to the development of atherosclerosis.88 The pooled cohort equation assigns race and uses an array of standard cardiovascular, behavioral, and lifestyle risk factors to estimate ASCVD risk. Critical analysis of estimator performance has revealed a 10-year increased risk differential as large as 22.8% for Black patients, the magnitude of which is described as "substantial and biologically implausible based on race alone."89,90 The accuracy of the ASCVD Risk Estimator using the pooled cohort equation approach has been challenged on the basis of the statistical overfitting required because of the small sample size of Black patients in the original developmental cohorts. Investigators posit that this overestimation factor has ultimately led to a poorly calibrated tool for Black patients. 91,92

One might argue that the ASCVD Risk Estimator may be protective in terms of potentially skewing early cardiovascular care toward Black patients. However, the inherent danger is directing differential treatment to Black versus White patients on the basis of a flawed phenotypic signal in the face of what might otherwise be identical underlying risk profiles. Incorporating race as proxy for the biological effects of differential lived experience is misplaced in this example. Moreover, the organized cardiovascular care community, having issued a clarion call to dismantle structural inequities, is well-positioned to consider removal of the race term in ASCVD risk

assessment as an important step toward achieving equity.

### Vaginal Birth After Cesarean Delivery

The vaginal birth after cesarean (VBAC) clinical algorithm was designed to predict risk associated with offering a trial of labor to someone who has undergone a previous cesarean delivery. The VBAC calculator, which has been endorsed as a predictive tool by the Eunice Kennedy Shriver National Institute of Child Health and Human Development, relies on specific factors such as age, BMI, and previous delivery history.93 Race and ethnicity modifiers for women who identify as Black or Hispanic are also included, but they "correct" the calculation in a negative direction, signaling lower likelihood of successful VBAC. The evidence behind the inclusion of race or ethnicity in the VBAC calculator is rooted in thinly veiled racialized science. Late 19<sup>th</sup>-century medical descriptions of normative pelvic variation characterize the pelvic anatomy of non-White women with such terminology as "degraded or animalized arrangement seen in the lower races."94 Even in 21st-century scientific literature, the residua of such characterization survives in the unsubstantiated hypothesis that raceand ethnicity-based variation in pelvic architecture is independently associated with lesser adequacy for successful vaginal delivery supporting a narrative of the white gynecoid pelvis as the standard. 95,96 This context influenced the inclusion of race and ethnicity as negative factors in the VBAC calculator, emphasizing the need for thorough reexamination. The National Institute of Child Health and Human Development Maternal-Fetal Medicine Units Network recently assessed the feasibility of using the VBAC calculator without race and ethnicity in the prediction model.<sup>97</sup> That study demonstrated that valid estimation is possible when race and ethnicity are eliminated and

that the probability of a successful VBAC can indeed be reliably predicted. Of note, the investigators added a variable for treatment of chronic hypertension before or during pregnancy to the revised equation, an excellent example of incorporation of an important evidence-informed measure. In recent practice advisories, the American College of Obstetricians and Gynecologists has stated that a VBAC calculator score should not be a barrier to the consideration of a trial of labor after cesarean delivery.98 The American College of Obstetricians and **Gynecologists Committee on Clinical** Practice Guidelines justifies its position by noting the higher likelihood of inaccuracy exists in the lower probability range precisely where race and ethnicity modifiers skew the original model.<sup>99</sup>

Finally, disparities in maternal morbidity and mortality are an escalating problem. In the United States, the maternal mortality rate for non-Hispanic Black women is 44 deaths per 100 000, which is 2.5 times that for non-Hispanic White women. 100 Similarly, the maternal mortality rate for American Indian women is 2.3 times than for non-Hispanic White women. 101 Surgery is a recognized contributor to maternal morbidity and mortality, and non-White women in the United States have persistently higher rates of cesarean delivery than White women. Any opportunity to objectively and safely promote vaginal birth and avoid unnecessary repeat cesarean delivery would result in more equitable obstetric care.

### **Recommendations**

The AAP has committed to laying the foundation for pediatricians to acknowledge and consider the social determinants of health in supporting every child to reach their fullest potential. The integration of health equity principles into practice is vital to address the structural and

systemic inequities that drive disparities among children of color and minoritized populations in general. Race-based approaches to the delivery of clinical care are a tangible outgrowth of these long present inequities across the health care landscape. Whether at the professional society, institutional, or individual pediatrician level, the task at hand is dependent on transparent recognition, declared opposition, and active replacement of race-based medicine. 103 However, it is simply not enough to dismantle the processes through which race-based medicine has evolved. Balanced scientific discourse argues that, even in the face of insurmountable evidence that race is not a direct proxy for genetic difference, there is certainly a role for what race represents in terms of differential lived experiences and exposures.42 104 Peeling back and rigorously sorting the social determinants of health, with integrity, is a core component of the necessary, transformative, and race-conscious discovery to which the scientific community must be accountable.  $^{25\,105}$ Now is the time to formally apply an equity lens to the development and reconsideration of all clinical decision-making tools, including clinical practice guidelines, clinical reports, policy statements, and technical reports. 106 Strategically, this is a mechanism through which organizations can tactically begin to incorporate antiracist principles into all of the work for which they are accountable and stimulate the creation of more equitable systems of care. It is through this lens that the following recommendations are framed:

## **American Academy of Pediatrics**

 The AAP will critically examine all policies and practice guidelines for the presence of race-

- based approaches in their development and deconstruct, revise, and retire, if necessary, all policies and practice guidelines that include race assignment as a part of clinical decision-making.
- The AAP will critically examine all policies and guidelines currently under development as well as consideration of all such future documents to ensure the exclusion of race assignment as part of clinical decision-making.
- The AAP will leverage the "Words Matter" document to ensure that all authors, editors, presenters, media spokespersons, and other content contributors recognize race as a social construct only and desist from any use, or its reference, as a biological proxy.

# **Professional Organizations and Medical Specialty Societies**

- All professional organizations and medical specialty societies should implement a process to identify and critically examine all organizational policies and practice guidelines that may incorporate race or ethnicity as independent variables or modifying factors within a reasonable timeframe.
- All professional organizations and medical specialty societies should advocate for the elimination of race-based medicine in any form.

#### **Institutions**

Institutions should collaborate
with learner-facing organizations
such as the Accreditation Council
on Continuing Medical Education,
the Accreditation Council on
Graduate Medical Education, the
Association of American Medical
Colleges, the Association of Medical School Pediatric Department
Chairs, the Association of Pediatric Program Directors, the

- Council on Medical Student Education in Pediatrics, the Latino Medical Student Association, and the Student National Medical Association to expose new and lifelong learners to health equity curricular content, including a specific focus on the elimination of race-based medicine.
- Institutions should collaborate
  with academic health systems,
  schools of medicine, and other
  higher education entities in support of the research and scholarship necessary to deconstruct
  race-based medicine and proactively reframe clinical decisionmaking tools using valid, evidence-informed measures that incorporate the social determinants
  of health.

#### **Pediatricians**

- Pediatricians should seek health equity continuing medical education programming and incorporate content on the elimination of raced-base medicine as a component of lifelong learning and maintenance of certification.
- Pediatricians should assess their practices and clinical environments for race-based care delivery and eliminate race-based medicine in any form from their practices.

#### **Summary**

Racism has infiltrated and impacted health care delivery and outcomes in this country for more than 400 years. The inclusion of race in algorithms and guidelines that direct clinical practice explicitly acknowledges this connection. Although it will continue to be important to collect clinical data disaggregated by race and ethnicity to help characterize the differential lived experiences of our patients, unwinding the roots of race-based medicine,

debunking the fallacy of race as a biologic proxy, and replacing this flawed science with legitimate measures of the impact of racism and social determinants on health outcomes is necessary and long overdue.

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#### **ABBREVIATIONS**

AAP: American Academy of Pediatrics

AHA: American Hospital Association

ASCVD: atherosclerotic cardiovascular disease

CKD: chronic kidney disease

eGFR: estimated glomerular filtration rate

PFT: pulmonary function testing

UTI: urinary tract infection VBAC: vaginal birth after cesarean

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