American Society of Pediatric Nephrology

October 16, 2020

The Honorable Richard Neal
Chair
Committee on Ways & Means
U.S. House of Representatives
Washington, DC 20515

Dear Chairman Neal:

On behalf of the American Society of Pediatric Nephrology (ASPN), thank you for the opportunity to respond to the Committee on Ways & Means' request for information (RFI) seeking more information on racial equity concerns in clinical algorithms and related health outcomes. As the voice for pediatric kidney disease, our members strive to ensure that infants, children, adolescents and young adults they care for receive appropriate and high-quality care.

Founded in 1969, ASPN is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. ASPN currently has over 700 members, making it the primary representative of the Pediatric Nephrology community in North America.

We are pleased to provide the following responses to the questions posed in the RFI.

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?

Race is a social construct with very little biological relevance.[1]

In many cases, the use of race and ethnicity in clinical algorithms contributes to practices that delay or reduce access to care for patients who identify as Black or African American. For example, our Black or African American patients can experience delays in in listing for kidney transplant because of the race-based correction of estimations of glomerular filtration rate, a metric that is key in determining eligibility for transplantation.[2]

---

[1] Fontanarosa PB, Bauchner H. Race, Ancestry, and Medical Research. *JAMA.* 2018;320(15):1539–1540. doi:10.1001/jama.2018.14438
[2] Eneanya ND, Yang W, Reese PP. Reconsidering the Consequences of Using Race to Estimate Kidney Function. *JAMA.* 2019;322(2):113–114. doi:10.1001/jama.2019.5774

The concept that there needs to be a correction factor in estimating kidney function for Black or African American race is rooted in a racist ideology regarding muscle mass that is simply not true for all Black or African American patients. Black or African Americans of Caribbean, Latino, and African descent have disparate genetic backgrounds, yet current algorithms would classify them similarly, and assume a common phenotype of increased muscle mass in the face of a very heterogeneous population.

Additionally, algorithms designed to optimize the match of kidneys from deceased donors to pediatric kidney transplant recipients include race, even though this inclusion actually increases barriers for Black or African American donors to provide kidneys to children who need a kidney transplant. In these current algorithms, kidneys from Black or African American are considered as coming from higher risk donors, thereby decreasing the chances that these kidneys will be used in children, where transplantation from high-risk donors is often avoided. Consequently, overall access to transplantation for children awaiting deceased donor kidneys is negatively impacted. Moreover, wait times until kidney transplantation for Black or African American kidney recipients are also longer with this algorithm, since there are fewer Black or African American donors considered appropriate.

ASPN would urge that both regulatory agencies such as the United Network for Organ Sharing (UNOS) and professional organizations such as the American Society of Transplantation (AST) work toward revising the current policies and practices that unfairly disadvantage Black or African American patients in obtaining kidney transplants.

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?

Many centers have removed race-based calculation of glomerular filtration rate when assessing if a child's kidney function has declined to the point that listing for kidney transplantation is deemed necessary and appropriate. Unfortunately, changes to broadly used electronic health record calculations of glomerular filtration rate and to the adoption of laboratory tests to assess kidney function such as cystatin C that are biologically divorced from concerns about muscle mass are costly to implement in the short term, though improved access to kidney transplantation would ultimately reduce health care costs and optimize patient outcomes.

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

Patients, community stakeholders, and physicians need to be better informed as to what clinical algorithms include race or ethnicity and the evidence that exists supporting such an approach. For instance, patients and families should be informed of the use of race in current equations estimating kidney function and the potential implications of this use of race on clinical outcomes such as access to transplantation. If a patient refuse to designate race, appropriate accommodations need to be made for this decision, and study staff should not make a subjective assignment of race. In addition, future research should focus on the development of biomarkers of kidney function or equations that accurately estimate kidney function   independent of race or ethnicity.

ASPN appreciates the opportunity to provide these comments. Please contact our Washington representative, Erika Miller, at (202) 484-1100 or emiller@dc-crd.com, if we can provide additional information or clarification.

Sincerely,

Michael JG Somers, MD
President