BRIGHAM HEALTH
BRIGHAM AND WOMEN'S
Center for Surgery and Public Health

Founded as a Joint Initiative of Brigham and Women's Hospital, Harvard Medical School and Harvard T.H. Chan School of Public Health

The Honorable Richard Neal
Chairman
House Committee on Ways and Means
1139 Longworth House Office Building
Washington, D.C. 20515

Re: Hearing Titled "The Disproportionate Impact of COVID-19 on Communities of Color"

Dear Chairman Neal,

The Center for Surgery and Public Health (CSPH) appreciates the opportunity to submit comment on the issue of the misuse of race and ethnicity in clinical algorithms, a topic raised in the hearing "The Disproportionate Impact of COVID-19 on Communities of Color."

The CSPH is a research division of the Department of Surgery at Brigham and Women's Hospital, focusing on surgical health services research. Since its founding in 2005, the CSPH has studied inequities in access, treatment, and outcomes related to surgical care delivery, including trauma, cancer, gynecological, and essential surgery. Utilizing hospital, state, and national databases; clinical trials; and provider education programs, CSPH has interrogated the role racism plays in causing inequities in healthcare and analyzed ways in which these inequities might be reversed.

Based on this experience, the following comment outlines CSPH's recommendations on how the misuse of race and ethnicity in clinical algorithms and research can be addressed:

Racism has tainted healthcare and medical research from its beginnings. It has profited off the use of Black and Brown bodies in the name of what was purported to be science and the pursuit of a "greater good" that did not include them. As noted in your invitation for submissions, the misuse of race in clinical algorithms and research remains one of the most significant contributors to the perpetuation of racial health inequities today. At the Center for Surgery and Public Health (CSPH) at Brigham and Women's Hospital in Boston, Massachusetts, we investigate how racism produces disparities in surgical outcomes in order to create targeted interventions to eliminate clinical racial inequity. In doing so, we strive to uphold rigorous standards for the use of "race" in the surgical research conducted at our institution. We submit the following comments based on our Center's experience in order to promote racial equity in the use of all clinical algorithms and research nationwide.

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?

Evidence has established that racial categories are a poor proxy of true genetic or biological difference (Mersha, 2015). Nevertheless, researchers frequently use patient-reported race/ethnicity, or rely on assumptions based on physical characteristics, to categorize patients into races to guide risk stratification and medical decision-making. These practices reflect a spurious equation of socialized racial categories with genetic ancestry and disease risk that is neither biologically accurate nor clinically meaningful. While genetic ancestry can provide useful information in certain disease processes, such as sickle cell and Tay Sachs, it poorly correlates with race/ethnicity categories. Furthermore, self-reported or clinician-assigned race perpetuates a myopic view of health disparities by masking the underlying social and structural forces that drive inequitable health outcomes between racialized groups. Equating race with biology reinforces historic and contemporary racist beliefs and institutions that systematically predispose marginalized racial/ethnic populations to poor health outcomes. Health-related researchers and organizations have an ethical and professional obligation to correct these injustices by addressing the false equivalency of race with biology in clinical algorithms and research.

Patients and their communities also have a critical role in addressing the misuse of race in clinical medicine and biomedical research. Incorporating their voices to reflect the full spectrum of diversity –not merely according to race/ethnicity –will be essential in these efforts. Engaging patient and community stakeholders in all stages of research and clinical algorithm development, from hypothesis generation to intervention implementation, will ensure that research endeavors reflect the health needs, priorities, and values of the communities they purport to serve. Such collaboration will produce more accurate clinical algorithms by providing a nuanced understanding of the social and structural factors that shape patients' risk and lived experience with disease.

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?

To address the misuse of race/ethnicity in research, we recommend strategies focused on interrogating the effect of racism (not solely race) on surgical outcomes, attempting to parse the complex interaction of sociodemographic variables that mediate this effect and centering the patient experience in research agendas. We provide examples of government funded projects that work towards doing so by:

Developing better metrics to capture the gap in access to surgical care for different underrepresented minority groups. Through the NIH-funded Metrics for Equitable Access and care in SURgery (MEASUR; NIH MD011695), a collaborative effort with the American College of Surgeons, members of CSPH developed a conceptual model and set of metrics that capture the multiple interrelated strata of disparities in surgical access that are unique to different medical specialties in order to foster the development of targeted interventions to address them (de Jager et al., 2019).

Optimizing patient-centered approaches to disparities research. By using clinical trials, such as the EQUALITY study (Haider et al., 2018; PCORI NCT02701049), to determine the best methods for collecting patient-reported identity data, CSPH has enhanced the ability to accurately capture personal descriptors and behaviors of members of underrepresented sexual gender minority groups. Obtaining high quality identity data is a critical step toward fully appreciating the diversity of these groups and their heterogeneous healthcare experiences, something often missed by using non-specific race, ethnicity, sexual orientation or gender categorization alone.

Training the next generation of medical researchers to think in culturally dexterous ways. Through the NIH-funded Provider Awareness and Cultural dexterity Toolkit for Surgeons (PACTS; NIH MD011685) trial, a curriculum to improve surgical residents' cultural dexterity during clinical encounters, CSPH is actively seeking to improve the ability of young surgeon scientists to appreciate and address the unique needs of cross-cultural encounters. A similar curriculum could be designed for all scientists and incorporated into the ethical training that researchers must undergo to qualify for NIH grants and financial support.

There are several primary challenges for advancing research that explicitly investigates racism as a mediator of racial disparity and aims to uncover the mechanisms of racial inequities. The first is that race is an easy to use, widely available variable that is documented in most administrative datasets. It is difficult to hold researchers to a more rigorous standard of studying the effect of racism when the crude proxy of race remains readily at their fingertips. A second and related barrier is that, because researchers have traditionally felt comfortable relying on race in their research, there has been a paucity of pressure to collect more granular and accurate metrics within large datasets. Thus, race often remains the only option when choosing predictors for disparities research. Finally, the dearth of funding for research about the effects of racism on health outcomes, resulting from the politicization of race in the US, dissuades researchers from pursuing the research that is most sorely needed.

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?

Based on current evidence and CSPH's unique expertise in race/ethnicity clinical research, we recommend the following strategies to build consensus and generate widely used guidelines for the research community:

- Acknowledge that socialized race and genetic ancestry reflect different dimensions of disease risk and clinical outcomes
- Create funding mechanisms that **reward research that directly addresses the complexities** of race/ethnicity:
  - Prioritize the **funding of research investigating racism**, rather than race, as a contributing mechanism for disparities
  - Require that researchers who wish to study race/ethnicity provide adequate justification for doing so in their applications for funding (e.g. by linking socialized race to social/structural disparity, rather than biological difference)
  - Promote racial/ethnic diversity within grant review committees at local and national levels
- Implement **Surgical Patient Advisory Councils**. In addition to working with an Institutional Review Board, incorporate more patient advisors to assess the merit of surgical research.
- Improve quality of data capturing race/ethnicity by:
  - Increasing collection of **reliable, self-reported racial/ethnic identity data**
  - **Aggregating data from all insurers** to allow for more accurate indirect estimation of race/ethnicity in the place of missing data (Weissman & Hasnain-Wynia, 2011)
  - **Correcting the misuse of race/ethnicity** as a marker for socioeconomic status, such as: social vulnerability, neighborhood disadvantage, residential segregation, income inequality, healthy literacy, proximity to health care, rates of incarceration, employment, and education
- Similarly, improve data analysis techniques to factor in these complex variables such as latent variable modeling
- Focus on developing and evaluating interventions targeted at eliminating surgical inequities
- Encourage **Community Based Participatory Research**:
  - Engage specifically with communities of color to better reflect patient priorities within research by collecting feedback on current and future research priorities and learning effective dissemination techniques to impacted communities
  - Expand research collaborations with community-based partnerships through funding allocations

Conclusion

Listed above are apt, actionable, and meaningful strategies to end the misuse of race and ethnicity in clinical algorithms and research. While CSPH has already started to implement many of these practices, standardization throughout the research community will promote the use of accurate measures of racial/ethnic identity, enhance the utility and predictive value of clinical algorithms, and identify more effective levers to reduce racial/ethnic disparities. Though there are various barriers to challenging the status quo in clinical research with respect to both methods and funding mechanisms, these strategies are crucial starting points to improve medical/surgical research and thereby our society as a whole.