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Committee on Ways and Means
U.S. House of Representatives
Washington, DC 20515

Re: Ways and Means Committee Request for Information on the Misuse of Race Within Clinical Care

Dear Chairman Neal,

Thank you for requesting information from health stakeholders as you work to address the misuse of race within clinical care across the health industry. From my perspective as a health equity researcher, clinician, and public health policy leader, race should play no role in clinical decision making, including but not limited to algorithmic processes. Informed by my expertise in precision medicine, the following summarizes issues of race and racism in precision medicine algorithms, and presents recommendations to address these issues, including conducting universal assessments for genetic variants; improving collection of race, ethnicity, and language data; expanding mechanisms for patient to report experiences of discrimination in care; and using precision medicine techniques to counter bias in care.

I. Misuse of race in precision medicine algorithms

While often understood solely as the application of genomic data to medicine, precision medicine approaches to patient care increasingly integrate and analyze multiple sources of data in order to make clinical decisions. The National Institutes of Health (NIH) accordingly defines precision medicine as "an emerging approach for disease treatment and prevention that takes into account individual variability in genes, environment, and lifestyle for each person."[1] As a data project, precision medicine thus follows the science that health outcomes are determined by complex biological and social factors. Yet rather than address racism as a determinant of health outcomes, the current integration of race and ethnicity within precision medicine limits access to precision technologies, reifies the concept of race as biology, and misuses flawed race data.

The use of race in precision medicine serves to restrict access to pharmacogenetic knowledge and reify race as biology. Precision medicine approaches to patient care often consider genomic information in order to make treatment decisions, requiring patient testing for genetic variants that are of clinical relevance. Access to this genetic variant testing is often based on race, operationalizing the logic that genetic variance is racial. Race as a proxy for genetic variance thus not only has the consequence of racializing access to precision technologies, but furthermore reifies the white supremacist construction of race as having a biological basis.

The racial data that informs decisions around access to precision technologies is biased. Health systems do not consistently and uniformly collect self-identified race and ethnicity data, resulting in discrepancies between self-identified and recorded race wherein people of color are disproportionately misclassified.[2] In the absence of uniform self-identification processes, electronic health record data—which is then fed into precision medicine algorithms—contains a mix of self-identified, observed, and

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[1] https://medlineplus.gov/genetics/understanding/precisionmedicine/definition/

[2] Kressin NR, Chang B-H, Hendricks A, Kazis LE. Agreement between administrative data and patients' self-reports of race/ethnicity. *American Journal of Public /.;Health.* 2003;93(10):1734-1739.

missing race. As a result, precision medicine algorithms, and thus access to tailored pharmacogenetic interventions, are often not based on accurate racial identity information, but rather on provider-observed race, i.e. physical appearance.

II. Strategies to end misuse of race in precision medicine

In order to end the misuse of race and ethnicity in precision medicine, it is not enough to simply remove race and ethnicity from clinical algorithms. Instead, the following strategies are intended to improve clinical care and decision-making processes as it pertains to race and ethnicity.

Conduct universal assessments for genetic variants: Whereas access to pharmacogenetic technologies is currently restricted by the physical appearance of patients, assessments for genetic variants that are of clinical relevance must be universally conducted. No assumptions about genetic makeup should be made on the basis of physical appearance. Furthermore, Black, indigenous, and other people of color are often unable to voice their own ancestry, as slavery, forced migration, and violence have severed the transmission of familial knowledge and histories. Thus, genetic testing is often the only way to illuminate the ancestry of diverse populations in order to accurately inform pharmacogenetic care.

Improve collection of race, ethnicity, and language data: While race and ethnicity should never factor into clinical care decisions, it is critical that accurate self-identified race, ethnicity, and language (REaL) data is collected across health systems. The collection of high quality REaL data will improve the ability of health researchers to measure the impact of racism on clinical care. In order to improve the collection of this data, large scale quality assessments of data collection processes are necessary.

Expand mechanisms for patients to report experiences of discrimination in care: In order to further advance our knowledge of the impact of racism on clinical care, expanding mechanisms for patients to report their experiences of discrimination is necessary. As Principal Investigator on the Patient-Reported Experiences of Discrimination in Care Tool (PreDict) project, funded by the National Institutes of Health/National Cancer Institute, I have led a team to develop, test, and implement a standardized measurement approach for patient-reported healthcare discrimination.

Use precision medicine techniques to counter bias in care: Though precision medicine currently utilizes the framework of race as biology, its goal of integrating multiple sources of data to tailor clinical interventions has the potential to detect and counter biases in care. The improvement of race and ethnicity data collection, as well as the expansion of mechanisms for patients to report experiences of discrimination, can provide input enabling algorithms to detect and predict biases in care. Rather than using race as a factor in clinical decision making, racism should be analyzed in order to create algorithms that predict when patients are at risk of differential care, and then provide clinical prompts and reminders of standard care protocols to ensure equitable high-quality care.

Thank you again for your leadership regarding the misuse of race in clinical care and research, as well as for the opportunity to provide input and recommendations. I look forward to working with you to advance racial equity in health care.

Sincerely,

Marcella Nunez-Smith, MD, MHS