CPEHN
California Pan-Ethnic Health Network

October 16, 2020

Congressman Richard Neal
Chair, House Ways and Means Committee
2309 Rayburn House Office Building
Washington, D.C. 20515
Via email: Rural_Urban@mail.house.gov

Re: Request for Information on Racial Bias in Clinical Algorithms

Dear Representative Neal:

On behalf of the California Pan-Ethnic Health Network (CPEHN), we thank you for the opportunity to provide comments on racial bias in clinical algorithms. CPEHN is a statewide, multicultural health advocacy organization dedicated to the elimination of health disparities for communities of color. Our organization has a long history of successfully advocating for equity in health care systems. We authored early reports on the efficacy of consumer assessments and surveys, advocated for Limited English Proficient (LEP) patients during managed care creation, passed successful language access policies in health care settings, demonstrated connections between social/environmental factors and health status and partnered with public programs to link disparities data and quality measures. We also served most recently on California's Department of Health Care Services' (DHCS) Medicaid 1115 waiver workgroup on California's proposed new Population Health Management strategy in Medicaid.

As requested, CPEHN provides detailed responses below to the House Ways and Means Committee's request for information on the following three questions:

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?**

   Currently, most insurance companies and health systems have instituted care management programs that provide extra resources to high-need patients at risk of poor outcomes. Adoption of care management programs has accelerated as the Centers for Medicare & Medicaid Services (CMS) and state health agencies are increasingly encouraging health and health related organizations to address the Triple Aim and move towards value-based care that reduces costs, improves quality and addresses population health. California for example, recently proposed as part of its 1115 waiver application to CMS to require Medi-Cal Managed Care plans to submit local

Population Health Management plans that include a cohesive plan of action for addressing member needs across the continuum of care based on data driven risk stratification, predictive analytics, and standardized assessment processes.[i]

While we understand the attraction and potential benefits of adopting risk stratification as part of a broader Population Health Management (PHM) strategy, we are troubled by reports of racial bias in many of these types of algorithms.[ii] Obermeyer et al. for example, recently found evidence of bias in their review of an industry-wide approach to predicting risk used by hospitals, health systems, insurance companies, and government agencies to predict which patients will benefit most from care management programs, and target them accordingly. The problem, they discovered, is "not from the particulars of the algorithm, but from the outcome the algorithm was asked to predict." Whereas most health systems choose "cost" as the proxy for "health," evidence shows that Black patients consistently generate fewer costs than White patients at the same level of health. The reasons are widespread and varying from unequal access to health care and treatment to a well-founded mistrust of health care institutions as a result of historic and systemic racism including a shameful history of discrimination, experimentation, and exploitation of Black and Indigenous bodies that impacts the quality of care that people of color receive today. This mistreatment also extends to persons with disabilities and LGBTQ+ communities. For example, many individuals with disabilities were forced to undergo sterilization and to enter institutions and asylums; psychiatry classified homosexuality as a mental disorder until 1973 and continues to pathologize transgender identities today.

You also ask what role patients and communities should play. Unfortunately, while the review of Obermeyer et al. was extremely informative, because most clinical algorithms are proprietary, the underlying formulas and identified outcomes are not transparent and therefore subject to objective or academic review. Patients and communities are willing and interested in engaging with health systems on population health management strategies and interventions. But they must have access to the data and underlying assumptions that underpin decisions regarding resource allocation in order to truly assist health and health related organizations in meeting their Triple Aim objectives.

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?**

   N/A

3. **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?**

   - ***Future algorithms should be based on health conditions, risk factors, and disease progressions*** rather than just utilization and cost which is not an accurate measure of health risk for communities of color and vulnerable communities who are less likely to utilize care per the findings of Obermeyer et al.

- ***CMS should provide a standardized, validated risk stratification/management tool*** as a floor for plans, health and health related organizations to use to assess and manage risk, then let organizations add to it. Risk should not change when people move from plan to plan or system to system.
- ***Entities should be required to publish their models:*** Because a lot of these models have racial, age and disability-related bias built in, each plan and/or organization should be required to publish their model so it's fully transparent and researchers can understand the models, critique them and suggest improvements.
- ***CMS should require and incentivize the use of broad risk assessment tools*** such as PRAPARE and trauma screenings to ensure plans and providers adequately capture the needs of the beneficiaries including children.
- ***CMS should require the collection and reporting of granular population data stratified by race, ethnicity, language, functional disabilities, sex, sexual orientation and gender identity*** and require the development of plans to address identified disparities. A critical underpinning of appropriate risk stratification is standardized collection and reporting of self-reported race and ethnicity and other demographic data. The absence of a national requirement has resulted in wide variation among health and health related organizations for the collection and reporting of this data. Self-reported data is the gold standard[iii] and yet most plans and providers are still not collecting this data and are relying clumsily on the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey which only requires a 411 sample size, not nearly a large enough sample to determine actual patterns in health conditions, risk factors, and disease progressions which are necessary to managing population health.

Thank you again for this opportunity to provide our comments on the House Ways and Means Committee's Request for Information on Racial Bias in Clinical Algorithms.

Sincerely,

Caroline B Sand

Caroline Sanders, MPP
Senior Policy Director
California Pan-Ethnic Health Network

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[i] "DHCS Cal-AIM Proposal," October 29, 2019.
https://www.dhcs.ca.gov/provgovpart/Documents/CalAIM/CalAIM_Proposal_102819.pdf

[ii] "Algorithmic Bias In Health Care: A Path Forward, " Health Affairs Blog, November 1, 2019.DOI: 10.1377/hblog20191031.373615

[iii] Institute of Medicine (US) Committee on Future Directions for the National Healthcare Quality and Disparities Reports; Ulmer C, Bruno M, Burke S, editors. Future Directions for the National Healthcare Quality and Disparities Reports. Washington (DC): National Academies Press (US); 2010. Appendix G, IOM Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement: Recommendations. Available from: https://www.ncbi.nlm.nih.gov/books/NBK220146/