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Title of proposal: Poor Quality Race/Ethnicity Data Is Systemic Racism

Objective/Focus

Asian Americans play critical roles in supporting the U.S. economy.¹ Poor quality race/ethnicity data disproportionately affects Asian Americans and other non-Black minority groups.^{2,3} The Asian American experience more specifically may be characterized by the following sequence of events:

- Data on Asian Americans is often missing, miscategorized, over-representative of higher income Asian Americans, or presented in aggregate across diverse American groups (e.g., “Asian” vs. “Chinese,” “Filipino/x/a,” “Asian Indian”).^{4,5}
- When these data are analyzed to compare racial/ethnic group disparities, Asian Americans are either completely absent from the conversation or misrepresented in their experience. Oftentimes, they appear to be doing better than other racial/ethnic groups.
- This allows local, state, and federal government to exclude Asian Americans from social service provision and other support. This exclusion is further exacerbated by services that are neither linguistically accessible nor culturally competent, as well as by a fear of being classified as a public charge on the part of eligible individuals.⁶⁻⁹
- Lastly, racialized stereotypes about Asian Americans provide a convenient explanation for these disinvestment patterns in health research – and broadly, society – and fuel inertia in engaging in the difficult work of altering data infrastructure and systems.¹⁰⁻¹⁴

The objectives of our proposal are to:

- Present a brief overview of the limitations inherent in the current collection of race/ethnicity data in administrative health databases in the United States (U.S.) and why it matters
- Offer practical recommendations and guidance on necessary infrastructure and funding for successful implementation of improved data capture of race/ethnicity

While we draw from our experience as health disparities researchers focused on the Asian American community to prepare this proposal, we strongly affirm that the capture of high-quality race/ethnicity data is a challenge for all racial/ethnic groups in alignment with national policy efforts.^{15,16} For example, the Latino/x/a category combines the experience of Mexicans, Puerto Ricans, and South Americans; the Black category combines African, Afro-Caribbean, and African Americans; the White category combines Western Europeans, Eastern Europeans, and Middle Eastern North Africans. Therefore, to

the extent possible, we present solutions that have a broad focus beyond just the Asian American experience.

Development

Our proposal builds on decades of advocacy by countless community groups and scholars for the collection and reporting of data for Asian Americans. The problem is twofold: 1) there is a lack of data collected and reported on Asian Americans; and 2) data are not consistently reported for specific Asian subgroups (e.g., Chinese, Asian Indian, Filipino/x/a) or “disaggregated” by subgroup.

The extensive list of active stakeholders in this dialogue includes our team at the NYU Center for the Study of Asian American Health (NYU CSAAH) – established in 2003, as well as our close collaborators the Asian Pacific Islander American Health Forum (APIAHF) and the Coalition for Asian American Children and Families (CACF). It also includes Dr. Ninez Ponce and her team at the UCLA Center for Health Policy Research, who have led groundbreaking work in this area.^{17,18}

The efforts to improve data quality for Asian Americans were accelerated during the COVID-19 pandemic as it became increasingly apparent that health data were lacking for Asian Americans and Asian American subgroups.¹⁹⁻²⁴ As a result, local and national efforts focused on the COVID-19 pandemic did not consistently include Asian Americans,²⁵ nor was linguistic translation of COVID-19 information prioritized.²⁶ For example, in September 2020, the National Academies of Science Engineering and Medicine (NASEM) announced their framework for equitable allocation of vaccines, and it did not include Asian Americans in its priority list of racial/ethnic minority groups.²⁷ This happened despite an NYU CSAAH and APIAHF submission of a 10-page letter, co-signed by 80 partners, describing the disparities being observed nationally in Asian Americans during the NASEM public comment period.

In recognition of deficits in the collection, analysis, and reporting of representative data for Asian Americans, in June 2020, NYU CSAAH joined the Centers for Disease Control and Prevention (CDC)-funded Forging Asian and Pacific Islander Community Partnerships for Rapid Response to COVID-19 Project (Forging Partnerships). This national partnership is led by APIAHF and eight coalitions. CSAAH’s role in the partnership was to build and define a comprehensive data approach to identify Asian American populations at high risk during the COVID-19 pandemic.

For this specific proposal, we draw upon the Forging Partnerships work and our deep experience in three major areas:

- 1) Conducting primary data collection and analysis of race/ethnicity data on thousands of individuals in partnership with community-based organizations
- 2) Analysis and reporting of race/ethnicity in numerous local, state and federal health datasets and systems
- 3) Leading the implementation of improved race/ethnicity data collection at our large academic health system and for New York State (NYS).

Current Race/Ethnicity Data Driving Policy Is of Poor Quality

Issue #1: Race/ethnicity data is missing.

According to the most recent Census data, the U.S. population is growing increasingly diverse. The biggest growth in population was observed in the multiracial category and for Asian Americans.²⁸ Asian Americans are projected to be the largest racial/ethnic immigrant group in the U.S. by 2055.²⁹ Despite this, Asian American communities and other racial/ethnic minorities have been historically excluded and remain underrepresented in clinical research and national data.^{4,5,10,11,17,30-32} Furthermore, in national, state and local data systems, non-Black minority groups such as American Indians, Alaska Natives, Asian Americans, Pacific Islanders, and Latino/x/a are more likely to be misclassified or classified as “Other,” “Unknown,” or “Missing.”^{2,3} The lack of investment to improve the data quality for these groups is systemic racism.

Race/ethnicity for COVID-19 data in the U.S. is currently missing for 37% of cases and 27% of deaths,³³ demonstrating that our present data systems can’t reliably track the overall impact of the COVID-19 pandemic for different racial/ethnic groups. **Yet, these flawed data are being used to drive funding decisions, policymaking, and resource allocation.**

Issue #2: Current race/ethnicity categories conceal meaningful differences.

The current standard for collection of race/ethnicity is determined by the Office of Management and Budget (OMB), which defines the minimum categories for race as American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White. The minimum categories for ethnicity are: Hispanic/Latino and Not Hispanic/Latino.³⁴ But from a health equity perspective, the lack of data on specific subgroups within these current race/ethnicity categories is another concern. Of 125 CDC-supported surveillance and health monitoring systems, only 21% collected data on racial/ethnic subcategories.³⁵ Subgroups within larger racial/ethnic categories have different histories, cultures, and demographic patterns that can greatly affect health outcomes and access to care. Research has shown that African Americans and Caribbean Black Americans have very different rates of heart disease and obesity.^{5,6} Smoking prevalence varies significantly among Hispanic subgroups.⁴ Native Hawaiians and Pacific Islanders represent a diverse group, speaking more than 1,000 different languages and making up more than 50 ethnic groups – yet they are often grouped indiscriminately with Asian Americans. Arab Americans are continuously classified as White and not recognized as a federal minority group, severely limiting research on health needs in Arab American communities.⁷

Commonly cited barriers to disaggregation include lack of stakeholder interest (i.e., limited prioritization of added granular information on racial/ethnic subgroups and use of subgroup data to guide planning/process), financial concerns, and space and time constraints.¹⁷ When subgroup analysis does occur, sample sizes are often too small for rigorous data analysis.¹⁷ As noted above, systemic racism plays a foundational role in the lack of data being collected and reported for specific subgroup communities.

Why Does It Matter?

Accurate data on race/ethnicity related to health outcomes and healthcare are essential for identifying and addressing the pervasive disparities between racial/ethnic groups in the U.S. Data are also a critical starting point in the pipeline of research, healthcare, and resource allocation. A failure to address basic infrastructure in our health systems – like poor quality race/ethnicity data – severely

limits the representativeness of the entire pipeline of research and healthcare quality and practice. For example, Asian Americans may require lower dosages of specific medications³⁶ and alternative risk thresholds for assessing chronic disease risk (e.g., higher disease risk at smaller body sizes)^{37,38} that differ by Asian subgroup.^{39,40} Yet, without high quality data on these communities, guidelines and practices cannot be universally altered and/or adopted. In some cases, the lack of data on Asian Americans leaves researchers and practitioners to glean lessons from Asians living in Asia – communities with entirely different living environments, sociocultural norms, and health behaviors. Or they apply Asian guidelines to Asian Americans to attempt to understand best practices and achieve optimal health outcomes in this community.^{41,42} This piecemeal strategy for Asian Americans and other communities that are under-represented in data is wholly inadequate, and ultimately impacts health, well-being, healthcare spending, and the nation’s productivity.

Implementation of Improved Race/Ethnicity Data Collection: Lessons Learned From a Work in Progress

Our proposal aims to not only underscore **why** it is important to collect improved data on racial/ethnic minority groups through policy and the other previously outlined partnerships,^{15,17,43,44} but to illustrate **how** to operationalize such an undertaking. The adoption, requirement, and enforcement of a standard for collecting and reporting data for specific racial/ethnic subgroups is critical across all health agencies at the state and federal levels, with added benefits if such actions are taken across all state and/or federal agencies. Such policy change would provide the opportunity to uncover and address the root causes of health disparities with more granular data for housing, income, and education, in addition to health data. We know there are data privacy and ethical concerns when reporting disaggregated data for small populations,^{45,46} so another policy consideration might be requiring reports to include an explanation for why disaggregated data cannot be reported.

We offer three recommendations.

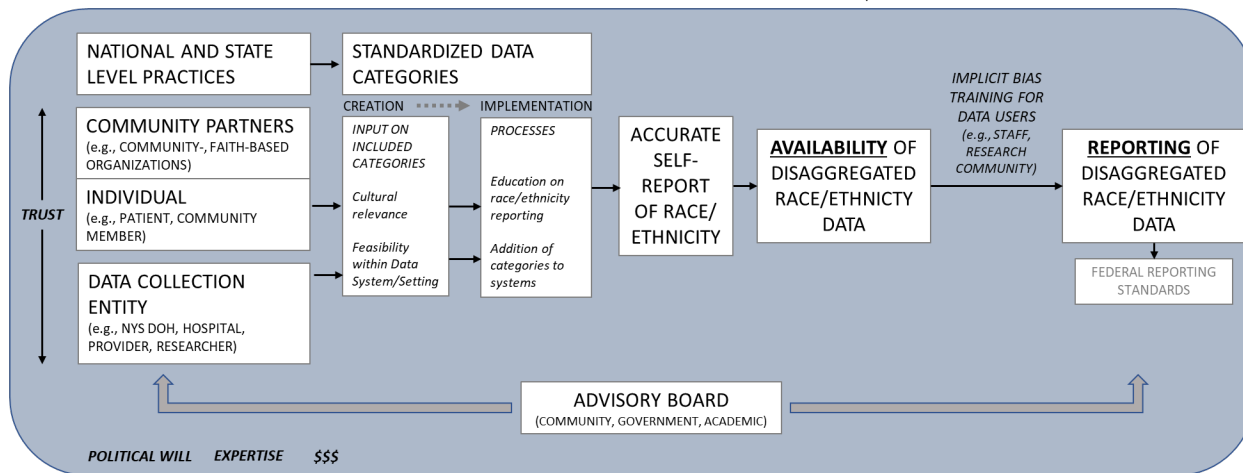
Recommendation #1: Recognize That Updating Race/Ethnicity Data Collection Is a Complex Undertaking

The process to improve the collection of disaggregated race/ethnicity data is complex, resource and time-intensive, and requires engagement at multiple levels – as would be the case for any systemic change. It is not as simple as adding response categories or fields within electronic data capture systems.

We have assembled a visual schematic to help describe the components of improving the collection of disaggregated race/ethnicity data (Figure 1). In brief, national and state-level practices may be used to guide the development of standardized data categories, which might be refined and implemented with input from community partners, community members, data managers, and healthcare/clinic staff. Engagement across these groups and with community groups would engender trust, a critical component to participation in this undertaking. An advisory board made up of multi-sector actors, political will, technical expertise, and sufficient funding is foundational to these activities. Education at these multiple levels on why these data are important to collect in the first place is also critical to this pipeline. This collective effort would ideally lead to accurate self-reporting of race/ethnicity and the availability of disaggregated data by racial/ethnic subgroups. However, the availability of this data is

not enough. Because of the implicit and explicit biases that exist about which racial/ethnic groups should be included in final analyses and reported on, education/training is also required at this step. The ideal outcome, then, is responsible and inclusive data reporting on racial/ethnic minorities that appropriately characterizes data limitations and exclusions.

FIGURE 1. PRELIMINARY SCHEMATIC OF SYSTEM TO COLLECT AND REPORT DISAGGREGATED RACE/ETHNICITY DATA IN NEW YORK STATE



Recommendation #2: Partnerships and Collaborations Across Multiple Sectors and Stakeholders Is Critical

Partnerships with community-based organizations and other stakeholders will be central to the success of this process. As an example from our current efforts, our advisory board is composed of multiple Asian American-serving community-based organizations and institutional partners and a scientific advisory board, including academics, public health practitioners, and subject matter experts from the NYS Department of Health. The project activities will focus on the largest subgroups in NYS within each racial/ethnic category, as determined by analysis of the American Community Survey data. Because we will be improving on the data collection and reporting for all racial/ethnic subgroups, we will ensure there is appropriate engagement with community and scientific representation with expertise and knowledge of the specific communities to inform the improvement of data systems.

The most often cited challenge we have encountered in working with government and health systems partners is that any granular data must be rolled-up to OMB categories. This sounds straightforward but is anything but. For instance, in the case of MENA populations, once the granular data has been collected, where do these individuals get grouped, in White or in Other? What happens when Other is not allowed? Other complex challenges arise when a small change, such as allowing people to select multiple race categories (e.g., Asian-White), introduces new levels of complexity in data cleaning and analysis. Other challenges include striking a balance between including enough categories for people to feel “seen,” but not so many as to overwhelm and make the system unusable, and discussion with community partners on and usage of demographic data to classify communities for which OMB offers no clear guidance (e.g., South African). Best practices on these types of factors are needed so any progress we make in “improving” race/ethnicity data collection processes is not undone, and we find ourselves back where we started.

Recommendation #3: Efforts to Improve Race/Ethnicity Data Should be Prospective and Retrospective

We cannot waste the data that we already have as we move forward for more inclusive practice and improved data systems. It is not simply a matter of focusing on how data will be collected in the future. We also must be mindful of what efforts can be made to retrospectively improve data quality on existing administrative datasets by reclassifying misclassified individuals.

To this end, we are conducting a systematic review of methods that have been used to improve retrospective race/ethnicity classification in secondary datasets for all race/ethnicity groups. Results from this review are forthcoming, but thus far, methods described in the literature include, but are not limited to, algorithms utilizing name and geocode data, Bayesian statistics, and probabilistic data linkage methods. At the policy level, advisory groups at the local, state, and/or federal level should be formed to identify and prioritize which specific datasets would be most valuable or useful to reclassify to better utilize the race and ethnicity data that has already been collected.

Closing Thoughts

We must capitalize on this period where there is political will for inclusion and data equity. Updating categories and our systems to better capture of race/ethnicity is critical, particularly considering the rapidly diversifying population and racial equity and justice challenges that the COVID-19 pandemic has magnified. Best practices and expertise are readily available from the recent Census experience, and at the state levels in, for example, California, Michigan, Oregon, and from our experience in New York. These efforts should be multi-sectoral and led by coalitions of communities, community-based organizations, healthcare systems, government, and academia. The time is now to update our data infrastructure at the state and federal levels in the U.S. for improved public health and for the health of our country's citizens.

Acknowledgements

The authors would like to thank Lan Doan; Rachel Suss; Iyanrick John; the APIAHF team including Juliet Choi, Mary Smith, Vincent Eng, Gabriel Cenizal and Lily Shen; the CACF team including Vanessa Leung, Anita Gundanna and Hallie Yee; Matthew Chin; Rienna Russo; the NYU Langone Physicians Quality Leadership Committee including Ilseung Cho and Elizabeth Haines; and Chau Trinh-Shevrin for their leadership, support, and partnership in developing the work that served as a backdrop for this proposal. This publication was supported by grant numbers U54MD000538 from the National Institutes of Health (NIH) National Institute on Minority Health and Health Disparities, and NU38OT2020001477 and 1NH23IP922639-01-00 from the Centers for Disease Control and Prevention (CDC) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$5,117,633 with 5% of the effort for this proposal funded by CDC/HHS. The contents are those of the author(s) and do not represent the official views of or an endorsement by the NIH, CDC/HHS, or the U.S. government.

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