



Commentary

With No Data, There's No Equity: Addressing the Lack of Data on COVID-19 for Asian American Communities

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Health data on Asian Americans were deficient pre-pandemic [1,2], with 0.17% of clinical research funded by National Institutes of Health focused on Asian American, Native Hawaiian and Pacific Islander participants between 1992 and 2018 [1], and this deficiency has been magnified during the COVID-19 pandemic [3]. Sparse COVID-19 data for Asian Americans and for specific Asian ethnic groups [4,5] has maintained the misconception that Asian Americans are a low share of the COVID-19 deaths and cases. In reality, Asian Americans have higher COVID-19 case fatality rates (CFR) than other racial/ethnic groups [6] and had the second highest increase (+37%) of excess mortality in 2020 [7].

In recognition of deficits in the collection, analysis, and reporting of representative data for Asian Americans, in June 2020, the NYU Center for the Study of Asian American Health (CSAAH) joined the Centers for Disease Control and Prevention-funded Forging Asian and Pacific Islander Community Partnerships for Rapid Response to COVID-19 Project, a national partnership led by the Asian & Pacific Islander American Health Forum and eight coalitions. CSAAH's role in the partnership was to leverage new/existing data to identify high-risk COVID-19 Asian American populations. Drawing upon this work, we offer the following recommendations from our experience which may be applicable to other communities and settings.

1) **Invest in improved, standardized data collection and reporting practices by race/ethnicity.** COVID-19 has exposed our flawed data systems. At the federal level, 36% of COVID-19 deaths and

17% of COVID-19 cases are missing race/ethnicity [8] and poor quality racial/ethnic classifications is differential by race/ethnicity – with Asian Americans, Hispanics and American Indian/Alaska Natives more likely to be misclassified in administrative data [9]. Moreover, datasets routinely and indiscriminately aggregate individuals into arbitrary 'race/ethnicity' categories (e.g., no distinctions between Chinese, Filipino), limiting the ability to describe and/or intervene on specific concerns for different groups. In addition to focusing on prospective data collection, it is important to improve the quality of race/ethnicity data in existing administrative data retrospectively through the use of race/ethnicity classification algorithms. Datasets including longitudinal health outcomes could be made available efficiently in electronic health record data for example, with such strategies.

- 2) **Place equal weight on community stories and published qualitative/quantitative literature.** To create educational materials, programs and policies that meaningfully reflect community experiences, community voices need to be heard [10]. 'Community engagement' is a phrase often used, but how does it actually get operationalized? What emerged from our experience was that there was a demand for data driven approaches and community partnerships, yet the definition of data was narrowly defined as published literature or quantitative survey data – which essentially deprioritized the community narratives by design. We recommend that a redefinition of 'data' occurs, where information gathered from community listening sessions be considered equivalent – or in some cases more valuable than quantitative data.
- 3) **Address systems-level implicit and explicit Asian American bias.** Our experience also revealed that even when data are available that demonstrate disparities in Asian Americans, the data are interpreted through a lens of 'Asian American' exceptionalism. For example, even if a health outcome appears graded by race/ethnicity, as being lowest in Whites, higher in Asian Americans, and highest in Latinx and Black communities, the Asian American data are interpreted as similar to Whites as opposed to on a spectrum of risk and/or similar to the other communities of color. Asian Americans are perpetually cast as a population that does not experience health disparities in the same way that other communities of color do. Education and training are needed to mitigate

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the deeply embedded bias related to the 'model minority' in U.S. policy, education, and public health. One's biases play a large role in how data are interpreted or reported.

Data with poor quality race/ethnicity classifications are being used to drive funding decisions, policymaking, and resource allocation. A failure to address basic issues like accurate collection of race/ethnicity will further limit the utility of healthcare innovations – such as artificial intelligence or machine learning, that are developed and validated in non-diverse populations, and that are devoid of community narratives. Forging Partnerships has strengthened partnerships and infrastructure, particularly around data collection and reporting, provided education on best practices in being inclusive of Asian Americans in data collection and reporting leveraging the experiences and knowledge of our multisector partners – small steps towards more equitable health practices during the pandemic and beyond.

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Declaration of Competing Interest

The authors have nothing to declare.

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