



Invited Commentary | Equity, Diversity, and Inclusion

Zooming in to Advance Health Equity for Heart Failure— Disaggregating Race, Ethnicity, and Social Data

Alejandro Plana, MD, MS; Bryan A. Smith, MD; Marshall H. Chin, MD, MPH

One of us (A.P.) was born in the US with a Cuban-born father and a Mexican American mother and was acutely aware of the different social and economic success achieved by Latinx subpopulations. The Cuban migration in the 1950s and 1960s was predominantly a middle-class exodus and is likely why economic and health trajectories of older Cubans in the US have been more favorable than the courses of Latinx ethnic subpopulations with poorer and less educated immigrants. Caring for patients with heart failure on Chicago's south side, we also recognize the increased challenges of Black patients from the Englewood neighborhood (median income 2018-2022, \$27 317) compared with Black patients from Chatham (median income 2018-2022, \$39 952).¹ Historically, our systems for analyzing ethnic and racial categories in the US have not recognized the heterogeneity of Latinx and Black populations. Similarly, the article by Cheng et al² demonstrates how an aggregate Asian ethnicity category makes important inequities in heart failure across ethnicities invisible. Specifically, Cheng et al found that Southeast Asian individuals have higher incidence and prevalence of heart failure compared with East Asian individuals.²

Heart failure is a model chronic condition for improving health inequities with state of the art, multidisciplinary team-based care. As clinicians, we need to tailor our care to the medical and social needs of individual patients. Overall, cardiologists do a good job determining how patients' guideline-based care should be based upon their heart failure class and medical features. However, the health care system does a worse job addressing the social needs of patients and implementing care plans that successfully provide evidence-based care. How can we, as individuals and health care systems, address the social barriers to care experienced in the clinic such as miscommunication, mistrust, health literacy, and limited English proficiency? Also, how can we address the barriers patients face obtaining medications, following exercise guidelines, and improving dietary habits?

The ethnicity category Southeast Asian encompass diverse ethnicities including Vietnamese, Cambodian, and Laotian. We describe Vietnamese history to illustrate why it is important to understand specific histories and lived experiences to tailor care, health systems, and policies to improve health equity.³ Among Asian American individuals in the California Health Interview Survey,⁴ Vietnamese individuals have worse health outcomes compared with Asian individuals overall for measures such as reporting fair or poor health (36.4% vs 17.8%), disability rates (30.1% vs 21.0%), and rates of heart disease (4.8% vs 4.4%). Vietnamese individuals reported higher rates of lacking a usual source of care than Asian individuals overall (18.4% vs 17.4%).⁴

To tackle these health inequities, we must understand the context of the Vietnam War, waves of immigration, and resettlement policy.⁵ The first wave of immigration occurred in 1975 before the fall of Saigon, favoring advantaged and privileged groups with ties to the US government. The second wave of immigration beginning in 1978 consisted of political refugees (ie, boat people) who frequently experienced extreme hardships and trauma at sea and in refugee camps before resettlement to the US. The third wave was family reunification efforts in the 1980s and 1990s. The Vietnam War forced people to migrate with little preparation and give up most of their possessions. Resettlement efforts were usually underresourced. Many Vietnamese immigrants obtained low-paying jobs below their training. Thus, compared with Asian individuals overall, Vietnamese individuals have high rates (21.3%) of being at or below 0% to 99% of the federal poverty level and fewer financial assets, both of which are associated with health inequities.⁵ In addition, racial

+ Related article

Author affiliations and article information are listed at the end of this article.

Open Access. This is an open access article distributed under the terms of the CC-BY License.

discrimination and limited English proficiency are associated with increased odds of poor self-reported health for Vietnamese people.⁶ Thus, programs to care for and prevent heart failure must account for diversity of Vietnamese experiences; interventions to improve health equity should address trauma, discrimination, limited English proficiency, and insufficient economic resources.

To identify risk factors and create solutions for health inequities among Latinx populations, it is also critical to disaggregate ethnicity and social data to understand lived experiences, such as immigration history. Following the Cuban revolution of 1959, approximately 250 000 mostly highly educated, middle class Cuban individuals emigrated to the US in the Golden Exile.⁷ However, 650 000 less advantaged Cuban Americans emigrated between 1995 and 2015 following the fall of the Soviet Union.⁷ These later emigrants were primarily unskilled, semiskilled, and service workers, similar to generations of Mexican immigrants to the US.

Clinicians caring for Cuban American patients must account for their economic and cultural diversity. According to the Pew Research Center,⁸ English literacy is lower among Cuban Americans (61%) than Mexican Americans (72%). Research has also demonstrated that health care mistrust is higher in patients with limited English proficiency. While clinicians might assume higher health literacy in a population with higher levels of formal education, a substantial proportion of Cuban Americans speak predominantly Spanish and would greatly benefit from language-concordant care. In addition, scales used to quantify and understand acculturation have mainly been validated in the Mexican American population and cannot be readily applied to other Spanish-speaking peoples. As new Cuban American concentrations arise in places like Nebraska, clinicians must understand their complex historical narratives.

It is critical to collect detailed social demographic data to identify inequities without otherizing patients into stereotypical aggregate wholes that do not make sense for heterogeneous populations. Thus, we applaud the Office of Management and Budget March 2024 revised standards for federal race and ethnicity data that "require the collection of detailed race and ethnicity categories as a default" and that create a new Middle Eastern or North African category separate from the White category.⁹ However, efforts to collect, analyze, and act upon granular race and ethnicity and social data must be supported. For example, the Centers for Medicare & Medicaid Services is financially rewarding the collection of health-related social needs data.¹⁰ More support and stronger incentives are needed from both public and private payers to advance health equity.

Health care delivery organizations, health plans, and policymakers need to use disaggregated race and ethnicity and social data to improve care. Heart failure care demands more than pulmonary artery catheter monitoring, inpatient titration of guideline-directed medical therapy, and organ transplantation when patients are at the end of the road. It should entail targeted preventive and maintenance measures, adjusted clinic hours for patients to come after work, and best practice alerts that monitor prescription refills for patients at risk for heart failure readmissions. Geospatial analysis of race and ethnicity data should identify access deserts and help prioritize outreach activities to patients and community members. It should help identify where to place new health care facilities and pharmacies. It should also identify what neighborhoods community-based organizations should partner with to improve access to food markets and safe green spaces. Just as importantly, detailed demographic data can assist clinicians in providing culturally sensitive and language-concordant care.

We can meet patients where they are when we understand the complete picture of their lives. Disaggregating race and ethnicity and social data may seem removed from patient care, but it represents a fundamental effort to see the humanity in each patient. Disaggregating data allows health care professionals to wield our full skill as clinicians caring for patients. It allows us to be institutional change agents improving systems of care and advocate for policies that meet each person's medical and social needs. We deepen our relationships with patients when we zoom in on the individual and work collectively toward advancing health equity.

ARTICLE INFORMATION

Published: September 26, 2024. doi:[10.1001/jamanetworkopen.2024.35617](https://doi.org/10.1001/jamanetworkopen.2024.35617)

Open Access: This is an open access article distributed under the terms of the [CC-BY License](https://creativecommons.org/licenses/by/4.0/). © 2024 Plana A et al. *JAMA Network Open*.

Corresponding Author: Alejandro Plana, MD, MS, University of Chicago Medicine, 5758 Maryland Ave, Chicago, IL 60637 (aplana@uchicagomedicine.org).

Author Affiliations: University of Chicago Medicine, Chicago, Illinois.

Conflict of Interest Disclosures: Dr Chin reported receiving grants from Robert Wood Johnson Foundation Advancing Health Equity Leading Care, Payment, and Systems Transformation National Program Office; National Institute of Diabetes and Digestive and Kidney (NIDDK) Diseases Chicago Center for Diabetes Translation Research; Agency for Healthcare Research and Quality; California Health Care Foundation; Health Resources and Services Administration; Kaiser Foundation Health Plan; and Merck Foundation; personal fees from Patient-Centered Outcomes Research Institute, Health Equity Advisory Team for the Centers for Medicare & Medicaid Services Health Care Payment Learning and Action Network, Bristol-Myers Squibb Company Health Equity Advisory Board, Blue Cross Blue Shield Health Equity Advisory Panel, Centers for Disease Control and Prevention, American College of Physicians Advisory Committee I Raise the Rates (Promotion of Influenza Immunization through Interprofessional Partnership), the Institute for Healthcare Improvement Health Equity Alliance Accelerator Sutter Health supporting the Institute for Healthcare Improvement Health Equity Alliance Accelerator in part with funding provided by Genentech, Sutter Health Sutter Health supporting the Institute for Healthcare Improvement Health Equity Alliance Accelerator in part with funding provided by Genentech, Genentech Sutter Health supporting the Institute for Healthcare Improvement Health Equity Alliance Accelerator in part with funding provided by Genentech, America's Health Insurance Plans (support for attending meetings and travel), Robert Wood Johnson Foundation, and NIDDK, Essential Hospitals Institute Innovation Committee Institute for Healthcare Improvement, American Medical Association National Initiative for Health Equity Steering Committee for Measurement, and National Committee for Quality Assurance Expert Work Group (on role of social determinants of health data in health care quality measurement); and serving as a member of the National Advisory Council of the National Institute on Minority Health and Health Disparities, the Health Disparities and Health Equity Working Group of the NIDDK, Families USA Equity and Value Task Force Advisory Council, National Academy of Medicine Council, and The Joint Commission Health Care Equity Certification Technical Advisory Panel outside the submitted work. No other disclosures were reported.

REFERENCES

1. Chicago Health Atlas. Median household income, 2018-2022. Accessed August 27, 2024. <https://chicagohealthatlas.org/indicators/INC?topic=median-household-income>
2. Cheng Y, Poon AN, Ling Y, et al. Heart failure among Asian American subpopulations. *JAMA Netw Open*. 2024;7(9):e2435672. doi:[10.1001/jamanetworkopen.2024.35672](https://doi.org/10.1001/jamanetworkopen.2024.35672)
3. Muramatsu N, Chin MH. Battling structural racism against Asians in the United States: call for public health to make the "invisible" visible. *J Public Health Manag Pract*. 2022;28(suppl 1):S3-S8. doi:[10.1097/PHH.0000000000001411](https://doi.org/10.1097/PHH.0000000000001411)
4. Adia AC, Nazareno J, Operario D, Ponce NA. Health conditions, outcomes, and service access among Filipino, Vietnamese, Chinese, Japanese, and Korean adults in California, 2011-2017. *Am J Public Health*. 2020;110(4):520-526. doi:[10.2105/AJPH.2019.305523](https://doi.org/10.2105/AJPH.2019.305523)
5. Vien MH. Vietnamese American health - chronic disease and COVID-19: A discussion of structural factors as health policies. *J Asian Health*. 2022;2(1):e202211. doi:[10.59448/jah.v2i1.17](https://doi.org/10.59448/jah.v2i1.17)
6. Gee GC, Ponce N. Associations between racial discrimination, limited English proficiency, and health-related quality of life among 6 Asian ethnic groups in California. *Am J Public Health*. 2010;100(5):888-895. doi:[10.2105/AJPH.2009.178012](https://doi.org/10.2105/AJPH.2009.178012)
7. Duany J. Cuban migration: a postrevolution exodus ebbs and flows. Migration Policy Institute. July 6, 2017. Accessed August 27, 2024. <https://www.migrationpolicy.org/article/cuban-migration-postrevolution-exodus-ebbs-and-flows>
8. Pew Research Center. English proficiency of Hispanic population in the U.S., 2021. August 16, 2023. Accessed August 28, 2024. <https://www.pewresearch.org/chart/us-hispanics-english-proficiency/>
9. Federal Register. Revisions to OMB's statistical policy directive No. 15: standards for maintaining, collecting, and presenting federal data on race and ethnicity. March 29, 2024. Accessed August 27, 2024. <https://www.federalregister.gov/documents/2024/03/29/2024-06469/revisions-to-ombs-statistical-policy-directive-no-15-standards-for-maintaining-collecting-and>

10. U.S. Department of Health and Human Services. call to action: addressing health-related social needs in communities across the nation. November 2023. Accessed August 27, 2024. <https://aspe.hhs.gov/sites/default/files/documents/3e2f6140d0087435cc6832bf8cf32618/hhs-call-to-action-health-related-social-needs.pdf>