HIGH QUALITY RACE & ETHNICITY DATA ARE ESSENTIAL FOR ACHIEVING HEALTH EQUITY

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INTRODUCTION

For as long as there have been health outcome indicators in the United States, there has been evidence of health inequities. Today, health disparities persist on the basis race and/or ethnicity, socioeconomic status, LGBTQ+ identity, and more.[1,2,3] Despite centuries of evidence of racial and ethnic health and other disparities, a uniform approach to collecting and analyzing race and ethnicity data has been a relatively modern undertaking.

It wasn't until 1977 that the Office of Management and Budget (OMB) introduced the Statistical Policy Directive No. 15 (SPD 15), which established minimum standards for federal government collection of race and ethnicity data. Over time, the societal conceptualizations of race and ethnicity have changed as the demographics of our nation continuously evolve. In 2024, OMB updated SPD 15 for the first time since 1997, which expanded the definition of race and ethnicity. In support of these updates to SPD 15 and its continued improvements over time, the National Minority Quality Forum (NMQF) and BlueCross BlueShield Association (BCBSA) have convened the Data Equity Coalition to advance data policy recommendations through collective advocacy to ensure health equity.[4]

The Center for Law and Social Policy (CLASP) is a national, nonpartisan organization advancing anti-poverty policy solutions that disrupt structural and systemic racism and sexism and remove barriers blocking people from economic security and opportunity. As a member of the Data Equity Coalition, CLASP believes that there is no pathway to health equity without robust and comprehensive race and/or ethnicity, language, and sexual orientation and gender identity data to inform decisions. The roots of structural racism in this country run deep;[5] therefore, efforts to address its insidious legacy in health care must also be based on a complete understanding of the problem. In short, there can be no health equity without data equity. CLASP supports the Data Equity Coalition's calls for the below four actions to advance data equity:[6]

1. Improve data collection requirements;
2. Update data standards;
3. Collaborate with diverse stakeholders; and
4. Enforce universal adoption of updated standards.

This brief will focus on race and ethnicity data standards, which contribute to a larger intersectional vision of data equity. A complete understanding of health equity would also include the effects of poverty, gender identity, immigration status, disability, and sexual orientation. The data we use to understand and address health inequities must also reflect the intersectional nature of individuals and communities. Race and ethnicity data are one important piece of this larger puzzle, but all these factors combine to form a person's identity and how they interact with our health care systems.

Addressing the historic and ongoing pervasive nature of health inequity requires a multi-sectoral strategy that includes the collaborative efforts of health care providers, payers, researchers, community service organizations, patient advocates, and policymakers. This level of stakeholder collaboration requires robust and publicly available race and ethnicity data to establish a shared basis of knowledge in monitoring and evaluating health equity interventions. CLASP and the Data Equity Coalition urge stakeholders to build data equity into their work with health data and join our calls for more robust data standards at all levels of government and within the health care ecosystem.

Strong Race and Ethnicity Standards are Necessary for Data Equity and Health Equity

Race and ethnic health disparities exist in almost every health access or outcome metric. Textbooks and reports have quantified the disparities in health care access, coverage, and outcomes for Black and brown communities.[7] In 2003, the National Academy of Medicine—then known as the Institute of Medicine—published a landmark report detailing the widespread racial and ethnic inequities in health care.[8] These inequities persisted even when other factors affecting access to health care (e.g., socioeconomic status) were accounted for. The report closed with a call for better data and recommendations for data collection. Twenty years later, over 200 local and state leaders are still declaring racism a public health crisis.[9] The Commonwealth Fund's 2023 Health Equity Scorecard found that in states with available data, Black and American Indian and Alaskan Native (AIAN) individuals are more likely than white Americans to die from preventable, treatable conditions.[10]

Acknowledging the severity and pervasiveness of racial health inequities is the first step to eliminating them. However, the interventions and strategic actions necessary to address these disparities continue to be stymied by a lack of robust race and ethnicity data standards that can go beyond measuring disparities and toward evidence-based strategic actions that can end these inequities.[11]

Race and ethnicity data collected across health programs—including Federally-Facilitated and State-Based Marketplaces, Medicare, Medicaid, Veterans Health Administration, and the Indian Health Service—vary widely in their completeness, accuracy, and availability for research, depending on the state and health program in question. As a result, it can be difficult for researchers to fully utilize and compare these datasets. To truly understand the complexities of racial and ethnic health disparities, we must have standardized race and ethnicity categories that accurately reflect how people see themselves and robust data collection that allows for intersectional analyses.

The OMB SPD 15 race and ethnicity data standards were updated in March 2024. One of the biggest changes to the directive is that it adds a new minimum category for individuals who identify as Middle Eastern or North African (MENA). Additionally, federal agencies will now be required to collect detailed race or ethnicity data as the default option, rather than only collecting minimum race and ethnicity data. Having this additional detailed ethnicity data paves the way for greater availability of disaggregated data. Although SPD 15 does not require the collection of race and ethnicity data by an agency, the directive does regulate how agencies maintain, collect, and present such data when they choose to gather that data. Agencies have until September 2025 to submit an action plan to OMB for how they will implement these changes and until March 2029 to bring their data collection and reporting processes into compliance. As agencies begin implementing the SPD 15 data standards, we urge them to consider how the process can be leveraged to close gaps in health data.

2024 Update to OMB's Race and Ethnicity[12]

Race and/or ethnicity will now be asked in a single question for federal data collection efforts, including the Decennial Census, and require the collection of detailed ethnicity data (e.g., a Black individual with one parent from Haiti and another from South Carolina would select "Black or African American" then specify both "Haitian" and "African American" below).

What is your race and/or ethnicity?
Select all that apply and enter additional details in the spaces below.

☐ **American Indian or Alaska Native** – *Enter, for example, Navajo Nation, Blackfeet Tribe of the Blackfeet Indian Reservation of Montana, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, Aztec, Maya, etc.*
[   ]

☐ **Asian** – *Provide details below.*
  ☐ Chinese   ☐ Asian Indian   ☐ Filipino
  ☐ Vietnamese   ☐ Korean   ☐ Japanese
Enter, for example, Pakistani, Hmong, Afghan, etc.
[   ]

☐ **Black or African American** – *Provide details below.*
  ☐ African American   ☐ Jamaican   ☐ Haitian
  ☐ Nigerian   ☐ Ethiopian   ☐ Somali
Enter, for example, Trinidadian and Tobagonian, Ghanaian, Congolese, etc.
[   ]

☐ **Hispanic or Latino** – *Provide details below.*
  ☐ Mexican   ☐ Puerto Rican   ☐ Salvadoran
  ☐ Cuban   ☐ Dominican   ☐ Guatemalan
Enter, for example, Colombian, Honduran, Spaniard, etc.
[   ]

☐ **Middle Eastern or North African** – *Provide details below.*
  ☐ Lebanese   ☐ Iranian   ☐ Egyptian
  ☐ Syrian   ☐ Iraqi   ☐ Israeli
Enter, for example, Moroccan, Yemeni, Kurdish, etc.
[   ]

☐ **Native Hawaiian or Pacific Islander** – *Provide details below.*
  ☐ Native Hawaiian   ☐ Samoan   ☐ Chamorro
  ☐ Tongan   ☐ Fijian   ☐ Marshallese
Enter, for example, Chuukese, Palauan, Tahitian, etc.
[   ]

☐ **White** – *Provide details below.*
  ☐ English   ☐ German   ☐ Irish
  ☐ Italian   ☐ Polish   ☐ Scottish
Enter, for example, French, Swedish, Norwegian, etc.
[   ]

Adding a new MENA category unlocks a critical opportunity for advancing health equity. In the absence of this category, there has been no baseline health data for Middle Eastern and North African communities, essentially rendering them invisible. Preliminary research suggests that significant health disparities exist between Arab or MENA populations and the general population.[13] Now that the federal data standard has been updated to include a MENA category, more health research must be done to identify the community's unique health patterns, outcomes, and care access needs.

Beyond the federal standard, it is worth noting that states have an enormous impact on achieving data equity. SPD 15 does not regulate a state's race and ethnicity data standards, which may differ from the federal standard. States are often responsible for the collection and reporting of health-related data, and some omit race and ethnicity information from their data reports. As such, a federal data standard is insufficient to meet the needs of health equity stakeholders. We need nationwide race and ethnicity data standards across the health care ecosystem to effectively monitor and evaluate progress in health equity. The Federal Government can do much more to incentivize and enforce state compliance with federal data standards. In the meantime, all stakeholders can use their influence to demand data equity across the health care ecosystem. Universal adoption of the 2024 OMB SPD 15 updates to the race and ethnicity data standard are needed to support stakeholders' efforts to eliminate deeply entrenched racial health disparities.

Race and Ethnicity Standards Must Reflect How People See Themselves

If the U.S. data ecosystem is to build toward health equity, race and ethnicity data standards must match how people and communities understand themselves. OMB federal data standards have evolved considerably from their first iteration in 1977, largely due to the advocacy of un- or underrepresented racial and ethnic minority groups.[14]

Of course, robust race and ethnicity data alone will not deliver data equity. Health care needs must be understood through an intersectional lens. Just as a person's lived experiences goes beyond their understanding of their own race or ethnicity, that person's experience of their gender, national, or sexual identity is also influenced by their experience of race. That is intersectionality: the overlapping nature of social categorizations such as race and ethnicity, class, and gender as they apply to a given individual or group, which create interconnected systems of discrimination or disadvantage based on societal biases.

Complete race and ethnicity health-related data are also critical for enabling intersectional analyses of health care experiences when seeking to address why health access and outcomes are unequal. A 2017 study of the discriminatory experiences of Hispanic or Latino individuals in the U.S. found that 20 percent of participants reported being personally discriminated against because they are Latino when going to a doctor or health clinic.[15] This finding was driven by the gendered experiences of Latina women, who were 11 percentage points more likely to report discrimination in a health care setting than men. Additionally, although public assumptions about the immigration status of Latino individuals can drive discriminatory experiences, non-immigrant Latinos reported more instances of discrimination than immigrant Latinos. Having complete race and ethnicity health-related data is also critical for enabling intersectional analyses of health care experiences when seeking to address why health access and outcomes are unequal.

Data Collection Efforts Must Allow for Disaggregation by Race, Ethnicity, and Subpopulations

Making race and ethnicity data disaggregation a standard in health research at all levels of government will be key to the fight for health equity. The unique health findings of minority ethnic groups are often made statistically invisible in research using aggregated data. Not having access to reliable and standardized data on marginalized racial and ethnic communities directly contributes to poorer health outcomes in these communities, especially in novel health situations (i.e., an emerging pandemic, a roll-out of new health policies, etc.). Often, smaller racial and ethnic groups and subpopulations are rendered invisible in data collection, sometimes due to the challenges and costs of collecting data on smaller groups. Federal data standards are also difficult to implement or enforce at the state or local levels, where most health data is usually gathered and reported up to the federal level.

One of the clearest demonstrations of the real-world consequences of failing to include all racial and ethnic groups in research was the omission of AIAN and Native Hawaiian and Pacific Islander (NHPI) communities from many states' COVID-19 case and mortality data. Despite anecdotal evidence from Native and Pacific Islander communities that COVID-19 was having a disproportionately severe impact on their communities, the available state-level case and mortality data often did not include race or ethnicity data.[16] When this data was available, it was often inaccurate or did not disaggregate AIAN or NHPI ethnicities.[17] In fact, AIAN and NHPI researchers and public health officials had to build their own data portals to have the data necessary to address the urgent health needs of their communities.[18] It was only through disaggregated data that researchers discovered that there were more COVID-19 deaths in the 18-64 age group among Fijians, Tongans, and Samoans than in the 65+ age group, which was the opposite of COVID-19 mortality trends within the general population.

With the 2024 OMB SPD15 update requiring the collection of disaggregated race and ethnicity data, federal agencies will have to implement an action plan to collect and disseminate disaggregated health data. CLASP strongly urges state, local, and private health stakeholders to leverage OMB's guidance and federal implementation plans to adopt their own disaggregated health data collection models.

Data Equity Requires Privacy, Transparency, Consent, Trust, and Partnerships

To achieve true health equity, more must be done to bring marginalized communities into the circle of decision-making and power. A robust federal data structure also requires transparent and strong privacy protections, a clear process to give and rescind consent for data sharing, and partnerships with trusted organizations to gather and share data back to the communities they came from. BCBSA and NMQF have outlined some fundamental principles in the ethnical and transparent use of data to reduce health inequities, including the need to address bias.[19]

CLASP believes that prioritizing the expertise of those with lived experience is essential to rooting out bias when addressing inequities. Data equity requires collaborating with the communities facing health inequities when interpreting health equity data and including them in any plans to repair those harms. Separating communities from their own data means that the broader health ecosystem loses the expertise of their insight. The factors that contribute to health disparities are not always clear; including communities in the

interpretation of their own data can build a collaborative dialogue that builds trust in the health care system and creates solutions to health inequities.

Ownership of collected data is also important to data equity. For example, tribal nations deserve ownership over their data. As sovereign nations with a government-to-government relationship with the United States, tribal governments have the right and responsibility to create public health laws and respond to public health emergencies within their own communities. However, state and federal data about tribal citizens are often collected without sharing ownership of that data or any findings with the tribes to which they belong.[20] This exclusion leaves tribal governments with a limited ability to respond to the health disparities of their citizens, particularly if they reside away from tribal lands, and gives tribes little control in how their data is used.

Finally, data must be gathered regularly from the entire U.S. populace, including those living in Puerto Rico, the U.S. Virgin Islands, American Samoa, the Northern Mariana Islands, and Guam, whose populations are often left out of the health equity picture. The Decennial Census, the American Community Survey, Population Estimates, and the Current Population Survey are the four foundational population-level datasets, yet only Puerto Rico is represented in all of them.[21] Data is only gathered from American Samoa, the Northern Mariana Islands, the U.S. Virgin Islands, and Guam once every ten years during the Decennial Census, meaning that more detailed or up-to-date health-related metrics are often missing for these territories. Health equity cannot be achieved in communities where health data is neither gathered nor prioritized.

CONCLUSION

Evidence of health inequities can be readily found in hundreds of studies on minority, immigrant, women, and LGBTQ+ health. However, to move from documenting and cataloguing health inequities to proactively addressing and eliminating them throughout the health ecosystem, we need data equity to light the way. A robust race and ethnicity data standard at the federal level should be universally adopted by state and local governments as well as health industry leaders. This will make it possible to better understand and address health inequities.

For policy organizations like CLASP, data equity means holding government agencies accountable for the equitable implementation of health policies and both funding and advocating for robust race and ethnicity data in public datasets. These actions are key to helping lawmakers to understand the unique needs of communities and create policies that are flexible enough to address those nuanced needs while ensuring accountability.

For health researchers, progress toward data equity would make it easier to evaluate new treatments or programs, which would in turn make more community-specific and equitable standards of care guidance possible. In addition to the four calls to action noted in this brief's introduction, we offer the following recommendations for achieving data equity in health.

Recommendations for Data Justice

- Federal, state, and local agencies must work with health care stakeholders to commit resources to building a disaggregated data infrastructure.

- Race and ethnicity data should be reported as disaggregated data to the maximum extent possible.

- The Federal Government should conduct a comprehensive study regarding the unique health patterns and outcomes of race and ethnic categories newly added to the OMB SPD 15 federal data standard (i.e., MENA populations).

- Researchers and government agencies should partner with trusted community organizations and researchers to center the experiences and perspectives of groups facing negative health outcomes when trying to understand how to address these disparities.

- Government agencies and researchers should support Indigenous data sovereignty by collaborating with tribal nations as they gather and disseminate data belonging their own communities, and by employing community-centered models of research.

- Government agencies should include U.S. territories in all federal statistical datasets.

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