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The Case for Improved Racial and Ethnic Public Health Data Collection Practices to Reduce Racial Disparities in Health

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Abstract

Racial disparities in health in the United States are largely the result of long-standing structural determinants that are deeply embedded into our nation's institutions, policies, and social norms. Race as a social construct influences people's prospects for well-being before they are even born, with racial disparities in health persisting for centuries. Domestically, race is a bigger predictor of someone's health outcomes than socioeconomic status, zip code, creed, or political leaning. The COVID-19 pandemic elucidated the existing barriers to health and how deleterious the consequences of unmitigated inequities were in populations with certain racial and/or ethnic identities. As such, data collection for public health resource allocation and intervention design should seek to uncover opportunities to tailor programming efforts that meet the needs of groups who have long been structurally underserved, neglected, and mismanaged. In a nation as diverse as the United States, collecting racial and ethnic demographic data without granularity can contribute to masking existing inequities and erasing the experiences of various subpopulations. While the Office of Management and Budget's recent move to update the federal standards for collecting information on race and ethnicity has improved data collection for a few groups, this policy statement seeks to explore opportunities to enhance public health racial and ethnic data collection efforts for more meaningful and sustainable interventions that forge a path toward health equity.

Keywords: data collection; racial and ethnic identity data; health equity, and health disparities.

Relationship to Existing APHA Policy Statements

- APHA Policy Statement 20227: A Strategy to Address Systemic Racism and Violence as Public Health Priorities: Training and Supporting Community Health Workers to Advance Equity and Violence Prevention
- APHA Policy Statement 20218: Call for Urgent Actions to Address Health Inequities in the U.S. Coronavirus Disease 2019 Pandemic and Response
- APHA Policy Statement 202116: Ensuring Equity in Transportation and Land Use Decisions to Promote Health and Well-Being in Metropolitan Areas
- APHA Policy Statement LB20-04: Structural Racism is a Public Health Crisis: Impact on the Black Community
- APHA Policy Statement 20189: Achieving Health Equity in the United States
- APHA Policy Statement 200311: Opposition to Eliminating or Compromising the Collection of Racial and Ethnic Data by State and Local Public Institutions
- APHA Policy Statement 20017: Research and Intervention on Racism as a Fundamental Cause of Ethnic Disparities in Health
- APHA Policy Statement 20005: Effective Interventions for Reducing Racial and Ethnic Disparities in Health

Problem Statement

The primary focus of the field of public health is to promote health and prevent disease. To mitigate health disparities, a particular type of health difference linked with social, economic, and/or environmental disadvantage, public health data sets must have comprehensive and consistent information related to race and ethnicity.[1] Health disparities in the United States are largely the result of cumulative disadvantages people with minoritized racial and ethnic identities experience as a result of structural racism.[2] It is well understood in the field of public health that chronic disease morbidity and mortality rates vary by race and ethnicity; even when the incidence of disease is lower, the prognosis is worse for certain subpopulations.[3] This is largely due to social and political determinants of health that are mediated by structural racism, the macro-level factors that restrict the opportunities, resources, power, and overall well-being of individuals, communities, and entire populations as a result of their race and/or ethnicity.[4–6]

In the United States, public institutions collect racial and ethnic data to better understand the demographics of the nation; the United States remains one of the few wealthy countries to prioritize this practice. Globally, there are not consistent practices for collecting racial and ethnic data because of reasons such as legality, different social constructs for race and ethnicity, and regional differences in the composition of the population.[7] Context-specific comprehensive data sets allow for a more refined assessment of the public health effects of structural racism.[4–6] For example, structural factors such as residential segregation and redlining have been associated with racial disparities in health related to adverse birth outcomes, asthma, diabetes, and food insecurity.[8] While the concepts of race and ethnicity are not unique to the United States, how the country collects data on a concept socially constructed and operationalized domestically has to be right-sized to serve the public health needs of our nation. Currently, White Americans constitute nearly 60% of the population.[9] However, projection tables released by the U.S. Census Bureau in 2023 indicate that, by 2050, individuals with minoritized racial and/or ethnic identities will represent the largest share of the population.[9] The absence of comprehensive racial and ethnic data hinders the field of public health from adequately addressing chronic and worsening racial disparities in health.[10]

As our nation’s diversity increases, public health data collection practices must be dynamic to capture the changing demographics of our nation and ensure that disparities are not masked by larger racial and/or ethnic groupings. The Office of Management and Budget (OMB) initially created Statistical Policy Directive No. 15 (SPD 15): Standards for Maintaining, Collecting, and

Presenting Federal Data on Race and Ethnicity in 1977 to ensure consistent data on race and ethnicity across the federal government by establishing minimum reporting categories.[11] Since 1977, SPD 15 has been revised to include a separate ethnicity question (in 1997), to allow the selection of multiple categories (in 2000), and to adjust language, include the Middle Eastern or North African category, and combine the questions for race and ethnicity (in 2024).[11]

While the recent federal revisions were long overdue, public health practitioners must take action alongside the federal government to ensure that our race and ethnicity data collection practices inform action to reduce racial disparities in health. As indicated by the Robert Wood Johnson Foundation, without disaggregated public health data sets, it is challenging to identify or address the needs of racial and ethnic subpopulations experiencing health inequities.[12] Localities with larger populations of diverse communities have recently demonstrated the need for this disaggregation: New York City released a series of reports documenting health differences within Latine, Black, and Asian populations.[13–15]

Public health practitioners are well positioned to forge a path toward improved racial and ethnic data collection practices. As major funders, including the U.S. government, move toward data-driven resource allocation, the effects of data genocide and underrepresentation of racial/ethnic groups within the country’s data infrastructure will continue to have short- and long-term consequences. The current approaches to capturing race and ethnicity data do not take into account the differences within subgroups of populations, and it is time for public health to move beyond the minimum and set a standard for collecting race and ethnicity data that seeks to achieve health equity and advance social justice for all.

Evidence-Based Strategies to Address the Problem

There are several strategies that can improve the collection of race and ethnicity data.

Establish public health racial and ethnic data collection standards

The most immediate opportunity resides in establishing consistent public health data collection standards. Although the recently updated OMB race and ethnicity data standards are a sign of progress for some racial and ethnic subgroups at the federal level, concerns remain. For example, the addition of Middle Eastern or North African as a new minimum category distinct from the White racial category is an improvement across broader racial groups: The lack of a racial identifier for this has masked disparities in COVID-19 cases, gestational diabetes, and preterm births in this population.[16] However, implementation of the new category will take time for updated data infrastructure and improved understanding of included populations. Also, the controversial decision to merge race and ethnicity into a single question to encourage more complete data collection among the U.S. Latine population does little to rectify how members of this population view themselves in the data: Data from the 2020 census indicate that 43.6% of the Latine population either skipped the race question or selected “some other race,” suggesting that a more nuanced data collection issue exists beyond instrument design.[17,18]

Aside from these two significant updates, language adjustments in the OMB revision will likely do little to improve data collection for the groups most at risk for racial disparities in health. For example, the revised proposal makes a recommendation to remove Negro from the expanded description of the Black or African American racial category but does not provide additional recommendations on how to better capture the diversity of this racial group beyond that change.[11] Within the context of public health, Black Americans who are descendants of chattel slavery have poorer health outcomes than Black immigrants or their descendants.[19] In an examination of cardiovascular disease risk factors among Black immigrants and African

Americans, the American Heart Association asserted that data on the Black population in the United States should be, at minimum, disaggregated by ethnicity and country of origin to inform public health strategies to reduce health disparities.[20]

There are also stark intragroup differences within the Asian American population that will continue to be masked if more granular public health data collection methods are not deployed. The Asian American population currently represents dozens of ethnic groups with major wealth, education, and health gaps by region and country of origin.[21] A New York City examination of the health burden of COVID-19 revealed that Chinese Americans had the highest mortality of all racial and ethnic groups assessed and that South Asians had the highest infection rate within the Asian American population.[22] Had more granular data collection practices been deployed earlier in the pandemic, these disparities across subgroups may have been mitigated by more tailored messaging and interventions.

There are numerous public health data issues when it comes to Indigenous communities, including poor data quality due to aggregation, a lack of clarity regarding definitions of who is American Indian or Alaska Native, exclusion from data collection altogether, and confusion about the political status held by citizens of tribal nations separate from race or ethnicity.[23,24] Described by Native American communities as “data genocide,” the elimination, erasure, misclassification, and concealment of populations from public health data perpetuate structural racism and impact progress toward health equity.[25] Data genocide has also been named as a threat to health equity for people currently categorized under the Native Hawaiian or Pacific Islander group. On the island of Hawaii, there are data collection challenges with respect to aggregating Native Hawaiians and Pacific Islanders. In a 2021 survey, 71% of Native Hawaiians identified with at least one other race, rendering more than half of the Native Hawaiian population invisible when single multiracial categories were used.[26] Furthermore, an examination showed that any health disparities that are present between Pacific Islanders and Native Hawaiians are masked when their groups are combined.[26]

Collecting data for public health planning, programming, and prevention efforts requires more nuanced efforts than what is currently mandated by the OMB. In addition, according to a report on data completeness and standards conducted by Grantmakers in Health and the National Committee for Quality Assurance, only four of the 10 programs reviewed used the same standards.[27] The standards most commonly used for collecting race and ethnicity data are the OMB standards; even more discouraging, only four programs provided complete race and ethnicity data, with two of those programs using OMB's standards.[27] As such, an evidence-based strategy to improve the public health collection of race and ethnicity data must focus on improving the completeness of racial and ethnic data collection practices and establishing standards for consistency beyond the existing minimum standards.

The Council for State and Territorial Epidemiologists recently released recommendations for addressing racial/ethnic COVID-19 data gaps that can be extended to public health data at large.[28] These recommendations include (1) mitigating patient hesitancy in providing data; (2) encouraging providers to collect data; (3) improving information system capacity to collect, manage, process, and transmit data; and (4) improving public health agency resources and staffing.[28] Prior to the release of these recommendations, localities had demonstrated success in improving the completeness of this information. During the COVID-19 pandemic, the New York City health department made meaningful improvements with respect to inclusion of racial/ethnic information in health data.[29] Although unable to ensure that providers adhered to the standards in the way they collected data, this approach did demonstrate the feasibility of health systems improving the completeness of their data using existing data infrastructure, even in emergency conditions.[29] In addition, New York City publicly reported the percentage of missing racial/ethnic data on their online COVID data portal, providing the general public with information on how the data are used. Ensuring that people understand how and why their data are being used and providing the data back to them are critical steps in earning the trust required for people to provide data.

Prioritize self-reported data as the gold standard and improve completion of racial and/or ethnic data sets

To improve the completeness of race and ethnicity data in federal health programs, self-reported data must be prioritized in data collection practices. While administrative reporting has been used to create efficiency in data collection, reliance on this type of reporting as opposed to self-reporting has had inconsistent validity across racial groups with dangerous implications in terms of racial disparities in health.[30] For example, a 2020 examination revealed that Medicare administrative data sources such as observational data models and causal modeling methods had high validity for the African American/Black population and low validity for the Indigenous population.[30] Given the changing demographics of our nation, such as a 276% increase in the size of the multiracial population since 2010, prioritizing self-reported data is the most accurate approach to collecting racial and ethnic data.[31] In addition, misclassification of race and ethnicity can mischaracterize the burden of health disparities. One examination showed that the number of Asian American and Pacific Islanders with dementia and diabetes was underestimated, while there was overattribution in the Latine population when race variables rather than self-reported data were used.[30] Failure to use self-reported data can affect the precision of resource allocations and public health programming designed to reduce racial disparities in health.

As a social construct, racial and ethnic identity is a complicated domain. For example, the minimum national standards for racial/ethnic data collection include combinations of race, ethnicity, national origin, sociopolitical identity, and more. Because of this fluctuating social construction, individuals have the potential to change the way they disclose their racial/ethnic identity over time, which can depend on the way the data are collected, the entity collecting the data, and the way the individuals providing information are perceived.[32] In situations in which individuals are able to provide more detailed racial and ethnic data, the data are often aggregated by the data collector in ways that mask health inequities or in ways that are incompatible with communities themselves.[33] As technology advances, there are ample opportunities for data scientists to leverage newly developed data management efficiencies to reduce the reliance on collecting aggregated data at the individual level. For example, by providing an option for individuals to self-identify in an open-answer question, data scientists can process the information on the back end to allow numerous ways to categorize it.[34]

To prioritize self-reported data, public health institutions must move from passive to more active approaches, including establishing data collection completeness targets (e.g., improving racial and ethnic data completeness to 90%), creating organizational policies around data collection, and equipping data collectors with the necessary training and scripts to reduce hesitancy. The American Hospital Association has developed a toolkit for eliminating health care disparities; in this toolkit, a response matrix is provided that offers a script for data collectors that is culturally competent and respectful.[35] The American Medical Association also encourages the use of scripts and procedures that empower patients by telling them how the information will be used and why it is meaningful to ensure that they receive the best care available.[36]

Use participatory action research (PAR) to adapt to and maintain dynamic definitions of race and ethnicity

While federal definitions and standards for the collection of data on race and ethnicity may remain unchanged for decades, this does not necessarily align with the way people experience and self-define their racial/ethnic group membership or the way our nation’s racial and ethnic composition evolves. Race, as a social construct, is nuanced and dynamic; languages and experiences will differ across generations and geographies and within groups. To ensure cultural sensitivity and validity, public health racial and ethnic data collectors should review existing instruments.[37] Although the established minimum standards set by the OMB are a good baseline to build from, there are additional approaches that are more adaptable to the dynamic definitions of race and ethnicity.

PAR is a partnership approach to research that involves community members, organizational representatives, and researchers in all aspects of the research process, including leadership and decision making.[38,39] All partners contribute their expertise and share responsibilities and ownership of projects designed to enhance understanding of a topic as well as integrate the knowledge gained with action to improve the health and well-being of community members. PAR is a highly feasible and powerful approach that leverages a variety of modalities, such as quantitative research, photovoice, and storytelling, that can contribute to filling gaps in public health knowledge, direct the focus of research to community priorities, identify barriers communities face that impact their ability to achieve wellness, bring forward community-specific solutions to ongoing health challenges, and offer benefits to the participants themselves.[38,40–42]

Data scientists, researchers, and public health practitioners can leverage PAR to investigate community-relevant research questions, develop community-meaningful racial/ethnic subgroups, and more. If open-answer data collection is unfeasible, PAR can be used to create the data collection instrument and a racial/ethnic data collection tool that is acceptable to the community. Creating a more inclusive data collection approach can improve future opportunities to compare data over time as social constructs change and particularly as multiracial/ethnic communities grow.

Train public health researchers and practitioners to responsibly and respectfully collect racial and ethnic data

Race and ethnicity data should be collected while accommodating any concerns of communities who are participating. Many communities have historically been harmed or severely mistreated by health researchers.[43] As a result, these communities may mistrust health researchers or public health practitioners and require accommodations for the management and storage of their data. In 2019, the National Institutes of Health (NIH) held a national tribal consultation on the NIH draft Data Management and Sharing Policy.[44] One important theme that emerged was the responsibility of NIH to train researchers it supports in the appropriate management and sharing of American Indian/Alaska Native health data.[44] This strategy involves strengthening transparency and accountability by making data management and sharing plans publicly available and accessible.[44] Using data in a responsible manner is critical given that the cause of racial disparities in health is structural racism and not an individual’s actual race and/or ethnicity.

In a 2021 equity report released by Blue Cross Blue Shield, it was recommended that all staff who collect data on race and ethnicity be trained on how to ask people for their personal information.[45] Training for staff who collect this information will need to be tailored to organizational policies and goals around race and ethnicity data collection but should center cultural humility, respect, and accuracy in the approach.[45] Centering cultural humility, the practice of improving rapport through respect and curiosity, can establish trust and improve the accuracy of data collection.[45] Although maintaining ongoing training involves additional organizational resources, improving the accuracy of public health data sets yields a greater return as institutions will be able to better scale their projects for maximum impact in reducing racial disparities in health.

Prioritize additional research inquiries into best practices for collecting racial and ethnic data on foreign-born, child and adolescent, and disenfranchised populations: The strategies outlined up to this point are broad and intended to be applicable across a range of public health settings. However, there are special considerations for populations with circumstances that may affect data collection. According to the Bureau of Labor Statistics, foreign-born workers accounted for 18.6% of the U.S. civilian labor force in 2023.[46] These workers are more likely than native-born workers to be employed in service occupations and less likely to have completed high school; also, they earn lower wages.[46] Given the growing number of foreign-born U.S. residents, additional research on how best to capture racial and ethnic data on this population is needed beyond the existing OMB categories. Currently, we know broadly that nearly one half of the foreign-born workforce is Latine and that one quarter is Asian; however, more granularity would greatly improve public health's ability to respond to and promote health in this population.[46] When collecting these data for public health programming, inquiring about country of origin in combination with open-ended questions can enhance the accuracy of data on this population.

Another area in need of additional research is collection of racial and ethnic data within populations of children and adolescents. Currently, standard practice for collecting these data in public health settings largely involves caregivers providing this information on behalf of their children. However, how caregivers view the racial and ethnic identity of children may be misaligned with how the child or adolescent identifies. The growing number of transracial adoptees and multiracial/multiethnic individuals in the United States, particularly among younger generations, supports the need for additional research into best practices for collecting racial and ethnic data among these populations.[47]

Lastly, there are additional groups of people who may be disenfranchised due to various social and economic inequities associated with their group membership. This includes but is not exclusive to people who are experiencing homelessness or are receiving inpatient services for various conditions. Self-identification should still be prioritized, but additional research to identify safeguards and approaches that cause the least amount of harm is needed.

Action Steps to Implement Evidence-Based Strategies

	Evidence-Based Strategy		**Action Steps**
1	Prioritize self-reported data and improve completion of racial/ethnic data sets.	1a	Health-determining systems and entities, including health departments, should require providers and public health more broadly to collect the data and include data completion reports and targets in quality assurance reviews.
		1b	Health-determining systems and entities, including health departments, should improve information system capacity to collect, manage, process, and transmit data at different levels, such as expanded categories and open-answer fields.
		1c	Federal, state, tribal, and local governments should improve public health agency resources and staffing.
2	Use participatory action research to adapt to and maintain dynamic definitions of race and ethnicity.	2a	Health-determining systems and entities, including health departments, should integrate community expertise through multiple modalities to improve inclusive design, collection, analysis, and reporting of racial/ethnic data.
		2b	Through community leadership models, health-determining systems and entities, including health departments, should establish relationships to ensure continuous and ongoing improvement in efforts as social constructs and community dynamics evolve over time.

3	Train public health researchers and practitioners to responsibly and respectfully collect racial and ethnic data.	3a	Academic institutions, funding agencies, health care systems, local health departments, nongovernmental organizations, professional associations, state health departments, the U.S. Department of Health and Human Services, and other health-determining entities should require the implementation of cultural sensitivity and humility training, create scripts, and provide ongoing education for all race and ethnicity data collectors.
		3b	Health-determining systems and entities should make organizational data management and sharing plans publicly available to increase trust of and support for data collectors.
4	Prioritize additional research inquiries into best practices for collecting racial and ethnic data on immigrant, child and adolescent, and disenfranchised populations.	4a	Model organizational policies for how to collect racial and ethnic data on immigrant, child and adolescent, and disenfranchised populations should be established and/or reviewed as the evidence base is being built.
		4b	Health-determining systems and entities should prioritize self-reported data in immigrant, child and adolescent, and disenfranchised populations over existing administrative data to improve accuracy and support respondents' agency to self-identify.

Opposing Arguments/Evidence

This policy statement has highlighted the benefits of collecting disaggregated racial and ethnic data. However, there are several concerns and issues that have to be considered.

Unintended consequences of data collection methods

Certain data collection methods should be changed to improve public health through better interventions, policies, and programs; however, some of these methods could have unintended harms, including further contributing to systemic racism and its impacts. As practitioners implement recommendations, care should be taken to consider how data are shared and how they could intentionally or unintentionally cause harm to different populations.[48]

Patient privacy and confidentiality challenges

When discussing privacy and confidentiality concerns, patients and consumers may view collecting information about an individual's race and ethnicity as intrusive and a potential invasion of privacy for various reasons. In addition, disaggregation of race and ethnicity data can increase the risk of "reidentification" for some groups when this information is made publicly available.[49] Reidentification refers to the ability to use data from a deidentified data set to identify individuals, and it is one of the biggest risks associated with disseminating disaggregated data on race and ethnicity. The risk of reidentification varies from one state or locality to another due to demographic differences because race and ethnicity can be "quasi-identifiers."[49] A strategy to combat this challenge is to selectively suppress race and ethnicity data in areas where there are too few individuals and privacy concerns are present.[49] As such, suppression guidelines and criteria should be a part of state, local, and/or institutional racial and ethnic data collection plans. Some states already have more broad privacy protections relating to public dissemination of data; California, Nebraska, New York, Tennessee, and Texas all have laws in place to protect privacy and/or explicitly reduce the risk of reidentification.[50] While reidentification is a valid risk that public health data collectors should be mindful of, the risk does not outweigh the benefit or utility of more detailed race and ethnicity data. There are resources such as the Network for Public Health Law's Disaggregation of Public Health Data by Race and Ethnicity: A Legal Handbook, which was created specifically to address the role of law in collecting and disseminating these important data to reduce racial disparities in health.[50]

Lack of resources and increased burden on data collectors

While additional training for data collectors, revised instruments, and more time on the front end do require resources, the potential fiscal and health returns from improved public health data sets outweigh the investment. According to an analysis by Deloitte of several high-cost chronic diseases (diabetes, asthma, and cardiovascular disease), health disparities account for $320 billion in annual health care spending.[51] If health disparities continue to go unmitigated, this figure is anticipated to grow to $1 trillion or more by 2040.[51] This projected increase in health care spending could cost the average U.S. resident at least $3,000 annually, which is triple the current cost.[51] Hence, while there is an ethical case to mitigate racial disparities in health, there are economic and social justifications as well.

To do our part to support the mitigation of racial disparities in health, it is time for public health to lead at the local, state, and institutional levels by providing more robust and complete data sets. With robust, accurate, and complete data, we can better allocate resources to support populations on the journey to dismantling long-standing barriers to health, equity, and justice.

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