# ADVANCING DATA EQUITY:
## NECESSARY FOR ADVANCING HEALTH EQUITY

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DATA EQUITY
COALITION

American Heart Association.

# INTRODUCTION

Over the past 70 years, the life expectancy of individuals living in the United States (U.S.) has increased dramatically (Woolf, 2023). However, the increase in life expectancy has not been equally realized by all communities. From 2000 to 2019, life expectancy increased in the U.S. with significant differences by geography, race, and ethnicity (Dwyer-Lindgren et al., 2022). The persistence of disparities in life expectancy and morbidity and mortality by race, ethnicity and income levels warrants attention and a commitment to eliminate those disparities. Data that are detailed enough to detect disparities are important for identification and elimination of those disparities. To support detection and elimination of these disparities in the U.S., the Federal Government should continue periodic revisions to the Office of Management and Budget's (OMB) Statistical Policy Directive No. 15 (SPD 15), which sets the government's standard for collecting data based on race and ethnicity. Although SPD 15 was recently revised in March 2024 (Office of Management and Budget, 2024), continuing to periodically update the policy directive would result in more comprehensive, accurate, and useful data being collected that would give a clearer picture of health equity/inequity across the U.S..

The World Health Organization (WHO) defines Health Equity as the absence of unfair and avoidable or remediable differences in health among population groups defined socially, economically, demographically, geographically, or otherwise (World Health Organization, 2024). The WHO definition continues: "health equity is intricately linked to both structural and social determinants of health, as these factors influence the distribution of power and resources, as well as health outcomes, experiences, and opportunities within and across populations"(World Health Organization, 2024). The American Heart Association (AHA) more succinctly defines health equity as "the opportunity for all people to be healthy"(American Heart Association, 2024a). Data.org, an organization seeking to democratize and reimagine the use of data to tackle society's greatest challenges and improve lives across the globe, defines data equity as "a set of principles and practices to guide anyone who works with data through every step of a data project"(data.org, 2024).

A 2018 PolicyLink report, Counting a Diverse Nation: Disaggregating Data on Race and Ethnicity to Advance a Culture of Health (PolicyLink, 2018), notes that disparities and inequities can only be eliminated if high-quality data are available to track immediate problems and the underlying social drivers of health and guide the design and application of culturally specific approaches to health and health care. The report points out that although health outcomes are disaggregated by broad racial and ethnic categories, the growing diversity of the U.S. population means that people's actual experiences are much more nuanced. The report grouped findings and recommendations into two areas:

1. Methods for collecting and analyzing data about race and ethnicity at more detailed levels; and
2. Government policies that can enable and enhance data disaggregation.

In calling out data as the building blocks of health, the CDC Foundation has developed five data equity principles,

1. Recognize and define systemic factors;
2. Use equity-mindedness for language and action;
3. Allow for cultural modification;
4. Create shared data agreement; and
5. Facilitate data sovereignty.

The principles are meant to be applied across all stages of data collection by organizations at any level from federal to tribal to local with community-level-centeredness and participation and with the aim of collecting population data sufficiently discriminating to capture disparities in health and health outcomes.

Classification categories of the population in the U.S. have changed over time and will need to continue to change. Although these categories are constructed socially and do not represent biological differences, they can be important for understanding and improving population health. As Kader et al. concluded, "State and local decision makers can no longer ignore empirical evidence accumulated over years of public health research that race/ethnicity disaggregation will have positive long-term and immediate benefits. Leaders have a responsibility to follow best practices for overcoming data disaggregation opposition. Ultimately, these efforts will strengthen their community ties, help identify more accurate risk factors of disease, and support targeted, culturally appropriate interventions in the pursuit of health equity" (Kader F et al., 2022).

In *Charting a Course for an Equity-Centered Data System*, the 2021 Robert Wood Johnson Foundation report called for federal, state, and local government actions and some specific public health actions (Robert Wood Johnson Foundation, 2021). Recommended federal government actions included developing minimum standards for data collection, disaggregation, presentation, and access; and prioritizing funding for a standards-based and interoperable data infrastructure. One state government action recommended in the report was to offer guidance on the interpretation of racial/ethnic variation in health-relevant data.

Contemporaneously, a Federal Government effort to incorporate the principle of equity was detailed by the Executive Order on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government (Equity EO) issued January 20, 2021 and resulting in the initiation of a whole-of-government effort to incorporate the principle of equity (The White House, 2021). Through the Equity EO, an Equitable Data Working Group was established and directed to study existing federal data collection policies, programs, and infrastructure to identify inadequacies and provide recommendations for increasing data available for measuring equity and representing the diversity of the American people (The White House, 2022). The resultant document states that disaggregated data (defined as data that can be broken down and analyzed by race, ethnicity, gender, disability, income, veteran status, age, or other key demographic variables) is essential to the incorporation of equity into data standards. The Working Group identified three priority uses for equitable data:

1. Generating disaggregated statistical estimates to characterize experiences of historically underserved groups;
2. Increasing non-federal research and community access to disaggregated data for evidence-building that supports equity efforts; and
3. Conducting robust equity assessments of federal programs to identify areas for improvement.

The Working Group also identified five practices with specific recommendations to guide its efforts:

1. Making disaggregated data the norm;
2. Leveraging federal infrastructure to use existing but underused data;
3. Building capacity for equity assessment;
4. Building partnerships beyond federal agencies; and
5. Being accountable to the U.S. public.

In the practice area of making disaggregated data the norm, revision of OMB's SPD 15: *Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity from 1997* (Office of Management and Budget, 1997) was explicitly recommended by The Working Group, as was establishing best practices for measuring sexual orientation, gender identity, disability, and rural location. As previously noted, revisions have been made to OMB's SPD 15.

Over the past six years, as described in this report, the issue of data disaggregation has been reviewed, deliberated, and reported on. While those efforts and others likely contributed to the recent revisions of OMB's SPD 15, OMB acknowledges there is additional work to be done in the collection of race and ethnicity data. There is also work to be done to standardize and codify the collection of language preference data, sexual orientation and gender identity data, disability-related data, and data related to rurality.

## Overview of Current Data Equity Landscape

To address ongoing disparities in health outcomes, there are increasing calls to better collect data by race, ethnicity, principal language, sexual orientation, and gender identity. Increasingly, the need to disaggregate data by race, ethnicity, language, sexual orientation, and gender identity beyond current standard practice has been acknowledged as necessary to avoid generalization errors in research, patient care, and other data analysis and interpretation.

The aggregation of data into broad, artificially homogenized groups can mask critical within-group differences and disparities and limit health and social services providers' abilities to focus resources where most needed. While researchers and policymakers have recognized the importance of disaggregating racial/ethnic data— many organizations have long advocated for data disaggregation—progress toward implementation has been slow and disparate. The current dearth of disaggregated racial/ethnic data contributes to persistent inequities in access to resources that can ensure equitable health and well-being (Kauh et al., 2021). Hospitals and HCOs with disaggregated data from their institutions may be more likely to look at disparities in care and health outcomes, design targeted programs to improve quality of care, and provide more culturally sensitive patient-centered care. Yet data collection is often fragmented and incomplete within and across organizations (Hasnain-Wynia & Baker, 2006).

There is value in characterizing the challenges and successes of achieving data equity by advocating for policies to fully disaggregate data. Populations with heritage in Asia, Hawaii, and the Pacific Islands have felt invisible from a data perspective. Led by the Coalition for Asian American Children and Families (CACF), the decade-long Invisible No More (INM) campaign for Asian American and Native Hawaiian/Pacific Islanders data disaggregation resulted in the first-ever data disaggregation law in New York City in 2016, followed by the enactment of a New York State Law in 2021. INM provides an important template for how coalition-based advocacy can successfully push for the passage and implementation of laws that mandate better data collection and usage (Gundanna et al., 2023). As outlined by Yi, et al. in the article, "With No Data, There's No Equity: Address the lack of Data on COVID-19 for Asian American Communities", and others, there was limited data on Asian Americans that fueled a misconception of a low share of COVID-19 deaths and cases, while this group had higher case fatality rates than other racial/ethnic groups and large within-group variation, masking risk (Yi et al., 2021; Yi et al., 2022).

Hispanic/Latino populations are heterogeneous as well. PolicyLink reported that three-fourths of the U.S. Hispanic/Latino population self-identify as Mexican, Puerto Rican, or Cuban, which represent strikingly different cultural and historic legacies (PolicyLink, 2018). Finally, the grassroots efforts in states with large populations of Middle Eastern or North African (MENA) residents to be able to self-identify as MENA rather than as white has helped to raise this misclassification and lack of recognition issue to the national discourse (ACCESS (Arab Community Center for Economic and Social Services), 2024; Stateline, 2014). Notably, the 2024 revisions to OMB SPD 15 include adding MENA as a new response and reporting category (Office of Management and Budget, 2024).

The value of disaggregated data was demonstrated in a recent report on the prevalence of cardiometabolic diseases among racial and ethnic subgroups in the U.S. which identified different diabetes prevalence among U.S. Asian subgroups ranging from 6.3% among Vietnamese adults to 15.2% among Filipino adults and differences in prevalence of coronary heart disease (CHD) among Hispanic subgroups (Koyama AK et al., 2024). Previous research assessing cardiovascular risk factors amongst Hispanic/Latino adults found substantial variation across Hispanic/Latino groups (Daviglus et al., 2012; Elias et al., 2023; Rodriguez et al., 2014).

Regarding principal language and health, in 2009, the Institute of Medicine (IOM) Subcommittee on Standardized Collection of Data for Healthcare Quality Improvement outlined the relationship between language barriers and health outcomes and offered recommendations on collection of language-related data including the recommendation that, at the very least, data should be collected on an individual's level of English proficiency and on preferred language spoken in a standardized manner (Institute of Medicine Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality, 2009). Since the IOM report was written, there has been an increase of more than 8 million persons speaking a language other than English at home in the U.S. (Dietrich S & Hernandez, 2022). In 2019, nearly 20% of individuals, over the age of 5, in the U.S. spoke a language other than English at home (Dietrich S & Hernandez, 2022). Accordingly, assessing and addressing language in health and health care settings is essential to best provide health care services.

Perhaps even less is known about health disparities by sexual orientation and gender identity (SOGI). Health care providers do not routinely discuss sexual orientation or gender identity (SOGI) with patients or document SOGI. Health care organizations (HCO) have not developed systems to collect structured SOGI data from patients. Lesbian, gay, bisexual, transgender, and queer (LGBTQ+) patients and their specific health needs and the health disparities they experience cannot be identified nor addressed, and important health care services may not be delivered (Centers for Disease Control and Prevention, 2022a). SOGI data collection has been recommended by both the National Academy of Medicine (Deutsch et al., 2013; Institute of Medicine, 2011) and the Joint Commission as a way to learn about which populations are being served and to measure the quality of care provided to people who are LGBTQ+ (Centers for Disease Control and Prevention, 2022a).

Caceres, et al. note that, to date, there is no published data on the cardiovascular health (CVH) of sexual minority adults in the U.S. using health record data (Caceres et al., 2020). In addition, Volpe et al. make a similar note, as it relates to stroke research, education and care (Volpe et al., 2023). The inclusion of SOGI

measures in electronic health records (EHR) provides an opportunity to use this data to examine CVH in LGBTQ+ individuals, including health care use among those with cardiovascular disease (CVD). Given the evidence that LGBTQ+ adults experience discrimination in health care settings, EHRs can be used to examine potential variations in care delivery among LGBTQ+ adults living with CVD (Blosnich et al., 2013; Institute of Medicine, 2011; Johnson et al., 2008; Pampati et al., 2021; Shipherd et al., 2011). In addition, the availability of data on social determinants of health (e.g. interpersonal violence, poverty, and food insecurity) in EHRs could allow researchers and clinicians to obtain a more comprehensive understanding of social factors associated with CVH in all adults, including LGBTQ+ adults. Others have identified strategies to enhance the ability to collect SOGI data to address LGBTQ+ cardiovascular health care disparities (Caceres et al., 2020; Deb et al., 2024; Tran et al., 2024).

## Summary of AHA Activities

AHA recognizes the need for continued focus on health equity across multiple facets of its work to improve cardiovascular health. This includes ongoing internal work to understand and address structural racism and inequities, work to impact hospitals and systems of care, policy advocacy work, and, most recently, work on data disaggregation.

The American Heart Association also recognizes the urgency to address, and is committed to eliminating, health disparities. Following an 18-month in depth review by a volunteer-driven Health Equity Task Force (HETF) AHA created its Office of Health Equity (OHE) in 2018. Among the recommendations of the HETF was to build organizational capacity, including growing human skill capacity and expanding/reframing science and research opportunities. The HETF asserted that AHA embraces and is committed to sharing ownership of advancing equity across AHA by the seven following principles:

1. Leveraging its financial assets, science knowledge, and voice to address issues of equity;
2. Embedding diversity and inclusion in its work, including volunteers, researchers, partners and collaborators;
3. Using its relationships with others to more effectively align the resources of all organizations to achieve health equity across ecosystems;
4. Acknowledging that systemic changes are needed to address long-standing issues of bias as well as current manifestations;
5. Acknowledging that engaged, committed activism for policy and systems change will be necessary at global, federal, state and community levels;
6. Acknowledging that public policy advocacy will require a broader scope of commitment; and
7. Emphasizing science as the core business of the AHA, seeking and applying evidence-based knowledge and filling gaps with research where such evidence does not exist.

In 2020, AHA's work addressing social determinants of health converged with the disproportionate disparities in COVID-19 infection and mortality rates and the killings of George Floyd, Breonna Taylor, and Ahmad Arbury. This culminated in the publication of a Presidential Advisory and call to action on Structural Racism as a Fundamental Driver of Health Disparities (Churchwell et al., 2020). The genesis of the response was attributed to the persistence of structural racism and institutional discrimination that impacts the health of Black Americans and other historically disenfranchised and underserved groups. Building on AHA's previously published statements addressing cardiovascular and cerebrovascular risk and disparities among racial and

ethnic groups in the U.S., the call to action highlighted structural racism as a fundamental cause of poor health and disparities in CVD. The advisory reviewed historical context, current state, and potential solutions to address structural racism in the U.S.. Several principles emerged: racism persists; racism is experienced; and the task of dismantling racism belongs to all of society. The advisory called on AHA to look internally to advance antiracist policies and practices regarding science, public and professional education, and advocacy.

As a reflection of the Association's belief that every person deserves the opportunity for a full healthy life, and to further the 2020 Presidential Advisory's call to action, the AHA announced 10 bold commitments in 2020 (American Heart Association, 2023) focused sharply on dismantling three barriers to health equity:

1. Negative social determinants of health (e.g., poverty, poor access to education, unemployment); (Centers for Disease Control and Prevention, 2022b)
2. The unique challenges faced in rural America; and
3. Structural racism.

These commitments and work are rooted in the research AHA funds and in science, programs, advocacy, and investments in communities. As a further demonstration of AHA's commitment to placing health equity at the forefront of its work, the Association in 2020 declared a 4-year goal: "As champions for health equity, by 2024, the American Heart Association will advance cardiovascular health for all, including identifying and removing barriers to health care access and quality."

AHA's Get with the Guidelines (GWTG) program is an evidence-based, in-hospital program of programs to improve patient outcomes and eliminate healthcare disparities across cardiovascular and stroke focus areas (American Heart Association, 2024b). More than 2,600 U.S. hospitals participate in at least one of five GWTG modules (Stroke, Heart Failure, Resuscitation, AFib, and Coronary Artery Disease), and nearly 80% of the U.S. population has access to a hospital that participates in at least one GWTG module. More than 13 million U.S. patient records have been entered into the GWTG registry. A reduction in health disparities has been observed at GWTG participating hospitals across several patient populations, including women, Hispanic people, and Asian American people (Ellrodt et al., 2013). Race, Sex, and Hispanic ethnicity have been categories in the GWTG registry since the early inception and are in alignment with OMB classifications. Gender Identity and Sexual orientation categories were added to align with the Office of the National Coordinator for Health Information Technology and Centers for Disease Control and Prevention guidance on the questions and categories. GWTG also collects various social determinants of health elements.

AHA's OHE has fostered and supported existing and new employee resource groups (ERG) as part of its commitment to organizational diversity and inclusion. ERGs reflect an important aspect toward addressing and realizing health equity. ERGs are groups of employees who join together in their workplace based on shared interests, characteristics, or life experiences and are generally based on providing strategic input to drive the mission, enhancing career development, and contributing to personal development in the work environment. Among AHA ERGs, Harmony, Health, & Happiness (H3) is supporting Asian American, Native Hawaiian, Pacific Islander and South Asian communities; Heart and Soul supports Black and African American communities; and Somos Corazon supports Hispanic/Latino communities. H3 has taken an organizational leadership role in elevating data disaggregation as an issue to understand and address through a data equity lens. H3 has participated in the work of the Data Equity Coalition co-led by the National Minority Quality

Forum (NMQ) and the Blue Cross Blue Shield Association (BCBSA) (see section on Data Equity Coalition below). In addition, AHA Hearts with Pride ERG supports the AHA LGBTQ+ community. On its web page, Hearts with Pride highlights that most research does not collect data on current gender identity, sex assigned at birth, and current sexual orientation which prevents researchers from accurately studying health and disease in LGBTQ+ people and assessing the health and well-being of sexual minority people.

The AHA established an internal AHA Data Equity Task Force in fall 2023 that convened staff from across the organization to share information, coordinate activities, and promote data equity within the organization and its work. Members of the task force represent AHA's work in the areas of health equity, science and research, policy, quality improvement, data science and evaluation, community engagement, professional membership, information technology, as well as the ERGs. The AHA Task Force serves as an important collaborator and advocate, and AHA's representative with the Data Equity Coalition also serves as a source of information for others in AHA, including the ERGs, and supports opportunities such as reviewing and editing this publication.

On January 16, 2024, AHA published Addressing Structural Racism Through Public Policy Advocacy (Albert et al., 2024). This policy statement describes a multipronged approach to addressing structural racism through public policy in six focus areas, including access to quality health care and education. While data disaggregation is not the focus of the policy statement, the following are included as examples of specific public policy actions to consider:

- Advance policies that compel public and private insurers to collect claims, quality, and other data aggregated by race and ethnicity to reveal and address inequities in coverage and care;

- Support companies' ability to track and report race-aggregated hiring and wage data to identify and address disparities;

- Eliminate bias in credit scoring systems to increase eligibility for historically disenfranchised racial and ethnic groups and social programs;

- Develop a comprehensive, standardized, nationwide data infrastructure; and

- Improve capture of social determinants of health data, including disaggregated data by race, ethnicity, sex, and gender identity at the patient and population level.

## Summary of Data Equity Coalition

On September 28, 2023, NMQF, BCBSA, and 17 partner organizations announced the formation of the Data Equity Coalition (Blue Cross Blue Shield, 2023). The coalition exists to improve health outcomes through better, accurate, representative data on race, ethnicity, language (REL), sexual orientation, and gender identification (SOGI). NMQF and BCBSA partnered to release an issue brief that outlined recommendations on REL and SOGI data collection for OMB. Called Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy, the issue brief, developed jointly by NMQF and BCBSA, describe policy challenges and makes recommendations to advance the data equity movement with governmental and nongovernmental partners, and served as the original grounding for the Data Equity Coalition (Blue Cross

Blue Shield Association & National Minority Quality Forum, 2023). The Coalition has advocated for uniform, non-voluntary minimum updated data standards not just for race and ethnicity but also sexual orientation and gender identity. Additionally, it has called on OMB to proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization.

The NMQF and BCBSA issue brief made four recommendations for inclusion in the OMB SPD 15 update:

1. Clear and consistent requirements for the collection of REL and SOGI data;
2. Incorporation of the current data standards promulgated by the DHHS Assistant Secretary for Planning and Evaluation/Office of Minority Health into the update and that these be the minimum standard categories for collecting disaggregated REL data;
3. Additional input from diverse stakeholders regarding SOGI data collection and utilization into the update; and
4. Enforcement of nonvoluntary, uniform and universal adoption of the updated standards upon release in 2024 for all government agencies and all private sector health care stakeholders.

## Summary of 2024 Revisions to OMB's Statistical Policy Directive No. 15 (SPD 15)

OMB initially developed SPD 15 in 1977 (Office of Federal Statistical Policy and Standards, 1977). Until 2024, SPD 15 had been revised once in 1997 (Office of Management and Budget, 1997). The objective of SPD 15 is to ensure comparability of race and ethnicity across Federal datasets and to maximize the quality of the data by ensuring consistent format, language, and procedures for collecting the data. The notice states that the SPD 15 race and ethnicity categories are "sociopolitical constructs" and in no way represent biologic or genetic definitions. The newest revision included internal and external stakeholder involvement described in a March 29, 2024 notice posted in the Federal Register (Office of Management and Budget, 2024).

The revisions to OMB SPD 15, while not all encompassing, offer several improvements in data collection that address health equity and disparity concerns. At the same time, the notice acknowledges the need for future research including identifying best data processing procedures and exploring a set of explicitly identified areas such as collecting data across different languages and translations and better understanding the ramifications of collecting data related to descent from persons enslaved in the U.S..

The new standards include the following:

1. Seven (7) minimum categories for data on race and ethnicity: American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Middle Eastern or Northern African, Native Hawaiian or Pacific Islander, and White. This includes a new category: Middle Eastern or Northern African.
2. A single combined race and ethnicity question – What is your race and /or ethnicity?
3. The removal of antiquated and disparaging terminology invites more inclusive participation.

The notice acknowledged that race and ethnicity are complicated, personal identity matters and that traditional definitions used in research may hinder accurate assessment of these complexities. Allowing respondents to select "all applicable descriptors" provides a community/individual driven solution to refining data collection.

**The new standards are effective March 28, 2024.**

## Next Steps

This document aims to define and differentiate health equity and data equity, provide an environmental scan of the U.S. data equity landscape, including the work of the NMQF/BCBSA-led Data Equity Coalition, a summary of the revisions to OMB SPD 15, and describe the evolution within AHA from health equity to data equity as areas of intentionality and strategic focus. There is more work to be done to address persistent inequities that burden U.S. communities.

The AHA supports the 2024 OMB SPD 15 revisions. Collecting better race and ethnicity data is imperative to eliminating health disparities and achieving health equity across all races and ethnicities. AHA has also identified the importance of quality SOGI data to better assess and address disparities in health, particularly cardiovascular health, in LGBTQ+ persons.  AHA, in its policy statement on addressing structural racism, identified examples of specific strategies that include data disaggregation. The American Heart Association is poised to engage in ongoing and future efforts to examine, advance, and apply the principles and practice of data equity in research and the translation of research, in programs, and in commitments to champion health equity, and work to eliminate health disparities for all individuals in the U.S..

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