# Data Equity Coalition

**MISSION:** The mission of the Data Equity Coalition is to develop and recommend policy solutions that advocate for race, ethnicity, language, as well as disability, geography, and sexual orientation and gender identification standards in support of health outcomes.

## BACKGROUND

In August 2022, the National Minority Quality Forum and Blue Cross Blue Shield Association jointly led four Data Equity Community Convenings collectively attended by over 25 organizations representing patients, consumers, payers, providers, businesses, and social change constituencies Leaders discussed gaps in data specificity that support efforts to address health equity, specifically the variability in the types of data collected, and how data is analyzed and applied. Participants emphasized the importance of understanding that the highest-quality data is self-reported.

NMQF and BCBSA took the learnings from these convenings and applied them in an issue brief, *"Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy."* The brief describes policy challenges and recommended solutions to advance a stakeholder-informed data equity movement that engages federal agencies, employers, labor, health systems, clinicians, and historically underrepresented populations. Specifically, the brief makes four recommendations to the Office of Management and Budget to update Statistical Policy Directive No. 15 (SPD 15), the federal government's minimum standard for collecting race and ethnicity data.

## ABOUT US

The Data Equity Coalition is a multi-stakeholder alliance dedicated to advancing data equity as a foundation for health equity. Through collective advocacy, education, and strategic engagement, the Data Equity Coalition works to strengthen the nation's data infrastructure and promote policies that improve the ability of healthcare organizations, policymakers, researchers, and communities to understand and address disparities across populations.

A cornerstone of the Coalition's work is advancing the implementation of the Office of Management and Budget's 2024 update to Statistical Policy Directive No. 15 (SPD 15), the first comprehensive revision to the federal standards for collecting race and ethnicity data in more than 25 years. The 2024 update represents a significant step forward in ensuring that federal data collection better reflects the diversity of the American population through modernized terminology, the establishment of a Middle Eastern or North African (MENA) minimum reporting category, and the adoption of a combined race and ethnicity question.

The Coalition recognizes the 2024 SPD 15 standards as the federal minimum standard for race and ethnicity data collection while advocating for more granular, standardized, and interoperable demographic data across race, ethnicity, language, sexual orientation and gender identity (SOGI), and disability status. Through public comment opportunities, convenings, strategic partnerships, and direct engagement with government and private-sector stakeholders, the Coalition advances policies and practices that improve the completeness, consistency, and usability of demographic data throughout the healthcare ecosystem.

Together, the Data Equity Coalition advances a shared vision of a healthcare system informed by robust and representative data, guided by diverse voices, and committed to serving all people with dignity, precision, and respect.