

April 27, 2023

Shalanda Young
Director
Office of Management and Budget
1650 17th Street NW
Washington, DC 20500

Re: Submission of Group Sign-on Letter to Revise OMB's 1997 Statistical Policy Directive No. 15

Dear Director Young,

The undersigned organizations appreciate the opportunity to comment on the initial proposals from the Federal Interagency Technical Working Group on Race and Ethnicity Standards (Working Group) for revising OMB's 1997 Statistical Policy Directive No. 15: Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity (SPD 15).

We represent patient advocacy, health care and business leadership organizations and have come together to advance a stakeholder-informed data equity movement that includes engagement with federal agencies, employers, labor, health systems, clinicians and historically under-represented populations. The recommendations that follow stem from three invitational stakeholder convenings in 2022 in which we participated to discuss the issues that attend data collection standards and ethical use with regards to race, ethnicity and language (REL) data and sexual orientation and gender identity (SOGI) data. They are explained in greater detail in an issue brief released in March by the National Minority Quality Forum and the Blue Cross Blue Shield Association entitled, *“Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy.”*

Significant health inequities plague the U.S. health care system, impacting historically marginalized racial¹, ethnic, socioeconomic² and LGBTQ+³ communities.⁴ There are many causes for these inequities, including, but not limited to, systemic racial, ethnic, language and LGBTQ+ biases and their intersectional relationship to concomitant sex, gender, age, disability, socioeconomic, cultural and geographic factors. Together, these forces have created, perpetuated and exacerbated inequalities in access to the benefits of the American health services research, delivery and financing system. The consequences of these biases manifest as disparate, but preventable and amenable morbidity and mortality every year.

The well-documented disparities in the availability of and access to high-quality health care in terms of diagnosis and treatment that could result in disparate outcomes are pervasive, multi-faceted and multi-

¹ U.S. Department of Health and Human Services Task Force on Black and Minority Health, 1985-1986.

https://collections.nlm.nih.gov/catalog/nlm:nlmuid-8602912-mvset?_gl=1*1kfz8hy*_ga*MTI0NDgzOTM2NS4xNjc3Njk2Mzg5*_ga_P1FPTH9PL4*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.*_ga_7147EPK006*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.

² Riley WJ. “Health disparities: gaps in access, quality and affordability of medical care.” *Trans Am Clin Climatol Assoc.* 2012. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3540621/>.

³ Baptiste-Roberts K, Oranuba E, Werts N, Edwards LV. “Addressing Health Care Disparities Among Sexual Minorities.” *Obstet Gynecol Clin North Am.* March 2017. <https://pubmed.ncbi.nlm.nih.gov/28160894/>.

⁴ Blue Cross Blue Shield Association. “The Ethical and Transparent Use of Data to Reduce Health Disparities,” page 2. https://www.bcbs.com/sites/default/files/healthequity/REL/HE_REL_Data_Paper.pdf.

sectorial. They are challenging, but not insurmountable. Failure to be proactive to redress these inequities compromises not only the health of families and communities, but also the financial health of employers and the bottom lines of businesses across all industry sectors.

The planned OMB update of Directive No. 15 can enable every sector of the health services research, delivery and financing system to advance the diversity, equity and inclusion plans that they have announced as priorities. Further, a case can be made that absent the Directive No. 15 update and other steps outlined below, collectively, these efforts will fail.

The value of comprehensive data on a full range of populations and population cohorts cannot be overstated. Standardized, precise data create opportunities for insurers, health care providers, employers and patient advocates to design and implement targeted solutions to better meet the needs of perpetually underserved groups. Through adoption of robust and comprehensive REL and SOGI data, health entities can better monitor health services access and utilization, design focused incentives for health providers to reduce inequities, track changes in health outcomes by population cohort and respond accordingly, and more accurately measure progress on reducing disparities. By incorporating a richer data set reflecting inclusive workforce composition, employers can make informed decisions on which health plan can best meet the needs of employees and their families.

Collecting and exchanging data with the right level of detail necessitates a multi-stakeholder effort. No single sector has sufficiently robust and precise data to redress systemic inequities in health care. The collaboration between health care leaders, social service agencies and community-based organizations supports working together to address data equity challenges. Because such inequities are universal, it is imperative the health care research, delivery and financing enterprise coalesce around adoption of national data collection and standards for health equity data sets. The Office of the National Coordinator for Health IT (ONC) noted that advancing the use of data standards and interoperability of health equity data is crucial to improving the health and well-being of all individuals and communities. Beyond adopting a common standard for health equity data, more work is needed across the ecosystem to solve this challenge.⁵

Industry adoption of updated Directive No. 15 standards is essential. During the Directive No. 15 updating process, the evolving nature of SOGI data must be accommodated. Equity in access to the data collection process, as well as assuring that all population cohorts are reflected in the data is at the crux of systemic equity.

In addition to technical standards, standards are needed to define how best to engage with individuals and their families. If trust is indeed a factor that affects the ability to collect reliable data, distrust must not be triggered during the data collection process. Uniformity in the data collection tools, lexicon and framing of questions is essential.

Accordingly, we support the following recommendations for inclusion in the OMB Directive No. 15 update that is scheduled for completion in 2024:

- Directive No. 15 should provide clear and consistent requirements for the collection, of REL and SOGI data that include a minimum standard for disaggregated R/E collection and are consistent with

⁵ Blue Cross Blue Shield Association. "The Ethical and Transparent Use of Data to Reduce Health Disparities," page 5. https://www.bcbs.com/sites/default/files/healthequity/REL/HE_REL_Data_Paper.pdf.

industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).

- OMB should incorporate the current data standards promulgated by the DHHS Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15 and require that these be the minimum standard categories for collecting disaggregated REL data.
- OMB should intentionally and proactively elicit and accept additional input from diverse stakeholders regarding SOGI data collection and utilization into the Directive No. 15 update.
- OMB should enforce non-voluntary, uniform and universal adoption of the updated OMB Directive No. 15 standards upon release in 2024 for all government agencies, and all private sector health care stakeholders including payers and providers.

Thank you for your consideration of these recommendations. We stand ready to work with the Working Group and OMB to implement an inclusive updating process that will serve to improve the inputs and outcomes of health care, inform research and innovation, and assure that coverage and payment policies reflect and assign equitable value to the full diversity of the American general population.

Sincerely,

Advocates for Community Health

Alliance for Women's Health & Prevention

American Benefits Council

American Cancer Society Cancer Action Network

American College of Physicians

American Diabetes Association

American Heart Association

American Nurses Association

Association of Black Cardiologists

Association of Black Health-system Pharmacists

Black Women's Health Imperative

Blue Cross Blue Shield Association

Minority Health Institute, Inc

National Health Council

National Hispanic Medical Association

National LGBTQ Task Force

National Minority Quality Forum

National Rural Health Association

Satcher Health Leadership Institute, Morehouse School of Medicine