



December __, 2023

The Honorable Xavier Becerra
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Re: Data Equity and Expansion of Language and SOGI to Statistical Policy Directive No. 15

Dear Secretary Becerra,

The National Minority Quality Forum and the Blue Cross Blue Shield Association submit this letter on behalf of the Data Equity Coalition, including patient advocacy, health care, and business leadership organizations collaborating to advance a stakeholder-informed data equity movement. We appreciate sharing our recommendations from the public comment opportunity to OMB for inclusion in the updated Statistical Policy Directive No. 15, due for release in Summer 2024:

- Directive No. 15 should provide clear and consistent requirements for collecting REL (race, ethnicity, language) and SOGI (sexual orientation and gender identification) data that include a minimum standard for disaggregated race and ethnicity collection that are compatible with industry interoperability standards (e.g., Fast Healthcare Interoperability Resources (FHIR) standards).
- OMB should incorporate the current data standards promulgated by the Department of Health and Human Services (DHHS) Assistant Secretary for Planning and Evaluation/Office of Minority Health into Directive No. 15, outlining a framework of two separate questions for race and ethnicity with seven categories and six subcategories, including the addition of a Middle Eastern or North African (MENA) ethnicity category, 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 in 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 healthcare stakeholders, including payers and providers.

The process that resulted in these recommendations and a more detailed discussion of the attendant issues is included in the issue brief, *“Standardizing Data to Advance the Health Equity Movement: A Multi-Sectorial Strategy.”*¹ which was released in March by the National Minority Quality Forum and the Blue Cross Blue Shield Association.

¹ Blue Cross Blue Shield Association and National Minority Quality Forum. March 28, 2023. “Standardizing Data to Advance the Health Equity Movement: A Multi-sectional Strategy.” https://dataequitycoalition.com/wp-content/uploads/2023/07/NMQF_Brief_Paper.pdf.

The planned OMB update of Directive No. 15 can enable every health services research, delivery, and financing system sector to advance diversity, equity, and inclusion plans. Absent an equitable update to Directive No. 15, efforts to ensure systemic change may be jeopardized.

Significant health inequities plague the U.S. healthcare system, impacting historically marginalized racial², ethnic, socioeconomic,³ and LGBTQ+⁴ communities.⁵ There are many causes, including, but not limited to, systemic racial, ethnic, language, and LGBTQ+ biases and their intersectional relationship to identification based on sex, gender, age, disability, socioeconomic, culture, and geography. The lack of availability and access to high-quality healthcare diagnosis and treatment within the American health services research, delivery, and financing system is a serious consequence. Failure to be proactive and redress these inequities and gaps in care compromises the health of families, communities, and the financial health of employers.

Value of Comprehensive Data

The value of comprehensive data on the full range of populations and population cohorts is evident. Standardized, precise data create opportunities for patients, healthcare providers, employers, and insurers to design and implement targeted, sustainable, and culturally relevant community solutions. The healthcare research, delivery, and financing enterprise must coalesce around adopting national data collection and health equity standards for comprehensive data sets.

Trust is a factor that impacts the ability to collect reliable data. Standards are needed to define how best to engage with individuals and their families in a manner that augments ethics, inclusivity, and integrity. Uniformity in data collection tools serve as one approach, as does the lexicon and framing of questions. Additional considerations related to culture and humility are imperative to evolve a more representative process.

HHS is critically important to advancing data equity. We respectfully request prioritizing the following recommendations:

- Upon release of the updated SPD 15 by OMB, HHS should act as efficiently and effectively as possible to adopt the standards as the minimum requirement for all HHS programs, existing and new, that collect data in the covered domains of race and ethnicity.
- HHS should require private-sector program participants to use the new minimum SPD 15 standards and provide technical assistance to help implementation.

² 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*1kzf8hy*_ga*MTIONDgzOTM2NS4xNjc3Njk2Mzg5*_ga_P1FPTH9PL4*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA..*_ga_7147EPK006*MTY3NzY5NjUwMS4xLjAuMTY3NzY5NjUwMS4wLjAuMA.

³ 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/>.

⁴ 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.

- HHS should build on SPD 15 by creating minimum standards for collecting language and SOGI data promulgated by Executive Order⁶ 14075⁷ and outlined in the 2022 NASEM Report⁸, and intentionally and proactively elicit and adopt input from diverse community stakeholders within and external to the federal government.

In closing, thank you for considering these recommendations. The Data Equity Coalition, co-founded by the National Minority Quality Forum, the Blue Cross Blue Shield Association, and our organizational colleagues stand ready to work with HHS to implement the new SPD 15 minimum standards and build on the standards by also including the HHS-created minimum standards for language and SOGI.

Together, these processes will improve healthcare outcomes, inform research and innovation, affirm community stakeholders, and assure that coverage and payment policies reflect and assign equal value to the full spectrum of our diverse population.

Sincerely,

Data Equity Coalition Stakeholders

⁶ The White House Briefing Room. June 15, 2022. "Executive Order on Advancing Equality for Lesbian, Gay, Bisexual, Transgender, Queer, and Intersex Individuals." <https://www.whitehouse.gov/briefing-room/presidential-actions/2022/06/15/executive-order-on-advancing-equality-for-lesbian-gay-bisexual-transgender-queer-and-intersex-individuals/>.

⁷ Federal Register, Vol. 87, No. 163. Aug. 24, 2022. "Request for Information; Federal Evidence Agenda on LGBTQI+ Equity." <https://www.govinfo.gov/content/pkg/FR-2022-08-24/pdf/2022-18219.pdf>.

⁸ National Academies of Sciences, Engineering, and Medicine. 2022. "Measuring Sex, Gender Identity, and Sexual Orientation." Washington, DC: The National Academies Press. <https://doi.org/10.17226/26424>.