

September 29, 2025

Thomas Keane, MD, MBA  
Assistant Secretary for Technology Policy  
U.S. Department of Health and Human Services  
330 C Street SW, 7th Floor  
Washington, DC 20201

Dear Dr. Keane,

The Data Equity Coalition thanks the Assistant Secretary for Technology Policy (ASTP) for the opportunity to provide recommendations for the United States Core Data for Interoperability (USCDI) version 7.

The Data Equity Coalition represents patients, businesses, and health care industry leaders committed to closing the gaps in health data collection standards to improve health outcomes. The adoption of comprehensive and standardized data collection categories is crucial for enhancing data access, utilization, and community-driven interventions. Our mission is to develop and recommend policy solutions that advance standards related to race, ethnicity, language, sexual orientation, and gender identity in support of addressing health issues, such as chronic conditions, and improving health outcomes.

The Data Equity Coalition is pleased to provide the following recommendations for USCDI version 7:

## **Patient Demographic Data/Information**

### **1. Race and Ethnicity**

**Recommendation Type:** Modification to existing USCDI elements

**Recommendation:** The Data Equity Coalition recommends that ASTP update the current race and ethnicity data elements to align with the 2024 revised Office of Management and Budget (OMB) Statistical Policy Directive No. 15 (SPD 15) standards for the collection and use of race and ethnicity data. We recommend that ASTP consolidate the current race and ethnicity data elements into a single data element, aligning with SPD 15.

**Rationale:** Persistent disparities in health outcomes, particularly among historically underserved communities, are exacerbated by outdated and incomplete data collection practices<sup>1</sup>. Standardizing these elements across federal health programs, health IT systems, and value-based care models is foundational to identifying disparities, mitigating bias in emerging technologies, and advancing health equity<sup>2</sup>. Incorporating the updated OMB SPD 15 categories into the USCDI will promote consistency across the ecosystem and support HHS's broader goals in prevention, wellness, and chronic disease management<sup>3</sup>.

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<sup>1</sup> [The Issues of Interoperability and Data Connectedness for Public Health - PMC](#)

<sup>2</sup> [Data Standards - Tools and Technologies for Registry Interoperability, Registries for Evaluating Patient Outcomes: A User's Guide, 3rd Edition, Addendum 2 - NCBI Bookshelf](#)

<sup>3</sup> [Dr. Mehmet Oz Shares Vision for CMS | CMS](#)

## 2. Sexual Orientation and Gender Identity

**Recommendation Type:** Reinstatement of previous USCDI elements

**Recommendation:** The Data Equity Coalition recommends that ASTP reinstate the sexual orientation and gender identity (SOGI) data elements that were removed from USCDI version 6. The data elements should align with USCDI version 3, with sexual orientation data elements utilizing SNOMED International, Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT®) U.S. Edition, March 2022 Release. The data elements for gender identity should align with SNOMED CT® and HL7 Version 3 Standard, Value Sets for AdministrativeGender and NullFlavor.

**Rationale:** Data elements for SOGI are integral to collecting health data and health information exchange. Collecting SOGI data is critical for understanding the lived experiences and health disparities that impact different populations<sup>4</sup>. Without data elements for SOGI, it becomes more challenging to measure population health and the effectiveness of interventions for different populations accurately and meaningfully, addressing their unique, intersectional needs. Reinstating the SOGI data elements in the USCDI will help HHS agencies and the broader health care ecosystem in understanding the health and well-being challenges people face related to their sexual orientation and gender identity.

We respectfully urge ASTP to align the race and ethnicity data elements with the revised OMB SPD 15 standards and reinstate the previously removed data elements on sexual orientation and gender identity into the USCDI version 7. Improving the quality and completeness of Race, Ethnicity, and Language (REL) data, along with SOGI data, will enable the health care system to better identify and understand health disparities and create initiatives to address them. We share this administration's goals of addressing the root causes of chronic conditions, and having complete data is essential to understanding and developing solutions that will help us make necessary progress.

As the conveners of the Data Equity Coalition, we thank you for the opportunity to comment on the USCDI version 7.

Sincerely,

Data Equity Coalition Stakeholders

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<sup>4</sup> [Collecting Data on Sexual Orientation and Gender Identity: A Promising Practice for Improving Population Health and Advancing Health Equity - PMC](#)