DATA EQUITY COALITION

Data Points

A Newsletter Update from the Data Equity Coalition

Protecting Representation Across Census 2030, Federal Data Standards, and State Advocacy

The third quarter brought a consequential shift in the federal data landscape. **The new Census Bureau proposal would restrict race and ethnicity questions on the 2030 Census form, coinciding with the delayed implementation and enforcement timeline for the Office of Management and Budget (OMB) revisions to the Federal Agency Action Plans for Statistical Policy Directive No. 15 (SPD15).** The impact would be non-enforcement of race and ethnicity categories as previously authorized. In response, the Data Equity Coalition sharpened its federal advocacy, highlighted why participation in the public comment process matters, refreshed state tools and resources, and continued building partnerships that connect standardized demographic data to healthcare access, quality, and accountability.

Census 2030 and the Connection to SPD 15

On September 10, the U.S. Census Bureau proposed regulations that would change who counts for apportionment, where and when people count, and what information the decennial census collects. The proposal would exclude the full population count as required by the Constitution, and exclude citizens without lawful permanent "residence criteria". To undermine SPD15, a separate provision proposed would prohibit race and ethnicity questions and ban any future sexual orientation questions from the 2030 Census form.

These changes could result in persistent undercounts, reduce participation, and distort representation and the distribution of public resources. For healthcare stakeholders, an inaccurate population count can affect the data used to plan services and understand community needs across Medicaid, Medicare, public health, and housing, upending equitable healthcare delivery and distorting the broader ecosystem of care.

Timely Update

URGENT! Please Submit a Public Comment here:



The public comment deadline for the Census 2030 proposed rule was extended to **November 2, 2026**. DEC members and partners are encouraged to explain the operational, civil rights, research, and healthcare consequences of limiting self-reported race and ethnicity data in the decennial census.

Resources







A Direct Challenge to SPD 15 Implementation

The 2024 revisions to SPD 15 require a combined race and ethnicity question, seven co-equal minimum categories, a new Middle Eastern or North African category, and additional detail beyond the minimum categories. The Census Bureau had been preparing to implement the updated standards in the 2027 American Community Survey and the 2030 Census.

The abrupt removal of race and ethnicity questions from the decennial census would go beyond a failure to implement the updated standards. It could eliminate a foundational source of self-reported demographic data and create a precedent for further retreat across federal agencies. Administrative records cannot fully replace direct self-identification because they may be incomplete, outdated, or collected for different purposes under inconsistent standards.

Similarly, the Data Equity Coalition also tracked federal proposals or policy changes affecting demographic data collection at the Equal Employment Opportunity Commission. Taken together, these developments could reduce or erase the visibility needed to ensure individuals are seen, counted, and represented; to accurately identify discrimination; measure disparities; and design responsive programs.

Public Comments Matter

Public comments give communities, healthcare organizations, researchers, and other stakeholders a formal way to place their experience and evidence into the federal rulemaking record before an agency issues a final rule. Agencies must review significant comments and explain their response. A strong public record can identify operational gaps, document likely harm, and offer workable alternatives.

Please watch the webinar below from the National Minority Quality Forum and the Data Equity Coalition



Standards decide what data moves and for whom

Federal rules often determine which health information technology standards systems must support. Those standards shape which data fields exist, what organizations capture, and what information follows a patient across settings. When a standard omits a data element or use case, the resulting gap appears later in care delivery, coverage, research, and performance measurement.

Stakeholders can provide input through proposed rules and requests for information, annual standards-development cycles such as the United States Core Data for Interoperability (USCDI), and federal advisory processes. Each pathway offers a different opportunity to explain how policy will operate in practice.

What makes a comment useful

- Be specific. Identify the provision and respond to the questions the agency asks.
- Show the evidence. Use data, field experience, and concrete examples.
- Describe the real-world effect. Explain who would be affected, how the change would occur, and why it matters.
- Offer a solution. Recommend a workable alternative, clearer guidance, additional time, flexibility, or implementation support.

Different sectors see different parts of the same policy. Patients and communities can describe trust and lived experience. Providers and health plans can identify workflow and implementation consequences. Public health agencies, community organizations, and technology developers can explain effects on surveillance, access, and interoperability. Joint comments can demonstrate shared priorities, while individual comments add distinct evidence to the record.

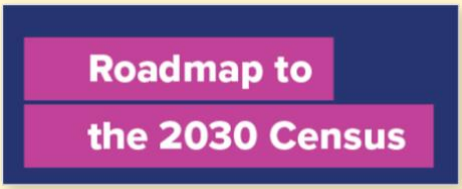
A Safety-First Framework ~ Thank you AAPI DATA

The SMARTT Data Framework offers six principles for responsible data practice: Safe, Meaningful, Accurate, Representative, Translatable, and Transformative. The framework reinforces that greater detail must be paired with privacy protections, community participation, accurate interpretation, and a clear purpose for improving policy or services.

Census 2030 Public Engagement

The volume and range of comments show why broad participation matters. Templates can help organizations begin, but comments carry greater value when they include sector-specific evidence, local examples, and the experience of the communities most affected.

Thank you to the Leadership Conference on Civil and Human Rights



State Action Through Data Disaggregation

State action remains essential as federal policy becomes less predictable. The Coalition refreshed its State Advocacy Toolkit to help partners translate SPD 15 into practical state strategies and prepare for upcoming legislative sessions. The updated materials emphasize adaptable messaging, model policy language, state examples, coalition-building guidance, and implementation resources.

Detailed data reveal needs hidden by broad categories

AAPI Data illustrated the stakes for Asian American, Native Hawaiian, and Pacific Islander communities. From 2020 to 2024, Asian American and NHPI populations grew by about 10 percent and 6 percent, compared with 4 percent nationally. Yet broad categories can conceal large differences within these populations. Nationally, 22 percent of Burmese households and 55 percent of Marshallese households experience overcrowding, compared with 3.4 percent of households overall.

These differences are not visible when communities are grouped into categories that are too broad for meaningful analysis. Detailed state data can help policymakers and healthcare stakeholders identify unmet needs, target resources, and evaluate whether programs reach the populations they intend to serve.

Additional Resources

- AHIP introduced the Demographic Data Element Modernization Initiative, developed with Civitas Networks for Health and HL7 to advance voluntary national standards for demographic data across ten identity domains.
- The Coalition reviewed Title I of the Health Equity and Accountability Act and its connection to SPD 15 implementation.
- The Data Equity Coalition website remained the central home for toolkits, public comments, webinars, and coalition materials, with additional recording updates underway.

Looking Ahead

The Coalition will continue defending complete and accurate demographic data while preparing partners for state legislative sessions and future federal comment opportunities. The next phase, post-Midterms, will determine strategy with OMB, connect policy advocacy to implementation, help DEC contribute stronger evidence, and support data practices that preserve the visibility of underrepresented and undercounted communities.



In case you missed it!



