

# New HHS Data Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status

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**M**ANY RACIAL AND ETHNIC MINORITIES, PEOPLE with limited English-language proficiency, people with disabilities, and other commonly underserved populations face unique health challenges, have reduced access to health care and insurance, and often experience poorer health throughout their lives.<sup>1,2</sup> In the past, identifying disparities and effectively monitoring efforts to reduce them have been limited by a lack of specificity, uniformity, and quality in data collection and reporting procedures. The importance in the documentation of disparities and the critical importance of rich data systems to understand and track interventions to reduce health disparities among population subgroups have been called for, dating back to the 1985 Report of the Secretary's Task Force on Black and Minority Health<sup>3</sup> and the recent Institute of Medicine report *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*.<sup>2</sup> As noted in those reports, consistent methods for collecting and reporting health data will help better characterize the nature of health problems in underserved populations.

The Department of Health and Human Services (HHS) has adopted new data standards for the collection of race, ethnicity, sex, primary language, and disability status for self-reported data collected from population-based health surveys.<sup>4</sup> Data standards were developed in accordance with section 4302 of the Affordable Care Act. That section of the act focuses on the standardization as well as collection, analysis, and reporting of health disparities data.<sup>5</sup> It requires the HHS secretary to establish data collection standards for race, ethnicity, sex, primary language, and disability status. The law requires that, once established, these data collection standards be used in national population health surveys. The law also gives the secretary the authority to require collection of additional demographic data on departmental population health surveys and to develop appropriate additional data collection standards.

Even though data collection will not reduce disparities, having such data is fundamental to the department's efforts to understand the causes of health disparities, design effective responses, and evaluate progress in reducing disparities. The new data standards for race, ethnicity, sex, primary lan-

guage, and disability status represent a critical step in uniformly collecting data needed to track disparities and to ensure continued progress in efforts to reduce disparities.

## Data Standards Development Process

In selecting the data standards, HHS examined current federal data collection standards, adequacy of prior testing, and quality of the data produced in prior surveys; consulted with statistical agencies and programs; and reviewed Office of Management and Budget data collection standards and the Institute of Medicine report *Race, Ethnicity, and Language Data*.<sup>2</sup>

The following criteria were applied for identifying appropriate data standards: (1) preference was given to data standards that are evidence based and demonstrated to have worked well in practice in current national surveys; (2) data standards would be framed as minimum data standards, with agencies permitted to collect as much additional detail and granularity as desired, provided that the standard is used, additional detail could be aggregated back to the minimum standard, and the sample size supports the estimates at that level of granularity; (3) data standards already mandated by the Office of Management and Budget would serve as the basis for any minimum standard; and (4) standards would apply to HHS-sponsored person-level data collected in population-based health surveys, in which survey participants either self-report information or a knowledgeable proxy provides information about the person or responds for all persons in a household survey.<sup>4,6</sup>

After several levels of internal HHS review, proposed data standards and supporting rationale were posted for public comment during July 2011.<sup>7</sup> Public comments were reviewed and considered in making recommendations for final data standards, along with the above-mentioned data standard criteria. The final data standards for race, ethnicity, sex, primary language, and disability status are listed in the TABLE, and supporting rationale for data standards are available.<sup>8</sup> HHS will begin implementation of these newly adopted data

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standards beginning in November 2011 for each new survey and at the next major revision for existing surveys. Missing from these requirements are data on socioeconomic status, which is clearly associated with health care disparities.<sup>9</sup>

## Conclusion

Section 4302 of the Affordable Care Act establishes a roadmap for improving data collection efforts for racial and ethnic minorities, individuals with disabilities, and populations with limited English-language proficiency. The goal of the section is to improve efforts to reduce disparities through the standardization, collection, analysis, and reporting of data on health and health care disparities.<sup>10</sup> This Commentary describes the first major steps along this data roadmap: adopting data collection standards for 5 demographic areas. The newly adopted data standards for race, ethnicity, sex, primary language, and disability status are designed to enhance data collection, reporting, and tracking of health disparities. Enhanced and standardized data in these demographic areas will allow better understanding of the health barriers faced by these populations.

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## REFERENCES

1. Institute of Medicine (IOM). *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Washington, DC: National Academies Press; 2002.
2. Institute of Medicine (IOM) Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality. *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Washington, DC: National Academies Press; 2009.
3. Heckler MM. Report of the Secretary's Task Force on Black and Minority Health. US Dept of Health and Human Services Web site. <http://minorityhealth.hhs.gov/assets/pdf/checked/1/ANDERSON.pdf>. 1985. Accessed August 31, 2011.
4. Office of Minority Health. Final data collection standards for race, ethnicity, primary language, sex, and disability status required by section 4302 of the Affordable Care Act. US Dept of Health and Human Services Web site. <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=208>. Accessed November 10, 2011.
5. Patient Protection and Affordable Care Act. Understanding Health Disparities: Data Collection and Analysis. Pub L No. 111-148 §4302. US Government Printing Office Web site. <http://www.gpo.gov/fdsys/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf>. March 23, 2011. Accessed November 7, 2011.
6. Office of Management and Budget. Recommendation from the Interagency Committee for the Review of the Racial and Ethnic Standards to the Office of Management and Budget Concerning Changes to the Standards for Classification of Federal Data on Race and Ethnicity. *Fed Regist*. 1997;62:36873-36946.
7. Department of Health and Human Services. Notice of Availability of Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act. *Fed Regist*. 2011;76(126):38396-38397.
8. Office of Minority Health. Explanation of data standards for race, ethnicity, sex, primary language, and disability. US Dept of Health and Human Services Web site. <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9228&lvl=2&lvlid=208>. Accessed November 10, 2011.
9. Winker MA. Measuring race and ethnicity: why and how? *JAMA*. 2004;292(13):1612-1613.
10. Joint Center for Political and Economic Studies. *Patient Protection and Affordable Care Act of 2010: Advancing Health Equity for Racially and Ethnically Diverse Populations*. Washington, DC: Joint Center for Political and Economic Studies; 2010.

**Table.** US Department of Health and Human Services Data Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status<sup>a</sup>

Demographic Variable	Data Standard
Ethnicity <sup>b</sup>	Are you Hispanic, Latino/a, or of Spanish origin (1 or more categories may be selected) a. ___ No, not of Hispanic, Latino/a, or Spanish origin b. ___ Yes, Mexican, Mexican American, Chicano/a c. ___ Yes, Puerto Rican d. ___ Yes, Cuban e. ___ Yes, Another Hispanic, Latino/a or Spanish origin
Race <sup>c</sup>	What is your race? (1 or more categories may be selected) a. ___ White b. ___ Black or African American c. ___ American Indian or Alaska Native d. ___ Asian Indian e. ___ Chinese f. ___ Filipino g. ___ Japanese h. ___ Korean i. ___ Vietnamese j. ___ Other Asian k. ___ Native Hawaiian l. ___ Guamanian or Chamorro m. ___ Samoan n. ___ Other Pacific Islander
Sex	What is your sex? 1. ___ Male 2. ___ Female
Primary language	How well do you speak English? (respondents 5 years or older) a. ___ Very well b. ___ Well c. ___ Not well d. ___ Not at all
Disability status <sup>d</sup>	1. Are you deaf or do you have serious difficulty hearing? a. ___ Yes b. ___ No 2. Are you blind or do you have serious difficulty seeing, even when wearing glasses? a. ___ Yes b. ___ No 3. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (respondents 5 years or older) a. ___ Yes b. ___ No 4. Do you have serious difficulty walking or climbing stairs? (respondents 5 years or older) a. ___ Yes b. ___ No 5. Do you have difficulty dressing or bathing? (respondents 5 years or older) a. ___ Yes b. ___ No 6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a physician's office or shopping? (respondents 15 years or older) a. ___ Yes b. ___ No

<sup>a</sup>Adapted from table available at <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9227&lvl=2&lvlid=208>. Supporting rationale for race, ethnicity, sex, primary language, and disability status data standards is available at <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9228&lvl=2&lvlid=208>.

<sup>b</sup>Data standard is in compliance with the Office of Management and Budget (OMB) minimum standard for ethnicity. The OMB considers race and ethnicity a single standard and mandates that ethnicity questions be asked first.<sup>6</sup> Explanation of how the ethnicity data standard aligns with the OMB ethnicity minimum standard is available at <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9228&lvl=2&lvlid=208>.

<sup>c</sup>Data standard is in compliance with the OMB minimum standard for race. Explanation of how the race data standard aligns with the OMB race minimum standard is available at <http://minorityhealth.hhs.gov/templates/content.aspx?ID=9228&lvl=2&lvlid=208>.

<sup>d</sup>Disability status data standard includes all 6 items.