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

Rashida Dorsey, PhD, MPH

Department of Health and Human Services

Office of the Assistant Secretary for Planning and Evaluation

Affordable Care Act Section 4302

Understanding Health Disparities: Data Collection and Analysis

- Requires the DHHS Secretary to establish data collection standards for five specific demographic data:
 - Race
 - Ethnicity
 - Sex
 - Primary language
 - Disability status
- Additional requirements for data standards
 - Based on self-reported measures
 - In compliance with OMB standards (race/ethnicity)
 - Used in federal data collection and reporting
 - To the extent practicable
 - Subject to appropriations

Data Standards for HHS Surveys

- Data standard development process
 - HHS Data Council led
 - Reviewed existing data standards, current data collection policies, and published reports
 - Criteria for data standards
 - Evidence-based and demonstrated to have worked well in practice in current national surveys
 - Represent minimum standards
 - Data standards already mandated by OMB would serve as the starting point for any standard
 - Standards would apply to HHS sponsored person-level data collected in population-based health surveys
- Draft set of data standards developed and subjected to several levels of internal review and public comment
- Final data standards adopted October 31, 2011
<http://minorityhealth.hhs.gov/section4302/>

NEW HHS DATA STANDARDS FOR MAJOR SURVEYS

Race, Ethnicity, Sex, Primary
Language and Disability Status

Race

■ What is your race? (One or more categories may be selected)

- White
 - Black or African American
 - American Indian or Alaska Native
- } Present OMB Minimum

- Asian Indian
 - Chinese
 - Filipino
 - Japanese
 - Korean
 - Vietnamese
 - Other Asian
- } Asian OMB Minimum

- Native Hawaiian
 - Guamanian or Chamorro
 - Samoan
 - Other Pacific Islander
- } Native Hawaiian or Other Pacific Islander OMB Minimum

Ethnicity

- Are you of Hispanic, Latino/a, or Spanish origin? (one or more categories may be marked)
 - No, not of Hispanic, Latino/a, or Spanish origin;
 - Yes, Mexican, Mexican-American, Chicano/a;
 - Yes, Puerto Rican;
 - Yes, Cuban;
 - Yes, another Hispanic, Latino/a, or Spanish origin-

Sex

- What is your sex?
 - Female
 - Male

Primary Language

- Measure of English Proficiency
- How well do you speak English? (5 years of age or older)
 - Very well
 - Well
 - Not well
 - Not at all

Primary Language

- The Department also provided measures to assess spoken language, for additional and optional granularity:
- Do you speak a language other than English at home?
 - Yes
 - No
- If yes, what is this language?
 - Spanish
 - Other language: _____

Disability Status

- Are you deaf or do you have serious difficulty hearing?
 - Yes
 - No
- Are you blind or do you have serious difficulty seeing, even when wearing glasses?
 - Yes
 - No
- Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions? (5 years of age or older)
 - Yes
 - No
- Do you have serious difficulty walking or climbing stairs? (5 years of age or older)
 - Yes
 - No
- Do you have difficulty dressing or bathing? (5 years and older)
 - Yes
 - No
- Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years and older)
 - Yes
 - No

Data Standard Implementation

- HHS-sponsored **population surveys** where **person-level data** is collected via either **self-report** or from a knowledgeable proxy
 - Representative **samples**
- Data standards represent **minimum standards**
- Standards apply to all new surveys and at the time of the next **major revision** for existing surveys

Data Standard Implementation

- Changing existing responses to questions
- Changing existing questions
- Adding new questions
 - Synthesizing existing questions with required standards

Medical Expenditure Panel Survey

Data Standard	2011 MEPS data collection
White	White
Black or African American	Black or African American
American Indian or Alaska Native	American Indian or Alaska Native
Asian Indian	Asian Indian
Chinese	Chinese
Filipino	Filipino
Japanese	Japanese
Korean	Korean
Vietnamese	Vietnamese
Other Asian	Other Asian
Native Hawaiian	Native Hawaiian or Other Pacific Islander
Guamanian or Chamorro	
Samoaan	
Other Pacific Islander	

Behavioral Risk Factor Surveillance System

Data Standard	2011 BRFSS Core
White	White
Black or African American	Black or African American
American Indian or Alaska Native	American Indian or Alaska Native
Asian Indian	Asian
Chinese	
Filipino	
Japanese	
Korean	
Vietnamese	
Other Asian	
Native Hawaiian	Native Hawaiian or Other Pacific Islander
Guamanian or Chamorro	
Samoan	
Other Pacific Islander	

National Survey of Child and Adolescent Well-Being

Data Standard

- How well do you speak English
 - Very well
 - Well
 - Not well
 - Not at all

2011 NSCAW

- How comfortable are you with speaking English?
 - Not at all comfortable,
 - Somewhat comfortable,
 - Very comfortable?

Medicare Current Beneficiary Survey

Data Standard

- Are you deaf or do you have serious difficulty in hearing
 - Yes
 - No

- Do you have serious difficulty walking or climbing stairs
 - Yes
 - No

2011 MCBS Survey Item

- Which of the statements best describes your hearing (with a hearing aid)
 - No trouble
 - A little trouble
 - A lot of trouble
 - Deaf

- Because of a health or physical problem, do you have any difficulty walking
 - Yes
 - No
 - Doesn't do

Implementation challenges

- Preserving data quality and integrity
 - Cognitive testing
 - “De Facto” standards
 - Preserving the ability to look at trends
 - Avoiding redundancy in questions
 - Survey mode
- Survey efficiency

Sample List of HHS Surveys New Data Standards Apply To

- **Agency for Health Care Research and Quality**
 - Medical Expenditure Panel Survey-Household Component
- **Substance Abuse and Mental Health Services Administration**
 - National Survey on Drug Use and Health

- **Centers for Disease Control and Prevention, National Center for Health Statistics**
 - National Health and Nutrition Examination Survey
 - National Health Interview Survey
 - National Survey of Family Growth

Summary

- Data standards will enhance HHS data collections
 - Uniformity of data collections across major HHS surveys
 - Expanded granularity for race and ethnicity
 - Self-reported language data
 - Disability status data
- Data standards will enhance uses of HHS data for disparities efforts

Thank you!

Rashida.Dorsey@hhs.gov

For information on HHS data standards:

[HTTP://MINORITYHEALTH.HHS.GOV/SECTION4302/](http://minorityhealth.hhs.gov/section4302/)