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/](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
- Asian Indian
- Chinese
- Filipino
- Japanese
- Korean
- Vietnamese
- Other Asian
- Native Hawaiian
- Guamanian or Chamorro
- Samoan
- Other Pacific Islander

Present OMB Minimum

Asian OMB Minimum

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
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

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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!

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For information on HHS data standards:

HTTP://MINORITYHEALTH.HHS.GOV/SECTION4302/