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

Virginia S. Cain, Ph.D.

National Center for Health Statistics

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

Requirements for Data Standards

ACA Requirements for Data Standards

- Developed within 2 years
- Used in data collection and reporting by any federally conducted or supported "health care or public health program, activity, or survey"
 - **▼** To the extent practicable

Data Standard Development Process

- HHS Data Council tasked with drafting recommendations for data standards
- Guided by existing federal data standards, the results of studies and public reports, and consultation with statistical agencies and programs

Criteria for Data Standards

- Evidence-based and demonstrated to have worked well in practice in current national surveys
- Minimum data standards
- Data standards already mandated by OMB would serve as the basis for any minimum standard
- Standards would apply to HHS sponsored person-level data collected in population-based health surveys, where subjects either self-report information or a knowledgeable proxy provides information about the subject or responds for all persons in a household survey.

OMB Standards for Race and Ethnicity

- OMB Standards for the Classification of Federal Data on Race and Ethnicity (1997)
 - Required in all federally sponsored data collections, including HHS data collection initiatives
 - o <u>http://www.whitehouse.gov/omb/fedreg_1997standards</u>
- OMB minimum categories for race
 - American Indian or Alaska Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White
- OMB minimum categories for ethnicity
 - Hispanic or Latino
 - Not Hispanic or Latino

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-

Race

- What is your race? (one or more categories may be marked)
 - White
 - Black or African American
 - American Indian or Alaska Native

Present OMB Standard for these Race Categories

Race (cont)

- What is your race? (one or more categories may be marked)
 - Asian Indian
 - Chinese
 - Filipino
 - Japanese
 - Korean
 - Vietnamese
 - Other Asian

Aggregate to the present OMB Asian Category

Race (cont)

- What is your race? (one or more categories may be marked)
 - Native Hawaiian
 - Guamanian or Chamorro
 - Samoan
 - Other Pacific Islander

Aggregate to the present OMB Native Hawaiian/Pacific Islander Category

Additional Granularity for Race Category

- New HHS Data Standards provide 6 additional categories beyond OMB Asian minimum standard
- New standards provide 3 additional categories beyond the OMB Native Hawaiian/Pacific Islander Minimum Standard

Sex

- What is your sex?
 - Female
 - OMale

Primary Language



- 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?
 - o Yes
 - o No
- If yes, what is this language?
 - Spanish
 - o Other language: _____

Disability Status

•	Are you deaf or do you have serious difficulty hearing?
	o Yes
	o No
•	Are you blind or do you have serious difficulty seeing, even when wearing glasses?
	o Yes
	o 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)
	o Yes
	o No
•	Do you have serious difficulty walking or climbing stairs? (5 years of age or older)
	o Yes
	o No
•	Do you have difficulty dressing or bathing? (5 years and older)
	o Yes
	o 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)

YesNo

Data Standard Implementation

- Adopted October 31, 2011
- Will apply to new surveys and at the next major revision for existing surveys
 - HHS-sponsored population surveys where person-level data is collected via either self-report or from a knowledgeable proxy
 - Data standards represent minimum standards
- Detailed information on Data Standards,
 Development Process and Rationale available at: http://minorityhealth.hhs.gov/section4302/