

## **Improving Data Collection to Reduce Health Disparities**

Many racial and ethnic minorities, people with disabilities, lesbian, gay, bisexual, and transgender (LGBT) communities, and other commonly underserved populations face unique health challenges, have reduced access to health care and insurance, and often pay the price with poorer health throughout their lives. These underserved populations are less likely to get the preventive care they need to stay healthy and are more likely to suffer from serious illnesses like diabetes and heart disease. When these populations do get sick, they are less likely to have access to quality health care. As a result, health disparities persist. For example:

- Although they represent only one-third of the total U.S. population, racial and ethnic minorities comprise more than half of the uninsured.
- Among women aged 50 years and over, mammography rates were lower for women with activity limitations than for women without such limitations
- Half of Latinos and more than a quarter of African Americans do not have a regular doctor.
- About 1 in 5 American Indians and Alaska Natives have two or more chronic conditions.

The leading health indicators have demonstrated little progress in reducing disparities over the past decade, according to recent analyses of progress on Healthy People 2010 objectives. The recent Institute of Medicine (IOM) Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality report emphasizes that inadequate data on race, ethnicity, and language lowers the likelihood of effective actions to address health disparities.

## **The Affordable Care Act and Health Disparities Data Collection**

The Affordable Care Act invests in the improvement of health data collection and analysis strategy. Section 4302 of the Affordable Care Act contains provisions to strengthen federal data collection efforts by requiring that all national federal data collection efforts collect information on race, ethnicity, sex, primary language, and disability status. The law also provides HHS the opportunity to collect additional demographic data to further improve our understanding of healthcare disparities. In the past, identifying disparities and effectively monitoring efforts to reduce them has been limited by a lack of specificity, uniformity, and quality in data collection and reporting procedures. Consistent methods for collecting and reporting health data will help us better characterize the nature of health problems in underserved populations.

## **Proposed Data Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status**

The following criteria guided development of data standards:

1. Standards would be evidence-based and demonstrated to have worked well in practice for national survey data collection.
2. Standards would represent a minimum data standard, with agencies permitted to collect as much additional detail as desired, provided that the additional detail could be aggregated back to the minimum standard.
3. Standards mandated by Office of Management and Budget (OMB) would serve as the starting point for any data standard

- Standards would be for population surveys of in which person-level data is collected via either self-report or from a respondent who **serves as a knowledgeable household representative**.

### **Race and Ethnicity**

The proposed standards for race and ethnicity build upon the OMB standard, adding the type of granularity for Asian and Latino populations that is used in the American Community Survey (ACS) and was used in the 2000 and 2010 Decennial Census. The data standard can be view at <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=208&id=9000#Race> .

### **Sex**

The proposed data standard for sex is male and female. The survey item can be viewed at <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=208&id=9000#Sex> .

### **Primary Language**

English proficiency is the minimum data standard proposed for the primary language data standard. The recommended question is used in the ACS. The data standard can be viewed at <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=208&id=9000#Lang1>.

Agencies would have the option of collecting data on the specific language spoken, using the categories used in the ACS. The data standard can be viewed at <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=208&id=9000#Lang2>.

### **Disability Status**

The six item set of questions used by on ACS and other major federal surveys to characterize functional disability is proposed as the minimum standard for collecting population survey data on disability. The question set was developed by a federal interagency committee and reflects how disability is conceptualized consistent with the International Classification of Functioning, Disability, and Health. The question set went through several rounds of cognitive testing and has been adopted in most major federal data collection systems. The data standard can be viewed at <http://minorityhealth.hhs.gov/templates/content.aspx?lvl=2&lvlid=208&id=9000#Disability>.

## **A Commitment to Reducing Health Disparities**

The Obama Administration and HHS recognize the importance of a broad approach to addressing the health and well-being of our communities. HHS continues to make significant progress toward improving the health of underserved populations, such as implementing the Affordable Care Act, the health care law helping to improve access to care for all Americans. For people with disabilities, important advances are being made to ensure that diagnostic equipment like imaging devices and examination tables are built consistent with new agency standards aimed at improving access and usability for people with certain disabilities. In addition, HHS supports Head Start and Child Care programs to ensure low income children have the support and education they need to adopt nutritious diets and active lifestyles. The Obama Administration and HHS are working to ensure every American - regardless of race, ethnicity, age, disability status, gender identity or sexual orientation - has the opportunity to live their healthiest life possible.