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August 1, 2011

Dr. Rochelle Rollins, PhD, MPH
U.S. Department of Health & Human Services
Office of the Assistant Secretary
Office of Minority Health Resource Center
Attention: Affordable Care Act, Section 4302 Data Standard Comments
P.O. Box 37337
Washington, D.C. 20013-73337

Re: Comments on Proposed Data Collection Standards for Race and Ethnicity Required by Section 4302 of the Affordable Care Act, docket ID # HHS-OMH-2011-0013

Dear Dr. Rollins:

Thank you for the opportunity to comment on the Proposed Data Collection Standards for Race and Ethnicity. While we believe the collection of standardized race and ethnicity data is a positive first step in identifying and addressing persistent disparities, for the data to be most effective, we urge HHS to strengthen these standards by including all of the recommendations of the 2009 Institute of Medicine Report, "Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement." Specifically:

1. When using the proposed data standard for primary language, Limited English Proficient (LEP) should be defined as "a person who speaks English less than very well."

2. HHS should include questions about spoken and written language needs and should adopt the comprehensive, standardized set of spoken language categories and coding included in the Institute of Medicine's 2009 report, Appendix I.

3. HHS should adopt an alternative standard to collect more detailed ethnicity data to address disparities as described below.

In addition, we recommend that:

1. Given that minority and immigrant populations are vulnerable to low health literacy, and that low health literacy is associated with poorer health outcomes, HHS should start collecting data to measure the impact of literacy level on health, such as including a question with regards to the highest level of education completed.

2. HHS should apply the proposed standards not only to health surveys but to all data collection points, including electronic health records.

The proposed HHS Standard perpetuates and codifies 4 basic flaws in the Office of Management and Budget (OMB) approach for the collection of race and ethnicity data:

1. Hispanic is the only ethnicity category: clearly, in the US there are many ethnicity groups. Considering Hispanic ancestry as the only recognized 'ethnicity' group fails to acknowledge the significance of all other ethnicity groups, limits our ability to monitor diversity and disparity, and leads to an enormous data collection issue described in # 4 below. HHS should include additional "granular ethnicity" categories by adapting one of the comprehensive lists for categorizing race and ethnicity data included in the Institute of Medicine's 2009 report, Appendix E. Specifically ethnicity categories should include groups such as Caribbean, Haitian, and African-American which are contained in the Massachusetts Superset provided below. We understand that regional variations also exist, so a mechanism by which to capture that regional variety with the ability for adaptation based on population shifts, would be beneficial.

2. Misidentification of ethnicity groups as races: many of the categories identified as races in the proposed standard are not races in any social context or by any other definition. The roll-up categories for Asian and Native Hawaiian/Other Pacific Islander are more appropriately considered ethnicity groups, ancestries, or national origins and should not be considered broad race groups.

3. This set of race categories used by the American Community Survey (ACS) and the Census were politically determined and have little to do with addressing disparities in health. For example, the inclusion of categories such as Guamanian, Chamorro, and Vietnamese are not priorities for most jurisdictions in order to address health disparities. To require all federally supported data collection efforts to collect these categories is inefficient and misguided.

4. The proposed data collection structure does not address the ongoing issue of Hispanics wishing to identify their race as Hispanic as well as their ethnicity as Hispanic. Clearly, results from all ACS, Census, and other data collection efforts highlight that approximately 40-50% of the US Hispanic population considers their Hispanic identity also as a race identity regardless of the initial response to the Hispanic ethnicity question. The proposed standard does not address this issue. It will lead to enormous confusion and will perpetuate difficulties for many persons of Hispanic ancestry.

There is a solution to these issues. The Massachusetts Department of Public Health (MDPH) has developed an alternative approach to collecting race and ethnicity data that is consistent with the OMB minimum race categories, allows for the collection of substantially more information to address disparities, and addresses the concern of Hispanic respondents. This approach is based on separating more distinctly the concept of 'race' and 'ethnicity' and using a two question approach to collect the data. Please see the MDPH recommended standard and rationale below. We hope you will consider using this approach as a much better alternative for data collection to address health disparities in the U.S. Please note: the ethnicity categories represent a minimum set of categories relevant to the population of Massachusetts. For the Federal standard, we recommend using ACS and Census data to develop an appropriate set of minimally required Federal categories.

MDPH Race and Ethnicity Data Collection Standard

Introduction: *In order to guarantee that all persons receive the highest quality of care and to ensure the best services possible, we are collecting data on race and ethnicity. Could you please select the category or categories that best describes your background?*

1. What is your ethnicity? (You can specify one or more)

- ❑ African (specify _____)
- ❑ African American
- ❑ American
- ❑ Asian Indian
- ❑ Brazilian
- ❑ Cambodian
- ❑ Cape Verdean
- ❑ Caribbean Islander (specify_____)
- ❑ Chinese
- ❑ Colombian
- ❑ Cuban
- ❑ Dominican
- ❑ European
- ❑ Filipino
- ❑ Guatemalan
- ❑ Haitian
- ❑ Honduran
- ❑ Japanese
- ❑ Korean
- ❑ Laotian
- ❑ Mexican, Mexican American, Chicano
- ❑ Middle Eastern (specify_____)
- ❑ Portuguese
- ❑ Puerto Rican
- ❑ Russian
- ❑ Salvadoran
- ❑ Vietnamese
- ❑ Other (specify_____)
- ❑ Unknown/not specified

2. What is your race? (You can specify one or more)

- ❑ American Indian/Alaska Native (specify tribal nation_____)
- ❑ Asian
- ❑ Black
- ❑ Hispanic/Latino/Black
- ❑ Hispanic/Latino/White
- ❑ Hispanic/Latino/other
- ❑ Native Hawaiian or other Pacific Islander (specify_____)
- ❑ White
- ❑ Unknown/not specified

Implementing New Race, Ethnicity, and Language Data Collection Standards

Background and Rationale

Addressing disparities in health and health care outcomes requires a deeper understanding of the populations we serve. Collecting detailed race, ethnicity, and language data are a means to providing this critical information. In 1997, the Federal Office of Management and Budget (OMB) promulgated revised standards for the collection of race and ethnicity data for use by Federal and state government agencies. These standards served as the basis for data collection in the 2000 Census and have been adopted by numerous public and private organizations for use in health care and other disciplines. MDPH has worked diligently to adapt these standards to the data collection needs of the Commonwealth by expanding response categories relevant to Massachusetts and adding questions to collect data on ethnicity and language.

In order to track and ultimately eliminate health disparities it is crucial to collect both broad race information and detailed ethnicity data. Race data are useful for monitoring discrimination, equality of opportunity and treatment, and indirectly, institutional racism. These broader categories yield more stable rates, are consistent with OMB Federal standard, and more routinely collected. While the OMB standard only calls for Hispanic ethnicity, detailed ethnicity data have enormous value as well, particularly tracking sub group differences masked by broad race categories. Ethnicity, also known as heritage or ancestry, is a more consistently understood concept, less likely to change over time, and less context dependent. It is more useful for program targeting and development than broad race categories. Ethnicity also may be a better measure of cultural practices, provide improved sensitivity to linguistic needs, and add insight into acculturation. Language information is the key to enhancing communication: it identifies needs for interpreter services and may help understand cultural practices related to health behavior.

Principles

The MDPH standards for the collection of race and ethnicity data are based on four principles. We will briefly describe the importance of each of these principles:

1. Encourage patient self-report in the registration process

   Comment: Self-report, where possible, is the mode of race and ethnicity ascertainment recommended by OMB. Studies have shown that self-identification provides the most consistent and valid information. Two alternative ascertainment methods: proxy (or informant) and observation, are less rigorous and more prone to misclassification error. Observation places an undue burden on the data collector, and both proxy and observation can be inconsistent across person, setting, and time. A key activity in the successful implementation of the MDPH standards is training intake personnel to gather race and ethnicity data consistently. MDPH and our partners have developed training materials specifically for race data collection in health care settings in Massachusetts. Also, there are many regional and national training resources available.

2. Allow for the selection of multiple race categories

   Comment: The OMB standards recommend that the format for individuals to report more than one race should be multiple responses to a single question rather than a catch all "multiracial" category. A "multiracial" category would be difficult to interpret and analyze. We strongly urge all MDPH Centers to explore data collection methods that will allow respondents to select more than one category. For those programs with limited data collection capacity, this standard could be implemented, for example, by the addition of a second variable, which, along with the first question would allow almost 95% of all patients with more than one race to identify themselves. For example, in Boston and Worcester, 95% of those who specified two or more races in Census 2000, had exactly two races.

3. Collect information on detailed ethnicity groups as well as broad race categories

   Race is defined as the group or groups that you identify with as having similar physical characteristics or similar social and geographic origins. *Ethnicity* refers to your background, heritage, culture, ancestry, or sometimes the country where you or your family were born.

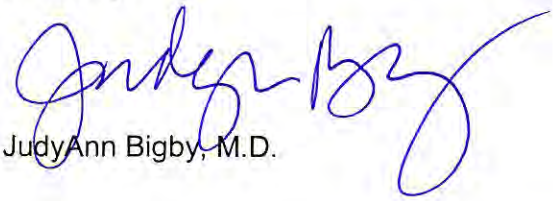
Comment: The Federal standards recognize only two ethnicities: Hispanic, and Non-Hispanic. The MDPH has found that there is a need for a greater number of ethnicities to be collected. Research at MDPH has found that there are significant differences in health outcomes *within* all broad race categories by ethnicity group. These differences are obscured when only broad race groups are examined. MDPH has also found that ethnicity data rather than race data are more useful for program development, targeting interventions, expanding access to health services, and monitoring disparities. Massachusetts has found that different ethnicities have different health behaviors and health outcomes; thus we are leading the movement to collect detailed ethnicity data to better serve all residents.

4. Maintain consistency with Federal OMB standards

   Comment: We recognize that it is important to collect data that comply with the 1997 OMB standards. Standardized race and ethnicity data will allow for direct comparisons within the state as well comparisons with other states and Federal databases.

Thank you again for the opportunity to comment on the proposed data collection standards.

Sincerely,



JudyAnn Bigby, M.D.