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August 1, 2011

Office of Minority Health Resource Center
Attn: ACA Section 4302 Data Standard Comments
1101 Wooton Parkway, Suite 650
Rockville, MD 20852

Re: Docket No. HHS-OMH-2011-0013

Dear Sir or Madam:

On behalf of the American Heart Association (AHA), including the American Stroke Association (ASA) and over 22.5 million AHA and ASA volunteers and supporters, we appreciate the opportunity to submit our comments on the Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status.

We commend the Department of Health and Human Services (HHS) for its work on developing the proposed standards. AHA has long recognized the importance of collecting and reporting standardized data as critical to identifying and eliminating health inequities. We strongly support section 4302 of the Affordable Care Act, which requires any federally conducted or supported health care program or survey to collect and report data by race, ethnicity, sex, primary language, and disability status. AHA shares the Department's commitment to eliminating health disparities and we are hopeful that new uniform data collection standards will improve our ability to identify and track health and health care disparities and facilitate efforts to reduce them. We are pleased to provide the following comments on the specific standards and hope our feedback will be of use to the Department.

Race and Ethnicity

AHA supports the proposed data standards for race and ethnicity; we do not have any recommended changes.

Sex, Sexual Orientation, and Gender Identity

AHA strongly supports the inclusion of sex as a data element in the proposed data collection standards. Sex is a critical piece of demographic information for the identification of health disparities among population subgroups.

We are also pleased that the Department plans to add additional data collection standards in the future that address sexual orientation and gender identity. We are, however, concerned that these additional data elements may not be in place for two more years. This time lag may adversely affect efforts to identify disparities in subgroups, such as among transgender individuals, and may result in a loss of information and data continuity from entities that already collect demographic information beyond “male” and “female”. If these entities revise their response options to comply with the new data collection standards, they will no longer be able to indicate when an individual declines to provide their sex or would better fit into another category.

Until the time that sexual orientation and gender identity standards can be added, we recommend that a third response option such as “other” be added to the sex data standard. A third response option would support efforts to identify disparities in this population. A third response option is also necessary to ensure that longitudinal data currently collected by entities using a third response is not lost, potentially affecting research.

For these reasons, AHA urges HHS to consider adding a third response option such as “other” to the sex data standard.

Language

As with the data elements above, AHA strongly supports the collection of primary language data. We are, however, concerned that the language data standard relies on the use of a free text field – “other” – to identify the primary language spoken at home. Individuals who indicate that they speak a language other than English or Spanish must select “other” and then write in the name of the language they primarily use.

AHA has serious concerns with the proposed “other” free text field for two reasons. First, the responses made in free text fields are hard to compile and may be ignored by researchers even if contained in a data warehouse. Second, future phases of the regulation to encourage meaningful use of health information technology will require that patient education materials be provided in the patient’s primary language. Collecting information on patients’ primary language will be crucial in identifying what languages the education materials should be provided in.

We, therefore, recommend that HHS revise this data collection standard to include all the major languages spoken within the United States as response options. The Department could, for example, list the major languages identified by the Census Bureau, as well as American Sign Language, as separate response options:

- English
- Spanish or Spanish Creole
- French
- Italian
- Portuguese or Portuguese Creole
- German
- Russian
- Polish
- Serbo-Croatian
- Armenian
- Persian
- Chinese
- Japanese
- Korean
- Vietnamese
- Tagalog
- American Sign Language
- Other

The “other” free text field would only be utilized when a respondent’s primary language is not one of the 17 languages listed above. This would help to ensure that more robust primary language data is collected, and that appropriate patient education materials and discharge letters are provided in the primary language.

Disability Status

As proposed, the disability data collection standard attempts to determine if an individual is disabled by asking a series of questions. The questions address hearing, sight, cognitive, ambulatory, self-care, and independent living ability. However, the data standard never directly asks the respondent if the individual is disabled.

We recommend that HHS revise this standard to include a preliminary question that specifically asks if the individual is disabled (i.e., Are you disabled?). The six questions contained in the proposed data standard could then be asked to determine how the individual is disabled.

Closing

In closing, AHA reiterates our overall support for the proposed data collection standards. To further refine the standards, we recommend that the Department add a third response option (other) to the data standard for sex; add American Sign Language and the 16 major languages identified by the Census Bureau as specific response options for the primary language standard; and add a question to the disability standard that explicitly asks if the individual is disabled.

We also encourage the Department to build on the momentum created by the release of these standards and move forward with the development of data collection standards for sexual orientation and gender identity, as well as broader application of the standards to all federally sponsored, conducted, or supported health programs, activities, and quality reporting programs, as the statute requires.

If you have any questions or would like additional information, please do not hesitate to contact Penelope Solis of AHA staff at (202) 423-3124 or penelope.solis@heart.org.

Sincerely,

A handwritten signature in blue ink, appearing to read 'G. Tomaselli', with a long horizontal flourish extending to the right.

Gordon F. Tomaselli, MD, FAHA
President
American Heart Association