



SOCIETY FOR PUBLIC HEALTH EDUCATION

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August 1, 2011

Office of Minority Health Resource Center
Attention: Affordable Care Act Section 4302 Data Standard Comments
1101 Wootton Parkway
Suite 650
Rockville, MD 20852

Re: Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status Required by Section 4302 of the Affordable Care Act (Docket ID Number: HHS-OMH-2011-0013)

To Whom it May Concern:

The Society for Public Health Education (SOPHE) is committed to successful implementation of the Patient Protection and Affordable Care Act and applauds HHS Secretary Sebelius on the approach taken to draft the Proposed Data Collection Standards for Race, Ethnicity, Primary Language, Sex, and Disability Status. We appreciate the opportunity to provide these comments on the proposed standards.

SOPHE is a 501 (c)(3) professional organization founded in 1950 to provide global leadership to the profession of health education and health promotion. SOPHE contributes to the health of all people and the elimination of health disparities through advances in health education theory and research; excellence in professional preparation and practice; and advocacy for public policies conducive to health. SOPHE is the *only* independent professional organization devoted exclusively to health education and health promotion. Members include behavioral scientists, faculty, practitioners, and students engaged in disease prevention and health promotion in both the public and private sectors. Collectively, SOPHE's 4,000 national and chapter members work in universities, medical/health care settings, businesses, voluntary health agencies, international organizations, and all branches of federal/state/local government. In the last decade, SOPHE has published more than a dozen scientific peer-reviewed journal supplements of *Health Education & Behavior (HE&B)* and *Health Promotion Practice (HPP)* dealing with health disparities, policy/systems changes for chronic disease prevention, and other topics. Our research agenda focuses on eliminating health disparities and achieving health equity.

Health disparities continue to be persistent, and are particularly pervasive in communities of color across a range of health indicators such as life expectancy, prevalence of chronic disease, and insurance coverage. Improving health data collection is an important step in identifying health disparities. Monitoring and analyzing the data will be crucial to developing the most effective strategies for improving poor health outcomes, and urging policy makers to take action.

In a previous *HE&B* article¹, the following recommendations were made for data to eliminate health inequities:

1. Place greater emphasis on collecting data from all levels of the ecological framework that can inform interventions at each level.
2. Create and empirically test models that articulate the pathways that demonstrate the relationship between fundamental determinants of health and health outcomes.
3. Provide more locally relevant and culturally appropriate data, and highlight the role of contextual evaluation.
4. Refine measures and strategies for facilitating community participation in monitoring, research, and evaluation.

Research has demonstrated that self-reported data are more accurate than reporting by health care staff. These data collection standards for race, ethnicity, primary language, sex, and disability status will help to ensure uniform reporting. SOPHE offers the following recommendations to strengthen the HHS standards so that sufficient, useful data may be collected:

Proposed Data Standard for Ethnicity

The options under this question should be expanded to include “**Yes, Hispanic**” as an option.

To appropriately identify prevalent health disparities, an additional question to include in this section should ask whether or not the individual was born in the U.S.

Proposed Data Standard for Race

It is important that more than one option can be selected here for those that self-identify as more than one race, and so we can continue to identify the changing perceptions of race and ethnicity. However, “Other” should be included as an option; omitting this option could result in missing data.

Please also consider rephrasing the question to read, “**How would you describe yourself in terms of race?**”

Proposed Data Standard for Sex

The stated guiding criteria for the proposed standards include “evidence-based and demonstrated to have worked well in practice.” Although the proposed standard’s rationale defines sex as biological and the male/female only response options as demonstrated best practice, such systems have contributed to the historic and ongoing discrimination against transgendered persons and related disparities in the social determinants of health and health outcomes. The Human Rights Campaign approach should be considered as an alternative:

¹ Griffith, D., Moy, E., Reischl, T., and Dayton E. (2006). National Data for Monitoring and Evaluating Racial and Ethnic Health Disparities: Where Do We Go From Here? *Health Education and Behavior, Special Issue, Eliminating Racial and Ethnic Health Disparities: Framing a Health Education Research Agenda*, 33 (4), 470-487.

What is your gender identity?

- **Female**
- **Female to male transgender**
- **Male**
- **Male to female transgender**
- **Not sure**
- **Other (please specify): _____**

SOPHE acknowledges and supports HHS' proposed efforts to develop a national data progression plan intended to begin the integration of sexual orientation and gender identity variables into a HHS national survey by 2013; and the inclusion of organizations such as the Fenway Institute in that process. We strongly urge HHS to proceed expeditiously in developing the full range of LGBT standards and their full integration into these diversity standards.

Proposed Data Collection for Primary Language and Spoken Language

SOPHE recommends the inclusion of questions about spoken and written language needs. We recommend adoption of the comprehensive, standardized set of spoken language categories and coding included in the Institute of Medicine's 2009 report (Appendix I). Information to be collected includes:

- Self-rated ability to speak English, and classification of someone who speaks English "less than "very well" as Limited English Proficient (LEP);
- Language preferred for encounters with health care personnel;
- Language spoken in the home; and
- Language in which they prefer to receive written materials.

In addition, the options under the question, "What is this language?" should be expanded to at least include the primary languages for the races that are listed in Question 2.

Thank you for consideration of our feedback and suggestions on the draft standards. SOPHE looks forward to working with you on implementing this and other provisions of the Affordable Care Act. Please contact Jerrica Mathis at jmathis@sophe.org or 202-408-9804 with any additional questions.

Sincerely,



Daniel Perales, DrPH, MPH
President



Elaine Auld, MPH, MCHES
Chief Executive Officer