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# Strategic Data and Research Opportunities on Asian American, Native Hawaiian, and Pacific Islander Health through the Patient Protection and Affordable Care Act

Winston Tseng, Priscilla Huang, and Won Kim Cook

## Summary

This paper summarizes the federal requirements under Section 4302(a) of the Affordable Care Act (ACA); the opportunities for improving data collection to address health disparities affecting Asian Americans, Native Hawaiians, and Pacific Islanders; the provision's limitations; and how to address these limitations. Our recommendations for ACA Section 4302(a) implementation include: (1) adhering to the 2009 Institute of Medicine's data standards on race, ethnicity, and primary language; (2) requiring federally-supported national surveys, health care providers, and publicly-administered health programs at the point of care and enrollment to comply with Section 4302 requirements; (3) ensuring compliance with Title VI and ACA Section 1557 non-discrimination requirements by providing translated health surveys and increasing language assistance capacity; and (4) engaging communities in the design of race, ethnicity, and language data to ensure community relevance.

## Introduction

The country's diverse ethnic populations contribute to America's vitality and health. Populations of color are projected to dramatically increase from 38 percent of the total U.S. population or 116.3 million in 2010 (U.S. Census, 2011b), to 57 percent of the total U.S. population or 250.3 million by 2050 (U.S. Census, 2008). In addition, immigrants continue to play a fundamental historical role in nation building and in transforming the social demographic characteristics of the United States, with about 13 percent of the

total population or 38.1 million people currently foreign-born (U.S. Census, 2011a). Immigrants, however, often face multiple barriers to accessing health insurance coverage and health care services due to statutory restrictions, culture, language, and confusion over complex eligibility requirements (Choi, 2009; Derose et al., 2009).

Asian Americans, Native Hawaiians, and Pacific Islanders (AANHPIs) are among the fastest-growing racial groups. Throughout the next few decades, Asian Americans will increase from 5.6 percent of the total U.S. population or 17.3 million people in 2010 (U.S. Census, 2011b) to 9.2 percent or 40.6 million people in 2050 (U.S. Census, 2008). NHPIs will increase from 0.4 percent or 1.2 million people in 2010 (U.S. Census, 2011b) to 0.6 percent or 2.6 million people in 2050 (U.S. Census, 2008). About 60 percent of Asian Americans or 9.2 million people are foreign-born, and 23 percent or 3.5 million people have Limited English Proficiency (LEP). Among NHPIs, 14 percent or 119,000 people are foreign-born, and 2 percent or 21,000 have LEP (U.S. Census, 2011a). These rapid demographic changes in the Asian American and NHPI communities are transforming contexts for national policy and population health.

To be responsive to the needs of these growing Asian American and NHPI populations, the way health care and preventive services are delivered across the United States needs to be transformed, particularly in terms of culturally and linguistically competent care. Data and research are important tools that can help ensure adequate resources and support for quality health care and preventive services for all, especially for underserved populations such as communities of color and indigenous people. The paucity of data and research on health care delivery and health disparities among Asian Americans and NHPIs are fundamental barriers to understanding population health and addressing the health care needs of these communities (Ghosh, 2003; Islam et al., 2010).

The Affordable Care Act (ACA) signed into law on March 23, 2010, offers a major opportunity for improving data and research on race, ethnicity, and language that supports quality improvement efforts to address unequal treatment and health disparities among Asian Americans and NHPIs and other underserved ethnic and indigenous populations (IOM, 2002). This article summarizes the new federal requirements under Section 4302(a) of the ACA; the opportunities they offer for improving data collection, analysis, and reporting that are necessary to identify and address health

disparities affecting Asian Americans and NHPs; the limitations of the provision; and how these limitations might be addressed.

### Section 4302(a) of the Affordable Care Act

Section 4302, entitled “Understanding Health Disparities: Data Collection and Analysis,” makes significant strides to improve identification of the health needs of underserved populations. Section 4302(a)(1) amends the Public Health Service Act and requires the secretary of the Department of Health and Human Services (DHHS) to develop standards for the collection of the federal statutorily required categories of race, ethnicity, sex, primary language, and disability status. Under the new law, the secretary must, within two years of enactment, establish methods to uniformly collect, analyze, and report these data categories to document and monitor the progress toward reducing disparities in health and health care.

As DHHS defines these standards, it must also determine the scope of this provision in its applicability and in its data categories. The statutory language of Section 4302(a)(1) applies data-collection requirements to any “federally conducted or supported health care or public health program, activity or survey . . . to the extent practicable.” A narrow definition could limit applicability of the new data requirements to existing federal health surveys, although a broader definition could direct the requirements to apply to all federally supported health care providers at the point of care, publicly administered or financially assisted health programs at enrollment, and any quality reporting measures. Section 4302(a)(1)(d) also gives the secretary discretionary authority to expand the number of data categories. Accordingly, DHHS could mandate the collection and reporting of sexual orientation, gender identity, and other demographic categories beyond those currently required in the statute.

Although the intent of this law is profound for all Americans, there are potential challenges in its implementation among Asian Americans and NHP communities and other underserved populations due to the lack of language and cultural access, health literacy, and trust in the data-collection process (Gollin et al., 2005; Ngo-Metzger et al., 2007). Current reporting standards and practices for Asian Americans and NHPs are a fundamental barrier to the improvement of care for these populations. The disaggregation of smaller racial groups such as Asian Americans and NHPs is important to identify diverse health needs and disparities affect-

ing them. However, even with some progress made, these racial categories have not been consistently used in collecting and reporting health data. The data collected and reported by federally supported health care programs and in national health surveys often fail to comply with the 1997 revised Office of Management and Budget (OMB) standards for race and ethnicity. Asian American and NHP data are often not collected, collected but not adequately analyzed by race and ethnicity, not reported due to small sample sizes, or lumped into the “Other” category exclusive of “Whites” and “Black or African Americans” in the reporting. Select federal DHHS programs such as Healthy People 2010 and Healthy People 2020 have been providing notations when data on Asian Americans and NHPs are not available, which has helped to raise visibility around the need for improved data collection and analysis (Jang and Tran, 2009). However, the core issues about lack of data among Asian Americans and NHPs persist.

### Standardizing Race, Ethnicity, and Primary-Language Data Collection

Section 4302(a)(2)(A) directs the Secretary of Health and Human Services to comply, *at a minimum*, with the 1997 revised OMB standards for race and ethnicity. Importantly, these OMB standards separated the traditional “Asian Pacific Islander” grouping into two groups: “Asian Americans” and “Native Hawaiians and Other Pacific Islanders” (Jang and Tran, 2009). This separation improved data collection for both groups to identify their unique health needs and disparities and also recognized the unique political status of NHPs within the United States (Spoehr, 2007). The five OMB standards categories for racial identification are “American Indian or Alaska Native,” “Asian,” “Black or African American,” “Native Hawaiian or Other Pacific Islander,” and “White,” and there are two categories for ethnicity: “Hispanic or Latino” and “Not Hispanic or Latino.” The development of new uniform standards of data collection in order to understand health disparities beyond these current standards and practices, particularly by granular ethnicity, are important to ensure that Asian Americans and NHPs are visible and that the data is available and appropriately reported (Asian & Pacific Islander American Health Forum [APIAHF], 2007, 2010).

Data reflecting primary-language use also remains a challenge for DHHS across communities of color. A majority of Asian

Americans (71%) and Latinos (77%) speak languages other than English in their home (U.S. Census, 2011a). Members of these communities are often linguistically isolated (defined as no one over the age of 14 in the household speaks English) and continue to encounter significant health and health care disparities (Ngo-Metzger et al., 2007). In addition, those with LEP may experience significantly greater barriers in accessing health care and information, often due to low health literacy, and thus suffer from poor health outcomes. The DHHS National Standards on Culturally and Linguistically Appropriate Services (CLAS) have supported new data standards for health care organizations such as hospitals and health plans. However, it has not yet led to their adoption across DHHS agencies and programs.

In June 2011, DHHS announced new standards for race, ethnicity, and primary-language data collection for complying with the ACA Section 4302, along with plans for initial implementation of these standards across the major DHHS surveys starting in 2012. The new standards have the potential to transform the paradigm for data collection to identify gaps and develop strategies in order to address racial, ethnic, and linguistic disparities in health and health care throughout the next decade (U.S. DHHS, 2011). The standards go beyond the OMB guidelines and include data collection by granular ethnicity for six Asian American subgroups (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and other Asian) and three NHPI subgroups (Native Hawaiian, Guamanian, or Chamorro, Samoan, and other Pacific Islander). In addition, new data standards for primary language include data collection on English language proficiency and primary language spoken at home.

However, the fragmented structure of the current U.S. health care system and the unfunded nature of this mandate will make it difficult for DHHS to enforce or hold programs accountable to the new Section 4302(a) standards. Four major issues must be addressed. First, a lack of uniformity exists on how race, ethnicity, language, and other demographic data is collected and reported across federal DHHS agencies, all federally supported health care programs, and publically administered or assisted health programs (IOM, 2009). For example, data are reported in different categories across DHHS health care programs such as the Medical Expenditure Panel Survey, Physician Quality Reporting Initiative, and Uniform Data System, with many continuing to lump Asian Americans and

NHPIs into the “Other” category while others still combine Asian Americans and NHPIs together into the single “API” category, thus not complying with the 1997 revised OMB standards.

The second issue is that few DHHS-supported health care programs incorporate appropriate in-language services and materials for data collection. Third, culturally sensitive designs in the front end of data collection are lacking, and few provide adequate and meaningful analysis and reporting of existing and new data for Asian Americans and NHPIs. A fourth issue involves the lack of national data standards for race, ethnicity, and language in electronic health records across the health care system. Health information technology (HIT) has the potential to advance or limit the standardization of race, ethnicity, and language. The close coordination and compliance with the new DHHS data standards among the Office of the National Coordinator for Health Information Technology, major regional HIT networks, and HIT corporations will be critical to ensure uniformity in data standards and implementation across health information exchanges and networks.

## Recommendations

We offer four key recommendations to support the implementation of ACA Section 4302(a)(1) by DHHS: (1) fully implement the 2009 Institute of Medicine’s (IOM) recommendations on the standardization of race, ethnicity, and primary-language data; (2) require federally supported national surveys, federally supported health care providers, and publicly administered health programs at the point of care and enrollment to comply with the Section 4302 requirements; (3) ensure compliance with Title VI of the Civil Rights Act of 1964 and ACA’s Section 1557 nondiscrimination requirements by providing translated health surveys and increase DHHS’s language assistance capacity; and (4) engage communities in the design, planning, implementation, and dissemination of data on race, ethnicity, and language to ensure community participation and relevance. More specific suggestions are provided for each of these four recommendations.

First, DHHS should adopt all of the recommendations from the 2009 IOM report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. In particular, the report highlighted the need for granular ethnicity data, recommended that DHHS develop and make available nationally standardized

lists for granular ethnicity categories, and proposed strategies for aggregating ethnicity categories with the broader OMB race and Hispanic ethnicity categories. DHHS should also follow the IOM report recommendations regarding language need. Although the statute requires “primary language” data collection, it is silent on the meaning and application of the term *primary language*. The report prioritizes spoken-language need for LEP individuals. Specifically, the report proposes a two-step process to assess spoken-language need: the first is to assess the respondent’s ability to speak English and the second is to determine the spoken language preferred in a health care setting by using a list of locally relevant response categories from a national standard list.

The recent proposed new DHHS data standards for race, ethnicity, and primary language take into consideration and propose to implement a number of 2009 IOM report recommendations (U.S. DHHS, 2011) and demonstrate a major commitment by the federal government and DHHS to transform the data-collection paradigm in order to reduce and eliminate health disparities. However, further steps are needed in implementing the new data standards in order to ensure inclusion of all medically underserved Asian Americans and NHPs in the data collection and reporting. The new standards include only select Asian American and NHPI ethnic groups with the largest populations and exclude some of the most medically underserved ethnic groups such as Cambodians, Hmong, Laotians, and Tongans. The categories for primary language spoken at home include “English,” “Spanish,” and “Other Language” categories and exclude additional language groups. Further refinement of the language data standards is needed to ensure that underserved Asian American and NHPI language groups are not lumped into the “Other Language” category or excluded from data collection and reporting.

Second, DHHS should interpret Section 4302 to apply to all federally supported health care providers and publically administered health programs at the point of care and enrollment, in addition to federally supported national surveys. For those programs utilizing or implementing electronic health records, the standardization of race, ethnicity, and language data collection with pull-down options for granular ethnicity and primary language based on the new DHHS proposed minimum data standards is a key starting point. Application of Section 4302 to these areas is necessary to iden-



tify and address health care disparities more fully. The collection of demographic data will be especially important as we move toward a health care payment system that rewards quality rather than quantity. Many health care providers already collect demographic data, either voluntarily or because of existing federal or state laws and regulations. Nationally, 82 percent of hospitals already collect race and ethnicity data and 67 percent collect data on primary language (Hasnain-Wynia et al., 2007). Twenty-two states have passed regulations requiring hospitals to collect race, ethnicity, and language data. Health Resources and Services Administration primary care grantees, including community health centers, are also required to collect and report patient demographic data. Publicly administered health programs such as Medicare should also be required to collect data at enrollment. Mandating and standardizing the national collection of demographic data is not only practicable but also critical to ensuring that these programs meet the needs of eligible participants.

Medicare does not currently collect language data and relies on data from the Social Security Administration (Form SS-5) for race and ethnicity, which is significantly flawed. An analysis of the 2002 Medicare administrative data on race and ethnicity revealed that only 52 percent of Asian beneficiaries and 33 percent of both Hispanic and American Indian / Alaska Native beneficiaries were correctly classified (McBean, 2004). Another analysis of 2000 to 2002 Medicare administrative data showed similar results with 55 percent of Asian / Pacific Islander, 30 percent of Hispanic, and 36 percent of American Indian / Alaska Native beneficiaries incorrectly identified (Eicheldinger and Bonito, 2008). Addressing existing inaccuracies in racial and ethnic classification and standardizing language codes for Medicare administrative data through the full adoption of the 2009 IOM report recommendations are key starting points in order to ensure improved analyses by race, ethnicity, and language and reduction of health care disparities. Recent changes to SS-5 improve data collection on race and ethnicity for new Social Security card applicants, now go a step further than the 1997 OMB guidance, and collect information on Asians, Native Hawaiians, and Other Pacific Islanders separately, but do not track granular ethnicity. In addition, ensuring data collection of race, ethnicity, and language at the point of Medicare enrollment and conducting a study to examine strategies for addressing the gaps in the accuracy of data by race and ethnicity, particularly among Asian Americans and NHPs, would

further reduce errors in racial and ethnic classification, improve evaluation of data on health care disparities, and support Medicare efforts to comply with Medicare Improvements for Patients and Providers Act of 2008 and ACA's Section 4302.

Third, DHHS must ensure compliance with Title VI and the ACA's Section 1557 nondiscrimination requirements and provide proper allocation of resources for written translation and spoken interpretation assistance for data collection in support of the implementation of Section 4302(a). Providing language assistance helps address privacy and confidentiality concerns of respondents and also ensures DHHS's compliance with Title VI of the Civil Rights Act of 1964, which prohibits any federally funded program or activity from discrimination due to race or national origin. Section 1557 reinforces this prohibition against discrimination by forbidding any federally conducted program or entity that receives federal funding or assistance from discrimination on the grounds of race, color, national origin, gender, or disability. National data-collection efforts should standardize language access by hiring bilingual interviewers and translators and translating and administering surveys and forms in multiple languages. Although the statute limits data-collection requirements to what is "practical," DHHS should not apply a strict interpretation to this limit and look to existing federal and state practices as models. For example, the U.S. Census Bureau hires bilingual enumerators to ensure meaningful participation, and the California Health Interview Survey reaches linguistically isolated communities through English simplification and linguistic interpretation (in Cantonese, Mandarin, Korean, and Vietnamese) of its survey.

Finally, DHHS should ensure that community health stakeholders representing Asian Americans and NHPs and other underserved populations are included in the decision-making process and testing of the secretary's new standards on data collection, reporting, and analysis protocol under Section 4302(a). The inclusion of nongovernmental partners would help address privacy concerns and the unique cultural, linguistic, and social barriers that prevent underserved populations from participation in data collection and research. In addition, DHHS should strengthen its community health partnerships to ensure sufficient geographic and population-specific representation in any data collected, reported, or analyzed pursuant to Section 4302.

Federal data and research efforts to fully understand Asian American and NHPI health disparities and solutions lag significantly behind efforts to do so for other racial and ethnic groups. Strategic data collection collaborations with Asian American and NHPI communities, especially NHPIs, will be critical for building the evidence base. Strategic public-private partnerships between Asian American- and NHPI-serving community organizations, federal agencies, and health care organizations are vital to support the implementation of ACA Section 4302(a) for all Americans; such collaborative efforts are especially important under the current tight-budget climate, ensure broad stakeholder engagement that is inclusive of Asian Americans and NHPIs, and create a transparent public process for designing and implementing uniform standards of data on race, ethnicity, and language across the various components of the health care system (e.g., HIT and accountable care organizations). Advancing the national standardization of Asian American and NHPI health data collection through ACA Section 4302(a) can be a major step forward to ensuring all Americans are counted and eliminating racial, ethnic, and linguistic health disparities.

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