RACE, ETHNICITY, AND LANGUAGE DATA

STANDARDIZATION FOR HEALTH CARE QUALITY IMPROVEMENT

Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement

Board on Health Care Services

Cheryl Ulmer, Bernadette McFadden, and David R. Nerenz, *Editors*

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> *Willing is not enough; we must do."*
> —Goethe

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This report has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published report as sound as possible and to ensure that the report meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the deliberative process. We wish to thank the following individuals for their review of this report:

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Although the reviewers listed above have provided many constructive comments and suggestions, they were not asked to endorse the conclusions or recommendations nor did they see the final draft of the report before its release. The review of this report was overseen by **Faith Mitchell,** Grantmakers In Health, and **Edward B. Perrin,** University of Washington. Appointed by the National Research Council and Institute of Medicine, they were responsible for making certain that an independent examination of this report was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this report rests entirely with the authoring committee and the institution.

Foreword

The Institute of Medicine report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (2002) called attention to poorer access to health care and worse health outcomes among certain racial and ethnic groups. According to reports from the Agency for Healthcare Research and Quality and others, disparities in the quality of care and in health outcomes persist. Accelerating progress toward eliminating these disparities depends in part on our ability to identify and track experiences in health care among individuals from a variety of racial and ethnic backgrounds and who speak a variety of languages other than English.

This report offers an approach to identifying racial, ethnic, and language categories that bear on disparities in health care and health outcomes. Extending beyond the broad racial and ethnic categories used by the Office of Management and Budget, this report provides a more granular classification of ethnicity and language needs. This standardized approach to classification will both help measure progress in eliminating disparities and assure that comparisons across different settings are based on similar groupings of individuals.

I want to express my appreciation to the subcommittee and staff for the tremendous effort that has gone into this report. Their work represents another positive step toward the goal of high quality health care for everyone.

Harvey V. Fineberg, M.D., Ph.D.
President, Institute of Medicine
August 2009

Preface

Calling attention to the need for improvement in quality of care has been a central theme for many Institute of Medicine (IOM) reports. *Crossing the Quality Chasm: A New Health System for the 21st Century* noted significant shortcomings in the nation's health care delivery system in terms of safety, effectiveness, timeliness, efficiency, patient-centeredness, and equity, while *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* documented that in a variety of organizational settings and clinical domains, members of racial and ethnic minority groups receive poorer quality care than their White counterparts.

While many studies published since the 2003 release of *Unequal Treatment* have shown similar patterns, there is evidence of some progress. Disparities in some domains (e.g., process of care measures such as use of beta blockers or aspirin after heart attack) have been shown to be shrinking over time for some populations but not others. Individual health plans, hospitals, and medical groups have organized quality improvement projects aimed at reducing disparities and have succeeded in doing so. The underlying reasons for disparities are increasingly understood so that initiatives to address disparities can be focused on factors that are likely to have the greatest positive effect. The impact of language, culture, and socioeconomic status, along with race and ethnicity, are also more clearly understood. Yet studies reveal that disparities remain on both process of care and outcome measures.

Continued work in addressing disparities requires the collection and use of data on race, ethnicity, and language in all health and health care data systems, as called for in 2004 by the National Research Council report, *Eliminating Health Disparities: Measurement and Data Needs*. These data provide the opportunity to monitor and analyze disparities, and are informative in identifying individuals and groups to whom quality improvement or other interventions can be directed. Across a range of organizational levels, from the Agency for Healthcare Research and Quality *National Healthcare Disparities Report* at one end, to the work carried out by individual physician offices and community health centers at the other, the collection and use of data on race, ethnicity, and language are key parts of the process of identifying health care needs and eliminating disparities.

Quality improvement can be organized as a collaborative effort at a local, regional, statewide, or even national level. Even when projects are carried out by individual organizations, the process of benchmarking involves sharing information from organization to organization. For some quality improvement projects, literal data sharing is important, as an entity collecting race, ethnicity, or language data (e.g., a multispecialty group practice) may provide that information to another entity (e.g., a managed care plan) in order for the second entity to use the information for analyses of quality of care data. Additionally, regional, state, and national health care agencies may wish to pool data from individual organizations to address disparities in a broader geographic context.

The collection of data on race, ethnicity, and language will, in principle, have the greatest impact if it is done according to standards that allow for comparison of data across organizations, sharing of individual-level data from one to another, and combining of data from multiple sources. The Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement was asked to examine the issue of how data on race, ethnicity, and language are collected in various contexts associated with health care, and to offer recommendations on standardization of the categories for these variables. This report addresses data collection challenges and proposes a framework for moving forward with standardized data collection across health care entities. Previous reports have reiterated the importance of collecting more detailed ethnicity data than are captured by the Office of Management and Budget (OMB) standard categories; this report proposes templates of granular ethnicity and language categories for national adoption so that entities wishing to collect detailed data can do so in systematic, uniform ways. The recommendations presented here provide guidance to entities on data collection to support their efforts to improve quality and eliminate disparities.

David R. Nerenz, *Chair*
Subcommittee on Standardized
Collection of Race/Ethnicity Data for
Healthcare Quality Improvement

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[1] Subcommittee members Ignatius Bau, David Nerenz, and Paul Schyve are also members of the Committee.

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Contents

APPENDIXES*

*Appendixes E through I can be found online at http://www.nap.edu.

Boxes, Figures, and Tables

Summary

Chapter 1

Chapter 2

Tables

Chapter 3

Boxes

Figures

Tables

Chapter 4

Boxes

Figures

Tables

Chapter 5

Boxes

Figures

Chapter 6

Figure

Summary

The goal of eliminating disparities in health care in the United States remains elusive. The findings of the *National Healthcare Disparities Report* reveal that even as quality improves on specific measures, disparities often persist (AHRQ, 2008a, 2008b). Addressing these disparities must begin with the fundamental step of bringing the nature of the disparities and the groups at risk for those disparities to light by collecting health care quality information stratified by race, ethnicity and language data. Then attention can be focused on where interventions might be best applied, and on planning and evaluating those efforts to inform the development of policy and the application of resources. A lack of standardization of categories for race, ethnicity, and language data has been suggested as one obstacle to achieving more widespread collection and utilization of these data. Many types of entities participate in initiatives to improve the quality of health care; health plans, hospitals, other providers, and health systems can and should obtain race, ethnicity, and language data so these data can be used to identify gaps and improve care for all individuals.

The purpose of this report is to identify standardized categories for the variables of race, ethnicity, and language that can be used to facilitate the sharing, compilation, and comparison of quality data stratified by the standard categories. The Institute of Medicine, under a contract with the Agency for Healthcare Research and Quality (AHRQ), Department of Health and Human Services (HHS), formed the Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement to identify current models for collecting and coding race, ethnicity, and language data; to ascertain the challenges involved in obtaining these data in health care settings; and to make recommendations for improvement. The language in the statement of task (Box S-1)—"in healthcare quality improvement" and "assess and report on quality of care"—led the subcommittee to focus its discussion and recommendations on data collection in the domain of health care services.

EXISTING GUIDANCE ON RACE, ETHNICITY, AND LANGUAGE CATEGORIES

The concepts of race and ethnicity are defined socially and culturally and, in the case of federal data collection, by legislative and political necessity (Hayes-Bautista and Chapa, 1987). With the aim of identifying important cultural and social groups for statistical reporting and civil rights monitoring, the Office of Management and Budget (OMB) has developed a minimum set of standardized categories for reporting on race and Hispanic ethnicity by federal agencies and recipients of federal funds (OMB, 1977, 1997b). The five race categories are now Black or African American, White, Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander.

BOX S-1
Statement of Task: Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement

A subcommittee of experts will report to the IOM Committee on Future Directions for the National Healthcare Quality and Disparities Reports regarding the lack of standardization of collection of race and ethnicity data at the federal, state, local, and private sector levels due to the fact that the federal government has yet to issue comprehensive, definitive guidelines for the collection and disclosure of race and ethnicity data in healthcare quality improvement. The subcommittee will focus on defining a standard set of race/ethnicity and language categories and methods for obtaining this information to serve as a standard for those entities wishing to assess and report on quality of care across these categories. The subcommittee will carry out an appropriate level of detailed, in-depth analysis and description which can be included in the overall report by the committee and as a separate stand alone report.

OMB describes these categories as the minimum set and encourages the collection of more detailed data provided those data can be aggregated back to the minimum categories (OMB, 1997a). Progress has been made in incorporating these categories into the collection and presentation of data in health care settings. However, some health care–related data collection efforts still do not employ these basic standard categories.

While OMB has not established a list of language categories, the collection of language data has been pivotal in determining whether there has been discrimination by "national origin" under Title VI of the Civil Rights Act of 1964,[1,2] and federal policies state that "reasonable steps" need to be taken so that persons of limited English proficiency can have "meaningful access" to programs or activities without charge for language services.[3] Additionally in 2000, HHS released its National Standards on Culturally and Linguistically Appropriate Services (CLAS), which encourage all health care organizations and individual providers "to make their practices more culturally and linguistically accessible," including the use of race, ethnicity, and language data in program assessments and incorporation of these data into health records and organizational management systems (HHS, 2007).

CATEGORIZING RACE AND ETHNICITY DATA

The OMB race and Hispanic ethnicity categories represent broad population groups used for an array of statistical reporting and analytic purposes, including health care quality assessment and identification of disparities (AHRQ, 2008a; Cohen, 2008; Flores and Tomany-Korman, 2008; IOM, 2008; Kaiser Family Foundation, 2009). Chapter 2 illustrates that these categories alone, however, are insufficient to illuminate many disparities and to target quality improvement efforts where they may be most needed. Since disparities can exist within those broad OMB categories, there is value in collecting and utilizing data incorporating more fine-grained categories than those of OMB (Blendon et al., 2007; Jerant et al., 2008; Read et al., 2005; Shah and Carrasquillo, 2006). The subcommittee recommends a separate question to collect data on granular ethnicity—defined as "a person's ethnic origin or descent, 'roots,' or heritage, or the place of birth of the person or the person's parents or ancestors…" (U.S. Census Bureau, 2008)—in addition to soliciting data in the OMB race and Hispanic ethnicity categories (Figure S-1). Research also shows that not all individuals identify with the current OMB race categories so the subcommittee recommends expanding the race categories to six choices by including a "Some other race" option

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[1] *The Civil Rights Act of 1964*, Public Law 88-352, 78 Stat. 241, 88th Cong., 2nd sess. (July 2, 1964).

[2] *Lau v Nichols*, 414 U.S. 563 (1974).

[3] *Improving Access to Services for Persons with Limited English Proficiency*, Executive Order 13166, August 11, 2000.

Race and Ethnicity

OMB Hispanic Ethnicity[a]

- Hispanic or Latino
- Not Hispanic or Latino

OMB Race
(Select one or more)

- Black or African American
- White
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Some other race[b]

Granular Ethnicity

- Locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes[c]
- "Other, please specify:___" response option
- Rollup to the OMB categories

Language Need

Spoken English Language Proficiency[d]

- Very well
- Well
- Not well
- Not at all

(Limited English proficiency is defined as "less than very well")

Spoken Language Preferred for Health Care

- Locally relevant choices from a national standard list of approximately 600 categories with coding to be determined
- "Other, please specify:___" response option
- Inclusion of sign language in spoken language need list and Braille when written language is elicited

FIGURE S-1 Recommended variables for standardized collection of race, ethnicity, and language need.

NOTE: Additional categories for HIT tracking might include whether respondents have not yet responded (unavailable), refuse to answer (declined), or do not know (unknown), as well as whether responses are self-reported or observer-reported.

[a] The preferred order of questioning is Hispanic ethnicity first, followed by race, as OMB recommends, and then granular ethnicity.

[b] The U.S. Census Bureau received OMB permission to add "Some other race" to the standard OMB categories in Census 2000 and subsequent Census collections.

[c] Additional codes will be needed for categories added to the CDC/HL7 list.

[d] Need is determined on the basis of two questions, with asking about proficiency first. Limited English proficiency is defined for health care purposes as speaking English less than very well.

SOURCES: CDC, 2000; Office of Management and Budget, 1997b; Shin and Bruno, 2003; U.S. Census Bureau, 2002.

to provide a response category for those Hispanics and others who do not relate to the current choices. Additionally, the subcommittee favors the collection and retention for analysis of specific multiple-race combinations (i.e., having data on each race that an individual selects), rather than losing that detail by only offering the more general category of "multiracial," whenever possible.

In Chapter 3, the subcommittee considers whether a national "OMB Plus" set of 10 to 15 granular ethnicity categories, similar to the Census Bureau approach, should be identified that would be optimal for collection by all health care entities. However, such a set would not be specific to and appropriate for the diverse communities in which health care entities operate. Instead, the subcommittee concludes that individual entities should select the granular ethnicity categories representative of their service population selected from a national list of standardized categories. Whenever a limited list of categories is offered to respondents, the list should include an open-ended response option of "Other, please specify:__" so that each individual who desires to do so can self-identify.

Recommendation 3-1: An entity collecting data from individuals for purposes related to health and health care should:

- **Collect data on granular ethnicity using categories that are applicable to the populations it serves or studies. Categories should be selected from a national standard list (see Recommendation 6-1a) on the basis of health and health care quality issues, evidence or likelihood of disparities, or size of subgroups within the population. The selection of categories should also be informed by analysis of relevant data (e.g., Census data) on the service or study population. In addition, an open-ended option of "Other, please specify:__" should be provided for persons whose granular ethnicity is not listed as a response option.**
- **Elicit categorical responses consistent with the current OMB standard race and Hispanic ethnicity categories, with the addition of a response option of "Some other race" for persons who do not identify with the OMB race categories.**

While several organizations provide lists of granular ethnicities (e.g., Centers for Disease Control and Prevention [CDC]/Health Level 7 [HL7] and the Commonwealth of Massachusetts/Brookings Institution), none of these lists is sufficient for a standard national set from which locally relevant choices could be made (CDC, 2000; Taylor-Clark et al., 2009). A merged list provides a template from which such a national standard set can be developed (see Appendix E). When a person does not check off an OMB race or Hispanic ethnicity and provides only a granular ethnicity response, a process for rolling granular ethnicity categories up to the OMB categories will, in some cases, be necessary for analysis and reporting purposes. However, some ethnicities do not correspond to a single OMB race category, necessitating a "no determinate OMB race classification" for analytic purposes (see Appendix F).

Recommendation 3-2: Any entity collecting data from individuals for purposes related to health and health care should collect granular ethnicity data in addition to data in the OMB race and Hispanic ethnicity categories and should select the granular ethnicity categories to be used from a national standard set. When respondents do not self-identify as one of the OMB race categories or do not respond to the Hispanic ethnicity question, a national scheme should be used to roll up the granular ethnicity categories to the applicable broad OMB race and Hispanic ethnicity categories to the extent feasible.

Eliciting accurate and reliable race, Hispanic ethnicity, and granular ethnicity data depends on the ways in which the questions are asked, the instructions provided to respondents (e.g., "Select one or more"), and the format of the questions (i.e., OMB one-question versus two-question format). This latter issue is especially relevant to how Hispanic populations self-identify. Pilot projects and further study are necessary to confirm the best ways to collect accurate data that are useful for health care quality improvement.

Recommendation 3-3: To determine the utility for health and health care purposes, HHS should pursue studies on different ways of framing the questions and related response categories for collecting race and ethnicity data at the level of the OMB categories, focusing on completeness and accuracy of response among all groups.

- **Issues addressed should include use of the one- or two-question format for race and Hispanic ethnicity, whether all individuals understand and identify with the OMB race and Hispanic ethnicity categories, and the increasing size of populations identifying with "Some other race."**
- **The results of such studies, together with parallel studies by the Census Bureau and other agencies, may reveal the need for an OMB review across all agencies to determine the best format for improving response among all groups.**

IMPROVING THE COLLECTION OF DATA ON LANGUAGE

Compelling evidence exists that having limited English proficiency (LEP) affects the delivery and quality of health care and can result in significant disparities in access to care (Hu and Covell, 1986; Weinick and Krauss, 2000), a decreased likelihood of having a usual source of care (Kirkman-Liff and Mondragon, 1991; Weinick and Krauss, 2000), an increased probability of receiving unnecessary diagnostic tests (Hampers et al., 1999), more serious adverse outcomes from medical errors (Divi et al., 2007), and more drug-related complications (Gandhi et al., 2000). To achieve safe, effective, patient-centered communication, attention must be paid to the language needs of patients, as addressed in Chapter 4.

Language Questions

Assessing each individual's language need is an essential first step toward ensuring effective health care communication. The subcommittee concludes that spoken language need can best be assessed by asking two questions: one aimed at determining whether an individual speaks English less than very well and a second aimed at identifying the individual's preferred spoken language during a health care encounter (Figure S-1). Having this information for each individual allows its use to ensure the quality of services in subsequent encounters, in analysis of health care disparities, and in system-level planning (e.g., determining the need for interpreters and matching patients to language-concordant providers).

The subcommittee establishes a hierarchy among the possible language questions, with questions about English proficiency and preferred spoken language identified as a higher priority than questions on language spoken at home or on preferred language for written materials. On average, 55 percent of those who speak another language at home speak English very well (Shin and Bruno, 2003), but asking about language spoken at home helps provide a window into the health beliefs and practices of the home environment. The correlation between those who need spoken and written language assistance appears to be high in many settings.

Recommendation 4-1: To assess patient/consumer language and communication needs, all entities collecting data from individuals for purposes related to health and health care should:

- **At a minimum, collect data on an individual's assessment of his/her level of English proficiency and on the preferred spoken language needed for effective communication with health care providers. For health care purposes, a rating of spoken English-language proficiency of less than very well is considered limited English proficiency.**
- **Where possible and applicable, additionally collect data on the language spoken by the individual at home and the language in which he/she prefers to receive written materials.**

When the individual is a child, the language need of the parent/guardian must be determined. Similarly, if an adult has a guardian/conservator, that individual's language need must be assessed.

Languages in Use

More than 600 languages are in use in the United States although a smaller number may be in use in health care contexts. In Chapter 4 the subcommittee evaluates options for determining what language categories entities should use for data collection (e.g., a uniform set for all entities, percentage or numerical thresholds based on the presence of languages in a service area, or local choice). Local choice informed by data on the languages spoken most frequently in the service area by persons with LEP is the preferred option. A single list does not suit all areas given that the top non-English languages vary greatly from area to area (for instance, Spanish is in the top 10 languages in 3,122 of 3,141 counties in the United States, while Turkish is in the top 10 in 12 counties, Laotian in 125, Navaho in 74, SerboCroatian in 58, and Portuguese in 229) (U.S. English Foundation, 2009). The aim is to have data on each individual's specific language need, but when an entity designs its collection instruments, whether paper or electronic, it may, because of space considerations, have to use a limited number of response categories. Therefore, such a response list should always include an "Other, please specify:__" option. Some electronic data collection systems are more sophisticated, and by using keystroke recognition can accommodate hundreds of languages.

> **Recommendation 4-2: The choice of response categories for spoken and written language questions should be informed by analysis of relevant data on the service area (e.g., Census data) or service population, and any response list should include an option of "Other, please specify:__" for persons whose language is not listed.**

The subcommittee has developed a template of languages used in the United States based on Census data and the experiences of certain health care providers. This template can serve as a basis for the national standard set called for in recommendations in Chapter 6 (see Appendix I for template). A uniform set of codes can facilitate sharing of data. Two possible language coding systems already exist (the Census and International Organization for Standardization [ISO] code sets) (SIL International, 2009; U.S. Census Bureau, 2007).

> **Recommendation 4-3: When any health care entity collects language data, the languages used as response options or categories for analysis should be selected from a national standard set of languages in use in the United States. The national standard set should include sign language(s) for spoken language and Braille for written language.**

IMPROVING DATA COLLECTION ACROSS THE HEALTH CARE SYSTEM

As discussed in Chapter 5, while each of the entities involved in the nation's health care system has some capability for the collection of race, ethnicity, and language data, some are better positioned than others to collect these data through self-report, the generally agreed-upon best way to define a person's racial and ethnic identity. In the future, information infrastructure may enable integrated data exchange so that all entities will not need to collect all data. For now, however, all health and health care entities have roles to play in collecting these data directly from individuals. Hospitals, community health centers, physician practices, health plans, and local, state, and federal agencies can all identify next steps toward improving or implementing direct data collection by understanding the unique contexts in which they operate. Across all these entities, these data must be collected and stored responsibly. Training of staff, upgrades to health information technology (HIT) systems, and communication with patients and enrollees are potential avenues for improved data collection and building of trust.

In the subcommittee's proposed framework, optional categories are offered (e.g., declined, unavailable, unknown, self-reported, observer-reported); these are not for patient response, but for tracking the portion of the patient population for which an entity has been able to collect data or the nature of the data collection. Until directly collected data are sufficient for analytic and quality improvement purposes, indirect estimation of race and ethnicity through techniques such as geocoding and surname analysis is useful for bridging data gaps.

Recommendation 5-1: Where directly collected race and ethnicity data are not available, entities should use indirect estimation to aid in the analysis of racial and ethnic disparities and in the development of targeted quality improvement strategies, recognizing the probabilistic and fallible nature of such indirectly estimated identifications.

- **Race and ethnicity identifications based on indirect estimation should be distinguished from self-reports in data systems, and if feasible, should be accompanied by probabilities.**
- **Interventions and communications in which race and ethnicity identifications are based on indirect estimation may be better suited to population-level interventions and communications and less well suited to use in individual-level interactions.**
- **An indirectly estimated probability of an individual's race and ethnicity should never be placed in a medical record or used in clinical decision making.**
- **Analyses using indirectly estimated race and ethnicity should employ statistically valid methods that deal with probabilistic identifications.**

IMPLEMENTING COLLECTION OF STANDARDIZED DATA

Now is an opportune time for action on standardization of the categories used to collect race, ethnicity, and language data. Efforts to share and evaluate quality data across states, regions, or payers would be facilitated by standardized categories.

HHS is a prime locus of the subcommittee's recommendations in Chapter 6 for implementation of improved collection of standardized data because of its focus on resolving health and health care disparities and its history of promoting the collection of race, ethnicity, and language data to ensure compliance with applicable statutes and regulations. National development of standardized categories and coding by HHS, along with a responsive updating process, would relieve each state and entity of having to develop its own set of categories and coding scheme, which could be incompatible with others. The subcommittee templates of categories along with an updated CDC/HL7 Code Set can form the basis for standardized race, Hispanic ethnicity, and granular ethnicity data while a determination will have to be made on coding for languages.

Recommendation 6-1a: HHS should develop and make available national standard lists of granular ethnicity categories and spoken and written languages, with accompanying unique codes and rules for rollup procedures.

- **HHS should adopt a process for routine updating of those lists and procedures as necessary. Sign languages should be included in national lists of spoken languages and Braille in lists of written languages.**
- **HHS should ensure that any national hierarchy used to roll up granular ethnicity categories to the broad OMB race and Hispanic ethnicity categories takes into account responses that do not correspond to one of the OMB categories.**

Standardization would support achievement of the goal set forth in the American Recovery and Reinvestment Act of 2009[4] (ARRA) of having a national electronic health record (EHR)[5] for each individual by 2014 that incorporates collection of data on the person's race, ethnicity, and primary language. Having the standards adopted by the other components of the health care industry, including the makers of HIT systems, would help ensure that a sufficient set of data fields are available to accommodate each element recommended for collection by the subcommittee.

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[4] *American Recovery and Reinvestment Act of 2009*, Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).

[5] In this document, EHR means a patient record owned and maintained by a provider entity; a personal health record is a medical or health record owned and maintained by a patient him- or herself.

Recommendation 6-1b: HHS and the Office of the National Coordinator for Health Information Technology (ONC) should adopt as standards for including in electronic health records the variables of race, Hispanic ethnicity, granular ethnicity, and language need identified in this report.

Recommendation 6-1c: HHS and ONC should develop standards for electronic data transmission among health care providers and plans that support data exchange and possible aggregation of race, Hispanic ethnicity, granular ethnicity, and language need data across entities to minimize redundancy in data collection.

Performance incentive programs tend not to be designed with reduction of disparities in mind, yet can have positive or negative effects on disparities in health care and on underresourced primary care safety net providers (Chien et al., 2007; Rust and Cooper, 2007; Williams, 2009). The subcommittee does not take a stand on whether incentive payments in HIT programs should exist, but when they do exist, the collection of race, ethnicity, and language data would be one activity for which positive incentives should be offered.

Recommendation 6-1d: The Centers for Medicare and Medicaid Services (CMS), as well as others sponsoring payment incentive programs, should ensure that the awarding of such incentives takes into account collection of the recommended data on race, Hispanic ethnicity, granular ethnicity, and language need so these data can be used to identify and address disparities in care.

Numerous past and present legislative and policy efforts stress the importance of collecting race, ethnicity, and language data in federal programs. HHS administers programs supporting the health care delivery system to provide care to persons at risk of receiving suboptimal care, and these programs present opportunities to influence the quality of care delivered to millions of Americans. Because the subcommittee's charge relates to health care, the following recommendation focuses on the HHS programs that deliver health cares services, pay for those services through insurance mechanisms, or administer surveys that increase knowledge on health care needs and outcomes. The Secretary, however, may find it useful to extend the standardized approach of this report to other HHS health-related programs or other data gathering activities.

Recommendation 6-1e: HHS should issue guidance that recipients of HHS funding (e.g., Medicare, the Children's Health Insurance Program [CHIP], Medicaid, community health centers) include data on race, Hispanic ethnicity, granular ethnicity, and language need in individual health records so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.

Having quality-of-care information from large federal delivery systems such as the Department of Veterans Affairs, the Department of Defense, and other federally funded programs, such as community health centers, stratified by the same variables and categories recommended in this report would provide rich sources for comparative analysis.

Recommendation 6-2: HHS, the Department of Veterans Affairs, and the Department of Defense should coordinate their efforts to ensure that all federally funded health care delivery systems collect the variables of race, Hispanic ethnicity, granular ethnicity, and language need as outlined in this report, and include these data in the health records of individuals for use in stratifying quality performance metrics, organizing quality improvement and disparity reduction initiatives, and reporting on progress.

Accreditation organizations and other professional and standards-setting bodies can play a key role in fostering the collection of race, ethnicity, and language data. Hospitals, health plans, and physicians have reported that a lack of standardization has been a barrier to using these data in quality improvement efforts (Bilheimer and Sisk, 2008; Lurie et al., 2008; NCQA, 2009; Siegel et al., 2008). The Joint Commission, the National Committee for Quality Assurance (NCQA), and URAC[6] have developed CLAS-like standards for their organizational reviews. The National Quality Forum (NQF) encourages the collection of race, ethnicity, and language data in accordance with the Health Research & Educational Trust (HRET) Toolkit (NQF, 2008); the subcommittee's recommendations include modifications to that toolkit. The American Medical Association, the National Medical Association, and the National Hispanic Medical Association's Commission to End Health Care Disparities have reaffirmed their collective commitment to bringing an end to health care disparities by increasing awareness in the physician community and promoting better data collection (AMA, 2005, 2009).

> **Recommendation 6-3: Accreditation and standards-setting organizations should incorporate the variables of race, Hispanic ethnicity, granular ethnicity, and language need outlined in this report and associated categories (as updated by HHS) as part of their accreditation standards and performance measure endorsements.**
>
> - **The Joint Commission, NCQA, and URAC should ensure collection in individual health records of the variables of race, Hispanic ethnicity, granular ethnicity, and language need as outlined in this report so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.**
> - **NQF should review and amend its recommendations on the collection and use of data on race, Hispanic ethnicity, granular ethnicity, and language need to accord with the categories and procedures outlined in this report.**
> - **Medical societies and medical boards should review and endorse the variables, categories, and procedures outlined in this report and educate their members on their use for quality improvement.**

States have an opportunity to shape the level of detail of race, ethnicity, and language data collected in their programs whether for use in reporting on quality measures by insurance programs, in disease registries, in hospital discharges, in health care surveys, in patient safety reporting, or in other activities. Through Medicaid and CHIP programs, states have leverage with managed care organizations and providers to require collection of the recommended data and their use in quality improvement. Medicaid provides coverage for a large portion of minority groups, and states have an interest in ensuring that the population covered is receiving appropriate quality care (Angeles and Somers, 2007).

> **Recommendation 6-4: Through their certification, regulation, and monitoring of health care providers and organizations within their jurisdiction, states should require the collection of data on the race, Hispanic ethnicity, granular ethnicity, and language need variables as outlined in this report so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.**

CONCLUSION

Efforts are under way to establish national standards for health care technology, performance measurement, and data aggregation and exchange that complement local data collection and experiences with performance improvement and reporting (Roski, 2009). To date, it has been difficult to either combine or compare performance data stratified by race, ethnicity, or language need across payment and delivery systems, which has limited the utility of such data for assessing the performance of the health system as a whole or in specific geographic regions with respect to disparities. Yet, these analyses have implications for the design of appropriate interventions by federal, state, and local policy makers and health care plans and providers.

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[6] Formerly known as the Utilization Review Accreditation Commission.

Standardization of the categories used to collect these data would promote greater comparability of patient-focused data collected directly by care providers or health plans, or, for instance, transferred from providers to multiple plans. Standardization would also eliminate the need for all health care entities to develop their own categorization schemes. Still, additional resources and leadership at the local, state, and national levels will be required to implement these recommendations. Although broad application of EHRs will take a number of years, the data collection issues for current systems do not differ significantly from those involved in future EHR applications, so providers could institute today the processes for the capture and sharing of race, ethnicity, and language data proposed in this report.

There is strong evidence that the quality of health care varies by race, ethnicity, and language. Quality metrics stratified by race, Hispanic ethnicity, granular ethnicity and language need can inform point-of-care services, application of resources, and decisions in patient–provider interactions in ways that can assist in improving overall quality and reducing disparities.

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1

Introduction

Ensuring the delivery of high-quality, patient-centered care requires understanding the needs of the populations served. The nation's health care data infrastructure does not provide the necessary level of detail to understand which groups are experiencing health care disparities or would benefit from targeted quality improvement efforts. Categories for collection and methods of aggregation for reporting race, ethnicity, and language data vary. Challenges to improving data quality include nonstandardized categories, a lack of understanding of why data are collected, health information technology (HIT) limitations, and a lack of sufficiently descriptive response categories, among others. Throughout the course of this report, the subcommittee addresses these challenges as it recommends a standardized approach to eliciting race, ethnicity, and language data and defines a standard set of categories for these data.

Hennepin County Medical Center in Minneapolis, Minnesota, may very well be one of the Midwest's most diverse hospitals. Its patient population includes persons of Somali, Mexican, Ecuadorian, Russian, Vietnamese, and Bosnian heritage, born in this country or elsewhere, to name but a few of the populations in a state that has historically been populated by persons identifying themselves as White and of German and Scandinavian origin. As a March 2009 *New York Times* profile of the hospital emphasized, each of these ethnic groups brings "distinctive patterns" of illness, injury, language, and health beliefs (Grady, 2009), all of which affect how health professionals can best provide safe, timely, effective, patient-centered, efficient, and equitable care, as delineated in the Institute of Medicine's 2001 report *Crossing the Quality Chasm: A New Health System for the 21st Century* (IOM, 2001).

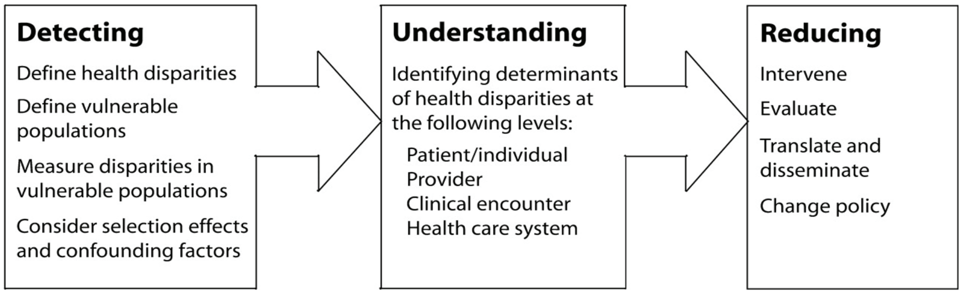
Cultural lifestyle patterns (e.g., food choices and smoking habits) and beliefs about the use of health care influence the quality of care received regardless of the person's country of origin, language, immigration status, or socioeconomic status (SES). The importance of knowing a patient's race, ethnicity, and language need is not limited to understanding the issues facing recent immigrants' health access or outcomes; race, ethnicity, and language data can reveal risks for health care disparities in native-born as well as foreign-born populations. Such data ideally allow:

- Targeted interventions by health plans and health system providers when certain populations have higher than average or potentially avoidable hospitalizations;

- Identification of differentials in health status, quality of care, and outcomes among populations (even when insurance status is the same) by agencies such as the Centers for Medicare and Medicaid Services (CMS);
- Planning of language assistance services to support physicians and other staff that interact directly with diverse patient populations; and
- Development of health promotion outreach strategies to specific groups (e.g., outreach efforts to Somali women who are susceptible to vitamin D deficiency to prevent later, more costly emergency department visits for diagnosis and pain treatment) by public health departments and health care providers working in collaboration.

One of the biggest barriers most health systems face in improving quality and reducing disparities within their own walls is systematically identifying the populations they serve, addressing the needs of these populations, and monitoring improvements over time. This systematic analysis may reveal no disparities in the delivery of health care, but that different groups may have different health care needs (e.g., educating Somali women on the need for vitamin D, earlier cancer screening for racial and ethnic groups at increased risk, addressing ethnocultural beliefs regarding temperature and onset of childhood asthma among Puerto Ricans, therapeutic strategies to reduce risk of diabetic kidney disease among Pima Indians) (American Cancer Society, 2009; Grady, 2009; Pachter et al., 2002; Pavkov et al., 2008). Identification of differences has the ultimate goal of being able to improve the quality of care for each person to enhance his or her health.

Strong evidence exists that there are disparities in health and the quality of health care received by different populations (AHRQ, 2008; IOM, 2003; Kaiser Family Foundation, 2009). In conceptualizing an approach to addressing disparities in health care systems, Kilbourne and colleagues describe three critical phases: detection of disparities, understanding of factors, and development and implementation of interventions (Figure 1-1) (Kilbourne et al., 2006). The detection phase includes three key components: defining health care disparities, identifying vulnerable populations, and developing valid measures. The detection phase requires organizations to systematically collect relevant demographic data and to link these data to measures of quality. This phase brings health systems one step closer to understanding where the disparities (or differential health care needs) exist, which can lead to understanding why they exist and identifying some of the causal factors. Once systems have detected and understood disparities, they are better positioned to develop and implement targeted interventions to reduce those disparities (Kilbourne et al., 2006). The fundamental step is collecting data that adequately describe populations, allowing for the stratification of quality measures at a level of detail that can identify variation in health and health care among at-risk groups (Hasnain-Wynia and Rittner, 2008).



Detecting

Define health disparities

Define vulnerable populations

Measure disparities in vulnerable populations

Consider selection effects and confounding factors

Understanding

Identifying determinants of health disparities at the following levels:

- Patient/individual
- Provider
- Clinical encounter
- Health care system

Reducing

Intervene

Evaluate

Translate and disseminate

Change policy

FIGURE 1-1 A framework for reducing disparities in health care systems.
SOURCE: Kilbourne et al., 2006.

The subcommittee's task is to develop recommendations on standardized categories of race, ethnicity, and language data to support the processes of recognizing differential needs in health care, and identifying and reducing or eliminating disparities. Race, ethnicity, and language information can inform point of care needs, application of resources, and decisions in patient–provider interactions in ways that improve absolute levels of health care quality for all. At the microsystem level, physician practices and individual hospitals can use data to understand the population being served, address disparities in care that exist, and monitor improvements over time. At an intermediate level, data can be used—for example by health plans or states—to make cross-institutional comparisons to detect variations in quality of care between entities serving similar populations. And at the macro level, through national reporting and aggregation, population data can indicate where consistent disparities in care exist nationally (Thomas, 2001).

This chapter provides background on key issues and challenges surrounding the categorization and collection of race, ethnicity, and language data for health care quality improvement. First, the complexity of defining the concepts of race and ethnicity is explored. Next, the chapter examines challenges to the collection of these demographic data, the impetus for standardization, the utility of the current Office of Management and Budget (OMB) race and Hispanic ethnicity categories, and the need for more detailed data on race, ethnicity, and language need. The chapter concludes by reviewing the subcommittee's study charge and providing an overview of the remainder of this report.

DEFINING RACE AND ETHNICITY

The concepts of race and ethnicity are defined socially and culturally and, in the case of federal data collection, by legislative and political necessity (Hayes-Bautista and Chapa, 1987). OMB, for example, states that race and ethnicity categories "are social-political constructs and should not be interpreted as being scientific or anthropological in nature" (OMB, 1997a). Scientific findings provide empirical evidence that there is more genetic variation within than among racial groups; thus, racial categories do not represent major biological distinctions (Cooper and David, 1986; Williams, 1994; Williams et al., 1994) and instead capture socially constructed intersections of political, historical, legal, and cultural factors.

People have been racially categorized by the federal government since the first U.S. Census was conducted in 1790 (Bennett, 2000). Since then, the national statistical system has employed a variety of racial categories, most of which stem from racial classifications that originated in the mid-eighteenth century (Witzig, 1996). Commentators have noted that it is remarkable how little the categories have changed, despite what is now known about the lack of correlation between racial phenotypes and genetic differences (Cavalli-Sforza et al., 1994; Diamond, 1994; Witzig, 1996).

The complex history of racial identification in the United States (Byrd and Clayton, 2000; Smedley, 1999) results in concepts of race and ethnicity that not only have changed over time,[1] but also are subject to self-perceptions, which may also change (Ford and Kelly, 2005; Hahn, 1992); technical decisions defining who belongs in which category; and the perceptions of a person recording another individual's race. In the latter instance, for example, individuals who self-identify as American Indians are frequently classified as White by health care workers when a determination is made by observation alone, without self-report (Izquierdo and Schoenbach, 2000).

Imprecision in defining and using the terms *race* and *ethnicity* is apparent in the conflicting and overlapping terminologies used even by the government bodies responsible for statistical data collection and classification. In some instruments, the federal government considers race and ethnicity to be distinct concepts (Grieco and Cassidy, 2001); in other instruments, questions on race include racial, national origin, and ethnicity response options. The term *race* is often used synonymously with ethnicity, ancestry, nationality, and culture (Williams, 1994; Yankauer, 1987). For example, Census 2000 and 2010 forms ask, "What is this person's race?" (U.S. Census Bureau, 2009) and provide response categories that blur definitions of race, national origin, and ethnicity. Such practices

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[1] *The 2000 Census: Counting Under Adversity* provides an extensive review of the historical development of the racial and ethnic classifications used by the Bureau of the Census. Chapter 3 in *Multiple Origins, Uncertain Destinies: Hispanics and the American Future* reviews the origins of Hispanic ethnicity and its relationship to race.

both reflect and reinforce the lack of uniformity in how the term *ethnicity* is perceived (Macdonald et al., 2005; Thernstrom et al., 1980). The term *Hispanic* is often listed alongside terms that define racial groups (e.g., Asian and White), resulting in many Hispanics beginning to view themselves as a separate race. Thus, when Hispanics are required to choose a race in addition to their Hispanic ethnicity, many self-identify as "Some other race" (NRC, 2006). The Census Bureau's definition of "Some other race" is included in Table 1-1.

Race and ethnicity can be important statistical predictors of an individual's risk for good or poor health outcomes and access to care (NRC, 2004b; Wallman et al., 2000; Williams, 1994). However, a multitude of factors that are both correlated with and independent of race and ethnicity may affect group differences in health and health care. The model presented in Figure 1-2 indicates the complex relationships between environmental conditions, socioeconomic status, discrimination, racism, and health care. In this model, health care (called medical care in the figure), or lack thereof, is viewed as both a risk factor and resource that impacts an individual's health status. Because of the complex relationships depicted in this model, the concepts of race and ethnicity should be dealt with deliberatively, purposefully, and thoughtfully (Williams et al., 1994).

A 2004 National Research Council committee charged with defining the measurement of racial discrimination concluded that "race is a salient aspect of social, political, and economic life" and that collecting data on race and ethnicity is therefore necessary to "monitor and understand differences in opportunities and outcomes for population groups" (NRC, 2004c, p. 33). Thus, while there have been flaws in applying the terms *race* and *ethnicity*, the terms remain important to use in distinguishing the diversity of the U.S. population.

While recognizing a certain lack of precision and consistency in the terms race and ethnicity for defining population groups that would be unacceptable with any other variable used in scientific inquiry (Kagawa-Singer, 2009), the subcommittee chose to adopt the definitions put forth in the 2003 IOM report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*. Race is considered a "socioeconomic concept wherein groups of people sharing certain physical characteristics are treated differently based on stereotypical thinking, discriminatory institutions and social structures, a shared worldview, and social myths" (IOM, 2003, p. 525).[2] For the purposes of this report, the subcommittee considers ethnicity to be a concept referring to a shared culture and way of life, especially reflected in language, religion, and material culture products (IOM, 2003). The subcommittee makes a distinction between the limited OMB and Census Bureau use of the term *ethnicity* to connote solely Hispanic ethnicity and the concept of granular ethnicity advanced in this report and further defined in Chapters 2 and 3. Additionally, the subcommittee recognizes that linguistic barriers can present significant challenges to both patients and providers and thus has adopted a definition of language that is inclusive of communication needs. This report develops an approach to the collection of data on these key variables and offers a framework of race, ethnicity, and language categories and questions for the collection and use of these data in health care quality improvement efforts.

CHALLENGES TO COLLECTING RACE, ETHNICITY, AND LANGUAGE DATA

A variety of entities, such as states, health plans, health professionals, hospitals, community health centers, nursing homes, and public health departments—as well as the public—play roles in obtaining, sharing, and using race, ethnicity, and language data. All of these entities, though, have different reasons for and ways of categorizing, collecting, and aggregating these data. In interviews and testimony before the subcommittee, representatives of hospitals, health plans, physicians, and custodians of federal health care databases consistently identified several challenges to improving the quality and availability of race, ethnicity, and language data in patient–provider encounters and at various levels of the health care system (Box 1-1). The principal challenges in obtaining these data for use in quality improvement assessments include a lack of standardization of categories to foster data sharing and aggregation (Lurie et al., 2005; Siegel et al., 2007), a lack of understanding of why the data are being collected

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[2] Other definitions of race abound. For example, OMB states that race and ethnicity should not be interpreted as being primarily biological or genetic in reference, but rather, thought of in terms of social and cultural characteristics as well as ancestry (OMB, 1997b). The Census Bureau complies with the OMB standards, noting that the standards "generally reflect a social definition of race recognized in this country. They do not conform to any biological, anthropological or genetic criteria" (U.S. Census Bureau, 2001).

TABLE 1-1 Categories and Definitions Promulgated by the OMB and the U.S. Bureau of the Census

OMB Category	OMB Definition of Category	Census Definition of Category
American Indian or Alaska Native	A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment	People having origins in any of the original peoples of North and South America (including Central America), and who maintain tribal affiliation or community attachment, including, for example, Rosebud Sioux, Chippewa, or Navajo
Asian	A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam	People having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, people who have indicated their race as Asian Indian, Chinese, Filipino, Korean, Japanese, Vietnamese, Burmese, Hmong, Pakistani, or Thai
Black or African American	A person having origins in any of the black racial groups of Africa. Terms such as “Haitian” or “Negro” can be used in addition to “Black or African American”	People having origins in any of the black racial groups of Africa, including, for example, Black, African American, Negro, Nigerian, or Haitian
Hispanic or Latino	A person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term, “Spanish origin,” can be used in addition to “Hispanic or Latino”	A person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race
Native Hawaiian or Other Pacific Islander	A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands	People having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands, including people who identify as Native Hawaiian, Chamorro, Tahitian, Mariana Islander, or Chuukese
White	A person having origins in any of the original peoples of Europe, the Middle East, or North Africa	People having origins in any of the original peoples of Europe, the Middle East, or North Africa, including Irish, German, Italian, Lebanese, Near Easterner, Arab, or Polish
Some Other Race		All other responses not classifiable in the White, Black or African American, American Indian or Alaska Native, Asian, and Native Hawaiian or Other Pacific Islander race categories; respondents providing write-in entries such as multiracial, mixed, interracial, “American,” or a Hispanic/Latino group (e.g., Mexican, Puerto Rican, Cuban)

NOTE: The Indian Health Service uses a narrower definition applicable to Alaska Natives and American Indians that have an affiliation with a tribal group of the United States to establish eligibility for their programs; thus, it does not include indigenous people of Latin America or Canada. “Any individual who (1), irrespective of whether he or she lives on or near a reservation, is a member of a tribe, band, or other organized group of Indians, including those tribes, bands, or groups terminated since 1940 and those recognized now or in the future by the State in which they reside, or who is a descendent, in the first or second degree, of any such member, or (2) is an Eskimo or Aleut or other Alaska Native, or (3) is considered by the Secretary of the Interior to be an Indian for any purpose, or (4) is determined to be an Indian under regulations promulgated by the Secretary” (*The Indian Healthcare Improvement Act,* Public Law 94-437, 25 U.S.C. 1603(c)-(d)).
SOURCES: OMB, 1997b; U.S. Census Bureau, 2000.

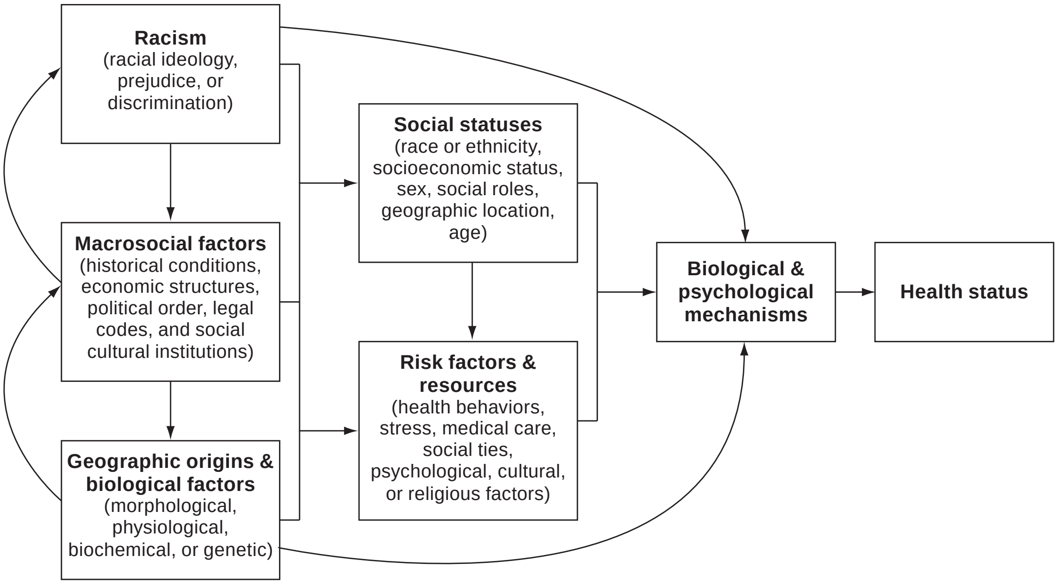

FIGURE 1-2 Williams, Lavizzo-Mourey, and Warren's framework for understanding the relationships between race, medical/health care, and health.
SOURCE: Adapted, with permission, from Public Health Reports 2009. Copyright 1994 Public Health Reports.

(Hasnain-Wynia et al., 2007; Regenstein and Sickler, 2006), a lack of space on collection forms and in collection systems (Coltin, 2009; Hasnain-Wynia et al., 2007; Ting, 2009), health information technology (HIT) limitations (e.g., field capacity and linkages among systems) (Coltin, 2009), and the fact that the current OMB categories are not sufficiently descriptive of locally relevant population groups (Friedman et al., 2000; NRC, 2004b). These issues, though challenging, are not insurmountable; thus, the subcommittee seeks to identify options for moving forward and improving the categorization, collection, and aggregation of race, ethnicity, and language data so

BOX 1-1
Barriers to Collection of Race, Ethnicity, and Language Data

System Level
- Lack of standardization of categories
- Lack of understanding why data are collected
- Provided response categories not sufficiently descriptive to relate to local populations
- HIT limitations (number of fields, comparability of categories among systems)
- Space on collection forms (paper or electronic)
- Discomfort on part of person collecting

Patient–Provider Encounter
- Lack of standardization of categories
- Lack of understanding why data are collected
- Provided response categories not sufficiently descriptive for local populations to self-identify with
- Privacy concerns

they can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.

Standardizing Categories

The reasons for standardizing race, ethnicity, and language categories for data collection for health care quality improvement are four-fold: (1) ensuring that equivalent categories are being collected and compared across settings; (2) minimizing the reporting burden that arises when multiple entities require different sets of incompatible categories; (3) optimizing the ability to share data across systems of payers, health care settings, government agencies, and political jurisdictions; and (4) going beyond the OMB categories to develop response options that are more relevant for the identification of needs for quality improvement. Sharing and comparing data across systems calls for a common vocabulary to avoid omission of categories that might be critical to monitoring disparities and to allow mapping of categories from one system to another.

The expansion of electronic health records (EHRs)[3] and integration of data systems creates an opportunity to establish uniform categories and coding practices. Developing linkages among health data systems would provide a more comprehensive picture of health care quality. Doing so would be greatly facilitated by having the ability to “read” comparable data from disparate sources, a proposition that requires standardized categories, coding, and procedures for aggregating granular data to broader categories whenever necessary.

Current Status of National Standards for Categorizing and Collecting Race, Ethnicity, and Language Data

In specifying a system that can provide uniformity and comparability in the collection and use of data by federal agencies, OMB provides a minimum standard for collecting and presenting data on Hispanic ethnicity and race (see Box 1-2) (OMB, 1997b). The driving force for the development of this standard in the 1970s was the need for comparable data for civil rights monitoring; thus the categories reflect legislatively based priorities for data on particular population groups, including congressionally mandated separate counts of the Hispanic population (Wallman et al., 2000). Because the standard was not designed with regard to health or health care specifically, the groups identified by the OMB categories may not be the only analytic groups useful for advancing health care quality improvement.

The OMB standard was envisioned as a minimum reporting requirement, and more discrete categorization is encouraged as long as these categories can be rolled up to the six OMB race and Hispanic ethnicity categories (OMB, 1997a). For example, the Census Bureau and some Department of Health and Human Services (HHS)–sponsored national surveys use the OMB minimum categories plus other categories that can be aggregated into the minimum categories for analysis and reporting.

No nationally standardized minimum set of languages comparable to the OMB race and Hispanic ethnicity categories exists. HHS, in conformance with Department of Justice principles to prevent discrimination and to ensure access to federally funded programs, has provided guidance on the importance of collecting language data (HHS, 2003) in its Culturally and Linguistically Appropriate Services (CLAS) standards. Four of the 14 standards are federally mandated for all health care organizations that receive federal funds. These organizations must offer and provide competent language assistance services and must make documents available in “the languages of the commonly encountered groups and/or groups represented in the service area.” The CLAS standards do not list language categories to be used for data collection and analysis but seek to ensure the provision of language assistance services and culturally competent care in all health care settings (Office of Minority Health, 2001).

In agencies that are not federal or organizations that do not receive federal funds or federal contracts, race, ethnicity, and language data may not be collected because state, local, and private sector data collection is not universally mandated. Furthermore, those data that are collected do not necessarily adhere to a uniform set of categories; hospitals, health plans, community health centers, employers, and providers collect data in disparate ways.

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[3] EHRs are further defined in Chapter 6 of this report.

BOX 1-2
The 1997 OMB Revisions to the Standards for the Classification of Federal Data on Race and Hispanic Ethnicity

Hispanic Ethnicity
- Hispanic or Latino origin
- Not of Hispanic or Latino origin

Race
- American Indian or Alaska Native
- Asian
- Native Hawaiian or Other Pacific Islander
- Black or African American
- White

Features
- Designed to be minimum categories. Additional categories can be used provided they can be aggregated into the standard categories
- Requires separate collection of Hispanic ethnicity and race data
- Requires Hispanic ethnicity question before race question, when the two-question format is used
- Requires allowance for selection of more than one race category (e.g., “Select one or more”)
- Preference for self-reported race and Hispanic ethnicity

Use of the Standards
- Used at a minimum for all federally sponsored statistical data collections that include data on race and ethnicity

An Approach to Improving the Categorization and Aggregation of Data

The OMB categories are not sufficiently descriptive to distinguish among locally relevant ethnic populations that face unique health problems and may have dissimilar patterns of care and outcomes (Hasnain-Wynia and Baker, 2006). When more detailed data are collected and used locally, aggregation to the OMB categories loses detailed quality-related information for specific populations. As linkages among quality reporting systems become more common and allow aggregation of data from multiple sources, consistent methods of identifying subgroups will facilitate more robust analyses of detailed population data at the local, regional, state, and national levels. Any national standard list of categories for those subgroups must capture the full diversity of the U.S. population. The keys to the usefulness of such a list across the country are balancing that comprehensiveness with the desired level of granularity to describe locally pertinent groups, and resolving any administrative and logistical barriers to collecting a sufficient number of informative categories to help guide quality improvement.

The three principal means of obtaining race, ethnicity, and language data are self-report, observation, and indirect estimation. Self-report, which reflects how individuals view themselves, is the widely preferred approach as it has been adopted by OMB (OMB, 1997b) and is considered by researchers to be the “gold standard” (Higgins and Taylor, 2009; Wei et al., 2006). The Interagency Committee for the Review of the Racial and Ethnic Standards reviewed the OMB standards prior to the 1997 revisions and determined that self-report respects “individual dignity” by allowing an individual to determine how he or she classifies himself or herself as opposed to classification being assigned by another person (OMB, 1997a).

The Health Research and Educational Trust (HRET) Toolkit and the National Health Plan Collaborative

(NHPC) have provided guidance on collecting data on race, Hispanic ethnicity, more detailed ethnicity, and language need (Hasnain-Wynia et al., 2007; NHPC, 2008). The HRET Toolkit was recently endorsed by the National Quality Forum (NQF, 2008); however, the languages are limited to those most common at the national level, it includes a single "multiracial" category instead of an instruction to allow persons to "Select one or more," and there is no "Other, please specify:__" option to capture additional categories with which individuals identify. Therefore, the framework for categorization and collection spelled out by this report provides a national standard for more thorough categorization and collection than has previously been put forth.

Addressing the Legality and Understanding the Purposes of Data Collection

The collection of data is impaired when its need is not well understood by health professionals and intake workers, and especially by patients themselves. Clinicians and administrators too often misperceive legal barriers and furthermore do not expect to see any disparities in their practice. Despite evidence of disparities at all levels of health and health care systems, hospital executives, physicians, and staff, for example, may believe that disparities are not a problem in their respective institutions (Weinick et al., 2008). Some worry that soliciting the information may put them at risk for offending patients, or if disparities are found, for accusations of discrimination (Hasnain-Wynia et al., 2004). Similarly, health plans have been concerned that they could be viewed as subjecting certain populations to discriminatory treatment by asking for such data in advance of enrollment. In fact, a few states prohibit the acquisition of race and ethnicity data at enrollment, but not thereafter.[4] A 2009 analysis of federal and state laws found no federal laws or regulations prohibiting health plans from collecting race and ethnicity data (AHIP, 2009).

The HRET Toolkit, the National Health Law Program (NHeLP), and the HHS Office of Minority Health (OMH) all emphasize that the collection of race, ethnicity, and language data is permitted under Title VI of the Civil Rights Act of 1964 and is, in fact, necessary to ensure compliance with the statute (Berry et al., 2001; Hasnain-Wynia et al., 2007; Perot and Youdelman, 2001).[5] The Civil Rights Act requires recipients of federal financial assistance to collect information that demonstrates compliance, including "racial and ethnic data showing the extent to which members of minority groups are beneficiaries of and participants in federally-assisted programs."[6] Furthermore, a July 2008 law[7] mandated the Secretary of HHS to implement the collection of race, ethnicity, and gender data in the Medicare program in fee-for-service plans, Medicare Advantage private plans, and Part D prescription drug plans. The American Recovery and Reinvestment Act of 2009 (ARRA)[8] also lays out expectations for the collection of race, ethnicity, and language data by specifying the inclusion of these variables in EHRs.

Although the legal basis for the collection of race and ethnicity data is well documented (AHIP, 2009; Perot and Youdelman, 2001; Rosenbaum et al., 2007; Youdelman and Hitov, 2001) and at least 80 program-specific statutes require the reporting and collection of race, ethnicity, and language data (Youdelman and Hitov, 2001), health care organizations may still perceive legal barriers, including concerns about the applicability of Health Insurance Portability and Accountability Act of 1996 (HIPAA)[9] regulations, to collecting, sharing, and reporting these data. HIPAA restricts the use and disclosure of identifiable health information, but does not limit the collection of demographic data for quality improvement purposes (Kornblet et al., 2008).

A 2007 National Committee on Vital Health Statistics (NCVHS) report addresses the concern of the potential of harm arising from the use of data enabled by their collection and exchange through HIT. The report acknowledges the potential for "discrimination, personal embarrassment, and group-based harm" when the data are compiled and exchanged (NCVHS, 2007, p. 5). The report recommends the protection of all uses of health data by all users

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[4] California, Maryland, New Hampshire, New Jersey, New York, and Pennsylvania prohibit insurers from requesting an applicant's race, ethnicity, religion, ancestry, or national origin in applications, but the states allow insurers to request such information from individuals after enrollment (AHIP, 2009).

[5] A list of legislation relevant to race, ethnicity, and language data is included in Appendix B.

[6] *The Civil Rights Act of 1964*, Public Law 88-352, 78 Stat. 241, 88th Cong., 2d sess. (July 2, 1964).

[7] *Medicare Improvements for Patients and Providers Act of 2008*, Public Law 110-275 § 118, 110th Cong., 2d sess. (July 15, 2008).

[8] *American Recovery and Reinvestment Act of 2009*, Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).

[9] *Health Insurance Portability and Accountability Act of 1996*, Public Law 104-191, 104th Cong., 2d sess. (August 21, 1996).

under a framework of data stewardship, a concept that encompasses "the responsibilities and accountabilities associated with managing, collecting, viewing, storing, sharing, disclosing, or otherwise making use of personal health information" (AMIA, 2007), and the subcommittee agrees.

Efforts to collect these data may also be hampered by intake workers and patient registration staff who feel uncomfortable soliciting them from patients, and who feel burdened by collecting data whose importance they do not understand and cannot adequately explain if patients challenge the need for these data. Patients, meanwhile, may be hesitant to provide race, ethnicity, and language data because of concerns about privacy and their own uncertainty as to why these data are needed. Perceived experiences of discrimination in medical care have been found to be associated with greater apprehension about providing race and ethnicity information among, for example, Blacks, Hispanics, and Mandarin/Cantonese-speaking Asians (Kandula et al., 2009). Potential health plan enrollees, for instance, may fear discriminatory access to coverage, while hospital patients may worry that language questions serve as a proxy for questions about immigration status.

Addressing Health Information Technology (HIT) Issues

Advances in HIT, including recent federal government financing and support, may open doors to advance data collection. Currently, however, collecting and utilizing race, ethnicity, and language data in health care settings may be complicated by challenges in capturing sufficient data and in linking available data from disparate sources (Schoenman et al., 2007). For example, many hospitals and physician offices that collect these data enter them with other demographic characteristics at intake. These demographic data, then, are typically included in practice management systems, which are separate from the HIT systems that capture clinical information used in quality measurement.

In many health care settings, space on data collection forms and space constraints in HIT systems can be barriers to including detailed demographic data (Hasnain-Wynia et al., 2007). For example, while OMB stipulates the separate collection of race and Hispanic ethnicity data, some legacy HIT systems allow only one field for capturing both elements. Similarly, some HIT systems are unable to collect the multiple responses that result from the "Select one or more" approach required by OMB (Coltin, 2009).

Some HIT collection systems utilize drop-down screens and keystroke pattern matching to increase the number of category choices they can offer. Other paper and electronic systems default to lengthy lists that are time-consuming for both staff and patients to comb through, or use shorter lists and classify many persons under an indiscriminant "other" category. Open-ended questions (e.g., "Other, please specify:__"), which allow write-in responses, may improve self-identification but can impose additional administrative burdens if labor-intensive manual coding must be undertaken in the absence of automated systems or optical scanning technology. However, the use of "Other, please specify:__" as an adjunct check-off box captures respondent answers and is thus useful to more accurately describing all members in a service population.

STUDY CHARGE AND APPROACH

The IOM, under a contract with the Agency for Healthcare Research and Quality (AHRQ), formed the Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement to report on the issue of standardization of race, ethnicity, and language variables; define a standard set of race, ethnicity, and language categories; and define methods of obtaining race, ethnicity, and language data (Box 1-3). To address this charge, the subcommittee identifies categories and types of questions that allow for the development of uniform standards for the collection, aggregation, and reporting of race, ethnicity, and language data for quality improvement in health care settings.

The subcommittee's title and its charge refer specifically to health care but not health in general. The subcommittee recognizes that health care is one element that contributes to people's health, and that the effects of race, ethnicity, and language on health in general are important. However, the language in the statement of task, specifically "in healthcare quality improvement" and "report on quality of care," led the subcommittee to focus its discussion and recommendations on the health care domain. In its recommendations regarding the collection of

BOX 1-3
Statement of Task: Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement

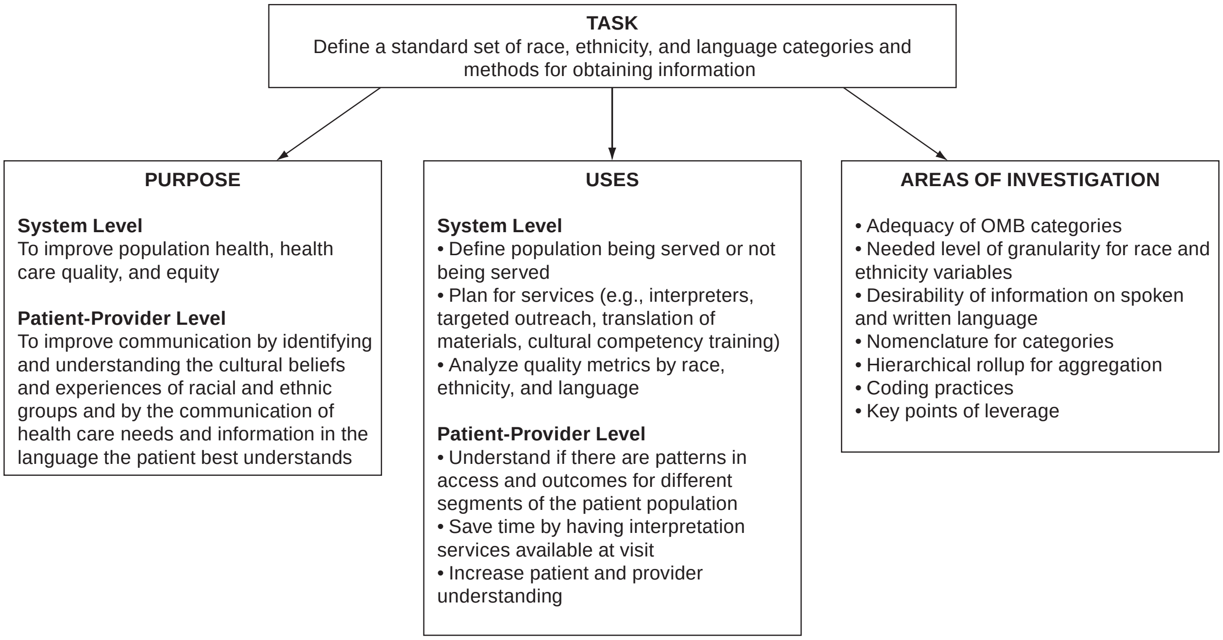
A subcommittee of experts will report to the IOM Committee on Future Directions for the National Healthcare Quality and Disparities Reports regarding the lack of standardization of collection of race and ethnicity data at the federal, state, local, and private sector levels due to the fact that the federal government has yet to issue comprehensive, definitive guidelines for the collection and disclosure of race and ethnicity data in healthcare quality improvement. The subcommittee will focus on defining a standard set of race/ethnicity and language categories and methods for obtaining this information to serve as a standard for those entities wishing to assess and report on quality of care across these categories. The subcommittee will carry out an appropriate level of detailed, in-depth analysis and description which can be included in the overall report by the committee and as a separate stand alone report.

race, ethnicity, and language data, the subcommittee emphasizes areas such as care delivery sites (e.g., hospitals, physician practices) and public and private insurers involved in measuring and improving the quality of health care. Nonetheless, recommendations can apply to data collection activities in public health (e.g., state-sponsored immunization registries) when those data can be used to target interventions and resources to ensure equity in care and health outcomes. The subcommittee's recommendations include surveys addressing the quality of care or the utilization of care.

Vital statistics data sets present a special case, since data from birth or death certificates may be linked to data from health care settings to identify disparities in health care and health outcomes. Knowledge about differentials in mortality along race and ethnicity lines can help care providers focus inquiries about specific populations to determine the quality of their care. However, these data collection activities are organized and supported for purposes beyond health care and health care quality improvement, and recommendations set in the narrower context of health care quality improvement may conflict with other important considerations. The subcommittee did not focus its discussions on vital statistics data collection processes, nor do its recommendations specifically include those processes. New national standards have been set for birth and death records, incorporating categories beyond those set by OMB; states and localities are free to use additional categories and are encouraged to do so along the lines of the subcommittee's recommendations.

The subcommittee was formed in conjunction with the Committee on Future Directions for the National Healthcare Quality and Disparities Reports. The subcommittee met in person four times during the course of the four-month study and conducted additional deliberations through telephone conferences. It heard public testimony from a wide range of experts during two public workshops and additional interviews. Staff and committee members met with and received information from a variety of stakeholders and interested organizations, including health plans, advocacy groups, health services researchers, and HIT implementation experts.

The subcommittee has approached its task by evaluating the two interrelated purposes and uses of data collection (Figure 1-3): improvements in individual patient–provider care interactions, and system-level improvement. In patient–provider interactions, effective two-directional communication is essential to the provision of high-quality, patient-centered care. Quality care can depend on a provider's identification and understanding of the cultural beliefs and experiences of his or her patients, and on the expression and understanding of health care needs communicated by patients. Health services researchers have adopted the term *cultural competence* to describe the goal of creating a health care system and workforce that are capable of delivering high-quality care to all patients through an array of efforts, including training of physicians and availability of health care interpreters (Betancourt et al., 2005). Knowledge of a patient's race, ethnicity, and language and communication needs can assist in the



TASK
Define a standard set of race, ethnicity, and language categories and methods for obtaining information

PURPOSE

System Level
To improve population health, health care quality, and equity

Patient-Provider Level
To improve communication by identifying and understanding the cultural beliefs and experiences of racial and ethnic groups and by the communication of health care needs and information in the language the patient best understands

USES

System Level
- Define population being served or not being served
- Plan for services (e.g., interpreters, targeted outreach, translation of materials, cultural competency training)
- Analyze quality metrics by race, ethnicity, and language

Patient-Provider Level
- Understand if there are patterns in access and outcomes for different segments of the patient population
- Save time by having interpretation services available at visit
- Increase patient and provider understanding

AREAS OF INVESTIGATION
- Adequacy of OMB categories
- Needed level of granularity for race and ethnicity variables
- Desirability of information on spoken and written language
- Nomenclature for categories
- Hierarchical rollup for aggregation
- Coding practices
- Key points of leverage

FIGURE 1-3 Overview of purposes and uses of race, ethnicity, and language data to guide subcommittee's investigation of issues of categorization and collection.

provision of patient-centered care by accounting for the "impact of emotional, cultural, social, and psychological issues on the main biomedical ailment" (Hedrick, 1999, p. 154). At the system level, race, ethnicity, and language data serve an evidentiary purpose for improving population health, health care quality, and equity by identifying variations related to these characteristics. System-level analyses include variations across a broad range of health care entities, including physician practices, community health centers, hospitals, health plans, state government bodies, and federal agencies.

The subcommittee approached its task by defining two terms in its framework for recommendations; the term *variable* refers to the dimensions of race, ethnicity, and language on which is it important to have data; the term *categories* refers to the possible discrete groupings of individuals that can occur in any variable. The subcommittee developed principles to guide its deliberations, including the need for:

- Nomenclature for each variable and its categories that would maximize individuals' ease and consistency of identification with those categories;
- Local decision making about categories that would be useful given the size and diversity of the population served or surveyed, as well as the consideration that quality improvement activities tend to be locally based;
- A framework that would allow some flexibility in approaches to collection but retain uniform categories, in recognition of the different capacities of information systems; and
- Fostering comparability across the variety of actors that collect and use these data.

Building on Previous Studies

In developing its rationale and framework for standardization, the subcommittee considers previous research on the categorization, collection, and use of race, ethnicity, and language data in health care settings. In 2000, Congress asked the National Academies to assess the ability of HHS data collection systems to measure racial, ethnic, and socioeconomic disparities. The request resulted in the 2004 National Research Council report *Eliminating Health Disparities: Measurement and Data Needs*, which recommends actions for HHS to take to ensure the routine collection and reporting of race and ethnicity data. The report acknowledges the importance of collecting data on race, ethnicity, socioeconomic status, and language and acculturation for use in making statistical inferences about disparities, but notes the lack of standardized collection and reporting of these data across all entities (NRC, 2004b).

NCVHS has historically emphasized to its HHS counterparts the necessity and benefits of collecting race, ethnicity, and language data, among other variables, under the premise that these data are essential to monitoring the health of the nation (NCVHS, 2001, 2004, 2005). In several reports over the past decade, the NCVHS Subcommittee on Populations has discussed challenges to collecting and using these data. The present report addresses these data collection challenges and proposes a framework for moving forward with standardized data collection across all health and health care entities, not just within HHS agencies or by recipients of federal funds. Previous reports have reiterated the importance of collecting more detailed ethnicity data than are captured by the OMB standard categories; this report proposes a template of categories so that entities wishing to collect detailed data can do so in systematic, uniform ways.

Limitations of the Study

Like previous IOM committees, the subcommittee recognizes the linkages among socioeconomic status, health literacy, and immigration with race, ethnicity, and language; however, these dimensions were beyond the scope of its charge. Lower socioeconomic status has been associated in the literature with poor health outcomes and high mortality rates since at least the early twentieth century (Isaacs and Schroeder, 2004; Link and Phelan, 1996; Lutfey and Freese, 2005). Time in the United States and immigration status also have implications for one's health and access to health care (Kagawa-Singer, 2006, 2009; Oh et al., 2002; Portes and Hao, 2002; Wadsworth and Kubrin, 2007).

While the subcommittee focuses exclusively on the categorization of race, ethnicity, and language—as it was charged to do—it recognizes that some differences in health care among racial, ethnic, and language groups reflect differences in socioeconomic status, immigration, and health literacy. Studying the roles of these constructs nevertheless presumes categorizations of race, ethnicity, and language of reasonable credibility and consistency for patients from whom the data are collected, providers who collect the data, and those analyzing the data for quality improvement purposes.

While the subcommittee concludes that a full consideration of HIT technicalities is beyond the scope of its charge, its members are mindful of HIT considerations in its recommendations. The subcommittee also notes the timeliness and relevance of its work to Section 13001 of ARRA.[10] The intersection between the subcommittee's work and emerging HIT standards will be further discussed in Chapter 6 of this report.

OVERVIEW OF THE REPORT

The subcommittee is charged with recommending standards for the categorization and collection of race, ethnicity, and language data. Collection of data at various levels of the health care system implies that the data must be amenable to reporting and aggregation in consistent ways. To frame how the purposes and uses outlined in Figure 1-3 could best be met, the subcommittee addresses the following areas:

- Defining the specific variables to be collected: race (including the applicability of the OMB categories), ethnicity (whether limited to Hispanic ethnicity or expanded to other groupings), language (whether encompassing English language proficiency and spoken and/or written language needed for effective communication);

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[10] Section 13001 is known as the Health Information Technology for Economic and Clinical Health Act or the HITECH Act.

- Describing the nomenclature for each variable to ensure that the categories for each contain as valid and reliable data as possible;
- Defining a classification system for race and ethnicity that allows a hierarchical rollup so categorical data can be combined;
- Suggesting standardized approaches to coding race, ethnicity, and language categories to foster data linkages; and
- Addressing key points of leverage to ensure both patient–provider and system-level improvement.

Chapter 2 reviews the available research on how more discrete categorization of ethnicity can reveal disparities and allow more precise targeting of initiatives for health care quality improvement. Chapter 3 addresses the utility of the OMB categories in capturing important cultural and social groups for statistical reporting before considering the collection of more granular ethnicity data and how standard coding of categories can allow for the sharing of data beyond a single service site. The chapter examines the geographic distribution of racial and ethnic groups across the United States and the need for balance between nationally uniform categories for data collection and flexibility in how different subsets of categories are used for local quality improvement. Chapter 4 reviews different approaches germane to the collection of language data, explores the need for data on spoken and written language, and examines language coding practices. Chapter 5 covers the challenges and barriers faced by health care organizations and providers of care in collecting these variables. The chapter explores how these challenges can be addressed through direct collection methods and use of indirect estimation techniques. Chapter 6 examines the role of various entities in informing and shaping the uptake of standardized categories of race, ethnicity, and language data. The chapter describes the opportunities afforded through the adoption of EHRs and more integrated HIT systems that are likely to extend the capabilities of health care providers at all levels to collect and use these data systematically.

Race, ethnicity, and language data are tools for fighting discrimination, understanding disparities, and providing culturally and linguistically relevant services (Burdman, 2003). Thus, these data are useful and important for identifying and, ultimately, acting to reduce and eliminate disparities in health status and health care. These data alone, however, cannot address how to fix the issues brought to light in Chapter 2. Measurement cannot ensure the provision of culturally and linguistically appropriate care that incorporates racial and ethnic sensitivities, accommodates diverse views and approaches, and reduces disparities by improving access and quality.

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2

Evidence of Disparities Among Ethnicity Groups

Research studies help provide an understanding of the extent of the health and health care disparities experienced by different racial and ethnic groups. While the Office of Management and Budget (OMB) race and Hispanic ethnicity categories can reveal many inequities, they also mask important disparities in health and health care. More discrete ethnicity groups, based on ancestry, differ in the extent of risk factors, degree of health problems, quality of care received, and outcomes of care. More granular ethnicity data could inform the development and targeting of interventions to ameliorate disparities in health care that contribute to poorer health.

The Institute of Medicine's landmark report on racial and ethnic disparities in health care, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, emphasizes the need for standardized collection and reporting of race and ethnicity data (IOM, 2003). While *Unequal Treatment* recommends the Office of Management and Budget (OMB) race and ethnicity categories as the minimum standard by which collected race and ethnicity data should be parsed and reported, the recommendations go further, calling for better data on racial and ethnic populations "to reflect the diversity within racial and ethnic populations (e.g., subgroups of Hispanics, African Americans, Asian Americans, etc.), particularly at the local level" (IOM, 2003, p. 233).

Since the release of *Unequal Treatment*, evidence of disparities in health and health care among racial categories at the broad OMB level (Black or African American, Asian, Native Hawaiian or Other Pacific Islander [NHOPI], White, and American Indian or Alaska Native [AIAN]) has continued to be documented. Similarly, distinct differences continue to be shown between the broad Hispanic and non-Hispanic ethnic categories. For example, there is more information on varying life expectancy (IOM, 2008) and mortality risks or rates for certain medical conditions (Murthy et al., 2005; Wang et al., 2006), along with knowledge of disparities in general health status, access to health care, and utilization rates of services among these larger population categories (AHRQ, 2008a; Cohen, 2008; Flores and Tomany-Korman, 2008; Kaiser Family Foundation, 2008, 2009; Ting et al., 2008). Even as quality-of-care indicators such as screening for colorectal cancer show improvement for the overall population, disparities persist among the OMB race and Hispanic ethnicity categories (AHRQ, 2008a, 2008b; Moy, 2009; Trivedi et al., 2005).

In contrast, systematic analysis of similar quality-related data as a function of more discrete ethnic groups *within* the OMB categories has hardly progressed. After defining the term *granular ethnicity*, this chapter summarizes the evidence showing health and health care disparities at more fine-grained levels of ethnic categorization. The literature has more to say about ethnicity and disparities in health than about ethnicity and disparities in health care; this is reflected in the balance of articles reviewed in this chapter. To complement the research studies, data are also presented for selected population characteristics that can place people at risk of disparities (e.g., low education levels, poverty, lack of facility with English among those speaking a non-English language at home, and place of origin).

This focus on literature with respect to more granular detail on subgroups is not to negate the important differences found among the OMB racial groups and for Hispanics compared with non-Hispanics, but to learn more about where to focus interventions when categorical differences are masked by the OMB categories. Being able to focus interventions at the more granular level has been posited as a way to use resources most efficiently to reduce disparities.

Awareness of health and health care disparities has been heightened through the release of multiple documents besides *Unequal Treatment*, including—Healthy People 2010 and the *National Healthcare Disparities Reports* (AHRQ, 2008a; HHS, 2000), and successful initiatives have addressed some disparities using a variety of approaches. For example, some successful initiatives have applied general quality improvement concepts and techniques, while others have developed and used culturally sensitive outreach and education materials for health plan members, and still others have involved training of staff in culturally competent communications. Common to virtually all successful projects are some fundamental steps, including the acquisition of data on race and ethnicity, the stratification of quality-of-care data by race and ethnicity, the use of race and ethnicity to identify members of a target population to whom elements of an intervention would apply, and reanalysis of stratified quality data to evaluate the impact of the activities. Data on race and ethnicity are a fundamental requirement for disparity reduction initiatives. Without these data, it is impossible to identify disparities and track the impact of initiatives over time, and it is difficult to target those aspects of interventions that involve direct contact with individuals. The presence of data on race and ethnicity does not, in and of itself, guarantee any subsequent actions in terms of analysis of quality-of-care data to identify disparities or any actions to reduce or eliminate disparities that are found. The absence of data, however, essentially guarantees that none of those actions will occur.

DEFINING RACIAL AND ETHNIC POPULATIONS IN THE UNITED STATES

The United States is a diverse country whose composition is changing. Table 2-1 shows the results of Census 2000 on the size and percentage distribution of the total U.S. population primarily by the broad OMB racial and Hispanic ethnic groupings. The Black and Hispanic groups are of equivalent size; the Census has multiple check-off boxes for specific Hispanic groups (i.e., Mexican, Puerto Rican, Cuban, and a write-in option for other groups) that it routinely reports, but there are no such more specific check-off boxes under the Black or White races. Asians and Pacific Islanders have many specific groups listed on the Census form from which to choose as well. There are efforts to legislatively mandate expansions to the current Census categories (e.g., add Caribbeans in general and Dominicans specifically).[1] The groups included in the OMB race and Hispanic ethnicity categories are defined in Chapter 1 (see Table 1-1).

Defining Ethnicity

Ethnicity is a concept that the subcommittee, for standardization purposes, distinguishes from race. The term *ethnicity* represents a common ancestral heritage that gives social groups a shared sense of identity that exists even though a particular ethnic group may contain persons who self-identify with different race categories. The OMB categories use the term ethnicity only in conjunction with Hispanic ethnicity. The U.S. Census captures data on a few discrete ethnic groups both under the Hispanic ethnicity question, by having check-off boxes for some Hispanic groups (e.g., Puerto Ricans, Dominicans), and under the race question, by listing some groups of

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[1] In the first session of the 111th Congress, bills were introduced to include check-off boxes on Census Bureau questionnaires for Dominican ethnicity (HR 1504 and SB 1084) and for Caribbean ethnicity in general (HR 2071 and SB 1083).

TABLE 2-1 Census 2000 Population by Race and Hispanic Ethnicity

Population Group	Number (in millions)	Percent of U.S. Population
Total Population	281.4	100
Hispanic Ethnicity[a]		
Not Spanish, Hispanic, Latino	246.1	87.5
Spanish, Hispanic, Latino	35.2	12.5
Mexican, Mexican American, Chicano	(20.9)	(7.4)
Puerto Rican	(3.4)	(1.2)
Cuban	(1.3)	(0.4)
Other Hispanic	(9.6)	(3.4)
Race[b]		
One Race		
White	211.4	75.1
Black, African American, or Negro	34.7	12.3
American Indian or Alaska Native	2.5	0.9
Asian	10.2	3.6
Native Hawaiian or Other Pacific Islander	0.4	0.1
Some Other Race	15.4	5.5
Two or More Races	6.8	2.4

NOTE: The number and percents on race in this table differ somewhat from later tables in this chapter because later tables combine persons that report a single race alone or in combination with other races (e.g., persons who are Black race alone plus multi-race persons who identify with both Black race and another race), whereas this table focuses on single-race reporting.

[a] Ramirez, 2004.

[b] Grieco and Cassidy, 2001.

Asian and Pacific Islander heritage (e.g., Japanese, Samoan) and leaving an option for American Indian and Alaska Natives to indicate a tribal affiliation.

Where one is born can make a significant difference in access to and use of health care, but the subcommittee adopts the concept of ethnicity (equated with one's ancestry) as more encompassing than questions about country of birth or origin. A person born in the United States might identify culturally with a specific ethnicity in ways that can affect his or her health-related behaviors and approach to utilizing health services. Also the subcommittee prefers the use of ethnicity over questions such as national origin because inquiring about national origin could engender mistrust on the part of respondents that they are being asked about immigration status (Carter-Pokras and Zambrana, 2006).[2]

Defining Granular Ethnicity

Granularity means a fine level of detail; the greater the level of granularity, the more finely detailed the data category is. The subcommittee adopts the term *granular ethnicity* to describe groups at a more specific level of categorization than the broad OMB categories, such as the ethnic groups that the Census lists as subgroups in its Hispanic ethnicity and race questions. The subcommittee, as will be examined in Chapter 3, believes a separate question on granular ethnicity would complement the OMB categories for race and Hispanic ethnicity without further intermingling the constructs of race and ethnicity. Additionally, this approach would allow more discrete categorization of large groups of the population who now have the option only of White or Black on the race question.

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[2] Personal communication, O. Carter-Pokras, University of Maryland School of Public Health, April 13, 2009.

The term granular has been used in describing more detailed categories in the Hospital Research & Educational Trust (HRET) Toolkit (Hasnain-Wynia et al., 2007), and the notion of the need for more detailed subgroup data has been raised in *Unequal Treatment* and by many others. Kaiser Permanente also uses the term granular ethnicity in describing its collection of more detailed information beyond the OMB categories (Tang, 2009). More detailed ethnicity categories provide a useful way of analyzing quality data about the populations served by providers, health plans, state and federal programs, and others to determine whether there are differential health needs and disparities in access to and use of appropriate health services. The level of detail for analysis for quality improvement can be influenced by the size of the ethnic population under study; the number or proportion of those ethnicities that might have a specific condition such as diabetes or be of an age at which immunization for pneumonia is needed; and the actual associations among ethnicity, other correlated factors (e.g., income, insurance coverage), and quality of care. While there are hundreds of possible ethnic categories, not all will have local relevance nor always have added value for designing targeted approaches to remediate health care needs. This report's recommendations are driven by a need to identify and address quality differentials not simply to collect information to classify and count people.

OVERVIEW OF DIFFERENTIALS IN CARE AND POTENTIAL QUALITY IMPROVEMENT INTERVENTIONS

Health is the physical, mental, and functional status of an individual or a population. Health has been shown to be the result of multiple factors, including nutrition, educational level, socioeconomic level, and lifestyle, and of the health care that the individual or population receives. Health care comprises the prevention, treatment, and rehabilitation interventions that are provided to an individual to maintain or improve health. Disparities in health care (e.g., in access, in the rate at which a treatment is provided when indicated, or in the incidence of adverse events in care) can be the cause of disparities in health (e.g., in the incidence or severity of a disease, in functional level, or in mortality rate). Therefore, analyses of disparities in health care can help identify opportunities for quality improvement in care provision that will reduce disparities in health. For the most part, entities use the same categories of race, ethnicity and language whether data are collected for health or health care purposes so the connections between health disparities and health care disparities can be drawn more easily.

Illustration of Differences Among Ethnic Groups Within Broad OMB Categories

A study by Blendon and colleagues (2007) illustrates the concept of differences among subgroups residing in the United States, even after controlling for demographic characteristics such as income, education, age, and sex. A number of differences in health care service utilization and satisfaction can be seen among more granular Black, Asian, and Hispanic ethnic groups. Blendon and colleagues' telephone survey of 4,157 randomly selected adults in the United States found that fewer Caribbean- and African-born Blacks received any care than U.S.-born African Americans in the past year but it was the latter group that rated their care more poorly than Whites. Certain Hispanic American groups (Mexican and Central/South American Hispanic) and Asian American groups (Chinese, Korean, and Vietnamese) also received significantly less health care in the last year compared with Whites, even though other ethnicities within these broad OMB race and ethnicity categories fared as well as Whites. Native Americans also received less care compared with Whites and less often rated their care as good or excellent—the lowest rating of any of the groups. Regressions that controlled for demographic characteristics reduced the number of groups receiving no care in the past year by half, but significant differences remained for African-born Americans, Mexican Americans, Chinese Americans, and Korean Americans compared with Whites that were independent of the demographic factors (Blendon et al., 2007). While for some groups the access and utilization issues may stem from economic challenges, the reality remains that there are differences among ethnic groups in utilization and ratings of caregiving within the broad OMB categories.

Potential Applications for Quality Improvement

Cooper and colleagues (2002) review a variety of successful interventions, and note that while there are many well-identified potential opportunities for certain conditions and services, there is a lack of information on “ethnic subgroups.” They also stress the need to improve the science of evaluating interventions to reduce disparities now that there is widespread acknowledgment of the existence of inequalities. A fundamental component of improving quality is collecting reliable demographic data to use in focusing attention on where interventions might be best applied.

Fiscella also observes that, “because disparities in healthcare represent inequities in the process of healthcare, they are potentially addressable through interventions designed to impact health delivery” (Fiscella, 2007, p. 142). Entities that collect race and detailed ethnicity data might use them in various ways to examine whether there are differentials in health care needs and to plan targeted interventions. For example, having read in published research that certain ethnic groups are at higher risk for cancer mortality and delays in care, a health plan could target educational calls to persons of these ethnic groups to make screening appointments for different site-specific cancers rather than having to contact a much larger number of persons (Bates et al., 2008). Or a hospital could look at the characteristics of patients who did not receive care according to evidenced-based protocols for acute myocardial infarction. Then the hospital could assess whether there were specific barriers that interfered with the appropriate delivery of care to specific populations and make concerted efforts to remove those barriers. Or the hospital might also want to take what it learned from that effort to institute strategies that could be applied universally to ensure that all patients with that condition receive the right care at the right time. Another hospital might be experiencing a high readmission rate; analysis of its readmission data might reveal a higher than expected rate for a specific ethnic group. From there, the hospital could determine whether culturally specific interventions at discharge planning are necessary to prevent unnecessary readmissions, and whether this patient group needs access to regular primary care. Similarly, a health center might find that women of a certain group are not coming in for prenatal care until late in their pregnancy; this finding could lead the health center to send community health workers out into the community to change attitudes and practices related to seeking timely care. Physicians receiving feedback on their practice patterns might discover that they are not giving the same evidence-based care to all patients, even though they believe they are, and when this is called to their attention, their practice improves. Fiscella reviews a variety of quality improvement tools, including reminders, provider feedback, provider education, intensive outreach, practice guidelines, patient education, cultural competency training, and organizational change/practice redesign and community-based interventions, and concludes that “the elimination of healthcare disparities will require the development and implementation of tailored interventions directed at multiple levels. Success will depend on the vision, leadership commitment, and allocation of resources by government, health plans, hospitals, communities, and practices…” (2007, p. 164).

The following sections examine further evidence of differences within the aggregate OMB categories. These studies are illustrative of how more granular ethnicity data reveal more precise opportunities for targeting health care quality improvement initiatives.[3] Notations are made when the studies are controlled for socio-economic factors when comparing health or health care differences among populations. Statistically significant associations and trends are emphasized.

HISPANIC OR LATINO GROUPS

In Census 2000, 12.5 percent of the U.S. population (35.2 million people) self-identified as Hispanic, with persons of Mexican origin representing the largest ethnicity group at almost 60 percent of the Hispanic population (Ramirez, 2004). Hispanic is the one distinct ethnicity included in the OMB basic categories and is defined by the Census and OMB as a “person of Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish

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[3] To identify relevant evidence on health and health care for this chapter, Medline articles were queried using keywords “subgroup,” “subpopulation,” “health disparities,” “racial,” “ethnic,” “Hispanic,” “Latino,” “African,” “Black,” “White,” and “Asian” in various combinations. Literature since 1997 was scanned and culled, first by title, then abstract, then full text. Reference sections of relevant articles were also scanned to find other relevant literature.

culture or origin regardless of race" (OMB, 1997; Ramirez, 2004). The question about Hispanic ethnicity used by the Census includes additional labels, such as Latino and Spanish, to delineate more clearly who is included since different people identify with one of the terms but not the others.

Demographic Characteristics

This ethnic category usually has been subdivided in the literature according to ancestry or according to regional designations of South and Central America (Table 2-2).[4] From this table, one sees that individual Hispanic groups[5] have different characteristics with respect to U.S. nativity, proficiency with English, educational attainment, and risk of poverty factors that have been shown to impact the quality of care those populations receive and their health outcomes. More than 40 percent of most ethnic groups who speak Spanish at home do not speak English very well, and some groups have almost twice the poverty rate of others (Ramirez, 2004).

Health-Related Differences Among Hispanic or Latino Groups

Differences in dimensions of health and health care among specific Hispanic or Latino populations in the United States have been identified and studied more extensively than other racial and ethnic populations. The available literature includes studies of health and health care disparities between Hispanic groups by overall self-rated health, access to care, mental health, cancer and cancer screening, low birthweight, asthma, and cardiovascular health.

Overall Self-Rated Health

In a national study comparing the overall mental and physical health of multiple Hispanic ethnicity groups, the Mexican group tended to have better scores on both components of the SF-12 than Whites and other Hispanic groups, whether those of Mexican ancestry were born in the United States or Mexico (Jerant et al., 2008). The study is based on cross-sectional analyses of linked data from the 1998–2004 National Health Interview Survey (NHIS) and the 1999–2005 Medical Expenditure Panel Survey (MEPS); the study population compared four Hispanic groups—Mexican (13,522 persons), Cuban (778), Puerto Rican (1,360) and Dominican (829) including persons born in the United States and elsewhere—with 45,422 English-speaking Whites born in the United States. After regressions adjusting for demographic and socioeconomic variables, those of Cuban ancestry had the worst mental health scores, while those of Puerto Rican heritage had the worst physical health scores; the scores for Cuban, Puerto Rican and Dominican groups on both components were worse than Whites. The authors' suggest that the "paradox" of better health status among the Mexican group even with low socioeconomic status can mask poorer health status of other smaller groups of Hispanics when the Hispanic data are examined as one group. The authors also underscored that the observed ethnic differences within the Hispanic groups on the mental health component met a criterion for clinical significance.

Access to Health Care Services

Shah and Carrasquillo (2006) used cross-sectional analyses of the Census Bureau's Current Population Survey (CPS) to examine differences in insurance coverage, focusing on Hispanic populations. As of 2004, those identifying with the Mexican ethnicity category had the highest rate of uninsurance (35.6 percent), and the Puerto Rican category the lowest rate (17.6 percent), with Cuban (22.1 percent), Dominican (25.3 percent) and other Hispanic

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[4] The form for this survey had check-off boxes for three specific categories (Mexican, Puerto Rican, Cuban), followed by a check-off box for "Other Spanish, Hispanic/Latino," accompanied by a space for writing in another specific Hispanic origin group. The numerous other identified subgroups are based on the "other" responses.

[5] The Census Bureau allows people of Brazilian heritage to self-identify whether they are Hispanic or not, but the Census does not automatically classify Brazilians who speak Portuguese as Hispanics. About half of Brazilians identified as non-Hispanic in both Census 2000 and the Current Population Survey (del Pinal and Schmidley, 2000).

TABLE 2-2 Selected Characteristics of the Hispanic/Latino/Spanish Population in the United States

Hispanic Groups	Number (in millions)	Percent of U.S. Hispanic Population	Percent of U.S. Population	Native Born (%)	Speak a Language Other Than English at Home and Speak English Less Than "Very Well" (%)	Less Than High School Graduation[a] (%)	Poverty Rate (%)
Mexican	20.9	59.3	7.4	58.5	43.1	54.2	23.5
Puerto Rican	3.4	9.7	1.2	98.6[b]	26.7	36.7	25.8
Cuban	1.2	3.5	0.4	31.5	45.9	37.1	14.6
Central American	1.8	5.1	0.6	24.5	56.8	54.0	19.9
Costa Rican[c]	(0.07)	(0.2)					
Guatemalan	(0.37)	(1.1)					
Honduran	(0.22)	(0.6)					
Nicaraguan	(0.18)	(0.5)					
Panamanian	(0.09)	(0.3)					
Salvadoran	(0.66)	(1.9)					
Other	(0.10)	(0.3)					
South American	1.4	4.0	0.5	23.4	47.6	23.9	15.0
Argentinean	(0.10)	(0.3)					
Bolivian	(0.04)	(0.1)					
Chilean	(0.07)	(0.2)					
Colombian	(0.47)	(1.3)					
Ecuadorian	(0.26)	(0.7)					
Paraguayan	(0.01)	(0.0)					
Peruvian	(0.23)	(0.7)					
Uruguayan	(0.02)	(0.1)					
Venezuelan	(0.09)	(0.3)					
Other South American	(0.06)	(0.2)					
Dominican	0.8	2.2	0.3	31.8	53.7	48.9	27.5
Spaniard	0.1	0.3	—	59.8	25.3	23.0	12.8
Other Hispanic[c]	5.5	15.7	2.0	72.4	29.8	40.0	21.5
Total Hispanic	35.3	100	NA	59.8	40.6	47.6	22.6
Total U.S. Population	281.4	NA	12.5	88.9	8.1	19.6	12.4

[a] Population 25 and older.

[b] Persons born in Puerto Rico are automatically U.S. citizens. In the case of Puerto Ricans, they are not considered foreign-born.

[c] Includes general responses such as Hispanic, Spanish, and Latino.

SOURCE: Ramirez, 2004.

groups (32.5 percent) having intermediate values (Shah and Carrasquillo, 2006). The socioeconomic profile of the groups did not always parallel the rate of uninsurance, for example the subgroups with the greatest proportion under 200 percent of poverty were Mexican and Puerto Rican. Weinick and colleagues (2004) using MEPS data similarly showed that persons identifying with Mexican ethnicity had higher uninsurance rates than Cuban and Puerto Rican groups, but persons with Central American and Caribbean ethnicities had even higher rates of uninsurance than the Mexican group.

Additionally, Weinick and colleagues (2004) examined differences in use of four health care services (ambulatory care visits, emergency department [ED] visits, prescription medications, and inpatient hospitalizations). After controlling for sociodemographics, including income and health insurance coverage, multivariate regression analyses of MEPS data showed that persons of Mexican and Cuban ancestry had lower rates of ED visits than other Hispanics. Additionally, more recent immigrants were less likely to have made any ambulatory care or emergency department visits in the past year. The English-speaking subgroups had a higher rate of ED visits and hospitalizations, and foreign-born Hispanics showed lower rates of ambulatory visits, ED visits, and prescription medications. Based on these results, the authors concluded that understanding disparities in health care utilization will require disaggregation of patient demographic data by ethnic groups, language, and length of U.S. residence (Weinick et al., 2004).

Mental Health

Alegría and colleagues (2007) examined the prevalence of depressive, anxiety, and substance use disorders among Hispanics living in the United States using data from the National Latino and Asian American Study (NLAAS).[6] Weighted logistic regression analyses controlled for age. In terms of lifetime prevalence, compared with the comparable Puerto Rican gender group, those of Mexican ethnicity showed lower rates of depressive disorders whether male or female and lower rates of substance abuse disorders for women, and lower overall psychiatric disorders for men. Cuban men were less likely to suffer from anxiety disorders and overall psychiatric disorders. Puerto Ricans tended to have the highest rates of lifetime and past year depressive, anxiety, substance use, and overall psychiatric disorders. Looking at all Hispanic groups in combination, those with higher English proficiency were significantly more likely to suffer from overall lifetime or past year psychiatric disorders than those with fair or poor English skills.

Cancer and Cancer Screening

Gorin and Heck (2005) used the 2000 NHIS to examine data from 5,377 Latinos on the use in the past 12 months of Pap smears, mammograms, breast self-examinations, and clinical breast exams among women; prostate-specific antigen (PSA) tests among men; and fecal occult blood tests (FOBT), sigmoidoscopy, colonoscopy, and proctoscopy among both men and women. Cancer risk factors such as smoking varied by ethnic group (e.g., over 25 percent of Puerto Rican and “other” Hispanics smoked while 13.9 percent of Dominicans did). For persons of average risk for cancer (i.e., did not have a personal or family history of cancer), ethnic group variations were apparent in use of Pap smears and clinical breast exams, but differed less on some tests such as FOBT where use was low for all groups. Multivariate logistic regression analyses revealed that Dominican women were 2.4 times more likely to have had mammography than other Latino women. Puerto Rican and the Central or South American groups had half the rate of colorectal cancer screening by endoscopy of others. Cuban males were five times more likely to have had a PSA test. Additionally persons with health insurance were 1.5 to 2.2 times as likely to have screening tests compared with the uninsured. Having visited a doctor in the past year, increased the odds of having screening tests to a level similar to having insurance, with the exception of PSA screening where the odds were almost five-

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[6] A survey of 2,554 Latinos aged 18 years and older, half monolingual Spanish, 868 Mexican, 495 Puerto Rican, 577 Cuban, and 614 other Hispanics. The NLAAS population was similar to the Census 2000 population distribution by gender, age, education, marital status, and geographic distribution, but differed in terms of nativity and household income.

fold greater. Greater acculturation,[7] visits to a primary care provider, and use of other screening tests, predicted the likelihood of Pap smear screening. Clinical breast exam rates were also predicted by greater acculturation, visits to a primary care provider in the last month, and use of other screening tests, along with having a bachelor's degree and a personal history of cancer (Gorin and Heck, 2005).

Using multiple logistic regression analyses of NHIS data pooled from 1990 and 1992, Zambrana (1999) compared the use of three cancer screening practices (Pap smear, mammogram, and clinical breast exam) for five categories of Hispanic women including women who identify as Mexican versus Mexican-American. While Mexican women were the least likely to have been screened in the past three years, no statistically significant differences were found in the rates between the Mexican-American (referent group) and any of the other Hispanic groups. In this study, access measures such as having a usual source of care and knowledge of other clinical cancer screening techniques were more strongly associated than ethnic or language factors with screening rates for the population studied (Zambrana et al., 1999). The authors posit that the higher than expected rates of screening in the sample population may be attributable largely to contemporaneous intervention strategies and community outreach to increase screening among Hispanic women, concluding that such efforts appeared effective and should be expanded.

The National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) data from 1992–1995 showed that while all Hispanic women had a greater likelihood of larger tumor size and advanced tumor stage than non-Hispanic Whites, women born in Latin America had higher odds of large tumors (e.g., larger than 1 cm and 2 cm) than Hispanic women born in the United States (Hedeen and White, 2001). The researchers were only able to identify the ethnic subgroup for 38 percent of the Hispanic women in the SEER database.

Low Birthweight

Logistic regressions on 2002 U.S. Natality Detail Data (n = 634,797) showed that after controlling for a variety of demographic, educational and clinical factors, foreign-born Latino mothers had a lower risk of having low-birthweight infants compared with U.S.-born Latino women. However, nativity patterns among Mexican-origin women explained these overall trends among Latino women and infants. Foreign-born women with Mexican ethnicity had about a 21 percent reduced risk of low birthweight, but the same phenomenon was not observed for other Latino women who were born outside the continental United States (i.e., Puerto Ricans, Cubans, Central/South Americans) (Acevedo-Garcia et al., 2007). Across each of the three regression models, Puerto Rican women had higher odds than other Hispanic subgroups of having a low-birthweight infant. The regression models for this study did not control for income or insurance status.

Asthma

Large differences also exist in asthma burden among Hispanic children. Based on weighted logistic regression analyses of merged 1997–2001 NHIS data, Puerto Rican children had the highest prevalence (26 percent) and rate of recent asthma attacks (12 percent) compared with children of Mexican heritage whose prevalence and recent attack rates were 10 percent and four percent, respectively (Lara et al., 2006). Rates for Cuban and Dominican ethnicities were intermediate and similar to Black children. Adjusted odds ratios followed the same relative pattern among Hispanic subgroups (e.g., lifetime odds of 2.3 for Puerto Rican children vs. 0.90 for Mexican children compared with the non-Hispanic White referent group). Birthplace influenced the association between ethnicity and lifetime asthma diagnosis differently for Puerto Rican and Mexican children. When both Puerto Rican children and their parents were born in the continental United States, the adjusted odds ratio (OR) was 1.95 (95 percent CI 1.48–2.57) but 2.5 (95 percent CI 1.51–4.13) for those who were island-born; the odds ratios were calculated using as the referent group U.S.-born non-Hispanic White children whose parents were born in the United States (Lara et al., 2006). In contrast, U.S.-born Mexican families had a higher adjusted OR for lifetime asthma diagnosis of 1.05 (95 percent CI 0.90–1.22) than the 0.43 (95 percent CI 0.29–0.64) for those born outside of the continental United States. Similar patterns were observed for recent asthma attacks. Birthplace was the only co-variant that affected

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[7] Acculturation was measured using a modified Marin Short Acculturation Scale.

the Hispanic subgroup results; numerous factors were considered including family income and insurance status. Overall Hispanic data mirror the Mexican ethnicity data, thus masking the results for Puerto Rican children.

Cardiovascular Health

Borrell and Crawford used NHIS data (1997–2005) to perform descriptive and logistic regression analyses assessing the strength of association between Hispanic ethnic groups and self-reported hypertension; self-report was based on the question of whether they had ever been told by a health professional that they had hypertension. Dominican ethnicity and non-Hispanic Black adults had an adjusted odds ratio of 1.67 and 1.48, respectively, compared with the referent group of non-Hispanic Whites. Results were adjusted for age, sex, marital status, survey year, U.S. region, nativity status/length in the United States, health insurance, education, income, and occupation. In contrast, persons of Cuban, Central or South American, Mexican (whether born in the United States or not), and other Hispanic groups all had lower odds than non-Hispanic Whites or Blacks or those of Dominican ethnicity (Borrell and Crawford, 2008).

Another study examined hypertension-related mortality rates among women of various Hispanic subgroups using data from the National Vital Statistics System's Multiple Cause Mortality Files and further tracked whether changes occurred over time (1995–1996 to 2001–2002). In 1995–1996, the age-standardized death rate per 100,000 for hypertension-related mortality was higher among the Puerto Rican group (248.5) than for non-Hispanic Whites (188.7), while Mexican American (185.4), and Cuban (139.7) rates were lower. Over time, the mortality rate decreased for Puerto Rican (215.5), non-Hispanic White (171.9), and Cuban American (104.6) women, with each group keeping their relative position. At the same time the rate for Mexican American women increased to 205.5, now making their risk higher than non-Hispanic White women. The authors suggest the need for strengthening interventions to reach these higher risk ethnicity groups and those who provide their care (Zambrana et al., 2007).

Summary

In the broad Hispanic ethnicity category, more granular ethnicities are associated with different levels on health indicators and access to and utilization of health care depending on ancestry. The authors of the studies reviewed in this section stress the importance of not viewing the Hispanic population as monolithic, and they point out the masking effect that the larger Mexican ethnicity group has on overall statistics when data are viewed to represent all Hispanic groups as one. Even after adjustment for factors such as insurance, education, and income, many ethnic differences were found to remain. The authors also comment on how Hispanic populations beyond Mexican, Cuban and Puerto Rican ethnicity are not well characterized, because in surveys their numbers are small resulting in heterogeneous groups being lumped into an "other" Hispanic category.

BLACK OR AFRICAN AMERICAN GROUPS

In Census 2000, 12.9 percent of the U.S. population (36.2 million people) self-identified with the Black or African American category.[8] The OMB and Census definition for the Black or African American race category is "a person having origins in any of the Black racial groups of Africa" (OMB, 1997; U.S. Census Bureau, 2000).

Demographic Characteristics

The Black population, like the AIAN and White populations, is more likely than other groups to be born in the United States (nearly 94 percent vs. 89 percent for the total U.S. population, as compared with 59.8 percent of Hispanics, 31.1 percent of Asians, and 80.1 percent of NHOPI). The origins of foreign-born Blacks are as follows: approximately 59 percent from the Caribbean, 24 percent from Africa, and 13 percent from Central and

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[8] 12.2 percent reported Black alone with the remainder reporting more than one race; of those checking more than one race, the largest combinations in order were 784,764 reporting both Black and White, followed by 417,249 reporting Black and "Some other race," generally Hispanic, and then 182,494 reporting Black and American Indian/Alaska Native.

South America (McKinnon and Bennett, 2005). While English is the primary language of 94 percent of Blacks, nearly one-third of those over age 5 who speak a language other than English at home speak English less than “very well”; additional detail is provided in Table 2-3 on groups who speak a language other than English at home. One in four Blacks live in poverty; 14 percent over age 25 have a bachelor’s degree, while 19.6 percent have not graduated from high school.

Health-Related Differences Among Black or African American Groups

For the most part, few studies subdivide the Black population for study; when they are, the literature has generally subdivided this category into U.S.-born Blacks, Caribbean-born Blacks, and African-born Blacks although some have distinguished other groups by using additional countries of birth which may not necessarily represent ethnicity (e.g., born in Europe to African parents). The available literature has examined health and health care differences among these groups by overall self-rated health, mental health, cancer, low birthweight, and cardiovascular health.

Overall Self-Rated Health

In a study comparing U.S.-born, European-born, African-born, and West-Indian-born Black ethnic groups aged 18 and older (utilizing merged 2000–2001 NHIS data), groups were examined for differences in self-rated health status, any self-assessed activity limitation in general and then specifically due to hypertension (Read et al., 2005b). Multivariate regression analyses adjusted for demographic characteristics and socioeconomic status including educational attainment, insurance status and income. The study does not distinguish between Blacks of different ethnicities born in the United States. U.S.- and European-born Blacks had worse ratings on all the measures compared with those born in Africa or Whites born in the United States. West Indian-born Blacks had poorer self-rated health status, more activity limitation, and more hypertension-related activity limitation compared with those born in Africa. European-born Blacks had the worst results of all categories; those who are African born had the best values. These findings lead the authors to conclude that the health advantage ascribed to Black immigrants in other studies can be due to the influence of data on African-born groups.

Mental Health

Williams and colleagues (2007) studied mental health among Caribbean Black groups of different ethnicities as well as African Americans with no Caribbean roots by using data derived from the National Survey of American Life. The Caribbean groups included persons born in the United States as well as those who immigrated to this country. Caribbean Black women had significantly lower odds than African-American women of suffering from any mental disorder in terms of either lifetime prevalence or occurrence in the last 12 months. Caribbean Black men were significantly more likely to suffer from any disorder in the past 12 months but not for lifetime prevalence compared with U.S. African American men. Among the Caribbean ethnicities, those whose ethnic origins were in Spanish-speaking countries had higher odds of lifetime prevalence of any disorder than those from English speaking countries. Using first-generation Blacks as the reference group, third-generation immigrants had greater odds of lifetime prevalence of any disorder. The authors note the importance of understanding associations between ethnicity and other factors in order to better describe heterogeneous populations, concluding “that the mental health risk profile of Caribbean Blacks differs from that of other African-Americans. Moreover, the Black Caribbean immigrant category itself masks considerable heterogeneity” (p. 57) as is illustrated by the differences exhibited for Spanish- and English-speaking countries of origin.

Rates of Cancer Mortality

Data on differences in cancer mortality rates among Blacks at more granular ethnicity levels are limited. One study, based on New York City death certificates dating from 1988–1992 linked with U.S. Census data, found that

TABLE 2-3 Selected Characteristics of the Black Population in the United States

Black Groups	Number[a] (in millions)	Percent of U.S. Black Population	Percent of U.S. Population	Native Born (%)	Speak a Language Other Than English at Home and Speak English Less Than "Very Well" (%)	Less Than High School Graduation[b] (%)	Poverty Rate (%)
African-American	24.5	67.0	8.6	99.0	[c]	24.3	23.2
Afro-Caribbean	1.6	4.4	0.6	30.4	[c]	27.6	15.5
African	1.5	4.2	0.5	68.3	34.2[c]	21.2	22.3
Other or no ancestry reported	9.0	24.5	3.1	91.0		38.8	29.8
Total Black	36.6	100.0	12.8	92.8	36.1[c]	27.7[d]	24.3
Total U.S. population	285.2	12.8	NA	88.9	8.1	19.6	12.4
Blacks speaking Spanish at home	1.5	4.0	0.5	78.7	37.5[c]	32.3	30.1
Blacks speaking other Indo-European languages at home	0.9	2.5	0.3	39.6	38.5[c]	31.1	20.3
Blacks speaking Asian and Pacific Islander languages at home	0.06	0.2	0.02	67.7	29.8[c]	21.1	16.7
Blacks speaking all other languages at home	0.06	0.2	0.02	55.8	28.4[c]	22.4	28.7

[a] Black race alone and in combination.

[b] Population 25 and older (20.8 million).

[c] U.S. Census Bureau, 2006b. Calculations using Census data. Black race alone. Population 5 years and older.

[d] U.S. Census Bureau, 2006a. Calculations using Census data.

SOURCES: McKinnon and Bennett, 2005, and Subcommittee tabulations from the 2000 Public Use Microdata Sample (PUMS).

Caribbean-born non-Hispanic Blacks had lower rates than U.S.-born non-Hispanic Blacks for the types of cancer studied with the exception of prostate cancer. For that, the Caribbean-born group rate was significantly higher than that of any other group (Fang et al., 1997). The authors posit that differences in the Caribbean diet may be protective for certain types of cancers such as colon, rectum, and breast. Descriptive statistics indicated that more Caribbean Blacks graduated from high school, but cancer rates were not adjusted for educational attainment.

Low Birthweight

Pallotto and colleagues (2000) used vital records from Illinois (1985–1990) to assess the low- birthweight distributions for infants born to U.S.-born Black women, Caribbean-born Black women, and U.S.-born White women. They classified women into low and high risk categories based on reproductive risk factors (e.g., trimester, parity) and socioeconomic risk factors (e.g., age, education). Even for the lowest risk mothers, there were differences in relative risks for moderately low birthweight infants (1,500–2,499 g); compared with infants of non-Hispanic White mothers, the risk for infants delivered of U.S.-born non-Hispanic Black mothers was 2.7 (95 percent CI 2.1–3.4) and for infants delivered of Caribbean-born Black mothers 1.2 (95 percent CI 0.4–3.1). This mirrored the relative risk profile for delivery of moderately low birthweight infants among all mothers in these ethnic groups regardless of whether they themselves were assessed as high or low risk for low birthweight outcomes. The relative risk for very low birthweight infants (less than 1,500 g) was elevated for both groups of Black mothers compared with non-Hispanic White mothers, but the Black groups were not significantly different from each other. A similar study of deliveries in Illinois found lower relative risk of low birthweight for infants whose mothers were born in Africa; in fact, for women classified as low risk on demographics and reproductive factors, the relative risk was similar for women born in Africa and for U.S. born White women, yet the risk remained high for U.S. born African-American women (David and Collins, 1997).

Cardiovascular Health

A study by Lancaster and colleagues (2006) used data from the National Health and Nutrition Examination Survey (NHANES) III to assess differences in dietary intake, coronary heart disease (CHD) risk factors, and predicted 10-year risk of CHD for subgroups of Black adults (non-Hispanic Blacks born in the United States and both non-Hispanic and Hispanic Blacks born outside of the United States). Multivariate analyses controlled for education as a socioeconomic marker as well as for age, sex, and body mass index. The study found that non-Hispanic Black, U.S.-born participants had a higher intake of calories and fat; a lower intake of fruits, fiber and micronutrients; and a higher predicted 10-year risk of developing CHD (5.8 percent) than both immigrant groups (non-Hispanic Black 3.7 percent, $p < 0.001$; Hispanic Black 4.7 percent, $p = 0.017$). However, it is notable that there are differences between the two immigrant groups in terms of their 10-year risk as well. In addition, proportionally more non-Hispanic Black immigrants had elevated fasting glucose, while more Hispanic Blacks had elevated serum triglycerides and low HDL cholesterol. The authors conclude that there is a need to study dietary and health differences within the Black population and tailor dietary interventions to subgroups of Blacks.

Summary

In the Black category, U.S.-born Blacks disproportionately suffered worse mental health and cardiovascular outcomes and were at greater risk for having low-birth-weight infants than Blacks born in the Caribbean or Africa. A few notable exceptions were found, such as a significantly elevated incidence of prostate cancer among Caribbean men. The authors of these studies and other studies describe heterogeneity within the Black population in health and cultural factors such as diet, and the need to continue to examine the Black population in greater detail (Kington and Nickens, 2001). Differentials have been primarily explored by distinguishing Black populations born in the United States and elsewhere. Heterogeneity, however, was also described among various immigrant ethnicities.

ASIAN GROUPS

While Census 1990 collected data for the single category "Asian or Pacific Islander," Census 2000 split the categories into "Asian" and "Native Hawaiian or Other Pacific Islander," as required by the 1997 OMB standards. The Census and OMB definition for who fits into the Asian category includes "people having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent" (OMB, 1997; U.S. Census Bureau, 2000).

Demographic Characteristics

In Census 2000, 4.2 percent of the U.S. population (11.8 million people) self-identified with the Asian category.[9] The largest Asian ethnic groupings are listed in Table 2-4. Each group has different characteristics pertaining to amount of time in the United States, English proficiency, educational attainment, and risk of poverty. Many of Chinese and Japanese ethnicity have lived in the United States for generations, while Vietnamese and Hmong populations are more often recent immigrants. The median age for Japanese is almost 43 years compared with the Hmong population, which has a median age of 16 years (Reeves and Bennett, 2004).

Health-Related Differences Among Asian Groups

For the most part, the Asian categories have been subdivided according to country of ancestry, although some authors also include more general categories (e.g., South Asian). The available literature has examined access to and utilization of health care, cancer and cancer screening, low birthweight, and asthma outcomes.

Access to and Utilization of Health Care Services

Huang and Carrasquillo (2008) used cross-sectional analyses of CPS data to examine differences in insurance coverage across the six largest distinct groups of Asian populations in the United States: Chinese, Filipino, Indian, Korean, Vietnamese, and Japanese. Differences among Asian subgroups in coverage can be greater than the difference between all Asians and non-Hispanic Whites. Persons of Korean heritage had the highest overall proportion lacking coverage (29.8 percent), followed by 21.5 percent in the Vietnamese group and 16.8 percent in the Chinese group (Huang and Carrasquillo, 2008). U.S. born-Koreans reported about twice the rate of uninsurance of other Asian subgroups born in the United States. People of Asian Indian, Filipino, and Japanese heritage had insurance rates similar or better than those of non-Hispanic Whites. The authors note that insurance expansions based solely on income may not resolve the higher rates of uninsurance for Koreans who may have incomes too high to qualify for public programs, but as small business owners find affordability of insurance an issue.

A lack of health coverage can lead to problems in having a usual source of health care. A recent study released by the Kaiser Family Foundation and the Asian and Pacific Islander American Health Forum found that uninsured Asians are more than four times as likely to lack a usual source of care compared with insured Asians (Kaiser Family Foundation and APIAHF, 2008). The same study found that 20 percent of Asian Indians and 21 percent of those falling into the Other Asian category lack a usual source of care, while Chinese and Filipino Americans have rates similar to those for non-Hispanic Whites. The percentage of uninsured persons having a doctor's visit in the past year also varies among subgroup ethnicities. The differential among Asian American groups—for example, fewer insured Filipinos lack a usual source of care (7 percent) compared with insured Asian Indians (13 percent)—is greater than a comparison of the broad Asian category (11 percent) with insured non-Hispanic Whites (9 percent).

Analyses of NHIS survey data from 2004−2006 reveal differences among Asian subgroups in access and utilization (CDC, 2008). For example, 25 percent of Korean adults are without a usual source of car, about twice

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[9] 3.6 percent reported Asian alone; Hispanic Asians make up about 1.0 percent of the Asian population. Of those checking more than one race, the largest combinations in order were Asian and White (0.9 million, 0.3 percent of the total population), Asian and "Some other race" (0.2 million, 0.1 percent), Asian and NHOPI (0.1 million), and Asian and Black or African American (0.1 million).

TABLE 2-4 Selected Characteristics of the Asian Population in the United States

Asian Groups	Number[a] (in 000s)	Percent of U.S. Asian Population	Percent of U.S. Population	Native Born (%)	Speak a Language OtherTthan English at Home and Speak English Less Than "Very Well" (%)	Less Than High School Graduation[b] (%)	Poverty Rate (%)
Chinese	2,858	23.8	1.02	29.1	49.6	23.0	13.5
Filipino	2,385	18.3	0.85	32.3	24.1	12.7	6.3
Asian Indian	1,855	16.2	0.66	24.6	23.1	13.3	9.8
Vietnamese	1,212	10.9	0.43	23.9	62.4	38.1	16.0
Korean	1,226	10.5	0.44	22.3	50.5	13.7	14.8
Japanese	1,152	7.8	0.41	60.5	27.2	8.9	9.7
Cambodian	212	1.8	0.08	34.2	53.5	53.3	29.3
Hmong	184	1.7	0.07	44.4	58.6	59.6	37.8
Laotian	196	1.6	0.07	31.9	52.8	49.6	18.5
Pakistani	209	1.5	0.07	24.5	31.7	18.0	16.5
Thai	150	1.1	0.05	22.2	46.9	20.9	14.4
Other Asians[c]	561	4.7	0.20	43.5	32.7	19.1	15.6
Total Asian	11,859	100	NA	31.1	39.5	19.6	12.6
Total U.S. Population	281,412	NA	4.21	88.9	8.1	19.6	12.4

[a] Asian alone and in combination.

[b] Population 25 and older.

[c] Bangladeshi, Bhutanese, Burmese, Indo Chinese, Indonesian, Iwo Jiman, Malaysian, Maldivian, Nepalese, Okinawan, Singaporean, Sri Lankan, Taiwanese.

SOURCES: Barnes and Bennett, 2002; Reeves and Bennett, 2004.

the rate of other Asian subgroups. Vietnamese adults are more likely to identify a clinic or a health center as their usual source of care (23 percent) compared with other groups (13–14 percent for Japanese, Asian Indians, and Filipinos). The Japanese group was more likely than others to receive influenza and pneumonia vaccinations; Asian Indians are more likely to have received hepatitis B vaccines. A study of Asian and Pacific Islander children using NHIS data from 1997–2000 showed that children identified as falling into the heterogeneous "other Asian and Pacific Islander" category were the most likely to lack a usual source of care (6.3 percent) compared with Chinese (3.8), Filipino children (3.6), Asian Indian (1.9) and non-Hispanic Whites (1.7) (Yu et al., 2004). The poverty rate was greatest among these categories for the Asian Indian and other Asian and Pacific Islander families, but their rates of access differed.

Health Status

Asian Americans tend to rate their health status more highly than do other groups, just 11 percent of Asian Americans rate their health status as fair or poor, compared with 13 percent of non-Hispanic Whites, 18 percent of Hispanics, 22 percent of African Americans, and 23 percent of American Indians/Alaska Natives (Kaiser Family Foundation and APIAHF, 2008). Among Asian American ethnic groups, the proportion rating their health status as fair or poor ranges from 8 percent among those of Japanese ethnicity to 15 percent among those of Vietnamese or South East Asian extraction. Thus, the difference among some Asian groups is greater than the difference revealed by simply comparing the rates for all Asian Americans to non-Hispanic Whites.

Cancer and Cancer Screening among Asian Ethnicities

Breast and cervical cancer screening rates are lower for Asian American women than for any other ethnic group in California. To better understand Asian intragroup differences, Kagawa-Singer and colleagues (2007) used the 2001 California Health Interview Survey to evaluate Pap smear and mammography screening rates for a representative sample of 2,239 Asian American women. Reported rates of Pap test use for those aged 18 and older ranged from 81 percent (Filipina) to 61 percent (Vietnamese). Reported mammography rates for women aged 40 and older ranged from 78 percent (Japanese) to 53 percent (Korean). Somewhat surprisingly, Korean and Japanese immigrants with more than 10 years of U.S. residency had higher rates of Pap screening than their U.S. born counterparts, but this pattern did not hold up for Korean immigrants on mammogram screening. While trends suggested increased used of screening with increasing income, the difference was only found to be significant for Chinese Americans utilizing Pap tests. For women whose income was less than 200 percent of the federal poverty limit (FPL), the Pap screening rates still varied by ethnicity from 53 percent for Chinese Americans to 78 percent for Filipina Americans. Similarly among insured women, the range was 64 percent for Vietnamese and Cambodian Americans to 82 percent for Filipina Americans. Utilization of mammography among women below 200 percent of FPL also varied by ethnicity, from 53 percent for Korean American women to 86 percent among Asian Indian women. Rates for insured women also varied from 59 percent among Korean Americans to 78 percent among Japanese American women. The authors stress that "different factors were independently associated with lower screening rates for each group" (p. 706), and thus it is important to tailor interventions to specific ethnic subgroups.

Asian groups differ with respect to not only screening rates but also mortality. Using data from the California Cancer Registry, which collects approximately 140,000 new cancer case reports annually, the Kaplan-Meier method was applied to calculate 5- and 10-year survival probabilities for cervical cancer by Asian subgroup, and the Cox proportional hazard method was applied for calculating adjusted survival rates (Bates et al., 2008). Among the California women, once adjusted for age, socioeconomic status, stage, and treatment, the risk of mortality was found to be significantly lower for all groups compared to non-Hispanic Whites except Chinese and Japanese women. Of the six groups studied (Chinese, Filipino, Japanese, Korean, South Asian, and Vietnamese), South Asian women were found to have the highest unadjusted survival rates at both 5 and 10 years (85.8 percent for both), followed by Korean (85.7 and 82.5 percent), and Vietnamese (82.1 and 79.7 percent) groups, compared with non-Hispanic Whites (77.5 and 75.4 percent) and Japanese (72.3 and 69.5 percent). Incidence rates are highest among Vietnamese, Filipino, and Korean ethnic groups and lowest among Chinese, Japanese, and South Asian groups; the authors note that incidence rates tend to mirror rates found in international surveillance reports for distinct ethnicities with a few exceptions.

The Centers for Disease Control and Prevention (CDC, 2008, p. 2) states that “although cancer mortality rates for Asian Americans are low compared with other U.S. populations, Asian Americans have the highest incidence rates of liver and stomach cancer for both sexes compared with Hispanic, non-Hispanic Whites, or non-Hispanic Blacks” (CDC, 2008). Furthermore, subgroup differences can be illustrated by differential mortality rates for liver cancer for different Asian ethnicities in California data: specifically 54.3 per 100,000 males for Vietnamese, 33.9 for Korean, 23.3 for Chinese, 16.8 for Filipino, and 9.3 for Japanese compared with a rate of 6.8 for non-Hispanic White males in the state. Disproportionate risks exist for some Asian subgroups, but not all, for a variety of other conditions, including chronic obstructive pulmonary disease, chronic hepatitis B, tuberculosis, and diabetes.

Low Birthweight

Comparisons of the birthweight outcomes for two Asian subgroups (Asian Indian and Chinese) were derived from analysis of the National Center for Health Statistics Natality File for 293,211 singleton births during 1998−2003. Even when the mothers were themselves born in the United States there were ethnic differences in outcomes. Infants born to Asian Indian mothers were more likely to have a lower mean birthweight as well as higher proportions of very low birthweight (VLBW) and moderately low birthweight (MLBW) compared with Chinese mothers, once data were adjusted for age, education, marital status, and parity. Infants born of U.S.-born Asian Indian mothers were 1.87 times as likely to be VLBW and 1.59 times more likely to be MLBW than infants born to U.S.-born Chinese mothers. The likelihood of VLBW and MLBW infants was even higher for non-U.S.-born Asian Indian mothers compared with non-U.S.-born Chinese mothers (Hayes et al., 2008).

Asthma

A large study published by Davis and colleagues (2006) compared asthma prevalence among various Asian American and Pacific Islander ethnic groups using data from the California Healthy Kids Survey on 462,147 public school students in the state from school years spanning 2001–2002 and 2002–2003. While the analyses could not adjust for sociodemographic characteristics beyond grade and gender, the existence of distinct rates among the groups is clear. Pacific Islander and Filipino groups had higher lifetime prevalence rates for asthma (21.0 and 23.8 percent, respectively) than eight other subgroups (e.g., Korean [10.9 percent], Vietnamese [13.6 percent], Chinese [14.4 percent], and Asian Indians [16.3 percent]). The authors note that prevalence studies can be influenced substantially by the composition of the population under study, and recommend more precise categorization by subgroups for utilization in such studies.

Summary

In the Asian category, differences exist across ethnic groups, and disparities differ on health care and health measures. For example, Japanese persons appear less likely to experience cancer screening disparities compared with the reference population, while differences were often noted for Korean, and Vietnamese subgroups. Yet Japanese women have high cervical cancer mortality. Each study stresses the importance of distinct reporting by subgroup to illuminate differences in order to tailor responses accordingly. Pooling of data over several years is often necessary to have a substantial sample to distinguish among subgroups.

NATIVE HAWAIIAN OR OTHER PACIFIC ISLANDER GROUPS

In Census 2000, 0.31 percent of the U.S. population (860,965 people) self-identified with the Native Hawaiian or Other Pacific islander (NHOPI) category.[10] This grouping is defined by the Census and OMB as “people

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[10] 0.13 percent (378,782) reported being NHOPI alone.

having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands" (OMB, 1997; U.S. Census Bureau, 2000).

Demographic Characteristics

The largest NHOPI groups are listed in Table 2-5. Native Hawaiians, Samoans, and Guamanians make up 74 percent of the Pacific Islander population. Fully 80 percent of NHOPIs are native to the United States since persons born in American Samoa, Guam, or Hawaii are included in the native-born population. Native Hawaiians fare better on ability to speak English, graduation from high school, and having a lower poverty rate relative to most of the other Pacific Islander subgroups (Harris and Jones, 2005).

Health-Related Differences Among Native Hawaiian or Other Pacific Islander Groups

The NHOPI group has been subdivided for analysis according to islands of ancestry. Few studies are available for examining this population in greater detail. Philippine Islanders are classified under the Asian category according the OMB convention; however, some studies examine their health and health care profile along with groups classified as Pacific Islanders by OMB definition.

Access to and Utilization of Health Care Services

A study using a three-year average from CPS data found that the most recent estimate of uninsurance for the NHOPI population was 20.5 percent (DeNavas-Walt et al., 2008). Another study found that the level of uninsurance to be 24 percent (Kaiser Family Foundation and APIAHF, 2008). Several studies also note the low health care utilization rates of Native Hawaiian women compared with other Asian populations (Blaisdell-Brennan and Goebert, 2001; Van Ta and Chen, 2008).

Cancer among Pacific Islander Groups

Among Pacific Islander groups living in all 17 SEER registry sites of the United States, significant health disparities have been found for Native Hawaiian and Samoan groups (Goggins and Wong, 2007; Miller et al., 2008). A study by Goggins and Wong (2007) showed that Samoans were significantly more likely to present with advanced cancer and had the poorest cause-specific survival of all groups studied, including Native Hawaiians, other Pacific Islanders, African Americans, Native Americans, and Whites. While all Pacific Islander ethnicities had poorer cause-specific survival than Whites, Samoan women had an especially elevated risk of mortality from breast cancer (relative risk [RR] = 3.05, 95 percent CI 2.31–4.02) and Samoan men had an especially elevated risk of mortality from prostate cancer (RR = 4.82, 95 percent CI 3.38–6.88). Similar findings are presented in a study by Miller and colleagues (2008), where overall cancer incidence rates were lower for Asians and Pacific Islanders in the sample (i.e., Asian Indians, Chinese, Filipinos, Guamanians, Japanese, Koreans, Native Hawaiians, Samoans, and Vietnamese) compared with White non-Hispanics in the United States; the one exception was Native Hawaiian women. The age-adjusted all cancer mortality rate among Asian and Pacific Islander men was highest for Native Hawaiians (263.7 per 100,000) and Samoans (293.9) in contrast to Guamanians (147.0) and Asian populations such as Japanese (173.7) or Vietnamese (159.9). The pattern of mortality rates among women was the same. The authors suggest that the higher risk for poor outcomes among Samoans may be due to failure to target interventions to small groups whose outcomes are masked when their data are combined with all Pacific Islander and Asian data.

Summary

Pacific Islander groups are little studied in comparative research, but among those studied, Samoans appear to suffer disproportionate rates of poor cancer outcomes. Additional data sources indicate that NHOPIs experience

TABLE 2-5 Selected Characteristics of the NHOPI Population in the United States[a]

NHOPI Groups	Number[b] (in 000s)	Percent of U.S. NHOPI	Percent of U.S. Population	Native Born (%)	Speak a Language Other Than English at Home and Speak English Less Than "Very Well" (%)	Less Than High School Graduation[c] (%)	Poverty Rate (%)
Native Hawaiian	400	36.8	0.14	97.8	04.3	16.8	15.6
Samoan	128	22.5	0.05	79.1	19.5	24.2	20.2
Guamanian	91	14.6	0.03	87.6	15.4	22.2	13.7
Tongan	37	7.3	0.01	48.6	32.7	34.7	19.5
Fijian	14	2.7	0.01	22.4	25.2	33.2	10.5
Marshallese	7	1.5		23.9	41.4	32.3	38.3
Other Pacific Islander	209	14.6	0.07	61.7	19.4	23.3	21.4
Tahitian[d]	(3.3)						
Tokelauan	(0.6)						
Mariana Islander	(0.1)						
Saipanese	(0.5)						
Palauan	(3.4)						
Carolinian	(0.2)						
Kosraean	(0.2)						
Pohnpeian	(0.7)						
Chuukese	(0.7)						
Yapese	(0.4)						
I-Kiribati	(0.2)						
Papua New Guinea	(0.2)						
Solomon Islander	(0.03)						
Ni-Vanuatu	(0.02)						
Unspecified	(193.6)						
Total NHOPI	860	100	NA	80.1	14.5	21.7	17.7
Total U.S. Population	281,412	NA	0.31	88.9	08.1	19.6	12.4

[a] Data for Pacific Islanders living in the U.S. Island Areas of Guam, American Samoa, and the Commonwealth of the Northern Mariana Islands are not included in the count.

[b] NHOPI alone and in combination.

[c] Population 25 and older.

[d] Ethnicities of Other Pacific Islanders from Grieco, 2001a.

SOURCE: Harris and Jones, 2005.

high levels of health disparities compared with other groups in the United States as well. For example, Native Hawaiians aged 36–65 are nearly 1.5 times as likely to experience heart disease as other racial groups in the United States (Asian & Pacific Islander American Health Forum, 2006). In California, NHOPI and Filipino adults have higher rates of obesity and being overweight (70 and 46 percent, respectively) compared with the state average (34 percent) (Ponce et al., 2009). Native Hawaiians also have the second highest rate of Type II diabetes among racial groups in the United States (Mau et al., 2001). However, sparse information on Pacific Islander subgroups may be related to the fact their numbers are proportionately small nationally and thus are not reflected in sufficient numbers for analysis in national surveys.

WHITE GROUPS

In Census 2000, 77 percent of the U.S. population (216.9 million people) self-identified with the White race (Grieco, 2001b).[11] Because this is the largest racial group in the United States, it heavily influences reported levels of quality of health and health care achieved in the nation, as well as national rates of indicators, such as poverty. The OMB definition for the White race is “a person having origins in any of the original peoples of Europe, the Middle East, or North Africa,” (OMB, 1997) and the Census Bureau definition further elaborates with examples including Irish, German, Italian, Lebanese, Near Easterner, Arab, or Polish (U.S. Census Bureau, 2000).

Demographic Characteristics

The poverty rate among those of White race alone in 2007 was 10.5 percent, nearly the same as the overall average rate for Asian and Pacific Islanders but half the rate among Blacks and Hispanics. The national poverty rate for the total U.S. population as of 2007 was 12.5 percent (DeNavas-Walt et al., 2008). With respect to the number of persons in poverty, however, there are more Whites (25.1 million) in poverty than Blacks (9.2 million) and Hispanics (9.9 million) combined. Similarly, as of 2000, White non-Hispanics included a lower percentage of persons aged 25 and older who did not graduate from high school (14.5 percent) compared with Blacks (27.7 percent) and Hispanics of any race (47.6 percent) (U.S. Census Bureau, 2006a)—a rate that still translates into 19.4 million White non-Hispanics over age 25 without a high school diploma (U.S. Census Bureau, 2003a). The White population, like the AIAN and Black populations, is more likely to be born in the United States than other racial groups (Malone et al., 2003). (See Table 2-6.)

Comparative information on different ethnicities within the White population is limited for both demographics and health and health care differences. The Census has published only one in depth analysis of an ancestry grouping that falls within the White category, and that is of the U.S. Arab population. Three-fifths of the Arab population is of Lebanese, Syrian, and Egyptian ancestry (de la Cruz and Brittingham, 2003), but Lebanese are the largest group, consisting of more than a quarter (28.8 percent) of the U.S. Arab population (Brittingham and de la Cruz, 2005). About half of all Arabs in the country were born here (46.4 percent) (Brittingham and de la Cruz, 2005). Of those who speak Arabic at home, approximately one in four speak English less than very well. Sixteen percent of Arabs here over age 25 have not graduated from high school. The overall poverty rate for U.S. Arab groups (16.7 percent) is somewhat higher than the national rate (12.5 percent) (Brittingham and de la Cruz, 2005); some Arab ancestry groups (e.g., Palestinian, Moroccan, Iraqi) have higher poverty rates. About half of the Arab population resides in only five states: California, Florida, Michigan, New Jersey, and New York (de la Cruz and Brittingham, 2003).

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[11] The number identifying as White alone or in combination was 216.9 million, 211.5 of which were White alone, followed by White in combination with “Some other race” at 2.2 million, White and AIAN at 1.1 million, White and Asian at 0.9 million, and White and Black at 0.8 million.

TABLE 2-6 Selected Characteristics of the White Population in the United States

White Groups Based on Language Ability	Number (in millions)	Percent of U.S. non-Hispanic White Population[d]	Percent of U.S. Population	Native Born (%)	Speak a Language Other Than English at Home and Speak English Less Than "Very Well" (%)	Less Than High School Graduation[b] (%)	Poverty Rate (%)
Whites speaking only English at home	175.0[a]	93.7	66.7	97.9			
Whites speaking Spanish at home	2.7[a]	1.4	1.0	91.5	46.7[c]	13.6	11.0
Whites speaking other Indo-European languages at home	8.6[a]	4.6	3.3	46.5	32.9[c]	23.8	11.6
Whites speaking Asian and Pacific Islander languages at home	0.4[a]	0.2	0.1	59.0	26.7[c]	12.6	10.0
Whites speaking all other languages at home	0.1[a]	0.03	0.02	61.5	29.4[c]	19.0	16.8
Total White	186.8[a]	NA	71.2	95.4	41.4 (31.3) [c]	14.2	8.1
Total U.S. Population	281.4	NA	93.2	88.9	8.1	19.6	12.4

[a] White non-Hispanic alone and in combination, 5 years of age and older.

[b] Population 25 and older (186.8 million).

[c] U.S. Census Bureau, 2003b, 2006b. Calculations using Census data. 41.4 is the White alone population aged 5 and older, and 31.3 is the White alone, not Hispanic or Latino figure.

[d] 262.4 was used as a denominator for this column (U.S. Census Bureau, 2003b).

SOURCES: Grieco, 2001b, and Subcommittee tabulations from the 2000 Public Use Microdata Sample (PUMS).

Health-Related Differences Among Select White Groups

While recent research is limited in this area, differences in health care and health outcomes among ethnicities who categorize themselves as White among the OMB categories have been documented. The sections that follow review more recent evidence on this topic, with an emphasis on differences found between groups of Arab and European descent. Reliable data on differences among other ethnic groups within the broad White category could not be identified, representing an area that could benefit from more study that would be informed by granular ethnicity data collection.

Self-Reported Health

Naturalized Middle Eastern immigrants reported worse health compared with their non-naturalized Middle Eastern counterparts in a study based on data from the NHIS. Overall, however, Arab Americans were less likely to report health-related limitations than U.S.-born Whites of European descent (Read et al., 2005a).

Cancer Screening

Lower rates of mammography have been found among Middle Eastern women than in the population as a whole. One telephone survey of 365 Arab American women in metropolitan Detroit found that only 70 percent reported ever having had a mammogram, compared with the overall rate for Michigan of 92.6 percent (Schwartz et al., 2008). This 70 percent rate is lower than the rate for other racial and ethnic groups nationally for mammograms as well. One group, Lebanese women, was considerably more likely than other groups of Arab women to have ever had a mammogram. Other predictors of screening among Middle Eastern women in this sample included being married, having health insurance, and having resided in the United States for 10 or more years (Schwartz et al., 2008).

Cultural beliefs pertaining to cancer among Middle Eastern immigrants in New York appear to be significantly different from those of their White peers of European descent and can affect their access to optimal care. In a qualitative study of focus groups designed to explore barriers to cancer care for Arab immigrants, barriers that emerged included experiences of discrimination, fears of immigration enforcement, and differences in beliefs surrounding causes of cancer (Shah et al., 2008).

However, another study that examined participation in breast cancer genetic counseling found no correlation between ethnicity of the participants in the study, which included European American women and women of Ashkenazi Jewish ancestry, and willingness to accept such counseling (Culver et al., 2001). This study did not control for socioeconomic factors except for level of education attained, because the genetic counseling was being offered at no charge in order to remove cost and access barriers for the participants.

Preterm Birth

A study found lower rates of preterm birth among mothers of Middle Eastern nativity than among those who were U.S.-born of Middle Eastern descent and U.S.-born non-Hispanic Whites (El Reda et al., 2007).

Summary

Disparities in health for non-Hispanic Whites compared with other racial groups include high levels of mortality from melanoma, chronic lower respiratory deaths, and prostate cancer, each of which is potentially responsive to health care interventions (Keppel, 2007). While the data on differences among White subgroups is very limited, significant differences can be found among persons of Middle Eastern and European descent. International statistics provide some insight into the differences among European nations, which make up the ancestry of significant portions of the U.S. citizenry as well as the recent immigrant population (Brittenham and de la Cruz, 2004). For example, life expectancy in Eastern European countries and Russia is lower than in Western Europe (Ginther, 2009;

WHO, 2009). Foodways, the eating practices and customs of a group of people (e.g., lack of vitamin C intake among Russian men), and high rates of smoking and alcohol consumption all contribute. A high incidence of more lethal cancers, particularly of lung cancer, is common in Eastern Europe (Bray et al., 2002). Men and women in these countries also have the highest mortality rates from ischemic heart disease of all the Organisation for Economic Co-operation and Development (OECD) countries (OECD, 2007). Breast cancer incidence and mortality differs across Europe, being higher in Denmark than other northern European nations (Althuis et al., 2005). These findings represent very preliminary evidence in favor of the collection and reporting of more granular ethnicity data separately for White subgroups. It remains to be seen which other White subgroups experience considerable differences in care or health outcomes, and collecting granular ethnicity data will make the picture clearer.

AMERICAN INDIAN OR ALASKA NATIVE GROUPS

The number and proportion of persons in the American Indian or Alaska Native (AIAN) racial group is heavily influenced by whether the numbers are for AIAN alone or AIAN in combination with other racial groups. In Census 2000, 2.4 million persons (0.87 percent) in the U.S. population, fell in the AIAN alone group, but AIAN in combination with other races numbered 4.3 million (1.5 percent of the U.S. population).[12] The Census and the OMB define the term AIAN as referring to persons with origins in the indigenous persons of North, Central, or South America (Ogunwole, 2006), while the Indian Health Service (a U.S. Department of Health and Human Services agency responsible for providing federal health services to AIAN persons) uses its own narrower definition, which is confined to those *enrolled* in any of the federally or state-recognized tribes within the United States.[13] To accommodate these identifications, Census 2000 provided space for a respondent to write in the name of his or her enrolled or principal tribe or affiliation.

Demographic Characteristics

As in the previous sections, Table 2-7 presents the larger population figures for the AIAN population alone and in combination with other races, along with variations in English proficiency and poverty rates for selected tribes. Not displayed in the table is the place of residence of the AIAN populations; one-third of American Indians live in tribal areas, 2.4 percent in Alaska Native villages, and the remaining 64.1 percent outside of tribal areas. Outside of tribal areas, 27.2 percent of AIAN individuals over age of 25 have less than a high school education, compared with 31.8–33.1 percent living in tribal areas (Ogunwole, 2006).

Health-Related Differences Among American Indian or Alaska Native Tribal Groups

In the literature, the AIAN group has been subdivided primarily based on tribal affiliation and/or geographic location. The available literature has examined health differences among these groups by measures of cancer, end-stage renal disease (ESRD), type II diabetes, and metabolic syndrome.

Cancer

Cancer rates among AIAN populations vary and are often misreported because of misclassification of race/ethnicity data in national AIAN cancer registries (Wiggins et al., 2008). This has posed problems for cancer surveillance, research, and overall public health practice (Johnson et al., 2009; Wiggins et al., 2008). Using population-based cancer registries, Wiggins and colleagues (2008) examined the incidence rates of cancer in AIAN and non-Hispanic Whites during 1999–2004 and found that national data masks regional and thereby tribal variation. When combining incidence rates for all cancer sites, AIAN rates were found to be higher than non-Hispanic White rates in the Northern Plains (538.1 versus 464.8 per 100,000), Southern Plains (492.6 versus 461.2), and Alaska

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[12] The most frequent combinations reported are AIAN and White (1.0 million), AIAN and Black (0.18 million).

[13] *The Indian Healthcare Improvement Act*, Public Law 94-437, 25 U.S.C. 1603(c)-(d).

TABLE 2-7 Selected Characteristics of the American Indian or Alaska Native (AIAN) Population in the United States

AIAN Tribal Groupings	Number^{a} (in millions)	Percent of U.S. AIAN	Percent of U.S. Population	Speak a Language Other Than English at Home and Speak English Less Than "Very Well" (%)	Less Than High School Graduation^{b} (%)	Poverty Rate (%)
AI, one tribe	2.88		1.02	9.9	27.4	25.8
Apache	(0.10)		0.04	12.4	31.0	33.9
Cherokee	(0.88)		0.31	2.0	23.4	18.1
Chippewa	(0.16)		0.06	1.6	22.1	23.7
Choctaw	(0.17)		0.06	4.3	20.4	18.5
Creek	(0.08)		0.03	2.4	18.1	18.0
Iroquois	(0.09)		0.03	2.0	20.4	19.0
Lumbee	(0.06)		0.02	0.8	35.3	18.2
Navajo	(0.31)		0.11	24.5	37.3	37.0
Pueblo	(0.07)		0.03	17.5	23.7	29.1
Sioux	(0.17)		0.06	3.4	23.8	38.9
AN, one tribe	0.12		0.04	9.3	25.4	19.5
Alaskan Athabascan	(0.02)		0.01	3.8	24.6	22.9
Aleut	(0.02)		0.01	3.0	22.5	15.0
Eskimo	(0.06)		0.02	15.7	29.7	21.3
Tlingit-Haida	(0.02)		0.01	1.7	17.6	15.2
One or more other specified tribe	1.78		0.45			
Unspecified tribal grouping	1.01		0.36			
Total AIAN	4.32		NA	10.3	29.1	25.7
Total U.S. Population	281.41	NA	1.53	8.1	19.6	12.4

[a] AIAN alone and in combination.

[b] Population 25 and older.

SOURCE: Ogunwole, 2006.

(511.0 versus 486.8). Rates in the Southwest, Pacific Coast, and the East, however, were found to be lower in AIANs than non-Hispanic Whites (218.3–308.9 per 100,000 vs. 398.9–574.4 per 100,000, respectively). When separating by cancer type, lung cancer, and colorectal cancer rates were found to be higher in AIANs than non-Hispanic Whites in Alaska and the Northern Plains. Stomach, gallbladder, kidney, and liver cancer rates were also found to be higher among AIANs than among non-Hispanic Whites overall, in Alaska, in the Plains regions, and in the Southwest (Wiggins et al., 2008). The analyses were limited to persons living within the Contract Health Service Delivery Areas of the Indian Health Service.

Kelly and colleagues (2006) found subgroup differences when comparing the cancer incidence rates of American Indians from New Mexico and Alaska.[14] Between 1993 and 2002, Alaska Indians had a higher incidence rate for all cancer sites combined than either New Mexico Indians or U.S. Whites; in-fact, the overall cancer incidence rate of Alaska Indians was 2.5 times higher than that of New Mexico Indians. The largest variations between the two Indian groups were found in rates of oral cavity/pharynx, esophagus, colon and rectum, pancreas, larynx, lung, prostate, and bladder cancer. Differences in esophageal, larynx, prostate, and bladder cancer were found only in men, while both Alaska Indian men and women had 7 to 10 times higher rates of lung cancer and approximately two-fold rates of all cancers. Cultural use of tobacco was credited as a major factor in these differences (Kelly et al., 2006). No data were collected on income in the different populations.

End-Stage Renal Disease

Using data from the U.S. Renal Data System, Hochman and colleagues (2007) examined the prevalence and incidence of ESRD in 200,000 adult members of the Navajo Nation in Arizona, New Mexico, and Utah. Prevalence and incidence rates are compared for ESRD among all adults in the United States; all Native Americans in the country; and Native Americans living in Arizona, New Mexico, and Utah and Colorado (outside of the Navajo Reservation). After adjusting for age, they found that the prevalence of ESRD in the Navajo Nation was 0.63 percent, higher than that in all U.S. adults (0.19 percent) and Native American adults (0.36 percent). However, this rate was lower than the prevalence among other Native American adults in the Southwest (0.89 percent) (Hochman et al., 2007). Incidence rates followed the same pattern. The study did not control for socioeconomic status.

Type II Diabetes

Type II diabetes affects a disproportionate number of AIANs; the highest rates in the country are among the Pima Indians of Arizona (Knowler, 1978). From 1990 to1997, the number of AIANs diagnosed with diabetes increased dramatically, from 43,262 to 64,474 (Burrows et al., 2000). While documentation of specific tribal differences is limited, Burrows and colleagues found prevalence to vary by region (3.0 percent in the Alaska region vs. 17.4 percent in the Atlantic region), suggesting tribal differences in population rates of diabetes (Burrows et al., 2000). Since no socioeconomic data were analyzed in this study, it is difficult to determine whether the regional differences alone are the underlying cause of the perceived tribal differences in diabetes rates, or regional location is correlated with other factors that could influence these rates.

Metabolic Syndrome

Often a predictor of diabetes, metabolic syndrome varies widely in prevalence across different AIAN adult populations. Shumacher and colleagues examined the prevalence of metabolic syndrome[15] among four groups, including the Navajo Nation from the southwestern United States and three within Alaska (Schumacher et al.,

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[14] Alaska Native people comprise three major ethnic groups: Eskimo, Indian, and Aleut.

[15] The National Cholesterol Education Program defines metabolic syndrome "by a group of metabolic risk factors in one person…. Abdominal obesity (excessive fat tissue in and around the abdomen); Atherogenic dyslipidemia (blood fat disorders—high triglycerides, low HDL cholesterol and high LDL cholesterol—that foster plaque buildups in artery walls); Elevated blood pressure; Insulin resistance or glucose intolerance (the body can't properly use insulin or blood sugar); Prothrombotic state (e.g., high fibrinogen or plasminogen activator inhibitor-1 in the blood); Proinflammatory state (e.g., elevated C-reactive protein in the blood)" (American Heart Association, 2009).

2008). Rates were age-adjusted to the 2000 U.S. adult population and compared with the rates of U.S. Whites, using NHANES data. Among those from the Navajo Nation, 43.2 percent of men and 47.3 percent of women had metabolic syndrome. These were much higher than rates in Alaska, where prevalence varied by region among men from 18.9 percent in western Alaska to 35.1 percent in southeast Alaska, and among women from 22.0 percent in western Alaska to 38.4 percent in southeast Alaska.

Summary

Studies have shown that disparities exist among AIAN groups. For conditions such as cancer, for which disparities appear to be even greater when one adjusts for misclassification of race/ethnicity, standardized collection of tribal identification as a granular ethnicity could provide the basis for better, more tailored health care responses.

SUMMARY

The available evidence on health and heath care disparities among granular ethnic groups in the U.S. population is limited primarily to those groups for which discrete categorization on national survey instruments currently exists. Many studies include large data sets, often national ones, pooled over multiple years that usually provide information that is sufficiently powered to support reliable inferences and conclusions. Evidence of health and heath care disparities among population subgroups is only beginning to emerge and our gaps in knowledge from the published literature are substantial. This is especially true for groups not captured in national data sets that may be of interest to local quality improvement efforts. However, the research reviewed in this chapter consistently finds significant variation across some of subgroups under each of the OMB categories, confirming the utility of collection and reporting of racial and ethnic data at a group level. Indeed, the need for further disaggregation beyond OMB race and ethnicity categories was emphasized by authors of many of the studies reviewed (Bilheimer and Sisk, 2008; Borrell and Crawford, 2008; Canino et al., 2006; Davis et al., 2006; Hayes et al., 2008; Huang and Carrasquillo, 2008; Jerant et al., 2008; Kagawa-Singer et al., 2007; Lancaster et al., 2006; Read et al., 2005b). After controlling for socioeconomic conditions, many of these differential effects remain.

The scientific findings in this chapter demonstrate the existence of disparities in health and health care at a level of categorization that is more detailed than the OMB categories of race and Hispanic ethnicity. Therefore, the subcommittee concludes that use of the broad OMB categories alone can mask identification of disparities at the more granular level.

Standardization of categories of granular ethnicity would enable valid comparisons across settings, across geographic locations, and over time. The level of granularity necessary for analysis will vary according to the composition of the population being served or studied, whether the size of subgroups is sufficiently large to make statistically reliable comparisons, and whether the pattern of differences experienced by subgroups identifies distinct needs that are not already revealed by data aggregated into broader categories. A recommendation regarding how ethnicity data should be collected to help inform improvements in health and health care quality among racial and ethnic subgroups is discussed in the next chapter.

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3

Defining Categorization Needs for Race and Ethnicity Data

The collection of data in the Office of Management and Budget (OMB) race and Hispanic ethnicity categories is improving across a variety of health care entities, but all entities do not yet collect or report data using these categories. Moreover, disparities within the broad groups represented by these categories support the case for collection of granular ethnicity data beyond the OMB categories. Given variations in locally relevant populations, no single national set of additional ethnicity categories is best for all entities that collect these data. Collection of data in the OMB race and Hispanic ethnicity categories, supplemented by more granular ethnicity data, is recommended, with tailoring of the latter through locally relevant categories chosen from a standardized national set. In most cases, rolling up the data on granular ethnicities to the OMB categories will be possible, but it will be necessary to exercise care as there are certain ethnicities that do not correspond with any one race. However, when questions about race and granular ethnicity are both answered, rollup is not necessary.

Collecting and maintaining demographic data in medical records and enrollment files allows for analyses stratified by race and ethnicity to identify needed improvements in health care, and for identification of individuals or population groups that might be the focus of interventions designed to address health care needs. The resultant analyses can be used, for example, to plan specific features of interventions (e.g., the use of culturally relevant content in outreach communications about preventive services) and to compare the quality of care being provided by various entities serving similar populations. The primary reason for standardizing categories for the variables of race and ethnicity is to enable consistent comparison or aggregation of the data across multiple entities (e.g., state-level analyses of providers under Medicaid or a health plan's analysis of disparities in multiple states where it is operating). At the same time, standardized categories must enable persons to self-identify with the categories and increase the utility of the data to the entity collecting them.

Both federal and state agencies (e.g., the Social Security Administration and state Medicaid programs) classify individuals by their race or ethnicity to obtain useful information for health and health care purposes (Mays et al., 2003). Other entities, such as health plans, health professionals, hospitals, community health centers, nursing homes, funeral directors, public health departments, and the public, play roles in categorizing, collecting, reporting, and using these data for quality improvement purposes. Coordinating efforts of these stakeholders to ensure accurate collection and reporting of uniformly categorized race and ethnicity data could lead to more powerful

TABLE 3-1 OMB Race and Hispanic Ethnicity Categories According to a One- and Two-Question Format

Responses for Hispanic ethnicity in two-question format	Hispanic or Latino Not Hispanic or Latino
Responses for race in two-question format	American Indian or Alaska Native Asian Black or African American Native Hawaiian or Other Pacific Islander (NHOPI) White
Responses to a single question combining race and Hispanic ethnicity (one-question format)	American Indian or Alaska Native Asian Black or African American Hispanic or Latino Native Hawaiian or Other Pacific Islander (NHOPI) White

SOURCE: OMB, 1997b.

analyses of aggregated data (Sequist and Schneider, 2006). While progress has been made in the past few years to incorporate the existing national standard set of categories promulgated by OMB (see Table 3-1) into the collection and presentation of data, many data collection efforts still do not fully employ these basic standard categories.

All health and health care entities are not required to collect data on race and ethnicity, but if they do, the OMB categories are the minimum that a federal agency or recipient of federal funds must include in its categorization and reporting. The OMB standards have acknowledged imperfections, though. The categories are often, as shown by the literature review in Chapter 2, too broad for effectively identifying and targeting disparities in health and health care. Additionally, a substantial portion of Hispanics do not relate to the race options, leading to many Hispanics being reported in Census data as “Some other race” because they do not choose any of the five OMB race categories (del Pinal et al., 2007; NRC, 2006; OMB, 1997a). While OMB allows two formats for the race and Hispanic ethnicity questions—one combining both race and Hispanic ethnicity in a single question and the other asking about them in two separate questions, with the Hispanic ethnicity question being asked first (Table 3-1)—OMB explicitly prefers the latter two-question format (OMB, 1997b). As discussed later in the chapter, the format used may have implications for Hispanic response rates (Baker et al., 2006; Laws and Heckscher, 2002; Taylor-Clark, 2009).

This chapter examines approaches to categorizing race and ethnicity by (1) reviewing the current state of standardized collection of race and ethnicity data, with a focus on the sufficiency of the OMB categories and their uptake in various areas of health care data collection; (2) examining the utility of the continued use of the current OMB categories; and (3) considering how the OMB race and Hispanic ethnicity categories can be combined with locally tailored, more detailed ethnicity categories selected from a national standard set, with standardized coding and rollup procedures, to capture important variations among ethnic groups. The chapter concludes by exploring approaches to eliciting responses on race, Hispanic ethnicity, and granular ethnicity, and reviewing models for data collection.

CURRENT STATE OF STANDARDIZED COLLECTION OF RACE AND ETHNICITY DATA

As previously noted, a variety of entities, many of which fall under the purview of the Department of Health and Human Services’ (HHS’) 1997 inclusion policy, collect race and ethnicity data for a variety of purposes. The HHS inclusion policy mandates the collection of at least OMB race and Hispanic ethnicity data in specific circumstances, such as in administrative records, surveys, research projects, and contract proposals associated with direct federal service programs. While the policy does not state which specific categories should be collected in addition to the OMB categories, it encourages the collection and reporting of subgroup data (HHS Data Council, 1999).

Exploring the current state of data categorization provides insight into the challenges faced by health- and health care-related entities in categorizing and collecting the data. Table 3-2 shows the categories used by various federally funded health surveys, state birth records, and cancer registries. Many of these data sources are national-level collection systems designed—among other purposes—to make comparisons across time, providers, and geographic areas (Madans, 2009). These surveys collect race and Hispanic ethnicity data in the six categories specified by OMB and a usually common set of 9 to 12 additional ethnicity categories. For example, the National Health Interview Survey (NHIS), National Survey on Drug Use and Health (NSDUH), and Medical Expenditure Panel Survey (MEPS) all include the OMB categories plus Mexican, Cuban, Puerto Rican, Asian Indian, Chinese, Filipino, Japanese, Korean, and Vietnamese categories, among others. These categories generally correspond to the 15 response check-off boxes included in Census 2000, Census 2010, and intercensal American Community Survey (ACS) questions on race and ethnicity (see Table 3-2).

Despite HHS' inclusion policy, some HHS agencies have not collected even the minimum OMB categories (e.g., Medicare enrollment files). In general, HHS-funded or -sponsored surveys collect the minimum OMB categories—and often additional categories—but all categories are not necessarily reported or analyzed because of small sample sizes. As specific stratifying variables are applied to survey data, for example, the pool of applicable respondents gets smaller (e.g., receipt of diabetes care services by age and race), which may make the number of cases of small racial or ethnic groups too small for analysis. In contrast to surveys, most national administrative datasets are case-rich, meaning they may contain enough data to allow for analyses of even small ethnic groups. For example, the Medicare databases contain a large number of cases and thereby could play an important role in stratifying data by race and ethnicity.

Race and Ethnicity Categorization in Medicare Data

Medicare, a large source of quality improvement data, has limited race and ethnicity data in the enrollment files for its 44.8 million beneficiaries. Because of the history of how race and ethnicity data have been captured (Reilly, 2009), the available race and ethnicity data are often of low accuracy and quality (Bilheimer and Sisk, 2008; Bonito et al., 2008; Eicheldinger and Bonito, 2008; Ford and Kelly, 2005; U.S. House Committee on Ways and Means Subcommittee on Health, 2008). Analyses of Medicare administrative enrollment data found that while the validity of individual data on race and ethnicity was high for Whites and Blacks (the sensitivity was 97 and 96 percent, respectively), only 52 percent of Asian, 33 percent of Hispanic or Latino, and 33 percent of American Indian or Alaska Native beneficiaries were correctly identified (McBean, 2006). Medicare has historically relied on the race and ethnicity data individuals provided when they applied for a Social Security number (SSN). Before 1980, the SSN application form limited respondents to choosing Black, White, and Other. Since most people age 65 and older today received a SSN prior to 1980, their racial and ethnic identifiers were limited to these responses unless the individual changed enrollment to a specific health plan. The current SSN application combines race and ethnicity into a single question and includes only five of the six OMB categories.[1] Consequently, Medicare data have been of limited use in studying differences in patterns of care for populations identified by the OMB categories (Bilheimer and Sisk, 2008; Bonito et al., 2008; Eicheldinger and Bonito, 2008; Ford and Kelly, 2005; U.S. House Committee on Ways and Means Subcommittee on Health, 2008).

The limitations of the Medicare data for race and Hispanic ethnicity have been acknowledged by Centers for Medicare and Medicaid Services (CMS) officials, and CMS is actively working to improve its coding of race and ethnicity data by working with the Social Security Administration (SSA) to ensure the capture of data according to the OMB minimum standards (Reilly, 2009). CMS has also explored a variety of indirect estimation techniques

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[1] The OMB-approved SSA Application for a Social Security Card instructs applicants to "Check one only": Asian, Asian-American or Pacific Islander; Hispanic; Black (Not Hispanic); American Indian or Alaska Native; or White (Not Hispanic). These five categories do not correspond to the 1997 OMB standards, which split Asians and Pacific Islanders into separate categories, nor do the instructions to "Check one only" allow multirace individuals to "Mark one or more."

TABLE 3-2 Race and Ethnicity Categories Collected by Various Data Sources

Categories Collected		Census 2010 and ACS (2009)	NHIS (2008)	NIS (2007)	NSDUH (2008)	MEPS (2006)	NAMCS (2008)	NHAMCS (2009)	Application for a SSN (update unknown)	CMS Nursing Home Minimum Data Set (updated 2000)	Standard Certificate of Birth and Death (updated 2003)	SEER (updated 2008)
Responses to combined race and Hispanic ethnicity format	Asian, Asian-American or Pacific Islander								X			
	Asian/Pacific Islander									X		
	Hispanic								X	X		
	Black (Not Hispanic)								X	X		
	North American Indian or Alaskan Native								X			
	American Indian/Alaskan Native									X		
	White (Not Hispanic)								X	X		
Responses for Hispanic ethnicity question in two-question format	Yes/Hispanic or Latino		X	X	X	X	X	X				
	No/Not Hispanic or Latino/Not of Spanish, Hispanic, Latino origin	X	X	X	X	X	X	X			X	X
	Puerto Rican	X	X	X	X	X					X	X
	Cuban/Cuban American	X	X	X	X	X					X	X
	Dominican (Republic)		X		X	X						X
	Mexican		X	X		X						X
	Mexican American		X	X		X						
	Mexican/Mexican American/ Mexicano/Chicano	X			X						X	
	Central or South American		X		X	X						X
	Central American			X								
	South American			X								
	Spanish (from Spain)				X							
	Spanish											X
	Spanish-Caribbean			X								
	Other Latin American		X			X						
	Other Hispanic/ Latino/Spanish, Specify	X	X								X	
	Other Hispanic/Latino, Specify				X	X						
	Other Spanish/Hispanic, Specify			X								X
	Refused		X	X	X	X						
	Don't know/Unknown		X	X	X	X						X

Categories Collected		Census 2010	NHIS	NIS	NSDUH	MEPS	NAMCS	NHAMCS	Application for a SSN	Minimum Data Set	Certificate of Birth and Death	SEER
Responses to race question in two-question format	White	X	X	X	X	X	X	X			X	X
	Black/African American		X	X	X	X	X	X			X	
	Black											X
	Black, African Am., or Negro	X										
	American Indian		X	X								
	Alaska Native		X	X								
	American Indian or Alaska Native				X	X	X	X				
	American Indian or Alaska Native – Print name of enrolled or principal tribe	X									X	
	American Indian, Aleutian, Alaskan Native, or Eskimo											X
	Native Hawaiian	X	X	X	X						X	X
	Native Hawaiian or Other Pacific Islander					X	X	X				
	Samoan	X	X								X	X
	Guamanian or Chamorro	X	X								X	X
	Micronesian											X
	Polynesian											X
	Tahitian											X
	Tongan											X
	Melanesian											X
	Fiji Islander											X
	New Guinean											X
	Other Pacific Islander, Specify	X	X	X	X						X	X
	Asian			X	X	X	X	X				
	Asian Indian	X	X		X	X					X	
	Asian Indian, Pakistani											X
	Chinese	X	X		X	X					X	X
	Filipino	X	X		X	X					X	X
	Japanese	X	X		X	X					X	X
	Korean	X	X		X	X					X	X
	Vietnamese	X	X		X	X					X	X
	Other Asian: Specify	X	X		X	X					X	X
	Laotian											X
	Hmong											X
	Kampuchean (including Khmer and Cambodian)											X
	Thai											X
	Some other race, Specify	X	X	X	X	X					X	X
	Refused		X	X		X						
	Don’t know/Unknown		X	X		X						X

to improve analyses of race and ethnicity differentials among individuals currently in the Medicare data system (Bonito et al., 2008; Wei et al., 2006).[2] Under the Medicare Improvements for Patients and Providers Act of 2008,[3] CMS is required to address quality reporting by race and ethnicity. A report by CMS detailing its proposed actions is due to Congress in January 2010.

Race and Ethnicity Categorization in State-Administered Programs

Much, but not all, of the collection of standardized data at the state level is done under federally funded programs, including Medicaid and the Children's Health Insurance Program (CHIP). Other state data collection systems, such as hospital discharge data systems and cancer registries, aim to use race and ethnicity data categories that are consistent with nationally collected denominator data (Friedman et al., 2000; Laws and Heckscher, 2002). States face difficulties, though, in consistently collecting accurate and reliable data that are uniformly classified.

Medicaid and CHIP

The Children's Health Insurance Program Reauthorization Act of 2009,[4] signed into law in February 2009, stipulates the development, by January 2011, of quality measures designed to identify and eliminate racial and ethnic disparities in child health and health care. This legislation has the potential to improve measurement of disparities for children in federally funded programs as it specifies that "data required for such measures is [*sic*] collected and reported in a standard format that permits comparison of quality and data at a State, plan, and provider level." A national standard set of race and ethnicity categories is necessary to stratify and compare these quality metrics across the nation.

Although states are mandated to submit Medicaid claims data electronically to CMS, there are anomalies in the submitted data (CMS, 2009). For example, in 2003, race and Hispanic ethnicity were listed as ''unknown'' for more than 20 percent of enrollees in New York, Rhode Island, and Vermont (McAlpine et al., 2007). A 2004 survey noted that while the majority of states were collecting self-reported race and Hispanic ethnicity from their Medicaid and CHIP beneficiaries, most commonly during the enrollment process (Llanos and Palmer, 2006), few states were collecting the six OMB minimum categories (Palmer, 2004). Many states were including Hispanic as an option in the race question instead of asking a separate question about ethnicity (McAlpine et al., 2007); as noted earlier, OMB permits this format but explicitly prefers the two-question format. The subcommittee's research indicates that some progress has been made in the past six years on the collection of Medicaid data using the OMB standards. The subcommittee examined state Medicaid and CHIP application forms and found improved standardization, most notably in collecting the Asian and Native Hawaiian or Other Pacific Islander (NHOPI) categories (Table 3-3).

Vital Statistics Data

Failure to use standard categories and nonreporting or misreporting of data complicate efforts to calculate national and state birth, mortality, and morbidity rates by the OMB race and Hispanic ethnicity categories or for more detailed categories. The National Vital Statistics System (NVSS), hospital discharge data, and state registries provide data needed to calculate these rates, but the data may not be collected and reported according to the OMB categories or may be of poor quality. While the standard birth, death, and fetal death certificates now include

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[2] A 2009 white paper by the U.S. Senate Finance Committee presented proposals to improve patient care and health delivery. One proposal included a comprehensive database required of CMS to expand existing data sources, data sharing, and matching across federal and state claims and payment data, including HHS; SSA; the Departments of Veterans Affairs (VA), Defense (DOD), and Justice (DOJ); and the Federal Employees Health Benefit Program (FEHBP) (U.S. Senate Finance Committee, 2009). The results of this and other proposals to revise payment systems and policies in the Medicare program remain to be seen.

[3] *Medicare Improvements for Patients and Providers Act of 2008,* Public Law 110-275 § 118, 110th Cong., 2d sess. (July 15, 2008).

[4] *Children's Health Insurance Program Reauthorization Act of 2009,* Public Law 111-3, 111th Cong., 1st sess. (February 4, 2009).

TABLE 3-3 Race and Hispanic Ethnicity Categories Used by State Medicaid and CHIP Programs

OMB Race and Hispanic Ethnicity Categories	2004: State Medicaid Programs Using (out of 21)[a]	2009: State Medicaid Programs Using (out of 33)[b]	2009: State CHIP Programs Using (out of 38)[c]
White	20	32	37
American Indian or Alaska Native	20	31	37
Black or African American	19	32	37
Hispanic or Latino	19[d]	32[e]	35[f]
Asian	16	32	37
Native Hawaiian or Other Pacific Islander	14	30	36
Other	9	5	8

[a] SOURCE: Palmer, 2004.

[b] 37 state applications were available online. Four states provided space to write-in a free-text response, so they are not included in the denominator. Of the remaining 33 states, all applications except one solicited race and ethnicity information with specific category choices.

[c] 45 state applications were available online. Seven states provided space to write-in a free-text response, so the categories collected by these states are not included. Of the remaining 38 states, all applications except one solicited race and ethnicity information with specific category choices.

[d] Seven of the 19 states also collected data on Not Hispanic or Latino, indicating differences in using the one-question versus two-question format.

[e] 18 of the 32 states also collected data on Not Hispanic or Latino, indicating about an equivalent number of states using the one- versus two-question format.

[f] 18 of the 35 states also collected data on Not Hispanic or Latino.

the OMB categories plus 13 other categories,[5] not all jurisdictions have adopted these standard certificates. As of April 1, 2009, 32 jurisdictions (56 percent) had adopted the 2003 standard birth and death certificates, and 22 jurisdictions (39 percent) had adopted the 2003 standard fetal death report. The percentage of these vital events covered by the states that have adopted the 2003 standard certificates is higher, however, because they are states with larger populations.[6]

Death certificates provide the numerator for calculating death rates, while Census data provide the denominator. A deceased individual's race and ethnicity are often identified by the funeral director relying on his or her own observation, which is often inaccurate, particularly for racial and ethnic groups with a large number of multiracial individuals (Arias et al., 2008; Durch and Madans, 2001). For example, an individual who may self-identify as White and American Indian or Alaska Native may be categorized as only White by a funeral director, resulting in undercounting of deaths in the American Indian or Alaska Native population. Misclassification on death certificates produces a substantial net underestimate of mortality rates for Hispanic, Asian, American Indian or Alaska Native, and NHOPI populations (Arias et al., 2008; Durch and Madans, 2001). An assessment of the quality of death rates found them to be understated by 11 percent for both Asians and Pacific Islanders and about 21 percent for American Indians and Alaska Natives (Rosenberg et al., 1999).

Hospital Discharge Data

Hospital discharge records sometimes lack race and ethnicity information (Gold et al., 2008; Schoenman et al., 2005) because hospitals either are not required to collect and report this information or choose not to do so (Romano et al., 2003). As of May 2009, at least 39 states included some race and ethnicity data in their discharge

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[5] The categories collected on the standard death certificate are included in Table 3-2.

[6] Personal communication, J. Madans, National Center for Health Statistics, April 17, 2009.

BOX 3-1
Race and Ethnicity Categories in the HCUP Databases

The Healthcare Cost and Utilization Project (HCUP), a family of health care databases sponsored by the Agency for Healthcare Research and Quality (AHRQ), relies on the voluntary participation of 40 states to submit hospital discharge data. HCUP databases contain clinical and nonclinical information, including patient demographics, diagnoses, procedures, discharge status, and charges for all patients, regardless of payer (e.g., persons covered by Medicare, Medicaid, and private insurance, as well as no insurance). One HCUP data element contains source-specific information about the race and ethnicity of the patient: “race” retains information on the race of the patient as provided by the data source, and “Hispanic” retains information on Hispanic ethnicity as provided by the data source.

Only 31 of the 40 participating states provide race and ethnicity data to HCUP. Some states report on all the OMB standard categories (e.g., Arizona, Missouri), some states (e.g., Hawaii, Massachusetts, New Jersey) collect more detailed ethnicity data, and some states do not report on the minimum OMB categories (e.g., Arkansas, North Carolina, Utah). HCUP recodes the data into the race and Hispanic ethnicity categories by which it analyzes and stratifies data: White, Black, Hispanic, Asian or Pacific Islander, Native American, and Other. These categories are similar to but do not in totality mirror the OMB standards.

SOURCES: AHRQ, 2006; Fraser and Andrews, 2009.

data reporting requirements. These data fields, however, are often added without additional resources to support complete and consistent reporting. Consequently, collection and coding practices vary, and data quality may be poor.[7]

Forty states voluntarily participate in the HCUP databases, but only 31 of these provide HCUP with race and ethnicity data. Of these 31 states, several do not report data using the minimum OMB race and Hispanic ethnicity categories, and others report the data in different categories that HCUP must recode to allow multistate and national-state comparisons (see Box 3-1) (AHRQ, 2006).

Cancer Registries

State cancer registries collect, classify, consolidate, and link information on new cancer cases from hospital reports, medical records, pathology reports, hospital discharge data, and death certificates (CDC, 2009). Cancer registries operate in 45 states, the District of Columbia, Puerto Rico, and the U.S. Pacific Islands, providing surveillance capabilities for identifying patterns, trends, and variation in disease burden and care among racial and ethnic groups. Difficulties may arise, however, in coding race and ethnicity from such disparate sources including, for example, the hand-written observations of physicians (Izquierdo and Schoenbach, 2000).

The National Cancer Institute’s Surveillance, Epidemiology and End Results (SEER) Program coding manual includes two of the OMB categories directly (e.g., White and Black) and more granular ethnicity categories that correspond to the other OMB standard categories (e.g., instead of a broad Hispanic ethnicity category, SEER asks more specifically whether a person is Puerto Rican or Cuban) (see Table 3-2 for the categories coded by SEER); altogether there are 34 categories. Because SEER stratifies the data whenever possible by more discrete groups, registries are instructed to categorize a patient’s ancestry by one of the 34 categories (Johnson and Adamo, 2008). SEER supplements and improves the data it receives from states by, for example, linking with the Indian Health Service to improve American Indian or Alaska Native data (see Box 3-2). SEER also uses an indirect estimation

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[7] Personal communication, D. Love, National Association of Health Data Organizations, June 5, 2009.

BOX 3-2
The Use of Data Linkages to Improve Data Coverage and Quality in Cancer Registries

The American Indian or Alaska Native population makes up just over one percent of the U.S. population and is dispersed throughout the country. This complicates the collection and aggregation of data on cancer incidence, an especially important task because unique circumstances of culture, locale, history, and health care produce unusual patterns of cancer occurrence among American Indian or Alaska Native populations (Cobb et al., 2008). Alaska Natives, for example, have rates of lung, colon, and breast cancer five times higher than those of Southwestern Indians.

Studies have demonstrated that many American Indian or Alaska Natives are misclassified as another race in cancer registry data, and dividing these numerators with population denominators from the Bureau of the Census has the effect of underestimating cancer rates for American Indian or Alaska Natives. To address this problem, SEER cancer registries (which cover 26 percent of the total U.S. population and 42 percent of the American Indian or Alaska Native population) have been linked with Indian Health Service (IHS) beneficiary records using LinkPlus, a probabilistic linkage software program developed by the Centers for Disease Control and Prevention (CDC), to identify records representing the same individual in the IHS and registry databases (Espey et al., 2008).

algorithm based on Spanish surnames and birthplace to improve Hispanic classification, and an algorithm based on surnames and birthplace to improve data on Asian and NHOPI ethnic groups (Edwards, 2009).

Review of the State of Standardization

This review of categories currently used in various data collection activities highlights that there are substantial efforts nationally, by a number of states, and by various health care organizations to collect race and Hispanic ethnicity data according to the OMB standards. However, not all of these efforts have yet achieved that level of categorization, and national surveys, nationally standardized birth and death certificates, and cancer registries have found it useful to use more fine-grained categorizations beyond the basic OMB categories. Efforts to standardize categorization and collection will eliminate some of the problems with comparability among data collected by disparate systems.

CONTINUED USE OF THE OMB CATEGORIES

The OMB race and Hispanic ethnicity categories were deemed to represent the country's broad population groups most necessary or useful for a variety of reporting and analytic purposes not specific to health care. The 1997 *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity* were developed over a 4-year period during which an interagency taskforce weighed public input, expert testimony, and other evidence to consider whether and how to modify OMB's 1977 standards (OMB, 1977, 1997b). OMB has no plans to change its current standards (Wallman, 2009).

Chapter 2 documented important variations in health and health care that may be masked when data are analyzed using only the OMB race and Hispanic ethnicity categories. Notwithstanding this limitation, a large body of studies has revealed disparities in health and health care among the groups represented by those categories. Thus, use of the OMB categories yields important data for quality improvement analyses and reporting efforts (AHRQ, 2008; Cohen, 2008; Flores and Tomany-Korman, 2008; IOM, 2008; Kaiser Family Foundation, 2009). Additionally, because OMB-level reporting is required by various federal agencies and recipients of federal funds, the

OMB categories serve as a denominator for many comparisons related to health and health care. Thus, the OMB categories are useful for high-level analysis, reporting, and policy intervention (e.g., in the *National Healthcare Disparities Report*), as well as more local uses. If all entities were to collect race and ethnicity data using the OMB categories, the process of combining or comparing data across reporting entities (e.g., hospitals in states contributing to HCUP or health plans' Healthcare Effectiveness Data and Information Set [HEDIS] data stratified by race and ethnicity) would be greatly facilitated. While the OMB categories do not define more specific subgroups and do not address how to include all difficult-to-categorize groups, they provide a useful common minimum platform for analyzing disparities in health care.

Past Activities to Improve the Collection of Data in the OMB Categories

One assumption underlying self-identified race and ethnicity data collection is that the categories and designations are recognized and accepted by the populations questioned (CDC, 1993; Lin and Kelsey, 2000). Improving the likelihood that respondents can identify with the races and ethnicities offered as response options is therefore essential to the quality of the data collected. Challenges in capturing accurate and reliable OMB-level data include the lack of detailed categories to which individuals can relate and the format of the questions used to elicit Hispanic ethnicity.

Categorizing Diverse Populations

A wide range of cultures, languages, and health-related behaviors are encompassed by each of the six OMB race and Hispanic ethnicity categories. For example, the Asian category blurs ancestry distinctions and vast cultural and geographic diversity (Holup et al., 2007). As a result, the Asian race identification may not resonate with all individuals of Pakistani, Vietnamese, or Filipino descent, for example, who might prefer to self-identify according to their ancestry (see Box 3-3) (Laws and Heckscher, 2002).

Similarly, the Black or African American, White, American Indian or Alaska Native, and NHOPI populations consist of heterogeneous groups and persons within these groups may not identify with the broader race categories (Bailey, 2001; Mays et al., 2003). The Census Bureau has recognized that check-off boxes that represent more detailed categories in addition to the broad OMB categories resonate better with respondents. The Census includes several ancestry options on the Hispanic origin question and several Asian and NHOPI ancestries on the race question (see Figure 3-1). Additionally, the inclusion of space to write in a free-text response permits individuals who do not identify with any of the provided check-off boxes to self-identify.

In Census 2000, about 15.4 million respondents were classified in the "Some other race" alone category, which was added to the OMB categories; this represents 5.5 percent of the total U.S. population.[8] More than 97 percent of those who chose this category were Hispanic (Rothenberg, 2006), and the remaining write-in responses included a range of answers, such as German and Guyanese. As Table 3-4 illustrates, 42.2 percent of the 35.2 million Hispanic respondents identified with the response category "Some other race." High rates of reporting "Some other race" on the Census may indicate that Dominicans, for example, are uncomfortable with saying "I am Black," or "I am White," and instead prefer to identify with a separate, distinct group (Bailey, 2001).[9]

Hispanics (discussed below) dwarf the other ethnicities in the "Some other race" category by virtue of their numbers, but individuals of other ethnicities, such as Cape Verdeans and Guyanese, also often do not self-identify with any of the OMB race and Hispanic ethnicity categories (Hernandez-Ramdwar, 1997; Laws and Heckscher, 2002; Model and Fisher, 2008). Consequently, these individuals, as well as many people of Filipino descent, among others, may not respond to the race question or may check "Some other race" if the option is available. The sub-

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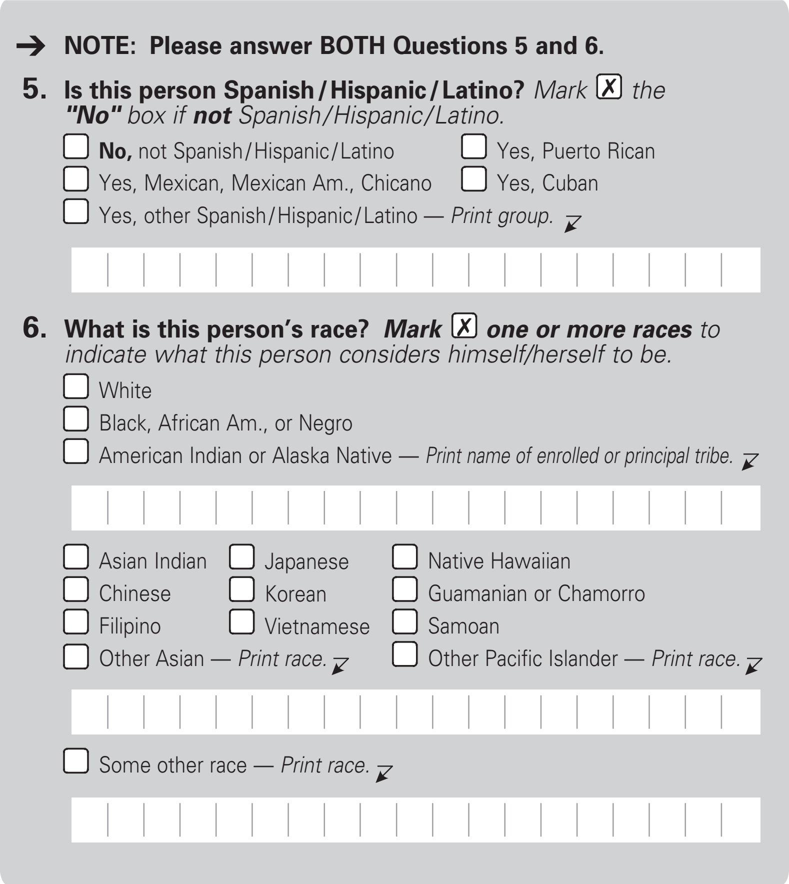
[8] The 2005 Omnibus Appropriations Bill, at the urging of Congressman José E. Serrano (D-NY), directed that any collection of Census data on race identification must include "Some other race" as a response category. In previous censuses, the Census Bureau had sought and received OMB approval to include "Some other race" as a response category (U.S. Census Bureau, 2002b).

[9] Dominicans (58 percent) were the group most likely to self-identify as "Some other race" in Census 2000 (NRC, 2006; Tafoya, 2004).

BOX 3-3
The Challenge of Categorizing Filipino Respondents

The Philippines consist of over 7,000 islands set in the western Pacific Ocean. The OMB standards define persons of Filipino descent as Asian. To evaluate Asian subgroup responses to race and ethnicity inquiries, Holup and colleagues (2007), asked a subset of adults participating in the Hemochromatosis and Iron Overload Screening Study to complete both the OMB-minimum and the expanded race and ethnicity measure used in the National Health Interview Survey (NHIS). The expanded measure used in the NHIS includes response categories for Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and Other Asian. While 89 percent of single-heritage Filipinos marked Asian in the OMB-minimum categorization, the remaining 11 percent marked primarily NHOPI. Filipinos have also been known to categorize themselves as Spanish (Mays et al., 2003), Pacific Islander, Asian American, or, if multiracial, White (Yu and Liu, 1992). Holup and colleagues note that while OMB's decision to separate the Asian and Pacific Islander category in the 1997 OMB revisions was a positive step, specification or provision of definitions when using the minimum OMB categories is "prudent."



→ **NOTE: Please answer BOTH Questions 5 and 6.**

5. Is this person Spanish / Hispanic / Latino? *Mark* ☒ *the* ***"No"*** *box if* ***not*** *Spanish/Hispanic/Latino.*

☐ **No,** not Spanish / Hispanic / Latino
☐ Yes, Puerto Rican
☐ Yes, Mexican, Mexican Am., Chicano
☐ Yes, Cuban
☐ Yes, other Spanish / Hispanic / Latino — *Print group.*

6. What is this person's race? ***Mark*** ☒ ***one or more races*** *to indicate what this person considers himself/herself to be.*

☐ White
☐ Black, African Am., or Negro
☐ American Indian or Alaska Native — *Print name of enrolled or principal tribe.*

☐ Asian Indian
☐ Chinese
☐ Filipino
☐ Other Asian — *Print race.*
☐ Japanese
☐ Korean
☐ Vietnamese
☐ Native Hawaiian
☐ Guamanian or Chamorro
☐ Samoan
☐ Other Pacific Islander — *Print race.*

☐ Some other race — *Print race.*

FIGURE 3-1 Reproduction of questions on race and Hispanic origin from Census 2000.

TABLE 3-4 Hispanic and Non-Hispanic Population Distribution by Race for the United States: 2000

Race	Hispanic or Latino Ethnicity (%)	Not Hispanic or Latino Ethnicity (%)
One race		
White	47.9	79.1
Black or African American	2.0	13.8
American Indian or Alaska Native	1.2	0.8
Asian	0.3	4.1
Native Hawaiian or Other Pacific Islander (NHOPI)	0.1	0.1
Some other race	42.2	0.2
Two or more races	6.3	1.9

SOURCE: Grieco and Cassidy, 2001.

committee concludes that making this option available in addition to the OMB categories would allow individuals who do not identify with one of the OMB race categories to respond (see Recommendation 3-1 below).

Format of the Race and Hispanic Ethnicity Questions

One of the principal challenges in capturing race and ethnicity data for purposes of improving health care is determining how best to capture the Hispanic or Latino population, a population comprising groups that vary widely in their characteristics (McKenney and Bennett, 1994; NRC, 2006). Many Hispanic individuals, including persons of Mexican, Puerto Rican, and Cuban heritage, prefer to self-identify using their specific ancestry as opposed to the general category Hispanic or Latino (Bowman, 1994; Gimenez, 1989; Hayes-Bautista and Chapa, 1987). The term “Hispanic” may not resonate with immigrants, in particular, because it is not used outside the United States (NRC, 2006). Many Hispanics choose “Some other race” instead of the OMB race options when given the opportunity to do so, or refuse to answer the race question when it is asked (Hasnain-Wynia et al., 2008). In a study of birth certificate data, for example, approximately two-thirds of the 15,074 mothers of Hispanic ethnicity reported their race as “Some other race” (Buescher et al., 2005). Research indicates that children of immigrants may be even more likely than their parents to self-identify as “Some other race” (NRC, 2006; Portes and Rumbaut, 2001).

As previously stated, the OMB standards encourage, “whenever feasible,” the separation of questions on race and Hispanic ethnicity, a distinction stemming from a 1976 law requiring documentation of the size and growth of the Hispanic population.[10] Some research prior to the 1997 OMB revisions indicated that the separate, two-question format in which Hispanic ethnicity is elicited before race[11] best identifies an OMB race category for as many Hispanic individuals as possible and allows analyses of combined race and Hispanic ethnicity categories (e.g., Hispanic Black and non-Hispanic Black). The two-question format may capture important health differences among groups. A 2006 study, for example, found that non-Hispanic Blacks have higher risks of developing coronary disease (5.8 percent) than Hispanic Blacks (4.7 percent, $P = 0.017$) (Lancaster et al., 2006). Additionally, a yet-to-be-released study of data from the NHIS indicates that Hispanic Blacks have a different health services and health status profile from that of either Hispanics or Blacks (Austin et al., 2009). However, the need for the dual categorization of Hispanic ethnicity and race for health care improvement purposes is not well studied.

At the same time, some research suggests that Hispanic respondents better identify with questions on race and Hispanic ethnicity when a one-question instead of a two-question format is used (Baker et al., 2006; Laws and Heckscher, 2002; Taylor-Clark, 2009). For example, the Census Bureau’s 1996 Racial and Ethnic Targeted Test (RAETT), which was administered to a sample of households in preparation for Census 2000, experimented with combining race and Hispanic ethnicity into a single question. Nonresponse to the one-question format was

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[10] *Joint resolution relating to the publication of economic and social statistics for Americans of Spanish-origin or descent,* Public Law 94-311 (15 U.S.C. 1516a), 94th Cong. (June 16, 1976).

[11] Non-response to the Hispanic origin question decreased to 5.2 percent from 8.6 percent when the Hispanic origin question was asked before rather than after the race question (U.S. Census Bureau, 1996b).

significantly lower than nonresponse to the two-question format. However, in the one-question format, many people who had identified as Hispanic *and* White or Black in the two-question format changed their response to only Hispanic, despite being permitted to "Select one or more" categories (Bennett et al., 1997).[12] Yet while conventional wisdom indicates that the combined format maximizes response among Hispanics (Hirschman et al., 2000; OMB, 1997a; Tucker et al., 1996; U.S. Census Bureau, 1996a), survey research has been inconclusive regarding the best way to capture information on race and Hispanic ethnicity among this population. Continued testing of a combined-question format during the 2010 Census may reveal additional information on this issue (Humes, 2009; NRC, 2009).

Legislative efforts are under way to increase the options on the Census 2020 forms to include Caribbean, Dominican, and other populations. In the first session of the 111th Congress, Representative Charles Rangel (D-NY) and Senator Kirsten Gillibrand (D-NY) introduced bills HR 1504 and SB 1084, respectively, to require that in Census questionnaires, a check-off box be included so that respondents may indicate Dominican ethnicity. Also in the first session, Representative Yvette D. Clarke (D-NY) and Senator Charles Schumer (D-NY) introduced bills HR 2071 and SB 1083, respectively, to include a Caribbean check-off box on all future Census forms. These efforts indicate a continued call for more detailed ethnicity data. The need for more detailed data and concerns about Hispanic response may require OMB to review its standards. Most important, the subcommittee concludes there is a need for an assessment of the extent to which lack of identification with the OMB categories interferes with accurate data collection for use in quality improvement efforts (see Recommendation 3-3 below).

Identification of Multiracial Individuals

The 1997 OMB standards require that respondents be allowed to report more than one race and recommend "Mark one or more" and "Select one or more" as the included instruction. Approximately 2.4 percent of the country's population (6.8 million persons) reported multiple races in Census 2000 (U.S. Census Bureau, 2000); this percentage can be expected to increase in the coming years (Edmonston et al., 2000). The largest percentage of multirace responses are from Hispanics; in Census 2000, Hispanics were more than three times as likely as non-Hispanics to self-identify with multiple race responses (NRC, 2006). As a result, like the "Some other race" category, multirace reporting is expected to increase with the growth of the Hispanic population. Additionally, in some areas of the country, the proportion of the population self-identifying as multiracial is substantial. In Census 2000, there were 14 states where the multiracial population was above the nationwide average of 2.4 percent. For example, the multiracial population in Hawaii totaled 21 percent, followed at a distance by Alaska at 5.4 percent (Jones and Smith, 2001).

In analysis and reporting, organizations often collapse reported multiracial combinations into an aggregate "more than one race" or a "multiracial" category because the sample sizes for the individual combinations are usually too small for analysis. The Census' 1996 RAETT found that the option to "Select one or more" captures the same number of individuals as a single, multiracial/biracial category (Hirschman et al., 2000). The former instruction, though, allows for the identification of specific races, whereas the latter does not. Where possible, information on specific combinations of races and ethnicities should be preserved so the data can be aggregated over enough reporting units or periods to provide more informative analyses and the basis for targeted interventions. A single category labeled "multiracial" or "more than one race" may mask valuable information that could be used in analyses. More accurate analyses may require detail on each category selected by a respondent.

Some health information technology (HIT) systems are unable to support the collection and reporting of data in a "Select one or more" manner.[13] OMB guidance stipulates that civil rights enforcement agencies must include the four "double-race" combinations most frequently reported. The U.S. Department of Housing and Urban

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[12] Sutter Health collects the five OMB race categories with a Hispanic/Non-Hispanic notation. For example, an individual may self-identify as Black/Hispanic or Black/Non-Hispanic (Personal communication, T. Van, Sutter Health, July 22, 2009). This is another way to capture these data in accordance with the OMB standards.

[13] All possible combinations of the six OMB categories results in 64 combinations.

Development, for example, tabulates respondents by the five OMB race categories and four specific multiple-race combinations:

- American Indian or Alaska Native *and* White
- Asian *and* White
- Black or African American *and* White
- American Indian or Alaska Native *and* Black or African American

A sampling of the local service population or an examination of applicable Census data could reveal the most common combinations that an organization might want to capture if its information system does not allow all combinations under the "Select one or more" option.

Counting multiracial individuals as members of each individual race they select (e.g., counting individuals who self-identify as Black and Native Hawaiian in both the Black and NHOPI categories) may double-count respondents and inflate the number of respondents in denominator data. Therefore, this practice may come "at the expense of misstating disparities in the health of specific racial/ethnic groups" (Mays et al., 2003, p. 89), especially among populations in which the ratio of responses involving multiple races to a single race is high (e.g., American Indian or Alaska Native and NHOPI populations). On the other hand, this practice allows analyses to include all those who identify with a specific group.

To avoid double-counting, prioritization schemes, commonly referred to as trumping rules, recategorize multiracial individuals into a single race category and facilitate comparison of the data with data from systems that allow only single-race categories. For example, OMB guidelines stipulate that when addressing civil rights claims, "responses that combine one minority race and white are allocated to the minority race" (OMB, 2000).

Prioritization schemes reflect a lack of consideration of multiracial respondents' preference, aversion, or indifference to identifying primarily with one race. The NHIS and the California Health Interview Survey (CHIS) ask respondents who report more than one race whether there is a category with which they most identify, providing an opportunity to categorize individuals in a way that most closely matches their preferred self-identification. Those responses then can be used to inform the assigning of multiracial individuals to single-race categories in a manner more informative than arbitrary prioritization schemes (Holup et al., 2007). However, while many multiracial individuals identify with one race (Mays et al., 2003), some multiracial individuals may hesitate to choose one racial identity over another. Asking such a question also requires the collection and coding of data on an additional variable, which may be burdensome for some data systems. The subcommittee concludes that retaining specific combinations or codes for more common combinations in data systems allows for more thorough analysis and reporting. Different ways of aggregating multiracial categories may be appropriate for different purposes; therefore, the subcommittee does not endorse any single analytic approach but concludes that, whenever possible, each race an individual selects on a collection form be available for analysis.

NEED FOR LOCALLY RELEVANT GRANULAR ETHNICITY CATEGORIES

As noted earlier, the OMB categories, when used alone, can mask important within-group variations in quality of care (Blendon et al., 2007; Jerant et al., 2008; Read et al., 2005; Shah and Carrasquillo, 2006). While the OMB standards include only two ethnicity categories (Hispanic and not Hispanic), many other ethnicities exist. Assessing and reducing disparities within the broad race and Hispanic ethnicity categories requires ethnicity data at a greater level of detail than is mandated by the OMB standards.

The subcommittee evaluated the necessary level of ethnicity detail beyond Hispanic ethnicity and considered whether it should include national origin, place of birth, and ancestry. The Supreme Court has interpreted national origin to refer to "the country where a person was born, or, more broadly, the country from which his or her ancestors came."[14] Thus, a person may identify with a national origin if he or she shares physical, cultural, or linguistic characteristics with the group. This terminology, however, may indicate only country of birth to

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[14] *Espinoza v. Farah Mfg. Co.*, 414 U.S. 86, 88 (1973).

some respondents. Therefore, the subcommittee determines that ancestry, which the Census Bureau defines as “a person’s ethnic origin or descent, ‘roots,’ or heritage, or the place of birth of the person or the person’s parents or ancestors before their arrival in the United States,” is the ethnicity concept most encompassing of the detail necessary in health care settings (U.S. Census Bureau, 2008). To distinguish the definition of ethnicity adopted by OMB (i.e., Hispanic ethnicity) from this more encompassing definition, the subcommittee refers to the latter concept as *granular ethnicity*.

Importance of Flexibility in Choosing Locally Relevant Categories

The subcommittee considered whether to recommend the OMB race and Hispanic ethnicity categories plus a uniform set of 10 to 15 additional ethnicity categories (i.e., an “OMB Plus” set similar to the categories used in national surveys outlined in Table 3-2). Demographic distributions confirm, however, that a uniform set beyond the OMB categories would include groups not relevant to all communities. The subcommittee concludes that, to allow for better understanding and serving of local populations, the categories collected and analyzed need to accurately reflect the population served. Thus, a fixed “OMB Plus” set of categories would be less desirable than local selection of ethnicity categories in addition to the OMB categories.

Ethnicity data must be specific and appropriate to the communities in which health care providers operate (Bilheimer and Sisk, 2008). Clustering of racial and ethnic groups in specific communities, such as a relatively large population of White persons of French descent in Maine or a large population of White persons of Armenian descent in Southern California, requires the use of locally relevant granular ethnicity categories. Figure 3-2 shows the county-level distribution of the country’s Asian population, revealing that there are higher concentrations of Asians in broad geographic regions (e.g., the West Coast and Northeast Corridor), as well as clustered within specific counties or metropolitan areas (e.g., Collin County, Texas; Atlanta, Georgia). In areas with larger and more diverse Asian populations, discrete categorizations are more useful than a single broad category for data collection. Even in the state of Minnesota, which has a reasonably average concentration of Asians (3.5 percent), the broad OMB Asian category masks the fact that a large portion of Asians in the state are Hmong, an important consideration for locally tailored health care interventions. Similarly, a health care provider may care for a large number of persons who belong to an ethnic group whose significant presence is masked even by county-level data in the aggregate OMB categories.

Ethnicity Categories on Data Collection Instruments

Health care entities must determine an approach to collecting granular ethnicity data that allows all individuals, if they desire, to self-identify and at the same time is feasible, given that the population of their service area may include hundreds of granular ethnicities. Individual self-identification enables entities to learn about the composition of their service population so they can decide which ethnicity categories will yield the most responses on data collection instruments, and can be used in analyses to generate information on where to target interventions. Additionally, such individualized data collection has the potential benefit of preserving small subgroup identities that might be of interest for analytic studies (assuming preservation of the specific identifiers during data transfer) at the state, health plan, or national level but that might prove too small to reveal any group-specific quality issues at the local level (e.g., higher cancer mortality among persons of Samoan descent). Of course, such aggregation presumes standardization of categories across entities.

Presenting respondents with a list of hundreds of categories (see Appendix E) poses logistical challenges. Models exist for the collection of data on highly diverse populations; Kaiser Permanente, for example, collects data using approximately 260 categories of granular ethnicity through a separate question in addition to collecting the OMB minimum categories (see Appendix G). Similarly, Contra Costa Health Plan uses 133 ethnicity categories (see Appendix H). Both of these entities have resolved having lengthy lists through software applications that recognize keystrokes to present the most pertinent categories on screen. The Contra Costa software first identifies the 15 most frequently encountered ethnicities. Both of these organizations ask about granular ethnicity after asking a single question to solicit the OMB race and Hispanic ethnicity categories.

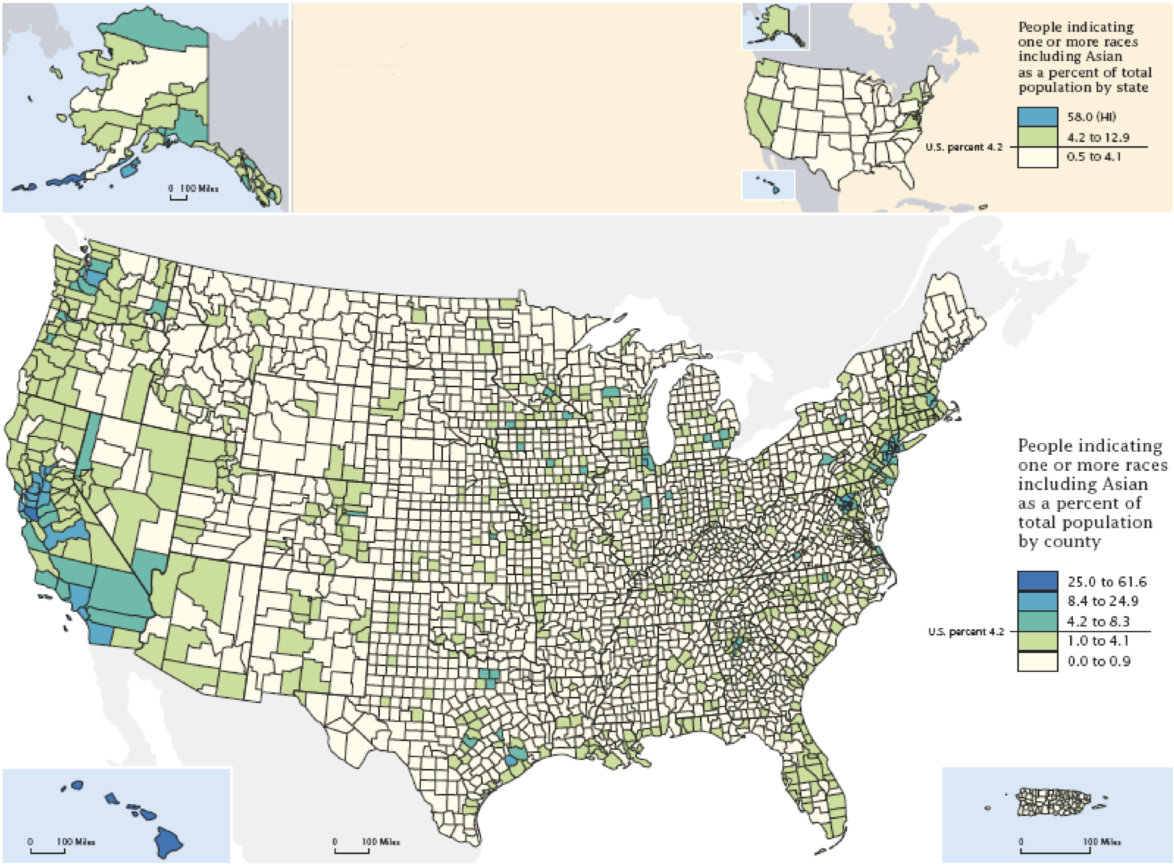

FIGURE 3-2 Geographic distribution of the Asian population.
SOURCE: Barnes and Bennett, 2002.

Respondents may find the task of self-identification from a lengthy list daunting or unreasonable when faced with a paper-based form. Likewise, it would not be feasible for staff to read through such lengthy lists when collecting the data by phone, for example, during preregistration for hospitalization. Instead, some health care entities ask patients to provide a response to an open-ended question and present no preselected response options, while others provide patients and staff with a short list of categories, often accompanied by an “Other, please specify:__” option. This latter response option is also open-ended, meaning individuals or staff can write in a self-identification if it is not included on the local list of response categories. Similarly, state or national surveys could have a limited list of categories, but also present the open-ended response option.

There are advantages and disadvantages to both open-ended and closed-ended question formats. For example, questions that list examples or check-off boxes may bias respondents to the given response options (Chesnut et al., 2007). Census research has indicated higher response rates for the ethnicities listed as examples, indicating that this question format may skew responses (Cresce et al., 2004; del Pinal et al., 2007). Traditionally, closed-ended questions have been used to elicit race and Hispanic ethnicity data. But open-ended questions may have advantages for some entities collecting granular ethnicity data, including that this format reduces the amount of space needed on paper data collection forms or electronic screens. However, collecting open-format data for hundreds of thousands of enrollees or respondents on a survey can make it difficult to use the data unless resources are devoted to coding those responses according to standardized categories. One of the difficulties with open-ended questions is that respondents may leave the item blank. Census studies have indicated that this may be the result of perceived redundancy when the open-ended ancestry question follows questions on race and Hispanic ethnicity (del Pinal, 2004; Martin et al., 1990). Open-ended questions often provide examples so respondents know what type of response is desired; for example, the Medi-Cal instruction sheet includes a list of nine examples of ethnicity (e.g., Hispanic, Cambodian, Asian Indian).

The subcommittee finds no positive evidence from a health care quality improvement standpoint to support conclusions about requiring multiple responses to a question about granular ethnicity (i.e., "Select one or more") for each individual. Additionally, the subcommittee acknowledges the potential HIT challenges of having multiple granular ethnicity responses. It is feasible and indeed required by OMB that entities collecting race and Hispanic ethnicity data according to the OMB standards allow individuals to "Select one or more," and these few categories can yield 64 combinations. However, the number of possible combinations from a list of several hundred granular ethnicities may increase the analytic burden, and multiple ethnicity combinations will result in small cell sizes and thus may not be useful for identifying patterns of care in all circumstances. Furthermore, response variation, which occurs when individuals intentionally or inadvertently make inconsistent choices over time (Snipp, 1989), increases when individuals have a greater number of choices with which to self-identify (Snipp, 2003). Kaiser Permanente's initiative to capture race, Hispanic ethnicity, and granular ethnicity does not currently allow multiple granular ethnicity responses because of collection and analytic considerations. However, there may be some communities where combinations of ethnicities may regularly occur, and health entities would find these combinations useful to collect.

Definition of a Standard National Set with Local Choices

To ensure standardized collection of race and ethnicity data, locally relevant choices of response categories should be selected from a national standard set, with appropriate coding to facilitate sharing of the data. The national standard set of categories needs to be comprehensive enough to capture changing demographic trends, geographically isolated subgroups, and groups relevant to the provision of culturally and linguistically appropriate care. While several organizations provide lists of granular ethnicities (see Table 3-5), none of these include all of the granular ethnicity categories required for a national set. Merging these sets, as is done in Appendix E, provides a starting point from which a national standard set could be developed. These sets are further explored in this section to identify the strengths and weaknesses of each.

The Centers for Disease Control and Prevention (CDC)/Health Level 7 (HL7) Race and Ethnicity Code Set 1.0 was developed to clarify the relationship of granular ethnicities to the broad OMB categories and to facilitate data exchange and analysis. In formulating this set, CDC worked with HL7 and X12, the leading standards-setting organizations for data interactions and for administrative transactions, respectively. The CDC/HL7 Code Set, which was introduced in 2000, incorporates ethnicity categories derived from write-in responses to the Census questions on race and Hispanic ethnicity, not responses to the Census ancestry question. Each ethnicity is assigned a permanent five-digit unique numerical code as well as a hierarchical code to associate with race or Hispanic ethnicity.

The CDC/HL7 Code Set, which has been under the jurisdiction of the National Center for Public Health Informatics, will be updated based on Census 2010 write-ins on the race and Hispanic ethnicity questions.[15] The addition of categories beyond those currently specified on the Census form (see Figure 3-1), however, requires respondents to give free-text responses on lines provided under Hispanic or Latino, Asian, American Indian or Alaska Native, and "Some other race." Thus, for example, the granular ethnicities of African immigrants who simply check "Black or African American" may not be represented in the CDC/HL7 Code Set. The current ethnicity list, for instance, notably does not include groups such as Somalis, Russians, Cape Verdeans, or Brazilians.

The U.S. Census Bureau, in addition to cataloging write-in responses to questions on race and Hispanic ethnicity, asks a separate ancestry question for which respondents are asked to write in their ancestry or ethnic origin; thus, a person might identify with an individual country (e.g., French), a region within a country (e.g., Corsican

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[15] Personal communication, S. Ganesan, Centers for Disease Control and Prevention, June 3, 2009.

TABLE 3-5 Comparison of Granular Ethnicity Categorization and Coding Systems

Category and Code Set	Total Number of Categories	Estimated Breakdown of Categories by OMB Race and Hispanic Ethnicity Category
CDC/HL7 Race and Ethnicity Code Set 1.0 (2000)	Over 925 categories	Over 800 American Indian or Alaska Native categories 21 White categories 19 Black or African American categories 24 Asian categories/codes categories 23 NHOPI categories 38 Hispanic or Latino categories
Census Ancestry Codes	993 categories	212 broad "ancestry descriptions" Approximately 780 more detailed response categories
Massachusetts Superset	173 categories	31 major ethnicities categories 140 sub-ethnicities categories
Kaiser Permanente Granular Ethnicity (2009)	268 categories	59 American Indian or Alaska Native categories 206 additional ethnicities
Wisconsin Cancer Reporting System Code Manual (2008)	648 categories	371 American Indian or Alaska Native categories 129 White categories 37 Black or African American categories 41 NHOPI categories 14 Other Race categories
Contra Costa Health Plan Race and Ethnicity	143 categories	130 categories from the CDC/HL7 Code Set 9 additional ethnicity categories: American, Bosnian, Brazilian, Kurdish, Mixtec, Portuguese, Punjabi, Russian, and Yao, Mien

NOTE: The estimated categories in the third column may not equal the total number of categories in the middle column due to additional response and coding options such as Unknown, Declined, and Unavailable.
SOURCES: CDC, 2000; Kaiser Permanente, 2009; Taylor-Clark, 2009; Tiutin, 2009; U.S. Census Bureau, 2005; Wisconsin Cancer Reporting System, 2008.

or Breton), or a broader category (e.g., European).[16] The Census maintains lists of write-in responses with corresponding three-digit numerical codes for its questions on race, Hispanic origin, and ancestry. The codes for each of these lists differ, although the lists overlap with many of the same categories. For example, 101 is the code for White on the Census Race Code List, the code for "Not Spanish/Hispanic" in the Hispanic or Latino Origin Code List, and the code for Azerbaijani in the Census Ancestry Code List (U.S. Census Bureau, 2002a). Korean is coded as 620 on the Census Race Code List and 750 on the Census Ancestry Code List.

The Massachusetts Division of Health Care Finance and Policy and the Massachusetts Quality and Cost Council mandated that the state's acute care hospitals and health plans, respectively, report uniform race and ethnicity data (Weinick et al., 2007). These requirements spurred development of an ethnicity categorization and coding list by the Brookings Institution. Entities responsible for the list's development considered recommending the CDC/HL7 Code Set but found it did not accurately capture all relevant population groups.[17] The category and coding list developed by the Brookings Institution includes 31 ethnicity categories and additional "sub-ethnicities" that are not required for reporting but that an organization can collect, if useful. Acute care hospitals and health

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[16] The separate ancestry question was included only on the Census "long form." This form was sent to one in six households. The American Community Survey (ACS), an annual survey sent to a sample of households, has replaced the Census "long form" and includes a question about ancestry.

[17] Personal communication, K. Taylor-Clark, The Brookings Institution, January 15, 2009.

plans are required to report (i.e., have the fields and categories available in their HIT systems) the basic OMB race categories along with the 31 ethnicity categories (Massachusetts Executive Office of Health and Human Services, 2009a, 2009b). When an organization collects any of the "sub-ethnicity" categories, it is required to roll that category up to one of the 31 broader ethnicity categories for reporting. The Massachusetts Superset, which is intended to serve as a guide for health plans and hospitals when they collect granular ethnicity beyond the 31 required categories, includes most of the CDC/HL7 categories and 87 additional categories representing African nations (e.g., Sudanese, Somali), synonyms for existing CDC categories (e.g., La Raza, Chicano), Middle Eastern nations (e.g., Saudi Arabian, Jordanian), and other ethnicities (e.g., Cape Verdean, Brazilian, Guyanese) (Taylor-Clark et al., 2009).

Similarly, Contra Costa Health Plan and the Wisconsin Cancer Reporting System (WCRS) developed their own categorization and coding schemes (Tiutin, 2009; Wisconsin Cancer Reporting System, 2008). Contra Costa's code set is based on the CDC/HL7 Code Set, but includes nine additional granular ethnicities, including American and Russian, which are two of Contra Costa's top 15 response categories, but are not included in the CDC/HL7 Code Set (see Appendix H).

In 2004, Kaiser Permanente began collecting member race and ethnicity data using the OMB categories and a limited number of detailed ethnicity groups. After implementation, Kaiser determined a need for more granular ethnicity categories to allow for better self-identification and analyses of health care data. As a result, Kaiser developed a list of granular ethnicities that could be used for self-reporting separately from the OMB race and Hispanic ethnicity categories. The code set includes 268 categories, and continual review is planned to ensure alignment with immigration trends and relevance to health care (Kaiser Permanente, 2009). Appendix G provides more detail on Kaiser Permanente's collection of data on race, ethnicity, and language need.

"Unavailable," "declined," and "unknown" codes, variations of which are included in the HRET Toolkit's suggested format, the Massachusetts Superset, the Contra Costa Health Plan code list, and the Kaiser Permanente code list, are frequently used in survey analysis. These codes are not presented as response options, but are recorded by registration/eligibility clerks or surveyors, for example, so that data systems can track the number of persons for whom the organization has attempted to collect race and ethnicity data. The subcommittee suggests that such categories be provided for individuals who have not responded (unavailable), refuse to answer (declined), or do not know (unknown). The "unavailable" category allows data collectors to see that the respondent has not yet provided the information, so the information should be solicited at a future point of contact with that individual. In contrast, the "declined" category indicates the individual should not be asked again. In some instances, the "unknown" category provides a response option if the respondent is adopted, for example, and does not know his/her race and ethnicity (Taylor-Clark, 2009).

SELECTION OF LOCAL GRANULAR ETHNICITY CATEGORIES

The list of granular ethnicities in Appendix E provides a baseline template for a national standard set of granular ethnicity categories. An entity can decide, based on local circumstances, whether to use 10 or 100 categories from the national standard list for collection and/or analysis. If the entity sees an increase in the use of the "Other, please specify:__" option, it should consider adding categories to its local list. If an organization chooses not to have a preset list of categories, it will need to compile responses according to the national standard list to ensure comparability with data collected by other entities.

Determining which locally relevant categories to include may initially require subjective judgments about subgroups believed to be present in large numbers. However, some organizations may not realize the diversity of their service population and thus may not understand the need to collect the OMB categories and granular ethnicity data (see Box 3-4). Therefore, specific, locally relevant categories can be determined using population estimates from geographic-based Census data, school enrollment data that identify newer and growing populations in service areas, indirect estimation techniques, or surveying. However, even constructing a survey may require some knowledge of persons in the service area; Anthem Blue Cross, for example, solicited through a mailed survey the race and ethnicity of its California members, but focused on the six OMB race and Hispanic ethnicity categories

BOX 3-4
Realizing the Necessity of Collecting Data: The University of Mississippi Medical Center

When informed they were to begin collecting race, ethnicity, and language data from patients, employees at University of Mississippi Medical Center (UMMC) almost uniformly indicated that patients would believe this information would be used to segregate services and would create racial tensions. In fact, the director in charge of implementing the data collection was convinced that UMMC and the organizations funding and administering the data collection initiative (The Robert Wood Johnson Foundation and The George Washington University through an Expecting Success project) were "taking gasoline and pouring it on a blazing fire."

The registration department initially thought registration staff were already asking for the patient's race. The director discussed this with staff and found out they were not asking the patients but were looking at patients to determine their race. Staff informed management that patients might be offended or become indignant when asked for the information. Observer report was indicating approximately 180 Hispanic patients per year registered at UMMC. So what was the point of collecting additional race and ethnicity data for a reasonably homogenous patient population?

With funding and support from Expecting Success, UMMC implemented a staff training program to ensure patients would be asked directly their race, ethnicity, and language need. Within months of implementation, UMMC learned it was registering approximately 600 Hispanic individuals per month (approximately 1.5 percent of the 40,000 individuals registered per month) and the patient population was found to be less homogenous than initially believed. Approximately 500 patients per month were from subgroups the medical center did not even realize existed in their service area (e.g., Japanese and Russian). UMMC found that between 3 and 4 percent of the population preferred to talk to a physician in a language other than English. UMMC now has three full-time Spanish interpreters (where they previously had none) and switched vendors to ensure their interpreter phone system could handle the types and numbers of interpreter services required. In-house physicians and researchers have begun to utilize the race, ethnicity, and language data to stratify quality measures.

SOURCE: Personal communication with Richard Pride, UMMC, June 3, 2009.

and 61 additional ethnicity categories considered most pertinent to its enrollees.[18] As all granular ethnicity lists should also include an "Other, please specify:__" option, the write-in responses may help organizations evaluate and expand as necessary the granular ethnicity response options provided. If an organization is receiving numerous write-in responses of "Russian," for example, it may consider adding a Russian response option.

A variety of entities participate in the health care system, and while each has roles to play in capturing race and ethnicity data, not all currently collect these data and those that do so may not use uniform methods or categories. There are other entities that collect and report detailed data in ways that comply with the OMB standards and produce data useful to local and national quality improvement efforts. The subcommittee's task is to provide standardized categories "for entities wishing to assess and report on quality of care." The subcommittee aims to accomplish this by imposing the least possible data collection burden and without hindering the progress and processes of entities already collecting detailed data.

The subcommittee focuses its recommendations on care delivery sites and public and private insurers, as these health care entities are involved in measuring and improving quality, as well as on data collection activities that provide information about equity in care, care outcomes, quality of care, or utilization of care (e.g., health surveys

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[18] Personal communication, G. H. Ting, Wellpoint, Inc., February 19, 2009.

asking about health care). Some public health activities involve delivery of care, but others do not. Because vital statistics and other public health surveillance systems are organized and supported for purposes beyond health care quality improvement, these collection activities may require different considerations. All entities related to health and health care, though, are encouraged to collect race, Hispanic ethnicity, and granular ethnicity data in accordance with the subcommittee's recommendations.

The subcommittee considered a stepwise approach to collecting race and ethnicity data, where entities would first emphasize collecting the data according to the OMB standards and then gradually implement granular ethnicity data collection over time. However, as discussed in Chapter 2, granular ethnicity data are useful for improving health care quality in many settings, and thus the collection of these data should not be considered a secondary aim in those settings. While the subcommittee recognizes that full implementation of its recommendations may require HIT and process changes for some entities (see Chapter 5), race, Hispanic ethnicity, and granular ethnicity data are all necessary to effectively and efficiently target health care quality improvement to groups that are at risk of suboptimal care.

Recommendation 3-1: An entity collecting data from individuals for purposes related to health and health care should:

- **Collect data on granular ethnicity using categories that are applicable to the populations it serves or studies. Categories should be selected from a national standard list (see Recommendation 6-1a) on the basis of health and health care quality issues, evidence or likelihood of disparities, or size of subgroups within the population. The selection of categories should also be informed by analysis of relevant data (e.g., Census data) on the service or study population. In addition, an open-ended option of "Other, please specify:__" should be provided for persons whose granular ethnicity is not listed as a response option.**
- **Elicit categorical responses consistent with the current OMB standard race and Hispanic ethnicity categories, with the addition of a response option of "Some other race" for persons who do not identify with the OMB race categories.**

Consistent Rollup of Granular Ethnicity to OMB Categories

While systems for rolling granular ethnicity categories up to broader categories have been developed by CDC/HL7 and the Commonwealth of Massachusetts, among others, an agreed-upon rollup strategy for granular ethnicities has not been determined or reviewed for its applicability nationwide and across the health care system. For example, the Massachusetts Superset aggregates its set of granular ethnicities to 31 mid-level aggregations whereas the CDC/HL7 Code Set aggregates its ethnicity categories to only the OMB race and Hispanic ethnicity categories. A process for rolling granular ethnicity categories up to the OMB categories is key to achieving two potentially contradictory objectives: on the one hand, consistency and standardization in analysis and reporting, and on the other hand, data collection tailored to local circumstances. Rollup procedures will need to be employed only when a person does not check off an OMB race or Hispanic ethnicity and only provides a granular ethnicity response or when only granular ethnicities are collected; however, the subcommittee prefers separate collection of granular ethnicity from OMB race and Hispanic ethnicity. The subcommittee chose not to define mid-level aggregations between granular ethnicity and the OMB categories.

Rollup Issues

The CDC/HL7 Code Set was designed in a hierarchical fashion such that each ethnicity category corresponds to one of the OMB race or Hispanic ethnicity categories (see Figure 3-3). This rollup scheme can be used when reporting is required to conform to the OMB categories or when an analyst needs a consistent set of minimum categories to make comparisons across systems reporting race and ethnicity at different levels of detail. For the vast majority of individuals, mapping from ethnicity to race categories is not problematic. As discussed in Chapter 1, however, ethnicity and race are two different concepts. Individuals who self-identify as Brazilian may also identify

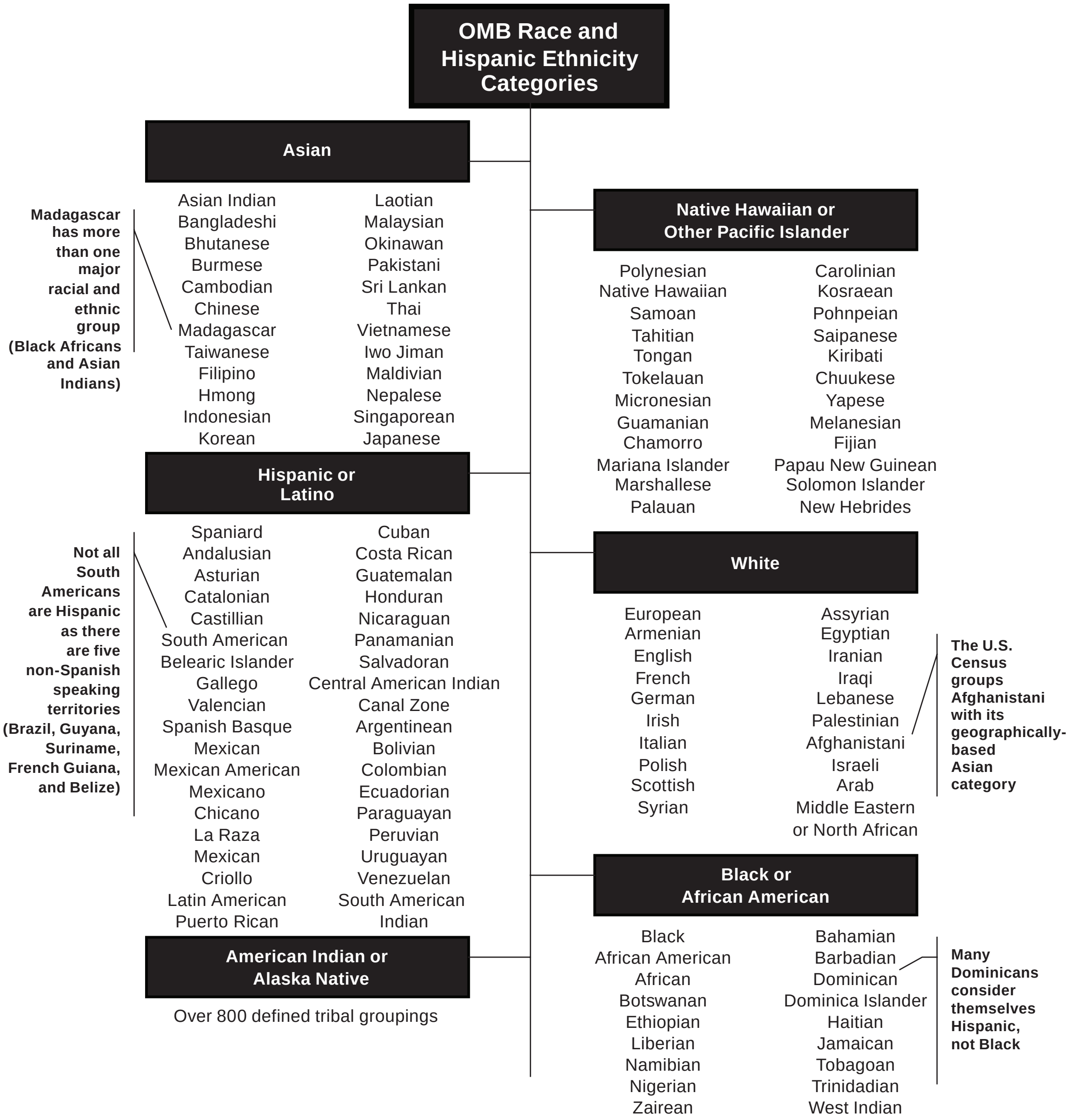

FIGURE 3-3 CDC ethnicities rolled up to the OMB minimum categories for race and Hispanic ethnicity with subcommittee annotations.

as White, Black, or some combination of races, or may see themselves as falling into no category beyond Brazilian. As a result, a rollup scheme that assumes all respondents who self-identify as Brazilian are White could wrongly assign a race to a number of individuals.

Figure 3-3 highlights some problems with current CDC rollup procedures. For example, Brazilians may not be considered Hispanic because they speak Portuguese rather than Spanish. Additionally, several national origins correspond to two or more major racial populations. For instance, the population of Madagascar is of mixed African, Malayo-Indonesian, and Arab ancestry. This means that rolling up Madagascan to Asian, as recommended by the CDC rollup scheme, would misclassify Africans of Madagascan descent as Asian. Rollup schemes are further complicated by misclassifications introduced by the use of geographic boundaries. While the CDC rollup scheme considers Afghanistan to be Middle Eastern and consequently categorizes Afghanis as White, the Census ancestry list classifies Afghanistan as an Asian country. Additionally, the WCRS coding manual notes that descriptions of religious affiliation should be "used with caution" when determining corresponding races.[19]

The above discussion highlights some of the difficulties inherent in rolling up some ethnicities because (1) ethnicities can include two or more major racial populations, (2) the geographic boundaries used to distinguish major groups in different classification schemes are arbitrary, and (3) many individuals may not associate with a specific race for cultural or other reasons. Thus, an individual's race cannot always be presumed based on his or her ethnicity. For this reason, the rollup assignment of a self-reported ethnicity to an OMB category should not be placed in an individual's health record or supersede a person's direct self-report. Analysts should understand that making an assignment using a 90 percent (or any other percent) threshold or an assignment based solely on geography incurs a higher probability that the rollup assignment misclassifies individuals based upon how they would self-identify their race. The rates of misclassification, even for granular ethnicities meeting a 90 percent threshold, underscores the fact that rollup schemes only provide probabilistic assignments useful for analysis at the group or population level.

Granular Ethnicities with an Indeterminate Race or Hispanic Ethnicity Classification

Various methods are used to distinguish ethnic groups that cannot be rolled up to a specific race category. For example, in Census 2010, the Census Bureau will use OMB's geographic definitions when it reclassifies ethnic responses in the race question to an OMB race category (e.g., all entries reflecting a sub-Saharan African nation will be counted as "Black"). In Census 2000, the Census Bureau applied a 90 percent rule to reclassify write-in responses on the race question according to the OMB race categories (del Pinal et al., 2007).[20] Single-ancestry responses were cross-tabulated by race responses, and if 90 percent or more of respondents in a specific ancestry group selected a particular race, that race was assigned to respondents who gave that ethnic response in the race question.

To determine whether groups included on the CDC, Census, Massachusetts, and WCRS category lists can be rolled up to a specific OMB race category with some degree of certainty, the subcommittee evaluated 2000 Public Use Microdata Samples (PUMS) data and used the methodology of the Census Bureau's 90 percent rule. The subcommittee cross-tabulated write-in responses on ancestry with the "alone or in combination with one or more other races" variable for each OMB race group. If fewer than 90 percent of respondents of a specific ancestry group selected an OMB race either alone or in combination with another race, the ancestry group was identified as being problematic for rolling up. The subcommittee did not have sufficient data on some granular ethnicity groups to apply the 90 percent rule to each ancestry subgroup (see Appendix F). The subcommittee finds some granular ethnicities could not be rolled up to an OMB race category with greater than 90 percent certainty. The difficult-to-categorize granular ethnicity groups are included in Appendix F.

The subcommittee suggests that those ethnicities that do not meet the 90 percent threshold be classified as "no determinate OMB race classification." This classification differs from the "Some other race" category because "Some other race" is a response option used by individuals who do not identify with a specific OMB race category. The "no determinate OMB race classification" would be used to identify entire ethnic groups that cannot be assumed to comprise one specific racial group. None of the granular ethnicities associated with the

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[19] The Census list of categories does not include religiously affiliated ancestries (e.g., Ashkenazi Jewish) because of the Bureau's constitutionally rooted decision not to identify or count religious populations. For health care purposes, religion may be coded as a separate variable from race and ethnicity. For example, the HL7 EHR System Functional Model states that systems shall provide the ability to capture, present, maintain, and make available for clinical decisions patient preferences such as language, religion, spiritual practices, and culture (Fischetti et al., 2007).

[20] Write-in responses to the questions on race and Hispanic ethnicity were allocated to an OMB race or Hispanic ethnicity category using the 90 Percent Rule only in the Census' Modified Race-Age-Sex (MARS) file. The MARS file is used by other agencies seeking denominators consistent with numerators collected in systems in which "Some other race" is not an option. Otherwise, write-in responses to "Some other race" are reported as they were received in all data released and published by the Bureau.

Hispanic ethnicity category can be assigned to an OMB race category with greater than 90 percent certainty. Granular ethnicities that cannot easily be rolled up to the OMB Hispanic ethnicity category include individuals identifying a granular ethnicity associated with the non-Spanish-speaking territories in South America (Guyana, Suriname, Brazil, and Belize); additionally, these granular ethnicities should be considered "no determinate OMB race classification" because they do not meet the 90 percent rule. Appendix F highlights some additional difficult-to-categorize granular ethnicity groups, including persons of Moroccan, Brazilian, Cape Verdean, Dominican, Guyanese, and South African descent.

Rollup Schemes

For interventions aimed at quality improvement and reduction of disparities at the local level, mapping granular ethnicities to the OMB race categories may be unnecessary. Locally tailored quality improvement activities may target subgroups without needing to relate those subgroups to a single OMB race category. Collecting race, Hispanic ethnicity, and granular ethnicity data separately allows reporting of the OMB categories when necessary without requiring rollup of the granular ethnicities, provided that individuals respond to all the questions asked.

Nonetheless, the subcommittee recognizes that some circumstances will require the use of a rollup scheme to link granular ethnicities to broader categories to allow comparison or data aggregation. The Massachusetts Superset was developed to guide health plans toward a uniform set of ethnicities; this set avoids rolling up granular ethnicities to races and instead aggregates granular ethnicities into broader groups of ethnicities. Such an ethnicity rollup scheme is useful when the sample of a granular ethnicity group is too small for analysis and needs to be aggregated with others.

The subcommittee merged several ethnicity lists into a template of granular ethnicity categories. These categories are mapped to the OMB race and Hispanic ethnicity categories (see Appendix E). National agreement needs to be reached on a rollup scheme, recognizing that all ethnicities do not necessarily map to an OMB race category, so that some respondents will have "no determinate OMB classification." The locus of responsibility for the development of a national standard set of ethnicity categories and a national rollup scheme is addressed in Chapter 6.

> **Recommendation 3-2: Any entity collecting data from individuals for purposes related to health and health care should collect granular ethnicity data in addition to data in the OMB race and Hispanic ethnicity categories and should select the granular ethnicity categories to be used from a national standard set. When respondents do not self-identify as one of the OMB race categories or do not respond to the Hispanic ethnicity question, a national scheme should be used to roll up the granular ethnicity categories to the applicable broad OMB race and Hispanic ethnicity categories to the extent feasible.**

ELICITING RESPONSES ON RACE, HISPANIC ETHNICITY, AND GRANULAR ETHNICITY

The ways in which entities inquire about an individual's race and ethnicity vary based on the setting in which the questions are asked. For example, paper survey forms use minimal words in questions and category descriptions to solicit race and ethnicity information from respondents. In contrast, surveys administered via an in-person interview can solicit more detailed information and explain the types of responses desired. Table 3-6 highlights ways in which race and ethnicity data are captured and illustrates how the questions may be tailored to specific contexts in health care.

Eliciting accurate and reliable race, Hispanic ethnicity, and granular ethnicity data depends on the ways in which the questions are asked, the instructions provided to respondents (e.g., "Select one or more"), and the format of the questions (i.e., one-question versus two-question format). As previously noted, this latter concern is especially relevant to accurately classifying individuals who self-identify as Hispanic. Ensuring that as many respondents as possible answer questions regarding their race and ethnicity will improve data quality. Pilot projects and further study can help determine the best ways to elicit accurate data that are useful for health care quality improvement and will guide current and future data collection systems.

Recommendation 3-3: To determine the utility for health and health care purposes, HHS should pursue studies on different ways of framing the questions and related response categories for collecting race and ethnicity data at the level of the OMB categories, focusing on completeness and accuracy of response among all groups.

- **Issues addressed should include use of the one- or two-question format for race and Hispanic ethnicity, whether all individuals understand and identify with the OMB race and Hispanic ethnicity categories, and the increasing size of populations identifying with "Some other race."**
- **The results of such studies, together with parallel studies by the Census Bureau and other agencies, may reveal the need for an OMB review across all agencies to determine the best format for improving response among all groups.**

MODELS FOR DATA COLLECTION

Figure 3-4 shows models for the collection of data on race, Hispanic ethnicity, and granular ethnicity, taking into account that the capacity of information systems may limit the number of questions that can be asked. This report emphasizes the importance of collecting granular ethnicity data in addition to the OMB race and Hispanic ethnicity questions. Using the approach preferred by OMB of asking two separate questions about Hispanic ethnicity and race and then asking additionally about granular ethnicity requires collecting three separate variables, regardless of whether through paper-based or electronic collection modes (Model A). For organizations constrained to two data fields, one collection field would be used to collect responses to the OMB combined race and Hispanic ethnicity question, followed by a second collection field for granular ethnicity data (Model B).

A distinction needs to be made between limits on collection and storage of coded response information in HIT systems; some organizations are limited in storage capacity by their legacy HIT systems, but could recode responses from multiple inputs to occupy fewer fields in HIT systems. For example, if an individual self-identified as non-Hispanic, White, and Russian on a paper form, the organization could store this information using one code in its HIT system. Doing so would, of course, introduce a very large number of possible combinations for which the organization would need to have codes.[21] Ultimately, to achieve compatibility across data systems, it may be necessary for organizations to upgrade their data collection and HIT systems to ensure the ability to collect, report, and use data as recommended in this report.

SUMMARY

This chapter has explained the subcommittee's rationale for recommending continued use of the OMB race and Hispanic ethnicity categories, supplemented by locally relevant granular ethnicity categories. The health and health care needs of all racial and ethnic groups can be best addressed through comprehensive strategies that recognize the importance of documenting and addressing variations among and within the locally relevant groups, and that further provide procedures for aggregating data to provide regional or national profiles.

To collect OMB race and ethnicity data, entities should use either the one-question or two-question format, depending on their system's field capacity. In accordance with OMB guidance, when the two-question format is used, the Hispanic ethnicity question should be first, and a "Select one or more" instruction should be included; OMB has indicated a preference for the two-question format. The recording of specific multiracial combinations (e.g., American Indian or Alaska Native *and* Black) is preferred by the subcommittee over assigning a single "multiracial" category to all persons of mixed race. A "Some other race" response category should be included for questions on race for respondents who do not identify with any of the OMB race categories. The minimum OMB categories to be collected are, then:

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[21] All possible combinations of just the six OMB categories results in 64 combinations. Introducing granular ethnicities would drastically increase the possible combinations.

TABLE 3-6 Examples of Instructions, Phrasing, and Terminology to Capture Race and Ethnicity Data

Source of Questions	Hispanic Ethnicity Question	Race Question	Granular Ethnicity Question
OMB's preferred format	Separate questions shall be used wherever feasible. Ethnicity shall be collected first **Response options:** Hispanic or Latino, Not Hispanic or Latino	Respondents shall be offered the option of selecting one or more racial designations. Recommended forms for the instruction are "Mark one or more" and "Select one or more" **Response options:** American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander (NHOPI), White	
Census 2000 long form (paper form)	Is Person 1 of Hispanic, Latino, or Spanish origin? **Response options:** Not of Hispanic, Latino, or Spanish origin; Mexican, Mexican Am., Chicano; Puerto Rican; Cuban; Another Hispanic, Latino, or Spanish origin	What is Person 1's race? Mark one or more boxes **Response options:** Five OMB race options plus six additional Asian origins, three additional NHOPI origins, and an option for "Some other race"	What is this person's ancestry or ethnic origin? **Response option:** write-in response
HRET Toolkit (in-person interview)	Do you consider yourself Hispanic/Latino? **Response options:** Yes; No; Declined; Unavailable/Unknown	Which category best describes your race? **Response options:** American Indian or Alaska Native; Asian; Black or African American; NHOPI; White; Multiracial; Declined; Unavailable/Unknown	"I would like you to describe your race or ethnic background. You can use specific terms such as Korean, Mexican, Haitian, Somali." **Response option:** free-text response
National Health Interview Survey (NHIS) (in-person interview)	Do you consider yourself to be Hispanic or Latino? **Response options:** Yes; No; Refused; Don't know Please give me the number of the group that represents your Hispanic origin or ancestry. You may choose up to five, if applicable **Response options:** Puerto Rico; Cuban/Cuban American; Dominican (Republic); Mexican; Mexican American; Central or South American; Other Latin American; Other Hispanic/Latino/Spanish; Refused; Don't know	What race or races do you consider yourself to be? Please select one or more of these categories **Response options:** White; Black/African American; Indian (American); Alaska Native; Guamanian; Samoan; Other Pacific Islander; Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Other Asian; Some other race; Refused; Don't know (If more than one race entered, which of these groups would you say best represents your race?)	

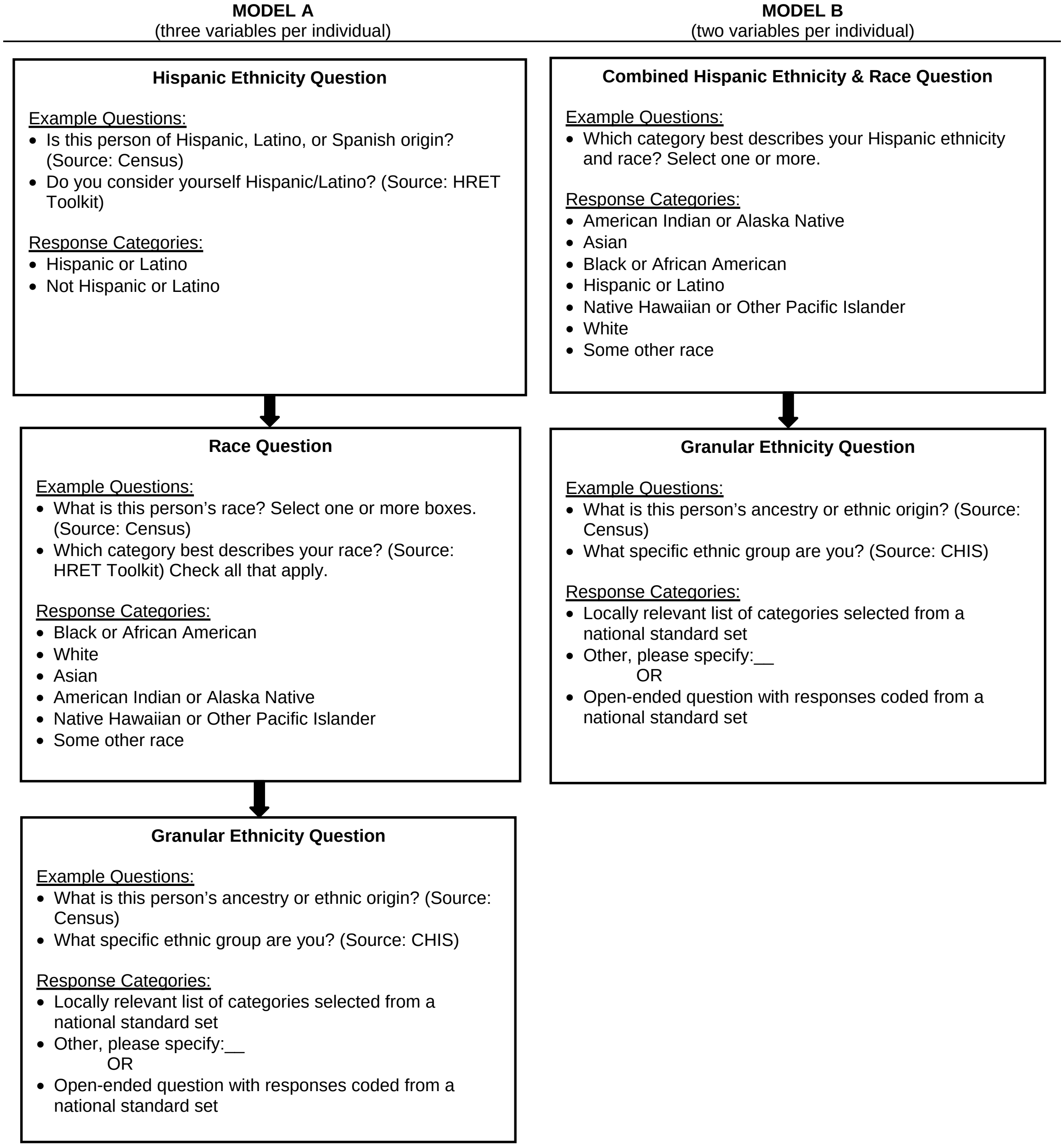
TABLE 3-6 Continued

Source of Questions	Hispanic Ethnicity Question	Race Question	Granular Ethnicity Question
National Ambulatory Medical Care Survey (paper form)	Ethnicity **Response options:** Hispanic or Latino; Not Hispanic or Latino	Race, mark one or more **Response options:** White; Black/African American; Asian; NHOPI; American Indian or Alaska Native	
Application for a Social Security Card (paper form)		Race/ethnic description (check one only) **Response options:** Asian, Asian-American or Pacific Islander; Hispanic; Black (Not Hispanic); North American Indian or Alaskan Native; White (Not Hispanic)	
U.S. Standard Certificate of Death (paper form)	Decedent of Hispanic origin? **Response options:** No, not Spanish/Hispanic/Latino; Mexican, Mexican American, Chicano; Puerto Rican; Cuban; Other Spanish/Hispanic/Latino (specify)	Decedent's race (check one or more boxes to indicate what the decedent considered himself or herself to be) **Response options:** Five OMB race options plus six additional Asian origins, three additional NHOPI origins, and other (specify)	

- Hispanic or Latino (in the two-question format, this is a separate question, having the choice of Hispanic or Latino and Not Hispanic or Latino)
- Black or African American
- White
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander (NHOPI)
- Some other race

The categories used for the collection of granular ethnicity should be locally relevant and selected from a national standard list. Each set of categories should include an "Other, please specify:__" option to allow individuals to self-identify if their category is not on the prespecified list. Similarly, state or national surveys might limit the number of listed categories, but should also present the "Other, please specify:__" response option. An open-ended approach with no pre-specific granular ethnicity response categories is acceptable in lieu of a specified list, but requires subsequent coding of responses according to the national standard set. The granular ethnicity question, whether presented as a closed- or open-ended question, should be separate from the question(s) involving the OMB categories.

Organizations may also want to use codes for tracking the current response status of individuals from whom they have attempted to collect race and ethnicity data, indicating unavailable (no response), declined (refused to answer), or unknown (respondent does not know) for those who fail to select a category.



MODEL A
(three variables per individual)

Hispanic Ethnicity Question

Example Questions:
- Is this person of Hispanic, Latino, or Spanish origin? (Source: Census)
- Do you consider yourself Hispanic/Latino? (Source: HRET Toolkit)

Response Categories:
- Hispanic or Latino
- Not Hispanic or Latino

Race Question

Example Questions:
- What is this person's race? Select one or more boxes. (Source: Census)
- Which category best describes your race? (Source: HRET Toolkit) Check all that apply.

Response Categories:
- Black or African American
- White
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Some other race

Granular Ethnicity Question

Example Questions:
- What is this person's ancestry or ethnic origin? (Source: Census)
- What specific ethnic group are you? (Source: CHIS)

Response Categories:
- Locally relevant list of categories selected from a national standard set
- Other, please specify:__
  OR
- Open-ended question with responses coded from a national standard set

MODEL B
(two variables per individual)

Combined Hispanic Ethnicity & Race Question

Example Questions:
- Which category best describes your Hispanic ethnicity and race? Select one or more.

Response Categories:
- American Indian or Alaska Native
- Asian
- Black or African American
- Hispanic or Latino
- Native Hawaiian or Other Pacific Islander
- White
- Some other race

Granular Ethnicity Question

Example Questions:
- What is this person's ancestry or ethnic origin? (Source: Census)
- What specific ethnic group are you? (Source: CHIS)

Response Categories:
- Locally relevant list of categories selected from a national standard set
- Other, please specify:__
  OR
- Open-ended question with responses coded from a national standard set

FIGURE 3-4 Models for data collection instruments to collect race, Hispanic ethnicity, and granular ethnicity data.

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4

Defining Language Need and Categories for Collection

Data on a person's language and communication needs should be part of any minimum data set related to health care delivery and quality improvement. The subcommittee recommends identifying spoken language need by determining first how well an individual believes he/she speaks English and then what language he/she needs for a health-related encounter. The subcommittee defines limited English proficiency (LEP) in the health care context as speaking English less than very well. To simplify the collection of language data, most entities should develop a list of common languages used by their service population, accompanied by an open-ended response option for those whose language does not appear on the list. When an entity has the capacity to collect additional information, the language preferred for written materials and the language spoken at home are also valuable. Locally relevant lists of language categories should be derived from a national standard list, with coding to facilitate information flow across entities.

The collection of data on the language needs of patients is important to improving health and health care. Collection of these data is necessary to meet legal obligations based on federal funding aimed at ensuring equitable access to health services and preventing discrimination based on national origin or limited ability to speak English. More important in the present context, however, knowledge of which patients have limited English proficiency (LEP) and of what their language needs are allows medical services and related interventions (e.g., provision of language assistance services, outreach, educational activities, translation of documents) to be targeted with the aim of improving the quality of care and reducing disparities. Not all persons with LEP are foreign born; more than one in four people aged 5 and over with LEP are born in the United States, and many more are naturalized citizens or documented immigrants (U.S. Census Bureau, 2003d; Youdelman, 2008).

Evidence on variations in health outcomes, medical errors, and receipt of quality health care as a function of English-language ability is persuasive that disparities exist, as reviewed in this chapter. Lack of English proficiency is a barrier not just to effective communication with individual health care providers, but also to accessing care in the first place. A review of the evidence base in this area convinced the subcommittee that the collection of data on language and communication needs is essential to safe, accessible, and effective, quality health care.

The subcommittee reviews various approaches to the collection of language data for health care improvement purposes. These approaches include practices of the U.S. Census Bureau because its data can easily be accessed to identify the spoken languages most often in use in a given geographic area, as well as a local population's proficiency with the English language. Additional guidance from the experiences of physicians, hospitals, health plans, states, and advocacy groups informed the subcommittee's deliberations. Issues surrounding the collection of language data include understanding whether there is demand for language services in the health care sector (e.g., among hospitals, physicians) and across states, whether data should be collected for both spoken and written language needs, what languages would make up a national standard set of categories, and how those languages should be coded for sharing of data beyond a single service site. It should be noted that the subcommittee's definition of language is one that is inclusive of communication needs such as sign language.

This chapter begins by reviewing what is known about the role of language in the provision of quality health care and health outcomes. It then summarizes estimates of populations needing language assistance and applicable legislation and regulatory requirements. Next is a discussion of various approaches used to question patients about their language needs. Language categories to be used by health care entities to collect these data and possible code sets are then considered.

THE ROLE OF LANGUAGE IN HEALTH AND HEALTH CARE

Interactions with Patients Needing Language Assistance

The number of people nationwide needing language assistance is growing rapidly (Shin and Bruno, 2003), and individuals with these needs interact with the health care system daily. The extent of this interaction is revealed by recent surveys on encounters with LEP patients in hospitals, physician offices, and community health centers:

- Eighty percent of hospitals provide services to LEP patients regularly, and 63 percent of hospitals encounter these patients daily or weekly (Hasnain-Wynia et al., 2006);
- Eighty-one percent of general internal medicine physicians commonly treat LEP patients (54 percent at least once a day or a few times a week; 27 percent a few times a month) (American College of Physicians, 2007);[1] and
- Eighty-four percent of federally qualified health centers provide clinical services each day to LEP patients—45 percent see more than 10 LEP patients per day; 39 percent see from one to 10 per day (National Association of Community Health Centers, 2008).

One study of hospitals indicated that 80 percent of hospitals have a health information technology (HIT) field dedicated to collection of language names, primarily to identify the languages needed for interpreter services (Regenstein and Sickler, 2006). Health care entities use a number of different approaches to collect this information: some limit the response categories to English, Spanish, and an "other language" category, while others offer respondents 200–300 languages from which to choose (Regenstein and Sickler, 2006; Tang, 2009). A study of the practice of internal medicine physicians found that only 28 percent kept detailed records of primary language needs, and about two-thirds of those who did record this information did so on paper rather than in a data system (American College of Physicians, 2007). By contrast, Kaiser Permanente, a health plan and a service provider covering eight states, began collecting data in 2009 in its electronic health record (EHR) system using a list of 131 spoken languages and 119 written languages (Tang, 2009).

Health care entities may serve LEP patients by using bilingual health care providers; other bilingual staff trained in medical terminology; or, frequently, ad hoc interpreters, such as family members or bilingual staff with no knowledge of medical terminology. The latter approach is particularly prone to error (Flores, 2005, 2006b). Telephone interpretation services are also available from numerous sources; more than 200 different languages are offered by some interpretation and translation services (ASIST Translation Services, 2009; Language Line Services, 2009). Depending on the diversity of the population served, an entity may encounter persons with language assistance needs in just a few or many languages. New York Presbyterian Hospital, for example, reports providing interpretation in 95 languages (NQF, 2009). Reimbursement for the provision of interpretation and translation

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[1] 12 percent of active patients in overall practice.

BOX 4-1
Language Concordance Between Patients and Providers

Being able to speak to patients in their own language breaks down barriers, and some entities try to assign patients to language-concordant providers whenever possible. A growing body of literature finds that language concordance between patients and providers (i.e., both speak the patient's primary language well) results in greater patient understanding, leading to increased satisfaction (Green et al., 2005; Ngo-Metzger et al., 2007), better medication adherence (Manson, 1988), greater understanding of diagnoses and treatment (Baker et al., 1996a), greater well-being and better functioning for persons with chronic disease (Perez-Stable et al., 1997), and more health education (Eamranond et al., 2009; Ngo-Metzger et al., 2007). When providers and patients are language discordant, some but not all effects can be mitigated by having trained interpreters (e.g., health education improves but not ratings of interpersonal care) (Ngo-Metzger et al., 2007). To ensure qualified interpreters or fully fluent providers, there has been movement toward training and certifying interpretation staff and ensuring the bilingual and cultural competence of providers (Cooper and Powe, 2004; Kettrick, 2008; Moreno et al., 2007; Youdelman, 2008).

services is not always available (e.g., not under Medicare, or when states elect not to provide a match for Medicaid funding for such services) (Bagchi and Stevens, 2006; Chen et al., 2007; Ku and Flores, 2005; Minnesota Department of Health Office of Rural Health Primary Care, 2008; Ponce et al., 2006b; Youdelman, 2007). Reauthorization of the Children's Health Insurance Program (CHIP) in 2009 increased federal matching for language services from 50 to 75 percent.[2] An analysis of the adequacy of different means of providing language services and the funding of such services is beyond the scope of this report, but the issues have been examined by others (Gany and Ngo-Metzger, 2007; Karliner et al., 2007; Saha and Fernandez, 2007).

Too often, either ad hoc or no interpretation services are available when LEP individuals seek health care services. There are no good estimates of how many LEP patients who need interpretation services fail to receive them, but a figure of nearly 50 percent was found in one emergency room study (Baker et al., 1996a).

Uses of Language Data

Entities that collect language data may use the data in various ways. The most obvious ways are to provide direct language assistance during a clinical encounter and information for follow-up care, such as chronic disease management education or discharge instructions in a patient's language. Categorical data on demand for language assistance can inform hiring of bilingual staff or arrangements for interpretation services. An entity also might want to make appointments for patients with providers who are language concordant (Box 4-1). A hospital might want to track whether patients who receive language assistance have better outcomes on quality metrics compared with those who do not receive those services, or it might want to track whether those services are timely (Box 4-2). Language data also are useful for determining the need for translated materials; for example, Kaiser Permanente translated its Health Care Glossary into six languages to communicate commonly used terms and explanatory information about tests or conditions more effectively (NCQA, 2007). The California Healthy Families program indicates in which languages health plans have written materials on coverage, medical care reminders, member handbooks, and newsletters (California Healthy Families, 2008b).

Additionally, the profile of patients being served can be compared with the population statistics of the service area to identify populations not being served. Yet while evidence shows that some health care entities collect language data on their patients, most entities fail to use these data to assess how language barriers impact

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[2] *Children's Health Insurance Program Reauthorization Act of 2009*, Public Law 111-3, 111th Cong., 1st sess. (February 4, 2009).

BOX 4-2
Assessing Whether Language Assistance Needs Are Met

The *Speaking Together: National Language Services Network* program engaged 10 hospitals with diverse patient populations to examine how to improve the quality and availability of health care services for LEP patients. According to Director Marsha Regenstein, "Screening for preferred language is a fundamental component in any measurement strategy related to quality improvement in language services." Screening for language service needs proved less difficult than linking data to patient care needs and assessing timeliness of services. Some possible performance metrics emerged from the program, including percentage of patients who have been screened for preferred spoken language and percentage of patients with language needs who receive an initial assessment and discharge instructions from assessed and trained interpreters or bilingual providers.

Cambridge Health Alliance took advantage of its EHR system to identify whether an interpreter was used, the time the interpreter spent, and the types of activities in which he/she engaged with patients (e.g., encounters with physician, informed consent, teaching, patient discharge). Another hospital tracked the increasing portion of patients who were screened for depression in their own language. Speaking Together, sponsored by The Robert Wood Johnson Foundation, offers a toolkit that details additional promising practices and lessons learned in implementation; see www.speakingtogether.org.

SOURCES: Regenstein, 2009; Regenstein and Sickler, 2006; RWJF, 2008.

the quality of care and ultimately patients' health status (Regenstein and Sickler, 2006). It should be noted that recommendations on which specific quality improvement actions should be undertaken by entities is beyond the subcommittee's charge.

Effect of Language on Health Status, Access to Care, Health Outcomes, and Patient Safety

It is well established that LEP patients encounter significant disparities in access to health care (Hu and Covell, 1986; Weinick and Krauss, 2000), decreased likelihood of having a usual source of care (Kirkman-Liff and Mondragon, 1991; Weinick and Krauss, 2000), increased probability of receiving unnecessary diagnostic tests (Hampers et al., 1999), and more serious adverse outcomes from medical errors (Divi et al., 2007) and drug complications (Gandhi et al., 2000).[3] The evidence also suggests that language barriers can increase the likelihood that patients will miss appointments, make less use of preventive care (Brach et al., 2005; Ku and Flores, 2005), or feel dissatisfied with health care services (Carrasquillo et al., 1999; Weech-Maldonado et al., 2003). On the basis of the findings detailed below, the subcommittee concludes that assessing language needs for each individual is an essential first step toward ensuring effective health care communication, and that provision of language assistance services is an actionable quality improvement option.

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[3] Search terms in PubMed included "health care quality," "limited English proficiency," "language barrier," and "health care disparity." Selected articles from this review are cited due to space limitations. Few studies were identified that reported no language proficiency effects, suggesting the possibility that the literature base itself is biased toward reporting positive effects. The few studies reporting no effects had methodological issues (Enguidanos and Rosen, 1997; Estrada et al., 1990; Stone et al., 1998).

Effect of Language on Health Status

A growing literature documents a link between language barriers and poor quality health care (Pippins et al., 2007; Woloshin et al., 1995) that can lead to lower health status (DuBard and Gizlice, 2008). Research also indicates that this link can be broken by the use of interpreters. For example, use of interpreters is associated with improvements in the rate of follow-up visits after a visit to the emergency department (Karliner et al., 2007), in prescriptions written and filled (Flores et al., 2005), and in the need for obstetrical interventions.

Many studies that do not directly evaluate how language barriers impact health status examine how language incompatibility or LEP leads to different medical management than that received by patients who do not have these limitations or are provided with interpreters (Bard et al., 2004; Bernstein et al., 2004; Sarver and Baker, 2000; Waxman and Levitt, 2000). For example, LEP patients who needed but did not receive interpreter services experienced less satisfaction with their health care interactions, including less friendliness, time spent, and perceived concern for the patient, than those provided with or not needing interpreters (Baker, 1998). Recent studies have also revealed how language barriers can result in delays in prehospital care (Grow et al., 2008), less social interaction between dental staff and LEP patients (Hammersmith and Lee, 2008), and more negative clinical experiences in health care settings (Hampers et al., 1999) relative to non-LEP patients. One survey of care provided mainly in safety net hospitals found that the experiences of uninsured patients with access to an interpreter were comparable to or better than those of insured patients with no need for an interpreter (Andrulis et al., 2002). Moreover, families of non-English-speaking patients receive less information relevant to high-quality end-of life-care (Thornton et al., 2009). Such evidence suggests that language is a central factor in being able to achieve optimal health status and that bridging language gaps is essential to ensure quality care.

Language barriers prevent providers from obtaining accurate patient histories, impair the ability to engage patients in joint patient–provider decision-making on treatment, and limit patients' ability to obtain sufficient information for self-care (Wisnivesky et al., 2009). Poor patient–provider communication has been linked, for example, to poor asthma management practices in children (Chan et al., 2005) and in adults (Wisnivesky et al., 2009). It has also been associated with poor adherence to medication regimens (David and Rhee, 1998; Derose and Baker, 2000; Orrell et al., 2003) and concerns about unequal power dynamics between patients and providers (Schlemmer and Mash, 2006).

Effect of Language on Access to Care

Language barriers are closely linked to limitations in access to care (Wu et al., 2004) and to underuse of primary and preventive services (Woloshin et al., 1997), such as preventive cancer screenings (Jacobs et al., 2005; Ponce et al., 2006a), immunizations (De Alba and Sweningson, 2006; Sun et al., 1998), and routine check-ups (Pearson et al., 2008). In their examination of language-concordant and language-discordant patient–provider interactions in emergency services, Sarver and Barker (2000) discovered that the latter patients were less likely to receive follow-up appointments.

LEP is also associated with lower rates of prescription medication use, ambulatory visits, dental visits, and appropriate mental health treatment (Brach et al., 2005; Derose and Baker, 2000; DuBard and Gizlice, 2008; Sentell et al., 2007). This lower use of services may be associated with feelings of being discriminated against, as well as lower levels of trust and less confidence in medical visits, for those with language barriers, noted in particular among older Latinos (Mutchler et al., 2007). Language barriers have also been closely related to patient-perceived quality of care; for example, 81 percent of English-speaking patients with colorectal cancer reported receiving high-quality care, compared with only 52 percent of non-English-speaking patients (Ayanian et al., 2005). The lower use of services by non-English speaking persons may also reflect the patient's inability to articulate medical or mental health concerns to health care providers that are less easily measured by objective laboratory tests so that appropriate diagnoses can be made (Sentell et al., 2007).

The inability to communicate with insurance personnel can also create difficulties in enrolling in a health plan (Feinberg et al., 2002), as well as in securing a usual source of care (Kirkman-Liff and Mondragon, 1991). One study, for example, found reduced enrollment of Medicaid-eligible children in publicly funded health insurance programs because of parental difficulties in understanding enrollment forms (Feinberg et al., 2002). Similarly, a study of LEP Medicare beneficiaries demonstrated poorer access to a usual source of care as compared with those who were not LEP (Ponce et al., 2006a).

Research suggests that Spanish-speaking patients, as well as Spanish-speaking parents of pediatric patients, experience worse communication with their provider as compared with their English-speaking counterparts and less overall satisfaction with care (Jacobs et al., 2006). In one study, 89 percent of LEP Latinos who reported having a usual source of care cited the presence of interpreters or bilingual providers (Brach and Chevarley, 2008), implying that language capacity may be required to provide continuity of care for LEP patients. In addition, LEP patients who are seen by language-concordant providers demonstrate decreased likelihood of omitting medications and visiting the emergency department relative to those seen by language-discordant providers (Carter-Pokras et al., 2004; Manson, 1988). Tocher and Larson found no differences in meeting quality-of-care guidelines for LEP patients with diabetes (1998) or in the amount of time physicians spent with primary care patients (1999) in a setting with certified interpretation services available.

Effect of Language on Health Outcomes

Research has documented that poor health outcomes are more likely when language and cultural barriers exist between patients and providers (Anderson et al., 2003). Communication breakdowns occur when patients and providers are language discordant (Baker et al., 1998; Karliner et al., 2004). Results from several studies (Marcos et al., 1973; Price and Cuellar, 1981) suggest that LEP patients provide more elaborate replies with greater disclosure when interviewed in their primary language and that conducting the assessment in the patient's primary language may be particularly relevant for accurate diagnosis. The absence of language concordance between patient and provider and consequent reliance on ad hoc interpreters may impede disclosure of sensitive information (Marcos, 1979). It also negatively impacts comprehension of instructions and other treatment information necessary for adherence to and continuity of treatment (Wilson et al., 2005). Flores and colleagues (2005), for example, found that LEP patients who need but lack access to an interpreter have a poorer understanding of their medical diagnosis and treatment (Flores et al., 2005).

Language also appears to impact health outcomes by influencing the quality of the patient–provider relationship, including the development of trust, adherence to treatment, and follow-up (Rivadeneyra et al., 2000). LEP patients are more likely than those with good English-language proficiency to report inaccurate diagnoses, inadequate treatments, or negative health outcomes (Phelan and Parkman, 1995). Thus, if language barriers exist, diagnostic assessments, symptom disclosure, confidentiality, and treatment adequacy may be compromised (Baker et al., 1996b; Carrasquillo et al., 1999; Perez-Stable et al., 1997) and health outcomes suffer as a result.

Effect of Language on Patient Safety

Systematic literature reviews find that use of ad hoc interpreters is related to higher rates of communication errors and increased likelihood of clinical errors (Flores et al., 2005; Karliner et al., 2007). Family members and friends who act as ad hoc interpreters and do not understand the medical terminology involved or lack sufficient fluency in both languages are likely to interpret with errors (Flores et al., 2003). Typical errors include omissions, additions, condensations or abbreviations, substitutions, editorialization (interpreter adds or substitutes words that change the message), and false fluency (use of inaccurate words or phrases) (Flores et al., 2003). Flores and colleagues (2003) found that Spanish-speaking patients in an outpatient pediatric clinic experienced an average of 31 errors in medical interpretation by ad hoc interpreters and providers without sufficient language fluency, and more than half of these patients could have experienced negative adverse effects as a consequence of those errors. (It should be noted that, although research has documented a variety of interpretation errors during assessments, the clinical significance of such errors has not been well characterized.) Elderkin-Thompson and colleagues also found interpretation errors in more than 50 percent of videotaped encounters with nine Spanish-speaking nurses untrained in medical topics they were regularly called upon to interpret for LEP patients (Elderkin-Thompson et al., 2001).

Linguistic discordance can encompass differences in the concepts behind words and in the contexts giving meaning to those words (Flores et al., 2005). As a result, some researchers recommend that providers partner with trained interpreters who can bridge not only linguistic gaps but also cultural gaps that may challenge patient–provider communication (Dohan and Levintova, 2007).

Also of concern is that LEP patients without interpreters (compared with English-speaking patients and LEP patients with professional interpreters) receive fewer tests and procedures, which could lead to an increased risk for problems in the emergency department (Bernstein et al., 2004). Likewise, the lack of English language proficiency among the parents of pediatric patients has been correlated with a doubling of the risk of adverse medical events during pediatric hospitalizations (Cohen et al., 2005). In addition, LEP patients evidenced increased risk of misunderstanding prescription labels when seeing language-discordant providers compared with English-fluent patients (Wilson et al., 2005). Similarly, in one study, 27 percent of patients who needed but failed to receive interpreter services did not understand their medication instructions, compared with 2 percent who received such services (Andrulis et al., 2002).[4]

ESTIMATES OF POPULATIONS NEEDING LANGUAGE ASSISTANCE AND APPLICABLE REQUIREMENTS

This section examines national estimates of the numbers of people in the United States whose primary language at home is not English and the portion who is not proficient in English who therefore may need language assistance during health care encounters. It also reviews applicable national legislative and regulatory requirements that may guide the collection of language-related data.

Estimates of Populations Needing Language Services

Census questions provide a starting point for determining the language needs of individuals in different geographic areas through a comparable data set (Shin and Bruno, 2003). Since 1980, the Census has asked whether each person aged 5 years and older speaks a language other than English at home. This population doubled in absolute numbers from 1980 to 2000, and its percentage of the population over age 5 grew from 11 percent (23.1 million) in 1980 and 14 percent (31.8 million) in 1990 to 18 percent (47 million) in 2000 (Shin and Bruno, 2003). Respondents who speak a language other than English at home are also asked to enter the language they speak on an open-format response line and to rate their facility with spoken English (Figure 4-1). The same questions will be posed in Census 2010 and on the American Community Surveys. The Census asks no questions about reading or writing ability in English.

Assessment of Limited English-Speaking Ability

One simplified approach to assessing English-speaking ability is to ask people to rate themselves. The Census asks people to rate their ability to speak English on a scale from "very well" to "not at all" (see Figure 4-1). These ratings are based on self-defined and -perceived ability and not any specific test. Of the 47 million people aged 5 and older who reported speaking a language other than English at home on Census 2000, 55 percent reported speaking English "very well," 22 percent "well," 16 percent "not well," and 7 percent "not at all" (Shin and Bruno, 2003). The proportion who spoke English very well was similar in 1980, when it was at 56 percent (Kominski, 1989).

The criteria chosen to define LEP significantly affect the size of the LEP population. If LEP is defined as those who speak English less than "very well," the Census 2000 LEP population numbers 21.3 million people over the age of 5 (more recent American Community Survey [ACS] LEP data estimate the total population at 23 million) (Youdelman, 2008). If it is defined as those who fall into the categories of "not well" and "not at all," the LEP population numbers 10.9 million. The Census employs another measure called "linguistic isolation," meaning that no one ages 14 or older in the household speaks English. This population of 11.9 million is similar in size to that

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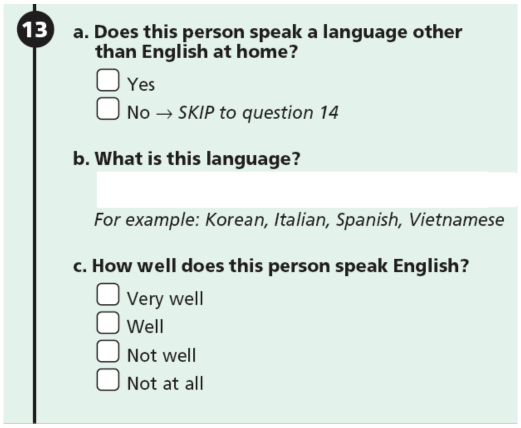
[4] New York State requires translation and interpretation services by pharmacies (Office of the Attorney General, 2008).



13 **a. Does this person speak a language other than English at home?**

☐ Yes
☐ No → *SKIP to question 14*

b. What is this language?

For example: Korean, Italian, Spanish, Vietnamese

c. How well does this person speak English?

☐ Very well
☐ Well
☐ Not well
☐ Not at all

FIGURE 4-1 Census 2000 questions about language.
SOURCE: Shin and Bruno, 2003.

resulting from the more constrained LEP definition (Shin and Bruno, 2003). LEP individuals may have someone in their family that they can call upon when they need help with interpretation, but those in linguistically isolated households must look elsewhere for language assistance.

Through schooling, children of immigrants eventually achieve a high degree of linguistic integration, and only a minority of immigrants' grandchildren retains bilingualism (Alba, 2005). A larger proportion of young people (aged 5–17) than of those who are older, who live in homes where a non-English language is spoken, speak English "very well" (U.S. Census Bureau, 2003b, 2003c). Even among first-generation immigrants to the United States, most children develop English-speaking ability; for example, 79 percent of Mexican and 88 percent of Chinese first-generation children speak English "well" or "very well," even while they continue to speak a language other than English at home (Alba, 2005). Thus, it is not surprising that children are often called upon to interpret for their parents and grandparents. As discussed above, however, the appropriateness of this arrangement for health care purposes has been questioned for several reasons, including the high frequency of errors with clinical consequences and the tendency to avoid sensitive and embarrassing subjects, such as those pertaining to sexual issues, domestic violence, abuse of drugs or alcohol, and the possibility of death (Flores, 2006a; McQuillan and Tse, 1995). Reflecting this concern, the California state assembly passed a bill in 2005 prohibiting the use of children under age 15 as medical interpreters; the bill was ultimately not enacted, however (EXODUS On-line, 2009).

Effect of Being Foreign Born

Being foreign born is not itself a marker for poor English skills: 39 percent of the 30.7 million foreign-born people aged 5 and over now living in the United States speak English "very well" and indeed may come from a country where English is spoken (e.g., Jamaica) (Grieco, 2003; Larsen, 2004; U.S. Census Bureau, 2003d). However, about three-fourths of the 21.3 million people identified in Census 2000, who are LEP by a definition of speaking English "less than very well," are foreign born; this accounts for 15.6 million people (U.S. Census Bureau, 2003d). More recent ACS data that estimate the LEP population at 23 million reveal that about 10.5 million are native born or naturalized citizens, and approximately 4 million more are documented immigrants (Youdelman, 2008). The proportion of the immigrant population that is proficient in English increases with time in the United States; for example, 36 percent of those in the country five years or less speak English very well, compared with more than 70 percent in the country for more than 30 years (Siegel et al., 2001).

Proficiency is lower among low-wage workers and those with less than a high school diploma—population groups that might be more likely to access public programs (Capps, 2003). High school graduation rates among the foreign-born populations from Europe and Asia now living in the United States are comparable to those among persons born in the United States—around 85–87 percent. However, the rate is much lower for immigrants from Central America, at 37.7 percent (Larsen, 2004). This is important because more than one-third of the U.S. foreign-born population comes from this region, particularly Mexico (Malone et al., 2003). Low literacy can compound the effect of a lack of English proficiency on understanding health-related information (Downey and Zun, 2007; Sudore et al., 2009; Zun et al., 2006).

Applicable Legal Requirements

Civil Rights Act Requirements to Identify the Service Population

Title VI of the Civil Rights Act of 1964 prohibits discrimination on the basis of race or national origin by those who receive federal funds:

> No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance.” {42 U.S.C § 2000d}

Language needs have been considered a factor in deciding discrimination cases based on national origin under Title VI[5] (Chen et al., 2007) and in determining whether there have been violations of equal access for language minorities under the Voting Rights Act.[6] Settlements have resulted in requirements to collect localized and granular data directly from those receiving services or indirectly through data descriptive of the service area (HHS, 2009c).

HHS’ Office for Civil Rights (OCR) states that HHS is “committed to enhancing access to HHS services by LEP persons and closing the health care gap” (HHS, 2009b). Language assistance is to be made available at all points of contact with federally funded programs—enrollment, registration, and direct medical services. HHS describes LEP persons more broadly than the Census questions, which focus on spoken English. For HHS, LEP includes persons:

- Who “are unable to communicate effectively in English because their primary language is not English and they have not developed fluency in the English language.”
- Who “may have difficulty speaking or reading English.”
- Who “will benefit from an interpreter who will translate to and from the person’s primary language.”
- Who “may also need documents written in English translated into his or her primary language so the person can understand important documents related to health and human services” (HHS, 2009a).

Executive Order 13166, *Improving Access to Services for Persons with Limited English Proficiency*, requires each federal agency to review its services and develop and implement reasonable steps by which LEP persons can have “meaningful access” to programs or activities without charge for language services (Executive Office of the President, 2000). The guidance seeks to clarify the obligations of recipients of federal funds to provide language assistance services. Additionally, LEP persons are to be notified that free interpretation services are available so that they can make an informed choice about whether to use a friend or family member as an interpreter instead. HHS Title VI Civil Rights guidance allows patients to choose whether to use a language service. But interpreter services still must be provided if good medical practice might be compromised, the competence of the family interpreter is in question, or issues of confidentiality or conflicting interests arise. The emphasis is on voluntary compliance with these provisions.

The Department of Justice issued four Title VI “balancing factors” to be applied across all federal agency–funded programs: the number or proportion of LEP persons in the service population, the frequency of contacts,

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[5] *Lau v Nichols*, 414 U.S. 563 (1974).

[6] Department of Justice. 42 U.S.C. Chapter 20 § 1973aa-1a. The Public Health and Welfare Act, Elective Franchise.

the importance of the services to the persons' lives, and the resources available to support services (U.S. Department of Justice, 2002). HHS subsequently revised its guidance accordingly (HHS, 2009b). Yet lack of knowledge of the requirements by both providers and patients or of willingness of LEP patients to pursue complaints when faced with language barriers leaves many persons without meaningful access to health care, and few states have comprehensive laws mirroring the federal requirements (Chen et al., 2007; Perkins and Youdelman, 2008).

Requirements of the Americans with Disabilities Act

Communication needs extend beyond spoken language capability to include barriers imposed by disabilities affecting hearing, speech, and vision. The Americans with Disabilities Act (ADA) of 1990 and Section 504 of the Rehabilitation Act of 1973 address nondiscrimination on the basis of such disabilities. Resolution of legal cases has resulted in requiring the availability of qualified sign language interpreters within a certain time frame (e.g., 2 hours) and the use of other auxiliary aids, such as TTY or TDD,[7] in venues such as hospitals (HHS, 2009c; U.S. Department of Justice, 2003). Further examples of the types of auxiliary aids or services that might be required to ensure accommodation of a person with a disability are outlined in regulations.[8]

There are an estimated 1 million functionally deaf persons in the United States (Mitchell, 2005), and up to 36 million people have some degree of hearing loss (National Institute on Deafness and Other Communication Disorders, 2009). Only rough estimates of 360,000 to 517,000 persons exist of the number of deaf individuals who use sign language (Mitchell, 2005). Of note, immigrants who are deaf may have learned a different sign language from that taught in the United States (Gordon, 2005).

State Laws

States have instituted a number of additional laws to address language access. These are not reviewed in detail in this report. However, the status of laws nationally was recently reviewed by Perkins and Youdelman (Perkins and Youdelman, 2008), and Au and colleagues focused on activities in three states—California, Massachusetts, and New York (Au et al., 2009). These laws address the provision of direct language assistance, the setting of thresholds for applicable languages, continuing medical education requirements for physicians, the availability of interpreters for specific services (e.g., admissions to mental health facilities), facility licensure, and certification of interpreters.

APPROACHES TO ELICITING LANGUAGE NEEDS

The subcommittee considered different approaches to questions to elicit language needs. Assessment of English-language ability is widely used in studies evaluating the effects of language proficiency on disparities in the quality of health and health care (Jacobs et al., 2001). Table 4-1 lists approaches to questioning about patients' language needs that are employed by some health care entities. Questions address the individual's English proficiency, primary or preferred spoken language, language spoken at home, and preferred written language.

English Proficiency

An advantage of using a question to assess English proficiency, such as that used on the Census (Figure 4-1), is the ability to determine quickly whether a patient is likely to have language barriers that will limit his/her ability to navigate the health care system and communicate effectively with health care providers. Proficiency level data can be obtained for the entire population or matched to different languages (for example, among persons who speak a language other than English at home, 66 percent of Vietnamese speak English less than very well, compared with 23 percent of Hindi-speaking Asian Indians) (Kagawa-Singer, 2009; U.S. Census Bureau, 2003e). When an entity

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[7] TTY stands for TeleTYwriter or text telephone, and TDD is telecommunication device for deaf persons.

[8] Department of Justice. 28 CFR Part 36 § 36.303. ADA Standards for Accessible Design (July 1, 1994).

TABLE 4-1 Summary of Question Types and Categories

English Proficiency	Question Examples: • How would you rate your ability to speak and understand English? (Hasnain-Wynia et al., 2007) • How well do you speak English? (Karliner et al., 2008) Categories: • Very well • Well • Not well • Not at all (Shin and Bruno, 2003)
Spoken Language	Question Examples: • What language do you feel most comfortable speaking with your doctor or nurse? (Hasnain-Wynia et al., 2007) • In what language do you prefer to receive your medical care? (Cambridge Health Alliance in RWJF, 2008b; Karliner et al., 2008) • What language do you want us to speak to you in? (California Healthy Families, 2008a) • What language do you prefer to speak when you come to the medical center? What language do you feel most comfortable speaking? (Tang, 2009) Categories: • Names of specific languages in use in the United States, approximately 600 categories Plus: • Other, please specify:____ • Sign language(s)
Language Spoken at Home	Question Examples: • What language do you speak at home? (Shin and Bruno, 2003) • What language(s) do you usually speak at home? (NCHS, 2009) • What is the primary language spoken at home? (Cambridge Health Alliance in RWJF, 2008b) Categories: • Names of specific languages in use in the United States • Census denominator available for many but not all languages
Written Language	Question Examples: • In which language would you feel most comfortable reading medical or healthcare instructions? (Hasnain-Wynia et al., 2007) • What language should we write to you in? (California Healthy Families, 2008a) • What is your preferred written language?[a] • In what language do you prefer to read health-related materials? (Cambridge Health Alliance in RWJF, 2008b) • What language do you prefer for written materials? (Tang, 2009) Categories: • Names of specific languages in use in the United States • Braille Mandated: • Threshold language categories may be required by law and applicable to an entity in different states

[a] *Health Care Language Assistance Act of 2003,* California S.B. 853 § 1367 (October 8, 2003).

is considering which languages to list on its data collection instruments, knowing not just how many people speak a language but also their level of English proficiency and thereby their need for services will be helpful.

Since the response is based on self-report, it is important to understand the question's reliability in determining proficiency. The Census Bureau does not define which level of ability represents LEP (Griffin and Shin, 2007). However, the Census Bureau field tested the question to assess the validity of responses. Respondents who indicated that they spoke English "less than very well" had difficulty with the tests administered in the English

Language Proficiency Survey (ELPS), and researchers found a strong correlation between self-assessment of speaking ability and understanding of tested concepts. The ELPS is a test of English-understanding ability and was administered in people's homes by the Census Bureau for the Department of Education. Those who rated their English-speaking proficiency as "very well" scored similarly on the test to those who spoke English as their first language, lending validity to the self-assessed ratings. Further analyses found that those who answered "not at all" and "not well" represented a distinct population that would definitely need English assistance because they rarely, if ever, spoke English and had limited reading skills as well (Kominski, 1989). Additionally, when setting threshold languages under the Voting Right Act, it was determined that people who spoke English less than very well were LEP (Kominski, 1985). Persons who fall into the category of speaking English "well" are assimilated to varying degrees but still speak English less frequently than those who rate their ability as "very well" (Kominski, 1989). The Census Bureau has done no recent analyses on the association between the LEP question and English-language abilities (Griffin and Shin, 2007).

One could argue that a person may have to have greater proficiency in English for health care encounters than for other daily tasks because of the unfamiliarity of health concepts and the complexity of medical terminology; such situational factors can affect people's assessment of their capability (Siegel et al., 2001). The association between the Census English proficiency question and accurate and effective communication in English in the health care setting remains undetermined. However, a recent article by Karliner and colleagues (2008) evaluated

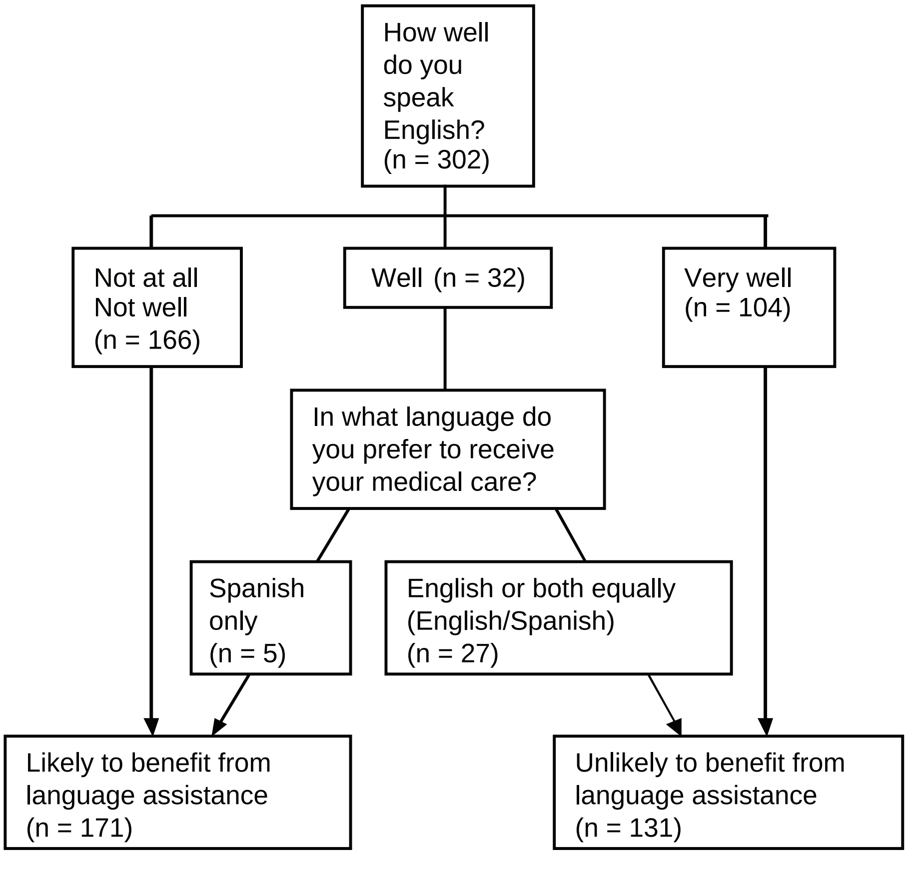

FIGURE 4-2 Karliner algorithm.
SOURCE: With kind permission from Springer Science+Business Media: Journal of General Internal Medicine, Identification of limited English proficient patients in clinical care, volume 23, 2008, page 1557, Figure 1.

the accuracy of the Census English proficiency question in predicting the ability of 302 patients from a cardiology clinic to communicate effectively in English (Figure 4-2) (Karliner et al., 2008). The authors reported that in evaluating the sensitivity and specificity of four different questions in predicting outcomes of patient-reported ability to discuss symptoms and to understand physician recommendations in English, "the Census-LEP item using the high-threshold of less than 'very well' was the most sensitive for predicting both of the effective communication outcomes" (p. 1558). Because the Census LEP question also had the lowest specificity, the authors recommend using a combination of that question and preferred language for medical care as a way to increase specificity with a marginal decrease in sensitivity. Different language groups may over- or underreport their competence; for example, Asians tend to underreport and Hispanics to overreport (McArthur, 1991; Zun et al., 2006). Therefore, health care entities may need to be mindful of their own population's response patterns.

Primary or Preferred Spoken Language

OCR has used the term "primary language" to mean the language that an LEP individual identifies as the one that he or she uses to communicate effectively and would prefer to use to communicate with service providers (HHS, 2008). The American Recovery and Reinvestment Act of 2009 (ARRA) similarly directs the inclusion of primary language in electronic health records.[9] The NQF cultural competency framework uses the following definition:

> Primary written and spoken language—the self-selected language the patient wishes to use to communicate with his or her health care provider. (NQF, 2009)

Alternative phrasings of questions can elicit the name of a specific language (see examples in Table 4-1).The Health Research & Education Trust (HRET) Toolkit suggests, "What language do you feel most comfortable speaking with your doctor or nurse?" California regulations suggest, "What is your preferred spoken language?" A Toolkit for Physicians developed for the California Academy of Family Physicians endorses a similarly phrased question as best practice: "In what language do you (or the person for whom you are making the appointment) prefer to receive your health care?" (Roat, 2005). It goes on to say, "Asking the question this way will provide you information on the language the patient feels he or she needs to speak in a health-related conversation. If the answer is a language other than English, you can plan to have language assistance available for the patient, and you can add this information to the record" (Roat, 2005, p. 5).

A concern with using a preference question alone is that it may not always capture a person's language need. For example, respondents may answer English if they believe that not doing so might limit their access to good medical providers. Similarly, respondents may state a preference for English because they know their providers are not fluent in their primary language. These examples are based on anecdotal report, and there are no research findings with which to assess the frequency of such occurrences. In practice, it is assumed that most people respond with their primary language so they can access the services of an interpreter or language-concordant provider.

The HRET Toolkit, endorsed by NQF, asks both the Census LEP question and a preference question. The subcommittee believes language need for effective communication with health care providers is defined by these two questions, and encompasses those with English proficiency of less than "very well." The subcommittee also believes the LEP question should be used to screen patients before they are asked about preference.

Language Spoken at Home

The Census asks whether a person speaks a language other than English at home and then asks what that language is (Figure 4-1). Detailed and comparable response data are available for states and localities on the languages spoken at home, so a health care entity can easily track what percentage of the population in its practice area reports using a language other than English in the home environment. Other data collectors, including National Health and Nutrition Examination (NHANES), ask about both language spoken at home and English proficiency.

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[9] *American Recovery and Reinvestment Act of 2009*, Public Law 115-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st Sess. (February 17, 2009).

Even when people speak English well, the language spoken at home is generally an indicator of one's cultural background, and that cultural knowledge may provide a window into beliefs about health care.

However, there are disadvantages in using solely a language spoken at home to evaluate individual needs and to plan for language assistance capacity. More than half of people who state they speak a language other than English at home also report speaking English very well (Glimpse, 2009; Shin and Bruno, 2003). This suggests that using only this question in the assessment of language capacity could result in overestimating the need for language assistance; this was a problem encountered in earlier national Censuses that helped lead to adding the question on language proficiency (Kominski, 1989). Also of concern is that this question does not allow respondents to indicate language dominance when they are bilingual/multilingual.

Preferred Written Language

The approach to asking about written language has been to ask people their preference or some variation thereof. For example, "In which language would you feel most comfortable reading medical or health care instructions?" (HRET Toolkit see Hasnain-Wynia, 2007) or "What language should we write to you in?" (California Healthy Families, 2008a). The phrasing of a preferred-language question may need to be tailored to particular circumstances (see Table 4-1). The phrasing of the first question would apply particularly within a health care delivery setting, while that of the latter might be sufficient for health plan communications, such as for enrollment or benefits information.

There is some evidence that the response to a written-language question will be the same as the response to a spoken-language question. To determine whether English-language proficiency in speaking varies significantly from that in writing and reading, the subcommittee conducted analyses using data on English-language proficiency for reading, speaking, and writing from the National Latino and Asian American Study (NLAAS) (Alegría et al., 2004a, 2004b). The NLAAS is a nationally representative household survey of Latinos and Asians aged 18 and older residing in the coterminous United States, where these data were collected. The findings show high-weighted Pearson correlation coefficients for English-language proficiency among speaking, reading, and writing ability. For example, for the full sample (both Asians and Latinos), the correlation between speaking and reading was 0.93, between speaking and writing was 0.90, and between reading and writing was 0.94 (Table 4-2). These results appear to indicate that English-language speaking proficiency can be extrapolated to English-language proficiency in reading and writing.

The Census Bureau does not routinely ask a question about a person's facility with written language. But two

TABLE 4-2 Correlations Between Self-Reported English Ability in Speaking, Reading, and Writing

English	Speak	Read	Write
Speak	1		
Read	0.9256	1	
Write	0.8974	0.9357	1
Latino	**Speak**	**Read**	**Write**
Speak	1		
Read	0.6735	1	
Write	0.6582	0.8548	1
Asian	**Speak**	**Read**	**Write**
Speak	1		
Read	0.8112	1	
Write	0.7736	0.925	1

SOURCE: Subcommittee analysis based on data from National Latino and Asian American Study (Alegría et al., 2004a, 2004b).

TABLE 4-3 Relationship of Speaking and Reading Ability

Reported English-Speaking Ability	Percent Who Say They Can Read a Newspaper in English, 1986 (%)	Percent Who Report No Difficulty Filling Out an English Form, 1980 (%)
Very well	98	96
Well	93	78
Not well	69	38
Not at all	0	5

SOURCE: Siegel et al., 2001.

studies assessed how well people's ability to read a newspaper or fill out a form (e.g., driver's license, job application) in English conformed to their reported speaking ability (Table 4-3) (Kominski, 1989; Siegel et al., 2001). Those who answered with the two lowest ratings clearly had diminished capability for reading, but the results were equivocal for the "well" category. Another study testing language ability and comprehension in an emergency room setting found that a person's ranking on verbal and written competence was similar (Downey and Zun, 2007).

Because of the overlap between speaking, reading, and writing ability, an additional question about written language may not be essential when an entity needs to limit the number of questions asked. At the same time, a person who is relatively fluent in speaking English and answers "very well" on English proficiency may read English "less well" or "not at all." Knowledge of the education level of the population served can help illuminate the risk of lower or higher reading comprehension. One cannot assume language ability from ethnicity; for example, Contra Costa Health Plan found that less than 2 percent of Hispanic commercial members wanted written materials in Spanish.[10]

Reading many health-related materials with comprehension requires education at the high school level as most materials are written at a 10th grade reading level or higher (D'Alessandro et al., 2001; Downey and Zun, 2007; IOM, 2004), and even when low-literacy health-related materials are available at the fifth-grade level or below, medical terminology can be mystifying (Health Literacy Innovations, 2007; RTI International—University of North Carolina Evidence-based Practice Center, 2009). Further it is noted that about 40 million people in the United States read below the fifth-grade level, and this cannot always be attributed to a lack of spoken English proficiency. To ensure effective communication, patients may need to discuss written materials with an interpreter or bilingual provider even if the materials are translated into the patients' primary language.

Medical information can be quite complex to understand even without the added barrier of having a primary language other than English. Health literacy has been defined as:

> The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions. (Ratzan and Parker, 2000, p. vi)

Half of LEP adults have a ninth-grade education or less (GCIR, 2008; Wrigley, 2003), making health-related materials less accessible to those who are less literate even in their native tongue. Twenty-two percent of non-English speakers indicate that they can read or write only in their own language, and 35 percent can be classified as functionally illiterate (IHA, 2009). Additionally, similar words can be confused. For example, someone who reads only Spanish might misread the English word "once" as meaning eleven times, creating the danger of taking a medication an inappropriate number of times (ISMP, 1997).

The subcommittee concludes that a patient's language preference for written materials is useful information, but if a health care entity must limit the number of questions it asks because of either administrative burden or HIT capacity, asking about written language is a lower priority than asking about spoken language since written-language needs can generally be inferred from responses about spoken language. Additionally, the subcommittee

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[10] Personal communication, O. Tiutin, Contra Costa Health Plan, August 4, 2009.

believes more effective communication occurs when LEP patients have the opportunity to discuss translated documents with an interpreter or bilingual provider.

Assessment of Language Need

The subcommittee concludes that collection of data on language need is fundamental to improving service delivery to LEP populations and to conducting research aimed at identifying disparities in access and outcomes. The subcommittee explored various ways to determine patient spoken and written language needs so that steps can be taken to best enhance effective communication between patients and providers. Patients' proficiency with English and the language needed for effective communication should be taken into account to gauge their ability to understand their options for health services and to follow through on care plans and self-management. The subcommittee concludes that two questions define language need: one that determines whether English-language proficiency is less than "very well" and a second that determines the preferred language needed for a health-related encounter. The subcommittee sets a hierarchy among four possible types of language questions in widespread use and based on the previous discussion, recommends:

> **Recommendation 4-1: To assess patient/consumer language and communication needs, all entities collecting data from individuals for purposes related to health and health care should:**
>
> - **At a minimum, collect data on an individual's assessment of his/her level of English proficiency and on the preferred spoken language needed for effective communication with health care providers. For health care purposes, a rating of spoken English-language proficiency of less than very well is considered limited English proficiency.**
> - **Where possible and applicable, additionally collect data on the language spoken by the individual at home and the language in which he/she prefers to receive written materials.**

When the individual is a child, the language need of the parent/guardian must be determined. Similarly, if an adult has a guardian/conservator, that person's language information must be assessed.

LANGUAGE CATEGORIES TO BE USED BY HEALTH CARE ENTITIES

The subcommittee considered whether a single limited list of languages (e.g., the top 10 or top 40 nationwide) should be used by all health care entities for quality improvement purposes. A precedent exists for recommending use of such a list—the HRET Toolkit, endorsed by the National Quality Forum (NQF) for achieving more culturally competent organizations. The subcommittee reviewed Census data to determine the usefulness of such lists. However, the subcommittee concludes that the language of each individual must be captured, regardless of whether that language is present on any list developed to facilitate data collection and analysis locally or nationally.

Top Languages Nationally

The subcommittee first reviewed Census data on the top 10 languages reported to be spoken most frequently at home besides English:

1. Spanish (28.1 million)
2. Chinese (2.0 million)
3. French (1.6 million)
4. German (1.4 million)
5. Tagalog (1.2 million)
6. Vietnamese (1.0 million)
7. Italian (1.0 million)
8. Korean (0.9 million)

9. Russian (0.7 million)
10. Polish (0.7 million) (Shin and Bruno, 2003; U.S. Census Bureau, 2003j)[11]

A list of these 10 languages would cover 38.6 of the 46.9 million U.S. residents who speak a language other than English at home—a figure that might argue for all entities to use this list for collecting data on language needs. However, analysis reveals that this list fails to capture the top 10 languages in each state, as shown in a sample of four states (Figures 4-3a–d). Numerous additional languages important for state-level planning—Navajo, Bengali, Afrikaans, Hindi, Dakota, Norwegian, Laotian, Amharic, Cushite, Hmong, Arabic, Urdu, Tagalog, Persian, Portuguese, Mon-Khmer—are among the top languages spoken in just these four states. Likewise, while Spanish is among the top 10 languages in 3,122 of 3,141 counties in the United States, numerous other languages are often at the top for example, Turkish in 12 counties, Laotian in 125, Navaho in 74, SerboCroatian in 58, and Portuguese in 229 (U.S. English Foundation, 2009a, 2009b). Thus, focusing on the collection of language data to a top 10 national list would not always be useful even for system-level planning for states and counties, and certainly would not capture the diversity among states or smaller jurisdictions or the specific needs faced by hospitals, health plans, or individual provider practices. However, similar approaches have been used for some national purposes; for example, section 118 of Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) requires translation of the Medicare Savings Program application form, at a minimum, into the 10 languages most used by persons applying for the program.[12]

Additionally, some of the top 10 languages nationally are declining in use, while others are increasing because of changing immigration patterns. The numbers of Italian, German, and Polish speakers have declined, while the numbers of Spanish, Vietnamese, Chinese, Russian, Tagalog, Korean, Arabic, and French Creole speakers have increased substantially since 1990 (Shin and Bruno, 2003). The number of Spanish speakers has increased by 62 percent since 1990, while the number speaking other Indo-European languages has increased by just 14 percent, Asian and Pacific Islander languages by 55.6 percent, and all other languages by 51.2 percent (Shin and Bruno, 2003).

The subcommittee then reviewed a longer list based on the 39 languages on which the Census routinely reports, consisting of 30 individual languages and the rest groups of languages (Table 4-4). The HRET Toolkit guidance for hospital collection of demographic data includes 35 language or language group choices; it also provides additional options for inclusion in the data system, such as the patient declined to answer. The HRET Toolkit list closely mirrors but improves upon the commonly reported Census categories by adding American Sign Language. The State of California requires under SB853 that each health plan survey its enrollees to understand the language needs of its members (CPEHN, 2008). Table 4-4 includes the language categories of one such survey, by Anthem Blue Cross, fielded in spring 2009. That list includes 37 individual languages or dialects, and also distinguishes between American and other sign languages and recognizes other communication difficulties, including hearing and speech loss (Ting, 2009). The list has many of the elements of the Census and HRET lists but incorporates several additional languages specific to its service population.

In reviewing the applicability of the 39 Census-reported languages for national use, the subcommittee found that in all but six states (Hawaii, Maine, New Hampshire, North Dakota, South Dakota, Vermont), people who speak Spanish at home are the largest group. Those who speak Chinese are the next-largest group nationwide, with large concentrations in California, New York, and Washington but located in every state. Although the penetration varies, each of the 39 languages included in Census 2000 is reported as being spoken in some homes within each state, with the following few exceptions: Gujarathi in Alaska; Navaho in Delaware and Vermont; Hmong in Delaware, District of Columbia, Idaho, Kentucky, Louisiana, New Hampshire, New Mexico, North Dakota, Vermont, West Virginia, and Wyoming; Mon-Khmer, Cambodian in Wisconsin and Wyoming; and Persian in Wyoming (U.S. Census Bureau, 2003j). Depending on an entity's collection approach, having 40 languages may prove unwieldy (see the section below on collection considerations).

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[11] CDC has access on its website to a limited set of informational materials based on top languages spoken in the United States: Spanish, German, Italian, Russian, Vietnamese, Chinese, French, Tagalog (CDC, 2008).

[12] *Medicare Improvements for Patients and Providers Act of 2008,* Public Law 110-275 § 118, 110th Cong., 2nd sess. (July 15, 2008).

TABLE 4-4 Language Categories in Selected Collection Instruments

Census Broad Categories	Census 39 Granular Categories for Reporting	HRET Toolkit	Anthem Blue Cross, CA
English	English	English	English
Spanish	Spanish[a]	Spanish	Spanish
Other Indo-European	Armenian[f]	Armenian	Armenian
	French (incl. Patois, Cajun)[a,b]	French	French
	French Creole[e]	French Creole	
	German[a,b]	German	German
	Greek[e]	Greek	
	Gujarathi[f]	Gujarathi	
	Hindi	Hindi	Hindi
			Irish
	Italian[a,c]	Italian	Italian
	Persian[f]	Persian	Persian/Farsi Polish
	Polish[a,d]	Polish	
	Portuguese or Portuguese Creole[e]	Portuguese Portuguese Creole	Portuguese
	Russian[a,c]	Russian	Russian
	Scandinavian languages[e]	Scandinavian languages	
			Scottish
	Serbo-Croatian[d]	Serbo-Croatian	
			Turkish
	Urdu[f]	Urdu	Pushto
	Yiddish[f]	Yiddish	
			Aramaic
	Other West Germanic languages[e]		
	Other Slavic languages[d]		
	Other Indic languages[e]		
	Other Indo-European languages[e]		
Asian and Pacific Islander			Cantonese
	Chinese[a,b]	Chinese	Chinese
			Mandarin
	Japanese[d]	Japanese	Japanese
	Korean[a,c]	Korean	Korean
	Laotian[e]	Laotian	Lao
	Miao Hmong[f]	Miao Hmong	Hmong
	Mon-Khmer Cambodian[f]	Mon-Khmer Cambodian	Cambodian/Khmer
			Mien
	Tagalog[a,c]	Tagalog	Tagalog
	Thai[f]	Thai	Thai
	Vietnamese[a,c]	Vietnamese	Vietnamese
	Other Asian languages[e]		
			Hawaiian
			Ilokano
			Indonesian
			Samoan
			Tahitian
	Other Pacific Islander languages[f]		
Native American	Navajo[f]	Navajo	
	Other Native North American languages[d]	Other Native North American languages	American Indian

TABLE 4-4 Continued

Census Broad Categories	Census 39 Granular Categories for Reporting	HRET Toolkit	Anthem Blue Cross, CA
Other Languages	Other and Unspecified		Other Non-English
	African languages[d]	African languages	Nigerian
	Arabic[a,c]	Arabic	Arabic
	Hebrew	Hebrew	Hebrew
	Hungarian	Hungarian	
NA	Unspecified or do not know in “other”	Do not know	Undetermined
		Unavailable	
		Declined	Decline to state
NA		American Sign Language	Sign Language American
			Sign Language Other
		Availability of Sign Language or other auxiliary aids or services	
			Hearing loss
			Speech Loss

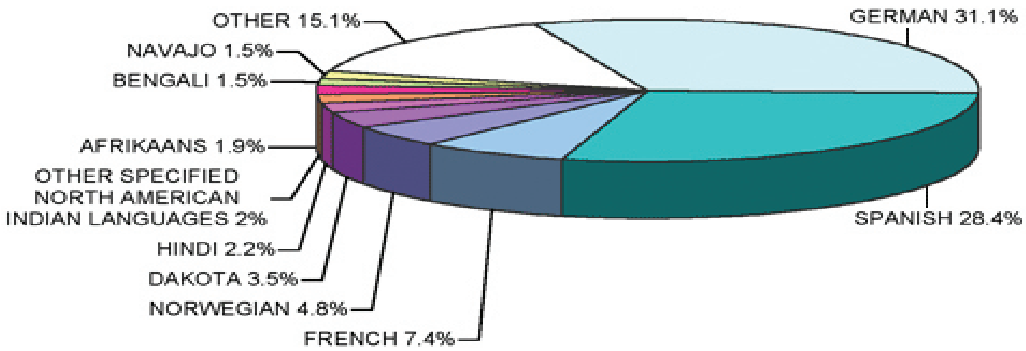
[a] Top 10 non-English languages in the United States.
[b] Top 10 of 50 individual states in addition to Spanish.
[c] Top 10 of 20 or more states in addition to Spanish.
[d] Top 10 of 10 or more states in addition to Spanish.
[e] Top 10 of 5 or more states in addition to Spanish.
[f] Top 10 of at least one state in addition to Spanish.
SOURCES: Hasnain-Wynia, 2007; Ting, 2009; U.S. Census Bureau, 2003e.

Neither the Census reporting list nor the HRET list captures all the top 10 languages in each state. For example, numerous individual languages are consolidated under such categories as “Other Native Northern American languages” or “African languages.” Approximately 2.2 million people who speak a language other than English fall into these general categories. These categories fail to capture, for example, Yupik, an Alaska Native language, that is among Alaska’s top 10 languages; Dakota, an American Indian language among the top ones encountered in North Dakota (Figure 4-3a); and Amharic, an African language, encountered in Minnesota (Figure 4-3b). In addition, it should be noted that within individually reported languages, such as Chinese, there are various languages/dialects, some of which are sufficiently different that they have been classified as separate languages by the Census Bureau (e.g., Mandarin and Cantonese).

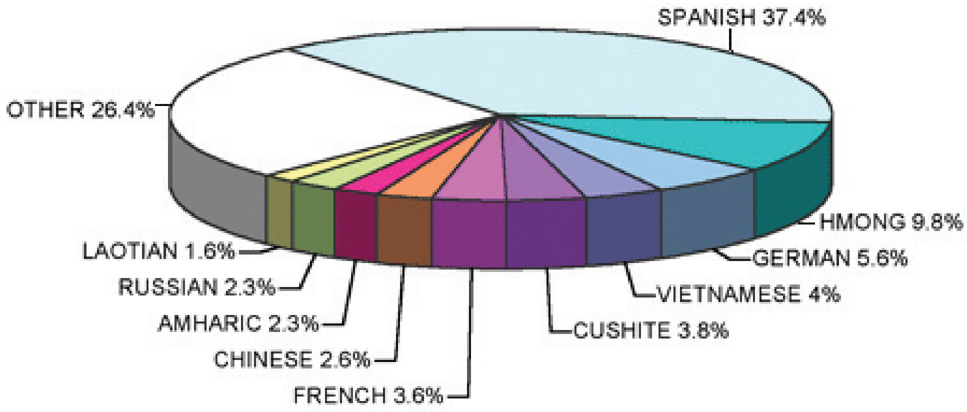
The number of languages spoken in each state is clearly diverse, in some states more so than others. As seen in Figure 4-4, which is based on Census 2000 data, the number of languages reported to be spoken at home ranges from 56 in Wyoming to 207 in California (U.S. English Foundation, 2009c). Thus, data collection instruments must take into account the diversity of the population of the service area and the feasibility of collecting data in lengthy lists of categories. This administrative issue is discussed later in this chapter in the section on collection considerations.

The subcommittee concludes that mandating data collection using a single national list of a limited number of languages might be useful for national population-level tracking and planning. For most entities, however, it would be less useful than locally relevant lists for assessment and planning to meet the diverse language needs of individuals, health care entities, and jurisdictions across the United States.

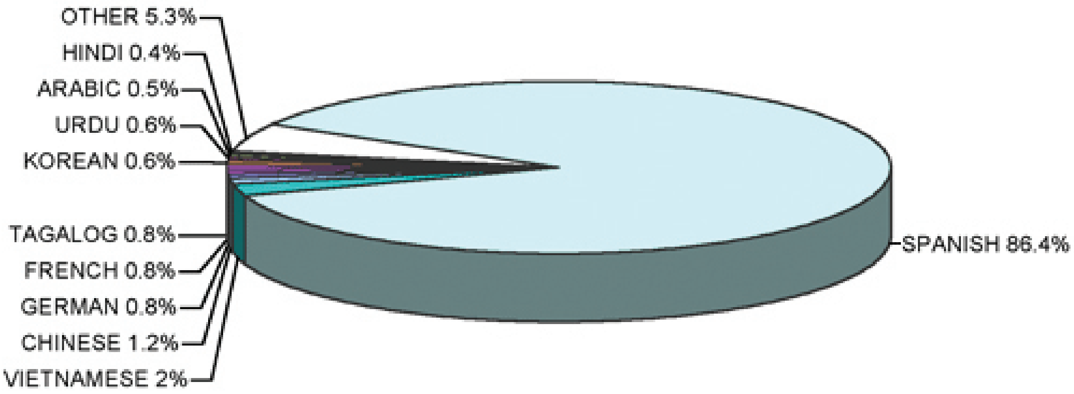
FIGURE 4-3 Most spoken languages in North Dakota, Minnesota, Texas, and Maine, 2005.
SOURCE: Reprinted, with permission, from Modern Language Association, 2009b. Copyright 2009 by Modern Language Association.



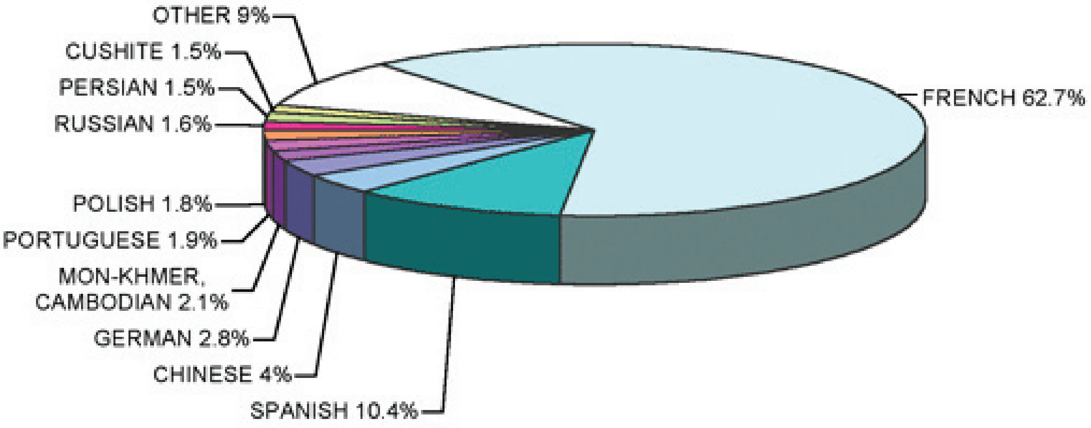
a. Most spoken languages in North Dakota in 2005
English is spoken by 93.83 percent of people over 5 years old in North Dakota.
Languages other than English are spoken by 6.16 percent.
Speakers of languages other than English are divided up as noted.



b. Most spoken languages in Minnesota in 2005
English is spoken by 90.34 percent of people over 5 years old in Minnesota.
Languages other than English are spoken by 9.65 percent.
Speakers of languages other than English are divided up as noted.



c. Most spoken languages in Texas in 2005
English is spoken by 66.35 percent of people over 5 years old in Texas.
Languages other than English are spoken by 33.64 percent.
Speakers of languages other than English are divided up as noted.



d. Most spoken languages in Maine in 2005
English is spoken by 92.87 percent of people over 5 years old in Maine.
Languages other than English are spoken by 7.12 percent.
Speakers of languages other than English are divided up as noted.

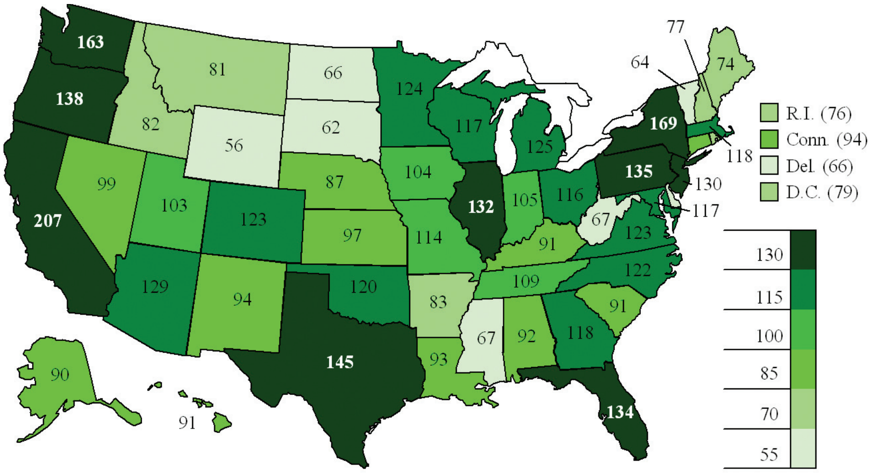


FIGURE 4-4 Number of languages spoken in each state.
SOURCE: Reprinted, with permission, from U.S. English Foundation, 2009c. Copyright 2009 by U.S. English Foundation.

Selection of a List Relevant to the Service Population

A variety of sources can be helpful for determining languages of interest in a service population. One approach is to survey the service recipients. For example, to assess which languages are most needed by their enrollees, managed care plans in California must survey their enrollees.[13] Mailed survey responses alone, however, can skew results if the responses are not representative. An entity's previous experience with language services or the most common languages in Census data on the service area can provide guidance on which languages may be most commonly spoken at home and which language groups represent the greatest proportion of people with LEP. Census tract data provide one indirect check on the proportions of different language groups; they can also reveal the languages of potential patients an entity might wish to serve but for whom lack of language outreach has presented a barrier.

The Census publishes detailed tables on English-language proficiency by language category for 39 individual languages or groupings nationally and by state (U.S. Census Bureau, 2003a). For example, more than a million people in the United States speak French at home, but 75 percent of them speak English very well, resulting in 300,000 persons in this language category who are LEP by the subcommittee's definition. Other language groups may have a smaller portion who can speak English proficiently (e.g., 34 percent of those speaking Vietnamese at home and 43 percent of Russian speakers) (U.S. Census Bureau, 2003e). Moreover, the proportion of persons who speak English very well can differ from state to state for the same language—for example, in Alabama the proportions are 43 percent for Vietnamese speakers and 56 percent for Russian speakers, while in Iowa they are 26 and 53 percent, respectively, and in Washington State 30 and 38 percent, respectively (U.S. Census Bureau, 2003f, 2003g, 2003h). These data are readily available for all geographic areas; using the Census 2000 Summary File 3 and the American Community Survey Factfinder allows one to investigate the ability to speak English by Census block group and higher geographic summary levels, including zip code, Census tract, and county.

The Modern Language Association, using data from the American Community Survey of 2005, has an easy-to-use mapping function that shows state-, county-, and zip code–level data for 30 of the most common languages in the United States based on responses to the question of what language is spoken at home (Modern Language Association, 2009b). These data can be sorted by age group, change from 2000 to 2005, and ability to speak English. Additionally, an interactive list of the languages that appeared in the Census reports can help locate states in which

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[13] *Health Care Language Assistance Act of 2003*, California S.B. 853 § 1367 (October 8, 2003).

any of the 377 languages are spoken at home and identify the level of English proficiency in those states (Modern Language Association, 2009a). The U.S. English Foundation has similarly sorted Census data on 322 languages by state, county, and selected cities (U.S. English Foundation, 2009a).

School-based data help identify emerging language populations in communities. Among LEP school-aged children, Spanish is the most common language in all states except Alaska (most common language Yup'ik), Hawaii (Ilocano), Maine (French), Montana (Blackfoot), North Dakota (Native American, unspecified), South Dakota (Lakota), and Vermont (Serbo-Croatian) (Kindler, 2002). What might be surprising is that more children needing language services in school are native rather than foreign born especially in the prekindergarten to fifth-grade age range (77 percent) as compared with the sixth- to twelfth-grade (56 percent) age range (Fix and Capps, 2005). The 2006 American Community Survey showed that there were 3 million children who spoke English less than very well (Kominski et al., 2008). The subcommittee concludes that there should be local flexibility in determining the language categories that are used for analysis, as long as the collection process captures language need for each individual so that entities can use the information for quality improvement purposes such as being able to provide language assistance services.

> **Recommendation 4-2: The choice of response categories for spoken and written language questions should be informed by analysis of relevant data on the service area (e.g., Census data) or service population, and any response list should include an option of "Other, please specify: __" for persons whose language is not listed.**

Thresholds for Collection of Spoken or Written Languages

The subcommittee considered whether there should be a percentage or numerical threshold requirement for establishing the minimum number of languages on which data should be collected by health care entities or states, given the flexibility recommended for use of locally relevant categories. Such thresholds have been set both for language assistance generally and translation of documents into specific languages. NQF has endorsed as a preferred practice to "translate all vital documents, at a minimum, into the identified threshold languages for the community that is eligible to be served," with the threshold set according to existing legislative requirements (NQF, 2009). It is outside the subcommittee's charge to make recommendations about specific interventions that may or may not follow from the collection of language data, so it is outside its charge to recommend any thresholds linked to those interventions (e.g., provide written language materials for every language present in a specific proportion of the population). Nonetheless, it is useful to review existing approaches to setting thresholds to determine whether any would serve as the basis for a recommendation on thresholds for specifying which language categories should be collected for health care quality improvement in general.

Thresholds for establishing the languages in which services and written materials must be made available often combine a percentage of 5 percent and a variable numerical cutoff point. For example, the California Health and Safety Code requires that general acute care hospitals in the state provide language assistance services 24 hours a day for language groups that make up 5 percent or more of the facility's geographic service area or actual patient population.[14] The California Department of Mental Health defines a threshold language for written materials as "a language identified on the Medi-Cal Eligibility Data System (MEDS) as the primary language of 3,000 beneficiaries or five percent of the beneficiary population, whichever is lower, in an identified geographic area."[15] Similarly, OCR's settlement of a Title VI case with the Hawaii Department of Human Services identified a threshold for translated documents of 5 percent or 1000 persons (whichever is less) who are "eligible to be served or likely to be directly affected or encountered by the department" (HHS, 2008). More recent legislative action (SB 853) in California requires the Department of Managed Health Care to ensure that health plans assess the number of persons needing language services and the languages that should be offered, and set standards for staff

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[14] California Health and Safety Code § 1259 (January 12, 2009).

[15] California Code of Regulations, Title 9 § 1810.410 (f) (3).

training, compliance monitoring, and translation of vital documents (CPEHN, 2008).[16] Specific tiered thresholds, with different combinations of plan enrollees and percentages and numerical thresholds, are established for the translation of documents:

- "For health plans with a million or more enrollees: they must translate vital documents into the top two non-English languages, plus any language whose number of speakers in the plan is either 15,000 enrollees or greater, or totals 0.75% of the enrollee population.
- For plans with 300,000 to one million enrollees: vital documents must be translated into the top non-English language plus languages whose speakers are 6,000 enrollees or 1% of the enrollee population.
- For plans with less than 300,000 enrollees: vital documents must be translated into any language whose speakers total 3,000 enrollees or 5% of the enrollee population." (CPEHN, 2008)

In the Voting Rights Act, specific population thresholds are established to determine what constitutes a language-minority group and for whom documents must be translated (U.S. Census Bureau, 2002). The thresholds are defined as more than 10,000 persons, more than 5 percent of all voting-age citizens in a district, more than 5 percent of residents of an Indian reservation, or a locale where the illiteracy rate is higher than the national rate (U.S. Department of Justice, 2008).

Examination of the effect of using a percentage threshold to identify which languages should be included as data collection categories at the state level reveals that significant subgroups would be omitted. For example, 815,386 people aged 5 and over speak Chinese at home in California (2.6 percent of the state population) but this percentage is far higher than the national figure of 0.7 percent (U.S. Census Bureau, 2003j). Application of a 5 percent threshold statewide in California would identify only Spanish, even though that state, with 39 percent of those aged 5 and over speaking a language other than English at home, is one of the most linguistically diverse states in the nation (U.S. Census Bureau, 2003j) and has a large LEP population, estimated at 6.3 million (U.S. Census Bureau, 2003i). Even a 1 percent population threshold in that state would make only Spanish, Chinese, Vietnamese, and Tagalog threshold languages for data collection. A 1 percent threshold applied to other states would for the most part yield only Spanish as a language to monitor (U.S. Census Bureau, 2003j). When applied to smaller geographic areas with more concentrated LEP populations, however, such percentages would yield additional language groups, and thresholds might be found useful for states or health plans in establishing the number of languages required for reporting and/or translation of materials.

The size of the population served should influence any numerical threshold; the service populations for all of the different entities potentially affected by a recommendation of this subcommittee are too variable for a single threshold number of 1,000 or some other value to be applied. Therefore, and because available information on thresholds is set in the context of a specific intervention (provision of language assistance services or translation of documents), the subcommittee decided not to specify a threshold (e.g., number of persons or percent of population speaking a language) for determining which spoken or written languages should be used as response options or as categories in analysis by states or other entities for the purposes of health care quality improvement. The subcommittee believes that any numerical or percentage thresholds for purposes of requiring the delivery of services or the translation of documents would best be determined by appropriate regulatory, licensing, or accrediting bodies.

Considerations for Modes of Data Collection

While the goal is to identify the specific language needs of each individual to enable effective health care communications, having lists of 400 to 500 language categories is impractical for most data collection instruments, whether in paper or electronic form, unless electronic systems have more sophisticated software to reduce staff or patient time required to search for the correct category. Accordingly, many entities will have to construct lists of perhaps 10 to 20 language categories that will be manageable within the space constraints of their paper or electronic data collection formats. These lists should always have an option to collect languages not listed by including

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[16] *Health Care Language Assistance Act of 2003*, California S.B. 853 § 1367 (October 8, 2003).

an "Other, please specify: ____" choice so that data on any language needed by an individual can be collected. Such an approach was employed in one study to identify the languages used among school-age children. A state survey of LEP students included 13 prespecified languages on the collection form, with the opportunity to list other languages; the responses ultimately yielded 460 languages (Kindler, 2002). For intake systems that do not allow for writing in an "other" response, more detailed lists will be required, as simply reporting a large "other" category with no specific language identifiers is not useful for understanding the language needs of individual patients.

An alternative to having a prespecified locally relevant list would be to include an open-response section on paper forms or computer input screens. Some find this approach desirable because a single free-response box takes up minimal space. For example, the California Healthy Family program uses an open-ended format that captures about 30 languages including American Sign Language.[17] The main drawback is that it is generally more time-consuming to enter each response manually into a database and to decipher handwriting on paper forms and spelling variations whether paper forms or computer input screens. The Census Bureau has the ability to scan optically or key in individually the free-response answers on language use (Shin and Bruno, 2003), but this is likely too costly an approach for many entities. Kaiser Permanente's computerized registration pages incorporate keystroke recognition; as a clerk types in the first couple of letters, the computer responds with a short list of alternatives out of the 131 options in the full set of language options (Appendix G) (Tang, 2009). Contra Costa Health Plan uses a system in which typing the initial letter of a language brings up one of the most commonly encountered languages (top 15 languages), such that typing an "s," for example, would bring up Spanish; if the desired response is not in the first grouping, a second keystroke on "s" will bring up Samoan and other selections (Appendix H).

In sum, as a practical matter, most individual providers, plans, or states may want to have a limited list of language categories for collection based on the languages most common among their populations with LEP, taking into account as well as the space limitations of their paper forms or the capacity of their computer systems. Any prespecified list of response categories should also include the option of "Other, please specify: _____" to capture an individual's language need when it does not appear on the list. Entities using open-format questions must make sure that responses are specific enough to be useful in planning services and in conducting analyses—for example, a response that says Asian language will not be specific enough to identify a language.

DEVELOPMENT OF A NATIONALLY STANDARDIZED LIST OF LANGUAGE CATEGORIES

Since effective patient–provider communication is central to patient-centered care and the overall quality of health care, knowing the language each individual needs to communicate effectively and to understand the care process is fundamental. The subcommittee sought to determine how many languages are in use in the United States to understand the scope of what might be encountered during a patient contact or visit. The subcommittee notes that any national list of languages ideally should have a common vocabulary of language names and unique codes for languages to facilitate data sharing. Every organization may not need to report language data to others, and thus may not need to participate in a uniform coding scheme or will be able to make a crosswalk from its own coding practices to a national standard set. Overall, however, comparability and interoperability will be enhanced by a coding system. The subcommittee has identified two major code sets for consideration: the Census Bureau and the International Organization for Standardization (ISO) 639 language code sets.

National Standard List of Spoken Language

As noted, the Census reports about 380 single languages, as well as several language groups (Scandinavian, American Indian, and African languages for general responses not captured by specific language names such as Norwegian or Navajo), with unique codes (Modern Language Association, 2009a; U.S. Census Bureau, 2007).

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[17] Personal communication, E. Sanchez, California Managed Risk Medical Insurance Board, July 20, 2009. Languages include English (46.1 percent of applicants), Spanish (45.3 percent), Asian (6.3 percent, including Cantonese, Chinese, Korean, Mandarin and Vietnamese), and other languages (2.1 percent, including Russian, Farsi, Armenia, Tagalog, Arabic, Hmong, Japanese, Cambodian, Thai, Hebrew, Lao, Portuguese, Samoan, Polish, Turkish, French, Mien, Llacano, Italian, and American Sign Language).

The subcommittee prepared a draft template of spoken languages in use in the United States, based on Census categories, and formal and informal reports from hospitals, community health centers, language assistance services, individual hospitals, and health plans. This compilation resulted in more than 650 languages or composite groupings; however, a smaller number may be needed for effective communication in a health care context (i.e., the subcommittee identified 300 from its limited survey of health care entities). The resulting list of spoken languages (Appendix I) can serve as basis for finalizing a national standard list of languages.

What defines a unique language versus a dialect? Linguistic scholars and those who speak a language do not always agree on what defines a distinctly unique language. For ISO 639, classification takes into account "linguistic similarity, intelligibility, a common literature," and whether speakers of one language can understand the other. Even with this understanding, however, there may be other "well-established distinct ethnolinguistic identities [that] can be a strong indicator that they should nevertheless be considered to be different languages." Thus, the ISO language lists and particularly their coding focus on distinct languages with distinct codes, whereas the Census Bureau is more likely to give related languages the same code. The ISO codes represent both spoken and written language names; separate script codes apply to written languages, as well, to describe their lettering (SIL International, 2009c).

The names of numerous languages have multiple possible spellings, even between the Census Bureau and ISO 639 language lists, and patients may provide an alternative spelling as well. Languages might even be called slightly different names, such as Amish, Pennsylvania Dutch, or Pennsylvania German. This need not be a barrier to the list of choices developed locally as long as it is clear on a national standard list how to categorize the alternative spellings or names.

The subcommittee did not generate a list of written languages, but illustrates these needs with the experiences of Kaiser Permanente (Appendix G) and Contra Costa Health Plan (Appendix H). ISO 15924 has four-letter script codes that can be appended to language names to distinguish how a language is written (e.g., use of Cyrillic [Cyrl], or Arabic [Arab] (Unicode ISO, 2009). Braille has the script code of Brai.

Coding of Responses

This section reviews approaches to coding the languages included on the Census and ISO/Ethnologue lists. Ethnologue studies the world's living and ancient languages (living languages now number more than 6000) and updates the language lists every four years. The Census set includes about 380 three-digit numeric codes (e.g., Spanish 625, Russian 639, Thai 720) for the languages it tracks (U.S. Census Bureau, 2007). This set actually covers a greater number of languages, about 530, since as noted, the same code is used for multiple related languages; by comparison, the languages in this larger set have their own unique codes under the ISO 639-3 classification system. The Census codes underlie the extensive data available on language spoken at home and level of English proficiency among subgroups.

The ISO codes have evolved from a first-generation two-letter coding system (ISO 639-1), to a three-letter system to accommodate additional languages primarily for bibliographic uses (ISO 639-2), to a set that now incorporates more three-letter codes to cover 6,000 languages (ISO 639-3). The ISO 639-3 codes are intended "to provide a comprehensive set of identifiers for all languages for use in a wide range of applications, including linguistics, lexicography and internationalization of information systems." (Library of Congress, 2007; SIL International, 2009b).

In some instances, the distinction among languages in the ISO coding system may be of less practical concern, but in other cases distinct coding may be necessary. For instance, the difference among German, Swiss German, and Austrian German will not matter for most analyses and quality improvement initiatives; these three languages have an identical code under the Census Bureau system (607), but are coded deu, bar, and gsw, respectively, under ISO 639-3. On the other hand, there are even cases in which very different languages have the same name but very different meanings; for example, the Census codes Mende as 793,[18] but one cannot know whether this is the Mende language of Sierra Leone (men) or of Papua New Guinea (sim) as distinguished by ISO 639-3. At the

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[18] Personal communication, H. Shin, U.S. Census Bureau, July 13, 2009.

local level, practitioners are likely to figure out the difference, but if it is desirable to aggregate such detail across multiple sites for various analytic purposes or to plan interventions, the more discrete codes may be better. Sorting the Chinese languages is particularly challenging for the lay person.

Health Level 7 (HL7), a standards-setting organization for electronic health records, worked with Centers for Disease Control and Prevention (CDC) to develop the unique codes for use in the CDC/HL7 Race and Ethnicity Code Set 1.0 for ethnicities (CDC, 2000). HL7 has not yet adopted any codes for languages. In its incidental collection of information on languages, the subcommittee encountered more instances of use of the ISO coding scheme. For example, the Illinois Department of Human Services and Contra Costa Health Plan use the ISO 639-1 two-letter alphabet code. Others are using the three-letter coding for tracking language needs and determining resources required to address them (e.g., the courts of New Jersey to identify persons who need interpreters and to plan for service enhancement; Anthem Blue Cross survey of language needs).[19]

In conclusion, the subcommittee believes that there are advantages to both the Census Bureau and ISO coding schemes for languages. In the next chapter, the subcommittee indicates the need for HHS to consult with the Census Bureau, the registration authorities for the ISO codes, and others that establish unique coding for interoperability, such as HL7; the subcommittee itself does not endorse one coding scheme over another.

If the Census coding approach were to be adopted, the subcommittee notes that the Census list of languages and codes would likely need some additional changes to be useful. Because of how the language question is asked on the Census (Does this person speak a language other than English? [Figure 4-1]), yes (language other than English) and no (English only) are responses coded just 1 and 2, respectively; there is no unique three-digit code for English. Sign language, an important communication tool, is not a language response on the Census. By contrast, ISO-639 has unique codes for 130 types of sign languages (SIL International, 2009a), such as aed for Argentine Sign Language and ase for American Sign Language. As the Census Bureau does not have a specific code for sign language, it would code a response of American Sign Language as English for its purposes[20]—an approach that is less helpful in responding to a person's language needs in the health care environment. A separate category for noting which persons have speech loss has been useful for some entities to understand the communication needs of all patients. Further options for "declined," "unavailable," or "unknown" are also useful when data are being recorded to determine the portion of the service population from whom language data have been collected; the Census Bureau does not generally code for these options.

> **Recommendation 4-3: When any health care entity collects language data, the languages used as response options or categories for analysis should be selected from a national standard set of languages in use in the United States. The national standard set should include sign language(s) for spoken language and Braille for written language.**

SUMMARY

The subcommittee has reviewed the frequency of health provider interactions with people needing language assistance and the impact of limited English proficiency on access to care, health outcomes, and patient safety. An estimated 21.3 to 23.0 million people in the United States would meet the subcommittee's definition of LEP for health care purposes—self-assessment as speaking English less than very well. The subcommittee has established a hierarchy of questions to ask about the language variable, with the highest emphasis on establishing language need based on two questions—a person's rating of their English language proficiency and the preferred language needed for health care interactions.

The subcommittee's task extended to exploring what a national standard list of language categories might look like. A number of approaches to designating languages for collection were considered, including whether there should be uniform collection nationwide of a limited number of categories or locally relevant lists chosen

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[19] During July 1, 2004, through June 30, 2005, interpretation was provided in Superior Court for 77 languages across 83,548 events, with 16 major languages accounting for most events (New Jersey Courts, 2009).

[20] Personal communication, H. Shin, U.S. Census Bureau, July 13, 2009.

by the individual data collection entity from a larger national list. A limited national list, whether of 10 languages or 40, would not be useful for every health care provider, state, or health plan. The subcommittee therefore favors the approach of allowing selection of locally relevant language categories from a national standard list, with a common category and coding framework. Local lists should provide an "Other, please specify: __" option in case an individual does not find a needed language on a collection instrument with check-off boxes or even if that language is not yet on the national standard list of names. Such a language list might need to be updated from time to time to accommodate new immigrant groups, and health care providers might encounter new names before a formal Census or ISO review takes place. The subcommittee provides a draft template of spoken language names and of Census and ISO identifiers as a list that might be encountered in health care settings (Appendix I). In Chapter 6, the subcommittee discusses a process for adoption of the language list and an associated code set for data aggregation and exchange.

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5

Improving Data Collection Across the Health Care System

While a range of health and health care entities collect data, the data do not flow among these entities in a cohesive or standardized way. Entities within the health care system face challenges when collecting race, ethnicity, and language data from patients, enrollees, members, and respondents. Explicitly expressing the rationale for the data collection and training staff, organizational leadership, and the public to appreciate the need to use valid collection mechanisms may improve the situation. Nevertheless, some entities face health information technology (HIT) constraints and internal resistance. Indirect estimation techniques, when used with an understanding of the probabilistic nature of the data, can supplement direct data collection efforts.

Addressing health and health care disparities requires the full involvement of organizations that have an existing infrastructure for quality measurement and improvement. Although hospitals, community health centers (CHCs), physician practices, health plans, and local, state, and federal agencies can all play key roles by incorporating race, ethnicity, and language data into existing data collection and quality reporting efforts, each faces opportunities and challenges in attempting to achieve this objective.

To identify the next steps toward improving data collection, it is helpful to understand these opportunities and challenges in the context of current practices. In some instances, the opportunities and challenges are unique to each type of organization; in others, they are common to all organizations and include:

- How to ask patients and enrollees questions about race, ethnicity, and language and communication needs;
- How to train staff to elicit this information in a respectful and efficient manner;
- How to address the discomfort of registration/admission staff (hospitals and clinics) or call center staff (health plans) about requesting this information;
- How to address potential patient or enrollee pushback respectfully; and
- How to address system-level issues, such as changes in patient registration screens and data flow.

Previous chapters have provided a framework for eliciting, categorizing, and coding data on race, ethnicity, and language need. This chapter considers strategies that can be applied by various entities to improve the collection of these data and facilitate subsequent reporting of stratified quality measures. It begins by examining current practices and issues related to collecting and sharing data across the health care system. Next is a discussion of steps that can be taken to address these issues and improve data collection processes. This is followed by a review of methods that can be used to derive race and ethnicity data through indirect estimation when obtaining data directly from many patients or enrollees is not possible.

COLLECTING AND SHARING DATA ACROSS THE HEALTH CARE SYSTEM

Health care involves a diverse set of public and private data collection systems, including health surveys, administrative enrollment and billing records, and medical records, used by various entities, including hospitals, CHCs, physicians, and health plans. Data on race, ethnicity, and language are collected, to some extent, by all these entities, suggesting the potential of each to contribute information on patients or enrollees. The flow of data illustrated in Figure 5-1 does not even fully reflect the complexity of the relationships involved or the disparate data requests within the health care system. Currently, fragmentation of data flow occurs because of silos of data collection (NRC, 2009).

No one of the entities in Figure 5-1 has the capability by itself to gather data on race, ethnicity, and language for the entire population of patients, nor does any single entity currently collect all health data on individual patients. One way to increase the usefulness of data is to integrate them with data from other sources (NRC, 2009). Thus there is a need for better integration and sharing of race, ethnicity, and language data within and across health care entities and even (in the absence of suitable information technology [IT] processes) within a single entity.

It should be noted that a substantial fraction of the U.S. population does not have a regular relationship with a provider who integrates their care (i.e., a medical home) (Beal et al., 2007). For some, a usual source of care is the emergency department (ED), a situation that complicates the capture and use of race, ethnicity, and language data and their integration with quality measurement. While health plans insure a large portion of the U.S. population, their direct contact tends to be minimal, even during enrollment. Hospitals, which tend to have more developed data collection systems, serve only a small fraction of the country’s population. As a result, no one setting within the health care system can capture data on race, ethnicity, and language for every individual.

Health information technology (HIT) may have the potential to improve the collection and exchange of self-reported race, ethnicity, and language data, as these data could be included, for example, in an individual’s personal health record (PHR) and then utilized in electronic health record (EHR) and other data systems.[1] There is little reliable evidence, though, on the adoption rates of EHRs (Jha et al., 2009). While substantial resources were devoted to this technology in the American Recovery and Reinvestment Act of 2009,[2] it will take time to develop the infrastructure necessary to fully implement and support HIT (Blumenthal, 2009). Thus, the consideration of other avenues of data collection and exchange is essential to the subcommittee’s task.

Until data are better integrated across entities, some redundancy will remain in the collection of race, ethnicity, and language data from patients and enrollees, and equivalently stratified data will remain unavailable for comparison purposes unless entities adopt a nationally standardized approach. Methods should be considered for incorporating these data into currently operational data flows, with careful attention to concerns regarding efficiency and patient privacy.

Hospitals

Because hospitals tend to have information systems for data collection and reporting, staff who are used to collecting registration and admissions data, and an organizational culture that is familiar with the tools of quality improvement, they are relatively well positioned to collect patients’ demographic data. In addition, hospitals have a history of collecting race data. With the passage of the Civil Rights Act of 1964[3] and Medicare legislation in 1965,[4]

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[1] A PHR is a medical or health record owned and maintained by a patient him- or herself. EHRs are further defined in Chapter 6.

[2] *American Recovery and Reinvestment Act of 2009,* Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).

[3] *The Civil Rights Act of 1964*, Public Law 88-352, 78 Stat. 241, 88th Cong., 2d sess. (July 2, 1964).

[4] *The Social Security Act of 1965*, 89th Cong., 42 U.S.C. § 7, 1st sess. (July 30, 1965).

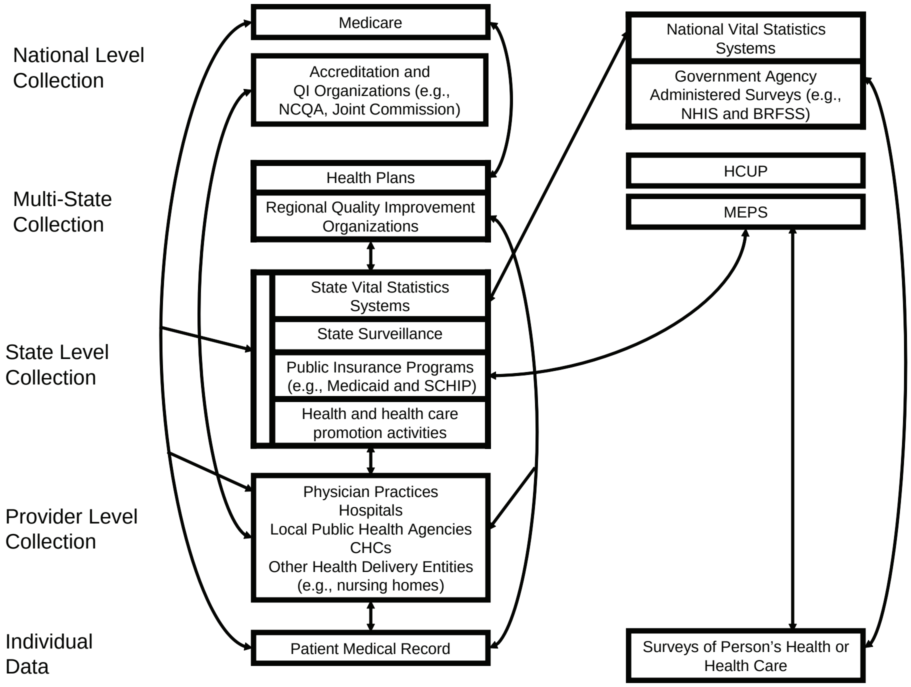

FIGURE 5-1 A snapshot of data flow in a complex health care system.

there was a legislative mandate for equal access to and desegregation of hospitals (Reynolds, 1997). Therefore it is not surprising that more than 89 percent of hospitals report collecting race and ethnicity data, and 79 percent report collecting data on primary language (AHA, 2008).

This culture of data collection has limitations, however. Historically, the data were never intended for quality improvement purposes, but to allow analysis to ensure compliance with civil rights provisions. Additionally, hospital data collection practices are less than systematic as the categories collected vary by hospital, and hospitals obtain the information in various ways (e.g., self-report and observer report) (Regenstein and Sickler, 2006; Romano et al., 2003; Siegel et al., 2007). Furthermore, compared with the number of people who are insured or visit an ambulatory care provider, a relatively small number of people are hospitalized in any one year (see Figure 5-2). Thus, while hospitals are an important component of the health care system and represent a major percentage of health care expenditures, they are only one element of the system for collecting and reporting race, ethnicity, and language data.

Hospitals also face challenges associated with collecting accurate data and using these data for quality improvement and reduction of disparities. A 2006 National Public Health and Hospitals Institute (NPHHI) survey asked hospitals that collected race and ethnicity data whether they used the data to assess and compare quality of care, utilization of health services, health outcomes, or patient satisfaction across their different patient populations. Fewer than one in five hospitals that collected these data used them for any of these purposes (Regenstein and Sickler, 2006). Additionally, only half of hospitals that collected data on primary language maintained a database of patients' primary languages that they could track over time (Hasnain-Wynia et al., 2006).

Many of the above challenges can be attributed largely to the many staff and departments or units that need to be engaged in the process to ensure systematic data collection and use. Hospitals have multiple pathways (inpatient, outpatient, ED, urgent care) through which patients enter the system. For example, the ED is the source of 45 percent of all hospital admissions (Healthcare Financial Management Association, 2007).

Systems changes can involve training a large number (possibly hundreds) of hospital registration/admission staff (many of whom may be off site) and modifying practice management and EHR systems to ensure that proper

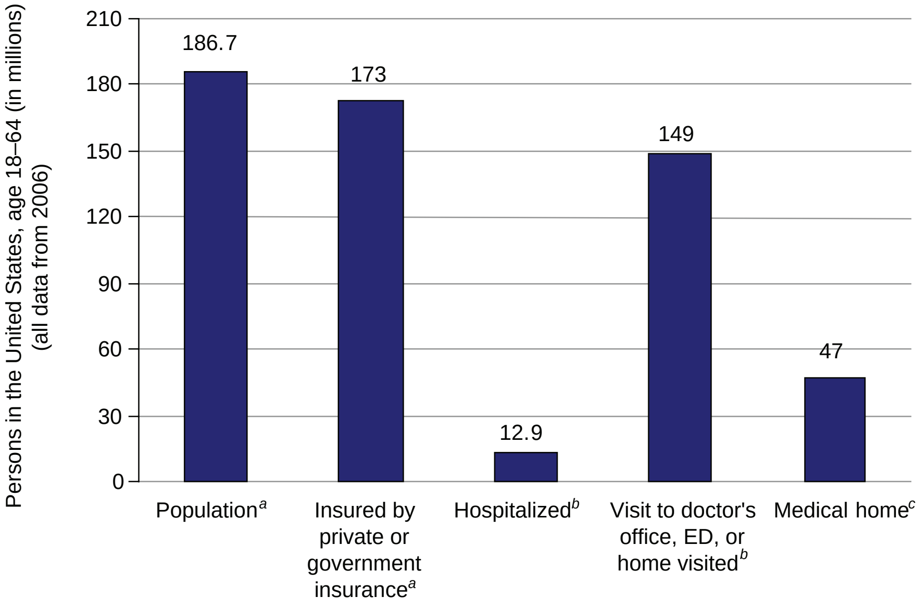

FIGURE 5-2 Opportunities to collect data within the health care system.
[a] U.S. Census Bureau, 2000.
[b] NCHS, 2009.
[c] Beal, 2004.

and consistent data fields are in place across multiple departments and units that serve as patient entry points. Ideally, these systems would be made interoperable through the development of interfaces that would make it possible to relay the data across different systems.

A Robert Wood Johnson Foundation initiative to reduce disparities in cardiac care required participating hospitals to systematically collect race, ethnicity, and language data and use the data to stratify quality measures. The ten hospitals in the collaborative initially cited the data collection requirement as one of the greatest challenges of the program, yet once they focused their efforts on these goals, they were able to bring together key stakeholders within each institution, implement needed IT changes, and train staff. As a result, they successfully began data collection within a relatively short time (Siegel et al., 2008). Other hospitals not part of this initiative are also successfully collecting race, ethnicity, and language data and linking them to quality measures (Weinick et al., 2008). Data collected at the hospital level are useful both for assessing the quality of hospital-provided services and, if shared with other entities, for facilitating analyses of quality across multiple settings. Box 5-1 provides an example of a statewide initiative to collect standardized race, ethnicity, and language data.

Community Health Centers

CHCs are front-line providers of care for underserved and disadvantaged groups (Taylor, 2004) and therefore are good settings for implementing quality improvement strategies aimed at reducing racial and ethnic disparities in care. Yet while CHCs serve diverse patient populations and, as organizations, understand the importance of demographic data for improving the quality of care, the accuracy of the race, ethnicity, and language data they collect may be limited (Maizlish and Herrera, 2006). More than 87 percent of surveyed CHCs reported inquiring about a patient's need for language services, and 73 percent reported recording this information in the patient record (Gallegos et al., 2008); less is known, however, about the extent to which CHCs consistently collect patient

BOX 5-1
Statewide Race and Ethnicity Data Collection: Massachusetts

In January 2007, all Massachusetts hospitals were required to begin collecting race and ethnicity data from every patient with an inpatient stay, an observation unit stay, or an emergency department visit. These data are included in the electronic discharge data each hospital submits to the state's Division of Health Care Finance and Policy. As part of this effort, a standardized set of reporting categories was created and train-the-trainer sessions were held across the state. A report on this initiative notes:

"The new efforts in Massachusetts are unique in the constellation of requirements and approaches being implemented in the state today. First, all acute care hospitals are required to collect these data, and a recommended data collection tool has been developed jointly by the city [Boston] and Commonwealth to standardize efforts across hospitals. Second, the tool and the required categories in which hospitals must provide patient-level discharge data to the [state] include an exceptionally detailed list of ethnicities, with 31 reporting categories that include 144 ethnicities or countries of origin. Third, the collaboration between the City of Boston, the Commonwealth of Massachusetts, and hospitals has been crucial to turning policy attention to reducing disparities in the quality of health care." Acute care hospitals are required to report the basic OMB race categories along with 31 ethnicity categories: Asian Indian, Cambodian, Chinese, Filipino, Japanese, Korean, Laotian, Vietnamese, African American, African, Dominican, Haitian, European, Portuguese, Eastern European, Russian, Middle Eastern (or North African), Caribbean Island, American, Brazilian, Cape Verdean, Central American (not otherwise specified), Colombian, Cuban, Guatemalan, Honduran, Mexican (Mexican, Mexican American, Chicano), Puerto Rican, Salvadoran, South American (not otherwise specified), and Other Ethnicity.

SOURCES: Massachusetts Executive Office of Health and Human Services, 2009; Weinick et al., 2007, 2008.

race and ethnicity data beyond the basic OMB categories included in their national Uniform Data System (HRSA, 2009).[5]

Like hospitals, CHCs face challenges to collecting data, such as the need to train staff, the need to modify existing HIT systems, and the need to ensure interoperability between the practice management systems where demographic data are collected and recorded and the EHR systems where the demographic data can be linked to clinical data for quality improvement purposes. In 2006, only 26 percent of surveyed CHCs reported some EHR functionality, yet 60 percent reported plans for installing a new EHR system or replacing the current system (Shields et al., 2007). Collection of demographic data can also increase the burden of data entry for staff, particularly for those CHCs that still use paper forms to collect these data from patients (Chin et al., 2008).

Limited resources (both financial and human) and a high-need patient population present ongoing challenges to CHCs in their data collection and quality improvement efforts (see Box 5-2). Because 40 percent of CHCs' patient populations are uninsured and because CHCs generally have a poor payer mix (Manatt Health Solutions and RSM McGladrey, 2007; National Association of Community Health Centers, 2006), they gain relatively less revenue than private physician practices from quality improvement interventions that lead to the delivery of more services (Chin et al., 2008). Even with increases in federal funding, CHCs struggle to meet the rising demand for care along with demands to increase quality reporting, reduce disparities, and develop EHR systems (Hurley et al., 2007).

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[5] More than 3 million of the 16 million users were recorded in 2007 under "Unreported/Refused to report." With these two categories being combined, it is impossible to tell if there was actually no data collection or if a large portion of people refused to respond.

BOX 5-2
Collecting and Using Data: The Alliance of Chicago Community Health Services

The Alliance of Chicago Community Health Services developed a customized EHR system to provide decision support for clinicians and link clinical performance measures with key patient characteristics to identify disparities in performance and inform quality improvement efforts. The alliance of four CHCs across 32 clinical sites implemented the centralized EHR system in 2005–2006. The system is hosted in a secure facility, allowing its data to be accessed by providers via the Internet. The aggregate data means CHCs can look at trends across populations and compare outcomes by different communities, different CHCs, or different demographic groups. The system integrates patient race and ethnicity data, which is collected and stored in the practice management system, with clinical data stored in the EHR system.

The processes of development and implementation required reconsiderations of workflow design, customization, and decision support. For example, implementation required analyzing and redesigning hundreds of clinical workflow patterns in busy CHCs and developing the right strategies for training staff. Additionally, some CHCs were collecting race and ethnicity data using paper forms and then transferring the data first into practice management systems and then into EHR systems for linkage with quality data. Lack of standardization for quality measures and data specifications made some of the tasks even more difficult. The standard ultimately decided upon for collection was the OMB standard categories. Now that the systems are in place, it is possible for clinics to move forward with collecting more granular data. The Alliance is now serving as a model for CHC systems in New York, California, and Detroit.

SOURCES: De Milto, 2009; Kmetik, 2009; Rachman, 2007.

Physician and Group Practices

The structure and capabilities of primary and specialty care entities vary tremendously, ranging from large groups or health centers with highly structured staff and advanced information systems to solo physician practices with correspondingly small staff. The ability and motivation of these entities to collect and effectively use race, ethnicity, and language data consequently also vary given the investments in HIT systems and staff training required for these functions. At the same time, these settings have direct contact with patients, ideally as part of an ongoing caregiving relationship. Thus, they are well suited to explaining the reasons for collecting these data, as well as using the data to assess health care needs and patterns of disparities. Physician practices, however, are less likely than hospitals or CHCs to collect race, ethnicity, and language data from patients (Nerenz et al., 2004).

Medical groups may believe either that it is unnecessary to collect these data or that collecting them would offend patients (Nerenz and Darling, 2004). Physician practices may not see the utility of the data and may believe that they should not bear the burden of collecting the data and linking them to quality measures (Mutha et al., 2008). A number of physicians and practice managers interviewed in 2007 thought it was illegal to collect these data, and many did not understand how the data would be used (Hasnain-Wynia, 2007). However, most of the interviewees (physicians, nurse managers, and practice managers) indicated that they thought it would not be problematic to collect these data from their patients if they could explain why the data were being collected and how they would be used (see Box 5-3). Indeed, Henry Ford Medical Group has collected race and ethnicity data for more than twenty years, and the Palo Alto Medical Foundation, a multispecialty provider group with several clinics, has recently begun to collect race and ethnicity data for use in analyses of disparities (Palaniappan et al., 2009).

Primary care sites typically do not have structured information available about care provided at other locations, so their ability to analyze data on quality of care by race, ethnicity, and language is generally limited to measures involving routine prevention and primary care. Physician practices with EHR systems tend to use the system for administrative rather than quality improvement purposes (Shields et al., 2007), but EHR systems can

BOX 5-3
Collecting Data in Small Physician Practices

The National Committee for Quality Assurance (NCQA) launched a quality improvement demonstration program for small physician practices serving minority populations. With funding from The California Endowment, NCQA provided grants and technical assistance to small practices (five physicians or fewer). The goal of the project was to learn what types of resources and tools these practices need in order to conduct and sustain quality improvement activities, especially in serving disadvantaged populations. After the project, participants reported a greater appreciation for the importance of collecting race and ethnicity data, although few practices began to do so systematically. Before the project, needs assessment surveys showed that only 15 percent of physicians had a "written standard identifying and prominently displaying in the medical record the language preferred by the patient." While few of the practices began formal data collection, staff at most practices expressed an understanding of the value of this information. The project also improved the participants' understanding of the legal issues related to collecting data from patients on race, ethnicity, and language need. For example, one physician reported, "You guys have taught me that it is not illegal to identify race. That's such a batted about issue, but it is not against HIPAA regulations to identify race and culture and language in the medical chart." However, practical barriers to data collection remained. One challenge faced by practices was the lack of standardized fields in EHR systems. Practices that sought to collect data usually created their own method for documenting race and ethnicity.

SOURCE: NCQA, 2009.

be tailored to link quality measures and demographic data (Kmetik, 2009). Data on race, ethnicity, and language need collected in these settings could be useful throughout the health care system if mechanisms were in place for sharing the data with other entities (e.g., health plans) that have an ongoing obligation and infrastructure for analysis of data on quality of care which can be stratified by race, ethnicity, and language need and can look at episodes of care and care coordination.

Multispecialty group practices, which provide a range of primary care, specialty care, inpatient care, and other services, may be in a strong position to collect race, ethnicity, and language data because they have regular contact with large numbers of patients over long periods of time, can place the data collection in the context of improvement of care rather than administration of health insurance benefits, and typically have the necessary staff and other forms of infrastructure (e.g., a shared EHR system at all care sites). A single EHR system may facilitate the sharing of race, ethnicity, and language data across sites and levels of care, assuming that the data are present and available in the system.

Health Plans

Health plans, including Medicaid managed care and Medicare Advantage plans, have the capabilities necessary to systematically compile and manage race, ethnicity, and language data, and thus have roles to play in quality improvement (Rosenthal et al., 2009). Plans, though, may have limited opportunities for direct contact during which the data can be collected and the need for the data explained. While there are multiple points at which the data can be collected (e.g., disease management programs, member surveys, enrollment), a principal occasion for contact is during enrollment, when fears about discriminatory use of the data may be greatest. California, Maryland, New Hampshire, New Jersey, New York, and Pennsylvania prohibit insurers from requesting an applicant's race, ethnicity, religion, ancestry, or national origin in applications, but the states do allow insurers to request such

BOX 5-4
Successful Collection of Data by a Health Plan: Aetna

Aetna was the first national, commercial plan to start collecting race and ethnicity data for all of its members. In 2002, Aetna began directly collecting these data using electronic and paper enrollment forms. Multiple mechanisms are now used to capture race, ethnicity, and language data. The data may be updated at any point of contact, including at enrollment, when members speak to customer service or patient management representatives, and when members access an online member portal. Since 2002, more than 60 million Aetna members have provided race, ethnicity, and/or primary language information. As of 2009, Aetna had collected this information from more than 6 million members, representing approximately 30–35 percent cumulative coverage of race, ethnicity, and language data for its currently enrolled population. Aetna's success with direct collection has shown that no negative public reaction occurs when plans collect this information.

SOURCES: NCQA, 2006; Personal communication, W. Rawlins, Aetna, May 3, 2009.

information from individuals once enrolled (AHIP, 2009). There are no legal impediments to collecting these data after enrollment.

As many individuals enroll in plans through their place of employment, employers provide one avenue for the collection of race, ethnicity, and language need data. It is possible in principle for individuals to self-identify during open enrollment in a health plan, with the individual's employer conveying the enrollee's race and ethnicity data to the plan through an electronic enrollment transaction. The plan could then use these data for quality improvement interventions and measurement. In fact, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) 834 enrollment standard[6,7] provides for the transmittal of race and ethnicity data. However, the HIPAA Transactions Rule applies only to health plans, health care clearinghouses, and certain health care providers. Thus, while race and Hispanic ethnicity may be captured in the enrollment transaction and plans are required to accept the standard transaction if it is sent to them, employers rarely use the standard and are not required to do so. As a result, this avenue of data collection is not currently operational, although pending legislation encouraging the use of electronic enrollment transaction standards may make it more common in the future.[8]

A study conducted by America's Health Insurance Plans (AHIP) found that 54 percent of plans collected race and ethnicity data, and 56 percent collected primary language data. The National Health Plan Collaborative (NHPC), a public–private partnership to improve quality of care and reduce disparities,[9] focused on collecting demographic data on enrollees. NPHC viewed direct data collection as the gold standard since this method supports interventions and direct outreach to individuals, but NHPC members realized that obtaining data through direct methods can take years to achieve in a health plan setting (Lurie, 2009). Likewise, the limited success of Aetna with data collection (see Box 5-4) after several years of concerted effort suggests that the upper limit of data collection by health plans with presently known direct methods may be far below the level necessary for

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[6] *Health Insurance Portability and Accountability Act of 1996,* Public Law 104-191, 104th Cong., 2d sess. (August 21, 1996).

[7] Version 4010 of the X12 standards defines the 834 enrollment transaction. Version 5010 was adopted in January 2009 and must be implemented by January 1, 2012. Under this version, the transaction will still need to come from a plan sponsor or employer, and as sponsors and employers are not covered entities under HIPAA, they are not required to use the enrollment standard (Personal communication, L. Doo, Office of E-Health Standards and Services, Centers for Medicare & Medicaid Services, July 14, 2009).

[8] As of July 2, 2009, the "Affordable Health Choices Act" included provisions that the Secretary of HHS shall streamline and simplify standards for electronic enrollment, including capability for individual enrollees to manage their enrollment online.

[9] NHPC was established in 2004 and included 11 national plans with more than 87 million members. As of 2009, its activities are coordinated by America's Health Insurance Plans (AHIP).

identifying disparities in quality of care through stratified analysis, for example, of Healthcare Effectiveness Data and Information Set (HEDIS) data.

While the use of racial, ethnic, and language identifiers for coverage, benefit determination, and underwriting is prohibited, the collection of these data for improving quality and reducing health care disparities is both permitted and encouraged. Low participation by plan members in reporting race, ethnicity, and language data may be indicative of low trust of the industry (Coltin, 2009). Despite informing members of how data will be used, plans may also face internal legal concerns about taking on unnecessary liability through threats of legal action due to misperceptions regarding the purposes of collection.

Surveys

Federal and state health agencies administer surveys that are primary sources for estimating the health of a population and current and future needs for health care services (Ezzati-Rice and Curtin, 2001; Mays et al., 2004). For example, a number of studies reviewed in Chapter 2 employed surveys such as the National Health Interview Survey (NHIS), the National Latino and Asian American Survey (NLAAS), and the California Health Interview Survey (CHIS). Surveys can capture data not included in administrative and utilization data—notably data on the uninsured and reports on financial and nonfinancial barriers to seeking care. Other surveys, such as the Consumer Assessment of Healthcare Providers and Systems (CAHPS), are designed to assess plans, hospitals, and medical groups and capture respondents' self-reported race and ethnicity. These surveys are resources for quality measurement and improvement. While some can be linked to specific health care delivery sites, most are not, so they tend to be a data collection system that is parallel to, rather than integrated with, care delivery.

A fundamental feature of surveys, whether self-administered by mail or interviewer-administered in person or by phone, is that a respondent's race, ethnicity, and language need are self-identified and not ascribed by the interviewer. However, cues from the interviewer, a respondent's suspicion of lack of confidentiality, or the social and political context can influence a respondent's answer (Craemer, 2009; Foley et al., 2005). Moreover, conducting surveys of representative population-based samples in diverse settings requires an assessment of the need for in-language interviews (Ponce et al., 2006), balanced by the costs associated with high-quality translations and trained bilingual interviewers. For surveys conducted in multiple languages (e.g., the CHIS is conducted in English, Spanish, Cantonese, Mandarin, Vietnamese, and Korean), the language of the interview conveys, to some extent, the respondent's language preference in communicating health information.

Surveys are charged with obtaining stable estimates for population groups defined not only by race, ethnicity, and language, but also by geography and other demographic characteristics. Cost, logistical issues, and protection of respondents' confidentiality constrain the granularity of reportable race and ethnicity estimates (Madans, 2009). To ensure usable data on population groups, the NHIS oversamples Blacks, Asians, and Hispanics (Madans, 2009), but lower coverage is provided for smaller groups, such as Native Hawaiian or Other Pacific Islanders (NHOPI), in the NHIS (e.g., there were fewer than 10 Samoan respondents in NHIS 2007).

Oversampling is a viable strategy to increase coverage of smaller populations. Yet oversampling incurs costs associated with the rarity of the population and the expense of the survey modality (e.g., the marginal cost of adding one more Samoan respondent would be greater for in-person household interviews than for telephone interviews). Other issues relate to the clustering of a population in a designated area (if area-based oversampling is used) and the specificity and sensitivity of surname lists (if list-assisted oversampling is used). Information on granular ethnicities may also be gleaned from surveys with an explicit focus on specific ethnic groups (e.g., NLAAS) and on subregions (e.g., CHIS).

Another strategy for estimating the health and health care needs of ethnic groups is to combine years of survey data (Barnes et al., 2008; Freeman and Lethbridge-Cejku, 2006; Kagawa-Singer and Pourat, 2000). Some of the findings on variations within and among population groups reported in Chapter 2 were generated from pooled analyses of the NHIS sample to increase the size of the samples. Pooling, however, may not work for the smallest population groups; for example, it would take at least 8 years of NHIS data to obtain the sample size needed for reportable estimates on the NHOPI population. Over such a long time span, significant changes can compromise the validity and relevance of such estimates for health care policy and planning purposes. Where pooling is useful, standardized measures of demographic variables would improve the quality of the pooled data. Given the limitations of survey sampling, administrative databases offer the potential to collect data on higher numbers of smaller ethnic groups and make statistically reliable analytic comparisons across groups (e.g., a hospital administrative database versus a sample of hospital patients).

IMPROVING DATA COLLECTION PROCESSES

The above discussion of challenges faced by various health and health care entities highlights how important it is for data capture and quality to overcome HIT constraints and minimize respondent and organizational resistance. Integration of data systems has the potential to streamline collection processes so that data can be reported easily, and an individual will not need to self-identify race, ethnicity, and language need during every health encounter. Until such integration is achieved, enhancing legacy HIT systems, implementing staff training, and educating patients and communities about the reasons for and importance of collecting these data can help improve data collection processes.

The collection of race, ethnicity, and language need data by various entities within the health care system raises the possibility that conflicting data may, in some instances, be assigned to a single individual. An individual may self-identify in one clinical setting according to a limited set of choices, whereas another setting may offer more detailed, specific response options, or the individual's race may have been observed rather than requested and then recorded by an intake worker. There is value in developing a hierarchy of accuracy by which conflicting data can be adjudicated. As previously discussed in this report, OMB prefers self-reported data, and researchers view self-report as the "gold standard" (Higgins and Taylor, 2009; OMB, 1997; Wei et al., 2006). Other methods of collecting these data (e.g., observer report) have been found to be inaccurate compared with self-reported data, resulting in undercounts of certain population groups (Buescher et al., 2005; Hahn et al., 1996; West et al., 2005; Williams, 1998). Thus, in this hierarchy of accuracy, self-report can be understood as being of superior validity. The subcommittee is aware of few systems in which race and ethnicity data are collected in more than one way and compared against self-report for validation. Therefore, the subcommittee cannot make generalizations about which sources or systems are likely to be of superior validity, other than commenting that self-report is preferred over observer-report.

The Health Level 7 (HL7) standards allow for data to be attributed as observer report or self-report, which may facilitate the resolution of conflicting data. There is no solid evidence in favor of the quality of data from any one locus of data collection (e.g., a health plan or hospital), except to the extent that location is correlated with data collection methods. If a provider, for example, collects these data through self-report and hospital records involve observer assignment, then favoring the self-reported data from the provider setting would make sense if the data were linked and conflicting data were found.

Not all data systems capture the method through which the data were collected, and some systems do not allow for data overrides. The interoperability of data systems may, for example, prohibit a provider from updating data on a patient that were provided by the patient's health plan. Thus, while self-reported data should trump indirectly estimated data or data from an unknown source, ways of facilitating this process logistically warrant further investigation. Data overriding should be used with caution, as overriding high-quality data with poor-quality data reduce the value for analytic processes.

Enhancing Legacy HIT Systems

The varied and limited capacities of legacy HIT systems challenge the collection, storage, and sharing of race, ethnicity, and language data. A single hospital, for example, may use different patient registration systems, which may not have the capacity to communicate with one another. Often, these systems operate unidirectionally, meaning that a system may be able to send or receive information but be unable to do both. Thus, a central system may be able to send data on a patient's race, ethnicity, and language to affiliated outpatient settings, but data collected in outpatient settings may not flow back to the central system (Hasnain-Wynia et al., 2004). Additionally, some quality data are derived from billing or other sources, requiring further linkages.

In ambulatory care settings (both CHCs and physician practices), race, ethnicity, and language need data are usually collected during the patient registration process and stored in practice management systems. However, clinical performance data may be captured in an another system, meaning that race, ethnicity, and language data in the practice management system need to be imported into the EHR system to produce quality measures stratified by these variables. Practice management systems and EHR systems therefore need to be interoperable.

As technology vendors have adopted standardized communication protocols such as HL7, interoperability has improved for exchange of data such as race and ethnicity (HL7, 2009). Such standards are not universally accepted, however, so some HIT components can communicate without modification, while others require upgrading to ensure that race, ethnicity, and language data can be collected, stored, and shared. While transitioning from legacy HIT systems to newer systems is challenging, especially in physician practices (Zandieh et al., 2008), the American Recovery and Reinvestment Act of 2009[10] provides stimuli for moving forward with national standard HIT systems.

Most hospitals have the capacity to make changes in their HIT systems, patient registration screens, and fields in house, but some hospitals must go through a corporate office to make these changes. The engagement and support of a hospital's IT department are important to the success of such efforts.

Implementing Staff Training

Staff of hospitals, physician practices, and health plans have expressed concern about asking patients, enrollees, or members to provide information about their race, ethnicity, and language need (Hasnain-Wynia, 2007). Staff may believe, for example, that patients might be confused or offended by such a request. Furthermore, staff may be concerned about the time-sensitive nature of modern clinical practice and want to ensure that these questions can be asked efficiently.

To ensure that these data are collected accurately and consistently, health care organizations need to invest in training all levels of staff. This may include incorporating the usefulness of these data for detecting and addressing health care needs into the training of health professionals, administrative staff, and hospital and health plan leadership. For example, those responsible for directly asking patients or enrollees for this information can receive front-line training to learn about the importance of collecting these data; how they will be used; how they should be collected; and how concerns of patients, enrollees, and members can be addressed (Hasnain-Wynia et al., 2004, 2006, 2007; Regenstein and Sickler, 2006). When there is direct contact between staff and patients, for instance, if staff do not understand the greater accuracy of directly reported data, they may make their own observations of an individual's race and/or ethnicity.

Specific training points to be emphasized will depend on the context and on how the data are being collected and utilized. For example, because health plan staff do not have face-to-face contact with enrollees, demographic information is often gathered through telephone encounters. Telephone training may also be needed for staff of hospitals, CHCs, and physician practices because preregistration by telephone may occur before hospital admission or ambulatory care appointments. Contra Costa Health Plan monitored the frequency with which staff were asking for these data and implemented performance metrics to ensure staff compliance. Generally, providers have face-to-face contact with patients and may find response rates are better during that time. Therefore, staff training at clinical sites may need to emphasize elements of face-to-face communication. The Health Research & Educational Trust (HRET) Disparities Toolkit, which has been endorsed by the National Quality Forum (NQF), offers a matrix for addressing patient reluctance under different scenarios (Hasnain-Wynia et al., 2007; NQF, 2008). Questions for requesting these data may introduce response bias, in the absence of adequate staff training.[11]

Before embarking on formally training staff to collect data, each entity needs to assess its data collection practices and delineate what is being done currently and what will change. The changes need to be clearly communicated during staff training sessions. Despite differences among health care settings, standardizing specific

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[10] *American Recovery and Reinvestment Act of 2009,* Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).

[11] Personal communication, O. Carter-Pokras, University of Maryland School of Public Health, April 13, 2009.

BOX 5-5
Standardizing Direct Data Collection

- **Who:** information should always be asked of patients or their caretakers and should never be gathered by observation alone
- **When:** information should be collected upon admission or patient registration to ensure that appropriate fields are completed when the patient begins treatment, or for plans, when the individual enrolls (as permitted by state law)
- **What:**
    - Questions about the OMB race and Hispanic ethnicity categories (one- or two-question format permitted)
    - A question about granular ethnicity with locally relevant response categories selected from a national standard set
    - A question to determine English-language proficiency
    - A question about language preference needed for effective communication
- **Where:** data should be stored in a standard format for easy linking to clinical data
- **How:** patient concerns should be addressed when the information is being obtained, and staff should receive ongoing training and evaluation

components of data collection within each organization will facilitate staff training processes. Suggestions to this end are presented in Box 5-5.

Educating Patients and Communities

Baker and colleagues (2005, 2007) found that while most patients believe health care providers should collect data on race and ethnicity, minority patients may feel uncomfortable with providing this information. Informing patients that the data are being collected to monitor and improve the quality of care for everyone helps improve patients' comfort level. Thus, in health and health care settings, providing a rationale for asking the questions may make patients and enrollees feel better about responding. The HRET Toolkit provides suggested wording for this purpose: "We want to make sure that all our patients get the best care possible. We would like you to tell us your racial/ethnic background so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care."

When Contra Costa Health Plan began requesting these data from its members, call center staff read a script developed from the HRET Toolkit before asking about race and ethnicity. Employees found the script time-consuming to read in the call center environment, resulting in a reevaluation of its collection methods. The rationale for the data collection is no longer automatically provided in advance; instead, the data are requested when other information, such as the member's address and phone number, are being verified.[12] Contra Costa's experience highlights the need for adapting best practices to what will be most successful in specific circumstances.

Informing and engaging communities may facilitate data collection efforts. For example, community-based organizations can be informed of the purposes of the data collection and be used as avenues for passing this information on to constituencies. Within health care settings, information pamphlets, cafeteria table tent cards, and posters in languages other than English (Hasnain-Wynia et al., 2007) may help patients and their families understand what is being asked and why.

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[12] Personal communication, O. Tiutin, Contra Costa Health Plan, July 10, 2009.

USING PROBABILISTIC INDIRECT ESTIMATION OF RACE AND ETHNICITY DATA

When direct collection of race and ethnicity data is incomplete or impossible, it may be useful to infer some information about a person's race or ethnicity from other information that is already available or can readily be obtained for use in analyses of associations between race and ethnicity and outcomes of interest. Such inferences can be useful when the limits of direct collection of racial and ethnic data have been reached for a given data system or as an interim measure while data are being collected from individuals. This use of predictive variables rather than direct collection of information from patients is termed "indirect estimation." A number of indirect estimation approaches can be applied to race and ethnicity data, including linking area-level population data from the Census Bureau to quality data, using names for indirect estimation, and attributing Bayesian probabilities to indirectly estimated data.

Linking Area-Level Data to Quality Data

One of the simplest indirect approaches is to use area-level population data derived from the Census. Such data include the racial and ethnic composition of an area (percent in each race and ethnicity category), as well as socioeconomic measures such as median income, percent in poverty, distribution by years of educational attainment, percent reporting limited English proficiency, or an overall indicator of socioeconomic status combining several such measures. Until 2000, these measures were collected from the long-form sample of the decennial Census and released in tabulations by a range of Census geographical units from the state to the block group. More recently, collection of these data has shifted to the American Community Survey, a continuous data collection process from which tabulations are released for 1-, 3-, or 5-year accumulations depending on the level and population of the geographic unit. The numerous applications of the methodology reflect the ease with which addresses can be linked to area data, either by "geocoding" addresses to small areas or by using tabulations for zip code tabulation areas, which approximate postal zip codes.

Analyses with area variables may proceed either by categorizing variables into ranges or by regressing on the numerical value of the variable. For example, researchers might block groups into categories with zero to 10 percent, 10 to 20 percent, and 20 to 30 percent Hispanic residents. If the researchers then found that the block groups with higher concentrations of Hispanic residents also had higher rates of diabetes, a higher rate of diabetes among Hispanics than non-Hispanics might be inferred. Additionally, it is possible to regress the diabetes rate on the percent Hispanic, finding that the diabetes rate increases (along the fitted regression line) by a certain amount (e.g., 0.15 percentage points) for each 1 percentage point increase in the percent Hispanic. Thus, it might be possible to conclude that 0.15 or 15 percentage points is the difference in rates for Hispanics and non-Hispanics. There is a substantial literature on the use of area measures in health research (Krieger et al., 2003a, 2003b, 2003c, 2005), comparing the effects of using data aggregated to various geographic levels; generally, the conclusion has been that effects are detected more sensitively when data are linked to smaller (more detailed) geographic units.

When an outcome is regressed on an area variable defined as the percentage in a particular group (such as the percentage African American or the percentage in poverty), the regression coefficient can be interpreted as the effect of being a member of that group. This analysis, sometimes known as "ecological inference," is technically correct only under the assumption that the outcome is related to individual effects (membership in the group), but not to the degree of concentration of the group in the area. For example, diabetes rates are higher for African Americans than for Whites; if rates for each group were uniform across the country (and assuming for presentation that there are only these two groups), the average rate in each area would be directly related to the percent African American. In fact, the rate would be a weighted average of the rates for the two groups, where the weights are the percentages of each group in the area; in other words, the effects would be purely compositional. The assumption of uniformity could be violated, however, if African Americans in highly segregated areas have different socioeconomic and health characteristics (e.g., probability of having diabetes) than their counterparts living in integrated areas.

Because of concerns about such possible "noncompositional" effects, the literature on the use of area effects often regards effects of area-level race and ethnicity measures as representing a combination of compositional effects (the average of effects of individual-level characteristics across the population of the area) and contextual effects (the effects of being in an area of a certain kind). By this logic, the area-level variables might be relevant to include in models even when individual-level measures are available and included. When individual-level variables are not available, the area composition variables can allow only approximate estimation of disparities at the individual level. However, results from area-level analyses can still be very useful in revealing disparities. For example, if residents of areas with high proportions of African American residents are shown to have higher rates of a health or health care problem than those in areas with few African American residents, this is good evidence for disparities even if a precise estimate of average African American–White differences cannot be obtained.

The accuracy of this method is directly dependent on the proportion of the targeted group in the particular area. Community rates of racial and ethnic segregation will affect the method's accuracy in catchment areas. This method also generally works better for African Americans than for other racial and ethnic groups because their rates of segregation, particularly in Eastern cities, are much higher than those of other groups. Also, rates may differ considerably depending on the unit of analysis (e.g., zip code, Census tract, Census block). Smaller units may be more useful, particularly for groups with lower numbers in the community. Zip code data are readily available, while analysis using Census blocks or block groups requires the additional step of geocoding addresses to the relevant unit of analysis.

Data collection efforts that include an individual's address can be useful for indirectly estimating race and ethnicity. EHR standards and other administrative databases (e.g., registration and billing) include demographic data elements such as address and date of birth (Certification Commission for Healthcare Information Technology, 2007). Appropriate handling of these data is important because addresses are highly identifiable. HIPAA Privacy Rule requirements for deidentifying data protect individuals but may, in some cases, raise barriers to exchanging address data, as is sometimes necessary for indirect estimation processes.

Using Names for Indirect Estimation

Names have been used as indicators of racial and ethnic identity. For each name there is a corresponding racial and ethnic composition based on self-identification of people with that name in Census data. These data have been summarized in lists of common Spanish and Asian surnames and more specific lists of surnames associated with different Asian-origin ethnicities (Elliott et al., 2008; Fiscella and Fremont, 2006; Sweeney et al., 2007; Wei et al., 2006), but the exact race and ethnicity of those with each name are more informative. For example, a large proportion of those with the surname "Rodriguez" are Hispanic, while those with the surname "Lee" might include substantial proportions of Asian Americans, African Americans, and Whites. While surnames are not useful for identifying groups without distinctive ethnicity-related surnames, identification of African Americans through distinct given names has shown some success (Ting, 2009).

Attributing Bayesian Probabilities to Indirectly Estimated Data

The distributions of race and ethnicity in an area or for a particular name can be interpreted as probabilities that a randomly chosen person from the class (of residents of the area or persons with that name) is a member of each race or ethnicity. For example, if all one knows about an individual is that he lives in a block group in which 37 percent of the residents are African American, one might say there is a 37 percent probability that he is African American. Similar statements can be made using names. Note that the information about race and ethnicity obtained in this way is probabilistic rather than deterministic: even if someone's block group is 90 percent Hispanic, one can say only that there is a 90 percent chance he is Hispanic, not that he is definitely Hispanic.

An important benefit of this formulation is that probabilities from different pieces of information can be combined formally to generate a summary combined probability. Technically, under the assumption that the two pieces of information—block group composition and name—are independent given the person's race, they can be combined using Bayes's theorem to produce a posterior probability for each race and ethnicity that summarizes the two pieces of information (Elliott et al., 2008; Fiscella and Fremont, 2006; Fremont et al., 2005). In particular, the racial and ethnic proportions in a small area can be regarded as prior probabilities that an individual from that area would be from each race and ethnicity group, while the probabilities that a person from each race and ethnicity would have the individual's name (e.g., the probability that a Hispanic would have the name "Gomez," the probability that a non-Hispanic White would have the name "Gomez") constitute the likelihood for each race and ethnicity. For example, a person named "Gomez" in a block group that is 50 percent Hispanic is more likely to be Hispanic than either a person named "Smith" in a block group that is 50 percent Hispanic or a person named "Gomez" in a block group that is 20 percent Hispanic.

The assumptions for this application of Bayes's theorem are not likely to hold exactly; for example, a Hispanic in an area of Hispanic concentration (perhaps with many recent immigrants) might be more likely to have the name "Gomez" and less likely to have the name "Smith" than a Hispanic in an integrated area. Nonetheless, this probability calculation provides a principled way of combining multiple indicators of race and ethnicity. This procedure has been implemented with health plan datasets (Elliott et al., 2008). A similar procedure, but using ad hoc rules based on lists and cutoffs rather than formal probability calculations, was used to create a file of imputed racial and ethnic identifications for Medicare beneficiaries (Bonito et al., 2008).

Combining evidence about individuals in this way will tend to improve the accuracy of predictions in the sense that individuals' probabilities of belonging to each race and ethnicity will become more differentiated and therefore more informative. For this reason, a combined approach is preferable when possible. However, the fact that these are still only probabilities and not certainties has several implications for the use of indirectly estimated race and ethnicity. First, collapsing probabilities to a single imputed racial and ethnic classification for each individual loses useful information and can be misleading. For example, suppose each person is assigned the race and ethnicity classification with the highest probability. Then in a population of individuals for whom the probability of being non-Hispanic White is 60 percent and the probability of being African American is 40 percent, all of those individuals would be classified as non-Hispanic White, although the proper inference would be that the split is 60/40 percent. Another classification approach would be to impute randomly from the given probabilities (in the previous example to divide the population randomly in a 60/40 ratio). While this approach would yield a more realistic distribution of race and ethnicity for the group, the random imputations would have no relationship to any actual differences between Whites and African Americans, and therefore an analysis using this approach would, perhaps falsely, lead to the conclusion that there are no health differences between the two groups. For these reasons, it is essential to record probabilities from indirect estimation rather than a single assignment.

On the other hand, probabilities can be used analytically to draw useful conclusions about disparities. As described above, regressing on probabilities can generate estimates of racial and ethnic differences, although these estimates are valid only under the assumption that variations in outcomes of interest within each racial and ethnic group are uncorrelated with the calculated probabilities. In several illustrative analyses, disparities identified with this methodology closely matched those identified using individual race and ethnicity variables (Elliott, 2009). For example, for estimates of disparities for Black versus White, Hispanic versus White, and Asian versus White, the sign of the coefficient based on indirectly estimated data matched that based on self-reported data 38 out of 39 times, with a significance level of 0.05 (Elliott, 2009).

Using Indirectly Collected Data

Indirect race and ethnicity identifications can be used in quality improvement efforts when direct identifications are unavailable (see Box 5-6). In addition to aggregate analyses such as those described above, they can be used in examining characteristics of patients who suffered specific health problems or health care deficits. For example, mapping of the residences of such patients together with indirectly derived race and ethnicity could illuminate patterns of problems that could be addressed through targeted interventions. To plan services and conduct community-based targeted interventions, NQF recommends using proxy data from geocoding, surname analysis, and Bayesian estimation. NQF's recommendation also states that indirectly estimated data should not be used to target interventions for individual patients (NQF, 2008).

Indirect methods are best applied to population-based assessments of quality of care and can be used to identify "hotspots" where individuals who are at risk of or are receiving poor care are clustered. Knowing that a provider group's service area overlaps with a hotspot can be instructive, allowing the group to improve service delivery to

BOX 5-6
The Use of Indirectly Collected Data by a Health Plan: Wellpoint, Inc.

Wellpoint, the largest member of the BlueCross BlueShield Association, recognizes that while it is preferable to collect race, ethnicity, and language data via self-report, plans often encounter data collection plateaus due to the costs of adding data collection and storage fields to HIT systems, the costs of multiple attempts at collection, inaccurate data from external entities, and internal legality concerns. Wellpoint partnered with the RAND Corporation to develop a low-cost, easy-to-implement alternative to collecting primary source data. The initiative resulted in an analytic model for indirectly estimating race and ethnicity using a combination of geocoding, surname analysis, a proprietary African American first-name list, and logistic regression.

The indirectly estimated data can be used to examine differences among groups in various health indicators by linking proxy race and ethnicity data with member claims data and quality process measures. The data are also used to develop maps used for business decisions regarding the design of quality improvement programs and community collaboration projects. In 2008, Wellpoint began using the proxy data to channel culturally and linguistically appropriate screening reminder messages to members. The indirect methodology allows analysis of members who do not respond to requests for self-reported data, decreases the selection bias among self-reported respondents, and makes plan, regional, and practice-level analysis more accurate.

SOURCES: NCQA, 2008; Ting, 2009.

specific communities. While targeting entire hotspots may be relatively ineffective for plans that do not dominate the market, community interventions in which plans pool efforts may be cost-effective (Fremont, 2009).

The use of indirectly estimated data at the individual level is limited by the probabilistic nature of the data and the consequent possibility of error. The subcommittee has considered a number of potential uses of indirect estimates, ranging from those that posed very little risk of harm to the patient to those that posed unacceptable risk. At one end of this spectrum, using indirect estimation to target mail distribution of health information tailored to the needs, language, or cultural style of a particular group would at worst lead to some misdirected and wasted mailing. At the other end, erroneous assumptions about race and ethnicity in personal contacts with patients could lead to offense and mistrust. In particular, the subcommittee finds that the clinical and interpersonal risks of including indirectly estimated identifications in individuals' medical records far outweigh any potential benefits given the danger of misreading the identification as certain, the likely interpersonal costs of such misreading, and the possibility of clinical consequences from relying on erroneous identification. Instead, if indirect estimation of race and ethnicity is to be used, the estimated probabilities should be stored in a system that is distinct from medical records but can be merged with medical record data to create analytic files for identification of disparities.

Recommendation 5-1: Where directly collected race and ethnicity data are not available, entities should use indirect estimation to aid in the analysis of racial and ethnic disparities and in the de-

velopment of targeted quality improvement strategies, recognizing the probabilistic and fallible nature of such indirectly estimated identifications.

- **Race and ethnicity identifications based on indirect estimation should be distinguished from self-reports in data systems, and if feasible, should be accompanied by probabilities.**
- **Interventions and communications in which race and ethnicity identifications are based on indirect estimation may be better suited to population-level interventions and communications and less well suited to use in individual-level interactions.**
- **An indirectly estimated probability of an individual's race and ethnicity should never be placed in a medical record or used in clinical decision making.**
- **Analyses using indirectly estimated race and ethnicity should employ statistically valid methods that deal with probabilistic identifications.**

SUMMARY

There are both opportunities for and challenges to the collection of data on race, ethnicity, and language need at all organizational levels in the U.S. health care system. The infrastructure of the current health care system does not facilitate the data exchanges necessary to capture race, ethnicity, and language data for all populations. No one locus of data collection has a clearly superior balance of opportunities and challenges and the ability to serve as the primary data collection point for a large fraction of the U.S. population. Until such a clearly preferred locus of data collection emerges, it will be necessary for existing entities to collect these data using standardized categories and work to develop methods and policies for sharing the data so as to reduce the duplication of effort that occurs when all entities attempt to collect the data at most or all encounters.

All entities should collect these data, knowing their limitations and constraints, and implement steps to address these limitations and constraints. These steps can improve data collection processes by addressing HIT constraints and minimizing respondent and organizational resistance. To enhance legacy HIT systems, standardized communication protocols are needed to permit interoperability, and some systems will require upgrading. Training staff and educating communities about the importance of collecting race, ethnicity, and language data for improving health and the quality of health care are also necessary.

Direct collection of race and ethnicity data is preferable to observation and to indirect methods. When direct collection is impossible or has not been completed, however, indirect approaches can be employed. These approaches include linking area-level population data from the Census to quality data, using data like names to infer race and ethnicity, and attributing Bayesian probabilities to indirectly estimated data. At the same time, indirect estimates are always inferior to data obtained directly from individuals, and data based on indirect estimation should never be included in an individual's medical record.

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6

Implementation

The subcommittee has proposed a standardized framework for the collection of race, ethnicity, and language data for use in efforts to improve the quality of health care. This framework combines the Office of Management and Budget (OMB) race and Hispanic ethnicity categories with categories for granular ethnicity and language need selected at the local level from national standard sets. Widespread adoption of this framework would ensure consistent categories for comparative analysis and facilitate data sharing across organizations and geographic areas. The U.S. Department of Health and Human Services (HHS) is a prime locus of the subcommittee's recommendations for implementation of these improvements because of its focus on resolving disparities in health and health care and its history of promoting the collection of race, ethnicity, and language data to ensure compliance with applicable statutes and regulations. Other federal agencies that deliver health care, states, accreditation and standards-setting organizations, and professional medical groups all have roles to plan in ensuring adoption and utilization.

The race and Hispanic ethnicity categories included in the Office of Management and Budget (OMB) 1977 Directive and its subsequent 1997 revisions stemmed primarily from a need to monitor civil rights, voting access, and changing population dynamics (OMB, 1997, 1999), and not from the perspective of health care quality improvement. The subcommittee's task is to delineate standardized categories for the collection of race, ethnicity, and language data to serve the latter purpose. Standardization of any demographic variable or quality indicator helps ensure more comparable and reliable data for analytic comparisons and for sharing across organizational boundaries. Additionally, when there is communication across information systems and consistency in defined categories, once a person has provided his/her race, ethnicity, and language data, these data would not have to be elicited repeatedly during each health-related encounter, reducing the collection burden on both staff and individual patients. Recognizing the need for more detailed data on race, ethnicity, and language to support improvements in health and the quality of health care, the subcommittee recommends combining the use of granular ethnicity categories with the broad OMB categories, as well as an assessment of a patient's language need (whether a person's spoken English proficiency is less than "very well," and what is his/her preferred spoken language for effective communication during health-related encounters). Quality measurement and interventions will be enhanced by having these data at the individual patient level (Nerenz and Darling, 2004).

In this chapter, the subcommittee offers recommendations for implementing standardization of race, ethnicity, and language need so that these data will be available to inform health care quality improvement endeavors. In accordance with the subcommittee's statement of task, the recommendations offered in Chapters 3 through 5 for gathering these data are intended "for those entities wishing to assess and report on quality of care across these categories." The subcommittee's recommendations, however, will likely have greater influence if they are adopted as HHS standards, required in federally funded programs, and incorporated into industry standards for electronic health record (EHR) systems and other forms of health information technology (HIT). Additionally, states, standards-setting organizations (e.g., the Joint Commission and the National Committee for Quality Assurance [NCQA]), and professional medical bodies have a role to play in fostering the adoption and use of standardized race, ethnicity, and language data for quality improvement purposes.

HHS ACTION

HHS is a prime locus of the subcommittee's recommendations for standardization and implementation because of its focus on health care quality and the elimination of disparities in health and health care in policy and through its funded programs, as well as its history in promoting the collection of race, ethnicity, and language data to ensure compliance with applicable statutes and regulations (AHRQ, 2008a, 2008b; HHS, 2000, 2003, 2007, 2009e). Additionally, HHS is responsible for implementation of health information technology provisions of the American Recovery and Reinvestment Act of 2009 (ARRA) (HHS, 2009d). Although broad application of the EHR[1] will take a number of years (Blumenthal, 2009), the need for race, ethnicity, and language data is now, so efforts to identify and address health care disparities can proceed, and thereby targeted actions can be taken to raise the overall quality of care in the nation. The EHR is a tool with the potential to reduce repetitive collection and to facilitate the linkage of demographics to some quality measures. The data collection issues for other current HIT systems do not differ significantly from those involved in future EHR applications, so providers should begin to put in place now the processes for the capture and sharing of race, ethnicity, and language data.

Framework for the Collection of Race, Ethnicity, and Language Variables

The framework for the collection of data on race, Hispanic ethnicity, granular ethnicity, and language variables proposed by the subcommittee and detailed in Chapters 3 through 5 is summarized in Figure 6-1. Templates for national lists of granular ethnicity and language categories are provided in Appendixes E and I, respectively. These templates can serve as building blocks upon which HHS can develop and maintain comprehensive national standard lists of granular ethnicities and languages based on the experiences of participants in health care delivery and quality improvement. The subcommittee does not specify a preset number of granular ethnicities or languages that all entities must collect; instead, in the previous chapters, it affirms the importance of selecting locally relevant categories from these lists, with an opportunity for self-identification through an open-ended "Other, please specify: __" response option.

Entities may also want to design their information system to have a way to track whether a person has "declined" to provide an answer, or the ethnicity is "unknown" (e.g., in the case of an adopted child) or "unavailable" (e.g., no direct contact has occurred to elicit information); these are not response categories for patients, but to be utilized for tracking. Additionally, some information systems and EHR systems have the capability to record whether information is directly "self-reported" by patients—the preferred approach—or is "observer-reported" (e.g., as is necessary when a person arrives unconscious in an emergency room).[2] It would be most useful if these terms were also standardized across collection systems.

Standard lists of categories of granular ethnicity and languages will need to be formalized from the category templates offered by the subcommittee for race and ethnicity (Appendix E) and for languages (Appendix I). As

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[1] In this document, EHR means a patient record owned and maintained by a provider entity; a personal health record is a medical or health record owned and maintained by a patient him- or herself. The Office of the National Coordinator's definition is included in the following section on Electronic Health Records.

[2] Personal communication, S. Ganesan, Centers for Disease Control and Prevention, June 3, 2009.

Race and Ethnicity

OMB Hispanic Ethnicity[a]

- Hispanic or Latino
- Not Hispanic or Latino

OMB Race
(Select one or more)

- Black or African American
- White
- Asian
- American Indian or Alaska Native
- Native Hawaiian or Other Pacific Islander
- Some other race[b]

Granular Ethnicity

- Locally relevant choices from a national standard list of approximately 540 categories with CDC/HL7 codes[c]
- “Other, please specify:___” response option
- Rollup to the OMB categories

Language Need

Spoken English Language Proficiency[d]

- Very well
- Well
- Not well
- Not at all

(Limited English proficiency is defined as “less than very well”)

Spoken Language Preferred for Health Care

- Locally relevant choices from a national standard list of approximately 600 categories with coding to be determined
- “Other, please specify:___” response option
- Inclusion of sign language in spoken language need list and Braille when written language is elicited

FIGURE 6-1 Recommended variables for standardized collection of race, ethnicity, and language need.
NOTE: Additional categories for HIT tracking might include whether respondents have not yet responded (unavailable), refuse to answer (declined), or do not know (unknown), as well as whether responses are self-reported or observer-reported.

[a] The preferred order of questioning is Hispanic ethnicity first, followed by race, as OMB recommends, and then granular ethnicity.

[b] The U.S. Census Bureau received OMB permission to add “Some other race” to the standard OMB categories in Census 2000 and subsequent Census collections.

[c] Additional codes will be needed for categories added to the CDC/HL7 list.

[d] Need is determined on the basis of two questions, with asking about proficiency first. Limited English proficiency is defined for health care purposes as speaking English less than very well.

SOURCES: CDC, 2000; Office of Management and Budget, 1997b; Shin and Bruno, 2003; U.S. Census Bureau, 2002.

noted in Chapter 3, within HHS, for example, there are different category sets in use: the Public Health Information Network (PHIN) uses the Centers for Disease Control and Prevention (CDC)/Health Level 7 (HL7) Race and Ethnicity Code Set 1.0 (CDC, 2009), whereas the Surveillance, Epidemiology and End Results (SEER) Program uses its own Coding and Staging Manual that does not always correspond with the CDC/HL7 Code Set (Johnson and Adamo, 2008). Likewise, states such as Massachusetts and Wisconsin have developed expanded sets of ethnicity categories and different rollup schemes for aggregation and reporting (Taylor-Clark et al., 2009; Wisconsin Cancer Reporting System, 2008). Some health plans, including Kaiser Permanente and Contra Costa Health Plan, also have their own granular ethnicity, spoken language, and written language categories (see Appendixes G and H, respectively). However, none of the current sets alone provides a complete set for the nation as a whole. Additionally, the subcommittee focuses its attention on a rollup scheme from granular ethnicities to the OMB race and Hispanic ethnicity; the subcommittee chose not to define mid-level aggregations between granular ethnicity and the OMB level, but HHS may wish to consider such mid-level aggregations of ethnicity. The Massachusetts Superset, for example, roles granular ethnicities to larger groupings of ethnicities.

HHS should develop national standard sets of granular ethnicity and language categories with a responsive updating process and associated coding, so that each state or entity would be relieved of having to develop its own category sets and coding schemes. Data would then have a greater likelihood of being compatible across entities. Although HHS may likely build on the CDC/HL7 Code Set for race and ethnicity, the national set's use extends to emerging requirements for EHRs and other applications beyond the CDC PHIN. Thus, the subcommittee believes that development of the granular ethnicity category set and associated codes may need to be elevated to a more cross-cutting entity, such as the Office of the National Coordinator for Health Information Technology (ONC) or the Office of the Assistant Secretary for Planning and Evaluation (ASPE). The subcommittee does not specify the location of this activity, but leaves it to the discretion of the Secretary. The CDC/HL7 Code Set does not include languages.

Coding for Interoperability

HHS will need to work with HL7, a clinical and administrative data standards-setting organization for EHRs (HL7, 2009), to update the five-digit unique numerical codes in the existing CDC/HL7 Code Set (CDC, 2000).[3] Additionally, interoperability standards may have implications for the number of fields available in EHRs to accommodate multiple questions on ethnicity and language variables as recommended in the subcommittee's framework, as well as other details analysts may wish to have, such as whether a response is self-reported by a patient, observer-based, or based on an indirect estimation. For language coding, HHS will have to develop or adopt a set of unique codes for languages analogous to the CDC/HL7 codes for race and ethnicity (CDC, 2000). While the Census Bureau and the maintenance agencies and registration authorities for the International Organization for Standardization (ISO)[4] each produce language lists that contain most of the same categories, they have distinctive coding practices. Additionally, as discussed in Chapter 4, the Census Bureau list uses the same code for multiple related languages, while the ISO list has unique codes for each language (see Appendix I). To the extent that patients who are not English proficient need language assistance services in distinct languages in order to facilitate understanding during patient–provider interactions, a care provider's ability to track specific languages would be enhanced by unique coding for distinct languages. HHS will need to consult with these entities to establish unique coding. While the subcommittee has identified approximately 600 languages in use in the United States, fewer—perhaps 300—will be encountered in a health care context.

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[3] In addition to the numerical codes, the CDC/HL7 Code Set includes an alphanumeric hierarchical code that places each category in a hierarchical position related to the OMB categories of race and Hispanic ethnicity.

[4] The Library of Congress is the registration authority for the ISO-639-2 codes, while SIL is the registration authority for the ISO-639-3 codes.

Regular Updating

A process for input on categories from the public and federally funded direct health care delivery and insurance programs (e.g., hospitals, clinics, health plans, community health centers, Medicaid programs) would help ensure that the initial category lists for granular ethnicities and languages are as comprehensive as necessary for use in the health care environment. Once standard national lists have been established, an ongoing process should be in place for responding within a reasonable time to questions about how to code specific groups if they are not on the initial lists. A designated component within HHS should update the category and code lists annually and be available to answer any questions related to rollup of individual ethnicities to broader OMB categories to ensure nationwide consistency in practice. It is expected that only a handful of categories will emerge yearly after comprehensive initial lists of ethnicity and languages are developed, so that updating the list by a few categories will not be onerous. Annual updating may be necessary in the initial years of implementation, over time it may become apparent that annual updates are not necessary, and another timeframe could be adopted. A local entity would not have to ask permission to use a specific category if it is not yet on updated national lists; rather, an entity could use its own provisional code until one was available at the national level.

Currently, updating of the CDC/HL7 categories and unique codes is tied to redeployment of the Census.[5,6] Every 10 years is not frequent enough to capture new immigrant groups, their languages, or emerging findings about disparities in health care. The Census Bureau could provide updated ancestry-based ethnicity and language categories more frequently from the ongoing American Community Survey.[7] As health care entities in communities across the nation collect data and begin to adapt to the use of standard categories and code sets, it is likely that they will encounter individuals, sooner even than the Census Bureau, who self-identify with a category that is not already listed. Thus, there will be a need for routine technical guidance, especially during the first few years of adoption of this report's recommendations.

> **Recommendation 6-1a: HHS should develop and make available national standard lists of granular ethnicity categories and spoken and written languages, with accompanying unique codes and rules for rollup procedures.**
>
> - **HHS should adopt a process for routine updating of those lists and procedures as necessary. Sign languages should be included in national lists of spoken languages and Braille in lists of written languages.**
> - **HHS should ensure that any national hierarchy used to roll up granular ethnicity categories to the broad OMB race and Hispanic ethnicity categories takes into account responses that do not correspond to one of the OMB categories.**

Electronic Health Records

The American Recovery and Reinvestment Act of 2009 (ARRA) provides opportunities for the inclusion of race, ethnicity, and language categories in standards for EHRs, thereby influencing which demographic data will be available for use when quality improvement data are stratified. ARRA authorizes and provides resources for the Office of the National Coordinator for Health Information Technology (ONC). The Coordinator is to guide the "development of a nationwide health information technology infrastructure that allows for the electronic use and exchange of information" for purposes that include quality improvement and reduction of disparities in health and health care, public health activities, clinical and health services research on quality, guidance for medical decisions at the time and place of care, and prevention and management of chronic diseases.[8] The Coordinator is to assess how information technology or its absence affects communities with known health disparities and/or a high

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[5] Personal communication, D. Pollack, Centers for Disease Control and Prevention, May 7, 2009.

[6] Personal communication, S. Ganesan, Centers for Disease Control and Prevention, and B. Hamilton, National Center for Health Statistics, June 3, 2009.

[7] Personal communication, H. Shin, Census Bureau, July 13, 2009.

[8] *American Recovery and Reinvestment Act of 2009*, Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).

proportion of individuals at risk of poor health because a lack of insurance and inadequate health care capacity, thus limiting their access to health care.

Of particular interest to the subcommittee is the provision of ARRA to "ensure the comprehensive collection of patient demographic data, including, at a minimum, race, ethnicity, primary language, and gender information." The act directs the Coordinator to consult with the National Committee on Vital and Health Statistics (NCVHS), whose mission is to improve information on population health. In the past, NCVHS had concluded that survey data on race, ethnicity, and language needed to be improved because broad categories such as Asian and Hispanic mask significant differentials in health status, access to health care, and service utilization (NCVHS, 2005). The subcommittee agrees with this assessment based on its review of studies in Chapter 2.

One goal stated within ARRA is an EHR for each person in the United States by 2014. An EHR is defined by ONC as:

> A real-time patient health record with access to evidence-based decision support tools that can be used to aid clinicians in decision-making. The EHR can automate and streamline a clinician's workflow, ensuring that all clinical information is communicated. It can also prevent delays in response that result in gaps in care. The EHR can also support the collection of data for uses other than clinical care, such as billing, quality management, outcome reporting, and public health disease surveillance and reporting. (HHS, 2009b)

Proposed regulations on implementation of EHR under ARRA are due by the end of 2009 (HHS, 2009a).

The subcommittee's recommended variables and categories for collection should be incorporated into each individual EHR, greatly expanding the availability of such data tied to information on health and health care for quality assessment purposes. Having the standards adopted by the other components of the health care industry, including the makers of information technology systems, would help ensure that a sufficient set of data fields are available to accommodate each element recommended for collection by the subcommittee. ONC is consulting with standards-setting organizations such as the Health Information Technology Standards Panel (HITSP) and the Certification Commission for Healthcare Information Technology (CCHIT) on harmonizing industry specifications and certification criteria.[9]

Recommendation 6-1b: HHS and the Office of the National Coordinator for Health Information Technology (ONC) should adopt as standards for including in electronic health records the variables of race, Hispanic ethnicity, granular ethnicity, and language need identified in this report.

Recommendation 6-1c: HHS and ONC should develop standards for electronic data transmission among health care providers and plans that support data exchange and possible aggregation of race, Hispanic ethnicity, granular ethnicity, and language need data across entities to minimize redundancy in data collection.

Incentive Programs

The collection of data on race, ethnicity, and language and use of these data to foster elimination of disparities in quality of care can be an element of either public or private pay-for-performance systems. In general, such systems reward providers for activities that purchasers deem desirable. A variety of such systems are in place; some provide incentives for specific structural features (e.g., presence of EHRs), some for a set of process-of-care activities (e.g., use of appropriate antibiotics for surgical patients), some for improved patient outcomes (e.g., in-hospital mortality rates), and some simply for the collection and reporting of quality data (Chien, 2007; Chien et al., 2007). As these systems continue to evolve over time, they can incorporate the collection and use of data on race, ethnicity, and language for quality improvement or the achievement of specific goals for reducing disparities as criteria for incentive payments.

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[9] D. Blumenthal, ONC, HHS at the IOM Meaningful Use Workshop, July 13, 2009.

Medicare Physician Quality Reporting Initiative (PQRI)

The Medicare PQRI establishes incentive payments for physicians who report on quality measures for Medicare beneficiaries (CMS, 2009). The Medicare Improvements for Patients and Providers Act of 2008 (MIPPA) has extended PQRI but not its funding indefinitely,[10] increased the measure set to 153 individual measures, and added a whole array of different reporting options that interface with both registries and EHRs. For 2009, quality measurement groups include preventive care, diabetes, end stage renal disease, chronic kidney disease, back pain, coronary artery bypass graft surgery, rheumatoid arthritis, and perioperative care (McGann, 2009).

Monitoring for Unintended Consequences

Performance incentive programs can have positive or negative effects on disparities in health and health care, but tend not to be designed with reduction of disparities in mind (Chien et al., 2007). Data from the *National Healthcare Disparities* and *National Healthcare Quality Reports* show that even as quality of care improves overall on specific measures, disparities persist (AHRQ, 2008a, 2008b). Monitoring of program effects along the dimensions of race, ethnicity, and language is desirable to forestall greater widening of gaps in care and to understand the effects of incentive programs on underresourced primary care safety net providers (Rust and Cooper, 2007; Williams, 2009).

The subcommittee does not take a stand for or against incentive payments in HIT programs. Rather, the subcommittee is recommending that, when such programs exist, it would be appropriate to include the collection of race, ethnicity, and language data as one activity for which positive incentives should be offered.

> **Recommendation 6-1d: The Centers for Medicare and Medicaid Services (CMS), as well as others sponsoring payment incentive programs, should ensure that the awarding of such incentives takes into account collection of the recommended data on race, Hispanic ethnicity, granular ethnicity, and language need so these data can be used to identify and address disparities in care.**

Recipients of Federal Funds

Health care entities have indicated that they have been reluctant to make changes to their systems until there is a standardized categorization approach for race, ethnicity, and language need (Bilheimer and Sisk, 2008; Lurie et al., 2005, 2008; NCQA, 2009; NRC, 2003; Siegel et al., 2007, 2008). This report addresses that barrier. An earlier report by the National Research Council, *Eliminating Disparities: Measurement and Data Needs*, stresses HHS's critical role in implementing change.

The federal government's authority to mandate the nature of data collection is limited, except in large federal health care delivery systems, through the purchasing power of programs such as Medicare, or for recipients of other federal funding mechanisms. HHS administers programs supporting the health care delivery system to provide care to persons at risk of receiving suboptimal care, and these programs present opportunities to influence the quality of care delivered to millions of Americans. For example, at least a 100 million of the 300 million people in the country are served by just three programs administered by HHS—Medicare, Medicaid, and community health centers.[11] Ensuring the quality of care to its programmatic participants is an HHS priority, and HHS leadership can make a difference in the adoption of this report's recommendations as it responds to recent legislation to ensure the use of race, ethnicity, and language data in assessing quality of care and building a national health information network (HHS, 2009c).

In earlier chapters, the legal basis for the collection of race, ethnicity, and language data has been established. HHS's 1997 inclusion policy mandates the collection of race and Hispanic ethnicity data for most of its

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[10] PQRI incentive payments are only currently authorized through 2010.

[11] 44.8 million Medicare beneficiaries in 2008 and 58.7 million Medicaid and CHIP recipients in 2006 with dual enrollment at about 10 million, plus 8.9 million of the 16 million served by health centers are uninsured or have insurance other than Medicare or Medicaid. The U.S. population, as of July 1, 2008, was 304 million (HRSA, 2008; Kaiser Family Foundation, 2005, 2008, 2009; U.S. Census Bureau, 2008).

programmatic applications (HHS Data Council, 1999). The policy encourages the inclusion of more detailed race and ethnicity categories than the OMB categories provide, but does not specify additional categories for uniform national use across all HHS programs or define a national standard set from which local programs could select. However, a need for more detailed population information has been apparent, and different entities within HHS have developed their own sets (e.g., PHIN and SEER) to foster the collection of comparative categories for use within their respective programs, but not necessarily across different types of programs. The subcommittee also believes the OMB race and Hispanic ethnicity categories are necessary but insufficient for identification of health care needs and elimination of disparities (see Chapter 2). Those categories are broad and may mask differences in receipt of appropriate care, and their sole use can end up being inefficient when interventions need only be targeted to a smaller portion of the broad category (for instance, only to populations of Vietnamese ancestry and not all people of Asian ancestry).

Besides ARRA, a new legislative effort that would require collection of race, ethnicity, and language data for use in quality reporting is section 185 of MIPPA. Medicare's plan for implementing this requirement has not yet been fully realized (McGann, 2009; Reilly, 2009b); in a report to Congress due in January 2010, CMS will address approaches to fulfilling the legislative mandate. CMS already uses a variety of direct and indirect methods in its analytic portfolio. Section 187 of MIPPA requires the Office of the Inspector General to examine implementation of culturally and linguistically appropriate services by Medicare providers and plans. In 2000, HHS released National Standards on Culturally and Linguistically Appropriate Services (CLAS) in an effort to influence all health care organizations and individual providers "to make their practices more culturally and linguistically accessible" (Office of Minority Health, 2007). The CLAS standards note the importance of using demographic data to understand and plan for the needs of the community served (standard 11); collecting data on the individual patient's race, ethnicity, and spoken and written language within both individual health records and organizational management information systems (standard 10); and using these data to monitor the cultural and linguistic responsiveness of organizations (standard 9) (Office of Minority Health, 2007). Additionally, section 201(b) of the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA)[12] provides an enhanced federal match for states to be used for language assistance services (interpretation and translation) for children in both CHIP and Medicaid programs. Knowledge of the language needs of people with limited English proficiency within the service population, not just knowledge of languages spoken at home, would be of significant use in understanding state program needs for language assistance. Previously, only about a dozen states and the District of Columbia participated in the matching program under Medicaid (Youdelman, 2007).

HHS's adoption of the subcommittee recommendations for its own programs would promote standardization. It is understood that changing information systems can be an expensive and time-consuming endeavor, and there will be a need for technical assistance and the application of additional resources. But the nation is now seeing the convergence of more nimble technology and efforts to build a stronger information infrastructure, along with federal economic stimulus funds for HIT.[13] Local programs often already collect more detailed data than the OMB categories in order to serve their populations, but these data are lost in aggregation in response to minimal reporting requirements. For others that do not yet have the capability to collect the specified data directly, methods are available for indirectly estimating race, ethnicity, and language need and applying these to quality metrics (see Chapter 5). Thus, efforts to identify differential needs and disparities need not be delayed.

The subcommittee's task was to recommend standardization of race, ethnicity, and language data for use in health care quality improvement. Thus, the following recommendation focuses on the HHS programs that deliver health care services, pay for health care services through insurance mechanisms, or administer surveys that increase the knowledge base on health care needs and outcomes. The Secretary, however, may find it useful to extend the standardized approach of this report to other HHS health-related programs, such as public health surveillance activities or surveys solely about health rather than also including health care issues.

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[12] *Children's Health Insurance Program Reauthorization Act of 2009*, Public Law 111-3, 111th Cong., 1st sess. (February 4, 2009).

[13] ARRA authorizes $20 billion for health information technology.

> **Recommendation 6-1e: HHS should issue guidance that recipients of HHS funding (e.g., Medicare, the Children's Health Insurance Program [CHIP], Medicaid, community health centers) include data on race, Hispanic ethnicity, granular ethnicity, and language need in individual health records so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.**

COORDINATION ACROSS FEDERAL HEALTH CARE DELIVERY SYSTEMS

The Department of Veterans Affairs (VA) medical system is noted for its use of EHRs, and its experience with quality improvement illustrates the potential of using EHRs throughout the nation's health care system. Realizing the full potential involves being able to stratify quality data by race, ethnicity, and language need. Having quality-of-care information from large federal delivery systems such as the Department of Veterans Affairs, the Department of Defense (DOD), and other federally funded programs, such as community health centers, stratified by the same variables and categories recommended in this report would provide rich sources for comparative analysis. Precedents for coordinating mechanisms for quality purposes exist. For example, ARRA authorizes a Federal Coordinating Council for Comparative Effectiveness Research to assist HHS, the VA, DOD, and other federal agencies in promoting the use of clinical registries, clinical data networks, and other EHRs to produce and obtain data on health outcomes (Rosenbaum et al., 2009). Such a council might serve as a mechanism for coordinating the standard collection of race, ethnicity, and language data among these agencies as part of their promotion of sources for quality data and development of quality metrics.

> **Recommendation 6-2: HHS, the Department of Veterans Affairs, and the Department of Defense should coordinate their efforts to ensure that all federally funded health care delivery systems collect the variables of race, Hispanic ethnicity, granular ethnicity, and language need as outlined in this report, and include these data in the health records of individuals for use in stratifying quality performance metrics, organizing quality improvement and disparity reduction initiatives, and reporting on progress.**

STANDARDS-SETTING AND PROFESSIONAL ORGANIZATIONS

Accreditation organizations and other professional and standards-setting bodies can play a key role in fostering the collection of race, ethnicity, and language data. Hospitals, health plans, and physicians have reported that a lack of standardization has been a barrier to collecting these data for quality improvement efforts (Bilheimer and Sisk, 2008; Lurie et al., 2008; NCQA, 2009; Siegel et al., 2008).

Joint Commission, NCQA, and URAC

Accrediting organizations such as the Joint Commission, National Committee for Quality Assurance (NCQA), and URAC[14] either have developed or are developing CLAS-like standards for their accreditation reviews or for voluntary self-analysis by organizations. These standards do not always cover all demographic variables (e.g., those of the Joint Commission cover language and communication needs but not race or ethnicity), or they may not go beyond requiring the collection of demographic data, leaving the use of those data for performance improvement optional (The Joint Commission, 2008; NCQA, 2008a; URAC, 2007).

For many years, the Joint Commission's accreditation standards for hospitals and other accredited entities (including, for example, those providing ambulatory health care, behavioral health care, home care, and hospice care) have required that patients' culture, ethnicity, race, and religious preferences and needs be respected and that their communication needs be met. To facilitate this patient-centered approach, in 2005 the Joint Commission proposed a standard that would have required documentation in each patient's health record of the patient's race,

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[14] Formerly known as the Utilization Review Accreditation Commission.

ethnicity, and language and other communication needs. The response from the field, while supportive of recording this information for each patient, argued that unless race and ethnicity data were recorded in standardized categories, their use for performance improvement would be limited. In light of this feedback, in January 2006 the Joint Commission began requiring that language and other communication needs be recorded in each patient's record, but it delayed requiring recording of race and ethnicity until a widely accepted standardized approach became available. As of this writing, the Joint Commission is again proposing a requirement that race and ethnicity be recorded and that these data be used in planning services to meet the needs of persons in the community and in performance improvement (The Joint Commission, 2009). The Joint Commission anticipates the response the field to be that standardized categories are needed.[15]

At this point, NCQA is planning to address CLAS as a voluntary accreditation module, to be available in 2010. It is expected that the module will address the use of race, ethnicity, and language data in stratifying quality performance data to identify both disparities in health care and problems in meeting language needs, as well as the use of those findings to drive quality improvement. Currently, NCQA has a program that rewards health plans for demonstrating innovative practices in providing for culturally and linguistically appropriate services (NCQA, 2006, 2007, 2008b). Previously, NCQA, with funding from The California Endowment, provided grants and technical assistance to small physician practices serving minority populations to learn about their needs for conducting and sustaining quality improvement activities. As a result of this initiative, the need for standardized collection of race, ethnicity, and language data in EHR systems was brought to light (NCQA, 2009).

National Quality Forum (NQF)

NQF is a membership organization whose mission is to "promote a common approach to measuring health care quality and fostering system-wide capacity for quality improvement" through endorsement of consensus standards (NQF, 2009). NQF recently released a framework for culturally and linguistically responsive services and encourages the collection of race, ethnicity, and language data in accordance with the Hospital Research & Education Trust (HRET) Toolkit (NQF, 2008). The subcommittee has suggested changes to elements of the HRET Toolkit, in particular incorporating separate collection of a granular ethnicity variable, adding "Some other race" to the OMB category set, and having a more expansive list of language categories. The subcommittee also favors the collection and retention for analysis of specific multiple-race combinations (i.e., having data on each race that an individual selects when given the option to select one or more races), rather than losing that detail by only offering patients the more general response option of "multiracial" as delineated in the Toolkit.

Commission to End Health Care Disparities

A collaborative partnership involving the medical community, the American Medical Association (AMA), the National Medical Association, and the National Hispanic Medical Association's Commission to End Health Care Disparities brings together 35 state and specialty medical societies. As a group, they have reaffirmed their collective commitment to ending disparities in health and health care by taking steps to (AMA, 2009b):

- Increase awareness of disparities in their own practices within the physician community,
- Promote better data collection,
- Promote workforce diversity, and
- Increase education and training.

The Commission is considering continuing medical education activities and exploration of core curriculum on health disparities for medical students that might be considered a criterion for medical school accreditation. The Commission also notes that race, ethnicity, and language proficiency data should be utilized for clinical quality

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[15] Personal communication, P. Schyve, The Joint Commission, May 11, 2009.

performance measurement, with disparities an appropriate area for the Physician Consortium for Performance Improvement to focus its efforts (AMA, 2009a).

The AMA Code of Ethics guides physicians to examine their practices to ensure that differences in care are based on clinical necessity or patient preference and do not constitute inequitable treatment. The code also states that physicians should take steps to minimize language barriers so as to enhance both patient and physician understanding of medical needs (AMA, 2005). Collection of race, ethnicity, and language data would allow stratification of quality measures in physician practices to create awareness of differential practice patterns or response among patient populations and accordingly identify opportunities for quality improvement. The ARRA provision for "meaningful use" of EHRs applies to enabling the exchange of health information and reporting on clinical quality measures to CMS, medical boards, private plans, and others. Medicare staff observed that CMS sees "in legislation and in operation, … a future for measuring quality in physician offices" (McGann, 2009). CMS sponsors quality improvement research projects at the practitioner level, such as the Generating Medicare Physician Quality Performance Measurement Results (GEMS) program which tracked 12 HEDIS (Healthcare Effectiveness Data and Information Set) ambulatory care measures in a physician group practice fee-for-service environment using an amalgam of Part A, B, and D claims data and race and ethnicity data from the enrollment database (McGann, 2009; Reilly, 2009a). Having race, ethnicity, and language data for their own patients would also enable providers to review performance at the point of care (Kmetik, 2009).

Recommendation 6-3: Accreditation and standards-setting organizations should incorporate the variables of race, Hispanic ethnicity, granular ethnicity, and language need outlined in this report and associated categories (as updated by HHS) as part of their accreditation standards and performance measure endorsements.

- **The Joint Commission, NCQA, and URAC should ensure collection in individual health records of the variables of race, Hispanic ethnicity, granular ethnicity, and language need as outlined in this report so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.**
- **NQF should review and amend its recommendations on the collection and use of data on race, Hispanic ethnicity, granular ethnicity, and language need to accord with the categories and procedures outlined in this report.**
- **Medical societies and medical boards should review and endorse the variables, categories, and procedures outlined in this report and educate their members on their use for quality improvement.**

STATE ACTION

States have an opportunity to shape the level of detail of race, ethnicity, and language data collected in their programs by establishing which categories of granular ethnicity and language should be used in addition to the basic OMB categories of race and Hispanic ethnicity. Each state organizes its own programs into different administrative units, so no attempt is made in this report to identify all state actors that have important roles in ensuring quality improvement in health care. State health or other departments have important responsibilities related to protecting and improving the health and health care of the population statewide, and are key players in ensuring the adoption of standards and collection of data. However, providers and plans have reported that they receive conflicting data requests from different agencies within the same state. Categories for race, ethnicity, and language can be selected at the state level, with careful consideration of local as well as national stakeholder needs when categories are defined for statewide aggregation and reporting for insurance program quality measures, disease registries, birth and death vital statistics, hospital discharges, health care surveys, patient safety reporting, and other activities. State-level aggregation and reporting can help illuminate the health care issues of population groups whose disparities may not be apparent because of small sample sizes at the local level.

As large purchasers of care through Medicaid and CHIP programs, states have leverage with managed care organizations and providers. States can use this leverage to ensure that health care entities collect the recommended race, ethnicity, and language data and use findings from analyses of these data to design quality improvement efforts. Medicaid provides coverage for a large portion of minority groups; thus, states have an interest in ensuring that the population covered is receiving appropriate levels of care (Angeles and Somers, 2007). Currently, some states report their HEDIS measures by race and ethnicity, and others do not (Michigan Department of Community Health, 2009; NC Department of Health and Human Services, 2009).

The subcommittee concludes that state entities can play a central role as aggregators and disseminators of provider, plan, community, and state-level quality improvement data.

> **Recommendation 6-4: Through their certification, regulation, and monitoring of health care providers and organizations within their jurisdiction, states should require the collection of data on the race, Hispanic ethnicity, granular ethnicity, and language need variables as outlined in this report so these data can be used to stratify quality performance metrics, organize quality improvement and disparity reduction initiatives, and report on progress.**

Although it was beyond the scope of the subcommittee's deliberations to determine the extent of the need, representatives of state data agencies noted that one of the greatest barriers to state health departments, Medicaid agencies, and regulatory agencies in fulfilling responsibilities related to certification, regulation, and monitoring activities has been the lack of funding to expand and improve state data collection activities. The collection of race, ethnicity, and language data across providers and plans in a community and state requires resources for rulemaking, provider training, implementation of reporting, and assurance of data quality, yet many states are cutting back their data reporting initiatives, including a reduction in workforce, because of state budget limitations (NRC, 2003).[16]

SUMMARY

Efforts are under way to institute national standards for technology, performance measurement, and data aggregation and exchange that complement local data collection and experiences with performance improvement and reporting (HHS, 2009c; Roski, 2009). To date, it has been difficult to either combine or compare performance data stratified by race, ethnicity, or language across payment and delivery systems, which has limited the utility of such data for assessing the performance of the health care system as a whole or in specific geographic areas with respect to disparities in care. Standardization of the categories of race, ethnicity, and language data will promote greater comparability of data collected directly by providers or health plans or, for instance, transferred from providers to plans. Estimates of health care disparities derived through indirect estimation techniques, such as geocoding and surname analysis, can provide a helpful bridge until directly collected demographic data are more universally available.

The subcommittee has proposed a framework for the collection of race, ethnicity, and language data that it believes would facilitate the collection of data by individual entities, the comparison of quality of care received by specific groups across entities and regions, and the combination of data for purposes of analyzing health care needs and identifying disparities. While important disparities in quality of care can be identified among the race and ethnicity groups captured by the OMB categories, those categories often are not sufficiently descriptive of local and state populations because of the diversity of ethnic groups in different parts of the country, states, or specific communities. A number of analyses have identified disparities among members of more granular ethnic categories that are masked by the aggregate OMB categories. More discrete population data could be used to identify opportunities for quality improvement and outreach without inappropriate or inefficient targeting of interventions to an entire broad racial or ethnic category.

The subcommittee recommends for quality improvement purposes: (1) the collection and use of data on granular ethnicity and language need, allowing local providers, communities, or states to select sets of categories from

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[16] Personal communication, D. Love, National Association of Health Data Organizations, and B. Rudolph, The Leapfrog Group, January 13, 2009.

national standard lists that are most informative about the populations they serve, and (2) the continued collection of data in the OMB race and Hispanic ethnicity categories to support consistency across as many complementary data collection efforts as possible (e.g., poverty statistics, educational attainment). The national categories should be consistently coded to foster exchange among systems of like data categories across providers, states, plans, or payers for aggregation or comparison purposes. Given space constraints of paper forms or intake screens, local category lists may be limited in the number of choices; electronic collection systems can often be designed to collect many more categories than would be optimal on paper forms. The categories used should be descriptive of the population served, reflect quality issues related to the health and health care of that population, and take into account evidence or the likelihood of disparities among ethnic groups within the population. To ensure that each individual has the opportunity to self-identify and that these identifiers will be captured, there should always be an opportunity to add ethnicities and languages not contained on a list of check-off boxes. Therefore, an open-ended "Other, please specify: ____" response option should be incorporated for both granular ethnicity and language when a limited list of categories is presented for response. These responses can help identify when additional categories may need to be added to prespecified lists on data collection instruments.

Many actors play a role in health care delivery and quality assessment, and each has a role to play in furthering the collection of meaningful race, ethnicity, and language data for quality improvement. National development of standardized categories by HHS, along with a responsive updating process, would relieve each state and entity of having to develop its own set of categories and coding scheme, which could be incompatible with others. The collection of these data in accordance with the framework proposed in this report should be reflected in guidance to recipients of HHS and state funding, incorporated into the accreditation standards and performance measurement endorsements of accreditation and standards-setting organizations, and coordinated across federal health care delivery systems.

Collecting race, ethnicity, and language data using standard categories can help promote equity through enhanced patient–provider communication and the provision of evidence-based quality care. Achieving the goals of quality care requires monitoring to ensure that all populations receive patient-centered, safe, effective, timely, efficient, and equitable care.

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Appendix A

Acronyms and Abbreviations

ACRONYMS

ACS	American Community Survey
ADA	Americans with Disabilities Act of 1990
AHA	American Hospital Association
AHIP	America's Health Insurance Plans
AHRQ	Agency for Healthcare Research and Quality, HHS
AIAN	American Indian or Alaska Native
AMA	American Medical Association
AMIA	American Medical Informatics Association
ARRA	American Recovery and Reinvestment Act of 2009
ASPE	Office of the Assistant Secretary for Planning and Evaluation, HHS
BRFSS	Behavioral Risk Factor Surveillance System
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CCHIT	Certification Commission for Healthcare Information Technology
CDC	Centers for Disease Control and Prevention
CHC	Community Health Center
CHD	Coronary Heart Disease
CHIP	Children's Health Insurance Program
CHIS	California Health Interview Survey
CLAS	Culturally and Linguistically Appropriate Services
CMS	Centers for Medicare and Medicaid Services
CPS	Current Population Survey
DMHC	California Department of Managed Health Care
ED	Emergency Department
EHR	Electronic Health Record
ELPS	English Language Proficiency Survey
ESRD	End Stage Renal Disease
HCUP	Healthcare Cost and Utilization Project
HHS	U.S. Department of Health and Human Services

HIPAA	Health Insurance Portability and Accountability Act
HIT	Health Information Technology
HITSP	Health Information Technology Standards Panel
HL7	Health Level 7
HRET	Health Research & Educational Trust
IOM	Institute of Medicine
ISO	International Organization for Standardization
LEP	Limited English Proficiency
MEDS	Medi-Cal Eligibility Data System
MEPS	Medical Expenditure Panel Survey
MIPPA	Medicare Improvements for Patients and Providers Act of 2008
NAMCS	National Ambulatory Medical Care Survey
NCHS	National Center for Health Statistics
NCQA	National Committee for Quality Assurance
NCVHS	National Committee on Vital and Health Statistics
NHAMCS	National Hospital Ambulatory Medical Care Survey
NHANES	National Health and Nutrition Examination Survey
NHDR	National Healthcare Disparities Report
NHeLP	National Health Law Program
NHIS	National Health Interview Survey
NHOPI	Native Hawaiian or Other Pacific Islander
NHPC	National Health Plan Collaborative
NHQR	National Healthcare Quality Report
NIS	National Immunization Survey
NLAAS	National Latino and Asian American Study
NQF	National Quality Forum
NRC	National Research Council
NSDUH	National Survey on Drug Use and Health
NVSS	National Vital Statistics System
OCR	Office for Civil Rights, HHS
OMB	Office of Management and Budget
OMH	Office of Minority Health, HHS
ONC	Office of the National Coordinator for Health Information Technology, HHS
PHIN	Public Health Information Network
PHR	Personal Health Record
PQRI	Medicare Physician Quality Reporting Initiative
PUMS	Public Use Microdata Samples
QI	Quality Improvement
RAETT	U.S. Census Bureau’s 1996 Racial and Ethnic Targeted Test
RWJF	Robert Wood Johnson Foundation
SEER	Surveillance, Epidemiology, and End Results
SES	Socioeconomic Status
SSA	Social Security Administration
SSN	Social Security Number
TDD	Telecommunication Device for Deaf Persons
TTY	TeleTYwriter or Text Telephone
UMMC	University of Mississippi Medical Center
URAC	Formerly known as the Utilization Review Accreditation Commission
WCRS	Wisconsin Cancer Reporting System

ABBREVIATIONS

CI	Confidence Interval
MLBW	Moderately Low Birthweight
OR	Odds Ratio
RR	Relative Risk
VLBW	Very Low Birthweight

Appendix B

Legislation Cited in Report

Chapter	Legislation Cited
Summary	*American Recovery and Reinvestment Act of 2009*, Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009). *The Civil Rights Act of 1964*, Public Law 88-352, 78 Stat. 241, 88th Cong., 2d sess. (July 2, 1964). *Lau v Nichols*, 414 U.S. 563 (1974). Department of Justice. 42 USC Chapter 20 § 1973aa-1a. The Public Health and Welfare, Elective Franchise.
Chapter 1	*The Civil Rights Act of 1964*, Public Law 88-352, 78 Stat. 241, 88th Cong., 2d sess. (July 2, 1964). *Health Insurance Portability and Accountability Act of 1996*, Public Law 104-191, 104th Cong., 2d sess. (August 21, 1996). *Medicare Improvements for Patients and Providers Act of 2008*, Public Law 110-275 § 118, 110th Cong., 2d sess. (July 15, 2008). *American Recovery and Reinvestment Act of 2009*, Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009). *The Indian Healthcare Improvement Act*, Public Law 94-437, 25 U.S.C. 1603(c)-(d).
Chapter 2	*The Indian Healthcare Improvement Act*, Public Law 94-437, 25 U.S.C. 1603(c)-(d).

Chapter	Legislation Cited
Chapter 3	*Medicare Improvements for Patients and Providers Act of 2008*, Public Law 110-275 § 118, 110th Cong., 2d sess. (July 15, 2008).
	Joint resolution relating to the publication of economic and social statistics for Americans of Spanish-origin or descent, Public Law 94-311 (15 U.S.C. 1516a), 94th Cong. (June 16, 1976).
	Espinoza v. Farah Mfg. Co., 414 U.S. 86, 88 (1973).
	Children's Health Insurance Program Reauthorization Act of 2009, Public Law 111-3, 111th Cong., 1st sess. (February 4, 2009).
Chapter 4	*Children's Health Insurance Program Reauthorization Act of 2009,* Public Law 111-3, 111th Cong., 1st sess. (February 4, 2009).
	Lau v Nichols, 414 U.S. 563 (1974).
	Department of Justice. 42 U.S.C. Chapter 20 § 1973aa-1a. The Public Health and Welfare, Elective Franchise.
	Department of Justice. 28 CFR Part 36 § 36.303. ADA Standards for Accessible Design. (July 1, 1994).
	American Recovery and Reinvestment Act of 2009, Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).
	Medicare Improvements for Patients and Providers Act of 2008, Public Law 110-275 § 118, 110th Cong., 2d sess. (July 15, 2008).
	Health Care Language Assistance Act of 2003, California S.B. 853 § 1367 (October 8, 2003).
	California Health and Safety Code § 1259, (January 12, 2009).
	California Code of Regulations, Title 9 § 1810.410 (f) (3).
Chapter 5	*American Recovery and Reinvestment Act of 2009,* Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).
	The Civil Rights Act of 1964, Public Law 88-352, 78 Stat. 241, 88th Cong., 2d sess. (July 2, 1964).
	The Social Security Act of 1965, 89th Cong., 42 U.S.C. § 7, 1st sess. (July 30, 1965).
	Health Insurance Portability and Accountability Act of 1996, Public Law 104-191, 104th Cong., 2d sess. (August 21, 1996).
Chapter 6	*American Recovery and Reinvestment Act of 2009,* Public Law 111-5 § 3002(b)(2)(B)(vii), 111th Cong., 1st sess. (February 17, 2009).

Chapter	Legislation Cited
	Children's Health Insurance Program Reauthorization Act of 2009, Public Law 111-3, 111th Cong., 1st sess. (February 4, 2009).

Appendix C

Workshop Agendas

Committee on Future Directions for the National Healthcare Quality and Disparities Reports and Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement

National Academy of Sciences' Keck Building
500 Fifth Street, NW, Room 100, Washington, DC

DAY 1—MONDAY, FEBRUARY 9, 2009
ROOM 100

CLOSED SESSION (Committee and Subcommittee Members and IOM Staff Only)

7:45–10:30 AM

END CLOSED SESSION-START OPEN SESSION

Public Workshop

11:00 **Welcome and Introductory Remarks**
Sheila Burke, Chair and Moderator

Session 1:	**Setting Future Directions for the National Healthcare Quality Report (NHQR) and National Healthcare Disparities Report (NHDR)**

11:05 **Lessons Learned in Developing NHQR and NHDR**
Earnest Moy, MD, MPH, Team Lead, NHQR & NHDR, Center for Quality Improvement and Patient Safety, Agency for Healthcare Research and Quality (AHRQ), HHS

11:45 **Remarks from Study Sponsor**
Carolyn Clancy, MD, Director, AHRQ, HHS

END OPEN SESSION-START CLOSED SESSION

12:25 PM **Working Lunch, Committee Members Only**

END CLOSED SESSION-START OPEN SESSION

Session 2:	Race/Ethnicity/Language Data Categories: Definitions, Collection, Aggregation, and Reporting for Quality Improvement

1:00 **Welcome**
David Nerenz, Subcommittee Chair and Moderator

1:05 **Rationale for Expanded Race/Ethnicity Data Collection and Lessons from the National Health Plan Collaborative**
Nicole Lurie, MD, MSPH, Director, RAND Center for Population Health and Health Disparities

1:40 **Standardizing Race/Ethnicity Categories Across a State and Within a Health Plan**
- *Kalahn Taylor-Clark, PhD, MPH, Senior Associate, Engelberg Center for Healthcare Reform, High Value Health Care Initiative, The Brookings Institution*
- *Kathryn L. Coltin, MPH, Director, External Quality Data Initiatives, Harvard Pilgrim Health Care*

2:20 **Break**

2:30 **Incorporating Language Needs into Quality Improvement**
- *Mara Youdelman, JD, LLM, Staff Attorney, National Health Law Program (NHeLP)*
- *Marsha Regenstein, PhD, Associate Research Professor and Co-Director Center for Health Care Quality, George Washington University*

3:00 **Current and Future Federal Standards for Race/Ethnicity/Language Data**
- *Katherine K. Wallman, BA, Chief Statistician, U.S. Office of Management and Budget*
- *Karen Humes, MA, Assistant Division Chief for Special Population Statistics, Population Division, U.S. Census Bureau*

3:50 **The HRET Toolkit and Hospital Data Collection**
Romana Hasnain-Wynia, PhD (Subcommittee Member), Director, Center for Healthcare Equity and Associate Professor, Institute for Healthcare Studies, Northwestern University, Feinberg School of Medicine

4:15 **Experiences of SEER and NHIS**
- *Brenda Edwards, PhD, Associate Director, Surveillance Research Program, Division of Cancer Control & Population Sciences, National Cancer Institute*
- *Jennifer Madans, PhD, Associate Director for Science, National Center for Health Statistics*

5:00 **Gathering Data on Subpopulations Beyond OMB Categories**
Deeana Jang, JD, Policy Director, *Asian & Pacific Islander American Health Forum, presenting for Out of Many, One (OMO) Health Data Taskforce*

5:25 **Questions from the Public**

5:35 **Adjourn**

END OPEN SESSION-START CLOSED SESSION

DAY 2—TUESDAY, FEBRUARY 10, 2009
ROOM 100

CLOSED SESSION (Committee and Subcommittee Members and IOM Staff Only)

7:45 AM **Continental Breakfast**

END CLOSED SESSION-START OPEN SESSION

Public Workshop

8:05 **Welcome**
Sheila Burke, Chair and Moderator

Session 3:	**Initiatives in Data Aggregation and Quality Measurement**

8:10 **Roadmap for Coordinated Quality Measurement and Reporting**
Joachim Roski, PhD, MPH, Managing Director, High-Value Health Care Project, Engelberg Center for Health Care Reform, The Brookings Institution

Physician-level Quality Measurement and Reporting
Karen Kmetik, PhD, Director, Clinical Performance Evaluation, American Medical Association and The Physician Consortium for Performance Improvement

9:15 **National Priorities Partnership's Priority Areas and Corresponding Goals**
Karen Adams, PhD, MT, Vice President, National Priorities, National Quality Forum

10:00 **Advancing Quality Improvement**
Don Berwick, MD, MPP, President and CEO, Institute for HealthCare Improvement

10:35 **Break**

Session 4:	**Select Federal Data Improvement Efforts**

10:50 **CMS' Recommendations for NHQR and NHDR and for Data Improvement**
- *Thomas Reilly, PhD, Deputy Director, Office of Research, Development and Information, Centers for Medicare and Medicaid Services (CMS)*
- *Paul McGann, MD, Deputy Chief Medical Officer, Office of Clinical Standards and Quality, CMS*

Lessons from Healthcare Cost and Utilization Project
Irene Fraser, PhD, Director Center for Delivery, Organization, and Markets, AHRQ

END OPEN SESSION-START CLOSED SESSION

12:00–3:00 PM

Committee on Future Directions for the National Healthcare Quality and Disparities Reports and Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement

Hyatt Regency Newport Beach
1107 Jamboree Road, Terrace Room, Newport Beach, CA

DAY 1—WEDNESDAY, MARCH 11, 2009
TERRACE ROOM

CLOSED SESSION (Committee and Subcommittee Members and IOM Staff Only)

7:45 AM–12:45 PM

END CLOSED SESSION-START OPEN SESSION

Public Workshop

12:45 **Welcome**
Sheila Burke, Chair and Moderator

12:50 **Defining Race, Ethnicity and Language Populations**
- *Marjorie Kagawa-Singer, PhD, MN, RN, Professor, UCLA School of Public Health and Professor, Department of Asian American Studies*
- *Gayle Tang, MSN, RN, Director, National Linguistic & Cultural Programs, National Diversity, Kaiser Permanente*

1:35 **Accounting for Diversity in Quality Improvement**
- *Michael Rodriguez, MD, MP, Associate Professor and Vice Chair of Research, George F. Kneller Endowed Chair in Family Medicine, Department of Family Medicine, David Geffen School of Medicine, UCLA*
- *Ron Hays, PhD, Professor, Division of General Internal Medicine and Health Services Research, UCLA*

2:20 **Quality Measurement**
- *Andrew Bindman, MD, Professor of Medicine, Health Policy Epidemiology and Biostatistics, UCSF and Director of CaMRI (CA Medicaid Research Institute)*
- *Patrick Romano, MD, MPH, Professor, Divisions of General Medicine and General Pediatrics, Center for Healthcare Policy and Research, UC Davis*

3:05 **Public Comment**

3:15 **Break**

END OPEN SESSION-START CLOSED SESSION

3:25–5:15

5:15 **Adjourn**

DAY 2—THURSDAY, MARCH 12, 2009
TERRACE ROOM

CLOSED SESSION (Committee and Subcommittee Members and IOM Staff Only)

7:45–8:40 AM

END CLOSED SESSION-START OPEN SESSION

Public Workshop

8:40 **Welcome**
Sheila Burke, Chair and Moderator

8:45 **Direct Collection and Indirect Estimation of Race/Ethnicity/Language Data**
- *Marc Elliott, PhD, Senior Statistician, RAND*
- *Allen Fremont, MD, PhD, Natural Scientist and Sociologist RAND Corporation*
- *Grace Ting, MHA, Health Services Director, Health Equities Programs, Wellpoint, Inc.*

9:50 **Break**

10:00 **Priorities for Quality Improvement and Ways to Leverage Collected Information**
- *David Lansky, PhD, President and CEO, Pacific Business Group on Health*
- *Maribeth Shannon, MS, Director, Market and Policy Monitor Program, California Healthcare Foundation*
- *Thomas Williams, MPH, MBA, Executive Director, Integrated Healthcare Association*

11:15 **Public Comment**

END OPEN SESSION-START CLOSED SESSION

11:30 AM–3:00 PM

Appendix D

Subcommittee Member and Staff Biographies

SUBCOMMITTEE

David R. Nerenz, Ph.D. (*Chair*), is the Director of the Center for Health Services Research at the Henry Ford Health System, Detroit, Michigan. He is also Director of Outcomes Research in Henry Ford's Neuroscience Institute. Dr. Nerenz received his doctorate in Social Psychology from the University of Wisconsin-Madison in 1979. From 1980 to 1984 he did research at the Wisconsin Clinical Cancer Center and was also Coordinator of Health Services Research for the Wm. S. Middleton Veterans Hospital in Madison. From 1984 to 1986 he was Director of the VA's Great Lakes Regional HSR&D Field Program in Ann Arbor. He has been at the Henry Ford Health System since 1987. For the past 10 years, he has led a series of demonstration projects on health plans' collection and use of data on race and ethnicity to eliminate disparities in quality of care. His areas of expertise include: performance measures for health care organizations; racial/ethnic disparities in quality of care; and use of patient-reported outcomes data to assess and compare health care providers.

Margarita Alegría, Ph.D., is a professor of psychology in the Department of Psychiatry at Harvard Medical School and currently serves as the Principal Investigator of three National Institutes of Health-funded research studies. Her research focuses on how to improve health care service delivery for diverse racial and ethnic populations; patient–provider interaction when treating multicultural populations; and how to bring the community's perspective in the design and implementation of health services. Dr. Alegría also conducts research that will contribute to understanding the factors influencing mental health and substance abuse service disparities, and testing interventions aimed at reducing these disparities. Her published work centers on the effects of immigration and integration into the United States on mental health among Latinos, Asians, and Afro-Caribbeans. Dr. Alegría has conducted epidemiologic research on the generalizability of the immigrant paradox (that being foreign-born is protective against psychiatric disorders). Her recent research has examined the complex factors related to the mental health of Latino immigrant children, such as increased risk of trauma, high school dropout and lack of access to adequate health care. As a result of her contributions, Dr. Alegría received the 2003 Mental Health Section Award of the American Public Health Association, the 2006 Greenwood Award for Research Excellence, and the 2007 Latino Mental Health Scientific Leadership Award given by New York University. In 2008, she received an APA Presidential recognition for her disparities work by the American Psychological Association, the National Award for Excellence in Research by a Senior Investigator from the National Hispanic Science Network, and the Carl Taube Award given by the Mental Health Section of the American Public Health Association. She is a member of the

Institute of Medicine's Public Health Board and past Chair of Academy Health. She also serves on several other boards, including the National Academy of State Health Policy and the Health Services Research Journal.

John Z. Ayanian, M.D., M.P.P., is a professor of medicine and health care policy at Harvard Medical School and a professor of health policy and management at the Harvard School of Public Health. He is the director of the Harvard Fellowship in General Medicine and Primary Care and director of the General Medicine Fellowship at Brigham and Women's Hospital. He is also a practicing general internist in the Division of General Medicine at Brigham and Women's Hospital, where he sees patients and teaches medical residents. Dr. Ayanian's research focuses on the effect of patients' race, ethnicity, gender, insurance coverage, and socioeconomic characteristics on access to care and clinical outcomes, as well as the impact of physicians' specialty and organizational characteristics on the quality of care. He is the principal investigator of the Harvard/Northern California research team in the Cancer Care Outcomes Research and Surveillance (CanCORS) Consortium, a multi-regional initiative funded by the National Cancer Institute to evaluate the experiences and outcomes of patients with colorectal cancer and lung cancer. He also leads an NCI-funded study evaluating randomized interventions to improve systems for colorectal cancer screening. Dr. Ayanian's recent research has studied trends in quality of care and racial disparities in Medicare managed care plans, the effect of Medicare coverage on previously uninsured adults, the impact of ambulatory care from primary care physicians and cardiologists on the outcomes of Medicare beneficiaries who have survived a heart attack, the relation of surgical volume to outcomes of colorectal cancer, and patients' perceptions of the quality of cancer care by race, ethnicity, and language. His previous research includes studies of the effects of race and gender on access to kidney transplants and cardiac procedures, and the quality of care for common medical conditions in teaching and nonteaching hospitals.

Ignatius Bau, J.D., is a Program Director at the The California Endowment, a private statewide health policy foundation. He focuses on issues of language access, cultural competency, health workforce diversity, and reduction of health care disparities and currently oversees grants to several national quality, health care accreditation and health professions educational accreditation organizations, as well as to hospitals and health systems, health plans, physician organizations, community health centers, health professions educational institutions, and community-based organizations throughout California. Bau previously worked as a program manager and policy director at the Asian and Pacific Islander American Health Forum (APIAHF) and as a staff attorney at the Lawyers' Committee for Civil Rights of the San Francisco Bay Area. Bau and APIAHF led community efforts that resulted in the creation of the White House Initiative on Asian Americans and Pacific Islanders and he was the principal author of the first report from the President's Advisory Commission on Asian Americans and Pacific Islanders. He has served on the board of directors of numerous organizations, including Funders for Lesbian and Gay Issues, the National Minority AIDS Coalition, the Northern California Coalition for Immigrant and Refugee Rights, the Asian and Pacific Islander Wellness Center, and the California Budget Project and on several government committees, including the President's Advisory Council on HIV/AIDS, the Centers for Disease Control and Prevention's National HIV Prevention Planning Group, and the California Department of Health's Task Force on Multicultural Health. He has been a member of the Institute of Medicine's Forum on the Science of Health Care Quality Improvement and Implementation, the Joint Commission Public Advisory Group, the National Quality Forum Work Group on Minority Healthcare Quality Measurement, and several Technical Advisory Committees for the California Health Interview Survey.

Roderick J. Harrison, Ph.D., is a scholar at the Joint Center for Political and Economic Studies, Howard University. Previously, he served as chief of the U.S. Census Bureau's Racial Statistics Branch where he helped to expand the content and number of the Bureau's publications and releases on racial and ethnic populations and director of DataBank, an online clearinghouse of data on African Americans and other ethnic populations. In 1998, the American Statistical Society awarded him the Roger Herriot Award for Innovations in Federal Statistics for his work in revising the racial and ethnic classifications used by all federal agencies and efforts in developing new classifications on race and ethnicity for the 2000 Census. Dr. Harrison held a joint appointment in the Afro-American Studies and Sociology departments at Harvard University and also taught at UCLA. He currently teaches in the Department of Sociology and Anthropology at Howard University. He received his Ph.D. in sociology from Princeton and his A.B. from Harvard.

Romana Hasnain-Wynia, Ph.D., is director, Center for Healthcare Equity and Associate Professor, Research at Northwestern University, Feinberg School of Medicine. Prior to joining Northwestern University, Dr. Hasnain-Wynia was vice president of research for the Health Research & Educational Trust (HRET), the research and education affiliate of the American Hospital Association, where she oversaw the overall HRET research agenda, maintained an individual portfolio of research projects focusing on equity and quality of care, and developed the HRET Toolkit on collecting race, ethnicity, and primary language information from patients, which has been endorsed by the National Quality Forum. She is the principal investigator of a number of studies examining quality of care for underserved populations and of studies that examine the impact of performance incentive programs on the health care safety net. She serves as a co-investigator on the evaluation team for the Robert Wood Johnson Foundation's national initiative, Aligning Forces for Quality, and is responsible for leading the evaluation of the disparities-equity component of the program. Dr. Hasnain-Wynia serves on a number of expert advisory panels and is Senior Associate Editor for the journal, *Health Services Research*. Dr. Hasnain-Wynia received her doctoral degree in health policy from Brandeis University's Heller School for Social Policy and Management.

Ninez Ponce, Ph.D., is an Associate Professor at UCLA's Department of Health Services. She is also Senior Research Scientist at the UCLA Center for Health Policy Research and member of UCLA/Jonsson Comprehensive Cancer Center, Division of Cancer Prevention and Control Research. Dr. Ponce's research has focused on understanding macroeconomic effects on health and health care access in low income countries, and, more recently, in low-SES neighborhoods and ethnic minorities in the United States. She was RAND's resident adviser to the Ministry of Health, Republic of Macedonia, and has worked at the World Bank, Catholic Relief Services in Thailand, the Asian and Pacific Islander American Health Forum, and the Berkeley Free Clinic. As Co-Principal Investigator of the California Health Interview Survey 2001 and 2003, she led efforts in the measurement of race/ethnicity, acculturation, physician-patient communication, and discrimination. In addition, she conceptualized the rationale and implementation of CHIS 2001's Asian ethnic oversamples and the cultural and linguistic adaptation of the survey. Dr. Ponce received a 5-year career-development award from the National Cancer Institute (NCI) to explore neighborhood effects and health care market factors that may explain persisting racial and ethnic disparities in cancer screening. Recently, NCI's Special Populations Health Network recognized Dr. Ponce as a "Rising Star" in cancer disparities research as part of her work with the Asian American Network in Cancer Awareness Research and Training. Dr. Ponce is faculty advisor to UCLA's student-run Samahang Pilipino Education and Retention (SPEAR) Project and Samahang Pilipino Advancing Community Empowerment (SPACE), and serves on several state and national committees: the Cultural and Linguistics Work Group of California's Office of the Patient Advocate, the Policy Board of the California Pan Ethnic Health Network, and the Executive Board of the Asian and Pacific Islander Caucus of the American Public Health Association.

Wayne S. Rawlins, M.D., M.B.A., is a national medical director at Aetna and Head of Medical Operations for Aetna Government Health Plans, Aetna's business unit responsible for Department of Defense uniformed services and VA customers. Prior to this, he was head of Aetna Condition Analysis, leading medical cost management activities. In addition, he is co-lead for Aetna's Racial and Ethnic Disparities in Health Care Initiatives. Dr. Rawlins is a liaison member of the National Vaccine Advisory Committee representing America's Health Insurance Plans. He also serves as the corporate clinical lead representing the chief medical officer in crisis and disaster preparedness, as well as the corporate clinical lead for pandemic planning at Aetna. Dr. Rawlins has been involved in crisis management at Aetna since September 11, 2001, when he was the senior physician in charge of clinical operations for Aetna's New York market. While at Aetna, Dr. Rawlins has served in several senior clinical operational roles prior to assuming his current role. These included head of business planning and reporting for National Medical Services reporting to Aetna's Chief Medical Officer. Prior to this he served as the regional medical director for Aetna's northeast region, providing access to health care services for more than two million members. He was senior patient management medical director for the northeast region. Dr. Rawlins also led the design, development, and implementation of Aetna's industry-leading end-of-life care program. Dr. Rawlins received his medical degree from the University of Connecticut in 1980, then completed an internal medicine residency and chief residency at the University of Rochester in New York. He is board certified in internal medicine. Dr. Rawlins received his M.B.A. from Rensselaer Polytechnic Institute in 2001. Prior to joining Aetna in 1997, he was a physician manager with the Northeast Permanente Medical Group for 13 years, treating a wide variety of patients in a busy primary care practice. He is a member of the National Medical Association, American College of Physicians, and the American College of Physician Executives.

Paul M. Schyve, M.D., is the Senior Vice President of The Joint Commission and is knowledgeable of requirements for language access in hospitals and disability issues. Prior to joining The Joint Commission in 1986, Dr. Schyve was the Clinical Director of the Illinois Department of Mental Health and Developmental Disabilities. Dr. Schyve received his undergraduate degree (Phi Beta Kappa) and his medical education and residency in psychiatry at the University of Rochester. He has held a variety of professional and academic appointments in the areas of mental health and hospital administration, including as Director of the Illinois State Psychiatric Institute and Clinical Associate Professor of Psychiatry at the University of Chicago. Dr. Schyve is certified in psychiatry by the American Board of Psychiatry and Neurology and is a Distinguished Life Fellow of the American Psychiatric Association. A former member of the Board of Directors of the National Alliance for Health Information Technology, a Founding Advisor of Consumers Advancing Patient Safety, the Chair of the Ethical Force Oversight Body of the Institute of Ethics at the American Medical Association, and a former Trustee of the United States Pharmacopeial Convention, he has published in the areas of psychiatric treatment and research, psychopharmacology, quality assurance, continuous quality improvement, health care accreditation, patient safety, the role of language, cultural competence, and health literacy in communication, and health care ethics.

Alan M. Zaslavsky, Ph.D., is a professor of health care policy (statistics) in the Department of Health Care Policy at Harvard Medical School. His methodological research interests include surveys, census methodology, microsimulation models, missing data, hierarchical modeling, small-area estimation, and applied Bayesian methodology. His health services research focuses primarily on developing methodology for quality measurement of health plans and other units and understanding the implications of these quality measurements. Other major areas include: health care disparities, psychiatric epidemiology, quality of care for cancer patients, and health effects of social networks.

STUDY STAFF

Michelle Bruno, M.P.P., is a Research Associate on the Board on Health Care Services. Michelle joined the IOM in 2007 and has contributed to a range of significant reports, including Resident Duty Hours: Enhancing Sleep, Supervision, and Safety, Retooling for an Aging America: Building the Health Care Workforce, and Opportunities for Coordination and Clarity to Advance the National Health Information Agenda. She is currently part of the staff for the Committee on the Future Directions for the National Healthcare Quality and Disparities Reports. Prior to joining the IOM, Michelle completed her master's degree in public policy with a dual concentration in health policy and public and nonprofit management at the Georgetown Public Policy Institute.

Cassandra Cacace, B.S., is a Senior Program Assistant for the Board on Health Care Services, assisting on a variety of projects, including the Committee on Continuing Education, the Committee on Resident Duty Hours and Patient Safety, and the Forum the Science of Health Care Quality Improvement and Implementation. She provides administrative and research support to the teams, as well as logistical support for all committee meetings. Prior to the IOM, Cassandra worked as a research associate at Oxford Outcomes, a health care consulting firm, where she performed outcomes research on a variety of health conditions. She is currently pursuing her master's degree in health policy from the George Washington University School of Public Health and Health Services.

Roger Herdman, M.D., born in Boston, MA, Phillips Exeter Academy, 1951; Yale University, Magna Cum Laude, Phi Beta Kappa, BS, 1955; Yale University School of Medicine, MD, 1958. Interned at the University of

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Bernadette McFadden, M.Sc., joined the Board on Health Care Services as a Research Associate in November 2008. Prior to joining the IOM, she completed a master's degree in social research at Trinity College Dublin and was employed by Dublin City Council's Homeless Agency, where she edited a volume of essays on homelessness in Ireland and wrote a report on how the city's management of public space impacts homeless persons. Her interests in health policy developed while serving as an AmeriCorps teacher in an Atlanta Public School. She graduated summa cum laude, Phi Beta Kappa, from Dickinson College in Carlisle, Pennsylvania. While in central Pennsylvania, she conducted research on local effects of implementing Medicare Part D and the state's long term care policies, interned with the Executive Policy Office of the Pennsylvania Department of Health, and served as a board member on the United Way of Cumberland County.

Adam Schickedanz, B.A., is a senior medical student at the University of California, San Francisco, graduate of Washington University in St. Louis, and Boston native. At UCSF Adam has developed a clinical focus in urban underserved patient care, while also advancing interests in professionalism and cultural competency in medical education, novel approaches to clinician-patient communication in medical decision making (particularly at the end of life), and the intersections of education and health. Adam was with the Board on Health Care Services as part of the staff and as a Mirzayan Policy Fellow through April of 2009, when he returned to UCSF to complete his MD.

Cheryl Ulmer, M.S., recently served as Co-director of the Resident Duty Hours study for the Institute of Medicine. Before that, she worked as an independent consultant on a wide-ranging set of health care issues, but with a primary focus on the delivery and content of health care services, disparities in health status across populations, options for financing and insurance, and quality of clinical care. Previous consulting work for the IOM included surveying CEOs of the state Quality Improvement Organizations and providing writing/editing services on the Pathways to Quality and the Consequences of Uninsurance series. Other illustrative independent consulting projects include: Serving Patients with Limited English Proficiency: Results of a Community Health Center Survey (NACHC, The California Endowment and National Health Law Program, 2007); Giving Back and Moving Forward, Finding a Future through Service in Community Health Corps (NACHC, 2006); Changing Lives through Service to Medically Underserved Communities (NACHC and Corporation for National Service, 2005); Assessing Primary Care Content: Four Conditions Common in Community Health Center Practice–Hypertension, Diabetes, Otitis, Asthma (HRSA, 2000); The Role of Behavioral Factors in Achieving National Health Outcomes (Robert Wood Johnson Foundation, 2004); Schools as Health Access Points for Underserved Children and Adolescents: Survey of School-based Programs (NACHC, CDC, and HRSA, 2003). She has served as a Senior Associate with MDS Associates, a health care consulting firm with public and private sector clients and in various positions within the U.S. Department of Health and Human Services including the Office of the Secretary, Assistant Secretary for Planning and Evaluation/Health; the Health Services Administration; the Health Resources Administration; Medicaid Services; and NIH. She has a master's degree from Georgetown University and a BS from Mary Washington College of the University of Virginia.

Appendix E

Subcommittee Template: Developing a National Standard Set of Granular Ethnicity Categories and a Rollup Scheme

The Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement recommends using the Office of Management and Budget (OMB) race and Hispanic ethnicity categories (Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White, American Indian or Alaska Native, and Hispanic or Latino) and using a national standard set of granular ethnicity categories based on ancestry. Not all entities collecting data will include the comprehensive list of granular ethnicity categories in their databases or on their data collection instruments as the categories most important for collection by a health plan in Boston might differ from the categories important for collection by a health system in rural Missouri. These entities can select whatever number of locally relevant categories from the national standard set to present as pre-specified categories for check-off of responses; local lists should also be capable of identifying other ethnicities for all who wish to self-identify by including an open-ended choice of "Other, please specify: __." The subcommittee believes it is important to supplement the OMB categories by collecting granular ethnicity data and to retain these in data systems so that more detailed analysis and reporting is possible than with the current OMB categories. The number of categories any entity finds necessary for analysis will vary according to the composition of the population being served or studied, whether the size of subgroups is sufficiently large to make statistically reliable comparisons, and whether the pattern of differences experienced by subgroups identifies distinct needs that are not already revealed by data aggregated into broader categories.

The national standard set must be comprehensive of the nation's population to ensure the capture of even small, geographically isolated population groups that would potentially be important in specific locales for analyses and the provision of culturally and linguistically appropriate care. Furthermore, the set must be responsive to changing demographic trends and thus must be regularly updated.

DEVELOPMENT OF THE TEMPLATE

The subcommittee did not identify a single existing category list believed to be comprehensive enough to serve as a national, standard set. For example, as discussed in Chapter 3, the Centers for Disease Control and Prevention (CDC)/Health Level 7 (HL7) Race and Ethnicity Code Set 1.0 does not include all relevant granular ethnicities. It does not, for instance, include Somali or Russian. The Massachusetts Superset was developed partially because of these noted absences in the CDC/HL7 Code Set and includes granular ethnicities that are locally relevant to the Commonwealth of Massachusetts. Demographic distributions confirm that there may be ethnic groups present across the country that may not have a large presence in Massachusetts (e.g., Navajo, which may be of importance in Arizona). Thus, the subcommittee concluded that the Massachusetts Superset provides an ample, but not complete, set of granular ethnicity categories. Similarly, the Kaiser Permanente Granular Ethnicity Code Set was determined to be representative of many, but perhaps not all, granular ethnicities.

To capture all of the granular ethnicities represented in the United States, the subcommittee reviewed the Census Bureau's Ancestry Code List. The Census Ancestry Code List is compiled from responses to the Census' open-ended ancestry question, which allows respondents to write in their lineage or ancestry.[1] Thus, the list includes a myriad of granular ethnicity categories, ranging from Hausa, an ethnic group in northern Nigeria, to more general responses of European and American.

The CDC/HL7 Code Set, Massachusetts Superset, Census Ancestry Code List, and Kaiser Permanente Granular Ethnicity Code Set interchangeably use country or place names to indicate ethnicities (i.e., Singapore to represent Singaporean). The subcommittee revised the list to represent categories with ethnicities as opposed to places, whenever possible; this is reflected in the subcommittee's template (Table E-1).

The CDC/HL7 Code Set includes an extensive list of American Indian or Alaska Native categories and codes. Thus, the CDC/HL7 Code Set may serve as the template from which entities can choose locally relevant tribal categories and codes. The Census Ancestry Code list does not include American Indian or Alaska Native tribes. The Massachusetts Superset and the Kaiser Permanente Granular Ethnicity Code Set both include limited lists of locally relevant tribes.

ADAPTION OF THE TEMPLATE TO A NATIONAL STANDARD LIST

The subcommittee presents a cumulative list of granular ethnicity categories from different sources (Table E-1) that may serve as a template from which the Department of Health and Human Services (HHS) should develop a national standard list of granular ethnicity categories with accompanying unique codes (Recommendation 6-1a). Some of these granular ethnicities have already been assigned permanent five-digit unique numerical codes by CDC/HL7. The remaining granular ethnicities included in the subcommittee template also need permanent five-digit unique numerical codes.

To indicate which categories and codes may be similar, the Public Use Microdata Sample File (PUMS) considers some Census ancestry codes to have "corresponding detailed ancestry codes" (i.e., Hausa may be said to correspond with Nigeria).[2] The subcommittee concluded that because of the large number of very specific ethnicities included on the Census Ancestry Code List, some ethnicities would be best presented as corresponding with others. Corresponding ethnicities are indicated in Table E-1 using indents. When HHS is developing codes for the granular ethnicity categories included in this template (per Recommendation 6-1a), corresponding ethnicities may have the same codes (i.e., one or more granular ethnicity categories may have the same code).

ROLLUP TO THE OMB RACE AND HISPANIC ETHNICITY CATEGORIES

Locally tailored quality improvement activities may target granular ethnicity groups without needing to relate those groups to a single OMB race category. Collecting race, Hispanic ethnicity, and granular ethnicity data separately, as the subcommittee recommends, allows reporting of the OMB categories when necessary without requiring rollup of the granular ethnicities, provided that individuals respond to all the questions asked. Nonetheless, the subcommittee recognizes that data collected under some circumstances (e.g., a reporting request for OMB-level data where only granular ethnicity is collected) cannot be used or compared with data collected using the OMB race and Hispanic ethnicity categories without the use of a rollup scheme to link granular ethnicities to the OMB categories. To examine both the feasibility and limitations of such schemes, the subcommittee mapped in Table E-1

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[1] The CDC/HL7 Code Set was developed using write-in responses to the Census questions on race and Hispanic ethnicity, not responses to the Census ancestry question. The Census ancestry list is more comprehensive than the list used to develop the CDC/HL7 Code Set.

[2] U.S. Census Bureau. 2007. *ACS 1-year PUMS code lists: Ancestry codes.* http://www.census.gov/acs/www/Products/PUMS/C2SS/CodeList/2007/Ancestry.htm (accessed June 23, 2009).

granular ethnicity responses collected from the ancestry question on Census 2000 to the OMB race and Hispanic ethnicity categories. Table E-1 uses the existing CDC/HL7 rollup scheme as a basis; the subcommittee tested the assumptions of those OMB category assignments with responses to the Census race and Hispanic ethnicity questions to determine if 90 percent of respondents giving a specific ancestry response identified with the category to which the CDC/HL7 rollup scheme assigns them.

For most granular ethnicity categories, 90 percent or more of respondents to Census 2000 did self-identify with the OMB category to which the CDC/HL7 rollup would assign them. However, Appendix F identifies a number of granular categories that do not meet the 90 percent threshold, and thus would have "no determinate OMB race classification" if this threshold was adopted. An analyst wanting to roll up the categories in Appendix F to an OMB race group or Hispanic origin would have to defer to existing OMB and Census definitions based on geographic ancestry (see Table 1-1 in Chapter 1 of the report). While many granular ethnicities can be mapped to the OMB Hispanic ethnicity category based on the existing CDC/HL7 roll-up, none of the granular ethnicities associated with the Hispanic ethnicity category can be assigned to an OMB race category with greater than 90 percent certainty. In addition, high percentages of persons who report an American Indian or Alaska Native ancestry have been known to identify as White, multiracial, or "Some Other Race" (see discussion of American Indian or Alaska Natives in Chapter 2). Similarly, substantial portions of respondents who report a Pacific Islander ancestry identify with a race besides with the Native Hawaiian or Other Pacific Islander race category. The tribal groups and Pacific Islander groups have been left by the subcommittee in the American Indian or Alaska Native and Native Hawaiian or Other Pacific Islander race categories, respectively rather than move them to a "no determinate OMB race classification." There was insufficient data to apply the 90 percent rule to all the individual subcategories under those headings.

Analysts should understand that making an assignment using a 90 percent (or any other percent) threshold or an assignment based solely on geography incurs a higher probability that the rollup assignment misclassifies individuals based upon how they would self-identify their race when asked directly about their race. The rates of misclassification, even for granular ethnicities meeting a 90 percent threshold, underscores the fact that rollup schemes only provide probabilistic assignments useful for analysis at the group or population level, and should never be used to assign an actual race to an individual's medical record.

Entities may, in some instances, want to aggregate granular ethnicity categories into broader ethnicity categories for analysis or to meet reporting requirements (e.g., aggregating all western European granular ethnicities into a broad "Western European" category). However, the granular ethnicity data should be retained in data systems when the data are shared and for use in future analysis, reporting, and service provision. The subcommittee notes that the Census ancestry code list groups ethnicities partially by geography (e.g., Western European [sans Spanish], South Asian, Sub-Saharan African) and partially by Hispanic ethnicity (e.g., Spanish, Central and South American, and West Indian).[3] The Massachusetts Superset includes 31 broader ethnicity categories and 140 sub-ethnicity categories. The sub-ethnicity categories can be aggregated to the broader ethnicity categories as needed for reporting and analysis. The subcommittee concluded though that these mid-level groups should not necessarily collapse into the OMB race categories.

The list of granular ethnicities presented below provides a baseline template for a national standard set of granular ethnicity categories. An entity can decide, based on local circumstances, whether to use 10 or 100 categories from the template for collection and/or analysis. If the entity sees an increase in the use of the "Other, please specify: __" option, it may consider adding categories to its local list. If an organization chooses not to have a preset list of categories, it will need to compile responses according to the template to ensure comparability with data collected by other entities.

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[3] U.S. Census Bureau. 2001. Ancestry code list. http://factfinder.census.gov/metadoc/ancestry.pdf (accessed June 18, 2009).

TABLE E-1 Template of Granular Ethnicity Category Lists and Coding Schemes with Rollup to the OMB Race and Hispanic Ethnicity Categories

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
Asian		2028-9	X	X	
	Asian Indian	2029-7	X[a]	X	X
	Kashmir			X	
	Andaman Islander			X	
	Andhra Pradesh			X	
	Assamese			X	
	Goanese			X	
	Gujarati			X	
	Karnatakan			X	
	Keralan			X	
	Madhya Pradesh			X	
	Maharashtran			X	
	Madras			X	
	Mysore			X	
	Nagaland			X	
	Orissa			X	
	Pondicherry			X	
	Rajasthan			X	
	Sikkim			X	
	Tamil Nadu			X	
	Uttar Pradesh			X	
	Bhutanese	2031-3	X	X	
	Baram/Burman				X
	Chinese	2034-7	X[a]	X	X
	Manchurian			X	
	Taiwanese	2035-4	X	X	X
	Tagalog				X
	Japanese	2039-6	X[a]	X	X
	Issei			X	
	Nisei			X	
	Sansei			X	
	Vonsei			X	
	Gonsei			X	
	Okinawan	2043-8		X	X
	Iwo Jiman	2048-7			
	Korean	2040-4	X[a]	X	X
	Vietnamese	2047-9	X[a]	X	X
	Katu			X	
	Ma			X	
	Mnong			X	
	Kihn/Viet				X
	Hmong	2037-0	X	X	X
	Malay				X
	Maldivian	2049-5	X	X	
	Singaporean	2051-1	X	X	X
	Punjab			X	
	Cantonese			X	

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Mongolian			X	
	Tibetan			X	
	Hong Kong			X	
	Macao			X	
	Ryukyu Islander			X	
	North Bornean			X	
	Formosan			X	
	Montagnard			X	
	Indo Chinese			X	
	Amerasian			X	
	Kazakh/Qazaq				X
	Kazakhstani				X
	Bangladeshi	2030-5	X	X	X
	Nepalese/Nepali	2050-3	X	X	X
	Bengali			X	X
	Pakistani	2044-6	X	X	X
	Sri Lankan	2045-3	X	X	X
	Singhalese/Sinhalese			X	X
	Veddah			X	
	Burmese	2032-1	X	X	X
	Shan			X	
	Cambodian	2033-9	X[a]	X	X
	Khmer			X	X
	Filipino	2036-2	X[a]	X	X
	Indonesian	2038-8	X	X	X
	Bornean			X	
	Javanese/Jawa			X	X
	Sumatra			X	
	Laotian/Lao	2041-2	X[a]	X	X
	Meo			X	
	Lao Loum/Lowland Lao				X
	Malaysian	2042-0	X	X	X
	Thai	2046-1	X	X	X
	Black Thai			X	
	Western Lao			X	
Black or African American		2054-5	X		
	Black	2056-0	X	X	
	African American	2058-6	X[a]	X	
	African	2060-2	X[a]	X	
	Botswanan	2061-0	X	X	
	Djibouti		X	X	
	Liberian	2063-6	X	X	X
	Namibian	2064-4	X	X	
	Nigerian	2065-1	X	X	X
	Fulani/Hausa			X	X
	Ibo/Igbo			X	X

continued

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Tiv			X	
	Voruba			X	X
	Zairean	2066-9	X	X	
	Angolese		X	X	
	Benin		X	X	
	Burkina Faso		X		
	Burundi		X	X	
	Cameroonian		X	X	X
	Central African Republic		X	X	
	Chad		X		
	Comoros		X		
	Congolese		X	X	X
	Ivoirian/Cote d'Ivoire		X	X	X
	Equatorial Guinea		X	X	
	Eritrean		X	X	X
	Gabon		X	X	
	Gambian		X	X	
	Ghanaian/Ghanian		X	X	
	Guinea		X	X	
	Guinea-Bissau		X	X	
	Lesotho		X	X	
	Libyan		X	X	X
	Malawi		X	X	
	Mali		X	X	
	Mauritanian		X	X	
	Mauritius		X	X	
	Mozambique		X	X	
	Reunion		X		
	Rwanda		X	X	
	Sao Tome and Principe		X		
	Senegalese/Senegal		X	X	
	Seychelles		X		
	Afrikaner			X	
	Natalian			X	
	Swazi		X	X	
	Tanzanian		X	X	X
	Togolese		X	X	X
	Ugandan		X	X	X
	Western Sahara		X		
	Zambian		X	X	
	Zimbabwean		X	X	
	Congo Brazzaville			X	
	Corsico Islander			X	
	Niger			X	
	Zulu			X	
	Tanganyikan			X	

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Zanzibar Islander			X	
	Upper Voltan			X	
	Volta			X	
	African Islander			X	
	Central African			X	
	Eastern African			X	
	Western African			X	
	Agikuyu/Kikuyu				X
	Akan				X
	Amara/Amhara				X
	Bantu				X
	Mende				X
	Oromo				X
	Shona				X
	Temne/Temme/Themne				X
	Tigrinya/Tigray/Tigraway				X
	Barbadian/Bajan	2068-5			X
	Dominica Islander	2070-1	X	X	
	Bermudan			X	
	Cayman Islander			X	
	U.S. Virgin Islander			X	X
	St Croix Islander			X	
	St John Islander			X	
	St Thomas Islander			X	
	French West Indies			X	
	Guadeloupe Islander			X	
	Cayenne			X	
	Caribbean Islander		X[a]		
	Antiguan/Burbudan			X	
	Nevis Islander/ Kittitian/Nevisian			X	X
	Grenadian			X	X
	Vincent-Grenadine Islander			X	
	St Lucia Islander/ Saint Lucian			X	X
	Afro			X	
	Bahamian	2067-7		X	X
	Jamaican	2072-7	X	X	X
	Haitian	2071-9	X[a]	X	X
	Tobagoan	2073-5	X		
	Ethiopian	2062-8	X	X	X
	Kenyan		X	X	X
	Sierra Leonean		X	X	
	Somali		X	X	

continued

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
Native Hawaiian or Other Pacific Islander		2076-8	X		X
	Polynesian	2078-4		X	
	Kapingamarangan			X	
	Maori			X	X
	Native Hawaiian/Hawaiian	2079-2		X	X
	Part Hawaiian				X
	Samoan	2080-0		X	X
	Tahitian	2081-8		X	X
	Tongan	2082-6		X	X
	Tokelauan	2083-4		X	
	Micronesian	2085-9		X	
	Other Pacific Islander	2500-7		X	
	Guamanian or Chamorro				X
	Guamanian	2087-5		X	
	Chamorro	2088-3		X	
	Mariana Islander	2089-1			
	Marshallese	2090-9		X	
	Palauan	2091-7		X	
	Carolinian	2092-5		X	
	Kosraean	2093-3		X	
	Pohnpeian/Ponapean	2094-1		X	
	Saipanese	2095-8		X	
	Kiribati/Kirabatese	2096-6		X	
	Chuukese/Trukese	2097-4		X	
	Yapese	2098-2		X	
	Melanesian	2100-6		X	
	Fijian	2101-4		X	X
	Papua New Guinean	2102-2			
	New Guinean			X	
	Papuan			X	
	Solomon Islander	2103-0		X	
	New Hebrides	2104-8			
	Australian			X	X
	Tasmanian			X	
	Australian Aborigine			X	
	New Zealander			X	X
	Cook Islander			X	
	Niuean			X	
	Nauruan			X	
	Tarawa Islander			X	
	Tinian Islander			X	
	New Caledonian			X	
	Vanuatuan			X	
	Chamolinian			X	

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
White		2106-3	X	X	
	Anglo			X	
	European	2108-9	X[a]	X	
	Central European			X	
	Southern European			X	
	English	2110-5	X	X	X
	British/Briton			X	X
	Channel Islander			X	
	Gibraltar			X	
	British Isles/ British Isles origin			X	X
	Portuguese		X[a]	X	X
	Cornish			X	
	Appalachian			X	
	Pennsylvania German			X	X
	Canadian			X	X
	Newfoundland			X	
	Nova Scotia			X	
	French Canadian			X	X
	Acadian/Cajun			X	X
	North American			X	
	French	2111-3	X	X	X
	Lorraine			X	
	Breton			X	
	Occitan			X	
	German	2112-1	X	X	X
	Bavaria			X	
	Berlin			X	
	Hamburg			X	
	Hannover			X	
	Hessian			X	
	Lubecker			X	
	Pomeranian			X	
	Saxon			X	
	Sudetenlander			X	
	Westphalian			X	
	East German			X	
	West German			X	
	Prussian			X	
	Irish	2113-9	X	X	X
	North Irish			X	
	Italian	2114-7	X	X	X
	Trieste			X	
	Abruzzi			X	
	Apulian			X	
	Basilicata			X	

continued

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Calabrian			X	
	Amalfin			X	
	Friulian			X	
	Emilia Romagna			X	
	Rome			X	
	Ligurian			X	
	Lombardian			X	
	Marche			X	
	Molise			X	
	Neapolitan			X	
	Piedmontese			X	
	Puglia			X	
	Sardinian			X	
	Tuscany			X	
	Trentino			X	
	Umbrian			X	
	Valle Daost			X	
	Venetian			X	
	San Marino			X	
	Ladin			X	
	Sicilian			X	
	Herzegovinian		X	X	X
	Polish/Pole	2115-4	X	X	X
	Kashubian			X	
	Scottish	2116-2	X	X	X
	Greek		X	X	X
	Cretan			X	
	Cyclades			X	
	Basque			X	X
	French Basque			X	
	Spanish Basque	2146-9		X	
	Azores Islander			X	
	Madeira Islander			X	
	Alsatian			X	X
	Andorran			X	
	Austrian			X	X
	Tirol			X	
	Belgian			X	X
	Walloon			X	
	Scotch Irish			X	X
	Flemish/Fleming			X	X
	Corsican			X	
	Cypriot			X	X
	Greek Cypriot			X	
	Turkish Cypriot			X	
	Danish/Dane			X	X
	Faeroe Islander			X	

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Dutch			X	X
	Frisian			X	
	Norwegian			X	X
	Finnish/Finn			X	X
	Karelian			X	
	Icelander			X	X
	Lapp			X	
	Liechtensteiner			X	
	Luxemburger			X	X
	Maltese			X	X
	Manx			X	
	Monegasque			X	
	Swedish/Swede			X	X
	Aland Islander			X	
	Swiss			X	X
	Suisse			X	
	Switzer			X	
	Romansch			X	
	Suisse Romane			X	
	Welsh			X	X
	Scandinavian			X	X
	Celtic			X	X
	Northern European			X	
	Western European			X	
	Bukovina			X	
	Silesian			X	
	Galician			X	
	Eastern European		X[a]	X	
	Carpatho Rusyn			X	X
	Carpathian			X	
	Rusyn			X	
	Albanian		X	X	X
	Azerbaijani		X	X	X
	Azeri				X
	Belorussian/Belarusian		X	X	X
	Bosniak		X		X
	Bulgarian		X	X	X
	Croatian/Croat		X	X	X
	Czech		X	X	X
	Moravian			X	
	Czechoslovakian			X	X
	Georgian		X	X	X
	Estonian		X	X	X
	Livonian			X	
	Hungarian		X		X
	Magyar			X	
	Latvian		X	X	X

continued

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Lithuanian		X	X	X
	Macedonian		X	X	X
	Montenegrin		X	X	X
	Romanian		X	X	X
	Moldavian		X	X	X
	Bessarabian			X	
	Wallachian			X	
	Serbian		X	X	X
	Slovak		X	X	X
	Slovene		X	X	X
	Sorbian/Wend			X	
	Ukrainian		X	X	X
	Lemko			X	
	Bioko			X	
	Husel			X	
	Russian		X[a]	X	X
	Muscovite			X	
	Ruthenian			X	
	Cossack			X	
	Bohemian			X	
	Finno Ugrian			X	
	Mordovian			X	
	Voytak			X	
	Gruziia			X	
	Soviet Turkic			X	
	Volga			X	
	Kalmyk			X	
	North Caucasian			X	
	North Caucasian Turkic			X	
	Ossetian			X	
	Bashkir			X	
	Chuvash			X	
	Gagauz			X	
	Mesknetian			X	
	Tuvinian			X	
	Yakut			X	
	Soviet			X	X
	Tatar			X	
	Soviet Central Asia			X	
	Turkestani			X	
	Uzbeg/Uzbek			X	X
	Uzbekistani				X
	Lebanese	2123-8	X	X	X
	Windish			X	
	Yugoslavian			X	X
	Slavic			X	X
	Tajik			X	
	Slavonian			X	

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Middle Eastern or North African	2118-8	X[a]		
	Syrian	2125-3	X	X	X
	Baluchistan			X	
	Pathan/Pashtun			X	X
	Israeli	2127-9	X	X	X
	Algerian		X	X	X
	Transjordan			X	
	Kurdish/Kurd			X	X
	Persian				X
	North African			X	
	Alhucemas			X	
	Berber/Amazigh/Imazighen			X	X
	Rio de Oro			X	
	Bahraini			X	
	Kuwaiti		X	X	X
	Omani		X	X	
	Qatar		X	X	
	Saudi/Saudi Arabian		X	X	X
	Muscat			X	
	Trucial States			X	
	Bedouin			X	
	Kuria Muria Islander			X	
	South Yemen			X	
	Aden			X	
	United Arab Emirates/Emirati		X	X	X
	Rom			X	
	Afghanistani/Afghan/Afghani	2126-1	X	X	X
	Dutch West Indian			X	X
	Egyptian	2120-4	X	X	X
	Iranian	2121-2	X	X	X
	Iraqi	2122-0	X	X	X
	Jordanian		X	X	X
	Armenian	2109-7	X	X	X
	Turkish/Turk			X	X
	Yemeni		X	X	X
	Palestinian	2124-6	X	X	X
	Gaza Strip			X	
	West Bank			X	
	Syriac			X	X
	Assyrian	2119-6	X	X	X
	Chaldean			X	X
	Mideast			X	
	Arab/Arabic	2129-5	X	X	X

continued

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
American Indian or Alaska Native		1002-5	X		
	American Indian	1004-1	X		
		553 additional categories			52 additional categories
	Alaska Native	1735-0	X		
	Alaska Indian	1737-6	X		
		271 additional categories			7 additional categories
No determinate OMB race classification					
	Brazilian		X[a]	X	X
	Cape Verdean		X[a]	X	X
	Belizean		X	X	X
	Guyanese		X	X	X
	German from Russian			X	X
	Creole			X	X
	American		X[a]	X	X
	Madagascan	2052-9	X	X	
	Tunisian		X	X	X
	Surinam			X	
	Trinidadian	2074-3	X	X	X
	West Indian	2075-0	X	X	X
	British Virgin Islander			X	
	British West Indian			X	X
	Moroccan		X	X	X
	Dominican	2069-3	X[a]	X	X
	South African		X	X	
	Sudanese		X	X	X
	Dinka			X	
	Nuer			X	
	Fur			X	
	Baggara			X	
	East Indian			X	X
	Eurasian			X	
Hispanic or Latino		2135-2			
	Latin American			X	
	Latino			X	
	Hispanic			X	
	Californio			X	
	Tejano			X	
	Nuevo Mexicano			X	
	Spanish American			X	
	Spanish/Spaniard	2137-8	X	X	X
	Andalusian	2138-6		X	
	Asturian	2139-4		X	
	Castillian	2140-2		X	
	Catalonian	2141-0		X	

TABLE E-1 Continued

OMB Race and Hispanic Ethnicity Category	Granular Ethnicity	CDC/HL7 Race and Ethnicity Code Set 1.0	Massachusetts Superset[a]	Census Ancestry Codes[b]	Kaiser Permanente Granular Ethnicity Code Set[c]
	Belearic Islander	2142-8		X	
	Gallego	2143-6		X	
	Valencian	2144-4		X	
	Canarian	2145-1		X	
	Salvadoran	2161-8	X[a]	X	X
	Central American	2155-0	X[a]	X	
	Costa Rican	2156-8	X	X	X
	Nicaraguan	2159-2	X	X	X
	Panamanian	2160-0	X	X	X
	Canal Zone	2163-4		X	
	Central American Indian	2162-6	X	X	X
	Guatemalan	2157-6	X[a]	X	X
	Honduran	2158-4	X[a]	X	X
	Mexican	2148-5	X[a]	X	X
	La Raza	2152-7	X	X	
	Mexican American	2149-3	X	X	
	Mexicano	2150-1	X	X	
	Chicano	2151-9	X	X	
	Mexican American Indian	2153-5	X	X	X
	Mexican State			X	
	South American	2165-9	X[a]	X	
	Argentinean/Argentine	2166-7		X	X
	Bolivian	2167-5		X	X
	Chilean	2168-3		X	X
	Colombian	2169-1	X[a]	X	X
	Ecuadorian	2170-9		X	X
	Paraguayan	2171-7		X	X
	Peruvian	2172-5		X	X
	Uruguayan	2173-3		X	X
	Venezuelan	2174-1		X	X
	South American Indian	2175-8	X	X	X
	Criollo	2176-6		X	
	Puerto Rican	2180-8	X[a]	X	X
	Cuban	2182-4	X[a]	X	X
Other ethnicity		2131-1	X[a]		

[a] The Massachusetts Superset includes 31 ethnicity categories and additional "sub-ethnicities" that are not required for reporting but that an organization can collect, if useful. Acute care hospitals and health plans are required to report the basic OMB race categories along with the 31 granular ethnicity categories noted in this table with a footnote (a).

[b] The Census Ancestry codes do not roll up to the OMB race and Hispanic ethnicity categories. There are grouped into more broad categories based on geography: Western Europe, Eastern Europe and Soviet Union, Europe, Hispanic (including Spain), West Indies (except Hispanic), Central and South America (except Hispanic), sub-Saharan African, South Asia, Other Asia, Pacific, and North America (except Hispanic).

[c] The Kaiser Permanente list also includes "Jew/Jewish."

Appendix F

Granular Ethnicities with No Determinate OMB Race Classification

The Subcommittee recommends collecting an individual's Hispanic ethnicity, race, and granular ethnicity. Separate questions to collect these data ensure the ability to report Office of Management and Budget (OMB)-compliant data without needing to aggregate granular ethnicity categories back to one of the six OMB categories (e.g., an individual can self-identify as Asian, non-Hispanic, and of Laotian ancestry and all of these data should be retained in a data system). Nevertheless, in some instances, granular ethnicity data may need to be rolled up to one of the OMB categories for purposes of analysis or reporting. For example, an individual may not have responded to the question on race and only responded to the question on granular ethnicity. If the individual's health plan is required to report data to the state using only the OMB race and Hispanic ethnicity categories, the health plan may want to aggregate the individual's granular ethnicity to an OMB category, whenever possible.

Aggregating data to the OMB race categories through rollup schemes, though, may inevitably contradict or misrepresent an individual's self-identification as not all Americans of South African descent are Black, for example. An individual's granular ethnicity does not automatically determine his or her race; consequently, any rollup scheme may falsely classify some individuals. Certain granular ethnicity categories are more prone to misclassification than others, primarily because several individual races as well as multiracial persons are represented within a single ethnicity.

The subcommittee identified some of these ethnicities by cross-tabulating write-in responses to Census ancestry data by the OMB single-race and Hispanic ethnicity categories. Since many of the ethnicity groups had large proportions of individuals who reported more than one race, the subcommittee then cross-tabulated the ancestry responses with "alone or in combination with one or more other races" variable for each OMB group to see if 90 percent or more in the ethnicity group reported an OMB race either alone or in combination with another race.[1] Many of the granular ethnicities that fell short of a 90 percent threshold based on single-race reporting exceeded that threshold when the identification was based on reporting the race group alone or in combination with other races.

Many of the granular ethnicity categories that still could not be assigned to an OMB race category using the 90 percent threshold for responses "alone or in combination" represented populations with long histories of intermarriage and multiracial identity (e.g., Native Hawaiian or Other Pacific Islander, American Indian or Alaska

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[1] The 90 percent rule used in this analysis is not the only method for identifying granular ethnicity categories that cannot or should not be rolled up to one of the OMB categories. Census 2010, for example, is, when necessary, rolling up write-in responses based on the OMB definitions of each race and Hispanic ethnicity category. Then, all sub-Saharan African ethnicities will be coded as Black, where necessary for analysis.

Native). These granular ethnicity categories could be assigned to the OMB race category of the same name on the basis of the OMB definitions for the Native Hawaiian or Other Pacific Islander and American Indian or Alaska Native categories. However, it is important to note that this assignment misclassifies many individuals based on the OMB race with which they would self-identify given the opportunity.

Additionally, Table F-1 includes granular ethnicities that are rolled up differently by different coding schemes. For example, the Centers for Disease Control and Prevention (CDC)/Health Level 7 (HL7) Race and Ethnicity Code Set 1.0 considers Madagascan in its Asian category while the Massachusetts Superset considers Madagascan under both Asian and African category. Thus, this ethnicity is included in Table F-1 and may be said to have "no determinate OMB race classification."

The subcommittee suggests that the Department of Health and Human Services (HHS) take into account that some ethnicities do not correspond with one specific OMB race category and that when rollup is necessary, these granular ethnicities be included in a category labeled "no determinate OMB race classification."

TABLE F-1 Granular Ethnicities That Cannot Be Rolled Up to an OMB Race Category with Greater Than 90 Percent Certainty

		OMB race categories (% of the population)					
Write-in Response to Census Ancestry Question	Population	White Alone or in Combination	Black or African American Alone or in Combination	AIAN Alone or in Combination	Asian Alone or in Combination	NHOPI Alone or in Combination	Some Other Race Alone or in Combination
Brazilian	177,483	77.3	3.3	0.4	0.2	0.0	30.3
Cape Verdean	76,476	15.7	45.4	2.0	0.8	0.9	58.4
Belizean	38,443	14.4	66.1	3.2	1.2	0.8	27.1
Guyanese	162,170	3.1	58.2	3.1	23.1	1.0	26.6
German from Russia	9,968	75.8	42.7	1.9	0.4	0.1	3.6
Creole American	18,821	19.3	73.2	5.1	0.8	0.0	27.5
Madagascan*							
Tunisian*							
Surinam*							
Trinidadian	160,715	4.4	88.8	1.4	8.0	1.2	9.3
West Indian	152,218	6.9	87.1	3.4	3.1	2.0	17.4
Moroccan	37,219	76.5	17.4	1.3	4.8	0.3	25.7
Dominican	915,208	30.0	14.8	1.5	0.9	0.3	62.3
South African	43,472	86.5	9.0	0.1	2.1	0.0	7.9
Sudanese	13,420	5.6	79.7	0.3	1.1	0.0	28.8
East Indian	61,510	8.5	10.9	2.9	83.1	2.1	15.2
Eurasian	12,473	68.8	0.6	1.5	40.0	2.0	27.3

* The granular ethnicities marked with an asterisk do not include percents of the population because the population size was too small for analysis in the 2000 Public Use Microdata Samples (PUMS).

Appendix G

Kaiser Permanente: Evolution of Data Collection on Race, Ethnicity, and Language Preference Information

NATIONAL DIVERSITY

KAISER PERMANENTE

Evolution of Data Collection on Race, Ethnicity, and Language Preference Information
June, 2009

Introduction

Kaiser Permanente is nationally recognized for its innovation and groundbreaking initiatives in health care. Over the years, we have continuously assessed the needs of our membership and public community, and proactively designed programs and solutions to meet the new challenges. Race, Ethnicity, and Language Data Collection underscores our commitment toward the elimination of health disparities and inequities for racial, ethnic, and linguistic groups.

Kaiser Permanente Policy

With the advocacy and leadership of our National Diversity Council, the *Member Demographic Data Collection Initiative* on Race, Ethnicity, and Language preference information became an organizational policy in 2004.

The objectives of the policy extend beyond collecting information for compliance reasons; it is intended to inform patient-centered care, culturally and linguistically competent care and services, and the elimination of health and health care disparities/inequities. Timely, valid, and representative data collection is essential to the provision of quality and equitable care.

Data Collection Improvement Process

As our commitment to continuous quality improvement, Kaiser Permanente National Diversity recommended several updates and modifications for *KP HealthConnect*, our electronic medical/health record system. These accepted recommendations are based on research and collaborative input from various stakeholders and constituents to improve Race, Ethnicity, and Language data collection.

During the initial phase of data collection, we utilized an approach that was common throughout the industry, which was to ask for the Office of Management and Budget (OMB) federal 'Race' and 'Ethnicity'[*] categories. We addressed the need to identify diverse sub-populations by also including a limited number of detailed groups.

At that juncture, our technical systems were not designed to house granular information separately on subpopulation groups, therefore, granular descriptions were coupled to the OMB federal standards to accommodate compliance and reporting needs.

During initial implementation, important concerns were raised, which included the following:

- ***The need for more granular categories for ethnicity***
- ***The feedback that Hispanic/Latino patients felt uncomfortable selecting 'Race' categories that they may not identify with***
- ***The issue of coupling of federal standards to granular information did not allow for self-identification***

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[*] 'Race' in quotes refers to the federal OMB defined race standards. 'Ethnicity' in quotes refers to the federally defined OMB ethnicity standards.

To address these concerns, in 2005, our National Diversity office undertook a comprehensive assessment, review, and analysis of industry collection standards, practices, and lessons learned as well as integrating notable work and contributions from the fields of public health, sociology, law, race relations, journalism, demography, and statistics.

During this assessment for quality improvement, collective discovery concluded that a new collection framework was needed. We explored and were able to identify technological innovations in our electronic medical/health record system that offered viable options in how the data fields and code sets could be built to accommodate the proposed changes.

We seized the opportunity to improve data collection by 1) further understanding the constructs of Race, Ethnicity, and Language as well as their intersections in-depth and 2) developing organizational structure, decision making processes, and guiding principles that would advance uniform, standardized, and systematic data collection.

Code Selection Process

The Race, Ethnicity, and Language Code Sets that were developed represent the first phase of Kaiser Permanente's *Member Demographic Data Collection Initiative* on Race, Ethnicity, and Language. Our Code Sets are open and responsive to accommodate preferred self-identification as well as changes in national/international developments and demographic trends.

Granular Ethnicity

Kaiser Permanente examined the significance of ethnicity in the context of health, and concluded that the creation of a more encompassing definition of *Ethnicity* was needed. *Granular Ethnicity* would be able to capture patient data at a level that would inform beyond the limited federal standards to ensure timely, valid, and representative data collection.

The Code Sets are reviewed on an on-going basis primarily to ensure alignment with changing demographic trends in the United States as well as relevance in culturally and linguistically competent care and patient-centered care.

Ongoing Analysis and Review for Comparability (Selected Examples Provided)

National Data Sets and Resources
- *U.S. Decennial Census/American Community Survey*
- *Yearbook of Immigration Statistics*

Health Surveys and Research (Population or Region Specific)
- *California Health Interview Survey*
- *National Latino and Asian American Study*

Transnational and International Data Sets and Resources
- *United Nations Statistics Division*
- *World Health Organization*

Data Aggregation (Roll-Up)

Kaiser Permanente's collection framework is asking the two part question separately (Combined Format and Granular Ethnicity), thereby eliminating the need/use of automatic linkage and data aggregation (commonly known as "roll-up"). Data aggregation should be specific to the research and/or reporting needs for the population groups under study/report.

Automatic linkage or aggregation would produce deteriorated or inaccurate data if patients are linked/aggregated in a way that contradicts or misrepresents their personal self-identification, especially for multiracial persons who identify with more than one federal 'Race'/'Ethnicity' standard.

The effects of globalization, population displacement, and social movements are undermining the capacity of one nation to fix a person's identity. Simply, national or geographic origin does not automatically determine one's race or ethnicity, nor does ethnicity determine race, nor does race determine ethnicity.

Data aggregation without the consideration of the intersecting layers that construct identity would be similar to suggesting that 'American' or being born in the United States could be automatically linked/aggregated into 'White'.

The Combined Format and Granular Ethnicity fields were developed as two separate questions to achieve health care, research, compliance, reporting, and resource allocation needs. As importantly, it ensures the patient's right to self-identify as well as ensures the highest data quality and integrity.

Language (Spoken and Written)

Kaiser Permanente focused on developing timely, valid, and representative language codes to capture our nation's increasing diversity. We are collecting both spoken and written language to ensure the provision of quality and equitable health care.

The Spoken/Written Language Code Sets are reviewed on an on-going basis primarily to ensure alignment with linguistic trends in the United States, current organizational language utilization, as well as relevance in culturally and linguistically competent care and patient-centered care.

Ongoing Analysis and Review for Comparability (Selected Examples Provided)

National Data Sets and Resources

- *U.S. Decennial Census/American Community Survey*

Organizational Language Utility (Regional and National)

- *Vendor Utilization Data*
- *Kaiser Permanente Utilization Data*

Transnational and International Data Sets and Resources

- *International Organization for Standardization*

Race, Ethnicity, and Language Code Sets

NOTES (Applies to all Code Sets):

'Decline to State', 'Other', and 'Unknown' are collection codes utilized by Kaiser Permanente.

Categories that represent one code in the collection system but have multiple names/designations are listed together and separated by a (/) slash mark.

Combined Format

Issued by the Office of Management and Budget

American Indian/Alaska Native
Asian
Black/African American
Hispanic/Latino
Native Hawaiian/Other Pacific Islander
White
Decline to State
Other
Unknown

The Combined Format is a multiple response field.

Granular Ethnicity

Acadian/Cajun
Afghan/Afghanistani
Agikuyu/Kikuyu
Akan
Alaska Athabascan
Albanian
Aleut
Algerian
Alsatian
Amara/Amhara
Amazigh/Imazighen/Berber
American/United States
Amerindian/Indigena/Indio
Antiguan/Barbudan
Apache
Arab/Arabic
Argentine/Argentinean
Armenian
Asian Indian/Indian (Asia)
Assyrian/Chaldean/Syriac
Australian
Austrian
Azerbaijani
Azeri
Bahamian
Bajan/Barbadian
Bamar/Burman
Bangladeshi
Bantu
Basque
Belarusian/Belorussian
Belgian
Belizean
Bengali
Blackfeet
Bolivian
Bosniak
Bosnian/Herzegovinian
Brazilian
British Isles/British Isles origin
British West Indian/Indies
Briton/British
Bulgarian
Burmese

Granular Ethnicity (cont'd)

Cambodian
Cameroonian/Cameroon
Canadian
Canadian American Indian
Cape Verdean
Carpatho Rusyn
Celtic
Central American Indian
Cherokee
Cheyenne
Chickasaw
Chilean
Chinese
Chippewa
Choctaw
Colombian
Colville
Comanche
Congolese/Congo
Costa Rican
Creek
Creole
Croat/Croatian
Crow
Cuban
Cypriot
Czech
Czechoslovakian
Dane/Danish
Delaware
Dominican
Dutch
Dutch West Indian/Indies
East Indian
Eastern Cherokee
Ecuadorian
Egyptian
Emirati/United Arab Emirates
English
Eritrean
Eskimo
Estonian
Ethiopian
Fijian
Filipino/Philippine
Finn/Finnish

Granular Ethnicity (cont'd)

Fleming/Flemish
French
French Canadian
Fulani/Hausa
Georgian
German
German Russian
Ghanaian/Ghanian
Greek
Grenadian
Guamanian/Chamorro
Guatemalan
Guyanese
Haitian
Hawaiian/Native Hawaiian
Hmong
Honduran
Hopi
Hungarian
Ibo/Igbo
Icelander
Indonesian
Inupiat Eskimo
Iranian
Iraqi
Irish
Iroquois
Israeli
Italian
Ivoirian/Ivory Coast
Jamaican
Japanese
Javanese/Java/Jawa
Jewish/Jew
Jordanian
Kazakh/Qazaq
Kazakhstani
Kenyan
Keres
Khmer
Kinh/Viet
Kiowa
Kittitian/Nevisian
Korean
Kurd/Kurdish
Kuwaiti

Granular Ethnicity (cont'd)

Lao Loum/Lowland Lao
Lao/Laotian
Latin American Indian
Latvian
Lebanese
Liberian
Libyan
Lithuanian
Lumbee
Luxemburger
Macedonian
Malay
Malaysian
Maltese
Maori
Mende
Mestizo
Mexican
Mexican American Indian
Mohawk
Moldovan/Moldavian
Montenegrin
Moroccan
Muscogee (Creek) Nation
Navajo
Nepalese/Nepali
New Zealander/New Zealand
Nicaraguan
Nigerian
Norwegian
Oglala Sioux
Okinawan
Oklahoma Choctaw
Oneida Nation of New York/Oneida
Oromo
Osage
Ottawa
Paiute
Pakistani
Palestinian
Panamanian
Paraguayan
Part Hawaiian
Pashtun/Pathan
Pennsylvania German
Persian

Granular Ethnicity (cont'd)

Peruvian
Pima
Pole/Polish
Portuguese
Potawatomi
Pueblo
Puerto Rican
Puget Sound Salish
Quechua
Romanian
Rosebud Sioux
Russian
Saint Lucian
Salvadoran
Samoan
San Carlos Apache
Saudi/Saudi Arabian
Sault Ste. Marie Chippewa
Scandinavian
Scotch-Irish
Scottish
Seminole
Seneca
Senegalese
Serb/Serbian
Shawnee
Shona
Shoshone
Sierra Leonean
Singaporean/Singapore
Sinhalese/Singhalese
Sioux
Slavic
Slovak
Slovene/Slovenian
Somali/Somalian
South African
South American Indian
Soviet/Soviet Union
Spaniard/Spanish
Spanish American Indian
Sri Lankan
Sudanese
Swede/Swedish
Swiss
Syrian

Granular Ethnicity (cont'd)

Tagalog
Tahitian
Taiwanese
Tanzanian
Temne/Temme/Themne
Teton Sioux
Thai
Tigrinya/Tigray/Tigraway
Tlingit
Tlingit-Haida
Togolese/Togo
Tohono O'Odham
Tongan
Trinidadian/Tobagonian
Tunisian
Turk/Turkish
Turtle Mountain Band/Turtle Mountain
U.S. Virgin Islander
Ugandan
Ukrainian
Uruguayan
Ute
Uzbek/Uzbeg
Uzbekistani
Venezuelan
Vietnamese
Welsh
West Indian
White Mountain Apache
Yakama
Yaqui
Yemeni
Yoruba
Yugoslavian
Yup'ik/Yupik Eskimo
Zimbabwean
Zuni
Decline to State
Other
Unknown

Currently, Granular Ethnicity is not available as a multiple response field for multiethnic persons. Request for IT change is underway.

Spoken Language

Abkhaz
Afar
Afrikaans
Akan
Albanian
Algonquin
American Sign Language
Amharic
Apachean/Apache
Arabic
Aramaic
Armenian
Assyrian Neo-Aramaic/Assyrian
Aymaran/Aymara
Aztec/Nahuatl
Bantu
Bashkir
Basque
Bengali
Bhojpuri
Bislama
Bosnian
Breton
Bulgarian
Burmese
Cantonese/Chinese, Yue
Catalan-Valencian-Balear
Cebuano
Chamorro
Chaochow/Chinese, Min Nan
Chaozhou/Chinese, Min Nan
Cherokee
Chuukese/Trukese
Corsican
Croatian
Cushitic/Cushite
Czech
Dakota
Danish
Dari, Zoroastrian/Dari
Dinka
Dutch
English
Esperanto

Spoken Language (cont'd)

Farsi/Persian
Fijian
Filipino
Finnish
Formosan
French
French Creole
French, Cajun/Cajun
Fukienese/Chinese, Min Nan
Fula/Fulani
Fuzhou/Chinese, Min Dong
Gaelic, Irish/Irish Gaelic
Georgian
German
German, Pennsylvania/Pennsylvania Dutch
Greek
Gujarati/Gujarathi
Guranai
Haitian Creole French/Haitian Creole
Hakka/Chinese, Hakka
Hawaiian
Hebrew
Hindi
Hmongic/Hmong
Hmong-Mien/Miao-Yao
Huizhou/Chinese, Huizhou
Hungarian
Igbo/Ibo
Ilocano
Indonesian
Inuktitut, Greenlandic
Italian
Iu Mien/Mien
Jamaican Creole English/Jamaican Creole
Japanese
Kannada
Kashmiri
Keres
Korean
Kru
Kurdish
Kusaiean/Kosraean
Ladino
Languedocien/Occitan
Lao/Laotian
Latvian/Lettish

Spoken Language (cont'd)

Lingala
Lithuanian
Macedonian
Malay
Malayalam
Mandarin/Chinese, Mandarin
Mande
Marathi
Marshallese
Maya, Yucatan/Yucateco
Micronesian
Mixteco
Mongolian Proper/Mongolian
Mon-Khmer/Khmer
Navajo
Nepali
Norwegian
Oriya
Oromo
Palauan/Palau
Pampangan/Pampango
Panjabi
Pashto
Patois
Pohnpeian
Polish
Portuguese
Provencal
Punjabi
Quechuan/Quechua
Romanian/Moldavian
Rundi/Kirundi
Russian
Rwanda/Kinyarwanda
Samoan
Sango/Sangho
Serbian
Shanghainese/Chinese, Wu
Shona
Sign Language (Other)
Sinhala/Sinhalese
Slovak
Somali
Songhai/Songhay
Soninke
Sorbian, Lower/Lusatian

Spoken Language (cont'd)

Sorbian, Upper
Sotho, Southern/Sesotho
Spanish
Swahili/Kiswahili
Swedish
Tagalog
Taiwanese/Chinese, Min Nan
Tamil
Tatar
Telugu
Thai
Tibetan
Tigrigna/Tigrinya
Toishanese/Chinese, Yue
Tonga/Western Nyasa
Tongan
Tsimshian
Tsonga
Tswana/Setswana
Tupi-Guarani/Guarani
Turkish
Turkmen
Twi (Akan)
Ukrainian
Urdu
Vietnamese
Vlaams/Flemish
Wolof
Xhosa
Yapese
Yi, Sichuan/Szechuan
Yiddish
Yoruba
Zulu
Do Not Speak
Decline to State
Other
Unknown

Spoken Language is a multiple response field.

Written Language

Abkhaz
Afar
Afrikaans
Akan
Albanian
Algonquin
Amharic
Apachean/Apache
Arabic
Aramaic
Armenian
Assyrian Neo-Aramaic/Assyrian
Aymaran/Aymara
Aztec/Nahuatl
Bantu
Bashkir
Basque
Bengali
Bhojpuri
Bislama
Bosnian
Braille
Breton
Bulgarian
Burmese
Catalan-Valencian-Balear
Cebuano
Chamorro
Cherokee
Chinese, Simplified
Chinese, Traditional
Chuukese/Trukese
Corsican
Croatian
Cushitic/Cushite
Czech
Dakota
Danish
Dari, Zoroastrian/Dari
Dinka
Dutch
English
Esperanto
Farsi/Persian

Written Language (cont'd)

Fijian
Filipino
Finnish
Formosan
French
French Creole
French, Cajun/Cajun
Fula/Fulani
Gaelic, Irish/Irish Gaelic
Georgian
German
German, Pennsylvania/Pennsylvania Dutch
Greek
Gujarati/Gujarathi
Guranai
Haitian Creole French/Haitian Creole
Hawaiian
Hebrew
Hindi
Hmongic/Hmong
Hmong-Mien/Miao-Yao
Hungarian
Igbo/Ibo
Ilocano
Indonesian
Inuktitut, Greenlandic
Italian
Iu Mien/Mien
Jamaican Creole English/Jamaican Creole
Japanese
Kannada
Kashmiri
Keres
Korean
Kru
Kurdish
Kusaiean/Kosraean
Languedocien/Occitan
Lao/Laotian
Latvian/Lettish
Lingala
Lithuanian
Macedonian
Malay
Malayalam
Mande

Written Language (cont'd)

Marathi
Marshallese
Maya, Yucatan/Yucateco
Micronesian
Mixteco
Mongolian Proper/Mongolian
Mon-Khmer/Khmer
Navajo
Nepali
Norwegian, Bokmal/Bokmal
Norwegian, Nynorsk/Nynorsk
Oriya
Oromo
Palauan/Palau
Pampangan/Pampango
Panjabi
Pashto
Patois
Pohnpeian
Polish
Portuguese
Provencal
Punjabi
Quechuan/Quechua
Romanian/Moldavian
Rundi/Kirundi
Russian
Rwanda/Kinyarwanda
Samoan
Sango/Sangho
Serbian
Shona
Sinhala/Sinhalese
Slovak
Somali
Songhai/Songhay
Soninke
Sorbian, Lower/Lusatian
Sorbian, Upper
Sotho, Southern/Sesotho
Spanish
Swahili/Kiswahili
Swedish
Tagalog
Tamil
Tatar

Written Language (cont'd)

Telugu
Thai
Tibetan
Tigrigna/Tigrinya
Tonga/Western Nyasa
Tongan
Tsimshian
Tsonga
Tswana/Setswana
Tupi-Guarani/Guarani
Turkish
Turkmen
Twi (Akan)
Ukrainian
Urdu
Vietnamese
Vlaams/Flemish
Wolof
Xhosa
Yapese
Yiddish
Yoruba
Zulu
Do Not Read/Write
Decline to State
Other
Unknown

Written Language is a multiple response field.

For more information, please contact:

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Appendix H

Contra Costa Health Plan Language Assistance Database and Ethnicity Categories

Contra Costa Health Plan (CCHP), founded in 1973, is sponsored by the county of Contra Costa, California. It is the only county run health plan in California, and it was the first federally qualified county sponsored HMO in the United States. Today, CCHP serves approximately 85,000 people, including public and commercial members. The plan is licensed by the California State Department of Managed Health Care and the provisions of California SB853 apply for determining the language needs of its membership.

CCHP has developed, in collaboration with other health plans, a set of race, ethnicity, and spoken and written language categories applicable to its service population (see following pages). After analysis of its membership needs, CCHP determined that there were 15 detailed ethnicity and language categories that would be most frequently used by its members at different sites. Initially, a top 10 list was compiled, but it was apparent that the top 10 list at each service site was not the same; by developing the top 15 list, the top 10 categories at all sites were covered. To further increase interoperability among parts of the health system, CCHP is trying to promote the top 15 categories into the data collection systems of all county health centers and the Contra Costa Regional Medical Center. A need remains, however, to crosswalk the CCHP codes to different codes used at the state level (e.g., for hospital discharges).

The top 15 ethnicities and languages are visible on drop down menus for selection by staff and the system has the capacity to access the full list if an individual self-identifies with a category not included in the top 15. For example, if a member services representative types the letter "e," English will pop up from the top 15 list, but if the patient speaks another language starting with "e," a second keystroke brings up other language choices beginning with "e" such as Estonian (see entry screen and training instructions on the next page). Additionally, they have helpful features such as allowing population of those fields for other family members at the same time. The CCHP phone script for member services staff has evolved over time from a lengthy explanation of the need for these data for quality improvement to simply request for verification; collection of the data takes practice and monitoring. Collecting these four variables (i.e., race, ethnicity, spoken language, and written language) takes, on average, one minute and thirty seconds per call. To ensure that the race, ethnicity, and language data are being collected, production metrics regularly report on the number of records fully completed by member services staff, which is reviewed by the member services manager.

CCHP collects ethnicity separately from race and avoids aggregating detailed ethnicities to OMB race categories whenever possible. To ensure compliance with HEDIS reporting requirements and minimize redundancy in data collection, CCHP automatically populates a variable on the individual's Hispanic ethnicity based on his or her responses to the language, race, and detailed ethnicity questions.

CONTRA COSTA HEALTH PLAN’S LANGUAGE ASSISTANCE DATA BASE
MEMBER SERVICES STAFF TRAINING

The collection of Spoken/Written Language, Race and Ethnicity is meant to be at the end of a call; after a member has been helped with the issue they called about.

Add this step to your conversation at the end of the call as a verification process. This sentence has been shown to be effective:

“We are verifying that we have the most accurate information about our members on file.”

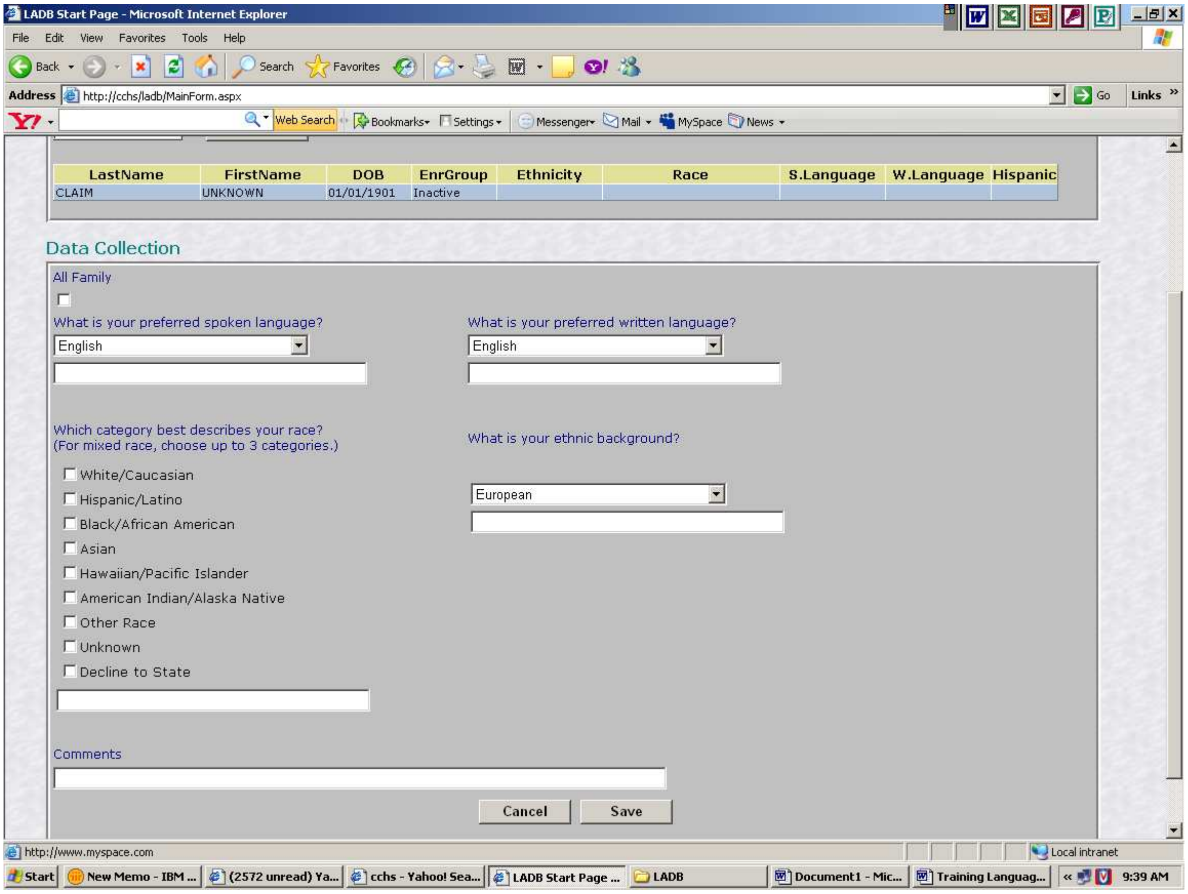
Then proceed to ask the four questions listed below.

Notice that the top 15 (most frequent) are at the top of the list; the complete list follows at the bottom. At the end, ask if the information applies to all family members. If it does check all family box in left corner of the screen, if it does not enter the family members individually.

Quick tips:

Tab—will move the cursor to the next field. Example: from Spoken Language to Written Language.

Pressing a letter: Example “S” will take to the cursor to Spanish in the top 15 list, by pressing S again will take you to Samoan, then Sangho and so on….



LastName	FirstName	DOB	EnrGroup	Ethnicity	Race	S.Language	W.Language	Hispanic
CLAIM	UNKNOWN	01/01/1901	Inactive					

Data Collection

All Family

☐

What is your preferred spoken language?

English

What is your preferred written language?

English

Which category best describes your race?
(For mixed race, choose up to 3 categories.)

- ☐ White/Caucasian
- ☐ Hispanic/Latino
- ☐ Black/African American
- ☐ Asian
- ☐ Hawaiian/Pacific Islander
- ☐ American Indian/Alaska Native
- ☐ Other Race
- ☐ Unknown
- ☐ Decline to State

What is your ethnic background?

European

Comments

TABLE H-1 Language Assistance Data Base (LADB), based on CDC Race/Ethnicity Codes and ISO Language Codes

CONTRA COSTA
HEALTH SERVICES

by Otilia Tiutin, Manager of Cultural & Linguistic Services

(For mixed race use boxes, can choose up to 3 categories)

Race Code	**Race Description**
R5	White/Caucasian
E1	Hispanic or Latino
R3	Black or African American
R2	Asian
R1	American Indian or Alaska Native
R4	Native Hawaiian or Other Pacific Islander
R9	Other Race
RZ	Unknown/Not Provided
EY	Decline to state

Ethnic Code	**Ethnicity Description**
Top 15 in Order of Frequency	
21089	European
00017	American
21352	Hispanic/Latino
21485	Mexican
21782	Latin American
20560	Black
20586	African American
20479	Vietnamese
20297	Asian Indian
21212	Iranian
20362	Filipino
21295	Arab
20412	Laotian
20347	Chinese
00016	Russian

Ethnic Codes and Description in Alphabetical Order

21261	Afghanistani
20602	African
20586	African American
21386	Andalusian
00017	American
21295	Arab
21667	Argentinean
21097	Armenian
20297	Asian Indian
21196	Assyrian
21394	Asturian
20677	Bahamian
20305	Bangladeshi
20685	Barbadian
21428	Belearic Islander
20313	Bhutanese
20560	Black
21675	Bolivian
00005	Bosnian
20610	Botswanan
00029	Brazillian
20321	Burmese
20339	Cambodian
21634	Canal Zone
21451	Canarian
20925	Carolinian
21402	Castillian
21410	Catalonian
21550	Central American
21626	Central American Indian
20883	Chamorro
21519	Chicano
21683	Chilean
20347	Chinese
20974	Chuukese
21691	Colombian
21568	Costa Rican
21766	Criollo
21824	Cuban
00000	Decline to state
20701	Dominica Islander
20693	Dominican
21840	Dominican
21709	Ecuadorian
21204	Egyptian
21105	English
20628	Ethiopian
21089	European
21014	Fijian
20362	Filipino
21113	French
21436	Gallego
21121	German

20875	Guamanian
20867	Guamanian or Chamorro
21576	Guatemalan
20719	Haitian
20022	Hindi
21352	Hispanic/Latino
20370	Hmong
21584	Honduran
20388	Indonesian
21212	Iranian
21220	Iraqi
21139	Irish
21279	Israeili
21147	Italian
20487	Iwo Jiman
20727	Jamaican
20396	Japanese
20966	Kiribati
20404	Korean
20933	Kosraean
00013	Kurdish
21527	La Raza
20412	Laotian
21782	Latin American
21238	Lebanese
20636	Liberian
20529	Madagascar
20420	Malaysian
20495	Maldivian
20891	Mariana Islander
20909	Marshallese
21006	Melanesian
21485	Mexican
21493	Mexican American
21535	Mexican American Indian
21501	Mexicano
20859	Micronesian
21188	Middle Eastern or North African
00026	Mixtec, Mexican Indian
20644	Namibian
20792	Native Hawaiian
20503	Nepalese
21048	New Hebrides
21592	Nicaraguan
20651	Nigerian
20438	Okinawan
00002	Other Ethnicity
00030	Other Latino
20446	Pakistani
20917	Palauan
21246	Palestinian
21600	Panamanian
21022	Papau New Guinean
21717	Paraguayan

21725	Peruvian
20941	Pohnpeian
21154	Polish
20784	Polynesian
00014	Portuguese
21808	Puerto Rican
00027	Punjabi, India
00016	Russian
20958	Saipanese
21618	Salvadoran
20800	Samoan
21162	Scottish
20511	Singaporean
21030	Solomon Islander
21659	South American
21758	South American Indian
21378	Spaniard
21469	Spanish Basque
20453	Sri Lankan
21253	Syrian
20818	Tahitian
20354	Taiwanese
20461	Thai
20735	Tobagoan
20834	Tokelauan
20826	Tongan
20743	Trinidadian
00001	Unknown
21733	Uruguayan
21444	Valencian
21741	Venezuelan
20479	Vietnamese
20750	West Indian
00025	Yao, Mien
20982	Yapese
20669	Zairean

TABLE H-2 Spoken Language Codes (ISO)

Language Code	Language Description
Top 15	
EN	English
ES	Spanish
VI	Vietnamese
FA	Farsi
LO	Laotian
AR	Arabic
TL	Tagalog
12	Cantonese
RU	Russian
KM	Cambodian
KO	Korean
14	Mandarin
PA	Punjabi
BG	Bulgarian
PL	Polish
Spoken Language Codes and Description in Alphabetical Order	
AB	ABKHAZIAN
OM	AFAN,OROMO
AA	AFAR
15	AF-MAAY
AF	AFRIKAANS
SQ	ALBANIAN,SHQIP
01	AMERICAN SIGN
AM	AMHARIC
AR	ARABIC
HY	ARMENIAN,HAYEREN
AS	ASSAMESE
16	ASSYRIAN NEO-ARAMAIC
AY	AYMARA
AZ	AZERBAIJANI
BA	BASHKIR
EU	BASQUE,EUSKERA
17	BEHDINI
BN	BENGALI,BANGLA
DZ	BHUTANI,BHUTANESE
BH	BIHARI
BI	BISLAMA
BS	BOSNIAN
BR	BRETON
BG	BULGARIAN
MY	BURMESE,MYANMASA
BE	BYELORUSSIAN
KM	CAMBODIAN,KHMER
12	CANTONESE
CA	CATALAN
19	CHALDEAN NEO-ARAMAIC
CH	CHAMARRO

CO	CORSICAN
HR	CROATIAN,CROAT,HRVATSKI
CS	CZECH
DA	DANISH
21	DINKA
NL	DUTCH,NEDERLANDS
EN	ENGLISH
ET	ESTONIAN
FO	FAROESE,FAEROESE
FA	FARSI,PARSIAN,PERSIAN
FJ	FIJI,FIJIAN
FI	FINNISH,SUOMI
22	FLEMISH (DUTCH)
23	FORMOSAN
FR	FRENCH
FY	FRISIAN
24	FUJIAN
25	FUKIENESE
FL	FULA, FULAH
GL	GALICIAN
KA	GEORGIAN,KARTULI
DE	GERMAN
EL	GREEK
KL	GREENLANDIC,KALAALLISUT
GN	GUARANI
GU	GUJARATI,GUJERATI
HT	HAITIAN CREOLE/FRENCH CREOLE
26	HAKKA
HA	HAUSA
27	HAWRAMI
HE	HEBREW,IWRITH
HI	HINDI
28	HMONG (BLUE/GREEN)
03	HMONG (WHITE)
29	HUNANESE
HU	HUNGARIAN,MAGYAR
30	IBO
IS	ICELANDIC,ISLENZK
04	ILACANO (ILOKO)
ID	INDONESIAN,BAHASA,INDONESIA
IU	INUKTITUT
IK	INUPIAK
GA	IRISH,GAEILGE
IT	ITALIAN
JA	JAPANESE,NIHONGO
JV	JAVANESE,BAHASA JAWA
KN	KANNADA
KS	KASHMIRI
KK	KAZAKH
RW	KINYARWANDA
KY	KIRGHIZ,KYRGYZ
RN	KIRUNDI
KO	KOREAN,CHOSON-O
31	KPELLE

KU	KURDISH,ZIMANY KURDY
32	KURMANJI
LO	LAOTIAN,LAOTHIAN,PHA XA LOA
LV	LATVIAN,LETTISH
LN	LINGALA
LT	LITHUANIAN
MK	MACEDONIAN
MG	MALAGASY
MS	MALAY, BAHASA MALAYSIA
ML	MALAYALAM
MT	MALTESE
14	MANDARIN
MI	MAORI
MR	MARATHI
MH	MARSHALLESE (EBON)
33	MENDE
06	MIEN
34	MIXE
35	MIXTECO-ALTA
36	MIXTECO-BAJA
MO	MOLDAVIAN
MN	MONGOLIAN
NE	NAPALI
NV	NAVAJO, NAVAHO
NO	NORWEGIAN
37	NUER
OC	OCCITAN
OR	ORIYA
PS	PASHTO,PUSHTO
PL	POLISH
PT	PORTUGESE
PA	PUNJABI,PANJABI
QU	QUECHUA
RM	RHAETO-ROMANCE,ROMANSCH
RO	ROMANIA,RUMANIAN
RU	RUSSIAN
SM	SAMOAN
SG	SANGHO
GD	SCOTS GAELIC
SR	SERBIAN,SRPSKI
ST	SESOTHO
TN	SETSWANA
38	SHANGHAINESE
SN	SHONA
SD	SINDHI
SI	SINGHALESE
SS	SISWATI
SK	SLOVAK
SL	SLOVENIAN
SO	SOMALI
ES	SPANISH
SU	SUDANESE
SW	SWAHILI
SV	SWEDISH,SVENSKA

TL	TAGALOG
TG	TAJIK
TA	TAMIL
39	TARASCO
TT	TATAR
TE	TELUGU
TH	THAI
BO	TIBETIAN,BODSKAD
TI	TIGRIGNA
40	TIO CHIU OR TEOCHEW
TO	TONGAN (LANGUAGE OF TONGA)
TS	TSONGA
TR	TURKISH
TK	TURKMEN
TW	TWI
UG	UIGUR
UK	UKRAINIAN
UR	URDU
UZ	UZBEK
VI	VIETNAMESE
CY	WELSH
WO	WOLOF
41	WU
XH	XHOSA
YI	YIDDISH,JIDDISCH
YO	YORUBA
42	ZAPTEC
ZA	ZHUANG
ZU	ZULU
8	Unknown
3	Unable to contact
98	DECLINED TO STATE
99	OTHER

TABLE H-3 Written Language Codes (ISO)

Language Code	Language Description
Top 15 (most frequently used)	
EN	English
ES	Spanish
VI	Vietnamese
FA	Farsi
LO	Laotian
AR	Arabic
TL	Tagalog
12	Cantonese
RU	Russian
KM	Cambodian
KO	Korean
14	Mandarin
PA	Punjabi
BG	Bulgarian
PL	Polish
Written Language Codes and Description in Alphabetical Order	
AB	ABKHAZIAN
OM	AFAN,OROMO
AA	AFAR
15	AF-MAAY
AF	AFRIKAANS
SQ	ALBANIAN,SHQIP
AM	AMHARIC
AR	ARABIC
HY	ARMENIAN,HAYEREN
AS	ASSAMESE
AY	AYMARA
AZ	AZERBAIJANI
BA	BASHKIR
EU	BASQUE,EUSKERA
17	BEHDINI
BN	BENGALI,BANGLA
BH	BIHARI
BI	BISLAMA
BS	BOSNIAN
02	BRAILLE/ALTERNATIVE FORMAT
BR	BRETON
BG	BULGARIAN
MY	BURMESE,MYANMASA
BE	BYELORUSSIAN
KM	CAMBODIAN,KHMER
12	CANTONESE (SIMPLIFIED)
CA	CATALAN
19	CHALDEAN NEO-ARAMAIC
CH	CHAMORRO
ZH	Chinese- simplified characters

20	Chinese- Traditional characters
CO	CORSICAN
HR	CROATIAN,CROAT,HRVATSKI
CS	CZECH
DA	DANISH
21	DINKA
NL	DUTCH,NEDERLANDS
DZ	DZONGKHA (BHUTANI,BHUTANESE)
EN	ENGLISH
ET	ESTONIAN
FO	FAROESE,FAEROESE
FA	FARSI,PARSIAN,PERSIAN
FJ	FIJI,FIJIAN
FI	FINNISH,SUOMI
22	FLEMISH (DUTCH)
23	FORMOSAN
FR	FRENCH
FY	FRISIAN
24	FUJIAN
25	FUKIENESE (traditional characters)
FL	FULA, FULAH
GL	GALICIAN
KA	GEORGIAN,KARTULI
DE	GERMAN
EL	GREEK
KL	GREENLANDIC,KALAALLISUT
GN	GUARANI
GU	GUJARATI,GUJERATI
HT	HAITIAN CREOLE/FRENCH CREOLE
26	HAKKA (traditional)
HA	HAUSA
27	HAWRAMI
HE	HEBREW,IWRITH
HI	HINDI
28	HMONG (BLUE/GREEN)
03	HMONG (White)
29	HUNANESE (traditional characters)
HU	HUNGARIAN,MAGYAR
30	IBO
IS	ICELANDIC,ISLENZK
04	ILACANO (ILOKO)
ID	INDONESIAN,BAHASA,INDONESIA
IU	INUKTITUT
IK	INUPIAK
GA	IRISH,GAEILGE
IT	ITALIAN
JA	JAPANESE,NIHONGO
JV	JAVANESE,BAHASA JAWA
KN	KANNADA
KS	KASHMIRI
KK	KAZAKH
RW	KINYARWANDA
KY	KIRGHIZ,KYRGYZ
RN	KIRUNDI

KO	KOREAN,CHOSON-O
31	KPELLE
KU	KURDISH,ZIMANY KURDY
32	KURMANJI
LO	LAOTIAN,LAOTHIAN,PHA XA LOA
LV	LATVIAN,LETTISH
LN	LINGALA
LT	LITHUANIAN
MK	MACEDONIAN
MG	MALAGASY
MS	MALAY, BAHASA MALAYSIA
ML	MALAYALAM
MT	MALTESE
14	MANDARIN (TRADITIONAL)
MI	MAORI
MR	MARATHI
MH	MARSHALLESE
33	MENDE
06	MIEN
34	MIXE
MO	MOLDAVIAN
MN	MONGOLIAN
NE	NAPALI
NV	Navajo, Navaho
NO	NORWEGIAN
37	NUER
OC	OCCITAN
OR	ORIYA
PS	PASHTO,PUSHTO
PL	POLISH
PT	PORTUGESE
PA	PUNJABI,PANJABI
QU	QUECHUA
RM	RHAETO-ROMANCE,ROMANSCH
RO	ROMANIA,RUMANIAN
RU	RUSSIAN
SM	SAMOAN
SG	SANGHO
GD	SCOTS GAELIC
SR	SERBIAN,SRPSKI
ST	SESOTHO
TN	SETSWANA
38	SHANGHAINESE (traditiona charactersl)
SN	SHONA
SD	SINDHI
SI	SINGHALESE
SS	SISWATI
SK	SLOVAK
SL	SLOVENIAN
SO	SOMALI
ES	SPANISH
SU	SUDANESE
SW	SWAHILI
SV	SWEDISH,SVENSKA

TL	TAGALOG
TG	TAJIK
TA	TAMIL
39	TARASCO
TT	TATAR
TE	TELUGU
TH	THAI
BO	TIBETIAN,BODSKAD
TI	TIGRIGNA
40	TIO CHIU OR TEOCHEW (verify character style)
TO	TONGAN (LANGUAGE OF TONGA)
TS	TSONGA
TR	TURKISH
TK	TURKMEN
TW	TWI
UG	UIGUR
UK	UKRAINIAN
UR	URDU
UZ	UZBEK
VI	VIETNAMESE
CY	WELSH
WO	WOLOF
41	WU (traditional)
XH	XHOSA
YI	YIDDISH,JIDDISCH
YO	YORUBA
ZA	ZHUANG
ZU	ZULU
8	Unknown
3	Unable to contact
98	DECLINED TO STATE
99	OTHER

NOTE: For more information on CCHP's LADB project, call Otilia Tiutin at 925-313-6063 or email otiutin@hsd.cccounty.us. Information about CCHP can be found at www.contracostahealthplan.org.

Appendix I

Subcommittee Template: Developing a National Standard Set of Spoken Language Categories and Coding

The Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement recommends the collection of the variable spoken "language need" for each individual. Language need is to be assessed through two questions: the first is an individual's personal assessment of his/her ability to speak English and then their preferred spoken language for a health-related encounter (Recommendation 4-1). Having this information for each individual allows its use to ensure the quality of services in subsequent encounters, in analysis of health care disparities, and in system-level planning (e.g., determining the need for interpreters and matching patients to language-concordant providers). The subcommittee defines limited English proficiency for health care purposes as someone who speaks English less than very well.

When data are shared from one entity to another (e.g., providers to health plan or health plans to states), standardization helps ensure that data can be combined for like categories. Unlike race and Hispanic ethnicity, there is no Office of Management and Budget (OMB) standard for language categories, thus the subcommittee recommends that the Department of Health and Human Services (HHS) develop national standard lists of spoken and written languages and codes (Recommendation 6-1a) and that entities choose their categories from the national standard list (Recommendation 4-3) according to the needs of the population they serve or study (Recommendation 4-2). When a health care entity designs its collection instruments, whether paper or electronic, it may, because of space considerations, have to use a limited number of pre-selected response categories. Therefore, such a response list should always include an "Other, please specify: __" option to ensure collection of each person's language need (Recommendation 4-2). Some electronic data collection systems are more sophisticated, and by using keystroke recognition can accommodate hundreds of languages.

DEVELOPMENT OF THE TEMPLATE

The subcommittee did not identify a single existing category list that it believed was ready to serve as a national standard set. To develop a template of spoken languages spoken in the United States, the subcommittee compiled the attached list to serve as a draft template of language names and coding possibilities. (An online searchable and sortable Excel version of the list is available at: www.iom.edu/datastandardization.) Census Bureau data on languages spoken at home was a logical place to start to compile lists of languages; the Census has compiled approximately 530 language names corresponding to about 380 language codes.[1] Some of these languages are nearing extinction. Another group, International Organization for Standardization (ISO) has established code sets for thousands of languages; the ISO language lists and particularly their coding focus on distinct languages with distinct codes, whereas the Census Bureau is more likely to give related languages the same code. The ISO codes have evolved from a first-generation two-letter coding system (ISO 639-1), to a three-letter system to accommodate additional languages primarily for bibliographic uses (ISO 639-2), to a set that now incorporates more three-letter codes to cover 6,000 known languages in the world (ISO 639-3). The ISO 639-3 codes are intended "to provide a comprehensive set of identifiers for all languages for use in a wide range of applications, including linguistics, lexicography and internationalization of information systems."[2]

The subcommittee list began with the Census Bureau's summary file 3 (SF3) technical documentation list of approximately 530 languages and 380 three digit numerical codes;[3] these are presented in the first two columns. Names that are not in all caps are considered to have a relationship to an ALL CAPS language name and receive the same code.[4] The Census Bureau could not confirm whether persons speaking the ALL CAPS languages would be understood by those with the same code; the online Excel file can be sorted by the code number to see which languages have overlapping codes. Additional language names, not on the Census list, were added to the Census names column based on previous surveys conducted by Hospital Research & Educational Trust (HRET) of a representative sample of hospitals and the National Association of Community Health Centers of a representative sample of health centers;[5] requests to Language Line, an interpretation and translation service;[6] and subcommittee collection of additional names from a handful of providers.[7] The languages added to the initial Census list are indicated by an * next to the Census code number; the code number assigned was provided by Census Bureau staff to indicate how they would have coded the response; some remain uncoded.[8] This resulted in approximately 650 total language names, of which approximately 300 were identified as being used in a health care context. A column was added to indicate categories for which the Modern Language Association reports there were responses in Census 2000;[9] the subcommittee ran Census PUMS data but did not find any further languages since languages with smaller numbers of persons reporting the language were aggregated together.

Each language in the first column was then matched to different generations of ISO codes which are alphabetic rather than numeric codes. ISO 639-2 codes are maintained by the Library of Congress and are coded as two letters; the ISO 639-3 codes are three letter codes currently maintained by SIL International. ISO codes start with the most comprehensive set (ISO-639-3); after the codes, the language name under the ISO categorization scheme is listed.

The names of languages often have multiple possible spellings, even between the Census Bureau and ISO 639 language lists there are alternate spellings, and patients may provide an alternative spelling as well. The column,

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[1] U.S. Census Bureau. 2007. Census 2000 Summary File 3–Technical documentation. Appendix G language code list. Washington, DC: U.S. Census Bureau.

[2] SIL International. 2009. *Relationship between ISO 639-3 and the other parts of ISO 639.* http://www.sil.org/iso639-3/relationship.asp (accessed July 20, 2009).

[3] The Census Bureau included the notation n.e.c. next to a language name to means not elsewhere categorized. Some of the languages that may have fallen into these categories may now be listed in column A due to the additions the subcommittee made to the list of languages.

[4] U.S. Census Bureau. 2002. *Census 2000 summary file 3: Technical documentation.* http://www.census.gov/prod/cen2000/doc/sf3.pdf (accessed August 3, 2009).

[5] Hasnain-Wynia, R., J. Yonek, D. Pierce, R. Kang, and C. H. Greising. 2006. *Hospital language services for patients with limited English proficiency: Results from a national survey.* Chicago, IL: Health Research and Educational Trust (HRET)/AHA; National Association of Community Health Centers. 2008. *Serving patients with limited English proficiency: Results of a community health center survey.* Bethesda, MD: National Association of Community Health Centers and National Health Law Program.

[6] Language Line Service. 2009. *List of languages by Language Line Services*. http://www.languageline.com/page/languages/ (accessed June 12, 2009).

[7] Personal communications from Emilio Carrillo, New York Presbyterian Hospital, May 11, 2009; Alice Chen, San Francisco General Hospital, July 7, 2009; Maria Moreno and Traci Van, Sutter Health, July 22, 2009; Shiva Bidar-Sielaff, University of Wisconsin Health, May 11, 2009.

[8] Personal communication, H. Shin, U.S. Census Bureau, July 13, 2009.

[9] Modern Language Association. 2009. All languages reported to the U.S. Census in 2000. http://www.mla.org/map_data_langlist&mode=lang_tops (accessed May 26, 2009).

Other Names and Additional Information includes some of the alternate spellings and names the subcommittee encountered, but these should not be considered all of the alternative names. Languages might even be called slightly different names, such as Amish, Pennsylvania Dutch, or Pennsylvania German, or be quite different. This need not be a barrier to the list of choices developed locally as long as it is clear on a national standard list how to categorize the alternative spellings or names.

Since the Census language list included names that appeared in responses to earlier censuses, some languages were thought to be no longer in use. The American Indian and Alaska Native languages were reviewed to determine whether they were now considered extinct or nearly extinct by Ethnologue which tracks the world's living languages. Ethnologue uses the term nearly extinct when "only a few elderly speakers are still living."[10] Notations are made of this status in the column titled, Other Names and Additional Information; approximately 80 of the 650 languages were identified as extinct or nearly extinct.

ADAPTATION OF THE TEMPLATE TO A NATIONAL STANDARD LIST

Arriving at the possible names for a national category list appears fairly straight forward; the accompanying list is likely to identify most that will be encountered. Changes in immigration patterns over time may result in additional names; thus, category and code lists will have to be maintained (Recommendation 6-1a). Deciding on which coding scheme to adopt is more challenging. In its incidental collection of information on languages, the subcommittee encountered more instances of use of the ISO coding scheme; however, the Census has data on languages spoken at home and the degree of limited English proficiency for many languages that entities use to learn about the populations in their service areas. The subcommittee believes that there are advantages to both the Census Bureau and ISO coding schemes for languages, and does not endorse one over the other. The subcommittee indicates the need for HHS to consult with the Census Bureau, the registration authorities for the ISO codes, and others that establish unique coding for interoperability, such as HL7.

If the Census coding approach were to be adopted, the subcommittee notes that the Census list of languages and codes would likely need some additional changes to be useful. The primary limitation of the Census Bureau coding scheme is that it uses the same code for multiple related languages, while the ISO list has unique codes for each language. To the extent that patients who are not English proficient need language assistance services in distinct languages in order to facilitate understanding during patient–provider interactions, a care provider's ability to track specific languages would be enhanced by unique coding for distinct languages; this could happen by either expanding the Census codes or adopting the detail of the ISO codes. Currently, there is no specific Census code for English. Sign language, an important communication tool, is not a unique language response on the Census, and generally would code the person as speaking English. By contrast, ISO-639 has unique codes for 130 types of sign languages. For health care purposes, some entities have found a separate category noting which persons have speech loss has been useful to understand the communication needs of all patients. Further options for "declined," "unavailable," or "unknown" are also useful when data are being recorded to determine the portion of the service population from whom language data have been collected.

The subcommittee did not generate a list of written languages, but illustrates these needs with the experiences of Kaiser Permanente and Contra Costa Health Plans in appendixes G and H. (Contra Costa used ISO two-letter codes supplemented by their own local coding). The ISO codes represent both spoken and written language names; separate script codes apply to written languages, as well, to describe their lettering.[11]

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[10] Ethnologue. Endangered languages. http://www.ethnologue.com/nearly_extinct.asp (accessed July 20, 2009).

[11] SIL International. 2009. *Scope of denotation for language identifiers*. http://www.sil.org/iso639-3/scope.asp (accessed July 20, 2009).

TABLE I-1 Subcommittee Template: Comparison of Spoken Language Categories and Coding

Census Language Name[a]	Census Code[a]	ISO 639-3 Individual language[b]	ISO 639-2 Individual language[b]	ISO 639-1 Individual language[b]	ISO Language Name[b]	Other Names and Additional Information	Reported in the Census 2000[c]	Kaiser Permanente Health Plan[d]	Contra Costa Health Plan[d]	HRET Hospital Survey[f]	NACHC Survey of CHCs[g]	Language Line Use[h]	NY Presbyterian Hospital[e]	SFGH[e]	UW[e]	Sutter Health[e]
Abkhazian	696*	abk	abk	ab	Abkhazian			x	x							x
ABNAKI	823	aaq, abe			Abnaki (Eastern, Western)	Eastern Abnaki - extinct	x									
ACHINESE	733	ace	ace		Achinese		x									
Acholi	785	ach	ach		Acoli											
ACHUMAWI	885	acv			Achumawi	Nearly extinct	x									
Acoma (same code as Laguna)	924	kjq			Western Keres (dialect-Acoma)											
Afar	783*	aar	aar	aa	Afar			x	x							x
Afghani (coded same as Pashto)	657	prs (Dari Persian) pst (Central Pashto) pbt (Southern Pashto) pbu (Northern Pashto) haz (Hazaragi) uzb (Uzbek)			Afghan Languages are multiple (about 50% use Dari and about 35% Pashto; other major languages: Hazaragi, Uzbek Southern)											
AFRICAN, not further specified	799						x									
AFRIKAANS	611	afr	afr	af	Afrikaans		x	x	x			x				x
Aguaceto	968	agu			Aguacateco											
AHTENA	848	aht			Ahtena	Nearly extinct	x									
Ainu	723	aib (China), ain (Japan)	ain (Japan)		Ainu											
Akan	796	aka (macro with 2 sub: fat (Fanti) and twi (Twi)	aka	ak	Akan			x				x				
Aklan	743*	mlz (Malaynon)			Aklan language of Phillipines include: Malaynon and Akeanon					x						
ALABAMA	915	akz			Alabama		x									
ALBANIAN	638	sqi (macro with 4 subs)	sqi / alb	sq	Albanian		x	x	x	x	x	x	x			x
ALEUT	800	ale	ale		ALEUT		x									
ALGONQUIAN	806	alq			Algonquin	Carolina Algonquin - extinct	x	x								
AMERICAN INDIAN	966				American Indian		x									
AMHARIC	780	amh	amh	am	Amharic		x	x	x	x	x	x			x	x
APACHE	862		apa (multiple other 639-3 codes)		Apache languages		x	x								

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ARABIC	777	ara (macro with 30 sublanguages)	ara	ar	Arabic		x	x	x	x	x	x	x	x	x	x
Arabic Morocan	777*	ary			Arabic, Moroccan							x				
Arabic Yemen	777*	ayh (Hadrami) ayn (Sanaani) acq (Ta'izzi-Adeni)			Arabic Yemen (multiple possibilities)								x			
Aramaic (see below Chaldean with same code)	779	aii (Assyrian Neo-Aramaic) jpa (Aramaic, Jewish Palestine) sam (Aramaic Samaritan) cld (Chaldean Neo Aramaic)			Numerous languages with Aramaic in name											x
ARAPAHO	807	arp	arp		Arapaho		x									
ARAWAKIAN	974	arw	arw		Arawak		x									
ARIKARA	934	ari			Arikara	Nearly extinct	x									
Arkansas	914	qua			Quapaw											
ARMENIAN	655	hye	hye / arm	hy	Armenian		x	x	x			x	x			x
Ashanti (see Twi which has same code)	796				The Ashanti language is Twi (see below)	Asante						x				
Asian Indian	662															
ASSAMESE	672	asm	asm	as	Assamese		x		x							
Assiniboine	907	asb														
Assyrian	779	aii			Assyrian Neo-Aramaic			x	x			x				x
ATHAPASCAN	847		ath (collective)		Athapascan languages		x									
ATSINA	808	ats			Gros Ventre		x									
ATSUGEWI	886	atw			Atsugewi	Nearly extinct	x									
Austrian	607	bar			Bavarian											
AYMARA	973	aym (macro with 2 sublanguages: Central and Southern)	aym	ay	Aymara		x	x	x							
AZERBAIJANI	690	aze (macro with 2 subs: North and South)	aze	az	Azerbaijani	Azeri	x		x			x				
AZTECAN	956	azc (639-5)			Uto-Aztecan		x	x								
Bahasa (same code as Malay)	739	msa (macro) zim (Malay individual language)	msa/may (macro)	Ms (macro)		Bahasa Kehangsaan (Indonesia) Bahasa Malaysian (Malaysia)						x				
BALINESE	734	ban	ban		Balinese		x									

TABLE I-1 Subcommittee Template: Comparison of Spoken Language Categories and Coding

Census Language Name^{a}	Census Code^{a}	ISO 639-3 Individual language^{b}	ISO 639-2 Individual language^{b}	ISO 639-1 Individual language^{b}	ISO Language Name^{b}	Other Names and Additional Information	Reported in the Census 2000^{c}	Kaiser Permanente Health Plan^{d}	Contra Costa Health Plan^{d}	HRET Hospital Survey^{f}	NACHC Survey of CHCs^{g}	Language Line Use^{h}	NY Presbyterian Hospital^{e}	SFGH^{e}	UW^{e}	Sutter Health^{e}
BALOCHI	659	bal (macro with 3 subs: Eastern, Southern, Western)		bal	Baluchi		x									
Bambara	793*	bam	bam	bm	Bambara							x	x			
Banjuni (see Swahili)	uncoded; code same as Swahili)											x				
Bannock	941	pao			Northern Paiute											
BANTU	792		bnt		Bantu (other)		x	x								
Bari	786	bfa			Bari											
Bashkir	688*	bak	bak	ba	Bashkir			x	x							x
BASQUE	697	eus	eus / baq	eu	Basque		x	x	x			x				x
Bassa	796*	bsq			Bassa										x	
Behdini	658*	kmr			Behdini's code (bdf) was retired from use and suggest kmr Northern Kurdish							x				
Bembe	792	bmb			Bembe											
BENGALI	664	ben	ben	bn	Bengali		x	x	x	x		x	x		x	x
BERBER	781		ber (collective)		Berber (other)		x					x				
Bhili	669	bhb			Bhili											
Bhojpuri	668*	bho	bho		Bhojpuri								x			
BIELORUSSIAN	640	bel	bel	be	Belarusian	Belorussian	x		x			x				
BIHARI	668		bih	bh	Bihari		x		x							
BIKOL	747	bik (macro with 5 subs)	bik		Bikol		x									
BISAYAN (has separate code from Cebuano)	743	bsb (Brunei) bsy (Sabah)			Bisayan (Cebuano is a subset of Bisayan)		x			x	x	x				
Bislama	604*	bis	bis	bi	Bislama			x	x							x
BLACKFOOT	809	bla	bla		Siksika		x									
Bosnian	649	bos	bos	bs	Bosnian			x	x	x	x	x		x	x	
BRAHUI	699	brh			Brahui		x									
BRETON	634	bre	bre	br	Breton		x	x	x							x
BUGINESE	730	bug	bug		Buginese		x		x							
BULGARIAN	647	bul	bul	bg	Bulgarian		x	x		x		x				x
BURMESE	717	mya	mya / bur	my	Burmese		x	x	x	x		x				x
BURUSHASKI	707	bsk			Burushaski		x									
Bushman	790	xuu			Kxoe	Khoe										
CADDO	935	cad	cad		Caddo	Kado, Caddoe; Nearly extinct	x									
Cahto	861	ktw			Kato	Extinct										
CAHUILLA	949	chl			Cahuilla	Nearly extinct	x									
CAJUN	624	frc			Cajun, French		x	x								

TABLE I-1 Subcommittee Template: Comparison of Spoken Language Categories and Coding

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Cambodian (same code as Khmer)	726				Cambodian (see Khmer)			x	x							
Canjobal	968	knj			Kanjobal, Western					x						
CANTONESE	711	yue (sub of Chinese)			Cantonese		x	x	x	x	x	x	x	x	x	x
Carib	974	car (Caribe) crb (Carib Island)														
CAROLINIAN	751	cal			Carolinian		x									
CATALONIAN	626	cat	cat	ca	Catalan		x	x	x			x				x
CAUCASIAN	696		cau		Caucasian (other)		x									
CAYUGA	929	cay			Cayuga		x									
Cebuano	744	ceb	ceb		Cebuano			x								x
CHADIC	782	shu (Chadian Arabic)			Chadian Arabic	Many languages belong to Chadic group and are used beyond borders of Chad; in Chad itself Chadic Arabic is a common language	x									
Chaldean	779	cld			Chaldean Neo-Aramaic	Chaldean dialects			x	x		x				
CHAM	735	cjm (Eastern), cja (Western)			Cham (Eastern, Western)		x									
CHAMORRO	752	cha	cha	ch	Chamorro		x	x	x							x
Chaochow; Chao-Chou; Chaozhou (code differs from Min Nan)	708				Chaochow; Chao-Chou; Chaozhou (see Min Nan-same ISO code)			x				x				x
CHASTA COSTA	859				Chasta Costa	extinct	x									
CHEMEHUEVI	943				Ute-Southern Paiute (see below)		x									
CHEROKEE	933	chr	chr		Cherokee		x	x				x				
CHETEMACHA	921	ctm			Chitimacha	Extinct										
CHEYENNE	810	chy	chy		Cheyenne		x									
CHIBCHAN	975	chb	chb		Chibcha		x									
Chickasaw	916	cic			Chickasaw											
CHINESE	708	zho (macro with 13 subs:including cmn Mandarin)	zho / chi	zh	Chinese		x			x						x
Chinese Wu, Shanghainese	715*	wuu			Chinese, Wu, Shanghainese											x
Chinook	883	chh			Chinook	Nearly extinct										
CHINOOK JARGON	965	chn	chn		Chinook Jargon		x									
Chippewa	819	ciw			Chippewa	Chippewah; Chipewyan				x						

TABLE I-1 Subcommittee Template: Comparison of Spoken Language Categories and Coding

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CHIRICAHUA	978	apm			Mescalero-Chiricahua Apache		x									
CHIWERE	908					Nearly extinct	x									
CHOCTAW	916	cho	cho		Choctaw		x									
CHUMASH	901				retired code for Chumash	Extinct	x									
Chuukese	761	chk	chk		Chuukese			x				x				
CHUVASH	684	chv	chv	cv	Chuvash		x									
Circassian (same code as Caucasian)	696				Circassian (see Caucasian languages)											
CLALLUM	835	clm			Clallam	Klallam; Nearly extinct	x									
COAST MIWOK	870	csi			Miwok, Coast	Extinct	x									
COCOMARICOPA	892	mrc			Maricopa		x									
Cocopah (see Delta River Yuman)	896	coc			Cocopa	Delta River Yuman										
COEUR D'ALENE	836	crd			Coeur d'Alene	Nearly extinct	x									
COLUMBIA	837	col			Columbia-Wenatchi		x									
Colville	841	oka			Okanagan-Colville											
COMANCHE	938	com			Comanche		x									
Concow	868	mjd			Northwest Maidu	Konkau; Nearly extinct										
Coorgi	698	kfa			Kodava	Coorge,Kurja, Khurgi, Kadagi										
Corsican	619*	cos	cos	co	Corsican			x	x							x
Coushatta	919	cku			Koasati											
COWLITZ	838	cow			Cowlitz	Extinct	x									
CREE	811	cre (macro with 6 sublanguages)	cre	cr	Cree		x					x				
Creek	920	mus	mus		Creek											
Creole	623*	many codes to match different types of creole			Creole (many choices)						x		x			
CROATIAN	650	hrv	hrv / scr	hr	Croatian		x	x	x			x				x
CROW	904	cro			Crow		x									
Cuna	975	kvn (Border Kuna) cuk (San Blas Kuna)			Border Kuna San Blas Kuna											
CUPENO	950	cup			Cupeno	Extinct	x									
CUSHITE	783		cus (collective)		Cushitic (other)		x	x								
CZECH	642	ces	ces / cze	cs	Czech		x	x	x	x		x				x
DAKOTA	907	dak	dak		Dakota		x	x				x				
DANISH	615	dan	dan	da	Danish		x	x	x	x		x				

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Dari	656	prs (gbz for Dari Zoroastrian)			Dari Persian			x		x		x				
DELAWARE	812	del (macro with 2 subs)	del		Delaware		x									
DELTA RIVER YUMAN	896	coc			Cocopa		x									
DIEGUENO	895	dih			Kumiai, Northern Diegueno	Ipai	x									
Dinka	784	din (macro with 5 sub)	din		Dinka			x	x	x		x				
DRAVIDIAN	698		dra (collective)		Dravidian (other)		x									
DUTCH	610	nld	nld/dut	nl	Dutch	Flemish	x	x	x	x		x			x	x
Dyula	793*	dyu	dyu		Dyula	Diula						x				
EFIK	797	efi	efi		Efik		x									
English		eng	eng	en	English		x	x	x	x				x		x
English Creoles Belize, Guyanese	601		cpe		English-based Creoles	English Creoles Belize, Guyanese										
Eosture	uncoded	uncoded			Eosture								x			
ESKIMO	802				Numerous possibilities		x	x								x
ESTONIAN	680	est (macro with 2 subs)	est	et	Estonian		x		x							
Ethiopian	780*				Ethiopian	See Amharic, Tigrigna								x		x
Ewe	796	ewe	ewe	ee	Ewe							x				
EYAK	865	ewk			Eyak	Nearly extinct	x									
Fanti	796	fat (sub of Akan)	fat		Fanti						x					
FAROESE	618	fao	fao	fo	Faroese		x		x							
Farsi	656	prs (same code as Dari Persian)			Farsi Eastern Persian	Farsi Persian		x	x	x	x	x	x	x	x	x
FIJIAN	771	fij	fij	fj	Fijian		x	x	x							
Filipino	742	fil	fil		Filipino			x		x					x	
FINNISH	679	fin	fin	fi	Finnish		x	x	x	x		x			x	
Flemish	610	nld (same as Dutch)	nld/dut	nl	Flemish			x	x			x				x
Foo Chow (see FUCHOW)	713*				see Min Dong								x			
FOOTHILL NORTH YOKUTS (distinguished from Tachi-Valley Yokuts)	876	yok			Yokuts (single code; also includes Tachi-Valley Yokuts)	Nearly extinct	x									
FORMOSAN (same code as Taiwanese)	714	multiple languages such as dru (Rukai) sai (Saisiyat) tay (Tayal) tsy (Tsou)			Formosan		x	x	x							

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FOX (see Meskawkie)	813	sac			Fox		x									
FRENCH	620	fra	fra/fre	fr	French		x	x	x	x	x	x		x	x	x
French Canadian (see FRENCH)	620*											x				
FRENCH CREE	816	multiple Cree languages			French Cree (see Michif)		x									
FRENCH CREOLE	623		cpf		French-based Creoles and Pidgin (other)		x	x		x						
FRISIAN	612	frr frs fry frr Northern; frs Eastern; fry Western	frr (No.) frs (East) fry West	fy (Western)	Frisian		x		x							
FUCHOW	713	cdo			Min Dong Chinese	Fuzhou; Foochow, Min Dong; Foochownese	x	x				x	x			
Fukianese (see Min Nan)	714*											x				
Fukien (see Min Nan)	714				Fukienese (see Min Nan)	Fukien; Fukianese		x	x		x	x	x			
FULANI	794	ful (macro with 9 sub languages)	ful	ff	Fulah (also Fula)		X	x	x			x	x		x	
Fur	789	fvr			Fur											
Ga	796	gaa	gaa		Ga							x				
Gaddang	uncoded	gdk			Gadang							x				
Garifuna	974	cab			Garifuna	Caribe										
Georgian	696	kat	kat/geo	ka	Georgian			x	x			x				x
GERMAN	607	deu	deu/ger	de	German		x	x	x	x	x	x		x	x	x
Ghani (multiple languages coded the same)	796*				multiple languages (see specific codes: Ga, Ibo, Igbo, Krahn, Kru, Twi, Ashanti, Bassa, Akan, Ewe, Fanti)	Ghanian				x						
GILBERTESE	753	gil	gil		Gilbertese		x									
GONDI	700	gon (macro with 2 subs)	gon		Gondi		x									
GORONTALO	749	gor	gor		Gorontalo		x									
GREEK	637	ell	ell/gre	el	Greek		x	x	x	x	x	x	x	x		x
Greenlandic	615*	kal	kal	kl	Greenlandic			x	x							x
Gros Ventre	808	ats			Gros Ventre	Nearly extinct										
Guamanian (see Chamorro, same code)	752	cha	cha	ch	Chammoro											
Guarani	976	grn (macro language with 5 subs)	grn	gn	Guarani			x	x							x
Guatemalan	968	multiple lanugages			Guatemalean					x						
GUJARATHI	667	guj	guj	gu	Gujarati		x	x	x	x		x	x		x	x

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GULLAH	605	gul			Sea Island Creole English		x									
GUR	795	gur			Farefare		x									
Gwichin (see Kuchin)	852	gwi	gwi		Gwich'in											
HAIDA	846	hai	hai		Haida	Northern Haida - nearly extinct	x									
Haitian Creole	623	hat	hat	ht	Haitian, Haitian Creole			x	x	x		x				x
HAKKA	709	hak (sub of Chinese)			Hakka Chinese		x	x	x			x				x
HAN	849	haa			Han	Nearly extinct	x									
Hausa	782	hau	hau	ha	Hausa											
HAVASUPAI	898	yuf			Havasupai-Walapai-Yavapai		x									
HAWAIIAN	776	haw	haw		Hawaiian		x		x			x				
Hawaiian Pidgin	603	hwc			Hawaiian Creole		x	x		x						x
HEBREW	778	heb	heb	he	Hebrew		x	x	x	x		x	x		x	x
HICHITA	918						x									
HIDATSA	905	hid			Hidatsa		x									
HINDI	663	hin	hin	hi	Hindi		x	x	x	x	x	x	x	x	x	x
Hindi Fijian	663/671	hif			Hindi Fiji							x				
Hindko	663*	hno (Hindko, Northern) hnd (Hindko, Southern)			Hindko						x					
Hmong	722	hmn (Macro with 24 subs)	hmn		Hmong		x	(2 types) xx	x							
Ho Chunk	909	win			Ho-Chunk											
Hokkien (same code as Fukien and Min Nan)	714				Hokkien (see Min Nan)	Fukien, Southern Min from Fukian				x						
HOPI	948	hop			Hopi		x									
Hopi-Tewa (see Tewa)	962	tew			Tewa (USA)											
Hualapai	899															
Huichole	957	hch			Huichol											
Hunanese		hsn			Xiang Chinese	Xiang, Hunan, Hsiang						x				
HUNGARIAN	682	hun	hun	hu	Hungarian		x	x	x	x		x	x		x	x
HUPA	860	hup	hup		Hupa	Nearly extinct	x									
Huron (see Wyandot)	932					Extinct										
Ibanag	742*	ibg			Ibanag							x				
Ibibio	797	ibb			Ibibio											
Ibo (also see Igbo)	796								x			x				
ICELANDIC	617	isl	isl/ice	is	Icelandic		x		x			x				x
Igbo	796	ibo	ibo	ig	Igbo	Ibo		x				x				
Igorot	746	multiple languages			Igorot	Igorot ethnic groups in Phillipines										
ILOCANO	746	ilo	ilo		Iloko	Ilokano	x	x	x	x		x		x		x

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Ilongo	743	Ilk			Ilongot											
India languages	662*															x
INDIA, nec	662						x							x		
Indigenous Central American	uncoded									x						
Indigenous Mexican	625*									x						
INDONESIAN	732	ind	ind	id	Indonesian		x	x	x	x	x	x			x	x
INGALIT	850					Nearly extinct	x									
Inupiaq	803	ipk	ipk	ik	Inupiaq				x							
INUPIK	803				(see Inupiaq)		x									
Iowa	908	iow			Iowa-Ota											
Iranian, other	656*				Iranian, other											x
IRISH GAELIC	635	gle	gle	ga	Irish		x	x	x							x
IROQUOIS	925		iro		Iroquoian languages		x									
Isleta (see Tiwa)	960				(see Tiwa)											
ITALIAN	619	ita	ita	it	Italian		x	x	x	x		x	x	x	x	x
Jakartanese	uncoded				Jakartanese							x				
JAMAICAN CREOLE	601	jam			Jamaican Creole English		x	x								
JAPANESE	723	jpn	jpn	ja	Japanese		x	x	x	x	x	x	x	x	x	x
JAVANESE	736	jav	jav	jv	Javanese		x		x			x				
JICARILLA	977	apj			Jicarilla Apache		x									
KACHIN	719	kac	kac		Kachin		x									
KALISPEL	981	fla			Kalispel-Pend d' Oreille		x									
KAN, HSIANG	710	hsn			Xiang Chinese	Xiang, Hunan, Hsiang	x					x				
Kanalese	uncoded									x						
Kanjobal/Kanjoval (see Conjobal)	968*	kgb for Kanjobal; knj for Kanjobal Western			Kanjobal					x						
KANNADA	702	kan	kan	kn	Kannada		x	x	x							x
KANSA	910	ksk			Kansa	Nearly extinct	x									
KARACHAY	688	krc	krc		Karachay-Balkar		x									
KARAKALPAK	685	kaa	kaa		Kara-Kalpak		x									
KAREN	718		kar (16 other specific Karen language codes)		Karen Languages		x					x				
KAROK	887	kyh			Karok	Nearly extinct	x									
KASHMIRI	673	kas	kas	ks	Kashmiri		x	x	x			x				x
KASHUBIAN	643	csb	csb		Kashubian		x									
KAWAIISU	944	xaw			Kawaiisu	Nearly extinct	x									
KAZAKH	686	kaz	kaz	kk	Kazakh		x		x			x				

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KERES	924	kee (Keres Eastern) kjq (Keres Western)			Keres		x	x								
Keresan	924															
Khmer	726	khm (Central Khmer) kxm (Northern Khmer)	khm	km	Khmer, Central and Northern)			x	x			x				
KHOISAN	790		khi (collective language)		Khoisan (Other)		x									
KICKAPOO	814	kic			Kickapoo		x									
Kikuyu	792	kik	kik	ki	Kikuyu											
Kinyarwanda	792	kin	kin	rw	Kinyarwanda			x	x							x
KIOWA	863	kio			Kiowa		x									
KIOWA-APACHE	980	apk			Kiowa Apache	Nearly extinct	x									
KIRGHIZ	687	kir	kir	ky	Kirghiz		x		x			x				
Kirundi	792*	run	run	rn	Rundi			x	x			x				x
KLAMATH	880	kla			Klamath-Modoc	Nearly extinct	x									
KOASATI	919	cku			Koasati		x									
Konkani	666	kok (macro with 2 subs) kmn (Konkani as an individual language)			Konkani											x
KOREAN	724	kor	kor	ko	Korean		x	x	x	x	x	x	x	x	x	x
Kosovan	uncoded											x				
Kosraean (see Kusaiean)	754	kos	kos		Kosraean											
KOYUKON	851	koy			Koyukon		x									
Kpelle	793	kpe (macro with 2 subs)	kpe		Kpelle				x							
Krahn	796*	kqo (Eastern Krahn) krw (Western Krahn)			Krahn							x				
KRIO	602	kri			Krio		x					x				
KRU, IBO, YORUBA	796		kro (collective)		Kru languages		x	x								
KUCHIN (see Gwichin)	852					Kutchin; Athabaschan language	x									
KURDISH	658	kur (macro with 3 subs) kmr (Northern Kurdish)	kur	ku	Kurdish		x	x	x	x		x				
Kurmanji	658	kmr				Kurdi			x			x				
KURUKH	705	kru	kru		Kurukh		x									
KUSAIEAN (see Kosraean)	754				Kusaiean		x	x								
KUTENAI	828	kut	kut		Kutenai	Nearly extinct	x									

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KWAKIUTL	830	kwk			Kwakiutl		x									
LADINO	627	lad	lad		Ladino		x	x								
Laguna (same code as Acoma)	924	kjq			Western Keres (dialect-Laguna)											
Lakota	907	lkt			Lakota						x	x				
LANGUAGE SPECIFIED, NOT LISTED	983-998															
LAOTIAN	725	lao	lao	lo	Lao		x	x	x	x	x	x		x	x	x
LAPP	681	smn	smn		Inari Sami		x									
Latin	coded as English	lat	lat	la	Latin											x
Latvian (see Lettish)	654	lav	lav	lv	Latvian			x	x			x				x
Lebanese	777*	apc			Northern Levantine Arabic					x						x
Lenape	812					extinct										
LETTISH (see Latvian)	654						x									
Lingala	792*	lin	lin	ln	Lingala			x	x			x				x
LITHUANIAN	653	lit	lit	lt	Lithuanian		x	x	x		x	x	x			x
LOWER CHEHALIS	833	cea			Lower Chehalis	Extinct	x									
Luganda	792	lug	lug	lg	Ganda							x				
LUISENO	951	lui	lui		Luiseno		x									
Lummi	839	str			See Salish, North Straits											
Luo	785	luo (Kenya and Tanzania) luw (Cameroon)	luo		Luo											
LUSATIAN	644	xls			Lusitanian		x					x				
Lusoga	792*	xog			Soga											
LUXEMBOURGIAN	613	ltz	ltz	lb	Luxemburgish	Luxembourgeois	x					x				
Maay	703*	ymm			Maay				x			x				
MACEDONIAN	648	mkd	mkd/mac	mk	Macedonian		x	x	x	x		x	x		x	
MADURESE	737	mad	mad		Madurese		x									
Maidu (see Mountain Maidu)	867	nmu (Northeast) vmv (Valley)			Northeast Maidu; Valley Maidu	Northeast Maidu- nearly extinct; Valley Maidu - extinct										
MAKAH	829	myh			Makah	Extinct	x									
MALAGASY	738	mlg (macro with 10 sub languages)	mlg	mg	Malagasy		x		x			x				
MALAY	739	msa (macro with 13 subs)		ms	Malay		x	x	x	x		x				x
MALAYALAM	703	mal	mal	ml	Malayalam		x	x	x			x	x			x
Maldivian	677	div	div	dv	Maldivian											
Maltese	777*	mlt	mlt	mt	Maltese				x			x				
Mam	968	mam			Mam					x						
MANDAN	906	mhq			Mandan	Nearly extinct	x									

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MANDARIN	712	cmn			Mandarin Chinese		x	x		x	x	x	x	x	x	x
MANDE	793						x	x	x							
Mandingo	793	man (macro with 7 subs: e.g., mnk Mandinka)	man		Mandingo	Mandigo; Mandinka				x		x	x		x	
MAORI	774	mri (Maori) rar (Maori Cook Islands)	mri/mao rar	mi	Maori		x		x							
MAPUCHE	970	arn	arn		Mapuche		x									
MARATHI	666	mar	mar	mr	Marathi		x	x	x			x				x
MARQUESAN	772	mrq (Marquesan North) mqm (Marquesan South)			Marquesan		x									
MARSHALLESE	755	mah	mah	mh	Marshallese		x	x	x	x		x				x
Masai	786	mas	mas		Masai											
Maya	968	yua			Yucateca											
MAYAN LANGUAGES	968		myn (collective)		Mayan Languages		x	x								
MBUM AND RELATED	798	mdd			Mbum		x									
MELANESIAN	765				Melanesian		x									
Mende	793	men	men		Mende (Sierra Leone)				x							
Mende	793	sim			Mende (Papua New Guinea)											
MENOMINI	815	mez			Menominee	Nearly extinct	x									
Mescalero Apache	978	apm			Mescalero-Chiricahua Apache											
Mesquakie	813	sac			Mesquaki											
Mexican	625*				Mexican					x						
Mexicano	956															
MIAMI	817	mia			Miami	Extinct	x									
MIAO, HMONG	722	7 different subs of Hmong (hmn) 20 specific Miao named languages			Miao, Hmong					x	x	x		x	x	x
MIAO-YAO, MIEN	721				Miao-Yao, Mien		x	x		x	x	x		x		x
Miccosukee	917	mik			Mikasuki											
MICMAC	818	mic	mic		Micmic		x									
MICRONESIAN	750						x	x		x						
Mien	721	ium			Iu Mien	Yiu Mien, Ban Yao		x	x							
MIKASUKI	917	mik			Mikasuki		x									

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Min (the 708 code differenciates from Min Nan)	708	mnp Min Bei Chinese cdo Min Dong Chinese nan Min Nan Chinese czo Min Zhong Chinese			Min dialects											
Min Nan	714	nan (sub of Chinese with dialects without codes: Hokkien			Min Nan	Minnan, including Taiwanese,						x				
Mina	uncoded	hna			Mina (Cameroon)											
Mina	uncoded	myi			Mina (India)											
MINANGKABAU	740	min	min		Minangkabau		x									x
Mirpuri	665				Mirpuri							x				
Miskito (see MISUMALPAN)	967	miq	cai (central American Indian collective code)		Miskito											
MISUMALPAN (see Miskito)	967						x									
Mitchif (see French Cree)	816	crg			Michif											
Miwok	872					Central Sierra Miwok, Northern Sierra Miwok, Lake Miwok - nearly extinct; Bay Miwok - extinct										
Mixtec	971	52 separate individual languages with no macro or collective category			Mixtec (Mixteco, Mixtex, Mexico)			x	xx 2 types	x	x	x	x			
Miytero	uncoded									x						
Modoc (see Klamath Modoc)	880	kla			Klamath-Modoc	Nearly extinct										
MOHAVE	893	mov			Mohave		x									
MOHAWK	926	moh	moh		Mohawk		x									
MOKILESE	756	mkj			Mokilese		x									
Moldovan (Romanian dialect)	631*	ron	ron/rum	ro	Moldovan (Romanian dialect)			x	x	x		x				x
MOLUCCAN	731	max (Northern Maluku) alo Larike-Wakasilu			Maluku		x									
MONGOLIAN	694	mon (macro with 2 subs)	mon	mn	Mongolian		x	x	x	x		x				

TABLE I-1 Subcommittee Template: Comparison of Spoken Language Categories and Coding

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MON-KHMER, CAMBODIAN	726		mkh (collective)		Mon-Khmer Other)		x	x		x	x	x	x	x	x	x
MONO	939					Nearly extinct	x									
Montenegrin	651*	srp			Serbian	South Slavic						x				
Mordvin	683	myv	myv		Erzya											
MORTLOCKESE	757	mrl			Mortlockese		x									
MOUNTAIN MAIDU (see Maidu)	867				(see Northeast Maidu)		x									
Muckleshoot (see Puget Sound Salish)	842															
MUNDA	706	unx (Munda as individual language)	mun (collective)		Munda		x									
MUONG	729	mtq			Muong		x									
MUSKOGEE (see Creek)	920	mus			Creek (Muskogee)		x									
Nahuatl	956	28 individual languages with codes	nah (collective)		Nahuatl											
Native American Indian	966*															
NAURUAN	758	nau	nau	na	Nauru		x									x
NAVAHO	864	nav	nav	nv	Navaho/Navajo				x	x		x				
Navajo	864	nav	nav	nv	Navajo		x	x								
Ndebele	792	nde (North) nbl (South)	nde (North) nbl (South)	nd (North) nr (South)	Ndebele											
Neapolitan	uncoded	nap	nap		Neapolitan							x				
NEPALI	674	nep	nep	ne	Nepali	Nepalese	x	x	x	x		x			x	x
NEZ PERCE	881	nez			Nez Perce		x									
Nigerian	796	mzk (Mabile) fuv (Fulfulde)			Nigerian											
Nigerian Pidgin English	796/604*	pcm			Nigerian Pidgin							x				
NILO-HAMITIC (see other languages coded 786)	786						x									
NILO-SAHARAN	789		ssa (collective)		Nilo-Saharan (Other)		x									
NILOTIC (see other languages coded 785)	785						x									
Nisqualli (see Puget Sound Salish)	842															
NIUEAN	769	niu	niu		Niuean		x									
NOMLAKI	873	wit			Wintu		x									
NOOTKA	831-832	noo			Nootka		x									x
NOOTSACK	840					Extinct	x									x
NORTHERN PAIUTE	941	pao			Northern Paiute		x									

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NORTHWEST MAIDU (see Concow)	869					Nearly extinct	x									
NORWEGIAN	616	nor (macro with 2 subs)	nor	no	Norwegian		x	x	x	x		x			x	x
Norwegian Bokmal	616	nob	nob	nb	Norwegian Bokmal											x
Norwegian Nynorsk	616	nno	nno	nn	Norwegian Nynorsk											x
NOT REPORTED	999															
NUBIAN	787		nub (collective)		Nubian Languages		x									
Nuer	785	nus			Nuer				x			x				
NUKUORO	775	nkr			Nukuoro		x									
Occitan	621*	oci	oci	oc	Occitan			x	x							x
Oglala	907				see Lakota											
OJIBWA	819	oji (macro with 7 subs)	oji	oj	Ojibwa	Ojibway	x					x				
OKANOGAN	841	oka			Okanagan		x									
OMAHA	911	oma			Omaha-Ponca		x									
ONEIDA	927	one			Oneida		x									
ONONDAGA	928	ono			Onondaga		x									
ORIYA	670	ori	ori	or	Oriya		x	x	x							x
Oromo	783	orm (macro with 4 subs)	orm	om	Oromo			x	x	x		x				
OSAGE	912	osa	osa		Osage	Nearly extinct	x									
OSSETE	661	oss	oss	os	Ossetian, Ossetic		x									
Otham	954*	stp			possibly Tephuan, Southeastern						x					
Other African languages	composite										x					
Other and unspecified languages	999					Miscellaneous	x									x
OTHER ATHAPASCAN-EYAK LANGUAGES	861															
Other Indic languages	composite						x									
Other Indo-European languages	composite						x									
Other language	composite													x	x	x
Other Native North American languages	composite						x									
Other Slavic languages	composite						x									
Other specified languages							x									

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Other West Germanic languages	composite						x									
OTO-MANGUEN	971		oto (collective)		Oto-Manguen		x									
Otomi	971	otm (Eastern Highland) ots (Estado de Mexico), otz Ixtenco , ote Mezquital), otq (Queretano), ott (Temoaya), otx (Texcatepec), otl (Tilapa)	oto (collective)		Otomi (9 individual languages)											
OTTAWA	820	otw			Ottawa		x									
PACHUCO	628						x					x				
PACIFIC GULF YUPIK	801	ems			Pacific Gulf Yupik (see Yupik for other languages)		x									
Pahari	665*	kfx (Kulla) pfz (Mahasu) phr (Potwari)			Pahari											
PAIUTE	940	pao			Northerrn Paiute (see Ute-Southern Paiute below)		x									
PAKISTAN, nec	676						x			x	x		x			
PALAU	759	pau	pau		Paluan		x	x								
Paleo-siberian	804*						x									
PAMPANGAN	748	pam	pam		Pampanga		x	x				x				
PANAMINT	947	par				Nearly extinct	x									
PANGASINAN	745	pag		pag	Pangasinan		x					x				
PANJABI	665	pan	pan	pa	Panjabi		x	x	x		x	x				x
Papago	954	ood			see Tohon O'odham											
PAPIA MENTAE	630	pap	pap		Papiamento		x									
PASHTO	657	pst (Central) pbt (Southern) pbu (Northern)			Pashto		x	x	x			x				x
PASSAMAQUODDY	821	pqm			Malecite-Passamaquoddy		x									
PATOIS	622	gcf (Guadeloupean Creole French), jam (Jamaican Creole), gcr (Guianese Creole French)			Patois (several options)		x	x				x				

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PATWIN (dialect of Wintu but Wintu has different code)	874						x									
PAWNEE	936	paw			Pawnee	Nearly extinct	x									
PENNSYLVANIA DUTCH	608	pdc			Pennsylvania German	Pennsylvania Dutch, Amish, Amish-German	x	x		x						
PENOBSCOT	822					Extinct	x									
PERSIAN	656	fas (macro with 2 subs: prs Dari Persian and pes Western Persian)		fa	Persian		x			x				x		
Phillipine Other	742				Phillipine Other											x
PICURIS (see Taos and separate code for Tiwa)	959						x									
PIDGIN	604	cpi (Pidgin English, Chinese), wes (Pidgin Cameroon), pcm (Pidgin, Nigerian), tvy (Pidgin Timor), dep (Pidgin Delaware)			multiple types of Pidgin	Delaware Pidgin - extinct	x									
PIMA	954	pia			Pima Bajo		x									
Pit River (see Achumawi)	885				(see Achumawi)											
PLAINS MIWOK	871	pmw			Plains Miwok	Nearly extinct	x									
POLISH	645	pol	pol	pl	Polish		x	x	x	x	x	x	x	x	x	x
POLYNESIAN	766				Polynesian		x									
POMO	888	pmm (Pomo)				Central Pomo, Southeasten Pomo, Southern Pomo - nearly extinct; Eastern Pomo, Northeastern Pomo, Northern - extinct	x									
PONAPEAN	760	pon	pon		Pohnpeian		x	x								
PONCA (see Omaha but different code)	913	oma			Omaha-Ponca (both languages given same code)		x									
PORTUGUESE	629	por	por	pt	Portuguese		x	x	x	x	x	x	x	x	x	x
Portuguese Creole	629		cpp		Portuguese-based Creoles and Pidgins (other)							x				
POTAWATOMI	824	pot			Potawatomi		x									

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PROVENCAL	621	frp			Franco-Provencal		x	x								
PUGET SOUND SALISH	842	slh (South Puget Sound) str (Straits)			PUGET SOUND SALISH, Southern		x									
Pular	794	fuf			Pular										x	
Punjabi	665	pan	pan	pa	Punjabi			x								
Pushto	656	pus (macro with 3 sub Pashto languages)	pus	ps	Pushto				x							
Puyallup (see Puget Sound Salish)	842				(See Puget Sound Salish, Southern)											
QUAPAW	914	qua			Quapaw	Nearly extinct	x									
Quechan	894	yum			Quechan		x	x	x							x
QUECHUA	972	que (macro with 44 subs of Quechua or Quichua)	que	qu	Quechua											
Quiche	968	quc			Quiche					x		x				
Quileute	830	qui			Quileute	Quileute; Nearly extinct										
QUINAULT	843	qun			Quinault	Extinct	x									
RAJASTHANI	669	raj (macro with 6 subs)	raj		Rajasthani		x									
RAROTONGAN	773	rar	rar		Rarotongan		x									
RHAETO-ROMANIC	632			rm	Rhaeto-Romanic		x		x							
Romanian	631	ron	ron/rum	ro	Romanian (See below)	Romanian	x		x	x	x	x	x			x
Romansch	632	roh	roh	rm	Romansch	Romance; Romany;Romansch										x
ROMANY	678	rom (macro with 7 subs of Romany or Romani)			Romany see above too		x									
RUMANIAN	631	ron	ron/rum	ro	Romanian											
RUSSIAN	639	rus	rus	ru	Russian		x	x	x	x	x	x	x	x	x	x
SAHAPTIAN (close to Nez Perce and Klamath)	882						x									
SAHARAN	788						x									
SAINT LAWRENCE ISLAND YUPIK	804	ess			Central Siberian Yupik		x									
SALISH	839	slh (South Puget Sound) str (Straits)			SALISH	SALISH; Straits Salish - nearly extinct										
SAMOAN	767	smo	smo	sm	Samoan		x	x	x	x	x	x		x		x

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Samoyed (see other Uralic languages)	683				multiple languages (Uralic and Samoyed roots like Enets, Forest enf and Enets, Tundra enh)											
SAN CARLOS	979	apw			Apache, Western (differs from other Apache codes)		x									
San Carlos Apache (different code than Apache)	979	apw			Apache, Western (differs from other Apache codes)											
San Juan	962	poe (S.J. Atzingo Popoloca), mjc (S.J. Colorado Mixtec), zab (S.J. Guelavia Zapoteca), xtz (S. J. Teita Mixtec)			San Juan (multiple languages)											
SANDIA (different code than Isleta)	961						x									
Sango	798*	sag	sag	sg	Sango			x								x
Sanskrit	662	san	san	sa	Sanskrit											x
Santa Clara (dialect of Tewa)	962															
SANTIAM	878	kyl			Kalapuya	Nearly extinct	x									
SARAMACCA	606	srm			Saramaccan		x									
Scandinavian languages	composite					Scandinavian languages	x									
SCOTTIC GAELIC	636	sco (Scots) gla (Scottish Gaelic	sco gla	gd (Scottish Gaelic)	Scots; Scottic Gaelic;	Scotish; Scottic Gaelic;	x		x							x
SEBUANO	744	ceb	ceb		Cebuano		x									
Seminole	920															
SENECA	930	see			Seneca		x									
SERBIAN	651	srp	srp/scc	sr	Serbian		x	x	x	x		x	x		x	x
SERBOCROATIAN	649	hbs (macro with 3 subs: bos Bosnian, hrv Croatian, srp Serbian)		sh	Serbo-Croatian		x				x		x	x	x	
Serokoli	uncoded					Serokola							x			
SERRANO	952	ser			Serrano	Nearly extinct	x									

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Sesotho	792*	sot (Southern) nso (Northern)	sot nso	st	Sotho			x	x							x
Setswana	792*	tsn	tsn	tn	Tswana			x	x							x
Shanghainese	715	wuu (sub of Chinese with own code)			Wu Chinese			x	x		x	x				x
SHASTAN	889	sht			Shasta	Extinct	x									
SHAWNEE	825	sjw			Shawnee		x									
Shona	792	sna	sna	sn	Shona			x	x			x				x
SHOSHONI	946	shh			Shoshoni		x									
SIBERIAN LANGUAGES, nec	727															
Siberian Yupik	804	ess			Central Siberian Yupik											
Sicilian	619*	scn	scn		Sicilian							x				
SIERRA MIWOK	872	skd			Southern Sierra Miwok	Nearly extinct	x									
SINDHI	675	snd	snd	sd	Sindhi		x		x			x				
SINHALESE	677	sin	sin	si	Sinhalese/Sinhala		x	x	x	x		x				
Sioux	907		sio (collective)		Siouan Languages											
SIUSLAW	879	sis			Siuslaw	Extinct	x									
Slavic	649		sla		Slavic (Other)											x
SLOVAK	646	slk	slk/slo	sk	Slovak		x	x	x			x				x
SLOVENE	652	slv	slv	sl	Slovenian		x		x			x				
Sogdian	689*	sog	sog		Sogdian											x
Somali	783	som	som	so	Somali			x	x	x	x	x	x			x
Songhai	789		son		Songhai languages			x								x
Soninke	793*	snk	snk		Soninke			x					x			x
SONORAN (n.e.c)	957-958						x									
Sorani	658*	ckb			Central Kurdish							x				
Sorbian languages	644*	hsb (Upper Sorbian) dsb (Lower)	wen (collective) hsb (Upper) dsb (Lower)		Sorbian languages			xx 2 types								x
South American Indian (Other)			sai (collective)		South American Indian (Other)											x
SOUTHERN MAIDU	869	nsz			Nisenan	Nearly extinct	x									
SOUTHERN PAIUTE (different code than Ute)	942	ute			(coded same as Ute-Southern Paiute)		x									
SPANISH	625	spa	spa	es	Spanish		x	x	x	x	x	x	x	x	x	x
SPOKANE	982	spo			Spokane		x									

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SUDANIC	784						x									
SUNDANESE	741	sun (Sudanese) apd (Sudanese Arabic) pga (Sudanese Creole Arabic)	sun	su	Sudanese	Sudanese/Nuer-Sudanese Sudanese Arabic	x		x	x	x	x				x
SUNDANESE	740															
Suquamish	842	squ			Suquamish											
SWAHILI	791	swa (macro with 2 subs) swh (swahili as an individual language)	swa (macro)	sw	SWAHILI		x	x	x	x	x	x				x
SWEDISH	614	swe	swe	sv	Swedish		x	x	x			x			x	x
Swiss	607	gsw	gsw		Swiss German											
Sylhetti	664*	syl			Sylheti							x				
SYRIAC	779	syr (macro language with Assyrian and Chaldean Neo Aramaic)	syr		Syriac		x									
TACHI (different code from Foothill North Yokuts)	877	yok			Yokuts (single code; see also Foothill North Yokuts)	Valley Yokuts	x									
TADZHIK (distinguished from Tajik)	660				Tadzhik (does not appear to be distinguished from Tajik)		x									
TAGALOG	742	tgl	tgl	tl	Tagalog		x	x	x	x	x	x	x	x	x	x
Tahitian	772	tah	tah	ty	Tahitian											
Taiwanese (see Min Nan)	714	dialect of Hokkien then of Min Nan			Taiwanese	Tawainese; Tiawanese		x		x		x			x	x
Tajik	656*	tgk	tgk	tg	Tajik				x			x				
TAMIL	704	tam	tam	ta	Tamil		x	x	x	x		x				x
TANACROSS	856	tcb			Tanacross	Nearly extinct	x									
TANAINA	854	tfn			Tanaina	Nearly extinct	x									
TANANA	855	taa (Upper) tau (Lower)			Tanana	Lower Tanana - nearly extinct	x									
Taos (see also Picuris)	959	twf			Northern Tiwa (Taos is dialect of)											

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Tarahumara	957	tar (Central), tac (Lowland), thh (Northern), tcu (Sutheastern), twr (Southwestern)			Tarahumara											
TARASCAN	969	tsz (Purepecha) pua (Western Highland Purepecha)			Purepecha		x		x							
Tatar	688	tat (Tatar) crh (Crimean Tartar)	tat chr	tt	Tatar			x	x							x
Teluga	701*															x
TELUGU	701	tel	tel	te	Telegu	Telegu	x	x	x	x		x				
Temne	794	tem			Timne	Themne										
Teochau	uncoded					Teochew (related to Southern Min)								x		
TEWA (Hopi-Tewa)	962	Twe (Indonesia) Tew (USA)			Tewa		x									
THAI	720	tha	tha	th	Thai		x	x	x	x	x	x		x	x	x
TIBETAN	716	bod	bod/tib	bo	Tibetan		x	x	x	x		x			x	x
Tigre	780*	tig		tig	Tigre							x				
Tigrigna	780	tir	tir	ti	Tigrinya	Tigrinian; Tigrigna; Tigrinya		x	x	x		x	x			x
TILLAMOOK	844	til			Tillamook	Extinct	x									
TIWA	960	lax			Tiwa		x									
TLINGIT	866	tli	tli		Tlingit		x									
Tohono O'Odham	954	ood			Tohano O'Odham	Tohono Odam				x						
Toishan	711					Taishanese (dialect of Cantonese, but understood only with great difficulty by Cantonese speakers; Toishanese, Toisan, Toishan, Toisanese						x		x		x
TOKELAUAN	770	tkl	tkl		Tokelau		x									
Tonga	792	tog	tog		Tonga [African Nyasa]			x								
TONGAN	768	ton	ton	to	Tonga [Tonga Islands]	Tonganese	x	x	x	x		x				x
TONKAWA	902	tqw			Tonkawa	Extinct	x									
TOWA	963	tow			Jemez	Walatowa	x									

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Trique	971	trc (Trique of San Juan Copala), trs (Trique, Chicahuaxtla), trq (triqui, Itunxosa)								x						
TRUKESE	761	chk	chk		Chuukese	Trukee	x			x						
Tshiluba	792*	lua	lua		Luba-Lulua							x				
TSIMSHIAN	884	tsi	tsi		Tsimshian		x	x								x
Tsonga	792*	tso	tso	ts	Tsonga			x	x							x
TUBATULABAL	953	tub			Tubatulabal	Nearly extinct	x									
Tulu	698	tul			Tulu											
TUNGUS	695	tuw (ISO-639-5)			Tungusic languages		x									
TUPI-GUARANI	976		tup (collective)		Tupi Languages (about 70 languages in S. America; Tupi-Guarani is of the best known)		x									
TURKISH	691	tur	tur	tr	Turkish		x	x	x	x		x	x	x	x	x
TURKMEN	692	tuk	tuk	tk	Turkmen		x	x	x							x
TUSCARORA	931	tus			Tuscarora	Nearly extinct	x									
TUTCHONE	858	ttm (Northern) tce (Southern)			Northern and Southern Tutchone		x									
TWANA	845					Extinct	x									
Twi	796	twi	twi	tw	Twi (sub of macro Akan)	Twi		x	x	x	x	x				x
UIGHUR	689	uig	uig	ug	Uighur		x		x							
UKRAINIAN	641	ukr	ukr	uk	Ukrainian		x	x	x	x	x	x	x		x	x
ULITHEAN	762	uli			Ulithian		x									
Umatilla	882	uma			Umatilla											
UP RIVER YUMAN	891	mov			Mohave	Yuman (Upriver), River Yuman	x									
UPLAND YUMAN	897	yuf			Havasupai-Walapai-Yavapai	Upper Colorado Yuman	x									
UPPER CHEHALIS	834	cjh			Upper Chehalis	UPPER CHEHALIS; extinct	x									
UPPER CHINOOK (see Wasco)	883	wac			Wasco-Wishram		x									
UPPER KUSKOKWIM	853	kuu			Upper Kuskokwim	Nearly extinct	x									
UPPER TANANA	857	tau			Upper Tanana		x									
URALIC LANGUAGES, OTHER	683															
URDU	671	urd	urd	ur	Urdu	Urdu-Pakistan	x	x	x	x	x	x	x		x	x

TABLE I-1 Subcommittee Template: Comparison of Spoken Language Categories and Coding

Census Language Name[a]	Census Code[a]	ISO 639-3 Individual language[b]	ISO 639-2 Individual language[b]	ISO 639-1 Individual language[b]	ISO Language Name[b]	Other Names and Additional Information	Reported in the Census 2000[c]	Kaiser Permanente Health Plan[d]	Contra Costa Health Plan[d]	HRET Hospital Survey[f]	NACHC Survey of CHCs[g]	Language Line Use[h]	NY Presbyterian Hospital[e]	SFGH[e]	UW[e]	Sutter Health[e]
UTE	945	ute			Ute (Southern Paiute)		x									
Uzbek	689	uzb (macro with 2 subs)	uzb	uz	Uzbek				x			x				
VIETNAMESE	728	vie	vie	vi	Vietnamese		x	x	x	x	x	x	x	x	x	x
Visayan	743	ceb			Cebuano	Bisayan (has a separate code), Sebuano										
Volapuk	uncoded	vol	vol	vo	Volapuk	Volapuk										x
WALAPAI	899	yuf			Havasupai-Walapai-Yavapai		x									
WAPPO	923	wao			Wappo	Extinct	x									
Warm Springs	882	tqn			Tenino											
Wasco	883	wac			Wasco-Wishram											
WASHO	890	was	was		Washo	Nearly extinct	x									
WELSH	633	cym	cym/wel	cy	Welsh		x		x			x				
Wenatchee	837	col			columbia-Wenatchi											
White Mountain	979	apw			Apache, Western (differs from other Apache codes)	White Mountain is dialect of Western Apache										
WICHITA	937					Nearly extinct	x									
Windish	644					Slovenian language group										
WINNEBAGO	909	win			Ho-Chunk		x									
WINTUN	875	wit			Wintu	Nearly extinct	x									
WIYOT	826	wiy			Wiyot	Extinct	x									
WOLEAI-ULITHI	763	woe			Woleaian		x									
Wolof	794	wol	wol	wo	Wolof			x	x	x		x	x		x	x
WU	715	wuu (sub of Chinese with own code)			Wu Chinese		x		x							x
WYANDOT (see Huron)	932	wya			Wyandot	Extinct	x									
Xhosa	792	xho	xho	xh	Xhosa			x	x							x
Yakama	882															
YAKUT	693	sah	sah		Yakut		x									
YAPESE	764	yap	yap		Yapese		x	x								
YAQUI	955	yaq			Yaqui		x									
YAVAPAI (different code than Havasupai)	900	yuf			Havasupai-Walapai-Yavapai		x									
Yenisei	683	kjh			Khakas	Abakan Tartar, Yennisej Tartar, Xakas										
YIDDISH	609	yid (macro with 2 subs)	yid	yi	Yiddish		x	x	x	x		x	x			x
Yoruba	796	yor	yor	yo	Yoruba			x	x			x				x
YUCHI	903	yuc			Yuchi	Nearly extinct	x									
Yugoslav	649															
YUKI	922	yuk			Yuki	Extinct	x									

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Census Language Name[a]	Census Code[a]	ISO 639-3 Individual language[b]	ISO 639-2 Individual language[b]	ISO 639-1 Individual language[b]	ISO Language Name[b]	Other Names and Additional Information	Reported in the Census 2000[c]	Kaiser Permanente Health Plan[d]	Contra Costa Health Plan[d]	HRET Hospital Survey[f]	NACHC Survey of CHCs[g]	Language Line Use[h]	NY Presbyterian Hospital[e]	SFGH[e]	UW[e]	Sutter Health[e]
YUMA	894	yum			Quechan	Kechan										
YUPIK	805	esu (Central) ess (Central Siberain) ynk (Naukan) ems (Pacific Gulf) ysr (Sirenic)	ypk (collective)		YUPIK		x					x				
YUROK	827	yur			Yurok	YUROK; nearly extinct	x									
Zapoteca	971	zap (macro with 47 subs	zap		Zapotec				x	x						
Zia	924	zia			Zia											
Zulu	792	zul	zul	zu	Zulu			x	x							x
ZUNI	964	zun	zun		Zuni		x									
	736					Bravanese (name for Swahili use in part of Somalia						x				
	uncoded	daw			Davawenyo	Davaweno					x					
	uncoded	hac			Gorani	Southern Kurdish language						x				
	uncoded					Manegra							x			
	uncoded written	Brai (4 letter script code ISO 15924)				Braille										x
	coded as English					Nonspeaking; speech loss										
	uncoded					Declined, Refused										x
	coded as English	ase			American Sign Language	Deaf; Hearing Impaired; Non Hearing		x	x	x	x	x	x		x	x
						American Sign Language tactive							x			
	uncoded	130 possible choices			Multiple Sign Language options	Other Sign Language		x						x		x
	uncoded	und				Undetermined; Unable to Determine; Unknown								x		x

[a] U.S. Census Bureau. 2007. *Census 2000 Summary File 2 - Technical documentation. Appendix G code lists.* Washington, DC: U.S. Census Bureau. Additional languages were added to this column based on the responses in columns on health plan, hospital, and community health center use. An asterisk indicates a language added to the Census 2000 list.

[b] SIL International. 2009. *ISO 639 Code Tables.* http://sil.org/iso639-3/codes.asp?order=639_3&letter=a (accessed August 25, 2009).

[c] Modern Language Association. 2009. *All languages reported to the US Census in 2000.* http://www.mla.org/map_data_langlist&mode=lang_tops (accessed May 26, 2009).

[d] See Appendixes G and H on Kaiser Permanente and Contra Costa for information on their approaches to data collection and categorization.

[e] Personal communications from Emilio Carrillo, New York Presbyterian Hospital, May 11, 2009; Alice Chen, San Francisco General Hospital, July 7, 2009; Maria Moreno and Traci Van, Sutter Health, July 22, 2009; Shiva Bidar-Sielaff, University of Wisconsin Health, May 11, 2009.

[f] Hasnain-Wynia, R., J. Yonek, D. Pierce, R. Kang, and C. H. Greising. 2006. *Hospital language services for patients with limited English proficiency: Results from a national survey* . Chicago, IL: Health Research and Educational Trust (HRET)/AHA.

[g] National Association of Community Health Centers. 2008. *Serving patients with limited English proficiency: Results of a community health center survey* . Bethesda, MD: National Association of Community Health Centers and National Health Law Program.

[h] Language Line Service. 2009. *List of languages by Language Line Serivces.* http://www.languageline.com/page/languages/ (accessed June 12, 2009).

Section 508 for PDF Verification Results

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Number of pages:	286
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Total of User Verify statuses:	0
Total of Not Applicable statuses:	3203

Page	Checkpoint	Status	Reason	Comments	Image
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