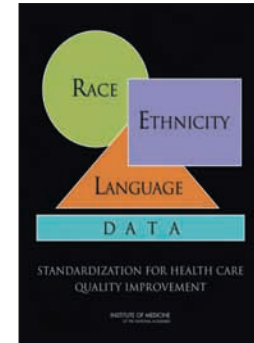


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RACE, ETHNICITY, AND LANGUAGE DATA: STANDARDIZATION FOR HEALTH CARE QUALITY IMPROVEMENT



The *National Healthcare Quality Report* (NHQR) concludes that the quality of health care in the United States is suboptimal, and the pace of improvement is slow. Across the core quality measures tracked in the NHQR, patients receive needed care less than 60 percent of the time. Even when measures of quality, such as receipt of appropriate screening for colorectal cancer, show improvement over time, the *National Healthcare Disparities Report*, for example, shows that disparities persist for specific population groups. A fundamental step in identifying which populations are most at risk is to collect data on race, ethnicity, and English-language proficiency. A large body of research has documented disparities in access to and quality of health care that are revealed when quality of care measures are examined by these variables. A lack of standardization of race, ethnicity, and language categories has been raised as one obstacle to achieving more widespread collection and utilization of these data.

In early 2009, the Institute of Medicine (IOM) at the request of the Agency for Healthcare Research and Quality formed the Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement to examine approaches to standardization. The subcommittee recommends collection of the existing Office of Management and Budget (OMB) race and Hispanic ethnicity categories as well as more fine-grained categories of ethnicity (referred to as granular ethnicity and based on one's ancestry) and language need (a rating of spoken English language proficiency of less than very well and one's preferred language for health-related encounters). Locally relevant categories of granular ethnicity and languages would be chosen from nationally standardized sets. Opportunities should be afforded for individuals who want to self-identify their ethnicity or language when it is not listed specifically on local data collection instruments. The presence of data on race, ethnicity, and language does not, in and of itself, guarantee subsequent actions in terms of analysis of quality-of-care data to identify disparities or actions to reduce or eliminate disparities that are found. The absence of data, however, essentially guarantees that none of those actions will occur.

COLLECTING RACE AND ETHNICITY DATA FOR QUALITY IMPROVEMENT

Hospitals, health plans, and physician practices, for example, can use the data to understand the population being served, address disparities in care that exist, and monitor improvements. The data can also be used by health plans or states to make cross-institutional comparisons to detect variations in quality of care between entities

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serving similar populations. Sharing and comparing quality data across systems calls for a common vocabulary of race, ethnicity, and language categories.

The OMB provides a minimum set of standardized categories for race and Hispanic ethnicity. (The five OMB race categories are: Black or African American, White, Asian, American Indian or Alaska Native, and Native Hawaiian or Other Pacific Islander. The only ethnicity choice is one of “yes” or “no” to Hispanic/Latino ethnicity.) While analyses based on these categories can reveal important disparities in care, they are not always sufficiently descriptive to target interventions most effectively. More discrete population data are needed to identify opportunities for quality improvement and outreach without inefficiently targeting interventions to an entire broad race or Hispanic ethnicity category. The OMB categories do not, for example, capture whether a Hispanic child has a Mexican or Cuban background, or whether an Asian adult is of Japanese or Vietnamese ancestry. These more granular ethnicity distinctions have revealed differentials in utilization of health care services and outcomes (for example, cancer or hypertension-related mortality) that were hidden by only using the OMB categories. Therefore, the subcommittee recommends collection of detailed, granular ethnicity data in addition to data that correspond with the OMB minimum categories. Not all of the hundreds of possible granular ethnicity categories are relevant to all health care entities; to foster understanding and service of local populations, the categories collected and analyzed need to reflect the population served. To ensure compatibility with other data collection efforts, local categories should be selected from a national standard set of granular ethnicities.

COLLECTING DATA ON LANGUAGE NEEDS FOR QUALITY IMPROVEMENT

Compelling evidence exists that patients with limited English-language proficiency encounter significant disparities in access to health care, decreased likelihood of having a usual source of care, increased probability of receiving unnecessary diagnostic tests, more serious adverse outcomes from medical errors, and drug complications. To enhance effective communication between patients and health care entities, the subcommittee concludes that the primary focus should be on collecting data on spoken language need. This can best be assessed by asking two questions: one assessing whether a person rates his or her ability to speak English as less than “very well” and a second one to determine the language preferred for encounters. Where possible and applicable, entities should additionally collect information on the language spoken by the patient at home as a view into the person’s culture, and the language in which he or she prefers to receive written materials.

IMPLEMENTATION

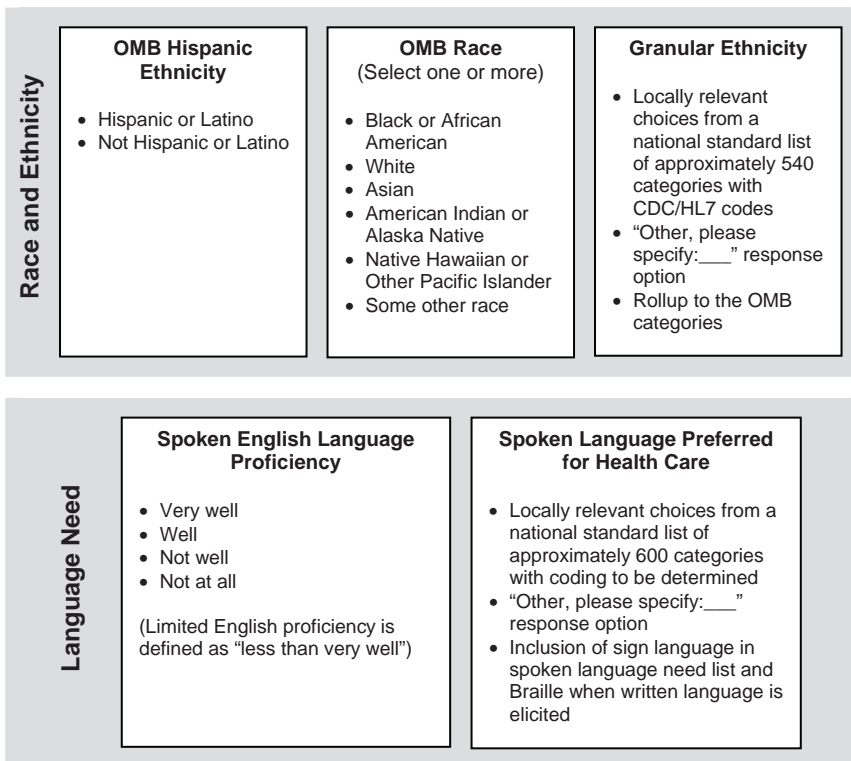
Greater understanding of how the collection of race, ethnicity, and language data underscores quality of care is necessary for patients, registration staff, and health professionals. Legislation supports the collection of these data for quality improvement and disparities reduction, and the data need to continue to be handled properly to maintain the public’s trust. Hospitals, community health centers, physician practices, health plans, health care researchers, and local, state, and federal agencies all have roles to play in gathering and analyzing data for use in designing interventions and informing policy. Some are better positioned than others to collect these data through self-reporting, the generally agreed-upon best way to define a person’s racial and eth-

nic identity. When directly collected data are not 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.

The subcommittee calls on the Department of Health and Human Services (HHS) to develop and make available nationally standardized lists for granular ethnicity categories, and spoken and written languages, as well as rules for aggregating granular ethnicity categories to the broader OMB race and Hispanic ethnicity categories. In addition, HHS and the Office of the National Coordinator for Health Information Technology should adopt for inclusion in requirements of federally funded health care-related programs and electronic health record standards the approach of collecting race, Hispanic ethnicity, granular ethnicity, and language need specified by this report and illustrated in Figure 1. Similarly, states, accreditation agencies, standards-setting bodies, professional organizations, and other federal agencies involved in the provision of health care services (for example, Department of Veterans Affairs and Department of Defense) can foster standardization by adopting the subcommittee’s recommendations. By inclusion of this standardized information in electronic health record systems, it will be possible to stratify quality performance metrics, combine data from various sources, and make comparisons across settings and payment mechanisms.

Having quality metrics stratified by race, Hispanic ethnicity, granular ethnicity, and language need can assist in improving overall quality and promoting equity.

FIGURE 1: RECOMMENDED VARIABLES FOR STANDARDIZED COLLECTION OF RACE, ETHNICITY, AND LANGUAGE NEED



CONCLUSION

There is strong evidence that the quality of health care varies as a function of race, ethnicity, and language. Having quality metrics stratified by race, Hispanic ethnicity, granular ethnicity, and language need can assist in improving overall quality and promoting equity.

FOR MORE INFORMATION . . .

Copies of *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement* are available from the National Academies Press, 500 Fifth Street, N.W., Lockbox 285, Washington, DC 20055; (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area); Internet, www.nap.edu. The full text of this report is available at www.nap.edu.

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SUBCOMMITTEE ON STANDARDIZED COLLECTION OF RACE/ETHNICITY DATA FOR HEALTH-CARE QUALITY IMPROVEMENT

DAVID R. NERENZ (Chair), Director, Center for Health Services Research, Henry Ford Health System, Detroit, MI; **MARGARITA ALEGRÍA**, Professor, Department of Psychiatry, Harvard Medical School, and Director, Center for Multicultural Mental Health Research, Cambridge Health Alliance; **JOHN Z. AYANIAN**, Professor of Medicine and Health Care Policy, Harvard Medical School and Brigham and Women's Hospital, Boston, MA; **IGNATIUS BAU**, Program Director, The California Endowment, Oakland, CA; **RODERICK J. HARRISON**, Senior Research Scientist, Office of the Vice President for Research and Compliance, Howard University, Washington, D.C.; **ROMANA HASNAIN-WYNIA**, Director, Center for Healthcare Equity and Associate Professor, Research, Feinberg School of Medicine, Northwestern University, Chicago, IL; **NINEZ PONCE**, Associate Professor, Department of Health Services, UCLA School of Public Health, Los Angeles, CA; **WAYNE S. RAWLINS**, National Medical Director, Aetna Government Health Plans, Aetna, Hartford, CT; **PAUL M. SCHYVE**, Senior Vice President, The Joint Commission, Oakbrook Terrace, IL; **ALAN M. ZASLAVSKY**, Professor of Health Care Policy (Statistics), Harvard Medical School, Boston, MA

STUDY STAFF

CHERYL ULMER, Project Director; **BERNADETTE MCFADDEN**, Research Associate; **MICHELLE BRUNO**, Research Associate; **ADAM SCHICKEDANZ**, Mirzayan Science and Technology Fellow; **CASSANDRA CACACE**, Senior Program Assistant; **ROGER HERDMAN**, Director, Board on Health Care Services

