

## Race, Ethnicity, & Language Data to Improve Health Care Quality: The IOM Recommendations and Implications for Health Care Providers



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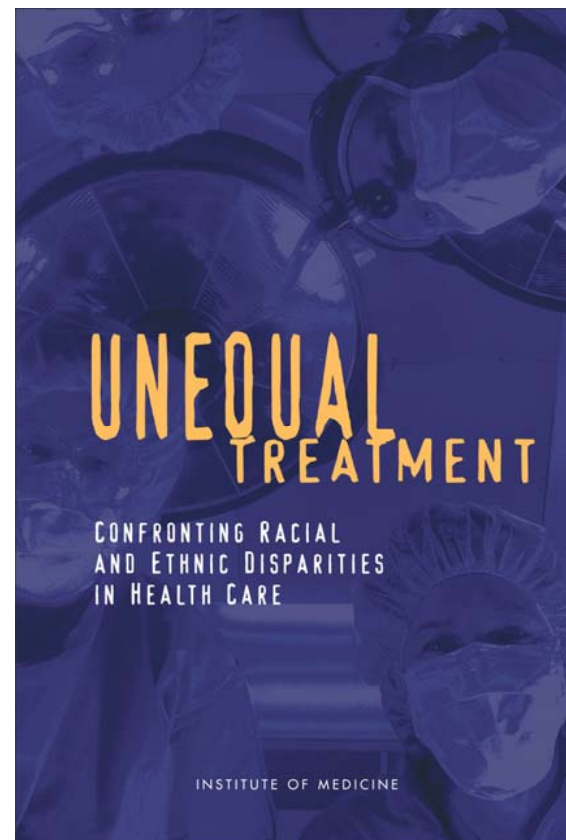
Member, Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement



# IOM Report, 2003: “Unequal Treatment”

*“Disparities in the health care delivered to racial and ethnic minorities are real and are associated with worse outcomes in many cases, which is unacceptable.”*

- Alan Nelson, retired physician, former president of the American Medical Association



# Subcommittee Charge

- Report on the issue of standardization of race, ethnicity, and language variables
- Define a standard set of race, ethnicity, and language categories, and methods of obtaining these data



# Key Messages

- Health care organizations must have data on the race, ethnicity, and language of those they serve in order to identify disparities and to provide high quality care.
- Detailed “granular ethnicity” and “language need” data, in addition to the OMB categories, can inform point of care services and resources and assist in improving overall quality and reducing disparities.





# The Case for Collection of Race, Ethnicity, and Language Data

Race, ethnicity, and language data are needed to:

- Stratify quality performance metrics
- Organize quality improvement and disparity reduction initiatives
- Track progress over time, locally and as a nation

# The Case for Standardization

Standardized race, ethnicity, and language data are needed to:

- Support comparison of data on disparities across organizations and regions, and over time
- Support combination of data across organizations or regions to create pooled data sets
- Support reporting of, and replication of, successful disparity-reduction initiatives



# Existing Guidance

- OMB Directive – 1997
  - Hispanic/Latino Ethnicity
  - 5 Race Categories
- Progress has been made in incorporating the OMB categories into many data collection activities – not all are aligned
- The OMB categories are insufficient to illuminate many disparities and to target QI efforts efficiently

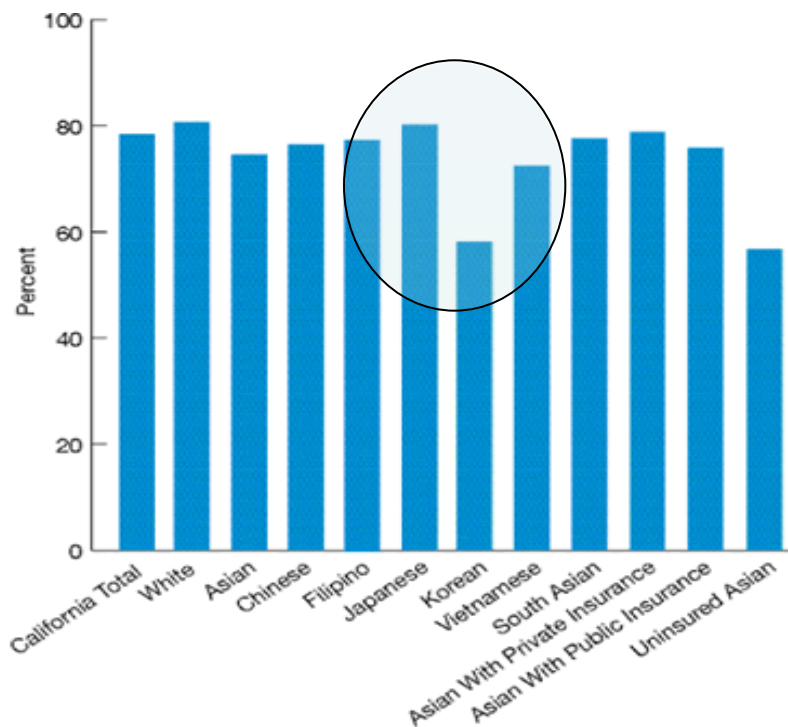


# The Rationale for Granular Ethnicity Data

- Disparities exist within the OMB categories
  - Differential pap screening rates among Asian subgroups even when insured
  - Higher rates of childhood asthma and recent attacks among Puerto Rican than Mexican ethnic groups
- It is still important to use OMB race and Hispanic ethnicity categories

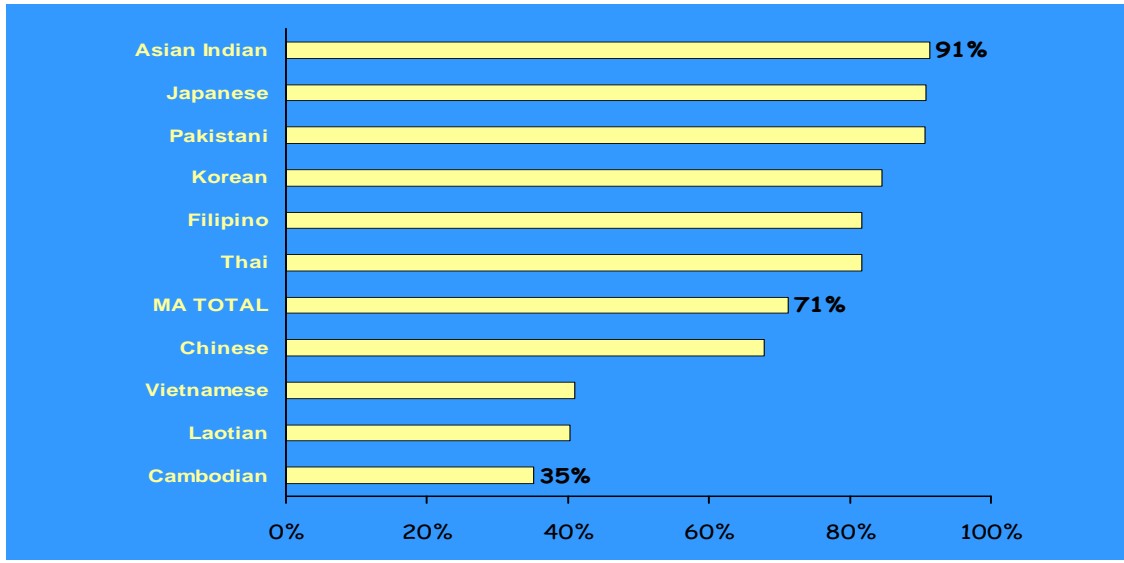


# Granular Ethnicity - Mammography





# Variation in Breastfeeding Rates by Asian Ethnicity



Source: Asian Births in Massachusetts: 1996-1999; Hispanic Births in Massachusetts: 1996-1999; and Black Births in Massachusetts: 1997-2000

# Definition of Granular Ethnicity

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 adopted by the subcommittee as the level of detail necessary for quality improvement



## Recommendation: Granular Ethnicity

- Collect granular ethnicity data as a separate variable from the OMB race and Hispanic ethnicity categories
- Granular ethnicity categories should be selected from a national standard list
- Lists should include an “Other, please specify:\_\_\_” option for additional self-identification



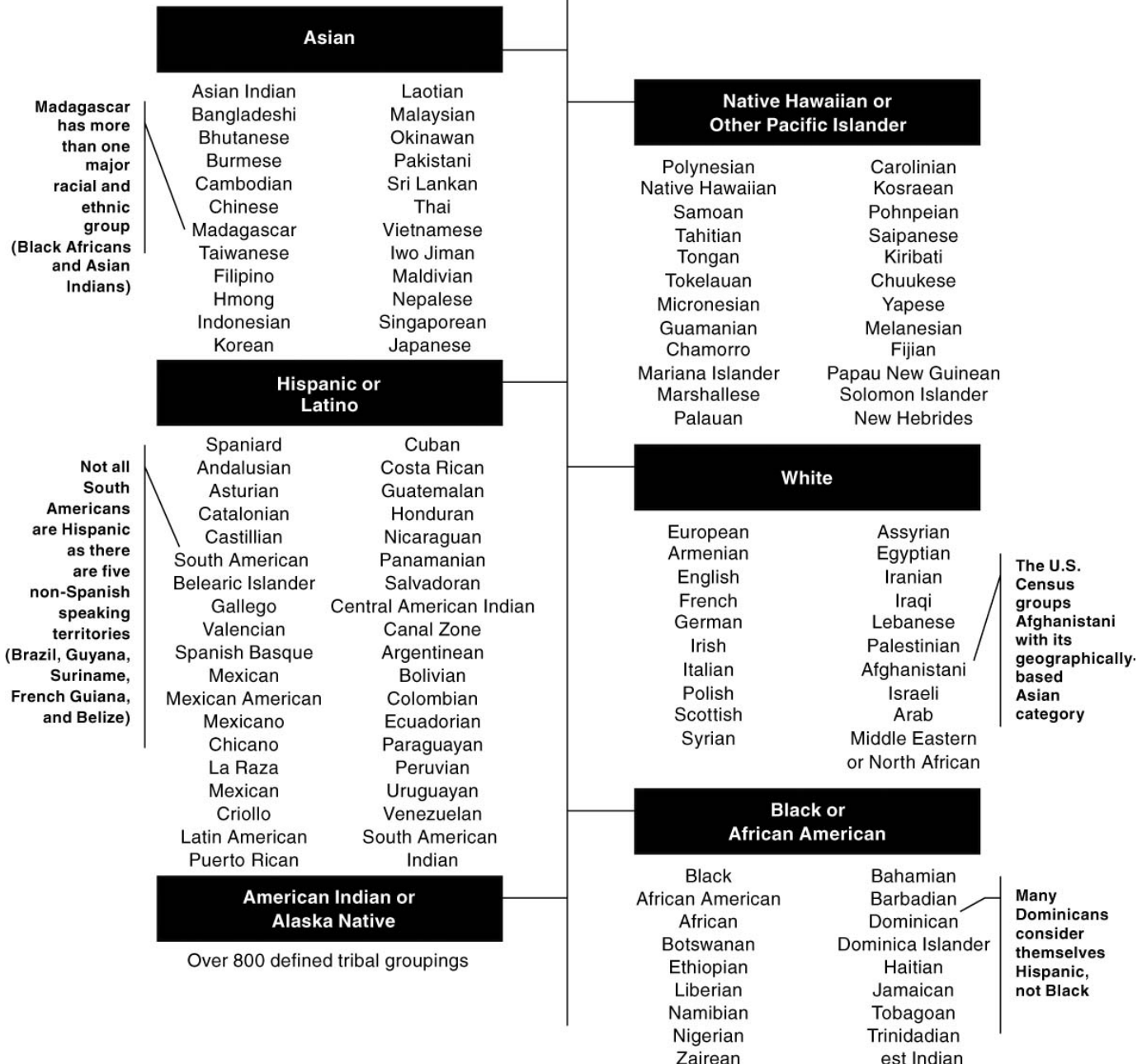
# Selecting Locally Relevant Granular Ethnicity Categories

Local circumstances can dictate whether an entity uses 10 or 100 categories from the national standard list; criteria for selection:

- Health and health care quality issues
- Evidence or likelihood of disparities
- Size of subgroups within the population
- Analyses of relevant data on the service or study population



# OMB Race and Hispanic Ethnicity Categories



# Recommendation: Further Study

- HHS should pursue studies on different ways of framing the questions and response categories at the level of the OMB standards
- Studies could also monitor implementation of granular ethnicity data collection
- HHS studies and Census testing may raise the need for an OMB review



# Rationale for Language Need Data

Persons with limited English proficiency are at risk for:

- Decreased access to care and having a usual source of care
- Adverse outcomes from medical errors and drug complications
- Less utilization of preventive care services



# Recommendation: Language Need

- Identify language need by determining:
  - how well an individual believes he/she speaks English
  - what language he/she needs for a health-related encounter
- “Less than very well” is defined as LEP
- Where possible, also could collect language spoken at home and language preferred for written materials



# Recommended variables for standardized collection of race, ethnicity, and language need

## Race and Ethnicity

### OMB Hispanic Ethnicity

- 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

### Granular Ethnicity

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

## Language Need

### Spoken English Language Proficiency

- 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 needs list and Braille when written language is elicited

# Improving Data Collection

- Self-report is the preferred method
- Educating patients, communities, and health care organization leadership and staff on need for and use of data
- Recommendation: Use indirect estimation where self-report is not available or adequate



# Improving Data Exchange

- Building information infrastructure to ideally enable integrated exchange within and among organizations so these data will not need to be repeatedly collected
- Ensuring privacy and data stewardship





## Recommendation: EHR Standards

ONC EHR standards should include variables for:

- Race
- Hispanic ethnicity
- Granular ethnicity
- English proficiency
- Preferred spoken language

# Recommendation: Payment Incentives

When payment incentives in HIT programs are used, the collection of race, ethnicity, and language data should be an activity for which positive incentives are offered



# Recommendation: HHS Avenues to Ensure Collection

- Recipients of HHS health care-related funding should include the recommended variables in data collection
- HHS, VA, and DOD should adopt the subcommittee's standards so that all federally funded health data systems have comparable data





## Recommendation: Other Avenues of Ensuring Collection

- Accreditation and standard setting organizations should include these variables in accreditation standards and performance measure endorsements
- States should require the collection of these variables

# 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.



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Questions?

Comments?

