



Federal Standards for Racial and Ethnic Data

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Why do we need racial & ethnic data?

- ◆ Monitor trends over time at national, state and local levels (growing socioeconomic inequality & worsening health with acculturation among Hispanics)
- ◆ Evaluate programs
- ◆ Understand etiologic process and identify points of intervention
- ◆ Monitor and enforce Civil Rights Act

NIH Policy on Reporting Race and Ethnicity Data: Subjects in Clinical Research (8/8/01)

- ◆ Collection of this information and use of these categories is required for research that meets NIH definition of clinical research.
- ◆ Applies to new applications and proposals, annual progress reports, competing continuation applications, competing supplement applications for research grants, contracts and intramural projects as of 1/10/02.

Quality of Care Across Entire System

- ◆ Do all parts of the population have access to needed and appropriate services?
- ◆ Do services meet or exceed their expectations?
- ◆ Is their health status improving?

Concerns Regarding Collection of Racial/Ethnic Data

- ◆ Confusion regarding legality of collecting information on racial/ethnic data
- ◆ Potential misuse or misinterpretation of data
- ◆ Lack of standards or enforcement
- ◆ Technical difficulties in collecting or using data
- ◆ Confidentiality/privacy
- ◆ Inconsistent/conflicting policy message
- ◆ Lack of centralized authority governing data collection.

Addressing Legality Concerns

- ◆ HCFA OPL-93 to Medicare+Choice
- ◆ OCR/OSG letters to managed care and health professional organizations
- ◆ OMH funded NHeLP project to review State laws & regs governing collection/reporting of data by health plans & insurers
- ◆ Commonwealth Fund project to review Fed laws/regs for Medicaid & SCHIP

NHeLP: Assessment of State Laws & Regulations for Health Insurers & Managed Care Plans

- ◆ 4 states (CA, MD, NH, NJ) statutorily prohibit health insurers &/or managed care plans from requesting racial/ethnic data during certain transactions
- ◆ A few states have indicated that they would disapprove submitted insurance forms containing racial and ethnic inquiries



SHIRE: Review of Federal Policies & Practices

- ◆ Health-related data collection by race, ethnicity & primary language is legal and fully authorized under Title VI of the Civil Rights Act of 1964
- ◆ No federal statutes prohibit collection of racial, ethnic or primary language health data

OMB Directive No. 15-- Separate Questions

- ◆ For race:
 - American Indian/Alaskan Native
 - Asian/Pacific Islander
 - Black
 - White
- ◆ For Ethnicity:
 - Hispanic
 - Not Hispanic



OMB Directive No. 15-- Combined Format

- ◆ Hispanic
- ◆ American Indian/Alaskan Native
- ◆ Asian/Pacific Islander
- ◆ Non-Hispanic Black
- ◆ Non-Hispanic White

Changes to Federal Standards

- ◆ Recommend Self-Identification
- ◆ Recommend 2 Separate Questions on Race and Ethnicity with Ethnicity First
- ◆ Allow persons to identify more than one race
- ◆ “Hispanic or Latino” instead of “Hispanic”; “Black or African American” instead of “Black”
- ◆ Separate Native Hawaiians or Other Pacific Islanders
- ◆ Include Central and South American Indians



Minimum Categories for Ethnicity



- ◆ Hispanic or Latino
- ◆ Not Hispanic or Latino



Minimum Categories For Race:

- ◆ American Indian or Alaska Native
- ◆ Asian
- ◆ Native Hawaiian or other Pacific Islander
- ◆ Black or African American
- ◆ White

Concerns

- ◆ Competition for resources, especially in light of budget cuts
- ◆ Discourage some from presenting/using racial/ethnic data
- ◆ Difficulty in predicting impact of change
- ◆ Possible inconsistency in how multiracial data are presented/analyzed
- ◆ Matching denominators to numerators especially with changes in how multiracial people are categorized

Concerns--II

- ◆ Too few numbers to present data on Native Hawaiians and Pacific Islanders, and perhaps Asian Americans
- ◆ Still did not address the numbers problem or the need for additional information such as subgroup, SES
- ◆ Did not address changes in reporting (repeatability)

Concerns--III

- ◆ Not sure it improved our ability to collect/report data for persons of more than one race, to monitor for discrimination, to assess progress for goals (e.g., HP2010)
- ◆ Hopefully discussion has increased recognition and understanding that race is a social construct, why we collect racial/ethnic data and what it means when we observe racial differences.

Multiple Options for Data Presentation

- ◆ Combine all who report multiple race
- ◆ Use a follow-up question on “best” or “preferred” to recode those who report more than one race
- ◆ Present data for most commonly reported multiple race combinations
- ◆ Ignore those who report more than one race

Minimum Presentation of Racial/Ethnic Data for Healthy People 2010

Race:

American Indian or Alaska Native

Asian or Pacific Islander

Asian

Native Hawaiian or Other Pacific Islander

Black or African American

White

Hispanic origin and race:

Hispanic or Latino

Not Hispanic or Latino

Black or African American

White

Using Multiple Race Responses

- ◆ If don't need to bridge data, leave multiple racial responses as separate categories; avoid reallocating back to single racial categories.
- ◆ If multiple responses could make an important difference in measuring such disparities, it would be important to use methods that more closely assign people who report more than one race to the single group they would otherwise report before the multiple-response option became available. (Joint Center for Political and Economic Studies)

Recommendations

- ◆ Everyone needs to spend time now to understand the changes and determine which approach is best for them--don't assume anything. There is no single best option for all purposes and data users.
- ◆ State data systems are unlikely to make the transition to the new standards by January 1, 2003.
- ◆ For future standards--use a combined race/ethnicity question rather than two separate questions.

Recommendations--II

- ◆ Conduct targeted studies on American Indians, Alaska Natives, Native Hawaiians and Pacific Islanders (groups with the smallest numbers who will be impacted the most by multiracial reporting)
- ◆ Get involved now in decision making at Federal and state level on how to monitor existing goals and objectives regarding health disparities (e.g., Healthy People 2010, national health care disparities report)

Strategies for Users Who Need to Bridge

- ◆ Plurality method or one of the Fractional Allocation methods provided the closest approximations to a past distribution.
- ◆ If interested in numerically small population and want to maximize numbers for analysis, Smallest Group method and Largest Group Other than White method would yield larger counts for the category--this could raise problems of misclassification of race for a certain proportion of responses.

SOURCE: Sharon M. Lee, Using the New Racial Categories in the 2000 Census, Prepared for the Anne E. Casey Foundation. March 2001.

NAS Study of DHHS Collection of Race & Ethnicity Data: 2001-3

- ◆ Examine the adequacy of race and ethnicity data collected or used by the Department of Health and Human Services program.
- ◆ Will review current policies and practices, examine data requirements and limitations, and suggest improved methods.
- ◆ December 12-13, 2002 Workshop on Improving Racial and Ethnic Data in Health and Healthcare Records in Washington DC. Contact: Tanya Lee: 202-334-3096

Primer on Measuring Disparities in Health

- ◆ Being prepared by NCHS. Contact Ken Keppel: Kkeppel@cdc.gov
- ◆ Discusses issues that arise in measuring differences among rates and in measuring changes in disparity over time
- ◆ Discusses strengths and limitations of specific statistics based on the purpose of the analysis and the number of groups to be compared