Challenges and Controversies

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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
Arguments to End Racial/Ethnic Data Collection

- End collection of racial/ethnic data because “race” is not “real” (i.e., biological)
- Because categories perpetuate racism
- Because of confidentiality/privacy concerns
- Race/ethnicity is just surrogate for SES
- Human Genome Project
Census 2000 Long Form Questions Viewed as Too Personal

![Bar chart showing questions viewed as too personal](chart.png)

- Housing
- Employment
- Race/Ethnicity
- Disabilities
- Income

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CA Racial Privacy Initiative

- Prohibit state from classifying individuals by race, ethnicity, color, or national origin in operation of public education, contracting or employment

- For other operations with exception of legislature identifying compelling state interest, medical research, needed to comply with federal law or eligibility
Public Health Research Still Lags Behind in Understanding Race

- Whether “race” (fundamental biologic category) or “racism” (fundamental but not inevitable social relationship) accounts for racial/ethnic disparities in health

- Population genetics to anthropology have long discredited notions of “race” as innate biologic construct
ICMJE Uniform Requirements for Manuscripts: May 2000

- Identify characteristics of subjects
- Justify use of ethnicity in report
- Avoid terms such as “race” & use alternative descriptors such as “ethnicity” or “ethnic group”
- Specify what descriptors mean
- Tell exactly how the data were collected (e.g., self-reported)
Journal Response

- Archives of Pediatrics & Adolescent Medicine: “ask authors to not use race and ethnicity when there is no biological, scientific or sociological reason for doing so”  (Feb. 2001)
Concerns of Managed Care

- Anti-discrimination obligations
- Perceived legal barriers to collecting such data
- Confidentiality concerns
- Cost of data collection (time & money)
- Health consumer perceptions regarding use of such data
Collection Issues

- Discrepancies between self-identification and observer identification
- Changes in preference and categories used over time (e.g., African-American and Black, more than one race)
- Need information on subgroups, socioeconomic status, risk behaviors, etc.
Addressing Legality Concerns

- HCFA OPL-93 to Medicare+Choice
- OCR letter to Academic Medicine & Managed Care Forum (AETNA)
- 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 prohibited health insurers & managed care plans from requesting racial/ethnic data during certain transactions.

- 3 states (CT, MN, SD) have indicated that they would use their insurance form prior approval process to prohibit racial & ethnic inquiries.
NHeLP Assessment

- SC requires collection of racial data by HMOs.
- TX requires collection of primary language data by HMOs.
Protection Against Discrimination--I

- 41 of 51 jurisdictions provide some level of protection against discrimination on basis of race or national origin for health insurance consumers or managed care plan enrollees.

- Level of protection provided for health care consumers is uncertain for HI, IN, IA, KS, OK, OR, VT
Protection Against Discrimination--II

- AL, GA, MS provide no protection for racial and ethnic minority health care consumers in their insurance laws, managed care laws, or general civil rights laws
Confidentiality Provisions

- Most common protection is provided for HMO enrollee’s medical information
- Over half of states have public information acts that include exemptions for medical records and information...state agencies must maintain confidentiality of medical information they collect
Confidentiality--II

- 22 states have confidentiality policies or provisions that protect MCO or HMO enrollees...those not in managed care may be subject to disclosure of sensitive medical information without redress under state law.
Collection of Racial/Ethnic Data by Medicaid and SCHIP

- Most states do not have statutes/regs that require the collection of racial & ethnic data by state Medicaid agencies, but most request this information from their Medicaid and SCHIP applicants.

- Some applications indicate this is voluntary; several note that refusing to provide info. will not affect eligibility status.
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.
SHIRE/NHeLP Review of Health Services Program Statutes

- 3 statutes require collection &/or reporting of racial/ethnic data—MCH Block Grant, SAMHSA surveys and grants for children of substance abusers.
- 2 statutes require collection of demographic or enrollee characteristics (SCHIP, Ryan White Care Act)
Two health services regulations require racial and ethnic data collection and/or reporting (End-Stage Renal Disease Program, SAMHSA applications for prevention activities (target population))

Potential requirements for Medicaid managed care and SCHIP regulations are undergoing administration review
SHIRE/NHeLP Review of Data Collection Vehicles

- Over 100 data collection vehicles reviewed
- All included fields for race and ethnicity
Addressing Data Quality Concerns

- OMH funded project with PHF to assess the quality of race/ethnicity data from State Medicaid agencies and foster collaborative analyses with public health departments

- HCFA funded project to analyze MCH data from State Medicaid agencies by race/ethnicity
HIPAA

- HIPAA required HHS to adopt code sets for electronic transmission of data--each code set is designated as “required”, “situational” or “not used”
- For healthcare encounters, race & ethnicity code set is “not used”
- For enrollment, race & ethnicity code set is designated as “situational”
Changes to Federal Standards

- Reflect social definition of race & do not conform to biological, anthropological or genetic criteria
- Recommend Self-Identification & 2 questions on race & ethnicity with ethnicity first
- Allow identification of ≥1 race
- “Asian”; “Native Hawaiian/Pacific Islanders”
- “Hispanic or Latino”; “Black or African American”
- Can identify all Hispanics
Data Quality Issues Considered

- Reliability (repeatability)
- Validity (misidentification)
- Item nonresponse of race question
- Reporting of “Other Race” by Hispanics
Minimum Categories For Race:

- American Indian or Alaska Native
- Asian
- Native Hawaiian or other Pacific Islander
- Black or African American
- White
Minimum Categories for Ethnicity

- Hispanic or Latino
- Not Hispanic or Latino
NOTE: Please answer BOTH Questions 5 and 6.

5. Is this person Spanish/Hispanic/Latino? Mark X 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 X 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
   - Japanese
   - Native Hawaiian
   - Chinese
   - Korean
   - Guamanian or Chamorro
   - Filipino
   - Vietnamese
   - Samcan
   - Other Asian — Print race.
   - Other Pacific Islander — Print race.
   - Some other race — Print race.
### Overwhelming Majority of U.S. Population Reported One Race

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<th>Race</th>
<th>Percentage</th>
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<td>One Race</td>
<td>97.6%</td>
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<tr>
<td>White</td>
<td>75.1%</td>
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<tr>
<td>Black or African American</td>
<td>12.3%</td>
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<tr>
<td>American Indian or Alaska Native</td>
<td>0.9%</td>
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<tr>
<td>Asian</td>
<td>3.6%</td>
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<tr>
<td>Native Hawaiian or Other PI</td>
<td>0.1%</td>
</tr>
<tr>
<td>Some Other Race</td>
<td>2.4%</td>
</tr>
</tbody>
</table>
Only 2.4% Reported Two or More Races

- 6.8 million respondents reported 2 or more races
- 93% of those reported exactly 2 races
- Most common combination was
  - White+Some Other Race (32%)
  - White+Amer Indian/Alaska Native (16%)
  - White+Asian (13%)
  - White+Black/African American (11%)
Census Quality Survey

- Census will conduct Census Quality Survey in Summer 2001 to assess reporting of race & Hispanic origin from Census 2000 (50,000 households)
- Data file will be produced that will assist users in developing ways to make comparisons between Census 2000 and single-race data collection
Census Bureau Tabulation of People Reporting $\geq$2 races

- 63 categories including 57 possible combinations of the six race groups (e.g., redistricting file)

- # times respondent reports one of the 6 categories alone or in combination with other 5 race categories (demographic profiles will use 7--single race alone, some other race, two or more races)
Hispanic Origin in Census 2000

- 12.5% or 35.3 million were Latino
- 58% increase between 1990 and 2000, largest census-to-census increase in the Hispanic or Latino population since Census Bureau began collecting data on this ethnic group in 1970
Nine out of Ten Hispanics Reported White Alone or Some Other Race Alone

- 47.9% reported only White while 42% reported Some Other Race.
- 6.3% reported two or more races compared with 1.9% of non-Hispanics.
- Vast majority (97%) of those who reported Some Other Race were Latino.
- Majority (90%) of Some Other Race alone or in combination were Hispanic.
Guidance on Aggregation and Allocation of Data on Race for Use in Civil Rights Monitoring and Enforcement OMB (BULLETIN NO. 00-02) - I

- **Aggregation**
  - five single race categories
  - four double race combinations
    - American Indian/Alaska Native and White
    - Asian and White
    - Black/African American and White
    - AI/AN and Black/African American
  - other combinations that rep. >1% of pop. in a jurisdiction
Guidance on Aggregation and Allocation of Data on Race for Use in Civil Rights Monitoring and Enforcement OMB (BULLETIN NO. 00-02) -II

- Allocation
  - Responses in the five single race categories are not allocated.
  - Responses that combine one minority race and white are allocated to the minority race.
Allocation (continued)

- Responses that include \( \geq 2 \) minority races:
  - If the enforcement action is in response to a complaint, allocate to the race that the complainant alleges the discrimination was based on.
  - If the enforcement action requires assessing disparate impact or discriminatory patterns, analyze the patterns based on alternative allocations to each of the minority groups.
Persons Reporting More than One Race: NHIS, 1997

- More than one race 1.4%
  - AIAN/White (39%)
  - API/White (23%)
  - Black/White (14%)
  - Other Multiple Race (24%)

- AIAN/White group is larger than AIAN single-race group
Primary Race by Multiple Race Group: NHIS, 1997

- AIAN/White (82% White, 17% AIAN)
- API/White (39% White, 49% API)
- Black/White (27% White, 50% Black)
Private Health Insurance Coverage Rates: NHIS, 1997

The graph shows the percentage of White, AI/AN, and AIAN/White populations covered by health insurance. The highest coverage rate is for the White population, followed by AIAN/White, and the lowest is for AI/AN.
Promising Bridge Methods

- Largest Group
- Plurality (assign to highest proportion of main race)
- Deterministic Fractional Assignment
Impact of Bridge Methods on Single Race Estimates Depends:

- Extent to which single or multiple race groups differ on characteristics that affect outcomes of interest
- Size of difference between single and multiple race respondents on outcomes
- Relative size of groups
- How multiple race respondents answered previous race questions
Percent Distribution of Race for Bridge Tabulation: NHIS, 1993-5

- White 80.3% (79.4%-80.8%)
- Black 12.7% (12.7%-12.9%)
- AIAN 0.9% (0.8%-1.8%)
- API 3.5% (3.4%-3.8%)
% No Health Insurance for Bridge Tabulation: NHIS 1993-5

- White 13.4% (13.4%-13.5%)
- Black 18.1% (18%)
- AIAN 32.2% (26.7%-32.3%)
- API 18.9% (18.2%-18.9%)
Issues When Comparing Rates

- Census undercount greater for racial/ethnic minorities & young than the total population -- may lead to overestimation of death rates.

- Changes over time in acceptance and use

- Use of different data collection methods (e.g., self-administered v.s. observer, racial/ethnic categories)

- Selection of comparison population & age-adjustment standard
FIGURE 2. A framework for understanding the relationship between race and health.
Socioeconomic Status (SES): Person’s position in society, usually expressed in terms of income, education, occupation, but could also be represented by net worth, ownership of assets such as a home, automobile, yacht etc.
Socioeconomic Status (SES) is Powerful Determinant of Health

- Inverse gradient between individual & household SES, & morbidity & mortality is well established.
- Association of SES and health has been found in different populations, using different indicators of SES and different health outcomes (e.g., Dubois, 1899).
- Impact of income is strongest at lowest levels (not linear).
Socioeconomic Status Can be Assessed at:

- Individual (e.g., education, income, occupation)
- Family/Household
- Community (e.g., Median income, % receiving public assistance, % families earning $30,000 or more, % Adult unemployment)
Opportunity Structures of Local Areas (Macintyre & Ellaway, 2000)

- Physical features of the environment shared by all residents
- Availability of healthy environment at home, work, play (education, transport, street lighting, policing, health services)
- Services provided, publicly or privately to support people in their daily lives
Opportunity Structures--II

- social-cultural features of neighborhood
- reputation of an area (perceptions by bank)
Potential CVD Intervention Points (Marmot, 2000)

- Medical care to lower plasma fibrinogen
- Influence individual behaviors
- Create more control of working conditions
- Attention to childhood social environment
Unexplained Health Disparities Could Reflect:

- Inadequate control for differences in current social class
- Failure to consider the effects of social class in earlier life (including childhood)
- Intergenerational effects of social class
- Influences of other variables not considered (e.g., psychosocial stress, nutrition)
SES Measures-II

- Employment
- Health insurance coverage
- Assets (e.g., home ownership, monthly payment, equity, cars, telephone)
- Financial strength (e.g., How often is it that you don’t have the money to buy things the family needs? How do things work out at the end of the month--enough or not?)
- Purchasing power
Income Inequality and Health

- U.S. studies show consistent associations for child health outcomes and cirrhosis--the exception rather than the rule.
- No association in Canada, Australia, & Japan with mortality.
- International comparisons using newly available data show no association.
Caution: Race/Ethnicity & SES

- SES measures may not be adequate
- Controlling for social class does not address noneconomic aspects of racism.
- If effect modification exists, only stratified results should be presented.
Use SES

- Means of determining extent to which black/white differences in health are mediated by the concentration of minorities in poverty and the working class.

- Race is not antecedent to class per se--more than racism (e.g., macroeconomics) is involved in creation & continuance of social classes in U.S.
Other variables could consider

- Quality of medical care, access to health care & health care barriers (e.g., waiting times)
- Low English proficiency
- Language, birthplace, acculturation
- Environmental exposure at home and work (e.g., fumes, smoke)
- Psychosocial risk factor measures
Measuring Racial & Ethnic Discrimination in Healthcare Settings (LaVeist 2001)

- Routine monitoring of administrative records to screen for patterns of racial disparities in the use of medical procedures
- Trained testers sent to facility to determine process whereby racial disparities are being produced
We DO need the data

“…measurable gains in advancing a civil rights agenda to bring all Americans into the economic, political & social mainstream would have been extremely difficult, if not impossible if we did not have adequate information on racial and ethnic groups.”