

Seizing the Opportunity: Race/Ethnicity Data Collection in Public Health and Health Care

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Outline

- Goals of Data Collection: Why Race/Ethnicity?
- Racial/Ethnic Disparities in Health and Health Care
- Lessons from the IOM Reports
- Experiences and Perspectives

Goals of Data Collection

- To improve health and health care, we must recognize and be able to accurately measure and monitor demographic shifts and population changes (Sondik)
 - Identify trends and emerging problems
 - Target and evaluate interventions

Why Race/Ethnicity?

- Federal Government states:

Race/Ethnicity collected to monitor equal access for health, housing, education, lending, employment because of previous discrimination

Why Race/Ethnicity?

- Epidemiologists state:
 - Suggest leads about disease etiology
 - Understand roles of, and interactions between, genetics and the environment
 - Consider whether biology different within groups
 - Identify subgroups receiving unequal health care so as to target programs

What have we learned? Disease and Etiology

- Breast Cancer:
 - Incidence 2x higher for W vs Asian Am Women
 - Soy, phytoestrogens, fat, black/green teas??
 - Incidence 3x higher in US Japanese w vs Native;
2x higher in US Chinese w v Native
 - Acculturation, difference in detection, genetic factors
 - 5yr survival 71% AA W, 86% W women
 - SES, mammography use, access, later detection

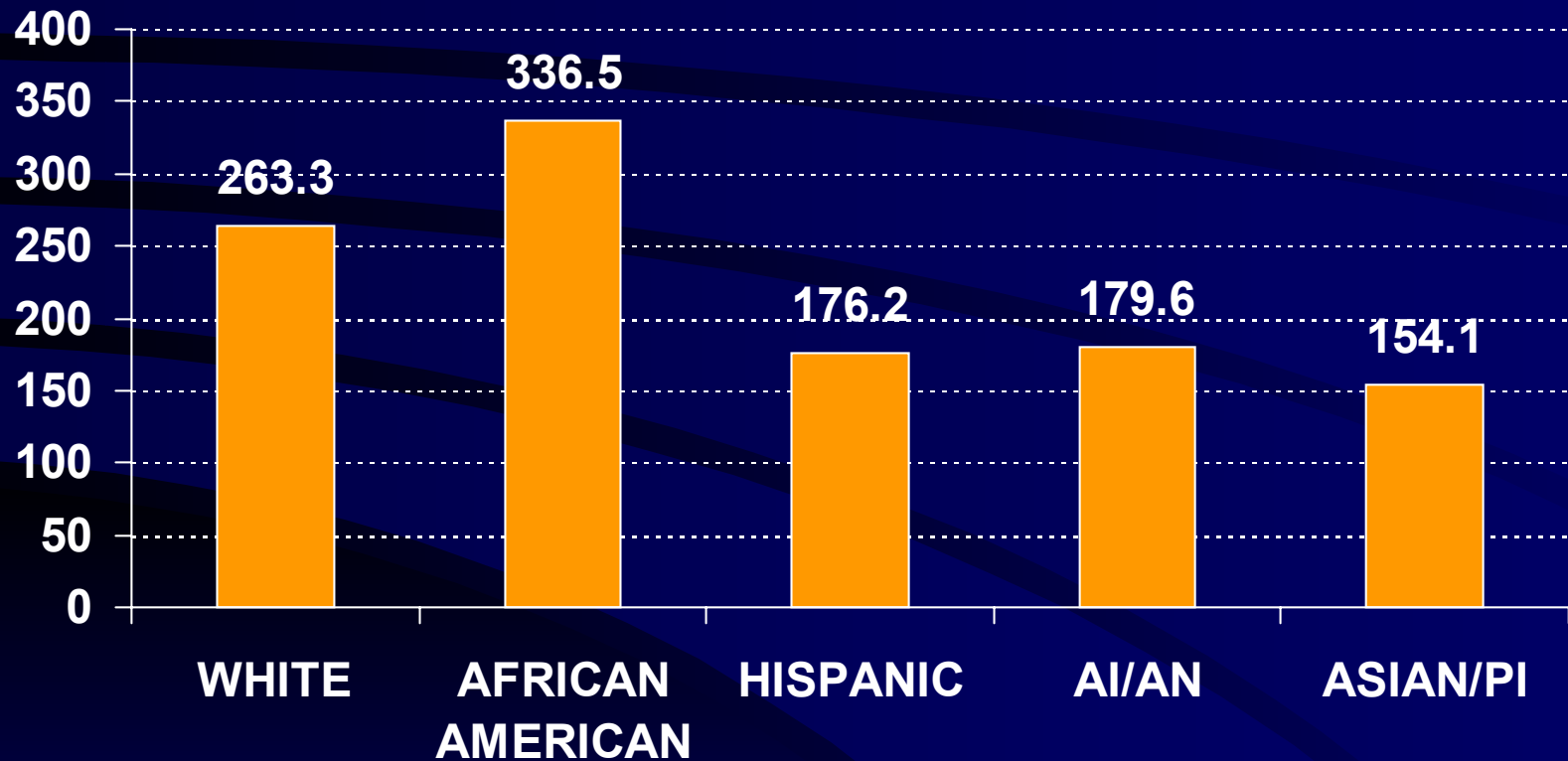
What have we learned? Health Outcomes

Racial/Ethnic Disparities in Health:

- Despite health promotion/disease prevention interventions that have improved the overall health of the majority of Americans, minorities have benefited less from these advances (NHLHI)

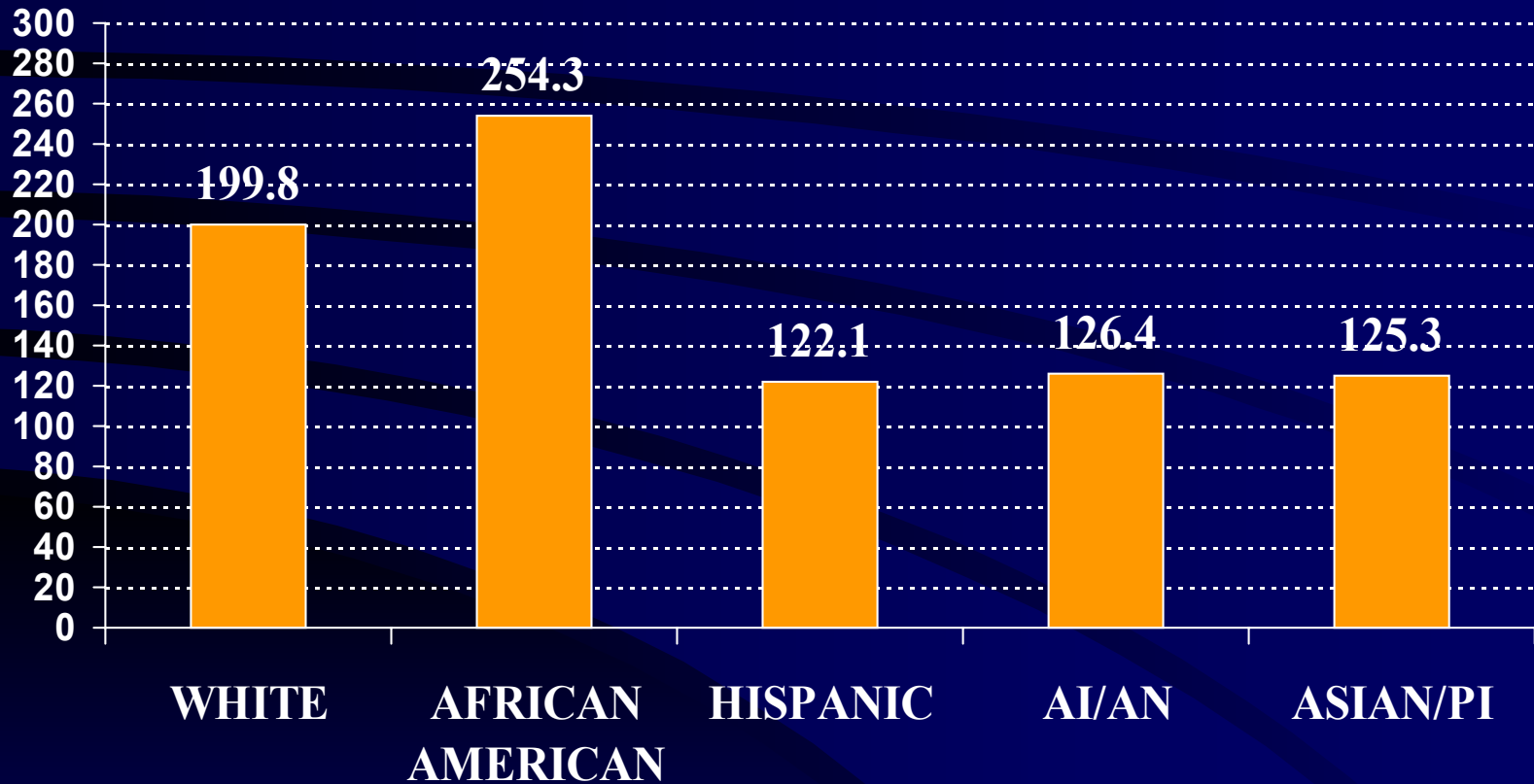
Cardiovascular Disease Death Rate, 1999

Deaths per 100,000 population



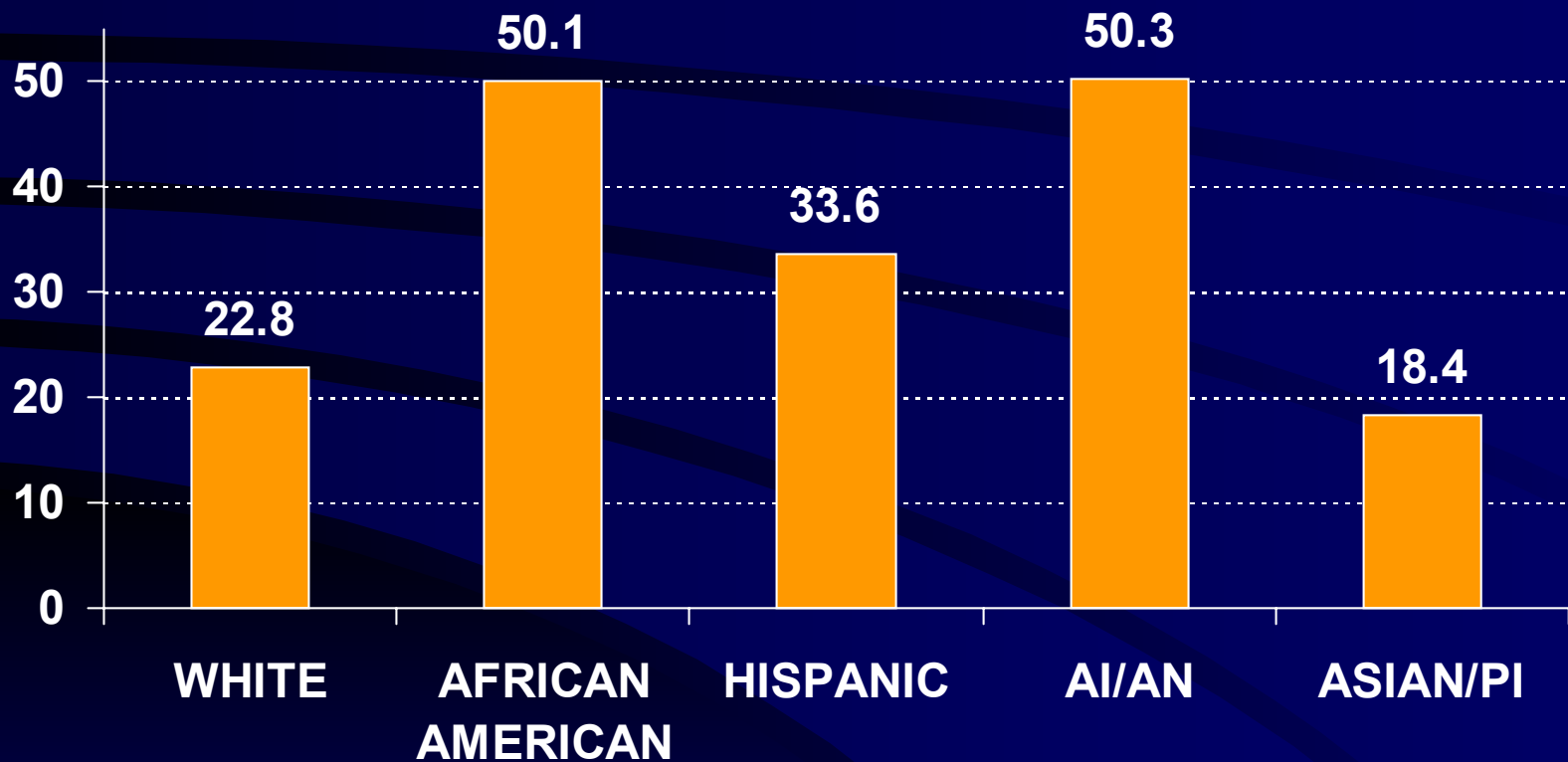
Cancer Death Rate, 1999

Deaths per 100,000 population



Diabetes-Related Death Rate, 1999

Deaths per 100,000 population



What leads to Disparities in Health?

- Social Determinants
 - Education, environment, housing, employment
- Access to Care
 - Insurance, continuity of care
- *Health Care?*
 - *Health systems and the medical encounter*

Social Determinants: The Latino Case Example

- Education
 - Latino children have highest high school drop-out rate at 29% (versus 23% for AA and 7% for Whites)
 - 36% live in poverty, yet 26% in Head Start
- Environment
 - Latino children have greater exposure to pollutants, waste sites, pesticides, lead and mercury
 - 3 of 5 largest landfills in Latino and AA communities
- Employment
 - Latinos well represented in workforce, yet work in small firms and industries that don't provide health insurance

Access to Care: The Latino Case Example

- 40% of Latinos under 65 uninsured
- Latino children make up 29% of uninsured children
- One quarter of nation's uninsured are Latino
(11 of 44 million Americans)
- Reasons include lack of employer-based health insurance, status concerns, family structure

Racial/Ethnic Disparities in Health Care

- Differential utilization based on race for:
 - Mammography (Gornick et al.)
 - Amputations (Gornick et al.)
 - Influenza vaccination (Gornick et al.)
 - Lung Ca Surgery (Bach et al.)
 - Renal Transplantation (Ayanian et al.)
 - Cardiac catheterization & angioplasty (Harris et al, Ayanian et al.)
 - Coronary artery bypass graft (Peterson et al.)
 - Treatment of chest pain (Johnson et al.)
 - Referral to cardiology specialist care (Schulman et al.)
 - Pain management (Todd et al.)

Congressional Action: Institute of Medicine Reports

- Private, independent non-profit Institute of National Academy of Sciences
- Examines issues related to health policy, health care, education and research
- Convenes “mixed” expert panel for deliberations (6-24 months) and findings to Congress and the public

IOM's Unequal Treatment

Study Charge

- Determine presence and extent of racial/ethnic disparities in health care *not attributable to access*
- Evaluate potential sources of disparities including the role of bias, discrimination, and stereotyping at the individual, institutional, and health systems level
- Provide recommendations regarding interventions to eliminate racial/ethnic disparities

IOM's Developing a National Health Care Disparities Report

Study Goal

- Advise AHRQ on content of annual report to Congress on prevailing disparities in quality based on geography, race/ethnicity, access, and SES
- Adjunct to National Health Care Quality Report
 - “National trends in American Health Care Quality”
 - Goal is to have yearly marker similar to CPI or Ed Markers
 - Framework in *Envisioning a Nat'l HC Quality Report*

Racial/Ethnic Disparities in Health Care

What did we learn?

How do we define Race?

- Social/Sociopolitical construct that is not genetic, biologic, or anthropological
 - Greater within vs between group genetic variation
 - 85% allele variation within, 15% between
 - Depends on needs and current social context
 - Varies worldwide; changes over time (NA '70 v '80)
 - May reflect way groups are viewed/treated
 - “Perception IS reality”; discrimination and health effects
 - Arbitrary
 - Methods of assignment

How is Data Collected? Is it accurate?

Methods

- Assignment
 - Health professional → birth
 - Clerk → hospital admission
 - Funeral Director → death
- Self identification
 - Voluntary versus required
 - “opinion poll”

What are we measuring?

- Race is an indicator of histories and conditions that bear on access to health services and patterns of medical care utilization (Williams)
- Used as a marker (perhaps inappropriately) for:
 - Socioeconomic status
 - Immigration status
 - Occupation
 - Discrimination
 - Beliefs, behaviors, attitudes

SES and Health

- Low SES and social class clearly linked to poorer health outcomes; gap widening
- SES measures have included:
 - Income (others consider wealth or deprivation)
 - Education (household?)
 - Insurance (changes in status?)
 - Occupation
 - Individual, Household and Neighborhood Level (surveying, admin data, census geocoding)

Race and SES

- Race strongly correlated with SES, yet:
 - 2/3 African-Americans (AA) not in poverty
 - 2/3 of those in poverty white
 - Despite correlation, doesn't explain all disparities
- SES not equivalent across race:
 - Low SES AA experience higher levels of certain stressors
 - Employed AA experience higher occupational hazards
 - Despite equal education, AA receive less compensation and have less purchasing power

Race/Ethnicity Data: Historical Perspective

- 1960
 - White, non-White
- 1970
 - White, Black, Other
- 1980
 - White, Black, Native American/Alaska Native, Asian/Pacific Islander, Hispanic
- 1990
 - White, Black, NA/AN, AAPI, Hispanic and certain other population subgroups

Race/Ethnicity Data: Year 2000 Census

OMB Directive 15 Update

- Spanish/Hispanic/Latino *ethnicity*
- White, African-American, AI/AN, Asian (Chinese, Japanese, Filipino, Korean, Vietnamese)
- Native Hawaiian, Pacific Islanders pulled out of Asian grouping
- Can check *multiple* races
- Hispanics have to check *ethnicity and race*
- Question on Ancestry/Ethnic Origin

Race/Ethnicity Data

The Saga of Medicare

- Prior to 1980
 - White, Black, Other, Unknown
 - *Via CMS Enrollment Data Base (EDB), from Soc Sec'y Master Beneficiary Record (MBR), from SS-5 upon getting SS#...and entering race/ethnicity is optional)*
- 1980 OMB Directive 15
 - White, Black, Hisp, AA/PI, NA/AN; no other; unknown kept
 - Integrated in 1982 into MBR's SS-5; CMS doesn't update because few who get SS# will be Medicare recipients
- 1994, 1997
 - CMS sporadically updates EDB from new MBR
- 1997 and Now...
 - 1997: CMS mailing to 2.2M “unknown” or Hisp surname beneficiaries (850K respond) to get race/ethnicity; Now: all data collection in compliance with OMB 15

English Proficiency and Quality of Care

Spanish-speaking patients discharged from ER less likely to understand diagnosis, medications, instructions, and plans for follow-up care ; less satisfied with care or willing to return if they had a problem; more likely to report problems their care; and less satisfied with the patient-provider relationship.

Hispanic patients with language discordant physicians are more likely to omit medication, miss office appointments, and visit the emergency room for care.

(Crane JA, Carrasquillo et al., Baker et al., Manson A, Baker et al., Hornberger et al., Erzinger S, Seijo R)

IOM's Unequal Treatment

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Major Finding

Racial/Ethnic disparities consistently found across a wide range of health care settings (managed care, public/private hospitals, teaching/community, etc.), disease areas (CVD, Ca, HIV, DM, etc.) and clinical services, even when various confounders are controlled for (i.e. SES, stage of presentation, comorbidities)

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Specific Findings

- Racial and ethnic disparities in health care exist and, because they are associated with worse outcomes in many cases, are unacceptable.
- They occur in the context of broader historic and contemporary social and economic inequality, and evidence of *persistent* racial and ethnic discrimination in many sectors of American life.
- Many sources – health systems, health care providers, patients, and utilization managers – contribute to racial and ethnic disparities in health care.

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Recommendations

- Collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language
- Include measures of racial and ethnic disparities in performance measurement

Race/Ethnicity and Language Data Collection

Experiences and Perspectives

What are the current debates?

- What are we measuring?
- Do we continue to measure it?
- How do we collect it?
- What other factors can we collect?
- What is the clinical impact?

What are the current policy debates?

- New Census and Challenges for the Future
- Managed Care and Federal Data Collection
- “Privacy Issues” (HIPAA)
- Methods of Collection

Race/Ethnicity Data: Pros and Cons

Pros

- Best current method of tracking inequities
- Systems have improved
- Inherent public health and planning value

Cons

- Appropriate measure?
- Subgroups
- Multiple markers
- Fluidity and multiracial groupings
- Increasing complexity given OMB and new census

Pushback and Resistance

- Before you didn't want us to collect it!
 - Why now?
- Too expensive and complex!
 - Will require new systems, forms, etc.
- Patients/Consumers won't like it!
 - Redlining, misuse; how would we do it??

Things to Consider

- Fine tune the disparities we're aware of...
 - Diversity within diversity
- Identify disparities we're uncertain of...
 - Expand knowledge of other groups & subgroups
- Consider interventions and the future.
 - What will r/e data collection look like ten years??

There is a window of opportunity...

What should we measure?

- Depending on goals, may want to locally identify:
 - Race/Ethnicity (OMB-15)
 - Subgroup (within reason)
 - Language Preference
 - *Appropriate/Available* measures of SES (education?)
 - Marker of Migration, Acculturation
- Large datasets may have limitations

Large Datasets?

- Medicare/Medicaid
- National Health Interview Survey
- Healthcare Cost & Utilization Project
- Medical Expenditure Panel Survey

Challenges and Approaches

- Slippery slope...
 - How about years in US? How about the Amish?
- Need for practicality
 - It's hard to collect everything
 - Avoid paralysis by analysis
- Incrementalism
 - Building new partnerships (i.e. Purchasers)

Future Directions

- Disparities provide a window of opportunity where race/ethnicity, language, SES, critical
- Data collection in health care can be couched within concept of quality (per Quality Chasm)
- Tiered systems should be developed *with* standardization and linkages (public health data, hospital data, etc)
- Measures for data collection should stand test of applicability, practicality and feasibility
- Some data collection may be driven locally