

# Genetic Research Issues among Specific Racial/Ethnic Minorities

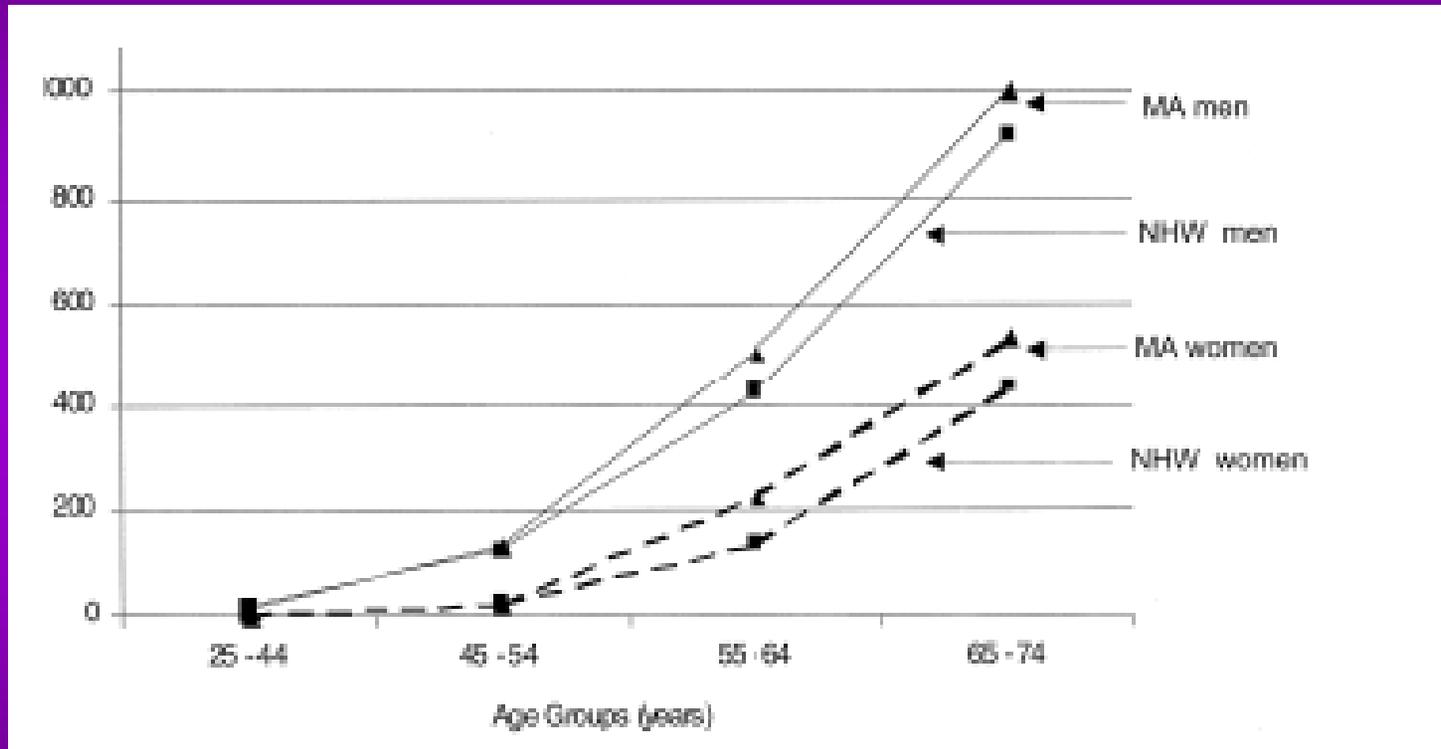
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# Mortality in Hispanic and Non-Hispanic Whites

Hispanics are reported to have lower age-adjusted CHD mortality rates than non-Hispanic Whites (NHW) in the U.S., but this was not the finding in the Corpus Christi Heart Study.



Average annual age-specific rates of death/100,000 from all CHD in Mexican-American (MA) and NHW women and men from the Corpus Christi Heart Study

Pandey D. *Am J Med.* 2001;110:81– 87

## Average Annual Prevalence\* of Asthma among Children Ages <18 Years (NHIS 1980-1996)

Asthma prevalence in Hispanic children was 38% lower in 1985 but 17% higher in 1996 than non-Hispanic White children

Asthma Prevalence				
Race/Ethnicity	1980-1981 Per 1000*(SE †)	1985-1986 Per 1000 (SE)	1990-1991 Per 1000 (SE)	1995-1996 Per 1000 (SE)
White, non-Hispanic	36.4 (2.7)	51.0 (4.0)	59.6 (3.6)	65.3 (4.2)
Black, non-Hispanic	41.9 (5.1)	59.8 (8.5)	72.6 (7.9)	82.1 (8.3)
Hispanic	NA	31.5 (7.2)	51.2 (7.3)	76.1 (6.9)

\*Per 1000 population.

†Standard error.

‡Not available. White and Black estimates for 1980-1981 include Hispanic ethnicity

# Hispanic Community Health Study – Study of Latinos (HCHS-SOL)



## ■ Primary Goals

- Identify prevalence of risk factors for diseases, disorders, and conditions in Hispanic/Latino population
- Follow cohort for morbidity and mortality

## ■ Sample population

- 16,000 persons (4,000 per field center – Bronx, Miami, San Diego, and Chicago)
- Emphasis on four Hispanic/Latino subgroups
  - Mexicans, Puerto Ricans, Cubans, Central/South Americans
- Ages: 18-74 years
  - 6,000 ages 18-44 years
  - 10,000 ages 45-74 years

# Genetic Research Issues in Racial/Ethnic Minorities

- The lack of definitional clarity and inconsistent use of racial/ethnic group membership in US health research is an issue<sup>1</sup>
- Lumping individuals of diverse backgrounds and heritages into one of four or five poorly defined groups may obscure relationships of environmental exposures to development of disease and may conceal biases distorting these associations
- Careful characterization of culture, SES, access to health care, and environment should be employed instead of limited racial “descriptions”, otherwise any/all “racial/ethnic” differences in disease risk factors and disease rates can erroneously be attributed to presumed population genetic differences (a longstanding issue in U.S. medical research)

<sup>1</sup>Wang VO et al. *Am Psychol.* 2005;60:37-45

# Genetic Research Issues in Racial/Ethnic Minorities (Cont.)

- Although race may have little value in genetic research, nevertheless, representation of all race/ethnic groups in research is essential
- Racial/ethnic group membership has been shown to be a significant predictor of consent/willingness to participate in genetic studies<sup>1</sup>
  - 37% African-Americans indicated willingness to enroll in a cancer genetics registry vs. 58% Whites
- Common concerns of minority individuals include discrimination, confidentiality, misuse of information, perceived disparities between the participants and beneficiaries of research, and perceptions of being used by researchers
- More specific to genetic research are issues regarding stigmatization, loss of health insurance, religious objections, and inability to separate the genetic, environmental, and racial/ethnic contributions to health

<sup>1</sup>Sterling R et al. *Am J Public Health*. 2006;96:112-18

# Recommendations

- Use in-depth state-of-the-art methods to assess environment (e.g., diet, physical activity) including socioeconomic background/status and related disease influencing exposures in future studies
- Perform community-based surveillance with validation of hospitalizations and causes of death, to avoid errors in defining outcomes
- Encourage emphasis on social and cultural issues in study design and implementation – facilitate minority representation and input during design phase
- Promote research on alternative methods of characterizing genetic backgrounds of individuals and subgroups, with explicit focus on differences between inter-individual and inter-population genetics, characterized either genomically or via questionnaire
- Discourage use of limited “racial” categories when reporting scientific results

# Recommendations (Cont.)

- Continue educating professionals in non-genetic medical specialties and communities through conferences, workshops, and multimedia
- Address the need for community education in a culturally sensitive context and build resources to provide this educational need in a sustainable manner
- Engage communities and their leaders in discussions about genomics and its application to health and society
- Fund research on methodology for culturally effective translation of study forms, instruments, and educational materials to meet needs of specific minority subgroups and indigenous populations
- Encourage/facilitate scientists from foreign/underdeveloped countries to apply for US research funds
- Invite foreign minority scientists for exchange of information/training

***Thank you!***



*The Arch*