

President's Cancer Panel Report of the Chairman

Highlights and Recommendations
From the President's Cancer Panel Meeting
April 9, 1997

*The Meaning of Race in Science —
Considerations for Cancer Research*

NATIONAL INSTITUTES OF HEALTH
National Cancer Institute

Concerns of Special Populations in the National Cancer Program

Report of The President's Cancer Panel

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Considerations for Cancer Research***

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April 9, 1997

New York, New York

National Institutes of Health
National Cancer Institute

This report is submitted to the President of the United States in fulfilment of the obligations of the President's Cancer Panel to appraise the National Cancer Program as established in accordance with the National Cancer Act of 1971 (P.L. 92-218), the Health Research Extension Act of 1987 (P.L. 99-158), the National Institutes of Health Revitalization Act of 1993 (P.L. 103-43) and Title IV, Part A, Public Health Service Act (42 U.S.C. 281 et seq).

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I. Introduction

In the past 20 years, population genetics has emerged as a science, informing our understanding of what race is, and what it is not. Technology that permits the identification of genetic differences and similarities among populations is forcing science to reassess the way it has categorized all organisms, but particularly it is causing science to reassess its definitions of race and the meaning of race in science.

On April 9, 1997, the President's Cancer Panel convened a group of sixteen nationally recognized scholars, including sociologists, anthropologists, philosophers, biologists, geneticists, and epidemiologists, among others, to confront these issues. Presenters provided both their diverse perspectives and data on race, racism, and the use of racial classifications in cancer research and in science broadly.

Our current views of race are based in conceptualizations derived from nineteenth and early twentieth century scientific thought. Racial categories were based on visible traits such as skin color, facial characteristics, and the shape and size of the head and body. It was presumed that certain visible traits were immutable and could produce the measure of all other traits in an individual or population.

What should have been apolitical scientific observations of racial differences were exploited to support racist doctrines such as the superiority of one race over another. For example, the studies of Samuel George Morton in the mid-nineteenth century on the sizes of human skulls contributed to the conclusion that Blacks and Native Americans had smaller brains and, therefore, less intelligence than whites. This added further credence to the theory of polygenism that held that human races were separate biological species.

Race has been a defining social issue in America since its discovery over 500 years ago as a land already inhabited by mature cultures of Native Americans. Black slaves were first brought to America in 1619 and slavery persisted for approximately 250 years. The Civil War (1861-1865) and the Emancipation Proclamation (1863) redefined the legal rights of Black Americans; and reconstruction began the post-war rebuilding process (1865-1877). In 1896, the Supreme Court decision, in *Plessy v. Ferguson*, reversed gains made under reconstruction and established "separate-but-equal" as the law of the land. Legalized segregation persisted until the 1960's civil rights movement, in effect, re-established equality under the law for all Americans. These historical events, supported by previous scientific thought, have deeply influenced the determination of racial categories in this country and continue to be reflected in today's scientific methodology. This is the context in which American science has been conducted.

The paragraphs below highlight the most noteworthy of the observations and data offered by the presenters, and conclusions drawn by the Panel from this highly thought-provoking meeting. The final section of this report provides the

Panel's recommendations for steps now needed to promote scientific inquiry based on current knowledge about race and to ensure social justice in the areas of research, careers in the sciences, and access to health care. A detailed summary of the testimony provided by each of the meeting participants is attached as an appendix to this report.

II. Meeting Highlights—Observations and Conclusions

Across all disciplines present, it was agreed that the biological concept of race is no longer tenable; rather, race is a social construct—a product of the Nation's social and political history. Based on the testimony and the data presented, the Panel specifically concludes that:

- Races in the sense of genetically homogeneous populations, do not exist in the human species today, nor is there any evidence that they have ever existed in the past. Generally traits used to characterize populations are either independently inherited or show only varying degrees of association with one another within a population. Therefore the combination of these traits in an individual commonly deviates from the average combination in the population, a fact that renders untenable the idea of discrete races made up chiefly of typical representatives.
- The biological concept of race is untenable and has no legitimate place in biological science. Studies using new technologies for understanding, measuring, and conceptualizing the sources of human variation reveal that approximately 85% of all variation in gene frequencies occurs within populations or races and only 15% variation occurs between such populations; there is no genetic basis for racial classification. By contrast, in the social sciences, studies of race from a social and political perspective may be justified, since these are studies of society as it exists.
- Old racial categories were based on externally visible traits such as skin color; it was presumed that visible traits could predict the measure of all other traits in the individual or population. Scientists now estimate that all externally visible traits represent only 0.01% expression of each individual's 100,000 genes. Moreover, it is known that these superficial visible traits are inherited individually, and are not transmitted in genetic clusters. While the frequency of finding a particular genetic variation may differ across classically defined racial groupings, race is neither defined by any collection of genetic variations nor does an individual's self identification according to race, predict genetic characteristics of that individual.
- Race reflects a cultural framework of societal, institutional, and civilizational values that has shaped scientific thought. Racism, founded in concepts of racial superiority, may occur at all of these levels and may be transparent to those in the dominant population group. For example, at the institutional level (e.g., academic, governmental, voluntary) this group may include those who decide what research questions are appropriate for study, how studies

are designed, who may conduct research, the validity and import of research results, what health services should be provided, and to whom.

- Racial and ethnic categories used in the U.S. census and to select population samples or establish reference groups for many scientific studies, are a product of the Nation's social and political history, and have changed over time. For example, prior to 1900, the term *mulatto* was used to indicate a person who had one Black and one White parent. In the 1900 U.S. census, the classifications, *quadroon* and *octoroon*, identified those who were one quarter and one eighth Black, respectively. The Office of Management and Budget has acknowledged that the four racial and two ethnic categories used currently, as defined in its "Directive No. 15," have no basis in science or anthropology; their principal intended purpose is to measure and monitor civil rights-related progress in population groups that have historically experienced government discrimination. A review of Directive No. 15, initiated in 1993 and completed in October 1997, was prompted by recognition of the limitations of currently used racial and ethnic categories for their stated purposes in an increasingly multiracial, multiethnic, and multicultural population.
- That race is a product of the Nation's social and political history is best illustrated by the "one-drop rule" that defines as Black anyone with even one Black ancestor, no matter how remote and regardless of the person's physical appearance – this is the current American definition of who is Black. This definition has had the practical effect of segregating all manner of racially mixed persons into the African American community. Ironically, despite the often negative societal ramifications of Black identity, the "one drop rule," for reasons of solidarity in the face of oppression and social pride, has been embraced by an extremely diverse group of individuals often sharing little in common except widely varying measures of African ancestry. It is currently estimated that between 3/4 and 9/10 of African Americans have some white ancestry, and approximately 1/4 have Native American ancestry.
- It is increasingly difficult to classify persons by race in a society that is moving towards a more multiracial identity – embracing one's entire ancestry and cultural environment. The difficulties this reality poses when attempting to sample populations for scientific study are obvious. This is not a problem unique to African Americans. Native American peoples, for example, experience a high percentage of misclassification, some of which has been the result of purposeful errors in self-report to avoid the stigma of being an American Indian in the United States. The limitations of existing racial and ethnic categories and the reliability of both assignment to and individual self-report of race raise serious questions about the accuracy and usefulness of existing cancer statistics on racial subsets.
- There is a need to distinguish between the meaning of race and socioeconomic status; racial differences in cancer outcome are greatly reduced and in some instances eliminated when socioeconomic status is taken into account. To

date, the link between race and socioeconomic status has been very poorly accounted for in scientific research. Clear disparities in health outcomes are detected between different racial groups (as currently defined); one explanation is that the apparent effects of race are largely a reflection of impoverishment. Poverty indirectly increases cancer risk through greater likelihood of environmental exposure to toxins, high risk behaviors, poor access to health care, unhealthful diet, and other factors. Accounting for such factors in multivariate analysis frequently reduces the effect of race, even eliminating it. But researchers should not assume that any remaining effects are biological. Measures of socioeconomic status remain crude; they are not uniformly defined and they focus principally on income, ignoring other important economic variables such as wealth and education that reflect position. Methods for correcting for socioeconomic status in scientific studies may not fully correct for all the attributes of socioeconomic position. Inequalities in income and wealth are widening, accentuating the need to incorporate measures of socioeconomic position into the routine collection of public health data.

- Non-economic effects of race, or the significance of having a racial identity, may also impact health. Historically, racism has been associated with lower economic status and appears to have negatively influenced health outcomes. Race, ethnicity, inequality, and justice are among the critical determinants of the public's health. As social beings and biological organisms, we may literally incorporate biologically our social experiences and express this embodiment in population patterns of health, disease, and well-being. In this context, biologic expressions of race relations, i.e., of racial oppression and resistance, theoretically produce racial and ethnic disparities in morbidity and mortality. For example, racial discrimination can impede access to appropriate health care leading to reduced survival and elevated mortality rates. It may restrict employment to more hazardous and lower wage occupations, thereby limiting possibilities for living in healthy homes and neighborhoods. Social trauma from discrimination can also induce stress-related health problems. Little public health or medical research has focused on the health consequences of racial discrimination. Appropriate racial/ethnic and socioeconomic data are needed in public health databases and the health effects of racial/ethnic position across the life span should be further explored.

These observations and conclusions raise significant questions and challenges for the scientific community and for society as a whole. These findings indicate that race does not exist from a biological perspective and that racial classifications, as reflected in census categories, are socially and politically determined. Yet, it is apparent that race is very real from a social perspective and that race has been a fundamentally defining issue in American society. This underscores a scientific dilemma: for centuries and to the present day, scientists have used social and politically determined racial categories to make scientific comparisons between races with little or no discussion about the meaning of race. Since the early 1970's,

for example, the National Cancer Institute SEER data (Surveillance, Epidemiologic and End Results) have provided valuable information on disparities in cancer incidence, mortality and survival according to race, but SEER also has been shaped by social and political definitions of race.

These difficulties, and their implications for cancer research and scientific inquiry overall, are further illustrated in our clinical trials system. Currently, the NIH Revitalization Act of 1993 [P.L. 103-43] calls for clinical trials to provide valid subset analysis among minority groups and their subpopulations of traditionally defined racial and ethnic groups (i.e., those defined in OMB Directive No. 15 and individuals' self-selection into those categories). This requirement was instituted in an effort to be just—to correct previous exclusions of certain populations from scientific study. Yet this may not be the best approach to obtaining scientific answers to questions pertaining to differences in disease among populations.

As scientists we must now ask certain critical questions:

- To what extent is race being used as a biological classification in science?
- What assumptions do scientists make when they compare races and how do these assumptions affect scientific conclusions?
- To what extent do societal and institutional values related to race shape the approach to scientific investigation in terms of the selection of problems considered worthy of research and the development of hypotheses to be tested?
- Should race be used as a scientific variable in biological studies?
- In an increasingly mixed-race society, how should multiracial identity be accounted for in the design, interpretation, and application of scientific research?
- How can race be applied validly to research studies that, in many cases, are designed to improve health conditions for specific populations?

III. Recommendations

The Panel believes the insights and information offered at this meeting will help us take another important step in a long journey toward achieving both scientific truth and social justice, for it is essential that we resolve existing conflicts between what is good science and what is fair. Many special populations, some of whom are defined by traditional racial classifications as well as in terms of age, socioeconomic position, or geographic location, bear a disproportionate cancer burden. The issues of race and racism as they are experienced at institutional, societal, and civilizational levels are, therefore, highly relevant to the Panel's charge to identify barriers to effective implementation of the National Cancer Program to reduce the burden of cancer in America.

At issue is the need to disentangle the social and political meaning of race from assumptions about its biological impact. It is nearly certain that future advances

in scientific knowledge gained from the Human Genome Project and continued progress in population genetics will further challenge us to re-examine how we group people for biological study. Moreover, as we seek to conduct science based upon what we now know to be true about human variation, we must also safeguard and champion the full access of populations disadvantaged by racial classification to health care resources, to participation in research, and to careers in science and medicine.

These issues and others call for serious dialogue in the scientific community. Given the facts that human populations do differ and that race is not the determinant of such differences, scientists face the challenge of elucidating how populations really differ. Expanded knowledge of population genetics and a more fundamental understanding of the effects of culture and economic status appear to be keys to this progress and essential in evaluating any use of race as a variable in scientific research. Within this context, the President's Cancer Panel recommends:

- To retain race as a variable with bearing on scientific research, it must be recognized that race is a social construct determined by how one group sees and behaves toward another. Race is a proxy for discriminatory experiences, culture, class, diet, or other factors. To be used validly in scientific research, what is being measured, and for what purpose, must be clearly defined. Such clarity of definition must be made a priority for the future.
- In attempting to understand why the burden of cancer is unevenly distributed across our population, we should design studies that seek to identify what variables determine these varying burdens of cancer rather than presume that culturally or politically defined groupings define relevant variables for the burden of cancer.
- Genetic techniques now available to study human variation should be used to identify subgroups of the general population whose profiles will elucidate the process of cancer as a disease.
- Data collection on race should be considered incomplete because it does not incorporate socioeconomic position – including the impact of education, income, wealth, and related social and cultural factors. We should move rapidly toward the incorporation of such information into our scientific systems.
- We must distinguish fairness in access to research participation from issues of valid research design. Moreover, the quest for truth in science must be conducted in the framework of social justice.
- Science has the capacity to produce systematic ignorance as well as systematic knowledge. The cultural framework in which science is conducted and the role science has played in constructing and legitimizing race and racism must be recognized and addressed.

IV. Action Items

As part of its statutory responsibility to identify any delays or blockages in the rapid execution of the National Cancer Program, the Panel has identified misconceptions about the meaning of race in science and the resultant pervasiveness of racist influences in scientific inquiry, access to health care, and ultimately , health status and survival, as a critical impediments to progress in cancer research. Through greater understanding about genetic variation and its relationship to racial groupings, these impediments can and should be eliminated. It is incumbent on this Nation to take the following initial steps toward this goal:

1. Education and information programs should be developed and disseminated to address the meaning of race in science and society. These programs should be keyed to the levels at which they will have the most impact, and especially, to the nation's young people.
2. The Secretary, Department of Health and Human Services, along with the Director, National Institutes of Health, should convene a process to reevaluate current policies about race and research in light of the issues raised in this document.

Concerns of Special Populations in the National Cancer Program

The Meaning of Race in Science— Considerations for Cancer Research

President's Cancer Panel Meeting Summary

April 9, 1997

New York, New York

OVERVIEW

The President's Cancer Panel was chartered to monitor and evaluate the development and execution of activities of the National Cancer Program and to report to the President on barriers to implementation of the Program. The purpose of this meeting, the first in a series of four meetings focusing on the concerns of special populations in the National Cancer Program, was to consider the meaning of race in science, specifically as it pertains to cancer research.

Sixteen speakers representing varied disciplines shared their perspectives and reviewed research concerning the history and use of racial classifications, the intersection of social definitions of race and their genetic underpinnings, the current scientific use of racial and ethnic classifications, and the scientific and societal implications of race in cancer research and its applications. Speakers offered specific recommendations for better addressing the issues of race in science for consideration by the Panel.

MEETING PARTICIPANTS

President's Cancer Panel:

Harold P. Freeman, M.D., Chairman

Paul Calabresi, M.D.

Frances M. Visco, J.D.

National Cancer Institute:

Otis Brawley, M.D., Assistant Director, Office of Special Populations, NCI

Maureen O. Wilson, Ph.D., Assistant Director, NCI, Executive Secretary,
President's Cancer Panel

SPEAKERS

Karen Antman, M.D.
Professor of Medicine Columbia
University
Chief, Division of Medical Oncology
Director, Herbert Irving Comprehensive
Cancer Center
177 Ft. Washington Avenue
New York, NY 10032

Claudia R. Baquet, M.D., M.P.H
Associate Dean for Policy and Planning
University of Maryland School of
Medicine
Bressler Research Laboratory 14-013
655 West Baltimore Street
Baltimore, MD 21201

Mary Bassett, M.D., M.P.H.
Director, Harlem Center for Health
Promotion and Disease Prevention
506 Lennox Avenue - MS NNR 524
New York, NY 10037

Richard Boxer, M.D.
Professor, Health Policy
Professor, Family and Community
Medicine
Medical College of Wisconsin
St. Michaels Professional Building
2350 W. Villard Avenue
Milwaukee, WI 53217

Otis Brawley, M.D.
Director, Office of Special Populations
National Cancer Institute
National Institutes of Health
Federal Building, Room 312
Bethesda, MD 20892

Linda Burhansstipanov, Dr.PH
Director
AMC Native American Cancer Research
Program
AMC Cancer Research Center
1600 Pierce Street
Denver, CO 80214

F. James Davis
Professor of Sociology Emeritus
Illinois State University
2025 East Lincoln Street
Apartment 2207
Bloomington, IL 61701

Suzann Evinger, B.A., M.A.
Policy Analyst
Executive Office of the President
Office of Management and Budget
725 17th Street, N.W.
Washington, DC 20503

Marcus Feldman
Professor, Biological Sciences
Stanford University
Department of Biological Science
Herrin Labs
Stanford, CA 94305-5020

Vanessa Gamble, M.D., Ph.D.
Director, Center for the Study of Race
and Ethnicity in Medicine
University of Wisconsin School of Medicine
1300 University Avenue
Madison, WI 53706

Robert Hahn
Epidemiologist
Centers for Disease Control and
Prevention
Epidemiology Program Office, MS D01
Atlanta, GA 30333

Sandra Harding, Ph.D.
Professor of Philosophy
School of Education
University of California at Los Angeles
Los Angeles, CA 90095

Solomon Katz, Ph.D.
Krogman Growth Center
University of Pennsylvania
4019 Irving Street
Philadelphia, PA 1910

Nancy Krieger
Assistant Professor
Department of Health and Social
Behavior
Harvard School of Public Health
3rd Floor
677 Huntington Avenue
Boston, MA 02115

Edison Liu, M.D.
Director, Division of Clinical Science
National Cancer Institute
31 Center Drive
Building 31, Room 3A11
Bethesda, MD 20892

Edward Sondik, Ph.D.
Director, National Center for Health
Statistics
Centers for Disease Control and
Prevention
Presidential Building, Room 1140
Hyattsville, MD 20782

OPENING REMARKS—Dr. Harold Freeman, Chairman, President's Cancer Panel

In opening the meeting, Dr. Freeman indicated that:

- This is the first of four meetings focusing on the concerns of special populations in the National Cancer Program. Subsequent meetings will be on "Cancer and the Aging Population," "The Real Impact of the Reduction in Cancer Mortality," and "A Review of the Health Care System and Its Responsiveness to Special Populations."
- Against an historic backdrop of 250 years of slavery, 100 years of legalized segregation, and more than 30 years of freedom under the law for all Americans, scientists have attempted to research issues related to race in the context of definitions that have come out of the history of slavery. These definitions are socially and politically determined, yet we are conducting scientific inquiry based on them.
- For at least a century, American medical and public health researchers have used race as a marker for biology and have documented race-associated differences in health and in disease prevention. Ethnicity, which takes into account social, cultural, religious, linguistic, dietary, and other variables, has also been used to determine reasons for differences in health outcome. There is, however, a lack of scientific consensus on the nature of race and ethnicity, their definitions, and how we use these categories to measure variables in medicine.
- Since socially constructed and assigned racial definitions are being used in medical teaching practice and research, it is important at this juncture to ask several key questions:
 - How valid is it to use a socially constructed category of human beings to make scientific conclusions that imply biological differences?
 - What are the consequences of the abuse of such a socially-determined classification?
 - What are the assumptions that scientists make when they study racial categories?
- What are perceived to be racial variations in health status may in fact be functions of social factors, such as socioeconomic status (SES), culture, access to health care, diet, nutrition, or other factors. Some researchers have advocated removal of the term "race" from all medical and public health research.
- Addressing these complex issues in light of history and the current use of these terms is particularly timely; it is important not only to accurately diagnose and treat cancer and other diseases, but to address continuing social inequalities in health care delivery and access.

WELCOME—Dr. Karen Antman, Professor of Medicine, Columbia University, Chief, Division of Medical Oncology, Director, Herbert Irving Comprehensive Cancer Center

Dr. Antman welcomed the Panel, speakers, and other attendees, adding that:

- It is particularly appropriate that this conference on race is being held in New York City, one of the most racially and ethnically diverse cities in the world.
- We have known about racial differences in cancer rates for decades; many have resulted from diet, habits, and exposures, and have changed when populations migrated. For the first time, however, we are quantifying racial differences in genetic susceptibility to endogenous hormones and environmental exposures.

DIRECTOR'S REMARKS—Dr. Otis Brawley, Assistant Director, Office of Special Populations, National Cancer Institute

Representing Dr. Richard Klausner, Director, NCI, Dr. Brawley indicated that:

- He and Dr. Vanessa Gamble recently attended a landmark meeting at Tuskegee University, at which there was considerable discussion not only of the Public Health Service syphilis trial held at the University but also about "race medicine." "Race medicine," commonly practiced in the United States in the 1800s and well into the twentieth century, was the belief that diseases affected people of different races quite differently. In many areas of medical science (e.g., concerning prostate cancer among African American versus white men) there is still a perhaps inappropriate level of interest in racial differences in disease occurrence and outcome. Even in the medical community, understanding is often lacking that discoveries about disease in one race are applicable to people of other races.
- Dr. Brawley expressed his interest in definitions of race, which may be socially, politically, or scientifically constructed. He also noted that influences of ethnicity and culture are of significant interest to the NCI, which recognizes that messages concerning health behaviors must be tailored to reach people of varying cultures.
- He noted that as we turn more toward genetics, we are turning more toward recognizing individual differences. It is his personal belief that such differences are familial more than they are racial; some concern exists that we will erroneously begin looking for "black genes" or "Asian genes" rather than families having a specific gene or gene mutation.
- Dr. Brawley also extended greetings from Dr. Klausner and from both Dr. John Ruffin, Director, NIH Office of Research on Minority Health and Dr. Vivian Pinn, Director, NIH Office of Research on Women's Health, NIH, who were unable to attend the meeting.

PRESENTATION HIGHLIGHTS—Racial Classifications—Their History and Use

Opening Remarks

Dr. Vanessa Gamble, Moderator

Key Points

- For the past six years, Dr. Gamble has taught a course at the University of Wisconsin entitled, "Race, American Medicine, and Public Health." One objective of the course is to help students understand that race is a social construct that has changed throughout history. This learning objective is predicated on, among other things, the observation that although most people think they understand what is meant by the concept of race, few find they are able to define it. Another objective of the class is to explore how race is used as a proxy (e.g., for class, racism, biology, or other categories).
- Mapping of the human genome may well reveal that people with differing skin color are in fact closely linked in far more important genetic ways. Dr. Gamble expressed hope that discussions in forums such as the current meeting will hasten the day when thoughtful and frank discussions of race and its meaning become part of the language of physicians and medical researchers.

History and Sociology

Dr. F. James Davis

Key Points

- Racial categories used in everyday life and for various administrative purposes in the United States are not based on the taxonomic efforts of either physical anthropologists or biologists. They are social constructions that reflect the history and current status of the Nation's racial and ethnic relations. Classification schemes that incorporate these social constructions have value for many practical purposes and for much of social science research; however, inferences about racial genetics, particularly about the African American community, must be made with informed caution.
- Lists of race groups have typically included ethnic and nationality groups as well as broad geographic areas (including such ambiguous categories as Asian and Hispanic) with no provision for the widespread phenomenon of racial mixture. To do so would run counter to the "one-drop rule," the American definition of who is black (i.e., an individual with even one black ancestor, however remote, is to be considered black).
- Race groups are at best overlapping statistical groupings based on combinations of visible anatomical traits. These traits, however, are biologically superficial, and they vary independently rather than being transmitted in genetic clusters. Disagreement is considerable as to whether racial classification schemes based on these or other criteria are biologically

meaningful or social constructions but, more recently, focus has shifted to differences in the frequencies of gene markers for single traits.

- Miscegenation has been occurring between European and African black populations in the United States for more than 350 years, generally by coercion of black women and without benefit of marriage. Estimates of the extent of miscegenation based on intermarriage data, particularly for past generations, are gross understatements.
- The one-drop rule has its origins in the Chesapeake area in the 1600s, when white-African black miscegenation was governed by a rule that assigned to mixed persons the status of slaves, and the same racial identity as African blacks. The one-drop rule emerged from the American South following the Civil War to become the Nation's rule; it thus reflects the country's unique history of slavery and segregation. Its effect is to assign persons with any black ancestry the same racial identity and social status as those of the socially subordinate parent group (in anthropology, the hypo-descent rule). The one-drop rule has had little challenge in the courts in the twentieth century. The civil rights movement of the 1950s and 1960s did not challenge the rule and, ironically, resulted in increased support for the rule among the African American community, since it catalyzed a sense of ethnic unity, pride, and a common culture among a diverse population of racially mixed persons.
- Outside of the United States, racially mixed persons are generally perceived simply as mixed, not as members of any one parent group. This perception can, however, take different forms, such that a mixed individual's social status may be:
 - (1) Lower than that of either parent group (e.g., the Métis in Canada, Eurasians in India, Amerasians in Korea and Vietnam, mulattos in Uganda)
 - (2) Higher than that of either parent group (e.g., Mestizos in Mexico, mulattos in Haiti, Namibia, or Liberia)
 - (3) Between that of the parent groups (e.g., coloreds in South Africa)
 - (4) Widely varied between parent groups, depending more on education and wealth than on race (e.g., lowland Latin America and most of the Caribbean)
 - (5) Equal with that of all parent groups (e.g., Hawaii)
 - (6) That of an assimilating minority (the implied rule for racial minorities in the United States other than African Americans. In practice, persons in the United States with 1/4 or less ancestry in such groups as Native Americans, Mexican American Mestizos, or Chinese or Japanese Americans, are treated as assimilating Americans. They are not subjected to a one-drop rule, have no need to "pass," and can be proud of their different ancestries.)

- One result of these cross-cultural differences in racial classification is that international comparisons of racial differences in disease rates are likely to be highly misleading. Most African Americans would be classified as some degree of colored in Brazil, for example, not as black. The same individual might be defined as black in the United States, as colored in Jamaica or Ghana, and as white in Puerto Rico.
- From 3/4 to over 9/10 of African Americans are estimated to have some white ancestry, and probably 1/4 have Native American ancestry. Thus, Americans defined as black range from a relatively small number of unmixed African blacks (i.e., individuals whose entire known ancestry is from populations of sub-Saharan Africa) to persons who appear white or Native American.
- Instances of rejection of the one-drop rule stand out because they are rare; deviation from the rule is conspicuous, and the typical response of both blacks and whites is to condemn it and affirm the rule. Nonetheless, a movement to permit mixed-race persons to adopt a biracial or multiracial identity has developed considerable momentum in the 1990s. This movement embraces all racial blends, not just those involving African black ancestry; yet to date the rule for African American ancestry has kept the multiracial option off the official list of racial categories.
- The emphasis of the current movement is on freedom to affirm one's whole self by acknowledging all of one's ancestries. Although the biracial or multiracial designations are ambiguous, unless the ancestries concerned are specified, such choices are still less ambiguous than the designation, "other."
- Several states have passed legislation permitting a multiracial option on state forms. A successful effort to include a multiracial category on the U.S. census forms and on health, welfare, and other Federal forms would significantly diminish the one-drop rule. It is expected, however, that such a change will encounter stiff opposition from the African American community, based on fears that whites supporting the movement want to divide and weaken the political power of the black community, as well as civil rights remedies now in place. Further, there is fear that persons who want to affirm their Native American, Asian, or other ancestry will deny their African ancestry. It is also likely that when statutes mandating the multiracial category are tested in the courts, judges may invalidate them or resist extending them to new situations.
- In addition to the personal, legal, and other problems stemming from defining a highly diverse population as black, the one-drop rule, a social construction, poses problems in medical and other scientific research. These problems vary, depending on the type and purpose of the research, and affect its design, interpretation, and application.
- Whether samples are taken from residential areas, from lists compiled at a health care facility, or from racial self-identifications of students, agency

clients, or medical patients, research subjects typically are selected by using the social definition of who is black.

- It is unclear whether concern with proportions of ancestry is misplaced; although genes are randomly distributed in individuals, ancestral fractions do provide useful probability estimates. Sampling the African American population of a given city becomes problematic for activities such as assessing the significance of racial differences in cancer rates. If, for example, a sample is taken from the total population, is it necessary to adjust the racial difference upward to account for estimates of the amount of non-African ancestry in the city's black population? This estimated proportion varies considerably from one region and city to another.
- If aggregate statistical adjustments are rejected, another option for improving measurement might be to use gene markers to determine what proportion of each individual's ancestry came from Africa. An issue in this strategy is determining who should be excluded from the sample (e.g., individuals whose ancestry is 3/4 or more non-African; half or more; some other percentage); it might be more useful to study differences among decile or quartile groupings of the proportions of African ancestry. Such efforts to account for the amount of miscegenation may be unwarranted in a group whose ancestry is predominantly from Africa; conversely, sampling only such individuals might reveal greater racial differences in certain diseases (e.g., sickle cell anemia) than had been appreciated previously.
- If the aim of a study is to determine the effects of differences in life experiences in the American black and white communities, the remote ancestry of the two populations becomes irrelevant, or an intervening variable to be controlled for. When the purpose is to study African Americans as a community rather than as a biological category, the social definition and representative sampling of the entire group would be appropriate.
- Socially constructed categories can have biologic effects. Over time, group differences in experience may produce adaptive genetic responses.
- Although difficult problems exist with racial and ethnic categories other than African American, the one-drop rule is a key roadblock to the American acknowledgment of racial mixture and the most revealing example of the social construction of racial categories.

Discussion—Dr. Davis

Discussion following Dr. Davis' presentation included several key points:

- As occurred in the African American population, the civil rights movement precipitated in Native Americans increased racial/cultural pride and brought to the forefront issues of identity and concerns about adoption. Prior to 1968, many Indians went to great extremes to hide their ancestry. For example, many infants born in non-Indian hospitals were listed as white, Hispanic, or another category to avoid the social stigma and accompanying disadvantage

associated with being Indian. The result relative to research is that racial misclassification of the American Indian population may approach 88 percent in some states.

- Currently, little data exist on the American Indian population; adoption of a multiracial classification may erode the data that do exist. Further, unless an individual indicates his/her various ancestries in addition to selecting the multiracial designation, the resulting data (for research or community intervention planning purposes) are no more informative than data for persons selecting the "other" racial designation.
- Most Indian tribes define minimum Indian ancestry (usually 25 percent) required for tribal membership; however, this designation has been affected by the rules for eligibility for tribal benefits. In addition, some tribes specify that tribal membership depends on which parent is Indian (i.e., an individual may have one parent whose ancestry is fully Indian, but may be listed in another racial category), and further misclassifications may occur in adoptive families.
- Native American communities are highly suspicious of genetic testing, which is perceived by many as another strategy for eliminating the Indian population. Thus, resistance to the use of biomarkers as an aid in classifying individuals' race is to be expected.
- Dr. Davis clarified that a multiracial category may add some flexibility for individuals and perhaps alleviate some of the problems associated with the one-drop rule; however, it should not be expected to eliminate the social construction of racial categories. Social definitions may be modified, but their eradication will involve a protracted historical process.
- Dr. Davis further clarified that while there has been little legal challenge to the one-drop rule in this century in America, racial classifications were a highly litigious matter in previous centuries and were also a matter of dispute among scholars.
- The Bureau of the Census has undertaken testing of responses to a multiracial category to try to assess how many people would take advantage of such an option if it was available. The results of two of these tests have become available; results of a third test will soon be released.
- At the NCI in the early 1980s, efforts were made to report racial classifications (black, white, and later, Native American and Latino) instead of using the groupings, "white/nonwhite." In conjunction with the 1985 Secretary's Task Force on Black and Minority Health, there were also efforts to promote awareness that racial groups are not homogeneous and do not necessarily have the same health care seeking behaviors, tobacco use rates, or delay in seeking diagnosis and treatment. At approximately the same time, there was greater discussion of the role of SES; similarly, there was a tendency to treat simplistically the topic of SES and cancer rates. Racial/ethnic classifications were considered a proxy for cultural influences on risk factors and exposures, and for health care seeking behaviors. Some of those behaviors

(including distrust of the health care system), it was realized, were initiated during childhood at a lower SES and were carried into adulthood, when a higher SES may have been achieved. Race has also been a proxy for SES-related discriminatory influences on the delivery of health care.

- When race is used as a proxy for discriminatory experiences, dietary practices, or other factors, it is essential to be explicit about what is being measured and for what purpose. It must always be recognized, however, that an indirect index of any kind may be faulty and based on assumptions that are unwarranted (e.g., regarding class).
- The history of racial classification cannot be separated from the history of racism.

Racial Economy of Science

Dr. Sandra Harding

Key Points

- Progressive anti-racist movements are needed to come to terms in the U.S. with the role of science in constructing and legitimizing racism, and the role of racism in constructing and legitimizing certain types of scientific projects. We cannot ignore the social dimensions of the systematic production of knowledge and the systematic production of ignorance that accompany these roles. The current meeting is an example of embracing the radical possibility of reshaping how people think not only about race and racism, but about the opportunities that exist for sciences that are progressive in the production of knowledge about these topics.
- Race is exceedingly difficult to define, because claims about race are both true and false; they are both not true and not false. Biological race claims are not true, yet race exists as a social construct and varies from culture to culture. At the same time, biological race claims are not false. They affect material lives, structure public policy and environmental influences, and therefore, have effects on people's biology. Since biological race claims have economic, political, social, and psychological effects that influence mortality, access to health care, and other health possibilities, they are true in a certain sense, if not the sense originally intended.
- Biological race theories such as the one drop rule that purport to establish distinctive races conflict with evolutionary theory and the principles of natural selection, which operate at the level of individual traits. As we know, there are no natural barriers (geographic or otherwise) to reproductive and gene flows, and variation within races is greater than variation between races. Therefore, population genetics maps genetic variation much more accurately than do race theories.
- Race is not a thing—it is a relation between groups in the same way as is class; it should be remembered that in the nineteenth and well into the twentieth century, class also was regarded as biologically determined. To understand

what is happening to one group, it is necessary to assess the other group(s) with which they have a race relationship. These relationships historically have been hierarchically organized. Typically, only the marginalized groups in a population are identified as having races.

- Moreover, race is a symbolic and structural relation with different meanings to different groups at different times (e.g., who gets to occupy what positions in society); this is illustrated by the use of race as a proxy for socioeconomic (SES) location. Assignment of individuals to races is a consequence of the symbolic meanings and the structural relations of races, not the reverse, which is what makes medical research on race so difficult and complex.
- Race is also part of a social matrix that includes the symbolic, individual, and structural forms as well as gender, class, ethnicity, and cultural relations. Therefore, when examining the impact of race (however it is classified) on people, it is also necessary to look within races at differences by gender, class, ethnicity, or culture.
- Race is dynamic because its parameters (e.g., social structures, meaning systems) change over time. A shifting, floating phenomenon, race has many biological consequences but is exceedingly difficult to pin down in ways customarily accepted in science.
- It is essential to consider the characteristics of all racial groups in a population (including the majority or dominant group) and how racism functions in science—in terms of how science is defined and conducted, and in terms of its objects of study.
- Racism is commonly defined as a property of individuals who intentionally exhibit or enact racist behaviors and racist speech. However, there are other forms of racism that are more important for the concerns of this Panel. Five types of racism may be distinguished; two of these are *overt* racism and *covert* racism (e.g., masked as appeals to standards of excellence), however, these are not the most significant types of racism for biomedical research or for any other understanding of race because they do not speak to the symbolic and structural forms of race and racism. In this regard, the more important forms are institutional racism, societal racism, and civilizational or philosophic racism.
- *Institutional* racism concerns the practices and cultures of institutions, including science and health care. *Societal* racism concerns the practices of the larger societies within which institutions are located. There may or may not be a gap between the way institutions of health care or biomedical research view race and the way the larger society views race. When there is no gap, as frequently occurs, it is very difficult to detect institutional racism. Currently, such a gap does exist, in that there appears to be a growing understanding that institutional practices and cultures can have racist consequences. The racial economy of science is reflected in how the costs and benefits of scientific institutions are differentially distributed by race. *Civilizational* racism refers to

aspects of these practices and cultures that are far larger than one society, pervading the philosophy of whole civilizations.

- In discussing racism in science, therefore, it is most important to examine the ways in which institutions, their practices and cultures, the larger society, and whole civilizations define their standards of good scientific research, method, and objectivity, and how these definitions have differential effects by race. It is not particularly productive to focus at the level of individual belief, attitudes, or behaviors.
- Eliminating racist elements in health care and biomedical research presents challenges, since the societal climate influences the direction of science. For example, the nineteenth century field of craniology, which attempted to document biological origins of intelligence and now can be clearly seen to have had a racist basis, was neither the product of bad science nor political regressiveness at that time. The social climate is not an extraneous element, but in fact is part of, and shapes the method of, science in discernible ways.
- Maximizing objectivity in the sciences has generally been approached by attempting to maximize social neutrality and the neutrality of the scientific process through the scientific method. This approach is insufficient, however, because method functions in a scientific project as the context of justification and does not control the selection of which phenomena are to count as problems worthy of scientific pursuit, the central concepts that will shape the research project, the favored hypotheses that will be tested, or the research designs deemed appropriate for testing hypotheses. Moreover, the requirement of the scientific method to repeat observations across legitimized observers will fail to detect racist values and interests if all of the observers have been similarly socialized (at the institutional, social, or civilizational levels) to have the same beliefs and values. The National Academy of Sciences has noted that methods also include, for example, the judgments scientists make about the interpretation of reliability of data, and the way scientists work together and exchange information. Taken together, methods constitute the craft of science and a person's individual application of these methods helps determine a person's scientific style.
- The notion of objectivity that requires the maximization of neutrality works against being able to recognize as legitimate contributors to the growth of knowledge, pro-democratic social forces within the scientific community. All sciences are local knowledge systems; they are not equally valuable, and some are far more powerful than others. Because of their local aspects, sciences can function either to increase knowledge or increase ignorance, and historically, have had a powerful role in producing both.

Additional Research Needs and Recommendations

- Research on race and cancer should take into account that:
 - Different social and cultural groups interact with different parts of the natural world. They exist in different locations or situations in the natural world (e.g., proximity to toxic waste dumps) for varied reasons.
 - Different groups have different interests in the natural world and will ask different questions about it based on the parts of the world with which they interact.
 - Different groups bring different discursive resources to thinking about the natural world. Various models for describing the body and its relationship to the world have the potential to produce systematic knowledge or systematic ignorance.
 - Different groups tend to organize the production of knowledge differently (e.g., laboratories, field sites, healers); all of these modes produce some knowledge and some ignorance.
 - Different groups have different positions in the political structures of societies, and these positions will tend to value or devalue their particular relationships to nature, discursive resources, and knowledge systems.
- Individual scientists can best avoid racist bias in their work by identifying their own values and studying the history, philosophy, and sociology of science. Since human values change slowly, the lessons of the past remain of great relevance.

Discussion—Dr. Harding

Key Points

- It was suggested that the definition of race as a relation, as described by Dr. Harding, challenges the methodologic individualism and reductionism that characterize scientists' research training. Scientists typically are not trained to identify explicitly the framework from which research questions are conceptualized. It was also noted that generally, only members of dominant groups are regarded as significant individuals (or having civilizations); when the benefits and privileges of the dominant group are extended to others, it is often done in a manner that restricts the possibility of identifying structural and symbolic relations that have created the dominant and subordinate groups. Thus, for example, non-dominant groups may be deemed to be sufficiently rational to be responsible for their cancer (e.g., due to lifestyle/behavior choices) but not sufficiently so to decide what types of research relative to their cancer should be pursued.
- In 1993, the Centers for Disease Control and Prevention (CDC) held a conference on the use of race and ethnicity in public health surveillance. The conference resulted in a set of recommendations including that when racial/ethnic categories are used in epidemiologic research and public health

research at CDC, the use of these variables should be justified, their sources explained, and the findings explained so that race interpretations are minimized. The conference report, now being finalized for agency-wide use at CDC, is used to train incoming epidemiologists and has been incorporated into the agency's policies concerning morbidity and mortality publications.

Additional Research Needs and Recommendations

- Illumination of the difficulties created by conventional notions of race, and re-education—through discussions such as the Panel's meeting, medical and scientific education, and more generally, in citizenry, public education, television programming, media discussions, and other communication channels—should be promoted to advance dialogue that will lead to changes in understanding about race and the types of scientific projects that are funded.

PRESENTATION HIGHLIGHTS—Social Definition Meets Genetic Underpinnings

Opening Remarks

Dr. Linda Burhansstipanov

Key Points

- The process and purposes of genetic testing have myriad cultural ramifications of which scientists involved in genetic research may be unaware. For example, among members of some Native American tribal nations, there is a reluctance to provide blood samples for genetic testing. This fear has many roots: strong basic distrust of the scientific and medical communities, fear that genetic information will be used to annihilate native populations, and a belief that without all of one's body parts intact, it is not possible to proceed on the spiritual path to meet one's ancestors in the afterlife. Similar cultural issues may exist within other underserved and racial minority groups, and there is a need to be more respectful of these issues.
- Recent focus groups with native peoples have also revealed widespread suspicion that researchers are trying to assume the role of the creator (through cloning research), deepening the resistance to providing blood samples for genetic testing.
- Misunderstanding about genetic testing in general, and about BRCA gene mutations in particular, is widespread. The media need to do a better job of explaining the purpose and meaning of genetic tests and their results. Individuals who are tested must receive appropriate counseling so that they understand clearly what the test results mean for themselves and their families.
- Breast cancer rates among native peoples historically have been lower than those of other populations in the United States. In the last ten years, however, breast cancer rates no longer are statistically significantly lower among native peoples (i.e., Northern Plains, northwest tribes have breast cancer rates

comparable to whites and African Americans) except in certain states (e.g., Arizona, New Mexico) with little or no racial misclassification problem. Attempts to identify factors that may be responsible for differential breast cancer rates among native peoples are hindered by a lack of accurate data on who is of American Indian ancestry.

- Poverty clearly is an issue in native peoples' cancer rates and access to care; sometimes, however, poverty may mask important cultural issues (e.g., belief that the mammography machine can give a woman breast cancer) that affect participation in screening programs.

World Wide Genetic Patterns

Dr. Marcus Feldman

Key Points

- The history of classification generally is both illustrious and infamous. Many of the original classifiers were interested in classification for its own sake, and the earliest were most interested in the philosophy of type and how a type was to be identified. Later, classification evolved toward issues related to natural selection. Blumenbach, regarded as the founder of modern anthropology, identified five varieties of humans; these classifications are still used. Later classifications included cephalic indices and in the nineteenth century, biometric classifications, which came to prominence simultaneously with the rise of racism. Various taxonomists over the years have listed between two and 200 racial classifications.
- In *The Descent of Man* (1871), Charles Darwin maintained that classification of humans was essentially unimportant and that the variability of characteristic differences between humans was of little importance. Further, he doubted that any characteristic could be named that is constant and distinctive to a particular race.
- Changes in racial definitions often depend on the definer and the number of people in the defined groups. In Brazil, for example, where the majority of the population is defined as non-white, racial classification as a tool has fallen into disuse. Instead, 40-60 different ways of describing people have developed; these are based on socioeconomic criteria — wealth, place of residence, type of agriculture undertaken. A similar phenomenon has been observed in other countries with largely non-white populations.
- The genetic approach to assessing human variation (as opposed to race) shifts the focus to populations, allows a precise definition of inherited material (if any) while avoiding or controlling for cultural trends, and allows the application of mathematical theory developed from population genetics.
- Definitions of race, maintaining that members of race groups have a significant proportion of their genes in common and that these are distinguishable from other races, remain in use today. Genetic variation within each racial group (approximately 85 percent), however, exceeds that

found between races (approximately 15 percent). Genetic variation in a population is usually assessed by estimating the level of heterozygosity (polymorphism). The earliest variations identified were blood groups, followed by circulating enzyme polymorphisms and nuclear restriction fragment-linked polymorphisms (RFLPs). All of these were originally detected in Caucasians who show high levels of variation for these compared with other populations. More recently, two kinds of DNA sequence variation have been studied: mitochondrial DNA variation, which is transmitted maternally and shows greatest variation in African populations, and repeated base pair sequences (microsatellites) that occur all across the genome. Microsatellites, which were studied simultaneously in a large sample of populations worldwide, were also found to have the highest level of polymorphism in African populations.

- Genetic variation has been studied in many populations around the world (including single, isolated villages of as little as 50 individuals, groups of villages, and samples of large subcontinental groups); approximately 85 percent of the genetic variation identified is within these populations. Moreover, the level of variation found in small populations is essentially the same as in large subcontinental populations. These findings bear out the irrelevance of the five races biologically defined by Blumenbach and support Darwin's view of gradual change in the genetic make-up of whole continents and a lack of sharp discontinuities of any importance.
- Given the demise of biological classification, another definition of race might be: a grouping of humans based on visual and/or cultural (including socioeconomic and linguistic) criteria.
- It is important to remember that heritability is a within-group statistic that does not permit comparisons between groups that have not been studied separately, together, or in some fashion.

Discussion—Dr. Feldman

Key Points

- Dr. Feldman indicated that his proposed definition of race includes political/legal criteria within the general definition of culture. It was suggested that the relationship of a visual/cultural definition of race to our social relations concerning property, power, and discrimination must also be considered.
- South Africa, with its small white colonial population, is an exception to the pattern of using non-racial classifications in majority non-white populations.
- It was also suggested that the fields of social and perception psychology, especially the work of Gestalt, provide useful frameworks for understanding why humans pay more attention to some characteristics (e.g., color) compared with others; greater attention to other characteristics of individuals may have led us to categorize people differently.

- A finer definition of human variation is needed to explain concentrations of certain diseases within so-called races or ethnic groups. For example, the large population generally defined as African is made up what were once much smaller population groups. In such small populations, a genetic mutation related to a disease may or may not increase in frequency and will not be found consistently across the larger population. For this reason, studies of the smaller populations are essential to identify these potential variations of importance to disease and disease prevention. Examples include hypercholesterolemia among Lapps in Europe, and Huntington's disease in small identified populations in Venezuela and the U.S.
- The validity of racial differences in clinical trial results is highly questionable, since the racial classification of individuals usually is based on self-report. This is equally problematic for trials conducted in what is often considered a single population or race (e.g., Africans who are then asked to designate tribal ancestry) as in the United States, where clinical trialists attempt to discern differences in outcome among whites, blacks, Hispanics, Asians, and other population groups.
- It was proposed that racial groups might better be defined, for medical or disease-related purposes, by the diseases (e.g., Ashkenazi Jews are people who have an elevated risk of Tay-Sachs disease). Dr. Feldman noted, however, that this approach raises issues as to whether and how to consider individual and familial risk factors and whether a more sophisticated empirical risk analysis is possible using information provided by the individual about his/her ancestry.

The Biological Anthropology of Race

Dr. Solomon Katz

Key Points

- The United Nations Educational, Scientific and Cultural Organization (UNESCO) created a statement on race in 1949 that had been revised periodically through 1964 to reflect knowledge base changes and contemporize the understanding of race-related terms in support of good science, recognizing also that contemporary science has a tremendous influence on public policy. In recent years, Dr. Katz has chaired the effort by the American Association of Physical Anthropologists (AAPA) to update the 1964 UNESCO statement on the biological aspects of race, which will be presented to UNESCO via its member organization, the International Union of Anthropological Scientists. The revised statement was developed wholly through the contributed efforts of the AAPA committee members and reflects the responsibility of scientists who study human evolution and creation to present the best and most complete knowledge in this area in a public arena. As a working statement, it is fully anticipated that it will be revised again in the future.

- As noted in the preamble to the revised statement, popular conceptions of race are derived from nineteenth and early twentieth century scientific formulations. These old racial categories are based on externally visible traits, primarily skin color, features of the face, and the shape and size of the head and body and the underlying skeleton. These characteristics were often imbued with non-biological attributes based on social constructions. These categories of race are rooted in the scientific traditions of the nineteenth century and earlier philosophic traditions that presume that immutable, visible traits can predict the measure of all other traits in an individual or population. Such notions often have been used to support racist doctrines, yet all racial concepts persist as social conventions that foster institutional discrimination.
- The revised statement contains eleven major points:
 - (1) All humans living today belong to a single species, *Homo sapiens*, and share a common descent. While opinions differ as to how and where different human groups diverged or fused to form new ones from a common ancestral group, all living populations in all geographic areas have evolved from the ancestral group over the same time period. Much of the biologic variation among populations involves degrees of variation in the frequency of shared traits. Though at times isolated, human populations have never diverged genetically enough to produce any biological barriers to mating between members of different populations.
 - (2) Biological differences between humans reflect the influence of both hereditary factors and natural and social environmental factors; the degree to which environment or heredity affects any particular trait varies greatly.
 - (3) Pure races, in the sense of genetically homogeneous populations, do not exist in the human species today, nor is there any evidence that they have ever existed.
 - (4) Obvious physical differences exist between populations living in different geographic areas of the world. Some of these differences are strongly inherited, while others are influenced by nutrition, way of life, and other environmental factors. Genetic differences commonly consist of variations in the frequency of all inherited traits, including those that are environmentally malleable.
 - (5) The species *Homo sapiens* has become a highly diversified global array of populations with a complex geographic pattern of genetic variation that, however, presents no major discontinuity. Humanity cannot be classified into discrete geographic categories with absolute boundaries. The complexities of human history make it difficult to determine the position of certain groups in classifications, and multiplying subcategories cannot correct the inadequacies of these classifications. Generally, traits used to characterize populations are either independently inherited or show only varying degrees of association with

one another within a population. Therefore, the combination of these traits in an individual commonly deviates from the average combination in the population, a fact that renders untenable the idea of discrete races made up chiefly of typical representatives.

- (6) As in other animals, the genetic composition of each human population is subject over time to the modifying influence of diverse factors including natural selection (promoting environmental adaptation), modification of genetic material through mutations, admixture (leading to genetic exchange between local populations), and randomly changing frequencies of genetic characteristics from one generation to the next. Human features with universal biological value for the survival of the species are not known to occur more frequently in one population than another. Thus, from a biological perspective, it is meaningless to attribute a general inferiority or superiority to one or another "race."
- (7) Human history is marked by migration, territorial expansion, and contraction. As a result, humans are adapted to many of the earth's environments in general but to none in particular. Human progress in any field has been based on culture and not on genetic improvement. Mating between members of different human groups tends to diminish differences between groups, has occurred consistently wherever different human populations have come into contact, and has played a significant role in human history. Obstacles to such interaction have been social and cultural rather than biological. Continuing global urbanization and intercontinental migration has the potential to reduce the differences among all human populations.
- (8) Partly as a result of gene flow, the hereditary characteristics of human populations are in a state of perpetual flux, with distinctive local populations continually coming into and passing out of existence.
- (9) The biological consequences of mating depend only on the individual genetic makeup of the couple, and not on their racial classifications. Therefore, no biological justification exists for restricting intermarriage between persons of different racial classifications.
- (10) There is no national, religious, linguistic, or cultural group or economic class that constitutes a race. However, humans who speak the same language and share the same culture frequently select each other as mates, with the result that there is often some degree of correspondence between the distribution of physical traits and the distribution of linguistic and cultural traits. But there is no causal linkage between these physical and behavioral traits, and therefore it is not justifiable to attribute cultural characteristics to genetic inheritance.
- (11) Physical, cultural, and social environments influence the behavioral differences among individuals in society. Although heredity influences the behavioral variability of individuals within a population, it does not

affect the ability of any such population to function in a given social setting. The genetic capacity for intellectual development is one of the biological traits of our species essential for its survival, and is known to differ among individuals. The peoples of the world today appear to possess equal biological potential for assimilating any human culture. Racist political doctrines find no foundation in scientific knowledge concerning modern or past human populations.

- Rejecting a biological concept of race, as detailed in the revised UNESCO statement, raises questions as to how we will adjust to the lack of a construct that has been accepted for more than two centuries. In fields relevant to anthropology and human biology, for example, committees have been formed to determine the extent to which the medical literature and research are influenced by older conceptualizations of race. In forensic anthropology, there may be a need for new terms to replace the use of race as a characteristic in the identification of human remains. Similar questions arise in other fields. The social and cultural construct of race becomes more important with the elimination of a biological definition of race. It remains to be seen if the social legitimacy of race will be reduced or heightened if the concept of race is no longer biologically tenable. The process of dealing with such questions will be complex and will require the enlightened cooperation of people from many disciplines.

Discussion—Dr. Katz

Key Points

- Dr. Katz reiterated that rejection of a biological definition of race does not diminish (and may in fact strengthen) the concept of race as a social construct that will remain important to each person's identity. It will be important to examine race from other perspectives (e.g., ethnicity) and determine how such alternative parameters impact health patterns and other biological phenomena and their implications for research.
- It was suggested that instead of studying disease, patterns of health or ill-health may be more informative of the social influences on disease. To study patterns of health and illness, the participation of economists, anthropologists, and sociologists should be sought in addition to biologists and medical researchers. To study a population whose life chances are shaped by features other than their biological histories, this additional expertise is needed to help specify and analyze factors creating patterns of health or illness. For example, the rise of managed care and any health status improvements resulting from it have been due more to an economically-motivated desire of the government and employers to avoid the financial costs of illness than a public health-motivated desire to maintain health for its own sake.
- It was noted that concepts of health and disease vary significantly between cultures. The challenge will be to encompass these concepts within discussions on the biology and social psychology of race.

- Responding to the concern that much of the scientific community may be proceeding with research founded on invalid assumptions about race, Dr. Katz reiterated the need to educate the scientific community about current understandings (per the UNESCO statement) and noted that science does not advance in a uniform wave of new knowledge. He recommended widespread communication on the topic of race and science through channels such as the Journal of the American Medical Association and other medical/scientific media and organizations.
- Observed differences in cancer risk among ethnic populations or so-called races should still be explored for their causative factors, however, these investigations should seek to uncover the role of environment, culture, and other factors. Although we may reject a biological definition of race, we should not ignore clues to cancer risk presented by apparent ethnic or racial differences, which can also usefully focus resources and concern.

PRESENTATION HIGHLIGHTS—Scientific Use of Racial/Ethnic Classification

Opening Remarks

Dr. Edward Sondik, Moderator

Key Points

- Any reporting of observed differences in cancer morbidity or mortality should include an explanation of the implications and uses of the data. The observed outcomes must be viewed in relation to the utilization and efficacy of preventive, diagnostic, therapeutic, and rehabilitative interventions to which the population has had access.
- Data on racial differences in cancer morbidity and mortality may provide clues to genetic/biologic, social (e.g., access to care), and behavioral factors of importance, but they seldom provide answers to questions of causation. These clues become the subject of hypotheses that must be tested. Importantly, the definitions of racial categories used in research are evolving, as evidenced by the morning's discussion.
- Current data on the relationship of income and poverty to cancer statistics suggest that income explains a substantial amount of the observed higher cancer incidence among African Americans. Weighting the incidence data by the percentages of the white and black populations at various income levels, however, indicates higher cancer incidence among whites at lower income levels compared with blacks. A similar pattern is found comparing weighted versus unweighted data for years of schooling completed. Although the differences are relatively small, these types of studies provide clues not just to why racial differences exist, but to why cancer incidence and mortality are so high.

Standard Federal Definitions for Statistical Purposes

Ms. Suzann Evinger

Key Points

- The racial categories currently in use by the Federal government have been unchanged since their adoption by the Office of Management and Budget (OMB) in 1977. They are contained in Statistical Policy Directive No. 15, and are used for record keeping, collection, and presentation of data on race and ethnicity. In addition to their use in Federal surveys and in the decennial census, they are used for program administrative reporting and for civil rights compliance monitoring in areas such as fair housing, mortgage lending, employment, education, and access to credit and health care services. The four racial categories defined in Directive 15 are :
 - American Indian or Alaska Native – persons with origins in any of the original peoples of North America and who maintain a cultural identification through tribal affiliation or community recognition.
 - Asian or Pacific Islander – persons having origins in any of the original peoples of the Far East, Southeast Asia, the Indian subcontinent, or the Pacific Islands.
 - Black – persons having origins in any of the black racial groups of Africa.
 - White – persons having origins in any of the original peoples of Europe, North America, or the Middle East.
- The two categories for data on ethnicity are: Hispanic origin, and not of Hispanic origin. These were added in the mid-1970s to implement requirements of a public law mandating collection of more information on persons of Spanish culture or origin.
- The racial and ethnic categories represent a political, social construct designed to be used in the collection of racial and ethnic data about major population groups. As such, they are a product of this Nation's political and social history; it has never been maintained that they have any basis in anthropology or science.
- The meaning and importance of the categories differ depending on how we identify ourselves, how we identify others, and how others identify us. There is, therefore, a tension between how we may identify ourselves and how society might identify us.
- A major driving forces in the development of the current categories was passage of the various civil rights laws. Data were needed to measure and monitor progress towards equal access to housing, education, employment, and other resources for population groups historically experiencing government discrimination. Directive 15 states that the categories are not to be used for determining eligibility for participation in Federal programs, but

some agencies do use the categories as a means of identifying socially and economically disadvantaged groups.

- Review of Directive 15, initiated in 1993, was spurred by criticism that the existing categories did not reflect the increasing diversity of the population resulting from greater immigration and interracial marriage. The review also is timely in that it will be possible to implement any needed changes identified in time for the Year 2000 census. In addition, data users now have had 20 years of experience with the existing standard and can evaluate the quality of the data it produces.
- The review is being conducted in collaboration with an interagency committee whose members represent the diverse Federal data needs of more than 30 agencies. Public comment on the existing standard and suggested changes was solicited on more than one occasion and identified four major areas of concern: (1) the need for a multiracial category and how that might be approached, (2) desire for expansion of the existing categories to collect more detailed information on certain populations, (3) interest in classifying data on Native Hawaiians as indigenous peoples in the American Indian/Alaska Native category rather than in the Asian or Pacific Islander category, and (4) a desire to eliminate the categories altogether based on the belief that they contribute to the over-emphasis on race and fragmentation in American society.
- In addition to the public comment component of the Directive 15 review, research and testing has been done to provide additional information on issues identified through the public comment phase. The research and testing has included a supplement to the Current Population Survey (May 1995) sponsored by the Bureau of Labor Statistics, and research by the Bureau of the Census on alternatives for collecting racial and ethnic data. For example, testing was done on the effect of having a multiracial or biracial category, including the option to "check one or more" or "check all that apply"; adding Hispanic to the current list of racial categories; the effect of sequencing questions on race and Hispanic origin; and testing of respondents' preferences for the names of the categories.
- To meet the timeframe for decennial census activities (particularly the dress rehearsal to be held in the Spring 1998), the review of Directive 15 must be concluded by October 1997. In July 1997, findings and recommendations of the interagency committee will be published in the *Federal Register*, and public comment will be invited for a 60-day period thereafter.

Racial Classifications in Public Health

Dr. Robert Hahn

Key Points

- Associations between racial and ethnic categories and health status may be expected for three principal reasons: (1) genetic disease patterns may exist,

but the heritability of these conditions must be demonstrated and the markers of heritability must be found among so-called racial and/or ethnic populations, (2) sociocultural differences among racial and ethnic populations are associated with behavior such as diet and preventive health care practice which are in turn associated with differential exposure to risk factors for disease and injury, and (3) if persons ascribed specific racial and ethnic identities are differentially treated in terms of employment, housing, education, and health care, these differences may affect health status.

- Statistics on disease rates in various minority and non-minority population groups are commonly reported, as are differences in insurance rates for minority and non-minority groups. It is important to understand how these statistics are derived and their limitations. Health statistics on racial and ethnic populations are critical in etiologic research, program design, implementation, and evaluation, yet the system of health statistics used in the United States has not been systematically evaluated and the quality of reported statistics may be questionable. Age, race, ethnicity, and sex are characteristics epidemiologists commonly take for granted but should not.
- The currently used system of statistics is based on four underlying assumptions: (1) that consistent and generic definitions are used by all of the Federal agencies involved in collecting health and racial/ethnic data, (2) that the people asked to identify their race or ethnicity understand what is being asked of them, (3) that there are high and comparable rates of enumeration, participation, and response among the populations of whom data is solicited, and (4) that people give consistent responses in different surveys and at different times. Other important assumptions concern the conceptual validity of racial/ethnic classifications, whether the categories are exclusive and exhaustive, and the extent of their measurability and flexibility.
- Myriad Federal agencies are involved in collecting race and ethnicity data, but the data are collected differently by different agencies, and in some cases (e.g., the Immigration and Naturalization Service, INS) data are only estimated on the basis of the racial/ethnic background of source populations. Agencies share their data for three basic purposes: (1) counting, e.g., the Bureau of the Census uses birth and mortality data from the National Center for Health Statistics (NCHS) and immigration data from INS to project census figures, (2) calculation of race (typically, census data are used as the denominator and numerator data comes from other agencies), and (3) evaluation of counts.
- The opening statement in OMB Directive 15, indicating that the racial and ethnic classifications defined are “neither scientific or anthropological in nature,” raises the question as to what their nature is and their success in assessing racial and ethnic populations. In addition, the OMB or other agencies do not define terms such as race, ancestry, national origin, cultural identification, or provide geographic definitions, and do not define the racial and ethnic classifications except as contained in the directive. As a result, for example, it is unclear how an individual of American Indian origin who does

not identify culturally with that group should categorized him or herself, since the definition stipulates that both conditions be met. The directive is also unclear as to whether self-identification or identification by others is to be the criterion for determining a person's race or ethnicity. An NCHS study found classification differences of up to 70 percent depending on whether the respondent or an interviewer made the classification.

- A study of the birth and death records of all U.S. infants who died between 1983-85 showed different races listed on the birth and death certificates of substantial percentages of some groups. In particular, infants listed on birth records as Japanese, Filipino, or Hispanic were most likely to be listed as white on death certificates. The effect of these changes was an overstatement of white infant mortality and a distortion of the difference in infant mortality rates between white and non-white populations. Other studies have found similar patterns of misclassification in both infant and adult populations. It appears that the rate of misclassification has not decreased significantly in the past 25 years. Two recent studies using cancer incidence and mortality data from the Puget Sound SEER cancer registry found that correct classification of American Indians was strongly correlated to the proportion of Indian heritage of the individual.
- An argument against changing existing categories is that the continuity of categories over time should not be disrupted; however, such continuity has not really existed. Since 1900, the only consistently used categories have been Chinese, Japanese, and white.
- Terminology within categories also varies, e.g., in the 1990 census Eskimos and Aleuts are designated separately from American Indians, but natality documents include these groups in a single category, and mortality documents also include Canadian Indians.
- Dr. Hahn has concluded that (1) the conceptual definitions of race and ethnicity are not available, scientific grounds for definition are not considered, and the grounds that are used are not clarified; (2) the procedures for ascertainment of race and ethnicity vary between and within data collection agencies; (3) miscounting and misclassification may vary by an order of magnitude in white races and races other than white; (4) individuals' responses to questions of race and ethnic identity differ for different indicators and different surveys and at different times; and (5) as a result, counts, rates, and ratios may not be meaningful or accurate.

Additional Research Needs and Recommendations

- There is a need for clearer goals in the definition of racial and ethnic categories, whether for purposes of planning, public health surveillance, administration, or research.
- Extensive effort should be made to scientifically validate these categories insofar as is possible, and to establish basic scientific and anthropological

principles for public health surveillance. Currently, what we describe as race in public health is largely ethnicity (i.e., self-perceived ancestry). If the classifications are proven valid, they must be clearly defined.

- The ways in which different segments of the population identify themselves should be investigated.
- To assure the quality of our health statistics, the surveillance system should be routinely and periodically evaluated.

Distinguishing Between the Effects of Race and Poverty

Dr. Mary Bassett

Key Points

- Black/white differences in disease rates and outcomes have been examined more extensively than have differential rates for other minority groups, since race in America has been largely regarded as concerning these two races. Vital statistics from the colonial era to the present show that blacks are sicker and die younger than whites. Cancer patterns reflect these longstanding disparities in overall health. Although incidence of most common cancers may be higher among whites, blacks are more likely to succumb sooner to cancer.
- Two competing hypotheses have been advanced to explain the difference in cancer mortality rates between blacks and whites. One is that blacks are inherently, racially, more susceptible to a variety of malignancies, and consequently the study of racial differences will help reveal the genetic basis of vulnerability to cancer. The alternative view is that the apparent effects of race are largely a reflection of the impoverishment of blacks. These divergent views lead to equally divergent remedies. If racial differences in cancer susceptibility and outcome are genetic, we must await genetic intervention to fundamentally address the excess mortality among blacks. In contrast, if differences are due to social factors, including socioeconomic position (which affects all people), then our task is to determine how poverty mediates exposure and susceptibility to cancer-causing agents and the experience of disease.
- Some of the factors known to be involved in the link between poverty and cancer are toxic exposures in the home and work place, individual behaviors such as cigarette smoking, and access to health care. Susceptibility factors such as age, diet, and immune status are also affected by poverty.
- The differences between blacks and whites in the U.S. in economic position (i.e., poverty income), and particularly wealth, are striking. Whites have about 12 times the assets of blacks in the U.S. Other economic gradients, socioeconomic differences, and risk factors are also of importance to cancer incidence and survival. Further, multivariate models for assessing whether socioeconomic position is a key intervening variable in cancer incidence and survival must also consider geographic origins, macro social factors, historical

conditions and recognize that all or most of these factors are at play simultaneously.

- To adjust for socioeconomic position, we need studies that jointly examine race in some measure of socioeconomic status. A computerized search of the cancer research literature revealed that few studies have jointly considered cancer and race, and only one in 10 studies have considered cancer, SES, and race together (representing approximately 0.1 percent of the total number of studies).
- When some measure of socioeconomic position is taken into account, most studies of cancer risk show that black/white differences disappear for some cancers, diminish for others, and for some cancers, remain unchanged. Similar observations have been made concerning cancer survival. Studies of the impact of socioeconomic position on stage at diagnosis or histology (an important predictor of outcome that varies by race) found that the racial difference is reduced when a measure of SES is included, though the risk for advanced disease between blacks and whites persists within income strata.
- The remaining difference in cancer incidence and survival after socioeconomic position has been taken into account is commonly considered a measure of the intrinsic risk attributable to race. Despite studies demonstrating the importance of socioeconomic position in determining survival, many researchers still conclude that it is the biological component that is most crucial. Socioeconomic position continues to be viewed as a nuisance confounder of evidence supporting the biological explanation. It is suggested only rarely that the adjustment for socioeconomic position may have been inadequate or incomplete.
- Our ability to measure the extent to which the health consequence of race is attributable to the economic consequences of race depends on how well we measure socioeconomic position. Most studies use U.S. census data for this purpose; aggregate data are then attributed to individuals according to their place of residence. This approach has enabled public health researchers to overcome the absence of such social data from hospital records, HMOs, medical records, and population-based cancer registries, but a great degree of variability exists in how the data are used. Of the types of census data available, block group data (compared with census tract or zip code data, listed in descending order of usefulness) are most likely to closely correspond to homogeneous neighborhoods and reveal pockets of poverty. Aggregate measures based on block groups may underestimate the measure of effect.
- Studies of variables that can be examined using census data (e.g., median income, poverty, education) have often been measured inconsistently, and cut points are often chosen without justification. In addition, even when individual measures are comparable, the ecologic niche in which people live is not. For example, equal income translates into different levels of buying power for blacks compared to whites because in black communities many goods and services have higher costs and income stability varies by race, with

blacks more likely than whites to have periods of poverty. In addition, blacks typically lack assets even when they have income. Similarly, education buys less for blacks (or results in less improvement in income) compared with whites, and college educated blacks are four times more likely than whites to experience unemployment. It is also the case that poor blacks are more likely than poor whites to live in poor neighborhoods, because of the effect of segregation. Current measures of SES do not capture these aspects of disadvantage.

- The effect of socioeconomic position over time is also important, i.e., the socioeconomic position a person occupies in childhood may have more relevance to a disease than adult position.
- For all of the above reasons, it is not surprising that when we adjust for social class with a dichotomous variable (e.g., income greater or less than \$15,000), racial differences, related to unmeasured differences in socioeconomic position, persists.
- There also are non-economic effects of race, including the impact of social class, cultural differences and discrimination.
- We cannot disentangle race and socioeconomic position because limited life chances and poverty are among the most important consequences of being black in America. It should also be recognized that in measuring racial differences in health, we are demonstrating the population experience of disease. In this regard, it should be remembered that poor whites likewise suffer poorer health; it should be a general truism that poverty leads to poor health and premature death for all populations.

Additional Research Needs and Recommendations

- Measures of socioeconomic position should be incorporated into the routine collection of public health data.
- Data presented by race should be considered incomplete without some effort to measure the extent to which they reflect the social consequences of poverty.
- Socioeconomic position should be added to the classic descriptive triad of age, race, and sex.
- Efforts are needed to more explicitly conceptualize socioeconomic position and the many dimensions of the relationship between race and health.

Discussion—Drs. Hahn and Bassett, and Ms. Evinger

Key Points

- Dr. Bassett reiterated that while adequate adjustment for socioeconomic position demonstrates that poor whites, like poor blacks, are at higher risk for cancer and suffer poorer survival, we have been slow to try to examine the experience of discrimination and the effect it may have on health.

- The imprecision in racial/ethnic classification found in vital statistics data is relatively minimal for the black population; in the American Indian and Asian populations, misclassification is far more pronounced and presents a serious impediment to cancer research seeking to identify outcome differences by race or ethnicity.
- Although recognizing biology/genetics or socioeconomic position as potential factors in disease may provide useful clues to the cause and course of illness, it must be kept in mind that identifying these factors is not itself the solution. Substantial research in the directions these clues suggest will still be needed.

Additional Research Needs and Recommendations

- Socioeconomic position should be classified independent of ethnicity. Like race, socioeconomic position should be considered a relational category, not a category that is intrinsic to the individual. Information about occupation and the individual's relationship to the workplace (e.g., ownership, supervisory status) should be gathered. Efforts should be made to measure social class at the individual, household, and neighborhood levels, which will be more meaningful at both theoretical and social levels. Gathering this additional information by expanding questions already routinely asked concerning SES will require added effort, but is feasible. More discussion is needed as to how public health surveillance data bases can reasonably be enhanced to capture more detailed data on socioeconomic position, as is currently the practice in many western European countries.
- It should be recognized that implementation problems resulting in misclassification will occur regardless of the set of racial/ethnic classifications used. To minimize this problem, greater attention should be paid to improving training of the collectors of vital statistics at the state level, medical examiners, and interviewers for major surveys, so that these individuals will be cognizant of the importance of the data and the ways in which they will be used.

PRESENTATION HIGHLIGHTS—Scientific and Societal Implications in Cancer Research and Applications

Opening Remarks

Dr. Claudia Baquet

Key Points

- While the United States offers the highest quality medical care in the world, and America's leadership in technological advances and biomedical research is uncontested, more than 40 million Americans had no health insurance during the period 1994-1995, and approximately 64 million had no health insurance for at least one month between 1990 and 1992. The insurance coverage and health care access problems of American children are particularly deplorable.

In 1995, 26.8 percent of Latino children, 15 percent of African American children, and 13 percent of white children were uninsured. Of children covered by Medicaid in 1995, 45 percent were African American, 37 percent Latino, and 18 percent white.

- Descriptive cancer statistics, and data on health care utilization, access, and delivery continue to be used to define areas of cancer care and cancer research needs in special population communities. The results of studies either using or producing these data are intended to facilitate the transfer and application of interventions or research to socially, economically, and culturally relevant settings. If we are to design culturally relevant interventions, more data are needed on diverse and complex factors of known or suspected relevance, including tobacco use, nutritional status, ability to purchase healthful foods, occupational exposures and discriminatory work assignments, health care access and utilization, poverty, cultural influences, and health care seeking behaviors.
- Minority communities' distrust of the research and health care establishments is widespread. The 1995 National Comparative Health Survey published by the Commonwealth Fund documents the feelings among substantial percentages of minority group members surveyed that they (1) would receive better health care if they were another race (i.e., white), (2) were treated badly when receiving health care due to their race or income level, (3) have limited trust of doctors, and (4) are more likely than whites to use alternative medicine. The traditional and persistent fear of the medical and scientific communities, resulting in delayed diagnosis and treatment, continues to affect racial/ethnic minorities of all social and economic conditions. Delay in seeking health care continues to affect minority group members of higher socioeconomic position; this fact reinforces the need to study the impact of childhood socioeconomic status. It appears that related behaviors (e.g., reliance on hospital emergency rooms and outpatient departments for care, lower utilization of preventive care services because of competing life pressures on time and resources) may have significant effects on health even in higher SES minority groups. The influence of biology, particularly as it may be affected by SES, also requires further study.

Additional Research Needs and Recommendations

- The issues of race and social class should form the core of a research agenda that addresses cancer, race, and clinical care differences in special populations. For example, transition of the Medicaid population to managed care raises new issues of access, participation in clinical research, and intervention in high risk populations.
- Both scientific and social aspects must be considered in designing and implementing cancer research and disseminating cancer research results on culturally diverse groups. Such research must include substantial funding for translating and applying research results in culturally diverse settings.

Racial Discrimination and Health: An Epidemiologist's Perspective

Dr. Nancy Krieger

Key Points

- Race, ethnicity, inequality, and justice are among the critical determinants of the public's health. The concept of embodiment—how we as social beings and biological organisms literally incorporate biologically our social experiences and express these in population patterns of health, disease, and well-being—can be useful in understanding how these critical determinants shape our health. We are always and at once members of societies structured by social relations involving property, labor, power, and procreation. Simultaneously, we are members of our biological species, shaped by evolutionary pathways contingent upon chance, selection, and the quirks of history. What we encounter and create in our lives necessarily reflects these interwoven histories, social and biologic, and is expressed in our patterns of individual and collective health.
- Ecosocial theory, emphasizing conjoint social and biologic determinants of population health as shaped by our social and biologic history, is radically opposed to the more traditional biomedical model that focuses on “the causes of cases rather than the causes of incidence” (Rose) and which holds that population patterns of disease can generally be explained by genetics and lifestyle.
- Race/ethnicity is a social, not biological, category referring to social groups, often sharing cultural heritage and ancestry, that are forged by oppressive systems of race relations and justified by ideology in which one group benefits from dominating other groups and defines itself and others through this domination and also by possession of selected arbitrary physical characteristics (e.g., skin color).
- Population groups loosely referred to as “races” may exhibit differences in gene frequencies for selected traits due to histories of voluntary or forced migration, geographic isolation, and restrictive customs or laws about marriage and procreation. Though construed as an essential biologic category, “race” is a human construct, not a fact of nature. We have a non-biologic reality of race combined with the everyday and powerful reality of race relations and racism.
- Two concepts are useful for understanding the impact of this contradictory situation on our health and our understanding of population health. The first, racialized expressions of biology, refers to how particular biologic attributes have been selected to define and/or come to be associated with the biologic construct of race. Examples of racialized components of biology include skin color, hair type, facial features, and genetic disorders such as sickle cell anemia, cystic fibrosis, and Tay-Sachs disease. Because they have been racialized, they are not seen as singular aspects of human diversity but instead evoke or conjure up notions of fundamental difference. The concept of

racialized biologic expression is useful for identifying instances in which so-called racial phenotypic characteristics are or are not informative about other aspects of our bodies.

- The second concept, biologic expressions of race relations (i.e., racial oppression and resistance) is far more relevant to understanding population health. This concept speaks to how we literally embody and biologically express these experiences from conception to death, thereby producing racial/ethnic disparities and morbidity and mortality across a wide spectrum of outcomes. To illustrate, racial discrimination can impede access to appropriate health care, leading to reduced survival and elevated mortality rates. It may restrict employment to more hazardous and lower wage occupations, thereby limiting possibilities for living in healthy homes and neighborhoods. Thus, discrimination can be seen to harm health jointly at work, at home, and in the community. Social trauma from discrimination can also induce stress-related health problems, potentially leading to faster aging among racially oppressed groups.
- The racial/ethnic inequalities in overall health, morbidity, and mortality in the U.S. are well known—people of color experience inadequate prenatal care, higher infant mortality, more hypertension and AIDS, greater mortality and lower survival from cancer, poorer overall health, and higher age-adjusted death rates for 13 of the 15 leading causes of death. The medical model may suggest that these disparities are due to genetic differences, however, this explanation would require that something different of importance is operating to produce every one of these undesirable outcomes. Contemporary understandings of genetics counter the view that any hypothetical set of genes associated with phenotypic markers of “race” could explain a predisposition to these myriad outcomes.
- A more plausible approach is to consider racial/ethnic disparities in living conditions, income and assets, and income benefit of education. Continuing inequities in these areas reflect pervasive patterns of past and present racial discrimination and several recent national polls suggest that racial stereotypes may be hardening rather than receding.
- Despite considerable evidence of racial discrimination in our society, remarkably little public health or medical research directly focuses on health consequences of racial discrimination. The research that has been done has followed one of two principal threads. One of these focuses on health services, and racial discrimination usually is inferred if racial/ethnic disparities in medical procedures persist, even after accounting for age, severity of disease, insurance status, socioeconomic position, and other factors germane to health service utilization. For example, a recent study of the Medicare population found black patients were far less likely to receive appropriate health services than their white counterparts despite comparable insurance coverage. A second approach examines the role of socioeconomic inequalities in racial/ethnic disparities in health, in which adjusting for socioeconomic

position often reduces, if not eliminates these disparities. In some cases it does not, either because real differences persist within economic strata, or because of residual confounding due to inadequate measurement of socioeconomic position. Neither of these approaches, however, directly delve into people's actual, self-reported experience of racial discrimination. A new, still small, yet provocative set of studies is beginning to do this.

- Dr. Krieger is currently studying cancer incidence variations by race/ethnicity and socioeconomic position, in which socioeconomic position is characterized at the level of the individual's census block group. Preliminary results concerning lung cancer rates among women indicate that rates rise most rapidly with age among the white and black women from the working class neighborhoods; rates are also relatively high among Hispanic women from non-working class neighborhoods. Rates are relatively low among working class Hispanic women and among Asian/Pacific Islander women from neighborhoods of both types. These results demonstrate that among the Asian/Pacific Islander women, there is no class gradient, while among the Hispanic women, the class gradient is the opposite of that among the white and black women. The results are consistent with current female smoking patterns in the U.S. — smoking is most common among materially deprived women and especially those caring for young children. In addition to its psychoactive effects, smoking affords a personal and private pleasure sanctioned by smoking breaks at work and breaks from the demands of home life. Diverse, albeit changing, cultural sanctions about what is appropriate behavior for women concerning smoking and work outside the home are also of importance. From this perspective, lung cancer incidence among women can be seen to constitute a biologic expression of race, class, and gender relations, as is also true for men.
- Another study by Dr. Krieger and colleagues examined the relationship of blood pressure levels to reported levels of racial discrimination. Young adult black and white women and men who were part of a cohort to study cardiovascular disease risk were asked at a follow-up examination to report their experience of discrimination in seven distinct settings (e.g., work, school, getting medical care). Overall, blood pressure levels were highest among those reporting either no discrimination or higher levels of discrimination. These apparently confusing findings concerning those reporting no discrimination can be explained by an ecosocial interpretation of the data — that the body has internalized and may be expressing (through higher blood pressure) experiences that the individual is unwilling or unable to articulate (the experience of discrimination), or perhaps has internalized such that the experience is perceived as deserved and not discriminatory. People with more power and resources may find it easier than those without to name and challenge discriminatory treatment.

Additional Research Needs and Recommendations

- Public health research needs to move from the tautology that “race” explains “racial” differences in health to a more substantive mode of inquiry examining how race relations, particularly racism, drive population patterns of health, disease, and well-being. This will require routine collection of appropriate racial/ethnic and socioeconomic data in public health data bases, including vital statistics and cancer and other disease registries. Thereafter, in more detailed studies, we will need to employ theoretically sound measures to capture social meanings of racial/ethnic position across the lifespan at both individual and population levels.
- Epidemiologic research on racial discrimination and health, i.e., biologic expressions of race relations, provides an important perspective on where and how the truths of the body and the body politic engage and enmesh.
- To expand discussion of the meaning of race in science specifically with regard to cancer research and to health more broadly, we need to document and analyze the health consequences of racial discrimination, taking into account likely effect modification by social class, gender, and age as related to birth cohort and period of time affected.
- We also need research on how people resist and work to end racial discrimination and the harm it causes in both our bodies and body politic; addressing racial discrimination is necessary for preventing cancer and promoting social equity and health.

Genetics of Race in Clinical Trials

Dr. Edison Liu

Key Points

- We are more alike than we are truly different; our differences, whether genetic, biologic, or socioeconomic, permit social and biological scientists to uncover risk and protective factors that may be engineered to be pertinent for all human beings. Race is a surrogate for environment, social, and behavioral risks.
- Studies of racial variation in breast cancer serve as a paradigm for discussing cancer genetics and race in clinical trials. The data showing that breast cancer incidence is higher among white women than black women, while breast cancer mortality is higher for black women, are well-known. Higher mortality among black women with breast cancer is associated with known prognostic factors—higher stage, more lymph node positivity, larger tumors, higher grade, higher S-phase fraction, lower estrogen and progesterone receptor levels. A review of large, carefully implemented breast cancer studies shows that when stage, socioeconomic factors, and treatment are controlled for, relative risk for mortality drops. The residual excess risk (approximately 10-30 percent for black women compared with white women) is frequently explained in a biologic context.

- A study of an unselected group of several thousand women found almost no difference in the molecular parameters of blacks and whites for major indicators of prognosis. In another study, despite equivalent proportions of black and white women with and without p53 tumor suppressor gene mutations, the negative impact of the mutation (mortality) was significantly greater for black women.
- Studies conducted through the Cancer and Leukemia Group B (CALG-B) have examined the influence of gene expression and mutation on adjuvant chemotherapy effects when given at low, intermediate, or high doses. In one such study, case patients negative for HER-2neu overexpression have equivalent survival regardless of dose. By contrast, patients with HER-2 overexpression have a near doubling of survival at the median dosage. In the larger population, there appears also to be a relationship between HER-2, p53, dosage, and survival. Individuals who are HER-2 positive (mutant) and p53 negative (normal) have a range of survival experience by chemotherapy dose. Those with double mutations have a trebling of survival as dose escalates from low to high. These findings suggest that dependent on molecular markers and their interaction, individual survival may be dramatically affected by how much chemotherapy is received, how well it is administered, and when it is received. These differences may be linked to socioeconomic status and related access to medical care issues that have not been addressed.
- Asian migration and cancer patterns also provide a model for assessing the issue of genes versus environment. For all major cancers, rates for migrating Asians adjust to the levels of white Americans, sometimes within the first generation after migration. This suggests that race and genetics are uncoupled, while race and environment are highly coupled.
- Genetics and cancer are highly coupled; it may be that we should segregate populations for study based on genetics rather than race. Current regulations require investigators conducting clinical trials of any size to enroll minority group members representative of the population and to document results by race. However, smaller studies, in particular, seldom enroll enough minority individuals to have sufficient statistical power to address many of the questions related to race, genetics, and the impact of socioeconomic status. Oversampling of minority populations is necessary to enable identification of effects that would not achieve statistical significance in a population sampled in accord with source population fractions. At the same time, it is recognized that sampling relies on individuals' self-report of race and that increasing interracial marriage will, over time, further complicate attempts to study populations by race.

Additional Research Needs and Recommendations

- Race should be used to identify cultural and social subgroups whose genetic pool and environmental exposure has been different from the general

population, and in this context is simply a tool to identify the social, economic, psychological, and biological variations in the human community.

- Instead of requiring that all clinical trials adhere to the current regulations regarding minority participation and reporting of results by race, resources might be better used in studies specifically designed to address race-related questions that could include sufficient numbers of individuals and appropriate sampling. Such studies would achieve interpretable results and, in addition, could focus on reducing barriers between the research and minority communities that investigators in most other clinical studies lack the resources to address.

The Other Side Of Health Care: A Physician Being Treated For Cancer

Dr. Richard Boxer

Key Points

- The true meaning of wealth is health, and it is impossible to truly understand the importance of health until it is seriously and personally threatened. Few physicians who have personally experienced the possibility of mortality extend this knowledge to their patients.
- A specialist in genitourinary disease, particularly malignancies, for over 25 years, Dr. Boxer has always believed himself to be a compassionate physician. His own experience with cancer has, however, given him an empathy with his patients that he did not have previously.
- Attitude is more than half the battle for an individual facing illness. Denial of the present is only pathologic if it interferes with one's life. For Dr. Boxer, denying the day-to-day miseries of cancer treatment and the potential fatality of a bone marrow transplant allowed him to live through that time and into his future. Without question, the physician must make a realistic assessment of the patient's disease, but such assessment notwithstanding, physicians do a great service to patients by projecting a positive attitude—the patient will live by, and may even live because of, the physician's words. In the words of Hippocrates, "For where there is love of man, there is also love of the art. For some patients, through conscious that their condition is perilous, they recover their health simply through contentment with the goodness of the physician."
- Health care professionals must understand that their profession gives them the privilege not only of altering the course of another person's life, but also of becoming part of that person's life. It is this humbling revelation that brings the life force to the true meaning of the word "doctor."
- Dr. Boxer noted that he has lived through his illness in large part because others participated in clinical trials that may not have helped them but that resulting in new knowledge and better treatment for those who followed. In this sense, patients are truly the physician's professors. In addition to teaching about disease and the disease processes that the physician treats, they also teach about the subtleties of life and illness, and how to live and die

with disease with dignity. For this health professionals owe their livelihoods, but more importantly, the spiritual understanding of life and death.

Discussion—Drs. Krieger, Liu, and Boxer

Key Points

- It was noted that in different ways, the presentations of Drs. Krieger, Liu, and Boxer all point to the enormous role in health played by the psychosocial dimension, yet it has not been explored even to the point of identifying its factors of greatest importance. Much of the psychosocial research has addressed issues such as the impact on cancer survival of participating in a support group, but has not dealt with the everyday effects of racial inequalities, racism, or the effects of stressors related to those experiences. These questions need to be addressed as the primary foci of studies rather than as tertiary issues. It is also important to recognize that measuring phenomena such as racial or other discrimination must be approached differently from measuring other psychosocial events; the repetition of similar discriminatory events over a life time requires measurement of the strategies that people use (and their effects on health) both to cope with and resist these conditions.
- Inadequate language currently exists to describe the lived experience of racial discrimination. Work is being done in this area to describe the experiences of everyday racism, the experiences of everyday resistance, and the ways that individuals define themselves affirmatively and not just in reaction to negative definition. Some sociologic and ethnographic research is just beginning to address these questions. The lack of inquiry in this area speaks to the need for it; both qualitative and epidemiologic studies will be needed.

Additional Research Needs and Recommendations

- Currently, only three percent of all adults with cancer participate in clinical trials; the percentage for minority group adults is much lower. Adequate funding is required to support participant recruitment and retention in clinical studies involving culturally diverse communities.
- In addition to lacking measures of racial discrimination in its diverse forms, a major obstacle in our efforts to deal with cancer in this country is a lack of socioeconomic data collected as a routine part of cancer registry reporting and surveillance, and public health surveillance. These data are key to understanding the health status of the Nation. The absence of these data reinforce the erroneous notion that race is biologic. Research is needed to determine the useful measures that can be included routinely, and these must be conceptually driven, based on an agreed-upon conception of socioeconomic position, coherent, and founded on clear notions of how the measures will be assembled once data are collected. It is unclear by whom such research should be funded.

- In-depth focus group testing and other qualitative research is needed to disaggregate the phenomena of race, ethnicity, and sociodemographic position before we are ready to develop meaningful quantitative measures. We also need funding for research on questions about access and barriers to care; these issues have received virtually no funding to date, yet with the growth of managed care, they are critically important to people with cancer and those who will be diagnosed in the future.
- We need to invest in the education of scientists and the public about the issues and understandings about race, ethnicity, and socioeconomic position raised at this meeting.
- The American College of Epidemiology has formed a subcommittee to address issues related to minorities and epidemiology and to characterize the deficiencies that currently exist (e.g., human resources drawn from minority populations, lack of data) within the entire discipline of epidemiology. This model may be useful for other disciplines and should be considered as a strategy for other medical, scientific, and health disciplines seeking to address their role in dealing with existing health disparities between populations.
- The Panel should consider the potential of the Health Insurance Portability and Accountability Act of 1996 (Kassebaum-Kennedy law) to strengthen health services research data and countervailing forces (private managed care providers) that may limit the availability of health service utilization and outcome data. An opportunity to improve data collection about children's health issues may be found in the Hatch-Kennedy bill on funding for children's health, now under development.
- It is important to study the health effects of poverty, but we must also study patterns of disease and determinants of health across the entire income spectrum. In addition, we need to look not just at the differences in rates between groups, but also assess and determine the causes of high base levels of cancer and other diseases.
- Longer term studies of identified populations are needed, focusing on social factors and forces that impinge upon health from the earliest ages. The benefit of these studies would not be fully realized for 25-30 years, but it is an investment that we should make.
- Investigators need some relief from the regulatory burdens of conducting research. In the aggregate, current regulations all but prohibit the conduct of the type of large scale research needed to answer questions about health disparities between populations. In fact, some investigators are choosing to conduct such large scale studies outside of the United States to escape the current regulatory burden. At the same time, any changes to the existing regulations must not compromise their intent—to ensure that clinical trials are conducted in minority populations. It must be remembered that these regulations were developed for good reason based on actual historical experience.

- It must be made clear that research on race as a social construct, racial inequality and discrimination, socioeconomic position, and related issues as they affect health is legitimate and is not ideological research. Research in these areas that speaks to the larger construct of how science has been done, by whom it has been done, and the research agenda within which it has been conducted must be undertaken to understand the essence of the race relations expressed in the health of all populations.

CLOSING REMARKS—Dr. Freeman

In his closing remarks, Dr. Freeman noted that:

- Albert Einstein observed that “what you see depends on where you stand,” i.e., the perspective from which scientists have approached the scientific investigation of race has been shaped by social and political thought. The discussion today has taken a unique look at the subject of race and has drawn together a diversity of disciplines perhaps unprecedented in American history to discuss this topic.
- Recounting highlights of the day’s presentations, Dr. Freeman expressed his view that as a result of the meeting, the President’s Cancer Panel—charged to identify, analyze and report to the President barriers to the progress of the National Cancer Program—will have the opportunity to bring a unique report to the White House on the issue of race and science.

I certify that this summary of the President’s Cancer Panel meeting on Concerns of Special Populations in The National Cancer Program, The Meaning of Race in Science—Considerations for Cancer Research, held on April 9, 1997, is accurate and complete.

Certified by: Harold P. Freeman Date: 1/28/98
Harold P. Freeman, M.D.
Chair, President’s Cancer Panel

President's Cancer Panel

National Cancer Program

National Cancer Institute

31 Center Drive - Room 4A48

Bethesda, MD 20892-2473

Phone: 301-496-1148

Fax: 301-402-1508

E-mail: PRESCAN@nih.gov

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A solid black horizontal bar located directly beneath the National Cancer Institute text.