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Use of Race and Ethnicity in Public Health Surveillance

Summary of the CDC/ATSDR Workshop

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Contents

PREFACE

This edition of *MMWR Recommendations and Reports* summarizes a workshop that addresses the role of race and ethnicity in public health surveillance. The importance of public health surveillance efforts in assuring the nation's health objectives cannot be overstated. However, because of a lack of consensus when defining and measuring race and ethnicity, public health surveillance systems have been limited. If the Year 2000 Health Objectives are to be met, recognizing and addressing these limitations are essential.

The issues addressed in this report highlight concepts, measures, and uses of race and ethnicity in public health surveillance. Representing the private sector, government and other public agencies, workshop participants assisted CDC and the Agency for Toxic Substances and Disease Registry (ATSDR) in describing, assessing, and improving the use of race and ethnicity in public health surveillance. The involvement of health professional organizations and minority health advocates ensured that relevant "real life" health concerns of racial and ethnic groups were addressed. This report includes summaries of plenary presentations by invited experts. The summaries do not necessarily represent the views or positions of CDC.

The workshop focused on the limitations of the current use of race and ethnicity in public health surveillance, and the problems that persist because of these limitations. Although conceptual alternatives and practical strategies for improvement were recommended, further refinement is necessary. For example, while race may have some biological basis, its significance is mainly derived from social arrangements. Thus, race should be viewed within public health surveillance as a sociological phenomenon. Race and ethnicity are not risk factors — they are markers used to better understand risk factors. For instance, homicide disproportionately impacts African American communities; however, when income status is considered, the impact of homicide in African American communities is similiar to that in white communities.

Finally, there should be further exploration of the full utility of the concept of ethnicity. This term generally has been limited to definers such as surname or language, while ignoring, for example, the importance of historical and sociological experiences.

The recommendations generated from the workshop were developed for CDC/ATSDR and some of them may be used to improve surveillance systems at CDC/ATSDR and in other parts of the Public Health Service. In addition, some of these recommendations may be used to update the 1985 Report of the Secretary's Task Force on Black and Minority Health, as well as in measuring progress in reaching the Year 2000 Health Objectives. These recommendations have been submitted to the Director of CDC for consideration. They are being published in this format to stimulate further discussion. Some of these recommendations may exceed the missions of CDC and ATSDR, may be in conflict with other recommendations, or may be in various stages of implementation. Any comments regarding these recommendations may be sent to me at: Centers for Disease Control and Prevention, Office of the Associate Director for Minority Health, 1600 Clifton Road, MS-D39, Atlanta, GA 30333.

Rueben C. Warren, D.D.S., M.P.H., Dr.P.H.
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Use of Race and Ethnicity in Public Health Surveillance

Summary of the CDC/ATSDR Workshop

Summary

Improvement of the health of racial and ethnic minority populations is a priority for CDC and the Agency for Toxic Substances and Disease Registry (ATSDR). Information on race and ethnicity is a critical element in public health surveillance efforts. To address this issue, CDC and the ATSDR conducted a 2-day workshop, "The Use of Race and Ethnicity in Public Health Surveillance," held in Atlanta on March 1–2, 1993. Workshop participants included CDC and ATSDR professional staff and invited experts from academia and the private sector. Objectives of the workshop were to:

- *Describe the current measures of race and ethnicity and their use in public health surveillance at CDC/ATSDR.*
- *Assess the epidemiologic basis of the use of race and ethnicity in surveillance for planning, operation, and evaluation of public health programs at CDC/ATSDR.*
- *Propose better use of existing measures for race and ethnicity or to identify alternative measures.*

Workshop participants addressed these objectives in small workgroups and summarized the limitations and recommendations regarding concepts, measures, and uses of race and ethnicity data in public health surveillance.

INTRODUCTION

Improvement of the health of racial and ethnic minority populations is a priority of the Public Health Service (*1,2*). This priority was underscored in the 1985 Report of the Secretary's Task Force on Black and Minority Health (*3*), which outlined the magnitude of health disparities among minority populations and proposed approaches to these problems. The 1985 Report is being updated by the Public Health Service Office of Minority Health, and by CDC's Office of the Associate Director for Minority Health and other parts of CDC (*4*). Recently, a Public Health Task Force on Minority Health Data issued a report reviewing data needs for the improvement of minority health statistics (*5*), while CDC's National Center for Health Statistics has awarded grants to develop methodologies to achieve these goals (*6*). In a related activity, the Bureau of the Census (BC) convened in Ottawa, Canada in April, the "Joint Canada-United States Conference on the Measurement of Ethnicity" to review the assessment of ethnic identity.

These activities underscore the critical role of information on race and ethnicity in public health surveillance, and the need for consensus regarding the use of these concepts. Therefore, CDC and ATSDR convened the workshop on "The Use of Race and

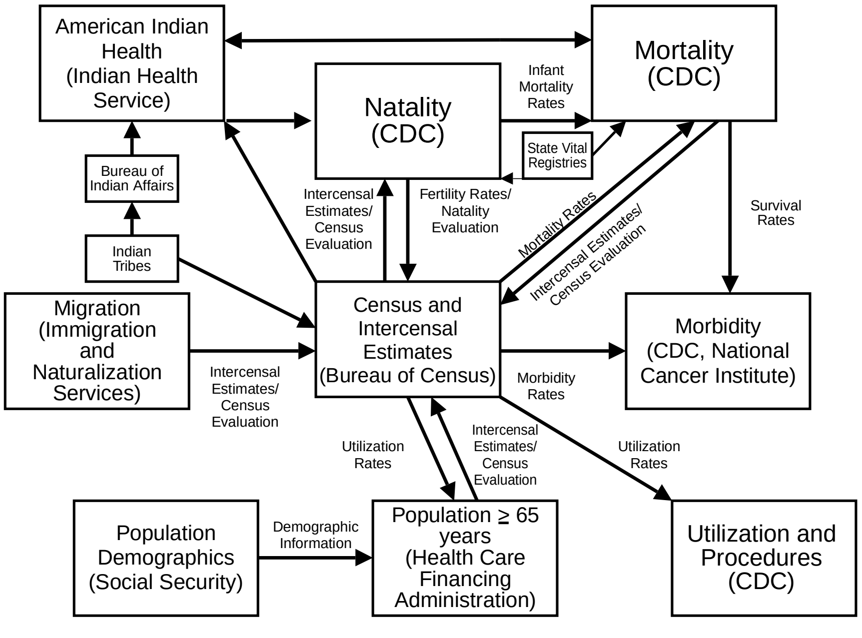
Ethnicity in Public Health Surveillance” held in Atlanta on March 1–2, 1993, to address concepts, measures, and uses of surveillance data on U.S. racial and ethnic populations. Participants in the workshop included CDC and ATSDR professional staff and experts from academia and the private and public sectors. This report provides background on the workshop, briefly summarizes presentations made during plenary sessions, and lists the limitations and recommendations the workshop developed regarding concepts, measures, and uses of race and ethnicity in public health surveillance.

BACKGROUND

The occurrence of many diseases, injuries, and other public health problems is disproportionately higher in some racial/ethnic minority populations in the United States. For example, since 1950, mortality has been reported to be approximately twice as high for black as for white infants (*7*). In the mid-1980s, Mexican Americans were 2.8 times more likely than non-Hispanic whites to be uninsured; and rates of death from unintentional injuries are substantially higher in Native Americans than other U.S. populations (*7*). Findings such as these are based largely on data from public health surveillance (*8*).

The collection of race and ethnicity information has been an important component of public health surveillance efforts used to identify differences in health status among racial/ethnic minorities. Sources for surveillance information regarding the health

FIGURE 1. Interrelations among data sources for health statistics on United States race and ethnic populations



status of the total U.S. population and racial/ethnic groups include state agencies and multiple federal agencies such as CDC, BC, the National Cancer Institute (NCI), the Indian Health Service (IHS), and the Immigration and Naturalization Service (INS) (Figure 1). Categories and types of information collected include births, deaths, population size and migration, disease and injury morbidity, health behavior and attitudes, and health service utilization. Such information may serve administrative, management, legal, research and evaluation, and archival purposes.

Although information is collected by separate agencies, published health statistics are frequently based on data from several sources (Figure 1). Data are combined in three interrelated ways: a) counts from one source may be used in the *estimation of counts* in another source (e.g., birth, death, and immigration records to estimate postcensal populations); b) counts from one source may be used in the *evaluation of counts* in another source (e.g., natality records to evaluate the completeness of census counts); and c) counts from separate sources may be used in the *estimation of combined statistics* (e.g., rates and ratios).

Because federal health statistics are calculated from information collected by different agencies, commensurate data categories and data collection procedures are essential to ensure compatibility. Current principles for the categorization of "race" and "ethnicity" in federal statistics are specified in the Office of Management and Budget's (OMB) Directive 15, "Race and Ethnic Standards for Federal Statistics and Administrative Reporting," developed in 1978 by OMB's Office of Federal Statistics Policy and Standards (*9*). This Directive was intended to standardize data collection and publication among federal agencies and, as required by legislation in 1976, to increase available information on persons of Hispanic origin.

Directive 15 was not developed to define the concepts of race or ethnicity. Instead, Directive 15 and the agencies of the Executive Branch whose data collection it regulates (e.g., CDC and BC) explicitly note the absence of scientific considerations in the designation of categories of race and ethnicity: "These classifications should not be interpreted as being scientific or anthropological in nature, nor should they be viewed as determinants of eligibility for participation in any federal program. They have been developed in response to needs expressed by both the executive branch and the Congress to provide for the collection and use of compatible, nonduplicated, exchangeable racial and ethnic data by Federal agencies." (*9*)

Directive 15 presents brief rules for the classification of persons into racial or ethnic categories, using four defining features: a) descent from "the original peoples" of a specified region, b) a specific cultural origin, c) cultural identification or affiliation, and d) race. For example, "American Indian or Alaskan Native" is defined as "a person having origins in any of the original peoples of North America, and who maintains cultural identification through tribal affiliation or community recognition," while "black" is defined as "a person having origins in any of the black racial groups of Africa."

The validity of health statistics for racial/ethnic minority groups is based on four assumptions: 1) the categories of race and ethnicity and specific racial and ethnic group designations are consistently defined and ascertained; 2) the categories and designations are understood by the populations questioned; 3) survey enumeration, participation, and response rates are high and similar for all populations; and 4) the responses of persons are consistent in different data sources and at different times

(*10*). Evidence suggests, however, that these assumptions frequently are not met—particularly for the American Indian, Asian/Pacific Islander, and Hispanic populations (*10–12*). The cultural diversity and rapid changes in demographics pose further challenges for the surveillance of health status in the United States.

Substantial efforts have been made recently to improve the quality of public health information regarding racial and ethnic populations. In addition to the efforts of the Public Health Service Task Force on Minority Health Data, CDC has made available a linked birth/infant death computer tape and implemented a rule assigning infants the race of their mothers in published statistics that will result in a more consistent classification of infants of all races. Further collaboration by federal, state, and local organizations in the collection, analysis, and reporting of population and health statistics will strengthen public health surveillance of racial and ethnic populations in the United States.

WORKSHOP OBJECTIVES AND AGENDA

The workshop on "The Use of Race and Ethnicity in Public Health Surveillance" was designed to achieve three objectives. These objectives were to:

- Describe the current measures of race and ethnicity and their use in public health surveillance at CDC/ATSDR.
- Assess the epidemiologic basis of the use of race and ethnicity in surveillance for planning, operation, and evaluation of public health programs at CDC/ATSDR.
- Propose better use of existing measures for race and ethnicity or to identify alternative measures.

Before the workshop, participants were provided articles and documents on public health surveillance and current uses of race and ethnicity. Participants were charged to recommend improvements in uses of race and ethnicity data in public health surveillance to assist in redressing the disproportionately poor health status of U.S. minority populations.

Following the plenary sessions — which served to provide background and to raise basic issues — workshop participants were divided into four work groups, which first identified limitations in current concepts, measures, and uses of race and ethnicity in public health surveillance, and then developed and prioritized recommendations to address these limitations. Rapporteurs presented the work group findings in reassembled plenary sessions.

SUMMARY OF PLENARY PRESENTATIONS

Issues in the Use of Race and Ethnicity in the United States

— J. Herman Blake, Ph.D., *Indiana University*

Public health programs and efforts should recognize the importance of the social context in which health problems occur and toward which health programs are directed. For example, by focusing on increasing birthweight in programs designed to reduce infant mortality, public health practitioners may fail to take into account the social environment where a risk behavior (e.g., smoking) is taken for granted. In addition, recognition of the social context is critical when using data on race and ethnicity because such data are never received in a neutral context. Even the term surveillance may have negative connotations because it is associated with police and criminal activity.

A basic public health consideration in the United States is the pattern of exclusion and restriction that has particularly affected blacks, Hispanics, Native Americans, and immigrant populations. Because some members of these and other groups perceive that race and ethnicity data have never been used to their advantage, they may be unwilling to cooperate with data collectors.

Current Use of Race and Ethnicity in Public Health Surveillance

— Donna F. Stroup, Ph.D., M.Sc., Robert A. Hahn, Ph.D., M.P.H.,
Epidemiology Program Office, CDC

Public health surveillance and other health information for the U.S. population and for specific racial and ethnic populations are obtained from state health departments and multiple federal agencies. Collection, analysis, and dissemination of U.S. surveillance data, including notifiable disease reports and vital statistics, are conducted principally by the CDC, the NCI, and the IHS. Data from the BC are also widely used in surveillance. Data are collected on natality, morbidity, mortality, health behavior and attitudes, health service utilization, population, and migration. Many analyses require combinations of data from multiple sources. Therefore, the use of commensurate categories, compatibly defined and collected among different agencies, is critical.

Current principles for categorization of race and ethnicity data are provided in OMB's Directive 15. This Directive was developed to standardize data collection and publication among federal agencies and to increase available information regarding persons of Hispanic origin. However, Directive 15 is not based on scientific principles and does not define race and ethnicity. Because this approach to classification is not based on scientific or anthropologic principles, this system does not meet common scientific standards such as clear definitions and exhaustive and exclusive categories.

Substantial inconsistencies exist in the categorization for race and ethnicity in data collecting and reporting. For example, an assessment of the National Notifiable Diseases Surveillance System, a major source for monitoring trends in vaccine-preventable diseases, indicated that in 1989 only 60% of case reports included information on race and ethnicity (*13*); the accuracy of reported race and ethnicity was not evaluated. Before 1989, natality statistics reported infant race as determined from a complex algorithm incorporating information on the race of both parents. Beginning in 1989, infants have been designated the same race as the mother in tabulated statistics. For mortality, only the race of decedents is collected and data are not available on the race of parents. Funeral directors are responsible for recording race and ethnicity data on death certificates by consulting the decedent's next of kin.

Most rates of health events are calculated with census population estimates as the denominator. Information regarding race and ancestry in the census depends upon self-identification, which may differ from race and ethnic categorization assigned by an interviewer. Differences in terminology, data collection procedures, perceptions of group identity, and changing demographics present particular challenges for surveillance.

Six criteria provide a basis for assessing and improving the use of race and ethnicity in public health surveillance: validity, exclusivity and exhaustiveness, meaningfulness to respondents, measurability, consistency, and reliability.

Validity. The generic categories of race and ethnicity, as well as specific racial and ethnic identifiers, require validation. Data on diverse populations should be aggregated with caution.

Exclusivity and Exhaustiveness. Categories useful for surveillance, such as race and ethnicity, should include all members of a population and should include each member in only one category.

Meaningfulness to Respondents. Perceptions of race and ethnicity may differ among diverse population segments and from the concepts of federal agencies. In addition, segments of the population may object to specific racial or ethnic designations.

Measurability. Even if distinctive genetic markers were available for race, these would not be measurable through routine public health surveillance. The measures developed should have reasonable sensitivity and positive predictive value for surveillance.

Consistency. Inconsistency over time in responses to questions about race and ethnicity may be explained by ambiguous group membership and by changes of individual identity. The surveillance system must be flexible to this change.

Reliability. Surveillance data for different population subgroups can differ by measure and method of data collection. Federal agencies also may use different terms in different collection instruments.

The common tendency to classify self and others as members of a group presents challenges to public health surveillance. The absence of scientific consensus on the nature of race and its relation to ethnicity has created further difficulties for public health surveillance. Although social categorizations may not be scientifically derived, they are important determinants of health status. In addition, the use of a category in public health surveillance may be perceived as an endorsement of its validity and legitimacy and may have an impact on allocation of resources. Given the evolving nature, circumstances, and needs of diverse U.S. populations, categories of race and ethnicity will change. Periodic evaluation of surveillance systems will contribute to the usefulness of information on race and ethnicity and to the improvement of the health of minority populations.

Measurement and Use of Race in Public Health Surveillance

— Nampeo R. McKenney, *Bureau of the Census*

The BC traditionally has addressed race and ethnicity as two separate concepts. Race and ethnicity classifications used by the BC follow federal Directive 15 that directs federal agencies to collect data on at least four racial groups: white, black, American Indian and Alaskan Native, and Asian/Pacific Islander; and one ethnic group, Hispanic. In the 1990 census, all respondents were asked to identify their own race; one possible answer to this question was “Other Race.” All respondents also were asked a separate question about Hispanic origin.

Healthy People 2000 and the Public Health Task Force on Minority Health Data report *Improving Minority Health Statistics,* emphasize the need for additional race/ethnicity data in the health field. This need is especially important because of current and projected increases in U.S. racial and ethnic subpopulations.

Census data and public health surveillance data have been historically interdependent. Census data serve as denominators for birth, death, and morbidity statistics and are used in the design of sampling frames. Public health vital statistics records are essential to BC projections and estimates.

Several factors influence race and ethnicity findings when census data are used as denominators and public health surveillance data are used as numerators. For example, census data rely on self-identification for race and ethnicity, while public health surveillance efforts employ a variety of methods, including direct interview, interviewer’s observation, and reporting by health providers. Although numbers obtained through self-identification and enumerator observation for white and black populations generally agree, there are substantial differences for the other groups.

Although the BC has determined that the questions on race and ethnicity are generally satisfactory, there are six areas requiring special consideration, including identification of race, definitions of Hispanic, consistency of responses, misreporting, overlapping concepts of race and ethnicity, and classification of persons of mixed race.

Identification of Race. In the 1990 census, determining race for three particular groups was difficult: a) those with mixed parentage or the parents of interracial children who wanted to report more than one race; b) persons of Hispanic origin who believed the race question was not relevant to them; and c) persons who were confused because of the inclusion of national origin groups in the race question.

Definitions of Hispanic. Directive 15 defines Hispanic as several diverse groups that share a common language and some common traditions. Not all persons included in this category identify themselves as Hispanic.

Consistency of Responses. Some inconsistency in responses is a consequence of ethnic flux. For example, the increase in the American Indian population during the last two decades exceeds that which can be attributed to natural increase, and probably reflects a shift in self-identification.

Misreporting. Misreporting occurred in the 1990 census because some respondents did not understand the intent or wording of the race question. This occurred especially among Hispanic persons and among persons in the American Indian/Eskimo/Aleut category.

Overlapping Concepts of Race and Ethnicity. Although the BC considers race and ethnicity as separate concepts, some researchers have suggested the need for a question that combines race and Hispanic origin. The 1990 census showed that many Hispanics view themselves as racially Hispanic.

Classification of Persons of Mixed Race. Classification of persons of mixed racial parentage poses a challenge to the programs and data bases that require persons to be classified in one category.

Measurement and Use of Ethnicity in Public Health Surveillance

— Elena S.H. Yu, PhD, M.P.H., *San Diego State University*

Statistical and methodological research is needed on current concepts of race and ethnicity to improve public health surveillance. During the 1990s and beyond, the validity of the concepts of race and ethnicity will become more critical as public health surveillance shifts to monitor individual characteristics and behaviors associated with specific diseases and to accommodate culturally appropriate intervention models. This new focus is important in relation to concerns expressed about existing race/ethnicity classifications mandated by OMB for all federal data collection agencies.

Although the OMB taxonomy has no scientific basis in physical anthropology or human genetics, OMB's Directive 15 has had a substantial impact on the quality and quantity of race data. The use of the four "racial" categories to classify U.S. populations denotes a set of biological characteristics that are heritable, not readily influenced by the environment in a single generation, and are difficult to modify. Directive 15 assumes there is some consensus on the basis for classification, that the categories are understood, and that individual responses to questions are consistent in different surveys and over time. Available evidence suggests the contrary. Other, more subtle and false assumptions that derive from this Directive are: a) that the four racial categories are "naturally" occurring and not arbitrary; b) technology and knowledge of cellular biology and human genetics will provide unequivocal evidence of "genetic" differences among racial groups; c) the differences among racial groups are larger than the differences within each group; d) knowledge of the race to which a person belongs will assist in the control of the spread of disease, implementation of effective public health programs, and improvements in surveillance; and e) the continued demonstration of statistically significant differences between these groups for a variety of outcome measures implies this classification system is valid and reliable.

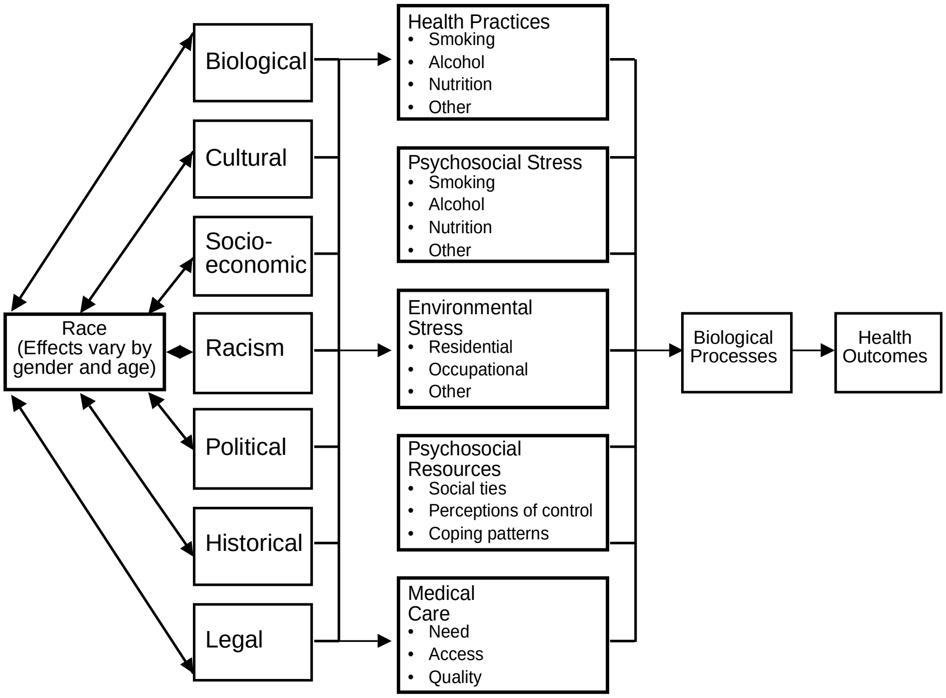
Such assumptions are not supported by the most current technology and knowledge of cellular biology and human genetics. These assumptions also minimize the importance of macro-social issues in unequal access to health care, and divert resources from health and human services in public health surveillance to medical forms of interventions, including genetic therapies.

Race in the Health of America: Problems, Issues, and Directions

— David R. Williams, Ph.D., M.P.H., *University of Michigan*

Understanding the differential distribution of adverse health consequences in racial groups is essential to developing effective solutions to these problems. However, limitations of available racial data preclude a clear understanding of the differential

FIGURE 2. A framework for understanding the relationship between race and health



distribution. For example, racial classification systems are neither clearly defined nor consistently used, and small sample sizes of minority groups produce unreliable estimates that preclude analysis of heterogeneity within racial groups. Failure to adjust for census undercount can distort patterns of disease distribution in particular subgroups; morbidity and mortality rates are overestimated in proportion to the undercount.

Efforts to improve race and ethnic data are constrained by problems such as bureaucratic inertia, statutorily mandated confidentiality requirements, and the potential opposition of advocacy groups. From a policy perspective, an important problem is that the causal dynamics that lead to observed racial and ethnic disparities are largely unknown.

The study of racial differences in the United States has been dominated by a genetic model that views race as primarily reflecting biological homogeneity (e.g., black/white differences in health are largely genetically determined). This model, which has been used to obscure the social origins of illness and demonstrate black inferiority, is based on three scientifically flawed genetic assumptions: a) race is a valid biological category, b) genes determining race are linked to those determining health, and c) the health of a population is largely determined by the biological constitution of the population.

An alternative model is that race is a societally constructed taxonomy that reflects the intersection of biological, cultural, socioeconomic, political, and legal determinants, as well as racism. These determinants of race could be conceptualized as a series of overlapping circles. Larger societal factors—socioeconomic, political, and legal—affect health through intermediary mechanisms and processes, including health practices, psychosocial stress, environmental stress, psychosocial resources, and medical care. These surface causes, in turn, affect health status through biological mechanisms and processes.

At least three important implications can be derived from the multidimensional model (Figure 2). First, even though their contribution to health is likely to be small, genetics and biological factors should not be ruled out. Second, social and economic structures by which groups live can shape values and behaviors in ways that have health consequences. In the United States, the differentials in health status associated with race are smaller than those associated with socioeconomic status as measured by income, education, occupational status, or some combination of the three. Third, the conceptual development of measures of racism and racial discrimination at both individual and institutional levels is needed to understand racial differences in health. According to the multidimensional model, age and gender also must be considered, and the processes by which all these factors relate to each other and influence health status must be understood within a historical perspective.

Additional data are required to better understand racial differences in health status. Failure to address the broader context in which risk factors for disease occur may make risk factor reduction an inadequate way to alter disease outcomes. Therefore, equal access to medical care alone will not eliminate racial differences in health. More deliberate explication of race and ethnicity is needed to chart a new research agenda on racial variation in health.

A Private Sector View of Health, Surveillance, and Communities of Color

— Steve A. Rabin, J.D., *Porter/Novelli Washington*

Major consumers of public health surveillance data include public relations and advertising firms retained by federal, state, and local governments. Private sector clients of these firms have provided important information concerning emerging trends, differentiations, and limitations of data focusing on race and ethnicity.

The U.S. population exhibits a complicated patchwork of behaviors, incomes, and ethnic backgrounds that defies simplistic cultural labeling. This position is underscored by BC statistics that indicate that several million persons in the United States cannot, or will not, describe their race in any of the standard census categories. As a consequence, the private sector has determined that statistical clusters based on geography, lifestyle, behavior, and attitudes provide more reliable profiles than race to guide interventions. Public health statistics compiled on the basis of race may obscure a more important determinant of health—poverty. Ironically, poverty may be an indicator that persons at risk are easy to reach because they have more available time.

Because many marketers historically have considered minorities as disadvantaged, advertising and public relations campaigns overlooked enormous cultural strengths in communities of color—including close family and neighborhood ties, deep religious beliefs, and thriving church communities. Even within the public health community, these strengths have been ignored, while stereotypes have guided programming. However, today's marketing executives engage people of color as national role models to increase sales.

Information that focuses on the similarities between people is essential. Education campaigns that rely on family imagery have an enormous capacity to carry health messages across race and class barriers. Further, a crucial common denominator of health risks in all communities is age. Teenagers may represent the most important risk group in public health. Targeting adolescents can allow community leaders to reach most people of color at risk because they represent a large proportion of the population at risk. Information on sports interests and team loyalties, religious preference, and media habits may also assist in defining and targeting diverse populations to ensure optimal use of limited resources.

Perspective of a Health Scientist: Use of Race in Public Health Surveillance

— Richard Cooper, M.D., *Loyola University*

Race is a biologic concept denoting a single breeding population that varies in definable ways from other subpopulations. However, there is no effective operational definition of race among humans. A logical approach to defining racial identity has been derived from advances in molecular biology. Race as a scientific concept ultimately could be tested by determining the proportion of persons who, based on allele frequencies, could be assigned with an acceptable degree of certainty to a genetically-defined population subgroup.

In practice, the designation of race is based on socially defined phenotypic traits as seen through the filter of individual and social perspective, while ethnicity is a category determined by genes, culture, and social class, a product of social evolution. An advantage of ethnicity (versus race) as a concept for public health surveillance is the implicit recognition of social arrangements on health. Ethnicity is the inevitable response of the species to changing opportunities and challenges in the social environment; therefore, ethnicity will change over time.

Ethnicity may be a more appropriate classification than race for public health surveillance, research, and practice for two reasons. First, the potential impact of population differences in gene frequencies is subsumed under the category of ethnicity. Second, since population groups do not exist in a fixed array, the mutability implied by ethnicity represents a strength of this category. Because the composition of U.S. ethnic groups is changing rapidly, public health surveillance systems must reflect these changes.

Rates of infant mortality and associated risk factors provide one illustration of the usefulness of ethnicity. For example, the incidence of low birthweight and infant mortality vary substantially among Hispanic groups. A complex set of social and historical factors likely explain the stepwise increase in rates of low birthweight among immigrants from Puerto Rico, Cuba, and Mexico. Use of a flexible construct for ethnicity allows disaggregation of rates and identification of important within-group variation.

In comparison to ethnicity, the basic construct used for race in public health surveillance and data collection is limiting. Underlying this construct is a hierarchial view in which race is more fundamental than ethnicity and takes precedence as the basic organizing element. The classification scheme forces all population groups into a category designating biological race, even though dissonant examples persist.

WORK GROUP SUMMARIES

LIMITATIONS OF CONCEPTS, MEASURES, AND USES

CONCEPTS

Current concepts of race and ethnicity in public health surveillance lack clarity, precision, and consensus.

- Race has no clear definition comparable to the “case definitions” of diseases.
- Because most associations between disease and race have no biologic basis, race—as a biological concept—is not useful in public health surveillance.
- Racial categories are too broad to be meaningful. Because of limitations in detail, within-group heterogeneity cannot be recognized, and important differences within racial groups may be masked.
- OMB Directive 15, which determines a minimum set of racial and ethnic categories for data collection by federal agencies, has no scientific basis and has institutionalized poorly conceived concepts and the misuse of race and ethnicity data in public health.
- Distinctions between race and ethnicity are unclear in public health surveillance and these classifications are neither mutually exclusive nor exhaustive.
- Concepts of race and ethnicity may change over time. For example, the increase in those who self-reported as American Indians in the 1990 census may reflect an increased tendency among persons of mixed racial background to claim their American Indian heritage.
- Categories of race and ethnicity may have different meanings for those who collect surveillance information, such as census enumerators or physicians, than for survey participants or patients who must categorize themselves when completing questionnaires.

Emphasis on race and ethnicity in public health surveillance diverts attention from underlying risk factors.

- Race is a marker for many underlying problems of greater relevance to health, including socioeconomic status and cultural behavior–characteristics, which are social and not biological.
- Consideration of race and ethnicity as risk factors rather than risk markers may compromise scientific rigor. For example, race and ethnicity data are often used epidemiologically to explain all variation between groups that remains after controlling for age and gender. Because data on socioeconomic status and income

are not available, associations between race or ethnicity and health outcomes may not be further examined for confounding.

Use of race and ethnicity data in surveillance may reinforce stereotyping, mistrust, and racism.

- The use of race and ethnicity data in public health surveillance may foster stereotyping and stigmatization.
- The collection of data on race and ethnicity may evoke mistrust of data gatherers by persons and grous about whom public health surveillance data are gathered.
- The use of race and ethnicity data fosters an inappropriate "minority model" of public health and health care, suggesting that affected subpopulations are "high risk," "hard to reach," "hard to serve," or "noncompliant."

MEASURES

Different methods of data collection on race and ethnicity result in inconsistencies across data sources.

- Information on race and ethnicity may reflect variations in the methods of different agencies and personnel who collect information, as illustrated by the different approaches of census enumerators, hospital personnel, and funeral directors.
- Discrepancies exist between race and ethnicity as self-reported or observer-reported.
- Data sources often do not measure variables that clarify race and ethnicity.
- Numerator and denominator data from different sources are often combined, even though race and ethnicity may have been determined differently for each source.
- As commonly assessed in federal health statistics, what is measured as "race" may be more accurately ethnicity or self-perceived membership in a population, defined by diverse characteristics.

Race and ethnicity data may be inconsistent because of temporal variations in definitions and responses.

- Race and ethnicity data may change because of changes in the way race and ethnicity are defined by data sources or because of changes in self-perception.

Current broad categories for data collection on race and ethnicity lack sensitivity to variations within groups that are defined in more subtle ways.

- Public health surveillance categories often fail to define subpopulations of interest or relevance. This consideration conflicts, however, with the need for larger groupings to calculate statistically reliable rates. In addition, although data on race may require broad aggregation, data on ethnicity may require excessive disaggregation.

USES

Public health surveillance race and ethnicity data are often not analyzed appropriately.

- Adjustments that are necessary because of errors in estimates (e.g.,population undercounts) often are not made.
- Analysis by race or ethnicity only, without control for confounding variables, may distort or misrepresent complex health risks.
- Data on race and ethnicity are often used as surrogates for socioeconomic status (SES), income, or other predictors that are less readily available.
- Analysis of race and ethnicity data may not take into account the context in which the analysis is to be used. For example, the appropriate use of race in genetic studies may differ from that in setting public health policy.

Public health surveillance data on race and ethnicity are often misinterpreted.

- Associating disease with racial groups may suggest a spurious biologic connection, while confounding effects of other factors are often not made explicit when data are interpreted.
- Misinterpretation of race and ethnicity surveillance data can lead to detrimental social and political consequences for racial and ethnic groups, (e.g., stereotyping, quarantining, and "blaming the victim").

Race and ethnicity data may not be disseminated to affected communities.

- Populations addressed or targeted by surveillance efforts may not be informed of surveillance findings.

Interpreted data on racial or ethnic groups may not be linked with practical action.

- Surveillance findings may not be used in the design, implementation, or evaluation of indicated programs.

RECOMMENDATIONS FOR CONCEPTS, MEASURES, AND USES

The work groups proposed these recommendations for consideration only. Some of these recommendations may exceed the missions of CDC and ATSDR, may be in conflict with other recommendations, or may be in various stages of implementation.

CONCEPTS

Study the concepts of race and ethnicity and prioritize issues in relation to public health surveillance, programs, and research.

- CDC should assemble several work groups to conduct these studies.
- Issues requiring further study include perceptions, identifications, membership affiliation, and concepts of race, ethnicity, and ancestry in the population. In addition, alternatives to the concepts of race and ethnicity as they are now used need to be explored.

Establish definitions for race and ethnicity tailored for specific purposes in public health surveillance.

- Health departments, community organizations, and other groups should participate in developing these definitions.

Improve specificity by adding information.

- Focus on subgroups, especially within those identified racially as blacks, but also within other racial and ethnic groups.
- Add Hispanic as a category for race.
- Because race and ethnicity are imperfect predictors of health status, information should be collected on other variables that would add a dimension of predictive power (e.g., years of education and number of generations a person's family has lived in the United States).

Periodically review and evaluate the definitions and uses of race and ethnicity in public health surveillance systems.

- Maintain flexibility of labels to accommodate changing needs and popular perceptions of group membership.

MEASURES

CDC, BC, other federal agencies, and state and local health departments should coordinate efforts to assure comparability and accuracy of measurements of race and ethnicity.

- Existing measures should be reviewed.
- A monitoring system should be established to ensure consistency and completeness.
- A consistent classification method is needed for people with mixed racial and ethnic backgrounds.
- Data collection forms should be revised to reflect consistent classification methods.

Race and ethnicity data should be compatible across data systems.

- Ensure that methods and definitions for ascertainment of numerators and denominators are comparable.
- In calculating rates, denominators should be adjusted for estimated census undercounts.

Race and ethnicity status should be self-identified using a multiple-choice option.

- Observer-derived measures of race and ethnicity should be eliminated.
- Eliminate, if possible, choice of the category “Other.”

Additional measures of socioeconomic status and social groupings should be developed to avoid univariate analysis of race and ethnicity.

- Adopt formal years of education completed as the best and most practical measure of SES in surveillance.

USES

Collect data on race and ethnicity when the data will be used to improve public health (e.g, to assist in obtaining and targeting resources for affected communities).

- Despite the potential limitations of the categories of race and ethnicity, such information can assist in public health efforts to recognize disparities between groups for a variety of health outcomes.

When possible, race and ethnicity data should be collected and analyzed in relation to potential intervening variables (e.g., socioeconomic status.)

In all reports and other uses of surveillance data, the reason for analyzing race and/or ethnicity should be given, approaches to measurement of race and ethnicity should be specified, and findings should be interpreted.

The limitations of race and ethnicity data should be clearly stated and communicated to persons and organizations using the data.

Conduct analyses to document the effects of racism.

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