

Race and Ethnicity in Public Health Surveillance: Criteria for the Scientific Use of Social Categories

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Synopsis

Public health surveillance is the cornerstone of public health practice. The uses of surveillance include the identification of patterns of health among population subgroups. The assessment of race and ethnicity in public health surveillance is fundamental to the reduction of preventable excesses in poor health among racial and ethnic populations. We review the use of race and ethnic variables in national public health surveillance systems in the United States.

One barrier to the use of race and ethnicity in public health surveillance is the lack of scientific consensus on the nature of race and ethnicity and the measurement of these variables. Differences in terminology, data collection procedures, perceptions of group identity, and changing demographics of the U.S. population present particular challenges for surveillance.

We propose criteria for any useful variables collected through surveillance. Application of these criteria to race and ethnicity suggests that race as assessed in surveillance is not primarily associated with biological characteristics, but it is more like ethnicity—a matter of self-perceived membership in population groups. Regular evaluation of surveillance systems will contribute to the usefulness of information on race and ethnicity in the improvement of the health of minority populations.

IN THE UNITED STATES, several minority populations are reported to bear a disproportionate burden of poor health. Infant mortality has been approximately twice as high for blacks as for whites at least since 1950, Mexican Americans are 2.8 times more likely to be uninsured than non-Hispanic whites, and Native Americans have substantially higher rates of death from unintentional injuries than other U.S. populations (1).

Such reports are based largely on data from public health surveillance: the ongoing, systematic collection, analysis, and interpretation of outcome-specific data essential to the planning, implementation, and evaluation of public health practice, and closely integrated with the timely dissemination of these data to public health practitioners responsible for prevention and control (2). The uses of public health surveillance for infectious conditions have been well documented (3) and have more recently

been recognized for chronic conditions as well (4,5).

The collection of race and ethnic information is a critical component of any public health surveillance system used to address differences in health status among population subgroups. This paper reviews the use of race and ethnicity in public health surveillance. First, we describe the elements of a national surveillance system in the United States, focusing on the use of racial and ethnic categorization. Then we describe general criteria that categories should satisfy to be useful for public health surveillance. Finally, we discuss the application of these criteria in the collection of information on race and ethnicity. Significant strides have been made in the collection of information on racial and ethnic populations. However, challenges remain, including questions of validity, lack of consensus on use, variability in terminol-

ogy, misclassification, undercounting, diversity in popular understanding, and lack of reliability (6).

National Public Health Surveillance Systems

Surveillance and other health data for the U.S. population and for specific racial and ethnic populations are obtained from State health departments and multiple Federal agencies (see figure). Data are collected on natality, morbidity, mortality, health behavior and attitudes, use of medical services, population, and migration. Many uses of these data require the combination of information from multiple sources. For example decennial census, birth, death, and immigration records are used to estimate intercensal populations; census data are used to assess the completeness of natality registration; and survival rates combine information on incidence and mortality.

Because national surveillance relies upon information from multiple sources, the use of commensurate categories, compatibly defined and collected among different agencies, is critical. Current principles for the categorization of race and ethnicity in Federal statistics are given in Directive 15 of the Office of Management and Budget (OMB) (7), developed to standardize data collection and publication among Federal agencies and to increase available information on persons of Hispanic origins. Directive 15 explicitly acknowledges the absence of a basis in scientific principles and does not define the concepts of race or ethnicity. Rather, the Directive presents brief rules for the classification of persons into racial or ethnic categories to ensure consistency across Federal data collection agencies (see box on page 11).

The collection, analysis, and dissemination of surveillance data for the U.S. population, including statistics on race and ethnic populations, are conducted principally by the Centers for Disease Control and Prevention (CDC), the National Cancer Institute (NCI), and the Indian Health Service (IHS). In addition, data from the Bureau of the Census (BC) are used widely in surveillance. We briefly describe examples of surveillance systems and other data systems used for surveillance and discuss their usefulness for assessing the health status of racial and ethnic populations.

Notifiable disease reporting. CDC, in partnership with the Council of State and Territorial Epidemiologists (CSTE), operates the National Notifiable Diseases Surveillance System (NNDSS) to provide weekly information on the occurrence of diseases

that are defined as “notifiable” by CSTE (8). State and territorial epidemiologists (who themselves receive reports from a variety of sources, such as individual practitioners, hospitals, laboratories, and health departments) report cases of 40 notifiable diseases on a weekly basis to CDC. CDC tabulates and publishes these data provisionally in the Morbidity and Mortality Weekly Report (MMWR) and in final form in the MMWR Summary of Notifiable Diseases. The National Electronic Telecommunications System for Surveillance (NETSS) has been developed by CDC and CSTE for collecting, transmitting, analyzing, and publishing weekly disease reports; each NETSS record now includes separate variables for race and ethnicity (9).

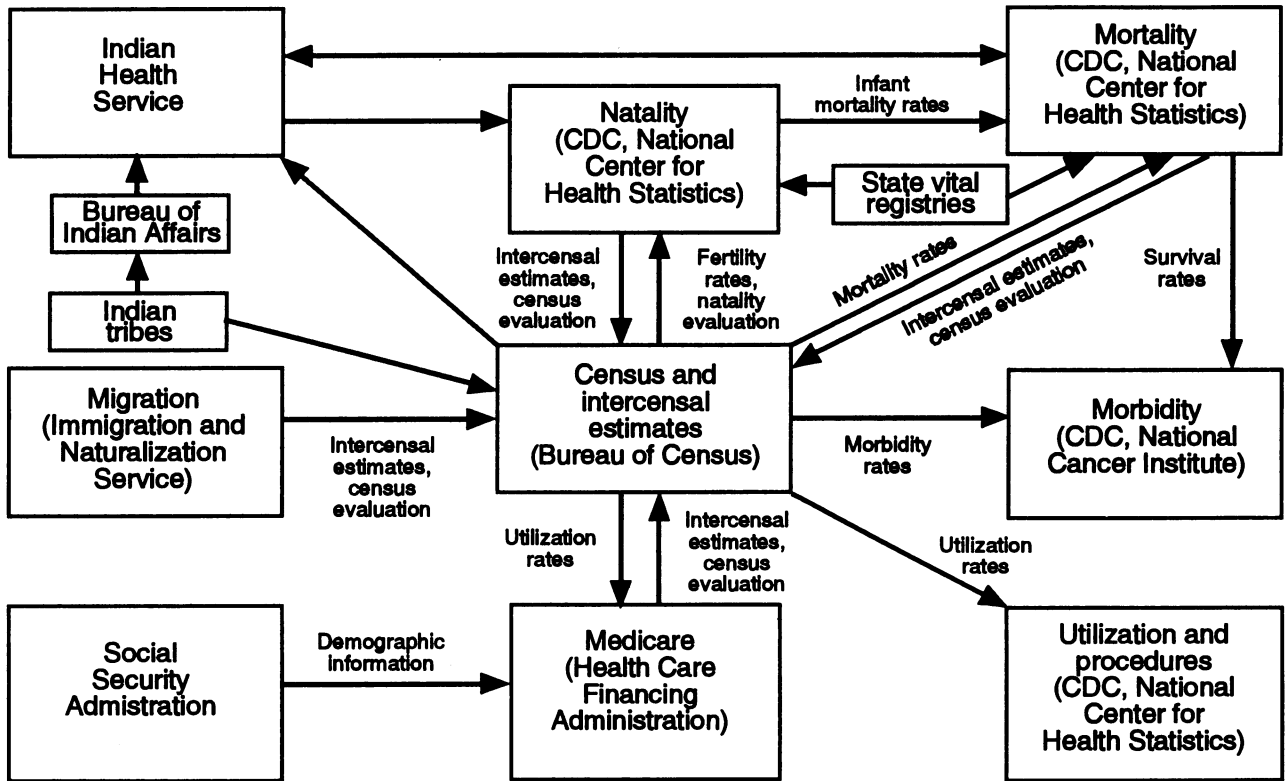
The NNDSS is one source for tracking trends in cases of vaccine-preventable diseases. Recent data indicate mixed trends toward achievement of objectives for immunizations and infectious diseases set in “Healthy People 2000: National Health Promotion and Disease Prevention Objectives” (10). For example, minority children (all groups combined) are less likely to be age-appropriately immunized than are whites (1).

Use of NNDSS data for minorities is limited by incompleteness of reporting of data on race and ethnicity. A 1989 study showed that only 60 percent of cases reported by means of NNDSS included information on race and ethnicity—far less than the proportion reporting age (95 percent) and sex (99 percent) (11). Reporting varied widely by region and disease. For 18 notifiable diseases, a median of only 6 reporting regions included race and ethnicity in at least 90 percent of case reports. Similar results have been found more recently (12). Procedures used to ascertain race and ethnicity (for example, clinician observation or patient self-report) and the accuracy of reported race and ethnicity are unknown.

Except for tuberculosis, AIDS, and several other sexually transmitted diseases, CDC has not routinely published surveillance data on infectious diseases by race or ethnicity until 1993 (13). Reports of disease rates (rather than counts) by race and ethnicity may be complicated by the difficulty of determining compatible population estimates.

Use of vital statistics for surveillance. Surveillance for natality and mortality commonly uses information from birth and death certificates collected locally, at the State, and at the national level by CDC’s National Center for Health Statistics through the Vital Statistics Cooperative Program (14). Geographic coverage for deaths has been

Interrelations among data sources for health statistics on U.S. race and ethnic populations



complete since 1933. This system provides a population-based enumeration of births and deaths and is quite timely at the local level (15). At a national level, estimates from a 10 percent sample are available within 1 year of the end of the calendar year in which the event occurred.

Birth certificate information on race and ethnicity has been used to estimate infant mortality and the proportions of low birth weight infants, infants born to unmarried mothers, and infants born to mothers beginning prenatal care within the first trimester of pregnancy (1). Methods for the ascertainment of parental "race," "Hispanic origin," and "ancestry" on birth certificates are prescribed for physicians and hospital staff (16). Until 1989, the race of an infant in published natality statistics was determined from parental race by a complex race-specific algorithm. In 1989, the algorithm was changed to be the same for all races: the infant's race is that of the mother. Applied retrospectively to births in 1987, the new procedure would "increase" white births by 1.7 percent, while "decreasing" black births by 4.7 percent, American Indian births by 19.2 percent, and Hawaiian births by 29.7 percent (17). An infant's ethnicity has been

tabulated as the same as its mother since this information was first published in 1984.

Mortality statistics have been used to investigate death rates, infant mortality, years of potential life lost, and life expectancy for racial and ethnic subpopulations (1). In published tabulations, the race of decedents is determined by an algorithm that differs from that used at birth; for example, race of parents is not recorded at death. Responsibility for the recording of race and ethnicity on death certificates rests with funeral directors, who are asked to consult the decedent's next of kin for needed information. However, inconsistency in the coding of race and ethnicity at birth and at death for U.S. infants who die at less than 1 year of age suggests that recorders of vital information may not elicit racial and ethnic information from next of kin (18). The practice of death certification by funeral directors is being studied by the CDC.

Surveillance in the Indian Health Service. Surveillance for conditions among Native Americans is conducted by IHS and CDC (1,19). Native Americans are unique in U.S. health care in that, with some restrictions, their race or ancestry is used

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legally to entitle a large proportion of them to a separate system of health care provided by the IHS. However, because Native Americans residing in different settings may identify themselves differently and are likely to have different characteristics (that is, health, behaviors, exposures, and treatments), surveillance findings from these settings also may vary. For example, IHS reports 1986–88 all-cause mortality among American Indians (in reservation States) to be 481.6 per 100,000, while the rate calculable from CDC reports for American Indians in the United States as a whole in the same years is 457.1 per 100,000; cause-specific variation is likely to be greater (20). Recent studies linking IHS with vital and other health records have shown substantial differences in racial classification (21,22).

Use of census data for surveillance. Most rates for health events are calculated using U.S. census estimates of the population as the denominator. Information on race and ancestry has been collected since the first census in 1790 (23). For the most part, current census information on the race and ethnicity of the U.S. population reflects self-identification of both racial and national origin or sociocultural group membership. However, questions of race and Hispanic origin have presented challenges to the BC. For example, a large propor-

tion of Hispanics do not specify a race and, for some purposes, are assigned a race in compliance with OMB Directive 15; race is assigned in proportion to the race of self-identified Hispanic respondents who do specify a race.

Postcensal and intercensal estimates of the population by age, sex, race, and Hispanic ethnicity are routinely made, based on a combination of data from the preceding (and, when available, the succeeding) decennial census and additional information about subsequent (or intervening) births, deaths, and migration. Information on births and deaths is supplied by CDC. Information on older persons is supplied by Medicare, which records race as "white" and "all other races," or as "white," "black," and "all other." Information on immigration derives from the Immigration and Naturalization Service, which does not record race or Hispanic origin. Estimates of the proportions of persons of different racial and Hispanic groups among immigrants from different countries are based on an algorithm.

Criteria for Surveillance Categories

We now propose seven criteria that variables in public health surveillance should meet for effective use.

Conceptual validity. A basic assumption of any scientific discipline, including public health surveillance, is that the categories under investigation are conceptually valid—that there is a real phenomenon to be measured and that the categories used provide substantial explanations of observable phenomena (24). Regarding race and ethnicity, it is important that both *generic* categories of "race" and "ethnicity" and *specific* racial and ethnic identifiers (for example, "white," "black," "Afro-American," "Hispanic," "Latino," and "Chinese") be conceptually validated. Conceptual validation of the generic categories of "race" and "ethnicity" will require review of their scientific status. In particular, validation of "race" in its biological sense would require assessment of whether or not historical patterns of human migration and intermarriage and the distribution of genetic characteristics are indicative of separate and distinctive populations. Conceptual validation of specific categories of ethnicity would require assessment of membership identification, group boundaries, and terminology in different segments of the population.

OMB Directive 15 does not conceptually define

Criteria for Definitions in Federal Statistical Policy Directive No. 15—Race and Ethnic Standards for Federal Statistics and Administrative Reporting

Definitional criteria				
<i>Racial or ethnic group</i>	<i>Original people of—</i>	<i>Cultural origin¹</i>	<i>Cultural identification, affiliation²</i>	<i>Race³</i>
<i>Races</i>				
American Indian, Alaska Native	North America		Yes	
Asian/Pacific Islander	Asia, Pacific Islands			
Black	Africa			Black
White	Europe, North Africa, Middle East			
<i>Ethnicity</i>				
Hispanic	Mexico, Puerto Rico, Central or South America, other Spanish countries	Mexico, Puerto Rico, Central or South America, other Spanish countries		

¹ Used only to define Hispanics.
² Used to define American Indians and Alaska Natives.
³ Used only to define blacks.

race or ethnicity and notes the absence of anthropological or other scientific considerations in its designations. Federal agencies (including CDC) are not consistent in their terminology for either generic concepts of race and ethnicity (for example, “race,” “ancestry,” “national origin,” and “ethnicity”) or for specific categories (for example, American Indian, Hispanic). For example, the category prescribed by Directive 15 “American Indians” is labeled “Indian (Amer.)” in the 1990 census and is listed separately from Eskimos and Aleuts; in natality documents, the category “American Indian” includes Aleuts and Eskimos; and in mortality documents, the category, “Indian” (or, beginning in 1987, “American Indian”) includes American, Canadian, Eskimo, and Aleut (25–27).

Aggregation of data on diverse and distinctive populations should be done with caution. For example, the recent “Atlas of U.S. Cancer among Nonwhites: 1950–1980” (28) combines data for all “nonwhite” populations. This generic categorization limits the use of the atlas for etiologic research and for the design and implementation of targeted intervention programs.

Measurability and measurement validity. In addition to conceptual validity, another criterion basic

to many scientific disciplines, including public health surveillance, is the measurability and measurement validity of categories under investigation; that is, the procedures used to collect information should actually measure the phenomenon of interest (24). Any measures chosen should have reasonable sensitivity and positive predictive value in surveillance (29). For biological categories, public health surveillance should assess measurable biological characteristics known to be associated with populations of interest. On the other hand, for categories defined by self-perception, effective surveillance must assure that self-perception, though subjective, is accurately assessed. Accurate assessment of self-perceived characteristics depends on rapport with surveillance subjects and on use of appropriate concepts, language, and cultural etiquette.

Exclusivity and exhaustiveness. To be useful in surveillance, categories of a variable must be exhaustive (that is, include all members of a population) and mutually exclusive (include members in only one category). The categories of Directive 15, (“American Indian or Alaskan Native,” “Asian or Pacific Islander,” “Black, not of Hispanic Origin,” “Hispanic,” and “White, not of Hispanic origin”) are neither exhaustive nor exclusive

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(30,31). For example, an American Indian or Alaskan Native is defined by regional origin and cultural identification (that is, "A person having origins in any of the original peoples of North America and who maintains cultural identification through tribal affiliation or community recognition"). A black is defined by regional origin and race (that is, "A person having origins in any of the black racial groups of Africa"), while whites are defined by regional origin only. Such definitions leave the status of certain groups unclear (see box). For example, descendants of the original people of North America without "cultural identification or affiliation," or blacks (however defined) not of African origin are not defined by the Directive. In addition, the growing proportion of persons of mixed parentage may complicate classification.

Meaningfulness to respondents. The design, interpretation, and use of surveillance information for different populations requires knowledge of how the surveillance categories, such as "race" and "ethnicity," are understood by survey respondents. This requirement is a complement of conceptual validity, since valid categories should be understood by surveillance respondents. While the understanding of race and ethnicity in segments of the U.S. population has not been comprehensively explored, there are indications that terminology and concepts of group memberships among diverse population segments differ from each other as well as from the concepts of Federal agencies that collect the information (32,33). For example, more than 40 percent of the self-identified Hispanic population did not respond to the race question on the 1990 census; this suggests that concepts of race and ethnicity among Hispanics may differ from those of census takers (34,35). The Bureau of the Census' "Ethnographic Census Evaluation Research Program," designed to address undercounting among minority ethnic populations, has pro-

duced critical insights in the understanding of the census process by racial and ethnic populations.

Internationally, the variety of racial, ethnic, and other ancestral classifications used complicates comparison (36). Perhaps for this reason, the World Health Organization does not record race or ethnicity in its international health statistics. As of 1977, a U.N. survey found that ethnic or national group was recorded on birth certificates in only 18 (20.5 percent) of 88 nations and on death certificates in only 16 (18.4 percent) of 87 nations (37).

Reliability. A fundamental characteristic of a scientifically useful category is the replicability of results—the ability to gather consistent information in different settings with comparable methods. In reporting of diseases in NNDSS, for example, case definitions have been developed to facilitate comparison of data across different reporting sites (38). For purposes of public health surveillance, racial and ethnic classification for population subgroups should be identical when measured with different instruments at reasonably similar times.

Problems in reliability for the classification of race in vital records are indicated in a study using the linked infant birth-death tape to compare the race assigned for tabulated statistics on the birth and death certificates of all U.S. infants born from 1983 through 1985 (18). Of infants classified as white at birth, 1.2 percent had a different race at death, 4.3 percent of black infants at birth had a different race at death, and 43.2 percent of infants of other races had a different race at death. Thus the reliability of race in infant vital records was lower for races other than white and was lowest for minority infants other than blacks. This examination indicated, for example, that infant mortality was 1.52 times higher among American Indians than among whites, a ratio 44.8 percent higher than that based on published information (1.05) in which infants may be assigned a different race at birth and at death. Similar results have been found in the classification of race at the death of adults (39).

Other studies have examined reliability in the classification of race and ethnicity in the census. For example, in March 1971 and again in March 1972, the Bureau of the Census interviewed a large sample of persons in U.S. households, eliciting the ethnic identity of all household members; from 1 year to the next, 34.3 percent of household members were reported to have different ethnic identities (40). In another study, comparison of five indicators of self-reported Hispanic identity pro-

duced estimates of the Hispanic population from 5.2 million (persons of Hispanic heritage) to 9.6 million (persons using Spanish language) (41). Furthermore, 41 percent of persons who identified themselves as American Indian in the 1980 census had also reported themselves as white (42). Low reliability in racial and ethnic classification has been explained in part by the phenomenon of "fuzzy group boundaries"—ambiguity about the criteria of group membership (41). Federal agencies have not always used the same procedures (for example, self-report, observer determination, hospital records [with unspecified sources], report by next of kin) to collect information on the racial or ethnic identity of individual persons.

Consistency. Consistency of classification over time is fundamental to the use of surveillance for the analysis of trends. However, responses to questions about "race" and "ethnicity" may not be consistent (41). Inconsistency may be due to "shifting identity"—persons changing their group identity over time—in addition to "fuzzy group boundaries." For example, demographic projections by the Bureau of the Census have underestimated the American Indian population by as much as 35 percent in the last three decades, perhaps due to both of these causes (43). A similar shifting perception of identity has been found in other race and ethnic groups (44).

Flexibility. For self-perceived categories, concept and terminology may change over time. Changing self-perception may explain demographic underestimates of the American Indian population (43). Public health surveillance of "racial" and "ethnic" health status must be sensitive and responsive to such changes. The criterion of flexibility conflicts with that of consistency. The public health practitioner must balance the need for consistency in responses over time with the need for meaningfulness of the terminology to respondents. Federal agencies have demonstrated an ability to adapt to changing conceptions of racial and ethnic group membership. For example, terminology has been modified from "colored" to "Negro" to "black," and diverse Hispanic terms have been added to data collection systems to reflect the growing Hispanic population.

Discussion

Social classifications such as "race" present five critical challenges to public health surveillance.

First, categories such as race and ethnicity have been and continue to be important determinants of access to societal resources. Individuals may seek to establish their membership in one plausible ancestral group in order to receive its benefits, while others attempt to restrict the membership of the same individuals in this group. Membership in different racial and ethnic groups also bears important social and symbolic meaning. For these reasons, the determination of racial or ethnic membership is not a simple matter of measurement. Because scientific use of a social category may be interpreted as endorsement of its validity, the use of these categories is not only a matter of scientific method, but also of policy and ethics (45).

Second, although popular categories of race and ethnicity may not be scientifically derived, they have been and continue to be important determinants of health status. Thus, practitioners of public health surveillance have no choice but to consider these categories.

Third, there is a lack of clear consensus in the scientific community about the validity of concepts of race and ethnicity, particularly about the biological basis of race (46–48). What is *measured* as "race" in public health surveillance is not a biological characteristic, but rather a self-perception for which phenotypic characteristics may be one among many criteria. As measured, "race" is similar to ethnicity, that is, self-perceived membership in a population defined by multiple, diverse features. (While others may also classify a person's ethnicity, they may or may not be correct in their conclusions; the principal criterion of ethnic membership is a person's self-perception.)

In the study of genetic associations of disease, biological characteristics should be appropriately measured. For purposes of public health surveillance, however, it may be reasonable to consider assessing one phenomenon, "race/ethnicity," or simply "ethnicity" rather than two. Even were distinctive biological markers of race determined, it would be difficult, if not impossible, to assess such markers in common surveillance processes and in the census.

Fourth, it is possible that racial, ethnic, and other forms of ancestral identification are not amenable to the standard scientific criteria that apply to characteristics such as age, weight, and sex. Numerous studies indicate that persons may have several racial and ethnic identifications and that their identification may change over time and across circumstance. It may be that race and ethnicity have essentially "fuzzy boundaries" and

that mutual exclusivity does not hold. "Fuzzy logic" might apply (49), and the assessment of basic epidemiologic rate measures might be difficult, if possible.

Fifth, given the evolving nature, circumstances, and needs of diverse ancestral populations in the United States, categories of race or ethnicity, or both, will change. Any surveillance system that measures the size and health of these populations must adapt to demographic circumstances by regularly assessing how population segments conceive of themselves. We may need to reconsider the comparison of racial and ethnic statistics over time; comparison will require an understanding of the social conditions of racial and ethnic populations. Flexibility of the system may require compromises in the consistency of categories.

Perhaps because of these challenges, standard scientific criteria have not been systematically applied to the categories of race and ethnicity in public health surveillance. The categories used are not always exclusive or exhaustive. Generic and specific terminology varies among and within agencies, and the understanding of terms by the population surveyed has not been systematically assessed. Consistent measurement procedures have not been widely examined or agreed upon, and have produced unreliable results. And, although the terminology used in surveillance has responded to some currents in popular thought, it has not always been flexible to substantial demographic changes.

Public health professionals pay keen attention to case definitions in their epidemiologic investigations and in the practice of public health surveillance. We propose that comparable attention be paid to demographic characterization of the persons among whom those cases are found. It is critical that researchers of "racial" and "ethnic" populations clearly formulate the purposes of their studies, that they define the methods by which their information is collected, and that they appropriately interpret their findings. The further development of public health surveillance of racial and ethnic populations will be enhanced by an exploration of common scientific criteria and, where appropriate, their application to these categories.

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