

# Assessing Race, Ethnicity and Gender in Health

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# Prologue

American studies are five times more likely than European trials to report in publications the race or ethnicity of the study participants (Sheikh, Netuveli, Kai, and Panesar, 2004). In a review of full-length articles appearing in three major pediatric journals, for instance, it was found that over one-half of the published reports contained data on participants' race and/or ethnicity (Walsh and Ross, 2003). Nearly 80% of hospitals in the United States collect data on race and ethnicity (Runy, 2004). Despite the relatively high prevalence of collecting and reporting race/ethnicity information, however, significant debate continues regarding the wisdom of this practice. The following objections have been voiced with regard to the collection and use of data relating to race and ethnicity.

- The categories once used are inadequate and categories change too frequently to make the collection of the data worthwhile. As an example, during the period from 1990 to 2003, hospitals in Rhode Island utilized three different classification systems for the collection and recording of race and ethnicity data (Buechner, 2004).
- Categories that we construct may not be valid due to intermarriage. The most recent census data indicates that over 2% of the American population, or more than 7 million persons, now acknowledge a multiracial identity (Ahmann, 2005). Children were more likely to be recorded as having a multiracial identity than adults, which suggests an increase in interracial coupling.
- Data collection based on self-reports is not valid because individuals change their self-identification depending upon the context in which they are asked to so designate (Kaplan and Bennett, 2003).
- Individuals grouped into the same category demonstrate significant genetic diversity, so that the construction of the categories is questionable (Erickson, 2003; Schultz, 2003). There are no gene variants that are present in all individuals of one population and that are absent in the individuals of another population group (Bonham, Warshauer-Baker, and Collins, 2005). For instance, Wilson and colleagues (2001) found in a study of drug-metabolizing enzymes and genotyping in eight populations around the world that genotypes clustered into four groups,

but the four groups did not correspond to the populations from which they had been drawn.

- Categorizations are too broad to have any definitive medical meaning (Schultz, 2003) and may obscure heterogeneity within groups (Kaufman, 1999; Williams, 2001). Gatrad and Sheikh (2000) have cautioned health care providers to refrain from making assumptions about patients' willingness or unwillingness to undergo particular screening tests or elective procedures on the basis of their ethnicity.
- Socially determined categories cannot be applied to biological science (Schultz, 2003).
- Classifying individuals on the basis of socially constructed categories of race and ethnicity serves to reinforce racial and ethnic divisions that already exist (Azuonye, 1996; Bogue and Edwards, 1971; Fullilove, 1998; Stolley, 1999).
- The categories developed for race and ethnicity are often used to compare minority groups to the majority population and these comparisons often focus on the negative aspects of the health and lives of minority group members (López, 2003).
- A focus on ethnic or racial groups may lead researchers to believe or encourage them to disregard relevant social or cultural processes that are shared across group boundaries (Garro, 2001).

Additional concerns have been voiced with regard to the assessment of acculturation level and immigration status, two constructs that are relevant to race and ethnicity.

- Categories of immigration status change too frequently to be useful over time. As an example, attempts to assess immigrants' utilization of publicly funded health care for specific services must be cognizant of the fluctuations in participants' eligibility for benefits as a result of changes in their immigration status and/or changes in the relevant legislation (Loue, Cooper, and Lloyd, 2005).
- Self-reports of immigration status will be inaccurate, if they are provided, due to fears of deportation.
- Questions relating to immigration status will result in poor recruitment and retention due to fears of the consequences that might ensue following disclosure.

Similar objections have been raised to the collection of data relating to sexual orientation and sexual identity:

- Sexual orientation and/or sexual identity are fluid over a lifetime and assessment at one point in time may be inaccurate.
- How an individual chooses to identify him- or herself may not be reflective of his or her true orientation because of concern about the consequences of self-disclosure and, accordingly, collection of this information is not valuable.
- Assessment of sexual orientation tends to compare homosexuals and heterosexuals, with the resulting inference that homosexuality is somehow "less than" or "worse than" or undesirable.

Indeed, with respect to any or all of these variables, there is little consensus among researchers as to how categories should be defined or who should be assigned to them. And, in view of such vociferous displeasure with the collection and recording of these variables in the context of health care and research, one must necessarily question why it is done.

Hospitals have been found to collect these data in order to meet the requirements of a law or regulation, to improve the quality of care, to ensure the availability of interpreter services, to improve or maintain community relations, to assist in targeting marketing efforts, and/or because it is perceived as beneficial (Runy, 2004). Pediatric researchers have reported collecting and reporting race and ethnicity data because it was required by the institutional review board of their institution, the National Institutes of Health, and/or the peer-reviewed journal in which they wished to publish; to conform to a tradition of reporting race and ethnicity data; to better describe the study population; and/or because they believed that it was relevant (Walsh and Ross, 2003).

Scholars have suggested other reasons underlying the necessity for the collection of data relating to race and ethnicity (Mays, Ponce, Washington, and Cochran, 2003). These reasons are relevant, as well, to data regarding sexual orientation.

(1) To describe vital and health statistics. These data provide information that can be utilized by public health programming and planning to develop programs targeting specific health issues of concern in a manner that is appropriate to the affected communities.

(2) To identify risk indicators for specific health outcomes. It has been argued that ethnicity itself constitutes a risk factor for specific diseases, such as Tay-Sachs, which occurs predominantly in individuals of Eastern European Jewish descent (Greenidge, 2004). Alleles associated with sickle cell anemia are not evenly distributed across racial/ethnic groups, but are found more frequently in African-American populations (Collins, 2004). The risk factor profile for breast cancer among African-American women has been found to differ from that of white women, although the underlying mechanisms of these differences require further investigation (Bernstein, Teal, Joslyn, and Wilson, 2003).

(3) To improve the delivery of health care services (Hasnaian-Wynia and Pierce, 2005). Nonwhite patients have been found to rate the quality of and their satisfaction with their health care lower than do whites (Haviland, Morales, Reise, and Hays, 2003). To some extent, this difference may be attributable to disparate treatment by health care providers associated with differences in patient self-identified or perceived race or ethnicity (Bach, Pham, Schrag, Tate, and Hargraves, 2004; van Ryn and Burke, 2000).

(4) To identify markers of unmeasured biological differences. Researchers have reported slower metabolism of some drugs in persons of Asian ethnicity, compared to white and blacks (Meadows, 2003). It has been hypothesized that this difference may be attributable, in part, to genetic factors that have not yet been identified.

(5) To identify proxy variables for unmeasured social factors. Race, ethnicity, sex, and sexual orientation may serve as markers for other variables that we are unable

to identify due to limitations in our knowledge and/or the methodologies available to us.

Accordingly, if we are to collect these data, we must confront and address numerous challenges. These include issues of operationalization of these constructs in a manner that is appropriate to the research question and the study and target populations, measurement, and sampling. Ethical issues are also raised by our construction of these categories that must be addressed if we are to remain respectful of the communities with which we work.

This text addresses many of these issues. Part I focuses on the foundations underlying the development of these categories and brings to the fore important ethical and methodological issues in their construction and their use. Part II provides a review of the literature that offers definitions of these constructs and their use in health research. Examples of research that has relied on categories of race, ethnicity, and/or sexual orientation are provided, with commentary that discusses the appropriateness of their use and the conclusions that were drawn as a result. The final portion of the text provides a summary of many measures currently available to assess race, ethnicity, sexual orientation, and related constructs.

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