

How Do We Fill the Data Gaps?

By Olivia Carter-Pokras, Ph.D., Director, Division of Policy and Data
Office of Minority Health, U.S. Department of Health and Human Services
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Advocacy groups working to improve the health of racial and ethnic minorities have long recognized that without that data to document a health problem, it is difficult to draw policy-makers' attention and acquire the resources needed to tackle the problem. As Dr. Nancy Krieger from Harvard University has stated, "If you don't ask, you don't know. If you don't know, you can't act."

Healthy People 2000 provides an excellent illustration. When the objectives were released in 1990, many problems long recognized by affected communities, like low birth weight among Puerto Ricans, were not included. In some cases, data had been released too late to be used. In other cases, data had been collected but not analyzed. These, along with more recent data, were used during the 1995 mid-course review to develop new objectives for racial and ethnic minorities. This more than doubled the number of objectives for minorities. Even so, important health problems were still not addressed during the review. There were several reasons: (1) data may have never been collected from a national data system, (2) national data systems may have had insufficient numbers of a particular group to make reliable estimates (e.g., overweight among Native Hawaiians), (3) Puerto Rico, the U.S. Virgin Islands and the U.S. Pacific Insular areas generally are not included in national data systems, and (4) for the most part, only racial and ethnic minority groups with a documented disparity versus the total population were included.

The lack of data is likely to have had a negative impact on availability of resources. Dr. Moon Chen, editor of the *Asian American and Pacific Islander Journal of Health*, examined NIH funding and Healthy People 2000, and reported that NIH was much less likely to fund AAPI health problems that were not targeted by Healthy People 2000. All Public Health Service grant announcements refer to Healthy People 2000 objectives.

Several actions have been taken to address these problems. During the mid-course review, data from several national data systems were analyzed by race and ethnicity for the first time. Several years of data from national databases such as the National Health Interview Survey and the National Vital Statistics System were combined to provide estimates for relatively smaller racial and ethnic groups. In October 1997, the Secretary of HHS issued an inclusion policy for racial and ethnic data in HHS data systems. A first for the entire Federal government, this policy requires that data systems funded and maintained by HHS collect racial and ethnic data, and requires that the Federal standards for racial and ethnic data (OMB Directive No. 15 and its successor) be followed.

In July 1998, the National Committee on Vital and Health Statistics (NCVHS) convened a public hearing on health data needs for Puerto Rico, U.S. Virgin Islands and the U.S. Pacific Insular areas. NCVHS will make recommendations this Fall to the Secretary on how to address the health data needs for these geographic areas.

To support the proposed goal of eliminating disparities for Healthy People 2010, draft Healthy People 2010 objectives follow the Federal standards for racial and

ethnic data. For objectives for which this recommendation is adopted, data will be presented for all racial and ethnic groups, whether or not there is a disparity with the total population. Not only will this identify missing data for racial and ethnic minorities, but will vastly improve access to the data by advocacy groups.

Despite this progress, data issues still remain for racial and ethnic minorities. Relatively smaller groups such as American Indians, Alaska Natives, Native Hawaiians and other Pacific Islanders, and certain subgroups of Asian Americans and Hispanics will still be represented in insufficient numbers by data systems designed to provide estimates for the total United States population. Estimates based on data systems which do not routinely use self-identification to collect racial and ethnic data (such as mortality data) may significantly underestimate the burden of disease, disability and death for certain racial and ethnic groups.

The change in Federal standards for racial and ethnic data will affect the monitoring of Healthy People 2010 objectives. After five years of research, public comment, and Congressional hearings, the Office of Management and Budget released its revision of the Federal standards for racial and ethnic data (OMB Directive No. 15) in October 1997. This revision is to be implemented by Federal agencies by January 1, 2003. Due to the usual time lags in collection and analysis of national data, baselines for Healthy People 2010 objectives will likely be from the mid-1990's, when OMB Directive No.15 was used.

The new standards for racial and ethnic data recommend that self-identification be used where possible, allow persons to report more than one race, and recommend that Hispanic ethnicity be asked as a separate question from race. Based on previous research, it is expected that 1-2 percent of the population will report more than one race. Guidelines for the implementation of the new standards for racial and ethnic data—including comparisons of data collected using the old and new standards—are now being developed by OMB.

Developmental objectives are proposed for Healthy People 2010. These are objectives that lack any national baseline data, but are important topics to measure over the next decade. As plans for data collection begin, a concerted effort should be made to collect these data by the new OMB standards.

A final issue is how racial and ethnic data are used. OMH encourages readers to help ensure that the right questions are asked, that our data systems are adequately funded, and that the data are appropriately used. Racial and ethnic data are descriptive and do not get at the underlying reasons behind the disparities. Additional information on socioeconomic status, program participation, behavioral risk factors, cultural differences, birthplace/generation, and the effects of racism and discrimination are needed. Our ability to monitor the health of the nation, including the health of our most vulnerable, is dependent on the strength and breadth of our data systems. ❖



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