Background
Americans receive health care services that are in sync with the latest scientific evidence only about half the time. Studies also find that racial and ethnic minorities in the U.S. receive a lower quality of care than non-minorities and are at greater risk for certain diseases. There is widespread agreement that valid and reliable data are fundamental building blocks to identifying differences in the care experienced by specific populations, to developing programs to address differences, and to ensuring a higher standard of care. To date, national studies have identified very few providers or institutions that address disparities in care using a data-driven, quality improvement approach.

In 2003/04, America’s Health Insurance Plans (AHIP) collaborated with The Robert Wood Johnson Foundation (RWJF) to survey health insurance plans about the extent to which they collect and use data on the race and ethnicity of their enrollees to improve quality of care. The primary objectives of the survey were to: 1) assess the extent to which health insurance plans collect these data (including primary language); 2) highlight barriers to the collection of these data; and 3) identify health insurance plans interested in potential future collaborations.

Collection of Data on Race and Ethnicity
Over half of all enrollees (53.5%) are covered by health insurance plans that responded to the survey and collect these data. There are two ways to collect these data: either directly from enrollees on a voluntary basis or indirectly using geocoding software or other proxies.

- The most common methods used to collect those data directly from enrollees are during plan enrollment (74.1%) and/or when an enrollee participates in a special program, such as disease management or health education programs (35.4%).
- Of the plans that indicated they collect these data indirectly, 38.5% use geocoding software to assign a proxy for race and ethnicity categories and 40.1% obtain data through files linked to external sources, such as Federal agencies or birth records. Nearly all plans that collect data on race and ethnicity use the six most common categories — African American, Asian American, Native American, Pacific Islander, Hispanic, and White — while 22.3% indicated that they include a category for multiple race/ethnicity, for example, African American and White.

Collection of Data on Primary Languages
In the absence of information on race and ethnicity, it is not uncommon to use primary language as a proxy for such information. Just over half of enrollees (56.4%) are covered by plans that responded to the survey and collect data on the primary language of their enrollees.

- The most common primary languages spoken by enrollees (other than English) include Spanish (96.7%), Chinese (76.2%), Korean (72.8%), and Vietnamese (49.1%). For plans that collect primary language data directly from enrollees, it is most commonly collected via the plan enrollment form (80.9%).
- Of the plans that responded that they collect language data indirectly, 27.8% use geocoding software to assign a proxy and 22% obtain data through files linked with an external source.

FAST FACTS
The 137 plans that responded to the survey represent 88.1 million Americans enrolled in health insurance plans across the U.S. All percentages are weighted by enrollment to reflect the experiences of health insurance plan enrollees.

Among health insurance plans that responded to the survey:
- Over half (53.5%) of enrollees are covered by plans that collect data on race and ethnicity.
- Among plans that collect data on race and ethnicity directly, 74.1% collect data on race and ethnicity during plan enrollment.
- Over half (56.4%) of enrollees are covered by plans that collect primary language data on their enrollees.
  - 80.9% collect information on primary language during enrollment.
- 65.2% of plans collect language data on their providers.
- 64% of plans collect language data on their customer service staff.
- 49.5% of plans that collect language data on their key staff publish the data in the provider directory.
Effective Use of Data
The most important reasons cited by health insurance plans for collecting these data were to identify enrollees with risk factors for certain conditions, reduce disparities identified in quality measures, assess variation in quality measures by racial and ethnic groups, and identify the need for translation materials.

In addition, plans indicated they use information on primary language to determine the need for interpreters and translation of materials, such as summary plan descriptions, directions, health education materials, and benefit materials.

Barriers to Collecting Data on Race and Ethnicity
Approximately forty-six percent (46.5%) of enrollees are covered by health insurance plans that stated that they do not collect these data. The most frequently cited reason for not collecting these data was concern about enrollees’ reactions. Other important factors contributing to plans’ decisions not to collect these data included concerns that state laws or regulations prohibit collection of such data; the belief that the collection of such data is not common in their markets; and the belief that good or reliable methods for data collection are lacking. A review of Federal and state laws showed no federal statutes prohibit the collection of these data and only four states (California, Maryland, New Hampshire, and New Jersey) that have laws or regulations barring health insurance plans from collecting these data.

Collection of Data on Providers
Health insurance plans are less likely to collect these data on their providers than they are about their enrollees. Approximately one-quarter of enrollees (24.5%) are covered by plans that collect these data about their providers. The most common methods for distributing this information to their enrollees are through health plan web sites (67%) and provider directories (26.6%). Plans are more likely to collect information on the primary language of their providers and other key staff that interact with enrollees, as this information is important for effective communication between the provider and the enrollee.

About the Survey
AHIP and RWJF collaborated on the 2004 AHIP/RWJF Collection of Racial and Ethnic Data by Health Plans Survey to obtain information on how health insurance plans collect and use data on race and ethnicity on their enrollees. A collaborative approach was used to develop a web-based survey instrument consisting of 57 questions. A stratified sample of 302 health plans was drawn from the universe of health insurance companies in the United States. The final sample of 302 health insurance plans included 135 commercial, 110 Medicaid, and 57 Medicare plans. Of the 302 health insurance plans in the combined sample, 34 refused to participate, 131 did not respond, and 137 (45.4%) completed all or some survey questions. When weighted by enrollment, these 137 health insurance plans represent 88.1 million covered lives. All percentages are weighted by enrollment to reflect the experiences of health insurance plan enrollees. For additional information about the survey, contact Deborah Wheeler, Deputy Director, Quality Initiatives and Industry Standards, Medical Affairs, at 202-778-3272 or dwheeler@ahip.org.