AHIP
America's Health Insurance Plans

Tools to Address Disparities in Health: Data as Building Blocks for Change

A Data Collection Toolkit for Health Insurance Plans/ Health Care Organizations

Tools to Address Disparities in Health: Data as Building Blocks for Change

A Data Collection Toolkit for Health Insurance Plans/ Health Care Organizations

Funding for this toolkit was provided by Pfizer Inc

AHIP

Preamble

Numerous studies document the extent to which health and health care disparities affect racial and ethnic minorities. The Institute of Medicine (IOM), for example, found that racial and ethnic groups receive lower quality of care and needed services than non-minorities even when factors related to access to care are controlled.[i] The Commonwealth Fund also has demonstrated how race, ethnicity, and English proficiency can affect access to quality health care.[ii] Although these and other studies provide substantial evidence about existing disparities, little is known about the most effective interventions and strategies for closing these gaps in health care.

There is widespread agreement, however, that the collection of valid and reliable data is a fundamental building block for health insurance plans/health care organizations, in collaboration with key stakeholders, to identify the variations and gaps in care experienced by diverse populations and those individuals at risk for certain conditions. Through the collection of these data - race, ethnicity, and primary language - health insurance plans can increase their understanding of health care disparities and make strides in advancing the quality of health care provided to all Americans.

America's Health Insurance Plans (AHIP) has designed this toolkit to assist in broadening our members' understanding of the issues surrounding data collection and its promising impact on improving quality care. We hope this publication serves as a stimulus to encourage the development of numerous quality initiatives that will make a difference in closing the gap.

---

[i] Smedley, BD, Stith, AY, Nelson, AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.* Institute of Medicine, Washington DC. National Academies Press, 2002.
[ii] Nerenz DR, et al. *Developing a Health Plan Report Card on Quality of Care for Minority Populations.* New York: Commonwealth Fund, July 2002.

TABLE OF CONTENTS

Description of Toolkit. AHIP's Tools to Address Disparities in Health: Data as Building Blocks for Change is divided into several components:

- The first four components provide the rationale for and highlight the importance of collecting and analyzing data on race, ethnicity, and primary language. An overview of current federal and state laws and regulations related to data collection, current policies and programs developed by federal agencies and other national organizations, and key perspectives of multiple stakeholders – health insurance plans, providers, purchasers, consumers, and community leaders – also help to strengthen the case for moving forward.
- The next three components of the toolkit provide an in-depth view about how to collect, analyze, and use data on race, ethnicity, and primary language.
- Examples of innovative strategies and models being implemented by health insurance plans are incorporated throughout the toolkit, as well as additional resources for those ready to initiate or continue such efforts are provided in the final three components of the toolkit.

Target Audience. The data collection toolkit is geared for health professionals at health insurance plans and health care organizations.

Important Note: The content for this toolkit was developed with the input from participants who attended AHIP's regional workshops on data collection held from January to April 2005. This toolkit replaces the prior three working versions (1.0, 2.0, and 3.0) of *Strategies for Collecting and Using Data on Race, Ethnicity, and Primary Language: A Data Collection Toolkit for Health Insurance Plans/Health Care Organizations,* provided to participants during the regional workshops.

Contact Information:
We welcome your comments on this toolkit and ask that you contact Rita Carreón, Program Manager, Diversity and Cultural Competency, AHIP, for further information at rcarreon@ahip.org.

[iii] David R. Nerenz, PhD is a leading expert on quality of care measurement in health care systems and racial and ethnic disparities.

[iv] AHIP staff who contributed to this project.

Component 1: Why Collect Data on Race, Ethnicity, and Primary Language?

Overview

The IOM's *Unequal Treatment* report defines "disparities" in health care as racial and ethnic differences in quality of health care that are not due to access-related factors or clinical needs, preferences, and appropriateness of intervention.[1]

As America becomes increasingly diverse, concrete strategies to address disparities are needed to prevent ever-widening gaps in health care. This component provides the initial framework for such a discussion and highlights the reasons why collecting data on race, ethnicity, and primary language is essential to improve the quality of health care for diverse populations and effectively address disparities in health.

Diversity, 2000
Hispanic or Latino Origin and All Races

Diversity index by state
- 0.49 to 0.73
- 0.30 to 0.48
- 0.07 to 0.29

The diversity index reports the percentage of times two randomly selected people would differ by race/ethnicity. Working with percents expressed as ratios (e.g., 63 percent = 0.63), the index is calculated in three steps: A. Square the percent for each group, B. Sum the squares, and C. Subtract the sum from 1.00. Eight groups were used for the index: 1. White, not Hispanic; 2. Black or African American; 3. American Indian and Alaska Native (AIAN); 4. Asian; 5. Native Hawaiian and Other Pacific Islander (NHOPI); 6. Two or more races, not Hispanic; 7. Some other race, not Hispanic; and 8. Hispanic or Latino. People indicating Hispanic origin who also indicated Black, AIAN, Asian, or NHOPI were counted only in their race group (0.5 percent of the population). They were not included in the Hispanic group.

Diversity index by county
- 0.60 to 0.77
- 0.49 to 0.59
- 0.40 to 0.48
- 0.30 to 0.39
- 0.15 to 0.29
- 0.01 to 0.14

Data Source: U.S. Census Bureau, Census 2000 Redistricting Data (PL 94-171) Summary File. Cartography: Population Division, U.S. Census Bureau. American FactFinder at factfinder.census.gov provides census data and mapping tools.

22 Mapping Census 2000: The Geography of U.S. Diversity

U.S. Census Bureau

A Culturally Rich Society - the New American Majority

According to the 2000 U.S. Census, the nation's cultural landscape has significantly shifted. Hispanic/Latinos have now surpassed African Americans as the largest minority group in the country and one in five people are fluent in a language other than English. Projections for the future estimate Asian and Native Hawaiian or Other Pacific Islander (NHOPI) and Hispanic/Latino populations to triple in size, making the overall minority population equal in numbers to the white population. By 2050, this new American majority will represent one in two Americans.

Our society's rich cultures, traditions, and languages will determine how we deliver and improve the quality of health care into the next century. As the U.S. population becomes increasingly diverse, America's health care system faces new opportunities and challenges in its efforts to better serve the needs of these communities. It is critical for health insurance plans, health care organizations, providers, and other key stakeholders to better understand and meet the cultural needs of these individuals in order to provide consistently high-quality health care. Systematic collection of valid and reliable data on race, ethnicity, and primary language can provide a key stepping stone towards accomplishing these goals.

Disparities in Health and Health Care

Despite significant improvements in the nation's overall health status, racial and ethnic minorities continue to face challenges in receiving appropriate health

Distribution of Major Race/Ethnicity Categories – 2000 Census
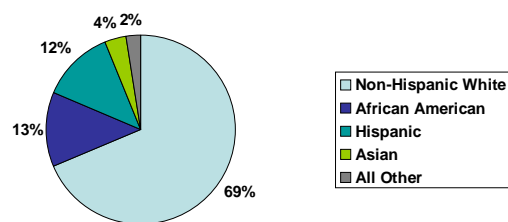
- Non-Hispanic White: 69%
- African American: 13%
- Hispanic: 12%
- Asian: 4%
- All Other: 2%

Source: U.S. Census Bureau, 2004, "U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin"

Distribution of Major Race/Ethnicity Categories – 2010 Projection
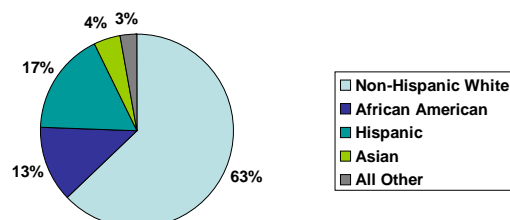
- Non-Hispanic White: 63%
- African American: 13%
- Hispanic: 17%
- Asian: 4%
- All Other: 3%

Source: U.S. Census Bureau, 2004, "U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin"

Distribution of Major Race/Ethnicity Categories – 2030 Projection

- Non-Hispanic White: 55%
- African American: 14%
- Hispanic: 20%
- Asian: 6%
- All Other: 5%
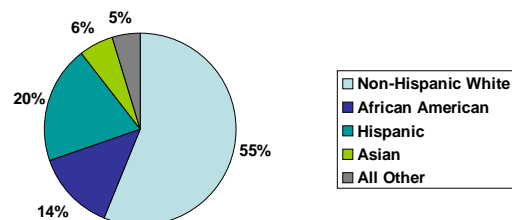
Source: U.S. Census Bureau, 2004, "U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin"

care. Recent reports by the IOM and the Agency for Healthcare Research and Quality (AHRQ) continue to demonstrate that racial and ethnic disparities for certain populations exist and in many cases, are associated with substandard health outcomes.[1,2] Improvement, however, is still possible with the appropriate resources and tools.

Health disparities exist across a wide range of diseases and clinical areas, even when the same stage of diagnosis, severity, and age are taken into account. Disparities in care can also be found across a range of clinical settings within both the public and private sectors.

These are just a few of the inequities in health care that indicate the need for changes to our current delivery system:

- African Americans have a higher mortality rate associated with coronary revascularization procedures than their white counterparts.[3]
- Mexican Americans are less likely to be aware of hypertension than their white counterparts, and when diagnosed, are less likely to get treated.[4]
- Hispanic and African American children are more likely to be hospitalized for asthma than their white counterparts. These children are also less likely to receive follow-up care after an asthma emergency department visit relative to white children.[5]
- Asian and Pacific Islander communities have lower rates of pneumococcal vaccination, cholesterol, and cervical cancer screening tests than their white counterparts.[6]

Why Do Disparities Exist? No <u>single</u> reason has been found to explain why racial and ethnic disparities exist. At the patient level, factors such as language barriers, socioeconomic status (education and income level), cultural norms and beliefs, and attitudes in the way individuals seek care, make decisions about their care, and adhere to treatments all contribute to disparities. Within the clinical setting – possible provider bias and stereotyping, in addition to limited time, and a limited understanding, knowledge, and sensitivity about a patient's culture may explain why the best optimal and equitable care is not always provided. Health care disparities may also stem from organizational barriers, such as the lack of diversity in the health care workforce, lack of access to affordable health care, and the limited availability of culturally and linguistically appropriate services and resources.

Identifying a potential source (or sources) of disparities– at the health system level, the patient level, and during the clinical encounter - is critical to understanding such inequities. Although the availability of data on race, ethnicity, and primary language is limited at the current time, collecting this information can help health insurance plans and health care organizations develop the necessary infrastructure to identify differences in health and health care that may exist among culturally diverse populations.

> Many health insurance plans have implemented initiatives to collect data on race, ethnicity, and primary language and developed initiatives to address health disparities. Some examples of these efforts are included throughout this toolkit.

Measuring and Improving Quality of Health Care and Services

A recent study by the RAND Corporation found that patients in the United States receive only 55 percent of recommended care according to current scientific evidence.[7] Systematic change is needed to improve the quality of care provided to all individuals across all populations.

The lack of valid and reliable data may lead to important missed opportunities to provide high quality of care for individuals with culturally diverse needs.[8] Identifying an enrollee's preferred language, for example, provides an opportunity for plans to design culturally and linguistically appropriate educational materials and assess the need for interpreter and translation services to reduce communication barriers. Health insurance plans can gain an understanding of the unique needs of their enrollees through collecting data on race and ethnicity, understanding their cultural beliefs, targeting health promotion and preventive health initiatives to specific demographic subgroups, and developing customized disease management strategies.[9]

The implementation of data collection strategies to address disparities may lead to the following outcomes:

- Increased compliance and adherence to follow-up treatment (lower rates for hospitalization and emergency room visits)
- Expanded access to and use of preventive care services
- Increased knowledge of health insurance plan benefits and navigation of the complex health care system
- Improved consumer/patient satisfaction
- Enhanced provider-patient communication

As health insurance plans contemplate the reasons why their organizations should collect data on race, ethnicity, and primary language, they should recognize not only what improvements are possible in health care outcomes and quality but also learn from the experiences of other plans. This approach allows health insurance plans to develop well thought-out and informed decisions to collect such data.

> **Reasons to Collect Data**. According to a recent study by America's Health Insurance Plans (AHIP) and The Robert Wood Johnson Foundation (RWJF), health insurance plans cited that their top five reasons for collecting data on race and ethnicity were to: 1) identify enrollees at risk for certain conditions; 2) support culturally and linguistically appropriate communications; 3) base quality improvement efforts to reduce disparities; 4) assess variation in quality measures; and 5) develop disease management or other specialized programs. In addition, health insurance plans collect data on enrollees' primary language to determine the need to translate materials such as summary plan descriptions, health education, and benefit materials; assess the need for interpreter services; and identify opportunities for culturally-appropriate interventions.

Component 2: A Legal Perspective for Health Insurance Plans

Overview

This component provides an analysis of the current federal and state laws and regulations related to data collection on race, ethnicity, and primary language. The collection of valid and reliable data can make a significant impact in understanding disparities and developing effective programs for the elimination of health care inequities experienced by many groups across the nation. These opportunities go hand in hand with the challenges in collecting and using data. This section addresses the current legal and regulatory environment and potential concerns from health insurance plans regarding real and perceived legal barriers that limit the collection of data on enrollees' race and ethnicity.

> **There Are No Legal Barriers to the Collection of Race and Ethnicity Data by Health Insurance Plans.**

Any discussion regarding the collection of race and ethnicity data by health insurance plans needs to consider whether there are any legal impediments to that collection. A recent study by America's Health Insurance Plans (AHIP) and The Robert Wood Johnson Foundation (RWJF) surveyed health insurance plans regarding the collection of race and ethnicity data,[v] and found those plans that do not collect such data expressed a number of reasons for not collecting it, including legal concerns. The study found, however, that more than half of the enrollees of the plans who responded to the survey are covered by plans that voluntarily collect race and ethnicity data.

Generally, there is no legal prohibition against collecting these data. Under Federal law, there is no prohibition on the collection of race and ethnicity data by health insurance plans, as discussed below. While six states have laws or regulations that restrict the ability of health insurance plans to collect such data, those laws have limited application. First, those state laws and regulations apply only to one aspect of the process, namely the collection of such data via an application. Those laws do not prohibit, for example, health insurance plans from collecting race and ethnicity data as part of a disease management program or on a voluntary basis, as long as the collection is not part of the application process. Second, those laws are limited depending on the language of the statute or

---

[v] America's Health Insurance Plans, <u>Health Insurance Plans Address Disparities in Care: Highlights of a 2004 AHIP/RWJF Quantitative Survey, Collection and Use of Data on Race and Ethnicity</u>, (June 1, 2004). Available at: <u>http://www.ahip.org/content/pressrelease.aspx?docid=112</u>.

regulation. For example, the restrictions imposed by California law do not apply to HMOs. Third, the state laws and regulations only apply to state-regulated insurance products.[vi]

Review of Federal Law

No federal law or regulation prohibits health insurance plans from collecting race and ethnicity data. For example, Title VI of the Civil Rights Act of 1964, 42 U.S.C. 2000d, et seq., which prohibits discrimination on the basis of race, color, or national origin under any program or activity receiving federal financial assistance, does not prohibit the collection of such data.[vii] Title VII of the Civil Rights Act of 1964, 42 U.S.C. 2000e, et seq., which prohibits employers from discriminating against individuals with respect to their compensation, terms, conditions, and benefits of employment due to their "race, color, religion, sex, or national origin," also does not prohibit the collection of such data.[viii] The Health Insurance Portability and Accountability Act of 1996 (HIPAA), Pub. L. No. 104-191, does not prohibit the collection of such data.[ix,x]

[vi] Note: Health insurance plans should review the conclusions discussed herein with their own counsel to confirm the conclusions and to apply applicable law to their own unique facts and circumstances.

[vii] In *Madison-Hughes v. Shalala*, 80 F.3d 1121 (1996), the 6th Circuit affirmed the lower court's dismissal of a lawsuit alleging, in part, that HHS discriminated against the plaintiffs in violation of Title VI by not collecting measures of the racial integration of health care providers and by not requiring uniform race or ethnic data collection or reporting from health care providers. The court found no statutory or regulatory requirements pursuant to Title VI that such data be collected, but rather that such data collection is left to HHS's discretion. *Id.*, at 1125. In fact, "Title VI … is considered the broadest mandate the federal government has to require collection and/or reporting of data on race, ethnicity, and primary language." Ruth T. Perot and Mara Youdelman, Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices, 3 (The Commonwealth Fund, Sept. 2001). Available at: http://www.cmwf.org/publications/publications_show.htm?doc_id=221295.

[viii] Titles VI and VII impose prohibitions on using ethnic and race data to discriminate.   As noted, Title VI (and its implementing regulations) prohibits recipients of financial assistance from HHS (and other federal agencies) from discriminating on the basis of ethnicity and race. Title VII prohibits discrimination in employment, including health coverage. Sheryl Tatar Dacso and Clifford C. Dacso, Managed Care Answer Book, 4th Ed., 5:38 (2000).

[ix] However, the HIPAA privacy regulations limit the use and disclosure by group health plans and health insurance issuers in the group market of race and ethnicity data for purposes other than treatment, payment, and health care operations without an individual's written authorization. Also, note that while HIPAA generally prohibits group health plans and health insurance issuers in the group market from denying eligibility for coverage based on health status related information or from requiring a higher premium for similarly situated enrolled individuals based on health status related factors, race and ethnicity have not generally been viewed as health status related factors.

[x] Employer-sponsored health plans that also conduct transactions electronically use the HIPAA 837 transaction for claims/encounters and HIPAA 834 transaction for enrollment. The HIPAA 837 transaction does not include fields for race and ethnicity. The HIPAA 834 transaction designates racial and ethnic data as

---

These conclusions are supported by a number of sources:

1. A study by the Summit Health Institute for Research and Education (SHIRE) and the National Health Law Program (NHeLP), supported by The Commonwealth Fund, concluded:
    a. "The collection of data on race, ethnicity, and primary language is legal and authorized under Title VI of the Civil Rights Act of 1964. No federal statutes prohibit collection of this information, although very few require it."[xi]
    b. The study cites a 2001 document commonly referred to as the "Aetna letter" from the HHS Office for Civil Rights and the Surgeon General and "[d]irected principally at health plans" which "reaffirmed the legality of racial and ethnic data collection."[xii]
2. The HHS Office of Minority Health (OMH) contracted with the National Health Law Program to assess state laws and regulations on this issue.[xiii] On its web site discussing the study, the Office of Minority Health notes that "Title VI of the Civil Rights Act of 1964 neither prohibits nor mandates the collection of racial and ethnic data."[xiv]
3. A 2002 *Health Affairs* article states that, "According to the HHS Office for Civil Rights, there is no such federal prohibition."[xv]
4. A November 2004 Issue Brief from The Commonwealth Fund notes, "Currently no federal statutes prohibit the collection of racial, ethnic or primary language data."[xvi]

---

a "situational field," meaning that such data is only transmitted under certain circumstances; in this case, if required under the insurance contract between the sponsor and the payor and allowable under federal and state regulations and if the enrollee is the subscriber.

[xi] Ruth T. Perot and Mara Youdelman, *supra* note vii.

[xii] *Id.* at 14. *See also*, Mara Youdelman and Steve Hitov, Racial, Ethnic and Primary Language Data Collection: An Assessment of Federal Policies, Practices and Perceptions, Vol. 2, 27 (National Health Law Program, Oct. 2001) (Noting that the letter, dated January 19, 2001, "was sent to 30 interested parties, [and] was written in response to questions from Aetna U.S. Healthcare to the Office for Civil Rights regarding parameters for racial and ethnic data collection.") Available at: http://www.healthlaw.org.

[xiii] HHS Office of Minority Health and National Health Law Program, Assessment of State Laws, Regulations and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans (2004). Available at: http://www.omhrc.gov/OMH/sidebar/datastats13.htm.

[xiv] *Id.*

[xv] Arlene S. Bierman, et al., Addressing Racial And Ethnic Barriers To Effective Health Care: The Need For Better Data, Health Affairs, Vol. May/June 2002, Vol. 21, No. 3, pp. 91-102, 97, *citing*, U.S. Department of Health and Human Services, "Performance Measurement in Managed Care and Its Role in Eliminating Racial and Ethnic Disparities in Health: Meeting Summary" (Unpublished report of June 7, 1999 meeting in Washington, D.C., 1999).

[xvi] Gilliam K. SteelFisher, Addressing Unequal Treatment: Disparities in Health Care, 5 (The Commonwealth Fund, Nov. 2004). Available at:
http://www.cmwf.org/publications/publications_show.htm?doc_id=247164.

Based on these conclusions, a number of health insurance plans have determined that collecting race and ethnicity data is not prohibited by the laws governing their activities, as demonstrated by the AHIP/RWJF survey discussed supra.

Review of State Laws

Six states—(California, Maryland, New Hampshire, New Jersey, New York, and Pennsylvania)— have laws or regulations which place restrictions on health insurance plans in collecting data on race and ethnicity.

However, the state law restrictions have limited applicability. As discussed below, the restrictions only apply to the collection of such data in insurance application forms and are further limited depending on state law.   As such, the restrictions do not prohibit the collection of race and ethnicity data from enrollees outside of the application process, for example, in disease management programs or voluntarily. In addition, the state restrictions only apply to state-regulated products. They do not apply to self-insured ERISA-governed employer-sponsored health plans as preempted by ERISA. Further, it is a reasonable conclusion that the restrictions do not apply to insured ERISA governed employer-sponsored health plans based on the U.S. Supreme Court's decision in *Kentucky Association of Health Plans, Inc. v. Miller*, 538 U.S. 329 (2003).[xvii]

[xvii] A state law or regulation will be saved from ERISA preemption pursuant to ERISA §514(b) as determined by the two-part test recently established by the U.S. Supreme Court in *Kentucky Association of Health Plans*, 538 U.S. at 342.   First, the law or regulation "must be specifically directed toward entities engaged in insurance" and second, the law or regulation "must substantially affect the risk pooling arrangement between the insurer and the insured." Applying the ERISA preemption principles stated above, the state laws and regulations (and practices) discussed herein which restrict the collection of race and ethnicity data in insurance applications relate to employee benefit plans (except for the New Jersey regulation which applies to individual insurance applications) and therefore would be preempted as to self-insured plans. Applying the two-pronged test to insured plans, the laws do not substantially affect the risk pooling arrangement between the insurer and the insured and therefore, those laws are not saved from ERISA preemption as they relate to insured plans.

State Limitations. The restrictions on collecting race and ethnicity data imposed by each of the six states are summarized below.[xviii] The way each state defines "insurer" varies by state and health insurance plans should consult the relevant state law to determine the applicability of the restrictions.[xix] The NHeLP study, conducted in 2000 and 2001, highlights the status of the fifty state laws, regulations, and practices. The second phase of the NHeLP project includes a report summarizing the findings from interviews with health insurance plans and state government offices about data collection. This report is scheduled to be released in 2005. To download a copy of individual state reports, please access the OMH's website at http://www.omhrc.gov/OMH/sidebar/datastats13.htm. Please note that the laws and regulations may have changed from when the first phase of this study was conducted in 2000.

California.[xx] California's Insurance code prohibits health insurers from identifying or requesting an applicant's race, color, religion, ancestry, or national origin on an insurance application. The law provides, "No application for insurance or insurance investigation report furnished by such an insurer to its agents or employees for use in determining the insurability of the applicant shall carry any identification, or any requirement therefore, of the applicant's race, color, religion, ancestry, or national origin."

Maryland.[xxi] Maryland's Insurance code, in a section entitled, "Discrimination in underwriting," provides that "an insurer…may not make an inquiry about race, creed, color, or national origin in an insurance form, questionnaire, or other manner of requesting general information that relates to an application for insurance."

New Hampshire.[xxii] A New Hampshire Insurance Department (NHID) regulation prohibits questions of race or color on "all application forms used in connection with the offer and acceptance of the insurance or annuity contract, whether or not attached to that contract."

New Jersey.[xxiii] A New Jersey Department of Banking and Insurance (DBI) regulation prohibits application forms for individual health insurance from including "provisions, statements or questions that pertain to race, creed, color, national origin, or ancestry of the proposed insured."

[xviii] The HHS Office of Minority Health/National Health Law Program study of state laws, *supra*, contains a detailed review of each of the fifty state's laws, regulations, and practices relevant to this issue. Note, however, that the study was conducted in 2000 and 2001 and the laws, regulations, and practices noted in that report may have changed.

[xix] For example, the restriction imposed by California law applies to insurers regulated by California's Department of Insurance and does not apply to HMOs or managed care organizations (other than Preferred Provider Organizations (PPOs)).

[xx] Cal. Ins. Code §10141.

[xxi] Md. Code, Insurance §27-501(c).

[xxii] N.H. Code Admin. R. Ins. 401.01(i) (5).

New York.[xxiv] New York, by regulation, provides that "No application [for insurance] shall contain questions as to the race of the applicant."

Pennsylvania.[xxv] A Pennsylvania regulation applicable to life, accident, and health insurance application forms provides, "Questions as to race or color are not permitted on the application."

Five states (Connecticut, Iowa, Minnesota, South Dakota, and Washington) have been identified as having prior approval processes before race or ethnicity questions can be included on applications for insurance, but such processes are not set forth in any formal law or regulation.[xxvi]

Conclusion

There are no legal barriers to the collection of race and ethnicity data by health insurance plans. Federal law contains no prohibitions, and the laws and regulations in the six states with restrictions on the collection of these data have limited applicability. Those laws and regulations only prohibit the collection of race and ethnicity data in the application process, are further limited by language in the specific statutes or regulations, and only apply to state-regulated insurance products.

> **Center for Health Services Research and Policy (CHSRP):** In June 2004, the CHSRP and the Department of Health Policy at George Washington University Medical Center School of Public Health and Health Services (SPHHS) received a grant from The RWJF to assess legal barriers in collecting quality improvement and disparities reduction data. Directed by researchers Phyllis Borzi, JD, MA and Sara Rosenbaum, JD, the purpose of this project is to analyze legal barriers that may impede efforts to collect, evaluate, and publish these data. CHSRP will release two reports addressing the current legal barriers associated with collecting and reporting these data and how to remove or mitigate these barriers to improve quality and reduce disparities. For more information about this project, please access the CHSRP website at www.gwhealthpolicy.org.

[xxiii] N.J.Admin. Code tit. 11, §4-16.7(a)(1).

[xxiv] N.Y. Comp. Codes R. & Regs. Tit. 11, §52.51.

[xxv] 31 Pa. Code §89.12.

[xxvi] The HHS Office of Minority Health/National Health Law Program study of state laws, *discussed supra*.

Component 3: National Activities Supporting Data Collection on Race, Ethnicity, and Primary Language

Overview

This component highlights the national activities — including policies and programs — that are being implemented by federal agencies and other national organizations to address racial and ethnic disparities and develop culturally and linguistically appropriate programs and services. These efforts consist of working groups, coalitions, programs, and campaigns designed to improve the quality of care for America's diverse population. This section illustrates the breadth of activities that support ways to improve the collection, analysis, and use of data. The following is a representative sample of key activities taking place currently at a national level.

The National Research Council

This private, non-profit institution is part of the National Academies which provides science, technology, and health policy advice to the federal government and the public. For more information, please access the National Academies website at www.nationalacademies.org.

Panel on DHHS Collection of Race and Ethnicity Data. The U.S. Department of Health and Human Services (HHS) asked the National Research Council of the National Academies in 2002 to convene a "Panel on DHHS Collection of Race and Ethnicity Data." The panel — representing leading health care researchers and stakeholders from the public and private sectors — was charged to:

1. Review the collection of data on race and ethnicity in HHS health and health care data systems, and more broadly in state and private sector health and health care data systems;
2. Identify the key data needs to evaluate the effects of socioeconomic status disparities (the panel added language and acculturation); and
3. Identify and assess critical gaps in health and health care data systems used to evaluate disparities and suggest ways in which data gaps can be filled.

The committee's 2003 report entitled "Eliminating Health Disparities: Measurement and Data Needs" provided the following recommendations regarding data collection and measurement[10]:

- Measures of race and ethnicity should be obtained in all health and health care data systems;
- Measures of socioeconomic position should, where feasible, be obtained along with data on race and ethnicity;

- Measures of acculturation and proxies such as language use, place of birth, and generation and time in the U.S. should, where feasible, be obtained;
- Health and health care data collection systems should return useful information to the institutions and local and state government units that provide the data; and
- Linkages of data should be used whenever possible, with due regard to proper use and the protection of confidentiality in order to make the best use of existing data without the burden of new data collection.

As a result of the panel's review of the private sector's current practices on the collection of data on race, ethnicity, language, and socioeconomic position, three recommendations were issued to HHS to improve the accuracy of data collection:

1. Require health insurers, hospitals, and private medical groups to collect data on race, ethnicity, socioeconomic position, and acculturation and language (section 6-1);
2. Provide leadership in developing standards for collecting data on race, ethnicity, socioeconomic position, and acculturation and language use by health insurers, hospitals, and private medical groups (section 6-2); and
3. Establish a service that would geocode and link addresses of patients or health plan enrollees to census data, with suitable protections of privacy, and make this service available to facilitate development of geographically linked analytic data sets (section 6-3).

AHIP Involvement with the Panel. AHIP was asked by the National Research Council Panel to evaluate whether and how health insurance plans collect racial and ethnic data. AHIP conducted telephone interviews with a sample of AHIP member health insurance plans across the country to identify and highlight the issues surrounding such data collection and summarize these efforts. Based on interview findings, the following key recommendations emerged:

- A coordinated, uniform approach should be developed across the health care industry to accelerate the collection of accurate racial and ethnic data. The most effective and well-received efforts included: community-based collaborations, mentorship initiatives with "smaller" health insurance plans, development of a strong business case for reporting by employers, and public/private efforts to educate health insurance plans and the industry about legal issues.
- Recognition, designation, and support of "champions" from designated populations to lead and guide the collection of racial and ethnic data at all stages.
- Identification of models that work to balance the extensive research concentrating on gaps in health care quality linked to race and ethnicity.
- Funding of new research directed at specific methods of how to reduce or eliminate gaps in medical care experienced by some racial and ethnic minorities.

Department of Health and Human Services (HHS)

A multitude of initiatives are being implemented to address disparities in health at HHS, the federal agency in charge of monitoring and protecting the nation's health. For more information, please access the HHS website at www.hhs.gov. The section below highlights selected examples of such activities and recommendations by several agencies and workgroups.

HHS National Committee on Vital and Health Statistics. The National Committee on Vital and Health Statistics (NCVHS) is the public advisory body to the Secretary of HHS on the information needs underlying health policy. The Committee is interested in ensuring that adequate, timely, and relevant data are collected and available for health care stakeholders to monitor and assess health status, health behaviors, care, and access to treatment in racial and ethnic minorities and other vulnerable populations. For more information regarding the NCVHS committee meetings, quality workgroup, and recommendations, please access the NCVHS website at www.ncvhs.hhs.gov.

I. Recommendations on Collection of the Nation's Data to Measure and Eliminate Health Disparities Associated with Race, Ethnicity, and Socioeconomic Position

In September 2004, NCVHS examined the limitations of health data on racial and ethnic groups that are currently being collected and used, and recommended a set of actions to address these issues.[11] Based on the committee's findings, the following actions and strategies were recommended to HHS to improve the current data available for measuring, tracking and reducing health disparities:

1. Extend and intensify its current leadership role with other Departments, the Office of Management and Budget (OMB), the Census Bureau, and private and academic organizations to promote and undertake methodological research associated with race, ethnicity, and socioeconomic position to improve the health and health care data collected on racial and ethnic minority populations and subpopulations.
2. Accelerate implementation of its multiple-strategy approach to data development on racial and ethnic minority populations and subpopulations, consistent with recommendations that appear in *Improving the Collection and Use of Racial and Ethnic Data in HHS*.[12]
3. Develop consistent strategies and mechanisms for the broad dissemination of data on racial and ethnic minorities, including data on socioeconomic position, that result from Departmental data collection efforts, when targeted to specific racial and ethnic minority populations.

Specific Strategies to Increase the Quality and Quantity of Data on Racial and Ethnic Populations and Subgroups

- Improve coordination of data collection and use, through partnership with entities responsible for data collection and through the issuance of consistent data requirements. This recommendation is consistent with the National Research Council Panel on DHHS Collection of Race and Ethnicity Data;
- Provide guidance on technical and methodological areas related to data collection, such as bridging old and new data methodologies, interpreting and analyzing primary and multiple race categories, improving the quality of race and ethnicity data in vital statistic records; oversampling and/or conducting targeted studies; developing a methodology to improve the quantity, quality, and participation rates in data collection; using Census denominators for rate calculation; validating data collection tools, and identifying mechanisms to augment existing samples to target specific race or ethnic groups; and
- Strengthen the capacities of the health statistics enterprise through improving access to HHS data on racial and ethnic minority subpopulations and disseminating research findings related to these populations.

II. Measuring Health Care Quality: Obstacles and Opportunities

The Quality Workgroup was established by NCVHS in 1998 to take the lead on the Committee's work on health data issues affecting quality measurement and improvement.

The NCVHS Quality Workgroup released a report in 2004 that includes candidate recommendations in four priority areas:[13]
1. Assessing and improving health care and health outcomes;
2. Reducing disparities in health and health care for minority populations;
3. Building the data infrastructure to support quality assessment and improvement; and
4. Balancing patients' interests in privacy protection and protection of their health and safety.

The workgroup issued three recommendations in the area of reducing disparities in health and health care for minority populations. These strategies identify ways to collect data on race, ethnicity and primary language to improve quality measurement, and reporting and tracking of health care for people in racial and ethnic minorities.

The recommendations are to:
- Modify existing mechanisms for reporting on the race and ethnicity of subscribers and dependents on the Health Insurance Portability and Accountability Act (HIPAA) enrollment transaction;
- Investigate how best to capture race and ethnicity on a standard provider transaction; and
- Modify existing mechanisms for reporting the primary language of both subscribers and dependents on the HIPAA enrollment transaction.

HHS Office of Minority Health. The Office of Minority Health (OMH) advises HHS on health policy issues affecting health status and access to care among minority populations and coordinates programs to help the Department implement minority initiatives. For more information, please access the OMH website at www.omhrc.gov.

I. Culturally and Linguistically Appropriate Services Standards

In 2000, the OMH released the *National Standards on Culturally and Linguistically Appropriate Services (CLAS) in Health Care.* [14] The CLAS standards are guidelines for health care organizations to make their systems more culturally and linguistically appropriate and accessible for racial, ethnic, and linguistic populations. The fourteen standards are organized in three themes: Culturally Competent Care (standards 1-3), Language Access Services (standards 4-7), and Organizational Supports for Cultural Competence (standards 8-14). Federal requirements mandate that all organizations that receive federal funds meet the Language Access Services standards, which are based on Title VI of the Civil Rights Act of 1964 with respect to services for limited English proficient individuals. The remaining standards are voluntary; Standard 14 is recommended for adoption by health care organizations and all others are recommended for adoption by accreditation organizations. The complete list of the CLAS standards can be accessed on the Office of Minority Health website at http://www.omhrc.gov/wwwroot/clas/finalcultural1a.htm.

II. National Study of CLAS in Managed Care Organizations

In August 2003, the OMH released a report entitled "*National Study of Culturally and Linguistically Appropriate Services in Managed Care Organizations.*" The report presented the findings from a survey of health insurance plans conducted by COSMOS Corporation to examine the nature and extent of CLAS in "managed care organizations" across the country and highlight promising CLAS practices implemented by these organizations.[15] The report's major findings demonstrated that:

- A range of "promising practices" utilizing the CLAS standards were being implemented by plans;
- Many health insurance plans have formal policies in place that address the quality of care and services to diverse populations;
- Multiple strategies are being used to measure and monitor CLAS quality but data on enrollees' race, ethnicity, or primary language spoken was lacking;
- A number of health insurance plans recognize and respect cultural diversity in their organizations; and
- Staff hiring and training as well as language assistance services were evident.

Agency for Healthcare Research and Quality. The Agency for Healthcare Research and Quality (AHRQ)'s mission is to improve the quality, safety, efficiency, and effectiveness of healthcare for all Americans, through the establishment of a broad base of scientific research and through the promotion of improvements in clinical and health systems practices, including the

prevention of diseases and other health conditions.[16] AHRQ has created a number of initiatives to address racial and ethnic disparities, including the development of annual national reports in 2003 and 2004 on health care disparities[17] and quality of care[18], the funding of "Centers of Excellence" to develop tools for diverse populations, and the *National Health Plan Learning Collaborative to Reduce Disparities and Improve Quality*. For more information, please access the AHRQ website at www.ahrq.gov.

National Health Plan Learning Collaborative to Reduce Disparities and Improve Quality.
Funded by AHRQ and The Robert Wood Johnson Foundation (RWJF), the National Health Plan Learning Collaborative to Reduce Disparities and Improve Quality is a public-private partnership designed to help reduce disparities in health care for people with diabetes and other conditions. This collaborative brings together nine of the nation's health insurance plans: Aetna, CIGNA, Harvard Pilgrim Health Care, HealthPartners, Highmark Inc., Kaiser Permanente, Molina Healthcare, UnitedHealth Group (UnitedHealthcare, Ovations and AmeriChoice) and WellPoint Inc. The supporting organizations include the Center for Health Care Strategies (CHCS), the Institute for Healthcare Improvement (IHI), and the RAND Corporation who are providing technical assistance to the participating health insurance plans.[19] AHIP and the Blue Cross and Blue Shield Association (BCBSA) are also working collaboratively with these organizations.

A key goal of this collaborative is to address and reduce the barriers to data collection and to facilitate the identification of disparities. Over the next three years (2004 – 2006), participants in the collaborative will test ways to improve the collection and analysis of data on race and ethnicity, match those data to existing quality measures in the Health Plan Employer Data and Information Set (HEDIS$^{®}$), develop quality improvement interventions to close the gaps in care, and produce results that can be replicated by other health insurance plans and providers serving the Medicare, Medicaid and commercial populations.

Centers for Medicare and Medicaid Services. The Centers for Medicare & Medicaid Services (CMS), the agency that provides services to Medicare and Medicaid beneficiaries, also addresses disparities in health. CMS is implementing initiatives that focus on disparities in health with Medicare Advantage plans—through voluntary Quality Assessment Performance Improvement (QAPI) projects that focus on culturally and linguistically appropriate services or clinical health care disparities. Medicaid plans have access to race and ethnicity data through CMS and also develop educational materials tailored to their specific populations. For more information, please access the CMS website at www.cms.gov. For specific information about the Medicare Advantage QAPI 2003 project, please access: www.cms.hhs.gov/healthplans/quality/project03.asp.

Centers for Disease Control and Prevention. The Centers for Disease Control and Prevention (CDC), the national agency that monitors public health and health promotion, has several initiatives underway to measure and eliminate health disparities among diverse populations. Under its Office of Minority Health, the CDC provides funding and disseminates information regarding minority health. Additionally, the CDC oversees the Racial and Ethnic Approaches to Community Health (REACH) 2010 initiative. This initiative focuses on six priority areas - cardiovascular disease, immunization, breast and cervical cancer screening and management, diabetes, HIV/AIDS, and

infant mortality. The REACH 2010 initiative provides funding to communities for coalition-building efforts to design, implement, and evaluate community-driven interventions and programs to reduce disparities among racial and ethnic groups. For more information, please access the CDC website at www.cdc.gov.

Healthy People 2010. Healthy People (HP) 2010 are a set of national evidence-based disease prevention and health promotion objectives for states, organizations and communities to use when developing new programs to improve the public health of the nation. Healthy People 2010's overall goals are to: help individuals of all ages increase life expectancy and improve their quality of life, help the nation eliminate health disparities among different segments of the country's populations, and improve the means of measuring health care access and disparities. HP 2010 objectives related to disparities call for an increase in: access to quality health services; community-based programs that are culturally and linguistically appropriate; minority health professional graduates; and improved data gathering to better understand health disparities and service needs. The focus areas also address ten leading health indicators which reflect the nation's major health concerns and their ability to motivate action. For more information, please access the Healthy People 2010 website at www.healthypeople.gov.

National Quality Organizations

National Quality Forum. In 2002, the National Quality Forum (NQF) convened an expert panel to identify strategies to improve the quality of care among racial and ethnic populations. The goals of the NQF's Minority Health Project were to: assess whether specific measures can or should be used to measure the quality of health care for minority populations, whether the existing and commonly used quality measures can be used for these populations and whether these data collection measures raises unique challenges. The project, funded by the Commonwealth Fund, also assessed whether existing mechanisms are adequate for assessing and reporting on minority's health care quality. The workshop proceedings were published in a 2002 report entitled, "Improving Healthcare Quality for Minority Patients."[20] For more information, please access the NQF website at www.qualityforum.org.

Joint Commission on the Accreditation of Health Care Organizations. National accreditation organizations such as the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) are actively involved in addressing disparities in health through research projects and standards development for health care organizations. In November 2004, JCAHO released in a "field review" proposed standards for health networks' collection of data on race, ethnicity, and primary spoken language.   The proposed standards may potentially require health networks to collect information about a patient's race, ethnicity, and primary spoken language through their practitioner sites.

Additionally, JCAHO heads the project *Hospitals, Language, and Culture: A Snapshot of the Nation,* funded by the California Endowment. This 30-month project (January 2004 - June 2006) will gather baseline data from a sample of hospitals and assess their capacity to address the issues of language and culture that impact the quality and safety of patient care. Activities will include the development of a data collection methodology, a sampling strategy, on-site data collection at a sample of hospitals across the nation, data analysis, and the communication of study results.[21] For more information, please access the JCAHO website at http://www.jcaho.org/about+us/hlc/index.htm.

National Committee for Quality Assurance. The National Committee for Quality Assurance (NCQA) is working on two research projects to determine the feasibility of assessing culturally and linguistically appropriate services (CLAS) and health disparities. Both projects were funded by the California Endowment Foundation in 2003-2004.

First, the feasibility study *Measuring and Assessing Culturally and Linguistically Appropriate Services (CLAS) in Managed Care for Public Accountability,* will investigate if health insurance plans can be evaluated in a scientifically sound and feasible manner with respect to their ability to provide CLAS to their enrollees. Second, the quantitative analysis project, *Using Quality Measurement to Address Disparities in Health Care: Medicare + Choice HEDIS Race/Gender Analysis* (Disparities Project), will examine whether important health disparities can be documented for select HEDIS measures. In addition, if such disparities can be identified, the project will further investigate if HEDIS measures can be stratified in a sound and feasible manner by race, ethnicity, and gender in order to promote efforts to reduce disparities in health care quality. The results of this analysis will be reviewed by the CLAS/Health Disparities expert panel to develop recommendations for NCQA.[22]

In November 2004, NCQA also initiated a research study to investigate gender differences in quality of care (prevention and treatment) of cardiovascular disease and its risk factors using HEDIS data. NCQA will work with 25-30 health insurance plans interested in serving as field test sites to utilize HEDIS 2005 data for 13-17 cardiovascular-related Effectiveness of Care and Use of Services measures. This study is being funded by the American Heart Association (AHA) and the Agency for Healthcare Research and Quality (AHRQ). For more information, please access the NCQA website at www.ncqa.org.

Additional Activities

National organizations representing the health care industry have been active in a number of initiatives to address disparities and collect data on race, ethnicity, and primary language.

AHIP and RWJF's Collaborative Study on the Collection of Race, Ethnicity, and Primary Language to Address Health Care Disparities

In 2003-2004, 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.[23] 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. Of the 302 health insurance plans in the combined sample, 137 (45.4%) completed all or some of the survey questions. When weighted by enrollment, these 137 health insurance plans represent 88.1 million covered lives. Table A provides a breakdown of the lines of business represented by health insurance plan respondents.

Table A

LINE OF BUSINESS	NUMBER OF HEALTH INSURANCE PLANS RESPONDING	ENROLLMENT
Commercial	58	79,317,743
Medicaid	46	6,342,917
Medicare	33	2,459,596
Total	137	88,120,256

Subsequent to the survey, AHIP conducted a phase of qualitative research, involving one-on-one telephone interviews, a focus group, and an expert panel meeting. This follow-up qualitative research sought to obtain more specific information about health insurance plans' practices and solicit recommendations on next steps, such as how to improve the collection and use of these data, and identify potential future collaborations. For more information, please access the AHIP website at www.ahip.org. Two issue briefs describing the results of this study can also be found in the Appendix section of this toolkit.

Health Research and Education Trust, American Hospital Association

The Health Research and Education Trust (HRET), the research and education affiliate of the American Hospital Association (AHA), is currently working on a framework for the collection of data on race and ethnicity. In February 2005, an online toolkit was released to help hospitals collect accurate information from patients and help clinicians and health care consumers gain a better understanding of the importance of collecting these data. For more information, please access the HRET website at www.hretdisparities.org.

In addition, HRET conducted a nationwide survey in 2004 on the collection of these data by hospitals. The survey found that the three most common methods for the collection of data on race, ethnicity, and primary language by hospitals are: upon admission for all types of units (85%); at first visits/new registration (60%); and through health care provider notes or medical records (12%).[24] The primary source of race and ethnicity data was from the patient directly or through an admissions clerk. The survey results were released in a Commonwealth Fund report, entitled "*Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals.*" For more information, please access the AHA website at www.hospitalconnect.com.

Congressional Leadership Alliance To Eliminate Health Disparities
In February 2005, the National Minority Health Month Foundation (NMHMF) announced the establishment of the Congressional Leadership Alliance To Eliminate Health Disparities. The NMHMF is a 501(c)(3) not-for-profit organization whose mission is to strengthen the ability of communities and policy-makers to eliminate the disproportionate burden of premature death and preventable illness in special populations through the use of evidence-based, data-driven initiatives.

The Leadership Alliance will function as a catalyst to promote public awareness and mobilize support to eliminate health disparities in key Congressional Districts. The major objectives of the initiative include:

– Building awareness of efforts to eliminate health disparities;
– Implementing targeted pilot programs in health disparity zones;
– Conducting groundbreaking studies on affected communities and identify trends and patterns; and
– Working with current Congressional members to address the need for additional legislation and resources to combat health disparities.

Through the use of evidence-based solutions and the use of a zip code database (the Zip Code Analysis Project, ZCAP®), the Leadership Alliance will implement pilot programs in Congressional Districts identified as *Health Disparities Zones*, areas with prevalence of chronic illness that disproportionately affects racial and ethnic populations and other minority groups. ZCAP is a database that includes a Health Assessment Tool (HAT®) to stratify health conditions by zip code, congressional district, or other geographic boundaries by linking to vital statistics, demographics, health care access points, and other data elements for measuring progress in eliminating disparities. For more information, please access the NMHMF website at www.nmhmf.org.

Component 4: Building the Case

Overview

There are several different ways to "build a case" for collecting data on race, ethnicity, and primary language and implementing a health insurance plan initiative that addresses disparities in health. This component discusses how to construct and present the case to key stakeholders. How to do this depends on the answers to some basic questions that include:

Whose perspective is being considered?

- health insurance plans

- providers

- health insurance plan enrollees

- community leaders

- employers or purchasers

All of these stakeholder perspectives will be discussed in the sections that follow, but it is important to note, however, that there is not one "case" for collecting data to address disparities in care; instead, there are many possible "cases," and it is feasible to select those that fit your local plan circumstances.

The second component of this toolkit reviews the legal perspective for health insurance plans on collecting data on race, ethnicity, and primary language. Therefore, the legal case for plans will not be expanded upon in this section.

Perspectives

Before providing specific examples of "building a case," the issues that matter to different organizations and individuals must be considered. An argument for collecting data to address disparities that appeal to one stakeholder may not be relevant to another. There also may be similar concerns represented by each of the stakeholders as to why a health insurance plan collects these types of data.

Health Insurance Plans. It is important for health insurance plans to be aware of potential issues and concerns that may be raised within their own organizations related to data collection. The following lists some of these issues and potential concerns:

– Perceived legal and regulatory issues inhibiting the collection of these data;
– Belief that the collection of such data is not common in the health insurance plan's local market;
– Potential enrollee reactions in response to a health insurance plan collecting and using these data;
– Potential employer/purchaser response;
– Additional resources needed to collect systematic data across the organization;
– Lack of standardized data collection methodologies across individual health insurance plans and throughout the health care system; and
– Lack of knowledge about how to use the data once collected to address disparities in health and health care.

Many health insurance plans are collecting data on race, ethnicity, and primary language. In 2004, the AHIP and The Robert Wood Johnson Foundation (RWJF) study[25] demonstrated that over half of enrollees are covered by health insurance plans that responded to the survey and are collecting such data. The most common reasons for data collection are to:

Percentage of Individuals Enrolled in Health Insurance Plans that Collect Data on Race and Ethnicity

Commercial (n=58)	50.9%
Medicare (n=33)	74.3%
Medicaid (n=46)	78.2%
All Plans (n=137)	53.5%

– Identify individuals at-risk for certain conditions;
– Base quality improvement efforts to reduce disparities;
– Assess variations in quality measures;
– Develop disease management or other specialized programs;
– Understand disparities in care in efforts to reduce these inequities among different racial and ethnic groups; and
– Support culturally and linguistically appropriate communications by providing translation services, disseminating culturally and linguistically appropriate educational materials, creating on-line websites in other languages; and designing provider networks that reflect the diversity of the enrolled populations.
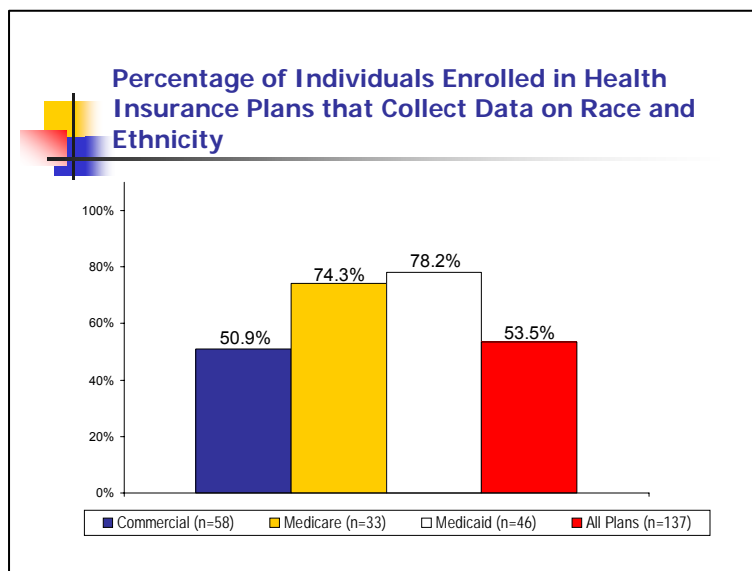
Investing in Data Collection – Common Issues

Investing in data collection on race, ethnicity, and primary language may help a health insurance plan to stay competitive in today's evolving health care environment and meet the needs of America's diverse society. Many plans already collect such data through several sources and within different departments or initiatives.

Some plans that have implemented data collection activities have found the technical and system issues to be the most challenging. Health insurance plans should fully consider the following issues prior to implementation — the investment and resources needed to support such efforts, how to appropriately manage and use the data once collected, and the processes needed to ensure the data are secure and confidential. In the end, however, health insurance plans should continue to emphasize within their own organizations how valid and reliable data will help to identify variations in patterns of care for different populations and lead to improved quality of care and outcomes for all enrollees.

There is no one strategy or solution to reduce disparities, nor one reason as to why a plan should invest in the collection of these data. To date, we are not aware of specific return on investment models that document the value of collecting data to reduce disparities. As the society becomes more diverse, health insurance plans will need to develop targeted and systematic approaches to reduce the disparities in health care.

> **Key Findings from AHIP/RWJF Survey**
> Either directly or indirectly, health insurance plans are collecting these data through plan enrollment, geocoding software, targeted programs such as disease management and health education, and files linked to external sources, including federal agencies and birth records.

Strategies to consider: Invest, commit, and prioritize. Educate health insurance plan executive leadership about how investing in data collection will improve the quality of care and services provided to all plan enrollees, strengthen linkages with community resources, and improve access to affordable health care. It is important to emphasize to senior management how data collection is part of, rather than separate from, other corporate-wide quality measurement or quality improvement activities. The identification and analysis of health care disparities and implementation of targeted interventions can assist health insurance plans in achieving benchmark levels of quality for all plan enrollees.

In addition to achieving senior management buy-in, identify other champions within the health insurance plan who will support the issue and are willing to take on this effort. Creating an internal task force and an expert advisory panel have been instrumental strategies for those plans that have already initiated the collection of these data and are establishing initiatives to meet the needs of their culturally diverse enrollees.

Potential Reactions in Response to the Collection of Data

A variety of reactions from plan enrollees, providers, or employers in response to the collection of data on race, ethnicity, and primary language by a health insurance plan should be anticipated. A recent study highlights some related findings.

In a separate RWJF-funded study conducted by Public Opinion Strategies on more than 1,000 adults with some form of health insurance, fifty percent of respondents did not find it acceptable for an HMO or health insurance company to collect racial and ethnic origin information.[26] African Americans were least supportive of this action.

Each of the ethnic groups surveyed, however, responded more positively to collecting this information after they were given additional information about the reasons why data were being collected. Fifty-four percent of survey respondents favored federal legislation to allow for the collection of this type of information when it is used to identify gaps in care and to ensure that all Americans receive high quality of care.

All survey respondents favored legislation if the data would be provided voluntarily, could help prevent and cure diseases that are prevalent among certain groups, and help ensure that all Americans receive equal access to high-quality health care. The Public Opinions survey also revealed that the majority of respondents believe hospitals, HMOs, and insurance companies already collect information about a person's race and ethnic origin.

Potential enrollee reaction – positive or negative – must be considered by a health insurance plan interested in collecting data on race, ethnicity, and primary language. The National Research Council (NRC) recommends that health insurance plans collect information about race, ethnicity, socioeconomic status, acculturation, and primary language on a voluntary basis from enrollees after they join the health insurance plan. In addition, Fremont and Lurie noted that employers and purchasers may fear that the data on their employees will be used detrimentally.[27] Any health care organization must build trust among all stakeholders — plan enrollees, purchasers, providers, and communities by demonstrating that the data will be collected voluntarily and used appropriately. An alternative suggested by the NRC is to ask employers or providers to collect these data.[28]

Provider Networks. Health insurance plans work with the providers in their networks to improve the quality of services offered and implement targeted initiatives for plan enrollees. Obtaining input from and involving providers in the development of quality improvement initiatives are critical to achieving buy-in and increasing the likelihood of a successful implementation.

A health insurance plan, therefore, needs to clearly communicate with its providers about its intent, goals, and objectives for collecting data on race, ethnicity, and primary language. The following issues and potential concerns of its provider network should be considered by a health insurance plan prior to implementation.

Although significant studies and recommendations have made the case for eliminating disparities within the clinical encounter, the existence of data will assist a provider to fully address and make progress in improving the quality of care of diverse populations.[29] There are different types of challenges that may arise from the provider perspective that include:

- Concerns about how health insurance plans will use the data;
- Concerns with privacy issues and confidentiality – How will the patient be protected?
- Investment in time, cost, or resources to establish a system to collect these data;
- Provider reaction to the issue of disparities in health and health care;
- Trust issues that may hinder a patient-provider or provider-health insurance plan relationship; and
- Hesitance of providers to ask questions of patients at the point of care.

Another challenge in asking providers to collect these data at the point of care is that only those enrollees that access the doctor for their care at a given year will be counted, capturing about two-thirds of enrollment.[30] The following discusses some potential ways to address the issues stated above.

Commission to End Health Care Disparities

In 2004, the "Commission to End Health Care Disparities," chaired by the American Medical Association in conjunction with the National Medical Association (NMA) and the National Hispanic Medical Association (NHMA), was established to eliminate disparities by focusing on the following four strategies:

- Increase awareness of disparities;
- Promote better data gathering;
- Promote workforce diversity; and
- Increase education and training.

This group, representing more than 30 state and specialty medical societies and other health professional organizations, focuses on physician leadership, quality, and system approaches to improvement.

The Commission recently released the preliminary findings of a comprehensive survey regarding an increase in physicians' awareness about health care disparities and the factors that cause them. The Commission is also promoting physician training programs to increase cultural competency.

For more information, please access the AMA website at www.ama-assn.org/go/healthdisparities.

Why is the collection of data on race, ethnicity, and primary language important for providers?

Minorities are disproportionately affected with chronic diseases than their white counterparts. These data provide the building blocks for understanding which patients are at risk for certain conditions or preventable diseases as well as identify the need for early treatment and services. Identifying certain risk factors may help providers communicate with their patients about the appropriate preventive screenings and behaviors and assists patients to manage their own health.

Identifying a patient's primary language spoken or preference can also enable a provider and health insurance plan to develop targeted messages and culturally appropriate educational materials, as well as to identify needed language translation services. These strategies will improve the patient-provider relationship and the ability for a physician to discuss a patient's health condition, cultural health beliefs, and practices.

> **Member Tracking Program for Language/Interpreter Utilization.** Santa Clara Family Health Plan (SCFHP) ensures that contracted providers record all members' language preferences in the medical record and document members' requests and refusals to receive language interpreter services. To ensure that these standards are met, the SCFHP's Quality Improvement Department monitors all contracting primary care providers and obstetricians through reviews of facilities and medical records every three years. If the review does not find evidence of these required procedures, points are deducted from the site review. This requires the provider to develop a corrective action plan. In addition, SCFHP provides a Patient Information Sheet, which meets all health insurance plan linguistic requirements, to include with the medical record. Providers also receive education on the importance of including linguistic and cultural information in the medical record, along with information on the plan's Language Interpreter Services.

Data can:
- Strengthen the patient-provider relationship and communication;
- Improve cross-cultural education and skills;
- Increase patient compliance and adherence to medication;
- Reduce potential for misdiagnosis of medical conditions due to language barriers;
- Identify needed interpreter and translation services; and
- Increase the proportion of racial and ethnic minorities in health professions.

Combined efforts between health insurance plans and providers will move the health care system toward greater long-term solutions, such as increased access to preventive services and wellness programs, and ultimately healthier outcomes among culturally diverse populations. These approaches appeal to the professional commitments of physicians and other health care providers who constantly strive to improve quality of care and achieve good health outcomes for all patients.

Health Insurance Plan Enrollees. It is essential for a health insurance plan, as it pursues data collection, to fully understand and respond to the potential reactions of its plan enrollees. The following identifies some of the most common challenges and potential benefits.

Common Challenges Regarding Data Collection
- Potential enrollee reaction in response to possible data misuse and risk for discrimination – mistrust in the health care system;
- Lack of understanding about how data can improve quality of care and access to preventive services, disease management programs, and treatment; and
- Lack of knowledge about how reducing disparities can reduce communication barriers, especially among persons with limited-English proficiency, through targeted strategies such as the availability of culturally and linguistically appropriate educational materials, and cross cultural education and training.

Benefits for Enrollees in Data Collection and Disparities-Reduction Initiatives
- Reductions in mortality and morbidity;
- Improvement in functional health status;
- Increased satisfaction;
- Enhanced respect and understanding about the cultural differences, health beliefs, and protective factors of plan enrollees;
- Access to appropriate language translation services and educational materials whenever needed; and
- Increased equity and fairness.

Expanding Initiatives to Include Additional Populations

The majority of this toolkit focuses primarily on the most common racial and ethnic groups – African Americans, Hispanic/Latinos, Asians, and American Indian/Alaskan Natives. When a health insurance plan addresses disparities, however, individuals who may also be affected by these inequities are those with limited English proficiency (LEP) and lower socioeconomic position. In addition, plans should also consider how gender, age, disability status, and where a person lives influence the way these groups view health and access the health care system. Many of the factors, for example, that contribute to disparities among racial and ethnic groups are also prevalent among the lesbian, gay, bisexual, and transgender (LGBT) population. The lack of sufficient data and research constrains efforts to fully meet the needs of all these groups.

> **Community Efforts in Minnesota.** With the recent arrival of the Hmong refugee population, which accounted for 34% of new arrivals nationally, a group of Minnesota health insurance plans and community organizations have developed programs and services to assist the Hmong population with access to health care, education, and social services. Examples of such efforts are free health screening clinics and a bilingual telephone line to assist this population in accessing and understanding the health care system in the United States.

Some plans have been innovative in their forward way of doing business by addressing the needs of these groups. An example of such efforts is Kaiser Permanente. Kaiser Permanente's National Diversity Council and the Kaiser Permanente National Diversity Department have developed a series of provider handbooks to address their diverse populations. These handbooks focus on providing care that is culturally and linguistically appropriate for Latinos, African Americans, Asian/Pacific Islander, and the LGBT populations. A case for addressing disparities should speak to these groups, in addition to focusing on fairness principles, and pointing out the potential cost savings related to improved quality of care for all individuals.

Community Leaders. Community leaders have a natural interest in supporting disparity-reduction initiatives. Health insurance plans may face some challenges from the communities in their service areas in regards to data collection. These challenges include the lack of trust and community leadership support. Community leaders may also have concerns about the possible misuse of race and ethnicity data that may be required for such initiatives.

"Building a case" for community leaders requires attention not only to data collection, but to the policies and procedures that ensure the data are confidential and protected.

How a plan frames this message is key. If launched appropriately, a health insurance plan's data collection effort may also identify additional opportunities for collaboration within the community to reduce racial and ethnic disparities and increase the support of other health insurance plan initiatives within its service area.

For example, the mayor of Boston, Massachusetts, Mayor Thomas Menino, recently led a community initiative to reduce racial and ethnic disparities. Within the last year, Mayor Menino convened two task forces: the *Hospital Working Group* and the *Mayor's Task Force on Racial and Ethnic Health Disparities*, composed of leaders from the health care industry, including two health insurance plans – Blue Cross Blue Shield of Massachusetts and Harvard Pilgrim

> **Community Coalition.** An example of a community-wide effort to address disparities is the New England Regional Minority Health Committee. Staffed by different participants across each state or Commonwealth, the goals of this initiative are for health professionals to share strategies and gain cross cultural skills and training in order to eliminate health disparities by 2010. Participants include representatives from health departments, health insurance plans, hospitals, consumers, community organizations, and patient advocates from Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont.

Health Care, academia, and minority communities. Both task forces provided recommendations to improve the health of people of color and the Hospital Working Group issued recommendations to ensure all patients at health care facilities are treated equally. About $1 million in private and public partnership funding has been contributed to implement the recommendations set forth in the mayor's blueprint.

Strategies to consider: Align and work with community leaders. Identifying community leaders and consumers who could become involved in the planning, implementation, and evaluation process will foster an exchange of ideas, lessons learned, and support in addressing disparities by improving the health of the overall community. A plan may highly depend on its community leaders, such as church or business leaders for support when an initiative is implemented.

Effective quality improvement initiatives that advance quality of care for all plan enrollees have the additional effect of reducing or eliminating disparities. A successful case to the community will demonstrate how many disparities are related to underlying risk factors, thereby requiring focused attention on the care provided to these populations.

One Health Insurance Plan's Approach to Community Outreach.
In 1994, Oxford Health Plans conducted a community needs assessment in the Chinese communities in the greater New York area. The study was developed to evaluate the health care needs of the community, including access to Chinese-speaking physicians, access to Chinese-centric medical offices and the availability of Chinese-specific wellness programs and disease management initiatives.

The study demonstrated that the Chinese community had little knowledge of the American health care system, was unaware of Chinese-specific diseases, paid little attention to preventive care and often opted to see a doctor only when really sick. In addition, many of the older adults in the community, who were first-generation immigrants from China or Hong Kong, primarily speak Cantonese, Mandarin or Toisanese. They, therefore, have very little to no knowledge of English, rely heavily on their children to interpret their health care benefits, and look to friends or family for medical advice or information on how to access the health care system.

In addition, lack of access to culturally-sensitive services, health information, and support and resources needed to make informed health care decisions were seen as obstacles to greater understanding and usage of the health care system among Chinese members. As a result, Oxford opened an office with a walk-in and call center in the heart of Chinatown to provide in-language service to its members, and tailor programs and educational materials targeting the Chinese population. To further alleviate this population's fears and reservations about accessing health care services and providers in the United States, Oxford worked closely with provider organizations to create a network of quality, board-certified, Chinese-speaking physicians and establish a positive reputation among the Chinese population. Oxford also reached out to other local organizations, including senior and social centers, pharmacies and pharmaceutical companies, the Chinese divisions of various non-profit organizations, Asian-based community health clinics, local hospitals, government agencies, and business associations.

Over the past eleven years, Oxford's Asian Initiatives has participated in numerous innovative programs, both independently and in collaboration with other community organizations. Culturally-

relevant messages were incorporated into educational materials, seminars and health screenings in these health and wellness programs. The impact of these programs in the community extends far beyond Oxford's 40,000+ Asian enrollees.

Developing Community-based Programs.
Cultivating long-term relationships with individuals and organizations in the local communities enabled Oxford Health Plans to more quickly understand and address the needs of individuals. The following is list from Oxford Health Plans on lessons learned when developing community-based programs:
- Survey the population to determine what are the community needs;
- Have an on-going, open dialogue with opinion leaders to help prioritize community needs today and in the future;
- Create a "community board" comprised of a broad cross-section of the community to act as a sounding board for ideas and to flag changing opportunities and issues;
- Incorporate grassroots findings when developing programs and strategies;
- Obtain a long-term commitment from highest level of management within the organization and demonstrate this long-term commitment to the community;
- Form a coalition of for- and not-for-profit organizations to jointly launch community-wide programs and campaigns, providing the often-necessary community "stamp of approval";
- Produce informational materials and messages that are culturally sensitive with consistent messages that address the community's needs; and
- Evaluate success of the initiatives based on the criteria established earlier by surveying community representatives and reviewing usage data.

Employers or Purchasers. Private employers and public agencies purchase health insurance on behalf of large numbers of employees or program beneficiaries. Disparities in health mean that some employees or some program beneficiaries are not receiving the same quality of care.

As health insurance plans consider collecting data on race, ethnicity, and primary language, they should consider any related issues that may be raised by employers and purchasers. A recent survey conducted on behalf of the National Business Group on Health, previously known as the Washington Business Group on Health,[31] can provide some context. The survey findings revealed that:

- Most companies do not assess whether health insurance plans collect data on race and ethnicity to address disparities;
- Only fifty-five percent of respondents were very or somewhat comfortable addressing the way the health care system treats racial and ethnic populations differently than whites;
- Despite some awareness of disparities, the majority of survey respondents indicated that their companies have done little to address health disparities with their employees; and
- The majority of respondents are willing to become more informed and make changes to eliminate racial and ethnic disparities in health and health care.

Since the NBGH survey was conducted, some large purchasers are beginning to ask health insurance plans about their strategies for addressing disparities. A common question that a purchaser may ask a health insurance plan is: "What current initiatives does your plan have in place to reduce racial and ethnic health disparities?" The survey concluded that: "although most companies do not currently encourage their health plans to reduce racial and ethnic disparities, seventy-one percent of respondents reported that their companies will to some extent take into account whether their health plan is working to reduce disparities in health and health care when their plan comes up for renewal."

Background of NBGH Survey: Employer Awareness
In 2003, an employer survey about racial and ethnic health care was conducted by Princeton Survey Research Associates for the National Business Group on Health (NBGH). The purpose of the survey was to determine the extent to which large employers (defined as employing at least 1,000 or more employees) are aware of health care disparities among their employees and dependents; identify employers' barriers in reducing health disparities; and identify the sources of information on disparities that employers value the most and the information needed to engender action.

In addition, large purchasers seek to assess whether health insurance plans can identify and incorporate such efforts into quality management programs. The NBGH recommends that purchasers use existing surveys, such as questions from the Consumer Assessment of Health Plans Study (CAHPS®), to assess the experience of employees with their health care services and interaction with their providers. Employers may use these survey findings to address employees' concerns at health insurance plan renewal meetings or to incorporate them into a renewal criterion for health insurance plans.[32]

"Building a case" for private or public purchasers, then, requires attention to both the tangible benefits that would accrue as a result of reducing or eliminating disparities, and the potential concerns of employers or purchasers about the potential liability associated with collecting this information.

Some tangible benefits to employers come in the form of lower "direct" and "indirect" health care costs. The "direct" costs are health care costs that are reflected in plan premiums; the "indirect" costs are the costs of absenteeism, productivity losses, or disability payments associated with poor health outcomes. When health insurance plans are at risk for direct health care costs, employers are insulated from these costs in the short run (i.e. within a two year period) but not in the long run. Employers pay for the indirect costs, although, so the case for addressing disparities by employers may focus on the indirect costs of poor quality care.

Culturally diverse populations disproportionately receive lower quality health care and face significant challenges in accessing the health care system. Altering this environment will take the collaborative efforts of all stakeholders. Health insurance plans can play a key role in these initiatives by improving the quality and access of services provided to their enrollees.

> **The National Business Group on Health (NBGH)** has developed a toolkit for employers interested in addressing health disparities, entitled "An Employer Toolkit – Reducing Racial and Ethnic Health Disparities." This toolkit provides information on strategies that employers can use to assess and reduce disparities; an overview of findings from the 2003 employer survey; and key issue briefs on building a case for addressing disparities and bridging language and culture in the workplace. For more information, please access the NBGH's website at http://www.wbgh.org/prevention/et_reducing disparities.cfm.

Component 5: Collecting Data on Race, Ethnicity, and Primary Language

Overview

A common strategy used to identify gaps in care or outcomes is through the collection of data. In seeking answers to health disparities for certain racial and ethnic groups, data collection and analysis become essential tools. In this component, several common methodologies to collect data on race, ethnicity, and primary language are highlighted in addition to the opportunities and challenges associated with each. Recommended strategies for implementing initiatives that use these data will be discussed in component seven of the toolkit.

> **Key Finding from AHIP/RWJF Survey:** The results from the AHIP and The Robert Wood Johnson Foundation (RWJF) survey found that over half (53.5%) of enrollees were covered by health insurance plans that responded to the survey and reported collecting data on race/ethnicity either through direct or indirect methods.[40]

Methods Used to Collect Data on Race and Ethnicity

One of two methods may be used to collect data on race, ethnicity, and primary language. Health insurance plans may collect data either *directly* from enrollees on a voluntary basis or *indirectly* using some other existing information about an individual plan enrollee (usually surname or zip code) to infer race or ethnicity. The end result, however, from either of these strategies is a race/ethnicity identifier that is assigned to each plan enrollee (or subset of the plan's enrollees for which the data collection process is targeted).

The set of categories used by individual health insurance plans to identify enrollees depends to some extent on local circumstances and population characteristics. A limited set of categories like "Black", "White", and "Other" may seem very crude and non-inclusive, but may actually be useful for plans in some parts of the country. On the other hand, health insurance plans with enrollees in large cities would want

> **Office of Management and Budget Census Categories.** Since 2000, federal agencies have been required to use a minimum of five race categories: White; Black or African American; American Indian or Alaskan Native; Asian; and Native Hawaiian or Other Pacific Islander. A sixth category – "some other race" – is also included in the U.S. Census and a few other federal data collection surveys.

to use racial and ethnic sub-categories that further identify Hispanic or Latino, Asian, and Native Hawaiian and Pacific Islander enrollees. Identifiers can be tailored to any level to meet local needs, but it is also useful to maintain an ability to "roll up" to the major U.S. Census categories established by the Office of Management and Budget (OMB)[33] in order to do comparisons with either published data or results from plans in other parts of the country.

Depending on geographic location, health insurance plans may wish to expand on the subgroups reported to better define the ethnicity of individual enrollees – for example, Salvadorian, Dominican, Columbian, or Portuguese. For example, the above text box describes how the OMB defines Hispanic or Latino.[34] Collecting this information will also enable plans to develop more targeted programs and strategies that meet the needs of their unique populations. It is important to note that one strategy for one subgroup may not work with other populations.

> **Defining Hispanic or Latino.** The OMB defines Hispanic or Latino as "a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race.[34]

Most Common Direct Methods of Data Collection

Health Insurance Plan Enrollment Process. Some health insurance plans voluntarily collect data on race, ethnicity, and primary language during the plan's enrollment process. These data are self-reported by enrollees and have been found to be fairly accurate. Component two of the toolkit notes that there are several states that limit health insurance plans from collecting data on race and ethnicity during the application process.

> **Key Finding from AHIP/RWJF Survey:** The most common methods used to collect 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%).[40]

Example of Race/Ethnicity Categories Included on a Health Insurance Plan Enrollment Form:

Race/Ethnicity – Optional* (This information is designed for the purpose of data collection and will not be used for determining eligibility, rating or claim payment.)

- White – 01
- African-American or Black - 02
- Hispanic or Latino – 03
- Asian – 04
- Other – 05 _____
    *This information cannot be used to deny your application for membership.

Excerpt taken from Aetna Golden Medicare Plan® and Aetna Golden Choice™ Enrollment Forms[35]

The previous example provides an open-ended response for race/ethnicity under the category, "other." A health insurance plan may consider providing an open-ended category for enrollees that do not fall under the main racial/ethnic groups or self-identify as bi-racial.

Disease Management (DM)/ Care Management Programs. Other health insurance plans collect data from individuals as they enroll in targeted disease management or similar programs. These data are self-reported by program participants as they enroll in the DM program or as case managers conduct interviews or telephone outreach with individual enrollees. While accurate and complete, this method covers only those individuals enrolled in these targeted programs and not all individuals enrolled in a health insurance plan.

Legacy WellPoint's Health Improvement (Disease Management) Program (HIP)

WellPoint, Inc. collects race and ethnicity data directly from their enrollees through their disease management enrollment survey for its most intensive health improvement program (HIP) – the Health Coaching Program. HIP offers high-risk members a combination of interventions that includes a condition-specific assessment survey to further stratify the member based on motivation to change, disease knowledge, and other factors. The assessment is designed to actively involve the member in developing a health coaching plan. Members identified as high risk are also offered the opportunity to engage in a more intense program involving individualized telephonic education with health coaches in addition to mailers and brochures. Members must agree to participate in the health coaching portion. This model allows WellPoint's programs to focus most of its resources on members who are ready to make behavior changes.

WellPoint's Challenges & Opportunities

To date, WellPoint, Inc. has not yet made the corporate decision to collect race/ethnicity data for its entire population. The plan is still working through system integration priorities as a result of a recent merger. As integration progresses, it is likely that several legacy membership/claims systems will continue to exist. Building consistent IT data fields and definitions for different systems will be an important consideration.

As a large company that is managed regionally, developing and implementing consistent policy and workflow for capturing race/ethnicity data for all enrollees will be a lengthy process. Given the size of WellPoint's membership base, however, if systematic data collection of race/ethnicity information is implemented, the potential and opportunity for robust clinical informatics and research opportunities in addressing the health status disparities issues, by region, will be tremendous and can benefit the entire industry.

When members agree to participate in the health coaching program, they must complete a telephonic enrollment survey, during which they are asked to self-report race/ethnicity information.

To date, about 95% of WellPoint's members enrolled in the program have provided the race/ethnicity information.

Established in year-end 2002, the health coaching program is currently evaluating the effectiveness of the program with assistance from the RAND Corporation through participation in the National Health Plan Learning Collaborative to Reduce Disparities and Improve Quality. By June 2005, an analysis of health outcomes and race/ethnicity data for health coaching members against race/ethnicity data obtained through proxy, geo-coded/surname analysis for all of WellPoint's HIP eligible members (2,000,000+ records). Legacy WellPoint's disease management program, which covers members in Blue Cross of California, Blue Cross Blue Shield of Georgia, Blue Cross Blue Shield of Missouri, Blue Cross Blue Shield of Wisconsin, and UNICARE consists of primarily commercial, large group members.

Preliminary Results: Blue Cross of California's Health Coaching Program

A preliminary study on 2003 utilization and quality outcomes for Blue Cross of California high-risk members with diabetes, enrolled in health coaching program and stratified by ethnicity, yielded some interesting patterns. The goal was to assess whether racial disparity in care of individuals with diabetes existed among these enrollees. Members included in this study appeared to have similar demographic and severity backgrounds; hence variation in care could not be explained by demographics and severity of illness. Different ethnic groups did appear to have very different utilization and quality patterns. Specifically:

- Asians had lower utilization and higher quality metric scores
- Blacks had higher utilization and lower quality metric scores
- Latinos had lower utilization and lower quality metric scores

Currently, reconciling these results is difficult, especially the low utilization and low quality metric scores for Latinos. However, since clear health status disparities patterns exist, current and future program enhancement activities will stress cultural sensitivity and linguistically appropriate services.

Health Risk Assessments. A health risk assessment is another way a health insurance plan may collect information on an enrollee's race, ethnicity, or preferred primary language. Health risk assessments assist health insurance plans in identifying needed resources and determining those individuals who can benefit from the plan's disease management or health promotion programs, especially those at risk for certain health conditions.

Example of Race/Ethnicity Categories Included on a Health Risk Assessment Form:

31. Which of the following categories best describes your race?

    Please check all that apply.

    American Indian or Alaskan native 1
    Asian 2
    Black or African American 3
    Native Hawaiian or Other Pacific Islander .. 4
    White 5
    Please describe any other racial
    category below: 6
    _____

32. Are you of Hispanic or Latino origin?

        Yes 1
        No 0

    Excerpt from Health Plan of Nevada's Health Risk Screen Survey for its Medicare program, Senior Dimensions.[36]

A Health Insurance Plan Linking Health Risk Assessments to Disease Management Programs.

PacifiCare's Evaluate Your Health™/ Evalúe Su Salud™ is a personalized, interactive, audio-visual health risk assessment on CD-ROM (in Spanish and English) that assists enrollees in identifying their respective health care needs and issues. As a result, plan enrollees receive an individual health profile that can be shared with their physicians. PacifiCare's Evaluate Your Health™/ Evalúe Su Salud™ program complements their plan's bilingual (English/Spanish) health management programs and serves as a "front end" to encourage enrollees to access these programs and take action to improve their lifestyle behaviors.

PacifiCare's health management programs address cardiovascular health, diabetes, depression, and smoking cessation. The Taking Charge of Your Heart Health[SM] and Taking Charge of Your Diabetes[SM] programs are mail-based and self-directed programs that provide education on managing these diseases through self-management and preventive care. These programs include Spanish-

language print materials that can also be accessed online. The Taking Charge of Your Depression[SM] and Free & Clear®/Stop Smoking[SM] programs are case-based, self-referred programs that provide written educational materials as well as telephonic support.

Enrollee Satisfaction Surveys.
Satisfaction surveys are another method used by health insurance plans to collect data on race, ethnicity, and primary language. Enrollees self-identify their race, ethnicity, and primary language resulting in high levels of accuracy and completeness. A challenge, however, in collecting survey data is to have a large enough sample size to further analyze specific subgroups.

One common survey administered by health insurance plans is the annual Consumer Assessment of Health Plans Study (CAHPS), a survey that evaluates the quality of services provided to health insurance plan enrollees. This standardized survey instrument, developed by AHRQ and NCQA, contains race and ethnicity categories.

> **Enrollee Surveys to Coordinate Care.** AvMed Health Plans in Florida conducted a survey of its enrollees with diabetes to identify potential sociodemographic factors (e.g., race/ethnicity and educational level) that may influence their ability to comply with recommended treatment. From that analysis, AvMed found that its members with diabetes and lower educational attainment did not fully understand the components of appropriate diabetes management. AvMed targeted the following interventions to increase the access to needed services among these enrollees:
> - Increased awareness of diabetes and receipt of appropriate screening tests through health fairs scheduled during non-work hours; and
> - Increased access to screening tests through home monitoring for lipid screening and HbA1c levels.
>
> Through routine feedback loops, these interventions have improved the coordination of care between enrollees, providers, and the health insurance plan.

Collecting Data Through A Health Insurance Plan's Diabetes Registry.
Since 1994, investigators at the Kaiser Permanente Division of Research have collected race, ethnicity, and primary language for the Kaiser Permanente Northern California Diabetes Registry (n ~199,000). These data have been ascertained in several ways:

1. Survey-based assessment of self-identified race, ethnicity, primary language, and educational attainment
    a. Surveyed enrollees in the whole diabetes registry 1994-1997 (83% response rate)
    b. Launching a new National Institutes of Health (NIH) - funded survey in a stratified (by race) random sample of ~40,000 subjects with diabetes in their diabetes registry (funded by two NIH grants: R01 DK65664 and R01 HD046113)
2. Electronic records (Race "flags" are incorporated in hospitalization records and preferred language is included in member records)

3.   Contextual assessment: Kaiser Permanente has geocoded all addresses to the Census block group level and linked with the U.S. Census 1990 and 2000 for estimates of neighborhood level race, language, and socioeconomic status distributions.

Kaiser Permanente has used the race, ethnicity, socioeconomic status, and primary language data in their research regarding social disparities. The registry is updated annually by identifying plan enrollees with diabetes from automated databases for pharmacy and laboratory information, hospitalization records, and outpatient diagnosis.[37] This information, in addition to impacting the public health through their published research, has influenced Kaiser Permanente's evolving models of care.

Most Common Indirect Methods of Data Collection

Many health insurance plans use indirect methods to collect data on race, ethnicity, and primary language through a variety of commonly accepted methods:

Geocoding. Geocoding is a technique that involves using residential address data to infer other characteristics of individuals, such as race/ethnicity, education, income, and social class. This method depends on the tendency of people with similar characteristics to live near each other. Using recent U.S. Census data at small units of aggregation ("census tracts" or "block groups"), geocoding allows organizations to make reasonably good inferences about individuals, including their race/ethnicity, based on their street addresses/zip codes.

> **Key Finding from AHIP/RWJF Survey:** Of those plans that collect data and responded to the survey, 38.5% collect these data using geocoding software and 40.1% obtain data through files linked to external sources, such as Federal agencies or birth records.[40]

Many health insurance plans use geocoding as an effective and practical strategy for assigning race and ethnicity categories to individual health insurance plan enrollees. Geocoding permits health insurance plans to use census data to create proxy variables for an enrollee's race and ethnicity and it also provides information on other important socioeconomic variables that can affect health risks and the provision of health care, such as education and income. [38]

There are, however, some limitations associated with this method. Geocoding can only be used to assign categories from the U.S. Census, and even then, only those categories with enough individuals living near each other can be used to assign one of those categories with some certainty to a person with a particular address. In addition, the method may not work well in highly integrated areas and it can only be used to identify individuals and groups who are "dominant" in at least some neighborhoods or parts of a plan's service area. Further, racially and ethnically diverse populations that are large in absolute or relative terms, but are distributed in a region so that they are a minority wherever they live, can never be identified by standard geocoding methods. Geocoding, therefore,

may lead to misclassification by race or ethnicity especially if racial and ethnic segregation is low in a specific geographic area. While geocoding is not 100 percent accurate, it may be useful to health insurance plans in identifying high-risk enrollees and potential disparities in care.

How a Health Insurance Plan Can Use Geocoding
There are several steps involved for a health insurance plan to use geocoding methods to make inferences about race/ethnicity of plan enrollees. The general sequence that an analyst (from a plan or third party vendor) would follow is:

- Begin with street addresses – in this case, the residential addresses of plan enrollees as recorded in the membership files;
- Use geocoding software to assign a specific latitude and longitude to each street address;
- Use the software to assign street addresses to census tracts, block groups, and other "units of geography"; and
- Use the census data for those geographic units to make inferences about the race/ethnicity of residents within those units.

The last step in the process is the one that can be difficult to assess in many health insurance plan service areas. If the analysis shows, for example, that 70% of the residents in a particular block group are African American, with the remaining 30% divided equally among Hispanic and non-Hispanic White residents, would this be sufficient to presume that a health insurance plan enrollee living in that block group was African American? If not, would it be sufficient if the block group residents were 80% African American? 90%? 95%? This decision to "imply" the race/ethnicity of plan enrollees must be discussed within an individual plan.

One of the options for information display "race" which allows the user to see the racial composition of the neighborhood around that address. For additional resources or software vendors, see the Resources and Tools section of the toolkit.

Although the majority of commercial geocoding firms use the TIGER/Line file from the U.S. Census Bureau as the basis for identifying the location of street addresses, there may be some variability in the accuracy and completeness of geocoding associated with each vendor. Health insurance plans considering geocoding as an option should ask potential vendors to provide background information about the accuracy and address match rates within the plan service area.

Surname Recognition. Another approach for plans, researchers, and marketing groups is to use surname recognition software and classification methods in addition to geocoding to obtain a more precise and accurate classification of individuals.

These software systems depend on the existence of recognizable features of surnames among people from specific countries or parts of the world. A name ending in "ez" (Gonzalez, Hernandez, Rodriguez), for example, might be identified as Hispanic or a short name starting with X and ending with a vowel (Xi, Xu) might be identified as Chinese. These systems work well to the extent that names in a particular group of interest really are distinct, and to the extent that members of a specific group tend to marry each other and use the distinctive surnames for all members of a household.

A commonly used surname recognition software program is GUESS (Generally Useful Ethnicity Search System). Although originally developed by the University of New Mexico in the 1960s, this software uses surnames to identify individuals as Hispanic or non-Hispanic descent and is estimated to be 85-90% accurate. Other systems have also been developed more recently to identify individuals with ancestry in individual countries or cultural or linguistic groups.

A recent study published by Morgan and colleagues showed that surname recognition software significantly enhanced the accuracy of identification of Hispanic males in Medicare files. This could be particularly useful for plans using CMS/Medicare data for Medicare Advantage products.[39]

Use of Surname Recognition Software. To identify possible disparities in care and outcomes by ethnicity, Lovelace Clinic Foundation and other Lovelace Sandia Health System-affiliated research organizations have explored the use of the GUESS software system developed at the University of New Mexico for assigning ethnic origins on the basis of surname. Although surnames are grouped into a variety of ethnic classes by the GUESS system, the only reliable classifications for New Mexico are Hispanic and non-Hispanic. The GUESS program is well-suited to the Lovelace Health Plan (LHP) population since LHP enrollees are primarily Hispanic (42%) and non-Hispanic. There are very few African-Americans in the LHP membership. Previous studies have shown the GUESS software to be 90% accurate for identifying Hispanic ethnicity in New Mexico. Validation of the GUESS program against the Surveillance, Epidemiology, and End Results (SEER) tumor registry records of Lovelace female members with breast cancer showed accurate assignment of ethnicity for 95.3% of non-Hispanic white women and 83.8% of Hispanic women.

A number of marketing firms have systems (usually proprietary) to classify names into ethnic and/or cultural groups. A list of vendors and their websites are provided in the Resources and Tools section of the toolkit. These web sites may provide detailed descriptions of what their software can do, and provide some interesting examples of the challenges in dealing with names that have to be phonetically transformed from a non-Roman character set and language to English.

Obtaining Data from Linked Files from External Sources

Health insurance plans have the ability to obtain data on race, ethnicity, and primary language through files linked to external sources.[40] Plans serving Medicare or Medicaid beneficiaries, for example, have the opportunity to use race/ethnicity data collected by CMS and the states at the time of eligibility determination for Medicaid. For plans participating in the Medicare Advantage program, CMS has provided data on race and ethnicity since 2003 through electronic data files. The race and ethnicity information from CMS is collected from the U.S.'s Social Security database.

The situation is similar for Medicaid plans; however, there is variation from state to state in terms of the process for collection of race/ethnicity data, the categories used, and the extent to which data are known to be accurate and complete. Since Fiscal Year 2003, state Medicaid programs have been required by CMS to make race/ethnicity data available to health insurance plans in order to support work related to disparities and/or cultural and linguistic competency. The extent to which this is done routinely, the processes for transferring data, the accuracy of the data, and the extent to which the data exist in eligibility files all differ from state to state. These data, though, have been the starting point for several demonstration projects on disparities involving Medicaid health insurance plans.[41]

A Medicaid Health Insurance Plan Monitoring HEDIS Measures with Enrollee and Provider Interventions

As part of Healthfirst's participation in the Center for Health Care Strategies' Best Clinical and Administrative Practices (BCAP) project, Healthfirst[42] obtained race and ethnicity data on their Medicaid enrollees from the New York State Department of Health. Linking these data with their Quality Assurance Reporting Requirements (QARR)/HEDIS rates from 2003, Healthfirst identified enrollees in specific racial and ethnic groups who were non compliant with their diabetes care in the areas of HbA1C control, eye exam, lipid control and nephropathy monitoring. To improve the compliance rates of their Hispanic and African American Medicaid enrollees with diabetes, Healthfirst will measure whether the following interventions are effective in improving the health care of their racially and ethnically diverse enrollees:

- Targeted outbound telephone calls from multi-lingual staff to encourage enrollees to ask their providers for screening tests during their next follow-up appointment;
- Continuing Medical Education training for providers about appropriate diabetes care in three of the plan's largest hospital affiliations; and
- Direct mailings of multi-lingual health education materials to enrollees.

The baseline QARR/HEDIS rates from 2003 will then be compared with the 2004 results in the Fall 2005 to determine any improvements.

Gathering Data from Employers. Most employers that currently obtain data on race and ethnicity of their employees do so through surveys. There have been some suggestions that employers, especially large employers, could voluntarily collect data on race and ethnicity and transmit this information to health insurance plans. Employers have concerns about potential HIPAA violations or other confidentiality policies. This situation may change in the future as local, state, or national purchasing coalitions identify disparities as an important area of focus and commit to solving the technical and policy problems associated with this data transfer.

Vital Statistics/Birth Records. All 50 states collect birth and death certificate data and provide this information to the National Center for Health Statistics (NCHS). Most states use standards for reporting to NCHS at the local level. Race and ethnicity are included as standards for reporting socioeconomic status of the parents from birth data records and of the descendent for death certificates.[43] The racial and ethnic categories are noted by the health care worker or funeral director, who requests it from the next of kin or family representative. Under the five minimum OMB categories, the Asian categories were recently recommended for expansion to include Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, and other Asian. Separate Pacific Islander categories would be Native Hawaiian, Guamanian or Chamorro, Samoan, or other Pacific Islander.

Other Potential National Data Collection Strategies on the Horizon

The addition of racial and ethnic categories have been suggested for inclusion on administrative transaction forms, such as the HIPAA transactions. This method can be a more direct way of collecting race and ethnicity data. The use of this method will increase standardization of data collection by health insurance plans, providers, and purchasers. However, there are initial steps that will need to take place in order for this method to be considered as a possible strategy. According to the National Research Council, the Secretary of HHS can propose changes to the current HIPAA standards with guidance and approval from designated standards maintenance organizations (DSMOs) and in consultation with other industry committees. One argument for proposing these changes would be to meet the Healthy People 2010 goals to eliminate disparities in health.[44]

> **Learning from Other Sectors in Health Care.** A group of researchers at the Health Research and Educational Trust (HRET), the Foundation associated with the American Hospital Association, has been working to develop a standardized set of questions for hospitals to use to identify the race and ethnicity of individual patients. The instrument template not only provides a specific question and answer format but also discusses the rationale behind collecting such data. Examples of HRET's current templates can be found at www.hret.org.

Enrollment transactions, such as HIPAA transaction 834, transmit enrollment and disenrollment information to a health insurance plan in order to establish or terminate an individual's health insurance coverage. Currently, information about race and ethnicity is designated as a "situational" field for transaction completion. A primary language data field is not available. This method is limited to only new enrollees, leaving out individuals who have not changed their plans for a number of years.

Claims/Encounter standard transactions, such as the electronic HIPAA transaction 837, currently do not have data fields for race, ethnicity, or primary language. Using these forms, however, would allow for a standardized method to collect this information across all health care providers and increase the ability of measuring disparities in health care. Misclassification of data on race and ethnicity by the provider may be a challenge without appropriate professional training. Providers may also see such requirements as a barrier to completing and transmitting a claim for payment in a timely manner and/or be wary of privacy protections.

New York Health Insurance Plans Using Claims & Zip Code Data To Develop Cross Cultural Training and Consumer Materials:
Under a one year grant from the New York State Department of Health, Office of Managed Care, the New York Health Plan Association Council, Inc. collaborated with three health insurance plans (Fidelis Care New York, Neighborhood Health Providers, and UnitedHealthcare/AmeriChoice), the Center for Immigrant Health, and the New York University School of Medicine, to address disparities in access and utilization of health services by minority and immigrant Medicaid enrollees living in New York City. The project's multi-pronged approach aimed to improve the levels of cultural competency among health insurance plan clinical and non-clinical direct service staff and network providers, and to empower the immigrant and minority enrollees to better understand, access, and utilize health services.

To identify the target populations for intervention, the three health insurance plans ran claims data to identify zip codes of enrollees with poor health care utilization rates. The data focused on low utilization rates for well visits, high utilization for emergency department visits, and *no* primary care visits. This information was then used to identify the racial and ethnic make up of the geographic areas within the five boroughs of New York. The racial and ethnic zip code data was taken from the New York City Department of Planning.

This neighborhood profile was used to create a training curriculum for primary care physicians and health insurance plan staff serving the targeted zip codes. To develop the training curriculum, the level of cultural knowledge among plan staff and network providers was obtained through needs assessment surveys designed to assess entitlement knowledge, immigrant knowledge, attitudes, and best practices for interpreter use. The information gathered from the surveys was explored in depth through focus groups. The cultural competence training programs were customized to reflect the

populations in the target zip codes and the needs of clinical and non-clinical plan staff and primary care providers (PCPs).

The data collection methodology was also used to identify four targeted languages (Spanish, Chinese, Russian, and Haitian/Creole), in addition to English, for the development of patient education materials called Patient Empowerment Tools (PETs). The PETs were designed to educate health insurance plan enrollees and other patients about the importance of preventive health practices, such as annual well visits, screenings, and immunizations. In addition, immunization and screening schedules were developed for patients and language access cards were provided for non-English speaking patients to request translation services.

> **Using Subcategories to Identify Race and Ethnicity.** If a health insurance plan finds it necessary to use additional sub-categories to identify plan enrollees, a recent study conducted by participants in the HMO Research Network describes how these categories can be "rolled up" to the standard census categories to allow for comparisons with other plans or other published data. For additional information, please access Ford's article in *Ethnicity & Disease*.[45]

Which Categories to Use?

As indicated above, selecting the specific race and ethnicity categories to use can be, and to some extent must be, tailored to local population characteristics. On the other hand, data available from public sources, such as Medicare, Medicaid, or the U.S. Census, may be limited to the five or seven major categories that are routinely used. Using surname recognition methods can provide greater detail, but the available software may not fit the needs of health insurance plans in many parts of the country.

In an initial effort to identify and understand what disparities exist among their enrollees, health insurance plans do not have to obtain data on every conceivable racial and ethnic subgroup. If a quality improvement initiative focuses on disparities in health for specific clinical areas evaluated by HEDIS, such as breast cancer screening, the limited sample size will require the plan to only address the disparities found in large populations. The standard census categories may be adequate initially, with more detailed data collection and analysis reserved for more comprehensive initiatives.[45]

Collecting Data on Primary Language. In the absence of information on race and ethnicity, it is not uncommon for health insurance plans to use primary language as a proxy for race and ethnicity. According to the AHIP/RWJF survey, 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. For health insurance plans that collect primary language data directly from enrollees, it is most commonly

collected via the plan enrollment form (80.9%) and indirectly through geocoding software (27.8%), and obtained through files linked with external sources (22%).

Examples of Primary Language Questions on Health Insurance Plan Enrollment Forms:

Example 1:
Is English your primary language? (optional) ▪ Yes ▪ No   If no, other language _____
{note: open-ended response}
See Enrollee Bill of Rights for your rights as a consumer of health care services

Excerpt taken from UCare for Seniors Enrollment Form, UCare Minnesota[46]

Example 2:
Primary Language Spoken (optional)*_____ {note: open-ended response}
*This information cannot be used to deny your application for membership.

Excerpt taken from Aetna Golden Medicare Plan® and Aetna Golden Choice™ Enrollment Forms

Example 3:
Language Preference/Spoken _____{note: open-ended response}
Language Preference/Written _____{note: open-ended response}

Excerpt taken from Presbyterian Senior Care Benefit Election Form[47]

One Health Insurance Plan's Approach.
PacifiCare established diversity initiatives such as Latino Health Solutions, Asian Health Solutions, African American Health Solutions and a Diversity Council to focus on serving and understanding the cultural preferences of minority enrollees, their employers as well as the brokers, consultants and health care providers who work with them. PacifiCare developed a broad range of programs and services for their health insurance plan enrollees focusing on health improvement and education as well as information about health insurance. For example, many materials are available in a bilingual format and include print, audio/visual, CD-ROM and web-based products. The company's website, www.pacificare.com, provides members with access to the Asian Health Solutions website, www.pacificareAsia.com (Chinese, Korean and Vietnamese) for their California enrollees, as well as access to the PacifiCare's Spanish-language website, www.pacificareLatino.com, for plan enrollees living in Arizona, California, Colorado, Texas, Nevada, Oklahoma, and Oregon.

Representing 27.4% of the total population in the eight states where PacifiCare operated in 2004, Latinos made up the largest minority group, more than 22.7 million Latinos. To address these needs, PacifiCare carried-out enterprise-wide system modifications enabling their health insurance plans in the Western part of the U.S. to capture language preference and ethnicity information.

Many of PacifiCare's Hispanic and Asian enrollees prefer to communicate in Spanish, Chinese, Korean or Vietnamese especially when dealing with complicated or personal issues regarding their health, health care and health insurance. Recognizing that while many Hispanic and Asian members may speak fluent English, they may live in households where their native language is preferred. As a result, Spanish speaking members are served by three regional bilingual customer service centers. The Asian language services are available only in California.

Moving Forward

The AHIP/RWJF survey findings show that there is a critical need for the health care industry to determine how to achieve commonalities and standardization in data collection.[48] Partnerships with other stakeholders such as CMS or the hospital industry were suggested in order to enable plans to standardize data collection processes that can then be replicated across the health care system to form the basis for "a common language." [49] Commonalities in data collection will also facilitate more effective use of these data in reducing disparities of care among racial and ethnic populations.[50]

Component 6: Analyzing the Data

Overview

Data analyses are driven by questions, so this component of the toolkit is organized around the kinds of questions that health insurance plan staff will typically ask if they have available data on the race/ethnicity of their enrollees. Technical issues like sample sizes for analysis and testing for statistical significance will also be discussed under each of the major headings.

Data are only useful when they become information – that is, when they are used to answer questions or identify patterns that lead us to ask new questions. When health insurance plans collect data on race and ethnicity, the next step is to analyze data to answer questions about patterns of care and services that are provided to plan enrollees. The most basic of these questions is: "Do enrollees within our health insurance plan and across different racial/ethnic groups receive the same quality of care or service?" Variations on this question could focus on racial/ethnic disparities in more specific domains, such as preventive screening, management of chronic conditions, or outcomes of treatment. Depending on what the data tells us about answers to these basic questions, there may be other questions that follow about *how* or *why* those patterns of care are observed.

Questions about the Race/Ethnicity of Enrollees

The most basic question to ask when using race/ethnicity data is: "*What is the racial and ethnic composition of our health insurance plan enrollee population?*" The categories used to classify enrollees can only be as detailed as the original source of data allows. For most plans, this question will be answered by counting the number of plan enrollees in each of the major census categories (e.g., "Asian," "Native Hawaiian and Pacific Islander," "African American," "White," etc.). Plans that take data collection and classification to another level of detail (e.g., breaking "Hispanic" down into "Mexican," "Cuban," "Puerto Rican," "Dominican," "Central American," "South American," and "Other") may want to display the counts in two ways – once with the sub-categories combined as "Hispanic" and once with the separate sub-categories shown. Calculating each group's percentage of the total plan enrolled population is almost always part of the basic descriptive analysis.

Additional Analysis

Race/ethnicity data can also be combined with other basic enrollee information to generate a potentially large number of two- or three-way tables. One may create, for example, a table showing a separate racial and ethnic distribution of male and female enrollees.

Table B: Sample Table

Race/Ethnicity Categories	Product Line			
	Medicare (Over 65)		Commercial	
	Male	Female	Male	Female
African American	1,467	2,217	34,612	36,731
Hispanic	756	812	27,311	27,899
Asian	62	67	378	326
White	4,691	5,236	94,558	96,151
Other	577	590	3,581	3,779

One may instead create a table highlighting the race/ethnicity of enrollees across different age bands (as in Table B above) or for enrollees who reside in specific counties within the health insurance plan service area. It will generally not be necessary or useful to apply tests of statistical significance to any of these tables, unless the plan specifically wants to know whether the distribution of race/ethnicity in one region is significantly different from that in another, or whether the distribution of race/ethnicity is different for men than for women. For those kinds of questions, a simple chi-square test[51] will almost always be adequate.

Questions about Other Characteristics of Enrollees

The process used by a health insurance plan to collect data on race/ethnicity may also have produced data on socioeconomic status (SES), primary language, or specific components of SES like income, job class, or education. The same basic descriptive tables can be created; however, it will be particularly useful to produce at least some selected "cross-tabs" relating some of these characteristics to each other. For example, a two-way table of primary language and Hispanic ethnicity will address the question of how many Hispanic enrollees report using Spanish versus English as their primary language. Tables of education by race or ethnicity may also show the number and percent of enrollees in specific groups who may have limited reading ability and who may benefit from an initiative focused on the development of low-literacy patient education materials. These options will most likely be available if race/ethnicity data were obtained through geocoding, so that SES data elements are available from the same census sources as race/ethnicity.

These one-way or two-way descriptive tables will be helpful in understanding the characteristics of the plan's enrollees, but are only the first step in understanding disparities in the actual care received. These tables will also be very useful in generating ideas about potential quality improvement projects if disparities in healthcare are found. For example, if an analysis shows that children who are identified as Hispanic are less likely to receive appropriate immunizations than those identified as non-Hispanic, the tables showing relationships between Hispanic ethnicity and Spanish as primary language, or education, or income, will help determine whether initiatives that focus on providing reminders in Spanish, low-literacy reminder materials in English, or reducing financial barriers to immunization would be the most helpful.

Disparities in Access or Utilization

Questions to Ask
Many health insurance plans will want to know whether there is any variation among different racial/ethnic groups on basic measures of access or utilization. These measures might include:
- Percent of enrollees with at least one primary care visit in the past year;
- Percent of enrollees with an Emergency Department or urgent care visit in the past year;
- Percent of enrollees with a hospital admission in the past year;
- Inpatient days per 1,000 enrollees; and/or
- Medical care expenses per enrollee per month.

For specific clinical and demographic subgroups, measures of access and utilization also may begin to look like measures of quality. Some of these measures might include:
- Percent of pregnant women with at least one prenatal care visit in the first trimester; and/or
- Percent of children with six or more well-child visits.

Example of Analysis
Questions about the existence of possible racial/ethnic disparities related to any of these measures require calculating the measures separately for members of each group of interest, and then comparing the separate measures to determine whether statistically significant differences exist.

For measures expressed as rates, percents, or proportions (i.e., those with a numerator and denominator), a chi-square test can be used to test the significance of differences across two or more groups of interest.   For example:

Table C:

Racial/Ethnic Group	Had Mammogram	Did Not Have Mammogram	Total
African American	67 (74%)	23	90
Hispanic	175 (69%)	79	254
White	128 (81%)	30	158

The *expected value* for the number of women in each of the three groups having a mammogram, if there were no disparities (i.e., the proportion of women in each group having a mammogram was equal) would be 66 for African American, 187 for Hispanic, and 116 for White. More White women than expected, but fewer Hispanic women than expected, received mammograms. The chi-square statistic compares the actual number in each cell to the expected number. The Chi-square value calculates to be 7.41 with 2 degrees of freedom, with a p value of .025. There is a significant disparity in mammography rates across the three groups.

For measures expressed as averages, a t-test can be used to compare averages across two groups; other statistics can be used to compare averages across two, three, or more groups. Try to do many of these tests on line at http://www.ifigure.com/math/stat/testing.htm.

The "power" of any of these statistical tests (i.e., the test's ability to detect a real difference), depends both on the size of the difference in the measure between groups and the sample size. Even a very large *apparent* difference between two or more groups will not be statistically significant if the size of one or more of the groups is very small. For example, a recent analysis of "door to needle time" for administration of thrombolytics to heart attack patients identified an apparent disparity in which Black patients received thrombolytics much more quickly on average than White patients. Interest in this difference waned quickly, however, when it was clear that fewer than twenty Black patients and fewer than ten White patients were included in the analysis, and the apparent difference was really due to just two White patients with unusually long administration times.

To address the issue of sample size in terms of a general rule of thumb, NCQA requires that there be a minimum sample size of 30 for any group of individuals upon which one of the HEDIS measures is calculated and reported. There are more precise formulas for calculating the power of statistical tests, given various sample sizes,[52] and it is common to try to have a sample size capable of producing a probability of 80% of detecting a difference of a pre-defined, meaningful size, if present.

Completing this sort of formal power calculation requires the analyst to decide how big a difference there needs to be in order to be meaningful. There is no widely accepted basis for doing this in the context of racial/ethnic disparities, although one published example uses five percentage points as an arbitrary cut-off for identifying a meaningful difference in a measure that has the form of a rate or percentage.[53]

Interpreting the Results. Even when differences in measures of access or utilization are significantly different across two or more racial and ethnic groups, interpretation of those differences may not be straightforward. Imagine that an initial round of analysis shows a significantly higher admission rate and inpatient days per 1,000 enrollees for Hispanic versus Asian plan enrollees. On its face, this suggests a possible problem in access for Asian plan enrollees. If, however, other data suggests that Hispanic plan enrollees are older on average, or have a higher

prevalence of diabetes, asthma, and hypertension, then the difference in admission rates may be a reflection of underlying clinical need and not have anything to do with access per se. Interpretation of racial/ethnic disparities in almost any measure requires detailed knowledge of the plan's enrolled population and local health care dynamics. In this example, if plan analysts also knew that many of their Asian enrollees also used traditional Chinese medicine providers who were less likely than allopathic physicians to admit patients to hospitals for invasive diagnostic procedures, then that knowledge would also help explain the observed difference in admission rates.

Disparities in Quality of Care

Many health insurance plans collect and report data about quality of care. Examples include the Health Plan Employer Data and Information Set (HEDIS) measures and the CAHPS survey results. These measures and survey results are reported annually by plans and include indicators, for example, that evaluate the percentage of women aged 52-69 years of age who have had a recent mammogram, the percentage of children who have had age-appropriate immunizations, and the percentage of individuals with diabetes who have had recent HbA1c and lipid screening tests.

Examples of Analysis
Identifying racial/ethnic disparities related to the topic areas measured by HEDIS involves a few key steps. These steps may be performed by programmers or analysts at the health insurance plan or by staff from a third party vendor, as long as the vendor relationship provides for this kind of "non-routine" data analysis and ensures the confidentiality and privacy of such data.

Steps would be to:
- Add a field in the HEDIS data set(s) to allow for the collection of race/ethnicity data for plan enrollees who have been identified in the numerator and/or denominator populations of specific rates;
- Use a unique identifier to assign a race/ethnicity category to each enrollee included in the HEDIS data set(s);
- Calculate performance rates separately for each racial/ethnic group; (presumably, only groups large enough to produce denominator populations of at least 30 are worth analyzing separately – anything smaller is not likely to yield rates that are stable enough to interpret);
- Identify differences that appear large enough to be clinically or administratively meaningful (see the "five percent" rule of thumb above as an example);
- Apply basic statistical tests like chi-square (again, see above for example) to determine whether differences are statistically significant; and
- Apply knowledge of plan enrollee clinical and demographic characteristics to go beyond statistical significance and decide whether any significant differences reflect a potential quality issue.

Example 1: Combining Claims Data with Medical Record Review

Table D provides an example of a round of baseline analysis done in a single Medicaid plan. The data on race/ethnicity came from the state Medicaid program and was then merged with the plan's HEDIS data files to produce rates of HbA1c testing stratified by race/ethnicity.

Table D: HEDIS Measures for HbA1c Testing By Race and Ethnicity

	Administrative Data				Hybrid Data		
	White	African American	Hispanic		White	African American	Hispanic
Numerator	211	202	13		121	120	9
Denominator	359	485	35		171	208	14
Rate	58.77%	41.65%	37.14%		70.76%	57.69%	64.29%

Even though this is a simple table, there are a few features worth noting:
  - The differences between White and African American HbA1c testing rates were statistically significant, using either the administrative or the hybrid data collection methodology, using Fisher's Exact Test for 2x2 tables.
  - The sample sizes for the Hispanic group were too small to permit meaningful analysis, even though the plan could conceivably have run statistical tests on the data.
  - The general patterns were consistent across the two data sources, so that follow-up analysis might conceivably have been conducted using either source if only one were available.

Example 2: Using Claims Data to Identify Disparities Among Enrollees with Asthma

Another example is how a health insurance plan used claims data to create a quality measure that was in turn used to identify a disparity and serve as the foundation for follow-up analysis after quality improvement was initiated. The clinical focus was asthma. Approximately 35% of the plan's enrollees with asthma were found to be African American, 24% were White, and 19% were Hispanic. The remaining number of enrollees with asthma (22%) included Asian/Pacific Islander and other racial and ethnic groups. The race/ethnicity data came from a state Medicaid program.

The plan decided that severity level would serve as a measure of quality of care, since the criteria for assigning severity levels include use of "rescue" medications and provider visits that could conceivably be deemed unnecessary through better use of preventive medications and avoidance of asthma triggers.

Severity levels were assigned using the following criteria:

High
- – Two or more hospitalizations in the past 12 months; OR
- – Two or more emergency department (ED) visits in the past 12 months; OR
- – Two or more anti-inflammatory medication AND two or more long beta agonists and one of the following medications:
    - ▪ Two or more short beta agonists; or two or more theophylline; or two or more ipratropium in 12 months

Moderate
- – One ED visit in the past 12 months; OR
- – One hospitalization in the past 12 months; OR
- – Three or more anti-inflammatory medications in the past 12 months; OR
- – Two or more anti-inflammatory medications and one reliever in the past 12 months; OR
- – Five or more relievers in the past 12 months; OR
- – Pharmacy sub-group intervention, reliever over-reliance (Three or more relievers and two or fewer controller's medications in the past 6 months).

Low / Mild
- – Not meeting the "high" or "moderate" severity levels

To assign severity levels to enrollees by race/ethnicity, the plan merged race/ethnicity data with pharmacy data to determine asthma medication utilization, and integrated inpatient and outpatient claims history to identify the rates for hospitalizations, emergency department visits, and outpatient visits.

Among these individuals identified with asthma, 32% of African American, 21% of White, and 13% of Hispanic plan enrollees were assigned to a moderate or high severity level. A key additional finding was that the majority of these enrollees resided in two communities. This created an efficient geographic target for the subsequent plan intervention.

Using HEDIS Measures for Identifying Disparities Gaps.
Using 2004 Medicare HEDIS data, Health Insurance Plan of New York (HIP) stratified specific measures by enrollee race and ethnicity. The findings suggest that some racial and ethnic disparities exist at HIP, especially in the areas of mental health treatment and diabetes management among African Americans, Hispanics and groups categorized under Other. For all mental health measures, the African American and Other groups had lower rates than the White group. For the diabetes HbA1c testing measure, the two groups with the lowest rates were the Hispanic and Other groups, and for the diabetes LDL-C screening measure, the two groups with the lowest rates were the

African American and Other groups. Furthermore, the breast cancer screening and osteoporosis measures showed no significant difference across the races.

The race/ethnicity groups existing in HIP's system are African American, American Indian/Alaskan Native, Asian, Hispanic, Other, Unknown, and White. Due to the small number of members in American Indian/Alaskan Native, Asian, Other, and Unknown categories for measures such as breast cancer screening and HbA1c testing and LDL-C screening for members with diabetes, these groups were collapsed into one group, Other. In addition, due to the small number of members within the Hispanic ethnic category for the mental health measures and the osteoporosis measure, Hispanic members were also included in the Other category for these measures. Rates by racial/ethnic groups were compared for each measure using a chi-square statistic. Statistical significance was established at $\alpha < 0.05$.

The factors associated with certain races and ethnicities, including specific cultural beliefs and attitudes about diet and nutrition, perceptions of mental health treatment, and the health care system in general warranted increased attention. As a result, HIP will be conducting focus groups with enrollees and developing an internal task force to gain a clearer understanding of the race- and ethnic-specific factors that influence treatment and management. An assessment of specific interventions may be designed to break down the barriers to obtaining quality health care and eliminating disparities that are currently observed by the plan.

Using Data From Multiple Sources:
Race and ethnicity information for Medicare Advantage members is populated in HIP's information system from one of two sources − collected directly from enrollees by HIP or information provided by CMS. In 2003, HIP sent out questionnaires to all current Medicare Advantage enrollees asking them to provide information on their race/ethnicity. HIP also revised the enrollment forms for new Medicare Advantage members by adding questions asking members about their race/ethnicity. The race/ethnicity information collected from the questionnaires and enrollment forms was then entered into HIP's information system. In 2004, CMS started sending HIP race/ethnicity information for HIP's Medicare Advantage enrollees. CMS data did not replace data in HIP's member file retrieved from self-responses by members who responded to the HIP questionnaire or the revised enrollment form, since it is believed that the self-responses are more accurate.

Using CAHPS to Identify Disparities

Identifying disparities related to the areas measured in the CAHPS survey is technically easier, since one of the demographic items in the survey itself is self-reported race/ethnicity. Identification of possible disparities involves calculating CAHPS survey indicators separately for enrollees of different racial/ethnic groups, again with the caveat that groups smaller than 30 are unlikely to yield stable findings.

The CAHPS survey, which is administered on an annual basis by most plans, is designed to produce scores on several "domains" of care and service that each involves a combination of responses from several specific survey items. If a plan's CAHPS data set already includes domain scores calculated for each survey respondent, then the analysis would produce a cross-tab analysis of across domain scores by race/ethnicity. If the data set includes only the individual item responses, then the domain scores would be calculated first and then broken down by race/ethnicity. If the sample sizes for specific racial/ethnic groups are too small in any one year for meaningful analysis, it may be possible to combine two or more years of survey data to at least identify general patterns of possible disparities.

One solution to the problem of small sample sizes is to combine analyses over multiple time periods. Another is to look for consistent patterns of difference across measures that are from the sample patient population or about the same general health care process. A difference in well-child visits or immunization rates, for example, might not be significant in one reporting year, but might be significant if data from two or more consecutive years were combined and the patterns were consistent in all years.

If a plan found instead that the rates for a particular racial/ethnic group was lower than the plan average for all measures related to well-child care, but none of the individual differences was significant because of small samples, a plan might be more likely to treat the differences as "real" because of the consistent pattern across multiple measures of quality or access in the same patient population.

Trends in Disparities Over Time

Presumably, a health insurance plan would analyze disparities in quality of care or access to care in order to find opportunities for improvement. Some knowledge about trends in disparities over time can be very useful in making good decisions about where to invest resources to address disparities, although data from just one time period is almost certainly better than nothing at all.

If a plan has relatively stable enrollment and has access to quality of care or utilization data sets from previous years, it may be worth retrieving data from two to three years prior and run the analyses stratified by race/ethnicity for those years as well as the most recent year. If that analysis shows that

a disparity has been present on a consistent basis in all time periods, then the plan can be very confident that the disparity is "real" and that changes observed in the future will be related in some way to specific actions taken by the plan.   In the table below, the disparity between Hispanic and White patients in terms of reported problems with doctor-patient communication appears to be relatively stable over four years of analysis.

Table E:

Race/Ethnicity Group	Percent Reporting Problem in Doctor-Patient Communication by Year				Total
	2001	2002	2003	2004	
African American	10/35 (29%)	9/38 (24%)	10/43 (23%)	9/44 (20%)	38/160 (24%)
Hispanic	6/20 (30%)	7/25 (28%)	9/30 (30%)	11/42 (26%)	33/117 (28%)
White	12/89 (13%)	15/97 (15%)	19/113 (17%)	19/120 (16%)	65/419 (16%)

If the analysis shows that a disparity is present, but the disparity gap is consistently diminishing over time and has almost disappeared in the most recent time period, then a plan may wish to look elsewhere for an opportunity to improve, as the problem seems to have been fixed with whatever mechanisms and causal processes are already in place. In Table E, the disparity between White and African American patients in terms of reported problems with doctor-patient communications was relatively large in 2001 but is much smaller in 2004. If the same trends continue, the difference will be gone in 2005 or 2006.

If the analysis shows the disparity present in some previous time periods but not in others, and the sample size seems adequate for drawing conclusions about each time period, then additional time should probably be spent in understanding the underlying reasons for the differences, and how those reasons may vary over time. Any project undertaken to address the disparity may be incorrectly judged either a success or failure in the future, depending on which way the "random" fluctuation is moving from this year to next. In Table E, if the rate for reported problems for African American patients returned to the range of 25-30%, then one might conclude that: (a) something good was going on between 2002 and 2004 but it stopped; or (b) the sample sizes are so small that the observed variation in rate from year to year was simply random, and that the overall rate across multiple years is the best estimate of what is really going on.

It is difficult to see any subtle trends over short periods of time in annual HEDIS or CAHPS results. If possible, it is better to base time trend analysis in quarterly, monthly, or even weekly reports that can be stratified by race/ethnicity. In most plans, administrative claims data for relatively frequent services like childhood immunizations, HbA1C tests for individuals with diabetes, mammograms, or prescriptions for appropriate asthma medications could be used to generate time trend analyses of disparities. Data collection processes like the hybrid method for HEDIS or annual CAHPS surveys will not be amenable to this kind of analysis, but it may be feasible for HEDIS measures that are collected using administrative data.

Challenges in Data Collection

As individual health insurance plans collect data on race and ethnicity, plans will need to develop comprehensive analysis plans to evaluate and interpret the results obtained from such activities. This section provides some concrete examples from which plans can learn.

What should you do if your plan does not have data for all of the populations that you are evaluating? It may turn out that only some of the data that your plan needs is available (or retrievable). Your plan, for example may be able to obtain race/ethnicity data from a single large employer/purchaser or receive only a subset of data from linking files to a state registry that contains birth records. Your plan may also only be able to get the data from hospitals for those of your enrollees who have been admitted, or may be able to get the information from some of your enrollees who provide it voluntarily, but not from others.

– The first question to ask is whether the subset of enrollees your plan has collected data on is representative of the larger group for which you want to generalize. In the first two examples, above, the answer to that question may be "yes".

– If the enrollee data that comes from one large employer are about the same age, gender, and income as your plan's entire enrolled population, and if these enrollees live across your plan's entire service area and see more or less the same providers as anyone else, then your plan may be able to safely use the information from the one employer and presume that the patterns you see are the same as one would see if the analysis was completed on your plan's entire enrolled population.

– In the last two examples, though, there is a clear bias in the process of data collection, so the enrollees on whom your plan has the information are different in some way from those on whom your plan does not have data. In this scenario, it does not make sense to go ahead with analyses of quality data and presume that the patterns observed are those your plan would see if you could do the analysis on your plan's entire population.

In all of these circumstances, it may be reasonable to use some sort of "proxy" method (e.g., geocoding, surname recognition) for assigning race/ethnicity to those enrollees for whom your plan does not have data. Your plan is then conducting analyses on the plan's entire enrolled population even if the data on race/ethnicity may be less than perfect for some subgroups. The biases produced by this difference will probably be less severe than the biases produced by only analyzing data for a subset of your plan's population.

Challenges in Data Collection (continued)

What do you do if your plan only started collecting data recently? How do you obtain data from previous years? There may be no effective way of going back to previous years, so any analyses may have to start with the current year. A potential inability of a plan to collect retrospective data will only limit discussing time trends but not analysis of current gaps. If it is important to examine time trends, then your plan may be able to go back to previous years' HEDIS data sets, link data on race/ethnicity to those enrollees in those data sets on which there is race/ethnicity data, and go ahead with analysis of that subset of enrollees. There are clearly potential biases here, though, as enrollee turnover will reduce the number of enrollees available for analysis the further back you go, and the enrollees who have remained over multiple years are not necessarily like either those who were enrollees earlier but have since left, or those who have joined the plan recently.

Component 7: Using Data on Race, Ethnicity, and Primary Language to Improve Health Care

Overview

The previous component provided an overview of some ways in which data on race, ethnicity, and primary language can be used to identify the characteristics of health insurance plan enrollees and potential disparities in health. These analyses can be informative, but only will become truly useful when linked to quality improvement or other health insurance plan initiatives designed to improve outcomes in health status and reduce or eliminate disparities.

This component highlights how data analyses like those described previously can be used to either identify areas for improvement or monitor the impact of ongoing initiatives. The sections that follow will touch on both issues.

This is clearly "a work in progress" as health insurance plans and other health care organizations are just beginning to develop interventions to address disparities and monitor the results of those interventions. As AHIP continues its work in addressing disparities in health care, it plans to identify and build a clearinghouse of health insurance plan data collection practices that can serve as innovative models to address disparities in health and health care within the industry.

Health Insurance Plans Use of Data to Improve Care:
In 2002, HealthPartners in Minnesota[59] reported on the goals and processes for collecting and using data on their plan enrollee's race, ethnicity, primary language, and socioeconomic status at a recent University of North Carolina and Centers for Medicare & Medicaid Services conference on disparities. These goals are to:
- Identify health disparities to support care improvement initiatives
  - health status
  - quality of care
  - access to services
  - utilization of services
- Identify key drivers of health disparities
- Support the delivery of culturally competent care
- Identify population demographics
- Identify language preferences
- Develop organizational capabilities to meet patient needs and preferences

---

Identifying Areas for Improvement

Recent experiences of a number of health insurance plans suggest that most plans will identify at least one, but probably more than one, significant disparity in their HEDIS measures and/or CAHPS survey results.[54,55] Figure 1 is an example of results from a plan participating in a recent disparities project.

Figure 1
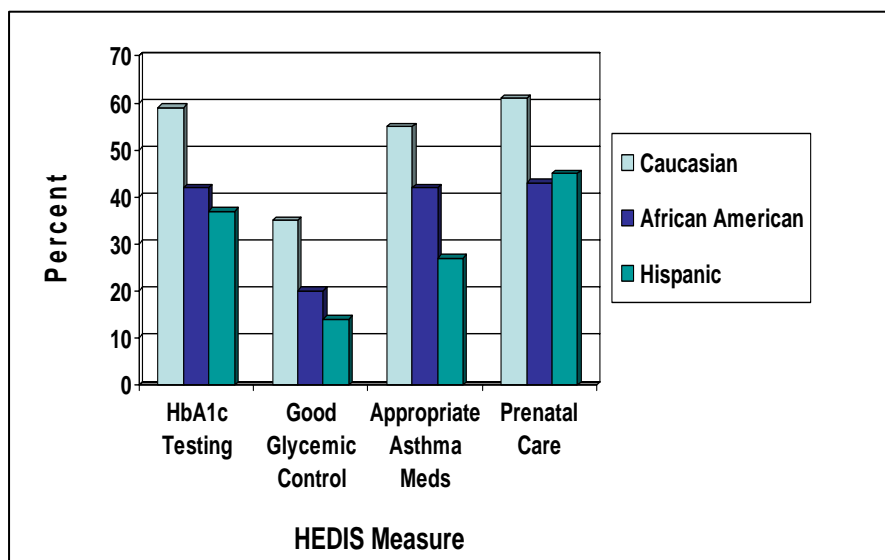
Even if some potential disparities can be dismissed as "not real" or not significant from a clinical or administrative perspective, it is likely that there will be multiple areas remaining in which disparities do exist. With limited resources, how may a plan select wisely among possible areas for intervention?

The answer to this question has both a "science" base and "local knowledge". The "science" of the answer has to do with responding to specific questions, such as:

- Which of the observed disparities affects the largest number of plan enrollees?
- Which of the observed disparities produces the most serious negative impacts on health?
- Which of the observed disparities has been shown to be amenable to some sort of quality improvement intervention?
- For which of the observed disparities is there a clear "business case" for quality improvement, at either the plan, purchaser, or provider level?

The "local knowledge" has to do with answering specific questions like:

- Which of the observed disparities is in a clinical area where your plan already has strong quality improvement initiatives or disease management programs that can serve as a starting point or foundation for new initiatives?
- Which of the observed disparities has the greatest impact on your plan's overall HEDIS or CAHPS survey results and which disparity reduction would give the plan the greatest increase in an overall HEDIS or CAHPS rates?

- In which of the observed disparity areas does your plan have the best understanding of underlying causes?
- In which of the observed disparity areas does your plan have the best ability to initiate a quality improvement initiative to address culturally and linguistically appropriate services?
- In which of the observed disparity areas does your plan have an opportunity for collaboration with community groups, other health insurance plans in the area, or to implement provider- or employer-based quality improvement initiatives?
- Have any of your plan's key employers identified one of the clinical areas in which your plan observes disparities as a priority target for quality improvement?
- In which of the observed disparity areas does your plan have the best ability to track data in "real time" in order to monitor the success of quality improvement initiatives?

One Health Insurance Plan's Commitment to Reducing the Gap.

Aetna has demonstrated a strong commitment to reducing racial and ethnic disparities in health care.[56] As part of Aetna's overall efforts to enhance quality of care, over the past two years the company has developed a coordinated, multidimensional program to address health disparities composed of research, education, customer service, data collection, direct health care, and general awareness initiatives. Aetna has been a national leader in using a direct approach to collect race/ethnicity data on its enrollees.

An integral part of Aetna's program is the collection of enrollee data on race and language preferences on a voluntary, self-identified basis. Aetna's efforts have expanded to 24 states and the District of Columbia for HMO enrollees, and 44 states and the District of Columbia for traditional/PPO enrollees. Data collected from their plan enrollees are then analyzed to develop and implement programs focused on improving specific health outcomes for identified enrollees with or at risk for diseases prevalent within minority populations. A further description of Aetna's data collection approach can be found at www.aetna.com.

Using Data to Identify Service Needs and Develop Programs

Some patterns of data analysis may suggest a need for an expanded service or program. A consistent pattern of disparity, for example, in which there were lower rates for Spanish-speaking Hispanic plan enrollees in receiving appropriate diabetes care, such as HbA1C tests, would suggest a need to develop a combination of Spanish-language patient education materials, improve translation services, or expand the number of Spanish-speaking disease management nurses or case managers. A consistent pattern of lower satisfaction with doctor-patient interactions among African American enrollees might suggest the need for a cultural competency training program for providers in the

plan's network. A consistent pattern of lower outcomes across all measures related to cardiac care may support the creation of a new disease management or case management program.

Self-Care Among Chronically Ill African Americans: Culture, Health Disparities, and Health Insurance Status.
In a 2003 study conducted by Gail Becker et.al, African American respondents with health insurance and at least one chronic illness reported having more frequent influences of physicians and health education programs in managing their chronic conditions than those without health insurance[57]. Access to programs, physician's advice, and a network of social support, can increase enrollees' control of their chronic conditions. When these programs address and incorporate cultural approaches – such as spirituality, social support and advice, and non-biomedical traditional medicines, there is a higher probability of improved health outcomes.

Unfortunately, there are no clear cut rules for deciding when a particular pattern of statistical results justifies a service expansion or the development of a new program or service. Lower satisfaction rates among one racial or ethnic group may suggest a need for cultural competency training, but the rates may also reflect a problem with translation services, a problem with hours and access at the physician offices or simply a cultural bias in filling out surveys. There is no substitute for good local knowledge and insight in determining the appropriate strategies to implement.

Analyzing Patient Satisfaction of Care to Enhance Services.
HealthPartners gathers self-reported data on race, country of origin, language preference (spoken and written), and socioeconomic status[58] of its enrollees at the clinic and hospital level. The data will be used to measure quality and disparities with key health indicators. The HealthPartners medical group is analyzing patient satisfaction utilizing race and ethnicity information, and also the effectiveness of diabetes care between commercially and publicly (Medicaid) insured individuals. HealthPartners also developed a website for cross-cultural care and service, and a leadership development program for managers across the enterprise. HealthPartners is upgrading its interpretive services for their Language Line telephone service to include all the key languages of their enrollees and improving the quality of interpreter services throughout the organization. To date, over 150 languages can be accessed for interpreter services.[59]

Using Data to Select Types of Quality Improvement Initiatives

The following two sections can serve as primers for health insurance plan staff who are just beginning to develop a disparities program. Some of this information may appear elementary to experienced quality improvement (QI) staff.

In some clinical areas, such as diabetes and well-child care, the analyses of disparities related to HEDIS measures can be used to select from among types of QI projects. We have presented elsewhere in this toolkit examples of QI projects aimed at reducing disparities – there is clearly a wide range of projects from which to choose.

There are several HEDIS measures, for example, that are related to diabetes care and reflect either specific clinical services and longer-range clinical targets for screening and control. If a baseline HEDIS data analysis demonstrated significant disparities in all measures in the data set, one would tend to think of broader, disease management, or case management programs that would have the potential to improve diabetes care across the whole set of measures. On the other hand, if HEDIS rates were good in general, and no disparities existed in any measures except lipid screening, one might think of a more clinically-focused, perhaps provider-directed, project aimed at improving the key underlying mechanisms for lipid control.

Similarly, if an analysis of well-child measures showed disparities in most or all measures, one would consider initiatives aimed at improving access to care or utilization of services for mothers with newborns. Alternatively, a case management program could be considered for a subset of new mothers with a high likelihood of not bringing children in for routine care. If high rates were achieved for most measures without disparities, but one observed disparities in one of the specific immunization rates, then one would consider a more tightly focused, provider-oriented quality improvement initiative aimed at ensuring that children received specific immunizations.

> **HEDIS Data Stratified by Race/Ethnicity**
> A health insurance plan in Washington state recently organized a QI initiative, starting with an analysis of all their HEDIS measures stratified by race/ethnicity, and then looked specifically at measures of well-child care. The analysis showed some disparities between Hispanic and non-Hispanic children, but the disparities were not observed in all measures. The most significant disparities seemed to be in the areas of immunizations and well-child visits for very young children. As a result of the analysis, culturally sensitive, Spanish-language reminders were developed for mothers of Hispanic newborns. Improvements in both immunizations and well-child visit rates were seen within a year following the start of the intervention.

The same sort of approach could be taken across clinical areas. If an analysis of all HEDIS measures demonstrated that disparities existed in those measures that reflected daily lifestyle issues for individuals with chronic conditions (e.g., level of glycemic control), but there were no disparities in those measures that reflected a physician's provision of recommended services (e.g., HbA1c testing), then the natural focus in planning a QI intervention would be enrollee outreach, case management, or some other form of behavioral intervention. On the other hand, if disparities existed mainly in the measures related to screening in otherwise healthy adults, QI projects aimed at either enrollees or providers targeting preventive services and screening in general might be helpful.

If the data analyses suggest that language or cultural barriers may be a cause of disparities in care, then there are a wide range of resources available to help plans in the design or expansion of programs in the area of culturally- and linguistically-appropriate services (CLAS). The federal government has developed a "toolkit" for Medicare Advantage health insurance plans related to the CLAS standards. The toolkit is described in more detail at:
http://www.ahcpr.gov/about/cods/planclas.htm.

For a collection of other web-based resources please access the HHS Office of Minority Health, Center for Linguistic and Cultural Competence in Health Care's (CLCCHC) website at
http://www.omhrc.gov/inetpub/wwwroot/cultural/background.htm.

Assessing the Impact of Disparity-Reduction Initiatives

Many of the same data sets and specific variables that were used to identify disparities and to select benchmarks are used to assess the impact of plan initiatives. Repeated measurement of that specific disparity over time is the main way to tell whether the goal has been met.

Continuous Quality Improvement. The simplest form of repeated measurement over time is a before/after measurement. In the context of disparities in plans, the typical example would be an analysis of HEDIS data in one year to identify possible disparities, implementation of QI initiatives to reduce or eliminate the disparities, then follow-up analysis of HEDIS data in the following year to see if the disparities have become smaller or been eliminated.

This approach can be useful, but it has some obvious challenges:
- If the QI initiative is not started in January and carried through December of a single calendar year, its full effect will not be felt in any one HEDIS measurement cycle;
- If a project is initiated in January of one year, it will be May or June of the following year before the first assessment of success is available, using only the HEDIS data;
- If the disparity in question is gradually being reduced or eliminated over a period of several years (due, for example to generally improving quality of care and greater standardization of care processes), then a QI initiative may appear to have had a significant effect in the before/after analysis when in reality the same change in HEDIS scores would have occurred in the absence of the QI program;

- If the underlying sample size is small, even an important and real reduction in disparity may be masked by the random variation in the rate from year to year.

One way to address some of these concerns is to pilot the QI intervention in *one* part of the service area or provider network and not all, and compare changes in the HEDIS measures over time between the "pilot" and the "comparison" parts of the service area or network. A reduction or elimination of disparity in the "pilot" but not the "comparison" part of the network would suggest a real effect of the QI program.

Another potential solution to the problem of HEDIS rates only being collected on a calendar year basis is to create "rolling 12-month" HEDIS reports at monthly or quarterly intervals. For example, rather than calculating breast cancer screening rates for calendar year 2004 using the standard HEDIS criteria, one would calculate rates for January 1, 2004 through December 31, 2004, then calculate April 1, 2004 through March 31, 2005, then calculate July 1, 2004 through June 30, 2005, etc. In this example, each calculation would involve a full year's worth of data and use the same inclusion/exclusion criteria, but the reports would be available on a quarterly rather than annual basis, and it would be possible to see a real effect of a QI intervention more quickly than if only calendar year data are used. One plan participating in the recent HRSA Medicaid disparities project did this – the same plan that focused its analyses and subsequent work on well-child care.

This approach clearly involves additional programming and analysis work, and can probably only be done when the HEDIS rates are calculated using administrative and not medical record data, but it has been used successfully by at least one plan in a project on racial/ethnic disparities in well-child care and childhood immunization rates.[1]

Finally, another solution to the "measurement lag" problem may involve the use of administrative (e.g., billing) data that are closely related to the HEDIS measure in which disparities were observed. For example, if a plan observed a disparity in childhood immunization rates in a particular year, rather than wait another full year to see if the disparity was reduced because of QI initiatives, it may be useful to examine billing data for immunizations on a monthly or even weekly basis to see whether the number of immunizations among children in the target minority group was trending upwards in response to the intervention put in place. Depending on sample size and data completeness, a plan could do this analysis for individual provider groups or clinic sites, and relate trends over time to the extent to when and which QI intervention was implemented in these groups or sites.[60]

Target Specific Medical Conditions.
A Medicaid health insurance plan recently focused its disparity-reduction efforts on its African American and White enrollees who had been diagnosed with diabetes. The African American (non-Hispanic) population was the plan's largest ethnic group, with the highest rate of poor HbA1C control (see Table F below). Baseline data also reflected a poor control rate for the plan's White population.

Table F:

	HbA1c Testing	HbA1c in Good Control	LDL-C Testing	LDL-C Control (<130)
African American	66.4%	27.7%	63.9%	25.3%
White	74.6%	35.5%	70.8%	29.0%

The Diabetes Navigator Program was implemented plan-wide for enrollees with diabetes with a special focus on the African American population. Program activities were targeted to two groups: 23 physicians in six participating group practices and plan enrollees with diabetes. Physicians received patient status reports showing enrollees' receipt of appropriate HbA1c testing, dilated eye exams, LDL testing, and urine microalbumin testing. Physicians also received professional education reminders based on the American Diabetes Association Standards of Care.

Enrollees received a series of educational tools including a diabetes calendar and pocket diary, a program magnet with contact information, educational booklets on diabetes and heart disease, proper eating, high blood pressure, cholesterol, renal complications, practical tips for living with diabetes, and the ABC's of diabetes and the heart.

Program interventions also included:

- "Supermarket shopping tours" for high-risk enrollees, during which a dietician helped enrollees make better food selections during a typical grocery shopping trip. Enrollees were taught how to read food labels, and most importantly, how to determine which foods to avoid;
- Diabetes cooking classes, in which two dieticians prepared healthy meals and demonstrated how to modify favorite recipes to improve glycemic control;
- High risk enrollees, as determined by A1C values, lack of routine testing, or physician referral, were contacted by project nurses on a regular basis and "coached" on development of realistic goals for improvement.

The next annual round of HEDIS data analysis showed improvements in both glycemic control and lipid control. Both African American and White enrollees showed improvement; although, the disparity observed at baseline was still present a year later. Rates of blood sugar and lipid control rose 12-14% in the African American target population. The project was judged a success by the plan, since previous efforts to improve these rates among African American patients with diabetes using other approaches had not been successful. If the Diabetes Navigator Program had only been offered to African American plan enrollees instead of plan-wide, a significant reduction in disparity might have been observed.

Table G:

	HbA1c Testing	HbA1c Good Control	LDL-C Testing	LDL-C Control (<130)
African American	65.9%	39.6%	67.5%	39.1%
White	72.1%	49.0%	74.8%	42.1%

Providing Culturally and Linguistically Appropriate Health Care Services

In accordance with the HHS Office of Minority Health, culturally and linguistic competence is defined as "the ability of health care providers and health care organizations to understand and respond effectively to cultural and linguistic needs brought by the patient to the health care encounter." Research suggests the need for improved cultural and linguistic competence in health care to reduce disparities. It is difficult to reduce health care disparities without first improving the cultural and linguistic competent care and services provided within a health care organization. As noted in this toolkit, health insurance plans have developed an array of services and programs that meet the needs of their enrollees. The plan example in this section provides an overview of how one health insurance plan has met the needs of their enrollees.

A Population-based Strategy.

In 2003, after finding a high incidence of asthma among African American children in West Philadelphia, Keystone Mercy Health Plan partnered with the Healthy Hoops Coalition, comprised of basketball coaches, area health organizations, and asthma health educators to create the Healthy Hoops Asthma Management Program. According to statistics from Keystone Mercy's Medical Affairs Department, West Philadelphia is the area that has the highest incidence of asthma among its members in the city of Philadelphia. The majority of West Philadelphia and Keystone Mercy's membership is of African American descent.

The Healthy Hoops program teaches children ages 7 through 15 and their parents how to manage asthma through effective medication use, proper nutrition, monitored exercise, and recreational activities. The program uses four main strategies to achieve its goals: outreach, program events, asthma disease management education, and member incentives, such as a full day basketball camp. As of 2003, about 130 children with asthma and 155 parents have participated in the 2003 Healthy Hoops Program.

To increase enrollment in the Healthy Hoops program, Keystone Mercy identified three zip codes in West Philadelphia with high rates of asthma among the plan's Medicaid enrollees and in the community at large. Mailings of the Healthy Hoops brochures and enrollment forms were sent to member families who had children between ages 7 and 15 with asthma. To increase enrollment among other low-income children with asthma in the Philadelphia area, Keystone Mercy collaborated with school nurses, community-based asthma coalitions, and local heath care organizations.

Program participation has resulted in a decline in the percentage of children with an emergency room visit for asthma from 40% to 6%; an increase in the appropriate use of controller medications from 48% to 77%; a reduction in children's hospital admission for asthma, from 10% six months prior to the program to 2% at the program's conclusion; and a decrease in the percentage of children with sleep disturbances due to asthma, from 36% to 32% respectively. In 2004, the program was expanded to the Hispanic community and in North and Northeast Philadelphia, communities that, per the data from its Medical Affairs department, have a large number of pediatric asthma diagnoses.

Component 8: Resources and Tools

For Health Insurance Plans:

America's Health Insurance Plans. *Health Insurance Plans Address Disparities in Care: Highlights of a 2004 AHIP/RWJF Quantitative Survey: Collection and Use of Data on Race and Ethnicity.* Washington, DC: America's Health Insurance Plans, June 2004.

America's Health Insurance Plans. *Health Insurance Plans Address Disparities in Care: Challenges and Opportunities.* Washington, DC: America's Health Insurance Plans, June 2004.

America's Health Insurance Plans, Center for Policy and Research. *Low-Income and Minority Beneficiaries in Medicare Advantage Plans, 2002.* Washington, DC: America's Health Insurance Plans. May 2005.

Health Affairs. *Racial and Ethnic Disparities.* Bethesda, MD: Project Hope-The People-To-People Health Foundation, Inc., 2005 March/April; 24 (2).

Nerenz DR, et al. *Developing a Health Plan Report Card on Quality of Care for Minority Populations.* New York: Commonwealth Fund, July 2002.

National Health Law Program, *Assessment of State Laws, Regulations and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans, Preliminary Findings: Phase I.* Washington, DC: HHS Office of Minority Health, 2002.

For Providers:

Commission to End Health Care Disparities. *Preliminary Survey Brief: Physicians are Becoming Engaged in Addressing Disparities.* Chicago, IL: American Medical Association, April 2005.

Fleming M and Towey, K. *Delivering Culturally Effective Health Care to Adolescents.* Chicago, IL: American Medical Association, 2001.

For Employers:

National Business Group on Health. *Analysis Paper: Why Companies Are Making Health Disparities Their Business: The Business Case and Practical Strategie*s, Washington, DC: National Business Group on Health, December, 2003.

Washington Business Group on Health. *An Employer Toolkit: Reducing Racial and Ethnic Health Disparities,* Washington, DC: Washington Business Group on Health, November, 2003.

Washington Business Group on Health. *Help Your Employees Reach Their Health Goals* (CD-ROM), Washington, DC: Washington Business Group on Health, 2003.

Weinstock, B. *Issue Brief: Reducing Health Disparities*: *Why Companies Are Making Health Disparities Their Business.* National Business Group on Health, November, 2003.

Weinstock, B. *Issue Brief: Bridging Language and Culture Gaps in the Workplace*, National Business Group on Health, September/October 2003, Vol. 1, No. 1.

For Hospitals & Health Care Organizations:
Association of State and Territorial Health Officials and National Association of County and City Health Officials. *Health Departments Take Action: A Compendium of State and Local Models Addressing Racial and Ethnic Disparities in Health.* Washington, DC: Association of State and Territorial Health Officials and National Association of County and City Health Officials, 2001.

Association of State and Territorial Health Officials and National Association of County and City Health Officials. *Health Departments Take Action: Case Studies of State and Local Models Addressing Racial and Ethnic Disparities in Health.* Washington, DC: Association of State and Territorial Health Officials and National Association of County and City Health Officials, March 2003.

Hasnain-Wynia, R, Pierce, D. *A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients.* The Health Research and Educational Trust, February, 2005.

Hasnain-Wynia, R, Pierce, D, and Pittman MA. *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals.* New York: Commonwealth Fund, May 2004.

Health Research and Educational Trust. *Phase I: Developing and Testing Uniform Framework for Collecting Race, Ethnicity, and Primary Language Data in Hospitals: Summary of the National Advisory Panel Meeting.* Chicago, IL: Health Research and Educational Trust, 2003.

Quality Improvement and Data Collection:
Collins, KS, Hughes, DL, Doty, MM, Ives, BL, Edwards, JN, and Tenney, K. *Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority American*s, New York: Commonwealth Fund, March 2002.

Grantmakers in Health. *Strategies For Reducing Racial and Ethnic Disparities in Health Issue Brief No. 5.* Washington, DC: Grantmakers in Health, 2000.

National Committee of Vital and Health Statistics, Workgroup on Quality. *Measuring Health Care Quality: Obstacles and Opportunities.* U.S. Department of Health and Human Services, 2004.

The National Quality Forum. *Improving Health Care Quality for Minority Patients.* 2002.

National Research Council. *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection of Race and Ethnicity Data, Michelle ver Ploeg and Edward Perrin, Editors. Committee on National Statistics, Division of Behavioral and Social Sciences and Education. Washington, DC: National Academies Press, 2004.

Perot, RT and Youdelman, M. *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices.* New York: Commonwealth Fund, September 2001.

Smedley, BD, Stith, AY, Nelson, AR, eds. *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care.* Committee on Quality Health Care in America, Institute of Medicine, Washington, DC: National Academies Press, 2001.

Swift, E. *Guidance for the National Healthcare Disparities Report.* Institute of Medicine. Washington, DC: National Academies Press, 2002.

U.S. Department of Health and Human Services. *Healthy People 2010: Understanding and Improving Health.* 2nd ed. Washington, DC: U.S. Government Printing Office, November 2000.

U.S. Department of Health and Human Services. *National Healthcare Disparities Report,* Rockville, Maryland: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2003.

U.S. Department of Health and Human Services. *National Healthcare Quality Report.* Rockville, Maryland: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2003.

U.S. Department of Health and Human Services. *2004 National Healthcare Disparities Report,* Rockville, Maryland: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2004.

U.S. Department of Health and Human Services. *2004 National Healthcare Quality Report.* Rockville, Maryland: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2004.

Primary Language:

Jacobs, E, Agger-Gupta, N, Hm Chen, A, Piortrowski, A, and Hardt, E. *Language Barriers in Health Care Settings: An Annotated Bibliography of the Research Literature.* New York: California Endowment, August, 2003.

Paez K, Gunter M, Kurtz P, and Brach C. *Providing Oral Linguistic Services: A Guide for Managed Care Plans. 2002*; AHRQ Contract No 290-00-0015. Available at http://www.cms.gov/healthplans/quality/project03.asp.

Paez K, Gunter M, Kurtz, P, and Brach C. *Planning Culturally and Linguistically Appropriate Services: A Guide for Managed Care Plans. 2002*; AHRQ Contract No 290-00-0015. Available at http://www.cms.gov/healthplans/quality/project03.asp.

Perkins, J, Youdelman, M, and Wong, D. *Ensuring Linguistic Access in Health Care Settings: Legal Rights and Responsibilities.* New York: California Endowment, 2003.

Published Literature

Bach PB, Pham HH, Schrag D, Tate RC, and Hargraves JL. "Primary Care Physicians Who Treat Blacks and Whites." *N Engl J Med.* 2004 Aug 5;351(6):575-84.

Becker, G, Gates, JR, and Newsom, E. "Self-care Among Chronically Ill African Americans: Culture, Health Disparities, and Health Insurance Status." *Am J Public Health.* 2004; 94: 2066-2073.

Bieran AS, Lurie N, Collins KS and Eisenberg, JM. "Addressing Racial and Ethnic Barriers to Effective Health Care: The Need for Better Data." *Health Affairs.* May/June 2002; 21(3):91-102.

Blanchard J and Lurie N. "R-E-S-P-E-C-T: Patient Reports of Disrespect in the Health Care Setting and its Impact on Care." *J Fam Pract.* 2004 Sep; 53(9):721-30.

Brach C and Fraser I. "Can Cultural Competency Reduce Racial and Ethnic Health Disparities? A Review and Conceptual Model?" *Med Care Res* Rev. 2000; 57 Suppl 1:181-217.

Bond DE, Zaccaro DJ, Karter AJ, Selby JV, Saad M, Goff DC. "Ethnic and Racial Differences in Diabetes Care: the Insulin Resistance Atherosclerosis Study." *Diabetes Care.* 2003;26:1040-1046.

Boulware, LE, Cooper, LA, Ratner, LE, LaVeist, TA, and Powe, NR. "Race and Trust in the Health Care System." *Public Health Reports* 2002 Jul/Aug; 118: 358-365.

Brown AF, Gerzoff RB, Karter AJ, Gregg E, Safford MM, Waitzfelder B, Beckles GL, Brusuelas R, and Mangione CM. "Health Behaviors of Care Among Latinos with Diabetes in Managed Care: The Translating Research Into Action for Diabetes (TRIAD) Study." *American Journal of Public Health.* 2003; 93:1694-1698.

Brown AF, Gregg E, Stevens MR, Karter AJ, Weinberger M, Safford MM, Gary TL, Caputo DA, Waitzfelder B, Kim C, and Beckles GL. "Race, Ethnicity, Socioeconomic Position, and Quality of Care for Adults with Diabetes Enrolled in Managed Care: The Translating Research into Action for Diabetes (TRIAD) Study." *Diabetes Care.* (In review)

Brown AF, Ettner SL, Piette J, Weinberger M, Gregg E, Shapiro MF, Karter AJ, Safford M, Waitzfelder B, Prata PA, and Beckles GL. "Socioeconomic Position and Health Among Persons with Diabetes Mellitus: A Conceptual Framework and Review of the Literature." *Epidemiol Rev.* 2004;26:63-77.

Carrasquillo O, Orav EJ, Brennan TA, and Burstin HR. "Impact of Language Barriers on Patient Satisfaction in an Emergency Department." *J Gen Intern Med.* 1999 Feb;14 (2):82-7.

Cooper, LA, Roter, DL, Johnson, RL, Ford, DE, Steinwach, DM, and Powe, NR. "Patient-Centered Communication, Ratings of Care, and Concordance of Patient and Physician Race." *Ann Intern Med.* 2003; 139: 907-915.

Fremont, AM, Bierman, A, Wickstrom, SL, Bird, CE, Shah, M, Escarce, JJ, Hortsman, T, and Rector. "Use of Geocoding in Managed Care Settings to Identify Quality Disparities." *Health Affairs.* 2005 April/March, 24 (2): 516-526.

Gearon, C. "Eliminating Disparities: Using a Quality-Improvement Focus." *Advances.* Princeton, NJ: The Robert Wood Johnson Foundation, 2005; 1: 1-4.

Green, L. "Better Data: The First Step in Reducing Disparities in Health Care." *Advances.* Princeton, NJ, The Robert Wood Johnson Foundation, 2004 3:1-2.

Hargraves, JL and Hadley, J. "The Contribution of Insurance Coverage and Community Resources to Reducing Racial/Ethnic Disparities in Access to Care." *Health Services Research.* 2003 38(3), 809-829.

Johnson, RL, Roter, D, Powe, NR, and Cooper, LA. "Patient Race/Ethnicity and Quality of Patient-Physician Communication during Medical Visits." *American Journal of Public Health.* 2004 Dec; 94(12): 2084-2090.

Johnson, RL, Saha, S, Arbelaez, JJ, Beach, MC, and Cooper, LA. "Racial and Ethnic Differences in Patient Perceptions of Bias and Cultural Competence in Health Care." *J Gen Intern Med.* 2004; 19:101-110.

Karter AJ, Ferrara A, Darbinian J, Ackerson L, and Selby J. "Self-Monitoring of Blood Glucose: Language and Financial Barriers in a Managed Care Population with Diabetes Mellitus." *Diabetes Care* 2000; 23:477-83.

Karter AJ, Ferrara A, Liu JY, Moffet HH, Ackerson LM, and Selby JV. "Ethnic Disparities in Diabetic Complications in an Insured Population: The Northern California Kaiser Permanente Diabetes Registry." *JAMA.* 2002; 287(19):2519-2527.

Karter AJ, Stevens MR, Herman WH, Ettner S, Marrero D, Safford MM, Engelgau MM, Curb JD, Brown AF, and the TRIAD Study Group. "Out-of-pocket Costs and Diabetes Preventive Services: The Translating Research Into Action for Diabetes (TRIAD) Study." *Diabetes Care.* 2003; 26:2294-2299.

Kelley E, Moy E, Kosiak B, et al. "Prevention Health Care Quality in America: Findings from the First National Healthcare Quality and Disparities Reports." *Prevent Chronic Dis.* 2004 Jul; 1(3):1-5.

McGlynn EA, Asch SM, Adams J, et al. "The Quality of Health Care Delivered to Adults in the United States." *N Engl J Med.* 2003; 348: 2635-45.

Ngo-Metzger Q, Kaplan SH, et al. "Surveying Minorities with Limited-English Proficiency: Does Data Collection Method Affect Data Quality Among Asian Americans?" *Med Care.* 2004 Sep; 42(9):893-900.

Petterson ED et al. Racial Variation in the Use of Coronary-Vascularization Procedures: Are the Differences Real? Do They Matter? *New England Journal of Medicine.* 1997; 336: 480-486.

Seid M, Stevens GD, and Varni JW. Parents' Perceptions of Pediatric Primary Care Quality: Effects of Race/Ethnicity, Language, and Access. *Health Services Research.* 2003 Aug; 38 (4):1009-31.

Schillinger D, Barton L, Karter AJ, Wang F, and Adler N. "Does Literacy Mediate the Relationship Between Education and Health? A Study of a Low-Income Population with Diabetes." *American Journal of Public Health.* (In review)

Schneider EC, Zaslavsky AM, and Epstein AM. "Racial Disparities in the Quality of Care for Enrollees in Medicare Managed Care." *JAMA.* 2002 Mar 13; 287(10):1288-94.

Shone LP, et al. "The Role of Race and Ethnicity in the State Children's Health Insurance Program (SCHIP) in Four States: Are There Baseline Disparities, and What Do They Mean for SCHIP?" *Pediatrics.* 2003 Dec.; 112(6 Pt 2):e521.

Wallman KK, Evinger S. and Schechter S. "Measuring Our Nation's Diversity: Developing a Common Language for Data on Race/Ethnicity." *Am J Public Health.* 2000 Nov; 90(11):1704-8.

Weech-Maldonado R, Morales, LS, Spritzer K, Elliot M, and Hays, RD. "Racial and Ethnic Difference in Parents' Assessments of Pediatric Care in Medicaid Managed Care." *Health Services Research* 2001; 36(3): 575-595.

Weinick RM, Jacobs EA, Stone LC, Ortega AN, and Burstin H. "Hispanic Healthcare Disparities: Challenging the Myth of a Monolithic Hispanic Population." *Med Care.* 2004 Apr;42(4):313-20.

Zambrana RE, Molnar C, Munoz HB and Lopez DS. "Cultural Competency as it Intersects with Racial/Ethnic, Linguistic, and Class Disparities in Managed Healthcare Organizations." *Am J Manag Care.* 2004 Sep; 10 Spec No:SP37-44.

Software Vendors

Disclaimer: The following vendors and websites are not endorsed by America's Health Insurance Plans. This list has been provided as a resource and is not all inclusive.

ajm Software provides geographic software and data utilizing geocoding, demographics, and U.S. Census information. For more information, please access ajm Software's website at http://www.ajmsoft.com/ac/index.php.

ESRI-The GIS Company. ArcGIS is an integrated collection of geography information software (GIS) products for building a complete GIS for organizations. For more information, please access the Environmental Systems Research Institute's (ESRI) website at www.esri.com. ESRI also hosts a website, www.gis.com, that serves as a portal of information about GIS applications.

Geo Choice Inc. (GCI) strives to provide state-of-the-art geographic information system (GIS) software and services in order to integrate both geographic factors and multiple perspectives into health care management decisions. For more information, please access Geo Choice Inc.'s website at www.geochoice.com.

GeoCoder and GeoNetworks are two products offered by Ingenix Inc. GeoCoder is a technology that assigns geographic information to street addresses and can help map access of health insurance plan enrollees to network providers. GeoNetworks helps to further analyze the accessibility of provider networks. For more information, please access Ingenix's website at www.ingenix.com.

Language Analysis Systems, Inc. provides multi-cultural name recognition software solutions to improve data quality. For more information, please access Language Analysis System's website at www.las-inc.com.

Mapping Analytics software, Demographic Analyzer, helps to analyze the demographics and market potential of any geography in the U.S. For more information, please access Mapping Analytics' website at www.demographicsnow.com.

Component 9: References

[1] Smedley, BD, Stith, AY, Nelson, AR, eds. *Uneqaul Treatment: Confronting Racial and Ethnic Disparities in Health Care.* Institute of Medicine, Washington DC: The National Academies Press, 2002.

[2] U.S. Department of Health and Human Services. *National Healthcare Disparities Report*, Rockville, Maryland: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2003.

[3] Petterson ED et al. "Racial Variation in the Use of Coronary-Vascularization Procedures: Are the Differences Real? Do They Matter?" *New England Journal of Medicine.* 1997; 336: 480-486.

[4] National Health and Nutrition Examination Surveys (NHANES) III (1998-1994) and NHANES (1999-2000). Centers for Disease Control and Prevention.

[5] Shields, AE, Comstock, C. and Weiss, KB. "Variations in Asthma Care by Race/Ethnicity Among Children Enrolled in State Medicaid Program." *Pediatrics.* 2004; 113: 496-504.

[6] Liao, Y, Tucker P, Okora, CA, Giles, WH, Mokdad, AH, and Harris VB. REACH 2010 Surveillance for Health Status in Minority Communities, 2001-2002. In: *Surveillance Summaries*, August 27, 2004. MMWR 2004; 53(No. SS-6): 1-38.

[7] McGlynn EA, Asch SM, Adams J. et al. "The Quality of Health Care Delivered to Adults in the United States." *N Engl J Med* 2003: 348: 2635-45.

[8] National Research Council. *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection of Race and Ethnicity Data, Michele Ver Ploeg and Edward Perrin, Editors. Committee on National Statistics, Division of Behavioral and Social Services and Education. Washington, DC: The National Academies Press, 2004.

[9] Ibid.

[10] National Research Council. *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection of Race and Ethnicity Data, Michele Ver Ploeg and Edward Perrin, Editors. Committee on National Statistics, Division of Behavioral and Social Sciences and Education. Washington, DC: National Academies Press, 2004.

[11] National Committee on Vital and Health Statistics. *Recommendations on the Nation's Data for Measuring and Eliminating Health Disparities Associated with Race, Ethnicity, and Socioeconomic Position: A Commentary by the National Committee on Vital and Health Statistics*, Washington DC: National Committee on Vital and Health Statistics, August 23, 2004.

[12] National Committee on Vital and Health Statistics. *Improving the Collection and Use of Racial and Ethnic Data in HHS, Joint report of the HHS Data Council Working Group on Racial and Ethnic Data and The Data Work Group on the HHS Initiative to Eliminate Racial and Ethnic Disparities in Health,* Washington, DC: National Committee on Vital and Health Statistics, December 1999.

[13] National Committee on Vital and Health Statistics. *Measuring Health Care Quality: Obstacles and Opportunities, Workgroup on Quality*, Washington, DC: National Committee on Vital and Health Statistics, May 2004.

[14] Federal Register - 65 Fed. Reg. 80865-80879 (December 22, 2000).

[15] Office of Minority Health (OMH), *National Study on Culturally and Linguistically Appropriate Services in Managed Care Organizations (CLAS in MCOs Study): Final Report*, Washington, DC, August, 2003.

[16] *Special Emphasis Notice: Research Priorities for the Agency for Healthcare Research and Quality.* AHRQ Notice number: NOT-HS-05-005, November 30, 2004. Agency for Healthcare Research and Quality, Rockville, MD. http://grants.nih.gov/grants/guide/notice-files/NOT-HS-05-005.html.

[17] U.S Department of Health and Human Services. *National Healthcare Disparities Report*, Rockville, Maryland: U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2003 and December, 2004. Available at www.qualitytools.ahrq.gov.

[18] U.S. Department of Health and Human Services. *National Healthcare Quality Report.* Rockville, Maryland: U.S Department of Health and Human Services, Agency for Healthcare Research and Quality, December, 2003 and December, 2004. Available at www.qualitytools.ahrq.gov.

[19] Major Health Plans and Organizations Join AHRQ To Reduce Racial and Ethnic Disparities in Health Care. Press Release, December 14, 2004. Agency for Healthcare Research and Quality, Rockville, Maryland http://www.ahrq.gov/news/press/pr2004/dispcolpr.htm.

[20] The National Quality Forum. *Improving Health Care Quality for Minority Patients: Workshop Proceedings.* Washington DC: The National Quality Forum, 2002.

[21] Joint Commission on Accreditation of Healthcare Organizations. *Hospitals, Language, and Culture: A Snapshot of the Nation Fact Sheet.* Oakbrook Terrace, Illinois: Joint Commission on Accreditation of Healthcare Organizations, 2004.

[22] National Committee for Quality Assurance. *Performance Measurement on Health Disparities and Culturally and Linguistically Appropriate Services (CLAS): Two Projects, Executive Summary.* Washington, DC: National Committee for Quality Assurance, October 20, 2003.

[23] *Collection and Use of Racial and Ethnic Data by Health Plans to Address Disparities: A Final Summary Report*, AAHP-HIAA (now known as the America's Health Insurance Plans (AHIP) and The Robert Wood Johnson Foundation, July, 2004.

[24] Hasnain-Wynia R, Pierce D, and Pittman MA. *Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals.* New York: Commonwealth Fund, May 2004.

[25] *Health Insurance Plans Address Disparities in Care: Highlights of a 2004 AHIP/RWJF Quantitative Survey: Collection and Use of Data on Race and Ethnicity.* America's Health Insurance Plans, June 2004.

[26] Public Opinion Strategies. *Key Findings from a National Survey Conducted among adults who have health care coverage on behalf of the Robert Wood Johnson Foundation on the issue of disparities in health care.* The Robert Wood Johnson Foundation; Princeton, NJ. February 10, 2004. Available at http://www.rwjf.org/news/releaseDetail.jsp?id=1074813646588&contentGroup=rwjfrelease.

[27] National Research Council. (2004). *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection on Race and Ethnicity Data, Michelle Ver Ploeg and Edward Perrin, Editors. Committee on National Statistics, Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press.

[28] National Research Council. (2004). *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection on Race and Ethnicity Data, Michelle Ver Ploeg and Edward Perrin, Editors. Committee

on National Statistics, Division of Behavioral and Social Sciences and Education. Washington, DC: The National Academies Press. Note: There may be federal and state laws as well HIPAA privacy or other regulations limiting the collection and use of these data by employers and providers. In addition, if health insurance plans ask employers to collect such information as part of open enrollment, such collection may be prohibited by some state laws.

[29] Ibid.

[30] Ibid.

[31] Weinstock, B. *Executive Summary: Employer Survey on Racial and Ethnic Health Care Disparities 2003.* Washington, DC: Washington Business Group on Health, November 2003.

[32] Washington Business Group on Health. *How Companies Can Make Reducing Health Disparities Their Business: Innovative Strategies.* Washington, DC: Washington Business Group on Health, 2003.

[33] Grieco, EM and Cassidy, RC. *Overview of Race and Hispanic Origin: Census 2000 brief.* United States Census Bureau. US Department of Commerce. Washington, DC, March 2001.

[34] Ibid.

[35] Aetna, Inc. *Aetna Golden Choice Plan Enrollment Form and Aetna Golden Medicare Plan Enrollment Form.* Hartford, CT: Aetna, Inc., September 2004. Available at www.aetna.com.

[36] Health Plan of Nevada. *Senior Dimensions Health Risk Screen Survey.* Las Vegas, NV: Health Plan of Nevada. Note: For more information, please contact K. Amy Kaltmam, QI Project Coordinator, Health Plan of Nevada, via e-mail at kaltmam@sierrahealth.com.

[37] Karter AJ, Ferrara A, Liu JY, Moffet HH, Ackerson LM, and Selby JV. "Ethnic disparities in diabetic complications in an insured population: The Northern California Kaiser Permanente Diabetes Registry." *JAMA* 2002; 287(19):2519-2527.

[38] National Research Council. *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection of Race and Ethnicity Data, Michele Ver Ploeg and Edward Perrin, Editors. Committee on National Statistics, Division of Behavioral and Social Services and Education. Washington, DC: The National Academies Press, 2004.

[39] Morgan, RO, Wei, II, & Virnig, BA. "Improving Identification of Hispanic Males in Medicare: Use of Surname Matching." *Medical Care*, 2004, *42*, 810-816.

[40] *Health Insurance Plans Address Disparities in Care: Highlights of a 2004 AHIP/RWJF Quantitative Survey: Collection and Use of Data on Race and Ethnicity.* America's Health Insurance Plans, June 2004.

[41] D.R. Nerenz & D. Darling, *Addressing Racial and Ethnic Disparities in the Context of Medicaid Managed Care: A Six-State Demonstration Project, Final Report for Project 250-02-0010.* Rockville, MD: Bureau of Primary Health Care, Health Resources and Services Administration, 2004.

[42] E-mail and phone correspondence with Anna Marie McCrohan, Sr. QI Clinical Manager, Healthfirst. Note: For more information, please contact Anna Marie McCrohan, Sr. QI Clinical Manager, Healthfirst, via e-mail at amccrohan@healthfirst.org.

[43] National Research Council. *Eliminating Health Disparities: Measurement and Data Needs.* Panel on DHHS Collection of Race and Ethnicity Data, Michele Ver Ploeg and Edward Perrin, Editors. Committee on National Statistics, Division of Behavioral and Social Services and Education. Washington, DC: The National Academies Press, 2004.

[44] Ibid.

[45] Ford, M.E, Hill, D.D., Nerenz, D.R., Hornbrook, M., Zapka, J., Meenam, R., Green, S. and Johnson, C.C. "Categorizing Race and Ethnicity in the HMO Cancer Research Network." *Ethnicity & Disease, 12*; 135-140.

[46] UCare Minnesota. *UCare for Seniors Enrollment Form.* St. Paul, MN: UCare Minnesota, September 2003. Available at www.ucare.org.

[47] Presbyterian Senior Care. *Presbyterian Senior Care Benefit Election Form.* Albuquerque, NM: Presbyterian Health Plan, February, 2003. Available at www.phs.org.

[48] *Collection and Use of Racial and Ethnic Data by Health Plans to Address Disparities: A Final Summary Report*, AAHP-HIAA (now known as the America's Health Insurance Plans (AHIP) and The Robert Wood Johnson Foundation, July, 2004.

[49] Ibid.

[50] Ibid.

[51] Munro BH & Page EB; Statistical Methods for Health Care Research (2nd ed); JB Lippincott (1993) or Norman GR & Streiner DL; Biostatistics: The Bare Essentials; Mosby Inc (1994).

[52] http://www.ifigure.com/math/stat/testing.htm

[53] Nerenz, D.R., Gunter, M.J., Garcia, M., Green-Weir, R.R., Wisdom, K., and Joseph, C. *Developing a Health Plan Report Card on Quality of Care for Minority Populations.* New York: The Commonwealth Fund. Available at http://www.cmwf.org/publications/publications_show.htm?doc_id=221275

[54] D.R. Nerenz & D. Darling, *Addressing Racial and Ethnic Disparities in the Context of Medicaid Managed Care: A Six-State Demonstration Project, Final Report for Project 250-02-0010.* Rockville, MD: Bureau of Primary Health Care, Health Resources and Services Administration, 2004.

[55] D.R. Nerenz et al., "Eliminating Racial/Ethnic Disparities in Health Care: Can Health Plans Generate Reports?" *Health Affairs* 21, no. 3 (2002): 259-263.

[56] www.aetna.com/foundation/health/disparity.htm, *Disparities in Health Care: Aetna's Commitment to Reducing Racial and Ethnic Disparities in Health Care.*

[57] Becker, G, Gates, JR, and Newsom, E. "Self-care Among Chronically Ill African Americans: Culture, Health Disparities, and Health Insurance Status." *Am J Public Health*, 2004; 94: 2066-2073.

[58] "Our Approach to Cultural Competence in Health Care", Patricia F Walker, MD, DTM&H, HealthPartners. Presentation at the Best Practices for Culturally and Linguistically Appropriate Services in Managed Care – UNC/CMS June 3-4, 2002, (June 3, 2002). Note: For more information, please contact Patricia F. Walker, M.D., Medical Director, Center for International Health, via e-mail at patricia.f.walker@healthpartners.com

[59] HealthPartners' website on cross cultural resources for providers. Accessed February 13, 2005. Available at http://www.healthpartners.com/portal/p300.html. Note: For more information, please contact Donna Zimmerman, Vice President, Government and Community Relations, HealthPartners, via e-mail at donna.j.zimmerman@healthpartners.com.

[60] J.C. Benneyan, R.C. Lloyd, and P.E. Plsek. "Statistical Process Control as a Tool for Research and Healthcare Improvement." *Quality and Safety in Health Care*, 12, no. 6 (2003): 458-464.

Health Insurance Plans Address Disparities in Care: Highlights of a 2004 AHIP/RWJF Quantitative Survey Collection and Use of Data on Race and Ethnicity

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.

✓ Among plans that collect data on race and ethnicity indirectly, 40.1% obtain data through files linked to external sources.

✓ 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.

Top five reasons cited by health insurance plans for collecting data on race and ethnicity:

♦ Identify enrollees at risk for certain conditions

♦ Support linguistically and culturally appropriate communications

♦ Base quality improvement efforts to reduce disparities

♦ Assess variation in quality measures

♦ Develop disease management or other specialized programs

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.**

Health Insurance Plans Address Disparities in Care: Challenges and Opportunities

Background

In 2002, the Institute of Medicine (IOM) released a landmark report indicating that racial and ethnic minorities receive lower quality health care than non-minorities, even when factors related to access (e.g., insurance status and income) are controlled. There is widespread agreement that 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. Since then, there has been growing interest in understanding the extent to which health insurance plans, providers, and other organizations collect and use data on race and ethnicity to reduce health care disparities. 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) worked 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. AHIP also conducted follow-up qualitative research to obtain more specific information, to solicit recommendations on how to improve the collection and use of these data, and to explore potential future collaborations. A number of challenges and opportunities emerged from this quantitative and qualitative research.

Challenges

Consumer Level

Nearly all health insurance plans noted that enrollees' perceptions about collecting data on race and ethnicity were of primary importance. Among plans that do not collect these data, concern about enrollee reaction was identified as one of the biggest barriers. Even among plans that do voluntarily collect such data, there was a concern raised that enrollees may not understand why the plan is collecting the data and/or how these data can be used to improve their health and health status.

Health Insurance Plan Level

Many health insurance plans noted that the information systems used throughout the healthcare system impose a major barrier to collecting these data. Future work is needed on how information technology (IT) systems could be enhanced for collecting, storing and/or retrieving information about enrollees' race and ethnicity to improve quality of care.

Similarly, many health insurance plans expressed concern about the sporadic and nonsystematic ways in which these data can be collected. In particular, the use of different racial and ethnic categories and the inability to have this information available in a variety of health care settings were identified as obstacles.

Finally, Medicaid, Medicare, and commercial plans are presented with different challenges. For example, Medicaid plans receive these data directly from the state. Many Medicare plans have the option to receive these data from the Centers for Medicare and Medicaid Services (CMS); however, it is still too early to assess the usefulness of these data. Commercial plans do not receive data from the state, employers, or other government agencies, so they first must develop a method and system to collect, store, and subsequently utilize the data for quality improvement efforts.

CHALLENGES

Health insurance plans that participated in the survey and subsequent qualitative research noted the following challenges:

✓ Enrollees' reactions to collecting data on race and ethnicity

✓ Lack of enrollee understanding about how data will be used to improve health status and safeguarded to ensure privacy

✓ Lack of standardized categories and multiple race and ethnicity categories used for the collection of these data

✓ Insufficient information systems used throughout the health care system for collecting and retrieving data on race and ethnicity

✓ Lack of information on how to design the most efficient and effective systems to collect data on race and ethnicity

✓ Lack of research on effective strategies for using data on race and ethnicity to improve health and health status

✓ Too few multiethnic health care professionals in the current health care system, which does not mirror today's multi-ethnic population

✓ Lack of an adequate infrastructure to create a culturally competent health care system

---

Opportunities

Consumer Education

Several health insurance plans cited the importance of educating consumers about why the collection of information on race and ethnicity is crucial and how such information can be used to enhance the quality of care received by minority populations. To that end, they proposed that communication strategies be developed to highlight the benefits of collecting this information while stressing the steps that insurance plans are taking to ensure that such information is used appropriately and privacy concerns are safeguarded.

Staff and Provider Education

Health insurance plans recognize that positive provider-patient communication is associated with greater patient satisfaction and improved health outcomes. Most plans agree that cultural competency programs can be effective in improving the dialogue between providers and patients, and cite the need to offer cultural competency training to providers. Plans also indicated that cultural competency programs should be offered throughout the healthcare system to non-physician health professionals in hospitals, clinics, and health plans.

Standardization of Data Collection

Many health insurance plan representatives noted that standardized data collection is critical in the effort to understand and eliminate racial and ethnic disparities in health care. Yet, Federal, private, and state-supported data collection strategies were described as scattered and unsystematic. Participants in the qualitative research called for the development of a systematic approach to the collection of these data across the health care industry, such as using a standard HIPAA enrollment form or encouraging vendors of claims administration software to expand demographic fields so that additional systems are not necessary.

Continued Research

The IOM's report on health disparities recommends that research be conducted to assess the effectiveness and cost-effectiveness of specific interventions designed to reduce health disparities and improve care for minorities. Health insurance plans support these key recommendations and further suggest the need for a comprehensive evaluation of initiatives to identify those with the greatest impact on improving quality of care. During the expert panel meeting, participants also spoke about the lack of research available on effective interventions. Health insurance plans suggested that the Agency for Healthcare Research and Quality (AHRQ), AHIP, RWJF, and health insurance plans work together to evaluate specific interventions and then widely disseminate the findings to the public.

About the Qualitative Research

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 these data on their enrollees using both quantitative and qualitative methods. A collaborative approach was used to develop a web-based survey instrument consisting of 57 questions. Subsequent to the survey, telephone interviews, a focus group, and an expert panel meeting were conducted to obtain more specific information about health insurance plans' practices in this area. Twenty-two plans were interviewed, 10 health plans participated in the focus group, and 15 health plan representatives and other well-known national experts participated in the expert panel meeting. **For additional information about the qualitative research, contact Deborah Wheeler, Deputy Director, Quality Initiatives and Industry Standards, Medical Affairs, at 202-778-3272 or dwheeler@ahip.org.**

OPPORTUNITIES

Plans that participated in the survey and subsequent qualitative research noted the following opportunities:

✓ Implement targeted programs, such as disease management and health education for enrollees at risk for certain conditions.

♦ African Americans are at high risk for cardiovascular disease and can benefit from health risk assessments, targeted screenings and individualized case management.

✓ Develop linguistically and culturally appropriate communications.

♦ Incorporate culturally relevant symbols and messages into enrollee educational materials.

♦ Availability of multilingual staff and advice lines in multiple languages.

✓ Enhance the health care workforce's sensitivity through targeted initiatives that increase cultural competency and awareness.

♦ Provide linguistically and culturally appropriate services, such as organizational assessment, interpreter services, and training for providers and health plan staff.

America's Health Insurance Plans
601 Pennsylvania Avenue, NW
South Building, Suite 500
Washington, DC 20004
202-778-3200
www.ahip.org

Providing health benefits to over 200 million Americans