

**COLLECTION OF RACIAL AND ETHNIC DATA BY HEALTH PLANS TO ADDRESS DISPARITIES:
FINAL SUMMARY REPORT
PREPARED BY AMERICA'S HEALTH INSURANCE PLANS**

I. PURPOSE OF STUDY

In 2003-2004, 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.

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. A number of challenges and opportunities emerged from this research, which will be discussed below.

The literature is replete with a discussion about the presence of disparities in care but there is a lack of focus on the solutions to this problem. This study enables AHIP and RWJF to identify ways to move towards finding effective solutions. Health insurance plans have developed prevention and disease management techniques that can play an important role in reducing existing disparities in care among different racial and ethnic populations.

II. SUMMARY OF KEY FINDINGS

Majority of Enrollees are in Plans that are Collecting Data. Over one-half of the individuals are enrolled in health insurance plans that responded to the survey and are collecting data on race and ethnicity about their enrolled population and/or information on the primary languages spoken by their enrollees in an effort to improve the quality of care their enrollees receive.

Plans are Collecting Data to Improve Care and Communication. Of those plans that are collecting such data, they are doing so for reasons that include the following:

- To identify enrollees with risk factors for certain conditions;
- To develop disease management or other specialized programs to benefit these enrollees;
- To facilitate communications between the plan, providers, and enrollees by providing translation services; disseminating culturally-appropriate educational materials; creating on-line websites in other languages; and designing provider networks that reflect the diversity of the enrolled population;

- To begin to identify variation in quality measures among different racial and ethnic groups; and
- To reduce disparities in care among different racial and ethnic groups.

Plans Not Collecting Data Do So Because of Real and Perceived Barriers. While the study suggests significant progress, health insurance plans continue to cite challenges to data collection, including enrollees' reactions to collecting these data, enrollee misperception in how this information will be used, lack of standardization in data collection, and concern that state or federal laws and regulations prohibit such collection, amongst others.

III. QUANTITATIVE RESEARCH: KEY POINTS

A web-based survey instrument consisting of 57 questions was disseminated to a stratified sample of 302 health insurance plans drawn from the universe of health insurance companies in the United States.

The optimal final sample size was determined to be 306 companies, based on 1,506 companies as the universe of health insurance companies in the United States (95% confidence level +/-5%). An over-sample was drawn from the frame to compensate for the possibility of having companies in the sample for which no contact information could be established, or for subsequent discoveries of ineligibility. With this in mind, a goal of 425 companies for the over-sample was set-- nearly 140% of the target sample of 306.

Ten large national health insurance companies were included with certainty under their respective designated product categories. Product designations for certainty companies were made by either the preponderance of their enrollment by product type, or to balance the survey sample so that the product enrollment in the overall sample reflected the industry as a whole.

Of the 424 companies in the initial sample, 108 companies were disqualified after further investigation of their eligibility¹ and for 14 companies, contact information at AHIP non-member health plans could not be found. Of the 122 companies that were excluded, 100 were Commercial, 7 were Medicare, and 15 were Medicaid.

The final sample of 302 health insurance plans, enrolling over 102 million health plan enrollees, included 135 commercial, 110 Medicaid, and 57 Medicare plans. 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.

The survey was designed to determine the extent to which health insurance plans are collecting data on race and ethnicity about their enrollees. Plans indicating that they do not currently collect such data were asked about their concerns with collecting these data and

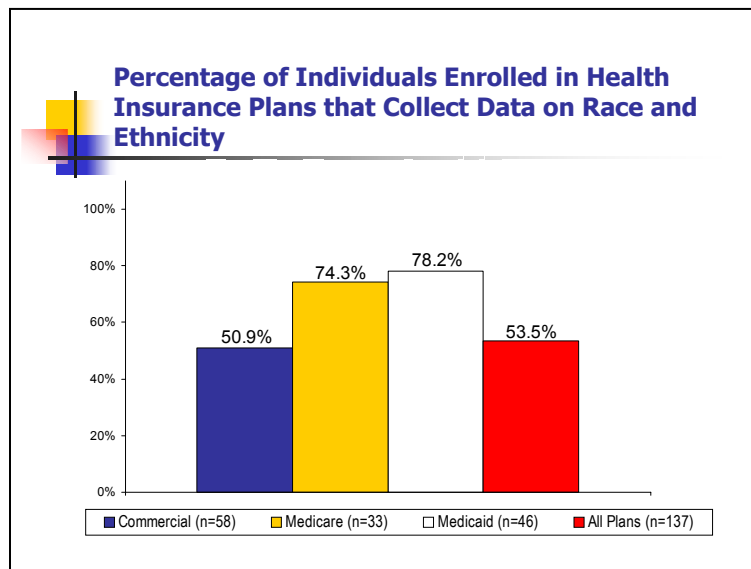
¹ Upon further investigation, health plans were determined to be ineligible due to the following reasons. Some plans were subsidiaries of other organizations in the sample, some companies were no longer in business, and some PPOs were considered to be "leased networks" and not integrated PPO plans.

whether similar data is collected on providers and made available to enrollees. Plans indicating that they do currently collect such data were asked about their collection methods, reasons for collecting these data, barriers, and perceived concerns with the collection of data on race and ethnicity. Health insurance plans were also asked to report on the primary uses of these data as well as whether they collect information on the primary language spoken by enrollees.

PRODUCT LINE	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

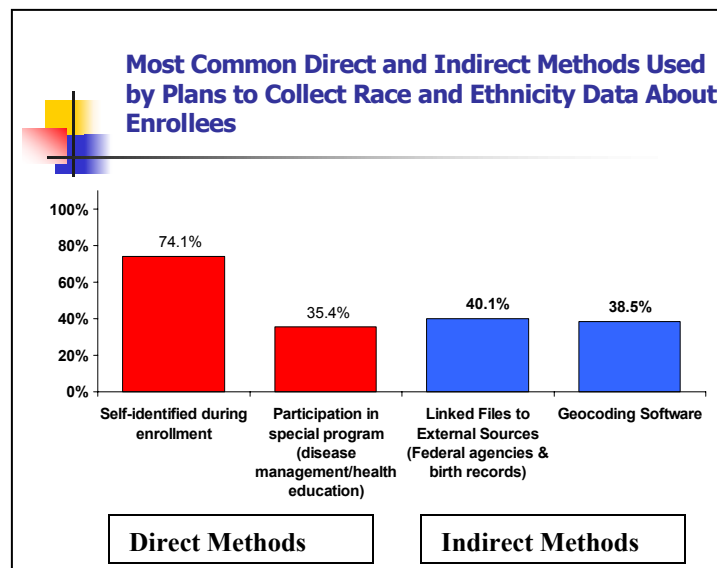
Collection of Data on Race and Ethnicity

According to the survey, just over half of enrollees (53.5%) are enrolled in health insurance plans that responded to the survey and collect data on race and ethnicity while 46.5% of those are enrolled in plans that responded to the survey and do not currently collect such data.



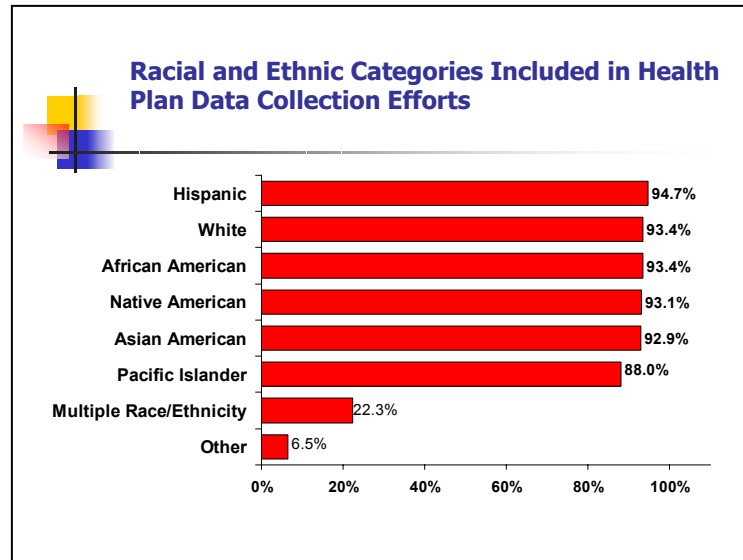
There are two methods of collecting data on race and ethnicity: either *directly* from enrollees on a voluntary basis or *indirectly* using geocoding software or other proxies. Of those plans that collect data on race and ethnicity and responded to the survey²:

- 74.1% collect these data *directly* from enrollees during plan enrollment.
- 35.4% collect these data *directly* from enrollees when an enrollee participates in a special program, such as disease management or health education programs.
- 38.5% collect these data *indirectly* using geocoding software that assigns a proxy for race and ethnicity categories.
- 40.1% obtain these data *indirectly* through files linked to external sources, such as Federal agencies or birth records.



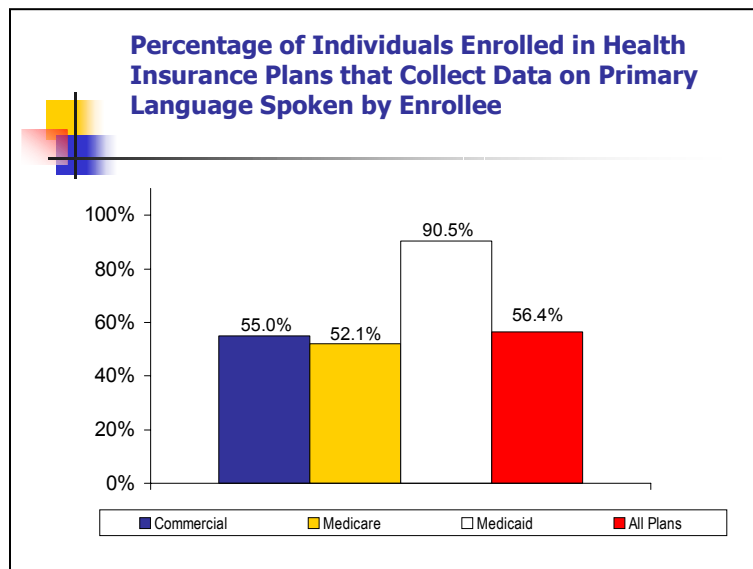
² The total number of responses does not equal 100 percent because respondents could answer one or more times.

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. A smaller percent of plans (22.3%) indicated that they also include a category for multiple race/ethnicity (e.g., African American and White).



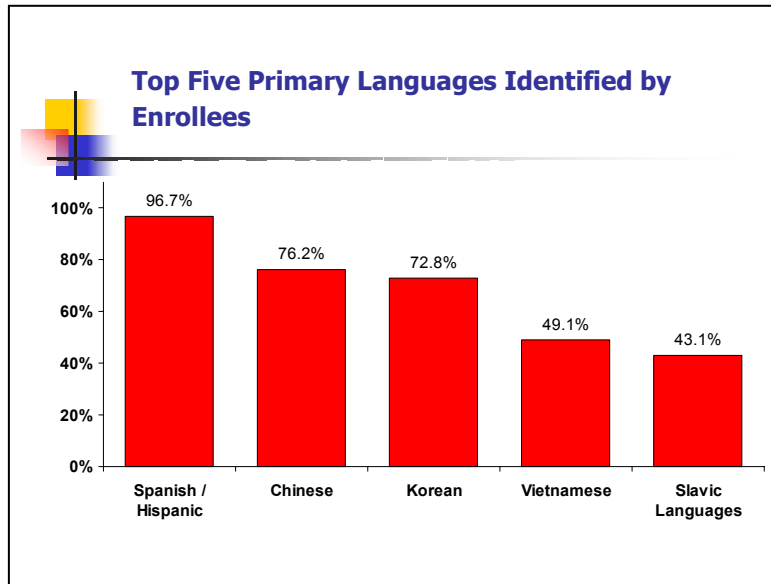
Collection of Data on Primary Languages

In the absence of information on race and ethnicity, and sometimes in addition to it, health insurance plans may collect data on the primary languages spoken by enrollees. Over half of enrollees (56.4%) are covered by plans that responded to the survey and collect data on primary language.



Of these plans (that responded to the survey and indicated that they collect such data):

- 80.9% collect information on primary language *directly* from the enrollee during enrollment.
- 27.8% obtain information on primary language *indirectly* using geocoding software.
- 22% obtain information on primary language *indirectly* through files linked to external sources.
- The most common primary languages spoken by enrollees (other than English) include Spanish (96.7%), Chinese (76.2%), Korean (72.8%), Vietnamese (49.1%), and Slavic languages (43.1%).



Effective Use of Data³

The top five reasons cited by health insurance plans for collecting data on race and ethnicity are to:

- Identify enrollees with risk factors for certain conditions;
- Support linguistically and culturally appropriate communications;
- Design quality improvement efforts to reduce disparities;
- Begin to assess variation in quality measures; and
- Develop disease management or other specialized programs.

³ The weighted score is calculated as such: Companies were asked to rank their concerns 1 through 5, with 1 being the highest and 5 the lowest. A rank of "1" earns one point; a rank of "2" earns 2 points, etc.

Step 1: A frequency was calculated for each rank (1-5) within a variable to show how many responders assigned a specific rank to the variable.

Step 2: A calculation was performed to show how many responders overall chose to rank the variable (1-5).

Step 3: A calculation was performed i.e. $[(frequency) \times (rank)] / overall\ number\ of\ responders$ to achieve the weighted score.

A lower score connotes a greater importance than a higher score. The frequencies are weighted by enrollment as reported by the survey responders.

Barriers to Collecting Data on Race and Ethnicity⁴

Of those health insurance plans that responded to the survey that they do not collect data on race and ethnicity, the reasons for not collecting these data were as follows:

- Concern about enrollees' reactions;
- Concern that federal and state laws or regulations prohibit collection of such data
 - ✚ A review of state and federal law showed no federal law or regulation prohibits the collection of these data. Only four states have laws or regulations that prohibit the collection of these data:
 - California
 - Maryland
 - New Hampshire
 - New Jersey
- Belief that the collection of such data is not common in their markets; and
- Belief that good or reliable methods for data collection are lacking.

Further, according to the survey responses, 96% of members are enrolled in plans that stated that they do not collect data on race and ethnicity and reported that they have no plans to do so within the next year. These same barriers, enrollee reactions, confusion about state and federal laws, the lack of a standardized approach, and a reliable method to data collection, impacted the decisions by plans not to initiate data collection.

Collection of Data on Providers

Health insurance plans are less likely to collect data on race and ethnicity on their providers than they are on their enrollees. Of those plans that responded to the survey that they collect these data from their providers (46.5%):

- 67% reported that they distribute this information to their enrollees through health insurance plan web sites; and
- 26.6% reported that they distribute this information to their enrollees through provider directories.

IV. HOW QUANTITATIVE RESEARCH WAS USED TO DESIGN QUALITATIVE RESEARCH ACTIVITIES

The quantitative survey results informed all aspects of the subsequent qualitative research conducted during this project. To select the health insurance plans for follow-up interviews, the survey responses were used to ensure that a broad range of health insurance plans participated (e.g., health insurance plans that collect and do not collect data, those plans indicating enrollees' reactions were a primary concern with data collection etc.).

The quantitative results also informed the discussions at the focus group and the expert panel meeting. Participants in the qualitative research phase were asked to review the results of the survey, provide their reactions to the survey results, and offer their insights regarding issues

⁴ The same weighting methodology explained in Footnote 3 was used to collect responses to this survey question.

surrounding the collection, analysis, and use of data on race and ethnicity to further highlight the experiences of health insurance plans in this area.

V. QUALITATIVE RESEARCH: KEY POINTS

In follow-up to the quantitative research conducted through the survey of health insurance plans, AHIP conducted qualitative research to obtain more specific information on health insurance plan collection and use of data on race and ethnicity. 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.

Telephone Interviews

Fifty-four responding health plans reported through the survey that their organizations were willing to participate in telephone interviews to share additional information on their practices of collecting racial and ethnic data. Of these fifty-four plans, a random sample of health plans was selected to ensure adequate representation among the different plans based on specific plan characteristics and certain trigger questions. One additional health plan was selected to provide information about their current activities due to their extensive work in ensuring the cultural competency of providers and in addressing disparities in care within their enrolled populations. Plan characteristics included: health plan size, product line, location, and service area. The main trigger question for interview selection was whether or not a health plan collects racial and ethnic data. Other questions reflected additional topics identified for further investigation, including the barriers to data collection, such as enrollee reaction or perceived federal/state laws, organizational approaches used by health plans to collect data (e.g., collecting data organization-wide, within specific departments, within one department, or only within one targeted program or initiative), and sharing racial and ethnic data with external groups for purposes of quality improvement. Twenty-two plans covering 39.7 million lives participated in the final interviews.

Focus Group

A focus group was conducted for health plan representatives in conjunction with a national research conference sponsored by America's Health Insurance Plans. Ten individuals from health insurance plans, who were either attending the conference or were interested in this issue, participated in the focus group representing different types of plans that covered various geographic areas and enrolled populations. The individuals also held a variety of different positions within the health plans, including four chief medical officers or medical directors, two individuals responsible for prevention/wellness and women's health services, two responsible for quality improvement or operations compliance, one researcher, and one individual responsible for civic affairs. An independent facilitator moderated the session and helped develop areas for future research and identified areas for future collaboration.

Expert Panel Meeting

An expert panel meeting was also convened to review the quantitative study results, develop a strategic action-oriented plan to focus current and future projects, and identify potential actions and areas for future research. To ensure a variety of perspectives, sixteen individuals

were selected to participate in the one-day expert panel meeting, including health plan executives and decision-makers, members of the project's advisory committee, and other national experts. An independent facilitator moderated the meeting to spur discussion amongst the expert panel members.

This follow-up research sought to solicit recommendations on how to improve the collection and use of these data, develop a strategic, action-oriented approach to reducing disparities in care, and identify areas for future collaborations. A number of challenges and opportunities emerged from this research.

CHALLENGES

Consumer Response

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 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.

Information Infrastructure & Availability

Information systems used throughout the healthcare system, including those at health insurance plans, can impose a major barrier to collecting and using these data (e.g., there is a lack of coordination of systems used to retrieve these data within and across organizations). Current information systems are not designed to collect, store, and/or retrieve data on race and ethnicity and health insurance plans find it difficult to coordinate organization-wide data collection initiatives using different systems and processes. 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 voluntary method and system to collect, store, and subsequently utilize the data for quality improvement efforts.

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 health insurance plans are taking to ensure that such information is used appropriately and privacy concerns are safeguarded.

Health Plan Staff and Provider Education

Discussion with health insurance plan staff during telephone interviews and at the expert panel meeting emphasized the relationship between positive provider-patient communication, 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 physicians and other health care professionals. The need for cultural competency training throughout the healthcare system of clinicians, support staff, and health insurance plan staff, was recognized as a priority by researchers, hospitals, and representatives of 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. Although health insurance plans found it important that relevant data on race and ethnicity be collected at the individual plan level and by all health care organizations, plans also acknowledged a need for a standardized method to collect these data to allow for greater comparison across health plans and the entire health care industry.

To date, federal, private, 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 Institute of Medicine's (IOM) 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. These key recommendations have been endorsed by most health care stakeholders and emphasize the need for a comprehensive evaluation of initiatives to identify those with the greatest impact on improving health care quality. 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.

VI. LESSONS LEARNED

Disparities Erode the Promise of the Health Care System. Cultural barriers impede access to care. These issues create gaps that put our health care system out of reach for the very individuals who may need it the most. We know from previous research that poor

access to care leads to more serious medical conditions, increased absenteeism, and reduced productivity. Disparities that result from cultural barriers prevent millions of Americans from benefiting from the promise of our health care system.

Health Insurance Plans that Collect Data are Taking an Important First Step. Health insurance plans that are collecting data on race and ethnicity are using it to improve the quality of care their enrollees receive. Plans are using the information to design targeted outreach programs for preventive care and disease management as well as to develop linguistically and culturally appropriate communications with their enrollees. The collection of data has enabled health insurance plans to take the very important first step of using these data to reduce disparities in care. There is more work to be done by using these data to design targeted programs and comparing outcomes by different racial and ethnic groups.

Need to Stimulate Additional Data Collection by Health Insurance Plans. As previously discussed, over one-half of the individuals (53.5%) are enrolled in health insurance plans that responded to the survey and are currently collecting data on race and ethnicity. Of those plans that indicated no activity in this area, very few (4%) indicated that they would begin collecting these data in 2005. Health plan leadership needs to be further educated about the importance of data collection to achieve the necessary buy-in to initiate these activities.

Commonalities in Collection are Essential. This research indicates that the lack of a standard approach across the entire health care system has made the collection of information very difficult. This is a challenge that all health care stakeholders must address by working together to promote the collection of data that can be used consistently across the health care system.

Need to Address Both Real and Perceived Barriers. Whether real or perceived, a barrier impacts the ability to progress forward and must be addressed. Clearly, there is a need to address the perceived barrier that state and/or federal law and regulations prohibit data collection. Awareness that no federal statutes currently prohibit such data collection and only four states restrict such data collection for certain product lines must be fully understood and acknowledged by all health care stakeholders. Overcoming this perceived barrier through education and reinforcement could yield much progress in the future.

Additionally, this research made clear that plans are concerned that enrollees may have reservations about disclosing information on their race and ethnicity. More effective communication about the positive uses and resulting effect associated with the collection of this information is necessary. This was a resounding message heard from the telephone interviews, focus group, and expert panel. Simple and consistent communication messages would also educate consumers and clinicians about the importance of these data.

Multiple Opportunities Exist for Education, Improvement, and Partnerships. While much progress has been made, there is still significant room for improvement. Many of the barriers to the collection of such data can be effectively addressed through collaborations across health insurance plans in the same market and partnerships with other stakeholders in the health care system. For example, collaborations among health plans in a given market

can facilitate the exchange of ideas regarding effective data collection practices, measurement opportunities and potentially lead to the development of best practices to reduce disparities. Partnerships with community-based organizations can help identify effective strategies to educate consumers and address misperceptions about data collection. Community partnerships can also be effective in identifying approaches for best addressing the cultural needs of individuals of different racial and ethnic backgrounds.

VII. NEXT STEPS

The key findings and lessons learned from this research have helped to identify several next steps toward the national goal of reducing disparities in health care. The information amassed from this study will help guide future work in addressing data collection and identifying and analyzing successful models that have improved health outcomes. Identified next steps include the following:

Encourage More Data Collection. Heightened sensitivities about potential enrollee reactions and legal and regulatory barriers may inhibit active collection of data on race and ethnicity by health insurance plans. To move forward, health plans must fully understand and address the impact of the current legal and regulatory environment and enrollee reactions in order to gain organizational support to collect these data. Health plans must also work to allay enrollee concerns about data collection by discussing strategies to safeguard the data once collected and explicitly identify the purposes of this data collection.

Given that some health insurance plans have made the decision to collect these data despite many of the previously identified barriers, forums that promote a discourse between plans to overcome these challenges would be an important step in increasing the number of plans currently collecting data. As effective strategies and models are shared, plans that may have had difficulty in data collection will have access to information and technical assistance to help them begin data collection. Such forums also will enable perceived barriers, such as enrollee reactions and federal and state laws and regulations, to be discussed and resolved.

Encourage Continued Use of Such Data for Quality Improvement. Data collection is an initial step in the implementation of quality improvement strategies that are designed for all health plan enrollees. As more plans begin to collect data on race and ethnicity, dissemination of information about how health plans utilize and monitor these data to improve quality will be instrumental in promoting data collection and use to improve health care outcomes for culturally-diverse health plan enrollees.

Achieve Commonalities and Standardization in Data Collection. Working with health insurance plans that are currently collecting data on race and ethnicity can help identify effective models for data collection. Partnerships with other stakeholders, including representatives from the Centers for Medicare and Medicaid Services (CMS), will 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.” Commonalities in data collection will facilitate more effective use of these data in reducing disparities of care among racial and ethnic populations.

Increase Consumer and Provider Support of Data Collection. As health insurance plans become more educated about the need for data collection, consumers and providers must also increase their understanding of the goals and benefits of collecting data on race and ethnicity. More focused communications between all health care stakeholders about the benefits of data collection will be necessary to further enable these activities to move forward.

As mentioned above, partnerships with community-based organizations can help identify effective strategies to educate consumers and address misperceptions about data collection. Partnerships with medical societies can be effective in airing and addressing provider concerns and questions and, ultimately, gain acceptance and support from this subset of health care stakeholders that is essential to effective data collection and use of data to reduce disparities and improve quality.

Support Research on Effective Interventions. In its *Unequal Treatment* report, the Institute of Medicine (IOM) 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. A public-private partnership between the Agency for Healthcare Research and Quality (AHRQ), AHIP, RWJF, and health insurance plans should be continued to evaluate specific interventions and then widely disseminate the findings to the public.