



**WHO, WHEN, AND HOW:
THE CURRENT STATE OF RACE, ETHNICITY, AND
PRIMARY LANGUAGE DATA COLLECTION IN HOSPITALS**

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May 2004

Support for this research was provided by The Commonwealth Fund. The views presented here are those of the authors and should not be attributed to The Commonwealth Fund or its directors, officers, or staff.

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ACKNOWLEDGMENTS

The authors would like to thank the key informants for their participation and insights and those individuals at each of the sites who helped to coordinate and facilitate our visits. We would also like to thank Peter Kralovec of the Health Care Data Center at AHA's Health Forum for assistance with questions on the AHA Annual Survey.

EXECUTIVE SUMMARY

According to the Institute of Medicine, standardized data collection is critical to understanding and eliminating racial and ethnic disparities in health care. A critical barrier to eliminating disparities and improving the quality of patient care is the frequent lack of even the most basic data on race, ethnicity, and primary language of patients within health care organizations. The methods for collecting these data are disparate and, for the most part, incompatible across organizations and institutions in the health care sector.

The Health Research and Educational Trust (HRET) is working with a consortium of six leading hospitals and health systems to address racial and ethnic disparities in treatment and outcomes. To identify current practices around race, ethnicity, and primary language data collection in hospitals, we conducted site visits to each of the consortium members (Henry Ford Health System, Kaiser Permanente, Massachusetts General Hospital, Northwestern Memorial Hospital, Parkland Memorial Hospital, and the University of Pittsburgh Medical Center Health System) to address questions about their data collection practices. In addition, we surveyed 1,000 hospitals nationwide to provide a wide-angle snapshot of what is taking place regarding race, ethnicity, and primary language data collection. The most recent (2003) American Hospital Association Annual survey, which is sent to 6,000 hospitals nationwide, also included two questions asking hospitals whether they gather information on patient race, ethnicity, and primary language; the survey has an 80 percent response rate.

HOSPITAL SURVEY FINDINGS

Who collects race/ethnicity data? A total of 272 of the 1,000 hospitals returned completed surveys during a one-month time period (27% response rate). The majority of hospitals (78% in both the 1,000-hospital survey and AHA Annual Survey) reported collecting race and ethnicity data about patients. The survey indicated that teaching hospitals, urban hospitals, and hospitals in states with a mandate to collect race/ethnicity data are significantly more likely to collect such data about patients. However, only 50 percent of respondents from the 22 states that have a mandate to collect such data were actually aware of the mandate.

How is it collected and why? Fifty-six percent of hospitals that collect data indicated that more than one unit or clinic within the hospital collects data about patients. In most cases, the primary source of information about race/ethnicity is the patient or an admitting clerk obtaining information from the patient directly. However, 51 percent of those hospitals also reported that admitting clerks determined race/ethnicity based on

observation. Most hospitals collect race and ethnicity data because it is required by law or regulation (42%) while 29 percent recognize the benefits of data collection and 22 percent use it for quality improvement purposes.

Which racial/ethnic categories are used? Eighty-six percent of hospitals indicated that they provide specific categories for patients or guardians to check off when data on race and ethnicity are collected, and 13 percent reported collecting the information using a “fill in the blank” open-ended question. None of the broad, standard U.S. Census categories used to specify race or ethnicity, i.e., white, black, Hispanic, Asian, Native American, and Alaska Native, were used by 100 percent of the hospitals. A number of narrower, “fine-grained” categories were used by up to 10 percent of the hospitals. These two observations suggest that hospitals did some significant tailoring of the standard U.S. Census categories to adjust to local circumstances.

Barriers and concerns. Among hospitals that collect data on race/ethnicity, 70 percent did not see any drawbacks to collecting the data. Drawbacks reported by the remaining 30 percent included: discomfort on the part of the registrar or admitting clerk asking the patient for the information; problems associated with the accuracy of the data collected; a sense that patients might be insulted or offended, or resist answering questions about their race and ethnicity; patients often did not “fit” the categories that were given; a fear that data may not be kept confidential; and the possibility that collecting data on race and ethnicity might be used to profile patients and discriminate in the provision of care.

SITE VISIT FINDINGS

Synthesis of the site visit findings confirms many of the findings from the survey and indicates that while there is a theoretical commitment to collecting race/ethnicity/primary language information and a basic understanding of its importance, operationally there are not consistent policies and practices to make it happen.

The site visit hospitals indicated that they collect data to understand the communities they serve; for grant applications; to match their workforce to the communities they serve; to provide certain donors with information about the patient mix; for targeting quality of care initiatives; for contractual compliance obligations, especially with government contracts (Medicare, Medicaid); and for the provision of interpreter services. Barriers to data collection include resource limitations, uncertainty about which racial/ethnic categorization system to use, negative perceptions of patients as to why data are collected, language and cultural barriers, lack of staff training, doubts as to the validity and reliability of the data, perceived legal barriers, and system or organizational

barriers. Facilitators of data collection include developing educational programs and training for staff about the importance of collecting this information, the use of self-report by patients to improve the validity and reliability of the data, leadership support, and regulatory measures.

RECOMMENDATIONS

From the results of the surveys and site visits, it is clear that the collection of data on patients' race, ethnicity, and primary language is not standardized within or among the hospitals surveyed and visited and that such collection must be standardized in order to be effective. We offer the following recommendations to achieve this goal:

1. **Hospitals should standardize who provides information.** Patients or their caretakers are more likely to provide accurate information about patients' race, ethnicity, and language than an admitting clerk or health care provider based on observation.
2. **Hospitals should standardize when data are collected.** Collection of data on patients' race, ethnicity, and language upon admission or patient registration will ensure that appropriate fields are completed at the time a patient begins treatment at the hospital.
3. **Hospitals should standardize which racial and ethnic categories are used.** If hospitals are going to use categories, then the Office of Management and Budget (OMB) categories should be used, which would allow for use of standard racial and ethnic categories by all hospitals (see Appendix 3). At the same time, hospitals can use fine-grained categories of Hispanic or Asian groups, for example, that could then expand to broader U.S. Census categories as needed.
4. **Hospitals should standardize how data are stored.** Race, ethnicity, and language data should be stored in a standard format that is compatible across hospitals and health systems. Many of the newer data systems used by hospitals have separate fields for race, ethnicity, and primary language. The data systems may allow for export and import and merging with clinical data files.
5. **Hospitals should standardize their responses to patients' concerns.** Patients' concerns about the ways in which data on race, ethnicity, and language will be used should be addressed prior to collecting the information. There should

be a uniform rationale offered to all patients before asking them to identify their racial/ethnic background.

Collection and reporting of data on patients' race and ethnicity are critical if hospitals and other private health organizations want to engage as active partners in improving overall quality of care and reducing racial and ethnic disparities. The availability of accurate and timely data on health care access and utilization by patients' race, ethnicity, and primary language will contribute to increased awareness of racial and ethnic disparities in health, identification of appropriate target populations for interventions to improve quality of care, and development of programs and strategies to eliminate disparities. It also will facilitate monitoring and evaluation of the effects of interventions, and ultimately provide the answer to the following questions: "For whom are we developing initiatives and are these initiatives appropriate for these populations?"

To accomplish the overarching goals of improving quality and reducing disparities, it is imperative that the leadership of hospitals and health systems be supportive and involved; invest in staff training at all levels; ask patients to self-identify their race, ethnicity, and primary language, and ensure that data collected are valid and reliable through constant monitoring and evaluation.

NEXT STEPS

The development of a framework to collect information on patient race, ethnicity, and primary language is a first step and lays the foundation in a long-term effort to improve quality of care and reduce disparities. Consortium members, along with a National Advisory Panel appointed by HRET, have been working to develop such a framework. Once a framework is agreed upon, a set of clinical conditions and a core set of indicators to track over time will be selected. By linking clinical information with information about patients' race, ethnicity, and primary language, consortium members will track the care process and where it breaks down, or has the potential to break down. In addition, they will develop interventions and initiatives to improve the care process for various population groups.

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INTRODUCTION

Recent reports, peer-reviewed articles spanning more than 20 years, anecdotal evidence, health and vital statistics, and many other pieces of evidence have shown that racial, ethnic, and language-based disparities in health care exist. According to a report released in 2002 by the Institute of Medicine:

Standardized data collection is critically important in the effort to understand and eliminate racial and ethnic disparities in health care. Data on patient race, ethnicity, and primary language would allow for disentangling the factors that are associated with health care disparities, help plans monitor performance, ensure accountability to enrolled members and payers, improve patient choice, allow for evaluation and intervention programs, and help identify discriminatory practices.¹

On the national front and in local communities, numerous organizations are attempting to address the reasons for these disparities and develop programs to reduce and, ultimately, eliminate them. Despite all the evidence showing disparities in treatment and outcomes, the underlying reasons for these disparities remain poorly understood. We know, for example, that there are variations in presentations of symptoms and description of pain; differences in the expectations and experiences of care; issues relating to trust, literacy, access, and the financing of health care services; as well as prejudice and racism. These and many other factors all contribute to disparities. In order to develop and implement initiatives that effectively target these factors, we need to know the answer to the “who” question—for whom are we developing initiatives and are these initiatives appropriate for these populations?

A critical barrier in our pursuit of understanding and eliminating disparities and improving the quality of care is the frequent lack of even the most basic data on race, ethnicity, and primary language of patients within health care organizations. The methods for collecting these data are disparate and, for the most part, incompatible across organizations and institutions in the health care sector. In an initial study by Gomez et al., the researchers found that there are variations in the practices of collecting race, ethnicity, and birthplace information for cancer patients in hospitals.² The fact that not all hospitals

collect this information all the time suggests that many hospitals do not have established policies regarding the collection of these data.

With a long-term goal of improving quality of care for racial and ethnic minority groups, the Health Research and Educational Trust (HRET), the research and educational affiliate of the American Hospital Association, has embarked on a project with a consortium of six hospitals and health systems (called the Consortium for Eliminating Disparities Through Community and Hospital Partnerships).³ The members of the consortium are Henry Ford Health System, Kaiser Permanente, Massachusetts General Hospital, Northwestern Memorial Hospital, Parkland Memorial Hospital, and the University of Pittsburgh Medical Center Health System (see Appendix I for a description of these hospitals).

METHODS

In order to address the long-term goals of the project, we first needed to assess the current state of how race, ethnicity, and primary language information is collected in hospitals. We engaged in a one-year data-gathering assignment. We conducted site visits to each of the consortium hospitals to address questions about their data collection practices. We met with key clinical, research, and operations staff to gain a better understanding of current practices in race, ethnicity, and primary language data collection. We also met with information technology, admitting, patient registration, and quality assurance staff at each site.

The site visits were coupled with a seven-page survey, developed by HRET and researchers at Michigan State University, which was sent to 1,000 hospitals nationwide to provide a wide-angle snapshot of what is taking place regarding race, ethnicity, and primary language data collection.⁴

In addition, the most recent (2003) American Hospital Association Annual Survey, which is sent to 6,000 hospitals nationwide, included two questions asking hospitals whether they gather information on patient race/ethnicity and primary language. The site visits and surveys have been an important first step in understanding the current lay of the land and will move us toward the goal of creating a framework for the systematic and comparable collection of data on race, ethnicity, and primary language in health care organizations.

Out of the 1,000 HRET surveys sent, a total of 272 completed surveys were returned during a one-month time period (27 percent response rate). We stratified our

sample by four dimensions: 1) whether the hospital was in a state where there was a state mandate to collect race/ethnicity data, 2) urban/rural hospitals, 3) teaching hospital status (identified as being a member of the Council of Teaching Hospitals and Health Systems [COTH] or having a residency training program), and 4) whether the hospital was part of a larger health system.

The survey also asked hospitals to indicate who provided information about patients' race and ethnicity. They were also asked to identify up to three units or clinics (which the respondents self-identified) within a hospital where these data may have been collected. After reviewing the units listed by the respondents, we created four categories of units for analysis: 1) admitting/registration, 2) emergency department, 3) outpatient/specialty clinics, and 4) hospital (unspecified).

HOSPITAL SURVEY FINDINGS

HRET Survey

Two hundred seventy-two hospitals responded to the survey.⁵ The majority of hospitals reported collecting race/ethnicity data about patients (78 percent, n = 213). Two hundred fifty of the 272 hospitals were analyzed based upon the four stratification dimensions; 22 respondents could not be analyzed due to missing data. Information on these 250 hospitals is presented in Table 1.

Table 1. Collection of Race/Ethnicity Data by Hospital Status

	Collect Data	Do Not Collect Data
State mandate (N=96)	91 (95%)*	5 (5%)
No state mandate (N = 153)	107 (70%)	45 (30%)
Urban (N = 133)	119 (89%)*	14 (11%)
Rural (N = 115)	36 (31%)	79 (69%)
Teaching hospital (N = 54)	52 (96%)*	2 (4%)
Non-teaching hospital (N = 194)	146 (75%)	48 (25%)
Large system (N = 120)	100 (83%)	20 (17%)
Stand-alone (N = 128)	98 (77%)	30 (23%)

* Represent significant differences at $p < .001$.

We hypothesized that hospitals in states with a mandate, teaching hospitals, urban hospitals, and larger health system hospitals would be more likely to collect race/ethnicity data. No significant relationship was found between system affiliation and the collection of data on race and ethnicity. States with a mandate, urban hospitals, and teaching hospitals were significantly more likely to collect race/ethnicity data about patients.

Twenty-two states have a mandate to collect race/ethnicity data. Of the 96 respondents from these 22 states, only 49 respondents, or a little over 50 percent, knew this to be the case (Table 2). In addition, 5 percent of hospitals located in states with a mandate to collect race/ethnicity data did not do so. This gap between knowledge and practice, and the apparent lack of enforcement of mandates, demonstrates the need for policies at the state and/or federal level regarding the collection of complete and accurate race/ethnicity data to improve quality of care and reduce disparities.

Table 2. Existence of State Mandates to Collect Race/Ethnicity Data: Hospitals' Perceptions vs. Reality

	Perception that There Is a Mandate	Perception that There Is No Mandate
State mandate (N = 96)	49 (51%)	47 (49%)
No state mandate (N = 154)	32 (21%)	122 (79%)

Who provides the information? Fifty-six percent of hospitals that collect race/ethnicity data indicated that more than one unit or clinic within the hospital collected data about patients.

The patient was identified as the primary source of information on race/ethnicity for all types of units (Table 3). Either an admitting clerk obtained the information from the patient and completed a form or typed the information into a computer, or the patient, who completed a form himself or herself, provided information about race/ethnicity.

Fifty-four percent of hospitals reported that a caretaker or guardian provided information on race/ethnicity; this was more likely to occur in a hospital (unspecified) or emergency department than in other units. Fifty-one percent of hospitals that collected data reported that admitting clerks determined a patient's race or ethnicity based on observation. Of the four types of units, this occurred most often in the emergency department. Other sources of data included pre-registration information and "referring facilities."

As one might expect, the patient or a relative provided information most often in situations where it was most feasible, such as in outpatient/specialty clinics and hospitals (unspecified), whereas an admitting clerk was more likely to collect the information through observation alone in the emergency department or at admitting/registration. Kressin et al., found that though clerks were encouraged to request racial/ethnic information from patients, this rarely happened.⁶ Clerks indicated that patients felt

uncomfortable providing this information or did not understand the question. Several clerks stated that they assigned race/ethnicity based on the patient’s last name or appearance.⁷

Table 3. Who Provides Information About Patients’ Race/Ethnicity?

Admitting clerk obtains information from patient	68%
Patient self-identifies on form	65%
Caretaker or guardian	54%
Admitting clerk obtains information based on observation	51%
Health care provider obtains information from patient	19%
Health care provider provides information based on observation	12%
Other	8%

Note: Percentages total more than 100 percent because hospitals use more than one method of data collection.

When are data collected? Information on race/ethnicity was most often collected upon admission for all types of units, or at first visit/new registration (Table 4). Data were collected less often through health care provider notes or the medical record, and rarely at discharge. “Other” responses included “during the hospital stay,” “upon subscribing to an HMO,” “during preadmission screening,” “at an initial intake assessment,” “when obtaining a birth certificate,” and “when making an initial appointment.”

Table 4. When Are Race/Ethnicity Data Collected?

Upon admission	85%
First visit/new registration	60%
Health provider notes/medical record	12%
At discharge	2%
Other	8%

Why is this information collected? We asked hospitals why they established policies/practices to collect data on patient race and ethnicity and gave the option to check all responses that applied (Table 5). The largest single set of respondents reported that their hospital established policies to collect data on patient race and ethnicity “because it was required by law or regulation” (42%). Twenty-nine percent “recognized the benefits of data collection,” 22 percent reported collecting the data for quality improvement purposes, 19 percent felt it was important for community relations, and 12 percent reported collecting data because it helped target marketing efforts. Seventeen percent of hospitals gave other reasons for collecting these data, such as it was required by the state; it was included as basic demographic information for medical records or a

hospital database or cancer registry; it was required by the state hospital association; and it was used for teaching and for conducting research on best practices, trends, and preventive care.

Table 5. Why Are Race/Ethnicity Data Collected?

Required by law or regulation	42%
Recognized benefits of data collection	29%
Used for quality improvement	22%
Important for community relations	19%
Target marketing efforts	12%
Other	17%

Which race/ethnicity categories are used? We asked hospitals if specific categories were used when data on race and ethnicity were collected, or “fill in the blank,” or if some other method was used. Eighty-six percent of hospitals indicated that they provided specific categories for patients or guardians to check off when data on race and ethnicity were collected, and 13 percent reported collecting the information using a “fill in the blank” open-ended question (Table 6). For hospitals that reported using specific categories, respondents were asked which categories they used from the minimum racial classifications used by the Census Bureau—American Indian and Alaska Native, Asian, Black or African American, Native Hawaiian and Other Pacific Islander, White—as well as other racial and ethnic categories that were reported in the profile of general U.S. demographic characteristics from the 2000 Census. Again, hospitals were asked to “check all that apply.”

None of the broad, standard U.S. Census categories used to specify race or ethnicity—White, Black, Hispanic (an ethnicity not a race), Asian, Native American, and Alaska Native—were used by 100 percent of the hospitals, and a number of narrower, more fine-grained categories were used by up to 10 percent of the hospitals. These two observations suggest that hospitals did some significant tailoring of the standard U.S. Census categories to adjust to local circumstances.

Table 6. Which Race/Ethnicity Categories Are Used?

U.S. Census Categories	
White/Caucasian	95%
African American/Black	94%
Spanish/Hispanic/Latino	81%
American Indian	78%
Asian	78%
Alaska Native	27%

More Fine-Grained Categories	
<i>(Hispanic/Latino)</i>	
Mexican, Mexican American, Chicano	10%
Puerto Rican	5%
Cuban	4%
<i>(Asian/Pacific Islander)</i>	
Other Pacific Islander	25%
Native Hawaiian	9%
Asian Indian	8%
Chinese	8%
Filipino	7%
Japanese	7%
Vietnamese	4%
Samoan	4%
Korean	4%
Guamanian or Chamorro	1%

When asked to list additional categories used to categorize the populations they served that were not included among those used on the U.S. Census, hospitals added Cambodian, Czech, Hindu, Hmong, Laotian, Middle Eastern, Persian, Polish, Portuguese, Russian, Thai, and Ukrainian.

Are race/ethnicity data complete? We asked hospitals in what percentage of cases were data on race and ethnicity missing or unavailable. Respondents gave the widest possible range of responses, from 0 to 100 percent. The 100 percent figure presumably represents data that were not collected in this area at all, thus indicating 100 percent missing; the 0 percent figure seems too good to be true, if in fact this indicates that all data fields for race and ethnicity were always filled. A more likely interpretation is that in that hospital there was always some entry made in the data field for race/ethnicity for every patient, regardless of whether the entry was “unknown” or “other.”

How are data on race/ethnicity stored and used? The majority of hospitals stored race/ethnicity data in an electronic database. In various institutions access to these

data was granted to hospital employees, health care providers, researchers, grantees/contractors, and the public (Table 7). Data were shared with a number of federal, state, and local governmental agencies including state health departments, Medicare, Medicaid, local health departments, and the Veterans Administration. Nongovernmental agencies/organizations were also given access to the data, including accrediting bodies, community groups, and purchasers (Table 8).

Table 7. Who Has Access to Race/Ethnicity Data?

Hospital employees	78%
Health care providers	40%
Researchers	15%
Grantees/contractors	7%
Public	3%
Unknown	5%

Table 8. With Which Organizations Are Race/Ethnicity Data Shared?

Governmental Agencies	
State health departments	36%
Medicare	26%
Medicaid	25%
Local health departments	15%
Veterans Administration	9%
Nongovernmental Agencies	
Accrediting bodies	21%
Community groups	5%
Purchasers	1%

Hospitals used race/ethnicity data for a variety of internal purposes including ensuring the availability of interpreter services, quality improvement or disease management programs, program/benefit design, marketing, actuarial purposes, and underwriting. Given the many competing demands hospitals and health systems face, it is interesting to note that 36 percent state that they use it for quality improvement (Table 9). Given that 78 percent of the hospitals indicated that they collect race/ethnicity information, the percentage that actually use it for quality improvement purposes is much lower (28%). A small number of respondents indicated that the data were collected but were not used.

Table 9. How Are Data on Race/Ethnicity Used?

Ensuring availability of interpreter services	36%
Quality improvement/disease management programs	36%
Program/benefit design	16%
Marketing	13%

Changes in policy on data collection. The majority of hospitals were not considering revising their policies regarding collection of data on race and ethnicity (73%). Those that were (6%) planned to increase the number of categories patients had to choose from when self-identifying race and ethnicity. The remaining respondents did not know if their hospitals were planning revisions to their data collection policies.

Barriers and concerns. Among hospitals that collected data on race/ethnicity, 70 percent did not see any drawbacks to collecting the data. Drawbacks reported by the remaining 30 percent included:

- discomfort on the part of the registrar or admitting clerk asking the patient for the information;
- problems associated with the accuracy of the data collected;
- a sense that patients might be insulted or offended, or resist answering questions about their race and ethnicity;
- patients often did not “fit” the categories that were given;
- a fear that data may not be kept confidential; and
- the possibility that collecting data on race and ethnicity might be used to profile patients and discriminate in the provision of care.

We asked hospitals that did not collect data on race and ethnicity (n = 57) to give reasons why (Table 10). Sixty-one percent stated that it was unnecessary to collect data on patients’ race and ethnicity. Smaller numbers of respondents stated that there was no reliable system for data collection; there was no good classification system for race or ethnicity; data were too costly to maintain; data would be unreliable; data collection was legally allowed, but not authorized by the hospital; and that collection of race/ethnicity data was prohibited by law or external regulation.

Table 10. Reasons Hospitals Did Not Collect Race/Ethnicity Data

Unnecessary	61%
No reliable system for data collection	17%
No good classification system for R/E	16%
Data too costly to maintain	7%
Data would be unreliable	7%
Legally allowed but not authorized by hospital	5%
Prohibited by law or external regulation	5%

Note: Percentages do total 100% because respondents were given the option to “check all that apply.”

Fifty-four percent of hospitals that did not collect data on race/ethnicity stated that there were drawbacks to data collection. Reasons included:

- time and resources involved in collecting and managing the data,
- data collection is an invasion of privacy, and
- concern that providers would use the information to discriminate in the provision of care.

Although it is clearly illegal to use the information to discriminate in the provision of care, there is concern that patients perceive that care would be different based on their race or ethnicity if they provided this information. One respondent voiced concern that knowledge of a patient’s race and ethnicity would lead to “segmenting service delivery, discrimination, and multiple standards of care.” Another wrote, “some people feel these questions signify that they will be treated differently from other patients.” Others took an almost defensive stance, questioning the need for such data and stating that “all of their patients are treated the same,” and “does it make a clinical difference?”

Hospitals that did not collect data were more likely to identify drawbacks than hospitals that collected data (Table 11). Time and resources needed to collect and manage the data were a major concern for hospitals that did not do so. Both expressed concern about the possibility that discrimination would result in the provision of care, although hospitals that did not collect the data mentioned it considerably more often than hospitals that did. The drawbacks mentioned most frequently by hospitals that did collect data were related to staff and patients feeling uncomfortable or offended by questions about race and ethnicity, and concerns about the accuracy of the data, particularly for individuals who did not “fit” the categories provided.

Table 11. Status of Race/Ethnicity Data Collection, by Perception of Drawbacks to Data Collection

	Hospitals that Collect Race/Ethnicity Data	Hospitals that Do Not Collect Race/Ethnicity Data
Drawbacks = Yes	64 (30%)	31 (54%)
Drawbacks = No	149 (70%)	26 (46%)
Total	213 (100%)	57 (100%)

Collection of data on primary language. In the case of primary language, we simply asked whether hospitals collected data on a patient’s primary language, but did not include detailed follow-up questions in order to keep the length of the survey reasonable. Thirty-nine percent of hospitals collected data on patients’ primary language, 52 percent did not, 3 percent of respondents reported they did not know, and 6 percent did not respond to the question.

Nonrespondents. We sent the survey to 1,000 hospitals, of which 272 responded. We analyzed the nonrespondents (n=728) based on the stratification dimensions displayed in Table 12. The majority of the hospitals that did not respond to the survey were non-teaching hospitals and were in a state where there was no mandate to collect these data.

Table 12. Nonrespondents Analysis (N = 1,000)

	Yes	No
Teaching hospital	92 (13%)	636 (87%)
Urban hospital	349 (48%)	379 (52%)
Part of a system	360 (50%)	368 (50%)
In state that mandates data collection	290 (20%)	438 (60%)

American Hospital Association Annual Survey

The American Hospital Association (AHA) Annual Survey has been conducted since 1946 and is widely regarded as the most authoritative and comprehensive source of individual hospital data available. The AHA sends the survey to 6,000 hospitals in the United States and Puerto Rico. The average response rate is 80 percent per year. The survey covers a broad range of questions on utilization, financial services, employees, demographic information, and bed size. The AHA annual survey (2003) included two questions that focused on the gathering of race, ethnicity, and primary language information:

- 1) Does your hospital gather information on a patient’s race/ethnicity at any point during his/her stay? Yes___ No___

- 2) Does your hospital gather information on a patient’s primary language at any point during his/her stay? Yes___ No___

The results for these two questions are presented in Table 13.

Table 13. AHA Annual Survey Results

	Yes	No
Hospitals gather information on patients’ race/ethnicity (N = 4,041)	3,173 (78.5%)	868 (21.5%)
Hospitals gather information on patients’ primary language (N = 4,036)	2,409 (59.7%)	1,627 (40.3%)

The results from the annual survey provide an excellent validation of the results for the 1,000-hospital survey we conducted. Of the 272 hospitals that responded to that survey, 78 percent indicated that they collect information on patient race/ethnicity at some point during the stay and 21 percent indicated that they do not collect data on race/ethnicity. These figures correspond directly with the results of the AHA Annual Survey.

SITE VISIT FINDINGS

There were surprising consistencies across many of the findings from our site visits. Of particular interest is the perception, at all levels of the organization, of data collection around race, ethnicity, and language at the consortium hospitals. The six consortium hospitals and health systems are leaders in the field and more likely to engage in leading-edge programs. All indicated that they collect information on a patient’s race, ethnicity, and language at some point. However, when we asked detailed questions related to the specifics of data collection (e.g., when, where, who collects it, do you have specific policies and practices about collecting it, etc.) it was clear that there was a great deal of both intra-organizational and inter-organizational inconsistency. What this information conveyed is that there is a theoretical commitment to collecting race/ethnicity/primary language information and a basic understanding of its importance, but operationally there are not consistent policies and practices to make it happen. Given this insight, we suggest that the race, ethnicity, and language data the hospitals currently collect are not necessarily valid or reliable and the data collection is ineffective and inefficient.

The hospitals and health systems within the consortium face many barriers to collecting these data as well, and there is a surprising degree of consistency across all sites. In addition, the synthesis of the findings from the site visits confirms many of the findings

from the survey. We have focused our findings on the common themes that were stated during the key informant interviews.

“We know that we have to collect this information, but we don’t know how to.”
Chief medical officer

“We have a race field but the information is rarely captured. Ethnicity is usually not collected. Primary language is collected in one of the systems but it is captured in a text field and probably not coded.”
IT manager

“Data has been a key problem at getting at disparities. The data are fractionalized. The way the data are fractionalized increases costs because you can’t get resources to those communities that are at risk....[And] it’s not just minority disparity, it’s health disparity.”
CEO

Why Hospitals Collect Race, Ethnicity, and Language Data

- To understand the community they are serving.
- For grant applications. The information flows down to research.
- They want the information to match their workforce to the communities they serve.
- Certain donors want to know information about the patient mix.
- For targeting quality of care initiatives.
- For contractual compliance obligations, especially with government contracts (e.g., Medicare and Medicaid).
- For the provision of interpreter services.

Barriers to Collecting Race, Ethnicity, and Language Data in Hospitals

After analyzing the interview transcripts from the site visits, we found that barriers to collecting race, ethnicity, and primary language data in hospitals cluster around seven dominant themes:

1. Resource limitations

- Time constraints during the registration process.
- Costs of collecting and monitoring the data, data systems integration, and staff training.

2. *Categorization*

- What is the best way to describe the patients? What types of descriptions are provided or should it be left open-ended? This is very difficult to do from a data management perspective.
- There is a concern with the current categories. Are they granular enough? Do the categories we currently have mean anything to the patients (e.g., the OMB categories)?
- Sometimes hospital staff members are not comfortable with the categories, let alone how they are supposed to collect the information.

“You need to have the same categories at each site to eliminate bias. You don’t want to eliminate any population. It’s important not to let the ‘system’ dictate who the patients are—self-identification. Need to remember that even people within the same ethnicity relate differently. Also need to acknowledge how different groups perceive the healthcare delivery system and how to change to better the system overall.”

Professor of family medicine

3. *Patients’ perceptions, language, and culture*

- Staff believe that patients will think they will receive poor care if they answer these types of questions.
- Staff believe that simply asking the questions could be perceived as a barrier to care.
- There are language barriers in collecting the information. Race is a confusing concept for many immigrants.
- Staff do not know how to quickly communicate to the patient the rationale for collecting this information to the patient.

“We leave the race and ethnicity question alone, because we don’t want to do anything that would contribute to or be perceived as a barrier to care. The barrier is that asking these types of questions is very sensitive. It is not easy to do because you need to show a relationship between asking the question and receiving better quality of care.”

Patient registration manager

4. *Staff training*

- Staff do not know how to interview a patient to get the right type of information each time. How should they ask the questions consistently?

- What is the difference between race and ethnicity? How can patients be asked to distinguish if staff cannot?
- Staff sometimes leave the race/ethnicity question alone because “we do not want to be contributing to creating barriers to care.”
- There has to be an investment made in ongoing staff training. It is not a one-shot deal.
- Staff need information and training on how to ask the questions effectively and efficiently, without offending people or being perceived as barriers.
- Staff sometimes feel it is better not to push these questions because it may lead to the perception that they will treat people differently, and they want to be viewed as treating everyone the same.
- Not all patient registration is done face-to-face. Registration often takes place over the telephone, sometimes making it more difficult to ask the race and ethnicity questions.

“The technical part, creating or changing data fields, reporting, etc., . . . can be done with some work. The technical part is not a huge barrier, especially if some basic systems are in place. Staff training is the hardest part. How it becomes part of the regular patient intake process is the more difficult piece.”

Manager of administrative services

5. *Validity and reliability of the data*

- A systematic approach is critical but the hospital may not have one. A standardized method for asking these questions is needed.
- Because hospitals do not have a systematic approach, they are not certain about the reliability of these data.
- There is substantial difficulty in managing care/following the care process from an analytical standpoint because hospitals do not have a clear description of the patient.
- Generally speaking, there is too much variation on how these data are collected and what categories are used. There is a lack of consistency even within the same institution.
- Many patient registration programs do not allow for moving ahead if the race field is not filled out. However, “deferred,” “unknown,” and “other” responses are acceptable, essentially leaving this field unfilled.

“We have across our system a high degree of variance in the categories reported. Some of them have combined race/ethnicity into one category. It is a really difficult task to take this on and fix it. Some of our hospitals are so old. Categories vary widely. Methods of collecting the data vary. We need a uniform framework for our employees to follow when asking these types of questions. We also need monitoring for quality purposes.”

Official with Medicaid and Uncompensated Care Programs

6. *Legal*

- There are perceptions that it is illegal to collect race and ethnicity information. Effective communication materials indicating that there are no legal barriers to collecting these data are needed.

7. *System/organizational*

- There is a perception that health care is just not the right place to collect these data.
- The message about the importance of collecting these data is not clear or forceful enough.
- Technology is an issue but not as daunting an issue as training employees.
- Adding a new data field (e.g., race, ethnicity, primary language) to a patient registration system can be resource intensive depending on the system. However, adding a table to an existing field is more doable.
- There is a need to ensure that all sides understand the importance of collecting data, from the registration clerks to the chief medical officer.
- Financial billing information is always checked and double-checked. Hospitals may not have the same checks in place for the collection of race and ethnicity data. In many instances, no one person is responsible for the collection of these data so it does not get done.
- Many hospitals ask the question over and over and over again. There is a lack of intra-hospital communication among the computer systems.

“We have multiple patient management systems but they don’t communicate. Information is not transferred from one system to another [e.g., inpatient and outpatient] or to downstream systems, such as radiology or labs.”

Chief information officer

Facilitators of Data Collection

Facilitators of collecting race, ethnicity, and primary language data in hospitals clustered around four themes: developing educational programs, use of self-report by patients, leadership support, and regulatory support.

1. Educational programs

- The education/training factor is critical. It can have a very positive impact and make a difference.
- A prepared script for staff can be a useful tool.
- It is useful to ask staff to provide feedback regarding what is working or what is not working for them.
- Educational programs are important but will only have an impact if the programs themselves are habit forming and practiced often. There is a need to examine repeatedly how data collection is done, reevaluate, and make appropriate changes.

“Educational programs are important, but usually have short-term effects. The programs must be habit forming and practiced often. Need to look at the data repeatedly, reevaluate, and make changes as appropriate. Constant checking, monitoring, and changing are all important aspects to educational programs to make them really work.”

Senior vice president of planning and strategic development

2. Use of self-report by patients

- It should be made clear to registration staff that eyeballing and recording patient race, ethnicity, and primary language information should never be done.
- Self-identification is the key to obtaining and maintaining valid data. The staff needs to be very forthcoming with patients as to why they’re asking these questions.
- Present patients with OMB categories but go beyond these as needed. Always allow patients to self-identify.

3. Leadership support

- The leadership of the hospital needs to be supportive of all components for reliable data collection, from staff training to monitoring and evaluating data collection process.

4. *Regulatory support*

- Link the collection of race, ethnicity, and language data with an accreditation body such the Joint Commission for the Accreditation of Health Care Organizations (JCAHO).

“If my business is improving the health of the community, I think it is important for me to know who my population is, what the breakdowns are. I should be able to answer these questions. It is our responsibility to serve our service area.”

Director of community services and relations

Other Critical Factors: Technology and Electronic Medical Records

Several overarching themes related to technology emerged that clearly affect the collection of race, ethnicity, and language data and its subsequent use in improving quality of care for all populations. The importance of electronic medical records (EMRs) to enable effective communication among all systems within a hospital cannot be overemphasized. Though some hospitals have an EMR system and most are working toward converting to such a system, a very small number are actually at that point. There are substantial costs associated with converting from paper to EMRs as well as institutional investment and energy.

However, there is unanimous agreement that the EMR is an excellent tool for improving patient care. It provides a foundation for standardizing all the systems by integrating around one major clinical management system. The ability to link patient registration systems to EMRs provides an excellent tool for tracking the process of care and for monitoring health outcomes to support ongoing quality improvement efforts, especially efforts targeted toward reducing and eliminating health disparities.

One individual we interviewed responded to a question asking about the value of EMRs in improving patient care: “Yes, we believe it can improve care. It is a huge financial investment, upwards of \$50 million over seven to eight years. Standardizing all systems is difficult because it means getting rid of a lot of the homegrown stuff in favor of what vendors are offering. Overwhelmingly, people are still relying on paper charts because of the complexity. We still need to recognize the value of switching to electronic medical records from an industry-wide perspective.” Kaiser Permanente has been working on an initiative for collecting race, ethnicity, and primary language data, which it will roll out this year at a number of its regions across the country. Kaiser understood the importance of EMRs to this effort and therefore timed its initiative to collect patient race, ethnicity, and language with Kaiser’s push to move to EMRs. Paul Wallace, M.D., head of Kaiser Permanente’s Care Management Institute stated “the timing was just right.”

Summary of Site Visit Findings

We learned through the site visits that there is a lack of an overall systematic approach in regard to collecting patient race, ethnicity, and primary language data both across different hospitals and also within the same hospital. There are inconsistencies in whether the data are collected, how they are collected, where they are collected, and who collects them. In many instances hospitals use different patient registration systems—again both across the different hospitals and within the same hospital—and these registration systems do not necessarily communicate with each other. For example, hospitals may use one patient registration system for inpatient admissions but use a different system for patients who come into hospital-affiliated outpatient clinics. In addition, there may be many outpatient/specialty clinics within a hospital, each with its own patient registration system. Generally, the ability of the systems to communicate is usually one-way, meaning that while some systems can send out information, they cannot receive it. In a practical application this means that it may be possible for the central system to send information to registration systems at outpatient and specialty clinics, but the information obtained at outpatient clinics may not flow back to the main system. However, there are also cases where the reverse is true. There is a trend in hospitals now to move toward “decentralized registration,” which provides the patient multiple opportunities to register, either at the point of care or even over the telephone before an appointment or admission.

We learned that the day-to-day practicality of collecting information on patient race, ethnicity, and primary language is a challenge. Many sites stated that the information has always been collected in whatever way the clerk feels comfortable with. The majority of individuals we interviewed stated that collecting race data was mandatory. The patient registration system makes it mandatory by not allowing the registration clerk to move on if that field is not filled. However, it can be filled out as a “don’t know,” “deferred,” “unknown,” and “other.” If “other” is the stated response, there is usually a text box that can be filled out but it generally is not filled out and, when it is, the data cannot be used for analytical purposes. Also, if the patient chooses not to respond, there is always an “opt out” option for the registration clerk.

Ultimately, based on our survey responses, 78 percent of hospitals are collecting information on race and ethnicity but only 28 percent of these hospitals are using the information for quality improvement efforts. In both the survey and site visits, hospitals report many barriers to collecting these data, which in turn lead to questions about the data quality. It may be that because the data quality is questionable, its usefulness for quality improvement efforts by hospitals is minimal. However, we know that these data, when reliable and valid, can contribute to improving quality of care, especially for

vulnerable populations. Health plans such as Prudential’s Center for Health Care Research and United Health Group collect race/ethnicity data for specific quality improvement efforts and Aetna U.S. Healthcare has determined that provision of high-quality care requires knowledge of enrollees’ race and ethnicity.⁸

“Data are a tool to engage hospitals. Hospitals can be leaders and help set the agenda. This work is going to position the industry to be major players.”
Official with National Association of Health Data Organizations

“Many people are not aware of the changing demographic in their community. Many people do not think that there is a need to collect this information.”
Professor of college of social work

CONCLUSIONS AND RECOMMENDATIONS

From the results of the surveys and site visits, it is clear that the collection of data on patients’ race, ethnicity, and primary language is not standardized within or among the hospitals surveyed and visited and that such collection must be standardized in order to be effective.

Standardization could be aided by providing technical assistance to create staff training manuals and to train staff at all levels about the importance of collecting this information and the best methods to collect it. A consistent message about what to collect and how to collect it must also be provided. If hospitals are faced with four or five different ways to collect these data (e.g., from CMS, JCAHO, insurers, and so forth), there will be a problem. If hospitals are taking a regulatory approach, then a consistent message must be provided to avoid redundancies, cross-purposes, and overlap. In a nutshell, we must make the regulatory approach as comprehensive as possible to avoid these pitfalls and the “negative” view administrators have toward regulation. Following are some basic guidelines:

Hospitals should standardize who provides information. Patients or their caretakers are more likely to provide accurate information about patients’ race, ethnicity, and language than an admitting clerk or health care provider based on observation.

Hospitals should standardize when it is collected. Collection of data on patients’ race, ethnicity, and language upon admission or patient registration will ensure that appropriate fields are completed at the time a patient begins treatment at the hospital.

Hospitals should standardize which racial and ethnic categories are used.

If hospitals are going to use categories, then the OMB categories should be used (see Appendix 3), which will allow for use of standard racial and ethnic categories by all hospitals. At the same time, hospitals can use fine-grained categories of Hispanic or Asian groups that could be broadened to U.S. Census categories as needed, based on their locations.

Hospitals should standardize where data are stored. Race, ethnicity, and language data should be stored in a standard format that is compatible across hospitals and health systems. Many of the newer data systems used by hospitals have separate fields for race, ethnicity, and primary language. The data systems may allow for export and import and merging with clinical data files (again, the importance of EMR needs to be underscored). However, in order to facilitate the use of standard formats, there needs to be agreement on the categories used. Even when the categories take into account the demographic makeup of the community, these categories should have the capacity to be broadened if needed.

Hospitals should standardize their response to patients' concerns. Patients' concerns about the ways in which data on patients' race, ethnicity, and language will be used should be directly addressed prior to collecting the information. There should be a uniform rationale offered to all patients before asking them to identify their racial/ethnic background.

“There are reactive reasons for collecting this information, such as measuring disparities in quality of care and utilization, but there are also proactive reasons for collecting this information, such as providing health care that is appropriate to your population. The distinction may be important to patients in terms of what matters and the message they want to hear. They may react more positively to a proactive desire rather than a reactive desire.”

Chief of division of general internal medicine

“On the IOM committee, we did not want to make the data system too burdensome so mainstream health care could not accept it and integrate it. Giving the main categories when collecting data is best—the five OMB groups. But give regions and localities flexibility to collect information on subgroups, like Haitians.”

Member of IOM Committee on Unequal Treatment

The collection and reporting of data on patients' race and ethnicity is critical if hospitals and other private health organizations want to engage as active partners in improving overall quality of care and reducing racial and ethnic disparities. The availability of accurate and timely data on health care access and utilization by patients' race, ethnicity, and primary language will contribute to increased awareness of racial and ethnic disparities

in health, identification of appropriate target populations for interventions to improve quality of care, development of programs and strategies to eliminate disparities, and monitoring and evaluation of the effects of interventions. It will ultimately provide the answer to the questions: “For whom are we developing initiatives and are these initiatives appropriate for these populations?”

To accomplish the overarching goals of improving quality and reducing disparities, it is imperative that the leadership of hospitals and health systems be supportive and involved; invest in staff training at all levels; ask patients to self-identify their race, ethnicity, and primary language, and ensure that data collected are valid and reliable through constant monitoring and evaluation.

Work on the Horizon

Currently, researchers at HRET and Northwestern University Feinberg School of Medicine are developing and testing a system that will allow patients to self-report their racial and ethnic background providing as much detail as they prefer. This system is being pilot-tested at Northwestern Memorial Hospital in Chicago to identify the most effective, efficient, and respectful means of collecting this information. In addition, we are developing a template that allows for “rolling up” the more granular self-identified categories into the OMB standards. There is additional work on the horizon, which will take this model to multiple sites across the country to ascertain whether self-reporting by patients (without providing any categories) is indeed the most effective, efficient, and respectful method of obtaining information on race and ethnicity.

Consortium member Kaiser Permanente has been working on an initiative to develop a comprehensive approach for collecting race, ethnicity, and language information across its eight regions. Kaiser began this initiative in 2000 and began to roll out its framework in 2003. In addition, Kaiser has developed a training protocol for educating its front-line personnel, who will be responsible for collecting this information. Kaiser has laid much of the groundwork and is sharing its framework and training materials with the consortium as we move toward the development of a uniform framework for collecting race/ethnicity/primary language information that can be used, initially, with the consortium sites and, in the future, with additional hospitals and health systems.

Next Steps

The development of a framework to collect information on patient race, ethnicity, and primary language is a first step and lays the foundation for a long-term effort to improve quality of care and reduce disparities. This foundation would provide hospitals with essential

tools toward improving quality of care. As hospitals invest in new information systems, they should simultaneously invest in ensuring that a framework is put in place to capture information on patient race, ethnicity, and primary language. For example, Partners Healthcare has put a priority on developing the use of EMRs and computerized provider order entry. According to James Mongan, M.D., current president and CEO of Partners, “those are the real spine and backbone of an integrated system like ours. You can work on safety issues, quality issues, you can link facilities and practitioners, and you’re able to gain efficiencies.”⁹

To address quality issues, especially for increasingly diverse populations, hospitals need to couple their commitment to improving information technology with a commitment to ensuring that mechanisms for collecting patient race, ethnicity, and primary language information is incorporated into new or upgraded information systems. On a national front, the time is ripe. Senator Hillary Rodham Clinton recently introduced a plan (S. 2003) to increase research on health care quality, improve investments in information technology, and establish a revolving loan fund for technology costs.¹⁰

In support of our next steps, we have appointed an advisory panel of nationally recognized experts (NAP) in health care disparities and quality of health care to determine priorities for developing a uniform framework for collecting race, ethnicity, and primary language data (see Appendix II for a list of NAP members). The NAP adds a level of expertise and credibility to the development and long-term success of implementing this framework. It is a critical feature of this framework that it be used as a tool to improve quality of care for all populations at a system-wide level. The first meeting of the NAP was held on November 5, 2003. The next meeting will be held in July 2004 to review the framework designed for collecting race, ethnicity, and primary language data in hospitals. The July meeting also will focus on next steps related to the clinical intervention phase of this project, specifically, using the framework to measure disparities and implement initiatives that improve quality of care at the six consortium sites.

Consortium members will use the framework for improving quality of care and reducing disparities by selecting a set of clinical conditions and a core set of indicators to track over time. By linking clinical information with race, ethnicity, and primary language information about patients, members will monitor the care process and where it breaks down or has the potential to break down, and develop interventions that seek to improve the quality of care for different population groups.

APPENDIX I. CONSORTIUM MEMBERS

Henry Ford Health System, Detroit, Mich.

Kaiser Permanente, Oakland, Calif.

Massachusetts General Hospital, Boston, Mass.

Northwestern Memorial Hospital, Chicago, Ill.

Parkland Hospital, Dallas, Texas

University of Pittsburgh Medical Center Health System, Pittsburgh, Pa.

DESCRIPTION OF HOSPITALS

We provide general descriptive information about the hospitals. As often as possible we use the words of those individuals at the institutions we interviewed to describe the relations between the hospital and the communities they serve as recognized by the hospital.

Henry Ford Health System

The Henry Ford Health System (HFHS) is a not-for-profit corporation and is one of the nation's leading vertically integrated health care systems. HFHS has more than 15,000 employees with 2.5 million patient visits annually, 30,000 ambulatory surgeries, and 65,000 hospital admissions. Nearly 35 percent of the population is African American. HFHS also serves a large Arab population. The components of HFHS include Henry Ford Hospital (903-bed tertiary-care hospital), Henry Ford Medical Group, Health Alliance Plan, Henry Ford Wyandotte Hospital (302-bed community hospital), Bi-County Community Hospital (203-bed osteopathic teaching facility), Riverside Osteopathic Hospital, Henry Ford Behavioral Health, Community Care Services, William Clay Ford Center for Athletic Medicine, Bon Secours Cottage Health Services, Henry Ford Mercy, and Health Network.

One of HFHS's efforts to reach out to the community is through a collaborative partnership with safety net providers (Voices of Detroit Initiative) to address cost and care issues as related to providing services for the underserved of Detroit. According to Gail Warden, former CEO of HFHS, "the bottom line is to get people enrolled in a system that can care for them—more than 16,000 people are currently enrolled. HFHS serves the largest Arab populations outside of the Middle East. HFHS has invested in staff training to work with the Arab population. HFHS is working with faith-based community leaders in the African American community. When working with communities it is not just important to hear, but to listen to what is being said and try to make changes that can be seen and understood."

Kaiser Permanente

Kaiser Permanente is the nation's largest nonprofit health plan, serving 8.4 million members, with its headquarters in Oakland, California. It is made up of the Kaiser Foundation Health Plan, Inc.; Kaiser Foundation Hospitals and their subsidiaries, The Permanente Medical Groups; and an affiliation with Group Health Cooperative based in Seattle, Washington. Kaiser Permanente has 135,200 employees and a network of 11,900 physicians. Kaiser operates 29 medical centers and 423 medical offices nationally within its seven regions, with 30.7 million outpatient office visits annually, 405,000 surgeries, and 87,000 babies delivered.

Kaiser Permanente fosters relationships with the communities it serves through various programs. Kaiser Permanente California created and sponsored more than 2,200 community health and education programs. Kaiser is investing in strengthening the safety net through formal partnerships with community clinics to deliver quality care. According to Paul Wallace, M.D., head of Kaiser Permanente's Care Management Institute, "Huge changes are necessary to transform the current approaches to health care delivery into competencies and systems that enable both consumers and clinicians to be confident that the health care they deliver and receive is safe, effective, patient-centered, timely, efficient, and equitable."

Kaiser has developed modules of culturally targeted health care delivery at the San Francisco facility. On a national level, Kaiser has a director of linguistic and cultural programs. Kaiser Permanente's Institute for Culturally Competent Care now has six current and future centers of excellence, each with a different mission and focus, targeting specific populations.¹¹

Massachusetts General Hospital

Massachusetts General Hospital (MGH) is the oldest and largest teaching hospital of Harvard Medical School. It is located in Boston with 868 beds, more than 16,000 employees, 42,000 inpatient admissions, and more than 1.2 million visits in its outpatient program, which includes four health centers. Its emergency department handles about 75,000 visits annually. In 1994, MGH joined with Brigham and Women's Hospital to form Partners HealthCare System, Inc.

MGH fosters its relationship with the community through the Community Benefits Program. The program works primarily in developing a collaborative relationship between MGH and underserved communities to make the hospital more accessible to diverse communities. The majority of patients from diverse racial and ethnic backgrounds

are Laotian, Asian, Cambodian, and African American, as well as a large concentration from countries in Africa and the Middle East. According to a key informant who works directly with communities, the barriers to care and the level of trust/distrust that communities have toward MGH can be attributed to geographic boundaries. However, if you ask the people in the community near the health center they frequent for care, there is a high degree of trust, which is not necessarily translated to trust of the hospital, though all the clinics are MGH centers and are subsidized by MGH.

Northwestern Memorial Hospital

Northwestern Memorial Hospital (NMH) is a nationally recognized hospital and is the primary teaching hospital of Northwestern University's Feinberg School of Medicine. NMH has 720 beds and more than 1,200 physicians are affiliated with the hospital. NMH had 36,868 inpatient admissions in 2001, 320,474 outpatient registrations, and 71,143 emergency room visits.

While Northwestern Memorial Hospital is an academic medical center and takes patients from a wide region, it still has a defined primary care area with a mix of patients that range from being affluent to uninsured. NMH partners with community health centers that serve a diverse group of people including those from Russia, Poland, Southeast Asia, and also serves a large African American and Hispanic population. NMH cares for undocumented individuals as well as a large number of immigrants and refugees, primarily through partnerships with community clinics. According to some of the clinical staff and interviews with key informants, patients feel more comfortable going to community clinics and from there they are referred to NMH if needed. NMH has been working actively to develop a mutually trusting relationship with diverse communities. "We have had partnerships with major community organizations for the past 30-plus years and it remains an ongoing mission for us. We need to continue to work on continuity of care and the recruitment of bilingual medical workers. In regard to trust, the relationship starts in the community so the trust is built early and once they come to NMH, they are confident in the care they will receive."

Parkland Memorial Hospital

Parkland Memorial Hospital is the primary teaching institution of the University of Texas Southwestern Medical School. It is Dallas County's only public hospital and, as such, ensures that health care is available to all area residents. Parkland has 990 beds, employs 6,155 people, admits over 40,000 patients per year, and treats 119,500 people in the emergency room each year. It has a network of nine neighborhood-based health clinics and its mission is to make health care available to all Dallas County residents. Parkland's

Community Oriented Primary Care Center was established in 1987 to provide health care to people in their neighborhoods.

According to Samuel Ross, senior vice president of ambulatory services at Parkland Memorial Hospital, Parkland does not just serve one community but rather multiple communities in the service area. The communities served are about 40 percent Hispanic, 30 percent African American, and 10 percent white. The remaining 10 percent comprises other populations that have recently migrated to the Dallas area. There also is a large and growing immigrant population and a large undocumented population. “We do not check documentation at all. No questions asked. The law/statute creating the hospital district requires us to ask county of residence so we can confirm that they are residents of Dallas County,” said Ross.

According to many clinicians, administrators, and community representatives, the community Parkland serves generally feels “safe” in the Parkland environment. There were some trust issues that were addressed through community outreach. There is a sense of safety in the Hispanic community in particular—they do not need to worry about their status in the United States when they come to Parkland for health care. Parkland Hospital has a good reputation as a safety net, mostly through word of mouth. A main goal for Parkland is to communicate to the community that they can be trusted. However, because Parkland serves multiple communities in its service area, there are road and other barriers that separate communities. For management purposes, Parkland has linked different community health center locations. However, in terms of point of service, people go only to the community health center in their own community or neighborhood.

University of Pittsburgh Medical Center Health System

Located in western Pennsylvania, University of Pittsburgh Medical Center Health System (UPMCHS) is one of the largest nonprofit integrated health care systems in the United States. UPMC is affiliated with the University of Pittsburgh School of Medicine and other schools of the health sciences. UPMC has more than 35,000 employees with 20 hospitals and more than 400 sites for UPMC Doctors’ Offices and Specialized Outpatient Centers. It has more than 4,000 licensed beds, 150,000 inpatient admissions, 3 million outpatient visits, and 350,000 emergency room visits. UPMCHS serves a large African American population. UPMCHS has been working with the community to open channels of communication and alleviate the community’s sentiments about “feeling safe” in the UPMC system. According to the leadership of UPMCHS, “We are working on community initiatives and working with partnerships, but this work needs to be ongoing. It is not a one-time event but an ongoing relationship-building enterprise.”

The Center for Minority Health in the Graduate School of Public Health at the University of Pittsburgh received a \$6 million grant from the National Institutes of Health's National Center on Minority Health and Health Disparities. The purpose of the grant is to establish a center for excellence designed to support community partnerships, outreach, research, and training to eliminate racial and ethnic health disparities. The grant has critical objectives over the next five years that include enhancing support for and participation in research by the African American community, developing a participatory research program where the community identifies and participates in research, and translating research into culturally competent, practical guidelines.

APPENDIX II: NATIONAL ADVISORY PANEL

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APPENDIX III. OMB REVISED STANDARDS (1997)

In 1997, the Office of Management and Budget (OMB) published *Revisions to the Standards for Classification of Federal Data on Race and Ethnicity* to address the need for more refined data on ethnicity than that mandated by OMB's 1977 Directive No. 15. The revised categories established by the 1997 standards are:

- American Indian/Alaska Native;
- Asian;
- Black/African American;
- Native Hawaiian/Other Pacific Islander; and
- White

The 1997 *Revisions* also established a minimum of two ethnic categories: (1) Hispanic or Latino; and (2) Not Hispanic or Latino.¹²

NOTES

- ¹ Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (Washington, D.C.: National Academy Press, 2003).
- ² S. L. Gomez, G. M. Le, D. W. West, W. A. Satariano, and L. O'Connor, "Hospital Policy and Practice Regarding the Collection of Data on Race, Ethnicity, and Birthplace," *American Journal of Public Health* 93 (October 2003): 1685–88.
- ³ The definition of "minority group" used in this report is consistent with that of the U.S. Office of Management and Budget (OMB-15 Directive) and includes African Americans, Hispanics, Asian/Pacific Islanders, and Native Americans/Alaska Natives.
- ⁴ The National Academy of Sciences provided partial support for implementation of the survey to inform their Panel on DHHS Collection of Race and Ethnicity Data.
- ⁵ Medstat and the National Association of Health Data Organizations, *Nationwide Data Inventory of Statewide Encounter-Level Data Collection Activities*, Report to the Agency for Healthcare Research and Quality (AHRQ), AHRQ Contract No. 290-00-0004 (April 2003).
- ⁶ N. R. Kressin, B. H. Chang, A. Henricks, and L. E. Kazis, "Agreement Between Administrative Data and Patients' Self-Reports of Race and Ethnicity," *American Journal of Public Health* 93 (October 2003): 1734–39.
- ⁷ Ibid.
- ⁸ A. S. Bierman, N. Lurie, K. S. Collins, and J. M. Eisenberg, "Addressing Racial and Ethnic Barriers to Effective Health Care: The Need for Better Data," *Health Affairs* 21 (May/June 2002): 91–102.
- ⁹ C. Serb, "Partners' Strategy: Bold with Balance," *H&HN Magazine* (2004 Suppl.): 9–14.
- ¹⁰ *AHA News Now* (January 28, 2004).
- ¹¹ J. R. Betancourt, A. R. Green, and J. E. Carrillo, *Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches* (New York: The Commonwealth Fund, October 2002).
- ¹² R. Perot and M. Youdelman, *Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices* (New York: The Commonwealth Fund, September 2001).

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#690 *Eligibility for Government Insurance if Immigrant Provisions of Welfare Reform Are Repealed* (October 2003). Olveen Carrasquillo, Danielle H. Ferry, Jennifer N. Edwards, and Sherry Glied. *American Journal of Public Health*, vol. 93, no. 10. *In the Literature* summary available at http://www.cmwf.org/programs/insurance/carrasquillo_immigrantprovisions_itl_690.asp; full article available at <http://www.ajph.org/cgi/reprint/93/10/1680.pdf>.

#682 *Healthcare Workforce Diversity: Developing Physician Leaders* (October 3, 2003). Anne C. Beal, Melinda K. Abrams, and Jolene N. Saul, The Commonwealth Fund. Few minorities are enrolling in health professional schools—an alarming trend being examined by a commission led by former D.H.H.S. Secretary Louis W. Sullivan, M.D. Commonwealth Fund Senior Program Officer Anne Beal testified at a Sullivan Commission hearing on the need for diversity among health care leaders, whose actions will have long-lasting impact on the health professions and the patients they serve. The testimony is available online only at http://www.cmwf.org/programs/minority/beal_sullivancommiss_682.pdf.

#676 *Quality of Care for Children in Commercial and Medicaid Managed Care* (September 17, 2003). Joseph W. Thompson, Kevin W. Ryan, Sathiska D. Pinidiya, and James E. Bost. *Journal of the American Medical Association* (*In the Literature* summary). This study is the largest comparative analysis of Medicaid and commercial managed care organization performance results to date. The authors demonstrate that Medicaid-insured children enrolled in managed care plans had lower immunization rates and fewer well-child visits than commercially insured children in such plans.

#576 *Cultural Competence in Health Care: Emerging Frameworks and Practical Approaches* (October 2002). Joseph R. Betancourt, Alexander R. Green, and J. Emilio Carrillo. This field report spotlights a diverse group of health care organizations striving to improve access to and quality of care for a growing minority and immigrant population through innovative programs that develop minority leadership, promote community involvement, and increase awareness of the social and cultural factors that affect health beliefs and behaviors.

Quality of Cardiac Surgeons and Managed Care Contracting Practices (October 2002). Dana B. Mukamel, David L. Weimer, Jack Zwanziger, and Alvin I. Mushlin. *Health Services Research*, vol. 37, no. 5. Copies are available from *Health Services Research*, Foundation of the American College of Healthcare Executives, Publication Services, One North Franklin, Suite 1700, Chicago, IL 60606-3491, Fax: 312-424-0703.

Toward a Systematic Approach to Understanding—and Ultimately Eliminating—African American Women’s Health Disparities (September/October 2002). Carol Hogue. *Women’s Health Issues*, vol. 12, no. 5. Copies are available from the Jacobs Institute of Women’s Health, 409 12th Street, SW, Washington, DC 20024, Tel: 202-863-4990, Fax: 202-488-4229.

Race, Ethnicity, and Disparities in Breast Cancer: Victories and Challenges (September/October 2002). Nina A. Bickell. *Women’s Health Issues*, vol. 12, no. 5. Copies are available from the Jacobs Institute of Women’s Health, 409 12th Street, SW, Washington, DC 20024, Tel: 202-863-4990, Fax: 202-488-4229.

Racial and Ethnic Disparities in Coronary Heart Disease in Women: Prevention, Treatment, and Needed Interventions (September/October 2002). Paula A. Johnson and Rachel S. Fulp. *Women’s Health Issues*, vol. 12, no. 5. Copies are available from the Jacobs Institute of Women’s Health, 409 12th Street, SW, Washington, DC 20024, Tel: 202-863-4990, Fax: 202-488-4229.

Association of Health Literacy with Diabetes Outcomes (July 24–31, 2002). Dean Schillinger et al. *Journal of the American Medical Association*, vol. 288, no. 4. Copies are available from Dean Schillinger, MD, University of California, San Francisco, Primary Care Research Center, Department of Medicine, San Francisco General Hospital, San Francisco, CA 94110, E-mail: dean@itsa.ucsf.edu.

#547 *A Health Plan Report Card on Quality of Care for Minority Populations* (June 2002). David R. Nerenz, Margaret J. Gunter, Magda Garcia, and Robbya R. Green-Weir. In this study, eight health plans participated in a demonstration project designed to determine whether health plans could obtain data on race/ethnicity of their members from a variety of sources and incorporate those data in standard quality of care measure sets, and whether the analyses would show significant racial/ethnic disparities in quality of care within plans, and/or significant differences across plans in quality of care provided to specific groups.

Designing and Evaluating Interventions to Eliminate Racial and Ethnic Disparities in Health Care (June 2002). Lisa A. Cooper, Martha N. Hill, and Neil R. Powe. *Journal of General Internal Medicine*, vol. 17, no. 6. Copies are available from Lisa A. Cooper, Welch Center for Prevention, Epidemiology, and Clinical Research, Johns Hopkins University, 2024 East Monument Street, Suite 2-600, Baltimore, MD 21205-2223, E-mail: lisa.cooper@jhmi.edu.

Addressing Racial and Ethnic Barriers to Effective Health Care: The Need for Better Data (May/June 2002). Arlene S. Bierman, Nicole Lurie, Karen Scott Collins, and John M. Eisenberg, *Health Affairs*, vol. 21, no. 3. Copies are available from *Health Affairs*, 7500 Old Georgetown Road, Suite 600, Bethesda, MD 20814-6133, Tel: 301-656-7401 ext. 200, Fax: 301-654-2845, www.healthaffairs.org.

#557 *Eliminating Racial/Ethnic Disparities in Health Care: Can Health Plans Generate Reports?* (May/June 2002). David R. Nerenz, Vence L. Bonham, Robbya Green-Weir, Christine Joseph, and Margaret Gunter. *Health Affairs*, vol. 21, no. 3 (*In the Literature* summary). The absence of data on race and ethnicity in health plan and provider databases is a significant barrier in the creation and use of quality-of-care reports for patients of minority groups. In this article, however, the authors show that health plans are able to collect and analyze quality of care data by race/ethnicity.

#541 *Providing Language Interpretation Services in Health Care Settings: Examples from the Field* (May 2002). Mara Youdelman and Jane Perkins, National Health Law Program. This field report profiles a variety of promising programs around the country that provide patients with interpretation services, and also identifies federal, state, local, and private funding sources for such services.

#532 *Racial Disparities in the Quality of Care for Enrollees in Medicare Managed Care* (March 13, 2002). Eric C. Schneider, Alan M. Zaslavsky, and Arnold M. Epstein, Harvard School of Public Health/Harvard Medical School. *Journal of the American Medical Association*, vol. 287, no. 10 (*In the Literature* summary). In this article the authors report that among Medicare beneficiaries enrolled in managed care plans, African Americans are less likely than whites to receive follow-up care after a hospitalization for mental illness, eye exams if they are diabetic, beta-blocker medication after a heart attack, and breast cancer screening.

#523 *Diverse Communities, Common Concerns: Assessing Health Care Quality for Minority Americans* (March 2002). Karen Scott Collins, Dora L. Hughes, Michelle M. Doty, Brett L. Ives, Jennifer N. Edwards, and Katie Tenney. This report, based on the Fund's 2001 Health Care Quality Survey, reveals that on a wide range of health care quality measures—including effective patient–physician communication, overcoming cultural and linguistic barriers, and access to health care and insurance coverage—minority Americans do not fare as well as whites.

#524 *Quality of Health Care for African Americans* (March 2002). Karen Scott Collins, Katie Tenney, and Dora L. Hughes. This fact sheet, based on the Fund's 2001 Health Care Quality Survey and companion piece to pub. **#523** (above), examines further the survey findings related to the health, health care, and health insurance coverage of African Americans.

#525 *Quality of Health Care for Asian Americans* (March 2002). Dora L. Hughes. This fact sheet, based on the Fund's 2001 Health Care Quality Survey and companion piece to pub. **#523** (above), examines further the survey findings related to the health, health care, and health insurance coverage of Asian Americans.

#526 *Quality of Health Care for Hispanic Populations* (March 2002). Michelle M. Doty and Brett L. Ives. This fact sheet, based on the Fund's 2001 Health Care Quality Survey and companion piece to pub. **#523** (above), examines further the survey findings related to the health, health care, and health insurance coverage of Hispanics.