

The Commission
to End Health Care Disparities

Collecting and using race, ethnicity and language data in ambulatory settings:

A white paper with recommendations from the Commission to End Health Care Disparities

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Executive summary

Health care disparities are differences in medical care that are not due to differing clinical needs, patient preferences or the appropriateness of the intervention. Disparities in health care for racial and ethnic minorities in the United States are long-standing, well-documented and have complex origins, both historic and contemporary.

Today there is broad agreement that quality health care must be safe, timely, effective, efficient, patient-centered and equitable. Because research demonstrates that our health care system remains far from equitable, health care disparities are widely understood to be important markers of poor quality care. As a result, the elimination of disparities is a matter of great moral and practical concern for our nation, including the more than 70 professional societies and aligned organizations that comprise the Commission to End Health Care Disparities.

This report on collecting demographic data in ambulatory practices is based on the fundamental proposition that to eliminate disparities in care one must first be able to detect them. Detecting disparities requires three steps: (1) collect valid and reliable data on the demographic characteristics of patients receiving care, (2) collect valid and reliable data on the quality of care delivered, and then (3) stratify the quality data by the relevant demographic subgroups.

For more than 10 years health care providers and practitioners have been urged to undertake step one, the systematic collection of basic demographic data on the patients they see. Yet research shows that most practitioners do not collect these data, or they do so in non-systematic and unreliable ways. Among those who do collect these data, very few use them to help address disparities.

This report therefore focuses primarily on step one, though each of the three steps are addressed in the commission's recommendations. In particular, the Commission to End Health Care Disparities is well aware of the many logistic, financial, socio-cultural, technological and other direct and indirect barriers that ambulatory practices face in collecting and using demographic data. A key motivation for this report, however, is that our research suggests some physicians and practice managers might choose not to collect patient demographic data because they simply do not see the value in doing so.

In this regard, the Commission to End Health Care Disparities believes that demographic data are worth collecting only if they are used to help physicians and other health professionals achieve practical, applied goals. While eliminating disparities is an important social task, detecting and eliminating disparities is rarely the only, and maybe not the most compelling, reason to collect patient demographic data for individual ambulatory practices. This report details and provides examples of several activities that are improved with accurate demographic data, and how these data can directly and substantively benefit ambulatory practices. These activities include optimizing practice resources to improve quality, improving the data used in pay for performance incentive programs and competing in a rapidly changing market, as well as ensuring equity and eliminating disparities.

Finally, the report provides a set of detailed recommendations for collecting and using patient demographic data in the ambulatory setting (a table of these recommendations appears on page 20 of the report). These recommendations are intended to guide not only physicians and health professionals but also vendors of electronic health record (EHR) systems, policymakers, purchasers, hospitals, health plans and others. In particular, the commission argues that new EHR systems, if they are properly developed and standardized across different platforms and systems so that data can be shared, should dramatically facilitate reliable demographic data collection, in addition to making it much easier for physicians and other health professionals to use these data in clinically meaningful ways.

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Introduction

Background

Health care disparities are differences in medical care that are not due to differing clinical needs, patient preferences, or the appropriateness of the intervention.¹ Racial and ethnic disparities within the United States health care system are long-standing^{2,3} well-documented¹ and have complex origins, both historic and contemporary.^{1,3,4} In recent years, a number of medical professional associations have undertaken efforts toward eliminating minority health care disparities, including recognizing and seeking to address the history of racial discrimination and segregation within the medical profession itself.⁵ Yet nationwide, racial and ethnic health care disparities have persisted, and in some cases worsened.^{1,3,4,11,12}

In 2003 a landmark report was published by the Institute of Medicine (IOM), titled “Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care”.¹ This report summarized decades of research demonstrating the existence of health care disparities in America, and it made clear some of the complex reasons why they have been so resistant to elimination. A subsequent IOM report in 2009 emphasized that standardized race, ethnicity and language data are needed to detect disparities, allow comparison of data on disparities across organizations and regions and over time, create pooled data sets across organizations or regions, and support reporting and replication of successful disparity-reduction initiatives.¹³ Given the challenges to be overcome, a key lesson from these reports has been that ending health care disparities will require the coordinated and focused efforts of multiple stakeholders across the health care system.

About the Commission to End Health Care Disparities

In 2004 the Commission to End Health Care Disparities was created to focus and coordinate the efforts of organized medicine to eliminate health care disparities. Today, the commission comprises more than 70 state and specialty medical societies and aligned organizations (Appendix 1). It is led by a Secretariat of the American Medical Association (AMA), the National Medical Association (NMA) and the National Hispanic Medical Association (NHMA). The commission’s primary role is to support health professionals and health professional associations in their efforts to eliminate health care disparities. This is accomplished through: (1) proactively collaborating to increase awareness and education among health professionals about health care disparities; (2) producing clinical tools and resources that promote the use of effective strategies to combat disparities in practice; and (3) coordinating advocacy to support policy and action that will lead to the elimination of disparities in health care and thereby strengthen the health care system and our nation.¹⁴

Quality, disparities, and demographic data collection

Health care disparities are an important marker of poor quality care. According to the Institute of Medicine report, “Crossing the Quality Chasm,” quality health care is defined as care that is safe, timely, effective, efficient, patient-centered, and equitable.¹⁵ This “six pillars” definition of health care quality has recently been adopted by the AMA and it has been broadly endorsed by governmental and private organizations.^{1, 16-17, 18} Yet while efforts to address and improve each of the six facets of health care quality are underway, numerous studies demonstrating disparities show that our health care system remains very far from equitable. In particular, while inequities exist and have been studied across many groups (by urban/rural, higher and lower socioeconomic status, insured versus uninsured, by sex, sexual orientation and more), hundreds of studies nationwide have documented that racial and ethnic minority patients too often receive lower quality care than non-Hispanic whites.¹ Even after adjusting for insurance and socioeconomic status, members of certain racial and ethnic groups are less likely to receive routine and preventive care^{19,22} and when they receive care it is more often of lower quality^{1 (pp.38-79)} and, partly as a result of these disparities, they experience worse health outcomes, including higher disease burdens

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Even after adjusting for insurance and socioeconomic status, members of certain racial and ethnic groups are less likely to receive routine and preventive care, and when they receive care it is more often of lower quality

and lower life expectancies compared to non-Hispanic whites. Recent national data suggest that some racial and ethnic health care disparities are declining or have been eliminated, but many others have remained the same or even increased in the last few years.^{16,23}

In 2000 the Minority Health and Health Disparities Research Act required the National Academy of Sciences (NAS) to study U.S. Department of Health and Human Services' (DHHS) data collection practices and report to Congress with recommendations. The NAS concluded that collecting accurate data on patient race and ethnicity should be a top priority in health care. The 2003 IOM report on health care disparities, "Unequal Treatment," recommended that providers should "collect and report data on health care access and utilization by patients' race, ethnicity, socioeconomic status, and where possible, primary language."^{1 (p.233)} More recently, the American Recovery and Reinvestment Act of 2009 included a section urging the "use of electronic systems to ensure the comprehensive collection of patient demographic data, including, at a minimum, race, ethnicity, primary language, and gender information."⁸⁴ Subsequent to this Act, providers are being offered financial incentive for the meaningful use of electronic health record (EHR) systems, which includes using these systems to collect basic patient demographic data, including each patient's race, ethnicity and primary language.²⁴ The Patient Protection and Affordable Care Act of 2010 (the health reform act) requires federally conducted or supported health care programs or surveys to collect and report demographic data, including ethnicity, sex, primary language, and disability status, at the smallest geographic level possible (§4302). It also requires the Secretary of Health and Human Services, with the Office of the National Coordinator for Health Information Technology, to develop national standards for data collection, interoperability and security. In September 2009 the IOM recommended standard methods for collecting data on race, ethnicity and language.¹⁷

Despite these new incentives for private practices, and requirements for federal programs, the best evidence suggests that, to date even health plans, hospitals, large medical group practices and community health centers often do not collect basic demographic information from their patients at all, or they collect it in non-systematic and unreliable ways.²⁴ For example, as recently as 2005 only 23 states had created standards for categories and definitions for race and ethnicity data collection deemed minimally acceptable by the federal Agency for Healthcare Research and Quality (AHRQ).²⁵ Moreover, when large care delivery organizations collect demographic data they infrequently use these data to stratify their quality data, which is necessary to detect and track disparities.²⁶

Among smaller practices in ambulatory settings, the situation is probably worse. While a number of important steps have been taken to facilitate race and ethnicity data collection in hospitals, relatively little attention has been given to demographic data collection in the ambulatory setting. Among smaller groups of physicians—practices with one to five members—there is reason to believe that collecting and using demographic data to document and address disparities, or for other purposes, is very rare. Recent work has documented a number of barriers to collecting such data in smaller practices, which can include concerns about privacy and legality, fear of resistance from patients and staff, and uncertainty on how to use the data to improve care.²⁸

In sum, for more than 10 years health care providers and practitioners have been urged to systematically collect demographic data on the patients they see, including those seen in clinics and practices as outpatients, but this initial step in reducing disparities apparently poses a number of challenges for many practices.^{24,29-30}

The reasons that physicians do not collect demographic data in the ambulatory setting are numerous, but can be roughly broken into two related categories. First, practices might face logistic, financial, socio-cultural, technological or other direct barriers to collecting demographic data from patients. Second, even without such barriers, physicians might choose not to collect these data because they simply do not see the value in doing so.³¹

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With regard to logistic and other barriers to demographic data collection, a careful exploration shows some to be based in false beliefs, while others are real but potentially surmountable once these data are understood to have practical value.

However, with regard to the practical value of these data, it is important to acknowledge that collecting patient demographic data serves no end in itself. The point of asking patients about their race, ethnicity and primary language is not simply to amass piles of data—the data are worth collecting only if they are used to help physicians and other health professionals achieve practical, applied goals. In this regard, we note that eliminating disparities is an important social goal, but for ambulatory practices it is not the only, and maybe not the most compelling, reason to collect patient demographic data. These data can also be used for several activities that can benefit ambulatory practices and potentially improve quality of care.

In the remainder of this white paper, we describe some practical uses for demographic data collected in the ambulatory setting and then we address potential barriers to collecting and using patient demographic data. We conclude with a set of consensus recommendations on demographic data collection in ambulatory settings from the Commission to End Health Care Disparities. These recommendations are intended to guide not only physicians and health professionals but also vendors of EHR systems, policymakers, purchasers, hospitals, health plans and others. In particular, we make the argument that new EHR systems, if properly developed and standardized across different platforms and systems so that data can be shared, should dramatically facilitate reliable demographic data collection, while also making it much easier for physicians and other health professionals to use these data for meaningful improvements in equity and other facets of health care quality.

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Using patient demographic data in ambulatory practices

There are several ways in which ambulatory practices can benefit from accurately documenting basic demographic information about the patients they serve.

Quality improvement and pay for performance

As in the rest of the health care system, ambulatory practices have limited resources available for quality improvement (QI) activities; persons charged with QI responsibilities should aim to get optimal value from their investments. One way to do so is to determine which sub-populations are more likely to receive poorer quality care and then target those sub-populations for specific QI interventions. Adopting a *low hanging fruit* approach to QI has been shown to help maximize the value of QI dollars in ambulatory practices.³¹

Obtaining optimal value for limited resources in QI is of particular importance for smaller physician practices. More than 75 percent of office visits take place in practices with less than five physicians³² and 44 percent of all physicians practice in such settings.²⁷ While these physicians presumably are as focused on providing high quality care as any others, and they have as much or more to gain from being able to document the quality of care they deliver, physicians in these settings have been relatively less involved in formal quality measurement and improvement activities compared to physicians in larger practices.³²

There are a number of reasons for this, including that EHR systems, which can facilitate quality measurement and tracking over time, are very expensive for smaller practices to obtain and use. In addition, quality measurement should entail using a broad set of performance measures, collected in a standardized way, with an adequate sample size for reliable estimates, and with adjustments for confounding patient factors including sociodemographic characteristics.³³ Small practices face barriers at each of these steps³¹ and obtaining statistically-reliable quality data from these practices is a challenge.³⁴ (See also Section IV below: Potential barriers to using demographic data.)

Yet even when reliable quality data are collected, if practices do not also collect accurate demographic data about their patients, they will be unable to adjust for practice mix, rendering their performance assessment results less valid. As measuring quality becomes increasingly important—and tied to payment—the importance of collecting accurate demographic data will rise. For instance, one recent study demonstrated that physicians caring for more minority patients face more barriers to meeting quality metrics, ranging from less time with patients to increased difficulty obtaining specialty care.³⁵ These and other findings suggest that physicians treating more minorities often begin at a disadvantage due to fewer resources.³⁶ If these practices cannot track their patient demographics, they are more likely to be punished by pay-for-performance programs, causing them, and the patients they serve, to fall even further behind.^{37-39, 40}

Competing in a rapidly changing market

Collecting demographic data on the patients served by a practice can facilitate efforts to meet the needs of evolving communities and expand the practice into untapped markets. Most U.S. communities are facing significant demographic changes some of which are occurring very rapidly.⁴¹ Where ambulatory clinics have been able to examine the demographic data of the patients they serve, they have been able to more effectively market their services to the local community and develop tailored services that are patient-centered and culturally sensitive.⁴² For smaller practices in particular, local minority populations often represent significant growth opportunities, since these practices can thrive by pursuing niches not recognized or pursued by larger organizations.⁴³

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Ensuring equity and eliminating disparities

While most physicians believe they provide equally high quality care to all of their patients,⁴⁴⁻⁴⁵ very few have the data necessary to prove the point one way or the other. Only measuring quality indicators and then stratifying those measures by race/ethnicity, language and gender can determine whether a practice is helping to alleviate, or is contributing to, regional or national health care disparities. The lack of basic demographic data on patients seen in the ambulatory setting has been repeatedly identified as a key barrier to tracking and eliminating disparities. For instance, Chien and colleagues⁴⁶ conducted interviews with leaders of 15 major performance incentive programs and found that the lack of reliable patient demographic data was consistently cited as a major barrier to assessing the impact of targeted physician practice incentive programs on reducing disparities.

On the other hand, where practices have collected demographic data, they have sometimes been used successfully to address disparities. For example, primary care practices in New York used vaccination data, stratified by demographic groups, to target disparities in immunization rates. The intervention reduced disparities from 18 percent to 4 percent across the board and the Hispanic-White disparity was reduced from 15 percent to 1 percent.⁴⁷⁻⁴⁸

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Potential barriers to collecting demographic data

Given that many practices do not collect patient demographic data today, it is important to understand the perceived and real barriers to collecting these data. A number of potential barriers have been studied, ranging from potential misuses of the data, to cost, to legal challenges, to patient and staff discomfort talking about race and ethnicity.⁴⁹⁻⁵⁰

Potential clinical misuses of the data

Patient demographic data are useful for many population-based purposes (such as quality improvement and community outreach, as noted above), yet it is also important to recognize that these data are easily misused if clinicians or others believe they are to be routinely used to change the care delivered to individual patients. One of the objections to collecting data on race and ethnicity that has been cited by practice managers and clinicians is the notion that collecting these data is contrary to a practice philosophy that treats all people equally, without regard to racial or ethnic background.⁴⁹

Of course clinicians will recognize that there are some genetic diseases that are more frequent in specific racial or ethnic groups (some of which are very well known, such as Tay-Sachs disease among Ashkenazi Jews or sickle cell disease among people from African, Mediterranean or South Asian origins), which might affect what medical care should be offered, such as specific screening protocols for members of the most-affected racial groups. There are also instances where racial or ethnic groups might merit consideration of different therapeutic protocols based on presumed genetic differences that have not yet been fully elucidated—the most famous and controversial of these being the use of specific medications for heart failure in African-American patients.⁵¹ However, it is important to bear in mind that race is a psychosocial construct, not a biological taxonomy, and a patient's race is a poor predictor of genetic makeup;⁵² a patient's family history often provides considerably better information on disease risks than will information on the patient's racial or ethnic categorization. In addition, the future is likely to bring increasing opportunities to obtain personal genomic data to inform testing or treatment decisions, which will be far superior to making genetic assumptions based on skin color, country of origin, or cultural heritage.

Even more important is to recognize that race and ethnicity are very unreliable predictors of a patient's health-related priorities, beliefs, goals and concerns. A physician or health care professionals should never assume that a patient from a particular racial or ethnic group holds certain health beliefs simply because they are a member of that group. This type of stereotyping is clinically dangerous and, moreover, there is no need for it because it is almost always possible to determine the patient's personal beliefs, priorities, goals and concerns simply by asking the patient about these issues. In sum, a patient's ethnic background is no substitute for eliciting a good, individualized, psychosocial history and a discussion about the patient's treatment preferences and goals.⁵³

The bottom line with regard to using demographic data to tailor individual patient care is that physicians should use the best data available to them when making clinical decisions. When there is scientific evidence indicating that a particular demographic characteristic, whether it is age, gender, race or ethnicity, is clinically important because it is associated with increased risk of a particular condition or differential efficacy of a particular therapeutic intervention, it may be appropriate to use these data to help tailor care. But demographic information is unlikely ever to be the best information available in determining a patient's individual priorities, goals and concerns with regard to their care. Using demographic data to infer anything about the patient's personality, beliefs, behaviors or priorities would be a significant misuse of these data. All patients deserve the opportunity to articulate their own personal health-related values to their physician—and to be free of concern that they might receive care based on racial or ethnic stereotypes.

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The collection of race and ethnicity data from patients in health care settings is legal under both state and federal law and does not violate the HIPAA Privacy Rule.

... several regulatory bodies have recently begun urging the collection of patient demographic information, including race, ethnicity and primary language.

Time and cost

In research conducted for the Commission to End Health Care Disparities,^{24,31,49} we found that, contrary to expectations, ambulatory practices rarely named time or cost as barriers to collecting demographic information on race or ethnicity. In fact, most practices, when asked explicitly about the cost and time required for demographic data collection, did not feel collecting these data would be particularly costly or time prohibitive. After all, patients must be checked in when coming to a medical visit and already may answer a number of questions at the front desk.

However, even a low cost and rapid activity can be thwarted if other barriers stand in the way or if it is seen as having negligible value.

Perceived legal barriers

A commonly perceived barrier to collecting demographic data involves legal and regulatory concerns, especially concerns about whether collecting patient race and ethnicity is allowed under the Civil Rights Act of 1964 and under the Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA).

Fortunately, these concerns are unfounded. The collection of race and ethnicity data from patients in health care settings is legal under both state and federal law and does not violate the HIPAA Privacy Rule.⁵⁴ In fact, some state laws actually require reporting patient data by race, ethnicity, and primary language, to help monitor for potentially discriminatory practices.⁵⁵ Federal law, meanwhile, offers numerous supports for the collection of race and ethnicity data, starting with Title VI of the Civil Rights Act of 1964. According to that Act, all recipients of federal funds must keep records and submit compliance reports “in such form and containing such information” as the responsible DHHS official determines necessary to ascertain whether the recipient is complying with the regulation.⁵⁶ According to an example included in the Civil Rights Act of 1964 regulations,⁵⁷ recipients of federal funds should have race and ethnicity data showing the extent to which members of minority groups are beneficiaries of and participants in the federally assisted programs. Title VI applies to all health care providers receiving federal funds, including physicians who treat patients enrolled in Medicare, Medicaid and the State Children’s Health Insurance Program. While physician offices were specifically exempted from requirements to certify their compliance with the Civil Rights Act (see The Civil Rights Act and the AMA, 1964, available at www.ama-assn.org/ama1/pub/upload/mm/369/civilrightsact.pdf) the act certainly supports and does not prohibit the collection of race and ethnicity data in ambulatory settings. Finally, the language a person speaks has been determined to represent a proxy for national origin, for purposes of interpreting Title VI. As a result, Title VI supports the collection of patients’ primary language data too.⁵⁴

With regard to HIPAA, the Act’s Privacy Rule does not restrict the type of data that may be *collected* from patients. Rather, HIPAA limits when data may be *disclosed*. When a practice collects demographic data linked to specific patients, these data must be protected from inappropriate disclosure—just like all other individually-identifiable health information.⁵⁴

Finally, several regulatory bodies have recently begun urging the collection of patient demographic information, including race, ethnicity and primary language. The Joint Commission requires demographic data collection⁵⁸ as does the National Committee for Quality Assurance (NCQA), in their accreditation requirements for hospitals and health plans, respectively.⁵⁹

Staff discomfort in talking about race

Some staff discomfort around collecting patient demographic information might be related to misunderstanding the legal and regulatory environment, as noted above. These concerns can be alleviated with better understanding of the various ways in which law and regulations support collecting demographic data.

Other staff concerns might stem from a general discomfort in talking about race. While such discomfort is not uncommon across the United States, the health care system addresses many personally sensitive topics (such as sexual and psychological health histories) on a routine basis and professionalism demands that we surmount any personal squeamishness or discomfort to do what is best for our patients. As we have learned in other areas of health care,⁶⁰ one way to alleviate such personal discomfort is to make the matter routine. When front desk staff regularly asks every patient about their race, ethnicity and primary language, asking these questions soon loses its novelty, along with any stigma the staff might have associated with it.

Another way to alleviate staff concerns is to provide training on how best to ask patients about their racial and ethnic background and how to answer questions that patients might raise when asked. Free online training materials are available for this⁶⁰⁻⁶¹ and additional supports should be built in to EHRs, as we will discuss below.

Staff concerns about the utility of collecting these data are perhaps the most important to address. Several important uses for these data were noted above, including the tracking and improvement of quality, effective promotion of the practice and its services, and monitoring and addressing racial/ethnic health care disparities. These and other reasons that might be important locally should be explained to the staff responsible for data collection whenever a practice initiates an effort to collect patient demographic data.

Patient concerns

A commonly cited barrier to collecting demographic data is the perception that some patients will be uncomfortable answering questions about their race or ethnicity. In Massachusetts, anecdotal reports suggest that greater staff comfort in asking these questions leads to less resistance from patients.⁶² Yet research also suggests that some patients will question why information on their race and ethnicity is being collected, and they might wonder if the data will be used to their disadvantage.^{24,63-64} In a study by Baker et al., for example, 80 percent of patients in a large, multi-racial clinic population in Chicago thought information on race and ethnicity should be collected, but 15.5 percent were uncomfortable providing their race and ethnicity to an admission clerk; among African Americans almost a quarter were uncomfortable (24.3 percent).⁶³ Fortunately, more than 50 percent of those who were initially uncomfortable also said their discomfort would be reduced if they were told the information was being collected to help monitor quality of care.

Potential barriers to using demographic data

Even among practices that succeed in collecting patient demographic data, several additional barriers exist to then using the information that has been collected. As noted earlier, collecting demographic data is not the goal—the goal is to use these data to help the ambulatory practice and improve the quality of care provided to patients.

Barriers to clinical performance measurement

A key barrier to practice improvement, with or without a focus on low hanging fruit or eliminating disparities, is the need to collect accurate clinical performance measures. The challenges in collecting accurate performance data, especially at the level of individual ambulatory practices, are beyond the scope of this report, but they are the topic of a great deal of work across the medical profession. In particular, the AMA-convened Physician Consortium for Performance Improvement® (PCPI™), convened by the AMA, includes more than 170 national medical specialty, state medical societies, the American Board of Medical Specialties and member boards, the Council of Medical Specialty Societies, health care professional organizations, federal agencies, individual members and others interested in improving the quality and efficiency of patient care. The aim of this broad membership is to enhance “quality of care and patient safety by taking the lead in the development, testing, and maintenance of evidence-based clinical performance measures and measurement resources for physicians.”⁶⁵

Small sample sizes

For individual clinicians, it is very difficult to find performance measures that are statistically robust, due to the relatively small numbers of patients with any particular disease.

One issue with regard to using demographic data that deserves special mention is the problem of small sample sizes. For individual clinicians, it is very difficult to find performance measures that are statistically robust, due to the relatively small numbers of patients with any particular disease.⁶⁶ This problem becomes even more acute when stratifying performance data by racial or ethnic subgroups. The American health care system remains strikingly segregated (with a large percentage of minority patients seen at only a small percentage of America’s hospitals) and even among hospitals and large physician groups it is common to have relatively small numbers of patients from certain racial or ethnic groups.⁶⁷

In the meantime, we and others have argued that detailed (or granular) ethnic categories can provide a useful way of examining and improving quality of care for specific populations served by an individual hospital or even a single ambulatory or physician’s practice. Yet the more granular the categories, the more the problem of small sample size is exacerbated. At all times, the level of statistical analysis that is possible will be influenced both by the size of the ethnic population in the community as well as by the number of those within the ethnic group that may have the specific condition being measured, such as diabetes, or who qualify for the measured service, such as screening mammography.¹⁶

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Despite limits on statistical testing with small sample sizes, it is still useful and important to examine quality data stratified by race, ethnicity and language. First, these data can provide an initial sense of possibly significant differences between groups. For example, if a small group shows trends toward worse care processes, this finding can be further explored using qualitative methods (such as case tracking and interviewing key personnel) and then addressed as appropriate.²⁴ Second, stratified quality measures can illuminate when individuals from certain groups are not receiving basic services they should.⁶⁸ After all, statistical significance is not needed to determine that care provided to specific patients has failed to meet quality standards. Moreover, determining how many individual failures of quality are *too many* is more a professional and ethical question than a statistical one. Third, the absence of statistical significance in any individual practice does not mean that disparities do not exist or that they

are not clinically meaningful. In this regard, it can be helpful to analyze data from individual practices in relation to benchmarks and other information derived from much larger data sets. For example, lower use of statins in African-American and Hispanic populations might be especially important to detect and address at the practice level because of the higher burden of heart disease that we know affects these groups at the national level.⁶⁹⁻⁷⁰ Finally, as alluded to above (in Section Iia: Quality improvement and pay for performance), small numbers of patients receiving lower quality care can have an outsized impact on a practice's overall quality scores. These small groups often represent *low hanging fruit* for quality improvement, and targeting QI activities towards these groups can be the most cost-effective way for a practice to boost its performance scores.

In sum, small sample sizes can make statistically reliable analysis of stratified data difficult or impossible, but it does not make these data useless. Organizations that see differences in the quality of care provided to a small subset of patients might not have the sample size needed to prove this to be statistically significant, but it can be clinically important nonetheless. Practices that approach this issue from the point of view of QI will be motivated to undertake efforts to improve quality for these small subgroups, regardless whether the differences are statistically significant, especially if that small subgroup is dragging down overall performance scores.

Stratification of performance measures by demographic groups

Once a practice or other care delivery organization has collected demographic and quality data, these data still must be stratified by race, ethnicity or other demographic features to detect disparities. While this might seem to be a simple step, many practices, and especially small ones, do not have the data management and statistical expertise needed to stratify their performance data by demographic groups. Physicians, nurses and other office personnel have limited time and generally will not have been trained in analyzing data in spreadsheets, let alone computer programming or the use of statistics packages. Even if a clinician knows how to use Excel or another program to create graphs and charts, and even when the clinician's data are in electronic systems, transferring those data into spreadsheets for basic data analysis can be challenging.

An example of the resources currently needed to ensure optimal use of demographic data is provided by the Aligning Forces for Quality (AF4Q) program, a national program funded by the Robert Wood Johnson Foundation, which is designed to lift overall quality of health care and reduce racial and ethnic disparities in 17 targeted communities across the country. AF4Q's equity framework includes the standardized collection of self-reported patient race, ethnicity and language and the stratification of specific performance measures by this demographic information.⁷¹ Because of the complexity of not only collecting performance data, but then stratifying these measures by race and ethnicity, the foundation has committed substantial technical assistance resources to help providers (hospitals and physician practices) overcome the technical hurdles of collecting and then reporting performance measures by patient demographic characteristics.⁵⁰ The need for intensive technical assistance resources, even when working with relatively large organizations in a confined set of geographic areas, suggests the hurdles faced when helping smaller practices nationwide in their efforts to collect and then stratify their quality data.

All of these challenges point to the need for widespread efforts to make the collection and use of demographic data easier and more routine in the ambulatory setting. One promising avenue for these efforts is the implementation of EHR systems, since these new tools can incorporate a number of important functions that could support demographic data collection and use.⁷²

... small numbers of patients receiving lower quality care can have an outsized impact on a practice's overall quality scores.

... small sample sizes can make statistically reliable analysis of stratified data difficult or impossible, but it does not make these data useless.

Recommendations for collecting and using demographic data

Recognizing the potential utility of collecting and using demographic data in the ambulatory setting, the Commission to End Health Care Disparities recommends that all practices should collect certain basic demographic data on each patient served. The commission defines “basic demographic data” as being, at minimum, patient race, ethnicity and primary language. The commission recognizes that many organizations will find it useful to also collect and use data on a variety of other demographic factors that have been tied to disparities in care and outcomes and that could be useful for developing patient education and practice outreach activities (such as patient age, gender, socioeconomic status, health literacy, sexual orientation and gender identify, and others). With regard to basic demographic information however, to aid in understanding what must be collected and how, and to standardize data collection and make it more useful, the commission has developed the set of specific recommendations shown in Table 1.

... the Commission to End Health Care Disparities recommends that all practices should collect certain basic demographic data on each patient served

Table 1. Recommendations of the Commission to End Health Care Disparities regarding routine collection and use of patient demographic information in ambulatory settings

1. All ambulatory practices should be able to describe the demographic characteristics of the patients they serve. At a minimum, demographic data should include patient race, ethnicity and primary language.
2. For quality improvement purposes, ambulatory practices should collect relevant quality data on the care they provide to patients; these performance data should then be stratified by relevant demographic categories.
3. When collecting demographic data from individual patients or their caregivers, the following six features of an ideal demographic data collection process should be standardized to facilitate collection of valid and reliable data in ambulatory practices:
 - Who provides the data—an individual’s racial or ethnic identity should always be provided by the individual or their caretaker. An individual’s race/ethnicity should be self-identified and never inferred from observation or name alone.
 - When to collect the data—when possible, data should be collected upon patient registration to ensure that appropriate fields are completed before the patient begins treatment. Ideally, data should be shared across practices, hospitals and health plans (in conformance with privacy rules, including HIPAA), so that patients are not asked to answer demographic questions more often than necessary.
 - What racial and ethnic categories should be used—at minimum, use the broad categories recommended by the U.S. Office of Management and Budget for purposes of the U.S. Census, but move toward collecting more granular categories based on the particular demographics of the community served.
 - How data should be stored—demographic data should be held in a standard database format to facilitate aggregation and linking to clinical data.
 - How patient concerns should be addressed—prior to asking for their demographic information, standard scripts should be used to reassure patients that data on their race and ethnicity are used to track quality and make sure all patients receive high quality care.
 - Staff training—staff responsible for collecting demographic data should receive regular training and evaluation, including on the reasons for data collection and how to explain the request to patients.
4. Governmental and other payers should support the collection of accurate demographic and quality data at physician practices and the analysis of quality data stratified by demographic categories.

An important caveat accompanies these recommendations. Research on how best to collect and use data on patient race and ethnicity is emerging along with changes in American demographics and how individuals define themselves, and the underlying technologies used to collect this data (such as EHR systems) are evolving rapidly. Therefore, this set of recommendations should not be considered static and is expected to be updated and to change over time.

In addition, the Commission to End Health Care Disparities notes that demographic data are sometimes collected at a variety of points in the health care system. Moreover, the uses of these data can provide benefits to many stakeholders. As a result, there are many questions about who should collect patient demographic data, how these data should be collected, stored and used, and who is to pay for these necessary activities. For example, demographic data need not be collected by ambulatory practices if they are already reliably collected elsewhere and are readily available for use at the practice level. If a health plan were to collect self-reported race, ethnicity and primary language data from enrollees and make these data available to clinicians, there would be no need to re-collect these data elements in the clinic for patients in that health plan. However, since most physicians contract with more than one health plan, and since demographic data collected by health plans are often imperfect and rarely immediately available to the practice, it will often be most efficient for the practice to collect these data locally. Our recommendations therefore focus on data collection in the ambulatory setting. Still, the purpose of the commission's recommendations is to provide guidance to practices and *also* to EHR vendors, policy makers, health plans and other stakeholders who must support clinicians in their efforts to collect these data and then use them to improve quality of care.

These recommendations address both demographic data collection and, equally important, the critical ways in which these data should and should not be used by ambulatory practices. The recommendations have been shared for review by the Commission to End Health Care Disparities for acceptability and feasibility and were approved by the commission's steering committee in January, 2011.

When to collect demographic data

The commission recommends that demographic information be collected by patient registration or front office staff when the patient first comes to the clinic or practice. This information can also be collected over the phone prior to the visit. Patients can also provide the information on a written form or at a registration kiosk. If a patient is given a written form but doesn't fill it out, this could indicate difficulty reading or understanding the form due to factors including marginal or low literacy or visual/hearing impairments, uncertainty about how to answer these questions (e.g., for a multi-racial individual), or concerns about why the data are being collected. We recommend that staff offer to provide such patients assistance in completing the form by asking, "Would you like help filling out the form?" Staff can then read the questions to the patient or the patient's proxy (e.g., parents or caretakers), or through an interpreter in the case of patients with limited English proficiency or who are deaf or hearing impaired and help them to complete these questions. Offering to provide help will also create an opportunity to explain why the data are being collected and to answer any other questions or concerns the patient might have (see below).

While a few people will change their racial or ethnic identification over time⁷³ it is not necessary to ask patients about their race and ethnicity at each visit. However, because race and ethnicity categories can change, and recommendations for how to record race and ethnicity have changed and may well continue to do so in the future, we recommend re-confirming race and ethnicity data intermittently (e.g., every five years). The commission acknowledges that the recommendation on reconfirmation is not based on strong evidence that five years is an ideal time frame, but rather on the more general understanding that changes in racial and ethnic categorizations can and do occur over time.

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What demographic data to collect

The commission recommends that practices start by collecting *self-identified* race, ethnicity and language data since these data elements are fundamental building blocks for identifying racial and ethnic health care disparities.

Race and ethnicity categories

The commission recommends following the guidelines for standard race and ethnicity categories set forth by the IOM in its 2009 report, “Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement.” (See chart below.)

Race and Ethnicity	<p>OMB Hispanic Ethnicity</p> <ul style="list-style-type: none"> • Hispanic or Latino • Not Hispanic or Latino 	<p>OMB Race (Select one or more)</p> <ul style="list-style-type: none"> • Black or African American • White • Asian • American Indian or Alaska Native • Native Hawaiian or Other Pacific Islander • Some other race 	<p>Granular Ethnicity</p> <ul style="list-style-type: none"> • Locally relevant choices from a national standard list of approximately 5640 categories with CDC/HL7 codes • “Other, please specify: _____” response option • Rollup to the OMB categories
Language Need	<p>Spoken English Language Proficiency</p> <ul style="list-style-type: none"> • Very well • Well • Not well • Not at all <p>(Limited English proficiency is defined as “less than very well”)</p>	<p>Spoken Language Preferred for Health Care</p> <ul style="list-style-type: none"> • Locally relevant choices from a national standard list of approximately 600 categories with coding to be determined • “Other, please specify: _____” response option • Inclusion of sign language in spoken language needs list and Braille when written language is elicited 	

Chart reprinted with permission from: Cheryl Ulmer, Bernadette McFadden, and David R. Nerenz, Editors; Subcommittee on Standardized Collection of Race/Ethnicity Data for Healthcare Quality Improvement; *Institute of Medicine Race, Ethnicity and Language Data: Standardization for Health Care Quality Improvement*. National Academies Press, Washington, D.C., 2009.

Note that ideally patients should be allowed to choose as many race/ethnicity categories as they feel describe them. Allowing patients to enter their own race (i.e., by writing in a response if they do not see a category that reflects how they would self-identify) is also recommended. Practices should be sensitive to the communities they serve and should include additional differentiation to standard categories when they think it is appropriate (for instance country of origin) or when they find significant numbers of patients entering their own racial category. In electronic data collection systems, EHR vendors could provide an almost unlimited number of choices in a drop-down menu that can then be rolled-up into standard Office of Management and Budget (OMB) race and ethnicity categories for regional and national analyses.¹⁶ Electronic systems can and should make it possible for patients or admissions staff to type any racial and ethnic categories into data entry fields, with auto-suggestion functions to save time.

Language categories

According to the IOM,¹⁶ “data on a person’s language and communication needs should be part of any minimum data set related to health care delivery and quality improvement.” A patient’s language always has direct impact on effective communication and care for that individual. In the 2000 Census, 8.1 percent of the U.S. population (~25 million people) spoke English “less than very well.”⁷⁴ The number of such individuals nationwide who need language assistance is growing and these individuals frequently interact with the health care delivery system.⁷³ According to the American College of Physicians (ACP), 81 percent of general internal medicine physicians treat patients with limited English proficiency (LEP) at least once a day or a few times a week.⁷³ The evidence suggests that language barriers increase the likelihood that patients will be less satisfied with their care, will miss appointments, and will not use preventive care services.^{16,73-77}

The IOM recommends (Figure 1) that health care providers and practitioners determine the language need of their patients by assessing:

- How well an individual believes he/she speaks English (less than “very well” is defined as LEP)
- What language he/she prefers for health-related encounters
- Where possible, language(s) spoken at home and language preferred for written materials

How to ask for self-reported race, ethnicity and primary language

For purposes of patient care, patients or their caretakers should always be the source of their own demographic data and this information should never be inferred by observation alone or by assumptions based on the patient’s name. This raises the question of how to ask these questions in a reliable and sensitive manner. This issue is most acute when staff is asked to request patients to verbally provide their race, ethnicity and language information, but even written forms should ask for this information in a sensitive manner that is most likely to produce reliable results.

Research on how best to ask patients about their racial and ethnic background provides several lessons. The key step is to succinctly explain to patients or their caregivers why this information is being collected. By offering a clear and concise explanation, whether written or verbal, of why the patient is being asked to provide this information, patients are put more at ease and staff might also increase their own comfort in bringing up the topic of race.

The most efficient way to provide staff tools and support for asking these questions might be to build these supports into EHR systems. For instance, a standard script for patient registration could be built into EHR registration systems and would provide a uniform, respectful way of asking these questions. A linked FAQ document could help staff provide answers to common patient questions.

Several example scripts are available. The Commission to End Health Care Disparities does not endorse a single script, but recognizes that model scripts should be piloted and tailored to specific local circumstances. The example script in the sidebar (right) was adapted from language tested and used by Boston Medical Center, Boston, Mass., and by the Palo Alto Medical Foundation, Palo Alto, Calif.

Using demographic data

Some potential uses of demographic data in physicians’ practices are explored in Section II above. The commission’s specific recommendations regarding the use of demographic data follow. First, we caution against using basic demographic data for tailoring diagnostic and medical treatment for individual patients, unless it is the best available information on presumed genetic conditions or risks. In particular, we recommend against making assumptions about an individual’s health-related preferences or attitudes based on broad demographic characteristics, such as race or ethnicity, as this constitutes a clinically dangerous form of stereo-

... a standard script for patient registration could be built into EHR registration systems and would provide a uniform, respectful way of asking these questions. A linked FAQ document could help staff provide answers to common patient questions.

An example script for front desk staff in ambulatory settings asking patients about their racial, ethnic and language background

Now I’m going to ask a few questions about your race and ethnic background. We collect this information from all our patients and use it to track quality of care. This information goes into your medical record and it is confidential.

1. First, how would you describe your racial background?
 2. Next, how would you describe your ethnicity, such as your family background or ancestry?
 3. What language do you usually speak at home? (If English, skip the remaining questions.)
 - 3a. Would you say you speak English very well, well, not well, or not at all? (If “very well,” skip the remaining questions.)
 - 3b. In what language would you feel most comfortable speaking with your doctor or nurse?
 - 3c. In what language would you feel most comfortable reading health care instructions?
-

typing. Experienced clinicians know that a patient's racial or ethnic background is no substitute for a careful family and social history that can explore the patient's possible genetic inheritance as well as the patient's personal health-related priorities, goals and concerns.

On the other hand, we believe it is often helpful to use aggregate demographic information on patient populations to craft outreach initiatives, address particular population needs, and detect, track and eliminate health care disparities.

With regard to disparities, using demographic information to detect and eliminate health care disparities requires that one (1) collect accurate demographic data, (2) collect accurate quality data, and then (3) stratify quality data by demographic groups. To perform the stratification task, patient demographic data must be linked to quality data. For this reason, the commission recommends storing both types of data in a standard database format to facilitate linking of the two data sources.

... patient demographic data must be linked to quality data. For this reason, the commission recommends storing both types of data in a standard database format to facilitate linking of the two data sources.

This also raises the question of what quality data are *relevant* for a particular practice. There are many potential quality measures and collecting data for these measures can be complex and costly. To determine which quality measures are relevant, we recommend that practices use quality indicators that have been endorsed by their specialty societies and/or approved by the membership of the Physician Consortium for Performance Improvement.⁶⁵ Linking demographic and quality data is so important to ensuring these data are useful for improving patient care that we recommend practices select (often with guidance from professional societies and support from EHR systems) which quality measures to use as early in the process as possible. In addition, because quality measurement is much more useful when one's data can be aggregated and compared across multiple sites or benchmarked against quality standards, practices collecting quality and patient demographic data need to be able to link and share these data to learn from each other. This will require that demographic data be interoperable across different electronic record systems. Therefore, as quality measures are being selected, plans for linking these data to a larger database, with attention to interoperability with larger systems where possible, should be developed, too.

Finally, both of these steps (selecting quality measures and planning for using these data for benchmarking and quality improvement) should be carefully explained to office staff *before* starting or revamping any demographic data collection process. Having a clear plan for how a practice intends to use data to examine and improve care can go a long way towards reassuring clinicians, staff and patients that collection of demographic data will be a useful exercise.

Even for practices that carefully select quality measures to use, stratification and other analyses of these data can be complex, time consuming, expensive and beyond the scope of expertise of most small practices. In addition, data analysis is often best accomplished at a level where multiple practices can combine data and learn from each other. As a result, the government, hospitals, health plans and professional societies all can play productive roles in supporting and coordinating the stratification and analysis of quality data. The special role of EHR systems is addressed below.

... the government, hospitals, health plans and professional societies all can play productive roles in supporting and coordinating the stratification and analysis of quality data.

“Two Clicks to Equity”—recommendations for electronic health records systems

Table 2. Recommendations for electronic health records (EHR) systems to facilitate basic demographic data collection and use

The Commission to End Health Care Disparities recommends that all electronic health records (EHRs) include the following three basic functions:

- 1. Demographic data collection supports:** Standard fields for data entry on patient self-identified race, ethnicity and primary language at a minimum, which allow a patient to select more than one race and/or ethnicity as they feel is appropriate in describing themselves. We suggest including a script for how best to ask about race, ethnicity and language, with easy access to answers to the most frequently asked questions that patients might pose when asked to report their race and ethnicity.
- 2. Performance data displays:** Basic bar or pie charts that can display any performance indicator selected.
- 3. Two-click access to displays of performance data stratified by any key demographic group.** Visualization of quality data by demographic groupings should require no more than one click to select a performance indicator of interest and a second click to choose a demographic stratification variable.

EHRs are widely viewed as tools for providing high quality care, but a focus on simply spreading the adoption of EHRs without consideration to specific functions and clinical utility will not be sufficient to improve quality and reduce disparities. Poon and colleagues⁷⁸ recently found that the availability and use of specific EHR features by physicians was associated with better performance on quality metrics. Based on their findings, Poon and colleagues concluded that “to maximize health care quality, developers, implementers, and certifiers of EHRs should focus on increasing the adoption of robust EHR systems and increasing the use of specific features.”⁷⁸ In other words, EHRs need to be user-friendly tools that enable clinicians to do specific, high-value tasks easier, faster or better. With regard to demographic data collection, this means EHRs need to provide specific functions that will facilitate the effective collection and use of patient demographic data in ambulatory settings. Specifically, the commission recommends that federal and private bodies involved in developing standards for EHR systems require that all EHRs incorporate the basic data collection and use functions noted in Table 2. The set of recommendations has been dubbed the “Two Clicks to Equity” agenda,⁷⁹ because it focuses on a few basic technical features of EHRs that would allow any ambulatory practice with any EHR and the desire to collect demographic data to be able to use these data to detect and address disparities, with very little technical, computer programming or statistics expertise required on the part of the clinician.

These recommendations derive from a recognition that simply implementing an EHR will not ensure that practices have the information needed to improve patient care. Baron⁸⁰ points out, for example, that when his practice set out to improve mammography rates after they had implemented their EHR, they assumed that routine patient registration would have captured the age and sex of each patient, and physicians in the practice expected the computer to calculate the number of female patients in their practice between 50–65 years of age for their denominator and, further, that the EHR would be able to tell them their numerator for this measure and identify women who had not had mammograms, enabling them to target their efforts to improve rates. It wasn’t quite so simple. After a series of setbacks, the authors conclude that an EHR alone is not sufficient (though it is helpful) for quality improvement activities, and that efforts to improve EHR adoption should be coupled with creation of EHR standards to make it easier for most physicians to use the data in their systems, as well as programs to enhance physician apprecia-

EHRs need to be user-friendly tools that enable clinicians to do specific, high-value tasks easier, faster or better. With regard to demographic data collection, this means EHRs need to provide specific functions that will facilitate the effective collection and use of patient demographic data in ambulatory settings.

EHR adoption should be coupled with creation of EHR standards to make it easier for most physicians to use the data in their systems ...

tion of structured data sets. Increasing demands on physician practices without increasing support and enhancing the utility and user-friendliness of tools such as EHRs to measure quality and reduce disparities will result in a substantial barrier to achieving quality goals.

To help physicians select EHRs that are appropriate for their specific practices, the American Recovery and Reinvestment Act of 2009 has provided funds for regional extension centers which provide a vendor neutral environment and are designed to help physicians choose systems that will allow them to meet the criteria for meaningful use of health information technology (IT), and thus qualify for federal incentive payments.⁸¹ A number of professional societies have also launched substantial efforts to assist physicians in selecting optimal EHRs and other health IT products, including the AMA's "Putting health IT into Practice" resources,⁸² the American Academy of Family Physician's Center for Health IT⁸³ and tips and advice from the ACP.⁸⁴

Finally, even with systems that remove barriers and provide support for data collection, there will be costs associated with collecting and using patient demographic data in the ambulatory setting. While demographic data collection will directly benefit ambulatory practices in several ways, many of the benefits of data collection will accrue to other stakeholders in the health care system—most notably, the government and other payers. For this reason, we recommend that government and payers share in the cost of implementing EHR-based demographic data collection and QI systems in ambulatory practices.

Conclusion

Ambulatory clinics and practices will benefit in a number of ways from collecting basic demographic data on the patients they see, since these data can be used to accomplish high-value performance improvement projects, reach out to untapped markets and generate more reliable quality metrics. In addition to these direct benefits for the medical practice and the patients served, these data are needed to help our nation move towards the elimination of health care disparities, an important national goal. The commission recommends that basic demographic information should be collected from patients seen in the ambulatory setting, and that these data should be used to improve quality, including by examining quality data stratified by race, ethnicity and primary language. Existing and emerging EHR systems should be upgraded and standardized to support the collection of accurate data on patient demographics and quality of care, with easy access to stratified displays of quality metrics by demographic fields.

Appendix 1: Commission to End Health Care Disparities Member Organizations

Alliance of Minority Medical Associations
American Academy of Allergy, Asthma and Immunology
American Academy of Dermatology Association
American Academy of Family Physicians
American Academy of Ophthalmology
American Academy of Pediatrics
American Academy of Physician Assistants
American Association of Public Health Physicians
American College of Cardiology
American College of Emergency Physicians
American College of Obstetricians and Gynecologists
American College of Physicians
American College of Preventive Medicine
American College of Surgeons
American Hospital Association
American Medical Association
AMA - Council on Ethical and Judicial Affairs
AMA - Council on Medical Education
AMA - Council on Science and Public Health
AMA - Minority Affairs Consortium
AMA - Women Physicians Congress
AMA – International Medical Graduates
American Medical Women’s Association
American Osteopathic Association
American Psychiatric Association
American Public Health Association
American Society of Addiction Medicine
American Society of Clinical Oncology
Association of American Indian Physicians
Association of American Medical Colleges
Association of Clinicians for the Underserved
Association of Haitian Physicians Abroad
Association of Minority Health Professions Schools
AstraZeneca Pharmaceuticals
Blue Cross Blue Shield Association
California Medical Association
California Medical Association Foundation
Chicago Medical Society
Coca-Cola North America
Connecticut State Medical Society
Eli Lilly & Company
Florida Medical Association
Gay and Lesbian Medical Association
Illinois State Medical Society
Massachusetts Medical Society
Medical Society of New Jersey
Medical Society of the State of New York
Michigan State Medical Society
National Alaska Native American Indian Nurses Association
National Association of Health Services Executives
National Association of Hispanic Nurses
National Black Nurses Association
National Council of Asian-Pacific Islander Physicians
National Hispanic Medical Association
National Medical Association
National Minority Organ Tissue Transplant Education Program
National Pharmaceutical Council
Network of Ethnic Physicians Organization
Ohio State Medical Association
Pfizer, Inc
Purdue Pharma
Renal Physicians Association
Society of Critical Care Medicine
Texas Medical Association
The CHEST Foundation (ACCP)
Uniformed Services University of the Health Sciences
United Health Care
White House Initiative on Asian Americans and Pacific Islanders
W. Montague Cobb/NMA Health Institute

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