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Looking Forward: Cross-cutting Issues in the Collection and Use of Racial/Ethnic Data

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Availability of reliable and valid race/ethnicity data is essential for monitoring and improving quality of care for minority groups. We explore the limitations and challenges posed by existing means of data collection and discuss issues that need to be considered as the data are analyzed and used.
Key Words. Disparities, race/ethnicity data

Numerous authors have advanced the premise that addressing racial/ethnic disparities in health care is best done by treating disparities in care as a health care quality issue. Like any other quality improvement undertaking, successfully eliminating racial/ethnic disparities in health care will be extremely difficult to achieve without a robust system of data collection and analysis with which to measure and track progress. The availability of data that capture information about the race/ethnicity of patients will be a critical element in examining patterns of health care quality for minority populations.

Several papers in this volume address specific issues facing the collection and use of race/ethnicity data. We discuss a series of cross-cutting issues involved in the collection and use of such information.

Race/Ethnicity Data Collection: Challenges, Limitations, and Concerns

Data are most useful when they can serve as a basis for action, such as for choosing a provider, implementing a quality improvement intervention, making contract decisions with a plan or provider, or developing population

health interventions. To be actionable, data need to be reliable and valid and identify for the user a compelling problem that can be ameliorated. In this paper, we discuss issues related to making race/ethnicity data collection reliable and valid for addressing minority health disparities and strategies for improving the provision of data. This paper does *not* attempt to examine the large legal literature on collection and use of race and ethnicity data.

Deriving Locally Actionable Data

Racial/ethnic data collected by the federal government for use in monitoring access to and quality of care for minorities fall into two broad categories: (1) racial/ethnic data self-reported on surveys and used to monitor aspects of population health, such as the Behavioral Risk Factor Surveillance Survey (BRFSS) and the National Health and Nutrition Examination Survey (NHANES); and (2) racial/ethnic data derived from administrative data in the health care system. The latter are often not derived from self-reported data. Despite their differences, both categories of racial/ethnic data share a number of issues common to their collection and to the measures derived from them. Foremost among those issues is the need to derive locally actionable data that can be used to address disparities.

Tip O'Neill, former Speaker of the U.S. House of Representatives, liked to say that "all politics are local." His adage is also apt for health care: All health care is local, and the closer to home the data are, the more difficult it is for the public or policy makers to dismiss the health care issues they pose as "someone else's problem." This point was driven home by a recent survey of cardiologists: although a third of the respondents felt that such disparities were common in the U.S. health care system, just over one in perceived disparities to be an issue in their own hospital, and only around three in 100 physicians believed that there were racial/ethnic disparities in care in their own practice (Lurie 2005). The point is that while national data are important, data may be even more useful in compelling action when they can both provide a basis for comparison with either national data or other similar populations *and* be localized to a state, community, or clinical population, such as those in a health plan, hospital, or clinic.

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However, data localization can pose analytical challenges and tradeoffs. The more local the data—whether geographic or at the provider level—the smaller the population size. Hence, even numerically large and clinically meaningful differences between groups of patients may not be statistically significant given a small sample size, and clinical judgment will be critical in determining when to take action in the face of relatively small sample sizes. The National Committee for Quality Assurance (NCQA) sets guidelines for reporting on quality at a minimum denominator of 30 and recommends a sample size of more than 100.

Ideally, such sample size guidelines would be achieved for each racial/ethnic group, relevant condition, and level of care reported on. Many of the issues that a local entity (e.g., hospital or health plan) might choose to address are prevalent enough to support at least basic analyses. These organizations may choose to consider the direction of effects as evidence for action, even if findings do not attain statistical significance at traditional levels when sample sizes are small.

Limiting analyses to regional or national data does not necessarily resolve the issues of small sample sizes. For example, despite the fact that some nationally available datasets are often quite large, or oversample selected minority populations (e.g., NHANES oversamples Mexican Americans), subgroups of clinical or policy significance may still be quite small. This was illustrated well by Virnig et al. (2002) who used administrative data from all Medicare+Choice plans and found that sample sizes were often too small for even seemingly large point estimates, such as care following myocardial infarction among Native Americans.

Constraints Imposed by Racial/Ethnic Categories

In collecting and acting on race/ethnicity data, health plans and hospitals often find themselves challenged by the limitations of the federally designated population categories imposed by the Office of Management and Budget (OMB). The current OMB categories are often considered too coarse and noninclusive by some researchers and may be particularly inadequate when trying to describe local ethnic populations. For example, in Omaha, Nebraska, it might be important to differentiate between American-born blacks and relatively new Sudanese immigrants. In this setting, it might make sense to collect information on both groups and when appropriate, aggregate subgroups to the larger OMB category. Likewise, hospitals in Detroit might want to distinguish among different Middle Eastern populations, which are not currently designated in the OMB categories.

The use (let alone the development) of an exhaustive list of racial/ethnic categories is overwhelming and impractical for most users. In cities like Los Angeles or New York, where over 150 languages are spoken, the problem of which subgroups to employ is particularly daunting.

Federal guidance is needed in terms of practical measurement, uniformity and aggregation into larger categories. The challenge is to develop category standards that are both parsimonious and useful on a local level. To that end, the standards developed by the HHS Office of Civil Rights may serve as a useful reference.

A related challenge is categorizing the growing number of individuals who identify with multiple racial and ethnic groups. Health plans and hospitals that are collecting race/ethnicity data now are already reporting an increase in the number of people who identify themselves as "other." Decision rules for how such groups are considered are important, as each multiracial/ethnic category risks being aggregated into a stereotyped or prevalent notion about one or more groups. At the same time, an "other" group risks becoming its own subgroup—too small from a statistical (or business case) perspective to focus on.

Data Collection Methods

The use of race/ethnicity data for measuring, monitoring, and acting on quality of care issues for minority populations is clearly influenced by the methods used to obtain the data. Several health plans, notably Aetna and Minnesota's HealthPartners, have already demonstrated the feasibility of collecting such information directly from individuals. Plans that serve Medicare and Medicaid populations can link their enrollee data with race/ethnicity data collected in the course of program administration, and there are numerous examples of this practice. The accuracy of Medicare's race/ethnicity data has been steadily improving. The accuracy of race/ethnicity data in Medicaid programs varies both by state and by eligibility category. Those states and categories that rely on an enrollee-completed application form are likely to have the most accurate data.

As reviewed by Fiscella and Fremont (2006), geocoding and surname analysis provide alternative approaches for estimating the racial or ethnic composition of various populations. These methods are relatively quick and easy to use, enabling estimates of population racial/ethnic composition and disparities in care. Furthermore, geocoding also offers the opportunity to obtain information with which to estimate socioeconomic status, which is a confounder in many analyses.

Fremont and colleagues (2005) recently demonstrated that race estimated from geocoding could produce accurate estimates of racial disparities in health plans across a range of HEDIS performance measures. Similarly, Nerenz and colleagues (Nerenz, Bonham et al. 2005) used surname analysis to demonstrate consistent patterns of disparities between Hispanics and other patients in health plans. Using imputed data to identify patterns of differences in care for these groups by clinical indicator, geographic region, or business unit, can play a significant role in helping to focus health plans' attention on disparities and to address them. One drawback is that geocoding and surname analysis are not appropriate to identify an individual's race or ethnicity. Thus, although it might be feasible to put in place a system-level intervention in a hospital or clinic based on such data, it would be difficult to use the data to target specific individuals for care, such as enrolling pregnant African American women in a high-risk pregnancy program or conducting person-level cervical cancer screening outreach to Vietnamese women.

The strengths and weaknesses of different approaches to data collection continue to be clarified. For institutions that want to quickly start obtaining race/ethnicity data and targeting differences in care, geocoding and surname analysis are a relatively inexpensive bridge to more precise, individual-level methods. The level of enrollee turnover may dictate how often the data need to be refreshed.

Developing efficient ways to sample different racial/ethnic groups in the U.S. has become increasingly important. The National Academy of Sciences (National Research Council 2004) calls for the development and testing of newer statistical methods for identifying and sampling population groups of interest.

Universal Data Collection: Promise and Concerns

Multiple groups, including the Institute of Medicine, the National Academy of Sciences, and an advisory committee to NCQA, have recommended universal race/ethnicity data collection as a strategy to reduce health care disparities. However, generating the political will to accomplish this, such as through a requirement to complete race/ethnicity fields on the electronic transaction forms through which health care entities submit information (e.g., Form 827) will require concerted efforts on the part of health care purchasers, payers, and the public.

Although most quality-of-care professionals advocate the near-universal collection and use of race/ethnicity data, some segments of the public are concerned about this strategy (Robert Wood Johnson Foundation 2004). The ethical principal of autonomy, as well as basic tenets of privacy, maintain that individuals must have the right to withhold such information if they so choose. Anecdotal experience to date suggests that the degree to which individuals choose to withhold their race/ethnicity may, in part, depend on how well the use of such data, and the safeguards for their use, are explained.

Concerns persist over data sharing and protecting personal information. For example, under what circumstances, if any, should a hospital share race/ethnicity data with a health plan seeking to address disparities in quality? Conversely, under what circumstances should a health plan that has collected such information through self-report share it with a hospital? Hosnain-Wynia and Baker (2006) have documented the nearly universal collection of race/ethnicity data by hospitals, albeit with varying methodologies and degrees of accuracy. Bocchino (America's Health Insurance Plans 2004), in a study of members of American Health Insurance Plans (AHIP), reported that over half of health plans have successfully collected some race/ethnicity data from enrollees in at least one product.

Similarly, should employers provide health plans race/ethnicity data on their employees in an effort to eliminate disparities in quality for their personnel? The question is relevant because some employers have asked health plans to address health care disparities in their workforce.

Absent an agreed-upon standard for data sharing, or a process for individuals to protect personal information from being shared if they so choose, there remains substantial variability in data practices. Currently, at least one employer is, in fact, providing data on race/ethnicity to plans as part of an agreement that requires them to monitor disparities in quality. Other plans and employers have chosen not to pursue such methods. Although it is possible to deidentify data so they could be shared for the purpose of examining patterns of care for population groups, this approach has its own limitations.

Uses of Race/Ethnicity Data

In this section, we discuss how race/ethnicity data are currently used to improve the quality of care for minority groups and for related activities, such as health plan marketing and purchasing. As this section also shows, issues surrounding the use of racial/ethnic data raise a number of important questions.

Using Racial/Ethnic Data to Improve Quality and Reduce Disparities

The literature are quite sparse when it comes to documenting strategies to address disparities (Epstein 2004) . Although a recent review (Long et al. 2004) identified a number of promising initiatives to reduce disparities, a robust set of tools and interventions for addressing disparities is still under development. For example, it is still not clear whether general quality improvement interventions are sufficient to eliminate disparities or whether some interventions need to be different for different populations.

Some demonstrations currently underway, such as those sponsored by the Agency for Healthcare Research and Quality (AHRQ), Commonwealth Fund, Robert Wood Johnson Foundation, American Hospital Association, and others, may help answer some of these questions.

In broad terms, these programs, which involve hospitals and health plans, begin with data acquisition, followed by stratification of quality of care measures by race/ethnicity. The goal of these efforts is to identify problem areas and test strategies to reduce disparities.

Even if these efforts are successful, a series of questions and challenges remain. What will it take to maintain these efforts? Will a health plan's good performance on quality of care measures for minority populations (e.g., for Hispanic diabetes) attract a disproportionate share of sicker minority patients to that plan? Is there a clear business case or return on investment from these activities?

If the number of minorities in a plan is small, improvement may come at a relatively high cost per enrollee. In such circumstances, should the efforts be continued and if so, why? Given the evidence that most people do not use information about quality when selecting a plan, can stratified quality of care information be used to mobilize consumers? A model for identifying the business case, not only for employers but also for insurers and for the public, needs further development and testing.

In addition to identifying areas for improvement, race/ethnicity data can be used to identify areas in which there are few disparities. Such examples may help identify exemplary practices and point the way to their more widespread adoption.

But such use of data brings up additional challenges. For example, when evaluating interventions, small sample sizes in some groups or for some quality measures, mean that only very large differences will be statistically significant. Massachusetts has developed an innovative strategy to deal with the

small sample size issue when it comes to examining quality of care. In that state, multiple health plans have agreed to pool quality measures at the individual provider level to attain adequate sample sizes for analysis (Jordan 1995). Health plans and employers could encourage similar efforts related to disparities data.

Selection of Quality of Care Measures for Addressing Disparities

A host of organizations now promote the use of quality of care measures for common clinical conditions. There is general agreement that many of these measures, particularly for chronic disease, can be used to reflect the quality of care for racial/ethnic groups. Should other measures or conditions be addressed by such efforts?

Nerenz, Gunter, García et al. (2002) provide a thoughtful discussion of this issue as they assess efforts to develop "minority health report cards." A recent review by Fiscella (in press) comes to the conclusion that existing quality measures are a reasonable place to start for such report cards. Regardless of the measures selected, it would be a mistake to assume that high levels of compliance or lack of disparity in process measures, for example, checking lipid or HbA1c levels, implies a similar lack of disparity in outcome, in this example, lipid or diabetes control. As quality measurement advances, it will be critical to balance the need for administrative simplicity with the ultimate goal of improved health outcomes.

Secondly, disparities on one quality indicator may not be indicative of performance in other quality domains. For example, one plan found no disparities in adult immunization rates but marked differences in care for diabetes and depression. Similarly, a plan with high rates of mammography may not have high rates of age-appropriate cancer screening for other conditions. Even within the domain of quality measures for a specific condition, patterns of disparity may differ by measure.

Finally, a lack of finding of disparities may not be a function of the specific measures, but rather may reflect poor care overall. Indeed, McGlynn and colleagues (2003) have documented that only half of recommended care is actually delivered to adults in the United States.

Use of Race/Ethnicity Data to Manage Population Health

Health plans can use race/ethnicity data to manage the health of their populations in several ways. Overall, they may provide additional information

about expected health needs based on epidemiology of common conditions, such as identifying an increased prevalence of diabetes in Hispanics or Native Americans.

The data may also provide information about the location (in geographic areas or business lines) of substantial concentrations of different population groups. Data might then be used to develop community-based strategies for addressing disparities or to focus on cultural competence interventions. Lieu et al. (2004) recently demonstrated that aspects of health plan cultural competence, such as workforce diversity and translation services, are associated with better asthma outcomes in Medicaid managed care plans.

Knowing where the priority areas are for implementation of such efforts could be helpful. Bach et al. (2004) recently reported that care for African Americans is concentrated among a small segment of physicians, and those physicians reported difficulty accessing high-quality support such as specialty care or diagnostic tests. Having better information on where such patients are cared for may help identify geographic areas or specific institutions in which additional support, such as specialty services, diagnostic procedures, or pharmacy access is needed.

Data Quality Issues

The method selected to obtain race/ethnicity data and its accuracy has important implications for its use. The tendency is to discount data that are not perfect or to "let the perfect be the enemy of the good." However, this strategy may lead to forgoing some imputation strategies, such as geocoding and surname analysis, thus risking substantial delays in data ascertainment and analysis, as well as losing clinically important opportunities.

Finally, determining whether improvement in overall patterns of quality also represents improved quality for individuals is an issue that will continue to warrant attention.

Moving to Action: Unanswered Questions

Assuming the availability of data or a commitment to obtain it poses several outstanding issues. Are the organizations that are already collecting data on race/ethnicity the same organizations that are likely to act on disparities? Is the federal government more or less likely to take action than private health plans? How generalizable are the findings from health plans and other organizations that have chosen to obtain data? Are some types of data elements more likely to facilitate action than others? For example, surname analysis that

identifies potential non-English speakers may be perceived as more actionable than data that identify differences in diabetes control between Hispanics and whites.

The use of race/ethnicity data for monitoring quality of care is new enough that we have not yet crossed the threshold of public reporting. Nonetheless, several large purchasers have set an expectation that plans conduct such monitoring. What type of data, if any, should be publicly reported? How confident do we need to be about the accuracy of race/ethnicity data before public reporting is considered reasonable? How should consumers or purchasers use such information? Should data be risk adjusted and what should it be adjusted for? Does public reporting increase the risk that plans will seek to avoid types of patients for fear they may negatively impact their publicly reported measures? These questions merit attention as efforts to wed disparities and quality improvement proceed.

Organizational Challenges to Using Race/Ethnicity Data

Another set of issues is whether an organization's structure is configured to facilitate action, or whether data, if collected, are accessible for quality improvement. Are the departments within organizations that have race/ethnicity data the ones that can organize activities to address them? In some health plans, for example, HEDIS reporting is handled in a separate unit from quality improvement. Even if HEDIS scores were stratified by race/ethnicity, the data would not be accessible for quality improvement or disease management. In others, one region or business unit may have implemented an innovative program and had promising results, yet the organization is not structured so that other units can learn from the experience.

Some efforts at data collection, such as Aetna's (Winslow 2003), were driven directly by the CEO. But even with clear leadership, organizations may need to work to overcome resistance to data collection by other staff.

In other plans, the efforts have been "bottom up," and the challenge is for staff to convince senior leadership about the importance of data collection. In either case, the component of the organization that is charged with taking action on the data must have the data available to it and take the responsibility to act on it. Organizations that are very decentralized, or in which each region or business unit is highly autonomous, may lose opportunities to share information about interventions that work.

Similarly, marketing departments may have potentially useful ideas about how to reach certain populations to improve the quality of care provided to them, and it may be in their own self-interest to share those ideas with the quality improvement and disease management components of their organizations.

The issues may be somewhat different for Medicare and Medicaid, where it is not always clear who is responsible for acting on race/ethnicity data. CMS administrative data, including race/ethnicity data, are used both for research and to underpin quality improvement strategies used by various parties, including quality improvement organizations, health plans and hospitals. However, it can be challenging to identify who the parties are that must take action once problems or opportunities for improvement are identified.

Use of Data for Research

Hospitals, health plans, and other organizations conduct research for purposes of strategic planning, generating new knowledge about patterns of disease or utilization and for quality of care research. Some health plans, such as Kaiser Permanente, United HealthCare, and Aetna, traditionally have had robust research units that could creatively use race/ethnicity data to advance new knowledge. Large data warehouses, compiled by entities such as health plans and pharmaceutical benefits managers, serve as the basis for much health services research, some of which may be able to inform quality improvement interventions in the future. Race/ethnicity should become a standard element in such repositories.

In research databases, the need to assure complete accuracy of racial/ethnic data at the individual level is not as great as it is for databases that support direct-to-patient interventions. Thus, indirect measures of race/ethnicity such as those based on geocoding and surname analysis will likely be useful additions to such databases.

Use of Race/Ethnicity Data for Marketing

The ability of many health plans to survive and thrive depends on maintaining and increasing market share. Many plans now view the demographic shifts in the U.S. population as an important business opportunity. They have developed strategies to increase market share by marketing to and enrolling individuals from various ethnic groups.

The data required for such marketing are largely derived from census estimates of where different ethnic groups reside (e.g., Koreans) as well as from

employers. Health plans conduct classic market research to develop marketing and sales strategies, including printed materials in various languages with pictures of individuals representing the target population; hiring and training a multiethnic marketing sales force; increasing provider networks and translation services to assure the population can be served in an appropriate language (and with understanding of culture); identifying preferences for various benefit structures, such as primary care versus catastrophic coverage; and including coverage of alternative therapies such as acupuncture or traditional healers. At least one health plan has begun explicit marketing to employers, highlighting its efforts to assure high-quality care for minority populations.

These marketing strategies have become more common over the past decade, but very rarely are the race/ethnicity data obtained by plan marketing departments also used by other plan divisions to manage quality of care. Although there may be clear business reasons to keep these areas separate, it is possible that marketing departments have acquired an additional understanding of some enrollee populations that could be harnessed to improve health care quality.

Whether commitments made at the time of marketing will be sufficient for purchasers and consumers or whether they will ultimately want to see evidence of actual disparities in care and their reduction, is not yet clear. If the field evolves to the point at which plan-to-plan comparisons based on race/ethnicity data are available, competitive strategies, as well as pay-for-performance efforts, may need to incorporate additional considerations, such as risk adjustment.

Use of Race/Ethnicity Data for Purchasing

As the field matures, health care purchasers may selectively contract based on information about disparities in quality of care. CMS already has the tools to examine patterns of disparities in Medicare+Choice plans and can use those in its contract negotiations if it chooses to do so.

Large employer groups such as Verizon are also active in this arena. The National Business Group on Health (2003) recently published a working paper outlining why collection of race/ethnicity data is in the business interest of its members and suggests some strategies for discussing the issue with plans.

But purchasing power is not solely the domain of employers. A health plan may wish to differentially steer patients to hospitals or clinics that take the step of collecting and analyzing their quality data for different race/ethnic groups, have few disparities in care or provide culturally appropriate care.

Given the extremely low rates at which the public currently uses information about quality of care for purchasing, it is not clear whether such arrangements would be attractive to patients. However, they might be important for plans if they produce better outcomes, and they may well be of greater interest to employers—both public and private—with large minority workforces. These employers in particular, along with CMS, may wish to make particular efforts to engage individuals from racial/ethnic minority groups in making purchasing decisions based on information on quality of care for minority populations.

Risk Adjustment

The uneven distribution of wealth in the U.S. means that, with few exceptions, racial/ethnic minority populations in this country are poorer, less well educated and have a higher burden of illness. Hence, many in the research community have advocated controlling for some measure of socioeconomic position when examining and explaining differences in quality of care. This may be particularly important in disentangling the relative contributions of various factors to poor health. From the perspective of measuring, acting on and reporting on disparities in care, the role of risk adjustment is more complicated. Routine risk adjustments for socioeconomic position could inadvertently mask differences between populations that may be important considerations in developing interventions. For example, identifying lower income or more poorly educated subpopulations may be important in the design of effective disease management strategies (Rothman and Dewalt 2004).

Finally, as we contemplate progression to the point of public reporting about disparities or to pay-for-performance initiatives that take disparities into account, it will be important for plans with more socioeconomically disadvantaged minority populations not to be unfairly penalized. Unless such a system to ensure fairness in payments is developed, cream skimming for socioeconomically advantaged minority populations is likely to occur.

Misuse of Racial/Ethnic Data

Two categories of concern about the misuse of racial/ethnic data merit discussion here. The first category is the use of data for redlining or for premium or product adjustments. Redlining is the practice of excluding a community or purchasing group from coverage because they represent a high risk or are otherwise undesirable. Although such practices are technically illegal, it seems difficult to imagine that additional data would not serve to make the results of such practices more transparent, and would hence serve as a deterrent. A

second category of concern to those contemplating data collection is whether it increases their exposure to legal action. Although a discussion of the legal issues surrounding data collection is beyond the scope of this paper, several groups have concluded that the collection of race/ethnic data per se is not illegal.

LOOKING AHEAD

The demographics of America are changing rapidly and the number of multiracial, multicultural families and children will grow. It is too soon to know whether and when this trend will counteract the forces that lead to current racial and ethnic disparities in health care. At the same time, it is likely that America will always be home to new immigrants, who may continue to face challenges in using the health care system. Despite continuing uncertainties surrounding collection and use of race/ethnicity data, it is clear that delaying action on the collection and use of racial and ethnic data within the health care system will only guarantee that opportunities to improve quality of care and eliminate racial and ethnic disparities in that care will continue to be missed.

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