NQF

THE NATIONAL QUALITY FORUM

Improving Healthcare Quality for Minority Patients

WORKSHOP
PROCEEDINGS

THE NATIONAL QUALITY FORUM

Foreword

Approximately 30 percent of Americans are racial or ethnic minorities, and even greater diversity of the U.S. population is expected in the future. Given this, the now well-documented disparities in healthcare access, healthcare quality and health outcomes seen across ethnic and racial populations in the United States is disturbing—especially since these disparities persist even when socioeconomic factors are considered.

This document reports the proceedings of a National Quality Forum workshop convened to identify strategies that would improve healthcare quality for minority populations. Ten specific recommendations for identifying and implementing measurement and reporting strategies emerged from the workshop's deliberations. If adopted, these recommendations hold great promise for significantly improving the healthcare quality provided to minority patients.

America needs to improve healthcare quality overall by implementing systematic and coordinated methods of measuring and reporting quality, but in doing so special attention needs to be directed to addressing the disparities that exist for racial and ethnic minorities. Healthcare quality in the United States must rise to both a higher and a more equitable level than currently exists.

We thank the Commonwealth Fund for its support of this workshop and for its exceptional commitment to improve healthcare quality for minority patients. We also thank the Workgroup participants and the many other individuals who contributed to the success of this effort.

Kenneth W. Kizer, MD, MPH
President and Chief Executive Officer

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Improving Healthcare Quality for Minority Patients

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Executive Summary

Over the past two decades, the quality of U.S. healthcare has come under increasing scrutiny. Substantial problems of overuse, underuse, and misuse of medical care have been found. A large body of evidence has accumulated that documents that the quality of healthcare for minority patients is often worse than care for non-minority patients.[29] In addition to highlighting the socioeconomic obstacles that frequently hinder minority patients' access to care, research also consistently reveals the disturbing finding that race and ethnicity are independently associated with poorer quality healthcare and worse health outcomes.

To explore how measurement and reporting strategies can be used to improve healthcare quality for minority patients, the National Quality Forum (NQF) held a workshop in June 2001. Under a grant provided by the Commonwealth Fund, the NQF convened a group of experts from minority consumer, advocacy, and community-based groups; academic, clinical, and research institutions; and policymaking and government agencies.

The Workgroup considered a number of specific issues involving healthcare quality and measurement and racial and ethnic minorities, framed within the following over-arching questions:

- Can existing, commonly used healthcare quality measures appropriately address the needs of minority patients, or are new measures needed to more accurately evaluate minority healthcare quality?
- What unique challenges are involved in reporting healthcare quality information to minority consumers?

The Workgroup concluded that better measurement and reporting are essential to improve healthcare quality for minority patients. The Workgroup recommended ten priority actions that should be taken to improve the quality of healthcare for minority patients. These strategies should become priorities for policymakers, regulators, researchers, healthcare delivery organizations, and all other groups involved in healthcare quality measurement and reporting:

1. National and local healthcare quality movements should adopt the specific goal of eliminating disparities in healthcare quality among racial and ethnic minorities.
2. Existing performance measure sets should be analyzed to better understand the state of minority healthcare quality disparities. They also should be refined to reflect the healthcare priorities of minority populations.
3. The development of new healthcare performance measures should focus on areas in which racial and ethnic minorities bear a disproportionate burden of disease or poor healthcare quality. Quality measurement organizations should consider adopting these measures as part of their general quality measurement strategy.
4. A standardized core set of performance measures based on cross-cutting quality issues that is broadly applicable across all healthcare settings should be adopted.
5. Healthcare quality standards should be established around population-based goals and should take into account the influence of patient characteristics on measure performance.
6. The federal government should support, sponsor, and sustain a long-term agenda to improve healthcare quality for minority populations through research that targets disparity-reduction strategies that have been proven to be effective and that can be broadly applied.
7. Federal policies should specifically promote standardized classification and collection of race and ethnicity data in healthcare settings.
8. Support and awareness should be built to improve race and ethnicity data collection practices in quality measurement efforts among healthcare organizations and the public.
9. Broad-based, inclusive strategies should be developed for engaging the disparate consumer audiences central to the drive for healthcare quality improvement.
10. Community-based intermediaries should be utilized to develop and disseminate healthcare quality information to minority consumers.

These recommendations are not the result of the NQF's formal consensus development process. Rather the NQF will utilize these recommendations to guide its strategy for endorsing national healthcare quality measurement and reporting standards so that these standards are sensitive to the needs of racial and ethnic minority patients and address the disparities in healthcare that they experience.

Existing efforts to improve healthcare quality throughout the U.S. system are particularly relevant to minority patients because of the disparities in care that they currently receive; the Workgroup's recommendations should enhance these efforts. Current quality measures can and should be leveraged to monitor and reduce the disparities in healthcare processes that lead to worse healthcare outcomes for minority populations. Moreover, since many of the healthcare quality-related problems faced by minority patients also occur for non-minority patients, the Workgroup recommendations have implications for all who are interested in achieving better healthcare quality.

Improving Healthcare Quality for Minority Patients

Introduction

In recent years, it has become acutely evident that the U.S. healthcare system is not providing the quality of care that it can and should offer to all patients. During the past two decades, various healthcare quality initiatives have been launched to address these pervasive problems, but healthcare quality has not progressed to where it should be despite these initiatives and the good work of many dedicated persons and organizations. This finding has been clearly reported in three independently conducted critical reviews of the state of U.S. healthcare quality published in 1998 by investigators at RAND,[1] the Institute of Medicine's National Roundtable on Healthcare Quality,[2] and the President's Advisory Commission on Consumer Protection and Quality in the Health Care Industry.[3]

That poor quality is widespread is only one of the critical issues involving healthcare quality that must be addressed. Unfortunately, those seeking to improve quality are often faced with more questions than answers because of a lack of sufficient information about healthcare quality in this country. To ensure that quality improvement strategies are targeted toward areas of need, healthcare quality performance measures are needed to determine whether, where, and to what degree specific problems exist.

According to the President's Advisory Commission, the lack of consistent quality measures and reporting standards has been a major barrier to wider use of such measures, especially by purchasers and consumers.[3] The Commission concluded that the existence of uniform reporting standards would increase the use of quality measurement, reduce its potential burden, facilitate the compilation of comparative information about healthcare quality, and stimulate quality improvement efforts.

Recognized even longer than the fact that the U.S. healthcare system suffers significant quality deficiencies is the irrefutable finding that disparities persist in the services delivered to racial and ethnic minority patients throughout the healthcare system. Equally clear is the fact that these disparities can lead to adverse outcomes for racial and ethnic minority patients, including disproportionate levels of discomfort, disability, and death. The President's Advisory Commission noted the importance of focusing attention on these disparities in "vulnerable populations," as defined by race, ethnicity, income level, disability, and gender.[3]

Even when socioeconomic and related factors are taken into account, minority patients with access to healthcare services still experience inferior care when compared to their non-minority counterparts.[4,5,6] For example, African Americans with colorectal cancer are treated less aggressively than Caucasians of similar socioeconomic status.[7] Differences in receiving specialty cardiovascular care among African Americans, Hispanics/Latinos, Asians, and Caucasians—even after adjusting for medical need—are also well documented.[8,9,28] Furthermore, minority Americans with mental illness are less likely than Caucasians to seek psychiatric care. Moreover, when they do seek care, they are more likely to be misdiagnosed or to receive inappropriate treatment.[10]

Poor quality of care for minority populations is not limited to acute care and can be unsettlingly subtle. For example, it has been documented that African American and Hispanic patients receiving palliative care in New York City were less able than Caucasian patients to obtain prescribed medication for pain management because pharmacies in their communities did not have, or had insufficient supplies of, opioid analgesics.[11] Findings such as these are deeply troubling, as they reveal the pervasiveness of quality disparities throughout the U.S. healthcare delivery system.

Although minority and non-minority patients face many of the same health challenges, the socio-cultural and environmental conditions that contribute to poor health disproportionately affect minority populations. Consequently, disparities in healthcare quality for minorities may have a greater adverse impact than the same quality defects in the general U.S. population. Identifying where and what kinds of interventions are needed to ease the unequal burden of poor healthcare quality on racial and ethnic minority patients is key. As such, the development of measurement and reporting strategies that can evaluate and report the quality of care in minority populations in a relevant, meaningful, and actionable manner is a critical first step.

Workshop Overview

The National Quality Forum (NQF), a private, nonprofit, open membership, public benefit corporation, was established in 1999 to, among other things, develop uniform measures and reporting mechanisms that would facilitate healthcare quality improvement and further the implementation of healthcare quality measurement throughout the private and public sectors. With a grant from the Commonwealth Fund, the NQF held a workshop in Arlington, Virginia, on June 28-29, 2001, to discuss key issues pertaining to disparities in minority healthcare in general and issues specifically involving the role of healthcare measurement and reporting in advancing quality improvement efforts for minority patients.

Purpose

The workshop was designed to explore the state of minority healthcare quality measurement, the application of existing and proposed measurements for identifying and reducing minority healthcare quality disparities, and strategies for effectively reporting healthcare information to minority consumers. Specifically, the workshop sought to address the following questions:

- Are existing, commonly used healthcare quality measures appropriate and adequate for minority populations? Are they being utilized to monitor healthcare quality in minority patients and, if not, what are the obstacles that are preventing such utilization?
- Are measures available that can or should be used to assess the quality of healthcare specifically for minority patients? Are or should there be metrics to specifically track such differences?
- What are the issues, barriers, and solutions to collecting appropriate and valid healthcare quality data for minority populations?
- Are the existing mechanisms to report healthcare quality to American consumers equally, more, or less effective for minority populations than for non-minority populations? What special challenges arise in efforts to communicate information about healthcare quality to minority populations? What solutions exist?

NQF Workgroup on Minority Healthcare Quality Measurement and Reporting

A diverse panel of individuals knowledgeable about healthcare quality measurement, consumer reporting, minority health, and racial and ethnic healthcare disparities was convened to address these complex questions, forming the NQF Workgroup on

Minority Healthcare Quality Measurement and Reporting ("the Workgroup") (appendix A). Workgroup representation included a broad range of healthcare stakeholders—consumer and community groups, academic and research institutions, health plans and healthcare provider organizations, and government agencies. The meeting also was open to individuals from NQF member organizations and the general public, and all who attended were given the opportunity to comment on the Workgroup's deliberations at multiple points throughout the workshop.

To provide a general framework for the Workgroup's discussion, the NQF commissioned experts to prepare three background papers that analyzed racial and ethnic disparities in health and healthcare, the state of healthcare quality measurement and reporting for minority populations, and communication of healthcare quality information to minority patients:

- *Kevin Fiscella, MD, MPH,* "Using Existing Measures to Monitor Minority Healthcare Quality" (appendix B). Dr. Fiscella reviewed information about minority health and the scope of healthcare disparities, specifically addressing the question of whether existing, commonly used healthcare quality measures are appropriate for assessing minority populations.
- *David R. Nerenz, PhD,* "Quality of Care Measures of Special Significance to Minority Populations" (appendix C). Dr. Nerenz explored existing quality measures that are relevant to healthcare needs unique to or disproportionately affecting minority populations. He also outlined logistical challenges, such as race and ethnicity data collection, that stand in the way of effectively quantifying the extent of minority healthcare disparities.
- *Christine Molnar, MSPH,* "Reporting Healthcare Quality to Minority Populations: Issues and Challenges" (appendix D). Ms. Molnar provided an analysis of the characteristics, needs, and expectations of minority patients and communities that affect their use of healthcare quality information and create special barriers to effective consumer reporting. She also proposed strategies to improve the delivery of useful information to minority consumers.

Key Issues and Recommendations

Workgroup members explored key issues and set forth a series of recommendations that are designed to alert healthcare facilities, quality/performance measure development and implementation groups, researchers, consumers, and policymakers to the many problems concerning healthcare quality for minority patients. The Workgroup identified several themes, as discussed further below, and also made specific recommendations that all stakeholders should deploy to reduce such disparities through measurement and reporting strategies that are relevant, appropriate, and adequate for addressing the healthcare needs of minority patients.

It is important to note that these workshop proceedings and the resulting recommendations are not the result of the NQF's formal consensus development process, as other NQF recommendations may be. They serve as a starting point for developing a consensus on how to approach the development of strategies that better address minority healthcare quality.

The National Quality Movement

The need for substantial improvement in healthcare quality has become increasingly visible in recent years, giving rise to a nascent national quality movement. This emerging movement opens the door to a promising opportunity to address minority healthcare disparities as part of the general healthcare quality problem. In fact, efforts to eliminate minority healthcare quality disparities must move in concert with the national quality movement or risk becoming marginalized. It also must be recognized that the existence of disparities in minority healthcare quality is itself inconsistent with the very concept of quality. Just as geographic variation in medical treatment is widely acknowledged as an indicator of possible quality problems, variation based on race or ethnicity likewise deserves close scrutiny.

Efforts to improve healthcare quality must be aimed at not only reducing medical errors and improving patient safety, but also at ensuring equitable treatment for all. In fact, a recent Institute of Medicine report named equitable care as one of six aims that healthcare organizations must undertake in order to fill the U.S. healthcare quality chasm.[12]

Nearly one in three Americans belongs to a racial or ethnic minority group.[13] Thus, healthcare quality measurement and reporting strategies that do not address the health needs of minority patients neglect a significant and growing portion of the U.S. population. The consequences of this neglect are further exacerbated by the fact that minorities often shoulder a disproportionate share of poor healthcare quality even when they have access to the healthcare system. In addition, disparities in healthcare quality for minority patients reflect the existence of underlying quality problems for all Americans. This inextricable link is evidence that more equitable care is required to improve healthcare quality nationwide.

RECOMMENDATION 1: National and local healthcare quality movements should adopt the specific goal of eliminating disparities in healthcare quality among racial and ethnic minorities. Engage national and state-level stakeholders from both private sector and government organizations, especially those already involved in quality measurement and reporting, to adopt the elimination of minority healthcare disparities as part of their overall missions. Use the current interest and momentum in general quality improvement to drive the elimination of racial and ethnic minority healthcare disparities.

The State of Minority Healthcare Quality Measurement

A key product of the quality movement has been the development and implementation of measurement systems. Some of these key measure sets include:

- *Centers for Medicare and Medicaid Services' (CMS) Quality Improvement Organization (QIO) measures.* State-based organizations—formerly referred to as Peer Review Organizations, or PROs—collect clinical quality measures from hospitals participating in Medicare for high-priority conditions such as acute myocardial infarction, congestive heart failure, and pneumonia. The QIO findings are used to drive quality improvement, but the results are legally protected from public disclosure.
- *Joint Commission on Accreditation of Healthcare Organizations' (JCAHO) ORYX core measures.* These measures are similar to the QIO measures, although they are not limited to Medicare patients. The ORYX core measures are currently undergoing evaluation and testing for future incorporation into the JCAHO accreditation process; this will affect healthcare organizations nationwide.
- *National Committee for Quality Assurance (NCQA) Health Plan Employer Data and Information Set (HEDIS).* Health plans seeking accreditation through NCQA must provide information related to access and availability of services, provider qualifications, health maintenance, recovery from illness, and chronic disease management. HEDIS also includes a consumer survey-based tool, the Consumer Assessment of Health Plans Survey (CAHPS).

Government agencies and private sector accreditation organizations seeking to improve performance have implemented measurement systems such as those noted above. It is clear that because the wide reach of these measures across the healthcare system makes them important indicators of U.S. healthcare quality, their usefulness in assessing minority healthcare needs as a component of overall healthcare quality is key. What is not clear is whether these influential measures include conditions frequently or disproportionately affecting minority populations or whether the specific measures accurately identify where disparities occur in the delivery of healthcare services.

In general, the Workgroup agreed that these common measure sets were relevant to minorities, at least in the sense that they address conditions important to them. In fact, the high-priority conditions that form the basis for the QIO, JCAHO, and NCQA measure sets are generally the same for minority and non-minority patients. These conditions include cancer screening and management, cardiovascular disease, cerebrovascular disease, chronic diseases, immunization, and maternal and newborn care.

There are, however, conditions for which minorities experience an unequal burden of morbidity or mortality that are not commonly measured. For example, HIV/AIDS is a major cause of death for African Americans and Hispanics/Latinos. The death rate for African American men with HIV/AIDS is six times that of the general population.[14] However, the quality of care for HIV/AIDS is not monitored in the QIO, JCAHO, or NCQA measure sets. Other key clinical areas for minority patients identified by the Workgroup include hepatitis, infant mortality, liver cancer, mental illness, organ transplantation, sickle cell disease, tuberculosis, and trauma.

Overall health is predicated on multiple biological, psychological, behavioral, and social factors that the provision of healthcare services has a limited capacity to influence. This becomes particularly significant when it is recognized that public health challenges that disproportionately affect minority patients (e.g., alcoholism, obesity, suicide, violence) typically involve social and other nonclinical aspects of healthcare.

Using measures that evaluate efforts to change modifiable risk factors is one potential strategy for addressing minority healthcare quality needs within a public health framework, especially in areas in which healthcare organizations can reasonably be held accountable. For example, the Foundation for Accountability (FACCT) has developed quality measures for alcohol misuse screening and counseling to address the alcoholism epidemic in American Indians. Several of the common measure sets evaluate smoking cessation counseling rates, and the expansion of these sets to include more modifiable risk factors that are common in minority patients would be especially useful.

Common measure sets also fall short when they fail to recognize the points during the care process at which disparities occur. For example, QIOs measure whether heart attack patients were prescribed beta-blocker medications upon hospital discharge. But, even when they receive the proper prescriptions, minority patients may be less likely to fill them or appropriately use the medications, since they are less likely than non-minority patients to have insurance and are often less able to afford the out-of-pocket costs.

Another example is breast cancer screening, a HEDIS measure. Workgroup members pointed out that even though a health plan may perform well on the screening measure, minority patients are less likely to receive adequate treatment following abnormal mammography results, resulting in poorer overall breast cancer survival rates. Thus, although a breast cancer measure is relevant to minorities because of its high disease prevalence, the screening measure returns deceptively encouraging results because it fails to account for processes that are closely linked to poor health outcomes in minorities. The process-outcome links that generally make measures such as these valid indicators of quality are sometimes more weakly associated in minority patients, which suggests the need to re-examine these links in the context of minority patients' needs.

Given their broad reach across the healthcare system, current performance measurement sets are potentially powerful tools for analyzing minority healthcare quality. Regrettably, simply utilizing these sets does not mean they are achieving their full potential for assessing disparities so that care and outcomes can be improved for minority patients. To help address this problem, the CMS Disadvantaged Area Support PRO[15,16] is analyzing the QIO measures for disparities. However, much more work must be initiated in other areas. From the provider/hospital to the health plan level (managed care organizations, fee-for-service plans, etc.), tremendous opportunities are available for collecting information regarding how and why minority patients persistently experience disparities within the U.S. healthcare system. Moreover, the wholesale revision or *de novo* development of new measurement sets, new measures, or new research may not be necessary for interim improvement efforts. Implementing a number of immediate, short-term steps that make better use of existing tools could more quickly improve the state of minority healthcare quality measurement.

RECOMMENDATION 2: Existing performance measure sets should be analyzed to better understand the state of minority healthcare quality disparities. They also should be refined to reflect the healthcare priorities of minority populations. Call upon organizations with wide reach in the area of measurement, e.g., CMS, JCAHO, and NCQA, to analyze their measures by race and ethnicity in order to pinpoint disparities in patterns of care and specifically identify key leverage points for improving healthcare processes to reduce such disparities. Refine measures to validly and accurately assess quality in the context of racial and ethnic minority patients' healthcare needs.

New Measure Development

Although short-term steps are important, they will not eliminate racial and ethnic healthcare quality disparities. A comprehensive framework for minority healthcare quality improvement also requires the development of long-term strategies that will expand upon the measures now used to evaluate quality and that will address the many conditions important to minorities.

Indeed, new measures should be developed with minority patients' healthcare needs as a priority. By and large, these measures also would be applicable to non-minority patients and could therefore be integrated into the broader measure sets that are applied to the general population. In fact, isolating new, minority-specific measures from the mainstream measure sets would make successful implementation of any new measures unlikely and would also undermine efforts to unify the general and minority healthcare quality movements.

Finally, efforts to develop and/or adopt standardized measure sets for specific healthcare settings (e.g., primary, subspecialty, hospital, or long-term care), such as the NQF's 'Hospital Performance Measures' project to standardize a core set of acute care hospital measures, should place priority on developing and using measures that relate to areas in which racial and ethnic disparities are pervasive in disease burden and/or healthcare quality.

RECOMMENDATION 3: The development of new healthcare performance measures should focus on areas in which racial and ethnic minorities bear a disproportionate burden of disease or poor healthcare quality. Quality measurement organizations should consider adopting these measures as part of their general quality measurement strategy. Identify key minority healthcare needs, placing priority on areas that are not now adequately measured. Standardized measure sets for specific healthcare settings should give priority to measures in areas in which minority disparities exist in disease burden and/or healthcare quality. Develop and/or adopt and implement new quality measures for the entire population, expanding when possible on existing minority-relevant measures that are not yet included in widely deployed measure sets.

Moving Beyond Traditional Clinical Quality: Cross-Cutting Measures of Quality

Most major healthcare quality measures are clinically oriented and based on a small set of major health conditions.[17] Their widespread application makes these condition-specific measures a useful starting point for identifying minority healthcare disparities, but clinical measures are often incomprehensible to the average healthcare consumer, regardless of race or ethnicity. For example, information on the percentage of patients who received beta-blocker medications for acute myocardial infarction has relatively little bearing within a consumer's decisionmaking framework. Workgroup members noted that both minority and nonminority consumers want information on cross-cutting areas related to satisfaction and experience with care. However, a gap exists between the nature of what is currently being measured in healthcare and what consumers want to know.

Cross-cutting measures of quality can provide salient information about the continuum of care for consumers. Unlike many traditional clinical measures, cross-cutting measures evaluate aspects of care that are not necessarily limited to a specific clinical condition or a unique point in the care process. Instead, they are common across the spectrum of care. The adequacy of pain management, for example, is of central concern to all patients, whether the pain is related to emergency room trauma care or end-of-life cancer care. Cross-cutting measures spark consumer interest in healthcare quality information because they are patient-centered and provide a more complete picture of quality across the care process.

In addition to general consumer satisfaction and experience with care measures, key examples of cross-cutting measures with particular relevance to minority patients include those related to the availability of social support services, the effectiveness of pain management, the process of informed decisionmaking, and the level of cultural competence among providers. For minority patients, cultural competency measures could call attention to the need for medical translators, who could help non-English-speaking patients communicate more effectively with physicians and other care providers.

For healthcare safety net facilities, where the majority of the patients are often racial and ethnic minorities, cross-cutting measures can more effectively target the services that their patients consider important. And given their economically under-privileged patient base, safety net hospitals often focus more than other hospitals on coordination and follow up of services across the continuum of care. For example, a cross-cutting measure related to how patients perceive the adequacy of pain management treatment might show that minority patients at a safety net hospital had better outcomes than those at non-safety net hospitals because they were given the pain medication itself instead of a prescription. In comparison, a parallel process-based measure might ask whether the patient was prescribed the pain medication without asking whether the patient was able to fill the prescription.

The FACCT measures are based in part on questions about patient experiences that look across multiple aspects of the care process. CAHPS, part of the HEDIS measurement tool, also uses a broad-based approach to evaluate consumer experience with health plans. This survey-based measurement tool for assessing consumer satisfaction also can be administered in multiple languages, including Spanish. Both measurement sets are widely used in the United States.

Efforts to further expand the application of such cross-cutting measures within standardized measurement tools, particularly for hospitals and other healthcare facilities, would make public healthcare quality information more valuable to patients by providing a bridge between condition-specific clinical measures and the interests of the U.S. healthcare consumer.

RECOMMENDATION 4: A standardized core set of performance measures based on cross-cutting quality issues that is broadly applicable across all healthcare settings should be adopted. Ensure that standardized quality measures begin with a core set that addresses cross-cutting issues relevant to all patients (e.g., pain management), but that also places priority on minority-specific needs such as cultural competence. Ensure that these measures are applicable across the continuum of care and in multiple healthcare settings.

Setting the Mark for Quality

In most clinical studies, disparities are generally identified by comparing performance levels for racial and ethnic minority patients to those for Caucasians. This is a useful strategy for highlighting differences in the quality of healthcare received by Caucasian patients versus minority patients; however, care must be taken to ensure that this method does not implicitly define the level of performance for Caucasian patients as the ideal standard of care. Even for Caucasian patients, healthcare quality often falls short of desirable levels.

Thus, rather than comparing quality of care for one population against another population, standards of care should be identified that “raise all boats” to an ideal level, benchmarking against a population-based target and not a specific portion of the population. Such an approach would be analogous to the nationwide “Healthy People 2010” strategy. Furthermore, statistical indicators of dispersion would help operationalize the concept of "raising all boats;" they would permit the identification of what constitutes "good quality" for healthcare providers, health plans, and organizations that demonstrate high performance and low variation for appropriate care, especially variation tied to racial or ethnic characteristics.

Population-based quality standards and the interpretation of racial and ethnic disparities in healthcare using those standards must, however, remain sensitive to any differences between racial and ethnic groups that may affect the relevance of certain standard processes of care. For example, if a population benchmark Cesarean section (C-section) rate were set and African Americans were found to have higher C-section rates than the benchmark rate, the disparity might actually represent more culturally appropriate care, because African American women are diagnosed with complications of pregnancy (due to a variety of factors) that would call for C-sections relatively more frequently than the general population of women.[18] In such cases, measure design and/or performance goals must take into account the influence of patient characteristics on the appropriateness of treatment.

RECOMMENDATION 5: Healthcare quality standards should be established around population-based goals and should take into account the influence of patient characteristics on measure performance. "Raise all boats" to a desired level of performance for the general population, remaining sensitive to any variation in patient characteristics that may differentially affect appropriate performance on a measure. Set overall quality standards for all patients instead of simply defining quality according to the relative performance between minorities and non-minorities.

Improving the Evidence Base

In some circumstances, biological differences associated with race or ethnicity may influence the effectiveness of standard treatment regimes for common conditions. For example, African Americans are slightly less likely to respond to treatment with beta-blocker or warfarin medications due to the somewhat lower prevalence of the drug's required biochemical receptors among this group.[19] Drug trials that establish the efficacy of such medications often do not include large enough numbers of minority participants for racial and ethnic differences to appear statistically significant.[20] Although these findings should not encourage physicians to withhold beta blockers in minorities, as they are still more effective than other treatments, further research in other areas where the differences in drug efficacy are clinically significant may be useful.[21]

While developing consensus and standard practice guidelines for the general population is difficult enough based on available evidence, far less evidence on clinically meaningful race- and ethnicity-based response differences for specific treatments is available; more research is needed before accepted practice standards can be modified.[21] Traditionally, minority healthcare research has focused on identifying where disparities occur in healthcare processes and health outcomes—an important starting point, as better measures require better evidence. Yet while the body of disparities research is substantial, without explicit efforts to identify the underlying mechanisms that contribute to them, it is not clear how useful the results will be for improving minority healthcare quality or for supporting better quality measures. Far more work is needed in areas that can directly improve the relevance of common quality measures for minorities.

In addition to expanding upon studies of differential clinical responses to standard treatment regimes, interventions to reduce disparities should be initiated through both health services research and local, community, or hospital-based initiatives. Work in these critical areas is expanding with the support of private foundations and federal programs such as the Agency for Healthcare Research and Quality's (AHRQ) Excellence Centers to Eliminate Ethnic/Racial Disparities (EXCEED) program, or the Centers for Disease Control and Prevention's Racial and Ethnic Approaches to Community Health (REACH) initiative. Continuing to promote a research agenda for public and private agencies that will emphasize ways to effectively reduce health and healthcare quality disparities, particularly through healthcare system interventions, is an essential first step to developing improved measures that address minority healthcare quality inequities.

> **RECOMMENDATION 6: The federal government should support, sponsor, and sustain a long-term agenda to improve healthcare quality for minority populations through research that targets disparity-reduction strategies that have been proven to be effective and that can be broadly applied.** Encourage public and private sector organizations to join the government in funding research in areas that lead to the development of better minority healthcare measures. Examine areas such as differential effectiveness of common treatments for various racial and ethnic groups; broadly apply interventions to decrease disparities that have worked at the facility, community, or regional level; and identify the points at which disparities occur in the process of care. Focus new disparities research on examining

previously unexplored areas for which the paths to developing interventions are clear, or focus on identifying the underlying, process-based mechanisms for these disparities.

Although this is a long-term research agenda, short-term improvement of minority-sensitive measures is also important and should make use of information that is available regarding areas where disparities have been documented and where the gaps are still large. Moving beyond known areas where disparities occur to find additional areas of need will become an important part of the longer-term process. In addition, it is important to assess all quality measures to discern patterns of racial and ethnic variability that will help identify both where healthcare quality disparities persist and where they have been eliminated.

Challenges in Analyzing Disparities

Simply put, effective minority healthcare quality measurement requires a set of well-developed measures that target the right conditions, provider-specific performance data on those measures, and race and ethnicity data. Data on race and ethnicity are critical for improving the health of minority patients as well as the healthcare services they receive. Such data allow healthcare organizations and health plans to assess and prioritize how they distribute their resources, given the varying needs of the populations they serve.[22] Although a large volume of healthcare quality data is available, the information sources are not centralized, and the analysis of minority healthcare patterns is complex. Furthermore, attempting to obtain sufficient information on race and ethnicity to track disparities gives rise to a series of obstacles that have yet to be fully overcome.

Lack of Standardized Racial and Ethnic Categories

One barrier to the collection of race and ethnicity data is the lack of consensus on a single data format. The 1997 Office of Management and Budget (OMB) revised guidelines for collecting federal data on race and ethnicity call for the following minimum categories: White; Black or African American;

Hispanic or Latino; American Indian or Alaska Native; Asian; Native Hawaiian or Other Pacific Islander.[23]

Although federal guidelines often are considered the standard for racial and ethnic classification, some criticism remains regarding the adequacy of the current scheme. For example, the OMB guidelines set only a minimum standard for race and ethnicity data. Although OMB allows for the use of racial and ethnic subgroups in data collection, the agency does not standardize these subgroup categories. Also, federal policies regarding the collection of race and ethnicity data are still widely inconsistent among agencies.[24]

Census 2000 expanded on the broad federal categories by further specifying subpopulations within the major racial and ethnic categories (e.g., the Hispanic or Latino group was subclassified as Mexican, Puerto Rican, Cuban, etc.), an approach that recognizes the intragroup heterogeneity within the broad federal classifications.

Concerns have been raised over the adequacy of this subpopulation classification scheme as well as the usefulness of its data. Yet subgroup data, even with their limitations, can still be quite valuable. For example, clinical studies with sufficient sample sizes to provide statistically significant results for racial and ethnic subgroups generally provide results for geographic areas that are too large to be useful for consumers who make decisions about healthcare at the local level. Still, patterns of care for specific racial and ethnic subgroups at the state or national levels is at least useful to policymakers, if not consumers. Subgroup data indicating general performance trends also is useful for internal, facility-specific analyses. For example, because some hospitals' market areas include large concentrations of specific minority subgroups, statistical analyses on the quality of care for these populations may be feasible at the facility level.

Forgoing the collection of subgroup data would limit analyses to broad racial and ethnic categories, with the potential loss of valuable information on subgroup disparities—information that disappears when aggregated to broad levels. For example, Hispanic/Latino women have infant mortality rates similar to those of Non-Hispanic Caucasian women (8.5 and 8.3 per 1,000 births, respectively). However, Puerto Rican women, a subgroup of Hispanic/Latino women, have a higher mortality rate (10.9 percent), which is balanced within the general Hispanic/Latino group by the lower rates for Cuban and Central/South American women (7.6 and 7.8 percent, respectively).[25] Only when the broad Hispanic/Latino ethnic group is stratified by subgroups are these disparities revealed. Subgroup data are easily aggregated into major racial and ethnic groups if necessary to show statistical significance, but subgroup analyses are impossible if only data on broader groups are collected.

The "Small Numbers" Problem

As noted above, small sample sizes can create problems in the statistical analysis of quality measurement results for minority patients. On a national scale, analyzing disparities is generally feasible even within racial and ethnic subgroups. However, the analysis of a smaller health plan, single facility, or provider can present challenges when attempting to compare even the largest minority group within that area to the general population. This results in a catch-22, because healthcare consumers generally place a higher value on information about local facilities, providers, and plans when making healthcare decisions.

The usefulness of cross-cutting measures re-emerges in this context because such measures are not restricted to individual conditions for which minority sample sizes may be small. For example, the numbers of minority patients with diabetes at individual hospitals in an area may be too small for meaningful hospital-to-hospital comparisons of the quality of diabetes care for minority patients. Data on cross-cutting measures, however, can be collected over multiple conditions to produce statistically meaningful results where data from condition-specific measures could not.

In other words, the small sample size issue with minority patients may only allow for detection of statistically significant differences that are very large. However, even when sample sizes in minority healthcare quality measurement are small, there is value in collecting these data. Such data can elucidate areas that are likely to have the greatest opportunity for quality of care improvement for minority patients and clearly justify measurement and reporting initiatives that are likely to have high relative impact in minority populations. Focusing first on areas where disparities are the greatest, rather than on very small gaps in performance and quality, will produce more noticeable results.

Standardizing the Point of Data Collection

The two general healthcare settings for which it is clear that race and ethnicity data can be collected are healthcare facilities and health plans. Race and ethnicity data collected from healthcare facilities can be, and often are, collected when a patient registers for care or during a physician-patient encounter. Such data gathering occurs along with, and in the context of, questions about other standard patient information (although this may not be done consistently or adequately). Members of the Workgroup agreed that while healthcare facilities should be encouraged to ask patients for their racial and ethnic status to ensure that patient preferences are respected, providing this information should be optional. In addition, individuals also should be allowed to self-identify their race and/or ethnicity, so as to minimize the potential for misclassification (which frequently occurs in American Indian and some Asian/Pacific Islander subgroups).[26]

Healthcare facilities may face fewer obstacles than health plans in obtaining race and ethnicity data from patients. However, no clear consensus emerged from the Workgroup regarding how and when health plans should collect race and ethnicity data. Public concerns can play a large role in deterring the collection of race and ethnicity data, given the public's general distrust of managed care organizations. For example, if the data were collected at the point of health plan enrollment, minority patients might fear they would be denied coverage based on race or ethnicity, although the extent to which health plans could or would actually engage in such a practice is unclear. Collecting race and ethnicity data after enrollment would presumably reduce the ability of health plans to discriminate; however, one Workgroup member pointed out that Harvard Pilgrim Health Care's attempt to collect race and ethnicity data after enrollment resulted in a dismal response rate.

An alternate strategy for analyzing disparities at the health plan level that avoids the enrollment versus post-enrollment data collection debate would be to use state-based data on payer information to determine whether membership in specific health plans is a significant predictor of minority healthcare quality disparities. One Workgroup member noted that this strategy was employed in Massachusetts. The extent to which this is possible, however, depends on the adequacy and design of other states' databases.

The questions of if, when, and where health plans can optimally collect race and ethnicity data remain unresolved. What is clear, however, is that the continuing lack of these data will preclude analysis of health plan disparities that could be very useful for quality improvement.

RECOMMENDATION 7: Federal policies should specifically promote standardized classification and collection of race and ethnicity data in healthcare settings.* Develop consensus around a single, standard classification scheme for race and ethnicity that expands upon the OMB census categories by further specifying minority subpopulations. Encourage hospitals to request race and ethnicity data from patients, allowing individuals to provide information regarding their race and ethnicity themselves or to opt out of providing this information. Pilot test race and ethnicity data collection in a variety of healthcare settings (e.g., pre- or post-health plan enrollment) to determine where and when data collection is most feasible and effective.

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*Federal policies in other sectors require standardized race and ethnicity data collection—e.g., collection of educational test scores, Census data, etc. The Workgroup did not *a priori* advocate that these methodologies be applied to healthcare. Rather, it was suggested that such methodologies should be examined to see how they apply to the healthcare sector. The development of a healthcare-specific, standardized classification scheme, and a mechanism for race and ethnicity data collection should be a federal priority.

Obtaining Race and Ethnicity Data

To know whether minority healthcare quality is improving, we must be able to measure it. Likewise, to measure disparities, we must have data on race and ethnicity. Yet these data often do not exist in a uniform, consistent, or accurate fashion that permits even routine analyses of the major measure sets. Although current mechanisms for measuring and reporting minority healthcare quality clearly leave much room for improvement, having race and ethnicity data is a prerequisite to using measures to improve healthcare quality for minority patients. Numerous databases with varying data elements are used for administrative, financial, and quality improvement purposes; some of these contain race and ethnicity data and others do not. Efforts should be made to identify key data sources and to link them when doing so can help facilitate the analysis of minority healthcare quality.

The challenges and logistics involved in collecting race and ethnicity data are tremendous and are based partly on fear of legal conflicts, which are generally unsubstantiated. Federal policy does not prohibit the collection of race and ethnicity data in the area of healthcare, and numerous federal health agencies actually have statutes that explicitly require that such data be collected and/or reported. Nevertheless, even in the absence of legal concerns, the unease about negative public reaction to collecting race and ethnicity data is understandable. Clearly, challenges such as conflicting policy messages, poor enforcement, potential high-profile and negative public reaction, and technical difficulties have undermined the effectiveness of such statutes.[24]

The Workgroup identified several barriers that deter health plans or healthcare facilities from obtaining data, including fears, misperceptions, and confusion about the legality of race and ethnicity data collection. The failure of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to include racial and ethnic data classification or collection requirements further exacerbates the problem. In California, the Racial Privacy Initiative is a ballot initiative that aims to ban the collection of race and ethnicity data, following passage of the state's affirmative action ban, although no such restriction currently exists in the state.[27]

Another major obstacle to collecting race and ethnicity data is the public's perception of how such information may be used—or misused. The Workgroup strongly supported the collection of race and ethnicity data to facilitate measurement and healthcare quality improvement for minority patients. At the same time, the Workgroup recognized that a significant number of minority patients consider collecting race and ethnicity data an invasion of privacy. A deeply held mistrust exists that healthcare entities will use the information to discriminate. Given this country's history on issues related to race and ethnicity (e.g., the infamous Tuskegee syphilis study), it is understandable that minority patients are likely to be much more reluctant than non-minority patients to provide race and ethnicity information. Minority patients likely feel that regardless of the potential importance for improving healthcare quality for minority patients, this potential benefit would not counterbalance the perception and fear that race and ethnicity data might be used to deny access to healthcare treatment or health insurance coverage.

To improve the collection of data on race and ethnicity, the fears of both the public and healthcare organizations must be addressed. Systems must be in place to protect the information from being used to discriminate in areas such as access to care or insurance coverage. Likewise, healthcare organizations need to be assured about the legality of collecting such data. Finally, an extensive outreach campaign could ameliorate to some extent the public's fear that race and ethnicity data will be misused.

> **RECOMMENDATION 8: Support and awareness should be built to improve race and ethnicity data collection practices in quality measurement efforts among healthcare organizations and the public.** Educate patients and providers about existing safeguards for the privacy and confidentiality of race and ethnicity data and strengthen those safeguards where needed. Initiate public education campaigns to reduce fear among the public by explaining that race and ethnicity data are needed to improve the quality of healthcare for minority patients. Provide healthcare organizations with information that helps clarify the legality of collecting and using race and ethnicity data, especially as it relates to the potential implications of regulatory requirements such as under HIPAA.

Ideally, all healthcare performance measures ultimately should be stratified by race and ethnicity. If this is not achievable in the near term, however, measure stratification should focus first on the high-priority conditions for minorities that exist in current measure sets so that, at a minimum, quality inequalities in major conditions are revealed. Once race and ethnicity data become routinely and consistently collected elements of the medical record, the wealth of information that can be gained about patterns of care for minority patients will far outweigh the burden of data stratification and analysis.

Motivating the Healthcare System to Reduce Disparities

Improving healthcare quality through measurement and reporting for any population is a resource-intensive effort. Without clear incentives for taking the needed steps and devising the appropriate systems, change is unlikely. Developing, implementing, and reporting on quality measures generates a significant administrative and financial burden for healthcare organizations. Thus, in the absence of new, additional regulatory requirements for the collection of race and ethnicity data to improve minority healthcare quality, healthcare organizations may require other incentives to increase reporting in order to help reduce healthcare quality disparities in minority populations.

The Data Collection Burden

Data collection, if required, should be purposeful. The data collected should be analyzed and used to enact meaningful change. Unfortunately, all too often, well-intentioned requirements for collecting and reporting data are created, but they do not include a requirement for feedback mechanisms that allow healthcare facilities to address their performance issues. Data collection requirements should be implemented only when an explicit mechanism is provided for delivering useful information back to the organizations that are providing the data.

Healthcare facilities often face more regulatory requirements for data reporting than do health plans and thus may be more resistant to the burden of additional data collection. On the other hand, it may be fair to ask whether the need to minimize quality measurement and reporting burdens on healthcare organizations is an appropriate rationale for justifying the perpetuation of healthcare quality disparities for as many as one in three Americans.

In fact, significant mechanisms are currently used to collect race and ethnicity data—or at minimum can easily be deployed to do so. Although hospital administrative data generally should include the appropriate information, too often the data are incomplete or not accurate enough to be used for meaningful analyses. For example, the AHRQ Healthcare Cost and Utilization Project databases, which contain hospital discharge data for more than half the states, has only limited utility for revealing minority disparities because race and ethnicity data provided by many states are sparse. Moreover, national analyses are limited only to four broad racial and ethnic categories: White, Black, Hispanic, and other.

Arguably, the main issue involved in requiring the collection of new data on race and ethnicity is not merely one of being sensitive to the real-world practicalities and burden of measuring and reporting healthcare quality data. Rather, the core issue is making a commitment to ensure that the collection of data is complete and appropriately conducted.

Rewarding Higher Quality Care

Incentives to improve minority healthcare quality can be generated outside the healthcare facility by non-provider groups such as CMS, health plans, or healthcare purchasers. Just as CMS can collect QIO measures from facilities participating in Medicare to evaluate healthcare quality for its beneficiaries, it can also implement measures of healthcare quality to ensure that these facilities are providing high-quality care to minorities. Employers and healthcare purchasing groups also could serve as levers to encourage health plans to reduce disparities. Entities that represent large numbers of minorities would be well served to consider the business case for minority healthcare quality in making healthcare purchasing decisions, in particular given the potential impact of poor minority healthcare quality on employee health and productivity.

An incentive-based strategy is also feasible in the commercial managed care sector, which is beginning to increase physician payments for improved performance. Rewarding through payment could occur when targets are met, and targets should be continually raised over time as performance improves. A “set aside” or “withhold payment” mechanism also could be used—i.e., some payment is withheld until an agreed-upon level of performance is achieved. Providers might be rewarded for collecting complete race and ethnicity data, demonstrating improvement in disparities in care, providing culturally sensitive services, and/or improving performance for cultural competency measures.

In this vein, mechanisms should reward both short-term improvement (e.g., improved immunization rates) and promote long-term health gains (e.g., decreased diabetic leg amputation rates). Alternately, if organizations do not change processes to improve their performance, payment penalties could be imposed on those entities that continue to have large disparities in health outcomes for minority patients compared to non-minority patients and/or a population-based benchmark.

Caution must be exercised, however, before any payment incentive policy is implemented, as such policies may lead to unintended consequences. One troubling implication of providing payment rewards for healthcare organizations that have only a narrow healthcare quality disparity between minority and non-minority patients is that it costs more to work toward equitable care when the incremental difference is narrow. Thus, a facility that had historically focused on healthcare quality generally, as well as specifically for its minority patients, could potentially receive no payment because it already had achieved the benchmark—while at the same time a poor performer could reap significant rewards as it finally implements quality improvement initiatives long-ago adopted by others. On the other hand, if a penalty-based policy is used, measures must be adjusted to account for case mix; otherwise, institutions such as safety net hospitals, which serve large numbers of minorities, may actually be unfairly penalized for caring for a higher risk population.

Within the context of this report, another central consideration to take into account before incentivizing healthcare quality is the need to standardize race and ethnicity data collection practices. Further, consensus on a core set of quality measures that addresses minority-relevant health issues ideally would be identified before policies that link payment, improved healthcare quality, narrowed levels of disparity, and robust reporting of race and ethnicity data are developed and implemented. Without standardization, benchmarking and comparative analyses will be far from optimal. Given these issues, the Workgroup did not directly recommend whether and how payment could be tied to minority healthcare quality improvement. Rather, Workgroup members suggested that adverse unintended consequences must be considered before financial incentives are implemented to reduce disparities.

Public Accountability to Minority Healthcare Consumers

Public accountability through healthcare quality reporting can improve care by allowing purchasers and consumers to make healthcare decisions based on the performance of a facility, provider, or plan. Individual consumer interest in such information has been limited by a number of factors, such as lack of understanding of what constitutes good or poor quality and preference for maintaining continuity of care with the same physician. The problems that arise in reporting useful healthcare quality information to minority populations are often the same as those found in reporting this information to the general population. Factors such as low socioeconomic status and poor literacy are prevalent across the board, although typically these factors are greater among minority groups.

Although consumers' level of interest in making healthcare choices based on quality information is sometimes limited, public demand for quality information may be even further diminished in minority communities because of poor access to and little or no choice of health plans, physicians, and healthcare facilities. This would apply, for example, to American Indians who live on reservations that have only one physician or to uninsured persons who rely on a single safety net hospital. In addition, for some minority communities, literacy, language issues, and socioeconomic barriers to using information sources such as the Internet further decrease minority consumers' interest in or ability to use information on healthcare quality.

Despite the perception that healthcare quality information is of limited relevance for some minority patients, the availability of such information can at least serve to raise consumer expectations and awareness about healthcare quality issues. Of note, however, mechanisms on how best to raise awareness about minority healthcare quality vary according to cultural values. For example, patient autonomy and shared decisionmaking are practices that have increased among the general U.S. population over the past few decades, but in some cultures the physician's word is still unquestioned. Recommending that a patient who lives in such a culture request a second opinion on a diagnosis may be ineffective because of the patient's fear that making such a request would offend the physician.

> **RECOMMENDATION 9: Broad-based, inclusive strategies should be developed for engaging the disparate consumer audiences central to the drive for healthcare quality improvement.** Increase consumer awareness of healthcare quality problems and support efforts to engage all consumers in the healthcare quality movement. Deliver strategic messages that empower patients and inspire the providers and facilities that serve them to take specific actions to address healthcare quality problems, especially racial and ethnic disparities. When possible and relevant, encourage consumers to take control of their healthcare choices and support their ability to do so.

Developing and Communicating Quality Information Effectively

Public messages relating to healthcare quality are often presented in tables and charts that are difficult to interpret or that are too dense with text for low-literacy groups. Instead, such information must be communicated clearly and effectively, be presented in ways that are understandable to target audiences, and be multi-lingual. In particular, because Hispanics/Latinos comprise the largest minority population in this country,[13] providing healthcare quality information in Spanish is essential.

Minority communities can play an important role in developing and disseminating healthcare quality information that is useful to them. Involving leaders and members of the community (especially minority healthcare workers) in the early stages of information design would help ensure that messages are culturally sensitive and understandable to the target population.

Public accountability does not occur on a single level. Just as healthcare quality information can be reported from various levels (individual institutions versus states or regions), it also can be reported to multiple tiers and types of public bodies—individual patients, community leaders, community-based organizations (CBOs), employers and purchasing groups, the ethnic media, and others. These public entities lie outside of the realm of internalized hospital quality improvement efforts and share an interest in advocating for high-quality minority healthcare services. In addition, patient-centered community and advocacy groups can help fill the void by increasing consumer awareness about healthcare quality information. Finally, having more than one type of organization report this information is likely to facilitate better dissemination and use among minority consumers.

> **RECOMMENDATION 10: Community-based intermediaries should be utilized to develop and disseminate healthcare quality information to minority consumers.** Use reporting formats that are user friendly, culturally sensitive, and comprehensible to patients with low literacy and/or limited English proficiency. Communicate information through a variety of intermediaries such as CBOs, minority community leaders, and the ethnic media. Target multiple public entities, not just individual patients, as the users of quality information.

Conclusions

Minority healthcare quality improvement requires the attention, commitment, and concerted action of all healthcare stakeholders, including patients, providers, health plans, researchers, regulators, accrediting bodies, and communities, among others. These stakeholders must work together to ensure that minority healthcare quality improvement efforts harness the growing momentum and resources that are part of the national movement for better healthcare quality.

The quality of healthcare services received by racial and ethnic minority patients must come to be understood as an inseparable component of overall healthcare quality. Healthcare quality measurement and reporting strategies must be evaluated to ensure that they address the needs of racial and ethnic minority patients, since in most cases there is considerable room for improving these tools. Even before new measurement and reporting strategies are developed and implemented, current data sources on healthcare system performance, which hold great potential for analyzing disparities, should be used to the extent possible. Finally, reporting healthcare quality information in a way that is understandable to and useful for minority consumers will help drive improvement by heightening public awareness of healthcare quality problems and facilitating actions that can be taken to address them.

NQF Response to Workgroup Recommendations

The Workgroup for the NQF's meeting on minority healthcare quality measurement and reporting developed a series of recommendations that addresses the most pressing needs for better healthcare quality measurement and reporting for racial and ethnic minorities. As an organization that represents all healthcare stakeholder groups—consumers, purchasers, providers, payers, health plans, researchers, and policymakers—the NQF's strength lies in the range of its membership and its mandate to convene the best thinkers and leaders in national healthcare quality. Thus, the NQF is uniquely positioned to apply this Workgroup's recommendations to its efforts to standardize national healthcare quality measurement and reporting strategies.

Through this workshop and the release of its findings, the NQF recognizes that, in addition to key issues such as patient safety and medical errors, minority healthcare quality disparities are an inseparable aspect of general healthcare quality. Racial and ethnic equity in the provision of healthcare is already embedded as a key principle in the NQF national framework for measurement and reporting.

The NQF currently has under way a project to endorse a standardized core set of acute care hospital performance measures. Many of the Workgroup's principles are already being applied to the framework for this project: the need for consistent, standardized race and ethnicity data collection in conjunction with data collection for healthcare quality measures; the importance of standardized cross-cutting measures of quality; the prioritization of measures in areas in which minorities bear an unequal burden of disease; and the importance of public reporting strategies that are understandable and meaningful to the socially, culturally, and linguistically diverse American public. The Workgroup recognized that many of the major health and healthcare challenges facing minority patients are embedded throughout the healthcare system and continuum of care, and so it specifically identified and targeted its recommendations to apply to the full range of stakeholders and care settings. Thus, the recommendations are likely to endure and remain highly relevant to future NQF projects—i.e., the impact of the recommendations will be sustainable for some time to come.

As a membership organization, the NQF will disseminate these workshop proceedings to all members, who are the agents of national healthcare quality change. Moreover, Workgroup recommendations related to future research needs and the improvement of new or existing measure development will be shared with those who can fund and carry out such projects. Finally, in order to drive healthcare quality improvement for both minority and non-minority patients, the NQF will continue to draw upon its members and Board of Directors to promote the Workgroup's recommendations and to integrate them in their own work.

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Appendix A

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One Board seat is vacant.

Appendix B

USING EXISTING MEASURES TO MONITOR MINORITY HEALTH CARE QUALITY

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July 2001

ABSTRACT

Racial and ethnic disparities in health care quality have been extensively documented, but progress towards their elimination has been hampered by limitations in deployment of existing quality measures. Thus, significant racial or ethnic disparities in health care quality go undetected with existing quality assessment. This flaw can be corrected by specifically assessing health care quality by race and ethnicity. Using existing quality measures for this purpose offers several compelling advantages over developing entirely new quality measures for minorities. Using the same quality measures for both majority and minority group members facilitates comparisons and makes disparities transparent. Using the same measures also mainstreams minority health care and establishes the elimination of disparities a central goal of quality improvement.

Nonetheless, existing measures should only be used if they are appropriate to the health care problems of minorities. This means that existing measures must address conditions that are relevant to minorities and must be useful for monitoring disparities. It also means that conditions relevant to minorities must be addressed by current measures.

This paper primarily focuses on the first two requirements, but briefly touches on the last. Conditions relevant to minorities are those for which feasible improvements in the quality of medical care are likely to result in significant improvements in the population health of a particular minority group. In the first section of the paper, racial and ethnic disparities in health and health care are reviewed and possible causes discussed. In the second section, the relevance of existing quality measures to minorities is examined. First, a set of criteria for evaluating these measures is established. Next, the relevant literature is reviewed to determine whether each measure satisfies these criteria. HEDIS (effectiveness, access, satisfaction, use of services, informed health care choices, and plan stability), HCQIP, ORYX, and FACCT measures are reviewed. In each instance, the condition/problem targeted by the measure is found to be relevant to minorities. However, several conditions, notably HIV prevention and treatment, pain management, and sickle cell disease are not adequately addressed by current measures. Last, major challenges to implementing existing measures to monitor minority health care quality are discussed. These include attitudinal factors, conceptual and logistical barriers. The paper concludes with a series of recommendations designed to address these barriers to implementation.

INTRODUCTION

National attention has focused on racial/ethnic disparities in health and health care. The elimination of racial/ethnic disparities in health by the end of the decade is a central goal of Healthy People 2010. The causes of racial/ethnic disparities in health care are currently under study by the Institute of Medicine. Despite extensive documentation of these disparities in the literature, current performance systems are not currently equipped to monitor the quality of care provided to members of racial and minority groups.[1] This paper will examine whether current quality measures can be used for this purpose.

The classification categories for racial and ethnic groups used by the Census Bureau will be used through out the paper. These are White or Caucasian, Black or African American, Hispanic or Latino, American Indian or Native Alaskan, and Asian American or Pacific Islander.

Data for this paper were gleaned from multiple literature searches conducted through MEDLINE, the National Center for Health Statistics, the Office of Minority Health, and bibliographies from key articles. For methodological reasons, data derived from periodic national surveys and vital statistics were given priority when making epidemiological inferences. These surveys include the National Health Interview Survey (NHIS), the Behavioral Risk Factor Surveillance System (BRFSS), the National Health and Nutrition Examination Survey (NHANES), and the National Ambulatory Medical Care Survey (NAMCS). The limitations of vital statistics on racial and ethnic minorities have been reviewed elsewhere;[2-4] only passing comments will be made in this paper on these limitations.

RACIAL AND ETHNIC DISPARITIES IN HEALTH AND HEALTH CARE

Disparities in Health

African Americans experience worse health than any other major racial or ethnic minority group in the United States. Black adult and infant mortality is appreciably higher than whites and Hispanics.[5-7] African Americans have higher age-adjusted mortality rates than whites from cardiovascular disease, cerebrovascular disease, cancer (including lung, colorectal, breast, and prostate), pneumonia and influenza, chronic liver disease, diabetes, HIV, unintentional injuries, pregnancy, sudden infant death syndrome, and homicide (Table 2).[8] Racial disparities in mortality and health status differ widely between communities within the U.S.[9,10] African Americans also have higher rates of lead toxicity, sexually transmitted diseases, Hepatitis B and C, bacterial vaginosis, hypertension, obesity, severe asthma, sarcoidosis, lupus, scleroderma, glaucoma, renal failure, uterine fibroids, sickle cell diseases, and prostate cancer.[8,11-15]

Hispanic Americans have higher rates of death from liver disease, diabetes, HIV, and homicide, but lower overall age-adjusted mortality including lower rates of death from cardiovascular and cerebrovascular disease and cancer (Table 3).[8] Rates of stomach, liver, and cervical cancer exceed those of whites.[16] Moreover, Hispanic Americans are by no means a heterogeneous group, but represent persons or descendants of persons who have immigrated from many different Spanish speaking countries with different cultures. Not surprisingly, health conditions differ between different Hispanic subgroups. For example, Puerto Ricans have higher rates of low birth weight infants than other subgroups,[17,18] and Mexican Americans have higher rates of functional disability than whites.[19]

Asian/Pacific Islander Americans have lower age-adjusted overall mortality and lower mortality for each of the major causes of death (Table 4),[8] but have higher rates of certain cancers including stomach, liver, and cervical exceeding those of whites.[16] Asian/Pacific Islanders are also comprised of members of many different cultures; health status differs markedly between subgroups. For example, overall age-adjusted death rates for Somoan Americans and Hawaiians are the highest of any minority group.[20] Hawaiians also have higher rates of cancer than other Asian groups.[21]

American Indian/Alaskan Natives comprise hundreds of different tribes with different traditions. They have slightly lower overall age-adjusted mortality, lower rates of cardiovascular and cerebrovascular mortality, and overall cancer mortality, but higher rates of morbidity and mortality from pneumonia and influenza, liver disease, obesity, pediatric tuberculosis, bronchiolitis, diabetes, sudden infant death syndrome, diabetic kidney disease,[22,23] unintentional injuries, motor vehicle related injuries, and homicide (Table 5).[8,24-27] However, these rates are likely underestimated. Overall mortality among American Indians is underestimated by more than 20%,[4] primarily due to misclassification of race on death certificates. Morbidity and mortality vary between Indian groups. For example, Pima Indians have the highest rates of diabetes in the world.[28]

Explanations for Disparities in Health

Most of the racial disparities in adult mortality,[29] but not infant mortality,[30,31] are explained by the significantly lower socioeconomic status (SES) of African Americans. African Americans, in addition to Hispanics, American Indian/Native Alaskans and members of certain Asian/Pacific Islander groups have higher rates of poverty, lower educational levels, and are more likely to reside in impoverished communities.[32] Much, though not all, of racial and ethnic disparities in specific morbidities are explained by these differences. Moreover, because the exact causes of many of the diseases that disproportionately affect minorities are not known, it is difficult to determine the reasons for racial or ethnic disparities in incidence, prevalence, or severity of disease. It is likely that these racial and ethnic disparities result from a complex interaction between SES, racism, segregation, culture, health behaviors and beliefs, access to and quality of health care, and genetics.[31,33] Without improved understanding of how these factors interact, it is difficult to assess the contribution of specific factors to disparities. However, it is likely that the salience of any one factor varies by condition and racial or ethnic group.

Disparities in Health Care

In addition to experiencing worse health, numerous studies have documented significant racial and ethnic disparities in health care quality. These disparities are summarized in Table 6. Most research has focused on black-white disparities in health care. African Americans receive less aggressive treatment of prostate cancer,[34] fewer antiretrovirals for HIV infection,[35] fewer antidepressants for depression,[36] less appropriate management of congestive heart failure (CHF) and pneumonia,[37] poorer quality of hospital care,[38] fewer pediatric prescriptions,[39] fewer admissions for chest pain,[40] and lower quality prenatal care.[41]

The most striking racial disparities in health care have been found for expensive, highly technological care provided by physician specialists.[42] African Americans make fewer visits to specialists than do whites,[43] receive fewer cardiovascular procedures and surgery,[44 45-48] carotid endarterectomies,[49] and kidney and bone marrow transplants,[50,51] are less likely to receive curative surgery for lung[52] and other types of cancer,[53,22,54] and receive less prenatal care technology.[55] African Americans also receive less adequate well child care,[56] fewer peripheral vascular procedures[57] and orthopedic procedures,[58] less intensive rehabilitation following a hip fracture,[59] lower intensity of hospital care,[60] poorer overall quality of hospital care and greater instability at time of discharge,[38] less treatment for acute and chronic pain,[61,62] and higher rates of preventable deaths.[63] Data based on physician observation of video tapes of simulated patients show that physicians are less likely to refer black women for coronary angiography than members of other groups.[64]

Although health care disparities in other ethnic minorities have been less extensively studied, available evidence suggest that Hispanics, Asian American/Pacific Islanders, and American Indian/Alaskan Natives also receive suboptimal care. Compared to whites, members of each of these groups experience reduced access to health care.[23] Hispanics receive fewer mammograms,[65] Pap smears,[65] and influenza vaccinations,[66] and less prenatal care,[66] fewer cardiovascular procedures[67] including re-perfusion therapy,[68,69] and less analgesia for metastatic cancer[62,70] and trauma.[71] Asian American/Pacific Islanders receive fewer pap smears, mammograms,[72] and influenza vaccinations.[66] Native American/Alaskan Natives receive the least prenatal care of any group.[66]

Racial and ethnic disparities are not confined to the uninsured or those with Medicaid, but extend to those with private insurance, including managed care. Our own, unpublished data from the Community Tracking Survey show appreciable racial and ethnic disparities in physician specialist use, mental health services use, surgery, hospitalizations, smoking cessation counseling, mammography and influenza vaccination among persons in managed care and indemnity plans. Zaslavsky *et al* reported significant differences in the Health Plan Employer Data and Information Set (HEDIS) performance based on percentage of African Americans in the community, a proxy for race.[73]

Explanations for Disparities in Health Care

The causes of racial and ethnic disparities in health care are multifactorial, and probably differ according to the particular health care service. One approach to understanding disparities is to view them as occurring within the context of patient and physician decision-making and the health care system, and more broadly within a sociocultural macro context. Examples of patient-level factors include job constraints,[74] child care demands,[74] skepticism toward medical care and physicians,[75] transportation,[76,77] competing necessities, self efficacy, health literacy,[78] knowledge,[79,80] trust in physicians[81] and health care institutions,[82] health beliefs,[83,84] and aversion to invasive procedures[85,86] and preference.[87]

Most of these patient-level factors are affected by broader societal factors including racism, poverty, culture, and macro-politics. For example, patients' decisions are affected by health care system factors including the presence and type of health care insurance,[88] availability of a regular source of care,[89,90] comprehensible health care plan policies, location of health facilities, co-payments and deductibles,[91,92] waiting times, presence of culturally competent staff, and availability of translation services.[93] Patients' knowledge, beliefs, attitudes, and behavior are influenced by subculture, education, SES, mass media, pharmaceutical marketing,[94,95] prior experience, segregation, racism, and stereotyping.[96,97]

The concept of diffusion of innovations[98] has particular relevance for understanding patient demand for services. It suggests that newer procedures are more likely to be adopted by persons with higher education or persons with greater contact with new adopters. Thus, demand for new innovations in health care technology is likely to be greater among whites and persons with more education. Patients are more likely to trust recommendations for new procedures, particularly those that entail some risk, when the recommendations are made by persons whom they trust and respect. Specific strategies designed to improve diffusion of innovations to lower socioeconomic groups have been developed.[98]

Physician-level decision-making is also a powerful, proximate determinant of disparities. It is influenced by health care plan factors including economic incentives and practice profiling, in addition to physician training, beliefs and attitudes including stereotyping, and patient demand.[99-104] Although evidence clearly implicates physician bias as a contributor to disparities,[105,106 64,107,108] the nature of this bias is not clear. It is likely that such bias is largely unconscious, unthinking, and unintentional,[96] and is not necessarily remedied by physician-patient racial concordance.[109]

The relative influence of patient and physician-level factors probably depends on the type of health care service. Patient-level factors probably predominate for services that are largely dependent on patient compliance. These include keeping medical appointments, following through on referrals, medication adherence, and complying with recommendations for preventive health services.[110-113] Provider-level factors become increasingly relevant for services that require active physician participation such as performance of a diagnostic or therapeutic procedure. Provider-level factors are likely to be paramount when indications for a particular procedure are unclear and medical uncertainty is high.[42] Examples of these instances include hospital admission or chest pain,[40,114] and performance of certain diagnostic or therapeutic procedures such as angiography,[46] coronary artery bypass surgery,[47] or total hip replacement.[115] Physicians may be more susceptible to unconscious stereotyping and/or patient demand when confronted by medical or surgical uncertainty. The net result is often a combination of underuse of the service by minorities and overuse by whites.[116,117]

Racial and ethnic disparities in health care are likely to be further amplified when receipt of the service requires a series of decisions by the patient, primary physician, and consulting physician. Although race or ethnicity may exert a modest effect through patient- or physician-level factors or both on any one decision, the cumulative effect is considerable. Einbinder and Schulman have clearly illustrated this effect for invasive cardiac care.[118] Other examples include cerebrovascular procedures, orthopedic procedures, and organ transplantation.[119,120]

The elimination of disparities in health care will not be easy and will probably require some combination of patient-targeted, community-targeted, physician-targeted, or health system-targeted interventions.[93] Regardless of the intervention, continuous, reliable, current data regarding a particular disparity will be required to monitor progress toward its elimination.

The large variation in disparities between regions of the country suggests that disparities are not immutable.[121] For example, black-white breast cancer screening rates differ by only 2% in New York compared to 11% in Alabama.[10] Disparities in use of cardiovascular procedures have been nearly eliminated by combining insurance with access to comprehensive, clinically appropriate care.[122] Racial differences in breast cancer survival were eliminated when mammography promotion was extended to all women enrolled in the Health Insurance Plan of Greater Western New York mammography screening study.[123] The provision of equal care (in the U.S. Military) has been shown to have eliminated racial disparities in cervical cancer mortality.[124] Rates of childhood immunizations among inner-city children in Rochester, New York exceed those of Healthy People 2000 and nearly match those of suburban children following implementation of a community-wide registry and follow-up program. Finally, simply monitoring and reporting performance seems to promote improved performance. National Committee for Quality Assurance (NCQA) data (based on participating HMOs who report results publicly) show that the mean reported rate for beta blockers following a myocardial infarction increased to 79.9% in 1998, from an initial rate of 62.5% in 1996. Similarly, the overall rate for varicella (chickenpox) vaccine in 1998 was 51.9%, up from 40% in 1997.[125] Thus, it is not implausible that the development and implementation of measures to monitor health care provided to minorities will result in similar improvements.

Disparities in Health Care Contribute to Disparities in Health

The World Health Organization defines health as “a state of complete physical, mental, social well-being, and not merely the absence of disease or infirmity.” Although it is tempting to attribute most of the disparities in health outcome to disparities in health process, available evidence suggests that health care probably makes a modest contribution to overall health.[126-128] Other factors such as socioeconomic status, racism, segregation, health beliefs and cultural practices exert major effects.[126,129] For example, higher socioeconomic position, as measured by income or education, is powerfully related to improved health status and lower mortality.[5,130,131]

In a few instances, elimination of disparities in use of certain health care procedures might actually worsen health care outcomes for minorities. For example, a recent study showed that despite receiving significantly lower rates of coronary angiography post-myocardial infarction, blacks had significantly *lower* 30 day adjusted mortality than whites.[109] In some studies, blacks have higher adjusted mortality following cardiac surgery,[132,133] and are more likely to undergo coronary artery bypass surgery from a lower quality surgeon than whites.[134] Thus, increasing rates of cardiac surgery, particularly if performed by less experienced surgeons, might actually result in higher mortality rates for minorities. Furthermore, higher rates of small vessel disease among blacks may result in less favorable outcomes following endarterectomy surgery even if performed by skilled surgeons. Nonetheless, disparities in other procedures such as cancer-curing surgery, renal transplantation, and joint replacements undoubtedly contribute to disparities in the length and/or quality of life for minorities affected by these conditions.

MONITORING RACIAL AND ETHNIC DISPARITIES IN CARE

Imperatives for Monitoring

There are three compelling reasons for monitoring and addressing racial and ethnic disparities in health care. The first is moral. Regardless of ideology, few people would defend the morality of provider-driven disparities. While some have argued that disparities simply reflect consumer-driven differences in preference and attitude related to race or ethnicity,[135] carefully controlled studies suggest otherwise.[85,87] Thus, disparities, particularly those involving surgical or invasive procedures, are at least in part, physician-driven. Moreover, both consumer and physician behavior is modifiable as shown by the success of physician and consumer targeted pharmaceutical marketing.

Racial and ethnic disparities in health care continue to make national headlines because they defy our national consensus that race or ethnicity should not be grounds for allocating organ transplants, life saving surgery, or invasive cardiovascular procedures. Thus, disparities do not persist because of a lack of a moral consensus that they are wrong. They persist because they are largely unseen. They operate below the radar screen of standard quality measures. In the absence of appropriately collected data, i.e., specific research studies, they go unrecognized. Although individuals or groups may perceive bias and discrimination in health care, in the absence of population-level data, these complaints are dismissed as anecdotal. For this reason, a system for tracking and monitoring these disparities is required.

The second reason for monitoring disparities is that they are incompatible with quality. Quality improvement entails two central goals: improving overall quality and reducing variation in quality.[136] Disparities are incompatible with the second goal. In this sense, quality implies equality. Unfortunately, a critical flaw in existing quality assurance design allows racial and ethnic disparities in quality to escape detection. In contrast, in the non-health care sector, high performing industries have achieved remarkable success using quality improvement technology to achieve both high overall quality and low variation in process and outcome. NCQA and the Joint Commission for the Accreditation of Health Care Organizations (JCAHO) are dedicated to similar achievements in health care quality. Each has developed benchmarks for which the quality of care provided by HMOs or hospitals can be assessed. Yet, until this design flaw is corrected, efforts at quality improvement will be seriously hampered. This flaw makes it possible, for example, for an HMO to achieve a high overall score on a particular quality measure while providing suboptimal care to vulnerable groups for whom the measure is most relevant. For example, data show large disparities by race in receipt of the influenza vaccine among the elderly. National rates for whites are 20% higher than blacks (60% vs. 40%). Consider an HMO comprised of 85% whites and 15% blacks. If the vaccination rate for whites is 80% compared to 60% for blacks, the overall rate of influenza vaccine is nonetheless a respectable 77%. Only by assessing relevant disparities in performance measures can these variations in quality be detected and addressed. The goal of eliminating disparities in health care is entirely congruent with the mission of organizations dedicated to improving health care quality.

The third reason to monitor (and address disparities) is that it represents sound public policy. Disparities often represent “reverse targeting” or the misallocation of health care resources away from populations with the greatest needs, i.e., minorities and lower SES persons, to those with the least needs. For example, disparities in use of invasive procedures appear to represent a combination of over-use, i.e., inappropriate use among majorities and under-use among minorities. If one of the goals of health care is to promote improvements in population health, then health care must be more appropriately allocated. Monitoring and eliminating disparities will help to minimize inappropriate allocation.

Existing Measures (If Relevant) Should Be Used

If existing measures are relevant to minorities, then they should be used to monitor minority health care quality. Use of existing measures offers several key advantages. First, disparities can only be identified when the same measures are used to monitor the quality of care for minority and majority group members. Use of separate measures perpetuates disparities by allowing them to remain undetected.

Second, use of existing measures brings disparities out of the exclusive domain of public health and into the mainstream of quality assurance where they can be best addressed. Mainstreaming disparities leverages the enormous organizational resources and commitment of NCQA and JCAHO. Mainstreaming disparities will likely generate support for further research designed to understand and address disparities. In contrast, use of entirely new measures for each minority group marginalizes minority health care quality and fosters isolation of racial and ethnic disparities in health care from mainstream quality improvement.

Last, the development of new measures and their accompanying technical specifications is time consuming and labor intensive. It is simply not cost-efficient to invest the resources in developing new measures if existing measures are appropriate. Not withstanding these advantages, existing measures should not be used if they are not appropriate for minorities. In the following sections, the suitability of these measures for this purpose is reviewed.

Criteria for Assessing Measures

In order for existing measures to be relevant to minorities they should satisfy four criteria. First, they should address conditions that are relevant to minorities. For example, a quality measure for the management of cystic fibrosis is not relevant because the incidence of cystic fibrosis is too low among most minorities to warrant a quality measure for these groups. Second, existing measures should address conditions where appreciable disparities in medical care have been documented. If one of the goals of monitoring health care provided to minorities is the elimination of disparities, then measures should be used that monitor care in areas where disparities have been shown. Third, measures should be feasible to implement. This is discussed in further detail under “challenges to implementation.” Last, conditions relevant to minorities should be addressed by these measures. This criterion represents the converse of the first criterion. It asks: are key conditions relevant to minorities not addressed by existing measures? This question is addressed in detail by Dr. Nerenz and will only be briefly discussed in this paper.

How should the relevance of conditions targeted by existing measures to minorities be assessed? A condition is relevant to a particular minority group based on the potential for feasible improvements in health care quality to significantly improve the population health for that group. This potential is in turn based on: (1) the prevalence/incidence of the condition, (2) the health impact of the condition on the group, e.g., age of onset, pain, function, and mortality, (3) presence of proven and cost-effective interventions, (4) evidence of a gap in the application of these interventions, and (5) evidence that the gap can be closed.

To illustrate, the criteria for assessing condition relevance will be applied to a current HEDIS clinical effectiveness measure, management of hypertension for minorities. Hypertension is one of the most widespread health problems among blacks. The age-adjusted prevalence among African Americans is 23%.[137] Hispanics, American Indians/Alaskan Natives and Asian/Pacific Islanders have comparable and in some instances lower rates than whites[23] (Criterion 1). The sequelae from hypertension have an enormous impact on the health of those affected. Untreated or inadequately treated hypertension is a major cause of premature morbidity and mortality resulting from cardiovascular, cerebrovascular, and kidney disease among minorities, particularly African Americans (Criterion 2). These complications result in high hospitalization and long term care costs. Treatment of hypertension has been conclusively shown to reduce complications among blacks[138] (Criterion 3). Treatment of hypertension is very cost-effective and feasible with existing agents (Criterion 3). However, the prevalence of both treated and untreated hypertension is higher among blacks, and probably other minorities, than among whites.[137] Adequate control of hypertension is suboptimal. Only 30% of all whites and 26% of all blacks with hypertension have their blood pressure adequately controlled.[137] Even among persons under treatment for hypertension, only about half have their blood pressure adequately controlled with rates lower for blacks than whites[137] (Criterion 4). Although quality improvement efforts designed to improve hypertension management have had limited success,[139] socioeconomic disparities in hypertension control were eliminated in the stepped care arm of the Hypertension Detection and Follow-up Program.[140] Similarly, the absence of co-payments in the RAND Health Insurance Experiment significantly improved hypertension control, particularly among the lower income group.[141] Recent data from the Achievable Benchmark of Care System show that physician performance feedback based on achievable benchmarks improves health care quality[142] (Criterion 5).

The feasibility/methodologic criteria used by organizations concerned with health care quality to select existing measures have included: (1) consistency with the goals of the organization or initiative, (2) measurable, achievable, feasible, (3) data collection burden and cost, (4) scientifically sound (evidence-based, reliable, valid, risk adjusted, reproducible and comparable), (5) timely data collection/reporting, and (6) comprehensible and easily disseminated to stakeholders. Most of these criteria have been satisfied for existing measures. However, their implementation specifically for minorities creates additional feasibility/methodologic challenges. These include developing reliable procedures for collecting race and ethnicity data, use of appropriate sampling procedures and statistical power, costs, consideration of SES adjustment, and a comprehensible reporting format. These issues are discussed in more detail under the section “challenges to implementation.”

In the next section, the relevance of key existing quality measures is reviewed. When reviewing specific conditions/measures, priority will be given to those with the potential for improving minority health and elimination of disparities. Thus, this review will focus on the prevalence/incidence and impact of the condition on minority health as well as evidence for racial and ethnic disparities in health care quality. In many instances, the condition under consideration is significantly more prevalent among minorities than among non-Hispanic whites. In the absence of an appreciable difference in disease impact, a higher prevalence suggests relevance. However, because a condition is significantly *less* prevalent among a particular minority group does not necessarily imply that it does not nonetheless contribute significantly to minority health. For example, Asian-Pacific Islanders have rates of death from heart disease that are 40% lower than non-Hispanic whites. Yet, because heart disease is the leading cause of mortality for this group it represents a condition very relevant to Asian-Pacific Islanders.

Less attention will be given to the remaining criteria such as availability of effective treatment or cost-effectiveness. These criteria have presumably been satisfied for the general population and, in the absence of evidence to the contrary, will be considered to be applicable to minorities. However, when there is evidence of a racial or ethnic difference in the effectiveness of a particular intervention, these data will be cited.

APPROPRIATENESS OF EXISTING QUALITY MEASURES

In this section, the suitability of commonly used quality measures will be discussed. These include measures used by National Committee for Quality Assurance (NCQA), Centers for Medicaid and Medicare Services (CMS), Joint Commission on Accreditation of Healthcare Organizations (JCAHO), the Foundation for Health Care Accountability (FACCT), and Agency for Healthcare Research and Quality (AHRQ). Table 3 summarizes the results for this review. Each of the key measures from these sets will be reviewed.

National Committee for Quality Assurance (HEDIS)

HEDIS is "a set of standardized performance measures designed to ensure that purchasers and consumers have the information they need to reliably compare the performance of managed health care plans."[143] HEDIS, produced by NCQA, is the set of performance measures most widely used by consumers to assess the quality of care provided by managed care organizations. Based on a public call for measures, NCQA selected measures based on three major attributes. First, the measures had to be relevant. That is, the measure addressed conditions that were known to affect health outcomes in the general population, the condition was treatable by medical intervention, and the measures were likely to be used by consumers in selecting health care plans. Second, the measures had to be scientifically sound. Measures that were selected were reliable, valid, accurate, and had sufficient statistical power to detect relevant differences between health care plans, and included a strategy to adjust for other factors. Third, measures had to be feasible. That is, measures had to be precisely defined, produced at a reasonable cost, and did not violate patient confidentiality. Although measures are updated annually, changes are usually modest in order to facilitate comparisons with previous years. HEDIS measures span seven domains: effectiveness of care, access/availability, satisfaction with the experience of care, health plan stability, use of services, informed health care choices, and health plan descriptive information.

HEDIS has been criticized because fewer than half of the leading causes of morbidity and mortality, such as dietary habits, activity levels, or alcohol abuse are addressed by it.[144] This critique undoubtedly applies to its use to monitor minority health. However, the potential for improving population health (given current, proven interventions) and not simply the impact on population health, is the primary criterion. For example, obesity and inactivity represent major determinants of population health. Yet, there are few medically based interventions that have been shown to improve these risk factors.

For each performance measure, the specifications of the measure and the mean performance scores for HMOs who report their performance are noted. As discussed earlier, appropriateness is judged primarily on evidence of impact of the condition on minorities (prevalence/incidence and/or contribution to mortality) and on evidence for disparities in quality of care using the measure. The results are summarized in Table 7.

Effectiveness measures

The effectiveness measures are primarily designed to assess the quality of clinical care and typically reflect adherence to generally accepted standards of care such as those set forth by the U.S. Preventive Services Task Force and other national organizations.

Childhood Immunization Status. This measure assesses the percent of children who are up to date by two years of age. The mean score for HMOs ranges from 47% to 87% depending on the combination of vaccinations given.[145] There is no evidence that childhood illnesses are lower among any of the minority groups. Rates of childhood infections including invasive pneumococcal infections and Hepatitis B are higher among blacks than whites.[146,147]Asian children have higher rates of infection with Hepatitis B.[147] Recently released 1999 data from the National Immunization Survey show that black, Hispanic, American Indian/Alaskan Native, and, in some instances, Asian/Pacific Islander children aged 19-35 months have lower immunization rates than white children.[148] For most vaccinations, black children have the lowest rates with gaps ranging from 5.5% for four series of Diphtheria Tetanus Pertussis to no gap for varicella. These gaps are not fully explained by differences in poverty levels between the groups. This measure is appropriate for minorities.

Adolescent Immunization Status. This measure assesses the percent of children 12 and over who are up to date with the Measles/Mumps/Rubella (MMR), Hepatitis B (HBV), Tetanus (Td), and Varicella vaccines. The mean score for HMOs range from 14% to 59% depending on the combination of vaccinations.[145]

There is no evidence of lower rates of these infections among adolescents from different minority groups. Rates of immunity among military recruits to measles, mumps, and rubella are lower among blacks.[149] Rates of Hepatitis B infection are higher among black adolescents than white adolescents.[13] Complications from these infections can result in lasting sequelae and, in some instances, death. HEDIS data show that persons from predominately black communities have lower rates of adolescent immunizations.[73] This measure is appropriate for minorities.

Breast Cancer Screening. This measure assesses the percent of women 52-69 years old who have had a mammogram in the past two years. The mean score for HMOs in 2000 was 73%.[145] The incidence of breast cancer is lower among black compared to white women, but black women have the highest mortality rates from breast cancer.[16] Breast cancer is the leading cause of cancer related mortality for Hispanic, Asian/Pacific Islander and Native American/Alaskan Native women.[72] Hispanic,[23,150] particularly Mexican-American women,[151] and Asian-Pacific Islander women[72] have lower mammography rates than whites. Reliable data for American Indian/Native Alaskan women are not available. The picture is less clear for blacks. Based on self-report data from the NHIS, black-white disparities in mammography were eliminated by 1992.[152] These findings are surprising given that nearly all of the barriers to receipt of mammography are associated with race.[65,151,153-167] Moreover, Medicare claims data show that black women have half the mammography rate of whites.[168] HEDIS data also show lower rates of mammography among persons from black communities.[73] This measure is appropriate for minorities. However, given the racial and ethnic differences in follow-up of abnormal mammograms,[169,170] a measure focusing on this problem might also be included.

Cervical Cancer Screening. This measure assesses the percent of women between the ages of 21-69 who have had a Pap smear performed in the past three years. The mean score for HMOs in 2000 was 72%.[145] The American Cancer Society estimates that 12,800 new cases of invasive cervical cancer are diagnosed annually and that 4,600 women will die from the disease.[171] Blacks, Hispanics and Asian/Pacific Islanders have higher incidence rates than whites, with the highest rates found among Vietnamese women.[16,171] Black women have the highest rates of death from cervical cancer.[16,172] The NHIS shows Hispanics, American Indian/Alaskan Native, and particularly Asian/Pacific Islander women, have lower rates of Pap smear screening than white women.[72,150,173,174] Although black women report the highest Pap smear rates,[150] HEDIS data show that persons from predominantly black communities have lower rates.[73] The measure is appropriate for minorities. A measure assessing follow-up on abnormal Pap smears would also be relevant to minorities.

Chlamydia Screening in Women. This measure assesses the percent of women between the ages of 16-20 who have been screened for Chlamydia in the past year. The mean score for HMOs in 2000 was 16%.[145] The CDC estimates that approximately 3 million cases of Chlamydia occur annually.[175] Most women are asymptomatic. Forty percent of untreated women develop pelvic inflammatory disease (PID) and 20% of women who develop PID become infertile.[175] Certain subtypes have been linked to cervical cancer.[176] Rates of Chlamydia,[177-179] PID, ectopic pregnancy, and infertility secondary to tubal disease are appreciably higher among black women.[180] Native American women may also have higher rates[181,182] as well as subgroups of Asian/Pacific Islander women and Hispanics. Effective screening tests and treatment are available. Although rates of Chlamydia screening by race are not known, blacks report higher rates of overall STD screening than whites.[183] Nearly fifty percent of black women ages 15-44, 27 percent of Hispanic, and 23 percent of white and other women were tested for STDs in the 12 months before the survey. These differences were partly, but not fully, explained by differences in source of care (private vs. family planning clinics). This measure is appropriate for minorities, although there may be subgroups for whom the prevalence is too low to warrant screening. Consideration might also be given to a similar measure for gonorrhea, particularly for blacks, who have very high rates.

Controlling High Blood Pressure. This measure assesses the percent of patients with a diagnosis of hypertension whose systolic blood pressure is below 140 and diastolic is below 90. The mean score for

HMOs in 2000 was 39%.[145] This measure was previously discussed in detail and shown to be very appropriate for blacks. The prevalence of hypertension among other minority groups and high levels of suboptimal control warrant its use for other minority groups.

Beta Blocker Treatment After a Heart Attack. This measure assesses the percent of patients who have had a myocardial infarction in the past year who, in the absence of a contraindication, received a beta blocker. The mean score for HMOs in 2000 was 85%.[145] Heart disease, particularly coronary artery disease, is the leading cause of death among members of all minority groups.[8] Rates of death following a myocardial infarction are higher for black men than whites.[184-186] Beta blockers have been conclusively shown to reduce mortality post-myocardial infarction.[187,188] Blacks, Hispanics, Asian-Pacific Islanders, and American Indian/Alaskan Natives are less likely to receive beta blockers post-myocardial infarction[189,190] or in the presence of coronary artery disease.[191] However, there are conflicting data as to whether blacks derive comparable benefits from beta-blockers post-myocardial infarction as do whites.[187,192] The measure is appropriate for minorities. Further data are needed regarding the effectiveness of beta-blockers among members of different minority groups.

Cholesterol Management After Acute Cardiovascular Events. This measures assesses the percent of patients who experienced an acute cardiovascular event in the last year who underwent LDL-C screening and also whose LDL-C levels are <130 mg/dl within 60 days. The mean score for HMOs in 2000 was 45%.[145] Cardiovascular disease is the leading cause of death among all minorities. Elevated cholesterol is an important risk factor for cardiovascular disease, the leading cause of death for all groups. NHANES, 1988-1994 show that serum cholesterol levels in the U.S. do not differ appreciably by race or ethnicity.[193] Blacks, Hispanics, and Asians or Pacific Islanders report slightly lower testing rates.[23] NAMCS shows that blacks receive less cholesterol reduction counseling than whites.[194] Although there appears to be little racial difference in use of hypocholesterolemic agents,[194-196] it is not known whether these findings apply to management following acute cardiovascular events. Given the large contribution of cardiovascular disease to mortality among minorities and uncertainty regarding the quality of cholesterol management after acute cardiovascular events, this measure is appropriate for minorities.

Comprehensive Diabetes Care. This is a set of 6 measures relating to diabetic management. They include glycosylated hemoglobin testing, poor glycemic control, diabetic retinal screening, lipid screening, lipid control, and screening for diabetic nephropathy. The mean score for HMOs in 2000 for these measures ranged from 36% for nephropathy monitoring to 75% for glycosylated hemoglobin testing.[145] American Indians (Native Alaskans excluded) have rates of adult onset Diabetes that are two to six times higher than whites.[197] In 1996, diabetes was the second leading cause of non-accidental death for American Indians/Alaskan Natives, third for Hispanics, sixth for Asians and Pacific Islanders, and seventh for African Americans.[11] Age-adjusted mortality rates for blacks and American Indians are twice those of whites.[8] Hispanics have intermediate rates. Blacks are at higher risk for complications of diabetes including amputation and renal failure.[198] NHANES, 1988-1994 shows that black diabetics have poorer glycemic control compared to whites.[199] However, Wisdom et al found no racial differences in diabetic management in an HMO.[200] Similarly, there was no racial difference from NHIS in self-reported receipt of a dilated eye examination among diabetics although higher income persons had nearly twice the rate as lower income persons.[201] However, CMS data show that black diabetics have lower rates of dilated exams;[202] NAMCS data show that black diabetics receive less eye care than whites.[203] Black diabetics also have fewer physician visits and more emergency department visits.[204] Feedback to physicians regarding their performance using achievable benchmarks for diabetic care has been associated with significant improvements in these measures.[205] Given the contribution of diabetes to minority mortality and evidence of suboptimal management, this measure is highly appropriate for use with minorities.

Use of Appropriate Medications for People with Asthma. This measure assesses whether patients with the diagnosis of asthma have received a prescription for an anti-inflammatory asthma medication in the past year. The mean score for HMOs for this measure in 2000 was 57% for all ages.[145] Asthma is one of the most prevalent childhood illnesses. NHANES, 1988-1994 results show appreciable differences in physician-confirmed diagnosis of asthma for children under 11 years: 3.3% for whites compared to 11.2% for Puerto Ricans, 5.9% for blacks, 5.2% for Cubans, and 2.7% for Mexican Americans.[206] Rates of asthma among American Indians/Alaskan Natives are comparable to those of whites.[207] Rates of disability and mortality for blacks with asthma are nearly double those for whites.[208,209] Asian/Pacific Islanders have also been reported to have worse asthma outcomes than whites.[210] Data from managed care organizations show that blacks and Hispanics made fewer visits to asthma specialists, filled fewer prescriptions for inhaled steroids, were more likely to visit the emergency department with asthma, and were more likely to be hospitalized with asthma.[211,212] Use of anti-inflammatory asthma medications have been shown through randomized controlled trials to reduce asthma exacerbation.[213,214] Professional education of clinic staff has been shown to improve continuity and quality of care among minorities with asthma.[215] This appears to be a very appropriate measure for minorities.

Follow-up after Hospitalization for Mental Illness. This measure assesses whether persons hospitalized for mental illness are seen in follow-up within 4 weeks of hospital discharge. The mean score for HMOs in 2000 was 70%.[145] Rates of mental illness do not differ appreciably between blacks and whites.[216,217] However, Native Americans have the highest rates of suicide of any group.[218] Among the insured, Blacks and Hispanics have lower use of outpatient mental health services than whites,[219] but comparable use of inpatient services.[220] Physicians spend less time with black patients in psychiatric emergency rooms and are more likely to prescribe antipsychotics.[221] No data could be identified regarding rates of follow-up post-hospitalization by race or ethnicity. However, given that blacks and Hispanics have consistently lower use of ambulatory mental health,[222] it is likely that there are disparities in this measure. This is an appropriate measure for minorities.

Antidepressant Medication Management. This set of measures assesses follow-up and continuity of care for depression. The mean score for HMOs in 2000 ranged from 21% to 59% depending on the follow-up measure.[145] Although rates of depression do not appear to differ significantly between whites and blacks,[217] American Indian/Alaskan Natives have suicide rates 50% higher than the overall population.[218] Antidepressant treatment has been shown through randomized controlled trials to improve symptoms associated with depression.[223,224] Whites receive a recommendation for antidepressants more often than non-whites.[36] There are conflicting findings regarding the existence of racial or ethnic disparities in treatment of depression.[36,225,226] However, NMACS shows racial differences in use of antidepressants or type of antidepressant prescribed.[227] This appears to be an appropriate measure for minorities.

Advising Smokers to Quit. This measure is based on patient surveys regarding receipt of smoking cessation advice. The mean score for HMOs in 2000 was 64%.[145] Smoking represents the single most important preventable risk factor for mortality regardless of race/ethnicity. Rates of smoking are highest among Native Americans.[23] National data from two different surveys show disparities in smoking cessation counseling. NAMCS data show that non-whites are less likely to be asked by physicians as to whether they smoke.[228] Data from the Community Tracking Survey show that black smokers are less likely to report they were counseled to quit smoking than did whites.[229] This represents a highly appropriate measure for minorities.

Flu Shots for Older Adults. This measures assesses whether patients ≥ 65 years received a flu shot in the past year. Pneumonia/influenza represent one of the 10 leading causes of death among all minority groups. Age-adjusted rates of death from pneumonia/influenza are 40% higher among blacks than among whites.[8] Influenza vaccines have been shown to be highly effective in preventing morbidity and mortality associated with influenza.[230] Data from the BRFSS show that 21% fewer elderly blacks than whites receive the influenza vaccine (39 vs. 60%).[231] Hispanics also have significantly lower rates of influenza vaccination than whites.[232] Rates among other minorities are not known. This represents a highly appropriate measure for minorities.

Medicare Health Outcomes Survey. This measure examines change in health status over time based on the Medical Outcomes Study Short Form 36 (SF-36) item health survey. Blacks and American Indians/Alaskan Natives report lower health status than whites and likely experience more rapid decline in health status.[11,23] What is less clear is the extent to which health status is sensitive to health care plan factors. Moreover, because so many factors affect health status, many of which are difficult to adequately measure and adjust, the validity of comparisons of changes in health status between plans is not known. This is an appropriate measure for tracking minority health over time. Although it is not clear to what extent it reflects the quality of care provided, it is no less appropriate for minorities than for the general population.

Pneumonia Vaccination Status for Older Adults. This measure assesses whether adults ≥ 50 or those with risk factors received a pneumococcal vaccine. As previously noted, pneumonia/influenza is one of the 10 leading causes of death for all minorities. Pneumococcal pneumonia is the most prevalent cause of bacterial pneumonia. Rates of invasive pneumococcal disease including pneumonia are significantly higher among blacks[146,233-235] and Native Americans.[11] Pneumonia vaccines have been shown to be cost-effective in preventing morbidity and mortality associated with pneumococcal pneumonia.[236] Data from the BRFSS show that 18% fewer elderly blacks than whites received the pneumococcal vaccine (20 vs. 37%).[231] Hispanics also have significantly lower rates than whites.[232] This represents a highly appropriate measure for minority health.

Access/availability of care

HEDIS includes a series of access/availability of care measures for primary care for children and adults, prenatal/postpartum care, dental care (Medicaid plans), and availability of language/interpretation services. Each of these measures is very relevant to minority health care. Racial and ethnic minorities experience worse first contact primary care, including longer waiting times and more difficulties obtaining an appointment.[237] Black adults make nearly half as many office visits as whites.[238] Among children less than 12 months of age, whites made 33% more total visits and 77% more well child visits than blacks.[239] Among children ages 1-4, whites made 47% more total visits and 25% more well child visits. Among children ages 5-14, the rates were 53% and 88% higher for whites. Similar disparities have been reported based on other data.[240,241] Black and Hispanic women are less likely to initiate prenatal care in the first trimester than whites.[11] Rates of prenatal care enrollment are the lowest for American Indians.[11] Similarly, based on NHIS data, blacks were significantly less likely than whites to have had a dental visit in the past year.[11] Given the health care access problems for minorities, even among those with health insurance,[242] these represent highly appropriate measures for minorities.

Availability of language/interpretation services is most likely to affect Hispanics, who now comprise the largest minority group in the U.S. In a recent national survey, nearly one third of the Hispanic respondents preferred to be interviewed in Spanish (unpublished observations). Preference for Spanish is associated with lower rates of satisfaction with physician communication.[243] Asian American/Pacific Islanders are also likely to be disproportionately affected by absence of translation services. This is a very relevant measure for minorities.

Satisfaction with the experience of care

This set of measures assesses patients' satisfaction with various aspects of care. It is based on responses to the Consumer Assessment of Health Plans Survey (CAHPS) originally sponsored/developed by AHRQ. This survey has been validated in diverse groups, possesses excellent psychometric properties and is available in Spanish.[244-249] In general, minorities report lower satisfaction with their ambulatory and hospital care.[250-254] Blacks report lower satisfaction, trust in their providers, and involvement in their own care than whites,[81,251] in some, but not all studies,[255,256] and have higher rates of hospital discharge against medical advice.[257] Nearly one fourth of blacks believe they received inferior care because of their race.[258]

These beliefs may not be unfounded. In at least one study, physicians reported less favorable attitudes towards black patients.[103] Hispanics also report greater dissatisfaction with care than whites,[259] and one out of six believe they have received inferior care because of their ethnicity.[258] Spanish-speaking Hispanics are especially dissatisfied with the quality of physician communication.[243] These effects are not confined to African Americans and Hispanics. Asians/Pacific Islanders rate physician primary care performance lower than whites, blacks or Hispanics.[256,260] In some, but not all studies,[261] racial concordance between physician and patient has been associated with improved sense of participation[81] or perceived quality of care.[262] Greater patient involvement in care predicts better outcomes.[263-265] The primary limitation of CAHPS is that it provides little consumer assessment regarding the single aspect of health care most sensitive to differences in culture: the physician-patient relationship. Soon-to-be published data show few significant differences by race or ethnicity in CAHPS measures,[266] suggesting that further refinement of the measure and/or its administration may be required. Nonetheless, it represents an important first step towards monitoring and addressing potential disparities in health care satisfaction.

Use of services

HEDIS also includes a series of health care utilization measures including frequency of prenatal care visits, births, Cesarean section rates, well-child and adolescents visits, use of selected procedures, and various inpatient utilization and outpatient utilization measures including mental health, substance abuse, and prescription utilization. Although these measures do not directly assess quality of health care, they could, with appropriate case-mix adjustment, be used to assess racial/ethnic disparities in access and/or resource allocation. Currently, none of the HEDIS measures assess disparities in use of surgical/invasive procedures. Notable among these are organ transplants, cardiovascular and cerebrovascular diagnostic and therapeutic procedures, orthopedic procedures, and curative cancer surgery. Although crude rates do not distinguish overuse among whites from underuse among blacks, both under or overuse warrant attention as quality problems. Thus, disparities in use of these procedures could be used to direct quality improvement activities or conduct more sophisticated analyses using case-mix adjustors and measures of appropriateness.

Of these procedures, priority might be given to access to renal transplantation. Blacks, American Indian/Native Alaskans, and possibly Hispanics are disproportionately affected by renal disease.[267] As of December 1999, more than 31,000 African Americans were on hemodialysis, comprising one-third of all hemodialysis patients.[268] The death rate per 100 patient-years for African Americans is 19.5. Moreover, Blacks receive lower quality dialysis as measured by urea clearance.[269] Renal transplantation has been shown to substantially improve the quality and length of life for African Americans.[270,271] There are appreciable racial disparities in access to renal transplantation that are not explained by control for case-mix, patient preferences, or appropriateness for transplant.[116] These disparities are not confined to African Americans, but include other minorities including American Indians.[272-274] One example of a potential measure is the number of transplants performed per year among persons from a particular racial or ethnic group divided by the number of persons in that group currently on dialysis. Alternatively, the numerator could be the number of persons in that group referred for transplant evaluation.

Although blacks are disproportionately affected by cardiovascular disease, they are less likely to undergo invasive diagnostic or therapeutic cardiovascular procedures such as angioplasty, stenting, thrombolytic therapy or coronary bypass surgery. What is less clear is the extent to which these differences represent overuse among whites versus underuse among blacks.[117,275,276] Furthermore, blacks are more likely be operated on by lower quality surgeons,[134] and have twice the five-year mortality following coronary artery bypass as whites.[270] Assessment of disparities in these procedures is complicated by the need for sophisticated adjustment and data collection. An example of a possible measure is the number of persons from a particular racial or ethnic group undergoing a diagnostic procedure divided by the number of persons from that group admitted for unstable angina or myocardial infarction.

Similar problems plague measures for cerebrovascular disease. Although blacks have higher rates of cerebrovascular disease, much of the disparity is attributable to small vessel disease that is not amenable to surgical intervention.[277-279] Moreover, the benefit of endarterectomies is confined to subsets of patients with severe, symptomatic carotid disease in hospitals with low operative morbidity and mortality.[280] Many minorities receive care at hospitals that do not meet these standards. Moreover, regionalization of cardiac procedures within the Department of Veterans Affairs has reduced utilization of these procedures by African Americans.[281] Another example of a potential measure is the number of carotid imaging studies performed among members of a particular racial or ethnic group divided by the number of persons in that group admitted for hemispheric symptoms/stroke.

Osteoarthritis is a major cause of disability among the U.S. population and minorities are disproportionately affected.[282,283] Hip and knee replacement surgery has been shown to significantly improve patient function and quality of life. Blacks and Hispanics are less likely to receive this surgery.[284,285] The major barrier to use of this measure is determining an appropriate denominator, i.e. the number of persons of different race/ethnicity who would be potentially eligible for this procedure. Nonetheless, large racial disparities in use of this procedure warrant exploration of causes.

There are similar problems associated with using measures of curative cancer surgery; it is often difficult to adequately adjust for stage at diagnosis and severity of co-morbidity that might preclude surgery, although these data can often be obtained from local cancer registries. Nonetheless, a measure of curative cancer procedures performed divided by number of palliative surgeries for different racial and ethnic groups signals a potential quality improvement problem for health care plans: either minorities experience relative underuse of these procedures or they are being diagnosed at later stages. Thus, a disparity in this measure suggests the need for further assessment of the reasons for the disparity within a particular health care plan followed by an appropriate intervention.

Informed health care choices

HEDIS 2001 also includes a measure designed to assess the extent to which consumers have been provided with sufficient information to make informed health care decisions. For this measure, women are surveyed about counseling they received regarding the risks and benefits of hormone replacement therapy and other treatments for menopause. The measure assesses several aspects of counseling, including whether women received any counseling, the breadth of counseling, and whether or not counseling was personalized to take into account personal and family history, concerns and preferences. Rates of osteoporosis are *lower* among black women and black women who receive fewer prescriptions for hormone replacement therapy during menopause.[286] Given the findings that minorities express lower satisfaction with the quality of physician communication, this measure is relevant despite the lower rate of osteoporosis among certain minorities. Consideration should be given to developing a similar measure for Prostate Specific Antigen (PSA) testing, a screening test for prostate cancer. Death from prostate cancer is significantly higher among black men than any other group.[11]

Plan stability

Previous versions of HEDIS have included disenrollment rates by health plan. Rates of enrollment and disenrollment by race/ethnicity could serve as one index of the attractiveness of the health care plan to minorities. The measure could also be used to monitor health care plan practices designed to discourage minority enrollment. Given the concerns about misuse of race/ethnicity data by health care plans, this measure might provide a necessary safeguard.

Measures not included in HEDIS

There are many conditions that are more prevalent or more severe among minorities, but many of these conditions do not meet all the above criteria for selection. For example, rates of extreme preterm birth infants are nearly four times higher among blacks than whites and represent the leading cause of infant mortality for blacks.[287] Unfortunately, data are mixed regarding the efficacy of interventions designed to reduce preterm birth, such as screening and treatment of bacterial vaginosis during pregnancy.[288]

However, there are a number of conditions not currently addressed through HEDIS that potentially qualify based on the criteria. These include HIV infection, sickle cell anemia, pain management, and possibly group B streptococcus colonization during pregnancy. HIV infection is the third leading cause of years of potential life lost for black women and the fourth cause for black men.[11] Rates of death from HIV infection are significantly higher among blacks and Hispanics.[11] Studies have shown that interventions can improve rates of safe sex behavior.[289] Antiretroviral and prophylactic antibiotic therapy have been conclusively shown to significantly improve survival.[290] Moreover, blacks and Hispanics are more likely to receive suboptimal care.[291] Blacks are less likely to receive treatment based on existing guidelines than whites.[35,292] Hispanics have lower survival following hospitalization for HIV infection.[293] Suitable HIV measures might include rates of screening for HIV, use of effective interventions to reduce risk behavior, and medical management of HIV infection. HIV measures are currently under development by FACCT.

Sickle cell disease is one of the 10 leading causes of death for African Americans under the age of 25.[8] Americans of non-African ancestry are rarely affected. Mortality for sickle cell disease varies dramatically between regions of the country, suggesting variation in care.[294] Hospitalization costs are considerable.[295] Sickle cell screening and counseling among young adults can help to reduce rates of the disease. Comprehensive care to patients has been shown to reduce hospitalization rates,[296] and specific interventions such as prophylactic penicillin have been shown to reduce mortality. Guidelines for management have been published by AHRQ.[297] Measures related to screening/counseling and/or management of this condition seem appropriate for health care plans and/or hospitals who serve a large number of African Americans.

Minorities, particularly African Americans, are at higher risk for acute pain resulting from traumatic injury or chronic pain resulting from metastatic cancer. Accidents and homicide are the first or second leading cause of death for blacks and Hispanics under the age of 25,[8] and rates of acute trauma requiring emergency attention are considerably higher among blacks, Hispanics, and Native Americans.[298,299] As discussed earlier, blacks have significantly higher rates of death from cancer, and rates of death from certain cancers are higher among Hispanics, Asian/Pacific Islanders, and American Indian/Native Alaskans. African Americans, and Hispanics have been reported to receive less appropriate analgesia for metastatic cancer[61,62,70] and trauma.[71,300] Although HEDIS has not yet introduced pain management measures, JCAHO has established a comprehensive set of standards for pain management. Unfortunately, there is not as yet a provision for assessment of these standards by race or ethnicity.

Group B streptococcus (GBS) is the most frequent cause of neonatal sepsis in the U.S. Rates of maternal colonization, neonatal disease, and mortality are significantly higher among blacks.[179,301,302] Introduction of intrapartum antibiotics has dramatically reduced rates of infection and mortality among blacks and whites, but disparities remain.[303] One obstacle to development of a quality measure has been debate regarding the optimal protocol for screening and treatment of maternal colonization. Measures related to screening and treatment of GBS during pregnancy or pre-partum appears appropriate.

Centers for Medicare and Medicaid Services

In September 1998, CMS proposed three principles to the committee planning the National Forum on Quality that guides CMS's national performance measurement strategy. These are (1) that the performance measures should be consumer and purchaser-driven, (2) that performance measures and the collection tools needed to collect them should be in the public domain, and (3) the content and collection of data and performance measures derived from that data should be standardized. CMS's current quality initiatives include HEDIS (discussed in detail above), the Medicare Health Outcomes Survey (based on changes in the SF-36 scores over time), CAHPS previously discussed, the Disenrollment Survey (queries beneficiaries about their experiences and reasons for leaving), End Stage Renal Disease (ESRD) clinical performance measures (a set of process measures relating to provision of dialysis), outpatient measures for diabetes (claims-based measures for diabetes), and a hospital core performance measurement set under development. In 1992, the CMS and its contractors, Peer Review Organizations (PROs), initiated the Health Care Quality Improvement Program (HCQIP). HCQIP projects focus on six national clinical topics, and CMS chose these areas based on their public health importance and the feasibility of measuring and improving quality. To ensure that HCQIP efforts improve health, the management guidelines for these clinical conditions are firmly evidence based. As the following review shows, each of these measures is relevant to minorities.

Health Care Quality Improvement Program measures

Acute myocardial infarction. These include process measures that have been conclusively shown to decrease mortality from myocardial infarction. These are appropriate use/prescription of aspirin, beta-blockers, angiotensin converting enzyme inhibitors (ACEI), reperfusion therapy, and smoking cessation counseling following acute myocardial infarction. Performance in median state ranges from 85% for aspirin therapy to 40% for smoking cessation counseling.[142] As indicated previously, blacks have higher rates of mortality from myocardial infarction. Ischemic heart disease represents the leading cause of death for members of most minority and majority groups. African Americans are less likely to receive beta blockers, aspirin, and reperfusion therapy.[190]

Breast cancer. This measure approximates the HEDIS measure discussed previously. Performance in median state was 55%.[142]

Diabetes. These measures are similar to those in HEDIS discussed previously and include 3 measures: rates of glycosylated hemoglobin testing, lipid testing, and dilated eye exams. Performance in median state ranges from 71% for gylcosylated hemoglobin testing to 57% for lipid testing.[142]

Congestive heart failure. This measure is based on the proportion of heart failure discharges with appropriate use/non-use of ACEIs and assessment of left ventricular ejection fraction. Performance in median state was 69%.[142] Blacks have a higher incidence and hospitalization rate for congestive heart failure.[304,305] Findings regarding racial disparities in mortality from congestive heart failure (CHF) have been conflicting,[304-306] although blacks appear to have higher all-cause mortality with equivalent left ventricular dysfunction.[307] Careful study of hospital care shows that blacks receive less appropriate management of (CHF)[37] including lower use of anticoagulants,[308] but comparable use of ACEIs in CHF.[309] Recently published data suggest that blacks may derive less benefit from ACEIs for left ventricular dysfunction than whites,[310] but comparable benefit from certain types of beta-blockers.[311]

Pneumonia. These measures include appropriate collection of blood culture, appropriate prescription of antibiotics, and vaccination for patients hospitalized for pneumonia. Performance in median state ranges from 85% for time to antibiotic therapy to 11% for screening for pneumonia vaccination.[142] As indicated earlier, blacks have higher death rates from pneumonia/influenza, the 10th leading cause of death for blacks. Pneumonia also represents one of the 10th leading causes of mortality for each of the other minority groups. African Americans have also been reported to receive less appropriate hospital care for pneumonia.[37]

Stroke. These measures are prescription at hospital discharge for an acute stroke of an antithrombotic, e.g. antiplatelet agent or anticoagulant, avoidance of sublingual nifedipine with acute stroke, and prescription (in the absence of contraindications) at hospital discharge for atrial fibrillation of warfarin. Performance in median states ranges from 95% for nifedipine therapy to 55% for warfarin for atrial fibrillation.[142] Blacks have age-adjusted rates of death from cerebrovascular disease that are 80% or more higher than all other groups.[11] Cerebrovascular disease is the third leading cause of death for blacks and Hispanics, second for Asian/Pacific Islanders, and fifth for American Indian/Alaskan Natives. Compared to whites, African Americans are significantly less likely to receive noninvasive cerebrovascular testing, cerebral angiography, or carotid endarterectomy, or to have a neurologist as their attending physician.[188] There does not appear to be a racial disparity in prescription of anticoagulants for atrial fibrillation.[312]

Joint Commission on Accreditation of Healthcare Organizations

Although JCAHO has lagged behind NCQA in the use of outcome measures, it has recently introduced them into the accreditation process. Last year, JCAHO approved the first five ORYX core measure sets for the Hospital Accreditation Program. These include measures for acute myocardial infarction (including coronary artery disease), heart failure, pneumonia (community-acquired), surgical procedures and complications, and pregnancy related conditions (including newborn and maternal care). A number of measures in the acute myocardial infarction, heart failure, and pneumonia measure sets are derived from the CMS's PRO 6th Scope of Work, discussed above. Each of these appears appropriate for minorities as discussed under HCQIP.

There are limited data regarding racial and ethnic disparities in surgical complications. Blacks have been reported to have higher rates of mortality following coronary bypass surgery than whites[132,133] and higher complications following vascular surgery, glaucoma surgery, and endarterectomy.[313-315] The extent to which these differences represent differences in health care quality as opposed to differences in morbidity is not known. Furthermore, many hospitals do not have sufficient surgical volume or rates of major surgical complications to meaningfully compare these rates by race or ethnicity. This measure is probably not appropriate.

As indicated earlier, blacks have higher rates of preterm birth in addition to pregnancy associated infections[316,317] and other complications of pregnancy.[318,319] The extent to which these outcomes are affected primarily by underlying differences in health care quality versus differences in morbidity is not known. For example, rates of post-partum endometritis are affected by rates of bacterial vaginosis,[320,321] which differs by race.[179]

Foundation for Accountability

The Foundation for Accountability is a not-for-profit organization devoted to providing consumers with improved health care information.[322] FACCT has developed eight quality measures that relate to adult asthma, alcohol misuse, breast cancer, diabetes, major depressive disorder, health status, health risks (smoking cessation), and consumer satisfaction. Measures for end-of-life care, HIV/AIDS, and pediatrics are under development. Most of the measures are based on response to consumer surveys and generally include more detailed outcome measures than most of the HEDIS clinical effectiveness measures. The breast cancer measures include proportion of women with stage I and II breast cancer who undergo breast conserving therapy and the proportion of breast conserving surgery patients who receive radiation (based on cancer registry or claims data). As indicated previously, asthma, breast cancer, diabetes, depression, health status, and smoking represent conditions relevant to minority health care. The remaining condition, alcohol misuse is also relevant. For this measure, three dimensions are assessed: health care plan population screening for alcohol misuse, routine assessment, and experience of care/satisfaction with alcohol screening/counseling. Rates of alcohol misuse/abuse from the BRFSS are appreciably higher among American Indians/Alaskan Natives than whites, but lower among blacks and Asians.[23] The overall effect of alcohol misuse on minority health is substantial, including higher rates of accidental death, homicides, cancer, and liver disease among blacks, Hispanics, and American Indian/Alaskan Natives. Thus, alcohol misuse is highly relevant to minorities. The primary limitation to FACCT is its use of a more limited range of measures, primary reliance on patient report as opposed to claims data, and its limited use by health care organizations.

Agency for Healthcare Research and Quality

AHRQ has developed a number of quality measures. These include the previously discussed, CAHPS, Health Care Utilization and Cost Project (HCUP) Quality Indicators (QIs), and CONQUEST. HCUP QIs comprise a set of 33 clinical performance measures designed for hospitals' self-assessments of inpatient quality of care as well as state and community assessments. HCUP QIs provide a low-cost, user-friendly approach to meeting short-term information needs that support and stimulate continuous quality improvement efforts. HCUP QIs assess three dimensions of care, potentially avoidable adverse hospital outcomes, potentially inappropriate utilization of hospital procedures, and potentially avoidable hospital admissions. These measures have not been specifically designed for consumers to compare hospital performance. Moreover, as indicated previously, there are limited data regarding potentially avoidable adverse hospital outcomes including mortality by race/ethnicity. Although avoidable hospitals admissions differ by race/ethnicity, this measure primarily reflects access to primary care, not differences in the quality of hospital care.

CONQUEST is a software package designed by AHRQ that allows users to access up to 53 sets of quality measures. Although AHRQ makes no claims regarding the reliability or validity of the measures, AHRQ does screen potential measures based on explicit criteria.

CHALLENGES

There are three major types of challenges to implementing use of quality measures for health care quality provided to minority groups. These are attitudinal, conceptual/methodologic, and logistical.

Attitudinal

The first and most serious challenge to implementation is attitudinal. A focus on health care disparities is unsettling. Discovering that African Americans or other racial or ethnic minorities are denied access to life-prolonging procedures at the local hospital is qualitatively different than learning that your local hospital has a Cesarean section rate higher than the national average. Such information, when devoid of an organizational commitment to addressing the disparity, justifiably engenders resentment among affected minorities and guilt among whites. For this reason, consumer quality reports should be accompanied by reports on quality improvement efforts.

The subject of disparities often conjures up painful images from American history including slavery, overt racial discrimination, and gross denial of civil rights. Disparities remind us that race continues to matter in America, a fact often denied by whites.[323,324] For many, the solution to the problem of race in the U.S. lies in focusing less, not more, on race-related problems. Thus, some will argue that existing quality improvement efforts are designed to improve the health care of all health consumers, and that an explicit focus on racial or ethnic disparities in health care is unnecessarily divisive. Although self-serving when advanced by privileged majorities, the argument does highlight the need to approach disparities in a constructive fashion. Toward this end, the ethos of quality improvement with its non-blaming, change systems, not people stance, should prove invaluable in developing interventions to eliminate disparities whatever their cause.

Disparities have been dismissed by some as being driven exclusively by consumer attitudes and preferences associated with race or ethnicity.[135] Such an argument is neither supported by existing data nor particularly relevant. Whether disparities are primarily consumer or provider-driven has no bearing on whether disparities should be monitored by quality measures. Rather, such a question is relevant for selecting the primary target for an intervention designed to eliminate disparities.

Last, many HMO and hospital administrators may resent collecting additional quality data, particularly if these efforts are not effectively integrated into existing quality reporting or yield data that are not perceived as useful. Many health care institutions, still struggling to implement existing measures, may balk at the prospect of monitoring the quality of care provided to specific groups. They may resent investing additional time, energy and resources in this effort particularly when competition for health care resources is growing. Many hospitals across the country are struggling for financial survival. With costs often increasing faster than reimbursement rates, many HMOs have abandoned caring for Medicare or Medicaid patients. Many HMOs have yet to obtain NCQA accreditation under existing standards. Many organizations may insist that they lack the resources to successfully implement new standards. The level of institutional resistance should not be underestimated. The establishment of effective partnerships with HMOs and hospitals represents an absolutely critical step in the implementation of quality standards for minority health care. This step will require strong leadership on the part of NCQA and JCACHO, and other the major stakeholders including the NQF, HCFA, and AHRQ. It will also require convincing HMO and hospital leaders that quality data for minority groups will be appropriately adjusted and can be effectively used to improve health quality for minority group members. Success will also depend on phasing-in standards over time and on the availability of adequate funding to support pilot initiatives implemented by hospitals and HMOs.

Conceptual

There are several conceptual challenges to implementation. The first is whether to use relative or absolute standards for monitoring disparities. Which standards should be used to assess the quality of care provided to minorities: national benchmarks or measures of racial/ethnic disparity? How should the performance of an HMO be viewed which achieves rates of annual mammography among white women of 90% versus 85% for black women? The HMO has exceeded overall national benchmark for its care to black women, yet it has not achieved racial parity among its members. Clearly, both standards convey different, but nonetheless important information to health care consumers.

Absolute standards are much more feasible to implement because of sampling size requirements. For example, HEDIS sampling methodology could be replicated for each minority group. Thus, HMOs using the increasingly popular hybrid approach might sample 411 medical records for each of the main racial or ethnic groups comprising plan membership. In contrast, very large sample sizes would be required to reliably compare disparities in rates between health care plans. Sample sizes requirements of this magnitude would make use of chart reviews unfeasible and necessitate exclusive reliance on claims data. However, many health care plans are not equipped to reliably track many of the HEDIS measures exclusively through claims data. In many instances, claims data underestimate the receipt of particular services. For example, a service may be obtained outside a plan, e.g. through community-based programs offering mammography or cholesterol screening, or childhood or adult immunizations. In other instances, an appropriate prescription may be written, but never filled by the patient.

Given these constraints, it is more feasible to use absolute standards when providing consumers with information and for quality assurance. Relative standards are most appropriately used internally for quality improvement. These points can be illustrated using the HEDIS measure for beta-blockers post myocardial infarction. Plan A reports the following rates: overall-87%, whites-90% and blacks-84%. In contrast, the corresponding rates for Plan B are 79%, 82% and 62%. Based on reporting of absolute standards, each plan would report these rates to consumers with a notation that the racial gap in performance was not statistically significant between plans. To determine whether a 6% gap was statistically different from a 10% gap would likely require sampling sizes that would vastly exceed the number of persons in each plan hospitalized for myocardial infarction in the last year, if not the last decade or more. Although differences in racial gaps *between* plans might not be statistically significant, the racial gap within plans might be significant depending on sampling size. Moreover, for the purposes of quality improvement, the plans might choose to use a p value less than 0.1 as opposed to 0.05. Using this standard, Plan A might focus its efforts exclusively on boosting rates for blacks while Plan B might focus on boosting overall rates, but with a particular focus on blacks.

Another conceptual challenge is whether to adjust/stratify results by SES. SES confounds racial/ethnic disparities in care. For example, patient educational level and/or income, both of which are strongly linked to race, are powerful predictors of receipt of preventive care. Although the nature of this relationship remains uncertain, it is probably attributable to fewer preventive care visits among persons with less education, lower health care literacy, greater biopsychosocial morbidity[325] resulting in greater competing demands on the provider at the time of the office visit,[326] and probably to differences in provider-patient communication.[108] Thus, an HMO that provides care to largely affluent minority members might be expected to have higher rates of preventive care than one providing care to poorer members. Existing studies suggest that adjustment for SES affects provider[327] and HEDIS profiles for some HMOs[73] although the overall effect may be modest.[73,202] Moreover, adjustment for SES introduces an additional level of complexity into performance assessment. Plan level, as opposed to individual level, adjustment might reduce the burden on plans.[73] Further study of this question is required before a definitive recommendation can be made regarding a routine requirement for SES adjustment. Ideally, quality measures would be also be stratified and reported by SES. However, because of the added challenges of doing so, this step should probably be deferred until reporting by race and ethnicity has been fully implemented.

A third challenge is the difficulty in distinguishing health care over-use by majorities from under-use by minorities. This is not a problem for the HEDIS effectiveness, FACCT, HCQIP, or ORYX measures where process is clearly defined, but is a problem for monitoring disparities in access to surgical/invasive procedures. For example, in the absence of expert review, it is difficult to determine the appropriateness of particular procedures. For this reason, disparities in utilization should be primarily used internally for quality improvement rather than reported externally for quality assurance until the problem of appropriateness is resolved. In the interim, consideration should be given to reporting intermediate process measures. For example, dialysis units could report results from surveys that assess the extent to which patients have been adequately informed regarding transplantation options.

A final challenge involves selection of racial and ethnic categories. Should reporting be limited to the four major minority groups or should additional subgroups be included? Should a multiracial or multiethnic category be included? These questions are best resolved following input from the different groups and careful consideration of statistical power.

Logistical

Logistical criteria used to select measures for the general population are also applicable to implementing measures for minorities. Because most measures have been screened based on use of these criteria with the general population, many of the criteria for use with minorities have also been satisfied. For example, the measures are measurable, achievable, feasible, and scientifically sound. The major challenges relate to data collection burden and costs and reporting formats and timeliness.

There are two data collection challenges: collection of race and ethnicity data and sampling considerations. Availability of race/ethnicity data differs between types of health care organizations. Most hospitals collect race/ethnicity data, although uniform methods for doing so have not been implemented. Nonetheless, hospitals could begin by stratifying their existing performance measures by race/ethnicity when currently feasible. They could add race and ethnicity to existing satisfaction surveys. Consideration should also be given to having CMS provide hospitals with health care quality reports for elderly minorities based on analysis of Medicare claims data. However, the timeliness of the reports would become an important consideration.

Absence of race/ethnicity data is a major barrier for HMOs, very few of which have these data on plan members. There are several potential solutions. The simplest approach is to collect data on members at the time of their enrollment in the plan. During this time, when members choose a health care plan and physician, members could indicate their race and ethnicity and their family's members. Socioeconomic data, such as educational level, could also be obtained at this time. This approach would require changing the information required for enrollment. A second, though less desirable option, is to collect data at the point of service. Providers could ask patients to self-identify their race/ethnicity at the time of their visit and then submit these data with their claims or separately with capitation. The problem with this approach is that providers may have different ways of collecting these data. Receptionists may be uncomfortable asking consumers to self-identify their race/ethnicity and may infer this information based on the patient's appearance or surname. Furthermore, data would not be available for members who did not yet register a visit. Other approaches such as use of geocoding to classify race/ethnicity based on community of residence misclassify large numbers of persons and introduce potential bias, e.g. more affluent blacks residing in predominately white neighborhoods would be misclassified as would poor whites living in predominately black neighborhoods. On balance, the first approach is likely to prove to be the most reliable and valid.

Sampling considerations also pose a challenge. Most HMOs currently use a hybrid method for data collection for HEDIS. Claims data are supplemented with manually collected medical record data. NCQA standards specify that up to 411 claims or records be included in the chart review. Implementation may require that up to 411 claims or records be sampled from each of the minority groups. Presumably, hospitals and HMOs with insufficient numbers of patients or plan members from particular minority groups will be exempt from reporting for these groups. As indicated previously, sample size requirements will probably preclude comparisons of rates of disparities between plans or hospitals for most measures.

An additional sampling consideration is potential racial and ethnic bias in response to surveys. For example, if less satisfied minorities respond to surveys at lower rates than less satisfied majorities or more satisfied minorities, then rates of satisfaction among this group will be underestimated. This bias may have contributed to the failure of the CAPHS to show differences in satisfaction rates by race and ethnicity. This problem warrants further study and consideration.

Last, consideration should be given to providing consumers with timely, comprehensible reports. Given the complexity of comparing multiple measures across 5 different groups, the challenge of doing so should not be understated. However, this important problem is discussed in detail in another paper.

CONCLUSION

There are large racial and ethnic disparities in health outcomes and health care quality in the United States. Among the major racial and ethnic groups, African Americans experience the highest mortality rates. However, disparities in process and outcome, at least for some health conditions, affect all the major minority groups. Although existing quality measures have been seldom used to monitor the quality of health care provided to racial and ethnic minorities, most measures are suitable for doing so. However, the challenges of implementing these measures for this purpose cannot be underestimated. Committed leadership on the part of the major stakeholders will be critical to success. Funding will be necessary to support pilot projects designed to assess the feasibility of particular measures for this purpose. Use of these measures will require that hospitals, HMOs and other health care organizations develop uniform, reliable and valid methods for collecting race and ethnicity data on patients or health plan members. Larger sample sizes will be required to obtain valid estimates of performance for specific groups. For conditions not currently addressed by existing measures such as management of HIV or sickle cell disease, additional supplementary measures will be required. In some instances, such as CAHPS, measures may need to be revised to capture important aspects of care including respect, communication, and trust.

RECOMMENDATIONS

1. The major stakeholders in health care quality, particularly NCQA and JCAHO, should consider formally committing to the elimination of disparities in health care by incorporating this goal into their mission statements. Once this critical step has been taken, successful implementation becomes a central organizational challenge. Such leadership will prove vital as health care organizations struggle to address the challenges of using current measures to monitor the quality of health care provided to minorities.

2. To minimize burden to health care organizations, use of measures for minorities should be gradually phased-in over time.

3. Selection of initial measures should be based in part on the ready availability of race or ethnicity data for that measure, e.g. CAHPS ratings or hospital discharge data. This process has in fact begun. NCQA will be providing detail-level CAHPS survey results by race to employers, health care plans and others.[328] Other survey data that could be easily stratified by race and ethnicity because it is collected by surveys that include self-identified race and ethnicity are receipt of flu and pneumonia shots, smoking cessation and receipt of smoking cessation counseling, and change in health status for seniors. Similarly, JCAHO could require hospitals to include race and ethnicity on all consumer surveys and/or require hospitals to stratify ORYX results by race or ethnicity. When race or ethnicity data are not directly available, other venues for obtaining these data should be explored such as through tumor registries, the BRFFS, public payees such as CMS or Medicaid/social services offices.

4. Technical specifications for data collection and analysis should be developed that will facilitate inter-organizational comparisons of health care quality by race or ethnicity. Technical specifications for data collection and analysis should also be developed that allow health care organizations to examine intra-organizational disparities in quality by race or ethnicity for the purposes of quality improvement.

5. Requirements for reporting for different groups should be based on the number of persons in that group for whom the measure is relevant. These standards should be based on sufficient statistical power for the particular measure that is being assessed.

6. Uniform standards for the collection of race, ethnicity, and educational data by health care organizations should be developed. The standards used by the Census 2000 should be adopted with two exceptions. First, the “some other race” category should not be included since each of the traditional race categories are already included. Second, respondents should be asked, as they are in NHIS, what they consider to be their primary racial/ethnic identification. Ideally, these data should be collected at multiple points, e.g., upon HMO enrollment, hospital admission, claims, and surveys. JCAHO could begin by establishing uniform procedures for hospital collection of race and ethnicity data and NCQA could do so for HMOs.

7. Health care plan enrollment/disenrollment by race and ethnicity rates should be publicly reported to avoid potential misuse of race/ethnicity data and provide consumers with important information.

8. Further study is required to determine whether the expense of adjusting for SES is justified and if so which method is optimal.

9. Funding mechanisms through AHRQ, the CDC, and CMS should be developed to sponsor HMO and hospital pilot initiatives to begin tracking and addressing disparities in health care.

10. Priority should be given to the development of measures related to conditions that disproportionately affect minorities that are not currently included in most performance sets. HIV/AIDS and sickle cell disease represent notable examples.

11. Uniform standards should be developed for assessing disparities in use of surgical/invasive procedures. Particular attention should be given to measures related to “informed choices” such as alternative to hemodialysis including peritoneal dialysis and transplantation, and discussion regarding invasive options for the management of coronary artery disease.

12. Criteria should be developed in order to prioritize the order in which measures stratified by race and ethnicity are introduced.

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TABLE 1. AGE-SPECIFIC CAUSE OF NON-ACCIDENTAL DEATH FOR WHITES IN THE U.S., 1996

RANK	CAUSE OF DEATH
1.	Heart disease
2.	Lung cancer
3.	Stroke
4.	Chronic lung disease
5.	Breast cancer
6.	Prostate cancer
7.	Pneumonia and influenza
8.	Diabetes
9.	Colorectal cancer
10.	Suicide

TABLE 2. AGE-SPECIFIC CAUSE OF NON-ACCIDENTAL DEATH FOR BLACKS IN THE U.S., 1996

RANK	CAUSE OF DEATH	RELATIVE RISK (COMPARED TO WHITES)
1.	Heart disease	1.48
2.	Lung cancer	1.26
3.	Stroke	1.80
4.	HIV/AIDS	5.75
5.	Prostate cancer	2.50
6.	Homicide	6.24
7.	Diabetes	2.40
8.	Breast cancer	1.34
9.	Pneumonia & Influenza	1.46
10.	Chronic lung disease	0.83

TABLE 3. AGE-SPECIFIC CAUSE OF NON-ACCIDENTAL DEATH FOR HISPANICS IN THE U.S., 1996

RANK	CAUSE OF DEATH	RELATIVE RISK (COMPARED TO WHITES)
1.	Heart disease	0.68
2.	Stroke	0.80
3.	Diabetes	1.57
4.	HIV/AIDS	2.26
5.	Lung cancer	0.40
6.	Breast cancer	0.65
7.	Cirrhosis	1.73
8.	Homicide	2.50
9.	Pneumonia & influenza	0.80
10.	Chronic lung disease	0.41

TABLE 4. AGE-SPECIFIC CAUSE OF NON-ACCIDENTAL DEATH FOR ASIAN-PACIFIC ISLANDERS IN THE U.S., 1996

RANK	CAUSE OF DEATH	RELATIVE RISK (COMPARED TO WHITES)
1.	Heart disease	0.55
2.	Stroke	0.98
3.	Lung cancer	0.45
4.	Pneumonia & influenza	0.81
5.	Breast cancer	0.65
6.	Diabetes	0.73
7.	Chronic lung disease	0.40
8.	Colorectal cancer	0.65
9.	Suicide	0.52
10.	Prostate cancer	0.66

TABLE 5. AGE-SPECIFIC CAUSE OF NON-ACCIDENTAL DEATH FOR AMERICAN INDIAN-ALASKAN NATIVES IN THE U.S., 1996

RANK	CAUSE OF DEATH	RELATIVE RISK (COMPARED TO WHITES)
1.	Heart disease	0.78
2.	Diabetes	2.32
3.	Lung cancer	0.63
4.	Stroke	0.86
5.	Cirrhosis	2.83
6.	Pneumonia & influenza	1.15
7.	Suicide	1.12
8.	Breast cancer	0.64
9.	Chronic lung disease	0.59
10.	Prostate cancer	0.73

TABLE 6. DISPARITIES IN HEALTH CARE BY RACE AND ETHNICITY

HEALTH CARE MEASURE	Blacks	Hispanics	Asians/Pacific Islanders	American Indians/Native Alaskans
Preventive health	+			
Prenatal care	+			+
Child immunizations	+	+		+
Well child visits	+	+		
Adolescent immunizations	+			
Pap smear screening	+/-	+	+	
Mammography	+/-	+	+	
Sigmoidoscopy	+			
Influenza immunizations	+	+	+	
Pneumococcal immunizations	+	+		
Smoking cessation advice	+			
Medical treatment				
Control of hypertension	+			
Management of diabetes	+			
Management of asthma	+	+		
Management of pneumonia	+			
Lipid management post MI	+/-			
Beta blockers post MI	+	+		
Management of CHF	+			
Management of stroke	+	+		
Management of depression	+			
Management of HIV	+	+		
Management of acute pain	+	+		
Management of chronic pain	+	+		
Management of dialysis	+			
Surgical and invasive procedures				
Joint replacement	+	+		
Invasive cardiac procedures	+	+	+	
Invasive cerebrovascular procedures	+			
Oncological surgery	+			
Organ transplantation	+	+		+

TABLE 7. APPROPRIATENESS OF EXISTING QUALITY MEASURES FOR MINORITIES

MEASURE	Blacks	Hispanics	Asians/Pacific Islanders	American Indians/Native Alaskans
NCQA - HEDIS				
Childhood immunizations	+	+	+	+
Adolescent immunizations	+	+	+	+
Mammography screening	+	+	+	+
Pap smear screening	+	+	+	+
Chlamydia screening	+	+	?	+
Hypertension control	+	+	+	+
Beta-blocker post MI	+	+	+	+
Cholesterol mgt post MI	+	+	+	+
Diabetes management	+	+	+	+
Asthma management	+	+	+	+
F/U for psychiatric hosp	+	+	+	+
Depression mgt	+	+	+	+
Advice to quit smoking	+	+	+	+
Influenza vaccinations	+	+	+	+
Health status of seniors	+	+	+	+
Pneumonia vaccinations	+	+	+	+
Access availability measures	+	+	+	+
Satisfaction with care	?	?	?	?
Use of services	+	+	+	+
Informed health choices	+	+	+	+
Plan stability	+	+	+	+
CMS – PRO				
Acute myocardial infarction	+	+	+	+
Breast cancer screening	+	+	+	+
Diabetes mellitus	+	+	+	+
Congestive heart failure	+/-	+	+	+
FACCT				
Asthma	+	+	+	+
Alcohol misuse	+	+	+	+
Breast cancer	+	+	+	+
Diabetes	+	+	+	+
Depression	+	+	+	+
Health status	+	+	+	+
Smoking cessation	+	+	+	+
Consumer satisfaction	+	+	+	+

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TABLE 7. APPROPRIATENESS OF EXISTING QUALITY MEASURES FOR MINORITIES (continued)

MEASURE	Blacks	Hispanics	Asians/Pacific Islanders	American Indians/Native Alaskans
JCAHO - ORYX				
Acute MI	+	+	+	+
CHF	+/-	+	+	+
Pneumonia	+	+	+	+
Surgical complications	+	+	+	+
Birth complications	+	+	+	+

Appendix C

QUALITY OF CARE MEASURES OF SPECIAL SIGNIFICANCE TO MINORITY POPULATIONS

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ABSTRACT

The literature on racial/ethnic disparities in health care clearly shows disparities in quality of care that adversely affect members of minority groups. Disparities exist for many different clinical conditions, settings of care, treatment modalities, and provision of preventive services. Standard quality of care measure sets (e.g., HEDIS, ORYX) include measures that address some of the most significant areas of disparity, but there are important areas not covered in those measure sets.

The clinical conditions of greatest significance to minority populations in terms of prevalence, morbidity, and mortality are essentially the same as those of significance to non-minority populations. These include heart disease, cancer, diabetes, asthma, stroke, HIV/AIDS, and prenatal/well-child care. There are a few conditions of unique significance to one or more minority groups (e.g., sickle cell disease), but for the most part the clinical conditions, evidence-based guidelines, and quality of care measures of greatest significance do not differ between minority and non-minority populations.

Within these major clinical conditions, though, it is possible to identify potential quality of care measures not currently included in standard measure sets that would be of special value for improving quality of care in minority populations and reducing disparities. These measures either address processes of care or outcomes where problems are more frequent in minority populations (e.g., lower-extremity amputations for diabetes) or areas with documented disparities in quality.

In addition to the standard challenges of quality measurement and reporting (accurate coding, completeness of data, timeliness of information), measures for minority populations will also have to deal with challenges of accuracy of data on race/ethnicity and adequacy of sample size.

OVERVIEW AND INTRODUCTION

There is a large and continually growing literature documenting disparities in health among racial and ethnic groups in the U.S.[1-4] With rare exceptions, African-American, Hispanic or Latino, and Native Americans are at a disadvantage on health indicators such as life expectancy, infant mortality, cancer survival, and incidence or prevalence of many diseases or risk factors for disease.

Some of the disparities in health status among groups can be linked to differences in economic conditions (e.g., income disparities), education, exposure to environmental hazards, and, in some cases, genetic predisposition to disease (e.g., higher prevalence of Type II diabetes among specific Native American tribes).[5-8] However, it is clear that a significant contributing factor to disparities in health is disparity in quality of health care provided to members of different racial/ethnic groups.[9,10]

Some of the disparities in receipt of health services can be linked to differences in insurance status and other indicators of access to care whose causes and solutions lie outside the health care system per se, but some are clearly appropriate to label as disparities in quality of care.[11]

Improving quality for health care in general requires:

- A science base from which conclusions can be drawn about relationships between diagnostic tests and treatments and desired patient outcomes;
- A conceptual framework for defining key dimensions and measures of quality, and setting priorities among the very large number of potential processes or outcomes of care that could be analyzed;
- A generally accepted “technology of measurement” – common vocabulary, operational definitions, categories, and numeric coding systems for key events related to quality of care;
- A system by which individual clinicians and larger organizations collect, analyze, and report quality-related data using standard definitions in order to allow comparisons across similar entities;
- A system of feedback within organizations so that data on quality can both prompt efforts at process change but also guide those change efforts in the direction of positive impact.

In addition, improving quality of care for members of racial/ethnic minority groups will require focused attention to key clinical areas where disparities exist, as well as a detailed understanding of the reasons for disparities and the changes in underlying processes that would be required to elimYinate them. This focused attention and analysis will inevitably require an expansion of our ability to measure and report quality of care for members of racial/ethnic minority groups.[12]

The purpose of this paper is to promote discussion of a set of quality of care measures that would serve as a catalyst for quality improvement efforts aimed at eliminating disparities in care. The measures either:

- focus on conditions of high prevalence and known quality problems in minority populations or,
- focus on conditions with known large disparities among groups in quality of care.

The paper will identify those clinical conditions of greatest impact among minority populations and identify potential quality of care measures in those conditions that are not already included in existing standard measure sets.

RACIAL/ETHNIC DISPARITIES IN QUALITY OF CARE

A significant scientific literature already exists about disparities in quality of care and possible reasons for those disparities. A number of excellent summaries of this literature have been published in the past two years[9-11], so it is not necessary to provide a detailed review here. There are some key points, though, that should be made in order to provide a context for discussion of measures and potential quality improvement efforts.

Basic Findings on Disparities in Quality

Preventive Services

The Guide to Clinical Preventive Services[13] provides a comprehensive summary of recommended preventive services for the complete spectrum of clinical conditions, and bases those recommendations on published scientific evidence on the value of those services. Guidelines issued by medical specialty societies and groups like the American Cancer Society also make recommendations about disease prevention and early detection services. In general, members of minority groups have been less likely to receive recommended preventive services than have Whites. Sample findings include:

- African American and Hispanic women have traditionally been less likely to receive screening mammograms than their White counterparts,[14] but these differences seem to have been eliminated in recent years.[15] Follow-up of abnormal mammograms and subsequent steps in the diagnostic and treatment process continue to be concerns, though.[16]
- African American and Hispanic children are less likely than their White counterparts to be up to date with recommended childhood immunizations.[17]
- African American, Hispanic, and Asian/Pacific Islander adults are less likely to have had pneumococcal immunizations than their White or Native American counterparts.[18] A similar pattern is seen for flu shots, except that Native American rates are lower than White rates and rates for all minority groups are below Healthy People 2000 targets.
- Pregnant women who are members of minority groups are less likely to start prenatal care in the first trimester, less likely to have adequate prenatal care according to a recommended schedule of visits, and less likely to receive adequate information during prenatal care on risk factors like cigarette smoking and alcohol use.[19,20]

Some of these disparities have a clearer link to measurable health status outcomes than others. Having early and adequate prenatal care has been linked to better outcomes in terms of avoiding low birthweight and its sequelae,[21,22] but there are marked differences in preterm birth and low birthweight rates between African American and Hispanic women, even though receipt of prenatal care services is comparable.[23] Although mammography rates are now similar between African-American and White women, follow-up of abnormal mammograms, stage of cancer at diagnosis, and survival are all still significantly different.

In choosing preventive care measures for a set focused on disparities in care, there should be a preference for preventive services that have a clear cause-and-effect link with significant health outcomes. That is, focused quality improvement efforts that reduce disparities in service provision should also have the effect of reducing disparities in health outcomes. A quality of care measure set must also include more than just access to preventive or screening services if it is to paint a comprehensive picture of quality of health care, since improved screening or early detection is not going to have an effect on outcomes if the subsequent steps in the process of diagnosis and treatment are not followed. A set of measures related to care of a major clinical condition like cancer or heart disease should include a range of primary prevention, diagnosis, secondary prevention, treatment, education, and late-stage care measures.

Surgeries and Other Invasive Procedures

One cannot automatically assume that higher rates of surgical procedures are better when analyzing rates in populations, but in situations where the benefits of a procedure have been clearly established (at least in the presence of specific indications), and where there is little evidence of inappropriate overuse, it can be assumed that disparities in rates of procedures among racial/ethnic groups reflect poorer quality of care for the group with the lower rate(s). There are many examples of disparities in rates for surgeries and other invasive procedures, particularly in the area of heart disease:

- In a large study of Medicare beneficiaries, African American patients (particularly women) were less likely to receive reperfusion therapy (either thrombolytics or angioplasty) than their White counterparts. Even after allowing for some differences in clinical characteristics, the rates were significantly different between African American men or women and White men.[24]
- African American patients were only 2/3 as likely as White patients in New York to receive bypass surgery, even when analysis was confined only to patients who met RAND criteria for appropriateness of surgery.[25]
- Even when African American patients receive bypass surgery, they are more likely to by operated on by a surgeon with higher risk-adjusted mortality rates (New York State system) than White patients.[26]
- African American men in the VA system were less likely than their White counterparts to receive carotid endarterectomy procedures. Adjusting for differences in clinical presentation accounted for some of the difference, but a residual effect for race remained even after clinical differences were included in the model.[27]
- Other minority groups have also been shown to be less likely to have bypass surgeries and other invasive procedures for heart disease.[28,29]

The New York state study suggests that analysis of quality of care in the area of surgical procedures should not only include rates of procedure in defined populations, but also information on other aspects of quality of care in domains of both process and outcome. Careful analyses of the effects of different clinical presentations and comorbidities or risk factors in different racial/ethnic groups will also be required in order to avoid exaggeration of the size of disparities. Even though all observed disparities do not go away with adjustment for clinical factors, the size of the originally observed disparities generally is reduced through adjustment.

Use of Medication

The literature on medication use is not as large as that for either preventive/screening services or surgical procedures, but there is evidence that minority patients are less likely to receive adequate antidepressant therapy[30], adequate pain control in ER and other settings,[31,32] and adequate doses of adjuvant chemotherapy for Stage II breast cancer.[33] African-American children with asthma are more likely to have prescriptions for (and use) "rescue" medications than are White children; the opposite pattern is true for longer-term "preventive" medications (inhaled corticosteroids and other anti-inflammatory medications).[34]

Analysis of patterns of medication use is somewhat more technically complex than analysis of preventive services or surgical procedures, since some of the essential information cannot be found in administrative databases. One may know whether a particular prescription was filled (i.e., paid for by an insurance company), but not whether the medications were taken or whether the dose prescribed was adequate for the patient's individual characteristics (e.g., body mass for cancer chemotherapy). Analysis of adequacy of medication actually received typically requires medical record review, patient interviewing, or both.

Other Quality Domains

Although results are occasionally hard to interpret, there is evidence of differences across racial/ethnic groups in surveys of satisfaction with care or problems with care.[35,36] The results are hard to interpret because the findings may reflect different cultural expectations about care or cultural patterns of use of rating scales and adjective descriptions. Differences for some groups may also reflect problems in use of English-language surveys for people whose first and preferred language is something else. Nevertheless, the patterns of findings are similar to virtually all other areas of quality of care – disparities in the direction of lower levels of satisfaction and higher levels of problems reported by members of minority groups.

Explanations for Disparities

A variety of explanations have been put forward for disparities of the kinds listed above. Some of them relate to quality of care (in the sense of processes controllable by health plans, hospitals, or providers) and others do not.

Economic access to care in the form of having health insurance is perhaps the most obvious explanation. If minority groups are less likely to have good health insurance (or health insurance at all), then members of those groups will almost certainly receive less care. In cases where services are clearly beneficial, then less care means lower quality. There is no question that members of some minority groups (African-American and Hispanic primarily) have less access to health insurance than other groups. Members of those groups are more likely to be uninsured and more likely to be insured through public programs (i.e., Medicaid) than are White or Asian/Pacific Islander groups.[37]

When studies have been able to take insurance status into account, some, but not all, of the disparities in care across groups go away.[38,39] Some remain, though, and some disparities have been reported among members of a single managed care plan, in the VA system, or among Medicare beneficiaries. Insurance is part of the disparity story, but it is not the whole story.

Other socioeconomic factors, like education, income, primary language spoken at home, marital status, and household composition, have also been shown to play a role in quality of care, but again, there are still effects for race/ethnicity that remain after these factors have been taken into account.

A mix of cultural and social beliefs can affect quality as measured by standard measures of services provided to a population. Beliefs about surgery, beliefs about the natural history of disease, beliefs about value of traditional or alternative medicine vs. “western” medicine, trust in doctors and hospitals, and language barriers in communications about health care all play a role in determining whether a patient, or a group of patients, receives a particular service. There is some evidence that beliefs about surgery, for example, affect avoidance of cancer surgery among members of minority groups, and that beliefs about research and trust in the medical care system affect enrollment in clinical trials.[40,41] These factors tend to be small, though, as explanations for observed disparities in rates of invasive surgical procedures.[25]

Prejudice or racism is another explanation for observed disparities in quality of care.[9] Individual racism refers to attitudes or beliefs on the part of clinicians, support staff, or administrators that members of minority groups either do not need, or deserve, or want, good health care. Those attitudes, when translated into behaviors like withholding of services, poor communication, outright hostility, result in lower quality of care. Institutional racism[42,43] is a more difficult concept, since it does not usually refer to a specific behavior or process that can be modified by QI methods. The term refers to a set of organizational policies, procedures, rules, structures, and other characteristics that have the effect of disparities in care. Translating this abstract term into a specific set of behaviors or processes, and then into formal quality measures, will be an important step forward in eliminating both the racism and the resulting disparities.

In the context of measuring and reporting quality of care for minority patients, and in using the data for process improvement purposes, some of the explanations above are more useful than others. Access to health insurance, for example, is a very important public policy issue, but is not under the control of health care organizations, and not directly related to many of the controllable diagnostic or treatment processes at the individual clinician or facility level. Similarly, many aspects of education, income, family structure, or language or literacy patterns are significant public policy issues whose solutions lie outside the acute care system.

This does not mean that such factors should be ignored by health care providers, or that health care providers should be "excused" for providing lower quality of care to poor, or uninsured, or poorly educated patients. It is possible to build statistical models for calculating and reporting quality of care measures that would essentially "eliminate" all the variance in the measures due to socioeconomic factors. Such an approach would assume that lower levels of quality are inevitably associated with these factors, and that those differences should be statistically controlled for in (and thereby eliminated from) quality reports. It would seem better to stratify quality reports for meaningful socioeconomic groups (whose definition would vary somewhat by region of the country) so that disparities can be seen clearly and used as a catalyst for QI efforts.

BASIC CONSIDERATIONS IN MEASURING AND IMPROVING QUALITY OF CARE FOR MEMBERS OF MINORITY POPULATIONS

Many basic concepts about measuring and improving quality of care are generally well accepted, and would not change with a focus on care of minority populations. These include a general definition of quality of care from the IOM: "…the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[44]

Within the general concept, Donabedian's distinction[45] among structure, process, and outcome dimensions is widely used and accepted, and the more recent distinction of overuse, underuse, and misuse is also widely used.[46]

There is general acceptance of the concept of "evidence-based medicine"[47] as the underlying philosophy for quality of care measurement, but there is still considerable debate, generally set in the context of managed care, about whether good quality for any individual patient involves trading off costs and benefits to achieve the greatest benefit in a larger group of people.[48-50] In the context of quality of care for minority populations, there is also a question of whether scientific conclusions and guidelines (and related quality measures) based on research in non-minority populations can be generalized to minority populations.[51] The fact that race and ethnicity are largely social, rather than biological, categories suggests that generalizing results of basic laboratory studies and clinical trials across groups is legitimate. On the other hand, if prevalence of disease or prevalence of complications or comorbidities varies across racial/ethnic groups, the relative importance of various quality measures, or the significance of process measures as predictors of outcome may vary.

Existing Measurement and Quality Improvement Initiatives

In the past ten years, an impressive set of national, regional, and local quality measurement and reporting systems has been developed. Except when they may be used for special research projects, none of these report quality of care separately for racial/ethnic minority groups.[52]

The Health Plan Employer Data and Information Set (HEDIS) is perhaps the best known standard performance measure set; it is the national standard for managed care plans.[53] The National Committee for Quality Assurance (NCQA), the sponsoring organization for HEDIS, does not require health plans to report HEDIS data separately by race/ethnicity, although the issue has come up in discussion (Greg Pawlson, personal communication). Health plans are not required to collect data on race/ethnicity of their members and most plans do not. Many believe that they are forbidden by state or federal law from doing so, even though this is not true.[54]

The Joint Commission's ORYX system provides a similar set of standard measures for hospitals. Hospitals do generally have data on race/ethnicity of patients, but hospitals are not currently required to report ORYX data separately by race/ethnicity.

A number of specialized state or regional quality measurement/improvement systems (e.g., New York State Cardiac Surgery system, Pennsylvania Cardiac Surgery System, Northern New England Cardiac Surgery Study Group) include detailed clinical and demographic information on patients; they can and have been used for special studies of quality of care for minority populations.[55] They haven't yet, though, been used for routine public reporting of quality of care information for minority groups.

The Organizational Context of Quality Measurement and Quality Improvement

Quality of care is a property of some defined entity – an individual clinician, a group of clinicians, a hospital, a health plan, a region, or perhaps the entire country. All of these organizations are presumably motivated to improve quality of care in general, or to improve quality of care for members of minority groups specifically, but some are more motivated or more able than others. Health plans are subject to explicit annual quality measurement and reporting, but almost never have data on race/ethnicity that would allow them to focus their QI efforts on specific groups. Hospitals have data on race/ethnicity of their patients (are required to do so to fulfill Title VI of the 1964 Civil Rights Act), but may not have data on race/ethnicity linked to the same databases that are used for quality measurement or quality improvement programs. For example, a field for race/ethnicity may be included in a patient registration and scheduling system, but not be included in an E.R. log that would be used to track "door-to-needle" times for administration of thrombolytics.

Individual clinicians or medical groups may have data on race/ethnicity (either in their patient registration systems or informally in individual patient records), but they are not required to collect or use data on race/ethnicity, so the completeness and accuracy of data are often questionable. Geographic areas have detailed census data on the race/ethnicity of resident populations, but it is difficult to link those data with data on health care services provided by organizations in those areas.

Data on race/ethnicity in any of these systems can be inaccurate[56] and data for the same patient in different data systems may be inconsistent within the same organization or program of care.[57] It is not clear how significant either of these problems is for purposes of measuring disparities in quality of care at various organizational levels. Inaccurate classification of individuals adds error variance to studies of disparities and may serve to hide real differences in quality of care, but would probably not bias the direction of observed differences. Inconsistent classification within an organization (or across any two data systems) causes a technical problem with assigning individuals to denominator populations, but does not necessarily cause bias if an assignment rule is developed and followed consistently.

Using Information on Disparities in Quality

All these organizations have two general reasons for wanting to incorporate race/ethnicity into quality measurement activities. One is "external" – the desire to provide information to purchasers, individual consumers, and the community in general about quality of care. The information is presumably used by those individuals and groups to make informed decisions about which health plans to join, which hospitals to go to, and which physicians to visit. The other is "internal" – the desire to improve processes and outcomes of care, either in general or for members of specific minority groups. Quality information is used by teams of clinicians, support staff, and managers to modify processes.

Health care organizations of all types would have no incentive to publicly report data on disparities in quality of care or on low levels of quality for minority patients. Those same organizations would, though, have an incentive to report data on absence of disparities or high levels of quality, particularly if they serve communities with significant minority group presence. Since purchasers, rather than health plans or health care providers, have been leading most public reporting initiatives though, local purchasers and other community groups (including state and federal Offices of Minority Health) can advocate for public reporting, even among organizations with significant disparities and/or low levels of quality.

There is no similar lack of incentive for the use of race/ethnicity data to drive internal QI efforts aimed at reducing disparities. Health plans, hospitals, medical groups, and other types of health care organizations have invested in quality improvement infrastructures and have made some impressive gains.[58] Resources are always limited, though, and QI efforts are typically focused on those issues of greatest significance to organizational leaders, purchasers, or regulatory agencies.

The fact that discussions about measuring and reporting quality of care for members of minority groups is relatively new suggests that the issue has not been a high priority to date for most health plans, providers, and purchasers. That situation is rapidly changing, though, as evidenced by the 1998 President's (now referred to as HHS) Initiative on Eliminating Disparities and subsequent actions by NIH, CMS, AHRQ, HRSA and other federal agencies.[59] New research programs, organizational structures, and QI initiatives are all moving forward. Support in the private sector is also increasing, with foundations like the Commonwealth Fund and the Kaiser Family Foundation actively supporting projects in quality measurement and quality improvement for members of racial/ethnic minority groups.[60] Private purchasers have not been as highly visible in promoting QI initiatives in minority populations, but existing local, state, regional, or national purchaser coalitions can be a powerful catalyst for change when they see a problem and can agree on a path to a solution.[61]

While the new initiatives hold great promise as avenues for improving quality of care, some key problems stand in the way:

- Except for hospitals, most providers and health care organizations do not have data on race/ethnicity of members or patients, and cannot easily generate quality data that includes race/ethnicity.
- Existing studies of disparities in quality of care are frequently dismissed as being fundamentally about large societal factors (income, education, insurance status, cultural preferences) outside the control of the health care system.
- Parallel demands by purchasers on providers to control costs and improve quality have "squeezed out" much of the opportunity for new QI initiatives or projects that focus on special populations. Until major public and private purchasers ask plans and providers to work on improving quality for minority groups, it is unlikely that time and effort will be focused on that objective.

The last problem is perhaps the most significant, since technical improvements in QI (i.e., including data on race/ethnicity in data bases used for quality measurement or adding focus areas of special interest to minority patients) all require resources that can be directed elsewhere. If purchasers or regulators require health care organizations to improve in the areas of patient safety, childhood immunization, and cancer screening, resources will be devoted to those problems and performance will improve. If purchasers or regulators push for reductions in racial/ethnic disparities with equal or greater intensity, resources will be devoted to disparity issues and disparities will be reduced.

The need for focused quality improvement efforts is clear, and the opportunity is great. The existing published literature on disparities clearly shows the need. The expanding federal research support will help clarify our understanding of disparities and what to do about them. A commitment on the part of purchasers, health plans, providers, and the community in general to eliminating disparities will provide the context and support for actual system change.

HIGH-PRIORITY CLINICAL CONDITIONS

Several researchers and QI experts have already developed systems for prioritizing measures and improvement initiatives.[62-64] One of the main criteria is the significance of the clinical condition for which preventive, diagnostic, or treatment services are given. Criteria for significance, in turn, reflect several factors:

- Prevalence of the condition in the defined population
- Extent to which the condition is associated with mortality
- Extent to which the condition is associated with significant morbidity, disability, or decrement in quality of life
- Extent to which the condition affects young people and/or has a long-lasting impact
- Extent to which known preventive, screening, diagnostic, or treatment procedures can affect the trajectory of the condition
- Extent to which the condition and its treatment are associated with high cost
- Extent to which the services provided for the condition are known to have either high variability or low quality.

The following clinical conditions meet most or all of these criteria, are included in most existing quality measure sets, and have been the focus of studies of disparities in quality of care:

Heart Disease

Heart disease is the leading cause of death for both minority and non-minority populations.[65] There is also significant morbidity associated with heart disease in both minority and non-minority populations.[66] In addition to its clinical and population health significance, heart disease is an attractive area for quality measurement and quality improvement because the underlying mechanisms of disease are relatively well understood, and there is reasonable consensus about best practices in the areas of primary prevention, secondary prevention, acute treatment, and post-acute event care.[67] For purposes of discussion in this paper, the term “heart disease” includes hypertension as a risk factor, coronary artery disease, and congestive heart failure. Other, rarer, conditions that affect the heart (e.g., endocarditis) will not be discussed.

Cancer

Although there are some exceptions, incidence rates for many cancers are not higher in minority than in non-minority populations. Mortality rates among those with disease, though, almost always are.[65] Cancer is the second leading cause of death among all minority groups (all ages combined). Cancer is actually a heterogeneous set of diseases from a quality measurement perspective. Some cancers (breast cancer in particular) have well-developed screening, diagnostic, and treatment guidelines, with related quality measures that are already in common use. Other cancers are not well-suited to quality measurement programs, either because there is little consensus about clinical best practices, or because it is not clear that preventive or treatment interventions have much impact on the overall course of disease.[66] For purposes of discussion in this paper, most of the recommendations about quality measures will have to do with breast cancer, but some attention will also be paid to lung and colon cancer. Some potential measures (e.g., rate of participation in clinical trials, adequacy of dose of chemotherapy) can apply across a range of cancer sites and stages.

Diabetes

Type I diabetes is not particularly prevalent in minority populations, but Type II diabetes is more prevalent in African-American, Hispanic, and Native American populations than in the Caucasian population.[67] Diabetes is not only a significant clinical condition in its own right, but it is a precursor condition for heart disease, kidney failure, blindness, and microvascular disease that leads to limb amputation.[68] Since complications affect members of minority groups disproportionately,[69] quality measures that reflect methods of preventing complications are of particular value. There are widely accepted guidelines and related quality of care measures for care of both Type I and Type II diabetics.

Pregnancy and Childbirth

The elevated rates of low birthweight, preterm birth, and infant mortality in many minority groups suggests the inclusion of pregnancy and birth outcomes in a quality measure set. There are generally accepted guidelines and quality measures for some basic elements of prenatal care (e.g., starting prenatal care in first trimester of pregnancy).[70] These guidelines are based on correlational studies that associate aspects of the prenatal care process to either birth outcomes or infant mortality. It is not clear, though, that improving access to prenatal care can have a positive influence on birth outcomes.[71] Even though there is evidence of disparities in receipt of prenatal care, and even though there is correlational evidence of a process-outcome relationship, a global measure of prenatal care may not be particularly useful as a means to reduce disparities in birth outcomes because process improvement may not produce outcome improvement. There may, though, be better evidence for a causal link between specific elements of prenatal care (e.g., smoking cessation) and birth outcomes, so measures of provision of those specific elements of recommended prenatal care may be more useful.

Stroke

Stroke is one of the leading causes of both morbidity and mortality in minority populations. There is evidence of higher incidence of stroke in minority populations,[72] and evidence of disparities in both quality of care and outcomes.[73] Quality of care measures for stroke are not included in some standard quality of care measure sets (e.g., HEDIS, QA Tools system), but are in the HCFA 6th Scope of Work measure set and in HCFA's Health Care Quality Improvement Program (HCQIP). The absence of stroke measures in some measure sets may reflect a relative absence of well-accepted guidelines until recently or a wide range of treatment options available once stroke occurs. (Administration of tPa is one treatment and a candidate quality measure, but the key issue is often one of patient or family delay in seeking care rather than actions of the health care system itself.) Quality measurement can, though, focus on some of the key areas of risk factor reduction – hypertension control, carotid endarterectomy when indicated, or use of warfarin therapy in patients with atrial fibrillation.

Asthma

Asthma is a more highly prevalent condition in minority children (particularly African-American children) and is responsible for significant morbidity and some mortality in minority children.[74] Adults are also affected by asthma, but many guidelines and related quality measures focus on care of children. There are generally well-accepted guidelines for use of maintenance medications like inhaled corticosteroids, and it is possible (with some caution) to use utilization measures like admissions or ER visit rates as proxies for patient outcomes. One major technical difficulty in measuring quality of care is to include information on severity of asthma in any reports that compare organizations in different regions or that serve distinctly different patient populations. Administrative databases do not typically include useful information on severity, so it is very difficult to define denominator populations in terms of severity or to adjust for differences in severity mix across organizations.[75]

Mental Health/Substance Abuse

This is a much more difficult area than those listed above, because statistics on incidence and prevalence are subject to unique reporting biases, and because the area includes a variety of conditions for which there may or may not be good evidence-based guidelines. Quality of care may refer to the location, duration, or provider of services as well as the specific service provided; there is not adequate evidence on many models of organizing services to make a clear judgment of quality.[76] Nevertheless, mental health and substance abuse rank near the top of health care purchasers' lists of conditions associated with insurance costs, time lost from work, or disability payments. There is not a well-developed literature on disparities in quality of care for minority groups, but a few articles can be found.[77,78] In spite of conceptual and technical difficulties in defining and measuring quality of care, a starting point is available in the form of some of the HEDIS measures on anti-depressant treatment and outpatient follow-up after admission for mood disorders.[79]

HIV/AIDS

HIV is more prevalent in the African-American population than in the Caucasian population, and is a high-ranking cause of both morbidity and mortality in that group.[80] The availability of complex medication regimens to control the progression of disease suggest the potential for quality of care measures based on the concept of adequacy of medication.

Other Conditions. The above list includes virtually all of the conditions that rank high on the criteria used to select quality of care measures. (Traumatic injuries are a notable exception. Trauma is a top-five cause of death in most minority groups, but is not well represented in the quality measurement or quality of care disparities literatures.) There are some other conditions, though, that deserve mention because they have some special significance, because there are unique opportunities for quality improvement, or because a literature base already exists about quality disparities. These include:

- Sickle cell disease. This is a disease of special significance in the African-American community, and is associated with both morbidity and mortality.[81] It is not included in existing "standard" measure sets, but should at least be considered for inclusion in a measure set focused on care for minority populations.
- Spine surgery. Low back pain is a highly prevalent condition in all populations; it is associated with significant morbidity and disability if not mortality. There are national guidelines for care of acute and chronic low back problems, and there is some evidence of racial/ethnic disparities in quality of care.[82]
- Fibroids. There is evidence of higher incidence of fibroids among African-American women and evidence of differences in patterns of care between African-American and White women.[83]

Other Quality Domains Not Related to Specific Clinical Conditions

Not all domains of quality link naturally to specific clinical conditions. Many important quality concepts relate to the coordination of care across multiple clinical conditions, or aspects of the care process that are generic and cut across many clinical conditions. These include:

- Satisfaction with care
- Reports of problems with care
- Functional status
- Quality of life
- Continuity of care
- Coordination of care
- Having a regular source of care
- Dimensions of access (insurance, geographic access, wait times, etc.)
- Cultural and linguistic competence

QUALITY MEASURES FOR HIGH-PRIORITY CLINICAL CONDITIONS

Tables 1-8 list candidate quality of care measures for all of the clinical conditions discussed above and for more global dimensions of quality that are not condition-specific. Within each table, measures are included that either:

- Are already included in existing measure sets and have also been shown in at least one study to have racial/ethnic disparities (e.g., mammography rates, immunization rates); or
- Are not in standard measure sets now, but have been identified in at least one published study of racial/ethnic disparities and are considered to have a clearly interpretable quality dimension (shaded rows).

In two different ways, then, all the measures listed in the tables are “new,” but the shaded measures are highlighted because they are potential additions to existing standard measure sets.

Table 1. Candidate quality of care measures for cancer

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Breast Cancer	Mammography Rate	HEDIS/FACCT	yes	H	
	Follow-up of Abnormal Mammograms		yes	AA	Radiology Data Required for Denominator
	“Sleepless Nights” (Delays in Diagnosis and Treatment)				May be able to use self-report survey
	Receipt of Clinical Breast Exam		yes?	H	
	Stage of Cancer at Diagnosis	FACCT	yes	AA, H	
	Receipt of Adjuvant Chemotherapy - Stage II	QA Tools*	yes?		Medical Records or Tumor Registry Data Required for Denominator
	Dose/Duration/Intensity of Adjuvant Chemotherapy		yes	AA	Requires Detailed Medical Record Review
	Rate of Breast-Conserving Surgery	FACCT/QA Tools			
	Radiotherapy following Breast-Conserving Surgery	FACCT			
	Annual Mammography in Women with Breast CA History	QA Tools			Requires Detailed Medical Record Review
	Five-Year Disease-Free Survival Rate	FACCT	yes	AA	
Cervical Cancer	Pap Screening Rate	HEDIS	yes	H	
	Incidence of Invasive Cervical Cancer				
Lung Cancer	Surgery Rate for non-Small Cell Lung Cancer		yes	AA	Requires Medical Record or Tumor Registry Data
	Radiation Therapy for Non-Surgery Stage I/II non-SC	QA Tools			Requires Medical Record or Tumor Registry Data
Colorectal Cancer	Fecal Occult Blood Test Screening Rate	QA Tools			
	Flexible Sigmoidoscopy Screening Rate	QA Tools			
	Colonoscopy Screening Rate	QA Tools			
	Barium Enema Screening Rate	QA Tools			
	Radiation Therapy for Stage II/III Rectal Cancer	QA Tools			Requires Medical Record or Tumor Registry Data
Prostate Cancer	Adequacy of Information about Treatment Options	FACCT			Patient Survey
	Treatment in Accord with Patient Preferences		?		Patient Survey
	Bone Scan for Newly Diagnosed Cases w/ PSA > 10	QA Tools			Requires Medical Record and/or Lab Data
	Androgen Blockade Therapy for Stage IV/D Patients	QA Tools			Requires Medical Record or Tumor Registry Data
Palliative Care	Adequate Pain Control		yes?	AA	Patient Survey

*QA Tools measures are from Kerr EA, Asch SM, Hamilton EG, McGlynn EA. Quality of Care for General Medical Conditions: A Review of the Literature and Quality Indicators. Santa Monica, CA: RAND Health, 2000.

Table 2. Candidate quality of care measures for heart disease

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Hypertension	Percent of Hypertensives Adequately Controlled	HEDIS			
Care of Acute Myocardial Infarction	Beta Blocker Post-MI	HEDIS, JCAHO			
	Aspirin Use Post-MI (within 24 hours and at discharge)	JCAHO			
	Use of Thrombolytics (yes/no)		yes	AA, H	May be available in administrative data sets
	"Door to Needle Time" for thrombolytics	JCAHO			
	Angioplasty Rate		yes	AA	Denominator best defined with medical records data
	Time from Arrival to Angioplasty	JCAHO			
	Use of Reperfusion Therapies in general		yes	AA	Denominator best defined with medical records data
	CABG Surgery Rate		yes	AA	Denominator best defined with medical records data
	Smoking Cessation Counseling During Hospitalization	JCAHO			
	Cholesterol Management Post-MI	HEDIS			
	Mortality Rate {time period?}				
Care of Coronary Artery Disease other than AMI	Use of Reperfusion Therapies		yes	AA	Difficult to interpret without case mix adjustment
	CABG Surgery Rate		yes	AA, H	Difficult to interpret without case mix adjustment
	Angioplasty Rate		yes	AA	Difficult to interpret without case mix adjustment
	Rate of Referral for Reperfusion Therapy		yes	AA	Requires Medical Record Review or Survey
	Rate of Referral for Cardiac Catheterization		yes	AA	Requires Medical Record Review or Survey
	Average Mortality Rate Where CABG Surgery Performed		yes	AA	May not be possible in all states
Treatment of Congestive Heart Failure	Rate of Prescribing of ACE Inhibitors	JCAHO			
	Inpatient Admission Rate				
	Transplantation Rate		yes	AA	Denominator best defined with medical records data

Table 3. Candidate quality of care measures for diabetes

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Diabetes	HbA1c Measured Twice per Year	HEDIS/FACCT	?		
	Retinal Exam Once Per Year	FACCT	yes		
	Foot Exam Once Per Year	FACCT	?		
	Smoking Cessation Counseling	FACCT	?		
	HbA1c > 9.5	FACCT/HEDIS*	yes	AA	
	Adequacy of Self-Management Education		?		Self-report survey
	Lower Extremity Amputation Rate		yes	AA	May require medical record review to define denominator

Table 4. Candidate quality of care measures for asthma.

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Asthma	Use of Inhaled Corticosteroids	QA Tools	yes	AA, H	Should be available in administrative data
	ER Visit Rate		yes	AA	
	Admission Rate		yes	AA	
	Use of Peak Flow Meter	FACCT			
	Use of Spacer or Holding Chamber	FACCT/QA Tools			
	Adequacy of Self-Management Education	FACCT			Self-report survey

Table 5. Candidate quality of care measures for stroke.

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Stroke	Use of tPa	HCQIP	yes?		Requires data on time of symptom onset
	Carotid Enderaterectomy Rate	QA Tools	yes	AA	Chart review required to define denominator population
	Antiplatelet Therapy in New Patients	QA Tools			
	Use of Warfarin in Patients with atrial fibrillation	HCQIP, ORYX			

Table 6. Candidate quality of care measures for maternal/child care

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Prenatal Care/ Childbirth	Initiation of Prenatal Care in First Trimester	HEDIS	yes	AA, H	
	Adequacy of Prenatal Care Index				
	Smoking, Alcohol, SA History at First Visit	QA Tools			Medical record review
	Smokers Advised to Quit		yes?	AA	Medical record review or survey
	Substance Abuse Advice/Counseling		yes?	AA	Medical record review or survey
	Chlamydia Screening	QA Tools, HEDIS			
	Amniocentesis Offered if Age >35	QA Tools			Medical record review or survey
	BP Measurements at Each Visit	QA Tools			Medical record review
	Zidovudine Treatment for HIV Positive	QA Tools			Medical record review or laboratory data
Well-Child Care	Childhood Immunization Rate	HEDIS	yes?	AA, H	
	Adolescent Immunization Rate	HEDIS			

Table 7. Candidate quality of care measures for other clinical conditions.

Condition	Measure	Source	Disparity?	Which Groups?	Comments
HIV/AIDS	Receipt of Antiviral Therapy	FACCT/QA Tools	yes	AA,H	
	PCP Prophylaxis	FACCT/QA Tools			
	MAC Prophylaxis	QA Tools			
Low Back Pain	Reoperation after Spine Surgery		yes?	AA	
	Treatment in Accord with AHRQ Guideline	AHRQ	?		Multiple possible measures derived from guideline
Sickle Cell	Screening for Sickle Cell in First Three Months	QA Tools			May be available from administrative data
	Pneumococcal vaccine for new patients/members	QA Tools			May be available from administrative data
Mental Health	Adequacy of Dose of Antidepressants	QA Tools			Available from pharmacy/encounter data
	Adequate Duration of Antidepressant Therapy	HEDIS			
	Outpatient Follow-up After Hospitalization	HEDIS			
	Outpatient Visits during Antidepressant Therapy	HEDIS			
End of Life Care	Percent Patients with Advance Directives				
	Adequate Pain and Symptom Control	FACCT			
	Treated with Respect for Patient/Family Preferences	FACCT			

Table 8. Candidate quality of care measures for other aspects of health care

Condition	Measure	Source	Disparity?	Which Groups?	Comments
Satisfaction and Interpersonal	Have a Regular Source of Care	National Survey of America's Families	yes	AA, H	
Aspects	Consumer Assessment of Health Plans Survey (CAHPS)	NCQA	yes?		disparities different for children vs. adults
of Care	Rating of Doctor	NCQA			
	Rating of Specialist	NCQA			
	Rating of Health Care	NCQA			
	Rating of Health Plan	NCQA			
	Getting Needed Care	NCQA			
	Getting Care Quickly	NCQA			
	Doctor Communication	NCQA			
	Courteous Staff	NCQA			
Cultural/ Linguistic Competence	Availability of translation services				
	Cultural competence training for staff/providers				
	Racial/ethnic diversity of provider network				
	Number/percent of providers fluent in other languages				
	Staff representative of community(ies) served				
Other	Health Status (SF-36 or SF-12)				
	Days Lost from Work or School				

This entire set of measures, if actually implemented by health plans, hospitals, or other health care organizations, would paint a comprehensive picture of quality of care for minority patients. In practice, though, resources for quality measurement are limited, as are resources for related QI initiatives. Many managed care plans struggle to produce HEDIS reports, so the addition of a large number of new measures to address racial/ethnic disparities may be impossible without additional funding.

With that in mind, the measures from the tables above that seem to offer the best opportunity for quality improvement or disparity reduction with the least additional effort for data collection and analysis include:

- Use of Reperfusion Therapies (CABG or angioplasty – either in patients with AMI or with heart disease in general)
- Percent of Heart Surgeries Performed at High Volume/Low Mortality Hospitals
- Use of Inhaled Corticosteroids for Children with Asthma
- Adequacy of Dose and Duration of Antidepressant Therapy

GAPS TO BE FILLED

Moving forward on a quality measure set like that reflected in the preceding tables will require political will, much energy, and solution to some important technical problems. The following are of particular importance:

Data on Race/Ethnicity

Not only must methods be developed for obtaining and using accurate data on race/ethnicity, but there must be some common approaches to questions of mixed or multiple-race individuals, changing of self-reported racial/ethnic designations over time, and how to categorize children of “mixed” marriages who are too young to assign themselves to a category. These are not problems that affect a large fraction of minority populations today (the estimate is that only about 2% of the respondents to the 2000 census and national surveys like the National Health Interview Survey chose multiple categories or “other” to describe themselves[84]), but they will become more significant with each passing year.

Coding of Diseases and Procedures in Administrative Data Sets

These concerns are not unique to minority populations, but continue to bedevil many quality measurement initiatives. Childhood immunizations, for example, continue to be under-reported in administrative data sets and not fully reported even with detailed medical record review. Depression is notoriously mis-coded in both administrative data sets and medical records,[85] so analyses of patterns of care must work around known and suspected data quality problems.

Severity, Complexity, and Risk Adjustment

Any comparisons of quality of care across racial or ethnic groups will inevitably bring questions of “apples and oranges” comparisons. If African-American children with asthma, for example, are more likely to have severe asthma than their White counterparts, than comparisons of ER visit rates or hospitalizations will not be clearly interpretable as quality of care comparisons. It will never be possible to develop models or associated data collection procedures that will account for all possible mediating variables, but acceptable models for dealing with the most important severity or risk factors must be developed.

Contribution of SES Factors

Similarly, comparisons of quality of care across racial/ethnic groups, or just analyses of quality for any one group, will raise questions about whether the underlying issues are factors under the control of health care organizations or whether they are larger social factors like education, income, and insurance status. In some instances, the effect of these factors is minimized by the way a group is defined or an analysis is done (e.g., analysis of patterns of breast cancer care for women insured by Medicaid). On the other hand, as long as disparities among groups remain on major SES variables, some methods must be developed to disentangle the effects of race/ethnicity from those of SES on quality measures.

Sample Size

Many existing quality of care measures depend on very large denominator populations from which to calculate rates of relatively rare events. When analyses focus on specific racial/ethnic minority groups within the overall population, the sample size problem inevitably becomes more severe. It has been estimated, for example, that a measure of breast cancer mortality would be only meaningful as a comparative measure in health plans with an overall membership of 2,000,000 or more.[86] A health plan wishing to compare that measure across three racial/ethnic groups of equal size would have to have an overall membership of 6,000,000! Less dramatic examples can be found in many other clinical conditions and specific measures.

Lag Time and Turnover in Populations

A common complaint about many quality measurement systems is that the data are out of date as soon as they are analyzed and reported.86 Measures derived from insurance claims data are likely to suffer from this problem because a period of time for claims processing, data base building, and data "cleaning" must precede any substantive analysis. While these processing delays are going on, members are changing plans and patients are changing providers. If quality measures are used to compare plans and providers on very stable aspects of performance, these issues are not significant problems, but if measures are used to establish and monitor ongoing CQI activities, or if the measures are used to direct the care of individual members or patients, then time lags and membership turnover are significant problems. To the extent that minority groups are over-represented in Medicaid plans with 30-day eligibility and membership requirements, this problem may be particularly severe for minority populations.

Incomplete Capture of Events

Except in tightly structured managed care plans, it is often difficult to assemble all relevant information for a single patient about an episode of care. Services may be obtained from multiple providers using multiple information systems and perhaps multiple payers. This problem is not necessarily more or less likely in minority populations (perhaps less likely in the Indian Health Service but more likely among uninsured Hispanic patients or in any groups with high rates of ER use), but must be addressed in any quality measurement initiatives.

CONCLUSION

The large and growing literature on racial/ethnic disparities in health care quality provides a basis for recommending a number of specific quality measures of special interest to minority populations. The measures highlighted in Tables 1-8 reflect a combination of attributes: important clinical condition, evidence of disparities in quality, feasible data element definition and data collection procedures, and likelihood of health benefit to follow from process improvement.

Most of the measures are important to one or more minority populations, but very few are unique to any minority population. It would be preferable then to include these measures in existing standard performance measure sets rather than to "collect" them and implement as a separate, stand-alone measure set. There are three specific reasons for this recommendation:

- With limited resources available for quality measurement and improvement, health care organizations will focus on what is required by purchasers and regulatory agencies. Incorporating measures into existing, required measure sets makes it much more likely that data will be collected and used than if the measures are in a separate, optional measure set.
- If data collection and analysis for a set of measures is focused only on minority populations, there will be no opportunity to study disparities across groups and work to reduce those disparities.
- There is little, if any, evidence to show that the underlying reasons for disparities are unique to minority populations. Many of the same QI techniques used for improving quality in general will be applicable to improving care for minority populations and reducing disparities. Incorporating new measures into existing measure sets will increase the likelihood that existing QI resources will be devoted, at least in part, to reducing disparities, particularly if purchasers and regulators place disparities at the top of the quality of care priority agenda.

The actual selection of measures and incorporation of measures into existing measure sets should be guided by members of the minority community(ies) affected by disparities in care. In our health plan Report Card project funded by the Commonwealth Fund, we started by convening groups of African-American and Hispanic community leaders to spend two days discussing quality of care concepts, high-priority clinical conditions, and specific quality measures. Open-ended discussion was followed by formal priority-setting exercises, and the resulting ratings were incorporated into the design and content of the Report Card that is now being tested in nine health plans.

In some cases, the community leader groups recommended attention to quality domains or clinical conditions that were impossible to implement, at least in existing quality measurement paradigms. Stress, for example, was a highly ranked clinical condition, but it was not possible, even after diligent efforts, to identify measurable aspects of quality of care. In our own work, we have thought about two partially overlapping domains – those aspects of quality of care most important to minority populations, and those aspects of quality of care for which measurement is technically feasible and for which an evidence base exists. We have tried to focus our work in the area of overlap, but not ignore the other areas. Expanding the area of overlap is an important research and QI agenda item.

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Appendix D

REPORTING HEALTH CARE QUALITY TO MINORITY POPULATIONS: ISSUES AND CHALLENGES

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ABSTRACT

While there is consensus among researchers and policy makers that minority consumers must have access to information on the quality of their health care providers, there is less surety that the data that is available will help consumers to use the information to make decisions that will favor the highest performing providers. African Americans, Hispanics and other disadvantaged minority groups are less aware of their health care options, have less access to health information, and have less education and skills with which to make decisions. Minority Americans are disproportionately poor, uninsured, undereducated, and have limited English and literacy skills. These realities pose potential barriers to targeting quality reports to minorities and contribute to disparities in health outcomes.

Minority American's experiences in the health care system may also contribute to the perception that quality data is not useful or valuable. African Americans and Latinos have less choice in insurance coverage and health care providers, less general knowledge of the health care system, perceive their care to be inferior to that of whites, and are less likely to participate in clinical decisions about their care. As a result, they may be less aware of and likely to use performance data in decision-making.

Targeted information and education campaigns on health care quality could help to reduce some of the barriers to broader use of quality data. This article provides some specific recommendations for targeting the design and implementation of information campaigns on health care quality to minority populations. These recommendations include: conducting extensive formative research to better understand the opportunities within targeted racial and ethnic communities for presenting and disseminating information; developing materials that are accessible to individuals with limited education, language and literacy skills but that also provide detailed enough information to set a context and establish a demand for quality information; and, developing the capacity within underserved communities, through partnerships with community organizations, to disseminate information about health care quality.

INTRODUCTION

Close to one-third of the United States population is non-white.[1] Demographers estimate that by mid-century, non-Hispanic whites will no longer be in the majority. This enormous demographic shift presents a serious challenge to the health care system that historically has provided less well for minority populations than for Whites. The changes in the population and the disparities in health care are powerful drivers for improvements in health care delivery. The growing emphasis on quality measurement and reporting to improve health care markets reflects policy makers' optimism that performance data can ultimately result in higher quality and more equitable care delivery systems.

While there is consensus among researchers and policy makers that consumers must have access to information on the quality of their health care providers, there is less surety that the data that are available will help consumers to use the information to make decisions that will favor the highest performing providers. In fact, much of the data that are currently available (patient-centered care, adherence to clinical guidelines, improved health outcomes) is not aligned with how consumers actually think about quality health care (qualifications of their doctors, costs, benefit package). For consumers – regardless of their race and ethnicity – to make better use of performance data, we need a common understanding of what we mean by quality in health care delivery.

Even with a common definition of quality, supporting consumers' use of performance data in decision-making will not be easy. The conditions for making an informed health care decision are several: first the consumer needs to know all their available options (the specific providers they can select, their treatment alternatives, etc.); they need to understand the differences between these options (quality differences, convenience and other preference considerations); they need to consider their overall health care needs; and, finally they need the language, literacy and cognitive skills to be able to make a decision based on all of these inputs. African Americans, Hispanics and other disadvantaged minority groups are less likely to meet all of these conditions than whites. They tend to be less aware of their health care options, have less access to health information, and have less education and skills with which to make decisions.

Although the barriers to using quality information may be higher for minority Americans than whites, they ultimately have the most to gain from quality improvements. Reporting performance data by race, and developing minority-sensitive performance indicators will help in the reduction of racial and ethnic disparities in health care. As the science of performance measurement progresses, the increasingly public availability of performance data will hold purchasers and providers accountable for reductions in disparities and improvements in quality.

For this vision of increased accountability to become a reality, minority consumers must become more aware of and more likely to use quality data in decision-making. This paper will examine the issues relating to increasing the demand, and use of performance data among minority populations. An understanding of the barriers faced by minority consumers in accessing, interpreting and using quality information is the necessary first step in the development of any effort to motivate consumers to use quality information in health care decisions.

The first two sections of the paper will explore the potential social and environmental barriers to providing information on health care quality to minority populations. The third section will provide some recommendations for the design and dissemination of quality information.

DEMOGRAPHIC AND PERSONAL CHARACTERISTICS AS POTENTIAL BARRIERS TO INFORMING MINORITY CONSUMERS ABOUT QUALITY

Minority Americans are disproportionately poor, uninsured, undereducated, and have limited English and literacy skills. These realities pose potential barriers to targeting quality reports to minorities and contribute to disparities in health outcomes.

Income

The pressures and competing priorities low income people face to maintain income levels and stable housing are significant barriers to seeking health information. Twelve percent of the population, or 32.3 million people, live at or below the federal poverty line.[2] Racial minorities are more likely than Whites to live in poverty. The poverty rate for non-Hispanic whites was 7.7%, whereas for American Indian and Alaskan Natives it was 25.9%, African Americans 23.6%, Hispanics 22.8%, and Asian and Pacific Islanders 10.7%. Despite the fact that lower income levels are highly correlated with higher morbidity and mortality, health information campaigns have not been an easy sell to populations that are over-stressed and overburdened by their lack of resources.

Immigrant Status

With close to one in ten Americans born outside of the United States,[3] informing immigrant populations about the performance of providers in their communities is a major priority. The challenge is that immigrant communities are more isolated than the general population and many lack any information about the U.S. health care system. Communicating information about health care quality to immigrant communities will require addressing their lack of insurance, and their need for information about public programs such as Children’s Health Insurance, Medicaid and Medicare.

Limited English Proficiency

Targeting minorities will require targeting communities with limited English proficiency. Materials must be available in multiple languages, but even more importantly, messages must be developed that are language and culture specific (not transliterations of English text). According to the 1990 Census Report (only the decennial Census asks about language proficiency), 25.5 million adults in the United States speak a language other than English. Of those, over 5 million indicated that they speak English “not well” or “not at all.” (The number of immigrants who have difficulties speaking English is probably much higher than what was reported by the Census.) Outreach for the State Children’s Health Insurance Programs (SCHIPs) have found limited English communities to be among the hardest populations to reach through the traditional mass media approach, and many states are mobilizing community organizations to help reach and communicate to this population.

Education

Racial and ethnic minority populations have lower levels of educational attainment and as a result have more poorly developed skills for interpreting health information. According to the 1999 Current Population Survey (CPS), 83% of all adults age 25 or older have at least a High School education. However, among Hispanics only 56% attained a high school education, 77% of African Americans, and 65% of all immigrants.

Literacy

Minority groups have higher rates of illiteracy and marginal literacy than the general population and rely more heavily on non-print sources of information (oral, television, radio, etc.) A full 90 million Americans, approximately 45% of the adult population, are functionally illiterate. This means they are unable to comprehend the concepts and tasks necessary to function in the health care system such as: reading consent forms, understanding written and oral information given by clinical staff, or following prescription or appointment schedules.[4] About 45% of all functionally illiterate live in poverty. A disproportionate percent of minorities have limited literacy skills: 50% of Hispanics, 40% of Blacks, and 33% of Asians. Immigrants who are not native English speakers are even more likely to have difficulty reading.[5]

The traditional approaches to reporting quality information through grids and charts are not effective in reaching this population as they require a high level of reading skill to be able to read across and down in order to interpret the scores for the various providers.

ENVIRONMENTAL FACTORS AS POTENTIAL BARRIERS TO INFORMING MINORITY CONSUMERS ABOUT QUALITY

One’s experience with the health care system may be an important determinant in their willingness to seek out and use performance data. Minority Americans have less choice in insurance coverage and health care providers, less general knowledge of the health care system, perceive their care to be inferior to that of whites, and are less likely to participate in clinical decisions about their care. As a result, performance data is of questionable value for many people of color.

Availability of Choice

Minority Americans have fewer opportunities to make a choice in where they receive their health care due to lack of insurance or type of insurance coverage, and are thus less likely to value or use performance data. As shown in Table 1, racial and ethnic minorities are far less likely to be privately insured (where the most choice of providers exists) than are white Americans and far more likely to be uninsured (where choice is limited to public hospitals or clinics).

TABLE 1

	Privately insured	Publicly insured	Uninsured
Whites	75%	12.9%	12.1%
Black/African Americans	53%	27.8%	19.2%
Hispanics	45%	20.3%	34.2%

Source: 1999 Medical Expenditure Panel Survey

Hispanics (30%), and blacks (28%) report very little or no choice in where they can go for medical care compared to 21% Asian American and 16% whites. African Americans and Hispanics have been found to rely more heavily on emergency rooms, outpatient departments or clinics for their health care perhaps because of the flexible hours and walk-in appointments.[6] Perhaps due to their insurance status, minorities rely more heavily on the public hospital system for primary care than whites: 43% of the patients seen at urban safety net hospitals are from minority groups compared to 19% in other urban hospitals.[7] In many communities where there is only one public hospital or clinic, what is the value of performance data to uninsured consumers? Clearly regulators and accrediting bodies need the data, but do consumers who have no alternatives in their choice of health care provider?

Less Knowledge of the Health Care System

Even among the Medicare-covered elderly, where, by definition, all beneficiaries have the same choice of plans and providers as well as the same benefits, African-Americans and Hispanics may be less likely to use performance reports. Recent work by the Barents Group found that African-Americans and Hispanics are less knowledgeable than the general Medicare population about: what Medicare is and what it covers; the availability of supplemental insurance options; what managed care is; and, whether and how to join a Medicare HMO.[8] That African American and Hispanics are more isolated from the majority of health information that is currently available is an indication that, among Medicare beneficiaries, these minority groups are less likely to be aware that performance reports exist or to use them.

Medicaid beneficiaries are also lacking the necessary background information on the Medicaid program and on Medicaid managed care to facilitate their use of quality information in choosing a Medicaid managed care plan.[9] In fact, across the country large numbers of Medicaid beneficiaries who are required to join managed care plans are not even making decisions about which health plans to join – instead letting the state assign them to a plan (called auto-assignment). In a preliminary analysis of auto-assignment rates in New York State, the state found that African Americans and Hispanics were more likely to be auto-assigned than whites or Asians. Few states have analyzed their auto-assignment data by race, but the New York experience is probably not unique. Education efforts targeting Medicaid beneficiaries have been focused on increasing the numbers of people who make a choice of health plan but few states have expanded that effort to include providing health plan report cards (which are rarely available for Medicaid plans) to better inform those choices.[10]

In both the Medicare and Medicaid programs, minorities lack basic knowledge about how their insurance program works, what the benefits are, and how to make decisions about plans and providers. Without this necessary information, consumers lack a context for understanding and using quality information.

Perceptions of the Health Care System

Recent work has found that African Americans and Hispanics perceive the health care they receive to be inferior to that received by whites. A recent Kaiser Family Foundation survey found that African Americans and Hispanics were more likely to perceive that they had more difficulties accessing care due to race and that the care they received was of lesser quality than that of whites. African-Americans and Latinos were also more likely than whites to feel that they had been treated unfairly because of race when getting medical care.[11] Blacks and Hispanics are also significantly more concerned about medical errors or mistakes than whites – perhaps another indication of their perception that they receive inferior care.[12]

Minority consumers' perception and experiences of health care disparities may have a negative influence on their view of report cards. Given their experience with the health care system, African Americans, Hispanics and other minority groups may not perceive that the data that are available about health care delivery reflects their primary issues and concerns. On the other hand, if minority consumers felt that report cards did provide an accurate reflection of the care and treatment that people like themselves received, they might be more motivated to use those reports to select the providers that could best meet their needs.

Trust is also an important issue: consumers want to know who is collecting and releasing the data and why. African Americans, in particular, are suspicious of the medical establishment in the wake of experiments such as the Tuskegee Study and others that threatened the lives of subjects for the sake of science.[13,14] To gain credibility, information about how performance is measured, how the data are collected, and the type of analysis that was performed to report the scores must be readily available for those who seek it.

Disparities in Decision-Making Behavior

African Americans and Hispanics may, in part, be less likely to use quality information because they are less likely than whites to have a regular provider of care (a potential source of clinical data) and because they are less likely to be involved in clinical decisions about their care. Physicians can be important allies in the effort to disseminate and interpret information about health care quality. However, minorities have less access to this resource: Hispanics followed by blacks are significantly more likely than whites to report not having a regular doctor. Members of minority groups are also less likely to be involved in decisions about their health. African Americans have been shown to rate their interactions with their physicians as less participatory than whites, although there is some improvement in cases where the patients and physicians are of the same race.[15]

Minority Americans, who are disproportionately poor, are also less likely to engage in a variety of preventive health care behaviors. For example: Blacks and Hispanics are less likely to have seen a dentist in the past year; fewer Hispanics over 40 received a mammogram in the past two years; Asian Americans have lowest rate of cervical cancer screening; Native Americans least likely to have received prenatal care in first trimester; African Americans Medicare beneficiaries least likely to have received an influenza vaccine in the past year. African Americans and Hispanics are more likely than whites to be hospitalized for preventable conditions.[16]

The fact that minority groups are less likely to participate in preventive care practices is instructive – often the benefits are long term and not immediately apparent. The same can be said for the benefits of using performance data in decision-making. If we expect minority consumers to make the investment of time and energy in seeking out and using report cards, we must convince them that there are tangible and valuable results (such as improving their relationship with their provider, fewer asthmatic episodes, reducing missed days at work, etc.). Linking the use of quality information to tangible benefits for the consumer is not a simple task, but until we do, only the most motivated consumers will seek out and use performance data.

Cultural Sensitivity in Performance Reports Is Lacking

For immigrant and non-English communities, cultural sensitivity and accommodation to cultural needs and differences is an important component of quality and, as such, the cultural competency of providers must be evaluated in report cards if culturally and linguistically diverse communities are to view them as relevant. Common techniques to improve culturally competent care that could be reported on include: interpreter services; recruitment and retention of multi-cultural staff; training; coordination with traditional healers, family and community members; and administrative and organizational accommodations. While evidence linking the successful implementation of these techniques to improved health outcomes is still lacking, consumers value these processes and, if given the information, might make decisions about providers based on the presence or absence of these practices.

Making report cards relevant to immigrant and non-English speaking communities will also require developing culturally sensitive information campaigns. For example, instructing consumers to contact government agencies for ratings of providers will be met with suspicion in immigrant communities that are already fearful that accessing health services may jeopardize their efforts to live and work in this country. Many Latin American and Asian immigrants – even those here legally – delay getting health care services (even those *with health insurance*) for fear that if they use the system too much there may be consequences. Quality messages that use fear tactics to motivate patients to seek out and use information on quality (i.e., be sure to find out how many times your doctor has performed the surgery) can also backfire in cultures where challenging authority is taboo. For example, some Asian and Native American cultures view asking questions of people in positions of authority (such as physicians) as a sign of disrespect and would not welcome the instruction to research a doctor's credibility.

RECOMMENDATIONS FOR THE DESIGN OF QUALITY REPORTS TARGETING MINORITY POPULATIONS

As discussed above, for quality reporting to be valued and useful to a larger segment of society, policy makers must address minorities' lack of skills and context for the information while, at the same time, tailoring the information collected and reported to reflect the actual experiences of minorities in the health care system. A re-examination of the dimensions of quality health care to better incorporate the concerns and preferences of minority patients is one important strategy. Reassessing how the information is communicated to patients is another. This section will explore several strategies for broadening the audience for quality report cards through targeting the development of quality messages and the strategies for dissemination to minority communities.

Define the Target Population and Tailor the Messages

The golden rule in effective communication is to identify the target population. The more clearly defined the population, the better the opportunity to build off of the specific values, preferences, opinion leaders, images, social references, role models, cultural and behavioral characteristics, and communication channels of that population. The HIV/AIDS prevention campaigns of the past decade provide many examples of education programs that have been successful by clearly defining the target population. For example, in an effort to lower infection rates in minority communities, different messages on HIV/AIDS prevention have been developed to target youth in specific ethnic communities and the campaigns have used community-specific dissemination techniques.

Social marketers, as part of the effort to define the target population, map out the behavior of the target population to identify opportunities to influence that behavior. This requires an understanding of the costs and benefits of adopting the desired behavior.[17] For a campaign on health care quality, this means understanding how consumers currently make health care decisions, and when and how to influence those decisions. A social marketing approach to developing a quality information campaign to support African American Medicaid beneficiaries in New York to select a managed care plan is illustrated below. The findings are based on the author's prior quantitative and qualitative work with the target population.

- **How does the target population define quality, and where does it fit into their list of priorities?** A primary concern among African American Medicaid beneficiaries in New York is the availability of appointments, whether they wait long hours in the waiting rooms, and that they are treated with respect. Health care in general may not be as high a priority as income security and housing, but concern for children's health is a priority. Choosing a health care plan is not high priority, as evidenced by the higher auto-assignment rate among blacks in New York than among other racial categories.

- **How do they currently make health care decisions?** In general, the health care decision-makers are the women in the households who are more often Medicaid eligible than the men and are the primary caretakers of the children. When choosing a health plan, the primary concern is to maintain existing provider relationships. Most people ask friends and family for input. There is little reliance on more formal information sources (i.e., enrollment materials, comparative data).

- **When can they make these decisions?** As New York State continues to transition to a mandatory program, most Medicaid beneficiaries have a choice of health plan and can make those selections once a year or when they first enroll in the Medicaid program. Fewer Medicaid beneficiaries are not required to join a plan and those may choose to join voluntarily at any point during the year.

- **What problem do they have that information about quality can solve?** Many Medicaid beneficiaries complain of long waits to be seen, difficulty finding a provider, and unfair or disrespectful treatment. If quality data can reliably show how well providers perform in these areas, consumers may find them valuable.

- **At what point could they use quality information to make a better decision?** When a beneficiary is required to enroll in a health plan, independent enrollment brokers or community agencies could provide comparative data on Medicaid managed care plans and could assist consumers to use this information in making their enrollment decision.

- **What are the obstacles to using quality information?** As discussed above, many consumers in this group have limited literacy, language and decision-making skills. Quality information is also hard to find, the performance measures are not readily understood, and there is little information available at the level of the provider – which is what consumers are most interested in.

- **What are the benefits? How tangible are they? Are they of high value to the target population?** The promise is that by measuring quality, providers will compete to provide the most appropriate and patient-centered care, ultimately resulting in improved clinical outcomes and higher patient satisfaction. These are long-term benefits that may not be of high value to consumers with more immediate needs. Short-term benefits, such as improved communication with one's physician or shorter waiting periods to be seen by a physician, may be more tangible and valued. Realizing these short-term benefits will require developing performance indicators, messages and education campaigns which can directly influence consumers and providers to improve in these areas.

- **What is a realistic action to ask them to take?** It may be realistic to ask people to seek advice from known and trusted resources in the community when making enrollment decisions. States are increasingly relying on community groups to help inform and educate beneficiaries to reduce the auto-assignment rates. But only a few states have developed Medicaid managed care report cards (New York, Washington) and none have trained the community groups on how to interpret or use these reports.

- **What can we promise in return?** This is the big question. Can we really promise the potential benefits of improved health outcomes, and more responsive health care systems? In how long? And if we focus on the short-term benefits, can we deliver on them? Why should anyone believe us?

Provide More Background Information

Contextual information on health care quality is necessary to establish *value*. To be able to use report cards, consumers need information about the health care system, and they need a working definition of health care quality that includes the concept that there are variations in quality. And they need to know when and how to use quality information. Yet, few report cards provide this context. Consumers need to understand why performance data is important, and how using it can provide them with some tangible gain. This is particularly important when targeting minority groups who have less information about the health care system, have fewer skills with which to interpret the data, and are more dissatisfied with and more distrustful of the health care that they receive than the general public.

Examples of this kind of contextual information exist. The Agency for Healthcare Research and Quality produced an excellent guide, *Your Guide to Choosing Quality Health Care* (1998), which provides comprehensive background information on quality measurement and on choosing a health plan, a doctor, and a hospital.[18] The *Guide* does not report any performance data, but rather directs consumers to state and local agencies to track the data down. The *Guide* also provides step-by-step worksheets to help consumers use quality information in their decision-making. The problem with the *Guide* for minority audiences is that it's 47 pages, has no pictures, very little white space, is written at a 7th grade reading level, is only available in English, and doesn't include any information on assessing the cultural competency of providers. It is, however, a starting point. Each section of the *Guide* is a useful primer that could be adapted as an introduction to a report card on providers, health plans, or hospitals. Targeting this information for minorities would require simplifying the language, adding illustrations to the text (including images of people of color), reducing the amount of information on each page, and providing more instruction on how to use the worksheets to help with decision-making.

Limit the Information to Smaller Geographic Areas and Stratify by Race/Ethnicity

Most quality reports are available at the state level rather than the community level. This data does not reflect the real choices faced by consumers, i.e., whether to get an invasive procedure performed at community hospital A or community hospital B. To be most meaningful, health care quality information should help consumers to distinguish among their actual choices or options. Quality report cards that are organized to provide quick and easy access to *brief and summary information* on local hospitals can enhance the probability that consumers – all consumers not just minorities – will be able to understand and use the information in decision-making.

Having performance data on all providers in the state can unnecessarily complicate and clutter reports with more information than one needs to make a choice. It can also be misleading and counter productive. For example, New York State created consumer report cards for Medicaid managed care plans using the state Quality Assurance Report Requirements (QARR) data. The report cards compared all of the Medicaid managed care plans in the state on approximately ten QARR measurements. Once the state got these reports into consumers' hands, they found that the first question consumers wanted to answer with the data was, which is the best plan (the one with the most stars on it)? Since it was a statewide report card, they would immediately discover that unless they lived in the county where that high performing plan operated, they could not join the "best plan." Rather than empowering consumers to make sound enrollment decisions, the report card served to frustrate them.

To appeal to minority consumers, particularly to those who perceive that they receive inferior care, report cards should be able to help consumers find the providers who can best care for people like themselves. This requires stratifying the data by race and ethnicity. Doing this will enhance the credibility and relevance of report cards for minorities. Because racial categories encompass many subgroups, limiting reports to the community level (assuming the community is large enough that the numbers are big enough for statistical comparisons) can minimize the differences within racial and ethnic categories. For example, reporting on the care of the Hispanic population in The Bronx, which is largely Puerto Rican and Dominican, will more accurately reflect the realities of treating that subgroup than reporting on the Hispanic population in New York City as a whole, which includes Central and South Americans.

Sequence Information About Quality

Currently, quality information campaigns follow a one-shot dissemination strategy: all the information (usually limited to ratings of providers) is conveyed in one booklet, brochure or pamphlet without any background information. Without the contextual information that consumers need in order to value, understand, and know how to use quality data, consumer demand for this information will remain low. An alternative approach to disseminating quality information which could result in increased use of report cards is to sequence information about quality: 1) provide a background on health care quality and quality measurement to those who need it; 2) provide quick and easy summary performance data that is accessible to the general population – including those with limited literacy; and, 3) provide more detailed data and reports for those who seek it.

A multi-tiered information campaign would build on these different levels of information. Initial messages might begin with setting the stage for comparison data by defining what is meant by quality care, how it is measured, and how the data can be useful to consumers. A case in point: consumers' demand for nutrition information, which ultimately led to the Food and Drug Administration's requirements for the labeling of food items, grew out of the public's increased awareness that good nutrition was important for staying healthy. A similar awareness about quality in health care is needed before consumers will value and demand report cards. Building this awareness within minority communities is particularly important for quality data to be a factor in reducing the racial and ethnic disparities in health care.

Once general awareness is raised on health care quality issues, producing quick and easy summary data on local providers – accessible information that most consumers want – will appeal to early adopters and lead to increasing the numbers of consumers using performance data. Data which is summarized and easy to interpret, the at-a-glance approach, is preferred by all consumers not just those with limited reading and cognitive skills.[19] The more we require people to work to find the information that is relevant to them, the less likely they will use it. Summary report cards need to be written in plain language, formatted in attractive colors (with pictures of consumers representing various races and ethnicities), and available in multiple languages. Although the comparative information in a report card may only require limited translation (often the text is limited to the names of providers and some scoring system such as stars, bar charts, or circles), producing the materials in multiple languages sends an important message to non-English communities that the information is intended for them.

Materials targeting the highly motivated/interested consumers ought to be more detailed as well as tailored to the consumer's interests. This might consist of overall summary data, data summarized by category (such as clinical care, support services, patient satisfaction), as well as specified performance measures. Consumers, particularly people with special health care needs, should have access to specific performance measures, such as the adequacy of the self-management education provided for asthma. Minority and disadvantaged communities have higher rates of chronic and disabling conditions and could find tremendous benefit in this information once it becomes more readily understandable and accessible.

Whatever the level of specificity in the report, performance data must be presented with a clear interpretation of its meaning. The New York State Department of Health (DOH) learned this lesson the hard way with the Cardiac Surgery Reporting System, a project collecting, analyzing and reporting data on all patients undergoing open-heart surgery in New York. When DOH released its first report, intended to provide consumers with information to help them make sound decisions when selecting cardiac service providers, initial press coverage tended to overemphasize numerical rankings, even when the differences between the hospitals was small and not meaningful statistically or clinically. The lesson: devote time and resources to educating the media and the public about the meaning and the appropriate use of the data.[20]

Improve Readability

Several tried and true strategies can help to minimize literacy barriers. The presentation of information should follow the principles of easy-to-read communication: large font size, pictures which illustrate the text, a lot of white space on the page, action-oriented text which clearly states what the readers should do. There are several excellent resources for developing low-literacy print material to help sponsors of quality information.[21,22]

Developing Print Materials for Limited Literacy Readers

Simplify the message (but don’t dumb it down)
Clearly state what the reader should do (action-oriented information)
Use large font size (14 point minimum)
Use pictures to illustrate the text (multi-ethnic, multi-cultural pictures)
Use stories and examples to illustrate the message
Avoid grids
Test the readability
Field test with target audience and revise

Literacy experts caution against using grids to display information. Reading down and across to find information is a skill that readers who function at low-literacy levels are unable to master. To reach low-literate audiences, the message on quality may need to be limited to the basics of what we mean by quality: that it varies, and that it can have an effect on the care you receive. Interested consumers could then take the next step, to find performance data on the providers they use. These motivated consumers could be directed to counselors/intermediaries to assist them in interpreting the data and making decisions.

Modify the Content and the Format to Meet the Needs of the Population

Translating text is often viewed as a simple matter of transliterating the text. However, straight translation rarely captures the same meaning as the original materials. Translations should include an assessment of the material to determine whether any of the text should be modified; for example, are the examples or the illustrations still relevant and culturally appropriate?[23] Most experts recommend, at the very least, to translate documents into the target language and then have a different translator convert the translated text back into English (called back-translation). While this process can catch the most glaring errors (i.e., contraceptive jelly for contraceptive foam, or federal government Medicaid for fee-for-service Medicaid), it does not catch nuances in dialects. Focus group testing is imperative both to improve the language, and to ensure that the translated messages and the layout of the material resonate with the target audience.

New formats should be considered when targeting particular minority groups. For example, Hispanics are receptive to information in novella form. An innovative New York City HIV/AIDS subway campaign was a series of comic strip installments that followed the story of a couple learning that the girlfriend was infected with the virus. The campaign is widely cited as one of the most successful public health information programs targeting Hispanics. For communities that prefer receiving information orally, creative use of radio and television can provide information while also modeling how to use the information. Call-in talk shows can be very effective in reaching African-American audiences. Ethnic radio stations reach the majority of non-English speakers, often playing all day long in workplaces that are predominantly mono-lingual. Effective use of these media will require developing messages that do not require visual cues.

Although the Internet holds a lot of promise for tailoring data and reports to meet the varying skills, needs, and interests of different populations, there remains a digital divide that has left many disadvantaged minority communities with limited access to the Internet. However, public libraries and schools enable more and more people of diverse backgrounds and skills to log on. Using the Internet to reach consumers with limited skills will require innovation in the design and layout of websites and rigorous pre-testing. Work in progress by Maximus' Health Literacy Center has found that most web sites require at least a 10th grade reading level. The Center has conducted an ethnographic study to understand how individuals with limited reading and writing skills use the web. The Center found that web pages are not sensitive to the needs of lower-skilled users. Participants in the study needed assistance scrolling the text, navigating the site, finding active buttons, and using pull down menus. Participants also needed assistance with spelling and typing in order to facilitate their use of the Internet.[24]

Build Consumers' Skills

Consider what we are asking consumers to do: be proactive and seek out report cards and patient satisfaction survey information from either their employer, Medicare, Medicaid or their health plan; determine the reliability of the source of the data (CAHPS, HEDIS, some other source); and assess their choices in light of the data. In addition, consumers must seek out and incorporate other data in their decision-making. For example, to choose a plan, the AHRQ *Guide* encourages consumers to: call their current doctors' offices to find out which plans they are in; get the list of the health plan's doctors; find out which hospitals their doctors have admitting privileges; evaluate the plan's benefit package; identify any health priorities in the family; consider the convenience of services (hours, location); and evaluate the plan's costs (deductibles, copayments, etc.).

For consumers to take these actions, they need to feel that they can. These actions can be overwhelming to anyone. For poorly educated, low-literate, and limited English speakers, they may seem impossible. A recent study found that Medicare beneficiaries with limited reading and cognitive skills were more likely than those with higher skills to prefer that someone else make their health plan decisions for them rather than having the burden of making their own choices.[25] The high numbers of Medicaid beneficiaries being assigned to managed care plans rather than choosing for themselves may indicate that many lower skilled Medicaid beneficiaries have this preference as well.

Community organizations can help to build consumers' ability to use quality reports by holding their hands through the information gathering, analyzing and decision-making process while also building their literacy, research, and decision-making skills. One promising strategy is to involve organizations that seek to empower minority communities, such as adult learning centers, in dissemination activities. In 1998, adult learning centers, which teach basic reading and writing skills and English as a Second Language classes, reached over 4 million adults (the majority from minority communities), 42% of whom were Hispanic, 29% White, 16% African American, 12% Asian/Pacific Islander and 1% Native American.[26] Fifty-five percent of adult learners are women – who often are the health care decision-makers within a family.

Adult learning centers are ideally suited for communicating complex information on health care quality. Adult education courses usually span a period of several weeks, giving students time to learn the comparison and research skills that are critical for decision-making. Most significantly, the people who attend these classes are the early adopters most health interventions hope to target – they are the individuals seeking new information, wishing to improve their condition, and who can communicate what they have learned back to their community.

Use Community Organizations as Information Intermediaries

Community organizations are uniquely positioned to support the dissemination of quality information to minority groups. The staff members are often residents of the community, and are well versed in the language and culture of the target population. Many minority groups (particularly African Americans) do not rely on print for their information, but prefer to get their information in person, or from a known resource in their community. Organizations that serve racial and ethnic minorities and that have established trust and continuity within their community such as health clinics, social service organizations, faith institutions, and educational organizations, can help to reduce the communication, trust, and skill barriers to using quality information that were previously discussed.

However, few community organizations are currently prepared to play this role. Research commissioned by CMS to identify the barriers to working with CBOs in the dissemination of Medicare information found that although there was widespread interest among community agencies to provide the information, the agencies needed guidance, training and resources. The agencies identified that functioning as information intermediaries on health care quality would be a natural extension of the social service work that they currently do, provided they had more training on the health care system generally and quality measurement specifically, adequate connections to policy and data resources, adequate financial resources, and adequate infrastructure to support dissemination activities.[27]

There are a few nascent efforts currently underway to build the knowledge base within minority communities about health care quality. The California HealthCare Foundation has launched a three-year initiative through grants to eight community groups in California to stimulate consumers' demand for quality information and improvement. Although the program is still in its infancy (the organizations began February 2001), the Foundation is finding that the organizations are requiring more time than anticipated to become fluent in the issue of health care quality. In addition, the materials that the Foundation sought to disseminate to consumers through the community organizations are targeted at policy makers rather than community members and are proving to be too technical for the organizations to use. The foundation is considering developing new materials and tools about quality for the grantees to use in their communities.[28]

A second project seeking to build capacity to develop and disseminate health information to minority communities is the Managed Care Consumer Assistance Program of the Community Service Society of New York (MCCAP) which has been operating since June 2000. The MCCAP is a network of 25 organizations each of which target a specific community. Each agency is trained to provide information on health insurance and providers, to help individuals research their choices, and to provide them with counseling and advice on health care decisions. The agencies are staffed by community residents, are well versed in the language and culture of the community they serve, and function as effective messengers of health care information. 75% of the MCCAP clients are non-white, only 37% speak English in their homes, and over 70% live in households with an annual income below $15,000.[29]

The MCCAP has found that tailoring the messages, the messengers, and the outreach to meet the needs of each of the communities it targets has been the key to its success. For example, a Korean organization in the network has focused on working through the Korean churches, which had previously been an untapped venue for disseminating health information. To reach Hispanics, MCCAP is focusing largely on youth programs such as after school enrichment programs, early childhood education and recreational services. The mono-lingual, Spanish-speaking communities are targeted separately through partnerships with new citizenship programs and English as a Second Language (ESL) programs. To reach the largely orthodox Jewish community, all materials and information is modified and incorporated into official communications and newsletters from influential Rabbis in the community.

Both of these programs reflect early efforts at working with community agencies to disseminate information about health care quality. In both cases, the emphasis is on setting a context for quality information. Both programs have found minority communities initially to be resistant to health care quality data, largely because it does not meet their needs: it remains too technical, and doesn't address the priorities of the community. Working with community agencies to define and refine quality information campaigns, we can begin to address these shortcomings, changing what we communicate and how we communicate it to build a broader base of support for information on health care quality.

CONCLUSIONS

As national efforts to reduce racial and ethnic disparities continue, there will be more data to monitor the progress of our efforts. This could lead to an increase in demand for quality reports. Communicating this information to minority consumers, who potentially have the most to gain from quality improvement efforts, will require intensive education to build literacy and decision-making skills and to build a context for health care quality. To increase the demand and usefulness of quality information, dissemination campaigns should be sequenced interventions, beginning with general information, building to simple summary reports on local providers, and finally providing information on how to access more specific and complicated measures. Partnerships with community organizations will help to make the information meaningful and to reduce the intimidation that immigrant populations and those with limited communication skills may experience when encountering quality information.

National efforts to increase awareness of the policy and science of quality measurement can help bring the discussion into the mainstream and can serve as a starting point for more targeted information campaigns. Entertainment programming that targets minority audiences, such as Oprah, radio call in shows, and Essence magazine, can help to lay the groundwork for further education and to demystify and make the science more accessible to a broader audience. Once awareness is raised, and the value of performance data is effectively communicated and demonstrated to minority communities, minority consumers may begin to demand more data on their health providers and, ultimately, they may hold purchasers and providers accountable for the quality of their care and their commitment to reducing racial and ethnic disparities.

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