

Assessing Health Care Quality for Minority and Other Disparity Populations

Prepared for:
**Agency for Healthcare Research and Quality
Rockville, Maryland**

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U.S. Department of Health and Human Services
Agency for Healthcare Research and Quality
May 2003
AHRQ Pub. No. 03-0047-EF

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Executive Summary

Introduction

Background

Considerable progress has been made over the past decade in the provision of quality health care. However, health care quality is not equitably distributed throughout the general population. Health care consumers who are members of certain groups, termed “disparity populations,” frequently confront disparities in health care quality relative to the general population. Members of these disparity populations include racial and ethnic minorities, low-income persons, children, women, the elderly, rural and urban residents, persons with disabilities and chronic illness, and persons near the end of life. In order to ensure the quality of care for members of these groups, quality measures relevant and/or specific to these populations are needed. This report describes the state-of-the-art quality measurements for disparity populations, identifies gaps in existing measures, and highlights critical areas for future research.

Framework for Assessing Quality in Health Care

An Institute of Medicine (IOM) report in 1990 defined health care quality as “the degree to which health care services increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”¹ A 2001 report by the Institute of Medicine, *Envisioning the National Health Care Quality Report*,² outlined a conceptual framework for assessing health care quality. It is based on two core dimensions: the components of health care quality and the purpose of health care. The first dimension is comprised of four components: safety, effectiveness, patient centeredness, and timeliness. The second dimension reflects consumers’ needs for different types of health care across the life cycle: staying healthy, getting better, living with illness or disability, and coping with the end of life. Equity represents a key parameter that cuts across both dimensions and reflects differences in quality of care received by different groups, including members of disparity populations. Most quality measures currently in use represent effectiveness measures. Fewer measures represent the dimensions of timeliness or patient centeredness. Very few assess health care safety.

Assessing Quality of Care for Disparity Populations

Quality measures specific to members of disparity populations are needed for two reasons: equity and relevance. First, quality measures help insure that health care is equitably provided. Given the racial and ethnic disparities in quality extensively documented in the IOM report *Unequal Treatment*,³ population-specific quality measures are needed to identify health care disparities that are typically hidden from view by current reporting procedures. Use of population-specific measures allows for targeted quality improvement interventions designed to eliminate disparities.

Second, quality measures developed for the general population may not be relevant to disparity populations. The prevalence and health impact of various conditions and type of health care needed to treat these conditions frequently differ between groups. Children experience health care problems and have health care needs that differ from those of adults. Some of the health care needs of women require female-specific quality measures (gender-specific measures are also needed for men but the number of key male-specific conditions is lower). Low-income persons often become chronically ill or die at earlier ages than those with higher incomes. Poorer persons experience many access barriers to quality health care such as affordability of care and low health care literacy. Inner-city and rural residents often reside in medically underserved areas and often face geographic and other barriers to care. Persons with chronic illnesses and disabilities have condition-specific health care needs that require specific quality measures; in addition, they may face barriers to health care access related to their disability. The elderly represent a heterogeneous population that includes healthy individuals living independently in the community and persons with a few mild chronic diseases, as well as those with multiple, complex health care problems that require specialty, rehabilitative, or long-term care. Persons near the end of life require health care that minimizes pain and suffering and addresses their spiritual and psychological needs. Measures are needed to address the needs of all these populations.

Evaluating Quality Measures

Quality measures are typically evaluated in terms of their significance, scientific soundness, and feasibility. *Significance* refers to the health impact of the targeted condition on years of healthy life, the ability of health care to reduce that impact, the gap in quality between actual and achievable care, and the capability or likelihood of reducing that gap. *Scientific soundness* refers to validity, reliability, and comparability of measures used to assess quality. *Feasibility* refers to the practicality of implementing quality measures in the real world. Although each of these criteria is relevant to assessing quality measures for disparity populations, a quality measure should have significance for that population. If a measure is especially significant to a disparity population, consideration should be given to separate reporting of that measure for that population—e.g., the disparate health impact of a disease such as the effect of HIV infection on African Americans.

Disparities in Health and Health Care

Racial and Ethnic Minorities

Health Outcomes

African Americans experience the poorest health outcomes of any major racial or ethnic minority group in the United States. Blacks have higher adult and infant mortality than whites or other minority groups;⁴⁻⁶ blacks also have higher age-adjusted mortality rates than whites from cardiovascular disease, cerebrovascular disease, cancer (lung, colorectal, breast, prostate, cervical), pneumonia/influenza, chronic liver disease,

diabetes, HIV, unintentional injuries, pregnancy, sudden infant death syndrome, and homicide.⁷ Cardiovascular disease, infection, and trauma are the major contributors to racial disparities in potential life-years lost.⁸ Hispanics have higher rates of death than non-Hispanic whites from liver disease, diabetes, HIV, cancer (stomach, liver, and cervical), and homicide, but lower overall age-adjusted mortality and lower rates of death from cardiovascular and cerebrovascular disease and cancer.⁷ Asians/Pacific Islanders have lower overall mortality and lower mortality for each of the major causes of death;⁷ but their rates of stomach, liver, and cervical cancer exceed those of whites.⁹ American Indians/Alaska Natives have slightly lower overall reported mortality than whites. However, because deaths among American Indians are underestimated by more than 20 percent, primarily due to misclassification of race on death certificates,¹⁰ it is likely that the overall death rate for this group is actually higher than that for whites. Compared with whites, American Indians/Alaska Natives have higher reported morbidity and mortality for pneumonia/influenza, liver disease, obesity, pediatric tuberculosis, bronchiolitis, diabetes, sudden infant death syndrome, diabetic kidney disease,^{11,12} unintentional injuries, and homicide.¹³⁻¹⁷ Racial/ethnic disparities in health outcomes likely result from the complex interaction between socioeconomic status (SES), insurance, racism, segregation, culture, and access to quality health care.^{18,19} The leading causes of death for all racial/ethnic groups are similar although groups differ widely in absolute rates of death.

Health Care Treatment

African Americans and other minorities confront significant treatment disparities. These disparities have been noted across most of the dimensions of health care process (effectiveness, safety, timeliness, and patient centeredness) and across most of the four consumer perspectives (staying healthy, getting better, living with chronic illness, and coping with the end of life). African Americans receive less appropriate treatment for breast, lung, and colorectal cancer²⁰ and less intensive treatment of prostate cancer (getting better),²¹ fewer anti-retrovirals for HIV infection (living with chronic illness),^{22,23} fewer antidepressants for depression (getting better),²⁴ less appropriate management of congestive heart failure (CHF) and pneumonia (getting better),²⁵ poorer quality of hospital care (getting better),²⁶ fewer pediatric prescriptions (getting better),²⁷ fewer admissions for chest pain (getting better),²⁸ lower quality prenatal care (staying healthy),²⁹ and less adequate treatment of cancer pain (coping with the end of life).³⁰

Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives also appear to receive suboptimal care although disparities are smaller than those observed for African Americans.³¹ Hispanics receive fewer cardiovascular procedures³² including re-perfusion therapy,^{33,34} fewer appropriate medications following a myocardial infarction,³⁵ and less analgesia for metastatic cancer^{30,36} and trauma.³⁷ American Indians/Alaska Natives have lower rates of mammography and poorer blood pressure control.³¹ As a group, care for Asians/Pacific Islanders may exceed that of whites in some instances,³¹ but subgroups clearly experience disparities.

The causes of racial and ethnic disparities in treatment are undoubtedly complex and include patient, physician, health system, and community factors. Patient-level factors include ability to afford insurance or copayments, knowledge of benefits of care, mistrust of providers and health institutions, and preferences for less invasive treatments.

Physician factors include bias, stereotyping and economic incentives. Health plan factors include size of copayments and deductibles, location of services, cultural diversity of provider staff, gatekeeping mechanisms, use of practice guidelines, and quality improvement activities. Community factors include availability and cost of health insurance, physician reimbursement, strength of safety net providers, and physician workforce distribution. These factors interact. For example, physician bias may generate greater patient mistrust and vice versa. Similarly, low insurance reimbursement (e.g., Medicaid payments) may provide incentives to physicians to minimize care.

Persons With Low Income

Socioeconomic status is a powerful determinant of health and mortality.^{4,38-40} Life expectancy for persons of lower SES is nearly 5 years less than that for those of higher SES.⁸ Cardiovascular disease and cancer are the largest contributors to socioeconomic disparities in mortality.⁸ This effect extends up the SES hierarchy and does not simply represent a poverty threshold. Explanations for the effect of SES on mortality are complex.⁴¹ Socioeconomic differences in health behavior such as smoking, body weight, and diet contribute modestly to socioeconomic differences in mortality.^{38,39,41} Additional explanations include childhood trauma, family stress, neighborhood effects, work environment, psychological stress, hostility, sense of control, and beliefs and attitudes related to SES.⁴¹⁻⁵²

Differences in health care quality by SES have been well documented. Low income is associated with receiving fewer Pap smears, mammograms,^{53,54} childhood and influenza immunizations,⁵⁵ and diabetic eye examinations,⁵⁶ and with later enrollment in prenatal care.⁵⁷ Low-income patients receive lower intensity hospital care,⁵⁸ including fewer cardiac procedures, and experience higher mortality following these procedures.⁵⁹ They also receive lower quality ambulatory⁶⁰ and hospital care,²⁶ including fewer prescriptions for aspirin and/or provision of thrombolysis for myocardial infarction.⁶¹ These disparities likely represent a combination of patient factors such as inability to afford health care, low health literacy, and lack of knowledge of health care topics, as well as physician bias, physician economic incentives, and other access barriers.

Children

Assessment of pediatric health care quality lags behind adult quality assessment. Various factors unique to child health care make quality measurement particularly challenging. These factors include a focus of pediatric care on not simply staying healthy, but also optimizing growth and development; differences in pediatric and adult disease patterns; and dependence of children on parents/caretakers. In addition, compared with the general population, children are disproportionately minority and poor⁶² and thus confront additional barriers to quality care. Although most pediatric health care focuses on health promotion and disease prevention, a sizable number of children suffer from chronic health care problems, some of which result in disability.

Women

The relationship between gender, health, and health care is complex. On one hand, the life expectancy of women exceeds that of men by more than 6 years;⁶³ women also

experience lower age-adjusted rates of coronary artery disease and have lower rates of accidental death and suicide.⁷ On the other hand, women report lower health status and higher rates of psychological distress; and they experience higher rates of various illnesses, particularly those thought to have an auto-immune etiology such as systemic lupus erythematosus, rheumatoid arthritis, and multiple sclerosis. Based on prevalence, morbidity, and mortality, the major conditions affecting women are cardiovascular disease, unintended pregnancy, osteoporosis, breast cancer, mental health disorders, violence, lung cancer, cervical cancer, and obesity/eating disorders.⁶⁴ Gender disparities in use of expensive technology have been extensively documented.⁶⁵ Most notably, rates of cardiovascular procedures are higher among men,⁶⁶ but it is not clear whether these disparities primarily represent underuse by women, overuse by men,⁶⁷ or differences in age or other confounders.⁶⁸ In other cases, there is clear evidence of worse care for women than for men. Women are less likely to receive appropriate medications such as aspirin and beta blockers following a myocardial infarction,^{61,35} less likely to receive a renal transplant^{69,70} (despite more female donors),⁷¹ and less likely to receive adequate treatment for pain.⁷² Many women also experience reduced access to reproductive services. Frequently health care plans do not cover the cost of contraceptive and abortion services, and the latter are not available in many communities.

Rural and Urban Residents

Most urban-rural-suburban differences in health are attributable to differences in the sociodemographic characteristics of the respective populations. Rural residents may have reduced geographic access to primary, tertiary, and mental health care. Inner-city residents often experience reduced access to quality primary care. Measures of access related to place of residence may be needed. However, until differences in health care quality independent of race/ethnicity and SES have been definitively established, routine stratification of most existing quality measures by place of residence cannot be recommended.

Persons With Disabilities and Chronic Illness

Few data exist regarding the quality of care received by persons with disabilities. Research is hindered by lack of suitable measures. Nonetheless, available evidence suggests that health care quality for this very vulnerable population is substandard. Persons living with disabilities and chronic illness often require ongoing medical management; yet sensory, mobility, or cognitive impairments often create barriers to care.

Elderly

Given the wide range in function and health among this population, care of the elderly requires addressing each of the consumer needs for health care: staying healthy, getting better, living with chronic illness, and preparing for the end of life. Age is strongly associated with morbidity and mortality; the prevalence of chronic disease and decline in health status rise sharply with age. The elderly are often confronted by multiple chronic conditions that require treatment with multiple medications.⁷³ Safety in terms of medication prescription is paramount. Not infrequently, impairments in vision, hearing,

mobility, and cognition result in disabilities that significantly diminish function and potentially affect access to quality care. Standard screening measures may not be appropriate for persons with limited life expectancy⁷⁴ and may result in inappropriate diagnostic evaluations without benefit.⁷⁵ There is a particularly strong need for quality measures that assess coordination of care among the elderly.

Persons Facing the End of Life

Dying persons are particularly vulnerable to receiving inadequate care. Their health care needs are unique; there is minimal overlap with the consumer needs for health care directed towards staying healthy, getting better, or living with chronic illness. Instead, the focus of health care is on maximizing the physical, psychological, social, and spiritual comfort of the dying person. In other words, the primary goal of palliative care is to help the person die with dignity and comfort.⁷⁶ A number of studies have documented suboptimal care for terminally ill patients,^{30,36,77,78} including children.⁷⁹ Members of disparity populations who cannot afford hospice care may be most vulnerable to suboptimal care.

Review of Current Measures

Most current quality measures in use have been developed by the Agency for Healthcare Research and Quality (AHRQ), the National Committee for Quality Assurance (NCQA), the Joint Commission on Accreditation of Health Care Organizations (JCAHO), the Centers for Medicare & Medicaid Services (CMS), and the Foundation for Accountability (FACCT). These measures, briefly described below, assess the health care needs of consumers across the life cycle.

Consumer Experience of Care

The Consumer Assessment of Health Plans (CAHPS®) was developed under the sponsorship of AHRQ. CAHPS® is set of surveys available in English and Spanish and includes a set of core surveys for adult and child health in addition to supplemental surveys. Core topics include enrollment/coverage, access, provider relationship, overall rating, utilization, communication/interaction, plan administration, health status, and demographics (age, gender, highest educational level, race, and ethnicity). Supplemental topics include communication with providers, interpreter services for hearing-impaired and foreign language speakers, dental care, mental health care, care for chronic conditions, pregnancy care, prescription medicines, and transportation, among others. The surveys include items that reflect patient centeredness and timeliness and, to a lesser extent, effectiveness and safety. The Picker Inpatient Survey is similar to CAHPS® in that it assesses the consumer experience of hospital care. These measures are particularly important for minority and disparity populations. Blacks report lower satisfaction and trust in their providers,⁸⁰ and Hispanics report dissatisfaction with provider communication.⁸¹ African Americans report lower involvement in their own care than whites.⁸² Both CAHPS® and the Picker survey measures should be reported separately by race, ethnicity, income, disability status, and, possibly, by place of residence.

Staying Healthy

The NCQA has developed a number of the Health Plan Employer Data and Information Set (HEDIS) measures in this dimension, especially measures relating to availability of care. They include access to prenatal care, well-child care, well-adult care, and dental care, as well as translation services and information necessary to make informed decisions. These measures are relevant to all disparity populations and should be reported separately by race, ethnicity, income, disability status, and, possibly, by place of residence.

NCQA's HEDIS and FACCT's Young Adult Health Care (YAHC) survey measures assess the quality of preventive health care in dimensions of effectiveness, timeliness, and patient centeredness and are relevant to nearly all disparity populations. These measures address screening for breast and cervical cancer, alcohol misuse, elderly health status, immunizations (child, adolescent, and adult), child development, chlamydial disease screening, teen confidentiality, diet, emotional health, exercise, smoking, sexual activity, and other risk behaviors. Many of these measures address conditions that disproportionately affect minorities and poorer persons. These measures should be reported separately by race, ethnicity, and income.

Getting Better

NCQA, FACCT, JCAHO (through its ORYX initiative), and the CMS Health Care Quality Improvement Program (HCQIP) have produced measures that address management of birth, breast cancer, mental illness/major depression, hospital management of congestive heart failure, myocardial infarction, pneumonia, and stroke, in addition to neonatal mortality and surgery and surgical complications. Most disparity populations are affected by some of these conditions. Significant disparities in treatment of these conditions have been found for racial and ethnic minorities, low income persons, and in some instances, women. Stratification of these measures by race/ethnicity and SES is warranted. These measures should be reported separately by race, ethnicity, and income. They should also be reported by gender for selected cardiovascular treatments and organ transplantation.

Living With Chronic Illness

Many of the conditions addressed in the dimension "getting better" represent management of acute conditions resulting from chronic underlying disease. Myocardial infarction, congestive heart failure, and stroke typically result from vascular disease. Similarly, acute depression and acute mental illness often represent exacerbations of a chronic disease. NCQA and FACCT have developed quality measures for ongoing management of asthma, breast cancer, diabetes, and hypertension. Minorities, particularly African Americans, low income persons, the elderly, and those with chronic diseases are disproportionately affected by these conditions. These measures should be reported separately by race, ethnicity, and income.

Preparing for the End of Life

FACCT measures for end-of-life care rely on both patient reports and surrogate reports. These measures address adequacy of advance planning, pain control, health status, symptom control, and patient-provider communication. Patient preference for do-not-resuscitate orders differ by race, age, income, and insurance status.⁸³⁻⁸⁶ Although black patients are less likely than whites to have had this type of communication,⁸⁴ they are interested in participating in these discussions. Not surprisingly, patients who lack English fluency are less likely to be involved in discussions regarding resuscitation.⁸⁵ These measures are relevant to members of all disparity populations and should be reported separately by race, ethnicity, and income.

All existing measures are relevant to racial and ethnic minorities. However, none of these measures is as yet reported separately by race or ethnicity despite evidence of disparate impact and unequal treatment. There is also a need for new quality measures that address conditions particularly relevant to minorities. These include prevention and treatment of HIV infection, prevention of preterm birth, and management of traumatic pain, among others. For similar reasons, quality measures should be reported separately by socioeconomic status. Measures related to health care affordability and literacy are particularly appropriate for low-income persons.

Challenges to Implementing Existing Quality Measures for Disparity Populations

Challenges to the implementation of existing measures for disparity populations include identification of members of different disparity populations, cost and burden of collecting additional data, privacy concerns, and development of suitable reporting formats. Information regarding membership in a disparity population is often missing from hospital, HMO, and office data. HMO and hospital claims data usually include age and gender. Some, but not all, hospitals include data on race and, in some instances, ethnicity. Neither HMOs nor hospitals collect data regarding SES (income, education, or occupation), disability, or place of residence, nor do they identify patients near the end of life. Until these data are collected, it is impossible for the hospital or HMO to insure comparable quality of care provided for members of disparity populations. However, these problems are not insurmountable. HMOs and hospitals can begin to routinely include questions regarding race/ethnicity, educational level, or disability status on existing quality surveys. Hospitals can compare results of their current quality assessments by race/ethnicity or insurance status. Both HMOs and hospitals have access to patient addresses and ZIP Codes. These data can be converted (geocoded) into community indicators of median income which can serve as a proxy for patient SES.

Privacy concerns and the potential for misuse of data represent important considerations. Safeguards proposed in an IOM report in 2000 could reduce the potential for misuse of data.⁸⁷ Standards for electronic data transmission under the 1996 Health Insurance Portability and Accountability Act (HIPAA) allow health care facilities to include race/ethnicity as a data element.⁸⁸ Similarly, the HHS privacy rule protects the confidentiality of individually identifiable health data used by health care providers using electronic transmission,⁸⁸ but the rule does not preclude collection of race/ethnicity data.⁸⁸ Annual reporting by hospitals and HMOs of patients served or

enrollment/disenrollment patterns by race/ethnicity, SES, or insurance will further minimize the potential for misuse of data. Thus, it is feasible to collect these data while minimizing the potential for breaches in confidentiality or misuse.

Separate reporting of quality by disparity population will involve additional data collection and increased costs. For this reason, only measures that reflect conditions especially relevant to members of disparity populations or for which there is firm evidence of a disparity in quality justify separate reporting. Race/ethnicity and SES meet these criteria for most measures. Selective reporting is needed for other populations.

Last, user-friendly formats for quality reporting are needed. The format should be determined by the needs and preferences of the target audience.⁸⁹ Printed reports with appropriate reading levels, language, and formats will be needed for different ethnic groups. Web-based reports offer the advantage of hypertext and allow Internet users to search for more details. Community-based organizations represent a means for disseminating results to targeted communities.

Gaps in Existing Quality Measures

Generic Gaps

The previous sections address the suitability of existing quality measures for members of disparity populations. However, an evaluation of existing measures does not address the question as to what *new* measures are needed for each population. This determination is time consuming and costly. It requires a systematic assessment of priority conditions for a given population followed by identification of established interventions and treatment guidelines. Established interventions that are not widely implemented for the population should be given priority. Scientifically sound measures must be developed to assess performance. Feasible and practical methods for collecting necessary data to assess the measures must be pilot tested and implemented. Last, dissemination plans are needed that include preparation and distribution of quality reports tailored to the needs of the relevant populations.

Although a full review of the question of where new measures are needed is beyond the scope of this report, several key points should be made. First, there are conditions that are not adequately addressed by current quality measures for *any* population. For example, medical errors result in thousands of needless deaths per year.⁹⁰ Yet, few quality measures address medical safety issues. Many, if not most, medical errors involve issues surrounding communication. Examples include inadequate communication between provider and patients or family, between physicians and other clinicians such as nurses and pharmacists, and between primary care physicians and consultants. Each of these is relevant to disparity populations—particularly patients with chronic diseases or disabilities or elderly who are elderly—who are more likely to have multiple, complex problems that require ongoing care provided by teams of professionals.

Another major safety issue that is not addressed by existing quality measures involves prescriptions. Examples include inappropriate use of antibiotics, selection of the wrong medication or dose, failure to adequately assess contraindications including allergies and serious drug interactions, and illegible handwriting. Again, these errors are likely to disproportionately affect disparity populations who require more multiple, recurring medications.

There are relatively few quality measures in the domains of mental health and very few that address management of drug abuse or use of ancillary services such as pharmacy services, dietary counseling, and physical/occupational therapy.

Development of New Measures

Racial and Ethnic Minorities

Some of the conditions relevant to minorities that are not adequately addressed by existing measures have been previously identified. These include asthma, maternal/child care, pain management, HIV/AIDS, low back pain, sickle cell anemia, mental health, end-of-life issues, and cultural competency. Other important conditions or issues include group B streptococcus colonization during pregnancy, neonatal care, chronic renal failure, management of hepatitis C, and management of uterine fibroids. Although existing measures target some of these conditions, many components of care are not adequately assessed. For example, HEDIS measures address breast and cervical cancer screening but do not adequately address followup of abnormal screening results even though there are significant racial disparities in mammography followup.⁹¹ Most of these candidate measures are also appropriate for the general population. Some are likely to be incorporated into existing measure sets.

Persons With Low Income

The most critical gaps in quality assessment for persons with low income relate to various measures of access to care. The most obvious example is affordability. Many persons with low income, even those with health insurance, are often unable to afford needed prescriptions and other health care. Questions about affordability could be easily added to CAHPS®. Such measures would allow health plans (and employers) to evaluate the impact of changes in premiums, deductibles, and copayments on the ability of persons with low income to access care.

Health care literacy represents another critical access barrier for low-income persons, who may lack the reading ability, knowledge, and skills to effectively navigate the health care system and thus leave their physician's office confused about instructions or the risks and benefits of a particular intervention. Measures designed to assess the reading levels (in appropriate language) of educational materials are needed.

Children

Well-child care is intended to promote the growth, development, and future health of children, and outcomes of this type of care are not easily measured. One review of the state of the science of quality measures for children's health care noted that there are few measures that reflect health care safety, living with illness, and care of the terminally ill or that reflect age-specific care for children.⁹² The authors specifically recommended the development of quality measures for newborn, intensive, and pediatric trauma care and the development of consumer surveys in languages other than English. Other areas in children's health for which there are few existing measures include care for children with disabilities.⁹² There is insufficient knowledge regarding standard interventions such as speech therapy for language delay, chest physiotherapy for various pulmonary conditions

including cystic fibrosis, and treatment for specific mental health problems.⁹² Also lacking are reliable measures of outcomes or health functioning.

Women

New quality measures are needed to assess the quality of care for gender-specific conditions, particularly reproductive care. These include care related to pregnancy, labor and delivery, post-partum care, family planning, fertility, fibroids, irregular or heavy bleeding, gynecological cancer, menopause, eating disorders, and mental health. The NCQA appointed a Women's Health Measurement Advisory Panel in 1997, charged with identifying, prioritizing, and stimulating the development of quality indicators in key areas related to women's health.⁶⁴ Many of the conditions listed above are expected to be addressed in future versions of HEDIS.

Elderly

Although many existing measures address conditions relevant to the elderly, many gaps remain. These gaps include many of the issues important to persons with disabilities and chronic disease (discussed below). In addition, gaps occur in access to expensive prescriptions, coordination of care, and communication. Many of these gaps in quality assessment for the elderly are addressed in the Assessing Care of Vulnerable Elders (ACOVE) project. This project developed a comprehensive set of evidence-based, quality assessment tools for ill, community-dwelling persons 65 years of age and older.⁹³ These include 236 measures comprising 22 topic areas: continuity and coordination of care, dementia, depression, diabetes, end of life, falls, hearing loss, heart failure, hospital care, hypertension, ischemic heart disease, malnutrition, medication use, osteoarthritis, osteoporosis, pain management, pneumonia, pressure ulcers, preventive care, strokes and atrial fibrillation, urinary incontinence, and vision care. These represent the most comprehensive measures for this population that have been developed to date and include many areas that are not addressed by current measures. Further research is also needed to develop evidence-based, reliable measures designed to assess the quality of health care provided to elderly persons in long-term care.⁹⁴

Rural and Urban Residents

The major gaps in quality measurement for rural and inner-city residents relate to access to primary, specialty, and, particularly, tertiary care. Not only are many rural and inner-city communities often resource depleted, but retention of physicians in health care shortage areas is difficult. Quality measures are needed to assess whether rural and inner-city residents have continuity with a regular source of care, to assess patient travel time to various sources of health care, and to assess whether health care providers working in rural and urban settings have access to adequate resources including information technology, specialty consultation and referral, and expensive hospital technology.

Persons With Disabilities and Chronic Illness

Currently, there are no quality measures in use that specifically address the quality of care provided to adults with disabilities. The measure set for care of children

with special health care needs (CSHCN) represents a significant advance in assessment of health care quality for children with disabilities. A similar measure set is needed for adults in order to assess such critical issues as access to primary and specialty care, coordination of care, and access to needed medications, supplies, and equipment. Furthermore, existing measures of health status such as the Medical Outcomes Study Short Form 36 item survey (SF-36) may not adequately capture the aspects of health status that are most relevant to persons with disabilities.⁹⁵ Little is known regarding which quality measures are most relevant to persons with particular disabilities or the impact that different disabilities have on accessing health care.

Many of the current quality measures under development address management of chronic illness. Existing measures address hypertension, lipid disorders, diabetes, asthma, depression, coronary artery disease, congestive heart failure, and breast cancer. The primary limitation of such measures is that they focus primarily on health care processes, such as documentation of appropriate testing or prescription of the appropriate medication. Second generation measures under development focus more on outcomes, such as proportion of patients with adequate control of their diabetes, hypertension, or cholesterol, or improvements in functional outcomes.⁹⁶ Common chronic conditions not adequately addressed by current measures include management of various types of arthritis, chronic low back pain, primary care of the cancer patient, liver disease including hepatitis C, chronic obstructive pulmonary disease, anxiety disorders, and renal insufficiency. Furthermore, there are relatively few scientifically proven interventions that are specific to persons with disabilities.⁹⁵ Last, research is needed to determine where the largest gaps in quality exist for consumers with different disabilities and then to begin developing measures to assess performance in these areas.

Persons Near the End of Life

The identification of key measures for end-of-life care presents unique challenges because the goal of care for the dying differs qualitatively from other types of care. Currently, no widely used quality measures exist for end-of-life care; the measure set under development by FACCT represents a major advance. Measures are also needed to determine the extent to which end-of-life care is meeting the social, psychological, and spiritual needs of the dying patient and his or her family. Further study is needed to determine the impact on families of inpatient versus home hospice care.

Research and Development

AHRQ is currently sponsoring research to ensure both the appropriate implementation of existing measures and the development of new measures for disparity populations. Research is needed to determine the most cost-effective and least intrusive means for identifying members of disparity populations, for obtaining data on quality of care, and for preparing and disseminating reports. Research in each of the phases necessary to develop new measures is critical—e.g., clinical trials to establish the efficacy of interventions among different disparity populations, and translational research to develop evidence-based practice guidelines and find ways to effectively implement these guidelines in practice. Also needed are development, pilot testing, and validation of reliable, cost-effective methods to implement quality measures that will fill the gaps in

existing measures. Finally, the impact of implementation of these measures on provider and consumer behavior and improvements in health outcomes must also be assessed.

Summary and Conclusions

This report has shown why population-specific quality measures are needed to monitor the quality of care provided to disparity populations. Many members of disparity populations face the double jeopardy of poor health coupled with inferior care. Health care for members of disparity populations is further hindered by common membership; persons frequently confront the challenge of membership in multiple disparity populations. The causes of disparities in health and health care are complex. They include patient-level factors such as ability to afford care, health care literacy, and culture; physician-level factors such as bias, competing demands, and time pressure; plan-level factors such as cost-containment policies and practice guidelines; and sociological factors such as racism, community poverty, and diffusion of information patterns. Regardless of the cause, quality of care for a population cannot be improved if it is not specifically assessed.

To ensure that members of disparity populations receive appropriate state-of-the-art health care two major improvements are required. First, existing quality measures must be stratified or reported separately by population when there is evidence of disparate impact of the health condition targeted by that measure. Second, existing quality measures must be supplemented with measures that assess conditions or interventions likely to have a significant impact on that population. These changes must be incorporated without allowing proliferation in the number of quality measures to the point that quality reports are ignored by consumers and purchasers. Preparation and dissemination of health care quality reports must take into account the needs and preferences of the intended audience.

Review of quality measures currently in use shows that most are relevant to disparity populations. For example:

- All existing measures are relevant to racial and ethnic minorities. However, none is currently reported separately by race or ethnicity although the National Quality Forum has recently endorsed this critical step.⁸⁹ Population-specific reporting represents a central challenge to current quality assessment. In the absence of measurement, the core dimension of equity cannot be assured. Additional measures relevant to racial and ethnic minorities are needed. Examples are access to expensive technology, prevention and treatment of HIV/AIDS, and cultural competency.
- Most existing measures are also relevant to persons with low income; separate reporting for this population is also needed. Measures of health care affordability and adequacy of communication would be particularly relevant to low-income persons.
- Quality measurement for children lags behind adults, but significant progress has been made. Notable advances include the YAHC and CSHCN surveys. New measures are needed for newborn care, intensive care, and trauma care; also needed is development of consumer surveys in languages other than English.
- Many priority conditions for women are addressed by current measures. Other measures relevant to women—such as violence, mental health, and eating disorders—

are also relevant to a number of other disparity populations and require a firmer foundation in the scientific evidence before they can be implemented.

- Many existing measures also address major conditions affecting the elderly. A key challenge is the development and implementation of measures to address the myriad of problems confronting this population. Many of these gaps in measures for the elderly are addressed through the ACOVE project.⁹³ However, the large number of ACOVE measures precludes its widespread use.
- Rural and urban residents have many of the same health care needs as the general population. However, additional measures focusing on access to primary, secondary, and tertiary care are needed.
- There are no quality measures in use that specifically address the health care needs of disabled adults although the CSHCN survey demonstrates that it is feasible to assess quality of care delivered to disabled persons. Critical areas for disabled adults include access to primary and specialty care, coordination of care, and access to needed medications, supplies, and equipment.
- Many existing measures address the consumer perspective of living with illness. There is a need for measures that reliably assess relevant outcomes in management of chronic illness.
- There are no widely used measures for persons near the end of life. The FACCT measures under development show major promise. Further research is needed to identify pivotal processes in the care of this unique population.

Available data show that quality improvement can reduce if not eliminate disparities in health care. This has been shown for childhood immunizations,⁹⁷ hemodialysis,⁹⁸ management of depression,⁹⁹ and influenza vaccination.¹⁰⁰ These findings offer promise for the elimination of many disparities in health and health care using existing technology and underscore the common pathway between improving quality and reducing disparities.¹⁰¹

I. Introduction

Background

National attention has focused on improving the quality of health care for all Americans and eliminating disparities in health and health care for members of vulnerable groups. Both the Institute of Medicine (IOM) and Commonwealth Foundation have released reports regarding racial and ethnic disparities in health care.^{3,102} In contrast, this report assesses the adequacy of currently used quality measures used for disparity populations. *Disparity populations* are defined as those groups for which there is a significant disparity either in the quality, outcomes, cost, or use of health care services or in access to or satisfaction with such services as compared to the general population.

Disparity populations include racial and ethnic minorities, persons with low income, rural and urban residents, children, women, persons living with chronic disabilities or illness, the elderly, and persons near the end of life. These populations are clearly not mutually exclusive but overlap considerably. Low-income persons, children, women, and persons living with disabilities and chronic illness are likely to be disproportionately minority. Similarly, minorities, women, children, elderly, rural and urban residents, and persons living with disabilities or chronic illness are more likely than nonminorities to be low income. Thus, it is not uncommon for members of a particular disparity population to contend with membership in other disparity populations. For example, 4.7 million Americans confront the triple jeopardy of low income, no insurance, and a chronic health condition requiring medical care.¹⁰³

Data for this paper were gleaned from multiple literature searches conducted using MEDLINE®, the National Center for Health Statistics, the Office of Minority Health, and Web sites for the Agency for Healthcare Research and Quality (AHRQ), the National Committee for Quality Assurance (NCQA), Centers for Medicare & Medicaid Services (CMS), the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), and Foundation for Accountability (FACCT). Manual bibliographic searches of key articles were used to supplement these searches. Because data derived from federally sponsored surveys tend to be methodologically stronger, these data were given priority when making epidemiological inferences. These surveys include the National Health Interview Survey (NHIS), the Medical Expenditure Panel Survey (MEPS), the Behavioral Risk Factor Surveillance System (BRFSS), the National Health and Nutrition Examination Surveys (NHANES), and the National Ambulatory Medical Care Survey (NAMCS). The limitations of vital statistics on racial and ethnic minorities have been reviewed elsewhere;^{10,104,105} only passing comments will be made in this report regarding these limitations.

A Framework for Assessing Quality in Health Care

An Institute of Medicine report in 1990 defined health care quality as: “the degree to which health care services increase the likelihood of desired health outcomes and are consistent with current professional knowledge.”¹ Developing explicit criteria to assess

whether health care meets this definition is challenging. Health care quality has most often been evaluated using a combination of structure, process and outcome measures.¹⁰⁶

- *Structural measures* include appropriate credentialing of health care professionals, presence of appropriate policies and procedures, and appropriate staff-to-patient ratios.
- *Process measures* indicate whether and when particular interventions were delivered to particular groups.
- *Outcomes measures* indicate the results of the intervention in terms of health, such as recovery from illness, change in quality of life, adverse effects, and mortality.

Structural measures are easier to assess, but less clearly linked to outcomes. Ideally, health quality should be evaluated primarily based on patient outcomes; but even under the best of circumstances, health care is often only one of many factors that contribute to favorable health outcomes.¹⁰⁷ For these reasons, most quality measures focus on health care process.

A particular process measure should only be used to assess quality when current scientific evidence has conclusively established a causal link between a particular health care process and a particular health outcome.¹⁰⁸ When health outcomes are used as quality measures, it is critical that measures adequately account for the effects of other factors. For example, if rates of hospitalization for asthma are used to assess the quality of care for asthmatics, then the quality measure must account for differences in patient characteristics between health plans such as prevalence and severity of asthma or patients' ability to afford asthma medications.

Functions of Quality Measures

Quality measures serve two primary functions: accountability and quality improvement. They insure accountability for the health care provided when they are publicly reported. For example, quality performance data informs consumer selection of health care plans and contracting decisions by purchasers such as employers, health maintenance organizations (HMOs), and State and Federal Government. Quality data inform the accreditation process for health care organizations. Quality measures are also increasingly being used by payers to guide reimbursement to individual health care providers. When used to insure accountability, quality assessment is often termed "quality assurance." However, because the stakes are higher when the performance of health care organizations is publicly reported, it is critical that only the most rigorous and valid measures be used. Failure to do so undermines the process of public reporting of health care quality and unfairly penalizes many health care providers.

Quality measures serve a second vital function. They provide the foundation for internal quality improvement efforts. Hospitals and HMOs can use their own internal performance data to identify areas of suboptimal performance, explore potential causes, develop action plans, and monitor their progress. This function of quality assessment is termed "quality improvement." Because the stakes are lower for internal use of quality measures than for public reporting and because internal quality measures are often used as screens for potential problems (that warrant further study), less rigorous measures are often used for quality improvement.

Dimensions of Quality

The report by the Institute of Medicine, *Envisioning the National Health Care Quality Report*, outlined a useful conceptual framework for national health care quality.² It is based on two core dimensions: specific components of health care quality and consumer perspectives on health care needs. The first dimension comprises four components: safety, effectiveness, patient centeredness, and timeliness. The second dimension reflects changes in consumers' health care needs across the life cycle: staying healthy, getting better, living with illness or disability, and coping with the end of life (see Figure 1). Equity represents a key parameter that cuts across both dimensions and reflects differences in quality of care received by different groups; i.e., members of disparity populations.

Figure 1. Matrix of the dimensions of health care quality

	Components of health care quality			
Consumer perspectives on health care	Safety	Effectiveness	Patient centeredness	Timeliness
Staying healthy				
Getting better				
Living with illness or disability				
Coping with the end of life				

Source: Institute of Medicine, *Envisioning the National Health Care Quality Report*. Washington, DC: National Academy Press; 2001.

Safety refers to the absence of errors in diagnosis or treatment, and the absence of delays or omissions in the initiation of appropriate diagnostic tests or treatment. Failure to follow up on an abnormal Pap test, for example, represents an error in safety related to staying healthy. Initiating treatment with a medication for a chronic condition in the presence of a contraindication represents an error in safety related to getting better.

Effectiveness refers to use of the appropriate intervention for the appropriate population. Failure to provide smoking cessation counseling to smokers or appropriate pain relief to a hospice patient could be construed as effectiveness errors.

Patient centeredness refers to the consumers' experience of the patient-physician relationship as caring, understanding, and characterized by partnership. Failure by health professionals to elicit the patient perspectives and preferences regarding cancer treatment represents a deficiency in patient centeredness.

Timeliness refers to the initiation and provision of care within an appropriate interval. Lack of timeliness can include unwarranted delays in the provision of preventive health services such as Pap smears or colorectal cancer screening, delays in appropriate diagnosis and treatment, and delays in the provision of appropriate end-of-life care such as discussion of transition to hospice.

As shown in Figure 1, use of the two quality dimensions results in a four-by-four matrix with safety, effectiveness, patient centeredness, and timeliness comprising four columns and staying healthy, getting better, living with illness/disability, and coping with the end of life comprising four rows. As the report indicates, every cell will not necessarily be of comparable significance to policymakers or consumers. Nor do existing quality measures necessarily correspond to every cell. As the IOM report also notes, most existing quality measures are primarily effectiveness measures. Measures of the other three quality dimensions, particularly safety, are much less developed.

Equity, or disparities in quality between groups, represents a cross-cutting dimension. It can be assessed by comparing rates within a given cell by race/ethnicity or income. For example, equity in effective interventions designed to keep consumers healthy can be assessed by comparing rates of annual mammography among women 40 and over according to income. Equity in timeliness related to getting better can be assessed by comparing rates of ruptured appendix by race or ethnicity. Equity together with the other components of quality can be used to insure health care quality for disparity populations.

Assessing Health Care Quality for Disparity Populations

Quality measures are needed for disparity populations for two reasons: to insure equity and to assess aspects of health care that are unique to a particular group.

Health care quality is not evenly distributed throughout the general population. Members of some groups receive better care than others. Although there is a significant gap between expected quality and the actual level of health care received by most Americans, this gap is much wider for many members of disparity populations. In some instances, this may be attributable to biologic differences and/or disease severity. For example, the elderly are less likely to have adequately controlled hypertension due to more severe hypertension, and children and adolescents are less likely to have their diabetes controlled than adults due to differences in type of diabetes. Some groups are at higher risk for substandard quality than are others. Although the reasons for this inequality in quality are complex, the bottom line is that quality measures applied to the general population will “hide” or mask deficiencies in quality provided to members of vulnerable groups or disparity populations. These population-specific deficiencies can only be identified when quality of health care to these groups is specifically assessed.

The second reason that measures developed for the general population may not be appropriate to a particular group is that the prevalence and health impact of different conditions may differ between populations. For example, cystic fibrosis is uncommon in African Americans compared with persons of northern European descent; the converse holds for sickle cell anemia. Thus, quality measures for cystic fibrosis are less relevant to African Americans. Similarly, quality measures for care of patients with sickle cell anemia are less relevant to persons of northern European descent. Breast cancer affects both women and men; but because the incidence of breast cancer in men is dramatically lower than in women, screening for breast cancer in men is not cost-effective. For these

reasons, the quality of health care provided to groups at risk for suboptimal care needs to be specifically assessed using state-of-the-art measures.

The National Quality Forum (NQF) is a nonprofit, private organization whose mission is to develop and implement a national strategy for health care quality measurement and improvement. The NQF concluded, based on a series of commissioned reports and workshops, that “better measurement and reporting are essential to improve health care quality for minority patients.”⁸⁹ The NQF report made 10 recommendations related to this goal; these recommendations included separate reporting for racial and ethnic minorities and development of new measures.

Reasons for Addressing Disparities in Health Care Quality

There are a number of compelling reasons for assessing and addressing disparities in health care, particularly racial and ethnic disparities in health care. The first is moral. The recently released report from the Institute of Medicine strongly suggests that physician bias contributes to racial and ethnic disparities in health care access and quality.³ Bias in health care, whatever the cause, is morally indefensible. Racial and ethnic disparities in health care make national headlines because they defy our national consensus that race and ethnicity are not appropriate grounds for allocating organ transplants, life-saving cancer surgery, or cardiovascular procedures. Disparities in health care persist despite a consensus that they are deplorable. They persist because they are largely unseen. Health care disparities operate below the radar screen of standard quality measures. In the absence of appropriately collected data, they cannot be addressed. Although individuals or groups may perceive bias and discrimination in health care, in the absence of population-level data, complaints may be dismissed as anecdotal. Thus, a system for tracking and monitoring these disparities is required.

As discussed in detail below, consumer attitudes, preferences, and beliefs also contribute to disparities in health care. For example, mistrust on the part of minorities may deter minorities from consenting to invasive surgical procedures. However, such mistrust is often rooted in reality. Africans Americans are more likely to be operated on by cardiac surgeons with lower quality ratings.¹⁰⁹ Africans Americans are more likely to receive care from physicians in training than are whites. Trust can be restored by insuring that minorities receive comparable quality care. Preferences are affected by information as illustrated by the success of direct-to-consumer pharmaceutical marketing.

A second reason for addressing health care disparities is that their elimination represents a necessary, but not sufficient, step towards the achievement of the *Healthy People 2010* goal of the elimination of disparities in health. That is, while the elimination of disparities in health care will not insure the elimination of disparities in health, the failure to do so will insure that disparities in health persist.

A third reason for monitoring disparities is that disparities are incompatible with quality. Both the IOM and the NQF acknowledge equity as a core component of quality. High performing industries in the non-health care sector have achieved remarkable success using quality improvement technology to achieve both high overall quality and low variation in process and outcome. The NCQA and 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 the quality of care for racial and ethnic minorities and other disparity populations is specifically

assessed, disparities will persist. This flaw makes it is possible 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, there are large disparities by race in receipt of the influenza vaccine among the elderly. National rates for whites (60 percent) are higher than for blacks (40 percent).¹¹⁰ Consider an HMO comprised of 85 percent whites and 15 percent blacks. If the vaccination rate for whites is 80 percent compared to 60 percent for blacks, the overall rate of influenza vaccine is nonetheless a respectable 77 percent. 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.

A fourth reason to monitor and address health care disparities is that doing so represents sound public policy. Disparities often represent “reverse targeting” or the misallocation of health care resources away from populations with the greatest health care needs (i.e. minorities, lower income persons, and persons living with chronic illness and disabilities) to those with the least need. Disparities in use of invasive procedures represent a combination of inappropriate overuse among majorities and inappropriate underuse among minorities.¹¹¹ If one of the goals of health care is to promote improvements in population health, then health care must be appropriately allocated. Monitoring and eliminating disparities will help to minimize inappropriate allocation.

A fifth reason for monitoring the care provided to members of disparity populations is that quality improvement interventions can eliminate disparities. Hospitals and HMOs have active quality improvement programs in place. These programs represent ideal ways to assemble multidisciplinary teams who can design interventions to eliminate disparities in health care processes within the health care organization.

Finally, lessons learned from assessing and addressing health care quality for members of disparity populations may ultimately benefit all. Improved understanding of the contribution of physician and patient factors to racial and ethnic disparities in health care may also improve the care provided to nonminorities. Improved understanding of gender disparities in outcome measures may provide key insights into underlying disease mechanisms that may facilitate the development of more effective therapies.

Evaluating Quality Measures

Most quality organizations use similar criteria to evaluate candidate quality measures. Criteria for publicly reported measures typically include significance, scientific soundness, and feasibility.² Each is discussed below.

Significance

Quality measures must be significant to the population for whom the measure is applied. Measures are significant if they address a health care process or intervention that appreciably improves the overall health of a particular subpopulation. The intervention will have an appreciable impact only if it targets a condition that is prevalent and that has a major adverse impact on the health of the population in terms of survival, quality of life, disability, pain, or stigma. Significance means that there is strong scientific evidence, such as findings from randomized controlled trials, showing the intervention is effective.

Significance also means that there is an appreciable gap in performance between current guidelines for care and care that is actually provided. Ideally, there should also be evidence that this gap in performance can be reduced or eliminated cost-effectively. In other words, there should be evidence that performance can be realistically improved and that costs associated with such improvement efforts are reasonable relative to the expected gains.

Scientific Soundness

Quality measures should meet scientific standards for validity, reliability, and comparability. A measure is valid insofar as it assesses what it purports to assess. A measure is reliable if it accurately measures the intervention in question and produces the same result upon repeated measurement. A measure is fair (between organizations or providers) when the measure provides for fair performance comparisons between health care organizations or providers. In other words, the measure primarily assesses the process or outcomes of health care rather than reflecting differences in consumer illness severity, preference, or adherence. When a measure does not adequately account for differences in illness prevalence or severity or other differences between groups, then comparisons between providers are meaningless and potentially harmful.

Feasibility

Last, measures should be feasible to implement and report. This means that the time and cost required to collect and analyze data in a timely manner are reasonable relative to the expected benefits of the quality assessment. Unfortunately, data are not always available in order to determine whether each of these criteria has been satisfied. At times, best estimates must be made.

Suitability of Existing Measures for Disparity Populations

Each of these three criteria is also relevant to assessing the suitability of existing quality measures for disparity populations. The criteria of significance, scientific soundness, and feasibility can be used to determine which quality measures are suitable for assessing health care quality for a particular disparity population. Most currently used quality measures have been validated by applying these criteria to the general population. Thus, attention should be given to potential differences between the disparity and general population in terms of significance, scientific soundness, and feasibility for a particular measure.

Significance for Disparity Populations

Significance is the first criterion for assessing relevance of an existing measure to a disparity population. It can be applied by asking three questions:

1. Is the prevalence and impact of the condition targeted by the quality measure comparable (or greater) in the disparity population than in the general population?
2. Is there evidence of disparity in quality for this measure between the disparity population and general population?
3. Are members of the disparity population at higher risk for adverse outcomes?

An affirmative answer to the first question suggests that the measure addresses a condition of significant impact to the particular disparity population. Most existing measures have been previously assessed based on their significance for the general population. In the absence of significant differences in disease prevalence, disease severity, and treatment between the general population and the disparity population, the measure is significant for the disparity population.

The presence of disparities in quality for a measure suggests the need to report findings for the disparity population separately from the general population. In other words, if there is appreciable evidence of a performance gap for the disparity population relative to the general population, the results should be stratified for this population.

When members of a disparity population are at higher risk than the general population for adverse outcomes, consideration should be given to reporting quality findings separately for the disparity population *even in the presence of parity in performance*. In other words, higher risk may justify separate reporting for that population. For example, Vietnamese women have five times higher rates of death from cervical cancer than white women. Simply because Vietnamese women may have Pap smears at comparable rates as white women is not sufficient to lump these groups together for quality reporting. Separate reporting for Vietnamese women in this case is needed to insure that Pap smear screening remains a priority among women at highest risk of death from cervical cancer.

Scientific Soundness for Disparity Populations

Measures that have been found to be scientifically sound for the general population are often scientifically sound for disparity populations. However, there are important caveats to this generalization. Self-report measures require independent validation in each population for which they will be used. For example, satisfaction measures developed for the general population may not be valid for ethnic minorities. Different groups may interpret questions differently or use different standards of reference. Furthermore, the effectiveness of treatments may differ between groups. For example, certain medications such as angiotensin-converting enzyme inhibitors (ACEIs) that have been shown to be effective for treating heart failure among whites may be less effective among blacks.¹¹² Other medications such as digoxin may be associated with greater risk of death in women than men.¹¹³ Unfortunately, there are often no data regarding the effectiveness of interventions for particular disparity populations.

Feasibility for Disparity Populations

Feasibility can be particularly challenging when existing measures are used to assess care for particular groups because the data needed to identify members of particular disparity populations are often lacking. For example, data regarding race, ethnicity, income, disability status, or the end of life are often lacking. These issues are discussed in detail in section IV.

II. Disparities in Health and Health Care

Racial and Ethnic Minorities

Racial/Ethnic Disparities in Health

Where possible, this paper uses the racial/ethnic classification categories in “Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity” published by the Office of Management and Budget (OMB) in a *Federal Register* notice of October 30, 1997 [62 FR 58782-58790]. These categories are “black or African American,” “American Indian or Alaska Native,” “Asian,” “Native Hawaiian or other Pacific Islander,” and “white” for race, and “Hispanic or Latino” for ethnicity.

African Americans

African Americans have three times the poverty rate of whites. Their health outcomes are worse than those of any major racial or ethnic minority group in the United States. Blacks have higher adult and infant mortality than whites and other minority groups.⁴⁻⁶ They have significantly higher mortality rates than whites from cardiovascular disease, cerebrovascular disease, cancer (lung, colorectal, breast, prostate, cervical), pneumonia/influenza, diabetes, HIV, unintentional injuries, pregnancy, sudden infant death syndrome, and homicide.⁷ The primary disease-specific causes of black-white disparities are cardiovascular disease, HIV, stroke, cancer, trauma, and diabetes.¹¹⁴ Cardiovascular disease fully accounts for one-third of racial disparities in adult mortality.¹¹⁴ Racial disparities in mortality and health status differ widely between communities within the United States.^{115,116} Despite these differences in mortality rates, the leading causes of death for whites (Table 1) and African Americans (Table 2) are similar (although the exact order of causes may differ). Disparities in cause-specific mortality are highest for prostate cancer, diabetes, HIV infection, and homicide. Suicide and chronic lung disease are the only causes where African Americans experience lower mortality rates.

Hispanics

Hispanic Americans have higher death rates than non-Hispanic whites from liver disease, diabetes, HIV, and homicide, but lower rates from cardiovascular and cerebrovascular disease and cancer (Table 3).⁷ Rates of death from stomach, liver, and cervical cancer exceed those of whites.⁹ Hispanic Americans are not a homogeneous group but represent persons or descendants of persons from many different Spanish-speaking countries with different cultures. Not surprisingly, health conditions differ between Hispanic subgroups. Puerto Ricans have higher rates of low birthweight infants than other subgroups,¹¹⁸ and Mexican Americans have higher rates of functional disability than whites.¹¹⁹ Despite these differences, the leading causes of death for Hispanics are generally similar to the white population (Table 3). Hispanics have lower rates of deaths from many causes than whites, but higher rates from diabetes, liver disease, HIV infection, and homicide.

Table 1. Leading causes of death for whites, 2000¹¹⁷

Rank	Cause of death	Rate*
1	Ischemic heart disease	188.1
2	Stroke	59.4
3	Lung cancer	58.9
4	Chronic lung disease	47.7
5	Accidents	35.4
6	Prostate cancer	28.3
7	Breast cancer	27.7
8	Influenza and pneumonia	23.7
9	Diabetes mellitus	22.0
10	Colorectal cancer	20.8
11	Suicide	12.1
12	Liver disease	9.0
13	Homicide	2.8
14	HIV	2.3

*Deaths per year per 100,000 persons adjusted for age.

Table 2. Leading causes of death for blacks, 2000¹¹⁷

Rank	Cause of death	Rate*	Risk relative to whites+
1	Ischemic heart disease	219.3	1.17
2	Stroke	82.4	1.39
3	Prostate cancer	65.3	2.36
4	Lung cancer	64.1	1.09
5	Diabetes mellitus	49.7	2.26
6	Accidents	38.4	1.08
7	Breast cancer	34.9	1.28
8	Chronic lung disease	31.7	0.66
9	Colorectal cancer	28.3	1.36
10	Influenza and pneumonia	25.8	1.09
11	HIV	23.7	10.30
12	Homicide	21.0	7.50
13	Liver disease	9.5	1.06
14	Suicide	5.6	0.46

*Deaths per year per 100,000 persons adjusted for age.

+ Rates calculated from available data.

Asians and Native Hawaiians or Other Pacific Islanders*

This group has lower death rates from each of the major causes of death except homicide (Table 4),⁷ but rates of stomach, liver, and cervical cancer exceed those of

* Prior to the revised 1997 OMB standards, the two categories “Asian” and “Native Hawaiian or Other Pacific Islander” comprised a single category, “Asian or Pacific Islander.” This terminology is maintained in Table 4 and elsewhere applicable in reporting of findings in this report.

whites.⁹ Rates of tuberculosis for Asian/Pacific Islanders are more than 10 times the rate for whites.¹²⁰ Asian/Pacific Islanders (and Hispanics) are most likely to reside in counties that exceed EPA air quality standards.¹²⁰ Members of many different cultures comprise the Asian and Native Hawaiian/Other Pacific Islander groups. Rates of illness differ markedly between subgroups. For example, overall death rates for Samoan Americans and Hawaiians are the highest of any minority group.¹²¹ Japanese Americans living in Hawaii also have higher rates of cancer than other Asian groups.¹²² Nonetheless, the leading causes of death are similar to those of the white population.

Table 3. Leading causes of death for Hispanics, 2000¹¹⁷

Rank	Cause of death	Rate*	Risk relative to whites+
1	Ischemic heart disease	128.8	0.68
2	Stroke	39.2	0.66
3	Diabetes	32.4	1.47
4	Accidents	30.6	0.86
5	Lung cancer	22.0	0.37
6	Chronic lung disease	17.7	0.37
7	Prostate cancer	17.6	0.64
8	Influenza and pneumonia	17.0	0.72
9	Breast cancer	15.8	0.58
10	Liver disease	15.7	1.74
11	Colorectal cancer	12.4	0.60
12	Homicide	8.4	3.00
13	HIV	7.0	3.04
14	Suicide	6.1	0.50

*Deaths per year per 100,000 persons adjusted for age.

+ Rates calculated from available data.

Table 4. Leading causes of death for Asians or Pacific Islanders, 2000¹¹⁷

Rank	Cause of death	Rate*	Risk relative to whites+
1	Ischemic heart disease	109.0	0.58
2	Stroke	52.5	0.88
3	Lung cancer	28.9	0.49
4	Influenza and pneumonia	19.3	0.81
5	Chronic lung disease	18.5	0.39
6	Accidents	18.4	0.52
7	Diabetes	16.6	0.75
8	Colorectal cancer	13.0	0.63
9	Breast cancer	12.7	0.47
10	Prostate cancer	12.4	0.45
11	Suicide	5.8	0.48
12	Liver disease	3.7	0.41
13	Homicide	3.1	1.11
14	HIV	0.7	0.30

*Deaths per year per 100,000 persons adjusted for age.

+ Rates calculated from available data.

American Indians/Alaska Natives

Hundreds of different tribes, each with different cultural traditions, comprise the American Indian/Alaska Native group. American Indians/Alaska Natives have slightly lower overall death rates than whites, including lower reported rates of death from cardiovascular, cerebrovascular, and cancer-related causes. However, deaths among American Indians are underestimated by more than 20 percent largely due to misclassification of race on death certificates.¹⁰ Thus, it is likely that the overall death rate for American Indians/Alaska Natives is actually higher than that for whites. Rates of disease and death for American Indians/Alaska Natives are higher than whites for pneumonia/influenza, liver disease, obesity, pediatric tuberculosis, bronchiolitis, diabetes, sudden infant death syndrome, diabetic kidney disease,^{11,12} unintentional injuries and homicide.¹³⁻¹⁷ American Indians and Alaska Natives have the highest death rate of any group from motor vehicle accidents.¹²⁰ Rates of diseases and mortality vary between American Indian/Alaska Native groups although reliable data are sparse. For example, Pima Indians have the highest rates of diabetes in the world.¹²³ In general, the leading causes of death for American Indians/Alaska Natives are generally similar to those for whites (Table 5). Reported rates are lower than rates for whites for most causes except for diabetes, liver disease, HIV infection, accidents, and homicide.

Table 5. Leading causes of death for American Indians and Alaska Natives, 2000¹¹⁷

Rank	Cause of death	Rate*	Risk relative to whites+
1	Ischemic heart disease	120.0	0.64
2	Accidents	59.6	1.68
3	Diabetes	41.4	1.88
4	Stroke	40.3	0.68
5	Lung cancer	32.7	0.56
6	Chronic lung disease	30.4	0.64
7	Liver disease	28.6	3.18
8	Influenza and pneumonia	19.5	0.82
9	Prostate cancer	16.9	0.61
10	Breast cancer	14.7	0.54
11	Colorectal cancer	13.0	0.63
12	Suicide	12.0	0.99
13	Homicide	8.1	2.89
14	HIV	2.7	1.17

*Deaths per year per 100,000 persons adjusted for age.

+ Rates calculated from available data.

Causes of Racial and Ethnic Disparities in Health

Much of the racial disparity in adult mortality,¹²⁴ but not infant mortality,^{19,125} is explained by the lower socioeconomic status (SES) of African Americans. African Americans, Hispanics, American Indians/Alaska Natives, and members of certain Asian/Pacific Islander groups have higher rates of poverty, lower rates of high school graduation, and are more likely to reside in impoverished communities.¹²⁶ Nonetheless, it is difficult to determine the reasons for racial or ethnic disparities in incidence, prevalence, or severity of disease because the exact causes of many of the diseases that

disproportionately affect minorities are not known. It is likely that racial disparities result from the complex interaction between SES, racism, segregation, culture, and access to quality health care.^{18,19} In the absence of clear understanding of how these factors interact, it is difficult to assess the contribution of specific factors to disparities. It is probably safe to speculate that the salience of these factors differs by condition and by racial/ethnic group.

Racial/Ethnic Disparities in Health Care

Although the causes of racial and ethnic disparities in health are multifactorial, disparities in health *care* undoubtedly contribute to disparities in outcomes. Racial and ethnic disparities in health care quality have been extensively reviewed by others^{3,127} and will not be reviewed in depth in this report. Most research on health care disparities has focused on black-white comparisons. Other minority groups have received less study. However, data from Medicare managed care enrollees show that disparities in quality measures are largest among African Americans, smallest among Asians, and intermediate for Hispanics and American Indians.³¹ In general, disparities in health care can be viewed across the spectrum of health care: access, satisfaction, process or treatment, and outcomes.

Access

Eisenberg and Power outlined a series of access barriers or “voltage drops” between the receipt of potential quality health care and delivery.¹²⁸ Most of these access barriers are related to the dimension of timeliness such as delays or failure to obtain needed care. Potential barriers include lack of availability of insurance, cost of insurance, lack of informed choice of providers, and limited availability of primary care and/or specialty care. Most of these barriers disproportionately affect members of disparity populations. Minorities are more likely to be uninsured and less likely to have a regular source of care or access to specialty care.^{12,129} Blacks and Hispanics receive fewer mammograms,¹³⁰ Pap smears,¹³⁰ influenza vaccinations,¹³¹ and less prenatal care¹³¹ and report lower use of prescribed antihypertensives.¹³² Asians/Pacific Islanders receive fewer Pap smears, mammograms,¹³³ and influenza vaccinations.¹³¹ Native Americans/Alaska Natives receive the least prenatal care of any group.¹²⁰

Treatment

Racial disparities have been noted across most of the dimensions of health care process (effectiveness, safety, timeliness, and patient centeredness) and across most of the four consumer perspectives (staying healthy, getting better, living with chronic illness, and coping with end of life). African Americans receive less appropriate treatment for breast, lung, colorectal, and prostate cancer (getting better)^{20,21} and HIV infection (living with chronic illness);^{22,23} fewer antidepressants for depression (getting better);²⁴ less appropriate management of congestive heart failure and pneumonia (getting better);²⁵ poorer quality of hospital care (getting better);²⁶ fewer pediatric prescriptions (getting better);²⁷ fewer admissions for chest pain (getting better);²⁸ lower quality prenatal care (staying healthy);²⁹ and less adequate treatment of cancer pain (coping with the end of life).³⁰

Health care disparities among other racial and ethnic minorities have been less extensively studied. Nonetheless, evidence suggests that Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives also receive suboptimal care in selected instances. Hispanics receive fewer cardiovascular procedures³² including re-perfusion therapy,^{33,34} fewer appropriate medications following a myocardial infarction,³⁵ and less analgesia for metastatic cancer^{30,36} and trauma.³⁷ Asians/Pacific Islanders receive fewer Pap smears, mammograms,¹³³ influenza vaccinations,¹³¹ and invasive cardiovascular procedures.¹³⁴ American Indians/Alaska Natives have lower rates of mammography and poorer blood pressure control than whites³¹ and, as noted, receive the least prenatal care of any group.¹²⁰ Among Medicare HMO enrollees, African Americans show the largest disparities in quality followed by Hispanics and American Indians/Alaska Natives. In this population, Asians/Pacific Islanders receive higher quality care than whites.³¹

Outcomes

As indicated earlier, minorities, particularly African Americans, experience worse health care outcomes than non-Hispanic whites. Minorities tend to have higher rates of hospitalization for conditions that are potentially treatable.¹³⁵⁻¹³⁸ African Americans have higher rates of death from conditions that are potentially treatable¹³⁹ including lower rates of curative lung surgery resulting in higher lung cancer mortality,¹⁴⁰ lower rates of cardiovascular procedures resulting in higher death rates from myocardial infarction,¹⁴¹ higher rates of orchiectomy from late stage prostate cancer, and higher rates of limb amputations among diabetics.¹⁴²

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^{143,144} and more complications following vascular surgery, glaucoma surgery, and endarterectomy.¹⁴⁵⁻¹⁴⁷ The extent to which these differences represent differences in health care quality as opposed to differences in disease is not clear. Having a chronic disease or major disability, particularly one related to mobility or major organ dysfunction, places one at higher risk for surgical morbidity and mortality. However, many hospitals do not have sufficient surgical volume to meaningfully compare rates of major surgical complications by subgroup. Thus limited statistical power and problems in case-mix adjustment make use of this measure problematic.

As indicated earlier, blacks have higher rates of preterm birth, low birth infants and pregnancy associated infections,^{148,149} in addition to other complications of pregnancy.^{150,151} The extent to which these outcomes are affected primarily by underlying differences in health care quality versus differences in disease is not known. For example, rates of post-partum endometritis are affected by rates of bacterial vaginosis^{152,153} which differs by race.¹⁵⁴ Nonetheless, complications related to pregnancy are quite relevant to women and children's health. Access to neonatal intensive care units (level III) may be particularly problematic for rural residents since these units are usually located in large metropolitan areas.

In several studies, minorities also report lower satisfaction with their ambulatory and hospital care.¹⁵⁵ Blacks report lower satisfaction, trust in their providers, and involvement in their own care than whites.^{80,82} Hispanics also report greater dissatisfaction with care than whites.⁸¹ One out of six Hispanics believes he or she received inferior care because

of ethnicity.¹⁵⁶ Spanish-speaking Hispanics are especially dissatisfied with the quality of physician communication.¹⁵⁷ Asians/Pacific Islanders rate physician primary care performance even lower than blacks or Hispanics.¹⁵⁸

Causes of Racial/Ethnic Disparities in Health Care

The causes of racial and ethnic disparities in health care are undoubtedly multifactorial. The relative contribution of particular factors probably differs according to the particular health care process, group, and region of the country. Contributing factors can be viewed at the patient, physician, health plan, and community/societal level.

Patient-level factors. Patient-level factors include job constraints,¹⁵⁹ child care demands,¹⁵⁹ skepticism toward medical care and physicians,¹⁶⁰ transportation,^{161,162} competing necessities, self efficacy, health literacy,¹⁶³ knowledge,¹⁶⁴ trust in physicians⁸² and health care institutions,¹⁶⁵ health beliefs,¹⁶⁶ and aversion to invasive procedures^{167,168} and preference.^{169,170} Patient-level factors are affected by presence and type of health care insurance,¹²⁸ availability of a regular source of care,¹⁷¹ comprehensible health care plan policies, location of health facilities, copayments and deductibles,¹⁷² prescription coverage,^{173,174} availability of medications in community pharmacies,¹⁷⁵ waiting times, presence of culturally competent staff, and availability of translation services.¹⁷⁶ Patients' knowledge, beliefs, attitudes, and behavior are influenced by culture, education, SES, mass media, pharmaceutical marketing,¹⁷⁷ prior experience, segregation,¹⁷⁸ racism,¹⁷⁹ and, most importantly, by information provided by physicians.

As discussed below, the relative influence of patient- versus provider-level factors may also depend on the type of health care service.

Physician-level factors. Physician- or provider-level factors are also important determinants of disparities. Although evidence clearly implicates physician bias as a contributor to disparities,¹⁸⁰⁻¹⁸⁴ the nature of this bias is not clear. It is likely that such bias is largely unconscious, unthinking, and unintentional,^{3,185} and is not necessarily remedied by physician-patient racial concordance.¹⁸⁶ Providers are influenced by health care plan factors, including economic incentives and practice profiling, as well as by provider training, beliefs, and attitudes (including stereotyping) and patient demand.¹⁸⁷⁻¹⁹²

Physician bias—Balsa and McGuire have suggested three types of physician bias that may contribute to disparities. These include frank prejudice, clinical uncertainty, and stereotypes that result in self-fulfilling expectations.¹⁹³

- Overt prejudice implies that physicians consciously choose to provide minority patients with less adequate care simply because they are minority. No studies to date provide direct support for this hypothesis.
- Physician clinical uncertainty can result from suboptimal communication between physicians and patients.^{194,195,196} The greater the cultural and socioeconomic divide between physician and patient, the greater the risk of miscommunication.^{195,196} Balsa and McGuire show how less effective communication can produce “statistical discrimination” in the absence of true bias.¹⁹⁷ Recent data suggest that physicians can assist low literacy patients

improve control of their diabetes by confirming the patients' understanding of their treatment plan.¹⁹⁴

- Physician stereotypes about patients may also generate disparities. For example, physicians may assume that poor or minority patients are less likely to adhere to treatment^{191,198} and, as a result, may be less likely to recommend a treatment or make a referral. Physicians may be particularly hesitant to recommend procedures to minorities when the costs and risks associated with the procedure are significant and the indications uncertain. Providers tend to engage in reverse targeting in terms of providing patient education. They often spend more time providing information to well informed patients and less time with less informed patients.¹⁸⁰ Physicians are less likely engage the active participation of less educated and minority patients in their own care.^{188,199} Both provision of relevant information and patient involvement in care improves adherence to treatment.²⁰⁰⁻²⁰⁴ Thus, it is not surprising that less educated patients have lower rates of adherence to treatment.²⁰⁵

Competing demands—Physicians may provide less optimal care to minorities (as well as low-income persons and those with chronic illness or disabilities) due to competing patient demands during an office visit.²⁰⁶ When confronted with a greater number of patient problems, physicians spend less time on health habit counseling,²⁰⁷ smoking cessation,²⁰⁸ depression screening,²⁰⁹ and are less likely to recommend preventive services such as mammography or hormone replacement therapy.^{210,211}

Presumably the effects of physician and patient on care are reciprocal. Physicians fail to provide adequate information and actively engage low SES or minority patients in their own treatment because they believe minority patients are less likely to follow through and because they have more difficulty interpreting symptoms and preferences from minority patients. Minority patients in turn may decline treatment or fail to adhere to physician recommendations because they have not been adequately informed or don't trust the physician. In this way, physician behavior tends to confirm the physician's own stereotypes.

Type of health care service—The relative influence of patient- and provider-level factors may depend on the type of health care service. Patient-level factors may predominate for services that are largely dependent on patient compliance. These include keeping medical appointments, medication adherence, and complying with recommendations for preventive health services.²¹²⁻²¹⁵ Provider-level factors become increasingly relevant for health care processes that require active physician participation such as initiating a referral or performing a diagnostic or therapeutic procedure.²¹⁶ Provider-level factors are likely to be paramount when indications for a particular procedure are unclear and medical uncertainty is high.²¹⁷ Examples include hospital admission for chest pain,²⁸ and performance of certain diagnostic or therapeutic procedures such as angiography,²¹⁸ coronary artery bypass surgery,²¹⁹ total hip replacement²²⁰ and renal transplantation.²²¹ Physicians may be more susceptible to unconscious stereotyping and/or patient demand when confronted by medical or surgical uncertainty.²²² The net result is often a combination of underuse of the service by minorities and overuse by whites.^{111,221}

Diffusion of innovations—The concept of diffusion of innovations²²³ has particular relevance for understanding patient demand and provider recommendation for services. According to Rogers, “diffusion is a process by which an innovation is communicated through certain channels over time among a social system.” A fundamental principle of human communication is that the exchange of information most often occurs between persons who are similar. Similarity refers to social status, education, employment, beliefs, and residence, among others.

Adopters of innovations can be grouped into ideal types: innovators, early adopters, early majority, late majority, and laggards. Depending on the type of innovation, diffusion occurs more quickly through some groups than others. For example, innovation in Rap music began among inner city African American youth, spread to young African American adults and then to white, suburban youth. In contrast, the diffusion patterns for innovations in medical technology such as laparoscopic surgery, coronary artery stents, angioplasty, and thrombolytic therapy are clearly different. Physicians involved in clinical trials of these procedures represent innovators. Early adopters likely include physicians in academic medical centers who are associated with the innovators. Key physician opinion leaders who have contact with these early adopters promote diffusion of these new technologies within the medical community.²²⁴

Many factors likely affect which patients receive which innovations. Patients involved in clinical trials represent patient innovators. However, minorities, particularly African Americans, are less likely to participate in clinical trials;^{225,226} so fewer patient innovators will be African American. Minorities are less likely to have adequate insurance coverage and more likely to be insured through Medicaid, which may not provide adequate reimbursements for new technology.

Last, African American patients are less likely to encounter African American physician innovators and less likely to see a physician of the same race as a white patient. African American physicians are sometimes on the periphery of these diffusion networks. They are underrepresented among clinical researchers and less likely to be promoted within academic medical centers, even when equally qualified.²²⁷ Patients experience greater partnership and trust when they see a physician of the same race/ethnicity.⁸² Patients are more likely to accept a recommendations from physicians they trust.²²⁸

The concept of diffusion of innovations suggests that new medical procedures are more likely to be adopted by whites and better educated persons.^{229,230} This hypothesis has been recently confirmed using newly introduced hospital procedures.²³¹ Specific strategies designed to improve diffusion of innovations to lower socioeconomic and marginalized populations have been developed.²²³

Plan-level factors. Plan-level factors affect disparities primarily through their effect on access. These factors include size of copayments and deductibles, location of services, cultural diversity of the work force, gatekeeping mechanisms, use of practice guidelines, and quality improvement activities.

Community/societal factors. Community and societal factors include availability and eligibility for public and private insurance, cost of insurance, residential segregation

patterns, availability of safety net providers such as community health care centers and hospital clinics, and availability of minority physicians.²³²⁻²³⁴

The elimination of disparities in health care will not be an easy task and will likely require a combination of patient-targeted, community-targeted, physician-targeted, and health system-targeted interventions.¹⁷⁶ Regardless of the intervention, continuous, reliable, current data regarding a particular disparity will be required to monitor progress toward its elimination.

Summary

In summary, one may say there is relatively little variation in the leading causes of death between racial and ethnic and majority and minority group members although African Americans generally show higher overall rates of death from these causes. These findings suggest that quality measures chosen on the basis of prevalence in the general population are, with a few notable exceptions, likely to prove relevant to minorities. Racial and ethnic disparities in health care quality have been well-documented, particularly for African Americans. Although the reasons for these disparities are complex, their continued existence necessitates monitoring of the quality of health care for those groups for which disparities have been shown.

Persons With Low Income

Together with age and gender, SES represents a key determinant of population health. Income represents one of the three standard measures of SES in addition to education and occupational status. Recently, Oakes and Rossi proposed a modified conceptual framework for SES based on Coleman's social theory.²³⁵ Briefly, they conceptualize SES as access to resources in three domains: material capital, human capital, and social capital.

- Material capital refers to material assets such as homes, cars, earnings, savings, stocks, bonds, and anticipated wealth such as inheritance or trusts.
- Human capital refers to both fixed endowments such as innate ability, appearance, and drive, but also to education, training, and other acquired skills.
- Social capital refers to access to social networks, social obligations to and from others, information channels, norms, and social status effects.

Income, education, and occupational status roughly map on to each of these domains. This framework highlights the myriad of ways that income or any other measure of SES may potentially affect access to and use of health care as well as health.

Socioeconomic Status and Health

Well designed studies have documented powerful effects of individual SES on subsequent health, including mortality.^{4,38-40} This effect extends up the SES hierarchy and does not simply represent a poverty threshold. The effect of SES on health and mortality is global; it cuts across different ages,²³⁶ diseases, and causes of mortality.^{237,238} There are few diseases that are specific to persons with low SES. Low SES is associated with increase in mortality that generalizes across all major causes of death.¹¹⁴ In other words poorer persons experience the same diseases as more affluent persons but often at an

earlier age. For this reason, quality measures selected for the overall population are likely to prove relevant to low-income persons.

Explanations for the effect of SES on mortality are likely complex.⁴¹ Socioeconomic differences in health behavior such as smoking, body weight, and diet contribute modestly to socioeconomic differences in mortality.^{38,39,41} Additional explanations focus on differences in childhood trauma, family stress, neighborhood effects, work environment, psychological stress, hostility, sense of control, and beliefs and attitudes related to SES.⁴¹⁻⁵²

Income and Health Care Quality

Lower SES, as measured by income or education, has been extensively linked to lower health care quality. Like race/ethnicity, it affects health care access, process, and outcomes. In many instances, it is not clear whether suboptimal care results from reduced access to care or from lower quality in process of care. For example, low income is associated with receiving fewer Pap smears, mammograms,^{53,54} childhood and influenza immunizations,²³⁹ and diabetic eye examinations⁵⁶ and with later enrollment in prenatal care.⁵⁷ These deficiencies could result from problems in accessing care due to cost, transportation, language, etc. They could also represent failure on the part of the providers to recommend these services. However, based on a study of direct observation of care provided by family physicians in Ohio, there are few difference in the content of care provided based on patient educational level.¹⁹⁹

Other studies show clear differences based on patient SES. Low-income patients receive lower intensity hospital care⁵⁸ and receive fewer cardiac procedures and have higher mortality following these procedures⁵⁹; they also receive lower quality ambulatory⁶⁰ and hospital care,²⁶ including fewer prescriptions for aspirin and for provision of thrombolysis for myocardial infarction.⁶¹ For example, the quality of care for angina, dyspnea on exertion, hearing impairment, and depression was assessed by gender, race, age, income, health status, and locale. In this study based on NHANES data, only low income was associated with receipt of deficient care.²⁴⁰ Similarly, BRFSS data show that persons with low income are less likely to receive mammography, Pap smears, protoscopic examination, influenza and pneumonia immunizations, and cholesterol checks.²⁴¹

Differences in health care quality and access translate into worse outcomes. Uninsured patients have poorer health status and higher mortality, independent of income, education, and other factors.^{242,243} Rates of preventable hospitalizations are significantly higher among lower income children and adults.^{136,138,244} Low-income persons have higher mortality following cardiovascular procedures. Low income has also been associated with lower patient satisfaction in some,^{245,246} but not all, studies.²⁴⁷

Factors Contributing to Socioeconomic Disparities in Health Care

Affordability

Explanations of the relationship between SES and health care quality are not fully understood. However, affordability is undoubtedly one of the most important factors mediating the relationship between material capital and health care. Health care affordability is not simply a problem for the 41 million Americans without health care

insurance, but also affects those with Medicare,¹⁷³ Medicaid,²⁴⁸ and private insurance^{172,249,250}

Human and Social Capital

Human and social capital also influences health care through job constraints,¹⁵⁹ child care demands,¹⁵⁹ attitudes,¹⁶⁰ beliefs,²⁵¹ transportation,¹⁶¹ waiting times, copayments, competing necessities, self-efficacy, literacy,¹⁶⁵ knowledge,¹⁶⁴ assertiveness,¹⁹² and diffusion of information through media and social networks.

Effects of Low Literacy

Low literacy levels represent an underappreciated contributor to socioeconomic disparities in health care quality.²⁰⁵ The inability to read or perform basic computations represents a major barrier to accessing and effectively navigating the health care system. A growing body of literature links low literacy to poor health care and worse outcomes.¹⁶³ According to a report on health literacy by the Council on Scientific Affairs of the American Medical Association, patients with greatest health care needs often have the least ability to read and comprehend health care information.¹⁶³ The 1992 National Adult Literacy Survey, the most comprehensive and reliable survey of literacy in the United States, showed that nearly one-quarter of the adult population is functionally illiterate and another quarter have marginal literacy skills. In other words, nearly 50 percent of the U.S. population manifest significant deficiencies in reading or computational skills.²⁵²

These findings are corroborated by studies in health care settings. Among patients at two public hospitals, Williams and colleagues reported that one-third of patients could not read or understand health-related materials.²⁵³ More than 40 percent could not comprehend directions for taking medications on an empty stomach, 25 percent could not understand information on an appointment slip, and 60 percent could not understand a standard consent form. Among elderly managed care enrollees, 27 percent to 44 percent of seniors had inadequate or marginal functional literacy skills.

Low literacy is associated with less knowledge regarding smoking risks,²⁵⁴ preventive health care,^{251,255,256} contraception,²⁵⁷ chronic illnesses,²⁵⁸⁻²⁶⁰ and adherence to antiretroviral therapy.²⁶¹ The relationship of literacy to health care process and outcomes has not been as well studied as SES and race/ethnicity. Low literacy has been strongly linked to worse health status,^{260,262,263} more diabetic complications,²⁶⁴ and higher rates of hospital admission.^{165,262,265} In fact, low literacy may be more strongly associated with health status than years of education.²⁶² It may also be a stronger predictor of preventive care, at least among the elderly, than educational level.²⁶⁶ In two studies, low literacy explained the relationship between stage of prostate cancer at diagnosis and black race.^{267,268} These findings suggest that literacy may explain to some extent racial/ethnic and socioeconomic disparities in health and health care. Health literacy has also been linked to diabetic outcomes. For example, after controlling for age, race/ethnicity, education, language, insurance, drug and alcohol use, depression, social support, and diabetic education, lower health literacy was associated with higher glycosylated hemoglobin levels and more frequent complications including retinopathy and cerebrovascular disease.²⁶⁹

The pathways through which literacy affects health have not been fully examined. However, there are several plausible mechanisms. Information diffuses more slowly to those with low literacy. Consequently, persons with low literacy are less knowledgeable and less informed about health care.^{251,254,255,257-260} Improved knowledge is associated with improved adherence to HIV and diabetic medications, and adherence to treatment is the single most important predictor of outcomes for these conditions.²⁰⁵ Although both the JCAHO and NCQA have developed guidelines to improve communication with patients with low literacy,^{270,271} many health care organizations have not fully complied.²⁷²⁻²⁷⁴

Moreover, low literacy is not only associated with lower levels of comprehension for written comprehension, but also extends to lower oral comprehension.²⁷⁵ Low literacy is associated with a smaller vocabulary and reduced problem solving abilities.^{258,259} In fact, literacy seems to promote cognitive complexity, which in turn improves comprehension and problems solving²⁷⁶ and ability to function in everyday life.²⁷⁷ Low literacy may also be associated with less adequate descriptions of medical symptoms;²⁷⁸ so physicians may have greater difficulty arriving at a correct diagnosis. Conversely, persons with low literacy report greater frustration with physician communication and responsiveness.²⁷⁹

Diffusion of accurate health care information to persons with low literacy may be hampered not only by reduced access to written information, but also by reduced access to networks of well informed peers. Finally, low literacy is associated with reduced self-efficacy and greater shame,^{280,281} while empowerment has been strongly linked to improved health.²⁸² Given these associations, it is not surprising that persons with low literacy are less likely to seek out preventive health.^{251,255} Nor is it surprising that patients with chronic illnesses who have low literacy have less knowledge about their diabetes, hypertension, asthma, or HIV infection.²⁵⁸⁻²⁶⁰ Thus, it is hardly surprisingly that low literacy is associated with lower patient adherence to treatments.²⁶¹

In summary, low literacy represents a major barrier to quality of care.²⁸³ Although further study is needed, it is likely that literacy is associated with each of the four dimensions of health care quality: effectiveness, safety, timeliness, and patient centeredness. Patients with low literacy may benefit from greater patient centeredness. In particular, physicians should spend more time exploring patients' understanding of their illness and their comprehension of physician explanations and recommendations.²⁸³ Only by actively eliciting the full participation of marginalized patients will physicians be successful in establishing an effective patient-physician partnership.¹⁸⁸

Physician Factors

Physician factors also contribute to disparities in care. Previous studies have shown that physician communication with lower SES patients is less effective.²⁸⁴ Physicians provide less information,^{183,285,286} less exercise counseling,²⁸⁷ write fewer prescriptions,²⁸⁸ and recommend less intensive followup²⁸⁹ to low-income patients. They also perceive persons with low income as less compliant.¹⁹¹ Bias towards the poor is not uncommon. The more affluent respond to the poor through cognitive and behavioral distancing.²⁹⁰ Such distancing by physicians may affect the quality of care they provide to low-income persons in addition to bias and competing demands.

Implications for Quality Measurement

The implications for monitoring quality of care provided to persons with low income are both similar and different than for minorities. Although persons with low income die younger, few conditions are specific to low-income persons. In other words, by and large, lower and higher socioeconomic persons are subject to the same illnesses; lower SES persons tend to experience them more frequently and at a younger age,²⁹¹ presumably as a result of greater cumulative stress.⁴⁰ For this reason, quality measures developed for the general population are appropriate for low-income persons. Quality measures stratified by socioeconomic position should target areas where disparities in health care processes have been documented.

In addition, quality measures should assess the disproportionate impact of various cost-containment policies on persons with low income. For example, do rates of prescriptions requiring copayments filled by consumers differ by socioeconomic position? Are there differences by socioeconomic position in the perceived burden of copayments on access to needed care? The role of literacy in health care suggests a need for health care plans to systematically evaluate literacy rates among their members and to consider examining quality measures by literacy level. Last, use of mailed surveys may not be appropriate to assess quality among populations with low literacy. Instead, in-person interviews in which health care jargon is explained may be needed to more accurately assess the health care experiences of persons with low literacy.

Children

Children are more likely to live in poverty than adults or the elderly. According to U.S. census data, 37 percent of children live in low-income families and 16 percent live in poverty.⁶² Two in five minority children live in poverty. Assessing health care quality for children is particularly challenging. Children are not simply little adults. They differ from adults in fundamental ways that affect their health care and the assessment of health care quality.²⁹²

First, the type and prevalence of disease differs sharply between adults and children. Mortality rates for adults are nearly 20 times the rates for children,⁷ and the leading causes of death differ between children and adults.⁷ Leading causes of infant death include congenital anomalies, prematurity, pregnancy and birth-related complications and sudden infant death syndrome (Table 6). Accidents, cancer, suicide, and homicide represent leading causes of death for older children (Table 7).

Second, the focus of health care is different for children. Pediatric care is largely devoted to the first stage of the continuum of care: staying healthy; office visits focus on disease prevention, health promotion, and treatment of acute, self-limited illnesses. In contrast, adult health care, particularly elderly care, often involves management of chronic conditions such as hypertension, diabetes, depression, arthritis, and coronary artery disease.

Third, childhood is characterized by rapid physical, social, emotional, and cognitive development; care is intended to maximize future well-being. Thus, the impact of well-child care is difficult to adequately assess.

Fourth, children, especially younger children, are dependent on parents or caregivers for access to health care and much of the medical history is obtained from the parents.

Quality measures based on response to surveys often rely on parents as proxy respondents for their children; so parental perceptions may bias reports of child's health.

Last, the demographic characteristics of children differ from those of adults. Until the development of the State Children's Health Insurance Program (SCHIP), children were more likely to confront more difficulties accessing health care than adults.²⁹³ Children are more likely to be poor and minority, and minority children have lower rates of recommended well-child care than whites.²⁹⁴ Differences in health by SES begin in childhood.²³⁶

Table 6. Leading causes of death children under 1 year of age, 2000

Rank	Cause	Mortality rate*
1	Congenital malformations, and chromosomal abnormalities	141.5
2	Prematurity	108.3
3	Sudden infant death syndrome	62.2
4	Pregnancy complications	34.6
5	Placenta, cord, and membranes	26.2
6	Respiratory distress syndrome	24.6
7	Accidents	21.7
8	Sepsis	18.8
9	Circulation	16.3
10	Hypoxia	15.5

* Deaths per year per 100,000 persons.

Table 7. Leading causes of death for children ages 1-19 years, 2000

	Ages 1-4	Rank	Ages 5-9	Rank	Ages 10-14	Rank	Ages 15-19	Rank
Congenital malformations and chromosomal abnormalities	3.3	2	1.0	3	1.0	5	1.1	6
Accidents	12.1	1	7.0	1	8.0	1	34	1
Cancer	2.8	3	2.5	2	2.6	2	3.7	4
Homicide	2.3	4	0.7	5	1.2	4	9.6	2
Heart disease	1.2	5	0.5	6	0.8	6	2.0	5
Influenza & pneumonia	0.7	6	0.2	9	0.2	10	0.3	8
Blood infections	0.7	7	0.2	8	-		-	
Birth complications	0.5	8	1.0	4			-	
Tumors (In situ, benign or unknown)	0.3	9	0.3	7	0.2	9	-	
Chronic lung disease	0.3	10	-	-	0.5	7	0.4	7
Stroke	-		0.1	10	0.3	8	0.3	9
Suicide	-		-		1.5	3	8.2	3
Diabetes	-		-		-		0.2	10

*Deaths per year per 100,000 persons.

These differences between children and adults necessitate development of child-specific quality measures. Because the nature and prevalence of health problems for children differ by age, different measures will be required for different ages.

Given the primary health care needs of children, pediatric quality measures tend to focus on staying healthy. However, not all children are healthy. Twenty million children live with chronic conditions.²⁹⁵ The most frequent chronic conditions among children include asthma, allergies/sinusitis, atopic dermatitis, attention deficit disorder, and learning disorders. These conditions differ by race and ethnicity. For example, rates of asthma are higher among African Americans and certain Hispanic groups.²⁹⁶ Rates of disability and mortality for blacks with asthma are nearly double those for whites.²⁹⁷⁻²⁹⁹ Black children have higher death rates from congenital heart disease than white children.³⁰⁰ Hispanic children have higher rates of dental caries and are at risk for behavioral and developmental disorders, diabetes, obesity, and asthma.³⁰¹ Asian/Pacific Islanders also appear to have worse asthma outcomes than whites.³⁰² Obesity rates are especially high among African American and Mexican American children.³⁰³ Poverty among children is strongly linked to poorer mental health,³⁰⁴ and minority and uninsured children have high unmet needs for mental health services.³⁰⁵ Children with chronic conditions are twice as likely as other children to have had at least one unmet health care need, such as dental care, prescription medications, eyeglasses, and mental health services. They also were more likely to have been unable to get needed medical care or to have delayed obtaining medical care because of worry about its cost.³⁰⁶ Children with chronic conditions were at greater risk for unmet needs than were children without conditions across all income levels.³⁰⁶

Although most children are healthy, 4 million children suffer from chronic disabling conditions.³⁰⁷ Children who are disabled and minority are more likely than white children to be without health insurance coverage, to be without usual source of care, and to be unable to get needed medical care.³⁰⁸ Minority children with special health care needs are less likely than whites to have seen a physician but more likely to be hospitalized during the past year.³⁰⁸ Specific quality indicators are needed to monitor the care provided to these children with special needs. Examples of these conditions include congenital heart disease, cerebral palsy, chronic renal failure, sickle cell anemia, cystic fibrosis, severe asthma, childhood cancer, major mental illness, severe developmental delay, and mental retardation.

Women

The relationship between gender, health, and health care is complex. On the one hand, the life expectancy of women exceeds that of men by more than 6 years.⁶³ Women experience lower age-adjusted rates of coronary artery disease and have lower rates of accidental death and suicide.⁷ On the other hand, women report lower health status and higher rates of psychological distress and experience higher rates of selected diseases, particularly those thought to have an auto-immune etiology such as systemic lupus erythematosus, rheumatoid arthritis, and multiple sclerosis. The major conditions affecting women based on prevalence, disability or mortality are cardiovascular disease, unintended pregnancy, osteoporosis, breast cancer, mental health, violence, lung cancer, cervical cancer, and obesity/eating disorders.⁶⁴ The leading causes of death differ only slightly by gender (Table 8).

Gender disparities in use of expensive technology have been extensively documented.⁶⁵ Most notably, women have lower rates of cardiovascular procedures,⁶⁶ but it is not clear whether these disparities primarily represent underuse by women or overuse by men,⁶⁷ or differences in age or other confounders.⁶⁸ In other cases, there is clear evidence of worse care for women. For example, women are less likely to receive appropriate medications such as aspirin and beta blockers following a myocardial infarction.^{61,35} They are less likely to receive an organ transplant^{69,70} (despite more female donors),⁷¹ and less likely to receive adequate treatment for pain.⁷²

Table 8. Age-adjusted causes of death by gender, 2000

Men		Women	
Rank	Cause of death	Rank	Cause of death
1	Heart disease	1	Heart disease
2	Cancer	2	Cancer
3	Stroke	3	Stroke
4	Accidents	4	Chronic lung disease
5	Chronic lung disease	5	Diabetes
6	Diabetes	6	Pneumonia and influenza
7	Pneumonia and influenza	7	Alzheimer's disease
8	Suicide	8	Accidents
9	Kidney failure	9	Kidney failure
10	Liver disease	10	Blood infection

*Deaths per year per 100,000 persons adjusted for age.

Gender bias in transplantation recommendation by nephrologists has also been documented.³⁰⁹ Women may also have lower rates of colonoscopy,³¹⁰ and may be less likely to receive new HIV medications than men.^{311,312} In other instances, women show improved access to health care. They make more visits to physicians and receive more health care than men.³¹³ They have better continuity of care,³¹⁴ ask more questions during physician visits,¹⁸⁰ and report more involvement in care.¹⁸⁸

Although studies on gender disparities in health care are mixed, disparities become more pronounced with the intersection of gender, race, and SES. Schulman et al. showed that primary care physicians, when confronted with identical scenarios, were less likely to recommend coronary angiography to black women compared to white men, white women, or black men.¹⁸⁴ Similarly, medical students rated the quality of life lower for black women compared to white men and were less likely to recognize women's anginal symptoms.¹⁸²

Much of health care to younger women involves reproductive health. These needs include family planning, vaginal infections, pregnancy, birth, and menopause. In the United States, roughly half of all pregnancies are unintended and nearly half of all women of reproductive age have experienced an unplanned pregnancy.³¹⁵ More than 40 percent of all U.S. women report having had a pregnancy termination.³¹⁵ Despite the high prevalence of unintended pregnancy and pregnancy termination, access to these services is often limited for many women. Insurance coverage for contraception and availability of pregnancy termination services is often limited in many health care plans and/or communities. A survey by the Alan Guttmacher Institute showed that nearly half of traditional indemnity (fee-for-service) health plans failed to cover any of the five leading

prescription contraceptive methods (oral contraceptives, IUD, diaphragm, Norplant, or Depoprovera) and only 15 percent covered all five.³¹⁶ Among HMOs, only about 40 percent covered all five methods. Only half of all indemnity plans covered annual gynecologic examinations. Furthermore, many women reside in communities in which no physician provide pregnancy termination. Almost one-third of women reside in a county where with no elective or emergency pregnancy termination services.³¹⁷ Some women must travel out of state to obtain a safe termination of a pregnancy. A state-by-state report card on women's health noted that there has been a 30-percent decline in the number of providers offering pregnancy termination since 1988.³¹⁸

Most health care plans do not provide coverage for mental health services comparable to coverage for medical services. Three out of four health plans place restrictions on mental health care services such as high copayments that are not applied to medical care.³¹⁹ These policies disproportionately affect women because rates of depression in women are double those in men.³²⁰

Rural and Urban Residents

Rural Residents

The U.S. Bureau of the Census classifies persons living in communities of less than 2,500 persons as "rural." Based on this definition, more than 60 million people are rural residents. A 2001 report by the National Center for Health Statistics compared the health and health care of rural-urban residents.⁷ In general, suburban residents experience better health than either rural or urban residents. Rural residents experience higher rates of death by motor vehicle accident, accidental injury, suicide, chronic obstructive pulmonary disease, and degenerative arthritis.^{7,321} Rural residents also have higher rates of admission for alcohol dependence, greater limitation in activities, and greater tooth loss. However, rural residents tend to be older and poorer than suburban residents. Most of the rural-suburban disparity in health is explained by these differences, but unique occupational and environmental exposures clearly contribute to worse rural health.

Given the concentration of physicians in larger metropolitan areas, it is not surprising that rural residents often experience reduced access to health care. In addition to travel time,³²² rural residents are often confronted by high rates of no health insurance. Compared to urban and suburban residents, rural residents have lower rates of enrollment in publicly sponsored health insurance including Medicare, Medicaid, and SCHIP. Presumably, lower enrollment reflects the greater stigma associated with government sponsored programs within rural communities. Rural employers offer health insurance less often.³²³ Racial disparities in access to care may be even greater in rural areas.³²⁴ Migrant farm workers represent a particularly marginalized and vulnerable health care population. Although federally sponsored migrant health centers provide care to this population, the mobility of migrant farm workers makes health care continuity virtually impossible.

Health care in rural communities is hindered by current Medicare payment policies. Payments to rural hospitals and providers are lower than fees to suburban providers for comparable procedures. Medicare utilization is significantly lower among rural residents.³²⁵ These barriers, in addition to greater travel time, hinder access to care for rural residents. Medicare beneficiaries living in isolated rural counties report more

difficulties seeing a physician and more often lack a usual source of care.³²⁶ Access to needed services for the disabled in rural communities are also problematic.³²⁷

There is little, if any, reporting of health care quality based on geography. Barriers to assessing rural health care quality include small sample sizes, limited data availability, difficulties in appropriately defining rural health service areas, rural population preferences, and the lower priority of formal quality-of-care assessment in shortage areas.³²⁸ Nonetheless, research shows lower use of cancer prevention and dental care,^{329,330} lower rates of prenatal care³³¹ and lower quality diabetic care.³³² Rural residents travel longer distances for physician visits and for hospitalizations.⁷ Travel time has been linked to lower quality treatment for depression³³³ and lower use of health care.³³⁴ Nearly three out of four rural residents travel to urban areas for HIV care.³³⁵

The quality of specialized inpatient care in rural areas may be lower because of reduced volume for technological procedures and reduced opportunity to affiliate with academic medical centers.²⁶ Hospital volume has been linked to survival after myocardial infarctions³³⁶ and rates of success from highly technological procedures such as endarectomy.³³⁷ Quality of care for myocardial infarction may be worse in some rural hospitals,³³⁸ and rates of revocation/suspension of physician privileges are higher among rural hospitals although the reasons for these differences are not clear.³³⁹

Urban Residents

Urban residents, particularly those in inner cities, often reside in communities with high levels of poverty, unemployment, adolescent pregnancy, and violent crime. Increases in poverty have been greater in cities between 1980 and 1990 than in counties despite greater concentrations of wealth in cities.³⁴⁰ The percentage of minority female-headed households and violence strongly correlate with child poverty and low birth weight rates in cities, but not in counties.³⁴⁰ Poverty in community of residence has been shown to have effects on health beyond individual measures of poverty.³⁴¹ The urban poor also confront higher levels of environmental hazards including lead exposure, air and noise pollution, toxic waste, and cockroach infestation.³⁴²⁻³⁴⁵ Although many poor communities are located near major medical centers, access to primary care is often limited. Central city communities have experienced more than a 20-percent drop in the number of hospitals since 1980.³⁴⁰ Public hospitals have experienced more than a 40-percent decline in numbers. Furthermore, most federally designated health manpower shortage areas are located in inner city and rural communities. Federally funded migrant and community health centers currently provide care to nearly 11 million residents in these communities. Data show that community health care centers provide care comparable if not superior to other providers and reduce racial/ethnic and geographic disparities in care.^{346,347} However, many of these centers are on the brink of insolvency; more than half experienced deficits between 1997 and 1999 in part due to low payments from managed care.³⁴⁸ Similarly, greater managed care penetration into urban communities is associated with reduced access to hospitals and specialists by minority physicians,³⁴⁹ fewer physicians providing charity care to indigent patients,³⁵⁰ and higher rates of uninsurance among persons with low income.³⁵¹

Persons With Disabilities or Chronic Disease

Persons With Disability

Disabilities and chronic disease are not synonymous. Disability refers to a limitation in function that often, but not always, results from chronic illness. For example, many members of the deaf community do not consider deafness an illness or a disease. Similarly, the presence of a chronic illness may or may not affect function and result in disability.

The proportion of persons who are disabled in the general population depends on the level of restriction used to define disability. Rates range from 15 percent for persons with some activity limitation to 4.6 percent of persons who are unable to carry out their major activities.³⁵² Disabled adolescents are at higher risk for emotional distress³⁵³ and health-related behavior including suicide attempts, sexual abuse, smoking, alcohol use, and drug use.³⁵⁴

Persons with disabilities typically confront two generic problems: access to care and coordination care.³⁵⁵ Access barriers can be physical, cognitive, communicational, or social. For example, many offices are not wheelchair accessible. Limitations of vision, of hearing, and of cognition may not only affect physical access but also affect doctor-patient communication. Most offices do not provide deaf interpreters. The presence of multiple chronic conditions is associated with lower provision of preventive care³⁵⁶ and lower satisfaction with health care.³⁵⁷ Women with limitations in mobility and other disabilities have lower rates of Pap smear and mammography screening.^{330,358} Children with spina bifida receive fewer immunizations.³⁵⁹ Disabled persons are often socially stigmatized. Physicians may decline to accept disabled patients and office staff may shun them.

Intersection With Other Disparity Populations

Typically, disability and chronic illness intersect with membership in other disparity populations including minority status, low income, rural or urban residence, or age (children or elderly).³⁶⁰ The disabled are disproportionately poor and unemployed. According to a 1994 Lou Harris poll, 25 percent of disabled persons never graduated from high school, 59 percent had household incomes under \$25,000 per year, and 71 percent were not employed. Disabled women have less informal support than disabled men.³⁶¹ Disabled persons have greater out-of-pocket expenses for health care.³⁵⁵ Disabled persons with major functional activity limitations are less likely to be employed and have private health insurance.³⁵⁵

Deaf Persons

Little research has been done on the deaf persons despite the unique access barriers faced by this population. Deaf persons comprise two distinct populations based on whether or not deafness preceded speech. Prelingually deaf persons often use American Sign Language and have low levels of literacy. They have lower levels of smoking³⁶² and lower levels of health care utilization than the general population.³⁶³ Collecting data from consumer surveys is challenging because of low literacy levels and reduced telephone access among prelingually deaf persons.³⁶⁴

Persons With Chronic Illness

Persons living with chronic disease are twice as likely to experience bad health days as others, and they experience additional burden if they have low income, less education, or have diabetes or heart disease.³⁶⁵ Data from AHRQ's Medical Expenditure Panel Survey show that hypertension, heart disease, asthma, and diabetes are the most prevalent chronic illnesses. Significant numbers of persons living with chronic illness report they are not able to obtain needed medical care. For example, nearly one-third of persons with depression and more than one-quarter of persons with asthma report they were not able to obtain needed care.³⁶⁵ Not surprisingly, persons with chronic disease fare no better and at times worse in terms of engaging in recommended health behaviors. For example, rates of smoking among persons with asthma, diabetes, coronary artery disease, and hypertension are 27 percent, 19 percent, 17 percent, and 25 percent, respectively, compared to national rates of 23 percent.³⁶⁵ Rates of binge drinking are slightly lower than the national average, but rates of physical inactivity are higher.³⁶⁵ A significant portion of persons with chronic illness report they have not been counseled by their physician to engage in health-promoting behavior. One-third report they were never advised to quit smoking, two-thirds were never counseled regarding exercise, and nearly 9 out of 10 at-risk drinkers were never advised to cut down or quit drinking.³⁶⁵ Similarly, a significant portion also report they received little education regarding disease management.³⁶⁵

Access among disabled minorities is worse than among disabled whites. With similar disabling conditions, blacks use fewer services, particularly prescription and physician services.³⁶⁶ These effects are not fully explained by differences in income or health.

Many persons with chronic illnesses report they are not able to obtain needed services.³⁶⁵ Two-thirds report they cannot obtain needed home health services or transportation. One-half report they cannot obtain counseling or rehabilitation services and 40 percent could not obtain special medical equipment. Common barriers include inability to afford medication, long waits to obtain an appointment, and lack of coordination of care between providers.³⁶⁵

Care for persons with disabilities or chronic illnesses may require longer physician visits due to problem complexity and/or barriers in communication. Disabled persons enrolled in Medicare have greater limitations in activities, worse health status, lower incomes, and worse access to care than elderly Medicare beneficiaries.³⁶⁷ Primary care providers often must coordinate care with multiple providers. Medicaid or Medicare frequently does not adequately reimburse providers for the costs of this care, and significant numbers of physicians have stopped taking new Medicare patients. Similarly, there are financial disincentives for HMOs to enroll disabled persons since their health care costs are typically higher.³⁶⁸ As a consequence, disabled persons frequently report they are unable to obtain needed health care.^{367,369}

Health care is also problematic for persons with chronic mental illness. Many physicians' offices are not compliant with standards established by the Americans with Disabilities Act.³⁷⁰ In general, there is a dearth of research related to the quality of care for persons with disabilities.

Unlike the relative plethora of quality measures for persons with chronic illness, there are few measures for persons with disabilities. Whereas persons with chronic illness can be identified from administrative data using diagnostic codes, most administrative data do

not include measures of function or disability.³⁷¹ Nonetheless, data continue to show that care provided to persons with chronic illnesses such as diabetes, hypertension, congestive heart failure, and coronary artery disease is suboptimal.³⁷²

Elderly

Given the wide range in function and morbidity, the elderly, more than any other population, represents each of the consumer perspectives on health care: staying healthy, getting better, living with chronic illness, and coping with the end of life. Aging is strongly associated with morbidity and mortality; so the prevalence of chronic disease and disease sequelae increase sharply with age. In contrast to younger persons, the elderly are often, but not always, confronted by multiple chronic conditions often requiring multiple medications.⁷³ Safety of medication prescription becomes paramount. Not infrequently, impairments in vision, hearing, mobility, and cognition result in disability that significantly diminishes function that may affect access to quality health care. Given the age-related differences in epidemiology, there is clearly a need for measures that are specific to the elderly or, at a minimum, effectively address care related to chronic conditions and disabilities. Standard screening measures may not be appropriate for persons with less than 5 years life expectancy⁷⁴ and may result in inappropriate diagnostic evaluations that provide no benefit.⁷⁵ Among the elderly, there is also a particularly strong need for quality measures that assess coordination of care between providers.

Persons Facing the End of Life

Dying persons are particularly vulnerable to receiving inadequate care. Their health care needs are unique. There is minimal overlap with the other consumer perspectives of staying healthy, getting better, or living with chronic illness. Rather the focus is maximizing the physical, psychological, social, and spiritual comfort of the dying person. In other words, the primary goal of palliative care is to help the person die with dignity.⁷⁶

The context in which persons die likely affects the quality of care they receive. A number of studies have documented suboptimal care for terminally ill patients,^{30,36,77,78,79} including children.⁷⁹ Age is associated with more advance planning and less aggressive care.³⁷³ A number of organizations have called for development of quality measures for end-of-life care. The American Geriatrics Society has proposed 10 domains for promoting health care quality to patients at the end of life that have been endorsed by 42 organizations.³⁷⁴ These domains include physical and emotional symptoms, support of function and autonomy, advance care planning, patient and family satisfaction, aggressive care near death, global quality of life, family burden, survival time, provider continuity and skill, and bereavement. However, many of these domains have not been shown to be clearly altered by medical intervention.³⁷⁵ Morrison et al. have suggested that development of quality measures focus on three areas: relief of pain and other symptoms, advance care planning, and patient and family satisfaction.³⁷⁵ Each of these outcomes has been shown to be potentially amendable to health care intervention. However, well validated, reliable measures for each are needed. As discussed later in this report, FACCT is currently developing measures in these domains. In summary, there is a pressing need for quality measures to assess end-of-life care.

III. Review of Current Quality Measures

This section reviews the relevance of established quality measures for each of the disparity populations. Large numbers of quality measures are available, many of which can be accessed through the National Quality Measures Clearinghouse*, a database sponsored by AHRQ. A comprehensive review of every proposed quality measure is beyond the scope of this report. Instead, this review will be confined to well established, quality measures that are in widespread use by hospitals, HMOs, and other health care organizations. Most of these measures have undergone an extensive process of development that includes a comprehensive review of the scientific literature; reliability, validity, and feasibility testing; and establishment of standard specifications for use.

Among the most widely used quality measures are:

- The Health Plan Employer Data and Information Set (HEDIS), used by the National Committee for Quality Assurance, which accredits HMOs.
- ORYX, a set of process measures used by the Joint Commission on Accreditation of Healthcare Organizations for hospitals, nursing homes, and other health care organizations.
- The Health Care Quality Improvement Program (HCQIP) measures used by the Centers for Medicare & Medicaid Services in cooperation with Peer Review Organizations (PROs).
- The Foundation for Accountability measures, which have been adopted by some HMOs.

In addition, two other widely used measure sets assess consumers' experience of health care, particularly focusing on patient centeredness and satisfaction with care. Sources of these measures, which are relevant to most disparity populations, are:

- CAHPS® (Consumer Assessment of Health Plans), a series of health care consumer surveys targeting different populations, including a set of core surveys for adult and child health in addition to supplemental surveys. CAHPS® was developed by AHRQ in collaboration with Harvard University, RAND, and the Research Triangle Institute.
- The Picker Inpatient Survey, which is similar to CAHPS®. It assesses the consumer experience of hospital care.

This section is divided into three major parts. First, research relating to racial and ethnic disparities in the experience of health care is briefly summarized. This is followed by a description of the quality measures currently in use. Finally, the relevance of existing quality measures to disparity populations[‡] is discussed in detail, using the IOM framework for quality presented in section I.

* The National Quality Measures Clearinghouse and other AHRQ quality initiatives, including AHRQ's recently revised quality indicators (QIs), are briefly discussed in Appendix A.

[‡] Quality measures relevant to racial/ethnic minorities, children, women, and the elderly are summarized, by consumer perspective, in Appendix B, Tables B1-B4, respectively.

Racial and Ethnic Disparities in the Experience of Care

There are conflicting research results regarding racial or ethnic differences in the experience of health care. In several studies, minorities report lower satisfaction with their ambulatory and hospital care.^{80,155,376-378} For example, in the Community Tracking Survey 1996-97, blacks reported lower satisfaction and trust in their providers.⁸⁰ They also report lower involvement in their own care than whites,⁸² and have higher rates of hospital discharge against medical advice.³⁷⁹ Nearly one-fourth of blacks believe they received inferior care based on their race.¹⁵⁶ These beliefs may not be unfounded. In at least one study, physicians reported less favorable attitudes towards black patients.¹⁹¹

Hispanics also report greater dissatisfaction with care than whites,⁸¹ particularly for physician communication when the consumers has limited English proficiency.¹⁵⁷ One out of six Hispanics believe they have received inferior care because of their ethnicity.¹⁵⁶ Asians/Pacific Islanders consistently report lower satisfaction levels than other groups.^{158,380,381} Persons with disabilities, chronic disease, and mental illness also report lower satisfaction.^{357,382} In many,^{82,383,384} but not all studies,³⁸⁵ racial concordance between physician and patient has been associated with improved sense of participation and improved perceived quality of care.⁸² Greater patient involvement in care has been shown to predict better patient outcomes.^{204,386,387}

Other studies have shown little difference in patient satisfaction by race/ethnicity.^{158,388} In a study using the Picker Inpatient Survey and CAHPS®, racial and ethnic disparities in ratings were modest.³⁸⁹ African Americans report similar levels of satisfaction as whites. Asians reported lower ratings on specific aspects of care, but similar overall satisfaction scores as whites. Hispanics' ratings were intermediate between whites and Asians.

Adult CAHPS® measures show few significant differences by race or ethnicity. Only Asian-American/Pacific Islanders rated their care lower than the other groups.³⁹⁰ In the California study of CAHPS®, Hispanics and Asians who spoke English at home gave similar ratings as whites in contrast to those who did not speak English at home.³⁸⁹ There are also relatively few differences in child CAHPS® by race. Minorities report comparable ratings of their children's overall care as nonminorities, but report worse access (getting needed care and timeliness).³⁹¹

The reasons for relatively few differences by race/ethnicity in CAHPS® ratings are not known. There are a number of potential explanations. First, it is possible that there are few meaningful differences by race/ethnicity in the process of care assessed by CAHPS®. However, it is difficult to reconcile this explanation with findings showing differences in satisfaction by race and ethnicity. Possibly, CAHPS® fails to capture key constructs such as trust and partnership that have been shown to differ by race/ethnicity. Second, sampling error may account for absence of differences. High rates of nonresponse to CAHPS® (40-50 percent) may bias findings.³⁹² For example, dissatisfied minorities be may less likely to respond to surveys than dissatisfied whites. Third, racial/ethnic differences in response patterns may obscure important differences—that is, members of different racial and ethnic groups may interpret the questions differently, thus blurring potential differences in experience. Last, racial/ethnic differences in expectations or standards of performance may confound ratings. Unfortunately, there are few data upon which to evaluate these competing explanations. Despite these caveats,

CAHPS® represents an important first step towards monitoring and addressing the experience of care for all consumers. Clearly, research is urgently needed to clarify these critical issues.

There are no appreciable gender disparities in satisfaction based on 1999 HEDIS/CAHPS® data.³⁹³

Major Existing Quality Measure Sets

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.”³⁹⁴ HEDIS has been criticized because it addresses fewer than half of the leading underlying causes of morbidity and mortality, such as dietary habits, activity levels, or alcohol abuse.³⁹⁵ Unfortunately, quality measures that address each of these underlying causes and adequately satisfy the criteria of significance, scientific soundness, and feasibility have not yet been developed. For example, obesity and inactivity represent major determinants of population health. However, there are few medically based interventions that have been shown to significantly improve these risk factors.

Existing HEDIS indicators were initially developed by Measurement Advisory Panels (MAPs) using criteria similar to those described earlier for selection of measures. MAPs consist of experts in various related fields who develop and recommend new measures to the HEDIS Committee for Performance Measurement. It is the latter group—which includes consumers, purchasers, quality experts, and health plans—that determines which measures are implemented as HEDIS indicators.

HEDIS include a series of *effectiveness* measures related to prevention (e.g., breast cancer screening, immunizations, cervical cancer screening, etc.), and disease management (for diabetes, hypertension, asthma, etc.); *access/availability* of care and *use of services* (number of visits by age group and availability of interpretation services, use of procedures); *satisfaction with the experience of care* (based on CAHPS®); *informed health care choices* (e.g., discussion of hormone replacement options); and *plan stability* (in the past, this has included rates of disenrollment by plan). Currently only the effectiveness, access, and satisfaction measures are publicly reported. Both accreditation by NCQA and public reporting of measures are voluntary. HMOs with lower HEDIS scoring tend to stop publicly reporting their performance.³⁹⁶

ORYX

Although JCAHO has lagged behind NCQA in the development and application of outcome measures, it has recently introduced them into the accreditation process. JCAHO has approved the first five core quality measure sets for the Hospital Accreditation Program termed ORYX. 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 included in the acute myocardial infarction, heart failure, and pneumonia measure sets are derived from the CMS’s

HCQIP, discussed below. Each of these appears appropriate for members of disparity populations as discussed earlier in this report.

CMS and the Health Care Quality Improvement Program

In September 1998, CMS (formerly the Health Care Financing Administration, or HCFA) proposed three principles to the committee planning the National Forum on Quality to guide CMS's national performance measurement strategy. These principles were:

1. Performance measures should be consumer and purchaser driven.
2. Performance measures and the collection tools needed to collect them should be in the public domain.
3. The content and collection of data and performance measures derived from that data should be standardized.

CMS's current quality initiatives include HEDIS, the Medicare Health Outcomes Survey (based on changes in the SF-36 scores over time), CAHPS®, the Disenrollment Survey (which queries beneficiaries about their experiences and reasons for leaving a health plan), 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 the PROs that are contracted to conduct quality assessments initiated the Health Care Quality Improvement Program. HCQIP projects focus on six national clinical topics. CMS chose these areas based on their public health importance and the feasibility of measuring and improving quality. The management guidelines for these clinical conditions are evidence based. As the following review shows, each of these measures is relevant to most disparity populations. However, these measures pertain primarily to adults because only children with qualifying disabilities and persons with ESRD are Medicare eligible.

FACCT

The Foundation for Accountability is a not-for-profit organization devoted to providing consumers with improved health care information.³⁹⁷ 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. In contrast to HEDIS effectiveness measures that focus on primarily on health care process, most of the FACCT measures include both process and outcome measures. Most of the data for these measures are collected through consumer surveys. The main limitations of this approach are potential biases in self-report that may differ by disparity population, potential bias in who responds to surveys, and confounding of outcome measures by unmeasured patient characteristics.

CAHPS®

As previously noted, CAHPS® includes both core and supplemental surveys on which consumers rate various components of care. Core topics include enrollment/coverage, access, provider relationship, overall rating, utilization, communication/interaction, plan administration, health status, and demographics (age, gender, highest educational level, race, and ethnicity). Supplemental topics include communication with providers, interpreter services for hearing-impaired and foreign language speakers, dental care, mental health care, care for chronic conditions, pregnancy care, prescription medicines, and transportation, among others. The surveys, which are available in English and Spanish, include items that reflect patient centeredness and timeliness and, to a lesser extent, effectiveness and safety.

Following the release of the first version of CAHPS®, the CAHPS® survey and the NCQA Member Satisfaction Survey were merged. NCQA now requires health plans to use the new questionnaire comprised of the core survey and the HEDIS supplement for HEDIS reporting and NCQA accreditation. This new NCQA instrument is called CAHPS® 2.0H. ARHQ publishes benchmarks for each item, which are adjusted for respondent's age, health status, and education.

CAHPS® represents an important advance in assessing health care quality provided to vulnerable groups. Two CAHPS items, "getting needed care" and "health plan information and customer service" are associated with health care plan quality based on HEDIS effectiveness measures.³⁹⁸ Given the combination of generic and group specific items, CAHPS® is relevant to each of the disparity groups. It is unique in that it is the only HEDIS measure that specifies the collection of race/ethnicity and data on socioeconomic status. It is also unique in that it assesses patient centeredness, along with access and availability of interpretation services. Plans could easily begin stratifying CAHPS® items by race/ethnicity and SES although larger samples will be necessary to generate more reliable estimates for these subgroups.

Picker Inpatient Survey

The Picker Inpatient Survey is similar to CAHPS® in that it assesses the consumer experience of hospital care. It assesses eight dimensions of care: access to care; respect for patients' values, preferences and expressed needs; coordination and integration of care; information, communication, and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity. It also collects data on age, gender, race, ethnicity, and educational level. Both adult and children versions of the survey are available.

Given the inherent value of consumer reports of their experience of ambulatory and inpatient care, strong consideration should be given to reporting these measures by race, ethnicity, income, disability status, and possibly by place of residence.

Relevance of Existing Quality Measures to Disparity Populations

Quality measures are grouped below according to whether they address the consumer goal of staying healthy, getting better, living with chronic illness, or preparing for the end

of life. Within these groups, measures are further categorized by effectiveness, timeliness, patient centeredness, or safety. In instances where a measure fits into several categories, the most suitable category has been selected.

Discussion of each quality measure begins with a brief introduction. The relevance of each measure to each disparity population is discussed including risk for developing the condition targeted by the quality measure. Evidence for disparities in treatment based on each measure for different disparity populations is cited. Last, the need for separate reporting of the quality measure for each population is addressed. The original criteria of significance, scientific soundness, and feasibility of these measures are not routinely discussed unless they are especially relevant for a particular disparity population because these criteria have been used in the selection and development of the measures for the general population.

Staying Healthy

Timeliness

The NCQA has developed a number of the HEDIS measures related to access to and availability of care in addition to use of services. Measures for access or availability of care reflect the dimension of timeliness. They include access to prenatal care, well-child care, well-adult care, and dental care, as well as translation services and information necessary to make informed decisions. Most of these measures related to access and availability of care address conditions that disproportionately affect members of many disparity populations for whom access is often problematic. Racial and ethnic minorities experience worse first contact primary care including longer waiting times and more difficulties obtaining an appointment.¹²⁹ Black adults make 40 percent fewer office visits as whites.²³³ Among children less than 12 months of age, whites made 33 percent more total visits and 77 percent more well child visits than blacks.³⁹⁹ Among children ages 1-4, whites made 47 percent more total visits and 25 percent more well-child visits. Among children ages 5-14, the rates were 53 percent and 88 percent higher for whites. Similar disparities have been reported based on other data.^{400,401} Black and Hispanic women are less likely to initiate prenatal care in the first trimester than whites.²³⁷ Rates of prenatal care enrollment are the lowest for American Indians.²³⁷ Similarly, blacks are much less likely than whites to have had a had dental visit in the past year.²³⁷ Persons with chronic illness and disabilities have greater need for health care, but they often face greater access problems because of their disability. For example, many physicians' offices are not accessible to persons with mobility limitations.³⁷⁰ Given the health care access problems confronted by members of many disparity groups, even among those with health insurance,⁴⁰² these measures are highly appropriate for persons with chronic disease and disabilities, minorities, low SES persons, elderly persons, and rural and urban residents. Stratification by each of these groups is indicated.

Availability of language/interpretation services is particularly relevant to Hispanics and Asians and Native Hawaiians and other Pacific Islanders who not only comprise the first and third largest minority groups, but also include many immigrants. In a national survey, nearly one-third of the Hispanics preferred to be interviewed in Spanish.⁴⁰³ Limited English fluency is associated with lower rates of satisfaction with physician

communication.¹⁵⁷ Deaf persons represent both a disability group as well a group with their own language (American Sign Language) and culture.⁴⁰⁴ Deaf persons confront unique access problems. In the absence of Telecommunications Device for the Deaf (TDD, also known as TTY) phone lines,⁴⁰⁵ many deaf persons cannot easily make an appointment, and in the absence of deaf interpreters, cannot easily communicate with their physicians. Prelingually deaf persons have lower rates of health care utilization than the general population.³⁶³ Clearly there is a need for public reporting of validated measures of availability language/interpretation including TTY services.

Patient Centeredness

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. These measures reflect patient centeredness. For example, women are surveyed as to whether they were counseled about 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 their counseling was personalized to take into account personal and family history, concerns and preferences. Osteoporosis is one instance in which disease prevalence is lower for black women compared to white women.⁴⁰⁶ Black women express greater skepticism about hormone replacement therapy⁴⁰⁷ and receive fewer prescriptions for it during menopause.⁴⁰⁸ Given the recent findings that show hormone replacement therapy is associated with higher risk of heart disease and breast cancer among women,⁴⁰⁹ this skepticism appears justified.

Nevertheless, given that minorities express a reduced sense of partnership,⁸² it is important to assess the extent to which consumers are informed about options. Assessment of informed choice is also very relevant to the elderly and persons with chronic disease and disabilities, who are often confronted with complex decisions. Consideration should be given to developing a similar measure for Prostate Specific Antigen (PSA) testing, a screening test for men for prostate cancer. Death from prostate cancer is significantly higher among blacks than any other group.²³⁷ Although use of the test is controversial,^{410,411} recent data suggest that early surgical intervention reduces death from prostate cancer.⁴¹² A measure designed to assess informed decisionmaking regarding prostate cancer would be particularly relevant to black men.

Effectiveness

FACCT's Young Adult Health Care (YAHC) survey measures and NCQA's HEDIS assess the quality of preventive health care in dimensions of effectiveness, timeliness, and patient centeredness and are relevant to nearly all disparity populations. These measures address screening for breast and cervical cancer, alcohol misuse, elderly health status, immunizations (child, adolescent, and adult), Child Dev, chlamydial disease screening, teen confidentiality, diet, emotional health, exercise, smoking, sexual activity, and other risk behaviors. Many of these measures address conditions that disproportionately affect minorities and poorer persons. These measures should be reported separately by race, ethnicity, and income.

FACCT has led development of the Child and Adolescent Health Measurement Initiative (CAHMI). It represents a collaboration between AHRQ, NCQA, the American

Academy of Pediatrics, Children Now, CDC, the Health Resources and Services Administration's Maternal and Child Health Bureau, and more than 50 other consumer organizations, public agencies, researchers, and health care plans and providers. CAHMI represents a set of quality measurement tools designed to improve the quality of care for children and adolescents. Most of these measures are derived from consumer surveys.

The FACCT measures address three key groups: children with special health care needs (CSHCN, previously discussed), Child Dev, and teen health (preventive health care).⁴¹³ As previously discussed, assessment of the quality of care to disabled persons is particularly challenging, and when the disabled person is a child, even more so. In response to this challenge, a CSHCN measure was developed from the CAHMI. The CSHCN measures address two key challenges in assessing quality of care to consumers with disabilities: identifying disabled persons and obtaining a sample of sufficient size to generate meaningful estimates of quality of care. The CSHCN measures addresses the first challenge through use of five screening questions to determine whether the child has particular limitations or sequelae, whether these sequelae result from a medical or other condition, and whether the duration or expected duration of limitations is 2 months or more.⁴¹⁴ In order to increase the power to detect meaningful effects, the survey combines the responses across children with different conditions. The survey is based on the CAHPS® and uses CAHPS® methodology and scoring protocols.⁴¹⁵ If a child screens positive for disability, then the parents are asked to complete a supplemental series of questions similar to CAHPS® that include ability to obtain needed medications or specialty care, receipt of family-centered care, having a primary physician or nurse who knows the child, and appropriate coordination of care and services. The CSHCN measures have been validated and are currently available on the Web.⁴¹⁵ HEDIS has approved use of CSHCN for HEDIS 2002. Given the unique needs of these children, these measures fill a critical void in quality measures for children and suggest potential methodology for assessing health care provided to disabled adults.

Provision of well-child care falls far short of preventive guidelines promulgated by the American Academy of Pediatrics and Bright Futures. Only 40-70 percent of care meets standards.⁴¹³ Minority children experienced poorer quality of primary care across most domains of care compared with white children while Asian American children reported the lowest quality of care across most domains, especially in first-contact utilization, interpersonal relationship, and comprehensiveness of services received.⁴¹⁶ The CAMHI measures for early childhood address age-appropriate anticipatory guidance and parental education; health information provided on safety tips, child care, child health care utilization, and Child Dev; followup on risks for developmental delay; assessment of parental well-being and safety; assessment of alcohol and drug use in the family; provision of family-centered care; and effect of anticipatory guidance on parental confidence.⁴¹³

Previously, there were no measures specifically designed to assess adolescent health. The YAHC survey was developed as part of CAHMI. The 56-item survey assesses the quality of health care received by adolescents over the past year in the following domains: counseling and screening to prevent risky behaviors, to reduce sexual activity and sexually transmitted diseases (STDs), to improve diet and exercise activity, and to promote emotional health and healthy relationships; care provided in a confidential and private setting; preventive health information; helpfulness of counseling; and experience

of care (based on CAHPS®). These measures fill an important gap in pediatric quality measures.

In addition, use of Guidelines for Adolescent Preventive Services in Community Health Centers have been shown to improve performance on these measures.⁴¹⁷ Rates of substance abuse are higher among lower SES adolescents⁴¹⁸ and rates of STDs are higher among minority youth.⁴¹⁹ Given prior studies showing disparities in preventive counseling,⁴²⁰ CSHCN, early childhood, and YAHC should be stratified by race/ethnicity and SES.

These measures are primarily designed to assess the quality of clinical care based upon commonly accepted standards of care such as those set forth by the U.S. Preventive Services Task Force and other national organizations. HEDIS does not currently report its measures by race/ethnicity or SES although some of the measures are gender or age specific.

Childhood immunization status. This measure assesses the percent of children who are up to date by 2 years of age on recommended immunizations. The mean scores for HMOs range from 47 percent to 87 percent depending on the combination of vaccinations given.⁴²¹ Minority children tend to have rates of childhood illnesses as high as, if not higher than, rates for white children. Rates of invasive pneumococcal infections and hepatitis B are higher among black and low-income children.^{422 423} Asian children have higher rates of infection with hepatitis B.⁴²³ Recently released 1999 data from the National Immunization Survey show that black, Hispanic, American Indian/Alaska Native, and, in some instances, Asian/Pacific Islander children aged 19-35 months have lower immunization rates than white children.⁴²⁴ In most instances, black children and those living in poverty have the lowest rates. Black-white gaps in childhood immunizations range from 5.5 percent for four series of DTP to none for varicella. Use of reminder/recall interventions in urban primary care practices have been shown to eliminate geographic, racial, and ethnic disparities in childhood immunization rates.⁹⁷ The childhood immunization measures are appropriate for all children regardless of racial or ethnic background or urban or rural residence. Because minority and low-income children are at higher risk for childhood infections and for under-immunization, these measures should be stratified by race/ethnicity and SES.

Adolescent immunization status. This measure assesses the percent of children 12 and older who are up to date with vaccines for measles/mumps/rubella (MMR), hepatitis B (HBV), tetanus (Td), and varicella. The mean scores for HMOs range from 14 percent to 59 percent depending on the combination of vaccinations.⁴²¹ Rates of immunity among military recruits to measles, mumps, and rubella are lower among blacks.⁴²⁵ Rates of hepatitis B infection are higher among black adolescents than white adolescents.⁴²⁶ Complications from these infections can result in lasting sequelae and, in some instances, death. HEDIS data show that persons from predominately black and low-income communities have lower rates of adolescent immunizations.⁴²⁷ This measure is relevant for all adolescents regardless of racial or ethnic background or urban or rural residence. Both higher risk and lower rates of immunization among minority and low-income adolescents suggest a need to stratify these measures by race/ethnicity and SES.

Alcohol misuse. Three dimensions of health care related to alcohol abuse are assessed: health care plan population screening for alcohol misuse, routine assessment, and satisfaction with alcohol screening/counseling. Rates of alcohol misuse/abuse from the BRFSS are appreciably higher among American Indians/Alaska Natives than whites, but lower among blacks and Asians.¹² Rates of alcohol abuse are slightly higher among lower SES persons. Rates of binge drinking are very high among adolescents.⁴²⁸ Hospital detoxification admissions for alcohol dependency are higher among rural residents.⁷ The overall effect of alcohol misuse on minority and rural health is substantial, including higher rates of accidental death, homicides, cancer, and liver disease among blacks, Hispanics, and American Indians/Alaska Natives.⁷ Thus, alcohol misuse is highly relevant to most disparity populations. Further study is needed to assess disparity in this measure.

Chlamydia screening in women. This measure assesses the percent of females who have been screened for chlamydia in the past year. The measure is applied to age groups of women: those 16-20 and 21-26. The mean score for HMOs in 2000 was 16 percent.⁴²¹ The CDC estimates that roughly 3 million cases of chlamydia occur annually.⁴²⁹ Most women are asymptomatic. Forty percent of untreated women develop pelvic inflammatory disease (PID) and 20 percent of women who develop PID become infertile.⁴²⁹ Certain subtypes of chlamydia have been linked to cervical cancer.⁴³⁰ Rates of chlamydia^{154,431,432} and complications of chlamydia including PID, ectopic pregnancy, and infertility due to tubal disease are higher among black women.⁴³³ Native American women^{434,435} as well as subgroups of Asian/Pacific Islander women and Hispanics may also have higher rates of chlamydia infection. Effective screening tests and treatment are available. Although rates of chlamydia screening by race are not known, blacks report overall higher rates of STD screening than do whites.⁴³⁶ These differences are partly, but not fully, explained by differences in source of care (private vs. family planning clinics). This measure is appropriate for adolescents and minority women, including rural and urban residents. Although rates of screening may be higher among African Americans, stratification by race/ethnicity and SES is nonetheless indicated based on the elevated risk of disease and complications.

Prenatal care and post-partum care. These two measures assess timeliness of care. The first measure assesses the percent of women who enroll in prenatal care in the first trimester. The second assesses the percent of women who see their provider on or between 21 days and 56 days after delivery. The mean scores for commercial HMOs in 2001 was 77 percent for both measures. The infant low birthweight rate and infant mortality among African Americans are more than double those of whites.⁴³⁷ Blacks and Hispanics have lower rates of early enrollment in prenatal care, but American Indians/Alaska Natives have the lowest rate of prenatal care enrollment of any group.¹²⁰ These measures should be stratified by race, ethnicity, and SES.

Breast cancer screening. This measure assesses the percent of women ages 52-69 who have had a mammogram in the past 2 years. The mean score for HMOs in 2000 was 73 percent.⁴²¹ The incidence of breast cancer is lower among black women compared to white women, but death rates from breast cancer are higher among black women than

among any other group.⁹ Breast cancer is the leading cause of cancer-related mortality for Hispanic, Asian/Pacific Islander and American Indian/Alaska Native women.¹³³ Hispanic^{12,438} particularly Mexican American women,⁴³⁹ and Asians, Native Hawaiians and other women⁴³⁷ and American Indian/Alaska Native women³¹ have lower mammography rates than whites. Although self-report data from the NHIS show that black-white disparities in mammography were eliminated by 1992,⁴⁴⁰ Medicare claims and Medicare HMO HEDIS data show that black women continue to have significantly lower mammography rates than whites.^{441,442} HEDIS data also show lower rates of mammography among persons from poor communities.⁴²⁷ Case management programs have been shown to reduce racial disparities in mammography.⁴⁴³ This measure is clearly appropriate for elderly and nonelderly women regardless of race or ethnicity or place of residence. As previously indicated, it is particularly pertinent to disabled women or those with multiple chronic conditions because they are at higher risk of not receiving mammography.³⁵⁶ Given the contribution of breast cancer to mortality for all women regardless of age, race, income, ethnicity, place of residence, or disability, this represents a relevant measure for members of each of these groups. Consideration should also be given to stratification of this measure by race, ethnicity, SES, and disability status given that members of these groups are at higher risk for death from breast cancer and/or higher risk for not being screened.

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 3 years. The mean score for HMOs in 2000 was 72 percent.⁴²¹ 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.⁴⁴⁴ Blacks, Hispanics and Asian/Pacific Islanders have higher incidence of cervical cancer than whites.^{9,444} Vietnamese women have the highest rates of any group.⁴⁴⁴ Black women have the highest rates of death from cervical cancer.^{9,445} Both race and poverty are independently associated with late-stage diagnosis.⁴⁴⁶ NHIS data show that Hispanic, American Indian/Alaska Native, and particularly Asian/Pacific Islander women, in addition to women living in poverty, have lower rates of Pap smear screening than white or more affluent women.^{133,438,447,448} Although black women report the highest Pap smear rates,⁴³⁸ HEDIS data show that persons from predominantly black and low-SES communities have lower rates.⁴²⁷ As with mammography, this measure is clearly appropriate for women regardless of race or ethnicity, place of residence, or disability status. Given the low rates of screening for members of selected minority groups, low-income women, and women with chronic disease, in addition to the higher risk of cervical cancer among many of these groups, consideration should be given to stratification of this measure by race/ethnicity, SES, and, probably, disability status.

Advising smokers to quit. Smoking is the single most important preventable risk factor for mortality in the United States.⁴⁴⁹ Physician advice has been shown through randomized controlled trials to improve rates of smoking cessation.⁴⁵⁰ The HEDIS and FACCT measure is based on patient report from surveys. The FACCT measure and the HEDIS measures include advice to quit smoking in addition to the proportion of smokers who quit and evidence that the health care organization surveys its members about their health habits. These measures have widespread relevance and probably should be

stratified by race/ethnicity and SES. The mean score for HMOs in 2000 was 64 percent.⁴²¹

All groups are affected by smoking, which often starts during adolescence. Rates of smoking are highest among Native Americans,¹² rural residents,⁴⁵¹ and persons with mental illness.⁴⁵² National data from two different surveys show racial disparities in smoking assessment and/or cessation counseling. NAMCS data show that minorities are less likely to be asked by physicians as to whether they smoke.⁴⁵³ Community Tracking Survey data show that black and Hispanic smokers are less likely than whites to report they were counseled to quit smoking.^{454,455} Given the enormous impact of smoking and demonstrated cost-effectiveness of smoking cessation counseling,⁴⁵⁶ this measure is appropriate for all groups with the exception of those near the end of life. Stratification by race/ethnicity and SES is warranted. Stratification by adolescence may also be indicated given the vulnerability of adolescents to smoking.

Flu shots for older adults. This measure assesses whether patients over 55 years of age or with risk factors received a flu shot in the past year. Pneumonia/influenza represents one of the 10 leading causes of death among all minority and nonminority groups. Age-adjusted rates of death from pneumonia/influenza are higher among blacks than whites and higher among persons with low versus higher income.⁷ Persons with chronic disease, including heart and lung disease and diabetes, are at higher risk for hospitalization and/or death resulting from pneumonia.⁴⁵⁷ Influenza vaccines have been shown to be highly effective in preventing morbidity and mortality associated with influenza among the elderly and those with chronic disease.⁴⁵⁸ Data from the BRFSS show that fewer elderly blacks (39 percent) than whites (60 percent) receive the influenza vaccine.¹¹⁰ Hispanics and lower income persons also have significantly lower rates of influenza vaccination than whites.⁴⁵⁹ This measure is specifically designed for older adults. It is particularly relevant to those with chronic illnesses who are at higher risk for influenza complications but is also appropriate for men and women, minorities, low-income persons, and rural and urban residents. Given the disparities in complications from influenza and influenza immunization by race/ethnicity and SES, stratification by race/ethnicity and SES is strongly needed. Given the higher risk associated with chronic disease, stratification by this variable should also be considered.

Medicare Health Outcomes Survey. This measure examines change in health status over time among Medicare HMO enrollees based on the Medical Outcomes Study Short Form 36 (SF-36) item health survey. Blacks and American Indians/Alaska Natives report lower health status than whites and likely experience more rapid decline in health status.^{12,237} However, the validity of comparisons of changes in health status between plans is not known. This measure targets the elderly and is especially relevant to those with chronic illness and disabilities. It is also particularly relevant to minorities and low-income persons who are at higher risk for more rapid decline in health status.⁴⁶⁰ However, as indicated previously, the SF-36 may not capture critical components of health status and quality of life that are relevant to persons with disabilities. Given these findings, stratification of this measure by age, race/ethnicity, income, chronic disease, and disability is warranted.

Pneumonia vaccination status for older adults. This measure assesses whether adults over 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,^{422,461-463} Native Americans,²³⁷ smokers, and persons with low SES.⁴⁶³ Pneumonia vaccines have been shown to be cost-effective in preventing morbidity and mortality associated with pneumococcal pneumonia.⁴⁶⁴ Data from the BRFSS show that fewer elderly blacks (20 percent) than whites (37 percent) received the pneumococcal vaccine.¹¹⁰ Hispanics also have significantly lower rates than whites.⁴⁵⁹ Like influenza vaccination, this measure is especially appropriate for persons with chronic disease and certain disabilities, but is also appropriate for the elderly regardless of their gender, race, income, or residence. Given the risk associated with pneumonia among persons with chronic disease, racial and ethnic minorities, and low-income persons, as well as the racial and ethnic disparities in immunization, stratification by these groups is clearly warranted.

Getting Better

HEDIS, ORYX, and HCQIP each have measures in this domain. Most of these reflect effectiveness of care. Several of HEDIS utilization measures reflect timeliness of care.

Acute myocardial infarction. These include process measures that have been shown to decrease mortality from myocardial infarction. These include appropriate use/prescription of aspirin, beta-blockers, ACEIs, reperfusion therapy, and smoking cessation counseling following acute myocardial infarction. These are measures of both effectiveness and timeliness and represent consumers' perspectives on getting better (recovery from myocardial infarction) and living with chronic illness (coronary artery disease). The median performance among States ranges from 85 percent for aspirin therapy to 40 percent for smoking cessation counseling.⁴⁶⁵ As indicated previously, blacks, low-income persons, the elderly, and men have higher rates of mortality from myocardial infarction. Ischemic heart disease represents the leading cause of death for not only whites, but members of most adult disparity populations. Nonetheless, African Americans are significantly less likely to receive beta-blockers, aspirin, and reperfusion therapy.^{61,466,467} Rural residents and women have been reported to receive lower quality care for myocardial infarction.^{35,338} Non-black minorities also have been reported to receive post-infarction beta-blockers less frequently than nonminorities.⁴⁶⁸ Patients with Medicaid have lower use of invasive procedures and reperfusion therapy.⁴⁶⁹ Women have been reported to receive reperfusion therapy less often than men,³³ but this disparity may be explained by gender differences in demographic and clinical characteristics.⁴⁶⁶ Women may be less likely to receive appropriate medications such as aspirin and beta-blockers following a myocardial infarction.^{35,61} These differences do not appear to represent confounding. Given the contribution of myocardial infarction to death rates among members of all groups, this measure is relevant to men, women, minorities, low-income persons, the elderly, and persons with chronic illness (coronary artery disease in

particular). Stratification of this measure by race/ethnicity and SES—and possibly by gender—is warranted.

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. This measure represents the consumer perspectives of getting better (recovery from a myocardial infarction) and living with chronic illness (coronary artery disease). It is both an effectiveness and timeliness measure. The mean score for HMOs in 2000 was 85 percent.⁴²¹ Heart disease, particularly coronary artery disease, is the leading cause of death among members of all minority groups.¹³ Rates of death following a myocardial infarction are higher for black men than whites.⁴⁷⁰⁻⁴⁷² Beta-blockers have been conclusively shown to reduce mortality post-myocardial infarction.^{473,474} Heart disease and myocardial infarctions are more frequent among the elderly. Blacks, Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives are less likely to receive beta-blockers after myocardial infarction^{61,442,468} or in the presence of coronary artery disease.⁴⁷⁵ A study of Medicare managed care enrollees showed an absolute difference of 23 percent between blacks and whites in the provision of beta-blockers after myocardial infarction.⁴⁷⁶ However, there are conflicting data as to whether blacks derive benefits from beta-blockers after myocardial infarction comparable to whites.^{473,477} The measure is appropriate for men and for women, minorities, and the elderly, those with chronic disease and urban and rural residents. Given the impact of myocardial infarction on African Americans and low-income persons, and the disparities in use of this intervention, stratification by race/ethnicity and SES is needed. Further data are needed regarding the effectiveness of beta-blockers following a myocardial infarction among members of different minority groups.

Breast cancer. The prevalence of breast cancer among different populations has been previously discussed. FACCT breast cancer measures include outcomes such as proportion of women with stage I and stage 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). Minorities undergo fewer breast conserving surgeries.²⁰ There are conflicting data as to whether minorities receive less radiation for breast cancer.²⁰ Rural residents may have reduced access to experienced breast cancer surgeons. This measure is very relevant to women, minorities, low-income persons, and the elderly. Stratification by race/ethnicity and SES is warranted.

Congestive heart failure. This measure is based on the proportion of patients discharged from the hospital with diagnosis of heart failure who receive ACEIs or an assessment of left ventricular ejection fraction. It is both an effectiveness and timeliness measure and represents the consumer perspective of getting better (recovery from an acute exacerbation of the illness) in addition to living with chronic illness (CHF). Median performance among all States was 69 percent.⁴⁶⁵ Blacks and elderly persons have a higher incidence and hospitalization rate for congestive heart failure.^{478,479} Findings regarding racial disparities in mortality from CHF have been conflicting⁴⁷⁸⁻⁴⁸⁰ although blacks with congestive heart failure experience higher all-cause mortality than do whites

with equivalent left ventricular dysfunction.⁴⁸¹ Detailed analysis of the quality of hospital care shows that blacks and lower SES persons receive less appropriate management of CHF²⁵, including lower use of anticoagulants.⁴⁸² There appears to be little difference in use of ACEIs in CHF by race.⁴⁸³ Blacks may derive less benefit from ACEIs for left ventricular dysfunction than whites¹¹² but obtain comparable benefit from certain types of beta-blockers.⁴⁸⁴ These measures are appropriate to adult men and women, minorities, those living with chronic illnesses and disabilities, the elderly, and rural residents. Stratification of this measure by race/ethnicity and SES is warranted, based on evidence of substandard care for these groups.

Pneumonia. These measures include appropriate collection of blood culture, appropriate prescription of antibiotics, and vaccination for patients hospitalized for pneumonia. They are both effectiveness and timeliness measures and relevant to the consumer perspective of getting better. Median performance among all States ranges from 85 percent for time to antibiotic therapy to 11 percent for screening for pneumonia vaccination.⁴⁶⁵ As indicated earlier, blacks, lower SES persons, smokers, persons with mobility impairment, persons with cardiovascular, hepatic and immunologic disease, and the elderly have higher death rates from pneumonia/influenza. Pneumonia represents one of the 10 leading causes of mortality for each of the minority groups,⁷ and for children including neonates, preschool, pre-adolescents, and adolescents.⁷ African Americans and persons with low income may receive less appropriate hospital care for pneumonia,²⁵ including less timely antibiotic administration.⁴⁸⁵ Rural hospitals and those located in the western part of the country provide more timely antibiotic administration to patients with pneumonia.⁴⁸⁵ Stratification of this measure by race/ethnicity and SES—and possibly by age—is warranted, based on these findings.

Stroke. These measures relate to hospital management of cerebrovascular accident and include prescription of an antithrombotic medications such as antiplatelet agents and anticoagulants, avoidance of sublingual nifedipine with acute stroke, and prescription at hospital discharge (in the absence of contraindications) of warfarin for atrial fibrillation. These represent effectiveness and timeliness measures, and in the case of nifedipine, safety measures. Median State performance ranges from 95 percent for nifedipine therapy to 55 percent for warfarin for atrial fibrillation.⁴⁶⁵ Cerebrovascular disease is the second leading cause of death for whites, blacks, Hispanics, and Asians or Pacific Islanders, and fourth for American Indians or Alaskan Natives (Tables 1-5). Risk of stroke is strongly associated with age and cardiovascular risk factors. Blacks have 40% higher age-adjusted rates of death from cerebrovascular disease than all other groups (Table 2). A mild stroke may prove more devastating to persons already disabled because of their lower functional reserve. 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.⁴⁷⁴ Recent reports suggest that Hispanics have lower rates of endarterectomies.⁴⁸⁶ Blacks have been reported to have higher mortality following endarterectomy.⁴⁸⁷ However, there does not appear to be a racial disparity in prescription of anticoagulants for atrial fibrillation.⁴⁸⁸ These measures are appropriate for adult men and women, minorities, low-income persons, the elderly

and persons with chronic disease and disability, rural residents, and the elderly. Stratification by race/ethnicity and SES is warranted.

Safety

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^{143,144} and more complications following vascular surgery, glaucoma surgery, and endarterectomy.¹⁴⁵⁻¹⁴⁷ The extent to which these differences represent differences in health care quality as opposed to differences in disease is not clear. Having a chronic disease or major disability, particularly one related to mobility or major organ dysfunction, places one at higher risk for surgical morbidity and mortality. However, many hospitals do not have sufficient surgical volume to meaningfully compare rates of major surgical complications by subgroup. Thus limited statistical power and problems in casemix adjustment make use of this measure problematic.

As indicated earlier, blacks have higher rates of preterm birth, low birthweight infants, and pregnancy-associated infections,^{148,149} in addition to other complications of pregnancy.^{150,151} The extent to which these outcomes are affected primarily by underlying differences in health care quality versus differences in disease is not known. For example, rates of post-partum endometritis are affected by rates of bacterial vaginosis,^{152,153} which differ by race.¹⁵⁴ Nonetheless, complications related to pregnancy are quite relevant to women and children's health. Access to neonatal intensive care units (level III) may be particularly problematic for rural residents since these units are usually located in large metropolitan areas.

Timeliness

HEDIS also includes a series of health care utilization measures including frequency of prenatal care visits, births, Cesarean section rates, well-child and adolescent's visits, use of selected procedures, and various inpatient utilization and outpatient utilization measures including mental health, substance abuse, and prescription utilization. In general, these measures address the question as to whether procedures are conducted in a timely fashion (or at all). With appropriate casemix adjustment, many of these measures could be used to assess racial/ethnic disparities in access and/or resource allocation. Although crude rates do not distinguish overuse among whites from underuse among minorities, either underuse or overuse among any group warrants attention as a potential quality problem.

Organ transplantation. Of these procedures, priority might be given to racial/ethnic disparities in renal transplantation. African Americans, American Indians/Alaska Natives, and possibly Hispanics are disproportionately affected by renal disease.⁴⁸⁹ As of the end of 1999, more than 31,000 African Americans were on hemodialysis; blacks alone comprise one-third of all hemodialysis patients.⁴⁹⁰ Moreover, blacks receive lower quality dialysis as measured by urea clearance.⁴⁹¹ Renal transplantation has been shown to substantially improve the quality and length of life for African Americans.^{492,493} Racial disparities in renal transplantation are not fully explained by other concurrent illnesses, patient preferences, or appropriateness for transplantation.²²¹ Disparities in

transplantation have also been noted for American Indians.⁴⁹⁴⁻⁴⁹⁶ Crude measures of access to transplantation can easily be constructed. These include the ratio of transplants performed per year to the number of persons currently on dialysis for each group or the ratio of number of persons referred for transplant evaluation to the number from that group who initiated dialysis in a given year. Consideration should also be given to stratification of this measure by gender.⁶⁹⁻⁷¹

Cardiovascular procedures. Although blacks are disproportionately affected by cardiovascular disease,⁷ they are less likely to undergo invasive diagnostic or therapeutic cardiovascular procedures such as angioplasty, stenting, thrombolytic therapy, or coronary bypass surgery.¹³⁴ The extent to which these differences represent overuse among whites versus underuse among blacks has not been fully clarified. However, underuse by minorities definitely contributes to the gap.^{111,497,498} Blacks may be less willing to undergo these procedures.⁴⁹⁹ However, such fears are not unfounded. African Americans are more likely to undergo cardiac surgery by surgeons with poorer outcomes.¹⁰⁹ Differences in patient preference do not appear to explain racial differences in these procedures.⁵⁰⁰ As with other procedures, quality measures in this realm are hindered by difficulties in determining appropriateness. For this reason, measures of disparities in cardiovascular procedures are probably more appropriate for internal rather than external quality assessment, although disparities in rates do signal overuse/underuse problems. The ratio of the number of persons who undergo a diagnostic procedure divided by the number of persons from that group admitted for unstable angina or myocardial infarction has frequently been used to assess disparities with administrative data.

Cerebrovascular disease. Similar problems plague measures for cerebrovascular disease. Although blacks have higher rates of cerebrovascular disease, some of the disparity in surgical procedures is attributable to higher rates among blacks of small vessel disease that is not amenable to surgical intervention.⁵⁰¹⁻⁵⁰³ Moreover, the benefit of endarterectomy is confined to persons with severe, symptomatic carotid disease who are operated on by experienced surgeons in hospitals with low operative morbidity and mortality.⁵⁰⁴ Many minorities receive care at hospitals that do not meet these standards. Yet, when the Department of Veterans Affairs regionalized cardiac surgery, utilization of these procedures by African Americans was reduced.⁵⁰⁵ An example of a potential measure of access to cerebrovascular diagnostic technology is the proportion of persons admitted for hemispheric symptoms/stroke who received carotid imaging studies.

Osteoarthritis. Osteoarthritis is a major cause of disability among the U.S. population and minorities are disproportionately affected.^{506,507} Hip and knee replacement surgery has been shown to significantly improve patient function and quality of life. Yet, blacks and Hispanics are less likely to receive this surgery.^{508,509} Blacks report more skepticism towards hip surgery⁵¹⁰ and may have inferior outcomes following hip replacement.⁵¹¹ Women also receive hip and knee replacements later in the course of their disease than men.⁵¹² The major barrier to use of a measure for access to joint replacement surgery is the determination of an appropriate denominator; i.e., the number of persons of different

race/ethnicity who would be potentially eligible for this procedure. Further research is required before this measure can be implemented.

Cancer surgery. Blacks are less likely to undergo curative lung¹⁴⁰ and other cancer-related surgeries.²⁰ Unfortunately, it is not possible to determine which patients are suitable for such surgery using hospital claims data because such data do not include stage at diagnosis and severity of comorbidity and other factors that might preclude surgery. However, these data can often be obtained from cancer registries. When disease stage data are unavailable by race and ethnicity, the number of curative cancer procedures performed divided by number of palliative surgeries for different racial and ethnic groups represents a measure potentially suitable for internal quality improvement. A disparity in this measure signals suboptimal care: either minorities experience relative underuse of these procedures or they are being diagnosed at later stages. In either instance, further assessment to determine the reasons for the disparity is needed followed by an appropriate intervention designed to remedy the gap. Alternatively, measures can be constructed using data from cancer registries such as the Surveillance Epidemiology and End Results (SEER) program that collects data on cancer treatment and outcomes by cancer stage among selected hospitals.¹⁴⁰ These data can be analyzed by hospital or linked to health care plan membership data.

Living With Chronic Illness

Asthma. Asthma is one of the few chronic illnesses that affects both children and adults. Use of appropriate medications for asthma represents both an effectiveness and timeliness measure. The HEDIS measure assesses whether patients with the diagnosis of asthma have received a prescription for an anti-inflammatory asthma medication in the past year. It is applied to three age groups: 5-9 years, 10-17 years, and 18-56 years. The mean score for HMOs for this measure in 2000 was 57 percent for all ages.⁴²¹

In contrast to the HEDIS measure that focuses on a single aspect of asthma management, FACCT uses a comprehensive range of indicators derived from patient surveys. These include whether patients received education, peak flow meters, and inhalers and whether they have been instructed in appropriate use. Outcomes include patient experience and satisfaction with asthma care, functional status (SF-36), and ability to maintain daily activities, symptoms, and self-management knowledge and behavior. Minority race has been linked to improper use of inhalers^{513,514} and hospitalizations and emergency department visits for asthma.⁵¹⁵ Moreover, low literacy is a barrier to asthma knowledge and self-care.²⁵⁹

Asthma is among the most prevalent chronic childhood illnesses. NHANES III data show appreciable differences by race/ethnicity in physician-confirmed diagnosis of asthma for children under 11 years: 3.3 percent for whites compared to 11.2 percent for Puerto Ricans, 5.9 percent for blacks, 5.2 percent for Cubans, and 2.7 percent for Mexican Americans.²⁹⁶ Rates of asthma among American Indians/Alaska Natives are comparable to those of whites.⁵¹⁶ Rates of disability and mortality for blacks with asthma are nearly double those for whites.^{297,298} Asians/Pacific Islanders have also been reported to have worse asthma outcomes than whites.³⁰² Rates of asthma appear to be particularly high among inner city residents in part due to cockroach infestation.³⁴³ 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.^{514,517,518} Hispanic children receive fewer beta2-agonists inhaled steroids than white children even after controlling for patients' race, age, gender, insurance status, symptom severity, number of primary care visits for asthma, number of urgent visits to the regular provider, family income, maternal education, and site of care.⁵¹⁹ Well designed studies show that anti-inflammatory asthma medications reduce asthma exacerbation.^{520,521} Professional education of clinic staff has been shown to improve continuity and quality of care among minorities with asthma.⁵²²

These measures target management of a prevalent, chronic disease and are appropriate for persons regardless of age, gender, race/ethnicity, SES, or residence. Stratification by race/ethnicity and SES is warranted, based on risk and disparities in treatment.

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 blood pressure is below 90 mm mercury. Depending on whether hypertension is defined as a chronic illness or as a risk factor for chronic illness, management of hypertension represents the consumer perspectives of staying healthy or living with illness. The mean score for HMOs in 2000 was only 39 percent.⁴²¹ Hypertension is one of the most widespread health problems among blacks. Hypertension represents the single largest contributor to black-white disparities in mortality.¹¹⁴ Hypertension is also strongly associated with advancing age. The age-adjusted prevalence among African Americans is 23 percent.⁵²³ Rates of uncontrolled hypertension are highest among those aged 65 and over.⁵²⁴

The sequelae from hypertension have an enormous impact on the health of minorities, particularly African Americans and result in premature mortality and morbidity including cardiovascular, cerebrovascular, and kidney disease. Treatment of hypertension has been conclusively shown to reduce complications among blacks.⁵²⁵ Treatment of hypertension is cost-effective and feasible with existing agents. However, the prevalence of hypertension, including untreated hypertension, is higher among blacks, and probably other minorities.⁵²³ Adequate control of hypertension is suboptimal. Only 30 percent of all whites and 26 percent of all blacks with hypertension have their blood pressure adequately controlled.⁵²³ Among persons under treatment for hypertension, less than half have their blood pressure adequately controlled and rates are lower for blacks than whites and for poor versus non-poor persons.^{31,523,524}

Although quality improvement efforts designed to improve hypertension management have had limited success,⁵²⁶ socioeconomic disparities in hypertension control were eliminated in the stepped care arm of the Hypertension Detection and Follow-up Program.⁵²⁷ Similarly, the absence of copayments in one of the arms of the RAND Health Insurance Experiment resulted in significantly improved hypertension control, particularly among the lower income group.⁵²⁸ Data from the Achievable Benchmark of Care System show that physician performance feedback based on achievable benchmarks improves health care quality for hypertension.⁴⁶⁵

This measure is relevant to men and women, minorities, persons with chronic illness, the elderly, and urban and rural residents. Given the disparities in detection and control by race, income, and age, this measure should be stratified by these categories.

Cholesterol management after acute cardiovascular events. This measure assesses the percent of patients who experienced an acute cardiovascular event in the last year who received LDL-C cholesterol screening and also whose LDL-C cholesterol levels were <130 mg/dl within 60 days of the event. The mean score for HMOs in 2000 was 45 percent.⁴²¹ Cardiovascular disease is the leading cause of death among all minorities and fully accounts for one-third of racial disparities in adult mortality.¹¹⁴ Elevated cholesterol is an important risk factor for cardiovascular disease, the leading cause of death for all groups. NHANES data show that serum cholesterol levels in the United States do not differ appreciably by race or ethnicity.⁵²⁹ However, blacks, Hispanics, Asian Americans or Pacific Islanders and American Indians or Alaska Natives report lower testing rates than whites,^{530, 12} and blacks and Mexican Americans with high cholesterol who were told to take medication were less likely to report being on medication.^{530,531} NAMCS shows that blacks receive less cholesterol reduction counseling than whites⁵³² and are less likely to have their cholesterol addressed. HEDIS data for Medicare managed care enrollees also show that blacks and Hispanics are less likely to meet criteria for this measure.³¹ Given the large contribution of cardiovascular disease to mortality among all groups, this measure is relevant to all adults. Given the uncertainty regarding the quality of cholesterol management after acute cardiovascular events and the cost of this intervention for those with inadequate insurance, this measure should probably be stratified by race/ethnicity and SES.

Comprehensive diabetes care. This is a set of six measures that assess the quality of care for diabetes. They include glycosylated hemoglobin testing, control of diabetes, diabetic retinal screening, lipid screening, lipid control, and screening for diabetic nephropathy.

Care of diabetes represents the consumer perspective of living with chronic illness. It is both an effectiveness and timeliness measure. The mean score for HMOs in 2000 for these measures ranged from 36 percent for nephropathy monitoring to 75 percent for glycosylated hemoglobin testing.⁴²¹

Rates of diabetes have increased in the past decade. Prevalence is higher among the elderly and members of certain racial and ethnic minorities and the poor.^{533,534} American Indians have rates of adult onset diabetes that are 2 to 6 times higher than whites.⁵³⁵ In 2000, diabetes was the fourth leading cause of death for blacks, third for Hispanics and American Indians or Alaska Natives, and seventh for Asians or Pacific Islanders (Tables 1-5). Age-adjusted mortality rates for blacks, Hispanics, and American Indians or Alaska Natives are significantly higher than those of whites. Blacks are also at higher risk for complications of diabetes including amputation and renal failure.⁵³⁶ NHANES III data show that black diabetics have poorer glycemic control compared to whites.⁵³⁷ Low education is also associated with poorer diabetic control and failure to undergo retinal examination.⁵³⁷ Both CMS and HEDIS data show that black diabetics have lower rates of dilated exams.^{442,538} Data from the 1993 Medicare Current Beneficiary Survey show that elderly African Americans received lower quality care including less frequent

glycosylated hemoglobin testing, eye examinations, influenza immunizations, lipid testing, and physician visits, but more emergency department visits.⁵³⁹ NAMCS data also show that black diabetics receive less eye care than whites.⁵⁴⁰ Rural residents have also been reported to receive lower quality diabetic care.⁵⁴¹ Interestingly, HEDIS data for Medicare managed care enrollees show that Asians have higher rates for these measures than whites.³¹

Feedback to physicians regarding their performance using achievable benchmarks for diabetic care has been associated with significant improvements in these measures.⁵⁴² Intensive management has been shown to eliminate socioeconomic disparities in diabetic control.²⁰⁵ Given the contribution of diabetes to mortality for minorities and low-income persons and evidence of suboptimal management among these groups, this measure is especially appropriate for use with these groups. Stratification by race/ethnicity and SES is warranted.

Depression. These HEDIS measures assess followup and continuity of care for depression. Depression can represent a single acute episode, but it often represents a recurrent relapse in what is most appropriately characterized as a chronic illness.⁵⁴³ The mean score for HMOs in 2000 ranged from 21 percent to 59 percent depending on the particular measure.⁴²¹

In contrast to HEDIS, FACCT includes depression outcome measures. The measure set includes proportion of patients who are lost to followup, patient satisfaction, patient functional status, recovery, and patients' ability to maintain activities. These measures are relevant to men and women, minorities, persons with low SES, elderly, persons with chronic illness and disabilities, rural residents, and to some extent persons near the end of life. As previously discussed, these measures should be stratified by race/ethnicity and SES.

Depression affects all ages, races, and ethnic groups although rates are higher among women.³²⁰ Rates of depression do not appear to differ significantly between whites and blacks, but rates are higher among persons with low income³²⁰ and among persons with chronic illness and those nearing the end of life.⁵⁴⁴⁻⁵⁴⁶ Rates of suicide are also higher among rural residents and among American Indians/Alaska Natives.^{7,547} Whites are more likely to receive antidepressants than minorities.^{24,548} Among patients receiving antidepressants, whites are more likely than minorities to receive selective serotonin reuptake inhibitors,⁵⁴⁸ and to receive guideline concordant treatment for depression.⁵⁴⁹ There does not appear to any difference in the quality of depression management in urban and rural areas.⁵⁵⁰ However, depression among those with chronic illness, the elderly, and those nearing the end of life often is unrecognized by clinicians.

This measure addresses a potentially chronic illness that often results in significant disability. It is appropriate for children, adults, men, women, minorities, low-income persons, elderly, and potentially those nearing the end of life. Stratification by race/ethnicity, SES, age, and gender is warranted, based on disparities in treatment and/or greater risk.

Followup after hospitalization for mental illness. This measure assesses whether persons hospitalized for mental illness are seen in followup within 4 weeks of hospital discharge. It is one of the few quality measures targeting persons with a chronic mental

illness. It represents the consumer perspective of getting better (from an acute exacerbation of illness) as well as the perspective of living with a chronic illness (mental illness). The mean score for HMOs in 2000 was 70 percent.⁴²¹ Rates of mental illness do not appear to differ appreciably between blacks and whites,^{320,551} although rates are higher among persons with low income. Native Americans may have the highest rates of suicide of any group¹²⁰ although misclassification of both race and cause of death on death certificates underestimate this rate. Even among the insured, blacks and Hispanics receive fewer outpatient mental health services than whites⁵⁵² but have comparable use of inpatient services.⁵⁵³ Physicians spend less time with black patients in psychiatric emergency rooms and are more likely to prescribe anti-psychotics.⁵⁵⁴ Among patients with schizophrenia who are insured through Medicaid, African Americans are less likely than whites to receive expensive, second generation anti-psychotic medications.⁵⁵⁵ Recently published data show that performance for this measure among Medicare managed care enrollees is markedly worse for blacks than for whites.⁴⁴² Care was also worse for low-income persons.⁴⁴²

This measure targets management of a chronic disease that often results in disability. It is appropriate for children, adults, men, women, minorities, elderly, and urban and rural residents (for whom mental health services are often suboptimal). Stratification by race/ethnicity and SES is warranted.

HIV/AIDS. There are not yet widely used quality measures for HIV/AIDS. However, the New York AIDS Institute has developed a series of guidelines with corresponding measures it uses to assess the quality of care in facilities it funds. They measures address CD4 count every 6 months, antiretroviral therapy usage (HAART) for patients with CD4 counts below 500 cells/ml, or viral load levels above 10,000/copies/mL, *Pneumocystis carinii* pneumonia (PCP) prophylaxis for patients with AIDS, tuberculosis screening every year, and pelvic exams every year. These measures require chart audits for assessment.

FACCT is also developing a measure set in this area. The proposed FACCT measures include HIV testing during pregnancy, HIV risk reduction counseling among HIV negative persons, and various measures related to care for persons with HIV including Pap smear frequency, appropriate laboratory testing/monitoring, use of appropriate antiretrovirals, prophylactic antibiotics, immunizations, functional status, access to care, medication adherence, and provider communication.

HIV infection is the third leading cause of years of potential life lost for black women and the fourth cause for black men.²³⁷ Rates of death from HIV infection are more than 10 times higher among blacks and 3 times higher among Hispanics than whites (Tables 2-3). Studies have shown that interventions can improve rates of safe sex behavior.⁵⁵⁶ Antiretroviral and prophylactic antibiotic therapy has been conclusively shown to significantly improve survival.⁵⁵⁷ Blacks, Hispanics, women, and persons insured through Medicaid are less likely to receive treatment based on existing guidelines.^{22,311,312,558} Hispanics have lower survival following hospitalization for HIV infection.⁵⁵⁹ Rural residents often have difficulty finding qualified providers.¹⁶¹ Moreover, low education and literacy are associated with lower levels of adherence.²⁶¹

These measures address a key gap in current performance measures and are relevant to persons of all ages, both genders, and rural and urban residents. However, they are

particularly relevant to minorities and low-income persons. Stratification of these measures by race/ethnicity and SES—and possibly by gender—is warranted.

Preparing for the End of Life

There are currently no quality measures for end-of-life care that are in widespread use. However, FACCT has a series of measures under development that rely on both patient reports and surrogate reports that offer considerable promise. They address adequacy of advance planning, pain control, health status, symptom control, and patient-provider communication. Patient preferences for do-not-resuscitate orders differ by race, age, income, and insurance status.⁸³⁻⁸⁶ Although minorities express as much interest as whites in end-of-life discussions,⁸⁴ a number of studies show they are less likely to report their providers engaged in these discussions with them.^{84,560-562} Furthermore, patients who lack English fluency are less likely to be involved in discussions regarding resuscitation.⁸⁵ Whether there are differences in preference based on disability status is not known. This measure is likely to prove relevant to members of all disparity populations. Stratification of these measures by race/ethnicity and SES is warranted.

IV. Challenges to Implementing Quality Measures for Disparity Populations

This section addresses the challenge of effectively implementing existing quality measures for disparity populations. Section V discusses the challenge of developing new measures that target conditions not adequately addressed by existing measures.

There are a number of challenges to effective implementation of existing quality measures that are common to disparity populations. Other challenges are population specific.

Challenges Common to All Disparity Populations

Common challenges to the implementation of existing measures for disparity populations include identification of members of different disparity populations, cost and burden of collecting required data, and development of suitable reporting formats.

Identification of Members of Different Disparity Populations

Key data regarding membership in a disparity population are often missing from hospital, HMO, and office medical records.⁸⁸ HMO and hospital claims data usually include age and gender. Most hospitals collect data regarding race and, in some instances, ethnicity although uniform procedures for data collection have not been established. Neither HMOs nor hospitals collect SES (income, education or occupation), disability, rural/urban residence, or end-of-life data. CMS enrollment data reliably identify whites and blacks, but frequently misclassify other groups.⁵⁶³ Until these data are reliably collected, it is impossible for the hospitals, HMOs, or even CMS to insure comparable quality of care provided for members of disparity populations. These issues are discussed in section V.

Privacy concerns and the potential for misuse of data are also obstacles. Safeguards proposed by the Institute of Medicine could reduce the potential for misuse of data.⁸⁷ Standards for electronic data transmission under the Health Insurance Portability and Accountability Act of 1996 allow health care facilities to include race/ethnicity as a data element.⁸⁸ Similarly, the HHS privacy rule protects the confidentiality of individually identifiable health data used by health care providers using electronic transmission,⁸⁸ but it does not preclude collection of race/ethnicity data.⁸⁸ Annual reporting by hospitals and HMOs of patients served or enrollment/disenrollment patterns by race/ethnicity, SES, or insurance will further minimize the potential for misuse of data. Thus, it is feasible to collect these data while minimizing the potential for breaches in confidentiality or misuse of the data.

Many members of disparity populations fear that data identifying consumers as members of particular disparity populations will be misused.⁵⁶⁴ Such fears among minorities represent the Tuskegee legacy and historical mistrust of “research.”^{565,566} Other groups such as poor, disabled, or rural-residing persons may also share concerns about privacy and misuse of data. These legitimate concerns highlight the need for public education regarding the purpose and use of these data. The advantages of group-specific data must be clear. Appropriate safeguards against abuse must be implemented.

Cost of Data Collection

In addition to privacy concerns, many HMOs mistakenly believe that it is illegal to collect these data.⁸⁸ In fact, there are no Federal and few State prohibitions.⁵⁶⁷ Forty-six States and the District of Columbia place no restrictions on the collection of these data.⁸⁸ The Department of Health and Human Services mandates that race/ethnicity be collected in all HHS sponsored or maintained activities.⁵⁶⁷

The financial and time costs associated with data collection represent another barrier to monitoring care provided to members of disparity populations. Most HMOs collect HEDIS data using a combination of claims data, manual chart reviews, and patient surveys. For HEDIS, claims data are supplemented with review of 411 patient medical records for each quality measure. If an HMO wished to stratify quality results by race, SES, and gender, it would need to review more than 1,000 charts in order to insure a reliable estimate for each subgroup (e.g., low-income, black women, high-SES white, male, etc.). In the absence of demand by members of disparity populations for quality measures, hospitals and HMOs have little incentive to commit the necessary resources to collecting and reporting such data. It currently is not feasible for health care organizations to stratify every measure for every disparity population. Thus, stratification should be supported by research demonstrating that members of the disparity population are at higher risk for adverse outcome and/or suboptimal care. (See section III for a review of this evidence.)

Just as the case for data collection needs to be made to members of disparity populations, the business case needs to be made to the health care industry.⁸⁸ There are several ways that quality measures for disparity-populations make good business sense. As consumers become more aware of good health practices, they are likely to demand more detailed data. Members of disparity populations and purchasers who represent members of various disparity populations are likely to begin questioning the relevance of generic measures of quality.

In addition, employers will want assurance that the health care plan they contract with will provide quality care to their employees. National consumers and purchaser groups recommended in May 2002 to the National Quality Forum that selected, health care quality measures be reported by age, gender, SES, and race/ethnicity.⁵⁶⁸ Included among these groups are: 3M, AFL-CIO, Buyers Health Care Action Group, California HealthCare Foundation, The Employer Health Care Alliance Cooperative, General Motors Corporation, The Leapfrog Group, Midwest Business Group on Health, Motorola, Inc, National Business Coalition on Health, National Health Care Purchasing Institute, National Partnership for Women and Families, Pacific Business Group on Health, and the Washington Business Group on Health. These groups may begin to gravitate towards plans that can provide that information. Plans that have been slow to implement these measures may lose market share. Jack Rowe, the Chairman and CEO of Aetna, the Nation's largest provider of health care and group benefits, suggests that it makes good business sense for Aetna to address disparities given the diversity of the work force of insurance purchasers.⁵⁶⁹

Furthermore, the costs of implementing these measures may ultimately be offset by lower costs of health care. Many disparity populations are at greater risk for incurring expenses related to avoidable hospitalizations. Improvement in their care is likely to reap

greater savings than improvement in the care of healthier populations. For example, implementation of a campaign designed to improve rates of influenza immunization among older, inner-city African Americans would likely reduce rates of unnecessary hospitalization much more than a campaign targeted to suburban whites.

Development of Suitable Reporting Formats

Simply collecting and reporting timely data is not enough. Careful consideration must be given to how results are reported. As quality reports become longer and increasingly complex, there is a growing risk that the reports will be ignored by consumers. There is mixed evidence that consumers use quality reports to make informed decisions regarding selection of health care plans or hospitals.⁵⁷⁰ The addition of new quality measures and stratification by subgroups will certainly complicate the challenge of making reports consumer friendly. These challenges can be addressed. Quality reports can be tailored to different groups based on audience testing and focus groups. Health care organizations can generate different quality reports for different audiences. Reports can differ in language, reading levels, complexity, detail, focus, and format. In addition, Web-based technology can be used to produce query systems for consumers that address questions regarding performance for specific groups.

Population-Specific Challenges

Racial and Ethnic Minorities

Effectively implementing existing quality measures for the purpose of monitoring care to racial and ethnic minorities is a complex and challenging task.⁸⁸ These include challenges related to the conceptualization of reporting, logistical challenges related to data collection and reporting, and the absence of validated measures related to conditions relevant to minorities. Preliminary data show that many of these barriers can be addressed.⁵⁷¹

Conceptual Challenges

Benchmark-based vs. relative performance. A key conceptual challenge is whether to focus primarily on benchmark-based performance or relative performance. Should quality of care for minorities be primarily assessed using a national benchmark such as a particular Healthy People 2010 objective or an NCQA benchmark, or should quality of care assessment for minorities be based primarily on the black-white gap in care? Which is more relevant: the overall mammography rate for black women relative to a national benchmark or the rate relative to white women? Both benchmarks and relative standards convey different, but nonetheless important, information to health care consumers. However, benchmark-based standards offer two key advantages:

- First, consumers are likely to be more concerned with overall performance for their group rather than performance for their group relative to another, particularly when performance for the other group is also substandard. In many instances the performance for whites does not meet benchmarks.²

- Second, absolute standards are much more feasible to implement because they require relatively smaller samples. Benchmark-based measures can be readily implemented by replicating HEDIS sampling methodology for each minority group. HMOs using the increasingly popular hybrid approach could sample 411 patient medical records for each of the main racial or ethnic groups comprising plan membership. HMOs can then assess performance based on a single national benchmark.

In contrast, unfeasibly large sample sizes are required to reliably compare *disparities in rates* between health care plans. Chart reviews become prohibitively expensive; HMOs would be forced to rely exclusively on claims data to monitor quality. 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 screening for mammography or cholesterol or childhood or adult immunizations. In other instances, a physician may write the appropriate prescription, but the patient may fail to fill it. In the absence of an electronic medical record and/or electronic pharmacy records, manual chart reviews are required to assess whether a particular medication was or was not prescribed and/or filled.

Given these constraints, benchmark-based standards are a more feasible way for providing consumers with information and for quality assurance reporting. Relative standards are most appropriately used internally for quality improvement. Use of a benchmark approach suggests that performance reports include a brief description of the measures, an overall benchmark, and performance rates stratified by each group. The report should indicate whether the performance for different racial and ethnic groups was statistically different from the benchmark. In that way, consumers could determine which health care organizations provided better care to members of their own racial or ethnic group. Hospitals and HMOs interested in closing their racial or ethnic gap in performance could use their own internal quality improvement efforts to examine reasons for performance gaps and develop interventions designed to eliminate these gaps.

Reporting effects of race/ethnicity and SES. A second conceptual challenge is how to sort out and report both race/ethnicity and SES effects. Patient educational level and income are both strongly linked to race. They are also both powerful predictors of receipt of preventive care. An HMO that provides care to largely affluent minority members would likely have higher rates of preventive care than one providing care to poor minority members. Existing studies suggest that SES affects provider⁵⁷² and HEDIS profiles for some HMOs⁴²⁷ although the overall effect may be modest.^{427,538}

There are two ways that performance reports for minorities can take SES into account. The first is to statistically adjust ratings. This approach has the advantage of generating a single, adjusted rate. However, it risks masking poor performance for low-SES members.^{546,573} A preferable approach is to stratify or report performance separately for each SES level. Thus, a report would include performance for high-income whites, blacks, Hispanics etc, and performance for low-income groups.

Distinguishing majority overuse vs. minority underuse. A third challenge is to distinguish health care overuse by majorities from underuse by minorities and less

commonly, to distinguish the reverse. This is less problematic for HEDIS effectiveness, FACCT, HCQIP, or ORYX measures. Most of these measures focus on clearly defined health care processes in which optimal performance is 100 percent. It is a major problem for monitoring disparities in access to services, particularly access to cardiovascular, cancer, and transplantation procedures. The recent IOM report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*³ showed that evidence for bias was strongest for these procedures.³

It is difficult, if not impossible, to determine the appropriateness of particular procedures in the absence of expert review. The time and costs required for an expert panel to review the appropriateness of procedures performed at every hospital nationally would be prohibitive. Nonetheless, a measure for disparity in the use of a major procedure that has been appropriately adjusted or corrected for differences in patient morbidity might be useful in signaling a quality problem even if it cannot distinguish underuse from overuse. Several promising access/utilization measures have been discussed in previous sections.

Selection of reporting categories. A final conceptual challenge involves the selection of racial and ethnic categories. Should reporting be limited to the four major minority groups or should additional subgroups be included? Should reporting include a multiracial or multiethnic category? Should health care plans that have few members from a minority group such as American Indians/Alaska Natives be required to report on their quality despite the inability of the plans to generate reliable estimates because of small samples? These important questions need to be resolved by the NQF and other quality organizations in consultation with representatives from these groups.

Feasibility Challenges

One of the most serious feasibility issues related to implementing racial and ethnic disparities measures pertains to the collection of race/ethnicity data. Although most hospitals collect race data, few have implemented uniform, reliable methods for doing so. Fewer hospitals collect ethnicity data. However, hospitals can begin using available data and stratifying their existing performance measures by race. Hospitals can include race and ethnicity questions in existing satisfaction surveys. Hospitals that have not yet implemented collection of ethnicity data can use software that codes Spanish surnames as an interim solution.⁵⁷¹ 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, this approach is likely to be limited by timeliness of the reports.

Absence of race and ethnicity data is a bigger barrier for HMOs than for hospitals. Very few HMOs collect 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. Typically, prospective plan members provide data regarding their age, gender, and names of family members. The race and ethnicity of prospective members and family could be included. Socioeconomic data, such as educational level, might also be obtained at this time.

A second approach is to obtain these data from employers (when data are available). This would likely require consent from members at the time of their enrollment. Both these approaches require changes in the enrollment process. A third 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 office visit and then submit these data with their claims (or separately under capitation). The primary limitation of this approach is that implementing uniform standards for collecting these data in physicians' offices across the country will be very difficult. Receptionists and registration clerks may be uncomfortable asking consumers to self-identify their race/ethnicity and may instead infer this information based on the patient's appearance. Data will not be available for members who have not yet registered a visit.

Other approaches such as use of geocoding to classify race/ethnicity based on community of residence offers promise,⁵⁷⁴ but may misclassify some plan members; 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 collection of race and ethnicity on enrollment is likely to prove to be the more reliable and valid although further research in this area is needed. When race and ethnicity data are collected, it will be critical to insure that health care organizations report enrollment/disenrollment patterns to payers and accreditors in order to minimize the risk of discrimination based on use of these data.

Persons With Low Income

Most of the issues that are relevant to quality measures for minorities are also relevant to low-SES persons. The primary challenges involve:

- Choice of SES measure.
- Procedure for data collection necessary to obtain SES-relevant data.

There is no consensus on the single best SES measure.^{575,576} Questions about personal or household income are highly sensitive. Respondents with very low income often overreport their income while respondents with very high income frequently underreport their incomes in response to surveys. Many respondents simply refuse to answer. Furthermore, individual income is less relevant than household income; a nonworking person supported by the income of the working partner should not be classified as having no income. Children and other dependents frequently do not know the income of their parents. Finally, the relative value of a particular income differs between communities depending on the cost of living. Despite these caveats, income serves as a useful proxy for ability to afford health care. Higher income is associated with receipt of health that requires appreciable out-of-pocket expenditures. Wealth is probably a more relevant measure of affordability and access to expensive, but uncovered, care than income; but personal wealth is even less reliably reported than income.

Questions about occupation are less sensitive than income. However, it is not clear whether occupational categories should be ranked on the basis of status, salary, level of authority/autonomy, or educational requirements. How persons who are unemployed, homemakers, or retired should be classified is also unclear.

Questions about educational level are less sensitive than those about family income. Education is probably a marker for literacy and knowledge, which in turn are associated with adherence. Education may be more strongly related than income to receipt of covered services such as preventive care. Unlike income, education tends to change little after early adulthood. Although educational level is a less appropriate measure of a

person's ability to afford health care, education may be a more salient predictor of health care quality among persons with health care insurance. On balance, education may be the least intrusive and most reliable way to assess SES for the purposes of monitoring health care quality.⁵⁷⁶

Because Medicaid eligibility is based on percent of Federal poverty level based on household income and family size, it represents a crude measure of SES. However, its use confounds insurance type with poverty. Furthermore, Medicaid eligibility requirements differ between States. Use of the presence of supplemental insurance among Medicare recipients (as a marker for higher SES) has similar limitations.

Geocoding of patient addresses to median income according to census block group, census tract, or ZIP Code represents the least invasive method for estimating SES. Address is a proxy for patient SES because persons of similar SES tend to live in the same areas. This approach avoids the need to ask people about their income or educational level. Although the median income of a community is by no means equivalent to household income, community of residence captures other contextual information that may affect health care access such as proximity to physician offices, rates of crime and pollution, and local neighborhood culture.⁵⁷⁷ Use of geocoded addresses represents a relatively straightforward and inexpensive means for hospitals and HMOs to assess socioeconomic status of the patients they serve.⁵⁷⁷

Children

Widespread implementation of children's quality measures lags behind those for adults. Fortunately, age is readily available through claims and administrative data. No additional data collection procedures are needed to identify children in different age groups. Measures for asthma, pneumonia, and smoking should be reported separately for children. The development of child CAHPS®, YAHC, and CSHCN measures represent significant advances in the measurement of quality care provided to children. It is likely that these measures will be increasingly implemented. The primary challenge for assessing quality of care for children relates to need for new measures, as discussed in section V.

Women

The primary challenge related to implementation of measures for women is determining which if any of the existing measures warrant separate reporting by gender. Gender is routinely available in most claims data; the primary limitations of gender-specific reporting are the need for increased sample size and greater complexity of gender-specific quality reports. As discussed in previous sections, there are disparities in some of the quality measures of care for heart disease and organ transplantation. Consideration should be given to stratifying these particular measures by gender.

Elderly

Most of the existing adult measures are relevant to the elderly. It is not clear that additional stratification by older age is needed, although age is readily available in administrative and claims data. A more important need is the development of new

measures that specifically target elderly who are living with multiple chronic diseases. These measures are discussed in detail in section V.

Rural and Urban Residents

Many existing measures are relevant to both rural and urban residents. However, currently there are limited data to support quality reporting by rural/urban/suburban residence. Most of the differences in quality by residence are explained by differences in SES and/or race/ethnicity. Barriers to implementing such reporting include problems in appropriately defining rural health service areas, accounting for rural population preferences, and the relatively low priority of formal quality-of-care assessment in health care shortage areas.³²⁸ Furthermore, most rural-urban comparisons of quality have focused on management of specific conditions and have ignored functioning of the entire system of rural health care.⁵⁷⁸ Notwithstanding these caveats, most hospitals and HMOs have the potential to create measures of rurality using patient addresses and then stratifying existing measures to determine whether there are any disparities. Questions regarding distance/time traveled could be added to CAHPS® surveys to assess potential access barriers related to geography.

Persons With Disabilities and Chronic Illness

A key challenge to assessing health care quality for persons with disabilities is the identification of persons with different types of disabilities. There is currently no reliable way for doing so using hospital or HMO claims data.³⁷¹ One approach is to add questions to CAHPS® such as the presence and type of disabilities. The major limitation to this approach is that the sampling size of CAHPS® would have to be enormously increased in order to generate reliable estimates for different types of disability. As suggested previously, this problem might be addressed through use of screening questions administered by phone or mail. Preliminary pilot data suggest this approach is feasible for adults.⁵⁷⁹

Insufficient sample sizes might be addressed by aggregating persons with differing disabilities. However, the health care needs and access barriers differ by disability status. For example, the needs (and barriers) of post-stroke patients differ markedly from those of a healthy deaf person. Another possible approach is to aggregate surveys across years and/or across plans. For example, NCQA, CMS, or States could aggregate, analyze, and report CAHPS® data (that included identification of specific disability status) collected from member plans. Another option is to query persons upon enrollment or registration. If this were done, steps would need to be taken to insure that HMOs didn't discourage enrollment or encourage disenrollment of disabled persons. A final possibility relevant to publicly sponsored insurance is to use data regarding categorical eligibility for Medicaid such as Supplemental Security Income or eligibility for Medicare through Social Security Disability Insurance to identify disabled persons.³⁷¹ However, this approach does not allow identification of the specific disability. Moreover, many persons with disabilities as defined by the Americans with Disability Act do not qualify for either program.

In contrast to disabled persons, persons with chronic illness can be readily identified using medical claims data. Many existing measures address health care for chronic illnesses. This area is likely to rapidly expand as research links health care process to

outcome. Measure development for this population is likely to continue to progress in concert with research on the effectiveness of various interventions for different chronic illnesses.

There is a pressing need for the development of reliable, user friendly quality measures for mental health⁵⁸⁰ and substance abuse.⁵⁸¹ The need is particularly acute for quality mental health measures for children and the elderly.⁵⁸⁰

Persons Near the End of Life

Quality measures for end-of-life care are not widely used. Assessment of health care quality for this population poses unique challenges based on the context in which people die. Dying represents a final common pathway for multiple diseases and causes. Morrison et al. enumerate five key challenges:³⁷⁵

1. Identifying persons who are very close to the end of life is itself challenging. With the exception of certain cancers, it is difficult to accurately predict life expectancy among terminal patients.
2. Patients die in many different settings including hospitals, home, long-term care facilities, and hospices. Care provided differs between settings. What organization should be the primary target for assessment: Hospitals? HMOs? Nursing homes?
3. When or where the quality assessment should take place is not clear. With the exception of certain forms of cancer, predictive models for life expectancy perform poorly.
4. Administrative data are of limited benefit in assessing the quality of care provided near the end of life.⁵⁸² Because of the highly personal and often emotionally demanding process of dying, it is difficult to ask patients or their families to complete surveys during the end-of-life period. Retrospective reports from families may be biased by circumstances unrelated to the health care provided. Medical records often do not adequately reflect the end-of-life care provided.
5. Quality measures should be evidence-based. Many of the 10 domains of quality for end-of-life care are not yet ripe for quality measure development. The measures proposed by FACCT that focus on several potentially improvable outcomes offer promise.³⁷⁵ However, further research is required to establish their validity, reliability, and effect on outcomes.

V. Gaps in Existing Quality Measures

Generic Gaps

The previous sections address the suitability of existing quality measures for members of disparity populations. However, an evaluation of existing measures does not address the question as to what *new* measures are needed for each population. This determination is time consuming and costly. It requires a systematic assessment of priority conditions for a given population followed by identification of established interventions and treatment guidelines. Established interventions that are not widely implemented for the population should be given priority. Scientifically sound measures must be developed to assess performance. Measures must meet scientifically established standards for reliability and reproducibility. They must be valid. They must assess what they purport to assess and be relatively free from confounding by other factors to allow for fair comparisons. Data collection procedures must be feasible and cost-effective to implement. Finally, dissemination plans are needed that include preparation and distribution of quality reports specifically tailored to the needs of the relevant population. Each of these steps is necessary to insure successful development of new measures.

Although a full review of the question of which new measures are needed is beyond the scope of this report, there are several key points that should be made. First, there are conditions that are not adequately addressed by current quality measures for *any* population. For example, medical errors result in thousands of needless deaths per year.⁹⁰ Yet, few quality measures address medical safety issues. Many, if not most medical errors involve issues surrounding communication. Examples include inadequate communication between provider and patients; between family, physicians and nurses; or between primary care physicians and specialist consultants, or physicians and pharmacists. Each of these is relevant to disparity populations, particularly persons with chronic disease or disabilities or elderly who are more likely to have multiple, complex problems that require ongoing care provided by teams of professionals.

Another major safety issue that is not addressed by existing quality measures involves medication prescriptions. Examples include inappropriate use of antibiotics, selection of the wrong medication or dose, failure to adequately assess contraindications including allergies and serious drug interactions, and illegible handwriting. Again, these errors are likely to disproportionately affect disparity populations who require more multiple, chronic medications.

There are relatively few quality measures in the domains of mental health and very few that address management of drug abuse or use of ancillary services such pharmacy, dietary counseling, and physical/occupation therapy. The following paragraphs review key conditions relevant to each disparity population for which quality measures are lacking and discuss the state-of-the-art in measure development in these areas.

Development of New Measures

Many of the steps necessary for the development of measures for different populations overlap with the steps required to develop measures for the general population. There are, however, important differences. First, development of new measures begins with an assessment of the impact of a particular condition on that

population. The impact of different conditions differs between populations. Research is needed to identify priority conditions for each disparity population based on the impact of the particular condition on years of healthy life within that population. Conditions with high impact affect large numbers of the population and result in early death or disability, pain, and high costs.

Even when the effectiveness of interventions has been established, there is often a delay of several years before findings are incorporated into national guidelines; development of quality indicators should follow, not precede, establishment of practice guidelines. AHRQ's support of Evidence-based Practice Centers (EPCs) directly addresses this need; the EPCs undertake systematic literature reviews in order to develop evidence reports that provide a foundation which both public and private entities may use to develop and implement their own practice guidelines, performance measures, review criteria, and other quality improvement tools. Recently, AHRQ has partnered with ePocrates, Inc. to disseminate findings from the U.S. Preventive Services Task Force to physicians using personal digital assistants (PDAs). Once evidence-based guidelines have been established and disseminated, then reliable, valid measures need to be developed. Development of measures requires time, funding, and a cadre of well-trained researchers. AHRQ is a major source of funding for this research.

When a quality measure is derived from survey findings, it is critical that the survey instrument be adequately validated for each of the disparity populations. Members of different groups may interpret questions differently, rendering comparisons between groups meaningless. It is critical to obtain an adequate response rate. Failure to do so introduces the possibility of biased results. For example, if less satisfied minorities are less likely to respond to a satisfaction survey than dissatisfied whites, findings will underestimate the level of dissatisfaction among minorities.

Racial and Ethnic Minorities

In a report to the National Quality Forum, Nerenz reviewed candidate quality measures that address aspects of health care targeting priority conditions for minorities.⁸⁹ Other priority conditions include preterm birth, group B streptococcus colonization during pregnancy, neonatal care, chronic renal failure, management of hepatitis C, management of uterine fibroids, asthma, maternal/child care, pain management, HIV/AIDS, low back pain, sickle cell anemia, mental health, end-of-life issues, and cultural competency. Although existing measures target some of these conditions, most of these conditions are not adequately assessed. For example, HEDIS measures address breast and cervical cancer but do not adequately address followup on abnormal screening results even though there are significant racial/ethnic disparities in followup for these conditions.

Most of these candidate measures are also appropriate for the general population. Some are likely to be incorporated into existing measure sets. In other instances, there are as yet no established interventions. Examples of conditions/areas potentially ripe for quality measures include HIV/AIDS, sickle cell anemia, pain management, group B streptococcal prophylaxis during pregnancy, and possibly cultural competency.

Quality measures related to prevention and treatment of *HIV infection* are urgently needed. Given the devastating impact of HIV on minorities and the dramatic impact of appropriate HIV treatment on survival, priority should be given to implementing quality

measures for HIV care. The measures under development by FACCT show promise. The New York State AIDS Institute has clearly shown that quality of HIV care can be feasibly evaluated statewide.⁵⁸³

Sickle cell disease is one of the 10 leading causes of death for African Americans under the age of 25.¹³ Americans of non-African ancestry are rarely affected. Mortality for sickle cell disease varies dramatically between regions of the country, suggesting variation in care.⁵⁸⁴ Hospitalization costs are considerable.⁵⁸⁵ 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,⁵⁸⁶ and specific interventions such as prophylactic penicillin have been shown to reduce mortality.⁵⁸⁷ Quality measures related to screening/counseling and/or management of this condition are 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 25,¹³ and rates of acute trauma requiring emergency attention are considerably higher among blacks, Hispanics, and Native Americans.^{588,589} As discussed earlier, blacks have significantly higher rates of death from cancer, and rates of death from certain cancers are higher among Hispanics, Asians/Pacific Islanders, and American Indians/Alaska Natives. African Americans, and Hispanics have been reported to receive less appropriate analgesia for metastatic cancer^{30,36,590} and trauma.^{37,591} Although HEDIS has not yet introduced pain management measures, JCAHO has established a comprehensive set of standards for pain management. Public reporting of adequacy of pain control by race, ethnicity, and income would help to ensure equity in this critical area.

Group B streptococcus is the most frequent cause of neonatal sepsis in the United States. Rates of maternal colonization, neonatal disease, and mortality are significantly higher among blacks.^{154,592,593} Introduction of intrapartum antibiotics has dramatically reduced rates of infection and mortality among blacks and whites, but disparities remain.⁵⁹⁴ Controversy regarding the choice of protocol for screening and treatment of maternal colonization has slowed development of quality measures. Nonetheless, quality measures related to screening and treatment of group B streptococcus during pregnancy or pre-partum appears appropriate.

There is growing recognition among policymakers and health care organization that simply providing technically proficient care is not sufficient. Health care should be *culturally sensitive*. Providers should be sensitive to differences in patients' beliefs, attitudes, customs, and styles of communication that are related to culture. Although it is not realistic to expect physicians and other health care providers to be fluent in the culture of every patient they see, it is reasonable to expect that they will be sensitive to potential differences and respectfully ask patients about their beliefs and preferences. Cultural competence also suggests that health care teams will include staff who are representative of the population they serve. The U.S. Department of Health and Human Services has published standards for culturally and linguistically appropriate services. Examples of these standards are as follows:

“Health care organizations should insure that patient/consumers receive from all staff members effective, understandable, and respectful care that is provided in a manner compatible with their cultural beliefs, practices and preferred language.” “Health care organizations must offer and provide language assistance services including bilingual staff and interpreter services at no cost to each patient/consumer...” “... and must provide patients/consumers in their preferred language both verbal and written notices informing them of their right to receive language assistance services.”⁵⁹⁵

Quality measures could be developed based upon these standards particularly for interventions that are evidence-based, such as use of trained translators^{596,597} and active involvement of patients in decisionmaking.²⁰³

Persons With Low Income

As discussed in section I, persons with low income often experience chronic diseases at younger ages and frequently die earlier than more affluent persons. Conditions that affect the general population affect low-income persons earlier in life. Among the few conditions strongly associated with poverty are tuberculosis, sexually transmitted diseases, and certain occupationally related injuries. Some of these conditions are addressed by existing measures. In other instances, such as tuberculosis, the overall impact on general population health is relatively modest because of the relatively low prevalence of active tuberculosis in the United States. Similarly, behavioral risk factors such as smoking, consumption of a high-caloric and high-fat diet, lack of exercise, and unsafe sexual activity that plague the general population are more prevalent among persons with low income. Many of these risk factors are addressed by current measures, particularly among adolescents when many of these behavioral patterns begin.

The most critical gaps in quality assessment for persons with low income relate to various measures of access to care. The most obvious example is *affordability*. Many persons with low income, even those with health insurance, are often unable to afford needed prescriptions and other health care. Questions about affordability could be easily added to CAHPS®. This would allow health plans (and employers) to evaluate the impact of changes in premiums, deductibles, and copayments on the ability of persons with low income to access care.

Health care literacy represents another critical access barrier for low-income persons. Many persons lack the reading ability, knowledge, and skills to effectively navigate the health care system. Many low-income persons leave their physicians' office confused about instructions or the risks and benefits of a particular intervention. Several instruments such as the Test of Functional Health Literacy in Adults (TOFHLA) and the Rapid Estimate of Adult Literacy in Medicine (REALM) test are available to assess a patient's health literacy. Use of these instruments can help health plans and hospitals to tailor communication media to their population. Quality measures that assess the adequacy of health care communication—particularly that provided to low-income persons at risk for low literacy—are needed. Brief instruments, perhaps conducted by office staff in person, could be used to assess a patient's understanding following office visits. JCAHO requires that hospitals and other health care organizations use written materials at appropriate literacy levels. Rates of compliance with this requirement should be publicly reported.

Children

AHRQ, in conjunction with the David and Lucile Packard Foundation, Commonwealth Fund, W.T. Grant Foundation, and American Board of Pediatrics co-funded a conference in February 2002 entitled “Quality Measures for Children’s Health Care: Assessing the State of the Science and Practice—A Strategy Development Meeting.” Other sponsors included the Center for Health Care Strategies, CMS, CDC, and HRSA. Participants were asked to rank the top three priorities for the field of quality measures for children’s health from both an organizational/personal perspective and national perspective. The top three priorities of participants were the same for both perspectives. These were:

1. Improvements in methodology of measures (reliability, validity, and feasibility).
2. Creation of an informatics infrastructure, such as use of electronic medical records and other electronic means for data collection..
3. Building public support for quality measurement and improvement.

Users, funders, physicians, and providers/plans differed in their rankings of various factors.

At the conference, Beal and colleagues presented their comprehensive review of the state of the science of quality measures for children's health care.²⁹² The report noted that no single instrument could be used to assess health care quality for children and that the level of validity and reliability testing varied widely between instruments. The report further noted that there are few child health quality measures that reflect health care safety, living with illness, and end-of-life care or that reflect age-specific care. The report specifically recommended the development of quality measures for newborn care, intensive care, and trauma care and the development of consumer surveys in languages other than English.

The challenges of assessing health care quality for children with disabilities have been recently highlighted.⁹² As Perrin notes, there is insufficient knowledge regarding standard interventions such as speech therapy for language delay, chest physiotherapy for various pulmonary conditions including cystic fibrosis, and treatment for specific mental health problems.⁹² In addition, there are few reliable measures of outcomes or health functioning. As with health care in general, there are no validated pediatric safety measures. For example, there are no measures that reliably assess provider-patient/parent communication, provider-provider communication, or medication-related errors.

The literature on pediatric quality improvement is less developed than the adult literature.⁵⁹⁸ Successful initiatives include reminder systems for office-based practices and inpatient clinical pathways.⁵⁹⁸ Absence of performance standards, reliable measures, and difficulties in changing physician practice patterns are barriers to quality improvement.

Women

Most of the existing measures address health conditions relevant to women although important gaps remain. In particular, measures are needed to assess the quality of care for gender-specific conditions, particularly *reproductive health*. Reliable, validated, evidence-based measures are needed for care related to pregnancy, labor, delivery, and post-partum complications, family planning, fertility, fibroids, irregular or heavy

bleeding, gynecological cancer, and menopause. Most of the generic challenges previously discussed are applicable to developing of new quality measures for women.

Further research is needed to establish evidence-based guidelines regarding Cesarean deliveries, hysterectomy for fibroids, and use of hormonal replacement therapy. More research is needed to determine whether women value certain aspects of health care delivery differently than men. Research is also needed to identify or develop tools designed to insure effective implementation of these guidelines. Only then may it be appropriate to focus efforts on the development of measures that target these areas. Research is also needed to generate reproducible measures in these key areas and develop feasible ways of implementing new measures. AHRQ is currently supporting research in each of these areas.

In recognition of the need for new measures for women's health, NCQA appointed a Women's Health Measurement Advisory Panel in 1997 charged with identifying, prioritizing, and stimulating the development of quality indicators in key areas related to women's health.⁶⁴ The top conditions included cardiovascular disease, unintended pregnancy, osteoporosis, breast cancer, mental health, violence, lung cancer, cervical cancer, and obesity/eating disorders. Following a comprehensive review, the following indicators were found to satisfy most of the selection criteria: preventive counseling on options for management of menopause, counseling to prevent unintended pregnancy, and *Chlamydia trachomatis* screening (which has since been incorporated). Additional conditions/procedures meriting quality measures for women include menstrual disorders, contraception, childbirth, and pregnancy termination, and osteoporosis. Further research is needed to develop valid, reliable, and feasible measures to assess care for the other priority conditions.

Elderly

Although many existing measures address conditions relevant to the elderly, many gaps remain. These gaps include many of the issues discussed under persons with disabilities and chronic disease in addition to access to expensive prescriptions, coordination of care, and communication problems.

Many of these gaps in quality assessment for the elderly are addressed in the Assessing Care of Vulnerable Elders (ACOVE) project. This project developed a comprehensive set of evidence-based, quality assessment tools for ill, community-dwelling persons 65 years of age and older.⁹³ These include 236 measures comprising 22 topic areas: continuity and coordination of care, dementia, depression, diabetes, end-of-life care, falls, hearing loss, heart failure, hospital care, hypertension, ischemic heart disease, malnutrition, medication use, osteoarthritis, osteoporosis, pain management, pneumonia, pressure ulcers, preventive care, strokes and atrial fibrillation, urinary incontinence, and vision care. These represent the most comprehensive measures for this population that have been developed to date and include many areas that are not addressed by current measures.

The major limitations of this measure set include the large number of measures and the fact that some of them have not been as rigorously evaluated as others. Specifically, some of the measures do not fully satisfy the standard criteria of significance, scientific soundness, and feasibility. Definitive evidence regarding the effectiveness of many of the interventions targeted by the measures is lacking. In many instances, the validity and

reliability of these measures has not been conclusively established. Furthermore, the measures are too numerous to implement on a wide scale. Research is needed to determine which of these measures are most relevant for which health care organizations, to assess the cost and burden associated with data collection, and to develop appropriate reporting formats. For these reasons, this measure set is likely to be used in selective instances to evaluate specific projects. Selected measures from ACOVE will likely be adopted by NCQA, JCAHO, FACCT, CMS, and other quality organizations over time.

Research is also needed to develop evidence-based, reliable measures designed to assess the quality of health care provided to elderly persons in long-term care.⁹⁴ The Resident Assessment Instrument (RAI) derived from the Minimum Data Set is the most widely used measure of quality.⁵⁹⁹ However, this instrument may not distinguish nursing homes that provide good quality care from those that provide poor quality care.⁶⁰⁰ Moreover, outcome measures for nursing home quality are plagued by inadequate risk adjustment^{601,602} as well as by many factors other than medical care that may affect outcomes in this population, including nursing care and recreational, environmental, and dietary services. Clearly, there is need for further research regarding these key issues.

Rural and Urban Residents

The major gaps in quality measurement for rural and urban residents relate to access to primary, specialty, and tertiary care. Many rural and inner-city communities are often resource depleted and many qualify for designation as Health Manpower Shortage Areas because of the difficulties of recruiting and retaining physicians and other health professionals. Quality measures are needed to assess rural residents' travel time to various sources of health care and to assess continuity of care for inner-city residents with the same provider. Measures are also needed to determine whether health care providers working in rural and urban settings have access to adequate resources including information technology, specialty consultation and referral, and expensive hospital technology.⁶⁰³

Persons With Disabilities and Chronic Illness

Currently, there are no quality measures in use that specifically address the quality of care provided to adults with disabilities. The CSHCN measures represent a significant advance in assessment of health care quality to children. The strength of the CSHCN measure set lies in its assessment of generic aspects of care to disabled children. It does not assess the quality of specific processes of care for children with specific conditions. Measures are needed that assess the quality of care provided to children with developmental disabilities and to those with chronic illnesses and/or developmental disabilities. Examples include congenital heart disease, type I diabetes, cystic fibrosis, chronic renal failure, cerebral palsy, and cancer, among many others. Global measures similar to the CSHCN ones are needed for adults in order to assess such critical issues as access to primary and specialty care, coordination of care, and access to needed medications, supplies, and equipment.

Existing measures of health status such as the SF-36 may not adequately capture the aspects of health status that are most relevant to persons with disabilities.⁹⁵ It includes questions that are inappropriate for wheelchair-confined persons and may have floor effects for physical function.⁶⁰⁴ Furthermore, persons with disabilities clearly distinguish

between quality of life and health status.⁶⁰⁵ Little is known regarding which quality measures are most relevant to persons with particular disabilities or the impact that different disabilities have on accessing health care. Furthermore, there are relatively few proven interventions that are specific to persons with disabilities.⁹⁵ Research in this area is clearly warranted. Last, research is needed to determine where the largest gaps in quality exist for consumers with different disabilities and to develop measures to assess performance in these areas.

Dejong and colleagues have recommended additional changes in quality measures for disabled persons.³⁵⁵ First, improvements in existing consumer surveys such as CAHPS® are needed. Questions regarding health plan coverage of durable medical equipment, off-formulary prescriptions, and urgent access to needed specialty care are needed. Second, improvements in the structure, modality, and administration of survey questions are needed. Persons with low literacy or cognitive impairments may have difficulty understanding mailed surveys. Telephone-administered surveys can be problematic for persons with speech or hearing impairments. Further research is needed to determine the major health care needs of persons with particular disabilities and to establish effective interventions and practice guidelines. Only then can valid, reliable, feasible quality measures be developed.

Many of the current quality measures under development address management of chronic illness in adults and, in some cases, children. Existing measures address hypertension, lipid disorders, diabetes, asthma, depression, coronary artery disease, congestive heart failure, and breast cancer. However, many of the older measures focus on health care process such as whether a hemoglobin A1C was ordered for a diabetic or whether an ACEI was prescribed for a patient with impaired left ventricular dysfunction. Second generation measures focus more on outcomes such as proportion of patients with adequate control of their diabetes, hypertension, or cholesterol or improvements in functional outcomes.⁹⁶ However, use of these measures requires careful attention to exclusions and risk adjustment.⁹⁶ Common adult conditions not (or minimally) addressed by currently used measures include management of various types of arthritis, low back pain, primary care of the cancer patient, liver disease including hepatitis C, chronic obstructive pulmonary disease, anxiety disorders, and renal insufficiency.

Persons Near the End of Life

The identification of key measures for this population presents unique challenges because the goal of care is qualitatively different. Currently, there are no widely used quality measures for this population; the measure set under development by FACCT represents a quantum advance. Measures are also needed to determine the extent to which care is meeting the social, psychological, and spiritual needs of the dying patient and his or her family. Further study is needed to determine the impact of inpatient versus home hospice care on families and the effect of quality measures on relevant outcomes.

Research and Development

Research is needed to ensure appropriate implementation of existing measures for disparity populations and to develop new measures. AHRQ is sponsoring much of this research. Research is needed to determine the most cost-effective and least intrusive

means for identifying members of disparity populations, for obtaining data on quality of care, and for preparing and disseminating reports. Research is also needed for each of the phases in the development of new measures. Established interventions that target a priority condition for a particular population must be identified or developed. Treatment guidelines must be promulgated. In many instances, absence of established interventions impedes progress. Examples include prematurity in African Americans and prevention of Alzheimer's disease in the elderly. Rates of extreme preterm birth are nearly 4 times higher among blacks than whites and represent the largest contributor to racial disparities in infant mortality.⁶⁰⁶ Severe prematurity is often associated with lifelong health impairments.⁶⁰⁷ Unfortunately, there are few interventions that have been shown to prevent preterm birth. The most promising interventions involve screening and treatment of bacterial vaginosis during pregnancy; but to date, data are mixed regarding its effectiveness.⁶⁰⁸ Alzheimer's disease has a devastating impact on affected individuals and families. The economic costs of long-term care for this disease are enormous. Yet, current medical treatments yield only modest improvements, and no preventive interventions have been developed.⁶⁰⁹

Translational research is also needed to develop evidence-based practice guidelines and to find ways to effectively implement these guidelines in practice. Research is needed to develop, pilot, and validate reliable quality measures to fill gaps in existing measures. Last, research is needed to assess the impact of implementation of these measures on provider and consumer behavior, costs, and improvements in health outcomes.

VI. Summary and Conclusions

This report has shown why quality measures are needed to monitor the quality of care provided to disparity populations. Many members of disparity populations face the double jeopardy of higher risk for morbidity/mortality coupled with higher risk for inferior care. This risk is further compounded by the intersection between disparity populations. A disabled, low-income, black, elderly, female, rural resident represents six different disparity populations.

The reasons for disparities in health and health care among different populations are multiple. They include patient-level factors such as ability to afford care, health care literacy, and culture; physician-level factors such as bias, competing demands, and time pressure; plan-level factors such as cost-containment policies and practice guidelines; and sociological factors including racism, community poverty, and diffusion of information patterns. Regardless of the cause, quality of care cannot be improved if it is not measured.

To ensure that members of disparity populations receive appropriate state-of-the-art health care, two types of quality measures are needed. First, existing quality measures should be stratified or reported separately for a disparity population when there is evidence of disparate impact of the health condition targeted by the quality measure. Second, existing quality measures should be supplemented with measures that assess conditions/interventions likely to have a significant impact on the disparity population.

Review of quality measures currently in use shows that many are relevant to disparity populations:

- All the existing measures are relevant to racial and ethnic minorities. However, none is currently reported separately by race or ethnicity although the National Quality Forum has recently endorsed this critical step. Population-specific reporting represents a central challenge to current quality assessment. In the absence of measurement, the core dimension of equity cannot be assured. Additional measures relevant to racial and ethnic minorities are needed, particularly for access to expensive technology, prevention and treatment of HIV/AIDS, and cultural competency among others.
- Most existing measures are also relevant to persons with low income; separate reporting for this population is also needed. Measures of health care affordability and adequacy of communication would be particularly salient for persons with low income.
- Quality measurement for children lags behind adults, but significant progress has been made in the past few years. Notable advances include the Young Adults Health Care Survey and the survey of Children with Special Health Care Needs. New measures are needed for newborn care, intensive care, and trauma care. Also needed is development of consumer surveys in languages other than English.
- Many priority conditions for women are addressed by current measures. Other priority conditions such as violence, mental health, and eating disorders require a firmer foundation in the scientific evidence before they can be appropriately targeted by quality measures.
- Many existing measures also address key conditions affecting the elderly. A key challenge is the development and implementation of measures to address the

myriad of problems confronting the elderly. Many of these gaps in measures for the elderly are addressed through the ACOVE project. However, the feasibility of widespread implementation of these measures poses a major challenge.

- Rural and urban residents have many of the same health care needs as the general population. In this respect, current measures are appropriate for this population. Additional measures focusing on access to primary, secondary, and tertiary care are needed.
- There are no quality measures that specifically address the health care needs of disabled adults. However, a measure for disabled children (CSHCN) demonstrates that it is likely to be feasible to do so. Critical areas for measurement for disabled adults include access to primary and specialty care, patient- and family-centered care, coordination of care, and access to needed equipment and supplies. Many existing measures address the consumer perspective of living with illness. New measures are needed that reliably assess relevant outcomes in management of chronic illness.
- There are no widely used measures for persons near the end of life. The FACCT measures under development show major promise. Further research is needed to identify pivotal processes in the care of this unique population.

Available data show that quality improvement can reduce if not eliminate disparities in health care. Use of immunization registries, tracking, and outreach have been shown to nearly eliminate childhood immunizations in Rochester New York.⁹⁷ A similar approach dramatically improved mammography rates among inner-city residents.⁴⁴³ A CMS-sponsored quality improvement project markedly reduced racial and gender disparities in adequacy of hemodialysis dose.⁹⁸ Training of physicians and nurses in detection and management of depression eliminated disparities in depression management and outcome between insured and uninsured patients.⁹⁹ Disparities by educational level in diabetic control were eliminated among subjects randomized to intensive education and followup in the Diabetes Control and Complications Trial (DCCT) in contrast to those randomized to standard treatment.²⁰⁵ Finally, the Department of Veterans Affairs (VA) health system has implemented a quality improvement program to boost rates of influenza vaccination that includes patient reminders, standing orders, free standing vaccination clinics, and most importantly assessment of vaccination rates with feedback to providers.^{610,611} At least in some sites, this program has not only exceeded 2010 goals for influenza immunization of 90 percent, but has eliminated racial disparities in receipt of influenza immunization.¹⁰⁰ These findings underscore that disparities are not inevitable, but can often be addressed using currently available quality improvement programs. Improving quality and reducing disparities are two sides of the same coin.¹⁰¹

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Appendix A. AHRQ Initiatives in Quality Measures Development

The Agency for Healthcare Quality and Research is the national leader in the development of quality measures including those relevant to disparity populations. Some of these projects are outlined below.

CAHPS®

CAHPS®, which was discussed in detail in section III, is used by the Federal Government, including Medicare, and by more than 20 States and many organizations in the private sector. Questions in CAHPS® include consumer ratings of health care access and quality. Question development for the survey was grounded in research from focus groups and consumer needs for health care decision making in addition to public and private survey and report card efforts. The CAHPS® 1.0 version was released in 1997. The following year, AHRQ and the CAHPS® Consortium revised it based on data from demonstration sites, cognitive testing results, and feedback from users. As noted in section III, the CAHPS® survey and the NCQA Member Satisfaction Survey were merged. NCQA now requires health plans to use the new questionnaire comprised of the Core survey and the HEDIS supplement for HEDIS reporting and NCQA accreditation. This new NCQA instrument is called CAHPS® 2.0H. CAHPS® has been validated in diverse groups and possesses excellent psychometric properties.⁶¹²⁻⁶¹⁷

Benchmarks published by AHRQ for each item are adjusted for respondent's age, health status, and education. For example, the adult commercial benchmarks show that 76 percent report getting needed care with a range between 54 percent and 95 percent. The adult Medicaid benchmark shows a 71 percent rate with a range of 51 percent to 90 percent. Interestingly, persons in Medicaid rated their primary care physicians, specialists, and overall care more highly than those insured through commercial plans and Medicare. An alternative approach to adjusting scores would be to establish benchmarks for specific disparity populations.

Healthcare Cost and Utilization Project Quality Indicators (HCUP QIs) and AHRQ Quality Indicators (AHRQ QIs)

The HCUP QIs comprise a set of 33 clinical performance measures that were designed for hospitals' internal assessment of inpatient quality of care as well as for State and community assessments along three dimensions of care: potentially avoidable adverse hospital outcomes, potentially inappropriate utilization of hospital procedures, and potentially avoidable hospital admissions.

AHRQ has recently revised these indicators to address several key limitations of the original HCUP QIs. These limitations include absence of any severity or risk adjustment, absence of population-based denominators, focus on surgical measures to the exclusion of others conditions, such as chronic medical conditions and pediatric illnesses, and use of low frequency measures that show considerable variation, or instability, from year to year. The revised indicators were based on a technical review developed by the University of California-San Francisco–Stanford Evidence-based Practice Center.

The AHRQ Quality Indicators comprise three modules:

- Prevention Quality Indicators—16 indicators that address prevention of potentially avoidable hospitalizations were released in November 2001.⁶¹⁸
- Inpatient Quality Indicators—29 indicators related to inpatient mortality, utilization, and procedure volume were released in May 2002.⁶¹⁹
- Patient Safety Indicators—26 indicators related to iatrogenic and surgical complications and preventable adverse events were released in March 2003.⁶²⁰

Many of these indicators can be stratified by various disparity population. For example, a hospital could use the software to compare the ratio of laparoscopic cholecystectomies to open cholecystectomies for whites and blacks. If the results show higher rates of laparoscopic procedures for whites then further assessment of potential causes e.g. insurance, surgeon, etc, could be conducted. Other uses include comparisons of avoidable hospital admissions for ambulatory care sensitive conditions between rural and suburban children, differences in COPD or CHF admissions rates by census tract, and complications by race or ethnicity. The major limitation is that measures are not sufficiently rigorous to be used for public reporting.

National Quality Measures Clearinghouse™ (NQMC™)

NQMC™ is a public repository for evidence-based quality measures and measure sets. The NQMC™ comprises a database and Web site for information on specific evidence-based health care quality measures and measure sets. It includes condition-specific measures and measures specific to many disparity populations. NQMC is sponsored by AHRQ to promote widespread access to quality measures by the health care community and other interested individuals.

NQMC™ builds on AHRQ's previous initiatives in quality measurement, including the Computerized Needs-Oriented Quality Measurement Evaluation System (CONQUEST), the Expansion of Quality of Care Measures (Q-SPAN) project, the Quality Measurement Network (QMNet) project, and the Performance Measures Inventory (PMI). NQMC™ can be accessed at: <http://www.qualitymeasures.ahrq.gov>.

National Healthcare Quality Report (NHQR)

AHRQ is preparing a congressionally mandated annual report on the state of health care in the United States. Public comment was solicited on the preliminary measures developed by an interagency work group. Writing of the report based on the final measure set is now underway. Updates on current status of the NHQR are available at: <http://www.ahrq.gov/qual/nhqract.htm>.

National Healthcare Disparities Report (NHDR)

This congressionally mandated annual report represents a companion to the NHQR and will assess racial and ethnic disparities in health care quality nationally. Updates on current status of the NHDR are available at: <http://www.ahrq.gov/news/nhdract.htm>.

Appendix B. Summary of Quality Measures, by Consumer Perspective, for Disparity Populations

Table B1. Quality measures for racial/ethnic minorities					
Condition	Disparity in impact	Measure	Source	Disparity in performance	Type of measure
Satisfaction*					
Consumer experience of care	AA, H, A/PI	CAPHS®	NCQA/FACCT	A/PI	Patient centeredness
Consumer experience of care	AA, H	Picker inpatient Survey		A/PI	Patient centeredness
Staying healthy					
Access to well-care	AA, H, AI/NA	Well-child visits in first 15 months	NCQA	AA, H, A/PI, AI, NA	Timeliness
Access to well-care	AA, H, AI/NA	Well-child visits 4-6 years	NCQA	AA, H, A/PI, AI, NA	Timeliness
Access to well-care	AA, H, AI/NA	Adolescent well-care visits	NCQA	AA, H, A/PI, AI, NA	Timeliness
Access to well-care		Adult well-care visits	NCQA	AA, H, A/PI, AI, NA	Timeliness
Access to dental	AA, H, A/PI, AI/NA	Annual dental visit	NCQA (Medicaid)	AA, H, AI/NA	Timeliness
Access to prenatal care		Trimester of prenatal care enrollment and post-partum check-ups	NCQA	AA, H, AI/NA	Timeliness
Access to prescriptions	AA	Ambulatory drug use	NCQA	AA, H	Timeliness
Adolescent infections	AA, A/PI	Adolescent immunizations	NCQA	AA	Effectiveness /timeliness

Alcohol misuse	AA, H,AI/NA	Rates of screening	FACCT		Effectiveness
Alcohol misuse	AA, H,AI/NA	Routine assessment	FACCT		Effectiveness
Alcohol misuse	AA, H,AI/NA	Satisfaction with screening	FACCT		Effectiveness
Breast cancer	AA	Mammography	NCQA/ HCQIP	AA, H, A/PI, AI/AN	Effectiveness /timeliness
Cervical cancer	AA, H, A/PI	Pap smear screening	NCQA	AA, H, A/PI, AI/AN	Effectiveness /timeliness
Childhood infections	AA, A/PI	Childhood immunizations	NCQA	AA, H, A/PI, AI/AN	Effectiveness /timeliness
Chlamydia	AA, H, A/PI, AI/AN	Screening in young women	NCQA		Effectiveness /timeliness
Confidentiality		YAHC	FACCT YAHC		Patient centeredness
Development	AA, H, AI/NA	Anticipatory guidance	FACCT		Patient centeredness
Development	AA, H, AI/NA	Followup on developmental problems	FACCT		Effectiveness
Development	AA, H, AI/NA	Communication and relationship with providers	FACCT		Patient centeredness
Development	AA, H, AI/NA	Helpfulness and effect on parental confidence	FACCT		Patient centeredness
Diet	AA, AI/NA	YAHC	FACCT YAHC		Patient centeredness
Emotional health	AA, H	YAHC	FACCT YAHC		Patient centeredness
Exercise		YAHC	FACCT YAHC		Patient centeredness
Health status	AA, H, A/PI, AI/NA	Change in health status among elderly	NCQA		Effectiveness
Influenza	AA, AI/NA	Immunization in older adults	NCQA	AA, AI/AN	Effectiveness /timeliness

Key to abbreviations in Appendix B: A=Asian; AA=African American; ACEI=angiotensin-converting enzyme inhibitor; AI/AN (or NA)=American Indian/Alaska Native (or Native Alaskan); A/PI=Asian/Pacific Islander; ED=emergency department; FACCT=Foundation for Accountability; H=Hispanic; HCQIP=Health Care Quality Improvement Project; MMR=measles/mumps/rubella; NCQA=National Committee for Quality Assurance; PTCA=percutaneous transluminal coronary angioplasty; VBAC=vaginal birth after cesarean; YAHC=Young Adult Health Care survey.

Informed consumers		Informed about hormone replacement therapy	NCQA		Patient centeredness
Language access	H, A/PI	Availability of interpretation services	NCQA	H, A/PI	Patient centeredness
Pneumonia	AA, AI/NA	Pneumococcal immunization in older adults	NCQA	AA, AI/AN	Effectiveness /timeliness
Risk behavior	AA, H, AI/NA	YAHC	FACCT		Patient centeredness
Smoking	AA, H, AI/NA	Screening for smoking and advice to quit	NCQA/ FACCT	AA	Effectiveness
Sexually transmitted diseases	AA, H	YAHC	FACCT YAHC		Patient centeredness
Teen sexual activity	AA, H, AI/NA	YAHC	FACCT		Patient centeredness
Use of procedures		Frequency of selected procedures	NCQA	AA, H, A/PI, AI, NA	Timeliness

Getting better

Birth		VBAC rate	ORYX	AA	Effectiveness
Birth		Third or fourth degree laceration	ORYX		Safety
Breast cancer	AA	Stage of cancer at diagnosis	FACCT	AA, H, A/PI, AI/AN	Timeliness
Breast cancer	AA	Informed of radiation options	FACCT		Patient centeredness
Breast cancer	AA	Use of breast conserving surgery	FACCT	AA, H, A/PI, AI/AN	Patient centeredness
Breast cancer	AA	Radiation therapy	FACCT		Effectiveness
Breast cancer	AA	Satisfaction with care	FACCT		Patient centeredness

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Congestive heart failure	AA	Prescription of ACEI at discharge	HCQIP/ORYX		Effectiveness/ Timeliness
Congestive heart failure	AA	Discharge instructions	HCQIP/ORYX		Effectiveness/ Timeliness
Congestive heart failure	AA	Assessment of LV function	HCQIP/ORYX		Effectiveness/ timeliness
Congestive heart failure	AA	Smoking cessation advice	HCQIP/ORYX		Effectiveness
Major depression	AI/NA	Followup and continuity	NCQA	AA	Timeliness
Major depression	AI/NA	Lost to followup	FACCT		Timeliness /safety
Major depression	AI/NA	Satisfaction	FACCT		Patient centeredness
Major depression	AI/NA	Recovery	FACCT		Effectiveness
Major depression	AI/NA	Functional status	FACCT		Effectiveness
Mental illness	AI/NA	Followup post hospitalization	NCQA	AA	Effectiveness/ safety
Myocardial infarction	AA	Beta-blocker upon arrival	NCQA/ORYX	AA, H, A/PI, AI/NA	Effectiveness/ timeliness
Myocardial infarction	AA	Beta-blocker upon discharge	NCQA/ORYX	AA, H, A/PI, AI/NA	Effectiveness/ timeliness
Myocardial infarction	AA	Cholesterol after cardiovascular events	NCQA	AA, H, A/PI	Effectiveness
Myocardial infarction	AA	Use of aspirin on arrival	HCQIP/ORYX	AA, H, A/PI	Effectiveness/ timeliness
Myocardial infarction	AA	Use of aspirin on discharge	HCQIP/ORYX	AA, H, A/PI	Effectiveness/ timeliness
Myocardial infarction	AA	Angiotensin-converting enzyme for patients with left ventricular dysfunction	HCQIP/ORYX	AA, H, A/PI	Effectiveness
Myocardial infarction	AA	Smoking cessation advice	HCQIP/ORYX		Effectiveness

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Myocardial infarction	AA	Time to thrombolysis	HCQIP/ ORYX		Timeliness
Myocardial infarction	AA	Time to PTCA	HCQIP/ ORYX	AA, H, A/PI	Timeliness
Myocardial infarction	AA	Intrahospital mortality	ORYX	AA,	Effectiveness
Neonatal mortality	AA	rate	ORYX		Effectiveness
Pneumonia	AA	Oxygenation assessment	ORYX		Safety
Pneumonia	AA	Collection of blood cultures	HCQIP/ ORYX	AA, H, A/PI	Effectiveness
Pneumonia	AA	Prescriptions of antibiotics	HCQIP/ ORYX	AA	Effectiveness
Pneumonia	AA	Pneumococcal immunization	HCQIP/ ORYX	AA	Effectiveness
Pneumonia	AA	Smoking cessation counseling	ORYX		Effectiveness
Stroke	AA	Antiplatelets and anticoagulants	HCQIP		Effectiveness
Stroke	AA	Avoidance of nifedipine	HCQIP		Safety
Stroke	AA	Warfarin for atrial fibrillation	HCQIP		Effectiveness
Surgery	AA	Timing of prophylactic antibiotics	ORYX		Timeliness
Surgical wound infection	AA	30-day rate	ORYX		Safety

Living with chronic illness

Asthma	AA, H	Prescription for anti-inflammatory agent	NCQA	AA, H	Effectiveness
Asthma	AA, H	ED visits	NCQA	AA, H	Effectiveness
Asthma, adult		Education re: peak flow meter use	FACCT		Patient centeredness/ Effectiveness

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Asthma, adult	AA, H	Education re: inhaler use	FACCT		Patient centeredness/ effectiveness
Asthma, adult	AA, H	Education re: patient experience and satisfaction	FACCT		Patient centeredness
Asthma, adult	AA, H	Patient self management knowledge	FACCT		Patient centeredness
Asthma, adult	AA, H	Ability to maintain daily activities	FACCT		Effectiveness
Asthma, adult	AA, H	Education re: patient experience and satisfaction	FACCT		Effectiveness
Breast cancer	AA	Experience and function	FACCT		Effectiveness
Breast cancer	AA	5-year disease free survival	FACCT	AA	Effectiveness
Children with special health care needs	AA	Receipt of family-centered care	FACCT		Patient centeredness
Children with special health care needs	AA, H	Getting needed medications and specialty care	FACCT		Effectiveness
Children with special health care needs	AA, H	Coordination of care	FACCT		Patient centeredness
Diabetes	AA, H, AI/NA	Hemoglobin A1 testing	NCQA/ FACCT	AA, H, AI/NA	Effectiveness/ timeliness
Diabetes	AA, H, AI/NA	Glycemic control	NCQA/ FACCT	AA	Effectiveness
Diabetes	AA, H, AI/NA	Eye exams	NCQA/ FACCT	AA	Effectiveness
Diabetes	AA, H, AI/NA	Foot exams	FACCT		Effectiveness
Diabetes	AA, H, AI/NA	Lipid screening	NCQA		Effectiveness
Diabetes	AA, H, AI/NA	Lipid control	NCQA/ FACCT		Effectiveness

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Diabetes	AA, H, AI/NA	Nephropathy screening	NCQA		Effectiveness
Diabetes	AA, H, AI/NA	Advice to quit smoking	FACCT		Effectiveness
Diabetes	AA, H, AI/NA	Ability to maintain activities	FACCT		Effectiveness
Diabetes	AA, H, AI/NA	Smoking cessation	FACCT		Effectiveness
Hypertension	AA	Hypertension control	NCQA	AA	Effectiveness

* Satisfaction measures may cut across one or more consumer perspectives.

Table B2. Quality measures for children

Condition	Measure	Source	Age range	Reported separately from adults	Type of measure
Satisfaction					
Consumer experience of care	CAPHS® 2.0 child	NCQA/ FACCT		Yes	Patient centeredness
	Picker Inpatient Survey			Yes	Patient centeredness
Staying healthy					
Access to well-care	Well-child visits in first 15 months	NCQA	0-15 mo	Yes	Timeliness
Access to well-care	Well-child visits 4-6 years	NCQA	4-6 years	Yes	Timeliness
Access to well-care	Adolescent well-care visits	NCQA	12-21	Yes	Timeliness
Use of procedures	Frequency of selected procedures	NCQA	0-19	Yes	Timeliness
Access to prescriptions	Ambulatory drug use	NCQA	0-9, 10-19	Yes	Timeliness
Access to dental	Annual dental visit	NCQA (Medicaid)	4-21	Yes	Timeliness
Language access	Availability of interpretation services	NCQA	Generic	No	Timeliness
Adolescent infections	Adolescent immunizations for MMR, hepatitis B, and varicella	NCQA	13	Yes	Effectiveness /timeliness
Childhood infections	Childhood immunizations	NCQA	2	Yes	Effectiveness /timeliness
Chlamydia	Screening in young women	NCQA	16-20	Yes	Effectiveness /timeliness
Confidentiality	YAHC	FACCT YAHC	14-18	Yes	Patient centeredness

Development	Anticipatory guidance	FACCT	14-18	Yes	Patient centeredness/ effectiveness
Development	Followup on developmental problems	FACCT	14-18	Yes	Timeliness
Development	Communication and relationship with providers	FACCT	14-18	Yes	Patient centeredness
Development	Helpfulness and effect on parental confidence	FACCT	14-18	Yes	Patient centeredness
Diet	YAHC	FACCT YAHC	14-18	Yes	Patient centeredness/ effectiveness
Emotional health	YAHC	FACCT YAHC	14-18	Yes	Patient centeredness/ effectiveness
Exercise	YAHC	FACCT YAHC	14-18	Yes	Patient centeredness/ effectiveness
Risk behavior	YAHC	FACCT	14-18	Yes	Patient centeredness/ effectiveness
STDs	YAHC	FACCT YAHC	14-18	Yes	Patient centeredness/ effectiveness
Teen sexual activity	YAHC	FACCT	14-18	Yes	Patient centeredness/ effectiveness

Getting better

Mental illness	Followup after hospitalization	NCQA	6-18	No	Safety/ timeliness
Neonatal mortality	Rate	ORYX	0-19	Yes	Safety
Pneumonia	Oxygenation assessment	ORYX	0-19	No	Safety
Pneumonia	Empiric antibiotic	ORYX	0-19	No	Effectiveness

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Pneumonia	Collection of blood cultures	HCQIP/ ORYX	0-19	No	Effectiveness
Pneumonia	Pediatric smoking cessation	ORYX	0-19	Yes	Effectiveness
Surgery	Timing of prophylactic antibiotics	ORYX	0-19	No	Timeliness
Surgical wound infection	30-day rate	ORYX	0-19	No	Safety

Living with chronic illness

Asthma	Prescription for anti-inflammatory agent	NCQA	5-9, 10-17	No	Effectiveness
Asthma	ED visits	NCQA	4-9,10-17,18	No	Safety
Children with special health care needs	Receipt of family-centered care	FACCT	0-19	Yes	Patient centeredness
Children with special health care needs	Getting needed medications and specialty care	FACCT	0-19	Yes	Effectiveness
Children with special health care needs	Coordination of care	FACCT	0-19	Yes	Patient centeredness

* Satisfaction measures may cut across one or more consumer perspectives.

Table B3. Quality measures relevant to women				
Condition	Measure	Source	Reported separately for women	Type of measure

Satisfaction*

Consumer experience of care	CAPHS®	NCQA/ FACCT	No	Patient centeredness
Consumer experience of care	Picker Inpatient Survey		Yes	Patient centeredness

Staying healthy

Access to dental	Annual dental visit	NCQA (Medicaid)	No	Timeliness
Access to prenatal care	Trimester of prenatal care enrollment	NCQA	Yes	Timeliness
Access to prescriptions	Ambulatory drug use	NCQA	No	Timeliness
Alcohol misuse	Rates of screening	FACCT	No	Effectiveness
Alcohol misuse	Routine assessment	FACCT	No	Effectiveness
Alcohol misuse	Satisfaction with screening	FACCT	No	Patient centeredness
Breast cancer	Mammography	NCQA/ HCQIP	Yes	Effectiveness /timeliness
Cervical cancer	Pap smear screening	NCQA	Yes	Effectiveness /timeliness
Chlamydia	Screening in young women	NCQA	No	Effectiveness /timeliness
Health status	Change in health status among elderly	NCQA	No	Effectiveness
Influenza	Immunization In older adults	NCQA	No	Effectiveness /timeliness
Informed consumers	Informed about hormone replacement therapy	NCQA	Yes	Patient centeredness
Language access	Availability of interpretation Services	NCQA	No	Patient centeredness

Pneumonia	Pneumococcal immunization in older adults	NCQA	No	Effectiveness /timeliness
Risk behavior	YAHC	FACCT	No	Patient centeredness
Smoking	Screening for smoking and advice to quit	NCQA/ FACCT	No	Effectiveness
STDs	YAHC	FACCT YAHC	No	Patient centeredness/ effectiveness
Teen sexual activity	YAHC	FACCT	No	Patient centeredness/ effectiveness
Use of procedures	Frequency of selected procedures	NCQA	No	Timeliness

Getting better

Birth	VBAC rate	ORYX	Yes	Effectiveness
Birth	Third or fourth degree laceration	ORYX	Yes	Safety
Breast cancer	Stage of cancer at diagnosis	FACCT	Yes	Timeliness
Breast cancer	Informed of radiation options	FACCT	Yes	Patient centeredness
Breast cancer	Use of breast conserving surgery	FACCT	Yes	Effectiveness
Breast cancer	Radiation therapy	FACCT	Yes	Effectiveness
Breast cancer	Satisfaction with care	FACCT	Yes	Patient centeredness
Congestive heart failure	Prescription of ACEI at discharge	HCQIP/ ORYX	No	Effectiveness/ timeliness
Congestive heart failure	Discharge instructions	HCQIP/ ORYX	No	Effectiveness/ timeliness
Congestive heart failure	Assessment of LV function	HCQIP/ ORYX	No	Effectiveness/ timeliness

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Congestive heart failure	Smoking cessation advice	HCQIP/ORYX	No	Effectiveness
Major depression	Followup and continuity	NCQA	No	Effectiveness
Major depression	Lost to followup	FACCT	No	Effectiveness
Major depression	Satisfaction	FACCT	No	Effectiveness
Major depression	Recovery	FACCT	No	Effectiveness
Major depression	Functional status	FACCT	No	Effectiveness
Mental illness	Followup post hospitalization	NCQA	No	Safety/timeliness
Myocardial infarction	Beta-blocker upon arrival	NCQA/ORYX	No	Effectiveness/timeliness
Myocardial infarction	Beta-blocker upon discharge	NCQA/ORYX	No	Effectiveness
Myocardial infarction	Cholesterol after cardiovascular events	NCQA	No	Effectiveness/timeliness
Myocardial infarction	Use of aspirin on arrival	HCQIP/ORYX	No	Effectiveness/timeliness
Myocardial infarction	Use of aspirin on discharge	HCQIP/ORYX	No	Effectiveness/timeliness
Myocardial infarction	Angiotensin-converting enzyme for patients with left ventricular dysfunction	HCQIP/ORYX	No	Effectiveness
Myocardial infarction	Smoking cessation advice	HCQIP/ORYX	No	Effectiveness
Myocardial infarction	Time to thrombolysis	HCQIP/ORYX	No	Timeliness
Myocardial infarction	Time to PCTA	HCQIP/ORYX	No	Timeliness
Myocardial infarction	Intrahospital mortality	ORYX	No	Safety
Neonatal mortality	rate	ORYX	No	Effectiveness

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Pneumonia	Oxygenation assessment	ORYX	No	Safety
Pneumonia	Collection of blood cultures	HCQIP/ORYX	No	Effectiveness
Pneumonia	Prescriptions of antibiotics	HCQIP/ORYX	No	Timeliness
Pneumonia	Pneumococcal immunization	HCQIP/ORYX	No	Effectiveness
Pneumonia	Smoking cessation counseling	ORYX	No	Effectiveness
Stroke	Antiplatelets and anticoagulants	HCQIP	No	Effectiveness
Stroke	Avoidance of nifedipine	HCQIP	No	Safety
Stroke	Warfarin for atrial fibrillation	HCQIP	No	Effectiveness
Surgical wound infection	30-day rate	ORYX	No	Safety
Surgery	Timing of prophylactic antibiotics	ORYX	No	Timeliness

Living with chronic illness

Asthma	Prescription for anti-inflammatory agent	NCQA	No	Effectiveness
Asthma	ED visits	NCQA	No	Safety
Asthma, adult	Education re: peak flow meter use	FACCT	No	Effectiveness
Asthma, adult	Education re: inhaler use	FACCT	No	Effectiveness
Asthma, adult	Education re: patient experience and satisfaction	FACCT	No	Patient centeredness/ effectiveness

Asthma, adult	Patient self management knowledge	FACCT	No	Patient centeredness /effectiveness
Asthma, adult	Ability to maintain daily activities	FACCT	No	Effectiveness
Breast cancer	Experience and function	FACCT	Yes	Effectiveness
Breast cancer	5-year disease free survival	FACCT	Yes	Effectiveness
Diabetes	Hemoglobin A1 testing	NCQA/ FACCT	No	Effectiveness /timeliness
Diabetes	Glycemic control	NCQA/ FACCT	No	Effectiveness
Diabetes	Eye exams	NCQA/ FACCT	No	Effectiveness /timeliness
Diabetes	Foot exams	FACCT	No	Effectiveness
Diabetes	Lipid screening	NCQA	No	Effectiveness
Diabetes	Lipid control	NCQA/ FACCT	No	Effectiveness
Diabetes	Nephropathy screening	NCQA	No	Effectiveness
Diabetes	Advice to quit smoking	FACCT	No	Effectiveness
Diabetes	Ability to maintain activities	FACCT	No	Effectiveness
Diabetes	Smoking cessation	FACCT	No	Effectiveness
Hypertension	Hypertension control	NCQA	No	Effectiveness

* Satisfaction measures may cut across one or more consumer perspectives.

Table B4. Quality measures relevant to elderly

Condition	Measure	Source	Reported separately for elderly	Type of measure
Satisfaction*				
Consumer experience of care	CAPHS®	NCQA/ FACCT	At times	Patient centeredness
Consumer experience of care	Picker Inpatient Survey	Picker Institute/	At times	Patient centeredness
Staying healthy				
Access to dental	Annual dental visit	NCQA (Medicaid)	No	Timeliness
Access to prescriptions	Ambulatory drug use	NCQA	No	Timeliness
Alcohol misuse	Rates of screening	FACCT	No	Effectiveness
Alcohol misuse	Routine assessment	FACCT	No	Effectiveness
Alcohol misuse	Satisfaction with screening	FACCT	No	Patient centeredness
Breast cancer	Mammography	NCQA/ HCQIP	No	Effectiveness /timeliness
Cervical cancer	Pap smear screening	NCQA	No	Effectiveness /timeliness
Health status	Change in health status among elderly**	NCQA	Yes	Effectiveness
Influenza	Immunization in older adults**	NCQA	Yes	Effectiveness /timeliness
Informed consumers	Informed about hormone replacement therapy	NCQA	No	Patient centeredness
Language access	Availability of interpretation services	NCQA	No	Patient centeredness
Pneumonia	Pneumococcal immunization in older adults**	NCQA	Yes	Effectiveness /timeliness
Smoking	Screening for smoking and advice to quit	NCQA/ FACCT	No	Effectiveness

Key to abbreviations in Appendix B: A=Asian; AA=African American; ACEI=angiotensin-converting enzyme inhibitor; AI/AN (or NA)=American Indian/Alaska Native (or Native Alaskan); A/PI=Asian/Pacific Islander; ED=emergency department; FACCT=Foundation for Accountability; H=Hispanic; HCQIP=Health Care Quality Improvement Project; MMR=measles/mumps/rubella; NCQA=National Committee for Quality Assurance; PTCA=percutaneous transluminal coronary angioplasty; VBAC=vaginal birth after cesarean; YAHC=Young Adult Health Care survey.

Use of procedures	Frequency of selected procedures	NCQA	No	Timeliness
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Getting better

Breast cancer	Stage of cancer at diagnosis	FACCT	No	Timeliness
Breast cancer	Informed of radiation options	FACCT	No	Patient centeredness
Breast cancer	Use of breast conserving surgery	FACCT	No	Effectiveness
Breast cancer	Radiation therapy	FACCT	No	Effectiveness
Breast cancer	Satisfaction with care	FACCT	No	Patient centeredness
Congestive heart failure	Prescription of ACEI at discharge	HCQIP/ ORYX	No	Effectiveness /timeliness
Congestive heart failure	Discharge instructions	HCQIP/ ORYX	No	Effectiveness /timeliness
Congestive heart failure	Assessment of LV function	HCQIP/ ORYX	No	Effectiveness
Congestive heart failure	Smoking cessation advice	HCQIP/ ORYX	No	Effectiveness
Major depression	Followup and continuity	NCQA	No	Safety/ timeliness
Major depression	Lost to followup	FACCT	No	Safety
Major depression	Satisfaction	FACCT	No	Patient centeredness
Major depression	Recovery	FACCT	No	Effectiveness
Major depression	Functional status	FACCT	No	Effectiveness
Mental illness	Followup post hospitalization	NCQA	No	Timeliness/ safety
Myocardial infarction	Beta-blocker upon arrival	NCQA/ ORYX	No	Effectiveness /timeliness
Myocardial infarction	Beta-blocker upon discharge	NCQA/ ORYX	No	Effectiveness /timeliness
Myocardial infarction	Cholesterol after cardiovascular Events	NCQA	No	Effectiveness /timeliness
Myocardial infarction	Use of aspirin on arrival	HCQIP/ ORYX	No	Effectiveness /timeliness
Myocardial infarction	Use of aspirin on discharge	HCQIP/ ORYX	No	Effectiveness /timeliness

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Myocardial infarction	Angiotensin-converting enzyme for patients with left ventricular dysfunction	HCQIP/ORYX	No	Effectiveness
Myocardial infarction	Smoking cessation advice	HCQIP/ORYX	No	Effectiveness
Myocardial infarction	Time to thrombolysis	HCQIP/ORYX	No	Timeliness
Myocardial infarction	Time to PCTA	HCQIP/ORYX	No	Timeliness
Myocardial infarction	Intrahospital mortality	ORYX	No	Safety
Neonatal mortality	Mortality rate	ORYX	No	Safety
Pneumonia	Oxygenation Assessment	ORYX	No	Safety
Pneumonia	Collection of blood cultures	HCQIP/ORYX	No	Effectiveness
Pneumonia	Prescriptions of antibiotics	HCQIP/ORYX	No	Timeliness
Pneumonia	Pneumococcal immunization	HCQIP/ORYX	No	Effectiveness
Pneumonia	Smoking cessation counseling	ORYX	No	Effectiveness
Stroke	Antiplatelets and anticoagulants	HCQIP	No	Effectiveness
Stroke	Avoidance of nifedipine	HCQIP	No	Safety
Stroke	Warfarin for atrial fibrillation	HCQIP	No	Effectiveness
Surgery	Timing of prophylactic antibiotics	ORYX	No	Timeliness
Surgical wound infection	30 day rate	ORYX	No	Safety

Living with chronic illness

Asthma, adult	Prescription for anti-inflammatory agent	NCQA	No	Effectiveness
Asthma, adult	ED visits	NCQA	No	Effectiveness
Asthma, adult	Education re: peak flow meter use	FACCT	No	Patient centeredness/ effectiveness

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Asthma, adult	Education re: inhaler use	FACCT	No	Patient centeredness/ effectiveness
Asthma, adult	Education re: patient experience and satisfaction	FACCT	No	Patient centeredness
Asthma, adult	Patient self management knowledge	FACCT	No	Patient centeredness/ effectiveness
Asthma, adult	Ability to maintain daily activities	FACCT	No	Effectiveness
Breast cancer	Experience and function	FACCT		Effectiveness
Breast cancer	5-year disease free survival	FACCT		Effectiveness
Diabetes	Hemoglobin A1 testing	NCQA/ FACCT		Effectiveness /timeliness
Diabetes	Glycemic control	NCQA/ FACCT		Effectiveness
Diabetes	Eye exams	NCQA/ FACCT		Effectiveness /timeliness
Diabetes	Foot exams	FACCT		Effectiveness /timeliness
Diabetes	Lipid screening	NCQA		Effectiveness /timeliness
Diabetes	Lipid control	NCQA/ FACCT		Effectiveness
Diabetes	Nephropathy screening	NCQA		Effectiveness /timeliness
Diabetes	Advice to quit smoking	FACCT		Effectiveness
Diabetes	Ability to maintain activities	FACCT		Effectiveness
Diabetes	Smoking cessation	FACCT		Effectiveness
Hypertension	Hypertension control	NCQA		Effectiveness

* Satisfaction measures may cut across one or more consumer perspectives.

** Reported separately for older adults.