

DRAFT-NOT FOR QUOTATION OR ATTRIBUTION

Measuring Disparities in Access to Care

DRAFT prepared for the Institute of Medicine

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Introduction

Since the landmark 1985 report entitled, *The Health of Black Americans*, minority Americans have been consistently shown to have poorer health status and worse health outcomes than white Americans. These differences have remained so persistent that Healthy People 2010 specified as one of its two overarching goals the elimination of disparities in health. Included among the health disparities of most concern are disparities between different race/ethnic groups and disparities associated with geography. There is now an emerging consensus that disparities, at least between different race and ethnic groups, arise from several factors, including differences in access to care and health insurance, in the amount and quality of care received, and in factors not directly related to the health care system, including socioeconomic status, literacy, language, community factors impacting on health, and differences in access to opportunity.

The national goal of eliminating health disparities has led to a reexamination of the health care system, and a call for intensive measures to move the nation well toward meeting the goal. Learning from the quality movement, there has been heightened is key to achieving success. Hence, in its reauthorization in 2000, the Agency for Healthcare Research and Quality was directed to prepare a National Disparities Report and it has formed an Office of Priority Populations. This development coincides with a closely related effort, the development and publication of the *National Quality Report*. A predecessor IOM report, *Crossing the Quality Chasm*, draws attention to the intimate relationship between quality and disparities in its articulation that one of the key aspects recognition that public reporting on the current status of disparities, and future progress, of quality is equity.

In preparation for the National Disparities Report, AHRQ has commissioned the IOM to provide guidance about how to address various topics, including access to care. This paper is intended to provide background and fresh thinking for the committee regarding the leading issues surrounding the measurement of disparities in access to care.

Setting the Context

In a seminal article that provides a conceptual framework for access to care, Aday and Andersen identify a combination of policy variables, such as the presence of health insurance, personal variables (predisposing, enabling and need), and process of care elements (e.g. use) that lead to an outcome.

Although much has changed regarding health care in the US since the Aday and Andersen publication over a quarter century ago, sadly much has remained the same. In that paper, lack of health insurance and the lack of primary care were identified as key problems for the health of Americans. They remain so today. But much has also changed, and the challenge of measuring disparities in access to care in the early 21st century must account for these new realities. Several are highlighted here:

- US population demographics are shifting dramatically, and the country is much more multi-ethnic than at any time in its history. Some states, such as California, are already 'majority minority' and the proportion of the population that is Hispanic is expected to grow dramatically in the next decade. Although African-Americans, as a group, continue to have some of the worst health outcomes, discussion of health disparities for

racial and ethnic minorities must move well beyond comparisons of African-Americans and whites.

Concurrently, there has also been a shift of the population from rural areas to urban and suburban ones. Populations in rural areas have declined and aged, as younger people have moved to more urban environments. The recent influx of immigrant populations, who work largely on farms and in meat processing plants, has changed the ethnic composition of rural areas as well.

- The aging of the population and increasing life expectancy means that chronic disease is much more common. Concomitantly, our understanding of how best to care for people with chronic disease is improving. Attention to end-of-life care has provided new opportunities for people to receive care at home, and the dying process has become more patient-centered.
- There have been major shifts in the financing and organization of care, and these are continuing. While most insured Americans are enrolled in some form of managed care, the heterogeneity among health plans means that is harder to generalize about managed care. Nonetheless, some common elements have facilitated our ability to examine and address disparities. Explicit attention to responsibilities to enrollees (or identification of a denominator population) creates important opportunities to measure both access and quality within health plans. With this has come increased accountability, a key element of which is measuring and reporting. Managed care has also reintroduced the concept of population health. Once considered analogous to public health, it is now well recognized that caring for populations is effectively done both *inside* the personal health care system and *outside* of it.
- Uninsurance, and underinsurance, remain major problems for over 60 million Americans, and there is no resolution on the horizon. The amount that individuals must pay for care is increasing, and half of seniors report needing to cut down on essentials such as food and heat in order to pay for medications. The uninsured, minorities, low-income populations, and rural residents disproportionately receive care in a separate, unmanaged system, composed of community health centers, non-profit clinics, various charity care arrangements, and emergency departments.
- Our understanding of what causes disease is becoming clarified. Specifically, it is now estimated that up to 50% of health status can be accounted for by health behaviors and only 15-20% by the health care delivery system. In other words, the health care system contributes proportionately little to health status compared to other factors, although the benefits are greatest for those in poor health and without access to care. Importantly, advances in genetics have confirmed that race is not a biologic construct, but a social one. There is more genetic variation within racial groups than between them.
- Our understanding of health has broadened. Specifically, mental health and oral health have been more clearly defined as important components of health, and concepts like well-being or spirituality are increasingly thought to impact on or be important components of health.

While the environment in which health services are provided has changed, the view of access to care has largely remained the same.

Evolving conceptual frameworks of access to care

Our understanding of access to care has evolved over the last 25 years. The conceptual framework developed by Aday and Andersen identified the relationships between personal characteristics, policy variables, utilization, and outcome. The 1983 President's Bioethics Commission declared that 'equitable access to health care requires that all citizens be able to secure *an adequate level* of care without excessive burdens,' further emphasizing the issue of equity in access. While it did identify a standard of 'equity,' it left open the definition of 'adequate level of care' or how it might relate to outcome.

The IOM revisited the issue of access to care in 1993, defining access as 'the timely use of personal health services *to achieve the best possible health outcomes*. Of note, in choosing indicators that represented access-related outcome measures, it more explicitly linked access to quality. The committee recommended a series of indicators that impact outcome measures through the processes of entering *and* staying in the health care system, utilization of services, and quality of care. The report depicts a more linear relationship between access and outcome starting with barriers (structural, financial and personal) and moving through use of services and "mediators" (which are largely measures of quality) to outcomes. It acknowledged the complexity of identifying access issues, but left open the question of how much of poor performance on outcome measures is a function of poor quality of care, or of barriers to accessing care (including cost) once an individual has entered the delivery system.

The advent of managed care brought with it a set of additional factors that relate to access. This expanded framework is embodied in the work of Docteur, et al, who identify a complex series of factors related to access and quality in managed care. They include a number of contextual community variables, such as available plan choices, active marketing and market characteristics, and stability of plan choices. They also recognize the special issues involved in navigating managed care plans, although it is not clear that this challenge is substantially different from navigating the health care system as a whole.

Finally, the guidance report for the National Quality Report, *Envisioning the National Quality Report*, has articulated a framework for consideration of quality, which is not unrelated to the frameworks described above. The rows describe the major functions of care (staying healthy, getting better, living with illness or disability, coping with end of life) and the columns represent attributes of the care system (safety, effectiveness, patient centeredness, timeliness). The relationship of access to this framework is important and is described in detail below.

None of the frameworks for deserving access or that for the *National Quality Report* build on our increased knowledge of what creates health or the evolution in the health care system. The Docteur framework is somewhat of an exception in its identification of community contextual variables such as market competition and available plan choices as access-related issues. However, as our understanding of factors that create health has developed, it is clear that the nature of communities themselves and access to a well functioning public health system are critical to achieving access to personal services. Consider, for example, factors that impact on access to HIV care. Twenty-five per cent of infected individuals in the US do not even know they are infected—and are thus completely unaware of the need for care. Late presentation of disease is a major determinant of bad outcome. HIV disproportionately impacts minority populations. While some of these individuals may have had missed opportunities for HIV

detection in the personal health care system (a quality issue), the failure of public or population health efforts in this regard is a major barrier to access, and that failure is associated with poor outcome.

The public health system has functioned unevenly with regard to minority populations in a number of areas, and its disparate performance in all likelihood contributes significantly to disparities in access and in outcome. A recent review of a campaign to promote smoking cessation during pregnancy found that the campaign did not focus on minority populations, where smoking rates (and SIDS) are the highest. Women who are unaware the risks of smoking during pregnancy are less likely to seek or use smoking cessation services. Another example of the importance of community factors is access to oral health services. It is well documented that low income and minority children have poorer oral health and less access to preventive dental services. Yet, although fluoridation is the single most effective intervention in preventing caries, approximately half of the population does not have access to fluoridated water. [*need to recheck data on minorities and rural residents*]. A similar case regarding population health in communities can be made with regard to late stage presentation of other diseases, including certain cancers, diabetes and heart disease.

That risk behaviors contribute significantly to health outcomes is indisputable, and many of these behaviors are modifiable. Changing health behavior is a joint responsibility of the individual, the public health system (largely through increasing awareness and education), and the delivery system. Yet, the current conceptualization of access to care with regard to behavior change places the responsibility either solely with the patient, or *inside* the health care system—often within the patient-provider encounter. A good example is smoking cessation, which can be significantly influenced by population health measures in a community as well as by health care visits. Finally, it is now recognized that for most chronic disease, the major caregiver is the patient and/or family themselves, and that most care (e.g. medication adherence and adherence to risk reduction behaviors, self-monitoring, etc) actually occurs in the home. It is clear that the community, the public health system, the personal delivery system, and the individual all have a shared responsibility and contribution to outcome. Figure 1 attempts to combine the frameworks discussed above.

Access to Care and the Quality Framework

Clearly, a policy goal is access throughout the lifespan to the full array of services identified in the rows of the quality framework. Timeliness is unquestionably a component of access. Key aspects of access are also related to safety, effectiveness, and patient-centeredness. Figure 2 identifies examples of access indicators that can easily be placed in different cells of the quality framework.

With regard to **safety**, several studies have suggested that poor and minority patients are more likely to experience medical errors, and are more likely to have cardiac procedures performed by providers with poorer outcomes. Whether this results from uninformed choice of providers, or whether these were the only providers available or willing to care for these individuals is unclear. Access to safe care is critical for optimal outcomes. Access to care that is not safe may be as bad or worse than no care.

With regard to **effectiveness**, we are not terribly concerned with ensuring access to care that is ineffective, provided it is not harmful. However, data suggest that minority patients receive fewer effective, need-based treatments that improve health and quality of life, such as knee replacement for severe arthritis, or renal transplants for end-stage renal disease. As is often the case, it may not be possible to disentangle access and quality because so many factors are involved. Insurance status, for example, is clearly related to arthritis care in general, and to knee replacement rates. Awareness that knee replacements are possible and being offered the procedure are non-financial access issues.

However, even when the insurance issue is removed, for example, in the ESRD program, factors such as lack of discussion or recommendations about options for treating renal failure appear to account for a substantial part of the difference in transplant rates between whites and African-Americans. While an argument can be made that this is a quality of care issue, one cannot access treatments one isn't aware of.

Using a non-procedural example related to effectiveness, minorities have been reported to receive less effective treatment for pain. For example, they receive less analgesia for pain due to long bone fractures or during labor and delivery. These examples demonstrate that even once inside the health care system, there are repeated problems with access to effective care. While the literature is replete with studies that suggest that whites and blacks (fewer studies with other minority groups) are treated differently in ways that might be due to bias, discrimination, or stereotyping, and that these may inhibit access to effective care, there are not yet good measures of bias or stereotyping that could be used to more directly test this hypothesis.

Access has key relationships with the **patient-centeredness** aspect of quality. For example, some work suggests that gender and race concordance is important in patient-doctor communication and receipt of preventive care. The degree to which the demographics of the health care workforce reflect the population cared for is felt to reduce some of the cultural barriers to care. Language access is unquestionably a feature of both effective and patient-centered care.

Access is also a consideration across the continuum of care. Each of the domains on the continuum of care identified by the National Quality Report should be examined throughout the lifespan and should consider changes in our understanding of what creates health and our expanded concepts of health. These components are briefly discussed with regard to access.

Staying healthy involves an array of access related health behaviors and preventive services that occur across the lifespan, and many of these are well understood.

Of note, more recent work is suggesting that appropriate follow-up after an abnormal Pap smear or mammogram is an important issue related to access, quality and outcome, and an area in which large disparities are still thought to exist.

Getting better refers primarily to getting acute care. Many of the measures related to getting better are discussed under **Core Measures**, below.

Two aspects of the continuum of care have changed substantially since access to care was initially conceptualized; care for chronic disease, and end-of-life care. As **living with chronic disease and disability** have become more common, and it is clear that aggressive management can prevent complications and declines in function, new models for chronic disease management have been evolving. These often involve team-based care, including, for example, nutritionists,

or physical therapists. As these models are increasingly shown be pathways for achieving the ‘best possible outcome’, access to chronic disease management services will become even more important. To the extent that minority patients are more often impacted by some of these diseases, e.g. diabetes, than others, access to disease management programs should be a consideration in the National Disparities Report. With regard to current measures, there are no large data systems that would reliably measure need-based access to, or use of, disease management services. Most that do exist are not yet reliably linked to data on race/ethnicity.

End-of-life care has also become more important as the population ages. Cultural differences associated with ethnicity and geography often impact the nature of the end-of-life care, and are associated with differing degrees of informal care giving. The wide variation in preferences make measures of service utilization somewhat difficult to interpret. Nonetheless, three common measures of use of end of life care services, use of nursing home care, use of home nursing, and use of hospice care, are available from Medicare administrative data. These have the added advantage of having linkages to race/ethnicity data. With regard to geography, only 11 counties in the US do not have a hospice provider serving them. This may be different, however, than realized accessibility. Recent work by Joanne Lynn and colleagues indicates relatively small race/ethnic differences in use of hospice services or skilled nursing facilities.

Medicare covers much of the population needing both chronic care and end-of-life care; hence access to these services has not been felt to be as problematic as if recipients were uninsured. However, older rural residents are less likely than the rest of the population to be covered by Medicare at all. The availability of Medicaid coverage for low-income senior populations, which are disproportionately rural and minority, is highly variable from state to state. Some states with large minority and rural populations have some of the least generous Medicaid programs. These insurance barriers may well affect care at the end of life.

Care allows all of dimensions of the continuum are impacted on by additional factors, such as, geographic access, the ability to understand the clinician and participate in informed decision making, ability to understand the process of navigating the health care system, language access and availability of translation services, and access to information before, during and after the health care encounter.

This discussion has highlighted the interrelated nature of the various frameworks for understanding access and its relationships to community and to what happens inside the health care system, considered for these purposes as quality. Figure 3, depicts the interrelated nature of these.

Challenges

Data

A series of data and measurement issues challenge the examination of disparities in access, and will be relevant to consideration of the types of measures used and how the data are to be presented. A forthcoming report from NCHS outlines some of the methodologic issues in calculating the disparity, such as whether the differences are relative or absolute, framed in the positive or negative, and whether a summary disparity score for a given measure is useful. Many of the decisions made regarding these issues depend on the context in which they are being used.

A more complicated set of issues concerns data availability and quality. Racial misclassification continues to be an issue of concern in many data sources. This is most likely to occur when an individual's race is not obtained by self-report, but rather by a third party, such as a clerk or eligibility worker. NCHS has examined the reliability of such data in the Medicare program, and finds it to be highly accurate for African Americans, of moderate accuracy for Hispanics, and poor for Native Americans. The Census has recently reported on the numbers of individuals who self-report mixed race or ethnicity, a different kind of classification issue. Continued increases in those reporting more than one race/ethnicity will make comparisons from baseline data difficult. OMB is developing a crosswalk that will facilitate examination of changes over time.

Another issue relates to heterogeneity of the populations studied. Each of the race/ethnic groups, and the groups of individuals considered 'rural' vary tremendously by subgroups. African and Caribbean born blacks have clearly different health status and health outcomes than American born blacks, Hispanics and Asians come from many countries, and they differ widely in the health behaviors and cultural patterns that affect access and use. There is tremendous variation in rural areas-- culture, lifestyle, and health needs differ widely between, for example, rural North Dakota, Texas, and Appalachia. Aggregation by race or by urban/rural status masks many of these differences, just as examining the total population masks differences by major race/ethnic groups.

While most of the large national survey efforts obtain self-reported information about respondent race and ethnicity, these data are not routinely collected and recorded in health care databases, which are often a source of information regarding utilization of care. Race/ethnicity data are sometimes available by linking from administrative and utilization data, and these vary in accuracy (e.g. Medicare and Social Security, Medicaid and eligibility files.) In addition, race/ethnicity data are available from hospital discharge data in states contributing to HCUP, although the amount of missing data is often substantial. Most health insurers and health plans *do not* routinely record this information, making it extremely difficult to measure utilization or quality for different race/ethnic subgroups. A recent review of all state laws regarding collection of race/ethnic data by health plans was recently published by the Commonwealth Fund and SHIRE Health Institute, and highlights that it is possible to collect race/ethnic data in all states. Laws in a few states preclude its collection prior to health plan enrollment. Efforts to encourage collection and use of race/ethnic data are underway in both the public and private sectors, suggesting it should be possible to use this information for future measures of access and quality.

Even when such data are available, additional issues complicate its use. In many epidemiologic databases and national access and utilization surveys, there is often insufficient sample size in minority subgroups to yield sufficient power in making comparisons between groups, especially when one is interested in information at the state or health plan level. This problem becomes even more acute when examining HEDIS or CAHPS-type measures in individual health plans, particularly within given diagnoses. Recent attempts to examine such data for Medicare+Choice health plans found no plans with at least 30 enrollees in each of the major race/ethnic classifications, and less than a dozen plans in which there were sufficient numbers of Asian-Americans or Hispanics to analyze. While there were many plans that had at least 30 African-American and white enrollees, sample sizes that small make within and across plan comparisons very difficult.

Additional issues

Socioeconomic position

Some conceptual and philosophical challenges underlie interpretation of race/ethnic and geographic differences. Foremost among them is the consideration of socioeconomic status and how it relates to race/ethnic or geographic disparities. A long literature has attempted to disentangle these relationships, finding that if SES is ‘controlled for,’ the magnitude of the disparity attributed to race or geography becomes smaller. However, such analyses are often used to dismiss the fact that serious disparities exist, and do little to disentangle the complicated relationships between factors such as opportunity, socioeconomic position, race, and discrimination, or the separate effects of education and income. Furthermore, if we accept that community level factors can present barriers to access or are etiologic in creating need, addressing them is ultimately the path to improved outcome. Some of these include conditions associated with poverty-poor access to good schools, poor housing, undernutrition, and substance abuse-all contribute to poor health. They act to impede access not only because of factors such as cost or transportation, but because the immediate needs for caring for one’s family survival often make prioritizing health needs nearly impossible. It is worth noting that both the stigma and the health consequences of being poor in an urban and a rural area often differ significantly. It is also important to keep in mind the wide variation in SES within all groups. Ultimately, this is a report about the experience of different race/ethnic and geographic populations. While some measures may not be interpretable without statistically accounting for SES, particularly those associated with need for care or burden of illness, examining the experience of minority and rural populations means that their experiences cannot be disconnected from their environments. One way to address this problem, at least partially, is to examine populations whose needs for care are as similar as possible. Controlling for health status can move us in that direction.

Cumulative effects

The relationships between access to care and key variables we have been discussing-ethnicity, insurance status, and rural residence have been extensively examined. Of note, however, is that very few studies have examined the cumulative effects of these factors. With very few exceptions, the relationship between insurance status and access or outcome has been examined *controlling for race/ethnicity*. A recent study has suggested that having a combination of variables may predict worse access or outcome than one alone; for example, being uninsured *and* Hispanic is associated with worse access than either alone. The addition of rural residence to this mix has not been examined.

Managed care

As noted above, managed care provides unprecedented opportunities to define a denominator population, and to monitor utilization, quality and outcomes for that population. Because significant penetration of managed care in rural areas is just beginning, it is probably premature to measure its effects on access there. The challenges with regard to race/ethnic data are discussed above. Nonetheless, two data sources can provide information on access for racial/ethnic minorities in managed care. The HEDIS measures for any use, mammography, and components of diabetes care are readily available from Medicare+Choice plans and

race/ethnicity data can be obtained through linking to social security data. A recent analysis indicates that across all plans, disparities remain quite substantial, but that there is wide plan-to-plan variation regarding the presence or degree of disparity. CAHPS data are available for both Medicare+Choice enrollees and the commercially insured population through the National CAHPS Benchmarking Data Set and the survey includes a self-reported measure of race/ethnicity. These include a measure of any use, any use of a specialist, and need to see a specialist. Data for both populations, even when adjusted for SES, indicate both significant disparities across all plans, and large plan-to-plan variation in the degree of disparities. Two significant problems with reliance on CAHPS data that are not present in Medicare+Choice are the degree to which cultural differences influence CAHPS scores, and the inability to examine response rates, particularly those for different race/ethnic or geographic populations.

Undercounted populations

Two distinct populations of high need may significantly skew assessments of both need for care and access. It is an unpleasant fact that minority populations, particularly African-Americans and Hispanics, are incarcerated at much higher rates than whites. Much of this is related to uneven sentencing for drug-related convictions. Currently, most population-based measures of access, including insurance status, do not include those who are incarcerated. This has led to serious undercounts of the uninsured in some areas, particularly African-American and Hispanic men. The degree to which care is accessible in prisons is highly variable, as is access to insurance after release. Most parolees do not get jobs that provide health insurance, and are ineligible for Medicaid [for 5 years...need to check this.]

The other population that is seriously underrepresented when it comes to assessing access to care or insurance status is undocumented immigrants. Many do not appear in the census or in surveys, yet they have substantial unmet health needs in both urban and rural areas.

Utilization as a measure of access

Some utilization measures that have long been considered indicators of access have been the subject of significant criticism, largely because they are felt to reflect preferences for care as much as unmet need. It has been argued that most people who are uninsured do not need or want insurance, although data consistently find this to be a small percentage of the uninsured. The issue is similar when examining the proportion with no visits, without a usual source of care, or without follow-up. When examined, only a small proportion of those without a usual source of care do not want one. The case of children and vulnerable adults is a special one; the adult acting on their behalf may not bring them for care for reasons unrelated to need; in these cases, the access barrier is often intrinsic to their caregiver. Some differences in utilization are felt to represent overuse by the white population. As is the case with socioeconomic position, stratifying measures by health status permits comparison of populations with more similar needs.

Use of emergency departments for non-acute, first contact care is a slightly different issue. Care is, in fact, accessible through emergency departments, and by law, emergency departments cannot refuse to see a patient. Increases in emergency department use are, in part, a function of not having an alternative place to go, not wanting or needing a regular provider, and convenience. This leads some to suggest that emergency department use is not an access problem, but rather, an expression of preferences. From a policy perspective, this is probably not

a desirable utilization pattern. Emergency department overcrowding has become a significant national concern, and as such, impedes access for those who truly need emergency care. Furthermore, when people seen in emergency departments are offered a primary care visit within a short time, most choose non-emergency department care.

In the setting of chronic disease, utilization patterns are likely a reflection of a combination of access and quality. For example, a set of quality indicators examines follow-up care or receipt of tests e.g. eye exam for diabetes. Such utilization is clearly dependent in part on quality, especially the provider's (or system's) recommendation for follow-up, and ability to prompt such the physician to provide, and the patient to obtain, such care. Patient follow-up is also likely to be a function of patient-centered issues, such as quality of communication, and the ability to understand the care plan. However, we must be careful not to assume that once a patient has entered the system, particularly for chronic care, that access is no longer a barrier. Co-payments frequently pose barriers to obtaining needed follow up care, as do the usual barriers ranging from transportation to availability of culturally proficient services. While it is impossible to disentangle access and quality, such measures, particularly when examined in relation to need, should also be considered in measuring access.

A final challenge in considering utilization as a measure of access relates to cultural factors that influence care seeking. A person's cultural beliefs (whether from a different country or a rural community) might lead to different definitions of illness or need for care, and in that case, many would argue that lack of care is not reflective of barriers to access. However, factors such as inability to speak the same language as the provider, fears of discrimination or that one's culture will not be respected, or prohibition by a male partner of a woman to seek care, all constitute barriers to accessing care which are reflected in utilization patterns. There is no easy solution to these problems; utilization measures must be interpreted with these issues in mind.

Principles guiding measurement of access in the National Disparities Report

Outlined below are key principles that should guide the development of access measures for the National Disparities Report.

- 1) Every effort should be made not to marginalize the National Disparities Report. This can be accomplished, in part, by assuring compatibility with the National Quality Report, and by using, when possible, the conceptual framework for understanding quality when reporting on access-related quality measures. Because equity is such a fundamental component of quality, it is expected that many quality measures will be reported by race/ethnic subgroups. Some overlap between disparities in access and quality measures should be expected, but it would be highly desirable to use similar reporting formats, where feasible. This will require close collaboration by the groups working on each report.
- 2) The National Disparities Report should be anchored in well accepted, regularly measured, existing measures of access, for reasons that include continuity, the need to 'mainstream' the report, and the fact that the process of creating and validating measures is expensive and time consuming. To accomplish this, some minority groups may need to be oversampled in order to examine disparities in access.

- 3) As has been recommended by Fiscella for the National Quality Report, measures should address access issues that are particularly relevant for minority or rural populations. To the extent possible, these measures should also be relevant for the general population, but they should focus on areas in which disparities are likely to exist. In addition to general population measures, the committee should identify a set of measures some of which may be condition specific, for which access to quality care is particularly (but not solely) relevant to minority populations. Prevalence and contribution to morbidity and mortality should guide selection of these conditions. Some measures, however, may only be relevant to specific ethnic populations, and are so important that they should not be omitted. Language access may be such an example.
- 4) While the report should be anchored in a core of existing measures, new measures need to be developed. These need to account for the trends described above, including increase in chronic disease, a broader definition of health, and a recognition that access to factors outside of the immediate delivery system have major impacts on health.

Core measures

The set of core measures traditionally considered to measure access should form the basis of this report. They are well accepted, and are relevant for all populations. Disparities are known to be of concern for all of them. Particular issues related to their use are discussed below.

Insurance status—That insurance is often a prerequisite to receiving care is undeniable. Disparities in the presence and type of insurance have been well documented, as have been the associations between insurance status and utilization, quality and health outcomes. Less well documented has been a causal the relationship between having insurance and health outcomes. Issues related to the uninsured are the subject of a separate, ongoing IOM project.

Several issues in the reporting of insurance status must be considered, and these are relevant regardless of whether the focus is disparities or the general population. First, multiple federal and private data collection efforts measure insurance status. However, each asks the questions slightly differently, and the wording of some of the measures has changed over time. Thus different surveys can yield different estimates of the rates of uninsurance, creating confusion for the public and for policy makers. These measures are well summarized in Table B1 of *Coverage Matters*. A related issue is the variation in publicly subsidized insurance plans from state to state. Many have different names; thus to be accurate, surveys need to be adapted to their local environments. Many survey respondents will not recognize Medicaid as insurance if they are asked directly if they have coverage.

The extent and type of coverage is extremely variable, and many Americans are considered uninsured relative to need. Perhaps the most common gaps in insurance are policies that do not cover primary and preventive care, and coverage for medications. Access to medications is a challenge for many seniors, and many with chronic disease. Unfortunately, when asked, a large proportion of the population does not know details of their health insurance coverage, or the procedures for obtaining care in managed care settings. Thus, although it may be desirable to measure disparities in the extent of coverage, this may not be feasible.

Proportion of adults and children without a visit, and their health status—These measures of utilization are often considered to be measures of access to care. General problems with utilization measures have been described above. While most guidelines call for young children to have preventive visits annually (or biannually for adolescents), there are not such clear standards for healthy adults other than for screening services, such as mammograms. Insurance status is one predictor of going without a visit. However, even within insured populations, minority populations are less likely to have any visits than are whites. In these cases, insurance is not a major determinant of first use. Having no visits may also reflect lack of need (real or perceived) or desire for care, or other barriers, such as language, culture or geography. This is less likely to be the case for those with chronic health conditions or those in worse health. Nonetheless, data on whether or not a visit was obtained is easily available, and reliable to the extent that race/ethnic data are accurate. As discussed earlier, stratifying by health status will help in interpretation of the data.

Regular site of care and regular provider—Measures of access have traditionally included measures of continuity of care and primary care, usually embodied in having a regular site of care or regular provider. The controversies around these measures relate primarily to the small number of individuals who do not want a primary provider, and the debate between whether a regular provider is as important as a regular system. In several studies, not having a regular site or provider was the primary reason for not seeking care when needed. With regard to obtaining preventive care or in the case of disease management, a system of care (at least those supported by information technology) is as or more important than having a regular individual caregiver. As managed care continues to evolve, attributes of the system may become more important than having a regular individual as provider. Additional issues with regard to a usual source of care have been discussed above. Nonetheless, these measures are readily available from national surveys, and the bulk of the evidence suggests they continue to be useful, particularly if conditioned on health status.

Preventable hospitalization for ambulatory sensitive conditions, stratified by population—Preventable hospitalizations for ambulatory sensitive conditions are most useful as measures of access when used alongside hospitalization for conditions that are not associated with access to care. ACS admissions are a function of access to care (they occur more often among low income and uninsured populations) quality of care, and factors that are less related to the health care system. These data are usually examined with regard to geography, and ACS admissions are more concentrated in low-income areas. The challenge here is in having enough knowledge of the denominator to know that actual rates of admission were different for different race/ethnic groups, or in stratifying the population in such a way (perhaps examining race differences within low income areas) to make the data interpretable. The census can serve that function to the extent that it is reliable, but it cannot account for disease prevalence in a community. The attractiveness of these measures is their implicit understandability and that they are readily available from HCUP data. While HCUP does not include all states, it now includes over half the states, and the number is continuing to grow. More work may be necessary for them to be most useful. A related measure, examination of primary care-sensitive of emergency department visits shows promise as a more sensitive measure of access. However, data are not yet routinely part of HCUP.

IOM Indicators—The 1993 IOM report identified a series of access indicators considered important in quality or outcome related objectives. These are discussed briefly.

Measures related to birth outcomes—Although recent studies have questioned the relationships between prenatal care (particularly the amount) and birth outcomes, they may reflect that we are victims of our own success. As it is increasingly possible to save babies born at increasing levels of prematurity, low birthweight babies have continued to rise. Other poor outcomes, such as maternal transmission of HIV or congenital syphilis remain strongly linked to prenatal care. Hence, measures of adequacy of prenatal care continue to be relevant.

Immunization—High levels of immunization for vaccine preventable illness remain important public health goals. However, several factors should be considered in the selection of immunization measures. First, as the vaccination schedule becomes more complex, we are likely to see greater disparities in use of some of the newer vaccines than older ones. This raises the question of whether being up-to-date on DPT+polio+MMR is the right measure, or whether uptake of newer vaccines (hepatitis B series, Hib and conjugate pneumococcal vaccines) are measures that are more likely to reflect ongoing disparity challenges. However, we have seen over the last decade the role of measurement in improving outcomes. An unintended consequence of switching measures may be less vigilance in the public health and provider community in achieving high rates of coverage. Second, an increasing number of parents are choosing not to immunize children for reasons unrelated to access. Whether these numbers are large enough to impact population-wide rates is unclear. Third, we now recognize that immunization is as essential for adults as for children, and that adult immunization rates are lower than those for children. A measure of access related quality for adults could include immunization rates themselves, or death from vaccine preventable illness.

Early detection and diagnosis of treatable disease—Despite the recent controversy, receipt of mammography and Pap smears continue to be important measures to care. Data indicate that preferences and culture play a relatively minor role in not receiving these services. Additional potential measures in this category are suggested below.

Reducing effects of chronic disease—The use of avoidable admissions as an access measure has been discussed above. Others are suggested in the following section.

Reducing morbidity and pain through timely treatment—As suggested by comments above, examining annual dental care visits remains an appropriate measure of access to dental care. Oral health care is known to be associated with profound disparities, associated with race/ethnicity and geography. Additionally, examining reports of delayed care when needed continues to remain an important measure of access. Incorporation of a need-based measure (such as care for serious symptoms) within it would be ideal, but data are not consistently available. It would, therefore, be useful to stratify this measure by those in fair/poor health. This would allow further inferences about timely treatment for exacerbations of chronic disease. While access for those usually in good health is also a concern, absent a need-based measure, this information is harder to interpret. Finally, as suggested below, additional measures in this area should be developed and used.

Conclusions

This section makes conclusions regarding use of existing measures, measures that take advantage of existing data or which data are readily available, and new measures that need development.

Existing measures

The following core measures should continue to serve as a foundation for the National Quality Report

- 1) Insurance status
- 2) Usual source of care and provider (stratified by health status)
- 3) Proportion of children and adults with no visits, stratified by health status
- 4) Proportion needing care and not getting it, (stratified by health status)
- 5) Preventable hospitalizations for ambulatory sensitive conditions, for both children and adults
- 6) Travel time to get to care
- 7) Adequacy and timeliness of prenatal care
- 8) Rates of congenital syphilis
- 9) Childhood immunization
- 10) Proportion of children and adults without a dental visit
- 11) Proportion with/without a mammogram or Pap test.

The need for stratification of measures 2-4 by health status has been discussed above. There is much less disagreement about the need for care for those in worse health. In the case of childhood visits or immunizations, one could still consider utilization patterns a matter of parental preferences, but as discussed earlier, children who do not get care that is generally felt to be needed may still be experiencing access barriers, even if it is because of their caregivers.

Additional measures related to points on the continuum of care are proposed below.

Staying Healthy

- 1) Rates of neonatal transmission of HIV
- 2) Proportion of children with EPSDT screening
- 3) Proportion of children screened for elevated lead levels
- 4) Distribution of housing with lead paint that has not been rehabilitated
- 5) Proportion of adolescents with no visit, and their health status
- 6) Proportion of adolescents with up to date vaccination
- 7) Proportion of adults with pneumococcal or influenza vaccine
- 8) Deaths from pneumococcal pneumonia
- 9) Deaths from complications of influenza
- 10) Rates of colon cancer screening by flexible sigmoidoscopy or colonoscopy
- 11) Proportion without a blood pressure check in past two years
- 12) Proportion without cholesterol screening
- 13) Proportion of diabetics whose first presentation is with end organ damage.
- 14) Proportion of individuals with end stage renal disease whose first presentation is for dialysis
- 15) Proportion of population with fluoridated water
- 16) Proportion of adults who are edentulous

Related to the goal of promoting good birth outcomes, rates of neonatal HIV transmission could easily be examined. However, those rates are falling rapidly, and may not provide additional information to that about congenital syphilis.

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In the domain of staying healthy, a goal of promoting healthy development should accompany the goal of promoting good birth outcomes. These would include measures of developmental screening and screening for lead. Measures of lead prevalence and screening have the advantage of addressing a community health issue, which ultimately is access to lead free housing.

Adolescents are a largely forgotten population when it comes to examining access, and disparities exist here as well. Measurement of access is made more difficult by the fact that many adolescents use confidential services. Standard questions about whether the adolescent received any care, and needed care but delayed/did not get it, should be added to the CDC's Youth Risk Behavior Survey, at which time they could replace the measure of the proportion of adolescents with no visit, and their health status. A parallel series of questions regarding mental health care should also be added in view of the high prevalence of depression and suicidal ideation reported on those surveys.

Immunization is an issue not only for children, but also for adults. Currently, the race/ethnic disparities in adult immunization are significantly greater than those for children. Data on adult immunization are available from the BRFSS and Medicare claims.

Preventing complications of disease through early detection and treatment continues to be goal of care. Currently, cancer screening for women is the most widely accepted measure, and monitoring cancer screening rates has done much to increase them. Colon cancer screening should be added to this list because it impacts men as well as women, and is a costly procedure (as well as an unpleasant one) in the absence of health insurance. Data are readily available from claims data for the Medicare population. A data source for the 50-65 year old population will need to be developed. While some would argue that non-receipt of these tests is largely a reflection of personal preference, it remains the case that the most common reason they are not done is lack of physician recommendation. To the degree that personal preference is a function of cultural beliefs or practices, understanding them will help develop interventions to improve screening.

Cancer screening is not the only way to prevent complications through early screening. Avoiding complications of chronic diseases such as diabetes is achievable with access to high quality care, but requires that the individual know they have the condition and need care. Developing measures of delayed detection (analogous to late stage presentation of cancer) should be possible using by using claims data to examine presence of end organ damage at presentation. Other data sources such as NHANES may also provide this information. The same situation is true for the relationship between hypertension, cholesterol and heart disease; but data regarding hypertension screening and cholesterol awareness are currently available from BRFSS. These measures would reflect the role of community/public health in identifying the need for care that triggers attempts to access the system, as well as quality for those in care. Because chronic renal failure is such a prevalent condition among some minority populations, examining rates of presentation of renal failure whose first presentation is dialysis would be a similar indicator. In this case, data are available from the ESRD program.

Finally, the proposed measures for oral health care (% with access to fluoridated water and percent of adults who are edentulous) serves to assess both a community level factor and long term access to quality dental services. .

Getting better

- 1) Rates of knee or hip replacement for arthritis among Medicare beneficiaries
- 2) Time to, and receipt of thrombolytic therapy for an acute MI
- 3) Mental health provider accessibility
- 4) Proportion of the population who needed mental health care but did not receive it
- 5) Rates of admission for serious mental illness
- 6) Proportion of admissions for mental health care without a follow up visit in 30 days
- 7) Rate of suicide
- 8) Proportion of those needing substance abuse treatment who did not receive it
- 9) Substance abuse provider accessibility
- 10) Breast cancer survival, adjusted for stage at presentation

The first two measures examine access to effective but costly care, and both are known to be associated with disparities. The mental health measures examine the supply of mental health providers in a community (there are fewer in minority and rural communities), and unmet need. Admission for serious mental illness, like admission for asthma or heart failure, is largely avoidable through access to high quality care, while the underlying prevalence of seriously mental illness is similar across all race/ethnic groups. Finally, rates of suicide serve to reflect community level of depression awareness as well as access to mental health services. Suicide rates among Native Americans are quite high, and they are increasing rapidly in African-American men. In the long run, rates of successful and unsuccessful suicide attempts would serve as a better measure, but it will need to be further developed. One exception would be for adolescents, where data on suicide attempts are reported through the YRBS.

The proposed measures regarding substance abuse reflect the importance of this problem for the population as a whole, the reported disparities in access to substance abuse treatment, and the particular role that substance abuse plays in the HIV epidemic.

The proposed breast cancer measure reflects the fact that the gap between African-Americans and whites with regard to breast cancer screening has been largely closed. Adjusting for stage at diagnosis also permits examination of populations with similar needs. Because equal treatment is felt to lead to equal outcomes, this measure likely reflects access to high quality care.

Living with illness or disability:

- 1) Proportion of HIV infected individuals who know their status
- 2) Proportion of HIV infected individuals who know their status and are receiving care
- 3) Proportion of ESRD patients referred for transplant evaluation or receiving renal transplant
- 4) Proportion of Medicare patients admitted for heart failure or acute MI who saw a specialist
- 5) Proportion of diabetics who received an eye or foot exam from a health professional
- 6) Proportion of diabetics who saw a nutritionist for counseling
- 7) Availability of Medicaid coverage for older adults below 200% FPL

The HIV epidemic disproportionately impacts minority communities. These proposed measures reflect access that is dependent on the functioning of the public health system as well

as entry and remaining in the health care system itself. Disparity in access to specialty services for people with chronic disease is a well-documented problem. The issue of renal transplantation was previously discussed. Use of this specialty measure for heart disease obviates the need to risk adjust to examine differential use of procedures. The diabetes measures reflect the evolving needs for disease management and team care. Diabetes is the recommended disease entity here because disease management has been best studied for this condition, and because of the high prevalence of diabetes in Hispanic, Native American and African-American populations. Data, at least for Medicare and Medicaid beneficiaries are readily available. Data from health plans are only available now to the extent that race/ethnicity data are available. Certainly, insurance coverage for elderly with chronic disease remains an issue in securing care for chronic disease.

Care at the end of life

- 1) Proportion of Medicare beneficiaries with death from a cancer diagnosis that received hospice services or home care in last 6 months of life
- 2) Proportion of Medicare or Medicaid beneficiaries with a death from HIV that received hospice services in last 6 months of life
- 3) Proportion receiving care in a skilled nursing facility in last year of life
- 4) Availability of Medicaid coverage for older adults below 200% FPL

Unfortunately, all of the recommended measures are based on utilization that is likely to reflect personal and cultural differences in preference for end of life care, and they will need to be interpreted in that light. Contrasting patterns of end of life care for cancer and HIV will enable examination of disparities in care for conditions with different degrees of social acceptance.

Indicators relevant to the entire continuum of care

- 1) Race/ethnic distribution of matriculating medical, dental and nursing students
- 2) Proportions of race/ethnic and urban/rural populations with internet access
- 3) Literacy, especially health literacy

Demographic characteristics of the emerging workforce are available from each of the professional societies and are one way to examine access to culturally appropriate care. Information regarding internet access is available through the Department of Commerce. This may serve as an indicator of access to information. The Department of Education is scheduled to begin data collection in Summer, 2002 on the NAALS (National Assessment of Adult Literacy Survey). A question regarding access to care is currently planned. This will facilitate further understanding of the relationships between literacy and access, as well as a direct assessment of literacy.

Measures that need to be developed

Measures most in need of development are those that reflect various aspects of culture, and the community role in access to care. These are described below.

- 1) Stereotyping/bias/discrimination- Many feel that conscious or unconscious bias can account for much of the difference in care that has been documented primarily between African-Americans and whites. While this has been easier to measure in other settings

such as housing or banking, in which testers can be used, it is more difficult in the health care setting. It may be possible to develop a community-wide measure of discrimination based on testing or measures of housing segregation, although this will be more of a population based measure. Kaiser Family Foundation has collected data on differences in perceptions of discrimination between whites Hispanics and African Americans. Such measures could be useful in examining macro-level trends if they were to be collected regularly. They have not yet been related analytically to other measures of access or care.

A related issue is trust, relevant for both the individual provider and the system overall. Here, some measures have been developed, and these show widely different levels of trust, at least between whites and African-Americans. However, these are not widely collected, or collected in association with information about race/ethnicity.

- 2) Cultural competency-Measures that examine cultural proficiency of the individual provider and of a health care institution are currently under development through funding from HRSA and the California Endowment.
- 3) Language access- While the DHHS Office of Civil Rights has promulgated standards for language access, there are not yet regularly accepted ways to assess this. Both institutional and patient-reported measures are critical, as this is one of the more actionable domains of access. New measures should consider whether language access is available and assess its quality.
- 4) Measures of community/public health contribution to access- The need for these measures, and some proposals for them, have been discussed above. One approach would be to develop measures that compare estimated incidence of disease in a community or population to actual rates of detection/reporting. This would probably easiest for a reportable disease, such as HIV, but ultimately might be applicable to other chronic diseases.

Access to information and education about health risks and behaviors should occur both in the community and in the personal delivery system and measures that assess that need to be developed. Again, awareness of the need for care often stimulates health-seeking behaviors. Cultural beliefs, values and opportunities that exist within communities all impact on the perceived need for care and care-seeking behavior. Community-level measures have not been well developed. Substantial work is needed in this area.

Finally, many would argue that access to communities with a low presence of conditions that are responsible for underlying causes of disease ought to be included in a report about disparities in access. These might include levels of educational attainment, employment, housing quality or access to supermarkets. If the committee wishes to pursue such measures further, they can be addressed in a subsequent draft of this paper.

- 5) Measures of access to specialty care and to disease management services-

As chronic diseases become more prevalent and complicated to treat, access to specialist may be necessary to achieve the best possible outcome. Utilization measures are fraught with the problems described above. Self-reported measures can be constructed from the measures of need to see a specialist and whether one actually saw one that are used in some CAHPS survey efforts. However, these measures rely on the patient’s understanding that specialist care is needed. As in the HIV and renal transplant examples, not knowing that care is needed is a major barrier to access. An additional, more general measure would be useful.

- 6) Better measures of access to mental health and oral health care, based on need.
- 7) Better need-based - measures that are both general and disease specific– Problems with interpreting utilization data in particular, and knowing whether access and use were appropriate to need, point to the necessity.

Summary

A combination of existing measures, measures that can be developed from existing data, and new measures should be included in the National Quality Report. When utilization measures are used as access measures, comparisons of groups with similar health needs will facilitate interpretation. Additional measures, particularly those representing the contribution of community and public health measures to access, and those focusing on prevalent health conditions in minority populations, should be developed.

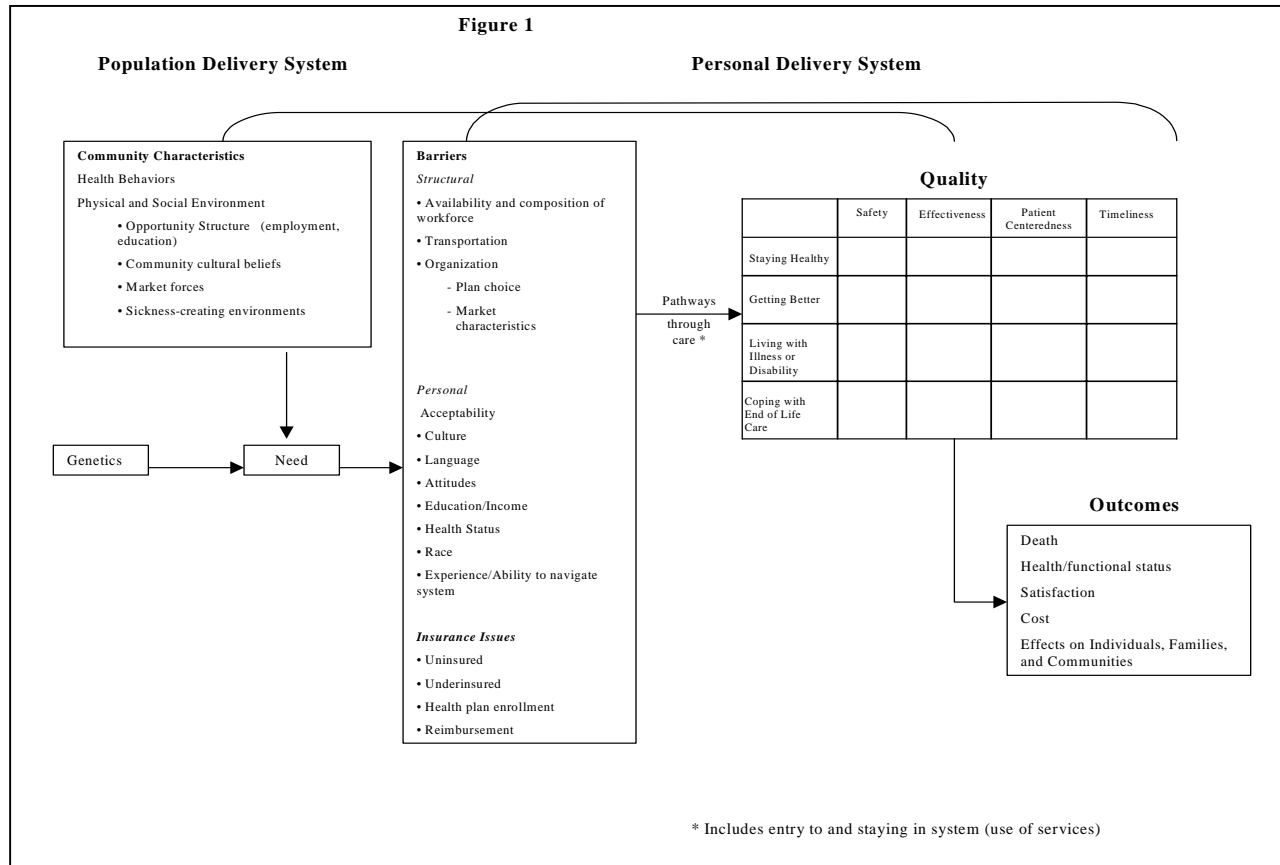


Figure 3: Relationships between Access to care, Community and health care quality: Some examples

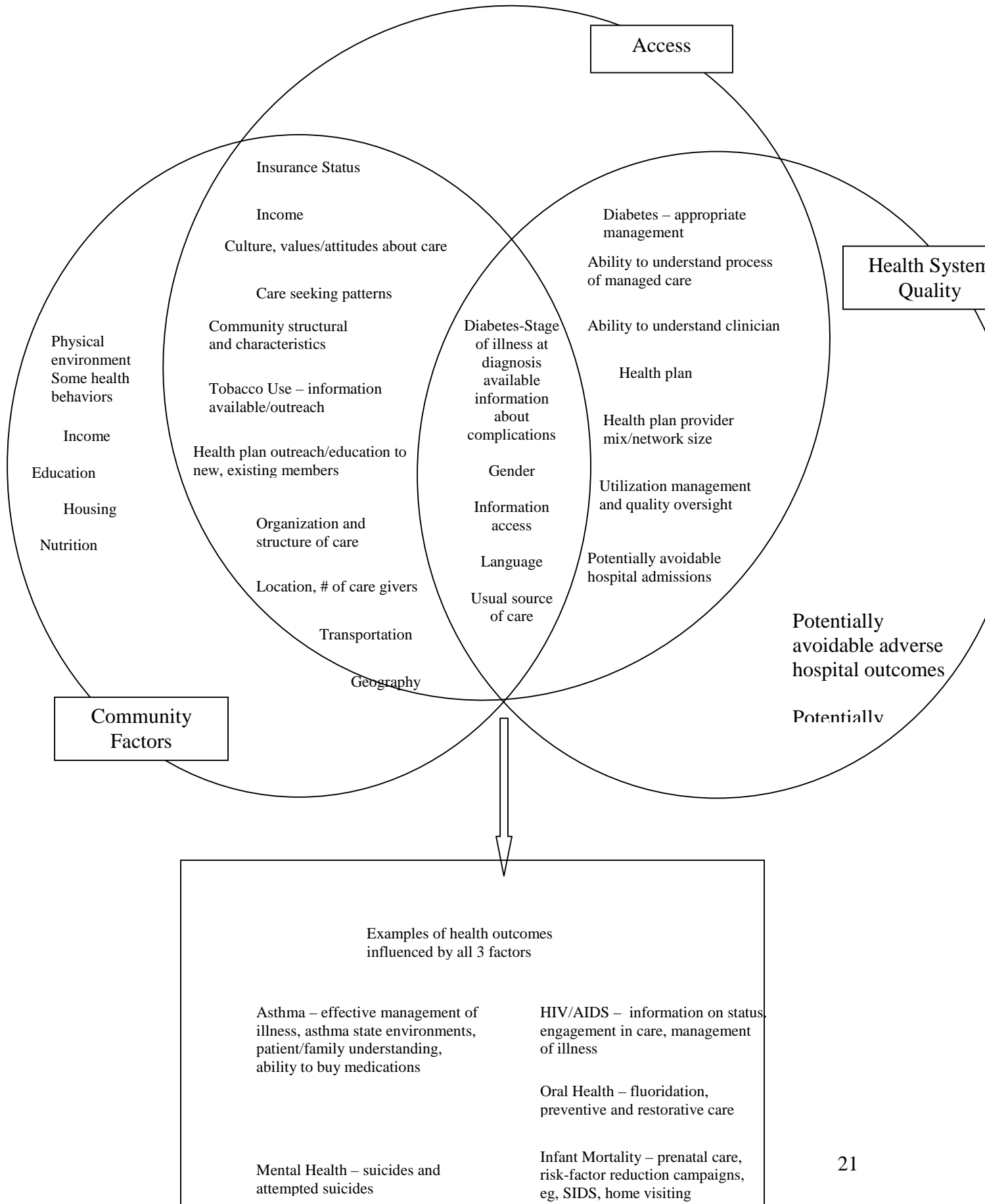


Figure 2: Examples of Access-Related Quality Measures

	Components of Health Care Quality			
Consumer Perspectives on Health Care Needs	<i>Safety</i>	<i>Effectiveness</i>	<i>Patient Centeredness</i>	<i>Timeliness</i>
<i>Staying Healthy</i>		Mammogram rate Pap Smear rates Prenatal care Immunization Hypertension awareness Cholesterol awareness	Ability to understand clinician Ability to understand process of managed care or navigate healthcare system Availability of language/interpretation services Composition of workforce Information that care is needed	Cancer screening and follow-up Preventive oral health care
<i>Getting Better</i>	Potentially avoidable adverse events Potentially inappropriate utilization of procedures	Knee replacement for arthritis Pain control	Ability to understand and follow treatment plan	Time to thrombolytic therapy for MI Time to setting long bone fracture
<i>Living with Illness or Disability</i>	Access to high-quality providers	Transplant for end-stage renal disease Foot and eye exams for diabetics	Culturally appropriate home nursing	ACS ED sensitive admissions
<i>Coping with End of Life</i>	Safe nursing homes	Effective pain management	Cculturally appropriate counseling or hospice services	Time from request for hospice to admission