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Measuring and Interpreting Health Care Quality
Across Culturally-Diverse Populations:
A Focus on Consumer-Reported Indicators of Health Care Quality

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Table of Contents

Executive Summary………………….……………………………………………………………... i

A. Purpose……………………………………………………………………………………. 1

B. Background……………………………………...…………………………………………… 4

C. Consumer-reported quality measurement…………………………………………………… 6

D. Key issues in measuring quality across culturally-diverse populations………..……………... 9

1. Matching methods to the purpose and goals for measurement…………………...………….... 9
2. Issues in identifying the population of interest……………………………………………..... 10
    a. Inconsistencies between self-identification of race/ethnicity and other data sources
    b. Heterogeneity of cultural groups
    c. Ethnicity as a continuous variable
    d. Self-reported health status and presence of health conditions
3. Issues in using consumers surveys to measure health care quality…………………………….. 14
    a. Survey content
    b. Survey translation
    c. Survey sampling
    d. Survey administration and response rates

E. Maximizing the use of existing consumer-surveys to assess health care quality across culturally-diverse populations………………………………………………………………… 19

1. Balance standardization with customized methods
2. Check translation and limit comparisons to common concepts
3. Assess metric equivalence or use survey items/scale tested for equivalence
4. Build validity checks into survey administration and analysis of data
5. Create profiles of performance and examine within group results
6. Contextualize interpretation of results
7. Communication of findings in a culturally sensitive manner
8. Complement quantitative data with qualitative findings

F. Additional priorities for future research and action…………………………………...….. 26

1. Inventory and adapt existing tools
2. Develop and diffuse innovative methods and models
3. Support consumer driven measurement and improvement strategies
4. Build the information infrastructure

G. Conclusions…….……………………………………………………………………….. 30

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Executive Summary

Differences in health status, use of health care services and health care quality have been documented across a wide range of demographic and socioeconomic subgroups (83-88). We observe differences across racial/ethnic groups, between men and women, across age groups, among people who vary in terms of their educational level and economic resources as well as across those living in different geographic areas. The direction and magnitude of these differences varies depending upon the specific population or health issue studied. Yet, in general, it is often minority groups and other population subgroups that are known to experience some form of discrimination whose health status is indeed poorer and/or risks to health increased. National attention has increasingly focused on the need to incorporate into quality measurement and improvement efforts the identification and elimination of cultural, racial and ethnic disparities in health care quality (1-4, 8).

A major focus of health services researchers has been to understand the association between observed differences in health status and risks to health and the availability, access to, organization and quality of health care services, with an emphasis on understanding the role of the availability and access to health care services. More recently, studies have begun to focus on documenting differences in health care quality that suggest that variations in health status and risks to health are also a function of disparities in the quality of health care individuals from different demographic and socioeconomic groups may receive. In particular, recent efforts focus on variations across racial and ethnic groups and efforts to reduce disparities in health and health care quality among these groups.

The gap between recommended standards of care and improved health outcomes for patients and what is actually experienced by American health care consumers has been widely acknowledged as a "chasm" (2). This is especially true for individuals who are more vulnerable due to their economic or social circumstances or because they are members of populations more likely to experience discrimination. As such, national, state and local efforts to measure and improve health care quality emphasize the importance of stratifying information about health outcomes and health care quality

according to race, ethnicity, language as well as other variables commonly associated with vulnerability such as socio-economic status and gender. (1-4)

Public and private sector purchasers, health care plans and providers face the challenge of demonstrating the provision of high quality and culturally sensitive health care. In turn, the assessment of health care quality for culturally-diverse populations is of increasing importance and relevance. Substantial work has been done in the area of culturally-competent care – improving the health care delivered to culturally-diverse populations and ensuring that care is appropriate, culturally-sensitive, and effective. (70, 95) Work has also been done to help health care organizations to conduct self-assessments of the degree to which they are culturally sensitive and competent. (92-94)

Less work has been done to ensure the valid and meaningful assessment of health care quality for culturally-diverse populations using information shared from members of these cultural groups themselves. (92, 96-97) Today, while numerous measures are available and in use to evaluate quality, very little information is actually made available to consumers, purchasers, providers or policymakers that compares quality across cultural groups. We observe that even in cases where the required data is available, users speculate about its validity, relevance and proper interpretation.

Many of the aspects of health care quality recommended be assessed require the use of consumer or patient-reported surveys, many of which have been developed and are available for this purpose. When we use consumer survey data to assess racial and ethnic differences in health care quality, it is important to assure that we are accurately and validly assessing variables on both sides of the equation. That is, we want to accurately measure both the construct of health care quality and the variables of race and ethnicity. Issues regarding consumer-reported surveys range from the relevance of the content, design and translation of these tools, to survey sampling, administration and analysis of data to create a picture of health care quality within and across cultural groups. Among the many issues relevant to the use of consumer-reported surveys of health care quality for culturally-diverse populations, three overarching issues require careful attention:

1. Matching methods to the purpose and goals for measurement
2. Issues in identifying the population of interest
3. Issues in the design and administration of survey tools

In addition to these broader issues, there are a number of potential problems with the reliability, validity and meaningfulness of assessing racial and ethnic differences in health care quality using available consumer-based survey methods. Several strategies can help ameliorate potential problems and maximize the use of existing measures with culturally-diverse populations:

1. Balance standardization with customized methods
2. Check translation and limit comparisons to common concepts

3. Assess metric equivalence or use survey items/scale tested for equivalence
4. Build validity checks into survey administration and analysis of data
5. Create profiles of performance and examine within group results
6. Contextualize interpretation of results
7. Culturally sensitive communication of findings
8. Complement quantitative data with qualitative findings

An extensive list of research and actions are required to advance the valid measurement and communication of health care quality and to use this information to stimulate and track success in efforts to reduce in disparities in quality across culturally-diverse populations. However, four action steps address immediate needs and opportunities in this area:

1. Inventory and adapt existing tools and fill measurement gaps
2. Develop and diffuse innovative methods and models for measuring and communicating quality information
3. Support consumer-driven measurement and improvement strategies
4. Build the information infrastructure

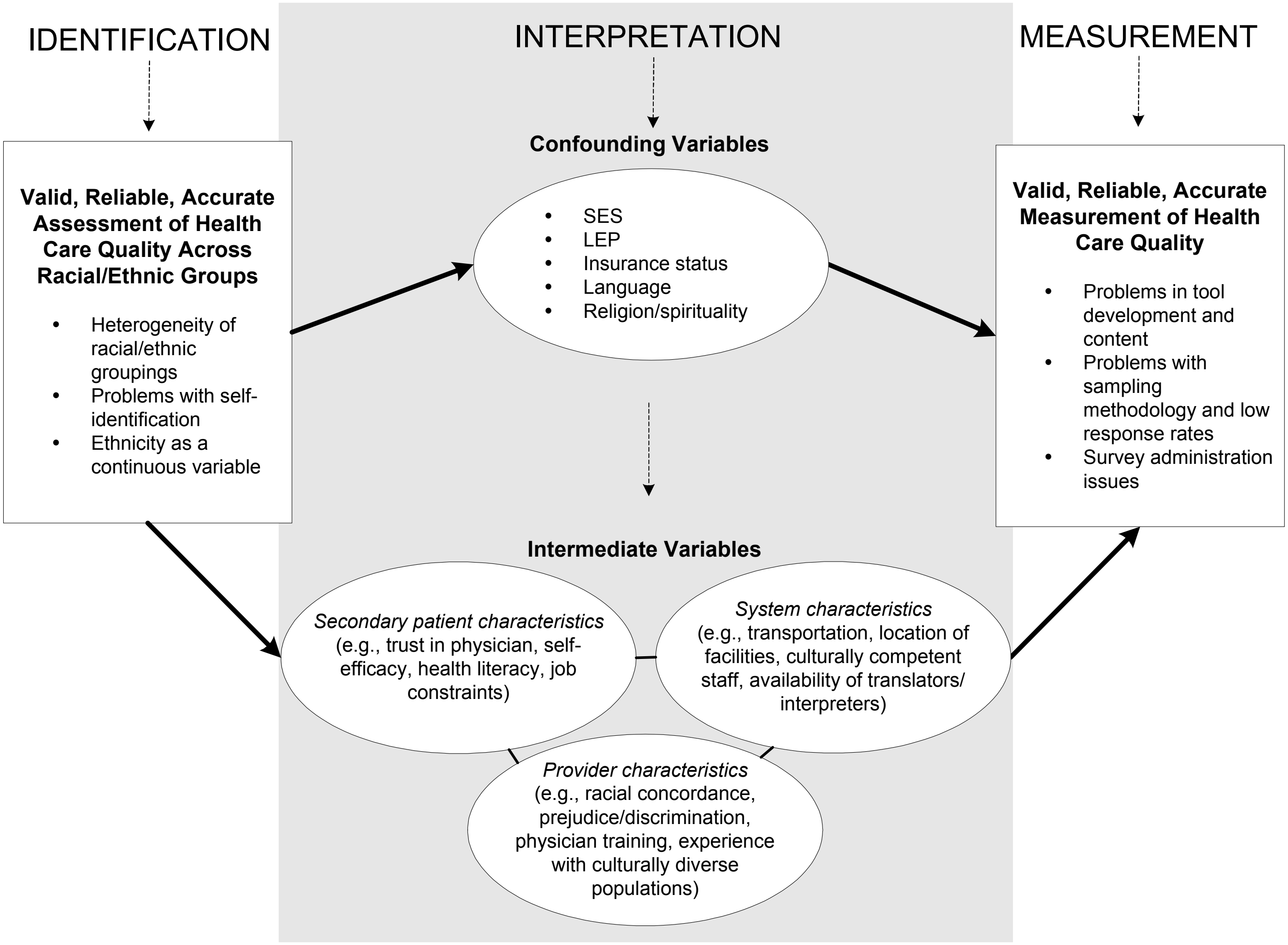
In recent decades, several federal agencies have emphasized the importance of improving the quality of health care delivered in the U.S., and various entities pursue the worthy goals of measuring, reporting and improving health care quality, and encouraging others to do so. The National Committee on Quality Assurance (NCQA) developed the Health Plan Employer Data and Information Set (HEDIS®) measures, and the Institute of Medicine (IOM) has produced numerous reports and calls for measuring and addressing health care quality concerns. The federal Agency for Healthcare Research and Quality (AHRQ) developed the National Quality Measures Clearinghouse (NQMC), and is also producing the National Health Care Quality Report (3) and the National Health Care Disparities Report (4) based on IOM recommendations. All of the efforts underway to address health care quality in America struggle with the issue of validly assessing health and health care quality across culturally-diverse populations and shaping the health care system to meet their needs in a way that addresses the added vulnerability that comes with being a minority in any population.

Our review of the literature, discussions with experts and others and our own experience in this area lead us to conclude that significant progress has indeed been made in recent years to validly assess disparities in health and health care quality across culturally-diverse populations. Yet, collectively, our work is in at a very nascent stage -- we lack even a basic inventory of candidate measurement tools for measuring quality across culturally-diverse populations and only a handful of reports comparing health care quality within or across cultural groups can be found at the national, state or local levels.

Currently, there is no agreed upon manner for using existing tools or developing new methods for assessing cultural competency from the point of view of the consumer or patient. Such consensus on a standardized measurement method is essential when comparing information across groups. However, some level of customization in the design and administration of consumer-reported quality surveys is acceptable and desirable to ensure the relevance of these tools and their ability of obtain information from representative samples and different racial and ethnic subgroups. These and other issues can and should be addressed using successful measurement development models such as that used in the development of the CAHPS survey and in the Child and Adolescent Health Measurement Initiative (CAHMI).

It is important to enter into this work understanding that while measurement biases can be minimized, they can not be eliminated. Therefore interpretation of data and results must take into account biases those can not be minimized through modifications to the design or administration of consumer-based quality surveys. Interpretations must be informed by a concrete understanding of the perspectives and values of the culture being assessed and this information is often best attained through qualitative methodologies. In short, we can not measure, interpret or communicate information about health care quality across culturally-diverse populations in a valid or actionable manner without full collaboration with individuals and organizations committed to and deeply familiar with these populations. Much work remains for this to become the norm in the development and use of health care quality measures in America.

Figure 1: Assessing Differences in Health Care Quality Across Culturally-Diverse Populations:
A focus on consumer-reported measures



A. Purpose and focus of paper

Public and private sector purchasers, health care plans and providers face the challenge of demonstrating the provision of high quality and culturally sensitive health care. In turn, the assessment of health care quality for culturally-diverse populations is of increasing importance and relevance. Substantial work has been done in the area of culturally-competent care – improving the health care delivered to culturally-diverse populations and ensuring that care is appropriate, culturally-sensitive, and effective (70, 95). Work has also been done to help health care organizations to conduct self-assessments of the degree to which they are culturally sensitive and competent (92-94). Less work has been done to ensure the valid and meaningful assessment of health care quality for culturally-diverse populations using information shared from members of these cultural groups themselves (92, 96-97).

While numerous measures are available and in use to evaluate quality, very little information is made available to consumers, purchasers, providers or policymakers that compares quality across cultural groups. We observe that even in cases where the required data is available, users speculate about its validity, relevance and proper interpretation. Questions remain regarding how to define, measure and report on quality for different cultural groups, especially when consumer-reported surveys are used. We know that culture influences expectations and may also influence some reported experiences of health care and health care quality. Cultural influences, survey translation and administration, and the traditional biases inherent in the health care system cloud attempts to measure quality, often leaving purchasers, providers and consumers unable to draw any definitive conclusions for performance assessment or quality improvement.

The purpose of this paper is to identify key issues and opportunities to advance the state of the art in consumer-reported measurement and communication of health care quality information for culturally-diverse populations. We focus on the issues of identification, measurement and interpretation of results from consumer-reported surveys of health care quality. See Figure 1.

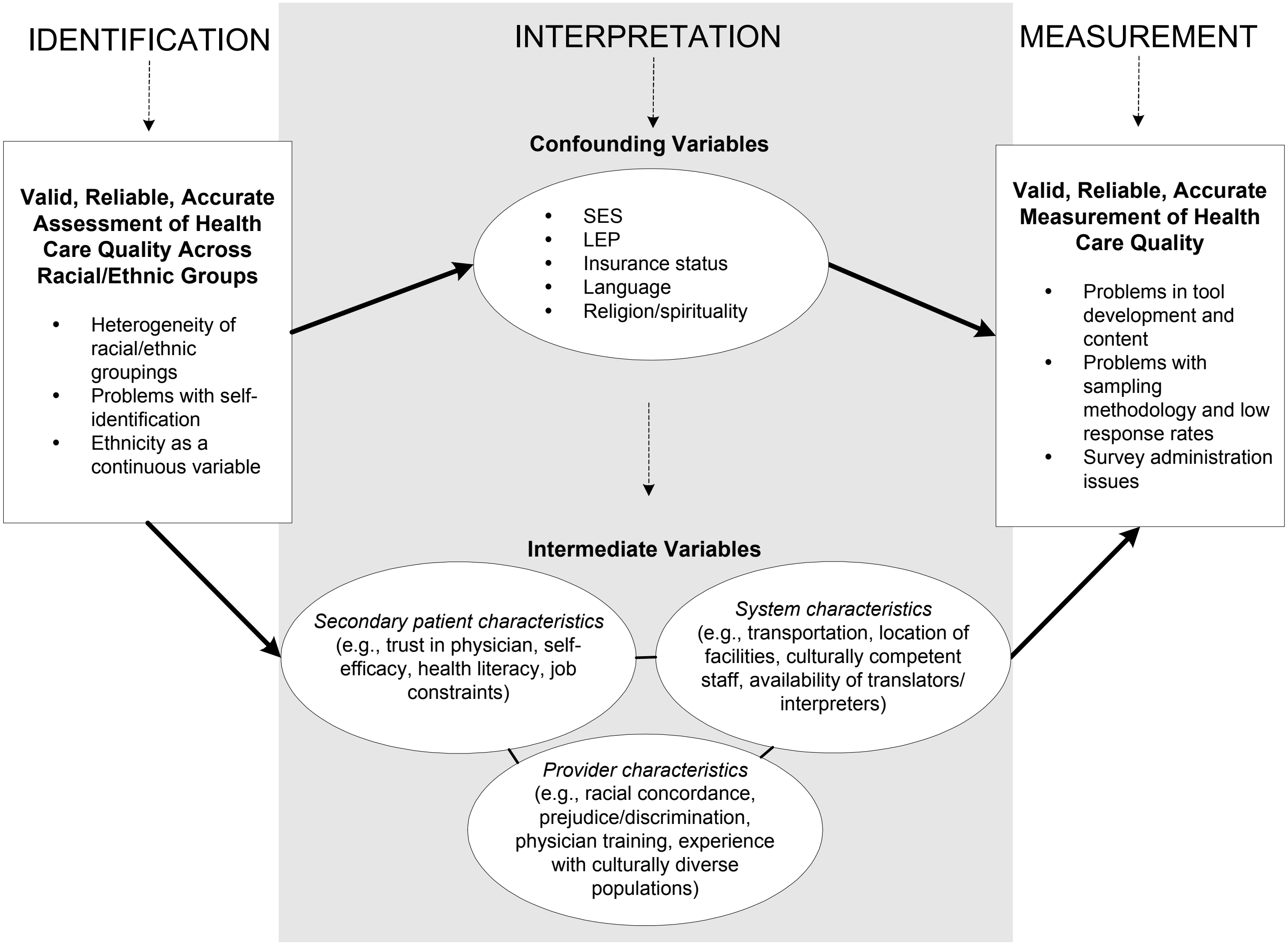
In order to narrow the scope of this report, we have chosen to focus on the Hispanic population, although the issues raised are largely relevant regardless of the cultural group of focus. There is an urgent need to understand the health care issues facing Hispanics in the U.S. and the measurement of health care quality for this population. According to projections made by the U.S. Census Bureau, by 2005, Hispanics will comprise the largest minority group in the U.S. (25). In 1996, the Hispanic population in the U.S. was larger than the total population of most Spanish-speaking countries (26). Furthermore, as the growth rate for this group is three times that of the American population as a whole (26), this population can be expected to continue to grow rapidly.

Presumably as a result of poorer quality of care, Hispanic-Americans experience fewer positive outcomes than do Whites. Hispanics living in the U.S. experience higher rates of pancreas, colorectal, stomach, liver and cervical cancer (38, 39). Hispanics in the U.S. also have a higher prevalence of obesity and diabetes, two conditions that increase the risk for coronary heart disease (40, 41). Hispanics also have higher death rates from liver cancer, diabetes and HIV than do Whites (42). Hispanic women are more likely to be diagnosed with advanced breast cancer (43), and Hispanic men are more likely to have uncontrolled hypertension (40). Among children, Puerto Ricans are four times more likely to have asthma than are whites (44).

Existing research on utilization-based measures of health care quality more often than not indicates that Hispanics and other minority group members are less likely to receive recommended care compared to Whites. For example, Hispanics receive fewer mammograms, Pap smears, influenza vaccinations, and less analgesia for metastatic cancer (7, 27, 28, 29) than Whites. Hispanic patients are also less likely than Whites to receive prenatal care (7, 29). Furthermore, when language is a barrier, these differences are more pronounced (27).

There are data to suggest that Hispanics experience lower levels of overall satisfaction with their health care than do Whites (29, 30) and more negative patient-physician interactions (28, 30, 31, 32, 33, 34, 35). Hispanics also report having less confidence in their physicians (9, 28, 30, 35, 36), and fewer instances of receiving important preventive counseling (e.g. for smoking cessation) (30). These differences are usually more pronounced for Spanish-speaking Hispanics (27, 37). Not all studies indicate poorer quality care for Hispanics (32, 37, 45, 46, 47).

**Figure 1: Assessing Differences in Health Care Quality Across Culturally-Diverse Populations:
A focus on consumer-reported measures**



B. Background

Differences in health status, use of health care services and health care quality have been documented across a wide range of demographic and socioeconomic subgroups. We observe differences across racial/ethnic groups, between men and women, across age groups, among people who vary in terms of their educational level and economic resources as well as across those living in different geographic areas. (9, 83-89) Epidemiologic studies often demonstrate striking differences in the prevalence of chronic conditions and disabilities and the impact of these conditions on daily functioning and quality of life as well as variations in the underlying biological, environmental, social and behavioral risks to health. The direction and magnitude of these differences varies depending upon the specific population or health issue studied. Yet, in general, it is often minority groups and other population subgroups that are known to experience some form of social discrimination whose health status is indeed poorer and/or risks to health increased.

When differences in health status and risks to health are assumed to be or understood to be a function of mutable factors that can be addressed through changes in policies or programs serving different population subgroups we often term observed variations “disparities”. Labeling differences “disparities” suggests that the groups for which health is less optimal are at a disadvantage because of factors associated with being a member of a certain demographic or socioeconomic subgroup and that these factors can be influenced such that disparities will be reduced. Researchers from a variety of fields examine this issue – studying the causes of variations in health and working to develop and evaluate strategies for reducing disparities.

Sociology and anthropology researchers often evaluate the social and cultural underpinnings of differences in health status, seeking to understand whether social and cultural factors vary systematically across demographic and socioeconomic groups in a way that contributes to observed differences in health and health risks. In contrast, rather than attributing variations to factors that systematically vary across groups, environmental scientists, biologists and psychologists often assess whether differences can be attributed to idiosyncratic variations in a person’s individual attributes and circumstances, such as the physical environment in which people live and variations in genetic propensities toward illness or personality. Results from these studies tend to favor strategies that focus on high-risk individuals rather than on populations of people who share overarching demographic characteristics or socioeconomic circumstances.

Whether we conclude that differences in health and health risks are a function of factors that systematically vary across groups or that the relevant factors vary as much or more among individuals within those groups than between them will greatly influence strategies to address disparities. Research supports both conclusions. Yet, the evidence is growing that, indeed, many factors that account for observed disparities in health status vary systematically across different demographic and socioeconomic groups and are within our reach to address.

A major focus of health services researchers has been to understand the association between observed differences in health status and risks to health and the availability, access to, organization and quality of health care services, with an emphasis on understanding the role of access to health care services. Results from these studies have shaped efforts to expand health insurance coverage and improve access to health care services for vulnerable populations. More recently, studies have begun to focus on documenting differences in health care quality that suggest that variations in health status and risks to health are also a function of disparities in the quality of health care individuals from different demographic and socioeconomic groups may receive. In particular, recent efforts focus on variations across racial and ethnic groups and efforts to reduce disparities in health and health care quality among these groups, especially for non-English speaking, limited English speaking and lower income members of minority racial and ethnic groups.

Changing U.S. demographics and known variations and deficiencies in quality of care provided to racial and ethnic minority groups make the identification and elimination of racial and ethnic disparities compelling issues. About 30 percent of the American population are members of a racial or ethnic minority group (7). According to the U.S. Census Bureau, the number of non-White children will surpass that of White children in the U.S. by 2040 (10). Furthermore, approximately 45 million people in the U.S. speak a language other than English at home, and approximately half of these have a limited command of the English language (11).

National attention has increasingly focused on the need to incorporate into quality measurement and improvement efforts the identification and elimination of cultural, racial and ethnic disparities in health care quality. National efforts to advance these goals include the U.S. Department of Health and Human Services' (DHHS) Healthy People 2010 initiative's aim to eliminate health disparities (6), the National Quality Forum's recommendation to implement 10 steps to improve the quality of health care provided to culturally-diverse populations (7), the US Department of Health and Human Services' (DHHS) Office of Minority Health's publication of National Standards for Culturally and Linguistically Appropriate Services in Health Care (8), the Institute of Medicine's effort to understand and eliminate racial and ethnic disparities in health care (CLAS) (9), and Agency for Healthcare Quality and Research's production of an annual National Healthcare Disparities Report (4). In addition, many state Medicaid programs are required or encouraged to collect racial and ethnic data on health care quality and/or to report disparities (5).

C. Consumer-reported quality measurement

Health care quality is defined as “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (1). The gap between recommended care and expected outcomes, and what is actually experienced by American health care consumers has been widely acknowledged as a “chasm” (2). Significant advancements in the measurement and reporting of health care quality have occurred in recent years. These advances focus on using quality measurement and reporting for the following purposes:

- to evaluate overall quality of care delivered to U.S. residents
- to rate and compare health plans, providers and facilities, as one way to hold health care providers and plans accountable for the care and service provided
- to identify problem areas, and inform efforts to improve care and health outcomes
- to educate consumers about health care quality and to empower them to make well-informed choices about health care
- as components of pay-for-performance compensation systems.

In 2001, the Institute of Medicine specified a framework for health care quality measurement and reporting that consists of two dimensions – assessing the components of health care quality and assessing the health care system’s ability to respond to consumers’ health care needs. The components of quality addressed in the first dimension are safety (diagnosis, treatment, and health care environment), effectiveness (preventive care, acute/chronic/end-of-life care, appropriate procedures), patient-centeredness (communication and caring, education and teamwork, consumer empowerment, systems of care) and timeliness (access, for a particular problem, within an episode of care, across multiple episodes of care for a particular problem). The second dimension identifies four consumer perspectives on health care needs: staying healthy, getting better, living with illness or disability, and coping with the end of life (2, 3). The goal of the framework is to clearly define health care quality, and to develop a matrix that can be populated with relevant quality measures. The framework is explicit in recommending the stratification of quality measures according to race, ethnicity and socio-economic status. Many of the patient-centered care, effectiveness, safety and timeliness aspects of health care quality recommended be assessed and reported by the IOM require the use of consumer or patient-reported surveys or can be reliably and validly measured using such tools. Fortunately, many such tools have been specifically designed for this purpose, although, while often translated into Spanish, few have been fully tested and adapted for use across culturally-diverse populations (96).

The two other data sources often used to measure health care quality in the areas emphasized by the IOM often do not include variables indicating the race, ethnicity or language of individuals, limiting their value for comparing quality across these groups. These two other sources of data are: (1) electronic records of utilization of services, often termed billing or administrative data and (2) hard-copy or electronic medical charts.

Each source of data for developing measures of health care quality has benefits and drawbacks. **Administrative data** are useful for counting specific services or transactions that are associated with discrete payments. For this reason, they are often used for computing utilization rates and procedure-specific "process" measures, particularly in fee-for-service reimbursement systems. This type of data provides no information about whether those who needed a service got it, whether those who got it needed it, or the quality or outcome of a service. Administrative data are also recognized as being notoriously subject to gaming and variations in coding and recordkeeping practices. After five years of HEDIS implementation, for example, virtually all HMOs ceased to rely solely on the administrative data method and moved to a "hybrid" methodology that counted supplementary data drawn from charts or surveys (12, 13, 14).

Medical charts can be rich sources of quality information, and provide an opportunity to look at history and comorbidity, care process, and some clinical outcomes. They are, however, extremely costly to review, physically difficult to access systematically, almost completely unstructured and uncoded, and reflect the subjective views and recordkeeping practices of individual clinicians. They rarely, if ever, include patient reports on their health or health care (15, 16, 17, 18, 19).

Historically, **consumer or patient surveys** were used primarily to generate hospital marketing reports and, more recently, for assessing the experience of consumers with managed care health plans (e.g., CAHPS®). Proponents of health outcomes research were among the first to recognize that only the patient can report on many salient objectives of care, such as pain relief, mobility, and functioning. Health status assessments, such as the SF-36 and its descendants, and quality of life measures, such as the FACT-B in cancer or the Arthritis Impact Measurement scale, are commonly used to assess outcomes.

In the 1990s, the Picker Institute developed a series of widely used tools that rely on patients to report on the performance of specific care processes, first in the context of hospital care and then for end-of-life care and ambulatory care. The Picker approach emphasized "reports" rather than "ratings" inquiring about such issues as "Did the appropriate process occur during your care?" or "How many minutes elapsed between the time you requested pain medication and the time it was administered?" The majority of patient-based surveys about health care quality have adopted this approach as well, dispelling the common myth that patient surveys are subjective assessments of satisfaction with care rather than direct reports of the quality of clinical care.

Since 1995, FACCT and other investigators have developed numerous patient-reported quality assessment tools which ask patients to report on whether specific services recommended by accepted practice guidelines were delivered. For example, was the asthma patient provided with a peak flow meter? Was the patient observed using it correctly by the clinician? Was the diabetic patient's eyes dilated and examined (for signs of retinopathy)? Studies using these tools have shown that patients can reliably report on many – though not all – of the recommended elements of quality care (20, 21, 22, 23).

In summary, many of the dimensions of "quality" can be assessed by patients, including some process measures such as conformity to practice guidelines, outcome measures such as pain relief, and experiential measures such as clear and respectful communication. Reliance on the patient for these reports has additional advantages, including use of a uniform data collection methodology (rather than relying on idiosyncratic and proprietary institutional information systems) and avoidance of provider gaming. Most importantly, the patient is the "customer" of the health care system. The patient is the user of the service and ultimately pays for the service through taxes, wages, or personal contribution.

For our purposes, however, the increasing use of patient and consumer-based measures also raises new challenges. Patients are not "objective" observers of their care any more than are clinicians (23, 24). The patient's expectations of care, communication style, educational level, primary language, cognitive abilities, and severity of illness may all affect her ability to report on specific aspects of her care. Sometimes, these considerations are central to the quality measures of interest. For example, if a patient expects to wait an hour to see a doctor, she may be more likely to report that she "usually or always" gets care as quickly as she needs. Observed variations in some quality scores hide these expectations-driven assessments of care. Other consumer-reported measures are less susceptible to these issues, and variations clearly reflect objective differences in quality of care. For example, if an asthma patient does not understand how to avoid environmental triggers in her home, because the doctor spoke too quickly or in an unfamiliar language, the quality of care was poor.

When we use consumer survey data to assess racial and ethnic differences in health care quality, it is important to assure that we are accurately and validly assessing variables on both sides of the equation. That is, we want to accurately measure both the construct of health care quality and the variables of race and ethnicity. Many concerns exist about the measurement of race and ethnicity, especially with respect to the Hispanic population – these primarily relate to the heterogeneity of the Hispanic population, problems with self-identification of race and ethnicity and health status, and ethnicity as a continuous variable. Issues regarding consumer-reported surveys range from the relevance of the content, design and translation of these tools, to survey sampling, administration and analysis of date to create a picture of health care quality within and across cultural groups.

D. Key issues in measuring quality across culturally-diverse populations

Among the many issues relevant to the use of consumer-reported surveys of health care quality for culturally-diverse populations, we emphasis three overarching issues:

1. Matching methods to the purpose and goals for measurement
2. Issues in identifying the population of interest
3. The design and administration of survey tools

Each of these issues is briefly discussed below.

1. Matching methods to the purpose and goals for measurement

A primary goal for accurately assessing racial and ethnic differences in health care quality and health outcomes is to identify problem areas, improve care in those areas, and ultimately eliminate racial/ethnic disparities in health care quality. It is widely acknowledged that everyone has an important role to play in improving health care quality – policymakers, purchasers of health care, health care providers as well as patients and consumers. Therefore each require valid and actionable information to inform the decisions and actions they may take to stimulate, shape and ensure improvements in health care and health outcomes. Yet, what information is relevant, how it is should be collected and how it is best analyzed and communicated can vary significantly depending upon the user and purpose for that information. Overall, the selection of quality measures will vary according to:

- the specific **purpose** for measurement (e.g. comparing performance vs. informing improvement efforts)
- the **audience** and use for quality information (e.g. consumers, providers, purchasers, policymakers, etc.)
- the specific **unit of analysis** for assessment (e.g. health plans, medical practices, individual doctors, geographic areas)
- the **subgroups** for which quality should be assessed (e.g. all members of a racial groups, limited or non-English speaking persons, persons with chronic illness or other risks to health, etc.)

For example, one important purpose for quality information is to make transparent the performance of health care providers and health care systems in order to ensure accountability and to stimulate efforts to improve. When comparisons across providers or systems of care is involved, highly standardized measurement tools are required and the amount of tailoring of the content, administration and scoring of quality measures is limited. However, when quality measures are used within a provider team or health system and are not designed for purposes of comparing performance, less standardization is required.

In addition to specifying the primary use for quality measures, is it critical that the unit of analysis and the specific racial or ethnic subgroups for which quality should be evaluated be specified in advance of the selection or use of quality measures. Clarifying these issues will ensure that survey sampling is designed to allow for statistically robust comparisons of subgroups of interest. It is surprising how often this issue is not fully considered prior to administering a quality measurement effort, resulting in data that lacks credibility for the very purpose for which is was collected (e.g. comparing English and non-English speaking persons within a racial group; compare people with chronic illnesses across racial groups, etc.)

Clarity about the goal for measurement will also bring to light which variables are needed for purposes of adjusting or stratifying quality measures in cases where comparisons within or across population groups or health care systems or providers is desired. For example, efforts to assess quality across cultural groups need to make clear whether the goal is to evaluate the presence of racial discrimination, per se, or to understand which subgroups within a racial group experience the greatest problems with health care quality. If the goal is to determine the presence of discrimination, confounding variables that may account for disparities in quality should be controlled for when comparing quality among different racial groups such as educational status, income and literacy. However, in other cases we seek to understand variations in care according to these confounding variables.

2. Issues in identifying the population of interest

Assessing racial and ethnic disparities in health care quality requires the accurate and meaningful measurement of race/ethnicity as well the measurement of variables for which we wish to stratify quality information, such as health status, health risks or the presence of a special health care need. Four issues that impact reliable and valid measurement of race and ethnicity are summarized here: a) Inconsistencies between self-identification of race/ethnicity and other data sources; b) heterogeneity of cultural groups; c) Ethnicity as a continuous variable (e.g., ethnic identity or acculturation); and d) self-identification of health status and presence of a health condition.

a. <u>Inconsistencies between self-identification of race/ethnicity and other data sources</u>

Determinations of the accuracy of assessing race and ethnicity requires specifying a gold standard against which to evaluate any given source of data regarding a persons race or ethnicity. Different sources of data produce different results. In addition, different data collection methods for a single source of data (e.g. consumer surveys that use different survey questions that ask about race/ethnicity) also produce different results. This lack of reliability in determining race or ethnicity is not unexpected given the complexities involved in making this determination (91). Self-identification of race and ethnicity, a method used in consumer-reported surveys, often produces results different from those obtained using administrative data or medical charts. For example, researchers have noted a 10-20 percent discrepancy in ethnic categorization between Medicaid administrative enrollment data and consumer-reported CAHPS® data (48).

The Office of Management and Budget (OMB) published Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity in 1997, in order to create consistent data collection standards for the variables of race and ethnicity. The standardized race categories according to this document are: American Indian/Alaskan Native, Asian, Black/African-American, Native Hawaiian/Other Pacific Islander, and White. The standards also stipulate two ethnic categories: Hispanic/Latino and non-Hispanic/Latino. However, even with standardized race and ethnicity categories, there still exist problems in the assessment of these variables. For example, in the 2002 National Survey of Latinos, which surveyed 2922 Latinos nationally, when asked about their preference of racial category, only 56 percent responded Latino/Hispanic, and 20 percent responded White. In the case of Cubans, this finding was even more pronounced -- more participants referred to themselves as White (55 percent) than as Hispanic (24 percent). In addition, many Hispanics identify with their country of origin rather than with the terms "Hispanic" or "Latino" (59, 75). These findings raise issues regarding whether an external gold standard can or should exist in determining race/ethnicity or if self-identification should be used as the gold standard.

b. *Heterogeneity of cultural groups*

Another issue in accurately assessing race and ethnicity is that Hispanics/Latinos in the U.S. are a heterogeneous group. Hispanic or Latino ethnicity is defined as being of "Hispanic or Latin origin or descent, such as Mexican, Puerto Rican, Cuban, Dominican, Central or South American, Caribbean or some other Latin background" (59 – p. 100). Including people from so many different cultures in one group implies that there is a shared culture across the group as a whole. However, while Hispanics share some common values like the importance of family (59, 70, 71) and the belief of a lack of control over one's destiny and future (59, 70), members of different Hispanic sub-populations vary in their attitudes and beliefs in general, their experiences with the health care system, and other health-related characteristics (40, 59, 70). Furthermore, 85 percent of those surveyed in the 2002 National Survey of Latinos (59) sponsored by the Kaiser Family Foundation and the Pew Hispanic Center agreed that Hispanics from different countries have separate and distinct cultures. This may be partly reflected in variations in care observed across these distinct subgroups. For example, we observe that breast cancer screening rates vary greatly across Hispanic sub-populations, even after controlling for factors commonly predictive of breast cancer screening (72). Health conditions also vary across subgroups (42). For example Puerto-Rican mothers are more likely to give birth to low-birthweight babies than are mothers of other Hispanic subgroups (73, 74). Rates of health insurance coverage (59) and disease-specific rates (40, 44, 71) also vary by Hispanic subgroup.

Furthermore, just as any other cultural group, Hispanics in the U.S. differ greatly on many individual-level characteristics such as socio-economic status, primary language spoken, foreign-born or native-born, and number of years living in the U.S. (40, 57, 59, 75). Some argue that by considering the heterogeneous group of Hispanics as a whole, we are obscuring the true within-group differences that exist. They suggest using these other factors as independent variables in an examination of variation in health care quality (48, 75), or defining ethnicity in a different, more accurate manner. Gimenez asserts that "...the label [of "Hispanic"] should be abandoned; social scientists and policy makers should instead acknowledge the existence of six aggregates, qualitatively different in their socio-economic stratification, needs and form of integration in the U.S. economy: two minority groups (people of Mexican and Puerto-Rican descent), and four immigrant populations (Cubans, Central American refugees, Central American immigrants, and South American immigrants" (75).

c. <u>Ethnicity as a continuous variable</u>

A third problem in accurately assessing ethnicity is the potential misrepresentation of ethnicity which some consider to be a continuous variable, as a dichotomous variable. Research has shown that individuals from other cultures living in the U.S. vary in their degree of identification with their cultures of origin and their levels of acculturation to American culture (59, 78). Furthermore, there is evidence to suggest that Hispanics with lower levels of identification with their countries of origin are more likely to be resourceful and satisfied with their lives in the U.S. (78). These individuals are also more likely to speak English and less likely to espouse traditional cultural values, such as "fatalismo" (40, 59), the belief that an individual can do very little to change his/her fate or destiny (59, 70). Hispanics' experiences with the U.S. health care system also vary according to level of acculturation (48, 49, 75). Therefore, creating an artificial dichotomy (Hispanic/non-Hispanic) may obscure important variations within the Hispanic population that are relevant to differences in health care quality. Using a measure of acculturation or ethnic identity may be more appropriate than using race/ethnicity as a basis for comparison when examining differences in health care quality across culturally-diverse groups.

Two proxies for acculturation are primary language spoken (English vs. non-English) and place of birth (U.S.-born vs. foreign-born). Hispanic individuals whose speak primarily English or who were born in the U.S. are more likely to be assimilated into U.S. culture. As such, they are more likely than their Spanish-speaking or foreign-born counterparts to be familiar with U.S. values and beliefs, and to experience health care in the same way as Whites. Although neither of these two variables reflects the continuous nature of level of acculturation, using at least one of them can add precision to an analysis of cultural differences in health care quality. For example, research has shown that English-speaking Hispanics are more likely to receive quality care than are Spanish-speaking Hispanics (27, 37, 68, 70), and that reports of health care quality made by English-speaking Hispanics more closely resemble those made by Whites than those made by Spanish-speaking Hispanics (27, 37, 70). Similarly, foreign-born Hispanics are more likely to report difficulties communicating with their doctors than are U.S.-born Hispanics (59). Language spoken, place of birth, and or other measure of level of acculturation may be more useful than race or ethnicity as bases for stratifying measures of health care quality.

d. Self-identification of health status and presence of a health condition

Health and the presence of illness is a socially constructed concept. What one group considers to be poor health another group may consider to be normal health. Also, some are more or less likely to acknowledge the presence of a health condition. These issues must be considered when subsetting quality measures according to self-reported health status or the presence of an illness or health condition. For example, we observe that when groups of Hispanic and White parents complete a well-tested screening tool to identify children with chronic conditions or special health care needs (the CSHCN Screener$^{©}$), a lower proportion of CSHCN are identified in the Hispanic group. Yet we also note that those Hispanic children that are identified are much more likely to visit the emergency room and experience a greater impact of their condition on their day to day functioning than White CSHCN (47, 65, 67, 82), suggesting that once they are identified using this tool their condition is more advanced or more severe. Similarly, in The Commonwealth Fund Health Care Quality Survey, Hispanics were less likely than Whites to report a health condition, but were more likely to report being in fair or poor health (68). These findings indicate that Hispanics may use a different threshold for defining illness or determining the severity level at which a problem is labeled and "health condition" or requires medical attention. It may also suggest that the cultural appropriateness of our tools to identifying individuals with health conditions needs to be improved.

3. Issues in using consumer surveys to measure health care quality

a. Survey content and design

When we measure health care quality using consumer or patient surveys developed by providers, policy-makers and researchers familiar with Western medicine, we need to ask whether we are assessing the underlying construct of health care quality, as understood and experienced by people of each of racial and ethnic groups for which we wish to use these surveys. Some researchers and policymakers argue that health care quality is a universal concept that can be objectively defined and measured; therefore, one comprehensive assessment of health care quality can be used for all cultures and languages (48). According to this perspective, either diverse cultural values are presumed to not affect the conceptualization of quality, or a subset of quality topics are assumed to be generically relevant for all cultural groups (49). Other individuals, however, assert that conceptualizations and definitions of health care quality depend on embedded cultural values and belief systems, and therefore inherently vary across cultural groups (35, 48, 49, 50). In other words, certain components of quality as we understand and measure it may not be relevant to members of other cultures.

Some consumer survey based quality measures are more or less sensitive to cultural factors. Setting issues with language translation aside, reports of objective healthy functioning and service quality or specific care processes (e.g., Can you walk up stairs? Did your doctor advise you to stop smoking?) are “objective” and are not expected to be influenced by culture. However, ratings of one’s own health status (e.g. rate your health on a 5-point scale), and ratings of service quality (e.g., Was your wait time reasonable or unreasonable?) may reflect cultural norms. Some research challenges assumptions that a particular numerical value assigned to a given concept represents the same amount, degree or level of that concept across different cultures. For example, studies show that members of some cultural groups are more likely to use the middle of a rating scale, and others are more likely to use the extremes (53, 54, 55).

Additionally, while most native-born Americans are accustomed to completing paper-and-pencil surveys in order to rate or evaluate various products and services, these experiences are not as common in other countries and cultures (48). Consequently, Hispanics may be more likely to have problems with commonly used survey formats such as skip patterns, 0-10 scales and the idea of averaging experience over time (e.g “In the last 12 months…”). As a result, observed differences between cultures may exist in part due to variations in the interpretation of survey item response sets. If Hispanics interpret response sets differently than Whites, comparisons between these two groups that do not take into account such cultural differences may be misleading. It is important to be aware of this issue when interpreting comparisons in consumer-reported quality across cultural groups.

The problem of conceptualization and measurement of concepts such as health care quality across cultures is not a new one. Researchers in other disciplines have addressed this same issue of one universal definition versus many culture-specific definitions of a particular concept (51, 52, 53). For example, Suh and Oishi (52) found that individuals from different cultures define happiness in different ways, and that these varying definitions are grounded in individuals' cultural values and belief systems. Furthermore, they found that because the social and emotional processes in judging personal satisfaction varied across cultures, the pathways to happiness differed across cultures as well. Cultural differences in the internal processes involved in judging personal satisfaction would affect the more subjective aspects of consumer reports of health care quality as well.

Similarly, Nisbett et al. (51) identified cross-cultural differences in cognitive processes. They determined that the thought processes that people utilize to organize information and make sense of their surrounding environments can vary in systematic ways across cultures. Specifically, people from individualistic cultures like the U.S. tend to think analytically; that is, they rely on logical reasoning, categorize information in order to better understand it, and detach objects from their contexts when thinking about them. People from collectivistic cultures (such as Hispanic and Asian cultures), on the other hand, are more likely to think holistically by paying more attention to relationships and context. They are also more likely to rely on experiential knowledge than on abstract logical reasoning. These cultural differences in cognitive processes may also impact some aspects of consumer assessments of health care quality.

In general, care should be taken in determining the degree to which variations in individual level interpretations of survey topics is problematic. Rarely will any two people from the same population subgroup or even the same family have precisely the same understanding of a survey item. Often differences in interpretations of items can vary more within a group than between groups. What we are most concerned about here are identifying survey concepts that simply are not relevant to a certain cultural group or that can not be communicated clearly.

b. *Survey translation*

Translation inaccuracy is a common source of bias when assessing health care quality for Hispanics using surveys. When a survey is translated from English to Spanish, translation errors often occur. Brislin (69) and other researchers (49, 56) recommend the use of back-translation when using surveys with different cultural groups. This process is thorough and most likely to produce accurate translations, but it is costly and time-consuming.

Translation errors are not the only methodological concern in making a survey available in multiple languages. Often, there is no equivalent word or phrase to accurately translate a concept from English to Spanish (48, 49, 56). In such cases, survey items that contain these words or phrases are not identical in the two versions of the survey. For example, in Spanish, there is no accurate translation for the commonly-used "somewhat agree" and "somewhat disagree" survey item response options (48). In our translation a parent reported quality survey for children with special health care needs we found there was no direct catch-all word in Spanish for "get". There are numerous words that are similar, such as receive, obtain, etc. However, the connotations for the Spanish words are slightly different. Spanish translations usually use "conseguir", which is most directly correlated to "get." "Conseguir", however, only pertains to getting objects or services, whereas one of the CAHPS questions asks about getting a doctor or other health provider. "Conseguir" was not appropriate in this context—it would be like getting a doctor as a birthday present. We used "Asignar", which is usually used in conjunction with people, but the connotation was more with the word "assign" than with "get." We also found that the word for "concern" in Spanish is not as commonly used as it is in English. To translate "concern" directly would mean placing a very complex vocabulary word into a survey. This causes the translated version of the survey to be at a higher reading level than the original. Other researchers note that the English words "doctor" and "health plan" are indistinguishable in Vietnamese (100).

Surveys translated into Spanish can also differ from their English versions in reading level. This problem occurs when an English concept does not translate well, and the translator must use more advanced or less commonly-used vocabulary words to convey the concept. For example, the Spanish words for "concern" and "get" are not as commonly used as they are in English (48). Thus, Spanish versions of surveys that use these words are translated at higher reading levels than their English counterparts. Furthermore, different dialects of Spanish use different words with more or less frequency. For this reason, some argue that multiple Spanish translations are necessary, one for each Hispanic sub-population (48).

To summarize, surveys are often translated into languages other than English in order to reach a broader population. However, translating surveys from one language to another can lead to measurement issues and analytic inaccuracies. There are four primary translation problems to be aware of:

1. Lack of an equivalent word
    - Oftentimes there is no equivalent word to accurately translate a concept from one language to another, which can make a survey item not identical to its exact meaning in its original language.
2. Translation of meaning or concepts

  - Meaning is conveyed through "tone, language, lingo, and connotations" and should be carefully considered when translating surveys from one language to another.
  - Since it is often that surveys originate in English and are then translated to different languages, this may cause reading level to increase. This happens when an English concept does not translate well, therefore the translator is forced to use more words or a more complicated way of transferring the meaning.

3. Clear errors in translation itself (e.g. translating "fair health status" as "regular health status" or "hot dog" as "warm puppies.")
4. Varying regional dialects within same language
   a. Different dialects of Spanish use different words with more or less frequency; for this reason, different Spanish translations may be needed for different Hispanic sub-populations.

c. *Survey sampling*

Perhaps one of the most difficult to address methodological problem in validly assessing health care quality for Hispanics and other cultural groups pertains to the sampling process, response rates, and the overall representativeness of respondents. For example, in general, lower-income Spanish-speaking individuals are less likely than their lower-income, White counterparts to meet the criteria for being sampled in studies of health care quality (47). These individuals are less likely to have health insurance (29, 30, 57, 58, 59), less likely to be continuously enrolled in health plans when they are insured (47), less likely to have reliable contact information (60), less likely to have a "qualifying health care visit" (29, 61), and in the case of online surveys, are less likely to have Internet access (62, 63). Furthermore, lower-income, Spanish-speaking individuals who are sampled are less likely to respond to health care quality surveys (60, 64). Many are less trusting of the system (9, 60), are afraid of their benefits being revoked (48), or simply are not English-proficient and cannot read the survey (48, 60).

The problems with sampling, response rates, and representativeness result in fewer data being collected from the desired population. Consequently, lower-income, Spanish-speaking Hispanics are likely underrepresented, and the data collected are more likely to reflect the responses and experiences of a more acculturated, higher-income subset of the Hispanic population, rather than the population as a whole.

d. *Survey administration*

Some suggest that the use of the standardized survey administration processes specified for surveys such as the CAHPS® may produce inaccurate results for Hispanics, primarily due to lack of familiarity with typical, standardized survey administration protocols. This lack of familiarity may result in a lack of trust that confidentiality will be maintained and a willingness to respond to either mailed or telephone administered surveys (47, 48, 60). In addition, some Hispanic survey respondents may not distinguish a telephone survey from a conversation (47, 48). As a result, they may feel awkward with the standardized telephone protocol process, and may feel uncomfortable discussing what they perceive to be intimate information with a stranger.

E. Maximizing the use of existing consumer-surveys to assess health care quality across culturally-diverse populations

As discussed above, there are a number of potential problems with the reliability, validity and meaningfulness of assessing racial and ethnic differences in health care quality exist using available consumer-based survey methods. We propose several strategies for addressing potential problems and maximizing the use of existing measures with culturally-diverse populations:

1 Balance standardization with customized methods
2. Check translation and limit comparisons to common concepts
3. Assess metric equivalence or use survey items/scale tested for equivalence
4. Build validity checks into survey administration and analysis of data
5. Create profiles of performance and examine within group results
6. Contextualize interpretation of results
7. Culturally sensitive communication of findings
8. Complement quantitative data with qualitative findings

1. Balance standardization with customized methods

Standardization of methods to measure health care quality is essential to making valid comparison across groups. This does not mean that comparisons using non-equivalent methods are invalid or uninformative. Rather, lack of standardization simply limits the ability to make “apples to apples” comparisons. However, some customization in the design and administration of consumer surveys may greatly improve the representativeness of survey respondents and have other benefits while not compromising the validity of comparisons across populations or across systems of care. Specifically, methods that balance a standardized survey process with customization to acknowledge cultural needs may be more effective in reaching the desired population.

As noted earlier, because low-income, Spanish-speaking Hispanics are less likely to meet the sampling criteria for many surveys on health care quality (29, 47, 48, 57, 58, 61), this group may be under-represented in samples using common sampling inclusion and exclusion criteria. Modifying sampling criteria to allow for oversampling members of this group may help alleviate this problem. In addition, allowing for some creativity to reach Hispanic individuals for whom no reliable contact information is available via conventional sampling methods should also be considered. For example, recruitment can be done through church leaders or other trusted members of the Hispanic community.

In addition, because low-income, Spanish-speaking Hispanics are also less likely to respond to surveys when they are sampled, being creative in the survey administration process may help boost response rates from this population. For example, Spanish-speaking Hispanics are more likely to respond by telephone than by mail, suggesting that telephone administration may be the more effective and cost-efficient mode of administration for this population. Using telephone administration also bypasses the problem of low literacy levels, and helps to avoid the pitfalls of participants' misunderstanding skip patterns.

In addition, brief educational efforts may be beneficial to increase familiarity with the consumer survey process in general and the reasons for the formality and structure of the telephone interview process in particular. For example, a one-day education session conducted through a local community center or church, or as part of a larger health fair, may help these individuals better understand the survey process and increase their level of comfort with telephone protocols, and could allay their fears of revocation of benefits. Individuals may also be allowed to complete a survey or have a survey administered to them during such an event as well.

2. Check translation and limit comparisons to common concepts

A thorough translation process maximizes the equivalence of the two versions of the survey, and minimizes potential differences in the meanings of the words, concepts or phrases, and variations in reading level. At a minimum, back-translation processes such as that suggested by Brislin (56, 69) should be used when translating health care quality surveys from English to Spanish. Furthermore, to assure that the final version of a survey is easily understood at all levels cognitive interviews should always be done using the translated version of the survey with members of the Hispanic population of varied socio-economic and educational backgrounds. When surveys are administered in multiple languages, comparisons of health care quality across linguistically diverse populations should be restricted to concepts that can be translated in consistent ways across these linguistic groups.

3. Assess metric equivalence or use survey items/scales tested for equivalence

Assessments of metric equivalence compare the psychometric properties of survey scales and survey items across in the different cultural groups. When results are equivalent or similar enough, the measure has demonstrated metric equivalence, and is presumed to be measuring the same underlying construct in both cultures. Assessments of metric equivalence can yield important information in two areas. First, they demonstrate if a single survey retains the same psychometric properties when used with different cultural groups and is therefore measuring the same underlying construct in the different cultures. And second, when an instrument's psychometric properties vary from culture to culture, these assessments can provide valuable information about culturally-different conceptualizations of the underlying constructs (in this case, health care quality) being measured by the instrument. Such information is very useful in understanding how people from other cultures define health care quality, and can provide a starting point for further research into more accurately measuring quality for all cultures.

Morales (37) and others have conducted analyses to assess the psychometric equivalence of the Consumer Assessment of Health Plan Survey (CAHPS®) for Whites and Hispanics. Using item response theory (IRT) procedures, the metric equivalence of health care ratings made by Whites and Hispanics has been demonstrated. In addition, the reliability of CAHPS® survey scales to summarize the information provided by individual items making up those scales were found to be the same for both groups. Results of the principal components factor analyses assigning survey items to specific aspects of quality were also similar. Furthermore, statistically significant differential item functioning (DIF) was observed for just two of the nine CAHPS® items evaluated, and the amount of bias introduced by these items did not significantly impact the comparisons of ratings for Whites and Hispanics. While this analysis generally demonstrates the metric equivalence of the ratings across the two cultural groups, the fact that two of the items functioned differently in the two cultures indicates that the constructs being measured may be defined differently by Whites and Hispanics. Although the different definitions or conceptualizations did not affect the overall comparison of ratings between Whites and Hispanics, further examination of these differences may aid in our understanding of the varying conceptualizations of health care quality across cultures.

The FACCT Promoting Healthy Development Survey (PHDS) has also demonstrated metric equivalence for Whites and Hispanics. Analyses yielded similar internal consistency values and factor structures for the two cultural groups. However, the factor analyses conducted on the responses of Spanish-speaking Hispanics did yield different results. For this group, the factors were reversed in their order of explanatory power.

Although analyses of metric equivalence and cross-cultural examination of psychometric properties, such as those noted here, have been conducted for some quality measures, they are not common. Such analyses are important because they assess metric equivalence, and can also provide insight into the nature of the different conceptualizations of health care quality across cultures. Data from these analyses can pinpoint specific areas of differences and provide a direction or springboard for subsequent qualitative research (54, 55, 56).

4. Build validity checks into survey administration and analysis of data

Much of the concern about the validity of existing health care quality measures is well-founded and based on strong theory and arguments, but little evidence exists to either support or refute these arguments and assertions. Therefore, building the evidence-base, and collecting information on the validity of existing measures would give us a more concrete understanding of the specific threats to validity that exist. If it is not possible to field test a survey to evaluate it's validity for a specific cultural group, validity checks can be conducted during the analysis of survey data. At a minimum, users should verify that expected associations among survey responses occur. Assessments of the convergent and divergent validity of survey items and scales are not difficult. This type of validity assessment evaluates whether a person who answers one survey item a particular way also answer another survey item in an expected or consistent manner as well.

5. Create profiles of performance and examine within group results

Research to date has demonstrated that cultural differences in health care quality can vary depending on the aspect of quality being measured (e.g. access to care vs. functional status vs. provision of recommended preventive services, etc.). Conclusions about differences in quality also vary for subgroups of individuals affiliated with any specific race or ethnicity. This is especially true when comparisons in quality are made between English and non-English speaking or higher or lower income members of a certain racial group. Each of these findings support the use of profiles of performance that seek to understand health care quality across a number of relevant domains of care as well as for subgroups of individuals within any specific racial or cultural group.

To illustrate, studies show that Hispanic adults generally experience more communication problems with their providers (28, 30, 31, 32, 33, 34, 35) and have less confidence in them (9, 28, 30, 35, 36) than White adults and that they also fare worse than Whites on population-based clinical outcomes (38, 39, 80). Yet, we also observe that Hispanic adults are more likely to be screened for alcohol/drug abuse (47) than White adults and that they often fare better than Whites on some measures of self-reported health status (29) and overall satisfaction with their health plans (37, 90).

Another example comes from assessments of health care quality in the provision of preventive and developmental services for young children using the PHDS (98-99). Here we observe that, overall Hispanic children are less likely to receive recommended care across four key aspects of preventive and developmental services (21.3% White children vs. 13.4% Hispanic children). Results show that Hispanic children are less likely to have one regular provider and their parents are less likely to receive care that is family-centered or to be assessed for mental and emotional issues (47). However, we also observe that Hispanic children are more likely than White children to receive certain aspects of preventive care (47) in areas of anticipatory guidance and parental education and psychosocial assessment of the family.

An elaboration of this example demonstrates the potential importance of stratifying information about quality within any racial group, especially according to language and other variables indicative of acculturation and degree of affiliation with a particular race or culture. When results from the PHDS are not only stratified by race, but also by language, we find substantial within racial group differences in experiences of care. For example, we observed that while Hispanic parents who completed the survey in English or Spanish were equally as likely to be counseled about the importance of reading to their children (63.7% vs. 65.9%), nearly 20% more Spanish speaking and English speaking parents of Hispanic chidren who were not counseled on this topic indicated that they wished that their child's pediatric clinician had discussed this issue with them (57% vs. 38%). Similar results occur when other aspects of health care quality are examined.

6. Contextualize interpretation of results

Cultural context should always be taken into account when interpreting cultural differences in health care quality. Different cultural attitudes, beliefs and values combined with varying circumstances related to other individual-level variables (i.e., transportation, location of facilities, migrant work schedules) can give new meaning to seemingly simple, straightforward differences. For example, the underutilization of PAP smears among Hispanic women could mean that providers are not recommending PAPs to these individuals. Alternatively, this statistic could reflect cultural attitudes towards sexuality and the genital area, could be the result of access-related issues such as lack of transportation or dearth of providers, could be the result of language and communication problems with providers, or could be due to the value of "fatalismo" and women's reluctance to interfere with their pre-determined fate (49).

Interpretation of findings such that improvements in care are achieved will benefits from the involvement of consumers, providers, health care quality researchers and policy makers, cross-cultural researchers, cultural anthropologists specializing in the specific cultural group being evaluated

7. Communicate findings in a culturally-sensitive manner

A measurement development model that "begins at the end" by defining how data is expected to be communicated will facilitate the development of culturally-relevant measures of health care quality. Collaboration with individuals to whom quality information is to be communicated is essential. Traditional report formats, while also requiring improvements, are more appropriate for communicating quality information to state and federal agencies, policy makers and other researchers. Different formats and communicate media may be more effective when sharing health care quality data with culturally-diverse consumers and their communities. For instance, research has shown that such consumers often find traditional formats such as a standard CAHPS® report confusing or meaningless (60).

Culturally-sensitive and culturally-responsive formats and methods for sharing health care quality information with culturally-diverse populations requires the involvement of trusted members of the community such as pastors, tribe leaders, and community health workers to develop. Methods should consider the cultural values and beliefs of the group, and explain the findings within the framework of the group's perspective on health, illness and spirituality.

For example, many Hispanics espouse the value of "fatalismo," the belief that there is little a person can do to alter his or her fate (59, 70). In a study conducted with Hispanics in Texas, it was found that many Hispanic parents did not use child safety seats with their children. Further investigation revealed that parents felt that by using car seats, they would be interfering with their pre-determined fate or God's will. The researchers chose to communicate the information in a culturally-sensitive way by emphasizing another Hispanic value, that of "familialismo," the importance of the family. They explained to parents that God wants them as guardians to protect their children, and that using child safety care seats was one way of doing this. The researchers also implemented a program where parents could bring their car seats to be blessed by a priest before using them. The program was successful in increasing the use of child safety seats among Hispanic families (66, 79).

8. Complement quantitative methods with qualitative methods

Focus groups and other qualitative research methods are important complements to quantitative data collection and are essential for gathering information about specific ethnic and racial perspectives, needs and expectations. Through the use of these methods, we can achieve a more robust understanding of the health and health care quality constructs being measured, and become more aware of the complex cultural biases and assumptions that may affect participants' responses. Surveys developed based on the results of culture-specific focus groups and other qualitative research are more likely to be meaningful to members of that specific culture. Consequently, the results of such surveys are more likely to accurately reflect the constructs being measured.

In order to better assess health care quality for culturally-diverse populations, we must first gather more information regarding how people in different cultures define health care quality. An earlier section of this paper addresses the issue of culturally-different definitions or conceptualizations of concepts in general and health care quality in particular. When people in different cultures have different understandings of what health care quality is, it is difficult to measure levels of quality in a uniform manner. Furthermore, we are faced with the moral dilemma of imposing our own cultural notions of what is “good” and “correct” with regard to health care onto individuals from other cultures, who may have very different ideas of what is “good” and “correct” health care.

Due to the problems with the use of standard survey formats and methods with some culturally-diverse populations, alternate assessments methods should be applied where possible. Nisbett (51) identifies a “scenario method” of assessment that produces more accurate, reliable, and valid results than ranking and rating methods when used with members of some cultures. The scenario method entails describing a brief scenario that illustrates a particular concept or value, and asking the respondent to choose one of several behavioral response options.

F. Additional priorities for future research and action

An extensive list of research and actions are required to advance the valid measurement and communication of health care quality and to use this information to stimulate and track success in efforts to reduce in disparities in quality across culturally-diverse populations. Here address four additional action steps that address some immediate needs and opportunities in this area.

1. Inventory and adapt existing tools

a. *Maintaining an Inventory of Tools*

A "living library" of consumer-based health care quality measures that have potential for use across culturally-diverse populations is needed. In this inventory of tools, a common set of features across tools should be specified and made clear to those considering their use. Features to be specified should include:

1. Intended Purpose: The specific original purpose for which the tool was developed.
2. Quality Framework: The specific definition of health care quality used in the development of the tool (whether explicit or implied).
3. General Description: Simple conceptual and technical description of the method. Included will be basic information about the required data, components of tool (e.g. number of items, etc), data collection burden (e.g. time to complete survey) and scoring process for identification.
4. Development Background: The development background will specify the individuals/organizations that developed the tool and any specific steps or processes that were used in its development.
5. Use History and Results: Results from using this tool across different populations and for different purposes should be summarized and stratified by special subgroups (e.g. age groups, racial groups, other demographic, geographic and service utilization subgroups).
6. Testing History: Summary of the testing conducted to assess the validity, reliability and feasibility of the tool. High level findings from this testing should be summarized and additional references provided.
7. Application Issues: Summary of the specific applications of the tool. Brief case studies of the use of specific methods should be provided

8. Availability/Cost: Where and how to obtain the tool and any associated cost or process for doing so.
9. Technical Support: Likely technical support that will be needed and where to get this support -- web-sites, researchers, organizations, agencies, etc.
10. Special Issues and Considerations: Other applications issues and options to be aware of that are not addressed above (e.g. options for combining the method with another method such as with administrative data based methods).

In addition, quality measurement tools and methods that meet the following criteria should be preferred for any inventory of quality measures:

Criteria 1: Readily available and documented. Tools should be readily available and detailed methods required to use the tool (e.g. administration and scoring) made explicit. Proprietary tools that can only be deployed by certain vendors or that are prohibitively expensive to purchase or burdensome to obtain for use should be discouraged from inclusion in any compendium.

Criteria 2: Development, use and testing history. Tools should be included for which the history of development, use and testing is known. This development, use and testing history may or may not be documented in the published literature.

Criteria 3: Potential for standardization. Tools should have the capacity to be used in a standardized way such that results obtained across population groups, states, managed care organizations and/or providers can be reasonably compared.

b. Adapting Existing Tools

Existing consumer-reported health care quality surveys can be adapted to better evaluate quality across culturally-diverse populations by considering the recommendations made above. In addition, new survey items and concepts should be added to these tools to ensure more meaningful interpretation of findings from these tools. Specifically, questions to document language proficiency, language preference and acculturation should be included.

For example, we often observe greater differences between Spanish-speaking Hispanics and English-speaking Hispanics than between English-speaking Hispanics and Whites, indicating that stratification of quality measures within a cultural group according to primary language or English proficiency is meaningful and informative. (27, 37, 59, 68, 70) Similarly, Limited English Proficiency (LEP) can influence the responses from an individual who takes a survey in English. A person with LEP may not fully understand the questions being asked; therefore, his/her responses would not accurately reflect his/her experiences with the health care system. For this reason, a measure of English proficiency may be an essential control variable when measuring racial/ethnic differences in health care quality.

Acculturation is a related but distinct concept. The longer someone has lived in the U.S., the more familiar he/she is with the health care system and American culture in general. Conversely, the less time someone has spent here, the less he/she may understand the English language (communication barrier), how the U.S. health system operates, common doctor-patient interaction, etc. Miscommunication and misunderstanding in health care can lead to serious problems, such as misdiagnosis, errors in prescription dosage and non-adherence. Therefore, acculturation is directly related to the quality of care an individual receives. Documenting acculturation in surveys will help determine aspects of the many clinical and communication aspects of health care quality may be attributed to differences in levels of acculturation within and across racial and ethnic groups.

Other survey questions to consider adding when existing tools are administered to culturally-diverse populations include inquiries about whether a provider attempted to work with a patient's belief system, the presence of a translator and level of family involvement. These and similar additions to these surveys will allow for the more meaningful measurement of cultural competency within and across health systems.

2. Develop and diffuse innovative methods and models

New efforts to evaluate and improve quality for culturally-diverse populations seem to emerge daily. As innovative measurement and improvement strategies develop, it will become critical to create mechanisms to identify and diffuse these innovation efforts. We should not wait for peer-reviewed publications reporting on work in the field. Rather, a less formal, real-time tracking and dissemination process is needed to expedite advances in this area. In addition, as research is published, efforts to translate this research into practice will be needed.

3. Support consumer-driven measurement and improvement strategies

Individuals who are members of racially and ethnically diverse populations are perhaps the greatest untapped resource for stimulating, shaping and ensuring improvements in health and health care quality. Tools and efforts to engage and empower consumers as evaluators and drives of improvements in health care quality are an essential complement to the many initiatives sponsored by health care systems and others. (93-96) Specifically, individuals who are educated and provided tools to understand and communicate their needs for health care services and needed improvements in the quality of their care may be a powerful force for change. In addition, advocates committed to ensuring quality health care for culturally-diverse populations require assistance and support to play their role in ensuring the valid measurement and communication of health care quality information for the populations they represent.

If consumer-based organizations committed to ensuring reductions in disparities in health and health care quality are to play an effective role in stimulating and shaping system changes, they will need education and support to use measurement tools, analyze and interpret data and to effectively communicate findings. While we outline many issues for users of consumer-based quality surveys to consider, few consumer-based organizations will be able to address these issues without support from other experts and other resources. Therefore, consideration should be given to developing an advocacy resource center to train and support these groups in this area.

4. Build the information infrastructure

If health care data systems routinely collected the information needed to identify individuals from culturally-diverse populations and routinely assessed their health and the quality of care, many of the struggles currently experienced in this area would be eliminated. However, existing data systems do not collect this information and, if they do, it is not done in a standardized manner across health systems. Currently, federal, state, and private agencies do not use the same standardized racial and ethnic categories (5, 75, 76, 77), thus making standard racial and ethnic comparisons across different data sources difficult or impossible. At a minimum, for health care quality assessments across racial and ethnic groups to be made routine, mechanisms to reliably identify individuals affiliated with different racial and ethnic groups, as well as information about their preferred language, should be included in administrative data and should be collected in a standardized manner across the various consumer-reported quality surveys available today.

Emerging electronic, Internet-based data collection systems have the potential to allow patients and consumers report on the quality of their health care. This data collection mode could greatly reduce costs of data collection, allow for real-time tailoring of survey tools and, in general, streamline the collection and communication of consumer-reported health care quality information. Many other data infrastructure needs and opportunities also exist.

G. Conclusions

In recent decades, several federal agencies have emphasized the importance of improving the quality of health care delivered in the U.S., and various entities pursue the worthy goals of measuring, reporting and improving health care quality, and encouraging others to do so. The National Committee on Quality Assurance (NCQA) developed the Health Plan Employer Data and Information Set (HEDIS®) measures, and the Institute of Medicine (IOM) has produced numerous reports and calls for measuring and addressing health care quality concerns. The federal Agency for Healthcare Research and Quality (AHRQ) developed the National Quality Measures Clearinghouse (NQMC), and is also producing the National Health Care Quality Report (3) and the National Health Care Disparities Report (4) based on IOM recommendations.

The National Quality Forum (NQF), FACCT -- Foundation for Accountability -- the Leapfrog Group, as well as numerous business coalitions on health care continue work to develop methods and advance a consumer-centered, information-rich health care system. Most recently, the Center for Medicare and Medicaid Services (CMS) is advancing quality measurement and public reporting as a core strategy for driving improvements in care (5). All of the efforts underway to address health care quality in America struggle with the issue of validly assessing health and health care quality across culturally-diverse populations and shaping the health care system to meet their needs in a way that addresses the added vulnerability that comes with being a minority in any population.

Our review of the literature, discussions with experts and others and our own experience in this area lead us to conclude that significant progress has indeed been made in recent years to validly assess disparities in health and health care quality across culturally-diverse populations. Yet, our work is in at a very nascent stage -- we lack even a basic inventory of candidate measurement tools for measuring quality across culturally-diverse populations and only a handful of reports comparing health care quality within or across cultural groups can be found at the national, state or local levels.

Currently, there is no agreed upon manner for using existing tools or developing new methods for assessing cultural competency from the point of view of the consumer or patient. Such consensus on a standardized measurement method is essential when comparing information across groups. However, some level of customization in the design and administration of consumer-reported quality surveys is acceptable and desirable to ensure the relevance of these tools and their ability of obtain information from representative samples and different racial and ethnic subgroups. These and other issues can and should be addressed using successful measurement development models such as that used in the development of the CAHPS survey and in the Child and Adolescent Health Measurement Initiative (CAHMI).

It is important to enter into this work understanding that while measurement biases can be minimized, they can not be eliminated. Therefore interpretation of data and results must take into account biases those can not be minimized through modifications to the design or administration of consumer-based quality surveys. Interpretations must be informed by a concrete understanding of the perspectives and values of the culture being assessed and this information is often best attained through qualitative methodologies. In short, we can not measure, interpret or communicate information about health care quality across culturally-diverse populations in a valid or actionable manner without full collaboration with individuals and organizations committed to and deeply familiar with these populations. Much work remains for this to become the norm in the development and use of health care quality measures in America.

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CULTURAL COMPETENCY ASSESSMENT TOOLS

Three tools for providers and/or organizations and agencies to assess their knowledge, skills and attitudes regarding the cultural groups they serve were found and are summarized in the table below. Each of these tools are designed for use with multiple ethnic groups.

Summary of tools for assessing the cultural competency of organizations and providers

Name of tool	Description	Application and Administration	Status
Cultural Competence Self Assessment Protocol (Andrulis, Delbanco, Avakian, Shaw-Taylor, 1999)	Organizations rate their cultural competence in four areas: (1) relationship with the community, (2) relationships with staff (3) inter-staff relationships and (4) patient-provider relationships. A five point spectrum of cultural competence is suggested: Inaction; Symbolic Action and Initial Organization; Formalized Action; Internal and External Cultural Diversity Initiatives; The Cultural Diversity Learning Organization	Staff, community representatives and patients are interviewed using a set of provided questions and response options. No patient survey provided.	Tool has been fielded and appears to be a feasible and useful organizational self-assessment tool. Information about the validity or reliability of this tool is not available.
Cultural Competence Self-Assessment Questionnaire (Mason, 1995)	Providers and organizations can assess their cultural competency in seven areas: 1. Knowledge of communities; 2. Personal involvement; 3. Resources and linkages; 4. Staffing; 5. Service delivery and practice; 6. Organization policies and procedures; 7. Reaching out to community	Administrators and providers self-administer a survey tool. No patient survey provided.	SAME AS ABOVE
Monitoring the Managed Care of Culturally and Linguistically Diverse Populations (Tirado, 1998)	Three aspects of health plan cultural competency are reviewed: 1. Human resource capacity; 2. Policies and procedures; 3. Managing/monitoring. Three aspects of the cultural competency of providers are reviewed: 1. Knowledge; 2. Practice behavior; 3. Attitudes toward diversity. Plans and providers are rated on a five point spectrum: 1. Culturally resistant; 2. Culturally unaware; 3. Culturally conscious; 4. Culturally insightful; 5. Culturally versatile. Member survey mirrors plan/provider self assessment and is used as a comparison with plan/provider self assessment.	Self administered health plan, provider and member surveys available.	Tool has not been widely fielded or tested.
Assuring Cultural Competence in Health Care (The Office of Minority Health, PHS, USDHHS. 199)	A list of fourteen standards is available. If operationalized, these standards may form the basis of evaluations of the cultural competency of health care organizations. The three tools listed above attempt to operationalize many of the standards.	Tool not available	NA

Example items from the Client Cultural Competency Inventory (Switzer, Sholle, Johnson, 1998) – Focus on cultural competency and mental health treatment

1. The caregiver uses everyday language that we can understand
2. The caregiver involves other family members in the therapy process whenever possible
3. The caregiver makes negative judgments about us because of the ways that we are different from him/her (such as race, income level, job or religion).

NOTE: Only very limited information on pscyhometric validity and reliability is available.

Example items from "Monitoring the Managed Care of Culturally and Linguistically Diverse Population" – Focus on cultural competency and managed care (Tirado, 1998)

1. When discussing diagnosis and treatment related to my condition , my doctor asks if I would like to include family members in the discussion
2. I don't have time during my visit with my doctor to ask the questions I would like
3. My doctor asked if I use healing methods traditional to my culture to treat my condition
4. I am clear how to follow my doctor's orders
5. I feel satisfied with the way my doctor treats me as a person
6. My doctor asks about the role of family in my health care

Response Options: Not at all, seldom, usually, often, always
NOTE: Information about the validity and reliability of these is not available