

Diverse Patients, Disparate Experience:

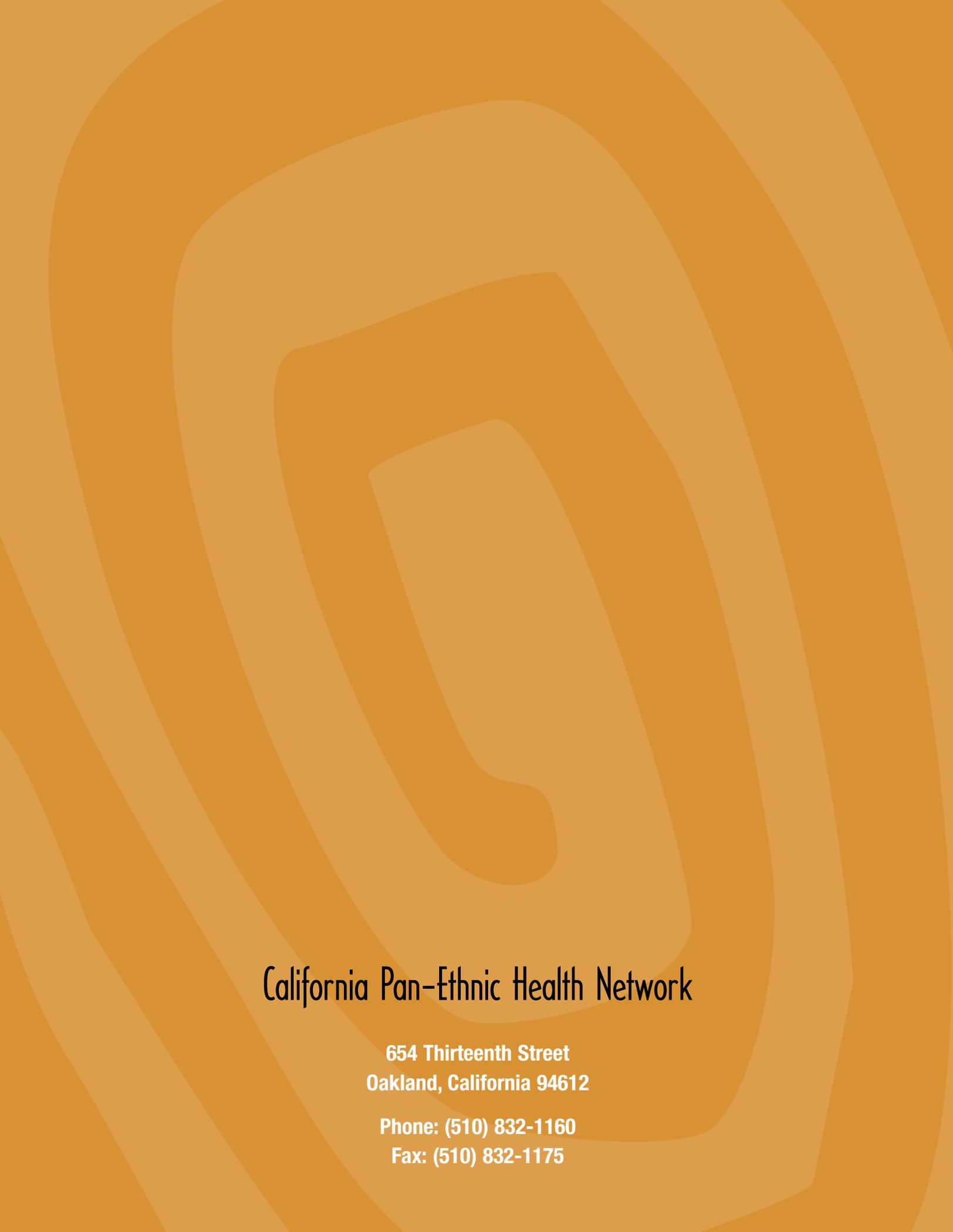
The Use of Standardized Patient Satisfaction
Surveys in Assessing the Cultural Competence
of Health Care Organizations



CPEHN

California Pan-Ethnic Health Network

March 2001



California Pan-Ethnic Health Network

**654 Thirteenth Street
Oakland, California 94612**

Phone: (510) 832-1160

Fax: (510) 832-1175



The mission of the California Pan-Ethnic Health Network is to promote changes to health policy decision-making and health care delivery systems that improve the health status of our communities.

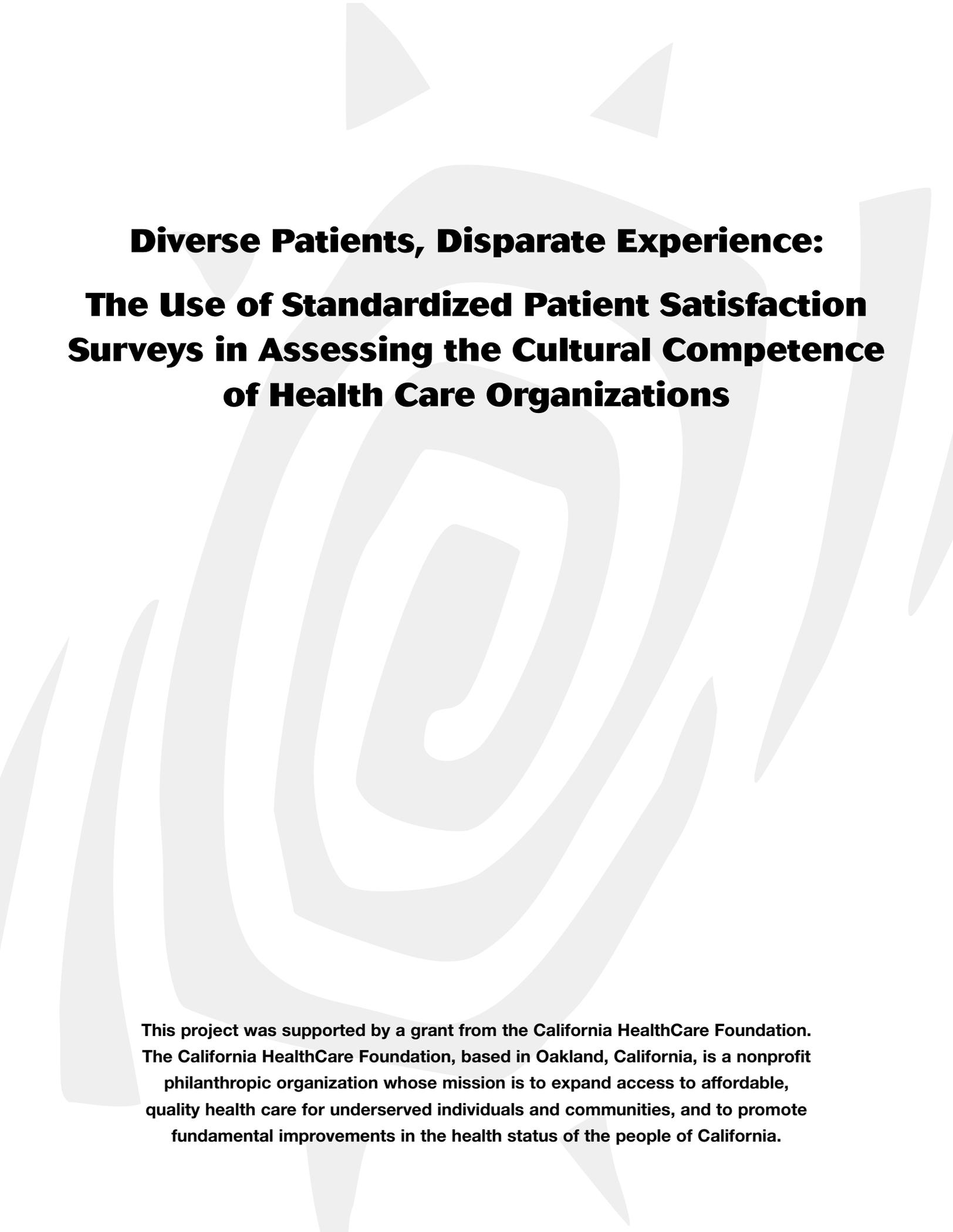
Through a collaborative process with its partners in the African American, Asian and Pacific Islander, Latino/Latina, and Native American communities, CPEHN monitors, analyzes, and informs health care policies, legislation, and business strategies.

CPEHN is a 501(c)3 nonprofit organization.

California Pan-Ethnic Health Network

**654 Thirteenth Street
Oakland, California 94612**

**Phone: (510) 832-1160
Fax: (510) 832-1175**



**Diverse Patients, Disparate Experience:
The Use of Standardized Patient Satisfaction
Surveys in Assessing the Cultural Competence
of Health Care Organizations**

This project was supported by a grant from the California HealthCare Foundation. The California HealthCare Foundation, based in Oakland, California, is a nonprofit philanthropic organization whose mission is to expand access to affordable, quality health care for underserved individuals and communities, and to promote fundamental improvements in the health status of the people of California.

Table of Contents

Executive Summary	1
Section I: Introduction	7
Section II: Theoretical Framework	9
Section III: Overview of the Three Consumer Surveys	13
Section IV: Findings and Recommendations	17
Section V: Conclusions and Next Steps	35
Appendices	
Appendix A: Methodology – The Three Project Phases	39
Appendix B: Project Partners	41
Appendix C: Priority Languages for the Administration of Consumer Surveys in California	43
Appendix D: Family Health Outcome Project (FHOP) Guidelines for Race/Ethnicity Coding	45
Appendix E: Characteristics of a Culturally Competent Health Care Organization	53
Appendix F: Process for Cultural Adaptation of Surveys	57
End Notes	59

Executive Summary

In December 1999 the California Pan-Ethnic Health Network (CPEHN) and the California HealthCare Foundation (CHCF) embarked on the Cultural Competence and Consumer Survey Project. The purpose of this project was to examine whether standardized surveys of consumers' experience and satisfaction with health care could provide useful information on certain dimensions of the cultural competence of health care organizations. Specifically, the project had three aims:

- To assess the potential usefulness of standardized consumer surveys for evaluating the cultural competence of health providers and plans. Our hypothesis was that a subset of items on these surveys would have the potential to contribute to an assessment of cultural competence.
- To develop recommendations for enhancing the ability of existing surveys to capture the experiences and assessments of patients from communities of color.
- To begin identifying alternatives to standardized surveys for assessing cultural competence.

This report documents our findings and recommendations.

Defining the Problem

Always an ethnically and culturally diverse state, California's population is now a "majority of minorities" with no one racial or ethnic group comprising a majority. As a result, consumers in California are increasingly likely to approach the health care system with cultural perspectives that diverge from those assumed and ingrained in mainstream health plans and provider organizations, leading to an environment characterized by confusion, frustration, and the potential for inadequate or inappropriate care. Also, the changes in the composition of our population far outstrip the increase in diversity of the health care providers, administrative staff, managers, and policymakers who are required to move the system toward improved quality. These trends are creating a situation in which flawed interactions between consumers and health care systems are occurring in numbers too large to ignore.

Recent research has confirmed the experience and observations of many consumers of color that they sometimes receive a lower level of quality of care than do their white counterparts. (For the purposes of this study, the term "consumers of color" refers to a variety of diverse ethnic and racial subgroups, including African Americans, Latinos, Asian Americans, American Indians, and Pacific Islanders.) Language and cultural differences also pose significant barriers to care. There is growing evidence of significant differences in quality of care, utilization, and outcomes across racial, ethnic, and cultural populations as well as language groups. However, few formal studies explore the underlying causes for these differences.





Specific Findings from Analyses of Survey Results

Analyses of aggregated survey data resulted in the following findings:

- Racial/ethnic minorities are confronted by access barriers in health care.
- Latinos and Asians who speak a language other than English at home report more negative experiences with care than do English speakers.
- Lower scores on reports of care do not necessarily translate into lower ratings of care among racial/ethnic minorities.
- Adult African Americans report more positive experiences with their own health care than do whites but more negative ratings for the care received by their children.

One of the keys to identifying and overcoming the differences in care across diverse populations will be our ability to measure and track the extent to which California's health care organizations are becoming "culturally competent," a term that encompasses a broad range of characteristics.

Overview of the Project

The project centered around an analysis of three standardized consumer surveys:

- 1) Consumer Assessment of Health Plans Survey (CAHPS®), designed for health plans
- 2) Picker Inpatient Survey, designed for hospitals
- 3) Physician Value Check (PVC), designed for medical groups

The project was implemented in three phases. In Phase I, the CPEHN elicited the expertise of key informants through a series of Working Group meetings and individual interviews. Phase II included additional interviews with expert informants, the analysis of pooled data commissioned by the California HealthCare Foundation from each of the surveys, and the convening of a panel of survey researchers, researchers in cultural competence, and advocates to review and begin to interpret the results.

During Phase III of the project, the original Working Group reconvened to:

- Review the findings of Phase II.
- Finalize recommendations for existing standardized surveys.
- Develop recommendations for alternatives to standardized surveys for assessing cultural competence.

The Findings

Based on the analyses conducted for this project, we found that aggregated data from standardized consumer surveys can reveal important information about disparities in consumers' experiences with health plans, hospitals, and medical groups. But, existing surveys are currently imperfect tools for measuring organizational cultural competence and identifying the factors that underlie differences in people's perceptions and judgments of their experiences.

What We Learned About Consumer Surveys

Standardized consumer surveys help to promote the quality of health care by capturing input from consumers, generating results relevant to the assessment of cultural competence, and providing data for comparative reports on quality that people can use to learn about their health care options.



The usefulness of these surveys for evaluating cultural competence is closely tied to the fact that both the instruments and their administration are standardized. Because everyone uses the same tool and handles it in the same way, researchers can:

- Aggregate data across ethnic/racial groups, organizations, programs, geographic areas, and other levels of analysis.
- Aggregate data for specific populations over time.
- Make comparisons across health care organizations.
- Make comparisons over time within the same organization.

Without the ability to pool survey results, it would be extremely difficult—if not impossible—to generate a sufficient amount of data to draw conclusions about the experiences of specific subgroups of the population. However, standardized surveys are limited in their ability to capture the voices of consumers of color and assess dimensions of the cultural competence of specific health organizations. The Working Group identified a number of factors that hinder consumer surveys from serving in this capacity. These factors fall into five broad categories:

- **The limited perspective of consumers:** Some aspects of cultural competence are simply not observable by consumers, even though its effects may contribute to the quality of the care they receive.
- **Survey readability:** Written surveys can be inaccessible for people with limited proficiency in English.
- **Survey content:** Consumers surveys have not been designed to measure cultural competence. Although they may contain a few relevant questions, they are not specifically intended to provide information regarding the experiences of consumers of color.
- **Sampling strategy:** The sample size for consumer surveys is too small to support generalizations about the experiences of people from ethnic, racial, and language subgroups.
- **Survey administration:** Because they are typically conducted through the mail or over the telephone, consumer surveys may fail to capture the views of people who are difficult to reach, either because contact information is unavailable or because they lack a telephone.

What We Learned About Alternative Measurement Tools

In light of these limitations, the Working Group also discussed alternatives to standardized consumer surveys, including focus groups, interviews, organization- and population-specific surveys, and other approaches to gathering information from consumers about their health care experience. Based on the experiences of institutions that have applied these alternative approaches, the Working Group members and researchers agreed that these other methods would be useful tools for



capturing in-depth information on the experiences and assessments of consumers of color with regard to health care.

In addition, the Working Group noted the importance of considering methods for evaluating the organizational aspects of cultural competence that may not be visible to consumers. Some options would include organizational surveys and audits, reviews of medical charts, interviews with staff, and analyses of utilization and outcome data.

Summary of Recommendations

Key recommendations that arose from this project include the following:

- Continue to refine the use of survey data as a tool for assessing the experiences of diverse groups of consumers. Perform further analyses of consumer survey data stratified by race, ethnicity, and language. Conduct analyses at program, regional, state, or other levels as permitted by current and improved sampling strategies.
- Perform analyses on clusters of questions to identify which items, singly or in combination, can reliably reflect differences in the experiences of various racial, ethnic, and language groups that are related to the underlying cultural competence of an organization.
- Assess the relative usefulness of various tools for developing measures of the degree to which organizations achieve the characteristics of culturally competent organizations. Examples could include standardized consumer surveys, nonstandardized methods for obtaining consumer input, organizational surveys and audits, utilization and outcomes studies, etc.
- Design comprehensive data-gathering systems that include both qualitative and quantitative measurement tools. In addition to standardized surveys, options include focus groups, surveys that target specific populations, and face-to-face and telephone interviews.
- Collect data on race, ethnicity, and language at the level of health plans and programs (such as Medicaid and Medicare) to facilitate analyses of variations in reports and ratings.
- Conduct further research on the cross-cultural equivalence of survey instruments.
- Promote requirements and incentives for making survey results public and develop effective strategies for the dissemination of the results of consumer surveys to potential audiences.

In Conclusion

The Cultural Competence and Consumer Survey Project represents a significant effort on the part of both the California Pan-Ethnic Health Network and the California HealthCare Foundation to promote the quality of health care for California's increasingly diverse population. Through this project and subsequent advocacy, we will encourage the health

care industry, policymakers, purchasers, researchers, and advocates to recognize the critical relationship between cultural competence and health care quality and become more appreciative of the potential value of consumer surveys for revealing disparities in the experiences of different consumer groups.



¹ US Census Bureau data, as reported in: America 2000: A Map of the Mix. *Newsweek*. (September 18, 2000); p.48.

² Carlisle D, et al. Racial and ethnic disparities in the use of cardiovascular procedures: Associations with type of insurance. *American Journal of Public Health*. 1997;87:263-267.; Burns R, E McCarthy, et al. Black women receive less mammography even with similar use of primary care. *Annals of Internal Medicine*. 1996; 125:173-182.

³ Smith M, A Ryan. Chinese-American families of children with developmental disabilities: An exploratory study of reactions to service providers. *Mental Retardation*. 1987;23(6):345-350.

⁴ Report by Ron Hays and Leo Morales of Rand Corp. at second Working Group meeting.

Section I. Introduction



Defining the Problem

Always an ethnically and culturally diverse state, California is now a "majority of minorities" with no one racial or ethnic group comprising a majority.¹ As a result, consumers in California are increasingly likely to approach the health care system with cultural perspectives that diverge from those assumed and ingrained in mainstream health plans and provider organizations, leading to an environment characterized by confusion, frustration, and the potential for inadequate or inappropriate care. Also, the changes in the composition of our population far outstrip the increase in diversity of the health care providers, administrative staff, managers, and policymakers who are required to move the system toward improved responsiveness. These trends are creating a situation in which flawed interactions between consumers and health care systems are occurring in numbers too large to ignore.

Recent research has confirmed the experience and observations of many consumers of color that they sometimes receive a lower level of quality of care than do their white counterparts.² (For the purposes of this study, the term "consumers of color" refers to a variety of diverse ethnic and racial subgroups, including African Americans, Latinas, Asian Americans, American Indians, and Pacific Islanders.) Language and cultural differences also pose significant barriers to care.³ There is growing evidence of significant differences in quality of care, utilization, and outcomes across racial, ethnic, and cultural populations as well as language groups.

Few formal studies, however, explore the underlying causes for these differences,⁴ and current research on quality of care pays only scant attention to the unique access and quality issues facing different communities. Yet there is a critical need to collect and analyze information about the experiences of diverse health care consumer groups and to evaluate the capacity of health plans and providers to provide culturally competent and language-appropriate health services. Attention to cultural competence as an integral component of health service delivery is essential to serving all Californians appropriately and responsively.

Consumer Surveys as Part of the Answer

Today's competitive health care environment has generated an unprecedented demand for feedback from health care consumers. In recent years, a few consumer surveys designed to measure quality of care from the consumers' perspective have emerged as standards in the field. These surveys, or adaptations of them, are widely used on a national level and increasingly in California. Their use has resulted in the development of rich data sets on patients' experiences and assessments of care.

To the extent that they can offer insights into the experience of consumers of color, these measures of consumers' and patients' experi-



An Overview of the Methodology

The project was implemented in three phases. In Phase I, the CPEHN elicited the expertise of key informants through a series of Working Group meetings and individual interviews. Phase II included additional interviews with expert informants, the analysis of pooled data commissioned by the California HealthCare Foundation from each of the surveys, and the convening of a panel of survey researchers, researchers in cultural competence, and advocates to review and begin to interpret the results. During Phase III of the project, the original Working Group reconvened to:

- Review the findings of Phase II.
- Finalize recommendations for existing standardized surveys.
- Develop recommendations for alternatives to standardized surveys for assessing cultural competence.

For more details, please see Appendix A.

ences with the delivery system may provide researchers with a unique opportunity to assess certain dimensions of the cultural competence of providers and health care organizations. Such assessments are needed to inform organizational planning and policy making and increase the accountability of health systems to all consumers, including those from diverse communities.

An emphasis on identifying variations in survey results across population segments is also critical from a public policy perspective. Over time, it is likely that the aggregated results of standardized surveys as well as other national quality measures will become an important input for policymakers as they make decisions about health care programs that affect the lives of communities of color. To the extent that survey instruments fail to capture the unique voices of these communities, there is a risk that future policies will not reflect the different experiences that diverse groups have with the health care system.

Finally, it is critical to recognize that standardized survey results can point out differences in experiences and assessments of care but not the reasons for those differences. If we want to understand what lies behind those differences, we will need to develop a comprehensive set of tools for gaining an in-depth understanding of cultural competence and how it affects the quality of care that people receive.

Purpose of This Project

To learn more about the value of consumer surveys as a tool for assessing cultural competence, the California Pan-Ethnic Health Network (CPEHN) and the California HealthCare Foundation (CHCF) embarked on the Cultural Competence and Consumer Survey Project in December 1999. The purpose of this project was to examine whether standardized surveys of consumers' experience and satisfaction with health care could provide useful information on certain dimensions of the cultural competence of health care organizations. Specifically, the project had three aims:

- To assess the potential usefulness of standardized consumer surveys for evaluating the cultural competence of health providers and plans. Our hypothesis was that a subset of items on these surveys would have the potential to contribute to an assessment of cultural competence.
- To develop recommendations for enhancing the ability of existing surveys to capture the experiences and assessments of patients from communities of color.
- To begin identifying alternatives to standardized surveys for assessing cultural competence.

Section II. Theoretical Framework



Why Focus on Cultural Competence?

Studies building on work in the fields of anthropology and sociology offer compelling reasons for focusing on the role of culture and cultural interactions in health care.⁵ As mental health professionals recognized more than a decade ago, there is growing evidence that ethnicity and culture are strongly related to health risks, care-seeking behavior, access to care, receptivity to health promotion/disease prevention strategies, and outcomes.⁶ The relationship is driven by a number of factors, including:⁷

- Language
- Culturally driven communication styles
- Beliefs about causes of and remedies for health conditions
- Access barriers
- Help-seeking traditions
- Historical relationships marked by racism and mistrust of medical care systems
- The availability of traditional healers and medicines
- Cultural differences in approaches to decision making

The promotion of cultural competence is ultimately a strategy to improve health outcomes for diverse populations. Cultural competence is a critical component of efforts to address racial and ethnic disparities in health status, which has become a national priority under the leadership of Surgeon General David Satcher. Specifically, formal research evidence as well as anecdotal reports suggest that increased cultural competence could have promising results, including:

- Better understanding of and communication within health systems
- Increased access to health care
- Increased and more appropriate utilization of services
- Higher levels of consumer satisfaction
- Improved quality of care

While there is a need for research to explore the link between cultural competence and health care outcomes, the evidence suggests that cultural competence is likely to enhance outcomes for individuals, families, and communities.

From the perspective of consumers, greater cultural competence results in increased comfort and satisfaction with health services, a sense of being respected and understood, and an increased confidence in the efficacy of the treatment. For providers, cultural competence offers a set of skills that provide knowledge of disease prevalence and etiology in specific populations, improved communication between consumer and



provider, increased trust and confidence in the provider, and increased adherence to treatment plans by patients. These products of cultural competence are believed to generate benefits important to a cost-conscious health system: better outcomes, appropriate utilization of services, more efficient office visits, and higher consumer satisfaction.

Although this paper focuses on issues of race and culture, it is important to note that race, ethnicity, culture, and language are not the only social factors that influence health outcomes. Age, gender, sexual orientation, immigration status, ability, place of residence, and socioeconomic status can also present barriers to effective health care for many consumers. Indeed, the failure of health care systems to consider the impact of these social constructs and how they interact with race, ethnicity, culture, and language can have severe and negative consequences for consumers and their communities. Few health care organizations give special attention to all of these factors and their interactions to ensure that no consumers are disadvantaged in the provision of health care.

Characteristics of Culturally Competent Organizations

For the purposes of this project, the following list of the characteristics of culturally competent organizations has been serving as a framework for assessing health care consumer surveys. This list was based on an extensive review of cultural competence definitions, assessment tools, and indicators and standards.⁸ Its purpose is to provide a common starting point for identifying the strategies, policies, and practices that will enhance cultural competence and lead to improvements in access to care, utilization of services, satisfaction with services, quality of care, and outcomes. However, there was no attempt to rank the elements of this list on their overall contribution to cultural competence.

The Characteristics of a Culturally Competent Organization

1. Develops knowledge of the populations it serves through ongoing assessments, and communicates this information throughout the organization.
2. Builds relationships with communities served by the organization by identifying, opening communication channels to, and working with community organizations and leaders.
3. Develops and implements plans, policies, and procedures for promoting staff diversity and culturally competent practices throughout the organization.
4. Conducts periodic assessments of organizational and provider-level cultural competence. Integrates performance standards and data elements related to cultural competence into ongoing quality assurance activities.
5. Promotes diversity in organizational governance and decision



making and ensures that providers, staff, and managers reflect the demographic characteristics of consumers and the overall community.

6. Provides enabling services that remove barriers to access to care. Examples include childcare, transportation, interpreters, and patient advocate services.
7. Conducts mandatory cultural competency training.
8. Measures access, utilization, consumer satisfaction, quality of care, and outcomes segmented by the various population groups served by the organization.
9. Ensures culturally and linguistically appropriate communications by offering trained interpreters, translated material, material at appropriate reading levels, and information presented through alternative media.
10. Ensures culturally appropriate health care encounters by providing services that are sensitive to cultural, family, and individual characteristics of consumers.
11. Promotes the delivery of effective health care that respects and incorporates the culture of the consumer.
12. Emphasizes the measurement of outcomes, including health status and consumer satisfaction with services, for different population segments.

See Appendix E for a full description of these characteristics.

It is important to note that these characteristics are a product of both the process of providing and managing care and the organizational structures in which care is delivered. Processes refer to practices, procedures, and policies that affect what the organization or its practitioners do and how they do it. Structures are defined as specific organizational units, staff positions, programs, and policies that affect the infrastructure of the organization or its patient care services.

Organizational structures and processes may profoundly influence the patient's experience in ways that are hidden from the direct view of the consumer. For example, an analysis of quality of care or outcome data by race/ethnicity may lead to improvements in the technical quality of care for segments of the patient population; this increases the cultural competence of the organization but not in a manner that consumers readily recognize. Similarly, when consumers report on the care they received, they are unlikely to realize that a positive experience can be attributed to the increased input by diverse communities into organizational decision making.

Additionally, the characteristics of cultural competence address measurement, the promotion of accountability, and a focus on outcomes. As with many structural issues, these categories are critical to the cultural competence of organizations, yet consumers may only be able to observe their effects indirectly.

Section III. Overview of the Three Consumer Surveys



This project focused on three consumer surveys that use standardized instruments and standardized administration methodologies:

1. Consumer Assessment of Health Plans Survey (CAHPS®), designed for health plans
2. Picker Inpatient Survey, designed for hospitals
3. Physician Value Check (PVC), designed for medical groups

For each survey, the Working Group reviewed survey development and administration issues, including translation, cultural adaptation, item development strategies, and sampling procedures.

Although all of these surveys focus primarily on eliciting patients' reports of their actual experiences, they also provide opportunities for patients to rate, or evaluate, their experiences. For example, in the CAHPS survey, respondents report their experiences by choosing among "Always/Usually/Sometimes/Never" to indicate how often something happened. In contrast, ratings measure consumers' reactions to their experiences, using response scales such as "poor to excellent," "very dissatisfied to very satisfied," or "0 to 10" with anchors of worst possible and best possible.

In addition, all three surveys request that respondents identify their race and ethnicity. But race and ethnicity data for patients in the *sample* are rarely available because most health care organizations do not collect this kind of information from their patients. As a result, survey analyses do not include calculations of response rates for various racial and ethnic groups nor do they estimate how representative the respondents are of the total population eligible for the survey.

The relatively small sample sizes and the lack of information about race, ethnicity, or language for the sample limit the ability of these standardized surveys to capture the experiences or assessments of groups that constitute a small percentage of the patient population for an individual health plan, hospital, or medical practice. For that reason, focus groups and interviews may be more appropriate vehicles for gathering information from these subgroups. But by pooling survey data from individual plans, hospitals, and medical groups, it is possible to capture the experiences of various ethnic and language groups across a state, region, or program, such as Medi-Cal.

The CAHPS Survey

The purpose of the CAHPS survey is to gather data on the experiences and assessments of health plan enrollees so that consumers can use this information to compare and select plans in a given market. Although it is currently used in managed care environments, CAHPS was designed to provide comparable information about the quality of care in other kinds of delivery systems as well.



Basic Facts About the CAHPS Survey

Unit of Analysis: Health plan

Source of Data for This Project:

Using the National CAHPS Benchmarking Database (NCBD), researchers gathered data from the adult commercial, adult Medicaid, and child Medicaid versions of the CAHPS 1.0 surveys conducted in 1997-98. (The current CAHPS survey is version 2.0.) The Medicaid and commercial databases included data from 31 and 54 plans, respectively. Overall response rates averaged about 52% for all plans but were lower for Medicaid plans. The adult database contained about 28,000 observations; the children's database had almost 10,000.

Sample Size/Number of Respondents:

Samples must be of sufficient size to generate 300 completed surveys per plan.

Eligibility Requirements:

To be eligible for the survey, respondents must have been enrolled in the plan for a specific period of time. They do not have to be users of the plan's services.

Survey Administration:

The survey is administered by mail, telephone, or both. It is usually administered by a third party.

Risk Adjustment:

Reported data are adjusted for age, gender, education (or parent's education), and overall health status.

There are four separate surveys associated with CAHPS:

- One for adults enrolled in commercial plans
- One for children enrolled in commercial plans
- One for adults enrolled in Medicaid
- One for children enrolled in Medicaid

(Parents complete surveys for services received by their children.)

CAHPS reports include scores for four global ratings (i.e., evaluations of health care) and five composites of reporting items (i.e., descriptions of experience). The four global ratings indicate satisfaction with the personal physician or nurse, specialist, health care received, and the overall plan. The composite scores represent consumers' experiences with getting access to needed care, the timeliness of care, provider communication, staff helpfulness, and health plan customer service. No survey item asks consumers directly about their perceptions of the technical quality of the care received. Generally, consumers' perceptions of technical quality are based on the quality of communications, whether they can get care and how fast, and the perceived quality of customer service.

CAHPS Surveys and Race, Ethnicity, and Language Issues

In the CAHPS survey, two questions collect information on race and ethnicity. The first asks about Hispanic origin while the second queries the race of the respondent. CAHPS codes the following race/ethnicity categories:

- Hispanic
- White
- African American
- Asian
- American Indian
- Mixed race
- Non-response

Of special note, the National CAHPS Benchmarking Database had sufficient responses from American Indians to develop precise estimates for this population group, although the sample of American Indians was not representative of American Indians nationally. Few health-related surveys include sufficient observations to provide information about the experience of this population group.

Only the Medicaid versions of CAHPS ask about language preferences. However, the developers of CAHPS were cognizant of the potential impact of language differences on perceptions of care. For example, the researchers relied on a considerable number of focus groups and cognitive interviews in developing the CAHPS surveys and reporting materials. Since they intended to create both English and Spanish versions of

CAHPS from the beginning, Spanish speakers were included in this initial testing and development process.

The Picker Survey

The Picker Survey is a tool for measuring the experiences of patients with hospital-based care. Developed by the Boston-based Picker Institute, the survey asks patients to report on the following eight aspects of their experiences:

- Access to care
- Respect for patients' values, preferences, and expressed needs
- Coordination of care
- Information and education
- Physical comfort
- Emotional support
- Involvement of family and friends
- Transition and continuity

However, the survey does not include any items about health insurance due to the difficulty of framing the question in a manner all consumers can understand; also, poor coding in hospital records precludes accurate stratification of samples on this variable.

Nearly 600 hospitals around the country use the Picker survey to help assess the quality of care they provide.⁹ Initially, hospitals were conducting the survey primarily for internal quality improvement purposes. Currently, organizations in California and Massachusetts are using the survey to develop comparative reports on hospital quality for the public.

The Picker Institute administers the survey for hospitals, which draw a sample sufficient to generate responses from 600 discharged patients, 200 each from medical, surgical, and childbirth services. Picker then uses the survey responses to construct problem scores, which it develops for each questionnaire item by combining all responses on the response scale that indicate any kind of problem or less than optimal service. For example, on an item rating quality of staff, Picker provides respondents with the following options: poor, fair, good, very good, and excellent. The problem score for that item is based on the responses of all patients who answer either "poor" or "fair" to the question. Picker then rolls up problem scores for related items into the eight reporting dimensions listed above. Hospitals receive reports of both their problem scores for individual items and their scores for each dimension.

The Picker Survey and Race, Ethnicity, and Language Issues

The Picker survey requests information on race and ethnicity from respondents and codes for the five major racial and ethnic groups in the



Basic Facts About the Picker Survey

Unit of Analysis: Hospital

Source of Data for This Project:

The data for this project came from surveys of California hospitals conducted in 1998 and 1999. The data set included responses from 30,441 patients.

Sample Size/Number of Respondents:

Samples must be of sufficient size to generate 600 completed surveys per hospital: 200 each from medical, surgical, and childbirth services.

Eligibility Requirements:

To be eligible for the survey, respondents must have been hospital inpatients during the year prior to the survey.

Survey Administration:

The survey is administered by mail.

Risk Adjustment:

Reported data were adjusted for age, sex, education, income, and health status.



Basic Facts About the Physician Value Check Survey

Unit of Analysis: Medical group

Source of Data for This Project:

The data for this project came from PBGH's 1996 survey of medical group patients in California. This survey was in English only. The PVC survey is currently available in both English and Spanish.

Sample Size/Number of Respondents:

The sample consisted of 1,000 patients selected from each of 59 participating physician groups. The sample from each medical group was stratified by age with 700 drawn from the 50-70 year-old age group, and 300 from ages 18-49. The survey generated a 55% response rate.

Eligibility Requirements:

To be eligible for the survey, respondents had to be commercial or Medicare-risk plan enrollees who had at least one visit in 1995.

Survey Administration:

The survey is administered using a mailed survey with a reminder postcard, second survey mailing, and telephone follow-up.

Risk Adjustment:

Reported data were adjusted to account for the sample weighting (i.e., for the fact that 70% of the sample were 50 and over). Data were also adjusted for age, gender, education, income, and score on the SF-12, a scale that measures the respondents' health status.

United States. Picker also requests these data for the patients in the sample provided by each hospital, but data for the sample are not usually available.

To date, the survey has been translated into Spanish, Cantonese, Khmer, Russian, Portuguese, and French Canadian; an Armenian version is also planned. The Spanish version of the survey has been used extensively in California; Picker's initial assessments indicate that it worked well with Spanish-speaking respondents. Also, when Picker performed psychometric testing of response scales, it found them to be reliable across various ethnic populations.

Physician Value Check (PVC) Survey

The PVC is a survey of HMO enrollees, primarily in California, whose care is managed by medical groups or IPAs (independent practice associations). The purpose of this survey is to collect information on patients' experiences and their assessments of the care received from physician organizations. Measures reported from this survey indicate how satisfied patients were with care and access to care, whether patients received preventive care services, whether patients with high blood pressure and high blood cholesterol received appropriate care, and the two-year change in patients' functional status. The survey was developed and continues to be supported by the Pacific Business Group on Health (PBGH), a regional coalition of large health care purchasers, including major employers and CalPERS. PBGH publicly reports the results in an effort to help consumers and purchasers choose physician groups for service.

Based on the results of the PVC survey analyzed for this project, respondents tended to be older, well educated (95% attended more than high school), and relatively high income (with a mean income of \$40,000). Some 70% were white, 11% Hispanic, 9% Asian, 3% African American, and 3% other race or ethnicity.

Section IV. Findings and Recommendations



This section presents the project's findings and recommendations, which are based on interviews with key informants, the three Working Group meetings, and the analyses of consumer survey data. The discussion of each finding includes a review of supporting data and other information, as well as a summary of the views expressed by participants in this project (see Appendix B for a list of participants). At the end of this section is a compilation of all of the recommendations, with an indication of which ones should be addressed immediately.

Summary of Findings

Based on the analyses conducted for this project, we found that aggregated data from standardized consumer surveys can reveal important information about disparities in the experiences of different racial and ethnic groups with health plans, hospitals, and medical groups. However, existing surveys are clearly imperfect tools for measuring organizational cultural competence and identifying the factors that underlie differences in people's perceptions and judgments of their experiences.

What We Learned About Consumer Surveys

Consumer surveys are useful for promoting quality.

Standardized consumer surveys help to promote the quality of health care by capturing input from many kinds of consumers, generating results relevant to assessments of cultural competence, and providing data for comparative reports on quality that people can use to learn about their health care options.

The usefulness of these surveys for evaluating cultural competence is closely tied to the fact that both the instruments and their administration are standardized. Without the ability to pool survey results, it would be extremely difficult—if not impossible—to generate a sufficient amount of data to draw conclusions about the experiences of specific subgroups of the population.

Although they have promise, consumer surveys are currently inadequate tools for assessing cultural competence.

Standardized surveys are limited in their ability to capture the voices of consumers of color and assess dimensions of the cultural competence of specific health organizations. The Working Group identified a number of factors that hinder consumer surveys from serving in this capacity. These factors fall into five broad categories:

- **The limited perspective of consumers:** Some aspects of cultural competence are simply not observable by consumers, even though its effects may contribute to the quality of the care they receive.



Specific Findings of This Project

Finding 1:

Preliminary analyses of existing survey data sets by race and ethnicity show differences across race, ethnicity, and language groups in their experiences and assessments of care.

Finding 2:

Standardized consumer surveys help to promote health care quality by capturing input from all consumers, generating results relevant to assessing disparities in the experiences of diverse consumers, and providing information appropriate for use and decision making by consumers.

Finding 3:

Standardized surveys are limited in their ability to capture the voices of consumers of color and assess dimensions of the cultural competence of specific health care organizations.

Finding 4:

The assessment of cultural competence requires the ability to analyze and compare measures for different racial, ethnic, cultural, and language populations and to ensure the validity of those analyses.

Finding 5:

Various tools and techniques have different roles, strengths, and limitations with respect to gathering information about the experiences and judgments of individuals from diverse communities.

Finding 6:

Because the characteristics of cultural competence are multidimensional in nature, an evaluation of an organization's cultural competence also requires the use of methods that go beyond reports and assessments of consumers' experiences.

- **Survey readability:** Written surveys can be inaccessible for people with low literacy or limited proficiency in English.
- **Survey content:** Consumer surveys have not been designed to measure cultural competence. While they may contain a few relevant questions, they are not specifically intended to provide information regarding the experiences of consumers of color.
- **Sampling strategy:** The sample size for consumer surveys is too small to support generalizations about the experiences of people from ethnic, racial, and language subgroups for individual organizations. Also, current sampling strategies preclude researchers from determining whether respondent data are representative of the overall population surveyed.
- **Survey administration:** Because they are typically conducted through the mail or over the telephone, consumer surveys may fail to capture the views of people who are difficult to reach, either because contact information is unavailable or because they lack a telephone.

To address these limitations of surveys, various health system stakeholders would need to apply resources, conduct additional research, advocate for change, and make significant changes in policies and practices. Specific recommendations are provided in Finding 3.

It is not clear whether a subset of survey items could be used to create an index for measuring cultural competence.

One of the goals of this project was to see whether one could use a subset of the items in standardized consumer surveys to develop an index that would contribute to the measurement of cultural competence. Unfortunately, we were not able to determine this with any confidence. Three sets of factors were responsible for this uncertainty:

- First, many critical dimensions of the cultural competence of an organization are not visible to consumers, even though their effects may contribute to the quality of the care they receive.
- Second, as explained above, consumer surveys—as they are currently formulated and administered—are not sufficiently effective at revealing discrepancies in the experiences and assessments of different racial, ethnic, and language groups.
- Third, the participants in this project were able to take only an initial step in the development and testing of a cultural competence index based on selected survey items. During the review of the consumer surveys, the Working Group identified a number of items from each instrument that might have special significance for consumers from diverse racial, ethnic or cultural background. In general, the items selected fell into three categories:
 1. Items that elicit reports about the attitude of staff and practitioners toward the patient and the adequacy of communications between practitioner and consumer
 2. Items that elicit patient ratings of various aspects of care



3. Items related to health status and health behaviors

These items were tabulated by race and ethnicity categories, but time did not permit full analyses of composites of these items that could be used as indices.

What We Learned About Alternative Measurement Tools

Alternatives to surveys offer the potential for exploring the causes of discrepancies in patients' reports at the organizational level.

Although surveys can reveal differences in experiences and perceptions, they cannot dig below the surface to identify the reason for inequities in care delivery or in other interactions with the surveyed health care organization. The documentation of disparities in the reports and ratings of patients of color and white patients is only a starting point for further examination into their underlying causes. The presence of disparities is not prima facie evidence of a lack of cultural competence, nor is their absence proof that an organization is culturally competent in all areas.

To learn more about the causes of such differences, and to explore ways to compensate for the limitations of surveys, the Working Group discussed several alternatives to standardized consumer surveys. These alternatives include focus groups, one-on-one interviews, organization- and population-specific surveys, and other approaches to gathering information from consumers about their health care experience. Based on the experiences of institutions that have applied these techniques, the Working Group members and researchers concluded that these other methods would be useful for capturing in-depth information on the experiences and assessments of consumers of color with regard to health care.

In addition to techniques that rely on reports from consumers, health care organizations need to explore ways to gather information about the aspects of cultural competence that are not visible to consumers.

Although consumers can provide useful information about some of the characteristics of cultural competence in health care organizations, they are not in a position to assess those aspects of cultural competence that are a function of the organization rather than of individual interactions. To obtain information about the characteristics that consumers may not be able to perceive, organizations may need to consider the use of other methods, including organizational surveys and audits, reviews of medical charts, interviews with staff, and analyses of utilization and outcome data.

Findings Related to Consumer Surveys

Finding 1: Preliminary analyses of existing survey data sets by race and ethnicity show differences across race, ethnicity, and language groups in their experiences and assessments of care.



Finding #1

Recommendations

for Immediate Action

- 1.1 Perform further analyses of consumer survey data stratified by race, ethnicity, and language.
- 1.2 When possible, use data sets pooled nationally, by program, by state, or by population group over time to generate sufficiently large samples for identifying differences in experience across race, ethnicity, and language.
- 1.3 Perform analyses on clusters of questions to identify which items, singly or in combination, can reliably reflect differences in the experiences of various racial, ethnic, and language groups that are related to the underlying cultural competence of an organization.

For Long-Term Implementation

- 1.4 Collect and analyze survey data that can be stratified by socioeconomic status and payer source.
- 1.5 Identify information about sources of care that can serve as independent variables in the analysis of consumer reports and ratings. Examples of potentially pertinent characteristics include: public or private hospital, patient population characteristics, diversity of provider staff, and existence of programs to promote cultural competence.

Analyses of the three surveys uncovered similar patterns in the experiences and assessments of people of color. For example:¹⁰

- Racial and ethnic minorities are confronted by barriers to access in health care.
- Latinos/Latinas and Asians who speak a language other than English at home report more negative experiences with care than do English speakers.
- Lower scores on reports of care do not necessarily translate into lower ratings of care among racial and ethnic minorities.
- Adult African Americans report more positive experiences with their own health care than do whites but more negative ratings of the care received by their children.

Specific Findings from Data Analyses

CAHPS: The pooled data set drawn from the National CAHPS Benchmarking Database offered enough responses to develop valid estimates for African Americans, American Indians, Asians and Pacific Islanders, Latinos/Latinas, and whites.

Statistically significant findings include the following:

- Compared to white respondents, Hispanics¹¹ generally had less favorable reports with respect to access, customer service, and promptness of services but a higher overall rating of their health plans.
- African Americans tended to report more positive experiences than whites, particularly in the domains of physician communication and the courtesy of office staff. They also gave higher ratings to their overall experience with health plans and the care they received. These high ratings are surprising in light of other studies that show bias in health care delivery and health statistics that show higher rates of morbidity and mortality for African Americans. But while overall ratings by African-American adults were as high as those for white adults, ratings of the care provided to African-American children were lower.
- Asian and Pacific Islander consumers consistently reported more negative experiences with care than did whites, although there was no difference in their overall rating of their health plan when compared to whites. As with Hispanics, negative reports of experiences with care were not reflected in lower ratings of care.
- Compared to white respondents, American Indians rated their physicians lower but reported similar experiences with care.
- The group characterized by missing race and/or ethnicity data had consistently more negative reports and ratings of care. In addition, this group had the largest magnitude of difference between their ratings and the ratings of whites.



Table 1	Composites					Ratings			
	Access to needed care	Timeliness of care	Provider communication	Staff helpfulness	Health plan customer service	Personal physician or nurse	Specialist	Health care received	Overall plan
Hispanic (reference = white)	↓	↓			↓			↑	
African American			↑	↑			↑	↑	
Asian/Pacific Islander	↓	↓	↓	↓	↓				
American Indian/Alaskan Native						↓	↓		
Multiracial/Other	↓	↓	↓	↓		↓		↓	↓
Missing	↓	↓	↓	↓	↓			↓	↓

- Hispanics and Asians who spoke English at home gave reports and ratings similar to those of whites, while those who spoke other languages at home had more negative reports and ratings than whites did.¹²

Table 1 above summarizes these results.¹³ Downward-pointing arrows indicate less favorable (more negative) reports or ratings of experience for that composite measure when compared to the reference point of white survey respondents. Correspondingly, upward-pointing arrows indicate more favorable (less negative) reports or ratings of experience.

Picker Survey: An analysis of data from the Picker survey showed patterns for race and ethnicity similar to those found with the CAHPS data. For example:

- Compared to whites, Asians had more negative reports but a similar rating of overall satisfaction.
- The reported experience of Hispanics was better than that of Asians and lower than that of whites.
- The reported experiences and overall ratings of African Americans were similar to those of whites.

Physician Value Check: The analyses of survey responses by race and ethnicity for PVC generated results similar to those of CAHPS and Picker. African Americans and whites had generally comparable experiences and ratings, Hispanics were somewhat more negative, and Asians had the lowest ratings of experience and satisfaction of all of the ethnic groups when compared to whites.

Finding 2: Standardized consumer surveys help to promote health care quality by capturing input from all consumers, generating



Finding #2

Recommendations

for Immediate Action

- 2.1 Promote requirements and incentives for making survey results public and develop effective strategies for the dissemination of the results of consumer surveys to potential audiences.
- 2.2 Support consumer organizations in developing reports designed specifically for diverse groups of consumers. Present data in a manner that helps consumers make decisions.

For Long-Term Implementation

- 2.3 Elicit ratings of specific aspects of patient care in all surveys. Although reports are very useful, it is important to go beyond what happened to capture people's judgments of the experience.
- 2.4 Using survey results as a starting point, perform in-depth assessments at the level of health plans, hospitals, and medical groups to identify underlying causes for relatively poor scores from communities of color.
- 2.5 Work with consumers and consumer groups on the interpretation of survey results and solicit input from consumers on the design of reports and the appropriateness of dissemination strategies for diverse consumers.
- 2.6 Encourage health plans, hospitals, and medical groups to maximize the use of survey data segmented by race, ethnicity, and language. One important use is to examine trends by race, ethnicity, and language of enrollees (e.g., trends in dissatisfaction or enrollment among particular population segments).
- 2.7 Support substantial and varied research efforts that explore the link between cultural competence and health care outcomes.

results relevant to assessing disparities in the experiences of diverse consumers, and providing information appropriate for use and decision making by consumers.

Several factors underlie the usefulness of standardized consumer surveys for gathering information from consumers of color:

- 1. Their ability to capture information about consumers' experiences as well as their assessments of that experience**
- 2. Their standardization in content, sampling, and administration, which facilitates valid comparisons across population groups**

Because the content, administration, and sampling strategies of the three survey instruments are standardized, researchers are able to use the results to do the following:

- Aggregate data across ethnic and racial groups, organizations, programs, geographic areas, and other levels of analysis
- Aggregate data for specific populations over time
- Make comparisons among health care organizations
- Make comparisons over time within the same organization

- 3. Their growing acceptance by the health care industry as valid tools for measuring aspects of quality**

The widespread use of standardized consumer surveys in the health care industry has resulted in large pooled data sets. With the availability of so many data on diverse population groups, it becomes possible to:

- Make statistically valid comparisons across racial and ethnic groups (and in some cases between English and non-English speaking consumers)
- Analyze data at national, state, or program levels
- Create a data set large enough to generate valid estimates for American Indians

- 4. The considerable resources committed to their development, validation, updating, and translation**

The resources available to support the development of standardized consumer surveys facilitated the use of extensive qualitative research in their preparation. For example, both CAHPS and Picker undertook numerous focus groups and interviews to ensure the content and item validity of survey questions for a representative sample of likely survey respondents. In addition, CAHPS has undergone an extensive cultural adaptation process for Spanish and Picker is currently being culturally adapted for Vietnamese and other languages.

- 5. Their potential value as an input for state and national policymakers when making decisions that affect communities of color**



6. The relative ease with which results can be disseminated to the public

The dissemination of survey results is critical to maximize their value in promoting cultural competence. The Working Group identified several audiences for consumer survey data analyzed by race, ethnicity, and language, including:

- Consumers and consumer organizations
- Surveyed health care organizations
- Private purchasers
- Government purchasers and regulators
- Practitioners

However, the dissemination of consumer survey information is sometimes hindered by policy decisions. For example, although the survey administrators intended to publicize the results of the two CAHPS surveys of enrollees in California's Medicaid program, the release of the data has been delayed as of the writing of this report.

7. The usefulness of the survey results for consumers and others

Consumer survey data should and can be used in health care decision making, advocacy, and quality improvement. Potential users of the data include:

- Consumers and consumer organizations: to inform choices about providers and health plans
- Health plans, institutions and medical groups: to improve performance
- Practitioners: to improve their performance and to strengthen their role as internal advocates for changes that improve health care quality and outcomes
- Policymakers and purchasers: to increase quality and promote accountability

That said, consumer survey data are most valuable when results are available by race, ethnicity, and language, and when they are used in conjunction with other more-detailed information gathered through a variety of means. For instance, some members of the Working Group expressed concern that many hospitals believe that the results of the Picker Survey "speak for themselves" rather than recognizing the need to use the information as a starting point for a more in-depth exploration of problem areas.

Finding 3: Standardized surveys are limited in their ability to capture the voices of consumers of color and assess dimensions of the cultural competence of specific health care organizations.

As indicated in Finding 2, surveys can contribute useful information about the quality of care received by different population groups. However, the three consumer surveys reviewed for this project were not

Guidelines for Coding for Race, Ethnicity, Culture, and Language.

Coding for race, ethnicity, culture, and language is a prerequisite for investigating disparities in the experience of various population groups. The Working Group was in general agreement with the guidelines developed by the Family Health Outcomes Project, a center at UCSF, regarding the collection and reporting of race and ethnicity (see Appendix D). These guidelines have been adopted by the California State DHHS and are consistent with the categories that were used in the Year 2000 census.¹⁵



Finding #3

Recommendations

for Immediate Action

- 3.1 Develop specific culture- and language-related questions to add to existing surveys as individual items or as supplements for use in settings with high levels of diversity. These questions could be used to probe more deeply into the nature of cross-cultural interactions. Patients could also be asked about their experiences with interpreters, signage, and other interventions that promote access for non-English speakers.
- 3.2 Develop systems for maintaining and updating contact information to improve response rates.

For Long-Term Implementation

- 3.3 Develop consumer survey instruments that explicitly address the relationship between patient satisfaction and experience and the cultural competence of health care providers and organizations. These tools should be designed to support analyses of patients' assessments of their interactions with providers by the race, ethnicity, and language of both the patient and the provider.
- 3.4 Identify "best practices" for surveying communities of color and collect tools developed for different populations.

developed as tools for assessing cultural competence. In fact, the Working Group identified a number of factors that affect the ability of these surveys to capture the experiences of patients of color and evaluate the cultural competence of organizations. Generally the limitations of the standardized surveys fall into five broad categories:

- The limited perspective of consumers
- Survey readability
- Survey content
- Sampling frame and strategy
- Survey administration

Factor 1: The Limited Perspective of Consumers

As noted earlier, certain dimensions of cultural competence are not directly observable by consumers. While information from consumers is an essential contribution to an assessment of the cultural competence of organizations, consumers cannot provide information on many of the structures, policies, and practices that are critical to ensuring a high quality of care for consumers of color. For example, consumers will not know if staff performance evaluations are tied to the delivery of culturally sensitive care or if health care organizations segment analyses of quality, utilization, or outcomes.

Factor 2: Survey Readability

An additional concern is that people with limited proficiency in English or low literacy sometimes have difficulty with written surveys and with understanding some of the complex concepts about the health system that are incorporated into surveys. The Adult Spanish and English CAHPS surveys have been analyzed for reading level; both the Spanish and English versions are about 7th-grade reading level.¹⁴ While lower-grade reading levels are often sought for consumer information, there is a tradeoff between readability and the complexity of terms required in the surveys.

Factor 3: Survey Content

The three standardized surveys were developed to gather data from the general population of patients who receive medical care about their experience with health plans, hospitals, and medical groups. The lack of a specific focus on patients of color and on cultural competence resulted in very few questions that address the cross-cultural experience of consumers. For example, although the CAHPS Medicaid survey does ask about the availability of interpreters, none of the three surveys contain questions that probe experiences with interpreters, multilingual signage, or educational material.

Although, the surveys do not focus on cultural competence per se, some items on all three indirectly address issues of cultural competence when analyzed by race and ethnicity. Examples include items related to perceptions of respectful care, quality of communications with providers and other staff, and trust of the provider.

All three surveys request that respondents indicate the racial or ethnic group to which they belong. But none of the surveys code beyond the five major racial/ethnic groups (African-American, Asian, Hispanic, Native American, or white), so they do not capture subpopulation ethnicity (such as Laotian or Cambodian) or mixed-race identification. The Medicaid versions of CAHPS (for adults and for children) are the only surveys that ask about language.

Similarly, little information is collected that would allow a determination of the respondents' socioeconomic status. CAHPS and Picker request information on the respondents' level of education. PVC requests information on income level, which allows for some analysis by socioeconomic status.

Another area that the surveys do not address directly is the dynamics of cross-cultural interactions between patients and providers and other staff.

The following questions suggest the kind of information it would be important to gather:

- Did the patient and physician share the same view of the patient's disease?
- Did the patient express all of his/her concerns to the physician?
- Did the patient and physician reach an agreement about what was wrong?

There are significant barriers to gathering this type of information through consumer surveys. For example, these questions may be difficult for most patients to answer directly. Patients may not be able to determine what the physician thinks about his or her condition or they may not think about the causes of disease using the same kind of medical model. In addition, there can be multiple reasons for poor communications between providers and patients.

The development of cultural competence items on a survey would also require considerable qualitative research, including cognitive testing, before their validity could be assured across a variety of groups. Furthermore, surveys are already somewhat burdensome to consumers; most require 20 to 30 minutes to complete and demand a relatively high degree of literacy to answer some of the more complex items.

Factor 4: Sampling Frame and Strategy

Several characteristics of the sampling frame and strategy of consumer surveys limit their ability to capture the experiences of consumers of color or generate information that can be used to assess cultural competence.

First, the three standardized surveys draw relatively small samples from each of the organizations they survey. CAHPS and Picker draw samples sufficiently large to generate 400 and 600 responses per health plan and hospital, respectively. PVC draws a larger sample from each medical groups: 1,000 patients with 70% of the total drawn from the 50–70-year-old age group. The small samples generally mean that one



Assessing the Equivalence of Scales Used in the English and Spanish Versions of CAHPS

In a presentation to the Working Group, Leo Morales, MD, PhD, reviewed his work adapting the CAHPS survey for Spanish-speaking consumers. Part of this task involved testing the equivalence of the English and Spanish versions of a nine-item scale that measures patient satisfaction.¹⁷ Item validation for multicultural and multilingual consumer surveys is critical to ensuring that measured differences reflect actual differences in patients' reports or assessments of experiences rather than a lack of measurement equivalence for survey items presented in different languages. In addition, there is a growing, but still insufficient, understanding of the impact of culture in determining consumers' expectations regarding their health care and the effect of those expectations on their ratings of experiences. Researchers suspect that the different expectations of consumers from different cultures may have a substantial effect on the way they evaluate similar experiences.



Finding #4

Recommendations for Immediate Action

4.1 Continue to refine the use of survey data as a tool for assessing the experiences of diverse groups of consumers. Conduct analyses at program, regional, state, or other levels as permitted by current and improved sampling strategies.

4.2 Collect data on race, ethnicity, and language at the level of health plans and programs (such as Medicaid and Medicare) to facilitate analyses of variations in reports and ratings.

4.3 Adopt the recommendations of the Family Health Outcomes Project on race and ethnicity coding. Enhance the demographic data collected through consumer surveys by eliciting and coding for:

- Tribal affiliation of American Indians
- Both race and ethnicity data for all respondents
- Multiple choices of race and ethnicity for multiracial/multiethnic people
- Language spoken at home and preferred language spoken and read
- At a minimum, items related to education and family income as proxies for socioeconomic status

Also, explore the feasibility of measures of socioeconomic status beyond education and household income.

4.4 Translate and adapt surveys for language and cultural groups that are a relatively large proportion of the service population, face especially significant barriers to health care or health disparities, or have been designated by government and other programs as significant for measurement purposes. (See Appendix C for priority threshold languages for California Medicaid and Healthy Family programs.)

For Long-Term Implementation

4.5 Conduct further research on the cross-cultural equivalence of survey instruments.

4.6 Conduct research to better understand how culture influences the formulation of expectations for patient care and how those expectations contribute to consumers' assessments of their experiences.

can make valid estimates only for the entire patient population of the surveyed organization, i.e., not for smaller groups of patients. That said, the ability to generate large data sets by pooling data across a number of organizations creates the potential for enough responses from specific population groups to calculate statistically valid estimates for those segments.

Although the survey methodology includes a request for health care organizations to provide race and ethnicity information for the patients in the samples they draw, this information is provided only infrequently. Most health care organizations do not collect such data and thus cannot identify the race or ethnicity of individual patients. Without these denominator data, researchers cannot determine whether respondents to the survey are representative of the racial and ethnic composition of the sample. Acknowledging that a more extensive collection of patient demographic data would create additional costs initially, the Working Group members expressed a belief that health plans, hospitals, and medical practice groups lack the motivation to collect, analyze, and report data by race, ethnicity, or language.

Another factor is that many consumers of color are simply not included in the sample. For example, both CAHPS and PVC survey only patients who are members of health plans and therefore have health insurance. They do not capture the experiences of many uninsured consumers, who are disproportionately people of color.

Factor 5: Survey Administration

The Working Group noted a number of limitations related to mail and telephone surveys, including the lack of accurate contact information and the fact that some potential respondents live in homes without telephones. Researchers reported that poor contact information was the major cause of low response rates in surveys of Medicaid members. Actual refusal rates were low.¹⁶

Finding 4: The assessment of cultural competence requires the ability to analyze and compare measures for different racial, ethnic, cultural, and language populations and to ensure the validity of those analyses.

The preliminary analysis of standardized consumer surveys presented in Finding 1 provides further evidence that different racial, ethnic, cultural, and language groups do not necessarily have the same experience in their interactions with components of health care systems. Failure to analyze and compare data from key population segments could hide potentially large variation in their experiences.

However, even standardized consumer surveys do not always lend themselves to valid comparisons across population groups. As discussed in Finding 3, problems with surveys include the following:

- Inadequate demographic coding that ranges from no data on race, ethnicity, and language to coding that neglects key subpopulations of major racial and ethnic groups



- Poor response rates to surveys due to a lack of contact information for people from diverse communities and inadequate outreach (see Recommendations 3.2 and 6.4)
- Sampling strategies that do not generate sufficient numbers for some population groups to generate statistically valid estimates about them (see Recommendation 1.1)

Another potential problem is associated with the failure to maintain the equivalence of survey instruments that are translated into multiple languages. While validated procedures for the cultural adaptation of survey instruments across languages are available (see Appendix F), the development of instruments that can be administered across languages or cultures is a serious challenge for survey developers. Even when accurately translated into a variety of languages, there are many significant threats to the equivalence of surveys. Some critical concerns include the following:

- **Words and phrases may not translate directly or have conceptual parallels from one language to another.** Literal translations can generate entirely unintentional and incorrect meanings. Also, the ways in which people from other cultures view the underlying factors affecting physical and mental health may not be consistent with the models common in American practice settings. Finally, certain concepts like "managed care" and "health care specialist" may have no equivalence in some languages.
- **There may be a cultural component to the way survey respondents interact with scoring scales.** In many cases, data analyses cannot determine retrospectively whether differences observed between racial and ethnic groups were due to real differences in care, or due to differences in how respondents perceived the items and/or the scoring of items. For example, two experts interviewed for this project reported anecdotal evidence that Asian survey respondents had a tendency not to give the highest ratings even when completely satisfied with services. It is therefore important to determine the degree to which similar responses across different groups truly reflect a similarity of experience and different responses truly reflect a difference in experience.
- **Certain questions, topics, or phrases may be offensive when translated across languages and cultures.**
- **Item prompts (e.g., lists of foods for nutrition-related questions) may not be meaningful for respondents from diverse cultures.**

All of these issues may be responsible for reduced response rates or non-equivalent responses.

Cross-cultural equivalency may also be an issue when surveys are administered to English speakers of different cultures, including American Indians, African Americans, Asians, Pacific Islanders, and Latinos.



Finding #5

Recommendations

for Long-Term Implementation

- 5.1 Design comprehensive data-gathering systems that include both qualitative and quantitative measurement tools. In addition to standardized surveys, options include focus groups, surveys that target specific populations, and face-to-face and telephone interviews.
- 5.2 Systematically explore with consumers how their cultural beliefs affect their communications and interactions with providers and the health care system.
- 5.3 Increase the use of focus groups and one-on-one interviews in the development of survey instruments and strategies for reporting and disseminating survey results.
- 5.4 Promote the use of nonstandardized methods to explore the implications of findings related to race, ethnicity, and language for specific health plans, hospitals, medical groups, and programs.
- 5.5 Promote an element of standardization in the development and administration of nonstandardized techniques for gathering information from consumers. Potential opportunities for standardization include the development of quality control standards for focus groups and interviews and agreement on a core set of questions about the consumer's experience that would be incorporated into all relevant protocols and interview guides.
- 5.6 To add to the field's understanding of the effects of cultural competence on quality, explore ways to encourage and support the sharing of results from organization-specific focus groups and surveys on consumers' experiences. Since organizations may be reluctant to disseminate their results, one option would be to develop a clearinghouse that could accept, organize, and compile anonymous reports.

Findings Related to the Use of Alternative Strategies

Finding 5: Various tools and techniques have different roles, strengths, and limitations with respect to gathering information about the experiences and judgments of individuals from diverse communities.

Given the limitations of consumer surveys, the Working Group discussed several other approaches to gathering information from consumers about their health care experiences. Based on the experiences of various health care organizations, the Group concluded that focus groups, one-on-one interviews, organization-specific surveys and other alternatives to standardized surveys would be useful tools for capturing in-depth information on the experiences and judgments of consumers of color. These nonrandomized approaches have the following advantages:

- They provide an opportunity for in-depth and interactive explorations of patients' experiences.
- If health care organizations have sufficient information on the race, ethnicity, and language preferences of the population they serve, they can use these techniques to focus their information-gathering efforts on representatives of specific population groups or languages. In some cases, they can even concentrate on learning about the experiences of relatively small racial, ethnic, or language groups that would tend to be invisible in randomized patient population surveys.
- Organizations can use these methods to gather input for particular purposes (e.g., to help evaluate providers).
- Focus groups and interviews can be designed in a way that optimizes communication across languages and cultures.
- Organizations can use the results to determine whether and how the general findings of standardized surveys are applicable in specific practice settings.

But methods that do not use randomized samples have the following limitations:

- Organizations cannot use the results with confidence to make general statements about the experiences of the larger population.
- It is very difficult to aggregate results or to make comparisons across organizations.
- Quality control issues exist. Just as standardized surveys must adhere to rather strict principles to ensure validity, interviews and focus groups must also be rigorous in their approach, especially when gathering information across cultures and languages. For example, when soliciting feedback from consumers, it is important to consider how the setting may bias responses. Soliciting feedback in a clinical setting immediately

after a clinical encounter, for instance, may be perceived as coercive in nature.

- Results are seldom provided to consumers to assist them in making decisions. Organization-specific approaches usually do not promote public accountability.



Finding #6

Recommendations

for Immediate Action

- 6.1 Assess the relative usefulness of various tools for developing measures of the degree to which organizations achieve the characteristics of culturally competent organizations. Examples could include standardized consumer surveys, non-standardized methods for obtaining consumer input, organizational surveys and audits, utilization and outcomes studies, etc.
- 6.2 Develop a comprehensive approach for evaluating the characteristics of culturally competent organizations in hospitals, health plans and provider groups on an ongoing basis. This should include qualitative and quantitative data from consumers, providers, and organizations that could be used to assess processes, structures and outcomes.
- 6.3 Using a comprehensive approach (see 6.2), gather information on the cultural competence of health care organizations with the goal of developing report cards or other comparative ratings.

For Long-Term Implementation

- 6.4 Use the "characteristics of culturally competent organizations" or an equivalent framework to assess tools for evaluating cultural competence.
- 6.5 Conduct additional research with consumers, providers, and administrators to understand their perceptions of cultural competence and the problems that arise with cross-cultural interactions. Incorporate the findings from this research into measurement tools.
- 6.6 When designing or revising organizational assessment tools for hospitals, health plans, and provider groups, incorporate measures that indicate the extent to which systems for measuring cultural competence are in place.

Finding 6: Because the characteristics of cultural competence are multidimensional in nature, an evaluation of an organization's cultural competence also requires the use of methods that go beyond reports and assessments of consumers' experiences.

The 12 characteristics of culturally competent organizations listed earlier provide a useful framework for assessing how effectively and appropriately a health care organization can serve different racial, ethnic, and language groups. This framework reflects the position of the Working Group that cultural competence should be considered as much a function of the organization as it is a result of the interactions between providers and patients. This viewpoint emphasizes organizational policies, practices, and structures that provide incentives and opportunities for culturally appropriate practices by individual providers and other staff.

As noted previously, information about consumers' experiences and assessments of health care can be indicative of the level of cultural competence of a health care organization, especially when there are consistent trends among members of particular racial, ethnic, or language groups. In addition to standardized surveys, one may use a variety of vehicles to obtain this kind of feedback, including focus groups, one-on-one interviews, ad hoc surveys, and other non standardized or organization-specific methods. The relative advantages of these various methods are discussed above in Finding 5.

That said, consumers are not in a position to directly assess the underlying mechanics of their health care interactions or to judge the degree to which cultural competence contributed to a satisfactory encounter. Any method that relies on eliciting information from consumers is limited in its ability to reveal aspects of cultural competence that are a function of the organization rather than of individual interactions. To explore this concern, the Working Group conducted a preliminary assessment of the usefulness of consumer surveys for evaluating the degree to which organizations exhibit the 12 characteristics of culturally competent organizations. The following characteristics were identified as most amenable for direct measurement through consumer surveys (numbering reflects position in the list of characteristics):

6. Provides enabling services that remove barriers to access to care.
9. Ensures culturally and linguistically appropriate communications.
10. Ensures culturally appropriate health care encounters.



11. Promotes the delivery of effective health care that is consistent with the patient's culture.

For other characteristics, consumer reports can only indirectly suggest the degree of its implementation in an organization, indicating a need for methods for assessing those aspects of cultural competence that cannot be reported by consumers. Some options include organizational surveys and audits, reviews of medical charts, interviews with staff, and analyses of utilization and outcome data. Measures generated through these methods can be standardized by incorporating them into new or existing accreditation program; they could also be combined with the results of consumer surveys to create report cards for the public.

Summary of Recommendations:

Recommendations:	Requires Immediate Attention
Finding 1: Preliminary analyses of existing survey data sets by race and ethnicity show differences across race, ethnicity, and language groups in their experiences and assessments of care.	
1.1 Perform further analyses of consumer survey data stratified by race, ethnicity, and language.	X
1.2 When possible, use data sets pooled nationally, by program, by state, or by population group over time to generate sufficiently large samples for identifying differences in experience across race, ethnicity, and language.	X
1.3 Perform analyses on clusters of questions to identify which items, singly or in combination, can reliably reflect differences in the experiences of various racial, ethnic, and language groups that are related to the underlying cultural competence of an organization.	X
1.4 Collect and analyze survey data that can be stratified by socioeconomic status and payer source.	
1.5 Identify information about sources of care that can serve as independent variables in the analysis of consumer reports and ratings. Examples of potentially pertinent characteristics include: public or private hospital, patient population characteristics, diversity of provider staff, and existence of cultural competence promoting programs.	
Finding 2: Standardized consumer surveys help to promote health care quality by capturing input from all consumers, generating results relevant to assessing disparities in the experiences of diverse consumers, and providing information appropriate for use and decision making by consumers.	
2.1 Promote requirements and incentives for making survey results public and develop effective strategies for the dissemination of the results of consumer surveys to potential audiences.	X
2.2 Support consumer organizations in developing reports designed specifically for diverse groups of consumers. Present data in a manner that helps consumers make decisions.	X
2.3 Elicit ratings of specific aspects of patient care in all surveys. While reports are very useful, it is important to go beyond what happened to capture people’s judgments of the experience.	
2.4 Using survey results as a starting point, perform in-depth assessments at the level of health plans, hospitals, and medical groups to identify underlying causes for relatively poor scores from communities of color.	
2.5 Work with consumers and consumer groups on the interpretation of survey results and solicit input from consumers on the design of reports and the appropriateness of dissemination strategies for diverse consumers.	
2.6 Encourage health plans, hospitals, and medical groups to maximize the use of survey data segmented by race, ethnicity, and language. One important use is to examine trends by race, ethnicity, and language of enrollees (e.g., trends in dissatisfaction or enrollment among particular population segments).	
2.7 Support substantial and varied research efforts that explore the link between cultural competence and health care outcomes.	

Summary of Recommendations: (continued)

Recommendations:	Requires Immediate Attention
Finding 3: Standardized surveys are limited in their ability to capture the voices of consumers of color and assess dimensions of the cultural competence of specific health care organizations.	
3.1 Develop specific culture- and language-related questions to add to existing surveys as individual items or as supplements for use in settings with high levels of diversity. These questions could be used to probe more deeply into the nature of cross-cultural interactions. Patients could also be asked about their experiences with interpreters, signage, and other interventions that promote access for non-English speakers.	X
3.2 Develop systems for maintaining and updating contact information to improve response rates.	X
3.3 Develop consumer survey instruments that explicitly address the relationship between patient satisfaction and experience and the cultural competence of health care providers and organizations. These tools should be designed to support analyses of patients' assessments of their interactions with providers by the race, ethnicity, and language of both the patient and the provider.	
3.4 Identify "best practices" for surveying communities of color and collect tools developed for different populations.	
Finding 4: The assessment of cultural competence requires the ability to analyze and compare measures for different racial, ethnic, cultural, and language populations and to ensure the validity of those analyses.	
4.1 Continue to refine the use of survey data as a tool for assessing the experiences of diverse groups of consumers. Conduct analyses at program, regional, state, or other levels as permitted by current and improved sampling strategies.	X
4.2 Collect data on race, ethnicity, and language at the level of health plans and programs (such as Medicaid and Medicare) to facilitate analyses of variations in reports and ratings.	X
4.3 Adopt the recommendations of the Family Health Outcomes Project on race and ethnicity coding. Enhance the demographic data collected through consumer surveys by eliciting and coding for: <ul style="list-style-type: none"> • Tribal affiliation of American Indians • Both race and ethnicity data for all respondents • Multiple choices of race and ethnicity for multiracial/multiethnic people • Language spoken at home and preferred language spoken and read • At a minimum, items related to education and family income as proxies for socioeconomic status Also, explore the feasibility of measures of socioeconomic status beyond education and household income.	X
4.4 Translate and adapt surveys for language and cultural groups that are a relatively large proportion of the service population, face especially significant barriers to health care or health disparities, or have been designated by government and other programs as significant for measurement purposes.	X
4.5 Conduct further research on the cross-cultural equivalence of survey instruments.	X
4.6 Conduct research to better understand how culture influences the formulation of expectations for patient care and how those expectations contribute to consumers' assessments of their experiences.	

Summary of Recommendations: (continued)

Recommendations:	Requires Immediate Attention
Finding 5: Various tools and techniques have different roles, strengths, and limitations with respect to gathering information about the experiences and judgments of individuals from diverse communities.	
5.1 Design comprehensive data-gathering systems that include both qualitative and quantitative measurement tools. In addition to standardized surveys, options include focus groups, surveys that target specific populations, and face-to-face and telephone interviews.	
5.2 Systematically explore with consumers how their cultural beliefs affect their communications and interactions with providers and the health care system.	
5.3 Increase the use of focus groups and one-on-one interviews in the development of survey instruments and strategies for reporting and disseminating survey results.	
5.4 Promote the use of nonstandardized methods to explore the implications of findings related to race, ethnicity, and language for specific health plans, hospitals, medical groups, and programs.	
5.5 Promote an element of standardization in the development and administration of non-standardized techniques for gathering information from consumers. Potential opportunities for standardization include the development of quality control standards for focus groups and interviews and agreement on a core set of questions about the consumer's experience that would be incorporated into all relevant protocols and interview guides.	
5.6 To add to the field's understanding of the effects of cultural competence on quality, explore ways to encourage and support the sharing of results from organization-specific focus groups and surveys on consumers' experiences. Since organizations may be reluctant to disseminate their results, one option would be to develop a clearinghouse that could accept, organize, and compile anonymous reports.	
Finding 6: Because the characteristics of cultural competence are multidimensional in nature, an evaluation of an organization's cultural competence also requires the use of methods that go beyond reports and assessments of consumers' experiences.	
6.1 Assess the relative usefulness of various tools for developing measures of the degree to which organizations achieve the characteristics of culturally competent organizations. Examples could include standardized consumer surveys, nonstandardized methods for obtaining consumer input, organizational surveys and audits, utilization and outcomes studies, etc.	X
6.2 Develop a comprehensive approach for evaluating the characteristics of culturally competent organizations in hospitals, health plans, and provider groups on an ongoing basis. This should include qualitative and quantitative data from consumers, providers, and organizations that could be used to assess processes, structures, and outcomes.	X
6.3 Using a comprehensive approach (see 6.2), gather information on the cultural competence of health care organizations with the goal of developing report cards or other comparative ratings.	X
6.4 Use the "characteristics of culturally competent organizations" or an equivalent framework to assess tools for evaluating cultural competence.	
6.5 Conduct additional research with consumers, providers, and administrators to understand their perceptions of cultural competence and the problems that arise with cross-cultural interactions. Incorporate the findings from this research into measurement tools.	
6.6 When designing or revising organizational assessment tools for hospitals, health plans, and provider groups, incorporate measures that indicate the extent to which systems for measuring cultural competence are in place.	

Section V. Conclusions and Next Steps



The Cultural Competence and Consumer Survey Project represents a significant effort on the part of both the California Pan-Ethnic Health Network and the California HealthCare Foundation to promote the quality of health care for California's increasingly diverse population. Through this project, we hope that the health care industry, policymakers, purchasers, researchers, and advocates for improved cultural competence will become more aware of the relationship between cultural competence and health care quality and more appreciative of the potential value of consumer surveys for revealing disparities in the experiences of different consumer groups.

We recognize that the ultimate success of this project depends on our ability to motivate health care agencies, organizations, and consumers to:

- Recognize the importance of cultural competence.
- Support the development of a variety of tools for assessing the cultural competence of health care organizations as part of a strategy that would enhance their ability to serve diverse communities effectively.
- Increase the ability of standardized consumer surveys to capture the experiences of diverse patients and contribute to the measurement of cultural competence in health care organizations.

To these ends, both CPEHN and the CHCF will be reviewing the findings and recommendations of this project to determine how to incorporate them into future initiatives. CPEHN will examine how to incorporate selected recommendations into its advocacy agenda and the CHCF will review ways to build them into its ongoing programs. To bring attention to the issues raised by the report, both organizations will also disseminate it to their respective constituencies and partner organizations.

What Health Care Organizations and Agencies Can Do

The chart on pages 36-37 displays the critical roles that various health care organizations and agencies must adopt to establish cultural competence as an essential element of California's health care systems.

The Working Group and other project participants recognized the considerable barriers that health care organizations and regulators face in addressing the health care needs of California's diverse communities. Issues of cost, opposition to regulation, staffing shortages, as well as institutional hesitancy to engage issues of race and racism in meaningful ways inhibit the implementation of the quality measurement and improvement strategies proposed in this report.

Yet the results of this project demonstrate that the combined efforts of advocates, funders, providers, researchers, and administrators can advance the field and provide a blueprint for health care system improvements that are feasible and cost-effective. We invite future efforts to build on the findings of this project and look forward to the day when all Californians have access to culturally competent health care.

Summary of Recommendations:

Health System Role	Description	Role in Addressing Project Recommendations
Advocates	Health policy advocates, consumer advocates, racial/ethnic community organizations	Advocate, mobilize consumers and communities, offer technical advice, and monitor progress.
Funders	Foundations and government grantmakers	Provide financial, convening, and intellectual support for basic and applied research; support survey development; advocate; disseminate information; and perform other tasks related to promoting cultural competence and the increased usefulness of consumer surveys.
Health Care Organizations	Health plans, medical groups, hospitals, and long-term care facilities	Adopt policies and practices that promote and assess cultural competence; use a variety of tools and techniques to obtain input from patients of color.
Policymakers	State and federal government legislatures and regulators	Promote the collection of data on quality and patients' experiences by race, ethnicity, and language; incorporate cultural competence and language accessibility into measures of quality.
Government Programs	Medi-Cal, Medicare, Healthy Families (California's CHIP), and other government-financed health insurance programs	Incorporate cultural competence requirements into contracts with health care organizations; require the collection and reporting of patient data by race, ethnicity, and language; assess cultural competence in programs and disseminate findings to enrollees.
Purchasers	Employers or individuals	Incorporate cultural competence requirements into contracts with health care organizations; require the collection and reporting of patient data by race, ethnicity, and language; assess cultural competence in programs and disseminate findings to enrollees.
Health Care Organizations	Health plans, medical groups, hospitals, and long-term care facilities	Adopt policies and practices that promote and assess cultural competence; use a variety of tools and techniques to obtain input from patients of color.

Summary of Recommendations: (continued)

Health System Role	Description	Role in Addressing Project Recommendations
Policymakers	State and federal government legislatures and regulators	Promote the collection of data on quality and patients' experiences by race, ethnicity, and language; incorporate cultural competence and language accessibility into measures of quality.
Government Programs	Medi-Cal, Medicare, Healthy Families (California's CHIP), and other government-financed health insurance programs	Incorporate cultural competence requirements into contracts with health care organizations; require the collection and reporting of patient data by race, ethnicity, and language; assess cultural competence in programs and disseminate findings to enrollees.
Purchasers	Employers or individuals	Incorporate cultural competence requirements into contracts with health care organizations; require the collection and reporting of patient data by race, ethnicity, and language; assess cultural competence in programs and disseminate findings to enrollees.
Researchers	Public, private, and academic entities that conduct or sponsor research	Conduct research on the interactions between patients' expectations, their culture, and consumer surveys; explore the relationship between culturally competent practices and patient outcomes.
Standard-Setting and Measurement Organizations	Groups that set, assess, and enforce quality and performance standards for health plans, hospitals, and medical groups	Incorporate meaningful measures of cultural competence into standards for health care organizations; gather data and disseminate results to consumers.
Survey Organizations	Organizations that develop, conduct, or sponsor consumer or organizational surveys (HEDIS, Picker, etc.)	Develop survey items that contribute to the assessment of cultural competence; construct composites of measures that are related to the experiences of patients of color.

Appendix A: Methodology – The Three Project Phases

The CPEHN and CHCF implemented this project in three phases:

Phase I: Gathering of Information, Development of Framework

In **Phase I**, the project first elicited the expertise of key informants through a series of Working Group meetings and individual interviews. These informants included survey researchers, experts in cultural competence, health care advocates, and providers. They brought a broad diversity of perspectives and experience to the assessment of cultural competence and the review of consumer surveys. California HealthCare Foundation staff and consultants also participated in the Working Group meetings. (See Appendix B for a list of participants.)

The Working Group first met in December 1999. Accomplishments of this first meeting included:

- The development of the list of the characteristics of culturally competent organizations as a working framework
- An initial review and critique of standardized surveys
- The development of recommendations for improving survey administration and content
- The development of recommendations for the analysis of survey data, including the identification of survey items of high interest to the Working Group

Phase II: Analysis

The second phase of the project included additional interviews with expert informants, analyses of pooled data for each of the three surveys commissioned by the California HealthCare Foundation, and the convening of an expert panel to review and begin to interpret the results. The purpose of the analyses was to identify any differences between the experiences and assessments of patients from ethnic and racial groups and those of white patients. The analyses also looked for differences in the experiences and assessments of patients who speak English and those who speak another language at home. The researchers performing the analyses controlled for a variety of demographic and health status characteristics where the data permitted; for the CAHPS results, they also performed statistical tests of significance for apparent differences. The methodology and results of those analyses are described in detail under **Finding 1**.

Researchers, survey developers, and project staff met in April 2000 to:

- Review the findings of the analyses of the three standardized surveys
- Discuss the usefulness of the items designated as high interest by the participants in the December meeting
- Discuss consumer survey development and administration issues, including translating and ensuring the cultural equivalence of surveys in different languages, sampling procedures and limitations, and analysis strategies and tools
- Develop recommendations for further research and development

Phase III: Development and Ratification of Recommendations

The original Working Group was reconvened in June 2000 to:

- Review the findings of Phase II
- Finalize recommendations for existing standardized surveys
- Develop recommendations for alternatives methods and tools for assessing cultural competence

Appendix B: Project Participants

Denise Adams-Simms, MPH
Executive Director
California Black Health Network

Amy Andersen
Senior Manager for the Quality Initiative
Pacific Business Group on Health

Richard Baker, MD
Charles R. Drew University of Medicine & Science

Tim Berthold, MPH
Director of Public Policy
Health Access

Tomiko Conner, MPP, MPH
Policy Director
California Pan-Ethnic Health Network

Cheryl Damberg, PhD
Director of Research and Quality
Pacific Business Group on Health

Charles Darby
Social Science Administrator
Agency for Healthcare Research and Quality
(AHRQ)

Calvin Freeman
Calvin Freeman & Associates

Ron Garcia, PhD
Director, Hispanic Center of Excellence
Stanford School of Medicine

Jean Gilbert, PhD
Director, Cultural Competence
Kaiser Permanente Health Care

Ron D. Hays, PhD
Professor of Medicine, UCLA Division of General
Internal Medicine and Health Services Research
Senior Health Policy Analyst, Rand Corporation

Michael Jang
Executive Director
The URSA Institute

Martha Jazo-Bajet
Preventive Services Manager
Community Health Group

Peter Long
Executive Director
Indian Health Center of Santa Clara Valley

Michael P. Massagli
Research & Development Director
The Picker Institute

Julio Mateo, Jr., JD
Latino Coalition for a Healthy California

Laurin Mayeno
Consultant

Leo Morales, MD, PhD
Assistant Professor
UCLA and Rand Corporation

Linda Okahara
Community Services Director
Asian Health Services

Maryann O'Sullivan, JD
Consumer Education Officer
Quality Initiative
California HealthCare Foundation

Lisa Payne-Simon
Deputy Director
Quality Initiative
California HealthCare Foundation

Latonya Slack, JD
Executive Director
California Black Women's Health Project

Brenda Solorzano, JD
Program Officer, Consumer Education and Policy
Quality Initiative
California HealthCare Foundation

Carol Somkin
Principal Investigator
Division of Research
The Permanente Medical Group, Inc.

Miguel Tirado, PhD
Professor
CSU Monterey Bay

Daniel Toleran
Policy & Planning Coordinator
Association of Asian and Pacific Community
Health Organizations

Appendix C: Priority Languages for the Administration of Consumer Surveys in California

The Medi-Cal Managed Care Program of the California State Department of Health Services and the Managed Risk Medical Insurance Board's Healthy Families Program have between them identified ten priority languages during the course of their operations. These languages are:

- Armenian
- Cambodian
- Chinese (Cantonese)
- Hmong
- Korean
- Laotian
- Mien
- Russian
- Spanish
- Vietnamese

Contractors in the two programs are required to ensure accessibility in these languages at key points of patient contact, including the medical care encounter and member information and patient rights materials.

Appendix D: Family Health Outcome Project (FHOP) Guidelines for Race/Ethnicity Coding

FHOP

FAMILY HEALTH OUTCOMES PROJECT

GUIDELINES ON RACE/ETHNICITY DATA COLLECTION, CODING AND REPORTING

I. INTRODUCTION

Throughout the 1970s, 1980s and 1990s, California has experienced a tremendous change in demographics due primarily to the arrival of immigrants from around the world. By 1996, nearly half of the births in California were to foreign-born women¹. The increasing number of cultures with their differing health beliefs and distinctive health status/outcomes will necessitate targeting resources and designing outreach and services that meet the needs of these various populations in a culturally sensitive and competent way. Many of the observed differences in health status/outcomes and in service utilization among race/ethnic subgroups are also known to be related to socioeconomic factors. Therefore, data elements indicating socioeconomic status should be analyzed along with data on race/ethnicity (R/E) to allow for more accurate assessment of the relative contributions of these factors to the health of these groups. In addition, to the extent possible, other state programs should share R/E information about the same individual to improve data reliability, facilitate program data collection and ease the program/service application process for clients.

Within this context, the Family Health Outcomes Project (FHOP) and its Work Group have developed the following recommendations in an attempt to guide both current and future efforts in collecting, reporting and coding data on race/ethnicity. The Work Group reviewed and considered guidelines produced by the Office of Management and Budget (October 30, 1997). The final recommendations for state policy will be submitted to the California Department of Health Services (DHS), Center for Health Statistics, for presentation to the Department of Health Services executive staff for implementation in all DHS programs. The Guidelines will then go through the Office of Health Information for Policy (OHIP) to all Departments within the Health and Welfare Agency. Final recommendations will be coordinated and compatible with Department of Finance standards.

II. PROPOSED RACE/ETHNICITY POLICY GUIDELINES

A. DATA COLLECTION

1. Data collection policies and forms should be uniform across all DHS programs.
2. California data collection practices for race/ethnicity should be compatible with the most recent guidelines from the Office of Management and Budget (OMB) and National Center for Health Statistics (NCHS).
3. The data collecting scheme should continue to provide a separate Spanish /Hispanic/Latino choice, to be consistent with current census definitions.
4. Race/ethnicity designation should be determined by self-declaration (or by parent or legal guardian for a minor), or by next of kin for deaths.
5. The collection scheme should not allow for self-declaration or administrative assignment of "refused" or "unknown" categories. "Other (Specify_____)" should be an option; "Specify" is not required. If a person refuses to respond, the R/E field should be left blank.
6. There should be a consistent way of collecting information that is designed to obtain the

¹1996: 45.2% of CA resident mothers were foreign born

greatest level of detail feasible (i.e., within some reasonable standard). This should include place of birth as well as single and/or multiple race/ethnic designation(s). (Note: Place of Birth has been accepted by the State Department of Health Services as a core data element for the common data set).

7. Race/ethnicity information should be collected at birth or at an initial program or service encounter.

B. DATA CODING

1. In general, coding of race/ethnicity data for all state and federal programs administered at the state and county levels should be compatible with the most recent guidelines from the OMB.
2. Coding designations should be consistent across all DHS programs.
3. Individual programs may choose to code data at more detailed levels.
4. Coding for place of birth should be consistent with the California common core data elements coding standards.
5. Any coding scheme should be flexible enough to allow for periodic updating (e.g., to allow more specific coding when data from other sources become available).
6. A "Non-Response/Unknown" code should be used if the field is blank, regardless of reason.

C. DATA REPORTING

1. All race/ethnic information must be able to be collapsed into categories consistent with the most recent guidelines from the OMB for reporting purposes.
2. Specific aggregate levels of reporting race/ethnicity should be consistent for use across all DHS programs.
3. Individual programs may choose to report data at more detailed levels.
4. Reporting formats should include mutually exclusive combinations of race /ethnicity with Spanish/Hispanic/Latino origin (e.g., white Hispanic and white non-Hispanic).
5. Reporting of "Non-Responders/Unknown" will be included with "Others" for reporting.

III. Data Collection, Reporting and Coding Recommendations

A. COLLECTION

1. Race/ethnicity data should be collected via self-declaration. The FHOP Workgroup recommends that self-selection be used to determine race/ethnicity for a client. Since there are no objective criteria by which individuals can be categorized by their race/ethnicity, the use of methods other than self-declaration will result in inconsistent and therefore, less useful data. In the case of a child where self-declaration is not possible, a parent, other family member or legal guardian should be asked.
2. Standardized worksheets/computer screen(s) should be used to facilitate self-declaration of race/ethnicity. This process should be developed and piloted by the state Department of Health Services. Worksheets should be provided to the data collectors to share with the clients to assist them in identifying the most appropriate race/ethnic category. These worksheets should be appropriately tested for reliability, consistency, sensitivity to client needs and time and work burden on staff. For example, if the Spanish/Hispanic/Latino category is chosen, and the individual desires to indicate greater category specification, a list of additional options should be provided to include common Spanish/ Hispanic/Latino origins

(e.g., Mexico, Guatemala, Nicaragua, Chile, Spain, etc.). A sample format is included as Attachment 1 for consideration.

3. When possible, all programs serving children should collect three variables for the mother, father, and child:

- a. Race/ethnicity
- b. Spanish/Hispanic/Latino origin
- c. Place of birth

4. A separate question should be asked first on Spanish/Hispanic/Latino origin to be consistent with the most recent guidelines from OMB. The following categories should be used in the Spanish/Hispanic/Latino origin field:

- North American (Mexican, Mexican-American, Chicano)
- South American
- Central American
- Other Spanish/Hispanic/Latino origin (Specify)
(e.g., Puerto Rican, Cuban, Haitian)

We recommend that these categories be listed as separate choices and then collapsed into the "Spanish/Hispanic/Latino" category for reporting and comparative use with the OMB categories.

5. Race/ethnicity data should be collected in such a way as to be collapsible into the minimum categories and be consistent with state statutes (Government Code Sections 8310.5, 11092 and 11092.5) and guidelines from the OMB. In addition, the FHOP work group recommends collection of race/ethnicity data into other suggested categories .

The categories are:

White³

Black, African American, or Negro³

American Indian (including North, South, and Central American Indian;

Specify Tribe _____); or Alaska Native (including Aleut and Eskimo)³

Asian Indian² Cambodian² Chinese² Filipino²

Japanese² Hmong⁴ Korean² Laotian²

Vietnamese² Other Asian² (Specify _____)

Native Hawaiian^{2,3}

Guamanian²

Samoan²

Other Pacific Islanders^{2,3} (Specify _____)

Other Race (Specify _____)⁴

Individuals should choose at least one, and may choose no more than three categories of race and/or ethnicity, but there will be no option for "multiracial" selection.

6. There should be no separate category for "non-response," "refused," or "unknown."

B. CODING

1. All race/ethnicity data should be stored as detailed codes to be accessible for future use. Coding should include a choice of a maximum of three separate race/ethnicity categories and one Spanish/Hispanic/Latino category.
2. Coding should be developed that allows for separation of two fields that could also be combined:
 - a. Spanish/Hispanic/Latino origin
 - b. Race/Ethnicity
3. Coding should be developed for use with Spanish/Hispanic/Latino categories to include additional Central American and South American places of birth.
4. Whenever possible, programs should use the same coding assignment numbers for race/ethnicity and country of origin to ensure consistency, regardless of differences in data collection or reporting approaches (e.g., data base revisions). See Attachment 2 for recommended codes.

C. REPORTING

1. The following race/ethnicity data should be reported in as many ways as feasible and appropriate to the program setting:
 - a. SPANISH/HISPANIC/LATINO ORIGIN
 - b. NON-SPANISH/HISPANIC/LATINO ORIGIN:

White³ only

Black, African American, or Negro³ only

American Indian (including North, South, and Central American Indian;
Specify Tribe _____); or Alaska Native (including Aleut and Eskimo)³ only

Asian Indian ^{2, †} only	Cambodian ^{2, †} only	Chinese ^{2, †} only	Filipino ^{2, †} only
Japanese ^{2, †} only	Hmong ^{4, †} only	Korean ^{2, †} only	Laotian ^{2, †} only
Vietnamese ^{2, †} only	Other Asian ^{2, †} only (Specify _____)		

²Required by state statute

³Required by OMB guidelines (Federal Registrar, Office of Management and Budget, October 30, 1997)

⁴Recommended by FHOP Work Group for DHS

Native Hawaiian^{2,3} only

Guamanian², †only

Samoan², †only

Other Pacific Islanders^{2,3} only (Specify _____)

Other Race only (Specify _____)⁴

More Than One Race⁷

2. It is recommended that these data elements be called "race/ethnicity" data elements. California law (Government Code Section 8310.5 and 11092 and 11092.5) describes the categories in which race/ethnicity data are to be reported.
3. When such detailed reporting is not feasible, the following ten (10) collapsed categories can be used at the minimum:

SPANISH/HISPANIC/LATINO ORIGIN

NON-SPANISH/HISPANIC/LATINO ORIGIN:

White only

Black, African American, or Negro only

American Indian or Alaska Native only (including Aleut and Eskimo)

Asian^a only

Southeast Asian^a only

Filipino^a only

Native Hawaiian or Other Pacific Islander only

Other Race only

More Than One Race

See Attachment 3 for recommendations on reporting categories and codes.

The definitions of the above R/E groups are based on categories from the U.S. Department of Commerce, Bureau of the Census.

In addition:

4. "OTHER:" Includes "non-responders," "refused," and "unknown" for the Spanish/Hispanic/Latino and Race/Ethnic questions, and should be reported under the "Other Race" category.

²Required by state statute

³Required by OMB guidelines (Federal Registrar, Office of Management and Budget, October 30, 1997)

⁴Recommended by FHOP Work Group for DHS

^aMay be combined under "Asian" for purpose of federal reporting

[†]May be combined under "Native Hawaiian or Other Pacific Islanders" for purpose of federal reporting

5. Spanish/Hispanic/Latino origin should be reported according to the collection fields noted in III A 4 under Collection.
6. The format used for reporting mutually exclusive Spanish/Hispanic/Latino and Race/Ethnic categories should be the standard used by the Department of Finance.^b

Attachment 1

RECOMMENDED FORMAT FOR RACE/ETHNICITY QUESTIONS

Are you Spanish/Hispanic/Latino?

Mark the "No" box if not Spanish/Hispanic/Latino.

- No, not Spanish/Hispanic/Latino
- Yes, North American (Mexican, Mexican American, Chicano)
- Yes, Central American
- Yes, South American
- Yes, Other Spanish/Hispanic/Latino

Specify: _____

What is your race/ethnicity?

Mark at least ONE. You may choose up to THREE boxes.

- | | |
|--|---------------------------------------|
| <input type="checkbox"/> White | <input type="checkbox"/> Asian Indian |
| <input type="checkbox"/> Black, African American, or Negro | <input type="checkbox"/> Cambodian |
| <input type="checkbox"/> American Indian or Alaska Native
(North, South, and Central American Indian) | <input type="checkbox"/> Chinese |
| Specify Tribe: _____ | <input type="checkbox"/> Filipino |
| <input type="checkbox"/> Native Hawaiian | <input type="checkbox"/> Japanese |
| <input type="checkbox"/> Guamanian | <input type="checkbox"/> Hmong |
| <input type="checkbox"/> Samoan | <input type="checkbox"/> Korean |
| <input type="checkbox"/> Other Pacific Islander | <input type="checkbox"/> Laotian |
| Specify: _____ | <input type="checkbox"/> Vietnamese |
| | <input type="checkbox"/> Other Asian |

Specify: _____

- Other

Specify: _____

^aMay be combined under "Asian" for purpose of federal reporting

^bThe method of reporting of race/ethnic data used by the Department of Finance is to report a single set of mutually exclusive race/ethnic categories by first selecting individuals who indicate they are of Spanish/Hispanic/Latino origin, and then to categorize the remaining non-Spanish/Hispanic/Latino origin and unknown Spanish/Hispanic/Latino origin individuals into their selected race/ethnic categories.

Attachment 2

RECOMMENDED CODES FOR RACE/ETHNICITY CATEGORIES

Spanish/Hispanic/Latino Origin

- 1 = Not Spanish/Hispanic/Latino
- 2 = North American (Mexican, Mexican American, Chicano)
- 3 = Puerto Rican
- 4 = Cuban
- 5 = Central American
- 6 = South American
- 7 = Other Spanish/Hispanic
- 8 = (available code for future use)
- 9 = Refused to state/unknown

Race/Ethnicity (May be repeated up to three times)

- 10 = White
- 20 = Black, African American, or Negro
- 30 = American Indian or Alaskan Native
- 40 = Asian Indian
- 41 = Cambodian
- 42 = Chinese
- 43 = Filipino
- 44 = Japanese
- 45 = Hmong
- 46 = Korean
- 47 = Laotian
- 48 = Vietnamese
- 49 = Other Asian
- 50 = Native Hawaiian
- 51 = Guamanian
- 52 = Samoan
- 53 = Other Pacific Islander
- 60 = Other race
- 99 = Refused to state/unknown

Attachment 3

Minimum Reporting Categories and Codes

	SPANISH/HISPANIC/ LATINO CODES	RACE/ETHNICITY CODES
SPANISH/HISPANIC/LATINO ORIGIN	2-8	-
NON-SPANISH/HISPANIC/LATINO ORIGIN	1,9	-
White	1,9	10
Black, African American, or Negro only	1,9	20
American Indian or Alaska Native only	1,9	30
Asian only	1,9	40,42,44,46,49
Southeast Asian only	1,9	41,45,47,48
Filipino only	1,9	43
Native Hawaiian or Pacific Islander only	1,9	50-53
Other race only	1,9	60,99
More than one race	1,9	10-60 +10-60

Appendix E: Characteristics of a Culturally Competent Health Care Organization

(Adapted from: Fortier, Julia Puebla and Yoku Shaw-Taylor. Cultural and Linguistic Standards and Research Agenda, Resources for Cross Cultural Health Care and DHHS Office of Minority Health, 1999; Cross, T, B Bazron, K Dennis, and M Isaacs. Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. Washington, D.C.: Georgetown University Child Development Center, CASSP Technical Assistance Center. 1991.)

1. Develops the organization's knowledge of the populations it serves.

On an ongoing basis, assesses the following:

- Demographic characteristics of the consumer population, the geographic catchment area, and the overall community, including racial, ethnic, and cultural populations and language groups
- Immigration and refugee status
- Health needs, beliefs, and practices
- Community resources, including alternative, traditional, and safety net health providers and social institutions
- Demographic trends regarding age, gender, education, income, occupations

Gathers information from community members and experts and from staff from diverse communities. Communicates information throughout the organization and incorporates findings into policies, procedures, and practices.

2. Builds relationships with communities served by the organization.

Develops knowledge of and establishes working relationships with community organizations and leaders. Involves community representatives in decision making; establishes communication channels and partnerships with traditional healers, safety net providers, and other community health resources as well as social, business, and cultural institutions; and communicates through community media.

3. Develops and implements plans, policies, and procedures for promoting staff diversity and culturally competent practices throughout the organization.

Develops and disseminates a formal plan with specific objectives, performance standards, and strategies to assess progress toward attaining cultural competence. Establishes an identifiable office or person within the organization responsible for promoting cultural competence. Provides adequate funding to cultural competence activities. Incorporates cultural competence into the organizational mission and throughout the strategic plan. Conducts proactive investigations of barriers to quality health care faced by culturally diverse consumers. Establishes incentives and accountability measures to ensure compliance with the organization's goals and policies related to cultural competence.

4. Conducts periodic assessments of organizational and provider-level cultural competence. Integrates performance standards and data elements related to cultural competence into ongoing quality assurance activities.

Conducts quality assurance studies that examine potential differences in quality of care and consumer satisfaction across racial, ethnic, and cultural populations and language groups. Uses a variety of strategies (including focus groups, targeted interviews, and assessments specific to cultural competence) to evaluate the overall status of the organization, staff performance, and interventions designed to promote cultural competence. Issues a periodic public report on progress.

5 (a). Promotes diversity in organizational governance and decision making.

Makes an effort to ensure that the race, ethnicity, and culture of the organization's top management and board of directors reflect the service population and/or geographic catchment area. Uses review and oversight committees, advisory groups, public meetings, and other outreach strategies to obtain input from community residents and organizations. Ensures that decision-making processes are visible and accessible to consumers and communities. Incorporates issues of race, ethnicity, and culture into the definition of medical ethics.

5(b). Ensures that provider staff, organization managers and supervisors, and staff responsible for contact with consumers reflect the demographic and cultural characteristics of consumers and the overall community.

Eliminates discriminatory practices in hiring, promotion, and contracting. Conducts active outreach to diverse populations for contract and staff positions at all levels. Supports training, internship, and mentoring programs targeted to diverse communities. Develops programs promoting retention of diverse staff. Seeks information from diverse staff to improve the quality of services. Establishes career ladders for employees.

6. Provides enabling services that remove barriers to access to care.

Provides childcare, transportation, language interpretation, and patient advocacy services to assist consumers with access to and utilization of services. Improves access through outreach and offsite services.

7. Conducts mandatory cultural competency training.

Provides training designed to assist providers and other staff in acquiring the knowledge and tools needed to work effectively in cross-cultural interactions. Effective training incorporates examination of one's own culture, information about diverse groups that are likely to use the organization's services, communication strategies for gathering and providing information across linguistic and cultural gaps, and sensitivity to avoid condescending and other inappropriate behavior. Training avoids stereotyping consumer groups and does not promote expectation of an "instant fix" to the challenges of cross-cultural interactions.

8. Measures access, utilization, consumer satisfaction, quality of care, and health status outcomes segmented by the various population groups served by the organization.

Implements management information systems and policies that allow analysis of critical data by racial, ethnic, cultural, and language groups. Routinely analyzes consumer data by socioeconomic status, gender, immigration/refugee status and level of acculturation, and other factors that might reveal differences in the experiences of socially vulnerable populations.

9. Ensures culturally and linguistically appropriate communications.

Makes available trained interpreters, translated material, material written at appropriate reading levels, and information presented through alternative media to ensure understanding. Uses interpreters proficient in medical terminology, English, and consumers' languages, and trained in the practice and ethics of interpretation. Trains monolingual staff in the use of interpreters, including the etiquette of speaking through an interpreter. Assesses language skills of all interpreters as well as bilingual staff used as interpreters. Establishes appointment systems that ensure the immediate availability of a needed interpreter. Ensures that the full range of written material is translated accurately and written at appropriate reading levels, with terminology familiar to the reading population. Uses videotapes, face-to-face communications, and other nonwritten forms of communications as appropriate.

10. Ensure culturally appropriate health care encounters.

Provides health care that is sensitive to cultural, family, and individual characteristics of consumers. Eliminates culturally inappropriate images, materials, or staff behavior. Uses welcoming images, culturally friendly designs, and multilingual signs. Promotes the staff's understanding of differences in communication and interaction styles, such as cultural preferences related to touching and personal space. Accurately pronounces names and uses appropriate forms of address. Avoids patronizing language or posture. Appropriately involves the family in health care decision making.

11. Promotes culturally appropriate health care.

Encourages the delivery of health care services in a manner that respects and incorporates the culture of the consumer. This consideration should be reflected in culturally appropriate diagnostic tests, health education programs, and dietary and other lifestyle recommendations. This trait includes a recognition of the role of alternative/native healers and medicines, an examination of potential pharmacological incompatibilities, and the incorporation of traditional beliefs about disease and wellness into therapy.

12. Emphasizes the measurement of outcomes for different segments of the population.

Focuses plans, policies, and practices on the achievement of positive outcomes related to accessibility, utilization, patient satisfaction, quality of care, and health status. Develops outcome measures that are used to promote organizational accountability, encourage appropriate policies and practices, and assess the cost-effectiveness of policies and practices. Evaluates outcomes in terms of both life-years saved and quality of life. Adds to the body of knowledge concerning cultural competence. Disseminates information both within and outside of the organization.

Appendix F: Process for Cultural Adaptation of Surveys

Steps in the Cultural Adaptation Process

(This section is adapted from "Cross-Cultural Adaptation of Survey Instruments: The CAHPS® Experience" by Robert Weech-Maldonado, Beverly O. Weidmer, Leo S. Morales, and Ron D. Hays, and incorporates recommendations from the Multicultural Issues Technical Advisory Committee of the California Health Interview Survey.⁶

Researchers have developed the following process to ensure the cross-cultural equivalency of surveys:

- Step 1. Conduct a qualitative analysis of the English version of the survey by bilingual/bicultural experts to simplify item language and identify problem areas for translation and cultural adaptation.
- Step 2. Synthesize the results of qualitative analysis and revise the English versions of instruments.
- Step 3. Test the survey (or only the problem areas identified in Step 1) with small groups of bilingual/bicultural representatives of the target language/cultural populations.
- Step 4. Translate the survey from English into other languages.
- Step 5. Test the translated surveys with monolingual groups. Revise the translation as needed and retest.
- Step 6. Back-translate the surveys into English.
- Step 7. Working with bilingual reviewers, compare back-translated surveys with the original English to assess the conceptual equivalence of both items and metric scales.
- Step 8. Have translators, back-translators, and reviewers for all languages collectively review back-translated surveys for inter-survey equivalence. Identify and resolve any discrepancies.
- Step 9. Train interviewers for telephone or field interview surveys.
- Step 10. Field test surveys.

End Notes

- ¹U.S. Census Bureau data, as reported in: America 2000: A Map of the Mix. *Newsweek*. (September 18, 2000); p.48.
- ²Carlisle D, et al. Racial and ethnic disparities in the use of cardiovascular procedures: Associations with type of insurance. *American Journal of Public Health*. 1997;87:263-267.; Burns R, E McCarthy, et al. Black women receive less mammography even with similar use of primary care. *Annals of Internal Medicine*. 1996; 125:173-182.
- ³Smith M, A Ryan. Chinese-American families of children with developmental disabilities: An exploratory study of reactions to service providers. *Mental Retardation*. 1987;23(6):345-350.
- ⁴Morales, LS, WE Cunningham, JA Brown, H Liu, and RD Hays. Are Latinos less satisfied with communication by health care providers? *J Gen Intern Med*. July 1999; 14(7):409-17.
- ⁵Clark, M. Margaret, Cultural Context of Medical Practice. *Western Journal of Medicine* 139 (Dec 1983);806-810; Salganicoff, A. Medicaid and Managed Care: Implications for Low-Income Women. *Journal of American Medical Women's Association*. 1997; 52(2): 78-80; Spring MA, PJ Ross, NL Etkin, AS Deinaud. Sociocultural Factors in the Use of Prenatal Care by Hmong Women, Minneapolis. *American Journal of Public Health*. 1995; 85(7): 1015-1017.
- ⁶Cachola, Shirley, Cultural Factors Affect Compliance in Filipino Patients, The Asian/Pacific Islander Task Force on High Blood Pressure Education and Control (June, 1984); Caudle, Patricia, Providing Culturally Sensitive Health Care to Hispanic Clients. *Nurse Practitioner*. 18 (Dec 1993):40-50; Westermeyer J. et al. Hmong Refugees in Minnesota: sex roles and mental health. *Medical Anthropology*. 1984; 8(4): 229-245; Takeuchi D, S Sue, M Yeh. Return Rates and Outcomes from Ethnicity-Specific Mental Health Programs in Los Angeles. *American Journal of Public Health*. 1995;85:638-643; Sanchez A, D Atkinson. Mexican American Cultural Commitment, Preference for Counselor Ethnicity, and Willingness to Use Counseling. *Journal of Community Psychology*. 1983;30:215-220; Cross, T, B Bazron, K Dennis, M Isaacs. Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed. Washington, D.C.: Georgetown University Child Development Center, CASSP Technical Assistance Center (1991).
- ⁷Pachter, Lee M., Culture and Clinical Care: Folk Illness Beliefs and Behaviors and Their Implications for Health Care Delivery. *JAMA*. 271 (March 2, 1994);690-694; Uba, Laura, Cultural Barriers to Health Care for Southeast Asian Refugees. *Public Health Reports*. 107 (Sept-Oct 1992); 544-548; Burns R, E McCarthy, et al. Black Women Receive Less Mammography Even with Similar Use of Primary Care. *Annals of Internal Medicine*. 1996;125:173-182; Woloshin, Steven, NA Bickell, LM Schwartz, F Gany, and HG Welch. Language Barriers in Medicine in the United States. *JAMA*; 273 (March 1 1995) 724-728; Klessig, Jill. The Effect of Values and Culture on Life-Support Decisions in Cross-cultural Medicine – A Decade Later (Special Issue). *Western Journal of Medicine*. 157 (Sept 1992); 316-321.
- ⁸To identify common elements and themes pervasive in current cultural competence practice, consultants to CPEHN reviewed documents by key experts in the field, including:
1. Fall/Winter 1995-1996 issue of the Family Resource Coalition's Report on culture and family-centered practice. From CASAnet Resource Library: <http://www.casanet.org/library/culture/comp.html>. Posted March 31, 1999.

2. Cross, T, B Bazron, K Dennis, M Isaacs. *Towards a Culturally Competent System of Care: A Monograph on Effective Services for Minority Children Who Are Severely Emotionally Disturbed*. Washington, D.C.: Georgetown University Child Development Center, CASSP Technical Assistance Center. 1991.
3. Tirado, Miguel D, PhD. *Tools for Monitoring Cultural Competence*. Final Report to the Office of Planning and Evaluation, HRSA. Latino Coalition for a Healthy California, January 31, 1996.
4. California Department of Health Services. *Draft Policy Letters on Cultural and Linguistic Services*. February 22, 1999.
5. Lavizzo-Mourey, R and ER Mackenzie. Cultural competence: Essential measurements of quality for managed care organizations. *Annals of Internal Medicine*. 1996;124(10), 919-920.
6. Pinderhughes, E. *Understanding Race, Ethnicity, and Power: Keys to Efficacy in Clinical Practice*. New York: The Free Press, 1989.
7. Fortier, Julia Puebla and Yoku Shaw-Taylor. *Cultural and Linguistics Standards and Research Agenda Project: Part One: Recommended Standards*. Resources for Cross Cultural Health Care with the Center for the Advancement of Health and the Department of Health and Human Services, Office of Minority Health. Final Draft, March 1999.
8. Garcia, Magda L, PhD. *Linguistic Competence and Cultural Competence: Health Plan Questionnaire*. Center for Healthcare Improvement, Memorial Hermann Healthcare System. 1998.
9. Mason, James. *Cultural Competence Self Assessment Tool*, Regional Research Institute for Human Services, Portland State University, 1994.
10. Stable, Eliseo Perez, MD. *Communication with Latino Patients: Questionnaire*, University of California, San Francisco, 1996.
11. Andrulis, Dennis, Ph.D. *Cultural Competence in Health Care Survey*, New York Academy of Science, 1996.

⁹Report from Michael Massagli, Research & Development Director of The Picker Institute, during second project meeting.

¹⁰Examples are drawn from a presentation by Drs. Ron Hays and Leo Morales of Rand Corp. at the second Working Group meeting.

¹¹"Hispanic" is the term used in the CAHPS survey.

¹²Findings regarding the experiences of non-English speakers are based on analyses of data from the children's Medicaid version of the CAHPS survey.

¹³Morales LS, R Weech-Maldonado, KL Spritzer, MN Elliott MN, RD Hays. Differences in CAHPS Adult Survey Ratings and Reports by Race and Ethnicity: An Analysis of the National CAHPS Benchmarking Data 1.0. Submitted: *Health Services Research*.

¹⁴Morales LS, BO Weidmer BO, RD Hays. Readability of the CAHPS[®] 2.0 Child and Adult Surveys. In Press: Conference Proceedings, Seventh Conference on Health Survey Research Methods.

¹⁵The Working Group had two concerns regarding the FHOP guidelines: 1) The use of the category "Asian Indian," which is not inclusive of all South Asians and 2) The use of the category "White" to

include recent immigrants and refugee groups despite considerable cultural and language differences between those groups and other "Whites."

¹⁶Based on interviews with Leo Morales, MD, PhD, Rand Corp., and Martha Jazo-Bajet, Preventive Services Manager, Community Health Group.

¹⁷For more information about this testing, see Morales, LS, SP Riese, and RD Hays. Evaluating the equivalence of health care ratings by whites and Hispanics. *Medical Care*. 2000;38(5), 517-27. In press.

The California Pan-Ethnic Health Network expresses its appreciation to all of the contributors to this project and especially to the members of the Working Group, to Tomiko Conner for her guidance of this project while CPEHN's Executive Director, to Laurin Yone Mayeno for her expert facilitation of the project Working Group, to Leo Morales, MD and Lisa Payne-Simon for their technical guidance, and to Ann Monroe for her continuous support throughout this project.

California Pan-Ethnic Health Network

**654 Thirteenth Street
Oakland, California 94612**

Phone: (510) 832-1160

Fax: (510) 832-1175