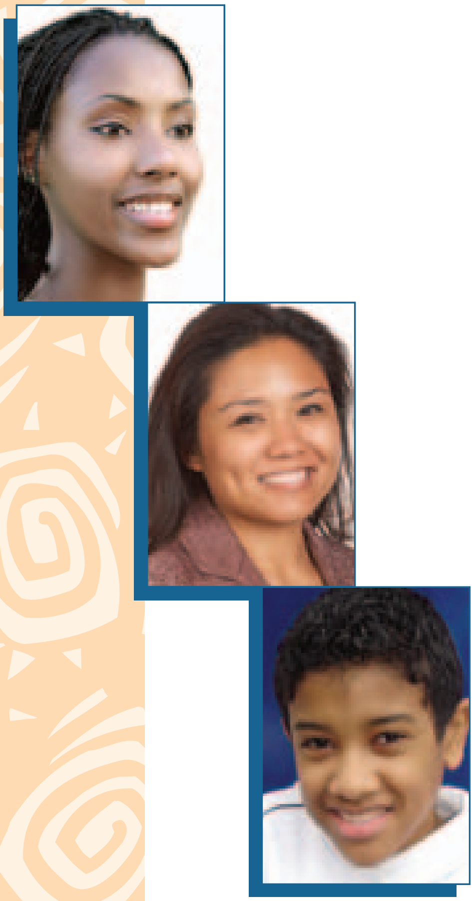
POLICY BRIEF

June 2005



Using Race, Ethnicity and Language Data to Eliminate Health Disparities

CPEHN

California Pan-Ethnic Health Network

California Pan-Ethnic Health Network (CPEHN)

CPEHN was established in 1992 and incorporated as a 501c(3) nonprofit organization in 1998 in response to the need for a representative community-driven voice in health policy. Our mission is to improve access to health care and eliminate health disparities by advocating for public policies and sufficient resources to address the health needs of communities of color.

Funded by:

California HealthCare Foundation

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Department of Health and Human Services
Office of Minority Health Region IX

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L.A. Care Health Plan

Co-hosted with:

California Medical Association Foundation

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Southern California Public Health Association

Solutions for Improving the Collection and Use of Race, Ethnicity and Language Data

CPEHN is dedicated to improving the health of California's communities of color, and it is clear that improvements cannot be made unless the growing problem of racial and ethnic disparities in our communities is addressed. However, as the National Health Disparities Report by the Agency for Healthcare Quality and Research[1] indicates, current efforts at data collection, analysis and usage to identify and address existing disparities in health are not adequate. State agencies do not do enough to collect, standardize, and share data, and most commercial health plans do not collect race, ethnicity or language data on their enrollees. The importance of racial and ethnic data for ensuring the health of all Californian was affirmed by voters with the overwhelming defeat of Proposition 54 in 2003, which would have eliminated race and ethnicity data collection by state agencies. It is time to make significant advancements in the use of race and ethnicity data to eliminate health disparities.

Participants at two CPEHN community convenings discussed and prioritized solutions for improving the collection and use of race and ethnicity data. The convenings were held in 2004 in Oakland and Los Angeles and were attended by over 75 participants, who included health care providers, health plans, government agencies, researchers, and community advocates, to develop this common agenda.

Presentations at the convenings made it clear that data collection, analysis, and reporting by race, ethnicity, and primary language is permissible for state agencies and health plans under both state and federal law .[2] The key recommendations from the convenings are:

- Public and private health agencies and organizations must request and encourage the reporting of race, ethnicity and primary language information by clients, patients and members. The disclosure of race, ethnicity, and language preference must be voluntarily self-reported and not based on perceptions of a person's race.

- Race, ethnicity and language categories need to be standardized to support aggregation and comparison of data from various sources.
- Reporting categories should reflect the diversity of ethnic groups and sub-populations within the major racial and ethnic groups. This requires both the identification and collection of data for sub-populations and standardized algorithms for aggregating sub-population information into larger population groups.
- Race and ethnicity categories should also make allowances for the increasing numbers of multi-racial and multi-ethnic individuals in the population.
- Health plans and health care providers should solicit race, ethnicity and language capability information from physicians, nurses and other staff to assess the diversity of their workforce. This information will enable stakeholders to determine the degree to which the health professions are representative of the communities served, and can be used to ensure there are diverse and culturally appropriate health care professionals.
- Government agencies should develop strategies for sharing data and linking related databases, while protecting confidentiality, to make maximum use of collected data. Government agencies must collaborate with each other, as well as with other institutions and community-based organizations, to ensure that the root causes of health disparities are addressed through interventions such as appropriate housing, employment assistance, and access to transportation.

Race and Ethnicity Data are Important to Ensure the Health of All Californians

Poor health status within one community or racial/ethnic group resonates throughout the health care system and society to the detriment of all racial/ethnic groups. Lack of insurance coverage increases pressure on our fragile system of emergency care. High rates of preventable diabetes and cardiovascular disease reduce economic productivity and increase public and private health care expenditures. Health problems in children, such as environmentally triggered asthma, impact school performance.

Analyses of health data have shown that California's various ethnic communities experience differences in the prevalence and severity of diseases. Multiple studies have also shown that the quality of care individuals receive frequently depends on their race, ethnicity and language they speak. A study by the Institute of Medicine found that health disparities exist even when adjusting for socioeconomic status and insurance coverage.[3] The collection of race/ethnicity data allows public health and health care professionals to increase the effectiveness and efficiency of policies, programs and health care interventions to address these problems.

Collecting and using race and ethnicity data is necessary to ensure that access to quality care and effective public health services is equitable for all consumers regardless of race, ethnicity or primary language by:

- Identifying populations most at risk for certain health conditions and their consequences.
- Understanding the underlying systemic and environmental factors that negatively impact the health of specific communities.
- Developing public health and health care interventions which are culturally appropriate.
- Efficiently allocating resources to communities and populations that are at highest risk.
- Assessing the impact of interventions on diverse communities as well as on the overall population.
- Assessing the ability of diverse communities to access needed services and receive quality health care.
- Measuring the degree of representation of diverse communities in the health professions.

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Principles for Improving the Collection and Use of Race and Ethnicity Data

The use of race/ethnicity data to assess quality of care and measure disparities in health status requires increased attention to the methods employed to collect and analyze these data and to use results in health policy and program decision making. The convening participants examined best practices in data collection and usage. Their recommendations are intended to expand the use of those practices among government agencies and health plans and providers.

Their recommendations reflected the following principles concerning the collection, analysis and use of race and ethnicity data:

- Collection of race and ethnicity data should be universal, standardized, voluntary, respectful, and confidential.
- Data categories should include small populations including people typically identified as Caucasians from highly diverse cultures and language groups.
- Data collection should be efficient and cost-effective.
- Collected data and analyses should be used to address disparities, not to reinforce deficit models.
- The collection, analysis and dissemination of data and analyses should be a shared responsibility among all stakeholders including community representatives.

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The implementation of these recommendations will require the commitment and contributions from the full range of practitioners, policy makers, government agencies and community advocates who operate in and influence the policies and practices that impact the health of Californians. We urge all sectors of the community to prioritize the implementation of these recommendations.

[1] "The National Healthcare Disparities Report," The Agency for Healthcare Research and Quality. February 2004

[2] "Assessment of State Laws, Regulations and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans – Phase I," Office of Minority Health and National Health Law Program, 2004

[3] Institute Of Medicine report 2003, "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care."

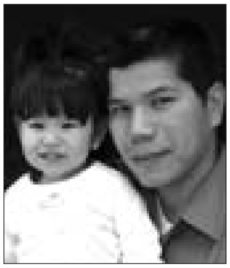
Policy Recommendations

Recommendations for Improved Data Collection to Address Health Disparities

In 2004, the California Pan-Ethnic Health Network (CPEHN) hosted two convenings to examine the collection and use of racial and ethnic data by public health and health care agencies and organizations. These convenings, held in Oakland on March 11 and in Los Angeles on June 30, brought together health care providers, health plans, government agencies, researchers and community advocates to develop a comprehensive policy and practice approach to collection and use of these data. The convening participants focused on recommendations to improve the quality of collected data, the effectiveness of data collection and analysis processes, and the usefulness of reported information for addressing the health disparities that impact communities of color.

The full set of recommendations developed by participants can be summarized under the following categories:

- Collection: Policies and procedures for government agencies, plans, and providers to collect data on race, ethnicity, and primary language (both spoken and written) at all the points of contact necessary to track disparities in access, utilization, quality of care, and outcomes. Data should be collected voluntarily and accurately.
- Standardization: Race and ethnicity categories and data gathering methods should be standardized to ensure comparability and consistency of information.
- Analysis: Data should be continually analyzed and updated to identify disparities, determine their causes, and track progress in eliminating them.
- Utilization: Agencies, plans, and providers should use data to develop programs to increase access, improve quality, and diversify the health care workforce.
- Community Considerations: Public education must be used to create an environment in which individuals understand the value of race/ethnicity data, are willing to provide this information, and are protected from inappropriate disclosure or discrimination based on the information they provide.



Convening participants identified the necessary partners who must take the lead for the implementation of each recommendation. To successfully address the elimination of racial and ethnic health disparities, collaboration among partners, ranging from government agencies to health plans, providers and community advocates, is critical.

In addition, a recent resource has become available to assist in the collection and best use of data. The Health Research and Educational Trust and its partners have developed A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients. The toolkit is designed to assist hospitals, health systems, community health centers, health plans, and other potential users understand the importance of accurate data collection, assess organizational capacity to do so, and implement a framework designed specifically for obtaining information from patients/enrollees about their race, ethnicity and primary (preferred) language efficiently, effectively, and respectfully. The toolkit can be found at: http://www.hretdisparities.org/hretdisparities/index.jsp.

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Rank	*Policy Recommendations*	Advocates	State Agencies	Local Public Health	Health Plans	Health Care Providers	Researchers
DATA COLLECTION							
1	Request each individual to voluntarily provide their race, ethnicity, and primary language when a person becomes a member or a patient.		X	X	X	X	
2	Collect data on the race, ethnicity and bilingual capability of providers and other health professionals.		X		X	X	
3	Ensure that clients, patients and members understand that their access to care will not be impacted by their disclosure of race, ethnicity or language information. Train staff collecting these data to eliminate biases or preconceptions that may influence reporting.		X	X	X	X	
4	Promote standardized and comprehensive collection of race and ethnicity data in departments of Health and Human Services Agency.		X				
5	Pass legislation to ensure that all state agencies, departments, and offices that provide or contract for services or information to the public collect information on race, ethnicity, and language of recipients.	X					
6	Conduct and disseminate an assessment of current health data collection efforts, including how individual programs collect, analyze and use race and ethnicity data.	X	X	X			
7	Convene health providers, health care plans, consumer and community advocates and other stakeholders to define a model health data set and data collection protocol. (OSHPD)	X	X				
8	Track the race, ethnicity, and preferred spoken and written language of callers along with the nature of the complaint to track problems related to cultural competence, language barriers, discrimination, and disparities and their resolution. (HMO Hotline and similar services.)		X		X	X	
9	Conduct periodic surveys of the health behaviors and health status of the community that include race and ethnicity data, such as is done by the Behavioral Risk Factors Survey.		X	X	X		X
10	Promote legislation to ensure that California's Health and Human Services Agency and Department of Finance strengthen their collection and standardization of health related data.	X	X				
11	Assess the educational level, economic status and literacy level of enrollees, clients, patients, members, and target communities.		X	X	X	X	
12	Assess the literacy level of health information provided to clients, patients and members. Ensure information is available at a 6th grade literacy level or below.		X	X	X	X	

Rank	*Policy Recommendations*	Advocates	State Agencies	Local Public Health	Health Plans	Health Care Providers	Researchers
STANDARDIZATION							
1	Ensure health plans, providers and state and local agencies use standardized race, ethnicity and language categories in their collection of population data. The accepted national standard for data collection relies on the categories included in the Federal Office of Management and Budget's Directive 15 (revised October 30, 1997).	X	X	X	X	X	
2	Include small populations in race and ethnicity categories, and develop standardized algorithms for aggregating this data into larger groupings for use in making comparative analyses. These categories should also include ethnic groups that are defined as Caucasian but who reflect distinct cultural and linguistic populations.		X	X	X	X	X
3	Develop consistent strategies to gather and classify data on multi-race individuals.		X	X	X	X	X
4	Promote sharing of data among government agencies and with other sectors to ensure development of a complete picture of community health.	X	X	X	X	X	X
ANALYSIS							
1	Develop models to determine the underlying causes of health disparities and differences in access to care. The models should identify the contributions of the health care system, environment and other factors to disparities in health status.		X	X			X
2	Centralize race and ethnicity health information collected by state agencies preferably in the Office of Statewide Health Planning and Development in the Health and Human Services Agency to facilitate identification of disparities.	X	X				
3	Continuously analyze state data to assess disparities and track the state's progress in eliminating them.	X	X				X
4	Analyze utilization and outcomes by race and ethnicity to identify disparities. Conduct analyses annually to track trends in disparities.		X	X	X	X	X
5	Report health plan information on disparities in access, utilization and outcomes to government agencies and disseminate to enrollees.	X			X		
6	Employ focus groups and surveys of enrollees to help identify disparities, health needs and barriers to good health of communities of color. Provide incentives to increase participation.		X	X	X		X

Rank	*Policy Recommendations*	Advocates	State Agencies	Local Public Health	Health Plans	Health Care Providers	Researchers
UTILIZATION							
1	Improve the cultural competency of providers and health plans through continuing education trainings, incentives, and enforcing existing standards. Disseminate and facilitate sharing of best practices in cultural competence.	X	X		X	X	
2	Collaborate to address the root causes of health disparities such as access to transportation, appropriate housing, and employment. Seamless health care coverage must be ensured.	X	X	X	X	X	X
3	Institute safeguards to prevent the inappropriate use or disclosure of data.	X	X	X	X		
4	Share language and other data on enrollees with health care providers so that providers may better plan and improve their services.		X	X	X	X	
5	Ensure that provider network is sufficiently diverse to ensure that the cultural needs of enrollees and potential enrollees are met. Collect data on their provider race, ethnicity, and language capability.		X		X	X	
6	Use information developed from tracking the race and ethnicity of callers to 'helplines', along with the nature of the complaint, to promote a culturally competent health care system..		X		X		
7	Provide enrollees with a directory that includes information on provider and staff language capabilities and background and training that reflects the cultural competence of providers.				X	X	
8	Embed a commitment to cultural and linguistic access and to the elimination of health disparities in every aspect of the work of health plans and health care providers from member services to complaints and grievances processes.	X	X		X	X	
9	Increase the diversity of medical and nursing students through outreach to communities of color.		X		X	X	
10	When funding or evaluating programs, use race and ethnicity data to assess the effectiveness of the programs in serving diverse communities of color.		X	X			
11	When releasing data to the public, agencies should put the data in context and explain what the numbers mean to allow community members to understand and respond to the data. However, if staff time limits the ability of agencies to provide that context, agencies cannot use this as a reason for not making the data available to the public.		X	X			
12	Convene stakeholders and community advocates to provide advice on the analysis and dissemination of data for addressing health disparities.	X	X				X

Rank	*Policy Recommendations*	Advocates	State Agencies	Local Public Health	Health Plans	Health Care Providers	Researchers
COMMUNITY CONSIDERATIONS							
1	Create additional legal safeguards to ensure that race/ethnicity data are used only to support the elimination of disparities in health and other social factors. Fear of discrimination must be ameliorated by strong enforcement of civil rights protections.	X	X				
2	Conduct a public education campaign to encourage individuals to disclose their race and ethnicity in appropriate settings. Employers and corporations must also be educated about the true meaning of disparities data, so that there not concerns with hiring people of color out of fears of higher health costs.	X	X	X	X		
3	Assess the impact of community concerns over 'privacy' and Health Insurance Portability and Accountability Act of 1996 (HIPPA) restrictions on the collection and analysis of data required to eliminate health disparities.	X	X		X		X
4	Mobilize communities to demand more and better data collection from health care providers and government agencies.	X					
5	Assess the need for statutory change to eliminate impediments to the collection of race and ethnicity data by health plans and providers. If there is a need for statute change, advocates, policymakers and other stakeholders should collaborate in the development of legislative solutions.	X	X				
6	Share best practices on data collection and analysis.	X	X	X	X	X	X
7	Encourage providers and health plans to partner with communities to create healthy environments that will benefit their members and the community at large.	X	X	X	X	X	
8	Work with community organizations, including clinics and advocates, to help them to collect and analyze their local community data.	X	X	X			X
9	Disseminate data to communities along with strategies and tools to address health status disparities	X	X	X			

CPEHN

Uniting Communities of Color for Better Health

Formed by the Asian & Pacific Islander American Health Forum, the California Black Health Network, the California Rural Indian Health Board, and the Latino Coalition for a Healthy California, CPEHN is an established leader in multicultural health advocacy. We gather the strength of the state's new majority to build a united and powerful voice. CPEHN organizes multicultural efforts to develop and advance public policies that promote equal treatment and universal access to care.

For more health policy resources and data or to
support our work, go to
CPEHN's Multicultural Health Web Portal at:

www.cpehn.org

CPEHN

California Pan-Ethnic Health Network

654 13TH Street
Oakland, CA 94612
(510) 832-1160 TEL
(510) 832-1175 FAX

info@cpehn.org

www.cpehn.org