November 7, 2005

The Honorable Michael O. Leavitt
Secretary
U.S. Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Leavitt:

I am pleased to transmit to you the NCVHS report *Eliminating Health Disparities: Strengthening Data on Race, Ethnicity, Language in the U.S.* The report is the culmination of extensive review, hearings, and testimony collected over the last three years on issues pertaining to race, ethnicity, primary language, geography, and measures of socioeconomic position.

Like the Department, the Committee has also maintained a consistent interest in this area since addressing the severe inadequacies in health information for racial and ethnic minorities in the 1960s. Over the last several years, the NCVHS Subcommittee on Populations has served as a public forum to discuss challenges in the collection and use of race and ethnicity categories in health data, including considerations of how to determine extent of health disparities. In this effort, the Subcommittee conducted a series of hearings designed to investigate the collection and use of data on racial and ethnic groups by data systems funded and maintained by the Department of Health and Human Services (HHS). The report reflects compelling needs to collect and access health data, specifically for targeted populations.

The intention of this report is to share what we have heard about health data needs from various policy perspectives. The findings and recommendations are intended to outline strategies for future action by HHS and its partnering agencies, and organizations within and outside of the Federal government. We hope that the recommendations will enhance productive consultation and discussion in which all stakeholders are engaged in determining the best steps forward.

We appreciate your consideration of this report, and we look forward to continued partnership in support of the Department's goals to eliminate health disparities in racial and ethnic populations.

Sincerely,

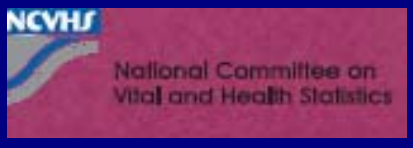
/s/

Simon P. Cohn, M.D., M.P.H., Chairman
National Committee on Vital and Health Statistic

Attachment
cc: DHHS Data Council

Eliminating Health Disparities

Strengthening Data on Race, Ethnicity, and Primary Language in the United States



Eliminating **Health Disparities**

Strengthening Data on Race, Ethnicity, and Primary Language in the United States

The National Committee on Vital and Health Statistics
Subcommittee on Populations

August 2005

National Committee on Vital and Health Statistics, 2005

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Acknowledgments

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A number of staff and consultants provided excellent guidance and contributions. In particular, Dale Hitchcock and Dr. Susan Queen served as lead staff for the February 2002 hearing on Federal population based health surveys, which serves as the core material for this report. As current lead staff, Audrey Burwell and Dale Hitchcock were instrumental in setting up other hearings, with support from Gracie White.

Several staff assisted throughout the process of the hearings and the development of the report. Jennifer Madans Ph.D. (NCHS) and Jacqueline Lucas, M.P.H. (NCHS) and Nancy Breen, Ph.D. (NCI) provided invaluable background, technical assistance, and reviews of the report, and Miryam Granthon (OMH) provided administrative support and technical assistance. Thanks also to Debbie Jackson (NCHS) for her administrative assistance in shepherding the report through to completion.

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Of course, we thank all who gave generously of their time to present at the hearings, recommend presenters, and attend the sessions. Our hearings would not have been as successful without the help of several Federal, state, and community agencies and individuals who helped in identifying key experts: The Asian Pacific Islander American Health Forum, Association of Asian Pacific Community Health Organizations, Samoan Nurses, California Pan Ethnic Health Network, PACE Kamehameha School, Alvin Onaka, Ph.D., of the Association of State and Territorial Health Officials (ASTHO), and HHS regional representatives Christina Perez, M.P.H. (Region IX), Mildred Hunter, MSW, M.P.H. (Region V), and Dorothy Kelly (Region III—a special thanks for her help with the Philadelphia hearing). We also thank Paul Ong, Ph.D., the Ralph and Goldy Lewis Center, University of California at Los Angeles (UCLA), and Marjorie Kagawa-Singer, Ph.D., UCLA School of Public Health.

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Executive Summary

Compelling evidence exists that differences in health status, access to care, and the provision of physical and mental health services are significantly related to race, ethnicity, primary language, geography, and various measures of socioeconomic position, such as educational status, income, wealth, and conditions in childhood. Efforts to improve health care and eliminate health disparities in the United States are an important element of the Secretary of Health and Human Services *500 Day Plan: Longer, Healthier, and Better Lives* (www.os.dhhs.gov/500DayPlan/500DayPlan.pdf). These efforts can succeed only when researchers, policy-makers, health care professionals, and community groups are equipped with complete and accurate data on the differences in health status, access to care, and the provision of services experienced by specific population groups in the U.S. This essential prerequisite for progress has been the focus of hearings and a lengthy review of available information conducted by the National Committee on Vital and Health Statistics (NCVHS) Subcommittee on Populations. The NCVHS is the statutory public advisory body that advises the Department of Health and Human Services (HHS) on information needs underlying national health policy.

The Committee offers this summary of its findings and recommendations so that the strategies outlined can provide an effective and useful roadmap for future action by HHS and its partnering agencies and organizations within and outside of the Federal government. The recommendations serve as a starting point for productive consultation and discussion in which all stakeholders are engaged in determining the next best steps forward. In summary these recommendations address four major components of the collection of data on race, ethnicity, and primary language in racial and ethnic minority populations: how to obtain, collect and store health data in ways that are usable, properly interpreted, and adequately protected.

The Committee presents its findings under two major recommendations. Each recommendation contains several component parts, which have one or more specific strategies for action. At the same time, the Committee recognizes that considerable overlap exists between the two recommendations. Efforts to carry out the strategies

proposed in one recommendation will almost certainly help to achieve the goals of the other recommendation. These recommendations and their components are:

HHS is urged to enhance the quality, reliability, and completeness of its data collection and data integration on racial, ethnic, and linguistic subpopulations in the United States and territories. This recommendation focuses on ways that HHS can improve its overall data collection effort through exhibiting national leadership, enhancing efforts to coordinate with other agencies and organizations, and fostering partnerships among stakeholders. The multiplicity of factors that contribute to health disparities requires enhanced availability of data on diverse subpopulations and collection of data on a broad array of variables beyond race and ethnicity. The recommendation indicates the importance of collecting data down to the lowest possible level of geography and on socioeconomic position. Critically important is improving and broadening technical assistance to the states in their data collection and dissemination efforts. This collaboration and guidance is key to Federal efforts to understand and ameliorate disparities when health datasets used by the Federal government are collected through states. Finally, HHS is urged to use its own health programs, such as Medicare and Federal employee health plans, to improve data collection on race, ethnicity, and language.

HHS is urged to increase and strengthen the capacity of its health statistics infrastructure to analyze, report, and disseminate data on the various ethnic/racial/linguistic subpopulations in the United States and territories. This recommendation focuses on practical issues that are essential to improving data collection efforts. Among these are supporting methodological research (such as best practices for handling the definitions of race and ethnicity as they are understood by various subpopulations) and providing technical assistance. One essential recommendation to improve the health statistics infrastructure is to facilitate access to data by increasing the number of, and resources within, secure data centers, including enhancing data users' opportunities for training. Another infrastructure issue is the need for technical assistance to help agencies "bridge" data collected before and after the Office of Management and Budget's 1997 revised standards for the classification of race and ethnicity in federal data systems. Finally, further development of policies and procedures is needed to ensure wider, but secure, access

to micro-data (i.e., non-aggregated data containing variables that make respondents potentially identifiable) for use in IRB-approved research. Policies and procedures also are needed to expand access to public use data to increase dissemination of data and facilitate much-needed research about race, ethnicity, language, and other characteristics of specific subpopulations.

Summary of Strategies in Recommendation 1

1	Enhance Quality, Reliability, and Completeness of Data Collection and Integration
A	***Advance HHS Leadership, Coordination, Partnerships***
1.	Hold conferences that focus on identifying best practices for data collection
2	Fund mechanisms to support research and training for collecting, classifying, analyzing, and disseminating data on racial and ethnic subpopulations
3.	Develop goals for the HHS Data Council Integration Group to increase linkages among surveys
4.	Develop mechanisms for working with federal and other agencies to transfer best practices for collecting, classifying, and linking race, ethnicity, and primary language data
5.	Conduct a study to determine how well racial and ethnic subpopulations are represented in HHS surveys and what benefits can be derived from additional survey integration
6.	Examine race and ethnicity coding categories and instructions to enhance quality of data received from states
7.	Collaborate with U.S. Census Bureau to conduct methodological work on post/intercensal estimates for racial, ethnic and linguistic subpopulations
8.	Continue providing technical assistance to state surveys, such as the New York Health and Nutrition Examination Survey and the California Health Interview Survey
B	***Increase Availability of Data on Diverse Subpopulations***
1.	Develop plan for conducting targeted surveys on specific racial and ethnic subpopulations at least once every 10 years
2.	Provide technical assistance on methods of aggregating small sample data across surveys and administrative data
3.	Fund research in survey methodology on how to reach and recruit difficult-to-access subpopulations, such as immigrants and the homeless
4.	Explore ways to increase self-reporting of race, ethnicity, and language designations by subpopulations
5.	Design and carry out an education campaign to improve participation in surveys by racial, ethnic, and linguistic subpopulations
6.	Explore feasibility and utility of expanding survey translation to languages other than Spanish
7.	Fund research on best practices for multiple race allocation, bridging, and classification definitions
C	***Improve the Collection of Data on Geography and Socioeconomic Position (SEP)***
1	Improve methods for capturing and using geocoding data
2.	Convene a group to assess what SEP measures are available in Federal data, what linkages are possible, and disseminate this information through the HHS Gateway
3.	Evaluate how best to collect socioeconomic information in electronic health records and encourage best practices in public and private health record systems.
D	***Enhance Data Collection in Federal Programs***
1.	Ensure that Medicaid captures race and ethnicity information that can be linked to

	administrative data

Summary of Strategies in Recommendation 2

2	Increase Capacity of Health Statistics Infrastructure to Collect, Integrate, Analyze, Report, and Disseminate Data
A.	***Expand Access to Data on Subpopulations***
1.	Work with the Census Bureau to place or share additional secure data centers in academic and community settings
2.	Consider options for and research on protecting identifiable data
B.	***Improve Data User Training***
1.	Support initiatives to enhance capacity of researchers to use race, ethnicity, and primary language data
2.	Expand grant programs to train researchers with an interest in health disparities and health statistics
3.	Support efforts to develop programs to train American Indians/Alaska Natives (AI/AN) to work with AI/AN data
C.	***Link Data Systems and Dissemination Methods to Bridge Old and New Data***
1.	Provide technical assistance by developing analytic guidelines on bridging data and disseminate widely
D.	***Improve Data Quality***
1.	Examine how to give states flexibility in collecting and reporting subgroup classification so that they can work within Federal data reporting requirements
2.	Conduct methodological research in issues related to reporting of race and ethnicity
3.	Identify ways to simultaneously analyze multiple socioeconomic measures
E.	***Increase Dissemination of Health Statistics and Research Findings***
1.	Continue and further develop aggressive public use data release programs for racial and ethnic subgroup data
2.	Identify ways to improve the accessibility of data on racial, ethnic and linguistic subpopulations (e.g., Internet, data query systems, CD-ROMS)

NCVHS Letters and Reports Recommending Strategies for Increasing the Quantity and Quality of Data on Racial, Ethnic, and Linguistic Subpopulations in the U.S. and Territories

1. August 23, 2004 **Letter to the Secretary** on Recommendations on Populations Based Data Collection. www.ncvhs.hhs.gov/040823lt.htm

2. September 26, 2003 **Letter to the Secretary** on Recommendations for Targeted Data Collection. www.ncvhs.hhs.gov/030926lt.htm

3. September 26, 2003 **Letter to the Secretary** on Collection of Racial and Ethnic Data by Health Plans. www.ncvhs.hhs.gov/030926ltb.htm

4. March 27, 2003 **Letter to the Secretary** on Populations-based Data for Racial and Ethnic Minorities. www.ncvhs.hhs.gov/030327lt.htm

5. October 19, 2001 **Letter to CMS** on Racial and Ethnic Data Collection. ncvhs.hhs.gov/011019lt.htm

6. July 6, 2001 **Recommendations to HCFA** on SCHIP Ddata Collection. www.ncvhs.hhs.gov/011019lt.htm

7. March 14, 2001 **Letter to Katherine Wallman, Chief Statistician, Office of Management and Budget** regarding Provisional Guidance on the Implementation of the 1997 Standards for Federal Data on Race and Ethnicity (December 15, 2000). www.ncvhs.hhs.gov/010314lt.htm

8. December, 1999 **Report** on Medicaid Managed Care Data Collection and Reporting. www.ncvhs.hhs.gov/managedcare.pdf

9. December, 1999 **Report** on Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands. www.ncvhs.hhs.gov/9912islandreport.pdf

Other Resources Available on the NCVHS Website

Agendas, Transcripts, and Summaries of Meetings and Hearings held by the Subcommittee on Populations

- June 27, 2001 –Subcommittee on Populations Breakout Session During Full Committee Meeting, Mr. Roderick Harrison, Joint Center for Political and Economic Studies. Discussion of Implementation of the Collection of data on race and ethnicity., Washington DC www.ncvhs.hhs.gov/010627a3.htm
- August 15, 2001 - Meeting on Future Directions for Work in the Implementation of OMB Standards for the Collection of Data on Race and Ethnicity, Rosemont IL www.ncvhs.dhhs.gov/010815ag.htm
- February 11-12, 2002 - Hearing on Measurement of Health Disparities in Racial and Ethnic Groups in Federal Surveys, Washington DC www.ncvhs.hhs.gov/020211ag.htm
- February 26-27, 2002 - Subcommittee on Populations Breakout Session During Full Committee Meeting, Review of February 11-12, Hearing on Measurements of Health Disparities in Racial/Ethnic Groups, Washington DC www.ncvhs.hhs.gov/020226a2.htm
- February 26, 2002 - Subcommittee on Populations Workgroup on Quality - Breakout Session, Washington DC www.ncvhs.hhs.gov/020226a3.htm
- September 27, 2002 - Hearing on Health Data Needs for American Indians - Denver, CO www.ncvhs.hhs.gov/020927ag.htm
- November 8, 2002 - Hearing on Health Data Needs for States, Vital Statistics, and Geocoding in Eliminating Health Disparities in Racial and Ethnic Subpopulations - Philadelphia, PA, www.ncvhs.hhs.gov/021108ag.htm
- May 22-23, 2003 - Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations - Los Angeles, CA, www.ncvhs.hhs.gov/030522ag.htm
- July 24, 2003 - Planning meeting and discussion of Small Area/Geographic Area Studies, www.ncvhs.hhs.gov/030724ag.htm
- November 13-14, 2003 - Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations - San Francisco, CA, www.ncvhs.hhs.gov/031113ag.htm

NOTE: These links take users to the webpages for the hearings or meetings. You will find additional links to summaries and individual testimonies by clicking on Transcripts and Minutes (www.ncvhs.hhs.gov/lastmntr.htm).

Testimony at Hearing on Measurement of Health Disparities in Racial and Ethnic Groups in Federal Surveys, Washington DC, February 11-12, 2002

- Medical Expenditure Panel Survey:
  - Steve Machlin, AHRQ, www.ncvhs.hhs.gov/020211tr.htm#machlin
  - Marsha Lillie-Blanton, Ph.D., User, Kaiser Family Foundation, www.ncvhs.hhs.gov/020211tr.htm#lillie-blanon
- Consumer Assessment of Health Plans User- Judy Sangl, Sc.D., AHRQ, www.ncvhs.hhs.gov/020211tr.htm#sangl
- Consumer Assessment of Health Plans User - James Moser, Ph.D., Brens Group of KPMG Consulting, www.ncvhs.hhs.gov/020211tr.htm#moser
- Medicare Current Beneficiary Survey User - Dan Waldo, M.A. Centers for Medicare & Medicaid Services, www.ncvhs.hhs.gov/020211tr.htm#medicare
- Medicare Current Beneficiary Survey User- Joan DaVanzo, MSW, Ph.D., Lewin Group, www.ncvhs.hhs.gov/020211tr.htm#medicarebeneficiary
- Policy Perspectives - Carolyn Clancy, M.D., AHRQ, www.ncvhs.hhs.gov/020211tr.htm#policyperspectives
- Socioeconomic Status - Patricia O'Campo, Ph.D., Johns Hopkins University, www.ncvhs.hhs.gov/020211tr.htm#socioeconomic
- National Survey of Family Growth - Joyce Abma, Ph.D., NCHS, www.ncvhs.hhs.gov/020211tr.htm#growth
- Behavioral Risk Factor Surveillance - Peter Mariolis, Ph.D., CDC, www.ncvhs.hhs.gov/020211tr.htm#behavioral

Testimony at Hearing on Health Data Needs for States, Vital Statistics, and Geocoding in Eliminating Health Disparities in Racial and Ethnic Subpopulations - Philadelphia, PA, November 8, 2002

- Massachusetts Department of Health - Bruce Cohen, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#massachusetts
- California Department of Health – Peter Abbott, M.D., www.ncvhs.hhs.gov/021108tr.htm#california
- Hawaii Department of Health - Alvin Onaka, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#hawaii
- California Department of Health - Jane McKendry,Ph.D. www.ncvhs.hhs.gov/021108tr.htm#california2
- Vital Statistics Re-engineering Project – Delton Atkinson, M.S.P.H., M.S.P, www.ncvhs.hhs.gov/021108tr.htm#reengineering
- Healthy Women: State Trends in Health and Mortality - Kate Brett, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#healthywomen
- National Women's and Minority Indicators Database Project - Alfred Meltzer, www.ncvhs.hhs.gov/021108tr.htm#database
- Geocoding State Data and Establishing Collaborations - Nancy Krieger, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#geocoding

- Alabama Department of Public Health - Dorothy Harshberger, www.ncvhs.hhs.gov/021108tr.htm#alabama
- Tennessee Department of Health - Richard Urbano, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#tennessee
- Commentary -Daniel Friedman, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#commentary

Testimony at the Hearing on Health Data Needs for Asian, Native Hawaiian, and Other Pacific Islander Populations, May 22-23, 2003, Los Angeles CA

- Hawaiian Matters: Data Considerations for Native Hawaiian and Pacific Islander Populations." Nolan Malone, Ph.D., PACE Kamehameha School. www.ncvhs.hhs.gov/030522p1.pdf
- Comments on AAPI Data to Subcommittee on Populations. Paul Ong Ph.D., Ralph and Goldy Lewis Center for Regional Policy Studies, UCLA. www.ncvhs.hhs.gov/030522p2.pdf
- Use of Census Data in Health Planning and Community Development in Support of Community Services. Bong Vergara M.A., M.S.W., and Malany Dela Cruz, Census Information Center. www.ncvhs.hhs.gov/030522p3.pdf
- Ethnicity, Culture, and Pharmacogenetics. Keh-Ming Lin M.D., Harbor-UCLA Medical Center. www.ncvhs.hhs.gov/030522p4.pdf
- Small AA/NHOPI Populations, Marjorie Kagawa-Singer Ph.D., R.N., UCLA School of Public Health and Asian American Studies Center. www.ncvhs.hhs.gov/030523p1.pdf

Testimony at the Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations, November 13-14, 2003, San Francisco CA

- Overview of Pacific Island Health Data Issues, Christina Perez M.P.H., Regional Minority Health Coordinator, Region X. www.ncvhs.hhs.gov/031113tr.htm#perez
- Health Data Needs for the Elimination of Health Disparities for Asian, Native Hawaiian, and Other Pacific Islander Populations. Ho Tran, M.D., Asian and Pacific Islander American Health Forum. www.ncvhs.hhs.gov/031113p1a.pdf and www.ncvhs.hhs.gov/031113tr.htm#tran
    - Policy Brief: Data Gaps and Health Disparities for Asians and Pacific Islanders Highlighted in the Healthy People 2010 Initiative. Ho Tran M.D., Asian and Pacific Islander American Health Forum. www.ncvhs.hhs.gov/031113p1b.pdf
- Accessing Census Data on Asians, Native Hawaiians, and Other Pacific Islander Populations: The Role of Census Information Centers. Gem Daus M.P.H., Asian and Pacific Islander American Health Forum. www.ncvhs.hhs.gov/031113p2a.pdf and www.ncvhs.hhs.gov/031113tr.htm#daus
    - Census Data: Top 10 States—Population by Asian (Alone) Ethnicity. www.ncvhs.hhs.gov/031113p2b.pdf

- ANHOPI Measurement and Classification Issues. Elena Yu, PH.D., Johns Hopkins University. www.ncvhs.hhs.gov/031113tr.htm#yu

- Healthcare Quality Indicators for ANHOPI Populations. Ellen Wu, M.P.H., California Pan Ethnic Health Network. www.ncvhs.hhs.gov/031114tr.htm#wu

- Asian Americans and Cancer. Scarlett Lin Gomez, Ph.D., Northern California Cancer Center. www.ncvhs.hhs.gov/031114tr.htm#gomez

- Data Challenges in the Western Pacific. Greg Dever, M.D., Palau Ministry of Health. www.ncvhs.hhs.gov/031114p1.pdf and www.ncvhs.hhs.gov/031114tr.htm#devor

- Data Challenges in Hawaii. Catherine Sorenson, Ph.D., Hawaii Department of Health. www.ncvhs.hhs.gov/031114tr.htm#sorenson

- Health Disparities Data Issues: Listening to the Voices. Carol Murray, Ph.D., University of Hawaii at Manoa. www.ncvhs.hhs.gov/031114p2.pdf and www.ncvhs.hhs.gov/031114tr.htm#murry

Background

Compelling evidence exists that differences in health status, access to care, and the provision of physical and mental health services are significantly related to race, ethnicity, primary language, geography, and various measures of socioeconomic position, such as educational status, wealth, and conditions beginning in childhood.[1,2,3,4,5,6] Disparities across subpopulations are reflected as deficiencies in the health of the population as a whole. This report from the National Committee on Vital and Health Statistics (NCVHS) comes at a time of increasing attention to these health disparities and their costs for the Nation.[7,8,9,10,11,12] Although there has been debate and at times a lack of consensus on how to define health disparities,[13,14,15,16] we have chosen in forwarding recommendations to the Department of Health and Human Services (HHS) to adopt as a minimum the National Institutes of Health (NIH) Health Disparities working group definition. This definition states that health disparities are "the difference in the incidence, prevalence, morbidity, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups."[17]

Federal efforts to eliminate health disparities and improve the health of all Americans depend on the ability to target those at high risk and with great need. This requires detailed information on the diverse array of subpopulation groups within the U.S. Subgroups may be characterized by country of origin, tribe, location in the U.S., dialect, or socioeconomic position. In its collection of racial, ethnic, and tribal classification, the U.S. Census Bureau lists 132 race groups, 78 American Indian and Alaska Native tribes, and 39 Hispanic[18] groups for a total of 249 subpopulation groups (www.census.gov/prod/cen2000/doc/sf2.pdf).* An example of the importance of subpopulation diversity is illustrated by work using the NCHS Hispanic Health and Nutrition Examination Survey (HHANES). Investigators using these data have produced

* The minimum categories for data on race and ethnicity for Federal statistics, program administrative reporting, and civil rights compliance reporting are defined in the Office of Management and Budget (OMB) *Revised Standards for the Classification of Federal Data on Race and Ethnicity.* The categories are: American Indian or Alaska Native, Asian, Black or African American, Hispanic or Latino, Native Hawaiian and Other Pacific Islander, and White. For simplicity, this report uses the term Black to refer to Black or African American and the term Hispanic to refer to Hispanic or Latino.

a number of revealing studies highlighting differences in health disparities and health risks among participating Mexican Americans, Cubans, and Puerto Ricans.[19,20,21] Despite their commonality as Hispanics, the subpopulations in the studies did not share the same health outcomes or even the same risks of chronic diseases. Although some broad similarities exist among Hispanic subgroups as a whole, such as language (Spanish) and religion (Christian), significant differences in cultural background and life experiences are nonetheless known to be critical factors in health status and health outcomes. We know that the U.S. Hispanic population is a heterogeneous mixture of subgroups in terms of cultures, ethnicities, and origins. Hispanic diversity covers a broad racial spectrum: Hispanics can be White, Black, Native Hawaiian or Pacific Islander, Asian, or Native American or Alaskan Native. This diversity can even extend to nationality, customs, heritage, lifestyle, and socioeconomic status.

Similar concerns exist for all of the other major population groups. American Indians and Alaska Natives encompass a vast number of tribes and residence in urban as well as rural areas. Native Hawaiians and Other Pacific Islanders (which consist of individuals of Polynesian, Micronesian, and Melanesian ancestry) include more than 25 diverse groups with various historical backgrounds, languages, and cultural traditions.[22,23] In many data collection efforts, they are grouped with Asians (e.g., Chinese, Japanese, Korean, Taiwanese, Mongolian, Indonesian), a very different population group whose ancestry, cultures, traditions, and languages are themselves highly diverse.

The diversity within major population groups and the growing body of research indicating differences in the health risks and health status within groups strongly indicate that effective strategies for eliminating health disparities rely on classification designations that break populations into their smaller subgroups. Throughout this report, the Committee calls for efforts to determine the subpopulation levels at which data for all of the racial ethnic groups (Black, Hispanic, American Indian or Alaska Native, Asian, Native Hawaiian or Other Pacific Islanders) are important in addressing health disparities. The Committee calls for their acquisition and use.

Recently, several landmark reports from the public and private sectors, which have focused the Nation's attention on health disparities, have highlighted the need for better data on racial, ethnic, and linguistic subpopulations.[24,25,26,27,28,29] Two reports from the Institute of Medicine – *Eliminating Health Disparities: Measurement and Data Needs* and *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* – have helped to create a new sense of urgency about the need for guidance, coordination, monitoring, funding, research, and partnerships to achieve the goal of healthier Americans. The Robert Wood Johnson Foundation's report *Tracking Health Plan Enrollees' Race and Ethnicity* describes the pivotal role of private health insurance plans in assessing the quality of health care received by different racial and ethnic groups.[30] The Agency for Healthcare Research and Quality's (AHRQ) *National Healthcare Disparities Report*[31] clearly demonstrates the persistence of inequalities in health status, health care, and health information across populations in the U.S. Eliminating health disparities among population groups is at the heart of *Healthy People 2010*, the Nation's premier statement of national health objectives.[32]

To help meet the NCVHS' responsibilities as the statutory public advisory body on the information needs underlying health policy, the NCVHS Subcommittee on Populations focuses both on data concerns for the entire U.S. population and for its vulnerable subgroups. Over the past 3 years, the Subcommittee convened hearings to investigate issues surrounding the paucity of data on racial, ethnic, and linguistic subpopulations and, more broadly, the collection and classification of data on race and ethnicity (the Appendix provides agendas and other information about these hearings; transcripts and minutes are available at www.ncvhs.hhs.gov). In its initial hearing (February 2002), the Subcommittee was particularly interested in learning about variables other than race and ethnicity that are available in HHS data systems to measure health disparities, what additional variables are needed, and how data systems across HHS and across other Federal agencies can be effectively linked to provide useful information about specific subpopulations and health disparities. Presenters included representatives from HHS's population-based surveys, provider-based surveys, and administrative data systems. Other presenters and audience members included data users from foundations, universities, and organizations, and representatives from community-based organizations and other groups interested in the issues of health disparities and data collection.

The Subcommittee used the information gained from its hearings and the findings of relevant recent reports to prepare this report, *Eliminating Health Disparities: Strengthening Data on Race, Ethnicity, and Primary Language in the United States*. Presented are two major recommendations and a series of specific strategies that are aimed at 1) enhancing the quality, reliability, and completeness of HHS' data collection and reporting on racial, ethnic, and linguistic populations and subpopulations, and 2) identifying ways that HHS can increase and strengthen the capacity of its health statistics infrastructure for collecting, reporting, and disseminating data on racial, ethnic and linguistic populations and subpopulations. Each recommendation begins with a brief overview followed by specific strategies. Although the Committee has articulated two separate recommendations and presented specific strategies for each, it recognizes that considerable overlap exists between the two recommendations. Efforts to carry out the strategies proposed in one recommendation will almost certainly help to achieve the goals of the other recommendation. The report notes those instances in which action on a particular strategy will help to achieve both recommendations.

In the face of the clear costs to the Nation of health disparities, the Committee views its recommendations as a plan for enhancing the data collection process. Better data will move the U.S. closer to recognizing, monitoring, and eliminating health disparities, thereby ensuring quality health care and improved health status for all Americans.

RECOMMENDATIONS

Recommendation 1

HHS is urged to enhance the quality, reliability, and completeness of its data collection and integration on racial, ethnic, and linguistic subpopulations in the United States and territories.

The Department of Health and Human Services has outlined as a priority for its agencies the reduction of health disparities in the United States, particularly among racial, ethnic, and linguistic subpopulations.[33,34,35] This bold step was taken because of the increasing identification of disparities in health status, health outcomes, access to care, and health care treatments. In its 2004 report, *Eliminating Health Disparities: Measurement and Data Needs*, the National Research Council underscored the importance of collecting data on race, ethnicity, socioeconomic position, acculturation, and language use as a way to understand and eliminate health and health care disparities in the United States.[36] National population-based surveys are essential sources of estimates on the health of the U.S. population. However, some of the groups at risk for ill health and poor health care are those about whom we have the most limited health statistics and contextual data. Although both the Office of Management and Budget (OMB) and HHS strongly encourage the collection of data on racial and ethnic subgroups, few Federal data systems report data at the level of subgroups, particularly subgroups within Blacks, Asians, Hawaiians or Other Pacific Islanders, and American Indians or Alaska Natives. The Office of the Assistant Secretary for Planning and Evaluation (ASPE), HHS, has developed a report assessing the analyses of Hispanic and Asian or Other Pacific Islanders and Native Americans subgroups that can best be conducted using the major Federal datasets (http://aspe.hhs.gov/hsp/minority-db00/task3/index.htm).[37] A number of subgroups are not covered in this report and even for those that are included, the report cautions about the extent to which the surveys provide sufficient precision for sophisticated subgroup analyses.

Research has long demonstrated that for some racial and ethnic populations (e.g., Blacks and Hispanics), important socioeconomic and health differences *within* the populations are missed by not collecting or using subgroup data (e.g., differences in birth outcomes based on whether Blacks are foreign-born or American-born).[38,39,40] Just as compelling is evidence of the importance of differences within these populations by immigrant status and place of residence.[41,42,43] For example, Cuban Americans living in Dade County, Florida, are a subgroup distinct from Puerto Ricans living in Manhattan, though both groups would classify as Hispanics.

Leadership at the level of the Secretary's office is necessary to foster a broad discussion of enhanced standards for collecting data on race, ethnicity, and primary language in survey and administrative data formats, with a goal to develop linkages across data sources. A coordinated action plan and partnerships within HHS agencies, such as the Centers for Disease Control and Prevention (CDC), Centers for Medicare & Medicaid Services (CMS), Health Resources and Services Administration (HRSA), Substance Abuse and Mental Health Services Administration (SAMHSA), Food and Drug Administration (FDA), and the National Institutes of Health (NIH), and with other Federal agencies, such as the U.S. Census Bureau (Census), the Social Security Administration (SSA), the U.S. Department of Veterans Affairs (VA), and the U.S. Departments of Labor (DOL), Education (DOE), Housing and Urban Development (HUD), Commerce (DOC), Homeland Security (DHS) and Interior (DOI), will improve methods of data collection.

One of the most useful actions that can be taken under the Secretary's leadership is to explore ways to improve linkages across Departmental agencies and their datasets and also to improve linkages between health and non-health datasets, such as those containing information on socioeconomic position, geographic location, and education. A growing body of literature indicates that these factors can have a distinct impact on health status. As an example, one of the best predictors of the health status of a population subgroup is its highest level of educational attainment, on average. Some policy experts have suggested that based on the strong association between education and health that one way to increase overall health in the population is to actually just increase, not the health interventions, but the population's level of educational attainment. To the extent that health data can be linked with educational data, we

can learn of better ways to reduce or eliminate factors associated with health disparities that are outside of health. Our ability to predict and correct health disparities may be enhanced by knowledge of other factors affecting respondents.

Enhancing health survey data through linkages between health datasets

The National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (NHANES) routinely link to mortality and Medicare data to enrich the health information available for selected racial and ethnic populations and for populations defined by socioeconomic status. These surveys, along with the National Survey of Family Growth (NSFG), also link to contextual measures of socioeconomic position at various levels of geography and from a variety of sources.

Although the HHS Gateway (www.hhs-stat.net/) lists existing links between some of the HHS surveys, more linkages between the HHS surveys and those of agencies outside of HHS, such as surveys conducted by SSA, DOE, HUD, and others would help to increase available information on contextual factors that critically shape health disparities. Agencies also should pay attention to fostering methodological and outcomes research on the health of racial, ethnic, and linguistic subpopulations. In recent reports, the National Research Council (NRC) and the Institute of Medicine (IOM) have noted that efforts to identify and alleviate health disparities would benefit from incorporating information on income, wealth, acculturation, and geocoded place so that researchers, health care providers, and community groups engaged in health care policy reform can more effectively get the information they need to answer questions related to the causes of and contributors to health disparities.

The NCVHS also recognizes the potentially important contribution of administrative data, such as health services claims, in identifying and clarifying disparities.[44] However, this contribution exists only if administrative health data systems include reliable, accurate, and complete racial and ethnic information. HHS can play an important leadership role in identifying the most effective means to achieve the inclusion of these data in both public and private sector administrative data systems. HHS's leadership will be critical in helping respondents understand why data on race, ethnicity, and primary language are necessary and how the data can be beneficial and useful to their own health care delivery and outcomes. Federal

leadership, coordination, and technical assistance also can help to dispel longstanding concerns of racial and ethnic populations, whose history is rich with instances of discrimination based on race and ethnicity. Inclusion of race and ethnicity data in administrative systems will provide valuable information, but NCVHS recognizes that such data will not capture all service utilization, particularly information on the uninsured. HHS should consider approaches for addressing this deficiency.

The impact of HHS's leadership, particularly through AHRQ's call to action to private sector health plans to collect complete and accurate data on race, ethnicity, and primary language, has been extremely beneficial to several activities underway in this arena.[45,46] NCVHS appreciates HHS's response to its letter of September 26th, 2003, requesting attention to the role that HHS could play through a partnership with the private sector health plans to investigate the feasibility of collecting such data. The letter also suggested an analysis of when and where to capture the data on racial/ethnic classification and how and when these data should be linked, particularly if self-reported designations are fluid. Indeed, several important feasibility studies are currently underway that can inform these efforts.[47,48,49] The Health Research and Educational Trust (HRET), an arm of American Hospital Association (AHA), also has developed an initiative to create and test a uniform framework for collecting hospital data on race, ethnicity, and primary language. This framework will be linked with AHA's information systems to assess quality and identify disparities in care.[50] AHRQ, along with the Robert Wood Johnson Foundation and ten major health plans have formed the National Health Plan Learning Collaborative to Reduce Disparities and Improve Quality.[51,52]

HHS is urged to pursue the following strategies that will help enhance the quality, reliability, completeness, and integration of data collected on racial, ethnic, and linguistic subpopulations.

A. Advance HHS Leadership, Coordination, and Partnerships

Currently, some Federal agencies have considerable experience and expertise in collecting data on race and ethnicity in surveys, translating instruments, and conducting analytic procedures. This experience and expertise is not shared consistently or equally across Federal agencies. The result is databases and data

across Federal agencies that often are not comparable and that cannot be easily linked. Moreover, data collection overall does not adequately benefit from the state-of-the-art expertise within particular Federal agencies. Although agencies should have flexibility in the way they collect data, some pay too little attention to the transfer of knowledge, possible linkages, and cross-agency coordination that would enhance HHS's efforts to address health disparities. HHS leadership in this arena is critical.

Federal agencies often work with states in data collection efforts and state databases are, in many ways, key to Federal efforts to reduce and eliminate health disparities. Many public health datasets used by Federal agencies to assess health disparities, such as those for births, deaths, AIDS surveillance, sexually transmitted disease incidence, and cancer, are collected through states.[53,54] A critical role that states can play is to provide geographically-specific population estimates for the subgroups for whom national data are limited or nonexistent in Federal population health data collection efforts. The Subcommittee learned, however, in a hearing (Philadelphia, November 2002), that states are already burdened with a number of under- or unfunded data activities. They vary greatly in their capacity to collect, analyze, and interpret data on racial and ethnic groups. Moreover, state and vital statistics representatives also indicated that at the state and local public health data needs often require race and ethnicity classifications at substantially greater detail than the minimum mandated in reporting to Federal agencies.[55] States described the burden involved in collecting data for state and local public health needs and aggregating data to the minimum set of categories most often employed in reporting to Federal agencies as presenting a burden that exceeds state capacity. Racially and ethnically heterogeneous states also commented on the dilemmas they face in assigning nationalities and ethnic designations to aggregated categories that do not necessarily include these nationalities and designations in their definitions.

States also require denominator level data at the sub-state levels in order to target local or population-specific interventions to reduce health disparities. This requires use of inter-censal population denominators by race, ethnicity, age, gender, county, city, and town.[56] States need Federal assistance on how to handle missing race and ethnicity data and they need guidance on how to aggregate race categories for small areas in which small denominators may result in suppressed data because of

privacy and confidentiality concerns. As states find themselves responsible for more and more of the health interventions needed to eliminate health disparities, accurate data—and guidance on how to collect and classify them—become ever more critical.

1. HHS should encourage its own agencies such as the National Center for Health Statistics (NCHS), NIH, SAMSHA, HRSA, and CMS, as well as other Federal agencies to hold national, state, and racial/ethnic subgroup-specific conferences that focus on improved methods for collecting data on health disparities in racial and ethnic subgroup populations as well as building strategies for closing the gap in those disparities. These conferences will enhance coordination among Federal agencies and promote sharing of expertise among Federal, academic, and private sector groups (e.g., health plans, hospitals) in ways to collect, classify, and aggregate for analyses data on racial and ethnic subpopulations. They also will contribute to improvements in the Nation's data collection infrastructure (Recommendation 2). These conferences also may be useful in broadening the discussion to include the importance of and methods for collecting other variables such as nativity, country of origin, educational attainment, socioeconomic position, place of residence, and primary language.

   The overall aim of these conferences would be to develop an action plan for:

   - identifying beneficial partnerships and data linkages across Federal agencies;
   - identifying constituency user groups at the academic, state, and community level who could contribute expertise about integrating subpopulation racial and ethnic classification and data capture issues in Federal surveys and administrative data;
   - determining operability and best practices mechanisms to transfer data between Federal and state and local agencies; and
   - identifying the training needed to collect such data.

Establishing a system to track the outcomes of these conferences (i.e., the improvement in available data on racial, ethnic, and linguistic populations and transfer of knowledge within Federal agencies) also is needed.

The Early Childhood Longitudinal Study (ECLS): An excellent example of enhancing data linkage through a partnership between the National Center for Education Statistics, National Institutes of Health, and the National Center for Health Statistics

The ECLS provides national data on children's status at birth and at various points thereafter. ECLS also provides data to test hypotheses about the effects of a wide range of family, school, community and individual variables on children's development, early learning, and early performance in school.

The ECLS-B is a multisource multimethod study focusing on the home and educational experiences of children during their first 6 years. ECLS-B's goal is to provide reliable and comprehensive data that may be used to describe and understand children's:

- early development;
- health care, nutrition and physical well-being;
- preparation for school;
- experiences in early care and education programs, kindergarten, and first grade; and
- how early experiences relate to later development, learning, and experiences in school.

To achieve this goal, the ECLS-B is following a nationally representative cohort of children born in 2001 from birth through first grade. The parents of 10,688 children participated in the first wave of the study when the children were approximately 9 months old.

This study illustrates how complex data can be gathered when three agencies such as NIH, NCHS and NCES partner. NIH provided some funding and also was instrumental in the design and instrument development for the birth cohort. NCHS facilitated the sample design. We encourage HHS to identify and adopt those opportunities for partnerships with non-health agencies that can provide data into how contextual variables such as education,

2. HHS is urged to use existing structures to develop and fund mechanisms that can support a research, training, and policy agenda for collecting, classifying, analyzing, and disseminating racial, ethnic and linguistic subpopulation data. This agenda would be invaluable for private data users, academic researchers, state and local health departments, and those who collectors of Federally-mandated data (e.g., funeral directors, hospitals, nursing homes). It will require an examination of policies and procedures that ensure both privacy and confidentiality of data and that ensure accessibility of data for analyses. It also will require an examination of how well HHS's data-sharing and data-linkage activities (linkage both within and outside of HHS) are progressing. In addition,

this agenda will require a mechanism to monitor on a biennial basis whether subpopulation data for each of the various racial, ethnic and linguistic subpopulations are being collected, released, and made available for public use.

3. HHS is urged to develop a set of specific goals for its Data Council Integration Group (http://aspe.hhs.gov/datacncl/index.shtml) that would result in actions to increase linkages among Federal surveys; highlight these linkages on HHS's Gateway; and to establish conceptual equivalency across surveys for already used variables such as income, education, and geographic location. All of these actions will serve to highlight the fact that disparities in these non-health variables often go hand in hand with health disparities. They will help increase data available for rigorous and complex analyses on the Nation's diverse racial, ethnic, and linguistic subpopulations. Finally, they will contribute to improving the Nation's data collection infrastructure (Recommendation 2).

4. HHS is urged to develop a mechanism by which it will work on an ongoing basis with other Federal agencies, such as the Census, DOL, DOE, Department of Commerce, and Department of the Interior, to transfer best practices knowledge on methods for collecting, classifying and linking complete and accurate data on subpopulation race/ethnicities, as well as primary language, and income and to develop policies and procedures that can increase linkages of health and non-health data to survey and administrative data held by other Federal agencies.

5. HHS should undertake a study to determine how well racial and ethnic subpopulations are represented in HHS surveys, and where data collection for these groups would benefit from survey integration. HHS began such an assessment in a report received by ASPE,[57] but this report was limited to a few racial and ethnic subpopulations and only to surveys. HHS should undertake a similar examination but with attention to levels of participation by smaller racial and ethnic subpopulations to determine whether the surveys are collecting detailed racial and ethnic classifications and what data benefits might accrue from survey integration. The question is whether, with coordination and preplanning, data from disparate sources can be collected or integrated based on

consistency in measurement in order to facilitate sophisticated analyses based on the aggregation of data on small racial and ethnic subpopulations.

6. HHS is urged to examine the racial/ethnic/nationality coding categories and instructions used by states in vital statistics and other sources of data reported to HHS to determine what steps can be taken to develop accuracy, ensure consistency, and enhance the quality of data received from the states. HHS should provide resources and technical assistance during this reengineering process to ensure that states have enough personnel who are trained sufficiently in collecting and classifying data on race, ethnicity, and nationality, and to ensure that they are able to fulfill Federal data reporting requirements without undue reporting burden.

7. NCHS and other private and academic partners, whenever feasible, should collaborate with Census to conduct methodologic work on and carry out post- and inter-censal estimates by race and ethnicity of: (1) the population by age and gender (state-level and below, including tribes and tribal land areas); and (2) socioeconomic and contextual characteristics (national, state-level, and below). Progress on this strategy also will contribute to improving infrastructure under Recommendation 2.

One promising approach to increase racial and ethnic subpopulations data may be through the American Community Survey (ACS), which is Census' reengineered approach to Census 2010. Data from the ACS will be released every year. The ACS replaces the decennial collection and estimation of detailed physical characteristics (long form), including race and ethnicity, with a data collection process lasting a decade.[58,59] This change from the once-every-10-years approach to an ongoing collection of data not only allows for more current data within specific geographic regions but could be a useful vehicle for states to obtain detailed subpopulation data. The Committee urges HHS through its Data Council to determine whether partnerships or coordinated field efforts with the ACS could provide a better economy of subpopulation data on race,

ethnicity, and primary language groups. The ACS has already demonstrated its ability to get more complete and accurate data on ancestry (June, 2004). The HHS investigation will need to examine the strict privacy and confidentiality rules maintained by Census to determine how states, NCHS, or others could conduct supplemental modules, add supplemental questions, or recruit particular subpopulations for survey participation.

8. NCHS is urged to continue providing technical assistance (e.g., similar to NCHS efforts in the New York City National Health and Nutrition Examination Survey or in the California Health Interview Survey) to facilitate increases in the number of data collection efforts targeted to particular subpopulations at the state, city, or county level. NCHS is urged to communicate with HHS and the Committee if such activities require budget enhancements, as it is critical that NCHS not undertake this process if its cost will lead to reductions in any of its current activities.

B. Increase the Availability of Data on Diverse Subpopulations

The ability to identify disparities and improve the health and health care of racial, ethnic, and linguistic subpopulations is directly tied to the availability of accurate health statistics specific to the various subpopulations as they vary in age, life-course, gender, language, geographic location, socioeconomic position, and access to and participation in health plans and health care. Currently, the quantity and quality of Federal data on these attributes of specific subpopulations of Black, Asian, Native Hawaiian and other Pacific Islanders, and some Hispanic groups are nonexistent or suffer from insufficient sample sizes, very limited accessibility for public use based on few secure data centers, use of minimum race categories, and questionable accuracy based on observational versus self-report of racial and ethnic classification.

The National Research Council's *Eliminating Health Disparities* report,[60] the AHRQ Report Card on Health Disparities, and a series of previous letters from this committee* have recommended various strategies for increasing both the quantity and

* NCVHS letters: August 23, 2004 Letter to the Secretary on Recommendations on Populations Based Data Collection; September 26, 2003 Letter to the Secretary on Recommendations for Targeted Data

improving the quality of data on diverse racial, ethnic, and linguistic subpopulations in the U.S. and territories. We offer several of those recommendations again, with the most compelling being the development and implementation of a plan for collecting data on a periodic basis, which will result in available data on all subpopulations residing in the United States.

1. HHS is urged to develop a plan for and criteria for conducting targeted surveys for those racial, ethnic, and linguistic populations whose numbers are so small or geographically disbursed that, due to privacy and confidentiality concerns, data on them are not available in current public data use files or for whom their small occurrence in population-based surveys precludes accurate subgroup analyses. These surveys should be repeated at least once every 10 years. HHS should ensure that new funding is available to support the development and implementation of this plan. Publication of a schedule for the collection, reporting, and public use of this data would be useful.

2. In order to derive enhanced benefit from currently available data on those racial, ethnic and linguistic populations whose occurrence in Federal population surveys is small, the Committee asks that HHS provide technical assistance. This technical assistance should include but be limited to the publication and wide dissemination of guidance on the methods of aggregating small sample data across Federal surveys and, where possible, administrative data. HHS currently has a number of existing mechanisms, such as conferences and data user meetings, advanced statistical reports, website postings, and technical notes that accompany surveys, which can be employed to disseminate this technical assistance.

3. HHS should fund additional basic research in survey methodology on how to reach and successfully recruit difficult-to-access subpopulations, such as migrant

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Collection; September 26, 2003 Letter to the Secretary on Collection of Racial and Ethnic Data by Health Plans; March 27, 2003 Letter to the Secretary on Populations-based Data for Racial and Ethnic Minorities; October 19, 2001 Letter to CMS on Racial and Ethnic Data Collection; July 6, 2001 Recommendations to HCFA on SCHIP Data Collection; March 14, 2001 Letter to Katherine Wallman, Chief Statistician, Office of Management and Budget regarding Provisional Guidance on the Implementation of the 1997 Standards for Federal Data on Race and Ethnicity (December 15, 2000); December, 1999 Medicaid Managed Care Data Collection and Reporting; December, 1999 Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands.

workers, homeless persons, persons in institutions, and persons who are only loosely connected to households.

4. Agencies such as NIH, NCHS, AHRQ, HRSA, SAMHSA, and the Indian Health Service (IHS) should explore incentives to increase the participation of racial, ethnic and linguistic subpopulations in surveys and other types of health research. Cultural sensitivity, confidentiality and incentives were identified by the committee as key to increasing participation of subpopulations. Agencies are urged to investigate religious and cultural principles that influence the donation of tissue, organs, or biological specimens that may be used in research, as well as identify procedures that will address and reduce racial, ethnic, and immigrant group concerns about privacy and confidentiality of data that may be reported, used, or linked to non-health agencies. HHS also is urged to explore incentives, such as payment for participation in data collection, that can serve as encouragements while not violating Federal, state, or local regulations. For example, because of local reporting requirements, study participants who receive cash for participating in data collection efforts may find that their other Federal, state, or local assistance payments can be reduced.

5. HHS is urged to implement an education campaign using media similar to "Take A Loved One For a Check-Up Day" (www.healthgap.omhrc.gov/2005factsheetdrday.htm) to inform racial, ethnic, and linguistic subpopulations of the benefits of reporting their racial, ethnic, and primary language designations. HHS should consider consulting and partnering with community-based agencies and with private sector health plans currently engaged in similar efforts to determine how best to carry out such a campaign. The Bureau of the Census, which conducted a similar campaign to ensure participation by diverse subpopulations in the 2000 Census, could provide valuable guidance to HHS.

   A necessary component of this effort is a thorough understanding of why people are reluctant to report their racial, ethnic, and primary language information. A number of studies have documented a variety of factors, such as fear of being treated differently or of receiving substandard care, that help to explain the

reluctance of individuals to report this information in health care encounters.[61] However, if we are to reduce these fears, it is necessary to document any such violations and develop adequate mechanisms to investigate and address them. Federal, state, and local Office of Civil Rights could be useful in monitoring these violations. We are encouraged by the feasibility studies that have been conducted on ways to reduce reluctance to provide this information. Their results will help to inform the education campaign recommended here.

6. HHS should examine the feasibility of expanding translating surveys into more languages, the latest research suggests that conceptual equivalency in translation is the gold standard. In other words translation methods must move beyond such techniques as back translation in order to ensure semantic, content, technical, construct and criterion equivalency across cultural groups. At present, most Federal population-based surveys and HHS's health information provided on the Internet are translated only into Spanish. As HHS increases the participation of subpopulations, particularly from Asian and Other Pacific Islander groups, whose languages may include as many as 32 linguistic groups,[62,63] translation of instruments and health information into additional languages will be necessary. Developing methods for training, accessing, maintaining, and expanding a pool of interviewers fluent in various languages also will be necessary.

7. NIH, NCHS, and AHRQ should use Requests for Applications (RFAs), Requests for Proposals (RFPs), and other mechanisms to fund methodologic and empirical studies on best practices for multiple race allocation, bridging of multiple race, definitions of race, ethnicity and nationality as understood by racial and ethnic subpopulations. These studies should highlight immigrants and circumstances that surround the fluidity of ethnic/racial identification.

C. Improve the Collection of Data on Geography and Socioeconomic Position

Reporting data on geographic location, along with age, language, race, ethnicity, and socioeconomic position, when possible, helps investigators identify environmental factors that contribute to health disparities. Including variables beyond an individual's demographic variables is also important in determining targets for interventions outside of the behavior of the individual.

At one of its hearings, the Population Subcommittee heard calls for measuring socioeconomic status beyond assessing income, assets, or education. The Committee recommends that HHS's efforts to collect data on socioeconomic information should be directed to understanding and using *socioeconomic position*.[64,65,66]

In the U.S., socioeconomic status has traditionally been measured by education and income. These variables as well as other possible indicators of socioeconomic status are found in the Census, the American Community Survey, the Current Population Survey, and other leading population-based surveys that do not collect health information. Federal population-based health surveys, on the other hand, tend to examine socioeconomic status more broadly by also including proxy variables, such as health insurance coverage, employment status, detailed occupation (e.g., worker, manager, supervisor), as well as by educational attainment, income, and occasionally wealth. Thus, if the information from these two different types of surveys could be linked, it could create opportunities to better assess the relationship of these socioeconomic factors in health status, health behaviors, access to health care, and treatment of physical and mental health. Surveys also should capture information about a range of contextual variables that have been found to be explanatory in health differences such as social support, social networks, family supports, social cohesion, community involvement, perceived financial burdens and differences in the health status of foreign-born versus U.S.-born individuals, which at times are also linked to socioeconomic status.

Administrative data, such as that captured from an individual's medical encounters, bills or claims, is often not likely to have detailed socioeconomic data associated with it, although health insurance information usually is available from administrative records. If address information is available, administrative data can be geocoded and linked with socio-economic variables available from the Census (at the block, tract, or county level). This procedure is routinely used to enhance SEER-Medicare administrative data, for example.*

* SEER is NCI's Surveillance, Epidemiology, and End Results program of cancer registries. SEER-Medicare data reflect the linkage of two large population-based sources of data that provide detailed information about elderly persons with cancer. For more information

Improving our capacity to geocode administrative data and link them with data on socioeconomic position also is critical. Administrative data as well as survey data would benefit from linkages to contextual data. Hearing participants recommended that Social Security Administration and CMS, the agencies that generate the two largest administrative data sets in the nation, collect socioeconomic data for individual beneficiaries and their spouses and make it available for research purchases. Participants in several of the Subcommittee's hearings suggested that HHS work with states to improve the accuracy and coverage of vital statistics and to increase response rates in the behavioral risk factor surveys (BRFSS, YBRFSS) to ensure that geographic measures will be available for data collection efforts, especially at the state level.

about SEER, visit http://seer.cancer.gov/. For more information about SEER-Medicare data, visit http://healthservices.cancer.gov/seermedicare/.

Enhancing data through linkage to place. Geographic location and its context have an important impact on the health status of individuals and their access to health care

In its hearings, the Population Subcommittee heard testimony about the essential value of area-based measures, such as the proportion in a specific area with and without college degrees (educational structure), with defined levels of income or wealth (economic structure), and with professional jobs (occupational structure). Location does matter, and geocoding offers the potential of accurate and inexpensive data on location.

Precise information about location and its context (e.g., location and characteristics of residence, school, employment, and health care provider) is essential not only for the analysis of single sources of information but also for linkage to other datasets that are similarly geocoded. This is particularly important for tribes of American Indians, urban American Indians or Alaska Natives, Native Hawaiians and Other Pacific Islanders, whose health may be affected by their place of residence. Geocoding and subsequent linkage of data sets increase the potential to understand the impact of location on health and health status of racial, ethnic, and linguistic subpopulations.

As discussed by Dr. Nancy Krieger in the Subcommittee's November 2002 hearing, the precision of geocoding can range from very low (e.g., state of residence) to very high (e.g., latitude and longitude coordinates obtained from satellite systems). Though geocoded data with high precision and accuracy are useful for explaining the impact of location on the health of specific populations, they also must be used with caution because they can increase the risk that individual respondents will be identified.

1. HHS is urged to improve methods for capturing and using accurate geocoding data while at the same time maintaining the highest standard of privacy and confidentiality protections.

2. HHS is urged to convene across Federal agencies a group to assess what measures of socioeconomic position are currently available in Federal data collections effort, what linkages are possible between health and non-health sources for socioeconomic data, and to disseminate this information through HHS's Gateway. It will be necessary to follow up to determine whether the recommended linkages occur and evaluate whether they result in increased data on socioeconomic position in health disparities of racial, ethnic or linguistic subpopulations.

Investigating health through linkages with non-health datasets: An example of what can be done now

It is now possible to match Medicare records to lifetime earnings records in Social Security, and in turn, match these data with survey records, such as those from the Survey of Income and Program Participation (SIPP). SIPP provides information on socioeconomic status, the Social Security records give a way of measuring longer-term and lifetime income, as well as mortality, and the Medicare records provide information on the actual use of medical care, at least among the disabled on Disability Insurance and the elderly on Old Age and Survivors Insurance.

Because access to such records are often limited, creating such linkages requires that agencies give attention to developing mechanisms to facilitate the engagement by researchers in using this data. Cooperative agreements, in which a government agency performs the statistical work in cooperation with non-government researchers, is one such mechanism. HHS is requested to encourage agencies to increase both linkages across datasets as well as develop mechanism that facilitate the use of such linked data for non-government researchers.

3. HHS should evaluate how best to collect socioeconomic information in electronic health records and encourage best practices in public and private health record systems.

D. Enhance the Collection of Data on Race, Ethnicity, and Primary Language in Federal Health Programs

HHS is urged to examine its own health programs to determine whether they can improve the collection of data on race, ethnicity, and primary language from individuals who receive care through Federal health programs.[67,68] Currently, more than half of the health care received by racial and ethnic populations in the U.S. is through Federally-funded programs (e.g., Medicare, Medicaid, VA, Department of Defense, or Federal employee health plans). HHS could by mandating the collection of data on race, ethnicity, and primary language determine and measure disparities in quality of care received by the users of its own systems.[69] This mandate would focus on improving collection of data on race, ethnicity, and primary language across a range of initiatives, including the Medicare Hospital Quality Initiative, CMS Abstraction and Reporting Tool (CART), all Medicare billing operations, Medicaid, State Children's Health Insurance Program (SCHIP), and the Health Insurance Portability and Accountability Act (HIPAA). Progress in this area also will benefit the data collection infrastructure strategies described under Recommendation 2.

1. The Committee recommends that HHS take steps to ensure that Medicaid administrative systems include race and ethnicity information that can be linked to encounter or claims data. Performance of these linkages should be required. The Committee requests that HHS track and report the extent to which this goal is met.

Recommendation 2

HHS is urged to increase and strengthen the capacity of its health statistics infrastructure to analyze, report, and disseminate data on the various ethnic/racial/linguistic subpopulations in the United States and territories.

In order to eliminate health disparities, HHS must ensure that the Nation has a strong and effective health statistics infrastructure for analyzing, reporting, and disseminating high-quality, complete, and reliable data and information on health and health disparities across subpopulations. Such an infrastructure requires well-trained investigators with ready access to the data of the highest quality and completeness on subpopulations and who are equipped with content expertise, cutting edge methodology, and statistical techniques. Researchers with the necessary background, skill, and interest are needed to shape and influence the health disparities research agenda, including identifying the variables on which interventions are most likely to eliminate health disparities.[70] In addition, researchers must be trained to analyze the data so they can help answer questions about the extent to which racial-ethnic groups vary in health care use, and their access to and satisfaction with care. At present, there is a shortage of researchers in this area who are themselves members of racial and ethnic subpopulations. HHS should increase ease of access to the data (e.g., increased remote and secure data access) for both intramural and extramural researchers of all racial and ethnic backgrounds to use HHS data to answer questions related to health status, health outcomes, use of health care services, and access to care for small racial and ethnic populations.

Researchers also must have access to data on the racial, ethnic, and linguistic subpopulations who most often face disparities in their health status, health outcomes, access to care and health care treatment. Easier access to Federal data collected on these diverse subpopulations can be achieved through increasing the number of secure data centers placed strategically throughout the country and revising procedures for access to microdata (non-aggregated data containing variables that may make respondents identifiable) used for research and statistical purposes outside of these data centers. A strong commitment to disseminating data and

facilitating its use by all interested parties also is essential to the success of this endeavor.

HHS is urged to identify the data tools necessary to track progress toward eliminating health disparities. Progress includes using best practice solutions, and improving the dissemination of data collected on racial, ethnic, and linguistic subpopulations. The following strategies will strengthen HHS's health statistics dissemination infrastructure, thereby helping HHS to achieve these objectives. Progress in many of the strategies below also will help improve the overall data collection efforts discussed for Recommendation 1.

A. Expand Access to Data on Subpopulations

Although HHS collects a great deal of data on some racial, ethnic, and linguistic populations, particularly in population-based surveys, these data are often not available for use outside of a secure-data-center setting because of the small numbers represented in these datasets and the consequent need to protect the privacy and confidentiality of the respondents. The risk to privacy arises out of the technical problem of "identifiability." This situation occurs when an individual can be identified by the values associated with variables in the health dataset or interview, even in the absence of direct identifiers. Identifiability is an especially acute problem with small populations, whether they are small in terms of absolute size or in terms of limited time of data collection or regional coverage. As hearing participants made clear, the very limited numbers of secure data centers that exist currently, do not provide adequate access to this type of data by potential users.

The Subcommittee urges that any approach to enabling greater access to these data should strike a balance between individual privacy and confidentiality and society's needs for data. Access to health information involves balancing an individual's expectation of privacy of personal and health information against society's need for information to monitor and improve the health and health care of all individuals.[71] This balance must be achieved to ensure the success of Federal data collection efforts. On the one hand, if individuals have few assurances of privacy, or if they lose trust in the promise of confidentiality, they will not consent to be

interviewed or will not provide accurate data. Low response and participation rates lead to bias in the samples and loss of efficiency of the survey design. On the other hand, if data are not accessible by the research and public health communities because of restrictions to preserve privacy, then little benefit accrues to the respondents who volunteer their time or to the public who fund the programs and expect results. The tradeoff and the controversies are especially acute in the study of racial, ethnic, and linguistic subpopulations, whose health status, health outcomes, and receipt of health care and treatment are often distinctly worse than that of other populations.

1. HHS should work with Census to place or share additional secure data centers in academic and community settings. Funding should ensure that all centers are adequately staffed and supplied with current hardware and all necessary software so that interested users will have ready access to data needed to assess the health of subpopulations. Options for remote access to data also should be expanded.

2. HHS should consider additional options, including disseminating and providing technical support for synthetic microdata, and promoting research on other forms of protecting identifiable data on subpopulations. These and other emerging methods can increase access to data on subpopulations for research and statistical purposes in a manner consistent with existing statutes and regulations and in alignment with the expectations of privacy of potential respondents.

B. Improve Data User Training

Several reports have noted the limited diversity of the U.S. health care professional workforce. The Sullivan Commission report *Missing Person: Minorities in the Health Professions*, the IOM's *Unequal Treatment*, and the NRC's *Eliminating Health Disparities* all have acknowledged the critical shortage of health professionals of diverse backgrounds and those with training in health problems and health care of diverse populations. The W.K. Kellogg Foundation, the Robert Wood Johnson Foundation, and a number of professional organizations have echoed these findings. NCVHS acknowledges the long history of HHS in preparing a well-trained and diverse health care and scientific workforce, particularly through its training mechanisms at NIH, its establishment of training as a priority for the NIH National Center for Minority

Health and Health Disparities, and the minority health statistics program at NCHS. However, it appears that in a time of shrinking resources and flat budgets, some of these programs and awards mechanisms have been cut back, become inactive, or been dropped due to a lack of funds. At this critical juncture, when HHS is calling for action to eliminate health disparities, a well-trained health care and scientific workforce with expertise in health disparities issues is essential.

1. HHS should support and fund initiatives that are directed to enhancing the capacity of health care professionals and researchers to use HHS data to address questions in the areas of health status, health outcomes, access to care and disparities in health care in racial, ethnic, and linguistic subpopulations.

2. NIH, HRSA, SAMSHA, and NCHS should renew and expand existing grant programs to train researchers with interests in health disparities and health statistics. In particular, these agencies should support programs that develop the expertise of researchers from racial and ethnic subpopulations. Programs such as minority supplements to existing awards, career development awards (K awards) in the area of minority health statistics, RFAs or RFPs to conduct methodological work in this area, calls for Centers on Minority Health Statistics, and other mechanisms used by NCHS, HRSA, SAMSHA or NIH, can be employed to train these researchers. A reporting system should be established to track progress in meeting this goal.

3. The federal government has specific treaty requirements with American Indian tribes. These create a special relationship as a function of sovereignty that governs data ownership and data collection. HHS should support existing efforts and develop new programs that will train American Indians and Alaska Natives and their community-based organizations and tribal governments to use and analyze American Indian and Alaska Native health statistics. A reporting system should be established to track progress in meeting this goal.

C. Link Data Systems and Dissemination Methods to Bridge Old with New Data

HHS is continually collecting and publishing new data on population groups. As agencies have adopted OMB's 1997 guidelines, the ways in which race and ethnicity have been reported have gradually changed. For example, data on Native Hawaiian and at times Other Pacific Islanders were previously nested in the larger category of

Asian and in some instances "Other." Now they are being reported separately. These shifts from one race group to another will likely be seen when analysts and other users cannot directly compare new data to data collected under the old standard. Monitoring health outcomes for new groups also will require changes from the old presentation style of data.

As a result, new methods for making old and new data comparable (bridging) will need to be noted in data publications. For example, age distributions of multi-racial populations will appear much younger, because the groups being displayed are sometimes younger in comparison to the White population. Estimates on health and access to health care for multi-racial persons will be highly variable due to relatively small sample sizes for these groups. Monitoring of the potential impact of the new Federal standards, with periodic reports to the Secretary through the HHS Data Council, would be both useful and important in ensuring both appropriate comparisons and ongoing trend analysis.

1. NCHS is urged to provide technical assistance around bridging by developing easily available analytic guidelines for recoding, tabulating, and bridging racial and ethnic data under the OMB guidelines of 1997. These should be summarized and placed on the NCHS and the HHS websites and included in other analytic guideline documents. This guidance should emphasize that collecting data on race and ethnicity is legal and appropriate and should present the potential beneficial for health planning and quality improvements in health services. NCHS also is encouraged to explain in those guidelines the implications and potential impact of various race allocations methods selected and their advantages and disadvantages for racial and ethnic subpopulations.[72]

D. Improve Data Quality

Incentives to improve the collection of data on subpopulations will only be frustrated if they lead to missing or inaccurate data. Missing or incorrect data lead to both biased estimates and/or to estimates with unnecessarily high variability. Efforts to increase the volume of data should not occur at the expense of procedures and incentives to ensure the accuracy and completeness of the data.

For example, in an attempt to reduce missing data and limit the use of "Other Race" as a response option, the new OMB standards requires that Federal survey instruments list the ethnicity question before the race question.[73,74,75,76] Even with this design, approximately 25 percent of respondents, most of them Hispanic, do not answer the race question. Approximately 40 percent of Hispanics select "Other Race," and approximately 90 percent of those who select "Other Race" are Hispanic. These response patterns are very similar to those seen in surveys taken before the change in Federal standards. Clearly, research is needed to understand how Hispanics interpret questions on race and ethnicity and what factors influence their reporting. Without such an understanding, it is unlikely that Federal agencies will be able to reduce the amount of missing data on this essential question.

States also need guidance in collecting and reporting subgroup classifications. In their study of racial and ethnic classification in the New England region, Laws and Heckscher[77] report the confusion among various states on how to classify some individuals. For example, in recording vital statistics, one state followed the Federal guidance and classified the racially diverse populations of Bolivians, Colombians, Cubans, Brazilians, Mexicans, South Americans, and people from the Middle East and North Africa as Whites. Those with the religious labels of Muslim, Islamic also were registered as White. In the U.S., Creole is a designation for a person of mixed African and European heritage. In Mexico, a Creole is a person of Spanish descent. In one New England state, persons with Creole written on the death certificates were classified as White, while in areas of the South, persons with this designation would be classified as Black. States are struggling with whether the classifications are appropriate and meaningful when a single category can include great within-group diversity.

1. HHS should provide leadership to identify how to give states needed flexibility in collecting and reporting racial and ethnic subgroup classifications so that they can work efficiently with Federal data reporting requirements.

2. NCHS is urged to conduct methodological research in several key areas:

a. Determine the degree and scope of racial and ethnic misreporting on death certificates and how multiracial reporting can be facilitated on birth and death statistics;

b. Identify ways to improve the frequency and accuracy of reporting of race and ethnicity for administrative and medical records.

c. Improve statistical methods and techniques to deal with missing or miscoded data on race, ethnicity, socioeconomic position, and place.

3. HHS is asked to take the lead in identifying and developing statistical methods and techniques to simultaneously analyze multiple socio-economic measures so as to overcome problems related to redundancy or multiway correlations across measures (data collinearity).

E. Increase Dissemination of Health Statistics and Research Findings

For agencies and organizations to take steps to reduce health disparities, they need access to data on racial, ethnic, and linguistic subpopulations. A key issue in ensuring access is determining the best ways to broadly disseminate information resulting from studies. Dissemination applies not just to the scientific community but also to decision-makers responsible for planning and providing health care and for developing health policy, as well as health advocates committed to changing health outcomes in their communities, and those who plan and carry out health promotion and disease prevention interventions, the media, and even the public. Moreover, information that reaches policy- and decision-makers several years after it is collected is not current enough, they need to know what is happening in the environment at the present time in order to make the right policy decision or appropriately pursue research questions. HHS has increased its partnerships with minority media to successfully develop chronic disease education and prevention campaigns. HHS's efforts in this regard could benefit from the development of a process or infrastructure whereby information derived from its health statistics and funded research and prevention efforts could be rapidly disseminated and translated to help in chronic disease prevention in racial, ethnic, and linguistic subpopulations.

Infrastructure and available funding are needed to ensure that all groups can benefit equally from HHS health statistics. As the Subcommittee learned in its hearings, for example not all racial, ethnic, or linguistic subgroups across the country routinely use or have access to the Internet. Studies consistently have shown that differences in age, race/ethnicity, and even geographic location (rural vs. urban) must be considered in selecting the best methods for disseminating information to diverse groups.

1. In conjunction with its largest agencies, NIH and CDC, HHS should continue and further develop aggressive public use data release programs, with appropriate confidentiality controls, to promote wider use and analysis of racial/ethnic health data that can be used to further improve health care quality and ameliorate disparities. This effort should include grant and contract support for data analysis and periodic data user conferences that focus on the methodology of using, analyzing, and disseminating small datasets on racial, ethnic and linguistic subpopulations. A reporting system should be established to track progress in meeting this goal.

   HHS is urged to consider methods for improving the accessibility of data on racial, ethnic, and linguistic subpopulations. These methods, which include CD-ROM versions of data or data query systems that can provide area-specific data, can be used by community-based organizations, health departments and local entities to further improve the quality of care and reduce or eliminate health disparities for these groups. HHS is urged to develop an assessment to determine whether its current mechanisms for ensuring accessibility of data, which relies heavily on Internet technology and English (and some limited Spanish), can be enhanced for wider distribution to a greater diversity of audiences. Possible enhancements could include a variety of dissemination mechanisms (e.g., minority radio and newspapers, printed copy, community-based agencies who can acts as disseminators), and increased availability in other languages.

Conclusion

As this report has shown, efforts to improve health care and eliminate health disparities in the United States can succeed only when researchers, policy-makers, health care professionals, and community groups are equipped with complete and accurate data on the differences in health status, access to care, and the provision of services experienced by specific subpopulation groups in the U.S.

In the face of the clear costs to the Nation of health disparities, the Committee views its recommendations as a starting point for productive consultation and discussion in which all stakeholders are engaged in determining the best steps forward. Better data and a strengthened ability to collect and use the data will move the U.S. closer to documenting, monitoring, and eliminating health disparities. In this way proving data systems will ensure improvements in health status and quality of health care for all Americans.

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Appendices

Appendix A: Online Resources Available from the NCVHS

Appendix B: Hearings Held by the NCVHS Subcommittee on Populations, 2001 – 2003

Appendix A: Online Resources Available from the NCVHS

NCVHS Letters and Reports Recommending Strategies for Increasing the Quantity and Quality of Data on Racial, Ethnic, and Linguistic Subpopulations in the U.S. and Territories

- August 23, 2004 **Letter to the Secretary** on Recommendations on Populations Based Data Collection. www.ncvhs.hhs.gov/040823lt.htm
- September 26, 2003 **Letter to the Secretary** on Recommendations for Targeted Data Collection. www.ncvhs.hhs.gov/030926lt.htm
- September 26, 2003 **Letter to the Secretary** on Collection of Racial and Ethnic Data by Health Plans. www.ncvhs.hhs.gov/030926ltb.htm
- March 27, 2003 **Letter to the Secretary** on Populations-based Data for Racial and Ethnic Minorities. www.ncvhs.hhs.gov/030327lt.htm
- October 19, 2001 **Letter to CMS** on Racial and Ethnic Data Collection. ncvhs.hhs.gov/011019lt.htm
- July 6, 2001 **Recommendations to HCFA** on SCHIP Ddata Collection. www.ncvhs.hhs.gov/011019lt.htm
- March 14, 2001 **Letter to Katherine Wallman, Chief Statistician, Office of Management and Budget** regarding Provisional Guidance on the Implementation of the 1997 Standards for Federal Data on Race and Ethnicity (December 15, 2000). www.ncvhs.hhs.gov/010314lt.htm
- December, 1999 **Report** on Medicaid Managed Care Data Collection and Reporting. www.ncvhs.hhs.gov/managedcare.pdf
- December, 1999 **Report** on Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands. www.ncvhs.hhs.gov/9912islandreport.pdf

Other Resources Available on the NCVHS Website

Agendas, Transcripts, and Summaries of Meetings and Hearings held by the Subcommittee on Populations

- June 27, 2001 –Subcommittee on Populations Breakout Session During Full Committee Meeting, Mr. Roderick Harrison, Joint Center for Political and Economic Studies. Discussion of Implementation of the Collection of data on race and ethnicity., Washington DC www.ncvhs.hhs.gov/010627a3.htm
- August 15, 2001 - Meeting on Future Directions for Work in the Implementation of OMB Standards for the Collection of Data on Race and Ethnicity, Rosemont IL www.ncvhs.dhhs.gov/010815ag.htm
- February 11-12, 2002 - Hearing on Measurement of Health Disparities in Racial and Ethnic Groups in Federal Surveys, Washington DC www.ncvhs.hhs.gov/020211ag.htm
- February 26-27, 2002 - Subcommittee on Populations Breakout Session During Full Committee Meeting, Review of February 11-12, Hearing on Measurements of Health Disparities in Racial/Ethnic Groups, Washington DC www.ncvhs.hhs.gov/020226a2.htm
- February 26, 2002 - Subcommittee on Populations Workgroup on Quality - Breakout Session, Washington DC www.ncvhs.hhs.gov/020226a3.htm
- September 27, 2002 - Hearing on Health Data Needs for American Indians - Denver, CO www.ncvhs.hhs.gov/020927ag.htm
- November 8, 2002 - Hearing on Health Data Needs for States, Vital Statistics, and Geocoding in Eliminating Health Disparities in Racial and Ethnic Subpopulations - Philadelphia, PA, www.ncvhs.hhs.gov/021108ag.htm
- May 22-23, 2003 - Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations - Los Angeles, CA, www.ncvhs.hhs.gov/030522ag.htm
- July 24, 2003 - Planning meeting and discussion of Small Area/Geographic Area Studies, www.ncvhs.hhs.gov/030724ag.htm

November 13-14, 2003 - Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations - San Francisco, CA, www.ncvhs.hhs.gov/031113ag.htm

NOTE: These links take users to the webpages for the hearings or meetings. You will find additional links to summaries and individual testimonies by clicking on Meeting Minutes and Transcripts.

Testimony at Hearing on Measurement of Health Disparities in Racial and Ethnic Groups in Federal Surveys, Washington DC, February 11-12, 2002

- Medical Expenditure Panel Survey:
  - Mr. Machlin, AHRQ, www.ncvhs.hhs.gov/020211tr.htm#machlin
  - Lillie-Blanton, Dr.P.H., User, Kaiser Family Foundation, www.ncvhs.hhs.gov/020211tr.htm#lillie-blanon
- Consumer Assessment of Health Plans - Judy Sangl, Sc.D., AHRQ, www.ncvhs.hhs.gov/020211tr.htm#sangl
- Consumer Assessment of Health Plans User - James Moser, Ph.D., Brens Group of KPMG Consulting, www.ncvhs.hhs.gov/020211tr.htm#moser

- Medicare Current Beneficiary Survey - Dan Waldo, M.A. Centers for Medicare & Medicaid Services, www.ncvhs.hhs.gov/020211tr.htm#medicare
- Medicare Current Beneficiary Survey - Joan DaVanzo, MSW, Ph.D., Lewin Group, www.ncvhs.hhs.gov/020211tr.htm#medicarebeneficiary
- Policy Perspectives - Carolyn Clancy, M.D., AHRQ, www.ncvhs.hhs.gov/020211tr.htm#policyperspectives
- Socioeconomic Status - Patricia O'Campo, Ph.D., Johns Hopkins University, www.ncvhs.hhs.gov/020211tr.htm#socioeconomic
- National Survey of Family Growth - Joyce Abma, Ph.D., NCHS, www.ncvhs.hhs.gov/020211tr.htm#growth
- Behavioral Risk Factor Surveillance - Peter Mariolis, Ph.D., CDC, www.ncvhs.hhs.gov/020211tr.htm#behavioral

Testimony at Hearing on Health Data Needs for States, Vital Statistics, and Geocoding in Eliminating Health Disparities in Racial and Ethnic Subpopulations - Philadelphia, PA, November 8, 2002

- Massachusetts Department of Health - Bruce Cohen, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#massachusetts
- California Department of Health – Peter Abbott, M.D., www.ncvhs.hhs.gov/021108tr.htm#california
- Hawaii Department of Health - Alvin Onaka, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#hawaii
- California Department of Health - Dr. Jane McKendry, www.ncvhs.hhs.gov/021108tr.htm#california2
- Vital Statistics Re-engineering Project – Delton Atkinson, MSPH, MSP, www.ncvhs.hhs.gov/021108tr.htm#reengineering
- Healthy Women: State Trends in Health and Mortality - Kate Brett, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#healthywomen
- National Women's and Minority Indicators Database Project - Alfred Meltzer, www.ncvhs.hhs.gov/021108tr.htm#database
- Geocoding State Data and Establishing Collaborations - Nancy Krieger, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#geocoding
- Alabama Department of Public Health - Dorothy Harshberger, www.ncvhs.hhs.gov/021108tr.htm#alabama
- Tennessee Department of Health - Richard Urbano, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#tennessee
- Commentary -Daniel Friedman, Ph.D., www.ncvhs.hhs.gov/021108tr.htm#commentary

Testimony at the Hearing on Health Data Needs for Asian, Native Hawaiian, and Other Pacific Islander Populations, May 22-23, 2003, Los Angeles CA

- Hawaiian Matters: Data Considerations for Native Hawaiian and Pacific Islander Populations." Nolan Malone, Ph.D., PACE Kamehameha School. www.ncvhs.hhs.gov/030522p1.pdf

- Comments on AAPI Data to Subcommittee on Populations. Paul Ong Ph.D., Ralph and Goldy Lewis Center for Regional Policy Studies, UCLA. www.ncvhs.hhs.gov/030522p2.pdf

- Use of Census Data in Health Planning and Community Development in Support of Community Services. Bong Vergara MA, MSW, and Malany Dela Cruz, Census Information Center. www.ncvhs.hhs.gov/030522p3.pdf

- Ethnicity, Culture, and Pharmacogenetics. Keh-Ming Lin M.D., Harbor-UCLA Medical Center. www.ncvhs.hhs.gov/030522p4.pdf

- Small AA/NHOPI Populations, Marjorie Kagawa-Singer Ph.D., RN, UCLA School of Public Health and Asian American Studies Center. www.ncvhs.hhs.gov/030523p1.pdf

Testimony at the Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations, November 13-14, 2003, San Francisco CA

- Overview of Pacific Island Health Data Issues, Christina Perez M.P.H., Regional Minority Health Coordinator, Region X. www.ncvhs.hhs.gov/031113tr.htm#perez

- Health Data Needs for the Elimination of Health Disparities for Asian, Native Hawaiian, and Other Pacific Islander Populations. Ho Tran, M.D., Asian and Pacific Islander American Health Forum. www.ncvhs.hhs.gov/031113p1a.pdf and www.ncvhs.hhs.gov/031113tr.htm#tran

    - Policy Brief: Data Gaps and Health Disparities for Asians and Pacific Islanders Highlighted in the Healthy People 2010 Initiative. Ho Tran M.D., Asian and Pacific Islander American Health Forum. www.ncvhs.hhs.gov/031113p1b.pdf

- Accessing Census Data on Asians, Native Hawaiians, and Other Pacific Islander Populations: The Role of Census Information Centers. Gem Daus M.P.H., Asian and Pacific Islander American Health Forum. www.ncvhs.hhs.gov/031113p2a.pdf and www.ncvhs.hhs.gov/031113tr.htm#daus

    - Census Data: Top 10 States—Population by Asian (Alone) Ethnicity. www.ncvhs.hhs.gov/031113p2b.pdf

- ANHOPI Measurement and Clissification Issues. Elena Yu, PH.D., Johns Hopkins University. www.ncvhs.hhs.gov/031113tr.htm#yu

- Healthcare Quality Indicators for ANHOPI Populations. Ellen Wu, M.P.H., California Pan Ethnic Health Network. www.ncvhs.hhs.gov/031114tr.htm#wu

- Asian Americans and Cancer. Scarlett Lin Gomez, Ph.D., Northern California Cancer Center. www.ncvhs.hhs.gov/031114tr.htm#gomez

- Data Challenges in the Western Pacific. Greg Dever, M.D., Palau Ministry of Health. www.ncvhs.hhs.gov/031114p1.pdf and www.ncvhs.hhs.gov/031114tr.htm#devor

- Data Challenges in Hawaii. Catherine Sorenson, Ph.D., Hawaii Department of Health. www.ncvhs.hhs.gov/031114tr.htm#sorenson

- Health Disparities Data Issues: Listening to the Voices. Carol Murray, Ph.D., University of Hawaii at Manoa. www.ncvhs.hhs.gov/031114p2.pdf and www.ncvhs.hhs.gov/031114tr.htm#murry

Appendix B: Hearings Held by the NCVHS Subcommittee on Populations, 2001 – 2003

February 2002 Hearing on Data Collection in Federal Surveys and Studies

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATIONS

Hearing on the Collection of Data on Race and Ethnicity in Federal Population-Based Data

February 11-12, 2002

Department of Health Human Services
Hubert HuM.P.H.rey Building, Room 800
200 Independence Avenue, SW
Washington, DC 20020

Hearing Questions

1. What contributions can be made to advance our knowledge of disparities in health and health care using your survey data?
2. Do we need additional variables beyond race and ethnicity to begin to document health and health care disparities among racial and ethnic groups? For example, how important is confounding and interactions among the variables as we try and assess disparities? Have such analyses been conducted in your survey data?
3. How can we best measure ethnic identity?
4. Is it feasible to link the various data sets to other contextual data really further understand some of the causes and consequences of disparities? For example, can these data sets be linked to tell us things such as physician supply, neighborhood characteristics?
5. Is there an interest in identifying the cost of health disparities? Can some or all of these costs in some way be documented? For example, if health disparities continue, what is the cost to us, both as a society, as well as in terms of a cost in terms of the budget?
6. Are survey instruments translated and interviews conducted in various languages, and if so, what are those languages? If not, do they plan to do this? Does the survey ask questions regarding language proficiency?
7. Does the survey deal with the issue of undercount, and how does it handle it? Does the survey over particular ethnic and racial groups in its current sampling frame? If so, what is the process?
8. What guidance are you providing to analysts on how to use multi-race responses?
9. What kind of training are you providing to minority researchers so they can access and use your data?

Agenda

	MONDAY, FEBRUARY 11	
9:00-9:30 a.m.	Call to Order, Introductions and Opening Remarks	Vickie M. Mays, Ph.D., MSPH, Chair James Scanlon, Director Div. Data Policy, DHHS
	Measurement of Health Disparities in Racial and Ethnic Groups in Federal Surveys	
9:30-9:50 a.m.	Medical Expenditure Panel Survey	Steve Machlin, *AHRQ*
9:55-10:15 a.m.	Medical Expenditure Panel Survey User	Marsha Lillie-Blanton, Dr.P.H., Kaiser Family Foundation
10:15-10:35 a.m.	Questions and Answers (MEPS)	
10:35-10:45 a.m.	Break	
10:45-11:05 a.m.	Consumer Assessment of Health Plans	Judy Sangl, Sc.D., AHRQ Chuck Darby, M.A., AHRQ
11:10-11:30 a.m.	Consumer Assessment of Health Plans User	James Moser, Ph.D., Barens Group of KPMG Consulting Inc.
11:30-11:50 a.m.	Questions and Answers (CAHPS)	
11:50-12:45 p.m.	Lunch	
12:45-1:00 p.m.	Remarks	Vickie M. Mays, Ph.D., MSPH, Chair
1:00-1:20 p.m.	Medicare Current Beneficiary Survey	Dan Waldo, M.A. Centers for Medicare & Medicaid Services
1:25-1:45 p.m.	Medicare Current Beneficiary Survey User	Joan DaVanzo, MSW, Ph.D., Lewin Group
1:45-2:05 p.m.	Questions and Answers (MCBS)	
2:10-2:40 p.m.	Policy Perspectives	Carolyn Clancy, M.D., AHRQ
2:40-3:00 p.m.	Discussion	
3:00-3:10 p.m.	Break	
3:10-3:40 p.m.	Socioeconomic Status	Patricia O'Campo, Ph.D., Johns Hopkins University
3:40-4:00 pm	Questions and Answers SES	
4:05-4:25 p.m.	National Survey of Family Growth	Joyce Abma, Ph.D., NCHS
4:25-4:45 p.m.	Behavioral Risk Factor Surveillance Survey	Peter Mariolis, Ph.D., CDC

4:45-5:05 p.m.	Questions and Answers NSFG/BRFSS	
5:05-5:15 p.m.	Wrap Up	Chair
5:15 p.m.	Adjourn	

	TUESDAY, FEBRUARY 12	
8:30-8:45 a.m.	Call to Order and Introductions	Vickie M. Mays, Ph.D., MSPH Chair
8:45-9:05 a.m.	National Health Interview Survey	Jacqueline B. Lucas, M.P.H., NCHS
9:10-9:30 a.m.	National Health Interview Survey User	Richard Hummer, Ph.D. University of Texas
9:30-9:50 a.m.	Questions and Answers NHIS	
9:55-10:15 a.m.	National Health and Nutrition Examination Survey	Lester R. Curtin, Ph.D., NCHS
10:15-10:35 a.m.	National Health and Nutrition Examination Survey User	Christopher Sempos, Ph.D., State University New York University at Buffalo
10:35-10:55 a.m.	Questions and Answers NHANES	
10:55-11:05 a.m.	Break	
11:05-11:35 a.m.	Multiple Race Data Use	Tom Smith, Ph.D., NORC/University of Chicago
11:35-11:50 p.m.	Questions and Answers Multiple Race	
11:50-12:20 p.m.	Policy Discussion	Raynard Kington, M.D., Ph.D., OBSSR/ NIAAA/ NIH
12:20-12:35 p.m.	Discussion	
12:35-12:45 p.m.	Adjourn	

Additional Hearings and Breakout Sessions Used to Develop the Report

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATIONS

Break-out Session at NCVHS Full Committee Hearing
June 27, 2001

Renaissance Hotel
999 9th Street, NW
Washington, D.C. 20001

Agenda

2:00 p.m.	Introductions	Dr. Vickie Mays
	Review agenda	
2:15 p.m.	Discussion of Implementation the Collection of race and ethnicity.	Mr. Roderick Harrison, Joint Center for Political and Economic Studies
2:45 p.m.	Future directions for further work in the area of data on race and ethnicity.	Subcommittee

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATIONS

Hearing on Health Data Needs for American Indians
September 27, 2002

Adams Mark Hotel
1550 Court Place
Denver, Colorado 80202-5107

Hearing Questions

1. Please describe barriers to data collection, analysis and disease surveillance for eliminating health disparities in American Indians and Alaska Natives.
2. Please describe strategies that DHHS could use to remove those barriers.
3. Please describe strategies that DHHS could use to increase the capacity for American Indian/Alaska Native researchers and organizations to conduct health disparities research, demonstrations and evaluations.
4. Please describe the strategies that DHHS could use to support relationships between tribal colleges and universities, academic researchers and State and local health entities.
5. Please describe the accountability mechanisms that DHHS could institute to ensure the development and maturation of these partnership relationships.
6. Please describe strategies that DHHS could use to support partnerships with American Indian/Alaska Native communities to improve safety and quality in health care.

Agenda

9:00 am	Call to Order and Introductions	Vickie Mays, Ph.D., Chair
9:15 am	Background of Subcommittee and Overview of Meeting	Chair
9:30 am	Opening Remarks: Eliminating Health Disparities in Indian Country	Yvette Joesph Fox National Indian Health Board (invited)
10:00 am	Identification of American Indian Alaska Native Health Disparity Issues	Nashville Area Representative Jennie Joe, Ph.D., Univ. of Arizona Dorrie Rhoades, M.D. ,Univ. of Washington
11:15 am	Break	
11:30 am	Discussion/Q & A	
12:00 noon	Lunch	
1:00 pm	Health Disparity Issues from the Tribal Perspective	Sally Smith Bristol Bay Area Health Corp

		(Transitions Report) James Oliver, NWPAIHB Rick Havertake, Intertribal Council of Michigan
2:30 pm	Urban/Rural Indian Issues	Beverly Russell, National Council of Urban Indian Health Sally Smith, Tribal Self-Governance Advisory Committee Rep.
3:00 pm	Break	
3:15 pm	Discussion/Q & A	
3:45 pm	Summary and Next Steps	
4:00 pm	Adjourn	

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATIONS

Hearing on Health Data Needs for States, Vital Statistics, and Geocoding in Eliminating Health Disparities in Racial and Ethnic Subpopulations
November 8, 2002

The Public Ledger Building
150 S. Independence Mall West, Conference Room 415
Philadelphia, PA 19106

Hearing Questions

1. To begin, would you please very briefly discuss the demographic composition of the State in terms of racial and ethnic subgroups and where these groups are concentrated?

2. In addition to data on racial identities, does your State routinely collected detailed data on ethnicity and national origin in its ongoing surveillance data sets? Are these data collected only for Hispanics, or for other groups as well? On what data sets are these data collected? Please provide examples.

3. Will all ongoing data sets maintained by your State health department use the same race/ethnicity standards for data collection, tabulation and reporting? If so, is this standard based on the 2000 Census standard, the OMB preferred standard, or some combination of both?

4. Do you believe that there is a significant problem of mis-classification into racial and ethnic categories in the State? For what data sets? For what racial and ethnic groups? What steps, such as possibly partnerships with advocacy groups, are in place for studying the issue and for making corrections?

5. Does the State plan to adopt the race and ethnicity items on the new NCHS standard birth certificate?

6. Do the race and ethnic guidelines from OMB have adequate utility for the State or does the State frequently find the need to collect information using other or expanded categories?

7. Are there any inconsistencies in ethnic and racial data collection methodologies between various instruments that the State uses to collect data either solely for State purposes or to provide to the Federal government?

8. Does the State have adequate guidance to do the bridging and tabulation from the older standards on the collection of race to the newer standards of the collection of race?

9. Does the State collect racial and ethnic data in their Medicaid managed care system?

10. If there is a State-wide hospital discharge data system and if so does it collect racial and ethnic data?
11. Are racial and ethnic data routinely reported in State health-related publications and reports?

Agenda

8:30 am	Call to Order and Introductionsand Overview of Meeting	Vickie Mays, Ph.D., MSPH, Chair
8:35 am	Background of Subcommittee and Overview of Meeting	Chair
8:45 am	Welcoming Remarks	Dalton Paxman, Ph.D. Regional Health Administrator Region III, Dept. of Health and Human Services
8:50 am	Massachusetts Department of Health	Bruce Cohen, Ph.D. Director, Division of Research And Epidemiology
9:15 am	California Department of Health Services	Jane McKendry, Chief, Vital Statistics Section Peter Abbott, M.D., Acting Deputy Director Health Information and Strategic Planning
9:30 am	Hawaii Department of Health	Alvin Onaka, Ph.D., Office of Health Status Monitoring
10:10 am	Discussion	
10:40 am	Break	
11:05 am	Vital Statistics Re-engineering Project	Delton Atkinson, MSPH, MSP Project Director, National Center for Health Statistics
11:45 am	Discussion	
12:00 pm	Lunch	
1:00 pm	Healthy Women: State Trends in Health and Mortality	Kate Brett, Ph.D., Office of Analysis and Epidemiology, NCHS
1:25 PM	National Women's and Minority Indicators Database Project	Colleen Goodman Alfred Meltzer, Quality Resource Systems, Inc
1:55 pm	Discussion	
2:10 pm	Alabama Department of Public Health	Dorothy Harshberger, State Registrar
2:35 pm	Tennessee Department of Health	Richard Urbano, Ph.D., Assistant Commissioner, Bureau of Health Informatics

3:00 pm	Discussion	
3:20 pm	Break	
3:40 pm	Geocoding State Data and Establishing Collaborations	Nancy Krieger, Ph.D., Associate Professor, Dept. of Health and Social Behavior, Harvard School of Public Health
4:05 pm	Discussion	
4:20 pm	Commentary	Daniel Friedman, Ph.D., Assistant Commissioner Bureau of Health Statistics, Research and Evaluation, Massachusetts Dept. of Public Health
4:30 pm	Summary and next steps	Chair/Subcommittee
5:00 pm	Adjourn	

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATIONS

Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations
May 22-23, 2003

J.D. Morgan Athletics Center
The Press Room
UCLA Athletics Bldg

Hearing Questions

1. For Pacific Island populations, what techniques are used to collect data on race and ethnicity? How does language, population size or population geography impact the ability to gather data on the health status, health behaviors, and health experiences of these populations? What recommendations could you make to DHHS for addressing these issues?
2. Do you believe that there is a significant problem of misclassification of racial and ethnic categories in existing data sets? For which data sets? For which categories? What steps, such as possibly partnerships with advocacy groups, are in place for studying the issue and for making corrections?
3. Is data collected on ethnicity, language spoken and national origin in ongoing surveillance data sets? On what data sets are these data collected? Please provide examples.
4. What barriers exist to data collection, analysis and disease surveillance for eliminating health disparities in ANHOPI populations? Describe strategies that DHHS could use to remove those barriers.
5. Is data collected on ethnicity, language spoken and national origin in ongoing surveillance data sets? On what data sets are these data collected? Please provide examples. What types of health data would you recommend that DHHS collect?
6. Current data collection methods eM.P.H.asize the protection of the privacy and confidentiality of survey respondents and require a certain number of responses in order to report data. Given these considerations as applied to small populations, what number of responses would you feel are to low to report?
7. What are some strategies that DHHS could use to increase the capacity? for ANHOPI researchers and organizations to conduct health disparities research, demonstrations and evaluations?
8. Please describe the strategies that DHHS could use to support relationships between universities, academic researchers, communities and State and local health entities.
9. Are there any accountability mechanisms you recommend that DHHS could institute to ensure the development and maturation of these partnership relationships?
10. How could DHHS support partnerships with ANHOPI communities to improve safety and quality in health care?

11. Do the race and ethnic guidelines from OMB have adequate utility for the ANHOPI populations or is there a need to collect information using other or expanded categories?

Agenda

	THURSDAY, MAY 22	
9:00-9:15 am	Call to Order and Introductions Review of Agenda Meeting Process	Vickie Mays, Ph.D., MSPH Chair
9:15-9:35 am	Diversity of the Asian, Native Hawaiian, and other Pacific Islander Populations	Dennis Arguelles, MA Assistant Director, UCLA Asian American Studies Center
9:35-9:50 am	Questions and Discussion	
9:50-10:20 am	Native Hawaiians and Mainland Hawaiians	Nolan Malone, Ph.D. PACE Kamehameha School
9:45-10:05 am	Questions and Discussion	
10:05-10:35 am	Data Issues in Asians, Native Hawaiians and other Pacific Islanders	Paul Ong, Ph.D. UCLA, Director of the Ralph and Lewis Goldy Center
10:35-10:55 am	Questions and Discussion	
10:55-11:40 am	Use of Census Data and Health Planning and Contextual Community Development in Support of Community Services	Melany Dela Cruz Asian American Studies Center UCLA, Census Information Coordinator Bong Vergara, MA, MSW Special Services Group PowerPoint Presentation
11:40-12:00 pm	Questions and Discussion	
12:00-1:00 pm	Lunch	
1:15-2:00 pm	Pharmacologic Differences in Asian Populations	Keh-Ming Lin, M.D. UC Harbor General, Director of the Center on the Psychobiology of Ethnicity
2:00-2:20 pm	Questions and Discussion	
2:20-2:40 pm	Break	
2:40-3:25 pm	Language and Translation Aggregation and Disaggregation	Ninez Ponce, Ph.D., UCLA School of Public Health and Co-Principal Investigator of the California Health

		Interview Survey
3:25-4:00 pm	Questions and Discussion	
4:45-5:00 pm	General Discussion & Wrap Up	Vickie M. Mays, Ph.D., MSPH
5:00 pm	Adjourn	

	FRIDAY, MAY 23	
8:50-9:00 am	Call to Order Welcome Introductions Summary of Previous Day	Vickie M. Mays, Ph.D., MSPH, Chair
9:00-9:30 am	Southeast Asians: Where's the Data and Why It is Needed	Naleem Gupta, M.P.H., MSW, Valley Care Community Consortium Pardeepta Upadhyah, Southeast Asian Network
9:30-9:45 am	Questions and Discussion	
9:45-10:35 am	Small and Geographic Populations Data Issues Hmong, Cambodian, Vietnamese	Marjorie Kagawa-Singer, Marjorie Kagawa-Singer, Ph.D, RN, MN, UCLA School of Public Health
10:35-11:00 am	Questions and Discussion	
11:00-12:00 pm	CRENCO/Policy Perspectives and Data Needs for Health Planning, Health Services	Ignatius Bau, California Endowment
12:00-12:20 pm	Questions and Discussion	
12:30-1:30 pm	Lunch	
1:30-2:30 pm	Other Pacific Islanders Mainland and Non Mainland	Mae Cruz Guenther, RN, Guam Communications Network (Chamorro) Kaiwi Victor Pang and Ka'ala Jane Pang, Native Hawaiian Civic Club (Native Hawaiians and Marshallese)
2:30-4:00 pm		Sala S. Mataalii, RN Chairman, Samoan National Nurses Association June Cruz Millington, Guam Communications Network
4:00-4:15 pm	Questions and Discussion	
4:15 pm	Wrap Up	
4:15 pm	Adjourn	

NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS
SUBCOMMITTEE ON POPULATIONS

Hearing on Health Data Needs for Asian, Native Hawaiian and Other Pacific Islander Populations
November 13-14, 2003

The Palace Hotel
2 New Montgomery Street
San Francisco, CA 94105

Hearing Questions

1. For Pacific Island populations, what techniques are used to collect data on race and ethnicity? How does language, population size or population geography impact the ability to gather data on the health status, health behaviors, and health experiences of these populations? What recommendations could you make to DHHS for addressing these issues?
2. Do you believe that there is a significant problem of misclassification of racial and ethnic categories in existing data sets? For which data sets? For which categories? What steps, such as possibly partnerships with advocacy groups, are in place for studying the issue and for making corrections?
3. Is data collected on ethnicity, language spoken and national origin in ongoing surveillance data sets? On what data sets are these data collected? Please provide examples.
4. What barriers exist to data collection, analysis and disease surveillance for eliminating health disparities in ANHOPI populations? Describe strategies that DHHS could use to remove those barriers.
5. Is data collected on ethnicity, language spoken and national origin in ongoing surveillance data sets? On what data sets are these data collected? Please provide examples. What types of health data would you recommend that DHHS collect?
6. Current data collection methods eM.P.H.asize the protection of the privacy and confidentiality of survey respondents and require a certain number of responses in order to report data. Given these considerations as applied to small populations, what number of responses would you feel are to low to report?
7. What are some strategies that DHHS could use to increase the capacity? for ANHOPI researchers and organizations to conduct health disparities research, demonstrations and evaluations?
8. Please describe the strategies that DHHS could use to support relationships between universities, academic researchers, communities and State and local health entities.
9. Are there any accountability mechanisms you recommend that DHHS could institute to ensure the development and maturation of these partnership relationships?
10. How could DHHS support partnerships with ANHOPI communities to improve safety and quality in health care?

11. Do the race and ethnic guidelines from OMB have adequate utility for the ANHOPI populations or is there a need to collect information using other or expanded categories?

Agenda

	THURSDAY, NOVEMBER 13	
9:00 a.m	Welcome and Introductions	Vickie Mays, Ph.D., M.S.P.H., Chair
9:05 a.m.	Overview of Subcommittee on Populations, NCVHS, Purpose for Hearing and Review of the Agenda	Chair
9:20 a.m.	A National Perspective on ANHOPI Health Data Needs	Christina Perez M.P.H., Regional Minority Health Coordinator, Region IX
9:30 a.m.	Overview of Pacific Island Health Data Issues	Christina Perez, M.P.H., Regional Minority Health Coordinator, Region IX
9:50 a.m.	Break	
10:00 a.m.	The Need for Detailed ANHOPI for Health Policy	Ho Tran, M.D., Asian Pacific Islander American Health Forum Policy Brief
Policy Brief		
10:20 a.m.	Accessing ANHOPI Data	Gem Daus, Asian Pacific Islander American Health Forum Census Information Center Census Data
Census Data		
10:40 a.m.	Questions and Discussion	Members and Staff
10:50 a.m.	Break	
11:00 a.m.	ANHOPI Measurement and Classification Issues	Elena Yu, Ph.D., The Johns Hopkins University
12:00 noon	Questions and Discussion	Members and Staff
1:00 – 2:15 p.m.	Lunch	
2:15 p.m.	Questions and Discussion	Members and Staff
2:45 p.m.	Subcommittee Deliberation of Testimony	Members and Staff
4:45 -5:00 p.m.	Adjourn and Closing Comments	

	FRIDAY, NOVEMBER 14, 2003	
9:00 a.m	Welcome and Introductions	Vickie Mays, Ph.D., M.S.P.H., Chair
9:15 a.m.	Healthcare Quality Indicators For ANHOPI Populations	Ellen Wu, California Pan Ethnic Health Network
09:35 a.m.	Asian Americans and Cancer	Scarlett Lin Gomez, Ph.D., Northern California Cancer Center
09:55 a.m.	Questions and Discussion	
	Health Data Needs for Pacific Islanders	
10:45 a.m.	Palau: Telephone Conference PresentationPalau **Telephone Conference** Presentation	Greg Dever, M.D., Director, Bureau of Hospital & Clinical Services Julie Tellei, Cultural Specialist, Palau Ministry of Health
11:15 a.m.	Questions and Discussion	
12:00 p.m.	Lunch	
01:00 p.m.	Hawaii	Catherine Sorenson, Ph.D., Dept. of Health, Hawaii
01::15 p.m.	Qualitative Data Issues for Native Hawaiians and American Samoans	Carol Murray, Dr.PH, University of Hawaii at Manoa Hardy Spoerhr, Executive Director, Papa Ola Lokahi Gerald Ohta, Hawaii Dept. of Health
01:45 p.m.	Questions and Discussion	Members and Staff
02:15 p.m.	Subcommittee Deliberation of Testimony	Members and Staff
03:30 p.m.	Next Steps – Adjourn	