



Health Brain Trust on Data & Research

Recommendations from 2007 and 2008



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Main Office: 450 Sutter Street, Suite
600, San Francisco, CA 94108
T 415-954-9988, F 415-954-9999

DC Office: 1828 L Street NW, Suite
802, Washington, DC 20036
T 202-466-7772, F 202-466-6444

www.apiahf.org

**Improving the Health and Well-being of Asian Americans,
Native Hawaiians and Pacific Islanders
April 29 - May 1, 2007
Washington, DC**

**Strengthening the Involvement of Asian Americans, Native Hawaiians
and Pacific Islanders in Community Based Participatory Research
May 1 - 2, 2008
Houston, Texas**

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EXECUTIVE SUMMARY

This document summarizes the recommendations and action items proposed by the participants of the 2007 and 2008 Health Brain Trust on Data & Research convenings.

Data and research are important tools in helping ensure access to quality primary and preventive services, especially for communities of color and indigenous people. There is a critical need for more data and research on the health of Asian Americans, Native Hawaiians and Pacific Islanders (AA and NHPI). The heterogeneity in languages, cultures, and approaches towards health all contribute to misperceptions about the community and its health and healthcare needs. Such misperceptions may be barriers to the provision of appropriate healthcare services and health education, and lead to the need for more data and research.

The Asian & Pacific Islander American Health Forum (APIAHF) is a national health policy organization for Asian Americans, Native Hawaiians and Pacific Islanders. APIAHF's mission is to advocate for greater recognition, inclusion and engagement of AAs and NHPs on policies and programs that are critical to the health and well-being of our diverse and vibrant communities. APIAHF has five policy priorities and one of them is to increase data and research on AAs and NHPs. APIAHF supports and promotes this policy in several ways including hosting the Health Brain Trust on Data & Research.

The Health Brain Trust on Data & Research convenes once a year and is organized around a particular topic of interest to AA and NHPI health data and research. The purpose of the meeting is to strengthen the understanding of AA and NHPI health data and research issues, develop new frames to address such data and research issues, explore different levers for change, and build consensus around an agenda for change. The HBT is a convening of selected participants consisting of community members, advocates, researchers, health professionals, public health officials, policymakers, and other leaders chosen for their experience and expertise depending

on the topic.

Thus far, there have been two meetings of the Health Brain Trust on Data & Research. So, each conference theme has been different but they have all fulfilled certain gaps in the data- and research-related issues of AA and NHPI communities.

The 1st Health Brain Trust on Data & Research convened in Washington, D.C., April 29 –May 1, 2007. The goal of this meeting was, *“To discuss data and research issues in the context of improving the health and well-being of Asian Americans, Native Hawaiians and Pacific Islanders, and general approaches to increasing data.”* This convening consisted of 53 participants from 9 states (California, Illinois, Maryland, Massachusetts, Michigan, New York, Pennsylvania, Texas, and Washington) and Washington D.C.

The 2nd Health Brain Trust convened in Houston, Texas, May 1-2, 2008. The goal of this meeting was *“To move forward the agenda to increase participation and action of researchers, communities, policymakers, and funders on Community Based Participatory Research on Asian Americans, Native Hawaiians and Pacific Islanders.”* This convening consisted of 41 participants from 11 states (Arizona, California, Georgia, Hawaii, Illinois, Maryland, Michigan, Minnesota, Ohio, New York, Texas) and Washington D.C. The meeting was held in Houston to increase geographic diversity. At this convening, experts strategized on community based participatory research (CBPR), which is important locally and nationally.

The collective experience and wisdom of the HBT participants resulted in highly informative presentations, insightful discussions, and actionable recommendations. Many recommendations were also made during panel discussions and small group breakout sessions at each convening.

APIAHF is committed to disseminating the results of these meeting, pursuing strategies, and taking action

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on the recommendations in partnership with the convening participants, as well as other community leaders and institutions who are interested in similar issues. APIAHF also supports and encourages the convening participants as well as other community leaders and institutions to pursue strategies to address these recommendations and action items.

The Health Brain Trust on Data & Research is sponsored by the Centers for Disease Control and Prevention and the W. K. Kellogg Foundation. For detail information related to specific sessions at the two convenings, please read the full proceedings from each meeting (available at www.apiahf.org).

Recommendations and action items prioritized at the two meetings are as follows.

The 2007 Health Brain Trust recommendations and action items:

I. Conduct Further Analysis and Dissemination of Existing Sources of Data

- There are many datasets yet to be mined. For example, analysis of health indicators in Healthy People 2010 shows that one-third are denoted “DNA” meaning data was collected but not analyzed for the AA and NHPI population. The reasons for such lack of analysis are many, including lack of funding and/or staff, confidentiality issues, and insufficient samples. Given the amount of data, conducting new analyses will require planning, prioritization and collaboration among agencies, researchers and community members, along with sufficient resources.

II. Conduct More Research, Nationally and Locally, and Address Sampling and Design Issues

- Improve ongoing surveys (i.e. National Health Interview Survey, California Health Interview Survey) and data collection systems (i.e. Medicare, hospitals, health plans, vital statistics, cancer registries), as well as initiating new research (i.e. for defined geographic areas or specific subpopulations).

- In order to yield sample sizes large enough for meaningful analysis, the effort to collect more data must address persistent sampling and design issues. It is also necessary to prioritize research questions with involvement and leadership from AA and NHPI communities, and to allocate funding towards data collection of small populations.

III. Strategic Advocacy and Communication Activities

- Strong advocacy and communication are essential to increase attention and resources dedicated to AA and NHPI health.
- Identify and nominate individuals to serve on federal advisory committees, peer review boards and other committees that influence data collection, survey (re)design and publication.
- Advocate for AA and NHPI data needs in other professional communities and associations beyond health care.
- Advocate for increased funding for the CDC National Center for Health Statistics.
- Develop web-based communications and networking space for AA and NHPI data stakeholders.
- Disseminate studies on AA and NHPI populations.
- Develop and disseminate guidance for translation and interpretation of surveys.

IV. Policy Assessment and Analysis

- Call for an HHS-funded report to revisit sample sizes being collected by subgroup.
- Monitor quality of data reporting from federal agencies and other institutions.
- Assess the compliance/adoption of the 1997 OMB Guidance relative to the NHPI category within HHS data sets.

The 2008 Health Brain Trust recommendations and action items:

I. Disseminate and Use Existing Sources of CBPR

- Create an electronic database and toolkit of existing CBPR models, best practices, successful CBPR projects, and funding resources, including

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translated instruments.

- Develop different types of publications such as a special journal issue (e.g. American Journal of Public Health) on CBPR on Asian American, Native Hawaiian and Pacific Islander health and healthcare issues highlighting successful models and how CBPR can benefit the community.

II. Build and Strengthen Community Capacity to Conduct CBPR

- Mentor community-based organizations to conduct CBPR.
- Provide training and education to strengthen community capacity for technical skills (i.e. grant writing and review, navigating federal system's grant administrative process, etc.), leadership skills, and partnering with academic institutions.
- Develop and mentor community Institutional Review Boards.

III. Build and Strengthen the Research Pipeline on CBPR

- Academic institutions and funding agencies need to support junior faculty and students interested in CBPR.
- Senior-level researchers need to be encouraged to mentor junior-level researchers and students on CBPR.
- Train researchers to learn best practices in working with and building trust with community groups.
- Develop pipeline programs for K-12 and college students to become CBPR researchers.

IV. Educate and Cultivate Relationships with Policymakers and Funders

- Request Institute of Medicine (IOM) reports on: CBPR, Asian American health, Native Hawaiian health, Pacific Islander health, and social determinants of health.
- Restructure review process so that review panels include qualified reviewers from the Asian American, Native Hawaiian and Pacific Islander community; submit reviewer list to NIH; and develop a mandatory training strategy for those who review CBPR proposals.
- Cultivate future/alternative funding sources. Contact and develop relationships with local and national funders. Funders should

include CBPR principles in their funding structure.

- Review national policy (e.g. past federal legislation and identify language for future bills) on CBPR, data and research, language access, Limited English Proficiency, literacy and enabling services, etc.

BACKGROUND

In 1985 the United States (US) Department of Health and Human Services (HHS) published its landmark Report on Black and Minority Health, which documented health disparities between certain ethnic/racial groups and the majority US population. The report was the catalyst for creating the HHS Office of Minority Health (OMH) next year to address these disparities. These two events paved the way for growth of a new line of research—the study of health disparities in communities of color—and laid the cornerstone for nearly a quarter-century of investigation of the complex relationship between race/ethnicity and health. However, the report was a setback for the Asian American, Native Hawaiian and Pacific Islander (AA and NHPI) community by claiming “.....the Asian Pacific Islander minority in aggregate is healthier than all racial/ethnic groups in the US including whites”. And due to its small size this population was categorized with “Other” races/ethnicities. This statement perpetuated the model minority myth that Asian Americans are healthy, wealthy, and wise. As a consequence, it would mean the federal government (and the newly created OMH) would not always recognize AAs and NHPs as underserved minorities, their needs would not be identified, much less addressed. Thus, the doors were effectively closed to investigators seeking funding to study health disparities in this population.

When OMH was created, the Federal government had an inconsistent record of counting and reporting health indicators for the AA and NHPI population. Although policy changes since 1986 have improved federal data collection and reporting policies and practices, problems nevertheless persist. While the 1997 Office of Management and Budget’s “Revisions to the Standards for the Classifications of Federal Data on Race and Ethnicity” created a new racial category, “Native Hawaiian and Other Pacific Islander”—separate from “Asian”—in federal data sets, this classification has not been universally adopted. At the state and local levels, the classification is rarely used. Executive Order 13166, “Improving Access to Services for Persons with Limited English Proficiency,” issued in 2000, led to a federal agency guidance encouraging collection of data on individual’s primary language. However, after nearly a decade, barriers continue to prevent

full implementation of the law. Thus, the AA and NHPI community’s healthcare needs sometimes fall below the surveillance “radar” with the consequence of disqualifying community-based organizations (CBOs) and researchers from applying for grants and receiving needed funding to address critical health disparities.

The OMB policy changes were made in 1997 and agencies were given until 2003 to change their data collection systems. Therefore, these changes are relatively recent and coupled with the normal lag from collection to reporting, and that means that data is still not available. This is most evident in Healthy People 2010, which is a set of health objectives for the nation to achieve over the first decade of the new century. Thus, when framing the objectives for AA and NHPI populations, many objectives were immeasurable because:

- “DNC” : data has not been collected at all
- “DNA” : data has been collected, but has not yet been analyzed
- “DSU” : data has been analyzed, but is not reported due to small sample size
- “- - -” : data not available

Asian American, Native Hawaiian and Pacific Islander health professionals and advocates responded to the problem of invisibility at the federal level by founding the Asian & Pacific Islander American Health Forum (APIAHF) in 1986. A national health policy and advocacy organization, APIAHF plays a crucial role in promoting its constituency’s interests by leading, coordinating, and assessing efforts to reduce—and ultimately eliminate—health disparities, thus leading to better health and well-being. APIAHF’s mission is to advocate for greater recognition, inclusion and engagement of AAs and NHPs on policies and programs that are critical to the health and well-being of our diverse and vibrant communities.

APIAHF has five policy priorities: increase access to healthcare, improve the quality of healthcare through cultural and linguistic competency, increase diversity in the healthcare workforce, increase investment in community-based health programs, and increase data and research on the AA and NHPI population.

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APIAHF supports and promotes its policy to increase data and research in several ways including hosting the Health Brain Trust on Data & Research.

Since the organization's inception in 1986, APIAHF has sponsored national health conferences focusing on the health needs of and disparities within the AA and NHPI population in 1986, 1988, 1990, 1992, 1994, 1997, 2001, 2004, 2006, and 2009. One of the most prevalent topics at the 2006 conference (with over 400 community members) was the need to address the data and research needs of AA and NHPI communities. This contributed to the development of the Health Brain Trust on Data & Research conferences.

Gaps in Data and Research

There are currently about 15 million AAs and NHPIs in the US (Khan et al. 2009). While some research has been conducted on specific diseases and access issues affecting AAs and NHPIs as a whole, or a specific ethnic group, within the past 20 years, the AA and NHPI population has tripled and diversified with political, economic, social and technological changes. About one out of every 10 Americans will be of AA or NHPI descent, within two generations from now. These demographic changes and increasing diversity create the need for further targeted research on specific AA and NHPI subgroups even more critical.

In the intervening decades some progress has been made in understanding the AA and NHPI population's major health problems, needs, and service gaps. Yet the community's disparate disease burden continues. For example, aggregate data show that AA and NHPI health insurance rates are similar to the white population; however, disaggregate data show that 31% of Korean Americans and 24% of NHPI are uninsured (Kaiser Family Foundation and APIAHF 2008). Anecdotal evidence suggests that obesity is >60% in many NHPI communities and diabetes rates are rising faster in the AA and NHPI population than in any other communities of color. These and other disparities warrant careful investigation to identify gaps in knowledge and develop appropriate interventions to reduce them.

Data collection, reporting, and dissemination are essential to identifying knowledge gaps and developing effective programs and policies to reduce health disparities. The heterogeneity in socioeconomic conditions, languages, cultures, immigration histories, and approaches to health all contribute to outsiders' misperceptions about the health and healthcare needs of AAs and NHPIs. Such misperceptions may be barriers to the provision of appropriate health services and health education, and contribute to the need for more data and research. This heterogeneity also indicates the need to analyze data by aggregated and disaggregated populations to understand the causes of the health disparities and inequities that affect this population.

The gaps in data and research on AAs and NHPIs can be attributed to multiple factors, including government and private-sector policy and funding practices. AAs and NHPIs comprise 4.9% of the U.S. population. Yet 2004 foundation funding to this group represented just 0.4% of all US foundation dollars, a slight increase from 0.2% between 1983 and 1990 (Asian American /Pacific Islanders in Philanthropy 2007). Between 1986 and 2000, only 0.2% of federal health-related grants and 0.01% of MEDLINE articles mention AA and NHPI communities (Ghosh 2003). These findings suggest that the AA and NHPI population receives a disproportionately low share of the nongovernmental funds distributed to the nonprofit sector and that it is both understudied and underserved by federal health initiatives. This is strong evidence that the population's healthcare needs have fallen below the radar of federal and private funders as well as researchers.

These deficiencies result in limited capacity to characterize the health status of AA and NHPI population. But as we endeavor to correct this, we must also improve our ability to explore not just in terms of incidence and prevalence of disease, but also in terms of social determinants of health (e.g. education, geography, income), immigration patterns and status, behavior patterns (e.g. nutrition, sex), acculturation, language, age, gender, healthcare access and utilization, and characterize the health of specific ethnic groups (e.g. Hmong, Samoan, Bangladeshi) not just in the aggregate.

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Research has in fact revealed considerable socioeconomic and health disparities among the AA and NHPI population. However, these types of research are few in number and there is still lack of crucial information about health issues that concern its members because very limited research has been conducted on specific diseases and access issues affecting them. Moreover, AA and NHPI communities consist of many ethnic groups that differ according to socioeconomic level, cultural beliefs, frequency of healthcare utilization, and immigration history. This diversity complicates the ability to characterize the health status of AA and NHPIs, and thus more data and research needs to be conducted to gain insight on the health disparities that affect this population.

Data collection (including subsequent analysis and dissemination) also allows us to identify when discrimination is occurring in the health care system and to ensure that discrimination does not continue. Thus, APIAHF advocates for data collection not for its own sake, but to achieve measurable improvements in health and healthcare. Accurate, timely, disaggregated, and representative data on AAs and NHPIs are vital to developing and monitoring programs and policies aimed at improving their health and well-being.

The Health Brain Trust on Data & Research

APIAHF's Health Brain Trust on Data & Research is an annual convening where a diverse group of experts—AA and NHPI community leaders, research scientists, advocates, public health officials, policymakers, and funders—discuss current research and identify solutions to data and research challenges that impact the health of the affected community. Issues, problems, and areas of knowledge are defined, explored, and clarified. Each year the HBT addresses a specific topic; thus, a new cohort of presenters and participants is selected to attend based on individuals' experience and expertise with the conference theme.

Health disparities are multifaceted and best addressed when approached by a multitude of stakeholders. At HBT conferences, stakeholders recognize their

interdependence and the need to understand each others' perspectives. This is a unique forum where scientists and community members come together with policymakers and funders to strategize about data and research issues that affect AA and NHPI populations. Whereas, typically, national meetings are convened by and for one constituency only—either academics or community leaders—in the HBT framework, community leaders identify priority data and research issues and researchers identify the most appropriate methodologies to study them (see Figure 1).

Figure 1: Logic Model for Health Brain Trust on Data & Research



The objectives of the HBT conference are to:

- Strengthen stakeholders' understanding of AA and NHPI data and research issues that affect the delivery of health services, health, and health disparities.
- Develop new frames to address data and research issues on AA and NHPI health and health disparities.
- Explore levers for change.
- Build consensus around an agenda for reducing health disparities in the AA and NHPI population

These objectives are modified each year based on the conference theme in coordination with which the

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program is planned.

In the theme selection process HBT makes every effort to fully engage and build consensus among its geographically-dispersed constituency. The topic of the HBT is determined by several factors utilizing APIAHF's well established protocol for ensuring accountability to the organization's key constituency, community-based organizations. Among these factors are new developments in the field and outcomes of the previous conference. All meetings convened by APIAHF are developed in this manner, in contrast to a traditional approach whereby an organization or funder announces a meeting topic without first soliciting interest from its constituency and identifying stakeholders' needs and priorities. So, each conference theme has been different but they have all fulfilled certain gaps in the data- and research-related issues of AA and NHPI communities.

For example, one of the discussions at the 1st HBT meeting in 2007 was the need for more Community Based Participatory Research (CBPR) on these communities. CBPR provides a foundation for communities to have an equitable voice in how research is conducted, which issues are addressed, and what questions are asked. As such, CBPR is a powerful strategy for promoting a community-relevant and culturally-appropriate approach to address health disparities and inequities. As such the theme for the 2008 HBT was CBPR.

Selecting the location of the HBT conference is also a strategic decision. Considerations such as raising visibility to policymakers, raising the profile of the AA and NHPI population in various locales, connecting national and local interests on a single platform, giving local experts national prominence, and providing opportunities for local experts/champions to participate in a national meeting they might otherwise be unable to attend are taken into consideration when selecting the location of the HBT convenings.

Thus far, there have been two HBT conferences. The

first HBT conference was held in Washington, DC to make an impact at the national level. Subsequently it was decided that the conference would be held in a different city each year to raise the visibility of local communities APIAHF works with, especially in ten states (AR, CA, GA, HI, MN, NY, OH, RI, TX, and UT) that are part of a capacity-development grant from the W.K. Kellogg Foundation.

The collective experience and wisdom of the HBT participants resulted in highly informative presentations, insightful discussions, and actionable recommendations. During the second day of each meeting, participants brainstormed on recommendations in small breakout sessions. The small breakout session was followed by a large group discussion to further clarify, refine, and prioritize the issues raised in the small groups. Many recommendations were also made during each panel discussion as well as the small group breakout sessions at each convening.

APIAHF is committed to disseminating the results of these meetings, pursuing strategies, and taking action on the recommendations in partnership with the convening participants, as well as other community leaders and institutions who are interested in similar issues. APIAHF also supports and encourages the convening participants as well as other community leaders and institutions to pursue strategies to address these recommendations and action items.

For detail information related to specific speaker sessions please read the full proceedings from the respective meetings (available at www.apiahf.org).

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Table 1: Health Brain Trust Conferences

Year	Goal	Objectives	Location	Participants	Area of Speaker Presentations
2007 (April 29 - May 1)	To discuss data and research issues that will lead to improvement of health and well being of AAs and NHPIs, and strategies to increase national-level data.	<ul style="list-style-type: none"> To examine the status of data collection and research related to AA and NHPi communities. To broaden participation in the national AA and NHPi health agenda from researchers, community members, advocates, health professionals, public health officials, academic institutions, think tanks, and other leaders. To share experiences and gain knowledge that enable participants to develop recommendations for future action. To identify policy and system levers for change related to AA and NHPi data collection and research. To develop and recommend policy strategies for increasing national and state health data on AAs and NHPis. 	Washington, DC	53 participants from 9 states (CA, IL, MD, MA, MI, NY, PA, TX, WA) and Washington, D.C.	<ul style="list-style-type: none"> Framing and overview of AA and NHPi health issues Models of national and state research Opportunities for AA and NHPi data collection, analysis and reporting Collecting and reporting data from health systems
2008 (May 1-2)	To move forward the agenda to increase participation and action of researchers, communities, policy-makers, and funders in Community-based Participatory Research (CBPR) on AAs and NHPis.	<ul style="list-style-type: none"> Discuss barriers for researchers and communities to conducting CBPR with AA and NHPi populations. Identify strategies for researchers and communities to overcome barriers to CBPR with AA and NHPi populations. 	Houston, TX	41 participants from 11 states (AZ, CA, GA, HI, IL, MD, MI, MN, OH, NY, TX) and Washington, D.C.	<ul style="list-style-type: none"> Models of Successful CBPR Barriers for Communities in CBPR Historical and Contemporary Issues in CBPR Barriers for Researchers in CBPR Review Process, Role of NIH Policy Issues in CBPR

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Recommendations from the 1st Health Brain Trust on Data & Research

April 29 - May 1, 2007, Washington, DC

“Improving the Health and Well-Being of Asian Americans, Native Hawaiians and Pacific Islanders”

The recommendations fall into the following broad categories:

- **Given the lack of national data, two general approaches to increasing data are to:**
 - I. **Look to existing sources of data for further analysis and dissemination**
 - II. **Conduct more research—nationally and locally—and address sampling and design issues.**
- **In order to move forward on the above recommendations, it continues to be necessary to gain political leverage via:**
 - III. **Strategic advocacy and communication activities**
 - IV. **Policy Assessment and Analysis**

What follows is a detailed list of recommendations in each broad category outlined above.

I. Look to Existing Sources of Data for Further Analysis and Dissemination

APIAHF’s analysis of the 22 leading health indicators in Healthy People 2010 shows that one-third (7 of 22) are denoted “DNA” meaning that data was collected but not analyzed for the Asian/Pacific Islander population in aggregate. There are many other datasets yet to be mined as listed in the text box “Existing data sets with AA & NHOPi populations.” The reasons for this lack of analysis are many, including lack of funding and/or staff, confidentiality issues, and insufficient samples.

For example, existing data sets with AA and NHPI populations [Compiled by Dr. Gilbert Gee]

- Asian Tobacco Education, Cancer Awareness & Research Survey (n=1174; PI-Dr. Grace Ma)
- California Health Interview Survey (n=4264 in

2001; n=3977 in 2003; PI-Dr. Rick Brown)

- Chinese American Psychiatric Epidemiologic Study (n=1700; PI-Dr. David Takeuchi)
- Filipino American Community Epidemiological Study (n=2200; PI- Dr. David Takeuchi)
- Korean American Community Health Survey, 1997 (n=1090; PI-Dr. Barbara Wismer)
- National Latino and Asian American Study (n=2095; PI-Dr. David Takeuchi)
- National Longitudinal Survey of Freshmen (n=959; PI-Dr.s Douglas S. Massey & Camille Z. Charles)
- Pilot National Asian American Political Survey, 2000-2001 (n=1218; PI- Pei-te Lien)
- South Asian Health Initiative (PI- Sapna Pandya)
- Survey on Disparities in Quality of Health Care, 2001 (n=669; PI- Mary McIntosh)
- 2004 assessment in Palau (100% household participation) (PI- Dr. Stevenson Kuartei)

Given the amount of data, conducting new analyses will require planning, prioritization and collaboration among agencies, researchers and community members. Resources will have to be allocated.

The Health Brain Trust 2007 offered several recommendations:

- A. Establish a national academic consortium of AA and NHPI researchers whose purpose would be to analyze selected data and research, and disseminate the findings. Funding can be allocated based on existing relationships with NIH and other government agencies
- B. Address sample size deficiencies in existing surveys by pooling several years’ worth of data and bridging data from different surveys. This can boost sample size and enable disaggregation

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across subgroups (provided subgroup data was collected in the first place).

1. NCI, NCHS, and other partners should provide guidance and conduct workshops for investigators to learn how to pool data and link existing databases.
2. Similarly, government agencies and research institutions can develop guidance for bridging datasets and databases. For example, a collaboration of NCI, NCHS and University of Michigan researchers are exploring combining information from BRFSS and NHIS to obtain small area estimates. Combining estimation procedures from various surveys helps to address noncoverage and non-response issues and to estimate prevalence rates of other factors. This collaboration plans to have a public website available at the end of the 2007 calendar year. In another example, RAND, with funding from the Office of Minority Health is investigating bridging methodologies in order to obtain greater precision in estimating AA and NHPI groups within the National Health Interview Survey (NHIS).

C. The Census Bureau should allow agencies and other researchers to correlate its data with Census surname and first name lists. NCI has funded an effort at the Census Bureau to develop surname and first name lists. It is almost complete; however, as of the date of this publication, it has not yet passed internal review.

D. HHS should ensure that it is consistently implementing OMB guidance on the 1997 Standards for Federal Data on Race and Ethnicity. HHS and OMB should develop additional guidance on presenting data to ensure that publications that show findings by race explicitly state the reason for data not being represented for any one of the minimum five race categories. Similar to the standard used by Healthy People 2010 (e.g. DNA, DNC,

DSU) this helps readers identify gaps in data and plan for future research needs.

II. Conduct More Research—Nationally and Locally—and Address Sampling and Design Issues

This means improving ongoing surveys and data collection systems, as well as initiating new research. Ongoing surveys include national and state population surveys such as the National Health Interview Survey or California Health Interview Survey. Data collection systems refer to Medicare, hospitals, health plans and other entities that process enrollment and claims data. Data collection systems also include vital statistics, cancer registries and other epidemiological surveillance tools and activities that are dependent on federal and state cooperation. New research includes special surveys for defined geographic areas (e.g. Pacific territories) or a specific subpopulation such as Native Hawaiians.

To yield sample sizes large enough for meaningful analysis, the effort to collect more data must address persistent sampling and design issues. As demonstrated by the NLAAS and CHIS, it is possible to focus on specific populations, overcome methodological issues, and produce data that takes causal and contextual factors into account. But, like the previous group of recommendations, it will be necessary to prioritize research questions with involvement and leadership from AA and NHPI communities, and to allocate funding towards data collection of small populations.

The Health Brain Trust 2007 offered several recommendations:

- A. Select specific national and state surveys to advocate for oversampling of Asian and Native Hawaiian and Other Pacific Islander populations. Recommend specific sampling methods and other design changes that will maximize the AA and NHPI samples in that survey. Develop an advocacy plan incorporating Congressional action, participation in federal advisory committees, and other avenues for

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influencing the design of the survey.

- B. Prioritize state and local research. Collect and analyze data by smaller geographic units such as counties or metropolitan statistical areas. Use geocoding for sample design and data analysis.
- C. Establish a NHOPI health survey with sufficient sample size to provide robust information and to improve understanding of the health and health care status of this subpopulation and subgroups. In tandem or to build support for this survey, the National Committee on Vital Health Statistics (NCVHS) Subcommittee on Populations should have a hearing to update its December 1999 report, Health Data Needs of the Pacific Insular Areas, Puerto Rico, and the U.S. Virgin Islands.
- D. Provide resources to states to analyze Medicare claims data by race and ethnicity. Doing so will provide state estimates, which will provide a more disaggregated picture for state and federal legislators and advocates at the state level to prove their case.
- E. Work with selected states and municipalities to encourage adoption of the 1997 OMB Standards for Maintaining, Collecting and Presenting Federal Data on Race and Ethnicity. States with large AA and NHPI populations should be encouraged to collect more than the minimum five race categories, and collect data on AA and NHPI subgroups. Community-based organizations in partnership with national organizations should advocate for this change.
- F. Work with selected health plans and hospitals to implement race, ethnicity and primary language data collection, and then to analyze the data for quality assurance purposes.
- G. The Centers for Medicare and Medicaid Services (CMS) and the Social Security Administration (SSA) should collaborate to improve its Medicare data.

- 1. The Social Security Administration and the Centers for Medicare and Medicaid Services should develop a program to collect data on race, ethnicity, and socioeconomic status at the time of enrollment in Medicare and for current enrollees.
- 2. SSA should collect information on race and ethnicity on Form SS-5 and through the Enumeration at Birth process using the 1997 OMB Standards.
- 3. CMS should evaluate the findings of recent studies of the effectiveness of using lists of surnames to identify the race and ethnicity of enrollees.
- 4. Medicare Advantage plans should be required to collect and report to CMS the race and ethnicity of all enrolled Medicare members.

H. Investigate ways to incorporate new technology in screening, data collection and analysis to yield granular data.

III. Strategic Advocacy and Communication Activities

The Health Brain Trust 2007 offered several recommendations:

- A. Identify individuals to serve on specific federal advisory committees, peer review boards and other committees that influence data collection, survey (re)design and publication. For example, the Committee on National Statistics of the National Academies (CNSTAT) works to improve the statistical methods and information on which public policy decisions are based.
- B. Advocate for AA and NHPI data needs in other professional communities and associations.
 - 1. The Association of State and Territorial Health Officers (ASTHO), National Association of City and County Health Officials (NACCHO) and Council of State and Territorial Epidemiologists (CSTE) may be helpful partners in developing

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- state policy campaigns.
- 2. Present at the annual meetings of the American Statistical Association, American Medical Association, American Nurses Association, National Governor's Association, and National Conference of State Legislators.
- C. Advocate for increased funding for the National Center for Health Statistics (NCHS). Provide specific recommendations to NCHS about what surveys and survey modules to save in an environment of flat funding.
- D. Develop a web-based communications and networking space for AA and NHPI data stakeholders to collaborate on research activities, share published and unpublished research and datasets, and provide mentoring opportunities for researchers.
- D. Widely disseminate studies to researchers and policy makers that document bias created when limited English proficient populations take surveys in English.
- E. Develop and disseminate guidance for translation and interpretation of surveys.

IV. Policy Assessment and Analysis

The Health Brain Trust 2007 offered several recommendations:

- A. In 2000, the HHS Assistant Secretary for Planning and Evaluation (ASPE) produced a report with analytic sample size by subgroup. But, due to reduced funding, many national surveys have since reduced sample sizes. Call for a follow-up ASPE funded report, to revisit the sample sizes being collected by subgroup, either through HHS or through Congressional action.
- B. Monitor quality of data reporting from federal agencies and other institutions. Develop an award to present at the biannual APIAHF Voices conference for an agency/branch that does this effectively and stands out. Develop a report card of agencies.
- C. Assess the compliance/adoption of the 1997 OMB Guidance relative to the Native Hawaiian and Other Pacific Islander category within HHS data sets.

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Recommendations of the 2nd Health Brain Trust on Data & Research May 1-2, 2008, Houston, Texas

“Strengthening the Involvement of Asian Americans, Native Hawaiians and Pacific Islanders in Community Based Participatory Research”

The recommendations fall into the following broad categories:

- I. Disseminate and Use Existing Sources of CBPR
- II. Build and Strengthen Community Capacity to Conduct CBPR
- III. Build and Strengthen the Research Pipeline on CBPR
- IV. Educate and Cultivate Relationships with Policymakers and Funders
- V. Promote Community Advocacy and Communication Activities

What follows is a detailed list of recommendations in each broad category outlined above.

I. Disseminate and Use Existing Sources of CBPR

Many communities have already conducted needs assessments using a CBPR approach, resulting in data specific for their communities. However, such projects are difficult to find and identify because they are not often published in prominent journals or not published at all. Therefore, many participants noted the importance of disseminating findings from CBPR projects and the practices of CBPR to not only Asian American, Native Hawaiian, and Pacific Islander communities, but also to the broader scientific community.

The Health Brain Trust 2008 offered several recommendations:

- A. Create an electronic database/clearinghouse/toolkit of existing CBPR models, best practices, successful CBPR projects, and funding

resources, including translated instruments.

- B. Develop different types of publications such as a special journal issue (e.g. American Journal of Public Health) on CBPR on Asian American, Native Hawaiian, and Pacific Islander health and healthcare issues highlighting successful models and how CBPR can benefit the community. Develop a journal on Asian American, Native Hawaiian, and Pacific Islander health and healthcare issues.
- C. Disseminate CBPR research and findings through local and national networks (i.e. Community Coalitions, Departments of Health, Academic Centers, and American Public Health Association Caucuses).
- D. Build relationships with international organizations who have conducted CBPR projects with Asian American, Native Hawaiian, and Pacific Islander communities (e.g. PRIA (Society for Participatory Research in Asia)).
- E. Develop a research listserv specific to the Asian American, Native Hawaiian, and Pacific Islander communities or incorporate such a listserv into an existing one such as for Community Campus Partnership for Health or the Asian Pacific Islander Caucus of American Public Health Association.

II. Build and Strengthen Community Capacity to Conduct CBPR

Communities have historical and current knowledge of the histories, health and healthcare issues, and needs and wants of their communities. However,

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they often do not have the knowledge or technical skills regarding standard research protocols, jargon, timelines, etc., to conduct research that the scientific community will validate. Therefore, building and strengthening community capacity to address these issues is vital.

The Health Brain Trust 2008 offered several recommendations:

A. Mentor community organizations to conduct CBPR.

1. Utilize existing models and trainings and mentor and develop a model for Community Based Organizations (CBOs), community health centers, community coalitions, faith based organizations, cultural and religious associations, and other mutual aid societies in various aspects of CBPR for the benefit of the community.
2. Learn from CBOs or academician/researchers who are already experienced in conducting CBPR.

B. Provide training and education to develop community capacity on technical skills, leadership skills, and partnering with academic institutions.

1. Overall training on how to administer and navigate the federal system's grant processes.
2. Grant Writing: Mentor CBOs on grant writing with regards to federal requirements and those of national foundations and philanthropic organizations.
3. Grant Review: Host a research/community reviewer workshop to help communities understand the review process of IRBs and grants.
4. Mentor CBOs on what federal agencies and national foundations look in community evaluation.
5. Training on if, when, and how to partner with academic institutions.
6. Skills building. CBOs need to know the vocabulary of the academic environment

in order to assert themselves and communicate effectively in an academic/institutional setting.

7. Build coalitions, within and across communities of color.

C. Develop and mentor community Institutional Review Boards (IRB).

1. Conduct IRB trainings.
2. Help communities understand the concept of human subjects' protection, confidentiality, and other ethical research issues.
3. Support organizations that have successfully set up IRBs; Provide opportunities for them to offer experiences to other CBOs in the planning/organizing process of similar IRBs.

III. Build and Strengthen the Research Pipeline on CBPR

On account of cultural and language barriers, many Asian American, Native Hawaiian, and Pacific Islander communities have historically not been active participants of traditional scientific research. CBPR with its "participatory" component is much more appealing to the communities. However, data sources from CBPR are not always seen as valid models of research.

Many participants of the Health Brain Trust stated that CBPR has sometimes struggled to maintain credibility within mainstream science. Many researchers, such as Barbara Israel, Meredith Minkler and other leading scholars of CBPR have laid the groundwork for CBPR. However, funding of CBPR projects can be uneven, particularly when reviewers are unfamiliar with CBPR principles. Moreover, there is the reality that CBPR often requires a large time commitment and often moves at a slower pace than other research projects. These constraints may dissuade newer investigators, particularly untenured ones, from embracing CBPR.

The Health Brain Trust 2008 offered several recommendations:

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- A. Academic institutions and funding agencies need to support/mentor junior investigators and students interested in CBPR.
- B. Senior-level researchers need to be encouraged to mentor and outreach to junior-level researchers and students on CBPR.
- C. Develop training for researchers to learn best practices in working with and building trust with community groups. Ensure such trainings are a core part of school curriculums and professional licensures (e.g. ASPH Accredited Schools, CHES Certifications, etc).
- D. Develop pipeline programs for K-12 and college students to become CBPR researchers. Work with local K-12 schools, community colleges and 4-year universities, schools of public health, academic institutions, to incorporate a health disparities curriculum into the classroom.
- E. Look to existing programs, such as the Asian American Students Leadership Projects for curriculum to encourage youth to enter health professions.
- F. Build a speaker's bureau of Asian American, Native Hawaiian, and Pacific Islander researchers who can mentor CBOs in the research process.
- G. Develop metrics/indicators and evaluation models to establish the benefits of CBPR as an effective way to address health disparities (e.g. cost, cultural competency, language access, community impact, etc.).

IV. Educate and Cultivate Relationships with Policymakers and Funders

Educating and cultivating relationships with policymakers and funders are key to developing the capacity of community organizations and researchers to conduct CBPR, and for CBPR to be supported and included in funding announcements. This requires

continued policy analysis, assessment, and advocacy. Policy principles regarding data and research may be discussed and debated with bills introduced, but not authorized on the federal level. Also, they may be authorized but not enforced. With a challenging policy environment, a worsening economy, and the constant fight against anti-immigrant policies the ongoing need to address policy changes via federal and academic institutions, foundations and the like are important to increase the data and research for Asian American, Native Hawaiian and Pacific Islander communities.

The Health Brain Trust 2008 offered several recommendations:

- A. Cultivate future/alternative funding sources. Contact and develop relationships with local and national funders.
 - 1. For example, connect and meet with Asian American/Pacific Islanders in Philanthropy (AAPIP) regarding the importance of funding for research and data collection in the community.
- B. Request the Department of Health and Human Services (DHHS) and the National Institutes of Health (NIH) to prioritize CBPR on Asian American, Native Hawaiian, and Pacific Islander populations.
 - 1. Request Institute of Medicine (IOM) reports on: CBPR, Asian American health, Native Hawaiian health, Pacific Islander health, social determinants of health, and developing standards of data collection for small populations.
 - 2. Ensure representation from the Asian American, Native Hawaiian, and Pacific Islander community in federal agency activities (e.g. Office of Minority Health (OMH), National Health Disparities Blueprint, and NIH December 2008 Conference).
 - 3. Compile lists of Asian American, Native Hawaiian, and Pacific Islander reviewers (including current and potential scientific, clinician, and community reviewers) and

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submit to the NIH, the Center for Scientific Review, and other DHHS Agencies.

4. NIH needs to develop a mandatory reviewer training strategy for those who review CBPR proposals that includes training on language access and cultural competency issues.
5. Increase capacity of governmental translation

C. Restructure the review process so that review panels include qualified reviewers from the Asian American, Native Hawaiian, and Pacific Islander communities.

D. Review national policy (e.g. past federal legislation and identify language for future bills) on CBPR, data and research, language access, limited English proficiency, literacy and enabling services, etc.

E. Request Health Resources and Services Administration (HRSA) to include disaggregated racial/ethnic groups and primary language data, as well as their cross-tabulations with other demographic and utilization data in their Uniform Data System.

F. Request the Associated Schools of Public Health (ASPH) support CBPR research on Asian American, Native Hawaiian, and Pacific Islander populations, and to support the pipeline of researchers.

G. Find champions at local universities to conduct research with local communities.

H. Funders should include CBPR principles in their funding structure.

V. Promote Community Advocacy and Communication Activities

CBPR is extremely effective when community partners are committed to taking action for social and economic justice. Building trust is essential to an effective and realistic CBPR project to produce useful

results. It is important that the community starts with their issues and goals and discusses how they are going to be accountable to the community before academia and institutional rules come into play. It is also important for the community to advocate for themselves and to hold other partners accountable. The media also plays a pivotal role in informing, educating, and motivating people through various forms of communication channels.

The Health Brain Trust 2008 offered several recommendations:

A. Begin at the local level:

1. Communities need to find commonalities that bring groups together via social activities or town hall forums before talking about possible data and research projects.
2. Bring local community leaders together to talk about needed data and research and develop champions for research and data projects. Have community leaders bring discussion to and from and to their communities. Communities identify what data and research are available and needed at the local-level. Identify any natural alliances, activities or existing resources.
3. Conduct community trainings on components of data and research (e.g. CBPR).
4. Conduct a community assessment and some pre-research before applying for funding. Gather community-level information to support funding application requests.
5. Facilitate the participation of staff from local community organizations in community explorations and coalition building. Encourage as well as provide time and funding for local community organizations staff to participate in such community explorations and coalition building.

B. Move from internal community partnerships

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to partnerships with those outside the community:

1. Identify trusted champions to participate in trainings, establish partnerships with outside organizations, and cultivate relationships with funders and follow-through with the community research process.
2. Identify and form coalitions across communities of color, partner with like-minded organizations, and partner with geographically close organizations.
3. Communities need to ensure that grants demonstrate commitment and funding to support regular meetings, an agreed upon site, revisit goals throughout the project, and commit funds to building the capacity of community participants to learn more about research and disseminate research findings.
4. Identify champions to participate in IRB and review processes.

C. Communication Activities:

1. Develop a local communications network (i.e. listserves, newspapers, websites) with regards to Asian American, Native Hawaiian, and Pacific Islander health/healthcare issues, including data and research.
2. Engage individuals from the media, both mainstream and ethnic specific, in participation at local community activities.
3. In partnership with media representatives, develop press releases and media advisories on events and research within local community for the media.
4. Develop presentations on the work within local community to present at local, state, and national conferences.
5. Engage respective local, state, and national government representatives regarding community successes and needs.

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