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AAPI Nexus: Policy, Practice and Community

Title

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Journal

AAPI Nexus: Policy, Practice and Community, 9(1-2)

ISSN

1545-0317

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Publication Date

2011

DOI

10.36650/nexus9.1-2_176-183_GorEtAl

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Peer reviewed

Collection of Local Asian American Health Data Closes Health Disparity Gaps

Beverly J. Gor and Lovell A. Jones

Summary

Lack of disaggregated health data for Asian Americans and Pacific Islanders (AAPIs) continues to be a barrier to identifying and addressing health disparities in the AAPI population. Because the AAPI population is relatively small, health surveillance groups frequently overlook or disregard them in their data collection, often citing that AAPIs are “difficult to reach,” or that it is too costly to include them in data sets. This brief addresses these barriers and demonstrates that when there is sufficient support from policymakers, committed academic partnerships, and genuine engagement of the community, scientifically sound health data can be collected in a cost efficient manner. Such data not only identifies health needs, but also may generate significant benefits to communities, health planners and researchers and can lead to funding to address those needs.

Introduction

The lack of disaggregated data on the health status of Asian Americans and Pacific Islanders (AAPIs) has been a persistent barrier to understanding the health issues and disparities that impact these populations (Ghosh, 2010). The paucity of useful information on the health concerns of AAPIs continues to perpetuate the myth of the model minority (Lee et al., 2011). Agencies responsible for health data collection cite the relatively small size of the population, language barriers, inadequate funding, and the perception of AAPIs as “difficult to reach” as reasons for not collecting health data among AAPIs (Ghosh, 2003). However, one might argue that this omission is a matter of social equity—especially in light of recent statistics that reveal how the AAPI population has increased

dramatically during the last decade, and particularly in new geographic areas (*Asian Week*, 2011).

Several organizations have successfully collected scientifically sound data on small populations of AAPIs. These projects include the Vietnamese Behavioral Risk Factor Survey (Luong, 1999), the King County Ethnicity and Health Survey (Epidemiology Planning and Evaluation Unit, 1995–6), the California Health Interview Survey (Yu, Huang, and Singh, 2010), Health Needs Assessment in Maryland (Lee et al., 2011), a Filipino diabetes prevalence study (Cuasay et al., 2001), monographs such as the Pacific Islander Pipeline, (Tran et al., 2009), and the Community Health Needs and Resource Assessment series in the New York Metropolitan area (Abesamis-Mendoza et al., 2007; Ahn et al., 2007a, 2007b; Ngo et al., 2007a, 2007b).

Until 2005, there was little available data on the health status of the Asian American community in Houston although its Asian American population was among the top fifteen largest in the United States and Texas had the fourth-largest AAPI population in the United States (Yi, Gor, and Hoang, 2004). Through collaborations between the research community (the Center for Research on Minority Health [CRMH] at the University of Texas M.D. Anderson Cancer Center) and community organizations, such as the Asian American Health Coalition, the Chinese Community Center, and VN Teamwork, which are supported by funding from the Centers for Disease Control and other sources, a telephone survey including more than four hundred Chinese and four hundred Vietnamese randomly selected households was conducted. This project generated data documenting the health and cancer needs of these two rapidly growing Asian subgroups. It also identified the educational and health care needs of the Chinese and Vietnamese communities, guiding the development of culturally and linguistically appropriate health programs and services.

Community organizations and other researchers utilized the data to write grant applications, which led to the development of additional health research and educational programs. One successfully funded application provided support to develop the capacity of Asian American community members to advocate for social justice in health care access and language services. Another successful application supports and evaluates cancer education among Asian Houstonians. This project demonstrated that an investment in lo-

cal data collection supported by policy makers, researchers, and community members can reap long-term, sustainable benefits for the Asian American community by expanding health care access, health literacy, and empowerment. This model may be useful in other communities to bring attention to the unique health issues of local AAPI populations and to develop sustainable and relevant programs to address them.

Methodology

In 1999, Congress funded the creation of the CRMH at the University of Texas M.D. Anderson Cancer Center. Among the key legislators supporting the CRMH was Senator Daniel Inouye, who insisted that one of the deliverables for the new center was to conduct an Asian American Health Needs Assessment (AsANA) in Texas.

To begin this process, CRMH researchers consulted with the Texas Department of State Health Services, specifically the individuals coordinating the Behavioral Risk Factors Surveillance System (BRFSS). State officials recommended the use of a telephone survey instrument called the Texas Community Health Survey (CHS), which was similar but more concise than the BRFSS. They suggested that it might be more acceptable to the Asian American population because it took less time to administer than the full BRFSS and because the Asian American population might be reluctant to participate due to their lack of familiarity with health surveys. It had also been used to collect health data from the Spanish-speaking population living along the Rio Grande Valley border, another rapidly growing minority U.S. population. Data from the proposed Asian CHS could be compared with the data collected from the survey along the border and data from other BRFSS-based studies to identify differences in health risks among populations in Texas.

An extensive literature review by the research team confirmed that few health studies were conducted on the Asian population in Texas, although several surveys had been conducted in other regions of the United States with large Asian American populations. They contacted the investigators in those studies regarding the logistics of carrying out an Asian health survey. One of the recommendations was to coordinate a media campaign prior to the implementation of the survey in order to improve participation rates. Experienced researchers also provided estimates of antici-

pated response rates, projected costs, and time frames. They also identified telephone survey companies with Asian-language capability and shared their survey instruments with the CRMH team.

Throughout a two-year period, the survey instrument was developed and refined to ensure its linguistic and cultural relevance through focus groups with content experts and community members and through several pilot tests, both in-person and over the telephone (Gor et al., 2007).

Findings

The AsANA data collection was completed over a nine-week period. More than four thousand phone calls were placed. Callers were successful in reaching approximately 2,500 community members, resulting in complete data collection on a statistically representative sample of 405 Chinese and 409 Vietnamese households randomly selected from Harris, Fort Bend, Brazoria, and Galveston counties. Highlights of the results were disseminated to the community in a simple, downloadable PDF format (Hoang et al., 2006), and peer-reviewed manuscripts are in preparation. Some noteworthy data from the AsANA study are:

- More than 90 percent of the Chinese and Vietnamese in the Greater Houston area were immigrants versus U.S.-born.
- Less than 50 percent of the Vietnamese respondents spoke English well and only 61 percent read English well. More than 95 percent of the Chinese and Vietnamese reported speaking Chinese or Vietnamese well.
- Approximately 20 percent of the Chinese and more than 30 percent of the Vietnamese participants lacked health insurance.
- Sixty-two percent of Chinese respondents reported no leisure-time physical activity.
- More than 92 percent of Vietnamese respondents reported consuming less than five servings of fruits and vegetables per day.
- Chinese and Vietnamese participants had lower screening rates for colorectal, cervical, and prostate cancer than Anglos, blacks, and Hispanics in Texas.

Recommendations

The Houston AsANA study was able to overcome the commonly cited barriers to local data collection, because several factors

helped to propel the project forward. These included the significant growth of the Asian American population in Texas; support from policy makers, community members, and culturally informed researchers in academia; coordination of the project through a collaboration that included individuals embedded in and knowledgeable of the communities involved; and adequate funding.

For communities seeking to conduct similar projects, we recommend becoming familiar with data sources, such as the 2010 Census, local health and surveillance agencies, state demographers' offices, university-conducted research, and national Asian American advocacy groups. These organizations can provide technical assistance in identifying the gaps in local Asian American data and suggesting scientifically sound data-collection methods so that results can be compared with that of other population groups. Academic institutions may also provide assistance with statistical and data-analysis services.

For very small Asian American populations, other data-collection methods such as focus groups, key informant interviews, or online surveys might be considered. These methodologies may be less costly than telephone surveys, and because many Asian Americans are abandoning landlines and solely depending on cell phones (Magazine Publishers of America, 2004), telephone surveys may become obsolete or irrelevant for Asian American populations.

Linguistically and culturally competent staff and community members should be engaged to develop a customized data-collection instrument. Each Asian American community may have significant differences in regional dialects or low health literacy, resulting in respondents misinterpreting questions and the subsequent collection of inaccurate data. Survey questions must be thoroughly pilot tested to ensure comprehension by respondents and instruments should be validated with Asian American populations. Dependence on volunteers or students for data collection is not recommended. Interviewers and focus-group facilitators should be trained as skilled professionals and in the protection of human subjects, including confidentiality and the ethical conduct of research.

In our experience, Asian Americans were not "difficult to reach." We attribute this ease of entry into the Asian community to the fact that the study coordinators were already embedded in Asian community organizations and had a history of community involvement. We also believe that the media campaign, which in-

cluded ethnic and mainstream radio and television, distribution of bilingual flyers, and announcements at Asian community meetings conducted prior to the launch of the survey, prepared and encouraged the community to respond.

We were fortunate to have political and financial support for the infrastructure and personnel to coordinate this project. Additional support was provided by the National Center (now Institute) for Minority Health and Health Disparities through a P60 grant. At that time, the CRMH was also affiliated with the Asian American Network for Cancer Awareness, Research and Training, which also provided support. Finally, a pharmaceutical company provided support in exchange for including questions on the survey instrument that were of interest to them. In the current era of fiscal constraints, plans to conduct assessments in additional Asian subgroups may require more innovative approaches to funding, including fundraising from the individual communities.

The AsANA study demonstrates that the collection of local Asian American data can narrow health disparity gaps. It has exponentially increased the health programs targeted at Asian Americans in Houston. The results of the AsANA study have been used to apply for funding to develop and evaluate programs to address hepatitis B, cervical cancer, breast cancer, cancer survivorship, tobacco cessation, and access to care. However, the collection of local health data requires committed personnel, community and political support, and sufficient time and funding. Communities that are dedicated to improving the health status of AAPIs can do so if policy makers make such objectives a priority.

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