

Health Equity through Enhanced Data

LEVERAGING COMMUNITY COALITIONS TO IMPROVE ASIAN AMERICAN, NATIVE HAWAIIAN, AND PACIFIC ISLANDER HEALTH DATA

BRIEF

The paucity of data on Asian American, Native Hawaiian, and Pacific Islander (AA and NHPI) health is a critical barrier that hampers community and policy efforts to address the needs of AAs and NHPIs. Data and research are important tools that can help policymakers ensure adequate and meaningful resources to improve health for all. In an effort to address the dearth of data, the Asian & Pacific Islander American Health Forum (APIAHF) launched the Health Equity through Enhanced Data (HEED) project with the support of the U.S. Department of Health and Human Services Office of Minority Health under a National Umbrella Cooperative Agreement. APIAHF worked with the lead agencies of community-led coalitions in five states to compile, review, and evaluate available existing state and local data sources on AA and NHPI health in their states, and conduct case studies of their own initiatives to improve data on AAs and NHPIs within their states and to disseminate their findings with state and local policymakers. This report provides a summary of HEED activities and lessons learned from the national and state perspectives.

EVALUATING DATA SOURCES IN FIVE STATES

APIAHF conducted an extensive literature search online to identify AA and NHPI data sources in the five states where the community coalitions were located: Arizona, Georgia, New York, Ohio, and Texas. The inclusion criteria for data sources that were evaluated include reporting: 1) health outcomes, physical or mental; 2) health care access and utilization; or 3) social determinants of health (e.g., income, education, and English language proficiency). Data sources were compiled from websites of various government agencies, community-based organizations, research centers, and universities across these states. Most of the 112 data sources APIAHF identified were online publications (91%), and only a small number of them were online data query systems (8%) and presentations (1%). Many of the data sources provided little specific information about the data used, failing to report, for example, sample sizes and languages used in administering the surveys.

AA and NHPI Data Were Seldom or Inconsistently Reported

The ways in which AA and NHPI data were reported differed across data sources. Only 36% of the compiled data sources reported data for AAs and even fewer, 20%, reported data for NHPIs. Additionally, 32% combined the AA and NHPI racial groups using the outdated “Asian & Pacific Islander (API)” category. Ethnicity-specific data (e.g., Chinese, Filipino) were reported in only a minority of the data sources (20%). Three states had a small number of data sources that reported data disaggregated by ethnicity—New York (12%), Ohio (35%), and Texas (22%)—however not a single data source reviewed from Arizona and Georgia reported any ethnicity-specific data even though both states are among the top five states that experienced the highest growth of AAs between 2000 to 2010. In data sources reporting ethnic-specific data, Asian Indian, Chinese, Filipino, Japanese, Korean, and Vietnamese, the largest AA ethnic groups in the U.S., were the most prominent ethnicities for which data was available. There were no data reported for any NHPI ethnic groups in any of the five states. A majority of data sources reporting AA, NHPI, or API data did not specify how race was defined—specifically, whether “alone” or “in combination with other race” was used—an important omission given the fast-growing multiracial populations among AAs and NHPIs.

Data sources from the five states reported a variety of health and demographic characteristics. Nearly all data sources included health outcomes (89%). The most frequently reported indicators of health outcomes were cancer (46%), followed by maternal and child health (30%), heart disease (26%), and diabetes (25%). Health insurance coverage was reported in 30% of the data sources, followed by usual source of care (25%) and preventive care (16%). Among health behaviors, alcohol or tobacco use (30%) was reported more frequently than other health behaviors such as overweight/obesity (25%) and physical activity (15%).

CASE STUDIES OF SUCCESSFUL COMMUNITY-LED INITIATIVES THAT IMPROVED DATA ON AA AND NHPI HEALTH

Five community coalitions are featured in this report: Coalition for Asian American Children & Families (CACF) in New York, Reaching Asian Americans through Innovative and Supportive Engagement (RAISE) in Ohio, the Georgia Asian Pacific Islander Community Coalition (GAAPICC), Health Through Action Arizona (HTAA), and the Asian American Health Coalition (AAHC) in Texas. The main thrust of all five data initiatives came from the community recognition that existing data collection and reporting efforts (or the lack thereof), are inadequate to demonstrate the health and health care needs of diverse AA and NHPI communities, and therefore hampered government and community efforts to address them as priorities in government resource allocation are driven by data. Their experiences offer lessons on how communities can engage in improving the collection and reporting of data on the health of AAs and NHPIs and other small populations.

Coalition for Asian American Children & Families (CACF) in New York

Recognizing that the existing data collection regime in New York State was ill-equipped to ensure equitable distribution of resources to prioritize the needs of AA, NHPI, and other small populations, CACF mounted a state-wide campaign in 2012 to focus attention on the need for improved data disaggregation. The “Invisible No More” campaign set a goal to pass state and local legislation requiring the standardization of data, advocating, most prominently, for the use of 18 AA and 4 NHPI ethnic categories, as well as the scheduled release of publicly-available health data. The coalition mobilized a broad-based network of organizations that served AAs, NHPIs, and other communities of color, as well as LGBT and disability communities and academic researchers who worked with elected officials to introduce State Assembly (A9792) and Senate (S7503) bills. Although the bills were not enacted, the campaign raised state-wide awareness of the need to improve data collection and reporting by government agencies and led to subsequent and current campaign efforts to push for the enactment of similar state and local legislation.

Reaching Asian Americans through Innovative and Supportive Engagement (RAISE) in Ohio

RAISE’s work was triggered by the inaccurate representation of AA health needs in the data collected and reported by the local county board of health in 2011. Attributing this to the limited participation of AAs in health surveys and the lack of culturally and linguistically appropriate instruments for AA communities, ASIA, Inc., the lead agency, brought together diverse stakeholders to collect quality data on their constituents by addressing these critical issues. ASIA, Inc. enlisted the county board of health in developing a culturally-tailored health assessment survey for AA communities and also worked with a non-profit community development corporation to investigate the built environment in the AA communities. RAISE then mobilized its community network to translate and administer the surveys in-language, Chinese and Korean. Through this work, RAISE increased policymakers’ awareness of the need to improve data on AA health (especially data disaggregated by ethnicity) in Ohio. Key findings from one of the surveys were also used to demonstrate to elected officials the need to improve street safety in order to promote physical activity.

Georgia Asian Pacific Islander Community Coalition (GAAPICC)

Supported by the Georgia State Legislature and the Governor's Council on Developmental Disabilities, the Center for Pan Asian Community Services (CPACS) led GAAPICC to conduct two consecutive research projects to demonstrate the health and health care access needs of Georgia's growing AA communities. Working closely with academic researchers at Georgia State University, CPACS developed and administered in-language surveys on the health and well-being of AAs, including a study that focused on a particularly vulnerable subgroup in the AA community, i.e., people with disabilities and their caregivers. CPACS reported key findings and articulated policy recommendations from the disability study in a white paper and presented key findings to developmental disabilities professionals including teachers, service providers, and therapists, as well as community members and policymakers, in order to raise awareness of disability issues and advocate for increased supportive services for the disability community. Thanks to this campaign, CPACS secured funding to develop local programs for the AA disability community.

Health Through Action Arizona (HTAA)

HTAA published a Data Book in 2008 compiling available data on AA and NHPI health to create an evidence base for progressive health policies and programs for AA and NHPI communities in Arizona. While working closely with Arizona State University faculty, Asian Pacific Community in Action (APCA), the lead agency, aimed to create a community-owned document of community health issues and resources. APCA enlisted local health practitioners to write articles on various health topics and pooled community resources to cover the design and printing of the report. The Data Book was unveiled at a symposium hosted by HTAA that engaged community leaders and activists in lively discussions of the issues covered and policies proposed in the publication. The Data Book became an important resource for various public and private entities such as the state and county health departments and the American Civil Liberties Union.

Asian American Health Coalition (HAAHC) in Texas

Prioritizing cancer as a critical health issue affecting the local AA and NHPI community, AAHC conducted comprehensive community health needs assessments and focus groups, and compiled and analyzed health services utilization data through HOPE Clinic it established to create an evidence base for cancer prevention work. They disseminated key findings through social media, local media, and at state and local conferences and meetings. As a result of this work, AAHC successfully secured additional private and public funding to expand screening activities and cancer education efforts and raised awareness of health disparity issues affecting Houston's AA and NHPI communities. In 2012, HOPE Clinic became a federally qualified health center (FQHC), greatly expanding its capacity to serve vulnerable AAs and NHPIs and members of other communities of color and low-income populations.

LESSONS LEARNED: FACILITATORS, BARRIERS, AND BEST PRACTICES

While the strategies used by the coalitions somewhat varied, there are significant commonalities both in the facilitators that led to their successes, as well as the barriers they encountered, some of which the coalitions successfully addressed. Lessons from their experiences will help guide future community-led coalition work to build an evidence base for advocating for their constituents.

Facilitators

The key factors that led to the success of these initiatives include: cultivating and leveraging a broad-based, multi-sector network to engage partners with expertise and capacity critical to the initiatives; progressive and tailored messaging that framed data improvements as an issue of advancing fairness and equity, which effectively mobilized coalition members and other key partners; learning from prior campaigns; and perhaps most importantly, strong and visionary leadership that effectively deployed these other elements to achieve the objectives.

Barriers

The key barriers that these community coalitions encountered in the course of these initiatives include the difficulties in securing resources to support the existing coalition network; varying degrees of readiness among coalition partners; challenges in effecting policy changes as informed by the findings of their projects, largely due to the lack of prior relationships or leverage with the entities with authority or resources needed to bring about changes; and erroneous perceptions among policymakers and researchers that AA and NHPI populations were “too small,” which undermined the coalition’s ability to push for improvements.

Best Practices and Successful Models of Collaboration

All five community-led initiatives featured in the report represent best practices, each of which offers lessons to communities in other states with similar profiles. For example, CACF took advantage of the relatively large AA communities in New York City to institute lasting, systematic changes that would improve future data collection and reporting to benefit AA and other small communities such as NHPs. In states such as Texas, Georgia, and Ohio with relatively small AA populations, AAHC, GAAPICC, and RAISE worked to collect primary data on the health of AA and NHPI communities to help the states better understand and assess the needs of their fastest growing racial groups. HTAA’s experience to compile data gleaned from the existing literature offers lessons to small AA and NHPI communities without the infrastructure of larger communities. Additionally, most of these coalitions made concerted efforts to raise local awareness of AA and NHPI health issues and health care needs to advocate for more resources, including developing and disseminating AA and NHPI data products (GAAPICC and HTAA), which is often the first step to address those needs.

Two broad successful models of collaboration emerge from the experiences of these coalitions, one involving partnerships with state and local governments (GAAPICC, RAISE, and CACF), and the other with academic researchers (CACF and HTAA). Both models point to the ways community coalitions can secure additional resources unavailable within existing community networks that are critical to the success of their campaigns. In particular, given the technical and financial resources government agencies can leverage, as well as their capacity to effect changes, collaborative relationships with government agencies are critical to improving AA and NHPI health.

CONCLUSIONS AND POLICY RECOMMENDATIONS

Findings from these case studies suggest that community organizations can play a leading role in collecting, compiling, and disseminating health data and key findings. Community coalitions that are familiar with their community conditions and can prioritize community needs might be able to effectively facilitate community participation in research on AA and NHPI health and to generate actionable knowledge to address those needs. To promote such work, we recommend the following:

- Existing data on AA and NHPI health tend to be inadequate to demonstrate health and health care needs of AA and NHPI communities. To ensure quality data, AA and NHPI data disaggregated by ethnicity should be collected and reported to reveal the distinct differences within the AA and NHPI populations and greater needs for some subgroups.
- Research studies on community health often lack community participation and relevance to community issues. Community-led efforts to investigate their own issues and to produce actionable knowledge should be promoted, and public and private funding need to be provided to legitimize and support such efforts.
- Public and private partnerships should to be promoted to facilitate multi-sectoral data collaborations to build and expand the evidence base for policy and community efforts to improve AA and NHPI health.