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An Opportunity to Partner with Community Organizations to Collect Data on Asian Americans

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Abstract

Background: There is a shortage of health data for Asian American (AA) populations. This shortfall may be improved through the involvement of AA-serving community-based organizations (CBOs).

Objectives: This study assesses the feasibility of and interest among CBOs in creating a AA community-based data registry.

Methods: Leaders of CBOs were interviewed to assess their current data collection framework and their attitudes towards a shared data registry.

Results: Qualitative analysis shows CBOs are active in data collection, find data to be instrumental to their mission, and are interested in contributing to a broader data registry.

Discussion: The inclusion of CBOs in large-scale survey efforts may indeed yield more valuable data regarding specific AA subpopulations relative to that which is currently collected by national survey efforts. Such a partnership would be beneficial to CBOs as well, as data collection challenges could be alleviated by the creation of a uniform data registry.

Keywords

Data collection; Community Based Participatory Research; Asian Americans

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ABSTRACT

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INTRODUCTION

Asian Americans (AA) are the fastest growing racial/ethnic group in the United States, passing 20 million in 2015 (Lopez et al., 2017). Despite this rapid increase in population growth, there remains a shortage of health data for AA populations both in aggregation and as more distinct ethnicities (Ghosh, 2003; Palafox & Kaanoi, 2000; Tendulkar et al., 2012). In a study on meeting Healthy People 2010 goals, only 0.2% of federal grants directly fund initiatives for AAs (Ghosh, 2003). The use of AA-specific data is essential in establishing a baseline for population health outcomes. For example, of the 16 goals of Healthy People 2010, existing publications on AAs only provided data on seven of these goals (Ghosh, 2003). A lack of basic health data creates barriers

to continuing research and efforts towards reducing healthcare disparities within the AA community.

The AA population is incredibly heterogeneous, comprising of individuals from 20 countries, and representing a wide range of health, social, and cultural characteristics among its many component ethnicities. Studies have shown that the lack of disaggregated data mask important disparities that persist for certain subgroups (Tendulkar et al., 2012; Yi & Trinh-Shevrin, 2015). For example, Asian Indians have higher rates of heart disease and diabetes (Enas & Senthilkumar, 2001) than the national average and Vietnamese Americans are eight times more likely to be diagnosed with liver cancer (Ramakrishnan & Ahmad, 2014). Socioeconomic differences vary significantly, with poverty rates ranging from 7.5 - 35%, depending on the subgroup (Lopez et al., 2017). Similarly, limited English proficiency (LEP) among the AA population averages 34% but vary significantly among Asian subgroups, from as low as 10% to upwards of 80% (Ramarkrishnan & Ahmad, 2014). Lastly, education levels also vary greatly among the Asian American population, with more than 50% of Indian, Malaysian, Sri Lankan, and Mongolian adults holding a bachelor's degree or more, while only 9-18% of Cambodians, Hmong, Laotians, and Bhutanese adults have achieved similar levels educational attainment (Lopez et al., 2017). These variations are of substantial significance as these sociodemographic factors are strongly associated with health outcomes (Enas & Senthilkumar, 2001; Palafox & Kaanoi, 2000; Ramakrishnan & Ahmad, 2014; Venkataramani et al., 2016). For these reasons, it is necessary to collect disaggregated data on AA subgroups (Hastings et al., 2016). Furthermore, the paucity of disaggregated data on AAs impedes efforts to identify potential variations in outcomes which may be influenced by socioeconomic indications, immigration history, language and cultural norms.

Unfortunately, the collection of granular data is not standard practice within most national health surveys. As seen in Table 1, the reporting demographics of five major national health surveys and the Illinois Behavioral Risk Factor Surveillance Study demonstrate that these instruments combine multiple AA ethnicities into the singular category of "Asian" or "Asian/Pacific Islander," even when more detailed information has been collected. There are several explanations for the lack of AA data within state and national datasets. First, it has proven difficult to obtain disaggregated data on the health status of AAs for lack of data collection instruments that have been translated into individual Asian languages. Most national health surveys, such as the National Health and Nutrition Examination Survey, are only conducted in English and Spanish. This is especially problematic for obtaining accurate data among AA populations, as 34% of AAs have limited English proficiency, representing the highest proportion of limited English proficiency among all minorities (Ramarkrishnan & Ahmad, 2014). Such a limitation may confound public health research efforts as limited English proficient individuals face greater challenges accessing healthcare and are more likely to report a lower quality of care (Weech-Maldonado et al., 2003). Therefore, by failing to conduct these national health surveys in accessible Asian languages, the data that is collected may be ineffective in identifying the needs of vulnerable patient sub-populations, thereby underestimating the burden of disease among Asian Americans (Waksberg et al., 2000).

Table 1. Major US surveys collected and reported demographics

Survey	Information collected	AA demographics surveyed	AA demographics reported	Survey administration languages
National Health and Nutrition Examination Survey (NHANES)	Variety of health conditions: Blood pressure, Cholesterol levels, Hepatitis B, Diabetes, Smoking status	Chinese, Filipino, Japanese, Korean, Asian Indian, Vietnamese, or Other Asian Pacific Islander	Asian	English, Spanish, Chinese, Korean, and Vietnamese
National Cancer Institute: Surveillance, Epidemiology, and End Results Program (SEER)	Cancer incidence and survival from population-based cancer registries	Asian/Pacific Islander	Asian/Pacific Islander	N/A
National Health Interview Survey (NHIS)	Health behaviors, insurance status, disease prevalence	Chinese, Filipino, Japanese, Korean, Asian Indian, and Vietnamese; or Other Asian Pacific Islander	Asian	English, Spanish, Chinese, Korean, Tagalog, Vietnamese
Behavioral Risk Factor Surveillance Survey (BRFSS)	Chronic health conditions, health awareness, substance abuse	Asian, Native Hawaiian, Other Pacific Islander	State dependent	English and Spanish, State dependent usage of interpretation line
BRFSS-Illinois	Childhood Asthma, Health Care Access, Pre-Diabetes, Sodium or Salt-Related Behavior	Asks for participant self-identification	None	English and Spanish, State dependent usage of interpretation line
United States Census	Location, Houshold income, education level	Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, Other Asian	Asian, Pacific Islander	English, Spanish, Chinese, Korean, Tagalog, Vietnamese

Moreover, national surveys may have difficulty reporting more granular data due to the difficulty inherent in recruiting participants in numbers sufficient to represent the sample sizes necessary to render statistically meaningful data. As such, these surveys can only perform analyses on the umbrella identifier "Asian" for reporting purposes (Aspinall, 2003). In their assessment of major federal data sets on minority populations, Waksberg and colleagues found that analysis by Asian or Pacific Islander subgroup is not possible for most federal data sets (Waksberg et al., 2000).

Data Collection Via Community-based Organizations (CBOs)

One effective means of increasing the representation of AA populations is to involve community-based organizations (CBOs) that have historically served these populations (Landey & Halpern, 2007). Community-based registries can overcome the barriers of language and small sample sizes found in national datasets by providing an opportunity for oversampling or cluster sampling (Hasnain et al., 2020) in their population's native language. Oversampling allows the selection of respondents to make up a proportionately larger share of a cohort and has been used for minority populations (Vaughan, 2017). For instance, the National Health and Nutrition Examination Survey (NHANES) began using oversampling to collect data from smaller populations, including Asian Americans. However, because of operational and sample design constraints, they only oversample Asians as a single group, limiting their ability to sub group specific data (Paulose-Ram et al., 2017). AA community-based data could serve as a supplement to that collected by national surveys, thereby increasing sample size and allowing researchers to differentiate between unique AA sub-populations (Holland & Palaniappan, 2012). Several communities have initiated data collection of their own populations. For example, the Navajo Tribe replicated the National Health Interview Survey, with response rates of 65-70 percent (*Navajo Epidemiology Center*, n.d.). In another instance, the Partnership for Healthier Asians combined an individual client survey and focus groups, implemented through eight community organization partners, to evaluate the implementation and dissemination of colorectal cancer screening recommendations (Kim et al., 2016). These examples highlight the use of community collaborations to expand on existing bodies of data, but there has been no exploration of using ongoing community data collection to build a data registry to contribute to the availability of disaggregated AA data. Collection and compilation of community data would create a new method through which to overcome the barriers of data collection of AAs while utilizing resources already in place. This project was created in response to concerns among AA community-based organizational leadership regarding the absence of high-quality data on their own populations. During prior meetings of the Partnership for Healthy Asians (PHA), an academic-community partnership funded by Agency for Healthcare Quality and Research, CBO leaders expressed a persistent challenge in data collection and raised interest in data-sharing across organizations. Specifically, AA leaders requested a better understanding of data capacity, shared governance models for data access, and data analytics. This paper assesses the feasibility of, potential concerns within, and interest in creating a community-based data registry with six CBOs that serve up to 23% of the Asian population in Chicago metropolitan area.

METHODS

Community-based Organizations

A small number of CBOs serve AAs in the Chicago area. In aggregate, there are 15 CBOs serving approximately 40% of the AA population. For this study, CBO partners were identified as organizations that have health programming and social service capacity. Six CBOs were identified as potential partners through their previous participation in PHA, an academic-community partnership formed to address cancer disparties across Chicago's Asian American communities (Crabtree & Miller, 1999). The CBO leadership met quarterly over the course of 4 years to develop shared resources, priority setting, and program evaluation in collaboration with academic leaders from the University of Chicago. For this study, we approached PHA CBOs who were interested in exploring how a partnership with an academic institution could aid their data collection and analyses needs. These CBOs served a wide array of mostly foreign born, largely limited English proficient clients from the Korean, Vietnamese, Chinese, Filipino, and Lao communities, and are further described in Table 2. The two Korean CBOs have about a 20% overlap in their catchment area and clients served, which was included in our estimates.

Table 2. Number of Clients Served by the Community-Based Organizations

Organization	Population Served	Number of Clients Served in 2017	Population in Chicago*	Representative (%)
CBO A	Korean	6,800	35,633	29%
CBO B	Korean	3,600		
CBO C	Chinese	11,000	54,489	20%
CBO D	Laotian	750	6,000	13%
CBO E	Filipino	1,200	31,053	4%
CBO F	Vietnamese	7,500	14,758	57%

CBO = Community-based organization
* Source: U.S. Census Bureau, 2013-2017 American Community Survey 5-Year Estimates.

Semi-Structured Interviews

Three research team members conducted semi-structured interviews with the leadership of six large CBOs serving specific Asian American populations to understand their mission, data usage, and data collection processes. Individuals were identified by the executive director within each organization as the personnel with the most familiarity with their own data governance and collection. One to two individuals from each CBO were interviewed, totaling in nine interviews. An interview guide (see Table 3) was created to elicit attitudes and beliefs on data usage within their organization, current data collection process and storage, data governance and reporting, and organizational interest in contributing to a local data registry. Input on the interview guide was obtained from two CBO leaders prior to implementation of the study (CBO A and B). Additionally, each individual was surveyed on their perspectives on working with an academic center to create a shared data registry and to provide opportunities for data analysis. Interviews lasted approximately 90 to 120 minutes. All interviews were conducted in English, audio-recorded, and transcribed by the study team.

Data Analysis

Qualitative data analysis of interview transcripts and field notes was performed using a modified template approach, with coding guided by initial code books derived from the interview guides, which were modified as additional themes and subthemes emerged from the data (*2015-2016 Data Documentation, Codebook, and Frequencies*, n.d.). Transcripts and field notes were reviewed by three members of the research team, who coded transcripts and field notes independently and then met to compare respective codes and discuss to consensus to ensure inter-rater reliability. Transcripts were uploaded to N'Vivo to facilitate coding and analysis. Categorical themes for each qualitative question were determined and a summary of all coded themes and developed categories were sent to all authors for final review and comment. Final qualitative analysis was conducted using N'Vivo software. This study was approved by the University of Chicago Institutional Review Board.

Table 3. Interview guide

1. Does your organization collect data from the community?
    a. Can you tell me about any data that you might collect from outside sources? (such as in research or partnership with other organizations)? If so, do you keep that data for your own records? Can you tell me about this experience?
2. In regards to data you collect, tell me about your data collection process: how did you come up with the survey questions, what format did you use, and how did you reach the people you wanted to collect data from?
    a. Approximately how many data points do you have?
    b. What was your overall data collection experience? Were there any drawbacks? Any lessons learned?
3. Can you tell me about your data management plan?
    a. Who has access to the data? Have you ever shared your data with other organizations before? What was successful and what was challenging about those collaborations?
4. How do you make use of the data you collect?
    a. Did you make any changes in your organization based off the data?
5. What do you think about using national data to inform your organization's decisions?
    a. Some people think that local data is more important than national data to address health disparities. What is your opinion on the matter?
6. What do you think about the idea of establishing a local registry comprised of different Asian community-based organizations' data?
    a. What pros/cons do you anticipate around this idea?
    b. How should it be done?
    c. On the scale of 1 to 10, 1 being extremely unlikely and 10 being extremely likely, how likely would you participate in the local registry and sharing your data? What should be done to improve your likelihood?
    d. What would you use the registry for?
    e. Besides compiling data, what roles and responsibilities do you think the registry should take on?

> f. What type of capacity building would your organization need to contribute data to a registry?
> 7. Is there anyone else in your organization who you think we should talk to?
>   a. Anyone who has been a part of the process in collecting and managing data who may have a different perspective?
>   b. What are your thoughts on having a standardized intake form between community organizations?

RESULTS

Organizational Capacity for Data Collection

In total, the six organizations collected data from 30,850 individuals as part of their catchment population. Per 2010 Census, there are 147,164 Asians in Chicago; thus these 6 organizations represent approximately 21% of Asians in Chicago. By comparison, NHANES 2015-2016 gathered information on only 1042 (0.7%) Asian participants nationwide (Meyers & Costanzo, 2015).

Data Collection among Participating CBOs

The data collection processes and major programs through which data are collected for each CBO is detailed in Table 4. Overarching themes on data collection and considerations of a local data registry are better detailed in Table 5.

Table 4. Data collection and programming by the Community Based Organizations

Organization	Population Served	Clientele Size	Intake data storage	Programming requiring data collection
CBO A	Korean	8,500	Electronic database	Hepatitis B screening, mammography referrals, ESL classes, citizenship assistance
CBO B	Korean	4,500	Electronic database, transcribed from pen and paper	Community assessments (mental health beliefs), senior services, ESL, after-school tutoring, citizenship assistance
CBO C	Chinese	11,000	Electronic database	After-school tutoring, senior services, job placement, financial literacy classes, ESL classes
CBO D	Laotian	750	Filing cabinets	Social services, health screening surveys
CBO E	Filipino	1,200	Filing cabinets, Excel	Citizenship assistance, political activism, health priority surveys
CBO F	Vietnamese	7,500	Electronic database	After-school tutoring, job placement, senior homemaking services

Data Usage

To understand data usage, we identified several themes (Table 5) including the use of data to assist with organizational development and fundraising, to measure community benefit, and to establish strategic planning. CBOs clearly recognize the benefits of collecting data from their own clientele to further organizational goals and enhance their mission. These include providing documentation for grant proposals, programmatic quality improvement, and improving the targeting of outreach services.

Table 5. Themes on Data Collection among Community Based Organizations

Question	Themes	Quotes
Data usage	1. Strategic planning 2. Measure impact and improvement of programs 3. Grant proposals 4. Targeting outreach efforts	"we want to be able to systematically change policies, and until [we] have numbers [we] cannot prove our point" "we need that data to showcase to our funders and partner organizations" "create a compelling reason for why we exist and why this service is necessary…making a compelling reason to funders that this is necessary work" "get a sense of the changing dynamics of where people are moving within the city and accessing services and resources"
Data Collection Process	1. Lack of standardization of data use requirements 2. Labor intensive process	"different programs have different required documentations…different unit of services, different ways of following-up, so that's really been very difficult to create one program that fits all different programming" "our staff are already overworked, and when I ask them to do even more, it's hard for them to see the forest for the trees"
Data Storage and Management	1. Trained staff access the data 2. Internal staffers manage 3. External sources manage	"we have a group of social workers, they usually come together to come up with a draft. And it goes through a lot of revisions, and revising, approval from different levels of staff."
Use of National Health Datasets	1. Useful as general trends, but not enough disaggregation	"it's good on a macro level" "I don't know if [the data] is broken down enough for us to use, but we can note trends in a broader sense".

Support for Local Data Registry	1. Easing the burden of data collection and analysis 2. Peer learning opportunity 3. Concern for client privacy 4. Concern for interorganizational competition	"I would love to get everything into one channel of data entry system, which is cloud based so that each one of our staff don't have to do their own collecting." "it helps us a lot if we…can learn from them." "For [organizations] with bigger capacity, are they just going to use data to come into certain communities to meet their numbers and deliverables at the expense of smaller organizations?"

Data Collection Process

Establishing processes for data collection are critical for data registries. Our respondents noted significant challenges with the data collection process. Generally, the labor-intensive process of data collection is often under-prioritized by organizational staff who are more concerned with maintaining CBOs' programs. Specifically, managing multiple modalities of data collection adds to already limited staff time. Uniformity in unique identifiers have not been implemented across systems.

Data Storage and Management

Data management varied significantly by organization. Depending on the capacity for data collection, management took two forms: Internal resources such as social worker assistance and external resources based on funding requirements. Several types of data storage processes exist among our CBO respondents. Electronic data systems and manual records are both being used for data entry, with electronic databases being the more common method of long-term data storage.

Use of National Datasets

CBO leadership noted the lack of disaggregation of available national data rendering such data useless for their own local strategic planning purposes. Respondents either did not use national data at all or only for general information.

Support for Local Registry

When presented with the idea of creating a shared data registry to expand each CBOs data analysis capacity, there was overall support for contributing data into a local registry. Understandably, there were significant concerns about data governance. Specifically, the most pressing concerns were around competition for clients and data transparency. There were also multiple CBO leaders who voiced concerns around the privacy of their clients' information. Overall, CBO leaders felt that a data registry would be a good opportunity for peer learning, a method of easing the burden of data collection, and a source for higher powered data for grant writing and reporting purposes.

DISCUSSION

There is a clear need to develop new data collection processes to ensure participation of vulnerable populations in order to reduce health disparities (Aspinall, 2003; Hasnain et al., 2020; Landey & Halpern, 2007; Waksberg et al., 2000). The undeniable benefit to CBO partnerships is that they have a unique ability to gather data from populations ordinarily excluded from national data sets: those with limited English proficiency and belonging to subsets of the AA population.

CBOs naturally address cultural and language barriers and, in our study population, collect data which represent up to 21% of all Asian immigrants in the Chicago metropolitan area. This is significantly greater than the representation among most national survey datasets. Additionally, CBOs are motivated to strengthen their capacity for data collection and analyses as a necessary component of grantsmanship.

The creation of a shared data registry would present a new collaboration between academic partners and the community that is not without challenges. Most notably, the questions regarding ownership and sharing of data between organizations were consistently an area where CBOs expressed the most concern. The pre-existing partnership (PHA) contributed to a sense of trust and shared values among CBOs, and the research team recognizes that this partnership will require a continued and ongoing discussion about how to maximize CBO benefit from the registry.

Additionally, numerous barriers specific to the data collection process would need to be addressed. First, data collection, entry, cleaning, and analysis are all very labor intensive and may exceed the organization's current capacities. Moreover, it can be difficult to analyze the data that is collected due to a lack of standardization within- and across-organizations. These barriers could be overcome through implementation of a uniform demographic data format across all CBO partners as well as standardization of scaled variables for comparison purposes. The goal is to maximize CBO resources without adding burden to their staff. As such, as a part of the academic-community partnership, data analyses would be performed by statisticians or members of the research team, thereby reducing the need for individual organizations to hire personnel to perform analyses or quality assurance of data collection. Both of these suggestions were well supported across our partners.

To address the concerns over the competitive nature of being the gatekeeper for valuable data expressed by a few of our CBOs, a transparent shared governance model might be one approach to address this concern. In practice, this may look like a the creation of a data request form and/or memorandum of understanding to be reviewed by a data committee comprised of CBO representatives and a members of the research team who meeting quarterly to review data requests to access the registry. The shared government model has been shown to functionally decentralized management and improve collective accountability (Meyers & Costanzo, 2015).

The fact that data collection is a priority for CBOs suggests that these organizations are willing to participate as partners in an innovative approach to ensure representation of these populations in reporting the health status of Asian Americans. Many of the challenges CBOs encounter in the data collection process could be ameliorated by having a centralized system from which CBOs could store information in a standardized fashion, receive support in performing data analysis, and compare their community impact with that of their peer organizations both local and nationally.

Our study is the first to understand the capacity and interest in enhancing Asian data through CBO partnerships. While important, our study has several limitations. We based our study in Chicago, which boasts the 5th largest population of AA nationally, but may not represent the attitudes of states where larger and more resourced Asian Americans reside. In addition, we included only six CBOs in our study, but together, these organizations serve over one fifth of the Greater Chicago AA community. Even though the inclusion of multiple community organizations broadened the ability to collect disaggregated, population-specific data, there was still very limited

data on many AA populations, especially among the Pacific Islander population. According to Census 2010, a Pacific Islander population size in Chicago was reported as just over 1,000, thereby minimizing our ability to include these populations in our current study (*2010 US Census Summary File*, 2012). For those CBOs that are also facing similar challenges in data collection and utilizing data to maximize the presentation of their impact, we would encourage consideration of local partnership among other CBOs with shared values to expand the reach of programming. We are hopeful that this study will empower CBOs and researchers to understand the tremendous capacity and potential contributions that community partners can have in reaching these vulnerable and underserved communities.

CONCLUSIONS

Data collected by community-based organizations are a unique source with which to understand subgroup differences. This study examines the feasibility of, potential concerns within, and interest in creating a community-based data registry among Asian American serving organizations in the Chicago metropolitan area. Using semi-structured interviews with the leadership of six large CBOs serving specific Asian American populations, we identified several overarching themes that support the need for, and feasibility of, a CBO partnered data registry. These organizations understand the power of using data to make persuasive arguments to support their mission. Although they are able to collect valuable data from their community members, the lack of resources, uniform data elements, and capacity to analyze and interpret the data may limit their usefulness. The major concerns of a local data registry are a fear of inter-organizational competition and data transparency. Prior studies on utilizing a shared governance model in which participating CBOs would have representation on a board that decides what data to collect, disseminate, and utilize has shown promising success. Overall, participating organizations appreciated that a local data registry would support their organizational mission for data reporting and capacity building through collective partnership. Furthermore, given the limited resources among the participating CBOs, there was hope that a shared data registry, supported by the academic center, would provide the needed process for uniformity in data reporting, analysis and community driven outcomes. This study provides compelling evidence supporting the important contributions of Asian serving CBOs in contributing local disaggregated data for the development of a shared data registry and may serve as an innovative solution for those populations not represented using national data capture methodology. Most importantly, the abilty of these ethnic specific partners to collect data from marginalized, largely non English proficient and underserved AA populations who seek services from these local community based organizations, provides a unique opportunity to establish a more representative sample of AA reflective of the AA national demographics.

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