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**Building a Chinese community health survey in Chicago: the value
of involving the community to more accurately portray health**

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Abstract

Title: Building a Chinese community health survey in Chicago: the value of involving the community to more accurately portray health.

Key Words: Chinese, local-level health data, urban population-based study, community-based participatory research, process

Category of Paper: Research (Methodology) Paper

Purpose of Paper: Little is known about the health of the Chinese living in the United States, especially at the community level. The aim is to detail a collaborative research process in which Asian community-based organisations and their academic partners developed a community needs assessment of the largest Asian communities in Chicago.

Methodology: The Asian Health Coalition of Illinois in partnership with Sinai Urban Health Institute, and the Chinese American Service League designed and administered a health survey with 383 randomly selected Asian adults in the Armour Square community of Chicago's Chinatown.

Findings: This report focuses on detailing the process of building a coalition and survey. Sample demographics were heavily focused towards elderly Chinese; with 50% over age 60. For the first time, disease prevalence and risk factor data are available about the Chinese subgroup of Asian American Pacific Islanders in Chicago.

Implications for Practice: Community-academic partnerships are essential to designing culturally appropriate instruments and effectively administering health surveys in the community, particularly in Asian communities.

Value of the Paper: This paper emphasises the importance of community-academic partnerships to ensure appropriate questions are asked, gain the trust of the community for participation and assure culturally and linguistically appropriate research is employed to improve health of minority populations.

Number of Pages: 18

Number of Tables/Figures: 2 tables; 3 figures

Section Headings: Introduction, Literature Review, Methodology, Results, Discussion, Conclusions, Acknowledgement

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Introduction

In 2050, compared to 2000, the Asian American Pacific Islander (AAPI) population in the United States is expected to surpass the Hispanic population and will represent the largest non-white group in the US (US Census Bureau 2004). Despite the growth of AAPI population in the US, few national and state-level data sources exist that provide detailed and accurate information regarding AAPI health disparities and needs at national, state and local levels (Tao 2006; Asian American Federation 2008; Asian Pacific Islander American Health Forum 2008). The paucity of data for AAPI populations is even more pronounced at the community level. Moreover, disaggregated Asian ethnic subgroup data and further stratification by age or gender are very difficult to retrieve. As such, health data on Asian subgroups are usually fraught with small sample sizes and lack of generalisability and thus are deemed insufficient to derive accurate estimates of health status for these individuals (Fielding 2004; Centres for Disease Control 2004; Misra 2005).

Despite this paucity of data, there is evidence to suggest that the AAPI population have significantly different health profiles comparing each Asian subgroup to other racial/ethnic subgroups, and the health burden among underserved AAPI communities is growing (Tao 2006; Centres for Disease Control 2004). Importantly, AAPI population is often misperceived to be advantaged as the 'model minority' compared to the general population in the US (Choi 2008; Maddux 2008; Ho 2001; Wong 1998; Yee 1992). Therefore, it is essential to have disaggregated Asian subgroup data and local data to either confirm or negate such long-standing assumptions.

Despite Chicago's diverse racial/ethnic population, local data that describe minority health are lacking, especially among the AAPI population (Illinois Public Health Institute 2004). Typically, in Chicago, data on AAPI population subgroups are gathered through health fairs and programs. Collecting systematic, local-level data is crucial for the AAPI population, particularly for each Asian subgroup that may have diverse and greater health risks due to language barriers, lower socioeconomic status, immigrant status, age, or access to or understanding of the US health system. This report offers one strategy aimed at capturing accurate health data of AAPI subgroups in Chicago. We detail the process of such efforts to collect local-level health data on the largest community of Chinese in Chicago, Chinatown – Armour Square community area.

Literature review

Local-level health data inform us about the true health status and access to health care of particular communities. Communities are more engaged when they uncover disproportionate rates of particular health problems in their own “backyards”. These data may help us to more effectively eliminate health disparities among vulnerable populations by catalysing targeted interventions and policies. Unfortunately, local-level data are rarely available (Brownson 2004). Whitman and colleagues have now published extensively on their local community area survey (Margellos-Anast 2008; Whitman 2007; Whitman 2006; Shah 2006; Dell 2005). These data from six Chicago community areas detail the importance of examining data at the local community level to examine important health inequities among racial/ethnic groups (Whitman 2006; Shah 2006).

Despite the recent increased understanding of low-income, minority health concerns, the health status of Chinese in the US and globally is poorly understood, and there is a great paucity of systematic research among the Chinese ageing population (Li 1999; Ma 2000; Mahon 2002; Banister 1990). Prior studies examined cause-specific mortality differences between Chinese and Non-Hispanic (NH) Whites in US (Liu WT 1985; Yu 1985). Chinese compared to NH-Whites have higher proportions of cancer mortality. Potentially preventable diseases such as pneumonia and influenza ranked higher as the cause of death for Chinese, compared to NH-Whites (Liu WT 1985; Yu 1985). The risk of death is much greater for Chinese immigrant population compared to US-born Chinese population – in cerebral vascular disease, atherosclerosis, suicide and self-inflicted injury, cancer, pneumonia and influenza and accidents (Liu WT 1985; Yu 1985). Major barriers to care described by the Chinese population include a lack of regular sources of health care and health information, language barriers, transportation issues, low levels of cultural competency and sensitivity among health care providers, and a sense of distrust with the US health care system (Au 2002; Arojan 2005; Yu 1982).

Illinois has the sixth-largest AAPI population in the US. The Chicago AAPI population has grown from 102,938 in 1990 to 125,974 in 2000 (US Census Bureau 1990, 2000), making AAPI the second fastest-growing minority subgroup next to Hispanic (Misra 2005).

Based on estimates from the 2000 US census there are about 15,997 Chinese in the Chicago. Of these, 7,137 Chinese live in Chicago’s Chinatown Armour Square community area). This community area roughly represents 6% of the total AAPI population in Chicago and is the second-largest grouping of AAPI population in any community area in Chicago (US Census Bureau 2000). Chicago’s Chinatown is one of the fastest growing racial/ethnic communities in the city, yet little is known about its health status. This makes developing strategic plans and implementing health programs challenging for community-based organisations serving these populations.

Prior studies in the Chicago Chinatown community area have been led primarily by academic institutions, with no infrastructure left behind, and without an equal partnership in every step of the process, which could have jeopardised the community’s willingness to participate in research. Moreover, insensitivity and lack of awareness to intricate cultural issues and values have further widened the distrust and became a serious impediment to productive research in the Chinese community (Li 1999; Ma 2000; Mahon 2002).

Several organisations joined forces to create this project. Community-based project partners included the Asian Health Coalition of Illinois (AHCI) and the Chinese American Service
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League (CASL). Academic and technical partners included Sinai Health System's Urban Health Institute (SUHI) and consulting assistance from the University of Illinois at Chicago's Survey Research Laboratory. After extensive literature research and review, the partners convened and discussed in detail the current state of knowledge and the great paucity of systematic data on AAPI populations in Illinois (Tao 2006) and the US.

Research design and methodology

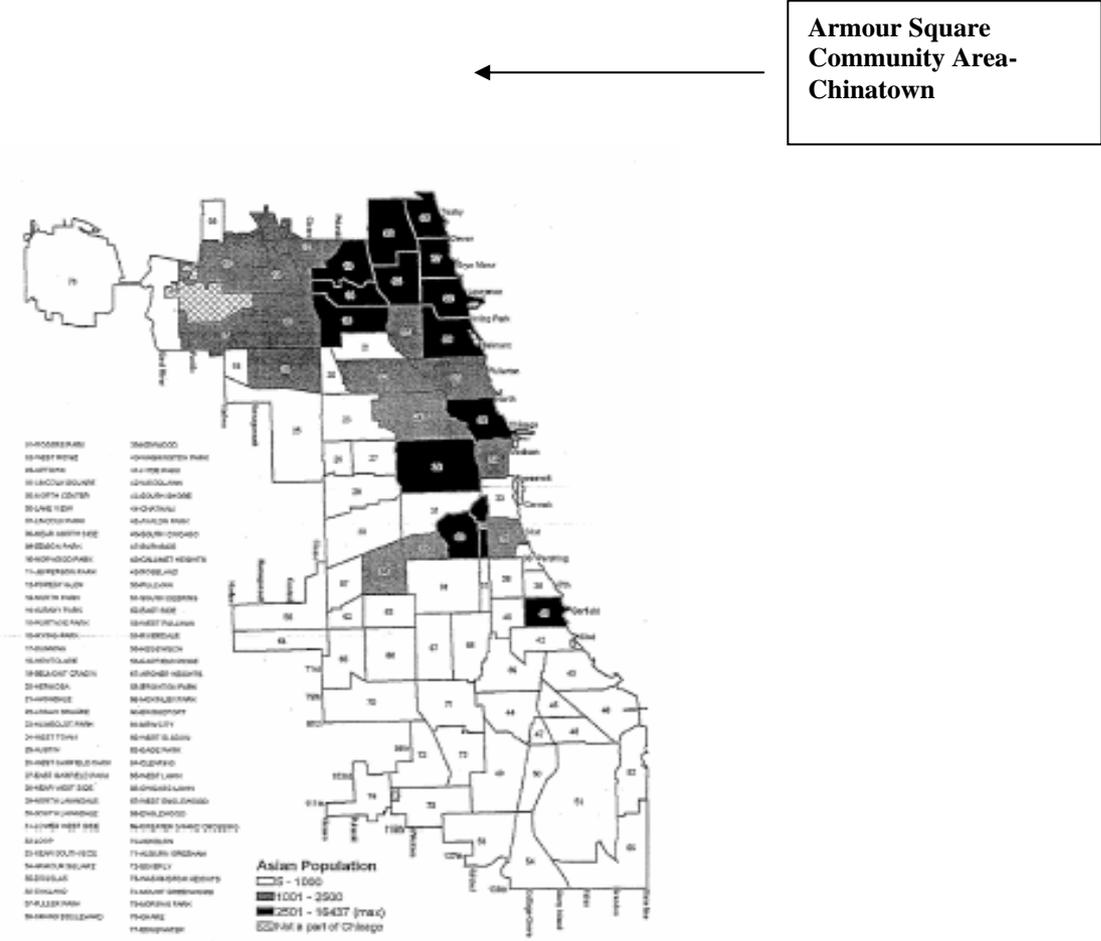
The project had three principal goals: 1) to document the general health status of the Chinese in Chinatown (Armour Square) using both scientifically accepted methods and community organisation input; 2) to compare survey findings with other analogous local, state and national health statistics; and 3) to use survey findings to guide targeted interventions and bring greater resources to the community for overall improved health.

The overall long-term goals of the study objectives were designed to occur in three distinct phases. Phase 1 encompasses the design of the questionnaire and the collection of data, which is the focus of this manuscript. Phase 2 is focused on data analysis and dissemination of findings. The final Phase 3 incorporates efforts to design, fund, implement and evaluate interventions addressing the most significant problems identified by the data.

Participatory action research (PAR) or community-based participatory research (CBPR) are methods of conceptualising, implementing and evaluating research that is aimed at promoting equal health for all. This report details the use of a community-engaged research approach on the spectrum of CBPR to gather, for the first time, local pilot health data on the AAPI population in Chicago. We were able to build relationships between partnering community organisations, to target the appropriate communities and garner community input while building capacity in the community. The community input complemented the knowledge and skills of researchers in acquiring the data. Such an approach balances research with outreach and action. The process of building these relationships is just as important as the final outcome of our research (Israel 1998; Cornwall 1995; Fielding 1999). Thus, community engagement is beneficial for the quality of the research and for affecting social change since it empowers communities to plan and promote their own health (Minkler 2003; US DHHS 1998; Green 1994).

The lack of local level data on AAPI populations in Chicago prompted these partners to study this population in an attempt to provide accurate data that will be used to empower AAPI communities to improve their health. To date, we are not aware of any studies of community health needs assessment for the AAPI population that have not only engaged the community as an equal partner with reciprocal transfer of expertise at all levels, but also integrated rigorous methodology of random sampling techniques to estimate population-level characteristics. This model of involving the community to build a survey to collect local-level data can be a powerful approach to understand the vast disparities facing the AAPI population and potentially serve as a model for studying other populations.

Figure 2: Asian population density in Chicago community areas



Source: Illinois Department of Public Health

The first step in the process was to design the survey instrument. The survey was carefully designed with both academic and community partners' input. The Asian Health Coalition of Illinois worked with an Advisory Board composed of members from the Chinese American Service League, Asian Cancer Prevention Organization and the University of Illinois at Chicago to finalise the instrument. Their shared goal was to develop a survey questionnaire specifically tailored to the health issues of the Chinatown community.

Community leaders at the Chinese American Service League and the Project Advisory Board were asked which topics were of the greatest interest to the community. Questions were selected that focused on health topics important to the Chinese population in Chicago's Chinatown. Most questions were adapted, where appropriate, from national surveys such as *International Journal of Health & Ageing Management*, December 2008, v2, n1

the National Health Interview Survey (NHIS) and Behavioural Risk Factor Surveillance Survey (BRFSS). Questions were reviewed and modified to best measure the health issues of interest to the Project Advisory Board. The wording of questions from national and state surveys was used in order to benefit from validated questions and to allow for the data to be comparable at the local, city, state and national levels.

The final survey was designed to measure not only community-level prevalence of health outcomes such as asthma, obesity and diabetes, but also important risk factors such as smoking, exercise, diet or nutrition, and perceptions of health (self-perceived health status and quality of life). It included 185 questions of which 168 questions came from the Centres for Disease Control's (CDC) BRFSS. Table 1 lists the topic areas included in the survey.

The English survey was designed, translated, back translated and tested in Cantonese and Mandarin between June 2006 and September 2006. The instrument was translated into Chinese script, while referencing previously translated versions of questions from the New York City Behavioural Risk Factor Surveillance System survey, when available (BRFSS 2000). Pilot testing was done for quality assurance and to ensure questionnaire comprehension. This survey was estimated to take about one hour to administer. **Table 1** lists the topic areas included in the survey.

Table 1: Topics included in the survey

Demographic and Socioeconomic Information
Education
Income
Marital Status
Nativity
Primary Language Spoken at Home
Ethnic Origin
Physical Health Status
Self-Rated Health
Cancer screening history
Chronic Conditions- including Asthma, TB, Hepatitis, Diabetes, Cardiovascular health
Disability
Mental Health Status
Quality of Life
Depression
Emotional Problems
Perceived Stress
Anger Management
Health Behaviours and Attitudes
Substance Abuse
Diet and Nutrition
Physical Activity
HIV/AIDS/STIs
Health Care Access and Utilization
Health Insurance
Primary Care
Preventive Health Care
Alternative and Complementary Treatments
Prenatal Care
Other Social and Environmental Factors
Domestic Violence
Perceived Discrimination

Source: Developed for this paper

All partners involved in this process recognise the importance of the interviewer-training process and the critical need for uniform data collection. Interviewers were trained at two full-day workshops in September 2006 and subsequently at weekly check-in meetings throughout the data collection period. The first day of the training addressed the project's background, offered general protocol guidelines, reviewed the survey instrument and highlighted the procedure for the protection of human subjects. During the second workshop, interviewers role-played the consent process and formal face-to-face interviews. Additional weekly training provided feedback to interviewers to improve the uniformity of data collection and protocol execution.

The survey instrument was tested in two ways. First, questions were selected and reviewed by AHC staff and then presented to the Project Advisory Board for further review. This committee read through the questionnaire and provided feedback concerning the cultural appropriateness of general topics and specific variables. The order of the variables was also influenced by the committee; they organised the questionnaire such that interviewers would more easily gain rapport with participants to improve accuracy of responses. Secondly, the instrument was tested at the Chinese American Service League (CASL) with volunteers from the Chinatown area. Project interviewers practiced 1-2 interviews each with community volunteers in October 2006. Following the practice interviews, the survey was modified according to interviewer feedback. Revisions were made to the questions and interviewers were retrained on these particular questions. The final survey instrument and protocol was approved by Sinai Health System's Institutional Review Board.

The community survey was conducted in the Chinatown community of Chicago with 383 randomly selected households of the census tracts: 3401, 3402, 3403 and 3404 as shown in **Figure 1**. The sampling unit for this study is the household. 19 blocks were randomly selected from the four Census tracts and all households in those blocks were visited (approximately 800). Interviewers screened the household to select a random adult employing Troldahl-Carter-Bryant methodology (Sudman 1976). Eligibility criteria included adults 18 years and older, self-identified as Asian and having lived in the area for more than six months. The final sample included of 383 surveys. All data were weighted to sex distribution of four selected tracts from the Census 2000. In the end, we are confident that we have a representative sample of the Asian population of these Census tracts in Armour Square, defined as Chinatown.

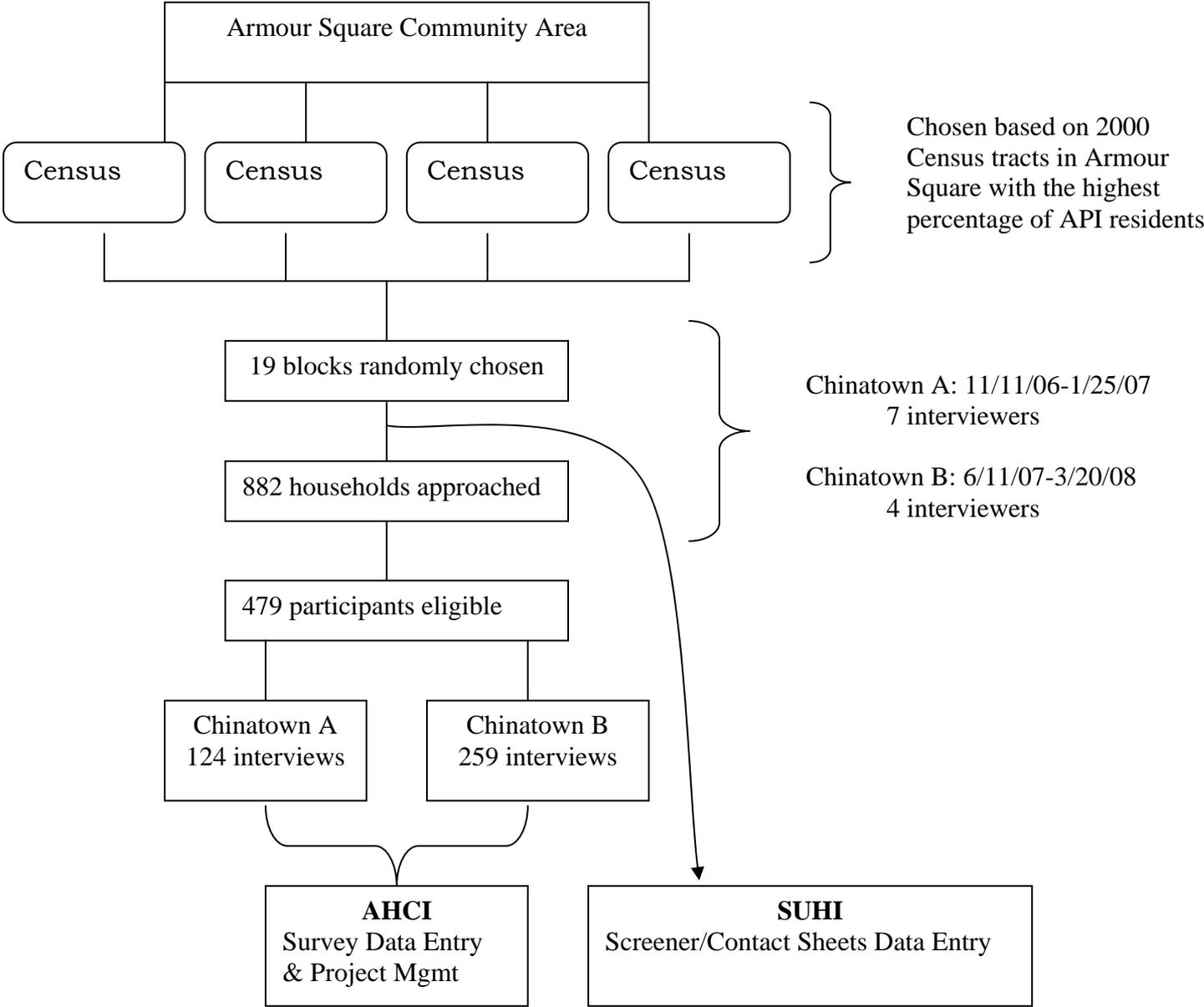
Figure 1: Study area – Census Tracts 3401-3404



Source: Developed for this paper

Each interview was performed face-to-face in English, Cantonese or Mandarin. Each interview lasted approximately one hour, and participants received US\$20 for their time and feedback. In all, 383 Chinese adults were interviewed between November 2006 and April 2007. **Figure 3** displays the study flow. The response rate, which measures the proportion of eligible respondents who completed an interview, was 86.1%.

Figure 3: Study Flowchart



Source: Developed for this paper

All selected individuals were sent an introductory letter signed by a local, well-known and trusted community organisation (CASL). These letters were on the organisation's letterhead and explained the importance of the survey and its sponsorship by CASL and the Asian Health Coalition of Illinois. The letters of notification included an introduction to the study, its activities and plans to visit their homes. In addition, a press conference was held and notices were posted in local community newspapers. A trained interviewer visited households to conduct face-to-face interviews with the selected adults. The interviewers introduced the project and themselves as being associated with CASL and showed the newspaper notices to potential participants.

Individuals selected for the interview were given information about the study and the opportunity to decline participation. An informed consent form was then signed or initialled (if anonymity is desired). Each individual had the option to decline participation at any time during the interview or to decline to answer selected questions.

Based on recommendations from community organisations, each individual who participated in the study was reimbursed US\$20 in appreciation for their time. The funds were disbursed in cash by the interviewer and a signature was required for receipt of the funds. Anyone who agreed to be interviewed received the reimbursement, even if they refused to answer some of the questions.

Results

Since the completion of the survey, we have found this sample represents predominantly older men and women. Of the 383 subjects surveyed, 367 had information available on age and gender. 144 respondents were men and 223 were women. The range of male ages included 18-89 with a median age of 57.5 (mean 57.9). The range of female ages was 18-96 with a median age of 63 (mean 60.6). Half of this sample was age 60 or over with a total of 193 respondents (124 female and 69 male). One hundred and forty respondents were over age 70 (49 male and 91 female). Fifty-nine respondents were over age 80 (17 male and 42 female). **Table 2** depicts the age stratification by gender of the survey respondents.

Table 2: Summary statistics of Chinatown community health survey participants

Age	Men N=144 n (%)*	Women N=223 n (%)*	Total N=367 n (%)*
≥60	69 (47.9)	124 (55.6)	193 (52.6)
60-65	12 (8.3)	16 (7.2)	28 (7.6)
66-70	8 (5.6)	17 (7.6)	25 (6.8)
71-75	13 (9.0)	23 (10.3)	36 (9.8)
76-80	19 (13.2)	26 (11.7)	45 (12.3)
81-85	13 (9.0)	27 (12.1)	40 (10.9)
>85	4 (2.8)	15 (6.7)	19 (5.2)
*Percentages are indicated within parentheses, (i.e., % of total men, % of total women, and % of total sample).			

Source: Developed for this paper

The majority of the participants were born in China. The average length of residence in Chinatown was 7 years. The median annual household income was \$22,756 (US\$). One-third of participants were employed and one-third were retired. Men were more likely than women to be never married (23.6 vs. 5.6%); and women were more likely than men to be widowed (17.8% vs. 8.7%). About half the men and women had received only some high school education or less.

Key findings suggest that thirty-one percent of men reported they currently smoke cigarettes. Sixty-six percent of men reported having ever smoked. Over one-quarter of participants reported diagnoses of high blood pressure and high cholesterol. Thirteen percent of the population reported having been diagnosed with diabetes.

Discussion

The survey design approach presented in this paper may serve as a model for developing a community health survey. It demonstrates the importance of involving community members and service providers in the research design. Moreover, it describes an experience in which researchers, health administrators and community members built trusting relationships and capacity for future research activities.

Even with the small amount of AAPI state-level data currently available and the local data we have collected through this survey, it is becoming more apparent that disparities in AAPI health exist and are likely to increase over time in Chicago and Illinois. Historically, all AAPI ethnic subgroups were considered as one entity and have generally performed favourably in comparison with Whites; however, when data from specific subgroups are isolated, striking differences in health indicators and outcomes become clearer. The extent and severity of health disparities in AAPI communities is slowly becoming evident, but the 'model minority' myth still pervades the American society in destructive ways: better local health data can combat this problem.

Chinese communities have not been fully engaged in the content and conduct of studies. Most prior research efforts have been driven by the research scientist, without community engagement and thus have left the community without capacity to advance their own needs. Even though Chinese were the first Asians to migrate to the US, they were also the first group to be legally barred from becoming US citizens. Harsh discrimination and racial tension have also created distrust among the Chinese community, especially among older generations, regarding the US government and federal-sponsored activities such as research projects and census tracking (Yu 1982). In addition, there is lack of information about government-sponsored research in the Chinese community and, combined with language barrier, health literacy and lack of access to health, has further prohibited the Chinese community from becoming well informed and thus unwilling to participate in research (Choe 2006; Zhan 1998).

The process of coalition and capacity building is described in this account. With this coalition, we were able to design and implement a community-level survey for the Chinese in Chicago. We will first share the results of this survey with the communities for validation. By asking the communities to participate in validation, we will maintain the confidence and ownership of the data and increase the likelihood of community-driven support for targeted interventions by driving the knowledge into action (Schmuckler 2001).

All community organisations will be involved in analysing, interpreting and disseminating the results of these surveys. The aim is to develop targeted intervention strategies and more specific, local-level health policies to promote health equity among Chinese in Chicago. The conversations on these data, we believe, will have implications for health services delivery, interventions and programming, and policy decisions specific to the Chinese in Chicago. The ramifications of the results of these local-level data will serve as models for other surveys to collect AAPI-specific subgroup data in order to reveal their true health status.

Through this process, many lessons have been learned. Implementing a survey in Chicago's highly concentrated Asian communities presents significant challenges. Many of the randomly selected addresses no longer existed when we returned for the interviewing after field enumeration. Eighty-six percent of the people to whom we spoke agreed to participate and completed the survey. It is unclear how these response rates affected our findings. Non-respondents often fare worse than respondents on many health measures (Shahar 1996; Cohen 2002), which suggests that we may have overestimated the quality of residents' health in these communities.

Community involvement, clear and open communication and cultural relevance were essential to earning trust and ensuring project success. Administering the survey door-to-door taught us a great deal more about barriers in finding selected respondents. Because the interviewers were associated with a major community-based organisation in Chinatown (CASL – by wearing their identification badge and presenting pictures from the press conference), participants felt more comfortable and were more willing to consent to the survey.

To promote cultural relevance, it is important to note that the vast majority of participants took the survey in their native language. All interviewers were Chinese and were from the community. Interviewers were age-appropriate and spoke the language of preference (e.g. Cantonese or Mandarin) when approaching households. Making initial household visits in pairs (male/female, older/younger) and working as a team proved to be most efficient and effective. In addition, culturally sensitive questions were self-administered and well-received as indicated by high response rates. It is important to consider cultural appropriateness and differences in interpretations of key health concepts, and conduct focus groups to guide the questionnaire development process.

It is critical to involve the community in every step of the research to ensure policy relevance and enhance the meaningfulness of research to the community. This study was built upon relationships that have evolved over many years. If financial resources allowed, we would have hired an external auditor to ensure exact adherence the CBPR methodology principles. Finally, it was important for community residents and organisations to understand that research findings may not always be immediately and tangibly applied to the community and that research findings are not absolute, even though they may have policy implications. Scientific results are inherently tentative, to be tested and challenged by other researchers.

Through comprehensive data analysis and community collaboration, we aim to disseminate the data and make the data a sustainable resource for the Chinatown Armour Square community to improve the health of their residents. The findings will be presented to community stakeholders, including lay leaders, community agency professionals and community members. In addition to a written community report, a series of meetings will be held. Each meeting will present the background, methodology and results and will conclude with question-and-answer sessions. Through these sessions, the study team anticipates the

most pressing health problems will be prioritised and potential interventions discussed in addition to identification of community members willing to be involved.

The policy implications of these local-level data are vast. Knowledge of the scope of the health issues that AAPI communities face is in its infancy. If the elimination of racial/ethnic disparities in health is truly a national, state and local priority, greater awareness of the cultural, linguistic and socioeconomic heterogeneity of the AAPI community must be established. The awareness of the disparities in health that exist among AAPI populations is needed to foster support for further in-depth investigations into the underlying social determinants of health (Ponce 2003). Better subgroup data will facilitate creation of culturally appropriate and sensitive health interventions, target root causes of disease, and thus improve overall health status of AAPI populations.

To address health disparities among Asian populations in Chicago, policy changes are needed for Illinois. Such policies need to be focused on improving data collection and improve and increase research on AAPI ethnic groups. Given the heterogeneity of AAPI subgroups and vast differences in culture, language, health beliefs and practices, and genetic backgrounds, it may be misleading to consider them as a whole. Disaggregation of AAPI data by ethnic subgroup in new studies as well as in existing data sources, such as health surveys, vital statistics and disease registries, may reveal unexpected trends and important risk factors and disease patterns for each subgroup (Gomez 2003; Srinivasan 2000). Understanding the diversity and cultural richness of the AAPI population will allow for more appropriate service delivery and hopefully improved health outcomes.

Conclusions

It is clear that collective and synergistic partnerships to build research projects at the local, grassroots level are potentially powerful contributors to both uncovering and eliminating health disparities. Understanding the need for local-level data, AHCI and its partners decided to embark on developing Chicago's Chinatown community health survey. The survey was the first step in gathering data to fill this gap in current knowledge about the health needs of Chicago's AAPI population. In this paper, we outline the process of building such partnerships and a survey.

With this joint effort, we were able to design and implement a community-level survey for the Chinese in Chicago. The essential part of this process is ongoing academic and community collaborative support and reciprocal transfer of expertise. Such collaborative support will be leveraged to afford sustainability to this project and subsequent intervention development. The findings will be leveraged to affect broader changes for their community by affecting relevant practice and policy changes to improve the health of the communities.

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