



Armour Square: Chinese Community



ASIAN
HEALTH
COALITION

*Chicago Asian
Community Surveys:
A Comprehensive Report*

Uptown: Vietnamese Community



Albany Park: Cambodian Community

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A Message to Our Readers:

The core mission of the Asian Health Coalition is to improve the health and well-being of Asian Americans. In order for us to succeed, it is imperative that we have local level data to better understand the health care needs of Asian American communities. We have collaborated with numerous community-based organizations, academic partners, foundations, and health agencies to scientifically study three separate Asian communities (Chinese, Cambodian, and Vietnamese) in Chicago. This report shares some of our key findings and will serve as a springboard for future research, policy reform, and improved delivery of care for our communities.

*The Asian Health Coalition is proud to share these meaningful results with you. They shed light, for the first time, on many areas of health that need to be addressed. As our population continues to grow, it will become increasingly important to recognize the similarities and differences between Asian communities in Chicago, to create policies to equalize access to care, and to highlight the growing health disparities faced by our communities. This survey, a work in progress, is our **CALL TO ACTION** to you. We hope that you gain an understanding of our community needs, the strengths of our collective partnerships, and our determination to be a catalyst for change and improve the health of Asian Americans in Chicago.*

Karen E. Kim, MD

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Table of Contents

Executive Summary		06
Section 1.	Introduction	09
Section 2.	The Communities	11
Section 3.	Development of the Survey	14
Section 4.	Data Collection and Analysis	16
Section 5.	Key Findings from the Survey	
	<i>Topic 1.</i> Insurance Coverage and Access to Health Care	20
	<i>Topic 2.</i> Diabetes	22
	<i>Topic 3.</i> HIV/AIDS	25
	<i>Topic 4.</i> Colorectal Cancer Screening	26
	<i>Topic 5.</i> Breast Cancer Screening	28
	<i>Topic 6.</i> Cervical Cancer Screening	31
	<i>Topic 7.</i> Mental Health	33
	<i>Topic 8.</i> Hepatitis	35
Section 6.	Overarching Public Health Implications	37
Conclusion		38

Glossary of Abbreviations

AHC	Asian Health Coalition
AIAN	American Indian or Alaskan Native
AIDS	Acquired Immunodeficiency Syndrome
AAPI	Asian American and Pacific Islander
BRFSS	Behavioral Risk Factor Surveillance System
CACS	Chicago Asian Community Surveys
CAI	Cambodian Association of Illinois
CASL	Chinese American Service League
CBO	Community Based Organization
CDC	Centers for Disease Control and Prevention
CDPH	Chicago Department of Public Health
CES-D	Center for Epidemiological Studies-Depression Scale
CHW	Community Health Worker
CMAA	Chinese Mutual Aid Association
CRC	Colorectal Cancer
FOBT	Fecal Occult Blood Test
HBV	Hepatitis B Virus
HIV	Human Immunodeficiency Virus
HPV	Human Papilloma Virus
IDPH	Illinois Department of Public Health
IRB	Institutional Review Board
MSM	Men who have Sex with Men
NCAHI	National Cambodian American Health Initiative
NHANES	National Health and Nutrition Examination Survey
NHIS	National Health Interview Survey
NHOPI	Native Hawaiians and Other Pacific Islanders
PAC	Project Advisory Committee
PN	Patient Navigator
RDS	Respondent Driven Sampling
RDSAT	Respondent Driven Sampling Analysis Tool
RRF	Retirement Research Foundation
SES	Socioeconomic Status
STI	Sexually Transmitted Infection
SUHI	Sinai Urban Health Institute
UIC SRL	University of Illinois at Chicago Survey Research Laboratory

Executive Summary

Background

With over 50 distinct ethnic subgroups embodying different linguistic and cultural characteristics, the Asian American and Pacific Islander (AAPI) population in the U.S. is markedly diverse. However, despite these differences, the limited available health data are often aggregated into a single broad classification, which masks the diversity of health outcomes, disease burdens, and health disparities within and across the AAPI population. Therefore, commonly collected aggregated data are not always useful for guiding community-specific health care programs or policies.

Even with the existing aggregated data, there is still a lack of baseline information on the health status, needs, and assets of the AAPI population. While research on the health disparities that this population encounters does reveal significant gaps in health care, the bulk of the research is considered to be preliminary and underdeveloped. According to the U.S. Census Bureau, there were 11.9 million AAPI's living in the U.S. in 2000, a number expected to triple within the next 50 years. In Chicago, 4.3% of the population identified themselves as Asian (about 126,000

people) and 0.1% as Pacific Islander (about 1,800 people). Among the 77 Chicago Community Areas, AAPI's comprise less than 1% of the population in certain areas and up to 60% in others. Also, 18% of current Chicago immigrants are from Asia. Given that the AAPI population in the United States is expected to rapidly increase, there is a growing need to gather disaggregated AAPI subgroup health data. Having information on the health status and needs of specific subgroups would allow policymakers, health planners, and community-based organizations (CBOs) to develop more effective and targeted health programs and policies, thereby improving health outcomes and reducing disparities within each distinct AAPI community.

The Chicago Asian Community Surveys (CACS) Project

In response to the limited health data of local AAPI subgroups, the *Chicago Asian Community Surveys* (CACS) project conducted a comprehensive assessment of the health needs, determinants of morbidity and mortality, and health care access patterns of three AAPI communities in Chicago: Chinese in Armour Square, Cambodian in Albany Park, and Vietnamese in

Uptown. Utilizing a community-based participatory research (CBPR) framework, which was designed to be culturally specific and sensitive, CACS consisted of face-to-face interviews aimed at increasing the understanding of each community's particular health needs and priorities. The three objectives of the project were: (1) to document community health statuses using scientifically accepted methods, (2) to compare survey findings with other analogous local, state, and national health statistics, and (3) to translate results into informed and targeted interventions and programs for the overall goal of achieving improved health in each of the communities.

With random sampling of the Chinese community and Respondent Driven Sampling (RDS) of the Vietnamese and Cambodian communities, 383 Chinese, 250 Vietnamese, and 150 Cambodian community members were interviewed using culture and language-specific survey guidelines. Eight health topics were discussed: diabetes mellitus, access to health care and insurance coverage, HIV/AIDS, colorectal cancer screening, breast cancer screening, cervical cancer screening, mental health, and Hepatitis B.

Key Findings

A key finding across the eight surveyed health topics was the pronounced deficiency in the provision of public health and medical services, especially those tailored to meet the cultural and linguistic needs of these AAPI communities. Furthermore, disaggregated data exposed important and marked differences in disease burdens and health care needs among the three communities.

The following summarizes the main findings in each of the eight health topics:

- Disaggregated data revealed large variations among AAPI subgroups regarding **access to care and insurance coverage**. Compared to 88% of Asian Americans nationally and 85% of adults in Chicago with insurance, only 51% of local non-elderly Chinese reported having some form of insurance. In contrast, 70% of local Vietnamese and 69% of local Cambodian were insured. The uninsured were less likely to have a usual source of health care or to receive preventative health care services. Furthermore, regarding communications with their health care providers, the majority of Vietnamese, Cambodian, and Chinese respondents preferred using a non-English language.
- The prevalence of **diabetes mellitus** was found to be disproportionately high for the Vietnamese and Cambodian populations. Of the three communities, the Vietnamese respondents had the highest proportion (14%) of those who self-reported ever being diagnosed with diabetes; the Chinese community had the lowest at 7%. Compared to the national AAPI rate of 7.5%, the local Vietnamese community had nearly twice the prevalence rate of diabetes mellitus. However, the Vietnamese community was also found to have the highest rate of being tested for diabetes, while Cambodians had the lowest. Significant barriers to receiving adequate screening and treatment included low levels of awareness of screening/ diagnosis related to insurance status and lack of language-appropriate educational strategies.
- The survey results highlighted several concerns surrounding the issue of **HIV/AIDS**, including disparately low levels of lifetime screening for all three communities, and a high degree of social stigma and lack of awareness of the condition. In contrast to 33% of U.S. AAPI's, 15% of Chinese, 29% of Cambodian, and 23% of Vietnamese reported ever getting tested for HIV. Those who were self-reported as speaking English well or very well were significantly more likely to have been screened.
- In all three AAPI subgroups the proportion of adults who had ever received **colorectal cancer screening** was significantly lower than the national average of 57%. Twenty three percent (23%) of Chinese, 32% Cambodian, and 29% of Vietnamese participants over the age of 50 had received a screening exam. Lack of insurance and limited availability of translators both were cited as frequent barriers.
- **Breast cancer screening** rates for women 40 years or older were significantly lower for all three communities compared to the U.S. estimate of 77%. Only 49% of Chinese, 42% of Cambodian, and 49% of Vietnamese women reported engaging in screening practices. Moreover, the primary reasons for not receiving mammograms included lack of awareness and knowledge of the importance of regular mammograms, lack of insurance coverage, and not being advised on screening practices by health care providers.
- Among women who should have received **cervical cancer screening** with Pap tests in the last three years, all three AAPI subgroups had screening rates well below the national average of 84%. However, disaggregated data reveal distinctly varied rates with 43% of Chinese, 51% of Cambodian, and 71% of Vietnamese women receiving Pap tests. Women least likely to be screened were uninsured, foreign-born, or newly arrived immigrants.
- While national comparison data are not available, findings from the **mental health** category

yielded an alarmingly high number of adults experiencing symptoms of depression. Eighty four percent (84%) of Chinese, 88% of Cambodian, and 63% of Vietnamese reported at least one depressive symptom. The Vietnamese community had the highest proportion of respondents who reported that they do not enjoy life, followed by the Chinese participants. Groups most affected by depressive symptoms included recent immigrants and those who were unemployed.

- **Hepatitis B** rates among AAPI populations are alarming, with AAPIs carrying the burden of the disease prevalence in the US. Survey findings revealed that Hepatitis B was the most commonly diagnosed type of Hepatitis. However, many participants were unaware of the type of Hepatitis that they were tested for or diagnosed with.

Implications

This report reveals that these Chinese, Vietnamese, and Cambodian communities in Chicago face significant health disparities across a wide range of health indicators, including low rates of cancer and HIV screening and high rates of diabetes, depression, and Hepatitis B. More importantly, significant differences in the health issues affecting these three communities are highlighted, which further stresses the need to collect disaggregated and culturally specific health data for distinct AAPI communities.

Understanding the particular health needs, determinants, and access for each ethnic community is integral to developing sensitive and appropriate public health programs, medical interventions, and local policies. The results from the CACS will help community leaders and policymakers to understand the Chicago AAPI communities included in this study, and expectantly, to develop appropriate outreach, advocacy, and intervention services. Also, this local subgroup health data will be instrumental in helping public health advocates and medical providers to develop tailored, culturally and linguistically appropriate health programs. By improving the patient-provider relationship through outreach and education, the negative health consequences that stem from stigma around HIV/AIDS, denial of mental health issues, lack of insurance coverage, and lack of awareness of screening practices can be greatly diminished.

The information gathered from the *Chicago Asian Community Surveys* provides a baseline forum through which health care providers, public health advocates, policymakers, local organizations, and community members can work collaboratively and effectively to address specific community needs. As a result, continuing to build a database of disaggregated data is critical for medical, public health, academic, government, and community partners to work towards eliminating health disparities affecting distinct AAPI communities across the U.S.

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Section 1. Introduction

Community health data are essential to reducing the health disparities experienced by racial and ethnic minorities. The availability of racial and ethnic specific health data enables policy advisors, researchers, and service providers to develop appropriate agendas that most effectively and efficiently improve health outcomes, monitor progress in reducing disparities, and make justifications for targeted interventions. Despite Chicago's diverse population, local data sets that describe minority health are lacking, especially among the Asian population.

Although it is well recognized that community-based prevention efforts are the most effective in making change and improving health, there are virtually no local level, AAPI health data available to guide such programs or policies. Furthermore, not only is the available health data on Asian subgroups limited, but the existing data are typically aggregated, often not scientifically accepted, and rarely accessible at the community level. In an attempt to meet the data needs for the Asian communities in Chicago, the Asian Health Coalition (AHC) implemented the Chicago Asian Community Surveys (CACS) research initiative.

To fill these data needs, the CACS surveys were designed to be culturally specific and sensitive, were administered by members from the community, in partnership with community-based organizations, and in the preferred language of choice. Chicago's Chinese, Cambodian, and Vietnamese communities were selected for study, and surveys were conducted with randomly selected residents from those communities so that the data would most accurately reflect each population. The purpose of the survey was to gather data that was previously not available and would inform policy and shape public health planning to improve the health of three Chicago Asian communities. The specific goals of the CACS project were to:

- 1) Document the health status of three Chicago Asian communities using scientifically accepted methods;
- 2) Compare survey findings with other analogous local, state, and national health statistics;
- 3) Translate results into informed and targeted local interventions and programs for the overall goal of achieving improved health in each of the communities.

The first phase of CACS began in the Chinese community with funding from the Illinois Department

of Public Health (IDPH) and the Retirement Research Foundation (RRF). Following its successful implementation, the United Way of Metropolitan Chicago provided additional funding for replicating the survey in the Cambodian and Vietnamese communities. The Chicago Community Trust and Northwestern University also provided funding for the implementation and analysis of the CACS project. Project activities began in June 2006 and were completed in February 2008.

This report is the first comprehensive publication on AHC's survey project. It is divided into seven sections. Following this introduction, Section 2 offers a brief report on the demographics of the three Chicago communities surveyed: Albany Park, Armour Square, and Uptown (corresponding to the Cambodian, Chinese, and Vietnamese populations). Sections 3 and 4 present a detailed description of the methods employed to implement CACS. Both cover the processes used to develop the survey instruments, sample the populations, collect the interview data, and analyze the information. Section 5 presents the primary results from the CACS data, including eight key health topics. The concluding section discusses the implications of

the survey findings for the Chicago public health community and offers suggestions for health policy and programming.

We hope the Chicago community will use these data to shape new initiatives, advocate for improved policies, and guide effective resource allocations for improved health of AAPI populations in the future. This report is only the beginning of much more to come.

Acknowledgements

Many persons and several organizations were instrumental in the funding, design, and implementation of CACS. Without the assistance and support of the following organizations, CACS would not have been possible. Although it is not possible to name all the individuals who played an important role in the project, the authors would like to acknowledge and thank the following:

- The residents and participants of Albany Park, Armour Square, and Uptown who graciously agreed to share personal information about their health and well-being.
- Partner Community-based organizations (CBOs) and their staff for their cooperation, input, and commitment to service. Particularly, special thanks to all of the project interviewers and interns, many of whom were

affiliated or worked closely with their respective organizations, for their hard work, patience, and ability to gain the trust and respect of survey participants.

- Cambodian Association of Illinois (CAI)
- Chinese American Service League (CASL)
- Chinese Mutual Aid Association (CMAA)
- Sinai Urban Health Institute (SUHI) for their expertise, advise, generosity, and technical assistance through all stages of the project. AHC extends their thanks to the Sinai Institutional Review Board for helping to improve the survey instrument and ensure ethical review of the project.
- The New York City Department of Health and Mental Hygiene for leading the way in gathering community health surveys in large urban settings. In particular, for sharing the NYC Community Surveys and their Chinese translations with AHC.
- The Project Advisory Committee (PAC) for dedicating time to reviewing protocols, survey instruments, and offering sage advice.
- The University of Illinois at Chicago Survey Research Lab (UIC SRL) for their technical assistance with sampling.

- The generous financial support and vision of the Illinois Department of Public Health, the Retirement Research Foundation, United Way of Metropolitan Chicago, Northwestern University and the Chicago Community Trust.

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Section 2. The Communities

Defining Asian Americans

Race data are typically collected in six categories: (non-Hispanic) White, Black or African American, American Indian or Alaskan Native, Asian and Native Hawaiian or Other Pacific Islander, Other Race, or two or more of the aforementioned race categories. They are determined by the Office of Management and Budget to fulfill a variety of federal requirements (such as promoting equal access to employment and assessing racial disparities in health and exposure to environmental risks). Data are gathered in this way based on social and political considerations and not for scientific reasons. Until the 2000 Census, Asians were collapsed into a group with Native Hawaiians and Other Pacific Islanders (NHOPI). Since then, the Census has disaggregated these categories and found significant variations in the sociodemographic and economic standings of these groups. Thus, the U.S. Census Bureau expanded its questions on race and Hispanic origin in the 2000 Census. The race question separated NHOPI from Asians and provided each with their own race categorization as a way to recognize the diversity of the population.

Asians are one of the fastest growing and most diverse racial

and ethnic minority groups. Within the terms Asian American, Native Hawaiian, and Pacific Islander, there are over 50 distinct ethnic subgroups who speak over 100 different languages and dialects. There are close to 12 million people (about 4% of the population) who identified themselves as Asians in the United States. The terms “Asian” or “Asian American” are used interchangeably and refer to people having origins in the Far East, Southeast Asia, or the Indian subcontinent (for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand and Vietnam). “Native Hawaiian and Other Pacific Islander” refers to people having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands. It is important to understand that each ethnic group has its own history, language, and cultural traditions. Asians are a heterogeneous population with great sociodemographic and economic variation, and thus reflective in their health indices as well.

For many advocacy initiatives today, Asian Americans, Native Hawaiians, and Pacific Islanders are often represented together as Asian American and Pacific Islanders (AAPI) to work together to galvanize resources, raise attention to Asian

American and NHOPI issues, and garner support from the government.

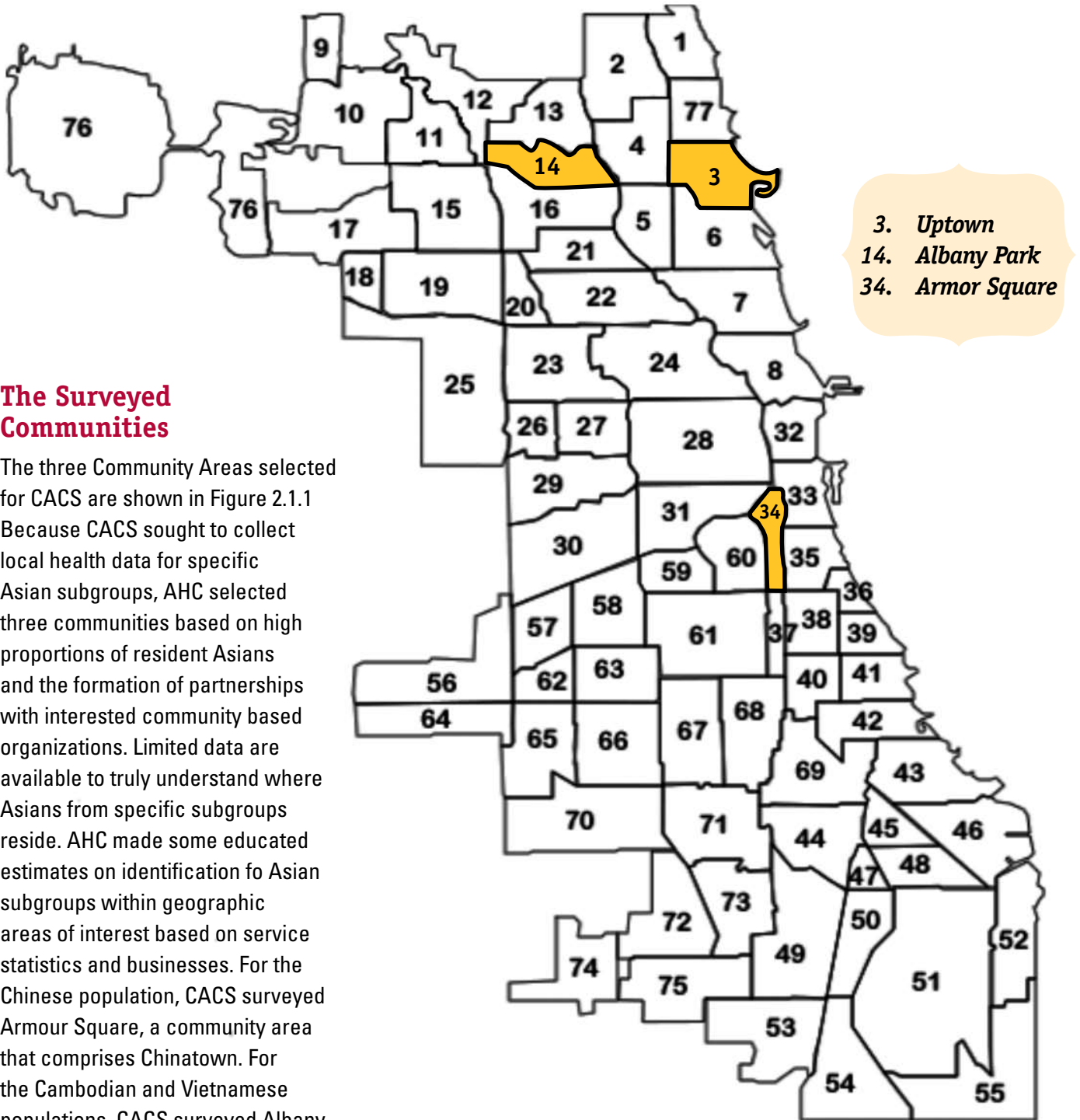
Background

In Chicago, there are about 126,000 people who identified themselves as Asian (about 4% of the population) and they live mostly on the north side of the city. The largest subgroup populations were reported as Chinese, Filipino and Asian Indian — followed by Korean, Vietnamese and Japanese populations. Asians are spread out in the different 77 Chicago Community Areas (Figure 2.1) and are at most 20–25% of a community area (except in Armour Square, also known as Chinatown, where Asians comprise 60% of the population) (Table 2.1).

Table 2.1: Top 5 Chicago Community Areas by Percent Asian Populations (2000 Census)

Community Area	% Asian	# of Asians
Armour Square	60.8	7,318
Bridgeport	26.1	8,790
North Park	23.8	4,422
West Ridge	22.3	16,286
Albany Park	17.7	10,199
Uptown	12.9	8,206

Figure 2.1.1: Chicago Community Area Map and Three AAPI Communities Surveyed



The Surveyed Communities

The three Community Areas selected for CACS are shown in Figure 2.1.1. Because CACS sought to collect local health data for specific Asian subgroups, AHC selected three communities based on high proportions of resident Asians and the formation of partnerships with interested community based organizations. Limited data are available to truly understand where Asians from specific subgroups reside. AHC made some educated estimates on identification of Asian subgroups within geographic areas of interest based on service statistics and businesses. For the Chinese population, CACS surveyed Armour Square, a community area that comprises Chinatown. For the Cambodian and Vietnamese populations, CACS surveyed Albany Park and Uptown, respectively. To the right is a description of each selected community area and the Asian population of interest.

Armour Square: Chinese

Armour Square, home of Chicago's largest Chinese community, was selected because nearly 61% of its residents identified as Asian on the 2000 U.S. Census. Moreover, AHC had a strong partnership with the Chinese American Service League (CASL), a well-established CBO in Armour Square that assisted AHC with community relations and data collection. For more details on the sampling design utilized for the Chinese community, see Section 3 and Section 4 of this report.

Uptown: Vietnamese

Uptown, located on Chicago's north side, was chosen for the second phase of CACS. Uptown is a diverse Community Area and historically a home to recent Asian and African immigrants. Nearly 13% of Uptown residents are Asian, of which 27% are Vietnamese (Chicago Asian Population Health Profile, CDPH 2005). Uptown was identified by the Chicago Community Trust and United Way of Metropolitan Chicago as a neighborhood of high need for comprehensive health data, which was a contributing factor in its selection for the CACS. Additionally, AHC's partner CBO, the Chinese Mutual Aid Association (CMAA), is located in Uptown.

Albany Park: Cambodian

The third CACS Community Area selected was Albany Park. Albany Park had the second largest number of Asians in Chicago, which was comprised of many different subgroups including Indians, Filipinos, Vietnamese, Korean, and Cambodians. However, there are no published Census data on the Cambodians living in Chicago. Unfortunately the smaller AAPI groups in Chicago are aggregated into a category of "other." Therefore, in partnership with the Cambodian Association of Illinois (CAI), a distinguished CBO serving Cambodians in Chicago since 1976, AHC implemented the CACS among Albany Park Cambodians.

As with the survey of the Vietnamese population in Uptown, the Cambodian population in Albany Park is geographically dispersed. The CACS used Respondent Driven Sampling (RDS) again in the Cambodian population of Albany Park. For more details, please see Sections 3 & 4.

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Section 3. Development of the Survey

The CACS created a comprehensive survey instrument that would cover a wide variety of health topics while maintaining the ability to compare results to analogous state and national data. Additionally, from the project's inception, AHC and its partners committed to ensuring that the communities being interviewed would have input into questionnaire design. Because the local leaders and partner CBO staff are most familiar with their communities' health needs and assets, they were recruited to oversee the survey instrument development by serving on the Project Advisory Committee (PAC).

The Chinese Community Survey

AHC and SUHI drafted the initial survey and modeled it on several national health surveys, including the Centers for Disease Control and Prevention's Behavioral Risk Factor Surveillance System (BRFSS), National Health and Nutrition Examination Survey (NHANES), and the National Health Interview Survey (NHIS). For the mental health section, questions were taken from the previously validated Center for Epidemiologic Studies-Depression Scale (CES-D). The CES-D is a 20-item questionnaire with response choices ranging on a scale from 1 to 4. The initial Chinese survey used a 10-item short version called

the CES-D 10. Nutrition questions were derived from NHANES and modified by the PAC to be more appropriate for the Chinese community's diet. In addition, the survey included culturally specific questions that the PAC determined to be important to the health of the Chinese community.

The Armour Square Project Advisory Committee

One of the objectives of this project was to engage the community in all of its steps, from the initial design of the survey to the implementation of the research protocol. To achieve this objective, AHC organized an advisory board called the Project Advisory Committee (PAC), which was composed of community members, community leaders, health administrators, and clinicians. PAC members including representatives from AHC, SUHI, the Chinese American Service League, the research and Education Foundation of Michael Reese Hospital, Rush University, Northwestern University, and the University of Chicago.

PAC members were solicited because of their leadership experience within the Chicago AAPI community and their knowledge of community health research. These members were essential in reviewing the project's materials and gaining support for the survey within

the community. The PAC provided feedback on the survey instrument to ensure that the questions asked and the health topics covered were the most relevant and important to the community being studied. The PAC met over a period of four weeks to review the research protocol, questionnaire design, and oversee the initial implementation of the project in the Chinese community.

Finalizing the Chinese Survey

After extensive review of the survey instrument, it was submitted for approval to the Sinai Health System's Institutional Review Board (IRB). Concurrently, the survey instrument was translated and back-translated from English to Chinese, and both versions were modified several times until the IRB gave final approval for the instrument. Both the Chinese and English versions were pilot tested among 20 community residents in Armour Square.

The initial set of questions for the Chinese community survey covered a range of health topics categorized into the following 4 groups: health conditions, health behaviors and attitudes, health care access, and other social or environmental factors (Table 3.1). Based on feedback from the interviewers, the Chinese survey was modified once during a pause in the data collection. Several items were added regarding child obesity,

and a few items were clarified to avoid misinterpretation. Additionally, the mental health section was modified to include the 20-item CES-D full version rather than the CES-D 10. The final revised instrument included a total of 173 items.

The Cambodian and Vietnamese Community Surveys

The Cambodian and Vietnamese survey development followed a similar process as the Chinese instrument. First, staff from CAI and CMAA met with AHC project staff to review the survey that was utilized in Chinatown. To facilitate comparisons among the Chicago AAPI communities, the survey for the Cambodian and Vietnamese was identical; additionally, whenever possible the same question utilized in the Chinese survey was included in the Cambodian and Vietnamese survey instrument. Some questions were removed and others added according to the suggestions of CBO partners and based on the response rates of questions in the Chinese survey. The principal changes in the Cambodian and Vietnamese survey instrument were to the nutrition and diet section. Rather than documenting the participant's nutritional intake, questions queried the nutritional value of certain foods (i.e. "Do you think mangos are high or low in added sugar?"). Questions asked about foods that were common to the Asian diet, such as rice noodles, tofu, and soy milk. Additionally the section on physical activity had a low response

Table 3.1: Survey Topics

Health Conditions	Health Behaviors and Attitudes	Health Care Access	Other Social or Environmental Factors
Tuberculosis	Diet/Nutrition	Primary Care	Education
Hepatitis	Smoking	Health Coverage	Employment
Diabetes	Alcohol	Cancer Screening	Income
Hypertension	Physical Activity	Vaccination	English Proficiency
Cholesterol	HIV/STDs	Medication/Supplements	Sense of Community*
Other Diseases	Obesity		
	Accident Prevention		
	Mental Health		
	Self-Rated Health		

* Topic in Cambodian and Vietnamese surveys only

rate from the Chinese survey and was omitted, while a section was added using the Sense of Community Index to capture other social or environmental health factors.

The Albany Park and Uptown Project Advisory Committee

After the survey draft was created by AHC, CAI, and CMAA staff, a PAC was recruited from community members of Albany Park and Uptown. The Uptown and Albany Park PAC members included representatives from AHC, SUHI, the University of Illinois Medical Center, Rush University, the Institute for Research on Race and Public Policy, and Northwestern University and functioned identically to the Armour Square PAC. Members met over a period of 5 weeks and reviewed the project's sampling design, survey instrument, and management plans. Questions on the survey instrument were modified according to the PAC's suggestions.

Following approval from the PAC, AHC worked closely with CAI and

CMAA to translate the document into Khmer and Vietnamese. Interviewers from CAI and CMAA worked with AHC's project director to translate and back translate the English version; additionally, each question was reviewed independently to ensure the meaning was accurately translated. Pilot testing was conducted informally at each study site (CAI and CMAA) with approximately 5 community volunteers per project interviewer. The interviewers practiced the instrument with volunteer participants and afterward discussed any difficulties with AHC's project director. The pilot testing gave interviewers the opportunity to practice asking the survey questions following protocol guidelines. Moreover, the pilot testing offered the interviewers and project director an opportunity to make final changes to specific questions and phrases that were problematic during the practice interviews. The final set of questions for the Cambodian and Vietnamese surveys contained 203 items (Table 3.1).

Section 4. Data Collection and Analysis

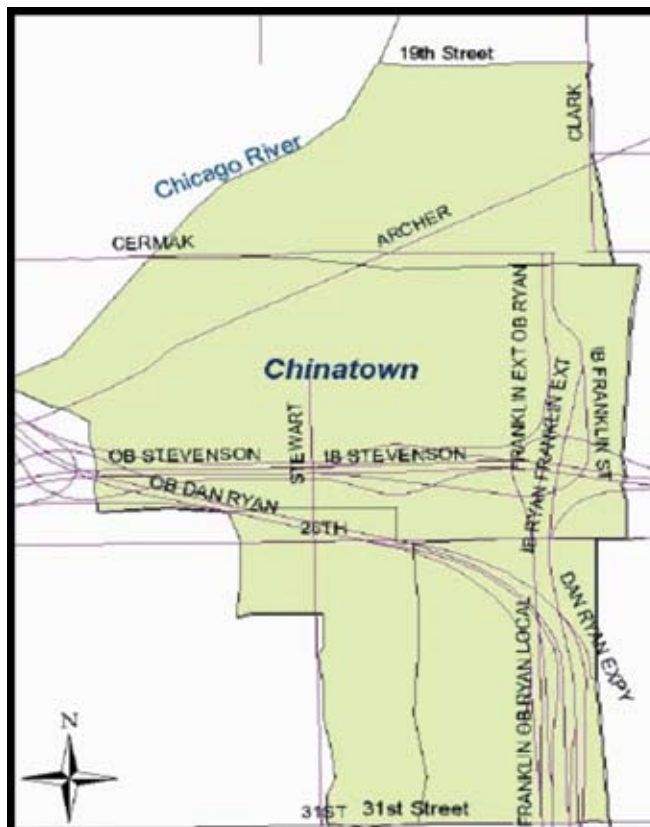
The first step of CACS data collection was to select a scientific sampling method that was feasible for each community. In collaboration with UIC's SRL, AHC and SUHI explored a variety of potential sampling methods. While telephone and internet surveys are popular methods for many research studies, AHC felt that many residents in the Asian community, particularly those with heavier health burdens, would be more receptive to face-to-face interviews. Since the Chinese survey

was conducted in Armour Square, where the community area was densely populated with Chinese residents, it was possible to conduct random door-to-door sampling. On the other hand, the Cambodian and Vietnamese residents were more widely dispersed in the Albany Park and Uptown community areas. Thus, AHC had to be creative in choosing a method that would find these harder to reach populations and decided to pilot test Respondent Driven Sampling (RDS) in these two communities.

Chinese Health Survey

Data collection for the Chinese health survey took place in two phases; first from November 2006 to January 2007 and resumed again from June 2007 to March 2008. The Armour Square community strongly supported the project and the response rate was higher than most community-based door-to-door surveys. The positive experience of the interviewers and project staff demonstrated the willingness of Chicago's Chinese community

Figure 4.1.1: Designated Study Area – Chinatown (Armour Square) Census Tracts



Census Tracts 3401–3404

Street Boundaries:

18–19th Street to North
Chicago River to West
31st Street to South
Clark/LaSalle Streets to East

to participate in such community-based health initiatives. Prior to data collection, the research protocol, survey materials, informed consent forms, and the interviewer trainings were approved by the Sinai Health System's IRB.

Sampling Design

The University of Illinois at Chicago's Survey Research Laboratory (SRL), a department at the university with expertise in survey organization, implemented a three-stage probability sampling design to gather the most accurate health profile of the Chinese community. In the first stage, 4 census tracts in Armour Square were chosen for having the highest percentage of Asian adults living in the area according to the 2000 U.S. Census (see Figure 4.1.1). Sampling in these tracts increased the probability that a randomly selected individual was Asian, and most likely Chinese. Next, 30 census blocks were randomly selected among the 4 census tracts. Utilizing U.S. Postal Service data, SRL compiled the addresses of every household and apartment building on those blocks and assigned identification numbers to each household. Finally, in the third stage, one member from each household was selected for participation in the study using a random selection tool derived from the Trodahl-Carter-Bryant selection matrix.

Random selection of household respondents was necessary to reduce selection bias and enable a diverse sample of participants according to demographic and

health characteristics. For instance, elderly residents were more likely to be home during regular working hours. However, if only elderly residents were recruited for the study, then AHC would not have collected a random sample of all Chinese residents in the Armour Square community. Using the selection matrix-insured that household members were selected at random, independent from factors such as who answered the door and whether or not they were home at the time. Household members were eligible if they self-identified as Asians, were at least 18 years of age, were able to provide written informed consent, and lived in the community for at least 6 months.

Data Collection

AHC hired and trained 8 interviewers for the Chinese survey, 5 of whom were residents from Chinatown. All of the interviewers spoke English and either Cantonese or Mandarin; 3 interviewers were able to conduct the survey in all three languages. AHC provided a series of 3 trainings that provided background about the research project, which included practice administering the survey, and gathered feedback about the questionnaire's translation. SUHI and UIC's SRL both assisted with the trainings to provide comments regarding their first hand experiences in other Chicago communities.

Prior to officially starting data collection, AHC and its partners held a press conference at CASL to introduce the project and the interviewers to the community.

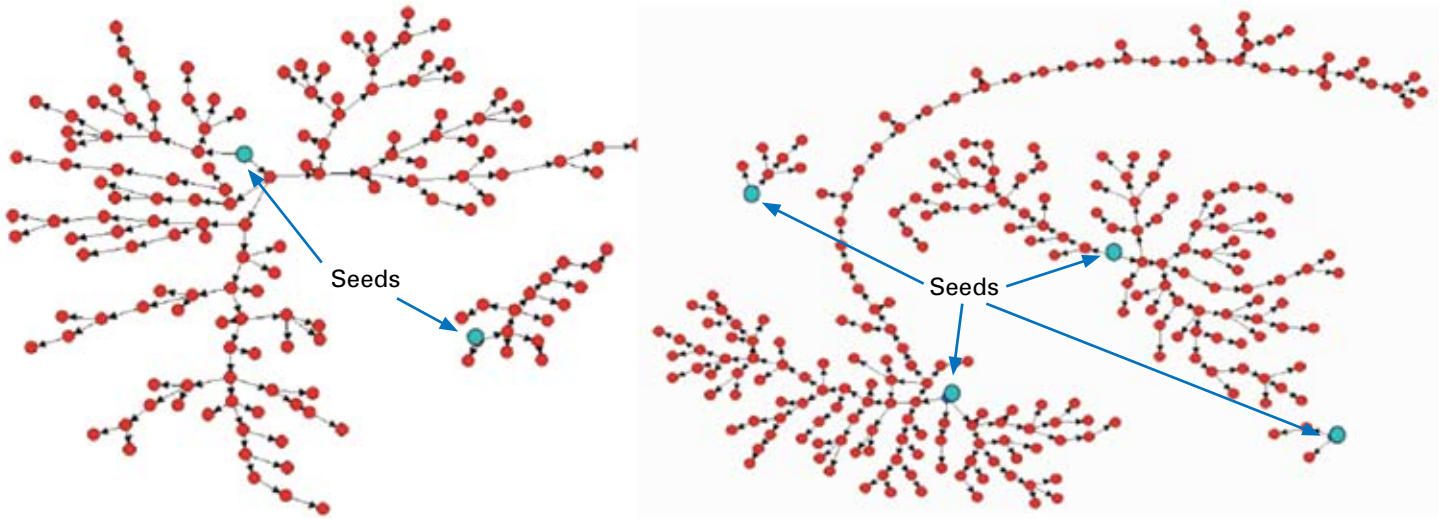
Popular Chinese newspapers published articles about the survey and included a picture of the project team so the community could become familiar with the interviewers.

The interviews were conducted in Cantonese, Mandarin, or English according to participants' preferences. The questionnaire took about 45 minutes to complete. Upon completion of the survey, participants received \$20 as compensation for their time. A total of 19 blocks were visited and 385 surveys collected. Two interviews were excluded because they were non-compliant with research protocol, and 383 were available for data analysis.

Response Rate

Interviewers were trained to explain the risks and benefits for completing the survey and participation was strictly voluntary. Interviewers visited a total of 904 households and of them, 572 (63%) of units were eligible (i.e. current residencies). Interviewers subsequently made contact with 447 eligible household members, of which 385 agreed to participate and complete the survey. The participation rate, defined as the number of interviews divided by the number of eligible respondents, was 86.1%. The overall response rate, defined as the number of interviews divided by the eligible sample, was 67.2%. According to interviewer feedback, common reasons for participant refusal were: 1) no time; 2) too busy; 3) generally not interested in surveys; and 4) wary of further solicitation and release of private information.

Figure 4.1.2: Albany Park (Cambodian Community) and Uptown (Vietnamese Community) Respondent Driven Sampling Waves



Data Analysis

Data was entered by AHC staff using Microsoft Excel and imported into SPSS version 14.0 for analysis. Paper copies of surveys, without identifiers or linking information, are stored in locked files at AHC. Survey data was weighted to account for the probability of selection from his/her household. For instance, while all the households on a block were sampled, a respondent living in a household of 2 had a higher probability of being selected than a respondent living in a household of 5.

Cambodian and Vietnamese Health Surveys

Although many AAPI residents live in Albany Park and Uptown, the communities are less densely populated than in Armour Square.

The relative dispersion of Albany Park’s Cambodian population and Uptown’s Vietnamese population prohibited AHC from using the door-to-door approach utilized in Armour Square. In an attempt to maximize resources, survey the largest number of Albany Park and Uptown participants, and maintain scientific sampling, AHC elected to pilot the use of a relatively new technique known as Respondent Driven Sampling (RDS) to obtain a representative sample from these hard to reach populations.

Sampling Design

RDS has emerged as an important scientific sampling method for reaching populations that are traditionally hard to recruit. Building on snowball sampling, after completing an interview RDS asks participants to invite their peers

to join the study. In this process, RDS also gathers information on social network size to consider the randomness and representativeness of its sampling.

Typically, three “seeds” are chosen to initiate the survey. They are given recruitment coupons to distribute to their peers. After the seeds are chosen, the only participants eligible for the study are those with a coupon (See Figure 4.1.2). Each coupon is given a serial number and the relationship between participants and their recruits is recorded.

Data Collection

CAI and CMAA staff interviewers were trained on RDS methodology and AHC’s CACS project protocol. After interviewers were familiar with the survey instrument, two and four seeds were chosen from Albany

Park and Uptown, respectively from the phone book, employing common-surnames. Each seed was given three coupons printed on heavy color-coded paper. The coupons contained contact information regarding how to participate in the study, and a serial number that was linked to the seeds' names in a database.

The seed participants were asked to recruit up to three eligible peers by giving them the coupons. Each new survey participant, upon completing the survey, was given the same instructions. Eligibility criteria for the survey included: 18 years of age or older, self-identifying as Vietnamese or Cambodian, able to speak English, Khmer, Vietnamese, or Cantonese, proof of Albany Park or Uptown residency, and a valid study coupon. If the new participant was deemed eligible by the study staff, they were given informed consent. The coupon numbers were recorded in a database. As per RDS guidelines, all new participants were asked to estimate their social network size, defined as an estimate of the number of people the participant knew in the community area, and describe the type of relationship between themselves and the referring participant (i.e. friend, relative, acquaintance). After completing the survey, participants were compensated \$20 for their time and \$5 for each referred participants.

The Cambodian survey achieved 100% of its target sample in 12 weeks and the Vietnamese survey completed 100% in 21 weeks. There are no participation or response rates in RDS methodology. Rather, participation is tracked by the number of recruitment waves it took to reach the target sample size. In general, the number of waves it takes to reach the target sample size depends on the social network size of the recruiters, and in particular the seeds. It took 13 waves to recruit 150 for the Cambodian survey and 35 waves to recruit 250 for the Vietnamese survey, both of which reached enough recruitment waves to achieve a random sample.

Data Analysis

Data was entered by AHC staff using Microsoft Excel and imported into SPSS version 14.0 for analysis. Paper copies of surveys, without identifiers or linking information, are stored in locked files at AHC.

Data was weighted to social network size using the RDS Analysis Tool (RDSAT) version 5.6. In particular, weighting accounts for oversampling of groups with larger social networks who tend to recruit more effectively than others and over represent certain social categories.

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Section 5. Health Topics

This section presents eight key survey findings from the CACS survey. Table 5.1 describes demographics of the study populations (Chinese, Cambodian, and Vietnamese). Data presented on each subsequent health topic include prevalence estimates (i.e. rate of diabetes) and relevant descriptive statistics (i.e. percent women who have diabetes).

5.1 INSURANCE COVERAGE AND ACCESS TO HEALTH CARE

Background

In 2006, there were 47 million people in the U. S. without health insurance (16% of the population). Minorities and youth are at greatest risk of not accessing essential health care and the proportions of uninsured have increased in recent years for all income levels, making health care increasingly inaccessible for all.

Asian American adults (18%) are less likely to be uninsured than White adults (15%) but more likely to be insured than others (41% of Hispanic, 40% American Indian or Alaskan Native (AIAN) and 23% of Black adults insured). However, among Asian American subgroups, Korean adults were least likely to be

Table 5.1: Survey Demographics

**Among those who are foreign born*

		Chinese % (N = 383)	Cambodian % (N = 150)	Vietnamese % (N = 250)
Gender	Male	44 (150)	37 (53)	41 (98)
	Female	56 (233)	63 (97)	59 (152)
Age	18-44	30 (91)	48 (63)	29 (66)
	45-64	34 (107)	36 (54)	47 (116)
	65+	37 (170)	16 (30)	24 (68)
Education	Less than HS	54 (218)	55 (89)	50 (134)
	HS or more	46 (158)	45 (61)	50 (112)
Income	Less than \$30,000	69 (283)	59 (88)	85 (83)
	\$30,000 or more	31 (98)	23 (45)	15 (12)
Birthplace	U.S. born	7 (24)	20 (20)	–
	Foreign born	93 (358)	80 (128)	100 (250)
Years in U.S.*	0-4 years	24 (74)	19 (13)	24 (43)
	5+ years	68 (275)	81 (137)	76 (207)
Spoken English Proficiency	Very well/Well	25 (85)	42 (63)	15 (31)
	Not well/Not at all	75 (297)	58 (87)	85 (210)
Self-Rated Health	Excellent/Very Good/Good	56 (198)	49 (69)	45 (112)
	Fair/Poor	43 (182)	51 (81)	55 (138)

Confidence intervals and statistical significance for all the data in this report are available and may be requested by contacting the Asian Health Coalition.

insured (36%). Insurance coverage varied substantially among Asian American subgroups, ranging from 9% uninsured among Japanese adults to 18% of Asian Indian adults and Vietnamese adults.

Having insurance coverage is associated with having a usual source of care, use of preventive services and timely, appropriate medical care. In general, Asians

are more likely to be without a usual source of care compared with Whites. However, insured Asians are more likely to have a usual source of care compared with uninsured Asians or uninsured Whites. Specifically, 52% of uninsured Asians lack a usual source of health care and 51% are less likely to have visited a doctor in the last year compared to their White counterparts (46% and

39%, respectively). Poor language concordance, lack of trust, limited cultural competency of provider and poverty are other barriers to usual care and routine services.

Survey Results

The Chicago Asian Community Survey contained 14 questions about access to health care services. Respondents were asked about insurance coverage, usual source of care, use of prescription medications, and language barriers to obtaining care.

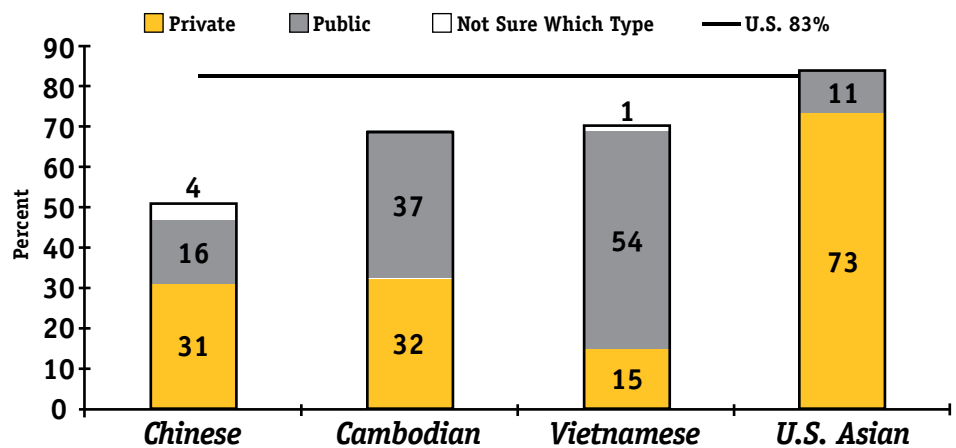
Insurance Status

Figure 5.2.1 presents the proportion of adults 18–64 years old who have health insurance. Compared to two-thirds of Cambodian adults (69%) and Vietnamese adults (70%) with insurance, only half (51%) of non-elderly Chinese American adults in Armour Square report having some form of insurance. In comparison, 88% of Asian Americans nationally and about 85% of adults in Chicago are insured.

Usual Source of Care

Non-elderly adults who were uninsured were less likely to have a regular health care facility (Table 5.2.2). They were also less likely to access preventive health care services, such as screening for high blood cholesterol (Table 5.2.2). For instance, among uninsured Chinese and Cambodian adults, only 34% and 39%, respectively, ever had their blood cholesterol checked.

Figure 5.2.1: Percent of Adults 18–64 Who Have Health Insurance



U.S. estimates of having any type of health coverage from the Behavioral Risk Factor Surveillance System, 2006

U.S. Asian estimate from Kaiser Family Foundation and the Asian Pacific Islander American Health Forum, Race, Ethnicity, and Health Care Fact Sheet, 2008.

Table 5.2.2: Percent of Adults with Selected Health Measures by Insurance Status

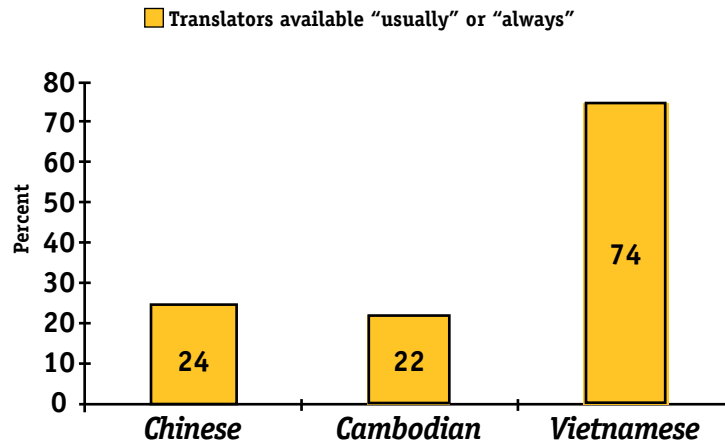
	Chinese		Cambodian		Vietnamese	
	Insured	Uninsured	Insured	Uninsured	Insured	Uninsured
Has a Usual Source of Care	90	42	84	46	98	72
Diagnosed with Hypertension	37	13	35	11	50	12
Diagnosed with Diabetes	13	6	16	11	22	16
Ever Checked Blood Cholesterol	73	34	69	39	92	72

In addition, we found that for all three subgroups, those who were insured were more likely to have been diagnosed with hypertension and diabetes.

Language Barriers

The survey also asked adults what language they preferred to communicate in with their doctor. The vast majority (89%) of the Vietnamese population preferred to communicate in non-English (Vietnamese) followed by 70% of Chinese (Mandarin or Cantonese) and 65% of Cambodians (Khmer).

Figure 5.2.2 shows that among those who preferred to speak a non-English language with their physician, only 24% of Chinese and 22% of Cambodian adults had frequent access to translator services compared to 74% of Vietnamese adults. In addition, 47%, 18%, and 22% of Chinese, Cambodian, and Vietnamese adults, respectively, “usually” or “always” brought a family member or friend to translate for them.



Conclusion

National averages for Asians conceal important variations in insurance coverage by subgroup. Consistent with national surveys, CACS findings suggest that there is large variation in health coverage among Chicago Asian subgroups. Asians in Chicago are more likely to be uninsured compared to national estimates of the same ethnic group. From available national data, 16% of non-elderly Chinese were uninsured compared with 49% of Chinese in Armour Square and 21% of Vietnamese compared to 30% of Vietnamese in Uptown. Survey data indicate substantial geographic and ethnic variation in health both between Asian communities and between national estimates.

Insurance coverage is important factor to understanding a population’s health status and access to health and preventive services. In all three Asian populations, the uninsured are less likely to have a routine source of care, receive preventive care or be aware of any chronic condition that they may have.

Health care interpreter services are available in different languages as mandated by law. However, CACS survey data show that limited translator services are available in Cantonese, Mandarin, Vietnamese, and Khmer for patients with limited English proficiency in these communities. In addition, certain Asian populations lack adequate health insurance coverage and consequently, limited access to essential primary care services. Most notably, data observed significant disparities in the diagnosis of diabetes and hypertension between insured and uninsured adults (Table 5.2.2). This is likely due to the way that prevalence questions are asked; adults were asked if they were ever told by a doctor or physician that they have a given condition. The likelihood of someone having been diagnosed with a condition assumes they have a doctor, usual source of care, and insurance. Lack of insurance often results in late diagnosis of health conditions and thus, could lead to higher costs for treatment or disease management, increased morbidity, or preventable death.

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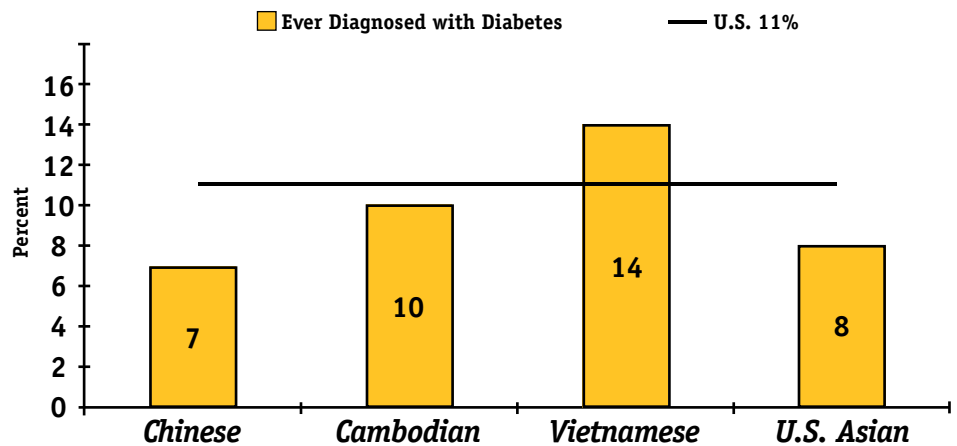
5.2 DIABETES

Background

An estimated 24 million Americans, or 11% of the adult population, has diabetes. Among them, 18 million have been diagnosed with

diabetes and an estimated 6 million are unaware that they have the condition. National data indicate that 8% of Asians have been diagnosed with diabetes compared to 7% of Whites, 10% Hispanics, and 12% non-Hispanic Blacks. Regional estimates of disaggregated Asian data suggest far greater disparities, particularly for certain populations such as Japanese Americans (5%) and Asian Indians (14%). Asians who migrate to the U.S. are at increased their risk of developing diabetes (and obesity) because of changes in the diet and activity level. However, the lack of prevalence data for this population often lead many health care providers, social service organizations, and even people of Asian descent under-recognize their increased risk of developing diabetes.

Figure 5.1.1: Percent of Adults Ever Diagnosed with Diabetes*



*Age-adjusted to the 2000 U.S. Census

U.S. estimate from the National Diabetes Information Clearinghouse, National Diabetes Statistics, 2007

U.S. Asian estimate from the National Health Interview Survey, 2004-2006 among adults aged 20yrs or older

† Note, sufficient data are not available to derive national prevalence estimates of both diagnosed and undiagnosed diabetes for Native Hawaiian and other Pacific Islander population.

Table 5.1.2: Percent of Adults Screened for or Diagnosed with Diabetes by Insurance

	% Screened		% Diagnosed	
	Insured	Uninsured	Insured	Uninsured
Chinese	66	39	13	6
Cambodian	64	37	16	11
Vietnamese	87	67	42	9

Survey Results

The survey instrument contained 12 questions on diabetes. In accordance with national health surveys, respondents were asked whether they had ever been diagnosed with diabetes by a doctor or other health professional, to estimate diabetes prevalence. Respondents were also asked whether they had ever been tested for diabetes, about their family history, and how individuals diagnosed with diabetes managed their condition.

Figure 5.1.1 presents variation in the prevalence of diabetes among the Chinese, Vietnamese and Cambodian populations surveyed compared to Asian Americans nationally

(7.5%). Among the Vietnamese population, 14% of adults reported they had ever been diagnosed with diabetes compared to 10% among Cambodians and 7% among Chinese.

Consistent with national trends on insurance coverage, survey data found that insured adults were likely to be screened for or diagnosed with diabetes than uninsured adults in all three Asian populations (Table 5.1.2).

Respondents were also asked several questions on family history of diabetes. Among adults who have an immediate family member with

diabetes, only 50% of the Cambodian population reported that they were ever tested for the condition. This compares to 74% of Chinese adults and 86% of Vietnamese adults with immediate family members with diabetes who reported ever being tested. Overall, more Vietnamese adults reported that they were ever tested for diabetes (80%) compared to Chinese (74%) and Cambodian (55%).

Lastly, with regards to the management of diabetes among those ever diagnosed, about 75% of all three Asian groups reported that they were taking pills to lower

their blood sugar and almost all respondents (89–100%) were managing their diabetes with changes to their diet, exercise or both. Similarly, 76% of Cambodian adults diagnosed with diabetes have ever taken a diabetes education class compared to only 20% of Chinese and 18% of Vietnamese adults.

Conclusion

While Chicago has been noted to have one of the highest diabetes rates among all metropolitan areas in the U.S., minorities are particularly at risk. For the first time, we have documented these rates for Chinese, Cambodian, and Vietnamese Asian subgroups and the need to address the burden of diabetes in these communities. Most notably, survey data found disproportionately high rates of diabetes prevalence among the Vietnamese population. To our knowledge, no other data source internationally or nationally has documented such high rates for this Asian subgroup population.

Survey data suggest that insurance status may contribute to the likelihood of being screened, diagnosed, and/or aware of their condition. This is consistent with national data that suggest, despite high rates of diabetes, roughly 33% of U.S. adults are still unaware of their condition due to lack of insurance and access to screening. Furthermore, even with access to care, only two-thirds of Cambodian and Vietnamese insured adults have been screened for diabetes and even fewer among those who

are uninsured. Such local evidence calls for greater resources and new programs to screen and treat adults in these communities.

In addition, language appropriate diabetes education classes need to be targeted in these Asian communities, particularly for the Chinese and Vietnamese populations in Armour Square and Uptown, respectively. The high enrollment of diabetes education classes observed among Cambodians might be the direct results of the Cambodian Association of Illinois (CAI)'s participation in the National Cambodian American Health Initiative (NCAHI), which includes a comprehensive diabetes campaign and training. Such data suggest that involving community based organizations in state or national initiatives may be an effective way to help management of diabetes in Asian populations.

Lastly, diabetes management and treatment places a tremendous burden on health care expenditures in the U.S. In 2007, the total estimated health care costs associated with diabetes was \$174 billion. Without more preventive efforts to increase screening and access to culturally appropriate diabetes education classes, the cost of managing diabetes will soon outweigh the burden of disease on society. Because diabetes incidence increases with age, more and more people are affected by this disease as the overall U.S. and U.S. Asian population ages.

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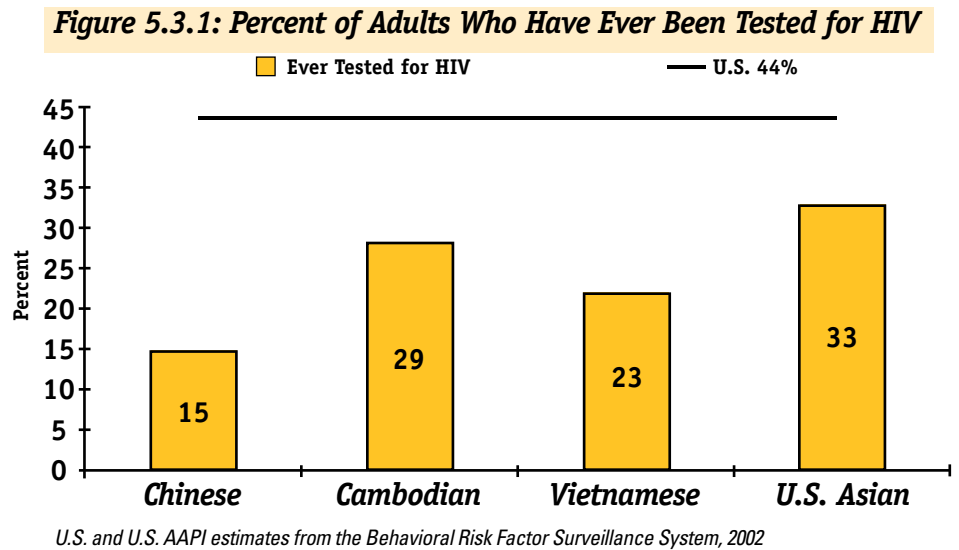
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5.3 HIV/AIDS

Background

In the U.S., the first available data under CDC's reorganized surveillance system estimated 56,300 new HIV infections in 2006, 16,000 more than was previously believed. Until recently HIV surveillance among Asian and Pacific Islanders was inconsistent or completely uncollected, and for many years the disease received little attention in the Asian community. However, in 2007, CDC reported that Asians were the only racial/ethnic group in the U.S. to experience statistically significant increases in HIV/AIDS diagnosis rates.

One major concern for the Asian community is inadequate HIV/AIDS counseling and testing. National data from 2002 demonstrated that only 33% of Asians and Pacific Islanders (APIs) had ever received an HIV test compared to 43.5% among the rest of the population. Similarly, only 10% of APIs had received an HIV test in the previous 12 months compared to 12.4% among the rest of the population. Due to high HIV/AIDS



stigma, low-levels of perceived risk, and a lack of language appropriate testing centers, Asians may have challenges learning their status. Nationally, 40% of APIs develop AIDS within a year of their first HIV test, a figure that is higher than any other racial/ethnic group. In 2004, more than 32% of Chicago Asians who tested positive for HIV progressed to AIDS within one year.

Survey Results

In the survey, participants were asked to answer a short section about their sexual health behaviors that included questions on HIV testing history and sexually transmitted disease prevention practices. Due to the sensitive nature of these questions, participants who could read and write in English, Chinese, Khmer, or Vietnamese received a separate response sheet to fill out instead of responding to interviewers' verbal questions. Linked only by study identification number, the completed HIV-section response sheet was

then enclosed in a sealed envelope to ensure the anonymity of participants' responses.

Nearly 88% of all participants responded to the survey question regarding lifetime history of HIV testing. Of those who responded, only 19.9% had ever been tested for HIV. Lifetime history of ever getting tested for HIV was reported in the Chinese, Cambodian, and Vietnamese survey, by 15%, 29%, and 23% of participants, respectively (Figure 5.3.1). This is compared to 53% for Chicago (not shown in figure), 33% for U.S. APIs, and 44% for U.S. overall. Compared to age adjusted city and national data, the percent of participants who received an HIV test is disproportionately low.

The CACS survey found that persons living in the U.S. for longer periods of time were more likely to report ever been tested for HIV. Similarly, participants who self-reported speaking English well or very well were significantly more likely

to report a lifetime history of an HIV test. Those participants who reported previous testing for sexually transmitted infections, knowledge of HIV, or who knew someone with HIV were also more likely to have ever been tested for HIV.

Conclusion

The surveys conducted in the three Chicago Asian communities highlight the need for more HIV related programming targeted at local Asian subgroups. Specifically, the Chicago Asian community still faces significant barriers due to HIV stigma. The low response rate to questions regarding HIV, coupled with anecdotal information from interviewers, suggests that the disease remains a source of embarrassment and fear for community members. Increased HIV educational programming that targets disease awareness and stigma reduction is recommended. While the Chicago community currently participates in national Asian HIV awareness activities, the development of community specific programs that are more frequent, individually tailored, and linguistically appropriate will help reduce existing stigma.

Another major concern highlighted by the survey is HIV testing frequency. Low testing rates are likely driven by lack of linguistically and culturally appropriate counseling and testing facilities. More HIV counseling and testing sites are needed with specific

services focused on AAPIs. Additionally, all HIV documentation and data collection activities should include disaggregated information on ethnicity and Asian race. Proper HIV data collection in Chicago is essential for the Asian community to track new infections and target prevention programs and resources.

Finally, more research on HIV risk behaviors among Asians in Chicago is needed. Although HIV rates among Asians in Chicago and the U.S. are lower than other minority groups, documentation of high-risk behaviors among AAPI men who have sex with men (MSM) exists in urban areas across the country. In Chicago, however, little or no information has been published on risk behaviors among Asians.

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5.4 COLORECTAL CANCER SCREENING

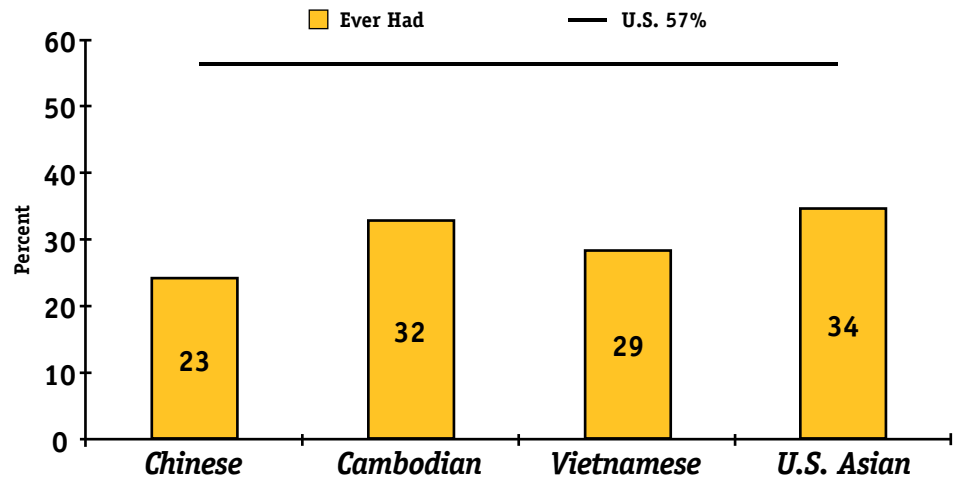
Background

Colorectal cancer (CRC) is a cancer that occurs in the colon or rectum. Most often, CRC develops from precancerous polyps (abnormal growths) that can turn into cancer over time. CRC affects both men and women and occurs more commonly among those 50 years and older. In the U.S., CRC is the second leading cause of cancer-related deaths. The incidence, anatomical distribution and mortality of CRC among Asians have changed significantly over the past few years. For instance, CRC incidence is greater in Singapore and several areas of Japan than in the U.S. In 2002, Japanese individuals born in the U.S. had higher rates of CRC than U.S. whites, with rates in Los Angeles and Hawaii ranking among the highest in the world.

Important screening exams for CRC are the fecal occult blood test (FOBT), sigmoidoscopy, and colonoscopy. These tests are recommended for all men and women age 50 years and older. About half of all CRC deaths can be prevented through routine screening. Lack of adherence to CRC screening recommendations is correlated with racial/ethnic minority status, lower income, lower educational level, and lack of health insurance. While CRC ranks among the top three most common cancers for several Asian ethnic groups, screening remains underutilized. Screening for CRC remains particularly low among Asians, with variation between specific Asian subgroups.

Obstacles to CRC screening include: low levels of knowledge about CRC; lack of familiarity with screening guidelines and tests; lack of perceived susceptibility to disease; perception that CRC screening is unnecessary in the absence of symptoms; lack of availability and access to screening tests; lack of recommendation by a doctor; general inconvenience; belief that the test is embarrassing and unpleasant; fear of abnormal results and surgery; and concern about financial costs. In addition to the barriers reported by the general population, foreign-born, low acculturation, and residing in households with three or more individuals are also negatively associated with CRC screening by Asians and Pacific Islanders.

Figure 5.4.1: Percent of Adults 50 Years or Older Who Have Ever Had a Colonoscopy or Sigmoidoscopy



**Age-adjusted to the 2000 U.S. Census
 U.S. estimate from the Behavioral Risk Factor Surveillance System, 2006
 U.S. Asian estimate from the National Health Disparities Report, 2007*

Table 5.4.2: Percent of Adults 50 Years or Older Who Have Ever Had a Colonoscopy or Sigmoidoscopy by Insurance

	% Screened	
	Insured	Uninsured
Chinese	31	8
Cambodian	34	40
Vietnamese	33	24

Survey Results

The CACS survey included two questions on CRC screening: “Have you ever had a sigmoidoscopy or colonoscopy?” and if so, “How long ago did you have a sigmoidoscopy or colonoscopy?” Questions were not asked about FOBT. Data are presented for adults age 50 years and older.

The proportion of adults aged 50 and older who reported ever having a sigmoidoscopy or a colonoscopy was 23% Chinese, 32% Cambodian, and 29% Vietnamese, compared to

57% nationally (Figure 5.4.1). Even fewer adults reported having had a screening exam in the past 5 years.

Survey data revealed that insurance played an important role in access and timely screening for CRC (Table 5.4.2). Overall, among adults 50 years and older, 75%, 88%, and 83% of Chinese, Cambodian, and Vietnamese, respectively reported they were insured and thus had access to CRC screening that would be covered by their insurance. However, only one-third of those insured actually were screened. Most notably, 31% of Chinese adults

50 years and older who were insured had ever been screened compared to only 8% without insurance. Thus, even in the face of insurance coverage for screening, eligible adults in this survey did not get screened.

Conclusion

Surveys among routinely understudied populations, such as CACS, reveal true estimates that empirically demonstrate areas of health need. Without an understanding of a population's cancer screening behaviors, how can providers and policy makers recognize that there is a true need for targeted programming? Lack of provider knowledge and little public knowledge about screening and screening guidelines pose significant barriers to improving CRC screening rates among Asians in Chicago and across the country. Both new and ongoing educational efforts must target patients and providers.

Routine screening is highly encouraged for the prevention of colorectal cancer. Culturally and linguistically appropriate educational campaigns that provide information regarding the importance of screening and how to obtain screening will benefit both providers and patients. Moreover, in order

to more accurately explain cancer screening tests, it is essential that providers who care for Asian patients have access to translators that are not family members.

Increasing Medicare reimbursements for colorectal cancer would alleviate patient concerns regarding out-of-pocket costs. Such public funding could also guarantee that patients needing follow-up would receive treatment and services without the burden of high costs. Lastly, we encourage health care systems to implement measures that will help providers and patients comply with testing procedures and referrals to increase screening rates and reduce mortality.

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5.5 BREAST CANCER SCREENING

Background

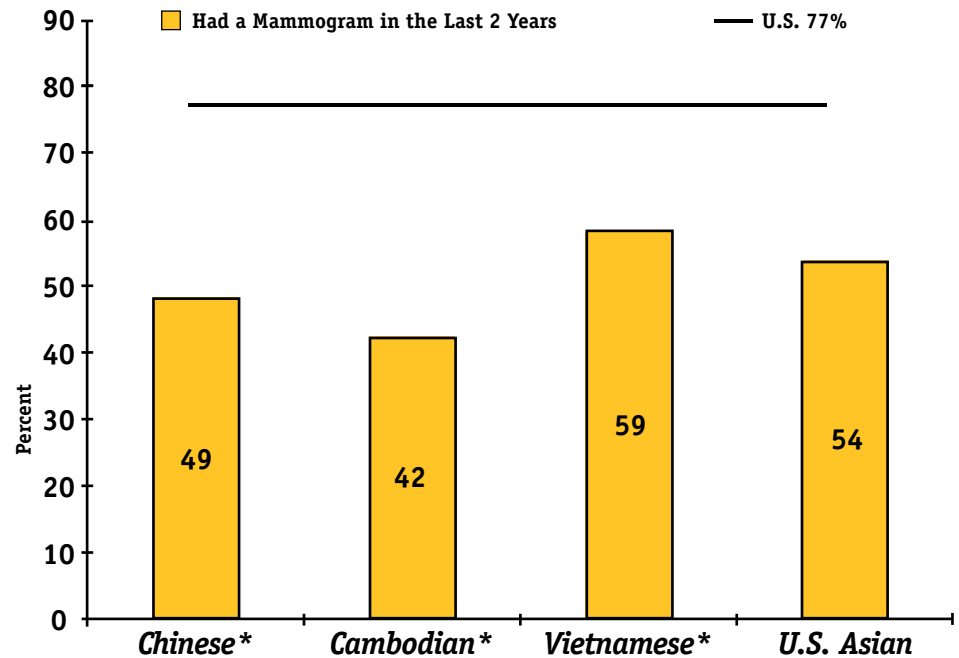
Breast cancer is the second leading cause of cancer death among women in the U.S. It is estimated that almost one out of every three cancers diagnosed is breast cancer. Although breast cancer rates among Asians are lower than other racial/ethnic groups, screening rates are also disproportionately lower.

Epidemiological evidence demonstrates that when women immigrate to the U.S., the risk of lifetime breast cancer rises to six times that of women in their native countries. Asian women overall have a lower incidence rate of breast cancer (97.2 per 100,000)

compared to their non-Hispanic white counterpart (140.8 per 100,000) and experience relatively low breast cancer mortality rates. Nevertheless, disparities in breast cancer outcomes are evident among Asian subgroups. For instance, breast cancer is the most commonly diagnosed cancer among Chinese American women. Breast cancer incidence for Japanese American women is now approaching rates for non-Hispanic White women. Moreover, several Asian subgroups experience increased risk of advanced stage cancer at diagnosis, higher rates of inappropriate treatment, and worse survival rates after breast cancer diagnosis.

Despite significant progress in the early detection of breast cancer in the U.S., such cancer continues to be the leading cause of death among Chinese and other Asian women. Few studies have reported specific rates of mammography screening among Asian subgroups. Mammography use by Asians in Illinois remains poorly documented because fewer than 50 respondents were represented in the state's Behavioral Risk Factor Surveillance Survey (BRFSS). Current research on breast cancer screening practices has demonstrated low rates of recent mammography use among various Asian groups. In addition, the perception that if one is feeling healthy a mammogram is unnecessary and the long wait time were common barriers to screening.

Figure 5.5.1: Percent of Women 40 Years or Older Who Had a Mammogram in the Last 2 Years



*Age-adjusted to the 2000 U.S. Census

U.S. estimate from the Behavioral Risk Factor Surveillance System, 2006

U.S. Asian estimate from the National Health Disparities Report, 2007

Survey Results

The CACS survey asked a series of questions regarding breast cancer screening. The first question asked was, "Have you ever had a mammogram or a breast X-ray?" If yes, women were then asked, "How long ago did you have your last mammogram?" These are the exact questions asked on the national BRFSS. Lastly, if they had never been screened, women were asked, "What is the main reason why you have not had a mammogram?" Data presented in this section is among women 40 years and older.

Overall, 63% of Chinese, 75% of Vietnamese, and 76% of Cambodian women 40 years or older have ever had a mammogram or breast X-ray. Figure 5.5.1 depicts the proportion of women aged 40 and older who reported having had a mammogram within the last two years. These screening rates ranged from 49% among Chinese women to 59% among Vietnamese women. All three Asian subgroups were well below the U.S. estimate of 77%.

For women who did not receive a mammogram in the last 2 years, they were asked to identify the main reason out of a list of reasons. Across all three communities, the top reason was, "Have not had any problems". Other important

factors were: "Did not need/know I needed the test." "Doctor did not say I needed it," and "No insurance coverage." Among all three groups surveyed, 17-20% reported that their doctors never advised them to have a mammogram. With respect to insurance coverage, while insured Cambodian and Vietnamese women had slightly higher screening rates (48% and 63%, respectively) compared to uninsured women (43% and 54%, respectively), 50% of insured Chinese women received a mammogram in the last 2 years compared to 27% of uninsured women.

Conclusion

Overall, the mammography screening rates in the CACS survey were well below the U.S. average. Despite national health initiatives and recommendations for screening, many Asian women may not even understand the benefits of receiving a routine mammogram. Moreover, the health care system may not be adequately providing services or may not be clearly communicating in a culturally and linguistically appropriate manner to emphasize the importance of routine screening. Each Asian subgroup may require a culturally-based intervention that is acceptable and feasible, tailored to each of the communities studied. In addition to improving Asian women's knowledge of breast cancer, campaigns must be targeted at health care providers of Asian women. Such screening education must incorporate appropriate messaging of cancer screening that

is appropriate and acceptable to each Asian subgroup culture.

Service delivery of cancer screening should also be addressed. Quality of cancer screening tests such as mammography (including detection rates at mammography centers) should be addressed. Follow-up rates of abnormal mammography and of abnormal clinical breast exams should be tracked to determine how best to deliver services so that delays in treatment and/or differences in quality do not result in disparities in breast cancer morbidity and mortality.

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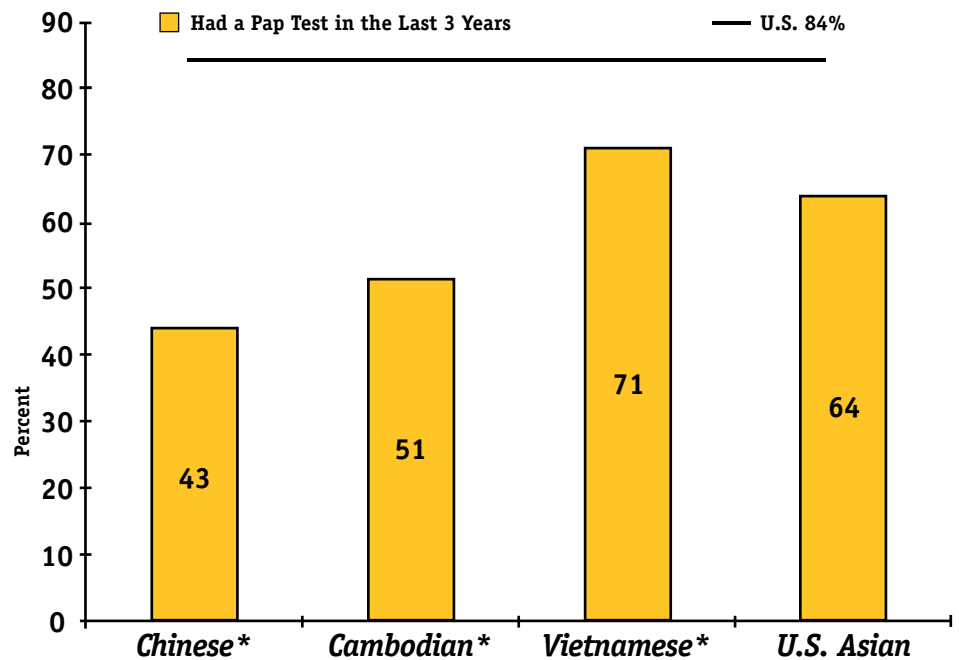
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5.6 CERVICAL CANCER SCREENING

Background

Disparities among cervical cancer incidence and mortality exist among Asian women. In the U.S., the incidence of cervical cancer is almost five times higher among Vietnamese women (43 per 100,000) than among non-Hispanic White women (7.5 per 100,000). Korean and Chinese women also have incidence rates (15.2 per 100,000 and 12.3 per 100,000 respectively) almost twice that of non-Hispanic White women. In addition to not obtaining routine screening, Asian women tend to present with later stages of cervical cancer than their non-Hispanic White counterparts. For instance, 21% of Chinese women presented with an advanced stage of disease, whereas only 8% of non-Hispanic Whites were similarly staged at the time of diagnosis.

Figure 5.6.1: Percent of Women Who Had a Pap Test in the Last 3 Years



*Age-adjusted to the 2000 U.S. Census

U.S. estimate from the Behavioral Risk Factor Surveillance System, 2006

U.S. Asian estimate from the National Health Disparities Report, 2007

Unscreened women are 2-10 times more likely to develop cervical cancer than women who are screened. Importantly, rates of screening among Asian subpopulations in the US have not changed over the last decades and data are still not being collected universally on Asian subgroups. Asian women are diagnosed at older ages and therefore at later stages of disease, which can result in fewer treatment options and sometimes less effective treatment.

Access to screening, appropriate diagnostics, and vaccinations can clearly prevent death and disability from cervical cancer. Routine tests are recommended for all women beginning when they become

sexually active (but no later than age 18 years) and repeated every 3 years for women at normal risk for cervical cancer. This interval for screening decreases for women at higher risk of the disease. Women over the age of 70 who remain at low risk for cervical cancer may no longer need to be screened. However, if an older woman is sexually active and has multiple partners, she is still at some risk for acquiring HPV and abnormal changes in her cervix tissue. Thus, when to stop screening for cervical cancer should be based on a conversation with an individual's health care provider.

Survey Results

The CACS survey asked a series of 4 questions on screening for cervical cancer. The first question asked women whether they had ever been screened for cervical cancer, "A pap smear is a test for cancer of the cervix. Have you ever had a pap smear?" Next, women were asked to report when they were last screened, "How long has it been since you had your last pap smear?" Lastly, we asked women, "Have you ever had a hysterectomy?", and to record the date if the response was yes. These are the exact questions asked on the national Behavioral Risk Factor Surveillance System survey. Data presented here are for all women aged >18 years.

Survey data revealed that the only about half of women who should be screened for cervical cancer in these three communities reported that they indeed have ever had a pap test. Findings indicate that 55% of Chinese women in Armour Square, 75% of Vietnamese women in Uptown, and 63% of Cambodian women in Albany Park reported having ever been screened for cervical cancer. Among them, only 43% of Chinese, 51% of Cambodian, and 71% of Vietnamese women had a Pap test in the last 3 years, the general recommendation for routine screening. Figure 5.6.1 displays the proportion of women who were screened within the last 3 years by community area. All three groups of women had routine screening rates well below national average of 84%.

Overall, the survey data revealed that women least likely to ever

had a Pap test were uninsured, foreign born, or lived in the US for less than 5 years. These trends are similar to those reported from national surveys. More specifically, survey findings indicated that more publicly insured Cambodian (56%) and Vietnamese (71%) women received screening in the last 3 years compared to privately insured women (54% and 67%, respectively). On the contrary, 26% of public insured Chinese women received screening in the last 3 years compared to 80% of privately insured women. In addition, 16% of Chinese, 23% of Cambodian, and 7% of Vietnamese women did not report having a regular health facility.

Conclusion

The CACS survey observed Pap test rates for the three Asian subgroups well below the national level. The rates of screening by insurance coverage are consistent with the general knowledge that people who are uninsured are less likely to receive routine preventative services such as a Pap test. Women who reported having a personal doctor or a clinic which they frequent when sick were similarly more likely to report that they had a routine screening. These data reflect a weakness of programs in providing access to cervical cancer preventative services to Asian subgroup populations.

National data demonstrate that efforts to ensure that women receive a pap test at least once every 3 years reflect some success. However, despite the tremendous

success of screening procedures to reduce the incidence and mortality from cervical cancer, disparities in health outcomes persist. Importantly, these local level data in this survey reflect that more efforts are needed to focus on Asian subgroups. It is essential that future prevention efforts in cervical cancer screening extend to Asian communities in Chicago to increase their utilization of the available health services.

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5.7 MENTAL HEALTH

Background

Despite the recent increased understanding of minority health concerns, there is a paucity of systematic research among the Asian population, and issues of mental health and depression among Asians in the U.S. are poorly understood. Recent findings suggest that Asians are less likely to seek help for their mental health problems than Whites, and there are significant barriers to meeting their mental health needs. Among the

Figure 5.7.1: Percent of Adults with Depressive Symptoms

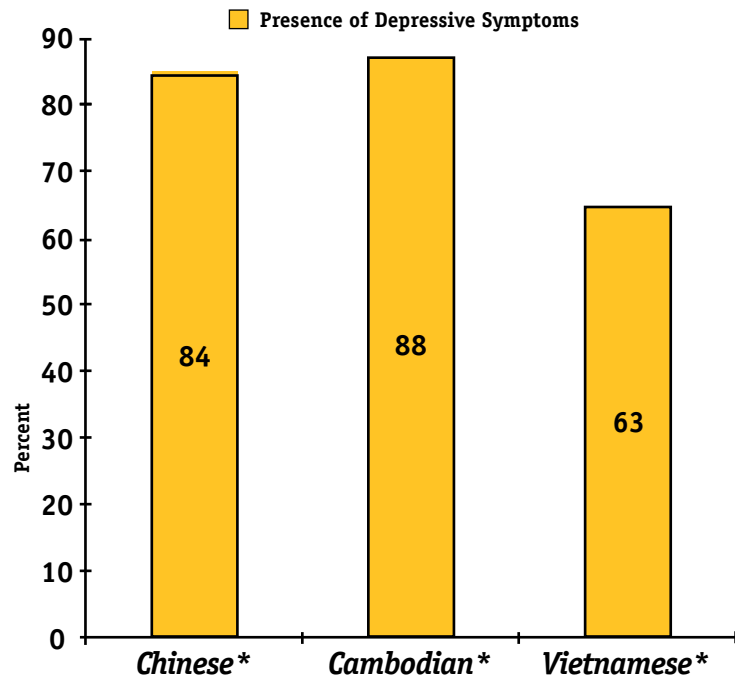
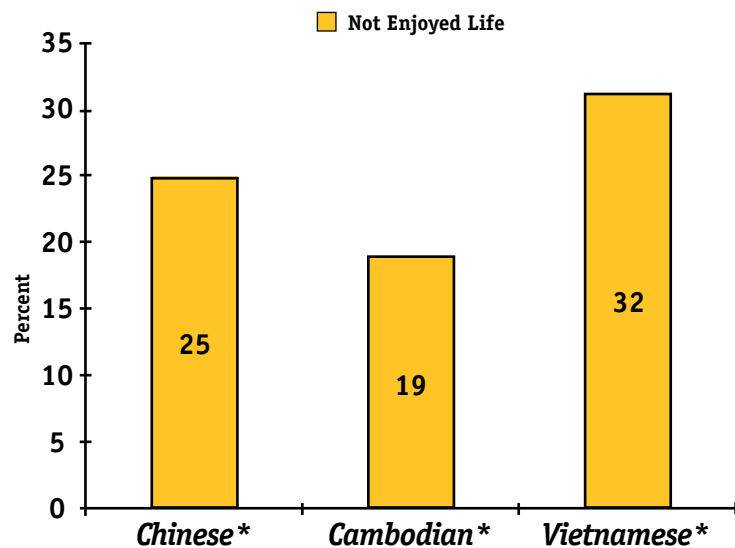


Figure 5.7.2: Percent of Adults Who Described that They Do Not Enjoy Life



Chinese population, one of the leading causes of depression was found to be family conflict. In addition, cause-specific mortality data has shown that suicide is far more prevalent among all Asians than Whites, especially among Chinese women.

Survey Results

The survey contained a 10-question instrument to measure depressive symptoms, and 2 questions asked the participant if s/he knew anyone in the family or in the community who had depression. The instrument used was derived from the Center for Epidemiological Studies Depression (CES-D) Short Form, which consists of ten questions assessing depressive symptoms. Example questions are "I felt lonely," "I could not get going," "I feel sad," and "I do not enjoy life." This is a widely used scale that has been used in other U.S. studies of the Asian population. Since the categorical definition of depression as a diagnosis has not been precisely defined, analysis focused on the presence and absence of depressive symptoms as a measure of mental health burden.

Figure 5.7.1 indicates an alarmingly high proportion of adults experiencing symptoms of depression. In the Asian populations surveyed, depressive symptoms were present in 84% of Chinese, 88% of Cambodian, and 63% of Vietnamese participants. Comparison data is not available for U.S. Asians or U.S. overall.

The survey further examined the sociodemographic characteristics and presence of depressive symptoms in the three Asian communities (Table 5.7.1). Results indicate a high degree of mental health burden in the Chinese and Cambodian populations. Furthermore, these findings may be particularly alarming in recent immigrants (< 4 years in the community) and in those who are unemployed.

The CES-D covers a range of different types of depressive symptoms, and responses to some questions may indicate even higher degrees of mental health burden. One such question is worth highlighting: "I enjoyed life." Data from the CACS survey observed that 25% of Chinese, 19% of Cambodian, and 32% of Vietnamese subjects described that they do not enjoy life (Figure 5.7.2). This is particularly concerning given that Asians have one of the highest suicide rates in the U.S.

Conclusion

The mental health burden is alarming in these three Asian population subgroups and provide further evidence to dispel the myths of Asians as being a "model minority". Mental health is a pervasive public health issue that deserves as much attention as other chronic illnesses . In addition, the Mental Health Equitable Treatment Act urges the health care system to rate mental health as being equally important

as physical health, as poor mental health impacts one's physical status as well.

In many Asian cultures, there is significant social stigma associated with mental illness, particularly with depression. Even within the three different ethnic groups, there are vast heterogeneities that health care providers should be aware of when treating mental illnesses. Recruitment of linguistically and culturally competent health care professionals should be a high priority. Health care professionals and primary care physicians who treat Asian Americans should be cross-trained to understand the cultural intricacies of screening, diagnosing, and treating mental health illness.

Mental health is a multidisciplinary issue that necessitates a collaboration of vastly different invested groups. Community-level campaigns are desperately needed to start these dialogues with community residents, to further understand the barriers at the community level. Educational initiatives are critically needed to educate the community regarding the morbidity, mortality, and suicide risks associated with mental illness. Screening for mental illness and suicidal ideation should be a routine part of health visits by all health care professionals. Local health workers and CBOs can serve as a bridge to help community residents navigate through the complex health care system and eliminate barriers to seeking culturally appropriate care.

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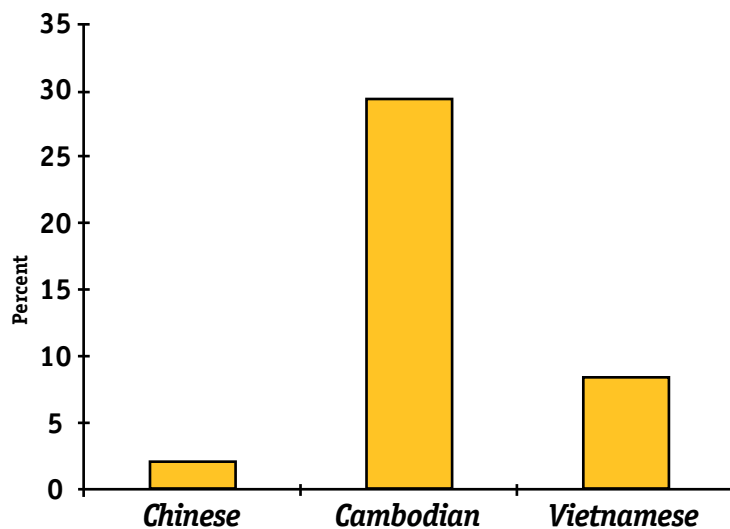
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Table 5.8.1: Percent of Adults Diagnosed with Hepatitis B



+37% of participants reported being tested for Hepatitis B

5.8 HEPATITIS B

Background

In the United States, Hepatitis B (HBV) is the most prevalent in the Asian American population, affecting 1 in 10 persons. The overall chronic infection rate among AAPIs is 9% (with a 9-15% rate for foreign born and 1.6% for U.S. born), compared to 0.1% in Caucasians and Hispanics, and 0.5% in African Americans. In fact, of the 1.25 million people infected with chronic Hepatitis B in the U.S., 1 million are in Asian. This results in the API population having the highest rate of hepatocellular carcinoma among all minority groups, representing one of the greatest cancer health disparities in the U.S.. In fact, HBV causes 80% of all liver cancer cases among AAPIs, compared to 19% among non-Latino Whites. While these statistics are shocking, the tragedy is that Hepatitis B and its sequelae are often preventable.

Survey Results

The survey contained 8 questions about Hepatitis screening, treatment, and vaccination. Respondents were asked if they have ever received HBV vaccination and if so, how many shots they received. To screen for jaundice, respondents were asked if they ever noticed yellowing of the whites of their eyes. In addition, they were asked if they have ever been screened or diagnosed with Hepatitis and to indicate which viruses (A, B, or C). Among those diagnosed with Hepatitis, respondents were asked if they have ever received treatment.

A large percentage of respondents did not know which type of virus they were exposed to. The survey results showed that Hepatitis B was the most common type of Hepatitis being screened or diagnosed. Figure 5.8.1 presents the prevalence of Hepatitis B among the Chinese, Cambodian, and Vietnamese populations.

Conclusion

The CACS survey showed alarming prevalence rates of Hepatitis B in our Asian community cohorts. Equally shocking was the extremely low rates of screening in these high-risk communities. The Centers for Disease Control (CDC) recommends Hepatitis B screening for all foreign-born Asian Americans, and recently, they expanded their recommendations to include second generation Asian Americans (born to immigrant parents). Despite these guidelines, only 37% of those surveyed had undergone screening. Without early detection and disease prevention, many individuals in these communities will die prematurely from liver related deaths. Despite these widely documented disparities in patients with chronic Hepatitis B and liver cancer among AAPIs, relatively little is known about how to reduce these disparities on a regional basis. In fact, most national and local data sets lack categories for AAPIs and/or fail to disaggregate Asian subgroups, potentially masking important difference among these non-homogeneous communities, who vary not only by cultural norms, literacy and language, but by immigration history and health care utilization. While national efforts to improve care and reduce disparities exist, health solutions are ultimately local. Innovative, sustainable models to improve Hepatitis B awareness, prevention,

and a decrease in liver cancer among AAPIs are desperately needed that take into account the local environment, cultural, racial/ethnic, organizational, and economic realities of their health setting. This data can be used to move beyond the science of Hepatitis B and think seriously about the epidemiologic, social, and community needs to decrease Hepatitis B disparities among Asian Americans.

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SECTION 6. Overarching Public Health Implications

Variations in Health Status

Analysis of such racial and ethnic subgroups are crucial to fully understand how different segments of the American population access medical care, as well as to maximize access to care and to dispel the myth of the model minority. Even with this relatively small snapshot of local data on three Asian subgroups in Chicago, it is clear that disparities among Asian subgroups do exist and that such disparities may be increasing over time.

Policy Implications

This report details survey development, methodology, and findings in three Chicago AAPI communities. Specific policy recommendations are included in each of the eight key health topic sections. In addition, we would like to highlight several key policy recommendations specific to community-based research practices and programs with ethnic populations. These recommendations are not directed only to CBOs, but pertain to a wide variety of invested individuals and groups interested in empowering racial and ethnic communities in Chicago to improve their health.

- Promote research activities that gather local subgroup health data, recognizing that cultural diversity is often reflected in differences in values, language, level of acculturation, and health outcomes. Local subgroup data should be compared against that of other racial and ethnic groups to create a comprehensive portrait of health disparities in Chicago, and dispel prevailing myths about the health status of any racial and ethnic group.
- Emphasize and expand on research frameworks that utilize community-based participatory research (CBPR) strategies to support community engagement and foster a sense of equity amongst a variety of organizations; integrate various sectors to create work groups and advisory committees, including but not limited to CBOs, government agencies, academic institutions, and schools, to establish best-practices that respect the need of the wide array of involved parties, while also strengthening the communities' capacity to develop and sustain health programs.
- Reinforce models that empower Community Health Workers (CHWs) and Patient Navigators (PNs) to provide community health education, outreach, and bridge the gap that exists in the current healthcare infrastructure.
- Advocate for accessible and relevant language assistance services in health care facilities across the Chicago area to address the unprecedented linguistic diversity that exists; a lack of policies to ensure language accessibility clearly illustrates the broken link between physical access and language appropriate access to healthcare in the U.S. and the need to strengthen the infrastructure of medical facilities to provide adequate language assistance to our growing immigrant communities.
- Increase culturally competent health care as an appropriate means to address racial and ethnic disparities, in addition to a lack of health care access to AAPIs; culturally competent education and training among health care providers and health workers will help to ensure that more AAPIs receive necessary health services and programs.

Conclusion

The health of communities cannot be improved upon unless appropriate and necessary health data are available. Research initiatives that promote local survey data, such as the Chicago Asian Community Surveys (CACS) project, aim to encourage organizations—community, government, and/or academic—to pursue similar projects with the overarching goal of improving health and reducing health disparities through tailored health prevention and promotion endeavors.

Through the initiative, local and disaggregated health data on three Chicago Asian subgroup communities—Chinese, Cambodian, and Vietnamese—were gathered. For the first time, baseline assessments on these three ethnic subgroups were conducted, describing each distinct community's specific health needs and priorities and their patterns of access to health care services and resources. The findings of the CACS project will allow public health agencies, CBOs, health policymakers, and other stakeholders to strategically formulate policies and programs that are culturally and linguistically relevant.

The AAPI population and its distinct ethnic subgroups are often left out of discussions and policy agendas addressing racial, ethnic, and geographic health disparities. The CACS project revealed significant health disparities and burdens which need to be considered when planning for Chicago-based health initiatives and interventions. We hope that this model of local research is mirrored for other communities committed to providing tailored health solutions, advocacy, and outreach.

In response to the preliminary findings of the Chicago Asian Community Surveys project, the Asian Health Coalition (AHC), in collaboration with community and academic partners has expanded and enhanced its programs to better address the pressing health needs and priorities in these distinct Chicago Asian communities.

Overview of Findings

This report reveals that the Chinese, Cambodian, and Vietnamese communities in Chicago face significant health disparities across a wide range of health indicators, from low rates of cancer and HIV

screening to high rates of diabetes, depression, and Hepatitis B. More importantly, noteworthy differences in the health issues affecting these three communities are highlighted, which further enhances the need to collect disaggregated and culturally specific health data for distinct AAPI communities in Chicago.

Research Limitations

It is important to mention a few of the methodology-based considerations for the three surveys. First, all survey data was self-reported. Therefore, the data might be under or over-estimated. However, all comparison data were also self-reported for consistency. Second, while Respondent Driven Sampling (RDS) (used with the Vietnamese community and Cambodian community) is a scientifically regarded technique, this is likely the first time it has been utilized within metropolitan Asian communities. Lastly, specific to the data collection in the Chinese community, budget constraints forced data collection to be stopped before visiting all of the pre-established blocks.



ASIAN
HEALTH
COALITION

*Chicago Asian
Community Surveys:
A Comprehensive Report*