

Resource Paper

# Measuring State-Level Asian American and Pacific Islander Health Disparities: The Case of Illinois

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## Abstract

Illinois is home to the sixth largest Asian American and Pacific Islander (AAPI) population nationwide. AAPIs suffer higher incidence, morbidity, and mortality rates from certain cancers, infectious, and chronic diseases. Despite the exponential growth of the AAPI population, few state-level data sources exist that provide detailed and accurate information regarding AAPI health disparities and needs. Efforts to improve health care for this population will require improved data collection and funding for research on AAPI ethnic groups.

## Introduction

In the United States racial and ethnic disparities in health status, disease burden, morbidity, and mortality persist (Department of Health and Human Services 2000a). A recent report to the Department of Health and Human Services (DHHS) concluded that while overall health status may be improving for all racial and ethnic groups, some groups continue to suffer disproportionate rates of death and disability (Department of Health and Human Services 2002). One of the primary goals of the DHHS' Healthy People 2010 Initiative is to eliminate these racial and ethnic health disparities by the year 2010 (Department of Health and Human Services 2000b). Furthermore, the Institute of Medicine (IOM) documented that definite racial and ethnic disparities in the provision of numerous medical services exist. The IOM investigation revealed that minority populations such as African Americans have lower rates of coronary artery revascularization procedures, kidney transplan-

tation, and antiretroviral treatment for HIV infection (Institute of Medicine 2003). Less is known about Latino populations, and even fewer studies involve Asian American and Pacific Islander (AAPI) communities. The lack of health data is particularly pronounced at the state level.

Hawaii, New York and California, with their larger AAPI populations, have relatively more AAPI health data from administrative sources and surveys, but most other states fare poorly in terms of collecting and publishing AAPI health information. Data from these states are often used to make generalizations about AAPIs residing throughout the US. However, given that migration and ethnic distribution patterns of AAPIs differ in the rest of the country, it is likely that health status and needs also differ significantly by region. There is, therefore, a critical need for state-specific information. The situation in Illinois provides insights into what is available and not available, and the implications of the paucity of data. In Illinois, home to the sixth largest AAPI population nationwide, AAPIs increased by 45 percent between 1990 and 2000 (Department of Commerce 2002). Despite the growing AAPI community in the state and particularly in the urban Chicago area, few data sources exist that detail local health outcomes and needs. We present a discussion of the current status of AAPI health data in Illinois, existing deficiencies, and the challenges in gathering and using local and state-level health data. In the conclusion we introduce policy recommendations to improve the quality and accessibility of AAPI health data.

### AAPI Health Disparities

Compared to other racial and ethnic populations, AAPIs bear higher incidence, morbidity, and mortality rates of several diseases. Trends in the burden of cancer among AAPIs are especially striking. AAPI women were the first U.S. population to have cancer as the leading cause of death, and cancer is the second leading cause of death in AAPI men. Between 1980 and 1993, mortality from cancer increased by 240 percent for AAPI women and 290 percent for AAPI men, the greatest increases reported for any ethnic group in the U.S. (Miller 1996). There is also emerging evidence that infectious and chronic diseases such as diabetes mellitus and hypertension may disproportionately affect the AAPI population (Chen 1993; Jin 2002).

## Colorectal Cancer

While incidence of colorectal cancer (CRC) among non-Hispanic Whites has been decreasing since 1985, the incidence among AAPIs has remained virtually unchanged. Japanese men have the second highest incidence rate of CRC of all ethnic groups, Japanese women have the third highest rate, and Filipinos have the second lowest five-year survival from CRC (Miller 1996). State-level cancer data reveal that in Illinois, CRC affects individual AAPI subgroups differently, variability that can only be documented by disaggregating AAPI data. For example, a study performed by the Illinois Department of Public Health (IDPH) found that CRC ranks as the second most commonly diagnosed cancer among AAPIs as a whole, compared to being ranked fourth in Whites. In subgroup analyses CRC is the most common malignancy in Japanese and Chinese Americans and the fourth most common in Asian Indians/Pakistanis (Dolock 2000). These statistics suggest that such subgroup-specific information may be crucial in identifying patterns of disease and addressing cancer prevention and treatment needs within ethnically different AAPI communities.

Screening for CRC with interventions such as fecal occult blood testing (FOBT) is an important part of decreasing overall mortality. CRC is often diagnosed at a later stage in African Americans, and studies have shown that this may be due in part to race, socioeconomic status, insurance status, or lack of use of screening procedures (Chen 1997; Mandelblatt 1996; McMahon 1999; Roetzheim 2000). It is noteworthy that AAPIs have not been adequately represented in any of these studies, nor have the studies been replicated with different AAPI subpopulations. In fact, due to small sample sizes in Behavioral Risk Factor Surveillance Survey (BRFSS) data, reliable estimates of CRC screening utilization among AAPIs in Illinois are unavailable (Dolock 2000). However, there is evidence of a significant difference in utilization by AAPIs. Although national rates of screening are almost equal when comparing non-Hispanic minorities to Whites, AAPIs have the lowest FOBT screening rate—more than two times lower than that of Whites and African Americans (American Cancer Society 2003a). Furthermore, data from the California Health Interview Survey highlights disparities in colorectal cancer screening rates for AAPIs, with almost all ethnic AAPI subgroups reporting significantly lower rates of recent screening compared to the rest of the state population (Ponce

2003). Because of the limitations of Illinois's BRFSS data, we are forced to speculate.

### Breast Cancer

National data indicates that AAPI women have a lower incidence rate of breast cancer (97.2 per 100,000) compared to their non-Hispanic White counterparts (140.8 per 100,000) and also experience relatively low breast cancer mortality rates (Miller 1996; Ward 2004). However, breast cancer continues to be the leading cancer diagnosed in AAPI women, and it is likely that the burden of breast cancer morbidity and mortality may be increasing rapidly within the AAPI population (Miller 1996). Epidemiological evidence indicates that when women immigrate to the U.S., their risk of breast cancer rises to six times that of women in their native countries over the course of their time in the U.S. (Ziegler 1996). This concept is illustrated in the higher rates of breast cancer seen in Japanese American women, an ethnic group that immigrated to the U.S. earlier than most other AAPI groups. Breast cancer incidence for Japanese American women has increased persistently since 1988 and is now approaching rates for non-Hispanic White women (Deapen 2002). In addition, subgroups such as Native Hawaiian women have the second highest breast cancer incidence rate in the U.S. (Miller 1996). Subgroup analyses further reveal that several AAPI subgroups experience increased risk of advanced stage of cancer at diagnosis, higher rates of inappropriate treatment, and worse survival rates after breast cancer diagnosis (Hedeem 1999; Li 2003). A report by the IDPH documents that AAPI women in Illinois are less likely to be diagnosed at an early (and more curable) stage of invasive breast cancer compared to their White counterparts, potentially reflecting suboptimal breast cancer screening among AAPI women in Illinois (Dolock 2000).

National data indicate that AAPIs have lower rates of recent breast cancer screening when compared to every racial/ethnic group other than American Indians/Alaska natives (American Cancer Society 2003b; Kagawa-Singer 2000; Ward 2004). However, data about AAPI mammography utilization is poor, and in many states, state-specific mammography rates cannot be determined due to insufficient data. For example, mammography use by AAPIs in Illinois remains poorly documented because fewer than fifty AAPI respondents were represented in the state's BRFSS (Bolen 2000).

When available, state and community-based research have revealed the presence of significant disparities in screening mammography among specific AAPI populations. Particularly low rates of mammography utilization have been documented among Chinese, Vietnamese, Korean, and Filipino women. For example, among multiethnic women in San Francisco, 73 percent of Chinese and 46 percent of Vietnamese women reported prior mammography, compared to 93 percent of White women (Hiatt 1996). The California BRFSS and Korean Health Survey show that Koreans are under-screened, with 45 percent to 52 percent of Korean women reporting no previous lifetime mammogram; only 10 percent of the state's general female population has never had a screening mammogram (Centers for Disease Control 1997; Wismer 1998). Low rates of recent mammography use have also been demonstrated among Cambodian women (12 percent to 40 percent) and Filipino women (55 percent) (Kelly 1996; Maxwell 2000; Tu 2000). Less is known about Asian Indian women's screening rates, although aggregated National Health Interview Survey (NHIS) data suggests significant under-screening, with 68 percent of Asian Indian women reporting no prior mammogram (Sadler 2001).

#### Cervical Cancer

In the United States the age-adjusted incidence rate of cervical cancer is almost five times higher among Vietnamese women (43.0 per 100,000) than among non-Hispanic White women (7.5 per 100,000) (Miller 1996). 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 (Parkin 1992). Furthermore, AAPI subgroups tend to present with more severe disease. Twenty-one percent of Chinese women presented with an advanced stage of disease, whereas only 8 percent of non-Hispanic Whites were similarly staged at the time of diagnosis (Jenkins 1994). Pacific Islanders also presented with a more advanced stage of disease (75 percent vs. 25 percent for non-Pacific Islanders), more lymph node involvement (23 percent vs. 7 percent) and poorer five-year survival rates (32 percent vs. 71 percent) (Robison 2002).

These findings suggest that the AAPI population is not optimally utilizing or being offered access to cervical cancer screening tests. A low ratio of in situ to invasive squamous cell neoplasms

among AAPIs further supports the hypothesis that these populations are not diagnosed or treated at an early preinvasive stage (Frisch 2000). Despite the fact that regular screening can decrease cervical cancer mortality, AAPIs constitute the group that has the lowest rate of use of the Papanicolaou screening test (American Cancer Society 2003b). Rates of cervical cancer screening among Vietnamese women are consistently lower than in the general population (Kagawa-Singer 2000; Ponce 2003; Taylor 2004). It is concerning that despite their high-risk status for cervical cancer, screening rates among Illinois AAPI women are not known due to insufficient representation in the state's behavioral health survey (Bolen 2000). However, the state's cancer registry indicates that AAPI females are less likely to be diagnosed with early and local stages of invasive cervical cancer in comparison to White women, further supporting the likelihood of under-screening in this population (Dolock 2000).

#### "Signature Cancers"

As a group AAPIs suffer a disproportionate burden of morbidity and mortality from specific cancers that are unique compared to non-AAPI populations. For example, AAPIs have the highest incidence and mortality rates of all racial and ethnic groups of nasopharyngeal, gastric, liver, and intrahepatic bile duct cancers (Centers for Disease Control 2003; Ward 2004). Vietnamese men have an incidence rate of liver and intrahepatic bile duct cancer that is more than 10 times higher than in non-Hispanic White men (41.8 per 100,000 vs. 3.3 per 100,000) (Miller 1996). AAPI women also have the highest incidence rates of endocrine and thyroid carcinomas (Miller 1996; Centers for Disease Control 2003). Illinois statistics confirm the increased incidence of these AAPI-prevalent cancer sites when compared to Whites. For instance, gastric cancer was the number one site for cancer mortality among Koreans in Illinois, and thyroid cancer was the fourth most common site of malignancy in AAPI women, whereas it was not even among the top ten sites in White women (Dolock 2000). Although the increased incidence of these "signature" AAPI malignancies are well documented and frequently screened for in other countries, guidelines for prevention and early detection are lacking in Illinois, as well as in the greater U.S.

## Tobacco Use

Current national data that reliably documents tobacco use in AAPI populations is lacking (Lew 2003). National and state-level health assessment surveys administered primarily in English show lower rates of tobacco use among AAPIs as a whole (Bolen 2000; Centers for Disease Control 1999). However, a growing number of state, regional, and community-based research studies have consistently revealed high rates of tobacco use among AAPI males. It is likely that prevalence rates of tobacco use range widely by ethnic group and gender; for example, the AAPI population in Illinois has a median tobacco use rate of 11 percent, but a range of 4 percent to 36 percent (Bolen 2000). AAPI subgroups such as Vietnamese, Pacific Islander, and Cambodian men have increased prevalence of tobacco use ranging from 38 to 58 percent (Lew 2003). The role of acculturation and tobacco use is not well understood or studied; for example, risk factors for tobacco use vary by AAPI subgroup. Some groups such as Chinese men appear to actually increase tobacco utilization with increasing acculturation and length of time spent in the U.S., while others such as Vietnamese men were less likely to smoke with increasing acculturation and English proficiency (Department of Health and Human Services 1998). It is concerning that the highest density of tobacco advertising, in the form of billboards and displays, has been found in AAPI communities when compared to other racial and ethnic communities (Department of Health and Human Services 1998).

## Chronic Illnesses: Diabetes and Hypertension

The prevalence of diabetes among AAPIs is not well known but is generally thought to be lower than that of other racial/ethnic groups. However, emerging trends indicate that this chronic illness is rapidly affecting AAPI populations. Analysis of data collected in Hawaii from 1996 to 2000 showed that Native Hawaiians were 2.5 times more likely to have diabetes than non-Hispanic White residents of similar age (National Diabetes Information Clearinghouse 2002). In Illinois, BRFSS data revealed that AAPIs had higher rates of reported diabetes than non-Hispanic Whites (Bolen 2000). Recent national analyses of the BRFSS also revealed that while similar proportions of AAPIs and non-Hispanic Whites report having diabetes, after accounting for their lower body mass index, the adjusted prevalence of diabetes is 60 percent higher in

the AAPI population (McNeely 2004).

Hypertension is a significant public health issue for all Americans. Approximately 50 million adult Americans have hypertension, and there is evidence that AAPIs are similarly, if not disproportionately, affected by this common condition (National Institutes of Health 1997). A cross-sectional survey noted that one-third of Korean Americans surveyed had hypertension, a percentage higher than that of Whites (24 percent) or native Koreans (22 percent); yet only 40 percent of hypertensive Korean Americans were taking medication for high blood pressure, and 74 percent were not controlled to target (Kim 2000). A similar survey of Vietnamese Americans noted a prevalence of 44 percent (Duong 2001). In Illinois BRFSS data revealed that the AAPI population had higher rates of self-reported high blood pressure than did non-Hispanic Whites (Bolen 2000). Few studies have investigated the root causes, behavioral risk factors, or barriers to diagnosing and treating AAPIs for this very common condition with significant morbidity and mortality.

#### Infectious Diseases: Tuberculosis and Hepatitis B

Immigration has contributed significantly to the incidence of tuberculosis (TB) infection in the United States, and the health of AAPI immigrants has been impacted severely. In 2002, tuberculosis case rates among AAPIs were nineteen times higher than among Whites (Chicago Department of Public Health 2002). Surveillance data indicates that TB in foreign-born persons accounts for a large proportion of the cases of TB in this country, and two-thirds of foreign-born TB cases were reported in AAPIs born in countries such as Vietnam, the Philippines, India, China, and South Korea (Talbot 2000). In addition, TB infection in foreign-born populations tends to require more aggressive treatment due to increased resistance to standard treatment regimens (Talbot 2000). Chicago ranks third in the national burden of tuberculosis, and AAPIs had the highest case rates (141 per 100,000) in Chicago in 2002 (Chicago Department of Public Health 2002). Approximately a quarter of TB cases were among foreign-born residents of the city, many of whom immigrated from AAPI countries such as the Philippines and India (Chicago Department of Public Health 2002).

The increased incidence of liver cancer in the AAPI population is almost entirely attributable to the high prevalence of chronic hepatitis B infection in these populations. Hepatitis B infection rates



are highest in AAPIs, with rates ranging up to 15 percent, compared to 0.3 percent in the general U.S. population (Nguyen 2003). Most chronic infections are acquired in native countries with high prevalence rates of hepatitis B and transmitted horizontally or vertically. In the 1970s, AAPIs had rates of hepatitis B infection twenty to thirty times higher than that of non-Hispanic Whites. In the 1990s, the rate of infection for AAPIs improved, but was still seventeen times higher when compared to Whites (Euler 2001). Recent attention has focused on prevention through vaccination. The importance of vaccination cannot be underestimated given the potential for development of hepatocellular carcinoma and the associated cost and disability related to chronic hepatitis infection. Although 90 percent of AAPI children born after 1993 have received the hepatitis B vaccine, those born before 1993 have not. Catch-up efforts to vaccinate children born before 1993 has resulted in improvement in the vaccination rate from 10 percent to 60 percent, but much still needs to be done in order to reach the goal of 90 percent coverage (Euler 2001). State and local data regarding levels of vaccination are not available.

### Conclusion

To address the above health disparities, policy changes are needed for Illinois, as well as other states.

### Improve Data Collection and Fund Research on AAPI Ethnic Groups

Even with the small amount of state-level data currently available about AAPI populations in Illinois, it is becoming more apparent that disparities in AAPI health exist and may be increasing over time. Historically, all AAPI ethnic subgroups were considered as one entity and have generally performed favorably in comparison with Whites; however, when data from specific subgroups are isolated, striking differences in health indicators and outcomes become clear.

Given the heterogeneity of AAPIs and the vast differences in culture, language, health beliefs and practices, and genetic backgrounds amongst the different AAPI subgroups, it may be misleading to consider them as a whole. Disaggregation of AAPI data by ethnic subgroup in new studies as well as in existing data sources, such as health surveys, vital statistics and disease registries, may

reveal unexpected trends and important risk factors and disease patterns for each subgroup (Gomez 2003; Srinivasan 2000). Understanding the diversity and cultural richness of the AAPI population will allow for more appropriate service delivery and, hopefully, improved health outcomes.

Unfortunately, large gaps in baseline AAPI health data remain and the majority of the Healthy People 2010 objectives have not been researched in Asian populations. Data summarized above relied heavily on the statistics reported by the Illinois BRFSS; yet many goals in health indicators are not currently measurable in Illinois due to small sample sizes. In order to find and better delineate existing disparities, AAPI populations must be over sampled in data collection efforts and research studies. Clinical research trials have focused on Native Americans (Howard 1993), African Americans (Brown 1993), and Hispanics (Zambrana 2001), but few studies focus specifically on the AAPIs. In fact, only 0.01 percent of studies found on the National Library of Medicine's MEDLINE database mention AAPIs as a studied group (Ghosh 2003). If information about the AAPI community is not available, then community and government organizations cannot begin to address their health needs and disparities. State and local governments must be educated about existing AAPI health disparities and encouraged to launch data collection efforts, such as those performed in California, to gain a better and more comprehensive understanding of local AAPI communities (Ponce 2003).

In Chicago we recently have formed an AAPI Research Interest Group, a network of academics, health care professionals and representatives from community-based organizations. Through meetings with both the Illinois and Chicago Departments of Public Health, we have begun work on the data issues described above and hope to launch research studies and primary data collection efforts of our own. An important component of these efforts will be to involve community leaders and to encourage minority communities to report accurate demographic and health data in order to maximize the accuracy and precision of disease prevalence and incidence rate statistics. A local example to follow may be that of the Sinai Urban Health Institute's recent population based survey that revealed significant ethnic subgroup variation in the health outcomes and behavioral risk factors of Hispanic populations living in six Chicago communities (Whitman 2004). Through

funding from the Robert Wood Johnson Foundation, this randomized household survey identified disparities between Mexican and Puerto Rican communities; it is imperative that similar surveys are conducted in the growing AAPI community as well.

Better local health data on AAPIs is needed not only to improve health services, but also to combat a larger problem facing this population. The extent and severity of health disparities in AAPI communities is slowly becoming evident, but the "model minority" myth still pervades American society in destructive ways. For example, the city of Chicago recently concluded, without significant supporting evidence, that AAPIs should no longer be deemed a disadvantaged minority group and, therefore, will not be allowed to compete for a portion of city construction contracts that are set aside for firms owned by African Americans, Hispanics, and women. The presiding judge relied on stereotypes when describing the problems with this program: "A third-generation Japanese-American from a wealthy family and a graduate degree from MIT (the Massachusetts Institute of Technology) qualifies, (and an Iraqi immigrant does not)" (Cho 2004). An alderman on the task force established to revise the city's construction policies further commented that "Asians are better educated than whites, so don't talk to me about discrimination" (Cho 2004). It is unconscionable that important policy decisions are continuing to be made on the basis of persistent and damaging stereotypes rather than on statistics or fact.

If the elimination of racial and ethnic disparities in health is truly a national and state priority, greater awareness of the cultural, linguistic, and socioeconomic heterogeneity of the AAPI community must be established. Only when policymakers and the lay public understand the fact that disparities exist in the AAPI community will research dollars be available to fund further studies to investigate the underlying social determinants of health. Better subgroup data and statistics on health outcomes and risk factors will then facilitate the ability of health care providers, community leaders, public health practices, and public policy initiatives to formulate culturally appropriate and sensitive health programs, target root causes of disease, and thus improve overall health status. We are only beginning to understand the scope of the health issues that AAPI communities face; it is imperative that we pursue these aims aggressively in the future lest disparities widen even further.

