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Utilizing Community Based Geographic Information System (GIS) to Recruit Older Asian Americans in an Alzheimer's Disease Study

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Utilizing Community Based Geographic Information System (GIS) to Recruit Older Asian Americans in an Alzheimer's Disease Study

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Abstract

Objective: This paper addresses both physical and sociocultural factors in recruitment and engagement of Asian American older adults in clinical studies and describes a novel recruitment strategy using community-based Geographic Information System (GIS). This GIS map visualizes sociocultural and geographic trends in the local population which may enhance our understanding of the heterogeneity of minority population distribution and inform community outreach efforts.

Methods: The recruitment strategies of Korean American (KA) subgroups as a part of ACAD cohort study, have been developed to evaluate a novel community-based GIS sampling method for delineating boundaries for geographic clusters and social networks of KA populations that are disproportionally understudied and under-served. A chain referral sampling method, like other form of respondent-driven sampling was utilized.

Results: GIS maps show a visualization of the heterogeneity of sociodemographic characteristics and the resources of faith-based organizations and KA serving local clinics. We addressed these factors that disproportionately affect accessing and participating in clinical research and successfully recruited the aimed participants (n=60) in the proposed period.

Discussion: This innovative strategy, using a target group tailored GIS map, will provide the necessary groundwork for a subsequent large-scale, fully powered clinical genetic epidemiology study to test the usefulness and effectiveness of our novel decolonizing community-centered recruitment method.

Policy Implication: This approach responds to the call from NIA to develop strategies to improve the health status of older adults in diverse populations. Results from the full-scale clinical study will provide health researchers and policy makers with practical evidence on how

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to identify and increase participation of Asian American older adults in clinical studies that could be used as a national model for reducing health and research disparities among minority older adult populations.

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Strengths and limitations

- This study responds to the call from NIA to build diverse community partnerships to improve recruitment of minorities (Milestone 12.a). We did so to engage community and academic partners by developing community-based GIS to identify and recruit hard-to-reach populations.
- This study created a novel community-based GIS maps which provides a comprehensive overview with visual representation of the heterogeneities of social factors and physical clusters for the targeted population.
- Our successful recruitment of KA older adults is due to multiple recruitment strategies including target population tailored GIS, detailed understanding of the target population as well as existing community capacity and respected relationships between the community and researchers
- Using publicly available social network data has inherent limitations related to completeness, correctness and timeliness reporting and there are limitations to using social networks observed in social datasets which may be different from the underlying (offline) networks.
- Though recruitment to clinical studies with Asian American older adults is complex, only Korean speaking Korean American older adults are included.

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Introduction

Alzheimer's Disease and related dementia (ADRD) affects 5.8 million people in the U.S. and 50 million worldwide.[1,2] The annual global cost of dementia is now above $1.3 trillion and is expected to rise to $2.8 trillion by 2030.[3,4] The literature on ADRD shows constant and adverse health disparities as well as research disparities across racial and ethnic groups.[5,6] Though many AD variants are population-specific or have different frequencies across populations, like most complex diseases, the AD literature has a strong bias toward European ancestry [6,7], and there are substantial disparities in minority participation in AD studies. Despite the call from the National Institute of Health (NIH) for the inclusion of more representative groups in clinical studies, racial/ethnic minorities, older adults, those with lower socioeconomic status, and immigrant subpopulations remain underserved, understudied, and underrepresented. [6,8-10]

Older racial/ethnic minority populations are growing faster than their non-Hispanic White counterparts and will comprise 45% of the older adult population by 2060.[11] The number of Asian Americans who are 65 years and older will increase by 352% by 2060 and comprise 21% of the total Asian American population by 2060.[11,12] Participation of Asian Americans in the ADRD interventional trials is very low (i.e., <1%) [6,13,14] and investigations of ADRD in Asian American populations are woefully inadequate, so the generalizability of scientific findings for Asian Americans is questionable. The availability of reliable data is imperative to the attainment of the regional profiles of health equity in the U.S. [15] However, in Healthy People 2020, as in most other national health reports, ADRD data about Asian Americans is absent. The main reasons for the omission of Asian Americans in health care studies are the barriers present in Asian American communities that include mistrust of outsiders, lack of knowledge, language barriers, lack of health insurance, and sociocultural barriers.[9-12,16-19] It is difficult to gain access

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to Asian Americans because they are dispersed throughout the country and tend to have a low level of contact with the healthcare system. However, there are states where Asian Americans are concentrated such as California, New York, and Texas, and ethnic enclaves in various metropolitan areas such as Chinatown, Koreatown, and Little Saigon as well as based on social factors including churches.[16-19]

There is a need to develop sampling methods that are responsive to ethnicity and sociocultural diversity among study populations and to be able to generalize scientific findings for Asian Americans. [9,10,18] As for older Asian American populations, they show specific characteristics that make them different from other ethnic groups and their younger counterparts, including language, health beliefs, health attitudes, lower economic status, and social networks.[17,19-22] These characteristics may act as either facilitators or barriers to participation in clinical studies, including ADRD.

The strategies to identify geographical and socio-environmental trends among Asian Americans, particularly in the older population, may enhance recruitment of the study participants. One strategy that may be efficient and productive in this endeavor is the use of Geographical Information Systems (GIS). GIS could enhance the visual perception of physical and social environments by mapping layers of data information and its relationship to the location of the study population. The use of GIS techniques in public health studies has developed significantly in recent years. [23-27] Many public health researchers have found that visualization of the spatial distribution of health-related events of target populations and making informed public health decisions faster are the two primary applications of GIS data/methods in health-related studies.[25, 28, 29]

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The purpose of this paper is to report on outreach and recruitment strategies employed by community-based participatory research participatory combined with GIS to address both space special and social factors in the recruitment and engagement of Korean American older adults which is a part of the ACAD pilot study. The ACAD is the first large AD cohort for Asian ancestry in America and Canada focusing on the recruitment of Chinese, Korean, and Vietnamese. Our main objective is to show the effectiveness of using community-based GIS to recruit a hard-to-reach Korean elderly population by 1) creating a few GIS maps to capture the physical and sociocultural characteristics of the sample population and 2) referencing the maps to effectively recruit the sample population. In doing so, we focus on identifying KAs with and without dementia in NJ.

Method

A pilot ACAD study has been conducted with KA subgroup aged 60 years and older in NJ. The goal was to recruit 60 KA individuals with and without dementia. This study is approved by the institutional review board of a university in the Northeast United States. This research paper only covers the recruitment strategy of the KA study site in NJ. We used a holistic community approach model by applying GIS to delineate boundaries for geographic clusters and church- and senior- networks, and KA serving ethnic clinics within identified clusters to recruit participants from the community.[30]

Geographic context of Korean Americans

Although there are concentrations of KAs in CA and on the East Coast, KAs are widely scattered throughout the U.S.[16,30-32] According to data from the 2010 Census, New Jersey's Asian population grew by more than 1,400 percent since 1970. The counties with the largest Asian American populations are Middlesex (24% of the county's residents), Bergen (16%), and

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Hudson (15%) in NJ. We choose NJ to carry out this pilot ACAD since the highest density of KAs (6.3%) resides in Bergen County, NJ. [32,33]

Sociocultural Contexts of Korean Americans

The history and socio-demographic characteristics of Korean immigration frames the sociocultural context of KAs, the majority of whom were not born in the U.S.[30-32] Roughly 10% of Asian American Pacific Islanders are KAs. There are two major paths for Korean immigration to the U.S.: to reunite with other family members already here or to offer professional and technical skills in demand in the U.S. [30,31] The majority of KA immigrants rated their English level as "minimum" and do not speak English at home regardless of their length of residence in this country. [21,22, 30-34] KA older adults reported relatively high levels of education, but not comparable levels of professional jobs. Studies of KAs have revealed that 30% to 40% are self-employed [30,33-36] which explains their relatively low rate of health insurance which is between 42% and 51%.[30,37-39]

Data Source for GIS

We incorporated a grey literature search to include a diverse and heterogeneous body of material available outside of the traditional academic peer-review process. [40-42] Data estimation of the study populations is mainly based on two sources: local KA community social data and statistical data produced by the U.S. Census Bureau. Census data for the state of NJ were extracted at the census tract geographical level using the American Community Surveys (ACS). The ACS is a publicly available survey administered by the U.S. Census Bureau annually. Our main socio-demographic data come from analyzing the 2015-2019 ACS 5-Year Estimates [43]

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from the Integrated Public Use Microdata Series.[44] However, we also utilized aggregated data for the 2011, 2015, and 2019 ACS retrieved from the data.census.gov website.[45]

Census aggregate data sets are typically large enough to cover state or county level geographic areas, but they are limited in content for small sized of racial/ethnic groups such as KAs. Therefore, we utilized a community participatory mapping approach to harness existing community resources to develop target group-tailored GIS. This participatory GIS relies on the integration of local perspective and knowledge about community capacity of conducting this proposed study.[46-48] We obtained expert consultation from community leaders, cultural navigators, and key informants with knowledge about ADRD, patterns of residence, health care use, and social activities of KA older adults. We used search keywords in both English and Korean such as Korean Americans (재미한국인) or Korean church (한인교회). We tried to use compound nouns such as Korean-American instead of Korean so that the findings were not from Korea. We also traced the community list in a hard copy by working with community leaders. Based on collaboration, we developed the list of local data sets including ethnic churches (from the Korean Catholic Peace Times Weekly [49] and Christian Daily [50]), and ethnic clinics (from the Korean Daily Service [51]). Regarding health services related to ADRD management, we searched websites for AD Research Centers (ADRCs) in the NYC and NJ regions and found that there are no institutions providing Korean-specific services. However, we have found a large number of Korean-serving medical clinics in NJ through our own community-based searches.[51] We then mapped the locations of these ethnic community resources to create our own community maps and incorporated them into community outreach activities.

Analysis

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In analyzing the county-level data from the ACS, we compared different socioeconomic characteristics among selective race/ethnic groups (White, Asians, Koreans, and Chinese) as well as between two age groups (ages 25-64 and 65 and up) within the KA population. In addition to illustrating demographic trends in the study area, we examined the levels of poverty, educational attainment, and limited English proficiency given their crucial impact on one's health condition, health care access, and research participation. For these three socioeconomic characteristics, we also included data for all adults (ages 25 and up) to provide general understanding of our samples (see Table 1). While the census data have large sample sizes to perform multiple between- and within-group comparisons, data from some counties were automatically excluded from analyses (counties with no color in figures). For our geo-spatial analyses, we utilized multiple GIS data sets including the distribution patterns of KA older adult populations, Korean preferred senior apartments, and locations of churches and clinics to integrate spatial and non-spatial (tabular) data sources of U.S. census demographic data.

Recruitment Plan

Recruitment of Asian American research participants presents challenges, and one needs to develop innovative target-population tailored strategies instead of utilizing methods developed by and for the mainstream population.[45,52-54] Thus, we developed a decolonizing recruitment approach to recruit participants from the community as a part of the ACAD cohort study to evaluate a novel CBPR sampling method using GIS maps to visualize unique patterns and trends of distribution of the study population who are disproportionally understudied and under-served. The decolonizing recruitment methods is an approach challenging the Eurocentric research methods pertaining to the norms of methodological conceptualization of conformity that

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undermine the local knowledge and experiences and disproportional socio-cultural characteristics of the marginalized study population groups.[5,46,54-56]

This project represents an academic-practice-community collaboration. Before beginning recruitment, we advertised in ethnic media and social networks to increase awareness and encourage participation in the study. We used "***Tell-A-Friend about Data is Power***" as an ad campaign to communicate the importance of having data from Koreans for Koreans. This recruitment strategy, using language and race matched recruiters and researchers,[30,57-59] would promote access to hard-to-reach KAs, and help participants to feel "listened to" and show the "value of their contribution to the study." As most KAs are connected and have ties to Koreans churches or senior associations, we utilized a chain referral sampling method, like other forms of respondent-driven sampling.[30,60-63] We asked the study participants to introduce us to other Korean American older adults and started with a small number of senior community leaders and cultural navigators who then recruited directly from their peers who go to the same churches or live in the same senior apartments. This approach leverages our well-established collaborations and coordination with a range of multilevel services and existing community capacity.

Results

We created unique socio-spatial and cultural landforms of KA older adults in NJ and the degree to which they are similar or different from other ethnic groups as well as their younger KA counterparts who show higher income and higher English proficiency. The GIS maps shown in Figures 1 through 8 are based on data from both government and local data sets to identify the target sample and improve recruitment. Bergen County in NJ is a growing hub and home to the top five municipalities by percentage of KA populations.[64] Compared to the total population in NJ (Figure 1a), KAs are mostly concentrated in three counties (Bergen, Hudson, and Union) and

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the highest density is in Bergen County (Figure 1b). The maps demonstrate that the study sites are located in population-dense areas of the KA subgroup, our study population, Bergen County. As indicated in Figure 2, there is a trend toward an increasing KA population in Morris County and Middlesex County from 2011 to 2019.

We have also found large numbers of Korean ethnic churches: 124 protestant churches and 11 Catholic churches are identified (Figure 3) and of KA serving medical clinics, most of them are concentered in Bergen County, NJ (Figure 4).

Figure 1. Population Density in New Jersey by County in 2019

a. All Population b. Korean population

Source: 2019 American Community Surveys 1 Year-Estimates, Census Bureau

Figure 2. Changes in Korean Population in New Jersey by County in 2011, 2015, and 2019

a. 2011 b. 2015

c. 2019

Sources: 2011, 2015, and 2019 American Community Surveys 1 Year-Estimates, Census Bureau

Figure 3. Number of Korean Churches in New Jersey

Sources: Korean Community Social Networking Service in New Jersey

Figure 4. Number of Clinics with Korean-Serving Providers in New Jersey

Sources: Korean Community Social Networking Service in New Jersey

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Table 1: Demographic and Socioeconomic Characteristics among Selected Age and Race/Ethnic Groups in New Jersey

Sources: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

When analyzed by age we learned that KA older adults (>_65 years) had higher poverty rates, lower educational levels, and more limited English proficiency levels than their White and Chinese American as well as their younger KA counterparts (Table 1 and Figures 5-8). These findings of low income and linguistic barriers were concordant with our community assessments that increasing presence of KA older adults residing in public senior apartments. We have learned that KA older adults preferred to live where a critical mass of KA reside and close to Korean markets and there was a waitlist to be moved into them. This understanding of geospatial trends of KA older adults housing helped us to design more precise recruitment efforts.

Figure 5. Proportion of Population Ages 65 and Up with Elementary Schooling or Less among Selected Racial/Ethnic Groups in New Jersey

a. Whites

b. Koreans

c. Chinese

Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Figure 6. Proportion of Population Ages 65 and Up Below Poverty Level by Selected Race/Ethnic Groups in New Jersey

a. Whites

b. Korean

c. Chinese

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Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

In particular, concerning education, only Hudson County had over 5% residents with reporting no education or only elementary education among White older adults, whereas several counties including Bergen County, Essex County, Middlesex County, Burlington County, and Camden County had over 5% reporting no or only elementary education among KA older adults (Figures 5a and 5b). We also investigated the different geographic distribution of poverty levels between ethnicities in NJ (Figure 6). Only one county (Hudson County) has over 6.8% below the poverty level and all other counties have less than 6.8% poverty levels among White older adults (Figure 6a). In contrast, a larger number of counties has over 6.8% of those living below the poverty level among KA and Chinese American older adults (Figure 6b and 6c). Bergen County, Union County, and parts of neighboring counties represented the areas with the highest level of poverty among KA older adults (Figure 6b), while Chinese American older adults living in the highest levels of poverty were primarily concentrated in Warren County and Somerset County (Figure 6c). Especially in Bergen County, although income levels are generally higher among the KA population, the older group has a higher poverty rate (25.1%) compared with the poverty level of 9.6% among all KA adults ages 25 and up, and others of the same age group of Whites (6.1%), Asian Americans (13.0%), and Chinese Americans (4.5%) (Table 1). Median income and English proficiency vary considerably among different age groups namely, those aged 25 to 64 and aged 65 and older in the KA population in NJ.

Generally, young Asian American adults have lower rates of English proficiency than other young adults in NJ. KA individuals have the lowest rates of English proficiency rates among all age groups (Table 1), and it was lower among KA older adults aged 65 and older compared to those aged between 25 and 64. For example, 58.1% of KAs aged 65 and over had

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limited English proficiency, whereas 4.1% and 26.9% had limited English proficiency among Whites and Chinese Americans respectively.

Findings also revealed that KA older adults had relatively lower median household incomes than KA younger adults. In detail, while northern NJ including Bergen County, Hudson County, and Somerset County represented the area with over $40,000 median income among KA younger adults (Figure 8a), KA older adults had below $30,000 median income in most counties (Figure 8b).

Figure 7. Percent of Korean Population with Limited English Proficiency by Different Age Groups in New Jersey

a. Ages 25-64 b. Ages 65 and Up

Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Figure 8. Median Income of Korean Population by Different Age Groups in New Jersey

a. Ages 25-64 b. Ages 65 and Up

Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Outcomes of Recruitment

Based on findings of clusters, we focused our recruitment effort in Bergen County, NJ. The recruitment utilizing GIS strategy we developed based on sociodemographic characteristics of KA older adults who are undereducated, have high poverty rates, and have limited English proficiency. We recruited participants from churches, senior apartments, and a Korean serving local neurologist clinic in Bergen County in order to find those without cognitive problems, with mild cognitive impairment, or with dementia from the community. We proactively identified

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specific churches and senior apartments with a high density of Korean American older adults as well as a Korean-speaking neurologist and successfully recruited the aimed subjects earlier than the planned time frame. We found that most study participants resided within a defined recruitment priority area identified by GIS (Table 2; Figure 9). However, half of the participants recruited from clinical sites traveled a distance to Korean-speaking physicians, coming either from NY or suburban areas in NJ.

Figure 9: Geographic Distribution of the Participants by Different Recruitment Sites

Table 2. Geographic Distribution of the Participants by Recruitment Sites

Discussion

We reached our goal of recruiting 60 KA individuals within the proposed period. Our successful recruitment of KA older adults, a hard-to-reach population, is due to our novel CBPR with multiple recruitment strategies including a target population tailored GIS, a detailed understanding of the target population as well as existing community capacity, and a respected relationship between community and researchers.[64-68] Our pilot data suggests that the target population is interested in participating in clinical studies and our approach would contribute to greater awareness of the important role of the community-based GIS recruitment method so that knowledge generated from this study can be used to inform planning and implementation of future studies with other Asian American older adults or other immigrant populations.

Over 15 million older adults aged 65 and older are economically insecure, with incomes below 200% of the federal poverty level.[69] Our findings reveal that KA older adults have distinct socioeconomic characteristics such as higher levels of poverty, lower education levels, and lower

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English proficiency levels compared with their younger generation counterparts (ages 25-64) than other racial/ethnic groups such as White and Chinese. These important differences make it more difficult for the KA older adults to access healthcare facilities compared to other ages and ethnic groups. Most KA older adults live in Bergen County, NJ, which borders NYC and is in the top five municipalities with KAs as a percentage of the overall population according to 2010 Census Data.[70] The study findings show that a GIS is useful to: 1) conveniently identify and quantify as well as cluster potentially eligible participants in a targeted geographic area; 2) visualize sociodemographic characteristics of KAs including age, poverty, education, and language; 3) visualize the resources of faith-based organizations and medical clinics. The geographic distribution of KAs is not evenly spread across the state, which is different from that of mainstream populations that might influence their access to health care and health research participation. Given the distinct sociocultural factors and high degree of local heterogeneity within geographic regions as well as a lack of data sets for small sized population, we have learned that conducting participatory GIS to address local level data deficiency for recruitment of KA older adults in NJ could be one solution to increase minority recruitments.

Most participants were recruited from KA dense areas, but the participants recruited from the clinical site did not all reside in KA dense areas but traveled a long distance to see the Korean speaking physician. With only a small number of Korean speaking physicians, ADRD patients or family caregivers are willing to travel a long distance to see culture and language matched health care professionals. The findings that no AD and dementia treating institutions provide KA-specific services even in NYC and Bergen County, NJ with a dense KA population points to the challenges KA older adults face with getting a dementia diagnosis and ADRD management. In the same vein, KA older adults inequitably share risks and benefits of clinical

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research participation while it also makes it more difficult for researchers to recruit and study this under-served and under-represented group.

A GIS visual presentation of numeric sociodemographic data serves an important role in assessing the variated distribution of the KA minority (small sizes) and is a powerful tool for recruitment strategies to increase understanding of the heterogeneity of minority population distribution, which may not be easily observed in typical numeric data analysis. In addition to standard typical datasets, unique data from the community-based social network data based on geodemographics at the local level provides comprehensive data on KA older adults and neighborhoods. We think that it is an excellent strategy that community leaders who provide SNS information continue to be involved in identifying and recruiting potential participants and that they work with senior community leaders at KA senior dense apartments rather than general community leaders as they have closer relationships with older adults. The benefit of providing a multitude of datasets for GIS development is that the application can be directly integrated with the recruitment plans. Based on our findings, we will continue to develop a novel and human centered community-based recruitment plan for Asian American older adults residing in the community in NJ and the northeast.

Implications

Our findings demonstrate the value of GIS for the recruitment of Asian American older adult immigrants through utilizing community resources. GIS findings provide a detailed knowledge of the spatial distribution of targeted population attributes of density, income, education, language, churches, and health care clinics for Korean speaking older adults. Moreover, the detailed spatial datasets help us to strategically recruit our target population. Asian Americans have been often referred to as “model minorities” based on their relatively higher

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median income and educational levels compared to other racial/ethnic groups in the U.S.[12,16,70,71] but within these groups, a huge variation in income and linguistics exist.[30,72,72] We showed this heterogeneity by disaggregating demographic, socioeconomic, and cultural characteristics of KAs who otherwise could have been overlooked. Health care and clinical studies for older adult immigrants are particularly challenged by difficulties in recruitment due to low education levels, low economic status and low English proficiency and their impact on recruitment should be addressed and further studied. However, developing and implementing GIS by health care researchers is not possible if there is no existing spatial data on the targeted populations. But in reality, there is a lack of community-based social network data for Asian Americans, especially the dataset that disaggregates Asian American subgroups.[73] Most population data tend to not collect relatively small-sized samples of Asian American subgroups; thus, it cannot be meaningfully used in GIS development. As a result, we created an innovative method of local community engagement to capture spatial data about the distribution of churches and KA serving healthcare clinics. These CBPR approaches based on respect for local knowledge and recognizing that the communities can make a critical contribution by creating and changing things.[18,55,64-66,74]

This approach responds to the call from the National Institute on Aging (NIA) to develop strategies to improve the health status of older adults in diverse populations. Results from the full-scale ACAD study will provide health researchers and policymakers with practical evidence on how to identify and increase the participation of Asian American older adults in clinical studies that could be used as a national model for reducing health and research disparities among minority older adult populations. Moreover, this study highlights the importance of GIS

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application in public health studies and has major implications for our understanding of the heterogeneity of minority population distribution and community outreach efforts.

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Table 1: Demographic and Socioeconomic Characteristics among Selected Age and Race/Ethnic Groups in New Jersey

	Total	White	All Asians	Korean	Chinese
All Counties in NJ	8,878,503	4,915,451	826,767	97,127	157,323
Bergen County, NJ	930,133	526,094	148,977	59,117	21,870
Ages 25+					
Elementary Education or Less	2.6%	1.6%	2.2%	2.5%	2.2%
Below Poverty	6.3%	4.9%	6.1%	9.6%	5.6%
Limited English	6.5%	2.2%	14.8%	24.3%	13.2%
Ages 65+					
Population	17.1%	22.0%	12.9%	13.5%	16.3%
Elementary Education or Less	5.1%	3.4%	7.2%	9.1%	6.4%
Below Poverty	7.7%	6.1%	13.0%	25.1%	4.5%
Limited English	11.1%	4.1%	37.1%	58.1%	26.9%

Sources: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Table 2: Geographic Distribution of the Participants

Recruitment Sources	N (%)	Geographic Distribution
Ethnic Churches	18 (30%)	NY (n=1), Bergen County (n=17)
Senior Apartment	27 (45%)	Bergen County (n=27)
Korean-Speaking Neurologist	15 (25%)	NY (n=4) & non-Bergen Counties (n=3) Bergen County (n=8)

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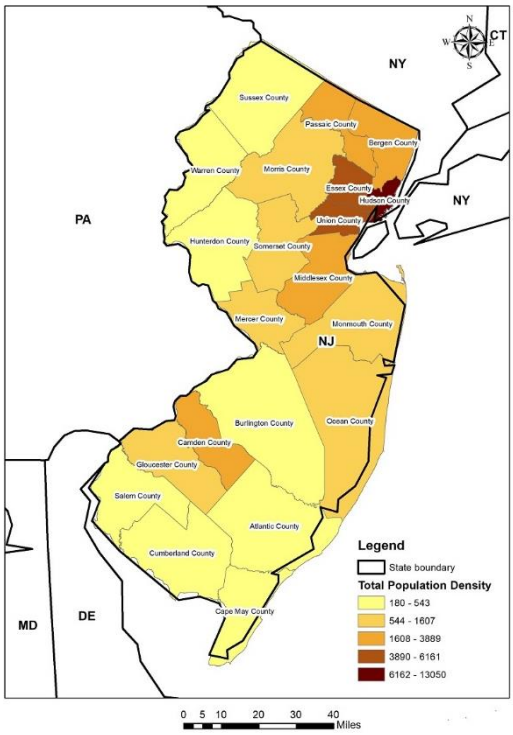
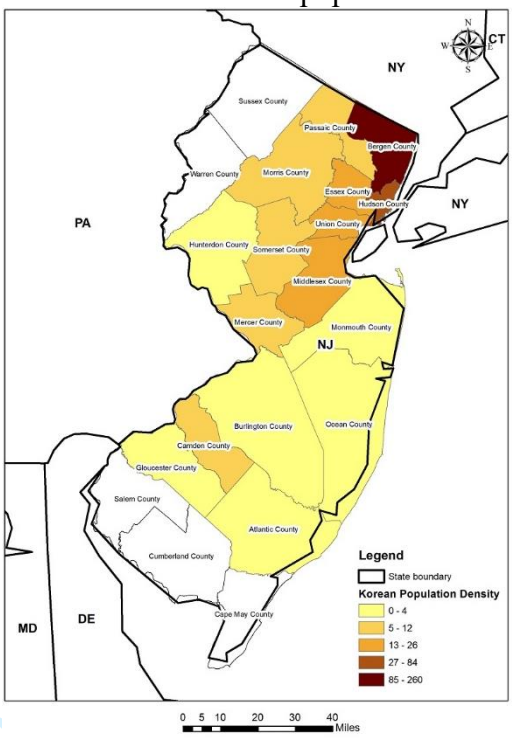
Figure 1. Population Density in New Jersey by County in 2019

a. All Population



b. Korean population



Source: 2019 American Community Surveys 1 Year-Estimates, Census Bureau

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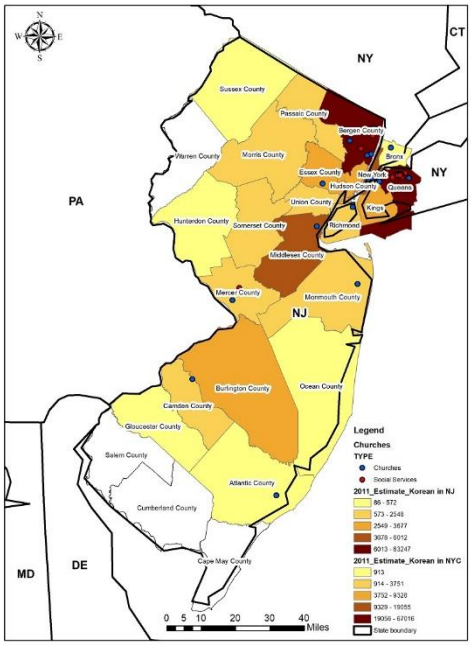
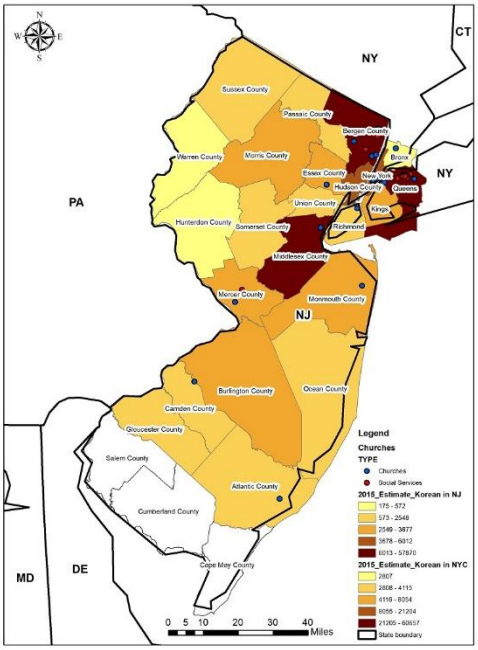
Figure 2. Changes in Korean Population in New Jersey by County in 2011, 2015, and 2019

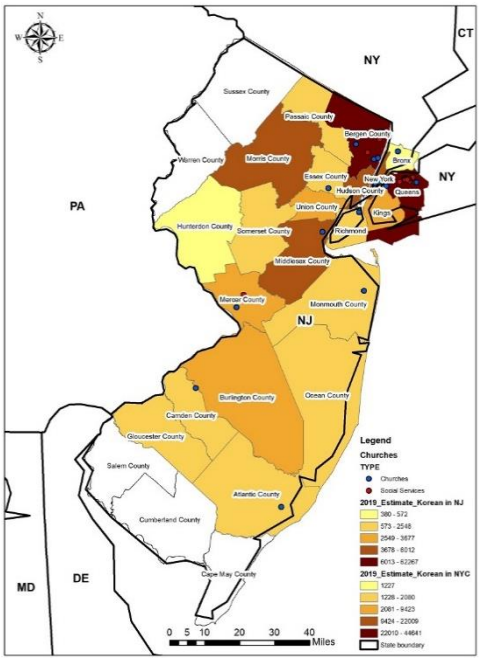
a. 2011



b. 2015



c. 2019



Sources: 2011, 2015, and 2019 American Community Surveys 1 Year-Estimates, Census Bureau

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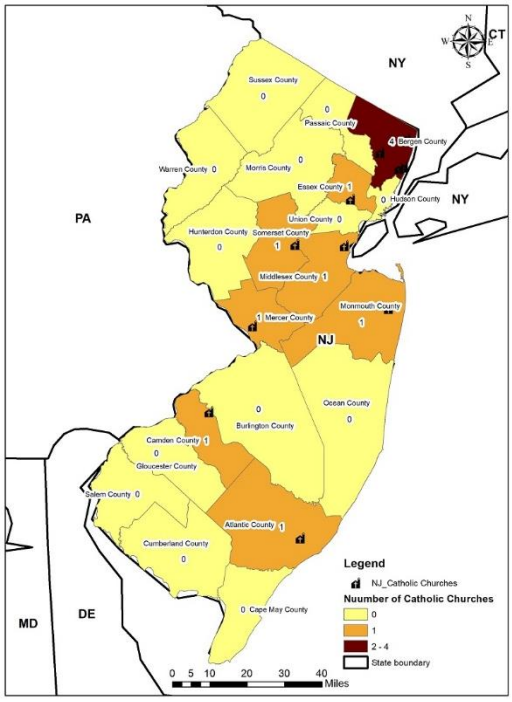
Figure 3: Number of Korean Churches in New Jergy

a. Cathonic churches



b. Protestant churches

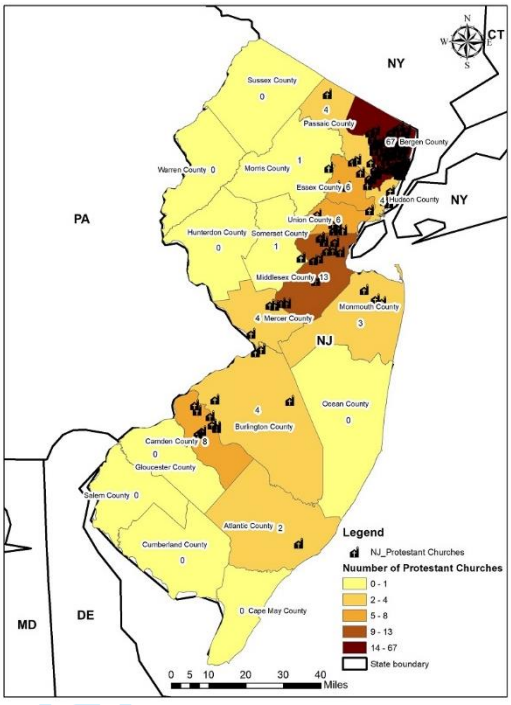


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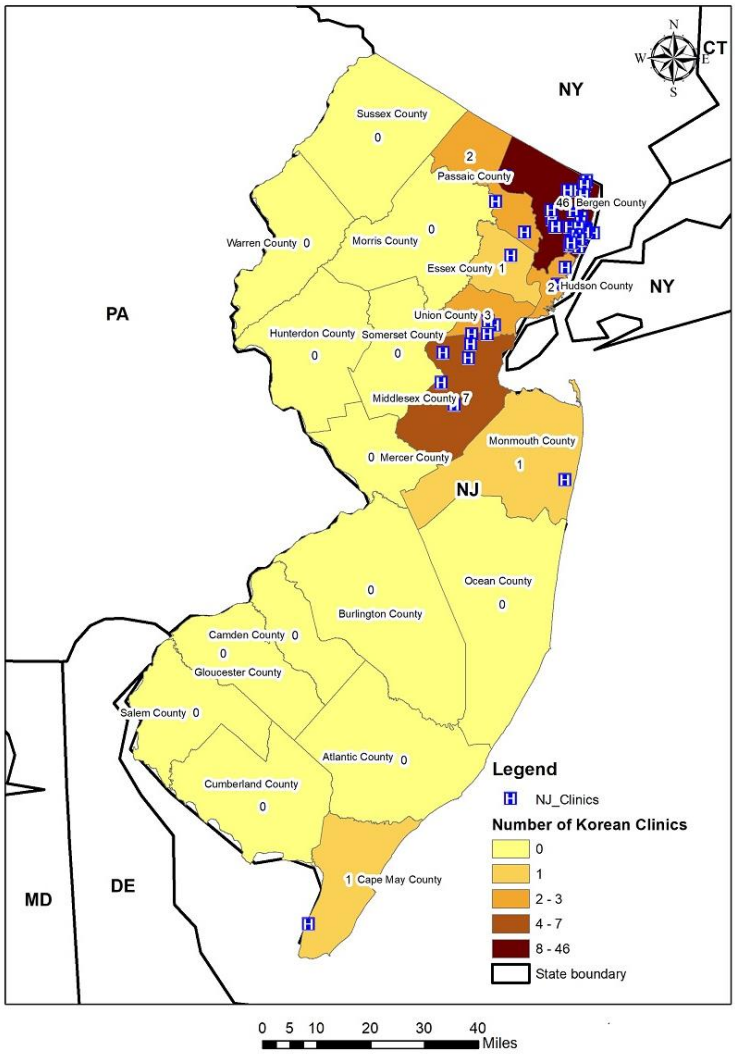
Figure 4. Number of Korean-Serving Clinics in New Jersey



Sources: Korean Community Social Networking Service in New Jersey

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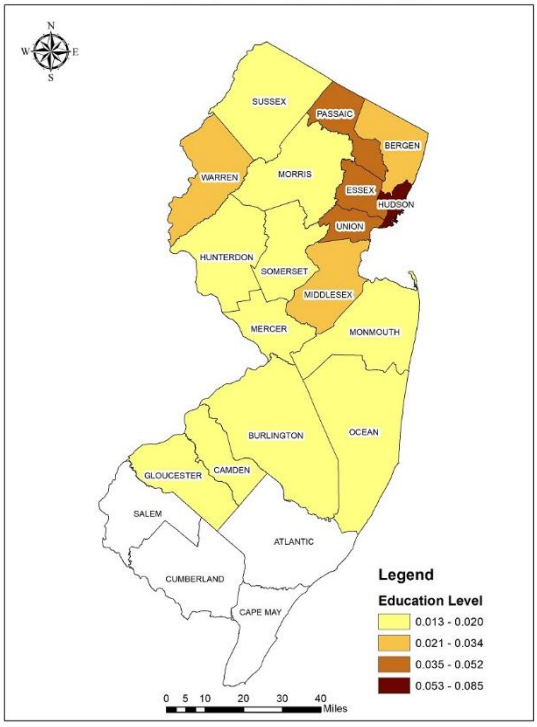
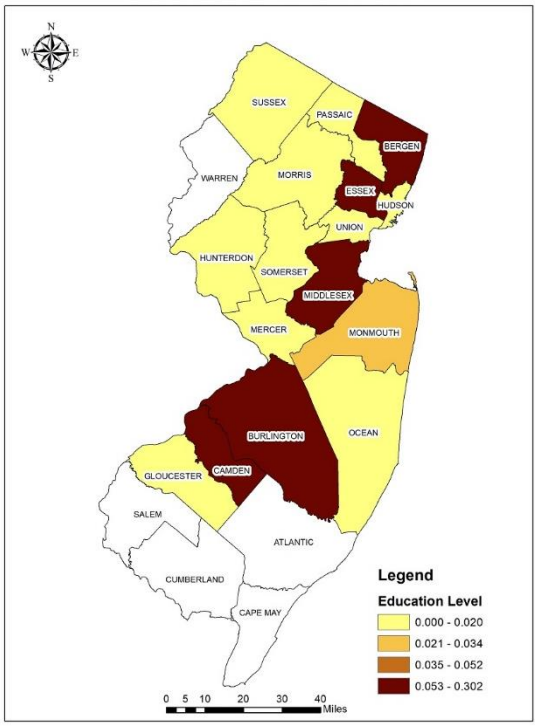
Figure 5. Proportion of Population Ages 65 and Up with Elementary Schooling or Less among Selected Racial/Ethnic Groups in New Jersey

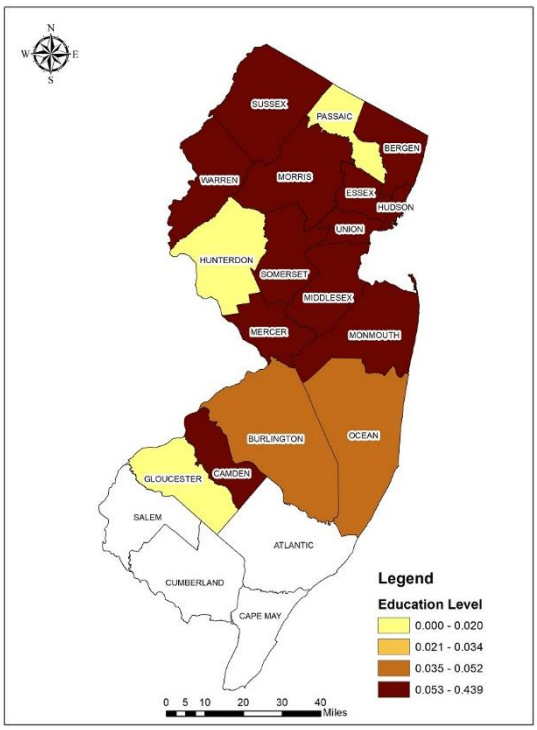
a. Whites



b. Koreans



c. Chinese



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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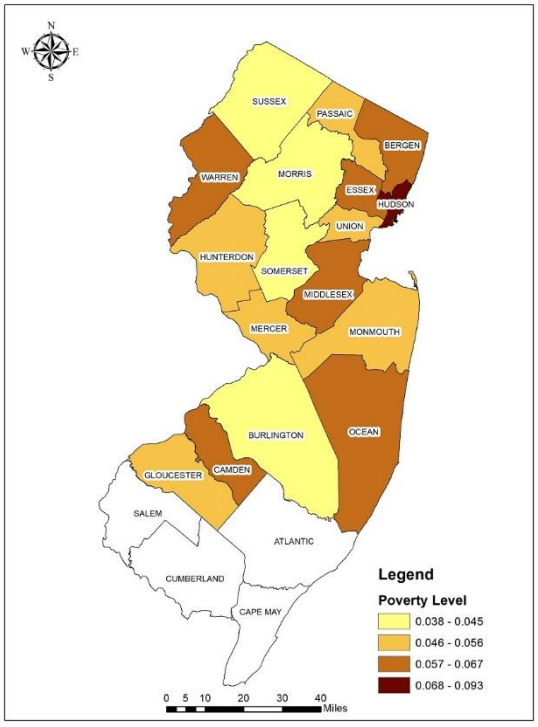
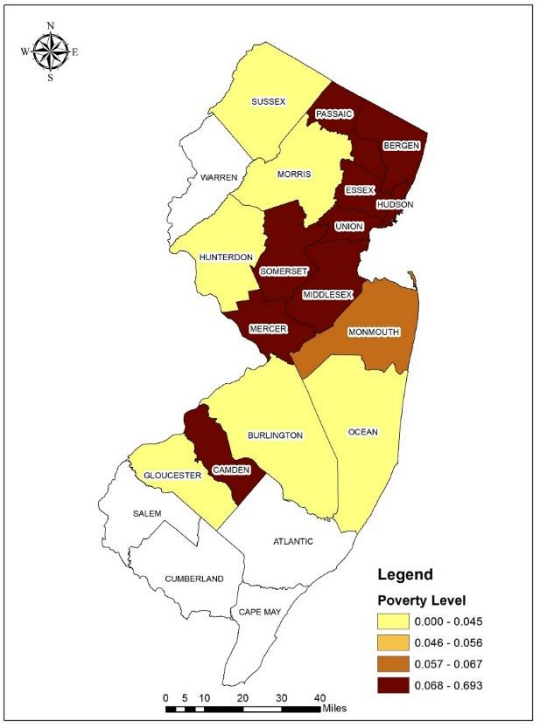
Figure 6. Proportion of Population Ages 65 and Up Below Poverty Level by Selected Race/Ethnic Groups in New Jersey

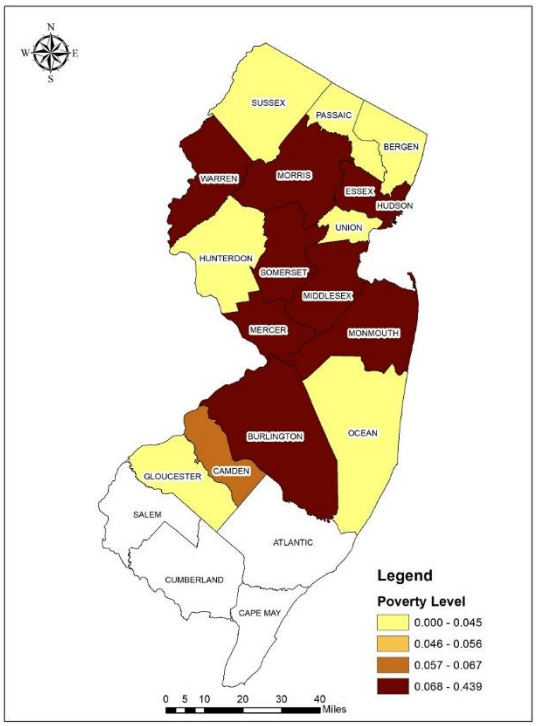
a. Whites



b. Korean



c. Chinese



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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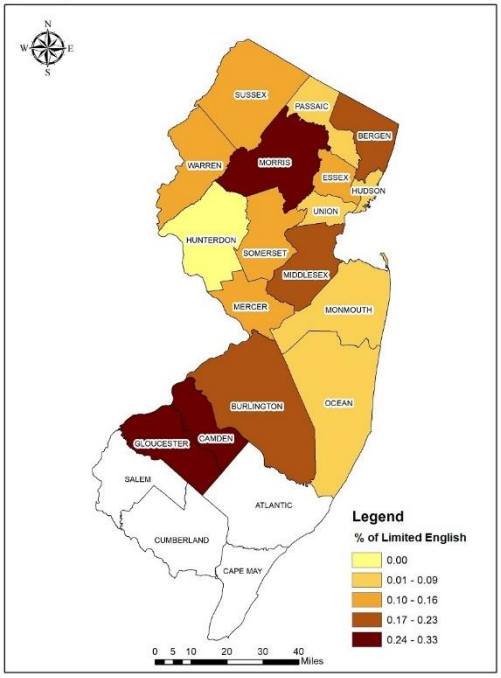
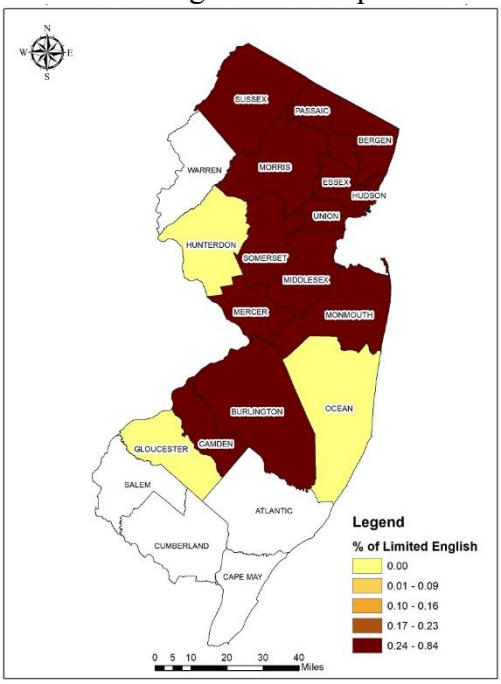
Figure 7. Percent of Korean Population with Limited English Proficiency by Different Age Groups in New Jersey

a. Ages 25-64



b. Ages 65 and Up



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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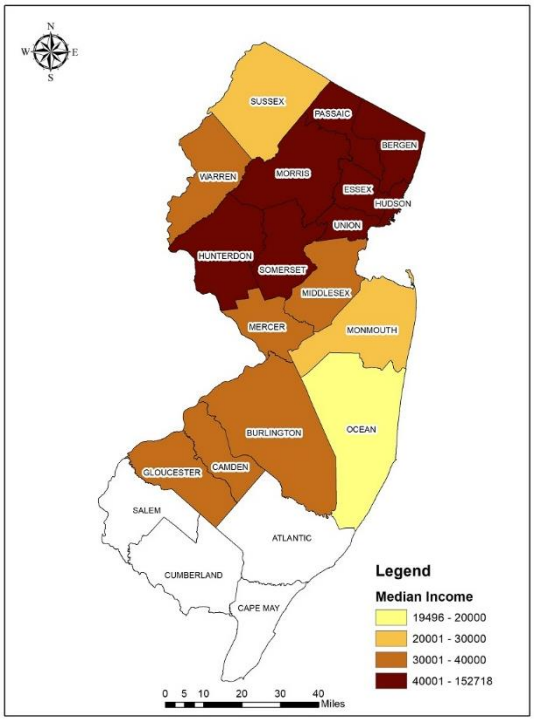
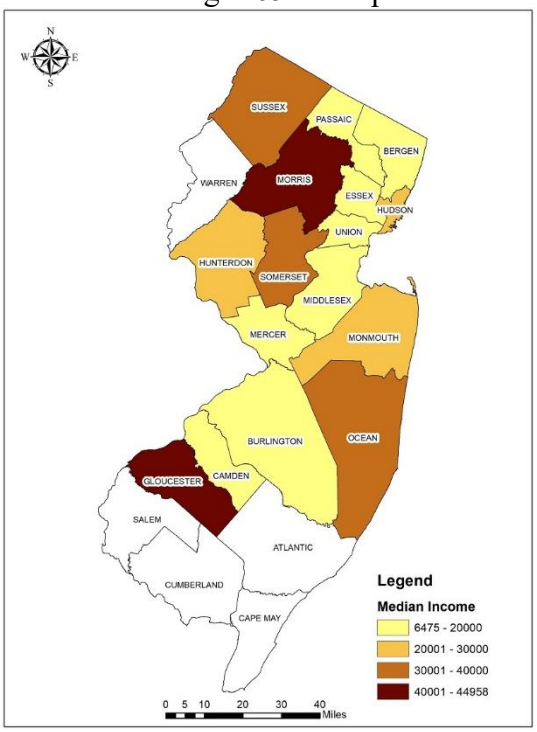
Figure 8. Median Income of Korean Population by Different Age Groups in New Jersey

a. Ages 25-64



b. Ages 65 and Up



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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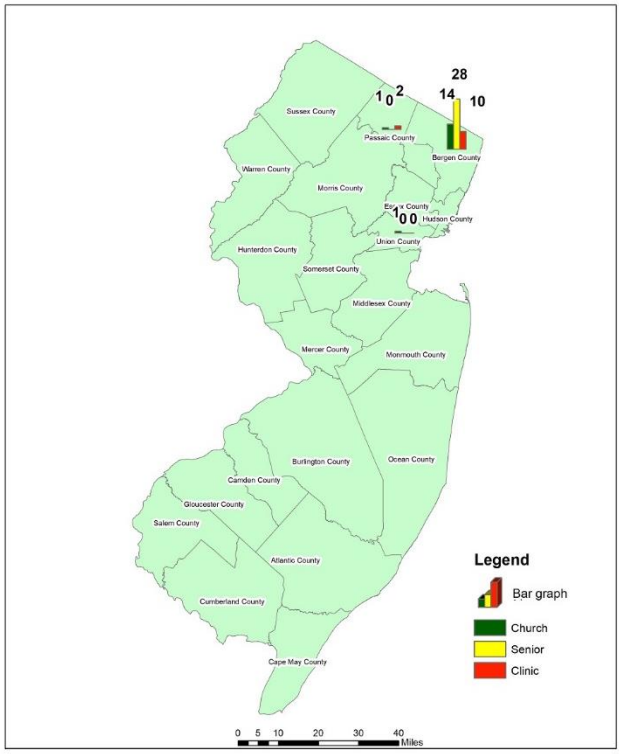
Figure 9: Geographic Distribution of the Participants by Different Recruitment Sites



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Utilizing Community Based Geographic Information System (GIS) to Recruit Older Asian Americans in an Alzheimer's Disease Study

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Primary Subject Heading:	Research methods
Secondary Subject Heading:	Epidemiology, Geriatric medicine, Public health, Health policy, Sociology
Keywords:	Aged, Dementia, Health Equity, EPIDEMIOLOGIC STUDIES, Patient Participation

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Abstract

Objective: is to show the usefulness of incorporating community-based Geographic Information System (GIS) in recruiting research participants for the Asian Cohort for Alzheimer's Disease (ACAD) study using the subgroup of Korean American (KA) older adults. The ACAD study is the first large study in the U.S. and Canada focusing on the recruitment of Chinese, Korean, and Vietnamese older adults to address the issues of underrepresentation of Asian Americans in clinical research.

Methods: To promote clinical research participation of racial/ethnic minority older adults with and without dementia, we utilized GIS by collaborating with community members to delineate boundaries for geographic clusters and enclaves of church and senior networks, and KA serving ethnic clinics. As well, we utilized socioeconomic data identified as recruitment factors unique to KA older adults which was analyzed for developing recruitment strategies.

Results: GIS maps show a visualization of the heterogeneity of the sociodemographic characteristics and the resources of faith-based organizations and KA serving local clinics. We addressed these factors that disproportionately affect participation in clinical research and successfully recruited the aimed participants (N=60) in the proposed period.

Discussion: Using a GIS map to locate KA provided innovative inroads to successful research outreach efforts for a pilot study that may be expanded to other underserved populations across the U.S. in the future. We will use this tool subsequently on a large-scale clinical genetic epidemiology study.

Policy Implication: This approach responds to the call from the National Institute on Aging (NIA) to develop strategies to improve the health status of older adults in diverse populations. Our study will offer a practical guidance to health researchers and policymakers in identifying

understudied and hard-to-reach specific Asian American populations for clinical studies or initiatives. This would further contribute in reducing the health and research disparity gaps among older minority populations.

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Strengths and limitations

- This study responds to the call from the NIA to build diverse community partnerships to improve the recruitment of minorities (Milestone 12.a). We did so to engage community and academic partners by developing community-based GIS to identify and recruit hard-to-reach populations.
- This study created novel community-based GIS maps which provide a comprehensive overview with a visual representation of the heterogeneities of social factors and physical clusters for the targeted population.
- Our successful recruitment of KA older adults is due to multiple recruitment strategies including target population tailored GIS, detailed understanding of the target population as well as existing community capacity and respected relationships between the community and researchers.
- Using publicly available social network data has inherent limitations related to completeness, correctness, and timeliness reporting and there are limitations to using social networks observed in social datasets which may be different from the underlying (offline) networks.
- Though recruitment to clinical studies with Asian American older adults is complex, only Korean speaking Korean American older adults are included.

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Introduction

Alzheimer's Disease and related dementia (ADRD) affects 5.8 million people in the U.S. and 50 million worldwide.[1,2] The annual global cost of dementia is now above $1.3 trillion and is expected to rise to $2.8 trillion by 2030.[3,4] The literature on ADRD shows constant and adverse health disparities as well as research disparities across racial and ethnic groups.[5,6] Though many AD variants are population-specific or have different frequencies across populations, like most complex diseases, the AD literature has a strong bias toward European ancestry [6,7], and there are substantial disparities in minority participation in AD studies. Despite the call from the National Institute of Health (NIH) for the inclusion of more representative groups in clinical studies, racial/ethnic minorities, older adults, those with lower socioeconomic status, and immigrant subpopulations remain underserved, understudied, and underrepresented. [6,8-10]

Older racial/ethnic minority populations are growing faster than their non-Hispanic White counterparts and will comprise 45% of the older adult population by 2060.[11] The number of Asian Americans who are 65 years and older will increase by 352% by 2060 and comprise 21% of the total Asian American population by 2060.[11,12] Participation of Asian Americans in the ADRD interventional trials is very low (i.e., <1%) [6,13,14] and investigations of ADRD in Asian American populations are woefully inadequate, so the generalizability of scientific findings for Asian Americans is questionable. The availability of reliable data is imperative to the attainment of the regional profiles of health equity in the U.S. [15] However, in Healthy People 2020, as in most other national health reports, ADRD data about Asian Americans is absent. The main reasons for the omission of Asian Americans in health care studies are the barriers present in Asian American communities that include mistrust of outsiders, lack of knowledge, language barriers, lack of health insurance, and sociocultural barriers.[9-12,16-19] It is difficult to gain access

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to Asian Americans because they are dispersed throughout the country and tend to have a low level of contact with the healthcare system. However, there are states where Asian Americans are concentrated such as California, New York, and Texas, and ethnic enclaves in various metropolitan areas such as Chinatown, Koreatown, and Little Saigon as well as based on social factors including churches.[16-19]

There is a need to develop sampling methods that are responsive to ethnicity and sociocultural diversity among study populations and to be able to generalize scientific findings for Asian Americans. [9,10,18] As for older Asian American populations, they show specific characteristics that make them different from other ethnic groups and their younger counterparts, including language, health beliefs, health attitudes, lower economic status, and social networks.[17,19-22] These characteristics may act as facilitators or barriers to participation in clinical studies or clinical trials for communities, including ADRD.

The strategies to identify geographical and socio-environmental trends among Asian Americans, particularly in the older population, may enhance the recruitment of the study participants. GIS would be an excellent tool for comparing spatial data on the relative concentrations of minority populations and identifying high-concentration areas or enclaves for the small sized study population. GIS can quickly and accurately create visual representations of multiple complex data sets. This makes it a more effective tool for developing recruitment strategies than other methods, such as text, charts, or tables. GIS could enhance the visual perception of physical and social environments by mapping layers of data information and its relationship to the location of the study population. The use of GIS techniques in public health studies has developed significantly in recent years. [23-27] Many public health researchers have found that visualization of the spatial distribution of health-related events of target populations

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and making informed public health decisions faster are the two primary applications of GIS data/methods in health-related studies.[25, 28, 29] The applications of GIS methodologies in older adults' care and research are growing,[30-32] however, there is limited research on GIS in assessing recruitment strategies among older adults with and without dementia. [33,34]

The purpose of this paper is to show the usefulness of incorporating community-based GIS in recruiting research participants for the Asian Cohort for Alzheimer's Disease (ACAD) study using the subgroup of Korean American older adults. Community-based GIS recruitment strategies can help researchers and community recruiters work together to develop recruitment strategies by creating and mapping the data and monitoring the recruitment process and outcomes. The ACAD study is the first large study in the U.S. and Canada focusing on the recruitment of Chinese, Korean, and Vietnamese older adults to address the issue of underrepresentation of Asian Americans in research. The study's long-term goal is to recruit over 5,000 participants to identify genetic and non-generic/lifestyle AD risk factors and to establish blood biomarker levels for AD diagnosis. The ACAD study is approved by the Institutional Review Board of a university in the Northeast U.S.

This paper summarizes only the strategies used to recruit KA older adults aged 60 years and older in New Jersey in the U.S. and discusses how the community-based participatory research method combined with GIS resulted in the successful recruitment of our target research participant. Our main objective is to show the effectiveness of using community-based GIS to recruit a hard-to-reach KA elderly population with and without dementia in New Jersey by 1) creating a few GIS maps to capture the physical and sociocultural characteristics of the sample population and 2) referencing the maps to effectively recruit the sample population.

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Method

We used holistic community-based participatory research combined with applying GIS to delineate boundaries for geographic clusters and church and senior networks, and KA serving ethnic clinics within identified clusters or enclaves to recruit participants from the community.[35] We integrated local knowledge and resources of the social environment into GIS by collaborating with community leaders for developing recruitment strategies. Recruitment was derived from linking data from identified diverse sources of geographic and social enclaves of KA populations and visualized geographic and sociocultural trends in the study populations. A chain referral recruitment method within identified enclaves, like other forms of respondent-driven sampling, was utilized.

Geographic Context of Korean Americans

Although there are concentrations of KAs in California and on the East Coast, KAs are widely scattered throughout the U.S.[16,35-37] According to data from the 2010 Census, New Jersey's Asian population grew by more than 1,400 percent since 1970. The counties with the largest Asian American populations are Middlesex (24% of the county's residents), Bergen (16%), and Hudson (15%) in New Jersey. We choose New Jersey to carry out this pilot ACAD since the highest density of KAs (6.3%) resides in Bergen County, New Jersey. [37,38]

Sociocultural Contexts of Korean Americans

The history and socio-demographic characteristics of Korean immigration frame the sociocultural context of KAs, the majority of whom were not born in the U.S.[35-37] According to the 2010 census, roughly 10% of Asian American Pacific Islanders are KAs. There are two major paths for Korean immigration to the U.S.: to reunite with other family members already

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here or to offer professional and technical skills in demand in the U.S. [35,36] The majority of KA immigrants rated their English level as "minimum" and do not speak English at home regardless of their length of residence in this country. [21,22, 35-39] KA older adults reported relatively high levels of education, but not comparable levels of professional jobs. Studies of KAs have revealed that 30% to 40% are self-employed [30,38-41] which explains their relatively low rate of health insurance which is between 42% and 51%.[35,42-44]

Data Source for GIS

We incorporated a grey literature search to include a diverse and heterogeneous body of material available outside of the traditional academic peer-review process.[45-47] Data estimation of the study populations is mainly based on two sources: local KA community social data and statistical data produced by the U.S. Census Bureau. Census data for the state of New Jersey were extracted at the county level using the American Community Survey (ACS). The ACS is a publicly available survey administered by the U.S. Census Bureau annually. Our main socio-demographic data come from analyzing the 2015-2019 ACS 5-Year Estimates [48] from the Integrated Public Use Microdata Series.[49] However, we also utilized aggregated data for the 2011, 2015, and 2019 ACS when presenting the general population distribution retrieved from the data.census.gov website.[50]

While the Census data contain various geographical and sociodemographic information about different racial/ethnic groups, the nature of the data set does not include community-specific information at a local level. Therefore, we utilized a community participatory mapping approach to harness existing community resources to develop target group-tailored GIS. This participatory GIS relies on the integration of local perspectives and knowledge about the community capacity of conducting this proposed study.[51-53] We obtained expert consultation

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from community leaders, cultural navigators, and key informants with knowledge about ADRD, patterns of residence, health care use, and social activities of KA older adults. When searching for the geographical locations of Korean community facilities online, we used search keywords in both English and Korean such as Korean Americans (재미한국인) or Korean church (한인교회). We tried to use compound nouns such as Korean American instead of Korean so that the search results did not include places in South Korea. We also traced the community list in a hard copy by working with community leaders.

Through the collaboration, we developed a list of local data sets comprised of ethnic churches (from the Korean Catholic Peace Times Weekly [54] and Christian Daily [55]), and ethnic clinics (from the Korean Daily Service [56]). Regarding health services related to ADRD management, we searched websites for AD Research Centers in the New York and New Jersey regions and found that there were no institutions providing Korean-specific services. However, we have found a large number of Korean-serving medical clinics in New Jersey through our own community-based searches.[56] We then mapped the locations of these ethnic community resources to create our own community maps and incorporated them into community outreach activities.

Pre-recruitment Analysis

In analyzing the county-level data from the ACS, we compared different socioeconomic characteristics among selective race/ethnic groups (White, Asians, Koreans, and Chinese) as well as between two age groups (ages 25 and up and 65 and up) within the KA population. In addition to illustrating demographic trends in the study area, we examined the levels of poverty, educational attainment, and limited English proficiency given their crucial impact on one's health condition, healthcare access, and research participation. While the census data have large

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sample sizes to perform multiple between- and within-group comparisons, data from some counties were automatically excluded from analyses (counties with no color in figures). For our geo-spatial analyses, we utilized multiple GIS data sets including the distribution patterns of KA older adult populations, Korean preferred senior apartments, and locations of churches and clinics to integrate spatial and non-spatial (tabular) data sources of U.S. census demographic data.

Recruitment Plan

Recruitment of Asian American research participants presents challenges, and one needs to develop innovative target-population tailored strategies instead of utilizing methods developed by and for the mainstream population.[50,57-59] Thus, we developed a decolonizing recruitment approach to recruit participants from the community as a part of the ACAD cohort study to evaluate a novel community-based participatory research sampling method using GIS maps to visualize unique patterns and trends of distribution of the study population who are disproportionally understudied and under-served. The decolonizing recruitment methods is an approach challenging the Eurocentric research methods pertaining to the norms of methodological conceptualization of conformity that undermine the local knowledge and experiences and disproportional socio-cultural characteristics of the marginalized study population groups.[5,51,59-61]

This project represents an academic-practice-community collaboration. Before beginning recruitment, we advertised in ethnic media and social networks to increase awareness and encourage participation in the study. We used "***Tell-A-Friend about Data is Power***" as an ad campaign to communicate the importance of having data from Koreans for Koreans. This recruitment strategy, using language and race matched recruiters and researchers,[35,62-64] would

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promote access to hard-to-reach KAs, and help participants to feel "listened to" and show the "value of their contribution to the study." As most KAs are connected and have ties to Korean churches or senior associations, we utilized a chain referral sampling method, like other forms of respondent-driven sampling.[35,65-68] We asked the study participants to introduce us to other Korean American older adults and started with a small number of senior community leaders and cultural navigators who then recruited directly from their peers who go to the same churches or live in the same senior apartments. This approach leverages our well-established collaborations and coordination with a range of multilevel services and existing community capacity.

Results

We created unique socio-spatial and cultural landforms of KA older adults in New Jersey and the degree to which they are similar or different from other ethnic groups as well as the general adult population. The GIS maps shown in Figures 1 through 8 are based on data from both government and local data sets to identify the target sample and improve recruitment. Bergen County in New Jersey is a growing hub and home to the top five municipalities by the percentage of the KA population.[64] Compared to the total population in New Jersey as shown in Figure 1a, KAs are mostly concentrated in three counties (Bergen, Hudson, and Union) and the highest density is in Bergen County as illustrated in Figure 1b. As indicated in Figure 2, there is a trend toward an increasing KA population in Morris County and Middlesex County from 2011 to 2019.

Moreover, we have found large numbers of Korean ethnic churches: specifically, 11 Catholic churches (Figure 3a) and 124 protestant churches (Figure 3b) and they are primarily located in Bergen County and Middlesex County in New Jersey. Furthermore, Figure 4

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illustrates the number of Korean-serving medical clinics and most of them are concentrated in Bergen County, New Jersey.

Figure 1. Population Density in New Jersey by County in 2019

a. All Population b. Korean population

Source: 2019 American Community Surveys 1 Year-Estimates, Census Bureau

Figure 2. Changes in the Korean Population in New Jersey by County in 2011, 2015, and 2019

a. 2011 b. 2015

c. 2019

Sources: 2011, 2015, and 2019 American Community Surveys 1 Year-Estimates, Census Bureau

Figure 3. Number of Korean Churches in New Jersey

Sources: Korean Community Social Networking Service in New Jersey

Figure 4. Number of Clinics with Korean-Serving Providers in New Jersey

Sources: Korean Community Social Networking Service in New Jersey

Table 1: Demographic and Socioeconomic Characteristics among Selected Age and Race/Ethnic Groups in New Jersey

Sources: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

When analyzed by age we learned that KA older adults (65 years and up) had lower education levels, higher poverty rates, and more limited English proficiency levels than their White and Chinese American as well as their younger KA counterparts (Table 1 and Figures 5-

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8). In detail, the proportion of the population with lower education and higher poverty rates were much higher for KA older adults compared to their White. A higher proportion of KA older adults' population for both socioeconomic factors were found in portions of northeast (Bergen, Essex, Union, Hudson), central (Middlesex, Somerset, Mercer), and southern counties (Camden) (Figures 5 and 6). For the maps in Figures 7 and 8, limited English proficiency and median income were compared between young KA adults and old KA adults respectively. A higher percentage of the KA Population with limited English proficiency and lower median income were found for KA older adults compared to KA younger adults in most of the counties in New Jersey. These findings of low income and linguistic barriers were concordant with our community assessments that there has been an increase in the presence of KA older adults residing in public senior apartments. We have learned that KA older adults preferred to live where a critical mass of KA reside and close to Korean markets and there was a waitlist to be moved into them. This understanding of geospatial trends of KA older adults housing helped us to design more precise recruitment efforts.

Figure 5. Proportion of Population Ages 65 and Up with Elementary Schooling or Less among Selected Racial/Ethnic Groups in New Jersey

a. Whites b. Koreans

c. Chinese

Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Figure 6. Proportion of Population Ages 65 and Up Below the Poverty Level by Selected Race/Ethnic Groups in New Jersey

a. Whites b. Korean

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c. Chinese

Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

In particular, concerning education, only Hudson County had over 5% of residents reporting no education or only elementary education among White older adults, whereas several counties including Bergen County, Essex County, Middlesex County, Burlington County, and Camden County had over 5% reporting no or only elementary education among KA older adults (Figures 5a and 5b). We also investigated the different geographic distribution of poverty levels between ethnicities in New Jersey (Figure 6). Only one county (Hudson County) has over 6.8% below the poverty level and all other counties have less than 6.8% poverty levels among White older adults (Figure 6a). In contrast, a larger number of counties has over 6.8% of those living below the poverty level among KA and Chinese American older adults (Figure 6b and 6c). Bergen County, Union County, and parts of neighboring counties represented the areas with the highest level of poverty among KA older adults (Figure 6b), while Chinese American older adults living in the highest levels of poverty were primarily concentrated in Warren County and Somerset County (Figure 6c). Especially in Bergen County, although income levels are generally higher among the KA population, the older group has a higher poverty rate (25.1%) compared with the poverty level of 9.6% among all KA adults ages 25 and up, and others of the same age group of Whites (6.1%), Asian Americans (13.0%), and Chinese Americans (4.5%) (Table 1).

Figure 7. Percent of Korean Population with Limited English Proficiency by Different Age Groups in New Jersey

a. Ages 25 and Up b. Ages 65 and Up

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Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Figure 8. Median Income of Korean Population by Different Age Groups in New Jersey

a. Ages 25 and Up b. Ages 65 and Up

Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Outcomes of Recruitment

Based on findings of clusters, we focused our recruitment effort in Bergen County, New Jersey. The recruitment utilizing the GIS strategy we developed based on sociodemographic characteristics of KA older adults who are undereducated, have high poverty rates, and have limited English proficiency. We recruited participants from churches, senior apartments, and a Korean serving local neurologist clinic in Bergen County in order to find those without cognitive problems, with mild cognitive impairment, or with dementia from the community. We proactively identified specific churches and senior apartments with a high density of KA older adults as well as a Korean-speaking neurologist and successfully recruited the aimed subjects earlier than the planned time frame. We found that most study participants resided within a defined recruitment priority area identified by GIS (Table 2; Figure 9). However, half of the participants recruited from clinical sites traveled a distance to Korean-speaking physicians, coming either from New York or suburban areas in New Jersey.

Figure 9: Geographic Distribution of the Participants by Different Recruitment Sites

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Table 2. Geographic Distribution of the Participants by Recruitment Sites

Discussion

We reached our goal of recruiting 60 KA individuals within the proposed period. Our successful recruitment of KA older adults, a hard-to-reach population, benefited from our approach with multiple recruitment strategies including a target population tailored GIS, a detailed understanding of the target population as well as existing community capacity, and a respected relationship between community and researchers.[69-73] Our pilot data suggests that the target population is interested in participating in clinical studies and our approach would contribute to greater awareness of the important role of the community-based GIS recruitment method so that knowledge generated from this study can be used to inform planning and implementation of future studies with other Asian American older adults or other immigrant populations.

We established a consensus-based diagnosis process for study participants to determine diagnostic categories. The consensus conference with more than two bilingual neurologists and bilingual registered nurse data collectors at the sites was completed. In addition, we used a randomized external review of the cases by two neurologists to assure harmonization of diagnosis among all ACAD sites which are in progress. Diagnosis categories included probable/possible AD, mild cognitive impairment, and normal control and the locations where the most AD cases were identified and recruited will be reported in the next report.

Over 15 million older adults aged 65 and older are economically insecure, with incomes below 200% of the federal poverty level.[74] Our findings reveal that KA older adults have distinct socioeconomic characteristics such as higher levels of poverty, lower education levels, and lower

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English proficiency levels compared to other racial/ethnic groups such as White and Chinese. These important differences make it more difficult for the KA older adults to access healthcare facilities compared to other ages and ethnic groups. Most KA older adults live in Bergen County, New Jersey, which borders New York City and is in the top five municipalities with KAs as a percentage of the overall population according to 2010 Census Data.[75] The study findings show that a GIS is useful to: 1) conveniently identify and quantify as well as cluster potentially eligible participants in a targeted geographic area; 2) visualize sociodemographic characteristics of KAs including age, poverty, education, and language; 3) visualize the resources of faith-based organizations and medical clinics. The geographic distribution of KAs is not evenly spread across the state, which is different from that of mainstream populations that might influence their access to health care and health research participation. Given the distinct sociocultural factors and a high degree of local heterogeneity within geographic regions as well as a lack of data sets for small sized population, we have learned that conducting participatory GIS to address local level data deficiency for recruitment of KA older adults in New Jersey could be one solution to increase minority recruitments.

Most participants were recruited from KA dense areas, but the participants recruited from the clinical site did not all reside in KA dense areas but traveled a long distance to see the Korean speaking physician. With only a small number of Korean speaking physicians, ADRD patients or family caregivers are willing to travel a long distance to see culture and language matched health care professionals. The findings that no AD and dementia treating institutions provide KA-specific services even in New York City and Bergen County, New Jersey with a dense KA population points to the challenges KA older adults face with getting a dementia diagnosis and ADRD management. In the same vein, KA older adults inequitably share risks and

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benefits of clinical research participation while it also makes it more difficult for researchers to recruit and study this under-served and under-represented group.

A GIS visual presentation of numeric sociodemographic data plays an essential role in assessing the varied distribution of the small-sized KA minority and is a powerful tool for recruitment strategies to increase understanding of the heterogeneity of minority population distribution, which may not be easily observed in typical numeric data presented in a tabular form. In addition to standard typical datasets, unique data from the community-based social network data based on geodemographics at the local level provides comprehensive data on KA older adults and neighborhoods. The GIS-based information helps us to develop specific group-tailored recruitment strategies by allowing us to conveniently visualize and link demographic, socioeconomic, and local community-level specific characteristics of the target population.

This study demonstrates the value of a community-based participatory research model combined with GIS in tailoring targeted outreach strategies by combining spatial and local resources to identify clusters or enclaves of a hard-to-reach population. When diagnostic data analysis is completed, GIS can define the magnitude of cognitive impairment, and the location of KA ADRD in populations for public health departments and ADRD researchers. We think that it is an excellent strategy that community leaders who provide local resource information continues to be involved in identifying and recruiting potential participants and that they work with senior community leaders at KA senior dense apartments rather than general community leaders as they have closer relationships with older adults. The benefit of providing a multitude of datasets for GIS development is that the application can be directly integrated with the recruitment plans. Based on our findings, we will continue to develop a community-based recruitment plan for

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Asian American older adults residing in the community in New Jersey and in the Northeast region of the U.S. to secure racially/ethnically diverse samples.

Limitations: There are several limitations. First, since we were only able to capture a snapshot of the specific socioeconomic characteristics of the Korean older population using the most recent available Census data prior to the recruitment, our pre-recruitment analysis did not reflect any long-term longitudinal changes and patterns of KA older population. Second, we only examined the socio-demographics of KA older adults in New Jersey and did not identify urban versus rural environments so that the findings must be cautiously applied to other geographic regions and other ethnic groups. Third, using publicly available online social network data has inherent limitations related to completeness, correctness, and timeliness in reporting as well as that data might be different from offline data.

Implications

Our findings demonstrate the value of GIS for the recruitment of Asian American older adult immigrants through utilizing community resources. GIS findings provide a detailed knowledge of the spatial distribution of targeted population attributes of density, income, education, language, churches, and health care clinics for Korean speaking older adults. Moreover, the detailed spatial datasets help us to strategically recruit our target population. Asian Americans have been often referred to as “model minorities” based on their relatively higher

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median income and educational levels compared to other racial/ethnic groups in the U.S.[12,16,75,76] but within these groups, a huge variation in income and linguistics exists.[30,77] We showed this heterogeneity by disaggregating demographic, socioeconomic, and cultural characteristics of KAs who otherwise could have been overlooked. Health care and clinical studies for older adult immigrants are particularly challenged by difficulties in recruitment due to low education levels, low economic status, and low English proficiency, and their impact on recruitment should be addressed and further studied. However, developing and implementing GIS by health care researchers is not possible if there is no existing spatial data on the targeted populations. But in reality, there is a lack of community-based social network data for Asian Americans, especially the dataset that disaggregates Asian American subgroups.[78] Most population data tend to not collect relatively small-sized samples of Asian American subgroups; thus, it cannot be meaningfully used in GIS development. As a result, we created an innovative method of local community engagement to capture spatial data about the distribution of churches and KA serving healthcare clinics. These community-based participatory research approaches are based on respect for local knowledge and recognizing that the communities can make a critical contribution by creating and changing things.[18,60,69-71,79] This novel approach based on spatial and non-spatial data into one framework have far-reaching implication in researching currently understudied populations and this is important for both fair representation of all populations and the translatability of the findings.

This approach responds to the call from the National Institute on Aging (NIA) to develop strategies to improve the health status of older adults in diverse populations. Results from the full-scale ACAD study will provide health researchers and policymakers with practical evidence on how to identify and increase the participation of Asian American older adults in clinical

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studies that could be used as a national model for reducing health and research disparities among minority older adult populations. Moreover, this study highlights the importance of GIS application in public health studies and has major implications for our understanding of the heterogeneity of minority population distribution and community outreach efforts.

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Contribution Statement

Haeok Lee, PhD: Substantial contributions to the conception, design, data collection, analysis, and interpretation.

Hoehun Ha, PhD: conception and design of the work, analysis, writing, final approval and agreement to be accountable for all aspect of the work.

Sejung Sage Yim, PhDc: design, acquisition, data analysis, interpretation of data, final approval and agreement to be accountable for all aspect of the work.

Hyun-Sik Yang, MD: design, acquisition, and interpretation of data, final approval and agreement to be accountable for all aspect of the work.

Veronica Lee: design, acquisition, reviewing, final approval and agreement to be accountable for all aspect of the work.

Eunju Hong: design, acquisition, reviewing, final approval and agreement to be accountable for all aspect of the work.

Tiffany Chow, MD: conception and interpretation of data, final approval and agreement to be accountable for all aspect of the work.

Van Ta Park, PhD, MPH: conception and interpretation of data, final approval and agreement to be accountable for all aspect of the work.

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Gyung Ah Jun, PhD conception and interpretation of data, final approval and agreement to be accountable for all aspect of the work.

Yun-Beom Choi, MD, PhD: conception and design of the work, interpretation, analysis and interpretation of data conception and interpretation of data, final approval and agreement to be accountable for all aspect of the work.

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No Competing Interest

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Table 1: Demographic and Socioeconomic Characteristics among Selected Age and Race/Ethnic Groups in New Jersey

	Total	White	All Asians	Korean	Chinese
All Counties in NJ	8,878,503	4,915,451	826,767	97,127	157,323
Bergen County, NJ	930,133	526,094	148,977	59,117	21,870
Ages 25+					
Elementary Education or Less	2.6%	1.6%	2.2%	2.5%	2.2%
Below Poverty	6.3%	4.9%	6.1%	9.6%	5.6%
Limited English	6.5%	2.2%	14.8%	24.3%	13.2%
Ages 65+					
Population	17.1%	22.0%	12.9%	13.5%	16.3%
Elementary Education or Less	5.1%	3.4%	7.2%	9.1%	6.4%
Below Poverty	7.7%	6.1%	13.0%	25.1%	4.5%
Limited English	11.1%	4.1%	37.1%	58.1%	26.9%

Sources: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

Table 2: Geographic Distribution of the Participants

Recruitment Sources	N (%)	Geographic Distribution
Ethnic Churches	18 (30%)	NY (n=1), Bergen County (n=17)
Senior Apartment	27 (45%)	Bergen County (n=27)
Korean-Speaking Neurologist	15 (25%)	NY (n=4) & non-Bergen Counties (n=3) Bergen County (n=8)

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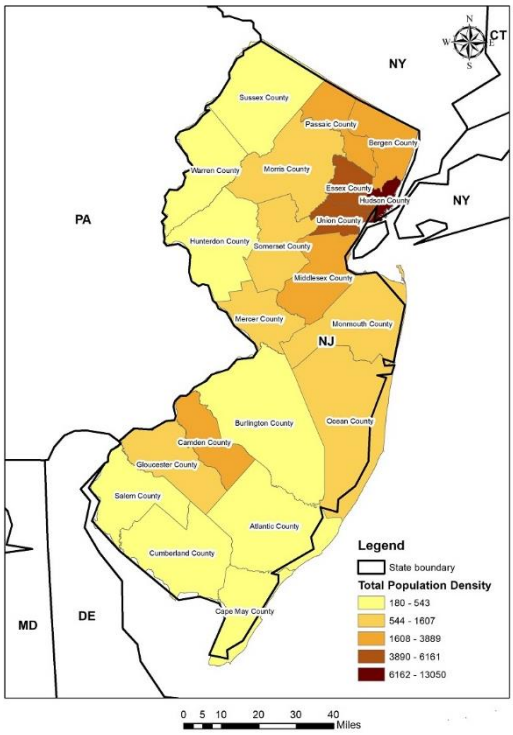
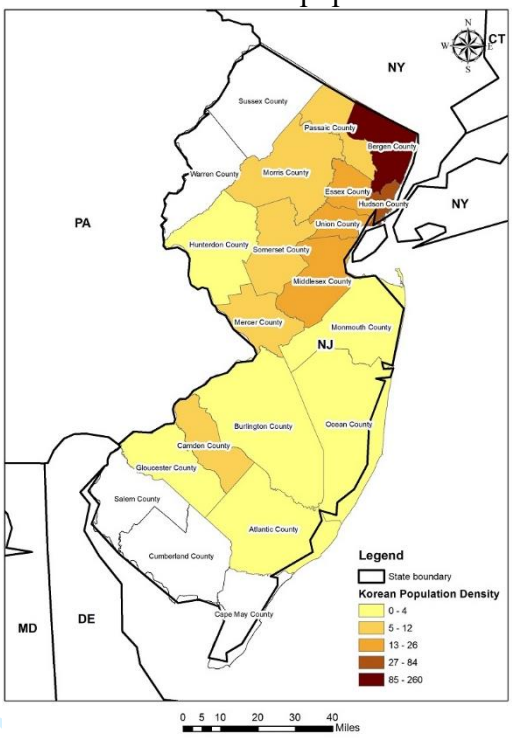
Figure 1. Population Density in New Jersey by County in 2019

a. All Population



b. Korean population



Source: 2019 American Community Surveys 1 Year-Estimates, Census Bureau

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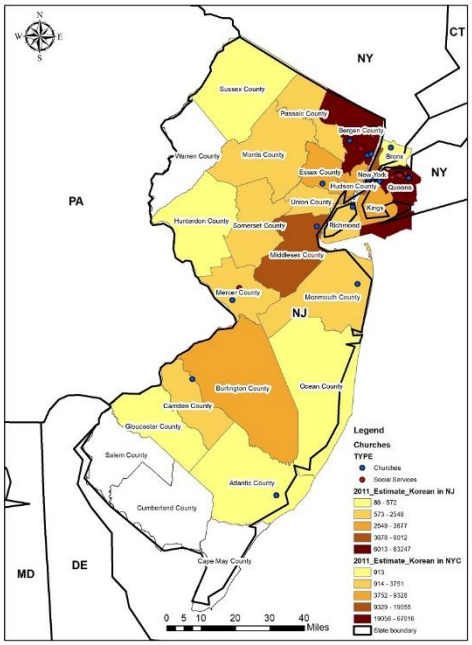
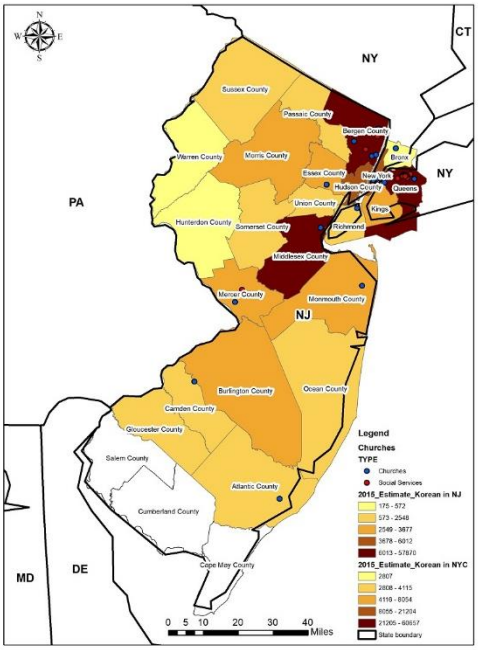
Figure 2. Changes in Korean Population in New Jersey by County in 2011, 2015, and 2019

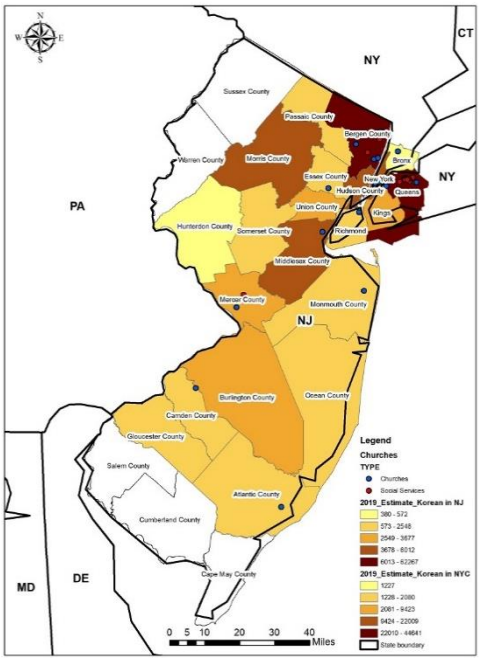
a. 2011



b. 2015



c. 2019



Sources: 2011, 2015, and 2019 American Community Surveys 1 Year-Estimates, Census Bureau

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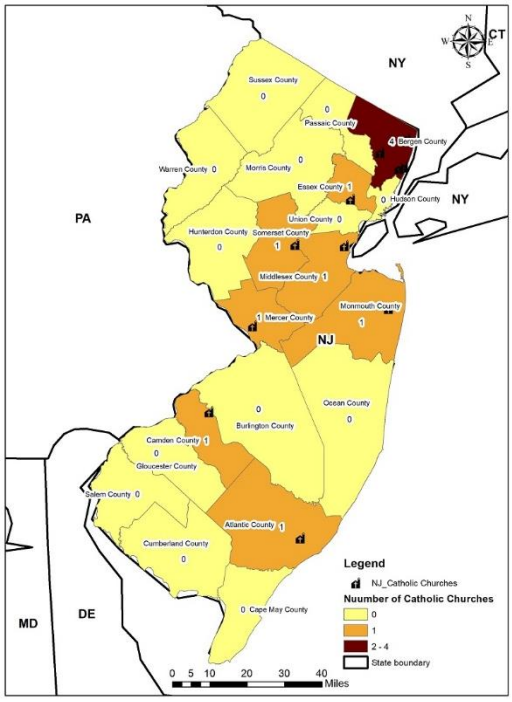
Figure 3: Number of Korean Churches in New Jergy

a. Cathonic churches



b. Protestant churches

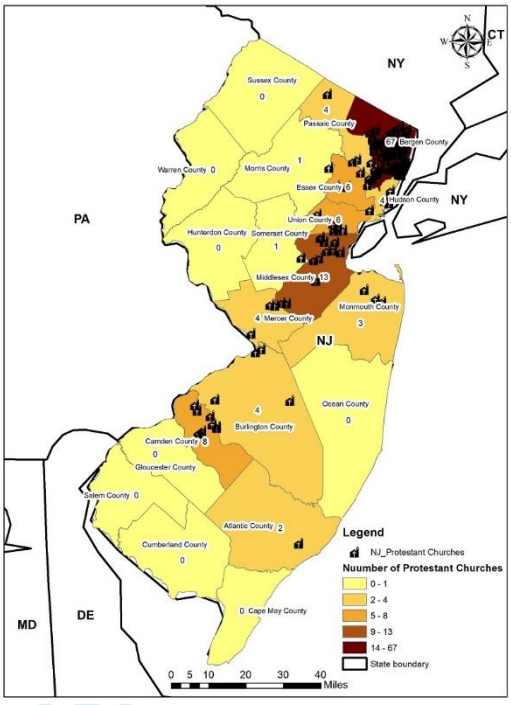


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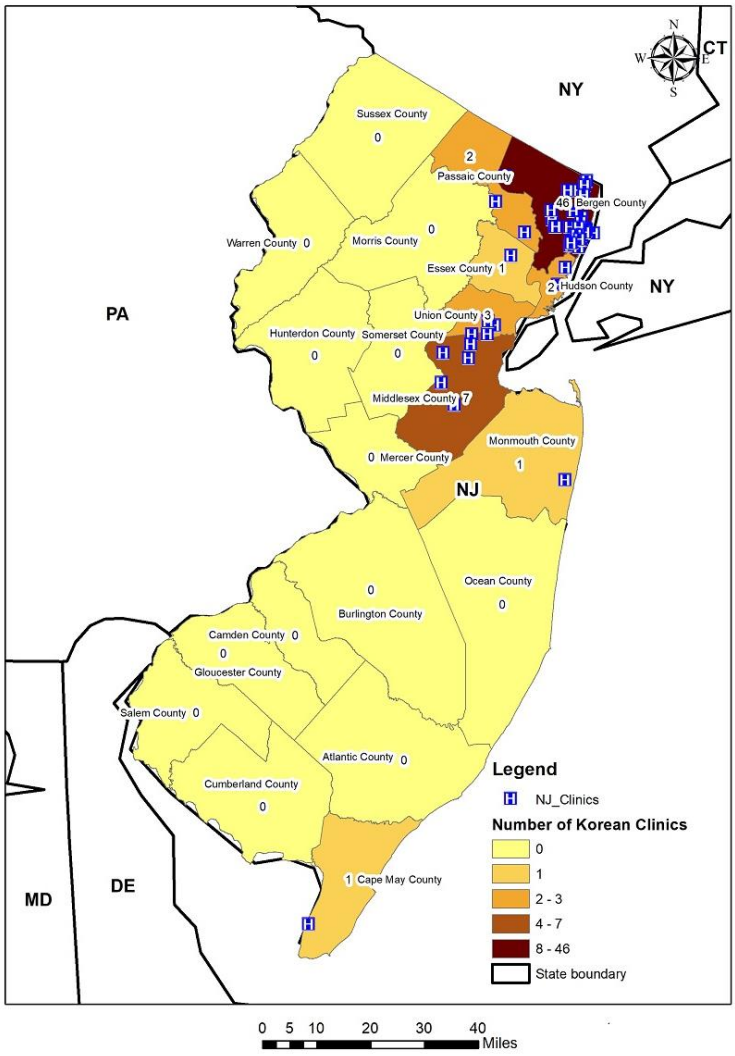
Figure 4. Number of Korean-Serving Clinics in New Jersey



Sources: Korean Community Social Networking Service in New Jersey

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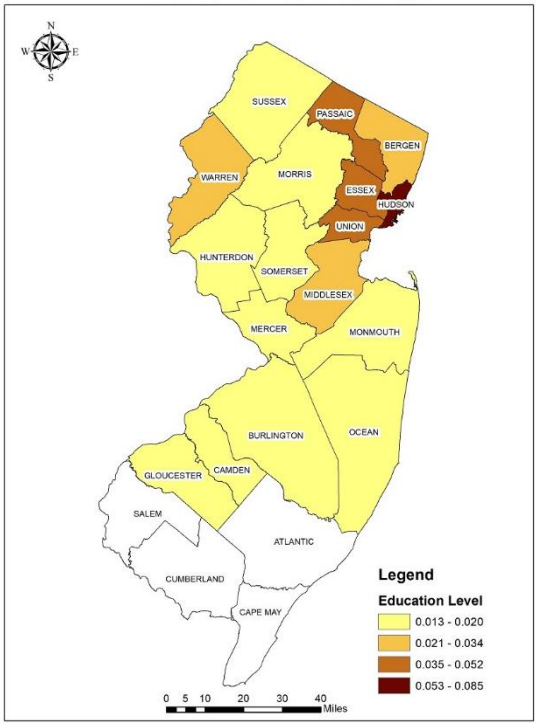
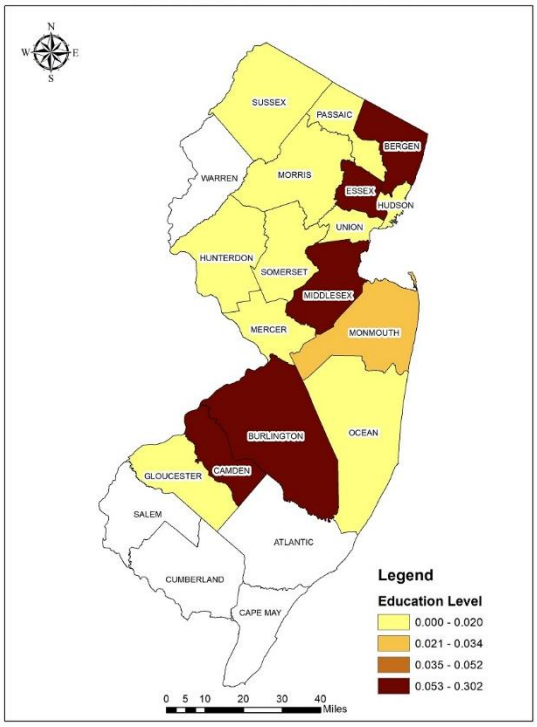
Figure 5. Proportion of Population Ages 65 and Up with Elementary Schooling or Less among Selected Racial/Ethnic Groups in New Jersey

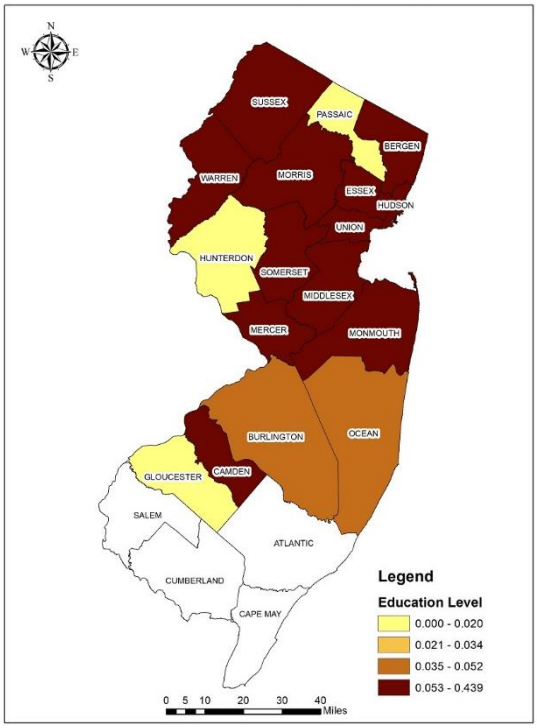
a. Whites



b. Koreans



c. Chinese



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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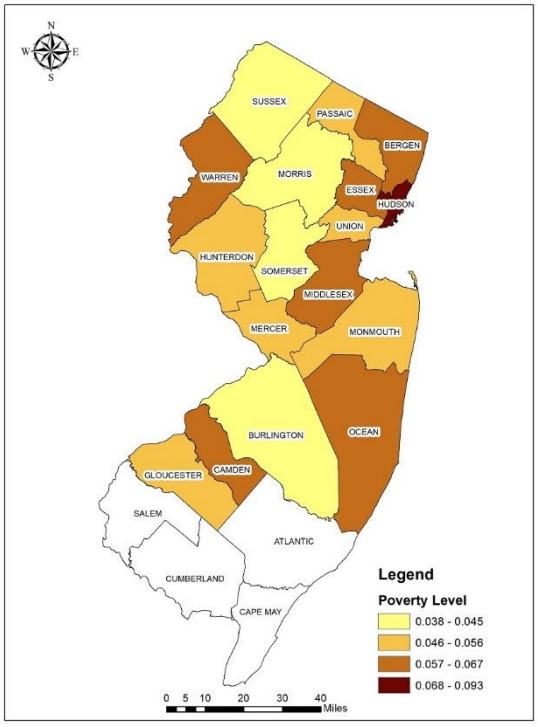
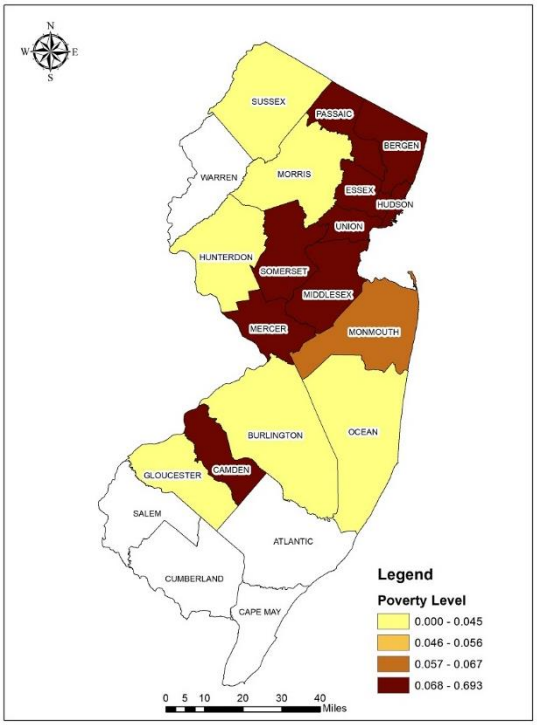
Figure 6. Proportion of Population Ages 65 and Up Below Poverty Level by Selected Race/Ethnic Groups in New Jersey

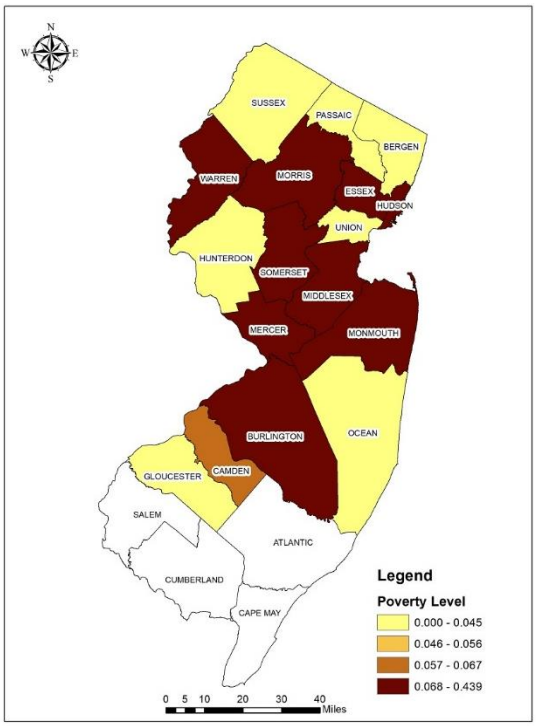
a. Whites



b. Korean



c. Chinese



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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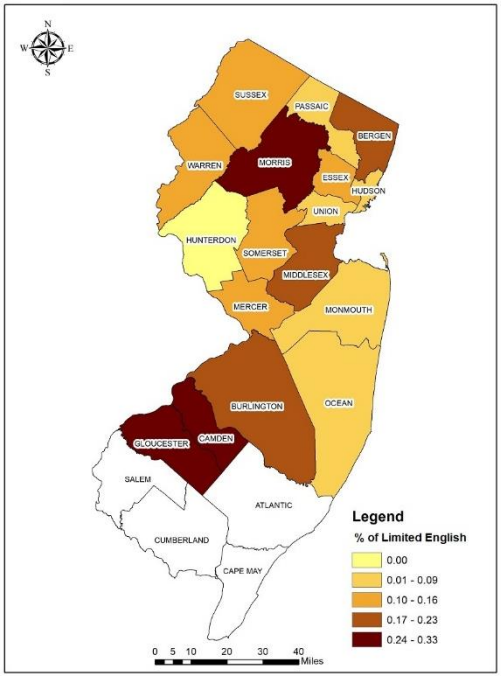
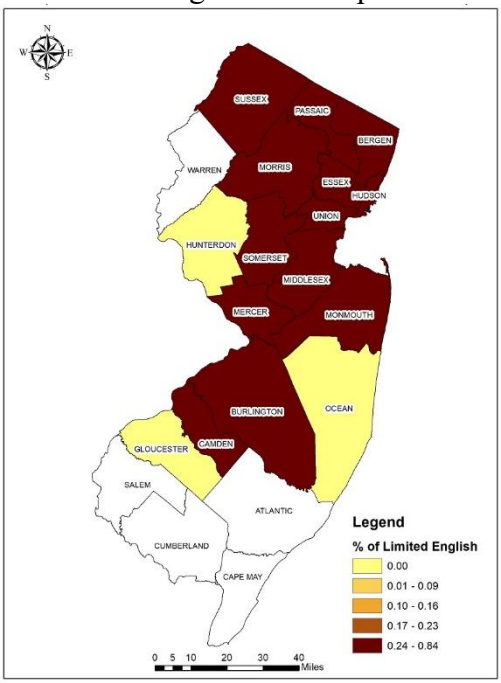
Figure 7. Percent of Korean Population with Limited English Proficiency by Different Age Groups in New Jersey

a. Ages 25-64



b. Ages 65 and Up



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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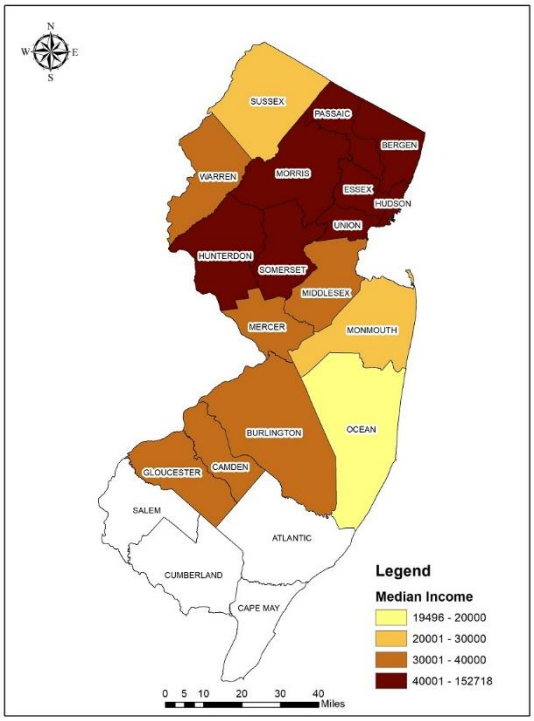
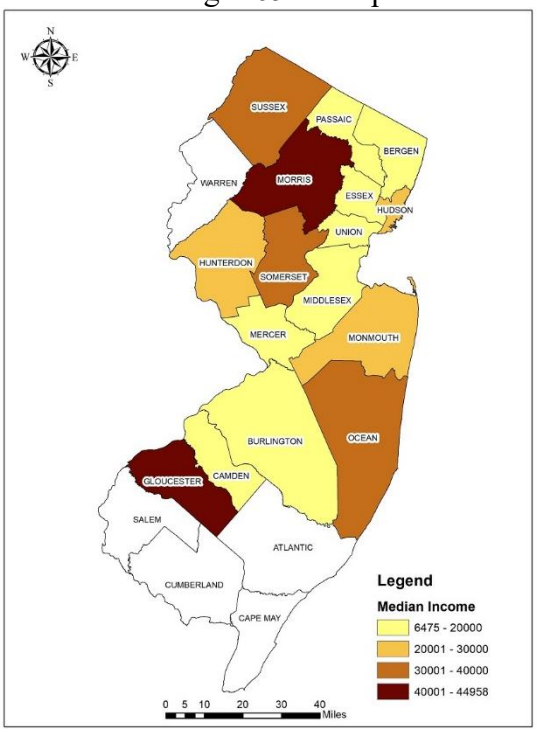
Figure 8. Median Income of Korean Population by Different Age Groups in New Jersey

a. Ages 25-64



b. Ages 65 and Up



Source: 2015-2019 American Community Surveys 5-Year Estimates, Census Bureau

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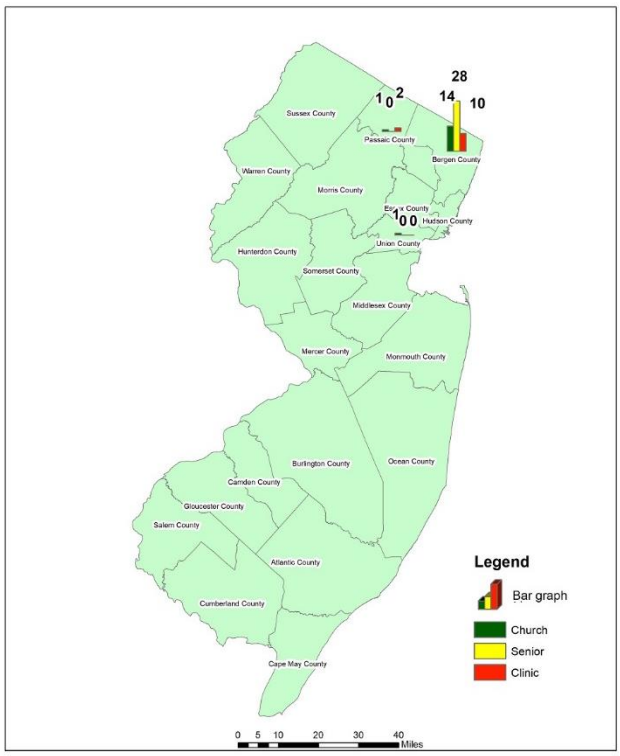
Figure 9: Geographic Distribution of the Participants by Different Recruitment Sites



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