

RESEARCH ARTICLE

Asian Americans and Pacific Islanders' perspectives on participating in the CARE recruitment research registry for Alzheimer's disease and related dementias, aging, and caregiving research

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Funding information

National Institute on Aging; National Institutes of Health, Grant/Award Number: R24AG063718; Collaborative Approach for Asian Americans and Pacific Islanders Research and Education (CARE) in Alzheimer's Disease and Related Dementias

Abstract

Introduction: This study elicited Asian Americans and Pacific Islanders' (AAPI) perspectives about recruitment strategies/messaging for participation in an aging, Alzheimer's disease and related dementias (ADRD), and caregiving research recruitment registry.

Methods: Using a mixed methods design, CARE (Collaborative Approach for AAPI Research and Education) conducted 14 focus groups (N = 123) with AAPI cultural groups (Asian Indian, Chinese, Filipino, Japanese, Korean, Samoan, Vietnamese) in different languages. Descriptive statistics and thematic qualitative analyses were conducted.

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Results: Mean age of participants was 54 years (median: 61; range 18–80), 66% were female, and 81% were foreign-born. Themes of consideration for recruitment emerged: (1) culturally/linguistically appropriate outreach in culturally specific spaces, (2) motivations for research participation, and (3) approaches to outreach and recruitment methods. Within each of these themes, there were ethnic differences in specific strategies/approaches reflected as subthemes.

Discussion: Recruitment and messaging strategies should be tailored uniquely for each targeted AAPI group, with a thorough understanding of the cultural/linguistic factors that facilitate research participation to increase AAPI participation in ADRD, aging, and caregiver-related research.

KEYWORDS

aging, Alzheimer's disease and related dementias, Asian Americans and Pacific Islanders, caregiving, research recruitment registry

1 | INTRODUCTION

Alzheimer's disease (AD) is the sixth leading cause of death in the United States,¹ but the fourth leading cause in California.² While the number of Americans with AD will balloon to 14 million and become increasingly diverse by 2050,¹ California already is home to a large and ethnically diverse population of AD sufferers that anticipates the future of the nation. Recently, findings from the Lancet Commission indicate that "12 modifiable risk factors account for around 40% of worldwide dementias, which consequently could theoretically be prevented or delayed."³ Several large-scale studies are currently underway to evaluate if modifying these risk factors is associated with reduced incidence of dementia in diverse populations; however, specific outreach efforts to include Asian Americans and Pacific Islanders (AAPI) in this work are limited.

AAPI are the most rapidly growing racial group of older Americans at risk for AD and related dementias (ADRD).^{4,5} By 2030, the number of California's AAPI living with AD will triple to nearly 200,000, comprising 17% of California's total AD population.⁶ Disparities exist in knowledge about ADRD among AAPI⁷ and AAPI ADRD caregivers' experience disparities in depression, burden, and physical health compared to non-Hispanic White caregivers.^{9,10} It is therefore imperative that underserved AAPI populations be educated, engaged, and enrolled in ADRD research.^{11,12}

Despite the growing AAPI population and the mandate to engage racial/ethnic minorities in research,¹³ AAPI participation remains limited.¹⁴ While the AAPI population is the fastest growing racial population in the United States,¹⁵ research involving AAPI receives less than 1% of clinical funding¹⁶ resulting in growing health disparities. To address this problem in California and beyond, researchers must develop methods to better recruit AAPI. AAPI are heterogeneous in English language proficiency, culture, nativity, and socioeconomic status,¹⁷ all of which contribute to health disparities. Data suggest that while AAPI are interested in being engaged, barriers must

be addressed to improve ADRD research participation.^{18–20} Clinical research recruitment is a consistent challenge to successful medical research.^{21–23} Without the inclusion of diverse AAPI, research findings may be underpowered and result in bias or scientific error.^{24,25} Clinical research recruitment requires outreach efforts that are time-consuming and costly,²³ and successful recruitment of underserved populations requires significant engagement with community partners who are trusted sources of information.^{23,26}

To address the underrepresentation of AAPI in ADRD research, we developed Collaborative Approach for AAPI Research and Education (CARE), a research recruitment registry focused on health across the lifespan in these unique communities. Recruitment registries are repositories of individuals who have expressed willingness to learn about studies for which they may be eligible.²⁷ Registries represent increasingly common tools to aid ADRD research recruitment²⁸ but critical questions, such as how best to use this tool to diversify study populations, remain unanswered.²⁷ CARE aims to increase AAPI participation in research studies by building a research recruitment registry of 10,000 AAPIs who would be willing to be contacted for health research studies. As the initial phase of building CARE, this article reports on focus groups we conducted with diverse AAPI communities in multiple languages (English, Mandarin, Cantonese, Korean, and Vietnamese) to advance our understanding of the best strategies and messaging for recruiting AAPI into the registry and eventually, future ADRD, aging, and caregiving-related research.

2 | METHODS

2.1 | Recruitment, eligibility, and procedures

This is a mixed-methods research that includes quantitative data from a survey with qualitative data from focus groups with AAPI adults to examine perspectives about recruitment strategies/messaging for

participation in an ADRD, aging, and caregiving research recruitment registry. Five CARE sites, consisting of two community partners and three academic institutions in northern and southern California, recruited participants and conducted a total of 14 focus groups from January to May 2020 using convenience sampling. The study was described as focus group interviews to understand and identify the best ways to recruit and tailor messages to AAPI; and ways to encourage them to sign up for a research registry for AD, aging-related, and caregiving research. Participants (N = 123) were made aware of the study through personal and professional networks (78.9%), e-mail or listservs (19.5%), flyers (8.1%), social media (4.9%), and ethnic media (radio/TV; 0.8%). To be eligible, participants had to be 18 years of age and older (to target caregivers who may be young); self-identify as one of the targeted AAPI groups (Asian Indian, Chinese, Filipino, Korean, Japanese, Samoan, or Vietnamese); able to speak English, Cantonese or Mandarin Chinese, Korean, or Vietnamese; and interested in topics related to ADRD, caregiving, or aging. The CARE team selected these AAPI groups for the focus group phase because they represent the largest AAPI groups in California.²⁹ Similarly, specific Asian languages were selected because these were the most commonly spoken Asian languages among those with limited English proficiency.³⁰

2.2 | Translation process and validity

Materials including recruitment flyers, screening eligibility questions, informed consent, a sociodemographic questionnaire, and focus group guides were translated into Chinese (simplified and traditional), Korean, and Vietnamese. The World Health Organization's guideline on translation and adaptation of instruments³¹ was used to guide the translations of the study materials. By using this established translation method, we were able to attain "conceptually equivalent" Chinese, Korean, and Vietnamese-language versions of the English materials, focused on "cross-cultural and conceptual, rather than on linguistic/literal equivalence."³¹ Bilingual and bicultural Chinese, Korean, and Vietnamese research staff conducted the translations.

2.3 | Focus group procedures

Focus groups are a form of "group interview" that generates data from participants.³² Advantages include convenience (of interviewing several participants at one time versus individually) as well as obtaining "group interaction" data. In other words, participants' comments may build off one another's comments (hence, a focus group "discussion"), participants may also feel encouraged to speak, and participants may express similar and/or different perspectives from one another to potentially provide a fuller illustration of participants' lived experiences. Moreover, focus groups "do not discriminate against people who cannot read or write."³²

Fourteen focus groups were conducted, initially in-person (4 groups) but due to COVID-19, the remaining planned focus groups were transitioned to an online, live format (10 groups; see Table 1). In-person focus

RESEARCH IN CONTEXT

- 1. Systematic review:** The authors reviewed the literature using traditional sources (e.g., Pubmed) and meeting abstracts and presentations as well as consulted with experts in Alzheimer's disease and related dementias (ADRD) in the United States. There are some ADRD, aging, and caregiving-related registries, but none that target Asian Americans and Pacific Islanders (AAPI) in multiple languages.
- 2. Interpretation:** Our findings suggest areas of consideration for AAPI recruitment into a research recruitment registry devoted to aging, ADRD, and caregiving research including: (1) culturally/linguistically appropriate outreach in culturally specific spaces, (2) motivations for research participation, and (3) approaches to outreach and recruitment methods. Within each of these themes, there were ethnic differences in specific strategies/approaches reflected as subthemes.
- 3. Future directions:** The meaningful inclusion of AAPI into ADRD and health-related research is critical to reduce ADRD and health-related disparities for this underserved and rapidly growing population. Additional research is needed to develop and evaluate culturally/linguistically appropriate outreach with diverse AAPI to help increase research participation for AAPI.

groups were held in a private room at a community center. Groups that were held remotely were hosted on the Zoom application. Seven AAPI cultural groups were targeted: Asian Indian, Vietnamese, Filipino, Japanese, Chinese, Korean, and Samoan. A total of seven groups were conducted in English; the other seven were conducted in either Cantonese, Korean, Mandarin, or Vietnamese. Groups that were conducted in-person had 11 to 12 participants, while those conducted over Zoom ranged from 4 to 10 participants.

Informed consent was obtained in-person or by phone. Prior to the focus groups, participants completed the sociodemographic questionnaire online or by phone (see below). During the meetings, facilitators followed a semi-structured focus group guide (described below) and asked participants to share their perspectives about research participation. Each group lasted 80 minutes on average (median: 78.5, range: 24– 120 minutes), and participants received a \$25 gift card for their time. All focus groups were audio-recorded. These recordings were transcribed verbatim and translated to English (for non-English focus groups) for analyses.

2.4 | Sociodemographic questionnaire

This questionnaire inquired about participants' race, ethnic/cultural group, sex, year of birth, nativity, years lived in United States,

marital status, type of medical insurance, employment, education, household income and size, and English-language proficiency. We also asked if they had ADRD or were an ADRD caregiver.

A total of 69 participants completed the survey online, while 54 filled out paper surveys due to lack of internet access and/or limited understanding of how to complete an online survey. The online survey used Research Electronic Data Capture (REDCap) tools hosted at the University of California, San Francisco (UCSF).^{33,34} REDCap is a secure, web-based software platform designed to support data capture for research studies. For those who completed paper surveys, research staff later entered their data into REDCap.

2.5 | Focus group guide

The focus group guide included key questions with optional probing questions, as well as suggested transitions between topics, and recommended time duration for each major topic. The major topics were: (1) knowledge, attitudes, and experiences with research participation; (2) understanding and experience with “research registry”; (3) perspectives, experiences, and suggestions with various recruitment methods for research participation and research registry enrollment; (4) insights on how to frame messages on research participation and research registries for the targeted AAPI community; (5) insights on how the research registry website should look; (6) views about participant incentives for enrolling in CARE registry; (7) informing participants about the next steps of CARE; and (8) recommendations for outreach and final comments.

2.6 | Data analysis

Quantitative data obtained from the sociodemographic questionnaires were analyzed using descriptive statistics, which were provided for the overall sample and separately for each cultural group. The data were analyzed using STATA 16 software.³⁵ Thematic analysis was conducted on each transcript by two raters; both were AAPI, with bachelor's degrees and had prior research experience with AAPI individuals. Raters used the focus group guide a priori as an initial starting point for their analysis, and independently conducted thematic coding of the qualitative data using Luborsky's thematic analysis approach.³⁶ This method is widely used in qualitative studies. Themes are analyzed and coded according to the point of view of each individual and then showcase direct representation of experience and salient perceptions of informants rather than of researchers or experts. Thematic analysis entails identifying repetition and analyzing central meaning; both approaches complement each other through introducing emergent themes and reinforcing recurrent ones via systematic comparison. After the initial thematic analysis, raters discussed discrepancies about the major themes and subthemes until agreement was achieved. The combined analysis was then reviewed by the principal investigator and the focus group facilitators to ensure accuracy and clarity of the themes and subthemes. Data saturation, defined

TABLE 1 Focus group formats, cultural groups, languages, and group sizes (N = 123)

	Medium	Cultural group [language]	Group sizes
Focus group	In-person (N = 46)	Asian Indian [E]	12
		Vietnamese [V]	11
		Filipino [E]	12
		Japanese [E]	11
		Chinese [C]	8 ^a
	Zoom (N = 77)	Korean [K]	12
		Chinese [M]	11
		Chinese [E]	12 ^a
		Korean [E]	12 ^a
		Vietnamese [E]	10 ^a
Survey	Online Survey		69
	Paper Survey		54

Notes: Languages used in focus groups: E = English; C = Cantonese; K = Korean; M = Mandarin; V = Vietnamese.

^aConducted in two groups; each had the same group size.

as no additional data were found, was reached for the prevalent themes.³⁷

2.7 | Human subjects protection

This research was approved by UCSF's Institutional Review Board (protocol #: 19-28027). Informed consent was obtained from participants prior to study participation.

3 | RESULTS

3.1 | Sociodemographic and background characteristics

A total of 123 participants participated in the 14 focus groups (Table 2). Overall, more women (65.9%) than men (34.1%) participated, and the mean age was 54 years old (median was 61 and range was 18–80). More than half (57.3%) were married or living with a partner, with the remaining reporting that they were single (19.5%) or divorced/separated/widowed (21.1%). More than three quarters (78.1%) of the participants had some college education or graduated from college. The majority of the participants (81.0%) was foreign-born and had lived in the United States for an average of 23 years. About 27% said they were not fluent or spoke some English. Most (86.2%) said they did not have ADRD or memory loss, 3.2% said they did, and 13.8%

TABLE 2 Sociodemographic characteristics of focus group participants by cultural group (N = 123)

Characteristics	All		Asian Indian		Chinese		Filipino		Korean		Japanese		Samoan		Vietnamese	
	N = 123		N = 12		N = 32		N = 12		N = 24		N = 10		N = 12		N = 21	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Age ^a	54.4 (18, 80)		62.5 (47, 76)		59.4 (21, 80)		46.8 (19, 78)		52.3 (26, 77)		63.1 (50, 75)		60.7 (24, 74)		41.0 (18, 73)	
Sex																
Female	81	(65.9)	7	(58.3)	25	(78.1)	8	(66.7)	17	(70.8)	6	(60.0)	9	(75.0)	9	(42.9)
Male	42	(34.1)	5	(41.7)	7	(21.9)	4	(33.3)	7	(29.2)	4	(40.0)	3	(25.0)	12	(57.1)
Marital status																
Single	24	(19.5)	1	(8.3)	6	(18.8)	3	(25.0)	5	(20.8)	0	(0.0)	2	(16.7)	7	(33.3)
Married or have a partner	73	(57.3)	10	(83.4)	17	(53.1)	6	(50.0)	14	(58.3)	7	(70.0)	6	(50.0)	13	(61.9)
Divorced/sepa	15	(12.2)	0	(0.0)	5	(15.6)	3	(25.0)	3	(12.5)	3	(30.0)	0	(0.0)	1	(4.8)
Widowed	11	(8.9)	1	(8.3)	4	(12.5)	0	(0.0)	2	(8.3)	0	(0.0)	4	(33.0)	0	(0.0)
Employment																
Employed	62	(50.4)	7	(58.4)	11	(34.4)	7	(58.3)	18	(75.0)	3	(30.0)	5	(41.6)	11	(52.4)
Unemployed or homemaker	11	(9.0)	2	(16.6)	3	(9.4)	3	(25.0)	1	(4.2)	1	(10.0)	0	(0.0)	1	(4.8)
Retired or disabled	33	(26.9)	3	(25.0)	15	(46.9)	2	(16.6)	1	(4.2)	6	(60.0)	4	(41.6)	2	(9.5)
Student	13	(10.6)	0	(0.0)	2	(6.3)	0	(0.0)	4	(16.7)	0	(0.0)	1	(8.3)	6	(28.6)
Other	4	(3.3)	0	(0.0)	1	(3.1)	0	(0.0)	0	(0.0)	0	(0.0)	2	(16.7)	1	(4.8)
Education																
Less than high school	10	(8.1)	0	(0.0)	1	(3.1)	1	(8.3)	2	(8.3)	0	(0.0)	4	(33.3)	2	(9.5)
High school graduate or G.E.D.	17	(13.8)	0	(0.0)	4	(12.5)	4	(33.3)	3	(12.5)	0	(0.0)	5	(41.7)	1	(4.8)
Some college or College graduate	61	(49.6)	5	(41.7)	13	(40.6)	7	(58.4)	13	(54.2)	6	(60.0)	2	(16.6)	15	(71.5)
Graduate degree	35	(28.5)	7	(58.3)	14	(43.8)	0	(0.0)	6	(25.0)	4	(40.0)	1	(8.3)	3	(14.3)
Income																
\$25,000 or less	36	(30.0)	2	(16.7)	6	(19.4)	3	(30.0)	11	(45.3)	0	(0.0)	7	(58.3)	7	(33.3)
\$25,001 to \$75,000	34	(28.3)	2	(16.7)	11	(35.5)	3	(30.0)	6	(25.0)	1	(10.0)	3	(25.0)	8	(38.1)
\$75,001 to \$150,000	29	(24.2)	3	(25.0)	9	(29.0)	3	(30.0)	1	(4.2)	6	(60.0)	2	(16.7)	5	(23.8)
\$150,001 or more	21	(17.5)	5	(41.6)	5	(16.1)	1	(10.0)	6	(25.0)	3	(30.0)	0	(0.0)	1	(4.8)
Insurance																
No insurance	2	(1.6)	0	(0.0)	1	(3.1)	0	(0.0)	0	(0.0)	0	(0.0)	0	(0.0)	1	(4.8)
Private insurance	66	(30.1)	7	(58.3)	18	(56.4)	7	(58.3)	10	(41.7)	7	(70.0)	4	(33.3)	13	(61.9)
Medi-Cal or state provided	32	(26.0)	1	(8.3)	6	(18.8)	2	(16.7)	14	(58.3)	0	(0.0)	4	(33.3)	5	(23.8)
Medicare	40	(32.5)	4	(33.3)	12	(37.5)	4	(33.3)	2	(8.3)	4	(40.0)	9	(75.0)	5	(23.8)

(Continues)

TABLE 2 (Continued)

Characteristics	All		Asian Indian		Chinese		Filipino		Korean		Japanese		Samoan		Vietnamese	
	N = 123		N = 12		N = 32		N = 12		N = 24		N = 10		N = 12		N = 21	
	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)	N	(%)
Nativity																
US-born	23	(18.7)	0	(0.0)	6	(18.7)	6	(50.0)	1	(4.2)	6	(60.0)	1	(8.3)	3	(14.3)
Foreign born	100	(81.3)	12	(100)	26	(81.3)	6	(50.0)	23	(95.8)	4	(40.0)	11	(91.7)	18	(85.7)
Years in US ^a	23 (0.5, 57)		23 (12, 52)		34 (.5, 57)		34 (9, 48)		23 (4, 46)		39 (18, 53)		30 (20, 53)		12 (3, 50)	
English fluency																
Native	22	(18.0)	0	(0.0)	6	(18.8)	2	(18.2)	4	(16.7)	6	(60.0)	2	(16.7)	2	(9.5)
Fluent	67	(54.9)	12	(100)	22	(68.8)	8	(72.7)	8	(33.3)	4	(40.0)	3	(25.0)	10	(47.6)
Some	27	(22.1)	0	(0.0)	2	(6.2)	1	(9.1)	10	(41.7)	0	(0.0)	6	(50.0)	8	(38.1)
Do not speak	6	(4.9)	0	(0.0)	2	(6.2)	0	(0.0)	2	(8.3)	0	(0.0)	1	(8.3)	1	(4.8)
ADRD caregivers	12	(9.8)	0	(0.0)	3	(2.4)	1	(8.3)	1	(4.2)	3	(30.0)	3	(25.)	1	(4.8)

^aMean (range).

Abbreviations: ADRD, Alzheimer's disease and related disorders; G.E.D., General Educational Development test.

said they were not sure. About 1 in 10 reported that they were caring for a family member or loved one who had ADRD or memory loss.

Vietnamese participants were younger (mean age = 41.0 years) than the other groups (Japanese = 63.1 years; Asian Indian = 62.5 years; Samoan = 60.7 years; Chinese = 59.4 years; Korean = 52.3 years; Filipino = 46.8 years). All Asian Indians (n = 12, 100%) and nearly all Koreans (n = 23, 95.8%) were foreign-born. The remaining groups had a combination of US-born and foreign-born, though more Japanese (n = 6, 60%) and Filipino (n = 6, 50%) participants were born in the United States than any other group (Chinese = 6, 18.7%; Samoan = 1, 8.3%; Vietnamese = 3, 14.3%). All Asian Indians/Filipino/Japanese reported being fluent in English, while nearly half of Korean (n = 12, 50%)/Samoan (n = 7, 58.3%)/Vietnamese (n = 9, 42.9%) reported limited English proficiency. Asian Indians had higher household incomes than other groups, and almost half reported having incomes of more than \$150,000. Fewer Samoans had a college education (n = 3, 24.9%) and more used Medicare (n = 9, 75%) as a source of insurance, compared to other groups.

3.2 | Qualitative themes and subthemes

Qualitative analysis of the focus groups revealed three emergent themes (Table 3). These included: (1) culturally/linguistically appropriate outreach in culturally specific spaces, (2) motivation for research participation, and (3) approaches to outreach and recruitment messaging. Table 4 displays the subthemes for each target cultural group.

3.2.1 | Theme 1: Culturally/linguistically appropriate outreach in culturally specific spaces

A common theme across all groups was a need for outreach/engagement to be conducted in culturally specific spaces. This included

festivals, cultural events, and spiritual spaces (temples and churches) that were accessible for the community in their preferred languages. The need for culturally and linguistically appropriate outreach was mentioned in every focus group. Several groups expressed the concern that AAPI are often perceived as a monolithic group in the United States. Participants stressed that Asian cultures are diverse, outreach should be targeted specifically to each Asian culture (Table 3, Subtheme 1.1).

Issues relating to linguistic accessibility were often discussed in focus groups. Participants expressed that linguistic accessibility was an important barrier to research participation within their communities. Many indicated that having a researcher who can speak the language within their community would not only reduce the barriers to recruitment, but also incentivize people to participate (Table 3, Subtheme 1.2). Linguistic accessibility was less of an issue among the English-speaking focus groups (Asian Indian, Filipino, and Chinese; Table 4).

All focus groups recommended using community spaces for the purposes of recruitment and advertisement. Across the groups, participants reported that community spaces where AAPI congregate, such as churches, community centers, and grocery stores, were important places for the exchanges of information (Table 3, Subtheme 1.3). Participating in church and temple activities was reported as an important opportunity, with participants in every focus group suggesting a spiritual place as a medium for outreach and engagement (Table 3, Subtheme 1.4). This was one of the most frequently recommended approaches for recruitment among all the focus groups (Table 4).

3.2.2 | Theme 2: Motivation for research participation

Participants across groups shared similar motivations for research participation. While many shared personal motivations, a common

TABLE 3 Qualitative themes, subthemes, and selected participants' quotes

Qualitative themes	Subthemes	Selected participants' quotes ^a
1. Culturally/linguistically appropriate outreach in culturally specific spaces	1.1 Culturally appropriate	Asian Indian: "Reaching out to different organizations within the Indian community ... we have lots of subgroups ... Sikh, Tamil, Bengali, groups ... reach out to each group individually, and they can pick their own champions to help you guys." Chinese Mandarin-speaking: "It just occurs to me that speaking of Asian representation it makes sense. I never saw that Cantonese advertise." Chinese Mandarin-speaking: "From the research point of view, Asian Americans have a lot of subgroups, Chinese, Korean, Japanese, Filipinos, Indians. We have different genetic profiles. If the registry can distinguish the subgroups it will very valuable for research."
	1.2 Linguistic accessibility	Korean: "I was also thinking about senior centers is one place where you can also recruit. I know many Korean Americans go there weekly, and if you were to do that, then you need someone who can speak Korean fluently and has all the forms in Koreans, so there is lower thresholds for them to participate." Samoan: "I would recommend that there is a tab specifically for all the Pacific Islander languages. So, there should be a tab where Samoans with access to technology can click on it and everything is translated correctly in Samoan, in our language. There should be a tab that's accessible for Tongan. There should be a tab that's accessible for Fijian and so-on and so-forth." Vietnamese Vietnamese-speaking: "The greater incentives, the better. Recruiting staff has to be able to speak in Vietnamese because it's easier to get the information across."
	1.3 Community spaces	Japanese: "I just thought the best way in my opinion was honestly through organizations that are Japanese centered." Korean Korean-Speaking: "Many Korean community organizations such as culture centers, senior club, church group, clubs can be useful, too."
	1.4 Spiritual locations	Asian Indian: "I'll say ... go to the senior centers where the Indians are, like ICC Milpitas, caters to almost 500 seniors there; so senior center is a good place to start with; temples, flyers in the temples." Samoan: "I think the best way to contact people is my own church." Japanese: "Also, the Buddhist church is almost all Japanese."
2. Motivation for research participation	2.1 Intellectual enrichment	Chinese Cantonese-speaking: "Second, I want to learn some new information that I can share with my friends or groups." Asian Indian: "I wanted to know more about Alzheimer's, and how does it happen, what can you do to prevent it and not to have it." Samoan: "I also think that research is very important in keeping the longevity of our people—the Samoan people. Especially educating our people I think is something very important so that we can see and get the help that we need."
	2.2 Intergenerational impacts	Japanese: "Also the sandwich generation you have people that are like me caring for parents and then also caring for your own children and you know being in that position it's—it has to be—you know something of a benefit." Vietnamese: "We are seeing them either have Alzheimer's or dementia and it is a heavy burden for the children or the relatives to take care of those people with Alzheimer's or dementia. So hopefully our participation will give the research more information and hopefully by the time we age or retire, if we somehow get Alzheimer's or dementia, they will have some treatment, especially for the older generation."
	2.3 Importance of caregiving	Japanese: "I think the Japanese culture is really rooted in a sense of obligation to take care of your family, take care of your elders." Korean: "To me, Alzheimer's is important because our parents or grandparents are going to be aging in the near future and we are the ones who need to be like, have the knowledge to take care of them and how to like, prevent them to have their memories lost. Or slow down the program, so it interested me." Asian Indian: "See, we are going through old age, and we may be encountering Alzheimer's down the line and that is the challenge. Be prepared if something happens to me or my dear ones."

(Continues)

TABLE 3 (Continued)

Qualitative themes	Subthemes	Selected participants' quotes ^a
	2.4 Community representation	Vietnamese: "I want to join because it relates to the Vietnamese group and I want to give my personal data to the research so they can have more data to compare to." Samoan: "I think this is important for us—I think it's important that we are part of the research because—specifically for Pacific Islanders, a lot of the times we get lumped in with—the data gets aggregated. ... We're just smaller in numbers compared to our larger Asian American brothers and sisters and community." Chinese Mandarin-speaking: "I feel blessed. There is funding for studying the health of Asian Americans and drugs." Korean Korean-speaking: "In the past, a group of doctors went to a community and said this and that is needed for that community. Now, if a research wants to help a community, the community's voice should be heard more. That is why I am participating in today."
3. Approaches to outreach and recruitment messaging	3.1 Ethnic-specific social media	Korean Korean-Speaking: "I think social media such as Facebook, Instagram, or KakaoTalk can effectively introduce focus group or research to people in the community. Social media is very popular among young people. If the research is introduced through social media, the information can be shared with many people." Chinese Mandarin-speaking: "I found a lot of people use Line or WeChat. They share video with each other." Filipino: "Yeah, some, like what she said, like vloggers, people who are influencers. If they partake in something like this, it will influence everyone, their viewers."
	3.2 Ethnic-specific traditional media	Chinese Cantonese-speaking: "Newspapers like WorldJournal ... places with free advertisements. Or even Chinese channels, like channel 8, sometimes they made do an interview of your organization." Japanese: "I think most first-generation Japanese subscribe to JCTV so if you created a public service announcement and tried to run that through that station you would probably get more awareness." Asian Indian: "Asian newspaper, India Post, India West, regional Punjabi papers and Hindi newspapers."
	3.3 Personalized narratives	Chinese Cantonese-speaking: "It's very simple. For example, the word 'care,' to most people elicits no emotion/feelings. But if you were to talk about it as if you were talking about their family and friends, and how they may be able to help them by joining, I think you would elicit more interest from people." Vietnamese Vietnamese-speaking: "It would have to be the right person at the right time. For instance, if it's a study about Alzheimer's, you need to find people with Alzheimer's. The right time means asking people when they are not busy, if you ask them to sign up when they are picking their kids from school, they won't have time to listen to you."

^aAll selected quotes are from English-speaking participants, unless otherwise specified.

sentiment endorsed was that research participation should provide resources and information to help members of their own community. Other motivations included personal curiosity and the desire to learn more about ADRD and clinical research (Table 3, Subtheme 2.1).

Among 11 groups, four English-speaking groups (Vietnamese, Filipino, Japanese, and Korean) suggested that the intergenerational impacts of research participation were motivators to participate in research (Table 3, Subtheme 2.2; Table 4). In addition, while six groups indicated that direct personal benefits (i.e., own intellectual enrichment) were motivators, only four suggested that intergenerational impacts, meaning a familial obligation, would motivate them to sign up for research studies (Table 3, Subtheme 2.3). These family obligations included efforts to help loved ones with

dementia, as well as concerns for loved ones and family members at risk for ADRD. Of all the subthemes that emerged, these two (intergenerational impact and the importance of caregiving) were the least commonly reported from all of the focus groups (Table 4).

Ten of the 11 focus groups expressed a desire to represent their community in research and to benefit their community through intellectual enrichment and the sharing of information (Table 3, Subtheme 2.4; Table 4). Numerous comments indicated the importance of cultural identity and community responsibility, with many concerned about the lack of representation and data specific to their cultural/ethnic group. Each cultural group presented their own combination of motivations with high degrees of variability; however, only Vietnamese

TABLE 4 Cross-reference table of all focus group themes

Qualitative themes												
Culturally/linguistically appropriate outreach in culturally specific spaces												
Subthemes	Culturally appropriate				Motivations for research participation				Approaches to outreach & recruitment messaging			
	Linguistic accessibility	Community spaces	Spiritual locations	Intellectual enrichment	Inter-generational impacts	Importance of caregiving	Community representation	Ethnic-specific social media	Ethnic-specific traditional media	Personalized narratives		
Cultural and language group												
Asian Indian [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Vietnamese [V]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Vietnamese [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Filipino [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Japanese [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Chinese [C]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Chinese [M]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Chinese [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Korean [K]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Korean [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Samoan [E]	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

Notes: Languages used in focus groups: E = English; C = Cantonese; K = Korean; M = Mandarin; V = Vietnamese.

(combination of English- and Vietnamese-speaking) and Japanese shared all four categories of motivation (Table 4).

3.2.3 | Theme 3: Approaches to outreach and recruitment messaging

Each focus group endorsed a multifaceted and multimedia approach to recruitment messaging and outreach (Table 3, Subtheme 3.1). Participants in each group mentioned the use of social media platforms such as Facebook, Instagram, WhatsApp, and WeChat. Participants in some cultural groups shared that they used a social media platform unique to their cultural group, such as KakaoTalk among Koreans.

Several groups suggested implementing recruitment messaging on traditional AAPI-specific media such as newspapers and radio programs (Table 3, Subtheme 3.2). Participants mentioned that compared to younger community members, older generations and AAPI with limited English proficiency may have limited familiarity with social media and access to digital technology and be more easily reached through traditional recruitment methods.

Besides using appropriate platforms for recruitment, participants from several groups recommended using personal stories and narratives to encourage AAPI to participate in research (Table 3, Subtheme 3.3). For instance, to elicit interest and feelings, messages would need to convey a story that readers could relate to. Participants from the Filipino and Korean focus groups suggested using pictures of younger generations taking care of older generation to elicit emotional responses.

4 | DISCUSSION

4.1 | Summary of findings

Little work has been done to engage AAPIs, the fastest growing racial/ethnic group in the United States, into aging and ADRD research. CARE is attempting to remedy this gap by developing a registry of diverse AAPIs that can be recruited into future research. Based on findings from the focus groups described above, recruitment and messaging strategies will be tailored uniquely for each target group, to encourage their enrollment into the CARE registry. The three broad themes that emerged in this analysis appear to be shared across AAPI populations, although there was also variability in subthemes that suggest cross-ethnic differences as well.

Similar to previous research, focus group findings indicated that outreach and recruitment of different AAPI groups for research participation had to be culturally and linguistically appropriate. Religious and spiritual institutions (temples, churches) were good sources of engaging AAPI into research because these are locations that AAPI frequent for spiritual practices as well as for community building. "Going to where the people are" is a crucial part of engaging AAPI.³⁸ Moreover, language is an important component of being able to make research accessible to AAPI populations. It has been understood for some time

that having recruitment materials in the language that diverse AAPI can understand is important to engage them, as well as having research personnel who speak the language of participants.³⁹ In terms of motivation for research participation, AAPIs were motivated by reasons as diverse as wanting to have more knowledge and understanding about cognitive impairment and ADRD, as well as helping to benefit families who are caregivers of older people but also have children of their own, or who are in the "sandwich generation." Another motivation was derived from a sense of needing to have one's voice or representation in research. Our last emergent theme was in the area of outreach and recruitment messaging. Similar to previous study findings, focus group participants mentioned a variety of ethnic-specific media for outreach.⁴⁰ A novel finding was the use of personal stories and narratives to connect potential participants to actual people that they could identify with.

Some groups discussed the intergenerational impacts of research participation as a motivating factor, which is not surprising given that family values, such as filial piety and respect for elders, are common in multigenerational households among AAPI. Community representation also was among the strongest motivator of participating in research. This suggests that AAPI are aware of their lack of representation in research and the need for inclusion so that results can be applicable to them. The variability across focus groups could be due merely to the conversations present in the group, but it may also demonstrate the variability across cultural and ethnic groups in perspectives about research engagement and recruitment. Variability in focus group themes highlight the need for engagement that is culturally specific and treats AAPI as a heterogeneous group rather than a monolithic one.

4.2 | Limitations and strengths

The onset of COVID-19 restrictions and the current ongoing pandemic limited our ability to directly connect with participants through in-person focus group sessions. However, we were successful in our ability to conduct the remaining focus groups over Zoom given this limitation. The ability to connect over Zoom, without requiring participants to spend additional time and resources to travel to the group site, are noted benefits from previous research.⁴²

Additional unique strengths of this study include the engagement of seven AAPI cultural groups and the ability to employ staff who spoke five languages, thus overcoming one of the key barriers that prevent AAPI from research participation—lack of language compatibility. In addition, this work underscores the value of community-academic partnerships: without the strong support and involvement of the various agencies who work directly with these AAPI groups, this work would not have been able to succeed. The multiple academic and community partnerships were necessary to build the registry and to have such wide reach, especially during the pandemic when in-person outreach opportunities were almost non-existent in California. Due to resource limitations, however, we were restricted in our ability to conduct the study in other AAPI cultural groups and in other AAPI lan-

guages. Last, this is the first research registry of such a diverse group of AAPI available in five different languages. It will pave the way for the meaningful inclusion of AAPI in research on aging, ADRD, and family caregiving.

5 | PUBLIC HEALTH IMPLICATIONS

Recent estimates indicate that AD may rank third, just behind heart disease and cancer, as a cause of death for older people.⁴³ It is therefore incumbent on society to conduct research focused on prevention of dementia, and to do that effectively, individuals need to be recruited into relevant studies. Yet, the under-representation of racial and ethnic minorities in this kind of research is well documented.^{44,45} From a public health perspective, this situation needs to be remedied and that can only be done through consistent and appropriate outreach efforts aimed at including these individuals. That is best accomplished by thoroughly understanding cultural and linguistic factors that either facilitate research participation or set up barriers against it. The current study's findings increase knowledge about methods likely to be effective to increase enrollment of AAPI in ADRD-related studies in the future.

ACKNOWLEDGMENTS

Research reported in this publication was supported by the National Institute on Aging of the National Institutes of Health under Award Number R24AG063718. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

CONFLICTS OF INTEREST

The authors do not have any conflicts of interest to declare.

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How to cite this article: Ta Park V, Grill JD, Zhu J, et al. Asian Americans and Pacific Islanders' perspectives on participating in the CARE recruitment research registry for Alzheimer's disease and related dementias, aging, and caregiving research. *Alzheimer's Dement*. 2021;7:e12195.
<https://doi.org/10.1002/trc2.12195>