Brain Trust Meeting

June 2, 2025

CARE

COLLABORATIVE APPROACH FOR
ASIAN AMERICANS, NATIVE HAWAIIANS &
PACIFIC ISLANDERS RESEARCH & EDUCATION

Agenda

10:00 – 10:15am	**Introduction & Overview of CARE Registry** Janice Tsoh, PhD (UC San Francisco)
10:15 – 10:30am	**How to Use CARE** Joshua D. Grill, PhD (UC Irvine)
10:30 – 10:40am	**Community Perspectives in Research: Partnership with CARE** Samira Khan, MPH (South Asian Public Health Association)
10:40 – 10:50am	**User Testimonial: Experiences with CARE for Study Recruitment** Kaipeng Wang, PhD, MSW (University of Denver)
10:50 – 11:00am	**Q&A + Raffles + Evaluation**

Introduction & Overview of CARE Registry

Janice Tsoh, PhD
CARE Multiple Principal Investigator

Department of Psychiatry & Behavioral Sciences,
UC San Francisco School of Medicine

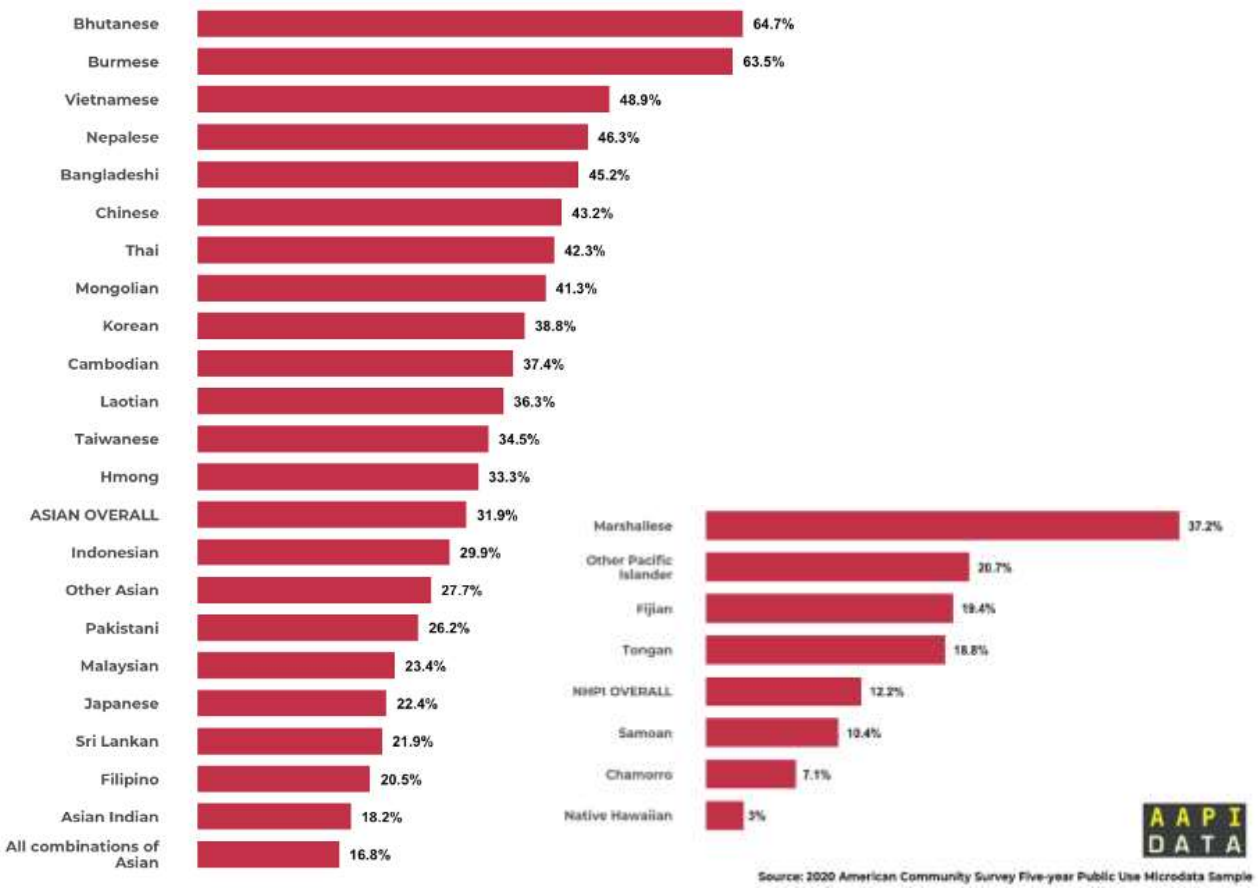
Asian Americans, Native Hawaiians & Pacific Islanders (AANHPI)

Asian Americans are the fastest growing racial group in the U.S.:[1]

- 7.7% of the population
- 30 AA & 21 NHPI groups
- 25 million AA & 1.8 million NHPI

- ○ Heterogeneous group
- ○ Languages & dialects (>100)
- ○ Cultural groups (>50)
- ○ Immigration patterns
- ○ Religions
- ○ Diet
- ○ SES

Percentage of population with Limited English Proficiency by Asian and NHPI national origin[2]



Source: 2020 American Community Survey Five-year Public Use Microdata Sample

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[1] Census Bureau: https://www.census.gov/newsroom/facts-for-features/2025/asian-american-pacific-islander.html

[2] AAPI Data: https://aapidata.com/blog/2022-national-demographics/

Background: Disparities in Research Participation for AANHPI Populations

- Clinical research projects focusing on AANHPI participants funded by the National Institute of Health (NIH) was less than 1% of its total budget between 1992 and 2018.[1]

- Of the 53,318 participants who were enrolled in ADRD studies at Alzheimer's Disease Research Centers, only 2.8% were AANHPI participants.[2]

- Considerations when engaging AANHPI communities to participate in research:
  - Cultural differences
  - Linguistic limitations
  - Need to increase awareness/outreach about what research is & the importance of research to targeted communities
  - Need to increase awareness/education to "research" communities & funders

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[1] *Doan, Takata, Sakuma, & Irvin (2019). JAMA Network Open.*

[2] *National Alzheimer's Coordinating Center (NACC). Web-query System. 2025; https://naccdata.org/requesting-data/web-query. Accessed May 28, 2025.*

Paving the Way for Meaningful Inclusion of AANHPI Participants in Research

- Funded by NIA R24AG063718 & R01AG083926
- Multiple Principal Investigators: Van Ta Park (Founder & Contact MPI), Janice Tsoh, Joshua Grill

To address the gap and reduce disparities in research participation in Alzheimer’s disease and related dementias (ADRD), aging, caregiving, and other health issues across the lifespan among AANHPI populations.

To give AANHPI individuals a voice and the opportunity to participate in research through enrollment in CARE.

To implement culturally appropriate and innovative recruitment strategies in collaboration with CARE’s community partners to enroll AANHPI adults who are interested in participating in health research.

CARE Partners & Community Advisory Board

UCSF University of California San Francisco
UCI MIND Institute for Memory Impairments and Neurological Disorders
UC DAVIS HEALTH
California State University East Bay
University of Hawai'i Mānoa
ICAN
MASALA
CSPP California School of Professional Psychology
CFI

ALZHEIMER'S ASSOCIATION
AARP California
OATS
Vietnamese American Cancer Foundation
Hội Ung Thư Việt Mỹ
VACF
SOMANG SOCIETY
OPTIMAL AGING CENTER
Asian Senior Citizens Service Center

ARCH
Yu-Ai Kai
Chinese Community Health Resource Center
www.cchrchealth.org
MX
ARI
BrainHealth Registry
Kōkua Kalihi Valley
Alliant International University
HAWAI'I PUBLIC HEALTH INSTITUTE

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ASIAN HEALTH SERVICES
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tayo
SAPHA
AARP California
NICOS Chinese Health Coalition

KACS
KCSC
Korean Community Service Center of Greater Washington
橙縣角聲中心 Orange County Herald Center
KCS
community health synergy
NYU Langone Health
caringkind The Heart of Alzheimer's Caregiving

CARE Registry

ENROLL HERE

http://tiny.ucsf.edu/CARERegistry2

Who can enroll?

- ○ AANHPI adults
- ○ 18+ years old
- ○ Speak and/or read English, Chinese, Hindi, Japanese, Korean, Tagalog, Vietnamese *or* Samoan
- ○ Willing to be contacted to participate in research

CARE Registry Enrollment Survey currently available in **8 languages**, in the process of expanding with more language options such as Ilokano.

Participants have the option to **receive a $10 gift card** after completing the enrollment survey

Participants complete an **online survey** (~10 min), **by phone**, or in-person

CARE

About ▾ Caregivers Researchers Ambassadors News ▾ Resources ▾ Contact

WELCOME TO CARE!

HEALTH ACROSS THE LIFESPAN

Paving the way for the meaningful inclusion of Asian American, Native Hawaiian and Pacific Islander (AANHPI) communities in clinical and caregiving research across the lifespan.

ENROLL IN CARE TODAY!

OUR PURPOSE

Purpose of CARE: To improve research participation and reduce health disparities in Alzheimer's disease, aging, caregiving, and other health issues in AANHPI communities through the creation of a health research registry of AANHPI adults who are interested in participating in various types of research.

The theme of the CARE registry is **"Health Across The Lifespan."**

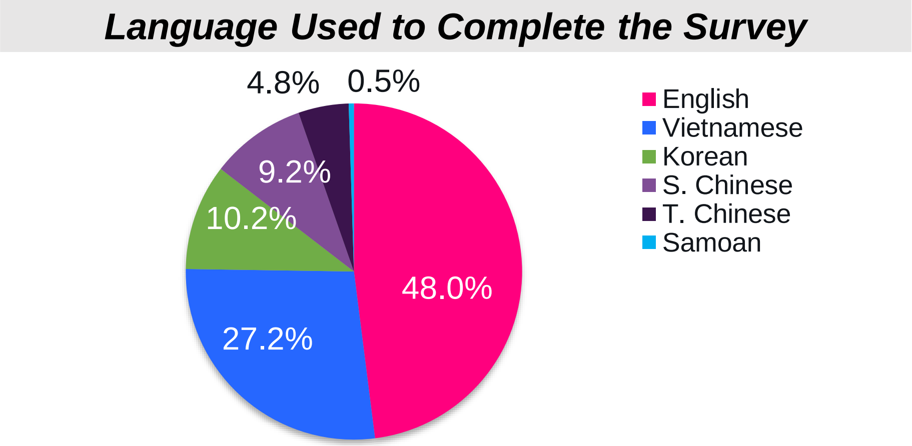
CARE Registry Enrollment Survey includes:

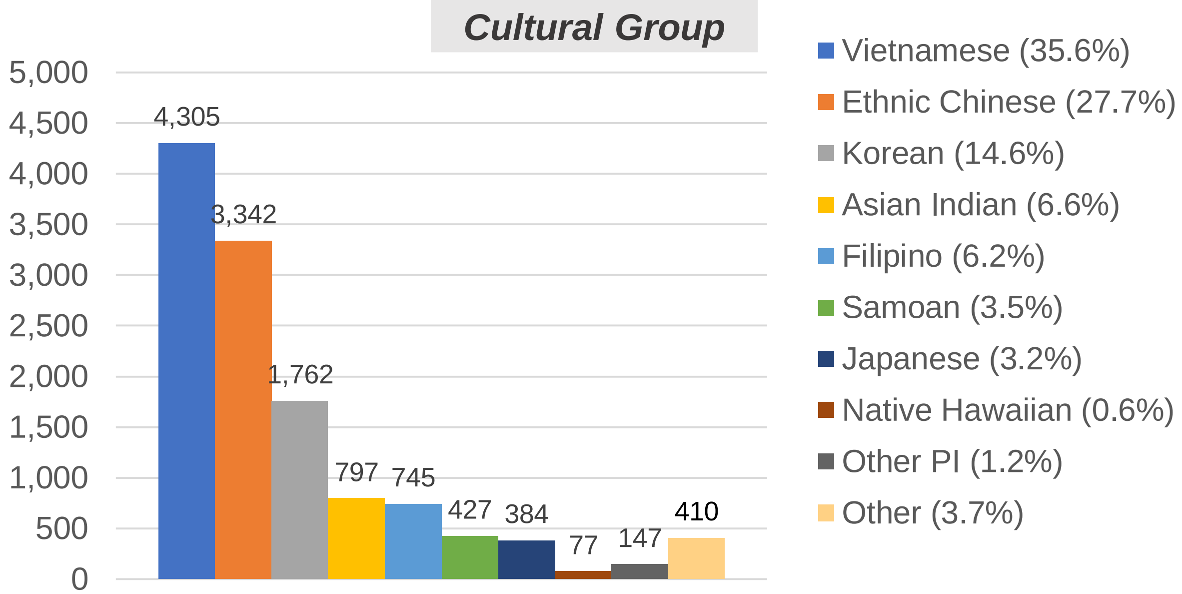
- ○ Sociodemographic Information
- ○ Health Conditions
- ○ Health Behaviors
- ○ Caregiving Experiences (if applicable)
- ○ Willingness and attitudes toward research

Official launch date: October 15, 2020

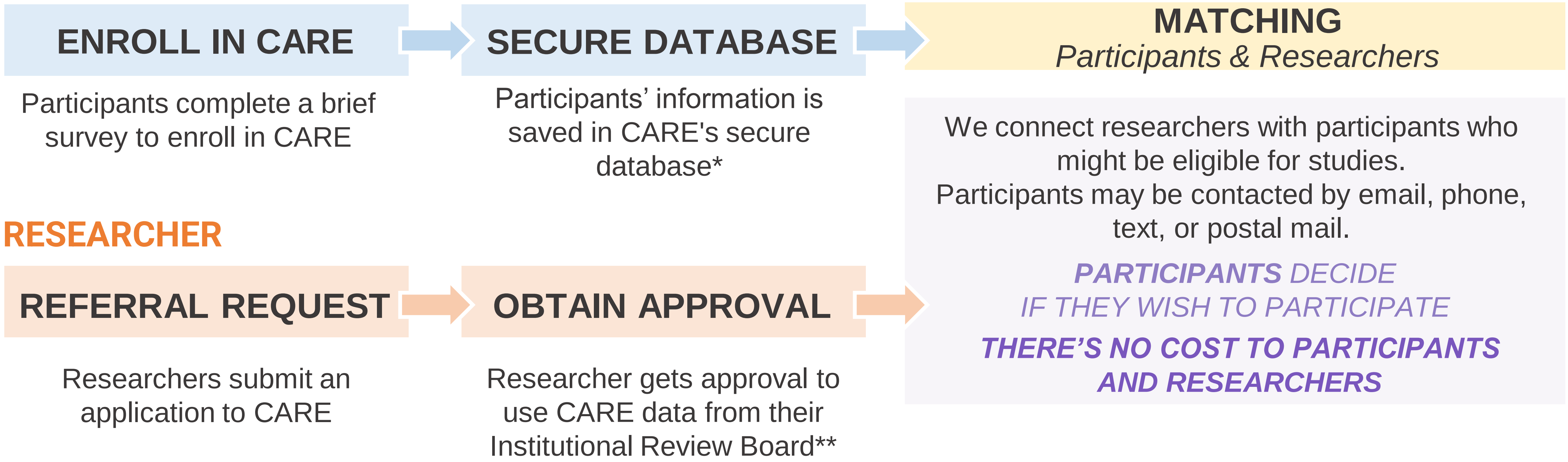
CARE Participant Snapshot: N=12,081 (as of May 26, 2025)

🌎	82.6%	Born outside of U.S.		
	80.2%	Californian		
🩺	11.1%	Caregivers of older adults or person with special needs		
💡	78.5%	No research participation experience		
🌎	54.6	Mean age (range 18-101)		
🚶	36.1%	Age over 65		
👫	63.0%	Female	35.5%	Male
💬	47.2%	Limited English proficiency		
🧠	12.5%	(N=1,505) with ADRD symptoms		





How CARE Works



PARTICIPANT

ENROLL IN CARE

Participants complete a brief survey to enroll in CARE

SECURE DATABASE

Participants' information is saved in CARE's secure database*

RESEARCHER

REFERRAL REQUEST

Researchers submit an application to CARE

OBTAIN APPROVAL

Researcher gets approval to use CARE data from their Institutional Review Board**

MATCHING
Participants & Researchers

We connect researchers with participants who might be eligible for studies.
Participants may be contacted by email, phone, text, or postal mail.

***PARTICIPANTS** DECIDE*
IF THEY WISH TO PARTICIPATE

THERE'S NO COST TO PARTICIPANTS AND RESEARCHERS

*CARE's database is HIPAA compliant, meaning it follows security measures to store protected health information.

** An Institutional Review Board (IRB) is made up of qualified individuals who carefully review research involving human participants. They ensure that these studies are ethical, follow all laws, and protect participants' rights and safety.

CARE Supported Recruitment Process

Referral Request Online Form

Submit CARE Referral Request Form (Online)

This is REQUIRED

- Project information: title, description, timeline
- Eligibility criteria
- Target sample size
- IRB Status: identify CARE as a recruitment source
- Funding source and status of funding

CARE Consultation Committee Review

- Requesting investigator will be given general information about CARE
- CARE will review study proposal, eligibility criteria, and sample size
- A meeting may be scheduled
- Decision within 1 month of request submission

Receive Participant Contact Information

- Requesting investigator will receive:
  - Name
  - Language preference
  - Contact info & method
- IRB approval required that listing CARE as a recruitment source and incorporating language about CARE to study materials before receiving the information.

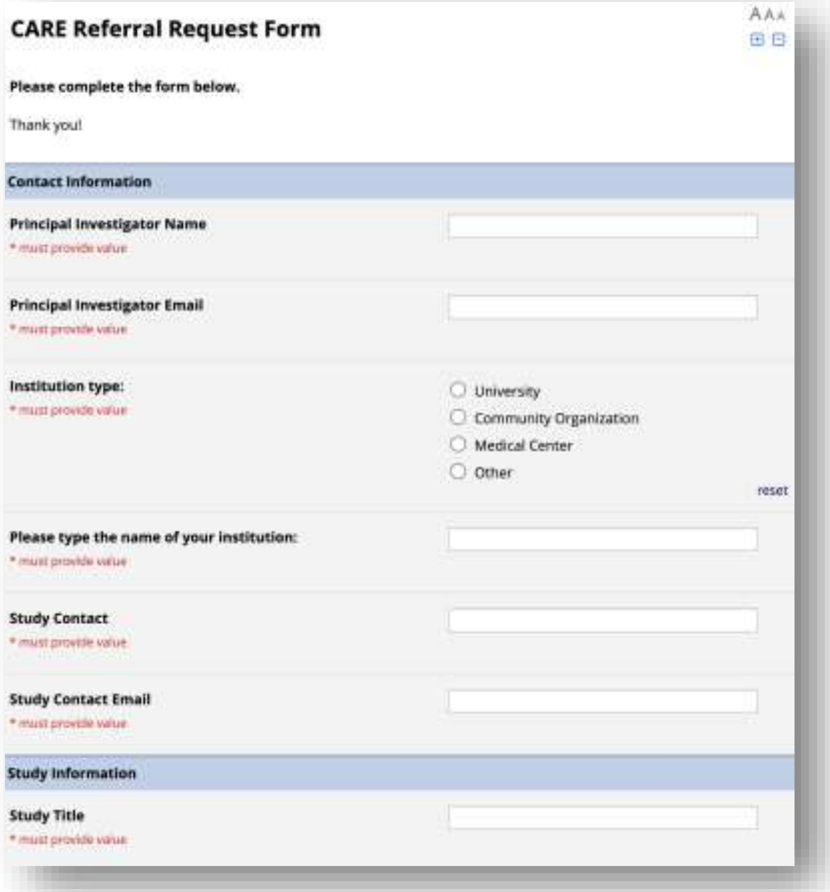
Investigator Responsibilities

- Contact potential participants within 1 month of receiving their contact information
- Notify CARE of the outcome of every registrant within 30 days of receipt
- PI information and study title posted on CARE website
- Cite CARE in publications or presentations
- Complete a post referral survey, including findings or links to publication(s)

For more information on CARE referral requests for researchers: https://careregistry.ucsf.edu/researchers

CARE-supported studies: https://careregistry.ucsf.edu/care-supported-studies

CARE Referral Request Form



CARE Referral Request Form

Please complete the form below.

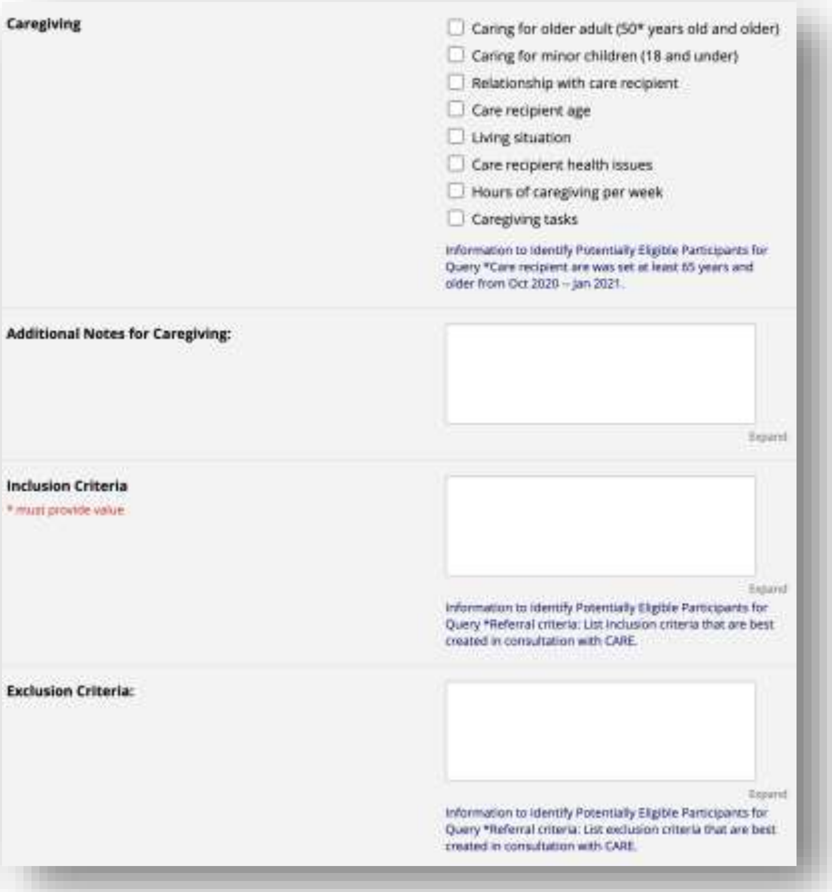
Thank you!

Contact Information

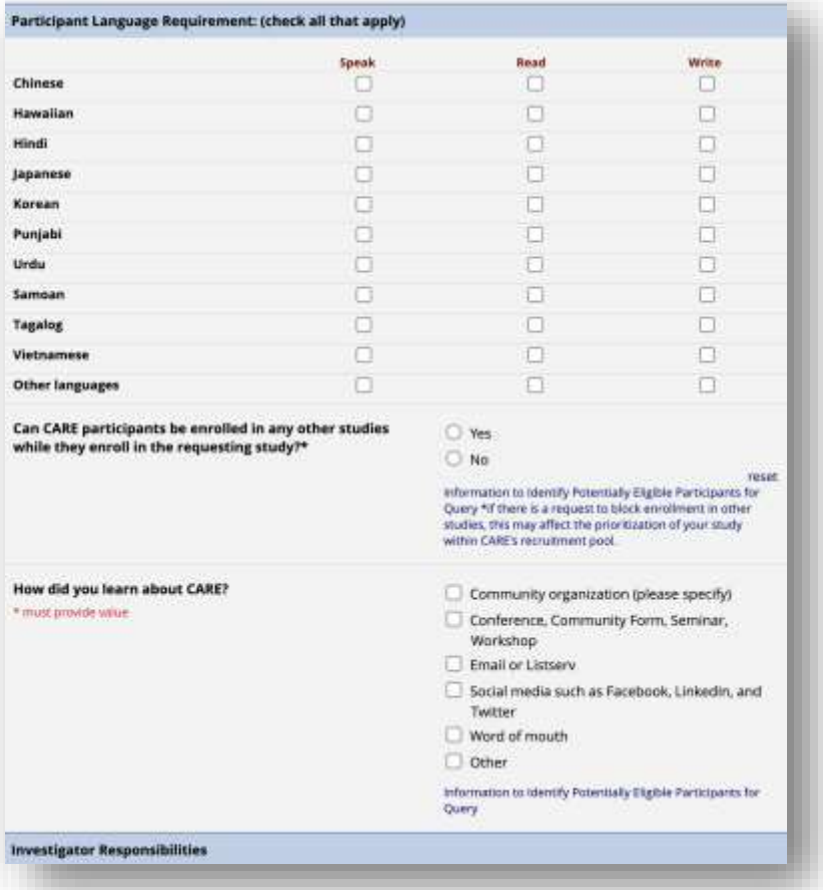
Principal Investigator Name * must provide value	
Principal Investigator Email * must provide value	
Institution type: * must provide value	○ University ○ Community Organization ○ Medical Center ○ Other reset
Please type the name of your institution: * must provide value	
Study Contact * must provide value	
Study Contact Email * must provide value	

Study Information

Study Title * must provide value	



Caregiving	☐ Caring for older adult (50* years old and older) ☐ Caring for minor children (18 and under) ☐ Relationship with care recipient ☐ Care recipient age ☐ Living situation ☐ Care recipient health issues ☐ Hours of caregiving per week ☐ Caregiving tasks Information to Identify Potentially Eligible Participants for Query *Care recipient are was set at least 65 years and older from Oct 2020 – Jan 2021.
Additional Notes for Caregiving:	Expand
Inclusion Criteria * must provide value	Expand Information to Identify Potentially Eligible Participants for Query *Referral criteria: List inclusion criteria that are best created in consultation with CARE.
Exclusion Criteria:	Expand Information to Identify Potentially Eligible Participants for Query *Referral criteria: List exclusion criteria that are best created in consultation with CARE.



Participant Language Requirement: (check all that apply)

	Speak	Read	Write
Chinese	☐	☐	☐
Hawaiian	☐	☐	☐
Hindi	☐	☐	☐
Japanese	☐	☐	☐
Korean	☐	☐	☐
Punjabi	☐	☐	☐
Urdu	☐	☐	☐
Samoan	☐	☐	☐
Tagalog	☐	☐	☐
Vietnamese	☐	☐	☐
Other languages	☐	☐	☐

Can CARE participants be enrolled in any other studies while they enroll in the requesting study?*	○ Yes ○ No reset Information to Identify Potentially Eligible Participants for Query *If there is a request to block enrollment in other studies, this may affect the prioritization of your study within CARE's recruitment pool.
How did you learn about CARE? * must provide value	☐ Community organization (please specify) ☐ Conference, Community Form, Seminar, Workshop ☐ Email or Listserv ☐ Social media such as Facebook, LinkedIn, and Twitter ☐ Word of mouth ☐ Other Information to Identify Potentially Eligible Participants for Query

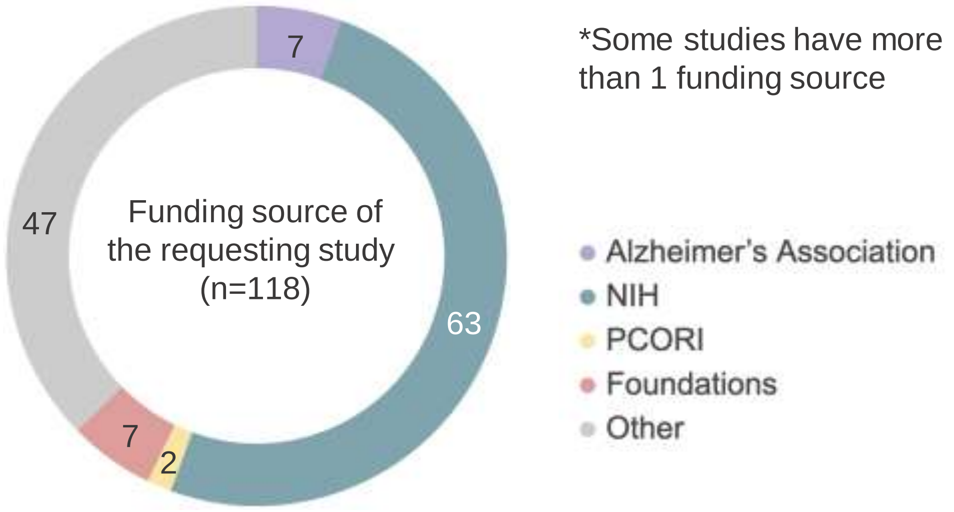
Investigator Responsibilities

Supporting Recruitment to Many Studies & Grant Applications

(N=147 as of May 28, 2025)

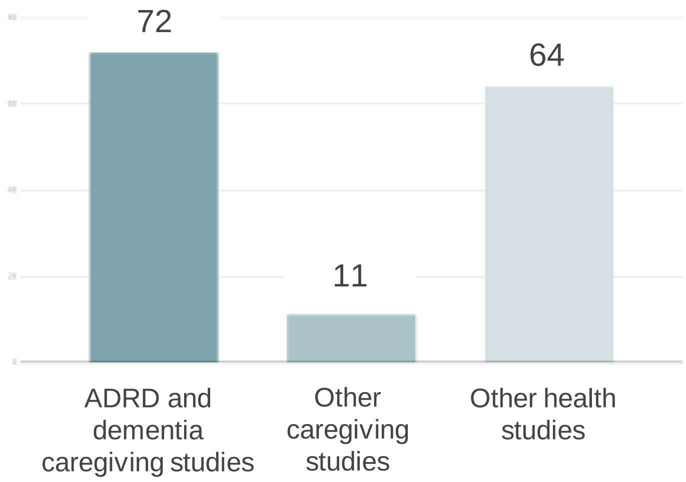
- ○ Since January 2021, 16,437 CARE referrals have been made to CARE-supported studies, and 7,621 unique CARE participants have been referred to at least one CARE-supported studies.
- ○ 65 (44.2%) of the requesting studies have study materials or personnel support for participants in English and at least one other AANHPI language.
- ○ Letters of support provided to 26 investigators for grant application, 21 of which to the NIH
- ○ List of CARE-Supported Studies: https://careregistry.ucsf.edu/care-supported-studies

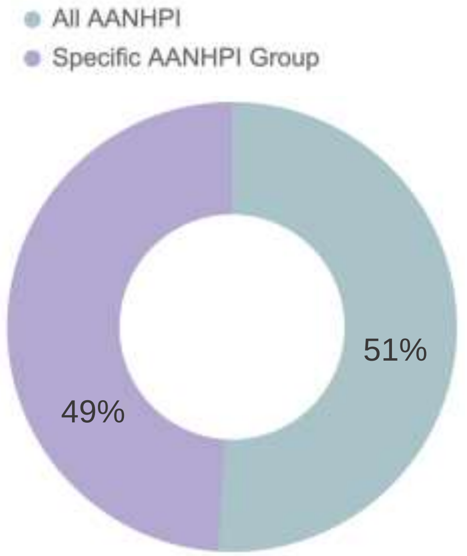
Funding Sources



*Some studies have more than 1 funding source

Research Area





How to Use CARE

Joshua D. Grill, PhD
CARE Multiple Principal Investigator

Director, Institute for Memory Impairments and Neurological Disorders (UCI MIND)
Co-Director, Alzheimer's Disease Research Center UC Irvine

UCI MIND

NIH National Institute on Aging
Designated
Alzheimer's Disease Research Center

Main Ways to Use CARE

1. Recruit participants to increase diversity of a study population
2. Recruit participants as a novel comparison group
3. Ask novel research questions about AANHPI

1. Recruit AANHPI Participants to Increase Diversity in Your Study

Faison et al.		
Race/Ethnicity	Industry (n=10,800)	ADCS (n=737)
White	96.8%	90%
Black	1.9%	6%
Asian	0.9%	NR
Hispanic	0.4%	4%

Faison WE, et al. Int Psychogeriatrics. 2007;19:539-558.

Franzen et al., Systematic review (n=101 trials)	
Race/Ethnicity	% (IQR)
White	94.7% (81.0–96.7%)
Black	1.2% (0.4–1.7%)
Asian	4.4% (0.3–17.3%)
Hispanic	5.6% (4.2–11.4%)

Franzen, et al. Alz & Dem. 2021.

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↓

Investigator

Example: Study Recruitment

- Study design: Randomized interview study assessing the impact of biomarker testing and disclosure on AD prevention trial recruitment
- Use of CARE: Recruit participants meeting inclusion criteria (age, English-speaking, no major neurological or psychiatric disorders/diagnoses)

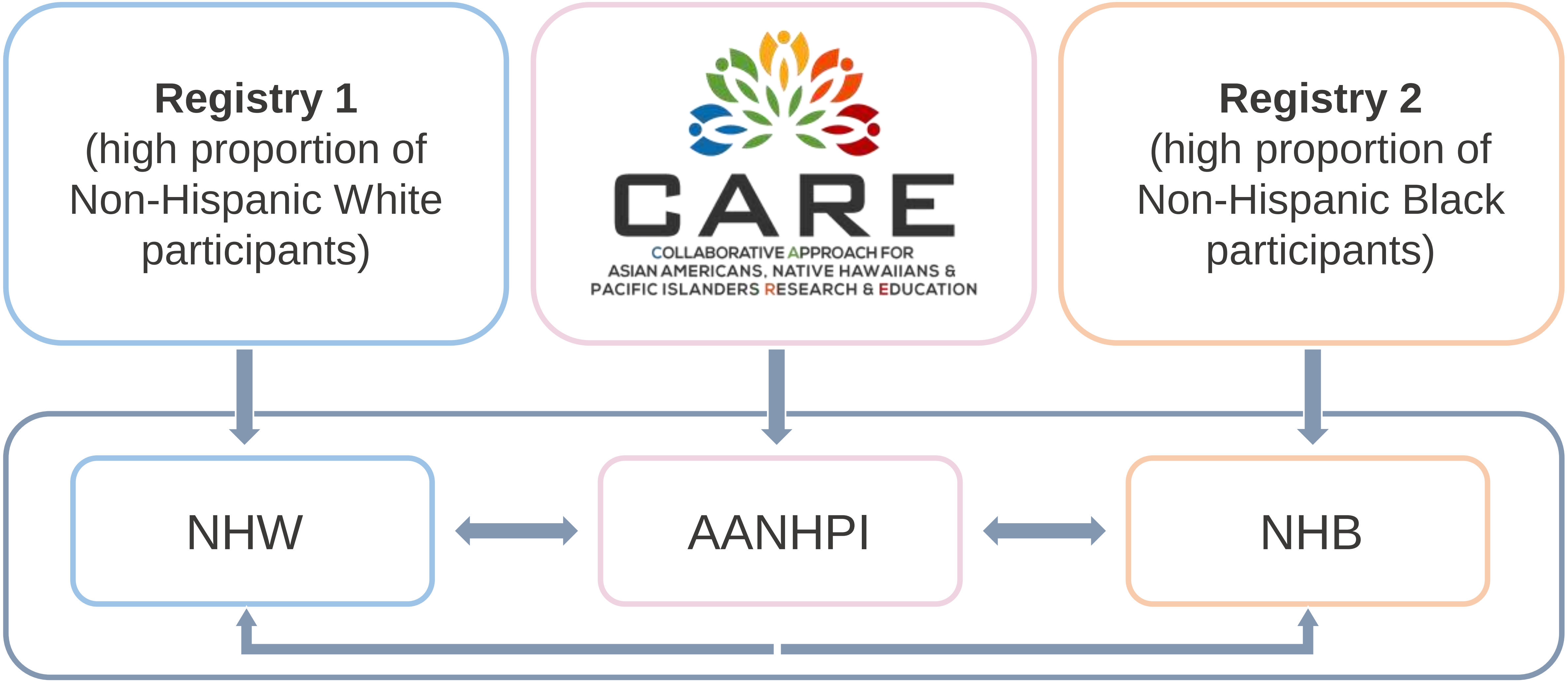
    - *Participants recruited from CARE included in study that also includes participants from other sources. Randomization overcomes issues around sample bias*
    - *Goal is to study more inclusive, representative sample*
    - *Secondary analyses might compare effect modification by race*

2. Recruit AANHPI Participants as a Novel Comparison Group

- Recruit CARE registrants to your prospective study*
  - *Recruit specific CARE registrants of interest to compare to other groups (e.g., non-Hispanic Whites)*
  - *Compare different AANHPI groups*

* Recruiting from CARE may produce important sample bias that is best addressed in study designs (post-recruitment)

Example: Study Recruitment



Registry 1
(high proportion of Non-Hispanic White participants)

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Registry 2
(high proportion of Non-Hispanic Black participants)

NHW

AANHPI

NHB

3. Answer Novel Research Questions About AANHPI

- Disseminate a survey to the CARE registrants
  - *All CARE registrants*
  - *Specific CARE registrants (e.g., Chinese immigrants >65 years)*
  - *Compare within or across AANHPI groups*

- Utility:
  - *Needs assessments*
  - *Preliminary data*
  - *Complete studies*

Investigator

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Example: Survey Study Design

- Hypothesis: Immigrants differ from second generation AANHPI in their attitudes toward Alzheimer’s disease prevention research
- Participants: Older (age 55 and up) CARE participants
- Methods: Send an electronic (REDCap) survey to all eligible CARE registrants
- Primary Analysis: Compare AANHPI born in this country to those born in another country for differences in willingness to participate in AD prevention research

Caveats and Conclusions

- CARE is not a community based epidemiologic cohort
- It cannot provide information (or opportunities to study) on disease prevalence or population characteristics
- Recruitment biases may differ among AANHPI subgroups in CARE
- CARE can assist in examining potential cultural and racial associations, hypothesis generation, and comparison studies
- CARE can improve recruitment of AANHPI and assist in diversifying research

THANK YOU!!

Community Perspectives in Research: Partnership with CARE

Samira Khan, MPH

CARE Community Advisory Board Member,

South Asian Public Health Association

SAPHA

SOUTH ASIAN PUBLIC HEALTH ASSOCIATION

VISION: SAPHA envisions better health and well-being for South Asians in the United States and the communities in which they live.

MISSION: Promote the health and well-being of South Asian communities in the United States through advocacy, collaboration, and communication.

GOALS:

- Advocate for South Asians in the United States on priorities that impact health
- Foster partnerships and collaborations with organizations, professionals, and community stakeholders
- Communicate current and relevant South Asian public health knowledge, research, and gaps

BOARD OF DIRECTORS


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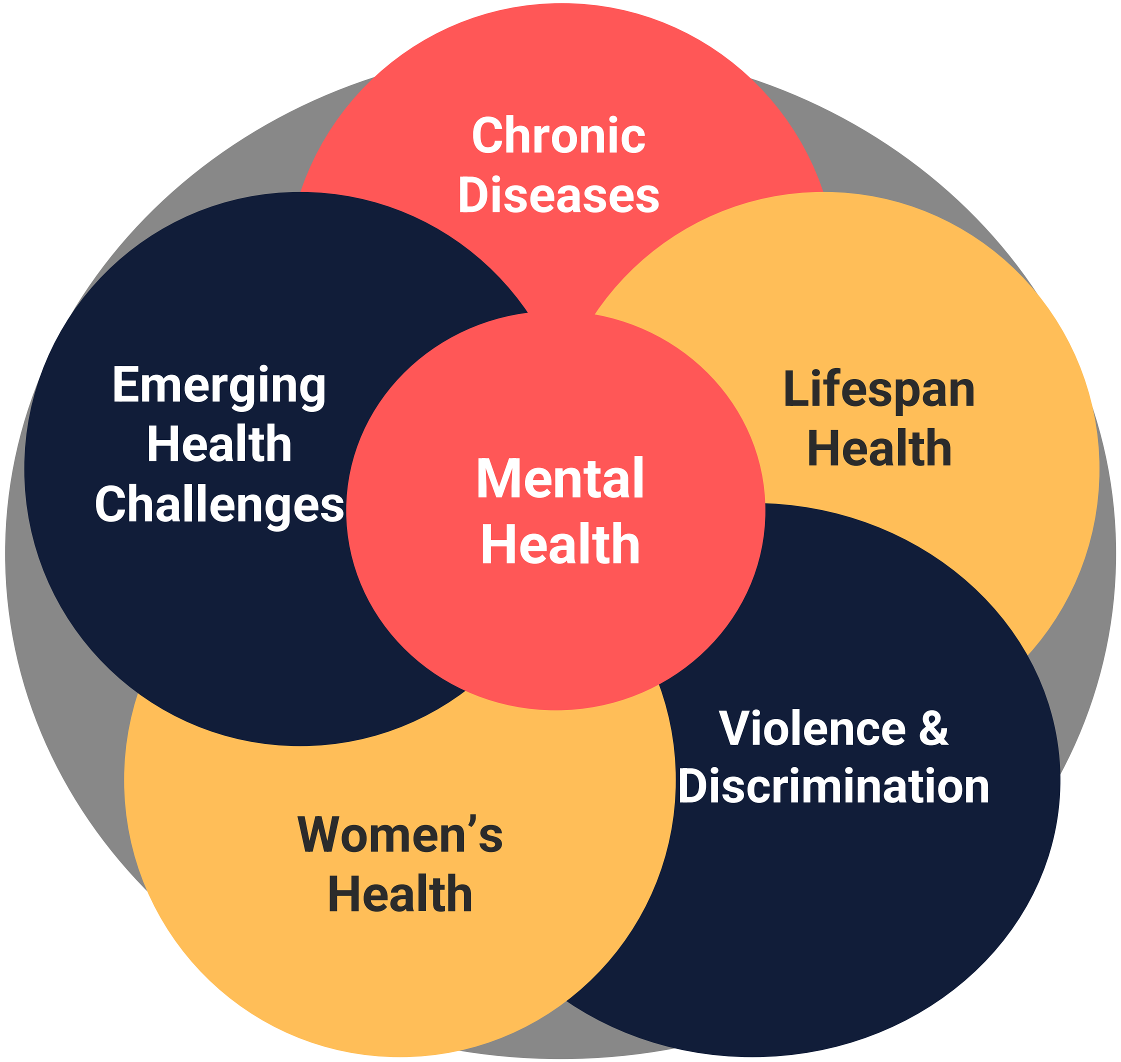
SAPHA’s Impact Areas



SAPHA’s Health Priorities

Community Partners with CARE - Why?

Importance of representation in aging research for South Asians.

Lack of data, invisibility in national datasets, and the need to disaggregate.

Alignment with SAPHA’s goals to address chronic disease, aging, and mental health.

Community empowerment through inclusion - An opportunity to be seen, counted, & understood.

Helps lay foundation for advocacy, policy change, and resource allocation.

Are you an Asian American, Native Hawaiian and/or Pacific Islander (AANHPI) adult and interested in future research participation?

VISIT
https://tinyurl.com/SAPHACARE

SAPHA is supporting the data collection efforts for Collaborative Approach for Asian Americans, Native Hawaiians, and Pacific Islanders Research and Education (CARE) 2.0, an NIH-funded, voluntary research study. CARE 2.0 aims to create a large repository of people of Asian American, Native Hawaiian and Pacific Islander (AANHPI) descent who can be contacted about Alzheimer's disease and related dementias, aging, caregiver-related research, and other health topics across the lifespan.

Our purpose

- CARE is a research registry designed to connect AANHPI communities to opportunities to participate in health research
- Some of the research focuses on cognitive decline, Alzheimer's disease and related dementias, aging, and caregiving-related topics

https://tinyurl.com/SAPHACARE

The Power of Partnership

Outreach, Awareness, Education

Translating materials, hosting info sessions, promoting in diaspora spaces

Community Trust, Culturally Grounded Communication

SOUTH ASIAN SOCIAL

FREE EVENT | REGISTRATION REQUIRED BY JUNE 16, 2025
REGISTRATION LINK: https://bit.ly/4kelzJM

Scan me

Delicious South Asian lunch will be provided!

Uplift your spirit and mental health through a Bollywood dance workshop!

SATURDAY JUNE 21, 2025
FRYING PAN FARM PARK AUDITORIUM
10:45 AM - 2:00 PM
2709 W Ox Rd, Herndon, VA 20171

ASHIYANAA

SAPHA

CARE

Hosted in partnership with the South Asian Public Health Association and the Collaborative Approach for Asian Americans, Native Hawaiians and Pacific Islanders (AANHPI) Research and Education Project.

This event is for adults only due to size constraints

Advance care planning among Filipino and Vietnamese Americans Aged 55+

Kaipeng Wang, PhD
Associate Professor
Graduate School of Social Work, University of Denver

Graduate School of
Social Work

Advance care planning (ACP)

planning for treatment preferences when people become unable to speak for themselves

Two Steps

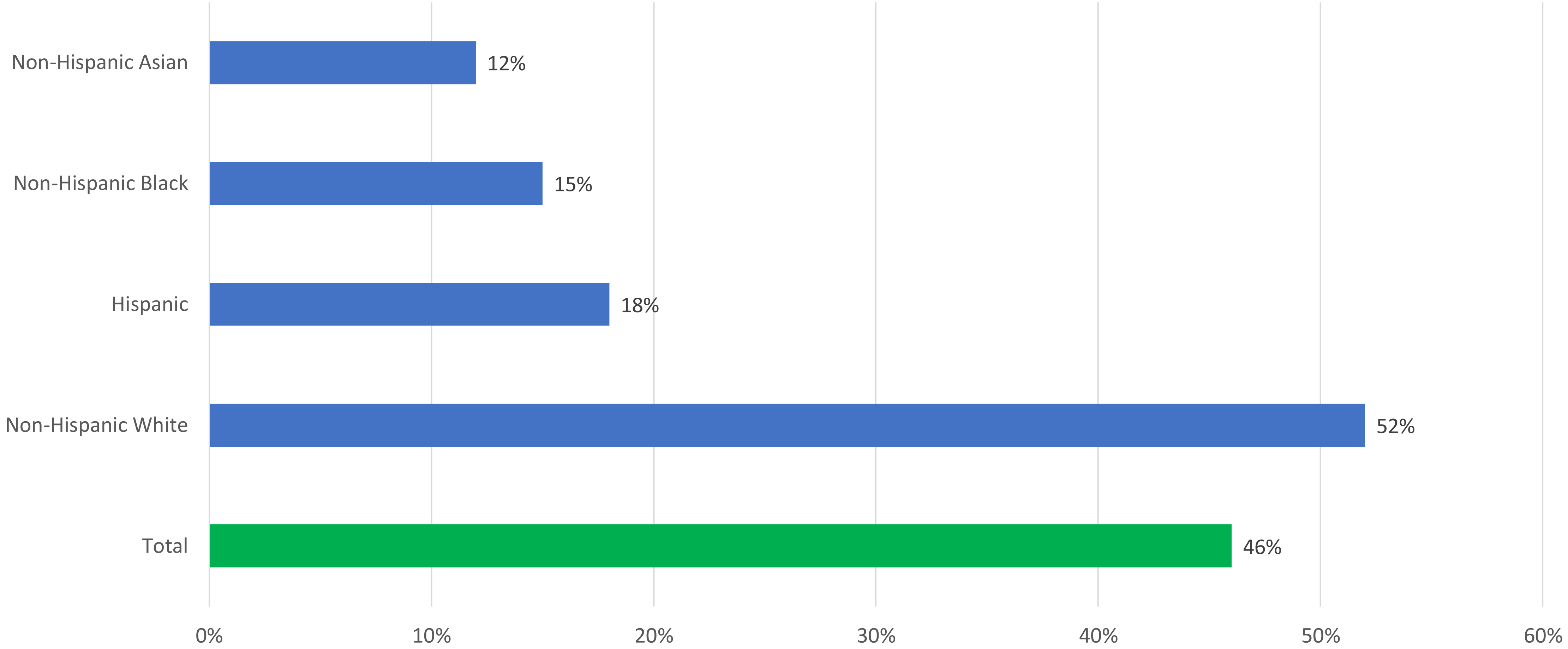
Discussion with family members and/or health professionals

Advance directives

Better quality of care, less unnecessary medical treatments and costs, lower anxiety and distress among patients and their surviving family members

Advance care planning by Race and Ethnicity

Advance Directive Completion Rate (50+) (Portanova, et al., 2017; **Wang**, et al., 2020)



Racial/Ethnic Disparities of ACP

- Research on ACP is limited for Asian Americans
  - Korean Americans 18.6% AD completion
    - Dobbs et al., 2015
  - Chinese Americans 14% AD completion
    - Wang et al, 2021
  - Lack of knowledge in ACP among other Asian Americans, especially southeast Asian Americans.

Goal and Specific Aims

- Goal: To examine the biopsychosocial factors of ACP-related outcomes among Filipino and Vietnamese Americans aged 55 or older.
- Specific Aims:
  - To examine the association between family relationships and experience of ACP and advance directive completion
  - To examine how resilience plays a role in ACP

Design

- Convergent Parallel Mixed Methods
  - QUAN + QUAL
- Eligibility criteria:
  - Self-identified Vietnamese and Filipino/a
  - 55 years old or older
  - Living in the U.S.
- Convenience sampling + snowball sampling

Design

Data collection:

- Quantitative survey
  - Online survey
  - In-person paper survey
- Focus groups
  - Filipino (one focus group) Vietnamese (one in English, one in Vietnamese)
- All recruitment and survey materials were translated into Vietnamese and Tagalog.

Participants each received a $25 gift card for completing the survey and $30 gift card for completing the focus group

Snapshot of Recruitment Activities

- February 2022 – August 2023
  - 7 community organizations serving Asian and Pacific Americans in six states
  - Colorado/Michigan (In person)
    - Temples, community events
  - All seven states (online)
    - flyers
  - Snowball sampling
  - 168 completed the survey (70 Vietnamese + 98 Filipinos)

Why CARE Registry

- Our planned sample size was 300
    - 132 more participants are needed
- Lack of representation for Vietnamese Americans
- Lack of representation for those who speak English or were born or immigrated at younger ages
    - Most people who participated in the community events do not speak English

Recruitment Result of CARE Registry

Period: May 2022 – May 2025

Total # of eligible participants contacted: 1833

Total # of people who completed the study: 163

- Almost half of the sample
- Total sample: 331

Methods of contact: Email three times

- Link to the questionnaire (including consent form) was included in the invitation email

Experiences Using CARE Registry

Registration:

- One-time registration through form
- Questions on the form are easy (almost all covered in proposal)
- Helpful recommendations from CARE Registry (e.g., language used in recruitment)

Experiences Using CARE Registry

Turnaround:

Usually within a week (Quick response if that cannot be achieved)

Names and emails are well formatted for group-sending

Preferred language is helpful

Priority may be requested or tailored (e.g., State)

Experiences Using CARE Registry

- Participant characteristics
    - Diversity (birthplace, language preference, etc.)
    - Recruitment at CARE Registry is ongoing and updated in a timely manner.

Lessons Learned

Include “final gentle reminder” to the last email outreach

Use multiple ways of outreach

Budget for staff who could follow up with phone calls, especially in a language you are not familiar with.

Acknowledgment

- CARE Registry: NIH/NIA R24AG063718 & R01AG083926
    - Dr. Ladson Hinton
    - Dr. Marian Tzuang
- Research assistants
    - Carson M. De Fries and My Ngoc To
- Community partners and agencies
- Rutgers RCMAR project funding: NIH/NIA P30AG0059304 Subaward

Thank You

- Kaipeng Wang
- Kaipeng.Wang@du.edu

Acknowledgments

Thank you to all the registry participants!

UC San Francisco

Van Ta Park (MPI)
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Thomas Hoffmann
Bora Nam
Marian Tzuang
Nicole Phan
Chandra Chak
Annie Ching
Bobin Kim
Daren Huang
Gabriel Fara-On
Seoyeon Yum
Anson Wong
Nimita Gaggar
Emily Dang
Linh Nguyen
Brian Nguyen
CARE Interns & Ambassadors

UC Davis

Oanh L. Meyer (Site PI)
Ladson Hinton

UC Irvine

Joshua D. Grill (MPI)
Hye-Won (Grace) Shin
Kenny Li

Stanford University

Dolores Gallagher-Thompson
Cati Brown-Johnson

ICAN

Quyen Vuong (Site PI)
Lam Pham
MaiHien Luu

CSU East Bay

Arnab Mukherjea (Site PI)
Feaba Anil

U of Hawaii

Christy Nishita (Site PI)
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