



CARE

COLLABORATIVE APPROACH FOR
ASIAN AMERICANS & PACIFIC ISLANDERS
RESEARCH & EDUCATION

HEALTH ACROSS THE LIFESPAN

Brain Trust Meeting

May 28, 2021

Agenda

12:00 – 12:10pm	Welcome and Background <i>Van Ta Park, PhD, MPH (UC San Francisco)</i>
12:10 – 12:20pm	Overview of CARE Registry <i>Oanh Meyer, PhD (UC Davis)</i>
12:20 – 12:35pm	CARE-Supported Recruitment <i>Joshua Grill, PhD (UC Irvine)</i> <i>Dolores Gallagher-Thompson, PhD (Stanford University)</i>
12:35 – 12:45pm	Lightning Talk – The COMPASS Study <i>Janice Tsoh, PhD (UC San Francisco)</i>
12:45 – 12:55pm	Q&A + Raffles
12:55 – 1:00pm	Evaluation and Adjourn

Asian Americans and Pacific Islanders (AAPI)



Asian Americans¹ are the fastest growing racial group in the U.S.:

7% of the population

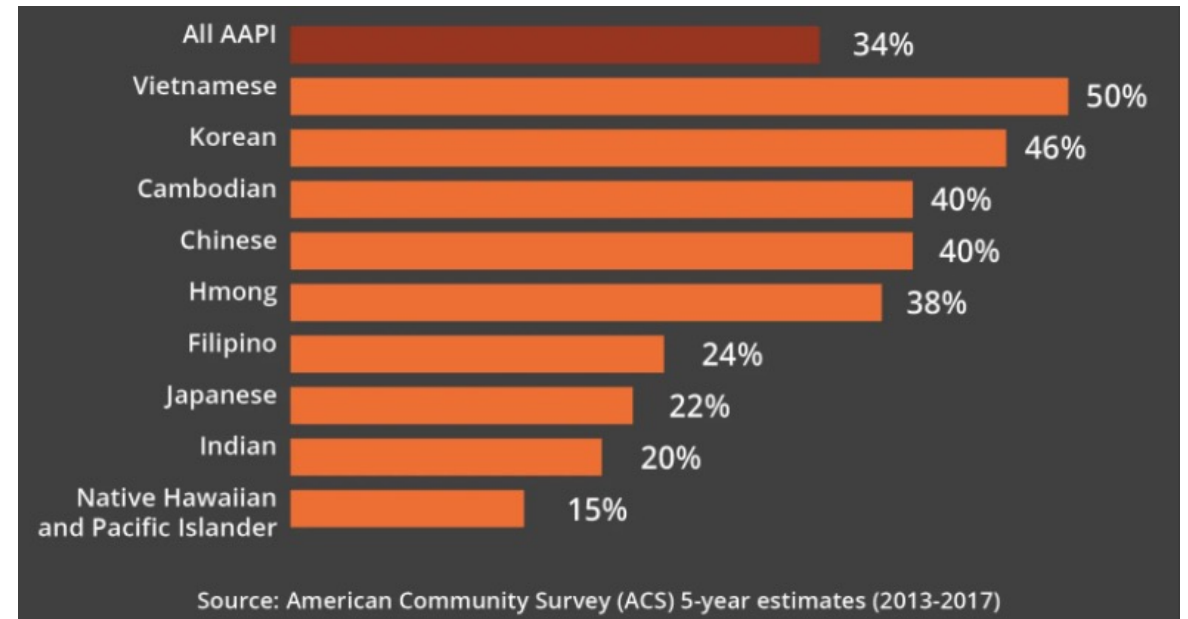
30 AA & 21 PI groups

20 million AA & 1.6 million PI



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

Percentage of AAPI with Limited English Proficiency ²



¹ http://www.census.gov/newsroom/release/archives/facts_for_features_special_editions/cb11-ff06.html

² AAPI Data: <https://aapidata.com/infographic-limited-english-2-2/>

Disparities in Research Participation for AAPI

- Clinical research projects focusing on AAPI participants funded by the National Institute of Health (NIH) was less than 1% of its total budget between 1992 and 2018.¹
- Out of 43,739 participants who were enrolled in ADRD studies at Alzheimer's Disease Research Centers, only 2.7% were AAPI.²
- Barriers to AAPI participation in research:
 - Cultural differences
 - Linguistic limitations
 - Lack of education in research practices



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

² National Alzheimer's Coordinating Center (NACC). Web-based Query System. 2018; <https://www.alz.washington.edu/WEB/naccquery.html>. Accessed April 27, 2021.

Paving the Way for Meaningful Inclusion of AAPI in Research

- To address the gap and reduce disparities in research participation in ADRD, aging, caregiving, and other health issues across the lifespan among AAPI.
- CARE will implement culturally appropriate and innovative recruitment strategies with our community partners across California to enroll 10,000 AAPI.
- We aim to give AAPI a voice and the opportunity to participate in such future research through enrollment in the CARE registry!



Overview of CARE Registry

Oanh Meyer, PhD
CARE Co-Investigator

Department of Neurology,
UC Davis School of Medicine

CARE: Multi-Site Collaboration



University of California
San Francisco



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<https://careregistry.ucsf.edu/>



NATIONAL ASIAN PACIFIC
CENTER ON AGING



Institute for Memory Impairments
and Neurological Disorders

CARE Partners & Community Advisory Board



CARE Registry

Who can enroll?

- AAPI
- 18+ years old
- Speak and read English, Chinese, Korean, Vietnamese or Samoan
- Interested in participating in potential research



Participants complete an **online survey** (10-15 min) **by phone**, or in-person

NAPCA toll-free lines:

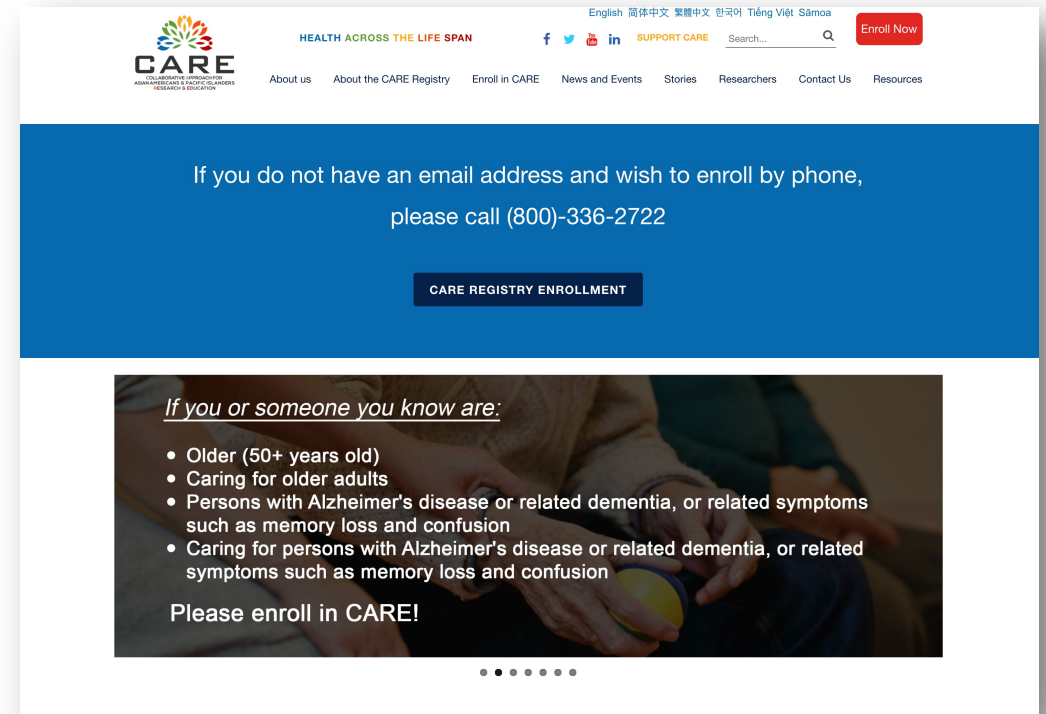
廣東話 / Cantonese (800) 582-4218 普通话 / Mandarin (800) 683-7427
한국어 / Korean (800) 582-4259 Tiếng Việt / Vietnamese (800) 582-4336



CARE Enrollment Survey available in **6 languages**



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



CARE Enrollment Survey Questions

Socio-demographic information

Health conditions (e.g., neurological disease and related symptoms such as Alzheimer's disease; heart disease; cancer; mood-related issues)

Health behaviors (e.g., smoking; physical activity; diet)

Caregiving experiences (if applicable)

CARE Snapshot (N=5,149 as of May 22, 2021)



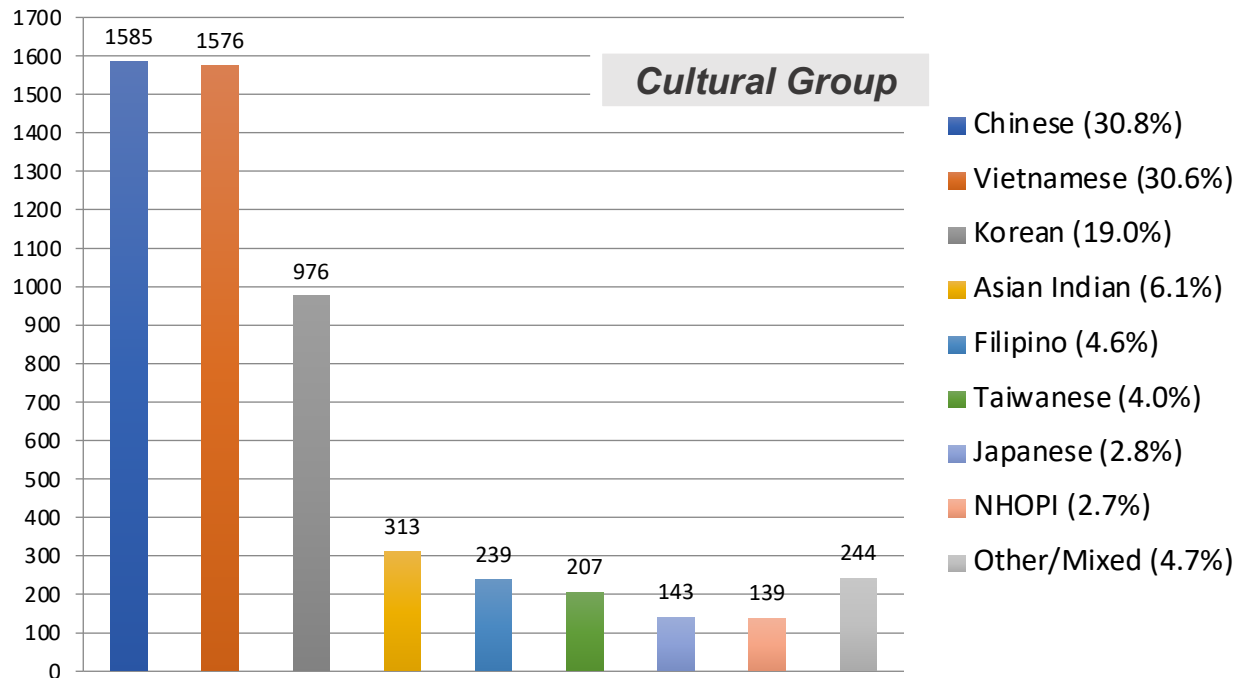
82.7% Born outside of U.S.



87.6% Californian



12.3% Caregivers of older adults or person with special needs.



Mean age = **51.9** (range 18-99)
Age over 60 = **27.1%**



62.0% Female



35.9% Male

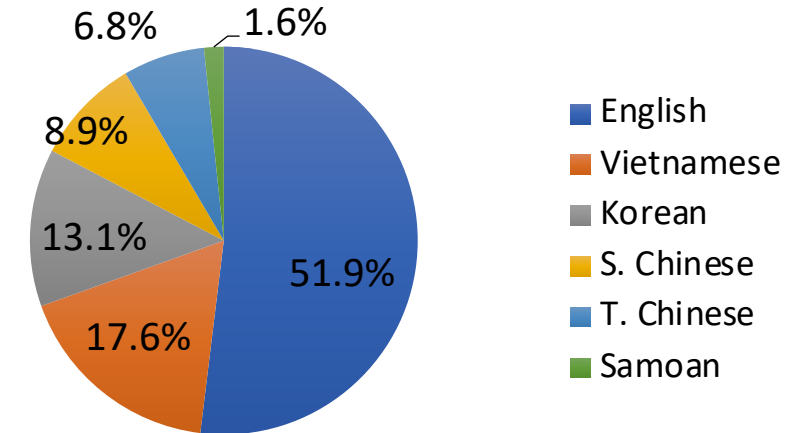


50.0% Limited English proficiency




6.4% with ADRD symptoms


Language Used to Complete the Survey




CARE Snapshot (N=5,459 as of May 31, 2021)

 **83.0%** Born outside of U.S.

 **88.7%** Californian

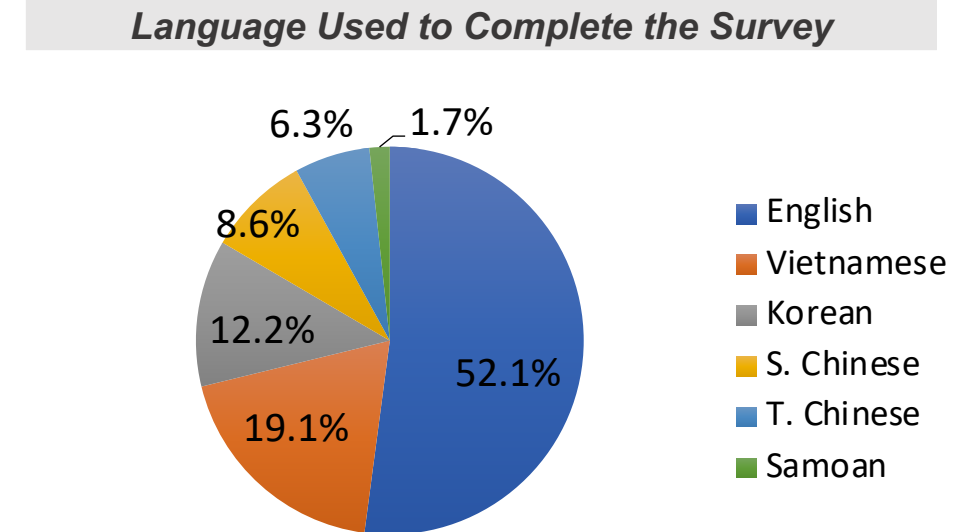
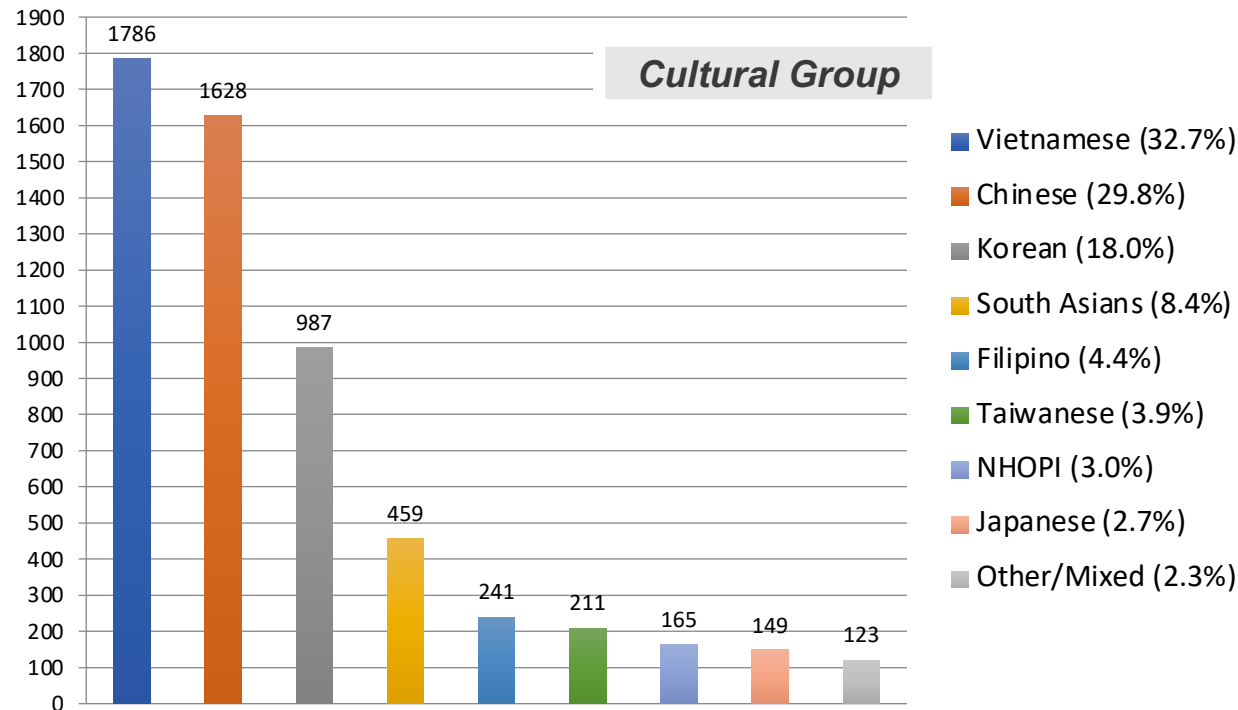
 **11.9%** Caregivers of older adults or person with special needs.

 Mean age = **52.2** (range 18-99)
Age over 65 = **21.4%**

 **61.9%** Female  **36.1%** Male

 **50.2%** Limited English proficiency

 **6.7%** with ADRD symptoms



CARE-Supported Recruitment

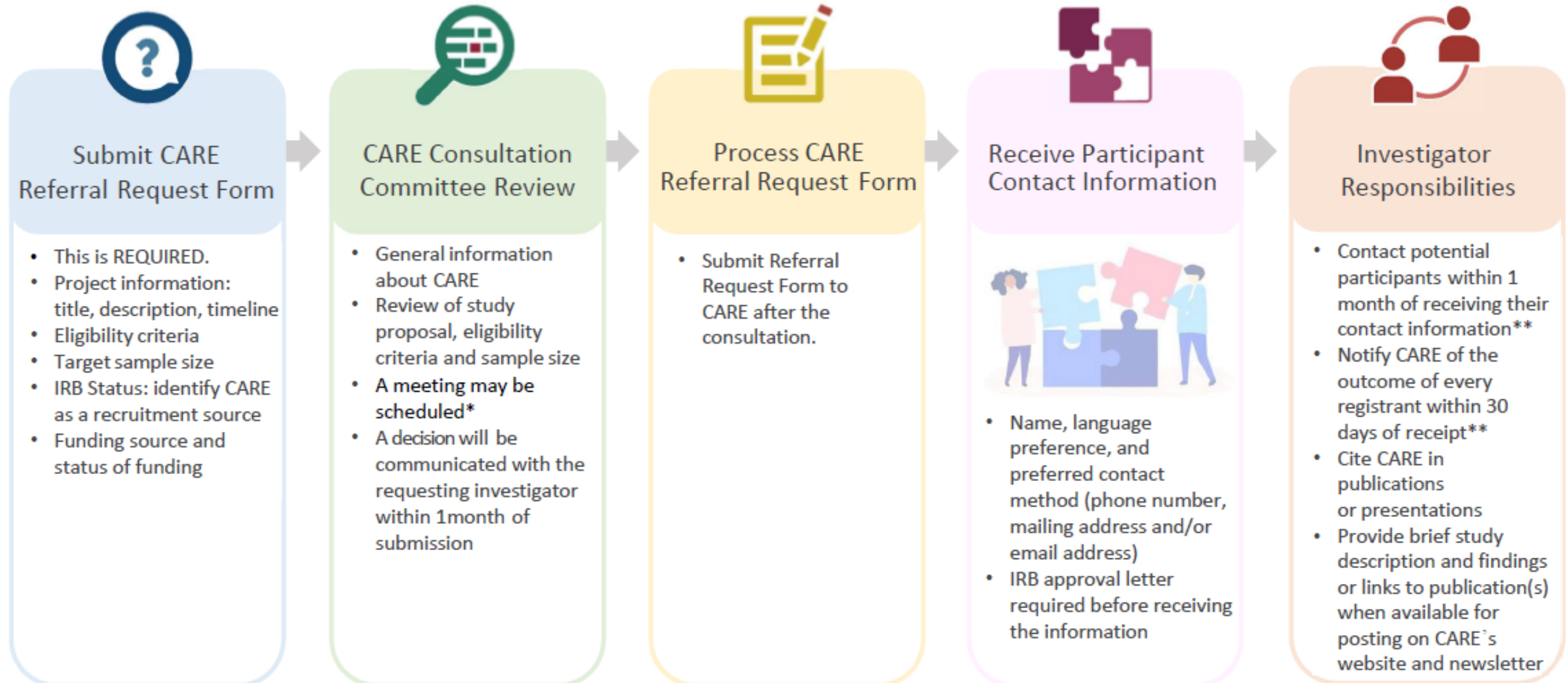
Joshua Grill, PhD
CARE Co-Investigator

Institute for Memory Impairments
and Neurological Disorders, UC Irvine

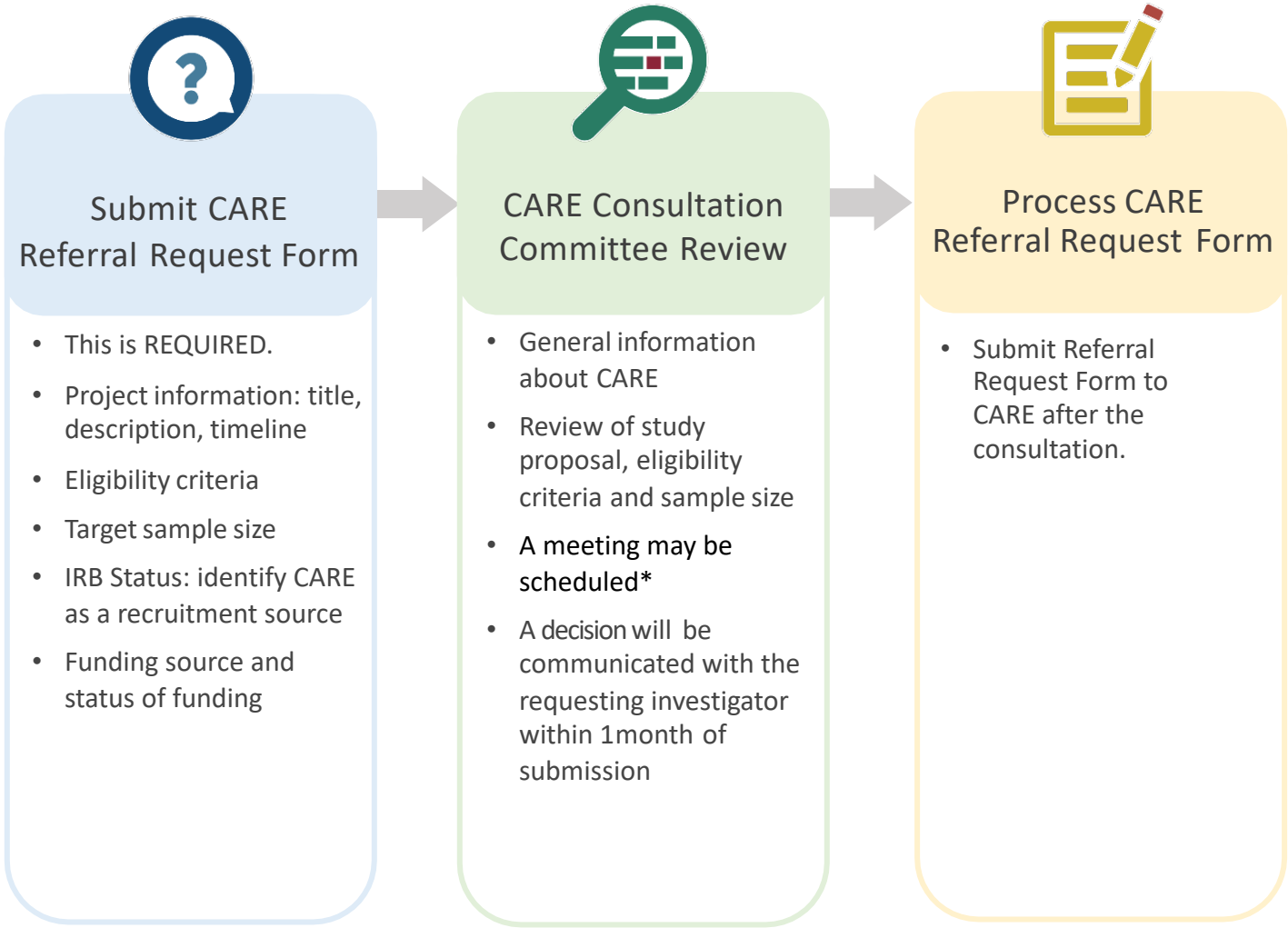
Dolores Gallagher-Thompson, PhD
CARE Co-Investigator


Department of Psychiatry
and Behavioral Sciences,
Stanford School of Medicine

CARE-Supported Recruitment Flowchart



CARE-Supported Recruitment Steps 1-3





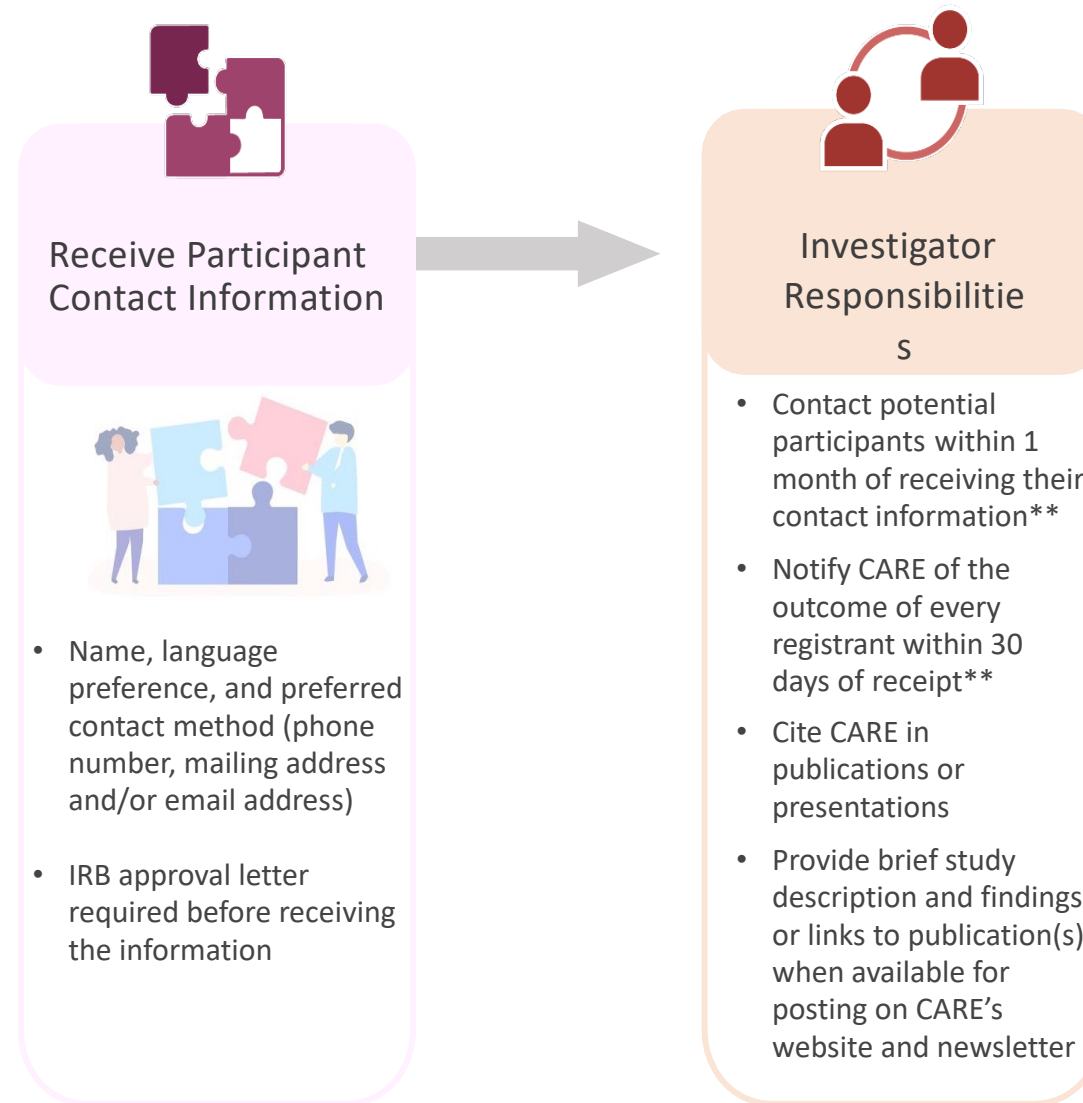
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CARE Referral Request Form

Contact information	
Principal Investigator:	PI Email:
Study Contact:	Study Contact Email:
Study Information	
Study Title:	
Have you scheduled a consultation meeting with us to discuss recruiting participants from CARE? (if not, please email Marian Tzuang, PhD, MSW, CARE Research Analyst at marian.tzuang@ucsf.edu to schedule it.) <input type="checkbox"/> Yes <input type="checkbox"/> No	
If "Yes", please fill out the sections below based on consultation with CARE.	
If "No", please fill out the sections below as appropriate.	
What kinds of assistance would you like to receive from the consultation? (check all that apply)	
<input type="checkbox"/> Study design <input type="checkbox"/> Eligibility criteria <input type="checkbox"/> Sample size <input type="checkbox"/> Translation <input type="checkbox"/> Letter of support	
<input type="checkbox"/> Templates for emails and participant communication	
<input type="checkbox"/> Other, please specify:	
*Consultation will be provided in the context of the CARE Registry.	
Study Recruitment Status:	
<input type="checkbox"/> Ongoing	
<ul style="list-style-type: none">• ClinicalTrials.gov ID (if applicable):• Study website (if applicable):• Other public access / study registration (if applicable):	
<input type="checkbox"/> Preparing for recruitment	
Asian Americans and Pacific Islanders (AAPI) Cultural Group of Interest:	
<input type="checkbox"/> All AAPI <input type="checkbox"/> Asian Indian <input type="checkbox"/> Chinese <input type="checkbox"/> Ethnic Chinese (Hauren) <input type="checkbox"/> Filipino <input type="checkbox"/> Korean	
<input type="checkbox"/> Japanese <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Samoan <input type="checkbox"/> Taiwanese <input type="checkbox"/> Vietnamese	
<input type="checkbox"/> Other AAPI cultural group(s), please specify:	
Study Description and Goals:	

*Depending on the nature of the request, the requesting investigator will be contacted by a CARE Consultation Committee member to discuss the proposal in detail and provide the consultation services requested. Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration by the CARE investigators before approval.

CARE-Supported Recruitment Steps 4-5









**This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys).

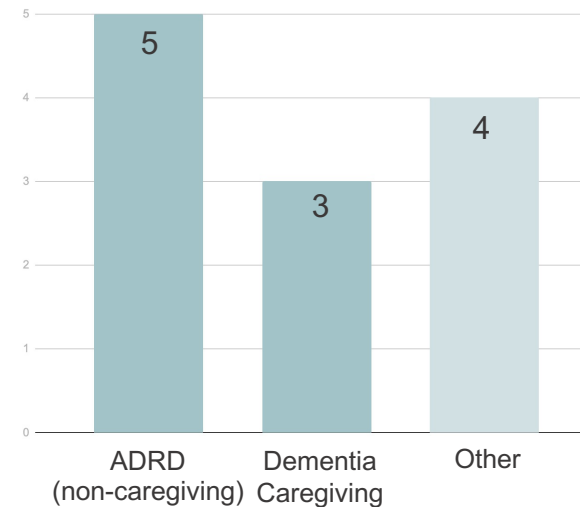
CARE-Supported Recruitment

- Download CARE Recruitment Referral Form at:
<https://careregistry.ucsf.edu/researchers>
- CARE team may request a consultation meeting to discuss the proposed recruitment referral in detail.
- Proposals that involve substantial commitment of CARE resources will receive further review and budgetary consideration by the CARE investigators before approval.
- The guidelines presented is primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs such as survey.

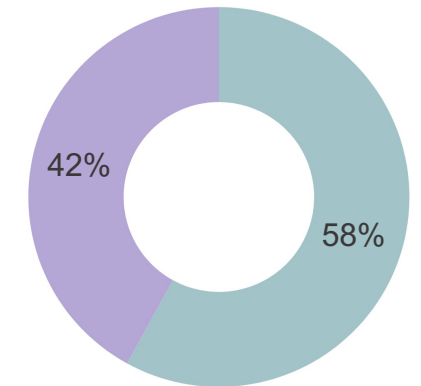
CARE-Supported Recruitment Requests (N=12 as of May 2021)

Institutions		# of request
	Stanford University	2
	Texas State University	1
	UC Irvine	1
	UC San Francisco	5
	University of Houston	1
	University of Southern California	2

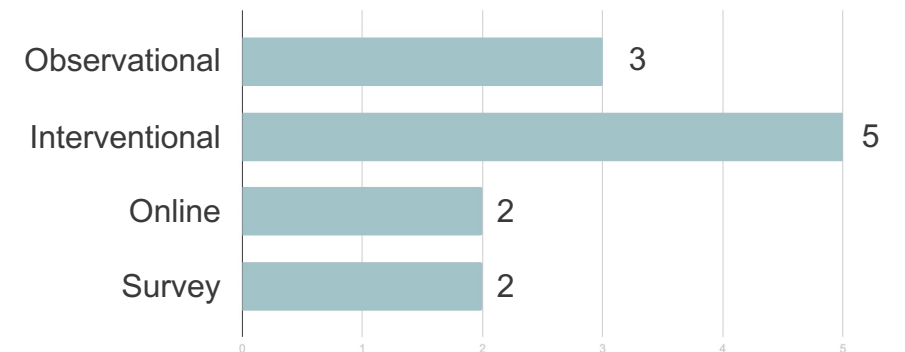
Research Area



● All AAPI
● Specific AAPI Subgroup



Study Design



Requesting Studies



Study Titles

SHARE (Share History, Activity, Resilience, and Experience) Project among Asian American Older Adult Caregivers of Individuals with Alzheimer's Disease and Related Dementias

Factors Affecting Dementia Care in Filipinos/Filipino-Americans Living in California

Development of a Speech and Language Battery for Tagalog Speakers with Cognitive Impairment

Revision and Psychometric Evaluation of the Diabetes Knowledge Questionnaire to Address Health Disparities among Chinese Americans with Type 2 Diabetes

Caregiver-Provided Life Review for Persons with Dementia in Care Facilities

All of Us Research Program at UC Irvine

Asian Cohort for Alzheimer's Disease (ACAD)

Physical Activity Smartphone App for People with Mild Cognitive Impairment or Dementia

Functional Neuromodulation/ADvance II Study

Improving Health Disparities by Promoting Physical Activity Among Asian American Older Adults with Cardiovascular Disease: A Pilot Study (The ACTION Study)

Looking to understand neuropsychiatric symptoms in Alzheimer's disease

A novel use of a sleep intervention to target the emotion regulation brain network to treat depression and anxiety

Example: SHARE Project (PI: Dr. JiWon Choi)

Referral Request Received

Late January 2021

CARE Committee Review

Early February 2021

- Ask PI to obtain IRB approval to include CARE as a recruitment source
- Clarify participant eligibility
- Initial query to identify potentially eligible participants:
 - 1) age ≥ 50 ; 2) male; 3) self-identified as Korean American; 4) caring for someone with dementia

Share CARE Participant Contact Information

Mid-February 2021

- Received IRB approval letter (including protocol that list CARE as recruitment source) from PI
- Name, language preference, and preferred contact method were shared with the study team
- Provided templates for invitation letter, email and phone script to explain why CARE participants are contacted
- Provided tracking log to study team to document contact outcomes (to be returned within 30 days of receiving participant contact information)

Notify CARE of Contact Outcomes

Mid-March 2021

Lightning Talk – The COMPASS Study

Janice Tsoh, PhD
CARE Co-Investigator

Department of Psychiatry and Behavioral Sciences
UC San Francisco School of Medicine



- **Purpose:** Nationwide survey about the COVID-19 mental and physical health effects on Asian Americans and Pacific Islanders (AAPI).
- **Participants:** 5,418 AAPI adults completed the survey online, by phone, or in-person. Overall, 20.2% (526 out of 2,600) of CARE participants completed the COMPASS survey.
- **Survey Period:** October 24, 2020 – January 26, 2021 for publicly available survey via COMPASS website. Targeted recruitment with community partners are closed on May 8, 2021.
- **Website:** compass.ucsf.edu
- **UCSF IRB Protocol #:** 20-31925



COMPASS Participants (N=5,418)

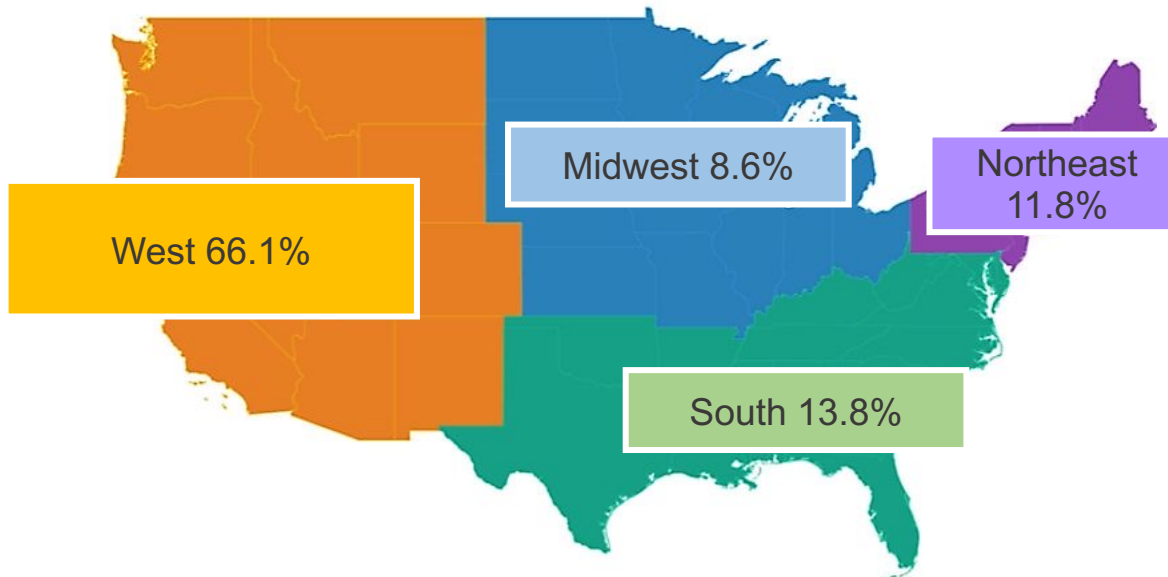
Survey period: Oct 24, 2020 – May 8, 2021

❖ Age

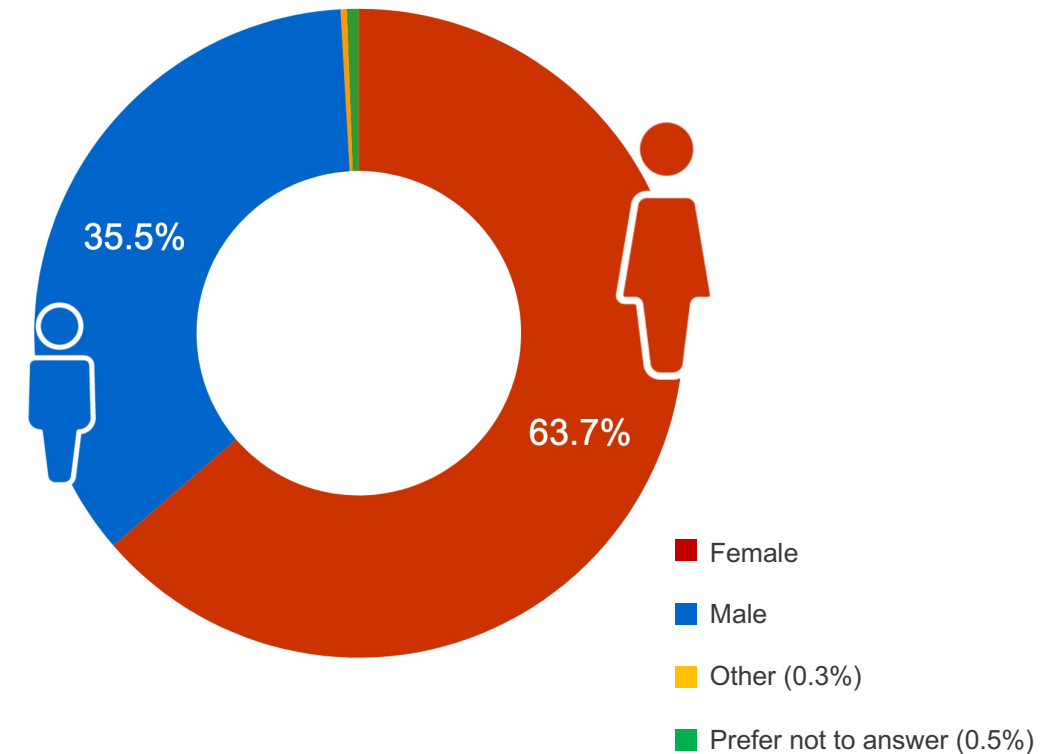
- Range: 19 – 98 years
- 47.1% were 50 years and older
- 16.8% were 65 years and older

Mean Age
47.2

❖ Regions



❖ Gender



COMPASS Participants (N=5,418)

Survey period: Oct 24, 2020 – May 8, 2021

❖ Cultural groups:

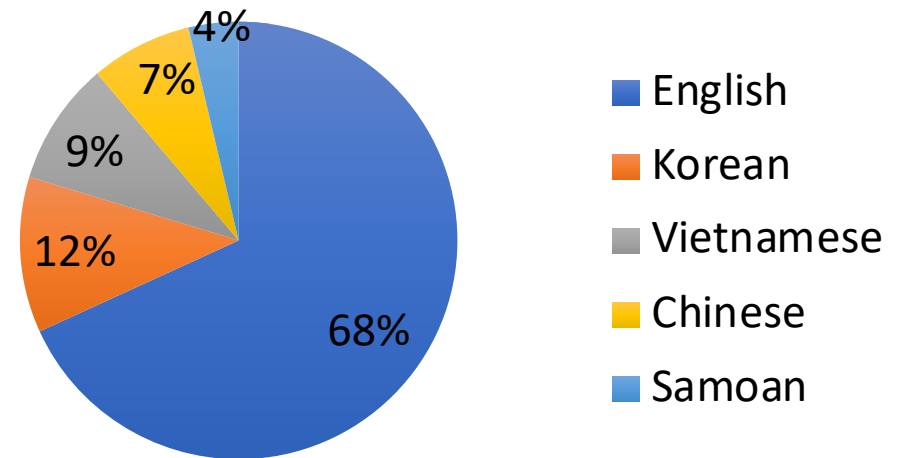
Ethnic Chinese	36.0%
Korean	21.6%
Vietnamese	20.0%
Asian Indian	6.1%
Taiwanese	5.3%
Japanese	5.1%
Native Hawaiians or Pacific Islanders	4.9%
Filipino	4.7%
Hmong	2.2%
Other	1.8%
More than one cultural group	1.3%

❖ **66.6%** born outside the U.S.

❖ **24.9%** have limited English proficiency

❖ **14.7%** are caregivers of older adults or persons with special needs

❖ Language of survey completion:

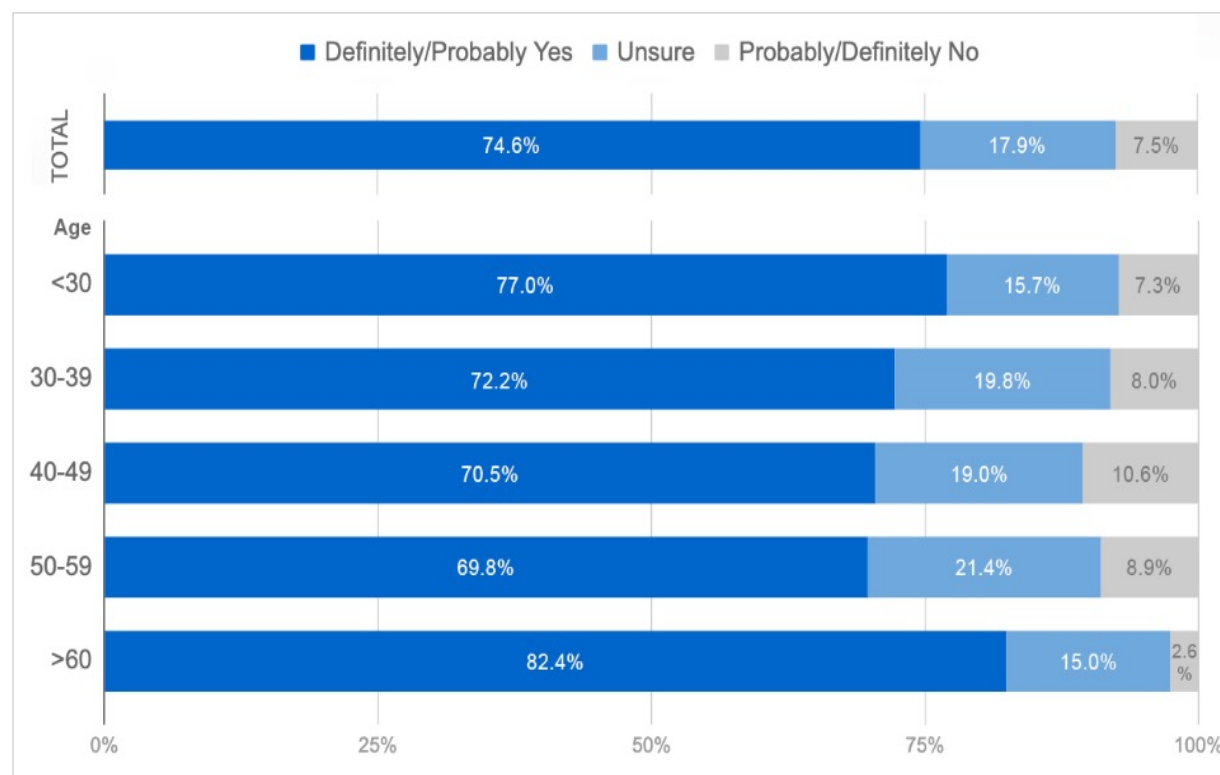


COMPASS: Vaccine Willingness (N=1,646)

Q. If a vaccine becomes available for COVID-19, would you get it?

- 25.4% said they were “unsure” or “probably/definitely no” to getting the COVID-19 vaccine
 - 24.8% for Asian Americans
 - 48.4% for NHPI

Willing to Receive COVID-19 Vaccination by Age Group



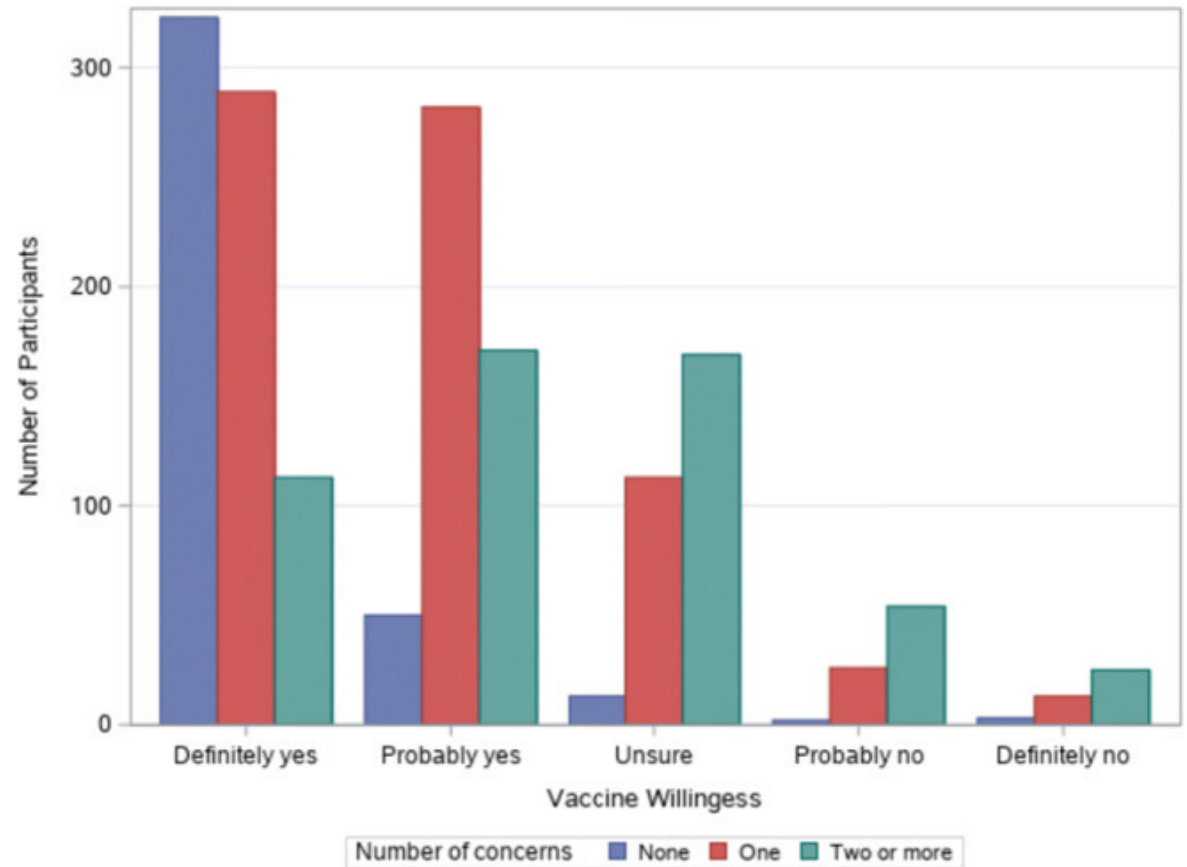
Survey period: Oct 24 – Dec 11, 2020 (the first day that the FDA authorized emergency use of the COVID-19 vaccine)

Park et al. (Under review)

COMPASS: Vaccine Concerns (N=1,646)

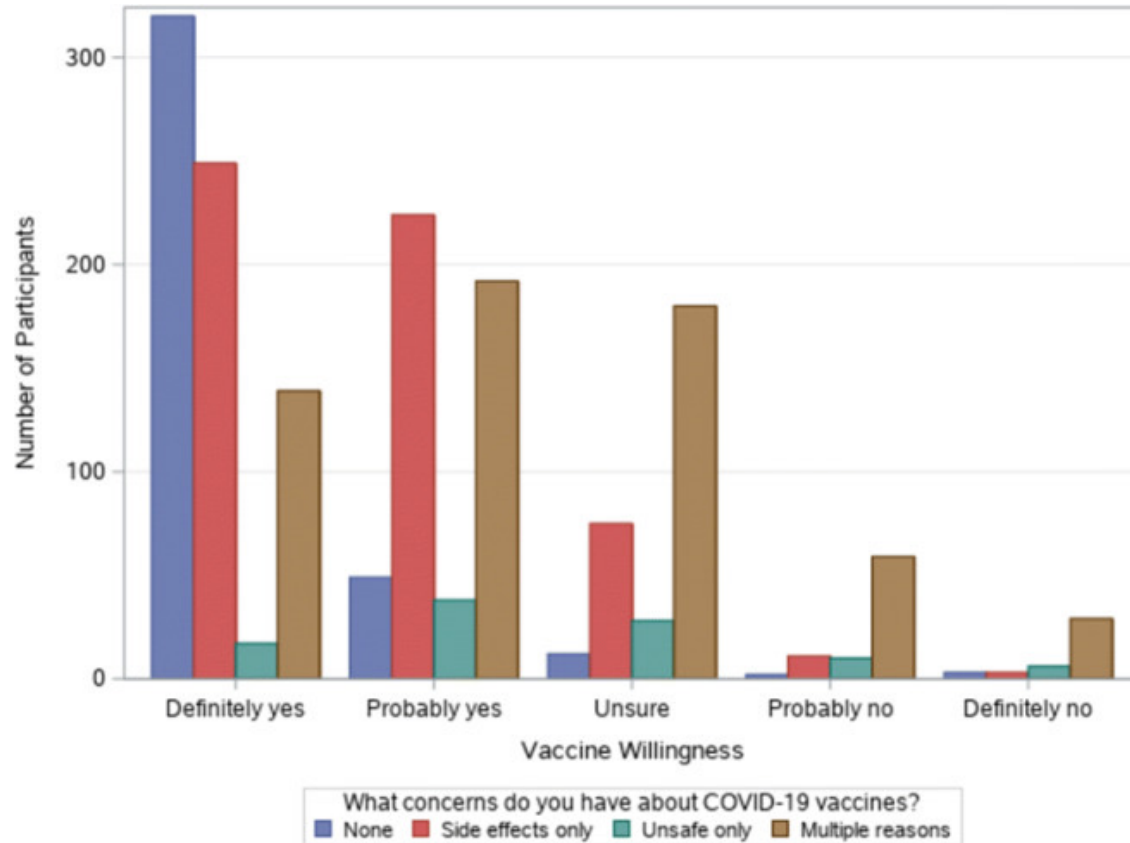
- 76% had ≥ 1 concerns about the vaccine
- Most common concern was side effects (65%)
- 34.1% only concerned about side effects
- 6.0% only concerned about vaccine safety
- 36.4% reported multiple concerns

Vaccine willingness by number of concerns



COMPASS: Vaccine Concerns (cont.)

Vaccine willingness by types of concerns



- Among those who said they would definitely get the vaccine (n=725), 44.6% said they had no concerns about the vaccine (vs. 15.6% had two or more concerns).
- Among those who said they definitely would not get the vaccine (n=41), 7% had no concerns (vs. 61% had two or more concerns).

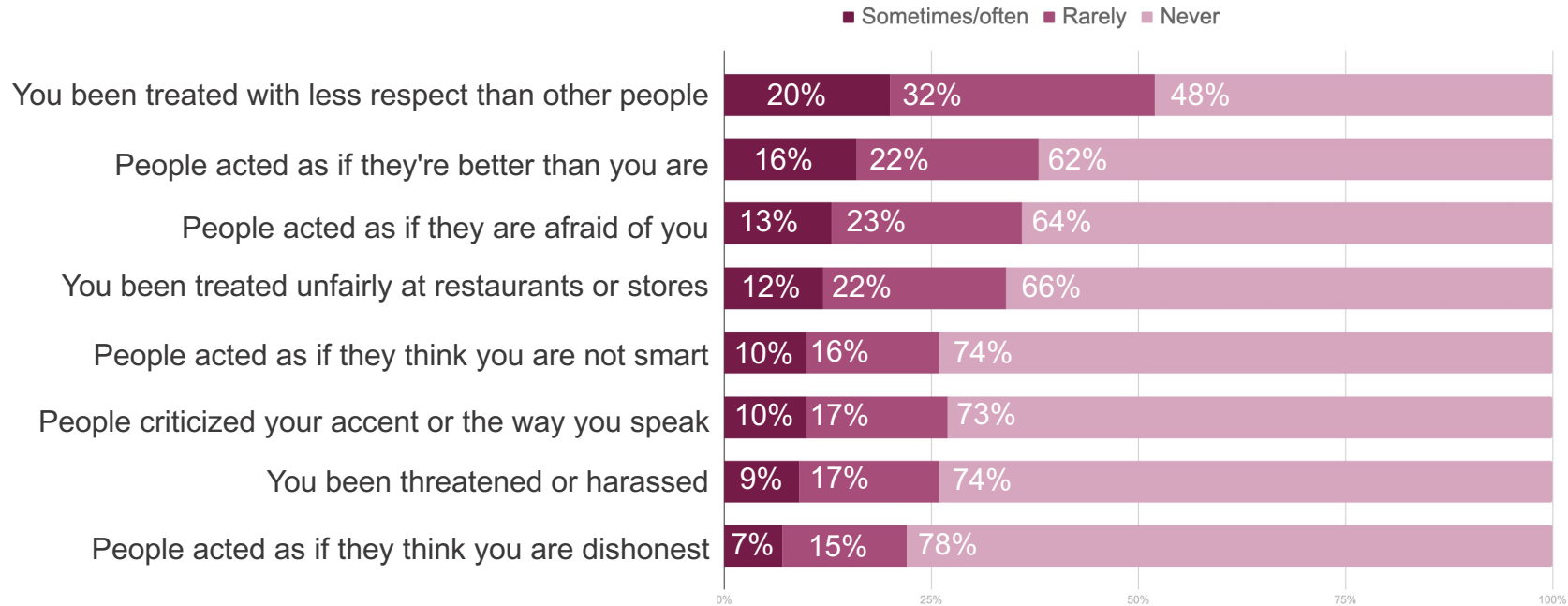
COMPASS: Vaccine Concerns (cont.)

Multivariable Analyses Result:

- **Those who had less vaccine concerns were:**
 - ≥ 60 years old (vs. <30)
 - Vietnamese Americans (vs. Chinese Americans)
 - who reported higher (vs. low) health status
 - separated/divorced/widowed (vs. single)
- **More concerns about the vaccine:**
 - Age 30-39 and 40-49 years old (vs. <30)
 - Filipinos and Koreans (vs. Vietnamese) in post-hoc analyses
 - females (vs. males)
 - experienced mild negative impacts from COVID-19 on family income/employment (vs. no change)

Everyday Discrimination (N=4,971)

Q: In the past 6 months, how often have...because you are Asian, Asian American or Pacific Islander?



Overall, 3 in 5 AAPI experienced at least one of the above everyday discrimination in the past 6 months

Note: Based on data from 4,971 COMPASS participants who completed the survey between 10/24/20 and 2/13/21 and answered all the discrimination questions. Ta Park et al. (Under review).

Coronavirus Racial Bias Scale (N=4,971)

Q: % who strongly/somewhat agree with beliefs concerning how the COVID-19 pandemic is affecting AAPI:

59.0%	believe that the country has become more dangerous for their ethnic group
46.2%	believe that negative social media posts against their race/ethnicity have increased because of COVID-19
40.6%	believe that most social/mass media reports about COVID-19 create bias against their race/ethnicity
39.0%	have seen a lot more cyberbullying of people of their race/ethnicity since the pandemic
34.1%	worry about people thinking they have COVID-19 because of their race/ethnicity
31.5%	believe that people of their race/ethnicity are more likely to lose their job
15.3%	believe that people of their race/ethnicity will not receive as good COVID-19 healthcare as others
10.6%	believe people of their race/ethnicity are more likely to get COVID-19
10.4%	reported being cyberbullied because of their race/ethnicity

Note: Based on data from 4,971 COMPASS participants who completed the survey between 10/24/20 and 2/13/21 and answered all the racial bias questions. Ta Park et al. (Manuscript in preparation).

Conclusions



To the best of our knowledge, COMPASS is the largest national survey of AAPI that are available in multiple languages



Success of engagements:

- Establishment of trust with community partners and CARE participants
- Relevant topic that resonates with the community



COMPASS provides valuable and updated disaggregated data

Q&A + Raffles

Please complete our evaluation survey:

https://ucsf.co1.qualtrics.com/jfe/form/SV_cBZyrtdY7XEI9qm



Acknowledgments

Thank you to all the registry participants!



UC San Francisco

Van Ta Park (PI)
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Sang Ngo
Shweta Srivastava
Marian Tzuang
Stuart Gansky (DCE)
Sarit Helman (DCE)
CARE Interns

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Anna Bach
Duyen Thi Ky Tran

UC Irvine

Joshua D. Grill (Co-I)
Ruobing Li
Hye-Won (Grace) Shin

Stanford University

Dolores Gallagher-Thompson (Co-I)

ICAN

Quyen Vuong (Co-I)
Isabella Luong
Anne Phan
Cecilia Phan

NAPCA

Joon Bang (Co-I)
Heather Chun
Dyanna Chung
Lisa Thong

Community Advisory Board

Araceli Antonio ▪ Joyce Cheng ▪ David Choi ▪ Sadhna Diwan ▪ Sophie C. Horiuchi-Forrester ▪ Joyce Javier ▪ Ryan Kawamoto
▪ Ruobing Li ▪ Tatiana Makoni ▪ Gerard Manuel ▪ Jennifer Masuda ▪ Becky Nguyen ▪ Phuong Christine Nguyen
Stephanie Nguyen ▪ Paula Palmer ▪ Lina Park ▪ Hye-Won (Grace) Shin ▪ Natalie Ah Soon ▪ Angela Sun ▪ Boon Lead Tee
▪ Quyen Tiet ▪ Bexx Toomalatai ▪ Ranak B. Trivedi ▪ Jennifer Wang ▪ Michael Weiner ▪ Edie Yau