



CARE

COLLABORATIVE APPROACH FOR
ASIAN AMERICANS & PACIFIC ISLANDERS
RESEARCH & EDUCATION

HEALTH ACROSS THE LIFESPAN

Brain Trust Meeting

February 28, 2022

Agenda

10:00 – 10:10am	Welcome <i>Van Ta Park, PhD (UC San Francisco)</i>
10:10 – 10:20am	Overview of CARE Registry <i>Alka M. Kanaya, MD (UC San Francisco)</i>
10:20 – 10:35am	How to use CARE <i>Joshua Grill, PhD (UC Irvine)</i>
10:35 – 10:45am	Community Perspectives in Research: Partnership with CARE <i>Heather Chun, MSW (National Asian Pacific Center on Aging)</i>
10:45 – 10:55am	Q&A + Raffles
10:55 – 11:00am	Evaluation and Adjourn

Asian Americans and Pacific Islanders (AAPI)



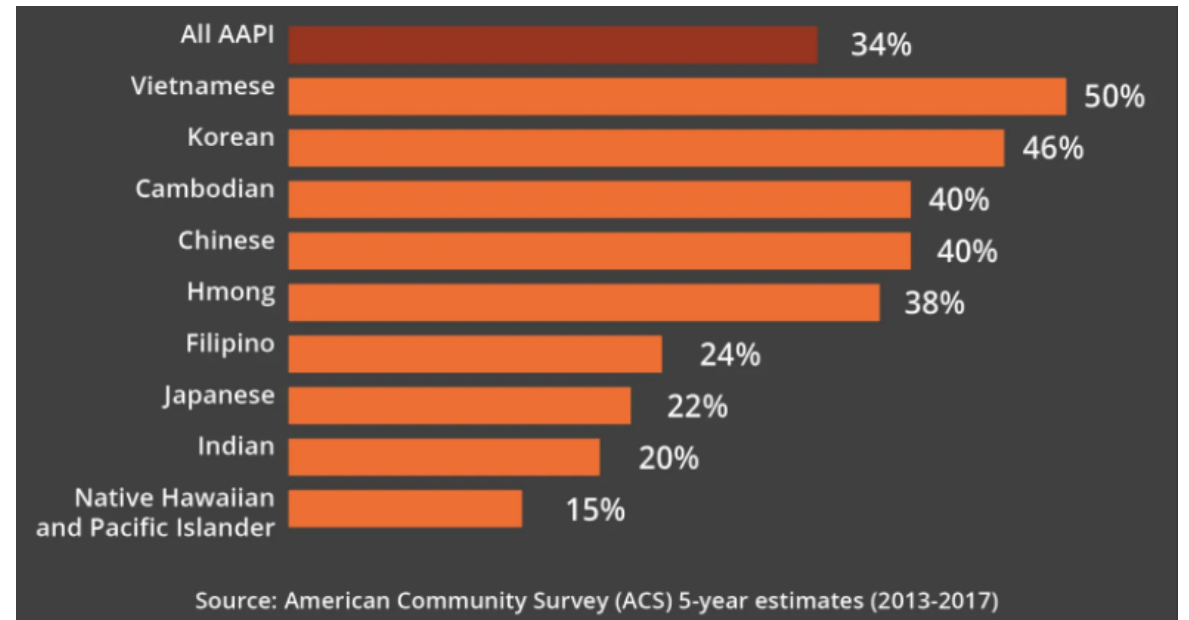
Asian Americans are the fastest growing racial group in the U.S.:¹

7.7% 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 Census Bureau: <https://www.census.gov/library/stories/2021/08/improved-race-ethnicity-measures-reveal-united-states-population-much-more-multiracial.html>

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

Background: Disparities in Research Participation for AAPI

- Clinical research projects focusing on AAPI participants funded by the National Institutes of Health (NIH) was less than 1% of its total budget between 1992 and 2018.¹
- Of the 44,713 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

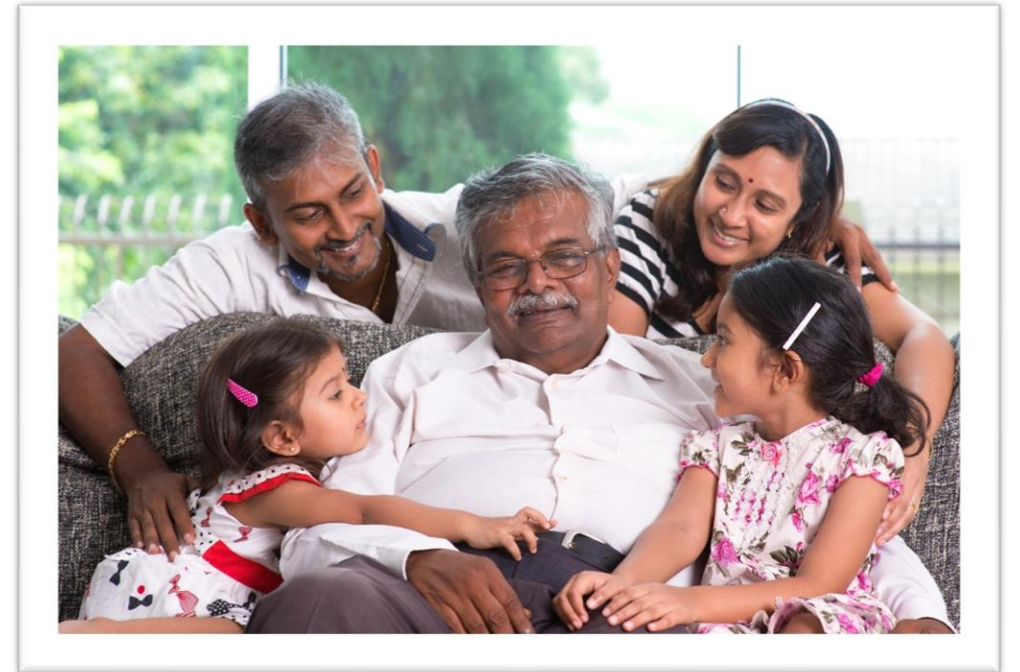


¹ Doan, Takata, Sakuma, & Irvin (2019). *JAMA Network Open*.

² National Alzheimer's Coordinating Center (NACC). Web-based Query System. 2018; <https://www.alz.washington.edu/WEB/naccquery.html>. Accessed February 8, 2022.

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 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!

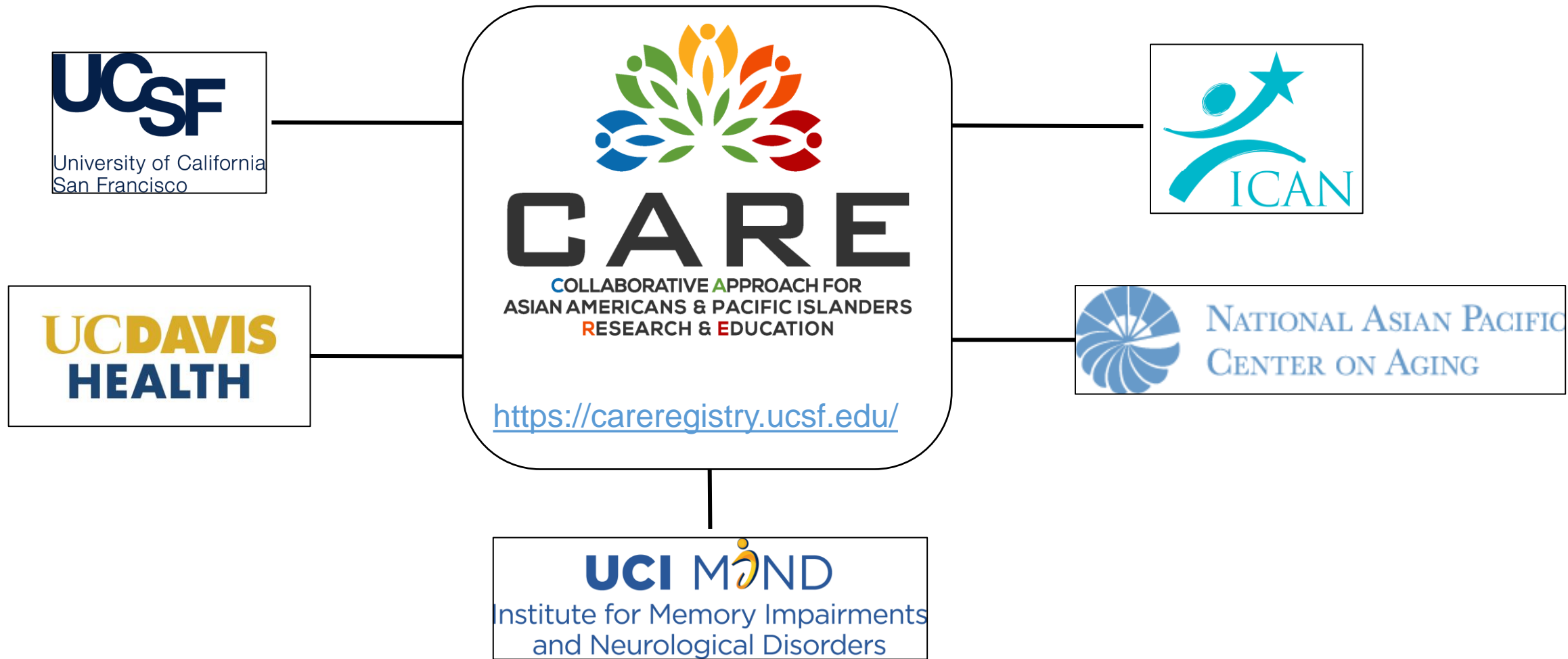


Overview of CARE Registry

Alka M. Kanaya, MD
CARE Co-Investigator

Division of General Internal Medicine,
UC San Francisco School of Medicine

CARE: Multi-Site Collaboration



CARE Partners & Community Advisory Board



CARE Registry

Who can enroll?

- AAPI
- 18+ years old
- Speak and/or read English, Chinese, Hindi, 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:

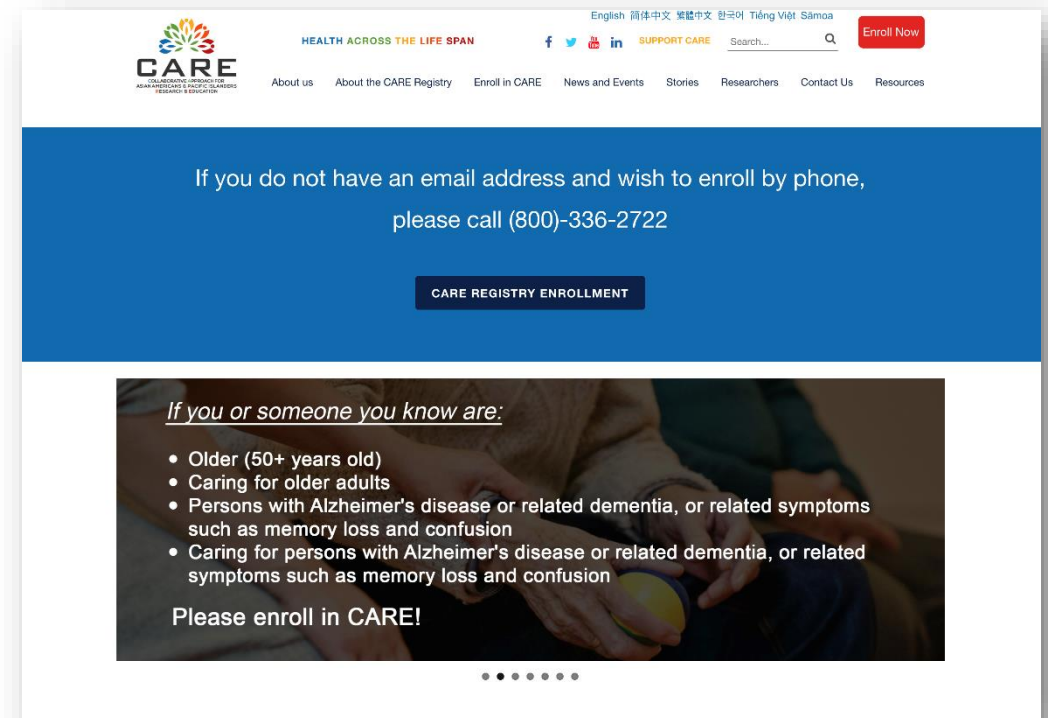
廣東話 / Cantonese (800) 582-4218 普通话 / Mandarin (800) 683-7427
한국어 / Korean (800) 582-4259 Tiếng Việt / Vietnamese (800) 582-4336



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

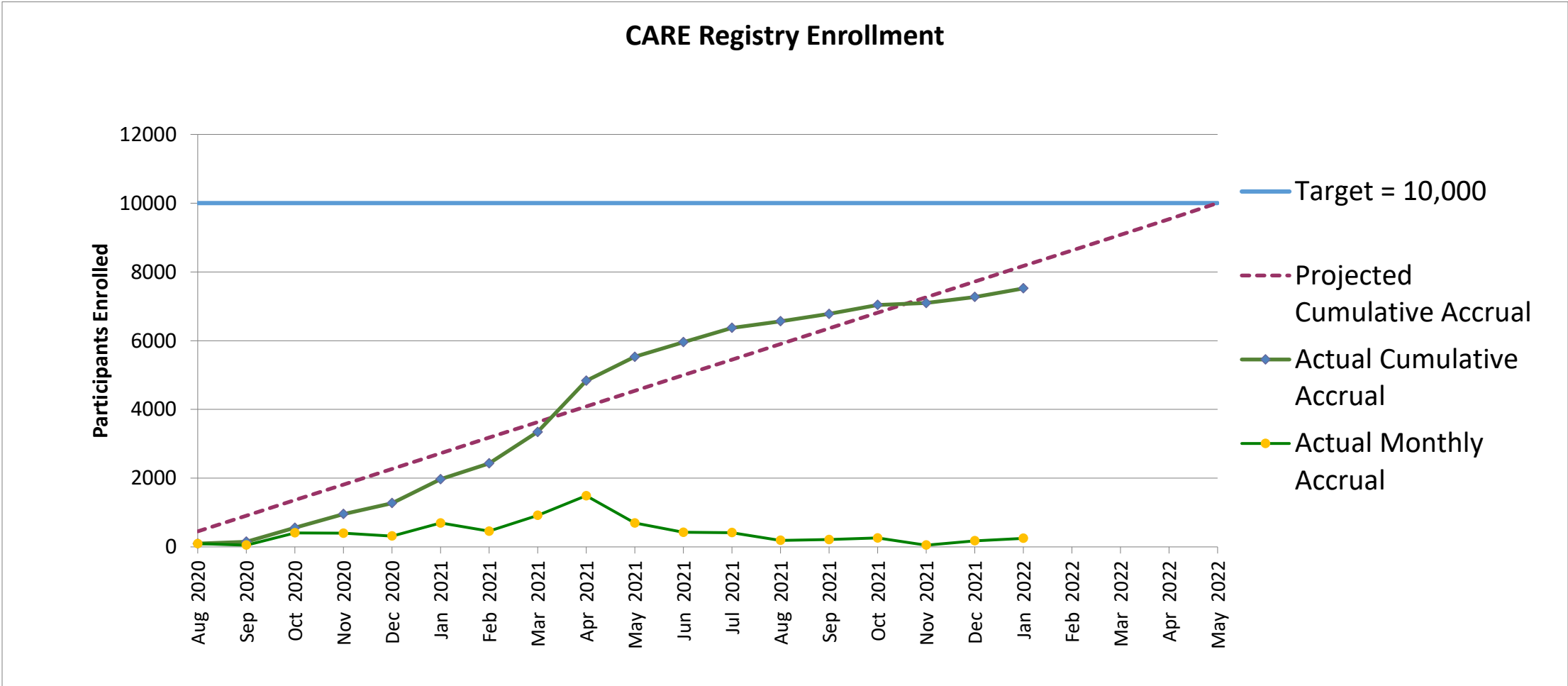
Health conditions (e.g., neurological disease and related symptoms such as Alzheimer's disease; heart disease; cancer; mood-related issues)

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

Caregiving experiences (if applicable)

CARE Enrollment:


N=7,615 as of Feb 13, 2021 (76% of our 10,000 target goal)




CARE Snapshot: N=7,615

 **84.5%** Born outside of U.S.

 **88.1%** Californian

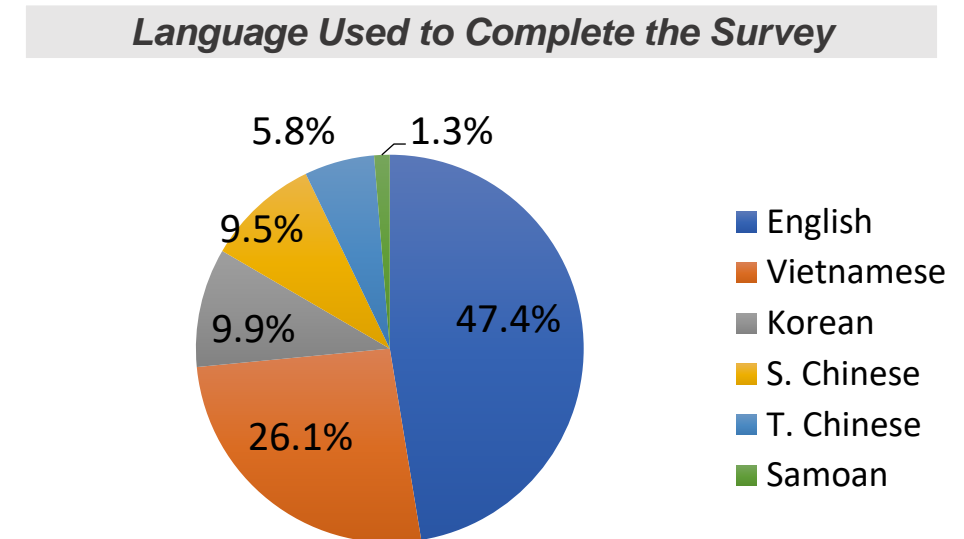
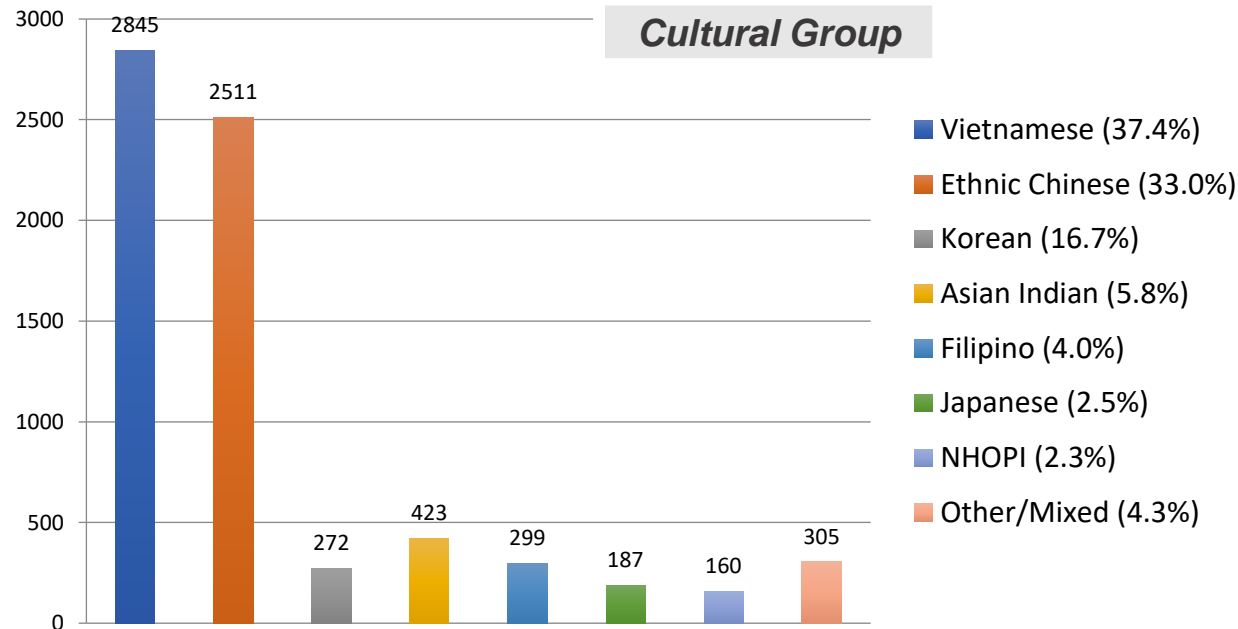
 **11.2%** Caregivers of older adults or person with special needs.

 Mean age = **53.5** (range 18-99)
Age over 65 = **32.0%**

 **63.2%** Female  **35.1%** Male

 **59.5%** Limited English proficiency

 **11.2%** (N=855) with ADRD symptoms



Profile of CARE Participants (N(%) or mean \pm SD)

	All (N=7,615)	Self-Reported ADRD (N=855)	ADRD Caregivers (N=311)
Age	53.5 \pm 17.2	63.0 \pm 15.1	53.7 \pm 13.43
Foreign-born	6,435 (84.5)	825 (96.5)	241 (77.5%)
Cultural groups			
Vietnamese	2,845 (37.4)	721 (84.3)	91 (29.3)
Ethnic Chinese	2,511 (33.0)	101 (11.8)	143 (46.0)
Korean	1,272 (16.7)	15 (1.8)	31 (10.0)
Asian Indian	423 (5.6)	10 (1.2)	24 (7.7)
Filipino	299 (3.9)	7 (0.8)	13 (4.2)
Japanese	187 (2.5)	10 (1.2)	23 (7.4)
NHPI	160 (2.1)	5 (0.6)	5 (1.6)
Mixed	78 (1.0)	6 (0.7)	4 (1.3)
Other	227 (3.0)	5 (0.6)	8 (2.6)

How to Use CARE

Joshua Grill, PhD
CARE Co-Investigator

UC Irvine Institute for Memory Impairments and Neurological Disorders

Main Ways to Use CARE

- Ask novel research questions about AAPI
 - Surveys of CARE participants
 - Recruitment of whole samples from CARE
- Recruit participants to increase diversity of a study population
- Recruit participants as a novel comparison group

Answer Novel Research Questions About AAPI

- Disseminate a survey to the CARE registrants
 - All CARE registrants
 - Specific CARE registrants (e.g., Chinese immigrants >65 years)
 - Compare within or across AAPI groups
- Utility:
 - Needs assessments
 - Preliminary data
 - Complete studies



Example Survey Study Design

- Hypothesis: Immigrants differ from second generation AAPI 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 AAPI born in this country to those born in another country for differences in willingness to participate in AD prevention research

Recruit AAPI to Your Study

- Recruit CARE registrants to your prospective study*
 - Answer specific questions about AAPI
 - Recruit AAPI CARE registrants to improve diversity in your sample
 - Recruit specific CARE registrants of interest to compare to other groups (e.g., non-Hispanic Whites)
 - Compare different AAPI groups



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

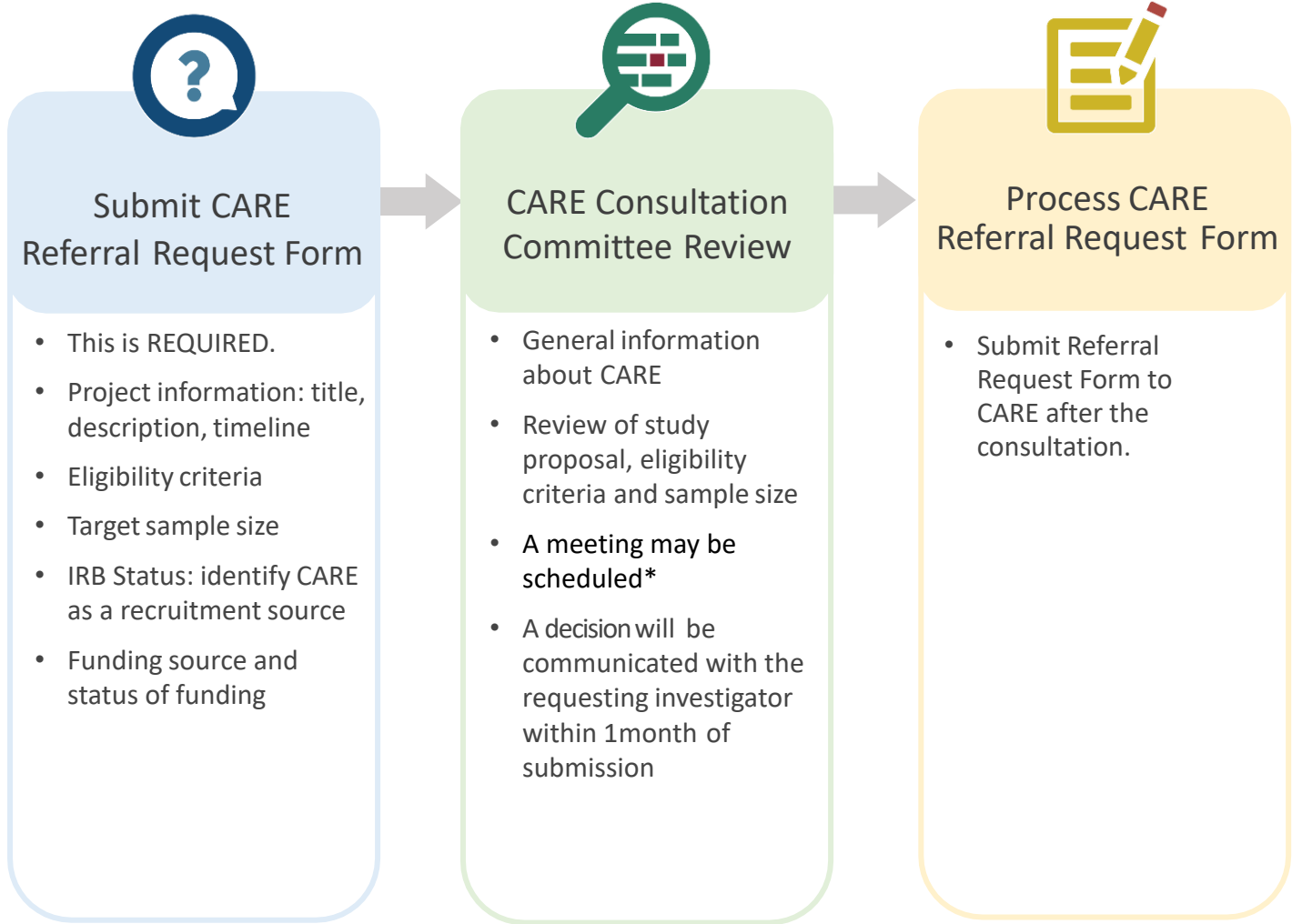
Example Study Recruitment


- 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

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
- It can assist in examining potential cultural and racial associations, hypothesis generation, and comparison studies
- It can improve recruitment of AAPI and assist in diversifying research

CARE-Supported Recruitment Steps 1-3





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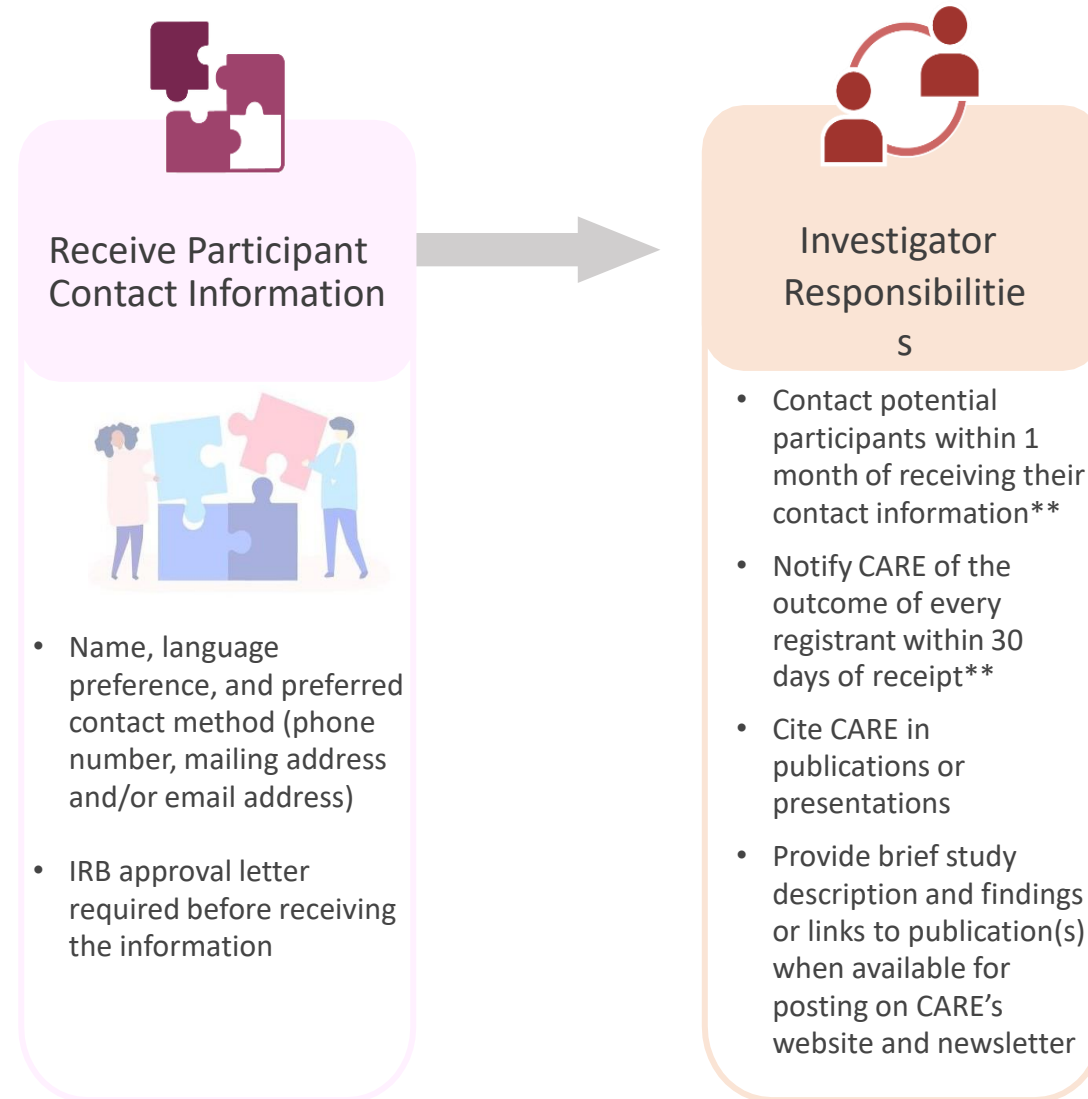
CARE Referral Request Form

Contact information	
Principal Investigator:	PI Email:
Study Contact:	Study Contact Email:
Study Information	
Study Title:	
<p>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 yan.tzuang@ucsf.edu to schedule it.)</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If "Yes", please fill out the sections below based on consultation with CARE.</p> <p>If "No", please fill out the sections below as appropriate.</p> <p>What kinds of assistance would you like to receive from the consultation?* (check all that apply)</p> <p><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</p> <p><input type="checkbox"/> Templates for emails and participant communication</p> <p><input type="checkbox"/> Other, please specify:</p> <p><small>*Consultation will be provided in the context of the CARE Registry.</small></p>	
<p>Study Recruitment Status:</p> <p><input type="checkbox"/> Ongoing</p> <ul style="list-style-type: none"> ClinicalTrials.gov ID (if applicable): Study website (if applicable): Other public access / study registration (if applicable): <p><input type="checkbox"/> Preparing for recruitment</p>	
<p>Asian Americans and Pacific Islanders (AAPI) Cultural Group of Interest:</p> <p><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</p> <p><input type="checkbox"/> Japanese <input type="checkbox"/> Native Hawaiian <input type="checkbox"/> Samoan <input type="checkbox"/> Taiwanese <input type="checkbox"/> Vietnamese</p> <p><input type="checkbox"/> Other AAPI cultural group(s), please specify:</p>	
<p>Study Description and Goals:</p>	

*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



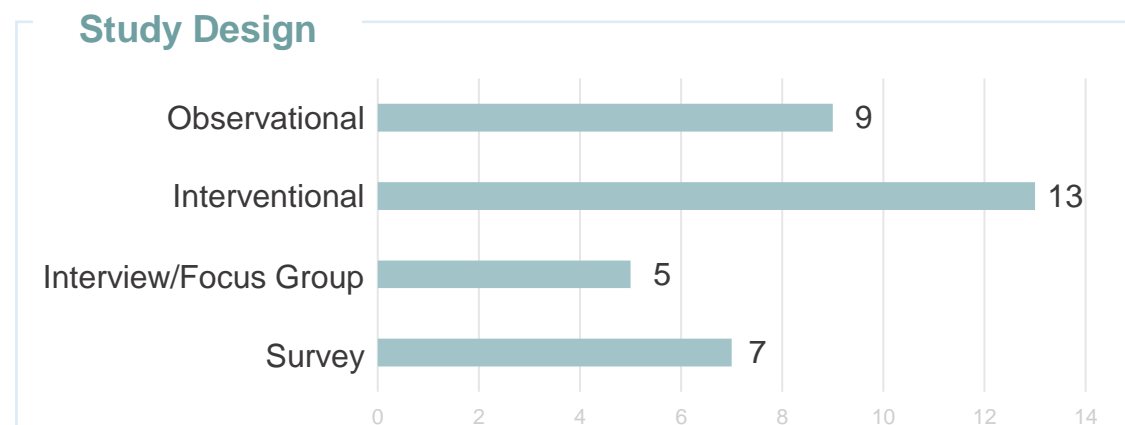
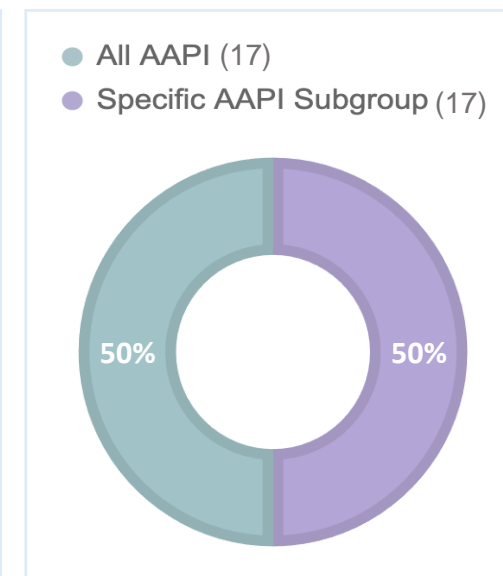
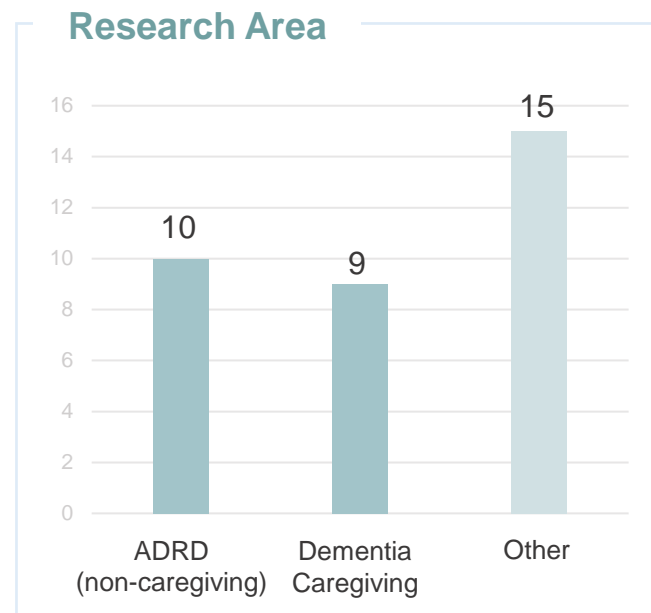
**This is a general guideline primarily for prospective and/or in-person studies. Investigator responsibilities may be discussed on a case-by-case basis for other types of study designs (e.g., surveys).

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.

CARE-Supported Recruitment Requests (N=34 as of February 25, 2022)

Institutions	# of request
UC San Francisco	14
Stanford University	4
University of Southern California	2
UC Davis	2
UC Los Angeles	1
UC Irvine	1
George Mason University	1
Texas State University	1
University of Houston	1
Montefiore Medical Center	1
University of Illinois at Urbana-Champaign	1
Korean Community Center of the East Bay	1
Oregon State University	1
University of British Columbia	1
Arizona State University	1
Dartmouth College	1



Community Perspectives in Research – Partnership with CARE

Heather Chun, MSW

CARE Community Advisory Board Member

National Asian Pacific Center on Aging (NAPCA)



Partnership with Communities Leads to Meaningful Inclusion

- Community-based organizations (CBOS) are the epicenter for research engagement of AANHPIs, especially for older adults
- Recruitment through trusted CBOs leads to meaningful inclusion
 - Language access enabled
 - Staff reflect communities targeted for recruitment; they have a strong desire to build representation of their community in research
- CBO research involvement supports strategic growth

Q&A + Raffles

Please complete our evaluation survey:

<https://tinyurl.com/CAREbraintrustFeb2022>



Acknowledgments

Thank you to all the registry participants!

UC San Francisco

Van Ta Park (PI)
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Marian Tzuang
Stuart Gansky (DCE)
Sarit Helman (DCE)
Niloufar Ameli (DCE)
CARE Interns

UC Davis

Oanh L. Meyer (Site PI)
Ladson Hinton (Co-I)
Anna Bach
Duyen Thi Ky Tran

UC Irvine

Joshua D. Grill (Site PI)
Ruobing Li
Hye-Won (Grace) Shin

Stanford University

Dolores Gallagher-Thompson (Co-I)

ICAN

Quyen Vuong (Site PI)
Isabella Luong
Anne Phan
Cecilia Phan

NAPCA

David Kim (Site PI)
Heather Chun
Dyanna Chung

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