Partnership for Cancer Health Disparities Research

Sora Park Tanjasiri, DrPH, MPH
Professor, UCI Department of Epidemiology
Associate Director, Cancer Health Disparities & Community Engagement
UCI Chao Family Comprehensive Cancer Center

ICTS CHRE July 26, 2019



PRESENTATION OBJECTIVES

By the end of this lecture, you will:

- 1. Increase your understanding of cancer health disparities and community-based participatory research (CBPR)
- 2. Describe strategies that promote cancer health behaviors in community-based settings
- Identify five strategies to cultural targeting/tailoring of health interventions
- 4. Explore the strengths and limitations of CBPR

CANCER HEALTH DISPARITIES

Cancer health disparities are adverse differences between certain populations groups, such as incidence (new cases), prevalence (existing cases), morbidity (cancer-related health complications), mortality (deaths), survivorship and quality of life after cancer treatment, burden of cancer or related health conditions, screening rates, and stage at diagnosis.

These population groups may be characterized by race, ethnicity, disability, gender and sexual identity, geographic location, income, education, and other characteristics.

WHAT ARE CANCER HEALTH DISPARITIES?

Cancer health disparities are defined by the National Cancer Institute as adverse differences in cancer measures such as number of new cases, number of deaths, cancer-related health complications, survivorship and quality of life after cancer treatment, burden of cancer or related health conditions, screening rates, and stage at diagnosis that exist among certain segments of the population (11), including:

racial and ethnic minority groups;





individuals of different ancestry;



individuals of low socioeconomic status;



individuals who lack or have limited health insurance coverage;



residents in certain geographic locations, including rural areas;



immigrants;



members of the lesbian, gay, bisexual, and transgender community;



refugees or asylum seekers;





individuals with disabilities;



adolescents and young adults; and

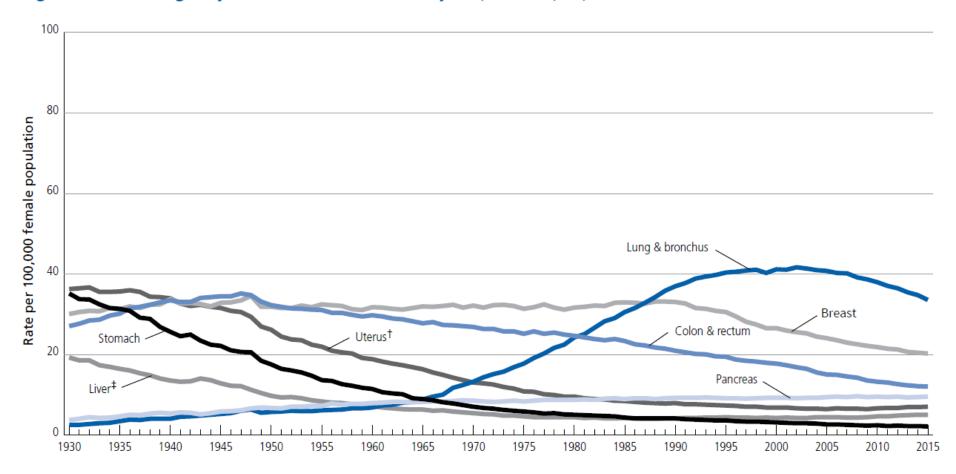


the elderly.



dapted from (1)

Figure 2. Trends in Age-adjusted Cancer Death Rates* by Site, Females, US, 1930-2015



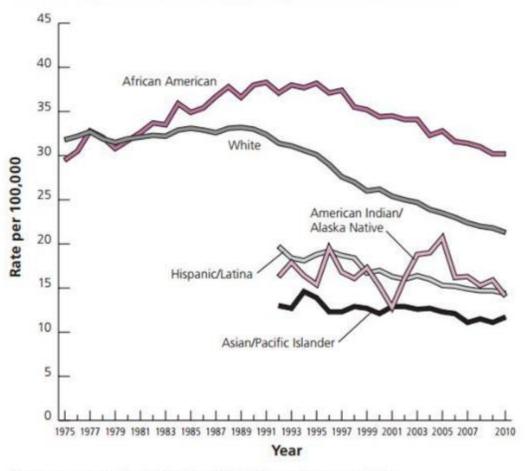
^{*}Age adjusted to the 2000 US standard population. †Uterus refers to uterine cervix and uterine corpus combined. ‡The mortality rate for liver cancer is increasing.

Note: Due to changes in ICD coding, numerator information has changed over time. Rates for cancers of the liver, lung and bronchus, colon and rectum, and uterus are affected by these coding changes.

Source: US Mortality Volumes 1930 to 1959, US Mortality Data 1960 to 2015, National Center for Health Statistics, Centers for Disease Control and Prevention.

©2018, American Cancer Society, Inc., Surveillance Research

Figure 5b. Trends in Female Breast Cancer Death Rates* by Race and Ethnicity, US, 1975-2010



^{*}Rates are age adjusted to the 2000 US standard population.

Source: National Center for Health Statistics, Centers for Disease Control and Prevention, as provided by the Surveillance, Epidemiology, and End Results Program, National Cancer Institute. Rates for American Indians/Alaska Natives are based on data from the Contract Health Service Delivery Area (CHSDA) counties. For Hispanics, mortality rates do not include data from Connecticut, Maine, Maryland, Minnesota, New Hampshire, New York, North Dakota, Oklahoma, Vermont, and the District of Columbia.

American Cancer Society, Surveillance and Health Services Research, 2013

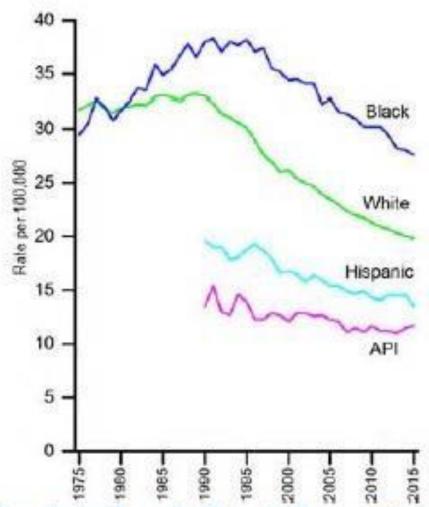


FIGURE 8. Trends in Female Breast Cancer Mortality Rates by Race/Ethnicity, United States.

Rates are per 100,000 females and are age adjusted to the 2000 US standard population. Data are not shown for American Indians/Alaska Natives because of unstable rates, reflecting small numbers of deaths. API, Asian/Pacific Islander. Source: National Center for Health Statistics, Centers for Disease Control and Prevention, 2017.

WHY DO CANCER HEALTH DISPARITIES EXIST?



WHY DO CANCER HEALTH DISPARITIES EXIST?

Complex and interrelated factors contribute to U.S. cancer health disparities.

The factors may include, but are not limited to, differences and/or inequalities in:

access to and use of health care;



treatments received;



exposure to environmental cancer risk factors:



genetics;



social and economic status;



clinical trial participation;



physical and mental health;



cultural beliefs;



health literacy; and



lifestyle, including weight, diet, and physical activity.

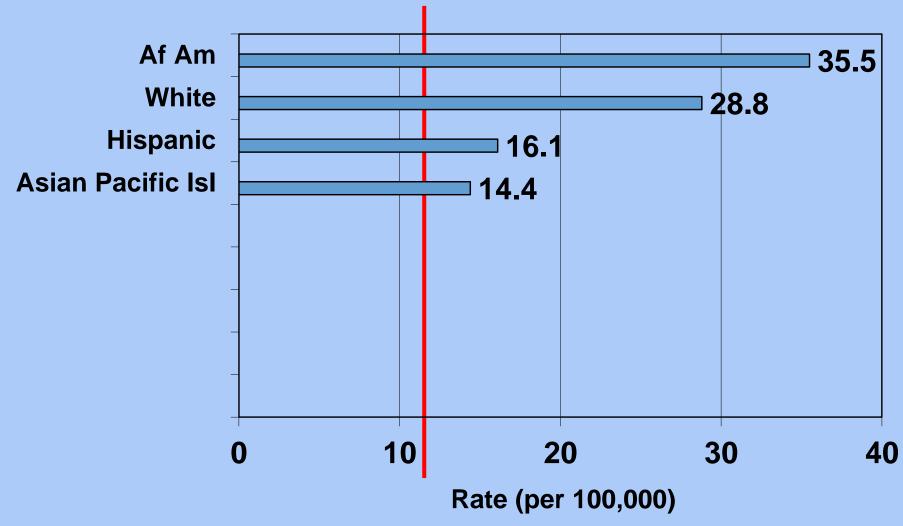






Adapted from (18)

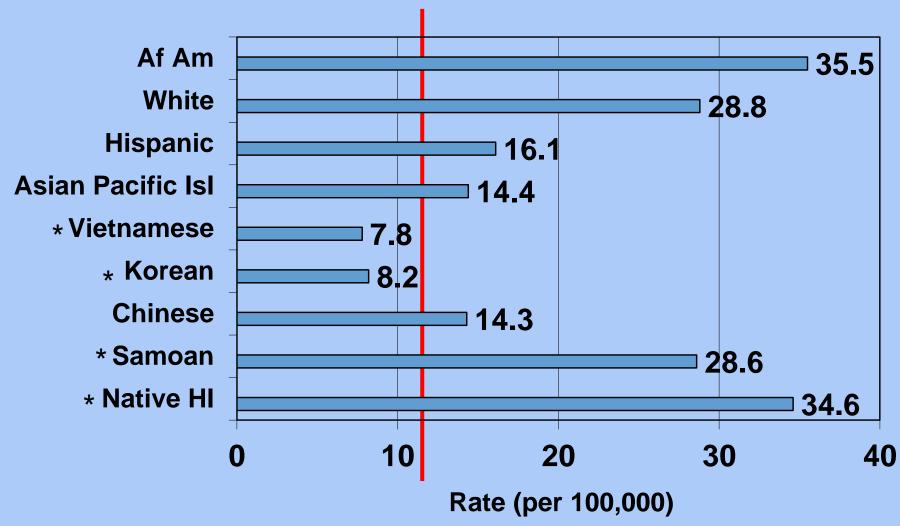
Breast Cancer Mortality in California



— Denotes Healthy People 2010 Target (22.3 per 100,000)

Data from the California Department of Health Services, Sentinel Health Indicators for California's Multicultural Populations, 1991-2001, CA: Center for Health Statistics, May 2004.

Breast Cancer Mortality in California



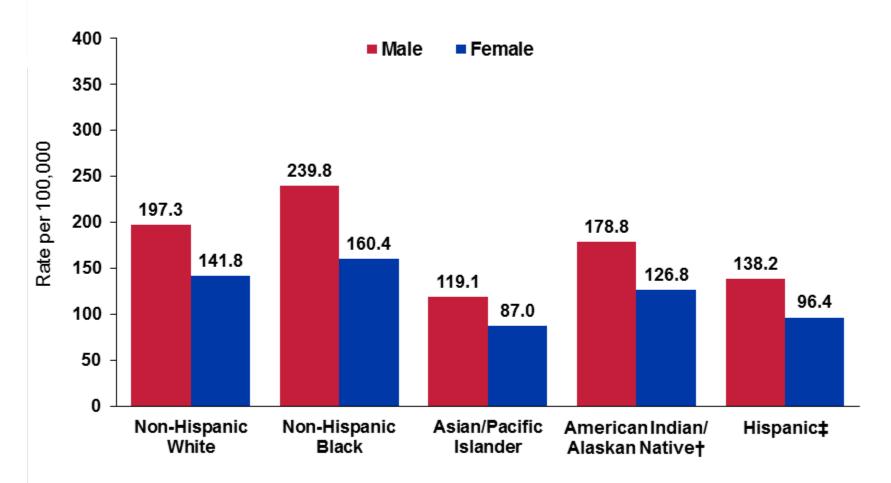
⁻ Denotes Healthy People 2010 Target (22.3 per 100,000)

Data from the California Department of Health Services, Sentinel Health Indicators for California's Multicultural Populations, 1991-2001, CA: Center for Health Statistics, May 2004.

^{*} Unreliable rate, Relative Standard Error (RSE) greater than 23 percent.

Cancer Death Rates* by Race and Ethnicity, US, 2012-2016

Cancer Facts & Figures (American Cancer Society, 2019)

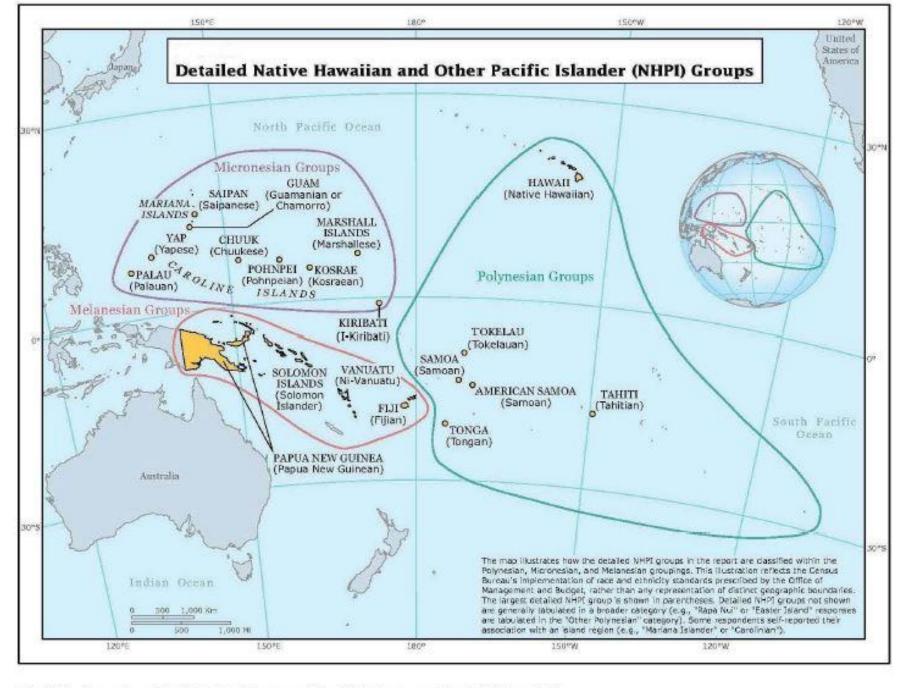


^{*}Per 100,000, age-adjusted to the 2000 US standard population. †Data based on Indian Health Service Contract Health Service Delivery Area counties. *Persons of Hispanic origin may be of any race.

Sources: National Center for Health Statistics, Centers for Disease Control and Prevention, 2018.

PROMOTING CANCER HEALTH BEHAVIORS IN COMMUNITY SETTINGS







PACIFIC ISLANDER CULTURE

- Families are extended with many social connections (e.g., Hawaiian ohana, Samoan aiga) (Palafox & Warren, 1980)
- Health is defined holistically, including balance between physical, mental, and spiritual (e.g., Hawaiian lokahi) (Wong et al., 2004)
- Traditional diets are rich in low-fat, high-complex carbohydrate plant and fish-based foods (Blaisdell, 1996)
- Traditional livelihoods are very physically active, including fishing and agriculture, and the importance of dance

THERE ARE OVER 221,458 PACIFIC ISLANDERS IN CALIFORNIA

	2000 California						
			% < HS		< 200%	% Pub	
	Alone	Inclusive	deg	FPL**	FPL	Assist	***
Native							
Hawaiian	20,571	60,048	14%	11%	27%	5%	3%
Samoan	37,498	49,804	22%	20%	45%	12%	17%
Chamorro/							
Guamanian	20,918	33,849	20%	10%	29%	6%	9%
Tongan	12,111	15,252	40%	18%	44%	10%	32%
NH Whites	15,816,790	16,538,491	10%	8%	20%	3%	3%

^{*} US Census 2000

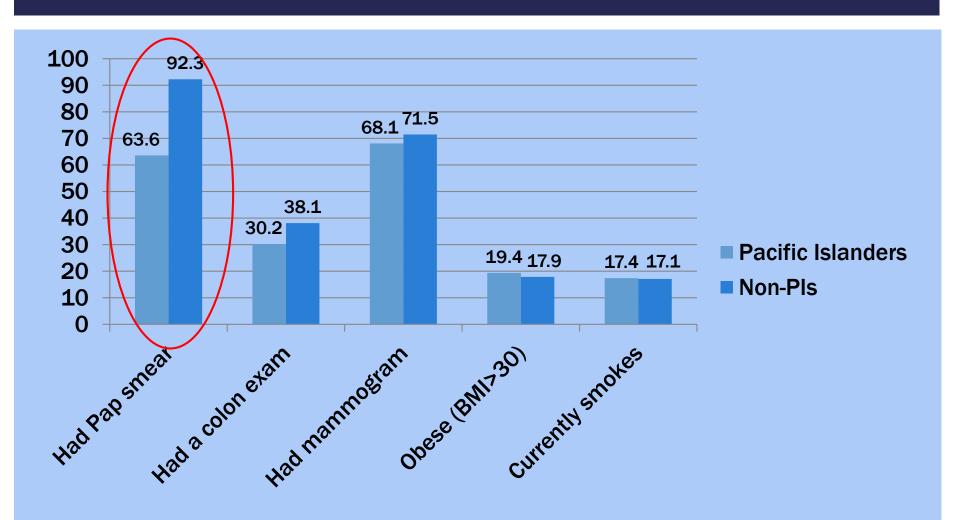
^{**} Federal Poverty Line

^{***} Limited English Proficient

PACIFIC ISLANDERS AND CERVICAL CANCER

- Cervical cancer is the 4th most common cause of cancer mortality among Pacific Islanders
- Age-adjusted incidence rates:
 - Samoans 15.1/100,000
 - Native Hawaiians 12.3/100,000
 - Whites 9.3/100,000
- 60% of cervical cancers among Samoans and Native Hawaiians were found at more advanced (regional/distant) stages
- Pap testing is the most important cervical cancer prevention, but Pacific Islanders have low rates (46-71%) of Pap testing compared to HP2020 goal of 93%

PACIFIC ISLANDER CANCER RISK IN SOUTHERN CALIFORNIA (2001)



California Health Interview Survey, 2001

COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)

Community
Leaders & Members

Academic
Researchers

- Collaborative approach to research
- Close partnerships between academic researchers and members of underserved communities
- Partners contribute expertise, share decision making and ownership of the research endeavor
- The aim is to increase knowledge and understanding of a given phenomenon leading to the development and testing of interventions to improve the health and quality of life of communities

SUPPORTING OUR WOMEN (SOW) STUDY: PARTNERSHIPS

Community Leaders & Members CBPR

NCI grant number 5R01CA149324-05

Academic Researchers

Guam Communications Network

Orange County Asian and Pacific Islander Community Alliance

Pacific Islander Health Partnership Samoan National Nurses Association Tongan Community Service Center/SSG



California State University, Fullerton



Multiple Pls: Lola Sablan-Santos & Sora Tanjasiri



SUPPORTING OUR WOMEN STUDY: PARTNERSHIP

Guam Communications Network

Lola Sablan-Santos Lou Quitugua
Perci Flores Pete Flores

1 0101 1 10100

Samoan National Nurses Association

Dorothy Vaivao Genesis Lutu

Marina Tupua Peni Taito

Caroline Pele*

Tongan Community Service Center / SSG

Vanessa Tuione-May

Elenoa Vaikona Isi Vunileva

Orange County Asian & Pacific Islander Community Alliance

Mary Anne Foo Jason Lacsamana

California State University, Fullerton

Sora Park Tanjasiri Michele Mouttapa
Jie Weiss Ciara Paige

Ualani Ho`opai

Jasmine DeGuzman Lacsamana

Community Advisory Board members

Lolini Vaimaona Albert Van Meter

Tamara Tavai Sione Holakeituai

Nuuausala Gafa Tina Holakeituai

Peka Petaia Katalina Fehoko

Nerisa Laufili Time Laulile Fehoko

Christina Dorame Akanesi Fehoko

Viola Johnson Setaleki Fehoko

Paua Manuatu (Tuisoso)

Semisi Uhi Joe Vaivao

Faleiva Seti Pauliasi Taufa













SUPPORTING OUR WOMEN STUDY: STUDY DESIGN

- Longitudinal randomized community trial with intervention vs. wait-list controls to increase Pap testing among Pacific Islander women in Southern California
- Targeted married Chamorro, Samoan and Tongan women age 21-65 years old
- Included their husbands
- Used CBPR in all aspects of the study design, implementation and evaluation





CULTURAL TARGETING/TAILORING

Five strategies for targeting of health promotion programs:

- Peripheral gives the appearance of cultural appropriateness to increase appeal (e.g., use of colors, images, fonts, pictures of group members, etc)
- **Evidential** incorporates evidence of impact on a group to enhance perceived relevance (e.g., mortality data for that specific group)
- Linguistic use of the dominant language to increase accessibility of the program (e.g., no Tongan word for cervix)
- Constituent involving draw on the experience of group members by including them in the planning and decision making of the program (e.g., CBPR)
- Sociocultural places the health-related topic within the context of the broader social and/or cultural values of the group (e.g., collectivism)

SUPPORTING OUR WOMEN STUDY: INTERVENTION

- WOMEN: Get Pap tests to stay healthy for your family
- MEN: Encourage your spouse to get Pap tests because you love her
- Materials
 - Brochure
 - PowerPoint
 - Video

http://youtu.be/0fX4M2OMKF8

Booster/reminder & magnet calendar





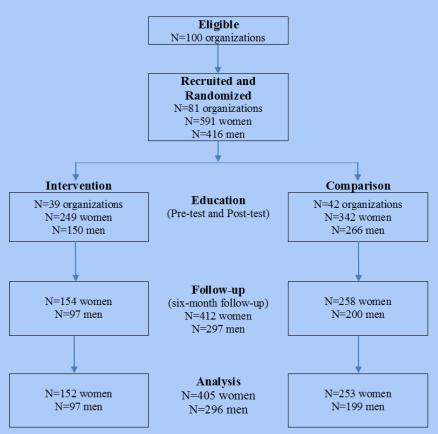
WHAT CULTURAL TARGETING STRATEGIES WERE USED?

- Peripheral?
- Evidential?
- Linguistic?
- Constituent-involving?
- Sociocultural?



SUPPORTING OUR WOMEN STUDY: METHODS

Figure 1: CONSORT Flow Diagram



- •Questionnaires: Completed prior to receiving the intervention (Pre-test), immediately after completing the intervention (Post-test1), and 6 months after completing the intervention (Post-test2).
- •Measures: Included demographics, Pap knowledge, attitudes, beliefs, behaviors, social support, and social desirability.
- •GLM mixed models with repeated measures were computed to determine intervention vs. comparison group changes.

Table 1. Baseline Characteristics

	Women (n=591)	Men (n-416)
Age (in years 21-39 30-39 40-49 50+	122 (20.8) 120 (20.4) 163 (27.7) 182 (31.0)	81 (20.0) 90 (22.3) 96 (23.8) 137 (33.9)
Employed	312 (58.3)	267 (65.9)
Has health insurance	461 (78.8)	298 (72.9)
Language at home PI only More PI PI/English More English English only	30 (5.2) 53 (9.2) 250 (43.2) 128 (22.1) 118 (20.4)	27 (6.6.) 44 (10.7) 157 (38.2) 80 (19.5) 103 (25.1)
Pap compliant	311 (53.2)	94 (32.0)
Pap intention	144 (52.7)	297 (74.4)

- Insurance status was significantly higher among intervention women compared to control women.
- There were no other statistically significant differences betweenintervention and control women and men.

SUPPORTING OUR WOMEN STUDY: 6-MONTH OUTCOMES

	Intervention		Comparison		Fixed Effects			
	Pre-test	Follow-up	Pre-test	Follow-up	Intervention vs.	Health	Acculturation	
					Comparison	Insurance	to the US	
					Group	Coverage		
	n	n	n	n	β	β	β	
	M	M	M	M	SE	SE	SE	
	SD	SD	SD	SD	95% CI	95% CI	95% CI	
					р	р	р	
Women's	135	135	218	218	.134	.452	.097	
knowledge	5.08	6.39	5.28	6.08	.286	.232	.046	
	2.56	2.53	3.04	2.64	428, .696	004, .908	.008, .186	
					.640	.052	.034	
Women's	129	129	211	211	109	185	059	
fatalistic	1.08	0.71	1.19	0.84	.146	.097	.019	
attitudes	1.08	1.10	1.28	1.20	395,176	376,006	10,02	
					.452	.058	.002	
Women's	135	135	225	225	.802	771	.607	
perceived	50.21	50.61	52.29	51.20	.881	.782	.151	
social	9.99	9.69	8.56	10.37	926, 2.53	-2.307, .764	.310, .903	
support					.363	.324	.000	
Men's	103	103	99	99	.515	N/A	N/A	
knowledge	3.17	5.77	3.84	5.38	.524			
	2.69	2.59	2.79	3.03	520, 1.549			
					.328			

• Regardless of group, women increased their knowledge and decreased fatalistic attitudes about cervical cancer, and men increased their knowledge



SUPPORTING OUR WOMEN STUDY: 6-MONTH OUTCOMES

	Intervention	Comparison	Fixed Effects						
			Intervention vs. Comparison Group	Health Insurance Coverage	Acculturation to the US				
	n (%)	n (%)	B (SE) 95% CI p	B (SE) 95% CI	B (SE) 95% CI p				
Only women not comp	Only women not compliant with Pap tests at pre-test								
Scheduled Pap test	41 (55.4)	43 (40.2)	.757 (.403) -0.04, 1.553 .062	.068 (.366) 655, .791 .853	.016 (.080) 142, .174 .840				
Received Pap tests	38 (51.4)	37 (34.9)	.820 (.451) 071, 1.171 .071	.044 (.391) 728, .816 .910	.115 (.086) 055, .286 .184				
Man talked to woman about Pap test ¹	38 (73.1)	45 (53.6)	.153 (.560) 959, 1.264 .785	N/A	N/A				
Man encouraged woman to get Pap test ¹	35 (71.4)	43 (52.4)	.354 (.525) 689, 1.396 .502	N/A	N/A				

¹ Analyses were adjusted for men's report at pre-test that they had, at least once, recommended to their wife/female partner to have a Pap test.

Women in the intervention group were more likely to have scheduled and to have received a Pap test compared to women in the comparison group.



High community engagement

Positive outcomes

Strength of cultural targeting

Wide dissemination to wait-list controls

WHAT DO YOU THINK WERE THE STRENGTHS & LIMITATIONS

Relied on self-reported Pap test behavior

Retention: overall 25%

loss to follow-up

Recruitment took time and multiple meetings

Uncertain generalizability



SUPPORTING OUR WOMEN STUDY: LESSONS LEARNED

- Importance of working with church and clan leaders to show respect regardless of denomination or clan ties
 - Ability to be flexible to accommodate schedules
 - Neutrality of community organizations and study staff
- Providing food at all recruitment and education activities as show of appreciation to organizations and individuals
- Emphasis on helping women and men overcome their reluctance to talk about the taboo subject of cervical cancer
 - Adding humor to all presentations
- Importance of wider dissemination: toolkit available at http://wincart.fullerton.edu

SUPPORTING OUR WOMEN STUDY: ACKNOWLEDGEMENTS

Guam Communications Network

Lola Sablan-Santos Lou Quitugua
Perci Flores Pete Flores

Samoan National Nurses Association

Dorothy Vaivao Genesis Lutu

Marina Tupua Peni Taito

Caroline Pele*

Tongan Community Service Center / SSG

Vanessa Tuione-May

Elenoa Vaikona Isi Vunileva

Orange County Asian & Pacific Islander Community Alliance

Mary Anne Foo Jason Lacsamana

California State University, Fullerton

Sora Park Tanjasiri Michele Mouttapa Jie Weiss Ciara Paige

Ualani Ho`opai

Jasmine DeGuzman Lacsamana

Community Advisory Board members

Lolini Vaimaona Albert Van Meter

Tamara Tavai Sione Holakeituai

Nuuausala Gafa Tina Holakeituai

Peka Petaia Katalina Fehoko

Nerisa Laufili Time Laulile Fehoko

Christina Dorame Akanesi Fehoko

Viola Johnson Setaleki Fehoko

Paua Manuatu (Tuisoso)

Semisi Uhi Joe Vaivao

Faleiva Seti Pauliasi Taufa













COMMUNITY-UNIVERSITY CANCER CBPR JOURNEY

OCAPICA, FiGH, UPAC, Stonesoup and UCLA get together to plan CBPR project

Community and researchers meet and decide to promote BC education in the Hmong community

In Hmong woman dies in Long Beach from breast cancer (BC) (1995)



OCAPICA and UCLA receive CA BCRP grants to develop and test BC materials and — education (1999-2002)

OCAPICA, CSUF
and UCLA receive
CDC REACH 2010
grant to build
larger coalition
with seven Asian and Pacific Islander
communities
(1999-2005)

OCAPICA, CSUF, and UCLA receive CDC CEED grant to disseminate best practices across the U.S. (2005-2010)

OCAPICA and CSUF receive NIH
WINCART grant to promote education, research and training for Pacific Islanders (2005-2016)

RWJ ACCT

CDC REACH 2010

OMH Men's Health

TCE PI Health

Komen









SOW Pap

Thank you & Questions

Sora Park Tanjasiri, DrPH, MPH
Professor, UCI Department of Epidemiology
Associate Director, Cancer Health Disparities & Community Engagement
UCI Chao Family Comprehensive Cancer Center
tanjasir@uci.edu

