

Developing a Community-Based Collaboration to Reduce Cancer Health Disparities among Pacific Islanders in California

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Abstract

Cancer is a leading cause of death for Asians and Pacific Islanders in the United States, but education and research efforts addressing the needs of Pacific Islanders in the continental U.S. is sparse. The purpose of this paper is to describe the development of a community-based participatory research network dedicated to addressing cancer health disparities among Chamorros, Marshallese, Native Hawaiians, Samoans and Tongans in Southern California. Community-based organizations (CBO) comprise the focus of the network, and their efforts have included increasing cancer-related awareness in their communities, developing capacities regarding cancer control, and initiating collaborative research efforts with academic partners. First year processes and outcomes are described, and specific examples are given from two CBO partners. (PHD 2007 Vol 14 No 1 Pages 57 - 65)

Introduction

This article describes the development of a community-based participatory research (CBPR) network dedicated to addressing cancer health disparities among Chamorros, Marshallese, Native Hawaiians, Samoans and Tongans residing in Southern California. Funded by the Center to Reduce Cancer Health Disparities of the National Cancer Institute (NCI), "Weaving an Islander Network for Cancer Awareness, Research and Training (WINCART)" involves a partnership between individuals from eight community-based organizations (CBO) serving Pacific Islanders and five universities. All WINCART efforts are based upon CBPR principles, which stress shared participation, cooperative engagement of community and university researchers

in processes of co-learning, systems and capacity development, and empowering processes that involve both research and action for community change.¹ We will describe WINCART's origins, our first year activities and achievements, and highlight case examples of community-based capacity building within two member CBO.

Background

Pacific Islanders in the continental U.S. are as diverse as their islands of origin, each having different reasons for leaving their home islands and coming to the continental United States. For example, migration from Tonga (an independent kingdom in the South Pacific) began in the mid-1970s, spurred by opportunities for higher education and/or jobs that could generate income to support families back home.² In contrast, migration from the Federated States of Micronesia and the Republic of the Marshall Islands was initiated after signing the Compact of Free Association in the mid-1980s, which allowed for open migration between the islands and the continental U.S. According to Census 2000, 874,414 Native Hawaiian and other Pacific Islanders were living in the U.S. (alone or in

combination with one or more other races). With 221,458 Pacific Islander residents, California is second only to Hawai'i as the state with the largest Pacific Islander population. In large part, this is due to California's geographic proximity to Hawai'i, American Samoa and other Pacific Island nations, as well as its large military bases, which have attracted Pacific Islanders, such as those from Guam and Hawai'i, with ties to the U.S. military. Southern California has become home to many Pacific Islanders, with concentrations of Samoans in the cities of Carson and San Diego, Tongans in Gardena, Marshallese in Costa Mesa, and Chamorros in Long Beach and San Diego. Although Pacific Islander social groups and religious organizations (e.g., churches) have been established in each of these cities, there are still relatively few culturally appropriate social service agencies to meet the health needs of these growing and largely underserved populations.

While data on cancer rates or needs of Pacific Islanders in the continental U.S. are sparse, available evidence universally points to critical needs for this diverse group. Among the primary factors associated with cancer onset, several are of particular concern for Pacific Islanders. In California, combined data from the 2001 and 2003 California Health Interview Surveys indicate that 30.4% of adult Pacific Islanders in Southern California (defined as the six counties of Imperial, Los Angeles, Orange, Riverside, San Bernardino and San Diego) were obese, with a body mass index ≥ 30 compared to only 19.8% of the non-Pacific Islander adult population.³ Studies have also documented high rates of tobacco use among Pacific Islanders. In Southern California, significantly more adult Pacific Islanders are current smokers (27.2%) compared to their non-Pacific Islander counterparts (16.9%).³

Pacific Islanders in the continental U.S. also face challenges in obtaining services across the cancer care continuum. In Southern California, Pacific Islanders have lower rates of screening for colon, breast and cervical cancers compared to non-Pacific Islanders. Of Pacific Islander women ages 40 and older in Southern California, 19.2% report never having had a mammogram compared to 11.1% of non-Pacific Islanders, and 18.9% of Pacific Islander women 18 and older were more likely to report never having had a pap test in comparison to 7.6% of non-Pacific Islanders.³ Other studies highlight cancer screening disparities within particular Pacific Islander ethnic groups. In the first study of Chamorro women in Southern California,

only 37% of participants had ever performed a breast self-examination (BSE), with 77% having obtained a mammogram.⁴ Studies of female Samoans residing in Hawai'i and California found that only 33% had ever received a mammogram and only 63% had ever had a pap smear.^{5,6} Tongans in California face considerable barriers (such as lower insurance coverage and higher language barriers) with baseline screening rates of only 40% for women who had ever performed BSE, 26% who had ever received a clinical breast exam, and 25% who had ever obtained a mammogram.⁷ Focus groups and interviews with Samoan and Tongan women in California identified barriers to obtaining mammogram and Pap tests, including cost, lack of transportation, lack of someone to accompany them to the tests, and difficulty communicating with doctors. The majority of women in both communities stated that mobile screening units

would facilitate their obtaining regular exams.⁸ These studies underscore the lower general screening rates with higher incidence and death rates from cancer among Pacific Islanders in California. In contrast, a study in Hawai'i found that Native Hawaiian women had higher mammography (50%) and pap smear (91%) rates, which suggests that the lack of availability of culturally appropriate services may be a major barrier to screening in the continental

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Published studies of follow-up care disaggregating ethnic Pacific Islanders on the continental U.S. are non-existent, and point to another gap in scientific knowledge. In addition, institutional barriers exist that place Pacific Islanders at high risk for fragmented cancer care in the U.S. For example, while nearly 17.3% of Pacific Islanders in the U.S. are linguistically isolated (in which no household member over the age of 14 has English proficiency), there is lack of institutional support of and adherence to existing legal mandates pertaining to language access (e.g., Title VI of the Civil Rights Act) and cultural standards for care, such as the U.S. Department of Health and Human Services Culturally and Linguistically Appropriate Services recommendations. One unpublished study in California found that while nearly 9% of medical providers surveyed included ethnic Samoan among their patient population, only 1% had Samoan language-specific interpreters,¹⁰ a contributing factor to Pacific Islanders being disproportionately affected by cancer health disparities across the cancer care continuum.

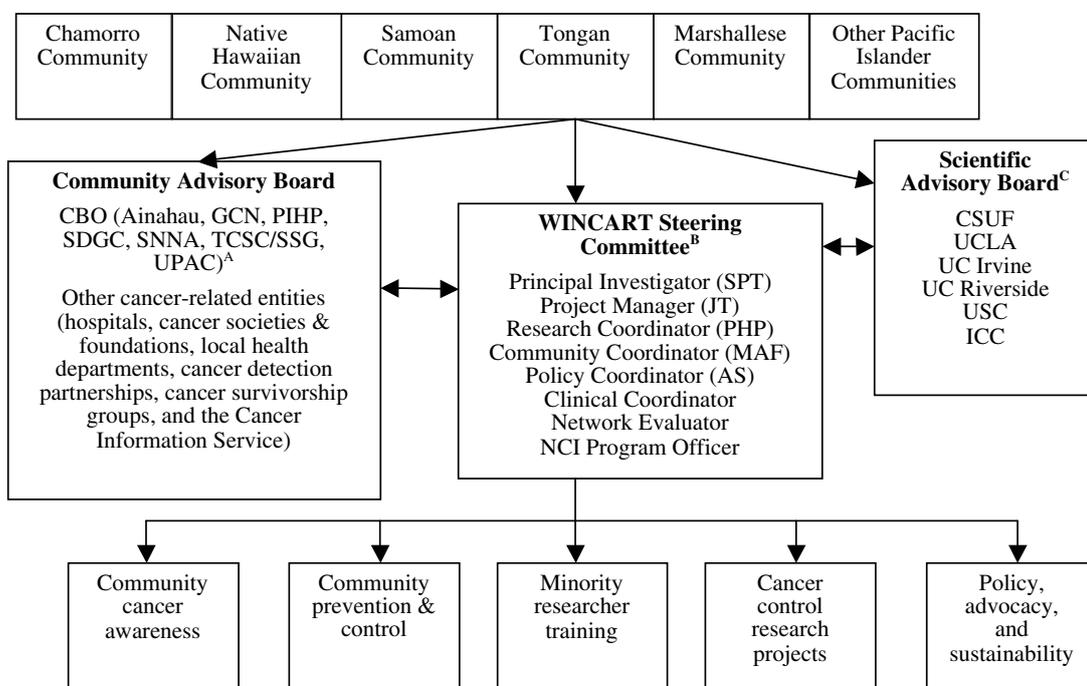
Methods: Development of the WINCART Network (A)

In late 2003 and early 2004, leaders from several Pacific Islander CBO in Southern California held informal conversations about the need to develop a collaborative network to address multiple cancer health disparities facing their communities, including lack of data, underserved status, and unrecognized health needs. Representatives from many CBOs were involved in these conversations, including the Samoan National Nurses Association (SNNA) based in Carson, Guam Communications Network (GCN) in Long Beach, the Orange County Asian Pacific Islander Community Alliance and Pacific Islander Health Partnership in Garden Grove, Tongan Community Service Center/Special Services for Groups in Gardena, and the Union of Pan Asian Communities in San Diego. These

conversations also included two university-based researchers, both of whom had a minimum eight-year history of collaborating with each of the participating CBOs on various Pacific Islander health programs and/or advocacy efforts. The authors' most recent collaborative effort was on a six-year, Centers for Disease Control and Prevention (CDC)-funded Racial and Ethnic Approaches to Community Health (REACH) 2010 initiative to increase breast and cervical cancer screenings among Pacific Islanders, through which a uniquely collaborative relationship between community partners and academic researchers was established.¹¹ These researchers were aware of a potential future funding opportunity, and suggested to the CBO leaders that they consider applying to NCI for grant funding to develop a cancer control network.

Figure 1. WINCART's Organizational Structure

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^A Ainahau 'Ainahau O Kaleponi Hawaiian Civic Club
 CBO Community-Based Organizations
 GCN Guam Communications Network
 PIHP Pacific Islander Health Partnership
 SDGC Sons and Daughters of Guam Club
 SNNA Samoan National Nurses Association
 TCSC/SSG Tongan Community Service Center/Special Services for Groups
 UPAC Union of Pan Asian Communities

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 AS Alec Sripipatana

^C CSUF California State University, Fullerton
 UCLA University of California, Los Angeles
 UC Irvine University of California, Irvine
 UC Riverside University of California, Riverside
 USC University of Southern California
 ICC Intercultural Cancer Council

April and May of 2004, two meetings were held with a larger group of CBO representatives, including leaders from the Ainahau O’Kaleponi Hawaiian Civic Club (Ainahau) in Huntington Beach, Hawaiian Daughters Guild in Los Angeles, Pacific Islander Community Council in Carson, and Sons & Daughters of Guam Club in San Diego, in addition to the aforementioned groups. While attendees represented primarily Chamorro, Marshallese, Native Hawaiian, Samoan and Tongan communities, many have worked (and continue to work) with other Pacific Islander groups, such as Fijians and Tahitians. Researchers from three universities; California State University Fullerton (CSUF), the University of California at Los Angeles (UCLA), and the University of Southern California (USC) also attended to help facilitate discussions as to whether sufficient interest existed to develop a Pacific Islander cancer control network. During their first meeting, 20 attendees (13 of whom were indigenous Pacific Islanders) discussed the goals of partnership, capacity and infrastructure building, based upon existing ties between organizations and members. Images such as weaving baskets, sewing leis (flower garlands) and building canoes were used to describe both the commonalities across Pacific Islander communities and the connections that needed to be made among all Pacific Islander groups. With universal and keen interest, attendees decided that this network would start in Southern California, with eventual ties to other regions on the continental U.S. (such as Northern California and states, such as Utah) as well as the island regions (such as Guam and American Samoa). The focus of work would be on issues that cross-cut all Pacific Islander populations, such as obesity, physical activity, and tobacco use, using cultural and community approaches, such as strengthening family supports, preserving cultural beliefs and behaviors, and mentoring young people. At the second meeting, the partners agreed to move forward with a grant proposal, brainstorming the name “WINCART: Weaving an Islander Network for Cancer Awareness, Research and Training”, and establishing an administrative structure for the network that specified key leadership positions, including identification of Steering Committee and Community Advisory Board members (see Figure 1 for details of the network structure). The relationships and decisions made at these two meetings formed the foundation of the structure and consensus-based processes of the proposed WINCART network.

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This collective effort led to development of a proposal, which was submitted to the NCI in July 2004 in response to its Request for Proposals (RFP) on Community Network Programs (CNP), by the identified principal investigator on behalf of the entire network. The collective communities served as the driving force for the collaborative, with the intentions of increasing cancer and other health-related data on Pacific Islander communities and increasing community capacity building to participate in health research, with the ultimate goal of improving the community health. Seven CBO comprised the founding members of WINCART’s Community Advisory Board, all of whom serve Pacific Islanders clients and community members. Eleven researchers from five universities (none of whom are Pacific Islander) agreed to serve as Scientific Advisory Board members, and the Core Steering Committee was comprised of eight lead staff, two of whom are Pacific Islanders.

In April 2005, a cooperative agreement was initiated between NCI and CSUF, awarding official CNP status to WINCART, with five main goals: 1) to identify individual, community and health service barriers to cancer control among five Pacific Islanders communities in Southern California: Chamorros, Marshallese, Native Hawaiians, Samoans and Tongans; 2) to improve access to and utilization of existing cancer prevention and control services among Pacific Islanders by enhancing existing relationships and services, and establishing new linkages between community members and service providers, including clinicians, social service agencies, NCI’s Cancer Information Service (CIS), etc.; 3) to facilitate the development, implementation and evaluation of CBPR studies that address the unique cancer needs of Pacific Islanders, with a focus on primary prevention (obesity and tobacco), access and navigation, and survivorship; 4) to create opportunities to increase the number of well-trained Pacific Islander researchers through training, mentorship and participatory research projects; and 5) to sustain community-based education, training and research activities by increasing partnerships with governmental and community agencies, funders and policymakers.

The remainder of this article will describe the efforts of WINCART’s first year, from the perspective of the entire network, as well as two CBO partners.

Figure 2.: Examples of WINCART’s First Year Capacity Building Activities and Outcomes

	Education	Training	Research
Capacity Building Activities	<ul style="list-style-type: none"> Worked with each member CBO to develop a scope of work, including their plans for community outreach and education Trained member CBO to complete an online education log form for each event they conduct during the year Created a project website to provide access to in-language cancer materials created by the WINCART partners Partnered with other NCI CNPs to create a web portal for Asian and Pacific Islander cancer education materials Increased access to quality in-language cancer materials (to be used for outreach and education) 	<ul style="list-style-type: none"> Bimonthly trainings for member CBO to increase knowledge and skills about a wide variety of cancer issues, including: basics of cancer, cancer epidemiology, diet and nutrition. Created pre- and post-test surveys of trainees to measure changes in knowledge and intentions 	<ul style="list-style-type: none"> Facilitated networking between researchers and member CBO about their interests in conducting CBPR studies on cancer prevention and/or control. Created WINCART policy on data sharing and publication for all WINCART-supported grant proposals Disseminated information to community and scientific members about grant opportunities Worked individually with community-researcher teams to develop proposals
Outcomes	<ul style="list-style-type: none"> A total of 41 educational events presented by member CBOs reaching 4,215 community members (cancer education topics: tobacco control, breast cancer, cervical cancer, colon cancer, liver cancer, lung cancer, prostate cancer, nutrition/diet, physical activity, cancer survivorship) 	<ul style="list-style-type: none"> Pre- and post-tests from two trainings showed an increase on 7 of 11 items (related to fat intake, whole grains, refined grains and data collection), with already high knowledge on the remaining 4 items (related to healthy diets, fruit/vegetable intake, and portion size) 	<ul style="list-style-type: none"> Facilitated submission of 9 CBPR research proposals on the topics of epidemiology, diet and physical activity, cancer screening, and cancer survivorship 6 of 9 proposals were led by community-based organizations or community members Successfully obtained funding for 2 proposals thus far

Results: WINCART’s Community Capacity Building Activities and Outcomes (A)

During its first year of existence (May 1, 2005 through April 30, 2006), WINCART initiated activities in several areas to increase local community and organizational capacity to become actively involved in cancer control education, research and training (see Figure 2). Each network CBO member developed a scope of work to address cancer disparities within their respective communities, based upon their pre-existing knowledge of and experience with the Pacific Islander communities they served. All plans include outreach education pertaining to different cancers, early detection practices, prevention methods, and information sharing to access health care facilities.

During the first year, educational activities primarily involved dissemination of cancer-related materials, including pamphlets, brochures and small incentive items. Printed materials were available in Chamorro, Marshallese, Samoan, and Tongan languages, and were developed prior to WINCART, originating from the CDC REACH 2010 project, the American Cancer Society (ACS), and the Susan G. Komen Breast Cancer Foundation (Komen).¹ Materials were disseminated at special community cultural events (e.g., Samoan Flag Day, Hawaiian Ho’olaule’a) and workshops, and community partners tailored their presentations to address the cancer topics in a context appropriate for each community and venue. A total of 41 outreach activities (e.g., one-to-one discussions, educational

¹ As of January 2007, the organization’s name has been changed to “Susan G. Komen for The Cure.”

presentations, and both small and large community events) were conducted by CBO members, reaching 4,215 community individuals. These presentations were made to community members and leaders, nurses, doctors, social service providers, researchers, students and cancer survivors, with topics including tobacco control, cancers of the breast, cervix, colon, liver, lung and prostate, nutrition/diet, physical activity, and cancer survivorship.

Members from each of the WINCART CBO also participated in bimonthly trainings to increase their knowledge and skills about a wide variety of cancer issues, such as “Cancer 101” (i.e., what is cancer?), cancer epidemiology, diet and nutrition, obesity, and cancer survivorship. Trainings were presented by WINCART Scientific Advisory Board members, as well as other cancer experts. Didactic information was augmented by skills-building exercises and sharing between CBO to promote “cross-training” and experiential learning. Pre-tests and post-tests from these trainings revealed an already high level of knowledge among CBO representatives, with enhanced knowledge on selected topics following the trainings. In addition, WINCART CBO representatives and steering committee members participated in a two-day “retreat” to encourage relationship- and team-building. During a visioning exercise designed to identify long-term goals for WINCART, community members surprised themselves with the near-consensus with which they articulated their vision: *“Empowered and Healthy Pacific Island Communities.”* Subsequently, the entire WINCART network adopted this vision statement to symbolize the goal of our cancer-related efforts toward broader and lasting community engagement and empowerment – the hallmarks of true CBPR.

Lastly, WINCART Steering Committee members and CBO representatives worked together on a case-by-case basis to develop and refine specific ideas for research proposals. Some ideas were initiated by Steering Committee members, such as an NIH R21 (Exploratory/Developmental Research Grant Award) proposal to measure physical activity and nutrition, while others originated from CBO members, as was the case for a proposal on assessing the needs of Samoan breast cancer survivors. Additional collaborative efforts were developed, not only between WINCART partners and external organizations, but also among WINCART partner agencies. A total of nine research proposals were developed and submitted during the

first year, generating two successfully funded projects. WINCART Steering Committee members also drafted a CBPR-founded data sharing and publication policy based on previous work from the CDC-funded REACH 2010 project, which articulated the shared nature of data ownership and dissemination of findings. The proposed policy was reviewed and approved by the WINCART’s Community Advisory Board.

In addition to the Network’s many first year successes, partnership with WINCART has also facilitated and enhanced the health promotion activities and profiles of existing CBO. Thus, the remainder of this article will describe differing capacities and activities of two CBO partners during WINCART’s formative period and through its first year.

Guam Communications Network (B)

GCN was established in 1993 as the sole non-profit 501(c)(3) corporation serving Chamorros in Los Angeles, Orange, Riverside and San Bernardino counties. GCN operates more than a dozen unique cultural enrichment and social service programs designed to encompass cultural promotion and preservation, health and welfare, breast cancer research, senior care management, tobacco education and prevention services, HIV/AIDS education, youth leadership and advocacy development, senior health and welfare, tobacco usage cessation, and free or low cost insurance enrollment application services.

As a founding community partner of the WINCART collaborative, GCN provided key input and guidance into the creation of grant proposals and first year activities. During WINCART’s first year, GCN was active in the three main areas; community education, research, and training, for Chamorros in Southern California, conducting eight community outreach/education events to provide information on breast cancer, cervical cancer, prostate cancer, nutrition and diet to 302 Chamorro community members. These outreach sessions provided information and resources on cancer awareness and screenings, including discussions pertaining to cancer survivorship. GCN also spent the first year developing relationships with Chamorro cancer survivors, Chamorro organizations, and Guam government agencies. This resulted in planning future activities for CNP grant Year 2 (May 2006 through April 2007), securing funding commitments from: 1) the Lance Armstrong Foundation (LAF) to develop a Chamorro cancer survivors network; 2) the Orange County Komen

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Affiliate to conduct Chamorro breast cancer forums, and 3) the Los Angeles Komen Affiliate to develop a Chamorro patient navigation program.

GCN took the lead in a collaboration with Partnered for Progress (Los Angeles County's breast and cervical cancer screening partnership, facilitating screening services for the County's uninsured and underinsured women),² developing a culturally-tailored breast cancer education/screening reminder card for Chamorro, Samoan and Tongan communities in Los Angeles. GCN also initiated collaborations with new researchers and organizations in the development of two research proposals on cancer screening and survivorship. For GCN, the WINCART collaboration has provided increased opportunities to expand and enhance its network as a community research entity and to contribute to the development of a true community-campus partnership model. Having participated in other CBPR projects, GCN has established a foundation of trust in the community to address cancer and other health issues, facilitating GCN's success in its outreach, intervention, and research efforts.

Samoan National Nurses Association (B) Established in 1996 by a dedicated group of health professionals serving U.S. Samoan communities, the SNNA is also a 501(c)(3) nonprofit organization, focusing on improving and expanding community opportunities through service, education, advocacy, organization, and research. SNNA employs 11 nurses who conduct outreach and education activities on a variety of health topics: 1) tobacco control; 2) Pacific Islander Women's Breast Health and Breast Cancer Early Detection Program; 3) Promoting Access To Health (PATH) for Women Project (advancing breast and cervical health); 4) Breast Cancer Awareness – the Fa'a Samoa Way Project; 5) Care and Resource Management for Asian and Pacific Islander Older Adults (CARE for APIs); and 6) the Health Access for Pacific Asian Seniors Project. SNNA is also a founding member of WINCART, bringing with them and contributing six years of experience in community cancer control education.

Since WINCART's inception, SNNA has conducted 20 outreach/education workshops, has participated in a large community event reaching 1,049 community members, and has exhibited health booths at two

community social events and one city health fair, providing cancer control education and resources on breast cancer, early detection and screening, diet and nutrition, and physical activity to nearly 4,000 individuals. SNNA established a Samoan Community Advisory Board, comprised of community members and leaders, medical professionals, and breast cancer survivors. Having successfully secured funding from the Los Angeles Komen Affiliate, the LAF, and the City of Carson in support of their activities pertaining to breast cancer survivorship, patient navigation, care giving, and prostate cancer outreach/education; SNNA's cancer control activities continue to increase. SNNA also applied for two research grants, one of which was successfully funded for \$125,000 by the California Breast Cancer Research Program to conduct research on survivorship and social support among Samoans in Southern California.

From SNNA's perspective, partnership with WINCART facilitates and empowers Pacific Islander-serving CBOs to "lengthen their stride" by participating in research opportunities that address, not only cancer disparities among Pacific Islander communities, but also enhance the capacities of CBOs to serve their respective communities.

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Allowing communities to develop their own scope of work, WINCART appreciates the differences between communities, such as their respective cultures, issues, and unique problems and challenges each participating CBO faces in its own communities, as well as the unique abilities each organization contributes to the Network, as a whole.

Collaborations across communities and researchers represents one of WINCART's aims, as well as one of its strengths, and GCN and SNNA have exemplified this by jointly partnering with two other entities on efforts of relevance to Pacific Islanders in the continental U.S. In 2005, both organizations partnered with the Asian Pacific Islander American Health Forum to assess the needs of Pacific Islander cancer survivors through focus groups and community report-back forums, conducted in both Northern and Southern California. Early in 2006, GCN and SNNA also assisted the LAF to conduct focus groups for the development of a Pacific Islander survivorship booklet. These are just a few examples of successful collaborations that expand the Network's reach and resources to and for Pacific Islander communities in cancer, strengthening the role of CBOs as expert resources for cancer control.

² Jointly funded through California's Department of Health Services' "Every Woman Counts" program and CDC's National Breast & Cervical Cancer Early Detection Program (NBCCEDP).

Discussion

Despite the many cancer health disparities faced by Pacific Islanders residing in the continental U.S., the development and implementation of the WINCART network demonstrates the existence and strength of considerable community resources and capacities to focus on these challenges. The Network was conceived and initiated by leaders from multiple Pacific Islander communities in Southern California, many of whom brought considerable knowledge and experience in addressing cancer-related problems in their respective communities. Several CBO partners were already actively involved in CBPR efforts, resulting in the development of true partnerships and trusted relationships with several university-based academic researchers. Thus, the two "founding" meetings out of which WINCART was developed were based on the experiences of community leaders, and reflected historical relationships of trust and respect with traditional (academic) researchers, who not only had experience working with community partners, but were also committed to engaging in a true CBPR model. WINCART exemplifies a successful community and academic partnership.

For some of the community partners, WINCART represents their first CBPR project and collaborative effort. As a result, the development of capacity and the ability to address WINCART's aims have occurred in variable activities at differing levels. Thus, while some partners have experience with research capacity and have initiated research proposal submissions, other groups have yet to fully engage in the academic research process. While some groups have developed multiple educational materials and tools to increase community cancer awareness, other groups are only beginning to identify and develop resources appropriate for and accessible to their communities. The broader Network vision of "*Empowered and Healthy Pacific Island Communities*" has helped to focus WINCART efforts at all levels, while acknowledging the various capacities and strengths of respective community groups. Trust and respect between individuals and across communities helped to facilitate the timely process of development and submission of the WINCART proposal. These relationships have endured, matured and grown throughout WINCART's first year, contributing to the strength of the collaborative process, and facilitating inclusion of many CBPR elements, as discussed by other researchers.^{12,13} CBPR rests firmly in the strength of relationships, not only between community and academia, but also across community groups.

WINCART's role is to strategically focus community and university efforts on decreasing cancer health disparities

through education, research and training. In its first year, WINCART's diverse partners have successfully established the groundwork in these three areas: 1) developing and implementing outreach education plans; 2) training leaders in additional cancer-specific topics; and 3) creating research ideas and proposals. Over the next four years, plans include increasing collaborations across communities on focused campaigns (such as decreasing obesity), creating a pipeline program to encourage and support Pacific Islander youth to go into health professions, and advocating for disaggregation of health data and oversampling of Pacific Islanders to improve understanding of community needs and intervention outcomes.

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