# **REACH 2010**



PROMOTING ACCESS TO HEALTH FOR PACIFIC ISLANDER AND SOUTHEAST ASIAN WOMEN



#### PROMOTING ACCESS TO HEALTH (PATH)

FOR PACIFIC ISLANDER AND SOUTHEAST ASIAN WOMEN
IN LOS ANGELES AND ORANGE COUNTIES,
CALIFORNIA

RECOMMENDATIONS

FOR THE BREAST AND CERVICAL CANCER

SCREENING NEEDS OF CAMBODIANS,

CHAMORROS, LAOTIANS, SAMOANS, THAIS,

TONGANS, AND VIETNAMESE



## **REACH** 2010

REACH 2010 (Racial and Ethnic Approaches to Community Health by the Year 2010): Promoting Access to Health (PATH) for Pacific Islander and Southeast Asian Women is a project of Special Service

for Groups (SSG). PATH for Women is a partnership between SSG, several community-based organizations serving the Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan, and Vietnamese communities, and the Universities of California at Irvine and Los Angeles.

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#### ABOUT THE DESIGN

ABOUT THE DESIGN

The PATH report had to communicate that it is a needs assessment report, but also convey the essential human element of the network of women from Asian & Pacific Islander communities in Los Angeles and Orange Counties, California. The path is clearly shared voices and shared concerns. Therefore, a small format was chosen to create a feeling of a handbook.

The technique of the stained-glass window using colors inherent to those cultures served as inspiration of the basis of the design. Though similar in color, each mosaic colored cell has variations of orange, gold, brown, lavender, fuschia and red, reflective of the individual woman and cultural sensitivity. A flesh-tone, almost

copper-like lines bond the mosaic cells together, instead of lead lines that traditionally bond stained glass.

Some mosaic cells are left empty intentionally for future voices. A Fran Lujan Design/ logo by Mari Nakamura

# I. Executive Summary



#### A. Introduction

Breast cancer is the leading site for cancer incidence and mortality for Asian American and Pacific Islander (AAPI) women in the nation (Jenkins and Kagawa-Singer, 1994). Although AAPI women as an aggregate group have a lower incidence of breast cancer, mortality rates are increasing (American Cancer Society, 2001). Cervical cancer rates for many AAPI women are significantly higher than for white women; for example, Vietnamese women develop cervical cancer at five times the rate of white women. Unfortunately, AAPI women have the lowest breast and cervical cancer screening rates compared to all other ethnic groups (Kagawa-Singer & Pourat, 2000), yet few programs have specifically targeted these women to promote and sustain screening practices.

## B. Project Methods

This needs assessment report reflects the work conducted in Phase I Pilot of the Promoting Access to Health (PATH) Project for Pacific Islander and Southeast Asian Women as part of the Centers for Disease Control and Prevention's (CDC) REACH 2010 Program. The ultimate goal of the PATH Phase II project is to reduce the disparities in breast and cervical cancer screening for seven AAPI populations in the Los Angeles and Orange Counties of California: Cambodian, Chamorro, Lao, Samoan, Thai, Tongan, and Vietnamese. Phase I, conducted between September 1999 and August 2000, involved documenting the health needs in these seven communities and eliciting suggestions from these communities on the best way to design and implement outreach and education efforts. We conducted focus groups and survey interviews in each of the seven PATH Project communities to better understand the unique needs within, as well as the common needs across, each community. Focus groups and interviews were conducted with women, men, community leaders, and health care providers to understand the community barriers and needs in six areas: 1) the general health needs and concerns in the community; 2) the barriers to basic health services; 3) knowledge of health promotion; 4) knowledge of breast and cervical cancer (causes, risks, and prevention); 5) knowledge and performance of breast and cervical cancer screening examinations; and 6) community resources to improve breast and cervical cancer screening and care. Each focus group was comprised of an average of 12-15 individuals per community (totaling 45 to 60 individuals per community), and 30 surveys per community were conducted with women over 18 years of age (with the majority being age 40). Although this report reflects the opinions and suggestions of more than 600 community members, leaders, and providers, it does not constitute a representative sample and should not be used to generalize the screening behaviors of each population. This report, however, does provide the first description of some of the broader issues and barriers to cancer screenings faced by the seven participating communities. Phase II of the project will use these findings to implement the culturally-tailored breast and cervical cancer health education and screening programs.

#### C. Findings

The findings identified unique needs within each community, as well as common themes and needs across all seven groups. Table I summarizes selected findings within each of the communities.



### Table I: Areas of Need and Resources for each PATH Participating Population:

Selected Phase I Survey and Focus Group Findings

Participating Population Selected Findings Regarding Needs and Resources

Cambodian Needs: The majority of women who had ever received a baseline

> mammogram, clinical breast examination (CBE), and Pap test were due to past prenatal care. The majority of women do not get rescreened within guidelines.

Barriers: Lack of health insurance, need for language interpretation, and

high levels of female modesty.

Resources: Strong informal social networks are available to promote self-

initiated baseline and follow-up screening.

Needs: Due in large part to their private insurance coverage, Chamorro Chamorro

women have the highest levels of breast and cervical cancer screenings of all our participating populations. Yet they express high dissatisfaction with

the quality of respect and care given by medical providers.

<u>Barriers</u>: They have problems communicating with physicians because their

respect for authority figures prevents them from asking questions.

Resources: Strong informal social networks exist. A list of providers who serve the Chamorros was identified, and these providers can be targeted for

cultural competency education.

Laotian Needs: These women have similar screening needs and barriers as the

Barriers: They have a high distrust of physicians and expressed many myths

about cancer causes.

Resources: Strong informal social networks exist to promote self-initiated

screening.

Samoan Needs: The majority of women who had ever received a mammogram, CBE,

and Pap test were due to recent church-based mobile programs. The

majority of women do not get rescreened within guidelines.

Barriers: Lack of health insurance and lack of emphasis on preventive care.

Resources: Strong church-based networks could promote follow-up

screening.

Thai Needs: One-third of the women have never had a mammogram, CBE, or Pap

> test, and the majority does not get rescreened within guidelines. Barriers: Most of the women do not have health insurance or legal immigration status, and express resistance to female examinations due to

cultural modesty.

Resources: Large numbers of Thai nurses in the community, as well as

strong media outlets for outreach.

Tongan Needs: The majority has never had a breast or cervical cancer screening

examination.

Barriers: Lack insurance coverage and the language ability to navigate the health care system. Although modesty is not an issue, cultural taboos prevent men and women from discussing female health concerns together. Resources: Strong church-based networks exist for baseline screening.

Needs: They have similar screening needs and barriers as Thais.

<u>Barriers</u>: No unique barriers noted beyond those indicated in the other groups.

Resources: Large numbers of Vietnamese doctors as well as nurses in the

community, and strong media outlets for outreach.

Vietnamese

Across all seven communities, many commonalities exist regarding barriers to breast and cervical cancer screening, beliefs, knowledge, and behaviors. Most prevalent across all seven communities is the lack of in-language materials and recommendations by health care providers for breast and cervical cancer screenings.

#### 1. Common Barriers to Screening

#### Structural Barriers

Lack of health insurance was ranked as the primary barrier to baseline and regular clinical breast exams, mammograms, and Pap smears by women in six of the seven communities — Cambodian, Laotian, Samoan, Thai, Tongan, and Vietnamese. Increased access to health insurance, including both enrollment in Medi-Cal for those in poverty and low-cost insurance products for the working poor, is one of the primary policy needs identified for AAPI communities.

Lack of time off from work, lack of transportation, lack of childcare, long waits at doctors' offices, and lack of female doctors were identified as major structural barriers to screening by women in all seven communities. Having male primary care providers was perceived as a barrier for women in all seven communities. Development of effective community-based programs must ensure that support systems are in place to reduce these barriers to cancer screening in these communities.

#### Language and Cultural Barriers

Language and communication problems were identified as barriers, particularly among older AAPI women in six of the seven communities — Cambodian, Chamorro, Laotian, Thai, Tongan, and Vietnamese. This issue emphasizes the need for trained interpreters to be available and accessible for AAPI women obtaining cancer screening examinations.

Cultural beliefs were mentioned as potential barriers by women in five of the communities — Cambodian, Laotian, Samoan, Tongan, and Vietnamese. For example, several groups mentioned that it is shameful to have women's private bodily

areas examined by male doctors and that they use traditional medicines for remedies for cancer prevention and treatment because it is easier and more familiar. Structural barriers to the mainstream health care system also make it more convenient to seek the assistance of familiar indigenous remedies and healers.

#### 2. Common Breast and Cervical Cancer Beliefs

## Misperceptions

Causes of breast cancer include: getting hit in the breast, having too many children, fondling breasts too much, using birth control (especially types that are used near the cervix), and having bad circulatory systems.

## Traditional beliefs with some scientific support

Women had many beliefs about the causes of cervical cancer including: poor hygiene, having too many children, and having husbands who have sex outside of marriage.

3. Screening Behaviors reported by the 30 women in each community:

Breast Self-Examinations (BSE): The proportion of women who reported performing BSE monthly ranged from 40% (12 of 30 Cambodian women) to 70% (21 of 30 Chamorro women), with an average of 52% (109 of the total 210 women) for the total seven communities. Women who reported never having been taught BSE ranged from 20% (6 of 30 Vietnamese women) to 53% (16 of 30 Laotian women), with an average of 29% (61 of 210 women).

Clinical Breast Examinations (CBE): The proportion of women who reported ever having received a CBE ranged from 10% (3 of 31 Tongan women) to 87% (26 of 30 Laotian women), with an average of 69% (21 women) per community. Of those who have had a CBE, the proportion of women getting a yearly CBE was lower, ranging from 13% (4 of 31 Tongan women) to 94% (28 of 30 Chamorro women), with an average of 56% (118 of 210 total women).

Mammograms: The proportion of women who reported ever having had a mammogram ranged from 13% (4 of 31 Tongan women) to 87% (26 of 30 Vietnamese women), with an average of 61% (18 women) across communities. Obtaining yearly mammograms, however, ranged from 19% (6 of 31 Tongan women) to 77% (23 of 30 Vietnamese women), with an average of only 50% (105 of the total 210 women).

Many women in the Thai and Samoan communities reported using mobile mammogram units for their yearly screenings. However, because this service was suspended in many areas due to discontinuation of mobile mammogram programs, we may see sharp decreases in the proportion of women getting rescreened.

Pap Smear Tests: The proportion of women who reported ever having had a Pap smear test ranged from 10% (3 of 31 Tongan women) to 97% (29 of 30 Chamorro women), with an average of 70% (147 of the total 210 women) across all communities. One reason this proportion is so high may be that many women reported receiving a Pap smear test during prenatal care. This may help to explain why the proportion of women receiving yearly Pap tests is lower: on average only 43% of women received Pap tests yearly (with a range of 10% for Tongans [3 of 31 women]) to 63% for Chamorros (19 of 30 women).

## D. Community Action Plan

After conducting this needs assessment, the partners used the information to develop community action plans in Phase II to promote breast and cervical health within each of their communities.

PATH's Community Action Plan is a comprehensive intervention focused upon four strategy areas to address the communities' knowledge, behaviors, beliefs about breast and cervical cancer, and their environmental resources and barriers affecting their access to care. These four strategy areas include community education, community training, screening, and policy.

Community education includes establishing community advisory committees to help lead and improve each partners' program, conducting community outreach and education, developing bilingual materials, working with ethnic media, and establishing cancer support groups and other survivor resources.

Community training includes the training and development of peer educators or lay health leaders; providing patient navigators in the health care system; providing medical interpretation; conducting health care provider education and training; building capacity of community and partnership resources; and disseminating mini-grants to other community organizations and associations to help strengthen and sustain the overall breast and cervical cancer prevention and control efforts.

Screening strategies include providing patient navigation and case management to assist women to gain access to free or low-cost screenings (breast self examination, clinical breast examination, mammograms, and pap smears); providing follow-up services and resources for women to understand their screening results; and providing education and follow-up to ensure women obtain rescreenings. As a partnership, we are also working to establish specialized screening clinics for low-income Pacific Islander and Southeast Asian women, as well as mobile clinics in the community especially during special cultural celebrations and events.

Policy strategies focus on broader sociopolitical influences that improve the communities' access to health care at the community, local, state, and national levels. Policy strategies will include encouraging legislators to support health care policy that would improve the community clinics' ability to offer free or low cost screenings and improve the enforcement of health care access and interpretation for limited English proficient patients at federally funded health care institutions.

Each community then established their particular focus for each of the four elements of the intervention plan, developed in Phase II of the project. For example, one common need identified among all

groups was for information dissemination. Ethnic media is so strong in the Thai and Vietnamese communities that it is a strong focus for both partners, whereas religious organizations are a strong asset in the Samoan community, and thus they will spend more time focusing upon educating and training pastors and other church leaders on the importance of breast and cervical cancer prevention and control.

Implementation and evaluation of the community action plans will occur in Phase II, years 2001-2004.



This needs assessment report reflects the Phase I work of the PATH (Promoting Access to Health) Project for Pacific Islander and Southeast Asian Women, a project of Special Service for Groups. This project, funded by a grant from the Centers for Disease Control and Prevention Inc., (CDC) Foundation REACH 2010 program, aims to reduce the disparities in breast and cervical cancer for seven Asian American and Pacific Islander (AAPI) populations in the Los Angeles and Orange Counties of California: Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan, and Vietnamese. The project effort was launched by a partnership between seven community-based organizations - Families in Good Health, Guam Communications Network, Orange County Asian and Pacific Islander Community Alliance, Pacific Asian Language Services (PALS) for Health, Samoan National Nurses Association, Tongan Community Service Center, and Special Service for Groups – and two universities – the Universities of California at Irvine and Los Angeles (See PAGE 2 for listing of organizations).

# II. Introduction



On June 14, 1997, President Clinton announced One America in the 21st Century: The President's Initiative on Race, which includes the goal of eliminating racial and ethnic disparities in health by the year 2010 in the African-American, Alaska Native, American Indian, Asian American, Hispanic American, and Pacific Islander communities. Racial and Ethnic Approaches to Community Health (REACH) 2010 is part\_of the U.S. Department of Health and Human Services' response through the Centers for Disease Control and Prevention (CDC) to President Clinton's Race Initiative to focus on the health status in six priority areas: Infant Mortality, Deficits in Breast and Cervical Cancer Screening and Management, Cardiovascular Diseases, Diabetes, HIV Infections/ AIDS, and Child and Adult Immunization. REACH 2010 aims to foster new strategies to close the health gaps and reduce disparities among racial and ethnic minority populations, and unveil the underlying causes of disparities. REACH 2010 projects are designed to foster community mobilization and the organization of resources in order to develop effective and sustainable programs to eliminate the health disparities of racial and ethnic minorities.

California's Los Angeles and Orange Counties have the largest Pacific Islander and Southeast Asian populations in the nation, as summarized in Table I. Each of the communities, however, reports a significant undercount of their populations. Table I indicates the 1990 and 2000 Census counts, but the communities report that in Los Angeles County, Hollywood has the largest Thai community with community estimates of more than 60,000. Long Beach has the largest Cambodian population and a significant Lao population. Orange County has the largest Vietnamese population. Southern California also has the largest Samoan population, with the largest concentrations living in the South Bay and South Central areas of Los Angeles County, such as Carson, Compton, Wilmington, and Long Beach, as well as the central area of Orange County: Santa Ana, Garden Grove, Westminster, and Anaheim. Approximately 18,000 Chamorros and Guamanians, and another 12,000 Tongans live in similar areas of the two counties.





Table I: PATH population sizes in Los Angeles and Orange counties, 1990 and 2000.								
	Los Ange	les County	Orange County					
API Population	1990 Census*	2000 Census*	1990 Census*	2000 Census*				
Vietnamese	65,594	89,080	71,822	151,164				
Cambodian	27,819	34,032	3,979	5,359				
Laotian	3,742	3,569	2,893	3,208				
Thai	19,016	24,151	2,227	3,822				
Samoan	11,934	16,163	2,979	4,555				
Tongan	1,546	2,627	345	610				
Guamanian or Chamorro	5,632	5,188	1,406	2,318				

<sup>\*</sup> U.S. Bureau of the Census, 1990 Census of Population and Housing (P007), Summary Tape File I.

Between September 1999 and August 2000, focus groups and interviews were undertaken in each of the seven PATH Project communities to better understand the unique needs within, as well as common needs across, each community. Informing the overall framework for the PATH needs assessment were the concepts of form and function (AAPCHO CARE Program, 2001). Our intent for this project was to specifically tailor each intervention to fit into each group's existing cultural framework. This tailored intervention is expected to facilitate the adoption of new behaviors through familiar channels using meaningful symbols and messengers, thus utilizing cultural consonant strategies. For this breast and cervical cancer screening promotion project, the functions of each educational strategy – outreach education, media (e.g., ethnic television, radio, and newspaper), provider training, or others – are common domains in community-based breast and cervical cancer control efforts. However, when working with unique cultural groups, the form of each of the domains must be culturally tailored and specific. PATH hypothesizes that by making the required function as explicit as possible, the outreach strategies can be modified more consistently to incorporate the most appropriate forms for intervention and will result in increased and effective breast and cervical cancer screening services within each target community.

This report is the culmination of the needs assessment effort during Phase I that became the framework for the PATH project Community Action Plan (CAP) that is currently being implemented in Phase II, 2001-2004. In the following sections we describe the background of the cancer health problem, the needs assessment methods, the findings for each community, and the recommended action plans for each community.

<sup>\*</sup> U.S. Bureau of the Census, 2000 Census of Population and Housing, Profile of General Demographic Characteristics (DP-I), Summary File I. Data shown is for race alone, or in any combination with any other racial group.

# III. Background on Breast and Cervical Cancer Among AAPIs



Breast cancer is the leading site for cancer incidence and mortality for AAPI women in the nation (Jenkins and Kagawa-Singer, 1994). Further, research suggests that breast cancer appears to occur at earlier ages and in a more aggressive form in Asian American women than in any other ethnic group (Menon, 1992). Although AAPI women, as an aggregate group, have a lower incidence of breast cancer, their mortality rates are increasing (American Cancer Society, 2001). Disaggregated data indicates that specific groups of AAPI women are diagnosed with more advanced stages of breast disease than their white counterparts (Menon, 1992). Some of the variance in breast cancer rates appear to be tied to acculturation, since migration studies indicate that breast cancer incidence and mortality rates for AAPI women in the U.S. are two to four times the rates in their native countries (Wismer et al., 1998). Immigrant women living in the U.S. for as little as one decade have an 80% higher risk of breast cancer than do new immigrants, and for American-born AAPI women, the risk of breast cancer is similar to that of white women (Chen et al., 1992). Most recently, a national study of breast cancer incidence and mortality found that while rates have decreased for all other racial groups, breast cancer incidence and mortality have increased for AAPI women (American Cancer Society, 1998).

Cervical cancer incidence rates for many ethnic AAPI women are higher than for white women. Data from California and Hawaii on selected AAPI populations indicate that the cervical cancer incidence rates for Chinese American, Vietnamese American, and Filipino American women are higher than for white women. The proportional incidence rate (that is, the ratio of the proportion of all cancers at a particular anatomical site in a population compared to the same proportion in the white population) for cervical cancer is 1.5 times higher for Laotian women, 2 times higher for Samoan women, and 5 times higher for Vietnamese women, as compared to white women (Jenkins and Kagawa-Singer, 1994; Mishra et al., 1996). The highest age-adjusted incidence rate for cervical cancer in the Surveillance, Epidemiology and End Results (SEER) areas occurs among Vietnamese women (43 per 100,000). Despite these incidence rates, AAPI women have the lowest breast and cervical cancer screening rates for cancer compared to all other ethnic groups (Kagawa-Singer & Pourat, 2000). Nevertheless, few programs have specifically targeted these women to promote and sustain screening practices.







# IV. Methods and Limitations



A complete description of the methodology used for this needs assessment was published by Tanjasiri, Kagawa-Singer, Nguyen, and Foo (2001). Focus groups and interviews were conducted in each of the seven participating communities. The group discussions focused on six aspects of health promotion and cancer control: I) the general health needs and concerns in the community; 2) the barriers to basic health services; 3) knowledge of health promotion; 4) knowledge of breast and cervical cancer (causes, risks and prevention); 5) knowledge and performance of breast and cervical examination screening examinations; and 6) community resources to improve breast and cervical cancer screening and care. Focus group participants were recruited in four categories; women, men, leaders, and providers. In most cases, these four types of focus groups were conducted separately so that women participated with other women, men with men, and so forth. However, in communities for which there were few health providers such as in the Cambodian and Laotian communities, community leaders and providers were brought together into one focus group.

PATH Project coalition members identified experienced and knowledgeable people from each community and recruited them by soliciting their ideas regarding breast and cervical cancer control. Signed consent forms approved by the UCLA Institutional Review Board were obtained from all participants. The group discussions were led by trained bilingual and bicultural facilitators who used standard focus group guides developed for each category of focus group participants to pose questions and probe for further information regarding culturally specific issues and barriers. All discussions were tape-recorded, transcribed and translated into English, and analyzed for emerging themes by the project partners within each community and with researchers from the collaborating universities.

In addition to these focus groups, individual survey interviews were conducted with approximately 30 women in each ethnic community. Interviews asked specifically about the women's personal knowledge, attitudes, and behaviors regarding breast and cervical cancer screening examinations, as well as their opinions about preferred ways to educate the women, men, and professionals in each community.

Respondents for both the focus groups and individual interviews were recruited via personal relationships with the PATH coalition members, and thus do not constitute a representative sample of women, men, leaders, and providers from the communities. The number of women interviewed was small (30 from each community). Therefore, their responses cannot be taken to represent the breast and cervical cancer knowledge, attitudes, and screening practices of the general ethnic population. Nonetheless, the pilot data provided important information for Phase II data collection and outreach efforts.

Community			Number of Participants		
	Focus Group Participants				Interviews
	Women	Men	Healthcare Providers	Community Leaders	Women
Cambodian	16	15	4*	- 11	30
Chamorro	15	15	0	7	30
Laotian	17	11	0	7	30
Samoan	35	23	1	15	29
Thai	16	15	9	22	30
Tongan	11	14	0	II	31
Vietnamese	13	14	II	10	30
Total: 7	123	107	25	83	210

<sup>\*</sup>Please note that these providers were interviewed individually.

# shared voices

# Cambodian Community Findings



the path shared voices shared concerns



#### V. FINDINGS FOR EACH ETHNIC GROUP

#### A. CAMBODIAN COMMUNITY

## Background

Families in Good Health in Long Beach conducted three focus groups with the Cambodian community: one with 16 women, one with 15 men, and one with 11 community leaders. In addition, four health care providers were also individually interviewed. Face-to-face standardized interviews were also conducted with 30 Cambodian women from the community; they were contacted through informal social networks. The location sites for these interviews were: Long Beach, Signal Hill, and Lakewood, particularly in neighborhoods with high concentrations of Cambodian families.

The ages of the 30 women interviewed ranged from 35 to 65 years, with the majority, 16 of 30 women, being older than 40. All of the women were born in Cambodia and immigrated to this country between 1976 and 1996. Only 13 of the women were married with 12 women widowed and 5 women single. Of the total number of women, 8 had never received any formal education, 12 had less than five years of education, and 9 had greater than seven years of education with 13 years being the highest number of years of education any woman received. Only 13 women said that they spoke Cambodian "very well" and 15 women said they spoke it "well." Thirty-four percent (10 women) said that they read Cambodian "poorly" or "not at all." Only 3 women said they spoke English "well." Ninety percent, 27 of 30 women, said that they spoke English "so-so," "poorly," or "not at all," and 25 said that they read English "so-so," "poorly," or "not at all." Only 5 women had private health insurance, while 17 women had Medicare, and 8 women had Medi-Cal.

### Major Health Concerns

All women, men, and community leaders agreed that the major health concerns for Cambodian women

were cancer, diabetes, and heart disease (including stroke, high blood pressure, and cholesterol). Men and women also emphasized the need for better nutrition and exercise. Community leaders and providers were also concerned about women's mental health. Providers identified that sharing medication was a problem among Cambodians, and stressed the need for a better health care approach that combines traditional practices with Western medicine.

According to one woman, "Elderly like to take the black medicine from Cambodia that the healer made." Use of traditional medicine is also cheaper than Western medicine and as such may be the only option for many Cambodians, especially for those not covered by insurance.

#### Barriers to Health Care

All women, leaders, and providers agreed that the major barriers to health care were no insurance, no transportation, language barriers and no available interpreters, and modesty of women who do not want doctors to check their private parts. Women want to see a female doctor, but there are none available in some clinics. Women also said that there are long waiting times at the clinic and that they cannot take time off to go to the doctor. Providers also mentioned that Cambodians do not practice preventive health care, and believed that Cambodian women would rather not address their health problems often until it is too late. One provider generalized "We would rather choose to deny it, not to hear or know and understand."

Breast and Cervical Cancer Knowledge, Attitudes, and Practices (Survey Results - Cambodian Community)

Overall focus group and interview data showed that there is a definite need to educate the Cambodian community about breast and cervical cancer. Many women are not getting screened at baseline and follow-up but feel that they would if doctors recommended the examinations to them.

#### Cambodian Community Findings

Thirty women were interviewed on their knowledge, attitudes, beliefs, and practices in relation to breast and cervical health: breast self examination (BSE), clinical breast examination (CBE), mammograms, and Pap tests.

#### **BREAST CANCER**

#### Breast Self Examination (BSE)

Findings from these interviews showed that in the Cambodian community the majority of women, 21 of 30 women, have heard of a breast self examination (BSE). While the same majority had been taught how to perform the BSE, only 12 women actually performed the examinations monthly. Nearly half, 14 of 30, of the women stated that they were not planning to perform the breast self examination monthly and another 9 women did not intend to perform BSE at all. While the findings indicate that Cambodian women know about BSE, there still exists a need to educate on the importance of consistently practicing such screenings, as they are early detection measures for breast cancer.

## Clinical Breast Examinations (CBE)

The majority, 23 of 30 women, had a CBE performed on them, and most (19 of 30 women) had the CBE more than a year prior to the interview. More than half of the women, 16 of 30, knew that they should have a CBE every year, however only 8 women were getting CBE yearly. Three of the women believed that a CBE should only be performed when they are pregnant and 11 women did not know how often they should be getting CBE. Even more alarming was that more than half, 16 of 30, of the women were not planning to get a CBE within the next twelve months.

In the focus group, several women spoke of how their doctors touched their breasts but said that they did not know why the doctors were touching them. One woman described the failure of doctors to conduct CBE on Cambodians as a problem:

"My aunt died from breast cancer, it's sad and scary when the doctor missed looking at the problem. When she was in Cambodian, she had pain in the breast and went to the healer and he gave her some herbal medicine and it healed. When she came to the USA, she went to the doctor for the same problem and the doctor said everything is okay. Four years later she died at a hospital."

#### Mammograms

In the focus group, 3 of 16 women had never had a mammogram. Among those that had, some said that it hurt so much that it is scary. One woman said that since she had a mammogram every year, there was no need to perform self-breast examinations, reflective of insufficient health education.

Much like the two previous breast screening methods, the majority of women, 26 of 30, had heard of a mammogram. Of this total, 16 women had a mammogram. Of those screened, 13 had gotten the mammograms for free or with a voucher, while the remainder received mammograms via insurance (two women) or Medicare (one woman). The interviews also revealed that rescreening was not an important issue for the women, as nearly half, 14 of 30, did not plan to have a mammogram within the next two years. According to women in the focus group, there were also many barriers to getting mammograms, including pain from the procedure, and no one to take them to the doctor.

The interview and focus group data showed that women are accessing mammography services; however, women do not see regular screening as a vital component to their health. For instance, some Cambodian women believed that one mammogram is enough to ensure that they are cancer-free for life. One woman also believed that since she had yearly mammograms, there was no need for her to do breast self examinations. These findings underscore the need for concerted education and screening that includes all three examination methods.

#### Cambodian Community Findings

#### **CERVICAL CANCER**

Pap Smears

Women in the focus group said that the barriers to Pap tests were no insurance, no time, no transportation, and fear and nervousness. Several women mentioned how embarrassing it was for the doctor to examine their private parts, especially when they do not feel sick. Another woman said that even though she wanted to get the test, she did not want to see a Cambodian doctor for a Pap test because she did not feel comfortable seeing a male provider of the same ethnicity.

Of the women interviewed, 26 of 30 women had heard of a Pap test and over half of the women, 19, had received a Pap smear. Of those screened, 15 received the Pap test for free, 3 were covered by insurance, and one was covered by Medicare. Twelve of the women screened were encouraged by family and friends to get Pap smears, reflecting the importance of support and recommendations.

# RECOMMENDATIONS FOR POSSIBLE HEALTH PROGRAMS ON BREAST AND CERVICAL CANCER FOR THE CAMBODIAN COMMUNITY

Sources of Information – Women said that they would like to learn more about breast cancer as well as cervical cancer screening. Most replied that they would want to learn this information from a doctor (all 30 women), a community worker (29 of 30 women), or a nurse (28 of 30 women).

Setting – The most popular setting for education would be a clinic (29 of 30 women), followed by a community site (27 of 30 women), and at home (21 of 30 women). Other sites noted for outreach were restaurants, stores, health fairs, temples and churches, clinics, beauty salons, and at community events.

Format/Medium — Video (all 30 women) and television (all 30 women) were the preferred formats for education, followed by radio (24 of 30 women), and brochures (24 of 30 women). Pictures were also mentioned by 4 women as a way to educate women in their communities, and focus group participants said not to use too many words in brochures.

Structure – When asked about how the educational programs should be structured, all of the women wanted a group structured with other women, while 29 of 30 women also wanted one-on-one education. Women did not want their husbands to be involved, but 23 women said husbands should be educated separately. Women from the focus group said that men should be educated, so that the men do not get angry when asked to take their wives to the clinic and to wait a long time.

Service Needs – In addition to education, the women who were interviewed expressed that the most important services that would help them to obtain a cancer screening examination in the future would be having a female doctor (all 30 women), low- or nocost services (29 of 30 women), an interpreter (27 of 30 women), someone to drive them to the appointment (22 of 30 women), a mobile unit (19 of 30 women), and knowing where to go for services (18 of 30 women). Ten women said bus tokens would help allay costs and only 3 women said that childcare would help.

# shared voices

# Chamorro Community Findings



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#### **B. CHAMORRO COMMUNITY**

#### Background

Guam Communications Network conducted three focus groups with Chamorro community members: one with 15 women, one with 15 men, and one with 7 community leaders. In addition, face-to-face standardized interviews were conducted with 30 Chamorro women from the community. The respondents were contacted through informal social networks. There are more Chamorros living in California than in Guam.

The ages of the women interviewed ranged from 32 to 74 years, with the majority, 25 of 30 women, in the 40 to 60 age range. About two thirds, 19 of 30, of the women were born in Guam, 10 in the U.S., and 3 in another country. About 24 of the women interviewed were married, with 6 single and 2 women widowed. Of the Chamorro women, 3 had less than three years of education, 13 had 9-12 years of education, and 14 had more than 13 years of education. Only 3 reported that they only spoke English "so-so," 2 women stated that they read English "so-so," and no one marked "not at all." Of those interviewed, 23 women had private health insurance and 4 had no insurance. Only one of the women had Medi-Cal, one had Medi-Cal and Medicare, and one woman had military coverage.

#### Major Health Concerns

The major health concerns mentioned by the Chamorro women were breast cancer and diabetes. Other major concerns noted were arthritis, Alzheimer's disease, Parkinson's disease, kidney problems, menopause, and lack of exercise. Several commented that fear of finding something was enough to keep them away from doctors.

Similarly, Chamorro men identified cervical cancer, cholesterol, high blood pressure, and lung cancer for women smokers as the leading women's health concerns. The community providers and leaders also felt that other cancers, such as breast

cancer, were major health problems for Chamorro women. In addition to those diseases noted by the men and women in the focus groups, the community liaisons also identified thyroid disease, weight problems or obesity, drug and alcohol use, and poor nutrition as significant problems.

#### Barriers to Health Care

The barriers to necessary health care noted by the three focus groups were strikingly similar. As one man stated, "they gotta be practically dead, bleeding, throwing up or can't move before they'll go to the doctor." One woman said, "I won't go to the doctor unless I'm dying," and another said "not supposed to get sick," "women are supposed to be strong," and "don't want to impose on anyone." They are afraid of hospitals or do not have the time to care for themselves, because their families are their priorities. In contrast, one woman said, "the family is most important. If job won't let you off, can always get another job, not another mother."

All community participants mentioned that communication was a major barrier to health care. One woman said "you need a doctor who talks to you, informal." In the case of the seniors, they do not want to challenge authority and will not give their complaints directly to the doctor, so if another family member is there to talk to the doctor, "the family member will tell."

A few of the participants mentioned that the women might go to a suruhanu, a traditional healer who uses herbs and ointments to treat illnesses, instead of a western doctor. Notably, both men and women mentioned that even if women visit a Westerntrained biomedical doctor and received a prescription, they would not take the medicine when they got home.

#### **Chamorro Community Findings**

BREAST AND CERVICAL CANCER KNOWLEDGE, ATTITUDES, AND PRACTICES (SURVEY RESULTS -CHAMORRO COMMUNITY)

#### BREAST CANCER

Breast Self Examination (BSE)

The Chamorro women interviewed had all heard of a breast self examination (BSE) and 24 of 30 women had been taught how to perform a BSE. Of those interviewed, 22 women correctly identified that breast self examination should be performed monthly, with 21 of the 30 respondents properly performing BSE on a monthly basis. Four of the nine remaining women reported that they had planned on performing a BSE next month. Our Chamorro interviewees reflected a high level of information and knowledge with regard to breast self examinations; however, this is not a complete reflection of the broader Chamorro community and their access to health services.

#### Clinical Breast Examination (CBE)

The Chamorro women interviewed also had a high knowledge regarding clinical breast examinations (CBE). Over three quarters of the women (25 of 30 women) had a CBE performed by a doctor, nurse, or medical provider. A majority, 26 of 30 women, identified that women should be receiving CBE on a yearly basis. Of the women interviewed, 18 of 30 were receiving yearly CBE with another 10 women planning to schedule a CBE within the next 12 months. Two women had never had a CBE and two other women were not sure what a CBE was; of these women, one had not even thought about having a CBE and another had thought about having a CBE but had no intentions of scheduling an appointment within the next twelve months.

#### Mammograms

Most of the women in the focus group reported having a mammogram. However, community leaders estimated that on average, less than half of Chamorro women were obtaining a mammogram. Many women in the focus group stated that they were afraid of receiving mammograms and getting rescreened because the procedure is painful.

All of the women interviewed had heard of a mammogram. Of these thirty women, twenty had received a mammogram. Seventeen of these women had their mammograms free of cost and 3 were covered for mammography services via insurance. The majority, 24 of 30 women, knew that they should get a mammogram on a yearly basis and half of the women were getting mammograms yearly. As well, of those who had a mammogram, 17 of 20, had the mammogram within the past year. While our interview group showed good breast health practice, particularly in regard to mammograms, many women in the Chamorro community are unable to access breast health services and must be reached.

#### **CERVICAL CANCER**

Pap Smears

As with breast cancer, knowledge regarding cervical cancer in the Chamorro community was very high. All of the women interviewed had heard of a Pap test and 29 had had a Pap test. A majority, 25 of 30 women, identified that a Pap should be done yearly, and 18 of the 30 women were getting yearly Pap smears. Twenty-seven women received their Pap smears via private insurance and 2 women received their Pap smears at no cost. A majority, 24 of 30 women, agreed that cervical cancer could be cured if found early. Most of the women interviewed were insured, which had a positive impact on their knowledge and attitudes about Pap tests and cervical cancer.

#### Chamorro Community Findings

RECOMMENDATIONS FOR POSSIBLE HEALTH
PROGRAMS ON BREAST AND CERVICAL CANCER
FOR THE CHAMORRO COMMUNITY

Sources of Information – Most of the focus group participants and all of the women interviewed said that they would like to learn more about breast cancer, and all but one interviewee stated that they wanted to learn about cervical cancer. Most replied that they would want to learn this information from a doctor (all 30 women), a nurse (27 of 30 women), or a community worker (21 of 30 women). The community leaders' focus group mentioned having groups of women get together to share their experiences of having the examinations, "like hand holding," to reduce fears and misconceptions that the mammogram is always painful. Another professional identified one strategy to reduce barriers for repeat mammograms; following up with women to make sure that they found out their results. In this respondent's experience, when the women never receive their results, it prevents them from going back for annual mammograms.

Setting - The most popular setting for education would be a clinic (all 30 women), followed by a community site (26 of 30 women); relatively few selected a home (II of 30 women) as an appropriate site for this information dissemination.

Format/Medium – The most preferred format or medium for learning about cancer screening was by video (all 30 women), then brochure (29 of 30) and finally television programming (27 of 30 women). Only 6 women noted radio as a preferred source of information. Other education media mentioned included community presentations, seminars, and focus groups, particularly with survivors.

Structure – When asked about how the educational programs should be structured, most of the women wanted a group structure (29 of 30 women), preferably a women-only group structure (23 of 30 women). In contrast with other ethnic groups,

all of the women wanted groups with their husbands and 24 women wanted groups for their husbands. Twenty-seven of the women wanted a mobile van service for screenings.

Service Needs – In addition to education, the women in the focus groups, as well as those who were individually interviewed, expressed that the most important services that would help them to obtain a cancer screening examination in the future would be knowing where to go for screening examinations (28 of 30 women), the availability of low- or no- cost services (27 of 30), and a mobile unit providing screening examinations (27 of 30 women). If a doctor recommends the screening tests, nearly all (29 of 30) of the women responded that they would have the screening tests. Other needed services included having female doctors (16 of 30 women) and someone to drive them to their health appointment (15 of 30 women). Having bus tokens to pay for transportation to an appointment (14 of 30 women) and having childcare services (14 of 30 women) were other factors that would encourage women to obtain a cancer screening examination.

Notably, the men's focus group was very clear that they wanted to support their wives. One man said, "Husbands should encourage them to go because it's a way to keep your wife longer." The men agreed that they were not concerned about the doctors examining their wives, because they feel it is important to have these examinations. The men said that they could make the decision for their wives to go for the tests, help make the appointments, and accompany them for moral support if they were afraid.

# shared voices

# Laotian Community Findings



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#### C. LAOTIAN COMMUNITY

#### Background

Families In Good Health conducted three focus groups: one with 17 women, one with 11 men, and one with seven community leaders. In addition, face-to-face standardized interviews were conducted with 30 Laotian women from the community; these women were contacted through informal social networks.

The ages of the women interviewed ranged from 35 to 74 years, with the majority, 19 of 30 women, in the 40 to 60 age range. Twenty-one of the women were born in Laos, 7 in Cambodia, and 2 in Thailand. All those interviewed immigrated to the U.S. between 1976 and 1996, with the majority, 24 of 30 women, immigrating in 1979 and 1980 with the second major wave of refugees from the Vietnam War. Nearly all (27 of 30) of the women interviewed were married, with one single and three widowed. Over one-fifth of the Laotian women (7 of 30) had received no formal education, 15 had received at least five years, 4 had received 6-9 years of education, and 4 had more than 10 years of education. The majority of women, 24 of 30, said that they spoke their ethnic language "very well," while large percentages also said that they spoke English "poorly" (II of 30) or "not at all" (5 of 30 women). About 12 of the women could not read anything in neither their ethnic language nor in English. Only 8 of those interviewed had private health insurance. Most women had Medi-Cal (II of 30), but 4 had no health insurance at all.

### Major Health Concerns

Some health concerns mentioned by the Laotian women were breast cancer and uterine problems. Another major concern was that some women felt afraid to go to the doctor. One person said, "We like doctor a lot, but sometimes we just scare to visit doctor. If it is not really dying, I will not go." A factor contributing to this fear is embarrassment or shameful feelings about female examinations. Many women do not want the doctor to see their personal

bodies. "I closed my face when doctor performed the exam," one woman remembered.

Similarly, Laotian men felt that the major health concerns that women have about their health are cancers, diabetes, high blood pressure, stroke, and blood discharge problems. The community providers and leaders also felt that cancers, such as breast cancer and lymphoma (non-Hodgkin's lymphoma), were major health problems for Laotian women. Oftentimes, people will go to Mexico to get these cancers treated. One leader shared, "they believe that this kind of cancer cannot be cured in the U.S. So they went to treat in Mexico. They paid \$25,000-\$30,000. When they came back to the U.S., it still not cured." The reason for this is that people feel that, "doctors do not really treat the poor people the same as rich people." They feel that in the United States, "businesses (insurance companies) out there only want healthy people...I am disappointed. They don't care whether you are going to die or live. Old people they don't care"

#### Barriers to Health Care

Community women, men, and leaders voiced similar concerns when discussing the barriers to their health care. They pointed out that many patients do not have health insurance. One privately insured participant expressed, "Medi-Cal recipients do not get a good treatment as insurance patients. Because they know that we will pay them (private insurance). They also give a better medication for us. For Medi-Cal patients, sometimes they cannot buy a brand name medication. They will give something that similar to the brand names, instead." Some women also shared that they were afraid of being used as guinea pigs for research. Many agreed when one woman admitted that she was "scared...we have only Medi-Cal, we don't have insurance...we scare that they might use us for learning purpose."

All community participants mentioned that language and communication problems were major barriers to health care. For these reasons, many women choose to go to Thai or Khmer doctors

#### Laotian Community Findings

because they can speak the same language. Sometimes the elders depend on their children to interpret, which can cause many problems in accuracy and confidentiality. Some women choose not to go to the doctor at all because of language problems. Instead, they go to traditional healers or they use traditional medicine or remedies ("rub, pull, massage...to get rid of bad wind") to treat their illnesses. It is also not uncommon for women to borrow medicine from friends to treat their illnesses. Many women believe that ancestor worship is important for good luck and good health. It is believed that if ancestors become upset, their spirits can cause a person to become ill, so many women pray to their ancestors for better health. One woman related a story about her niece: "Couple years ago, my niece always fainted. We took her to see doctor, they did examination and x-ray. But they could not find anything wrong with her. When we got back home, she fainted again and again...when she fainted; she mentioned that our ancestor needed us to do worship for them. After we did the service, my niece's symptom just went away."

Additional barriers to health care include the lack of familiarity with Western medical systems; many feel that if their physicians do not recommend tests, then they do not need to go to the doctor until they get sick. Other barriers to health care included having to wait too long in the doctor's office, having previous bad experiences with doctors (e.g., someone died from getting the wrong medication), and having to pay for medication themselves because Medi-Cal does not cover the medication. Transportation is also a barrier for some women who must rely on their family or friends to take them to the health care facility.

BREAST AND CERVICAL CANCER KNOWLEDGE, ATTITUDES, AND PRACTICES (SURVEY RESULTS – LAOTIAN COMMUNITY)

#### BREAST CANCER

The Laotian participants identified many causes of cancer. Many of those in the focus groups thought

that cancer is caused by something bad in the body, such as bad blood, breast milk, nerves, the circulation system, ulcers, or infection in the breasts. Some believed that getting cancer is a matter of bad luck or worrying too much. One woman professed, "If I think about cancer too much, I might get it. If I don't think about it, then I will be OK." Others believed that behavioral factors cause cancer, such as touching or playing with the breasts too much, getting breast implants, feeling stressed, or working in sweatshops and inhaling dust.

#### Breast Self Examination (BSE)

Knowledge of breast self examinations in the Laotian community was more moderate. Of the women interviewed, slightly more than half, 17 women, had heard of a breast self examination (BSE). Nearly half, 14 women, had been taught how to perform a breast self examination and 12 of the 30 women practiced BSE consistently on a monthly basis. As well, men in the focus groups were very interested in learning how to properly conduct breast self examinations on their wives while the women wanted to learn to practice on themselves.

#### Clinical Breast Examination (CBE)

Although knowledge and history of clinical breast examination (CBE) screening was high, 26 of 30 women, just half, 16 women, were getting their clinical breast examinations on a yearly basis. A higher number of women (22) identified that a CBE should be given once a year. However, the data reflects that women are not acting on this knowledge. Twenty-six of the women also agreed that most women can live a normal lifetime if breast cancer is discovered and treated early; however, 12 of the women admitted that they were too busy to get their CBE. The interview and focus group data showed that education and information on clinical breast examinations exist in the community; however there needs to be education and reinforcement on the importance of the actual practice of screening. The men in the focus groups generally

#### Laotian Community Findings

did not know much about clinical breast examinations, as most usually wait outside while the women get their examinations and do not know what happens during the examination.

#### Mammograms

Many community providers and leaders stated that women do not get mammograms unless they notice something very wrong with their breasts. Many women were also afraid that the mammogram would be painful.

Our assessment data showed that a majority, 24 of 30, of the women have heard of a mammogram. Eighteen women have had a mammogram within the last year. Of these 18 women, 11 received mammograms via insurance and 7 received their mammograms via Medi-Cal. Eighteen of the women identified that a mammogram should be performed every year; however, only 15 women were getting their mammograms on a yearly basis. Indeed, many community providers and leaders expressed that women did not get mammograms unless they noticed something very wrong with their breasts. Many women were also scared that the mammogram would be painful. Similar to other breast screening practices, the knowledge of the interviewees and focus group was fairly high, but the actual practice of screening methods was much lower.

#### **CERVICAL CANCER**

## Pap Smears

As with breast cancer, the knowledge regarding cervical cancer in the Laotian community is quite varied. Some women and men believed that the cause of cervical cancer is related to hygiene. One woman asserted, "Women don't clean their private body that's why they get cervical cancer." Others believe that it is tied to childbirth; "I think women give birth to too many children, their uterus work too hard. Even when women notice that they have uterus problem, they don't go to see doctor. They wait too long until it

become cancer," claimed one participant. Others believed that cervical cancer is caused by bad blood, family history, or genetics.

Some in the focus groups reasoned that many women do not get Pap smears because they do not know about the benefits of Pap smears in detecting cervical cancer. Furthermore, many women will not get a Pap smear unless they are encouraged to do so by their family, friends, or doctors. Many also stated that doctors sometimes do not recommend Pap smears because some women do not have health insurance. One person articulated, "some has Medi-Cal but their doctor may not recommend them to do the test. Because Medi-Cal doesn't cover very good."

A majority, 28 of 30, of the women had heard of and had had (26 of 30) a Pap test. However, only thirteen women were getting yearly Pap smears; the same proportion of women reported that they were too busy to get Pap smears. Twenty-one of the women identified that a Pap smear should be performed yearly. A majority of the women also believed that smoking cigarettes increased a woman's chances of getting cervical cancer (15 of 30 women), chances of cervical cancer also increased with early onset of sexual activity (19 of 30 women), and having many sexual partners also increased the risk of cervical cancer (24 of 30 women). Twenty-two of the women reported that they had family or friends who encouraged them to get their Pap smears. While focus group data showed that women were unclear of the benefits of Pap smears in detecting cervical cancer, the interview respondents agreed that cervical cancer could be cured if it is found in its early stages.

RECOMMENDATIONS FOR POSSIBLE HEALTH PROGRAMS ON BREAST AND CERVICAL CANCER FOR THE LAOTIAN COMMUNITY

Sources of Information - Most focus group participants and all but two of the 30 women interviewed said that they would like to learn more about breast cancer and cervical cancer screening. Most replied that they would want to learn this information from a community worker (29 of 30), a

#### **Laotian Community Findings**

doctor (26 of 30), or a nurse (25 of 30 women). Some also noted that they would want to learn about breast and cervical cancer screening from an "expert," a bilingual person, a friend, and/or a cancer survivor. Focus group participants also mentioned that other sources of information for health issues should include relatives.

Setting - The most popular setting for education would be at home (25 of 30), followed by at a clinic (21 of 30), and a community site (18 of 30 women). Other possible locations mentioned were at the workplace, at the market, at a friend's house, or at a place near home.

Format/Medium - The most preferred format or medium for learning about cancer screening was video (all 30 women). Television programming (28 of 30), radio (18 of 30), and brochures (16 of 30) were also popular formats. Other media for education that were mentioned include audiotape, newspaper, posters, flyers, songs, and word of mouth.

Structure – When asked how the educational programs should be structured, most of the women wanted a women-only structure (29 of 30 women). A group education structure was more popular (28 of 30) than a one-on-one situation (25 of 30 women). The women were evenly split about programs structured with their husbands (15 "Yes", 14 "No"), with more preferring that programs for their husbands also include, rather than exclude, other women. A very low percentage (10%-3 women) wanted to structure educational programs with men and women together.

Service Needs - In addition to education, the women who were interviewed conveyed that the most important services that would help them to obtain a cancer screening examination in the future would be the availability of low- or no- cost screening examinations (28 of 30) and a mobile unit providing

screening examinations (28 of 30 women). Other needed services include an interpreter to help communicate with doctors (26 of 30), someone to drive them to their health appointments (26 of 30), someone to accompany them to their appointments and provide them with support and help in filling out forms (25 of 30), a recommendation from their doctor to get a screening examination (22 of 30), and having a female doctor (22 of 30 women). Knowing where to go for screening examinations (20 of 30), having bus tokens to pay for transportation to an appointment (15 of 30), and having childcare services (12 of 30 women) were other factors that would be helpful in encouraging women to obtain a cancer screening examination. Both men and women in the focus groups and interviews emphasized that all of these services should be bilingual, since language is one of the major barriers to health care.

# shared voices

# Samoan Community Findings



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#### D. SAMOAN COMMUNITY

#### Background

The Samoan National Nurses Association conducted three focus groups — one with 35 women, one with 23 men, and one with 15 community leaders and one health care provider. In addition, face-to-face standardized interviews were conducted with 29 Samoan women from the community (these women were contacted through informal social networks).

The ages of the women interviewed ranged from 35 to 66 years, with the majority, 21 of 30 women, in the 40 to 65 age range. Twenty-seven of the thirty women were born in Samoa, while 2 were born in the United States. Of those born in Samoa, all had immigrated to the United States between 1954 and 1988. Twenty-one of the women interviewed were married, with 2 single, 3 divorced, and 3 widowed. The majority, 24 of 30, of the Samoan women had more than II years of education, while 5 had less than 10 years of education. The majority of the women, 12 of 29, said that they speak their ethnic language "very well," or "well" (13 of 29 women), while the majority also said that they speak English "very well" (7 of 29) or "well" (II of 29 women). About half, 15 of 29, of the women could read their ethnic language "very well," while II women said that they could read English "well." Sixty one percent (18 of 29) of those interviewed had private health insurance, while 4 women had no health insurance at all.

## Major Concerns

Some health concerns mentioned by the Samoan providers and leaders were diabetes, high blood pressure, heart disease, and weight problems.

Another major concern was that Samoan children, especially girls, lack education. One person said, "Kids that are coming up in high schools, a lot of our kids, especially Pacific Islanders, aren't going to college with that information provided, aren't furthering their education, so it stops there at the high school level."

#### Barriers to Health Care

The providers/leaders also mentioned that there were many barriers to health care for the Samoan community. One major barrier is embarrassment. One participant said, "We still believe very strongly, I'm sure both men and women, but...mostly women because we don't' like to go see the doctor, we don't want to discuss personal issues." Many women said that they prefer to go see a female doctor. Another cultural barrier to health care expressed was the "blind faith" in Samoan spirits and traditional herbs and medicines, with many believing that faith in God will cure an illness. One leader suggested, "We have to educate our people. We have to tell the Samoan people, look, there is a difference in believing in God, and you go to the hospital to get well. Your faith has nothing to do with that healing."

Another major barrier is lack of insurance and not being able to afford health services. Many Samoans do not have a primary doctor they can go see. Lack of transportation is also a major barrier.

BREAST AND CERVICAL CANCER KNOWLEDGE, ATTITUDE, AND PRACTICES (SURVEY RESULTS – SAMOAN COMMUNITY)

#### **BREAST CANCER**

Breast Self Examination (BSE)

Although most of the women, 17 of 30, reported performing a BSE monthly, the healthcare providers and community leaders in the focus groups believed that the percentage of women who actually performed BSE are very low. Nearly all of the women (28) had heard of a breast self examination; however, only 23 had ever been taught how to perform a BSE. Sixteen of the women identified that a BSE should be performed monthly, while 7 of the women had not even thought about doing a breast self examination at all.

#### Samoan Community Findings

#### Clinical Breast Examination (CBE)

The majority of the Samoan women, 22 of 29, interviewed had a clinical breast examination (CBE) in the past. Sixteen of the women identified that a CBE should be performed yearly; however only I3 women were receiving yearly CBE. Four of the women had had a clinical breast examination in the past but were not planning to get another one, and 5 of the women knew that they should get a CBE someday, but had no intentions of planning/scheduling the CBE. One woman stated that she had a CBE in the past; however she was not thinking about getting another one "because I am getting old, no transportation, leaved it to my Lord to cure me."

## Mammograms

Nearly all of the women, 26 of 30, had heard of a mammogram, however of these women only 19 had ever had a mammogram. Of the Samoan women who had received a mammogram, 16 received their mammograms via insurance while 3 received their mammograms at no cost (two women) or with a voucher (one woman). Fourteen of the total 29 women identified that they should be getting a mammogram yearly and II women were getting their mammograms on a yearly basis.

Compared to 63% of the women screened in our sample of 29, the healthcare providers and community leaders focus groups estimated rates of screening to range from 3% to 35%, with lower screening rates among the elderly. Indeed, many healthcare providers and community leaders expressed that women do not get mammograms unless they notice something very wrong with their breasts, or they get encouragement and support from their family to get a mammogram. Many women were also afraid that the mammogram would be painful.

#### CERVICAL CANCER

## Pap Smears

Nearly all of the women, 24 of 29, had heard of a Pap smear and 20 women had had a Pap smear. All of the women had received their Pap smears via health insurance, and 19 women knew that Pap tests should be performed annually. Twenty-six of the women agreed that cervical cancer could be cured if it is found in its early stages. Seven women agreed that a woman is more likely to get cervical cancer if she has had many sexual partners, and 12 women believed that a woman who began having sex at an early age has an increased risk of cervical cancer. The focus group participants stated that many women would not get a Pap smear unless they are encouraged to do so by their family, friends, or doctors. The interview data also supported this concept. Of the 20 women who had a Pap smear, 18 of them had friends and/or family that encouraged them to get a Pap smear. However, of the nine women who did not have a Pap smear, one felt that they had support of friends and/or family, one woman felt that she did not have friends and/or family support, and seven women were not sure if they had support. The lack of support, as mentioned by focus groups participants, may contribute to the lack of screening.

# RECOMMENDATIONS FOR POSSIBLE HEALTH PROGRAMS ON BREAST AND CERVICAL CANCER FOR THE SAMOAN COMMUNITY

Sources of Information – All of the women interviewed said that they would like to learn more about breast cancer as well as cervical cancer screening. Most replied that they would like to learn this information from a doctor (28 of 29) or a nurse (28 of 29 women). Only II women said that they wanted to learn from a community health worker. Some also noted that they would want to learn about breast and cervical cancer screening from a friend,

#### Samoan Community Findings

and/or a cancer survivor. Focus group participants also mentioned that other sources of information for health issues include relatives and church ministers.

Setting – The most popular setting for education would be a clinic (27 of 29), followed by a community site (25 of 29), and at home (I2 of 29 women). Other possible sites mentioned were at the hospital or at a church.

Format/Medium – The most preferred type of format or medium for learning about cancer screening was video (all 29 women). Television program (25 of 29), brochure (25 of 29), and radio (9 of 29) were also popular formats.

Structure – When asked about how the educational programs should be structured, all of the women wanted both a one-on-one structure as well as a group structure with women only. Only 6 of 29 women wanted to structure educational programs with men and women together. However, the women also wanted educational programs for their husbands, with more preferring that programs with their husbands also include, rather than exclude, other women.

Service Needs - Besides education, the women, who were interviewed, expressed that the most important services that would help them to obtain a cancer screening examination in the future would be the availability of low- or no-cost screening examinations (28 of 29) and a mobile unit providing screening examinations (27 of 29 women). In addition, all of the women expressed that they would get a screening examination if they received a recommendation from their doctor to get one. Other needed services would be having a female doctor (27 of 29), knowing where to go for screening examinations (27 of 29), having bus tokens to pay for transportation to an appointment (25 of 29 women), and having someone to accompany them to their appointment and provide them with support and help in filling out forms (24 of 29 women). Having an interpreter to help communicate with doctors (23 of 29), someone to drive them to their health appointment (23 of 29), and childcare services (20 of 29) were other factors that would be helpful in encouraging women to get cancer screening examinations.

# shared voices

# Thai Community Findings



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#### E. THAI COMMUNITY

#### Background

Three focus groups were conducted in the Thai community: one with 16 women, one with 15 men, and one with 31 health care providers and community leaders. In addition, face-to-face standardized interviews were conducted with 30 Thai women from the community; these women were contacted through informal social networks.

The ages of the women interviewed ranged from 26 to 65 years, with the majority, 24 of 30, in the 40 to 60 age range. Twenty-eight of the women were born in Thailand and two women in the U.S. Over half, 18 of 30, of the women interviewed were married, with 5 single, and 3 widowed. Nearly one fifth (5 of 30) of the women had less than six years of education while 22 had more than ten years of education. The majority of women, 23 of 30, said that they spoke their ethnic language "very well," while 7 women said that they spoke English "poorly" or "not at all." Eighteen of the women could read English "so-so." Only 2 women said they spoke English "not at all". Fourteen of those interviewed had private health insurance, an equal number had no insurance, and one woman had Medi-Cal.

## Major Health Concerns

Health concerns mentioned by the Thai women were breast cancer and cervical problems. Some women expressed that they were afraid to go to the doctor for fear of cancer. Several commented that the fear of cancer is the fear of death and women are also too shy and embarrassed to have their breast and cervix examined for cancer by a male physician.

Similarly, Thai men felt that the major health concerns that women have about their health are breast and cervical cancers, cancers in general, diabetes, and high blood pressure. The community providers and leaders also felt that cancers, such as breast cancer were major health problems for Thai women, but they also identified mental health,

religious problems, changes in social structure, and being uncomfortable with communication with health practitioners as major problems. One participant said, "These women have to work until late at night and struggle to support their families. They don't have time to care for their physical health, and they are under so much stress. Need to find ways to relax."

#### Barriers to Health Care

The community women, men, providers, and leaders identified many of the same barriers for women in obtaining good or necessary health care. They expressed that many patients do not have health insurance and even if they did, when they went to the doctor's office for an appointment, the wait was too long. One community leader said, "These women have to work or they have no income, and when they go to the doctor, they have to wait too long and they can't afford the time." Others agreed, "they have to care for their families and that comes first" or "they care more about their families than themselves."

All community participants mentioned that language and communication problems were major barriers to health care. Transportation is also an impediment for some women who must rely on their family or friends to take them to the health care facility.

All three focus groups and interviewees mentioned fear of cancer, but it was not only about death. One respondent said that one woman would not go in for a mammogram because "she was afraid she couldn't afford the treatment if breast cancer found – if found, she go home to Thailand to die." Thus, for her there was no desire to be screened. Other leaders and professionals felt that most Thai women do not think breast cancer is a problem for Thai women, so they do not know they should be screened and they do not know where to go for the examination. One practitioner reported that a woman "feared that breast self examination would disturb sleeping cancer cells," so she refused to do it. Most agreed that Thai women would only go the doctor when "you feel something is wrong." One nurse said,

#### Thai Community Findings

"even though I'm a nurse I don't do BSE or get my mammogram every year or my Pap. I feel healthy so I don't go even though I know you should."

BREAST AND CERVICAL CANCER KNOWLEDGE, ATTITUDES, AND PRACTICES (SURVEY RESULTS -THAI COMMUNITY)

#### **BREAST CANCER**

There were many ideas about the causes of cancer in the Thai community. Some believed that behavioral factors cause cancer, such as touching or playing with the breasts too much, getting breast implants or being under too much stress. Several noted that it must be genetic since some knew families in which two or three generations of women in a family had breast cancer.

#### Breast Self Examination (BSE)

Nearly all the women, 29 of 30, had heard of a breast self examination and 23 women had been taught how to perform a BSE. Half, 16 of 30 women, practiced BSE monthly and 17 identified that women should practice BSE monthly. Ten women had not planned on doing monthly BSE and 4 women had not thought about doing BSE at all.

#### Clinical Breast Examination (CBE)

A majority of the women, 23 of 30, had received a clinical breast examination. Of these women, 22 had their CBE within the last year. Eighteen women identified that a woman should have a CBE once a year and 17 of the women were receiving CBE on a yearly basis. Two of the women identified that they knew about CBE but were not planning to schedule an appointment for one within the next 12 months.

## Mammograms

Nearly all of the women, 28 of 30, had heard of a mammogram and 22 of the women had received a

mammogram. Fourteen of the women had their mammogram within the last year. Half, II of 22, received their mammograms for free, while the other half had their mammogram paid through insurance. Twenty women correctly identified that a woman should get a mammogram every year.

#### CERVICAL CANCER

## Pap Smears

As with breast cancer, the knowledge regarding cervical cancer in the Thai community is varied. All three focus groups believed that the cause of cervical cancer is related to hygiene. One woman expressed, "Women don't clean their private body that's why they get cervical cancer." This was equivocal since another individual said, "I don't know, some people say you should douche, others say you shouldn't, but maybe not being clean causes cancer." Others believe that family history or genetics causes cervical cancer. Some in the focus groups volunteered that many women do not get Pap smears, because they do not know about the benefits of Pap smears in detecting cervical cancer.

Twenty-eight of the 30 women had heard of a Pap smear and 24 women reported having had a Pap smear. Thirteen of the women were covered for their Pap smears through their insurance, 5 had the Pap smears at no cost (one with a voucher), and 6 women paid cash for their Pap smears, ranging from \$30-\$50. Twenty-six of the women identified that Pap tests should be performed annually; however II of the women had not had a Pap test in over two years. This data supported the focus group statement regarding the lack of knowledge regarding the benefits of Pap smears detecting cervical cancer. Twenty-seven women agreed that cervical cancer could be cured if it was detected early, 14 women agreed that having many sexual partners would increase the changes of cervical cancer, 8 women agreed that sexual activity at an early age makes a woman more likely to get cervical, and 8 women felt that smoking might be related to cervical cancer.

RECOMMENDATIONS FOR POSSIBLE HEALTH
PROGRAMS ON BREAST AND CERVICAL CANCER
FOR THE THAI COMMUNITY

Sources of Information - Most of the focus group participants and women interviewed (24 of 30) said that they would like to learn more about breast cancer as well as cervical cancer screening. Most replied that they would like to learn this information from a doctor (all 30 women), a nurse (22 of 30), or a community worker (15 of 30 women). Focus group participants also wanted their examinations and information from female providers, rather than male providers. Having a male provider was a barrier since many women felt embarrassed, especially in relation to Pap smears.

Setting - The most popular settings for education selected were a community site (24 of 30), followed by a clinic (23 of 30), and at home (18 of 30 women).

Format/Medium - The most preferred format or medium for learning about cancer screening was by video (29 of 30), and then by brochure (24 of 30 women). Other formats were television programs (21 of 30) and radio (13 of 30 women). Other educational media that were mentioned include songs and stories by women, audiotape, newspaper, posters, flyers, the Internet, and word of mouth.

Structure – When asked about how the educational programs should be structured, most of the women wanted group structure (25 of 30) and a women-only group structure (22 of 30 women). Twenty-three women wanted separate groups for their husbands and only fifteen women wanted groups with their husbands.

Service Needs - In addition to education, the women in the focus groups as well as those who were interviewed expressed that the most important services that would help them to obtain a cancer screening examination in the future would be the availability of low- or- no cost screening examinations (27 of 30) and a mobile unit providing screening examinations (24 of 30 women). Other needed services included having a female doctor (25 of 30), knowing where to go for screening examinations (25 of 30), and having an interpreter to help communicate with doctors (22 of 30). Someone to drive them to their health appointment (15 of 30), having childcare services (15 of 30), and having bus tokens to pay for transportation to an appointment (10 of 30), were other factors that would be helpful in encouraging women to get cancer screening examinations. Both men and women in the focus groups and interviews emphasized that all of these services should be bilingual, since language is one of the major barriers to health care. Another barrier was the lack of time for the Thai women, since many of them are working in long-hour jobs such as, garment workers. They felt that what little time they had they should focus upon their family rather than themselves.

Notably, the men's focus group clearly asserted that the women should have someone accompany them to the examinations. The men said that they could help make the appointments and accompany them for moral support if they were afraid. One husband said that his wife asked him how he would feel if she had to have a breast removed from breast cancer and he responded that he told her, "even without breast if she lived it is good, if she died, it would affect the family."

# shared voices

# **Tongan Community Findings**



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#### F. TONGAN COMMUNITY

#### Background

Three focus groups were conducted in the Tongan community with a total of II women, I4 men, and II community leaders. In addition, face-to-face standardized interviews were conducted with 31 Tongan women from the community. These women were contacted through informal social networks.

The ages of the women interviewed ranged from 35 to 65 years, with the majority, 21 of 31, in the 40 to 60 age range. All the women were born in Tonga. All those interviewed had immigrated to the United States between 1967 and 1999. Nearly all, 26 of 31, of the women interviewed were married, with 2 single and 3 women widowed. Nearly half of the women, 14 of 31, had 6-9 years of education, while 15 had 10-15 years of education; the majority, 30 of 31, received all their education in Tonga. All of the women said that they spoke and read their ethnic language "very well." However, the majority said that they spoke English "so-so" (14 of 31) or "poorly" (11 of 31 women). The number of women who could read English "so-so" (15 of 31) was higher than those who could read English "poorly" (II of 3I women). Sixty-eight percent (21 of 31) of the women had no health insurance.

#### Major Health Concerns

The Tongan women identified cancer, heavy menstruation, depression, and having hemorrhoids after giving birth as health concerns. Some women also felt afraid to go to the doctor due to fear of the unknown. Others said that they feel lazy and do not have time to go to the doctor. Many also expressed that they were embarrassed to get the examinations, especially if the doctor is male. One participant shared the story of a friend's experience: "One lady says that she was sick almost like a stroke and the doctor examined her and put something inside her through her anus and that time she's full of scared but as long as she found out that is an examination for cancer then she calmed down."

Similarly, Tongan men, providers, and leaders identified diabetes, high blood pressure, heart problems, and cancer as major health concerns for women. Some said, "there is a belief which we all know of, for it originated in Tonga...which states that once cancer is known, there comes...the end of life...and that belief is in the minds of us Tongans." There is also a big taboo in the Tongan community that prohibits women from discussing their health problems with their husbands or family members of the opposite sex. Many focus group members stated "we still practice and observe the "taboo" between brothers and sisters...we cannot discuss certain problems with them nor in front of each other...we tend to keep things for ourselves and it is hard sometimes." Therefore, women tend to think of the welfare of their families first before they think of themselves and "most of the time her major concerns are not of hers...but she is so concerned of her husband and children." Often, the women may worry about all kinds of stress factors, such as her physical appearance, family problems, and financial problems. Many men expressed that they would like their wives to take better care of themselves by exercising regularly, eating a well-balanced diet, getting enough rest, and going to the doctor regularly. Quite a large number of the men offered ways to help their wives improve her health, such as helping the women with housework, taking them to church, and being honest and loving in their relationships with their wives.

#### Barriers to Health Care

Community women, men, providers, and leaders expressed similar concerns regarding barriers to health care. Tongans do not have health insurance. One participant acknowledged, "Sometimes we felt sick but we don't have the chance to go to the doctor because there is no insurance. Some people have low income and she needs some help of how to get to see a doctor that is free."

#### **Tongan Community Findings**

All community participants mentioned that language and communication problems were major barriers to health care. For these reasons, many women choose to go to traditional healers or use traditional medicine or remedies to treat their illnesses instead of going to see a physician. Many also use prayer to deal with their illnesses. Additional barriers to health care include the lack of familiarity with a Western medical system: many feel that if their physicians do not recommend tests, then they should not ask for them. Transportation is also a stumbling block for some women, who must rely on their family or friends to take them to the health care facility. Those who have children also have to worry about childcare.

BREAST AND CERVICAL CANCER KNOWLEDGE, ATTITUDES, AND PRACTICES (SURVEY RESULTS – TONGAN COMMUNITY)

#### **BREAST CANCER**

Many ideas circulated about what causes cancer in the Tongan community. Some of the focus group participants thought that cancer is caused by carelessness with birth control and having too many children. Some believed that cancer is something that occurs naturally in the body or in the blood when we do not take care of our body (such as when someone smokes). Others believed that lack of exercise, poor diet, or bad blood circulation also cause cancer. Some declared that the breasts should be used for breastfeeding and if it is not used for this, then cancer develops. Men expressed that too much fondling or playing with the breasts may also cause cancer. Others believed that cancer is hereditary. Most agreed that early detection examinations are important and that women should get screening examinations when they start menstruation or when they are expecting a child.

Breast Self Examination (BSE)

None of the men participating in the focus group knew what a BSE was, and both women and men in the focus groups were very interested in learning how to do breast examinations on themselves or their wives.

A majority of the women, 24 of 31, had heard of a breast self examination and 15 women had been taught how to perform a BSE. Half of the women practiced monthly BSE and 20 women correctly identified that they should practice a BSE monthly. However, 12 women had never even thought of doing a BSE.

#### Clinical Breast Examination (CBE)

Alarmingly, almost none (28 of 31) of the Tongan women had ever had a clinical breast examination. Twelve of the women surveyed recognized that they should get a CBE once a year, however only 4 women reported that they were actually getting their CBE yearly. More than half, 18 of 31, of the women reported having never thought about getting a clinical breast examination. Nearly all the women, 30 of 31, agreed that most women can live a normal lifetime if her breast cancer is discovered and treated early. Despite this knowledge, the women were not accessing breast cancer detection screenings, as noted previously.

#### Mammograms

Much like breast self examinations and clinical breast examinations, a majority of women, 27 of 31, had heard of a mammogram; however only 4 women had ever had a mammogram. All of the four women screened were covered for their mammography services through insurance; however 3 of the 4 women had not had the mammogram within the past year. About half, 17 of 31, of the women correctly identified that they should get a mammogram every year; however only 4 women reported getting mammograms on a yearly basis. Two of the women reported that a mammogram should be done yearly; however they

#### **Tongan Community Findings**

themselves reported that they know that they need to think about getting a mammogram someday, but most likely will not schedule an appointment within the next one to two years. In addition, 3 other women, who have not had a mammogram, reported that women should only seek mammography services if they feel pain.

In the focus groups, many community providers and leaders observed that women do not get mammograms unless they notice something very wrong with their breasts. Many women expressed fear that the mammogram would be painful. Some men in the focus groups mentioned that their wives have had mammograms, but they were not sure what actually constitutes a mammogram.

#### **CERVICAL CANCER**

Pap Smears

As with breast cancer, the knowledge regarding cervical cancer in the Tongan community is varied and wide-ranging. Some women and men believe that the cause of cervical cancer is related to hygiene or improper care of the body. One woman expressed, "Women do not take proper care of themselves when they have their monthly periods...they often take cold showers, baths which contribute to the possible cause of the cervical cancer." Some men felt that having sex during a woman's period can cause her to have cancer. Others believe that certain medical treatments, such as birth control or injections, can affect the cervix. Some also expressed that having too many lovers or having a husband who "fools around" with several women are possible causes of cervical cancer. Thirteen women believed that having sex at an early age increases a woman's chances of getting cervical cancer, and 14 women felt that cigarette smoking affects cervical cancer. Twenty-eight women agreed that a woman is more likely to get cancer of the cervix if she has had many sexual partners, mirroring the comments from the focus groups.

In contrast to the level of knowledge of breast screening methods, only 15 of the 31 women had heard of a Pap smear. Of the women surveyed only 3 women had ever had a Pap smear. Twelve of the women identified that they should get an annual pap smear; however, only 3 women were getting their Pap smears annually. Nearly all (29 of 31 women) agreed that cervical cancer could be cured if it was found early.

Some in the focus groups stated that many women do not get Pap smears, because they do not know about the benefits of Pap smears for detecting cervical cancer. Furthermore, many women will not get a Pap smear unless they are encouraged to do so by their family, friends, or doctors, but notably, only three women felt that they had the support of family and friends in getting a pap smear.

## RECOMMENDATIONS FOR POSSIBLE HEALTH PROGRAMS ON BREAST AND CERVICAL CANCER FOR THE TONGAN COMMUNITY

Sources of Information - Most focus group participants and all of the women interviewed said that they would like to learn more about breast cancer as well as cervical cancer screening. Most replied they would like to learn this information from a doctor (all 31 women), a nurse (30 of 31), or a community worker (28 of 31 women). Focus group participants also mentioned that other sources of information for health issues include relatives, women's support groups, pharmacists, other health professionals, church members, friends and co-workers, and cancer survivors.

Setting - The most popular setting for education would be at a clinic (all 31 women), followed by a community site (20 of 31) and at home (19 of 31 women). Another possible site mentioned was a hospital.

#### **Tongan Community Findings**

Format/Medium - The most preferred format or medium for learning about cancer screening was by brochure (all 31 women). Video (30 of 31), television programming (25 of 31), and radio (22 of 31) were also popular formats.

Structure – When asked about how the educational programs should be structured, all of the women wanted a women-only structure; no one wanted to structure educational programs with men. Most women also preferred a group structure (30 of 31) to a one-on-one structure (17 of 31 women). Only four women wanted separate programs structured for their husbands.

Service Needs - In addition to education, the women who were interviewed concluded that the most important services that would help them to obtain a cancer screening examination in the future would be the availability of a mobile unit providing screening examinations (all 31 women) and low- or no- cost screening examinations (30 of 31 women). Other needed services include interpreters to help communicate with doctors (27 of 31), knowing where to go for screening examinations (27 of 31), having a female doctor (26 of 31), and having someone to accompany them to their appointment to provide support and encouragement (25 of 31 women). Having bus tokens to pay for transportation to an appointment (20 of 31), having a doctor recommend an examination (16 of 31), having someone to drive them to their health appointment (13 of 31), and having childcare services (7 of 31 women) also figured as important factors that would help in encourage women to get cancer screening examinations.

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### Vietnamese Community Findings



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#### G. VIETNAMESE COMMUNITY

#### Background

Two focus groups were conducted in the Vietnamese community: one with 13 women and one with 14 men. In addition, 11 health care providers and 10 community/spiritual leaders were individually interviewed. Face-to-face standardized interviews were also conducted with 30 Vietnamese women from the community, who were contacted through informal social networks in the following cities: Costa Mesa, Santa Ana, Garden Grove, Westminster, and Stanton.

The ages of the women interviewed ranged from 35 to 77 years, with the majority, 16 of 30, in the 40 to 60 year age range. Ninety-seven percent, 29 of 30, of the women were born in Vietnam and immigrated to this country between 1965 and 1998, with the majority, 19 of 30, arriving before 1990. Nearly two-thirds (21 of 30) of the women interviewed were married, 6 women were single and 3 women were widowed or divorced. Almost one-third (8 of 30) of the women had less than five years of education, 2 women had less than ten years of education, and the majority, 19 of 30, had more than eleven years of education. Three-fourths (23 of 30) of women said that they spoke Vietnamese "very well," with the same percentage saying that they spoke and read English "so-so," "poorly," or "not at all." A majority, 16 of 30, had private health insurance, 6 women had combined Medicare/Medi-Cal, 4 women had Medi-Cal only, and 4 women had no insurance at all.

#### Major Health Concerns

Some health concerns mentioned by the Vietnamese women were breast cancer and diabetes. Vietnamese providers and community leaders felt that the major health concerns that women have about their health are high blood pressure, diabetes, gastrointestinal upset, mental health, smoking, alcohol use (among men), lack of family planning and exercise, and verbal abuse (from husbands to wives).

#### Barriers to Health Care

Community women, men, providers, and leaders all mentioned similar barriers to health care. They explained that many patients do not have health insurance. "In term of financial, many of us can't afford insurance," said one focus group woman. A provider explained that in Vietnam, there is no health insurance. Therefore, when immigrants come to the U.S. they are not familiar with insurance and the health care system. According to another woman, for people who do not have insurance, "[we have to] find a low cost clinic" just to get health care. One problem with public clinics, however, is the long waiting time. Women who have to work, particularly at sweatshops or restaurants, cannot take the time off to go to these clinics for care, so many women just do not go for any preventive care.

Women and providers also mentioned that language and communication problems were major barriers to health care. Cultural modesty is also a barrier, because women are embarrassed by examinations like clinical breast examinations and Pap smears. Pap smears are especially embarrassing and even taboo, because it is believed that the examination will make public a woman's sexual activity and status. Providers believed that Vietnamese in general do not go to their Western biomedical doctors for preventive physical examinations. Elderly Vietnamese also do not want to bother their children to take them to the doctor. Vietnamese tend to wait until they feel symptoms. If treatment is painful or invasive, they will also refuse it and possibly turn instead to traditional home remedies.

Because of language competency and modesty, many women want to see Vietnamese doctors, especially female doctors, but there are few available. One provider explained, "Most women feel more comfortable with a female doctor. In Pomona, there is only one female Vietnamese doctor but with the HMO, not everyone can go to see her." Men, providers, and leaders also believed that Vietnamese women have too much respect for their doctors which prevents them from asking the authority figures questions about their

#### Vietnamese Community Findings

own health. Older women are especially shy and need to be taught to be their own advocates.

BREAST AND CERVICAL CANCER KNOWLEDGE, ATTITUDES, AND PRACTICES (SURVEY RESULTS – VIETNAMESE COMMUNITY)

#### **BREAST CANCER**

Women knew that heredity plays a role in breast and cervical cancer, but they also believed in other risks: having children, breast feeding, and not massaging your breast lumps while you breastfeed. According to one women's focus group participant, "Women have children and that makes them more susceptible to all these sicknesses." Another woman said, "When you detect a lump on your breast when breastfeeding, you have to rub it until it goes away. If you leave it there it will develop into sickness."

#### Breast Self Examination (BSE)

A majority of the women, 28 of 30, had heard of a breast self examination and had been taught (24 of 30) how to perform a BSE. Slightly more than half, 16, of the women practiced BSE monthly, while 8 women had no thoughts of performing a BSE at all. While only half of the women actually practiced monthly BSE, slightly more than half, 19 of the women, correctly identified that BSE should be performed monthly.

#### Clinical Breast Examination (CBE)

A majority of the women surveyed, 24 of 30, had had a clinical breast examination, and 20 of them had had their CBE within the last year. Four of the women were not sure about how often to have a CBE and 5 of the women were not planning to get a CBE within the next 12 months. Of particular concern was that providers from the focus group stated that Vietnamese women believe CBE and BSE are not necessary if they are already getting mammograms.

#### Mammograms

Providers and leaders from focus groups said that there is higher community awareness about the importance of getting mammograms. Interview data supported this as 29 of the 30 women had heard of a mammogram and 26 women had a mammogram. Of the women screened, 14 women received mammography services through private insurance, 5 women through Medi-Cal, 4 through Medi-Cal/ Medicare, and 3 through free programs. Unfortunately, 7 of these women had their mammogram more than one year ago, and 4 women were not planning to have another mammogram within the next two years, which indicates that re-screening is still an issue.

#### **CERVICAL CANCER**

#### Pap Smears

Women, providers, and community leaders from the focus groups stated that Vietnamese women do not know about the importance of getting Pap tests. They also have little scientific or medical understanding regarding their sexual reproductive organs. According to one focus group woman, "That place is moist so you have to be careful and always keep it clean...[if you] don't make an effort to thoroughly dry that part, you are more susceptible to cervical cancer." Women are very uncomfortable and embarrassed about getting the examination and will not request one unless they detect symptoms.

Doctors also do not emphasize Pap tests, although this is changing due to HMO and IPO policies.

Similar to mammography knowledge, 29 of 30 women had heard of a Pap test and 26 women had a Pap smear. Of those women screened, II women were covered by insurance, 4 women had Medi-Cal, 4 women had Medi-Cal/Medicare, one woman had Medicare, one woman received the Pap smear free of cost, and 4 women paid cash, ranging from \$25-\$100. Twenty-seven women identified that they should get a

#### Vietnamese Community Findings

Pap smear screening once a year, but only 18 women were getting their Pap test on an annual basis.

Slightly more than half, 16 of 30, of the women stated that family and/or friends encouraged them to get Pap smears. Twenty-seven women believed that many sexual partners increased the risk of cervical cancer, 22 women felt that smoking cigarettes also had an impact on cervical cancer, and 20 women felt that women who begin having sex at an early age have a more likely chance of getting cancer of the cervix.

## RECOMMENDATIONS FOR POSSIBLE HEALTH PROGRAMS ON BREAST AND CERVICAL CANCER FOR THE VIETNAMESE COMMUNITY

Sources of Information – All focus group participants, most of the providers and community leaders, and all but one of the 30 women interviewed, said that they would like to learn more about breast cancer as well as cervical cancer screening. When asked from whom they would want to learn this information, most replied from a doctor (all 30 women), a nurse (29 of 30), or a community worker (23 of 30). Some also noted that they would want to learn about breast and cervical cancer screening from other experts, their friends, co-workers, and family members. Providers and leaders believed that Vietnamese doctors should also be trained to speak about breast and cervical cancer screening.

Setting - The most popular setting for education would be at a clinic (24 of 30), followed by at home (22 of 30) and a community site (22 of 30 women). Other possible sites mentioned were at the pharmacy, supermarket, and their friends' homes.

Format/Medium – Ninety-seven percent, 29 of 30, of the women preferred video, television, and radio equally for learning about cancer screening, with twenty-two women preferring brochures. Newspapers were also cited as important formats for the community.

Structure – When asked about how the educational programs should be structured, most of the women were open to having husbands educated with wives (25 of 30). Most women wanted a group structure (24 of 30), followed by one-on-one formats (23 of 30 women).

Service Needs - In addition to education, the women interviewed conveyed that the most important services that would help them to obtain a cancer screening examination in the future would be the availability of low- or no- cost screening examinations (all 30 women), recommendation from the doctor to get an examination (26 of 30), knowing where to go for examinations (25 of 30), having an interpreter (24 of 30), bus tokens to pay for transportation (21 of 30) or someone to drive them to the appointment (21 of 30), having a female doctor (19 of 30), and a mobile unit providing screening examinations (18 of 30 women).

## VI. Recommendations for Community Intervention

#### A. Development of the PATH Community Action Plan

The purpose of the needs assessment was to collect data on the healthcare needs of our seven partner communities — Cambodian, Chamorro, Laotian, Samoan, Thai, Tongan, and Vietnamese - and to begin the development of a Community Action Plan and intervention strategy to decrease the disparities in breast and cervical health.

The Community Action Plan was developed in two steps. First, we analyzed existing data and conducted focus groups and individual interviews to determine the communities' barriers to care, behavior, beliefs, health education, and policy strategies. Second, after the partners had developed a draft of a community action plan, community forums were held in each of the seven ethnic communities to release findings and to gather feedback about the plan. The community forums were crucial to the development of the Community Action Plan, because they promoted the project and recruited community members and leaders to the advisory committees. Many community members said this was the first time they had been given the results of studies done in their communities. Many had previously participated in other research projects, but had never been informed of the outcomes. After holding the forums, we incorporated the feedback and finalized a four-year plan for Phase 2 of the project to reduce disparities in breast and cervical health among the seven communities.

#### B. Specific Community Action Plan Strategies

The general PATH Community Action Plan involves four strategic areas to address the common concerns of all seven communities: community education, community training, screening, and policy. Each community, in turn, has tailored the general plan to the specific and unique assets and processes of their community. The following section describes the action plan strategies and provides some examples of community tailoring.

#### I. Community Advisory Committees

It is vital that this project is community-led. Therefore, each partner community has established a community advisory committee to help guide the program, develop materials, recruit peer leaders and patient navigators, promote mini-grants, and provide overall leadership and guidance to the project. Community advisory committees are made up of community members, cancer survivors, and their families, community leaders and community providers, and the committee meetings are conducted in the appropriate languages. For example, the Thai community advisory committee is comprised of members representing the Thai Consulate General's Office, the media, health-related fields, cancer survivors, and the community members (involved in various community activities) who attend meetings held in Thai.

#### 2. Community Outreach and Education

PATH found that community outreach and education was a priority, because many community members had misunderstandings regarding breast and cervical cancer, and sometimes, overall health. Since most of the communities are limited English-proficient (LEP), few of the existing breast and cervical cancer education materials were useful to them. Also, most community members requested that information in their own language, with photos and depictions representing their communities, be created. They also wanted information about how cancer affects their communities and about their risks for cancer. Our needs assessment found that the most popular education methods were individual or family education, small group education with only females, and small group education for their husbands.

PATH partners will be conducting community outreach and education daily. Education will be done through home visits, community events and celebrations, community-based organizations, clinics, temples and churches, and other gathering sites, such as beauty salons, stores, and women's group meetings.

The Tongan community, for example, did outreach at Men's Kava meetings, which are traditional gatherings comprised mostly of men to discuss important issues about the Tongan community.

PATH will also address another important issue men's health. The community members said that in order for men to be involved in women's health, they must first understand their own health. By educating the entire family about health, everyone will understand the importance of prevention and encourage each other to obtain annual check-ups and screenings. PATH partners suggested focusing not only on specific diseases, but rather to concentrate on family health. Our partner health educators have stated that when they go into a home for outreach education they need to first address the family's questions, such as medication management, translation of information they received from their health care providers, misunderstandings about their health care coverage, other illnesses, economic issues in the family, and other issues before talking about breast and cervical cancer. Our partner health educators felt it was important not to make breast and cervical health a separate issue, but to integrate it into an overall health care education for the family.

#### 3. Materials Development

Developing bilingual education materials is essential to this project. Few materials (and for some communities, no materials) related to breast and cervical cancers exist. There are difficulties with using existing materials because they cannot be directly translated. Materials must be culturally adapted and in most cases, new materials must be created by the community in-language. As previously stated, community members want to see "their community's faces" and to "hear their voices" discuss the importance of breast and cervical cancer screening and treatment. As such, community members want these faces and voices to be reflected in the graphics, presentation, and content of the health education materials.

Through the needs assessment, PATH found that the most desired education materials and methods

were videotapes, television and radio programs, newspaper articles, brochures, and other materials, such as calendars with educational messages and music tapes. For example, the Thai community suggested creating a drama series depicting a woman with breast or cervical cancer and developing a story around her treatment. The drama series can be a vehicle to generate discussion within the family about cancer and related issues. The drama would educate while entertaining watchers at the same time.

PATH will focus on the development of bilingual materials related to breast and cervical cancer and overall family health during the first year of Phase II. The materials will be bilingual and bicultural, with the medium (video, tape, brochure) tailored to the preferences of each community.

#### 4. Media

There is an abundance of media outlets in each of the Cambodian, Thai, and Vietnamese communities. Newspapers, radio, and television reach a large percentage of the populations, making it easier to outreach to these communities with health education messages. The Thai media, for instance, has already shown support by publishing several newspaper articles and airing television news stories about PATH, all before the start of the Community Action Plan. PATH will be working with the ethnic media to outreach to women and their families about breast and cervical health. This will include monthly newspaper articles, ongoing radio programs, and television shows. For the populations who have few ethnic media, such as the Pacific Islanders, the community partners will be working to improve their own media. For example, the Chamorro, Samoan, and Tongan partners have planned to publish a joint newsletter and possibly conduct a radio program.

#### 5. Support Groups and Survivor Resources

Many of our cancer survivors in these communities have felt alone with cancer, because they have felt little support and found few resources dealing with cancer with which they can relate. PATH will work with the National Asian and Pacific Islander Cancer

Survivors' Network to link our communities to national and local support networks and resources. Each partner agency will also be developing their own cancer support groups. The Samoan National Nurses Association has already started their support groups with more than 20 women and their families attending regularly. These support groups are conducted bilingually to involve all family members and to help them to understand cancer issues, needs, services, and treatment.

#### 6. Web Site

Community members at the forum suggested designing a multilingual website related to cancer education. The site will be interactive with cancer-related information in many Asian and Pacific Islander languages and will contain bilingual health education materials that can be easily downloaded and printed off the site. We plan to develop a page for community members and their families, as well as separate pages for health care providers needing materials to disseminate to their patients. Older adults who may not have experience on the Internet can ask their children to access the information.

#### 7. Peer Educators

Each PATH partner community will recruit bilingual peer educators to act as health educators and patient advocates. Each community will recruit four to six women who will go through extensive training on health care, breast and cervical cancer, and accessing the health care system. Peer educators will work closely with our partner community health educators to outreach to the communities. They will each receive a stipend to honor their services and commitment.

#### 8. Patient Navigators

The planning stage confirmed a great need for patient navigators. Many community members were confused by the health care system and wanted help in making appointments, understanding their treatment and service regimen, knowing where to go for services, understanding referral and follow-up care and

procedures, and learning how to access resources. A clear example of how a patient navigator could have been vital is in a case with a homeless Thai woman who had been diagnosed with breast cancer. She had received four prescriptions from different health providers and was confused about why and where to get the medication, and so she went without them for two months. Our Thai health educator was able to make the necessary appointments for her to resume her treatments and obtain the care she needed. By having bilingual patient navigators for each community, we will be able to assist community members in accessing care and explaining procedures so that they can make informed decisions about their care.

#### 9. Medical Interpretation

PATH will provide bilingual medical interpretation through referrals to Pacific Asian Language Services (PALS), a lead partner in the PATH project and a provider of trained bilingual medical interpreters for the Asian and Pacific Islander community. Often, community members do not access health care because of a language barrier and when they do, they rely on family members who are not trained for medical interpretation to translate for them. PALS will further examine ways to support and encourage health care providers to incorporate trained medical interpreters into their own health care systems. They will particularly target health care providers and systems that are funded through federal funds in order to meet guidelines in providing accessible health care for limited English-speaking patients.

#### 10. Mini-Grants: Resources for Community Associations and Organizations

In order to be fully successful in educating the communities and to ensure that other organizations and associations integrate breast and cervical health programs at their sites, PATH will be establishing a mini-grant program during the third and fourth years of the project. We will offer seed grants of \$2000 to \$7000 to organizations looking to establish their own breast and cervical health programs. This will

increase the number of resources and support for women and their families. This will also help to build the involvement capabilities in women's health care for many organizations. An example of how mini-grants promote capacity building is our partner agency, Guam Communications Network (GCN), whose health programs began with a mini-grant for a tobacco program and is now a leader in promoting Asian and Pacific Islander health. GCN provides evidence of how a mini-grant can have a positive long-term effect in the community.

#### II. Accessible Screenings

Participants in the needs assessment community forums stated that they needed accessible screening services. Free and mobile screenings were the most popular services. Another suggestion was for community clinics to allot specific days targeting one ethnic group. For example, a community clinic could set the last Friday of every other month for free Pap smears to the Tongan community with bilingual support available. Most of the women in the communities work long hours and cannot afford to take time off to seek care and so having a mobile unit was described as the best way for them to get screened. Re-screening and follow-up care were equally important concerns. Many of the women had previously had a mammogram, but either had not been re-screened to continue annual examinations or had never been informed of their results. PATH for Women will be working with local Breast Cancer Education Detection Programs, Breast Cancer and Cervical Cancer Programs, and other health care providers to improve access to re-screenings, results, and follow-up care.

#### 12. Provider Training

Almost all the women participating in the needs assessment stated that if their physicians had recommended breast or cervical cancer screenings, then they would have gotten them. Most said that their providers never recommended or educated them about cancer screenings. PATH will encourage community health care providers to educate women

regarding the importance of screenings. Mainstream providers who are not familiar with the communities will also be targeted for cultural competency trainings and for education on how to support and work with ethnic communities. All health care providers will be referred to the Asian American National Cancer Awareness Research and Training (AANCART), a national program funded by the National Cancer Institute through Ohio State University. The University of California at Los Angeles is one its partners and several of PATH program staff members are a part of AANCART's steering committee as well. AANCART has established a provider education and training component for cancer control.

#### 13. Policy Advocacy

One of the most important strategies in the Community Action Plan is policy development. We found that most of the health care access needs were related to policy, rather than individual or ethnic community behavior. Language and financial access were the most important policy issues. Most of the families in the communities are underinsured. uninsured, or work long hours and are unable to access after-hours care. Moreover, community clinics that service particular ethnic community members face many barriers as well, such as a large amount of paperwork to qualify them for special programs or failure to receive reimbursement for the services they provide. The Asian and Pacific Islander American Health Forum, the national health advocacy agency for AAPIs, will take the lead in identifying key policy issues to improve health care access for which the communities can also advocate.

[This Community Action Plan is our beginning. Throughout the project's planning and implementation process, the strategies for health promotion in each community will continuously change and improve. The findings from the focus groups and survey interviews form the foundation for our efforts to develop programs to eliminate disparities in breast and cervical cancer outcomes among the seven Asian and Pacific Islander communities. Since each community is unique in their needs and strengths, PATH will regularly examine the effectiveness of each strategy and the degree to which these communities can further develop, tailor, and implement their programs to better serve their communities.]

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