

CULTURAL CONSIDERATIONS IN DEVELOPMENT CHURCH-BASED PROGRAMS
TO REDUCE CANCER HEALTH DISPARITIES AMONG SAMOANS

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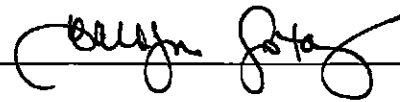
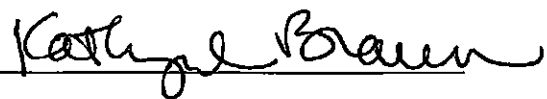
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Abstract

We examined receptivity to developing church-based cancer programs with Samoans. Cancer is a leading cause of death for Samoans, and investigators who have found spiritually linked beliefs about health and illness in this population have suggested the Samoan church as a good venue for health-related interventions.

We interviewed 12 pastors and their wives, held focus groups with 66 Samoan church members, and engaged a panel of pastors to interpret data. All data collection was conducted in culturally appropriate ways. For example, interviews and meetings started and ended with prayer, recitation of ancestry, and apology for using words usually not spoken in group setting (like words for body parts), and focus groups were scheduled to last 5 hours, conferring value to the topic and allowing time to ensure that cancer concepts were understood (increasing validity of data collected).

We found unfamiliarity with the benefits of timely cancer screening, but an eagerness to learn more. Church-based programs were welcome, if they incorporated *fa'aSamoa* (the Samoan way of life)—including a strong belief in the spiritual, a hierarchical group orientation, the importance of relationships and obligations, and traditional Samoan lifestyle. This included training pastors to present cancer as a *palagi* (white man) illness vs. a Samoan (spiritual) illness about which nothing can be done, supporting respected laity to serve as role models for screening and witnesses to cancer survivorship, incorporating health messages into sermons, and sponsoring group education and screening events.

Our findings inform programming, and our consumer-oriented process serves as a model for others working with minority churches to reduce cancer health disparities.

LIST OF TABLES

<u>Table</u>		<u>Page</u>
1	Demographics	11
2	Survey Responses regarding <i>fa'aSamoa</i> and cancer knowledge	13
3	Age Appropriate Screening Practices	17
4	Fa'aSamoa and Health Prevention	20

TABLE OF CONTENTS

Acknowledgments.....	iii
Abstract	iv
List of Tables.....	vi
Chapter 1: Introduction.....	1
Cancer in Samoans.....	1
Samoaans in Hawaii	2
Samoaan Culture.....	2
Chapter 2: Methods	5
Design.....	5
Measures.....	6
Participants.....	7
Procedures.....	9
Analysis.....	10
Chapter 3: Findings.....	11
Demographics.....	11
Themes.....	12
Chapter 4: Conclusion.....	22
Appendix A: Focus Group Guide and Questions.....	27
Appendix B: Female Questionnaire.....	37
Appendix C: Male Questionnaire.....	43
References.....	47

CHAPTER 1

INTRODUCTION

Cancer is a growing health problem among Samoans residing in the United States (US). Although cancer mortality data from American Samoa are not available (Ruidas et al 2004; Tsark et al in press), mortality rates for Samoans in the US have been estimated at 251-287 per 100,000 for males and 171-198 per 100,000 for females (Chu & Chu, 2005). These rates are similar to those for Native Hawaiians, and these two groups have the highest cancer mortality rates of the major Asian Pacific Islander subgroups in the US (Chu & Chu 2005). Epidemiological data suggest that Samoan are diagnosed at relatively late stages of cancer and at younger ages than white Americans and that utilization of cancer prevention services is low (National Cancer Institute [NCI] 2006; Hubbell et al 2005; Mishra et al 1996a; Mishra et al 1996b; Mishra et al 2000; Mishra et al 2001a; Mishra et al 2001b). Surveillance data from the late 1990s suggest that only 33% of Samoan women over the age of 40 had ever had a mammogram and only 64% of Samoan women over the age of 18 had ever had a Pap smear, and that these rates are among the lowest reported for any ethnic group in the United States (NCI 2006; Mishra et al 2001a; Mishra et al 2001b). Unfortunately, few culturally appropriate cancer interventions have been developed for Samoans residing in Samoa or in the US (NCI 2006; Hubbell et al 2005; Ishida 2001).

Literature regarding Samoans' attitudes towards cancer mentions passive or fatalistic attitudes. For example, participants in focus groups and surveys of Samoans in different communities have attributed cancer to *aitu* (spirits) or *Atua* (God), although some considered cancer a *palagi* (western or white man) disease (Hubbell et al 2005; Ishida 2001; Mishra et al 2000). Fear, fatalism, and taboos about touching the body have been given by Samoan women as

reasons for delaying mammograms (Hubbell et al 2005; Ishida 2001; Mishra et al 2000).

However, acculturation may play a role in Samoans' interpretation of cancer. For example, in research with Samoans residing in three sites—American Samoa, Hawai'i, and Los Angeles—residents of American Samoa were most likely to say that cancer can be caused by *aitu* (spirits) and *Atua* (God) and could be cured by *fofo* (traditional healing); Samoan residents in Honolulu were less likely to believe so, while residents in Los Angeles were least likely to feel so (Mishra et al 2000). Samoan research participants also have indicated enthusiasm for learning more about cancer prevention and control (Hubbell et al 2005; Mishra et al 2000).

Samoans represent the second-largest Pacific Islander group in Hawai'i and the US, following Native Hawaiians (U.S. Census, 2006; Hawaii Department of Business, Economic Development and Tourism 2006). According to the 2000 Census, 133,281 Samoans and part-Samoans were living in the US (U.S. Census 2006). An estimated 28,184 live in Hawai'i, comprising 2.3% of the state's population (Hawaii Department of Business, Economic Development and Tourism 2006). Samoans' traditional home is an archipelago of 9 islands in the southwest Pacific Ocean. The eastern part of the archipelago is called American Samoa, which became a US territory in 1898 and served as an important military base in World War II. The western part is an independent nation formerly known as Western Samoa and now officially called Samoa. Samoans have immigrated from both jurisdictions to the US, although those from Samoa must apply to become permanent US residents, and American Samoans do not (Hawaiian Roots Genealogy 2006; Saau 1996).

Discussions of Samoan society refer to the concept of *fa'aSamoa*, which is defined as the Samoan way of doing things and the social, economic and political system of the Samoan people (NCI 2006; Hubble et al 2005; Samoan Dictionary 1999). Four major components of *fa'aSamoa*

include a strong belief in the spiritual, a hierarchical group orientation, the importance of relationships and obligations, and traditional Samoan lifestyle. Spirituality is the belief in God and the spirit world, including control of God and spirits over health and the concept of illness as imbalance among the spiritual, social, and personal aspects of one's life. Samoans differentiate between *palagi* (white person) illnesses (those that can be explained by health professionals and cured by Western medicine) and *ma'i Samoa*, which are illnesses or infirmities that cannot be explained by Western Medicine, thus requiring the attention of *fofo* or traditional healer.

Fa'aSamoa emphasizes a hierarchical group culture in which roles and responsibilities are guided by gender, age and social status. Manifestations of the group culture include the sharing of genealogy to place yourself within a family, clan, and village. It also includes respect for parents, elders, and *matai* (chiefs), and the use of the polite language form when addressing them. It is not uncommon for decision making to be deferred up the hierarchy, and for decisions to be made for the good of the group, rather than the individual.

All relationships are very important, including those between parents and children, within the extended family, with neighbors, and within the village system. Maintenance of relationships is critical, as summarized in this saying, "*Ia teu le va*," in which *va* is the space between two people and *teu* is to attend to, cultivate, and nurture. Obligation and reciprocity are vital processes in the maintenance of these relationships. In Samoan culture, obligation is much more than carrying out one's individual responsibility; rather it is the source of one's blessing. Reciprocity is much more than doing what is right; it is doing what is fundamental to the survival of the Samoan culture. Traditional lifestyle included fishing and cultivation of animal and plant foods. *Fa'aSamoa* also refers to traditional practices, including participating in ceremonies and

festivals, consuming Samoan food, listening to Samoan music, understanding and speaking the Samoan language, and utilizing Samoan traditional healers and medicine.

Church affiliation is important in Samoa, but plays an even greater role for Samoans in the US, where the church serves as a framework for organizing Samoan society in the absence of the traditional village/clan structure found in Samoa (NCI 2006). In fact, an estimated 85-90% of American Samoans residing in Hawai'i belong to a Samoan church (Mishra et al 2000). Because of the importance of the church in Samoan life and the predominance of spiritually linked beliefs about health and illness, investigators have suggested that the Samoan church may be a good venue for health-related interventions (Braun et al 2004; Ishida et al 2001). Church-based health programs have proven successful in other cultures with strong church and group orientations (Peterson et al 2002; Quinn & McNabb 2001; Castro et al 1995).

Despite recommendations for Samoan church-based interventions (Braun et al 2004; Ishida 2001), we found no literature testing cancer-related interventions in Samoan churches. Neither were there published data on pastors' willingness to allow cancer education and control activities in their churches, information about the receptiveness of congregants to church-based cancer education activities, or literature on which educational approaches work best with Samoans. The purpose of this study is to look at the feasibility of utilizing Samoan churches for cancer education and outreach and appraise cultural considerations in developing church-based programs to reduce cancer health disparities in this population.

CHAPTER 2

METHOD

Design

In this study, we employed community-based participatory research (CBPR) methods to gather data that would address these gaps (Minkler & Wallerstein 2003). CBPR refers to research designed and conducted with the community as an equal partner, from priority setting and planning, to implementation and interpretation and dissemination of findings. CBPR builds on strengths within the community, promotes co-learning and knowledge transfer, and provides tangible benefits to the community (Fong et al 2003). Because of our commitment to working in partnership with the Samoan community, this study was preceded by interviews at 12 churches with the pastor (who is both a leader and a gatekeeper) and, because of clear gender roles in Samoan communities, his wife or female designee. These 12 churches were purposefully selected to reflect the range of Samoan churches in the state, including large (> 50 members), small, urban, and rural churches in the denominations most subscribed to by Samoans in Hawai'i— Assembly of God/Pentecostal, Catholic, Congregationalist, Methodist, Mormon, and Seventh Day Adventist. Interviews were conducted in Samoan and followed cultural protocol (displaying respect, sharing genealogy, and using the polite form of Samoan speech). In general, respondents felt that the church was a good venue for reaching Samoans and were willing to consider their churches as sponsors of health promotion activities. Representatives from all 12 churches “blessed” the proposed survey and focus group questions and procedures, and all agreed to join a Blue Ribbon Panel to help interpret research findings and make

recommendations. In keeping with the CBPR practice of transferring skills, six Samoan health workers were recruited and trained to facilitate focus groups and record and transcribe data.

Focus groups, consisting of small groups of individuals responding to a set of open-ended questions, provide a means of gaining a broad understanding of values, meanings, and perceptions of phenomena (Morgan & Krueger 1998). This methodology was appropriate because investigators wanted to understand Samoan attitudes and behaviors with regards to cancer and cancer screening, while also observing influence of cultural involvement and the church setting.

Measures

Focus group discussion (Appendix A) was organized around seven questions: 1) Is cancer a problem in your community, your church, or your family? 2) Have you ever been told to be screened for cancer? By whom? 3) Have you ever been screened for cancer? If yes, what has been your experience? 4) What makes it easy or hard to be screened? 5) In terms of cancer education and screening, what should be done by the individual, family, extended family, and the church? 6) What do you think about conducting cancer awareness and prevention activities in your church? and 7) Which types of activities would you recommend?

Along with the discussion, participants were directed to complete a multi-page survey (Appendix B). To assure that participants understood and had time to respond to each item, the focus group facilitator guided the group through the items. Demographic data included age, gender, education, occupation, health insurance status, birth place and number of years living in Hawai'i and other US locales. Seven items measured elements of *fa'aSamoa*, including celebration of Samoan festivals, use of Samoan language, eating of traditional foods, use of traditional healers, and strength of religion; items were scored on a 4-point scale from rarely or

strongly disagree to all the time or strongly agree. Participants were asked about specific cancer screening tests and when they had last had them, if ever. Cancer knowledge was measured by three true-false items (Having a family history of cancer increases your chance of developing it, Only people with signs and/or symptoms of cancer need screening, and Smoking increases the risk of cancer) and fill-in-the-blank items related to ages at which people should start screening for specific cancers. Nine Likert-scored items measured attitudes toward cancer and screening, e.g., “I don’t want to know if I have cancer,” and “If you have cancer, it means that it is your time to die.”

Participants

From among the 12 large and small churches participating in the pastor survey, the 6 large churches were asked to help organize congregant focus groups, and five agreed. One of the churches declined because they felt their congregants would be too busy to participate. Their Samoan congregants tend to be young and English-speaking, and the church offered no special services or activities for their Samoan congregants. Pastors and/or their designees identified men and women to represent the congregation in the focus groups. These individuals were all Samoan speaking, age 35 or older, and willing to actively participate in the focus groups. In all, 80 individuals were invited to participate in 10 gender-specific focus groups held between February and October 2005 (one male and one female at each of 5 churches), and 66 did so. Those that did not attend cited illness or last-minute commitments. Focus group size ranged from 5 to 10, with an average size of 7. Because group orientation is a cultural norm, host churches were given a \$100 gift (rather than giving gifts to individual participants).

Procedures

Six Samoan health workers—three females for the women’s focus groups and three males for the men’s focus groups—attended 3 hours of training in conducting focus groups. A Samoan language focus group guide, which included general rules and a script, was provided to each trainee. All focus groups were supervised by the Principal Investigator to assure protocol fidelity.

Focus groups were conducted in Samoan, which helped build trust and reduced the chances of being given socially acceptable and misleading responses. In contrast to most focus groups, Samoan church liaisons suggested that their focus groups run 4 to 5 hours. This would emphasize their importance, allow the observance of Samoan protocol (described below), assure that participants understood the questions about cancer screening (about which there might be misconceptions) (Hubbell et al 2005; Ishida 2001; Mishra et al 2000), and increase the validity of data collected.

Each focus group opened with a prayer by one of the elders. This was followed by a traditional apology in which the PI requested forgiveness for possible offenses, including those resulting from reference to body parts involved in cancer screening. Next, each member of the group introduced him or herself by sharing his or her name and some background information, typically including ancestral and familial lineage. Although this level of sharing may be considered a breach of individual confidentiality in mainstream focus groups, it is appropriate and expected in Pacific Islander groups and is essential for building a supportive environment for dialog (Braun et al 2002). Informed consent was obtained, and focus group conversations were audio-taped with permission. Key ideas also were recorded on paper posted on the wall for all to review, and participants were free to offer corrections to this record.

The survey questions were distributed, and survey data were collected over the course of the conversation. For example, participants were guided through the first page of the survey, which contained the demographic and Samoan activity items, and members of the research team assisted those who needed help marking their responses. The facilitator then asked the first focus group question, “Is cancer a problem in your community, your church, or your family?” After a break for refreshment and fellowship, the facilitator reconvened the group and attended to the next page of the survey, which included items on cancer screening behaviors. For each screening method, the facilitator used educational posters and anatomical models to describe the screening procedure and its purpose and benefits. Participants were encouraged to ask questions until the facilitator was assured that they understood the screening test in question. The facilitator then guided the group through the cancer knowledge and attitude items. A discussion of cancer screening followed, with congregants asked about their experience with screening, who had asked them to get screened (if anyone), and why they got screened or not. After another break, the conversation turned to ideas for programming, with particular focus on the feasibility of the church as a venue for cancer education and screening events. When discussion ended, another prayer was offered, and food was served. Participants were then asked to answer three Likert-scored survey items regarding their intentions to talk to family members and physicians about cancer screening and to follow through with screening recommendations.

Analysis

Focus group conversations were translated and transcribed simultaneously from Samoan to English, with each remark attributed to its speaker. Analysis was inductive and followed the following steps. The Principal Investigator and three other researchers independently read the focus group transcripts to consider potential themes and structures in the data. Several team

meetings were held to present identified themes and to discuss possible meanings, perspectives, and frames of reference about the attitudes of Samoans toward cancer. After researchers reached consensus on a structural framework that encompassed the themes and suggested their underlying meaning, a codebook of themes and sub-themes was developed for co-coding. Three investigators reread the transcripts, noting which participants supported each theme and highlighting particularly illustrative passages. In general there was high agreement among the three investigators on themes and on which individuals spoke to each, and any disagreement was discussed until consensus was reached. In both the female and male focus groups, there were many instances where the transcriber noted that many or all agreed non-verbally, or with a simple, "we all agree." Because not every individual spoke to every theme, non-verbal communication such as head nods and other gestures of agreement, as noted in the typed transcripts, were counted in analysis of data. Survey data (e.g., age, gender, insurance status, etc.) were managed and analyzed with SPSS (SPSS 1999).

In December 2005, the Principal Investigator communicated back to the churches through the pastors and the church leaders the results of the focus group during a Blue Ribbon Panel meeting. The PI presented the results using the tables presented in this article, and testimonies of focus group participants were shared. Pastors and church leaders were invited to comment on the data and make recommendations related to further work in this area.

CHAPTER 3

FINDINGS

Demographics

Characteristics of the 66 participating congregants are shown in Table 1. The mean age of both male and female participants was 55 years. Two-thirds were born in American Samoa and a third in Samoa. The mean household size was 6, and about half reported a close blood relative with cancer. More men were currently married (77% vs 51% of women) and working for wages (68% vs 49% of women). Only 18 participants had attended some college. Almost all had a doctor who they could see on a regular basis, and about half had medical insurance.

The figures on place of birth, marital status, number in household and highest grade completed was comparable to the Samoan demographic data in Hawaii. The mean age of the participants (55.08 years) was higher than the mean age of the general population (38.5 years). There were no Samoan population demographic data available for the other items (Department of Business, Economic Development, and Tourism, 2005).

Table 1. Demographics

	Males N=31 N (%)	Females N=35 N (%)
Mean Age	55.26 years	54.9 years
30-39	2 (6)	3 (9)
40-49	10 (32)	11 (31)
50-59	7 (23)	11 (31)
60+	12 (39)	10 (29)
Age Range	35-82 years	38-85 years
Birthplace		
American Samoa	21 (68)	25 (71)
Samoa (formerly Western Samoa)	8 (26)	9 (26)
Hawaii	0	1 (3)
Other	1 (3)	0
Missing	1 (3)	0

Marital Status		
Single	2 (7)	1(3)
Married	24 (77)	18 (51)
Divorced/Widowed	5 (16)	16 (46)
Number in Household		
Mean	6.29	6.86
Minimum	3	3
Maximum	10	11
Highest Grade Completed		
Primary	4 (13)	9(26)
High School	18(58)	17(49)
College	9(29)	9(26)
Where did you go to school		
American Samoa	18(58)	12(34)
Samoa (formerly Western Samoa)	5(16)	12(34)
Hawaii	5(16)	7(20)
Other	3(10)	4(11)
Currently working for wages? ^a	21(68)	17(49)
Do you have a doctor who you see on a regular basis?" ^a	26(84)	29(83)
Do you have Medical Insurance? ^a	30(97)	33(94)
Have you or anyone close to your ever had cancer (now or in the past)?" ^a	13(42)	19(54)

^a Number and percent answering in the affirmative
Note: Percents may not total 100% due to rounding

Themes

Given the intermixing of questionnaire completion and group discussion over the course of the 4-to-5-hour focus groups, findings from both sources are presented in 5 thematic areas common to both: 1) cancer as a problem; 2) *fa'aSamoa*; 3) cancer knowledge and attitudes; 4) cancer practices and barriers; and 5) ideas for programming.

Cancer as a Problem. Conversation in all 10 focus groups suggested that Samoans recognized cancer as an increasing problem in their community, noting that very few people had cancer in the past but that now it was becoming more common. One elderly participant stated:

I've been living in Hawai'i for a very long time and I lived in the same neighborhood for a very long time. Before, I heard of very few people who have cancer, maybe 1 or 2. But

now in my neighborhood there are more than 30 people that I personally know that either died from cancer or have cancer. That is a very large number.

Nine of 10 groups noted that cancer is an escalating problem in the church community. A church leader captured this by saying, “In our church there are about 5 people who died from cancer and 8 who are going through it right now. When the church started nearly 25 years ago we did not have anyone with cancer for the entire first 10 years.”

In the survey, 48% of the respondents reported a close blood relative with cancer. In the focus group discussion, however, 71% of the participants made reference to a family member with cancer; these included extended family, spouses, and in-laws. Nine groups and 61% of the participants commented that few Samoans participate in cancer screening. A participant noted, “Cancer screening is a foreign concept to us. In the past we only go in to the doctor or get *fofo* if we feel pain or sick.” Five groups and 23% of the congregants made the link between low screening rates, late diagnosis, and untimely death among Samoans.

Fa'aSamoa. Items tapping participation in Samoan activities and strength of religion were included in the survey (Table 2). The majority of participants said they often or always spoke Samoan at home (79%), ate Samoan food (86%), and listened to Samoan music (67%). Just under half said they often or always celebrated Samoan festivals (45%), and only 20% reported seeking *fofo* when sick. All women and 90% of the men considered themselves as deeply religious and relied on religion during difficult times.

Table 2. Survey responses regarding *fa'a Samoa* and cancer knowledge and attitudes items

	Males N=31 N (%)	Females N=35 N (%)	Chi- square test	p-value
Fa'a Samoa				
Celebrate Samoan festivals and holidays ^a	15(48)	15(43)	.203	ns
Speak Samoan at home ^a	26(84)	26(74)	.904	ns
Eat Samoan food ^a	23(74)	34(97)	7.35	0.01
Listen to Samoan music ^a	17(55)	27(77)	3.68	0.06
Seek out Samoan traditional healers when sick ^a	6 (19)	7 (20)	.004	ns
Consider self to be deeply religious ^b	28 (90)	35 (100)	3.55	0.06
Rely on religion during difficult times ^b	27 (87)	35 (100)	4.81	0.03
Knowledge				
Smoking increases cancer risk. ^c	24 (77)	33 (94)	3.97	0.05
Family history of cancer increases risk. ^c	24 (77)	25 (71)	.309	ns
Cancer is most curable when it is caught early through screening. ^c	18 (58)	29 (83)	4.93	0.03
At what age should start screening? ^d				
Breast	--	5 (14)		
Cervical	--	13 (37)		
Prostate	3 (10)	--		
Colorectal	4 (13)	5 (14)	.0267	ns
Attitudes^b				
There is not much I can do to prevent cancer.	22 (71)	22 (63)	.487	ns
Cancer is God's will so there is no point of getting screened.	7 (23)	7 (20)	.066	ns
Cancer screening is embarrassing.	26 (84)	30 (86)	.043	ns
Cancer screening is painful.	16 (52)	21 (60)	.469	ns
If I have cancer, I don't want to know.	16 (52)	21 (60)	.469	ns
I trust more in God to cure cancer than MD and medical treatment.	28 (90)	35 (100)	3.54	0.06
God works through health providers to cure cancer.	28 (90)	35 (100)	3.54	0.06
Cancer can be cured by <i>fofo</i> .	18 (58)	4 (11)	16.0894	<0.001
If you have cancer, its better to go to a <i>fofo</i> than an MD.	16 (52)	3 (9)	14.8552	<0.001

^aScored on 4-point scale from 1=rarely to 4=always. Shown are individuals scoring 3-4.

^bScored on a 4-point scale from 1=strongly disagree to 4=strongly agree. Shown are individuals scoring 3-4.

^cScored true or false. Shown are individuals answering correctly.

^dFill in the blank. Shown are individuals answering correctly.

Although no specific focus group question on *fa'aSamoa* was asked, values and orientations relevant to *fa'aSamoa* were discussed in all 10 groups. Specifically mentioned by 79% of the participants was the strong role of God and church in their lives. One participant said,

Church is an extended family. One hurts, we all hurt. I know other [cultures] see family as people with blood relations, but in the *fa'aSamoa* we are all family and we do all we can to support our family, so our church is very involved.

Another noted the great amount of time Samoans spend in church. "We are here all the time sometimes 3 to 5 times a week, and during special occasions we are here 7 days a week."

The value of personal relationships to *fa'aSamoa* was mentioned specifically by half of the males and almost all of the females. As a female participant summarized, "[For] us Samoans, it is all about personal relationship and caring for one another."

As mentioned was the centrality of the group in *fa'aSamoa*, mentioned specifically by 79% of participants. As summarized by a male participant:

We do everything in groups. And if we all do it together, it is best because we can support each other especially those who are just lazy or having second thoughts. Also it is good for accountability. We all say we are going to do this and, lo and behold, we are all going to do it. And those who want to back down will really get motivated to be in line with the troop. It is positive group reinforcement.

Also noted was the importance of hierarchy with Samoan society, suggesting that the larger group will follow the recommendations of civic and church leaders. As one woman reported, "If someone come to this church and ask us to do these things, and our *faletua* (pastor's wife) supports it, then in my mind I think this must be important and I need to go."

Knowledge and Attitudes. Per survey data, most participants knew that smoking increased cancer risk (86%), that family history increased risk (74%), and that cancer is most curable when it is caught early through screening (94%). However, very few knew when

screening should begin as recommended by the American Cancer Society. Among the 35 women, only 5 knew the right age to start breast cancer screening, only 13 knew when to start cervical cancer screening, and only 5 knew when to start colorectal cancer screening. Among the 31 men, only 3 knew when to start prostate cancer screening, and only 4 knew when to start colorectal cancer screening (Table 2). Thus, although participants were aware of cancer, they were not very educated about cancer. In focus group discussions, participants in all 10 groups said they wanted more information about cancer, its etiology, and the reasons and recommended timing for screening.

Analysis of the 9 attitude-related survey items revealed that about 67% agreed that there was not much they could do to prevent cancer. However, only 21% agreed that cancer was God's will so there was no point in getting screened. Rather, attitudes that may prevent or delay screening were fear that screening is painful (reported by 56% of the participants) and embarrassing (reported by 85% of the participants). About half also agreed with the statement, "If I have cancer, I don't want to know." In terms of treatment, 95% of the participants agreed with survey item asking if they had more trust in God to cure cancer than in physicians and medical treatment; 95% also agreed with the survey item asking if they thought God worked through health providers to cure cancer. More than half of the men agreed with the statement that cancer could be cured by *fofo*, but only 4 of the women so agreed (Table 2).

In focus group discussions, participants in 8 of the 10 groups spoke specifically about screening as shameful, with one woman noting, "We were taught to keep our privates private." However, 22 participants (10 men and 12 women) told the group that they had been screened and that "it was not as bad as they expected."

Given the literature that supports Samoans as fatalistic in the face of cancer (Mishra et al 2000; Hubbell et al 2005), we were surprised that only 21% of the participants agreed with the survey item stating that cancer was God’s will and there is no point in getting screened (Table 2). In fact, this pattern was repeated in focus group discussions, in which only 7 women and none of the men reported that fatalistic attitudes deterred cancer screening. In fact, several participants spoke against this notion, with one participant explaining:

God does have a will for our lives, and His ultimate will is for good not for evil. It says so in the bible. Also God gave us free will and a good working brain to think and discern. For example, if the house is on fire you just don’t sit there and wait for the fire to consume you saying this must be God’s will for me to burn in this house and that it why the house in on fire. No! You jump up and run outside to prevent you from death! There are many things we can do to prevent us from death. This “God’s will” attitude is taken out of context.

We also heard the comment, “God does not give you something you cannot handle,” along with suggestions that cancer was a challenge from God, rather than punishment.

Practices and Barriers. Despite the fact that half of participants had health insurance and most had a primary care provider, survey data revealed a low level of screening compliance (Table 3). Among the 35 women, only 9 had ever had a clinical breast exam, 3 a mammogram, 10 a pelvic exam and Pap smear, 1 a sigmoidoscopy, and 1 a colonoscopy. Among the 31 men, only 5 had ever had a digital rectal exam, 4 men and women agreed that they had more trust in God to cure cancer than physicians and medical treatment and that God works through health providers to cure cancer' and that 'cancer could be cured by *fofo* and that it would be better to see a *fofo* than a medical doctor' had had a prostate-specific antigen test, and none had been screened for colorectal cancer.

Table 3. Age-appropriate screening practices

Test	Informed by MD	Ever had	Current
Females Breast self exam (n= 35)	12 (34)	6 (17)	6 (17)

Clinical breast exam (n=35)	13 (37)	9 (26)	3 (9)
Mammogram (n= 32, age > 40)	10 (31)	3 (9)	2 (6)
Pelvic exam (n=35)	15 (43)	10 (29)	4 (11)
Pap smear (n=35)	18 (51)	10 (29)	3 (9)
FOBT (n=21, age ≥ 50)	10 (48)	4 (19)	0
Sigmoidoscopy (n=21, age ≥ 50)	9 (43)	1 (5)	1 (5)
Colonoscopy (n=21, age ≥50)	7 (33)	1(5)	0
Males			
Digital rectal exam (n=29, age≥40)	9 (31)	5 (17)	3 (10)
Prostate specific antigen (n=29, age ≥40)	5 (17)	4 (14)	2 (7)
FOBT (n=19, age≥50)	5 (26)	4 (21)	2 (10)
Sigmoidoscopy (n=19, age≥50)	0	0	0
Colonoscopy (n=19, age≥50)	0	0	0

Focus group discussion revealed several reasons for these findings. First, in 7 of the 10 focus groups, participants told us that Samoans did not visit doctors unless they felt pain or were giving birth. Whether they saw physicians or not, 77% of the men and 51% of the women said their physician had not told them to get screened or, if they had mentioned it, they did not convince participants of its importance. Only 13% of the men and 20% of the women said they received a strong screening message, but chose not to follow-through with screening. Eleven women said they deferred screening because they “put others’ needs before their own,” and 2 women said that they were too busy to get screened.

Ideas for Programming. From discussions about the lack of cancer information, several ideas for programming emerged. In general, participants called for cancer education and programs that fit with *fa'aSamoa* in that they involved church, noted God’s position on cancer and cancer screening, were group oriented, and strengthened personal relationships, and honored Samoan traditions (e.g., presented in Samoan language, stressing the health aspects of traditional Samoan foods and activities, and addressing potential roles of traditional leaders).

Specific ideas were provided for outreach/education programs and for the educational curriculum. Seventy nine percent of the participants stated in focus groups that the church is a good place for cancer outreach programs. As a participant noted, “We are here all the time, so it is a good place to catch us [for health education].” A woman noted the important role of hierarchy by saying, “We do this because if the person who does the education and the *faletua* (pastor’s wife) care enough to educate us, then we need to honor that by going and get checked.”

To increase information about cancer, 61% of the participants recommended workshops, led either by outside providers (preferably Samoan speaking) or by Samoan health providers within the church who received training in cancer. Two women noted that while pastors and their wives could be excellent teachers and role models, they would need to be educated about cancer and specific screening tests. More than half noted that education should be targeted to entire families so that family members could help support each other with screening compliance. A third wanted the pastor to include health and cancer messages in his sermons. Eight of the groups discussed the importance of multiple screening reminders, e.g., through sermons, church bulletins, workshops, and tracking documents like “those yellow cards we get to track our children’s immunizations.” Although none of the groups called for “cultural sensitivity” education of health care providers, 13 women commented that clinics could increase the likelihood of getting Samoan women to screening if they offered same-sex providers and if providers were more personable and communicative.

Regarding ideas for educational curriculum, participants wanted programs that “appealed to the heart,” for example through the presentation of personal testimonies of Samoans who had been through screening and who had survived cancer and through the use allegories and scripture. A participant commented:

To develop a program to get women to get mammograms, you need to go further. We are different from other people. Include a section on why is it important to go get one and not just the generic one I hear all the time – save your life, do it for yourself and your health. You need to touch the core of my spirit and my heart. You see most of the health education stuff that is available out there only touches the “information” part of my brain; it is all information. For example, I know I need to get a mammogram. I read the brochures, and I heard all the messages. But you did not touch my “heart” and my “spirit” or say why it’s important. Not the western definition of why it is important, but our definition of why it is important. You need to move our heart and spirit. If you can move my heart and spirit, you can screen and test my breast all you like.

In line with the culture’s strong family orientation, a woman who had been screened told her group,

The health professionals need to know our shortcomings and the way we see things. Most of us do not want to go for screening because we are afraid to find out something is wrong. As my kids say – “hello!” That is why you need to go to screening. So the health professionals need a stronger message, like, “Don’t be afraid to find out that something is wrong, because the sooner you find it the better chances you have for survival and to live longer.” Who does not want to live longer to see their children and grandchildren grow up?

Although there was limited conversation about Samoan traditions, participants expressed an expectation that workshops would be provided in the Samoan language and that healthy Samoan foods should be served at events, and that the potential roles of traditional leaders (pastors, *faletua*, *fofo*) be recognized.

Table 4: Fa’aSamoa and Health Prevention

	Religion (God & church)	Value of Family	Value Personal Relationship	Putting others Before self	Respect for others	Respect For elders	Group orientation
Programs in church	X						X
Workshops in church	X		X				X
Health fairs in church	X						X
Message in bulletins	X						X

Health Sermons	X		X		X	X	
Utilize Pastors and <i>Faletuas</i>	X		X		X	X	
Utilize health professionals in church	X		X		X	X	
Utilize cancer survivors			X				
Utilize family members cancer patients		X					
Utilize congregants who went to screening			X	X	X		
Message: appeal to the heart	X	X	X	X	X	X	X
Message: get screened for family sake		X	X	X	X	X	X
Use testimonies	X	X	X	X			
Use stories			X	X			X
Use allegories			X	X			
Educate whole family		X					
Providers: more communicative			X	X	X		
Providers: chit chat			X	X	X		
Same sex providers							

Post-discussion Intentions. Asked toward the end of the focus group sessions, three survey items queried participants about talking to family members and physicians about cancer screening and following through with screening recommendations. More than 90% either agreed or strongly agreed with these three items (not shown in table).

Recommendations. Blue Ribbon Panel members responded positively to the information presented at the December 2005 meeting. They nodded throughout the review of findings, and confirmed the interpretation presented above. They were very excited to hear the ideas generated by the participants and how they reflected the spiritual and group orientations of *fa'aSamoa* and honored the centrality of relationships. The group unanimously supported a motion to establish a cancer program based on the *fa'aSamoa*-based ideas for programming. One panel member said, "We need to support this, and we need to get started right away because our people are dying of this disease."

CHAPTER 4

CONCLUSION

Findings from this study confirmed a number of those from other researchers (NCI 2006; Hubbell et al 2005; Ishida 2001; Mishra et al 2000). For example, we confirmed the importance *fa'aSamoa*—including spirituality, group orientation, relationships, and traditions—to Samoans in Hawai'i. We also confirmed that Samoans are interested in learning more about cancer prevention and control. In advancing the literature, we found that church-based cancer programming is appealing to Samoan congregants and clergy and, in fact, fits well with *fa'aSamoa* as it is manifested in the US. We also gained suggestions for programming.

Recommendations to educate the family and use family-oriented messages also have emerged from focus groups with other cultures (Braun et al 2002). In Samoan culture, the family is central both because it is a group (Samoan Dictionary 1999) and because it is the nexus for the most sacred relationships—those among family members. Recognizing this, traditional Samoan healers often engage the whole family in diagnosis and treatment recommendations, which lends to their appeal. In contrast, the majority of health messages and services in the US are targeted to individuals and depend on individual responsibility for self-care. In addition to education about cancer etiology and screening, Samoan families also could benefit from training in supporting members with cancer; families serve as the first line of support for cancer patients in all cultures (Bloom 2000), but especially in cultures, like the Samoan culture, which boast large extended family networks and put such a strong emphasis on obligation and reciprocity.

The significance of spirituality and church in the Samoan community is reported in nearly all studies about Samoans. Several researchers note that Samoans attribute cancer to punishment from God or God's will (Hubbell et al 2005; Mishra et al 2000); however our

participants provided a more sophisticated view of the relationship between cancer and God. Rather than punishment, cancer is a trial or challenge from God, which can be interpreted as an honor. Because Samoans believe that God does not give you something that you cannot handle, the trial of cancer is only visited upon the very strong. Also, we learned that, regardless of a Samoan's choice of Western or traditional healing, they believe that a positive outcome is a manifestation of the healing power of God through health providers. A person with cancer should not assume that the disease will kill them; rather they should rise to God's challenge of cancer, a view that also was heard in focus groups with Native Hawaiian cancer survivors (Braun et al 2002). Interpreting cancer as God's will also implies that this diagnosis serves a higher purpose and is within His grander plan, thus giving patients strength to endure treatment and, if terminally ill, hope beyond death. Educational programs for Samoans should emphasize the positive aspects of cancer as God's will, especially for terminal patients.

Others have reported on the hierarchical group orientation of Samoan society, and this translated into suggestions for the pastor and the *faletua* (pastor's wife) to talk about cancer, recommend screening, and role model appropriate health-seeking behaviors. Given the likelihood that these leaders are not up-to-date on cancer etiology and screening recommendations, they must be targets of education in addition to whole families and congregants. It also is likely that church leaders are too busy to be cancer educators, and training church members who are health professionals to serve as educators was a good suggestion from the groups. Organizing tips may be gleaned from parish nurse programs (Hughes et al 2001). The request for educational approaches that "appeal to the heart" reflect the importance in this culture of affective learning (Bloom et al 1964). This can be facilitated by featuring testimonials

of individuals within the church community who have participated in screening and coped with cancer.

In terms of educational objectives, programs should help Samoans move cancer from the *ma`i Samoa* category, reserved for unknown and potentially supernatural illnesses, to the *palagi* illness category. This takes cancer out of the realm of the *fofo* and into the realm of Western medicine, which will lead to increased receptivity to Western approaches to cancer prevention and control. It was gratifying that only 10% of women in our focus groups (compared to more than half of our men) would see a *fofo* for cancer, suggesting that most of the women already classify cancer as a *palagi* illness. This also supports the role of women as family health educators.

A second objective would be to increase physician visits among Samoans. We heard that Samoans avoid accessing care (either *fofo* or physician) until they are in pain (even if, as in our case, they have insurance and a medical home). This was especially true among males, mirroring lower health utilization by men in the US as a whole (Cherry et al 2003) and among Native Hawaiians (Hughes 2004). That Samoan women also avoid visiting providers may be due to lack of same-gender providers or because they do not understand preventive health concepts (both noted in focus groups), and/or because primary and secondary prevention services are very limited in their homelands, where their health behaviors were shaped (Ruidas et al 2004; Mishra et al 2000). As provider recommendations (Coughlin et al 2005; Wee et al 2005) and health maintenance visits (Ruffin et al 2000) are leading determinants of screening compliance, efforts need to be made to increase physician visits among this group. Providers likely could benefit from training on Samoan culture and developing ways to meet expressed needs for relationship building and communication.

A third objective would be to increase screening compliance. If Samoans are not accessing physicians, then programming must go beyond education to include screening. Several models are available to increase screening among under-utilizers. It is likely that values-based interventions proven successful with Native Hawaiians can be adapted to Samoans. These include a navigator-type program utilizing kinship networks and *kokua* (cooperation) groups (Gotay et al 2000) and the 'Ohana (family) Day program that attracted whole families to a *ho'olaulea* (community celebration) featuring cancer screening by same-sex Native Hawaiian physicians (Gellert et al 2006), both of which were successful in increasing cancer screening rates.

We realized several benefits to using CBPR methods in conducting this study (Minkler & Wallerstein 2003). First, by engaging Samoan pastors and churches in designing and coordinating the focus groups, we secured their buy in for the process and supported their ownership of the findings. By conducting the focus groups in Samoan and using native Samoans as facilitators and note-takers, we were able to capture and accurately interpret the discussion, including poetic meanings and non-verbal cues common in Samoan language and culture. We respected advice to allot 5 hours for each focus group, segregate groups by gender, serve Samoan food, incorporate prayer, honor hierarchy, and engage churches in data interpretation, and these actions helped build a trusting relationship between the researchers and the church members. We also build capacity in the community; the facilitators and note-takers that we trained have since been hired by other researchers and community groups interested in assessing need.

As with most qualitative studies, our research was limited by its small size and convenience sampling. Those who participated were likely to be different from those who did not. For example, we asked pastors to identify participants who would be willing to share their

thoughts on cancer, so our participants likely reflected the “talkative” rather than the “shy” congregants. Because the focus group was conducted in Samoan, however, we do not feel that these “talkative” ones were any more Westernized or health compliant than other church members. Another limitation is the lack of participation by one of the churches. This group would have provided a different perspective, one of Samoans who are young, English-speaking, and are well integrated into the mainstream culture. Thus, our findings are most relevant for Samoans who attend churches offering Samoan-language services and activities. In Hawai‘i, we estimate that two-thirds of Samoan adults fall into this category. Since the focus group facilitators were cultural insiders and had their own biases, they were trained to use the focus group guide and ask participants to clarify responses instead of assuming the answers.

Because our study focused in Hawai‘i and used a CBPR approach, we feel confident that our findings can be used to develop church-based programming in this state, and church leaders have requested assistance in doing so. We believe that cancer programming based on the values and traditions of *fa‘aSamoa* also would appeal to residents of American Samoa, which was awarded a Community Networks Program (CNP) grant from NCI in 2005 (CNP 2006), and perhaps among some Samoans residing on the continental US. Future research is planned that will test these hypotheses, as well as the effectiveness of church-based programming using a positivistic research approach. Finally, we believe that our process, grounded in CBPR, can serve as a model for other researchers working with minority churches to reduce cancer health disparities.

INTRODUCTION

This Focus Group Guidebook is designed to help coordinators and facilitators plan and conduct focus groups in their churches. This guidebook has been developed specifically for the Samoan Church-based Cancer Project a program of `Imi Hale/Papa Ola Lokahi.

Why are we conducting focus groups?

- ✓ The purpose of these focus groups is to gather cancer information from the pastors, their wives, and congregants. We will use this information to design culturally appropriate church-based interventions to improve cancer screening among Samoans in Hawai'i.

What is a Focus Group?

A community discussion group is like a "talk story" session. It is a valid research process that is especially useful when:

- ✓ The researcher wants to find out **how** and **why** something happens.
- ✓ The researcher just wants to understand more about how people think about or approach an issue.

This method allows individuals to freely express their thoughts and feelings. It also allows the researcher to observe how people in the group change their opinion, as group and individual opinions may influence each other.

In some cases, the researcher might have to adapt this "talk story" approach and meet one-on-one or in pairs, depending how people feel about being interviewed.

Why the Samoan community?

- ✓ Cancer is a growing health problem in the Samoan community.
- ✓ Compared with whites diagnosed with cancer in Hawai'i, Samoans have a higher rates for cancers of the nasopharynx (especially males), stomach, liver, lung (especially males), uterus, thyroid, and blood.
- ✓ Data also suggest that Samoans are diagnosed at relatively late stages of cancer and at younger ages than white Americans and that utilization of cancer prevention services is low.
- ✓ Samoan screening rates for breast and cervical cancers are among the lowest reported for any ethnic group in the United States

Why Samoan churches?

- ✓ Religion plays an important role in the Samoan life, and an estimated 85-90% of American Samoans residing in Hawai'i belong to a Samoan church.
- ✓ Although the church is very important to the Samoan community, is the center of all Samoan activities, and has been utilized to recruit participants for cancer research we found no program/research testing cancer-related interventions in Samoan churches.

Why should we get our church involved?

This means the community needs to play an active role in assessing their own community. Community involvement is important for many reasons. Advantages of community involvement and participation are:

- ✓ Culturally appropriate solutions to problem
- ✓ Greater community ownership
- ✓ Improved community organization
- ✓ Greater skill in solving other problems
- ✓ Self-confidence and pride leading to increased self-reliance
- ✓ Support (buy-in) and acceptance from the community

What language will be used?

The use of language is one of the most powerful ways culture is transmitted. We encourage you to use the language that the participants find most comfortable for expressing their ideas. Sometimes people are comfortable using the Samoan language and other times it is easier to use the English language, especially when describing technical and medical terms. We found great success in using both the Samoan and English language.

If the Samoan language is used, allow enough time for transcribing and translating the information back to English.

PREPARATION

You will need 1-2 months to prepare for the focus groups. Involve pastors, their wives, church leaders, and other representatives from the church in focus group preparation.

Who are you going to invite to the focus group?

Samoans who are over the age of 35 are invited to participate in the focus group. Please note that there will be two focus groups in each church, one for the males and the other for females.

How many people to invite?

Ideally, Focus Groups consist of **5-10** people. If you have too few members, you will not get much information or interaction. If you have too many, some people will get bored and drift off. If you have talkative participants, 5-6 members are enough. If you have quieter participants, 8-10 members are better.

How are you going to invite people to the training?

When inviting people to participate (either verbally or in writing), be sure to tell them:

- ✓ Purpose of the focus group
- ✓ What to expect
- ✓ Location - include a map
- ✓ Meeting date and day
- ✓ Start and ending time

Where is the training going to be?

The focus groups will be held at the churches. A quiet and comfortable setting is needed for the discussion group. A small round table is ideal. This will allow tape recording of the session and will give people a place to write and put name cards, refreshments, etc.

Will there be food?

Hospitality in the Samoan culture includes food. You can serve food before the meeting to give people something to do while waiting for others to arrive.

What resources do you need for training?

- ✓ Stand-up Name Cards. Bring paper for each person. Have them fold an 8 1/2 x 11" piece of paper into thirds and write their name in BIG LETTERS on one of the sides. Unfold the paper so it looks like a triangle from each end. This shape stands on the table by itself in front of the person. This way, the group leader can read each person's name easily.
- ✓ Pens and Pencils. Bring plenty of pens or pencils for people to use when they fill out forms. Also bring colored magic markers – you will need these to make name cards and for recording data on the flip charts.
- ✓ You will need flipcharts (with topic headings pre-printed), extra flipchart paper, and masking tape or push pins.
- ✓ For Tape Recording, bring 2 tape recorders and at least 4 blank audiocassettes, already marked with the date and name of the discussion group.
- ✓ Kleenex, in case someone needs to use it. If someone has had cancer or has lost a loved one to cancer, talking about cancer may trigger an emotional reaction.
- ✓ Refreshments. It is important to share food and drink together, as this makes people more comfortable and gives them some energy for the discussion. Offering food and drink also is a way to say "thank you" to the participants.

SHARING ENVIRONMENT

Most Samoans do not share personal information or feelings. Your challenge is to create an environment in which people feel safe and comfortable about sharing their thoughts and feelings.

Make people feel welcome. As people arrive, greet them warmly and thank each person for coming. Offer them some refreshments, and help them find a seat. When it feels right, you can help fix their name cards, and encourage them to complete the one-page *Getting to know you!* (Appendix B).

Getting Started. Once most of the people have arrived, have them make their name cards and place it in front of them. You are ready to start. Begin by thanking them for coming. Remind them of the purpose of the group. Introduce yourself and the staff assisting with note taking and explain your roles.

Set the Tone.

- ✓ Start the meeting with a prayer and introduction.
- ✓ Let group members know that there are no right and wrong answers.
- ✓ Let group members know that you will listen to all the people's thoughts, may call on people who are quiet, and may ask talkative ones to "hold that thought" so everyone is heard.

Consent Forms. Before having the participants sign the consent forms, explain the following:

- ✓ The purpose of the discussion group,
- ✓ That the discussion will be tape recorded, and
- ✓ That their answers will be included in a report, and that no one's name will be used in the reports to maintain confidentiality.

Once Consent Forms are completed and collected, you may proceed to the first question.

Listen for the Long Answer. The purpose of holding a community discussion group is to get people to talk. So your questions should be open-ended. That means that they can't be answered by a "yes" or a "no." We're listening for a longer answer.

Be Interested. Don't Pass Judgment. It is important for the facilitator to be nonjudgmental and interested in what each person has to say. A good facilitator responds to each participant with statements like, "OK, I see," "how interesting," "good point," or "thank you for that contribution."

Ask "How many?" The facilitators can also try to get a sense of how prevalent an issue is by asking, "Several of you have mentioned _____, how many others feel that way?" The recorders should note the level of agreement.

Time Limits Are Relative. Use your good judgment and cultural sensitivity when it comes to how much time you need. An average gathering might be 90 minutes altogether, including the initial gathering, the eating, and the talking phases. But if clock-watching is not part of your group's usual perspective, don't be limited to 90 minutes. Be respectful of participant's time. If the session will benefit by going over the time allotted, ask the group members if they will stay longer.

What to do if a participant gets emotional and starts crying? Be sure to bring Kleenex. If someone has had cancer or has lost a loved one to cancer, talking about cancer may trigger an emotional reaction. One of the assistants should bring the box of tissue to the person who needs it and provide comfort. If the person cannot be comforted, seek assistance from the pastor or pastor's wife.

What to do when participants ask medical or cancer questions? Remind the group that this is not an education session. Instead, the purpose of the focus group is to learn what cancer-related programs Samoan church members would want. Write down all the questions, as these will help us design a future program. At the end of the session, you can distribute cancer education materials, answer questions, and make referrals to the Cancer Information Service 1-800-4-CANCER.

Close. Ask for any last thoughts. Thank participants again.

- ✓ If you have included cultural protocol throughout your discussion group, a specific closing may be part of this protocol.
- ✓ A gift of appreciation is often given to someone who has shared something of value with you. You should investigate and plan for this type of "thank you."
- ✓ Remind the group about the usefulness of the data. Ask if they would like to participate in a future discussion group where the findings are shared.

RECORDING THE DATA

The facilitator will work very closely with a team of recorders. It is best to have two or three recorders for each focus group.

Recorders are responsible to make sure people's thoughts and feelings are written down. Several tools will be used including:

- ✓ **“Getting to Know You” Sheets.** People will be asked to write information on prepared forms. See Appendix for copies of:
 - ❖ Consent Forms, and
 - ❖ Background Data Sheets asking for the person's age, gender, and other demographic items.
- ✓ **Flip Charts.** A scribe or recorder will write information shared by the participants on flip chart sheets. The sheets should be prepared ahead of time with the proper headings that correspond with the facilitator's script (Appendix C.) Recorders will also count and record “how many” people agree with certain answers. Pages should be numbered and taped on the wall for all to see as the meeting progresses.
- ✓ **Tape Recorder.** The entire discussion will be recorded on cassette tape. If the community's language is not English, the transcript of the discussion will need to be transcribed then translated to English prior to analysis.
- ✓ If possible a simultaneous English translation of the discussion may be done. A simultaneous translation involves one person translating and speaking into a tape recorder while a second person listens to this simultaneous translation and takes notes. Whew! It's not an easy task, but it's one way to accurately capture the meaning of the speakers.

THE SCRIPT

Welcome & Prayer

Talofa ma Afio mai! Before we begin, I would like to ask _____ to open and bless this gathering with a prayer.

Prayer

Fa'afetai tele _____ for the prayer. And again, Talofa and Welcome to the Samoan Cancer Focus Group. My name is _____. Let me also introduce _____ and _____ who will be helping today. We are working on a project called the Samoan Church-based Cancer Project. A program of Imi Hale-Papa Ola Lokahi and is funded by the National Cancer Institute.

We are interested in finding out the best way to design cancer programs for Samoans in Hawaii and we believe that the best way to design a cancer program for Samoans is to ask Samoans (just like you) to tell us how to do it. Your participation is very important to all Samoans in Hawaii, as it will help plan for future cancer programs.

Since we are very interested in what you have to say, we are going to tape record this session. When you sign the consent form, you give us permission to record what you say. The audiotape will help us to know that we have correctly recorded the information you shared. Your identity will be kept private. These tapes will be kept confidential, stored in a locked cabinet and destroyed at the end of the project.

You may hear comments that you may not agree with, but all answers are OK. We are interested to hear whatever you have to say, no matter what or how unusual it may seem. There are no right or wrong answers to our questions.

If you have not filled out the Consent Form and the Get to know you! Sheet, please do that now. This information you give us today will be used for educational purposes, but what you say or write will be kept confidential and nothing will be linked to your name. If you would like a copy of the results of the discussion group, please provide your mailing address on the sign in form.

Thank you very much for agreeing to talk story with us today.

Notes:

Facilitator: If possible, please review Consent Form and Background Data Sheet with participants as they arrive. Help them fill out forms if needed.

Facilitator: Please explain this procedure and note that they give their permission for taping in the consent form.

Facilitator: If participants have not already done this, give everyone time now to fill them out.

Opener

I know that all of you know each other and some of you have known each other for a very long time BUT for my benefit and the benefit of our recorders, please introduce yourselves. Tell us your name and little bit about yourself. For example – since we are here to talk about cancer, do you know anyone that has cancer or has died of cancer?

Recorder: Please record names and cancer experiences.

<p>Focus Group Question #1 Is cancer a problem for your community, your church, or your family? Why or why not?</p> <p>Thank you all for sharing, I know that sometimes it is very hard for us to share that kind of information so really appreciate you sharing all that with us.</p>	
<p>Focus Group Question #2 Have you ever been told to be screened for cancer? By whom? Why is screening important?</p> <p>Now let move forward – How you ever have been told to be screened for cancer? Just to clear things, when I say screened for cancer I mean cancer tests like:</p> <ul style="list-style-type: none"> ◆ Women: Pap Smear, Mammogram, ◆ Men: <p>By a show of hands, how many of you have been told to be screened for cancer?</p> <p>Ask those who raised their hands: Who asked you to go in?</p> <p>After everyone answered – ask: Why do you think it is important to go in for screening? Note: this is the good time to mention the YOUR TURN RULE since everyone need to answer this question.</p>	<p>Facilitator: If you ask a question and no one is volunteering to use the “Your Turn Rule” Everyone’s answer is very important. Remember there are no right or wrong answer therefore you will always have something very valuable to say. We will take turns by going around the room. This time we will start on the left, next time we will start from the middle, and so on.</p> <p>Recorder: Use Flip Chart 2A: By whom and Flip Chart 2B: Why is screening important.</p>
<p>Focus Group Question #3 Have you ever been screened for cancer? If yes, what has been your experience?</p> <p>By a show of hands, how many of you have ever been screened for cancer or go in for cancer testing?</p> <p>Ask those who raised their hands: What has been your experience? Was it hard for you to find the right office to call? Was it hard for you to make an appointment? How was the location – is it near by or far away? How hard was it for you to get a ride to the place? Was it painful? Was it embarrassing? Was it painful? Please, in your own words, share with us your experience.</p> <p>Ask those who haven’t raised their hands: Why haven’t you gotten screened?</p>	<p>Facilitator: If you feel that the conversation is drifting off track, remind the group the question.</p> <p>Recorder: Use Flip Chart 3A: Experience and 3B: Why not?</p>
<p>Focus Group Question #4 What makes it easy/hard to be screened?</p> <p>Now that we talked about your experience with screening and by the way thank you for sharing! We now want to know what makes screening hard/easy. We already got some idea from your stories BUT we want to make sure we get everything.</p> <p>What makes it easy or hard to be screened? We have two sheets up so please</p>	<p>Recorder: Use Flip Chart 4A: Easy and Flip chart 4B Hard</p>

<p>feel free to say anything and _____ will put your answer on the right sheet.</p>	
<p>Focus Group Question #5 In terms of cancer screening what should be done by the individual, family, extended family, and the church?</p> <p>One of the BEST things about our Samoan culture is that we have a wide net of people who help and supports us. This is also true when it comes to health care and cancer screening. When it comes to cancer screening what should be done by the:</p> <ul style="list-style-type: none"> ◆ Individual? ◆ Immediate family? ◆ Extended family? ◆ Church? 	<p>Recorder: Use Flip Chart 5A: Individual 5B: Immediate Family 5C: Extended Family and 5D Church.</p>
<p>Focus Group Question #6 What do you think about conducting cancer awareness and prevention activities in your church? Which type of activities would you want and allow in your church and how involved would you want your church to be? How involved do you want to be?</p> <p>We talked about what the church can do in the previous discussion BUT now we talk cancer awareness and prevention activities in your church. Activities like health education, health fairs, health announcements and health inserts in your bulletin.</p> <ul style="list-style-type: none"> ◆ What do you think about conducting cancer awareness and prevention in your church? Just to make things clear, when I say “church” it doesn’t necessarily mean during “church service” or on Sunday. It can be before/after the service, before/after choir practice, etc. ◆ Which type of activities would you want and allow in your church? How involved would you want your church to be? Do you want your church to plan health fairs, coordinate cancer screening days, etc. ◆ How involved do you want to be? For example: do you want to be part of the planning team, do you want to be trained to be cancer educator? Etc. 	<p>Recorder: Use Flip Chart 6A: Cancer Awareness, 6B: Church activities 6C: Individual involvement</p>
<p>Focus Group Question #7 Who is the best liaison between health care providers and the church? Our final question: If your church wants to be more active and involved in health and cancer issues, who is the best person to represent your church or who is the best liaison between health care providers and your church.</p>	<p>Recorder: Use Flip Chart 7</p>
<p>Fa’afetai</p> <p>Thank you very much for sharing your thoughts with us today. We learned a lot. We will be analyzing the data and bringing back a summary to you. We will invite you to a meeting to hear about the findings and to help us interpret them. I will also hang around after the session to answer any questions you might have. Again, Fa’afetai tele for sharing. Ia soifua ma ia manuia!</p>	<p>Recorder: Please make sure all the Flip chart papers are in numerical order, folded and put in the <i>brain</i>.</p>

Consent Form

I agree to participate in a Focus Group on Cancer. The purpose is to learn what is needed to improve cancer prevention, screening and control for Samoans in Hawaii. I understand that I will be asked questions on how I feel about cancer, and what I think can be done to reduce the problem of cancer in the Samoan community in Hawaii.

I understand that the discussion group will be tape recorded, but that my name will not appear in any written or oral report about the results of this discussion. All tapes and written records from this Focus Group will be kept in a locked file. These tapes and survey forms will be destroyed after 3 years.

I understand that the Focus group is expected to take about two hours, and that I will be asked to provide personal information to complete a short form at the beginning of the discussion group. I know that I am taking part in this project of my own free will, and that I have the right to change my mind and leave the Focus Group at any time for any reason.

I certify that I have read this form, or I have had it read to me.

Print Name

Signature

Date

NOTE: If you cannot obtain good answers to your questions, or you have comments about your treatment in this study, please contact Dr. Kekuni Blaisdell

Appendix B Female Questionnaire

Project

Date: _____

Female Questionnaire

Thank you for helping us to learn what women think about screening tests for cancer. There is no right or wrong answers to these questions - we are interested in your beliefs and opinions. All of your answers will be keep strictly confidential, and we do not ask your name. Your answers will help us improve cancer prevention services for Samoans and Pacific Islanders.

Background:

Age: _____

Work: (Currently - for wages): No Yes

Type _____

Ethnicity: _____

Birthplace: _____

Marital Status: Single Married
 Divorced Widowed

Number people living in your house _____

Highest grade completed? _____

Where was this? Samoa Hawaii
 Other _____

1. I celebrate Samoan Flag day and other Samoan festivals
 All the time Most of the time Some of the time Hardly
2. I speak Samoan at home
 All the time Most of the time Some of the time Hardly
3. I eat Samoan food
 Daily At least once a week Only on Special Occasions Never
4. I listen to Samoan music
 Daily At least once a week Only on Special Occasions Never
5. When I get sick, I use Traditional Samoan Healing methods
 All the time Most of the time Some of the time Hardly
6. I am proud that I and my family are Samoans
 All the time Most of the time Some of the time Hardly

Screening Tests for Cancer:

Now we will ask you about screening tests to find cancer in women. Doctors use several tests and they can get confusing. So before we ask the questions, we will describe each test.

Test for Breast Cancer

1. Self breast exams (BSE) -this is when you look for any lumps or skin changes in your own breasts

- Did a doctor or nurse ever show you how to do this?
 No Yes Not sure
- Have you ever examined your breast on your own?
 No Yes If yes, what was the date of your last examination? ___/___/___
 ___ Don't know

Mo Yr

2. Clinical breast exam (CBE)-this is when a doctor examines your breasts for lumps

- Did a doctor ever ask you to get this test?
 No Yes Not sure
- Have you ever had a CBE?
 No Yes If yes, what was the date of your last CBE? ___/___/___
 Don't know

Mo Yr

3. Mammogram (breast x-ray)-a special x-ray designed to find abnormalities in your breast

- Did a doctor ever ask you to get this test?
 No Yes Not sure
- Have you ever had a Mammogram?
 No Yes If yes, what was the date of your last Mammogram? ___/___/___
 ___ Don't know

Mo Yr

Test for Cervical Cancer

1. Pelvic Exam (PE): Your doctor feels the internal sex organs, bladder and rectum for any changes in size and shape

- Did a doctor ever ask you to get this test?
 No Yes Not sure
- Have you ever had a PE?
 No Yes If yes, what was the date of your last PE? ___/___/___ Don't know

Mo Yr

2. Pap smear-cells from your cervix are collected by the doctor and checked for abnormalities.

- Did a doctor ever ask you to get this test? ?

No Yes Not sure

➤ Have you ever had a DRE?

No Yes If yes, what was the date of your last DRE? ___/___ ___ Don't know

Mo Yr

Test for Colorectal Cancer (Women over 50)

1. Fecal occult blood test (FOBT)-a stool sample is examined for hidden blood

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a FOBT?

No Yes If yes, what was the date of your last FOBT? ___/___ ___ Don't know

Mo Yr

2. Sigmoidoscopy-A thin flexible tube with a light is used to look inside the rectum and colon for abnormalities.

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a Sigmoidoscopy?

No Yes If yes, what was the date of your last test? ___/___ ___ Don't know

Mo Yr

3. Colonoscopy-a thin flexible tube is used to look 6 ft. into the rectum and colon for abnormalities

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a colonoscopy?

No Yes If yes, what was the date of your last test? ___/___ ___ Don't know

Feelings about Cancer and Cancer Screening Tests:

1. Cancer screening (e.g. breast exam, pelvic exam, colonoscopy and FOBT) is embarrassing
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 2. I'm afraid that some cancer screening tests are painful.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 3. There is not much I can do to prevent cancer.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 4. If I have cancer, I don't want to know about it.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 5. If I have cancer, it will kill me anyway, so there is no point in getting screened.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 6. Cancer is God's will so there is no point of getting screened.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 7. Cancer can be cured by traditional Samoan healers (fofo)
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 8. If you have cancer, it's better to go to a Samoan healer than a regular doctor.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
- Because I think finding cancer early is important:
9. I plan to talk to my doctor about screening.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 10. I plan to talk to my family members and other people about screening
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 11. I plan to participate in cancer screening.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree

Beliefs about Cancer, Healing, and Spirit

1. Having a family history of breast/cervical cancer increases your chance of developing the disease True OR False
2. Cancer is most curable when it is caught early through screening
 True OR False
3. Smoking increases the risk of having cancer True OR False
4. At what age you should start screening for
Breast Cancer _____ Cervical Cancer _____ Colorectal Cancer _____
5. Do you consider yourself to be
 Deeply religious Somewhat religious Slightly religious Not at all religious?
6. During difficult times, do you rely on religion a
 Great deal Somewhat Not very much Not at all
7. I trust more in God to cure cancer than in doctors and medical treatment
 Great deal Somewhat Not very much Not at all
8. God works through the doctors and nurses to cure cancer
 Great deal Somewhat Not very much Not at all
9. Only a miracles cure cancer, not medical treatment.
 Great deal Somewhat Not very much Not at all

Appendix C
Male Questionnaire

Yellow
Sheet

Samoan Church-based Cancer Project

Date: _____

Male

Thank you for helping us to learn what men think about screening tests for cancer. There is no right or wrong answers to these questions - we are interested in your beliefs and opinions. All of your answers will be keep strictly confidential, and we do not ask your name. Your answers will help us improve cancer prevention services for Samoans and Pacific Islanders.

Background:

Age: _____

Work: (Currently - for wages): No Yes

Type _____

Ethnicity: _____

Birthplace: _____

Marital Status: Single Married

Divorced Widowed

Number now living in the Household: _____ **Where did you go to school?** _____ **Highest grade completed?** _____

1. I celebrate Samoan Flag day and other Samoan festivals
 All the time Most of the time Some of the time Hardly

3. I speak Samoan at home
 All the time Most of the time Some of the time Hardly

4. I eat Samoan food
 Daily At least once a week Only on Special Occasions Never

4. I listen to Samoan music
 Daily At least once a week Only on Special Occasions

5. When I get sick, I use Traditional Samoan Healing methods
 All the time Most of the time Some of the time Hardly

6. I am proud that I and my family are Samoans
 All the time Most of the time Some of the time Hardly

Screening Tests for Cancer:

Test for Prostate Cancer (Men over 40)

1. Digital rectal exam (DRE)-your doctor feels for any bumps or irregularities in the rectum.

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a DRE?

No Yes If yes, what was the date of your last DRE? ___/___ ___

Don't know

Mo Yr

2. Prostate specific antigen test (PSA)-measures the level of this specific protein in your blood.

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a PSA?

No Yes If yes, what was the date of your last PSA? ___/___ ___

Don't know

Mo Yr

Test for Colorectal Cancer (Men over 50)

4. Fecal occult blood test (FOBT)-a stool sample is hidden blood examined for

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a FOBT?

No Yes If yes, what was the date of your last FOBT? ___/___ ___ Don't know

Mo Yr

5. Sigmoidoscopy-A thin flexible tube with a light is used to look inside the rectum and colon for abnormalities.

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a Sigmoidoscopy?

No Yes If yes, what was the date of your last test? ___/___ ___ Don't know

Mo Yr

6. Colonoscopy-a thin flexible tube is used to look 6 ft. into the rectum and colon for abnormalities

➤ Did a doctor ever ask you to get this test?

No Yes Not sure

➤ Have you ever had a colonoscopy?

No Yes If yes, what was the date of your last test? ___/___ ___ Don't know

Feelings about Cancer and Cancer Screening Tests:

1. Cancer screening (e.g. rectal exam, colonoscopy and FOBT) is embarrassing
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 2. I'm afraid that some cancer screening tests are painful.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 3. There is not much I can do to prevent cancer.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 4. If I have cancer, I don't want to know about it.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 5. If I have cancer, it will kill me anyway, so there is no point in getting screened.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 6. Cancer is God's will so there is no point of getting screened.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 7. Cancer can be cured by traditional Samoan healers (fofo)
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 8. If you have cancer, it's better to go to a Samoan healer than a regular doctor.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
- Because I think finding cancer early is important:
9. I plan to talk to my doctor about screening.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 10. I plan to talk to my family members and other people about screening
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree
 11. I plan to participate in cancer screening.
 Strongly Agree Somewhat agree Somewhat disagree Strongly Disagree

Beliefs about Cancer, Healing, and Spirit

10. Having a family history of prostate/colorectal cancer increases your chance of developing the disease True OR False
11. Cancer is most curable when it is caught early through screening True OR False
12. Smoking increases the risk of having cancer True OR False
13. At what age you should start screening for **Prostate Cancer**? _____ **Colorectal Cancer** _____
14. Do you consider yourself to be
 Deeply religious Somewhat religious Slightly religious Not at all religious?
15. During difficult times, do you rely on religion a
 Great deal Somewhat Not very much Not at all
16. I trust more in God to cure cancer than in doctors and medical treatment
 Great deal Somewhat Not very much Not at all
17. God work through the doctors and nurses to cure cancer
 Great deal Somewhat Not very much Not at all

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