



Asian American and Pacific Islander Cancer Survivors Capacity Building Project

Focus Group Summary and Recommendations Report

Project Partners

Asian & Pacific Islander American Health Forum
Association of Asian Pacific Health Care Organizations
Family Health Center, Inc. of Worcester, MA
Kalihi-Palama Health Center



Cancer Survivors Capacity Building Project

The Asian American and Pacific Islander Cancer Survivors Capacity Building (AAPI CSCB) Project is a five year project funded by the Centers for Disease Control and Prevention under the program announcement 03050. This project serves the AAPI cancer survivor population through the facilitation of a network of cancer support groups and resources and provides capacity building and trainings to mainstream and AAPI serving organizations. The AAPI CSCB Project Consortium Partners include Association of Asian Pacific Community Health Organizations, Family Health Center, Inc. of Worcester, MA, and Kalihi-Palama Health Center.

Asian & Pacific Islander National Cancer Survivors Network

The Asian & Pacific Islander National Cancer Survivors Network (APINCSN) is national network of cancer survivors, caregivers, advocates, health care providers, researchers, community organizations and cancer programs that are concerned about the issue of cancer in the Asian American and Pacific Islander (AAPI) Community. Founded in 1997 by Susan M. Shinagawa and Reverend Frank Chong, APINCSN became a program of the Asian & Pacific Islander American Health Forum (APIAHF), which is a national health policy and advocacy organization whose mission is to enable Asian Americans and Pacific Islanders to attain the highest possible health and well-being. The AAPI CSCB Project utilizes the APINCSN to increase organizational and individual membership and to assist in participating in and completing activities. Through the education on AAPI cancer issues and training materials and activities, participants will learn to provide peer-to-peer education, de-mystify cancer detection, screening, and treatment, and provide support to cancer patients and survivors.

Asian & Pacific Islander American Health Forum

The Asian & Pacific Islander American Health Forum (APIAHF) is a national advocacy organization dedicated to promoting policy, program, and research efforts to improve the health and well-being of Asian American and Pacific Islander (AAPI) communities. APIAHF's mission is to enable AAPIs to attain the highest possible level of health and well-being. APIAHF envisions a multicultural society where AAPIs are included and represented in health, political, social and economic areas, and where there is social justice for all.

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Asian American and Pacific Islander Cancer Survivors Capacity Building Project Focus Group Summary and Recommendations

Background

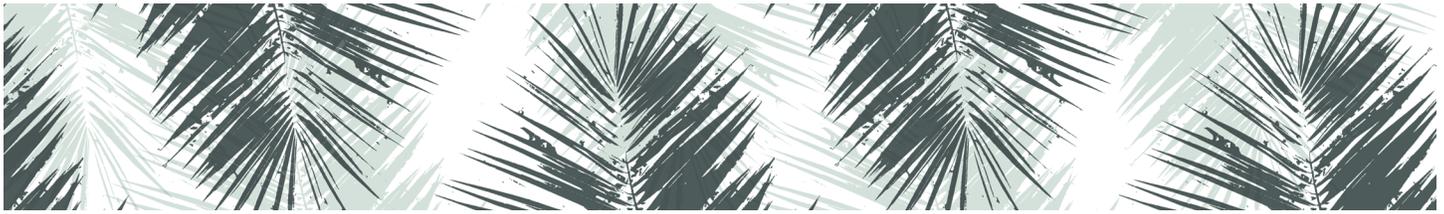
The National Cancer Institute estimates that there are approximately 9.6 million Americans with a history of cancer were alive in January 2000. However, there is still no accurate data on the number of Asian Americans and Pacific Islanders (AAPIs) affected by, living with, or surviving cancer. It is known that among Asian Americans and Pacific Islanders (AAPIs), cancer deaths have increased at a faster rate compared to any other racial and ethnic population. For instance, American Samoan men living in Hawaii and in California were ten times more likely to be diagnosed with nasopharyngeal cancer, seven times more likely to be diagnosed with liver cancer and three times more likely to be diagnosed with stomach cancer as compared to White American Males.¹ It has been reported that less than 70% of Asian American women over the age of 18 reported a pap testing the past three years, which is much lower than that of non-Hispanic White women (82%).² Factors such as acculturation, low cancer screening rates, and lack of cultural sensitivity continue to place a toll on the cancer morbidity and mortality rates of AAPIs.

Purpose of Focus Group Implementation

As an effort of the Asian American and Pacific Islander Cancer Survivors Capacity Building Project (AAPI CSCB), the Asian & Pacific Islander American Health Forum (APIAHF) and its Consortium Partners in California, Hawaii, and Massachusetts recently implemented a series of focus groups during a two year period to assess AAPI community needs in regards to cancer and survivorship. The focus groups gathered cancer survivors, health care providers, and community members to exchange information about existing support services and their efficacy in the provision of care, encourage dialogue about the challenges and barriers in patients' pursuit of healthcare services, and brainstorm methods by which to address patient needs and concerns. The insightful feedback of patients and providers at these respective sessions have been instrumental in deepening APIAHF's and consortium partners' perspectives on appropriate care for AAPI cancer survivors and strengthening efforts to develop groundbreaking, relevant programs and resources. In addition to conducting face-to-face focus groups, APIAHF worked with evaluation consultants, La France Associates, LLC, to develop an online survey with similar questions from the focus group protocol. This online survey was sent to the Asian & Pacific Islander National Cancer Survivors Network (APINCSN) membership to capture those geographic areas not covered by the focus groups.

¹Mishra, S.I., Luce-Aoelua, P., Wilkens, L.R., and Berstein, L., 'Cancer among American-Samoans: Site-specific incidence in California and Hawaii,' *International Journal of Epidemiology*, 1996.

²Ponce, N., Gatchell, M., and Brown, E.R., 'Cancer screening rates among Asian ethnic groups,' *UCLA Center for Health Policy Research Policy Fact Sheet*, 2003.



Focus Group Outcomes

2004 Focus Groups

From March to August 2004, a total of four focus groups were conducted in Washington D.C., Hawaii, and Massachusetts. Focus groups were conducted with cancer program staff, cancer advocates, cancer survivors, health providers, community members, and caregivers.

Focus Group 1: Intercultural Cancer Council Symposium, Washington D.C.

Participants were comprised of cancer program staff representing community based organizations (CBOs), medical centers, research institutions, and national cancer programs. In total, over thirty participants attended representing twenty-three different organizations. The participants were asked to share information about the availability of cancer support services and programs in their region. Brief descriptions of services and programs available to AAPI cancer patients, survivors, and caregivers in different regions of the U.S. were shared by the participants. Many of the programs outreached to specific AAPI communities and focused on education and screening efforts. It was apparent through this discussion that many of the programs expressed interest in providing services to cancer survivors however did not have the resources or the capacity. Support group facilitators also expressed their concerns over the limited resources and funding sources available to sustain their programs. Many participants brought up their concerns and challenges in providing culturally and linguistically appropriate services. For instance, the lack of trained and certificated bilingual medical interpreters, access to updated educational materials, information on the modes of communication specific for AAPI communities, and information assisting cancer patients to access appropriate programs and services

Focus Group 2: Honolulu, Hawaii

This focus group was conducted with the fifteen provider staff from Kalihi-Palama Health Center serving AAPI

patients in Honolulu, Hawaii. The participants were asked to describe the types of cancer support services and programs available to their patients. Programs ranged from breast and cervical cancer control programs (BCCCP), Buddhist groups, hospice, and the American Cancer Society. Since the participants of the focus group interact with cancer patients in a direct basis, they expressed their frustrations with the lack of services, challenges, and barriers addressing cancer through their stories of working with the patients. Their concerns around cultural and linguistic issues echoed the comments from the focus group conducted in Washington D.C. However, many of the concerns were unique and specific to the clinical setting. For instance, issues were focused on how to explain false-positive vs. false negative, paternalistic approach vs. patient centered view of healthcare, delays in treatment, and patients returning to their country of origin after treatment.

Focus Group 3: Worcester, Massachusetts

This focus group was conducted in Vietnamese and a total of thirteen participants attended the discussion. There was a mix of community members, cancer survivors, family members, and caregivers. Focus group participants expressed the lack of information about cancer as well as surviving cancer. They attributed the hiding of the disease as an Asian cultural practice. Community members felt that it was important to have materials, information, and activities available in Vietnamese. Based on the discussion, it was apparent that the participants had limited and at times incorrect information about cancer, prevention, and survival. However, most were very hopeful that cancer was not a death sentence even though there was fear about the disease. There was recognition of the need for support groups, but one participant expressed that the existing support groups held through the churches and temples do not specifically provide support for those with cancer.



2005 Focus Groups

Focus Group 4: Worcester, Massachusetts

This focus group was conducted in Cambodia and a total of five Cambodian community members participated. The comments overall were similar to that of the Vietnamese focus group. Participants mentioned that the disease was scary and that people die when they have cancer. There was a clear lack of understanding about prevention and early detection of cancer. Participants indicated that death was inevitable for those diagnosed with cancer. Similar to the other focus group, participants felt there was a need to provide psychological support, support groups, and community education for the Cambodian community.

Focus Group 1: Seattle, Washington

This focus group was primarily comprised of cancer survivors from the Asian American community. Participants expressed concerns about the availability of culturally appropriate and cost-effective health care. Most participants agreed that it was challenging to find physicians who provide cancer information to them that was easy to understand and dedicate more time during office visits to answer their questions and concerns. In addition, participants expressed frustration in finding credible cancer resources and information online. Despite concerns about the number of challenges faced in accessing reliable physicians and information, participants acknowledged that the availability of comprehensive information distributed through the cancer-focused websites was helpful in guiding their treatment and recovery process. In addition, members of the group strongly attributed their healing progress to their participation in programs that promoted fitness and health education, the guidance and support of fellow cancer survivors and family members, and spiritual practices.

Focus Group 2: Minneapolis, Minnesota

The discussions that emerged primarily focused on issues of cancer treatment and survivorship in Hmong, Vietnamese, and Cambodian communities. Among the number of concerns addressed was the issue of language and cultural competency. Participants expressed concern around the lack of resources, such as interpretation services and print materials, which could successfully convey important treatment information to patients. Focus group participants also mentioned the lack of physicians that can accommodate to specific cultural and linguistic needs in treatment. In addition, there was an extensive discussion on issues related to health care costs. Participants mentioned that costs for visits, screenings, cancer treatment, and post-treatment follow-up exceeded their ability to pay, regardless of whether or not they



had health insurance coverage. Furthermore, there was also discussion about the lack of advocates in Hmong, Vietnamese, and Cambodian communities who are able to assist in the development of culturally appropriate programs.

Focus Group 3: Pacific Global Health Conference, Honolulu, Hawaii

This focus group was held during the Pacific Global Health Conference and was primarily aimed towards cancer program staff working in the Pacific Island Jurisdictions. The participants discussed the barriers in Pacific Island regions that have prevented Pacific Islander patients from participating in support groups and from seeking timely and appropriate cancer care. Such barriers include cultural belief models that discourage individuals from discussing their diagnosis and treatment if individuals “do not feel sick”. Other barriers include the lack of non-governmental organizations and comprehensive cancer centers that provide primary care and cancer treatment, respectively. More notably, focus group members emphasized that the low usage of available health care can be attributed to high rate of poverty and lack of insurance coverage.



Focus Group Recommendations

Based on the recommendations provided by the focus group participants, the specific and detailed recommendations are separated into three categories, 1) funding for adequate cancer services, 2) coordination of cancer resources and services, and 3) provide culturally and linguistically appropriate cancer related resources and services.

Funding for and Access to Adequate Cancer Services

While there is funding available for cancer education and basic screenings for certain cancers, access to free or inexpensive services are still needed for AAPI communities. Cancer services need to include transportation, financial assistance related to public health insurance, access to specialists, and other cancer support services. Other cancer services recommended include:

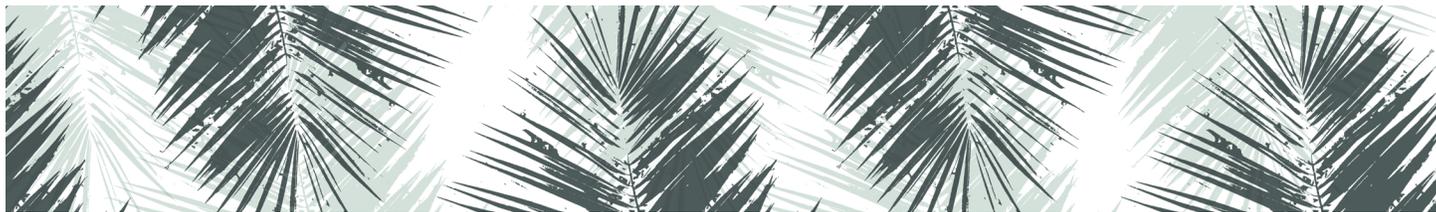
- ◆ Increase access to free or inexpensive services and resources (education, prevention, screening, early detection, treatment, survivorship, and end of life – inclusive of the continuum of care)
- ◆ Increase programs that address financial barriers for care

Coordination of Cancer Resources and Services

There are various programs throughout the United States that do provide cancer support related services to AAPI communities. However, there is limited coordination and communication of the availability to these programs. Below is a list of what could improve coordination of cancer resources and services for AAPIs:

- ◆ Increased coordination and communication of free and accessible resources (education, prevention, screening – inclusive of the continuum of care)
 - Develop a list of available cancer resources available to AAPI communities
 - In-language cancer informational and educational materials/resources

- Raising awareness of what cancer resources are available to community members
- Develop a web-based database through which patients can access: 1) lists of hospitals and physicians that specialize in cancer care; 2) information about language-specific programs and resources; and 3) contact information of cancer survivors and resource persons
- ◆ Increase availability of information and education specifically for families and caregivers
 - Patient empowerment along with education
 - General cancer education (screening, early detection, survivorship, treatment, etc.) for AAPI communities
 - Increase access to information about health insurance and coverage for those under 40 years of age, a group that has been noted as needing the most financial assistance
 - Develop more educational programs that could provide the community with basic knowledge of cancer, cancer treatment, and other available services geared towards preventing the onset of other chronic diseases in AAPI communities
 - Advocate to provide other services related to cancer support (ex: home health care for cancer patients, chore services, psychological support, patient navigation, individual counseling, and transportation)
 - Advocate for increased coverage of cancer screenings by insurance companies and access to services for the uninsured
 - Stronger advocacy efforts to be spearheaded by physicians and other health care providers



Online Survey Results

Provide Culturally and Linguistically Appropriate Cancer Related Resources and Services

Focus group participants expressed that there is a need to address cultural barriers such as the issues of fear, shame, and fatalism. Participants provided the following recommendations:

- ◆ Increase cultural competency of AAPI communities at all level of cancer services/programs
 - Addressing cultural barriers: fear, shame, anxiety, and fatalism
 - Understanding AAPI cultural considerations in disclosing cancer to the family
 - Consider working with families instead of solely the patients since most medical decisions are made by the entire family
 - Conduct cultural sensitivity trainings for providers, cancer program staff, and cancer control advocates
 - Cross-cultural provider trainings and education
 - Consider involving non-traditional partners (e.g. faith based organizations) in cancer education, awareness, and support activities
 - Integrate ethnic-specific medical beliefs into the delivery of health care. Often, AAPI communities prefer their care to be collectively shaped and administered; patients appreciate it when doctors consult with and empower their loved ones to have a role during the treatment and recovery process.
 - Develop materials in various Pacific Islander languages and brainstorm methods to create support groups
 - Develop AAPI specific cancer support groups throughout the U.S.

Many responses in the online survey were very similar to those from the focus groups. The online survey was directed at service providers, which included state health departments, local community based programs, volunteer agencies, local health departments, cancer support groups, hospitals, national cancer programs, and other cancer services/programs/foundations. In addition, family members and survivors were also surveyed. Questions directed to service providers were similar to the in person focus group protocol. Questions directed to family members and survivors included answering what types of programs or services would have helped survivors, family members, friends, or patients deal with cancer. In addition, from the individual perspectives on the cancer experience, suggestions were solicited for health care providers, for cancer support groups, and for those helping others affected by cancer.

The online survey results were divided into responses to barriers to services, services available and desired, and responses to aspects of cancer as a patient. Over half of the survey respondents were service providers. Survey respondents said that the top four types of cancer programs and/or resources available in their communities were education, screenings, breast and cervical cancer control and breast and cervical early detection programs, and cancer support groups. The online survey results also highlighted the similar findings in the focus groups in terms of the areas of funding for and access to adequate cancer services, coordination of cancer resources and services, and providing culturally and linguistically appropriate cancer related resources and services.

The online survey results and specific recommendations are listed and highlighted in the Appendix.

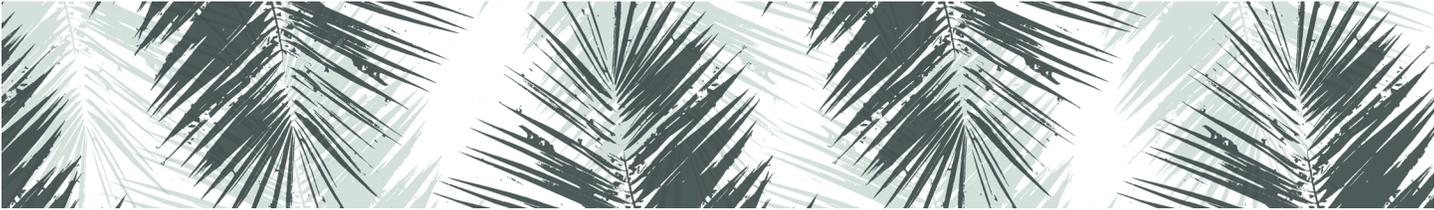


Conclusion

It is the intent of this report to inform community-based organizations, health care providers, health departments, cancer services and programs, foundations, and advocates of the needs of AAPIs in regards to cancer and survivorship. Responses from the community of individual and organizational advocates in addition to the APINCSN Steering Committee Members and Network membership have shaped current and future activities to address gaps discussed and recommendations provided. For instance, to respond to newsletters and resources/referrals, APIAHF has developed informative newsletters to disseminate.

APIAHF is not a direct services organization. APIAHF is a policy advocacy organization. APIAHF's priority areas in the areas of expanding access to health care, improving quality of care by promoting cultural and linguistic competency, ensuring a diverse and culturally competent health care work force, increasing research on and improve data collection of AAPI health needs, and increasing investment in community-based health promotion programs. APIAHF has worked on developing legislation to improve delivery of care, for example, with language access and interpretation and has advocated for improving linguistic access in government programs. In addition, APIAHF has developed a National Council of Asian and Pacific Islander Physicians to harness the advocacy power of health care providers. APIAHF is working on a AAPI Research Agenda to address issues such as the capacity of community-based organizations to participate in academic research, recruiting and supporting young professionals interested in a career in health disparities research. As far as increasing investment in community-based health programs, that has always been the root of APIAHF's capacity building efforts over the past 20 years. APIAHF's cancer program will be offering some funding opportunities in grants to assist beginning organizations to being addressing survivorship in their communities and provide as needed capacity building assistance and training to succeed and be sustained. In addition, APIAHF has responded to the need for more resource materials for AAPIs and

has created informative newsletters, conducted strategy exchange teleconferences, and has developed a print and online AAPI cancer resource directory. There is a commitment from APIAHF to work on improving health on a broader level to make impacts on disease areas such as cancer.



APPENDIX

- Focus Group Guide/Protocol
- Focus Group Participant Consent Form
- Online Survey Questionnaire
- Online Survey Results

APIAHF AAPI Cancer Survivors Capacity Building (CSCB) Project Focus Group Guide

I. Introduction (10 minutes)

- Good evening and thank you for coming. My name is _____. Thank you for agreeing to take part in this discussion. We hope to learn about better ways to coordinate cancer support resources between cancer programs and AAPI community based organizations. We are interested in better understanding the availability of cancer support resources, challenges and barriers, and recommendations to improve access to culturally and linguistically appropriate cancer survivorship/support services and programs.
- The AAPI Cancer Survivors Capacity Building Project is a program of the Asian & Pacific Islander American Health Forum (APIAHF) and is currently being funded by the Centers for Disease Control and Prevention (CDC). The project aims to improve cancer prevention, early detection, and survivorship among AAPI communities. The AAPI Cancer Survivors Capacity Building project serves the AAPI cancer survivor population through the facilitation of a network of cancer support groups and coordination of resources. We will be working with local, state, and national organizations to reach and involve those working with AAPI communities.
- Your participation is very important because you will help to provide recommendations for the development of AAPI cancer survivorship programs and resources. There are no right or wrong answers to any of the questions – please respect other’s points of view if different from your own. Feel free to express your ideas, opinions, or experiences. Many important things need to be discussed during our hour together, so at times we may change the subject or move ahead. We’ll try to come back to earlier points at the end of our conversation if time permits.
- As you may have noticed, there is a tape recorder in the room. We hope that having a tape recorder will not make you feel uncomfortable. We want to make sure we capture all of your ideas and that we don’t miss any valuable information the group may offer. The tape recorder ensures this. There will be a couple of notetakers who will be recording your response to ensure that we capture what you are saying accurately.
- Please be assured that your individual comments here today are confidential in the sense that we will not identify anyone’s statements by name. If you have not done so, we would like you to sign a consent form to ensure your confidentiality and to affirm your voluntary participation in this discussion.
- Before beginning, are there any questions or comments?
- Let’s start our discussion....

II. Support Services Available (15 minutes)

- What types of AAPI cancer programs and/or resources are available in your community or region? (e.g. cancer support groups, screening, etc) Please briefly describe those programs and/or resources.
- What types of programs and/or services have helped you, your family member, or your clients deal with cancer?
 - Are there particular services? Please briefly describe the services.
 - Are there existing activities that you now participate in?

III. Challenges and Barriers (15 minutes)

- What are challenges/ barriers you face in addressing cancer in your region? (screening, prevention, survivorship, quality of life, access, etc – continuum of care)
- What are issues faced by you/family member/ patients around cancer?
- What are challenges in getting AAPI participation in cancer services?
 - Specifically survivorship/support services

IV. Recommendations (15 minutes)

- What has worked well in approaching AAPIs to participate in survivorship/support services?
- Do you have any recommendations for working with AAPI cancer support groups?
- For cancer survivors participating in this focus group, do you have any recommendations for
 - healthcare providers around the issues of cancer?
 - specific types of support groups that would work for your community?
 - other needs for your community around cancer?
- For cancer program staff participating in this focus group, do you have any recommendations for
 - improving quality of life of cancer patients and survivors?
 - increasing the number of programs and services serving AAPI communities?
 - increasing accessibility of existing programs/services for cancer patients/survivors?
 - increasing the number of culturally and linguistically appropriate services, materials, approaches

V. Closing and Evaluation (5 minutes)

- We are now finished with the discussion. Before we leave, do you have other responses or comments about the information discussed today?
- As part of our evaluation of the focus group session, were there components of the process that you liked or thought needed to be changed for future focus groups? (pluses and delta evaluation)

record comments made by the focus group participants

- Once again, we'd like to reassure you that everything you said here today is strictly confidential and anonymous. Your name will not be connected to the information given today.
- Thank you for coming. The information that you have provided is very important and we appreciate you spending the time with us.

Asian & Pacific Islander American Health Forum (APIAHF) Cancer Focus Group Participant Consent Form

_____ (insert date)

Thank you for your interest and willingness to help us. You are being asked to participate in a discussion group. We hope to learn more about better ways to coordinate cancer support resources between cancer programs and AAPI community based organizations. We want to do this by better understanding available cancer support resources, challenges and barriers, and recommendations to improve access to culturally and linguistically appropriate cancer survivorship/support services and programs for Asian Americans and Pacific Islanders (AAPI). We do not expect these discussion questions to cause you any discomfort.

You will be asked to participate in a discussion group that should require one (1) hour.

Participant's Initials: _____

This community assessment may have implications for the development of culturally and linguistically appropriate cancer support programs to improve the quality of life and health of the AAPI community.

The discussion will be recorded to capture your comments and recommendations so that we will not miss your valuable information. Any identifying information will not be included in our written summary.

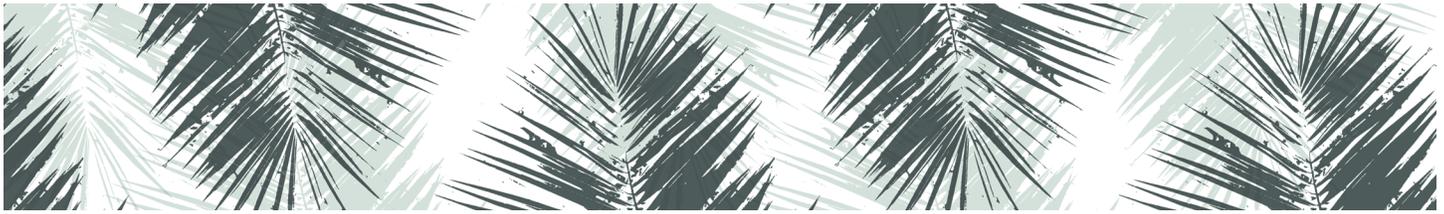
If you feel uncomfortable at any time, you should feel free to leave the discussion.

Participant's Initials: _____

Permission: Your signature, below, will indicate that you have decided to volunteer as a discussion participant and that you have read and understood the information provided above.

Signature of Participant: _____ **Date:** _____

Signature of Coordinator: _____ **Date:** _____



APIAHF Asian American and Pacific Islander (AAPI) Cancer Survivors Capacity Building (CSCB) Project Online Survey

Introduction:

APIAHF hired, LaFrance Associates, LLC (LFA), an independent nonprofit research and evaluation consulting group to conduct the AAPI CSCB Project Survey in an effort to learn about better ways to coordinate cancer support resources between cancer programs and AAPI community based organizations. APIAHF is interested in better understanding the availability of cancer support resources, challenges and barriers, and recommendations to improve access to culturally and linguistically appropriate cancer survivorship/support services and programs. This online survey will take you approximately 5-10 minutes to complete.

Background:

The AAPI Cancer Survivors Capacity Building Project is a program of the Asian & Pacific Islander American Health Form (APIAHF) and is currently being funded by the Centers for Disease Control and Prevention (CDC). The project aims to improve cancer prevention, early detection, and survivorship in the AAPI cancer survivor population through the facilitation of a network of cancer support groups and coordination of resources. APIAHF is working with local, state, and national organizations to reach and involve those working with AAPI communities.

(1) Are you a service provider?

- Yes
- No

(2) Organization Type

- State Health Department
- Local Community Based Program
- Volunteer Agency
- Local Health Department
- Cancer Support Group
- Hospital/Service Provider
- National Cancer Program
- Cancer Services/Programs/Foundations
- Other (please specify): _____

(3) What types of AAPI cancer programs and/or resources are available in your community or region?

Check all that apply.

- Cancer support groups
- Screenings
- Education
- BCCCP (Breast and Cervical Cancer Control Program)/BCEDP (Breast and Cervical Early Detection Program)
- Faith-based/religious groups
- Hospice care
- Home healthcare
- Chore services
- Transportation
- American Cancer Society
- Financial assistance
- Access to specialists
- Counseling services
- Culturally and linguistically appropriate care and services
- Other (please specify): _____



(4) What are barriers you have faced in addressing cancer in your region? Check all that apply.

- Limited resources and funding/financial sources
- Access to updated educational materials
- Information assisting cancer patients to access appropriate programs and services
- Proper screening of patients because of embarrassment, lack of insurance, etc.
- Prevention information and education
- Lack of survivorship support services and follow-up care
- Resources to properly address all aspects of quality of life such as physical, spiritual, family, and emotional concerns.
- Access to health care services and specialists
- Availability of support groups
- Lack of culturally and linguistically appropriate resources and services
- Other (please specify): _____

(5) What are challenges in getting AAPI participation in cancer survivorship/support services, specifically survivorship/support services?

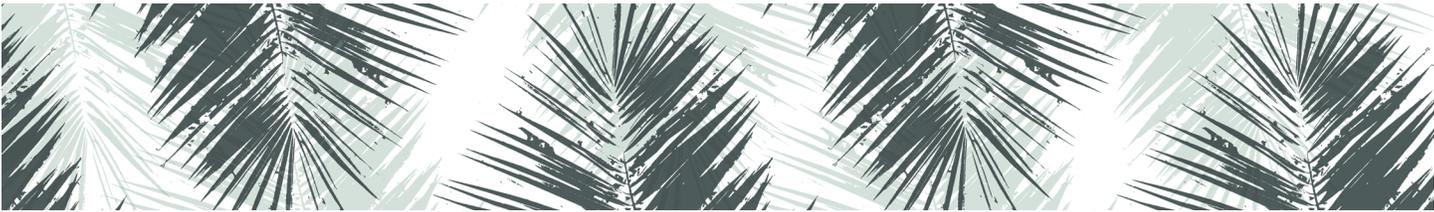
- Lack of trained and certified bilingual medical interpreters
- Information on the modes of communication specific to AAPI communities
- Culturally and linguistically appropriate resources and services
- Lack of cultural sensitivity trainings for providers, cancer program staff, and cancer control advocates

(6) What has worked well for your organization in approaching AAPIs to participate in survivorship/support services?

1. _____
2. _____
3. _____

(7) What are your recommendations for improving quality of life of cancer patients and survivors?

(8) What are your recommendations for increasing the number of program and services serving AAPI communities?



(9) What are your recommendations for increasing accessibility of existing programs/services for cancer patients/survivors?

- (11) Are you:**
- A survivor
 - Family member of a survivor
 - Friend of a survivor
 - Caregiver to a patient
 - None of the above

(12) What types of programs and/or services have helped you, your family member, friends deal with cancer?

(10) What are your recommendations for increasing the number of culturally and linguistically appropriate services, materials, and approaches?

	Had access to...	Would have liked access to...
Cancer support groups		
Screenings		
Education		
BCCCP (Breast and Cervical Cancer Control Program)/ BCEDP (Breast and Cervical Early Detection Program)		
Faith-base/religious groups		
Hospice care		
Home health care		
Chore services		
Transportation		
American Cancer Society		
Financial assistance		
Access to specialists		
Counseling services		
Culturally and linguistically appropriate care and services		
Patient Navigators/Patient Navigation services		
Other		



(13) If you selected 'Other,' please specify: _____

(14) In thinking about your experience with cancer, do you agree with the following statements?

Check all that apply.

- I had enough money for basic needs or medical care.
- I received up-to-date information about cancer.
- I received information about programs for cancer patients.
- I received information about services for cancer patients.
- I received a proper screening from a doctor.
- I received information on prevention.
- I received survivorship support services.
- I received proper follow-up care.
- I thought the resources available addressed aspects of my life that are important to me, like my physical, spiritual, family, and emotional concerns.
- I had access to health care services.
- I had access to specialists (e.g. oncologists, surgeons, health care providers specializing in specific cancers - e.g. leukemia, bone, thyroid, and prostate).
- I found a support group that I liked.
- I attended a support group.
- I had access to culturally appropriate resources and services (e.g. translated materials, interpretation services, ethnic and language specific materials and/or programs)
- I had transportation to and from appointments.
- I had someone assigned from an agency to help me through the process of diagnosis, education, treatment, and resources.
- I had someone to accompany me to the doctor and hospitals for appointments (e.g. family member, friend, etc.).

(15) Thinking about your experience with cancer, what suggestions would you give to your healthcare providers (e.g. doctors, local hospitals, clinics, etc.)?

(16) Thinking about your experience with cancer, what suggestions would you give about specific types of support groups that would work for people like you?



(17) Thinking about your experience with cancer, what suggestions would you give for helping with other needs of people affected by cancer in your community?

18) What state are you in? _____

(19) Do you have any additional comments?

Thank you for your participation!



APINCSN Online Survey Results

Asian & Pacific Islander American Health Forum staff and evaluation consultant, LaFrance Associates (LFA), developed a member survey for APIAHF’s Asian & Pacific Islander National Cancer Survivors’ Network (APINCSN). This brief presents data about survey respondent characteristics, key findings, and full responses for open-ended questions.

Description of Survey Respondents

Over half (55%) of survey respondents are service providers. The top three respondent categories are:

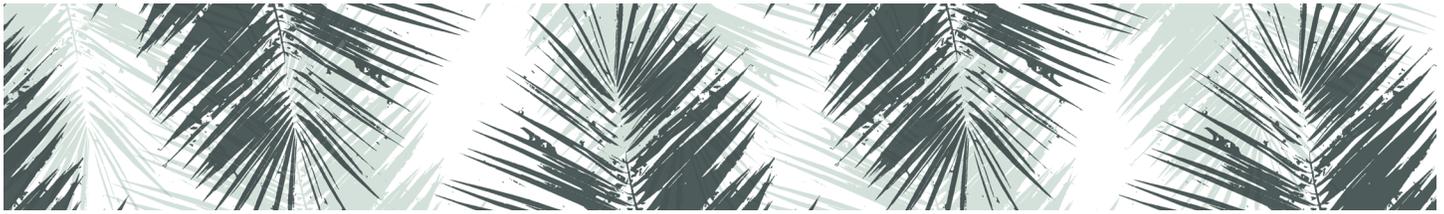
- Local, community-based program (28.2%)
- State Health Department (15.4%)
- Cancer Services/Programs/Foundations (15.4%)

Nearly half (47.4%) of the survey respondents answered that they were neither: survivors themselves; family members of survivors; friends of survivors; nor caregivers to a patient. If respondents answered yes to any of the previous relationships, the most common response (22.4%) identified them as family members of a survivor.

	Response Percent	Total
A survivor	13.20%	10
A family member of a survivor	22.40%	17
A friend of a survivor	11.80%	9
A caregiver to a patient	5.30%	4
None of the above	47.40%	36
	Total Respondents	76
	(skipped question)	37

The survey includes citizens of twenty-three states, with the largest percentage of survey respondents (38.7%) living in California.

State	Percentage
California	38.70%
Oregon	9.70%
Texas	9.70%
Hawaii	6.50%
Massachusetts	3.20%
Pennsylvania	3.20%
Washington	3.20%
Alaska	1.60%
Colorado	1.60%
Connecticut	1.60%
Illinois	1.60%
Maryland	1.60%
Michigan	1.60%
Minnesota	1.60%
Mississippi	1.60%
Nebraska	1.60%
Nevada	1.60%
New Mexico	1.60%
North Carolina	1.60%
Oklahoma	1.60%
Rhode Island	1.60%
South Carolina	1.60%
South Dakota	1.60%
Virginia	1.60%
Total Respondents	25
(skipped this question)	88



Description of Community or Region

Survey respondents said that the top four types of cancer programs and/or resources available in their communities are:

- Education (86.8%)
- Screenings (84.2%)
- BCCCP (Breast and Cervical Cancer Control Program) / BCEDP (Breast and Cervical Early Detection Program) (76.3%)
- Cancer Support Groups (73.7%)

Nearly two-thirds (65.8%) of survey respondents said that culturally and linguistically appropriate care and services were available in their communities.

Barriers to Services

The top three barriers survey respondents said they have faced in addressing cancer in their region are:

- Limited resources and funding/financial sources (84.2%)
- Proper screening of patients because of embarrassment, lack of insurance, etc. (78.9%)
- Lack of culturally and linguistically appropriate resources and services (68.4%)

Services Available and Desired

In dealing with cancer either as patients themselves, or as relatives or friends of cancer patients, survey respondents mentioned screenings (91%) and faith-based or religious groups (90%) as the most common services and/or programs offered. Survey respondents would most like (86%) to have access to Chore services.

	Had access to...	Would have like access to...
Cancer support groups	74%	32%
Screenings	91%	15%
Education	84%	17%
BCCCP/ BCEDP	76%	26%
Faith-based/religious groups	90%	13%
Hospice care	74%	30%
Home healthcare	53%	50%
Chore services	14%	86%
Transportation	56%	44%
American Cancer Society	88%	14%
Financial assistance	43%	57%
Access to specialists	79%	26%
Counseling services	61%	39%
Culturally and linguistically appropriate care and services	41%	59%
Patient Navigators/Patient Navigation services	36%	64%
Other	57%	71%

* BCCCP (Breast and Cervical Cancer Control Program) / BCEDP (Breast and Cervical Early Detection Program)



When asked to think about their cancer experiences, all nine of the respondents indicated that they had access to specialists. **Only one of the nine respondents (11.1%) indicated that they had access to culturally appropriate resources and services.** When asked if they agreed to the following statements, regarding the various aspects of their experiences as patients, the survey respondents

Aspect of experience as cancer patient	Response Percent
I had enough money for basic needs or medical care.	88.90%
I received up-to-date information about cancer.	88.90%
I received information about programs for cancer patients.	66.70%
I received information about services for cancer patients.	77.80%
I received a proper screening from a doctor.	66.70%
I received information on prevention.	33.30%
I received survivorship support services.	33.30%
I received proper follow-up care.	66.70%
I thought the resources available addressed aspects of my life that are important to me, like my physical, spiritual, family, and emotional concerns.	22.20%
I had access to health care services.	88.90%
I had access to specialists (e.g. oncologists, surgeons, health care providers specializing in specific cancers- e.g. leukemia, bone, thyroid, and prostate).	100%
I found a support group that I liked.	44.40%
I attended a support group.	33.30%
I had access to culturally appropriate resources and services (e.g. translated materials, interpretation services, ethnic and language specific materials and/or programs).	11.10%
I had transportation to and from appointments.	55.60%
I had someone assigned from an agency to help me through the process of diagnosis, education, treatment, and resources.	11.10%
I had someone to accompany me to the doctor and hospitals for appointments (e.g. family member, friend, etc.).	66.70%
Total Respondents	9
(skipped this question)	104



When asked to consider the experience of their family, friend, or patient with cancer, only 12% of survey respondents believed that the patient with whom they were familiar, had found a support group that they liked. The respondents indicated the following about the experience of their family member or friend:

Aspect of experience of family member/friend as cancer patient	Response Percent
S/he had enough money for basic needs or medical care.	48%
S/he received up-to-date information about cancer.	44%
S/he received information about programs for cancer patients.	52%
S/he received information about services for cancer patients.	56%
S/he received a proper screening from a doctor.	72%
S/he received information on prevention.	36%
S/he received survivorship support services.	44%
S/he received proper follow-up care.	64%
S/he thought the resources available addressed aspects of my life that are important to me, like my physical, spiritual, family, and emotional concerns	20%
S/he had access to health care services.	88%
S/he had access to specialists (e.g. oncologists, surgeons, health care providers specializing in specific cancers- e.g. leukemia, bone, and thyroid, prostate).	68%
S/he found a support group that I liked.	12%
S/he attended a support group.	20%
S/he had access to culturally appropriate resources and services (e.g. translated materials, interpretation services, ethnic and language specific materials and/or programs).	20%
S/he had transportation to and from appointments.	72%
S/he had someone assigned from an agency to help her/him through the process of diagnosis, education, treatment, and resources.	16%
S/he had someone to them accompany to the doctor and hospitals for appointments (e.g. family member, friend, etc.).	64%
Total Respondents	25
(skipped this question)	88



Service Providers

What has worked well for your organization in approaching AAPIs to participate in survivorship/support services?

- Indigenous outreach workers
- Direct community outreach
- Community involvement
- Church meetings
- Community driven “talk story” strategies
- Being community-based
- FBOs (faith based organizations)
- Working through Community Health Centers where services are provided in a multicultural and bilingual setting
- Word of mouth
- We are culturally and linguistically sensitive and appropriate
- Involve AAPI community members & leaders
- Health fairs
- Bilingual volunteers
- Community-based programs
- Preventive medicine approach
- The best way is to work with community-based organizations - they have access and trust of the community
- Teleconference
- Interpreters
- Having a Chinese program advocate who is involved in local AAPI community based organizations (CBOs)
- Advertise in newspaper, radio and
- Translated materials
- Support group
- Peer influence
- Recruit concerned Asian health professionals
- Providing practical education related to self-care and coping
- Culturally appropriate materials
- Personal referrals
- Focus groups
- Community developed, implemented
- Having an established and trusted network of community partners
- Cultural competence
- Our participants known of our program by words of mouth
- Provide services in communities where AAPIs live
- Enrollment in BCEDP
- Patient navigation
- Identifying key community leaders
- Lifestyle change
- Updated of news
- Participatory family members
- Collaborations with Asian medias
- Television
- Partnerships with CBOs
- Counseling Services
- One-on-one counseling
- Utilize the support of the American Cancer Society
- Providing incentives such as food and transportation
- Culturally competent staff
- Language-specific material/information
- One on one
- Survivorship leadership and involvement in all aspects of activity, project, program
- Adherence to the principles of community-based participatory research
- Non traditional approaches
- Culturally appropriate information dissemination
- Being flexible
- Qigong therapies
- Collaborations with AAPI CBOs
- Have regular meetings to discuss cancer support needs
- Providing opportunities for community building



Service Providers

What are your recommendations for improving quality of life of cancer patients and survivors?

- Equal access and quality of care. Culturally competent health care staff.
- Emotional support and encouragement. Assistance with treatment side effects. Support for friends/family going through this with the patient.
- Agencies such as APIAHF should be more inclined to go directly into the communities, such as API Wellness Center and Asian Health Services, and other smaller organizations. APIAHF is viewed as remote and insensitive - these are direct quotes from our clients.
- Having an aftercare type of program available to cancer patients, family, survivors. Having appropriate translation services available (i.e., translation, materials, etc.)
- More funding to better avail services.
- More funding opportunities to explore community designed activities for survivors and families. Pacific Islander community focus is “not on self” but rather the `ohana (Hawaiian for ‘family’) or entire inter-generation family - not found in current “mainstream” programs, services. Development of more holistic approaches, one that involves mind-body-spiritual considerations, not only relations and body “illness process, medical treatment approaches.” Special consideration for respite and transportation supports for projects and communities of survivors to meet.
- First of all, a service system for AAPI patients and survivors need to be established (including psychosocial issue, quality of life, and pain management, etc.) and then work on the quality improving.
- Providing education, training and technical assistance to the public and health care professionals so that patients and survivors are equipped to make informed health care decisions and able to overcome barriers of access, e.g. transportation, insurance, etc.
- Access to a broad range of effective and appropriate pain management and palliative care services that are provided in a culturally sensitive manner. Self advocacy or patient navigation skills. Education for health care professionals about community based resources for AAPI populations.
- Bring it home and hire and work with folks from the community.
- Placing a high priority on hiring staff from multicultural backgrounds. Providing extensive training for workers on cultural sensitivity particularly around discussion of symptoms, and pain assessment.
- Accessible support groups with linguistically appropriate counselors.
- Patients and survivors need to participate or be a part of a support group. They need a place where they can share and feel that they are not alone.
- Utilize a more integrated approach to cancer care, i.e. utilize both traditional, clinical therapies as well as complementary therapies.
- Peer support services with appropriate language and cultural background.
- Access to support groups, especially faith based ones.
- Understand that a single approach will not work for all survivors - that a variety of different kinds of supports are important so that families have options



- Grants needed.
- More access to health care facilities and appropriate information available in respective languages. Also strict enforcement of use of medical interpreters instead of family members.
- Make sure to send them newsletter or updated information. Always follow up with patients to see how they're doing. Let them know that there always someone out there that can help them in anyway.
- Education on screening, supervised support groups by professionals to head off mass hysteria.
- Cultural sensitive materials that will educate the AAPI community. Educating members of various Asian communities so each community has a rep that will head cancer awareness programs.
- 1. Be happy
 2. Exercise everyday
 3. Have a positive thinking
- Improved referral systems. Too often, patients are diagnosed at smaller, community clinics that don't that the referral resources/connections required to help patients access specialty and sub-specialty care.
- Provide cancer information and in AAPI languages. Provide interpretation services in hospitals.
- Seek funding sources to provide services.
- I suppose you mean of AAPI cancer patients and survivors? Quality of life could be improved through support groups, education programs, assistance programs, patient navigation services, caregiver support groups, increased awareness of resources
- We have a very successful program (Cancer Awareness Resources and Education - CARE) that provides education and psychosocial support for Spanish and English speaking cancer patients who receive their care and treatment at San Francisco General Hospital. We have thus far, been unable to attract the interest of funders, in our effort to replicate the program for our large Cantonese-speaking cancer patient population.



Service Providers

What are your recommendations for increasing accessibility of existing programs/services for cancer patients/survivors?

- Assertive outreach and culturally appropriate communication efforts.
- The challenge is making sure people know about the existing programs/services.
- Training and education.
- More funding to better avail services.
- More local sites, local approaches, smaller neighborhood projects that permit linguistic and cultural relevance than many other programs.
- It is important to let AAPI population know the existing programs/services (accessibility and availability)
 1. By disseminating educational materials,
 2. Utilizing media (newspaper, radio, TV, etc),
 3. Through activities at community based organizations.
- Patient navigation and coordination of services between community and clinical providers.
- Placing information of available resources on state systems, hospital and managed care plan systems, and patient navigation systems. Also for example in Connecticut, adding the info to 211.
- Support communities to transport themselves and bring services to the community (on-site location).
- Use the patient navigator model to assist patients in accessing existing programs/ services for cancer patients/ survivors.
- We need to publicize and to advertise our availability of the resources for cancer patients/survivors.
- Identify more bilingual staff to conduct outreach and education.
- Training providers in the community regarding access and needs within each ethnic group.
- Linguistically appropriate services, bilingual personnel at the facilities with these programs, perhaps designated days for Asian individuals with limited English proficiency.
- Recognizing that culturally appropriate advertising may mean getting the word out about programs in less traditionally accepted ways; word of mouth is very important; move beyond health fairs and fliers to creatively promote programs and services.
- Interactive website for health education and focus groups.
- More language appropriate materials for all AAPI populations.
- Need more money and better fundraisers. Need professionals who have access to the communities so they can hear from someone they trust.
- We need to have some type of national networking system. I really like the teleconferencing and discussion of different services out there. Perhaps a national APIA support group that has a monthly teleconference call.
- Stronger community networks, coordination of services, referral recommendations for specific conditions.



- We need to reach out and let the AAPI communities to know and utilize our services. I do think that media plays an important role.
- Develop language appropriate materials that can list existing resources. Provide more Asian language certified translators or recruit and train volunteers to work with existing programs/services. Provide transportation or patient navigation services.
- Again, help us secure funding. We have learned a lot about outreach, recruitment, retention, and implementing a program that provides meaningful education and psychosocial support to a diverse group of cancer patients. If we had the funds, we could provide this program to our large Cantonese-speaking cancer patient population.



Service Providers

What are your recommendations for increasing the number of culturally and linguistically appropriate services, materials, and approaches?

- Truly valuing diversity within organizations which will dictate resource allocations and program/ service focus.
- It would be nice to find a centrally located translation service where the cost is minimal that all could tap into.
- More funding to better avail services.
- Community based “focus groups” with sufficient funding support to complete implementation, evaluate process.
- Developing culturally appropriate and relevant health education materials for the target population using their language, local champions, and cultural or local pictures in a manner that is acceptable, readable and attractive to them.
- Mandate it by law.
- Work with those not in the communities.
- A large number of the educational materials are developed by the American Cancer Society and the National Cancer Institute. If those materials could be made available in a variety of culturally and linguistically formats, this could be used at the state and local level. Look at setting up a series of mini special population network projects that could be used as pilot projects to communities.
- We can translate and create appropriate services, materials, and approaches.
- Create a clearinghouse for culturally and linguistically appropriate services and materials
- Collaboration between all community resources so that efforts are not duplicated and patients can access services and information that they need.
- Showing the need for these, volunteer, but good translators, research to show that these are effective.
- Workshops and trainings
- There should be a clearinghouse that has a list of all the AAPI resources available.
- Just kept on spreading the words eventually they will get it.
- Need money to pay people to do this. Medically competent personnel, such as nurses, physician assistants, medical students, and residents are perfect people to approach for interpretation services.
- APIAHF set up training for health care providers. Or perhaps partner with CBOs to make sure that their materials are appropriate and culturally acceptable.
- Translate culturally appropriate materials and distribute to community.
- People need help in better understanding how to connect culturally and linguistically appropriate services (CLAS) to their organization’s business mission and financial plan. If they can’t justify the cost effectiveness/reduction of liability to the organization, it won’t happen.
- Translation. Have cancer materials website accessible.
- “Grow your own.” Start recruiting high school students who speak Asian languages fluently to consider careers in allied health professionals and health education. Support them in their education and employ them when they have completed their educational training. They will then go on to develop more culturally and linguistically appropriate services, materials, and approaches.



Family Members and Survivors

Thinking about your experience with cancer, what suggestions would you give to your healthcare providers (e.g. doctors, local hospitals, clinics, etc.)?

- Focus on life of patient beyond the disease. Patients do not live in a social vacuum.
- Give written materials - difficult to remember details. Direct client to resources in their area. Don't assume the client will be able to find what she needs by going to the phone book or internet. She may not even know what she needs or have the energy to search for it. A small roadblock may be enough to discourage her from continuing to ask for help - it's hard to ask for help especially when you are overwhelmed with your diagnosis.
- Be more human and compassionate.
- While the patient is the focus of treatment, family members are integral to their "circle of influence". Healthcare providers should speak WITH the family and provide access to family support services (i.e., family therapists and other behavioral health personnel).
- Better outreach.
- I don't have cancer, but my sister is a cancer survivor.
- Be sensitive to the cultural differences in approaching the patient.
- More clear medical information - not always understood, at times too medically directed, not enough resources and time to absorb information.
- Be more culturally appropriate in their interaction with the patients they treat.
- Give more information on diet and exercise - as well as more information on pain management - Listen when a patient says they are in pain.
- Make connection with info/resource person.
- Follow on care after prostate cancer treatment is very important. Men don't adequately managed impotence and incontinence. Healthcare providers need to be as proactive regarding these areas as they are about eliminating the cancer. Men stay "silent" and don't discuss with their wives or with their physicians the emotional pain associated with impotence and incontinence.
- Listen to the patient/family Take the needed time with the patient/family Provide patient navigation services that include financial assistance information Ensure the patient receives appropriate/effective pain management/palliative care services Address the whole person Provide educational resources and websites
- Treat us as you would your own family member.
- Rural local hospitals need to work on getting specialists in and also to offer treatment. Clinics need to give more educational materials to patients. Doctors need to make sure their patients have the information that they need - example: screening guidelines and prevention information.
- Recommend support groups.
- Aside from treatment options, healthcare providers should share information about support services available at the health care site (hospital or clinic). Information from resources such as cancer.org about treatment side effects or how to deal with life after chemo should be shared with patients and their families.
- Doctors - slow down, don't dismiss questions, and affirm a patient's concern.



- Be flexible with benefits/payments with uninsured and underinsured patients
- Don't assume that they understand the condition and what its implications are.
- More sensitivity to the cancer patient and family members. Good follow-up and referrals; able to answer questions that patient may have.
- Educate patients and caregivers, navigate them through treatments. It is important to use capable translators who are both linguistically and culturally appropriate. Financial aid is also very important.
- It is important to make sure that funds for patient navigation are always included and that they aren't seen as for translation services alone; they are important for emotional support when people don't have relatives or friends to get them through the trauma of this disease process.
- Keep up the good work.
- Encourage screenings for cancers that affect minority populations that are not common - including stomach and liver cancer.
- Get cultural sensitivity training. Hospitals need to have proper translators rather than just calling another staff down the hall to help with translation. That is how miscommunication begins. Communities need to set up our resource center to aide many that are falling through the system (those without insurance do not qualify for Medicaid/Medicare and no money to pay hospital bills).
- More clear description of the diagnosis, implications, management, and if possible, to prevent future occurrence. Use of terminology needs to be simplified for the patient's understanding; allow the patient to ask more questions. Some times, patients don't know what to ask - so, offer them the opportunity to know what to ask and ask them if they want to know more. Also, include the family members (immediate) in the discussion and information. Remember to ask the patient and/or the person responsible for the patient for their family members, especially if they are of Asian descent.
- Listen for "clues" about my other needs other than clinical care
- Treat your patients as a human being. Treat them equally.
- Provide support and follow up. Some patients may not need these, but make them aware of their availability. Call them after their treatment is complete to see if everything is okay.



Family Members and Survivors

Thinking about your experience with cancer, what suggestions would you give about specific types of support groups that would work for people like you?

- Have culturally specific facilitators, support groups, and resources.
- There are very few women of color support groups and/or groups that are led by language-specific facilitators. This would have been very helpful.
- Support groups should tell others what life is like for the cancer patient - from the view of their head and heart.
- All the places mentioned above should have a certified interpreter at all times.
- Groups need to be targeted and tailored for the survivors, i.e.: young women under 40 find it difficult to locate young breast cancer survivor groups - with issues for single women facing chemo different than older women, these guys need support groups meeting to address their own issues. These groups not available in the best of programs. Therefore, AAPI community offers even greater challenges due to language and cultural beliefs, values, practices, healing strategies.
- More support for the family to help them understand what the patient is experiencing.
- I was a young adult when I had cancer. It would have been so helpful to meet other young adults with cancer.
- Prostate cancer support groups i.e.
(1) American Cancer Society Man To Man program
(2) US TOO International support groups.
- On-line as well as face/face for people like me (care-giver support as well as patient support).
- Train and have support groups run by us.
- Create awareness - let people know when and where you meet, who meets, and what you can provide.
- Faith-based support groups, culturally based support groups.
- The support groups should be in-language and tailored to address the needs of the patients and not what the moderator/facilitator thinks the patients need. They should be conducted in a central place that is accessible for most people or provide transportation services to the support group sessions.
- Since I am don't have limited English proficiency (LEP), English speaking groups made of mainstream individuals are OK for me, but for those who are of LEP or who are less acculturated, groups need to be in their language and conducted in a culturally sensitive manner
- The same survivors meet weekly, not a drop-in support group. I attended a drop-in group and every week there were different women with different problems - they were not at the same stage of cancer as I was. I attended a 10-week support group with 3 other women. The facilitators had people come in to educate us on diet, breast self exam, and how to deal with our feelings after cancer. I still get together with my fellow survivors at least once or twice a year.
- Counseling is vital during and after treatment. More so for someone who has lost a limb to cancer. Counseling is very important so they could accept the loss of the limb.



- I think it is important to empower patients to question the medical establishment in the kind of treatment that they do after surgery because often there is overkill in treatments for Tamoxifen or the latest equivalent and it isn't always necessary. Some of it is to prevent law suits. The patient's age and quality of life need to also be considered. I think reconstruction needs to be better explained - particularly the non invasive type that is done with implants. It isn't difficult and is so much easier to live with in comparison to a prosthesis. I know. I have had one for 7 years and it's silicone gel and considered a research experiment. I doubt that it's dangerous.
- Filled with people who had good outcomes as well as bad, so as not to perpetuate the idea that cancer is a death sentence.
- I learn that not all first generation Asians like to admit their illness. Rather than having one face-to-face support group where you chit-chat about your problems, why not have teleconference (in various native languages) where the specialist can talk and answer questions.
- For caregivers; Support to provide resources and information that do not always include the medical community - patients and families need people who can provide objective solutions and not get tied up with the medical system constraints. Coalitions who are involved with advocacy efforts can be a good source of information and support. Peer support groups - same type of cancer, same background etc can be helpful but need to ask the patient and/or family.
- Leukemia & Lymphoma Society-family support group.
- Support group which really cares about patients. To run the support group because of the need of patients, not because of the requirement of the grant.
- Faith based, culturally and linguistically appropriate, convenient, relevant, educational, and informative.



Family Members and Survivors

Thinking about your experience with cancer, what suggestions would you give for helping with other needs of people affected by cancer in your community?

- Inform yourself on your options, available resources, diagnosis, and draw upon family/friends for emotional support.
- Too many to mention.
- More community outreach programs.
- Even though I don't have cancer, I would tell them not to lose their faith, and hang on to it.
- More cultural and linguistic relevance of projects and programs; more AAPI practitioners trained and experienced in the field; more scholarships and training programs to promote career opportunities for AAPI students and community at large.
- Be open to suggestions.
- Volunteer to be part of support groups and relate your experiences to others and volunteer with the American Cancer Society.
- Make services more personal.
- Men should be referred to a support group as part of their treatment.
- Talk to a nurse to see who they would go to. They know who treats people like people, not just a tumor cell. Healing is more than chemo, surgery, or radiation. Find a patient navigator.
- Ask the community in person.
- Utilize services from organizations such as the Asian American Cancer Support Network.
- If I understand correctly, help others by providing in-language information and explaining the importance of the info/resource to their health.
- Let them know what resources are available to them in their community at no charge or lowest cost possible.
- Don't be afraid to get screened. Early detection improves chances for cure. Tell your doctor about any concerns or barriers to care.
- Make sure they have someone to talk to that has been through what they are going through. Encourage them to talk about it - whether they are the survivor or a family member. Be sure that the children are included, and not informed about what is going on with mom. They will be affected, too.
- Dispelling the stigma, starting support groups, counseling for family and friends and especially for survivor.
- More education, awareness and resources in language, to the ethnic media and ethnic community-based organizations. In addition, government agencies, private hospitals, and private providers, should increase their community outreach to include Asian/Pacific Islander languages, and ethnic-specific health disparity awareness work.
- Resources that will educate the people currently undergoing treatment and ensuring they know what to do post cancer.
- As above, survivors and families need to be educated about not only the diagnosis, prognosis, and treatment. Rather, navigating the system, points of referral, etc.
- Attend to body, mind, and spirit.
- Holistic approach. Do they have other needs besides those relevant to their cancer problem? Food, transportation, companionship, financial assistance, employment, etc.



For All Respondents

Do you have any additional comments?

- Need to schedule a focus group!
- Sorry a lot of sections left blank. I work in the Public Health Department. Work with Family planning, Immunizations, Oregon Mothers Care. Also, I started doing the Oregon Breast and Cervical Cancer Program in September. My goal is to screen (annuals and mammograms) around 22 women each year. Those I have screened, one had cervical Cancer in Situ and had treatment done out of state as she is a migrant worker.
- Be Safe.
- I don't believe we have enough AAPI people here to give valid information.
- Our organization, Taulama, needs more accessibility to funding opportunities because our services are greatly impacted by this.
- I want all the people with cancer and the survivors that they are in our prayers all the times.
- Appreciate a report of this survey! Mahalo, Komol tata!
- Good luck on your survey.
- Thanks for the opportunity to provide my input, but let's go into the community for a face to face.
- My grandfather died of colon cancer, but we were in different cities, so I was not able to assist in his care.
- I currently work on a NCI grant funded project, the Cooperative Planning of the SDSU/UCSD Cancer Center Partnership, whose purpose is to provide opportunities for intensive collaborations among Minority Serving Institutions (in our case San Diego State University) and Cancer Centers (i.e. Moores UCSD Cancer Center) in order to develop stronger national cancer programs aimed at understanding the reasons behind the significant cancer disparities and impact on minority populations.
- Cancer has been a killer for my people. Extensive outreach, education and advocacy are desperately needed. Recruiting people for screening, encouraging them to go for treatment and not just accept the disease with out fighting. Information should be readily available in culturally appropriate brochures. Educational programs through radio and television. Train people in the field of research.
- There's practically not enough cancer information translated into different languages and no API cancer support groups. The need for interpretation/ translation and transportation is still very much in demand. But sadly not so much effort has been done so far in that direction.
- My friend died of stomach cancer at age 22 years, and I know of others who died of this disease because they were only aware of it at an advanced stage. Due to the high prevalence of this outside of the United States, but not compared to other diseases within the U.S., it is important that immigrant and minority communities be especially apprised of their need to screen for this sudden and painful disease.



- Texas legislators really need to put more emphasis on cancer care/screening for minorities. It is more cost effective to catch it early then to have to waste county hospital's money trying to heal a cancer patient.
- Only other thing I would reiterate: engage the patient & the family member(s) who are working along with the patient's care and management and be respectful of their concerns and actually consider them in the care of the cancer survivor. Thank you for the opportunity.
- Just to reiterate, we have a tremendously successful, award-winning program that has been providing education and psychosocial support to medically underserved minorities for nearly 3 years. Please help us secure funding to replicate this valuable and important program for our Cantonese-speaking cancer patients!



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