

ID #: _____

Thank you for agreeing to participate in this research study, which consists of a confidential survey. The data from this study will be used for assessing the psychosocial needs of Asian American and Pacific Islander (AA&PI) cancer survivors nationally. The information gathered will be used for research on cancer survivorship among AA&PI communities. The survey questions will be about 20-30 minutes. You have been invited to participate because you are self identified as Asian American and/or Pacific Islander and self identified as a cancer survivor. You must be 18 years of age or older to participate. You may choose to participate or not. You may answer only the questions you feel comfortable answering, and you may stop at any time.

We will ask you to provide your name and address so we can mail you a \$10 Amazon gift card to thank you for your time. Your name and address will be stored in a separate database and will not be connected to your survey answers. If you do not wish to receive the gift card, you do not need to complete the name and address form. If you participate, completion of the survey indicates your consent to the above conditions.

Any questions or concerns should be directed to the principal investigator, Dr. Giang Nguyen at 215-615-0355 or Dr. Mai-Nhung Le at mainhung@sfsu.edu

Unmet Needs of Asian American & Pacific Islander Cancer Survivors Survey

PLEASE DO NOT WRITE YOUR NAME ON THIS SURVEY

Marking Instructions: Please complete the choice which best reflects your experience, opinion or feeling. All responses are completely confidential.

1. How old are you? _____ (number of years)
2. What is your ethnicity?
 Chinese Filipino Asian Indian Vietnamese
 Korean Japanese Other _____
3. Are you male or female?
 Male Female
4. What state do you currently live in? _____
5. What best describes the area where you live?
 City Suburb Rural
6. Where were you born?
 United States Other _____
If not born in the U.S. → In what year did you come to the U.S.? _____
7. In what country was your mother born?
 United States Other _____
8. In what country was your father born?
 United States Other _____
9. What is your current marital status?
 Single
 Widowed
 Separated
 Divorced
 Married or living with someone in a marriage- like relationship

10. What is your current living situation?

- Live alone
- Live with spouse/partner
- Live with spouse/partner and children
- Live with children only
- Live with spouse/partner, children and other family
- Other family members only
- Friend
- Other

11. How many children do you have? None One Two or more

12. Do you have children in the following age groups? [Choose all that apply]

- | | | |
|-----------------------|------------------------------|-----------------------------|
| Under the age of 5 | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 6-9 years old | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 10-12 years old | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 13-18 years old | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 19 years old or older | <input type="checkbox"/> YES | <input type="checkbox"/> NO |

13. What education have you received? [Choose one]

- 5th grade or less
- 6th-12th grade, but no degree
- High School degree
- College degree

14. What is your total household income?

- Less than \$10,000
- \$10,000 to \$19,999
- \$20,000 to \$39,999
- \$40,000 to \$59,999
- \$60,000 to \$79,999
- \$80,000 to \$99,999
- \$100,000 or greater
- I don't want to answer

15. How many people does this income support? _____

16. How well do you speak English?

- Very Well / Fluently like a native
- Well
- Not Well
- Not at all

17. What is the main language that you speak at home?

- English
- Mandarin
- Cantonese
- Vietnamese
- Other: _____

18. What is your preferred language to receive printed health information?

- English
- Chinese
- Vietnamese
- Other: _____
- I cannot read

19. What is your current employment status?

- Working full-time or part-time
- On temporary medical leave
- Full-time mother/homemaker
- Unemployed
- Receiving disability income and not working
- Other

20. What kind(s) of health insurance do you have?

- Medicare/Medicaid
- Private Insurance
- Medicare and Private Insurance
- Medicaid and Private Insurance
- No Insurance
- Don't Know

MEDICAL HISTORY

In general, would you say that your health is:

- Excellent
- Good
- Fair
- Poor

In the past 12 months, how many times have you seen a health professional, including a dentist, about your own health? _____

In the past 12 months, how many nights have you spent in the hospital? _____

In the past 12 months, how many days have you stayed in bed for half a day or more (including days spent in the hospital) because of illness or injury? _____

In what year were you FIRST diagnosed with cancer? _____

Which kind of cancer were you diagnosed with?

- Breast
- Colon
- Lung
- Liver
- Prostate
- Stomach
- Cervix
- Other: _____

What stage was the cancer when you were diagnosed? _____

Which of the following treatments were you offered for your cancer? (please mark all that apply)

- Surgery
- Radiation
- Chemotherapy
- Hormonal Therapy
- Bone Marrow
- Transplant
- Immunotherapy
- Other: _____

Which of these treatments have you had since your diagnosis with cancer? [Check one per category]

	CURRENT TREATMENT	HAVE HAD, BUT IS NOT CURRENT	NEVER HAD
Chemotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Radiation	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Surgery/Recovering from Surgery	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hormonal Therapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Bone Marrow	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Transplant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Immunotherapy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Experimental treatments in clinical trials	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

When did you last receive treatment for your cancer? ____/____/____

DIRECTIONS:

The following questions are about the needs and problems you may have had since your cancer diagnosis. By "need" or "problem" we mean something that interfered with your normal functioning, enjoyment of life, or meeting of obligations. In each of the following sections, **FIRST** indicate if the item has been a problem for you at ANYTIME since your diagnosis; **THEN**, tell us HOW much help you received for the problem.

You can mark more than one box if more than one answer applies.

DAY-TO-DAY ACTIVITIES

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Preparing meals or doing light housework or yard work

Getting transportation for medical treatments.

Getting transportation for work or household activities.

Other problem with everyday activities or transportation?

(Please list): _____

Where did you receive help for these difficulties?

Self Family Friends Medical or Hospital Staff

Community Agency: (please list): _____

Other: _____

FINANCIAL EXPENSES

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Paying for prescription medications.

Paying for other medical treatments.

Meeting your basic living expenses.

Other financial problems?

(Please list): _____

Where did you receive help for these difficulties?

- Self Family Friends Medical or Hospital Staff
 Community Agency (please list): _____
 Other: _____

Have you had to borrow money because of the costs of your illness?

- Yes
 No

INSURANCE

Do you have health insurance, or are you enrolled in any kind of program that helps to pay for your health care?

- Yes
 No

Does your insurance plan or program allow you to go to any doctor or does it require you to choose from a group or list of doctors?

- Any doctor
 Select from group or list
 Don't Know

Does your insurance plan or program pay all, part or none of the cost for prescription medicine?

- ALL
 PART
 NONE
 DON'T KNOW

Have you had payments for treatment denied by your insurance carrier.

- ALL
 PART
 NONE
 DON'T KNOW

On average, how much do you spend out of your own pocket each month on prescription medicines?

- Nothing
 Less than \$20
 \$20 to \$50 dollars
 \$51 to \$100 dollars
 \$101 to \$150 dollars
 More than \$150

In the last 6 months, have you ever had to go without health care or medicine that you needed because you needed the money for living expenses?

- Yes
 No

Where did you receive help for these difficulties?

- Self
 Family
 Friends
 Medical or Hospital Staff
 Community Agency: (please list): _____
 Other: _____

What other types of help would you have liked to receive in dealing with these difficulties?:

HOME CARE

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Learning how to care for your medical needs at home

Knowing how to access groups or agencies that could help you at home

NUTRITION

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Changing in weight

Knowing what foods to eat

PHYSICAL

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Getting tired easily.

Changes in physical appearance.

Nausea or vomiting.

Pain.

FRIENDS AND FAMILY RELATIONSHIPS

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Increased tension or arguments at home

Increased emotional problems at home

In the past month, how often did you get together with friends or relatives?

Once 2-7 times 8-14 times 15-21 times More than 21 times

SPIRITUALITY

How much of a problem has this been for you since your diagnosis?

If it is a problem, how much assistance have you received in dealing with the problem?

Did not Experience Small Problem Moderate Problem Significant Problem

Enough Some but not enough None

Feeling a need for spiritual help.

Since your cancer diagnosis, have you or others done or plan to do any of the following?

I have done this in the past year.

I plan to do this in the next 3 months.

Pray for your own health?

Yes No

Yes No

Have others pray for your health?

Yes No

Yes No

Participate in prayer groups?

Yes No

Yes No

How important is religion in your life?

Not Important Somewhat Important Very Important Extremely Important

Are you satisfied with your life?

Yes No

Do you feel needed?

Yes No

Do you have plans for the future?

Yes No

Do you suffer from loneliness?

Seldom or Never Sometimes Often or Always

What is your religion?

None Catholic Protestant Buddhist Muslim Sikh Jewish Other: _____

How much do you agree with each of the following?

Disagree Completely Disagree Somewhat Agree Somewhat Agree Completely

I didn't know where to go for more help.

I didn't want to bother others with my troubles.

I couldn't get information specific to my culture or in my own language.

I was embarrassed by my illness.

QUALITY OF LIFE

We are interested in knowing how your experience of having cancer affects your quality of life. Please answer all of the following questions based on your life at this time. **Please circle the number from 0 - 10 that best describes your experiences:**

1. To what extent is fatigue a problem for you?

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

2. Rate your overall physical health

Extremely poor 0 1 2 3 4 5 6 7 8 9 10 Excellent

3. How difficult is it for you to cope today as a result of your disease and treatment?

Not at all difficult 0 1 2 3 4 5 6 7 8 9 10 Very difficult

4. How good is your quality of life?

Extremely poor 0 1 2 3 4 5 6 7 8 9 10 Excellent

5. Do you feel like you are in control of things in your life?

Not at all 0 1 2 3 4 5 6 7 8 9 10 Completely

6. To what extent are you fearful of future diagnostic tests?

No fear 0 1 2 3 4 5 6 7 8 9 10 Extreme fear

7. To what extent are you fearful of spreading (metastasis) of your cancer?

No fear 0 1 2 3 4 5 6 7 8 9 10 Extreme fear

8. How distressing has illness been for your family?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

9. Is the amount of support you receive from others sufficient to meet your needs?

Not at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

10. To what degree has your illness and treatment interfered with your employment?

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

11. To what degree has your illness and treatment interfered with your activities at home?

No problem 0 1 2 3 4 5 6 7 8 9 10 Severe problem

12. How much financial burden have you incurred as a result of your illness and treatment?

None 0 1 2 3 4 5 6 7 8 9 10 A great deal

13. How important to you is your participation in religious activities such as praying, going to church?

Not at all important 0 1 2 3 4 5 6 7 8 9 10 Very important

14. How important to you are other spiritual activities such as meditation?

Not at all important 0 1 2 3 4 5 6 7 8 9 10 Very important

15. How much has your spiritual life changed as a result of cancer diagnosis?

Less important 0 1 2 3 4 5 6 7 8 9 10 More important

16. How much uncertainty do you feel about your future?

Not at all uncertain 0 1 2 3 4 5 6 7 8 9 10 Very uncertain

17. To what extent has your illness made positive changes in your life?

None at all 0 1 2 3 4 5 6 7 8 9 10 A great deal

18. How hopeful do you feel?

Not at all hopeful 0 1 2 3 4 5 6 7 8 9 10 Very hopeful

Is there anything else you would like to tell us about your experience with cancer?

That concludes our survey. If you have any questions or concerns, please contact Dr. Giang Nguyen at (215) 615-0355 or the University of Pennsylvania Office Human Research at (215) 898-2641; or Dr. Mai-Nhung Le at (415) 338-6161 or the San Francisco State University Office of Protection for Human Subjects at (415) 338-1093. For helpful cancer resources/information, please contact the Asian & Pacific Islander National Cancer Survivors Network at (415) 954-9988 or the Asian American Cancer Support Network at (650) 968-8488. Thank you for your time.

Do not staple this page to the survey.

If you wish to receive the \$10 gift card, please complete the following page. Your identity will not be linked to your survey answers.

Name: _____

Street Address: _____

City, State: _____

Zip Code: _____

May we keep your name and address to contact you in the future for other research opportunities? Yes No

If yes, may we also have your e-mail address? _____ No e-mail

Thank you!

We will mail your gift card shortly after we receive your information and survey responses.

Please mail your survey papers to

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University of Pennsylvania
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