# Asian Patient Perspectives Regarding Oncology Awareness, Care, and Health (APPROACH)

For interviewer: Fill in questionnaire.	n the following ir	nformation afte	r you have completed the
PARTICIPANT CODE: (FROM CONSENT FORM)		Date Of (dd/mm/yyyy):	INTERVIEW//
TIME STARTED:	TIME ENDED:	Total	INTERVIEW TIME:
INTERVIEWER NAME:			
COUNTRY:		INTERVIEW LANC	GUAGE:
NAME OF THE INSTITUTIO	N:		
PATIENT TYPE: 1 OU	TPATIENT	□2 INPATIENT	
SITE OF RECRUITMENT: 1 DEPARTMENT OF ME 5 DEPARTMENT OF SUI 6 INTERNATIONAL MED 7 DEPARTMENT OF RAI 8 PALLIATIVE CARE UN 9 OTHER,	RGERY ICAL DEPARTMENT DIATION ONCOLOGY IIT		
10 ONCOLOGY DEPARTI	MENT, HUE CENTRAL H	OSPITAL BASE 2	
Fill in the	PATIENT GENDER	: 🗆 1 Male 🗆 2 F	EMALE
information from patient's medical	PATIENT'S DATE (	of Birth (dd/mm/	/YYYY):/
records.	TYPE OF CANCER		

### INTRODUCTION

We are conducting a survey to understand the quality of life of patients, quality of care they are currently receiving and their treatment preferences. Your opinions are important to the success of this study. The survey usually takes about **45 minutes**.

There are no right or wrong answers to the questions and you do not have to respond to any questions that you feel uncomfortable answering. Your identity and the information given will be kept strictly confidential and only group data will be reported.

### SECTION S: SCREENER

Have you ever been diagnosed with any of the following health conditions? Check all that apply.				
	Health Conditions	Yes		
]1	Diabetes			
]2	Heart conditions (e.g. heart attack, blocked blood vessels)			
⊒3	Lung/Liver disease (e.g. bronchitis, hepatitis)			
□4	Cancer			

### [TERMINATE if option 4 'Cancer' is NOT checked] [Thank you for your interest, but you are not eligible to continue with this survey]

### SECTION A: BASIC INFORMATION

[For questions A1 to A5, you do not need to read the response choices out loud to the patient. Allow the patient to first respond directly, and prompt him/her with relevant choices depending upon his/her response]

A1	What	is your age?				
	years old					
A2	How many years of education have you completed (including higher education) years					
A3	What	is your current marital status?				
	□1	Married	□4	Divorced		
	□2	Separated	□5	Never married		
	□3	Widowed	□6	Other, specify:		
<b>A</b> 4	What is your religion?					
	□1	Hindu	□7	Jewish		
	□2	Muslim	□8	Parsi/Zoroastrian		
	□3	Christian (including Roman Catholic, Protestant, Orthodox, other)	□9	Taoist		
	□4	Sikh	□10	Confucian		
	□5	Buddhist	□11	No religion		
	□6	Jain	□12	Other, specify:		

Refuse to answer

A4.3	What is your ethnicity?						
	□30	Kinh	□33	Mường			
	□31	Tày	□17	Others			
	□32	Thái					
A5	What t	ype of cancer have you been diagn	osed w	ith?			
	□1	Bladder	□11	Lung			
	□2	Brain	□12	Nasopharyngeal			
	□3	Breast	□13	Oesophageal			
	□4	Cervical	□14	Ovarian			
	□5	Colorectal	□15	Oral			
	□6	Endometrial	□16	Pancreatic			
	□7	Gastric	□17	Prostate			
	□8	Intestinal	□18	Vulva			
	□9	Kidney	□19	Others, please specify			
	□10	Liver	□20	Don't know			
A6	Do you know the current stage (i.e. severity) of your cancer?						
	□1	Early Stage (Stage I, II or III)					
	□2	Advanced Stage (Stage IV)					
	□3	l don't know					
A7	[If A6= about	2] What was the stage (i.e. severity it?	) of you	r cancer when you <u>first</u> learned			
	□1	Early Stage (Stage I, II or III)					
	□2	Advanced Stage (Stage IV)					
	□3	I don't know					

### **SECTION B: QUALITY OF LIFE**

# B1<sup>1</sup> Below is a list of statements that other people with your illness have said are important or bothersome for them. Some of the items may appear to be repetitive, but please bear with us. Please indicate one number per line as it applies to the past 7 days.

		Not at all	A little bit	Some- what	Quite a bit	Very much
B1.1 GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
B1.2 GP5	I am bothered by side effects of treatment	0	1	2	3	4
B1.3 GP6	I feel ill	0	1	2	3	4
B1.4 GP7	I am forced to spend time in bed	0	1	2	3	4

		Not at all	A little bit	Some- what	Quite a bit	Very much		
B1.5 GS1	I feel close to my friends	0	1	2	3	4		
B1.6 GS2	I get emotional support from my family	0	1	2	3	4		
B1.7 GS3	I get support from my friends	0	1	2	3	4		
B1.8 GS4	My family has accepted my illness	0	1	2	3	4		
B1.9 GS5	I am satisfied with family communication about my illness	0	1	2	3	4		
B1.10 GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4		
	Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box and go to the next question.							
B1.11 GS7	I am satisfied with my sex life	0	1	2	3	4		

Refuse to answer

<sup>&</sup>lt;sup>1</sup> Items in B1 are from the Functional Assessment of Chronic Illness Therapy system of Quality of Life questionnaires ("FACIT system"). Items B1.1–B1.24 are from FACT-G (Version 4), Items B1.25–B1.36 are from FACIT-Sp (Version 4) and B1.37 from FACIT-Pal (Version 4).

		Not at all	A little bit	Some- what	Quite a bit	Very much
B1.12 GE1	I feel sad	0	1	2	3	4
		Not at all	A little bit	Some- what	Quite a bit	Very much
B1.13 GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
B1.14 GE3	I am losing hope in the fight against my illness	0	1	2	3	4
B1.15 GE4	I feel nervous	0	1	2	3	4
B1.16 GE5	I worry about dying	0	1	2	3	4
B1.17 GE6	I worry that my condition will get worse	0	1	2	3	4
		Not at all	A little bit	Some- what	Quite a bit	Very much
B1.18 GF1	I am able to work (include work at home)	0	1	2	3	4
B1.19 GF2	My work (include work at home) is fulfilling	0	1	2	3	4
B1.20 GF3	I am able to enjoy life	0	1	2	3	4
B1.21 GF4	I have accepted my illness	0	1	2	3	4
B1.22 GF5	I am sleeping well	0	1	2	3	4
B1.23 GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
B1.24 GF7	I am content with the quality of my life right now	0	1	2	3	4
		Not	A little	Some-	Quite	Very
		at all	bit	what	a bit	much
B1.25 Sp1	I feel peaceful	0	1	2	3	4
B1.26 Sp2	I have a reason for living	0	1	2	3	4
B1.27 Sp3	My life has been productive	0	1	2	3	4

B1.28 Sp4	I have trouble feeling peace of mind	0	1	2	3	4
B1.29 Sp5	I feel a sense of purpose in my life	0	1	2	3	4
		Not at all	A little bit	Some- what	Quite a bit	Very much
B1.30 Sp6	I am able to reach down deep into myself for comfort	0	1	2	3	4
B1.31 Sp7	I feel a sense of harmony within myself	0	1	2	3	4
B1.32 Sp8	My life lacks meaning and purpose	0	1	2	3	4
B1.33 Sp9	I find comfort in my faith or spiritual beliefs	0	1	2	3	4
B1.34 Sp10	I find strength in my faith or spiritual beliefs	0	1	2	3	4
B1.35 Sp11N I	Difficult times have strengthened my faith or spiritual beliefs	0	1	2	3	4
B1.36 Sp12N I	Even during difficult times, I know that things will be okay	0	1	2	3	4
B1.37 Sp21	I feel hopeful	0	1	2	3	4

The next three questions will focus on your finances.

B2		How well does the amount of money you have enable you to cover the cost of your treatment?					
	□1	Very well					
	□2	Fairly well					
	□3	Poorly					
<b>B</b> 3	How wel	I does the amount of money you have take care of your daily needs?					
	□1	Very well					
	□2	Fairly well					
	□3	Poorly					
B4		I does the amount of money you have enable you to buy those little that is, those small luxuries?					
	□1	Very well					
	□2	Fairly well					

□3	Poorly
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B10.1	In the las	st 24 hours, have you taken any medication for pain relief?	
	□1	Yes	888
	□2	No	Refuse

	SYMPTOM MANAGEMENT	Not at all	A little bit	Some- what	Quite a bit	Very muc
B13.1 GP4	I have pain	0	1	2	3	4
B13.2 B1	I have been short of breath	0	1	2	3	4
B13.3 PAL5	I am constipated	0	1	2	3	4
B13.4 C2	I am losing weight	0	1	2	3	4
B13.5 O2	I have been vomiting	0	1	2	3	4
B13.6 PAL6	I have swelling in parts of my body	0	1	2	3	4
B13.7 PAL7	My mouth and throat are dry	0	1	2	3	4
B13.8 GP1	I have lack of energy	0	1	2	3	4
B13.9 GP2	I have nausea	0	1	2	3	4
B13.10	Any other symptom, please specify:		1	2	3	4

<sup>&</sup>lt;sup>2</sup> Items B13.1–B13.6 are from FACIT-Pal (Version 4) and B13.8–B13.9 are from FACT-G (Version 4). Both FACIT-Pal and FACT-G are from the Functional Assessment of Chronic Illness Therapy system of Quality of Life questionnaires ("FACIT system").

B15	(If B14=2 apply.	2) Why did you not tell your doctor about your symptoms? Check all that
	□1	I can manage my symptoms myself
	□2	I want the doctor to focus on the treatment of my cancer
	□3	I did not get an opportunity to tell the doctor
	□4	I believe that it is easier to put up with symptoms than with the side effects that come from medicines to treat these symptoms.
	□5	I will use medicines only as a last resort to treat my symptoms
	□6	I believe that good patients avoid talking about symptom/s
	□7	I can get addicted easily to medicines needed to treat these symptoms
	□8	I believe that tolerating symptoms builds character—it's good for me.
	□9	Any other reason, specify
	□10	I believe that tolerating pain and symptoms would help me get rid of my sins.

B16 Below is a list of the ways you might have felt or behaved. For each of the following statements, please choose the option that best describes how often you felt or behaved this way during the <u>PAST WEEK</u>.

		Rarely or none of the time (Less than 1 day)	Some or a little of the time (1-2 days)	Occasi onally or a moder ate amount of the time (3-4 days)	Most or all of the time (5-7 days)	
B16.15.1	I was bothered by things that usually don't bother me.	1	2	3	4	88
B16.15.2	I did not feel like eating; my appetite was poor.	1	2	3	4	88

<sup>&</sup>lt;sup>3</sup> Items from B16.15 are from the CES-D 20-item scale. Radloff, L.S. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied psychological measurement, 1(3), 385-401.

B16.15.3	I felt that I could not shake off the blues even with help from my family or friends.	1	2	3	4	8
B16.15.4	I felt that I was just as good as other people.	1	2	3	4	Refuse answer
B16.15.5	I had trouble keeping my mind on what I was doing.	1	2	3	4	888
B16.15.6	I felt depressed.	1	2	3	4	
B16.15.7	I felt that everything I did was an effort.	1	2	3	4	888
B16.15.8	I felt hopeful about the future.	1	2	3	4	
B16.15.9	l thought my life had been a failure.	1	2	3	4	
B16.15.10	l felt fearful.	1	2	3	4	
B16.15.11	My sleep was restless.	1	2	3	4	888
B16.15.12	I was happy.	1	2	3	4	888
B16.15.13	I talked less than usual.	1	2	3	4	888
B16.15.14	I felt lonely.	1	2	3	4	888
B16.15.15	People were very unfriendly.	1	2	3	4	888
B16.15.16	l enjoyed life.	1	2	3	4	
B16.15.17	I had crying spells.	1	2	3	4	888
B16.15.18	I felt sad.	1	2	3	4	888
B16.15.19	I felt that people dislike me.	1	2	3	4	888
B16.15.20	I could not get "going".	1	2	3	4	

B17	l feel like	e I have become a burden on my loved ones.		
	□1	Not at all	8	388
	□2	A little bit		
	□3	Somewhat		

□4	Quite a bit
□5	Very much

# SECTION C: QUALITY OF CARE

Refuse to answer

C1⁴	Now we would like to ask you some questions related to your experience in dealing with health care providers for your current illness. Think of all the healthcare providers (doctors, nurses, and allied health providers) that you have seen for your current illness since it was diagnosed. These include those in the hospital, polyclinics, private clinics, hospice, nursing homes or other places.											
		Always (1)	Somet imes (2)	Never (3)	Not applicable (4)							
C1.1	How often did your doctors listen carefully to you?											
C1.2	How often did your doctors explain things in a way you could understand?											
C1.3	How often did your doctors give you as much information as you wanted about your treatments, including potential benefits and side effects?											
C1.4	How often did your doctors encourage you to ask all the cancer related questions you had?											
C1.5	How often did your doctor treat you with courtesy and respect?											
C1.5.1	How often did your doctors spend adequate time with you to address all your concerns?											
C1.6	How often were your nurses as helpful as you thought they should be?											
C1.7	How often did your nurses treat you with courtesy and respect?											
C1.8	How often did you think that your health problems related to your cancer or its treatment were handled quickly enough?											
C1.9	How often were you able to see the specialist doctors you wanted to see for your cancer?											
C1.10	How often did the doctors, nurses, and other medical staff providing your care seem to work well together as a team?											

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C1.11	aware	often did your doctors seem to be of treatments for your cancer that doctors recommended?	t						
C1.12	you h	often did you know who to ask whe ad any questions related to your er or its treatments?	en						
C1.13	nurse every proble	often did you feel that your doctors es, and other medical staff did thing they could to treat your healt ems related to your cancer or its nents?							
C1.14	involv	often did you feel you were as muo ved in decisions about your care as vanted?							
C1.15		all how would you rate the qualinosis?	ty of	your ł	nea	Ith care	since yo	ur	
	□1	Excellent	□4	Fa	air				
	□2	Very good	□5	P	oor	•			
	□3	Good							

# C2 Now I would like you to think about your most recent visit again. I want to know your impressions of your most recent visit for health care. I would like you to rate your experiences using the following questions.

For your last visit to a health care provider, how would you rate the following:

		Very Good	Good	Moderate	Bad	Very Bad
C2.1	your experience of being treated respectfully?	1	2	3	4	5
C2.2	how clearly health care providers explained things to you?	1	2	3	4	5

<sup>&</sup>lt;sup>4</sup> Items from C1 except for C1.5.1 and C1.14 are from CanCORS Full Patient Baseline Interview (Version 7); Ayanian JZ, Zaslavsky AM, Arora NK, Kahn KL, Malin JL, Ganz PA, van Ryn M, Hornbrook MC, Kiefe CI, He Y, Urmie J, Weeks JC, Harrington DP. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. J Clin Oncol 2010; 28:4154-61.

Malin JL, Ko C, Ayanian JZ, Harrington D, Kahn KL, Ganther-Urmie J, Catalano PJ, Nerenz DR, Zaslavsky AM, Wallace RB, Guadagnoli E, Arora NK, Roudier MD, Ganz PA. Understanding cancer patients' experiences and outcomes: development and pilot study of the Cancer Care Outcomes Research and Surveillance patient survey. Supp Care Cancer 2006; 14:837-48.

C2.3	your experience of being involved in making decisions for your treatment?	1	2	3	4	5	5

C3⁵	I am now going to read you stories describ illness have had with health care services. experiences as if they were your own. Onc ask you to rate what happened in the story bad.	I want yo e I have	ou to thin finished	ik about thes reading each	e people story, l	e's will
C3.1	[Tý] went to a crowded clinic. No-one greet nurse called for her for an examination beh area from the examination area.					
	How would you rate [Tý's] experience of being greeted and talked to	Very Good	Good	Moderate	Bad	Very Bad
	respectfully?	1	2	3	4	5
C3.2	The doctor has very briefly explained to [Ta there is a queue of patients waiting to see					
C3.2	The doctor has very briefly explained to [Ta there is a queue of patients waiting to see his illness, but feels that there is no time to [Tẩn], and [Tẩn] leaves the office.	him. [Tẩr ask que	n] would stions. T	like to know i he doctor sa	more ab	out bye to
C3.2	there is a queue of patients waiting to see his illness, but feels that there is no time to [Tẩn], and [Tẩn] leaves the office. How would you rate [Tẩn] experience of	him. [Tẩr	n] would	like to know i	more ab	out
C3.2	there is a queue of patients waiting to see his illness, but feels that there is no time to [Tẩn], and [Tẩn] leaves the office.	him. [Tẩr ask que Very	n] would stions. T	like to know i he doctor sa	more ab ys good	oout bye to Very
C3.2	there is a queue of patients waiting to see his illness, but feels that there is no time to [Tẩn], and [Tẩn] leaves the office. How would you rate [Tẩn] experience of how clearly health care providers	him. [Tẩr ask que Very Good 1 scan for [	n] would stions. T Good 2 Hàn]. [H	like to know i he doctor say Moderate 3 àn] didn't kno	more ab ys good Bad 4 ww why	vout bye to Very Bad 5 he
-	<ul> <li>there is a queue of patients waiting to see his illness, but feels that there is no time to [Tẩn], and [Tẩn] leaves the office.</li> <li>How would you rate [Tẩn] experience of how clearly health care providers explained things to him?</li> <li>The doctor ordered some blood tests and s needed blood tests and scan and was work</li> </ul>	him. [Tẩr ask que Very Good 1 scan for [	n] would stions. T Good 2 Hàn]. [H	like to know i he doctor say Moderate 3 àn] didn't kno	more ab ys good Bad 4 ww why	very Bad 5 he

Refuse to answer

<sup>&</sup>lt;sup>5</sup> Adapted from WHO SAGE Wave 1 Individual questionnaire obtained from http://www.who.int/healthinfo/sage/cohorts/en/index2.html.

Refuse to

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#### answer

### SECTION D: PROGNOSIS, TREATMENT PREFERENCES, AND DECISION MAKING

D1	(If A6 ≠	2) When did you <u>first</u> learn that y	vou have	e cancer?
	□1	Less than 6 months ago	□4	2 to 3 years ago
	□2	6 months to 1 year ago	□5	More than 3 years ago
	□3	1 to 2 years ago		
D2	(If A6 ≠	2) Who informed you about it?		
	□1	Doctor	□4	Guessed from the worsened condition
	□2	Family member	□5	Other, please explain:
	□3	Learned by chance		
D3	(If A6 =	2) When did you <u>first</u> learn that y	ou have	e <u>advanced</u> cancer?
	□1	Less than 6 months ago	□4	2 to 3 years ago
	□2	6 months to 1 year ago	□5	More than 3 years ago
	□3	1 to 2 years ago		
D4	(If A6 =	2) Who informed you about it?		
	□1	Doctor	□4	Guessed from the worsened condition
	□2	Family member	□5	Other, please explain:
	□3	Learned by chance		
D5 <sup>6</sup>	How in	formed are you regarding how yo	our illnes	ss will change over time?
	□1	Very informed	□3	Unsure

<sup>&</sup>lt;sup>6</sup> CanCORS Full Patient Baseline Interview (Version 7); Ayanian JZ, Zaslavsky AM, Arora NK, Kahn KL, Malin JL, Ganz PA, van Ryn M, Hornbrook MC, Kiefe CI, He Y, Urmie J, Weeks JC, Harrington DP. Patients' experiences with care for lung cancer and colorectal cancer: findings from the Cancer Care Outcomes Research and Surveillance Consortium. J Clin Oncol 2010; 28:4154-61.

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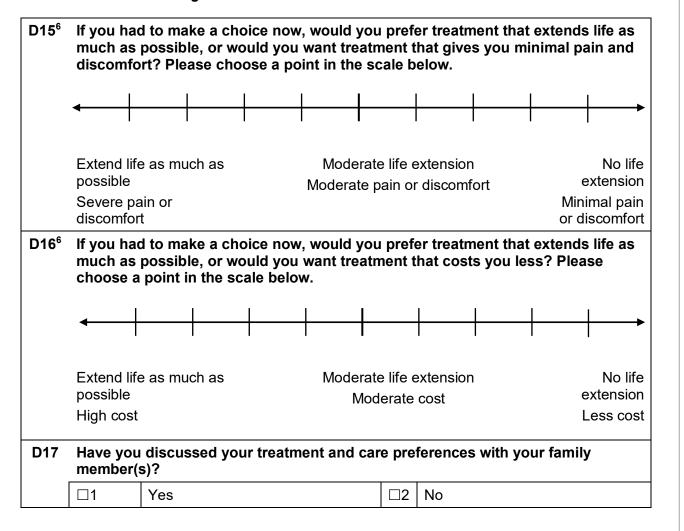
The next items ask what you think about the possible results of cancer treatments. Do you think  $\ldots$ 

D6 <sup>6</sup>	The curr	ent treatments you are taking for your cancer will help you live longer?
	□1	Yes
	□2	No
	□3	Not sure
D7 <sup>6</sup>	The curr	ent treatments you are taking for your cancer will cure you?
	□1	Yes
	□2	No
	□3	Not sure
D8	There an longer?	e other treatments (besides your current treatment) that will help you live
	□1	Yes
	□2	No
	□3	Not sure
D9	There ar	e other treatments (besides your current treatment) that will cure you?
	□1	Yes
	□2	No
	□3	Not sure
D10 6		agnosis, who has been responsible for the most important decisions about atment? Check all that apply.
	□1	Myself
	□2	My family
	□3	My doctors
D11 6	<b>`</b>	than one option is checked in D10.) Which statement best describes the n person played when making decisions about your treatment?
	(If "myse	elf" and "my family" are checked, options are)
	□1	I made the decisions after considering my family's opinion
	□2	My family made the decisions after considering my opinion
	□3	My family and I made the decisions together
	(If "myse	elf" and "my doctors" are checked, options are)
	□4	I made the decisions after considering my doctors' opinions
	□5	My doctors made the decisions after considering my opinion
	□6	My doctors and I made the decisions together

	□7	My family made the decisions after considering my doctors' opinions
		My doctors made the decisions after considering my family's opinion
	□9	My family and my doctors made the decisions together
	·	ree are checked, options are)
	□10	I made the decisions after considering my family's and doctors' opinions
	□11	My family made the decisions after considering my and my doctors' opinions
	□12	My doctors made the decisions after considering my and my family's opinions
	□13	My family, my doctors and I made the decisions together
D12		iagnosis, who do you wish had been responsible for the most important ns about your treatment? Check all that apply.
	□1	Myself
	□2	My family
	□3	My doctors
D13 6	role you treatme	
		self" and "my family" are checked, options are)
	□1	I wish that I made the decisions after considering my family's opinion
	□2	I wish that my family made the decisions after considering my opinion
	□3	I wish that my family and I made the decisions together
	□3	
	□3	I wish that my family and I made the decisions together
	□3 (If "mys	I wish that my family and I made the decisions together self" and "my doctors" are checked, options are)
	□3 (If "mys	I wish that my family and I made the decisions together <b>celf</b> " and "my doctors" are checked, options are) I wish that I made the decisions after considering my doctors' opinions
	□3 (If "mys □4 □5 □6	I wish that my family and I made the decisions together <b>celf" and "my doctors" are checked, options are)</b> I wish that I made the decisions after considering my doctors' opinions I wish that my doctors made the decisions after considering my opinion
	□3 (If "mys □4 □5 □6	I wish that my family and I made the decisions together         self" and "my doctors" are checked, options are)         I wish that I made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my opinion         I wish that my doctors and I made the decisions together
	□3 (If "mys □4 □5 □6 (If "my f	I wish that my family and I made the decisions together         self" and "my doctors" are checked, options are)         I wish that I made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my opinion         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my family made the decisions after considering my doctors'
	□3 (If "mys □4 □5 □6 (If "my t	I wish that my family and I made the decisions together         self" and "my doctors" are checked, options are)         I wish that I made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my opinion         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my family made the decisions after considering my doctors' opinions         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors'         opinions         I wish that my doctors made the decisions after considering my family's
	□3 (If "mys □4 □5 □6 (If "my f □7 □8 □9	I wish that my family and I made the decisions together         self" and "my doctors" are checked, options are)         I wish that I made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my opinion         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my family's opinion
	□3 (If "mys □4 □5 □6 (If "my f □7 □8 □9	I wish that my family and I made the decisions together         ielf" and "my doctors" are checked, options are)         I wish that I made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my opinion         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my family's opinion         I wish that my doctors made the decisions after considering my family's opinion         I wish that my family and my doctors made the decisions together
	□3 (If "mys □4 □5 □6 (If "my f □7 □8 □9 (If all th	I wish that my family and I made the decisions together         I wish that my doctors" are checked, options are)         I wish that I made the decisions after considering my doctors' opinions         I wish that my doctors made the decisions after considering my opinion         I wish that my doctors and I made the decisions together         family" and "my doctors" are checked, options are)         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my doctors' opinions         I wish that my family made the decisions after considering my family's opinion         I wish that my doctors made the decisions after considering my family's opinion         I wish that my family and my doctors made the decisions together         ree are checked, options are)         I wish that I made the decisions after considering my family's and doctors'

	□12	I wish that my doctors made the decisions after considering my and my family's opinions	Refuse to
	□13	I wish that I, my family and my doctors made the decisions together	answer
D14	appropri	s a difference in opinion between you and your family regarding the ate course of treatment for you, whose opinion do you think will be <u>most</u> <u>at</u> in deciding the treatment that you receive?	888
	□1	My own	
	□2	My family's	
	□3	My doctor's	

We will now ask you questions about your treatment preferences. The next questions that I am going to ask you are very sensitive in nature. Please skip the questions that you do not feel comfortable answering.



# SECTION E: HOSPICE PALLIATIVE CARE AWARENESS AND UTILIZATION

E1 <sup>6</sup>	Please indicate if you are aware of hospice palliative care services? (Hospice palliative care is a comprehensive program that focuses on providing relief of pain and other distressing symptoms, as well as ensuring emotional, spiritual and practical support for the patient and the family. These services can be given in the patient's home, in an in-patient hospice, hospice day care centre, in a palliative care clinic or in the ward of a hospital)					
	□1	Yes				
	□2	No (Go to E8)				
	□3	Not sure (Go to E8)				
E2	How di	d you first learn about hospice pall	iative o	care services?		
	□1	From doctors or other healthcare professionals	□4	From the media	88	
	□2	From family/friends	□5	From others, please specify:		
	□3	Through personal research				
E3 <sup>6</sup>	Did any to you?	doctor or other health care provid	er <u>reco</u>	ommend hospice palliative care	88	
	□1	Yes				
	□2	No (Go to E5)				
	□3	Not sure (Go to E5)				
E4	When o	lid the doctor recommend hospice	palliat	ive care for you?		
	□1	Within the last month	□4	1 year ago	88	
	□2	2 to 3 months ago	□5	More than 1 year ago		
	□3	4 to 6 months ago				
E5 <sup>6</sup>	Since t	he diagnosis of your illness, have y	/ou rec	eived hospice palliative care?		
	□1	Yes			88	
	□2	No (Go to E7)				
	□3	Not sure (Go to E7)				
E6 <sup>6</sup>		) Please tell us who had the FINAL a palliative care.	say in	deciding for you to receive	88	
	□1	Me only	□5	Me and my doctor		
	□2	My family only	□6	My family and my doctor		
	□3	My doctor only	□7	Me, my family and my doctor		
	□4	Me and my family	□8	Others, please specify:		

Refuse to answer

E7		and prompt him/her with relevant choices depending upon his/her response]
	(If E5≠1) that app	) Why are you not receiving hospice palliative care at this time? Check all ly.
	□1	I am still receiving treatment for my disease
	□2	I do not believe it's time for hospice palliative care
	□3	I do not think that hospice palliative care would be of help to me
	□4	Some of my doctors do not think that hospice palliative care would be of help to me
	□5	My family does not believe it's time for hospice palliative care
	□6	My family does not think that hospice palliative care would be of help to me
	□7	I don't know much about it
	□8	I think getting hospice palliative care will be like giving up on life
	□9	It is expensive
	□10	Any other reason, please specify:
	health,	It questions that I am going to ask you are very sensitive in nature. We ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. skip the questions that you do not feel comfortable answering.
E8	health, ( Please s	ng you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. skip the questions that you do not feel comfortable answering. you like to know how long you are likely to live under various treatment
E8	health, o Please s Would y	ng you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. skip the questions that you do not feel comfortable answering. you like to know how long you are likely to live under various treatment
E8	health, o Please s Would y options	ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. skip the questions that you do not feel comfortable answering. you like to know how long you are likely to live under various treatment ?
E8	health, o Please s Would y options	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. skip the questions that you do not feel comfortable answering. You like to know how long you are likely to live under various treatment ?
E8	health, or Please statements of the second statement o	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. Skip the questions that you do not feel comfortable answering.         You like to know how long you are likely to live under various treatment?         No         Yes, in general terms (such as 'a few months' or 'a few years')
_	health, e Please s Would y options 1 2 3 4 [You do	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. Skip the questions that you do not feel comfortable answering.         You like to know how long you are likely to live under various treatment?         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')
-	health, e Please s Would y options 1 2 3 4 [You do directly, Conside	ing you these questions to better understand your thoughts on your         quality of life and the quality of care you receive from this hospital.         skip the questions that you do not feel comfortable answering.         you like to know how long you are likely to live under various treatment?         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')         Not Sure         not need to read response choices out loud. Allow the patient to first respond
_	health, e Please s Would y options 1 2 3 4 [You do directly, Conside	ing you these questions to better understand your thoughts on your         quality of life and the quality of care you receive from this hospital.         skip the questions that you do not feel comfortable answering.         rou like to know how long you are likely to live under various treatment         ?         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')         Not Sure         not need to read response choices out loud. Allow the patient to first respond and prompt him/her with relevant choices depending upon his/her response]         ering your current health condition and treatment plan, how long do you
-	health, e Pleases Would y options 1 2 3 4 [You do directly, Conside think yo	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. Skip the questions that you do not feel comfortable answering.         You like to know how long you are likely to live under various treatment?         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')         Not Sure         not need to read response choices out loud. Allow the patient to first respond and prompt him/her with relevant choices depending upon his/her response]         ering your current health condition and treatment plan, how long do you ou are likely to live?
-	health, e Pleases Would y options	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital.         Skip the questions that you do not feel comfortable answering.         rou like to know how long you are likely to live under various treatment         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')         Not Sure         not need to read response choices out loud. Allow the patient to first respond and prompt him/her with relevant choices depending upon his/her response]         ering your current health condition and treatment plan, how long do you ou are likely to live?         Less than 1 year
_	health, e Pleases Would y options	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. Skip the questions that you do not feel comfortable answering.         Instruction of the experiment of
_	health, e Please s Would y options 1 2 3 4 [You do directly, Conside think you 1 2 3	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital.         Inskip the questions that you do not feel comfortable answering.         rou like to know how long you are likely to live under various treatment         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')         Not Sure         not need to read response choices out loud. Allow the patient to first respond and prompt him/her with relevant choices depending upon his/her response]         ering your current health condition and treatment plan, how long do you use are likely to live?         Less than 1 year         1 up to 2 years         2 up to 3 years
E8	health, e Please s Would y options 1 2 3 4 (You do directly, Conside think you 1 2 3 2 4	Ing you these questions to better understand your thoughts on your quality of life and the quality of care you receive from this hospital. skip the questions that you do not feel comfortable answering.         rou like to know how long you are likely to live under various treatment?         No         Yes, in general terms (such as 'a few months' or 'a few years')         Yes, in specific terms (such as 'on average 6 months')         Not Sure         not need to read response choices out loud. Allow the patient to first respond and prompt him/her with relevant choices depending upon his/her response]         ering your current health condition and treatment plan, how long do you use are likely to live?         Less than 1 year         1 up to 2 years         2 up to 3 years         3 up to 5 years

888

E10	spend the	ople have a strong preference concerning where they would like to eir last days prior to death. If you had a chance, where would you like to I the last days of your life?
	□1	At my home
	□2	In the home of a friend/family member
	□3	In the hospital where I have been receiving medical care
	□4	Hospice
	□5	Nursing home
	□6	Any other place, please specify:
	□7	Doesn't matter
E11 <sup>7</sup>	Do you e	ver wish that your life would end sooner?
	□1	Yes
	□2	No
	□3	Not sure

<sup>&</sup>lt;sup>7</sup> From the Desire for Death Rating Scale. Chochinov HM, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, Clinch JJ: Desire for death in the terminally ill. Am J Psychiatry 1995; 152:1185–1191.

Refuse to

ECTIC	)N F: <u>SE</u>	LF BLAME AND SOCIAL STIGMA	
F1 <sup>6</sup>		ou smoked at least 100 times in your	life?
	□ 1	Yes	Answer Qs. F1.1 & F1.2
	□ 2	No	
	□ 3	Don't know	Skip to Qs. F2
F1.1 6	How o	d were you when you started to smol	ke regularly?
F1.2	Are yo	u currently smoking?	
	□ 1	Yes	
	□ 2	No	
F2	Have y	ou ever chewed betel nut/tobacco reg	
	□ 1	Yes, I currently chew betel nut/tobac	co regularly
	□ 2	Yes, I have chewed betel nut/tobacco	o in the past but not anymore
	□ 3	No	
F2.1	(If F2= regula	1 or 2) How old were you when you s rly?	tarted to chew betel nut/tobacco
		years old	
F3 <sup>6</sup>		you were diagnosed with cancer, ho lic beverage?	w often did you drink any type of
		Less than once a month	
	□ 2	A few times a month	
	□ 3	A few times a week	
	□ 4	Daily	
F3.1 6	•	1) Before you were diagnosed with ca / have each time you had drinks?	ncer, how much alcohol did you
	□ 1	1 – 2 drinks	
	□ 2	3 – 4 drinks	
	□ 3	5 or more drinks	
F3.2	Are yo	u currently consuming any alcoholic	beverages?
6			

We have found that some people blame themselves for their cancer and some people don't blame themselves at all.

How much do you blame yourself for:

F4	How m	uch do you blame yours	self for:					
			Not at all (1)	Some (2		Very m (3)		Completely (4)
i.		naviour that may have our cancer?			]			
ii.	(e.g., be who has	d of person you are eing the unlucky person s things like cancer to them)?			]			
F5		extent of your knowledg e of illness you have? C			wing (	if any) a	ire rea	asons for
	1	Smoking						
	2	Chewing betel nut/toba	cco					
	3	Consumption of alcohol						
	4	Being overweight						
	5	Stress/ Anxiety						
	6	Previous bad deeds						
	7	God's will						
	8	Old age						
	9	Others, please specify						
F6 <sup>8</sup>	change	e found that some peop s in their social interact and indicate how often t	tions due to	their ca	ncer. (			
			Never (1)	Rarely (2)		etimes (3)	Ofte (4)	,
i.		hers consider me sible for my cancer.						
ii.	l am en people	barrassed when I tell my diagnosis						
iii.	l feel as develop	hamed for having ed cancer						
iv.	People my can	avoid me because of						
<b>v</b> .	I have a	in urge to keep my a secret						
vi.	l sense	that others feel strained ey are around me.						
	1		1		1			

<sup>8</sup> Item is from the Shame Stigma Scale. Kissane DW, Patel SG, Baser RE, Bell R, Farberov M, Ostroff JS, et al. Preliminary evaluation of the reliability and validity of the shame and stigma scale in head and neck cancer. Head Neck. 2013;35:172-83. Refuse to answer

F7		ou think your family and frie			us (		
	□ 1	Yes, most of them	□ 3	No			
	□ 2	Yes, some of them	□ 4	Not sure			
F8	How	How much control do you believe you personally have over:					
			Absolutely no control (1)	Little bit of control (2)	Some control (3)	Total Control (4)	
i.	The s	tress from your illness?					
ii.	disea	cal symptoms of your se or side effects of your nent (e.g., pain)?					
iii.		/pe of medical treatment eceive?					
iv.	Whet better	ner your condition will get ?					
F9	Do yo	ou believe God will cure yo	ur illness one	day?		_	
	□ 1	Yes					
	□ 2	No					
	□ 3	Not sure	Not sure				
F9.1	[If F9	=Yes] How will this happen?					
	□ 1	Through a miracle with	nout medical tre	eatment			
	□ 2	Through medical treat	ment				

### SECTION G: USE OF/INTEREST IN USING MENTAL HEALTH SERVICES

G1		ou seen any of the mental health ca	are wor	kers listed below as part of your
	cancer	treatment? Check all that apply. Psychiatrist		Answer Qs. G2 to G4
	□ 2	Psychologist		
	□ 3	Medical social worker (for psycholog support)	gical	
	□ 4	Community counsellor		
	□ 5	Others, please specify		
	□ 6	Don't know		Skip to Q. G5
	□7	No		
G2	[lf G1=	1 to 5] What type of mental health s	service	did you receive?
	□ 1	Medications	□ 3	Support group
	□ 2	Therapy/counselling	□ 4	Other, please specify:
G3	[lf G1=	1 to 5] Where did you receive ment	al heal	th services?
	□1	At the hospital as part of inpatient tr	eatmen	t
	□2	At the hospital in an outpatient appo	ointmen	t
	□3	I found a mental health professional	myself	
	□4	As part of homecare service		
G4	[lf G1=	1 to 5] How helpful did you find ree	ceiving	mental health services?
	□ 1	Very helpful	□ 3	I am not sure
	□ 2	Quite helpful	□ 4	Not helpful at all
G5	[lf G1=	6 or 7] Would you use mental healt	h servi	ces if you were referred?
	□ 1	Yes		
	□ 2	No		
	□ 3	Not sure		
G6	Did you	delay medical treatment for cance		-
	□ 1	Yes, I delayed my medical treatment for some time	Answ	er Q. G6.1
	□ 2	No, I sought medical treatment immediately	Skip t	o Section H

Refuse to

answer

888

G6.1	[lf G6=1	] What were the reasons for delay in your treatment? Check all that apply.
	□1	Trouble in identifying a suitable treatment plan
	□2	Cost of treatment
	□3	Using alternative methods of healing before medical treatment (e.g., herbal treatment, prayer, homeopathy, diet therapy)
	□4	I felt overwhelmed/confused and did not know what to do
	□5	I felt ashamed to get help for my illness
	□6	My family did not think that I need medical treatment
	□7	Other reasons, please specify

### SECTION H: USE OF COMPLEMENTARY AND ALTERNATIVE THERAPY

Complementary and Alternative Therapies refer to treatments that are used either (1) together with medical treatment, or (2) instead of medical treatment. Examples include herbal treatment, diet therapy, exercise (e.g., qi gong, yoga) and spiritual healing.

H1 <sup>6</sup>		e diagnosis of cancer, what type of compleme you used? Check all that apply.	entary and alternative therapy	
	□1	Traditional Chinese Medicine		888
	□2	Traditional Indian Medicine (e.g., Ayurveda, ur	nani, siddha)	
	□3	Homeopathy		
	□4	Western herbal/health supplements		
	□5	Others, please specify		
	□6	None of above		
	□8	Traditional Vietnamese Medicine		
H2 <sup>6</sup>	Have	you used any of the therapies listed below fo	or your cancer? Check all that	
		Herbal medicine to consume	Answer Qs. H2.1 to	888
	□2	Diet therapy (e.g., macrobiotic diet)	H2.6	
	□3	Acupuncture/ acupressure/ moxibustion		
	□4	Massage/ Reflexology		
	□5	Exercise (e.g., qi gong, tai chi, yoga)		
	□6	Spiritual/faith healing by others		
	□7	Others, please describe		Refuse to
	□8	None of above	Skip to next section	answer
H2.1	[If H2	=1 to 7] When did you start using this therap	y for cancer?	
	□1	Before being treated in the hospital		888

	□2	While I was being treated in the hos	Pitai				
	□3	After being treated in the hospital					
H2.2	[If H2=1 to 7] Is the therapy meant to replace your medical treatment?						
	□ 1	Yes	□ 2	No			
H2.3 <sup>6</sup>	[If H2 cance	=1 to 7] Did you tell your doctor that er?	nt you ar	e using this therapy for your			
	□ 1	Yes					
	□ 2	No					
H2.3.1	[If H2	.3=1] How supportive was your doo	tor of th	nis therapy?			
	□ 1	Supportive	□ 3	Neutral			
	□ 2	Not supportive	□ 4	Don't know			
H2.4 <sup>6</sup>	[If H2=1 to 7] What is the main reason for using this therapy?						
	□1	1 To boost my immune system					
	□2	To reduce side effects of treatment					
	□3	To control my symptoms (e.g. pain). If so, describe the symptom					
	□4	To prolong life					
	□5	To cure my illness					
	□6	Others. Please describe					
H2.5	[If H2=1 to 7] How long have you been using this therapy?						
	□1	Less than 1 month					
	□2	Between 1 to 3 months					
	□3	Between 3 to 6 months					
	□4	More than 6 months					
	□5	I am no longer using this therapy					
H2.6 <sup>6</sup>		=1 to 7] Roughly how much did you alternative therapies in the last 3 mo		in total, on complementary			

### **SECTION I: DEMOGRAPHICS**

11	What is your current occupation?							
	□1	Farmer	□6	Service- Government				
	□2	Wage labourer	□7	Homemaker				
	□3	Skilled worker	□8	Retired				
	□4	Shop keeper	pp keeper □9 Ⅰ					
	□5	Self-employed	□10	Others, please specify				
12	Were yo	Were you working before you were seeking care at this hospital, for your illness?						
	□1	Working full-time	□4	Homemaker				
	□2	Working part-time	□5	Unemployed				
	□3	Retired and not working						
13	How many persons live in your household?							
	Number of people							
14	How would you rate the economic status of your household?							
	□1	Poor	□3	Jpper Middle Class				
	□2	Lower Middle Class	□4	Vealthy				

Thank you for completing the survey.

Refuse to

answer

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## POST INTERVIEW: OBSERVATIONS OF THE INTERVIEWER

[Interviewer: Please fill in the following questions based on your observations during the interview.]

INT1	During the survey, was there someone either present in the room or in a room nearby who could hear the contents of the interview?									
	□1 Yes, during most of the interview									
	□2	Yes, during half of the interview								
	□3	Yes, at times during the interview								
	□4	For the most part, no other person was present to hear								
INT2	To what extent did this person influence the patient's responses?									
	<ul> <li>Would correct the patient's responses or prevent the patient from giving his her own responses</li> <li>Listened to the interview, but did not interrupt verbally</li> <li>Hardly paid any attention to the interview</li> </ul>									
	□4 Didn't seem to have any effect on the patient's responses									
INT3	The following concerns your impression of the patient.									
			Yes	Some	Not	No	Not			
			(1)	what (2)	really (3)	(4)	sure (5)			
i.	Did vo	ou feel that the patient was		(-)	(0)		(0)			
		ally competent enough to								
		le adequate responses?			_		_			
ii.	Did you feel that the patient									
		stood the questions?								
iii.	Did you feel that the patient was									
	respo	nsive to the interview?								
iv.	Did yo	ou feel the patient's								
	hearin	ng/visual difficulties								
	adversely affected the survey?									
INT4		How tired did the patient appear after the interview?         □1       Very								
	-									
	-	□2 Somewhat								
	□3	Not at all								