

# **SJLIFE** Home Survey

The questions in this booklet relate to:

Name Person completing this questionnaire is: text percomp Your relationship: coded 1 Self 2 Parent 3 Other: percode relation Our mailing address is: St. Jude Children's Research Hospital Today's date: Department of Epidemiology Mail Stop 735 d m m d у У У У 262 Danny Thomas Place datecomp Memphis, TN 38105-3678 Toll-free phone number: 1-800-775-2167 e-mail: SJLIFE@stjude.org STUDYNAME **SJLIFEID** MRN Please! Do not mark below this line -

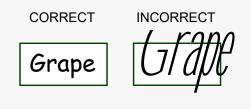
Survey #310 06/10/2022 02:03:49 PM



#### INSTRUCTIONS FOR COMPLETING THE QUESTIONNAIRE

Please follow these rules in completing this questionnaire. If you have any questions about completing this questionnaire, please call 1-800-775-2167.

- 1. Use a black ballpoint pen. Do not use a felt-tip or roller-ball pen. These may cause smudging.
- 2. When marking boxes, make an x inside the box (see examples below).
- 3. Make no stray marks of any kind. Please keep the form as clean as possible.
- 4. Written responses must stay within the boxes provided:



#### MARKING EXAMPLES

Below are some examples of how to fill out this questionnaire. Please look these over before you begin.

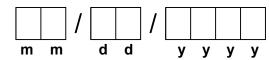
#### EXAMPLE 1

<ol> <li>During the past month, did you participate in any physical activities or exercises such as running, calisthenics, golf, gardening, bicycling, swimming, wheelchair basketball, or walking for exercise?</li> </ol>		Not sure	If yes, age
□ No 🛛 Yes		Yes	at first use
<ul> <li>EXAMPLE 2</li> <li>2. Have you ever taken</li> <li>a. BIRTH CONTROL PILLS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil</li> </ul>	No     		vears
<ul> <li>If yes, specify the name of the drug(s) or indicate you do not know the specific name</li> <li>MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES, such as Zocor, Pravachol, Lipitor, Colestid (colestipol), Tricor, Lescol, Lopid (gemfibrozil), Mevacor,</li> </ul>			
niacin, or Lorelco			37
myes, specify the name of the drug(s) of indicate you do not know the specific name			
ματικά τη			
EXAMPLE 3			
3. When was this condition diagnosed?			
$\begin{array}{ c c c c c c c c c c c c c c c c c c c$			
Please! Do not mark below this line			

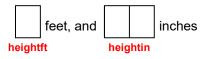
2



A1. What is your date of birth? d\_birth



- A2. What is your sex? sex
  - 1 🗌 Male
  - 2 🗌 Female
- A3. To the nearest inch, what is your current height without shoes?



A4. To the nearest pound, what is your current weight without shoes? weight

pounds
--------

- A4a. Since this time last year, have you lost more than 10 pounds <u>unintentionally</u> (not due to dieting or exercise)? wgtloss
  - 1 🗌 Yes
  - 2 🗌 No
  - 3 🗌 Not sure
- A5. To which one of the following groups do you belong? race
  - 1 🗌 White
  - 2 🗌 Black
  - 3 🗌 American Indian or Alaskan Native
  - 4 🗌 Asian
  - 5 🗌 Pacific Islander

Specify

6 🗌 Other

raceoth coded

#### A5a. Are you Hispanic? racehsp

- 2 🗌 No
- 1 🗌 Yes
- A6. Are you a twin or born of a multiple birth? twin
  - 2 □ No Go to Question A7.
  - A6a. If yes, which type of multiple are you? twin\_typ
    - 1 🗌 Identical twin
    - 2 🗌 Fraternal (non-identical) twin, same sex
    - 3 🗆 Fraternal (non-identical) twin, opposite sex
    - 4 🗆 Not sure what type of twin, same sex
    - 5 🗌 More than twin



- A7. Were you adopted? adopted
  - 2 🗆 No
  - 1 🗆 Yes
- A8. How many <u>full</u> brothers and sisters (living or dead) do/did you have? Include only those brothers and sisters who have the same birth (biological) mother <u>and</u> father as you. n\_sibls



A9. Concerning your <u>current</u> residence, do you: res (Mark all that apply)

Own your residence res\_own

- Rent res\_rent
- Live with parents res\_par
- Other res\_oth

Specify	
res sp	coded





## **Medical Care**

The next questions are about health care received during the last two years.

B1. During the <u>last two years</u> , which of the following healthcare providers (excluding dentists) did you see or talk to for medical care? This includes routine and sick care. mdcr (Mark all that apply)	<ul> <li>B3. During this last two years, how many times did you see a physician? visphys</li> <li>1 □ 0 times → Go to Question B5a.</li> <li>2 □ 1 - 2 times 5 □ 7 - 10 times</li> </ul>				
□ None → Go to Question B7, next page. mdcr_none					
Primary care clinician in the community (e.g., family physician, general internist, pediatrician, nurse practitioner, physician's assistant) mdcr_prim	3 □ 3 - 4 times       6 □ 11 - 20 times         4 □ 5 - 6 times       7 □ More than 20 times				
<ul> <li>Clinician at a cancer center (e.g., oncologist, nurse practitioner or physician's assistant, other cancer specialist) mdcr_cactr</li> <li>Other Medical specialist (e.g., endocrinologist,</li> </ul>	B4. As you know, you were asked to participate in thi study because you were once diagnosed with a cancer, leukemia, tumor, or similar illness. How many of the visits to the physician indicated in question B3 (during the past 2 years) were related				
cardiologist, surgeon) mdcr_spec	to this previous illness? cvisphs				
Psychiatrist mdcr_psymd	1 □ 0 visits				
□ Psychologist or counselor mdcr_psy	2 □ 1 - 2 visits				
Physical or occupational therapist mdcr_ptot	<mark>3</mark> □  3  -  4  visits				
☐ Other mdcr_othprov	4 □ 5 - 6 visits				
If Other, please specify.	5 □ 7 - 10 visits				
dothprov1-10 text	<mark>6</mark> □ 11 - 20 visits				
	7 ☐ More than 20 visits				
B2. During this <u>last two years</u> , where did you receive your health care? <u>hlcr</u> (Mark all that apply)	B5a. During this <u>2 year period</u> , how often did you telephone a doctor's office, regarding an illness or a medical condition you may have had? teldoc				
□ Doctor's office hlcr_droff	1 □ 0 times				
Oncology (cancer) center or clinic					

B7. When was your <u>most recent</u> routine check-up where a doctor examined you and did tests to see if you had any health problems from your cancer or your cancer treatment? chkup	B7d. When was the <u>last time</u> that you visit with a cancer specialist (or 1 □ Less than 1 year ago
1 $\Box$ Less than 1 year ago	2 🗌 1-2 years ago
$2 \square 1-2$ years ago	<sup>3</sup> □ More than 2 years but less that
$3 \square$ More than 2 years but less than 5 years ago	4 🗆 5 or more years ago
$4 \square 5$ or more years ago	5 🗌 Don't know
5 □ Never → Go to Question B7d.	B7e. When was the <u>last time</u> you ha special clinic for <u>cancer surviv</u>
B7a. Where was this check-up? (Mark only one) chkuploc	1 🗌 Less than 1 year ago
1 🗌 At a cancer survivor clinic	<mark>2</mark>
2 $\Box$ At a cancer center, but not in a cancer survivor clinic	3 □ More than 2 years but less that
3 At my primary care doctor's office	4 🔲 5 or more years ago
4 Other	5 🗖 Never
If Other, please specify.	6 🗖 Don't know
chkupoth text	
	B7f. When do you plan to have your doctor in order to examine you problems from your cancer or treatment? nxtchkup
	<sup>1</sup> □ Less than 1 year from now
	<mark>2</mark> □ 1-2 years from now
	$3 \Box 3-4$ years from now

- B7b. At this check-up, did your doctor give you advice about what to do to reduce risks or discuss medical screening tests? chkupadv
  - 2 🗆 No
  - 1 🗌 Yes
  - 3 🗌 Not sure
- B7c. At this check-up, did your doctor order medical screening tests? chkuptest
  - 2 🗌 No
  - 1 🗌 Yes
  - 3 🗌 Not sure

- ou had a medical (oncologist)? oncologist
  - han 5 years ago

#### ad a visit to a ivors? survclin

- han 5 years ago
- ur <u>next</u> visit with a ou for any health r your cancer
  - 3 □ 3-4 years from now
  - 4 🗆 5 or more years from now
  - 5 🗌 Never
  - 6 🗌 Don't know
- B7g. During the past 12 months, how many times have you gone to a HOSPITAL EMERGENCY ROOM about your own health (This includes emergency room visits that resulted in a hospital admission)? ervisit





B7h. Do you currently have a cancer survivorship care B7j. How often do you carefully check your whole plan and/or a summary of treatment for your body (including the skin on your back and back of cancer (records from your cancer doctor that have your legs) for any sign of skin cancer? skinck details about your cancer treatment and medical 1 Once a month tests you should have to check for future health problems)? survplan 2 Every few months 2 No 1 Yes 3 Not sure 3 Every 6 months B7i. Does your local or primary care doctor have a 4 🗌 Every year copy of your cancer survivorship care plan and/or 5 🗌 Never a summary of your treatment for your cancer? plancopy 1 🗌 I don't have a primary care doctor B7k. In the past 12 months, has your regular healthcare provider carefully examined your <sup>2</sup> I have a primary care doctor but he/she does not whole body for any sign of skin cancer? skinckdr have a copy of my cancer survivorship care plan 2  $\square$  No 1 $\square$  Yes 3 $\square$  Not sure and/or a summary of my treatment for my cancer 3 □ Yes 4 🗌 Not sure B8. Please indicate all medicines/drugs you took regularly during the last two years. - We are only asking about medicines/drugs which you took If yes, If yes, consistently for more than one month, or for 30 days or more in a year. are you age at currently first use taking? - Please list only drugs prescribed by a doctor and filled by a pharmacist. Include pills, syrups, injections, patches, or creams. 3 Not sure 1 Yes 1 Yes - Please do NOT include medicines/drugs that you bought without a 2 No prescription (over-the-counter drugs). 2 No vears 1. BIRTH CONTROL MEDICATIONS such as Demulen, Lo-Ovral, Loestrin, Norinyl, Norplant, Ortho-Novum, Ovral, Triphasil, Depo Provera ----If yes, specify the name of the drug(s) or indicate you do not know the specific name bcpill2 bcpill abcpill bcpillc1-4 coded aestprog estprog estprog2 2. ESTROGENS OR PROGESTERONES (FEMALE HORMONES) such as Estrace, Estraderm, Premarin, Provera, Medroxyprogesterone, Vivelle------If yes, specify the name of the drug(s) or indicate you do not know the specific name estproc1-6 coded testot atestos testos2 3. TESTOSTERONES (MALE HORMONES) such as Androgel, Delatesteral, Testosterone cypionate, Testosterone enanthate-----If yes, specify the name of the drug(s) or indicate you do not know the specific name testosc1-5 coded

- We are only asking about medicines/drugs which you took			_
consistently for more than one month, or for 30 days or more in a year		lf yes, age at first use	   a   CL
- Please list only drugs prescribed by a doctor and filled by a			ta
pharmacist. Include pills, syrups, injections, patches, or creams.	3 Not sure	$\sim$	
- Please do NOT include medicines/drugs that you bought without a prescription (over-the-counter drugs).	1 Yes 2 No		2 N
<ol> <li>PILLS OR INSULIN FOR DIABETES such as Glucophage (metformin), Glucotrol (glipizide), Glynase (glyburide), Prandin, Amaryl, Avandia, Actos, or insulin injections (such as Humulin, Novolin, Lantus)</li> </ol>		years	Ľ
If yes, specify the name of the drug(s) or indicate you do not know the specific name	diadrug	adiabdr	c
diabdrc1-7			
coded			
<ol> <li>MEDICATIONS FOR HIGH BLOOD PRESSURE OR HYPERTENSION such as hydrochlorothiazide (HCTZ), Dyazide (triamterene/HCTZ), Tenormin (atenolol), Lopressor (metoprolol), Zestril or Prinivil (lisinopril), Vasotec (enalapril), Cozaar, Hyzaar, Diovan, or others</li> </ol>			C
If yes, specify the name of the drug(s) or indicate you do not know the specific name	hrtdrg	ahrtdrg	. I
hrtdrgc1-5			
coded			
6. MEDICATIONS TO LOWER CHOLESTEROL OR TRIGLYCERIDES such	1		
as Lovastatin, Zocor (simvastatin), Pravachol (pravastatin), Crestor, Lipitor			_
Zetia, Tricor, Vytorin, gemfibrozil If yes, specify the name of the drug(s) or indicate you do not know the specific name			L
	chodrg	achodrg	С
chodrgc1-6			
coded			
7. MEDICATIONS FOR HEART CONDITIONS, INCLUDING ANGINA,			
CORONARY ARTERY DISEASE, CONGESTIVE HEART FAILURE, OR			_
IRREGULAR HEART BEAT If yes, specify the name of the drug(s) or indicate you do not know the specific name			
	hrtcon	ahrtcon	h
hrtconc1-7			
coded			
8. THYROID MEDICATIONS such as Synthroid (levothyroxine or L-thyroxine			
Levothroid, or others			C
If yes, specify the name of the drug(s) or indicate you do not know the specific name	thydrug	athydrg	th
thydrgc1-4			
coded			

38. (Cont) Please indicate all medicines/drugs you took regularly during the	<u>last two years</u> .	If yes,	If yes,
<ul> <li>We are only asking about medicines/drugs which you took consistently for more than one month, or for 30 days or more in a year.</li> </ul>		age at first use	are you currently taking?
- Please list only drugs prescribed by a doctor and filled by a pharmacist. Include pills, syrups, injections, patches, or creams.	3 Not sure		1 Yes
- Please do NOT include medicines/drugs that you bought without a prescription (over-the-counter drugs).	2 No		2 No
<ol> <li>MEDICATIONS FOR DEPRESSION such as Prozac (fluoxetine), Serzone Celexa, Zoloft, Wellbutrin, Effexor, Desyrel (trazodone), or Vivactil</li> </ol>		years	
If yes, specify the name of the drug(s) or indicate you do not know the specific name depressc1-8 coded	antidep	adepress	depress2
10. MEDICATIONS FOR TREATMENT OF LOW BONE MINERAL DENSITY (OSTEOPOROSIS/OSTEOPENIA) such as Fosamax (alendronate), Boniva (ibandronate), Actonel (risedronate), or Evista (raloxifene) If yes, specify the name of the drug(s) or indicate you do not know the specific name			
lobmddr1-5 coded	lobmd	alobmd	lobmd2
11. MEDICATIONS TO CORRECT LOW BLOOD LEVELS OF POTASSIUM, MAGNESIUM, PHOSPHOROUS, OR BICARBONATE such as KCI, KPho NeutraPhos, or Bicitra			
loelecd1-5 coded	lowk	alowk	lowk2
12. MEDICATIONS FOR ATTENTION OR MEMORY PROBLEMS such as Ritalin, Adderall, Concerta, Strattera, Aricept (donepezil), or Provigil (modafinil)			
If yes, specify the name of the drug(s) or indicate you do not know the specific name attenc1-6 coded	atten	aatten	atten2
13. OTHER PRESCRIBED DRUGS			
If yes, specify the name of the drug(s) or indicate you do not know the specific name <b>and</b> specify the reason the drug was prescribed.	othpdrug	aopdrug	opdrug2
opdrugr1-29 opdrugc1-29			
coded			
	]		

B9. Please list all over the counter medications (<u>NOT</u> prescribed by a doctor) which you took *regularly* during the last two years.

We are only asking about medications which you took consistently for more than one month, or for 30 days or more in a year. Include pills, syrups, injections, patches, or creams.

ccmed1-13 text			

B10. Please list all supplements which you took *regularly* during the <u>last two years</u>.

We are only asking about medicines which you took consistently for more than one month, or for 30 days or more in a year. Include pills, syrups, injections, patches, or creams.

suppl1-19 text				

Continue on next page.

### **Medical Conditions**

The next series of questions relate to medical conditions that have ever occurred in your lifetime.

Please indicate, by marking the box (either "No", "Yes", or "Not sure") if a doctor or other health care professional has told you that you have or have had any of the following conditions. In addition, please give your approximate age when the condition first occurred. (If more than one occurrence, please give age at first occurrence.)

Because we need definite responses, it is very important to mark an answer for each question, even if you have never had that condition. <u>Please do not leave any questions blank (unmarked)</u>.

#### **DENTAL HEALTH**

Questions C1 to C19 are about your general dental health and any dental care you may have received.

			Have you received
In addition to the above instructions, if you answered either "Yes" response to any of the items below, please also mark	4 Not sure	If yes, age at first occurrence	care for this in the <u>last</u> two years?
"Yes" or "No" to whether you have received this care in the last 2 years.	3 Yes, but the condition is no longer present		$\sim$
received this care in the <u>hast 2 years</u> .	1 Yes, and the condition is still present	years	2 No
Have you <u>ever</u>	2 No	a_mistth	1 Yes
C1. Had one or more missing teeth because	they did not develop?		
C2. Had a lack of or decreased amount of er surface of teeth (hypoplasia)?	namel on enamel	a_enamel	c_mistth
C3. Had abnormal shaped (small or malform	ed) teeth?	a_abntth	c_enamel □ □ c abntth
C4. Had abnormal root development?	abnrt 🛛 🗖 🗖	a_abnrt	c_abntt
C5. Had difficulty in producing saliva (dry mo treatment such as artificial saliva?	uth) that required drymth a label of the second sec	a_drymth	c drymth
C6. Had severe gingivitis or gum disease req	uiring surgery or deep cleaning?	a_gumdis	 c_gumdis
C7. Had root canal therapy?		a_rtcanl	□ □ c_rtcanl
C8. Had more than 5 cavities?	cavities 2 No 1 Yes 3 Not Sure		
C9. Lost 6 or more teeth due to decay or gun	n disease? <mark>2 No 1 Yes 3 Not Sure</mark>		
C10. Worn a dental bridge (for missing or ren	noved teeth)?	a_dntbrg	c dntbrg
C11. Worn removable dentures (complete or	partial upper or lower or both)?	a_dentur	c dentur
C12. Worn a prosthesis to lift your palate to in	nprove the quality of your voice?	a_dntpros	c_dntpros
C13. Had other dental treatment or surgery?.		a_othdntx	
If yes, explain type of procedure. dothdntx1-6 text			c_othdntx
C14. Had any other dental problems?	······································	a_othdnpr	c_othdnpr
dothdnpr1-3 text			

C15	. Have you <u>ever</u> had dental braces? <sub>dntbrace</sub>			/e you <u>ever</u> been told by a doct e professional that you have, o			
	<mark>₂</mark> No <mark>1</mark> Yes 3 Don't know			, , , , , , , , , , , , , , , , , , ,	4 Not		
C16	. Do you <u>currently</u> have dental insurance? dr	ntins		3 Yes, but the condition is no longe		1	If yes, age at first
	2 No 1 Yes 3 Don't know			1 Yes, and the condition is still pre	· 1		occurrence
C17	. Have you visited the dentist or a dental clin within the <u>past year</u> for any reason? <sub>dntvisit</sub>		D8.	Legally blind in only one eye?			years
	<mark>2</mark> □ No <mark>1</mark> □ Yes <mark>3</mark> □ Don't know			<b>If yes,</b> do you have any			a_oneeye
C18	. Have you had your teeth cleaned by the der dental hygienist within the past year? teeth			sight in this eye? onesight 2 No 1 Yes			
	<mark>2</mark> ☐ No 1 ☐ Yes 3 ☐ Don't know			Legally blind in both eyes?		_	
C19	<ul> <li>Do you have problems finding a dentist to I with your dental care because of your previous cancer or similar illness? finddnt</li> <li>No 1 Yes 3 Don't know</li> </ul>		03.	If yes, do you         have any sight?         2       No         No       1         Yes			a_twoeye
			D10	. Cataracts? <mark>catar</mark>			a_catar
	ARING/VISION/SPEECH			. Glaucoma (excess pressure in the eyeball)?□			a_glauc
	e you <u>ever</u> been told by a doctor or other hea e professional that you have, or have had	alth	D12.	. Problems with double vision? <mark>dblvis</mark> . □			a_dblvis
	4 Not sure		D13	. A detached retina or any			
	3 Yes, but the condition is no longer present	lf yes,		other condition of the retina?			a_retina
	1 Yes and the condition is still present	age at first occurrence		If yes, describe the other condition first occurrence for each problem			age at
D1.	2 No Hearing loss requiring a hearing aid?	years	,	dretina1-3 coded aretina1-3			
D2.	Deafness in both ears not completely corrected by hearing aid?	a_deaf1		. Crossed or turned eyes (strabismus)? <mark>croseye</mark> □			a_croseye
D3.	Deafness in only one ear not		D15.	. Lazy eye (amblyopia)? <mark></mark> □			a_lazyeye
D4	completely corrected by hearing aid? deaf2	a_deaf2	D16.	Any other trouble seeing with one or both eyes even when wearing glasses?□			a_othsee
D4.	ears?	a_tinn	D17	. Very dry eyes requiring eye			
D5.	Persistent dizziness or vertigo?	a_dizzy		drops or ointment? dryeyes □ . Any other eye problems? □ otheye			a_dryeye a_otheye
D6.	Hearing loss, not requiring a hearing aid?	a_hearlos		If yes, describe the other eye pro		List	
D7.	Any other hearing problems?	a_othhpr		first occurrence for each problen dotheye1-5 coded	і зерага	iery.	
	If yes, describe the other hearing problem(s). List age at first occurrence for each problem separate			aotheye1-5			
	dothhpr1-5 aothhpr1-5	y.					

Please! Do not mark below this line -

11

Remember, it is very important that you mark an answer for each of the following questions, even if you have never had that condition.

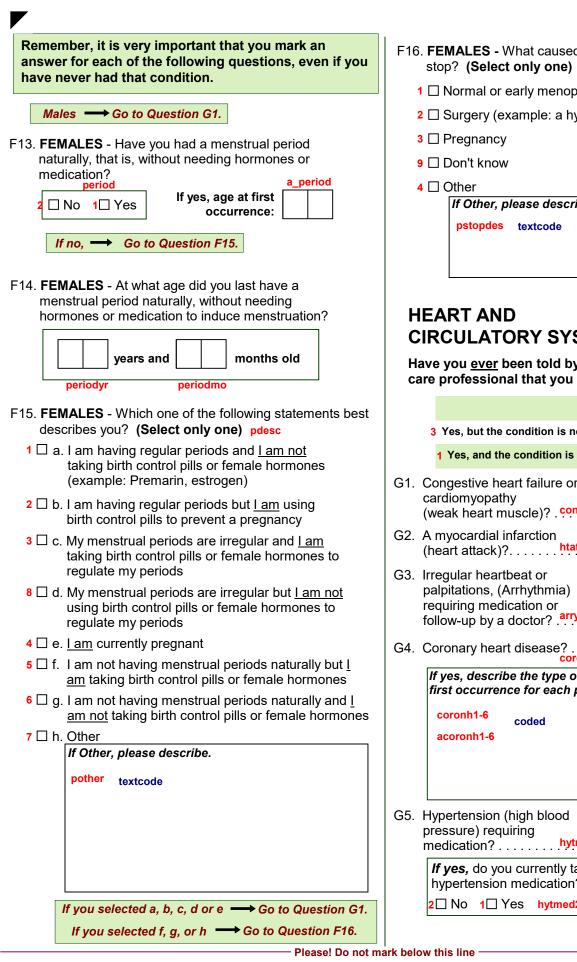
Have you <u>ever</u> been told by a doctor or other health care professional that you have, or have had. . .

						1
		4	Not	sure	If yes, age at first	
	3 Yes, but the condition is no longer	r pres	ent		occurrence	F1. An
	1 Yes, and the condition is still pre-	sent				(hy
	2 No				years	F2. An
D19	. Stammering or stuttering?				a_stammr	gla F3. Th
D20	. Any other speech defects? □ othspk				a_othspk	F4. Sw
	If yes, describe the other speech of at first occurrence for each proble	lefec m se	t(s). epar	List ately	t the age v.	thy
	dothspk1-4 coded					F5. Dia co
	aothspk1-4					F6. Dia pil
						F7. Dia ins
	. Abnormal sense of taste? abtast . Loss of taste lasting				a_abtast	F8. De
	for 3 months or more? tastlos				a_tastlos	ho F9. Ha
D23	. Loss of smell lasting for 3 months or more? <sup>smellos</sup> □				a_smellos	inj ho
UR	INARY SYSTEM					Nu Hu
	Kidney stones?kidstn				a_kidstn	Sa
	REPEATED (more than 3 in any 12 month period) kidney or bladder infections?		П		a_kidinf	in_
	Dialysis?				a_dialys	F10. Os
	Blood in your urine?				a urblood	os
E5.	Protein in your urine?.				_ a_urprot	F11. Ha
E6.	Urinary incontinence?. incont				a_incont	lf Li
	Any other kind of kidney, bladder or urinary tract disorder? <mark>othkud</mark> . □				a_othkud	t
	If yes, describe the other disorder occurrence for each disorder sepa			the a	ge at first	F12. Ar
	dothkud1-4		-			lf th
	aothkud1-4 coded					se
						de

#### **HORMONAL SYSTEMS**

Have you <u>ever</u> been told by a doctor or other health care professional that you have, or have had. . .

		4 Not sure							
	3 Yes, but the condition is no longer	s, but the condition is no longer present							
	1 Yes, and the condition is still pre-	sent			age at first occurrence				
F1.	An overactive thyroid gland (hyperthyroid)? ovthyr				years				
F2.	An underactive thyroid gland (hypothyroid)?. unthyr .				a_unthyr				
F3.	Thyroid nodules? thynod .				a_thynod				
F4.	Swollen or enlarged thyroid gland? thyenl				a_thyenI				
F5.	Diabetes that can be controlled with diet?. diabd □				a_diabd				
F6.	Diabetes controlled with pills or tablets? diabp				a_diabp				
F7.	Diabetes controlled with insulin shots?				a_diabi				
F8.	Deficiency of growth hormone?				a_ghdef				
F9.	Have you received injections of growth hormone (such as Nutropin, Genotropin, Humatrope, Norditropin, Saizen)?								
	If yes, do you currently take injections of growth hormone?				a_injghr				
F10	2 No 1 Yes injghr_c Osteoporosis or osteopenia (thin, brittle, or fragile bones)?ostpor. □				a_ostpor				
F11	. Have you ever broken a bone? <mark>bknbon</mark> . □				a_bknbon				
	If yes, describe <u>all</u> occurrences List the age for each individual bknbon1-16 abknbon1-16				one(s).				
F12	Any other hormonal problems? <mark>othhor</mark>				a_othhor				
	If yes, describe the other hormo the age at first occurrence for e separately. dothhor1-4 coded aothhor1-4								



F16. FEMALES - What caused your menstrual periods to stop? (Select only one) pstopwhy

- 1 🗌 Normal or early menopause
- 2 Surgery (example: a hysterectomy)

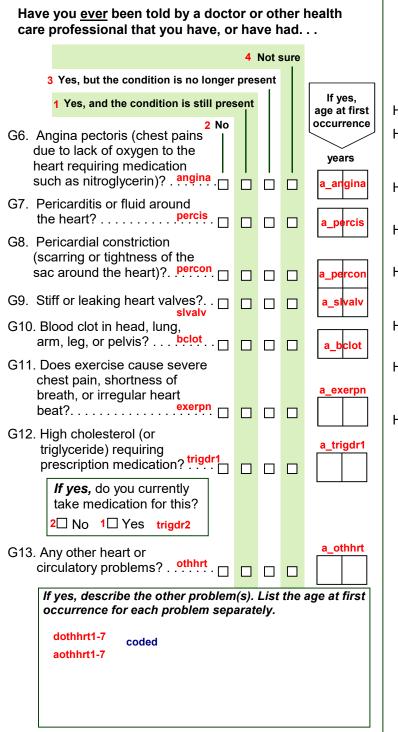
If Other, please describe.

## **CIRCULATORY SYSTEM**

Have you ever been told by a doctor or other health care professional that you have, or have had. . .

4 Not sure
3 Yes, but the condition is no longer present If yes, age at first
1 Yes, and the condition is still present
G1. Congestive heart failure or <sup>2</sup> No years
cardiomyopathy
G2. A myocardial infarction (heart attack)?htatt
G3. Irregular heartbeat or palpitations, (Arrhythmia) requiring medication or follow-up by a doctor?
If yes, describe the type of problem(s). List the age at first occurrence for each problem separately. coronh1-6 acoronh1-6
G5. Hypertension (high blood pressure) requiring medication? <u>hytmed</u> <b>a_hytmed</b> <b>If yes,</b> do you currently take hypertension medication? 2 No 1 Yes hytmed2

It is very important that you mark an answer for each of the following questions, even if you have never had that condition.



## G14. Has anyone in your immediate family (biological mother, father, brothers, sisters) had a heart attack before the age of 55? fmi55

2 No 1 Yes 3 Unsure

#### **RESPIRATORY SYSTEM**

Have you <u>ever</u> been told by a doctor or other health care professional that you have, or have had. . .

			sure	If yes,		
	3	Yes, but the condition is no longer		age at first		
		1 Yes, and the condition is still pres	occurrence			
		2 No				years
11.	As	thma?				
12.		ronic cough or shortness breath for more than one				a_asthma
		onth?				a_ccough
13.		ive you had a need for				
		tra oxygen? <mark>evoxy</mark> □				a_evoxy
14.		eumonia, 3 or more nes in the past 2 years? □	_	-		
15		pneum3				a pneum3
10.	ob	nphysema or other chronic structive pulmonary disease				~_p
	(C	OPD) emphma				a_emphma
16.	Lu of	ng fibrosis or "scarring" the lung? <mark>Ingfib</mark> ⊡				a_Ingfib
17.		oblems with breathing				
		hile at rest that lasted for ore than 3 months? brhprb				a_brhprb
18.		y other breathing or lung oblems? <mark>othres</mark>				a othres
	·		<u> </u>			
		yes, describe the other problem ccurrence for each problem sepa			the a	age at first
		dothres1-4				
		coded aothres1-4				

Continue on next page.



It is very important that you mark an answer for each of the following questions, even if you have never had that condition.

#### **DIGESTIVE SYSTEM**

Have you ever been told by a doctor or other health care professional that you have or have had

care professional that you have, or				J1. Amputation of an arm, leg,					
	4	Not	sure	If yes,	If yes, specify (example: left hand, right foot). List the				
3 Yes, but the condition is no longer	pres	sent		age at first occurrence	age for each amputation separately.				
1 Yes, and the condition is still pres	sent			damputn1-3 coded aamputn1-3					
2 No				years					
I1. Hepatitis? hepats					J2. Scoliosis surgery (insertion				
If yes, what type(s)? (Mark all tha		ply	)	a_hepats	of rods or other methods to straighten the spine)? sclsis				
☐ Hepatitis A hepatyp_a hepa □ Hepatitis B hepatyp_b	цур				J3. Other surgery of spinal cord				
Hepatitis C hepatyp_c					or spine?				
Don't know hepatyp_dk					If yes, specify all surgeries of the spinal cord or spine.				
Other hepatyp_ot				a cirliv	List the age at which each surgery occurred.				
I2. Cirrhosis of the liver? $\ldots$ $\overset{\text{cirliv}}{\ldots}$ $\ldots$					dothspn1-12 coded aothspn1-12				
I3. Any other liver trouble?. •••••••				a_othliv					
If yes, describe the liver problem(s occurrence for each problem sepa dothliv1-4 aothliv1-4			he a	ge at first	J4. Leg lengthening or shortening procedures?lensht.       Image: shortening procedures?lensht.       I				
I4. Intestinal (colon) polyps? polyps				a_polyps	If yes, specify all joint replacements. List the age at which each joint replacement occurred.				
I5. Fatty liver?				a_fatliv	djntrep1-6 coded				
I6. Esophageal strictures		-			ajntrep1-6				
(narrowing of the esophagus)? esophs □				a_esophs	J6. Other bone surgery?				
I7. Rectal or anal fistula? recfis .				a_recfis	If yes, specify all other bone surgeries. List the age at				
I8. Rectal or anal stricture (narrowing or scarring)? recstr□				a_recstr	which each bone surgery occurred.				
I9. Stricture (narrowing or scarring) of the small or large intestine?		_	_		coded aothbon1-10				
	Ц			a_intestr					
I10. Any other stomach or digestive trouble?				a_othdig	J7. Coronary artery bypass surgery?				
If yes, describe the other problem occurrence for each problem sep			the	age at first					
dothdig1-6 aothdig1-6	arat	ery.							

SURGICAL PROCEDURES

3 Not sure

1 Yes

2 No

If yes, age at first

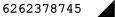
occurrence

years

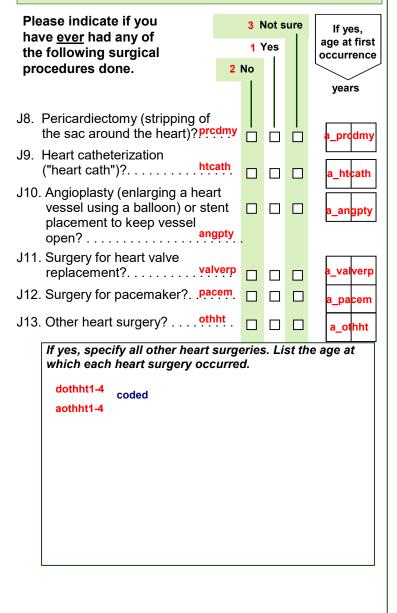
Please indicate if you

have ever had any of the following surgical

procedures done.



It is very important that you mark an answer for each of the following questions, even if you have never had that procedure.

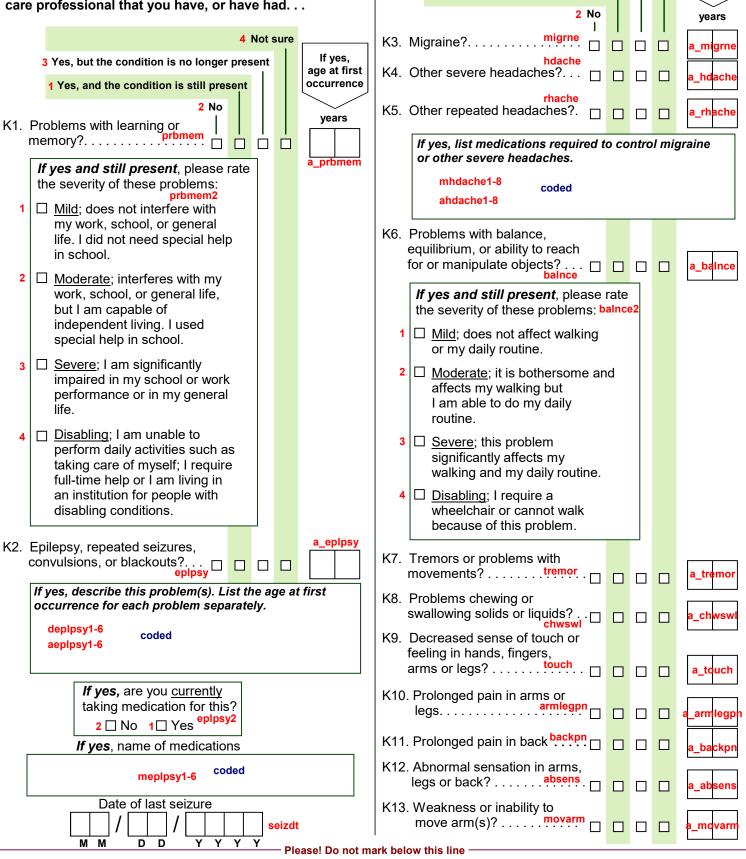


		3 Not sure			If yes,	
			1	Yes		age at first occurrence
		2 N	lo			
a t	Surgery to repair a fistula (an abnormal connection between he intestine or rectum and othe	er				years
	structures)?	·				a_fistul
	Surgery for intestinal obstruction blocked intestines)?					a_intobs
	Colostomy or ileostomy stool going into a bag)?.colsty	• [				a_colsty
J17. F c	Removal of part or all of the colon	ol [				a_colon
J18. F r	Removal of part or all of the ectum	<mark>с</mark>				a_rectum
	Biopsy or removal of lump in hyroid gland? <mark>biothy</mark>	• [				a_biothy
J20. F t	Removal of part or all of he thyroid gland? <mark>remthy</mark>	• [				a_remthy
J21. F	Removal of the spleen? remspl	• [				a_remspl
	Bladder, ureter, or kidney urgery? <mark>bladsur</mark>	. [				a_bladsur
	Removal of all or part of a idney? <mark>remkidn</mark>	· [				a_remkidn
J24. L	iver or gall bladder surgery?	C				a_livsur
( a	/entriculoperitoneal (VP) shunt tube from the brain to the bdomen under the skin) that emoves excess spinal fluid? vpshunt	. [				a_vpshunt
J26. E	Breast biopsy?	· [				a_brstbio
t	Breast-conserving or preast-sparing surgery lumpectomy)? lumpsur	· [				a_lumpsur
	Aastectomy or removal of a breast?	· [				a_mastec
brstspe	If yes, was one or both breas	ts i	ren	nove	ed?	
	1 Left Only 2 Right Only	/ 3		Botł	า	

•									<b>_</b>
It is very important that you mark an answer for each of			1			3	Not s	sure	If yes,
the following questions, e						1	Yes		age at first occurrence
that procedure.					2	No			
									years
Please indicate if you	3 Not sure		J37.	Cataract surgery?	catsrg	Ċ	Ċ	Ċ	a_catsrg
have <u>ever</u> had any of	1 Yes	If yes, age at first		Males Go to Que	stion J42.	7			
the following surgical procedures done.	2 No	occurrence				_			
procedures done.		years	J38.	Removal of one ovary					a_recneov
J29. Any lung surgery?	igsur	a_lungsur	J39.	Removal of both ovar	ies?				a_retwoov
			J40.	Removal of uterus?	reutrs				a_reutrs
If yes, specify all other which each lung surger		st the age at	1/11	Surgery of the vagina	o vagsrg				
			341.	Females		<b>–</b>			a_vagsrg
dingsur1-6 coded									
alngsur1-6			J42.	Removal of one testis	? reonete				a_reonete
			J43.	Removal of both teste	s?retwote				a retwote
				Removal of part or all		_	_	_	
			145	prostate gland (prosta	itectomy) repros				a_repros
			J45.	Any other surgery?	othsg				a_othsg
				If yes, specify all of			. Lis	t the	age at which
				each other surgery	occurred	-			
				dothsg1-36	oded				
				aothsh1-36					
J30. Periodontal (gum) surger	y?. □ □ □	a_gumsur							
J31. Heart transplant? hrt	t <u>rn</u> . 🗆 🗆 🗆	a_hrttrn							
J32. Lung transplant? Ing		a_Ingtrn							
J33. Kidney transplant? kid		a_kidtrn							
J34. Liver transplant? tra		a_trasliv							
J35. Bone marrow transplant?		a_bmrtrn							
J36. Other organ transplant?		a_othtrn							
If yes, specify all other of for each individual trans		List the age							
	prant.								
dothtrn1-6 aothtrn1-6				Cont	inue on n	ext p	oage	-	
		— Please! Do not m	l nark bel	ow this line ———					

## BRAIN AND NERVOUS SYSTEM

Have you <u>ever</u> been told by a doctor or other health care professional that you have, or have had. . .



4 Not sure

3 Yes, but the condition is no longer present

1 Yes, and the condition is still present

If yes,

age at first occurrence

7	
Just a reminder - it is very important that you n answer for each of the following questions, eve	
have never had that condition.	3 Yes, but the condition is no longer present
Have you <u>ever</u> been told by a doctor or other he	1 Yes, and the condition is still present
care professional that you have, or have had.	2 No
4 Not sure	h. Did you have paralysis of
3 Yes, but the condition is no longer present	If yes,
1 Yes, and the condition is still present	
2 No	occurrence     Both sides of the body     Image: Constraint of the body       vears     If yes, describe the paralysis. List the age at first
K14. Weakness or inability to	occurrence for each episode of paralysis separately.
move leg(s)? movleg	a_movleg dsrkpar1-7 coded
K15. Paralysis of any kind?. parlys.	a_parlys asrkpar1-7
If yes, describe the paralysis. List the age at f	
occurrence for each episode of paralysis sepa	K17. In your meume, now many
aparlys1-6 coded	strokes have you had?
aparije. e	If yes, age at first
K16. Stroke?	
If no → Go to K18.	a_srk1 K19 Any other brain or nonyous
If yes, as a result of the stroke	K18. Any other brain or nervous system problems?
a. Did the symptoms last	If yes, describe the other problem(s). List the age at
more than 24 hours?	first occurrence for each problem separately.
2 No 1 Yes srkday	dbnspro1-10 coded
Did the stroke affect:         b. Speech	abnspro1-10
- Delanas and econdination	
c. Balance and coordination.	
Only one side of the body .	
Both sides of the body	
consciousness?	
2 No 1 Yes srkcons	K19. Do you have any driving restrictions because of brain or nervous system problems (such as seizures)? drrestr
e. Did you experience sensory loss (vision, taste, smell)?	2 □ No
Strsens Only one side of the body	1 🗌 Yes, but I am able to drive
Both sides of the body	4 🗌 Yes, I am unable to drive
f. Did you have weakness or	3 🗌 Unsure
inability to move arm(s)?.	K20. Do you have any work restrictions because of
Only one side of the body	brain or nervous system problems (such as
Both sides of the body	seizures)? wkrestr
g. Did you have weakness or inability to move leg(s)?	2 🗆 No
Only one side of the body	1 🗌 Yes, but I am able to work
Both sides of the body	4 🔲 Yes, I am unable to work
srƙmlg2	3 🗌 Unsure
Ple	lease! Do not mark below this line

## CANCER, LEUKEMIA, OR TUMORS

- L1. At any time following your original diagnosis, were you diagnosed with another cancer, leukemia, tumor, or similar illness? (Include any relapse or recurrence of your original diagnosis). cancer2
  - 2 □ No Go to Question M1, page 22.
  - 1 🗌 Yes
- L2. What was the name of this disease?

cond2 text

L3. Where was it located? (Example: right upper arm, left ear)

loc2\_1-9 text

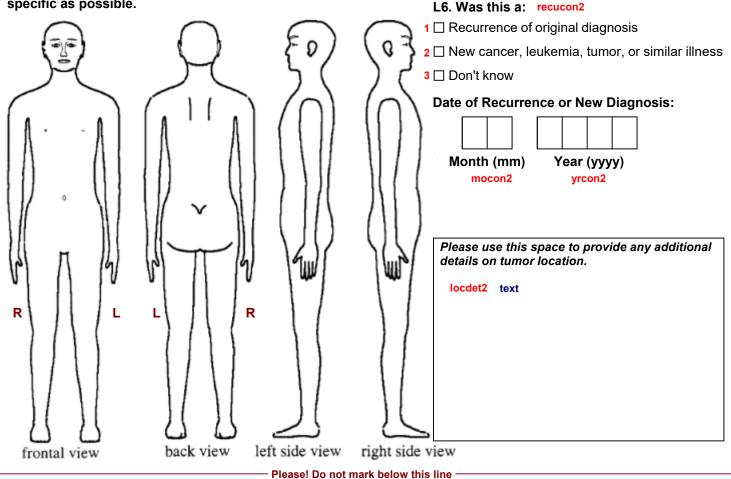
If the condition in item L2 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible.

L4. Did you have treatment for this disease? txcond2							
2 □ No	Skip L4a and go to Question L5.						
<mark>1</mark> □ Yes	→ L4a. What treatments did you receive? (Mark all that apply) tx2						
	Chemotherapy tx2_chemo						
	Radiation therapy tx2_rt						
	Surgery tx2_surg						

#### L5. Where was this diagnosed?

Doctor's name		
Hospital or clinic	 	
Address	 	

City, State, Zip code



L7. Have you had any additional cancers, leukemias, tumors, or similar illnesses after this second one? cancer3

2 🗌 No	Go to Question M1, next page.
<b>1</b> 🗌 Yes	Г

L8. What was the name of this disease?

cond3 text

L9. Where was it located? (Example: right upper arm, left ear)

loc3_1-4	text

If the condition in item L8 above was a skin cancer or solid tumor (not a leukemia), please mark an "X" at the location(s) of your cancer(s). We are interested in the most exact location(s) you can provide so please be as specific as possible. L10. Did you have treatment for this disease? txcond3 2 □ No → Skip L10a and go to Question L11. 1 □ Yes → L10a. What treatments did you receive? (Mark all that apply) tx3 □ Chemotherapy tx3\_chemo □ Radiation therapy tx3\_rt □ Surgery tx3\_surg

### L11. Where was this diagnosed?

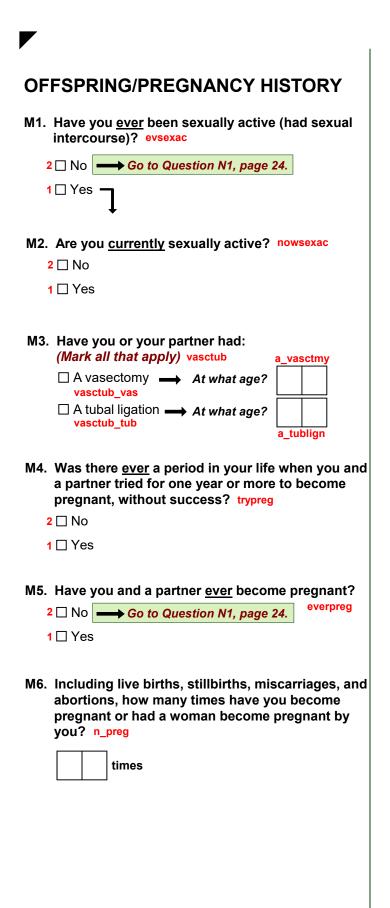
Hospital or clinic	

Address

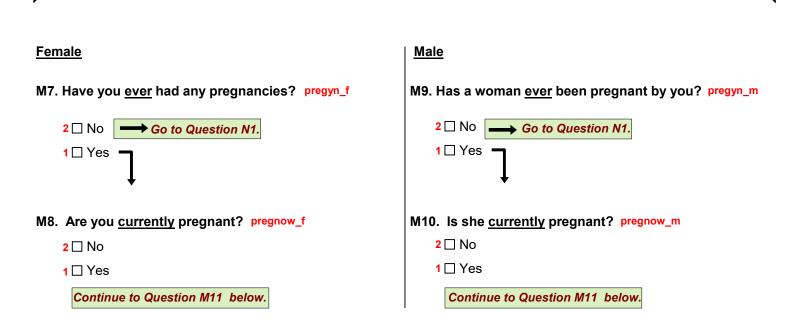
City, State, Zip code

#### L12. Was this a: recucon3

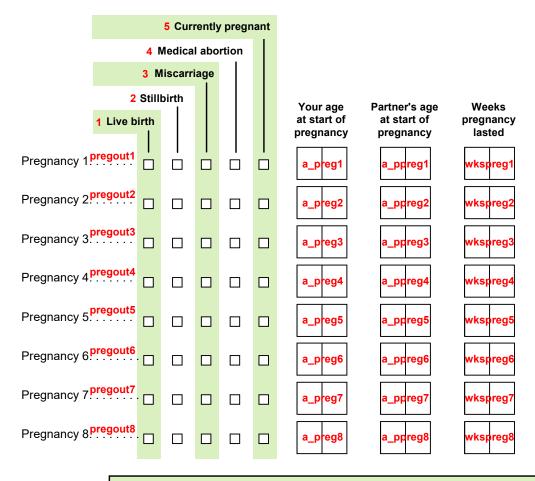
1 
Recurrence of original diagnosis 2 New cancer, leukemia, tumor, or similar illness 3 🗌 Don't know Date of Recurrence or New Diagnosis: Year (yyyy) Month (mm) mocon3 yrcon3 Please use this space to provide any additional details on tumor location. locset3 text R L R Please use a separate sheet of paper for additional cancers left side view right side view back view frontal view Please! Do not mark below this line -



Continue on next page.



M11. Please fill in the following information for each of your pregnancies, or each time a woman has become pregnant by you, regardless of the outcome.



#### Pregnancy outcome

Please attach a separate sheet of paper, if more than 8 pregnancies

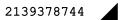
### **HEALTH BEHAVIORS**

#### Alternative Medicine

	his section, we would like to w about any alternative therapy	3	Not s	ure
ore	complementary healing	1 Yes		
	hniques that you have used ring the <u>last year</u> .	No		
(Ма	ark all that apply)			
a.	Acupuncture amaccp			Ċ
b.	Biofeedback			
C.	Chiropractor amchir			
d.	Crystals/magnets ammag			
e.	Nutritional supplements (such as Omega-3 fatty acids)			
f.	Herbal remedies (such as St. John's Wort, Echinacea) amhebr			
g.	Homeopathic remedies amhopa			
h.	Hypnosis/guided imagery amhyp .			
i.	Massage/body work			
j.	Meditation/relaxation			
k.	Modified diet (gluten-free, vegan)ammod	i 🗆		
I.	Naturopathic treatments amnatu			
m.	Spiritual healing/prayer amspir			
n.	Therapeutic touchamther			
0.	Vitamins/minerals (not regular multi-vitamin, but high dose C, zinc, etc.)			
p.	Yoga/Tai Chi/Qi Gong/special exercise			
q.	Other amoth			
,	lf Other, please specify.			
	damoth1-9			
	text			

- N2. Some people get a general physical examination from a doctor once in a while even though they are feeling well and have not been sick. When was the <u>last time</u> you had a general physical examination when you were not sick? wellexam
  - 1 🗌 Never
  - 2 □ Less than 1 year ago
  - 3 □ 1-2 years ago
  - 4 ☐ More than 2 years ago but less than 5 years ago
  - **5** ☐ 5 or more years ago
  - 6 🗌 l don't know if l ever had one
  - 7 🗌 I had one, but I don't recall when
- N3. When was the <u>last time</u> you had an echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves)? echoexam
  - 1 🗌 Never
  - 2 🗌 Less than 1 year ago
  - 3 🗌 1-2 years ago
  - 4 🗌 More than 2 years ago but less than 5 years ago
  - 5 🗆 5 or more years ago
  - 6 🗌 I don't know if I ever had one
  - 7 🗌 I had one, but I don't recall when
- N4. When was the <u>last time</u> you had a test to measure your bone strength or bone mineral density (such as a DEXA, quantitative CT scan, or ultrasound)? dexaexam
  - 1 🗌 Never
  - 2 ☐ Less than 1 year ago
  - 3 1-2 years ago
  - 4 ☐ More than 2 years ago but less than 5 years ago
  - 5 ☐ 5 or more years ago
  - 6 🗌 I don't know if I ever had one
  - 7 🗌 I had one, but I don't recall when

N5. How long has it been since you last went to a dentist? dentexam	N9. When was the <u>last time</u> you had an ultrasound of the carotid arteries (blood vessels in the neck)?
1 🗌 Never	1  Never carotidus
2 ☐ Less than 1 year ago	2 □ Less than 1 year ago
3 □ 1-2 years ago	<mark>3</mark> □ 1-2 years ago
₄ ☐ More than 2 years ago but less than 5 years ago	4 $\Box$ More than 2 years ago but less than 5 years ago
₅ 🔲 5 or more years ago	<mark>5</mark> □ 5 or more years ago
6 □ I don't know if I ever had one	<sup>6</sup> □ I don't know if I ever had one
7 □ I had one, but I don't recall when	7 🗌 I had one, but I don't recall when
N6. When was the <u>last time</u> you had an MRI of your heart (you were placed inside a scanner, like a long tube)?	N10. When was the <u>last time</u> you had a skin exam for cancer by a healthcare provider? skinexam
1 🗌 Never	1 🗋 Never
2 □ Less than 1 year ago	2 □ Less than 1 year ago
<mark>3</mark> □ 1-2 years ago	<mark>3</mark> □ 1-2 years ago
₄ ☐ More than 2 years ago but less than 5 years ago	<b>4</b> ☐ More than 2 years ago but less than 5 years ago
₅ 🔲 5 or more years ago	<mark>5</mark> ☐ 5 or more years ago
6 □ I don't know if I ever had one	<mark>6</mark> ☐ I don't know if I ever had one
7 □ I had one, but I don't recall when	7 🗖 I had one, but I don't recall when
N7. When was the <u>last time</u> you had an MRI of your head or brain? headmri	N11. When was the <u>last time</u> you had a home blood stool test to determine whether your stool contains blood? <u>stooltest</u>
1 🗆 Never	1 🗆 Never
2 🗆 Less than 1 year ago	2 □ Less than 1 year ago
3 □ 1-2 years ago	3 □ 1-2 years ago
4 🗌 More than 2 years ago but less than 5 years ago	4  ☐ More than 2 years ago but less than 5 years ago
<mark>5</mark> ☐ 5 or more years ago	5 □ 5 or more years ago
<mark>6</mark> ☐ I don't know if I ever had one	6 □ I don't know if I ever had one
7 🔲 l had one, but l don't recall when	7 🗖 I had one, but I don't recall when
N8. When was the <u>last time</u> you had an ultrasound of the thyroid gland? thyus	N12. When was the <u>last time</u> you had a sigmoidoscopy or colonoscopy to view the colon for signs of cancer or other problems? <u>colonexam</u>
1 🗆 Never	1 🗆 Never
2 □ Less than 1 year ago	2 □ Less than 1 year ago
3 🗌 1-2 years ago	3 □ 1-2 years ago
4 $\Box$ More than 2 years ago but less than 5 years ago	4 ☐ More than 2 years ago but less than 5 years ago
5 □ 5 or more years ago	<sup>5</sup> □ 5 or more years ago
6 🗌 I don't know if I ever had one	6 □ I don't know if I ever had one
7 □ I had one, but I don't recall when	7 □ I had one, but I don't recall when



- N13. During the past 12 months, have you had either a flu shot or a flu vaccine that was sprayed in vour nose? fluvac 1 Yes 2 No 3 Don't Know N14. A pneumonia shot or pneumococcal vaccine is usually given only once or twice in a person's lifetime and is different from the flu shot. Have you ever had a pneumonia shot? pneumovac 2 No 1 Yes 1 Yes 2 No 3 Don't Know N15a. Have you ever had zoster (shingles)? shingles\_yn 2 □ No Go to Question N16. 1 
  Never 1 🗌 Yes If yes, indicate number of times and date(s) of occurrence(s). shingmo3-6 Times Month Year shingyr3-6 shingmo1 shingyr1 shingno shingyr2 shinamo2 Please use a separate sheet of paper for additional dates. N15b. Since completing your cancer treatment, did you take chronic medications because of shingles? shingmed 2 No 1 Yes N15c. Do you currently take chronic (for more 1 Never than 1 month) medications because of shingles? shmednow 2 No 1 Yes N16. Since completing your cancer treatment, have you ever been hospitalized for infection? infecthosp 2 □ No 1 □ Yes -Note date(s) and sites(s) of infection: Site of infection (lung, blood, sinus, Date of infection brain, etc.) infdte1-8 infeste1-8 1 
  Never text Please use a separate sheet of paper for additional dates and sites. Please! Do not mark below this line -
  - N17. **FEMALES** How often do you perform monthly breast self-examinations? breastex
    - 1 Regularly (once a month)
    - 2 Occasionally
    - 3 🗌 Rarely or never
  - N18. FEMALES Have you ever required surgical treatment for an abnormal Pap smear (cone biopsy, laser surgery, loop electrosurgical excision (LEEP), removal of cervix, etc.)? abpapsmr
  - N19. FEMALES When was the last time you had a breast examination by a doctor or a health care professional? Istbrex
    - 2 Less than 1 year ago
    - 3 🗌 1-2 years ago
    - 4 🗌 More than 2 years ago but less than 5 years ago
    - 5 5 or more years ago
    - 6 🗌 I don't know if I ever had one
    - 7 🗌 I had one, but I don't recall when

#### N20. FEMALES - Have you ever had a mammogram?

1 □ Yes 2 □ No		
↓ mamgrm	a_m	amo
N20a. How old were you when you had your first mammogram?		

#### N20b. When was the last time you had a mammogram?

- 2 Less than 1 year ago
- 3 1-2 years ago
- 4 More than 2 years ago but less than 5 years ago
- 5 □ 5 or more years ago
- 6 l don't know if I ever had one
- 7 I had one, but I don't recall when

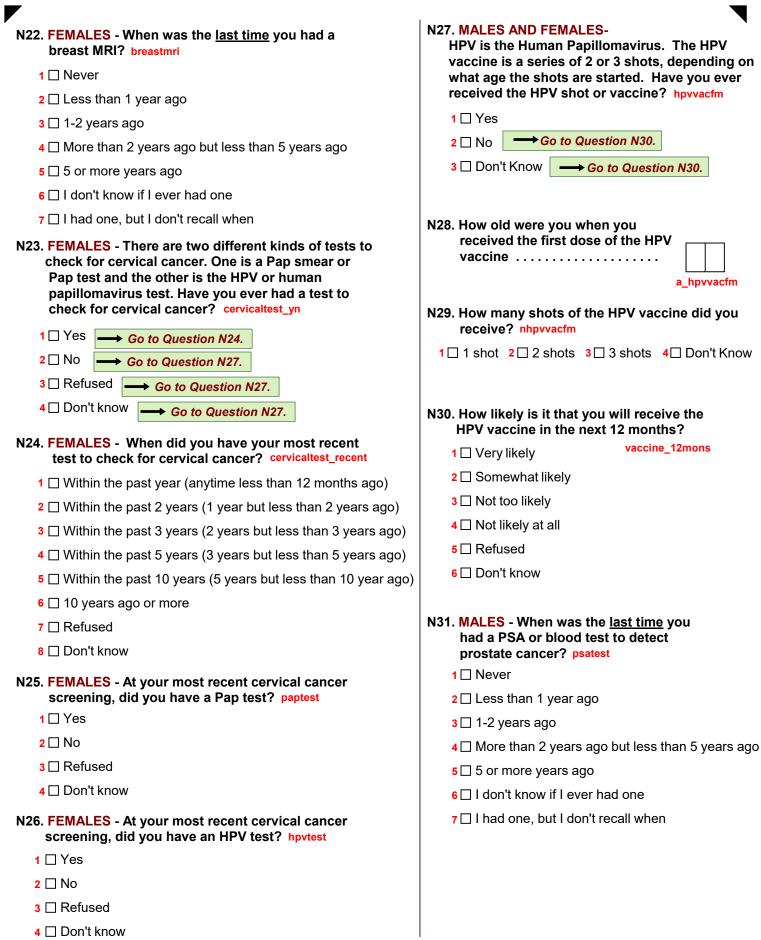
#### N21. FEMALES - When was the last time you had a breast ultrasound? breastus

- 2 🗌 Less than 1 year ago
- 3 🗌 1-2 years ago
- 4 🗌 More than 2 years ago but less than 5 years ago
- 5 5 or more years ago
- 6 🗌 I don't know if I ever had one
- 7 🗌 I had one, but I don't recall when



Istmamgrm





## HOSPITALIZATIONS

We are interested in any admissions to the hospital for illness, surgical, or diagnostic procedures, including psychiatric/mental health hospitalization or short stays of 24 hours or less that you may have had in the last 12 months. <u>DO NOT INCLUDE PREGNANCY RELATED ADMISSIONS</u> or <u>EMERGENCY ROOM VISITS</u>.

O1. Have you been admitted to a hospital in the <u>last 12 months</u> ? hospadm	O4. What was the reason for the <u>second</u> hospitalization?
2 □ No → Go to Section P, next page. 1 □ Yes	ha2reason1-4 coded
O2. How many times have you been admitted to a hospital in the <u>last 12 months</u> ?	
O3. What was the reason for the <u>first</u> hospitalization?	O4a. What procedures/surgeries were performed?
ha1reason1-6 coded	ha2proced1-6 coded
O3a. What procedures/surgeries were performed?	O4b. Where were you hospitalized?
ha1proced1-9 coded	Address
O3b. Where were you hospitalized?	City, State, Zip code
Hospital	Doctor's name
Address	
City, State, Zip code	O4c. Date of second hospitalization:
Doctor's name	Month (mm) Year (yyyy) ha2mo ha2yr
	O4d. How many days were you hospitalized?
O3c. Date of first hospitalization:	ha2days
Month (mm) Year (yyyy)	Days
ha1mo ha1yr O3d. How many days were you hospitalized?	Please use a separate sheet of paper for additional hospitalizations
ha1days	ha3reason-ha5reason ha3mo-ha5mo
Days Please! Do not m	ha3proced-ha5proced ha3yr-ha5yr ark below this line ————————————————————————————————————



## GENETIC CONDITIONS

Please mark the appropriate box (either "No", "Yes", or "Not sure") for each of the listed conditions. Indicate "Yes" only if a physician has told you that you were born with, or have the condition.

Because we need definite responses, and questions left blank are difficult to interpret, it is very important that you mark an answer for each of the following questions, even if you have never had that condition. If you have never heard of these conditions, it is unlikely that you have had them. <u>3 Not sure</u>

P1a. Have you ever been told by a 1 Yes				
de	octor that you have	2 No		
a.	Ataxia telangiectasiagcataxtg	· 🗆		
b.	Beckwith-Wiedemann syndrome	. 🗆		
C.	Bilateral acoustic neurofibromatosis (Neurofibromatosis Type 2)			
d.	Bloom's syndrome gcbloom	· □		
e.	Down syndrome gcdown	· 🗆		
f.	Klinefelter's syndromegckline	· 🗆		
g.	Fanconi's anemia			
h.	Multiple exostoses gcmexos	· 🗆		
i.	Familial adenomatous polyposis (FAP or Gardner syndrome)	· 🗆		
j.	Neurofibromatosis (Type 1)			
k.	Nevoid basal cell carcinoma syndrome			
I.	Turner's syndrome			
m.	Von Hippel-Lindau syndrome. gcvhl	· 🗆		
n.	Wiskott-Aldrich syndrome gcwasynd	· 🗆		
0.	Xeroderma pigmentosum gcpigmen	t.		
p.	Polycystic kidney disease gcpkd	· 🗆		
q.	WAGR syndrome			
r.	Li-Fraumeni syndrome (p53 gene abnormality)	· 🗆		
S.	Any other genetic disorder	· 🗆		
	If yes, describe this disorder.			
	dgcoth1-3 coded			

#### P1b. Has anyone in your immediate family (blood relatives only) or your spouse <u>ever</u> had any of the conditions in question P1a? *(Mark all that apply)*

gc	What conditi	ons?	
☐ Mother → gc_mom	dgcmom1-4	coded	
☐ Father → gc_dad	dgcdad1-4	coded	
□ Full brother → gc_bro	dgcbro1-4	coded	
☐ Full sister → gc_sis	dgcsis1-4	coded	
□ Son → gc_son	dgcson1-4	coded	
□ Daughter → gc_dau	dgcdau1-4	coded	
□ Spouse → gc_spo	dgcspo1-4	coded	

### **CONDITIONS PRESENT AT BIRTH**

Because we need definite responses, and questions left blank are difficult to interpret, it is very important that you mark an answer for each of the following questions, even if you have never had that condition. If you have never heard of these conditions, it is unlikely that you have had them.

P2. Have you <u>ever</u> had genetic counseling for cancer risk? grounsel

2 🗌 No

**1** 🗌 Yes

Continue on next page.

		3	Not s	ure	P3b. Has anyone in v	your immediate family (blood	
a. To the best of your knowledge,		1 Yes			relatives only) or your spouse <u>ever</u> had any of		
w	ere you born with	2 No			conditions in C	uestion P3a? (Mark all that apply)	
a.	Cleft lip or palate	· 🗆			bd	What conditions?	
b.	Club footbdclub	· 🗆			☐ Mother →		
C.	Large or multiple birthmarks (any 1 larger than a quarter, or 6 larger than a dime)bdmarks				bd_mom □ Father →	dbdmom1-4 coded	
d.	Deafness or impaired hearing at birth bdhear				bd_dad	dbddad1-4 coded	
e.	Blindness or difficulty seeing at birth				□ Full brother → bd_bro	dbdbro1-4 coded	
f.	Eyes different colors or missing an iris (the colored part of the eye) bdeye	· 🗆			☐ Full sister → bd_sis	dbdsis1-4 coded	
-	Hydrocephalus (excessive water around or within the brain) bdhydro				□ Son → bd_son	dbdson1-4 coded	
	Spina bifida or other neural tube defect bdnt Unusually small head (microcephaly)				□ Daughter →	dbddau1-6 coded	
i. i.	Unequal sized limbs (hemihypertrophy).				□ Spouse →		
k.	Extra fingers, deformed chest, bdlimbs				bd_spo	dbdspo1-4 coded	
	shortened limbs or any other skeletal abnormalitybdskel	· 🗆					
I.	Hole in the heart or other congenital heart defect bdheart						
	If other defect, please specify.					our immediate family (blood or your spouse <u>ever</u> had cancer? o <mark>ply)</mark>	
	coded				catypes	What types?	
					☐ Mother → catypes_mom	dcamom1-5 coded	
					☐ Father → catypes_dad	dcadad1-8 coded	
m.	Any congenital abnormality of the pancreas, liver, or digestive tract (stomach, intestines)bddigest				□ Full brother → catypes_bro	dcabro1-4 coded	
n.	Any kidney, bladder, or genital abnormalitiesbdurin	· 🗆			□ Full sister → catypes_sis	dcasis1-4 coded	
	Undescended testes bdtestes				□ Son →	coded	
p.	Any other birth defects bdoth	· 🗆			catypes_son	dcason1-4	
	If other, please specify.				☐ Daughter → catypes_dau	coded dcadau1-4	
	coded				□ Spouse → catypes_spo	dcaspo1-4 coded	



## CONTACT INFORMATION

<ul> <li>1. Do you use a cell phone? cellyn <ul> <li>Yes</li> <li>No → Go to question 3.</li> </ul> </li> <li>1 2 <ul> <li>1 2</li> </ul> </li> <li>1a. Would you be willing to send/receive study-related texts <ul> <li>Yes</li> <li>Yes</li> <li>Yes</li> <li>No</li> <li>My phone is not text capable</li> </ul> </li> </ul>	<ul> <li>3. Which of the following types of devices do you use to access the internet? (Mark all that apply) devices <ul> <li>Computer or laptop devices_comp</li> <li>Tablet (iPad or similar) devices_tab</li> <li>Smartphone devices_smrtphn</li> </ul> </li> <li>s? Other, specify: devices_oth othdevs_1-2 <ul> <li>I don't access the internet devices_noint</li> </ul> </li> <li>4. If you can recall, what was your home address at the</li> </ul>
2. Do you use a "smartphone" that can access the internet or download "apps" (e.g. iPhone, Android, Blackberry, Windows)? smartyn	time you were treated for childhood cancer? Address trtaddr
1 □ Yes 2 □ No	City State trtcity trtst Zip Code trtzip
We have your current address and phone as:	Is this information correct, or are you planning on moving in the next 6 months? addrstat 1 Correct 2 Not correct 3 Moving
addr city	Do you have an email address we could use to contact you? emailyn
state zipcode homephone phonenumber2	2 No 1 Yes Your Email Address email

Please give us your correct address or location (if different from above):

Address	upaddr			
City	upcity		State upstate	
Zip Code	upzip	Home Phone Number uphomeph		Cell Phone Number upcellph

Please provide the name and address of someone who could give us your new address should you move. We will contact this person only if we are unable to reach you at your home address.

Name	cntname		
Address	cntaddr	Relationship to you cntrel	
City	cntcity	State cntst	
Zip Code	cntzip	Phone Number cntph	





## For our future planning, what type of information or help do you think should be available to survivors of childhood cancer, leukemia, tumor, or similar illnesses?

comments

text

Attach additional pages, if necessary.

#### When you have completed this questionnaire please return it to us in the enclosed envelope.

Mail to:

SJLIFE STUDY St. Jude Children's Research Hospital Department of Epidemiology Mail Stop 735 262 Danny Thomas Place Memphis, TN 38105-3678

#### Thank you!

