

Mayo Study of Lymphoma and Leukemia (6-Year Follow-Up)



Survey Research Center

Thank you for taking the time to complete this survey. We are trying to better document and understand the needs and outcomes of lymphoma and leukemia survivors, and one of the best ways to do that is to collect information directly from persons such as you.

The questions on this survey address many issues related to health, physical and emotional function, and quality of life. While some of these questions may seem different from the usual questions asked in a health survey, they have been developed by experts in the field to help us understand all aspects of cancer survivorship.

We ask you to complete the survey to the best of your ability, and you are free to skip those questions that you are not comfortable answering. There is no "right" or "wrong" answer. Please also be aware that to make the study as scientifically strong as possible, we ask all survivors, no matter what their current health status or concerns, to answer the same questions. It is important to hear from everyone who has survived this disease.

Thank you for your time, and if you have any questions do not hesitate to contact the study staff (contact information on your cover letter).

1-7 8-12	Clinic Number: SPORE ID:
0-12	
	INSTRUCTIONS: PLEASE CHECK THE APPROPRIATE BOX OR FILL IN THE BLANK AS INDICATED.
13-20	Today's Date: ///
21_	1. What is your current marital status?
	1 Married or living as married 2 Widowed 3 Divorced or separated 4 Single, never married
22-29	2. What is your current employment status? (Mark all that apply.)
	1Employed full-time1Student1Homemaker1Disabled1Employed part-time1Retired1Medical leave1Unemployed
	HEALTH STATUS
30_	3. Would you say that your current health is:
	1 Excellent 2 Very good 3 Good 4 Fair 5 Poor
31-33	4. What is your current weight in pounds? Pounds
34:35-36	5. What is your current height? Feet Inches
	PERFORMANCE STATUS
37_	6. Select one of the following that best describes your ability to carry on daily activities.
	$_0$ \Box Fully active, able to carry on all activity without restriction.
	Restricted in physically strenuous activity but able to walk and able to carry out work of a light or sedentary nature, e.g., light housework or office work.
	2 Able to walk and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours.
	³ Capable of only limited self care, confined to bed or chair more than 50% of waking hours.
	4 Completely disabled. Cannot carry on any self care. Totally confined to bed or chair.
	5 🗌 Not known
	6 Prefer not to answer
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	 7. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Please mark one response per line.) 	Yes, limite a lot	d limited	No, not limited at all
38_	<u>Vigorous activities</u> , such as running, lifting heavy objects, participating in strenuous sports	3	2	1
39_	Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	3	2	1
40_	Lifting or carrying groceries	3	2	1
41_	Climbing several flights of stairs	3	2	1
42_	Climbing <u>one</u> flight of stairs	3	2	1
43_	Bending, kneeling, or stooping	3	2	1
44_	Walking <u>more than a mile</u>	3	2	1
45_	Walking <u>several blocks</u>		2	1
46_	Walking <u>one block</u>	3	2	1
47_	Bathing or dressing yourself	3	2	1
48-50 51_	 8. How many times have you fallen in the last 6 months? 9. Are you currently (within the last month) smoking or using or 		(Enter 000 if y not fallen.)	you have
	1 No, I have never used tobacco products			
52-57	3 No, I quit/ (To the best of my recolled Month Year	tion.))	
	If yes, what tobacco products are you currently using? (Ma	ark al	l that apply.))
58-62	1 Cigarettes 1 Pipes 1 Cigars 1 Che toba		g 1 □ Sn	uff
	How many cigarettes do you smoke per day?			
63-65	Cigarettes per day			
	How has your smoking changed since your diagnosis of ly	mph	oma or leuke	emia?
66_	1 No change 2 Decreased 3 Increased	d		

	Diet						
10.	Please answer the following questions about your eating habits over the past month. (Mark only <u>one</u> response for each question.)	Never	Rarely	Sometimes	Often	Almost always	Don't eat food(s)
	How often did you substitute low fat dairy products for regular products?	1	2	3	4	5	6
	How often did you eat hamburgers, hot dogs, or luncheon meats?	1	2	3	4	5	6
	If you ate chicken, how often did you have it fried?	1	2	3	4	5	6
	How often did you eat at least 2 servings a day of vegetables like carrots, celery corn, peppers, broccoli, etc.?	1	2	3	4	5	6
	How often did you eat at least one serving of cereal a day?	1	2	3	4	5	6
	If you eat salads, how often did you use light, fat free, or no dressing?	1	2	3	4	5	6
	How often did you reduce the amount of butter, margarine, or oil in a recipe to cut down on fat?	1	2	3	4	5	6
	If you ate fish, how often did you have it fried?	1	2	3	4	5	6
	How often did you have at least 1 serving of fruit a day?	1	2	3	4	5	6
	When you include cheese on sandwiches or in cooking, how often did you substitute reduced-fat or low-fat cheese for regular cheese?	_	2	3	4	5	6
	If you ate red meat, how often did you eat small portions to cut down on fat?	1	2	3	4	5	6
	If you ate chicken, how often did you bake or broil it?	1	2	3	4	5	6
	How often did you have fruit or vegetables as a snack?		2	3	4	5	6
	How often did you substitute low fat foods for high fat foods?	1	2	3	4	5	6
					Contin	ued nex	t page.

			Never	Rarely	Sometimes	Often	Almos always	
81_	How often did you eat tacos, ham and other fast foods?		1	2	3	4	5	6
82_	If you ate fish, how often did you baked, broiled, or poached?		1	2	3	4	5	6
83_	How often did you have at least 3 a week of broccoli, cabbage, or ca		1	2	3	4	5	6
84_	If you use mayonnaise, how often use light, low fat, or fat free mayo instead of regular?	onnaise	1	2	3	4	5	6
85_	How often did you avoid putting margarine on your bread to cut do		1	2	3	4	5	6
86_	How often did you pan fry foods	?	1	2	3	4	5	6
87_	How often did you eat bread, roll muffins made from whole grains wheat, rye, or pumpernickel)?	(whole	1	2	3	4	5	6
88_	How often did you eat french frie	es?	1	2	3	4	5	6
89_	How often did you eat dark bread	d?	1	2	3	4	5	6
	11. How confident are you that you w overcome the following barriers to changes in your eating habits?		Not a confi		Not too confident	Somev confid		Extremely confident
90_	I can manage to stick to healthful I need a long time to develop the routines.	necessary	_		2	3]	4
91_	I can manage to stick to healthful if I have to try several times until				2	3]	4
92_	I can manage to stick to healthful I have to rethink my entire way o				2	3]	4
93_	I can manage to stick to healthful I do not receive a great deal of su others when making my first atte	pport from	_		2	3]	4
94_	I can manage to stick to healthful I have to make a detailed plan				2	3]	4

		Physical Activity										
	12.	During a typical <u>7-day period</u> (a week), how many times on average do you do the following kinds of exercise for <u>more than 15 minutes</u> during your free time (write on each line the appropriate number).										
95-96		a. STRENUOUS EXERCISE (HEART BEATS RAPIDLY) Times per week (e.g., running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long-distance bicycling)										
97-98		 b. MODERATE EXERCISE (NOT EXHAUSTING) Times per week (e.g., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing) 										
99-100	-	c. MILD EXERCISE (MINIMAL EFFORT) Times per week (e.g., yoga, archery, fishing from river bank, bowling horseshoes, golf, snowmobiling, easy walking)										
101_	13.	During a typical <u>7-day period</u> (a week), in your leisure time, how often do you engage in any regular activity <u>long enough to work up a sweat</u> (heart beats rapidly)?										
		1 Often 2 Sometimes 3 Never/rarely										
102_	14.	How has your level of physical activity changed since your diagnosis of lymphoma or leukemia?										
		1 No change 2 Decreased level of activity 3 Increased level of activity										
	15.	On a scale of 1 to 10, with 1 being "Not at all confident" and 10 being "Extremely confident," how confident are you that you can participate in regular exercise when:										
		Not at allExtremelyconfidentconfident										
103-104		I am tired 1 2 3 4 5 6 7 8 9 10										
105-106		I am in a bad mood 1 2 3 4 5 6 7 8 9 10										
107-108		I feel I don't have the time										
109-110		I am on vacation. 1 2 3 4 5 6 7 8 9 10										
111-112		It is raining or snowing. 1 2 3 4 5 6 7 8 9 10										

16. Below and on the next page is a list of statements that other people with your illness have said are important. By checking one (1) number per line, please indicate how true each statement has been for you <u>during the past 7 days</u>.

	PHYSICAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much
110			2			5
113_	I have lack of energy 1 I have nausea 1		2	3	4	5
114_			2	3	4	5
115_	Because of my physical condition, I have trouble meeting the needs of my family.	1	2	3	4	5
116_	I have pain 1	ι 🔲	2	3	4	5
117_	I am bothered by side effects of treatment 1	1	2	3	4	5
118_	I feel ill.	1	2	3	4	5
119_	I am forced to spend time in bed 1	1	2	3	4	5
	SOCIAL/FAMILY WELL-BEING					
			. 🗖	. 🗖	. 🗖	- 🗔
120_	I feel close to my friends.		2	3	4	5
121_	I get emotional support from my family 1	_	2	3	4	5
122_	I get support from my friends 1	_	2	_	4	
123_	My family has accepted my illness.		2	3	4	5
124_	I am satisfied with family communication about my illness	1	2	3	4	5
125_	I feel close to my partner (or the person who is my main support)	ı 🗌	2	3	4	5
	Regardless of your current level of sexual activity, ple If you prefer not to answer it, please check the box be emotional well-being section below.	low an	d cont	2	h the	
126_	$_{0}$ I prefer not to answer it.	Not at all	A little bit	Somewhat	Quite a bit	Very much
127_	I am satisfied with my sex life 1	1	2	3	4	5
	EMOTIONAL WELL-BEING					
128_	I feel sad	1	2	3	4	5
129_	I am satisfied with how I am coping with my illness.	1	2	3	4	5
130_	I am losing hope in the fight against my illness 1	ı 🔲	2	3	4	5
				Continu	ed next	page
						. 0

		Not at all	A little bit	Somewhat	Quite a bit	Very much
101	I feel nervous.		2	3	4	5
131_			2	3	4	5
132_ 133_	I worry about dying I worry that my condition will get worse		2	3	4	5
	FUNCTIONAL WELL-BEING					
134_	I am able to work (include work at home)	1	2	3	4	5
135_	My work (include work at home) is fulfilling	1	2	3	4	5
136_	I am able to enjoy life	1	2	3	4	5
137_	I have accepted my illness.	1	2	3	4	5
138_	I am sleeping well.	1	2	3	4	5
139_	I am enjoying the things I usually do for fun	1	2	3	4	5
140_	I am content with the quality of my life right now.	1	2	3	4	5
	ADDITIONAL CONCERNS					
141_	I feel fatigued.	1	2	3	4	5
142_	I feel weak all over.	1	2	3	4	5
143_	I feel listless ("washed out").	1	2	3	4	5
144_	I feel tired.	1	2	3	4	5
145_	I have trouble <u>starting</u> things because I am tired	1	2	3	4	5
146_	I have trouble <u>finishing</u> things because I am tired.	1	2	3	4	5
147_	I have energy	1	2	3	4	5
148_	I am able to do my usual activities.	1	2	3	4	5
149_	I need to sleep during the day	1	2	3	4	5
150_	I am too tired to eat	1	2	3	4	5
151_	I need help doing my usual activities.	1	2	3	4	5
152_	I am frustrated by being too tired to do the things I want to do	1	2	3	4	5
153_	I have to limit my social activity because I am tired	1	2	3	4	5

a lot a little disagree a little a 160_ In uncertain times, I usually expect the best. 1 2 3 4 5 161_ If something can go wrong for me, it will. 1 2 3 4 5 162_ I'm always optimistic about my future. 1 2 3 4 5		17.	Please check the number (0 - 10) that best descriweek, including today. How would you descri		ir ieell	ngs <u>aurir</u>	<u>ig the pa</u>	ast
As bad as it can be As good as it can be Your overall spiritual well-being? 156-157 0 1 2 3 4 5 6 7 8 9 10 As bad as it can be As bad as it can be 10 10 2 3 4 5 6 7 8 9 10 As bad as it can be 18. We are interested in learning whether or not you are affected by pain. Please mark the number below that describes your pain in the past 2 weeks. 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 158-159 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 158-159 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 158-159 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 1 1 1 1 1			Your overall quality of life?					
it can be it can be Your overall spiritual well-being? 156-157 0 1 2 3 4 5 6 7 8 9 10 As bad as it can be As bad as it can be As good as it can be As good as it can be 18. We are interested in learning whether or not you are affected by pain. Please mark the number below that describes your pain in the past 2 weeks. 0 1 2 3 4 5 6 7 8 9 10 18. We are interested in learning whether or not you are affected by pain. Please mark the number below that describes your pain in the past 2 weeks. 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 18. Please be as honest and accurate as you can throughout. Try not to let your response one statement influence your responses to other statements. There are no "correct" and "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. I I I I Ineither I I I I I I I I I I I I I I I I<	154-155			7	8			
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156-157 0 1 2 3 4 5 6 7 8 9 10 As bad as it can be As good as it can be As good as it can be As good as it can be Image: Comparison of the past 2 weeks. Image: Comparison of t								
As bad as it can be As good as it can be 18. We are interested in learning whether or not you are affected by pain. Please mark the number below that describes your pain in the past 2 weeks. 158-159 0 1 2 3 4 5 6 7 8 9 10 158-159 0 1 2 3 4 5 6 7 8 9 10 . 158-159 0 1 2 3 4 5 6 7 8 9 10 . 158-159 0 1 2 3 4 5 .			Your overall spiritual well-being?					
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158-159 0 1 2 3 4 5 6 7 8 9 10 158-159 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 19. Please be as honest and accurate as you can throughout. Try not to let your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. I Interest and the agree or a little agree or a littl								
158-159 0 1 2 3 4 5 6 7 8 9 10 158-159 0 1 2 3 4 5 6 7 8 9 10 No pain Severe pain 19. Please be as honest and accurate as you can throughout. Try not to let your responses to other statements. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. I Interest and the agree or a little agree or a littl								
No pain Severe pain 19. Please be as honest and accurate as you can throughout. Try not to let your responses to other statements. There are no "correct" incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. I I I neither I I neither I agree a little I agree nor disagree dis alittle I agree nor disagree dis alittle I agree a little I agree a little I agree alittle		18.					Please r	nark
 19. Please be as honest and accurate as you can throughout. Try not to let your responses to other statements. There are no "correct" incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. 100_ In uncertain times, I usually expect the best 1 11. 2 12. 3 14. 5 161_ If something can go wrong for me, it will 1 12. 3 14. 5 162_ I'm always optimistic about my future 1 12. 3 14. 5 163_ I hardly ever expect things to go my way 1 12. 3 14. 5 164_ March 1 164_ Overall, I expect more good things to happen 				7	8	9 10		
one statement influence your responses to other statements. There are no "correct" incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. I<	158-159				0	10		
think "most people" would answer.agree a lotagree a littleagree disagree a littleagree of disagree a little160_In uncertain times, I usually expect the best.12345161_If something can go wrong for me, it will.12345162_I'm always optimistic about my future.12345163_I hardly ever expect things to go my way.12345164_mee12345Overall, I expect more good things to happen00000	158-159		No pain					
161_ If something can go wrong for me, it will 1 2 3 4 5 162_ I'm always optimistic about my future 1 2 3 4 5 163_ I hardly ever expect things to go my way 1 2 3 4 5 164_ I rarely count on good things happening to me	158-159	19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to		Try no	Seve ot to let yo	re pain our respo	
162_ I'm always optimistic about my future. 1 2 3 4 5 163_ I hardly ever expect things to go my way. 1 2 3 4 5 164_ I rarely count on good things happening to me. 1 2 3 4 5 0verall, I expect more good things to happen 1 2 3 4 5	158-159	19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to your own feelings, rather than how you	I agree	Try no ents. Th	Seve of to let yo here are n I neither agree nor	re pain our respo o "corre I disagree	ct" or I
163_ I hardly ever expect things to go my way. 1 2 3 4 5 164_ I rarely count on good things happening to me. 1 2 3 4 5 0verall, I expect more good things to happen 0 0 0 0 0		19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer.	I agree a lot	Try no ents. Th agree a little	Seve of to let you here are n I neither agree nor disagree	re pain our respo o "corre I disagree	tr or I disagree a lot
164_ I rarely count on good things happening to me. 000000000000000000000000000000000000	160_	19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. In uncertain times, I usually expect the best.	I agree a lot	Try no ents. Th agree a little 2	Seve t to let you here are n I neither agree nor disagree 3	re pain our respo o "corre I disagree	tr or I disagree a lot
164_ me. 1 2 3 4 5 Overall, I expect more good things to happen	160_ 161_	19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. In uncertain times, I usually expect the best If something can go wrong for me, it will	I agree a lot 1 1 1	Try no ents. Th agree a little 2	Seve t to let your here are nor disagree 3 3 3	re pain our respo o "corre a little 4	t" or I disagree a lot 5
	160_ 161_ 162_	19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. In uncertain times, I usually expect the best If something can go wrong for me, it will I'm always optimistic about my future	I agree a lot	Try no ents. Th agree a little 2 2 2 2	Seve t to let your here are nor disagree 3 3 3 3 	re pain our respo o "corre disagree a little 4 4 4 4 4 4 4 4 4 4 4 4 4	t" or I disagree a lot 5 5
	160_ 161_ 162_ 163_	19.	Please be as honest and accurate as you can thro one statement influence your responses to other "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. In uncertain times, I usually expect the best If something can go wrong for me, it will I'm always optimistic about my future I hardly ever expect things to go my way I rarely count on good things happening to me	I agree a lot	Try no ents. Th agree a little 2 2 2 2 2 2	Seve t to let your here are nor disagree 3 3 3 3 3 3 3 3 3 3 3 3 3	re pain our respo o "corre disagree a little 4 4 4 4 4 4 4 4 4 4 4 4 4	t" or I disagree a lot 5 5 5 5 5 5 5

166_	20. In the last year, have you had 12 drinks or more of any kind of alcoholic drink? (One drink of alcohol is equal to one can of beer, one glass of wine, or one shot of liquor, e.g., whiskey, brandy, or gin.)
	$1 \square No 2 \square Yes$
	On average, how many drinks of alcohol do you usually have?
167_	1 Less than one each month
	$2 \square 1$ to 3 each month
	$3 \square 1$ to 2 each week $4 \square 3$ to 6 each week
	$5 \square 1$ to 2 each day
	$6 \square 3$ or more each day
	How has your use of alcohol changed since your diagnosis of lymphoma or leukemia?
168_	1 No change 2 Decreased use 3 Increased use
	Your Risk and Concerns About Lymphoma or Leukemia
169_	21. Compared with lymphoma or leukemia survivors of your same age, sex, and ethnic background, what do you think your chances are of getting leukemia or lymphoma cancer again sometime in your life?
	1 🔲 I have a much higher chance
	2 I have a little higher chance
	3 I have about the same chance
	4 I have a little lower chance
	5 🔟 I have a much lower chance
170_	22. How likely do you think it is that you will get lymphoma or leukemia cancer again?
	1 Very likely
	2 Somewhat likely
	3 Somewhat unlikely
	 4 Very unlikely 5 I have no feeling or opinion on my chances of getting lymphoma or leukemia cancer
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23. Cancer patients sometimes feel that having cancer makes positive changes in their lives, as well as causes problems. Indicate how much you agree with each of the following statements.

		Not at all	A little	Moderately	Quite a bit	Extremely
	Having had lymphoma or leukemia					
171_	has led me to be more accepting of things	1	2	3	4	5
172_	has taught me how to adjust to things I cannot see.	1	2	3	4	5
173_	has helped me take things as they come	1	2	3	4	5
174_	has brought my family closer together.	1	2	3	4	5
175_	has made me more sensitive to family issues.	1	2	3	4	5
176_	has taught me that everyone has a purpose in life.	1	2	3	4	5
177_	has shown me that all people need to be loved.	1	2	3	4	5
178_	has made me realize the importance of planning for my family's future	1	2	3	4	5
179_	has made me more aware and concerned for the future of all human beings.	1	2	3	4	5
180_	has taught me to be patient.	1	2	3	4	5
181_	has led me to deal better with stress and problems.	1	2	3	4	5
182_	has led me to meet people who have become some of my best friends.	1	2	3	4	5
183_	has contributed to my overall emotional and spiritual growth.	1	2	3	4	5
184_	has helped me become more aware of the love and support available from other people	1	2	3	4	5
185_	has helped me realize who my real friends are.	1	2	3	4	5
186_	has helped me become more focused on priorities, with a deeper sense of purpose in life.	1	2	3	4	5
187_	has helped me become a stronger person, more able to cope effectively with future life challenges.	1	2	3	4	5

h

			DRT				
24.	Is there someone available			A little of the time		Most of the time	All of the tim
	you can count on to listen to you when you need need to talk?		1	2	3	4	5
	to give you good advice about a problem	n?	1	2	3	4	5
	who shows you love and affection?		1	2	3	4	5
	to help with daily chores?		1	2	3	4	5
25.	Can you count on anyone to provide you emotional support (talking over problem helping you make a difficult decision)?	ns or	1	2	3	4	5
26.	Do you have as much contact as you wou with someone you feel close to, someone whom you can trust and confide in?	e in	_	2	3	4	5
	CANCER AND	o Your	R FAMILY				
27.	Cancer can have both positive and nega has cancer affected your family? Please			a family.			n, how
27.	has cancer affected your family? Please disagreement with each statement.	e indica Strongly	ite your Moderately	a family. level of a Mildly	ngreeme Mildly	nt or Moderately	Strongly
27.	has cancer affected your family? Please disagreement with each statement.	e indica Strongly disagree	te your	a family. level of a	ngreeme	nt or	
27.	has cancer affected your family? Please disagreement with each statement. Having cancer in my family has torn	e indica Strongly disagree	Moderately disagree	a family. level of a Mildly disagree	Mildly agree	nt or Moderately agree	Strongly
27.	has cancer affected your family? Please disagreement with each statement. Having cancer in my family has torn us apart in some ways. My family sees cancer as a curse on	e indica Strongly disagree	Moderately disagree	a family. level of a Mildly disagree 3	Mildly agree	nt or Moderately agree 5	6

_	5 5					
198_	I think other people pity our family because we have cancer in our family. 1	2	3	4	5	6
199_	People in my family who have had cancer seem to be united by a special bond 1	2	3	4	5	6
200_	Having cancer in our family has made us a close (or closer) family. $\dots \dots 1$	2	3	4	5	6
201_	In my family, cancer is seen as a family issue rather than just a problem for the people who have cancer 1	2	3	4	5	6

28. Family members sometimes influence other members' actions related to cancer prevention and screening. These actions could include things like going to the doctor, getting cancer screening, or changing your lifestyle. To what extent does your family influence your cancer prevention and screening activities? Please indicate your level of agreement or disagreement with each statement.

	I feel a lot of pressure from my	Strongly disagree	Moderately disagree	Mildly disagree	Mildly agree	Moderately agree	Strongly agree
202_	family to do things to avoid getting cancer again.	1	2	3	4	5	6
203_	Someone in my family often reminds me to do things to avoid getting cancer again		2	3	4	5	6
204_	Some people in my family are critical of the relatives who don't take good care of their health	1	2	3	4	5	6
205_	Most of the people in my family do things to avoid getting cancer.	1	2	3	4	5	6
206_	My family members praise me when I do things to avoid getting cancer again.	1	2	3	4	5	6
207_	I try to influence my family members to do things to avoid getting cancer	1	2	3	4	5	6

29. Families sometimes have different rules about and ways of discussing cancer. How does your family discuss cancer? Please indicate your level of agreement or disagreement with each statement.

	disagreement with each statement.	Strongly	Moderately	Mildly	Mildly	Moderately	Strongly
	People in my family who have	disagree	disagree	disagrée	agree	agree	agree
208_	cancer generally keep their feelings about it to themselves.	1	2	3	4	5	6
209_	For the most part, people in my family who have had cancer only talk to each other about it	1	2	3	4	5	6
210_	My family usually tries to keep children from hearing conversations about cancer.	1	2	3	4	5	6
211_	Cancer is an open topic for discussion in my family.	1	2	3	4	5	6
212_	Most of my family is uncomfortable discussing cancer.	1	2	3	4	5	6
213_	There are one or two main people in my family who usually keep us informed about cancer	1	2	3	4	5	6
214_	I have learned most of what I know about cancer from my family	1	2	3	4	5	6
215_	Cancer-related topics are frequently discussed in my family.	1	2	3	4	5	6
216_	My family is very open in discussing cancer family history.	1	2	3	4	5	6

30. A number of statements which people have used to describe themselves are given below. Read each statement and then check the appropriate box to the right of the statement to indicate how you feel <u>right now</u>, that is, <u>at this moment</u>. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

		Not at all	Somewhat	Moderately so	Very much so
217_	a. I feel calm	1	2	3	4
218_	b. I feel secure	1	2	3	4
219_	c. I am tense	1	2	3	4
220_	d. I feel strained	1	2	3	4
221_	e. I feel at ease	1	2	3	4
222_	f. I feel upset	1	2	3	4
223_	g. I am presently worrying over possible misfortunes	1	2	3	4
224_	h. I feel satisfied	1	2	3	4
225_	i. I feel frightened	1	2	3	4
226_	j. I feel comfortable	1	2	3	4
227_	k. I feel self-confident	1	2	3	4
228_	1. I feel nervous	1	2	3	4
229_	m. I am jittery	1	2	3	4
230_	n. I feel indecisive	1	2	3	4
231_	o. I am relaxed	1	2	3	4
232_	p. I feel content	1	2	3	4
233_	q. I am worried	1	2	3	4
234_	r. I feel confused	1	2	3	4
235_	s. I feel steady	1	2	3	4
236_	t. I feel pleasant	1	2	3	4

31. A number of statements which people have used to describe themselves are given below. Read each statement and then check the appropriate box to the right of the statement to indicate how you generally feel.

		Almost never	Sometimes	Often	Almost always
237_	a. I feel pleasant	1	2	3	4
238_	b. I feel nervous and restless	1	2	3	4
239_	c. I feel satisfied with myself	1	2	3	4
240_	d. I wish I could be as happy as others seem to be	1	2	3	4
241_	e. I feel like a failure	1	2	3	4
242_	f. I feel rested	1	2	3	4
243_	g. I am "calm, cool, and collected"	1	2	3	4
244_	h. I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
245_	i. I worry too much over something that really doesn't matter		2	3	4
246_	j. I am happy	1	2	3	4
247_	k. I have disturbing thoughts	1	2	3	4
248_	1. I lack self-confidence	1	2	3	4
249_	m. I feel secure	1	2	3	4
250_	n. I make decisions easily	1	2	3	4
251_	o. I feel inadequate	1	2	3	4
252_	p. I am content	1	2	3	4
253_	q. Some unimportant thought runs through my mind and bothers me	1	2	3	4
254_	r. I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
255_	s. I am a steady person	1	2	3	4
256_	t. I get in a state of tension or turmoil as I think over my recent concerns and interests		2	3	4

32. Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate how distressing each difficulty has been for you <u>during the past 7 days</u> with respect to your lymphoma or leukemia.

		Not at all				Extremely	
257_	Any reminder brought back feelings about it.	1	2	3	4	5	
258_	I had trouble staying asleep.	1	2	3	4	5	
259_	Other things kept making me think about it.	1	2	3	4	5	
260_	I felt irritable and angry	1	2	3	4	5	
261_	I avoided letting myself get upset when I thought about it or was reminded of it	1	2	3	4	5	
262_	I thought about it when I didn't mean to	1	2	3	4	5	
263_	I felt as if it hadn't happened or wasn't real	1	2	3	4	5	
264_	I stayed away from reminders of it.	1	2	3	4	5	
265_	Pictures about it popped into my mind	1	2	3	4	5	
266	I was jumpy and easily startled.	1	2	3	4	5	
267_	I tried not to think about it.	1	2	3	4	5	
268_	I was aware that I still had a lot of feelings about it, but I didn't deal with them	1	2	3	4	5	
269_	My feelings about it were kind of numb	1	2	3	4	5	
270_	I found myself acting or feeling like I was back at that time.	1	2	3	4	5	
271_	I had trouble falling asleep.	1	2	3	4	5	
272_	I had waves of strong feelings about it.	1	2	3	4	5	
273_	I tried to remove it from my memory	1	2	3	4	5	
274_	I had trouble concentrating.	1	2	3	4	5	
275_	Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.	1	2	3	4	5	
276_	I had dreams about it.	1	2	3	4	5	
277_	I felt watchful and on guard.	1	2	3	4	5	
278_	I tried not to talk about it.	1	2	3	4	5	

	LIFESTYLE					
279_	33.		gram to teach you how to use the Internet and other sources to get how interested would you be in taking part?			
		$1 \square$ Not at all inte	erested 2 Somewhat interested 3 Definitely interested			
280_	34.		m to reduce your cancer risk (i.e., exercise, nutrition, smoking red, how willing would you be to take part in the program?			
		1 \square Not at all	If not at all, skip to question 35 on page 17.			
		² Somewhat	If you answered "Somewhat" or "Definitely"			
		3 Definitely	Would you prefer a program just for you or one that includes you and your family? (Mark ALL that apply.)			
281-283			1 Just me 1 Me and others (i.e., people outside family like friends or coworkers)			
			What type of program would be of interest? (Mark ALL that apply.)			
284_ 285_ 286_			 A. Exercise B. Weight management C. Nutrition 			
287_ 288_ 289_			 D. Tobacco cessation (to quit smoking) E. Stress reduction F. Other, specify:			
			Of the programs listed above, what would be your <u>top</u> choice? (Please record the letter of your choice from above.)			
290_						
			How likely would you be to take part if the program was delivered by:			
291_			Telephone 3 2 1			
292			Web/Internet (password protected/ confidential site)			
293_			In person			
			Of the three ways to deliver the program, which one would be your top choice?			
294_			1 Telephone 2 Web/Internet 3 In person			

35. We welcome any comments you may wish to provide.

Thank you for taking the time to participate in this survey!

Question 13: © US English 1987, 1997, David Cella, Ph.D., Fact-G (Version 4).

Question 18: Complementary/Alternative Medicine Survey developed by Boon et al, 2004.

Question 22: © Godin, G. and Shephard, R. J., A Simple Method to Assess Exercise Behavior in the Community. Can. J. Appl. Spt. Sci. 10:3 141-146, 1985.

Questions 30 and 31: ©Marcus, B. H., Rossi, J. S., Selby, V. C., Niaura, R. S., & Abrams, D. B. (1992). The stages and processes of exercise adoption and maintenance in a worksite sample. Health Psychology, 11, 386-395.