

## Mayo Study of Lymphoma and Leukemia (9-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	Clinic Number:
8-12	
	INSTRUCTIONS: PLEASE CHECK THE APPROPRIATE BOX OR FILL IN THE BLANK AS INDICATED.
.3-20	Today's Date:    ///
.1	1. What is your current marital status?
	1       Married or living as married       2       Widowed       3       Divorced or separated       4       Single, never married
2-29	2. What is your current employment status? (Mark all that apply.)
	1       Employed full-time       1       Student       1       Homemaker       1       Disabled         1       Employed part-time       1       Retired       1       Medical leave       1       Unemployed
	HEALTH STATUS
)	3. Would you say that your current health is:
	$1 \square \text{ Excellent}  2 \square \text{ Very good}  3 \square \text{ Good}  4 \square \text{ Fair}  5 \square \text{ Poor}$
3	4. What is your current weight in pounds? Pounds
	PERFORMANCE STATUS
	5. Select one of the following that best describes your ability to carry on daily activities.
	0 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.
	<sup>3</sup> 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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	6. 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, limited a lot	Yes, limited a little	No, not limited at all
35	Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports	3	2	1
36	<u>Moderate activities</u> , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	3	2	1
37	Lifting or carrying groceries	3	2	1
38	Climbing <u>several</u> flights of stairs	3	2	1
39	Climbing <u>one</u> flight of stairs	3	2	1
40	Bending, kneeling, or stooping	3	2	1
41	Walking more than a mile	3	2	1
42	Walking <u>several blocks</u>		2	1
43	Walking <u>one block</u>	3	2	1
44	Bathing or dressing yourself	3	2	1
45-47	7. How many times have you fallen in the last 6 months?	(] n	Enter 000 if y ot fallen.)	vou have
	8. Are you currently (within the last month) smoking or using	other I	tobacco pro	ducts?
48	1 No, I have never used tobacco products			
49-54	3 No, I quit/ (To the best of my recolle	ction.)		
		ction.)		
	3 No, I quit/ (To the best of my recolle Month Year 2 Yes			
	3 No, I quit/ (To the best of my recolle Month Year 2 Yes If yes, what tobacco products are you currently using? (M	ark all	that apply.)	
	<ul> <li>3 No, I quit/ (To the best of my recolle Month Year</li> <li>2 Yes</li> <li>If yes, what tobacco products are you currently using? (M</li> <li>1 Cigarettes 1 Pipes 1 Cigars 1 Ch</li> </ul>	ark all		
49-54	<ul> <li>3 No, I quit/ (To the best of my recolle Month Year</li> <li>2 Yes</li> <li>If yes, what tobacco products are you currently using? (M</li> <li>1 Cigarettes 1 Pipes 1 Cigars 1 Ch</li> </ul>	ark all ewing	that apply.)	
49-54	3 □ No, I quit/ (To the best of my recolle Month Year 2 ↓ Yes If yes, what tobacco products are you currently using? (M 1 ↓ Cigarettes 1 □ Pipes 1 □ Cigars 1 □ Ch tob How many cigarettes do you smoke per day?	ark all ewing	that apply.)	
49-54	3 No, I quit/ (To the best of my recolle Month Year 2 Yes If yes, what tobacco products are you currently using? (Month Year) 1 Cigarettes 1 Pipes 1 Cigars 1 Character (Month Year) How many cigarettes do you smoke per day?Cigarettes per day	ark all ewing bacco	that apply.) 1 🗌 Snu	ıff
49-54	3 No, I quit/ (To the best of my recolle Month Year 2 Yes If yes, what tobacco products are you currently using? (Month Year) 1 Cigarettes 1 Pipes 1 Cigars 1 Chettor How many cigarettes do you smoke per day?Cigarettes per day How has your smoking changed since your diagnosis of by	ark all ewing bacco	that apply.) 1 🗌 Snu	ıff
49-54	3 No, I quit/ (To the best of my recolle Month Year 2 Yes If yes, what tobacco products are you currently using? (Month Year) 1 Cigarettes 1 Pipes 1 Cigars 1 Character (Month Year) How many cigarettes do you smoke per day?Cigarettes per day	ark all ewing bacco	that apply.) 1 🗌 Snu	ıff

	9.	How many	servings of	<u>fruit</u> do you u	usually eat each o	day? (Check the	e best answer.)
64		0 0	1 1	2 2 2	3 🗌 3 to 4	$4 \square 5$ to 6	5 🗌 7 or more
	10.	How many answer.)	servings of	<u>vegetables</u> do	) you usually eat	each day? (Che	eck the best
65		0 0	1 1	2 2 2	3 🗌 3 to 4	4 🗌 5 to 6	5 🗌 7 or more
				Physi	CAL ACTIVITY		
	11.	following k	inds of exe		k), how many tin than 15 minutes		do you do the ee time (write on
66-67		(e.g., ru basketl	inning, jogg oall, cross c	ging, hockey, ± ountry skiing,	RT BEATS RAPI football, soccer, s , judo, roller skat ong-distance bicy	squash, ting,	_ Times per week
68-69		(e.g., fa volleyb	st walking, all, badmir	baseball, ten	EXHAUSTING) nis, easy bicyclin mming, alpine g)		_ Times per week
70-71		(e.g., yo	oga, archery		FFORT) 1 river bank, bow , easy walking)	ling — —	_ Times per week
	12.				k), in your leisu to work up a swe		en do you engage apidly)?
72		1 Ofter	n 2[	Sometimes	3 🗌 Ne	ever/rarely	
	13.	How has yo leukemia?	our level of	physical activ	ity changed sinc	e your diagnosi	s of lymphoma or
73		1 No cl	hange 2	Decreased	level of activity	3 Increased	d level of activity

14. 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
I have lack of energy	1	2	3	4	5
I have nausea	_	2	3	4	5
Because of my physical condition, I have trouble meeting the needs of my family	1	2	3	4	5
I have pain	1	2	3	4	5
I am bothered by side effects of treatment	1	2	3	4	5
I feel ill	1	2	3	4	5
I am forced to spend time in bed	1	2	3	4	5
SOCIAL/FAMILY WELL-BEING					
I feel close to my friends	1	2	3	4	5
I get emotional support from my family	1	2	3	4	5
I get support from my friends.	1	2	3	4	5
My family has accepted my illness	1	2	3	4	5
I am satisfied with family communication about my illness	1	2	3	4	5
I feel close to my partner (or the person who is my main support)	1	2	3	4	5
Regardless of your current level of sexual activity, p question. If you prefer not to answer it, please chec the emotional well-being section below.				ntinue Quite	with Very much
□ ☐ I prefer not to answer it.					
I am satisfied with my sex life	1	2	3	4	5
EMOTIONAL WELL-BEING					
I feel sad	1	2	3	4	5
I am satisfied with how I am coping with my illness.	1	2	3	4	5
I am losing hope in the fight against my illness		2	3	4	5
			Continu	ied nex	t page

		Not at all	A little bit	Somewhat	Quite a bit	Very much
92	I feel nervous.	1	2	3	4	5
93	I worry about dying	1	2	3	4	5
94	I worry that my condition will get worse	1	2	3	4	5
	<b>FUNCTIONAL WELL-BEING</b>					
95	I am able to work (include work at home)	1	2	3	4	5
96	My work (include work at home) is fulfilling	1	2	3	4	5
97	I am able to enjoy life	1	2	3	4	5
98	I have accepted my illness.	1	2	3	4	5
99	I am sleeping well.	1	2	3	4	5
100	I am enjoying the things I usually do for fun	1	2	3	4	5
101	I am content with the quality of my life right now.	1	2	3	4	5
	ADDITIONAL CONCERNS					
102	I feel fatigued.	1	2	3	4	5
103	I feel weak all over	1	2	3	4	5
104	I feel listless ("washed out").	1	2	3	4	5
105	I feel tired	1	2	3	4	5
106	I have trouble <u>starting</u> things because I am tired	1	2	3	4	5
107	I have trouble <u>finishing</u> things because I am tired.	1	2	3	4	5
108	I have energy	1	2	3	4	5
109	I am able to do my usual activities	1	2	3	4	5
110	I need to sleep during the day	1	2	3	4	5
111	I am too tired to eat	1	2	3	4	5
112	I need help doing my usual activities.	1	2	3	4	5
113	I am frustrated by being too tired to do the things I want to do	1	2	3	4	5
114	I have to limit my social activity because I am tired	1	2	3	4	5

	15.	Please check the number (0 - 10) that best descriweek, including today. How would you descri		ur feelings	<u>during the</u>	<u>e past</u>
		Your overall quality of life?				
115-116		0 1 2 3 4 5 6 As bad as it can be	7	8 9	10 As good a it can be	
		Your overall spiritual well-being?				
117-118		0 1 2 3 4 5 6 As bad as it can be	7	8 9	10 As good a it can be	
	16.	How important do you think the following health behaviors are to your health? (Check one box per line.)	Not at all	A little important	Somewhat important	Very important
119		Exercise	1	2	3	4
120		Nutrition	1	2	3	4
121		Weight	1	2	3	4
122		Alcohol use? 0 🗌 I do not drink	1	2	3	4
123		Tobacco use?0 I do not use tobacco	1	2	3	4

		ol is equal to one can of beer, one glass of wine, or one shot of liquor, e.g., dy, or gin.)
124	1 🗌 No	$2 \bigvee_{\mathbf{V}} \mathbf{Yes}$
		On average, how many drinks of alcohol do you usually have?
125		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?
126		1   No change   2   Decreased use   3   Increased use
	YOU	IR RISK AND CONCERNS ABOUT LYMPHOMA OR LEUKEMIA
127	background,	th lymphoma or leukemia survivors of your same age, sex, and ethnic what do you think your chances are of getting leukemia or lymphoma cometime in your life?
	$1 \square$ I have a	a much higher chance
	2 🗌 I have a	a little higher chance
	3 🗌 I have a	about the same chance
	4 🗌 I have a	a little lower chance
	5 🗌 I have a	a much lower chance
128	19. How likely do	o you think it is that you will get lymphoma or leukemia cancer again?
	1 🗌 Very lil	<i>kely</i>
	·	hat likely
		hat unlikely
	4 🗌 Very ui	
	·	no feeling or opinion on my chances of getting lymphoma or leukemia

	20. Cancer patients sometimes feel that having can lives, as well as causes problems. Indicate how following statements.					
		Not at all	A little	Moderately	Quite a bit	Extremely
	Having had lymphoma or leukemia					
129	has led me to be more accepting of things	1	2	3	4	5
130	has taught me how to adjust to things I cannot change.	1	2	3	4	5
131	has helped me take things as they come	1	2	3	4	5
132	has brought my family closer together	1	2	3	4	5
133	has made me more sensitive to family issues.	1	2	3	4	5
134	has taught me that everyone has a purpose in life	1	2	3	4	5
135	has shown me that all people need to be loved.	1	2	3	4	5
136	has made me realize the importance of planning for my family's future	1	2	3	4	5
137	has made me more aware and concerned for the future of all human beings	1	2	3	4	5
138	has taught me to be patient	1	2	3	4	5
139	has led me to deal better with stress and problems	1	2	3	4	5
140	has led me to meet people who have become some of my best friends	1	2	3	4	5
141	has contributed to my overall emotional and spiritual growth	1	2	3	4	5
142	has helped me become more aware of the love and support available from other people	1	2	3	4	5
143	has helped me realize who my real friends are	1	2	3	4	5
144	has helped me become more focused on priorities, with a deeper sense of purpose in life	1	2	3	4	5
145	has helped me become a stronger person, more able to cope effectively with future life challenges	1	2	3	4	5

21. 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
146	a. I feel calm	1	2	3	4
147	b. I feel secure	1	2	3	4
148	c. I am tense	1	2	3	4
149	d. I feel strained	1	2	3	4
150	e. I feel at ease	1	2	3	4
151	f. I feel upset	1	2	3	4
152	g. I am presently worrying over possible misfortunes	1	2	3	4
153	h. I feel satisfied	1	2	3	4
154	i. I feel frightened	1	2	3	4
155	j. I feel comfortable	1	2	3	4
156	k. I feel self-confident	1	2	3	4
157	l. I feel nervous	1	2	3	4
158	m. I am jittery	1	2	3	4
159	n. I feel indecisive	1	2	3	4
160	o. I am relaxed	1	2	3	4
161	p. I feel content	1	2	3	4
162	q. I am worried	1	2	3	4
163	r. I feel confused	1	2	3	4
164	s. I feel steady	1	2	3	4
165	t. I feel pleasant	1	2	3	4

22. 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
166	a.	I feel pleasant	1	2	3	4
167	b.	I feel nervous and restless	1	2	3	4
168	c.	I feel satisfied with myself	1	2	3	4
169	d.	I wish I could be as happy as others seem to be	1	2	3	4
170	e.	I feel like a failure	1	2	3	4
171	f.	I feel rested	1	2	3	4
172	g.	I am "calm, cool, and collected"	1	2	3	4
173	h.	I feel that difficulties are piling up so that I cannot overcome them	1	2	3	4
174	i.	I worry too much over something that really doesn't matter	1	2	3	4
175	j.	I am happy	1	2	3	4
176	k.	I have disturbing thoughts	1	2	3	4
177	1.	I lack self-confidence	1	2	3	4
178	m	I feel secure	1	2	3	4
179	n.	I make decisions easily	1	2	3	4
180	0.	I feel inadequate	1	2	3	4
181	p.	I am content	1	2	3	4
182	q.	Some unimportant thought runs through my mind and bothers me	1	2	3	4
183	r.	I take disappointments so keenly that I can't put them out of my mind	1	2	3	4
184	s.	I am a steady person	1	2	3	4
185	t.	I get in a state of tension or turmoil as I think over my recent concerns and interests	1	2	3	4

	Thank you for taking the time to	participate in this survey!
Questi	ion 12: © US English 1987, 1997, David Cella, Ph.D., Fact-G	(Version 4).
	ion 19: © Godin, G. and Shephard, R. J., A Simple Method l. Spt. Sci. 10:3 141-146, 1985.	to Assess Exercise Behavior in the Community
	ions 21 and 22: ©Marcus, B. H., Rossi, J. S., Selby, V. C., Ni ses of exercise adoption and maintenance in a worksite sam	

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