1-12 **Site ID Number:** __ __ __ __ __ __ __ __ __ __ __ __

13-20 **LEO ID Number:** __ __ __ __ __ __ __ __

21-28 **Date of Birth:** __ __/__ __/__ __ __ __
Month Day Year

INSTRUCTIONS: PLEASE CHECK THE APPROPRIATE BOX OR FILL IN THE BLANK AS INDICATED.

29-36 **1. Today's Date:** __ __/__ __/__ __ __ __
Month Day Year

HEALTH BEHAVIORS

2. During a typical 7-day period (a week), how many times, on the average, do you do the following kinds of exercise for <u>more than 15 minutes</u> during your free time?
(Please write the appropriate number on each line.)

37-38 **STRENUOUS EXERCISE (HEART BEATS RAPIDLY)** __ __ Times per week
(eg, running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming, vigorous long-distance bicycling)

39-40 **MODERATE EXERCISE (NOT EXHAUSTING):** __ __ Times per week
(eg, fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing, popular and folk dancing)

41-42 **MILD EXERCISE (MINIMAL EFFORT):** __ __ Times per week
(eg, yoga, archery, fishing from river bank, bowling, horseshoeing, golf without using a cart, snowmobiling, easy walking)

3. In the past 12 months and excluding any recent changes, on average, how many hours a week did you spend in the following physical activities?

	Never	Half-hour to 1 hour	2 to 3 hours	4 to 6 hours	7 to 10 hours	11 to 20 hours	21 to 30 hours	31 or more hours
43 **Strenuous recreational activities** (running, jogging, biking, tennis, swimming, aerobics, weights, etc.)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
44 **Strenuous work** (moving heavy furniture, unloading trucks, construction work, etc.)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
45 **Moderate recreational activities** (brisk walking, golfing, gardening, dancing softball, etc.)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐
46 **Moderate work** (housework, yard work, restaurant work, sales work, etc.)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐	7 ☐

4. In the past 12 months and excluding any recent changes, on average, how many hours a week did you spend in the following sitting activities?

	Never	Less than 1 hour	1 to 2 hours	3 to 4 hours	5 to 6 hours	7 to 10 hours	11 hours or more
47 **Sitting in a car, bus, or train**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
48 **Sitting at work**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
49 **Watching TV**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
50 **Sitting at meals**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐
51 **Other sitting activity** (reading, playing cards, sewing, using a computer)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐	6 ☐

52 **5. During a typical 7-day period (a week), how often do you engage in any regular activity long enough to work up a sweat (heart beats rapidly)?**

1 ☐ Often 2 ☐ Sometimes 3 ☐ Never/rarely

53 **6. Have you smoked at least 100 cigarettes in your entire life?**

1 ☐ No 2 ☐ Yes 3 ☐ Don't know/Unsure

54-55 **If yes, how old were you when you first started smoking cigarettes on a regular basis?**

__ __ Age

56 **On average, how many cigarettes did you or do you smoke per day?**

1 ☐ 1 to 10 cigarettes per day (up to ½ pack)
2 ☐ 11 to 20 cigarettes per day (½ to 1 pack)
3 ☐ 21 to 40 cigarettes per day (1 to 2 packs)
4 ☐ 41 or more cigarettes per day (2 packs or more)

57 **Do you currently smoke?**

1 ☐ No → **If no, at what age did you quit?** __ __ Age

58-59 2 ☐ Yes

60 **7. On average, how often did you have a drink containing alcohol <u>in the past 12 months</u>?**

0 ☐ Never → **Skip to page 4, question 8.**

61
1 ☐ Less than 1 each month
2 ☐ 1 to 3 each month
3 ☐ 1 to 2 each week
4 ☐ 3 to 6 each week
5 ☐ Daily

→ **How many drinks did you have on a typical day when you were drinking <u>in the last 12 months</u>?**

1 ☐ 0 to 2 drinks
2 ☐ 3 to 4 drinks
3 ☐ 5 to 6 drinks
4 ☐ 7 to 9 drinks
5 ☐ 10 or more drinks

62 **How often did you have 6 or more drinks on one occasion <u>in the past 12 months</u>?**

1 ☐ Never
2 ☐ Less than monthly
3 ☐ Monthly
4 ☐ Weekly
5 ☐ Daily or almost daily

Activities and Function

63 **8. In general, compared to other people your age, would you say that your health is:**

1 ☐ Excellent 2 ☐ Very good 3 ☐ Good 4 ☐ Fair 5 ☐ Poor

9. How much difficulty, on average, do you have with the following physical activities?

	No difficulty	A little difficulty	Some difficulty	A lot of difficulty	Unable to do
64 **Stooping, crouching, or kneeling**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
65 **Lifting or carrying objects as heavy as 10 pounds**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
66 **Reaching or extending arms above shoulder level**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
67 **Writing or handling and grasping small objects**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
68 **Walking a quarter of a mile**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
69 **Heavy housework, such as scrubbing floors or washing windows**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

10. Because of your health or a physical condition, do you have any difficulty:

70 **Shopping for personal items (like toilet items or medicines)?**

1 ☐ No

71 2 ☐ Yes → **Do you get help with shopping?** 1 ☐ No 2 ☐ Yes

72 3 ☐ Don't do → **Is this because of your health?** 1 ☐ No 2 ☐ Yes

73 **Managing money (like keeping track of expenses or paying bills)?**

1 ☐ No

74 2 ☐ Yes → **Do you get help with managing money?** 1 ☐ No 2 ☐ Yes

75 3 ☐ Don't do → **Is this because of your health?** 1 ☐ No 2 ☐ Yes

Continues next page...

Because of your health or a physical condition, do you have any difficulty:

76 **Walking across the room? (Use of a cane or walker is OK.)**

1 ☐ No

77 2 ☐ Yes → **Do you get help with walking?** . . . . . 1 ☐ No 2 ☐ Yes

78 3 ☐ Don't do → **Is this because of your health?** . . . . . 1 ☐ No 2 ☐ Yes

79 **Doing light housework (like washing dishes, straightening up, or light cleaning)?**

1 ☐ No

80 2 ☐ Yes → **Do you get help with housework?** . . . . . 1 ☐ No 2 ☐ Yes

81 3 ☐ Don't do → **Is this because of your health?** . . . . . 1 ☐ No 2 ☐ Yes

82 **Bathing or showering?**

1 ☐ No

83 2 ☐ Yes → **Do you get help with bathing?** . . . . . 1 ☐ No 2 ☐ Yes

84 3 ☐ Don't do → **Is this because of your health?** . . . . . 1 ☐ No 2 ☐ Yes

85 **11. Over the past month, I would generally rate my activity as:**

1 ☐ Normal with no limitations
2 ☐ Not my normal self, but able to be up and about with fairly normal activities
3 ☐ Not feeling up to most things, but in bed or chair less than half the day
4 ☐ Able to do little activity and spend most of the day in bed or chair
5 ☐ Pretty much bedridden, rarely out of bed

86 **12. Which of the following best describes you?**

1 ☐ Working full-time for pay (35 or more hours per week)
2 ☐ Working part-time for pay
3 ☐ Not working for pay at present

→ **Are you...** (Mark all that apply.)

87:90 1 ☐ A full-time homemaker 1 ☐ Disabled
88:91 1 ☐ A seasonal worker 1 ☐ Retired
89:92 1 ☐ In school 1 ☐ Other, specify: _____

13. In the past 7 days...

		Never	Rarely	Sometimes	Often	Always
93	I had to force myself to get up in the morning	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
94	I had trouble stopping my thoughts at bedtime	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
95	I had trouble sleeping because of bad dreams	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
96	I had trouble falling asleep	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
97	Pain woke me up	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
98	I avoided or cancelled activities with my friends because I was tired from having a bad night's sleep	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
99	I felt physically tense during the middle of the night or early morning hours	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

14. In the past 7 days...

		Never	Rarely (once)	Sometimes (2 or 3 times)	Often (about once a day)	Very often (several times a day)
100	My thinking has been slow	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
101	It has seemed like my brain was not working as well as usual	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
102	I have had to work harder than usual to keep track of what I was doing	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
103	I have had trouble shifting back and forth between different activities that require thinking	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

EMOTIONAL WELL-BEING

15. Please respond to each question or statement by marking one box per row.

In the past 7 days...

		Never	Rarely	Sometimes	Often	Always
104	I felt fearful	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
105	I found it hard to focus on anything other than my anxiety	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
106	My worries overwhelmed me	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
107	I felt uneasy.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
108	I felt nervous	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
109	I felt like I needed help for my anxiety	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
110	I felt anxious	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
111	I felt tense	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

16. Please respond to each question or statement by marking one box per row.

	In the past 7 days...	Never	Rarely	Sometimes	Often	Always
112	**I felt worthless**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
113	**I felt helpless**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
114	**I felt depressed**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
115	**I felt hopeless**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
116	**I felt like a failure**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
117	**I felt unhappy**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
118	**I felt that I had nothing to look forward to**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
119	**I felt that nothing could cheer me up**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

17. 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 DURING THE PAST SEVEN DAYS with respect to your lymphoma. How much were you distressed or bothered by these difficulties?

	During the past 7 days...	Not at all	A little bit	Moderately	Quite a bit	Extremely
120	**Any reminder brought back feelings about it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
121	**I had trouble staying asleep.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
122	**Other things kept making me think about it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
123	**I felt irritable and angry.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
124	**I avoided letting myself get upset when I thought about it or was reminded of it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
125	**I thought about it when I didn't mean to.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
126	**I felt as if it hadn't happened or wasn't real.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
127	**I stayed away from reminders of it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
128	**Pictures about it popped into my mind.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
129	**I was jumpy and easily startled.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
130	**I tried not to think about it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
131	**I was aware that I still had a lot of feelings about it, but I didn't deal with them.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
132	**My feelings about it were kind of numb.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
133	**I found myself acting or feeling like I was back at that time.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
134	**I had trouble falling asleep.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
135	**I have waves of strong feelings about it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

Continues next page...

During the past 7 days...

	Not at all	A little bit	Moderately	Quite a bit	Extremely
136 **I tried to remove it from my memory.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
137 **I had trouble concentrating.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
138 **Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
139 **I had dreams about it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
140 **I felt watched and on guard.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
141 **I tried not to talk about it.**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

18. Below is a list of statements that are related to your lymphoma and possible future concerns. Some questions may not apply to you. For example, if you are retired, you will not be able to answer the questions about your employment. Please make an "X" under "Never" in these cases.

	Never	Seldom	Sometimes	Often	Very often
142 **I become anxious if I think my disease may progress.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
143 **I am nervous prior to doctors' appointments or periodic examinations.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
144 **I am afraid of pain.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
145 **The thought that I might become less productive at my job disturbs me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
146 **When I am anxious, I have physical symptoms, eg, rapid heartbeat, stomach ache, nervousness.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
147 **The possibility of my children contracting my disease disturbs me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
148 **It disturbs me that I may have to rely on strangers for activities of daily living.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
149 **I am worried that at some point in time, because of my illness, I will no longer be able to pursue my hobbies.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
150 **I am afraid of severe medical treatments in the course of my illness.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
151 **I worry that my medication could damage my body.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
152 **I worry about what will become of my family if something should happen to me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
153 **The thought that I might not be able to work due to my illness disturbs me.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

19. In the past 2 years...

154 **have you taken prescription medication for depression?** (Mark ONE response only.)

- 1 ☐ Yes
- 2 ☐ No — I did not have depression
- 3 ☐ No — I had depression, but did not need medication
- 4 ☐ No — I needed medication for depression, but could not get it
- 5 ☐ No — A medical professional prescribed medication for depression, but I chose not to take it

155 **have you participated in individual counseling or psychotherapy for depression?** (Mark ONE response only.)

- 1 ☐ Yes
- 2 ☐ No — I did not have depression
- 3 ☐ No — I had depression, but did not need individual counseling/ psychotherapy
- 4 ☐ No — I needed individual counseling/psychotherapy for depression, but could not get it
- 5 ☐ No — A medical professional recommended individual counseling/ psychotherapy for depression, but I chose not to participate

156 **have you participated in group counseling or psychotherapy for depression?** (Mark ONE response only.)

- 1 ☐ Yes
- 2 ☐ No — I did not have depression
- 3 ☐ No — I had depression, but did not need group counseling/ psychotherapy
- 4 ☐ No — I needed group counseling/psychotherapy for depression, but could not get it
- 5 ☐ No — A medical professional recommended group counseling/ psychotherapy for depression, but I chose not to participate

157 **have you taken medication for anxiety?** (Mark ONE response only.)

- 1 ☐ Yes
- 2 ☐ No — I did not have anxiety
- 3 ☐ No — I had anxiety, but did not need medication
- 4 ☐ No — I needed medication for anxiety, but could not get it
- 5 ☐ No — A medical professional prescribed medication for anxiety, but I chose not to take it

Continues next page...

In the past 2 years...

158 **have you participated in individual counseling or psychotherapy for anxiety?**
(Mark ONE response only.)

- 1 ☐ Yes
- 2 ☐ No — I did not have anxiety
- 3 ☐ No — I had anxiety, but did not need individual counseling/ psychotherapy
- 4 ☐ No — I needed individual counseling/psychotherapy for anxiety, but could not get it
- 5 ☐ No — A medical professional recommended individual counseling/ psychotherapy for anxiety, but I chose not to participate

159 **have you participated in group counseling or psychotherapy for anxiety?**
(Mark ONE response only.)

- 1 ☐ Yes
- 2 ☐ No — I did not have anxiety
- 3 ☐ No — I had anxiety, but did not need group counseling/ psychotherapy
- 4 ☐ No — I needed group counseling/psychotherapy for anxiety, but could not get it
- 5 ☐ No — A medical professional recommended group counseling/ psychotherapy for anxiety, but I chose not to participate

SOCIAL SUPPORT

160 **20. Are you currently...**

- 1 ☐ Married
- 2 ☐ Living with someone in a marriage-like relationship
- 3 ☐ Separated
- 4 ☐ Divorced
- 5 ☐ Widowed
- 6 ☐ Never been married

21. How much of the time...

		None of the time	A little of the time	Some of the time	Most of the time	All of the time
161	**is there someone available to you whom you can count on to listen to you when you need to talk?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
162	**is there someone available to you to give you good advice about a problem?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
163	**is there someone available to you who shows you love and affection?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
164	**is there someone available to help with daily chores?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
165	**can you count on anyone to provide you emotional support (talking over problems or helping you make a difficult decision)?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
166	**do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in?**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

LIVING SITUATIONS

167 **22. Which of the following best describes your current living situation?**
(Mark ONE response only.)

1 ☐ Live alone in my own home (house, apartment, condo, trailer, etc.); may have a pet
2 ☐ Live in a household with other people
3 ☐ Live in a residential facility where meals and household help are routinely provided by paid staff (or could be if requested)
4 ☐ Live in a facility such as a nursing home that provides meals and 24-hour nursing care
5 ☐ Temporarily staying with a relative or friend
6 ☐ Temporarily staying in a shelter or homeless

168 **23. Has your living situation changed since your lymphoma diagnosis?**

1 ☐ No 2 ☐ Yes

Side Effects of Treatment

169 **24. Cancer drug therapy involves taking medicine to treat cancer. Examples of cancer drug therapy include chemotherapy and immunotherapy. Have you ever received cancer drug therapy or radiation treatment for lymphoma?**

1 ☐ No 2 ☐ Yes 3 ☐ Don't know/Unsure

As individuals go through treatment for their lymphoma, they sometimes experience different symptoms and side effects. Some symptoms and side effects may persist even after treatment has stopped.

170 **When was the last time you received treatment for lymphoma?**

1 ☐ Less than 3 months ago
2 ☐ At least 3 months but less than 6 months ago
3 ☐ At least 6 months but less than 12 months ago
4 ☐ At least 12 months ago

Thinking about your overall experience with treatment for lymphoma, how would you rate the severity of the side effects?

171-172 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐

No side effects — Worst side effects imaginable

173 **Has a doctor or other health professional ever <u>reduced</u> the dose of a cancer drug you were receiving because of side effects?**

1 ☐ No 2 ☐ Yes 3 ☐ Don't know

174 **Has a doctor or other health professional ever <u>stopped</u> the dose of a cancer drug you were receiving because of side effects?**

1 ☐ No 2 ☐ Yes 3 ☐ Don't know

ROUTINE HEALTH CARE

175 **25. <u>During the past 2 years</u>, how many times did you see a health care provider?**

1 ☐ None → **Skip to page 14, question 29.**
2 ☐ 1 to 2 times
3 ☐ 3 to 4 times
4 ☐ 5 to 6 times
5 ☐ 7 to 10 times
6 ☐ 11 to 20 times
7 ☐ More than 20 times

26. Did you discuss any of the following issues with a health care provider during any of these visits?

		No	Yes
176	**Heart disease**	1 ☐	2 ☐
177	**Osteoporosis (weak or brittle bones)**	1 ☐	2 ☐
178	**Risk of developing cancer (breast, skin, other)**	1 ☐	2 ☐
179	**Hepatitis C**	1 ☐	2 ☐
180	**Dental problems**	1 ☐	2 ☐
181	**Fertility issues**	1 ☐	2 ☐
182	**Mental health**	1 ☐	2 ☐
183	**Other issues related to your history of lymphoma**	1 ☐	2 ☐

184 **27. As you know, you were asked to participate in this study because you were once diagnosed with lymphoma. How many of the visits to a health care provider indicated in question 29 (<u>during the 2-year period</u>) were related to lymphoma?**

1 ☐ None
2 ☐ 1 to 2 visits
3 ☐ 3 to 4 visits
4 ☐ 5 to 6 visits
5 ☐ 7 to 10 visits
6 ☐ 11 to 20 visits
7 ☐ More than 20 visits

185 **28. <u>In the past 2 years</u>, did you go to a health care provider for a "routine medical check-up"?**

1 ☐ No 2 ☐ Yes

186 **29. For your non-emergency care, do you have a primary care provider or place that you go for health care?**

1 ☐ No 2 ☐ Yes

187 **30. When was the last time you had a blood or DNA stool test using a home kit, such as Cologuard or fecal occult blood test?**

1 ☐ Never
2 ☐ Less than 1 year ago
3 ☐ 1 to 2 years ago
4 ☐ More than 2 years but less than 5 years ago
5 ☐ 5 or more years ago
6 ☐ Don't know

188 **31. Sigmoidoscopy and colonoscopy are exams in which a tube is inserted in the rectum to view the colon for signs of cancer or other health problems. When was the last time you had either of these exams?**

1 ☐ Never
2 ☐ Less than 1 year ago
3 ☐ 1 to 2 years ago
4 ☐ More than 2 years but less than 5 years ago
5 ☐ 5 or more years ago
6 ☐ Don't know

FEMALES ONLY Section; MALES proceed to page 15, question 34.

189 **32. A mammogram is an x-ray of each breast to look for breast cancer. When was the last time you had a mammogram?**

1 ☐ Never
2 ☐ Less than 1 year ago
3 ☐ 1 to 2 years ago
4 ☐ More than 2 years, but less than 5 years ago
5 ☐ 5 or more years ago
6 ☐ Don't know

190 **33. Magnetic resonance imaging [MRI] is a procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. Most MRI machines are large, tube-shaped magnets. When was the last time you had a breast MRI?**

1 ☐ Never
2 ☐ Less than 1 year ago
3 ☐ 1 to 2 years ago
4 ☐ More than 2 years, but less than 5 years ago
5 ☐ 5 or more years ago
6 ☐ Don't know

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

191 **diabetes that can be controlled with a diet?**

1 ☐ No
2 ☐ Yes, and the condition is still present
192-193 3 ☐ Yes, and the condition is no longer present
4 ☐ Not sure

→ **If yes, age at first occurrence:** __ __ Age

194 **diabetes controlled with pills or tablets?**

1 ☐ No
2 ☐ Yes, and the condition is still present
195-196 3 ☐ Yes, and the condition is no longer present
4 ☐ Not sure

→ **If yes, age at first occurrence:** __ __ Age

197 **diabetes controlled with insulin?**

1 ☐ No
2 ☐ Yes, and the condition is still present
198-199 3 ☐ Yes, and the condition is no longer present
4 ☐ Not sure

→ **If yes, age at first occurrence:** __ __ Age

200 **hypertension (high blood pressure) requiring prescription medication?**

1 ☐ No
2 ☐ Yes, and the condition is still present
201-202 3 ☐ Yes, and the condition is no longer present
4 ☐ Not sure

→ **If yes, age at first occurrence:** __ __ Age

203 **high cholesterol (or triglyceride) requiring prescription medication?**

1 ☐ No
2 ☐ Yes, and the condition is still present
204-205 3 ☐ Yes, and the condition is no longer present
4 ☐ Not sure

→ **If yes, age at first occurrence:** __ __ Age

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

1 ☐ No 2 ☐ Yes 3 ☐ Not sure

207 **36. When was the last time that you had an echocardiogram (ultrasound of the heart to look at the heart muscle and heart valves) or Multigated Acquisition Scan (MUGA)?**

1 ☐ Never
2 ☐ Less than 1 year ago
3 ☐ 1 to 2 years ago
4 ☐ More than 2 years but less than 5 years ago
5 ☐ 5 or more years ago
6 ☐ Don't know

208 **37. When was the last time that you had a stress test of the heart (to look for coronary artery disease or blockages of the arteries, usually done while exercising on a treadmill)?**

1 ☐ Never
2 ☐ Less than 1 year ago
3 ☐ 1 to 2 years ago
4 ☐ More than 2 years but less than 5 years ago
5 ☐ 5 or more years ago
6 ☐ Don't know

38. Have you ever had...

	No	Yes	Not sure
209 **an influenza vaccination ("flu shot" usually given in the fall to prevent getting the flu)?**	1 ☐	2 ☐	3 ☐
210 **a pneumonia vaccination?**	1 ☐	2 ☐	3 ☐
211 **a shingles vaccine?**	1 ☐	2 ☐	3 ☐
212 **the HPV vaccine (Gardasil)?**	1 ☐	2 ☐	3 ☐

213-218

If yes, when did you have your most recent flu shot?

__ __ /__ __ __ __
Month Year

FOLLOW-UP SCANS

219 **39. A surveillance CT or PET scan is done at a time when patients are not on treatment and not experiencing any symptoms of lymphoma. How many surveillance CT or PET scans have you had <u>in the last 2 years</u>?**

1 ☐ 0
2 ☐ 1
3 ☐ 2
4 ☐ 3 to 4
5 ☐ 5 to 9
6 ☐ 10 or more

220 **40. A "false positive scan" is a scan that indicates a person has lymphoma when the person actually does not have lymphoma. The scan often times leads to additional testing, such as a biopsy. <u>Since your diagnosis of lymphoma</u>, have you ever had a false-positive scan?**

1 ☐ No
2 ☐ Yes

41. Imaging scans (CT scans, PET scans) have risks and benefits associated with their use. Please indicate how much you agree or disagree with each of the following statements by marking the most appropriate answer.

		Strongly agree	Agree	Neutral	Disagree	Strongly disagree
221	**Scans provide reassurance that the lymphoma is under control.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
222	**Scans are important so that we catch lymphoma early when it is more treatable**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
223	**I am worried about an incorrect or unclear result from a scan leading to unnecessary testing.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
224	**Scans are inconvenient**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
225	**I am concerned about my out-of-pocket costs for scans.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
226	**I am concerned about being exposed to radiation during a scan.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
227	**I am concerned about the intravenous contrast that I receive during a scan**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
228	**Before doing a scan, I feel anxious or worried about what it will show.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
229	**I trust my doctor's recommendations about how often to do scans**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Advanced Health Care Planning

An advanced health care directive (or living will) is a legal statement of your choices for future health care if you are unable to speak yourself. It can give instructions and may name someone to make choices for you.

230 **42. Do you have an advanced health care directive/living will?**

1 ☐ No 2 ☐ Yes 3 ☐ Not sure

231 **If yes, did you discuss this directive with your lymphoma doctor?**

1 ☐ No 2 ☐ Yes

232 **Did you discuss this directive with your primary health care provider?**

1 ☐ No 2 ☐ Yes

CANCER INFORMATION

233 **43. Have you ever looked for information about cancer from any source?**

1 ☐ No → **Skip to question 44 below.**

2 ☐ Yes

Based on the results of your most recent search for information about cancer, how much do you agree or disagree with each of the following statements?

	Strongly agree	Somewhat agree	Somewhat disagree	Strongly disagree
234 **It took a lot of effort to get the information you needed.**	1 ☐	2 ☐	3 ☐	4 ☐
235 **You felt frustrated during your search for the information..**	1 ☐	2 ☐	3 ☐	4 ☐
236 **You were concerned about the quality of the information..**	1 ☐	2 ☐	3 ☐	4 ☐
237 **The information you found was hard to understand.**	1 ☐	2 ☐	3 ☐	4 ☐

238 **44. Overall, how confident are you that you could get advice or information about cancer if you needed it?**

1 ☐ Completely confident
2 ☐ Very confident
3 ☐ Somewhat confident
4 ☐ A little confident
5 ☐ Not confident at all

45. In general, how much would you trust information about cancer from each of the following?

	Not at all	A little	Some	A lot
239 **A doctor**	1 ☐	2 ☐	3 ☐	4 ☐
240 **Family or friends**	1 ☐	2 ☐	3 ☐	4 ☐
241 **Newspapers or magazines**	1 ☐	2 ☐	3 ☐	4 ☐
242 **Radio**	1 ☐	2 ☐	3 ☐	4 ☐
243 **Internet**	1 ☐	2 ☐	3 ☐	4 ☐
244 **Television**	1 ☐	2 ☐	3 ☐	4 ☐
245 **Government health agencies**	1 ☐	2 ☐	3 ☐	4 ☐
246 **Charitable organizations**	1 ☐	2 ☐	3 ☐	4 ☐
247 **Religious organizations and leaders**	1 ☐	2 ☐	3 ☐	4 ☐

USING YOUR MEDICAL RECORD

248-249 **46. Imagine that you had a strong need to get information about cancer. Where would you go first?** (Mark ONE response only.)

1 ☐ Books
2 ☐ Brochures, pamphlets, etc.
3 ☐ Cancer organization
4 ☐ Family
5 ☐ Friend/co-worker
6 ☐ Doctor or health care provider
7 ☐ Internet
8 ☐ Library
9 ☐ Magazines
10 ☐ Newspapers
11 ☐ Telephone information number
12 ☐ Complementary, alternative, or unconventional practitioner
13 ☐ Other

Next, we are going to ask you some questions about patient portals and medical records. A patient portal is a secure online website that gives patients access to their medical records from anywhere with an Internet connection. Medical records are defined as medical history, such as laboratory test results, clinical notes, and current list of medications.

250 **47. Have you ever been offered online access to your medical records through a patient portal by your health care provider or health insurer?**

1 ☐ No → **Skip to page 22, question 60.**

2 ☐ Yes → **Skip to page 20, question 48.**

3 ☐ Don't know → **Skip to page 22, question 60.**

251 **48. How many times did you use your patient portal <u>in the last 12 months</u>?**

1 ☐ 0

2 ☐ 1 to 2 times
3 ☐ 3 to 5 times
4 ☐ 6 to 9 times
5 ☐ 10 or more times

→ **Skip to question 49 below.**

Why have you not accessed your medical records online? Is it because...

		No	Yes
252	you prefer to speak to your health care provider directly?	1 ☐	2 ☐
253	you do not have a way to access the website?	1 ☐	2 ☐
254	you did not have a need to use your online medical record?	1 ☐	2 ☐
255	you were concerned about the privacy or security of the website that had your medical records?	1 ☐	2 ☐
256	you don't have an online medical record?	1 ☐	2 ☐
257	other?	1 ☐	2 ☐

Skip to page 22, question 60.

49. <u>In the past 12 months</u>, have you used your online medical records to...

		No	Yes
258	request refill of medications?	1 ☐	2 ☐
259	fill out forms or paperwork related to your health care?	1 ☐	2 ☐
260	request correction of inaccurate information?	1 ☐	2 ☐
261	securely message health care provider and staff (for example, e-mail)?	1 ☐	2 ☐
262	download your health information to your computer or mobile device, such as a cell phone or tablet?	1 ☐	2 ☐
263	add health information to share with your health care provider, such as health concerns, symptoms, and side effects?	1 ☐	2 ☐
264	help you make a decision about how to treat an illness or condition?	1 ☐	2 ☐

265 **50. <u>During the last 12 months</u>, have you viewed results of a medical test, such as a blood test or imaging test, using your patient portal?**

1 ☐ No → **Skip to page 22, question 60.**

2 ☐ Yes → **Skip to page 21, question 51.**

266 **51. How often did you view results using your patient portal <u>during the last 12 months?</u>**

1 ☐ 1 time 2 ☐ 2 to 5 times 3 ☐ 6 to 10 times 4 ☐ More than 10 times

267 **52. Were any of your tests done <u>during the last 12 months</u> to check on your lymphoma?**

1 ☐ No → **Skip to page 22, question 60.**

2 ☐ Yes → **Skip to question 53 below.**

3 ☐ Don't know → **Skip to page 22, question 60.**

268 **53. <u>In the last 12 months</u>, were the result of any of your tests done to check on your lymphoma <u>abnormal</u>?**

1 ☐ No 2 ☐ Yes 3 ☐ Don't know

269 **54. When was the last time you viewed test results using your patient portal?**

1 ☐ Within the last month
2 ☐ 2 to 3 months ago
3 ☐ 4 to 6 months ago
4 ☐ More than 6 months ago
5 ☐ Don't remember

270 **55. Think of the most recent time you received an abnormal test result. Which of the following best describes how you first learned of the abnormal result?**
(Mark ONE response only.)

1 ☐ My cancer care team called me with the results
2 ☐ My cancer care team sent me a message through the patient portal
3 ☐ My cancer care team told me in person at a scheduled visit
4 ☐ I saw the result in my patient portal before the cancer care team communicated with me

271 **56. When you viewed your most recent test results using the patient portal, did you understand the results?**

1 ☐ No 2 ☐ Yes

272-279 **57. How did you feel when you saw the results?** (Mark all that apply.)

1 ☐ Confused	1 ☐ Curious	1 ☐ Calm	1 ☐ Sad
1 ☐ Frustrated	1 ☐ Relieved	1 ☐ Worried	1 ☐ Surprised

280 **58. The most recent time you viewed a test result, how helpful did you find the information?**

1 ☐ Not at all helpful
2 ☐ Somewhat helpful
3 ☐ Helpful
4 ☐ Very helpful

59. Which of the following actions did you take after the most recent time you viewed a test result? (Mark all that apply.)

281 1 ☐ Called my health care provider
282 1 ☐ Looked up information online
283 1 ☐ Looked up information from another source
284 1 ☐ Sent an email to my health care provider
285 1 ☐ Made an appointment to see my health care provider
286 1 ☐ Waited for my scheduled appointment with my health care provider
287 1 ☐ Talked to family or friends
288 1 ☐ Did nothing

SURVIVORSHIP CARE

A Survivorship Care Plan is a written document summarizing the lymphoma treatment you received (chemotherapy drugs, radiation, etc.), recommendations for follow-up care (future testing and appointments), and potential future or long-term side effects of the cancer treatment you received.

289 **60. Have you ever been given a written Survivorship Care Plan?**

1 ☐ No → **Skip to page 24, question 66.**
2 ☐ Yes → **Skip to page 23, question 61.**
3 ☐ I don't remember → **Skip to page 24, question 66.**

290 **651 If yes, how did you receive the Survivorship Care Plan?**

1 ☐ In-person visit with doctor
2 ☐ In-person visit with another member of the care team (eg, physician assistant, nurse practitioner, nurse)
3 ☐ In the mail
4 ☐ Electronic delivery (email or online patient portal)

291 **62. When did you receive the Survivorship Care Plan?**

1 ☐ During cancer treatment
2 ☐ Within 3 months of completing cancer treatment
3 ☐ Within 4 to 6 months of completing cancer treatment
4 ☐ Within 7 to 12 months of completing cancer treatment
5 ☐ Between 1 to 2 years after completing cancer treatment
6 ☐ 3+ years after completing after cancer treatment

292 **63. How would you rate the timing of when you received the Survivorship Care Plan?**

1 ☐ Too soon
2 ☐ Just right
3 ☐ Too late

293 **64. Did you discuss the Survivorship Care Plan with your primary care provider?**

1 ☐ No 2 ☐ Yes 3 ☐ Not sure

294 **If yes, was the Survivorship Care Plan helpful in increasing communication between you and your primary care provider about monitoring your health after lymphoma treatment?**

1 ☐ No 2 ☐ Yes 3 ☐ Not sure

295 **65. Have you ever had an appointment in a clinic dedicated to cancer survivorship care?**

1 ☐ No 2 ☐ Yes 3 ☐ Not sure

FERTILITY

MALES ONLY Section, FEMALES proceed to page 25, question 67.

296 **66. Have you ever had any procedures performed to prevent you from fathering a a child, such as a vasectomy?** (Mark ONE response only.)

1 ☐ Yes, before your diagnosis of lymphoma

2 ☐ Yes, after your diagnosis of lymphoma

3 ☐ No

4 ☐ Not sure

5 ☐ Choose not to answer

→ **Have you fathered a child after treatment without the use of your sperm collected prior to treatment for lymphoma?**

297 1 ☐ No 2 ☐ Yes

If yes, how many children have you fathered after treatment for lymphoma?

298-299 __ __ Number

What is the birth year of the first child born after your treatment for lymphoma?

300-303 __ __ __ __ Year

Since receiving treatment for lymphoma, have you attempted to father a child but been unable or been told by a physician that you are unable to father a child?

304 1 ☐ No 2 ☐ Yes

MALES: Thank you for completing the survey!

FEMALES ONLY Section

305 **67. Have you ever had any procedures performed to prevent you from conceiving a child such as a hysterectomy (removal of uterus), oophorectomy (removal of ovaries), or tubal ligation (tubes tied)?**

1 ☐ Yes, before your diagnosis of lymphoma → **Skip to page 26, question 68.**

2 ☐ Yes, after your diagnosis of lymphoma

3 ☐ No

4 ☐ Not sure

5 ☐ Choose not to answer

Since receiving treatment for lymphoma, have you become pregnant without the use of your eggs collected prior to the treatment for lymphoma?

306 1 ☐ No 2 ☐ Yes

If yes, how many times have you become pregnant since receiving treatment for lymphoma?

307-308 __ __ Number

What is the year of your first pregnancy achieved after your treatment for lymphoma?

309-312 __ __ __ __ Year

Since your treatment for lymphoma, have you attempted to become pregnant but been unable or have you been told by a physician that you are unable to become pregnant?

313 1 ☐ No 2 ☐ Yes

314 **68. Have your menstrual periods stopped permanently?**

1 ☐ No 2 ☐ Yes 3 ☐ Not sure

If yes, at what age did you have your last menstrual period (if unsure, please estimate)?

315-316 __ __ Age

317 **For what reason did your periods stop?**

1 ☐ Natural menopause
318 2 ☐ Due to surgery → **If yes, please specify:**
3 ☐ Radiation
4 ☐ Chemotherapy
5 ☐ Other, please specify:

_____

1 ☐ Removal of both ovaries and uterus
2 ☐ Removal of one ovary and uterus
3 ☐ Removal of uterus only
4 ☐ Removal of both ovaries only
5 ☐ Unsure

FEMALES: Thank you for completing the survey!

Question 2 and 3: Godin G & Shephard F J. A Simple Method to Assess Exercise Behavior in the Community. *Can J. Appl. Spt. Sci.* 10:3 141-146, 1985. Used with permission.

Questions 12 through 14: Vulnerable Elders Survey (VES-13): A Tool for Identifying Vulnerable Elders in the Community. © 2001. Saliba A, Elliott M, Rubensten L A, Solomon D H, et al. *J Amer Geriatric Soc* 2001; 49:1691-9.

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Question 22: Mehnert A, Herschbach P, Berg P, Henrich G, Koch U. Fear of cancer progression and cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncolog*y 18: 1273-1280 (2009). Copyright © 2009 John Wiley & Sons, Ltd. Used with permission.

Question 25: Social Support Measure Enhancing recovery in coronary heard disease patients (ENRICHD): study design and methods. The ENRICHD investigators. *Am Heart J.* 2000:139:1-9. {PubMed]

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If your envelope is missing, please mail your survey to:

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