ID:___________________________

# Experience of Care and Health Outcomes of Survivors of Non-Hodgkin's Lymphoma (ECHOS-NHL) Study

Conducted by:

And

## PLEASE READ THESE INSTRUCTIONS CAREFULLY

### GENERAL INSTRUCTIONS

- Answer each question as best you can. Please do not leave any question blank.
- Put an x or a ✓ in the box next to your answer and erase or cross out completely if you make any changes.

  **Example:** 1☑ Yes : 1☒ Yes

- Please follow any instructions that direct you to the next question**.**

  **Example:** 2☑ No ➔ **GO TO A11**

- For a question with a line after it, please write the specific information on the line provided.

  **Example:** 1☑ Other, please specify: *cardiologist*

- Mark only one response for each question, unless directed to **"MARK ALL THAT APPLY."** For those questions, please mark every response choice that applies to your situation.
- As far as possible, please try to answer all the questions in one sitting and, where asked, please record the time you started and ended this survey.

# A. Cancer Treatment History

A1. Please record the time you started answering this survey.

Time started: ______________ 1☐ AM
2☐ PM

A2. Today's date:

______________ ______________ ______________
MONTH DAY YEAR

A3. What is your date of birth?

______________ ______________ ______________
MONTH DAY YEAR

A4. Are you male or female?

1☐ Male
2☐ Female

## Your cancer history

A5. When was the **first time** that a doctor or other health care professional told you that you had non-Hodgkin's lymphoma? Non-Hodgkin's lymphoma is a type of cancer of the white blood cells and is also called NHL or simply lymphoma.

______________ ______________
MONTH YEAR

A6. Did you **ever** receive any surgery as part of your cancer treatment? Please DO NOT consider any biopsy you had or insertion of medication ports such as a Hickman catheter to be surgery.

1☐ Yes
2☐ No → **GO TO A7, PAGE 4**

A6.a. On what part of your body did you have surgery?

Please specify: ______________________________________________

A6.b. When was the **last time** you had surgery as part of your cancer treatment?

______________ ______________
MONTH YEAR

A7. Did you **ever** receive any chemotherapy as part of your cancer treatment? Please include both IV (that is, intravenous) and oral forms of chemotherapy.

1☐ Yes
2☐ No ——→ **GO TO A8**

A7.a. When was the **last time** you received chemotherapy?

______________ MONTH     ______________ YEAR

A8. Did you **ever** receive any radiation therapy as part of your cancer treatment?

1☐ Yes
2☐ No ——→ **GO TO A9**

A8.a. What parts of your body were treated with radiation therapy?
**MARK ALL THAT APPLY**

1☐ Head, neck, or brain
2☐ Chest, back, or stomach
3☐ Pelvic area (below the navel and above the thighs)
4☐ Received total body radiation therapy
91☐ Other, please specify: ______________________________
99☐ Don't know

A8.b. When was the **last time** you received radiation therapy?

______________ MONTH     ______________ YEAR

A9. Did you **ever** receive a bone marrow or stem cell transplant as part of your cancer treatment? Please DO NOT consider a bone marrow biopsy to be a bone marrow transplant.

1☐ Yes
2☐ No ——→ **GO TO A10, PAGE 5**

A9.a. How many bone marrow or stem cell transplants have you had so far? _________

A9.b. When was the **last time** you received a bone marrow or stem cell transplant?

______________ MONTH     ______________ YEAR

A9.c. Who was the donor of the bone marrow or stem cells you received as part of the transplant(s)?
**MARK ALL THAT APPLY**

1☐ Your sibling (brother or sister)
2☐ Your parent or your child
3☐ Another relative (such as a cousin, aunt, or uncle)
4☐ Someone not related to you
5☐ Yourself (that is, you received your own blood cells)

A10. Did you **ever** receive any other medical treatments for cancer that were not mentioned above?

1☐ Yes, please specify: ____________________
2☐ No

A11. **At any time** since you were first diagnosed with lymphoma, did a doctor or other health care professional tell you that your cancer had come back (that is, you had a recurrence)?

1☐ Yes
2☐ No ⟶ **GO TO A12**

A11.a. How many times have you had a recurrence of your cancer? ____________

A11.b. What was the approximate date of your **most recent** recurrence?

____________ ____________
MONTH YEAR

A12. In the **last 6 months**, have you received any of the following medical treatments for cancer?
**MARK ALL THAT APPLY**

0☐ I did not receive any medical treatment for cancer in the last six months
1☐ Surgery (do not consider biopsy or insertion of medication ports to be surgery)
2☐ Chemotherapy
3☐ Radiation therapy
4☐ Bone marrow or stem cell transplant (do not consider bone marrow biopsy to be a transplant)
91☐ Other, please specify: ____________________

A13. To the best of your knowledge, are you **now** free of cancer (that is, **at this time**, your cancer is in remission)?

1☐ Yes
2☐ No

## B. Cancer Care in the LAST 12 MONTHS

**Cancer survivors often see a doctor for follow-up care for many years. Questions in this section are about your experience of getting follow-up cancer care in the LAST 12 MONTHS.**

B1. In the **last 12 months**, did you see any doctor for follow-up cancer care?
This could either be a cancer specialist or some other doctor you saw to get follow-up medical tests, or to treat symptoms and treatment-related side effects, or to get medical treatments for cancer.

1 ☐ Yes → **GO TO B2**
2 ☐ No ↓

B1.a. What are the main reasons you did NOT see a doctor for follow-up cancer care in the **last 12 months**?
**MARK ALL THAT APPLY**

1 ☐ I felt I didn't need to see one any more
2 ☐ Another doctor told me I didn't need to see one any more
3 ☐ Cost too much OR insurance didn't cover it
4 ☐ Didn't know a good cancer doctor
5 ☐ It made me anxious or worried
6 ☐ Getting there was too hard
91 ☐ Other, please specify: ____________________

B1.b. When was the **last time** you saw a doctor for follow-up cancer care?

______________ MONTH ______________ YEAR

**PLEASE GO TO B26 ON PAGE 12**

B2. In the **last 12 months**, what were the reasons you saw a doctor for follow-up cancer care?
**MARK ALL THAT APPLY**

1 ☐ To receive medical treatments for cancer
2 ☐ To discuss and/or treat symptoms and side effects
3 ☐ To receive follow-up medical tests *(such as blood test, biopsy, CAT/CT scan, PET scan, etc.)*
4 ☐ To receive a physical examination
91 ☐ Other, please specify: ____________________

## The Doctor You Saw Most Often For Follow-Up Cancer Care in the LAST 12 MONTHS

B3. What is the specialty of the doctor you saw most often for follow-up cancer care in the **last 12 months**?

1☐ Primary care (such as internal medicine, family practice)
2☐ Medical oncologist or hematologist
3☐ Radiation oncologist
4☐ Surgeon
91☐ Other, please specify: ____________________
99☐ Don't know

B4. Is this doctor a male or a female?

1☐ Male
2☐ Female

B5. For how many months or years have you been going to this doctor for any kind of medical care?

1☐ Less than 12 months
2☐ 1 to 2 years
3☐ More than 2 years but less than 5 years
4☐ 5 or more years

B6. In the last **12 months**, how many times did you see this doctor for follow-up cancer care?

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

B7. When did you **last** see this doctor for follow-up cancer care?

1☐ Less than 4 weeks ago
2☐ 1 to 3 months ago
3☐ 4 to 6 months ago
4☐ 7 to 12 months ago

B8. In the **last 12 months**, did you see this doctor for medical conditions not related to cancer?

1☐ Yes
2☐ No

B9. In the **last 12 months**, where did you usually go to receive follow-up cancer care from this doctor?

1☐ Your doctor's private practice
2☐ A clinic in a hospital
3☐ A clinic run by an HMO
4☐ A local community health clinic
91☐ Other, please specify: ____________________
99☐ Don't know

**In the following questions, "your follow-up care doctor" refers to the doctor you saw most often for follow-up cancer care in the LAST 12 MONTHS.**

## Overall Communication

B10. In the **last 12 months**, how often did your follow-up care doctor listen carefully to you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B11. In the **last 12 months**, how often did your follow-up care doctor explain things in a way you could understand?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B12. In the **last 12 months**, how often did your follow-up care doctor show respect for what you had to say?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B13. In the **last 12 months**, how often did your follow-up care doctor encourage you to ask all the cancer-related questions you had?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B14. In the **last 12 months**, how often did your follow-up care doctor answer your cancer-related questions to your satisfaction?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B15. In the **last 12 months**, how often did your follow-up care doctor make sure that you understood all the information he or she gave you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B16. In the **last 12 months**, how often did your follow-up care doctor spend enough time with you?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B17. In the **last 12 months**, how often did you feel rushed by your follow-up care doctor?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B18. In the **last 12 months**, how often did your follow-up care doctor give you as much cancer-related information as you wanted?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

B19. In the **last 12 months**, how often did your follow-up care doctor involve you in cancer-related medical decisions as much as you wanted?

0☐ No cancer-related medical decisions were made in the last 12 months
1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

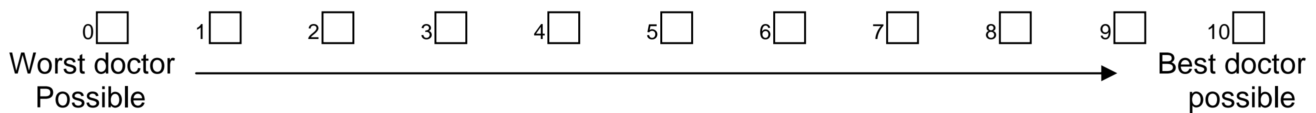
B20. In the **last 12 months**, how often did you leave your follow-up care doctor's office or clinic with unanswered questions related to your cancer?

1☐ Never
2☐ Sometimes
3☐ Usually
4☐ Always

## Evaluation of Your Care

B21. Overall, how would you rate your follow-up care doctor?

Use any one number from 0 to 10 where 0 is the worst doctor possible and 10 is the best doctor possible.




B22. Based on your interactions with your doctor, the nurses, and other staff, how would you rate the quality of care you received from your follow-up care doctor's office or clinic in the **last 12 months**?

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

B23. If you needed follow-up cancer care in the **next 12 months**, would you go back to your follow-up care doctor's office or clinic?

1☐ Definitely Yes
2☐ Probably Yes
3☐ Not Sure
4☐ Probably No
5☐ Definitely No

B24. Would you recommend your follow-up care doctor's office or clinic to your family members and friends if they needed cancer-related care?

1☐ Definitely yes
2☐ Probably yes
3☐ Not sure
4☐ Probably not
5☐ Definitely not

B25. How much do you agree or disagree with the following statements about cancer-related follow-up care visits?

| | Strongly Agree | Somewhat Agree | Neither Agree nor Disagree | Somewhat Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| a. Regular cancer follow-up visits give me a feeling of security | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. I always get nervous before my cancer follow-up visit | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. I always feel reassured after my cancer follow-up visit | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. I don't sleep as well in the week before my cancer follow-up visit | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| e. I usually postpone new plans till after the cancer follow-up visit | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| f. Cancer follow-up visits have more advantages than disadvantages | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| g. I would worry more about my cancer if there were no follow-up visits | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| h. I normally dread my cancer follow-up visits | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| i. I would rather have cancer follow-up visits less frequently | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

**Questions B26 to B29 are about any other doctors you saw in the LAST 12 MONTHS for any kind of medical care.**

B26. In the **last 12 months**, in addition to your follow-up care doctor, did you see any other doctor or doctors for any kind of medical care?

1☐ Yes
2☐ No ⟶ **GO TO SECTION C, PAGE 13**

B26.a. How many other doctors did you see? _______________

B27. What were the reasons you saw this (these) other doctor or doctors?
**MARK ALL THAT APPLY**

1☐ For cancer-related issues or problems
2☐ For medical care not related to cancer

B28. What is the specialty of the other doctor or doctors you saw in the **last 12 months**?
**MARK ALL THAT APPLY**

1☐ Primary care – internal medicine
2☐ Primary care – family practice
3☐ Medical oncologist or hematologist
4☐ Radiation oncologist
5☐ Surgeon
6☐ Gastroenterologist
7☐ Urologist
8☐ Cardiologist
9☐ Gynecologist
10☐ Rheumatologist
11☐ Endocrinologist
12☐ Pulmonologist
13☐ Neurologist
14☐ Dermatologist
15☐ Psychiatrist
16☐ Psychologist, psychotherapist, or any other mental health professional
91☐ Other, please specify: ________________________________________________
99☐ Don't know

B29. How would you rate the quality of care you received from the other doctor or doctors you saw in the **last 12 months**?

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

## C. Need for Information About Cancer-related Topics

C1. **At this time**, do you feel you need more information about any of the following cancer-related topics?

| Cancer-related Topics | I NEED … NO more information | SOME more information | MUCH more information |
|---|---|---|---|
| a. Follow-up tests/procedures that you should have | 1☐ | 2☐ | 3☐ |
| b. Symptoms that should prompt you to call your doctor | 1☐ | 2☐ | 3☐ |
| c. What late and long-term side effects of cancer treatment to expect | 1☐ | 2☐ | 3☐ |
| d. Dealing with late and long-term side effects of cancer treatment | 1☐ | 2☐ | 3☐ |
| e. Decreasing the risk of having cancer again | 1☐ | 2☐ | 3☐ |
| f. Managing your anxiety about recurrence | 1☐ | 2☐ | 3☐ |
| g. Staying physically fit | 1☐ | 2☐ | 3☐ |
| h. Nutrition and diet | 1☐ | 2☐ | 3☐ |
| i. Cancer risks to your family | 1☐ | 2☐ | 3☐ |
| j. Dealing with sexual problems | 1☐ | 2☐ | 3☐ |
| k. Having children after cancer treatment | 1☐ | 2☐ | 3☐ |
| l. Complementary and alternative treatments | 1☐ | 2☐ | 3☐ |
| m. Medical advances in cancer treatment | 1☐ | 2☐ | 3☐ |
| n. Talking about your cancer experience with family, friends, and co-workers | 1☐ | 2☐ | 3☐ |
| o. Dealing with people who may avoid you | 1☐ | 2☐ | 3☐ |
| p. Getting or retaining health, life, or disability insurance after cancer | 1☐ | 2☐ | 3☐ |
| q. Any other need, please specify: ______________________ | 1☐ | 2☐ | 3☐ |

C2. Has any doctor or other health care professional **ever** discussed with you what late or long-term side effects of cancer treatment you may experience over time?

1☐ Yes, discussed in detail
2☐ Yes, discussed somewhat
3☐ No, did not discuss

## D. Everyday Health Problems Experienced in the LAST 6 MONTHS

**Have you experienced any of the following problems in the LAST 6 MONTHS?**

**D1. Shortness of breath or difficulty breathing**

0☐ No
1☐ Yes → D1.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D2. Ankle swelling**

0☐ No
1☐ Yes → D2.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D3. Problems with memory, attention, or concentration**

0☐ No
1☐ Yes → D3.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D4. Frequent headaches or migraines**

0☐ No
1☐ Yes → D4.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D5. Numbness or tingling**

0☐ No
1☐ Yes → D5.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D6. Dizziness, vertigo, or problems with balance or equilibrium**

0☐ No
1☐ Yes → D6.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**Have you experienced any of the following problems in the LAST 6 MONTHS?**

**D7. Tremors (shaking of fingers or hands), or weakness in arms or legs**

0 ☐ No
1 ☐ Yes

D7.a. Did you discuss this problem with any doctor?
0 ☐ No
1 ☐ Yes

**D8. Frequent cough**

0 ☐ No
1 ☐ Yes

D8.a. Did you discuss this problem with any doctor?
0 ☐ No
1 ☐ Yes

**D9. Frequent or severe heartburn, indigestion, or stomach pain**

0 ☐ No
1 ☐ Yes

D9.a. Did you discuss this problem with any doctor?
0 ☐ No
1 ☐ Yes

**D10. Blood in the urine**

0 ☐ No
1 ☐ Yes

D10.a. Did you discuss this problem with any doctor?
0 ☐ No
1 ☐ Yes

**D11. Ringing in the ears**

0 ☐ No
1 ☐ Yes

D11.a. Did you discuss this problem with any doctor?
0 ☐ No
1 ☐ Yes

**D12. Blurred or double vision, or dry eyes**

0 ☐ No
1 ☐ Yes

D12.a. Did you discuss this problem with any doctor?
0 ☐ No
1 ☐ Yes

**Have you experienced any of the following problems in the LAST 6 MONTHS?**

**D13. Dry mouth**

0☐ No
1☐ Yes

D13.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D14. Sensitivity (of teeth) to hot or cold, or other dental problems (e.g., cavities, bleeding gums)**

0☐ No
1☐ Yes

D14.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D15. Joint pains**

0☐ No
1☐ Yes

D15.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D16. Leg or muscle cramps**

0☐ No
1☐ Yes

D16.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D17. Frequent back or neck pain**

0☐ No
1☐ Yes

D17.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D18. Unexplained weight loss**

0☐ No
1☐ Yes

D18.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D19. Unexplained weight gain**

0☐ No
1☐ Yes

D19.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**Have you experienced any of the following problems in the LAST 6 MONTHS?**

**D20. Frequent fevers**

0☐ No
1☐ Yes

D20.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D21. Lack of restful sleep**

0☐ No
1☐ Yes

D21.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D22. Frequent tiredness or fatigue**

0☐ No
1☐ Yes

D22.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D23. Frequent mouth sores**

0☐ No
1☐ Yes

D23.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D24. Dry skin or frequent itching**

0☐ No
1☐ Yes

D24.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D25. Night or cold sweats**

0☐ No
1☐ Yes

D25.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

**D26. For WOMEN ONLY — hot flashes**

0☐ No
1☐ Yes

D26.a. Did you discuss this problem with any doctor?
0☐ No
1☐ Yes

## E. Medical Conditions You May Have Had in Addition to Cancer

**Has a doctor or other health care professional EVER told you that you had any of these conditions?**

**E1. Irregular heartbeat or palpitations or frequent skipped beats**

0☐ No
1☐ Yes →

E1.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E2. Heart failure or congestive heart failure**

0☐ No
1☐ Yes →

E2.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E3. Weak heart muscle (cardiomyopathy)**

0☐ No
1☐ Yes →

E3.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E4. Heart attack or myocardial infarction**

0☐ No
1☐ Yes →

E4.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E5. Chest pain or angina**

0☐ No
1☐ Yes →

E5.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E6. High blood pressure (hypertension)**

0☐ No
1☐ Yes →

E6.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**Has a doctor or other health care professional EVER told you that you had any of these conditions?**

**E7. Fluid around your heart (pericarditis)**

0 ☐ No
1 ☐ Yes →

E7.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**E8. Stiff or leaking heart valves**

0 ☐ No
1 ☐ Yes →

E8.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**E9. Blood clots in the veins of the legs or in the lungs**

0 ☐ No
1 ☐ Yes →

E9.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**E10. Stroke or brain hemorrhage**

0 ☐ No
1 ☐ Yes →

E10.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**E11. Epilepsy**

0 ☐ No
1 ☐ Yes →

E11.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**E12. Seizures or convulsions**

0 ☐ No
1 ☐ Yes →

E12.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**E13. Nerve pain (neuropathy)**

0 ☐ No
1 ☐ Yes →

E13.a. Did you have this condition **before** your lymphoma diagnosis?
0 ☐ No
1 ☐ Yes

**Has a doctor or other health care professional EVER told you that you had any of these conditions?**

**E14. Chronic lung disease or bronchitis or emphysema**

0☐ No
1☐ Yes

E14.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E15. Asthma**

0☐ No
1☐ Yes

E15.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E16. Inflammation of lining of the lungs (pleurisy)**

0☐ No
1☐ Yes

E16.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E17. Scarring of the lung (lung fibrosis)**

0☐ No
1☐ Yes

E17.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E18. Pneumonia**

0☐ No
1☐ Yes

E18.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E19. Medical tests indicating abnormal liver function**

0☐ No
1☐ Yes

E19.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E20. Liver disease or cirrhosis**

0☐ No
1☐ Yes

E20.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**Has a doctor or other health care professional EVER told you that you had any of these conditions?**

**E21. Inflammatory bowel disease or colitis or Crohn's disease**

0☐ No
1☐ Yes → E21.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**E22. Gallbladder problems, such as gallstones**

0☐ No
1☐ Yes → E22.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**E23. Kidney stones**

0☐ No
1☐ Yes → E23.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**E24. Kidney or bladder infections**

0☐ No
1☐ Yes → E24.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**E25. Overactive thyroid gland (HYPERthyroid)**

0☐ No
1☐ Yes → E25.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**E26. Underactive thyroid gland (HYPOthyroid)**

0☐ No
1☐ Yes → E26.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**E27. Diabetes or high blood sugar**

0☐ No
1☐ Yes → E27.a. Did you have this condition **before** your lymphoma diagnosis?
 0☐ No
 1☐ Yes

**Has a doctor or other health care professional EVER told you that you had any of these conditions?**

**E28. Osteoporosis or brittle bones**

0 ☐ No
1 ☐ Yes → E28.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**E29. Weakening or degeneration of bones of hip or shoulder joint (avascular necrosis)**

0 ☐ No
1 ☐ Yes → E29.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**E30. Partial or complete deafness in one or both ears**

0 ☐ No
1 ☐ Yes → E30.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**E31. Cataracts**

0 ☐ No
1 ☐ Yes → E31.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**E32. Problems with the retina**

0 ☐ No
1 ☐ Yes → E32.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**E33. Arthritis or rheumatism**

0 ☐ No
1 ☐ Yes → E33.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**E34. Swelling of arm or leg due to collection of lymph fluid (lymphedema)**

0 ☐ No
1 ☐ Yes → E34.a. Did you have this condition **before** your lymphoma diagnosis?
 0 ☐ No
 1 ☐ Yes

**Has a doctor or other health care professional EVER told you that you had any of these conditions?**

**E35. Anemia**

0☐ No
1☐ Yes

E35.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E36. Shingles**

0☐ No
1☐ Yes

E36.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E37. HIV or AIDS**

0☐ No
1☐ Yes

E37.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E38. Sciatica**

0☐ No
1☐ Yes

E38.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E39. Depression or anxiety**

0☐ No
1☐ Yes

E39.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E40. Reduced or limited fertility (potential difficulty in having children of your own)**

0☐ No
1☐ Yes

E40.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E41. Graft-versus-host disease (GVHD) as a result of a bone marrow or stem cell transplant**

0☐ No
1☐ Yes

E41.a. Did you have this condition **before** your lymphoma diagnosis?
0☐ No
1☐ Yes

**E42. Do you have any other medical condition(s) not mentioned above?** Please specify the condition(s) below and whether you had the condition(s) **before** your lymphoma diagnosis:

**Other conditions:**

1) ________________________________________ → 1.a. Did you have this condition **before** your lymphoma diagnosis?
- 0☐ No
- 1☐ Yes

2) ________________________________________ → 2.a. Did you have this condition **before** your lymphoma diagnosis?
- 0☐ No
- 1☐ Yes

3) ________________________________________ → 3.a. Did you have this condition **before** your lymphoma diagnosis?
- 0☐ No
- 1☐ Yes

E43. Are any of your **current** activities limited by any of the condition(s) marked in questions **E1 to E42**?

- 0☐ I don't have any medical condition(s) listed in E1 to E42 → **GO TO SECTION F, PAGE 25**
- 1☐ Yes, limited a lot
- 2☐ Yes, limited somewhat
- 3☐ No, not limited at all

E44. Are you **currently** taking any prescription medicine for any of the medical conditions you have in addition to your cancer?

- 1☐ Yes → E44a
- 2☐ No → **GO TO SECTION F, PAGE 25**

E44a. Please write the names of the prescription medicines that you **currently** take for these medical conditions:

________________________________________

________________________________________

________________________________________

________________________________________

## F. General Health

F1.* In general, would you say your health is:

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

F2. Compared to **1 year ago**, how would you rate your health in general **now**?

1☐ Much better now than 1 year ago
2☐ Somewhat better now than 1 year ago
3☐ About the same as 1 year ago
4☐ Somewhat worse now than 1 year ago
5☐ Much worse now than 1 year ago

F3. The following questions are about activities you might do during a typical day. Does your health **now** limit you in these activities? If so, how much?

| | | Yes, Limited a Lot | Yes, Limited a Little | No, Not Limited at All |
|---|---|---|---|---|
| a. | Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports | 1☐ | 2☐ | 3☐ |
| b. | Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | 1☐ | 2☐ | 3☐ |
| c. | Lifting or carrying groceries | 1☐ | 2☐ | 3☐ |
| d. | Climbing several flights of stairs | 1☐ | 2☐ | 3☐ |
| e. | Climbing one flight of stairs | 1☐ | 2☐ | 3☐ |
| f. | Bending, kneeling, or stooping | 1☐ | 2☐ | 3☐ |
| g. | Walking more than a mile | 1☐ | 2☐ | 3☐ |
| h. | Walking several hundred yards | 1☐ | 2☐ | 3☐ |
| i. | Walking one hundred yards | 1☐ | 2☐ | 3☐ |
| j. | Bathing or dressing yourself | 1☐ | 2☐ | 3☐ |

* Questions F1-F11 are from SF-36v2 Standard, US Version 2.0. SF-36v2™ Health Survey © 1996, 2000 by QualityMetric Incorporated and Medical Outcomes Trust – All Rights Reserved. SF-36 is a registered trademark of Medical Outcomes Trust

F4. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

| | | All of the Time | Most of the Time | Some of the Time | A Little of the Time | None of the Time |
|---|---|---|---|---|---|---|
| a. | Cut down on the amount of time you spent on work or other activities | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. | Accomplished less than you would like | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. | Were limited in the kind of work or other activities | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. | Had difficulty performing the work or other activities (for example, it took extra effort) | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

F5. During the **past 4 weeks**, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

| | | All of the Time | Most of the Time | Some of the Time | A Little of the Time | None of the Time |
|---|---|---|---|---|---|---|
| a. | Cut down on the amount of time you spent on work or other activities | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. | Accomplished less than you would like | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. | Did work or other activities less carefully than usual | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

F6. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?

1☐ Not at all
2☐ Slightly
3☐ Moderately
4☐ Quite a bit
5☐ Extremely

F7. How much bodily pain have you had during the **past 4 weeks**?

1☐ None
2☐ Very mild
3☐ Mild
4☐ Moderate
5☐ Severe
6☐ Very severe

F8. During the **past 4 weeks**, how much did pain interfere with your normal work (including both work outside the home and housework)?

1☐ Not at all
2☐ A little bit
3☐ Moderately
4☐ Quite a bit
5☐ Extremely

F9. These questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

How much of the time during the **past 4 weeks**…

| | | **All of the Time** | **Most of the Time** | **Some of the Time** | **A Little of the Time** | **None of the Time** |
|---|---|---|---|---|---|---|
| a. | Did you feel full of life? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. | Have you been very nervous? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. | Have you felt so down in the dumps that nothing could cheer you up? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. | Have you felt calm and peaceful? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| e. | Did you have a lot of energy? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| f. | Have you felt downhearted and depressed? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| g. | Did you feel worn out? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| h. | Have you been happy? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| i. | Did you feel tired? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

F10. During the **past 4 weeks**, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?

1☐ All of the time
2☐ Most of the time
3☐ Some of the time
4☐ A little of the time
5☐ None of the time

F11. How TRUE or FALSE is <u>each</u> of the following statements for you?

| | Definitely True | Mostly True | Don't Know | Mostly False | Definitely False |
|---|---|---|---|---|---|
| a. I seem to get sick a little easier than other people | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. I am as healthy as anybody I know | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. I expect my health to get worse | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. My health is excellent | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

F12. During the **past 4 weeks**, how much of the time did you…

| | All of the Time | Most of the Time | Some of the Time | A Little of the Time | None of the Time |
|---|---|---|---|---|---|
| a. Have difficulty reasoning and solving problems; for example, making plans, making decisions, learning new things? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. Forget, for example, things that happened recently, where you put things, appointments? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. Have trouble keeping your attention on any activity for long? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. Have difficulty doing activities involving concentration and thinking? | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

## Discussion of Daily Functioning Problems with your Cancer Doctor

F13. If you had any problems in doing your regular, daily activities as a result of your health (including your job, household chores, or things you regularly do for leisure), would you talk about them during a visit with the doctor you see most often for follow-up cancer care?

- 0 ☐ I no longer see a doctor for follow-up cancer care → **GO TO SECTION G, PAGE 30**
- 1 ☐ Yes, I would bring up this issue on my own → **GO TO SECTION G, PAGE 30**
- 2 ☐ Yes, but only if my doctor raised the issue
- 3 ☐ No, preferably not

F13.a. Why would you prefer not to discuss these problems or discuss them only if your doctor raised them?
**MARK ALL THAT APPLY**

- 1 ☐ I don't think anything can be done about these problems
- 2 ☐ I'm not comfortable discussing these problems with my doctor
- 3 ☐ I don't think my doctor is interested in discussing these problems
- 4 ☐ I don't think my doctor has the time to discuss these problems
- 5 ☐ I don't think it's my doctor's job to address these problems
- 6 ☐ I would prefer to talk about these problems with some other doctor or health care professional
- 91 ☐ Any other reason, please specify: ______________________________

______________________________________________________________

## G. Feelings and Emotions in the LAST ONE WEEK

**For questions G1 to G14, please mark the response that best describes <u>how you have been feeling</u> in THE LAST WEEK.**

G1. I feel tense or "wound up":

1☐ Most of the time
2☐ A lot of the time
3☐ From time to time, occasionally
4☐ Not at all

G2. I still enjoy the things I used to enjoy:

1☐ Definitely as much
2☐ Not quite so much
3☐ Only a little
4☐ Hardly at all

G3. I get a sort of frightened feeling as if something awful is about to happen:

1☐ Very definitely and quite badly
2☐ Yes, but not too badly
3☐ A little, but it doesn't worry me
4☐ Not at all

G4. I can laugh and see the funny side of things:

1☐ As much as I always could
2☐ Not quite so much now
3☐ Definitely not so much now
4☐ Not at all

G5. Worrying thoughts go through my mind:

1☐ A great deal of the time
2☐ A lot of the time
3☐ From time to time, but not too often
4☐ Only occasionally

G6. I feel cheerful:

1☐ Not at all
2☐ Not often
3☐ Sometimes
4☐ Most of the time

G7. I can sit at ease and feel relaxed:

1☐ Definitely
2☐ Usually
3☐ Not often
4☐ Not at all

G8. I feel as if I am slowed down:

1☐ Nearly all the time
2☐ Very often
3☐ Sometimes
4☐ Not at all

G9. I get a sort of frightened feeling like “butterflies” in the stomach:

1☐ Not at all
2☐ Occasionally
3☐ Quite often
4☐ Very often

G10. I have lost interest in my appearance:

1☐ Definitely
2☐ I don’t take as much care as I should
3☐ I may not take quite as much care
4☐ I take just as much care as ever

G11. I feel restless as if I have to be on the move:

1☐ Very much indeed
2☐ Quite a lot
3☐ Not very much
4☐ Not at all

G12. I look forward with enjoyment to things:

1☐ As much as I ever did
2☐ Rather less than I used to
3☐ Definitely less than I used to
4☐ Hardly at all

G13. I get sudden feelings of panic:

1☐ Very often indeed
2☐ Quite often
3☐ Not very often
4☐ Not at all

G14. I can enjoy a good book or radio or TV program:

1☐ Often
2☐ Sometimes
3☐ Not often
4☐ Very seldom

## Discussion of Emotional Problems with your Cancer Doctor

G15. If you had any emotional problems or concerns as a result of your health (such as being worried, feeling sad, tense, frustrated, anxious, depressed, etc.), would you talk about them during a visit with the doctor you see most often for follow-up cancer care?

0☐ I no longer see a doctor for follow-up cancer care → **GO TO SECTION H, PAGE 33**
1☐ Yes, I would bring up this issue on my own → **GO TO SECTION H, PAGE 33**
2☐ Yes, but only if my doctor raised the issue
3☐ No, preferably not

G15.a. Why would you prefer not to discuss these problems or discuss them only if your doctor raised them?
**MARK ALL THAT APPLY**

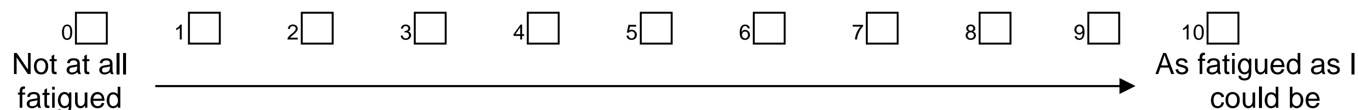
1☐ I don't think anything can be done about these problems
2☐ I'm not comfortable discussing these problems with my doctor
3☐ I don't think my doctor is interested in discussing these problems
4☐ I don't think my doctor has the time to discuss these problems
5☐ I don't think it's my doctor's job to address these problems
6☐ I would prefer to talk about these problems with some other doctor or health care professional
91☐ Any other reason, please specify: ______________________________

______________________________

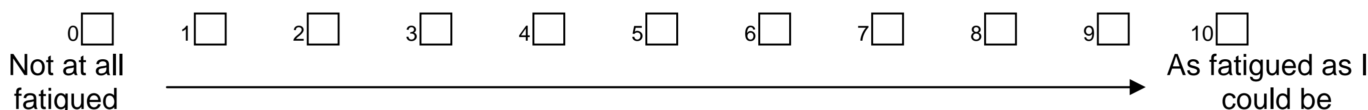
## H. Fatigue in the LAST ONE WEEK

**For each of the following, mark the <u>one number</u> that best indicates how that item applies to you.**

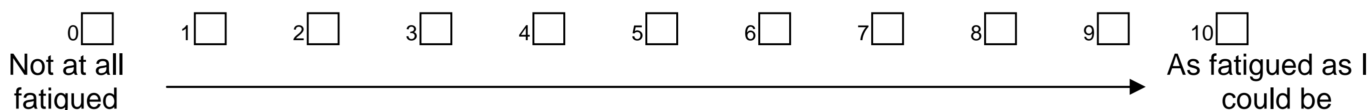
H1. Rate your level of fatigue on the day you felt <u>most</u> fatigued during the **past week**.



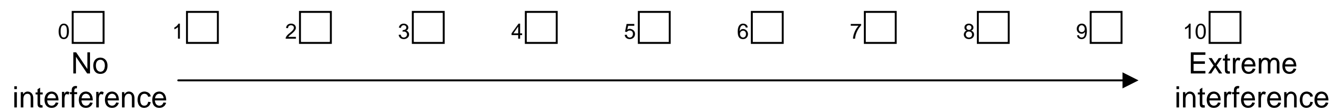

H2. Rate your level of fatigue on the day you felt <u>least</u> fatigued during the **past week**.



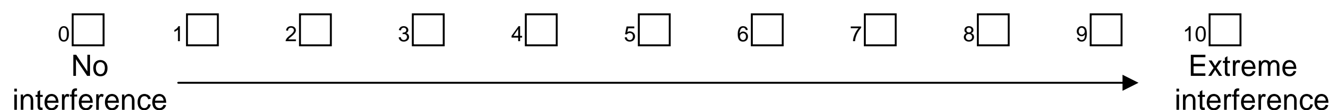

H3. Rate your level of fatigue on the <u>average</u> during the **past week**.



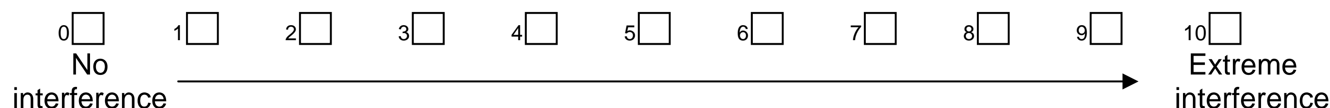

H4. Rate how much, in the **past week**, fatigue interfered with your <u>general level of activity</u>.



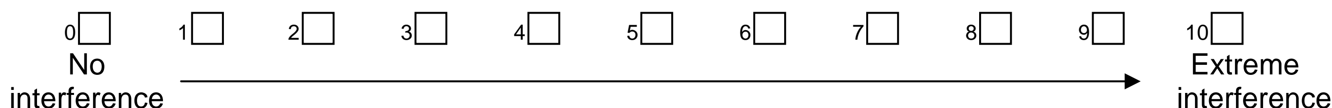

H5. Rate how much, in the **past week**, fatigue interfered with your <u>ability to bathe and dress yourself</u>.




H6. Rate how much, in the **past week**, fatigue interfered with your <u>normal work activity</u> (include both work outside the home and housework in your rating).




H7. Rate how much, in the **past week**, fatigue interfered with your <u>ability to concentrate</u>.



H8. Rate how much, in the **past week**, fatigue interfered with your relations with other people.

0☐ 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐

No interference → Extreme interference

H9. Rate how much, in the **past week**, fatigue interfered with your enjoyment of life.

0☐ 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐

No interference → Extreme interference

H10. Rate how much, in the **past week**, fatigue interfered with your mood.

0☐ 1☐ 2☐ 3☐ 4☐ 5☐ 6☐ 7☐ 8☐ 9☐ 10☐

No interference → Extreme interference

## Discussion of Physical Problems with your Cancer Doctor

H11. If you had any problems with your physical health (such as feeling pain, tired, dizzy, short of breath, etc.) would you talk about them during a visit with the doctor you see most often for follow-up cancer care?

0☐ I no longer see a doctor for follow-up cancer care → **GO TO SECTION I, PAGE 35**

1☐ Yes, I would bring up this issue on my own → **GO TO SECTION I, PAGE 35**

2☐ Yes, but only if my doctor raised the issue

3☐ No, preferably not

H11.a. Why would you prefer not to discuss these problems or discuss them only if your doctor raised them?
**MARK ALL THAT APPLY**

1☐ I don't think anything can be done about these problems

2☐ I'm not comfortable discussing these problems with my doctor

3☐ I don't think my doctor is interested in discussing these problems

4☐ I don't think my doctor has the time to discuss these problems

5☐ I don't think it's my doctor's job to address these problems

6☐ I would prefer to talk about these problems with some other doctor or health care professional

91☐ Any other reason, please specify: ______________________________

______________________________

## I. Health Appraisal

I1. What do you think are the chances that your cancer will come back or get worse within the next 10 years?

1☐ Very low
2☐ Fairly low
3☐ Moderate
4☐ Fairly high
5☐ Very high

I2. How often do you worry that your cancer may come back or get worse?

1☐ Never
2☐ Rarely
3☐ Sometimes
4☐ Often
5☐ All the time

I3. To what extent do you feel you have **control** over…

| | | **No Control at All** | **A Little Control** | **Moderate Amount of Control** | **A Great Deal of Control** | **Complete Control** |
|---|---|---|---|---|---|---|
| a. | Your emotional responses to your cancer (such as worrying, feeling anxious, feeling depressed) | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. | The physical side effects of your cancer and its treatment (such as feeling pain, tiredness) | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. | The kind of follow-up care you receive for your cancer | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. | The course of your cancer (that is, whether your cancer will come back, get worse, or you will develop a different type of cancer) | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

I4. How much do you agree or disagree with the following statements?

| | Strongly Agree | Somewhat Agree | Neither Agree nor Disagree | Somewhat Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| a. No matter how hard I try, my health doesn't turn out the way I would like | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. I am usually unable to find effective solutions for my health problems | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. My efforts to change things about my health are usually ineffective | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. Typically, my plans for my health don't work out well | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

I5. How much do you agree or disagree with the following statements?

| | Strongly Agree | Somewhat Agree | Neither agree nor Disagree | Somewhat Disagree | Strongly Disagree |
|---|---|---|---|---|---|
| a. In uncertain times, I usually expect the best | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. If something can go wrong for me, it will | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. I'm always optimistic about my future | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. I hardly ever expect things to go my way | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| e. I rarely count on good things happening to me | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| f. Overall, I expect more good things to happen to me than bad | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

## J. Social Support Available to You

J1. People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

| | | All of the Time | Most of the Time | Some of the Time | A Little of the Time | None of the Time |
|---|---|---|---|---|---|---|
| a. | Someone to help you if you were confined to bed | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. | Someone to take you to the doctor if you needed it | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. | Someone to have a good time with | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. | Someone to give you information to help you understand a situation | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| e. | Someone to confide in or talk to about yourself or your problems | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| f. | Someone who hugs you | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| g. | Someone to get together with for relaxation | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| h. | Someone to prepare your meals if you were unable to do it yourself | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| i. | Someone to help with daily chores if you were sick | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| j. | Someone to turn to for suggestions about how to deal with a personal problem | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| k. | Someone who understands your problems | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| l. | Someone to love and make you feel wanted | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

J2. Are you **currently** married or in a significant relationship?

1☐ Yes
2☐ No ⟶ **GO TO J3, PAGE 38**

J2.a. How long have you been in this relationship with your spouse or significant other?

1☐ Less than one year
2☐ More than one year, please specify the number of years: _________________

J3. Think about all the people who know about your cancer diagnosis and treatment. From the following options, please mark the **one person** who is **currently** the most helpful to you?

1☐ Your child (son or daughter)
2☐ Your partner (spouse or significant other)
3☐ Your sibling (brother or sister)
4☐ Your parent (mother or father)
5☐ Your friend
91☐ Other, please specify: ________________________________

## Discussion of Relationship Problems with Your Cancer Doctor

J4. If you had any problems in your relationship with your partner, family members, or close friends, would you talk about them during a visit with the doctor you see most often for follow-up cancer care?

0☐ I no longer see a doctor for follow-up cancer care → **GO TO SECTION K, PAGE 39**
1☐ Yes, I would bring up this issue on my own → **GO TO SECTION K, PAGE 39**
2☐ Yes, but only if my doctor raised the issue →
3☐ No, preferably not →

J4.a. Why would you prefer not to discuss these problems or discuss them only if your doctor raised them?
**MARK ALL THAT APPLY**

1☐ I don't think anything can be done about these problems
2☐ I'm not comfortable discussing these problems with my doctor
3☐ I don't think my doctor is interested in discussing these problems
4☐ I don't think my doctor has the time to discuss these problems
5☐ I don't think it's my doctor's job to address these problems
6☐ I would prefer to talk about these problems with some other doctor or health care professional
91☐ Any other reason, please specify: ________________________________

________________________________

# K. Intimate Relationships

Although the questions in this section are sensitive and personal, they are important in determining how cancer and its treatments may have affected your sexual functioning. Please be assured that your responses to these questions **will remain confidential**.

While responding to the questions, remember that sexual activities can include **any form of intimate contact as long as it results in sexual pleasure, including kissing, touching, masturbation, and intercourse.**

K1. In the **last 4 weeks**, which of the following activities did you engage in that gave you sexual pleasure?
**MARK ALL THAT APPLY**

- 0 ☐ I did not engage in any sexual activity during the last 4 weeks
- 1 ☐ Hugging or kissing or touching
- 2 ☐ Intercourse
- 3 ☐ Masturbation
- 4 ☐ Any other form of intimate contact

K2. In the **last 4 weeks**, how often did you engage in any sexual activity either alone or with a partner?

- 1 ☐ Not at all
- 2 ☐ 1 time
- 3 ☐ 2 to 3 times
- 4 ☐ 4 times
- 5 ☐ 5 times or more

K3. In the **last 4 weeks**, did you engage in any form of sexual activity with a partner?

- 1 ☐ Yes
- 2 ☐ No

K4. During the **last 4 weeks**, were you limited in your sexual activity due to any of the following reasons?
**MARK ALL THAT APPLY**

- 0 ☐ I had no limitations on my sexual activities in the last 4 weeks
- 1 ☐ I didn't have a partner
- 2 ☐ I was too tired
- 3 ☐ My partner was too tired
- 4 ☐ I was not interested in sex
- 5 ☐ My partner was not interested in sex
- 6 ☐ I was taking a medication that negatively affected my sexual interest or performance
- 7 ☐ I had a physical problem that made sexual relations difficult or uncomfortable
- 8 ☐ My partner had a physical problem that made sexual relations difficult or uncomfortable
- 91 ☐ Other reasons, please describe: ____________________

K5. In the **last 4 weeks**, how satisfied were you with the frequency of your sexual activity?

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

K6. In the **last 4 weeks**, how frequently did you experience the following?

| | Does Not Apply | Never | Sometimes | Usually | Always |
|---|---|---|---|---|---|
| a. Lack of sexual desire | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |
| b. Lack of sexual arousal | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |
| c. Difficulty reaching orgasm | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |

K7. **For MEN ONLY:** In the **last 4 weeks**, how frequently did you experience the following?

| | Does Not Apply | Never | Sometimes | Usually | Always |
|---|---|---|---|---|---|
| a. Difficulty getting an erection | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |
| b. Losing an erection during sexual activity | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |

K8. **For WOMEN ONLY:** In the **last 4 weeks**, how frequently did you experience the following?

| | Does Not Apply | Never | Sometimes | Usually | Always |
|---|---|---|---|---|---|
| a. Lack of wetness in your vagina as you became sexually excited | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |
| b. Vaginal tightness | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |
| c. Painful penetration on intercourse | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ |

**For Both MEN and WOMEN:**

K9. In the **last 4 weeks**, how big a problem did you consider your sexual functioning to be?

1☐ No problem
2☐ Very small problem
3☐ Small problem
4☐ Moderate problem
5☐ Big problem

K10. In the **last 4 weeks**, how satisfied were you with your sex life?

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

## Discussion of Sexual Functioning Problems with your Cancer Doctor

K11. If you had any problems with your sexual functioning, would you talk about them during a visit with the doctor you see most often for follow-up cancer care?

0☐ I no longer see a doctor for follow-up cancer care → **GO TO SECTION L, PAGE 42**

1☐ Yes, I would bring up the issue on my own → **GO TO SECTION L, PAGE 42**

2☐ Yes, but only if my doctor raised the issue →

3☐ No, preferably not →

K11.a. Why would you prefer not to discuss these problems or discuss them only if your doctor raised them?
**MARK ALL THAT APPLY**

1☐ I don't think anything can be done about these problems

2☐ I'm not comfortable discussing these problems with my doctor

3☐ I don't think my doctor is interested in discussing these problems

4☐ I don't think my doctor has the time to discuss these problems

5☐ I don't think it's my doctor's job to address these problems

6☐ I would prefer to talk about these problems with some other doctor or health care professional

91☐ Any other reason, please specify: ______________________________

______________________________________________________________

## L. Women's Health

**If you are MALE, GO TO SECTION M on page 43.**

L1. At the time you were **first diagnosed** with lymphoma, what was your menstrual status?

1☐ I was having a menstrual period every month
2☐ I was having a menstrual period once every few months
3☐ I didn't have a menstrual period for at least 12 months

L2. **At this time**, what is your menstrual status?

1☐ I have a menstrual period every month
2☐ I have a menstrual period once every few months
3☐ I haven't had a menstrual period for at least 12 months

L3. How has your menstrual cycle changed since you were **first diagnosed** with lymphoma?
**MARK ALL THAT APPLY**

0☐ My menstrual period had already stopped at the time of my lymphoma diagnosis
1☐ My menstrual cycle did not change
2☐ My menstrual flow got lighter
3☐ My menstrual flow got heavier
4☐ My menstrual flow got more variable and/or unpredictable
5☐ The length of my menstrual cycle got shorter
6☐ The length of my menstrual cycle got longer
7☐ The length of my menstrual cycle got more variable and/or unpredictable
91☐ Other, please specify: ____________________

L4. Have you ever had any gynecologic (female) surgery?

1☐ Yes
2☐ No ⟶ **GO TO SECTION M, PAGE 43**

L5. If yes, please tell us what type of surgery you had:

1☐ Removal of the uterus or womb (hysterectomy)
2☐ Removal of ovaries (oophorectomy)
3☐ Removal of the uterus and ovaries

L6. When did you have this surgery?

1☐ Before my lymphoma diagnosis
2☐ After my lymphoma diagnosis

# M. Health Behaviors

M1. Do you participate in any <u>regular</u> activity or program (formal or your own) designed to improve or maintain your physical fitness? *(By <u>regular</u> we mean you do the activity at least once a week).*

1☐ Yes
2☐ No

M2. In the **last 4 weeks**, did you get <u>regular vigorous</u> exercise *(that is, at least once a week)* through activities such as running, aerobics, heavy yard work, tennis, or any other activity that causes large increases in breathing or heart rate?

1☐ Yes
2☐ No ⟶ **GO TO M3, PAGE 44**

M2.a. In the **last 4 weeks**, how many times <u>each week</u> did you do such activities?

1☐ Once
2☐ 2 to 4 times
3☐ 5 to 7 times
4☐ 8 to 10 times
5☐ 11 times or more

M2.b. On an average, for how many <u>minutes</u> did you do such activities each time?

1☐ Under 10 minutes
2☐ 10 to 19 minutes
3☐ 20 to 29 minutes
4☐ 30 to 59 minutes
5☐ 60 minutes or more

M3. In the **last 4 weeks**, did you get regular moderate exercise *(that is, at least once a week)* through activities such as walking, playing golf, gardening, or any other activity that causes small increases in breathing or heart rate?

1☐ Yes
2☐ No ⟶ **GO TO M4**

M3.a. In the **last 4 weeks**, how many times each week did you do such activities?

1☐ Once
2☐ 2 to 4 times
3☐ 5 to 7 times
4☐ 8 to 10 times
5☐ 11 times or more

M3.b. On an average, how many minutes did you do such activities each time?

1☐ Under 10 minutes
2☐ 10 to 19 minutes
3☐ 20 to 29 minutes
4☐ 30 to 59 minutes
5☐ 60 minutes or more

M4. Have you smoked at least 100 cigarettes in your **entire lifetime**?

1☐ Yes
2☐ No ⟶ **GO TO M8, PAGE 45**

M5. Did you smoke cigarettes **at the time** you were **first diagnosed** with lymphoma?

1☐ Yes, I smoked daily
2☐ Yes, I smoked some days a month
3☐ No, I didn't smoke at the time of my lymphoma diagnosis

M6. How often do you **currently** smoke?

1☐ Every day
2☐ Some days
3☐ I don't smoke any more ⟶

M6.a. When did you quit smoking?

1☐ 1 to 6 months ago
2☐ 7 to 12 months ago
3☐ 1 to 4 years ago
4☐ 5 to 9 years ago
5☐ 10 or more years ago

**PLEASE GO TO QUESTION M8, PAGE 45**

M7. On the days you **currently** smoke, about how many cigarettes, on average, do you smoke?

1☐ 1 to 5
2☐ 6 to 10
3☐ 11 to 20
4☐ 21 to 30
5☐ 31 to 40
6☐ 41 or more

M8. Have you had more than 10 drinks of alcohol in **your life**? *(A drink means a can of beer, a glass of wine, a wine cooler, a shot of hard liquor, or a mixed drink that has a shot of hard liquor in it.)*

1☐ Yes
2☐ No → **GO TO SECTION N, PAGE 46**

M9. On how many of the **last 14 days** did you have a beer, glass of wine, whisky, or any other alcoholic drink?

1☐ None → **GO TO SECTION N, PAGE 46**
2☐ 1 to 3 days
3☐ 4 to 6 days
4☐ 7 to 9 days
5☐ 10 to 12 days
6☐ 13 to 14 days

M10. On the days that you did drink during the **last 14 days**, how many drinks per day, on average, did you have?

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

## N. Your Use of Complementary and Alternative Therapies

N1. **At any time** since you were first diagnosed with lymphoma, have you used any of the following complementary and alternative therapies?

| | Yes | No |
|---|---|---|
| a. Special diets such as mostly vegetarian or low fat | 1☐ | 2☐ |
| b. Movement or physical therapies such as yoga, tai chi, massage, chiropractic, or electromagnetic therapy | 1☐ | 2☐ |
| c. High dose or mega vitamins (DO NOT include 1-a-day multivitamins), nutritional supplements, or herbal remedies | 1☐ | 2☐ |
| d. Homeopathy | 1☐ | 2☐ |
| e. Mind/body therapies such as guided imagery/visualization, biofeedback, meditation, relaxation techniques, hypnosis/hypnotherapy, energy healing, therapeutic touch, or music therapy | 1☐ | 2☐ |
| f. Oriental therapies such as acupuncture, acupressure, Qigong, or Shiatsu | 1☐ | 2☐ |
| g. Self-help or support groups (either face-to-face or on the Internet) | 1☐ | 2☐ |
| h. Psychological therapy or counseling from a psychologist, psychiatrist, social worker, or any other mental health professional | 1☐ | 2☐ |
| i. Faith healing, laying on of hands, or any other spiritual or religious group experience | 1☐ | 2☐ |
| j. Personal prayer or personal spiritual healing | 1☐ | 2☐ |
| k. Other, please specify: ______________________ | 1☐ | 2☐ |

N2. What were the major reasons why you used any of these therapies discussed above in question N1? **MARK ALL THAT APPLY**

- 0☐ I didn't use any of the above therapies → **GO TO SECTION O, PAGE 49**
- 1☐ To relieve symptoms or any treatment-related side effects (such as pain, nausea, fatigue, anxiety, depression, or other similar symptoms/side-effects)
- 2☐ To relieve stress
- 3☐ To treat my cancer
- 4☐ To prevent my cancer from coming back
- 5☐ To help deal with a medical condition other than cancer, please specify: ______________
- 91☐ Other, please specify: ______________________

N3. Overall, how helpful were any of these therapies in meeting your goals?

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

N4 Did you use any of the above complementary and alternative therapies discussed in question N1 **while receiving medical treatments** for cancer?

1☐ Yes
2☐ No ⟶ **GO TO N7, PAGE 48**

N5. Did you discuss your use of any of these complementary and alternative therapies with the doctor you saw most often **at the time of receiving medical treatments** for cancer?

1☐ Yes
2☐ No ⟶ **GO TO N6**

N5.a. Which of the following best describes your doctor's response? Your doctor …

1☐ Encouraged you to use it
2☐ Didn't care whether you used it or not
3☐ Told you about the risks in using it
4☐ Encouraged you to stop using it
5☐ Made no comment
91☐ Other, please specify: ______________________________

______________________________________________

**PLEASE GO TO QUESTION N7, PAGE 48**

N6. What were the main reasons why you didn't discuss your use of complementary and alternative therapies with this doctor?
**MARK ALL THAT APPLY**

1☐ Your doctor never asked
2☐ You thought that your doctor wouldn't approve
3☐ It wasn't important for you to tell your doctor
4☐ You felt your doctor might refuse to continue to be your doctor
91☐ Other, please specify ______________________________

N7. In the **last 4 weeks**, did you use any of the following complementary and alternative therapies?

| | Yes | No |
|---|---|---|
| a. Special diets such as mostly vegetarian or low fat | 1☐ | 2☐ |
| b. Movement or physical therapies such as yoga, tai chi, massage, chiropractic, or electromagnetic therapy | 1☐ | 2☐ |
| c. High dose or mega vitamins (DO NOT include 1-a-day multivitamins), nutritional supplements, or herbal remedies | 1☐ | 2☐ |
| d. Homeopathy | 1☐ | 2☐ |
| e. Mind/body therapies such as guided imagery/visualization, biofeedback, meditation, relaxation techniques, hypnosis/hypnotherapy, energy healing, therapeutic touch, or music therapy | 1☐ | 2☐ |
| f. Oriental therapies such as acupuncture, acupressure, Qigong, or Shiatsu | 1☐ | 2☐ |
| g. Self-help or support groups (either face-to-face or on the Internet) | 1☐ | 2☐ |
| h. Psychological therapy or counseling from a psychologist, psychiatrist, social worker, or any other mental health professional | 1☐ | 2☐ |
| i. Faith healing, laying on of hands, or any other spiritual or religious group experience | 1☐ | 2☐ |
| j. Personal prayer or personal spiritual healing | 1☐ | 2☐ |
| k. Other, please specify: ____________________ | 1☐ | 2☐ |

## O. Impact of Cancer

O1. Looking back, **since the time** you were first diagnosed with lymphoma, how much of an impact has cancer and its treatments had on the following areas of your life?

| | Does not apply | Very negative impact | Somewhat negative impact | No impact | Somewhat positive impact | Very positive impact |
|---|---|---|---|---|---|---|
| a. Your education plans | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| b. Your work life or career | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| c. Your ability to date people | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| d. Your desire to have children | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| e. Your ability to have children | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| f. Your relationship with your spouse/partner | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| g. Your sex life | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| h. Your relationship with your children | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| i. Your relationship with other family members and friends | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| j. Your participation in social activities | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| k. Your financial situation | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| l. Your diet | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| m. Your exercise activities | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| n. Your smoking of tobacco products | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| o. Your alcohol consumption | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| p. Your retirement plans | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| q. Your ability to get or retain health, life, or disability insurance | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| r. Your religious or spiritual beliefs | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| s. Your ability to enjoy life | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |
| t. Other changes? Please specify: ____________ ____________ | 0☐ | 1☐ | 2☐ | 3☐ | 4☐ | 5☐ |

## P. Background Information

P1. What is the highest level of formal education you have completed?

1☐ Less than high school
2☐ High school graduate or GED
3☐ Some college or technical or vocational school
4☐ College graduate
5☐ Some graduate school
6☐ Graduate degree

P2. Do you consider yourself to be…

1☐ Hispanic or Latino?
2☐ NOT Hispanic or Latino?

P3. Which of the following best describes your race?
**MARK ALL THAT APPLY**

1☐ American Indian or Alaska Native
2☐ Asian
3☐ Black or African American
4☐ Native Hawaiian or Other Pacific Islander
5☐ White

P4. What is your **current** marital status?

1☐ Married or living as married
2☐ Divorced
3☐ Separated
4☐ Widowed
5☐ Single (never married)

P5. How tall are you without shoes? ______ feet _____ inches

P6. What is your **current** weight? _________ lbs

P7. What was your weight when you were **first diagnosed** with lymphoma? ________ lbs

P8. Who lives with you **currently**, at least some of the time?
**MARK ALL THAT APPLY**

1 ☐ I live alone
2 ☐ Spouse or significant other
3 ☐ Children under age 18, please specify how many: _________
4 ☐ Children age 18 or older, please specify how many: _______
5 ☐ One or both parents
6 ☐ Other relatives, please specify how many: ___________
7 ☐ Friends or roommates
91 ☐ Other, please specify: ____________________________________________

P9. What is your **current** employment status?
**MARK ALL THAT APPLY**

1 ☐ Working full time
2 ☐ Working part time
4 ☐ Full-time homemaker or family caregiver
5 ☐ Retired
6 ☐ Unemployed
7 ☐ Student
91 ☐ Other, please specify: ____________________________________________

P10. Which of the following categories best describes your total household income, before taxes, from all sources **last year**?

1 ☐ Less than $10,000
2 ☐ $10,000 to $19,999
3 ☐ $20,000 to $39,999
4 ☐ $40,000 to $59,999
5 ☐ $60,000 to $99,999
6 ☐ $100,000 or more

P11. Do you **currently** have any form of health insurance coverage?
1 ☐ Yes → P11.a
2 ☐ No → **GO TO SECTION Q, PAGE 52**

P11.a. How is this health insurance provided?
**MARK ALL THAT APPLY**

1 ☐ Through my employer
2 ☐ Through my spouse's or parent's policy
3 ☐ Through a private policy I purchased
4 ☐ Medicaid
5 ☐ Medicare
6 ☐ Military health care (including CHAMPUS/TRICARE/CHAMP-VA)
91 ☐ Other, please specify: ___________________________

## Q. Additional Comments

Q1. In looking back, what things do you think have helped you the most during the experience of becoming a cancer survivor?

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

Q2. Finally, if you have any comments about this survey or would like to share any concerns or problems related to or due to your cancer that we did not cover in this survey, please feel free to do so below.

____________________________________________________________

____________________________________________________________

____________________________________________________________

____________________________________________________________

Q3. Please note the time at which you finished the survey: ___________________ 1☐ AM 2☐ PM

If you answered the survey in more than one sitting, please fill in the approximate total time you spent answering all the questions in this survey: ________________

**THANK YOU** for taking the time to fill out this survey.

Please return the survey along with forms A and B
in the enclosed postage-paid envelope
as soon as possible.