The LILAC Study
Life and Longevity after Cancer

BASELINE QUESTIONNAIRE

Instructions:

To help us learn more about cancer treatments and their effects on the lives of women, we would like to ask more information about the cancer you have had.

When completing the questions about cancer, please refer only to the cancer diagnosed in the year noted on the cover memo. Please answer each question as best you can for this specific type of cancer.

This booklet has questions about:

- The cancer, cancer treatments, and health issues after cancer treatment. The questions about treatment are about the treatments that you received right after the cancer diagnosis.
- Health insurance.
- Your experience since the diagnosis of cancer.

Please use a pencil or black pen only to complete this form.

OFFICE USE ONLY

1. Date received:
   ____/____/_____
   MM DD YYYY

2. Reviewed by: 80 - ___ ___ ___
   ○ RCR ○ OU1 ○ OU2

3. Contact Type:
   ○1 Phone
   ○2 Mail

Participant ID Label

○○○○○○○○○○○○○○○○○○○○○○○○○ 01234

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Please complete the following questions regarding treatments you may have had for cancer. If you have had more than one type of cancer, please refer only to the cancer diagnosed in the year noted in the cover letter.

1. After you were first diagnosed with cancer, did you have **chemotherapy**? This means you took a drug by pill or through an IV to kill cancer cells. Some drugs might have made you sick to your stomach, lose your hair, or itch, for example.

○1 Yes ○0 No ○9 Don't know → Go to question 2.

Name of doctor and facility where you received chemotherapy:

1.1 Doctor's name: _____

1.2 Name of facility: _____

_____

1.3 City and state of facility: _____

1**.4** Date chemotherapy started: __ __ - __ __ __ __
month year

1.5 Date chemotherapy ended: __ __ - __ __ __ __
month year

2. Did you have **radiation** to treat your cancer? There are two types of radiation treatment to consider: Beam radiation (external radiation) is given by a machine in a hospital or clinic and directed to a specific part of your body; or an implant (internal radiation) is placed in your body, usually under anesthesia, and delivers radiation continuously.

○1 Yes ○0 No ○9 Don't know → Go to question 3 on the next page.

Name of doctor and facility where you received radiation therapy:

2.1 Doctor's name: _____

2.2 Name of facility: _____

_____

2.3 City and state of facility: _____

2.4 Date radiation started: __ __ - __ __ __ __
month year

2.5 Date radiation ended: __ __ - __ __ __ __
month year

3. Some cancers, such as breast cancer and endometrial cancer, are treated with **hormone-related or anti-estrogen pills**. Some common pills include Tamoxifen, Arimidex, Femara, and Megace. Did you use **hormonal treatments** for your cancer?

○1 Yes ○0 No ○9 Don't know → Go to question 4 on the next page.

Name of doctor who prescribed the first hormonal therapy after the diagnosis of the cancer:

3.1 Doctor's name: _____

3.2 Name of facility: _____

_____

3.3 City and state of facility: _____

3.4 Did a different doctor prescribe the most recent hormonal therapy?

○1 Yes ○0 No → Go to question 4 on the next page.

Name of doctor who prescribed the most recent hormonal therapy:

3.5 Doctor's name: _____

3.6 Name of facility: _____

_____

3.7 City and state of facility: _____

3.8 Date first hormonal therapy started: __ __ - __ __ __ __ (month / year)

3.9 Date first hormonal therapy ended: __ __ - __ __ __ __ (month / year)

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4. Did you have any other type of treatment for your cancer such as **Herceptin**, immune therapy/immunotherapy (usually given through an IV), or another targeted therapy (often given through a pill)?

○1 Yes ○0 No ○9 Don't know → Go to question 5 on the next page.

Treatment	Doctor and Facility
4.1 Herceptin ○1 Yes ○0 No →	Doctor's name: _____ Name of facility: _____ _____ City and state of facility: _____ Date treatment started: __ __ - __ __ __ __ month year
4.2 Immunotherapy ○1 Yes ○0 No → *Examples include:* pembrolizumab/Keytruda, rituximab/Rituxan	Doctor's name: _____ Name of facility: _____ _____ City and state of facility: _____ Date treatment started: __ __ - __ __ __ __ month year
4.3 Targeted Therapy ○1 Yes ○0 No → *Examples include:* bevacizumab/Avastin, cetuximab/Erbitux, erlotinib/Tarceva	Doctor's name: _____ Name of facility: _____ _____ City and state of facility: _____ Date treatment started: __ __ - __ __ __ __ month year
4.4 Other ○1 Yes ○0 No → Specify: _____ _____ _____	Doctor's name: _____ Name of facility: _____ _____ City and state of facility: _____ Date treatment started: __ __ - __ __ __ __ month year

We are interested in learning about any health issues that you experienced after the completion of your initial cancer treatments.

5. Please indicate the symptoms that were **NEW** to you <u>after</u> your cancer treatment, and <u>not</u> due to some other known medical condition.			**If yes**, how soon after treatment did symptoms occur – in a matter of days, months, or years?			Do you still have the symptom?		Have you been treated for the symptom?	
Did this occur?	**No**	**Yes**	**Days**	**Months**	**Years**	**No**	**Yes**	**No**	**Yes**
5.1 Low blood counts (anemia, neutropenia)	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.2 High blood pressure	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.3 Kidney problems	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.4 Liver problems	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.5 Blood clots (venous thromboembolisms)	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.6 Nerve problems tingling sensations	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.7 Hearing changes	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.8 Skin rash or other skin disorders	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.9 Memory problems	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.10 Aching joints	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.11 Hot flashes	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.12 Radiation burns	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.**13** Shortness of breath	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.14 Mouth sores or dry mouth	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.15 Insomnia or sleep problems	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.16 Heart disease, like congestive heart failure	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.**17** Bleeding too easily	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.18 Weight gain > 10 lbs	○0	○1 →	○1	○2	○3	○0	○1	○0	○1
5.19 Other: Specify: _____	○0	○1 →	○1	○2	○3	○0	○1	○0	○1

Recurrence

6. Has your doctor ever told you that this cancer came back (a recurrence), that it had spread, or that you now have another cancer of this same type?

○1 Yes ○0 No ○9 Don't know → Go to question 7.

Name of the doctor who told you that the cancer came back:

6.1 Doctor's name: _____

6.2 City and state: _____

6.3 Date: __ __ - __ __ __ __
month year

Insurance

7. Please tell us the type of health insurance that you had when you were first diagnosed with the cancer that you currently have. For each type of insurance coverage please mark one circle under "Insurance coverage at diagnosis" and one circle under "Current insurance coverage."

Type of Insurance	Insurance coverage at diagnosis			Current insurance coverage		
	Yes	**No**	**Don't know**	**Yes**	**No**	**Don't know**
7.1 Medicare (Federal health insurance for people age 65 or older or who are disabled).	○1	○0	○9	○1	○0	○9
7.2 Medicare supplement (Additional insurance to Medicare that you buy yourself, such as Medex, Medigap, or AARP).	○1	○0	○9	○1	○0	○9
7.3 Medicaid (state program for persons with incomes below a certain level).	○1	○0	○9	○1	○0	○9
7.4 Private or commercial insurance (such as Blue Cross, Aetna, Prudential, Hancock, and others).	○1	○0	○9	○1	○0	○9
7.5 HMO (Health Maintenance Organization, such as Kaiser Permanente) or IPA (Individual Practice Association).	○1	○0	○9	○1	○0	○9
7.6 Veterans, CHAMPUS, or TRICARE (Insurance for people in the military and their families).	○1	○0	○9	○1	○0	○9
7.7 Other state medical assistance or free care programs. Specify: _____	○1	○0	○9	○1	○0	○9

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These next questions refer to the present time.

8. Do you often feel sad or depressed?
○1 Yes ○0 No

9. Please rate your pain by marking one circle that best describes your pain at its worst in the last 24 hours.

○	○	○	○	○	○	○	○	○	○	○
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
No pain										**Pain as bad as you can imagine**

10. For each of the next three questions, please mark one circle to best reflect your feelings during the past week, including today.

10.1 Your overall level of anxiety?

○	○	○	○	○	○	○	○	○	○	○
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
None					**Moderate**					**Worst**

10.2 Your overall level of fatigue?

○	○	○	○	○	○	○	○	○	○	○
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
None					**Moderate**					**Worst**

10.3 Your overall level of distress?

○	○	○	○	○	○	○	○	○	○	○
0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
None					**Moderate**					**Worst**

11. People sometimes look to others for companionship, assistance, or other types of support. This question covers the types of support that would be available to you if you needed it. Please mark one circle based on the support available to you during the past 4 weeks.

How often is someone available…	None of the time	A little of the time	Some of the time	Most of the time	All of the time
11.1 To take you to the doctor if you need to go?	○1	○2	○3	○4	○5
11.2 To have a good time with?	○1	○2	○3	○4	○5
11.3 To hug you?	○1	○2	○3	○4	○5
11.4 To prepare your meals if you are unable to for yourself?	○1	○2	○3	○4	○5
11.5 To understand your problems?	○1	○2	○3	○4	○5

12. In the next section is a set of statements about how you might feel. Please indicate which of the following four possible answers best captures how often you feel the way that is described in each statement.

		Often	Some of the time	Hardly ever (or never)	No answer
12.1	How often do you feel you lack of companionship?	○1	○2	○3	○4
12.1	How often do you feel left out?	○1	○2	○3	○4
12.3	How often do you feel isolated from others?	○1	○2	○3	○4

13. What is your current weight? ⌊___|___⌋ lbs.

14. What is your current marital status?

○1 Married/living as married
○2 Widowed
○3 Divorced/separated
○4 Never married

Thank you.

Please take a moment to review any questions you may have missed.

Comments

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