



# 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

3. Contact Type:

- 1 Phone
- 2 Mail

2. Reviewed by: 80 - \_\_\_ \_\_\_ \_\_\_

- RCR
- OU1
- OU2

Participant ID Label



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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)?

Yes

No

Don't know



→ Go to question 5 on the next page.

Treatment	Doctor and Facility
<p><b>4.1 Herceptin</b> <input type="radio"/> Yes <input type="radio"/> No →</p>	<p>Doctor's name: _____</p> <p>Name of facility: _____</p> <p>City and state of facility: _____</p> <p>Date treatment started: ____ - ____ - ____ month year</p>
<p><b>4.2 Immunotherapy</b> <input type="radio"/> Yes <input type="radio"/> No →</p> <p><i>Examples include:</i> pembrolizumab/Keytruda, rituximab/Rituxan</p>	<p>Doctor's name: _____</p> <p>Name of facility: _____</p> <p>City and state of facility: _____</p> <p>Date treatment started: ____ - ____ - ____ month year</p>
<p><b>4.3 Targeted Therapy</b> <input type="radio"/> Yes <input type="radio"/> No →</p> <p><i>Examples include:</i> bevacizumab/Avastin, cetuximab/Erbitux, erlotinib/Tarceva</p>	<p>Doctor's name: _____</p> <p>Name of facility: _____</p> <p>City and state of facility: _____</p> <p>Date treatment started: ____ - ____ - ____ month year</p>
<p><b>4.4 Other</b> <input type="radio"/> Yes <input type="radio"/> No →</p> <p>Specify: _____</p> <p>_____</p> <p>_____</p>	<p>Doctor's name: _____</p> <p>Name of facility: _____</p> <p>City and state of facility: _____</p> <p>Date treatment started: ____ - ____ - ____ month year</p>

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 after your cancer treatment, and not due to some other known medical condition.

Did this occur?			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?	
	No	Yes	Days	Months	Years	No	Yes	No	Yes
5.1 Low blood counts (anemia, neutropenia)	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.2 High blood pressure	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.3 Kidney problems	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.4 Liver problems	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.5 Blood clots (venous thromboembolisms)	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.6 Nerve problems tingling sensations	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.7 Hearing changes	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.8 Skin rash or other skin disorders	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.9 Memory problems	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.10 Aching joints	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.11 Hot flashes	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.12 Radiation burns	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.13 Shortness of breath	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.14 Mouth sores or dry mouth	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.15 Insomnia or sleep problems	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.16 Heart disease, like congestive heart failure	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.17 Bleeding too easily	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.18 Weight gain > 10 lbs	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 1
5.19 Other: Specify: _____	<input type="radio"/> 0	<input type="radio"/> 1 →	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 0	<input type="radio"/> 1	<input type="radio"/> 0	<input type="radio"/> 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?

- <sub>1</sub> Yes     
 <sub>0</sub> No     
 <sub>9</sub> 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).	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>
7.2 Medicare supplement (Additional insurance to Medicare that you buy yourself, such as Medex, Medigap, or AARP).	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>
7.3 Medicaid (state program for persons with incomes below a certain level).	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>
7.4 Private or commercial insurance (such as Blue Cross, Aetna, Prudential, Hancock, and others).	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>
7.5 HMO (Health Maintenance Organization, such as Kaiser Permanente) or IPA (Individual Practice Association).	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>
7.6 Veterans, CHAMPUS, or TRICARE (Insurance for people in the military and their families).	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>
7.7 Other state medical assistance or free care programs. Specify: _____	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>0</sub>	<input type="radio"/> <sub>9</sub>



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**These next questions refer to the present time.**

8. Do you often feel sad or depressed?  
<sub>1</sub> Yes    <sub>0</sub> No

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

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
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?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
None			Moderate				Worst			

10.2 Your overall level of fatigue?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
None			Moderate				Worst			

10.3 Your overall level of distress?

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>
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
<b>11.1</b> To take you to the doctor if you need to go?	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>2</sub>	<input type="radio"/> <sub>3</sub>	<input type="radio"/> <sub>4</sub>	<input type="radio"/> <sub>5</sub>
<b>11.2</b> To have a good time with?	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>2</sub>	<input type="radio"/> <sub>3</sub>	<input type="radio"/> <sub>4</sub>	<input type="radio"/> <sub>5</sub>
<b>11.3</b> To hug you?	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>2</sub>	<input type="radio"/> <sub>3</sub>	<input type="radio"/> <sub>4</sub>	<input type="radio"/> <sub>5</sub>
<b>11.4</b> To prepare your meals if you are unable to for yourself?	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>2</sub>	<input type="radio"/> <sub>3</sub>	<input type="radio"/> <sub>4</sub>	<input type="radio"/> <sub>5</sub>
<b>11.5</b> To understand your problems?	<input type="radio"/> <sub>1</sub>	<input type="radio"/> <sub>2</sub>	<input type="radio"/> <sub>3</sub>	<input type="radio"/> <sub>4</sub>	<input type="radio"/> <sub>5</sub>

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?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
12.1 How often do you feel left out?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4
12.3 How often do you feel isolated from others?	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 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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