# SURVIVOR CARE AFTER CANCER STUDY

**Thank you for taking the time to complete this survey. The information you provide will be used to help future cancer survivors.**

**Your answers are very important to us and will be kept *strictly confidential* .**

**Please read each question in this booklet carefully. If none of the answers provided seem exactly right, choose the one that comes closest to being right for you.**

**Please fill out and return this double-sided survey (*with blue or black pen*) as soon as possible in the enclosed postage-paid envelope. If you have any problems or questions, please call Bridget Neville, MPH at 617-632-4871.**

**We greatly appreciate your participation.**

## Instructions

Please fill in the ovals completely for each question, **with blue or black pen**.

Example: In general, how would you say your health is?

- ○ Excellent
- ● Very good
- ○ Good
- ○ Fair
- ○ Poor

For questions that ask age, weight, etc., fill in the corresponding ovals AND write the numbers in the provided boxes.

Example: How old are you (in years)?

| 5 | 8 |
|---|---|
| ⓪ | ⓪ |
| ① | ① |
| ② | ② |
| ③ | ③ |
| ④ | ④ |
| ● | ⑤ |
| ⑥ | ⑥ |
| ⑦ | ⑦ |
| ⑧ | ● |
| ⑨ | ⑨ |

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1. In what year were you originally diagnosed with your most recent cancer, not including relapse?

| | | | |
|---|---|---|---|
| 0 | 0 | 0 | 0 |
| 1 | 1 | 1 | 1 |
| 2 | 2 | 2 | 2 |
| 3 | 3 | 3 | 3 |
| 4 | 4 | 4 | 4 |
| 5 | 5 | 5 | 5 |
| 6 | 6 | 6 | 6 |
| 7 | 7 | 7 | 7 |
| 8 | 8 | 8 | 8 |
| 9 | 9 | 9 | 9 |

2. What type of cancer were you most recently diagnosed with?
Write the cancer type (to the best of your knowledge) in the box below.

3. Did you receive any treatment for your most recent cancer?

- ◯ No — ***Go to question 5 (next page)***
- ◯ Yes — ***Continue with question 4***

4. Please **mark all** treatments that you received, or are currently receiving, for your most recent cancer.

| | Treatments received | Treatments you are still receiving |
|---|---|---|
| a. Surgery to remove the cancer | ◯ | ◯ |
| b. Other surgery (such as breast reconstruction, colostomy) | ◯ | ◯ |
| c. Chemotherapy | ◯ | ◯ |
| d. Radiation treatment | ◯ | ◯ |
| e. Bone marrow transplantation | ◯ | ◯ |
| f. Hormonal therapy for cancer (such as Tamoxifen, Arimidex, Flutamide, Lupron) | ◯ | ◯ |
| g. Immunotherapy for cancer (such as antibodies, tumor vaccines, BCG, Interferon, Interleukin, Rituxan, Herceptin) | ◯ | ◯ |
| h. Other treatment | ◯ | ◯ |

**(Please list any other treatments you received or are still receiving in the box to the right)**

5. Which statement best describes the role you and/or your family played in treatment decisions for your most recent cancer? ***Mark only one.***
   - ⬭ You and/or your family made the decisions with little or no input from your doctors.
   - ⬭ You and/or your family made the decisions after considering your doctors' opinions.
   - ⬭ You and/or your family and your doctors made the decisions together.
   - ⬭ Your doctors made the decisions after considering you and/or your family's opinion.
   - ⬭ Your doctors made the decisions with little or no input from you and/or your family.

6. To the best of your knowledge, are you now cancer-free?
   - ⬭ No
   - ⬭ Yes
   - ⬭ I Don't know

7. Please provide the name and address of the one doctor who primarily follows you for your most recent cancer at this time. ***If no one follows you for your cancer, go to question 11 (on the next page)***.

   **Physician Name:** ______________________________

   **Physician Address:** ______________________________

   ______________________________

   **Physician Telephone Number:** _(_____)______________________________

8. What type of doctor is s/he?
   - ⬭ Medical oncologist
   - ⬭ Surgeon
   - ⬭ OB/GYN
   - ⬭ Don't know what type
   - ⬭ Radiation oncologist
   - ⬭ Primary Care Physician (PCP)
   - ⬭ Other ***(specify)***: ____________

9. Over the course of the last year, which of the following was done by this doctor to follow your most recent cancer? ***Mark all that apply.***
   - ⬭ Physician examination
   - ⬭ Scopes (e.g. colonoscopy)
   - ⬭ Blood work
   - ⬭ Scans (X-rays, ultrasounds, CT scans, mammograms, etc.)
   - ⬭ Other ***(specify)***: ____________

10. How many outpatient clinic visits have you had with this doctor in the last year?
    - ⬭ None
    - ⬭ 1
    - ⬭ 2
    - ⬭ 3
    - ⬭ 4
    - ⬭ 5
    - ⬭ 6
    - ⬭ 7 or more

11. Some people have a Primary Care Physician (PCP). This doctor may be your family doctor, a general internist, or a specialist doctor. Sometimes your PCP is someone who has known you for many years and sometimes it may be a doctor that your insurance company or health plan assigns to you who may not know you very well. Please answer the following questions about your PCP. ***If you do not have a PCP, go to question 13 below***.

**Physician Name:** ______________________________________________

**Physician Address:** ____________________________________________

______________________________________________

**Physician Telephone Number:** _(_____)________________________________

12. How many outpatient clinic visits have you had with this doctor in the last year?

| | | | |
|---|---|---|---|
| ⬭ | None | ⬭ | 4 |
| ⬭ | 1 | ⬭ | 5 |
| ⬭ | 2 | ⬭ | 6 |
| ⬭ | 3 | ⬭ | 7 or more |

13. Have you seen another kind of healer other than your regular doctors, such as an acupuncturist, herbalist, homeopath, chiropractor, practitioner of Ayurveda or Chinese medicine, curandera or spiritual healer?

⬭ No ***Go to question 15***

⬭ Yes ***Continue with question 14***

14. Please specify the type of healer in the box below, regardless of whether it was listed above.

15. Have you received an influenza vaccination (flu shot) in the past 2 years?

⬭ No ***Go to question 17 (next page)***

⬭ Yes ***Continue with question 16***

16. Where did you receive the influenza vaccination?

⬭ From my PCP

⬭ From one of my cancer doctors

⬭ From another doctor ***(specify type)*** →

⬭ Not from a doctor (e.g., pharmacy, free clinic)

17. How much responsibility should each of the following doctors have **to follow you for your most recent cancer?**

| | None | A little | Some | A lot | Full |
|---|---|---|---|---|---|
| Cancer doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Primary Care Doctor (PCP) | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Other doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |

**(Please specify type of other doctor here)** → ____________________

18. How much responsibility should each of the following doctors have **to screen you for cancers other than your most recent cancer**? By this we mean, in general, ordering mammograms for women who did not have breast cancer, arranging colon cancer screening, etc.

| | None | A little | Some | A lot | Full |
|---|---|---|---|---|---|
| Cancer doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Primary Care Doctor (PCP) | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Other doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |

**(Please specify type of other doctor here)** → ____________________

19. How much responsibility should each of the following doctors have **to provide general preventive health care**, like flu shots or cholesterol testing?

| | None | A little | Some | A lot | Full |
|---|---|---|---|---|---|
| Cancer doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Primary Care Doctor (PCP) | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Other doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |

**(Please specify type of other doctor here)** → ____________________

20. How much responsibility should each of the following doctors have **to treat other medical problems besides cancer**, such as diabetes, high blood pressure or arthritis?

| | None | A little | Some | A lot | Full |
|---|---|---|---|---|---|
| Cancer doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Primary Care Doctor (PCP) | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |
| Other doctor | ⬭ | ⬭ | ⬭ | ⬭ | ⬭ |

**(Please specify type of other doctor here)** → ____________________

21. Did you and each of your doctors ever have a discussion about which doctor would **follow you for your most recent cancer**?

| | No | Yes | Don't know |
|---|---|---|---|
| Cancer doctor | ⬭ | ⬭ | ⬭ |
| Primary Care Doctor (PCP) | ⬭ | ⬭ | ⬭ |
| Other doctor | ⬭ | ⬭ | ⬭ |

**(Please specify type of other doctor here)** → ____________________

22. Did you and each of your doctors ever have a discussion about which doctor would **handle your other medical problems besides cancer**, such as diabetes, high blood pressure or arthritis?

| | No | Yes | Don't know |
|---|---|---|---|
| Cancer doctor | ⬭ | ⬭ | ⬭ |
| Primary Care Doctor (PCP) | ⬭ | ⬭ | ⬭ |
| Other doctor | ⬭ | ⬭ | ⬭ |

**(Please specify type of other doctor here)** → ____________________

23. Mark the type of doctors that you currently see for each medical condition listed. If you had or have a condition but are not currently being seen for it, fill the circle in the "No doctor" column.

| | PCP | Cancer doctor | Other doctor | No doctor | Never had condition |
|---|---|---|---|---|---|
| a. Diabetes or high blood sugar | ◯ | ◯ | ◯ | ◯ | ◯ |
| b. High blood pressure or hypertension | ◯ | ◯ | ◯ | ◯ | ◯ |
| c. Heart attack | ◯ | ◯ | ◯ | ◯ | ◯ |
| d. Congestive heart failure | ◯ | ◯ | ◯ | ◯ | ◯ |
| e. Stroke, blood clot or brain bleeding | ◯ | ◯ | ◯ | ◯ | ◯ |
| f. Peripheral vascular disease (includes aortic aneurysm, leg artery bypass) | ◯ | ◯ | ◯ | ◯ | ◯ |
| g. Emphysema, chronic bronchitis, lung disease or asthma | ◯ | ◯ | ◯ | ◯ | ◯ |
| h. Stomach and/or intestinal problems, such as ulcers, Crohn's disease or inflammatory bowel disease | ◯ | ◯ | ◯ | ◯ | ◯ |
| i. Chronic back pain, including sciatica | ◯ | ◯ | ◯ | ◯ | ◯ |
| j. Osteoporosis (loss of bone mass) | ◯ | ◯ | ◯ | ◯ | ◯ |
| k. Rheumatologic disease (includes arthritis, lupus, schleroderma, etc.) | ◯ | ◯ | ◯ | ◯ | ◯ |
| l. Kidney problems | ◯ | ◯ | ◯ | ◯ | ◯ |
| m. Liver disease (cirrhosis/hepatitis) | ◯ | ◯ | ◯ | ◯ | ◯ |
| n. Paralysis | ◯ | ◯ | ◯ | ◯ | ◯ |
| o. Depression, emotional, nervous or psychiatric problems | ◯ | ◯ | ◯ | ◯ | ◯ |
| p. Severe problems with memory or concentration | ◯ | ◯ | ◯ | ◯ | ◯ |
| **Please list other medical conditions below** | | | | | |
| q. ____________________ | ◯ | ◯ | ◯ | ◯ | ◯ |
| r. ____________________ | ◯ | ◯ | ◯ | ◯ | ◯ |
| s. ____________________ | ◯ | ◯ | ◯ | ◯ | ◯ |

The following questions (24-28) are for patients who were treated for breast cancer. ***If you were not treated for breast cancer, please go to question 29, on page 11.***

Follow-up for breast cancer survivors consists primarily of a review of recent symptoms, breast examination, and mammography or other breast imaging. We're interested in how acceptable you would find **"virtual visits"** as a way to provide follow-up for your breast cancer. In the following questions, **"virtual visit"** refers to a conversation by phone or over the internet with a breast cancer doctor or nurse which could safely replace a clinic visit.

24. On average, how many times per year are you seen for breast cancer follow-up visits? This does **not** include radiology appointments for a mammogram. Please write the number in the blue box below.

25. Do you think the number of times you mentioned above is:
- Too many
- Just enough
- Too few

26a. How do you think appointments with the following types of providers would affect **your overall chance of surviving your cancer**?

| | Will decrease | May decrease somewhat | Neither increase or decrease | May somewhat increase | Will increase |
|---|---|---|---|---|---|
| Medical oncologist | ○ | ○ | ○ | ○ | ○ |
| Radiation oncologist | ○ | ○ | ○ | ○ | ○ |
| Surgeon | ○ | ○ | ○ | ○ | ○ |
| Nurse practitioner | ○ | ○ | ○ | ○ | ○ |
| PCP | ○ | ○ | ○ | ○ | ○ |
| Virtual visit | ○ | ○ | ○ | ○ | ○ |

26b. Please rank the providers below by how much you think seeing them would **increase your survival from cancer**. Rank from 1 (most likely to increase survival) to 6 (least likely to increase survival).

______ Medical oncologist
______ Radiation oncologist
______ Surgeon
______ Specialized nurse practitioner
______ PCP
______ Virtual visit
◯ None of the above will increase my survival from cancer.

27a. How do you think appointments with the following types of providers would **affect your worrying about your cancer**?

| | Will decrease | May decrease somewhat | Neither increase or decrease | May somewhat increase | Will increase |
|---|---|---|---|---|---|
| Medical oncologist | ◯ | ◯ | ◯ | ◯ | ◯ |
| Radiation oncologist | ◯ | ◯ | ◯ | ◯ | ◯ |
| Surgeon | ◯ | ◯ | ◯ | ◯ | ◯ |
| Nurse practitioner | ◯ | ◯ | ◯ | ◯ | ◯ |
| PCP | ◯ | ◯ | ◯ | ◯ | ◯ |
| Virtual visit | ◯ | ◯ | ◯ | ◯ | ◯ |

27b. Please rank the providers below by how much you think seeing them would **decrease your worrying about your cancer**. Rank from 1 (most likely to decrease worrying) to 6 (least likely to decrease worrying).

______ Medical oncologist
______ Radiation oncologist
______ Surgeon
______ Specialized nurse practitioner
______ PCP
______ Virtual visit
◯ None of the above will decrease worrying

28a. How do you think appointments with the following types of providers would **affect your stress around each follow-up visit**?

| | Will decrease | May decrease somewhat | Neither increase or decrease | May somewhat increase | Will increase |
|---|---|---|---|---|---|
| Medical oncologist | ○ | ○ | ○ | ○ | ○ |
| Radiation oncologist | ○ | ○ | ○ | ○ | ○ |
| Surgeon | ○ | ○ | ○ | ○ | ○ |
| Nurse practitioner | ○ | ○ | ○ | ○ | ○ |
| PCP | ○ | ○ | ○ | ○ | ○ |
| Virtual visit | ○ | ○ | ○ | ○ | ○ |

28b. Please rank the providers below by **how much stress you would have at follow-up visits with them**. Rank from 1 (most likely to find the visit stressful) to 6 (least likely to find the visit stressful).

_______ Medical oncologist
_______ Radiation oncologist
_______ Surgeon
_______ Specialized nurse practitioner
_______ PCP
_______ Virtual visit
○ None of the above will cause me stress

29. How old are you (in years)? Write numbers in the boxes and then fill in the corresponding circles.

| | |
|---|---|
| ⓪ | ⓪ |
| ① | ① |
| ② | ② |
| ③ | ③ |
| ④ | ④ |
| ⑤ | ⑤ |
| ⑥ | ⑥ |
| ⑦ | ⑦ |
| ⑧ | ⑧ |
| ⑨ | ⑨ |

30. Are you? ***Mark only one.***
- ◯ Male
- ◯ Female

31. What is your current marital status? ***Mark only one.***
- ◯ Married/Living in a marriage-like relationship
- ◯ Separated/Divorced/Widowed
- ◯ Single/Never married

32. What is the **highest** grade or level of school you have completed? ***Mark only one.***
- ◯ 8th grade or less
- ◯ Some high school (grades 9 to 12)
- ◯ High school diploma or GED
- ◯ Vocational school or some college
- ◯ College graduate (Bachelor's degree)
- ◯ Professional or graduate school experience

33. Please indicate all categories that **best** describe your **current** employment situation.
- ◯ Paid full-time
- ◯ Paid part-time
- ◯ Homemaker
- ◯ Retired --- not working
- ◯ Self-employed
- ◯ Volunteer
- ◯ Student
- ◯ Unemployed, looking for work
- ◯ Unemployed, not looking for work
- ◯ Not employed --- disabled

34. Have any of the following things happened to you since you were diagnosed with your most recent cancer?

| | **Mark all that apply** |
|---|---|
| a. You were laid off or fired | ◯ |
| b. Your responsibilities on the job were cut | ◯ |
| c. You were passed over for a raise/promotion | ◯ |
| d. Your salary was reduced | ◯ |
| e. You were demoted | ◯ |
| f. You were given an easier assignment | ◯ |
| g. You were treated differently by people at work | ◯ |
| h. You felt less comfortable with people at work | ◯ |
| i. You felt supported by your employer | ◯ |
| j. You felt supported by your coworkers | ◯ |
| k. You were transferred or moved | ◯ |
| l. You had to go on disability | ◯ |
| m. You were forced into retirement | ◯ |

35. What was your **primary** occupation (job) when you were diagnosed with your most recent cancer (example: manager, engineer, machinist, etc.)? ***Please specify*:**

36. What best describes your racial background? ***Mark only one.***

- ◯ African American/Black
- ◯ American Indian/Aleut/Eskimo
- ◯ Asian/Pacific Islander
- ◯ Caucasian/White
- ◯ Multi-racial
- ◯ Other ***(please specify)***:

37. Do you consider yourself Hispanic or Latino(a)?

- ◯ No
- ◯ Yes

38. Including income provided by **you**, your **spouse/partner**, and others you regard as **family** who live in your household, what was your total household income (from all sources) before taxes in the **last calendar year**? Please remember that your answers are confidential. ***Mark only one.***

- ◯ Less than $20,000
- ◯ $20,000 - $39,999
- ◯ $40,000 - $59,999
- ◯ $60,000 - $79,999
- ◯ $80,000 or more
- ◯ Prefer not to answer

39. Have you ever smoked cigarettes/cigars regularly - that is, at least one cigarette/cigar every day?

- ◯ No ***Go to question 41 (next page)***
- ◯ Yes ***Continue wth question 40***

40. If you answered yes in question 39, please fill in the following boxes/circles.

a. Enter how old you were when you first started smoking.

| | |
|---|---|
| 0 | 0 |
| 1 | 1 |
| 2 | 2 |
| 3 | 3 |
| 4 | 4 |
| 5 | 5 |
| 6 | 6 |
| 7 | 7 |
| 8 | 8 |
| 9 | 9 |

b. Enter the year you stopped smoking. If you are still a smoker, leave it blank.

| | | | |
|---|---|---|---|
| 0 | 0 | 0 | 0 |
| 1 | 1 | 1 | 1 |
| 2 | 2 | 2 | 2 |
| 3 | 3 | 3 | 3 |
| 4 | 4 | 4 | 4 |
| 5 | 5 | 5 | 5 |
| 6 | 6 | 6 | 6 |
| 7 | 7 | 7 | 7 |
| 8 | 8 | 8 | 8 |
| 9 | 9 | 9 | 9 |

41. How often do you drink any type of alcoholic beverage?

- ⬭ None/never — ***Go to question 43***
- ⬭ Less than once a month — ***Go to question 42***
- ⬭ Once a month to once a week — ***Go to question 42***
- ⬭ 2 to 3 days per week — ***Go to question 42***
- ⬭ 4 to 6 days per week — ***Go to question 42***
- ⬭ Daily (7 days per week) — ***Go to question 42***
- ⬭ Don't know — ***Go to question 43***

42. On those days that you drink alcoholic beverages, on average, how many drinks do you have?

- ⬭ 1-2 drinks
- ⬭ 3-4 drinks
- ⬭ 5 or more drinks
- ⬭ Don't know

43. How tall are you without shoes? Mark your height in feet and inches using the boxes below. Please write the numbers and fill in the corresponding circles.

| Feet | / Inches | |
|---|---|---|
| | | |
| 0 | 0 | 0 |
| 1 | 1 | 1 |
| 2 | 2 | 2 |
| 3 | 3 | 3 |
| 4 | 4 | 4 |
| 5 | 5 | 5 |
| 6 | 6 | 6 |
| 7 | 7 | 7 |
| 8 | 8 | 8 |
| 9 | 9 | 9 |

44. How much do you currently weigh (lbs.)? Please write the numbers and fill in the corresponding circles in the box to the right.

| | | |
|---|---|---|
| 0 | 0 | 0 |
| 1 | 1 | 1 |
| 2 | 2 | 2 |
| 3 | 3 | 3 |
| 4 | 4 | 4 |
| 5 | 5 | 5 |
| 6 | 6 | 6 |
| 7 | 7 | 7 |
| 8 | 8 | 8 |
| 9 | 9 | 9 |

45. Do you currently have any kind of health care coverage, including health insurance, prepaid plans such as HMOs, or government plans such as Medicare or Medicaid?

- ⬭ No — ***Go to question 47***
- ⬭ Yes — ***Continue with question 46***

46. What best describes the **primary** type of health care coverage you currently have? By **primary** we mean the type of coverage you use to pay for **most** of your medical care, not a supplemental or secondary plan. ***Please mark only one response.***

- ⬭ HMO or Health Maintenance Organization (I have to go to a doctor on the list given to me by my insurance company to be covered)
- ⬭ PPO or Preferred Provider Organization (I can go to any doctor, but it costs less if I go to doctors on the list my insurance company gives me)
- ⬭ Traditional Fee for Service or Standard Indemnity Insurance Plan (I can go to any doctor; my insurance company does not give me a list of doctors to choose from)
- ⬭ Military/Veterans Association (CHAMPUS, TriCare)
- ⬭ Medicaid or Medical Assistance
- ⬭ Medicare

47. When you first went to see a doctor for your most recent cancer, did you have health insurance coverage?

- ⬭ No
- ⬭ Yes
- ⬭ Don't know

48. Were there any tests or treatments that your doctor recommended for you and your most recent cancer that you did **not** get because of problems with insurance coverage or because you were unable to pay for them?

- ⬭ No — ***Go to question 50 (next page)***
- ⬭ Yes — ***Continue with question 49***

49. What tests or treatments were those? ***Please list them.***

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

50. What number would you use to rate the quality of your overall medical care from all doctors in the last 12 months?

| ◯ | ◯ | ◯ | ◯ | ◯ | ◯ | ◯ | ◯ | ◯ | ◯ | ◯ |
|---|---|---|---|---|---|---|---|---|---|---|
| 0 | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| **Worst** | | | | | | | | | | **Best** |

51. In general, would you say your health is:
- ◯ Excellent
- ◯ Very good
- ◯ Good
- ◯ Fair
- ◯ Poor

52. Should another relevant medical study come up, can we contact you again?
- ◯ No, please don't contact me again
- ◯ Yes, you may contact me again

**Thank you for participating in this study! Please use the space below or on the back of this survey to provide any comments you may have. Should you have any further questions or concerns about this survey or any of its questions, please contact Bridget Neville, MPH at 617-632-4871. Please return your completed survey in the envelope provided to Dr. Earle at Dana-Farber Cancer Institute, 44 Binney St., Boston MA 02115.**