

Your Experiences with Cancer

Your opinion matters!



This survey is about the lasting effects of cancer and cancer treatments on the lives of those who have been diagnosed with cancer. The survey will ask about the effects of cancer, its treatment, or the lasting effects of that treatment on your employment, finances, and life in general. The goal of this survey is to help improve experiences of people diagnosed with cancer in the future.

Survey Instructions

- ◆ Please take the time to answer these questions about your experiences with cancer.
- ◆ Your participation is voluntary and all of your answers will be kept confidential as required by law. If you have any questions about how to complete this booklet, please call Alex Scott at 1-800-945-MEPS (6377).
- ◆ Answer each question by marking ☒ your response or filling in a number when necessary. If you are unsure about how to answer a question, please give the best answer you can.
- ◆ You may skip any questions you do not wish to answer or to stop taking the survey at any time.

This Booklet Should Be Completed By	REGION:		RUID:		PID:	
	NAME:					
	DOB:		/		/	
MONTHDAYYEAR						

This survey is authorized under 42 U.S.C. 299a. Privacy is protected by the Privacy Act and Section 308(d) of the Public Health Service Act [42 U.S.C. 299c-3(c) and 42 U.S.C. 242m(d)]. The confidentiality of your responses to this survey is protected by Section 944(c). Information that could identify you will not be disclosed unless you have consented to that disclosure. Public reporting burden for this collection of information is estimated to average 20 minutes per response, the estimated time required to complete the survey. An agency may not conduct or sponsor, and a person is not required to respond to, a collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden, to: AHRQ Reports Clearance Officer Attention: PRA, Paperwork Reduction Project (0935-0118) AHRQ, 5600 Fishers Lane, Room #07W42, Rockville, MD 20857.



The Agency for Healthcare Research and Quality
of the U.S. Department of Health and Human Services

Section 1. Cancer History

➡ This first section asks about your cancer history.

1. Have you ever been told by a doctor or other health professional that you had cancer or a malignancy of any kind?

Yes
No

Please stop. Thank you for your time. This survey is complete.

☐ ☐

2. Was your only cancer diagnosis or treatment before the age of 18?

Yes
No

Please stop. Thank you for your time. This survey is complete.

3. Are you currently being treated for cancer – that is are you planning or recovering from cancer surgery, or receiving chemotherapy, radiation therapy, or hormonal therapy for your cancer?

☐ Yes ➡ **GO TO Question 7, Page 3**
☐ No

4. About how long ago did you receive your last cancer treatment?

☐ Less than 1 year ago
☐ 1 year ago to less than 3 years ago
☐ 3 years ago to less than 5 years ago
☐ 5 years ago to less than 10 years ago
☐ 10 years ago to 20 years ago
☐ More than 20 years ago
☐ I have not been treated for cancer

5. Did a doctor or other health professional ever tell you that your cancer had come back?

☐ Yes
☐ No ➡ **GO TO Section 2, Page 3**

6. What was the most recent year a doctor or health professional told you that your cancer had come back?

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YEAR

➔ **GO TO Section 2**

7. Is this the first time you have ever been treated for cancer?

☐ Yes

☐ No

Section 2. Impacts on Work

8. At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business (including being self-employed)?

← Yes

☐ No ➔ **GO TO Question 18, Page 5**

- ➔ These next questions ask about different ways cancer, its treatment, or the lasting effects of that treatment may have affected your work – that is, your hours, duties, or employment status.
- ➔ As you answer these questions, please think about the entire time from when you were first diagnosed with cancer to now.
- ➔ If you have had more than one type of cancer, please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

9. Because of your cancer, its treatment, or its lasting effects, at any time since your first cancer diagnosis:

Mark ☒ yes or no for each item below.

	Yes ▼	No ▼
a) Did you ever take extended (more than an occasional day off here and there) paid leave (vacation, sick leave, or disability leave) from work?	☐	☐
b) Did you ever take extended unpaid leave from work (including taking Family Medical Leave)?	☐	☐
c) Did you ever change from working full-time to working part-time or change to a less demanding job?	☐	☐
d) Did you ever quit your job (leave your job and plan to find another job at some point)?	☐	☐
e) Did you ever change from a set work schedule, where you start and end at the same time every day, to a flexible work schedule, where your start and end times vary from day-to-day?	☐	☐

10. Because of your cancer, its treatment, or its lasting effects, at any time since your first cancer diagnosis:

Mark ☒ yes or no for each item below.

	Yes ▼	No ▼
a) Did you ever decide not to pursue an advancement or promotion?	☐	☐
b) Did you retire earlier than you had planned?	☐	☐
c) Did you delay retirement beyond when you had planned?	☐	☐

11. Did or does your cancer, its treatment, or its lasting effects limit the kind or amount of paid work you could do?

- ☐ Yes
☐ No

12. Because of your cancer, its treatment, or its lasting effects, did any of your employers do anything to help you out so that you can continue working?

Mark ☒ all that apply.

- ☐ Get someone to help you with your work duties
☐ Shorten your work days
☐ Allow you to change the time you came to and left work
☐ Allow you more breaks and rest periods
☐ Change the job to something you could do
☐ Help you learn new skills or get you special equipment or a computer for the job
☐ Assist you in receiving rehabilitative services from an external provider
☐ Allow you to work from home
☐ Any other things to help you out
☐ I did not need help from my employer
☐ My employers didn't offer me any help
☐ Not applicable

13. Because of your cancer, its treatment, or its lasting effects, did you ask any of your employers for help to do your job that you did NOT receive?

- ☐ Yes
☐ No, because I didn't need any help from my employer
☐ No, because I received all the help I needed
☐ No, but I would have liked to get help (or more help) from my employer
☐ Not applicable

14. Because of your cancer, its treatment, or its lasting effects, at any time since your first cancer diagnosis, have you experienced any of the following?

Mark ☒ all that apply.

- ☐ Had job hours or wages reduced without your request
- ☐ Was let go, laid off, or fired from a job
- ☐ Was passed over for a promotion or job advancement
- ☐ Was assigned job duties or to a job location you didn't want
- ☐ Not applicable / None of the above

15. Did you ever feel that, because of your cancer, its treatment, or the lasting effects of that treatment, you were less productive at work?

- ☐ Yes
- ☐ No

16. Did you ever worry that, because of the effects of cancer on your health, you might be forced to retire or quit work before you are ready?

- ☐ Yes
- ☐ No

17. Did you ever stay at a job in part because you were concerned about losing your health insurance?

- ☐ Yes
- ☐ No

18. Since your cancer diagnosis, did your spouse or significant other ever stay at a job in part because he/she was concerned about losing health insurance for the family?

- ☐ Yes
- ☐ No
- ☐ No spouse / significant other

Section 3. The Effects of Cancer and Its Treatment on Finances

- The next questions ask about different kinds of financial burden you or your family may have experienced because of your cancer, its treatment, or the lasting effects of that treatment.
- Please continue to think about all the time from when you were first diagnosed with cancer to now.
- If you have had more than one type of cancer, please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

19. Because of your cancer, its treatment or the lasting effects of that treatment, did you have any costs you had to pay out of your own pocket in the following categories?

Mark ☒ all that apply.

- ☐ Medical expenses (e.g., medications, medical equipment or supplies)
- ☐ Transportation
- ☐ Lodging
- ☐ Child care
- ☐ Home or respite care
- ☐ I had no out-of-pocket costs
- ☐ I am not sure

20. Have you or has anyone in your family had to borrow money or go into debt because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes
- ☐ No ➤ **GO TO Question 22, Page 7**

21. How much did you or your family borrow, or how much debt did you incur because of your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Less than \$10,000
- ☐ \$10,000 to \$24,999
- ☐ \$25,000 to \$49,999
- ☐ \$50,000 to \$74,999
- ☐ \$75,000 to \$99,999
- ☐ \$100,000 or more

22. Have you or your family had to make any other kinds of financial sacrifices because of your cancer, its treatment, or the lasting effects of that treatment?

Mark ☒ all that apply.

- ☐ Reduced spending on vacation or leisure activities
- ☐ Delayed large purchases (e.g., car)
- ☐ Reduced spending on basics (e.g., food and clothing)
- ☐ Used savings set aside for other purposes (e.g., retirement, educational funds, family support)
- ☐ Made a change to living situation (e.g., sold, refinanced, or moved to a smaller residence)
- ☐ Other
- ☐ No

23. Please think about medical care visits for cancer, its treatment, or the lasting effects of that treatment. Have you ever been unable to cover your share of the cost of those visits?

- ☐ Yes
- ☐ No

24. Have you ever worried about having to pay large medical bills related to your cancer?

- ☐ Yes
- ☐ No

25. Have you ever worried about your family's financial stability because of your cancer, its treatment or lasting effects of that treatment?

- ☐ Yes
- ☐ No

26. Have you ever been concerned about keeping your job and income, or that your earnings will be limited in the future because of your cancer?

- ☐ Yes
- ☐ No

27. Did you ever delay, forego, or have to make other changes to any of the following cancer care because of cost?

Mark ☒ all that apply.

- ☐ Prescription medicine
- ☐ Visit to specialist
- ☐ Treatment (other than prescription medicine)
- ☐ Follow up care
- ☐ Mental health services
- ☐ Other

☐ No

Section 4. Medical Care for Cancer

- These next questions ask about certain experiences you may have had when receiving medical care for cancer from the time you were first diagnosed to now.
- If you have had more than one type of cancer, please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

28. At any time since you were first diagnosed with cancer, did any doctor or other healthcare provider, including your current healthcare provider, ever discuss with you...

a. Your emotional or social needs related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

b. Participating in cancer clinical trials?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

c. Your costs for cancer care paid out of your own pocket?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

d. The impact of cancer, its treatment, or its lasting effects on your ability to work?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

e. The need for regular follow-up care and monitoring even after completing your treatment?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

f. Late or long-term side effects of cancer treatment you may experience over time?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

g. Lifestyle or health recommendations such as diet, exercise, quitting smoking?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

h. A summary of all the cancer treatments you received?

- ☐ Discussed it with me in detail
- ☐ Briefly discussed it with me
- ☐ Did not discuss it at all
- ☐ I don't remember

29. Over the past year, have you experienced any of the following conditions that lasted longer than 3 months?

Mark ☒ yes or no for each item below.

	Yes ▼	No ▼
a) Cognitive impairment (for example, having difficulty remembering things, or 'chemobrain')	☐	☐
b) Neuropathy (numbness or tingling feelings)	☐	☐
c) Fatigue (always tired or sleepy)	☐	☐
d) Nausea	☐	☐
e) Pain	☐	☐
f) Problems with your mouth or teeth	☐	☐
g) Other condition(s) not listed	☐	☐

30. About how long ago was your most recent cancer diagnosis?

- ☐ Less than 2 years ➔ **GO TO Section 5, Page 12**
- ☐ 2 years to less than 5 years
- ☐ 5 years to less than 10 years
- ☐ 10 years to less than 20 years
- ☐ 20 years or more

31. In the past 2 years, did you see any health care provider specifically for cancer-related follow-up care? This could either be a cancer specialist or some other health care provider.

☐ Yes

☐ No ➔ **GO TO Question 36, Page 11**

32. In the past 2 years, what were the reasons you saw any health care provider for cancer-related follow-up care?

Mark ☒ all that apply.

- ☐ To check for a recurrence or metastasis of your original cancer
- ☐ To receive additional treatment for your cancer if needed
- ☐ To determine if you have developed any health problems as a result of your cancer or its treatment
- ☐ To receive treatment for any symptoms or side effects of treatment
- ☐ To receive a routine physical exam
- ☐ To receive any screening test for other cancers (including such tests as mammogram or Pap smear for women, colonoscopy, sigmoidoscopy, stool check for blood, or PSA or digital rectal exam for men)
- ☐ To obtain a referral to other specialist(s)
- ☐ Other

33. In the past 2 years, how often did the health care provider(s) you saw for cancer-related follow-up care...

	Never	Sometimes	Usually	Always
a) <u>listen carefully</u> to you?	☐	☐	☐	☐
b) <u>explain things</u> in a way you could understand?	☐	☐	☐	☐
c) <u>show respect</u> for what you had to say?	☐	☐	☐	☐
d) <u>spend enough time</u> with you?	☐	☐	☐	☐

34. What were the specialties of the health care providers you saw for cancer-related follow-up care in the past 2 years?

Mark ☒ all that apply.

- ☐ Primary care (such as internal medicine, family medicine, or general practice)
- ☐ Medical oncology or hematology
- ☐ Radiation oncology
- ☐ Surgery
- ☐ Obstetrics / Gynecology (Ob-Gyn)
- ☐ Dental or oral care
- ☐ Other medical or surgical specialties
- ☐ I am not sure

35. In the past 2 years, have you seen a mental health professional (psychiatrist, psychologist, or other mental health professional) for cancer-related follow-up care?

- ☐ Yes
- ☐ No
- ☐ I am not sure

GO TO Section 5, Page 12.

36. What are the main reasons you did NOT see a health care provider for cancer-related follow-up care in the past 2 years?

Mark ☒ all that apply.

- ☐ I felt I didn't need follow-up care
- ☐ My health care provider(s) told me I didn't need follow-up care
- ☐ Cost too much
- ☐ Insurance didn't cover it
- ☐ Problems finding a health care provider, making an appointment, or getting to an appointment
- ☐ It made me anxious or worried
- ☐ Getting to the doctor was just too hard
- ☐ I didn't know about it
- ☐ Other reason not listed above

Section 5. The Effects of Cancer and Its Treatment on Life in General

- ➔ The last few questions in the survey ask about how your cancer, its treatment and the lasting effects of that treatment may have influenced certain parts of your life.
- ➔ If you have had more than one type of cancer, please think about your experiences across all of them. If that is not possible, please focus on the most severe, and if they were equally severe, please focus on the most recent.

37. Did your cancer, its treatment, or the lasting effects of that treatment ever limit the kind or amount of activities you do outside of work, such as shopping, child care, exercising, studying, work around the house, and so on?

☐ Yes

☐ No ➔ **GO TO Question 40**

38. How long were you or have you been limited in the kind or amount of usual daily activities?

- ☐ Less than 6 months
- ☐ 6 months to less than 1 year
- ☐ 1 year to less than 3 years
- ☐ 3 years to less than 5 years
- ☐ 5 years to less than 10 years
- ☐ More than 10 years

39. Is this limitation ongoing?

- ☐ Yes
- ☐ No

40. Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any mental tasks as part of your usual daily activities?

- ☐ Yes
- ☐ No

41. Did you ever have a problem understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?

- ☐ Yes
- ☐ No

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

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ All the time

43. Have any of the following been positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment?

Mark ☒ yes or no for each item below.

	Yes ▼	No ▼
a) It has made me a stronger person	☐	☐
b) I can cope better with life's challenges	☐	☐
c) It became a reason to make positive changes in my life	☐	☐
d) It has made me have healthier habits	☐	☐

44. In general, how would you rate your physical health?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

45. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?

- ☐ Completely
- ☐ Mostly
- ☐ Moderately
- ☐ A little
- ☐ Not at all

46. In the past 7 days, how would you rate your pain on average?

- ☐ 0 – No pain
- ☐ 1
- ☐ 2
- ☐ 3
- ☐ 4
- ☐ 5
- ☐ 6
- ☐ 7
- ☐ 8
- ☐ 9
- ☐ 10 – Worst imaginable pain

47. In the past 7 days, how would you rate your fatigue on average?

- ☐ None
- ☐ Mild
- ☐ Moderate
- ☐ Severe
- ☐ Very Severe

48. In general, would you say your quality of life is:

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

49. In general, how would you rate your mental health, including your mood and your ability to think?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

50. In general, how would you rate your satisfaction with social activities and relationships?

- ☐ Excellent
- ☐ Very Good
- ☐ Good
- ☐ Fair
- ☐ Poor

51. In the past 7 days, how often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

52. In the last 30 days, did you ever cut the size of your meals or skip meals because there wasn't enough money for food?

- ☐ Yes
- ☐ No
- ☐ I am not sure

53. Please indicate whether the following statements were often true, sometime true, or never true over the past 30 days:

	Often true ▼	Sometimes true ▼	Never true ▼
a) The food that we bought just did not last, and we did not have money to get more.	☐	☐	☐
b) We could not afford to eat balanced meals.	☐	☐	☐

54. How worried are you right now about not having enough money for retirement?

- ☐ Very worried
- ☐ Moderately worried
- ☐ Not too worried
- ☐ Not worried at all

55. How worried are you right now about not having enough to pay your normal monthly bills?

- ☐ Very worried
- ☐ Moderately worried
- ☐ Not too worried
- ☐ Not worried at all

56. How worried are you right now about not being able to pay your rent, mortgage, or other housing costs?

- ☐ Very worried
- ☐ Moderately worried
- ☐ Not too worried
- ☐ Not worried at all

57. Please respond to each item by marking one box per row.

	Never ▼	Rarely ▼	Sometimes ▼	Usually ▼	Always ▼
a) Do you have someone to help you if you are confined to bed?	☐	☐	☐	☐	☐
b) Do you have someone to take you to the doctor if you need it?	☐	☐	☐	☐	☐
c) Do you have someone to help with your daily chores if you are sick?	☐	☐	☐	☐	☐
d) Do you have someone to run errands if you need it?	☐	☐	☐	☐	☐

Date completed:

		/			/				
MONTH			DAY			YEAR			

Who completed this form?

- ☒ Person named on front of this form
- ☐ Someone else

If Someone Else, what is person's relationship to the person named on the front of this form?

- ☐ Husband or wife
- ☐ Unmarried partner
- ☐ Mother, father, or guardian
- ☐ Son or daughter
- ☐ Other relative
- ☐ Not related

Thank you for taking the time to complete this survey.

- ➔ Please place this survey in the envelope provided to you and give it to the MEPS interviewer.
- ➔ If the interviewer is no longer available, place the survey in the return envelope provided to you by the interviewer and mail as soon as possible. If the envelope is missing, mail this survey to:

MEPS
c/o Westat
1600 Research Blvd, Room GA51
Rockville, MD 20850