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Form Approved
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Medical Expenditure Panel Survey

Your Experiences with Cancer

- 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, health insurance coverage, and life in general. The goal of this survey is to help improve experiences of people diagnosed with cancer in the future. 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 to the extent permitted by law. If you have any questions about this survey, please call Alex Scott at 1-800-945-MEPS (6377).
- The person named in the box below should complete this survey:

NAME: _____

DOB: / / PID:

MONTH DAY YEAR

RUID:

- When you have completed the survey, return it to your interviewer.
- Complete your survey now, by continuing to the next page.

Your responses will be kept confidential to the extent permitted by law, including AHRQ's confidentiality statute, 42 USC 299c-3(c). That law requires that information collected for research conducted or supported by AHRQ that identifies individuals or establishments be used only for the purpose for which it was supplied unless you consent to the use of the information for another purpose. 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 and
The Centers for Disease Control and Prevention of the
U.S. Department of Health and Human Services



Section 1. Cancer History

- ▶ This first section asks about your cancer history.
- ▶ Answer each question by marking your response or filling in a number when necessary.

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

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 2

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, page 2

7. Is this the first time you have been treated for any type of cancer?

Yes

No

▶ Continue with Section 2, page 2.



Section 2. Changes to Your Work Schedule

8. At any time from when you were first diagnosed with cancer until now, were you working for pay at a job or business?

- Yes
 No → **GO TO Question 23, page 4**

- ▶ 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. At any time since your first cancer diagnosis, did you take extended paid time off from work, unpaid time off, or make a change in your hours, duties or employment status?

- Yes
 No → **GO TO Question 15, page 3**

10. Did you make these work changes...

- Because of your cancer, its treatment or its lasting effects?
 Some other reason? → **GO TO Question 15, page 3**

11. Did you ever take extended paid time off from work (vacation, sick time and/or disability leave)? By extended time off, we mean more than an occasional day off here and there.

- Yes
 No → **GO TO Question 13**

12. When did you take extended paid time off from work?

Mark all that apply.

- At the time of diagnosis
 During treatment
 Less than one year after treatment was finished
 One year or more after treatment was finished

13. Did you ever change from working full-time to working part-time or change to a less demanding job?

- Yes
 No

14. 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?

- Yes
 No



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15. **Because of your cancer, its treatment, or its lasting effects, did you ever decide not to pursue an advancement or promotion?**

Yes

No

16. **Because of your cancer, its treatment, or its lasting effects, did you retire earlier than you had planned?**

Yes

No

Section 3. Other Aspects of Work

▶ Please continue to think about all your work experiences from the time 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.

17. **Did you ever feel that your cancer, its treatment, or the lasting effects of that treatment interfered with your ability to perform any physical tasks required by your job?**

Yes

No

I was never required to perform physical tasks as part of my job

18. **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 required by your job?**

Yes

No

19. **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



20. 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

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

- Yes
 No → **GO TO Question 23**

22. Were you concerned about losing your health insurance because of your cancer?

- Yes
 No

23. 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
 Does not apply

Section 4. Caregivers

- ▶ This section is about caregivers, meaning friends or family members who may have provided help with getting to the doctor, going to appointments with you, making decisions about treatment, or providing other types of care and support during or after cancer treatment.
- ▶ Please continue to think about the time 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.

24. Since the time you were first diagnosed with cancer, has any friend or family member provided care to you during or after your cancer treatment?

- Yes
 No → **GO TO Section 5, page 5**

25. Who was your caregiver?

Mark all that apply.

- Spouse/partner
 Child
 Sibling
 Parent
 Other relative
 Friend
 Other



26. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties or employment status?

- Yes
- No
- None of my caregivers were employed
- I don't know

GO TO Section 5

27. Did any of your caregivers ever take extended paid time off from work, unpaid time off, or make a change in their hours, duties, or employment status for at least 2 months?

- Yes
- No
- I don't know

Section 5. Experiences with Health Insurance

- ▶ The next few questions are about health insurance coverage from the time 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.

28. At any time from when you were first diagnosed with cancer to now, were you covered by health insurance that paid for all or part of your medical care, tests or cancer treatment?

- Yes
 - No
 - I don't know
- GO TO Section 6, page 7

29. What type of health insurance did you have when you were diagnosed with cancer?

Mark all that apply.

- Private
- Medicare
- Medi-gap
- Medicaid
- Military (TRICARE, VA, CHAMPUS)
- Indian Health Service
- State-sponsored health plan
- Other government program
- Single service plan (e.g., dental, vision, prescriptions)
- No coverage of any type



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30. Was there ever a time when health insurance refused to cover a visit for your cancer to the doctor or facility of your choice, or a specific treatment or procedure?

- Yes
- No
- Does not apply

31. Was there ever a time when your current health insurance did not provide adequate coverage for your cancer and care- related expenses?

- Yes
- No
- Does not apply

32. In regard to your current health insurance coverage for your cancer, how does it compare to a year ago? Is it better, worse, or about the same?

- Better
- About the same
- Worse
- I don't know
- Does not apply

33. How difficult was it to find a plan with the type of coverage you needed for your cancer, including your cancer doctor, prescription medication, or other treatment? Would you say...

- Very difficult
- Somewhat difficult
- Not at all difficult
- I don't know
- Does not apply

34. How difficult was it to find a plan you could afford for your cancer, including your cancer doctor, prescription medication, or other treatment? Would you say...

- Very difficult
- Somewhat difficult
- Not at all difficult
- I don't know
- Does not apply

▶ **Continue with Section 6, page 7.**



Section 6. 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.

35. 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 don't know/I am not sure

36. 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 38**

37. 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

38. 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



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39. 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

40. Did you or your family ever file for bankruptcy because of your cancer, its treatment, or the lasting effects of that treatment?

- Yes
- No

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

- Yes
- No

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

- Yes
- No

43. 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

Section 7. 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.

44. 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. 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

b. 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



c. 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

d. 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

e. 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

f. 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

45. 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

46. At any time since you were first diagnosed with cancer, did you get all of the medical care, tests, or treatments that you or your doctor believed were necessary?

- Yes → GO TO Section 8, page 10
- No

47. Which of these are reasons you did not get all of the medical care, tests, or treatments you or a doctor believed you needed?

Mark yes or no for each item below.

Yes, a reason
No, not a reason

- a. Couldn't afford care
- b. Insurance company wouldn't approve or pay for care
- c. Doctor did not accept your insurance
- d. Had problems getting to doctor's office
- e. Couldn't get time off from work
- f. Didn't know where to go to get care
- g. Couldn't get child care/adult care
- h. Didn't have time, care/test/treatment took too long

▶ Continue with Section 8, page 10.



Section 8. 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.

48. 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 51**

49. 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

50. Is this limitation ongoing?

- Yes
 No

51. 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

52. 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

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

- Never
 Rarely
 Sometimes
 Often
 All the time

54. 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 | <input type="checkbox"/> | <input type="checkbox"/> |
| b. I can cope better with life's challenges | <input type="checkbox"/> | <input type="checkbox"/> |
| c. It became a reason to make positive changes in my life | <input type="checkbox"/> | <input type="checkbox"/> |
| d. It has made me have healthier habits | <input type="checkbox"/> | <input type="checkbox"/> |



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

- Excellent
- Very Good
- Good
- Fair
- Poor

56. 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

57. 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

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

- None
- Mild
- Moderate
- Severe
- Very Severe

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

- Excellent
- Very Good
- Good
- Fair
- Poor

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

- Excellent
- Very Good
- Good
- Fair
- Poor

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

- Excellent
- Very Good
- Good
- Fair
- Poor

62. 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



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Date completed:

<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
MONTH			DAY			YEAR			

- ▶ Thank you for completing this survey. Please place this survey in the envelope provided to you and give it to the MEPS interviewing team member.
- ▶ If the interviewer is no longer available, place the survey in the return envelope provided to you by the interviewer. If the envelope is missing, mail this survey to:

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Rockville, MD 20850

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