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OMB #: 0935-0118
Exp. Date: 1/31/2013

MEPS

Medical Expenditure Panel Survey

Your Experiences with Cancer

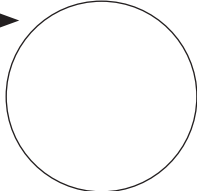
- This survey is about the lasting effects of cancer and cancer treatments on the lives of those who have been diagnosed with cancer.
- The survey will ask about the effects of cancer, its treatment, or the lasting effects of that treatment on your employment, finances, health insurance coverage, and 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 this survey, fold it, then seal with this label →  and place it in the envelope provided.

- 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, 540 Gaither Road, Room #5036, Rockville, MD 20850.



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

Attach label here (see back→cover) →



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 8**

No

4. To the best of your knowledge, are you now free of cancer?

Yes

No

I don't know

5. 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

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

Yes

No → **GO TO Section 2, page 2**

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

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→ **GO TO Section 2, page 2**

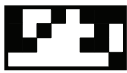
YEAR

8. 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

9. 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 47, page 6**

- ▶ 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.

10. 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 → **GO TO Question 13**

No

11. At any time since your first cancer diagnosis, did you ask for extended paid time off from work, unpaid time off, or a change in your hours, duties or employment status?

Yes

No → **GO TO Question 36, page 4**

12. Did you ask for these work changes...

Because of your cancer, its treatment or its lasting effects?

Some other reason?

GO TO Question 36, page 4

13. Did you make these work changes...

Because of your cancer, its treatment or its lasting effects?

Some other reason?

→ **GO TO Question 36, page 4**

14. 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 18, page 3**

15. 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

16. What do you estimate was the total amount of extended paid time off from work that you took?

Less than 2 months

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years



17. Is your extended paid time off from work ongoing?

- Yes
- No

18. Did you ever take unpaid time off from work?

- Yes
- No → **GO TO Question 22**

19. When did you take unpaid 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

20. What do you estimate was the total amount of unpaid time off from work that you took?

- Less than 2 months
- 2 months to less than 6 months
- 6 months to less than 1 year
- 1 year to 3 years
- More than 3 years

21. Is your unpaid time off ongoing?

- Yes
- No

22. Did you ever change from working part-time to working full-time?

- Yes
- No → **GO TO Question 26**

23. When did you change from working part-time to working full-time?

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

24. What do you estimate was the total amount of time you worked full-time?

- Less than 2 months
- 2 months to less than 6 months
- 6 months to less than 1 year
- 1 year to 3 years
- More than 3 years

25. Is this change ongoing?

- Yes
- No

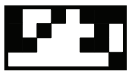
26. Did you ever change from working full-time to working part-time?

- Yes
- No → **GO TO Question 30, page 4**

27. When did you change from working full-time to working part-time?

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



28. What do you estimate was the total amount of time you worked part-time?

- Less than 2 months
- 2 months to less than 6 months
- 6 months to less than 1 year
- 1 year to 3 years
- More than 3 years

29. Is this change ongoing?

- Yes
- No

30. 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 → **GO TO Question 32**

31. When did you change to a flexible work schedule?

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

32. Did you ever change to a less demanding job?

- Yes
- No → **GO TO Question 36**

33. When did you change to a less demanding job?

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

34. How long did you stay in the less demanding job?

- Less than 2 months
- 2 months to less than 6 months
- 6 months to less than 1 year
- 1 year to 3 years
- More than 3 years

35. Is this change ongoing?

- Yes
- No

36. Did you make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- Yes
- No → **GO TO Question 37, page 5**

→ Please describe:



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

- Yes
- No

38. Because of your cancer, its treatment, or the lasting effects of that treatment, did you retire earlier than you had planned?

- Yes → **GO TO Section 3**
- No



39. Because of your cancer, its treatment, or the lasting effects of that treatment, did you delay retirement beyond when 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.
- 40. 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
- 41. 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
- 42. 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



Section 4. Caregivers

43. 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

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

- Yes
- No → *GO TO Question 46*

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

- Yes
- No

46. Thinking about your work life or career, what effect has your experience with cancer, its treatment, or the lasting effects of that treatment had on it?

- Mostly positive effect
- Mostly negative effect
- Equally positive and negative effect
- Neither positive nor negative effect

47. 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

▶ 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.

48. 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 8*

49. 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 → *GO TO Question 63, page 8*
- None of my caregivers were employed while caring for me → *GO TO Section 5, page 8*
- I don't know → *GO TO Question 63, page 8*

GO TO Question 50, page 7



50. 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 → *GO TO Question 63, page 8*

51. Did any of your caregivers take extended paid time off from work (vacation and/or sick time)?

Yes

No → *GO TO Question 54*

52. How long do you estimate this caregiver took extended paid time off from work?

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

53. Is this caregiver's extended paid time off from work ongoing?

Yes

No

54. Did any of your caregivers take unpaid time off from work?

Yes

No → *GO TO Question 57*

55. How long do you estimate this caregiver took unpaid time off from work?

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

56. Is this caregiver's unpaid time off ongoing?

Yes

No

57. Did any of your caregivers change from working part-time to working full-time?

Yes

No → *GO TO Question 60*

58. How long do you estimate this caregiver worked full-time?

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

59. Is this change ongoing?

Yes

No

60. Did any of your caregivers change from working full-time to working part-time?

Yes

No → *GO TO Question 63, page 8*

61. How long do you estimate this caregiver worked part-time?

2 months to less than 6 months

6 months to less than 1 year

1 year to 3 years

More than 3 years

62. Is this change ongoing?

Yes

No



63. Did any of your caregivers make any other type of work arrangements because of your cancer, its treatment, or the lasting effects of that treatment?

- Yes
 - No
 - I don't know
- } **GO TO Question 64**

Please describe:

64. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers change to a less demanding job?

- Yes
- No
- I don't know

65. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers retire early?

- Yes
- No
- I don't know

66. Because of your cancer, its treatment, or the lasting effects of that treatment, did any of your caregivers delay retirement?

- 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.

67. 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 Question 70**

68. Was there ever a time when health insurance refused to cover a visit for your cancer to the doctor or facility of your choice?

- Yes
- No
- Does not apply

69. Was there ever a time when health insurance refused to cover a second opinion about your cancer?

- Yes
- No
- I never asked for a second opinion

70. Were you ever denied health insurance coverage because of your cancer?

- Yes
- No
- I never applied for health insurance



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.

71. 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 74*

72. 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

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

- Yes
 No

74. 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?

- Yes
 No → *GO TO Question 75*

▶ **Please describe:**

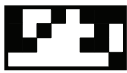
75. Have you ever worried about having to pay large medical bills related to your cancer?

- Yes
 No

76. 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

▶ **Continue with Section 7, page 10.**



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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.

77. 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

78. 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 11**
- No

79. 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 | <input type="checkbox"/> | <input type="checkbox"/> |
| b. Insurance company wouldn't approve or pay for care | <input type="checkbox"/> | <input type="checkbox"/> |
| c. Doctor did not accept your insurance | <input type="checkbox"/> | <input type="checkbox"/> |
| d. Had problems getting to doctor's office | <input type="checkbox"/> | <input type="checkbox"/> |
| e. Couldn't get time off from work | <input type="checkbox"/> | <input type="checkbox"/> |
| f. Didn't know where to go to get care | <input type="checkbox"/> | <input type="checkbox"/> |
| g. Couldn't get child care/adult care | <input type="checkbox"/> | <input type="checkbox"/> |
| h. Didn't have time, care/ test/treatment took too long | <input type="checkbox"/> | <input type="checkbox"/> |
| i. Other reason | <input type="checkbox"/> | <input type="checkbox"/> |

! If you answered 'Yes' to only one reason in Question 79, GO TO Section 8 on page 11. Otherwise continue with Question 80, on page 11.



80. Which one of these is the main reason that you did not get all of the medical care, tests, or treatments you or a doctor believed you needed?

Mark ONE only.

- Couldn't afford care
- Insurance company wouldn't approve or pay for care
- Doctor didn't accept your insurance
- Had problems getting to the doctors' office
- Couldn't get time off from work
- Didn't know where to go to get care
- Couldn't get child care/adult care
- Didn't have time, care/test/treatment took too long

Some other reason.



Please describe:

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.

81. 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 84**

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

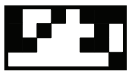
- Less than 6 months
- 6 months to less than 1 year
- 1 year to less than 3 years
- 3 years to less than 5 years
- 5 years to less than 10 years
- More than 10 years

83. Is this limitation ongoing?

- Yes
- No

84. 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



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85. Have you ever asked for help getting to a doctor or other healthcare provider because of your cancer, its treatment, or the lasting effects of that treatment?

- Yes
- No → *GO TO Question 87*

86. Did you ever receive help getting to a doctor or other healthcare provider?

- Yes
- No

87. Have you ever asked for help understanding health insurance or medical bills related to your cancer, its treatment, or the lasting effects of that treatment?

- Yes
- No → *GO TO Question 89*

88. Did you ever receive help understanding health insurance or medical bills?

- Yes
- No

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

- Never → *GO TO Question 91*
- Rarely
- Sometimes
- Often
- All the time

90. How often do you worry that if your cancer came back or got worse it might keep you from fulfilling responsibilities at home or at work?

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

91. In your own opinion, what do you think are the chances that your cancer will come back or get worse within the next 10 years?

- Very low
- Fairly low
- Moderate
- Fairly high
- Very high
- I don't know

92. 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"/>

93. Please use the space below to tell us anything else about your experiences with cancer.

- ▶ 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:

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

MEPS
Medical Expenditure Panel Survey

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