

# Your Experiences with Cancer

04/13/11

Placeholder for Introduction

**1. Have you been diagnosed with...**

- One type of cancer, or
- More than one type of cancer?

**2. Are you currently being treated for cancer?**

- Yes
- No → GO TO question 5.

**3. Is this treatment for. . .**

- A first diagnosis of this cancer, or
- A reoccurrence of this cancer?

**4. Does your current treatment protocol include:**

<u>Treatment</u>	<u>Yes</u>	<u>No</u>
a. Surgery	<input type="checkbox"/>	<input type="checkbox"/>
b. Chemotherapy (pills only)	<input type="checkbox"/>	<input type="checkbox"/>
c. Chemotherapy (intravenous)	<input type="checkbox"/>	<input type="checkbox"/>
d. Radiation	<input type="checkbox"/>	<input type="checkbox"/>
e. Other	<input type="checkbox"/>	<input type="checkbox"/>

► **If you are currently receiving treatment for your cancer, GO TO question 9 on the next page. If you are not currently receiving cancer treatment, continue to question 5.**

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

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

- Less than 12 months ago
- At least 1 year ago, but less than 3 years ago
- At least 3 years ago, but less than 5 years ago
- At least 5 years ago, but less than 10 years ago
- More than 10 years ago → GO TO question 59 on page X

**6. Did your last treatment protocol include:**

<u>Treatment</u>	<u>Yes</u>	<u>No</u>
a. Surgery	<input type="checkbox"/>	<input type="checkbox"/>
b. Chemotherapy (pills)	<input type="checkbox"/>	<input type="checkbox"/>
c. Chemotherapy (intravenous)	<input type="checkbox"/>	<input type="checkbox"/>
d. Radiation	<input type="checkbox"/>	<input type="checkbox"/>
e. Other	<input type="checkbox"/>	<input type="checkbox"/>

**7. At any point, did a doctor or health professional tell you that your cancer had come-back?**

- Yes
- No

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

- 1  Yes
- 2  No
- 8  I don't know

**9. Please think about your most recent cancer diagnosis. At that time, were you working for pay at a job or business?**

- Yes
- No → GO TO question 22 on page Y

▶ These next questions ask about different ways cancer or its treatment may have affected your job. As you answer these questions, please think about your most recent cancer diagnosis and its treatment.

**10. Did you ask to change your hours, duties or employment status because of your most recent cancer diagnosis or its treatment?**

- 1  Yes
- 2  No -- GO TO Q22

11. Did you change from a set schedule to a flexible schedule?

- 1  Yes
- 2  No -- GO TO Q12

11a. Did you change to a flexible schedule during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

11b. How long did you stay on a flexible schedule?

-----WEEKS

-----MONTHS

-----YEARS

12. Did you get approval to work from home for some or all of your regular hours?

- 1  Yes
- 2  No -- GO TO Q13

12a. Did you start working from home during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

12b. How long did you work from home for some or all of your regular hours?

-----WEEKS

-----MONTHS

-----YEARS

13. Did you change from full-time to part-time status?

- 1  Yes
- 2  No -- GO TO Q14

13a. Did you change to part-time status during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

13b. How long did you stay part-time?

-----WEEKS

-----MONTHS

-----YEARS

14. Did you change from part-time to full-time status?

- 1  Yes
- 2  No -- GO TO Q15

14a. Did you change to full-time status during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

14b. How long did you stay full-time?

-----WEEKS

-----MONTHS

-----YEARS

15. Did you take time off from work with pay (vacation and/or sick pay)

- 1  Yes
- 2  No -- GO TO Q16

15a. Did you take time off with pay during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

15b. How much time off did you take with pay?

-----WEEKS

-----MONTHS

-----YEARS

16. Did you take time off from work without pay?

- 1  Yes
- 2  No -- GO TO Q17

16a. Did you take time off without pay during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

16b. How much time did you take off without pay?

-----WEEKS

-----MONTHS

-----YEARS

17. Did you change to a less demanding job?

- 1  Yes
- 2  No -- GO TO Q18

17a. Did you change to a less demanding job during your treatment or after your treatment was finished?

- 1  During treatment
- 2  After treatment was finished

17b. How long did you stay in the less demanding job?

-----WEEKS

-----MONTHS

-----YEARS

18. Did you decide not to pursue an advancement or promotion?

- 1  Yes
- 2  No

19. Did you retire early?

- 1  Yes
- 2  No

20. Did you delay retirement?

- 1  Yes

2  No

21. Did you leave work on disability?

1  Yes

2  No

22. **Did your most recent cancer diagnosis or its treatment limit your ability to perform the following physical activities at work?**

	Yes	No	Not part of my job
a. Lift heavy loads	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
b. Stoop, kneel, or crouch	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>
c. Perform other physical tasks	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>

23. **How much of the time do you worry that, because of your health, you will be forced to retire or quit work before you are ready?**

1  All of the time

2  Some of the time

3  A little bit of the time

4  None of the time

24. **Do concerns about losing health insurance keep you in the job you have now?**

1  Yes

2  No

3  Don't currently have health insurance

25. **Do concerns about losing health insurance keep your spouse/significant other in the job he/she has now?**

1  Yes

2  No

3  Spouse/significant other not currently employed

26. **Is there one person who helped care for you the most during your most recent treatment for cancer?**

- Yes
- No → GO TO question 37

27. Did this person's hours, duties or employment status ever change because of your cancer or its treatment?

1  Yes

2  No -- GO TO Q37

This person was not employed at the time of my most recent cancer diagnosis -- GO TO Q37

28. Did this person change from full-time to part-time status?

1  Yes

2  No -- GO TO Q29

28a. How long did this person stay part-time?

-----WEEKS

-----MONTHS

-----YEARS

29. Did this person change from part-time to full-time status?

1  Yes

2  No -- GO TO Q30

29a. How long did this person stay full-time?

-----WEEKS

-----MONTHS

-----YEARS

30. Did this person take time off from work with pay (vacation and/or sick pay)

1  Yes

2  No -- GO TO Q31

30a. How much time did this person take off with pay?

-----WEEKS

-----MONTHS

-----YEARS

31. Did this person take time off from work without pay?

1  Yes

2  No -- GO TO Q32

31a. How much time did this person take off without pay?

-----WEEKS

-----MONTHS

-----YEARS

32. Did this person change to a less demanding job?

1  Yes

2  No -- GO TO Q33

32a. How long did this person stay in the less demanding job?

-----WEEKS

-----MONTHS

-----YEARS

33. Did this person decide not to pursue an advancement or promotion?

1  Yes

2  No

34. Did this person retire early?

1  Yes

2  No

35. Did this person delay retirement?

1  Yes

2  No

36. Did this person leave work on disability?

1  Yes

2  No

► **The next few questions are about health insurance coverage when you were diagnosed and treated for your most recent cancer.**

37. **At any time during your most recent cancer diagnosis and treatment, did you have health insurance that paid for all or part of your medical care,**

**tests or cancer treatment?**

- 1  Yes
- 2  No
- 8  I don't know

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

- 1  Yes
- 2  No

**39. Were you ever denied long term care insurance coverage because of your cancer?**

- 1  Yes
- 2  No

► **These next questions ask about different kinds of financial burden you may have experienced because of your most recent cancer diagnosis or its treatment.**

**40. Have you had to borrow money or go into debt to pay for medical care related to your cancer?**

- 1  Borrowed money
- 2  No -- GO TO Q43

**41. How much did you borrow or how much medical debt did you incur because of your cancer?**

- 1  Less than \$25,000
- 2  \$25,000 to \$49,999
- 3  \$50,000 to \$99,999
- 4  \$100,000 or more

**42. Did you or your family ever file for bankruptcy protection because of medical debt related to your cancer?**

- 1  Yes
- 2  No

**43. Have you or your family had to make any other kinds of financial sacrifices because of your cancer or its treatment?**

- 1  Yes
- 2  No

44. **During your most recent cancer diagnosis or its treatment, how much of the time did you worry about having to pay large medical bills related to your cancer?**

- 1  All of the time
- 2  Some of the time
- 3  A little bit of the time
- 4  None of the time

45. **Please think about the medical care visits you've had for your most recent cancer diagnosis. For how many of those visits were you unable to cover your share of the cost?**

- 1  All of the visits
- 2  Some of the visits
- 3  A few of the visits
- It's only been a problem for one or two visits
- 4  It's never been a problem to cover the cost of medical care visits related to cancer

► **These next questions ask about certain experiences you may have had when receiving care for your most recent cancer.**

46. **At any time since your most recent cancer diagnosis, were you told that you would need regular follow-up care and monitoring even after treatment was completed?**

- 1  Yes
- 2  No
- 8  I don't know or remember

47. **During your most recent cancer or its treatment, did a doctor discuss each of the following with you, either briefly or in detail?**

know/ briefly remember	Discussed briefly	Discussed in detail	Did not discuss	I don't
a. Late or long-term side effects of cancer treatment you may experience over time	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	
	4 <input type="checkbox"/>			

- b. Your emotional or social needs related to your cancer, its treatment, or side effects 1  2  3   
4
- c. Lifestyle or health recommendations (e.g., diet, exercise, quitting smoking) 1  2  3   
4

**48. During your most recent cancer diagnosis or its treatment, were you unable to obtain medical care, tests, or treatments that you or your doctor believed were necessary?**

- 1  Yes  
 2  No -- GO TO INTRO BEFORE Q51  
 3  Did not need cancer care in the last 12 months -- GO TO INTRO BEFORE Q51

**49. Which of these are reasons you were unable to get medical care, tests, or treatments you or a doctor believed you needed?**

	<b>Yes, a reason</b>	<b>No, not a reason</b>
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/tests/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 Q49, GO TO THE NEXT SECTION.**

**50. Which one of these is the main reason you were unable to get medical care, tests, or treatments you or a doctor believed you needed?**

MARK ONE

- 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:
-

► **The last few questions in the survey ask about how your most recent cancer and its treatment may have influenced certain parts of your life.**

**51. Now, please think about your usual daily activities other than what you would do for your job. By usual daily activities we mean work around the house, shopping, child care, exercising, studying, etc.**

**Were you ever unable to perform any of your usual daily activities because of your most recent cancer or its treatment?**

- 1  Yes
- 2  No -- GO TO Q53

52. How long were you unable to perform your usual daily activities?

- DAYS
- WEEKS
- MONTHS

**53. Have you been limited in the kind or amount of your usual daily activities because of your most recent cancer or its treatment?**

- 1  Yes
- 2  No -- GO TO INTRO BEFORE Q55

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

- DAYS
- WEEKS
- MONTHS

**55. How often have you needed any of the following kinds of help because of your most recent cancer or its treatment? PLEASE MARK ONE ANSWER IN EACH ROW.**

	All of None of the time	Most of the time	Some of the time	A little of the time	the
a.. <b>Help getting to the doctor or other health professional</b>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
b. <b>Help with medications</b>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
c. <b>Help understanding health insurance or medical bills</b>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
d. <b>Help with household activities</b>	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

► **These last few questions ask about possible effects your cancer or its treatment may have on your life now.**

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

- 1  Never -- GOT TO Q61
- 2  Rarely
- 3  Sometimes
- 4  Often
- 5  All the time

60. **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?**

- 1  Never
- 2  Rarely
- 3  Sometimes
- 4  Often
- 5  All the time

61. As a result of your cancer or its treatment, are you experiencing any lasting side-effects such as pain, fatigue or other physical discomforts?

- Yes
- No

62. What have been some positive things about your experiences with your cancer, its treatment, or the lasting effects of that treatment? PLEASE MARK ALL THAT APPLY

- 1  It's made me a stronger person
- 2  I can cope better with life's challenges
- 3  It became a reason to make positive changes in my life
- 4  It's made me have healthier habits
- Other positive experiences of cancer (please describe)
- 5  There have been no positive experiences because of cancer

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