



## ***Toplines***

The **USA Today/Kaiser Family Foundation/Harvard School of Public Health**

# ***National Survey of Households Affected by Cancer***

**November 2006**

## **Methodology**

The *USA Today*/Kaiser Family Foundation/Harvard School of Public Health Survey Project is a three-way partnership. *USA Today*, Kaiser, and the Harvard School of Public Health jointly design and analyze surveys examining health care issues.

Representatives of *USA Today*, The Henry J. Kaiser Family Foundation, and the Harvard School of Public Health worked together to develop the survey questionnaire and analyze the results. *USA Today* retains editorial control over the content published by the paper. The project team included Jim Norman, USA Today polling editor; Drew E. Altman, president of the Kaiser Family Foundation, Mollyann Brodie, vice president and director of public opinion and media research, and Liz Hamel, associate director of public opinion and media research; and Robert J. Blendon, professor of health policy and political analysis at the Harvard School of Public Health and the John F. Kennedy School of Government, and John M. Benson, managing director of the Harvard Opinion Research Program in the Harvard School of Public Health.

The *National Survey of Households Affected by Cancer* is a nationally representative survey of 930 adults ages 18 years and older who say they, or another family member in their household, have been diagnosed with or treated for cancer in the past five years (excluding non-melanoma skin cancer). The survey was conducted by telephone between August 1 – September 14, 2006. Telephone interviews were conducted by ICR/International Communications Research of Media, PA.

The margin of sampling error for the survey is plus or minus 3.6 percentage points for total respondents. For results based on smaller subsets of respondents the margin of sampling error is higher. Sampling error is only one of many potential sources of error in this or any other public opinion poll.

Values less than 0.5% are indicated by an asterisk (\*). “Vol.” indicates that a response was volunteered by respondent, not an explicitly offered choice. Percentages may not always add up to 100% due to rounding.

A note about question wording: For most questions in the survey, wording differed slightly depending whether the respondent or another family member in the household was the person diagnosed with cancer. Alternate question wording is shown in parentheses for each question.

S01. In the past 5 years, have you personally been diagnosed with or undergone treatment for any type of cancer?

- 46** Yes
- 54** No
- Don't know
- Refused

S02. In the past 5 years, has another family member living in your household been diagnosed with or undergone treatment for any type of cancer?

- 58** Yes
- 42** No
- \* Don't know
- Refused

S01/S02. Combo Table Based on Total

- 42** Respondent has been diagnosed only
- 54** Other HH member has been diagnosed only
- 4** Both Respondent and HH member

**Note: If both respondent and household member were diagnosed with cancer, subsequent questions were asked about respondent's experience with cancer.**

#### A. GENERAL QUESTIONS

A01. What is this person's relationship to you?

- 25** Spouse
  - \* Unmarried partner
  - \* Boyfriend
  - \* Girlfriend
- 2** Son
- 1** Daughter
- 10** Mother
- 7** Father
  - \* Brother/step-brother/half-brother
- 1** Sister/step-sister/half-sister
- 2** Grandmother
- 2** Grandfather
- 1** Aunt
  - \* Uncle
  - \* Niece
- 1** Cousin
  - \* Mother-in-law
- 1** Father-in-law
  - \* Sister-in-law
- 1** Other relative
  - \* Friend
  - \* Other
- 46** Respondent
  - Don't know/Refused

A01a. What is this person's gender?

Gender of Person with cancer (including respondent's gender)

- 51** Male
- 49** Female
- Refused

A02. What is this person's current age? (asked of those who have not passed away)

A02a. What was this person's age when they passed away? (asked of those who have passed away)

Age of Person with Cancer (including respondent's age and age when passed away)

- 1** <18
- 2** 18-29
- 17** 30-49
- 34** 50-64
- 46** 65+
- \* Don't know
- 1** Refused

A03. How long ago was (your/your [RELATIONSHIP]'s) cancer diagnosed? Was it in the past year, between one and three years ago, between three and five years ago, or more than five years ago?

- 20** In the past year
- 32** Between one and three years ago
- 27** Between three and five years ago
- 21** More than 5 years ago
- \* Don't know
- Refused

A04. What type of cancer (were you/was that person) diagnosed with? Was it (prostate/breast), lung, colon or rectal cancer, melanoma, or non-Hodgkins lymphoma, or was it some other kind of cancer?

- 17** Breast
- 15** Prostate
- 11** Melanoma
- 10** Lung
- 10** Colon or rectal
- 4** Non-Hodgkin's Lymphoma
- 3** Leukemia
- 3** Esophageal
- 3** Ovarian
- 2** Bladder
- 2** Kidney
- 2** Uterine
- 2** Cervical
- 2** Thyroid
- 1** Pancreatic
- 1** Liver
- 1** Stomach
- 1** Lymphoma
- 1** Sarcoma
- 1** Bone
- 1** Brain
- \* Carcinoma
- \* Glioblastoma
- \* Myeloma/multiple myeloma
- \* Gall bladder
- \* Testicular
- 4** Some other kind
- 2** Don't know
- Refused

A06. What is (your/your [RELATIONSHIP FROM Q.A01]'s) current situation: (have /has) (you/she/he) been told by a doctor (you/she/he) (are/is) in remission or cured, (do/does) (you/she/he) still have cancer and (are/is) currently receiving treatment, (or do you/does (he/she)) still have cancer and (are/is) NOT receiving treatment, [or has (she/he) passed away]?

- 54** In remission or cured
- 17** Still have cancer and currently receiving treatment
- 6** Still have cancer and NOT receiving treatment
- 21** He/She passed away
- 2** Don't know
- \* Refused

A07. Did (he/she) pass away from cancer, or from something else?

Based on total whose household member with cancer passed away (N=179)

- 84** Cancer
- 14** Something else
- 2** Don't know
- Refused

A06/A07. Combo Table Based on Total

- 54** In remission or cured
- 17** Still have cancer and currently receiving treatment
- 6** Still have cancer and NOT receiving treatment
- 21** Passed away
- 18** From cancer
- 3** From something else
- \* Don't know/refused
- 2** Don't know/Refused

A08. How long ago did (your/your [RELATIONSHIP FROM Q.A01's) cancer treatment end?

Based on total whose Cancer is in remission or cured (N=521)

- 2** 3 week or less
- 18** 4 weeks to 6 months
- 24** 7 months to 1 year
- 44** 2 years to 5 years
- 6** 6+ years
- 5** Don't know
- 1** Refused

B. DIAGNOSTIC PHASE

B01. When (you were/your [RELATIONSHIP] was) diagnosed with cancer, did the doctor tell (you/your [RELATIONSHIP]) what the likely outcome of having the cancer would be?

- 69** Yes
- 22** No
- 9** Don't know
- \* Refused

B02. Did the doctor say it could be cured or go into long-term remission, or didn't the doctor say that?

Based on total who were told by a doctor what the likely outcome would be (N=636)

- 59** Yes, doctor said that
- 37** No, doctor didn't say that
- 4** Don't know
- \* Refused

B03. Did the doctor say the cancer was likely to be fatal or lead to death?

Based on total who were NOT told by a doctor what the likely outcome would be (N=260)

- 58** Yes
- 39** No
- 3** Don't know
- Refused

B01/B02/B03. Combo Table Based on Total

- 69** Was told by doctor what likely outcome of cancer would be
- 41** Doctor said cancer could be cured/go into long-term remission
- 28** Doctor did NOT say cancer could be cured/go into long-term remission/DK
- 16** Doctor said that cancer was likely to be fatal/lead to death
- 11** Doctor did NOT say the cancer was likely to be fatal/lead to death
- 1** Don't know/refused
- 22** Was NOT told by doctor what likely outcome of cancer would be
- 9** Don't know if told by doctor what likely outcome of cancer would be
- \* Refused

B04. When (you/your [RELATIONSHIP]) first found out (you/he/she) had cancer, (were you/was he/she) mostly (optimistic) or mostly (pessimistic) about surviving cancer?

- 67** Mostly optimistic
- 21** Mostly pessimistic
- 11** Don't know
- 1** Refused

### C. CONTINUING CARE AFTER DIAGNOSIS

C01. (First/Next), how would you rate the doctors and other health professionals (you have/your [RELATIONSHIP] (has/had)) seen during the course of (your/his/her) cancer treatment when it comes to their (INSERT)? Would you say excellent, good, only fair, or poor?

	Excellent	Good	Fair	Poor	Don't know	Refused
a. Knowledge and expertise in handling (your/his/her) medical issues	<b>61</b>	<b>24</b>	<b>9</b>	<b>4</b>	<b>1</b>	*
b. Level of compassion	<b>56</b>	<b>24</b>	<b>11</b>	<b>5</b>	<b>4</b>	*

C02. (Do you/Does/Did your [RELATIONSHIP]) have a doctor who (pays/paid) attention to factors outside of (your/his/her) direct medical care, including (your/his/her) support network for dealing with cancer, or (do you/(does/did) (he/she)) not have a doctor who (pays/paid) attention to this?

- 63** Have a doctor who pays attention to factors outside of direct medical care  
**28** Do not have a doctor who pays attention to this  
**9** Don't know  
\* Refused

C03. During the course of (your/his/her) cancer treatment, ((Did you receive/Have you received)/(Did your [RELATIONSHIP] receive/Has your [RELATIONSHIP] received)) conflicting information about (your/his/her) cancer from different doctors or health care professionals, or not?

- 25** Yes, received conflicting info  
**72** No, did not receive conflicting info  
**3** Don't know  
-- Refused

C04. When getting care for (your/his/her) cancer, (was there ever/has there ever been) a time when (INSERT), or not?

	Yes, there has been a time	No, there has never been a time	Don't know	Refused
b. (Your/Your relationship's) medical records or test results did not reach (your/his/her) doctor's office in time for (your/his/her) appointment	<b>13</b>	<b>80</b>	<b>6</b>	--
c. (You were/Your relationship was) sent for duplicate test or diagnostic procedures by different doctors, nurses, or healthcare workers	<b>21</b>	<b>74</b>	<b>5</b>	*
d. (You/Your relationship) left a doctor's office without getting important questions about (your/his/her) care or treatment answered	<b>15</b>	<b>80</b>	<b>5</b>	--
e. (You were/Your relationship was) confused about the medication the doctor prescribed	<b>20</b>	<b>77</b>	<b>3</b>	*

C05. Was there ever a time during (your/your [RELATIONSHIP]'s) cancer treatment when (you/he/she) had to wait longer than (you/he/she) thought (you/he/she) should to find out the results of medical tests, or not?

- 22** Yes, there has been a time  
**75** No, there has never been a time  
**3** Don't know  
-- Refused

C06. Did waiting for these test results produce a lot of stress and anxiety for (you/your [RELATIONSHIP]), just some stress and anxiety, or no stress and anxiety?

Based on total who had to wait longer than thought they should to find out test results (N=187)

- 56** A lot
- 38** Just some
- 6** No stress and anxiety
- 1** Don't know
- Refused

C05/C06. Combo Table Based on Total

- |           |   |
|-----------|---|
| <b>22</b> | Had to wait longer than thought they should for test results          |
| <b>12</b> | Caused a lot of stress and anxiety                                    |
| <b>8</b>  | Caused some stress and anxiety  |
| <b>1</b>  | Caused no stress and anxiety  |
| *         | Don't know/refused  |
| <b>75</b> | Did not have to wait longer than thought they should for test results |
| <b>3</b>  | Don't know  |
| --        | Refused   |

C07. (Was there ever/Has there been) a time since (you were/your [RELATIONSHIP] was) diagnosed with cancer when (you/he/she) did not follow (your/his/her) doctor's advice or treatment plan, or not?

- 12** Yes, there has been a time
- 86** No, there has never been a time
- 2** Don't know
- Refused

C08. (Did you not follow/Do you think your [RELATIONSHIP] did not follow) (your/his/her) doctor's advice or treatment plan (INSERT)?

Based on total who did not follow doctor's advice/treatment plan at some point (N=107)

	Yes	No	Don't know	Refused
a. Because (you/he/she) didn't understand what (you were/he/she was) supposed to do	<b>20</b>	<b>79</b>	--	<b>1</b>
b. Because (you/he/she) disagreed with what the doctor recommended	<b>61</b>	<b>39</b>	--	--
c. Because it cost too much	<b>21</b>	<b>79</b>	--	--
d. Because it made (you/him/her) very ill	<b>37</b>	<b>62</b>	<b>1</b>	<b>1</b>
e. Because it wasn't helping	<b>33</b>	<b>66</b>	<b>1</b>	<b>1</b>
f. Some other reason I haven't mentioned	<b>9</b>	--	--	--
Gave up/acceptance of death	<b>6</b>	--	--	--
Laziness/procrastination	<b>1</b>	--	--	--
Stubbornness	<b>4</b>	--	--	--
Inconvenience	<b>3</b>	--	--	--

C07/C08. Combo Table Based on Total

<b>12</b>	Did not follow doctor's advice/treatment plan at some point
<b>8</b>	Because they disagreed with what the doctor recommended
<b>5</b>	Because it made them very ill
<b>4</b>	Because it wasn't helping
<b>3</b>	Because it cost too much
<b>3</b>	Because didn't understand what they were supposed to do
<b>1</b>	Gave up/acceptance of death
<b>1</b>	Stubbornness
*	Laziness/procrastination
*	Inconvenience
<b>1</b>	Because of some other reason
<b>86</b>	Always followed doctor's advice/treatment plan
<b>2</b>	Don't know
--	Refused

C09. In the course of (your/your [RELATIONSHIP]'s) cancer treatment, ((did you have/have you had)/(did he/she have/has he/she had)) any of the following, or not?

	Yes	No	Don't know	Refused
a. Chemotherapy	<b>40</b>	<b>59</b>	<b>1</b>	--
b. Radiation treatment	<b>42</b>	<b>56</b>	<b>2</b>	--
c. Prescription drugs related to (your/his/her) cancer treatment	<b>59</b>	<b>39</b>	<b>2</b>	--
d. Surgery, such as the removal of a tumor or other cancerous mass	<b>67</b>	<b>31</b>	<b>1</b>	--

C10. Was that outpatient surgery or inpatient surgery?

Based on total who had surgery (N=644)

<b>34</b>	Outpatient
<b>65</b>	Inpatient
<b>2</b>	Don't know
--	Refused

C09d/C10. Combo Table Based on Total

<b>67</b>	Had surgery
<b>23</b>	Surgery was outpatient
<b>44</b>	Surgery was inpatient
<b>1</b>	Don't know/refused
<b>31</b>	Did not have surgery
<b>1</b>	Don't know
--	Refused

C11. How severe (were/have) the side effects from (your/your [RELATIONSHIP]'s) cancer treatment (been)? Would you say very severe, somewhat severe, not too severe, or not severe at all?

Based on total who had chemotherapy, radiation treatment, prescription drugs, or surgery (N=872)

- 22** Very severe
- 25** Somewhat severe
- 24** Not too severe
- 26** Not severe at all
- 2** Don't know
- \* Refused

C12. (Did/Has) the treatment ever (leave/left) (you/him/her) so weakened or ill that (you/he/she) (were/was) unable to go to work or go about usual activities, or not?

Based on total who had chemotherapy, radiation treatment, or prescription drugs (N=668)

- 60** Yes, treatment ever left patient unable to go to work or go about usual activities
- 38** No, treatment never left patient unable to go to work or go about usual activities
- 1** Don't know
- Refused

C13. Was there ever a time when (your/your [RELATIONSHIP]'s) treatment (or surgery) left (your/his/her) appearance altered in a way that made it very uncomfortable for (you/him/her) to go out in public or go about (your/his/her) usual activities, or not?

Based on total who had chemotherapy, radiation treatment, prescription drugs, or surgery (N=872)

- 36** Yes, appearance made (you/him/her) very uncomfortable
- 63** No, did not
- 1** Don't know
- \* Refused

C14. During and immediately after the treatment (or surgery), ((did you have/have you had)/(did he/she have/has he/she had)) any of the following problems, or not? How about (INSERT)?

Based on total who had chemotherapy, radiation treatment, prescription drugs, or surgery (N=872)

			Yes	No	Don't know	Refused
a. Severe pain			<b>45</b>	<b>52</b>	<b>2</b>	--
b. Nausea			<b>46</b>	<b>52</b>	<b>2</b>	--
c. Hair falling out ( <i>asked of those who had chemo only; n=364</i> )			<b>67</b>	<b>32</b>	*	--
d. Serious stress and anxiety			<b>47</b>	<b>52</b>	<b>1</b>	--

C15. People with cancer often have to make very difficult decisions regarding their treatment options. Did (you/your [RELATIONSHIP]) ever have to make a decision about whether to undergo a treatment that would increase (your/his/her) chances of survival by only a small amount, but could potentially lead to severe side effects, or not?

- 27** Yes, had to make decision  
**68** No, did not have to make decision  
**4** Don't know  
\* Refused

C16. Did (you/he/she) decide to undergo the treatment, or not?

Based on total who had to make decision about whether to undergo treatment (N=240)

- 71** Yes  
**28** No  
**1** Don't know  
\* Refused

C15/C16. Combo Table Based on Total

- 27** Had to decide whether to undergo treatment that could increase chances of survival but could lead to severe side effects  
**19** Decided to undergo the treatment  
**8** Decided NOT to undergo the treatment  
\* Don't know/Refused  
**68** Did NOT have to decide whether to undergo treatment  
**4** Don't know  
\* Refused

#### D. SELF-HELP AND ALTERNATIVE THERAPIES/MEDICINES

D01. ((Did you do/Have you done)/(Did your [RELATIONSHIP] do/Has your [RELATIONSHIP] done) any of the following in order to try to deal with (your/his/her) cancer, or not? How about (INSERT)?

	Yes	No	Don't know	Refused
a. Take large doses of vitamins	<b>17</b>	<b>82</b>	<b>1</b>	--
b. Take dietary supplements OTHER than conventional vitamins and minerals	<b>16</b>	<b>81</b>	<b>3</b>	--
c. Take treatments that (you/he/she) did not discuss with (your/his/her) doctor	<b>4</b>	<b>94</b>	<b>2</b>	--
d. Smoke marijuana for medicinal purposes	<b>4</b>	<b>95</b>	*	<b>1</b>
e. Travel to another country to get treatment not available in the U.S.	<b>1</b>	<b>99</b>	*	*

D02. You said (you/your [RELATIONSHIP]) (INSERT "YES" ITEMS FROM D01). (Was/Has) the cost of this (been) a financial burden to (you/him/her), or not?

Based on total who have taken large doses of vitamins or supplements, taken treatments not discussed with doctor, smoked marijuana for medical purposes, or traveled to another country for cancer treatment (N=229)

- 29** Been a financial burden
- 70** Not been a financial burden
- 1** Don't know
- Refused

#### D01/D02. Combo Table Based on Total

- 27** Have done any specified things to deal with cancer
- 8** Have been a financial burden
- 19** Has not been a financial burden
- \* Don't know/refused
- 73** Have NOT done any specified things to deal with cancer

D03. (Have you)/(Did/Has your [RELATIONSHIP])) (seek/sought) information about cancer treatment from any of the following? How about from (INSERT)?

	Yes	No	Don't know	Refused
a. A medical website, such as WebMD	<b>30</b>	<b>66</b>	<b>3</b>	--
b. A cancer organization, such as the American Cancer Society	<b>28</b>	<b>66</b>	<b>5</b>	--
c. A religious leader, such as a minister, priest, or rabbi	<b>16</b>	<b>83</b>	<b>1</b>	--
d. The National Cancer Institute	<b>20</b>	<b>72</b>	<b>7</b>	--

#### E. IMPACT ON FAMILY MEMBERS

Next, I'd like to ask you about the impact cancer has had on you and your family...

E01. Overall, would you say that (your/your [RELATIONSHIP]'s) experience with cancer has had ANY positive impact on (your/his/her) life, or would you say that the impact of this experience has ONLY been negative?

Based on total, excluding those whose household member with cancer has passed away (N=751)

- 63** Has had ANY positive impact
- 27** Has ONLY had a negative impact
- 9** Don't know
- 1** Refused

E02. Overall, would you say that your [RELATIONSHIP]'s experience with cancer had ANY positive impact on YOUR OWN LIFE, or would you say that the impact of this experience has ONLY been negative?

Based on total where only household member had cancer (N=459)

- 55** Has had ANY positive impact
- 34** Has ONLY had a negative impact
- 11** Don't know
- 1** Refused

E03. Would you say that this experience with cancer has fundamentally changed your outlook on life, or not?

Based on total, excluding those whose household member with cancer has passed away (N=751)

- 53** Has fundamentally changed outlook on life
- 47** Has not changed outlook on life
  - \* Don't know
  - Refused

E04. And would you say that change has been mostly in a positive direction, or mostly in a negative direction?

Based on total whose outlook on life changed (N=382)

- 84** Positive direction
- 11** Negative direction
- 5** Neither positive or negative
- 1** Don't know
- Refused

E03/E04. Combo Table Based on Total, excluding those whose household member with cancer has passed away

- 53** Experience with cancer has changed outlook on life
  - 45** Positive direction
  - 6** Negative direction
  - 2** Neither positive or negative
    - \* Don't know/refused
- 47** Experience with cancer has NOT changed outlook on life
  - \* Don't know
  - Refused

E05. How important a role (did/has) religion (play/played) in helping (you/your [RELATIONSHIP]) get through (your/his/her) experience with cancer? Very important, somewhat important, not too important, or not at all important?

- 49** Very important
- 21** Somewhat important
- 10** Not too important
- 19** Not at all important
- 1** Don't know
- \* Refused

E06. How important a role (did/has) religion (play/played) in helping YOU get through your [RELATIONSHIP]'s experience with cancer? Very important, somewhat important, not too important, or not at all important?

Based on total where only household member had cancer (N=459)

- 50** Very important
- 19** Somewhat important
- 9** Not too important
- 21** Not at all important
- 1** Don't know
- \* Refused

E07. Has this experience with cancer had any of the following effects on you or anyone else in your household, or not? Has it (INSERT ITEM)?

	Yes	No	No one works	Don't know	Refused
a. Caused you or someone in your household to lose or change a job or have to work fewer hours	<b>19</b>	<b>79</b>	<b>2</b>	*	--
b. Caused you or someone in your household to have a lower income	<b>22</b>	<b>78</b>	--	*	--
c. Caused you or someone in your household emotional or psychological problems	<b>32</b>	<b>67</b>	--	<b>1</b>	*
d. Caused (you or) someone else in your household (besides the person with cancer) to have health problems	<b>10</b>	<b>90</b>	--	<b>1</b>	--
e. Caused severe strains with other family members	<b>25</b>	<b>75</b>	--	*	--

## F. HEALTH INSURANCE AND IMPACT ON FINANCES

F01. (Are you, yourself/Is your [RELATIONSHIP]) now covered by any form of health insurance or health plan, or ((do you)/(does he/she)) not have health insurance at this time? (CONTINUE TO READ ONLY IF RESPONDENT SAYS NO) A health plan would include any private insurance plan through your employer or a plan that you purchased yourself, as well as a government program like Medicare or Medicaid?

Based on total, excluding those whose household member with cancer has passed away (N=751)

- 92** Covered by any form of health insurance or health plan
- 7** Not covered by any form of health insurance or health plan
- 1** Don't know
- Refused

F02. Which of the following is (your/his/her) MAIN source of health insurance coverage? Is it (READ LIST)?

Based on total who are covered by any form of health insurance or health plan (N=701)

- 39** A plan through an employer or union
- 8** A plan (you/he/she) purchased (yourself/himself/herself)
- 38** Medicare, the program that provides health insurance primarily to people age 65 and older
- 5** Medicaid (or State-specific name), the program that provides health insurance and long term care to certain low-income families
- 6** Some other government program
- 2** (Do you/Does he/she) get (your/his/her) health insurance from somewhere else
- 1** Don't know
- \* Refused

### F01/F02. Combo Table Based on Total

Based on total, excluding those whose household member with cancer has passed away (N=751)

- 92** Covered by any form of health insurance/plan
- 36** A plan through an employer or union
- 8** A plan purchased for self
- 35** Medicare
- 5** Medicaid
- 5** Some other government program
- 2** Gets insurance from somewhere else
- 1** Don't know/refused
- 7** NOT covered by any form of health insurance/plan
- 1** Don't know
- Refused

F03. During the time (you were/your [RELATIONSHIP] was) being treated for cancer, (were you)/(was he/she) covered by health insurance the entire time, or was there any time during (your/his/her) cancer treatment when (you/he/she) did not have any health coverage?

Based on total who are covered by any form of health insurance or health plan (N=701)

- 92** Covered by health insurance the entire time
- 7** Not covered by health insurance the entire time
- 1** Don't know
- Refused

F01/F03. Combo Table Based on Total

Based on total, excluding those whose household member with cancer has passed away (N=751)

- 92** Covered by any form of health insurance/plan
- 85** Covered by health insurance the entire time
- 6** NOT covered by health insurance the entire time
- 1** Don't know/refused
- 7** NOT covered by any form of health insurance/plan
- 1** Don't know
- Refused

F04. During the time (you were/your [RELATIONSHIP] was) being treated for cancer, (were you)/(was he/she) covered by health insurance, or not?

Based on total who are NOT currently covered by any form of health insurance or health plan or whose household member has passed away (N=224)

- 82** Covered by any form of health insurance or health plan
- 17** Not covered by any form of health insurance or health plan
- 1** Don't know
- Refused

F01/F03/F04. Combo Table Based on Total

- 85** Covered by health insurance now AND during entire cancer treatment
- 13** Not covered by health insurance AT SOME POINT during or since cancer treatment
- 2** Don't know/Refused

F04a. What type of health insurance coverage was that? Was it ...?

F01/F02/F04/F04a. Combo Table Based on Total

<b>95</b>	Currently covered/Covered by insurance at some point during cancer treatment
<b>38</b>	A plan through an employer or union
<b>8</b>	A plan purchased for self
<b>34</b>	Medicare
<b>5</b>	Medicaid
<b>5</b>	Some other government program
<b>2</b>	Gets insurance from somewhere else
<b>2</b>	Don't know/refused
<b>5</b>	NOT covered by insurance
<b>1</b>	Don't know
--	Refused

F05. I'm going to read you a list of problems some people experience with their health insurance plan. Please tell me if (you have/your [RELATIONSHIP] has) had these problems with a health insurance plan related to (your/his/her) cancer treatment. How about (INSERT)? Has this ever happened during (your/his/her) cancer treatment, or not?

Based on total who are/were covered by any form of health insurance or health plan during their treatment (N=892)

	Yes, has happened	No, has not happened	Don't know	Refused
a. (You were)/(He/she was) surprised to find out that (your/his/her) plan would not pay ANYTHING for care (you/he/she) received, that (YOU/HE/SHE) thought was covered	<b>13</b>	<b>83</b>	<b>4</b>	*
b. (Your/His/Her) plan paid less than (you/he/she) expected for a bill (you/he/she) received from a doctor, hospital, or lab	<b>23</b>	<b>72</b>	<b>5</b>	<b>1</b>
c. (You/He/She) reached the limit of what (your/his/her) insurance company would pay for (your/his/her) cancer treatment	<b>10</b>	<b>84</b>	<b>5</b>	*
d. (You/He/She) (was/were) turned away or unable to get a specific type of treatment because of insurance issues	<b>8</b>	<b>89</b>	<b>3</b>	*

F06. How much of a burden on (your/your [RELATIONSHIP]'s) family (were/are) the costs of (your/his/her) overall medical care, including any services ((you needed/need)/(he/she needed/needs)) to cope with (your/his/her) cancer—a major burden, a minor burden, or not a burden at all?

<b>17</b>	A major burden
<b>29</b>	A minor burden
<b>52</b>	Not a burden at all
<b>2</b>	Don't know
*	Refused

F07. Over the past year, have the costs (you have/your [RELATIONSHIP] has) to pay for prescription drugs related to (your/his/her) cancer gone up a lot, gone up a little, stayed about the same, or gone down?

Based on total who are currently being treated for cancer and taking prescription drugs (N=107)

- 56** Gone up
- 39** Gone up a lot
- 18** Gone up a little
- 30** Stayed about the same
- 3** Gone down
- 9** Don't know
- 1** Refused

F08. (Did/Have) any of the following things ever (happen/happened) to (you/your [RELATIONSHIP] as a result of the financial cost of dealing with (your/his/her) cancer, or not? How about (INSERT)?

	Yes	No	Don't know	Refused
a. (You/He/She) used up all or most of (your/his/her) savings	<b>25</b>	<b>73</b>	<b>2</b>	*
b. (You/He/She) (was/were) unable to pay for basic necessities like food, heat, or housing	<b>11</b>	<b>88</b>	*	*
c. (You/He/She) borrowed money or got a loan or another mortgage on (your/his/her) home	<b>7</b>	<b>91</b>	<b>1</b>	*
d. (You/He/She) borrowed money from relatives	<b>13</b>	<b>87</b>	*	*
e. (You/He/She) (was/were) contacted by a collection agency	<b>13</b>	<b>85</b>	<b>2</b>	*
f. (You/He/She) declared bankruptcy	<b>3</b>	<b>96</b>	<b>1</b>	*
g. (You/He/She) sought the aid of a charity or public assistance	<b>11</b>	<b>88</b>	<b>1</b>	*
h. (You/He/She) lost (your/his/her) health insurance	<b>6</b>	<b>93</b>	<b>1</b>	*
i. (You/He/She) couldn't buy health insurance because of having cancer	<b>11</b>	<b>86</b>	<b>3</b>	*

F09. (Did you/Have you)/(Did your [RELATIONSHIP]/Has your [RELATIONSHIP])) ever delay(ed) or decide(d) not to get care for (your/his/her) cancer because of the cost?

- 8** Yes
- 91** No
- 1** Don't know
- \* Refused

F10. (Did you/Have you)/(Did your [RELATIONSHIP]/Has your [RELATIONSHIP])) ever (choose/chosen) one cancer treatment over another because of the cost?

- 4** Yes
- 93** No
- 3** Don't know
- \* Refused

F11. Did (delaying or not getting care/choosing one cancer treatment over another/delaying or not getting care or choosing one cancer treatment over the other) because of the cost, cause any of the following things to happen, or not? (First/Next,) did (this decision/these decisions) (INSERT ITEM) or not?

Based on total who delayed or decided not to get care or chose one treatment over the other because of cost (N=73; insufficient data to report separately)

#### F09/F10/F11. Combo Table Based on Total

- 9** Ever decided to delay/not get care or chose one treatment over another because of cost
- 5** Caused a significant loss of time at work, school, important activities
- 8** Seriously increased stress
- 6** Caused a significant amount of pain and suffering
- 5** Caused medical condition to get worse
- 91** Never decided to delay/not get care or chose one treatment over another because of cost

#### G. IMPACT ON WORK

G01. At the time (you were/your [RELATIONSHIP] was) diagnosed with cancer, (were you/was he/she) working full-time, working part-time, or (were you/was he/she) retired, unemployed, a student, a homemaker, or something else?

- 44** Employed
- 39** Working full-time
- 5** Working part-time
- 37** Retired
- 3** Unemployed
- 2** A student
- 8** A homemaker
- 5** Something else
- 1** Don't know
- Refused

G02. At the time, (were you/was he/she) self-employed, or did (you/he/she) work for someone else?

Based on total who were working when diagnosed with cancer (N=406)

- 20** Self-employed
- 80** Worked for someone else
- Don't know
- Refused

G01/G02. Combo Table Based on Total

- |           |                         |
|-----------|-------------------------|
| <b>44</b> | Employed                |
| <b>9</b>  | Self-employed           |
| <b>35</b> | Worked for someone else |
| <b>37</b> | Retired                 |
| <b>3</b>  | Unemployed              |
| <b>2</b>  | A student               |
| <b>8</b>  | A homemaker             |
| <b>5</b>  | Something else          |
| <b>1</b>  | Don't know              |
| --        | Refused                 |

G03. How well (did/has) (your/your [RELATIONSHIP]'s) employer (treat/treated) (you/him/her) during (your/his/her) experience with cancer? Would you say very well, somewhat well, not too well, not well at all?

Based on total who were working for someone else when diagnosed with cancer (N=320)

- |           |                 |
|-----------|-----------------|
| <b>76</b> | Very well       |
| <b>10</b> | Somewhat well   |
| <b>2</b>  | Not too well    |
| <b>5</b>  | Not well at all |
| <b>6</b>  | Don't know      |
| <b>1</b>  | Refused         |

G04. Do you feel that (your/your [RELATIONSHIP]'s) having cancer had a negative impact on how (you were/(he/she) was) viewed in terms of (your/his/her) ability to do (your/his/her) job, or not?

Based on total who were working when diagnosed with cancer (N=406)

- |           |            |
|-----------|------------|
| <b>20</b> | Yes        |
| <b>76</b> | No         |
| <b>4</b>  | Don't know |
| --        | Refused    |

G05. As a result of (your/your [RELATIONSHIP]'s) having (had) cancer, did any of the following happen, or not?

Items a-d based on total who were working when diagnosed with cancer; Items e-f based on total

	Yes	No	Don't know	Refused
a. (You were/(he/she) was) unable to do (your/his/her) job as well as (you/he/she) could before <b>N=406</b>	<b>36</b>	<b>61</b>	<b>3</b>	--
b. (You were/(he/she) was) removed from a job <b>N=406</b>	<b>10</b>	<b>89</b>	*	--
c. (You//he/she) had to change jobs <b>N=406</b>	<b>10</b>	<b>89</b>	<b>1</b>	--
d. (You/he/she) stayed in a job longer than (you/he/she) otherwise would in order to maintain health insurance coverage <b>N=406</b>	<b>12</b>	<b>86</b>	<b>2</b>	--
e. (You were/he was/she was) turned down for a job	<b>3</b>	<b>96</b>	*	*
f. (You/he/she) tried to purchase life insurance but (were/was) unable to do so	<b>8</b>	<b>89</b>	<b>3</b>	*

## H. POST-CANCER LIFE

H01. You said earlier that (you/your [RELATIONSHIP]) ((are/is) in remission from/ (or have/or has) been cured of) the cancer (you/he/she) had. Which of the following best describes (your/your [RELATIONSHIP]'s) situation after all the cancer treatment was completed?

Based on total who are cured or in remission (N=521)

- 72** ((You have)/(He/She has)) been able to return to the same activities and pursuits that (you/he/she) had before (you/she/he) became ill with cancer
- 19** The cancer and the subsequent treatment has SOMEWHAT limited the activities and pursuits that (you/she/he) can now do
- 8** The cancer and the subsequent treatments have SEVERELY limited the activities and pursuits that (you/she/he) can now do
- 1** Don't know
- \* Refused

H02. (Do you think of yourself/Do you think your [RELATIONSHIP] thinks of (himself/herself) as a cancer survivor, or not?

Based on total who are cured or in remission (N=521)

- 82** Yes
- 16** No
- 1** Don't know
- \* Refused

H03. (Have you/Has your [RELATIONSHIP]) had any other health problems or illnesses as a result of (your/his/her) having had cancer, or not?

- 12** Yes
- 64** No
- 2** Don't know
- Refused
- 21** Passed away

## I. END-OF-LIFE AND HOSPICE CARE

You said earlier that your [RELATIONSHIP] who had cancer has passed away. I want to ask just a few questions about (his/her) last days.

- I01. Did your [RELATIONSHIP] receive hospice care, either at home or in a hospice facility, at any time before (his/her) death, or not?

Based on total whose household member with cancer has passed away (N=179)

**57** Yes  
**42** No  
**1** Don't know  
-- Refused

- I02. The death of any loved one is a traumatic experience, but some people have used the term "good death" to refer to one that goes about as well as a person could expect. Was your [RELATIONSHIP]'s death a "good death," or did things happen that made it a "bad death?"

Based on total whose household member with cancer has passed away (N=179)

**62** A "good death"  
**27** A "bad death"  
**10** Don't know  
**1** Refused

- I03. In your opinion, were your [RELATIONSHIP]'s wishes about care at the end of (his/her) life generally followed, or not?

Based on total whose household member with cancer has passed away (N=179)

**88** Yes  
**8** No  
**4** Don't know  
\* Refused

## J. GENERAL FOLLOW-UP

Next, I would like to ask you just a few more general questions...

J01. How would you rate the health care system in America today when it comes to providing cancer care? Would you say it is excellent, very good, good, fair, or poor?

- 22** Excellent
- 21** Very good
- 26** Good
- 14** Fair
- 12** Poor
- 3** Don't know
- 1** Refused

J02. As a result of your experience with cancer, have you done any of the following things, or not? How about (INSERT)?

	Yes	No	Don't know	Refused
a. Volunteered for a cancer organization such as the American Cancer Society	<b>17</b>	<b>83</b>	*	*
b. Donated or helped raise money for a cancer charity	<b>58</b>	<b>41</b>	1	*
c. Joined a cancer self-help group	<b>6</b>	<b>94</b>	*	--
d. Counseled others who have family members with cancer	<b>39</b>	<b>61</b>	*	*
g. Voted for a candidate because he or she supported increased funding for cancer research	<b>13</b>	<b>85</b>	2	*

J03. Do you have a legal document such as a living will or advance treatment directive that states how doctors should treat you if you can no longer communicate your wishes, or don't you have one?

- 47** Yes
- 53** No
- \* Don't know
- \* Refused

J04. I am going to read you descriptions of two types of medical treatment a patient might prefer to receive if they were terminally ill. If you had to choose, which of the following types of treatment would you prefer?

- 12** Having your life extended as long as possible, even if it means more pain and discomfort
- 81** Being kept as comfortable and pain-free as possible, even if it means not living as long
- 5** Don't know
- 1** Refused

## K. DEMOGRAPHICS

Now I have just a few more questions for classification purposes only.

### S5. GENDER

- 54** Male
- 46** Female

K01. In politics today, do you consider yourself a Republican, Democrat, Independent, or something else?

- 28** Republican
- 33** Democrat
- 22** Independent
- 11** Something else
- 3** Don't know
- 3** Refused

K02. What is your age?

- 16** 18-34
- 19** 35-49
- 30** 50-64
- 34** 65+
- 1** Refused

K03. What is the LAST grade or class that you COMPLETED in school?

- 46** High school graduate or less
- 16** Less than high school graduate
- 5** None, or grade 1-8
- 11** High school incomplete
- 30** High school graduate
- 54** Some college or more
- 31** Some college or technical school, no 4-year degree
- 23** College Graduate
- 12** College graduate
- 11** Post-graduate training
- \* Don't know
- 1** Refused

K03a. What is your marital status: Are you married, LIVING AS married, divorced, separated, widowed, or have you never been married?

- 53** Married
- 2** Living as married
- 9** Divorced
- 1** Separated
- 17** Widowed
- 17** Has never been married
- \* Don't know
- 1** Refused

K04. How important is religion in your everyday life? Is it the most important thing in your life, very important, but not the most important thing, somewhat important, or not too important?

- 25** The most important thing in your life
- 38** Very important, but not the most important
- 19** Somewhat important
- 16** Not too important
- 1** Don't know
- \* Refused

K05. What is your religious preference? Are you Protestant, Roman Catholic, Jewish, Muslim, some other religion, or no religion?

- 52** Protestant (include Baptist, Lutheran, Methodist, Presbyterian, Episcopalian, Pentecostal, Jehovah's Witness, Church of Christ, etc.)
- 24** Roman Catholic
- 3** Jewish
- \* Muslim
- 10** Some other religion
- 9** No religion
- 1** Refused

K05/K06. Combo Table Based on Total (Religion Summary 1)

- 52** Protestant
- 24** Roman Catholic
- 3** Jewish
- \* Muslim
- 10** Some other religion
  - 9** Christian
  - 1** NOT Christian
- 9** No religion
- 1** Refused

#### K05/K06/K07. Combo Table Based on Total (Religion Summary 2)

- 85** Christian
- 34** Born again
- 47** Not born again
- 3** Jewish
- \* Muslim
- 2** Some other religion
- 9** No religion
- 1** Refused

#### Race Summary Table

- 77** White (non-Hispanic)
- 6** Black/African American (non-Hispanic)
- 1** Asian American (non-Hispanic)
- 10** Hispanic
  - 7** White Hispanic
  - 1** Black Hispanic
  - 2** Hispanic unspecified
- 5** Some other race
- Don't know
- 1** Refused

#### Income Summary

- 46** Less than \$40,000
- 12** Less than \$15,000
- 8** \$15,000 but less than \$20,000
- 6** \$20,000 but less than \$25,000
- 8** \$25,000 but less than \$30,000
- 9** \$30,000 but less than \$40,000
- 2** Less than \$40,000 (unspecified)
- 43** \$40,000 or more
  - 10** \$40,000 but less than \$50,000
  - 14** \$50,000 but less than \$75,000
  - 6** \$75,000 but less than \$100,000
  - 10** \$100,000 or more
  - 2** More than \$40,000 (unspecified)
- 3** Don't know
- 8** Refused

#### K15. REGION FROM SAMPLE

- 18** Northeast
- 24** North Central
- 35** South
- 23** West

#### K16. METRO STATUS FROM SAMPLE

- 29** Urban
- 41** Suburban
- 30** Rural



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