**Edge Research for NCCS**

**Cancer Survivorship 2022 Survey**

**FINAL: 6/30/2022**

|  |  |
| --- | --- |
| Sources | Desired Total Completes |
| * Commercial online panel | * Adult cancer patients/survivors, N=1300 * OS of Metastatic Breast Cancer patients N=100 (Q03=4 AND Q05=4) |
| * NCCS List: Outreach through email list and other channels | * Adult cancer patients/survivors, N @ 400-500, based on 2021 response rates |

NOTE: ALL ADDITIONS, DELETIONS, AND/OR OTHER CHANGES ARE HIGHLIGHTED IN YELLOW. (KEPT QUESTION NUMBERS THE SAME UNLESS NOTED). THIS YEAR SURVEY WILL BE OFFERED IN SPANISH TOO

**SCREENING QUESTIONS AND CHARACTERISTICS**

***Objectives:*** *Make sure the appropriate audience takes the survey. Collect key characteristics of survey respondents for profiling and subgroup analysis.*

**INTRO FOR NCCS LIST ONLY (ONLINE PANEL WILL BE BLIND):** The purpose of this survey is to better understand the needs and experiences of cancer survivors. This survey is being conducted by Edge Research on behalf of the National Coalition for Cancer Survivorship (NCCS). Many of the questions will be about your experiences during and after cancer treatment, and your feedback will help inform NCCS’ services and outreach. This survey is for research purposes only. Your information and opinions are confidential. Nothing you say will be attached to your name, and your responses will only be reported together with the responses of others. The survey should take about 15 minutes to complete.

1. Are you willing to take this survey?

1 Yes

2 No **TERMINATE AND PROCEED TO THANK YOU PAGE**

1. **[ASK ALL]** You can take this survey in English or Spanish. Which would you prefer?

Ud. puede completar esta encuesta en Ingles o en Español, cual prefiere?

* 1. English/Ingles
  2. Español/Spanish
  3. Neither/Ninguno **TERMINATE**

1. Please indicate your age:

**NUMERIC ENTRY FIELD ALLOWING 0-99**

**OPTION FOR “Prefer not to say”**

**TERMINATE if under 18**

**ASK IF “PREFER NOT TO SAY” ABOVE**

1A. You must be 18 years of age or older to complete this survey. Are you:

1 Under 18 years old **THANK AND TERM**

2 18 years of age or older **CONTINUE TO SURVEY**

3 Prefer not to say **THANK AND TERM**

**[ASK IF SOURCE: NCCS LIST]**

1. Have you ever been diagnosed with cancer?
   1. Yes
   2. No **THANK AND TERM**
   3. Prefer not to say **THANK AND TERM**

**[ASK IF SOURCE: ONLINE PANEL]**

2a. Have you ever been diagnosed with any of the following conditions?

**RANDOMIZE**

1. Cancer **CONTINUE. TERMINATE IF DON’T SELECT**
2. Heart disease
3. Diabetes
4. Arthritis
5. What type of cancer(s) did, or do, you have? *Select all that apply.* 
   1. Bladder Cancer
   2. Bone Cancer
   3. Brain Tumor
   4. Breast Cancer
   5. Cervical Cancer
   6. Colorectal Cancer
   7. Endometrial Cancer
   8. Esophageal Cancer
   9. Gastric Cancer
   10. Kidney Cancer
   11. Leukemia
   12. Liver Cancer
   13. Lung Cancer
   14. Lymphoma - Hodgkin's
   15. Lymphoma - Non-Hodgkin's
   16. Melanoma
   17. Multiple Myeloma
   18. Oral Cancer
   19. Osteosarcoma
   20. Ovarian Cancer
   21. Pancreatic Cancer
   22. Prostate Cancer
   23. Renal Cell Carcinoma
   24. Sarcoma
   25. Skin Cancer **TERMINATE IF ONLY SELECTED**
   26. Stomach Cancer
   27. Testicular Cancer
   28. Thyroid Cancer
   29. Uterine (Endometrial) Cancer
   30. Other specify:\_\_\_\_\_\_\_
6. At what age were you first diagnosed with cancer?

**NUMERIC ENTRY FIELD ALLOWING 0-99**

**OPTION FOR “Don’t know/Not sure”**

1. At **diagnosis**, did the doctor discuss the stage of your cancer? Was it…
   1. Stage I
   2. Stage II
   3. Stage III
   4. Stage IV or Metastatic (cancer has spread to other organs)
   5. Stage was not discussed
   6. Not sure
2. Which of the following applies to you? *Select one.*
3. I am currently receiving treatment for my initial cancer diagnosis
4. I am currently receiving treatment for cancer that has recurred
5. I have completed treatment and/or am not currently in active treatment for cancer
6. Other, specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **TERMINATE**

1X. When did you complete your most recent treatment for cancer?

* 1. Still undergoing treatment for cancer
  2. Less than 6 months ago
  3. 6 months to less than one year ago
  4. 1-5 years ago
  5. 6-10 years ago
  6. More than 10 years ago
  7. Have not/never received treatment **TERMINATE**

1. [REVISED] Which of the following cancer treatment(s) and/or test(s) have you undergone? Select all that apply.
2. Currently undergoing
3. In the past
4. Never **[EXCLUSIVE]**
5. Not sure/Don’t know **[EXCLUSIVE]**

**RANDOMIZE**

1. Surgery
2. Chemotherapy
3. Radiation therapy
4. Targeted drug therapy
5. Immunotherapy/immuno-oncology
6. Bone marrow transplant
7. Palliative/supportive care
8. **[NEW IN 2022]** Biomarker testing
9. **[NEW IN 2022]** Genetic counseling
10. Another treatment **[ANCHOR]**

**HQ\_Group1: Completed Treatment IF Q6=3 AND AT LEAST ONE Q7A-F=2**

**HQ\_Group2: In Treatment IF Q6=1 or 2 AND Q7A-F=1 FOR AT LEAST ONE**

**IF NOT GROUP 1 OR 2, THANK AND TERM**

1. Deleted in 2020 (note any “deleted” questions that are not highlighted in yellow were deleted in previous years)

**[WILL NEED TO SET QUOTAS ON PANEL SAMPLE]**

1. Do you describe yourself as a man, a woman, or in some other way?
   1. Man
   2. Woman
   3. Describe in some other way

**[WILL NEED TO SET QUOTAS ON PANEL SAMPLE]**

1. In which state do you live? [PULL DOWN MENU, INCLUDE PREFER NOT TO SAY]

**[WILL NEED TO SET QUOTAS ON PANEL SAMPLE]**

33a. Are you Hispanic, Latino or of Spanish descent?

1. Yes
2. No
3. Prefer not to say

33\_REVISED: To be sure we have a representative sample, which of the following categories describes your ethnic background/race?

Select all that apply.

1. White
2. Black/African-American
3. Asian/Pacific Islander
4. American Indian/Alaska Native
5. Other
6. Prefer not to say

**[ASK HISPANIC AUDIENCE ONLY, Q33a=1]**

**[ACCULTURATION WILL BE DETERMINED USING Q33b+Q33c+Q33d]**

**[Q33b-d USES A POINTS SYSTEM; POINTS ARE LISTED NEXT TO RESPONSES BELOW IN BRACKETS]**

**[ACCULTURATION LEVELS ARE AS FOLLOWS:**

|  |  |
| --- | --- |
|  | **Q33b-d POINTS TOTAL** |
| **UNACCULTURATED** | **10-15** |
| **BI-CULTURAL** | **5-9** |
| **ACCULTURATED** | **1-4** |

**PROVIDE TWO VARIABLES IN DATA:**

* **ACCULTURATION SCORE= SUM OF POINTS ON Q33b-d**
* **ACCULTURATION LEVEL = LEVEL/CATEGORY THEY FALL INTO]**

33b. **[NEW IN 2022] [ASK HISPANIC AUDIENCE ONLY, Q33a=1]** What language do you usually speak at home?

**[ROTATE LIST, ANCHOR OTHER]**

1. Only Spanish [5 POINTS]
2. Mostly Spanish [4 POINTS]
3. Spanish and English equally [3 POINTS]
4. Mostly English [2 POINTS]
5. Only English [1 POINT]
6. Other [0 POINTS]

33c. **[NEW IN 2022] [ASK HISPANIC AUDIENCE ONLY, Q33a=1]** Thinking of your media habits, including television, the internet, social media, radio, and print newspapers and magazines, would you say you use …

**[ROTATE LIST, ANCHOR OTHER]**

1. Only Spanish language media [5 POINTS]
2. Mostly Spanish language media [4 POINTS]
3. Spanish and English language media equally [3 POINTS]
4. Mostly English language media [2 POINTS]
5. Only English language media [1 POINT]
6. Other [0 POINTS]

33d. **[NEW IN 2022] [ASK HISPANIC AUDIENCE ONLY, Q33a=1]** Thinking about the first 18 years of your life, how many of those years did you live in the U.S.? *Your best estimate is fine.*

1. 0 (none) [5 POINTS]
2. 1-5 years [4 POINTS]
3. 6-10 years [3 POINTS]
4. 11-15 years [2 POINTS]
5. 16-18 years [1 POINT]

**DIAGNOSIS EXPERIENCES**

***Objectives:*** *New section of questions to better understand the diagnosis experience.*

1. [NEW] When were you first diagnosed with cancer?
   1. Less than a year ago
   2. 1-2 years
   3. 3-5 years
   4. 6-10 years
   5. 11-20 years
   6. More than 20 years
   7. Don’t know/not sure

**SHOW Q55 AND Q56 ON THE SAME PAGE**

1. [NEW] How old were you when you were first diagnosed with cancer?
   1. 0-10 years old
   2. 11-17 years old
   3. 18-25 years old
   4. 26-35 years old
   5. 36-49 years old
   6. 50-64 years old
   7. 65-74 years old
   8. 75 years or older
   9. Not sure
2. [NEW] What year was that? [OPEN END NUMERIC; RANGE 1920-2022; INCLUDE OPTION FOR NOT SURE]
3. [NEW] How long did you have symptoms before a health care provider suspected and/or gave you a cancer diagnosis?
   1. Less than a month
   2. 1-3 months
   3. 4-6 months
   4. 7-12 months
   5. 1-2 years
   6. 3-5 years
   7. More than 5 years
   8. I did not have symptoms before I was diagnosed (i.e., through routine check-up/screening, while dealing with another health issue, etc.)
   9. Not sure

**SHOW Q58 AND Q59 ON THE SAME PAGE**

1. [NEW] How many different doctors did you visit regarding your initial symptoms before you received a diagnosis of cancer? Your best estimate is fine.

\_\_\_\_\_\_\_\_\_\_ [OPEN END NUMBERIC, GIVE OPTION FOR NOT SURE, RANGE 0-99]

1. [NEW] Before receiving your cancer diagnosis, were you ever misdiagnosed or given an incorrect diagnosis?
   1. Yes
   2. No
   3. Not sure
2. [NEW] Where/how did you receive your cancer diagnosis?

RANDOMIZE

* 1. The emergency room
  2. A Cancer Center
  3. A doctor’s office
  4. From a phone call
  5. From an email
  6. From the patient portal
  7. Other (please specify) [ANCHOR]
  8. Not sure [ANCHOR, EXCLUSIVE]

**TREATMENT EXPERIENCES**

***Objectives:*** *Better understand the patient experience, including new questions around site of care, satisfaction with treatment, and quality of life.*

9a. [REVISED] Please think about your mindset and experiences as a cancer patient. ~~For each set of statements,~~ Select the statement that describes you best, or if you are somewhere in the middle.

|  |  |  |
| --- | --- | --- |
| ~~1~~ | ~~2~~ | ~~3~~ |
| ~~Describes Me~~ | ~~Somewhere in the middle~~ | ~~Describes Me~~ |

~~[FIRST PAIR: INFORMATION]~~

1. ~~I want/wanted to find out all I can/could about my cancer diagnosis and my treatment options.~~
2. ~~I do not/didn’t want to think or read about cancer and hear about all of the bad things.~~

[SECOND PAIR: DECISIONS]

1. I am/was very involved in researching and deciding on the best treatment options for me.
2. I rely/relied on the doctor to decide on treatment options and chose the best course of action.
3. Somewhere in the middle.

~~[THIRD PAIR: GOALS]~~

1. ~~My focus is/was getting rid of the cancer no matter what.~~
2. ~~My focus is/was on maintaining my quality of life as much as possible.~~

9b. [NEW] And still thinking about your mindset and experiences as a cancer patient, how well do each of the following statements describe you?

1. Describes me perfectly
2. Describes me somewhat
3. ~~Describes me a little~~
4. ~~Does not describe me well~~
5. Does not describe me ~~at all~~
6. Not sure

RANDOMIZE

1. I want/wanted to find out all I can/could about my cancer diagnosis and my treatment options
2. I do not/didn’t want to think or read about cancer and hear about all of the bad things
3. My focus is/was getting rid of the cancer no matter what
4. My focus is/was on maintaining my quality of life as much as possible
5. **NEW:** I tried to ignore my symptoms for as long as I could before getting a cancer diagnosis
6. **NEW:** I delayed going to the doctor for as long as I could before getting a cancer diagnosis
7. **NEW:** I feel/felt uncomfortable telling people that I have/had cancer
8. **NEW:** I feel/felt a lot of pressure from others to remain strong during my cancer treatment
9. **NEW:** My faith is/was critical in helping me through my cancer treatment
10. **NEW:** My friends and family are/were critical in helping me through my cancer treatment
11. **NEW:** My health care team is/was critical in helping me through my cancer treatment

10X. Where are you receiving/did you receive your cancer treatment? *Select all that apply.*    
**RANDOMIZE**

* 1. Community hospital and/or cancer center
  2. Academic medical center/teaching hospital (affiliated with a medical school at a university)
  3. Private cancer center (not affiliated with a hospital)
  4. Outpatient clinic
  5. Doctor’s office
  6. Home infusion/home health
  7. Other (please specify) **[ANCHOR]**
  8. Not sure **[ANCHOR. EXCLUSIVE.]**

10a. What is the name of the place where you receive/ed your cancer treatment? [OPEN END, OPTIONAL]

1. [NEW] Have you ever had to travel more than an hour from your home to visit a health care provider related to receiving your cancer treatment?
   1. Yes (Please specify how many times you had to travel. Your best estimate is fine.) [RANGE 1-999]
   2. No

10bb. [NEW] **[IF Q10=1]** How far did you have to travel for your care?

* 1. An hour to two hours away
  2. Two hours to three hours away
  3. Three hours to four hours away
  4. Four hours to five hours away
  5. More than five hours away
  6. Not sure

10b. DELETED 2022

10bc. [NEW] How long is/was a typical treatment appointment for the following?

* 1. Less than an hour
  2. An hour to two hours
  3. Two hours to three hours
  4. More than three hours
  5. Take/took medication at home
  6. Not sure

**RANDOMIZE, PULL IN RESPONSES WHERE Q07 A-I =1 OR 2**

10bd. [NEW] Thinking about a typical treatment appointment, do/did you attend…?

[ITEMS 2,3,4 CAN BE MULTI-SELECT]

* 1. By yourself [EXCLUSIVE]
  2. With a family member
  3. With a spouse/partner
  4. With a friend
  5. Not sure [EXCLUSIVE]

7a. At any point, did you participate in a clinical trial related to your cancer diagnosis?

* 1. Yes
  2. No
  3. Not sure

7b. **[If Q7a=2 OR 3]** Did your health care team offer/discuss a clinical trial with you?

1. Yes
2. No
3. Not sure

10a. Which of the following health care providers are you seeing/did you see during your cancer treatment? *Select all that apply.*

**RANDOMIZE**

* 1. Primary care physician
  2. Oncologist
  3. Nurse/Nurse practitioner
  4. Patient navigator
  5. Care coordinator
  6. Social worker
  7. Psychologist or Psychiatrist
  8. Physical therapist
  9. Speech therapist
  10. Occupational therapist
  11. Rehabilitation specialist
  12. Home health aide
  13. Radiation oncologist
  14. Surgeon
  15. Nutritionist/dietician
  16. Palliative care
  17. Pain specialist
  18. Hematologist
  19. Other (please specify \_\_\_\_\_\_\_\_\_) **[ANCHOR]**
  20. None of these **[ANCHOR, EXCLUSIVE]**

**[ASK IF Q10A≠20]**

10b**.** How helpful are/were each of the following health care providers in aiding you during your treatment?

* 1. Very helpful
  2. Somewhat helpful
  3. Not helpful
  4. Not sure

**[INSERT ANY CARE TEAM MEMBERS SELECTED IN Q10a]**

10c. How well do/did your health care providers coordinate your care with one another?

1. Very well
2. Somewhat well
3. Not well
4. Not sure/not applicable

10d. How often do/did you have to share information from one health care provider with another provider, so they are/were informed about your cancer care?

1. All the time
2. Some of the time
3. Only a few times
4. Never
5. Not sure/not applicable

10e. [NEW] How well do/did your health care providers do each of the following?

1. Very well
2. Somewhat well
3. Not well
4. Not sure/not applicable

RANDOMIZE

1. Share test results with all of your health care providers (i.e., primary care physician, oncologist, specialists, nurses, etc. share with one another)
2. Review your health records before appointments
3. Help you transition to different care with another provider
4. Help you transition to post-treatment care with another provider
5. Help you find a specialist to address specific concerns
6. Address all your health care needs
7. Provide clear information you understand
8. Provide a care plan that helps/helped you understand what to expect

11a. DELETE 2022

11b. DELETE 2022

11bb. [NEW 2022] Overall, how much do you/did you trust your health care team to act in your best interests during your cancer treatment and care?

1. Completely

2. Somewhat

3. Not at all

4. Not sure

11c. Thinking about your cancer treatment and care, how often did you feel like you could talk to your health care providers about any concerns related to your treatment and care?

1. Always
2. Most of the time
3. Some of the time
4. A little
5. Not at all

11d. Thinking about your cancer treatment and care, how often did you feel like your health care providers listened to and respected your questions and concerns?

1. Always
2. Most of the time
3. Some of the time
4. A little
5. Not at all

11e. [ON SAME PAGE AS 11D]: What made you feel that way? [Open End, optional]

1. [REVISED] Which of the following, if any, did you experienced during treatment? *Select all that apply.*
2. [ONLY ASK IF COMPLETED TREATMENT] Which of the following, if any, did you experience after treatment was completed? Select all that apply.
3. [ONLY ASK IF COMPLETED TREATMENT] Which of the following, if any, are you still experiencing today? Select all that apply.

**RANDOMIZE**

1. Skin irritation/rash, blisters, sunburns, or other dermatological problems
2. Nausea/vomiting or diarrhea
3. Fever/chills
4. Low blood pressure **[ALWAYS APPEAR WITH 11]**
5. Feeling overly tired
6. Muscle/joint pain
7. Depression, anxiety, and/or other mental health issues
8. Endocrine issues (e.g., thyroid issues, diabetes, pituitary gland)
9. Neuropathy (e.g., weakness, numbness, and pain from nerve damage, usually in the hands and feet)
10. Cardiac issues
11. High blood pressure **[ALWAYS APPEAR WITH 4]**
12. Memory loss, cognitive issues
13. Respiratory issues
14. Lymphedema (e.g., swelling in arm and/or leg)
15. Uncertainty around status of your cancer
16. Uncertainty around when to stop or how long to continue therapy
17. Weight loss
18. Loss of appetite and/or taste
19. Mouth sores

Sexual concerns (e.g., intimacy issues, loss of desire, painful intercourse, vaginal dryness, erectile dysfunction, etc.)

Insomnia/sleeplessness

Speech/language loss

Fertility issues

1. Other, please specify **[ANCHOR]**
2. None of the above **[ANCHOR. EXCLUSIVE]**
3. DELETED
4. DELETED

12a. How informed do/did you feel about the potential side effects from your cancer treatment?

1. Very informed
2. Somewhat informed
3. Not informed
4. Not sure

12b.DELETED

13a. **[ASK IF Q11=1-22]** How helpful is or was your health care team in addressing your side effects?

1. Very helpful
2. Somewhat helpful
3. Not helpful
4. Not sure

**[INSERT ANY SIDE EFFECTS EXPERIENCED IN Q11, Q12, Q13]**

1. DELETED

14A. [NEW IN 2022, ASK ALL] At any point, have you had a virtual/telehealth appointment during your cancer treatment? Select all that apply.

1. Before the COVID-19 pandemic

2. During the height of the COVID-19 pandemic (2020, 2021)

3 This year (2022)

4. No

5. Not sure

[MOVED]

44. [ASK IF 14A=1 OR 2 Yes] Overall, how would you rate the telehealth appointment(s) you attended virtually?

* 1. Excellent
  2. Very good
  3. Good
  4. Fair
  5. Poor
  6. Not sure

[MOVED]

45. [ASK ALL] In the future, would you prefer in-person or virtual appointments for each of the following?

* 1. Prefer in-person appointments
  2. Prefer virtual appointments
  3. No preference
  4. Not sure

[RANDOMIZE]

1. First visit with a health care provider [ALWAYS ASK FIRST]
2. Regular well-visits
3. Follow-up appointment(s)
4. Counseling and education
5. Medication management
6. Sharing test results
7. Mental health services
8. Physical therapy/rehabilitation
9. Getting a second opinion
10. Surgical consult
11. Survivorship appointment
12. Treatment planning and decision-making

**Understanding Post-Treatment Experiences**

***Objectives:*** *To better understand needs and experiences following cancer treatment.*

**[SKIP TO Q23, IF IN TREATMENT (Q6=1 or 2 AND Q7A-F=1 FOR AT LEAST ONE TYPE OF TREATMENT)]**

The next set of questions are about the transition from being treated for cancer to your post-treatment care.

1. DELETED TRANSITION SERIES 15-18
2. DELETED
3. DELETED
4. DELETED

Who is the primary health care provider managing your post-treatment medical care?

1. Primary care provider
2. Oncologist
3. Other specialist, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. Not sure/Don’t know
5. DELETED
6. Overall, how would you evaluate the **post-treatment medical care** you are currently receiving?
7. Excellent
8. Good
9. Fair
10. Poor
11. Not sure/not applicable
12. Prefer not to say

21a. DELETED

21b. [REVISED] Which of the following topics have your health care providers discussed with you regularly during your post-treatment care? *Select all that apply.*

**RANDOMIZE**

1. Your quality of life
2. Your physical function
3. How much pain is interfering with your daily life
4. How much fatigue is interfering on your daily life
5. Your cognitive function
6. The mental and emotional impact of your illness (e.g., anxiety, depression, etc.)
7. Financial services/support
8. Health insurance options
9. Exercise and nutrition
10. Access to support groups

Your post-treatment survivorship care plan or next step summary

[IF Q5=4 Stage IV/Metastatic] Palliative care/support services

[IF Q5=4 Stage IV/Metastatic] Hospice Care

Fertility concerns

[NEW] Follow-up tests to monitor your cancer reoccurring or spreading

1. Other (please specify)
2. None of the above **[ANCHOR, EXCLUSIVE]**

21bb. [NEW] Which of the following topics would you like to talk about with your health care providers during your post-treatment care? *Select all that apply*

**RANDOMIZE**

1. Your quality of life
2. Your physical function
3. How much pain is interfering with your daily life
4. How much fatigue is interfering on your daily life
5. Your cognitive function
6. The mental and emotional impact of your illness (e.g., anxiety, depression, etc.)
7. Financial services/support
8. Health insurance options
9. Exercise and nutrition
10. Access to support groups

Your post-treatment survivorship care plan or next step summary

[IF Q5=4 Stage IV/Metastatic] Palliative care/support services

[IF Q5=4 Stage IV/Metastatic] Hospice Care

Fertility concerns

Follow-up tests to monitor your cancer reoccurring or spreading

1. Other (please specify)
2. None of the above **[ANCHOR, EXCLUSIVE]**

21bc. [NEW] What else, if anything, would you like to talk about with your health care providers during your post-treatment care? [OPEN END, NOT REQUIRED]

1. DELETED

21c. DELETED

1. [REVISED] Below are several issues and concerns that cancer patients and survivors might have. How concerned are you, personally, about each?
   1. Very concerned
   2. Somewhat concerned
   3. Not concerned
   4. Not sure/not applicable

**RANDOMIZE**

**[WILL NOT SEE CATEGORY NAMES IN LIVE SURVEY: PHYSICAL/HEALTH]**

1. Managing ongoing side effects from treatment
2. Having the energy to make it through the day
3. Maintaining a proper diet
4. Maintaining a healthy weight
5. Getting enough exercise
6. [IF Q5=4 Stage IV/Metastatic] Planning for end-of-life care

ff. Managing appointments

**[ADHERENCE/INSURANCE]**

1. Managing all of your prescribed medications and other treatments
2. Visiting your doctor regularly

Getting/keeping health insurance

1. Getting/keeping disability insurance

Understanding the health insurance benefits available to you

**[EMOTIONAL/RELATIONSHIPS]**

1. Uncertainty about the future
2. Ability to maintain relationships with significant other, family and/or friends
3. Being there for your family and friends
4. Starting a family/having children
5. Having the emotional support you need
6. Support with mental health issues (e.g., anxiety or depression)
7. DELETE
8. Feeling isolated and lonely
9. DELETE
10. [IF Q5=4 Stage IV/Metastatic] Emotionally preparing for end-of-life
11. [IF Q5=4 Stage IV/Metastatic] Preparing to make/making end-of-life decisions

**[EMPLOYMENT/EDUCATION/OTHER LIFESTYLE]**

1. Work/employment issues, like finding and keeping a job
2. Long-term planning/career goals
   * + - 1. [NEW] Changes to daily lifestyle/activities

**[FINANCIAL]**

1. Having the financial support you need
2. Cost of prescriptions and treatments
3. Cost of medical care (including insurance premiums and co-pays)
4. Cost of non-medical expenses (e.g., food, housing, transportation)
5. Cost of professional caregiving
6. Loss of income
7. Learning how to apply for grants, scholarships, or government benefits to help with medical and living costs

23a. [REVISED] As a result of your cancer, have you…?  Select all that apply.

RANDOMIZE

1. Applied for government financial assistance such as unemployment, SNAP/food stamps, Medicaid, etc.
2. Asked for rent or mortgage relief
3. Delayed or reduced payments to credits cards or loans
4. Received help with food or housing from a charity, community center, or place of worship
5. Delayed a major life event (marriage, trip, starting family, etc.)
6. Spent savings/retirement money to cover living expenses
7. Delayed a major purchase (house, car, etc.)
8. Applied for grants or scholarships to help with medical and living costs
9. Started a GoFundMe or similar campaign to help with medical and living costs or had one started for you by others
10. [NEW] Borrowed money from family or friends
11. [NEW] Had to sell property or belongings to cover expenses
12. [NEW] Lost your insurance coverage
13. [NEW] Declared bankruptcy
14. None of these [ANCHOR AND MAKE EXCLUSIVE]

23b. [REVISED] As a result of your cancer, have any of the following happened to you?

RANDOMIZE

1. Changed jobs or employers
2. Taken a leave of absence
3. Quit your job
4. Been let go or fired
5. Missed work
6. Worked fewer hours
7. Turned down a job or promotion
8. Felt that your work suffered
9. Felt your co-workers treated you badly
10. Felt your supervisor treated you badly
11. [NEW] Lost salary or wages
12. [NEW] Taken family medical leave (offered by job)
13. [NEW] Gone on short-term disability
14. [NEW] Not been able to find a job with enough flexibility to accommodate your health needs
15. [NEW] Not received the federal and/or employer disability insurance you needed
16. [NEW] Taken early retirement
17. [NEW] Missed school or delayed your education
18. None of these [ANCHOR AND MAKE EXCLUSIVE]
19. DELETED
20. DELETED

52bb. **[NEW]** Now, thinking about the many different phases of your cancer journey, how satisfied are/were you with your care during each phase?

1. Very satisfied
2. Somewhat satisfied
3. Neither satisfied nor dissatisfied
4. Somewhat dissatisfied
5. Very dissatisfied
6. Not sure/not applicable

DO NOT RANDOMIZE

* 1. Screening and risk assessment
  2. Cancer diagnosis
  3. Treatment decision making and selection
  4. Treatment and care
  5. Coordination of care
  6. Post-treatment care

52b. **[REVISED]** Thinking about your cancer journey, what is one thing for which you wish you had received more support from either your healthcare team or a patient support organization? **[PROGRAM OPEN-END, OPTIONAL]**

52bc. [NEW 2022] When it comes to monitoring or surveillance checks for your cancer, which of the following best describes your current situation?

1. Have not been checked since the start of the COVID-19 pandemic and have yet to resume monitoring/surveillance checks
2. Did not get checked during the COVID-19 pandemic but have resumed checks
3. Appointments were delayed during the COVID-19 pandemic but still got checked during that time
4. I had no delays or postponements of appointments to be checked and continue on a regular schedule
5. Not applicable

52c. [NEW] What resources, if any, do you use for up-to-date information on cancer (disease, treatment, side effects, etc.)? Please select your top 3.

**RANDOMIZE**

1. Medical/scientific journals
2. Medical/scientific conferences
3. Healthcare websites like WebMD
4. Online medical videos on YouTube, Vimeo, etc.
5. Podcasts
6. Social media (Facebook, Instagram, Twitter, etc.)
7. Google or another search engine
8. Pharmaceutical company websites
9. Patient education materials given to you by doctor, hospital, or treatment center
10. Medical newsletters
11. Patient advocacy organizations
12. Support groups/other patients
13. News stories on TV, radio, newspaper
14. Other (please specify)
15. None of the above [ANCHOR]

**~~Understanding Support Systems~~**

***~~Objectives:~~*** *~~To better understand how they are feeling about their quality of life and support systems.~~*

1. **DELETED 2022**

27a. DELETED

27b. DELETED

27d. DELETED

26a. **DELETED 2022**

1. **DELETED 2022**
2. **DELETED 2022**
3. DELETE

**~~COVID-19 AND TELEHEALTH~~**

*~~Objectives: Better understand cancer patients’ concerns during the pandemic and with the vaccine, telehealth experiences, and the future of telehealth.~~*

1. **DELETED 2022**
2. **DELETED 2022**
3. **DELETED 2022**
4. **DELETED 2022**
5. **MOVED**

44A. **DELETED 2022**

1. **MOVED**

27c. **DELETED 2022**

1. **DELETED 2022**
2. **DELETED 2022**

47b. **DELETED 2022**

1. **DELETED 2022**
2. **DELETED 2022**
3. **DELETED 2022**

**INTEGRATIVE CARE [FOR NCCS LIST ONLY]**

***Objectives: New section on integrative care.***

**[NEW,]** Switching topics … some health care providers offer integrative oncology, which uses mind and body practices, natural products, and/or lifestyle modifications along with traditional cancer treatments.

64. **[NEW 2022]** Since your diagnosis, which of the following, if any, have you had or used to help treat cancer and/or its side-effects? Select all the apply.

[RANDOMIZE]

* 1. Massage

1. Chiropractic
2. Yoga
3. Prayer, spiritual practices
4. Dietary supplements (including vitamins, herbs)
5. Mindfulness, meditation, mantra
6. Relaxation techniques, visual imagery
7. Movement or exercise
8. Special diets
9. Acupuncture
10. Energy healing
11. Traditional or folk medicine
12. Naturopathy
13. Hypnosis
14. Biofeedback
15. None of the above [ANCHOR]

65. **[NEW 2022, ASK IF Q64=a-o, ASK]** Which of the following describe your reasons for using these services/therapies? Select all the apply.

RANDOMIZE

1. Managing symptoms, side effects of cancer
2. Managing symptoms, side effects of cancer treatment
3. Coping with emotional, mental impact of cancer
4. General wellbeing
5. Treating my cancer
6. Preventing cancer recurrence
7. Giving me a sense of control over my illness
8. Providing hope
9. Suggested by people I trust
10. Other, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_

66. **[NEW 2022, FOR EACH SELECTED IN Q64]** How would you rate the effectiveness of each?

1. Very effective
2. Somewhat effective
3. Not effective
4. Not sure

[PULL THROUGH ALL SELECTED IN Q64, SAME ORDER]

67. **[NEW 2022, ASK IF Q64=p, NONE OF THE ABOVE]** Why did you choose not to use any of the integrative oncology services/therapies? Select all that apply.

[RANDOMIZE]

1. Was not aware these therapies existed
2. Too expensive
3. Not covered by my health insurance
4. Not supported by my healthcare team
5. My healthcare team recommended against using
6. Concerned about potential side effects
7. Concerned about interactions with my cancer treatment
8. Concerned about lack of evidence supporting their safety, efficacy
9. Other, please specify \_\_\_\_\_\_\_\_
10. Not sure

**HEALTH STATUS AND DEMOGRAPHICS**

***Objectives: These questions will give us more information on current health status and demographic characteristics.***

1. **DELETED 2022**
2. **DELETED 2022**

Thank you for all your feedback so far.

This last set of questions are related to your health and also include some demographic questions that are for statistical purposes only. All feedback is anonymous and confidential and will only be reported together with the answers of others. You can choose not to answer any questions you don’t want to by selecting “prefer not to say.”

1. How would you describe your current state of health?
   1. Excellent
   2. Good
   3. Fair
   4. Poor
   5. Not sure
   6. Prefer not to say
2. How would you describe your current state of emotional health/psychological wellbeing?
3. Excellent
4. Good
5. Fair
6. Poor
7. Not sure
8. Prefer not to say

31a. Have you applied for disability insurance as a result of your cancer treatment?

* 1. Yes
  2. No
  3. Prefer not to say

1. MOVED UP
2. MOVED UP
3. MOVED UP
4. MOVED UP
5. What is the highest level of education you have completed?

1 Grade school

2 Some high school

3 High school graduate

4 Some college, no degree

5 Vocational training/2-year college

6 4-year college/bachelor's degree

7 Some postgraduate work, no degree

8 2 or 3 years postgraduate work/master's degree

9 Doctoral/law degree

10 Prefer not to say

1. What is your current marital status?
2. Single (never married)
3. Living with partner
4. Married
5. Separated
6. Divorced
7. Widowed
8. Prefer not to say
9. [REVISED] What type of health insurance do you have? *Select all that apply.*
   1. Private insurance through employer
   2. Private insurance through parents or spouse
   3. Private insurance through Health Insurance Marketplace
   4. Private insurance purchased on own
   5. Medicare
   6. Medicaid or state insurance
   7. Supplemental or gap insurance
   8. Veterans’ Administration
   9. Department of Defense or Tri-Care
   10. Other type of insurance (please specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_) [ANCHOR]
   11. No insurance [ANCHOR, EXCLUSIVE]
   12. Prefer not to say [ANCHOR, EXCLUSIVE]
   13. Not sure [ANCHOR, EXCLUSIVE]

36a. **[NEW, IF Q36=1-4 OR 7]** Who is your primary insurance provider?

1. Anthem/Blue Cross Blue Shield
2. Centene
3. Cigna
4. CVS Health/Aetna
5. GuideWell
6. HCSC
7. Humana
8. Kaiser Permanente
9. Molina Healthcare
10. UnitedHealth Group
11. Other (please specify)

**[MOVED DOWN]**

1. [REVISED] For statistical purposes only, which of the following categories best represents your total household income in 2021?
   1. Less than $25,000
   2. $25,000 but less than $50,000
   3. $50,000 but less than $75,000
   4. $75,000 but less than $100,000
   5. $100,000 but less than $150,000
   6. $150,000 but less than $200,000
   7. $200,000 or more
   8. Prefer not to say
2. How would you describe the area in which you live?
   1. Urban
   2. Suburban
   3. Small town
   4. Rural
   5. Prefer not to say
3. **[NEW IN 2022]** Do you work, have you worked, and/or gotten a degree in any of the following areas? *Select all that apply.* 
   1. Science
   2. Technology
   3. Engineering
   4. Math
   5. Healthcare
   6. None of the above
4. **[NEW IN 2022]** Have you or has any member of your household ever served in the military? *Select all that apply.* 
   1. I’m active duty
   2. I’m a veteran
   3. A member of my household is active duty
   4. A member of my household is a veteran
   5. No **[EXCLUSIVE]**

63. **[NEW IN 2022]** Generally speaking, do you think of yourself as a…

1. Republican
2. Democrat
3. Independent
4. Something else (please specify:\_\_\_\_\_\_\_\_\_)
5. Prefer not to say

Thank you very much for your time and participation. Your feedback is extremely valuable.

**[MESSAGE BELOW FOR NCCS LIST ONLY]**

The first 100 people to take this survey are eligible for a $10 Amazon gift card. Please enter your email address here if you would like to participate (Note: only the first 100 people will be selected): \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ *(optional)*

*Please note: your email will only be used to notify you if you have received a gift card; your email address will never be sold or shared, or attached to your survey responses.*

**CLOSING PAGE: Thank you very much for your time and participation. Your feedback is extremely valuable, and your responses have been submitted.**

**ONLY SHOW IF NCCS LIST:**

**You will be notified by email if you are eligible for an Amazon gift card (please note that it will take several weeks to award the prizes).**