**Edge Research for NCCS**

**Cancer Survivorship 2023 Survey**

**DRAFT: 04/27/2023**

|  |  |
| --- | --- |
| Sources | Desired Total Completes |
| * Commercial online panel | * Adult cancer patients/survivors, N=1300 * Adult caregivers of cancer patients/survivors N=500 (SPECS TBD) |
| * NCCS List: Outreach through email list and other channels | * Adult cancer patients/survivors, N @ 400-500, based on 2022 response rates |

NOTE: ALL ADDITIONS, DELETIONS, AND/OR OTHER CHANGES ARE HIGHLIGHTED IN YELLOW. (KEPT QUESTION NUMBERS THE SAME UNLESS NOTED). 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 and caregivers. 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: NCCS LIST, AND Q02=2,3]**

2b. **[NEW IN 2023]** Are you currently responsible for caring for a loved one who suffers from cancer, or have you done so within the past 5 years?

Yes, currently caring for someone

Yes, within the past 5 years

Yes, but more than 5 years ago **TERMINATE**

No **TERMINATE**

Prefer not to answer **TERMINATE**

**[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. None of the above

**[ASK IF SOURCE: ONLINE PANEL, AND Q02a≠1]**

2ab. **[NEW IN 2023]** In the last 5 years, have you cared for a family member or close friend who suffers from health problems that keep them from fully participating in work, school, housework, or other daily activities?

1. Yes, currently caring for someone
2. Yes, within the past 5 years
3. Yes, but more than 5 years ago **TERMINATE**
4. No **TERMINATE**
5. Prefer not to answer **TERMINATE**

**[ASK IF SOURCE: ONLINE PANEL, AND Q02ab=1 or 2]**

2ac. **[NEW IN 2023]** And which of the following medical conditions does the person that you have or are caring have:  
**RANDOMIZE:**

1. Heart disease
2. Diabetes
3. Cancer **MUST SAY YES TO CONTINUE**
4. Arthritis
5. None of the above
6. Prefer not to answer

**IF Q2A≠1 OR Q2AC≠3, TERMINATE.**

1. [REVISED] What type of cancer(s) did, or do, [IF PATIENT, Q02=1/Q02A=1 :you/IF CAREGIVER, Q02B=1,2/Q02AB=1,2: does your loved one] 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:\_\_\_\_\_\_\_

3a. **[NEW IN 2023] [IF CAREGIVER, Q02B=1,2/Q02AB=1,2]:** What is your role in caregiving for someone with cancer?

1. I am their sole/primary caregiver
2. I am their primary caregiver, with some help from someone else/others
3. I share the caregiving responsibilities equally with someone else/others
4. I share the caregiving responsibilities, but someone else is the primary caregiver **TERMINATE**

3b. **[NEW IN 2023] [IF CAREGIVER, Q02B=1,2/Q02AB=1,2]:** Is the person with cancer:

1. Your spouse
2. Your parent
3. Your sibling
4. Your child
5. Another family member
6. Your friend
7. Your employer/you are a professional caretaker **TERMINATE**

3c. [NEW] [IF CAREGIVER] Which of the following best describes your role as caregiver?

1. I attend/ed all appointments with my loved one
2. I attend/ed most appointments with my loved one
3. I attend/ed some appointments with my loved one
4. I don’t/didn’t attend appointments with my loved one
5. [REVISED] At what age were [IF PATIENT, Q02=1/Q02A=1 :you/IF CAREGIVER, Q02B=1,2/Q02AB=1,2: was your loved one] first diagnosed with cancer?

**NUMERIC ENTRY FIELD ALLOWING 0-99**

**OPTION FOR “Don’t know/Not sure”**

1. [REVISED] At **diagnosis**, did the doctor discuss the stage of [IF PATIENT, Q02=1/Q02A=1 :your/IF CAREGIVER, Q02B=1,2/Q02AB=1,2: your loved one’s] cancer? Was it… *Please think about the most recent diagnosis.*
   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

5a. **[NEW IN 2023] [IF CAREGIVER, Q02B=1,2/Q02AB=1,2]:** Is your loved one with cancer still living?

1. Yes
2. No
3. [REVISED] Which of the following applies to [IF PATIENT, Q02=1/Q02A=1 :you/IF CAREGIVER, Q02B=1,2/Q02AB=1,2, AND Q05a=1: your loved one]? *Select one.*
4. Currently receiving treatment for initial cancer diagnosis
5. Currently receiving treatment for cancer that has recurred
6. Completed treatment and/or not currently in active treatment for cancer
7. Other, specify\_\_\_\_\_\_\_\_\_\_\_\_\_\_ **TERMINATE**

1X. [REVISED] When did [IF PATIENT, Q02=1/Q02A=1 :you/IF CAREGIVER, Q02B=1,2/Q02AB=1,2, AND Q05a=1: your loved one] complete the 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 [IF PATIENT, Q02=1/Q02A=1 :you/IF CAREGIVER, Q02B=1,2/Q02AB=1,2: has your loved one] undergone? Select all that apply.
2. [ONLY SHOW IF PATIENT OR CAREGIVER Q05A=1] 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. Biomarker testing
9. Genetic counseling
10. Hospice
11. CAR T cell therapy
12. Another treatment **[ANCHOR]**

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

**HQ\_Group2: In Treatment IF Q6=1 or 2 AND Q7A-I or K=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. **[ASK HISPANIC AUDIENCE ONLY, Q33a=1]** What language do you usually speak at home?

**[ROTATE LIST, ANCHOR OTHER]**

1. Only Spanish
2. Mostly Spanish
3. Spanish and English equally
4. Mostly English
5. Only English
6. Other

33c. **DELETE**

33d. **DELETE**

**DIAGNOSIS EXPERIENCES**

***Objectives:*** *To better understand the diagnosis experience.*

1. [REVISED] When P\_PK were you/P\_PK2 was your loved one] 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. [REVISED] How old were P\_PK you/P\_PK2 was your loved one] when P\_PK you/P\_PK2 they] were first diagnosed with cancer?
   1. Under 15 years old
   2. 15-19 years old
   3. 20-29 years old
   4. 30-39 years old
   5. 40-49 years old
   6. 50-59 years old
   7. 60-69 years old
   8. 70 years or older
   9. Not sure
2. What year was that? [OPEN END NUMERIC; RANGE 1920-2023; INCLUDE OPTION FOR NOT SURE]
3. **DELETE 2023**
4. **DELETE 2023**
5. **DELETE 2023**
6. DELETE

**TREATMENT EXPERIENCES**

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

9a. Please think about your mindset and experiences as a cancer patient [IF PATIENT, Q02=1/Q02A=1/P\_PK2 as a caregiver]. Select the statement that describes you best, or if you are somewhere in the middle.

1. I am/was very involved in researching and deciding on the best treatment options for me [IF PATIENT, Q02=1/Q02A=1/P\_PK2 my loved one].
2. I rely/relied on the doctor to decide on treatment options and chose the best course of action.
3. Somewhere in the middle.
4. [CAREGIVER’S ONLY] I wasn’t involved in this.

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

1. Describes ~~me~~ perfectly
2. Describes ~~me~~ somewhat
3. Does not describe ~~me~~
4. Not sure

RANDOMIZE

1. I want/wanted to find out all I can/could about my CAREGIVER my loved one’s] 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 [CAREGIVER: my loved one’s] cancer no matter what
4. My focus is/was on maintaining my [CAREGIVER: my loved one’s] quality of life as much as possible
5. I CAREGIVER My loved one] tried to ignore ~~my~~ symptoms for as long as ~~I could~~ possible before getting a cancer diagnosis
6. I CAREGIVER My loved one] delayed going to the doctor for as long as ~~I could~~ possible before getting a cancer diagnosis
7. **[ASK PATIENTS ONLY, Q02=1/Q02A=1]**I feel/felt uncomfortable telling people that I have/had cancer
8. I feel/felt a lot of pressure from others to remain strong during ~~my cancer~~ [CAREGIVER: my loved one’s] treatment
9. My faith is/was critical in helping me through ~~my cancer~~ [CAREGIVER: my loved one’s] treatment
10. My friends and family are/were critical in helping me through ~~my cancer~~ [CAREGIVER: my loved one’s] treatment
11. ~~My~~ The health care team is/was critical in helping me through ~~my cancer~~ [CAREGIVER: my loved one’s] treatment
12. [CHEATER FLAG] For data quality purposes, please select describes ~~me~~ somewhat

10X. **DELETE 2023**

10a. **DELETE 2023**

1. **DELETE 2023**

10bb. **DELETE 2023**

10b. DELETE 2022

10bc. **DELETED 2023**

10bd. **DELETE 2023**

7a. At any point, did you CAREGIVER your loved one] participate in a clinical trial related to your CAREGIVER their] cancer diagnosis?

* 1. Yes
  2. No
  3. Not sure

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

1. Yes
2. No
3. Not sure

10a. [REVISED] Which of the following health care providers are you CAREGIVER is your loved one] seeing/did you CAREGIVER your loved one] 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. [NEW] Pharmacist
  20. [NEW] Cardiologist
  21. [NEW] Audiologist
  22. [NEW] Fertility specialist
  23. Other (please specify \_\_\_\_\_\_\_\_\_) **[ANCHOR]**
  24. None of these **[ANCHOR, EXCLUSIVE]**

**[ASK IF Q10A≠24]**

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 ~~you’re~~ the 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 CAREGIVER your loved one] have to share information from one health care provider with another provider, so they are/were informed about your CAREGIVER their] cancer care?

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

10e. [DELETE 2023]

11a. DELETE 2022

11b. DELETE 2022

11bb. Overall, how much do you/did you trust ~~you’re~~ the health care team to act in your CAREGIVER your loved one’s] 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 CAREGIVER you and your loved one] could talk to ~~your~~ the health care providers about any concerns related to your CAREGIVER their] 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~~ the health care providers listened to and respected your CAREGIVER: your and your loved one’s] 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, REQUIRED]

11f. [NEW] Please rank the following below in terms of how important each was in making decisions about treatment. You can click on the items and move them around from most important (at the top), to least important (at the bottom). **RANDOMIZE ORDER, SET UP AS DRAG/DROP. MUST MOVE AT LEAST ONE ITEM TO CONTINUE**

1. Doctor’s recommendations
2. Likelihood that the treatment will work
3. How I/the patient will feel during treatment
4. Clinical trial data from other people who have taken the treatment
5. Real-world data from other people who have taken the treatment
6. Whether I/your loved one will be able to continue working during treatment
7. Whether I/your loved one will be able to continue daily activities during treatment
8. Which of the following, if any, did you CAREGIVER your loved one] experience~~d~~ during treatment? *Select all that apply.*
9. **[DELETE 2023]**
10. [ONLY ASK IF COMPLETED TREATMENT or Q5a=1] Which of the following, if any, are you CAREGIVER your loved one] 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~~ the 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

[NEW] Hearing loss

[NEW] Vision loss

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

12a. How informed do/did you CAREGIVER your loved one] 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=1-25]** How helpful is or was ~~you’re~~ the health care team in addressing your CAREGIVER your loved one’s] 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. **DELETE 2023**

44. **DELETE 2023**

45. **DELETE 2023**

**Understanding Post-Treatment Experiences**

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

**[SKIP TO Q21be, 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

**[SKIP IF Q05a=2]** Who is the primary health care provider managing your CAREGIVER your loved one’s] post-treatment medical care?

1. Primary care provider
2. Oncologist
3. Other specialist, please specify: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_
4. Not sure/Don’t know
5. DELETED
6. DELETE 2033

21a. DELETED

21b. **[SKIP IF Q05a=2, ONLY ASK OF CAREGIVERS WHO SELECT Q03c=1-3]** Which of the following topics have your CAREGIVER: your loved one’s] health care providers discussed with you [CAREGIVER: them] 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 cancer ~~your illness~~ (e.g., anxiety, depression, etc.)
7. Financial services/support
8. Health insurance options
9. Exercise and nutrition
10. Access to support groups

~~You’re~~ A 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

[NEW IN 2023] [IF Q5=4 Stage IV/Metastatic] End-of-life support

Fertility concerns

Follow-up tests to monitor ~~your~~ cancer reoccurring or spreading

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

21bb. **[SKIP IF Q05a=2, ONLY ASK OF CAREGIVERS WHO SELECT Q03c=1-3]** Which of the following topics would you like to talk about with [PATIENT: your; CAREGIVER: your loved one’s] health care providers during ~~your~~ post-treatment care [CAREGIVERS: , on behalf of your loved one]? *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 cancer ~~your illness~~ (e.g., anxiety, depression, etc.)
7. Financial services/support
8. Health insurance options
9. Exercise and nutrition
10. Access to support groups

~~You’re~~ A 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

[NEW IN 2023] [IF Q5=4 Stage IV/Metastatic] End-of-life support

Fertility concerns

Follow-up tests to monitor ~~your~~ cancer reoccurring or spreading

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

21bc. **[SKIP IF Q05a=2, ONLY ASK OF CAREGIVERS WHO SELECT Q03c=1-3]** What else, if anything, would you CAREGIVER you and your loved one] like to talk about with ~~your~~ health care providers during ~~your~~ post-treatment care? [OPEN END, NOT REQUIRED]

21be. [NEW] Did P\_PK your/P\_PK2 your loved one’s] health care team provide a care plan that helps/helped you understand what to expect?

1. Yes
2. No
3. Not sure
4. DELETED

21c. DELETED

1. DELETE 2023

Q23c. **[NEW. ASK CAREGIVERS ONLY, Q02B=1,2/Q02AB=1,2]** Below are several issues and concerns that **caregivers** might have. While caregiving, how concerned are/were you about each for **YOURSELF**?

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

**RANDOMIZE**

1. Having the energy to make it through the day
2. Maintaining a proper diet
3. Maintaining a healthy weight
4. Getting enough exercise
5. Ability to maintain relationships with significant other, family and/or friends
6. Being there for your family and friends
7. Having the emotional support you need
8. Support with mental health issues (e.g., anxiety or depression)
9. Feeling isolated and lonely
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
12. Work/employment issues, like finding and keeping a job

23a. As a result of P\_PK your/P\_PK2 your loved one’s] cancer, have you personally…?  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 your personal living expenses
7. Delayed a major purchase (house, car, etc.)
8. Applied for grants or scholarships to help with your personal medical and living costs
9. Started a GoFundMe or similar campaign to help with your personal medical and living costs or had one started for you by others
10. Borrowed money from family or friends
11. Had to sell property or belongings to your personal cover expenses
12. [PATIENT ONLY] Lost your insurance coverage
13. Declared bankruptcy
14. [PATIENT ONLY] [NEW] Delayed treatment to get insurance authorization/approval
15. [PATIENT ONLY] [NEW] Applied for co-pay assistance from drug manufacturer or non-profit organization/foundation
16. None of these [ANCHOR AND MAKE EXCLUSIVE]

23d. [NEW, ASK IF PATIENT, Q02=1/Q02A=1] How interested would you be in the ability to enroll in a monthly payment plan to spread your prescription drug costs out over the year, rather than paying all at once?

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

23b. MOVED DOWN

1. DELETED
2. DELETED

52bb. [REVISED]Now, thinking about the many different phases of P\_PK your/P\_PK2 your loved one’s] cancer journey, how satisfied are/were you with P\_PK your/P\_PK2 their] 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
  7. NEW [IF METASTATIC PATIENT OR CAREGIVER: Q5=4] End of life planning and care

1. [BACK FROM 2021, ASK IF PATIENT, Q02=1/Q02A=1] Do you consider yourself a cancer survivor?
   1. Yes
   2. No
   3. Not sure

52e. [NEW] [CAREGIVERS ONLY: Q02B=1,2/Q02AB=1,2] What does being a “caregiver” mean to you? [PROGRAM OPEN-END, OPTIONAL]

52f. [NEW] [CAREGIVERS ONLY: Q02B=1,2/Q02AB=1,2] Which of the following terms do you prefer to describe yourself?

1. Caregiver
2. Care partner
3. Caretaker
4. Carer
5. Other (please specify)

52b.  **DELETE 2023**

52bc. DELETE 2023

52c. [REVISED] What resources, if any, do you use for up-to-date information on cancer (disease, treatment, side effects, etc.)? Please select up to 3. ALLOW UP TO THREE RESPONSES

**RANDOMIZE**

1. Medical/scientific journals
2. ~~Medical/scientific conferences~~
3. Health care 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. Cancer non-profit organizations (like American Cancer Society, The Leukemia & Lymphoma Society, Susan G. Komen, etc.)
12. Support groups/other patients or caregivers
13. News stories on TV, radio, newspaper
14. [NEW] Commercials/advertisements for cancer treatments
15. Other (please specify)
16. None of the above [ANCHOR]
17. **DELETED 2022**

27a. DELETED

27b. DELETED

27d. DELETED

26a. **DELETED 2022**

1. **DELETED 2022**
2. **DELETED 2022**
3. DELETE
4. **DELETED 2022**
5. **DELETED 2022**
6. **DELETED 2022**
7. **DELETED 2022**
8. **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**

**PRESENTEEISM**

***Objectives: New section to understand the burden and impact cancer has on employment and presenteeism.***

71. [NEW] What is or was your employment status during P\_PK your/P\_PK2 your loved one’s] cancer treatment?

1. Part-time employment
2. Full-time employment
3. Self-employed
4. Full-time stay-at-home parent
5. Not employed, looking for work
6. Not employed, not looking for work
7. Student
8. Disabled/On disability
9. Active-duty military
10. Retired
11. Prefer not to say

Q23b. [MOVED] [REVISED] As a result of P\_PK your/P\_PK2 your loved one’s] 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. Lost salary or wages
12. Taken family medical leave (offered by job)
13. Gone on short-term disability
14. Not been able to find a job with enough flexibility to accommodate your CAREGIVER your loved one’s] health needs
15. Not received the federal and/or employer disability insurance you CAREGIVER your loved one] needed
16. Taken early retirement
17. Missed school or delayed your education
18. [NEW] Worked remotely/worked from home
19. None of these [ANCHOR AND MAKE EXCLUSIVE]

73. [NEW] [IF LEFT JOB, Q23B=1-3] What made you decide to leave/stop working? [PROGRAM OPEN-END, OPTIONAL]

74. [NEW] [IF Q23b=5 and/or 6] Thinking about a typical week, how many hours have/did you miss from work because of your CAREGIVER your loved one's] cancer? (This can include hours you missed on sick days, times you went in late, left early, etc. because of these heath issues) \_\_ \_\_ \_\_ [GIVE OPTION FOR NOT SURE/CANNOT REMEMBER]

74a. [NEW] Thinking about a typical week, how much did your CAREGIVER your loved one's] cancer affect your productivity while working? (Think about days you were limited in the amount or kind of work you could do, days you accomplished less than you would like, or days you could not do your work as carefully as usual.)

1. Cancer had no effect on my productivity while working
2. Cancer had a small effect on my productivity while working
3. Cancer had a large effect on my productivity while working
4. Cancer completely prevented me from working
5. Not sure

75. [NEW] [IF IN TREATMENT AND CURRENTLY WORKING, OR Q71=1,2] How much do you agree or disagree with the following statements?

Strongly agree

Somewhat agree

Neutral

Somewhat disagree

Strongly disagree

Not sure

**RANDOMIZE**

1. Because of my CAREGIVER my loved one's], the stresses of my job are/were much harder to handle.
2. Despite my CAREGIVER my loved one's] cancer, I am/was able to finish my work and meet deadlines.
3. My CAREGIVER my loved one's] cancer distracts/distracted me from enjoying my work.
4. The quality of my work suffers/suffered due to my CAREGIVER my loved one's] cancer.
5. At work, I am/was able to focus on achieving my goals despite CAREGIVER my loved one's] cancer.
6. Despite my CAREGIVER my loved one's] cancer, I have/had enough energy to complete all my work.
7. My colleagues and supervisors are/were understanding of my circumstances.
8. I rely/relied on my work colleagues for support and encouragement.
9. I rely/relied on work to get my mind off cancer.
10. Working helps/helped me stay motivated.

76. [NEW, ASK ALL] How do you feel about advertising (on TV, online, etc.) for different cancer treatments?

5 Very positive

4 Somewhat positive

3 Neutral

2 Somewhat negative

1 Very negative

6 Not sure

77. [NEW, ASK ALL] What makes you say that?

**INTEGRATIVE CARE [ASK PATIENTS ONLY]**

***Objectives: Better understand the use and impact of integrative care.***

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. **[REVISED]** 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. **[REVISED, 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. 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. **[REVISED, 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 health care team
5. Health care 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 P\_PK your/P\_PK2 your loved one’s] 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.”

28a. [NEW] ASK CAREGIVERS **[SKIP IF Q05a=2]**: How would you describe your loved one’s current state of health?

1. Excellent
2. Good
3. Fair
4. Poor
5. Not sure
6. Prefer not to say
7. 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

29a. [NEW] ASK CAREGIVERS **[SKIP IF Q05a=2]**: How would you describe your loved one’s current state of emotional health/psychological wellbeing?

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

31a. [REVISED] Have you CAREGIVER Has/did your loved one applied/apply] applied for disability insurance as a result of 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. What type of health insurance do you CAREGIVER does/did your loved one] 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. **DELETE 2023**

**[MOVED DOWN]**

1. [REVISED] For statistical purposes only, which of the following categories best represents your total household income in 2022?
   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. 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. Health care
   6. None of the above
4. 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. Generally speaking, do you think of yourself as a(n)…

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

68**. [NEW]** Do you identify as a member of the LGBTQ+ community?

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

68a. **[IF Q68=1]** Which of the following best represents your gender identity? *Select all that apply.*

**SHOW IN THIS ORDER (ALPHABETICAL)**

1. Agender
2. Genderfluid
3. Genderqueer
4. Man
5. Non-binary
6. Transgender man
7. Transgender woman
8. Woman
9. I’m unsure
10. I use another term (please specify:\_\_\_\_\_\_\_\_\_\_)

68b. **[IF Q68=1]** How would you describe your sexual orientation? *Select all that apply.*

**SHOW IN THIS ORDER (ALPHABETICAL)**

1. Asexual
2. Bisexual
3. Gay
4. Lesbian
5. Pansexual
6. Queer
7. Questioning/Unsure
8. Straight/Heterosexual
9. I use another term (please specify:\_\_\_\_\_\_\_\_\_\_)
10. 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).**