

Clinical Trial Participation Costs Survey

This survey includes questions about your participation in a clinical trial for cancer treatment and any costs and/or financial impacts associated with participating in that clinical trial.

What is a cancer clinical trial? A cancer clinical trial is a research study where doctors test new ways to treat cancer. Clinical trials may involve new drugs or combinations of drugs, new surgical procedures or devices, or new ways to use existing treatments. Clinical trials can also test other aspects of care, such as ways to improve the quality of life for people with cancer.

Screener

S1. Have you participated in a cancer clinical trial anytime between 2018 and 2024?

If you began participating prior to 2018 and participation continued in 2018, please mark "Yes".

If you are currently participating in a cancer clinical trial, please mark "Yes".

If you participated in a clinical trial prior to your cancer diagnosis or unrelated to your cancer diagnosis, please mark "No".

☐¹ Yes

☐⁰ No (END SURVEY)

Section I. Cancer clinical trial participation

Thinking about the cancer clinical trial in which you participated or are participating.....

1. In what month and year did you begin participating in your clinical trial? <month dropdown> / 2 0 __ __
2. How old were you at the time you began participating in your clinical trial? __ (age) (If <18, END)
3. Which type of cancer were you diagnosed with that led to your clinical trial participation? <dropdown list of common cancers listed alphabetically including bladder, brain, breast, cervical, colon, head / neck, kidney, leukemia, liver, lung, lymphoma, melanoma, pancreatic, prostate, rectal, testicular, thyroid, uterine, other (specify)>
4. What stage was your cancer at the time of you began participating in your clinical trial?
☐¹ Stage I ☐⁴ Stage IV
☐² Stage II ☐⁵ Not sure / don't know
☐³ Stage III

Throughout this survey, we ask you about the cancer care you received or are receiving as part of your clinical trial participation. We refer to this as "trial-specific cancer care".

5. Which of the following types of treatment did you receive or are you receiving as part of your clinical trial?

Mark all that apply.

☐¹ Chemotherapy

☐² Radiation therapy (including pellets or seeds)

☐³ Surgery

☐⁴ Immunotherapy

☐⁵ Photodynamic therapy

☐⁶ Hormone therapy

☐⁷ Stem cell transplant

☐⁸ Targeted therapy

☐⁹ Hyperthermia

☐¹⁰ Not sure / don't know

☐¹¹ Other (please specify): _____

6. Are you still participating in your clinical trial?

☐¹ Yes (Go to programmer note before Q10)

☐⁰ No

7. In what month and year did your participation in your clinical trial end? <month dropdown> / 2 0 __ __

8. Did you complete your clinical trial or did you end participation sooner than expected?

☐¹ Completed participation (Go to programmer note before Q10)

☐² Ended participation sooner than expected (Go to programmer note before Q9)

PROGRAMMER NOTE: If Q8=2, then Q9. Else, go to programmer note before Q10.

9. Did your clinical trial participation end sooner than expected because of the COVID-19 pandemic?

☐¹ Yes

☐⁰ No

PROGRAMMER NOTE: The logic below is intended to capture anyone active in clinical trial between 2020 and 2024, including those starting before 2020 and continuing participation into/after 2020.

If ((Q1_year >= 2020) OR (Q1 <2020 and Q6=1) OR (Q1 <2020 and Q6=NO and Q7 >= 2020)), then Q10. Else, go to definition page.

10. What did you learn from your clinical trial team about aspects of care that would be different to prevent getting or spreading COVID-19? *This may include, but is not limited to, frequency of office visits and/or treatment, duration of the clinical trial, and location of office visits and/or treatment.*

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<Definition page>

You reported that you started your clinical trial participation in <Fill with Q1 mm/yyyy><if Q6=1 fill with “and is ongoing”>.

<If Q6=no> You reported that you ended your clinical trial participation in <Fill with Q7 mm/yyyy>

- In this survey, the time between when you started your clinical trial participation and ended your clinical trial participation is called your “clinical trial period”.
- If you are **still enrolled** in your clinical trial, the “clinical trial period” is the time between when you started your clinical trial and the date you complete this survey.
- In this, survey, unless otherwise specified, please tell us about your experience during the “clinical trial period”.

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Section II. Employment and clinical trial participation

In this section we ask you questions about your employment before and during your clinical trial participation.

11. Prior to beginning your clinical trial participation, were you working for pay? *If you were self-employed, please mark "Yes".*

☐¹ Yes

☐⁰ No (Go to Section III)

12. Prior to beginning your clinical trial participation, how many hours per week were you regularly scheduled to work? *This means the hours you were officially prescribed to work. If your hours varied from week to week, please provide the average number of hours over the course of a typical week.*

Your best estimate is fine.

__ __ __ (hours)

13. Did you continue to work after you started your clinical trial participation?

If you changed jobs but continued to work for pay, please mark "Yes".

☐¹ Yes

☐⁰ No (Go to Q18)

14. How many hours per week were you regularly scheduled to work while participating in your clinical trial? *This means the hours you were officially prescribed to work. If your hours varied from week to week, please provide the average number of hours over the course of a typical week.*

Your best estimate is fine.

__ __ __ (hours)

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The next questions ask about how your clinical trial participation impacted your ability to work.

15. Did you miss any workdays or parts of workdays because of your trial-specific cancer care?

☐¹ Yes

☐⁰ No (Go to Q18)

16. In total, how much work did you miss because of your trial-specific cancer care?

☐¹ Less than 1 week

☐² 1-4 weeks

☐³ 5-8 weeks

☐⁴ 9-12 weeks

☐⁵ More than 12 weeks

17. How did missing work impact your pay?

- ☐¹ I received my regular pay during the time I took off (includes paid time off for holiday, vacation, personal or sick leave)
- ☐² I received some pay during the time I took off, but not the total amount
- ☐³ I did not receive any pay during the time I took off

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The next questions are about health insurance.

18. Did you have health insurance through your employer at the time you began participating in your clinical trial?

- ☐¹ Yes
- ☐⁰ No (Go to Section III)

19. Did your health insurance status, cost, or plan change because of the time you had to take away from work or because you left your job?

- ☐¹ Yes
- ☐⁰ No (Go to Section III)

20. In what way did your health insurance status, cost, or plan change because of the time you had to take away from work or because you left your job?

- ☐¹ I kept the same health insurance but had to pay more per month
- ☐² I changed health insurance, but did not have any gap in coverage
- ☐³ I was uninsured for at least one month during or after my leave or after I left work
- ☐⁴ I lost my health insurance
- ☐⁵ Other (specify): _____
- ☐⁶ Not sure / don't know

PROGRAMMER NOTE: If Q13=1, then Q21. Else, skip to Section III.

21. Did you remain at your job so that you had health insurance to help with the cost of cancer care?

- ☐¹ Yes
- ☐⁰ No

Section III. Cancer care location

22. Thinking about where you went for most of your trial-specific cancer care, was it:

	Yes	No
a. easy to get to?	☐ ¹	☐ ⁰
b. close to where you lived?	☐ ¹	☐ ⁰
c. the same place you went for your cancer care that was not part of your clinical trial?	☐ ¹	☐ ⁰

23. Were you given an option of receiving some trial-specific cancer care at a different location than the main site of your clinical trial?

☐¹ Yes

☐⁰ No

Section IV. Travel, Housing/Lodging, and Child Care

The next questions are about your travel, housing/lodging, and child care while you were receiving your trial-specific cancer care.

24. On average, how many miles did you travel to receive your trial-specific cancer care?

Please report one-way travel only.

If you traveled to multiple facilities, report the number of miles for the facility that was farthest. Your best estimate is fine.

____, ____ (# of miles)

a. How many trips did you make? *Your best estimate is fine.*

____ (# of trips)

b. What mode of transportation did you use most frequently?

☐¹ Personal car

☐⁵ Walked

☐² Bike

☐⁶ Airplane

☐³ Local bus, metro, or subway

☐⁷ Long-distance train or bus (i.e., Amtrak, Greyhound)

☐⁴ Taxi, cab, Uber, Lyft

☐⁸ Other (specify): _____

c. Thinking about trips you made, how often did someone accompany you?

☐¹ Someone accompanied me on every trip

☐² Someone accompanied me on most trips

☐³ Someone accompanied me on a few trips

☐⁴ I never had anyone accompany me on trips

These next questions are about housing when you traveled to get your trial-specific cancer care. This includes, but is not limited to, stays at hotels, Airbnb, and other short-term rentals. It also includes housing made available through your clinical trial.

25. When you traveled to get your trial-specific cancer care, did you need to obtain housing/lodging?

☐¹ Yes

☐⁰ No (Go to Question 26)

- a. Thinking about the housing / lodging you obtained, what was the average cost you paid per night, week, or month?**

Please consider the costs of your housing as well as the costs of housing for anyone accompanying you on your visits. If housing was free or you stayed with family and/or friends, please record \$0. Your best estimate is fine.

\$ __ __ __, __ __ __ <dropdown per night, per week, per month>

☐¹ Click here if you cannot recall housing/lodging costs.

- b. For each trip in which you required housing/lodging, how long did you typically stay? Your best estimate is fine.**

__ __ __ <dropdown days, weeks, months>

26. While you received trial-specific cancer care, did you have to arrange child or dependent care?

☐¹ Yes

☐⁰ No (Go to Question 27)

- a. How much did you pay for child or dependent care each time? If the amount you paid varied, please pick the range that includes the average amount you paid. Your best estimate is fine.**

☐¹ \$0, care was free

☐⁴ Between \$50 and \$74

☐² Less than \$25

☐⁵ Between \$75 and \$99

☐³ Between \$25 to \$49

☐⁶ \$100 or more

Section VI. Other costs associated with trial-specific cancer care

Sometimes clinical trial participants have costs other than those related to transportation and housing.

27. Did you miss out on leisure time and/or spend less time with family and friends because of your trial-specific cancer care?

☐¹ Yes

☐⁰ No

28. Did a family member, friend, or caretaker miss work to support you during your trial-specific cancer care?

☐¹ Yes

☐⁰ No

Section VII. Clinical trial activities

In this section, we ask about how you participated in different aspects of your clinical trial.

29. As a clinical trial participant, did you...

	Yes	No
a. participate in phone or video appointments via Zoom, WebEx, or similar platform with members of your <u>clinical trial</u> care team?	☐ ¹	☐ ⁰
b. communicate with members of your <u>clinical trial</u> care team via online patient portal?	☐ ¹	☐ ⁰
c. receive any <u>clinical-trial</u> related care in your home?	☐ ¹	☐ ⁰
d. have <u>clinical trial</u> medications delivered to your home?	☐ ¹	☐ ⁰

30. Did clinical trial staff ask you to use home devices or wearable devices to gather information about your health and then report that information to them? *Examples of home devices or wearable devices include, but are not limited to, smart watches, heart rate monitors, blood glucose machines, pulse oximeters, and electronic blood pressure machines.*

☐¹ Yes

☐⁰ No

31. Did clinical trial staff ask you to use an app to monitor and track symptoms or to help you remember to take medications, get lab tests done, or do other clinical trial related activities?

☐¹ Yes

☐⁰ No

32. In what ways did your clinical trial team make it easier for you to participate in clinical trial activities? *Please explain.*

<FREE TEXT FIELD>

Section VIII. Financial aspects of clinical trial participation

33. Patients sometimes receive compensation for their time spent participating in clinical trials. Separate from reimbursements you may have received for other expenses, did you receive compensation for your time participating in your clinical trial from any of the following? *Select all that apply.*

☐¹ Yes, from my clinical trial sponsor

☐² Yes, from an outside organization or foundation (for example, Lymphoma Research Foundation, Lazarex, or Susan G. Komen Breast Cancer Foundation)

☐³ Yes, not sure of the source

☐⁰ No, did not receive compensation (Go to Q35)

34. What would you estimate was the amount of compensation you received during your clinical trial participation? *Your best estimate is fine.*

\$ __, __ __ <drop down – in a lump sum, per visit >

35. As a result of clinical trial participation, did you receive reimbursement for any of the following or receive any of the following for free or at a reduced cost? *Check all that apply.*

☐¹ Parking

☐⁵ Gasoline

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- ☐ ² Food
☐ ³ Transportation
☐ ⁴ Road tolls
☐ ⁶ Housing or lodging
☐ ⁷ Child care
☐ ⁸ Medications to manage treatment side effects
☐ ⁹ Internet service or plan
☐ ¹⁰ Other (please specify)

36. Thinking about your clinical trial participation overall, how much money did you personally spend for trial-specific cancer care and related services? Cancer care and services include, but are not limited to, laboratory tests, imaging studies like X-rays or MRIs, cancer treatment, prescription and over-the-counter medications, hospitalization, equipment, and in home care.

If you are currently participating in a clinical trial, please report the total you have personally spent from the time between when you started your clinical trial to date.

Your best estimate is fine.

\$ _____ , _____

37. Is the total amount of money you personally spent during your clinical trial participation higher than you thought it would be, lower than you thought it would be, or about what you thought it would be?

- ☐ ¹ Spending was higher than I thought it would be
☐ ² Spending was lower than I thought it would be
☐ ³ Spending was about what I thought it would be

38. The following are elements of trial-specific cancer care that you may have paid for, in whole or in part. For each, please indicate if you had to pay for some or all the trial-specific care received during your clinical trial participation? If you are not sure, please select the 'Not sure/ don't know' box.

	Had to pay for some or all the trial-specific cancer care			
	Yes	No	Not sure / don't know	Did not need service
a. Laboratory tests such as blood draws, urine tests, and the like	☐ ¹	☐ ²	☐ ³	☐ ⁴
b. Imaging studies such as X-rays, MRIs, CT scans, and the like	☐ ¹	☐ ²	☐ ³	☐ ⁴
c. Clinical trial treatment (chemo, radiation, surgery, etc.)	☐ ¹	☐ ²	☐ ³	☐ ⁴
d. Prescription medications associated with cancer care	☐ ¹	☐ ²	☐ ³	☐ ⁴
e. Over-the-counter medications to manage side effects	☐ ¹	☐ ²	☐ ³	☐ ⁴
f. Office visits with oncologists to monitor your health status	☐ ¹	☐ ²	☐ ³	☐ ⁴
g. Physical or occupational therapy to address effects of cancer and cancer care	☐ ¹	☐ ²	☐ ³	☐ ⁴
h. Mental health services or counseling to address mental health burden of cancer and cancer care	☐ ¹	☐ ²	☐ ³	☐ ⁴
i. In home care by nurses and trained aides	☐ ¹	☐ ²	☐ ³	☐ ⁴
j. Equipment such as wheelchair, cane, oxygen, compression devices, etc.	☐ ¹	☐ ²	☐ ³	☐ ⁴
k. Hospitalization related to cancer	☐ ¹	☐ ²	☐ ³	☐ ⁴
l. Emergency department or urgent care visits related to cancer	☐ ¹	☐ ²	☐ ³	☐ ⁴

Section IX. Financial stress

39. Have any of the following happened because of expenses related to your clinical trial participation?

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	Yes	No	Not sure/ don't know
a. Put off major purchases, such as a new home or car	☐ ¹	☐ ⁰	☐ ⁹⁹
b. Difficulty paying for basic necessities like food, heat, or rent	☐ ¹	☐ ⁰	☐ ⁹⁹
c. Reduced spending on leisure activities	☐ ¹	☐ ⁰	☐ ⁹⁹
d. Had to take money out of savings or retirement account	☐ ¹	☐ ⁰	☐ ⁹⁹
e. Sold possessions or property	☐ ¹	☐ ⁰	☐ ⁹⁹
f. Took out a mortgage against your home or took out a loan	☐ ¹	☐ ⁰	☐ ⁹⁹
g. Had to borrow money from family or friends	☐ ¹	☐ ⁰	☐ ⁹⁹
h. Family members had to work more	☐ ¹	☐ ⁰	☐ ⁹⁹
i. Took on credit card debt	☐ ¹	☐ ⁰	☐ ⁹⁹
j. Thought about filing for bankruptcy	☐ ¹	☐ ⁰	☐ ⁹⁹
k. Filed for bankruptcy	☐ ¹	☐ ⁰	☐ ⁹⁹
l. Spent more than 10% of your household income on medical expenses	☐ ¹	☐ ⁰	☐ ⁹⁹

40. During your clinical trial participation, did your financial situation cause you no stress at all, a little stress, a lot of stress, or extreme stress?

- ☐¹ No stress at all
☐² A little stress
☐³ A lot of stress
☐⁴ Extreme stress

Section X. About you

The following are questions about you. If you do not feel comfortable answering a question you may skip it.

41. How do you describe yourself?

- ☐¹ Female
☐² Male
☐³ Transgender female
☐⁴ Transgender male
☐⁵ Gender non-binary
☐⁶ Prefer not to say

42. Which of the following best describes your sexual orientation?

- ☐¹ Heterosexual or straight ☐⁵ Gay
☐² Asexual ☐⁶ Pansexual
☐³ Bisexual ☐⁷ Queer
☐⁴ Lesbian ☐⁸ Other (specify): _____
☐⁹ Prefer not to say

43. What is your race and/or ethnicity? Select all that apply.

- ☐¹ American Indian or Alaska Native
☐² Asian
☐³ Black or African American
☐⁴ Hispanic or Latino

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- ☐⁵ Middle Eastern or North African
☐⁶ Native Hawaiian or Pacific Islander
☐⁷ White

44. At the time you began your clinical trial participation, what was your household income? Please include income from all family members living in your household and before taxes.

- ☐¹ \$35,000 or less
☐² \$35,001 to \$70,000
☐³ \$70,001 to \$125,000
☐⁴ More than \$125,000
☐⁵ I prefer not to answer
☐⁶ Not sure / don't know

45. At the time you began your clinical trial participation, what was your highest grade or level of schooling you completed?

- | | |
|--|---|
| ☐ ¹ Less than high school degree | ☐ ⁵ Associate degree |
| ☐ ² High school degree or equivalent (GED) | ☐ ⁶ Bachelor's degree |
| ☐ ³ Post high school training other than college (vocational or technical) | ☐ ⁷ Post-graduate/Advanced degree |
| ☐ ⁴ Some college | ☐ ⁸ Prefer not to say |

46. At the time you began your clinical trial participation, which of the following best describes your marital status

- ☐¹ Single
☐² Married or partnered
☐³ Divorced or separated
☐⁴ Widowed
☐⁵ Other (specify): _____

47. At the time you began your clinical trial participation, how many children under the age of 18 were living in your household? <dropdown 0,1, 2, 3, 4, 5, More than 5>

48. At the time you began your clinical trial participation, what state did you live in? <state dropdown>

49. At the time you began your clinical trial participation, what zip code did you live in? _ _ _ _ _

50. At the time you began your clinical trial participation, what was your primary source of health insurance or health care coverage?

- ☐¹ Employer-provided insurance
- ☐² Privately purchased health insurance – for example, through the marketplace
- ☐³ Medicare (including Medicare Advantage or other supplemental Medicare plans)
- ☐⁴ Medicaid [INSERT STATE-SPECIFIC LABEL FROM Q50; If Q50=missing, just display Medicaid]
- ☐⁵ Military health care (TRICARE/VA/CHAMP-VA)
- ☐⁶ Indian Health Service
- ☐⁷ No health insurance or health care coverage of any type
- ☐⁸ Not sure / don't know
- ☐⁹ Other (specify): _____

51. At the time you began your clinical trial participation, which of the following best describes the area in which you lived?

- ☐¹ Rural
- ☐² Suburban
- ☐³ Urban
- ☐⁴ Prefer not to say