Understanding the Cancer Survivor Experience

Today's Chat Agenda

- **Updates: Community Oncology Alliance (COA) and COA's Patient Advocacy Network (CPAN)**
- **Shelley Fuld Nasso, MPP, National Coalition for Cancer Survivorship**
  - The latest results from the annual State of Survivorship Survey
    - Treatment Decision-making
    - Cancer Care Experiences
    - Post-Treatment Care and Survivorship

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NATIONAL COALITION
FOR CANCER SURVIVORSHIP

STATE OF SURVIVORSHIP

2024 Survey

Findings from a National Survey of Cancer Patients, Survivors, and Caregivers

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Methodology

Nationwide Survey of Adult Cancer Patients, Survivors, and Caregivers

- Nationwide sample of n=2134, fielded August 6th – September 9th, 2024
    - Patients n=1620
    - Caregivers n=514
- Oversample of Younger Patients (age 18-39) n=375
- Set quotas to make sure the sample was representative by age, gender, race/ethnicity, and region (using ACS and NCI data)
- Surveys were recruited through an online non-probability sample with quotas set to ensure demographically representative audiences, following AAPOR best practices

Nationwide Survey of “NCCS Connected” Patients and Survivors

- Nationwide sample of n=714, same field period as nationwide survey
    - Patients n=674
    - Caregivers n=40
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders
- Survey link also sent to partner organizations, and includes data from those including Stupid Cancer

Blue/**red** = statistically **higher**/**lower** by audience | ▲▼= change from 2023 survey

Full text of survey questions is in the notes section of slides

Key Findings

Treatment Decision-Making

Majorities of cancer patients continue to rely primarily on their doctor to choose the best treatment for them – twice as many as those who say they were actively involved in this decision. At the same time, a third of patients report needing to advocate for themselves to get the best treatment and care, significantly higher among: Blacks, Hispanics, urban, low income, women, and younger (ages 18-39) patients. These groups are also less likely to rely on
their doctors for treatment decisions.

Doctors' recommendations are also by far the main driver and barrier to clinical trial participation. Three-quarters of those who did not participate in a clinical trial said it was because they were not asked.

Care Experiences

Most Patients continue to be very satisfied with each phase of their cancer care. However, younger patients are significantly less satisfied and less likely to trust their HCPs.

Nine-in-10 patients report experiencing side effects; with fatigue, mental health issues, and fear of recurrence having the biggest impact on quality of life. More than 4-in-10 also report being financially impacted by cancer, significantly higher among Caregivers, Blacks, Hispanics, younger, stage IV, and LGBTQ+ patients. Caregivers and younger patients are also more likely to say they didn't have a choice and had to keep working during cancer treatment.

Post-Treatment Care

Two-thirds of Patients surveyed who are *within* 5 years of finishing treatment say they are currently receiving post treatment care, and nearly half have received a survivorship plan. Most of these patients are seeing an oncologist or other specialist. The number who report seeing a PCP dropped over the last few years (only 19% today), although twice as many (38%) say they would consider seeing one. Some have concerns about PCP's knowledge and ability to detect a recurrence.

At the same time, majorities of those who are *over* 5 years out are not receiving post-treatment care, with most saying their doctor told them it was no longer needed.

The number who report seeing a PCP for post-treatment care dropped over the last few years

Treatment Decision-making

Patient and Caregiver Mindset

Patients are equally focused on getting rid of their cancer at all costs and quality of life, with caregivers more focused on quality of life.
A third say they had to advocate for themselves to get the best treatment – higher among some key groups.
Younger patients are less likely to accept they may have cancer, but once receiving a diagnosis, are more likely to advocate for themselves.

"I have to advocate for myself in order to get the best treatment and care" higher among:

59% Black
48% Hispanic
45% Urban
45% HHI <$25k
39% Women

(% Describes perfectly)	National Patients	National Caregivers	NCCS Connected Patients	Younger Patients (18-39)
My focus is/was on maintaining my/my loved one's quality of life as much as possible	74%	85%	65%	67%
My focus is/was getting rid of the cancer no matter what	73%▼ *(-4 pts.)*	67%	67%	76%
I want/wanted to find out all I can/could about my/my loved one's cancer diagnosis and treatment options	60%	75%	72%	70%
[NEW] I have to advocate for myself in order to get the best treatment and care	35%	N/A	56%	56%
I/My loved one tried to ignore symptoms for as long as possible before getting a cancer diagnosis	12%	28%	7%	27%
I do not/didn't want to think or read about cancer	10%	11%	6%	20%

Source= National Patients (n=1620); National Caregivers (n=514); NCCS Connected Patients (n=674)

Treatment Decisions

After a dip during COVID, "Doctor knows best" mentality persists in 2024, with twice as many saying they relied on their doctor to choose the best treatment, vs. being active in the decision.

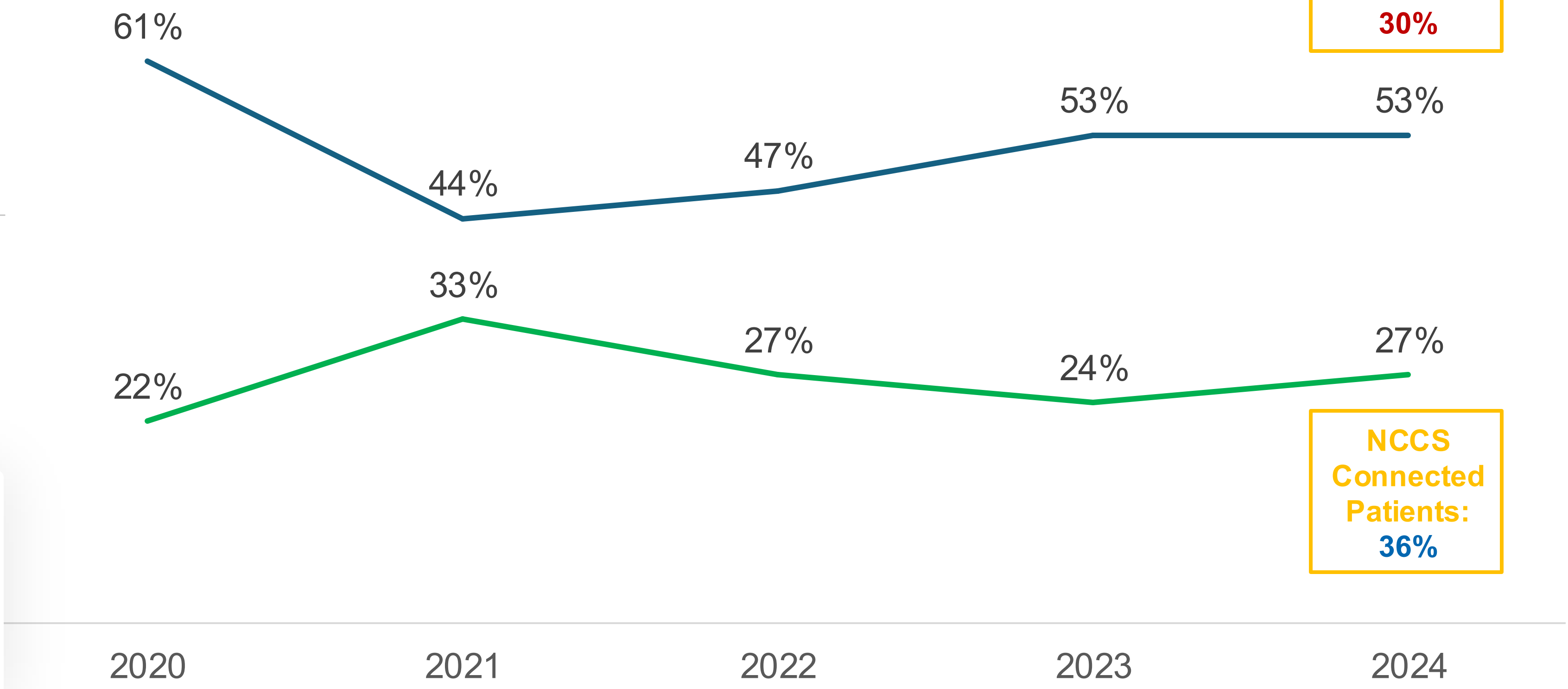
Relied on the doctor to decide on treatment options and choose the best course of action

I am/was very involved in researching and deciding on the best treatment options.

An additional 20% this year are "somewhere in the middle"

(**34%** among **NCCS Connected Patients**)

Patient National Sample



NCCS Connected Patients 30%

NCCS Connected Patients: 36%

Source= National Patients (n=1620)

Treatment Decisions

Almost half of younger and Hispanic patients report they were very involved in their treatment decisions. Medicare/Advantage/seniors are more likely to rely on their doctors to choose their treatment.

	National Patients	National Caregivers	NCCS Connected Patients	Younger Patients (18-39)	Seniors (65+)	Black	Hispanic	Medicare	Medicare Advantage	Medicaid	Private
I rely/relied on the doctor to decide on treatment options and choose the best course of action.	53%	37%	30%	30%	58%	43%	42%	57%	59%	51%	49%
I am/was very involved in researching and deciding on the best treatment options.	27%	36%	36%	47%	22%	35%	47%	23%	24%	26%	30%

Source= National Patients (n=1620); National Caregivers (n=514); NCCS Connected Patients (n=674)

Second Opinions

Less than a third of patients sought a second opinion, primarily because of trust in their health care provider.

At any stage of the experience, did you seek a second opinion?
% "Yes"

Patients 29%

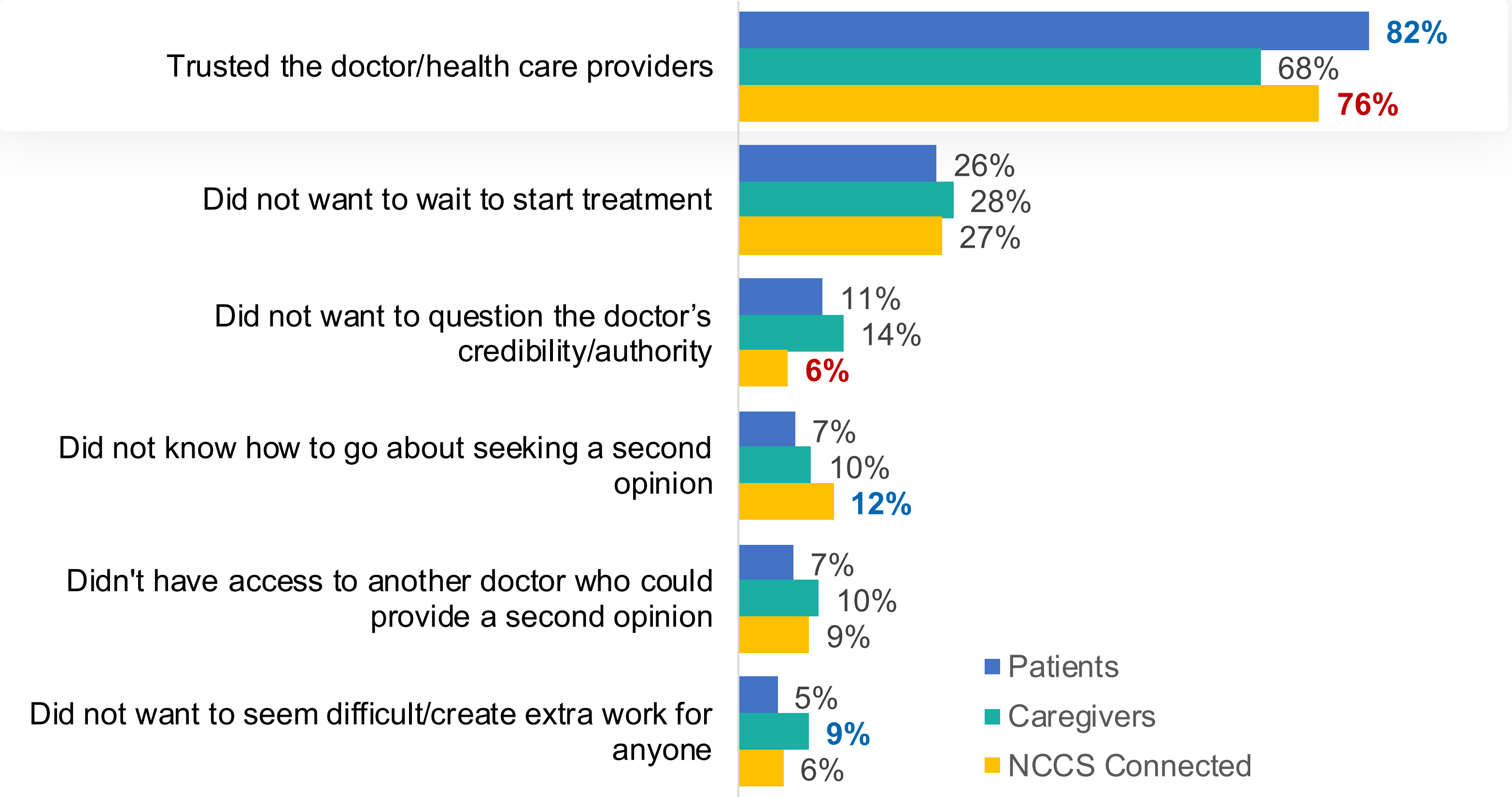
Caregivers 39%

NCCS Connected 52%

Higher among:

47% Younger Patients
43% Hispanic Patients
42% LGBTQ+ Patients
41% Stage IV Patients
36% Post-grads
34% $100K+ Household Income
33% Private Insurance

Which of the following describes why you/your loved one DID NOT seek a second opinion? Select all that apply.
(Only asked if did not seek second opinion)

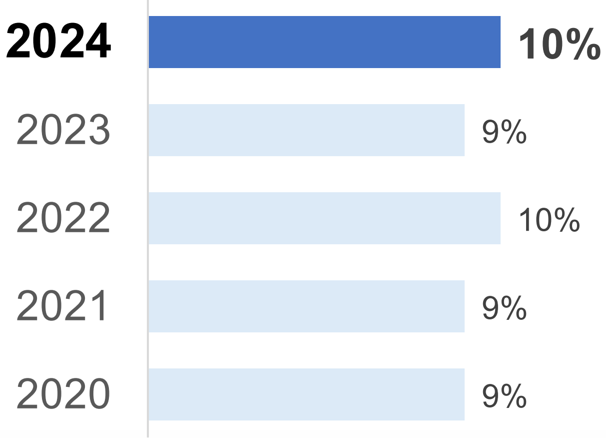


Source= National Patients (n=1620); National Caregivers (n=514); NCCS Connected Patients (n=674)

Clinical Trial Participation

Participation is on-par with previous years. New in 2024 are reasons for participating and “doctor knows best” reigns supreme.

Did you participate in a clinical trial related to your cancer diagnosis?



Higher among:

- **27%** Younger (18-39)
- **21%** Hispanic
- **23%** Palliative Care
- **19%** Immunotherapy
- **19%** Recurrence
- **18%** Still In Treatment
- **16%** Black
- **18%** NCCS Connected
- **16%** Sought 2nd Opinion
- **16%** Chemo

What influenced your decision to participate in a clinical trial? Select all that apply.
(Only asked if did participate)

		Higher among
The doctor’s recommendation	**51%**	
Wanted to contribute to science/help others	**41%**	**64% NCCS Connected**
Prospect of access to new treatments	28%	
Wanted to be proactive/have a sense of control	26%	**31%** Medicare*
It was the best treatment option	26%	**36%** Medicare*
Improved or extra level of care	25%	
Looked into it/researched being in a clinical trial	21%	
Reduced cost of treatment/receive financial reimbursement	18%	**33%** Hispanic*
Was out of treatment options	7%	**21%** Hispanic*
Other	1%	

**Small n size (Hispanic n=46, Medicare n=42)*

Source= National Patients (n=1620)

Clinical Trial Barriers

The number one barrier to participation is not being asked. Younger patients and patients of colors are slightly more concerned than others about treatment protocol and side effects, but these are still secondary.

What influenced your decision NOT to participate in a clinical trial? *(Only asked if did not participate)*		**NCCS Connected**	**Younger Patients (18-39)**	**Black**	**Hispanic**	**Academic Medical Center**
Was not asked to participate in a clinical trial	**74%**	75%	**51%**	72%	**63%**	71%
Was not eligible/did not qualify to participate in a clinical trial	13%	**22%**	21%	9%	8%	14%
Concerned about possible side-effects	6%	**2%**	**16%**	8%	**12%**	6%
Concerned about type of treatment that would be received	5%	4%	**13%**	**11%**	**10%**	8%
Location of clinical trial(s) was too far away	5%	4%	12%	7%	8%	7%
Overall health did not allow participating in a clinical trial	4%	3%	8%	**8%**	7%	6%
Concerned about costs/coverage for treatment	4%	2%	**13%**	5%	5%	5%
Did not trust the HCPs suggesting had my best interests at heart	2%	1%	**7%**	3%	**6%**	4%
Costs to participate were too high	2%	1%	**6%**	1%	3%	3%
Non-medical factors such as work/school interruption or childcare	2%	2%	**5%**	3%	4%	1%
Other	4%	5%	2%	5%	1%	6%

No differences by when completed treatment (+/- 5 years ago)

Source= National Patients (n=1620); NCCS Connected Patients (n=674)

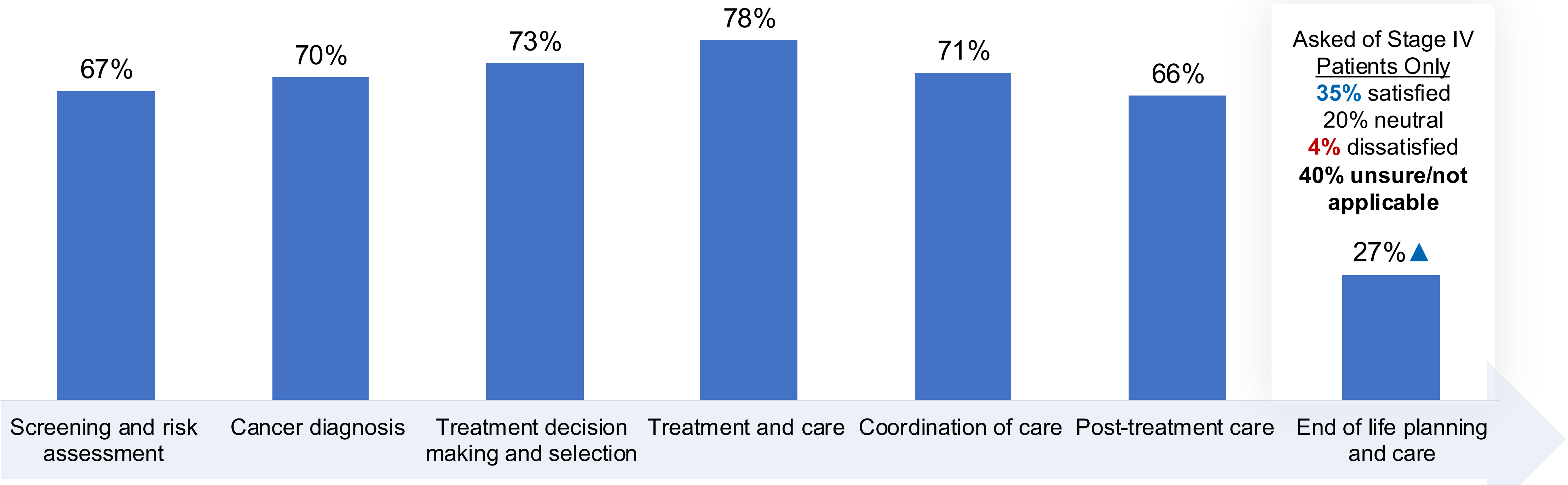
Cancer Care Experiences

Patient Satisfaction With Care

Satisfaction across most phases stayed consistent from last year.
Younger patients (aged 18-39) are less likely to say they were very satisfied across care stages.

How satisfied are/were you with your/their care during each phase?

% Very satisfied (Patients)



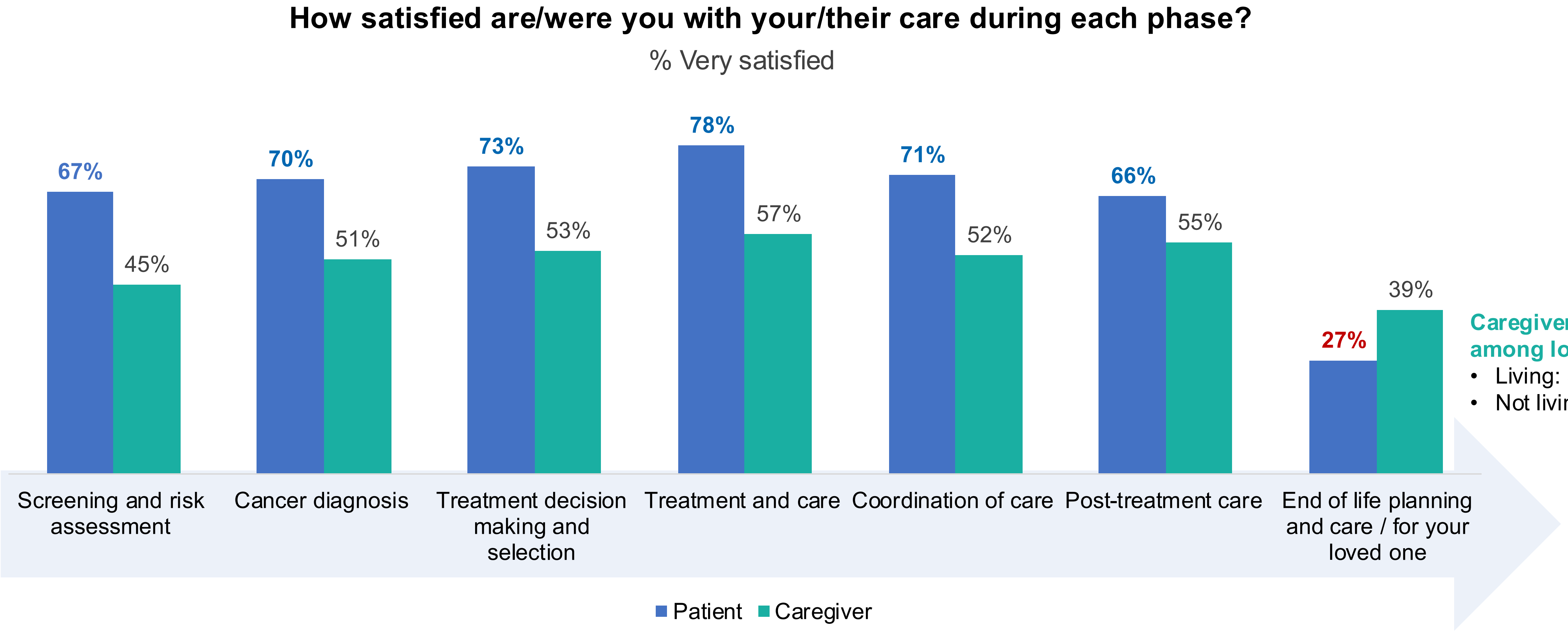
Asked of Stage IV
Patients Only
35% satisfied
20% neutral
4% dissatisfied
40% unsure/not applicable

	Screening and risk assessment	Cancer diagnosis	Treatment decision making and selection	Treatment and care	Coordination of care	Post-treatment care	End of life planning and care
Among younger patients	**43%**	**49%**	**51%**	**58%**	**55%**	**48%**	27%

Source= National Patients (n=1620)

Satisfaction With Care: Patients vs. Caregivers

As in 2023, caregivers are significantly less satisfied/more critical with each phase of the care journey, with the exception of end-of-life planning.

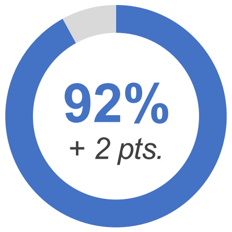


Caregiver Sat among loved one:
- Living: 32%
- Not living: 42%

Source= National Patients (n=1620); National Caregivers (n=514)

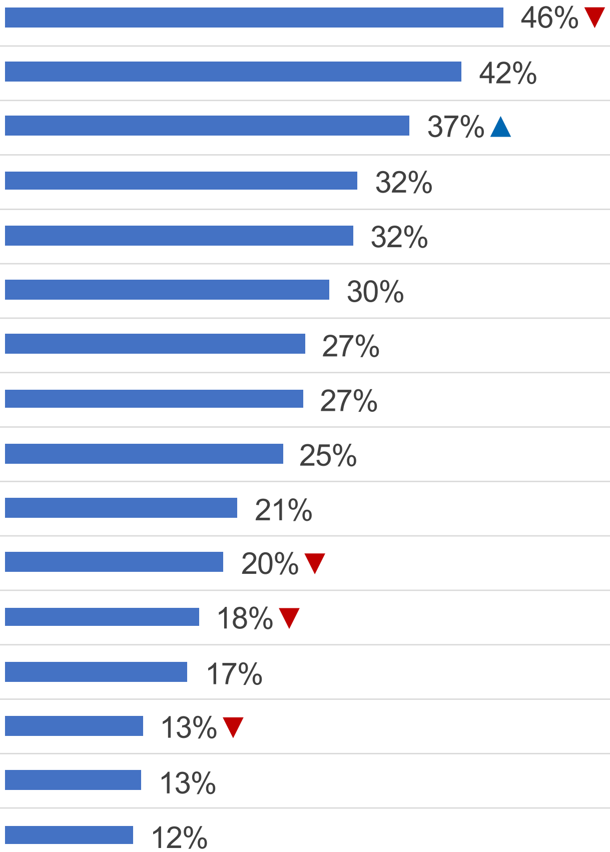
Side Effects Experienced

Feeling overly tired continues to be the symptom experienced most often.
This, plus fear of reoccurrence and depression/anxiety impact patients the most.



of Patients experienced at least one symptom during or after treatment

Symptoms experienced *(top 16 out of 32 shown)*



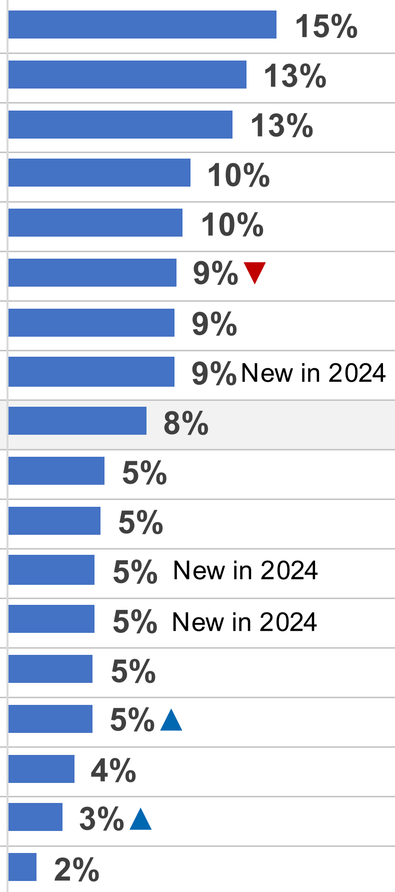
		Women	Men	Black	Hispanic	18-39	Impacted Most
Feeling overly tired	46% ▼	**55%**	**36%**	**36%**	43%	59%	**18%**
[NEW] Fear of a recurrence	42%	**51%**	**32%**	40%	42%	45%	**18%**
[REVISED] Pain	37% ▲	**43%**	**30%**	41%	**46%**	**66%**	13%
Uncertainty status of the cancer	32%	34%	30%	32%	26%	36%	12%
Depression, anxiety, mental	32%	41%	22%	30%	33%	**57%**	**15%**
Loss of appetite and/or taste	30%	**37%**	**22%**	30%	33%	**48%**	6%
Nausea/vomiting or diarrhea	27%	**36%**	**19%**	30%	31%	**46%**	9%
Sexual concerns	27%	**20%**	**35%**	30%	34%	**40%**	9%
Weight loss	25%	26%	25%	**35%**	**38%**	**46%**	5%
Neuropathy	21%	**28%**	**15%**	**28%**	21%	29%	10%
Insomnia/sleeplessness	20% ▼	**27%**	**12%**	24%	**31%**	**40%**	6%
Skin irritation/rash	18% ▼	**23%**	**12%**	21%	13%	**27%**	4%
[NEW] Concerns around body image	17%	**24%**	**9%**	15%	15%	**32%**	5%
Memory loss, cognitive issues	13% ▼	**17%**	**8%**	9%	**19%**	**29%**	4%
Fever/chills	13%	**14%**	**10%**	**17%**	**19%**	**29%**	1%
High blood pressure	12%	13%	10%	**22%**	**17%**	15%	3%

Source= National Patients (n=1620)

Financial Impacts

The number of Patients impacted financially is consistent with last year; Younger Patients have higher rates of financial consequences.

NCCS Connected: 66%



Impacted Financially: 44%		Caregivers	18-39	African American	Hispanic	Stage IV	LGBTQ+	Medicare	Non-Medicare Insurance
		69%	**90%**	**55%**	**68%**	**62%**	**69%**	**36%**	**46%**
Spent savings/retirement money to cover living expenses	15%	**29%**	26%	17%	14%	21%	19%	12%	**16%**
Applied for government financial assistance	13%	**21%**	**31%**	**19%**	**23%**	24%	**25%**	10%	**14%**
Borrowed money from family or friends	13%	**24%**	**35%**	**22%**	**21%**	16%	**21%**	8%	**14%**
Received help with food or housing	10%	**17%**	**26%**	**15%**	**20%**	15%	**20%**	8%	11%
Delayed or reduced payments to credits cards or loans	10%	**16%**	**20%**	13%	15%	15%	15%	8%	11%
Delayed a major purchase (house, car, etc.)	9% ▼	**22%**	**26%**	11%	14%	**21%**	15%	7%	**10%**
Delayed a major life event (marriage, trip, starting family, etc.)	9%	**22%**	**34%**	**13%**	**18%**	15%	14%	8%	10%
PATIENT ONLY: Had difficulty affording prescription drugs	9% New in 2024	N/A	**25%**	12%	11%	13%	**23%**	10%	9%
PATIENT ONLY: Applied for co-pay assistance from drug manufacturer	8%	N/A	**16%**	8%	**18%**	**19%**	**16%**	5%	**9%**
PATIENT ONLY: Delayed treatment to get insurance authorization	5%	N/A	**17%**	7%	**10%**	7%	8%	4%	6%
Had to sell property or belongings to cover your personal expenses	5%	**13%**	**13%**	7%	5%	5%	7%	4%	6%
PATIENT ONLY: Had trouble getting insurance to cover screenings	5% New in 2024	N/A	**20%**	5%	8%	6%	7%	3%	**6%**
PATIENT ONLY: Stopped, took less than, or switched meds b/c of cost	5% New in 2024	N/A	**15%**	7%	8%	8%	9%	4%	5%
Asked for rent or mortgage relief	5%	7%	**12%**	**11%**	4%	9%	**10%**	4%	5%
Applied for grants or scholarships to help with medical and living costs	5% ▲	**7%**	**15%**	**8%**	**10%**	5%	8%	2%	**6%**
Started a GoFundMe or similar campaign	4%	**7%**	**17%**	5%	**8%**	5%	**9%**	2%	**4%**
PATIENT ONLY: Lost your insurance coverage	3% ▲	N/A	**9%**	5%	4%	3%	4%	2%	**4%**
PATIENT ONLY: Declared bankruptcy	2%	3%	3%	3%	3%	2%	3%	1%	2%

9% Medicare Advantage

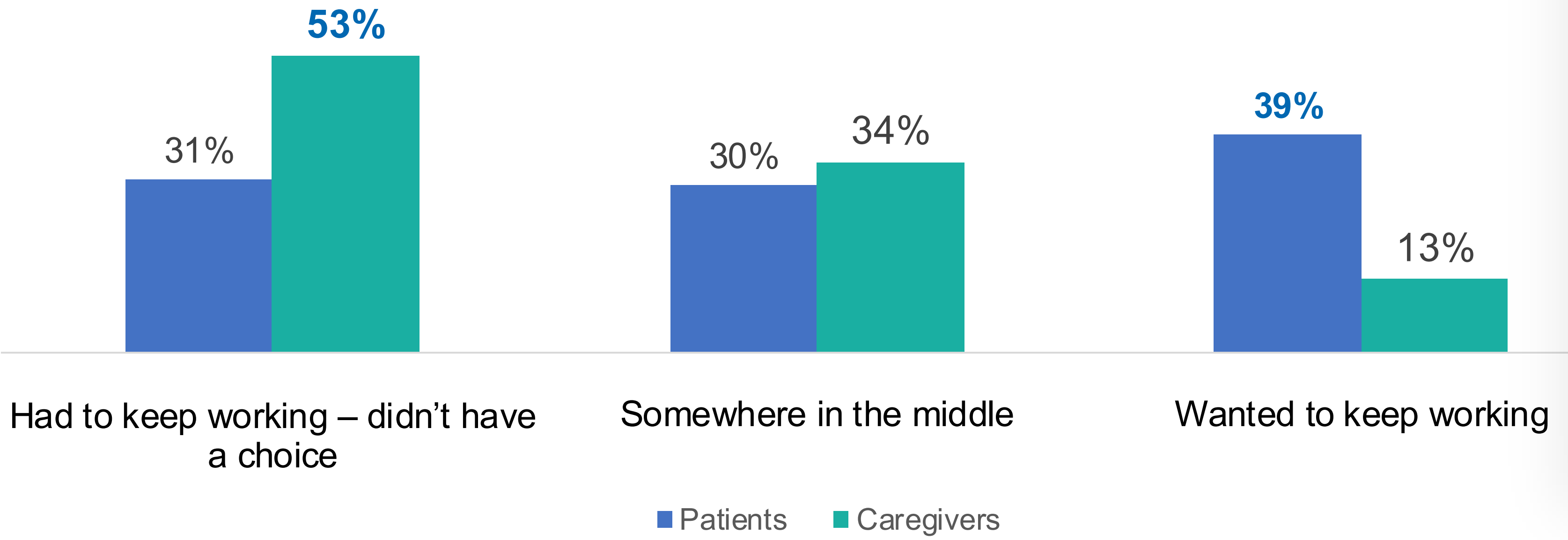
Source= National Patients (n=1620); National Caregivers (n=514); NCCS Connected Patients (n=674)

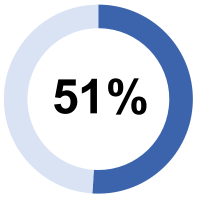
Employment Status during Treatment

Over a third of Patients wanted to keep working during their treatment, while half of Caregivers felt obligated to work. Younger Patients are significantly more likely to say they didn't have a choice.

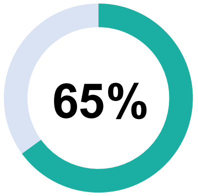
You indicated you were employed during your/your loved one's treatment. Which of the following best describes you?

Among Patients who are…	Had to keep working – didn't have a choice	Somewhere in the middle	Wanted to keep working
Younger (18-39)	**48%**	37%	**16%**
Impacted Financially	**42%**	**34%**	**25%**





of Patients worked during treatment



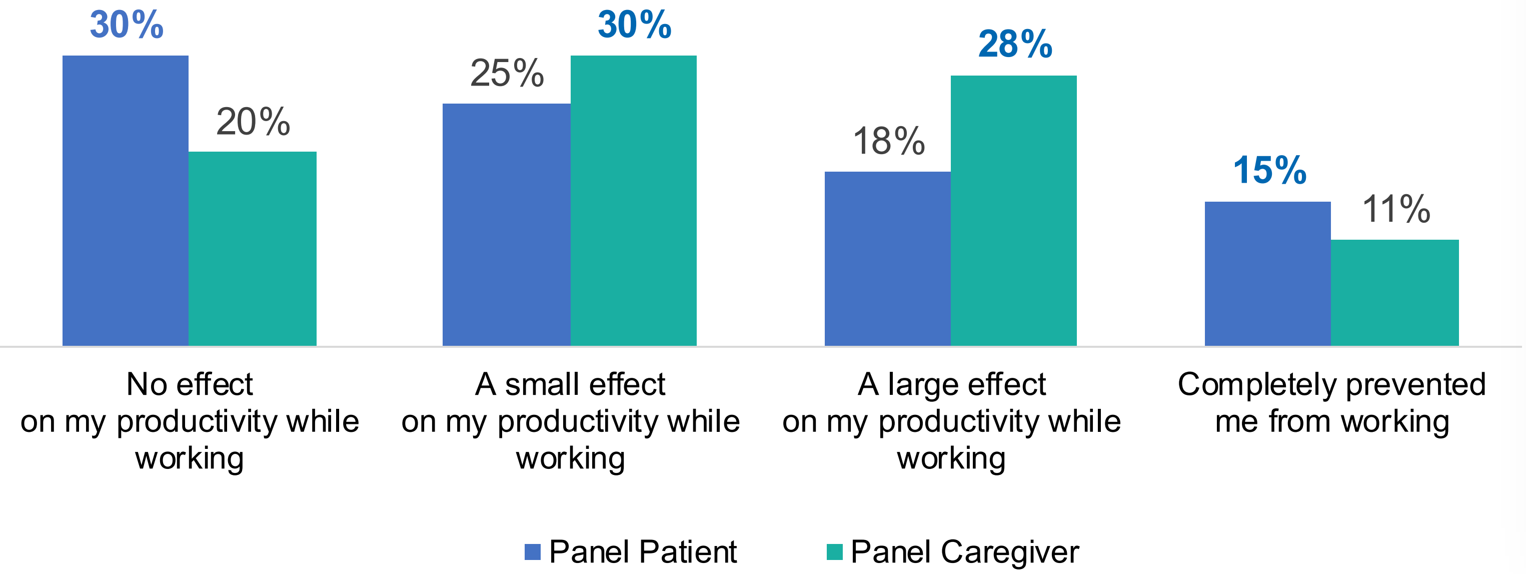
of Caregivers worked during loved one's treatment

Source= (Showing among those who worked during treatment) National Patients (n=875); National Caregivers (n=336)

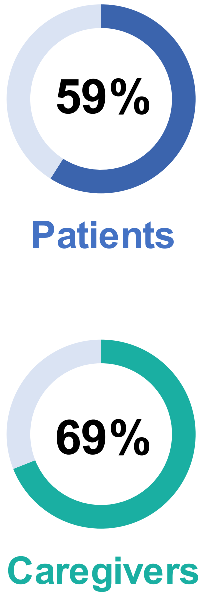
Impact on Work and School Productivity

A majority of Patients and Caregivers say their productivity was impacted to some degree. More than two-thirds of Younger Patients say their work or school was largely/completely impacted due to their cancer.

Among Patients who are…				
Younger (18-39)	**7%**	23%	**47%**	20%
Employed	**24%**	**38%**	**24%**	**12%**
Students*	**8%**	16%	**61%**	13%



Work productivity was impacted overall



**Small n size (Students n=38)*

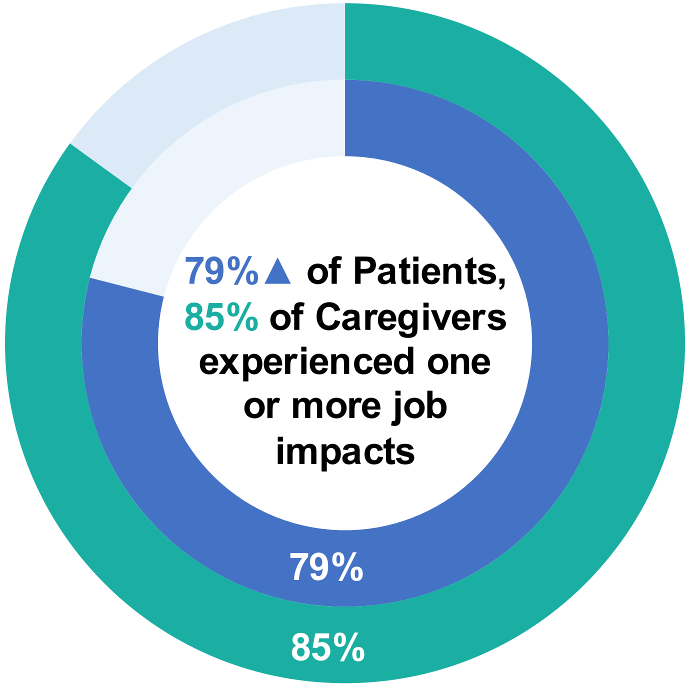
Source= National Patients (n=1620); National Caregivers (n=336)

Work Impacts

Most who worked during treatment experienced at least one issue, and the number of Patients impacted increased.

Impacts on Work/Job

(among those who worked during cancer treatment)



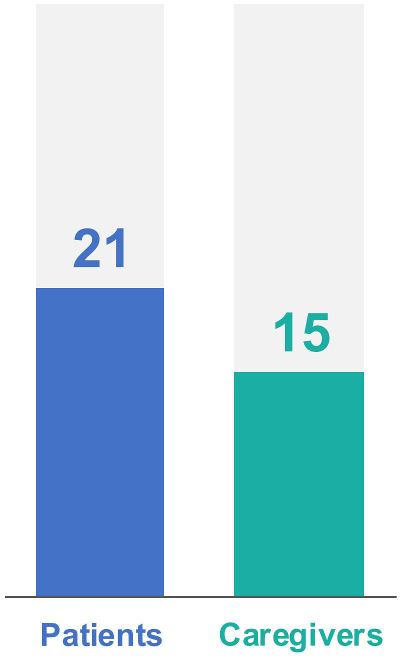
79%▲ of Patients, 85% of Caregivers experienced one or more job impacts

Impacts experienced *(among those who worked)*

	Patients	Caregivers
Missed work	39%	42%
Lost salary or wages	22%	23%
Took paid medical leave	19%	13%
Took a leave of absence	16%	19%
Worked remotely/worked from home	14%	23%
Worked/went to school for fewer hours	11%	16%
Gone on short-term disability	10%	2%
Had to ask for accommodations at work/school	10%	18%
Felt that your work/schoolwork suffered	10%	16%
Took unpaid family medical leave	7%	13%
Been let go or fired	7%	7%
Quit your job	6%	7%
Did not receive the disability insurance needed	5%	6%
Took early retirement	5%	2%
Felt your co-workers/peers treated you badly	4%	4%
Felt your supervisor/teachers treated you badly	4%	5%
Changed jobs or employers	3%	7%
Was not able to find a job with enough flexibility	3%	5%
Turned down a job or promotion	3%	10%
Missed school or delayed your education	2%	4%
None of these	21%	15%

Missed work/ worked fewer hours

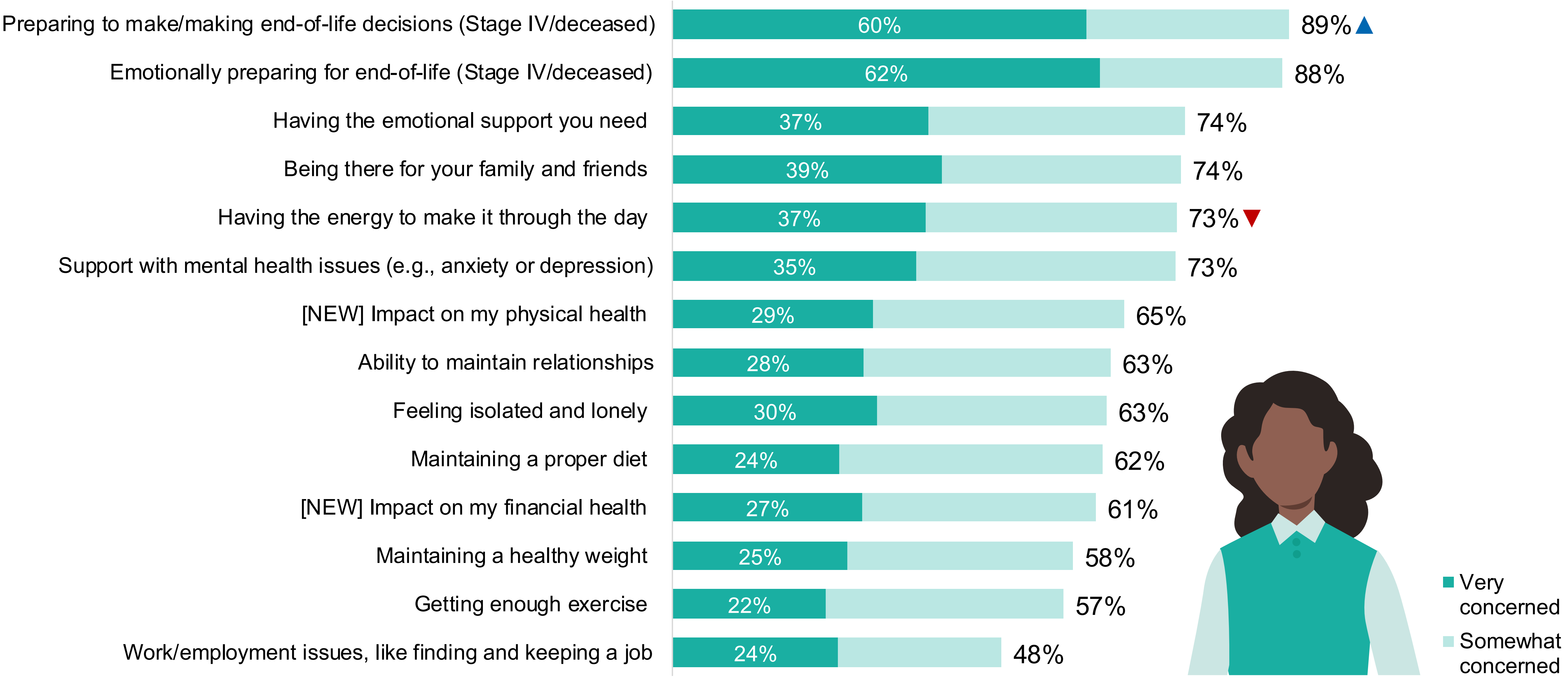
Hours missed in typical week



Source= (Showing among those who worked during treatment) National Patients (n=875); National Caregivers (n=336)

Cancer’s Impact on Caregivers

Majorities of Caregivers struggled with physical, emotional, mental health issues during their loved one’s cancer journey.



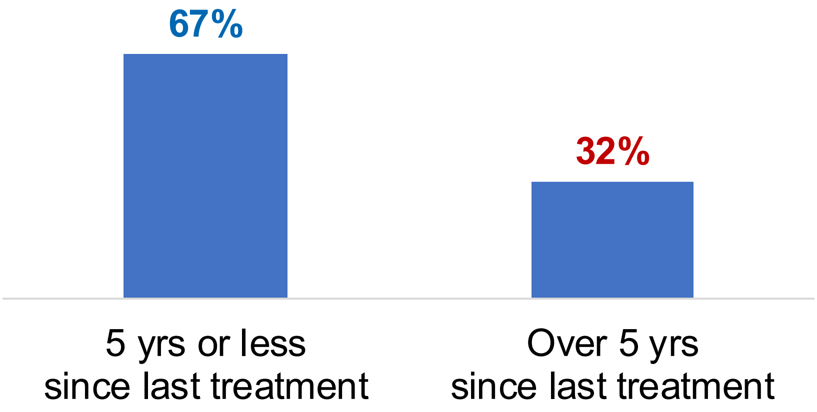
Source= National Caregivers (n=514)

Post-Treatment Care and Survivorship

In Post-Treatment Care

Just over half of national patients who have completed treatment are in post-treatment medical care, mostly a function of time since diagnosis.

Currently under the care of a health care provider for post-treatment medical care by time since treatment



	5 yrs or less since last treatment	Over 5 yrs since last treatment
NCCS Connected	89%	58%

Which of the following describes the reason/reasons you are not currently in post-treatment medical care?
Select all that apply. (Asked of those not currently in post-treatment care)

Doctor said there is no need for post-treatment care at this time or anymore	64%
Health care providers didn't recommend getting post-treatment care	17%
Do not believe cancer diagnosis and the treatments received will affect my current or future health	4%
I am just sick of going to doctor visits	3%
Other health needs are more challenging to manage/a priority	3%
Costs of post-treatment care are too high	2%
Moved and have not found another doctor for post-treatment care	2%
Unsure of who to go to for post-treatment care	2%
Transportation issues getting to post-treatment care	2%
Insurance didn't cover the tests doctor recommended	1%
Takes too much time to go to appointments for post-treatment care	1%
Cannot take time from work/school for post treatment care	1%
Still on a waiting list for post-treatment care	1%
Providers or survivorship clinic are not in-network or covered by insurance	0%
Other (please specify)	11%
None of the above	11%

No differences by time since treatment

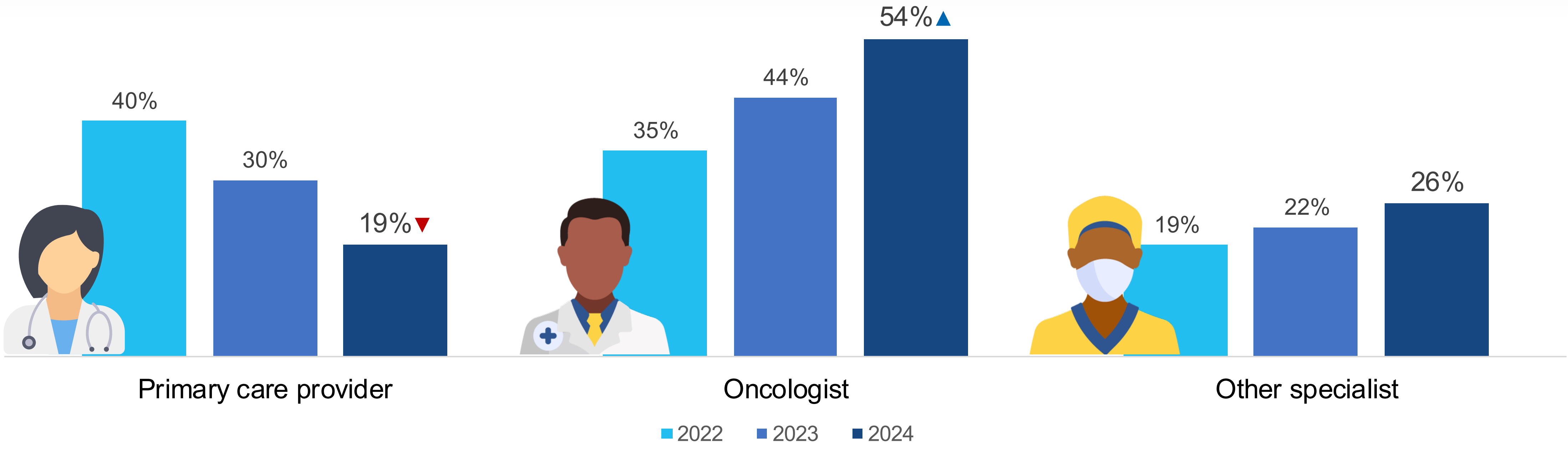
Source= National Patients (n=1620); National Caregivers (n=514); NCCS Connected Patients (n=674)

Post-Treatment Experiences

Within the last three years, the number of patients who report seeing a PCP has gone down dramatically.

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

<5 Yrs. Since Treatment	**13%**	**62%**	25%
5 Yrs.+ Since Treatment	**35%**	**34%**	31%

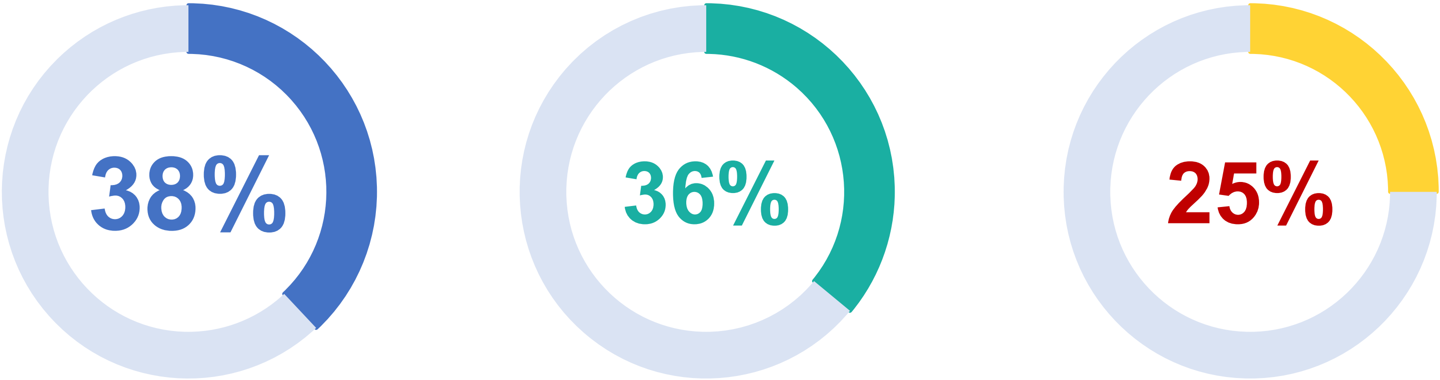


Source= National Patients (n=1620)

Willingness to See a PCP for Post-Treatment Care

Only a third or less are willing to have a PCP manage their post-treatment care, citing concerns about their knowledge and ability to detect a recurrence.

Would you be willing to have a primary care provider manage the post-treatment care for you/your loved one?
(asked of those NOT seeing a PCP)



of Patients “Yes”

of Caregivers “Yes”

of NCCS Connected “Yes”

What, if any, concerns do you have about a primary care provider managing post-treatment care?

“That they won't catch the symptoms if it comes back.”

“Cancer is not the specialty of a primary care provider and extra doctor visits are unnecessary.”

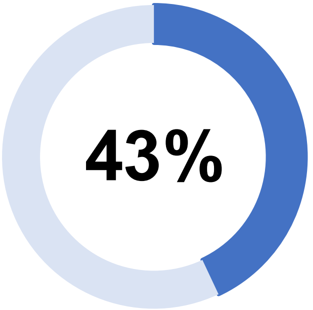
“My primary care doctor is not a specialist in breast cancer, and that is not their field of knowledge.”

Source= National Patients (n=1620); National Caregivers (n=514); NCCS Connected Patients (n=674)

Survivorship Plans

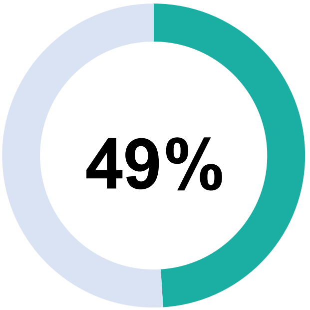
Slightly less than half of those who completed treatment received a survivorship care plan. Those in rural areas are less likely to receive a plan.

After treatment, some survivors get a care plan (sometimes called a survivorship care plan) that provides information about what to expect after treatment and recommendations on care and lifestyle. Did your/loved one's health care team provide a care plan that helps/helped you understand what to expect after treatment?



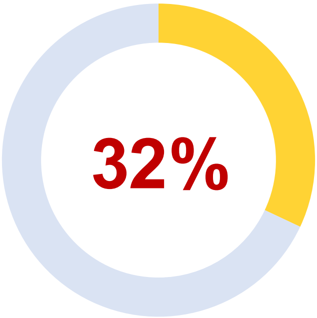
of Patients "Yes"

58% Urban
42% Suburban
34% Small town/Rural



of Caregivers "Yes"

50% Urban
54% Suburban
40% Small town/Rural



of NCCS Connected "Yes"

40% Urban
29% Suburban
28% Small town/Rural

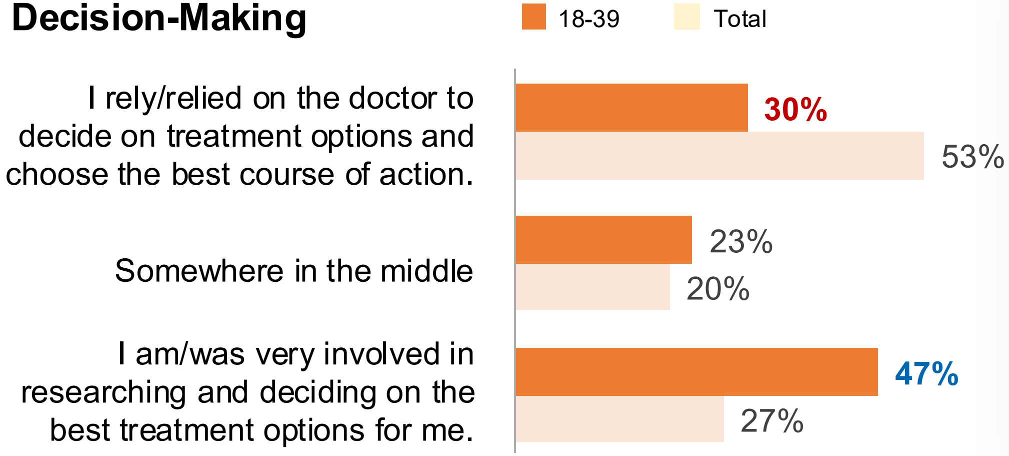
Source= COMPLETED TREATMENT, National Patients (n=1034); National Caregivers (n=119); NCCS Connected Patients (n=495)

APPENDIX A:

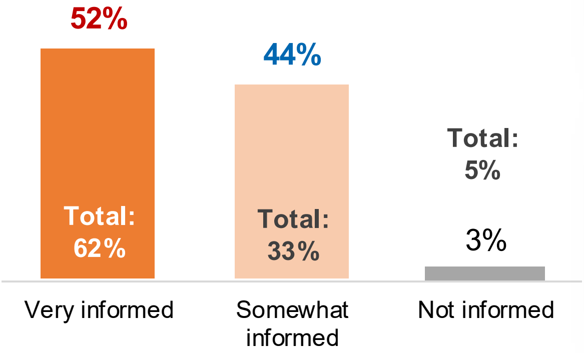
Survey Participant Profiles

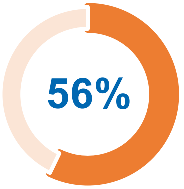
Patient Profile: Younger Cohort (Age 18-39)

Decision-Making

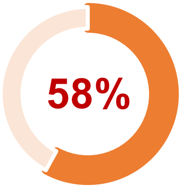


How **informed** do/did you feel about the potential **side effects** from your cancer treatment?





say they have to advocate for themselves in order to get the best treatment and care
Total: 35%



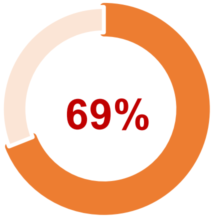
say they are very satisfied with their treatment and care
Total: 78%

Top 3 Financial Impacts	**18-39**	**Total**
Borrowed money from family or friends	**35%**	13%
Delayed a major life event	**34%**	9%
Applied for government financial assistance	**31%**	13%

Top 3 Employment Sacrifices	**18-39**	**Total**
Missed work	**37%**	24%
Lost salary or wages	27%	15%
Felt that your work/schoolwork suffered	**25%**	7%

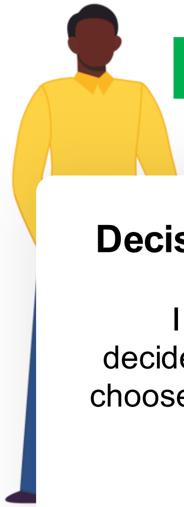
Current State of Health

Excellent: 8%	**Total: 7%**
Good: **31%**	**Total: 48%**
Fair: 42%	**Total: 35%**
Poor: 17%	**Total: 9%**



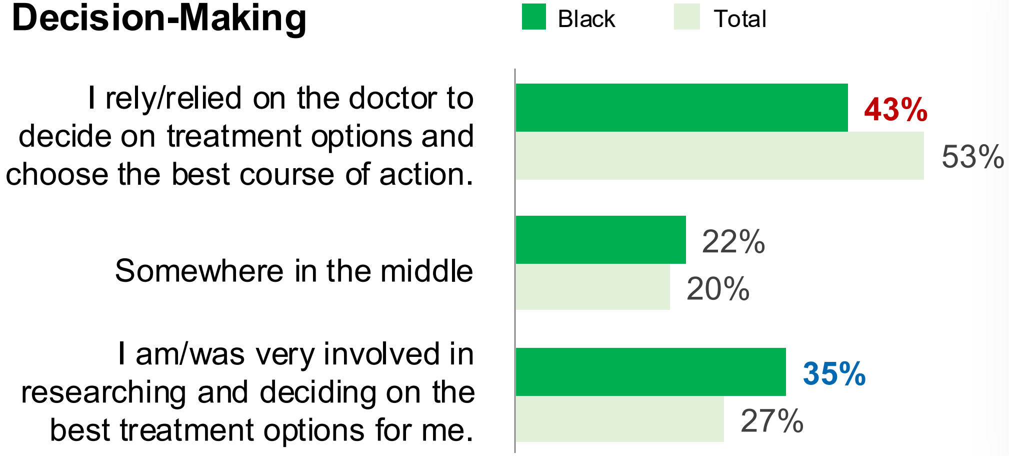
say they *completely* trust their health care team to act in their best interests
Total: 84%

Base: Younger Patients, Age 18-39 (n=375)

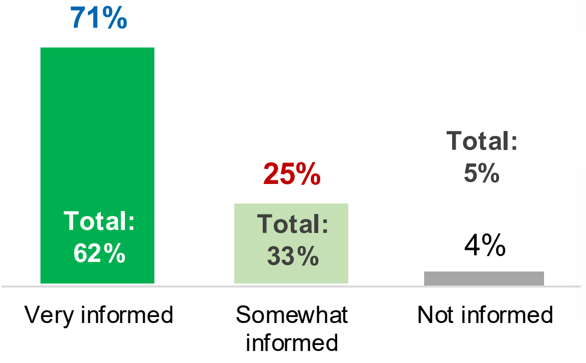


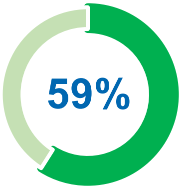
Patient Profile: Black Patients

Decision-Making

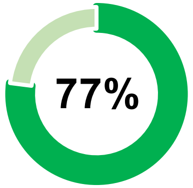


How **informed** do/did you feel about the potential **side effects** from your cancer treatment?





say they have to advocate for themselves in order to get the best treatment and care
Total: 35%



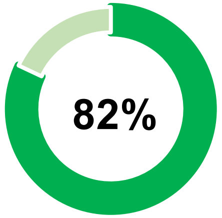
say they are very satisfied with their treatment and care
Total: 78%

Top 3 Financial Impacts	Black	Total
Borrowed money from family or friends	**22%**	13%
Applied for government financial assistance	**19%**	13%
Spent savings/retirement money	17%	15%

Top 3 Employment Sacrifices	Black	Total
Missed work	22%	24%
Lost salary or wages	14%	15%
Took a leave of absence	11%	10%

Current State of Health

Excellent: 5%	**Total: 7%**
Good: **39%**	**Total: 48%**
Fair: **43%**	**Total: 35%**
Poor: 13%	**Total: 9%**

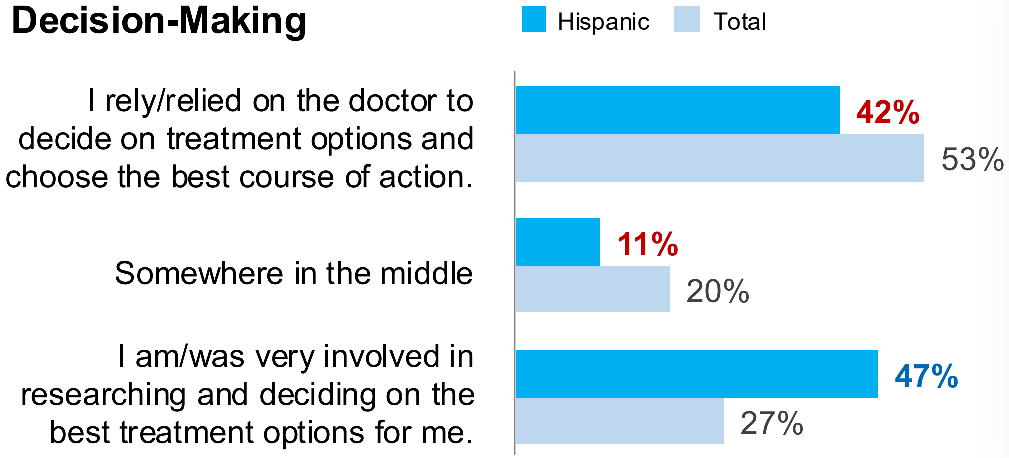


say they *completely* trust their health care team to act in their best interests
Total: 84%

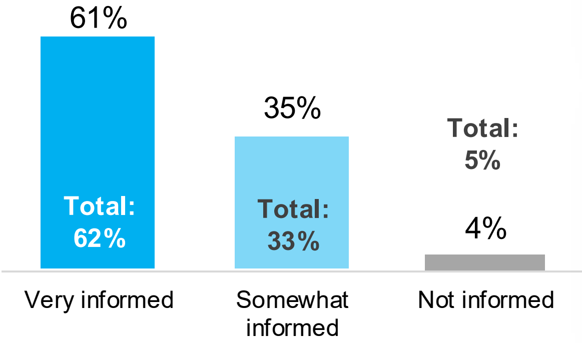
Base: Black Patients (n=208)

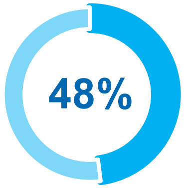
Patient Profile: Hispanic Patients

Decision-Making

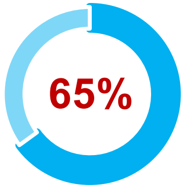


How **informed** do/did you feel about the potential **side effects** from your cancer treatment?





say they have to advocate for themselves in order to get the best treatment and care
Total: 35%



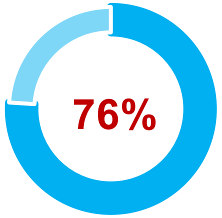
say they are very satisfied with their treatment and care
Total: 78%

Top 3 Financial Impacts	Hispanic	Total
Applied for government financial assistance	**23%**	13%
Borrowed money from family or friends	**21%**	13%
Received help with food or housing	**20%**	10%

Top 3 Employment Sacrifices	Hispanic	Total
Missed work	31%	24%
Took paid medical leave (offered by job)	**24%**	11%
Took a leave of absence	**23%**	10%

Current State of Health

Excellent: 9%	**Total: 7%**
Good: 40%	**Total: 48%**
Fair: 37%	**Total: 35%**
Poor: **14%**	**Total: 9%**

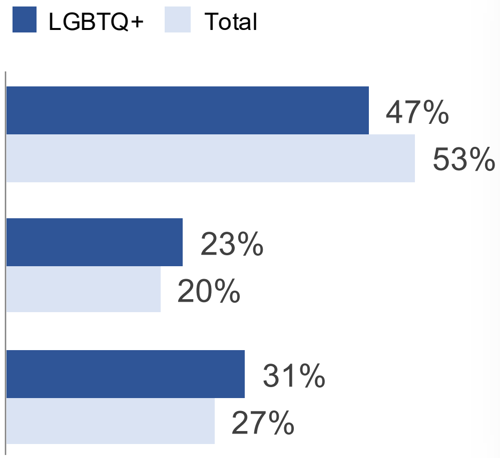


say they *completely* trust their health care team to act in their best interests
Total: 84%

Base: Hispanic Patients (n=161)

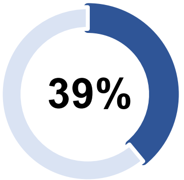
Patient Profile: LGBTQ+

Decision-Making

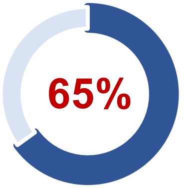


More on Mental Health

- More likely to see a Psychologist or Psychiatrist during treatment: **LGBTQ 15%, Total 8%**
- More likely to experience depression/anxiety during or after treatment: **LGBTQ 47%, Total 32%**



say they have to advocate for themselves in order to get the best treatment and care
Total: 35%



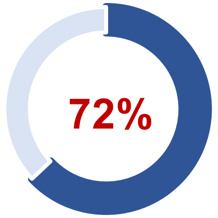
say they are very satisfied with their treatment and care
Total: 78%

Top 3 Financial Impacts	LGBTQ+	Total
Applied for government financial assistance	**25%**	13%
Had difficulty affording prescription drugs	**23%**	9%
Borrowed money from family or friends	**21%**	13%

Top 3 Employment Sacrifices	LGBTQ+	Total
Missed work	27%	24%
Lost salary or wages	**22%**	15%
Took a leave of absence	**21%**	10%

Current State of Emotional Health

- Excellent: 16% **Total: 23%**
- Good: **23%** **Total: 41%**
- Fair: **41%** **Total: 26%**
- Poor: **19%** **Total: 9%**

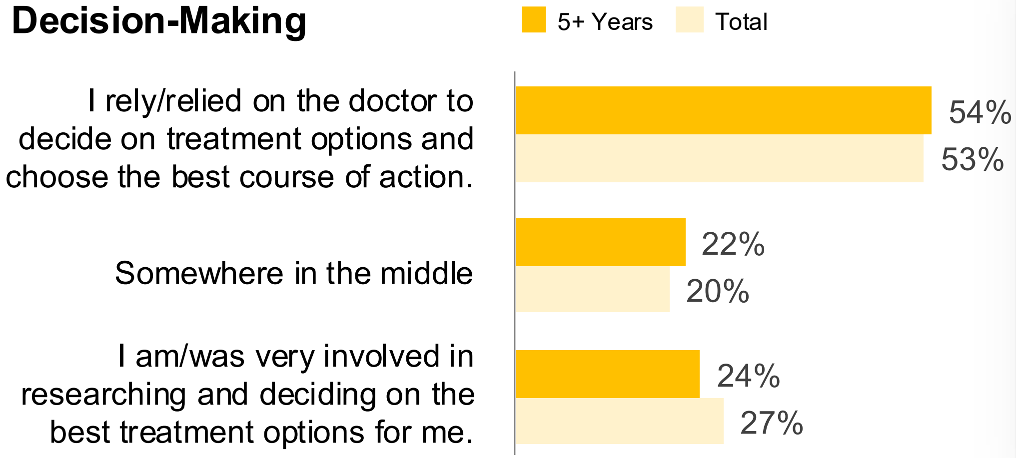


say they *completely* trust their health care team to act in their best interests
Total: 84%

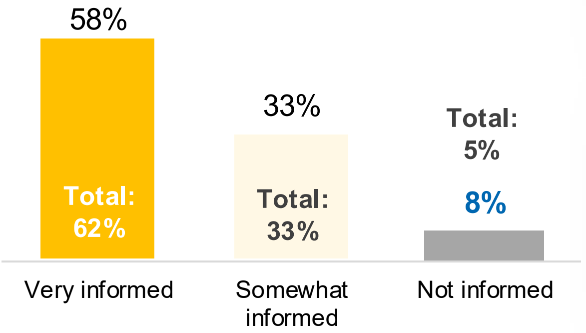
Base: National LGBTQ+ Patients (n=128)

Patient Profile: Treated More than 5 Years Ago

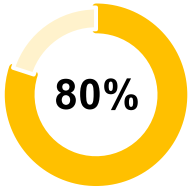
Decision-Making



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



say they have to advocate for themselves in order to get the best treatment and care
Total: 35%



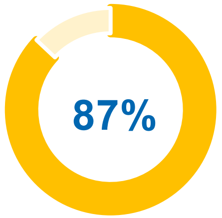
say they are very satisfied with their treatment and care
Total: 78%

Top 3 Financial Impacts	5+ Years	Total
Spent savings/retirement money	11%	15%
Applied for government financial assistance	10%	13%
Borrowed money from family or friends	9%	13%

Top 3 Employment Sacrifices	5+ Years	Total
Missed work	24%	24%
Lost salary or wages	13%	15%
Took paid medical leave (offered by job)	13%	11%

Current State of Health

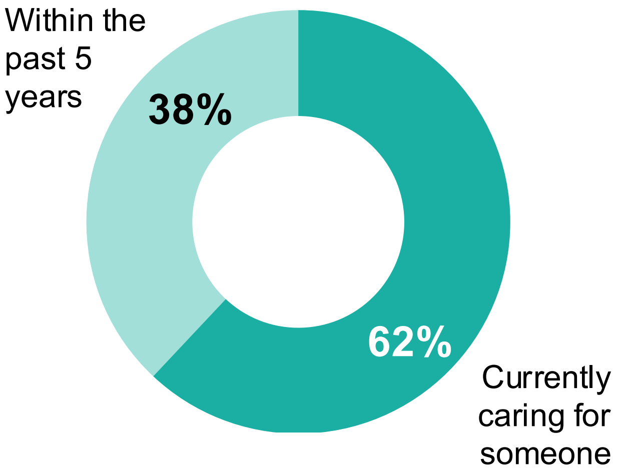
- Excellent: 10% **Total: 7%**
- Good: 55% **Total: 48%**
- Fair: 29% **Total: 35%**
- Poor: 6% **Total: 9%**



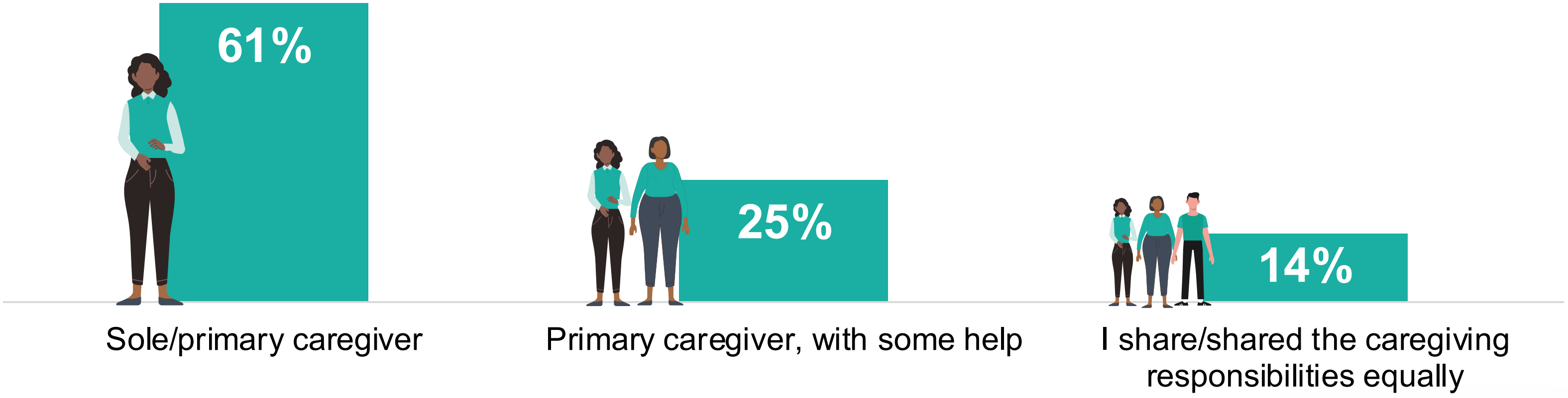
say they *completely* trust their health care team to act in their best interests
Total: 84%

Base: Patients Last Treated Over 5 Years Ago (n=453)

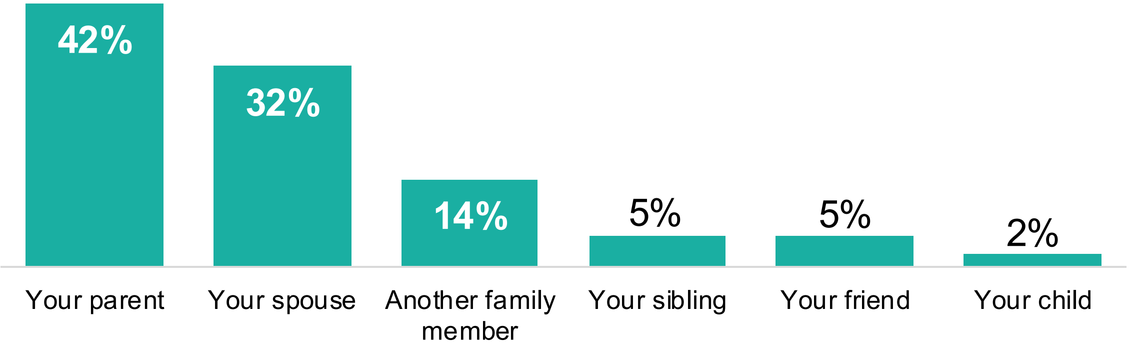
Caregiver Profile/Experiences

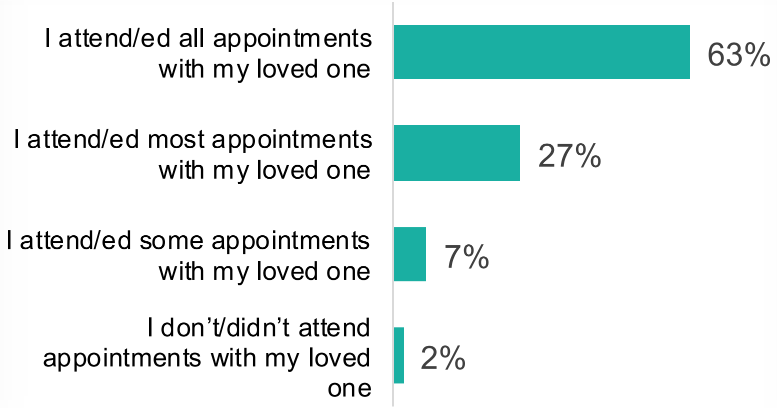


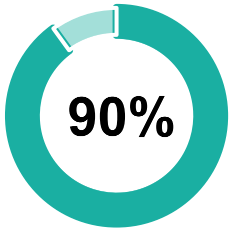
What is/was your role in caregiving for someone with cancer?



Is/was the person with cancer:







attended all or most appointments with their loved one

Source=National Caregivers (n=514)

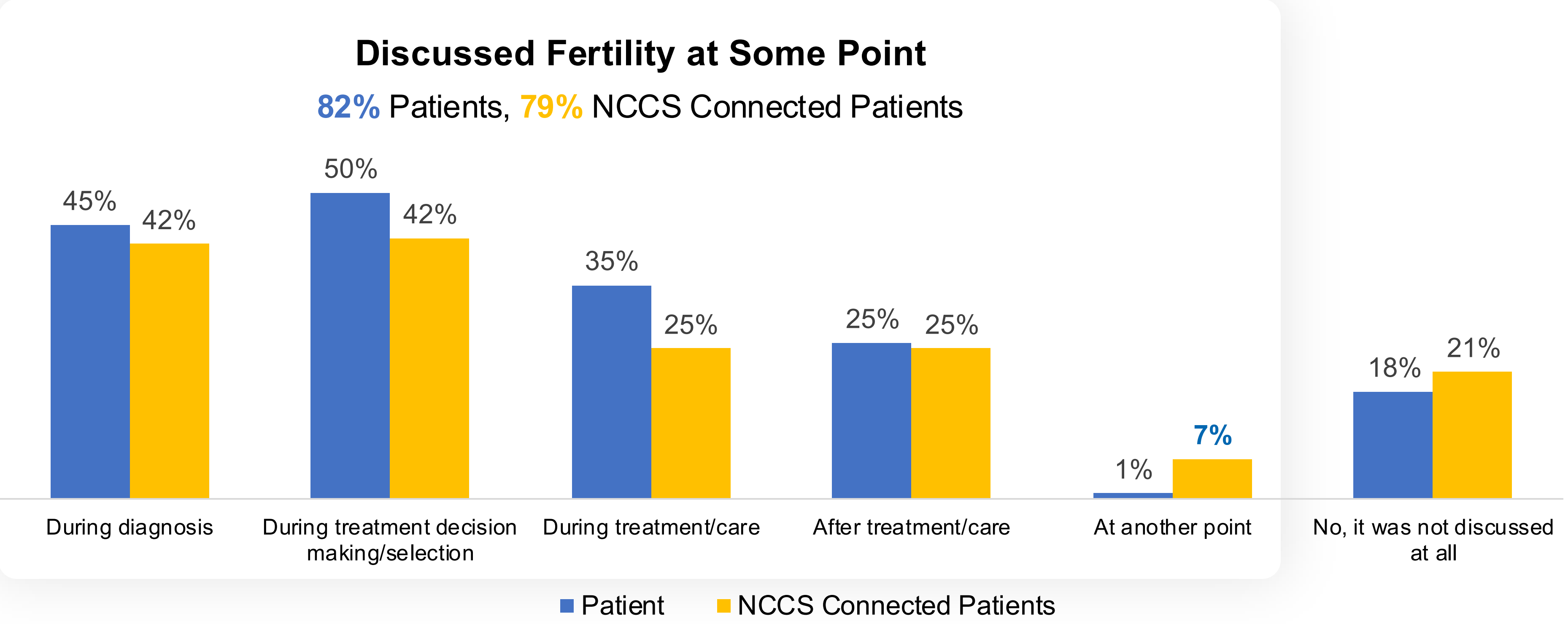
APPENDIX B:

Additional Subgroup Analysis

Impact of Treatment on Fertility

Most under 40 recall having a conversation with their health care team about fertility implications.

Did your health care providers discuss the impact treatment(s) could potentially have on your/your loved one's fertility at any of the following points in time? Select all that apply.



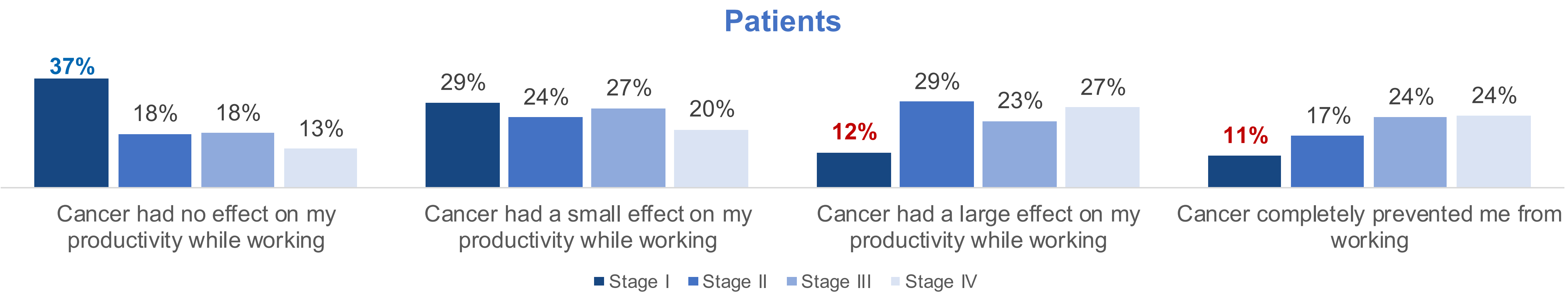
Discussed Fertility at Some Point

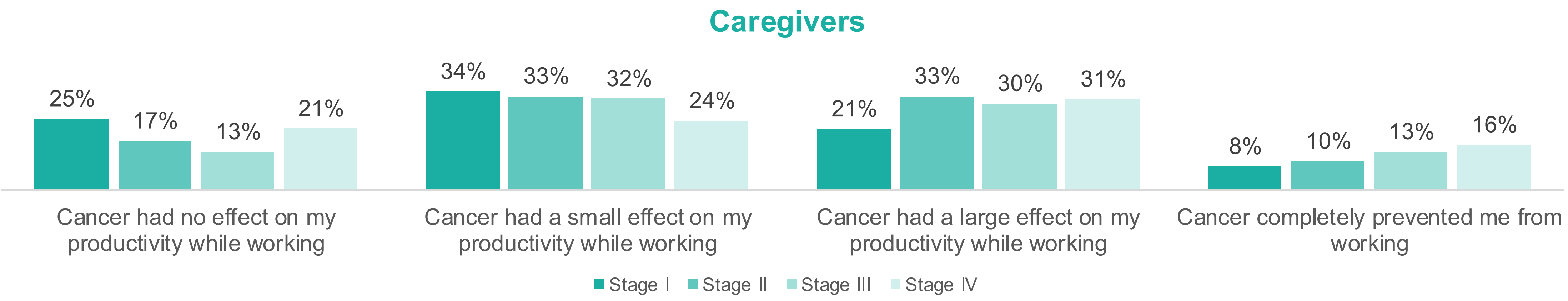
82% Patients, **79%** NCCS Connected Patients

No differences by gender

Source= YOUNGER, UNDER 40; National Patients (n=379); National Caregivers (n=141); NCCS Connected Patients (n=106)

Impact on Work Productivity by Cancer Stage





Source= National Patients (n=1620); National Caregivers (n=336)

Healthcare Providers Visited and Helpfulness, all provider types

	% Patients who saw provider	Very Helpful (among Patients who saw provider)	Very Helpful (among Caregivers whose loved one saw provider)
Oncologist that treats adults	59%	89%	81%
Surgeon	53%	90%	80%
Primary care physician	48%	71%	63%
Radiation oncologist	42%	85%	74%
Nurse/Nurse practitioner	26%	81%	72%
Pharmacist	17%	66%	65%
Cardiologist	11%	70%	62%
Hematologist	11%	77%	66%
Nutritionist/dietician	11%	54%	48%
Patient navigator	9%	66%	45%
Social worker	9%	59%	45%
Pain specialist	9%	68%	62%
Psychologist or Psychiatrist	8%	64%	65%
Endocrinologist	8%	71%	63%
Physical therapist	8%	65%	61%
Home health aide	5%	65%	68%
Rehabilitation specialist	4%	62%	65%
Occupational therapist	4%	62%	33%
Palliative care	3%	64%	70%
Speech therapist	2%	69%	53%
Audiologist	2%	52%	38%
Fertility specialist	1%	43%	50%
Pediatric oncologist	1%	69%	73%
Prosthodontist	1%	84%	38%
Pediatrician	1%	74%	88%
Hospice	1%	62%	83%

Survivorship Plan Details

There are not a lot of differences in experiences or preferences by time since treatment.

	Received in Care Plan			**Would be Helpful to Get in a Care Plan**		
	Total	**Treatment <5 Yrs.**	**Treatment 5 Yrs.+**	**Total**	**Treatment <5 Yrs.**	**Treatment 5 Yrs.+**
Side effects that might be experienced	67%	66%	69%	42%	46%	39%
Recommended future screening(s)	65%	65%	64%	39%	43%	35%
Summary of all treatments received	64%	68%	59%	25%	26%	23%
Information about the cancer type, stage	57%	61%	52%	26%	29%	23%
Information about recommended exercise/physical activity	48%	47%	51%	17%	**22%**	13%
Diet and nutrition recommendations	46%	49%	41%	22%	25%	19%
Possible support groups	37%	36%	40%	17%	16%	17%
Information about ways to reduce risk for a recurrence and other cancers	37%	36%	38%	27%	30%	24%
Information about depression, anxiety, and other mental health concerns	36%	37%	33%	20%	17%	22%
Information about sexual health concerns after cancer	31%	28%	35%	18%	17%	18%
Resources in the community to go for help	29%	27%	34%	11%	11%	11%
Recommendations for screening for other cancers	29%	30%	28%	24%	24%	24%
Information about integrative (complementary) medicine approaches	13%	15%	9%	7%	8%	6%
Information about palliative, hospice, and/or end-of-life care	5%	7%	3%	2%	1%	2%
Other	2%	1%	3%	1%	1%	0%
None of the above	1%	2%	-	23%	22%	24%

Source= RECEIVED SURVIVORSHIP PLAN, National Patients (n=459); DID NOT RECEIVE PLAN, National Patients (n=575)

Reminder

Ways to Stay Engaged and Educated with CPAN

1. **Participate** in our Monthly CPAN Advocacy Chats: Educational Conversations on Cancer Advocacy & Policy
2. **Signup** for the CPAN newsletter
3. **Visit** our website to learn more and take action
4. **Share** Your Story
5. **Follow us** on social media


A Network of Community for Oncology Advocates

coaAdvocacy.org

Join our next CPAN Advocacy Chat on **Wednesday, July 9, at 12:00 pm ET**

advocacy
CHATS
EDUCATIONAL CONVERSATIONS ON CANCER ADVOCACY & POLICY