

STATE OF SURVIVORSHIP

2024 Survey

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

Research Objectives and Questions

Build on previous studies, exploring patient journey/experiences, attitudes, and needs.

Continue to explore the cancer patient and survivor journey from a range of perspectives to better understand how NCCS can support its mission to advocate for quality cancer care for all.



NEW THIS YEAR:

- Oversample of Younger Patients (aged 18-39) to better understand their experiences
- Reasons for participating or not participating in a clinical trial
- Second opinions
- Interest in oral treatment at home
- Deeper dive on post treatment care
- Survivorship Care Plans

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

National Patients



Gender

49% Male	17% Male
51% Female	82% Female

Age

9% Age 18-39	14% Age 18-39
40% Age 40-64	50% Age 40-64
50% Age 65+	34% Age 65+

Education

18% Less than college	3% Less than college
35% Some college/2-year degree	21% Some college/2-year degree
24% Bachelor's degree	25% Bachelor's degree
23% Postgraduate degree	50% Postgraduate degree

Income

13% Less than \$25k	8% Less than \$25k
25% \$25k-\$50k	13% \$25k-\$50k
21% \$50k-\$75k	12% \$50k-\$75k
15% \$75k-\$100k	16% \$75k-\$100k
25% More than \$100k	37% More than \$100k

Insurance

26% Medicare	20% Medicare
19% Medicare Advantage	10% Medicare Advantage
13% Medicaid	9% Medicaid
35% Private/employer	49% Private/employer
7% Private/spouse or parents	19% Private/spouse or parents

Race/Ethnicity

78% White	81% White
11% AA/Black	10% AA/Black
7% Hispanic	4% Hispanic
6% Other	6% Other

Treatment

45% 5 Years Ago or Less, 31% Over 5 Years Ago	40% 5 Years Ago or Less, 37% Over 5 Years Ago
---	---

Region

19% Northeast	21% Northeast
23% Midwest	19% Midwest
38% South	38% South
21% West	22% West

LGBTQ+

6% Yes	8% Yes
--------	--------

NCCS Connected Patients



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)

My focus is/was on maintaining my/my loved one's quality of life as much as possible

National Patients

74%

National Caregivers

85%

NCCS Connected Patients

65%

Younger Patients (18-39)

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%

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 chose the best treatment, vs. being active in the decision.



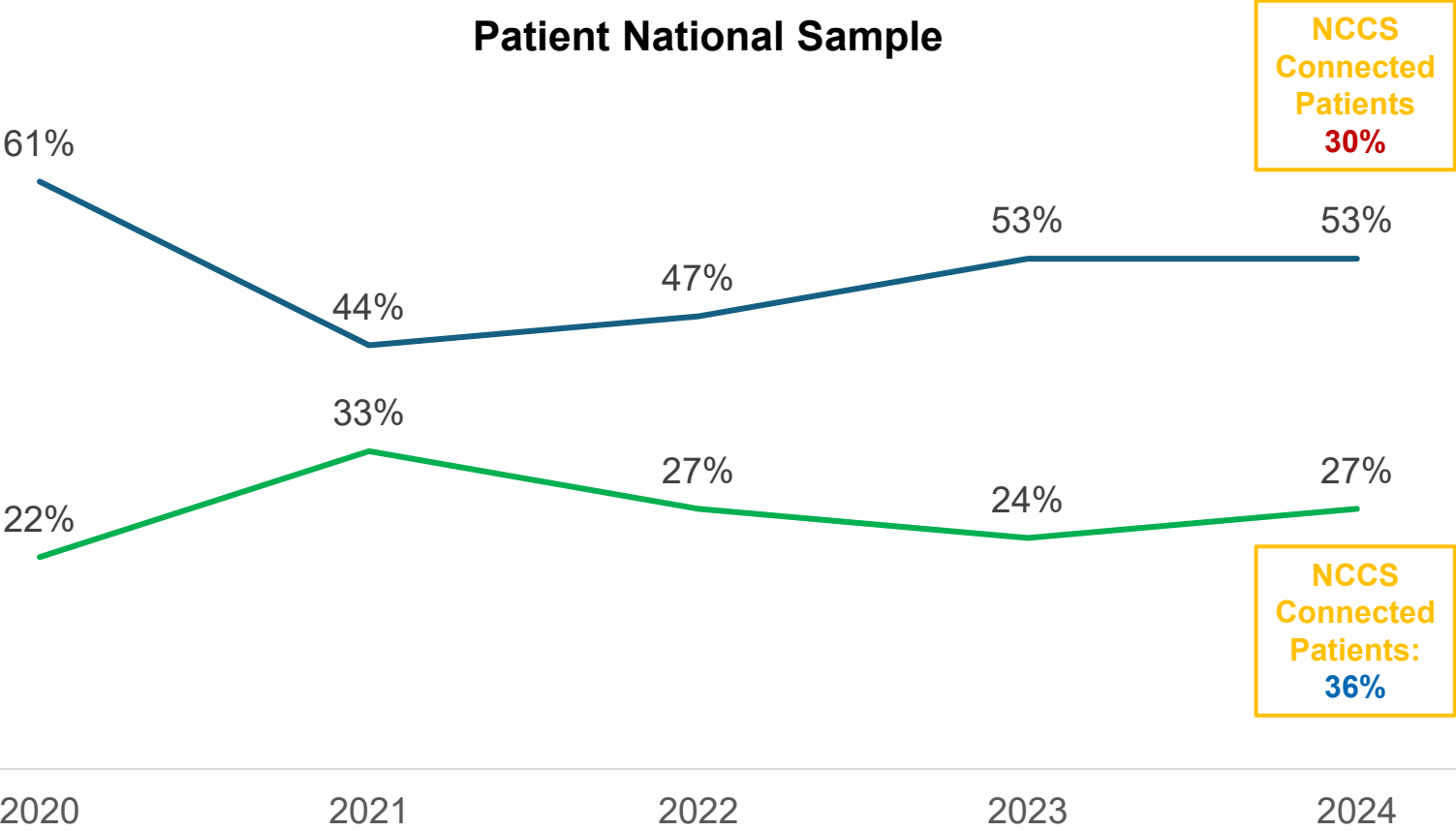
Relied on the doctor to decide on treatment options and chose the best course of action



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**)


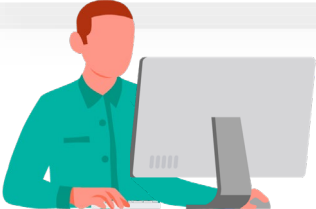
Patient National Sample



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
 <p>I rely/relied on the doctor to decide on treatment options and chose the best course of action.</p>	53%	37%	30%	30%	58%	43%	42%	57%	59%	51%	49%
 <p>I am/was very involved in researching and deciding on the best treatment options.</p>	27%	36%	36%	47%	22%	35%	47%	23%	24%	26%	30%

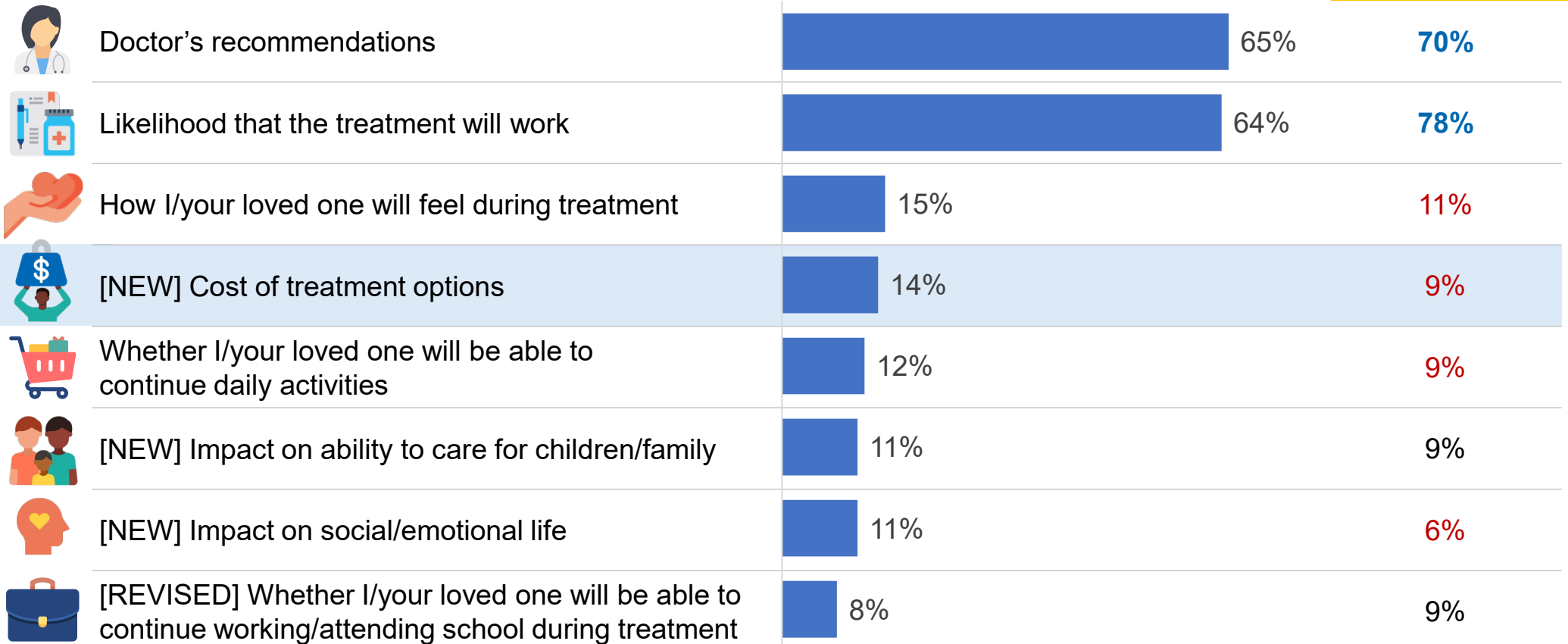
Treatment Decision-making Priorities

“Doctor’s recommendations” remains the top decision-making factor.

Cost of treatment is low on the list, but slightly more important to younger patients and patients of color.

How important each was in making decisions about treatment: Top 2 Box

**NCCS Connected
Patients**



Higher among:

- 26% Younger (18-39)
- 28% Hispanic
- 18% Black

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%

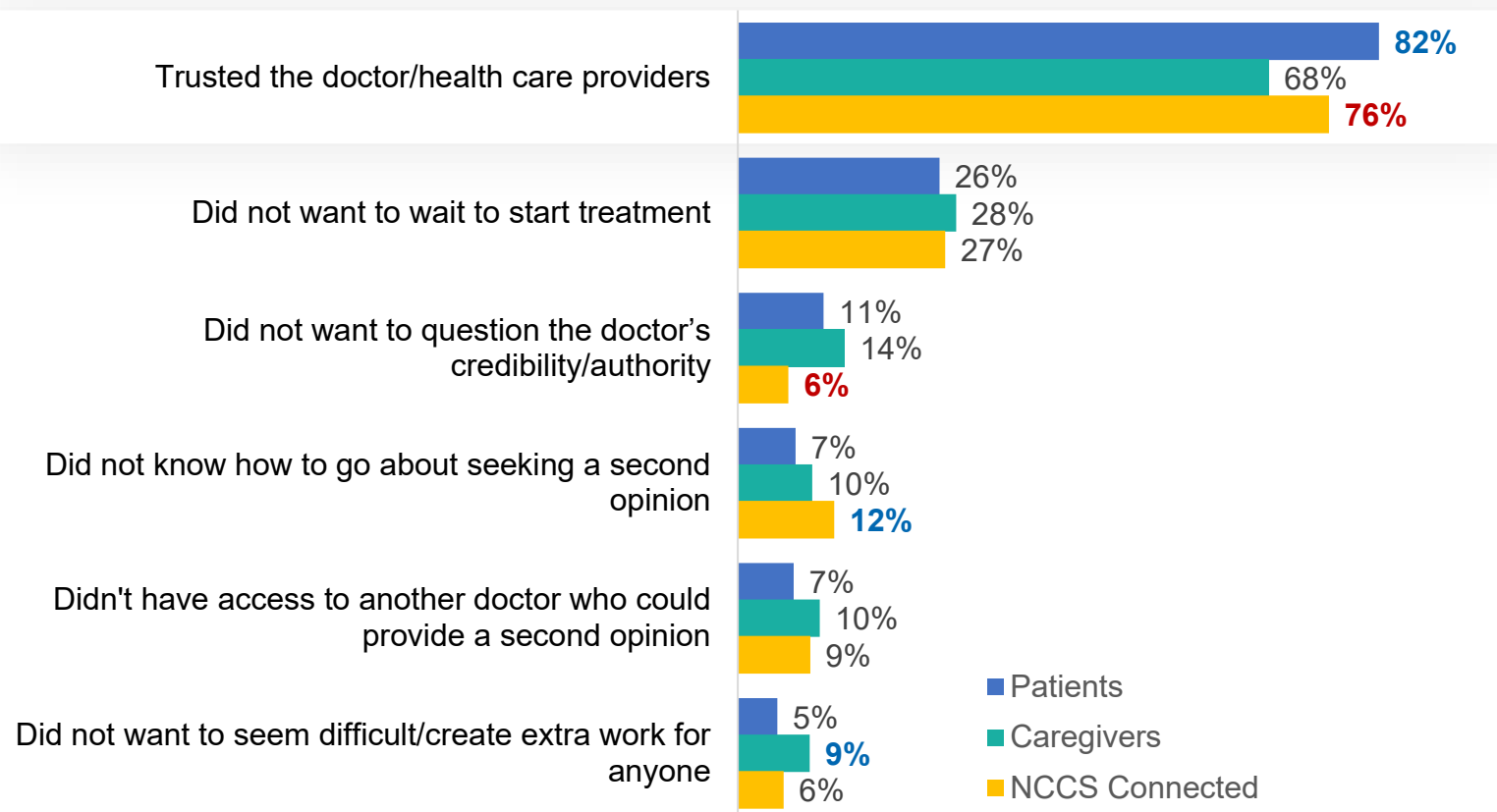
Caregivers 39%

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

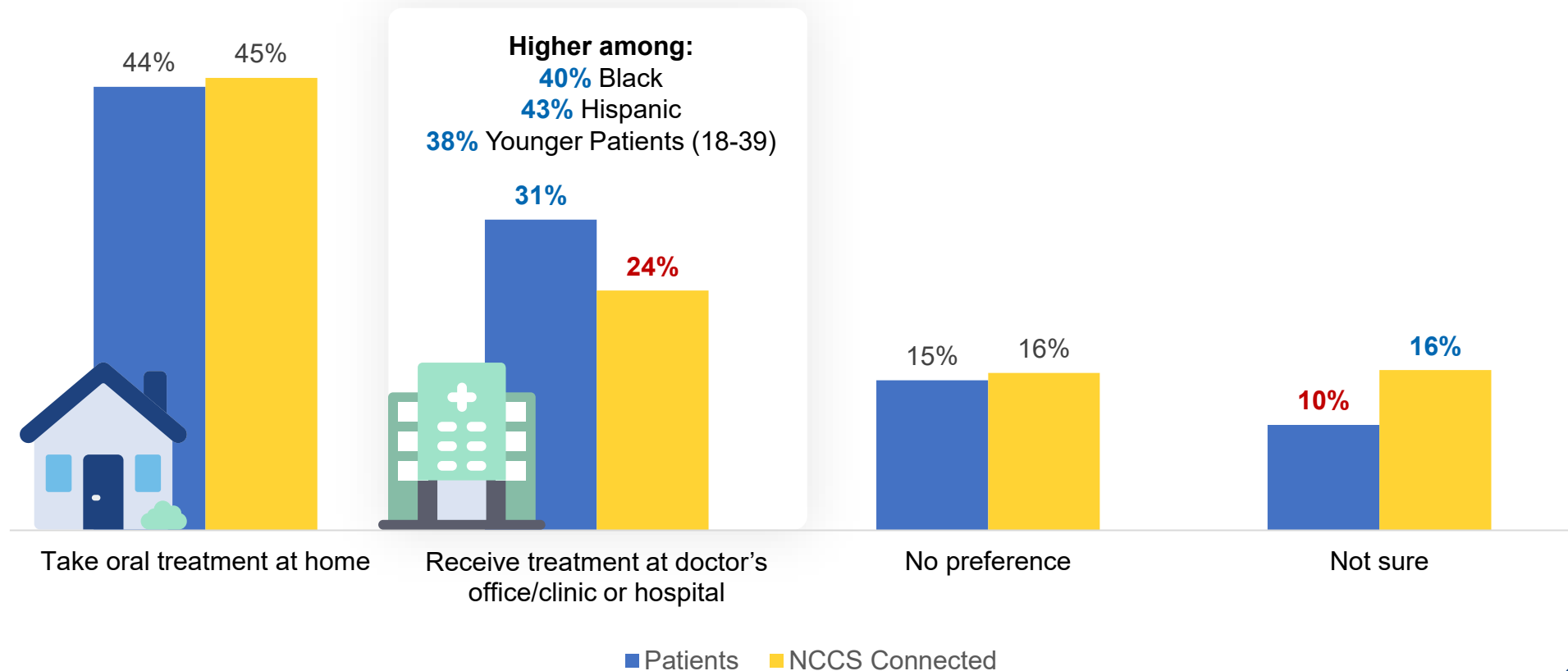
Which of the following describes why you/your loved one DID NOT seek a second opinion? Select all that apply.
(Only asked if did not seek second opinion)



Treatment Location Preference

4-in-10 are interested in the option to take treatment at home.

Thinking about receiving treatment, if you had the option to take treatment orally (e.g., a pill that you can take at home following instructions from your health care provider) or receive treatment (e.g., chemotherapy, immunotherapy, etc.) via an infusion or injection at the doctor's office or hospital, which option would you prefer?

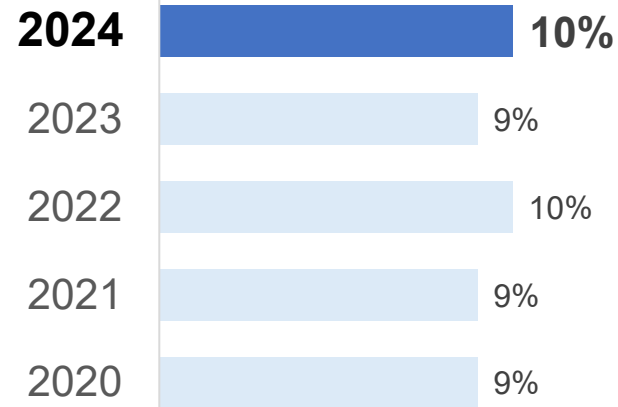


Source= National Patients (n=1620); NCCS Connected Patients (n=674)

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)

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.

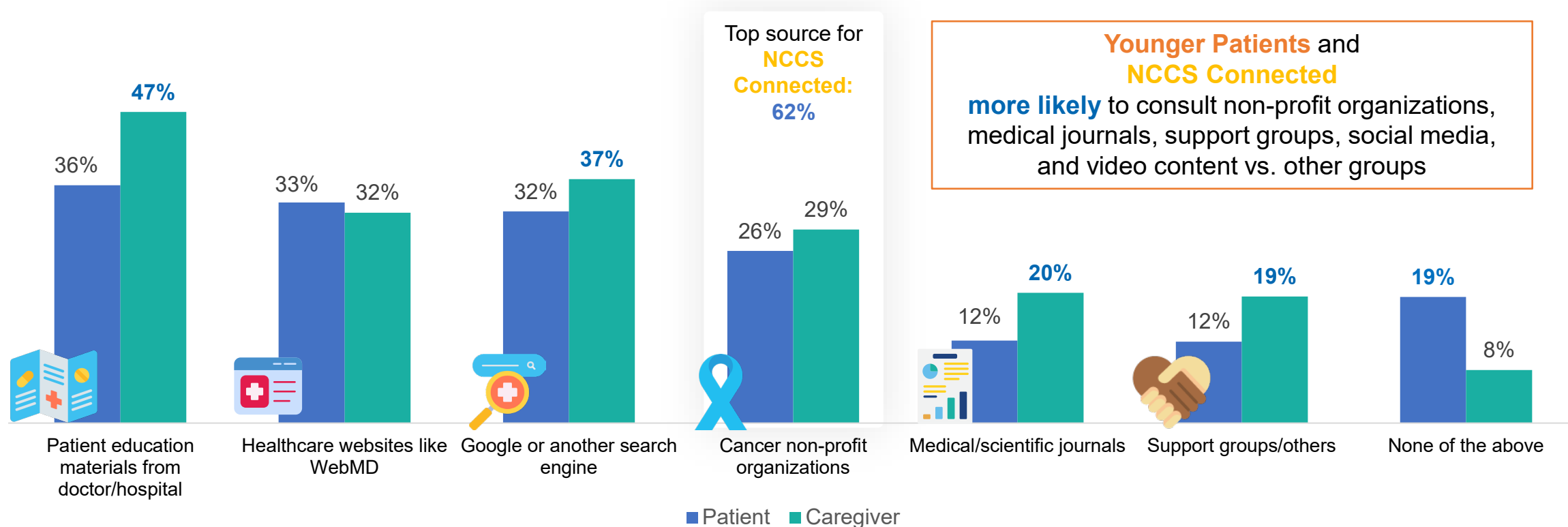
What influenced your decision NOT to participate in a clinical trial? <i>(Only asked if did not participate)</i>		NCCS Connected	Younger Patients (18-39)	Black	Hispanic	Academic Medical Center
Was <u>not</u> asked to participate in a clinical trial	74%	75%	51%	72%	63%	71%
Was not eligible/did not qualify 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)**

Resources for Cancer Information

Caregivers are more likely to seek out information from multiple sources.

What resources, if any, do you use for up-to-date information on cancer? Select up to 3.



Less used sources: news, videos, social media, commercials

Cancer Care Experiences



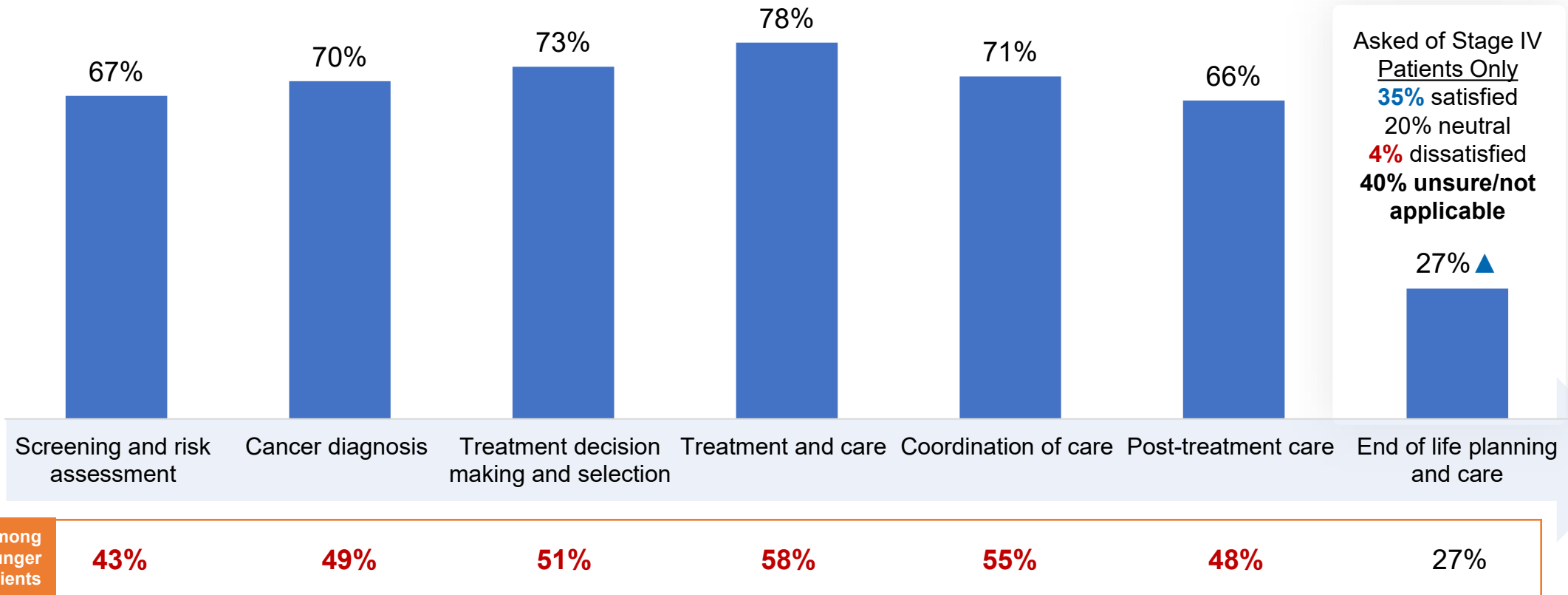
Patient Satisfaction With Care

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)

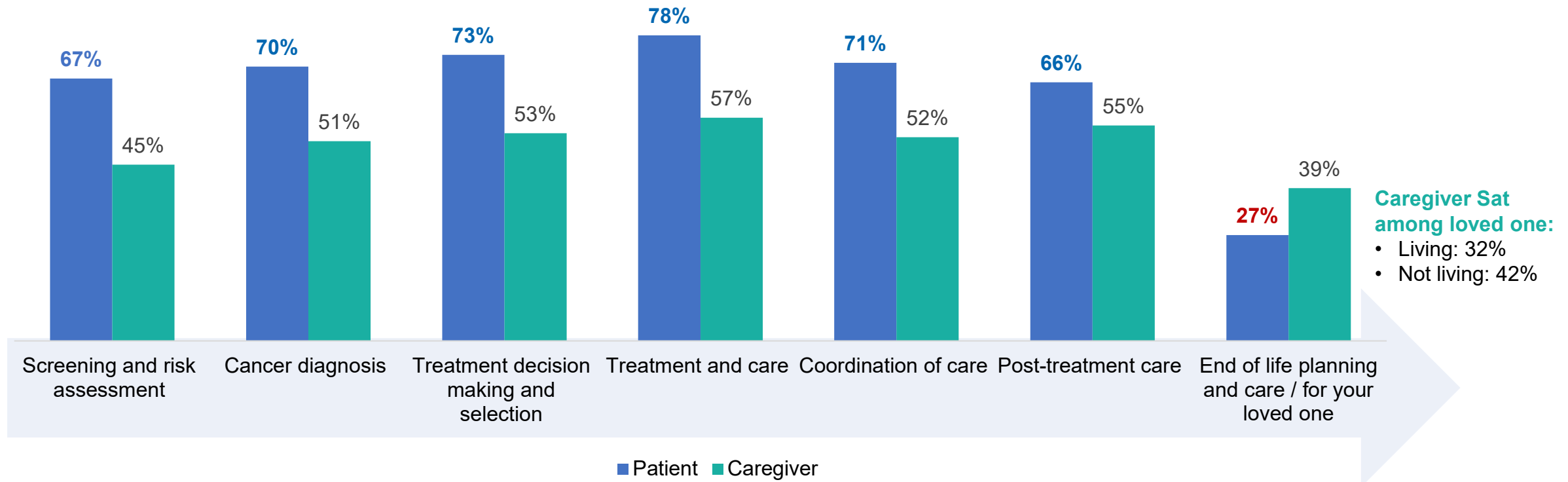


Satisfaction With Care: Patients vs. Caregivers

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.

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

% Very satisfied



Patient Satisfaction With Care by Insurance Types

Those with public insurance are more satisfied with their screenings, care coordination, and post-treatment care. There are no differences between those with Medicare vs. Medicare Advantage.

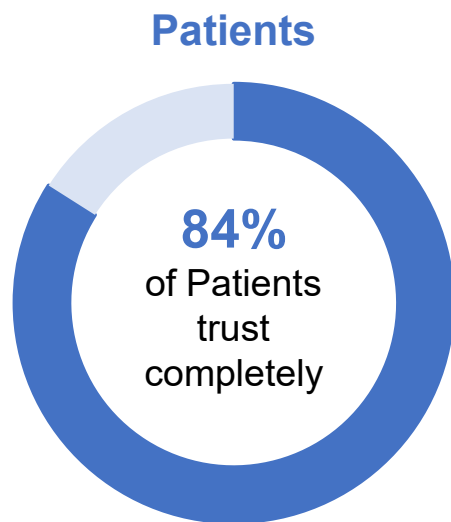
Now, thinking about the many different phases of your cancer journey, how satisfied are/were you with your care during each phase? (% Very Satisfied)

		Private Insurance	Public Insurance	Medicare	Medicare Advantage
Screening and risk assessment	67%	65%	71%	73%	75%
Cancer diagnosis	70%	69%	73%	74%	76%
Treatment decision making and selection	73%	73%	76%	78%	80%
Treatment and care	78%	77%	80%	81%	85%
Coordination of care	71%	69%	74%	75%	75%
Post-treatment care	66%	64%	70%	72%	72%
End-of-life planning and care	27%	29%	25%	23%	25%

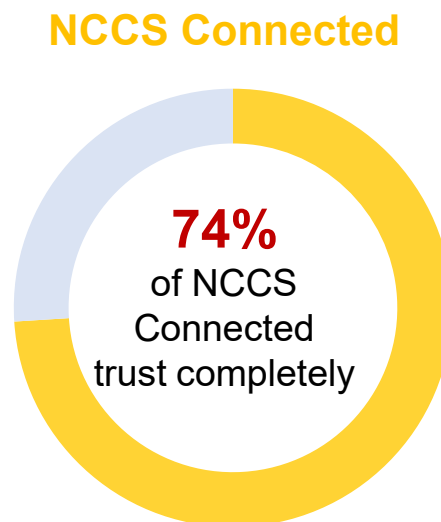
Trust of Health Care Team

Majorities of patients trust their health care teams to act in their best interests, consistent with previous years.

Overall, how much do you/did you trust the health care team to act in your/your loved one's best interests during cancer treatment and care?



Lower among:
76% Hispanic
72% LGBTQ+
69% Younger



Lower among:
64% Younger
67% Still in Treatment

Among those who don't trust completely:

*"It seemed very much **dependent on my health insurance** rather than my health and healing."*

*"**Lack of information** about my treatment choices."*

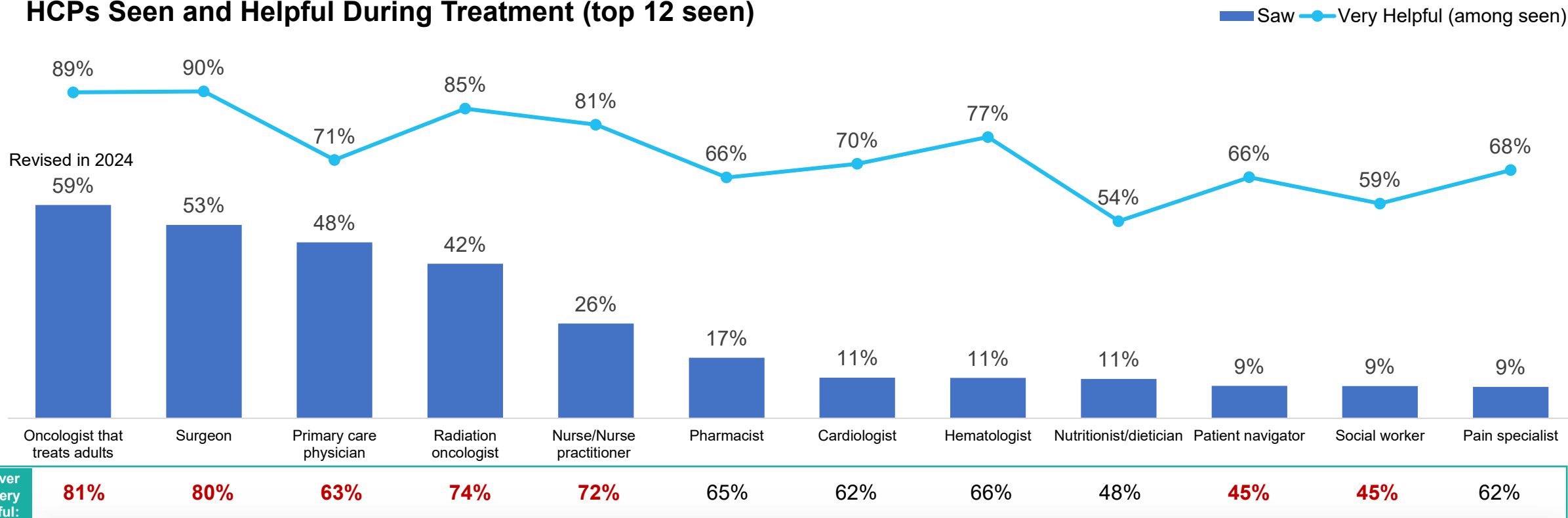
*"I was **misdiagnosed by several doctors** before being correctly diagnosed with breast cancer."*



Healthcare Providers Visited and Helpfulness

Findings are very similar to previous years – oncologists and surgeons are seen by the greatest percentage of Patients and get high ratings; PCP's get lower scores on helpfulness.

HCPs Seen and Helpful During Treatment (top 12 seen)



NCCS Connected: more likely to see a range of HCPs.

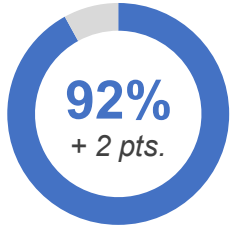
Lower scores on helpfulness for PCP, Oncologist, Radiation oncologist, Surgeon, Pain specialist, Cardiologist.

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

Less than 9% saw: Psychologist/Psychiatrist, Endocrinologist, Physical therapist, Home health aide, Rehab specialist, Occupational therapist, Palliative care, Speech therapist, Audiologist, Fertility specialist, Pediatric specialist, Prosthodontist, Pediatrician, Hospice

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**

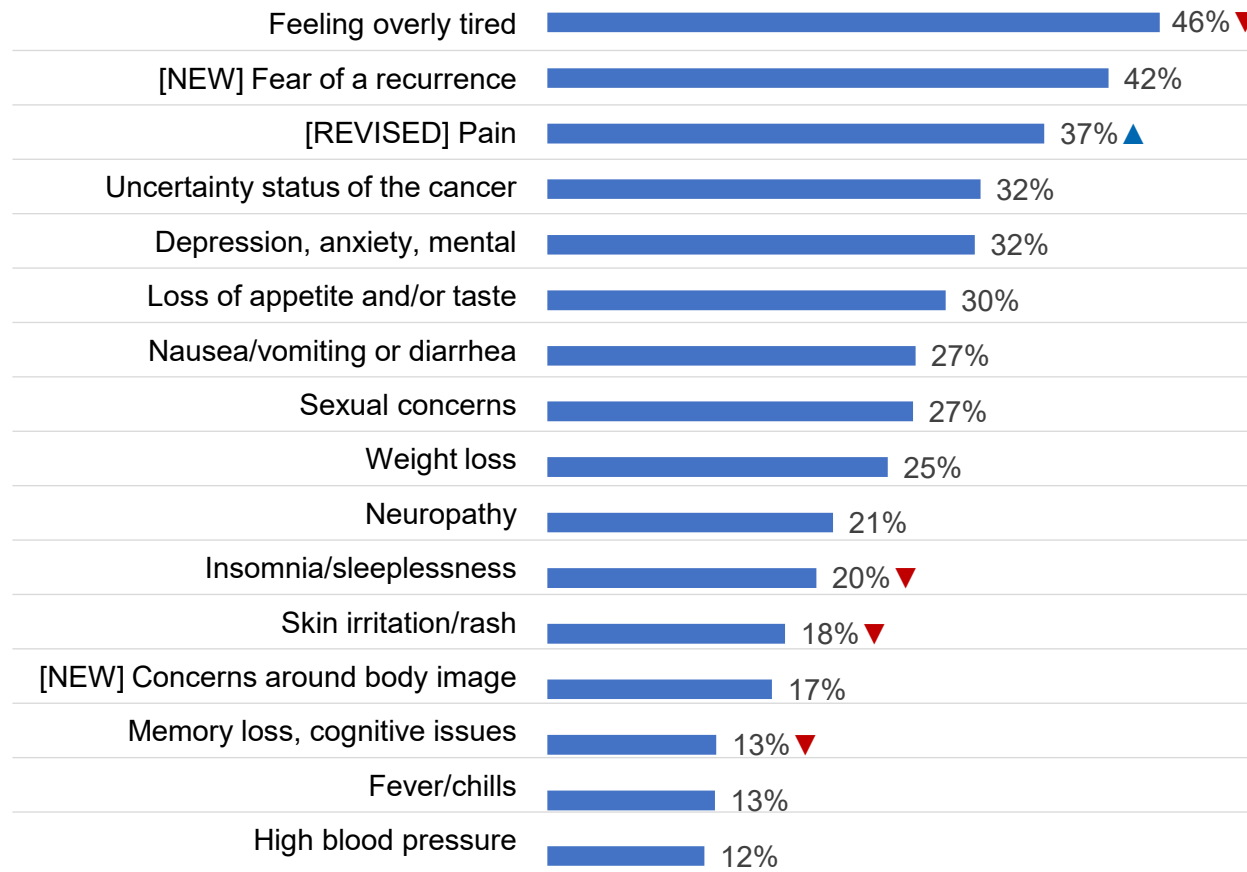
Symptoms experienced (top 16 out of 32 shown)

		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%

Side Effects Experienced by Treatment Status

Those currently in-treatment are more likely to cite or remember side effects.

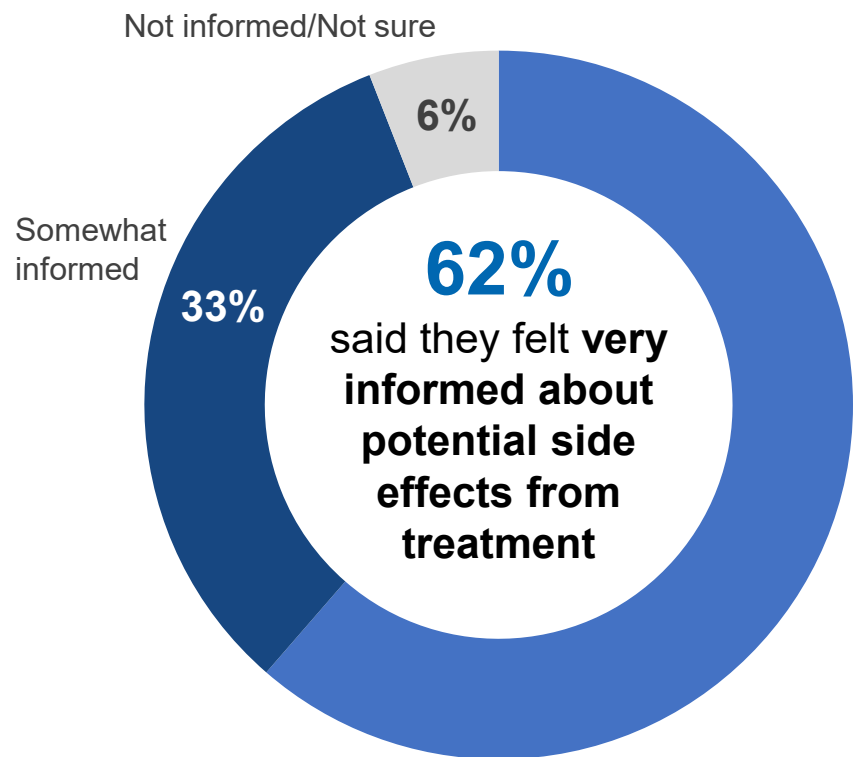
Symptoms experienced (top 16 out of 32 shown)



Currently In Treatment	Completed Treatment
58%	42%
35%	45%
43%	35%
36%	32%
41%	30%
41%	26%
38%	24%
23%	30%
39%	21%
29%	19%
30%	17%
20%	17%
17%	17%
15%	12%
21%	10%
19%	9%

Addressing Side Effects

8-in-10 say no symptom caused them to discontinue or change treatment.



Caregivers:
58% very informed

NCCS Connected:
39% very informed

Symptoms experienced (top 15 out of 32 shown)

Cause to Discontinue Treatment (among those who experienced)

Feeling overly tired	3%
[NEW] Fear of a recurrence	2%
[REVISED] Pain	5%
Uncertainty status of the cancer	1%
Depression, anxiety, mental	3%
Loss of appetite and/or taste	2%
Nausea/vomiting or diarrhea	2%
Sexual concerns	2%
Weight loss	2%
Neuropathy	2%
Insomnia/sleeplessness	2%
Skin irritation/rash	1%
Memory loss, cognitive issues	1%
Fever/chills	1%
High blood pressure	1%
None of the above	79%

Financial Impacts

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

NCCS Connected: 66%

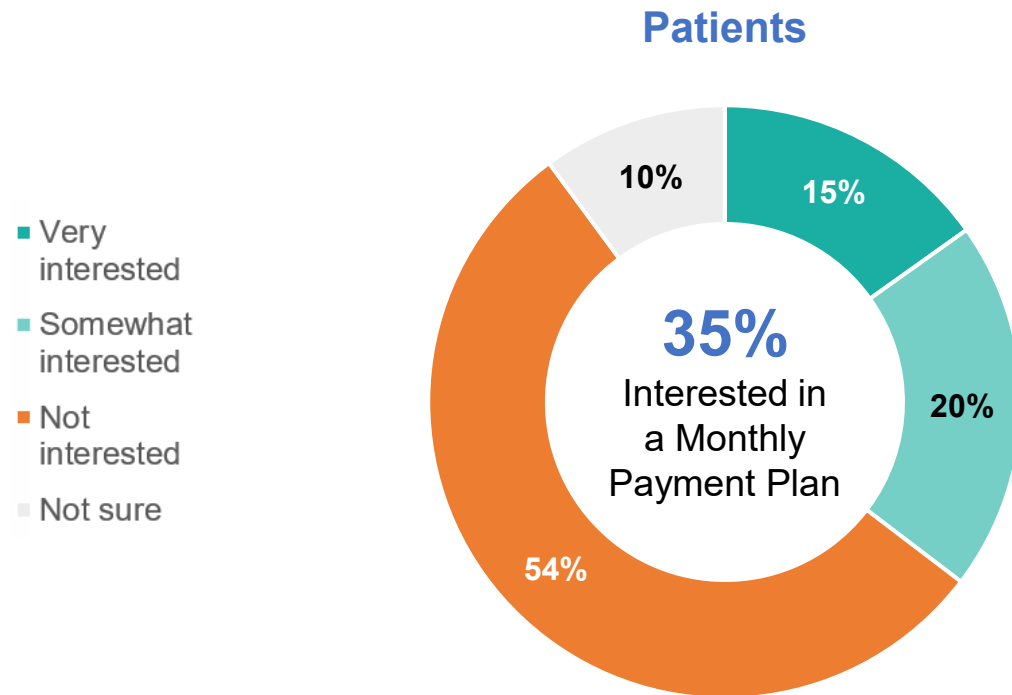
Impacted Financially: 44%

		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%	9%
PATIENT ONLY: Applied for co-pay assistance from drug manufacturer	8%	N/A	16%	8%	18%	19%	16%	5%	9%	9% Medicare Advantage
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%	

Monthly Prescription Payment Plan

A third of Patients are interested. There is significantly higher interest among younger patients vs. Medicare patients.

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?



On average, paid \$935 out-of-pocket for prescription drugs in the last 12 months

- **57%** of Patients In Treatment interested, spent an average of **\$1,941 out-of-pocket** in the last 12 months
- **73%** of Younger Patients interested; spent on average **\$2,482 out-of-pocket** in the last 12 months
- **30%** of Medicare Patients interested; spent an average of **\$873 out-of-pocket** in the last 12 months

Employment Status during Treatment

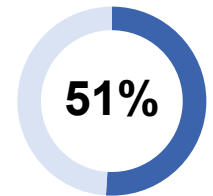
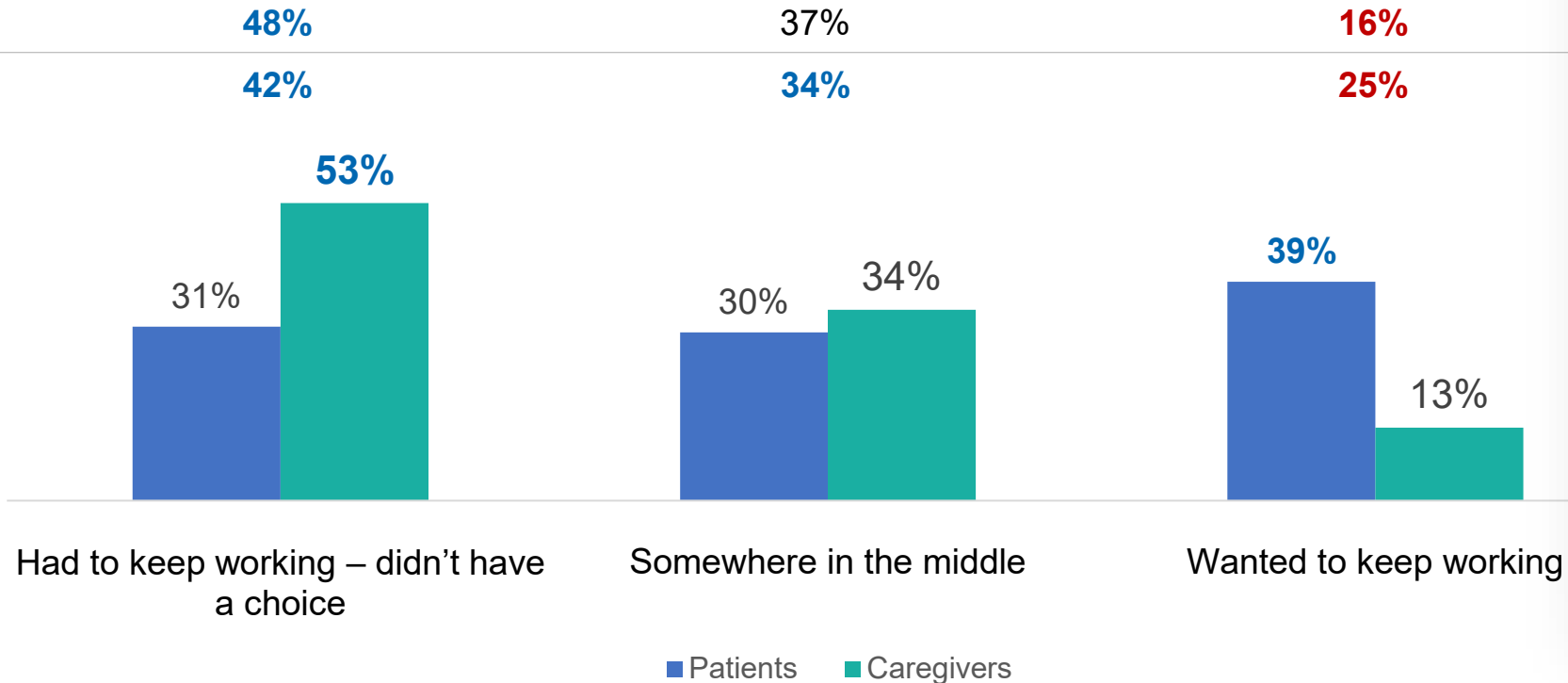
Over a third of Patients wanted to keep working during their treatment, while half of Caregivers felt obligated to work. Younger Patients are significantly more likely to say they didn't have a choice.

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

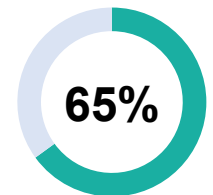
Among Patients who are...

Younger (18-39)

Impacted Financially



51%
of Patients worked during treatment



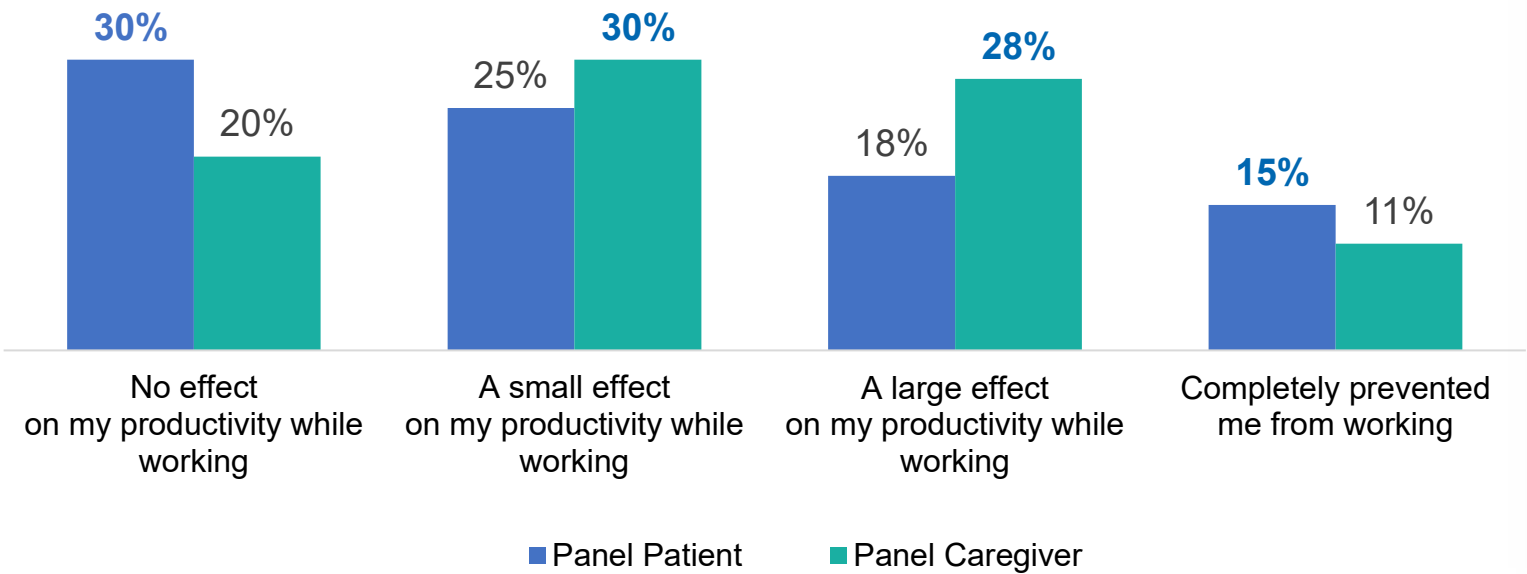
65%
of Caregivers worked during loved one's treatment

Impact on Work and School Productivity

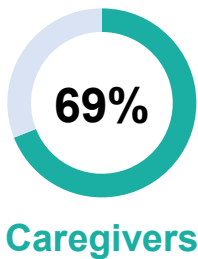
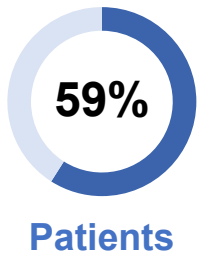
A majority of Patients and Caregivers say their productivity was impacted to some degree. More than two-thirds of Younger Patients say their work or school was largely/completely impacted due to their cancer.

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



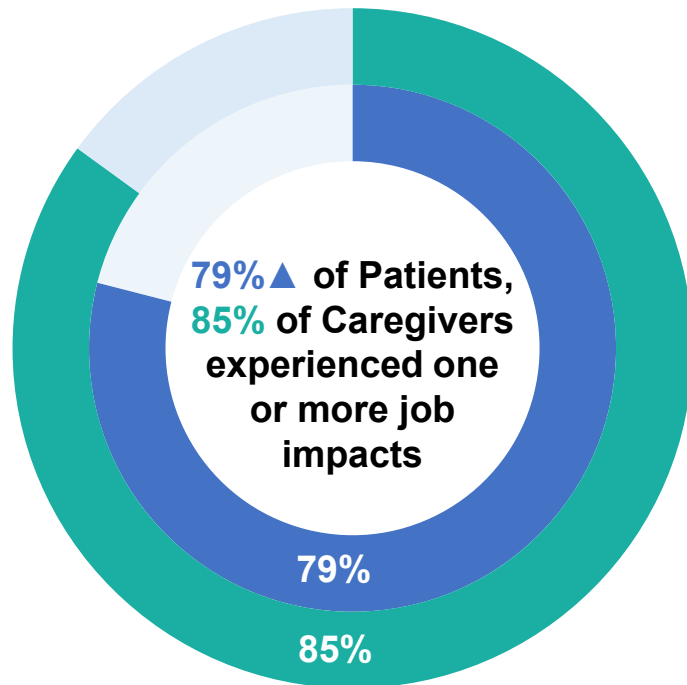
*Small n size (Students n=38)

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.

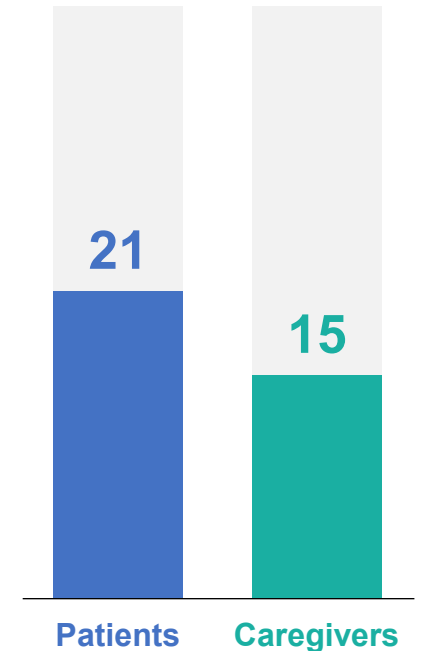
Impacts on Work/Job (among those who worked during cancer treatment)



Impacts experienced (among those who worked)

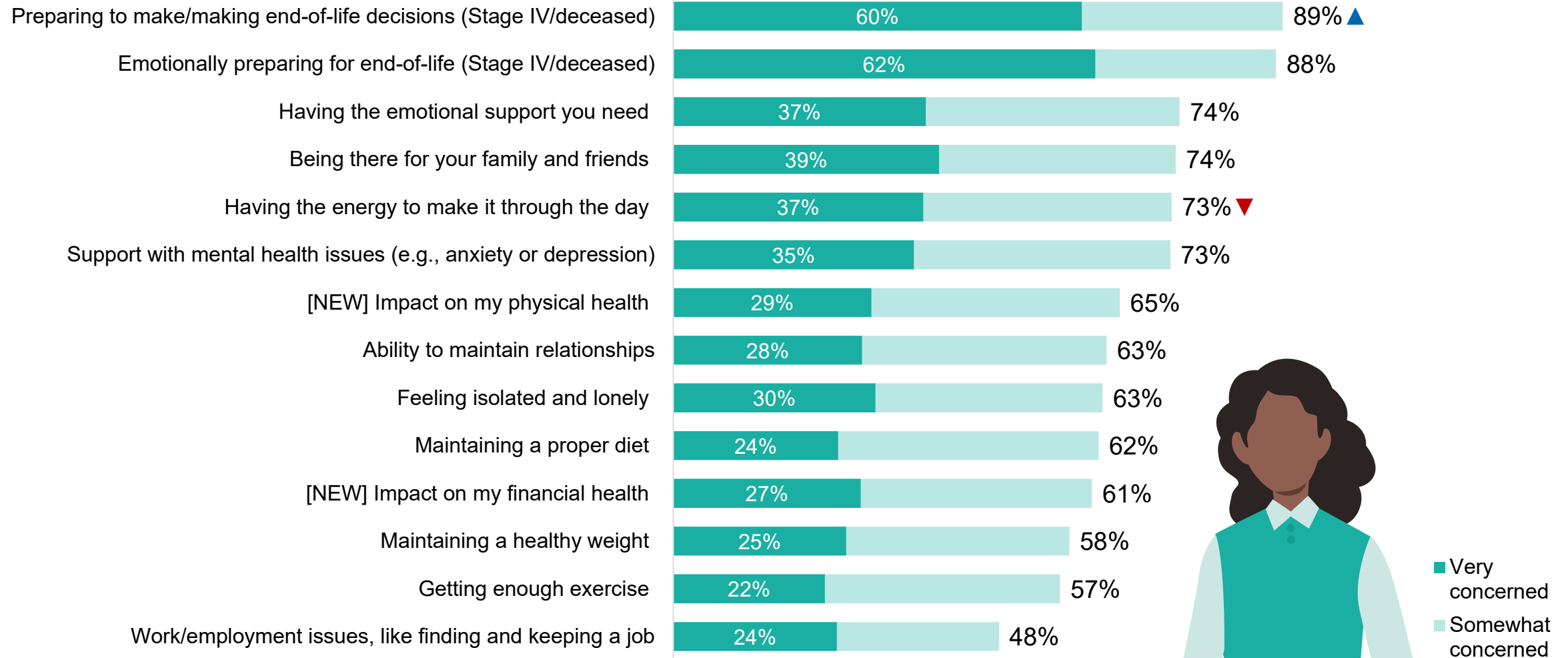
	Patients	Caregivers
Missed work	39%	42%
Lost salary or wages	22%	23%
Took paid medical leave	19%	13%
Took a leave of absence	16%	19%
Worked remotely/worked from home	14%	23%
Worked/went to school for fewer hours	11%	16%
Gone on short-term disability	10%	2%
Had to ask for accommodations at work/school	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



Cancer's Impact on Caregivers

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



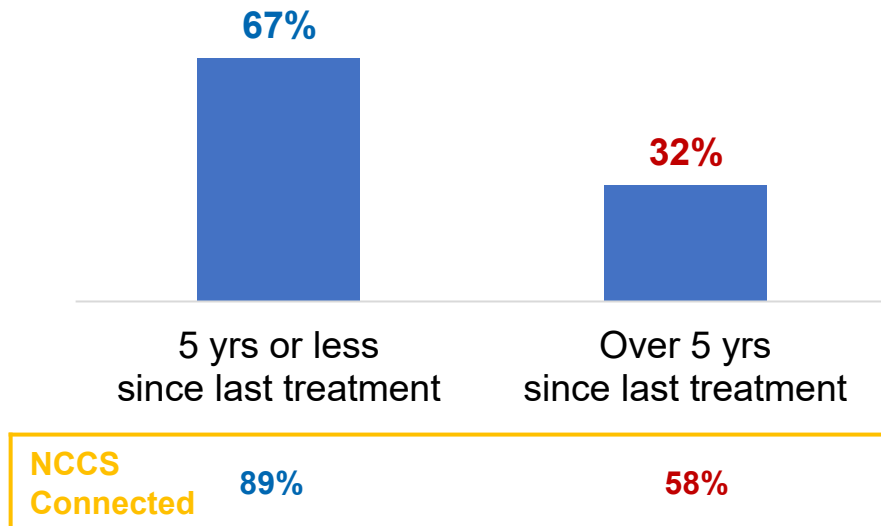
Post-Treatment Care and Survivorship



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



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%

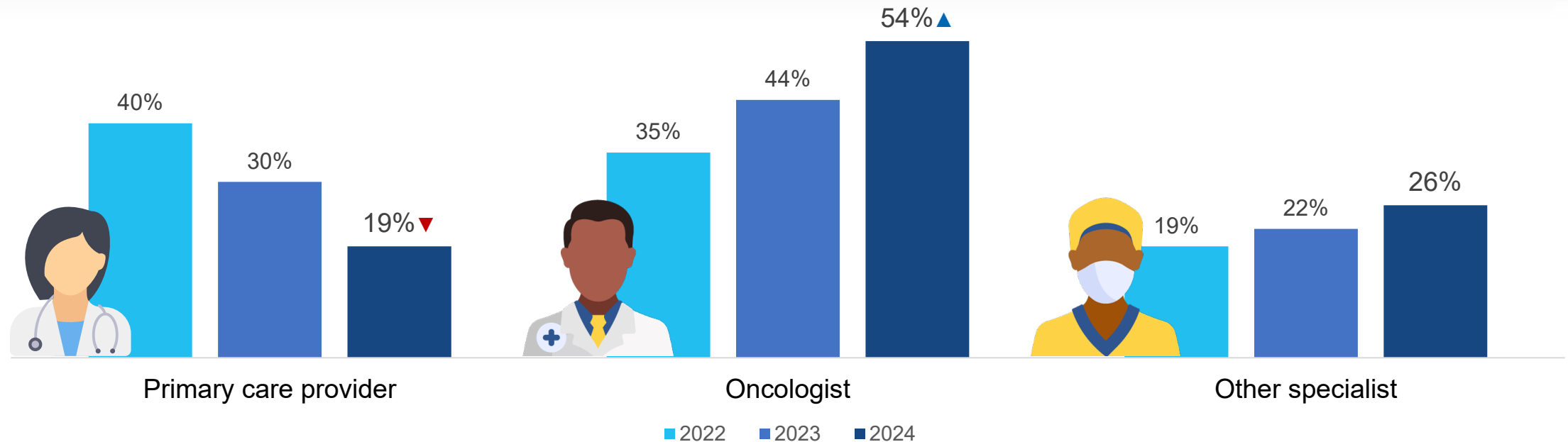
No differences by time since treatment

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?

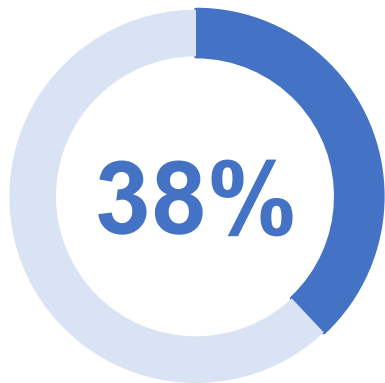
<5 Yrs. Since Treatment	13%	62%	25%
5 Yrs.+ Since Treatment	35%	34%	31%



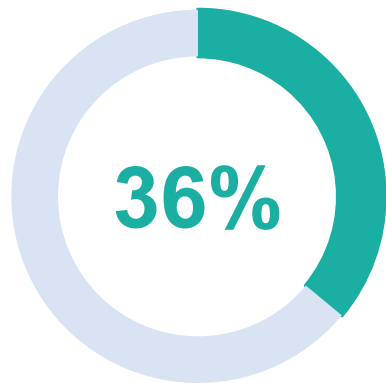
Willingness to See a PCP for Post-Treatment Care

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.

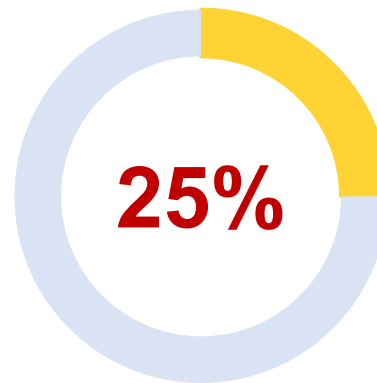
Would you be willing to have a primary care provider manage the post-treatment care for you/your loved one?
(asked of those NOT seeing a PCP)



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."

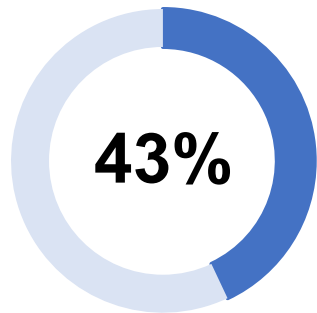
"My primary care doctor is not a specialist in breast cancer, and that is not their field of knowledge."



Survivorship Plans

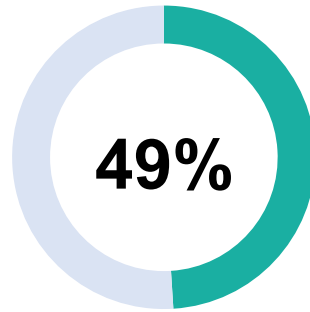
Slightly less than half of those who completed treatment received a survivorship care plan. Those in rural areas are less likely to receive a plan.

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?



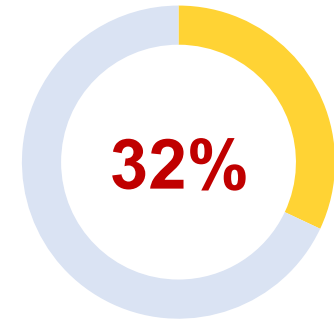
of Patients “Yes”

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

Survivorship Plan Process

Majorities are receiving their care plan verbally, and/or with a hard copy. Nine times out of ten, a team member will walk through the plan with the patient.

How was your/loved one's care plan provided?

Select all that apply.

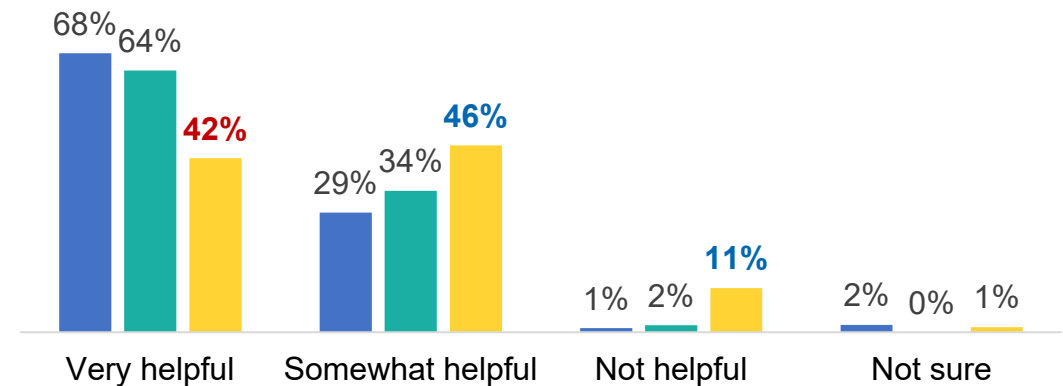
Through a discussion/conversation	63%
On paper, as a printout or hard copy in person	63%
Via a patient portal	18%
Digitally/electronically in some other way	6%
Via email	6%
In the mail	3%
Other	1%
Cannot remember	2%



94% say a health care team member walked through the plan

How helpful has the care plan been?

■ Patients ■ Caregivers ■ NCCS Connected



Survivorship Plan Details

Patients are most interested in plans that focus on their cancer experiences and treatments, vs. other quality of life recommendations.

Which of the following did the care plan include?/ If you had received a care plan, which of the following would have been helpful?	Received in Care Plan	Would be Helpful to Get in a Care Plan
Side effects that might be experienced	67%	42%
Recommended future screening(s)	65%	39%
Summary of all treatments received	64%	25%
Information about the cancer type, stage	57%	26%
Information about recommended exercise/physical activity	48%	17%
Diet and nutrition recommendations	46%	22%
Possible support groups	37%	17%
Info about ways to reduce risk for a recurrence and other cancers	37%	27%
Information about depression, anxiety, mental health concerns	36%	20%
Information about sexual health concerns after cancer	31%	18%
Resources in the community to go for help	29%	11%
Recommendations for screening for other cancers	29%	24%
Information about integrative (complementary) medicine approaches	13%	7%
Information about palliative, hospice, and/or end-of-life care	5%	2%
Other, please specify	2%	1%
None of the above	1%	23%

APPENDIX A:

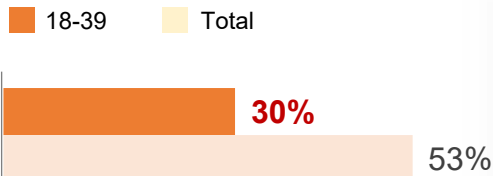
Survey Participant Profiles



Patient Profile: Younger Cohort (Age 18-39)

Decision-Making

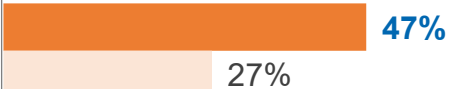
I rely/relied on the doctor to decide on treatment options and chose the best course of action.



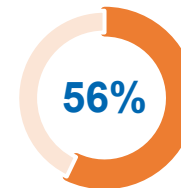
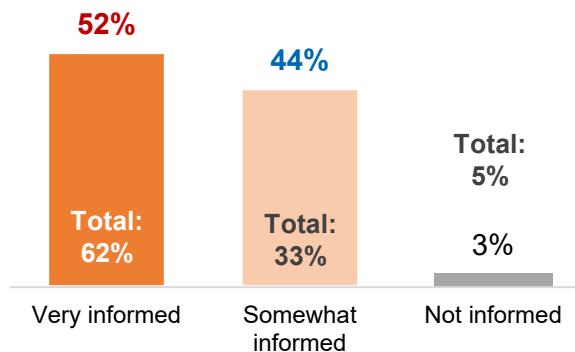
Somewhere in the middle



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



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

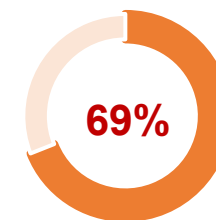
	18-39	Total
Borrowed money from family or friends	35%	13%
Delayed a major life event	34%	9%
Applied for government financial assistance	31%	13%

Top 3 Employment Sacrifices

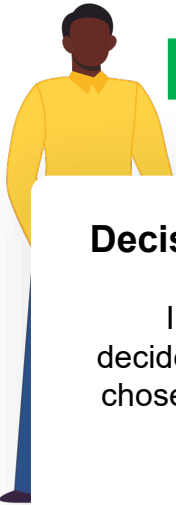
	18-39	Total
Missed work	37%	24%
Lost salary or wages	27%	15%
Felt that your work/schoolwork suffered	25%	7%

Current State of Health

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



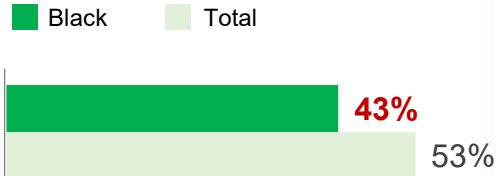
say they *completely* trust their health care team to act in their best interests
Total: 84%



Patient Profile: Black Patients

Decision-Making

I rely/relied on the doctor to decide on treatment options and chose the best course of action.



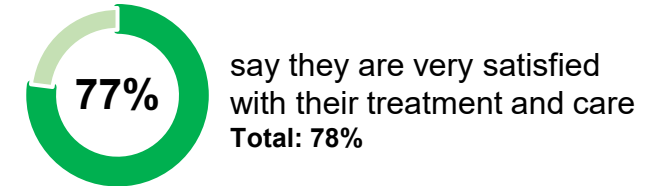
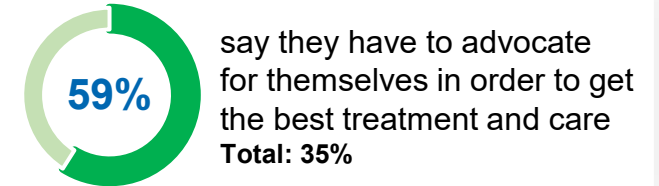
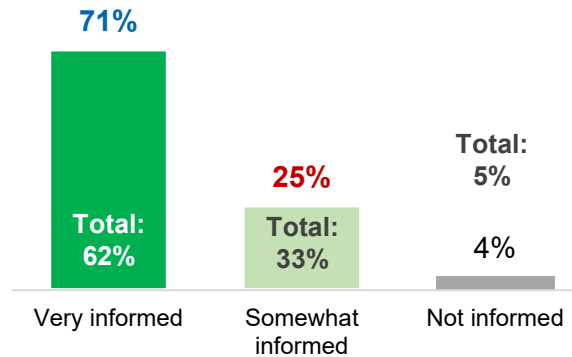
Somewhere in the middle



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



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



Top 3 Financial Impacts

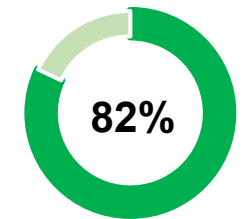
	Black	Total
Borrowed money from family or friends	22%	13%
Applied for government financial assistance	19%	13%
Spent savings/retirement money	17%	15%

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%



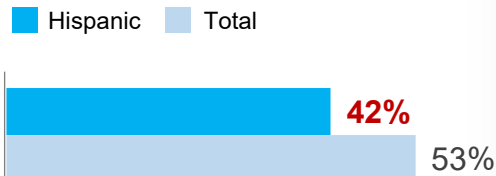
say they *completely* trust their health care team to act in their best interests
Total: 84%



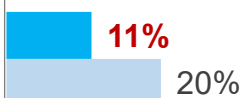
Patient Profile: Hispanic Patients

Decision-Making

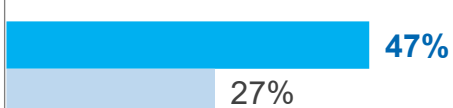
I rely/relied on the doctor to decide on treatment options and chose the best course of action.



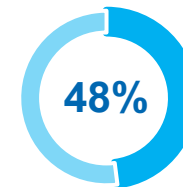
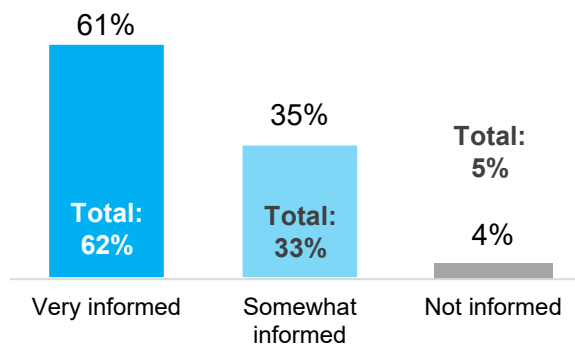
Somewhere in the middle



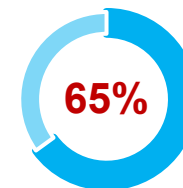
I am/was very involved in researching and deciding on the best treatment options for me.



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

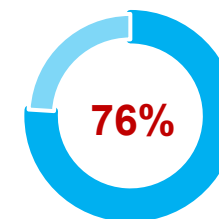
	Hispanic	Total
Applied for government financial assistance	23%	13%
Borrowed money from family or friends	21%	13%
Received help with food or housing	20%	10%

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%



Patient Profile: LGBTQ+

Decision-Making

■ LGBTQ+ ■ Total

I rely/relied on the doctor to decide on treatment options and chose the best course of action.



Somewhere in the middle

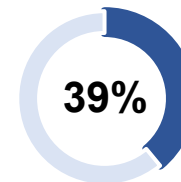


I am/was very involved in researching and deciding on the best treatment options for me.

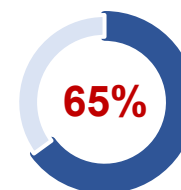


More on Mental Health

- 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%

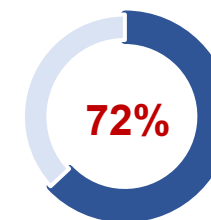
Took a leave of absence

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%



Patient Profile: Treated More than 5 Years Ago

Decision-Making

■ 5+ Years ■ Total

I rely/relied on the doctor to decide on treatment options and chose the best course of action.



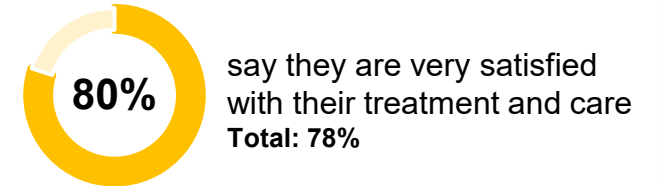
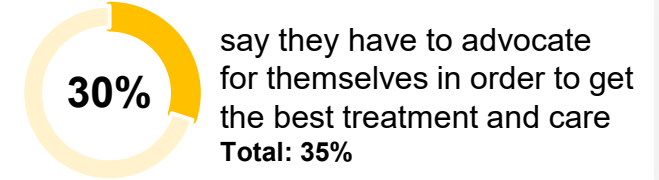
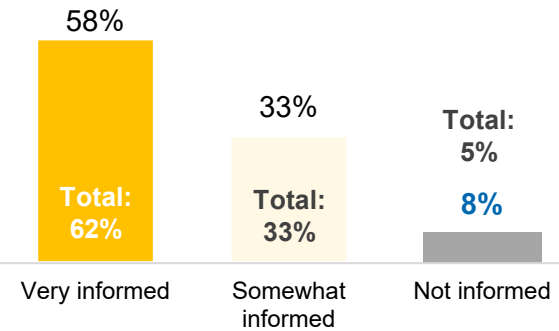
Somewhere in the middle



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



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



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%

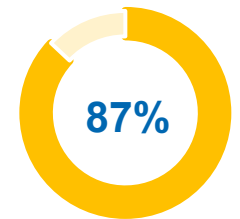
Took paid medical leave (offered by job)

13%

11%

Current State of Health

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

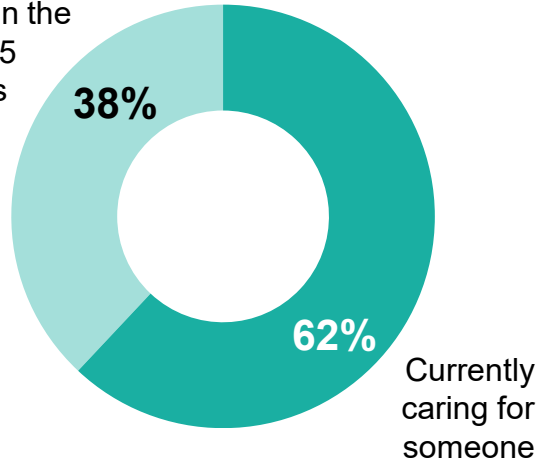


say they *completely* trust their health care team to act in their best interests
Total: 84%

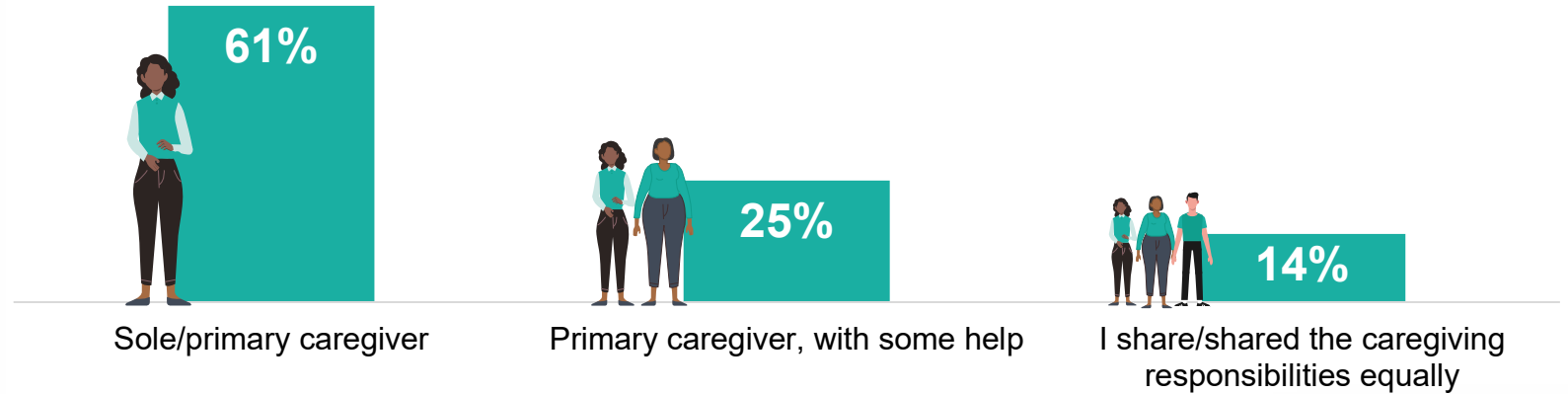


Caregiver Profile/Experiences

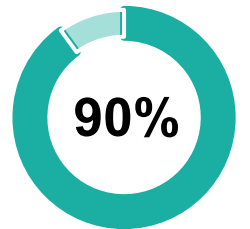
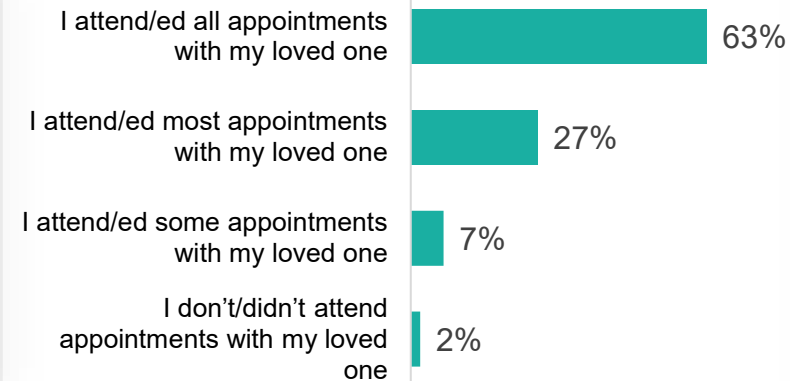
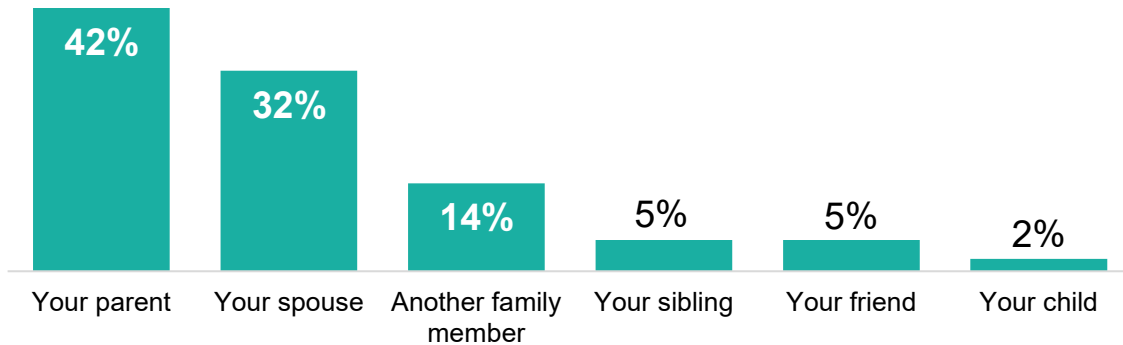
Within the
past 5
years



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

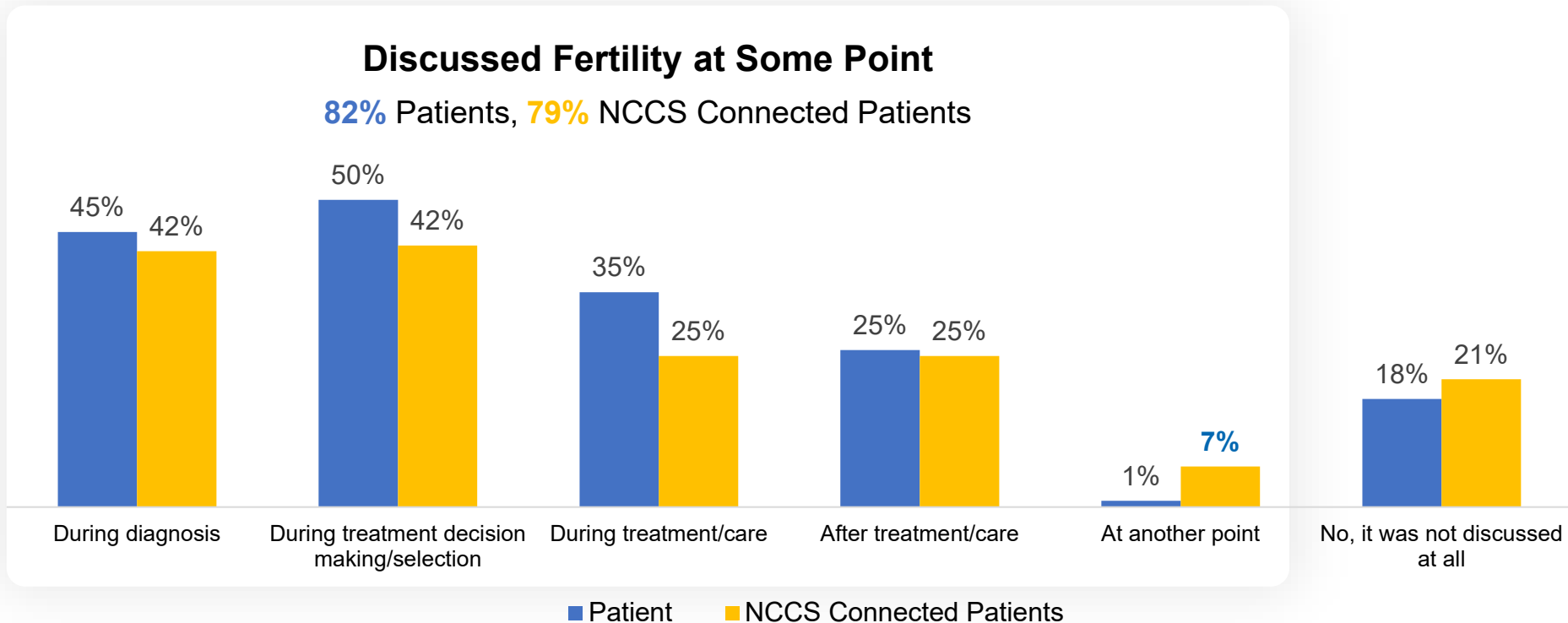
APPENDIX B:

Additional Subgroup Analysis

Impact of Treatment on Fertility

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

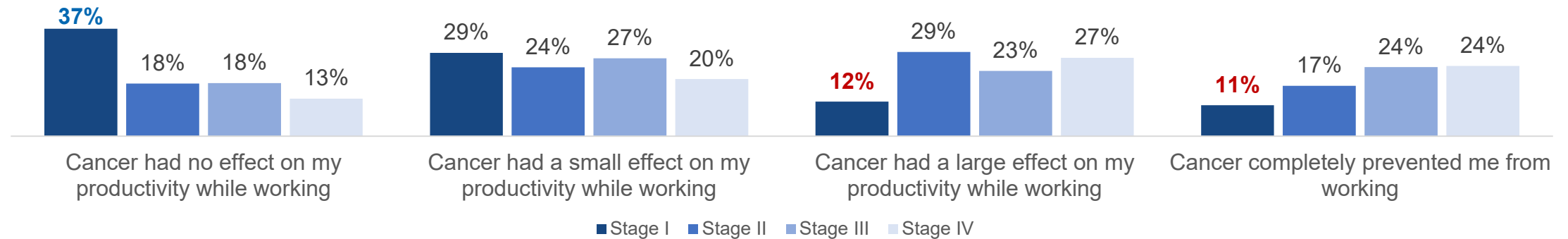
Did your health care providers discuss the impact treatment(s) could potentially have on your/your loved one's fertility at any of the following points in time? Select all that apply.



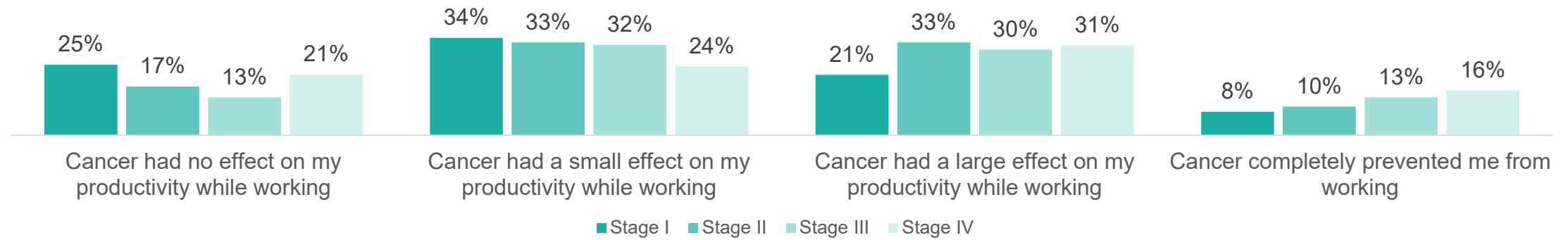
No differences by gender

Impact on Work Productivity by Cancer Stage

Patients



Caregivers



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%

PRESENTING SPONSOR



ADVOCACY PARTNER



SPONSORS



The Anna Fuller Foundation

