

STATE OF SURVIVORSHIP

2023 Study

Findings from In-depth Interviews and National Surveys
of Cancer Patients, Survivors, and Caregivers

Research Objectives and Questions

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

Continue to delve into 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:

- Included Caregivers to better understand their perspective, how they align and differ from Patients, and several questions specific to this audience
- Treatment decision-making priorities
- Working with cancer
- Interest in prescription drug monthly payment plan
- Advertising for cancer treatment
- Integrative care questions for all

Methodology

PHASE 1

In-depth Interviews with Cancer Patients and Caregivers

- Fifteen (15) virtual interviews, approximately 60 minutes-each, February-March 2023
- Focused on a few audiences:
 - 10 Caregivers
 - 5 Patients, Employed
- Nationwide recruit: mix of cancer types, stages, time since diagnosis, treatment status, and income

PHASE 2

Nationwide Survey of Adult Cancer Patients, Survivors, and Caregivers

- Nationwide sample of n=1809, fielded May 9th – June 6th, 2023
 - Patients n=1303
 - Caregivers n=506
- 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

PHASE 3

Nationwide Survey of “NCCS Connected” Patients and Survivors

- Nationwide sample of n=536, same field period as nationwide survey
 - Patients n=507
 - Caregivers n=29
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders
- Survey link also sent to partner organizations

Blue/red = statistically higher/lower by audience | ▲ ▼ = change from 2022 survey

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

National Patients



Gender

49% Male	22% Male
51% Female	78% Female

Age

7% Age 18-39	18% Age 18-39
40% Age 40-64	50% Age 40-64
53% Age 65+	31% Age 65+

Education

17% Less than college	8% Less than college
37% Some college/2-year degree	28% Some college/2-year degree
23% Bachelor's degree	23% Bachelor's degree
23% Postgraduate degree	40% Postgraduate degree

Income

15% Less than \$25k	10% Less than \$25k
21% \$25k-\$50k	13% \$25k-\$50k
21% \$50k-\$75k	14% \$50k-\$75k
16% \$75k-\$100k	14% \$75k-\$100k
24% More than \$100k	33% More than \$100k

Insurance

57% Medicare	36% Medicare
15% Medicaid	7% Medicaid
20% Private/employer	36% Private/employer
7% Private/spouse or parents	16% Private/spouse or parents

Race/Ethnicity

81% White	73% White
10% AA/Black	11% AA/Black
7% Hispanic	12% Hispanic
4% Other	8% Other

Treatment

22% Biomarker testing, 24% Genetic counseling	40% Biomarker testing, 55% Genetic testing
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Region

19% Northeast	19% Northeast
22% Midwest	16% Midwest
40% South	35% South
19% West	30% West

LGBTQ+

5% Yes	10% Yes
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NCCS Connected Patients



Key Findings



Patient Mindset

Patients' reliance on their doctor to make treatment decisions is trending back up this year after a decline during the pandemic – with over half reporting they relied on their doctor to choose the best course of action, vs. just a quarter who said they were very involved in deciding what treatment was best for them, and another quarter somewhere in the middle. This aligns with Patients' strong emphasis on doctors' recommendations vs. other factors (like real-world and clinical trial data), and a decline in consulting other information resources to stay informed on their cancer diagnosis.



Caregiver Mindset

Caregivers report being more proactive, with a large majority saying they wanted to find out all they could about their loved one's diagnosis and treatment options. Their top information sources are Google, healthcare websites, doctor provided education materials, and cancer non-profit organizations. Involvement comes at a cost – majorities of Caregivers grapple with their own physical, emotional, and mental health issues; and three-quarters worry about having the support they need.



Care Experiences

Majorities of Patients continue to be satisfied with each phase of their care and their health care team. Caregivers are more critical – satisfaction with care is at least 10 points lower on each phase of the cancer journey and assessments of the care team.

Both Caregivers and Patients who report having a care plan tend to be more satisfied with their care and informed about side effects. The one glaring exception is end-of-life planning and care. Majorities of Stage IV Patients who were asked this question could not comment – meaning they most likely have avoided this.

Key Findings



Working with Cancer

Large numbers of Patients and Caregivers who worked during cancer treatment experienced some type of problem, the most common: missing work, working fewer hours, and loss of salary/wages. Most say their productivity was impacted, though this is more pronounced among Caregivers – who are also more likely to say they were stressed and distracted on the job.

Many Patients wanted to continue working during this time, because it got their mind off the disease, and they appreciate the support of co-workers. Those who were diagnosed early/Stage I are less likely to report impacts on their job.



Integrative Oncology

Six-in-10 Patients report using some form of integrative care during their cancer journey, particularly women, younger Patients, Black and Hispanic Patients, and those who are connected to NCCS. The most common forms are spiritual practices, exercise, and dietary supplements. Those who practice these cite the desire to focus on wellbeing, and/or cope with mental health issues resulting from their cancer. The biggest barrier to integrative oncology is awareness.



Patient and Caregiver Mindset

Patient vs. Caregiver Mindset

Patient's more focused on eradicating cancer no matter what, Caregivers on maintaining their loved one's quality of life.




Caregivers are more likely to say they felt pressure to remain strong during treatment, less likely to say they had a support network.

% Describes perfectly	National Patients	National Caregivers	NCCS Connected Patients
My focus is/was getting rid of the cancer no matter what	77% ▲	67%	63%
My focus is/was on maintaining my/my loved one's quality of life as much as possible	74%	87%	67%
The health care team is/was critical in helping me through my/my loved one's treatment	71% ▲	64%	65%
I want/wanted to find out all I can/could about my/my loved one's cancer diagnosis and treatment options	58%	72%	68%
My friends and family are/were critical in helping me through treatment/my loved one's treatment	53%	47%	56%
My faith is/was critical in helping me through treatment/my loved one's treatment	43%	49%	40%
I feel/felt a lot of pressure from others to remain strong during treatment/my loved one's treatment	25%	43%	33%
I feel/felt uncomfortable telling people that I have/had cancer	18%	-	22%
I/My loved one tried to ignore symptoms for as long as possible before getting a cancer diagnosis	10%	26%	13%
I do not/didn't want to think or read about cancer	9% ▼	13%	8%
I/My loved one delayed going to the doctor for as long as possible before getting a cancer diagnosis	9%	21%	11%

Source= National Patients (n=1303); National Caregivers (n=506); NCCS Connected Patients (n=507)

Treatment Decisions








Patient's reliance on the doctor is trending back up. The NCCS Connected audience continues to be more proactive. Caregivers are split between saying they relied on the doctor vs. being actively involved in decision-making.

		Patient National Sample				Caregiver 2023	NCCS Connected Patients
		2020	2021	2022	2023		
	I rely/relied on the doctor to decide on treatment options and chose the best course of action.	61%	44%	47%	53%▲	42%	31%
	Somewhere in the middle	18%	22%	26%	22%▼	19%	29%
	I am/was very involved in researching and deciding on the best treatment options.	22%	33%	27%	24%	38%	40%

Source= National Patients (n=1303); National Caregivers (n=506); NCCS Connected Patients (n=507); 2022 National Patients (n=1408)

Treatment Decision-making Priorities

Doctor's recommendations are more important, while clinical trial data and whether they can continue working are less important.

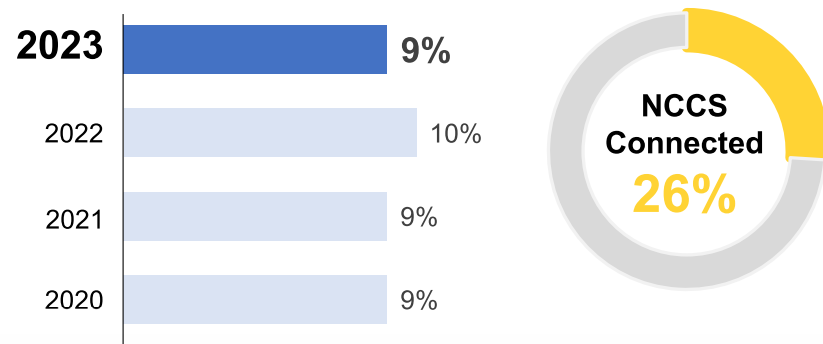
		Patient		Caregiver	
How important each was in making decisions about treatment		Most Important	Least Important	Most Important	Least Important
	Doctor's recommendations	53%	1%	34%	4%
	Likelihood that the treatment will work	28%	3%	31%	4%
	How I/your loved one will feel during treatment	5%	10%	18%	5%
	Real-world data from other people who have taken the treatment	5%	13%	5%	13%
	Whether I/your loved one will be able to continue daily activities during treatment	4%	11%	7%	9%
	Whether I/your loved one will be able to continue working during treatment	3%	29%	3%	44%
	Clinical trial data from other people who have taken the treatment	2%	32%	2%	22%

Source= National Patients (n=1303); National Caregivers (n=506)

Clinical Trials

Participation in clinical trials is on-par with previous years at 9%.

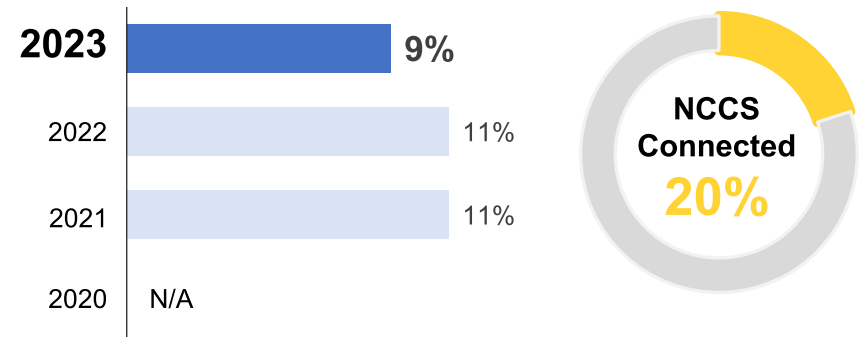
Did you participate in a clinical trial related to your cancer diagnosis?



Higher among:

- 19% Younger (18-39)
- 18% Hispanic
- 16% Palliative Care
- 19% Immunotherapy
- 15% Biomarker Testing
- 15% Genetic Counseling
- 14% Targeted Drug Therapy
- 14% Chemo
- 13% Still In Treatment

Did your health care team offer/discuss a clinical trial with you?



Higher among:

- 25% Younger (18-39)
- 29% Black
- 25% Hispanic
- 22% Palliative Care
- 21% Still In Treatment
- 20% Immunotherapy
- 18% Biomarker Testing
- 18% Targeted Drug Therapy
- 17% Urban
- 16% Genetic Counseling
- 16% Chemo

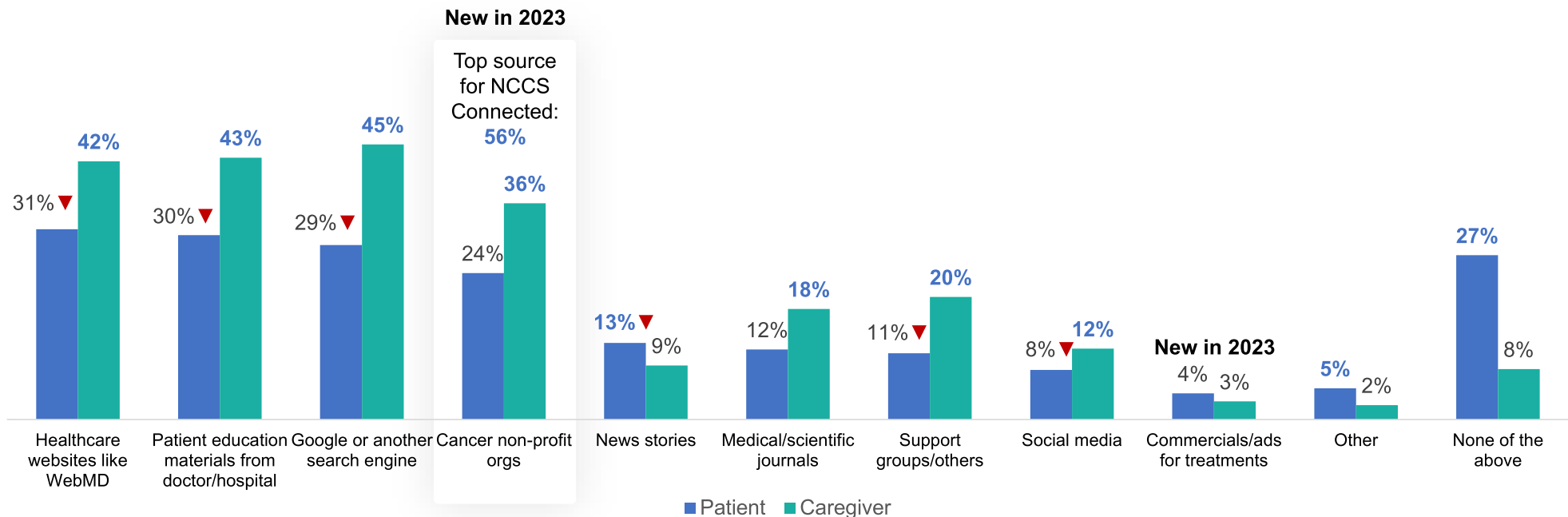
Source= National Patients (n=1303); NCCS Connected Patients (n=507)

Resources for Cancer Information

The top three resources are healthcare sites, materials from doctors, and Google.

As Patients rely more on doctors this year, their use of info sources declined. Caregivers are more likely to use most resources.

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



NCCS Connected more likely to select non-profit organizations, medical journals, support groups, and social media

Source= National Patients (n=1303); National Caregivers (n=506)

Advertising for Cancer Treatments

Feelings about advertising are mixed. Caregivers skew more positive than Patients, NCCS Connected is least positive.

Feelings about Advertising for Cancer Treatments

No differences:

TOTAL PATIENTS POSITIVE:

47%

Involved in
Decisions

44%

Relied on
Doctor

TOTAL CAREGIVERS POSITIVE:

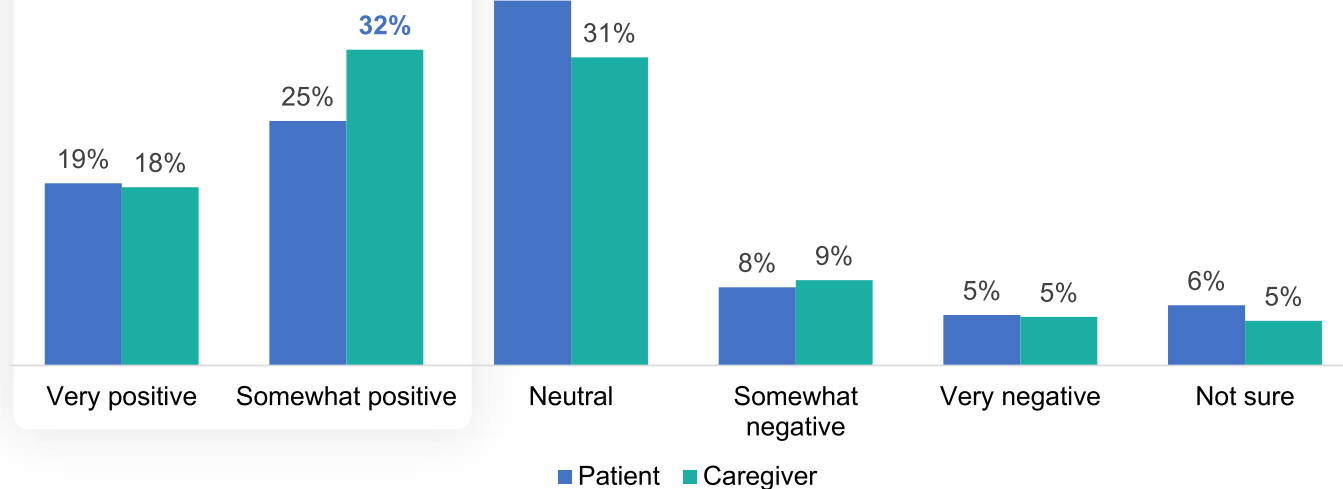
52%

Involved in
Decisions

49%

Relied on
Doctor

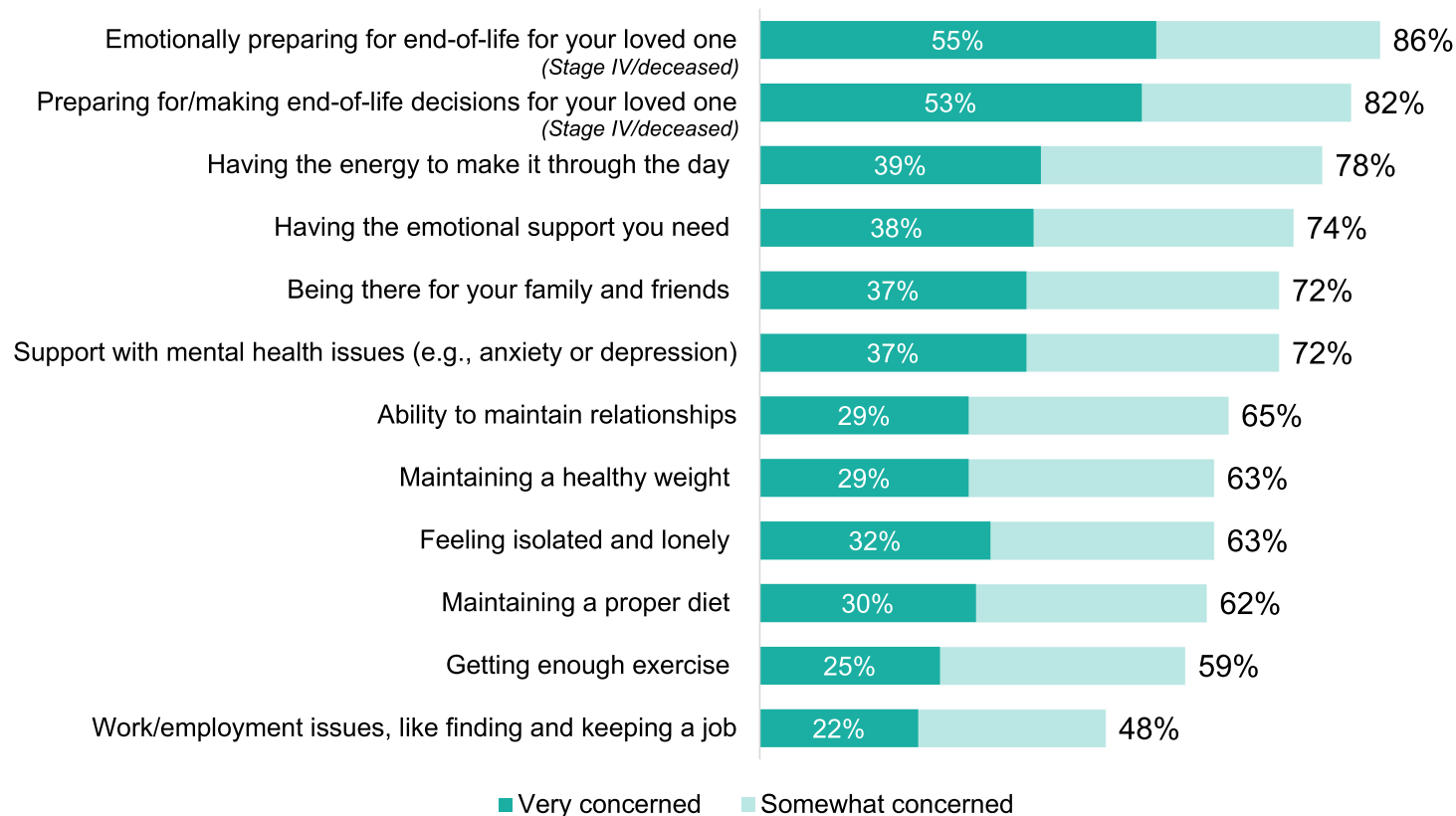
Total Positive
Patient: 44%
Caregiver: 50%
NCCS Connected: 31%



Source= National Patients (n=1303); National Caregivers (n=506)

Cancer's Impact on Caregivers

Majorities of Caregivers report grappling with a variety of physical, emotional, and mental health issues of their own.



Source= National Caregivers (n=506)

"I got kidney stones because I wasn't drinking enough water. I was very sleep deprived. I had to take Xanax there for a little bit, because my nerves were just unhinged. I gained weight, lost weight. I fluctuated. But there's different stages of my health that were hindered as well."

– Caring for Mother

"I'm looking to see a therapist. I'm just not happy. I don't blame anyone, God always has the last say, raised to believe. I'm not the same person that I was 2-3 years ago."

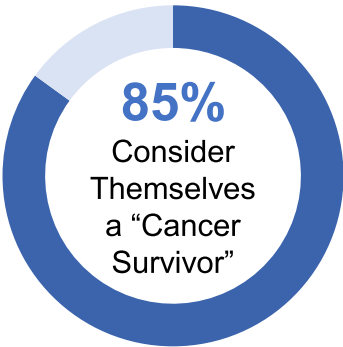
– Caring for Husband



Terminology

Most Patients consider themselves “Cancer Survivors.”
Majorities prefer the term “Caregiver,” though almost 4-in-10 spouses like “Care Partner.”

Patients



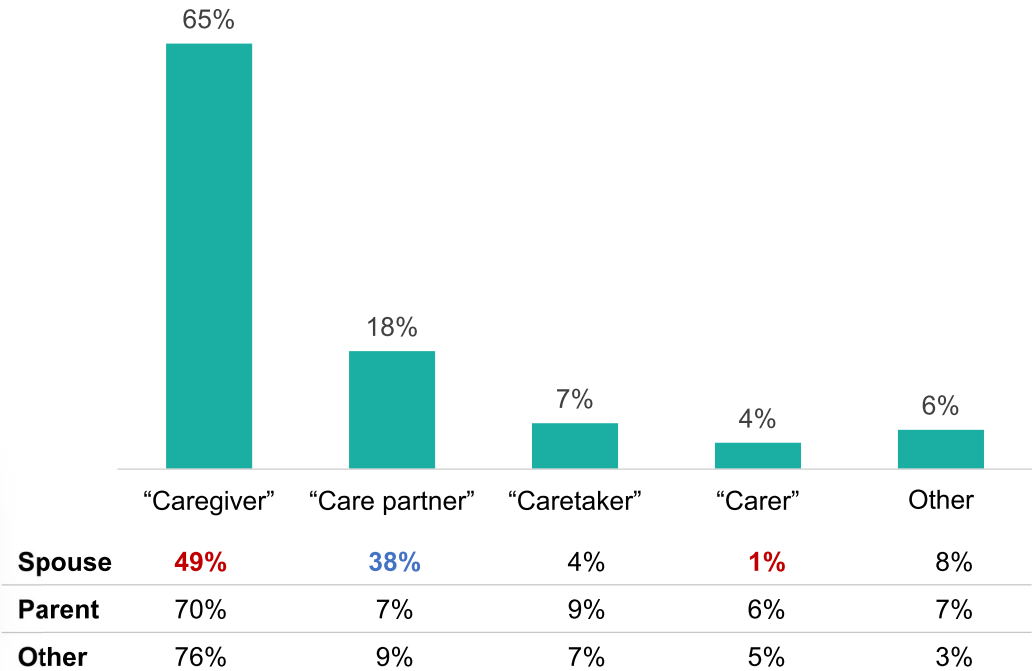
Still in Treatment: **67%**
Completed Treatment: **90%**
Stage IV: **72%**

Consistent with 2021 Survey

84% of **NCCS Connected**
Patients agree, a 6-point
decrease since 2021

Caregivers

Which of the following terms do
you prefer to describe yourself?



“A caregiver is
somebody who will
give you their all, to
take care of you. It
implies love. ‘Care
partner’ means you
were just a partner;
he was more than
my partner.”

– Cared for
Husband



Source= National Patients (n=1303); National Caregivers (n=506)

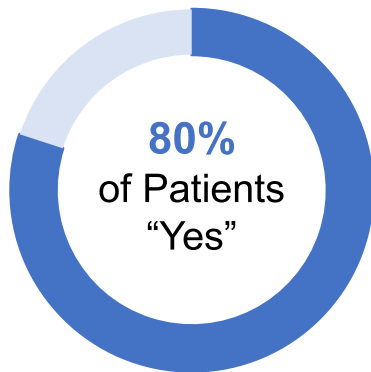


Cancer Care Experiences

Cancer Care Plan

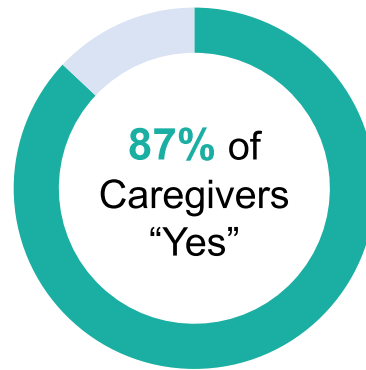
Eight-in-10 Patients say their health care team provided a care plan; although this is significantly lower among NCCS Connected audience.

Did the health care team provide a care plan that helps/helped you understand what to expect?



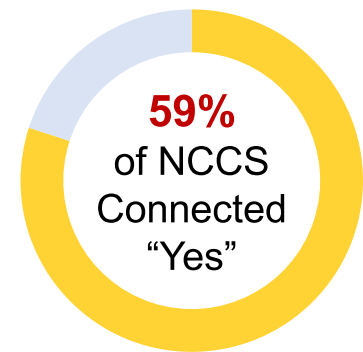
Higher among:

85% Still in treatment
86% Biomarker testing
85% Private insurance



Higher among:

95% Genetic counseling



Higher among:

72% Patients still in treatment
78% Younger Patients (18-39)
68% Immunotherapy Patients
67% Biomarker testing Patients

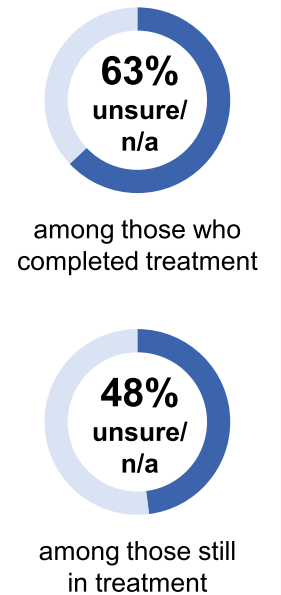
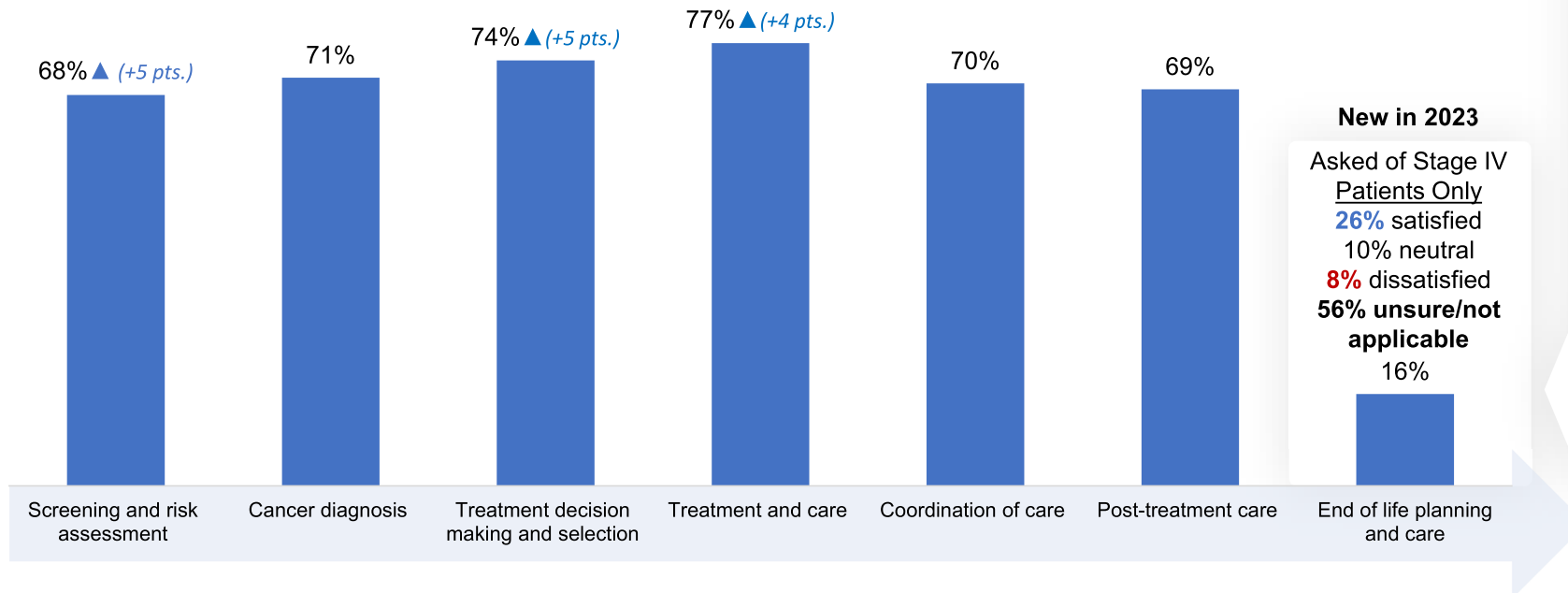
Source= National Patients (n=1303); National Caregivers (n=506); NCCS Connected Sample (n=536)

Patient Satisfaction With Care

Most Patients remain very satisfied with each stage of their care, and satisfaction has increased this year on several dimensions. Stage IV Patients were asked about satisfaction with end-of-life planning/care, and majorities could not comment.

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

% Very satisfied (Patients)



Source= National Patients (n=1303); National Caregivers (n=506)

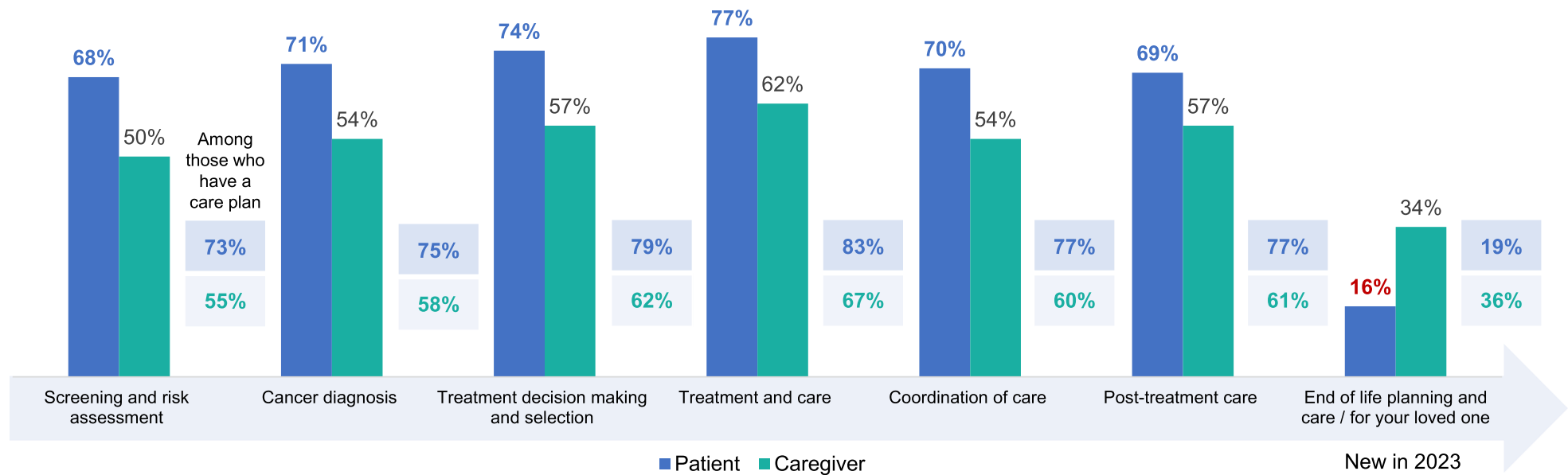
Satisfaction With Care: Patients vs. Caregivers

Caregivers are significantly less satisfied/more critical with each phase of the care journey.

However, both Caregiver and Patient satisfaction is higher among those who/whose loved-one has a care plan.

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

% Very satisfied



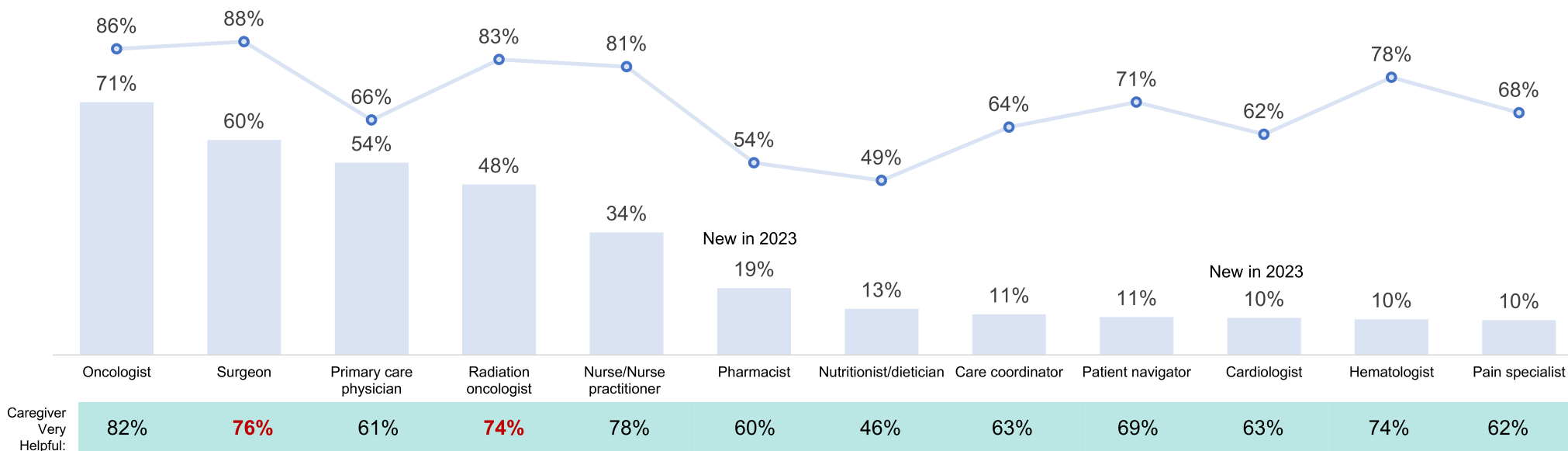
Source= National Patients (n=1303); National Caregivers (n=506)

Healthcare Providers Visited and Helpfulness

Findings are very similar to last year – oncologists and surgeons are seen by the greatest percentage of Patients and get high ratings; PCP's get lower scores on helpfulness. Caregivers give lower scores to their loved ones' surgeons and radiation oncologists.

HCPs Seen and Helpful During Treatment (top 10 seen)

— Saw — Very Helpful (among seen)



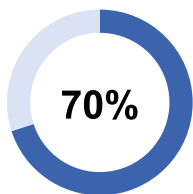
Source= National Patients (n=1303); National Caregivers (n=506)

NCCS Connected: more likely to see a range of HCPs. **Lower scores on helpfulness** for PCP, Nurse, Radiation oncologist, Surgeon, Cardiologist.

Less than 10% saw: Social worker, Physical therapist, Psychologist/Psychiatrist, Home health aide, Rehab specialist, Palliative care, Occupational therapist, Speech therapist, Audiologist, Fertility specialist

Patient Experiences with Health Care Team

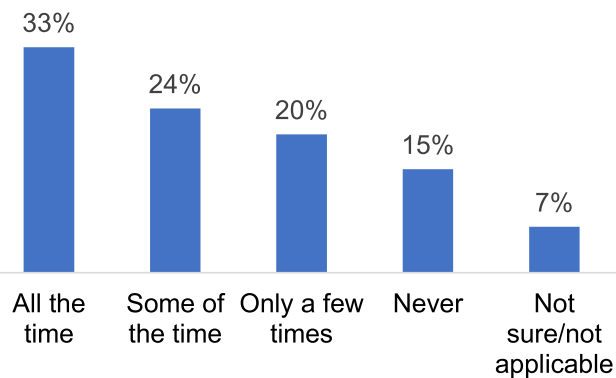
Consistent with previous years, most Patients report positive experiences with their health care team.



of Patients said their HCPs **coordinated** "very well" with one another;

92% said "Very/somewhat well"

How often do/did you have to share information from one HCP with another?



How often did you feel like you could **talk to the HCPs** about any concerns?

Always



60% Black Patients

71%

Most of the time



21%

Some/
A little/
Not at all



8%

How often did you feel like the **HCPs listened and respected** your questions and concerns?

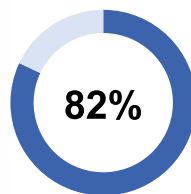


69%

24%



7%



completely trust their health care team to act in their best interests

98% said "completely/somewhat trust"

Completely trust:

83% White Patients

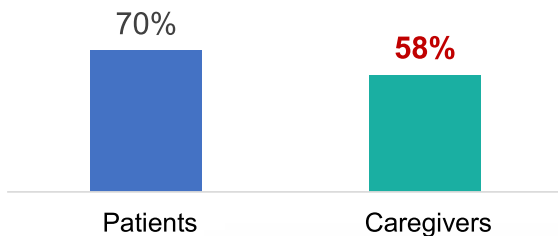
74% Black Patients

73% Hispanic Patients

Caregivers Significantly More Critical of Healthcare Team

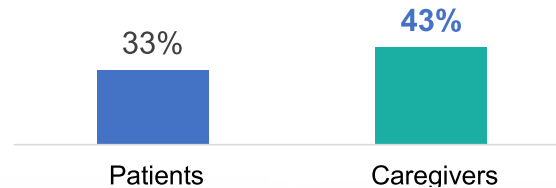
How well do/did the health care providers coordinate care with one another?

% Very well



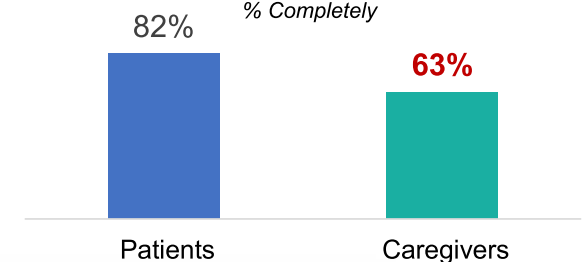
How often do/did you have to share information from one HCP with another?

% All the time



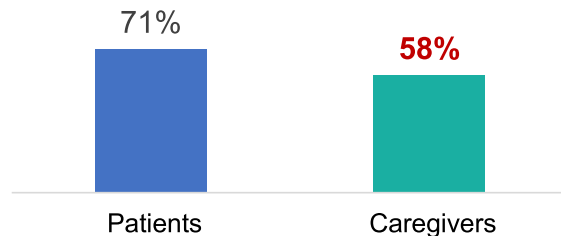
Overall, how much do/did you trust the health care team to act in your/loved one's best interests?

% Completely



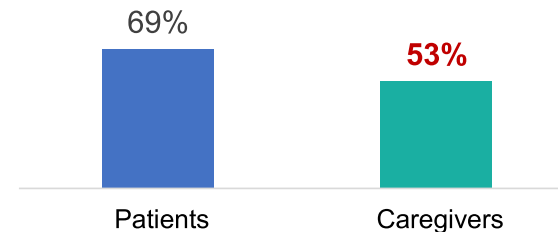
How often did you/your loved one feel like you could talk to the HCPs about any concerns?

% Always



How often did you feel like the HCPs listened and respected your/loved one's questions and concerns?

% Always

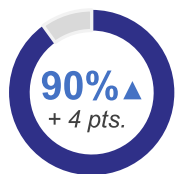


Source= National Patients (n=1303); National Caregivers (n=506)

Side Effects

Feeling overly tired and mental health are still the top three symptoms – ALL increased since 2022.

Women, POC, and younger Patients are more likely to experience myriad symptoms. Six-in-10 younger Patients report mental health issues.



of Patients
experienced
at least one
symptom
during
treatment

Symptoms experienced (top 15 out of 25 shown)

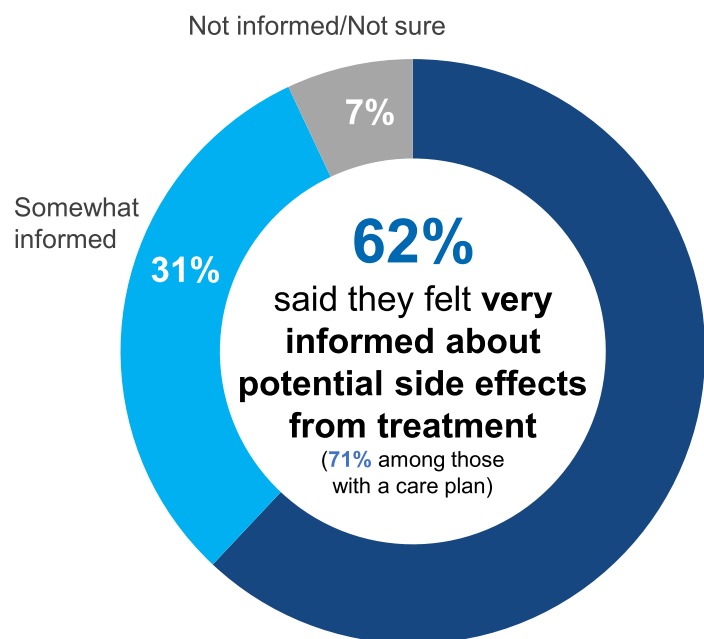
		Women	Men	Black	Hispanic	18-39	Still Experiencing*
Feeling overly tired	54%▲ + 7 pts.	65%	43%	47%	59%	72%	18%
Depression, anxiety, mental	35%▲ + 4 pts.	43%	26%	40%	43%	62%	18%
Uncertainty status of the cancer	32%▲ + 10 pts.	31%	33%	34%	25%	36%	8%
Loss of appetite and/or taste	32%	38%	26%	39%	51%	54%	4%
Nausea/vomiting or diarrhea	30%	37%	23%	42%	38%	52%	2%
Sexual concerns	27%	19%	37%	30%	30%	29%	19%
Weight loss	27%	27%	27%	30%	37%	55%	3%
Muscle/joint pain	27%	34%	19%	29%	43%	46%	12%
Insomnia/sleeplessness	25%	33%	17%	26%	37%	51%	12%
Neuropathy	23%	29%	16%	19%	23%	34%	17%
Skin irritation/rash	21%	29%	13%	18%	25%	28%	4%
Memory loss, cognitive issues	15%	20%	10%	14%	22%	31%	8%
Fever/chills	14%	17%	12%	19%	17%	28%	1%
High blood pressure	12%	11%	12%	19%	21%	18%	12%
Mouth sores	11%	14%	7%	9%	11%	21%	1%
MEAN EXPERIENCED	5.04	5.73	4.29	5.09	5.98	7.37	2.76

*Completed treatment (n=1015)

Source= National Patients (n=1303)

Addressing Side Effects

While majorities continue to say they feel informed about side effects, when asked about specifics, in many cases less than half say their healthcare team was very helpful. Those with a care plan feel more informed and that their care team was helpful.



Caregivers:
61% very informed

NCCS Connected:
44% very informed

Symptoms experienced (top 15 out of 25 shown)

Healthcare team very helpful (among those who experienced)

(Among those with a care plan)

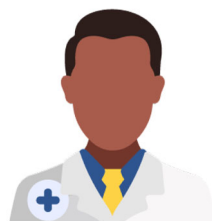
Feeling overly tired	40%	47%
Depression, anxiety, mental	41%	50%
Uncertainty status of the cancer	50%	59%
Loss of appetite and/or taste	42%	49%
Nausea/vomiting or diarrhea	57%	65%
Sexual concerns	29%	36%
Weight loss	39%	45%
Muscle/joint pain	46%	53%
Insomnia/sleeplessness	29%	37%
Neuropathy	38%	47%
Skin irritation/rash	57%	66%
Memory loss, cognitive issues	28%	37%
Fever/chills	48%	54%
High blood pressure	56%	63%
Mouth sores	53%	62%

Source= National Patients (n=1303); National Caregivers (n=506); NCCS Connected Sample (n=536)

Post-Treatment Experiences

More in post-treatment report seeing their oncologist for follow-up care and are more regularly discussing their follow-up tests.
Far fewer discuss other issues, nor do they want to.

Who is the primary health care provider managing your/your loved one's post-treatment medical care?



30% ▼ PCP

Caregivers: 37%

NCCS Connected: 36%

Cervical cancer: 62%

10+ Years Since Treatment: 42%



44% ▲ Oncologist

Caregivers: 53%

NCCS Connected: 46%

Breast cancer: 60%

1 Year or Less Since Treatment: 52%

1-5 Years Since Treatment: 53%

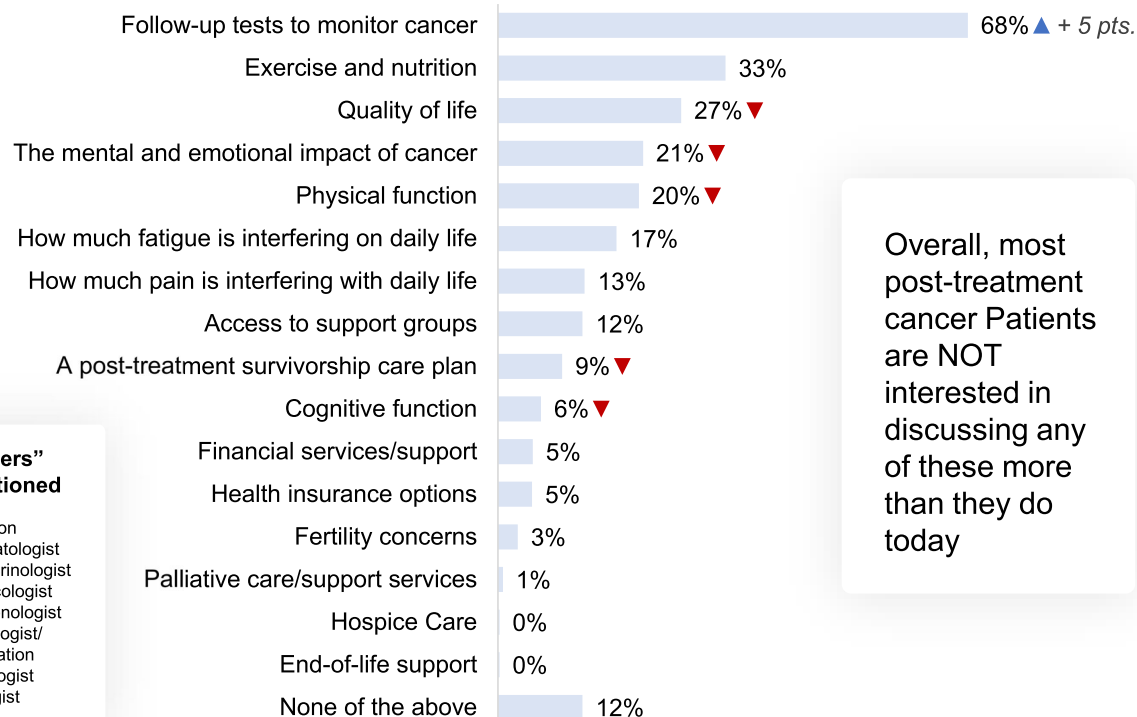
5% Not sure

Caregivers: 1%
NCCS Connected: 5%

22% Other

Caregivers: 9%
NCCS Connected: 14%

Which topics do your HCPs discuss with you regularly during your post-treatment care?



"Others" Mentioned

Surgeon
Dermatologist
Endocrinologist
Gynecologist
Pulmonologist
Radiologist/
Radiation
Oncologist
Urologist

Overall, most post-treatment cancer Patients are NOT interested in discussing any of these more than they do today

Financial Impacts

The number of Patients who were impacted financially decreased slightly nationally; but young, Black, Hispanic, Stage IV, and less educated Patients continue to report more financial hardship. Caregivers also have higher rates of financial consequences.

NCCS Connected: 71%▲

Impacted Financially: 43%▼ (-4 points)

Caregivers 69% 18-39 78% African American 78% Hispanic 75% Stage IV 66% No College 49%

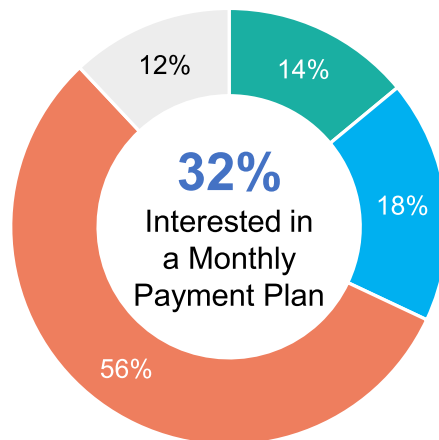
Spent savings/retirement money to cover living expenses	17%▼	30%	22%	22%	29%	31%	20%
Applied for government financial assistance such as unemployment, SNAP/food stamps, Medicaid, etc.	14%	24%	32%	28%	22%	28%	18%
Borrowed money from family or friends	13%	24%	31%	31%	27%	20%	18%
Delayed a major purchase (house, car, etc.)	12%	24%	28%	21%	23%	26%	13%
Delayed a major life event (marriage, trip, starting family, etc.)	11%	23%	28%	25%	27%	18%	12%
Received help with food or housing from a charity, community center, or place of worship	10%	18%	20%	19%	16%	14%	14%
Delayed or reduced payments to credits cards or loans	10%	22%	22%	9%	16%	10%	11%
Applied for co-pay assistance from manufacturer or non-profit	8% New in 2023	N/A	16%	12%	16%	18%	8%
Had to sell property belongings to cover your personal expenses	6%	14%	14%	3%	14%	14%	7%
Delayed treatment to get insurance authorization/approval	5% New in 2023	N/A	18%	6%	11%	6%	6%
Asked for rent or mortgage relief	5%▼	8%	12%	9%	7%	8%	6%
Applied for grants or scholarships to help with your personal medical and living costs	3%▼	7%	8%	8%	4%	6%	4%
Started a GoFundMe or similar campaign	3%▼	7%	14%	3%	4%	10%	3%
Declared bankruptcy	2%▼	2%	1%	1%	-	1%	2%
Lost your insurance coverage	2%	-	2%	3%	3%	3%	2%

Source= National Patients (n=1303)

Monthly Prescription Payment Plan

Only a third of Patients are interested, and interest drops among those who have Medicare.

National Patients

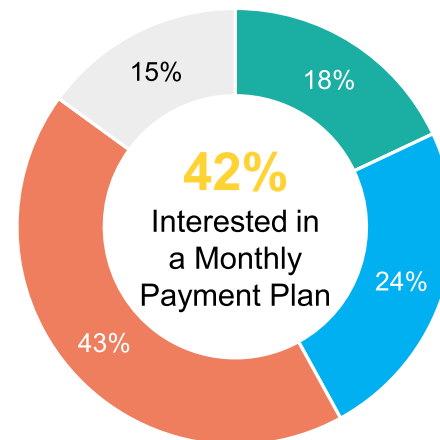


24% of Medicare Patients are interested

42% Non-Medicare

*21% of Medicare Patients also have
supplemental or gap insurance*

NCCS Connected Patients



31% of Medicare Patients are interested

48% Non-Medicare

*30% of Medicare Patients also have
supplemental or gap insurance*

- Very interested
- Somewhat interested
- Not interested
- Not sure

Source= National Patients (n=1303); NCCS Connected Patients (n=507)

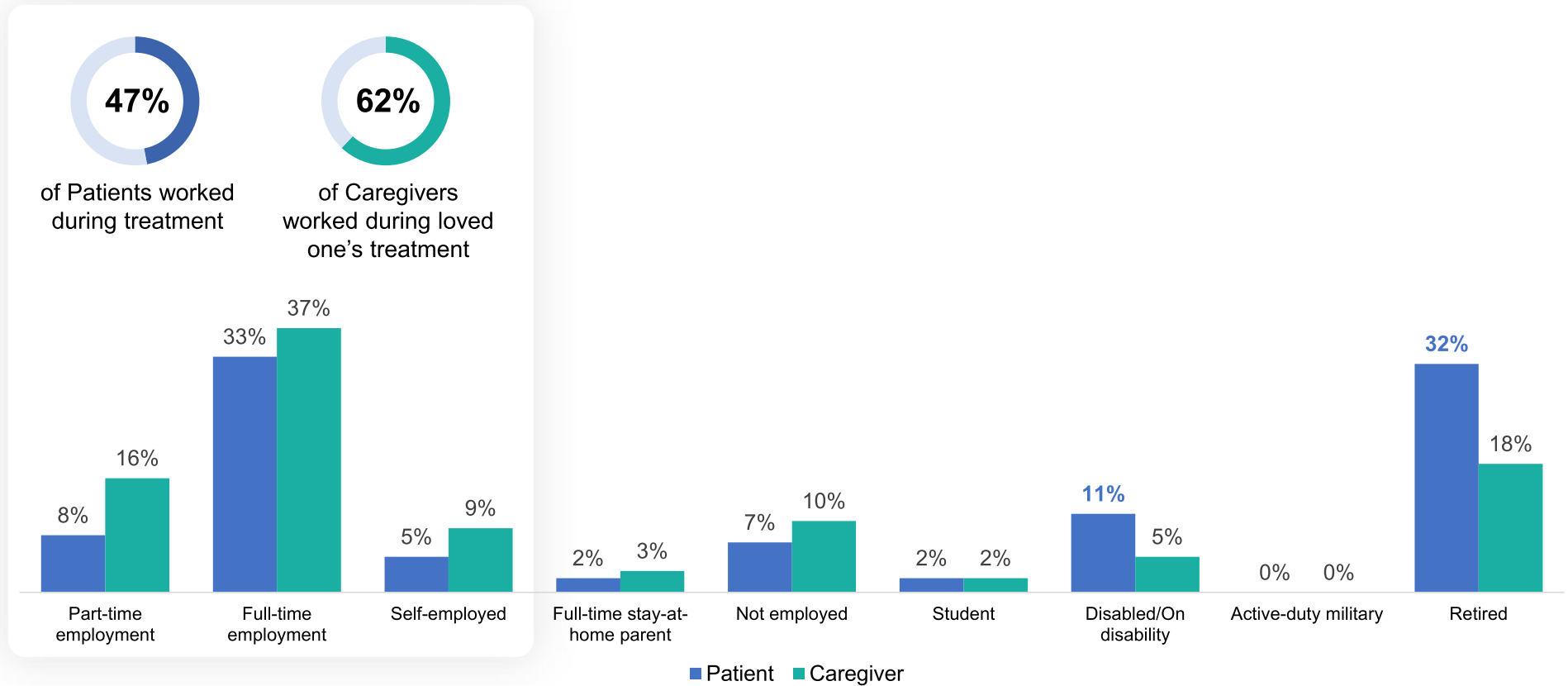


Working with Cancer

Employment Status during Treatment

Nearly half of Patients report working during treatment, a third were retired, one-in-10 on disability.

Two-thirds of Caregivers say they worked during their loved one's cancer treatment.



Source= National Patients (n=1303); National Caregivers (n=506)

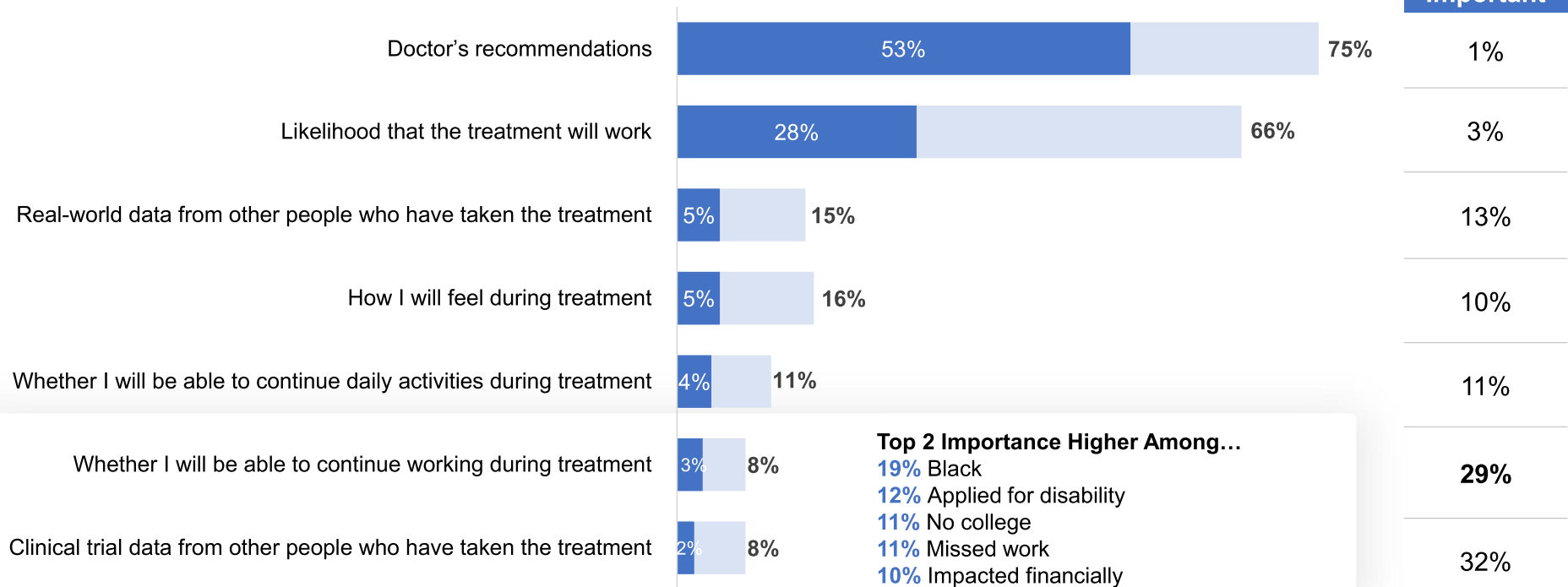
Employment Factoring into Treatment Decision

Few said concerns about continuing to work factored into their treatment decisions.

There are a few audiences who are more likely to rate it higher, but still in the single digits.

Importance When Making Decisions About Treatment

■ Most Important ■ Most/Second Most Important



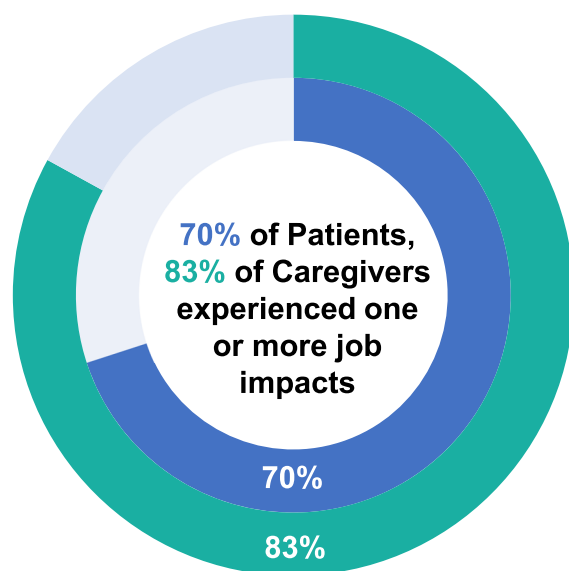
Source= National Patients (n=1303)

Cancer Impacts on Working

Most Patients and Caregivers who worked during treatment experienced at least one of the issues included in the survey. This is even higher among those Patients who delayed going to the doctor when they first started experiencing symptoms.

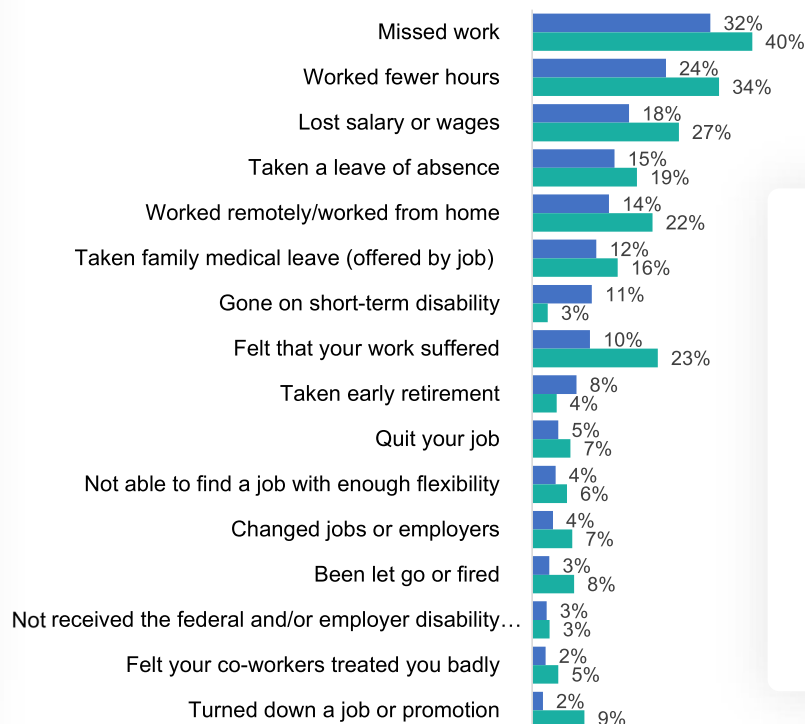
Caregivers are more likely to say their work was impacted.

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



Higher among Patients who Delayed Going to Doctor: **84%**

Impacts experienced **% experienced**
(among those who worked)



Those who delayed going to doctor more likely to report missing work, working fewer hours, taking leave of absence, among other issues

**Missed work/
worked fewer hours**
Hours missed in
typical week

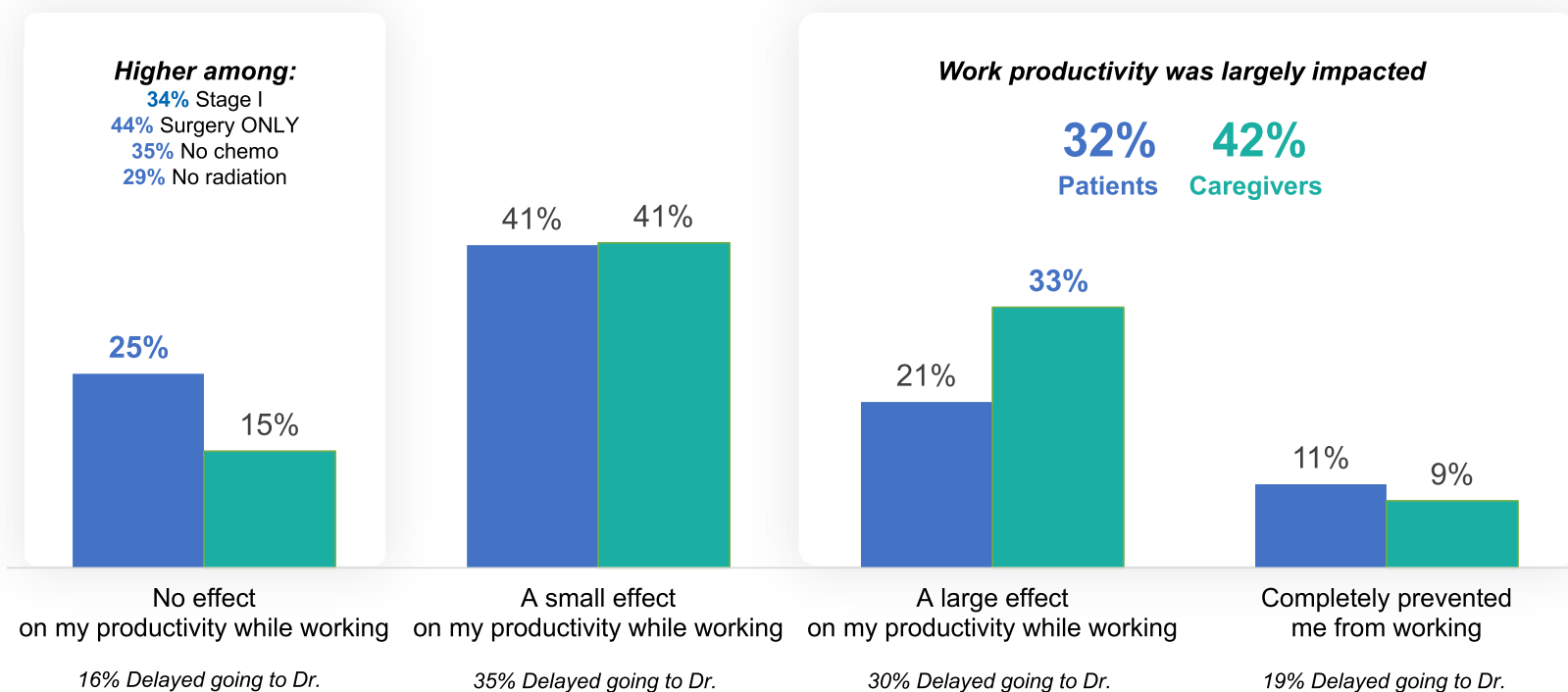
18 **15**
Patients Caregivers

Source= (Asked among those who worked during treatment) National Patients (n=610); National Caregivers (n=316)

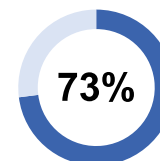
Impact on Work Productivity

Most Patients and Caregivers say their productivity was impacted, with Caregivers reporting greater impacts.

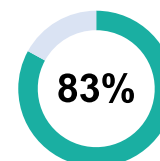
■ Panel Patient ■ Panel Caregiver



Work productivity was impacted overall



Patients



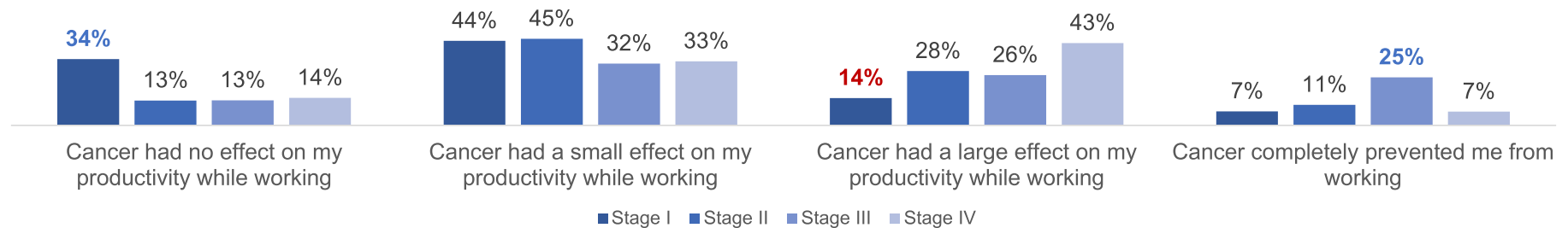
Caregivers

Source= (Asked among those who worked during treatment) National Patients (n=610); National Caregivers (n=316); Patients Who Delayed Going to Dr. and Worked During (n=57)

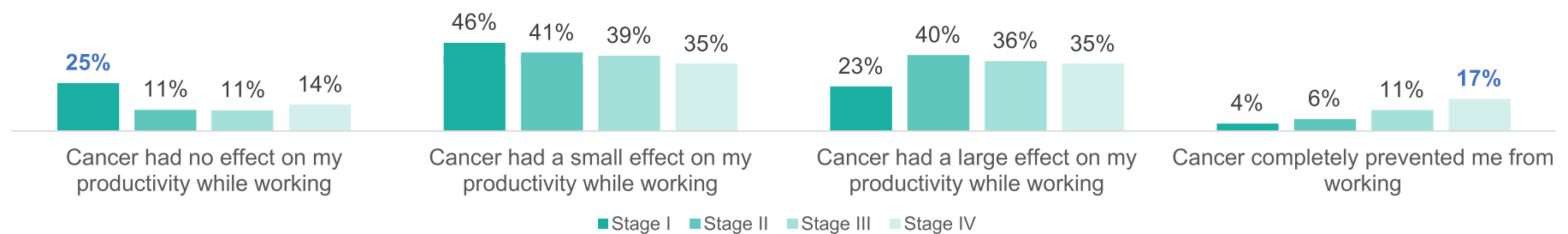
Impact on Work Productivity by Cancer Stage

Stage I Patients and Caregivers are more likely experience zero impact to their productivity. Stage III Patients and Stage IV Caregivers are significantly more likely to say cancer completely prevented them from working.

Patients



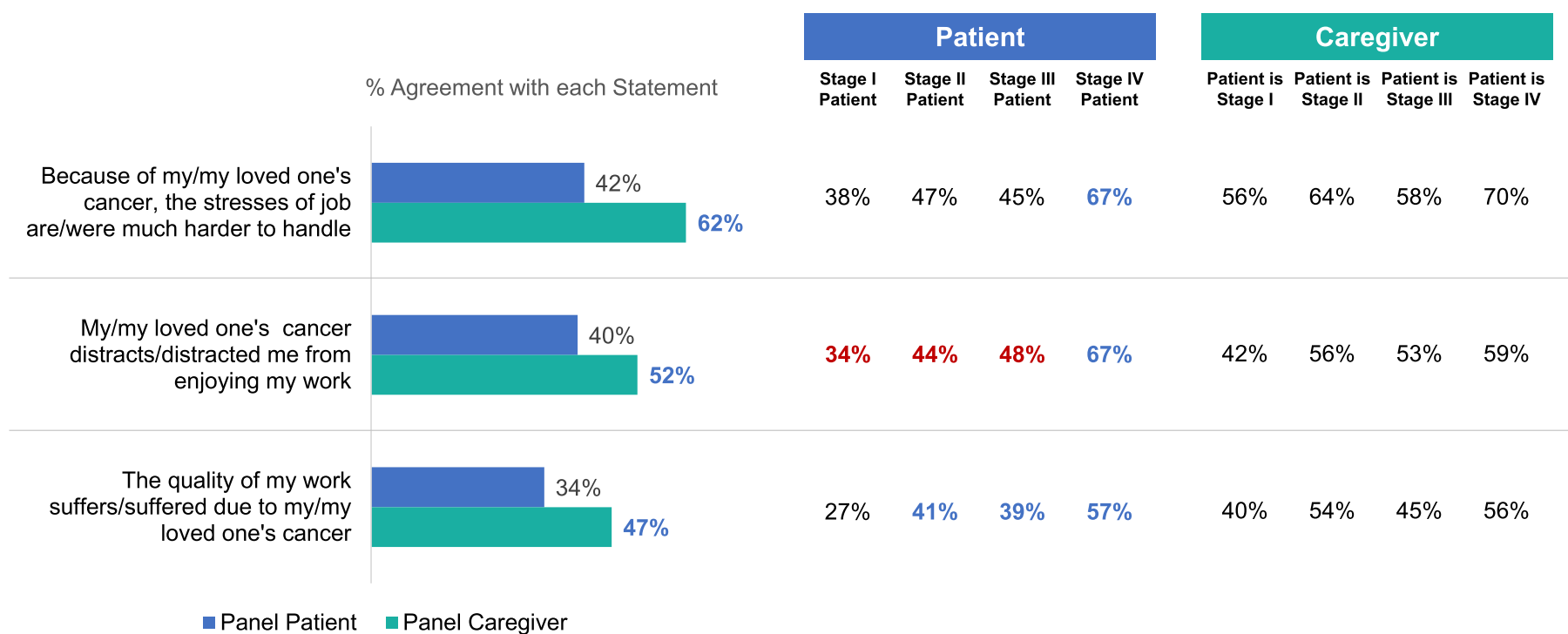
Caregivers



Source= (Asked among those who worked during treatment) National Patients (n=610); National Caregivers (n=316)

Negative Impacts on Work Experience

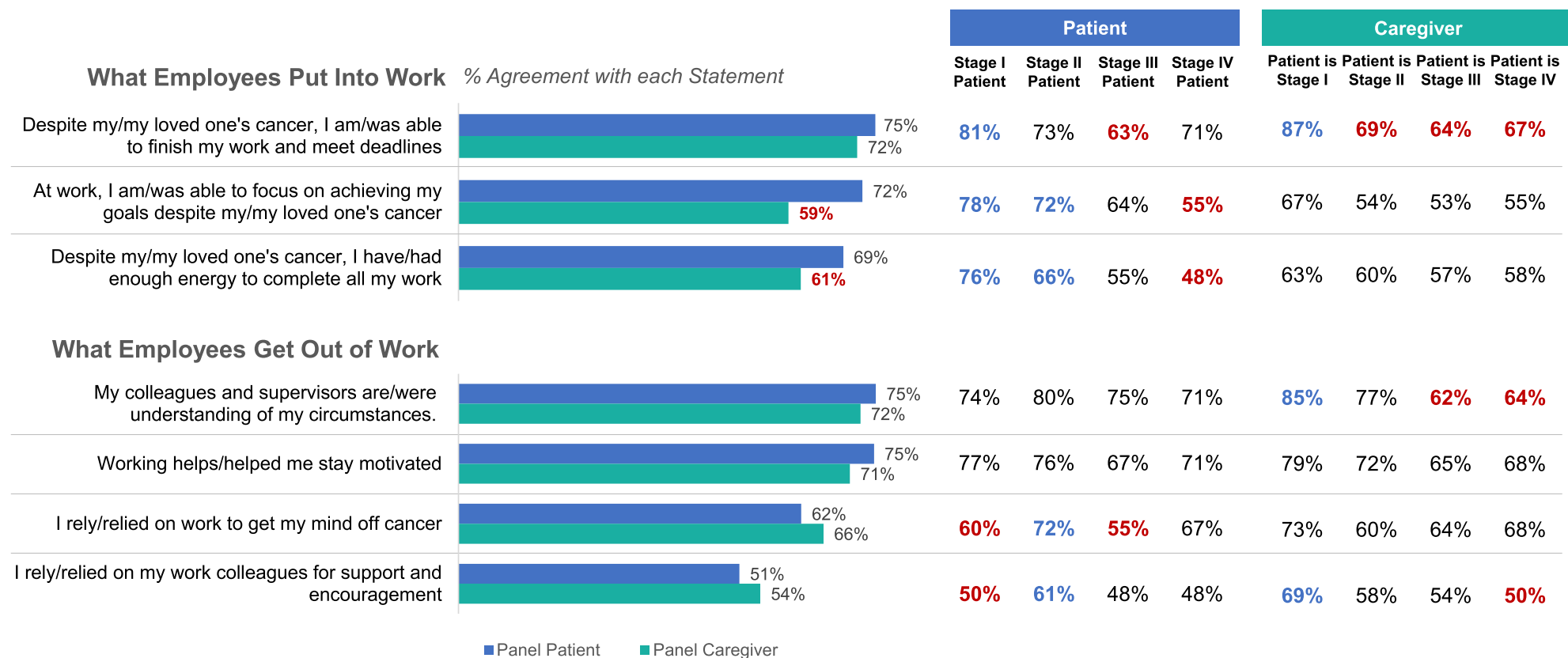
Majorities of Caregivers report being stressed and distracted at work. Just 4-in-10 Patients felt this way, although this is substantially higher among Stage IV Patients who continued to work during treatment.



Source= (Asked among those who worked during treatment) National Patients (n=610); National Caregivers (n=316)

Positive or Neutral Impacts on Work Experience

Majorities of Patients and Caregivers report colleagues being sympathetic, work helping them stay motivated, keeping their mind off cancer. Stage I Patients are more likely to say they had the energy to focus and finish their work.



Source= (Asked among those who worked during treatment) National Patients (n=610); National Caregivers (n=316)

Impact on Work: In Their Own Words

Patients on work as a support system

*"Going to work is helpful. Because **I talk to my co-workers, they're there to support me.** So that's the reason why I doubt myself to stop working. My coworkers would come and pick me up in the morning, take me to work, I have that support. My boss is so very flexible, very understanding."*

- Stage IV Cancer Patient

*"**I like going to work, having something to do, I'm driving myself nuts** (now that not working). I should go back to work, because it will make me feel better. But I don't want to hurt anyone, embarrass myself. I never wanted to show weakness. **Being in this state puts you in a vulnerable position.**"*

- Stage IV Cancer Patient



Caregivers on impact to their routine

*"I was absolutely overwhelmed, completely overwhelmed. There was no routine at all, you know, and ... you have to have a routine in your life. **I was used to going to work 40 hours a week. And then, when Mom's diagnosis happened, I got sleep when I could get sleep and ate when I could eat. Everything becomes about caring for your loved one. You really do diminish. You fade into the background because it was all about just keeping Mom alive.**"*

- Caring for Mother

*"**I have to work around his schedule,** taking care of him first. When he's at work, that's my time."*

- Caring for Uncle





Integrative Oncology

Integrative Oncology Experiences

6-in-10 Patients nationally used some form of integrative care -- spiritual practices, exercise, and mindfulness deemed the most effective. NCCS Connected Patients were even more likely to embrace this type of care.

	Integrative Oncology Used	Treatment Very Effective (among those who used)
Prayer, spiritual practices	<div><div></div></div> 29%	80%
Movement or exercise	<div><div></div></div> 28%	60%
Dietary supplements	<div><div></div></div> 26%	38%
Relaxation techniques, visual imagery	<div><div></div></div> 13%	56%
Mindfulness, meditation, mantra	<div><div></div></div> 13%	60%
Massage	<div><div></div></div> 12%	56%
Special diets	<div><div></div></div> 12%	48%
Yoga	<div><div></div></div> 7%	51%
Acupuncture	<div><div></div></div> 5%	37%
Chiropractic	<div><div></div></div> 5%	43%
None of the above	<div><div></div></div> 40%	

Less than 5%: Energy healing, Traditional/folk medicine, Naturopathy, Biofeedback, Hypnosis

6-in-10
did some form of
integrative care

Higher Among:

- Women
- Younger (18-39)
- Black
- Hispanic
- NCCS Connected

87%
of **NCCS Connected** did
some form of integrative
cancer care

Source= National Patients (n=1303); NCCS Connected Patients (n=507)

Integrative Care Motivators and Barriers

*General wellbeing and mental health are key drivers to integrative oncology.
The biggest barrier continues to be awareness.*



Reasons for Using Integrative Care Services/Therapies

General wellbeing	62%
Coping with emotional, mental impact of cancer	44%
Giving me a sense of control over my illness	37%
Providing hope	33%
Managing symptoms, side effects of treatment	31%
Managing symptoms, side effects of cancer	30%
Preventing cancer recurrence	25%
Suggested by people I trust	20%
Treating my cancer	18%



Reasons for NOT Using Integrative Care Services/Therapies

Was not aware these therapies existed	31%
Not covered by my health insurance	12%
Concerned @ lack of evidence on safety, efficacy	9%
Not supported by my healthcare team	7%
Too expensive	7%
Concerned about potential side effects	2%
Concerned @ interactions w. cancer treatment	2%
My healthcare team recommended against using	1%
Not sure	26%

Source= National Patients (n=1303); NCCS Connected Patients (n=507)

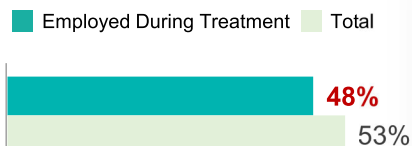
Appendix A: Survey Participant Profiles



Patient Profile: Employed During Treatment

Decision-Making

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



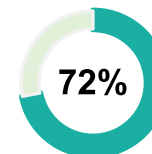
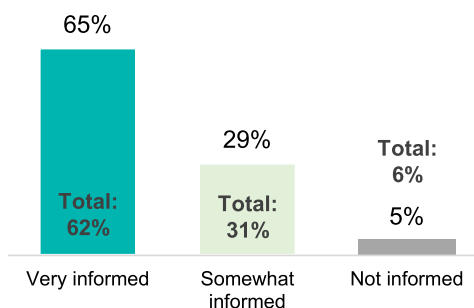
Somewhere in the middle



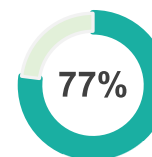
I am/was very involved in researching and deciding on the best treatment options for me.



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



say their health care providers coordinated very well with one another
Total: 70%



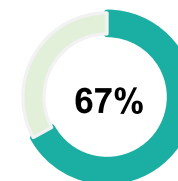
say they are very satisfied with their treatment and care
Total: 77%

Top 3 Financial Impacts	Employed During Treatment	Total
Spent savings/retirement money to cover living expenses	18%	17%
Borrowed money from family or friends	12%	13%
Applied for government financial assistance	11%	14%

Top 3 Employment Sacrifices	Employed During Treatment	Total
Missed work	32%	20%
Worked fewer hours	24%	14%
Lost salary or wages	18%	13%

Current State of Health

- Excellent: 10% Total: 8%
- Good: 52% Total: 49%
- Fair: 30% Total: 34%
- Poor: 7% Total: 9%



say their health care providers *always* listened to and respected their concerns
Total: 69%



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

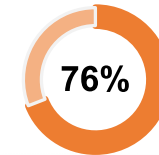


I am/was very involved in researching and deciding on the best treatment options for me.

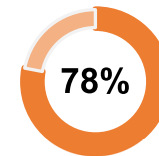


More on Mental Health

- More likely to see a Psychologist or Psychiatrist during treatment: **LGBTQ 17%, Total 9%**
- More likely to feel pressure to remain strong during treatment: **LGBTQ 40%, Total 25%**
- More likely to still be experiencing depression/anxiety after treatment: **LGBTQ 34%, Total 18%**
- More likely to discuss mental health post-treatment: **LGBTQ 36%, Total 21%**



say their health care providers coordinated very well with one another
Total: 70%



say they are very satisfied with their treatment and care
Total: 77%

Top 3 Financial Impacts

LGBTQ+

Total

Applied for government financial assistance

27%

14%

Delayed a major life event

22%

11%

Spent savings, retirement money to cover living expenses

17%

17%

Top 3 Employment Sacrifices

LGBTQ+

Total

Missed work

33%

20%

Worked fewer hours

24%

14%

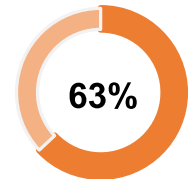
Lost salary or wages

17%

13%

Current State of Emotional Health

- Excellent: **14%** Total: 25%
- Good: 40% Total: 44%
- Fair: 29% Total: 23%
- Poor: **16%** Total: 8%



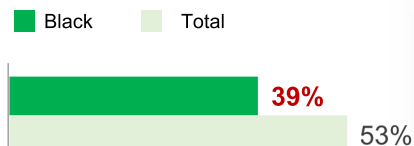
say their health care providers *always* listened to and respected their concerns
Total: 69%



Patient Profile: Black Patients

Decision-Making

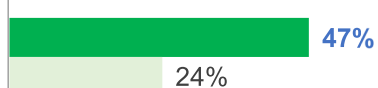
I rely/relied on the doctor to decide on treatment options and chose the best course of action.



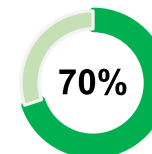
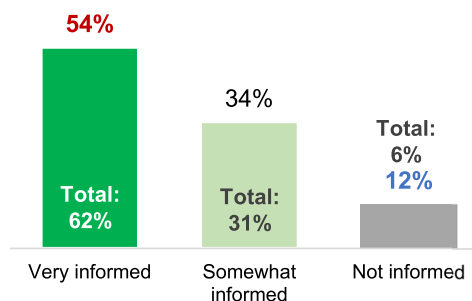
Somewhere in the middle



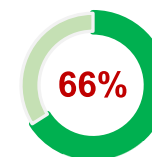
I am/was very involved in researching and deciding on the best treatment options for me.



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



say their health care providers coordinated very well with one another
Total: 70%



say they are very satisfied with their treatment and care
Total: 77%

Top 3 Financial Impacts

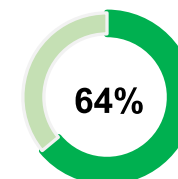
	Black	Total
Borrowed money from family or friends	31%	13%
Applied for government financial assistance	28%	14%
Delayed a major life event	25%	11%

Top 3 Employment Sacrifices

	Black	Total
Taken a leave of absence	22%	10%
Missed work	19%	20%
Worked fewer hours	15%	14%

Current State of Health

- Excellent: 8% Total: 8%
- Good: 33% Total: 49%
- Fair: 36% Total: 34%
- Poor: 22% Total: 9%



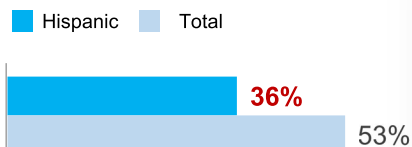
say their health care providers *always* listened to and respected their concerns
Total: 69%



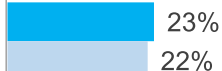
Patient Profile: Hispanic Patients

Decision-Making

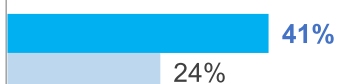
I rely/relied on the doctor to decide on treatment options and chose the best course of action.



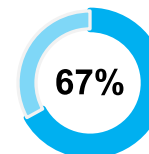
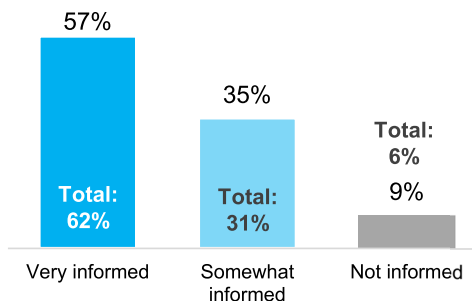
Somewhere in the middle



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 their health care providers coordinated very well with one another
Total: 70%



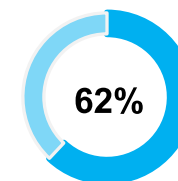
say they are very satisfied with their treatment and care
Total: 77%

Top 3 Financial Impacts	Hispanic	Total
Spent savings/retirement money to cover your personal living expenses	29%	17%
Borrowed money from family or friends	27%	13%
Delayed a major life event	27%	11%

Top 3 Employment Sacrifices	Hispanic	Total
Missed work	25%	20%
Lost salary or wages	20%	13%
Taken a leave of absence	18%	10%

Current State of Health

- Excellent: 7% Total: 8%
- Good: 36% Total: 49%
- Fair: 35% Total: 34%
- Poor: 22% Total: 9%

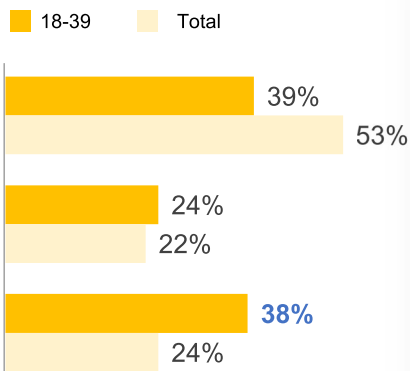


say their health care providers *always* listened to and respected their concerns
Total: 69%

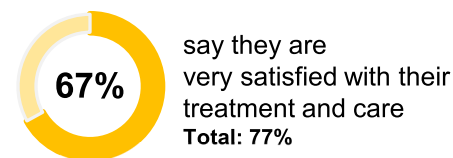
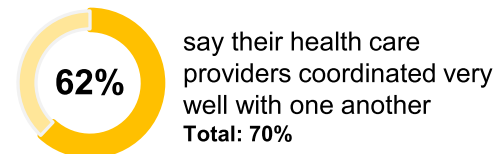
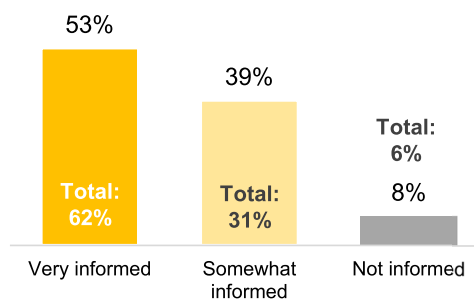


Patient Profile: Younger Cohort (Age 18-39)

Decision-Making



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



Top 3 Financial Impacts

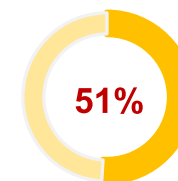
	18-39	Total
Applied for government financial assistance	32%	14%
Borrowed money from family or friends	31%	13%
Delayed a major life event	28%	11%

Top 3 Employment Sacrifices

	18-39	Total
Missed work	44%	20%
Worked fewer hours	36%	14%
Taken a leave of absence	26%	10%

Current State of Health

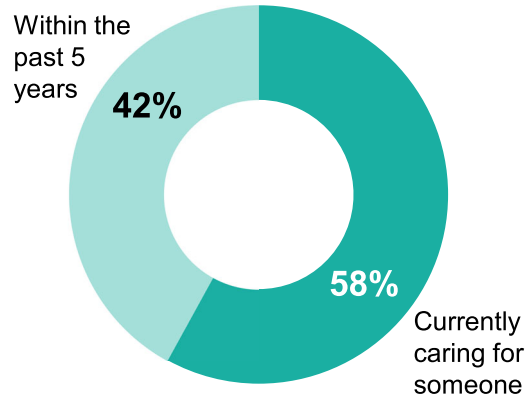
- Excellent: 6% Total: 8%
- Good: 38% Total: 49%
- Fair: 41% Total: 34%
- Poor: 12% Total: 9%



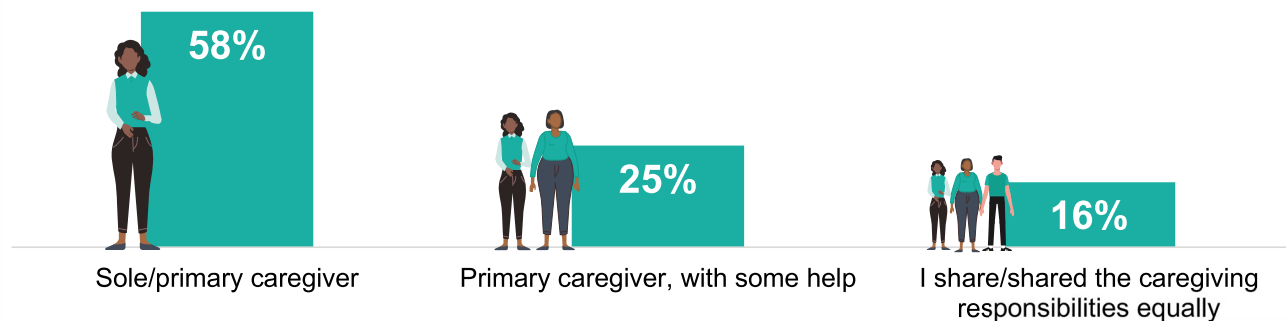
say their health care providers *always* listened to and respected their concerns
Total: 69%



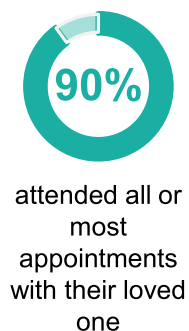
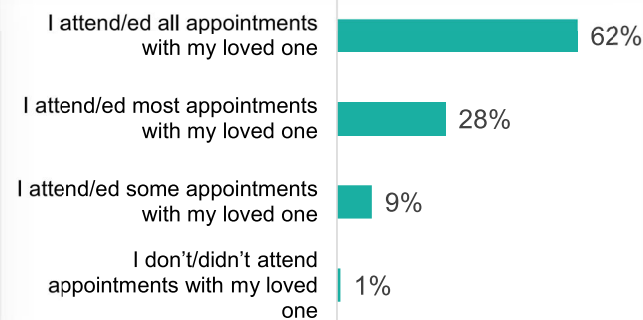
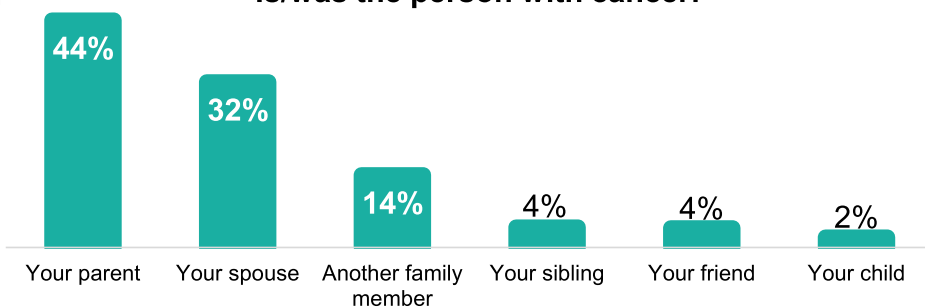
Caregiver Profile/Experiences



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



Is/was the person with cancer:

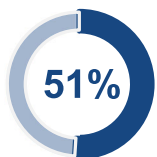


Source=National Caregivers (n=506)



Patient Profile: Delayed Going to the Doctor

Gender:



Male



Female

Education:

28% HS Degree or less
40% Some college
18% Bachelor's degree
14% Post-grad degree

Stage at Diagnosis:

19% Stage I

24% Stage II

24% Stage III

13% Stage IV

Age:

Age Group	Percentage
18-34	9%
35-49	20%
50-64	34%
65-74	19%
75+	18%

Race/Ethnicity:

75% White
19% Black/African American
13% Hispanic

Patients who said the following statement describe them “perfectly”:
“I delayed going to the doctor for as long as possible before getting a cancer diagnosis”

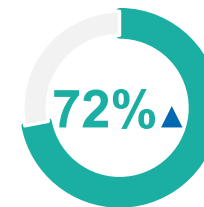
Experiential Patient Segments

In 2022, we did a deep dive to try to better understand how different audiences experience the cancer journey. The percentage of Patients that had a positive experience increased by 4 points.

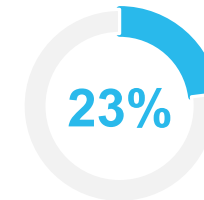
Methodology:

Segmentation is an analytical tool used to sort people into exclusive groups, or clusters with similar attitudes and experiences. For this analysis, we looked at satisfaction across the different stages of the cancer journey:

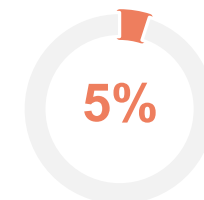
- Screening and risk assessment
- Cancer diagnosis
- Treatment decision making and selection
- Treatment and care
- Coordination of care
- Post-treatment care



Positive Experience
+ 4 pts. from 2022



Mixed Experience
- 2 pts. from 2022



Negative Experience
- 1 pt. from 2022

Audience Demographics

Demographics for Positive and Negative Experiences are consistent with last year, while Mixed Experience saw a few significant changes.

	Positive Experience		Mixed Experience		Negative Experience	
Gender	50% female	50% male	53% female	47% male	59% female	41% male
Race/Ethnicity	84% White 8% Black 6% Hispanic		74% White 14% Black 9% ▼ Hispanic		74% White 15% Black 18% Hispanic	
Age	43% under 65 7% 18-44 36% 45-64	56% 65+	58% under 65 18% 18-44 40% ▼ 45-64	42% ▲ 65+	49% under 65 18% 18-44 31% 45-64	50% 65+
Education	53% no college	47% college	57% ▲ no college	43% ▼ college	57% no college	43% college
Income	35% below \$50K		42% ▼ below \$50K		44% below \$50K	
Financial Impact	36% Impacted financially		59% impacted financially		74% impacted financially	
Employment Sacrifices	46% made sacrifices		63% made sacrifices		65% made sacrifices	
Treatment Status	82% ▲ completed	18% ▼ still in	68% completed	32% still in	60% completed	40% still in
Stage at Diagnosis	37% Stage I 20% Stage II	14% Stage III 7% Stage IV	31% ▲ Stage I 23% Stage II	14% Stage III 10% ▼ Stage IV	15% Stage I 18% Stage II	25% Stage III 13% Stage IV
Current Health Status	9% Excellent 53% Good	31% Fair 6% Poor	5% Excellent 42% Good	39% Fair 14% Poor	0% ▼ Excellent 24% Good	50% Fair 26% Poor

As seen across studies, groups who have a less positive experience:

- More female
- POC
- Younger

As well as:

- Time/memory – those in treatment more negative
- Stage of diagnosis
- Current health

Source= National Patients (n=1303)

Appendix B: Additional Questions Not Included in Main Report

Treatment Decision-making Priorities

Doctor's recommendations are more important, while clinical trial data and whether they can continue working are less important.



Doctor's recommendations



Likelihood that the treatment will work



How I/your loved one will feel during treatment



Real-world data from people who have taken the treatment



Whether I/your loved one will be able to continue daily activities



Whether I/your loved one will be able to continue working



Clinical trial data from people who have taken the treatment

	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver	Patient	Caregiver
1 – Most important	53%	34%	28%	31%	5%	18%	5%	5%	4%	7%	3%	3%	2%	2%
2	22%	20%	38%	28%	11%	23%	10%	8%	7%	9%	5%	4%	7%	6%
3	10%	16%	15%	13%	23%	24%	19%	15%	14%	14%	8%	7%	12%	11%
4	7%	11%	8%	10%	20%	16%	17%	16%	22%	27%	14%	9%	13%	11%
5	4%	8%	5%	7%	18%	9%	16%	25%	22%	20%	19%	13%	15%	19%
6	3%	6%	3%	7%	12%	5%	20%	18%	20%	14%	22%	20%	20%	29%
7 – Least important	1%	4%	3%	4%	10%	5%	13%	13%	11%	9%	29%	44%	32%	22%
Average rating	2.01	2.71	2.46	2.71	4.13	3.09	4.41	4.53	4.57	4.21	5.23	5.60	5.19	5.13

Source= National Patients (n=1303); National Caregivers (n=506)

Job Impacts (among total sample)

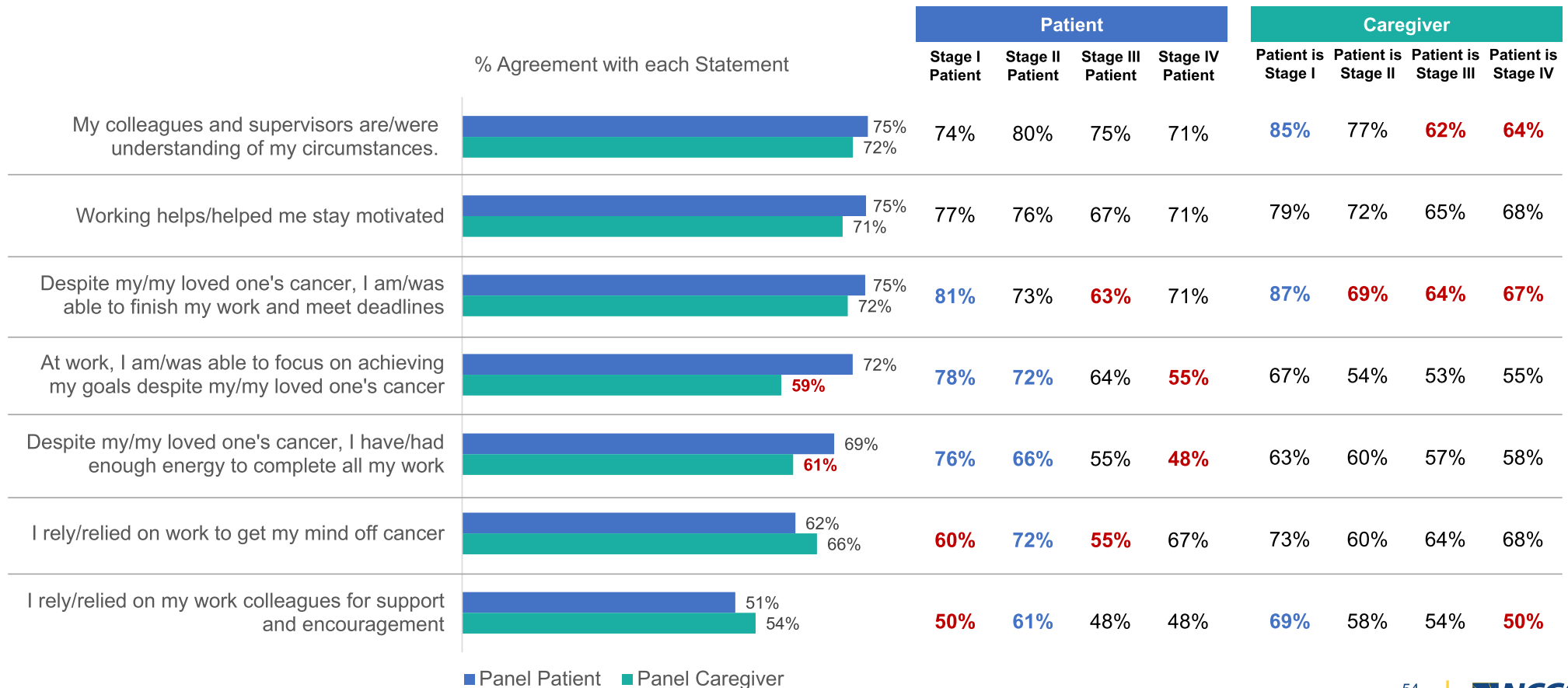
Stage I Patients and their Caregivers are less likely to have experienced job impacts.

	Patient	Caregiver	Patient				Caregiver			
	Panel Patients	Panel Caregivers	Stage I Patient	Stage II Patient	Stage III Patient	Stage IV Patient	Patient is Stage I	Patient is Stage II	Patient is Stage III	Patient is Stage IV
Mean experienced	2.6	2.8	2.22	2.65	2.47	3.03	2.39	2.99	2.82	2.97
Left job	16%	21%	13%	21%	21%	25%	12%	27%	20%	28%
Missed work/fewer hours	26%	37%	24%	31%	25%	34%	29%	49%	44%	30%
Average number of hours missed in typical week	19.56	15.14	17.17	17.19	23.13	21.84	<i>N size too small</i>			
Missed work	20%	27%	19%	22%	19%	24%	24%	39%	28%	24%
Worked fewer hours	14%	23%	11%	20%	15%	19%	21%	30%	28%	18%
Lost salary or wages	13%	22%	11%	14%	14%	19%	19%	32%	25%	15%
Taken a leave of absence	10%	14%	8%	13%	12%	14%	6%	18%	12%	17%
Gone on short-term disability	9%	2%	5%	11%	13%	13%	4%	1%	3%	3%
Taken early retirement	8%	5%	5%	11%	13%	18%	6%	3%	4%	8%
Felt that your work suffered	8%	16%	6%	11%	8%	12%	17%	19%	17%	17%
Taken family medical leave (offered by job)	8%	11%	6%	11%	10%	9%	4%	12%	16%	9%
Worked remotely/worked from home	8%	15%	5%	13%	7%	13%	14%	24%	15%	14%
Quit your job	6%	7%	4%	6%	9%	11%	3%	7%	9%	10%
Not been able to find a job with enough flexibility to accommodate your health needs / Not been able to find a job with enough flexibility to accommodate your loved one's health needs	5%	8%	3%	4%	7%	10%	9%	8%	10%	8%
Been let go or fired	4%	6%	2%	3%	5%	8%	1%	10%	8%	7%
Felt your supervisor treated you badly	4%	5%	2%	4%	4%	6%	3%	4%	6%	9%
Not received the federal and/or employer disability insurance you needed / Not received the federal and/or employer disability insurance your loved one needed	3%	3%	2%	4%	4%	10%	4%	3%	4%	4%
Changed jobs or employers	3%	5%	2%	4%	4%	3%	5%	10%	4%	4%
Missed school or delayed your education / Missed school or delayed your education	3%	5%	2%	5%	3%	4%	5%	7%	3%	6%
Felt your co-workers treated you badly	2%	4%	2%	3%	2%	6%	1%	4%	5%	4%
Turned down a job or promotion	2%	8%	3%	2%	1%	6%	4%	11%	13%	5%
None of these	49%	33%	57%	40%	40%	32%	37%	19%	25%	39%

Source= National Patients (n=1303); National Caregivers (n=506)

Positive or Neutral Impacts on Work Experience

Majorities of Patients and Caregivers report colleagues being sympathetic, work helping them stay motivated, keeping their mind off cancer. Stage I Patients are more likely to say they had the energy to focus and finish their work.



Source=(Asked among those who worked during treatment) National Patients (n=610); National Caregivers (n=316);

Cancer Care Plan

Patients currently in treatment are more likely to say their health care team provided a care plan, while those who completed are more unsure.

Did the health care team provide a care plan that helps/helped you understand what to expect?

	Total	Stage I	Stage II	Stage III	Stage IV	Completed Treatment	In Treatment
Yes	80%	83%	82%	75%	80%	78%	85%
No	13%	11%	9%	20%	15%	13%	12%
Not sure	8%	6%	9%	5%	5%	9%	3%

Source= National Patients (n=1303)

Healthcare Providers Visited and Helpfulness

	Patient Seeing	Patient Very Helpful	Caregiver Very Helpful
Oncologist	71%	86%	82%
Surgeon	60%	88%	76%
Primary care physician	54%	66%	61%
Radiation oncologist	48%	83%	74%
Nurse/Nurse practitioner	34%	81%	78%
Pharmacist	19%	54%	60%
Nutritionist/dietician	13%	49%	46%
Care coordinator	11%	64%	63%
Patient navigator	11%	71%	69%
Cardiologist	10%	62%	63%
Hematologist	10%	78%	74%
Pain specialist	10%	68%	62%
Social worker	9%	55%	46%
Physical therapist	9%	68%	56%
Psychologist or Psychiatrist	9%	63%	60%
Home health aide	5%	62%	62%
Rehabilitation specialist	5%	48%	67%
Palliative care	4%	60%	63%
Occupational therapist	4%	59%	51%
Speech therapist	2%		
Audiologist	2%		
Fertility specialist	1%		

N sizes too small

Source= National Patients (n=1303); National Caregivers (n=506)

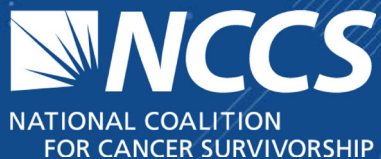
Post-Treatment Experiences

Those that continue to see their Oncologist during post-treatment care are more likely to discuss follow-tests, quality of life, support groups, and a care plan than those who see their primary care providers.

Which topics do your HCPs discuss with you regularly during your post-treatment care?

		PCP	Oncologist
Follow-up tests to monitor cancer	68% ▲	54%	76%
Exercise and nutrition	33%	37%	36%
Quality of life	27% ▼	25%	30%
The mental and emotional impact of cancer	21% ▼	24%	23%
Physical function	20% ▼	21%	20%
How much fatigue is interfering on daily life	17%	18%	22%
How much pain is interfering with daily life	13%	15%	13%
Access to support groups	12%	9%	16%
A post-treatment survivorship care plan	9% ▼	5%	13%
Cognitive function	6% ▼	7%	8%
Financial services/support	5%	5%	6%
Health insurance options	5%	7%	4%
Fertility concerns	3%	3%	2%
Palliative care/support services	1%	1%	1%
Hospice Care	0%	0%	0%
End-of-life support	0%	0%	1%
None of the above	12%	17%	8%

Source= National Patients (n=1303)



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