NCCS
NATIONAL COALITION
FOR CANCER SURVIVORSHIP

STATE OF SURVIVORSHIP

2023 Study

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

www.canceradvocacy.org/survey

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

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.

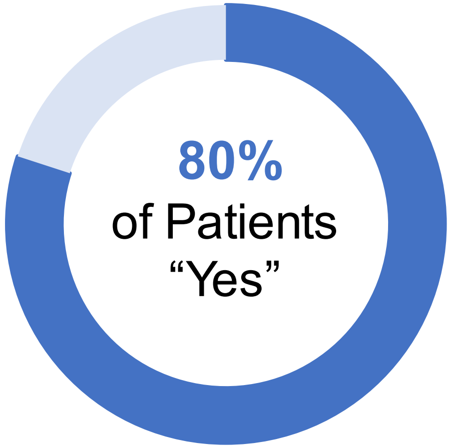
		Patient National Sample					
		2020	**2021**	**2022**	**2023**	**Caregiver 2023**	**NCCS Connected Patients**
	I rely/relied on the doctor to decide on treatment options and chose the best course of action.	61%	44%	47%	**53%▲**	**42%**	**31%**
	Somewhere in the middle	18%	22%	26%	**22%▼**	**19%**	29%
	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)

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.

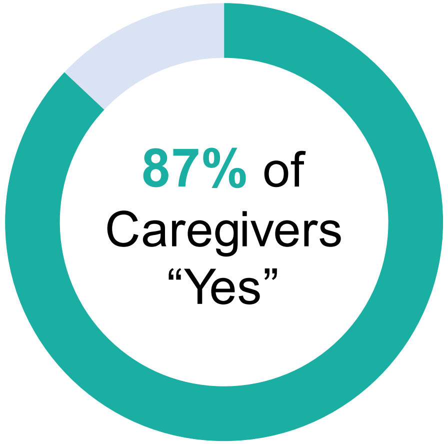
Did the health care team provide a care plan that helps/helped you understand what to expect?



80%
of Patients
“Yes”

Higher among:

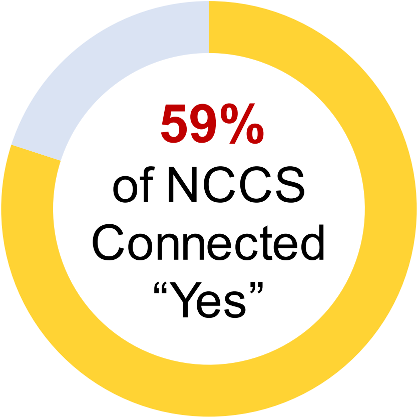
85% Still in treatment
86% Biomarker testing
85% Private insurance



87% of
Caregivers
“Yes”

Higher among:

95% Genetic counseling



59%
of NCCS
Connected
“Yes”

Higher among:

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

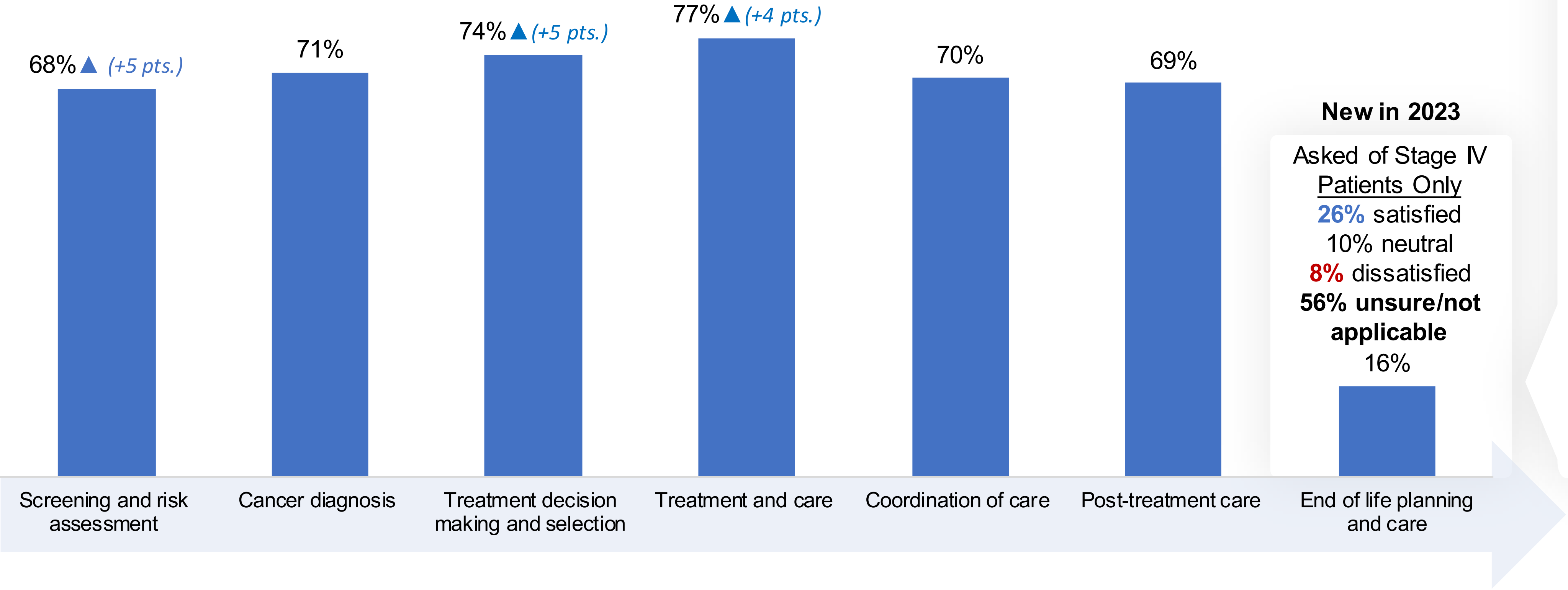
Source= National Patients (n=1303); National Caregivers (n=506); NCCS Connected Sample (n=536)

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.

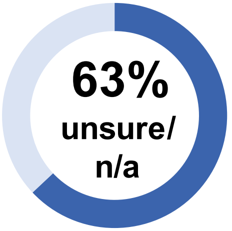
How satisfied are/were you with your/their care during each phase?

% Very satisfied (Patients)



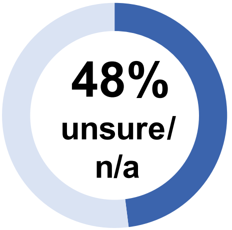
New in 2023

Asked of Stage IV Patients Only
26% satisfied
10% neutral
8% dissatisfied
56% unsure/not applicable



63% unsure/ n/a

among those who completed treatment



48% unsure/ n/a

among those still in treatment

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

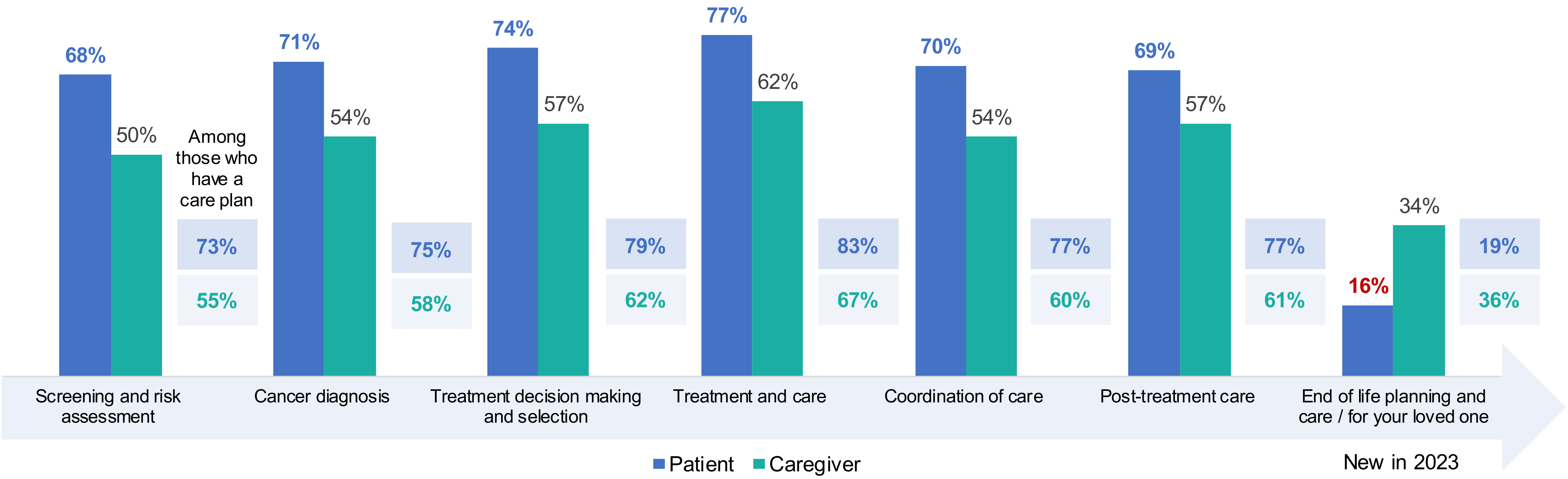
Satisfaction With Care: Patients vs. Caregivers

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?

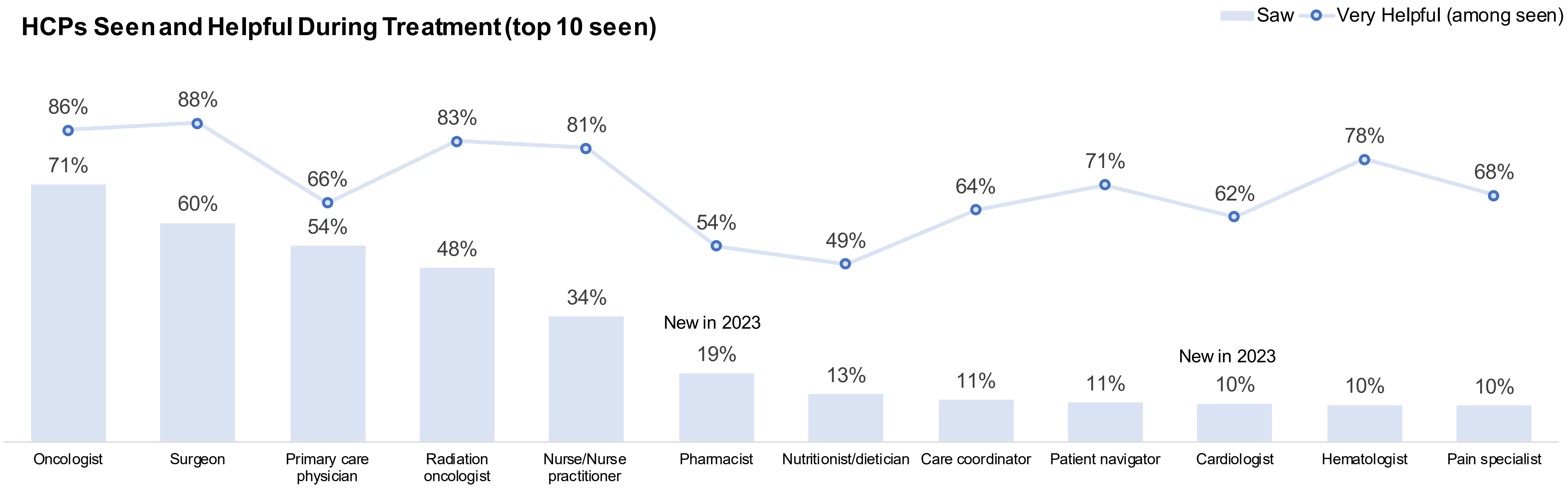
% Very satisfied



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)

	Oncologist	Surgeon	Primary care physician	Radiation oncologist	Nurse/Nurse practitioner	Pharmacist	Nutritionist/dietician	Care coordinator	Patient navigator	Cardiologist	Hematologist	Pain specialist
Caregiver Very Helpful:	82%	76%	61%	74%	78%	60%	46%	63%	69%	63%	74%	62%

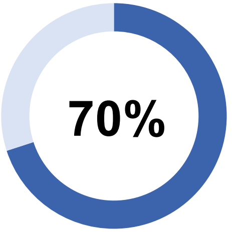
Source= National Patients (n=1303); National Caregivers (n=506)

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

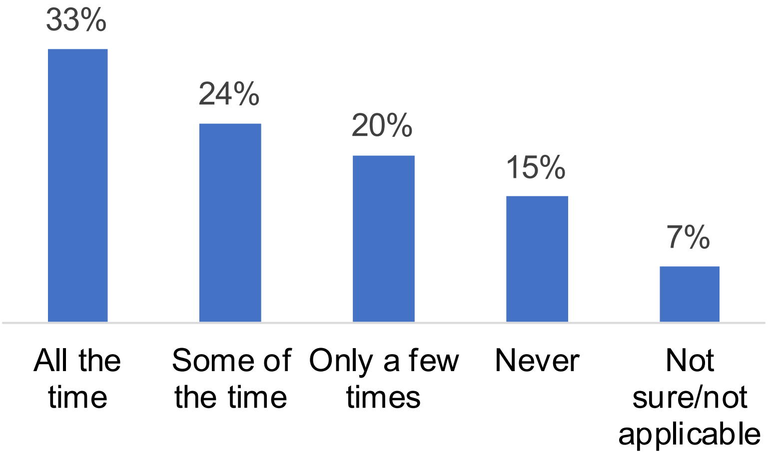
Consistent with previous years, most Patients report positive experiences with their health care team.



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

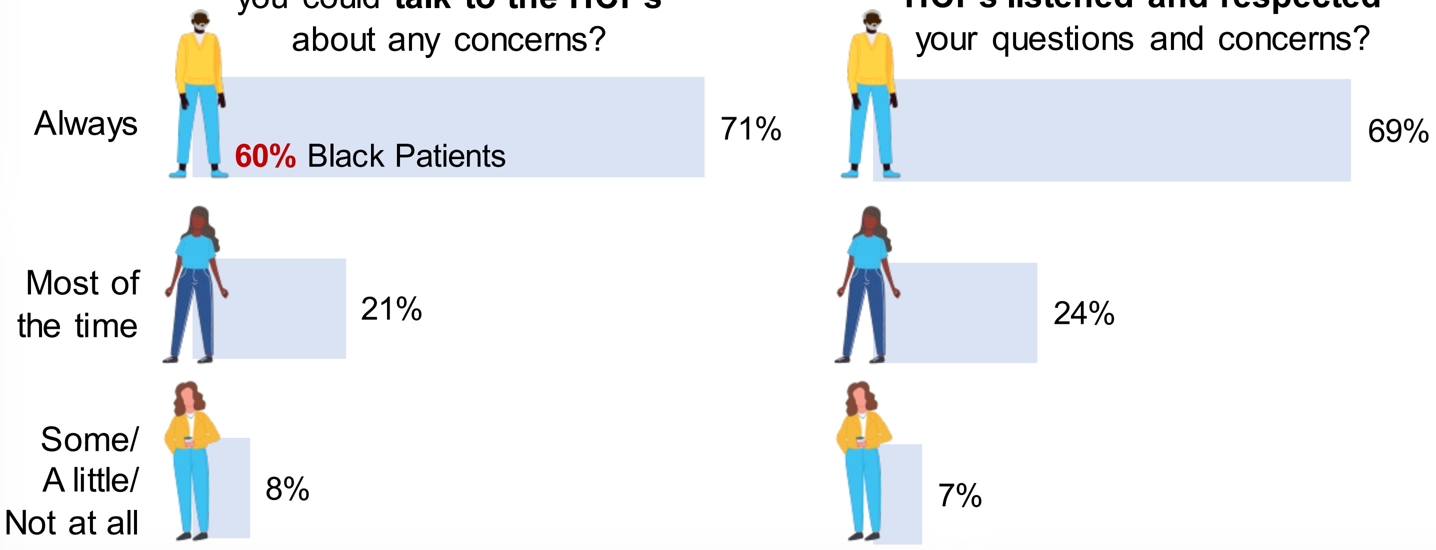
92% said “Very/somewhat well”

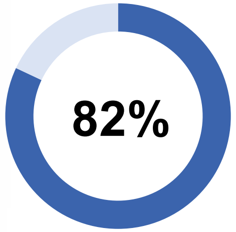
How often do/did you have to share information from one HCP with another?



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

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





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

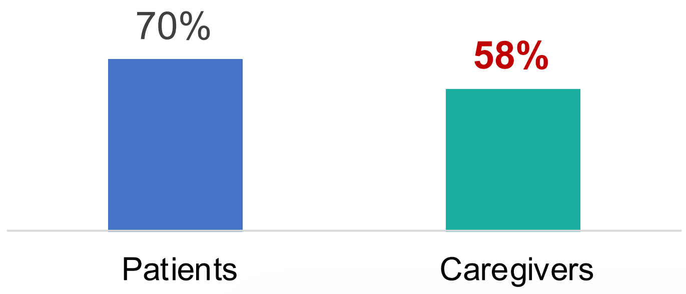
98% said “completely/somewhat trust”

Completely trust:
83% White Patients
74% Black Patients
73% Hispanic Patients

Caregivers Significantly More Critical of Healthcare Team

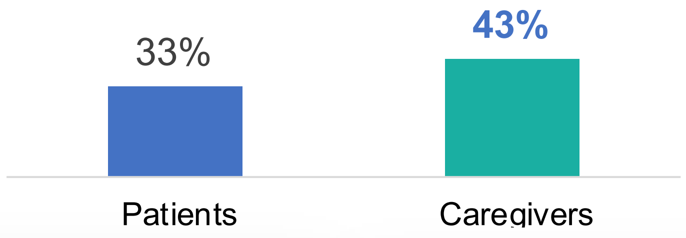
How well do/did the health care providers coordinate care with one another?

% Very well



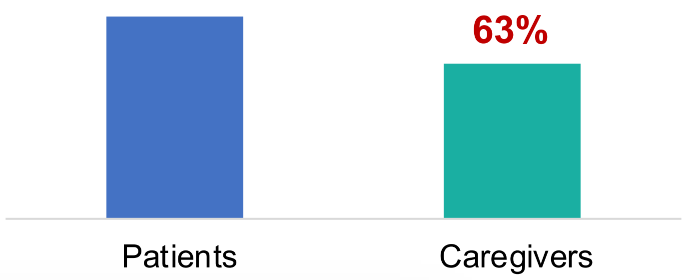
How often do/did you have to share information from one HCP with another?

% All the time



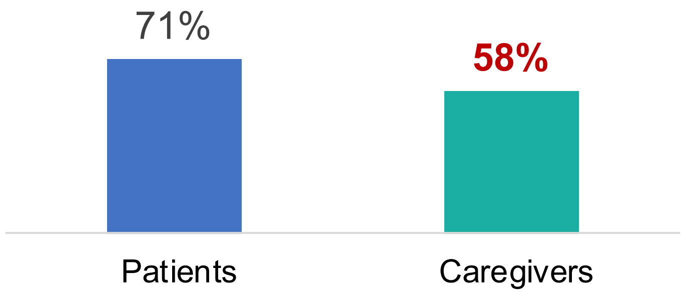
Overall, how much do/did you trust the health care team to act in your/loved one's best interests?

% Completely



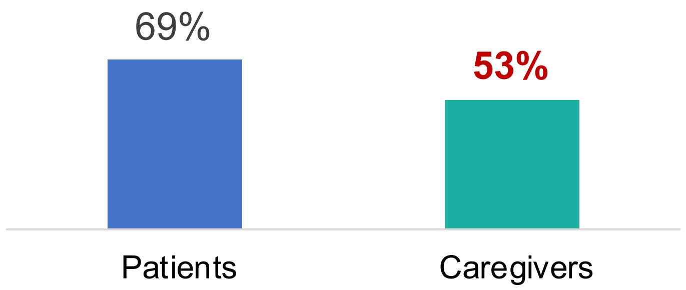
How often did you/your loved one feel like you could talk to the HCPs about any concerns?

% Always



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

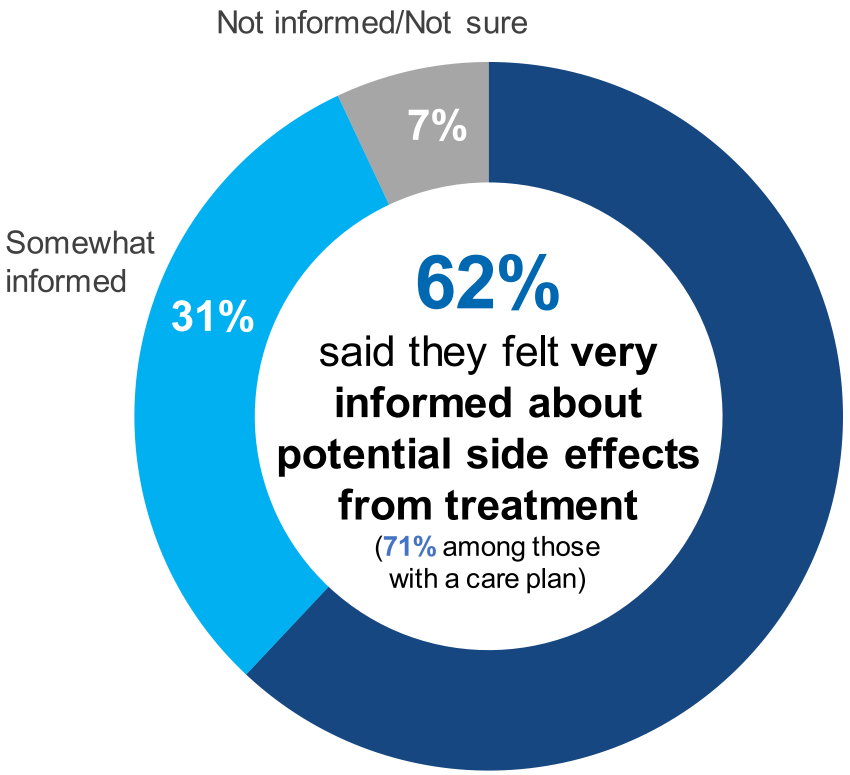
% Always



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

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.



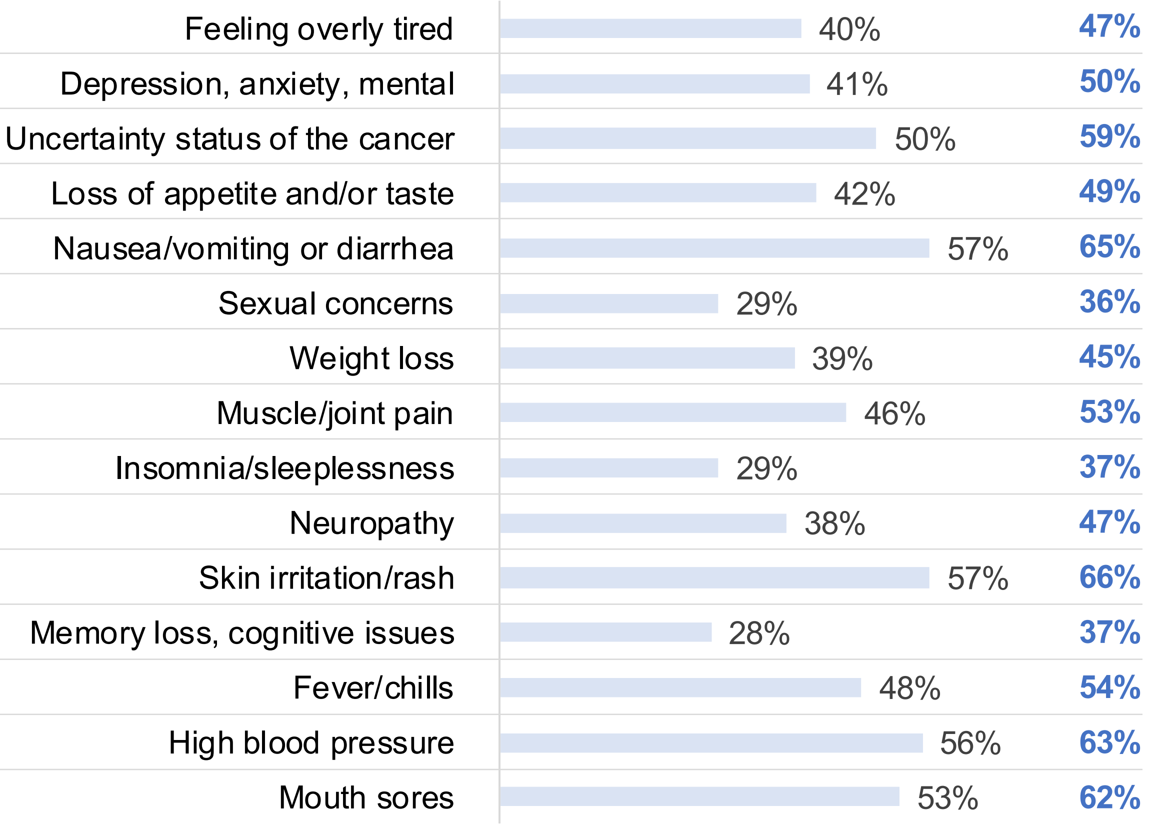
62%

said they felt **very informed about potential side effects from treatment**

(71% among those with a care plan)

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)

National Patients

NCCS Connected Patients

National Patients	NCCS Connected Patients
Gender	
49% Male 51% Female	22% Male **78%** Female
Age	
7% Age 18-39 40% Age 40-64 **53%** Age 65+	**18%** Age 18-39 **50%** Age 40-64 31% Age 65+
Education	
17% Less than college **37%** Some college/2-year degree 23% Bachelor's degree 23% Postgraduate degree	8% Less than college 28% Some college/2-year degree 23% Bachelor's degree **40%** Postgraduate degree
Income	
15% Less than $25k **21%** $25k-$50k **21%** $50k-$75k 16% $75k-$100k 24% More than $100k	10% Less than $25k 13% $25k-$50k 14% $50k-$75k 14% $75k-$100k **33%** More than $100k
Insurance	
57% Medicare **15%** Medicaid 20% Private/employer 7% Private/spouse or parents	36% Medicare 7% Medicaid **36%** Private/employer **16%** Private/spouse or parents
Race/Ethnicity	
81% White 10% AA/Black 7% Hispanic 4% Other	73% White 11% AA/Black **12%** Hispanic **8%** Other
Treatment	
22% Biomarker testing, 24% Genetic counseling	**40%** Biomarker testing, **55%** Genetic testing
Region	
19% Northeast **22%** Midwest 40% South 19% West	19% Northeast 16% Midwest 35% South **30%** West
LGBTQ+	
5% Yes	**10%** Yes