



Cancer Survivorship Study

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

August 2020





Research Objectives and Questions

Better understand the cancer patient and survivor journey from a range of perspectives

- Building on 2018-2019 NCCS survey findings, get feedback from those who are connected to NCCS, as well as a more representative sample of the US adult cancer population, including traditionally underserved audiences
- Better understand the patient experience, including new questions around mindset, the multi-disciplinary team, clinical trials, and help with side effects
- Learn more about preparation, experiences, and needs in post-treatment information and care, and interest in various survivorship resources
- Drill down on experiences with “redefining functional status”

Methodology

Phase 1

In-depth Interviews with Cancer Patients and Survivors

- Fifteen (15) virtual interviews, approximately 60 minutes-each, March 2020
- Diagnosed within the last 2 years; mix of stages and cancer types
- Nationwide recruit: mix of age (half over 65+), race/ethnicity, income (half low income, half middle-upper)

Phase 2

Nationwide Survey of Adult Cancer Patients and Survivors

- Nationwide sample of n=840, fielded April 15-May 1, 2020
- Oversamples of Blacks, Hispanics, low income, 65+ to analyze these groups with more statistical reliability
- Set quotas to make sure representative of US cancer population: age, gender, race/ethnicity, and region (re: ACS and NCI)
- Used Dynata, a non-probability online panel provider

Phase 3

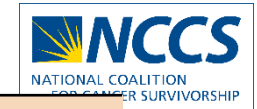
Nationwide Survey of “NCCS Connected” Patients and Survivors

- Nationwide sample of n=479, same field period as above
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders

Blue/red = statistically **higher/lower** by audience
Full text of survey questions is in the notes section of slides

National Sample

NCCS Connected



Gender

49% Male 51% Female	16% Male 84% Female
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Age

9% Age 18-44 38% Age 45-64 52% Age 65+	13% Age 18-44 53% Age 45-64 31% Age 65+
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Education

19% Less than college 32% Some college/2-year degree 26% Bachelor's degree 22% Postgraduate degree	3% Less than college 24% Some college/2-year degree 26% Bachelor's degree 48% Postgraduate degree
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Income

17% Less than \$25k 26% \$25k-\$50k 20% \$50k-\$75k 14% \$75k-\$100k 20% More than \$100k	10% Less than \$25k 14% \$25k-\$50k 14% \$50k-\$75k 15% \$75k-\$100k 35% More than \$100k
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Insurance

56% Medicare 13% Medicaid 24% Private/employer 6% Private/spouse or parents	38% Medicare 5% Medicaid 43% Private/employer 13% Private/spouse or parents
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State of Physical

7% Excellent 50% Good 37% Fair 6% Poor	10% Excellent 59% Good 25% Fair 5% Poor
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Treatment

43% had Chemotherapy	75% had Chemotherapy
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Overview of Findings



Mindset

“Doctor Knows Best” about treatment is the prevailing mindset of cancer patients nationally, and majorities say they are satisfied with their care. But if you go a layer deeper, there are cracks in this foundation. And those who report being *more* involved in treatment decisions tend to have more positive post-treatment experiences.



Expectations

Patients who are “connected” to an advocacy group like NCCS are clearly a different audience. They have higher expectations of care and their HCP’s, and more interested in a range of resources to help them with decision-making and self-advocacy.



Side Effects

Fatigue and mental health issues continue to be the most common side-effects. Few feel their HCP’s are very helpful in addressing these during treatment, nor do most doctors bring-up these key aspects of functional status during post-treatment care.



Concerns

Survivors are most concerned about a range of physical health and financial issues. These continue to be areas where they do not get a lot of support from their health care team. There is interest in a website where info can be customized by cancer type.



Demographic Differences

Across the survey, there are a few key audiences whose post-treatment concerns are greater: younger, Blacks, Hispanics, women, and chemotherapy patients.

Audience Mindset



Nationally, Most Cancer Patients Say They Rely on Doctors to Make Treatment Decisions

- By almost a 3-to-1 margin, cancer patients/survivors nationally say that they relied on their doctor to tell them what treatment option was best, vs. being involved in the research and decision.



Please think about your mindset and experiences as a cancer patient. For each set of statements, select the statement that describes you best, or if you are somewhere in the middle.



A “Doctor Knows Best” Mentality Is Typically the Default

Doctor Knows Best Mentality



I trust my oncologist completely, and I go by what he says. He's never tried to pacify me. Told me what I needed to do. - Female, 49, Stomach

I contemplated a second opinion, but I felt comfortable with my oncology team right away. Confident with them. - Female, 29, Breast

I haven't questioned him thus far. - Male, 69, Prostate

Self Advocates

Be your own advocate. Since I have a family history, I was clued in. Don't just blindly take prescriptions or go into a surgery. Ask questions, be informed. Do what's best for you. You know your body the best. - Female, 50, Skin

I've learned that I have to advocate for myself. They know I want them to coordinate, especially when it comes to my depression and weight. I ask questions. I don't just settle for just one opinion anymore. - Female, 47, Thyroid

Mindset Varies Slightly by Audience

Groups More Likely to Rely on Doctor:

- Metastatic: **71%**
- Surgery only: **69%**
- 65+ years: **66%**
- Males: **65%**
- Low income: **63%**
- White: **63%**
- Gov insurance: **63%**

Groups More Likely to Be Involved in DM:

- 18-39: **40%**
- Prostate: **35%**
- Targeted drug: **32%**
- Clinical Trial: **31%**
- Disability Ins: **30%**

Please think about your mindset and experiences as a cancer patient. For each set of statements, select the statement that describes you best, or if you are somewhere in the middle.

**No differences by education*

Source=National Sample, n=840



The Survey Suggests that Initial Involvement Helps Improve Post Treatment Care Experiences

Patients Who Report Being Involved in Treatment Decisions	Patients Who Report Relying on their Doctor
Felt prepared for post treatment, 55%	Versus 50%
Spoke to their HCP about post-treatment care, 53%	Versus 40%
Describe their post-treatment medical care as "excellent," 59%	Versus 50%

Patients Are More Proactive in Other Areas

Please think about your mindset and experiences as a cancer patient. For each set of statements, select the statement that describes you best, or if you are somewhere in the middle.

INFORMATION:
I want/ed to find out all I could about my cancer diagnosis and my treatment options.



I do not/didn't want to think or read about cancer and hear about all of the bad things.



SUPPORT:
I take/took advantage of any help, resource my health care team offered me to help me through my cancer journey.



I am/was self-reliant and went through my cancer journey without a lot of help from health care providers.



GOALS:
My focus is/was getting rid of the cancer no matter what.



My focus is/was on maintaining my quality of life as much as possible.



Not Every Patient Is Willing to be a Self Advocate or Accept Support

SUPPORT: I take/took advantage of any help, resource my health care team offered me to help me through my cancer journey.

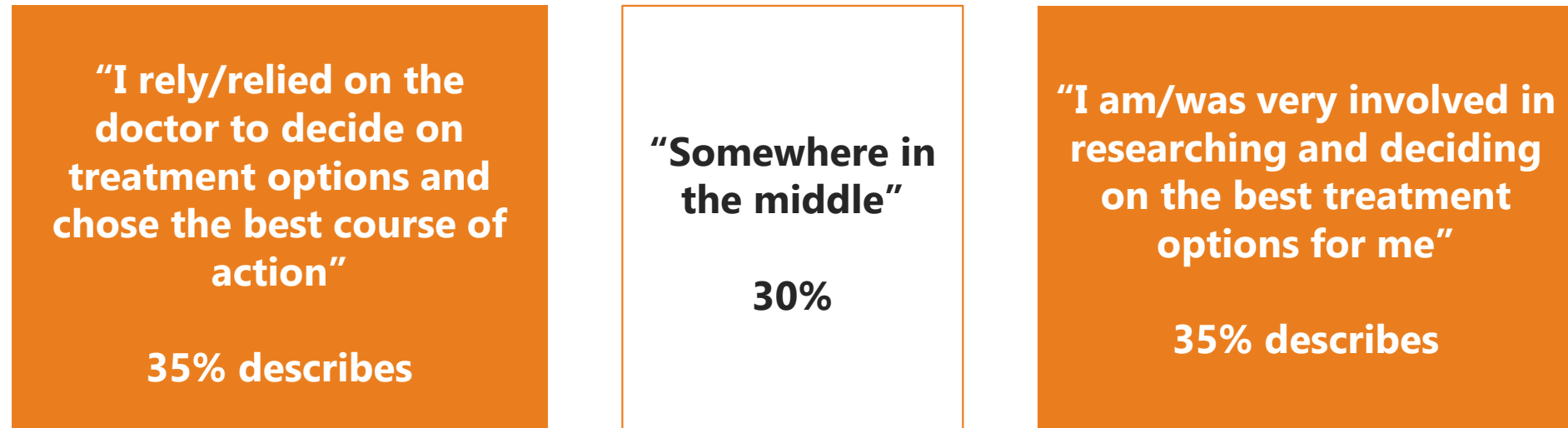
<i>Gender</i>		National
	Male	57%
	Female	50%
<i>Age</i>		
	18-39	55%
	40-64	51%
	65+	54%
<i>Race</i>		
	White	51%
	African American	60%
	Hispanic	59%
<i>Income</i>		
	Less than \$50k	55%
	More than \$50k	52%
<i>Education</i>		
	No college	54%
	College+	52%

I had both, a nurse navigator and a social worker. The nurse navigator, she was great. She started setting up my appointments and she gave me all kinds of...pamphlets for me to read while I was going through my diagnosis and I found that very helpful. The social worker set up rides for me to get back and forth to get back from the hospital. - Female, 49, Stomach

I don't have any outside help like social workers or case workers. I have no help except my oncologist introducing me to this chemo. - Female, 39, Breast

Mindset Differs among those Connected with NCCS

- Those who have opted-in to communication with NCCS are mixed in their treatment decision-making: a third relied on their doctor, a third were very active in making decisions, and another third were somewhere in the middle.



Please think about your mindset and experiences as a cancer patient. For each set of statements, select the statement that describes you best, or if you are somewhere in the middle.

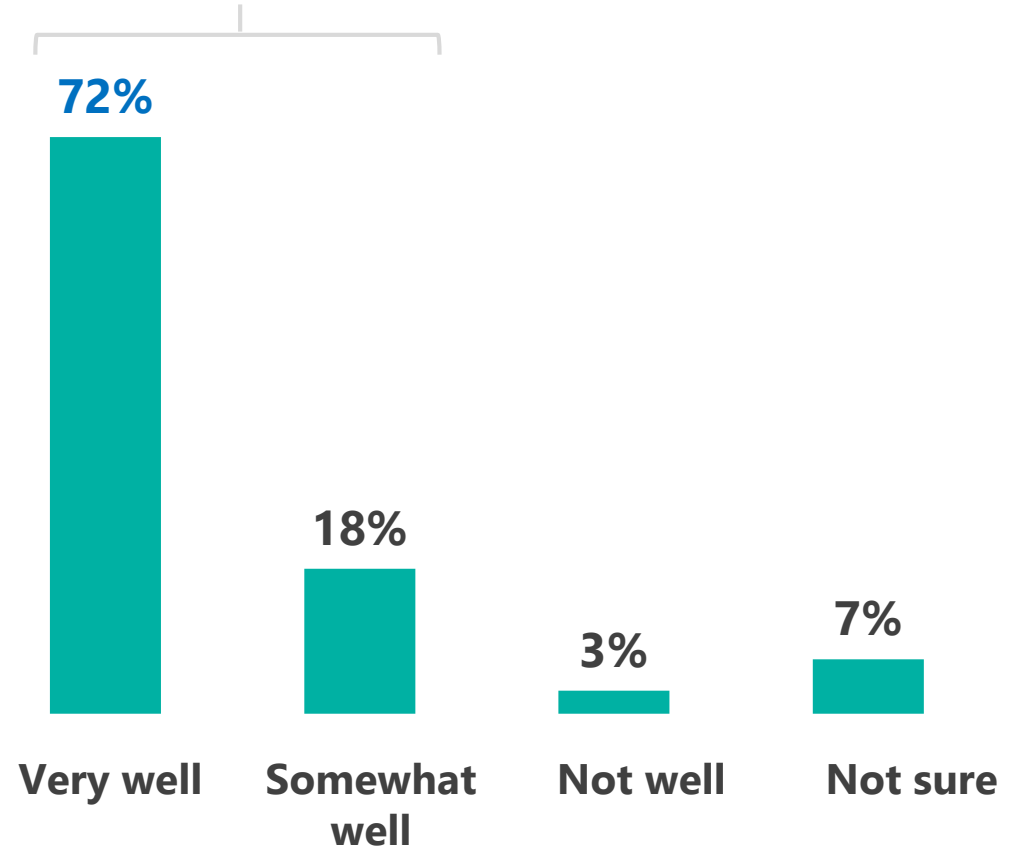
Treatment Experiences



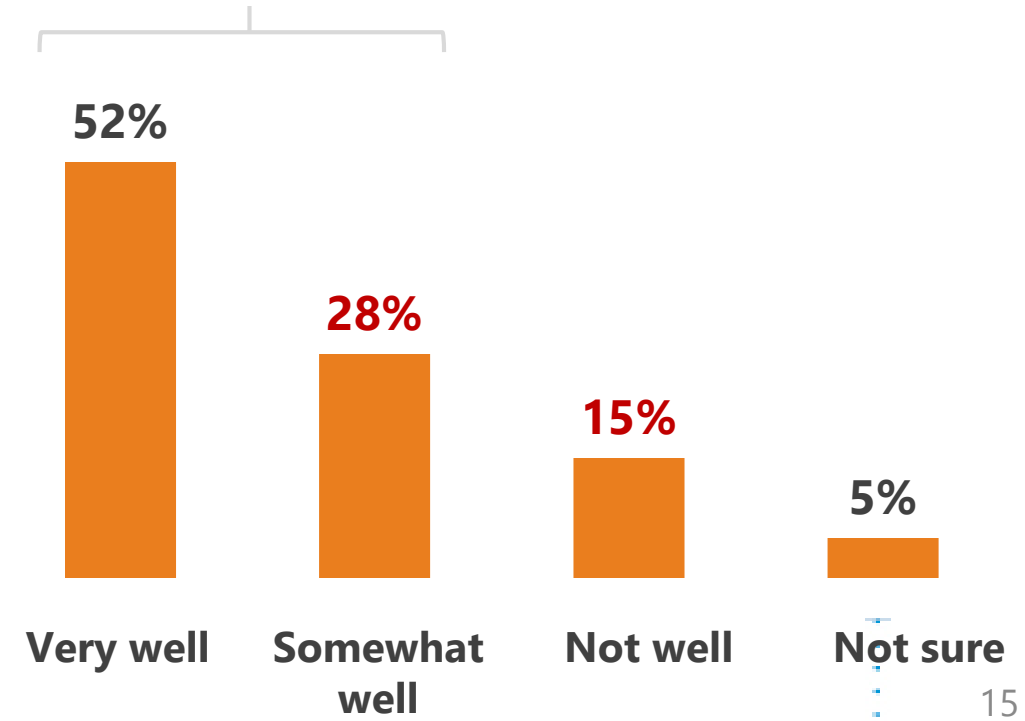
Most Cancer Patients Nationally Believe their HCP's Did a Good Job Coordinating their Care

- Those who are connected to NCCS are less likely to feel this way strongly and are generally have higher expectations of health care professionals.

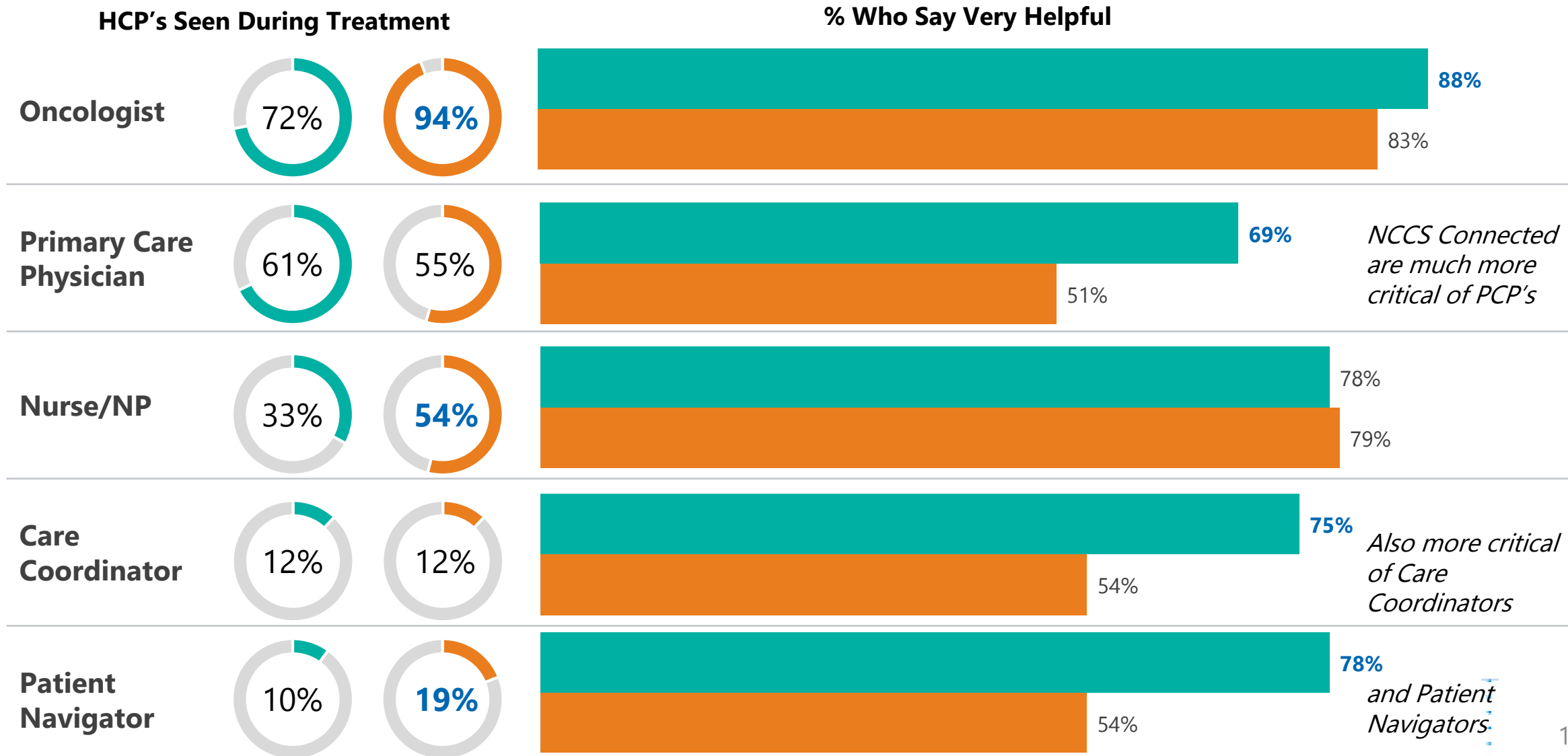
90% say HCP's coordinated care well



80% say HCP's coordinated care well



Most Saw Oncologists and Found Them Helpful, But Fewer Saw and/or Give Mixed Feedback on Other HCP's

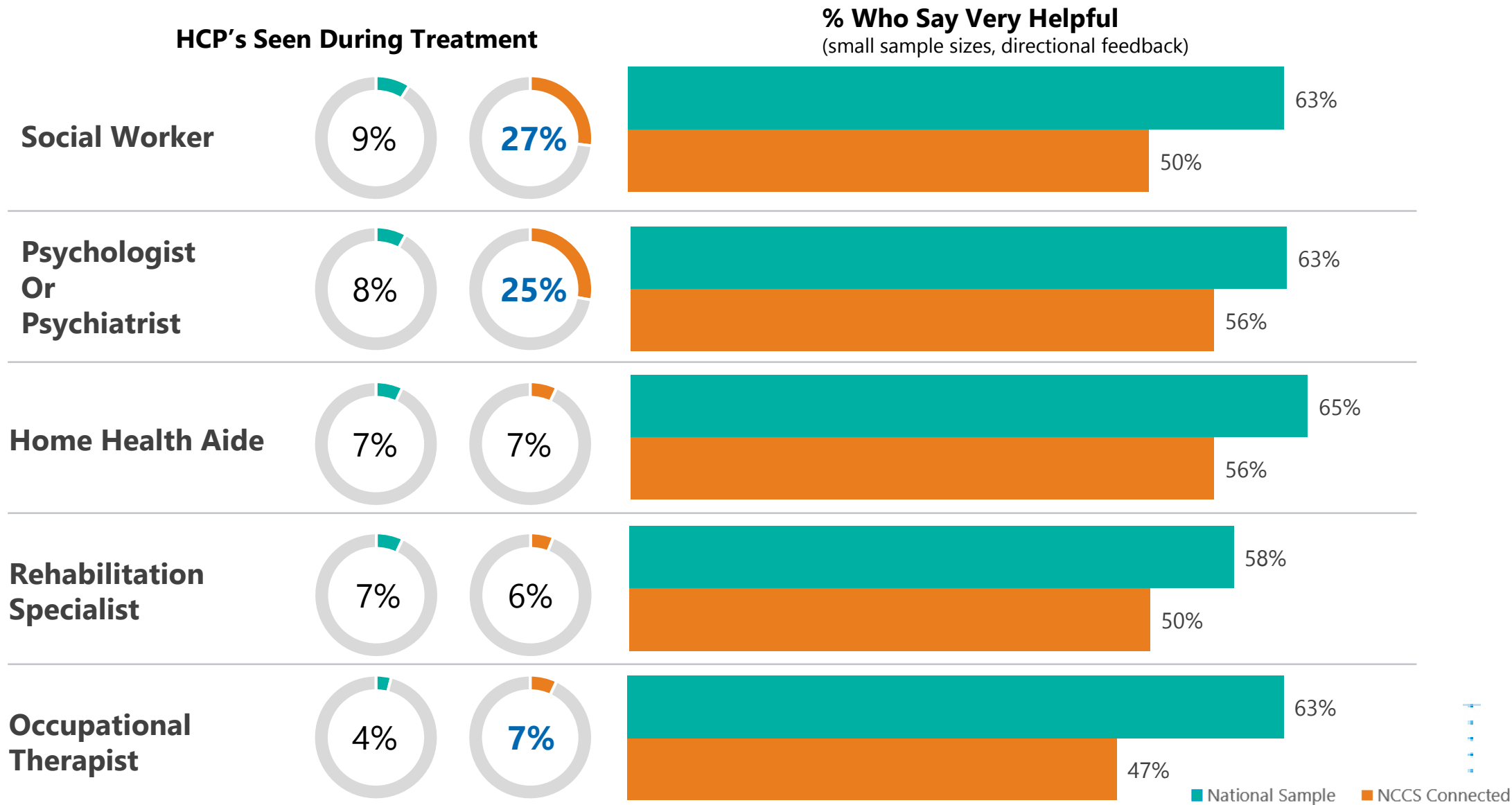


Source=National Sample, n=840 and NCCS Connected, n=479

Source=National Sample, n=20-607 and NCCS Connected, n=19-450

■ National Sample ■ NCCS Connected

NCCS Connected Are More Likely to Have Seen Mental Health Professionals; They Give Most HCP's Lower Ratings



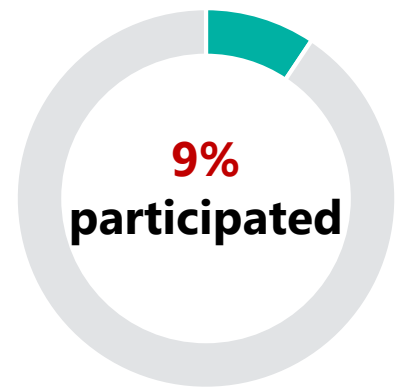
Source=National Sample, n=840 and NCCS Connected, n=479

Source=National Sample, n=20-607 and NCCS Connected, n=19-450

Most Patients are Not Participating in Clinical Trials and Voiced Concerns in the Interviews

- Those who are NCCS Connected are more likely to have participated, as well as immunotherapy patients.

At any point, did you participate in a clinical trial related to your cancer diagnosis?



Higher among:
Immunotherapy patients
Younger
African American



Higher among:
Immunotherapy patients




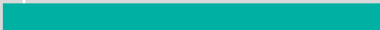

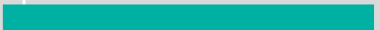

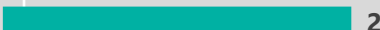




I was told of one, right before the last surgery. I was scared. I didn't do the clinical trial. I wanted to try the chemo. I was afraid to be a guinea pig. Something that may not work and get my hopes up. I was scared it would produce more tumors. – Female, 49, Stomach

My feelings on these are you do it if you run out of all options. But if they had a medical plan, didn't see the sense to go into a clinical trial. – Female, 65, Lymphoma NH

I would be worried on a clinical trial and they give you the placebo, and however long has gone by, the cancer could be going crazy in my body. If there was no placebos, I would consider it. – Female, 71, Lung

Fatigue & Depression Are Most Common Side Effects

Symptoms experienced (top 12 out of 19 shown)

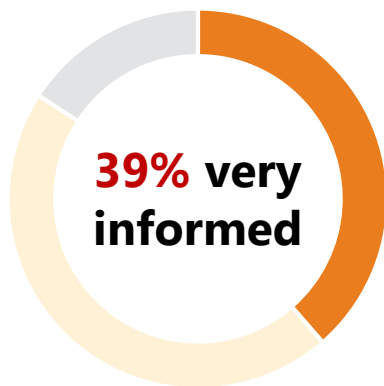
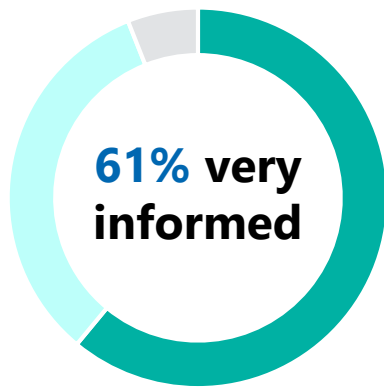
		18-39	40-64	65+	Male	Female	Black	Hispanic	Low income	Chemo	Treatmt 6+ years
Feeling overly tired	 49%	63%	60%	39%	37%	61%	52%	60%	53%	72%	48%
Depression and/or anxiety	 30%	50%	44%	17%	21%	39%	36%	46%	39%	41%	32%
Loss of appetite and/or taste	 28%	45%	35%	20%	19%	36%	27%	46%	33%	52%	27%
Muscle/joint pain	 27%	42%	35%	19%	18%	37%	31%	39%	32%	43%	24%
Nausea/vomiting or diarrhea	 27%	48%	38%	15%	16%	37%	33%	41%	38%	51%	26%
Neuropathy	 26%	33%	37%	16%	19%	33%	36%	37%	30%	47%	21%
Weight loss	 25%	42%	29%	20%	24%	26%	27%	37%	29%	43%	25%
Sexual concerns	 24%	34%	26%	22%	28%	20%	32%	31%	19%	27%	25%
Uncertainty status of cancer	 24%	28%	28%	20%	25%	23%	17%	31%	23%	25%	16%
Skin irritation, derm. problems	 19%	24%	23%	16%	14%	24%	14%	23%	28%	23%	15%
High or low blood pressure	 17%	24%	18%	15%	16%	18%	18%	11%	22%	21%	14%
Memory loss, cognitive issues	 13%	16%	21%	7%	5%	21%	9%	19%	20%	26%	14%

Source=National Sample, n=840

Six-in-10 Nationally Believe They Were Informed about Side Effects, Most through Verbal Communication

- The NCCS Connected group feels *less* informed, even though they are *as or more* likely to have received information in a variety of ways, underscoring differences in expectations.

How informed about potential side effects?

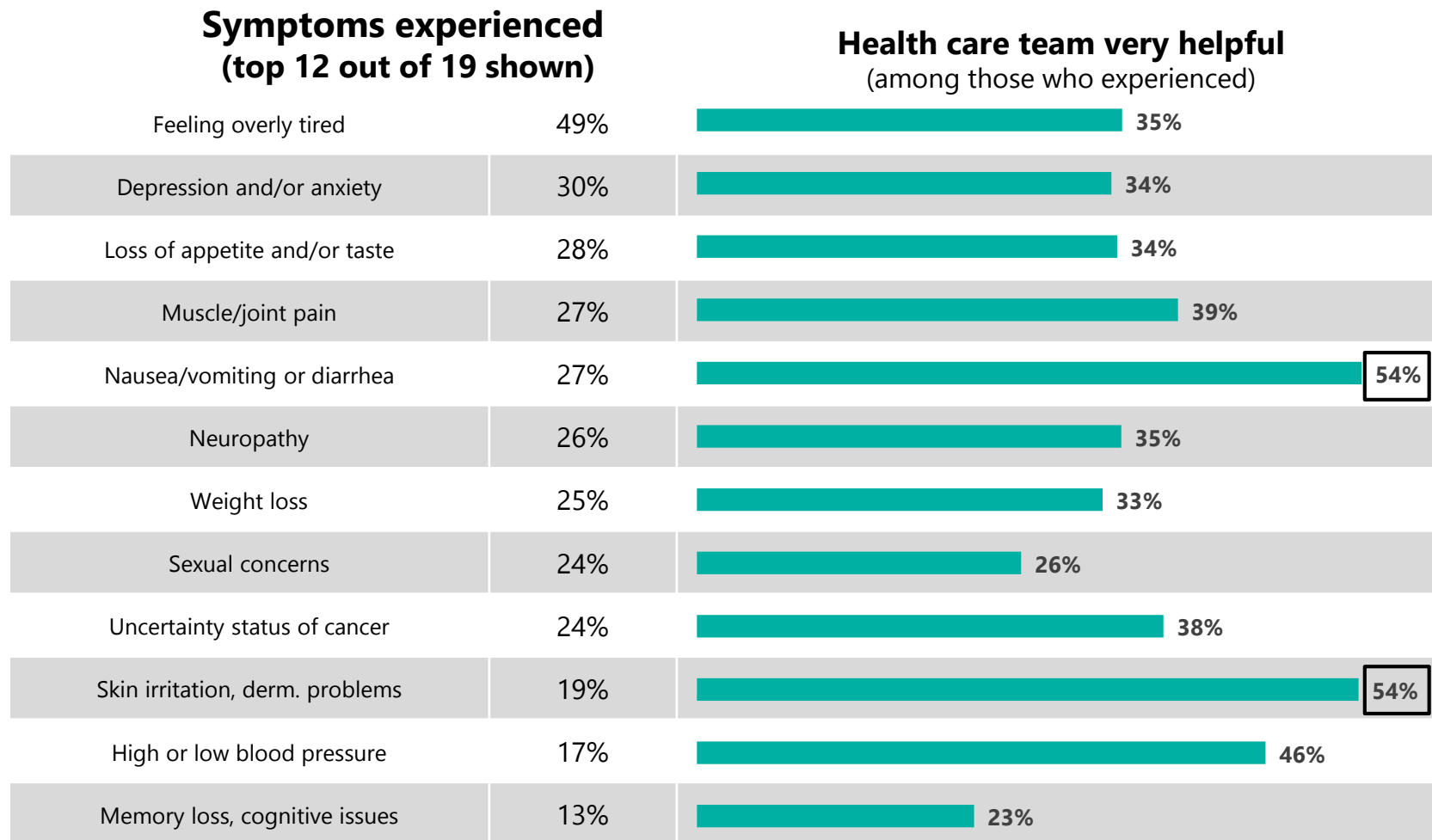


■ National Sample ■ NCCS Connected

Which information did you receive about potential side effects?	National Sample	NCCS Connected
My health care provider discussed potential side effects with me	72%	70%
My health care provider gave me written information about potential side effects	47%	53%
My health care provider gave me supplies to deal with my side effects	23%	29%
My health care provider recommended a website on potential side effects	6%	7%
My health care provider offered a class on potential side effects	5%	9%
My health care provider showed me a video on potential side effects	4%	4%
None of the above	9%	9%

Source=National Sample, n=840 and NCCS Connected, n=479

Going a Layer Deeper, Less Than Half Say Their HCP Was Helpful Addressing *Specific* Side Effects



What bothered me, you have heavy doses of chemo which affects your body, but no one says it will affect your brain. When I mentioned to my oncologist that I was depressed and anxious, knot in my stomach, shaking. He'd say this is very normal, it will go away. - Female, 65, Lymphoma NH

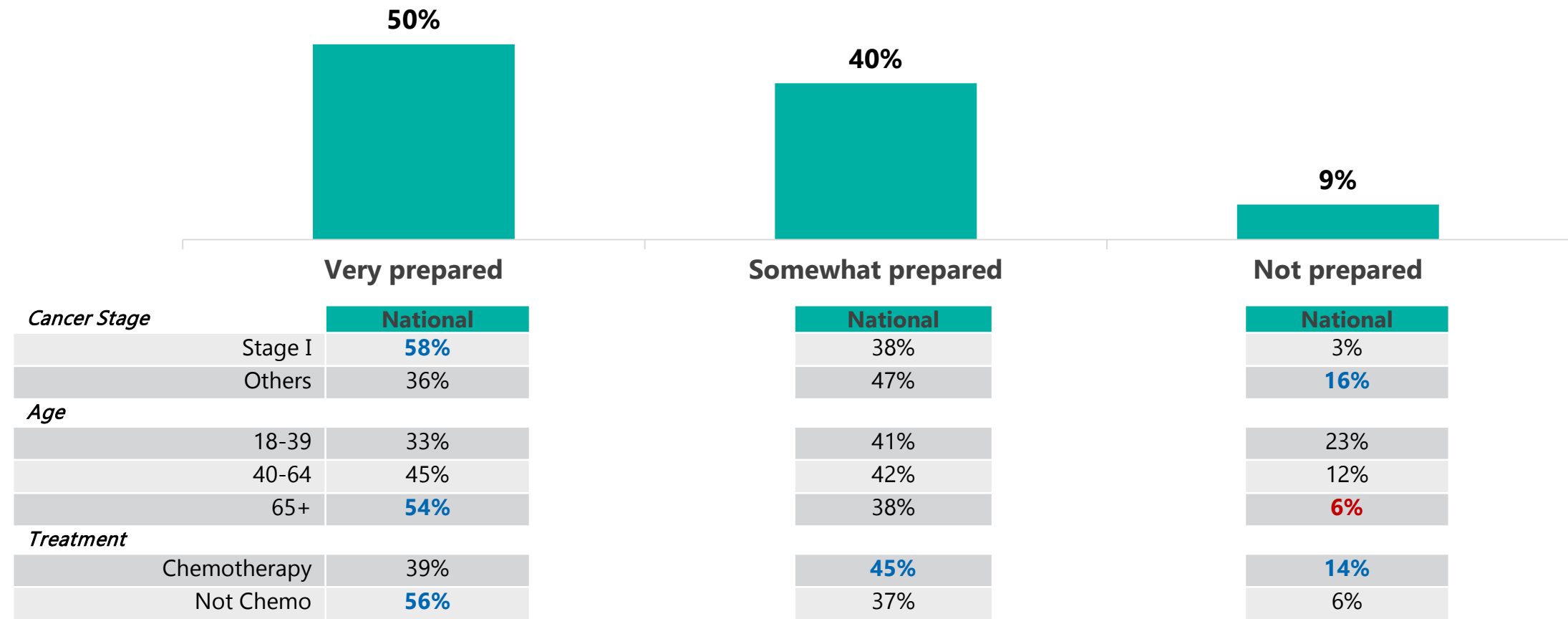
Transition to Post-Treatment Care



Half of Patients Describe Themselves a “Very Prepared” for Post-Treatment

- Younger patients, those in later stage cancers, and those who had chemo are less confident.

How well prepared for transition to Post-Treatment

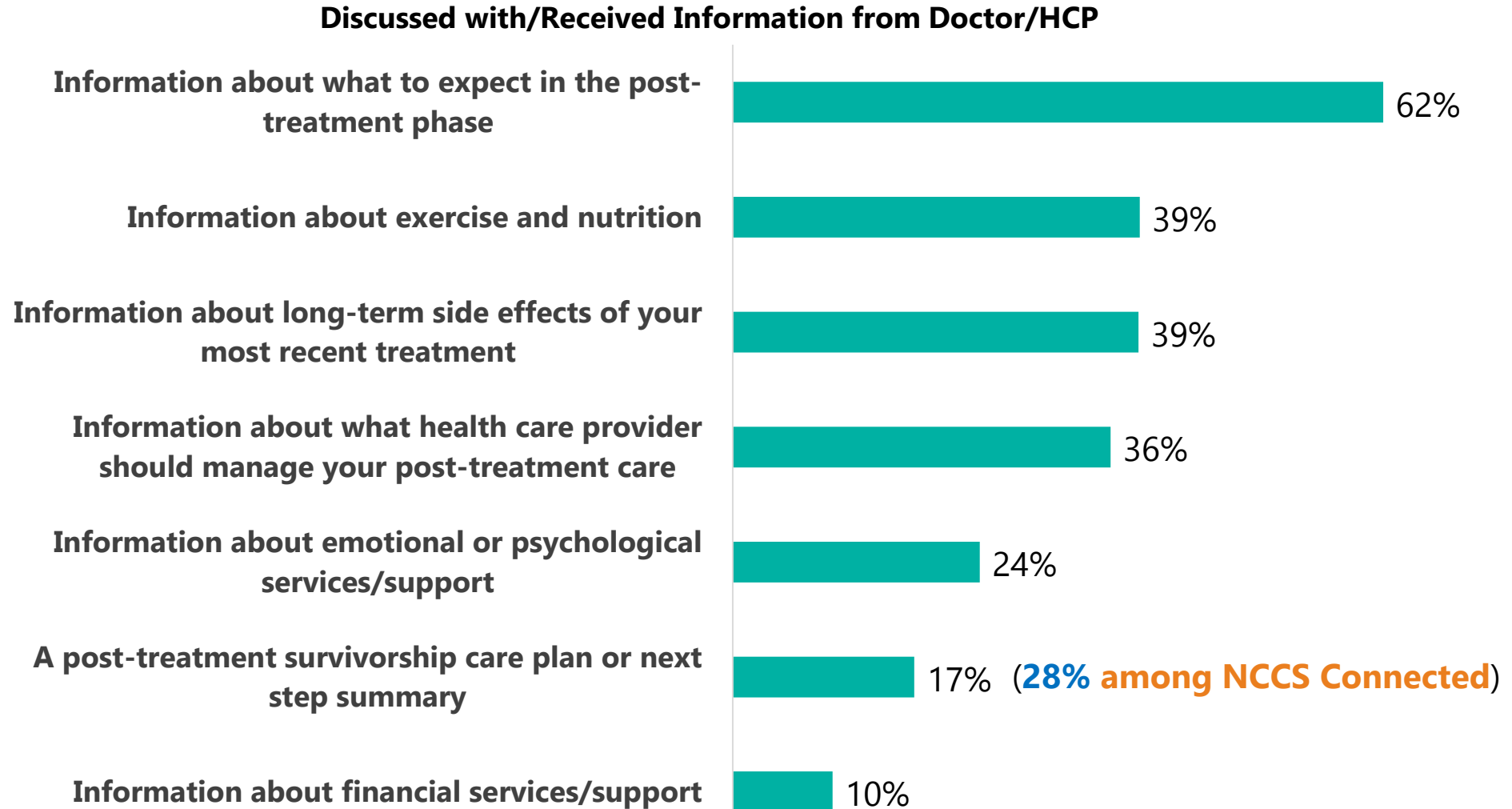


Source=National Sample, n=638



Majorities Discussed What to Expect Post-Treatment; Fewer Got Additional Information

- Few report getting a post-treatment survivorship plan (although this is significantly higher among the NCCS Connected audience).

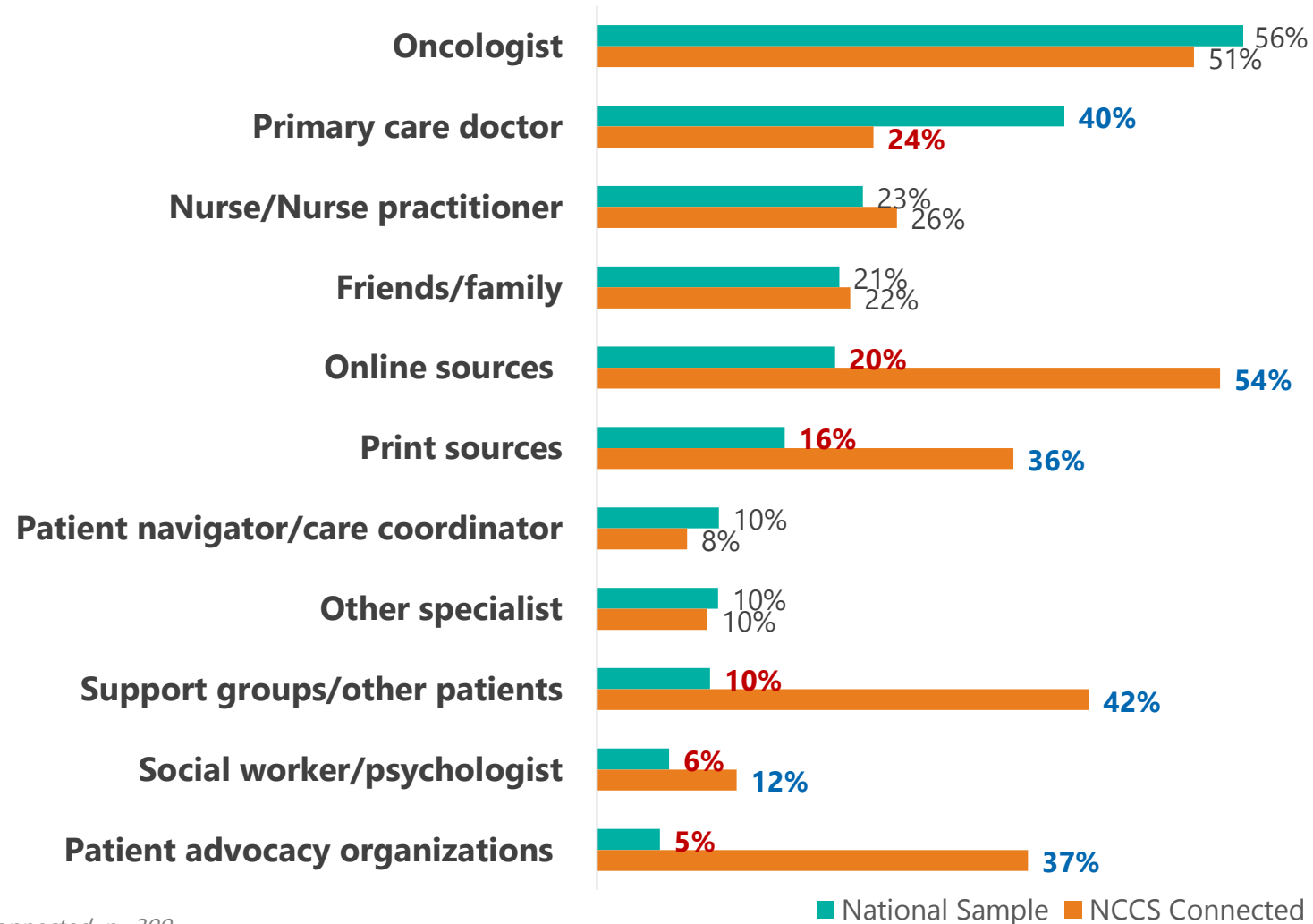


Source=National Sample, n=531

Cancer Patients Nationally Mainly Rely on HCPs for Post-Treatment Information and Support

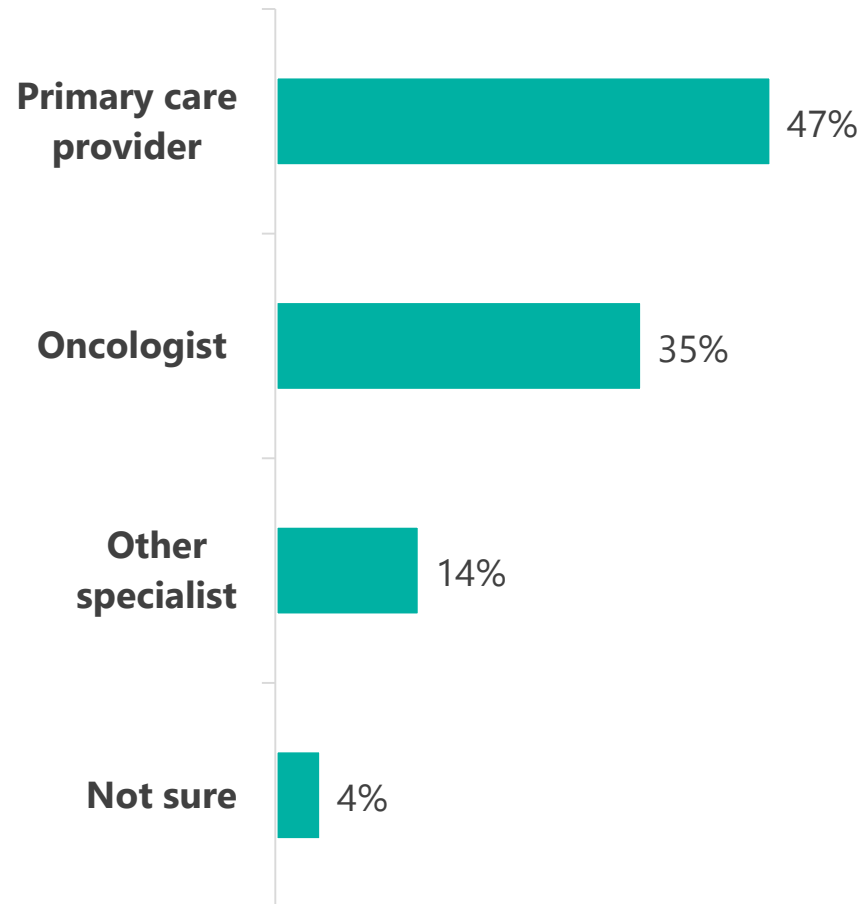
- The NCCS Connected is much more likely to use sources outside of medical professionals.

Post-Treatment Resources for Care and Support

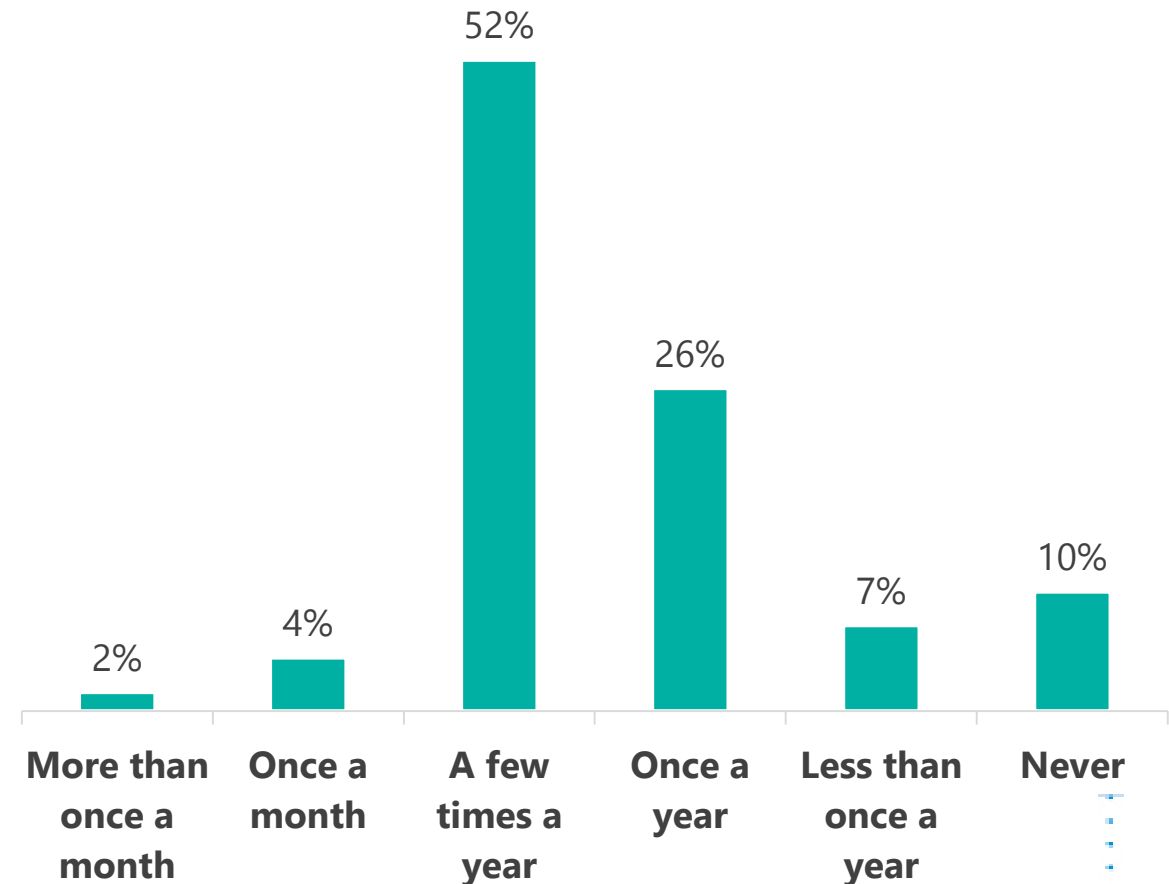


A Plurality Say Their PCP Is Handling their Post-Treatment Care, with Check-ups A Few Times a Year or Annually

Primary HCP for Post-Treatment Care

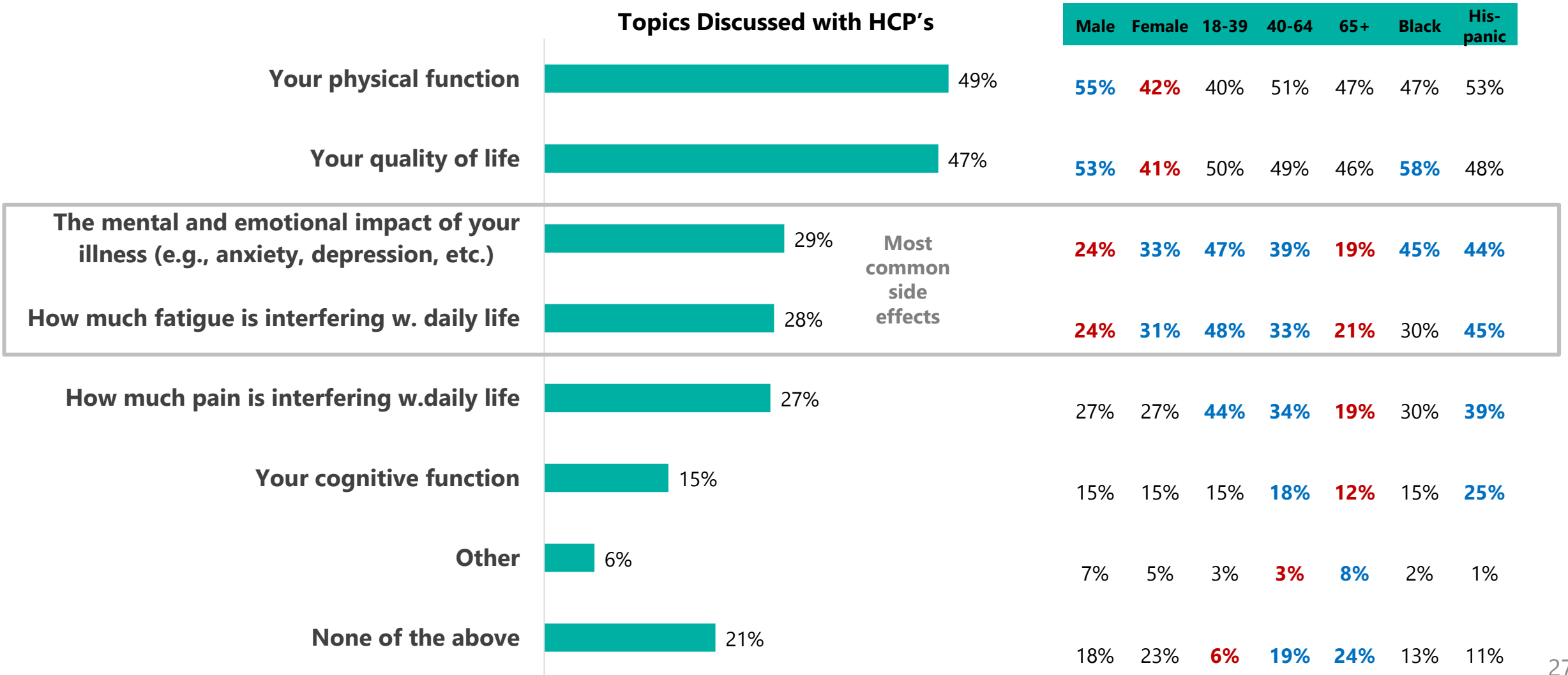


Frequency of Post-Treatment Care



Half of Patients Discuss Physical Function and Quality of Life with HCP's, But Few other Aspects of Functional Status

- Less than a third discuss fatigue nor mental health – the two most prevalent side effects.

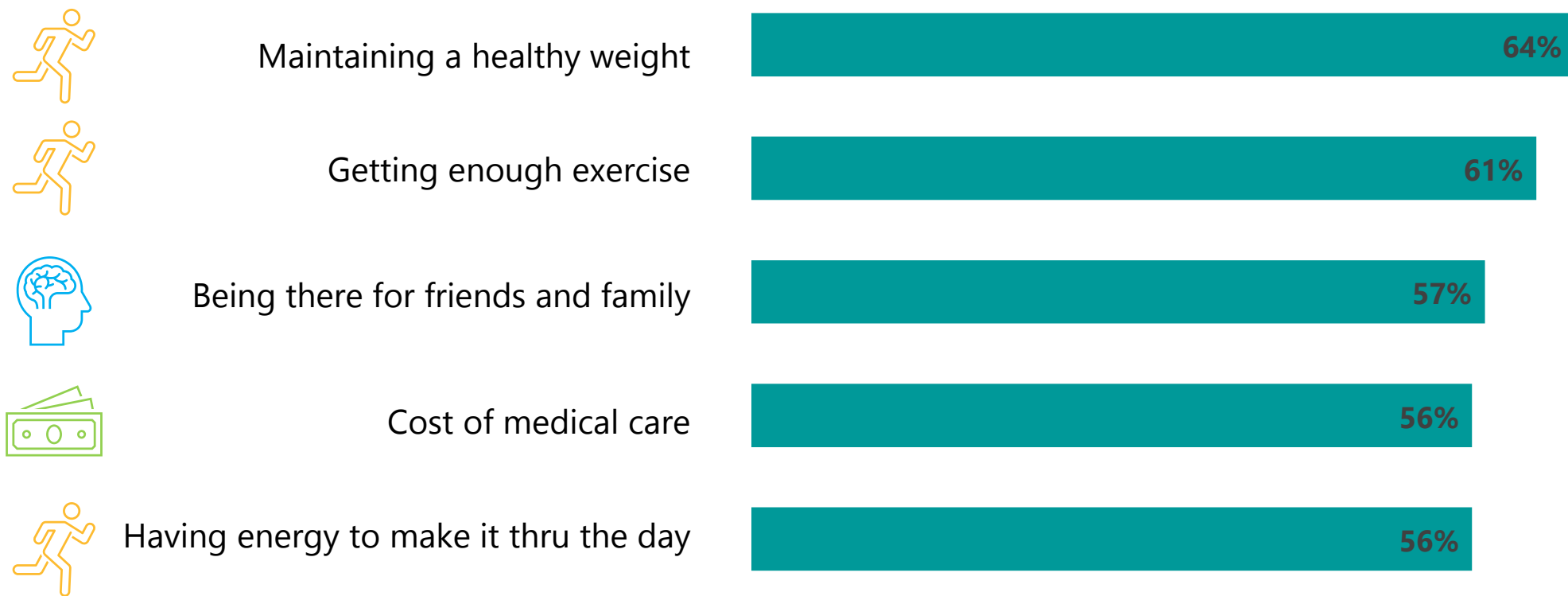


Survivorship Needs



Survivors' Top Concerns Are about Physical Health Issues, the Future, and the Cost of Medical Care

Top Concerns: % concerned



 Physical health/adherence
  Financial/Insurance
  Emotional/Lifestyle

Younger, Black, Hispanic, Women, and Chemo Patients Are More Concerned about a Host of Physical, Emotional, & Financial Issues



Physical health/adherence



Financial/Insurance



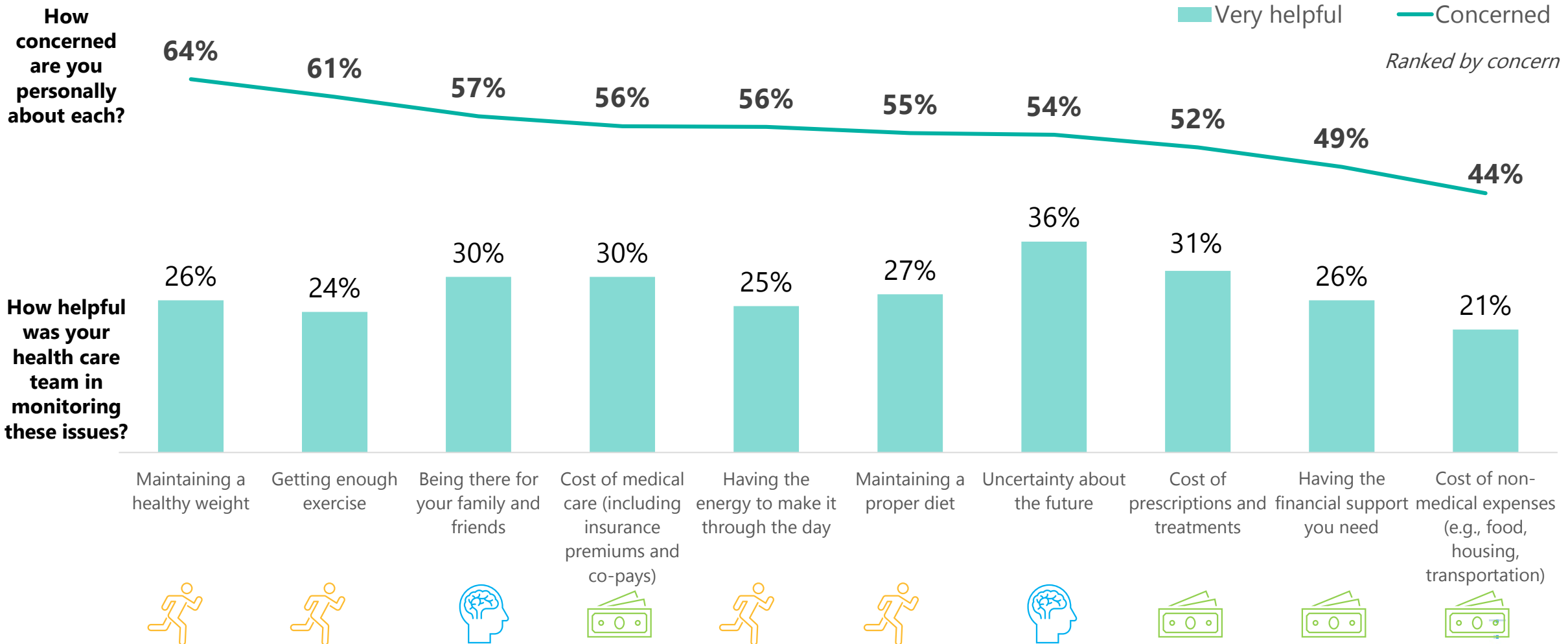
Emotional/Lifestyle

	National Sample	Black	Hispanic	18-39	Age 65+	Women	Low Income	Chemo
Maintaining a healthy weight	64%	72%	71%	78%	55%	70%	69%	69%
Getting enough exercise	61%	72%	72%	72%	53%	67%	58%	69%
Being there for your family and friends	57%	66%	67%	79%	47%	58%	62%	68%
Cost of medical care	56%	60%	71%	75%	42%	61%	61%	64%
Having the energy to make it through the day	56%	66%	67%	89%	44%	63%	60%	68%
Maintaining a proper diet	55%	66%	63%	63%	45%	62%	56%	61%
Uncertainty about the future	54%	55%	66%	71%	43%	57%	57%	65%
Cost of prescriptions and treatments	52%	56%	68%	75%	40%	56%	52%	62%
Having the financial support you need	49%	59%	65%	78%	35%	57%	61%	58%
Managing on-going side effects from treatment	49%	64%	61%	77%	39%	52%	45%	64%
Understanding the health insurance benefits available	46%	53%	61%	72%	34%	49%	53%	53%
Cost of non-medical expenses	44%	50%	63%	72%	32%	51%	56%	52%
Getting/keeping health insurance	41%	59%	68%	72%	23%	48%	49%	51%
Ability to maintain relationships	39%	55%	49%	72%	30%	41%	42%	51%
Having the emotional support you need	38%	61%	53%	73%	25%	43%	45%	45%
Cost of professional caregiving	38%	42%	51%	61%	32%	37%	35%	40%
Support with mental health issues	37%	56%	61%	77%	22%	43%	39%	48%
Managing all of your prescribed medications	35%	56%	50%	66%	25%	39%	38%	44%
Visiting your doctor regularly	35%	47%	57%	60%	25%	40%	41%	41%
Loss of income	35%	47%	58%	74%	17%	42%	47%	46%
Long-term planning/career goals	32%	52%	55%	81%	18%	36%	32%	41%
Learning how to apply for grants to help with costs	27%	46%	50%	71%	14%	32%	38%	35%
Getting/keeping disability insurance	27%	46%	51%	57%	9%	31%	36%	35%
Work/employment issues, like finding and keeping a job	23%	39%	49%	64%	8%	29%	28%	32%
Starting a family/having children	8%	19%	26%	57%	2%	8%	10%	12%

Source=National Sample, n=840



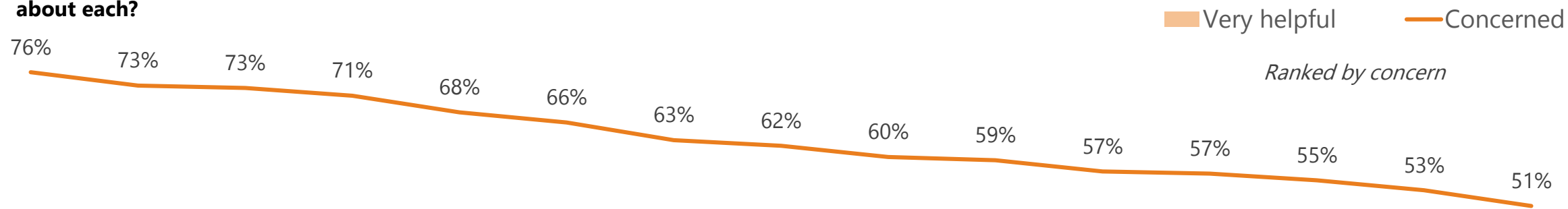
Nationally, there Are 10 Key Concerns (Mostly Physical and Financial) Where Few Patients Found their HCP's Very Helpful



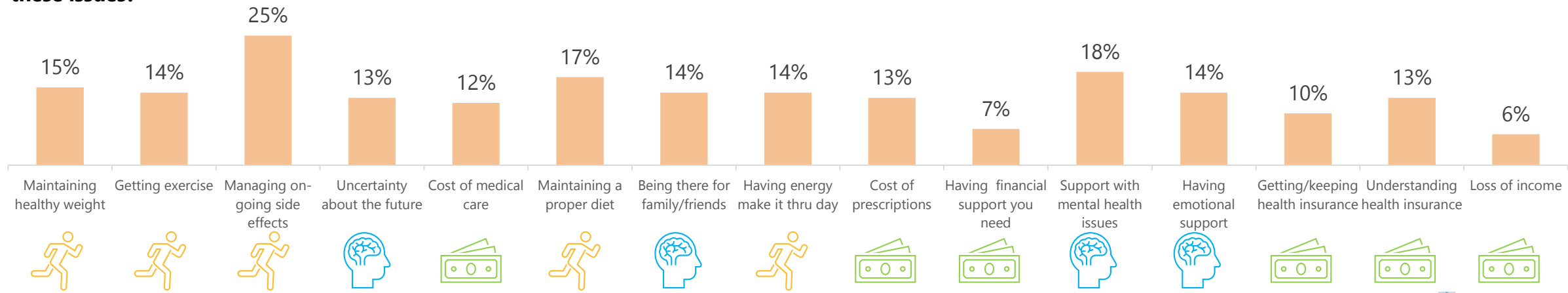
Source=National Sample, n=840

NCCS Connected Patients Not Only Have Greater Concerns but Higher Expectations of HCP's, Leading to a Wider Gap on All Areas Tested

How concerned are you personally about each?

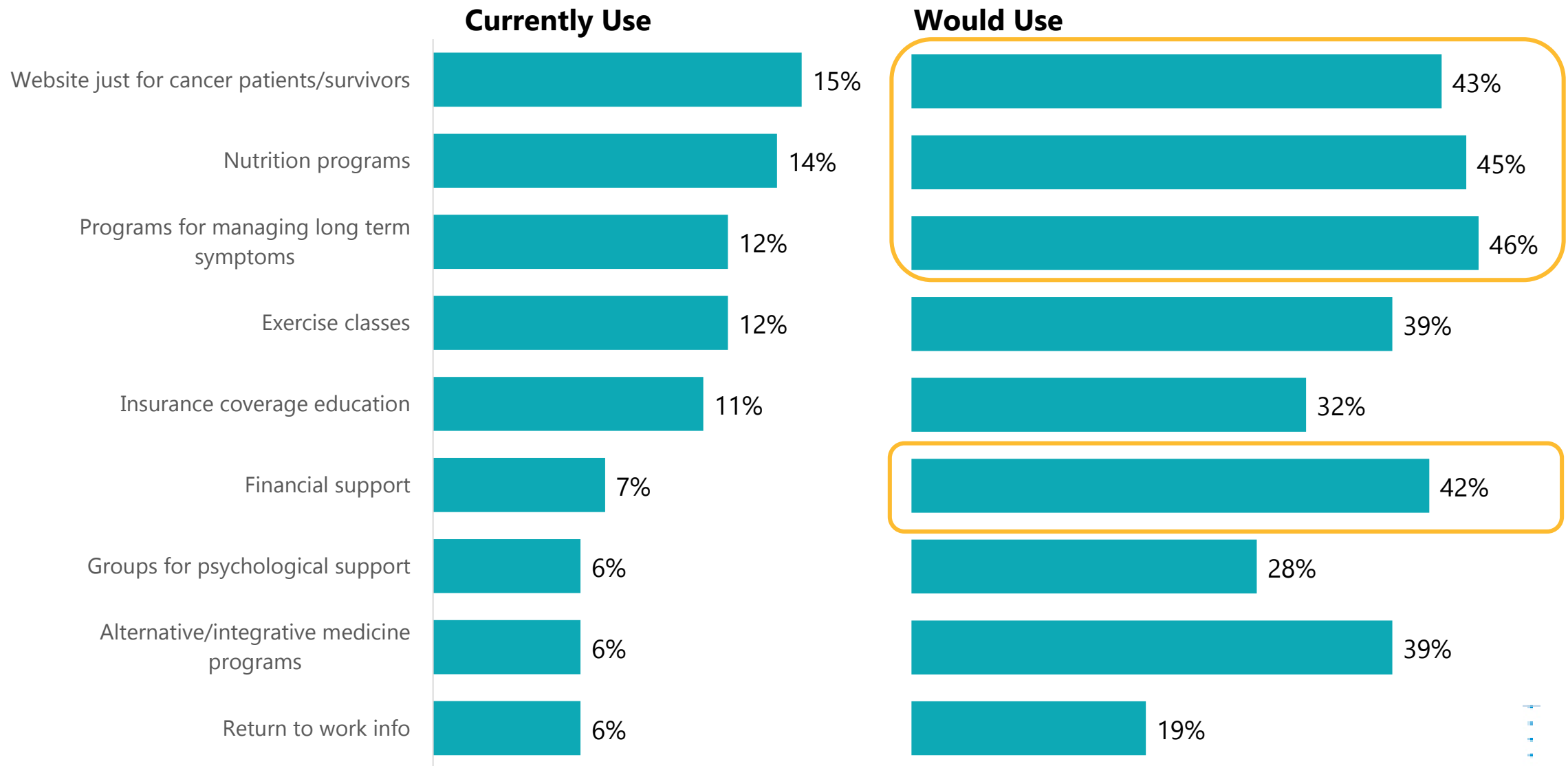


How helpful was your health care team in monitoring these issues?



Source=NCCS Connected, n=3479

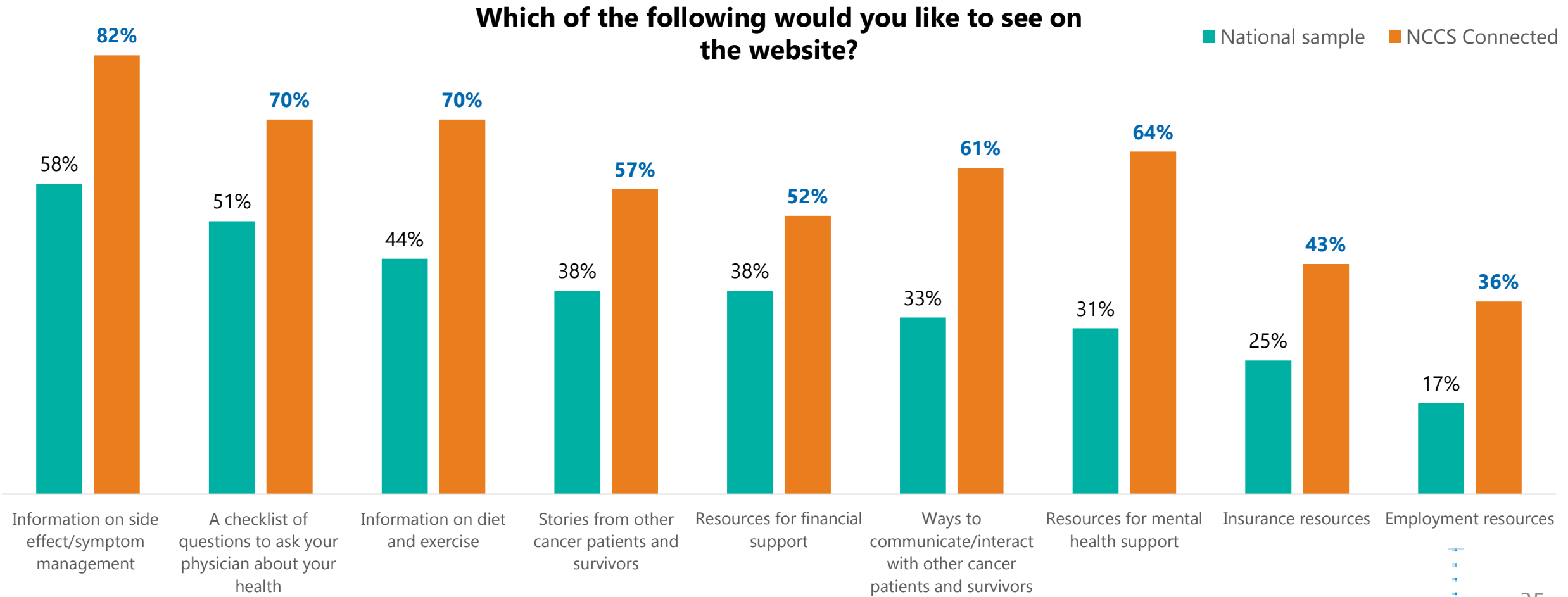
Few Use Any Resource Tested. Most Interest in Website, Nutrition & Long-Term Symptom Programs, Financial Support



Source=National Sample, n=840

Website Features of Most Interest Are Symptom Management Info and a Checklist for Doctor Appointments

- The NCCS Connected are also interested in resources for diet/exercise and mental health, and community with other patients/survivors.



Takeaways: Advice from Cancer Survivors

*Stuff they didn't tell me during treatment to help with nausea, sores, muscle pain. I couldn't lift my head – was not prepared. **Tell patients that it's normal to have anxiety and depression after chemo.***

- Female, 65, Lymphoma NH

What's worked for me is to think of it as a job that you push through. Make a check list, celebrate each victory, got to focus on the end point, take control of what you can, and let go of what you can't. -

Female, 29, Breast

*Trust the process and listen. Just continue to move forward and **get it out of the way.***

*- Male, 29,
Testicular*

*I would tell them to keep your faith because you need that. Think about your outcome. I would tell them to fight as hard as you can. And prepare yourself for the biggest fight of your life. It feels like your body betrayed you, so now you have to fight. Keep your head up and keep trucking. **Cancer is not going to overcome you.***

- Female, 39, Breast

Pick doctors who will spend time with you and answer your questions. Find someone who is understanding and willing to listen.

- Female, 71, Lung

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Funding for this research was provided by an educational Grant from Bristol-Myers Squibb.