



# Annual State of Survivorship Study

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

June 2021



## Research Objectives and Questions

**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**

# Methodology

## Phase 1

### **In-depth Interviews with Cancer Patients and Survivors**

- Sixteen (16) virtual interviews, approximately 60 minutes-each, March 2021
- Mix of Stage IV/Metastatic patients and low income/socio-economic status
- Nationwide recruit: mix of race/ethnicity, years living with cancer, cancer types, and where they live (urban, suburban, or rural)

## Phase 2

### **Nationwide Survey of Adult Cancer Patients and Survivors**

- Nationwide sample of n=1104, fielded May 5-May 24, 2021
- Set quotas to make sure the sample was representative by age, gender, race/ethnicity, and region (using ACS and NCI data)
- Oversamples of Stage IV/Metastatic patients to analyze this group with more statistical reliability
- 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=500, same field period as above
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders

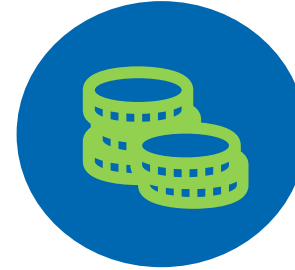
# Overview: Topics Covered



**Mindset Shift**



**Disparities in Care**



**The Costs of Cancer**



**Support Systems**




**Treatment During  
COVID**



**The Meaning of  
“Survivorship”**

# Mindset Shift

# Pluralities say they relied on their doctor to make their cancer treatment decisions, though this number decreased dramatically from just a year ago

2020		2021
61%	I rely/relies on the doctor to decide on treatment options and chose the best course of action.	44% ▼
18%	Somewhere in the middle	22%
22%	I am/was very involved in researching and deciding on the best treatment options for me.	33% ▲



### More Likely to be Involved in Decision Making

- Younger ages (18-29) **49%**
- Hispanic/Latino **45%**
- Urban **43%**
- Clinical Trial **47%**
- Immunotherapy **43%**
- Targeted Drug Therapy **41%**
- Palliative Care **46%**
- In-treatment **41%**
- College **37%**

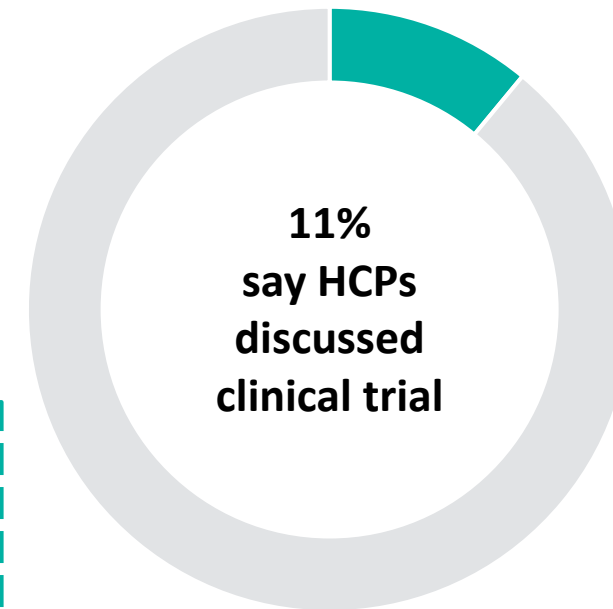
**NCCS Connected:** **43%** Very involved, 22% In the middle, **35%** Relied on the doctor

# Few patients are informed about nor are participating in clinical trials

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



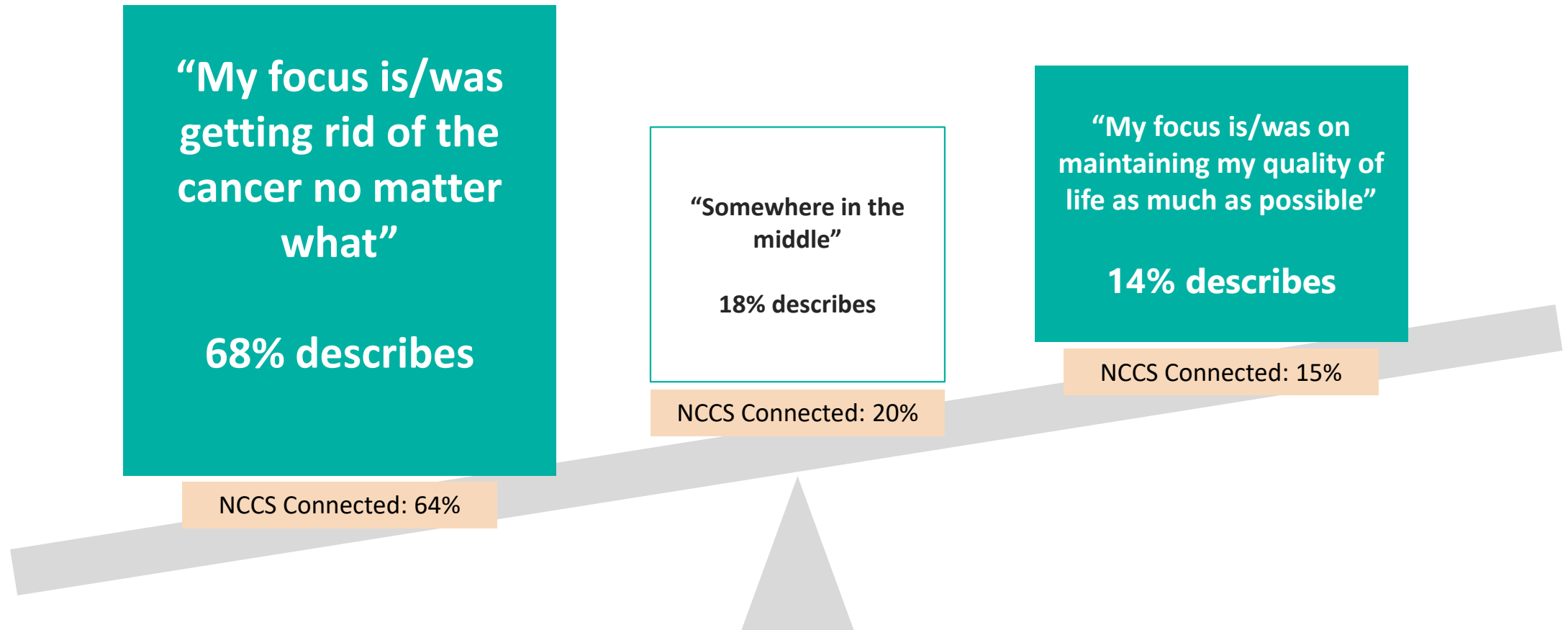
Did your health care team offer/discuss a clinical trial with you?



**Higher for both among:**  
Younger  
Hispanic/Latino  
Urban  
Higher SES  
In-treatment  
Academic Medical Center  
Chemotherapy  
Targeted Drug Therapy  
Immunotherapy  
NCCS Connected

# Patients are far more focused on getting rid of cancer than maintaining their quality of life

- Those still undergoing treatment (**24%**) and Stage IV/Metastatic patients (**29%**) are more likely to focus on maintaining quality of life, but they still heavily lean towards being cancer free.

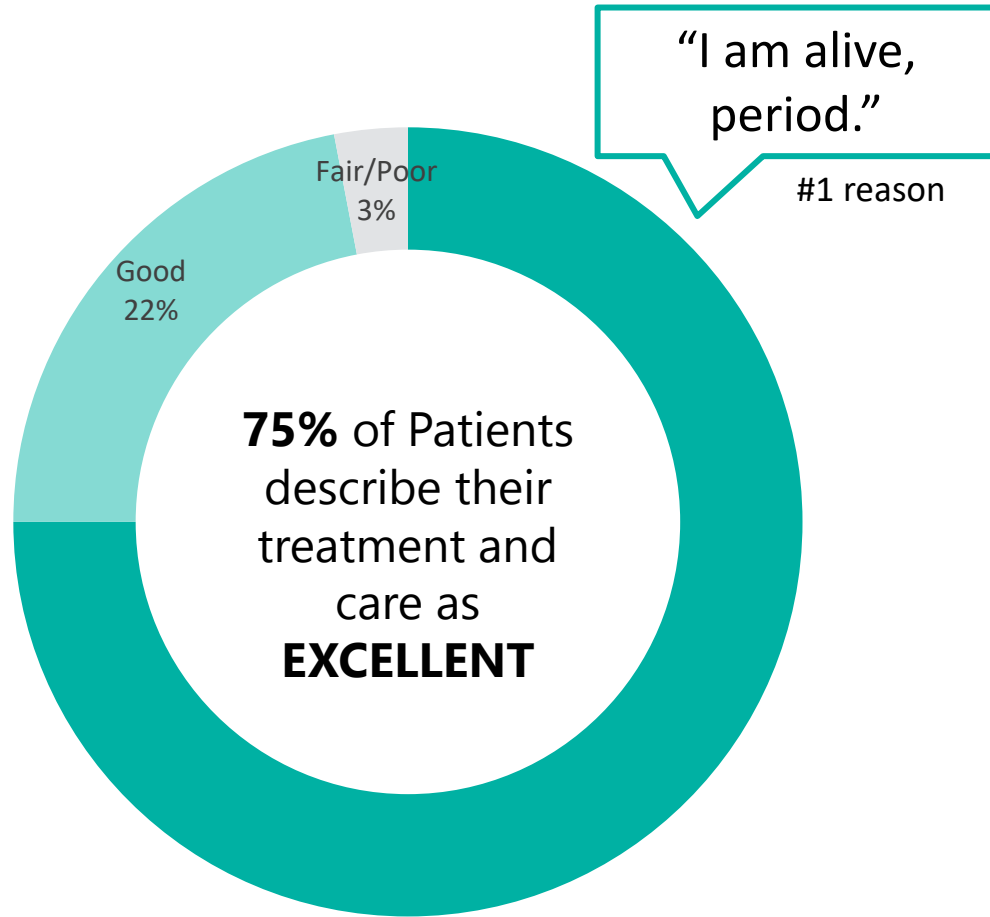


Please think about your mindset and experiences as a cancer patient. For each set of statements, select the statement that describes you best, or if you are somewhere in the middle.



# Disparities in Quality of Care

# Most cancer patients nationally describe their treatment and care as “excellent,” but there are demographic and psychographic differences



There are significant differences by age, race/ethnicity, type of treatment, support, and how long since treatment

65+ ( <b>78%</b> )	18-39 ( <b>57%</b> )
White ( <b>77%</b> )	Black ( <b>69%</b> ) Hispanic/Latino ( <b>64%</b> )
Surgery ONLY ( <b>80%</b> )	Chemotherapy ( <b>71%</b> ), Targeted drug therapy ( <b>71%</b> ), Immunotherapy ( <b>71%</b> )
Support excellent ( <b>90%</b> )	Support just fair ( <b>51%</b> )
Very informed side effects ( <b>85%</b> )	Somewhat informed ( <b>55%</b> )
Completed treatment ( <b>77%</b> ), 10+ years since ( <b>77%</b> ) 21+ years diagnosis ( <b>82%</b> )	Still in-treatment ( <b>64%</b> ), First year diagnosis ( <b>68%</b> )

**NCCS Connected: 51% Excellent, 35% Good, 13% Fair/Poor**

Source=National Sample, (n=1104), NCCS Connected Sample (n=500)

# In addition to poor outcomes, several themes emerge among those who felt they had just good/fair/poor care

## **Income disparities:**

*To be honest, I'm poor. I just went with the program, tried not to bother anybody. (Hispanic/Latino, low income)*

## **Lack of Support and Coordination of Care:**

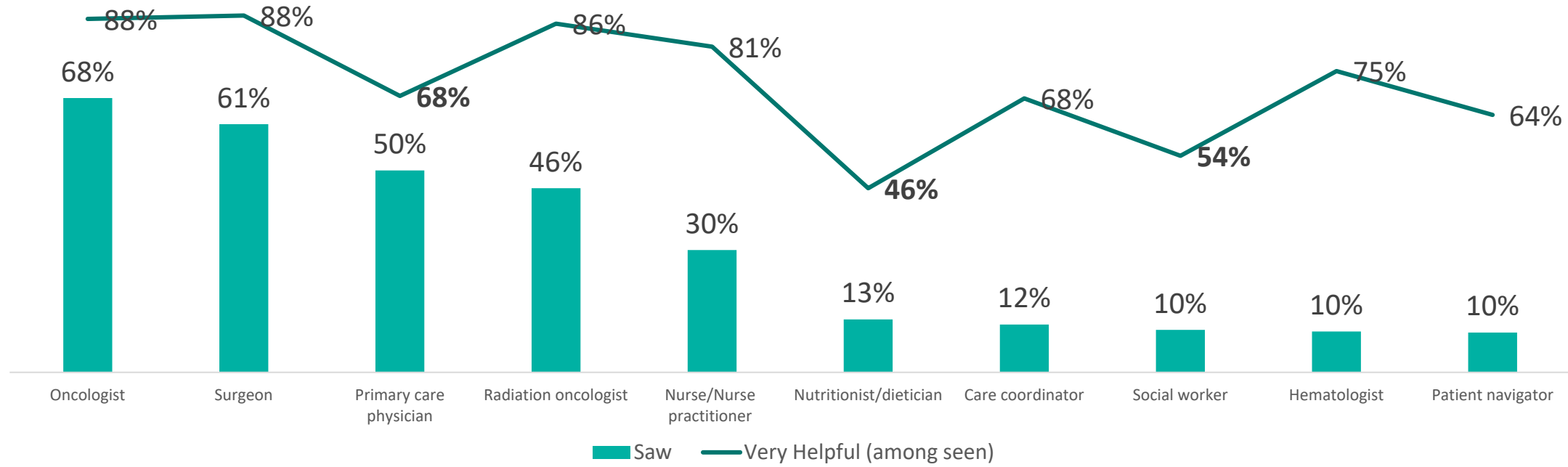
*No continuity. I see a different infusion nurse every time. I see a different NP every time. We discuss medication or scans, and they never get ordered. Insurance companies and doctors' offices don't communicate. No one seems to know me. (Metastatic)*

## **No Options nor Voice:**

*I do not feel that I was even consulted about options, because I was young and considered not smart enough to be in charge of my own care. I feel like when I finished treatment I was just dumped. There was very little care given to how I would have a lifetime of survivorship ahead of me. No one even wanted to hear about complications I was having, even though some ended up being early signs of poor lifelong outcomes. (18-39)*

# Oncologists and surgeons are popular. PCP's get significantly lower ratings. Fewer accessed dieticians or social workers and not as many saw them as helpful

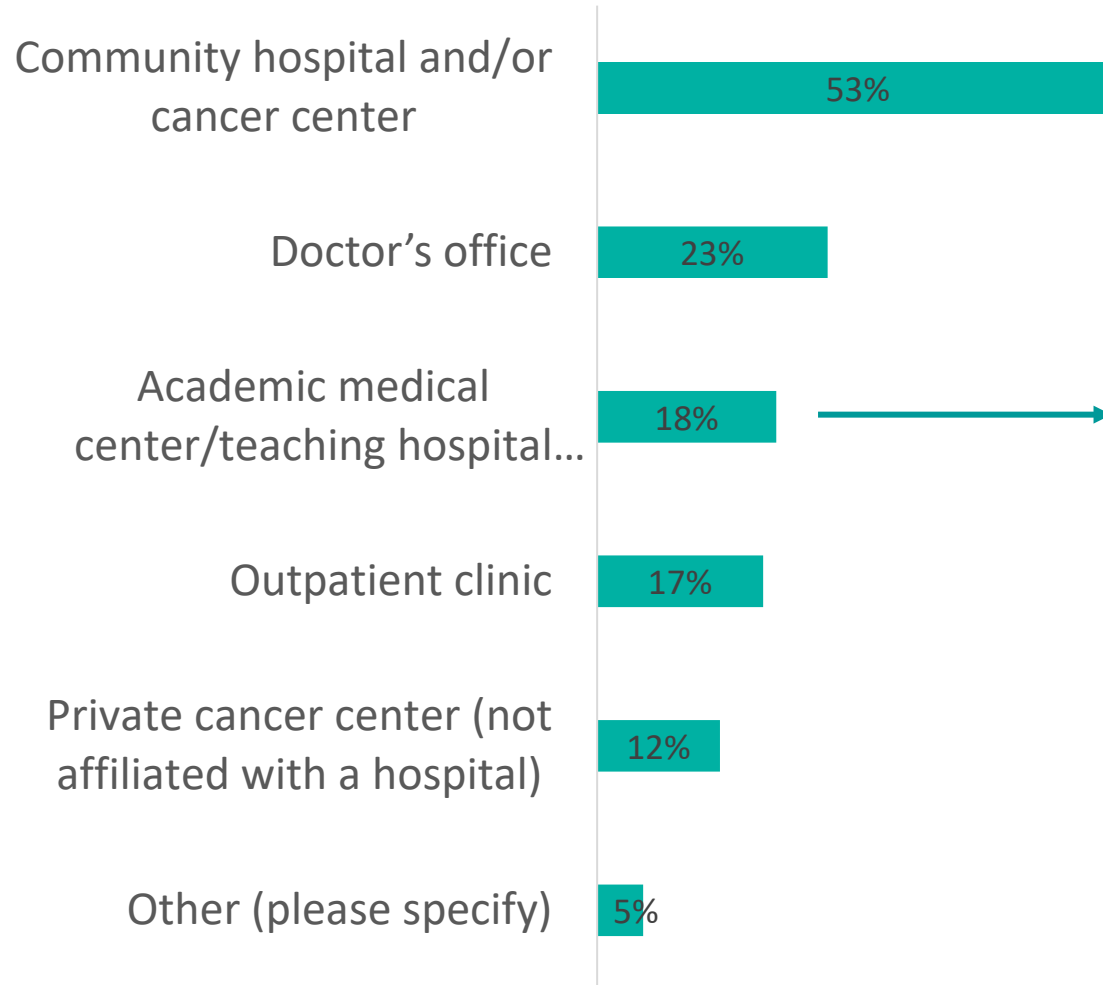
HCPs Seen and Helpful During Treatment  
(top 10 seen)



**NCCS Connected: lower scores helpfulness to PCP, Nurses, Care Coordinator, Surgeon**

# There is some confusion over where treatment happened/type of facility

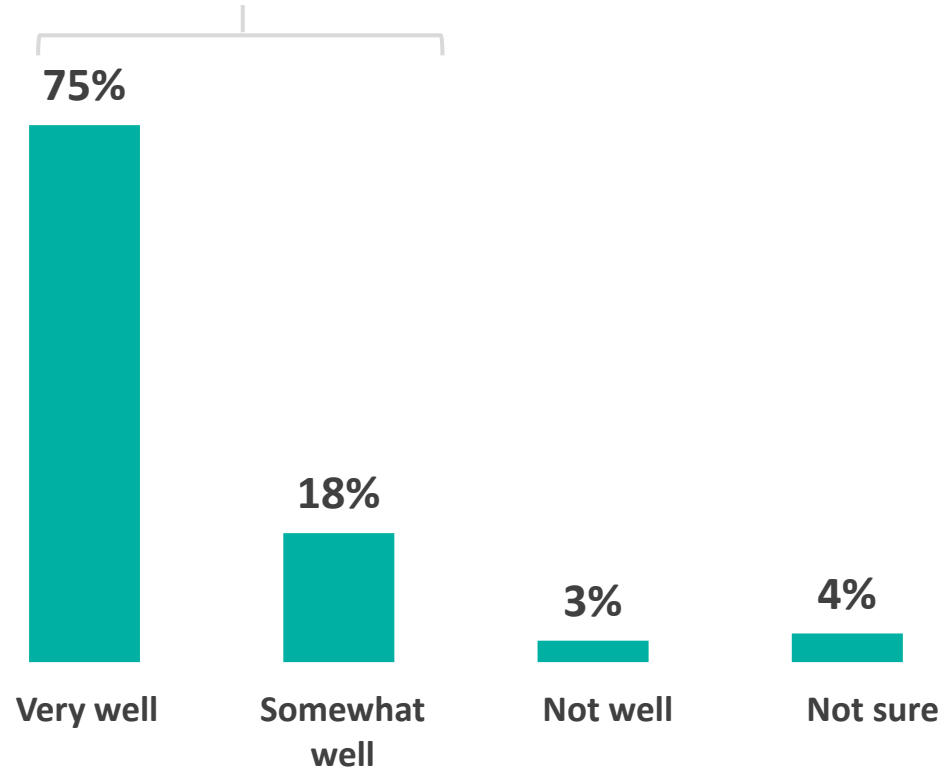
## Where Patients Think They Received Cancer Treatment



**27% of Patients Were Actually Treated at an Academic Medical Center**

# Most give high scores on coordination of care, despite needing to regularly share info across providers

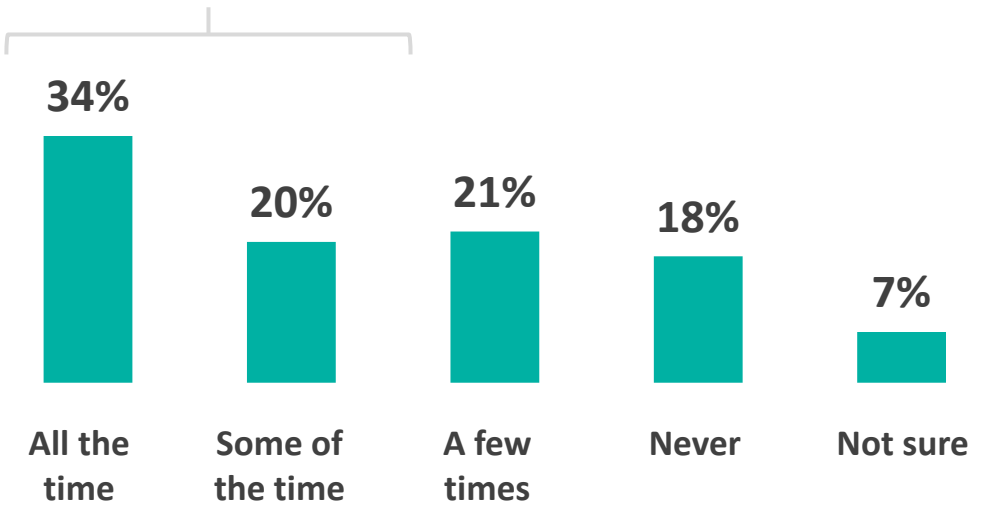
93% say HCP's coordinated care well



NCCS Connected: 54% Very well, 35% Somewhat, 8% Not Well

54% said they had to share info from one health care provider with another

Higher among:  
18-39 (79%)  
Immunotherapy (72%)  
Hispanic/Latino (69%)  
In-treatment (65%)  
Metastatic (67%)



NCCS Connected: 29% All the time, 41% Sometimes, 26% Few/Never

# Majorities feel like their HCPs were approachable and respectful, but there are key demographic differences

Again, there are ...

## Age differences (61% 18-39, 72% 40-64, 77% 65+):

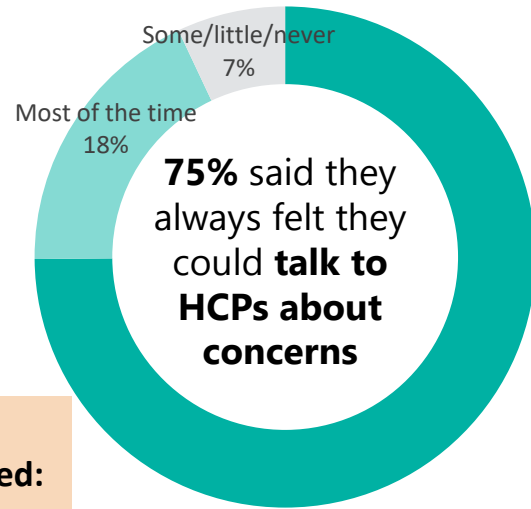
- *They were always in a rush or assumed I didn't know what I was talking about, meanwhile I am a healthcare professional myself. (18-39)*

## Ethnic differences (75% White, 73% Black, 63% Hispanic/Latino):

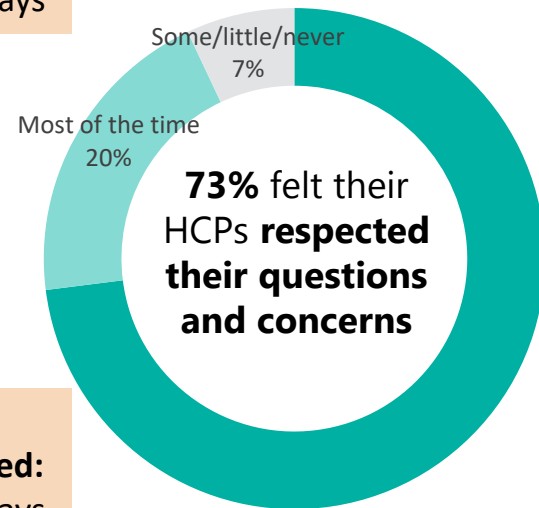
- *Again, some of the doctors, all of them white and male, seemed to project their biases onto me. (Hispanic/Latino)*

## Gender differences (77% Male, 70% Female):

- *Dismissing me out of hand regarding pain - don't feel as a middle-aged woman I am heard. (Female)*



NCCS  
Connected:  
46% Always








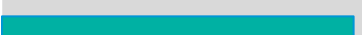

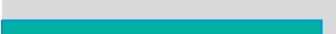

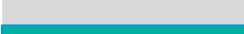


NCCS  
Connected:  
41% Always

# While almost all patients experience at least one side effect, female, Hispanic/Latino, younger, and low-income patients are disproportionately affected

## 84% of Patients experienced at least one symptom

### Symptoms experienced (top 12 out of 24 shown)

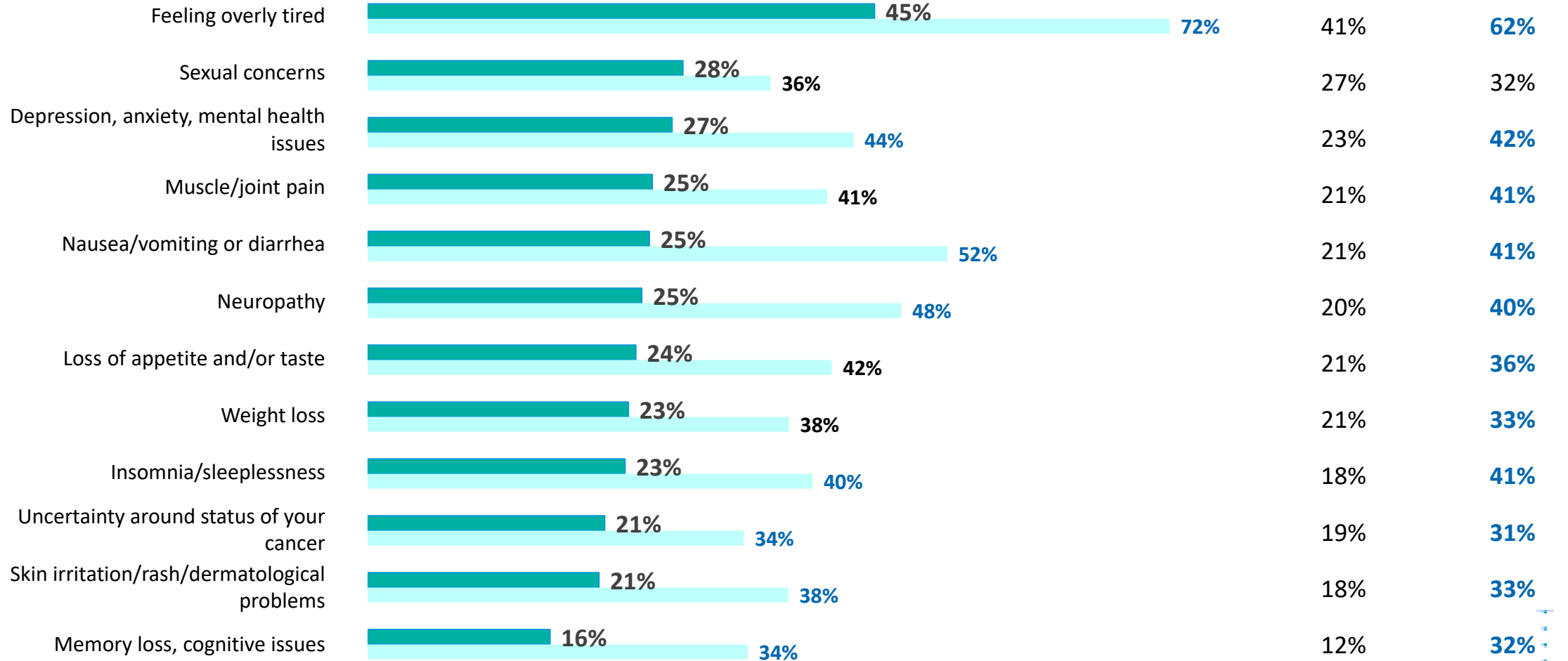
		Male	Female	18-39	Hispanic/Latino	Low income
Feeling overly tired	 45%	34%	56%	61%	53%	57%
Sexual concerns	 28%	38%	19%	27%	26%	17%
Depression, anxiety, mental health issues	 27%	17%	37%	52%	43%	43%
Muscle/joint pain	 25%	16%	34%	39%	33%	40%
Nausea/vomiting or diarrhea	 25%	17%	33%	56%	33%	38%
Neuropathy	 25%	18%	31%	40%	28%	33%
Loss of appetite and/or taste	 24%	18%	30%	48%	32%	34%
Weight loss	 23%	24%	23%	53%	38%	31%
Insomnia/sleeplessness	 23%	14%	31%	40%	36%	28%
Uncertainty around status of your cancer	 21%	21%	21%	26%	21%	28%
Skin irritation/rash/dermatological problems	 21%	12%	29%	30%	22%	22%
Memory loss, cognitive issues	 16%	7%	25%	33%	30%	24%



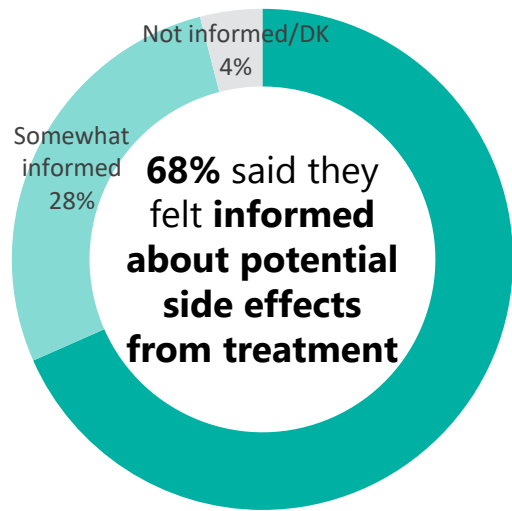
# Metastatic patients are more likely to experience almost all major symptoms tested in the survey

Symptoms reported/recalled decrease as time passes

Symptoms experienced (top 12 out of 24 shown)



# While two-thirds felt informed about side effects, in most cases less than half believe their HCP was very helpful in addressing them (consistent with previous waves)

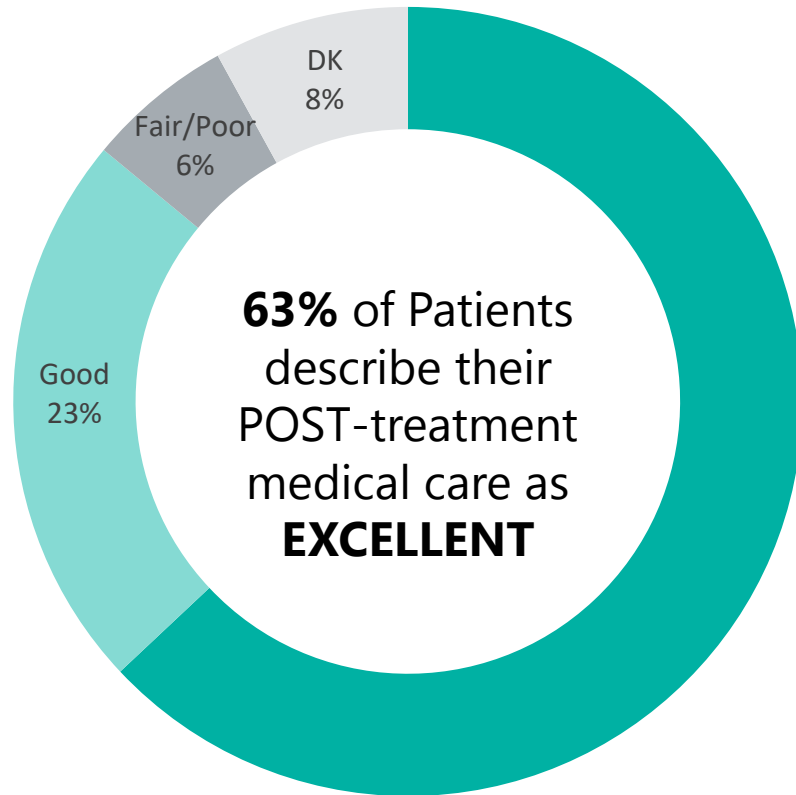


**NCCS Connected: 34% Very informed**

Symptoms experienced (top 12 out of 19 shown)		Health care team very helpful (among those who experienced)
Feeling overly tired	45%	46%
Sexual concerns	28%	35%
Depression, anxiety, mental health issues	27%	47%
Muscle/joint pain	25%	46%
Nausea/vomiting or diarrhea	25%	66%
Neuropathy	25%	44%
Loss of appetite and/or taste	24%	48%
Weight loss	23%	52%
Insomnia/sleeplessness	23%	40%
Uncertainty around status of your cancer	21%	50%
Skin irritation/rash/derm problems	21%	62%
Memory loss, cognitive issues	16%	30%

(scores went up on many items this year)

# The number who describe their post-treatment care as excellent is 12 points lower than how patients' rate their cancer treatment



Topics discuss w/ HCPs during post-treatment care	Total	Excellent	Good	Fair/Poor
Your quality of life	37%	41%	38%	<b>18%</b>
Exercise and nutrition	35%	41%	30%	<b>13%</b>
Your physical function	34%	39%	31%	<b>19%</b>
Mental and emotional impact of illness	25%	29%	23%	<b>12%</b>
Your post-treatment survivorship care plan	20%	23%	18%	12%
Fatigue interfering on your daily life	19%	21%	18%	15%
Pain interfering with your daily life	17%	19%	18%	19%
Access to support groups	15%	18%	13%	<b>4%</b>
Your cognitive function	7%	8%	6%	4%
Health insurance options	6%	6%	9%	-
Financial services/support	5%	5%	7%	2%
Fertility concerns	4%	5%	4%	-
Palliative care/support services	0%	0%	1%	-
Hospice Care	0%	0%	0%	-
None of the above	22%	15%	20%	<b>47%</b>

**NCCS Connected: 38% Excellent, 35% Good, 24% Fair/Poor**

# The Costs of Cancer

# Cancer patients are concerned about a host of physical, emotional, and financial issues (same issues rose to top in 2020)



Physical Health/Adherence	Emotional/Lifestyle	Financial/Insurance
Maintaining healthy weight 56%	Uncertainty about future 56%	Cost of medical care 47%
Having energy for day 50%	Being there for family/friends 48%	Cost of prescriptions 43%
Getting enough exercise 49%	Emotional support you need 37%	Financial support you need 43%
Managing side effects 47%	Mental health support 36%	Understanding insurance 37%
Maintaining proper diet 45%	Maintaining relationships 33%	Non-medical expenses 34%
	Family/caregiver support 33%	Getting/keeping insurance 33%
	Feeling isolated/lonely 33%	

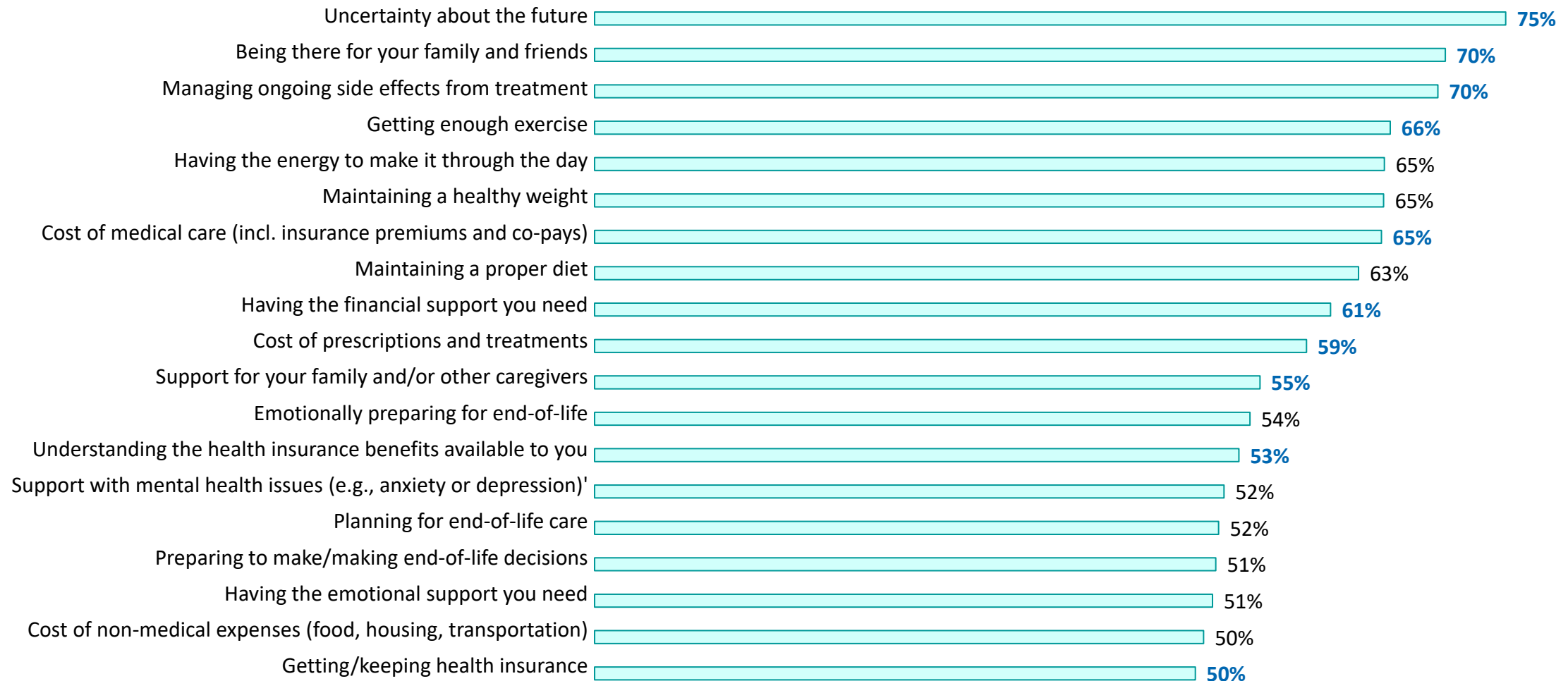
(a third or more concerned about each item about, out of 30 items tested)

# Women, younger, Hispanic/Latino, and low-income patients are more concerned about the range of issues

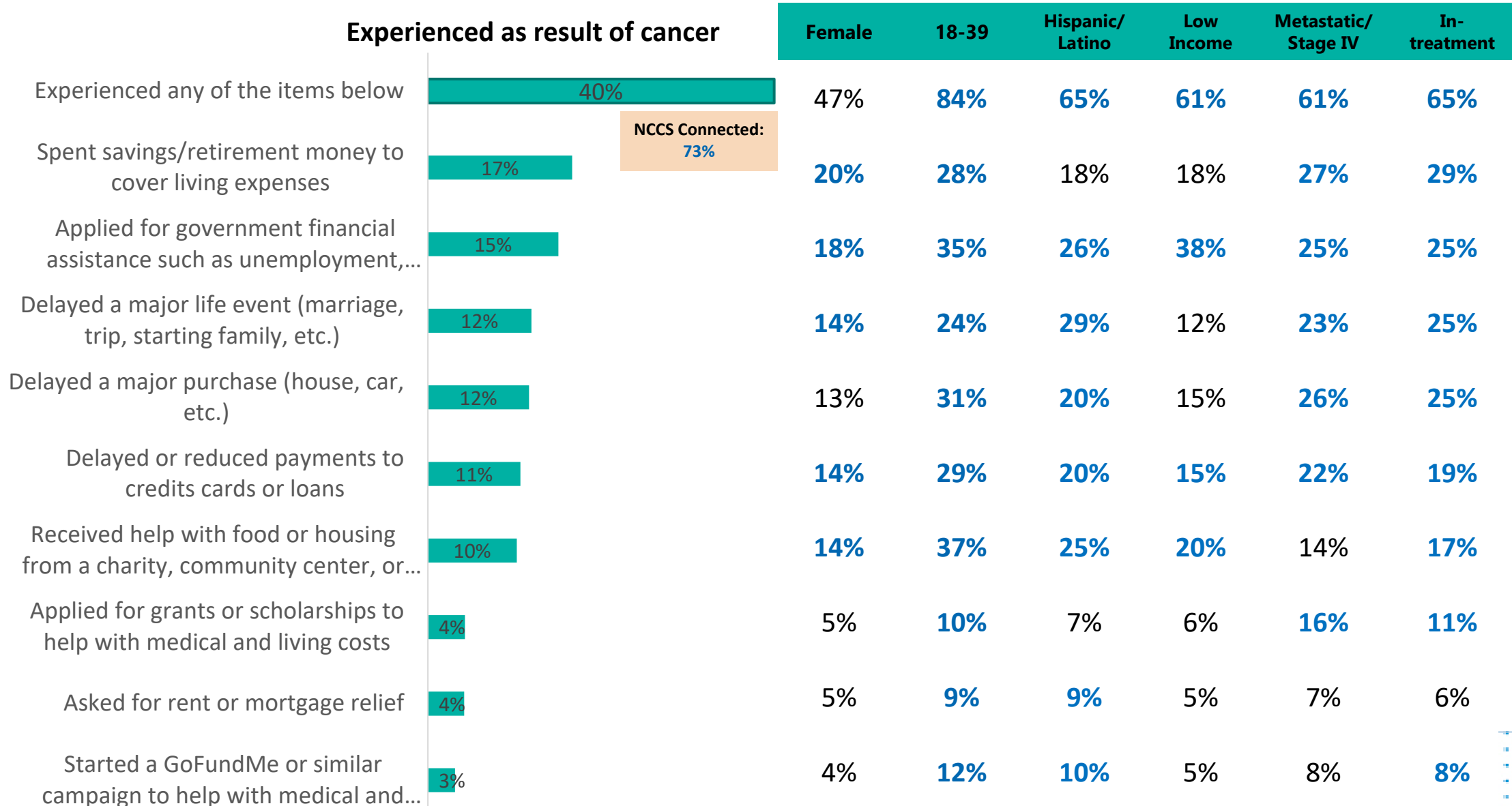
	Physical health/ adherence	Financial/ Insurance	Emotional/ Lifestyle	National Sample	Female	18-39	Hispanic/ Latino	Low Income
Maintaining a healthy weight				56%	63%	78%	73%	63%
Uncertainty about the future				56%	62%	85%	70%	67%
Having the energy to make it through the day				50%	57%	88%	65%	62%
Getting enough exercise				49%	55%	66%	62%	57%
Being there for your family and friends				48%	57%	78%	67%	55%
Managing ongoing side effects from treatment				47%	51%	78%	59%	54%
Cost of medical care (incl. insurance premiums and co-pays)				47%	53%	68%	50%	47%
Maintaining a proper diet				45%	51%	68%	63%	53%
Cost of prescriptions and treatments				43%	51%	68%	50%	46%
Having the financial support you need				42%	54%	81%	64%	56%
Having the emotional support you need				37%	47%	71%	61%	50%
Understanding the health insurance benefits available to you				37%	45%	66%	51%	40%
Support with mental health issues (e.g., anxiety or depression)				36%	44%	75%	57%	48%
Cost of non-medical expenses (e.g., food, housing, transport)				34%	42%	71%	50%	52%
Ability to maintain relationships with significant other, family, friends				33%	37%	66%	54%	41%
Support for your family and/or other caregivers				33%	39%	65%	49%	37%
Feeling isolated and lonely				33%	40%	72%	57%	49%
Getting/keeping health insurance				33%	43%	66%	48%	41%
Loss of income				32%	40%	81%	54%	44%
Long-term planning/career goals				32%	38%	78%	54%	38%
Change/decline in your interest in socializing with others				32%	38%	66%	54%	46%
Managing all of your prescribed medications and other treatments				30%	36%	66%	50%	37%
Cost of professional caregiving				29%	33%	55%	39%	34%
Visiting your doctor regularly				28%	34%	62%	46%	35%
Managing appointments				23%	30%	58%	41%	33%
Work/employment issues, like finding and keeping a job'				22%	29%	70%	46%	27%
Learning how to apply for grants, scholarships, or government benefits to help with medical and living costs'				21%	25%	65%	36%	32%
Getting/keeping disability insurance				20%	27%	57%	39%	31%
Starting a family/having children				9%	9%	54%	28%	10%

# Many concerns are more pronounced/needs are greater for metastatic patients as they face uncertainty and manage side-effects

## Top Concerns (50% or more) among Metastatic/Stage 4 Patients



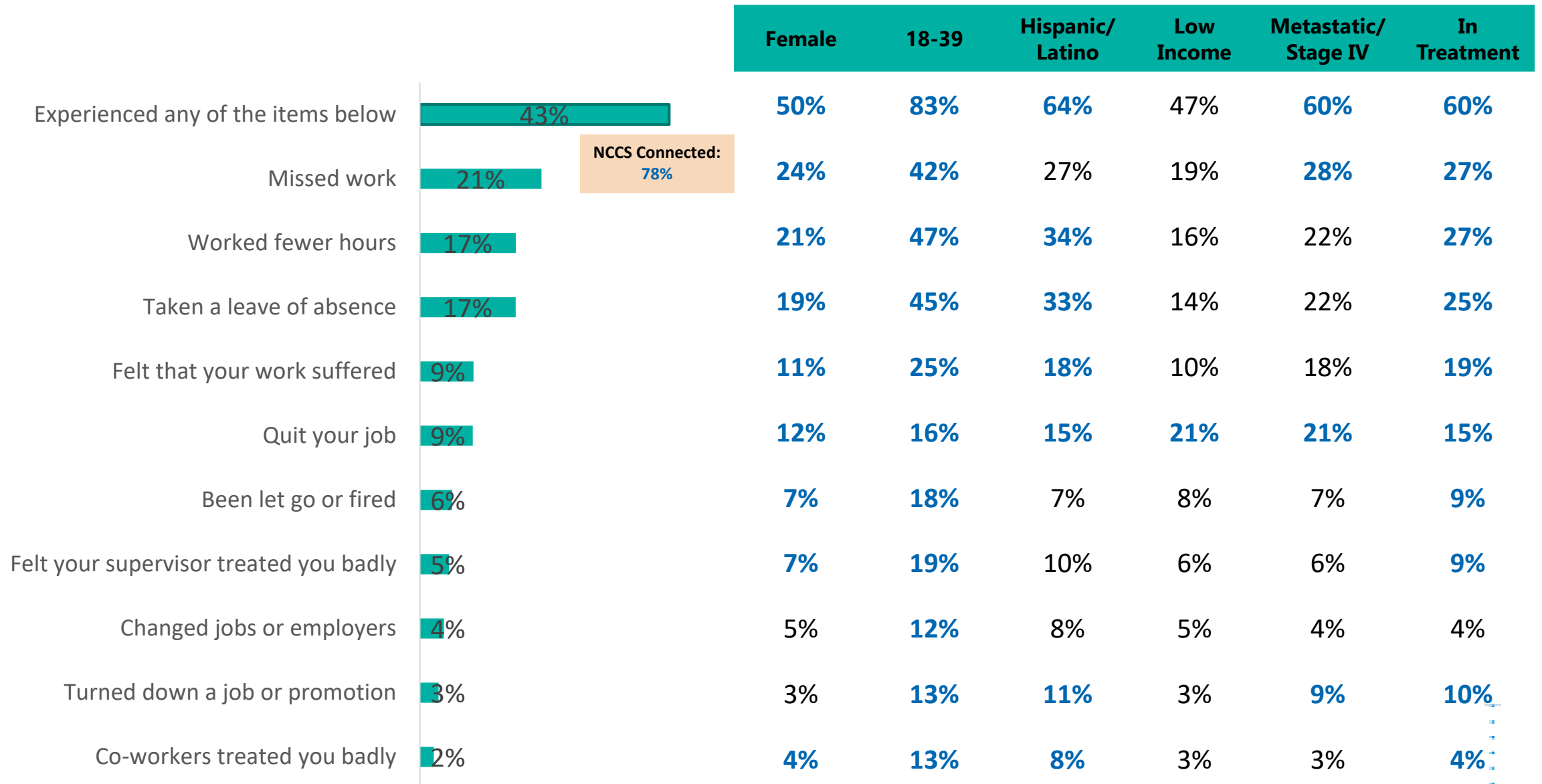
# Four-in-10 overall have made at least one of the following financial sacrifices, with numbers much higher among vulnerable audiences



Source=National Sample, n=1104



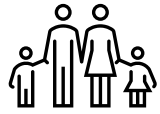
# Similarly, about 4-in-10 have seen their diagnosis impact their work status/environment, with similar groups reporting impact



Source=National Sample, n=1104

Support Systems Are Key

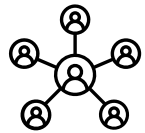
# Consistently in qualitative, patients' #1 piece of advice to others is to have a support system



- **Their immediate family** – while they are typically the main source of support, they also have a stake in the cancer diagnosis



- **Their care team** – many mentioned their nurses and doctors were “cheering them on”



- **Their friend network** – mainly on the fringes, though some had friends stand in for family or a significant other



- **Faith/God** – more talked about their faith more than their physical congregation (though COVID may have impacted this)



- **Support groups** – participants were able to share their experiences as well as resources and tips



- **Social media groups** – provide resources from other cancer patients and survivors

*First my wife, then family, then social media group, keep my mind focused. Normally you live life nonchalantly, INVINCIBLE. Never worried about tomorrow, but now I want to see my nieces and nephews grow up. Mind over matter, positive things will happen, maybe that's my spiritual thing.*

– Male, 39, Stage 2

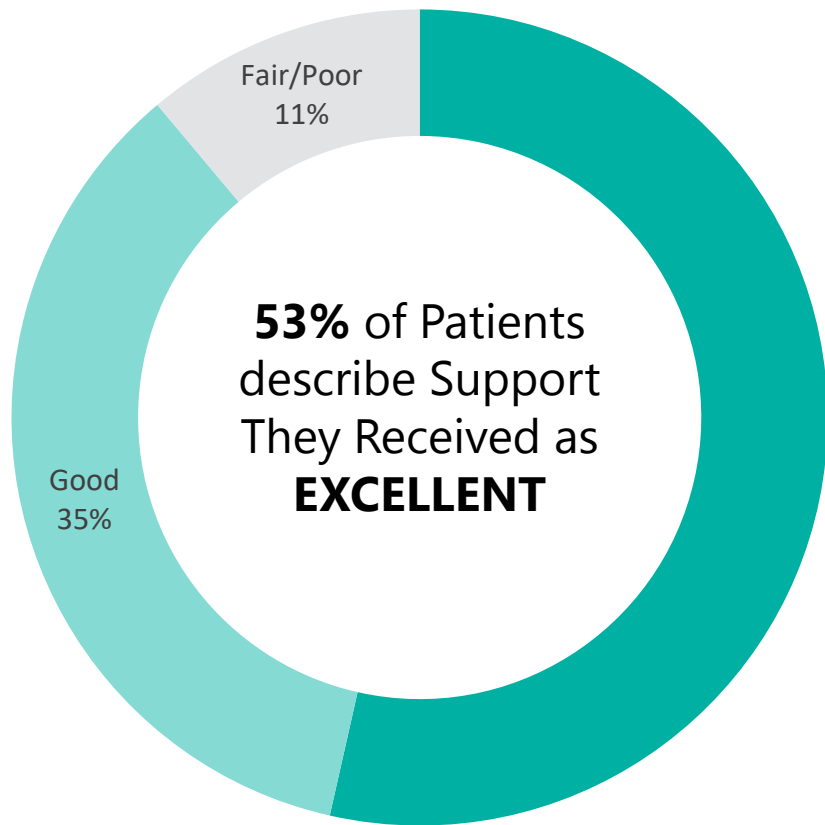
*The most support that I have received has been through my healthcare provider. Oftentimes when you're dealing with family members, some people don't cope well with the diagnosis, I think that it's been harder for my family to cope with it than it has been for me. They haven't been really that great of a support system.*

– Female, 43, Stage 4

*I think prayer does a lot, I believe God hears and answers prayers. Whether I continue to live here or have died, I will be healed because I believe in God. What next, I can't handle this this and this, that lasted for about 20 seconds, until I can do this, and He can give me strength to do this.*

– Male, 71, Stage 4

# About half say the support they have received has been excellent, but this is not universal



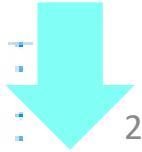
**NCCS Connected: 35% Excellent, 42% Good, 22% Fair/Poor**

Source=National Sample, n=1104

There Are Large Gaps in Perception of Support by Age, Income, Gender, Stage, How Informed Feel About Side Effects, and Quality of Care



65+ ( <b>61%</b> )	18-39 ( <b>29%</b> )
\$100K+ ( <b>61%</b> )	<\$25K ( <b>39%</b> )
Men ( <b>57%</b> )	Women ( <b>49%</b> )
Stage 1 ( <b>59%</b> )	Metastatic ( <b>49%</b> )
Very Informed about Side Effects ( <b>62%</b> )	Not Informed about Side Effects ( <b>22%</b> )
Excellent care ( <b>64%</b> )	Fair/poor care ( <b>4%</b> )



# There is a big difference between those who can rely on family, versus those who cannot

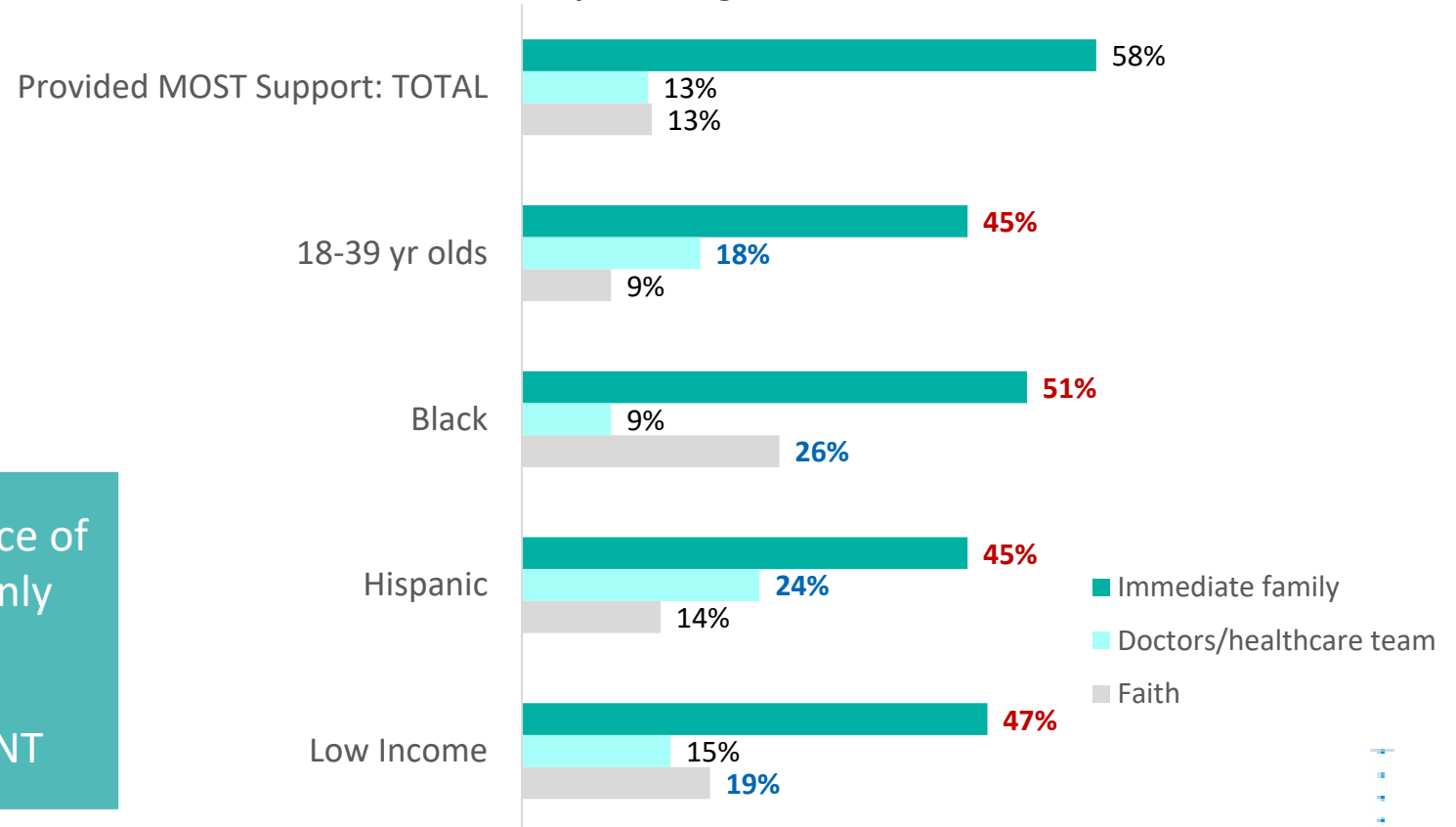
- Compared to others, younger, Black, Hispanic/Latino, and low-income patients rely less on their immediate family. Black and low-income patient are more likely to rely on their faith compared to others

Among those whose main source of support is their immediate family,  
**62%**  
describe support as EXCELLENT

vs.

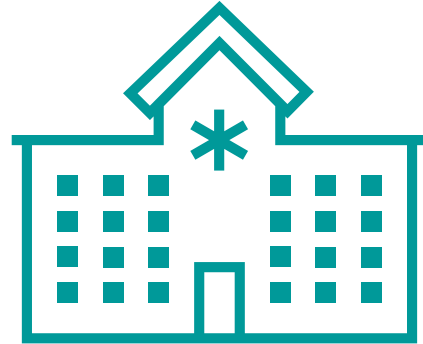
Among those whose main source of support is NOT their family, only  
**40%**  
describe support as EXCELLENT

### Biggest Support System (by demographics)



# Cancer Treatment/Post-Treatment During COVID-19

# The COVID-19 pandemic did not have a huge impact on *perceptions* quality of care



**53%** had a cancer care appointment during the COVID-19 pandemic

**92%** among those still in-treatment



**8%** say their care was better than before the pandemic



**82%** say their care stayed the same



**4%** say their care was worse than before the pandemic

In-treatment: **14%** better, **74%** same, **7%** worse

# Four-in-10 of those who attended appointments used telehealth services



**41%** of those with appointments had them via telehealth

More likely to have a telehealth appointment:

- NCCS Connected (**51%**)
- Stage IV/Metastatic (**59%**)
- Palliative Care (**54%**)
- Private Cancer Center (**54%**)
- In-treatment (**49%**)

	Had Telehealth Appointments	Rate the Appt. Excellent/Very Good
Follow-up appointment(s)	61%	73%
Regular well-visits	34%	77%
Sharing test results	34%	78%
Medication management	24%	75%
Treatment planning and decision-making	20%	77%
First visit with a health care provider	18%	58%
Mental health services	16%	67%
Counseling and education	11%	80%
Surgical consult	9%	78%
Getting a second opinion	4%	58%
Survivorship appointment	4%	89%
Physical therapy/rehabilitation	3%	61%



# Post-COVID, in-person appointments are preferred for most situations, except counseling, medication management, and getting test results

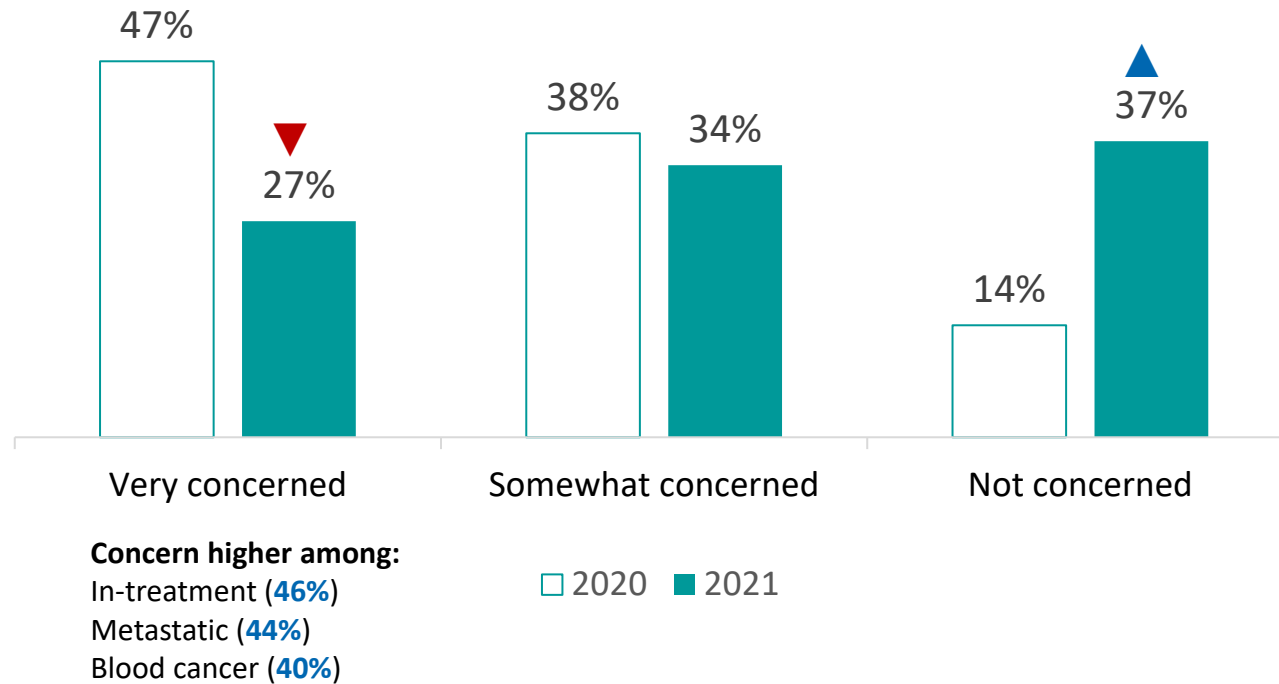
***With the physical therapy, difficult. They're saying its so much better because if you come in, you'll be exposed to COVID, but it's not the same. Let me at least come in one time so I can see what you're doing in-person and then I'll try to do it at home.***  
 – Female, 62, Metastatic

	Prefer in-person	Prefer telehealth/ No Preference
First visit with a health care provider	87%	12%
Physical therapy/rehabilitation	81%	14%
Surgical consult	80%	17%
Getting a second opinion	75%	21%
Regular well-visits	75%	24%
Follow-up appointment(s)	69%	30%
Treatment planning and decision-making	65%	32%
Mental health services	54%	37%
Counseling and education	47%	48%
Medication management	45%	51%
Survivorship appointment	45%	39%
Sharing test results	45%	53%

***It makes it convenient. My refills, and things like that. But there are some things you can't do telehealth, like mammograms.***  
 – Female, 51, Stage 4

# Concern about COVID-19 risk has decreased significantly since 2020, most respondents who took the 2021 survey are vaccinated

As a cancer patient/survivor, how concerned are you about your risk of getting Coronavirus (COVID-19)?



**78%** have received one or both doses of the COVID-19 vaccine

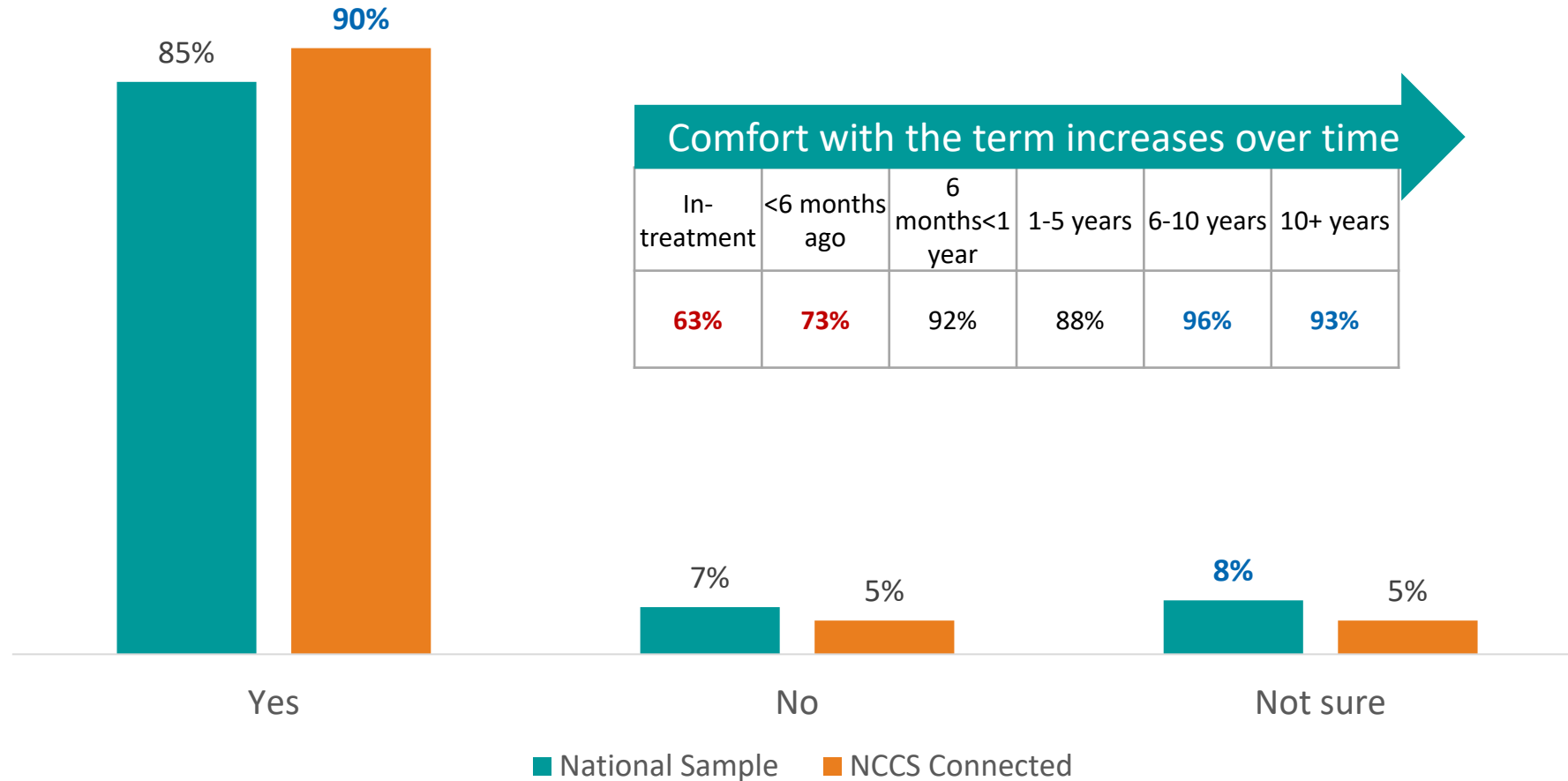
35% of those that haven't are likely to get vaccinated  
20% are neutral  
46% are unlikely

Trust is the biggest issue among those unlikely to get the vaccine

# The Meaning of “Survivorship”

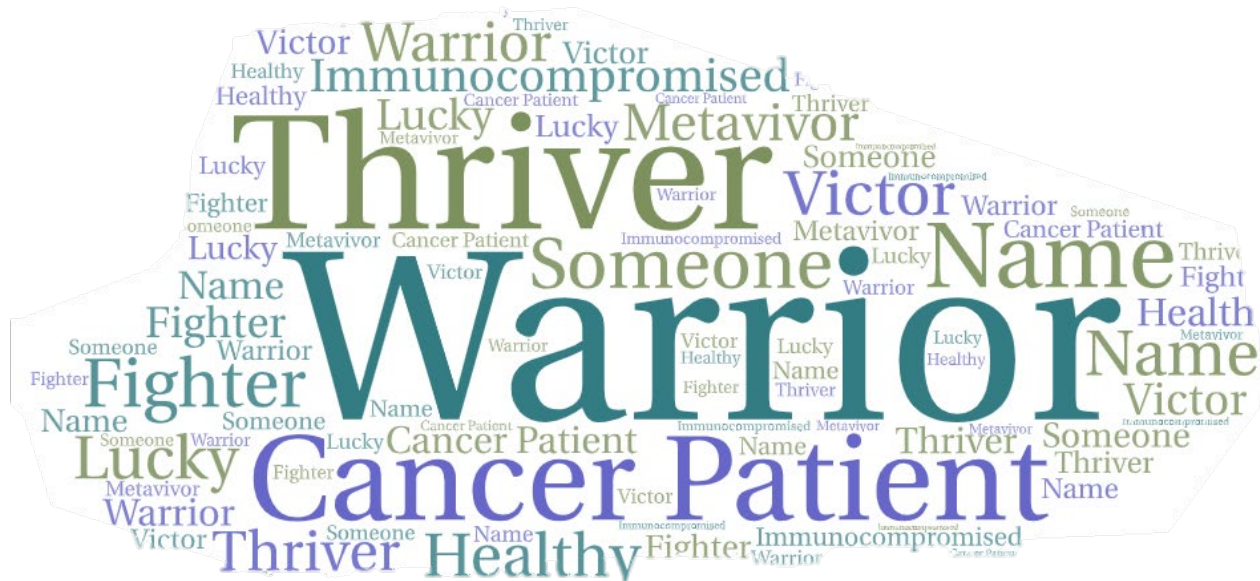
# For most, the term “cancer survivor” resonates

Do you consider yourself a cancer survivor?



Just a few feel that it's not strong enough, or do not want to use this term while still in treatment

Is there another word or phrase that describes you and/or you prefer?



*It seems past tense, but I don't feel like I will ever be done with it. Manage, live with it, keep getting tested, would rather use another word but don't know what it is.*  
– Male, 39, Stage 2

*I like organizations that are not just about getting by, but about living your best life, emphasize living.*  
– Male, 59, Stage 4

# What does a “cancer survivor” mean to you?

*Being a cancer survivor is like getting a second chance at life. It makes you feel differently about every decision you make. It also makes you feel incredibly lucky and gives you a new look on life.*

*- Female, 66, Stage III*

*As far as testing can demonstrate, there are no signs of remaining cancer at this time.*

*- Male, 39, Stage II*

*Being able to live my life peacefully surrounded by family.*

*- Female, 75, Stage IV*

*I feel like anyone is a survivor once they receive a cancer diagnosis.*

*- Male, 59, Stage Not Discussed*

*It means someone living with cancer or who had cancer. I don't like the term because it creates a hierarchy compared with those who have died. Cancer is not something to beat or fight, but to heal and learn from.*

*- Female, 38, Stage III*

*I feel that anyone that fights cancer is a survivor... whether they win or lose the battle.*

*- Female, 60, Stage IV*

*I was diagnosed with cancer, and I am still alive. I worry it may come back and it's something I never tell people and I don't walk around like I'm important as a "survivor."*

*- Male, 48, Stage I*