

STATE OF SURVIVORSHIP

SURVEY: 2022

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

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:

- Measure satisfaction across different points in the cancer journey
- Better understand under-served audiences, who they are, their specific challenges, and how the system can better meet their needs
- Learn more about what "coordination of care" means to patients and how they feel their health team performed, explore trust in the care team
- Continue to explore the costs of the disease time, money, physical and mental health
- · Learn more about experiences with biomarker and genetic testing

Methodology

PHASE 1

PHASE 2

In-depth Interviews with Cancer Patients and Survivors

- Fifteen (15) virtual interviews, approximately 60 minutes-each, April 2022
- Focused on a few audiences:
 5 young adults (18-39);
 5 Hispanic adults (mix of acculturation);
 5 men (non-prostate cancer)
- Nationwide recruit: mix of cancer types, stages, time since diagnosis, treatment status, and income

Nationwide Survey of Adult Cancer Patients and Survivors

- Nationwide sample of n=1408, fielded July 12th – August 8th, 2022
- Oversamples of Stage IV/Metastatic Breast cancer patients to analyze this group with more statistical reliability
- 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 nonprobability 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=670, same field period as nationwide survey
- Emailed invitation to all NCCS email contacts, inviting them to take the survey + 2 reminders

Blue/red = statistically higher/lower by audience | ▲ ▼ = change from 2021 survey Full text of survey questions is in the notes section of slides



Key Findings



Deep Dive into the Cancer Journey

- Over the years, majorities of patients continuously express a high degree of satisfaction with their cancer journey, then in qualitative discussions, there is a disconnect with the many problems they describe. To better understand this dynamic, we conducted an analysis that segmented patients into experiential categories: those who have had mostly positive experiences during their journey, mixed, and mostly negative.
- The results show that part of this is demographic – people of color, younger, and lower SES patients are more likely to be in the Mixed and Negative Experience segments. And part of it is experiential – these patients struggle more at each phase of their cancer journey.

Cancer Journey: Screening and Diagnosis

- The three audiences have significantly different satisfaction levels, starting with screening and diagnosis. While majorities typically have symptoms for up to 3-months and see an average of 2 doctors before they are diagnosed, the Negative Experience segment and many of the under-served groups had symptoms for longer and saw more doctors. Younger patients (18-39) are also 2.5x times more likely to first have a misdiagnosis.
- A little over half of patients say they were proactive in reading up on their diagnosis and treatment options, while around 1-in-10 admit to sticking their head in the sand, ignoring symptoms, delaying going to the doctor, and/or not doing any background research. The top info sources are HCPs, healthcare websites, and Google.





Cancer Journey: Treatment and Care

- Almost three-quarters overall report being very satisfied with their treatment and care, thanks to a high degree of trust in and rapport with their health care team.
- But again, large disparities exist between those in the Negative Experience segment, including many underserved audiences.
 They give health care providers lower scores across the board, and use terms like "bullied," "ignored," "test subject," and "rushed" to describe their care.
- There is also a disconnect on feeling as if care is well-coordinated, yet still needing to share information from one provider to the next regularly. This, too, helps contribute to a negative treatment experience.



Key Findings



Cancer Journey: Post-treatment Care

- While 6-in-10 say they are satisfied with their post-treatment care, this is notably 10-points lower than satisfaction with in-treatment care. When you get into specifics, only 4-in-10 say their HCP did a good job transitioning them to this phase.
- Patients tend to have low expectations at this stage. While majorities say their HCP discusses follow-up tests and monitoring, far fewer talk about quality of life and other physical and mental health issues.
- Those in the Negative Experience group want their team to be more proactive in discussing a host of post-treatment issues, including mental health, exercise, nutrition, and the fatigue and pain they still experience.

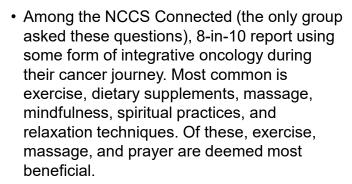


Costs of Cancer

- Over the last several years of surveys, the same physical, emotional, and financial issues have emerged as top concerns. But this year, the number who experience/d each is up across the board, particularly on the financial front (most likely tied to concerns about rising costs/inflation generally).
- About half of patients' report being impacted financially and making employment and/or educational sacrifices because of their cancer care.
- In all these areas the Negative and Mixed Experience groups, as well as under-served audiences, over-index.



Integrative Oncology



• 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.





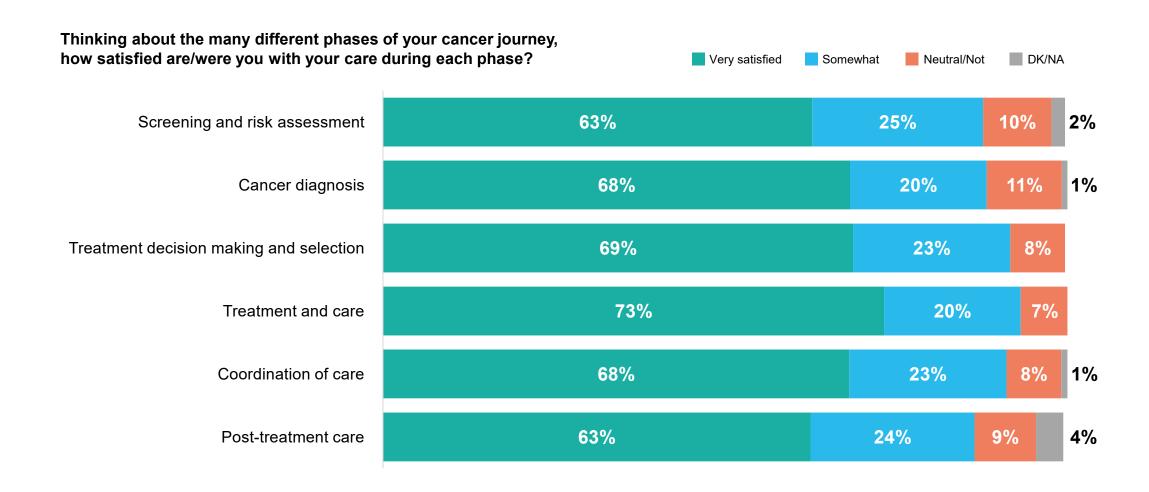


Deep Dive into The Cancer Journey



Satisfaction with Cancer Journey

Majorities of patients report a high degree of satisfaction at each stage of their cancer journey.



Satisfaction with Cancer Journey: The Disconnect

Yet in qualitative research, there is often a **disconnect** between the ratings patients give and the journey they describe



I was very satisfied. They were very attentive to my questions... they were just very available to patients...

Before I was diagnosed it took them three years to find out that I had cancer. I think the doctors in general should do a better job at believing when people say they're in pain... instead of blowing it off, might be psychosomatic and stress. But three years,... maybe that's why they were more attentive to me.

- Young Adult



My lower back was hurting really bad, and... everyone kept telling me there was nothing wrong... [I went] to the emergency room and they said, "We're going to give you a CT scan just to prove nothing wrong with you," because I had been going for three or four months. They did a CT scan and said, "We're going to... have you taken to MD Anderson." which is the cancer

[Satisfaction] is pretty much a 5... I'm here, so I'm good.

place in Houston.

- Male



I was actually initially misdiagnosed. They had thought it was melanoma, so I went through the surgery and chemo, and then I just kept having these skin lesions pop up... I decided to look into it a little deeper and found out that it was actually fibrous histiocytoma. So that diagnosis came about 18 months later.



- Male



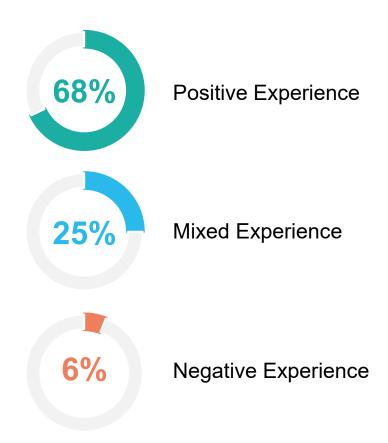
Understanding the Range of Experiences

This disconnect lead us to do a deeper dive and try to better understand how different audiences experience the cancer journey. For those who do NOT have a positive experience, who are they, what challenges do they face, and how can the system better meet their needs?

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





Audience Satisfaction Across Cancer Journey

This gives you a sense of how far apart the different groups are in their experiences on every dimension.





Audience Demographics

Part of the audience differences is related to demographics and where they are in their cancer journey.

	Positive Experience		Mixed Ex	xperience	Negative Experience	
Gender	50% female	50% male	54% female	46% male	57% female	41% male
Race/Ethnicity	84% White 8% Black 6% Hispanic		74% White 10% Black 15% Hispanic		67% White 20% Black 8% Hispanic	
Age	45 % under 65	55 % 65+	65 % under 65	35 % 65+	57% under 65	43 % 65+
	6% 18-39 39% 40-64		9% 18-39 56% 40-64		12% 18-39 45% 40-64	
Education	49% no college	51% college	49% no college	51% college	64% no college	36% college
Income	34% below \$50K		31% below \$50K		51% below \$50K	
Financial Impact	40% Impacted financially		62% impacted financially		65% impacted financially	
Employment Sacrifices	50% made sacrifices		68% made sacrifices		58% made sacrifices	
Treatment Status	78% completed	22% still in	65% completed	36% still in	57% completed	43% still in
Stage at Diagnosis	36% Stage 1 17% Stage 2	14% Stage 3 9% Stage 4	21% Stage 1 21% Stage 2	13% Stage 3 25% Stage 4	24% Stage 1 13% Stage 2	18% Stage 3 24% Stage 4
Current Health Status	11% Excellent 52% Good	31% Fair 6% Poor	3% Excellent 41% Good	41% Fair 14% Poor	4% Excellent 28% Good	40% Fair 26% Poor

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

- More female
- POC
- Younger
- Lower SES

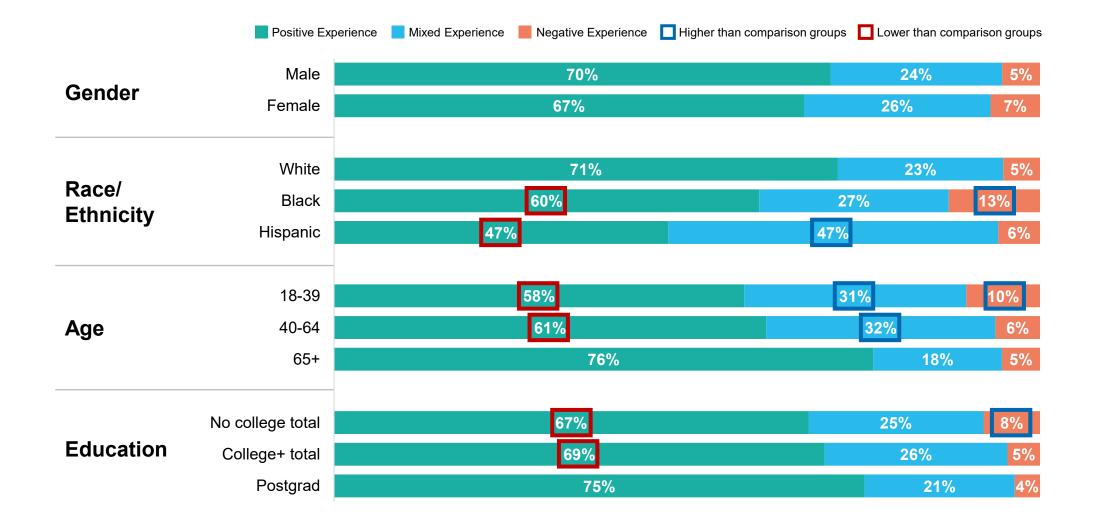
As well as:

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





Experience by Demographics





Cancer Journey: Screening and Diagnosis



Audience Experiences: Screening and Diagnosis

Part of the audience differences are about very different experiences during each stage of their cancer journey.

Mean satisfaction scores (1 very dissatisfied – 5 very satisfied)



Screening & Risk Assessment



Cancer Diagnosis

What's going on at the early stages?

 The Negative Experience Group Had Symptoms for Longer:

The Negative Experience group is more likely to have symptoms for longer prior to diagnosis (51% 3 months+); vs. Positive, where 4-in-10 (40%) had no symptoms before they were diagnosed

They Saw More Doctors Prior to Diagnosis:

The Negative Experience group saw substantially more doctors (3.6) before they received a cancer diagnosis vs. the Positive group (1.78 average)

 And They Are More Likely to be Misdiagnosed:

The Negative Experience group was more likely to be misdiagnosed (20%) vs. Mixed (14%) or Positive (12%) groups



Length of Symptoms

While majorities are diagnosed by the 3-month mark, it takes some groups notably longer to receive their diagnosis.

No symptoms			After				
	before diagnosis	1 month	3 months	6 months	12 months	5 years	5 years
National Sample	36%	48%	66%	79%	87%	95%	97%
Women	37%	50%	68%	80%	88%	96%	98%
18-39 year olds	7 60/-	27%	51%	71%	85%	93%	96%
Black	26%	33%	51%	67%	84%	97%	99%
Hispanic		21%	45%	65%	80%	96%	99%
Living with Metastatio		16%	36%	62%	84%	97%	98%
Negative Experience	17%	29%	46%	62%	82%	93%	95%

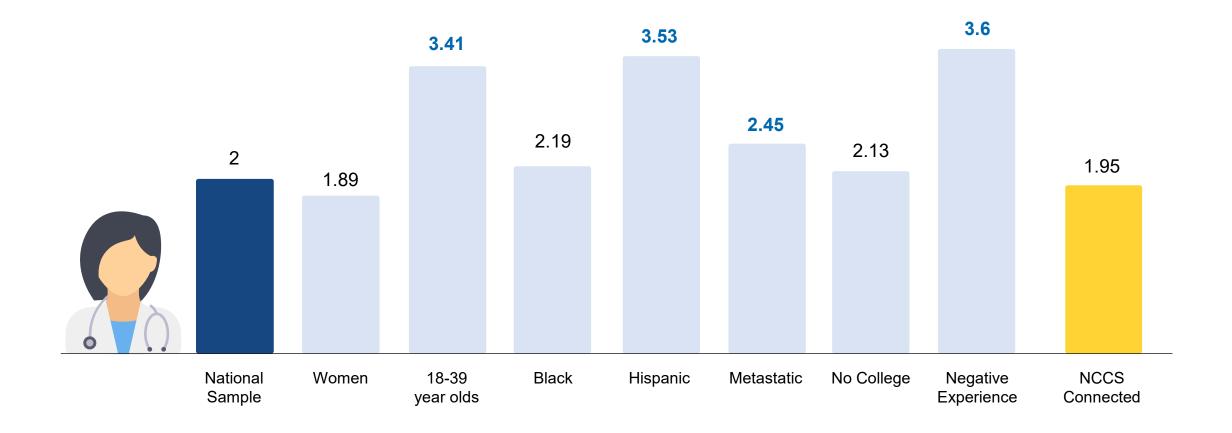
NCCS
Connected
group
significantly
more likely to
say they had
symptoms for
less than
three months.

After twelve months, one fifth of Hispanic patients and those in the Negative Experience group still await their diagnosis.



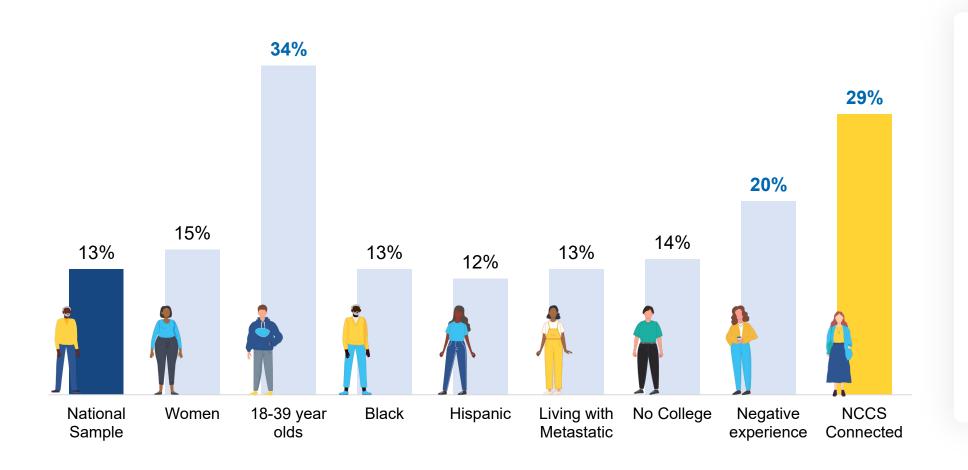
Doctors Seen to Receive Initial Diagnosis

On average patients see two doctors before getting their initial diagnosis, though People of Color, younger survivors, and people living with metastatic cancer tend to see more.





Misdiagnosis



- Slightly more than 1-in-10 report an initial misdiagnosis.
- Misdiagnosis is 2.5x more likely among 18-39 year olds than other patients.
- The NCCS
 Connected group is
 2x as likely to have
 had a misdiagnosis.



Understanding Diagnosis & Treatment Options

- Those in the Positive Experience group, who skew upper SES, are more likely to report being proactive.
- There is also a correlation among those who had genetic and/or biomarker testing.
- About 1-in-10 admit in the sand. This group skews female and POC; they are also more likely to still be in treatment.



"I want/wanted to find out all I can/could about my cancer diagnosis and my treatment options"

Higher among:

- Positive **Experience** group
- Biomarker Testing
- Genetic Counseling
- HHI \$100k+
- College Degree+
- STEM Background



Describes perfectly

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

Higher among:

- In Treatment
- Women
- Black
- Hispanic
- Metastatic **Breast Cancer**
- Immunotherapy
- Misdiagnosed



10% tried to ignore symptoms and 9% delayed going to the doctor for as long as they could before getting a diagnosis (higher among **Negative** and **Mixed Experience** groups)









Information Sources

Patients top 3 cancer information sources are materials provided by their HCPs, healthcare websites, and Google. The NCCS Connected group relies on patient advocacy organizations.

Top 3 cancer information sources



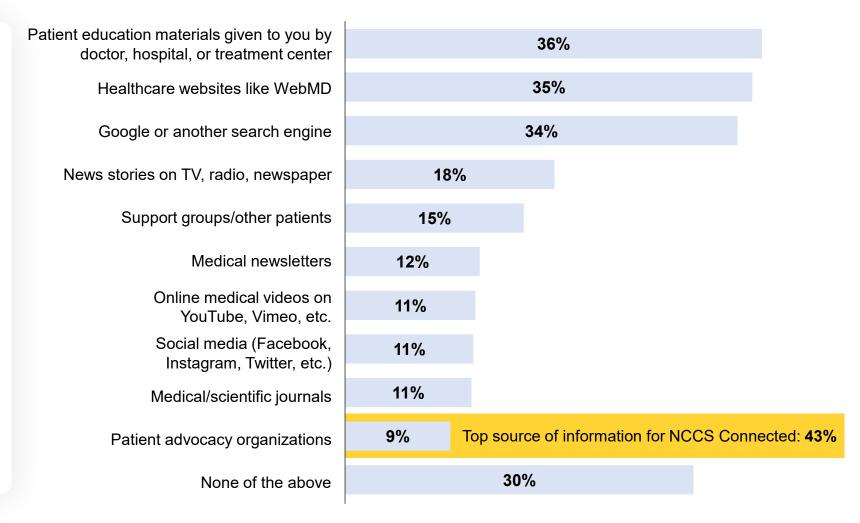
Patient education materials given to you by doctor, hospital, or treatment center



Healthcare websites like WebMD



Google or another search engine

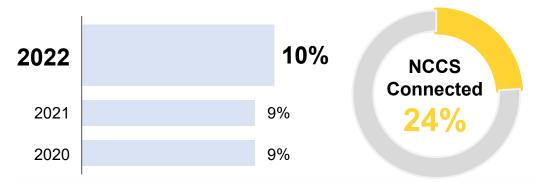




Clinical Trials

Participation in clinical trials is on-par with previous years at 10%.

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

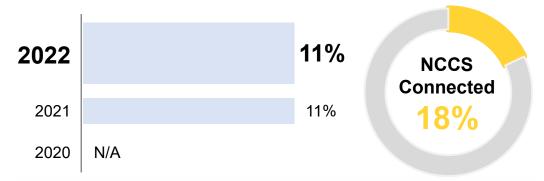


Higher among:

- 25% Metastatic Breast Cancer
- 23% Younger (18-39)
- 21% Stage IV/Metastatic
- 21% Palliative Care
- 20% Immunotherapy
- 20% Biomarker Testing

- 20% Private Cancer Center
- 18% Targeted Drug Therapy
- 17% Genetic Counseling
- 17% Still In Treatment
- 16% Chemo
- 15% Urban

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



Higher among:

- 27% Younger (18-39)
- 26% Metastatic Breast Cancer
- 24% Black
- 20% Immunotherapy
- 20% Still In Treatment

- 19% Private Cancer Center
- 18% Palliative Care
- 18% Chemo
- 17% Targeted Drug Therapy
- 14% Private Insurance





Cancer Journey: Treatment and Care



Treatment Decisions

Once again, pluralities say they relied on their doctor to make their treatment decisions. Fewer report self-advocating vs. last year, though still more than in 2020 when we first asked the question.

	2020	2021	2022	NCCS Connected
I rely/relied on the doctor to decide on treatment options and chose the best course of action.	61%	44%▼	47% 49% Positive experience group	33%
Somewhere in the middle	18%	22%	26%▲	29%
I am/was very involved in researching and deciding on the best treatment options for me.	22%	33% ▲	27%▼	38%

More Likely to be Involved in Decision- Making:

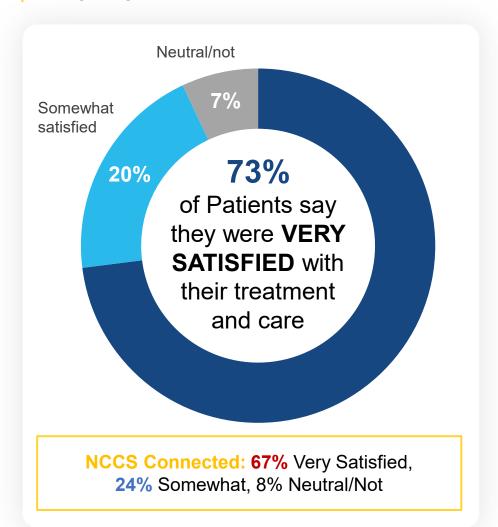
- 46% Younger ages (18-39)
- 42% Clinical trial
- 42% Treated at private cancer center
- 40% Prostate cancer
- 38% Misdiagnosed
- 37% HHI \$100k+
- 37% Metastatic breast cancer
- 35% Palliative care
- 35% Biomarker testing
- 34% Genetic counseling
- 33% STEM background
- 30% College degree+



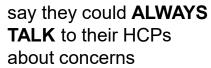


Satisfaction with Treatment and Care

Most cancer patients nationally say they are "very satisfied" with their treatment and care, and they have a high degree of trust in their health care team; but there are disparities in these opinions.







Lowest among:

- 66% Women
- 64% Black
- 63% Under 65
- 57% In Treatment
- 50% Metastatic
- 46% Hispanic
- 54% NCCS Connected





Lowest among:

- **65%** Women
- 62% Under 65
- 58% In Treatment
- 47% Metastatic
- 47% Hispanic
- 52% NCCS Connected



say they TRUSTED their HC team COMPLETELY

Lowest among:

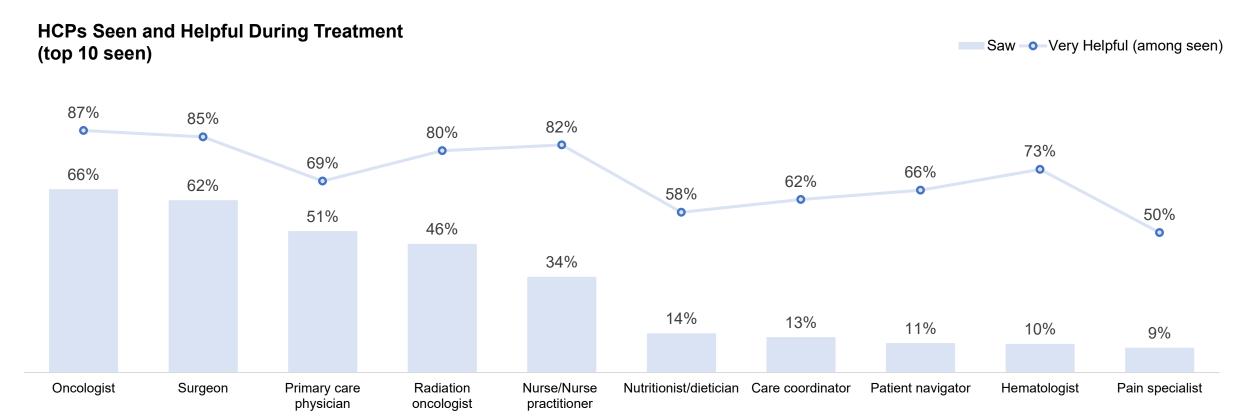
- **72%** 18-39
- 72% In Treatment
- **72%** Black
- 66% Metastatic
- 63% Hispanic
- 74% NCCS Connected





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.



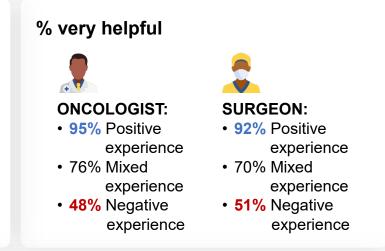
NCCS Connected: more likely to see a range of HCPs. Lower scores on helpfulness for PCP, Nutritionist.

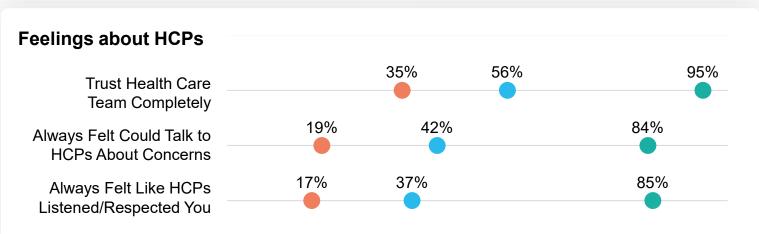


Audience Experiences: Treatment and Care

There are large discrepancies by group on HCP ratings, trust, and rapport.

Treatment and Care Mean Satisfaction Score on Treatment and Care (1-5) 4.93 4.24 Positive Mixed Negative experience experience experience





"Made me feel safe"

"Understood what I was going through"

"Built a relationship"

"Interested in me and my family"

"Compassionate and good eye contact"

"Never rushed, patient"

"Contact by phone or online, quick response"

"There, day and night"

"Open and honest"

Positive Experience Feedback



"Bullied"

"Ignored"

"Acted as if I was lying about my symptoms"

"Telling me I was over-reacting"

"If you had better insurance, we would have taken better care of you"

"Number instead of a patient with individual needs"

"Rushed"

"Felt like a test subject"

Negative Experience Feedback



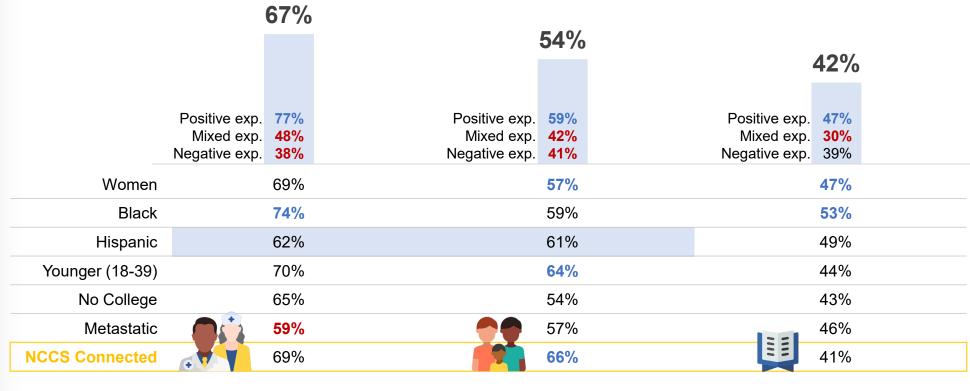




Support During Treatment

- More patients say their healthcare team were a critical support network during treatment, vs. family or faith.
- Negative and Mixed Experience groups are lacking in all forms of support.
- For Hispanic patients, family/ friends are as important as the healthcare team.





My **HEALTH CARE TEAM** is/was critical in helping me through my cancer treatment

My **FRIENDS AND FAMILY** are/were critical in helping me through my cancer treatment

My **FAITH** is/was critical in helping me through my cancer treatment



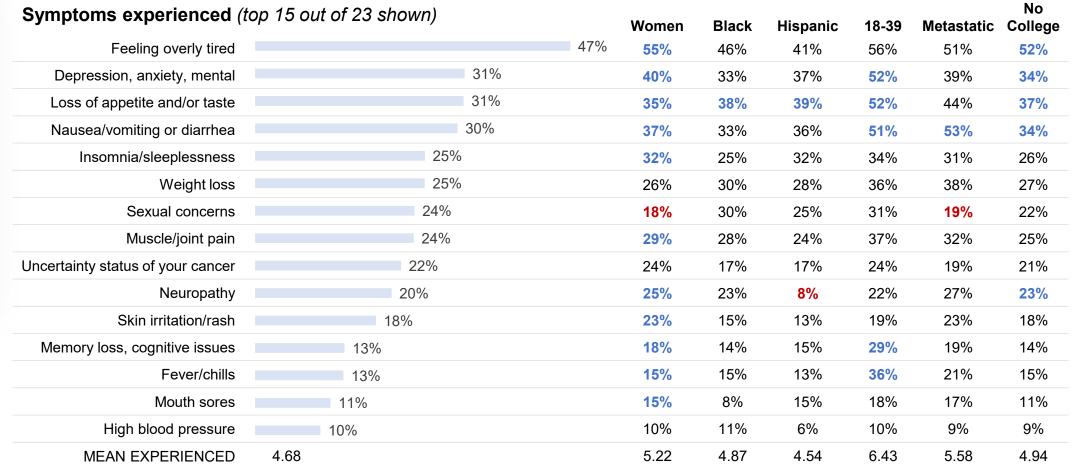


Symptoms Experienced During Treatment

Female, younger, and less educated patients are disproportionately affected by treatment symptoms.



of Patients
experienced
at least one
symptom
during
treatment



Positive Exp.: 4.58 | Mixed Exp.: 4.76 | Negative Exp.: 5.32



Treatment Symptoms: During, After, and Still Today

- 6-in-10 still experience symptoms today, mental health and sexual issues are most likely to be prolonged.
- The Negative Experience group is more likely to still be experiencing a host of issues.

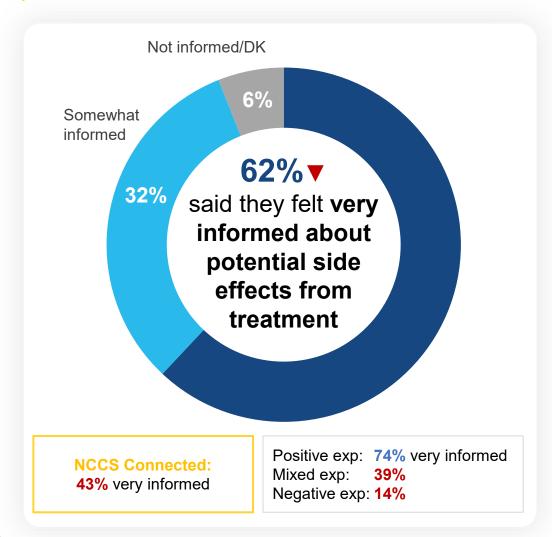
Symptoms experienced (top 15 out of 23 shown)

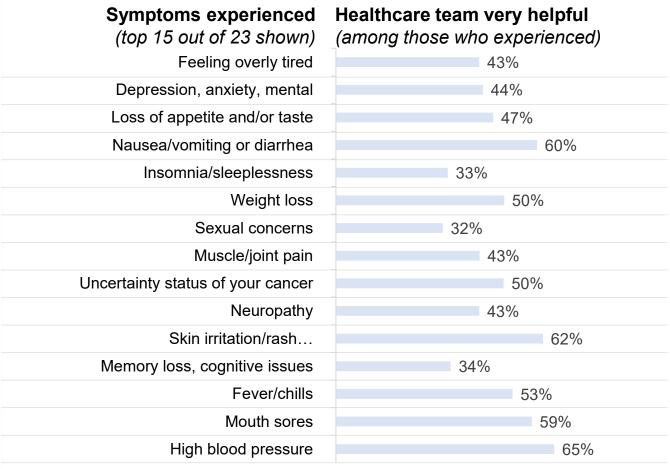
	During Treatment	After Treatment Completed*	Still Today*
	86% experience symptoms	74 % experience symptoms	60% experience symptoms
Feeling overly tired	47%	28%	14%
Depression, anxiety, mental	31%	22%	★17%
Loss of appetite and/or taste	31%	13%	3%
Nausea/vomiting or diarrhea	30%	9%	3%
Insomnia/sleeplessness	25%	14%	★ 11%
Weight loss	25%	10%	2% ■
Sexual concerns	24%	22%	★19 %
Muscle/joint pain	24%	12%	★ 12%
Uncertainty status of your cancer	22%	17%	★ 7%
Neuropathy	20%	15%	15%
Skin irritation/rash	18%	6%	4%
Memory loss, cognitive issues	13%	10%	7%
Fever/chills	13%	4%	2%
Mouth sores	11%	2%	★ 2% ■
High blood pressure	10%	7%	9%
MEAN EXPERIENCED	4.68 symptoms	3.07 symptoms	2.56 symptoms
		Positive Exp.: 2.97 Mixed Exp.: 3.27 Negative Exp.: 3.93	Positive Exp.: 2.63 Mixed Exp.: 2.97 Negative Exp.: 3.65



Addressing Symptoms

There are also large distinctions by audience on how informed they felt about potential side effects. For many of the most common symptoms, less than half believe their HCP was very helpful in addressing them.





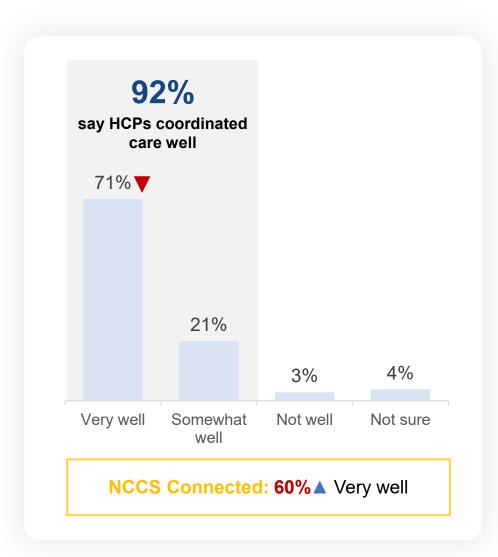
(Although not statistically significant, scores went down on many items this year)

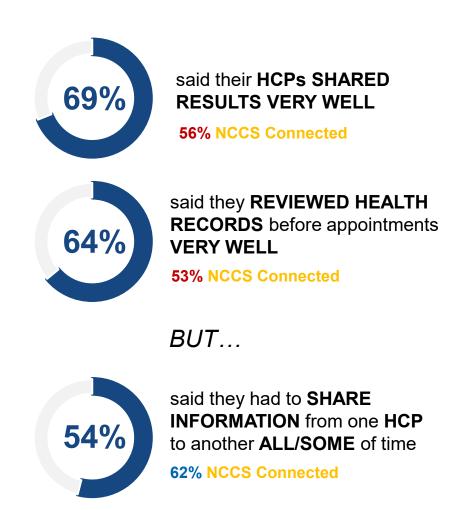




Coordination of Care

Once again, there is a disconnect on feeling as if care is well-coordinated, yet still needing to share information across providers regularly.

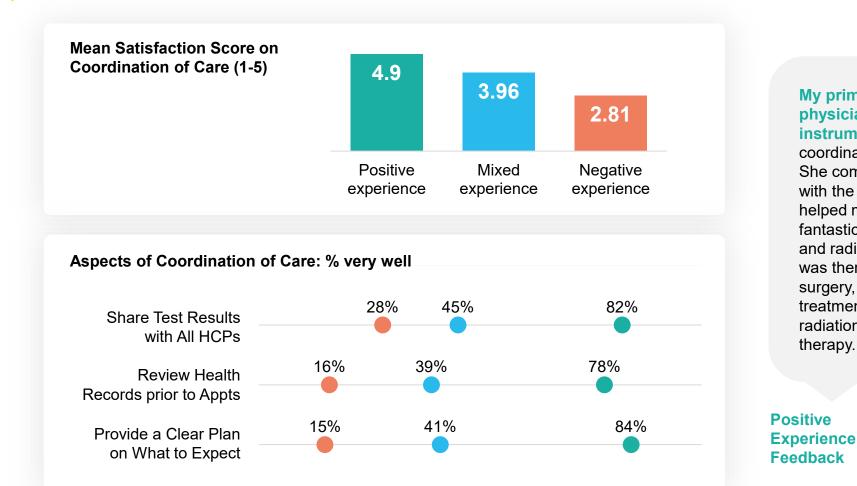






Audience Experiences: Coordination of Care

This is another issue that impacts satisfaction with the cancer journey.



My primary care physician was instrumental in coordinating my care. She communicated with the surgeon, helped me find a fantastic oncologist and radiologist. She was there through the surgery, chemo treatments and radiation therapy.

I often filled out forms with new information that was never looked at, and then I repeat the information verbally in the room with a nurse before the doctor got there, who also never referred to anything.

Negative Experience Feedback



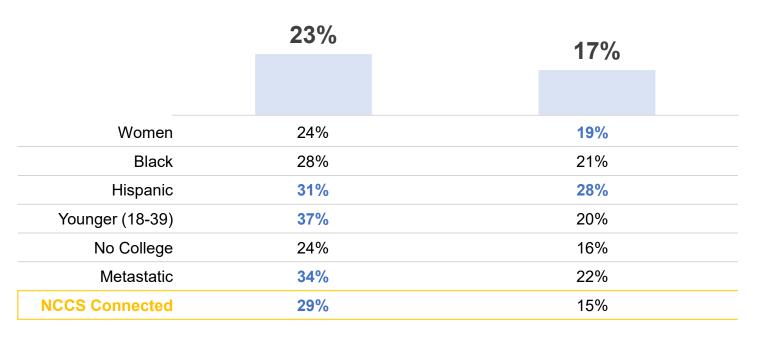




Cancer Stigma

Few feel a stigma around their cancer diagnosis; however, younger, female, Hispanic, and people living with metastatic cancer are less comfortable telling people they have/had cancer and/or feel more pressure to remain "strong" during treatment.

% Describes me perfectly



I feel/felt a lot of pressure from others to remain strong during my cancer treatment I feel/felt uncomfortable telling people that I have/had cancer

I will love to go to like a group therapy or something with other women that have been through this, because if I talk to my family, I have to be strong ... I feel like I have to pretend like it's going to be okay. Like I'm just getting a tooth pulled out.



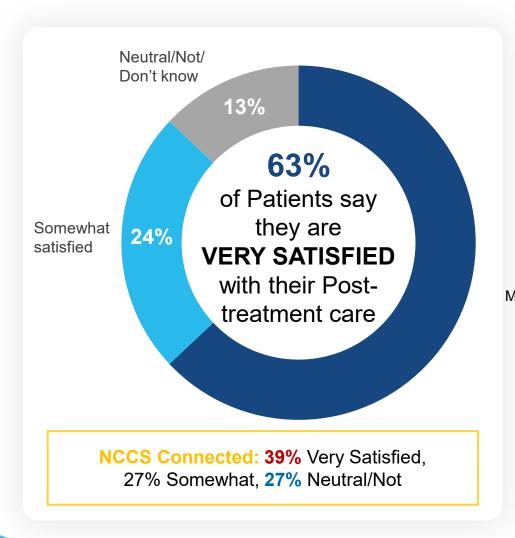


Cancer Journey: Post-treatment Care



Satisfaction with Post-treatment Care

While majorities say they are very satisfied with their post-treatment care, this is 10-points lower than satisfaction with in-treatment care; and less than half say their provider did a very good job helping them make the transition.





BUT...

Just 45% say **HCP DID A VERY GOOD JOB** of helping transition to post-treatment care with another provider (28% DK)

26% NCCS Connected | 23% Not Well

Which topics do your HCPs discuss with you regularly during your post-treatment care? (Completed Treatment)



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

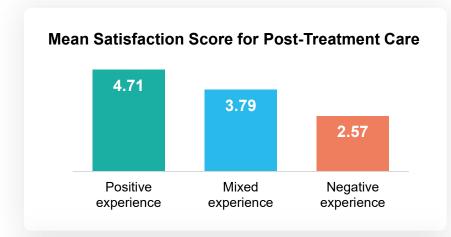
63%

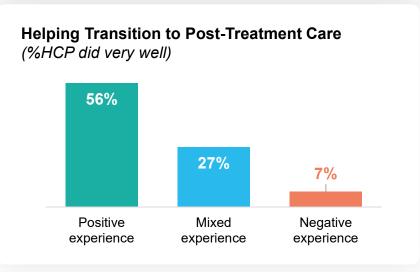


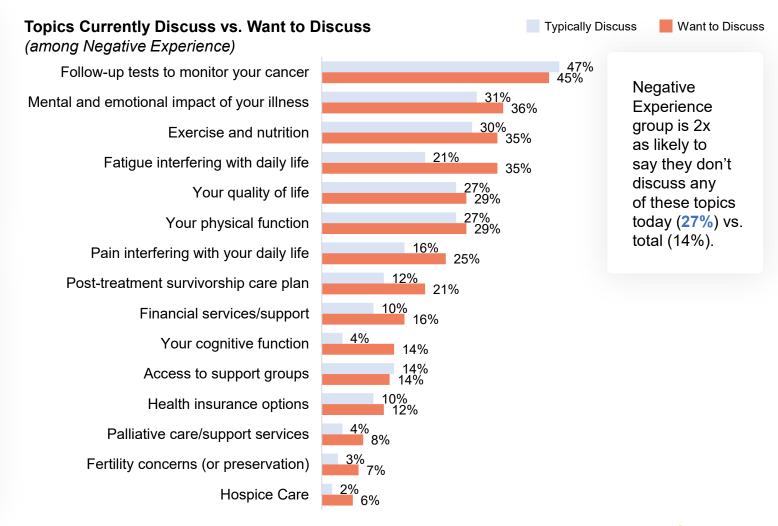


Audience Experiences: Post-treatment Care

This is another area where the Negative Experience group has decidedly different experiences. There are several places where they want to see their post-treatment care team be more proactive.



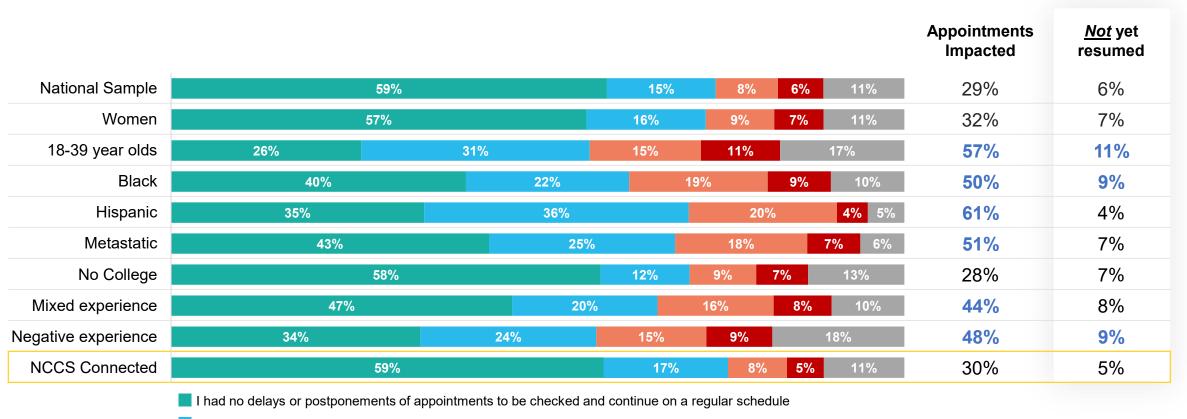






COVID-19 Impact on Surveillance Appointments

The pandemic was more likely to impact surveillance appointments among younger, Black, Hispanic and people living with metastatic cancer (and the Mixed and Negative Experience groups where they over-index).



Appointments were delayed during the COVID-19 pandemic but still got checked during that time

N/A

Did not get checked during the COVID-19 pandemic but have resumed checks

Have not been checked since the start of the COVID-19 pandemic and have yet to resume monitoring/surveillance checks



The Costs of Cancer



Top Financial, Physical, and Mental Health Concerns

Over the last few years, NCCS has tracked a variety of concerns. While the same issues consistently rise to the top (see below), more are concerned about almost all of these in 2022, particularly financial concerns.

Physical Health/Adherence	Emotional/Lifestyle	Financial/Insurance
Maintaining healthy weight 61% ▲ (+5)	? Uncertainty about future 60% ▲ (+4)	Cost of medical care 55% ▲ (+9)
Getting enough exercise 55% ▲ (+7)	Being there 4 family/friends 55% ▲ (+7)	Cost of prescriptions 54% ▲ (+11)
Having energy for day 52%	Changes to daily life/activities (new)	Financial support you need 50 % ▲ (+8)
Maintaining proper diet 52 % ▲ (+6)	Mental health support 44% ▲ (+8)	Non-medical expenses 48% ▲ (+14)
Managing side effects 51% ▲ (+4)	Emotional support needed 42% ▲ (+5)	Understanding insurance 46% ▲ (+9)
	• Maintaining relationships 41% ▲ (+7)	Getting/keeping insurance 40% ▲ (+7)
	Feeling isolated/lonely 39% ▲ (+6)	Cost of care-giving 40% ▲ (+11)

A third or more concerned about almost every item out of 30 items tested





Financial, Physical and Mental Health Concerns

Mixed and Negative Experience groups (and the under-served audiences in them) over-index on many items.

Physical health	Financial/ Insurance	Emotional/ Lifestyle	National Sample	Women	18-39	Black	Hispanic	Metastatic	No College	Mixed Experience	Negative Experience
Emotionally preparing f	for end-of-life <i>(among people livi</i>	ng with metastatic cancer)	62%	70%	n/a*	n/a*	74%	62%	58%	78%	n/a*
Maintaining a healthy w	veight		61%	66%	70%	69%	80%	67%	60%	68%	64%
Uncertainty about the f	uture		60%	63%	83%	64%	79%	69%	61%	75%	70%
Preparing to make/mak	king end-of-life decisions (among	people living with metastatic cancer)	58%	65%	n/a*	n/a*	70%	58%	57%	75%	n/a*
Planning for end-of-life	care (among people living with	metastatic cancer)	56%	65%	n/a*	n/a*	70%	56%	53%	72%	n/a*
Getting enough exercise	se		55%	59%	59%	61%	69%	64%	55%	66%	65%
Cost of medical care (in	ncluding insurance premiums an	d co-pays)	55%	61%	69%	60%	76%	67%	58%	68%	61%
Being there for your far	mily and friends		55%	57%	68%	63%	74%	70%	55%	69%	65%
Cost of prescriptions ar	nd treatments		54%	58%	64%	56%	73%	64%	56%	64%	58%
Having the energy to m	nake it through the day		52%	59%	80%	56%	75%	74%	54%	66%	66%
Maintaining a proper di	iet		52%	56%	65%	57%	73%	66%	51%	66%	57%
Managing ongoing side	e effects from treatment		51%	53%	72%	59%	73%	74%	51%	68%	61%
Changes to daily lifesty	/le/activities		51%	54%	65%	61%	74%	68%	52%	66%	63%
Having the financial su	pport you need		50%	55%	71%	60%	69%	61%	57%	62%	58%
Cost of non-medical ex	xpenses (e.g., food, housing, tran	nsportation)'	48%	52%	67%	56%	68%	64%	54%	59%	61%
Understanding the hea	lth insurance benefits available t	o you	46%	48%	52%	50%	64%	60%	48%	59%	57%
Support with mental he	ealth issues (e.g., anxiety or depr	ression)'	44%	51%	76%	55%	72%	62%	46%	63%	55%
Having the emotional s	support you need		42%	46%	64%	50%	70%	60%	44%	59%	58%
Ability to maintain relati	ionships with significant other, fa	mily and/or friends'	41%	40%	63%	54%	66%	62%	41%	55%	61%
Getting/keeping health	insurance		40%	45%	58%	51%	62%	55%	42%	56%	51%
Cost of professional ca	regiving		40%	42%	48%	49%	71%	59%	41%	55%	42%
Feeling isolated and lo	nely		39%	45%	66%	44%	67%	57%	40%	57%	57%
Loss of income			39%	42%	64%	55%	69%	58%	43%	51%	48%
Managing all of your pr	rescribed medications and other	treatments	39%	41%	58%	52%	67%	60%	41%	53%	44%
Visiting your doctor reg	jularly		38%	41%	57%	46%	74%	61%	41%	55%	55%
Long-term planning/car	reer goals		36%	39%	65%	51%	64%	54%	36%	49%	40%
Learning how to apply	for grants, scholarships, or gove	rnment benefits to help with medical and living costs'	31%	32%	56%	46%	54%	52%	36%	42%	46%
Managing appointment	ts		30%	32%	61%	43%	55%	50%	32%	45%	46%
Getting/keeping disabil	lity insurance		29%	32%	58%	42%	53%	52%	32%	44%	42%
Work/employment issu	es, like finding and keeping a job	o'	28%	30%	51%	45%	56%	48%	30%	42%	37%
Starting a family/having	g children		14%	15%	56%	29%	40%	34%	13%	26%	19%



Financial Impacts

Overall, nearly half have been impacted financially by cancer. That number goes up among young, Black, Hispanic, metastatic and less educated patients – and the Mixed and Negative Experience groups that they are more likely to be a part of.

	NCCS Connected: 63%	Women	18-39	Black	Hispanic	Metastatic	No College	Mixed Experience	Negative Experience
Impacted	d Financially: 47%	50%	76 %	63 %	69%	74%	51%	62%	65%
Spent savings/retirement money to cover living expenses	21%	22%	27%	23%	21%	29%	22%	25%	26%
Borrowed money from family or friends	15%	19%	31%	27%	22%	23%	20%	22%	27%
Applied for government financial assistance such as unemployment, SNAP/food stamps, Medicaid, etc.	14%	15%	24%	20%	15%	20%	19%	17%	28%
Delayed a major purchase (house, car, etc.)	14%	15%	26%	14%	17%	21%	15%	18%	21%
Delayed or reduced payments to credits cards or loans	12%	14%	24%	17%	14%	17%	13%	12%	18%
Delayed a major life event (marriage, trip, starting family, etc.)	12%	13%	37%	11%	20%	16%	11%	19%	16%
Received help with food or housing from a charity, community center, or place of worship	12%	15%	26%	21%	13%	16%	15%	14%	20%
Had to sell property or belongings to cover expenses	7%	8%	19%	7%	10%	10%	9%	9%	14%
Asked for rent or mortgage relief	7%	8%	13%	9%	15%	13%	8%	8%	18%
Started a GoFundMe or similar campaign to help with medical and living costs or had one started for you by others	5%	5%	15%	7%	10%	12%	6%	7%	11%
Applied for grants or scholarships to help with medical and living costs	5%	5%	10%	4%	7%	11%	5%	7%	5%
Declared bankruptcy	4%	4%	3%	5%	2%	6%	4%	4%	8%
Lost your insurance coverage	3%	2%	8%	4%	8%	7%	4%	5%	5%



Employment and Education Sacrifices

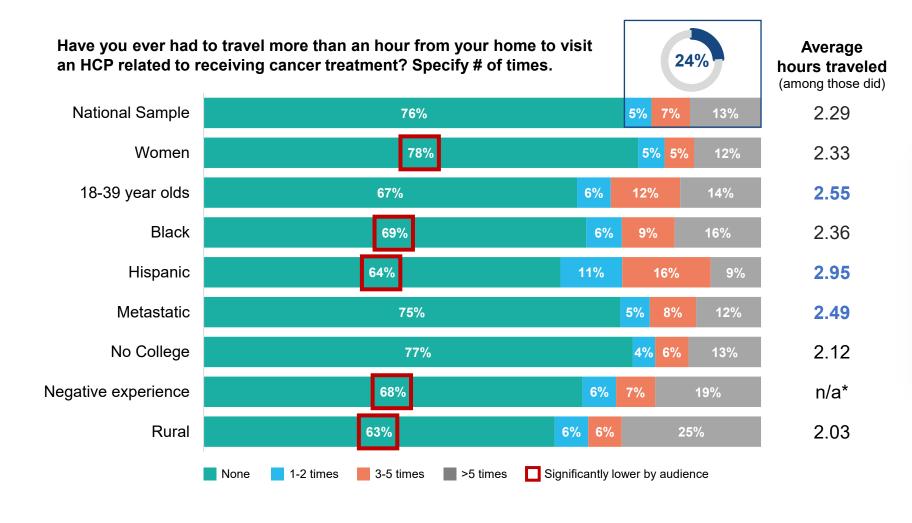
Over half feel they've made sacrifices, with the same audiences standing out. This is one area where the Mixed Experience group over-indexes even more than the Negative Experience group.

	NCCS Connected: 77%	Women	18-39	Black	Hispanic	Metastatic	No College	Mixed Experience	Negative Experience
Mad	de sacrifices: 55%	60%	78%	63%	79%	77%	56%	68%	58%
Missed work	25%	28%	41%	24%	26%	18%	27%	29%	18%
Worked fewer hours	18%	20%	39%	20%	32%	24%	17%	24%	15%
Lost salary or wages	15%	15%	25%	19%	16%	19%	17%	19%	23%
Taken a leave of absence	12%	14%	23%	15%	28%	18%	11%	18%	9%
Felt that your work suffered	12%	13%	26%	10%	19%	18%	11%	17%	13%
Taken family medical leave (offered by job)	11%	13%	15%	11%	18%	11%	11%	11%	11%
Taken early retirement	10%	9%	5%	15%	10%	17%	9%	11%	11%
Gone on short-term disability	10%	10%	12%	10%	10%	12%	12%	11%	8%
Quit your job	7%	8%	7%	5%	5%	12%	9%	8%	17%
Not been able to find a job with enough flexibility to accommodate your health needs	6%	7%	19%	7%	6%	10%	8%	9%	14%
Changed jobs or employers	6%	6%	12%	11%	6%	7%	6%	9%	9%
Not received the federal and/or employer disability insurance you needed	5%	6%	9%	5%	10%	6%	7%	5%	8%
Been let go or fired	5%	5%	11%	9%	5%	8%	6%	7%	11%
Felt your supervisor treated you badly	4%	5%	6%	3%	6%	10%	4%	8%	6%
Turned down a job or promotion	4%	4%	16%	7%	9%	7%	4%	6%	5%
Missed school or delayed your education	3%	4%	15%	5%	7%	4%	4%	4%	4%
Felt your co-workers treated you badly	2%	3%	4%	4%	4%	4%	2%	4%	4%



Time Costs: Traveling For Care

About a quarter have had to travel more than an hour away at least once during their care.



NCCS Connected:

35% had to travel 1+ hours

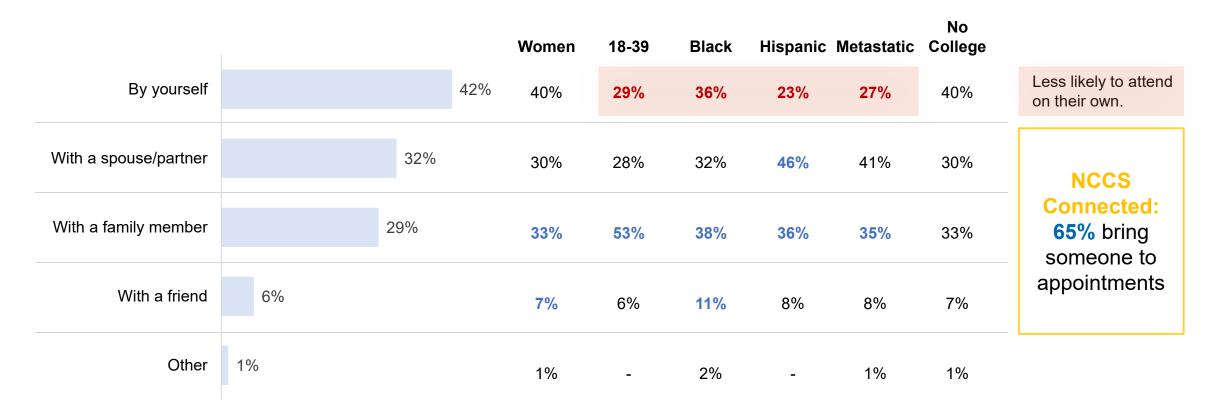
About a third of younger patients as well as Black, Hispanic, Negative Experience and rural patients have needed to travel to receive care.



People Costs: Help with Care

Majorities attend their treatment appointments with a friend or family member, particularly under-served audiences.

Thinking about a typical treatment appointment, do/did you attend...?



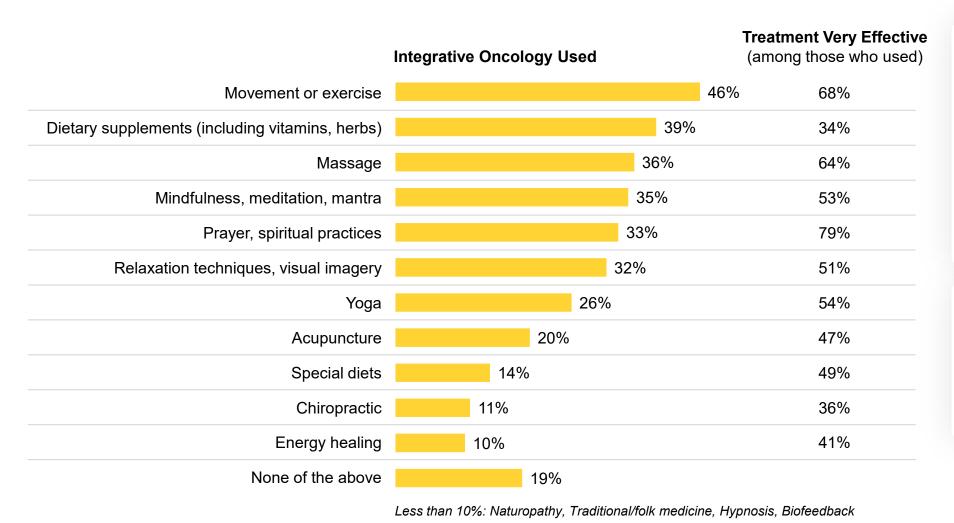


Integrative Oncology



Integrative Oncology Experiences

8-in-10 of the NCCS Connected group used some form of integrative oncology, with spiritual practices, exercise, and massage deemed the most effective.



8-in-10

did some form of integrative oncology

4 Mean # used

Higher Among:

- Black
- Hispanic
- STEM Background





Integrative Oncology Motivators and Barriers

General wellbeing and mental health are key drivers to integrative oncology. The biggest barrier is awareness; few are worried about coverage, expense, or lack of evidence.



General wellbeing	67%
Coping with emotional, mental impact of cancer	59%
Managing symptoms, side effects of cancer treatment	47%
Managing symptoms, side effects of cancer	42%
Giving me a sense of control over my illness	39%
Providing hope	34%
Preventing cancer recurrence	30%
Suggested by people I trust	22%
Treating my cancer	13%



Reasons for <u>NOT</u> Using Integrative Oncology Services/Therapies

Was not aware these therapies existed	30%
Not covered by my health insurance	10%
Not supported by my healthcare team	9%
Too expensive	7%
Concerned about lack of evidence supporting their safety, efficacy	6%
Concerned about interactions with my cancer treatment	4%
My healthcare team recommended against using	2%
Concerned about potential side effects	2%
Not sure	20%



NCCS Thanks Our Generous Sponsors













DOWNLOAD THE REPORT

NCCS represents more than 18 million Americans who share the survivorship experience living with, through, and beyond a cancer diagnosis. Our 2022 State of Survivorship Study shows us where there are gaps in care and support, resulting in unequal outcomes for cancer survivors. Our work has never been more urgent.



Edge Research is a woman-owned marketing research company based in Rosslyn, VA, that works for many patient advocacy organizations. Edge's goal is to blend wisdom, experience, and innovation to drive change. Edge has had the honor of partnering with NCCS since 2016, including on its annual "State of Survivorship" studies.

canceradvocacy.org

info@canceradvocacy.org

Appendix A: Survey Participant Profiles

National Sample NCCS Connected Gender 48% Male 16% Male 51% Female 84% Female Age 7% Age 18-39 15% Age 18-39 44% Age 40-64 53% Age 40-64 **49%** Age 65+ 32% Age 65+ **Education** 4% Less than college 15% Less than college 35% Some college/2-year degree 29% Some college/2-year degree 27% Bachelor's degree 26% Bachelor's degree 41% Postgraduate degree 23% Postgraduate degree Income 13% Less than \$25k 10% Less than \$25k 15% \$25k-\$50k 21% \$25k-\$50k 23% \$50k-\$75k 16% \$50k-\$75k 16% \$75k-\$100k 14% \$75k-\$100k 25% More than \$100k 31% More than \$100k Insurance 51% Medicare 40% Medicare 10% Medicaid 11% Medicaid 24% Private/employer 35% Private/employer 15% Private/spouse or parents 8% Private/spouse or parents Race/Ethnicity 81% White 78% White

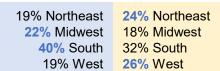
81% White
10% AA/Black
8% Hispanic
3% Other

78% White
11% AA/Black
10% Hispanic
4% Other

Treatment

27% Biomarker testing, 29% Genetic counseling 37% Biomarker testing, 49% Genetic testing

Region







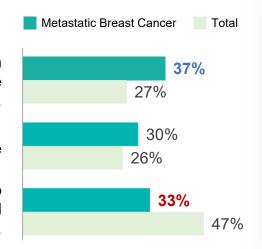
Patient Profile: Metastatic Breast Cancer

Decision-Making

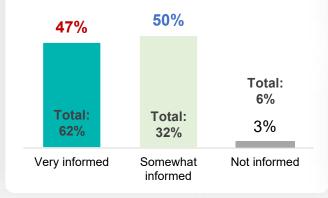
I am/was very involved in researching and deciding on the best treatment options for me.

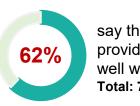
Somewhere in the middle

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

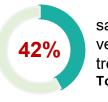


How **informed** do/did you feel about the potential **side effects** from your cancer treatment?





say their health care providers coordinated very well with one another Total: 71%



say they are very satisfied with their treatment and care Total: 73%

Top 3 Financial Impacts	Metastatic Breast Cancer	Total
Spent savings/retirement money to cover living expenses	28%	21%
Borrowed money from family or friends	25%	15%
Delayed a major purchase (house, car, etc.)	24%	14%

Top 3 Employment Sacrifices	Metastatic Breast Cancer	Total
Worked fewer hours	30%	18%
Missed work	21%	25%
Felt that your work suffered	21%	12%

Current State of Health

• Excellent: 3% Total: 8%

• Good: **38%** Total: 48%

• Fair: 40% Total: 34%

• Poor: **18%** Total: 9%

Top 3 Treatment Centers

Community

hospital: 41% Total: 52%

Private cancer

center: 34% Total: 13%

Academic medical

center: 27% Total: 20%



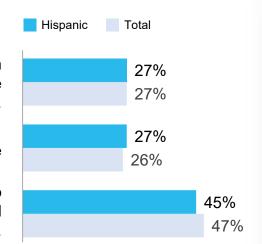
Patient Profile: Hispanic Patients

Decision-Making

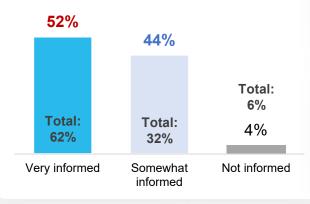
I am/was very involved in researching and deciding on the best treatment options for me.

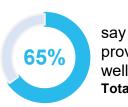
Somewhere in the middle

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

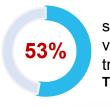


How **informed** do/did you feel about the potential **side effects** from your cancer treatment?





say their health care providers coordinated very well with one another Total: 71%



say they are very satisfied with their treatment and care Total: 73%

Top 3 Financial Impacts	Hispanic	Total
Borrowed money from family or friends	22%	15%
Spent savings/retirement money to cover living expenses	21%	21%
Delayed a major life event (marriage, trip, starting family, etc.)	20%	12%

Top 3 Employment Sacrifices	Hispanic	Total
Worked fewer hours	32%	18%
Taken a leave of absence	28%	12%
Missed work	26%	25%

Current State of Health

• Excellent: 9% Total: 8%

• Good: 42% Total: 48%

• Fair: 34% Total: 34%

• Poor: 13% Total: 9%

Top 3 Treatment Centers

• Community

hospital: 47% Total: 52%

Academic medical

center: 24% Total: 20%

• Private cancer

center: 23% Total: 13%





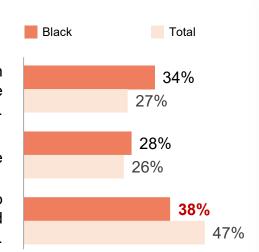
Patient Profile: Black Patients

Decision-Making

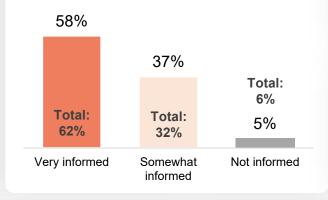
I am/was very involved in researching and deciding on the best treatment options for me.

Somewhere in the middle

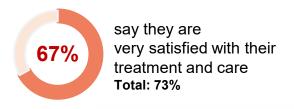
I rely/relied on the doctor to decide on treatment options and chose the best course of action.



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







Top 3 Financial Impacts	Black	Total
Borrowed money from family or friends	27%	15%
Spent savings/retirement money to cover living expenses	23%	21%
Received help with food or housing from a charity, community center, or place of worship	21%	12%

Top 3 Employment Sacrifices	Black	Total
Missed work	24%	25%
Worked fewer hours	20%	18%
Lost salary or wages	19%	25%

Current State of Health

• Excellent: 7% Total: 8%

• Good: 41% Total: 48%

• Fair: 40% Total: 34%

• Poor: 10% Total: 9%

Top 3 Treatment Centers

Community

hospital: 39% Total: 52%

Academic medical

center: 28% Total: 20%

Doctor's

Office: 19% Total: 20%





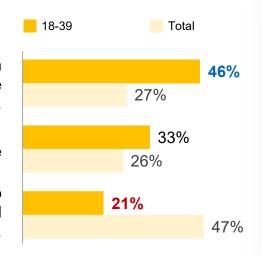
Patient Profile: Younger Cohort (Age 18-39)

Decision-Making

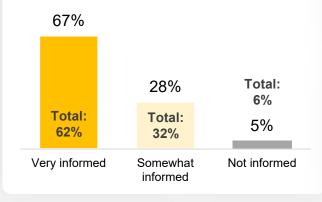
I am/was very involved in researching and deciding on the best treatment options for me.

Somewhere in the middle

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

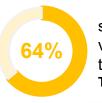


How **informed** do/did you feel about the potential **side effects** from your cancer treatment?





say their health care providers coordinated very well with one another Total: 71%



say they are very satisfied with their treatment and care Total: 73%

Top 3 Financial Impacts	18-39	Total
Delayed a major life event (marriage, trip, starting family, etc.)	37%	12%
Borrowed money from family or friends	31%	15%
Spent savings/retirement money to cover living expenses	27%	21%

Top 3 Employment Sacrifices	18-39	Total
Missed work	41%	25%
Worked fewer hours	39%	18%
Felt that your work suffered	26%	12%

Current State of Health

• Excellent: 13% Total: 8%

• Good: 36% Total: 48%

• Fair: 38% Total: 34%

• Poor: 12% Total: 9%

Top 3 Treatment Centers

• Community

hospital: 44% Total: 52%

Doctor's

Office: 26% Total: 20%

Private cancer

center: **25%** Total: 13%

Appendix B: Additional Questions Not Included in Main Report



Treatment Goals

Getting rid of cancer "no matter what" and maintaining quality of life are not mutually exclusive. Most patients have both thoughts during their treatment

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



Higher among:

- Positive Experience group
- Completed Treatment
- Stage I
- Women
- White
- Rural

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



Higher among:

- Positive Experience group
- Older (65+)





Still Experiencing Symptoms Today

Nearly 6 in 10 of those diagnosed 10 or more years ago still experience symptoms today.

Which of the following, if any, are you still experiencing today?

Symptoms experienced (top 15 out of 23 shown)

	Diagnosed 3-5 years ago	Diagnosed 6-10 years ago	Diagnosed 10+ years ago
Feeling overly tired	20%	20%	13%
Sexual concerns	21%	16%	18%
Depression, anxiety, mental	22%	15%	19%
Neuropathy	15%	17%	14%
Muscle/joint pain	17%	17%	12%
Insomnia/sleeplessness	17%	13%	12%
Uncertainty status of your cancer	12%	9%	8%
High blood pressure	10%	10%	9%
Memory loss, cognitive issues	9%	8%	8%
Endocrine issues	8%	7%	7%
Nausea/vomiting or diarrhea	9%	7%	3%
Loss of appetite and/or taste	7%	6%	3%
Skin irritation/rash, blisters, sunburns, etc.	6%	5%	4%
Weight loss	5%	4%	3%
Lymphedema (e.g., swelling in arm and/or leg)	4%	6%	4%
None of the above	26%	31%	42%
MEAN # EXPERIENCED	3 symptoms	3 symptoms	3 symptoms



Diagnosis Setting

Most are diagnosed at a doctor's office, but Hispanics are the one group more likely to report being diagnosed at a Cancer Center.

			Women	18-39	Black	Hispanic	Metastatic	No College
A doctor's office		59%	52%	55%	51%	39%	47%	60%
From a phone call	17%		24%	10%	12%	9%	11%	17%
A Cancer Center	13%		13%	23%	21%	45%	33%	12%
The emergency room	4%		3%	9%	7%	6%	5%	5%
From the patient portal	1%		1%	-	2%	1%	1%	1%
From an email	0.3%		0%	1%	1%	1%	0%	0%
Other	5%		5%	3%	5%	-	3%	5%



Average Length of Treatment Appointment

	I		Women	18-39	Black	Hispanic	Metastatic	No College
Surgery		2.18 hours	2.18	2.19	2.02	2.23	2.22	2.06
Chemotherapy		2.14	2.30	1.96	2.08	2.07	2.33	2.15
Bone marrow transplant	1.7	2	*n/a	*n/a	*n/a	*n/a	*n/a	*n/a
Immunotherapy/immuno-oncology	1.50		1.62	1.41	1.36	1.75	1.67	1.48
Genetic counseling	1.21		1.20	1.69	1.27	1.77	1.59	1.16
Biomarker testing	1.19		1.16	1.35	1.42	1.96	1.56	1.14
Palliative/supportive care	1.15		1.11	1.30	1.34	1.51	1.54	1.19
Radiation therapy	1.01		1.01	1.45	1.32	1.40	1.58	0.99
Targeted drug therapy	0.94		0.90	1.12	1.00	0.98	1.12	1.02

Appointments for immunotherapy, genetic counseling, biomarker testing, palliative care and radiation therapy take longer than average for Hispanic and people living with metastatic cancer.

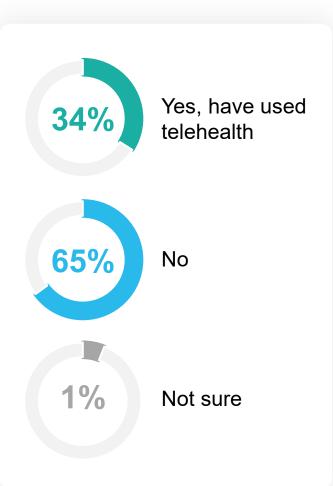


^{*} N size too small to report



Telehealth/Virtual Appointments

One third have had telehealth/virtual appointments – twice as many were likely to do so during COVID than this calendar year.



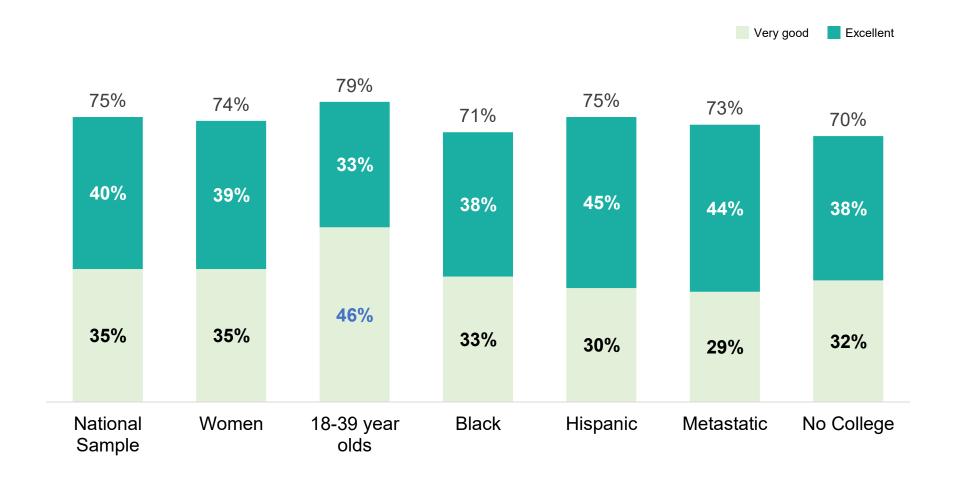
	National Sample	Women	18-39	Black	Hispanic	Metastatic	No College
Yes, have used telehealth	34%	33%	63%	52%	69%	65%	37%
Before the COVID-19 pandemic	7%	7%	18%	8%	16%	12%	6%
During the height of the COVID-19 pandemic (2020, 2021)	26%	26%	44%	42%	54%	49%	21%
This year (2022)	13%	12%	19%	20%	33%	24%	9%
No	65%	66%	35%	47%	30%	35%	70%

Telehealth/
virtual
appointments
are more
common



Rating Telehealth/Virtual Appointments

Among those who used it, one third rate telehealth appointments as excellent; three quarters say they were excellent or very good.





In-person vs. Telehealth

Similar to last year, in-person appointments are preferred for most types of health care visits. Patients are most open to telehealth for medication management, sharing test results, and counseling.

	Prefer in-person	Prefer telehealth/ no preference
First visit with a health care provider	85%	14%
Surgical consult	80%	17%
Physical therapy/rehabilitation	80%	17%
Getting a second opinion	74%	23%
Regular well-visits	69%	29%
Treatment planning and decision-making	69%	30%
Follow-up appointment(s)	63%	35%
Mental health services	53%	40%
Survivorship appointment	48%	36%
Medication management	48%	50%
Sharing test results	46%	52%
Counseling and education	46%	50%

Preference for in-person appointments is **higher** for many visit types:

- among those 65+
- earlier stage patients
- white patients
- those with no college education