STATE OF SURVIVORSHIP

SURVEY: 2022

NCCS

NATIONAL COALITION
FOR CANCER SURVIVORSHIP

INTRODUCTION

The National Coalition for Cancer Survivorship (NCCS) conducts an annual State of Survivorship Survey, in partnership with Edge Research, to delve into the cancer survivor journey. This study captures a range of perspectives to better understand how NCCS can support its mission to advocate for quality cancer care for all.

Conducted in the spring and summer of 2022, the research helps NCCS build upon and track findings from previous years to better understand the differences in survivor attitudes, experiences, and needs. Through 15 in-depth interviews and a nationwide survey of 2,078 survivors, 670 of whom have a connection to NCCS, this survey highlights the experiences and impact that cancer treatment and care have for survivors. Survey respondents in the national sample represent a wide range of stages of diagnosis, demographics, and socioeconomic levels, and NCCS used a sampling plan to ensure the survey was representative of cancer survivors nationally by age, gender, race/ethnicity, and region (based on data from the American Cancer Society and National Cancer Institute). All data presented are from the national sample (n=1408) unless otherwise noted.

In this year's survey, NCCS built upon previous surveys and delved deeper into the cancer journey, measuring satisfaction across different points, including screening and diagnosis, treatment and care, and post-treatment care. This report will present survivor experiences at each of these stages. Additionally, to better understand how different audiences experience the cancer journey, this year, we segmented respondents into three categories according to their experience. Further, as in previous years, we explored the financial, physical, and emotional costs that cancer can have for those who receive a cancer diagnosis. Overall, the data repeatedly show that significant disparities exist in the experience of cancer care, with a disproportionate effect among specific populations, including people of color, young adults, women, and individuals with metastatic cancer. Also, as we've seen in previous years, respondents who are connected to NCCS consistently had higher expectations and lower satisfaction in their assessments of quality care and were more likely to feel empowered to be active in their care.

NCCS' mission is to advocate for quality cancer care for all people touched by cancer. The data in this survey demonstrate an urgent and ongoing need to fulfill this mission.

DEEP DIVE INTO THE CANCER JOURNEY

As demonstrated in survey results in previous years, majorities of patients express a high degree of satisfaction with their cancer journey; however, it is clear in qualitative discussions that there is a disconnect with the many difficulties they describe. For instance, a young adult survivor rated their care highly, stating,

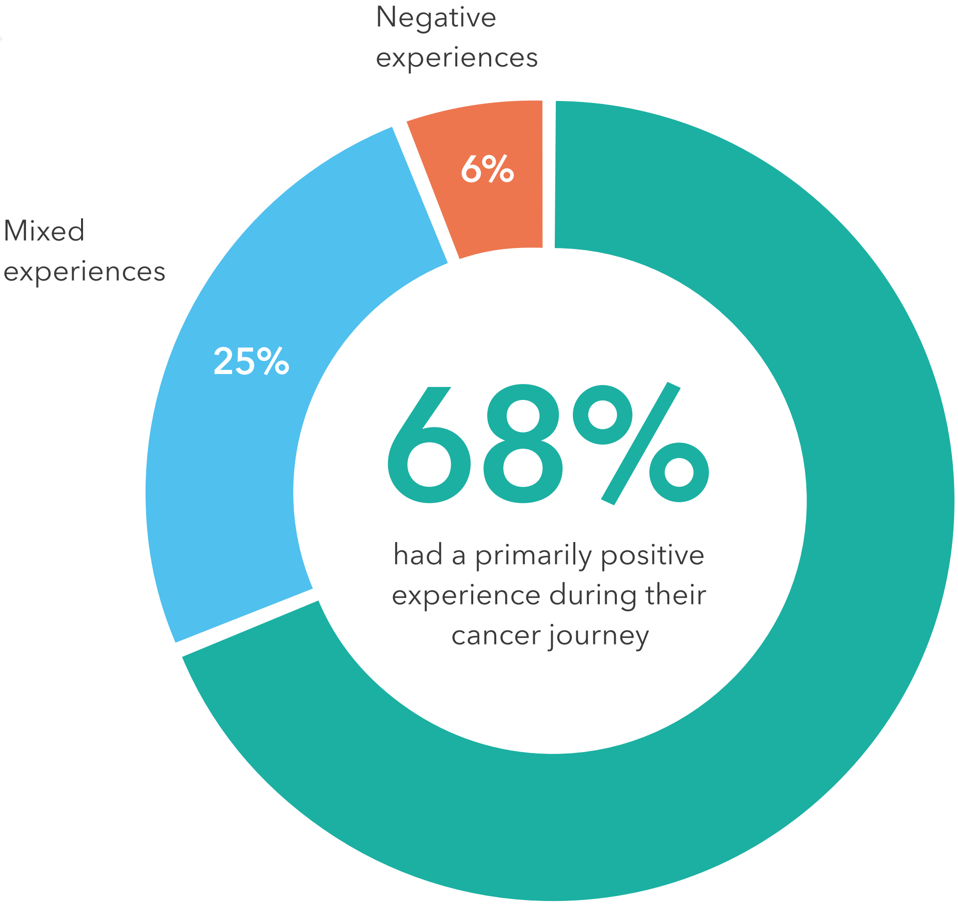
★★★★★

"I was very satisfied. They were very attentive to my questions…they were just very available to patients…" Yet, when discussing their diagnosis, this survivor shared, **"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?"**

To better understand this dynamic, we segmented survivors into three categories by experience: those who have had primarily positive experiences during their cancer journey, mixed experiences, and mostly negative experiences.

The results show that people of color, younger individuals, people living with metastatic cancer, and survivors with lower socioeconomic status (SES) are more likely to be in the Mixed Experience and Negative Experience segments. Additionally, these patients struggle more at each phase of their cancer journey.

Survivor Experiences During their Cancer Journeys

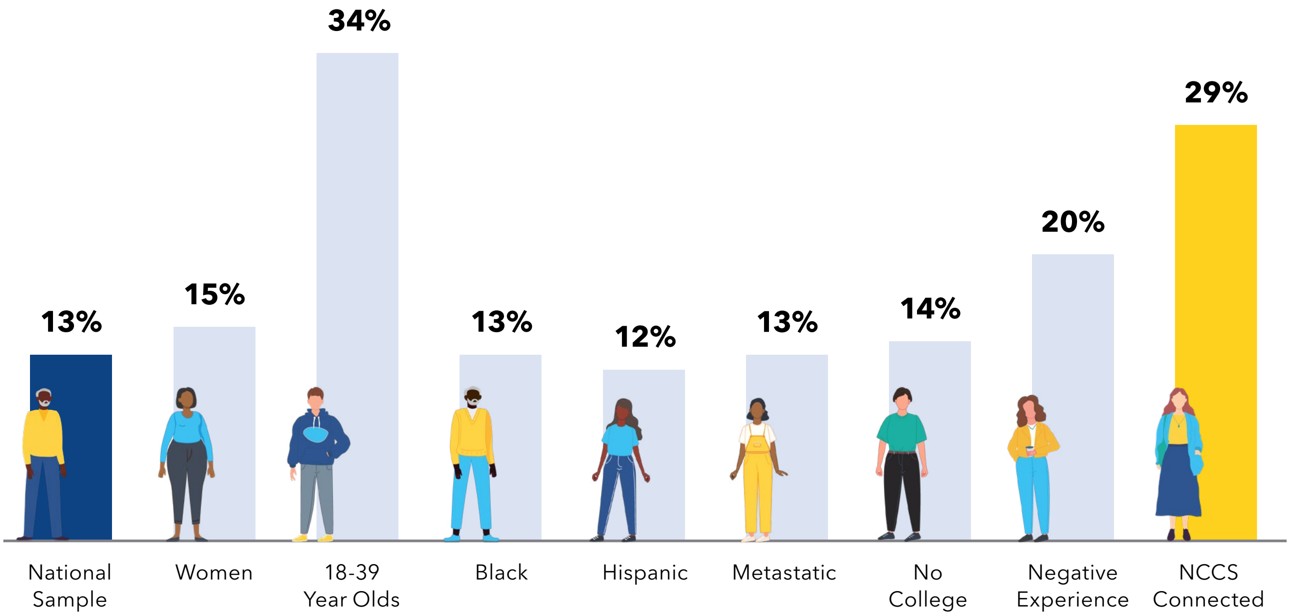


SCREENING AND DIAGNOSIS

Individuals in the three experience categories have significantly different satisfaction levels, beginning with screening and diagnosis.

While majorities of respondents typically have symptoms for up to three months and see an average of two doctors before they are diagnosed, the Negative Experience segment and many underserved groups went undiagnosed longer and saw more doctors. Notably, the respondents in the Negative Experience group saw an average of 3.6 doctors before receiving a diagnosis, Hispanic respondents saw an average of 3.5, and young adults (18-39) saw an average of 3.4. After twelve months, one-fifth of Hispanic patients and those in the Negative Experience group still awaited their diagnosis. Unfortunately, more than 1 in 10 respondents reported receiving an initial misdiagnosis, with young adults 2.5 times as likely and the NCCS-connected group twice as likely to first be misdiagnosed.

Percentages of People Misdiagnosed



TREATMENT AND CARE

Nearly three-quarters of respondents reported they were very satisfied with their treatment and care, due to a high degree of trust in and the relationship with their health care team.

However, large disparities exist for those in the Negative Experience segment, including many underserved audiences. For example, 68% of respondents overall said they always felt their health care provider listened to and respected their concerns, while only 47% of Hispanic respondents and 47% of individuals with metastatic cancer agreed. Similarly, 68% overall said they could always talk to their health care provider about their concerns, while 46% of Hispanic respondents and 50% of individuals with metastatic cancer agreed. Further, levels of trust were high, but for a number of groups levels of trust were lower, including for young adults, people in treatment, Blacks, Hispanics, people living with metastatic cancer, and the NCCS connected group. The Negative Experience group gave providers lower satisfaction scores and used terms like “bullied,” “ignored,” “test subject,” and “rushed” to describe their care. While majorities of patients said their health care team was a critical support network during treatment, followed by family/friends and faith, the Negative Experience and Mixed Experience audiences were significantly less likely to report support in any areas of their life during treatment.

73%
of Patients were
VERY SATISFIED
with their treatment
and care

Respondents Who Always Felt Their Health Care Provider Listened to and Respected Them

68%
Overall

47%
Metastatic

47%
Hispanic/
Latino

Respondents Who Felt They Could Always Talk to Their Health Care Provider about Concerns

68%
Overall

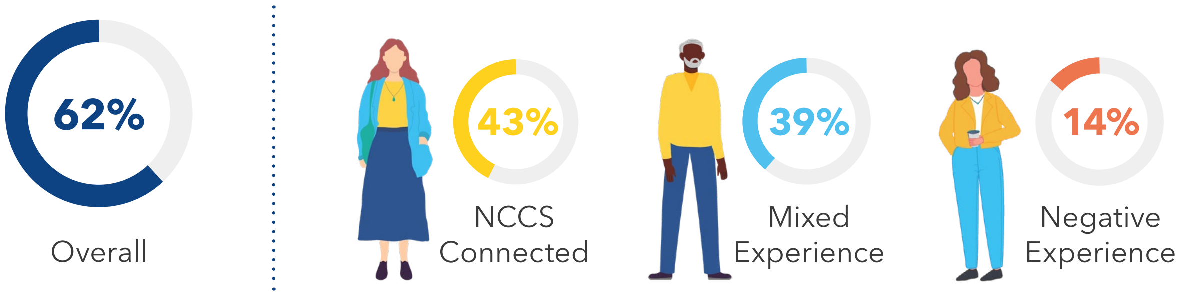
50%
Metastatic

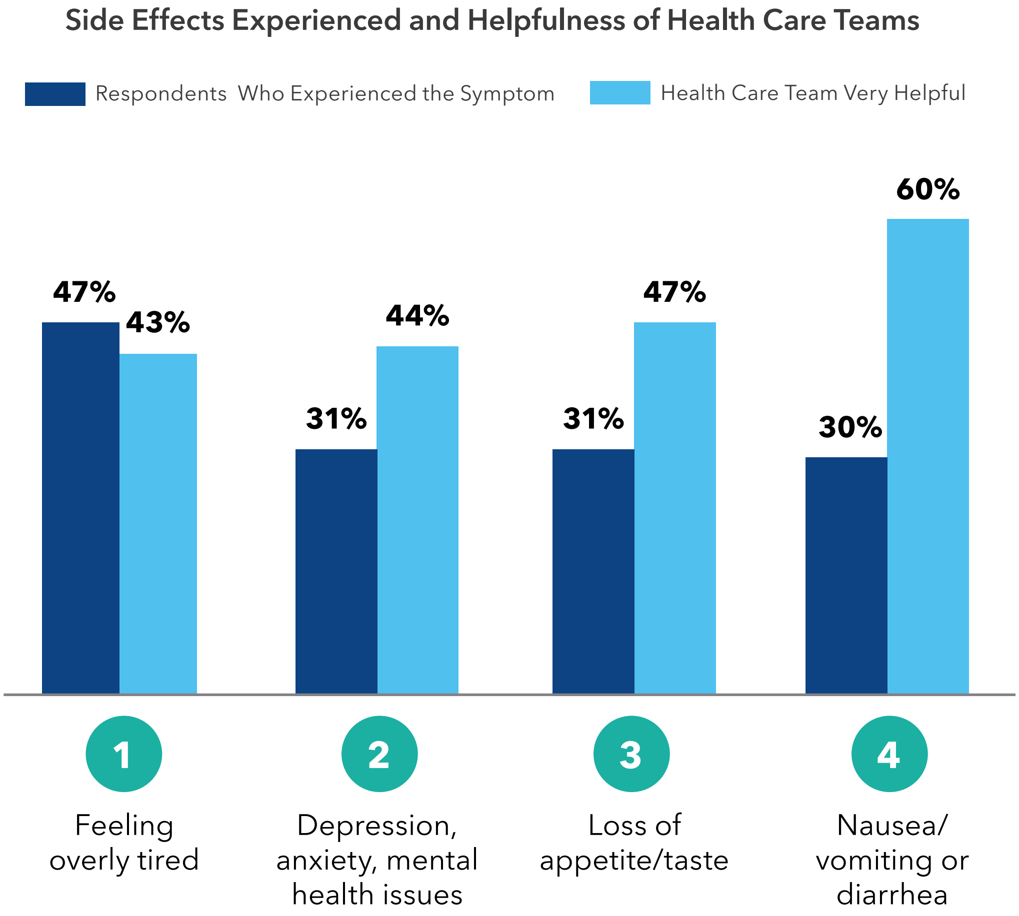
46%
Hispanic/
Latino

The survey also shows that participation in clinical trials remains low as demonstrated in previous survey results. Only 10% of respondents reported participating in a clinical trial related to their diagnosis, while only 11% of respondents said their health care team offered or discussed clinical trials with them.

When asked about symptoms, 86% of respondents reported experiencing at least one symptom during treatment. Notably, female, younger, and less educated patients were disproportionately affected by treatment symptoms. While 62% overall said they felt very informed about potential side effects from treatment, only 43% of the NCCS-connected group, 39% of the Mixed Experience group, and 14% of the Negative Experience group felt very informed. For many of the most common symptoms, less than half believe their health care team was very helpful in addressing them. Unfortunately, some survivors are still impacted by their symptoms even today. Nearly six in 10 of those diagnosed 10+ years ago said they still experience symptoms, with mental health and sexual concerns the most likely to be prolonged.

Respondents Who Felt Very Informed about Potential Side Effects from Treatment





While use of telehealth has declined since the early days of the COVID-19 pandemic, substantial percentages of individuals still utilize the service, particularly people of color, individuals with metastatic cancer, and young adults. Further, among those who used telehealth, three-quarters rated their appointments as excellent or very good. Similar to last year, in-person appointments are preferred over telehealth for most types of health care visits. Preference for in-person appointments is higher for many visit types among those 65+, earlier stage respondents, white respondents, and those with no college education. Patients more often prefer telehealth for medication management, sharing test results, and counseling and education.

Also, as we have seen in previous surveys, there is still a disconnect with respect to care coordination. Of the respondents, 92% say health care providers coordinated care well, but 54% still said they had to share information from one health care provider to another all or some of the time, an indication of poorly coordinated care.

A number of respondents this year also expressed concerns related to the stigma they experienced related to their cancer diagnosis and journey. Just under one-quarter of respondents said they feel or felt a lot of pressure from others to remain strong during their cancer treatment, while 17% said they feel or felt uncomfortable telling people they have or had cancer. Most notably, younger, female, Hispanic, and people living with metastatic cancer were less comfortable telling people they have or had cancer and/or felt more pressure to remain "strong" during treatment.

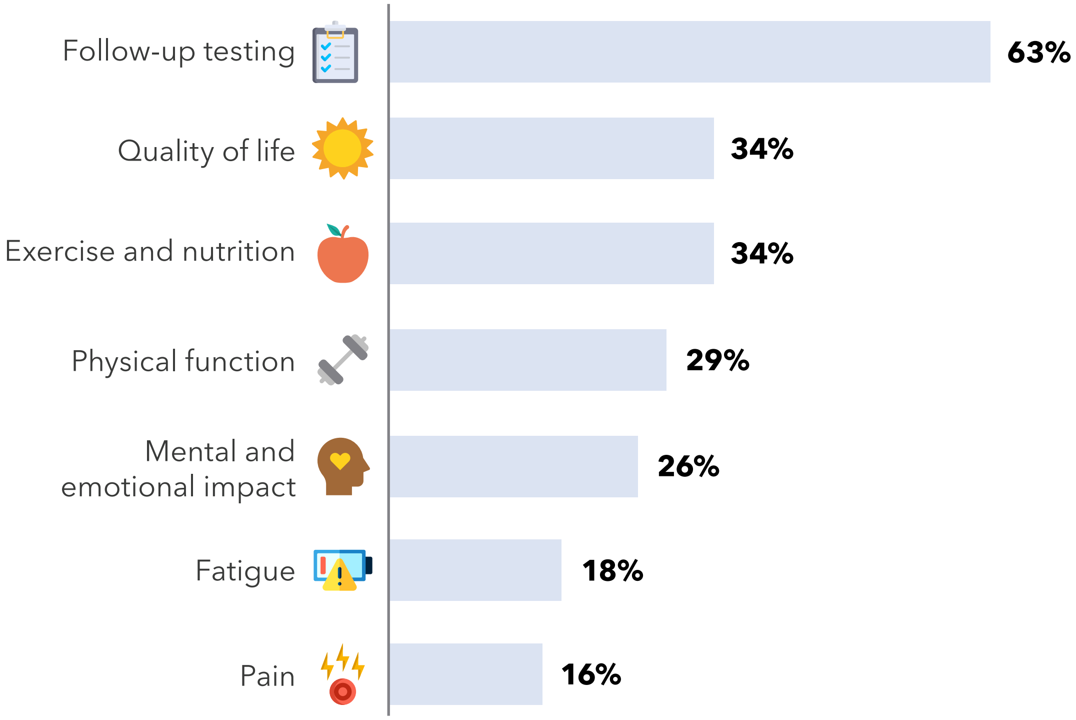
As one Hispanic respondent shared, **"I will love to go to group therapy or something with other women that have been through this, because if I talk to my family, I have to be strong… I feel like I have to pretend like it's going to be okay. Like I'm just getting a tooth pulled out."**

POST-TREATMENT CARE

Survivors tend to have low expectations during the post-treatment stage.

When asked about their post-treatment care, approximately six in 10 respondents say they are satisfied – which is 10 points lower than satisfaction with in-treatment care – and less than half of respondents say their health care provider did a good job transitioning them to this stage. During this stage, 63% of survivors reported that they discuss follow-up tests to monitor their cancer with their health care provider, but far fewer discuss other critical issues like quality of life (34%), exercise and nutrition (34%), physical function (29%), the mental and emotional impact of their illness (26%), and fatigue (18%) and pain (16%) that interfere with daily life.

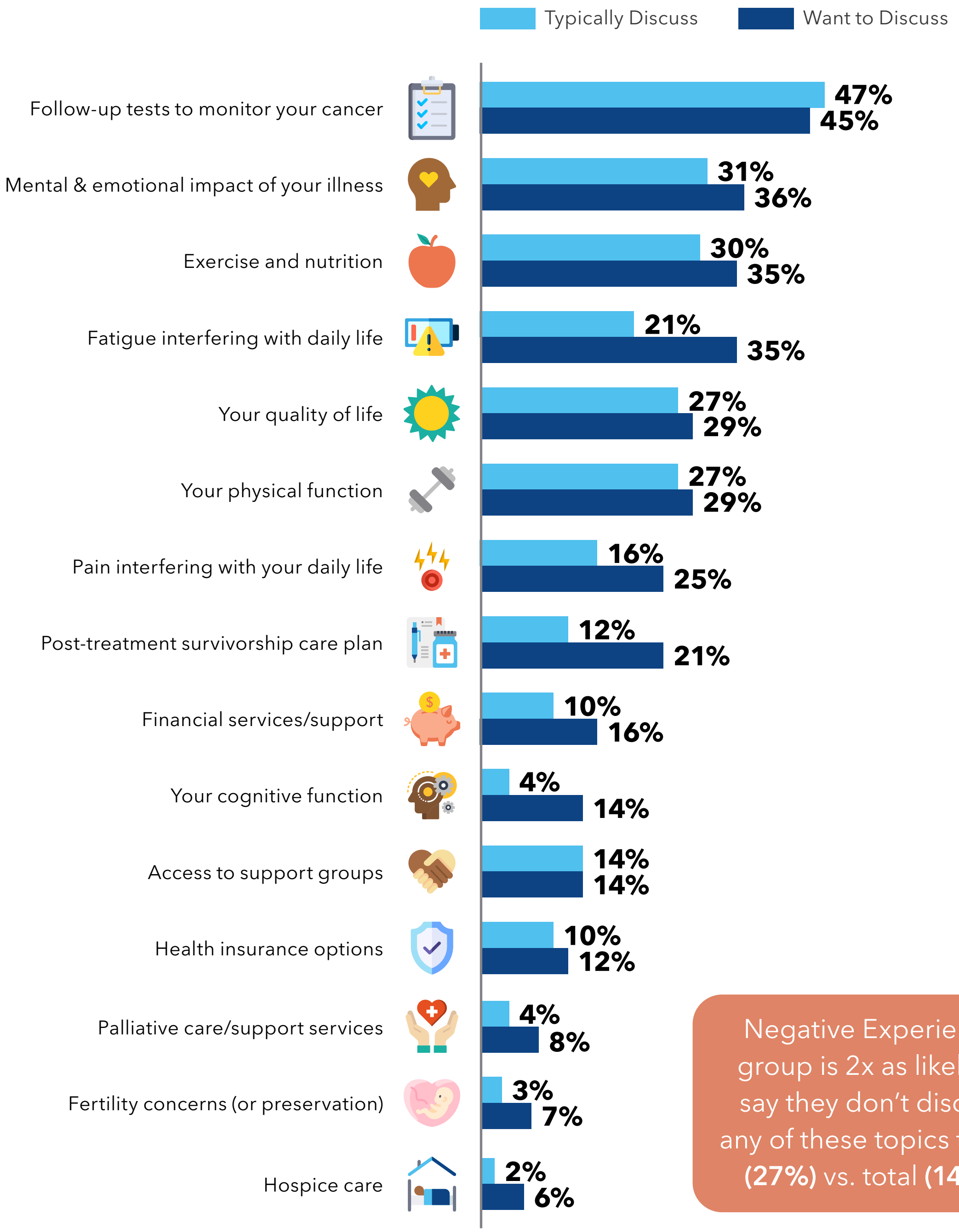
Topics That Survivors Discuss with Their Health Care Provider Post-Treatment



Those with the most negative experiences during their cancer journey indicate they still need help. The Negative Experience segment would like their health care team to be more proactive in discussing post-treatment issues, especially mental health, exercise, nutrition, and the fatigue and pain they still experience. The Negative Experience group is also twice as likely to say that they do not discuss any of the typical topics (27%) compared to the national sample total (14%). Overall, it is clear that there is a definite need for greater communication between survivors and health care providers at this stage.

Topics Currently Discussed vs. Want to Discuss

(among Negative Experience)



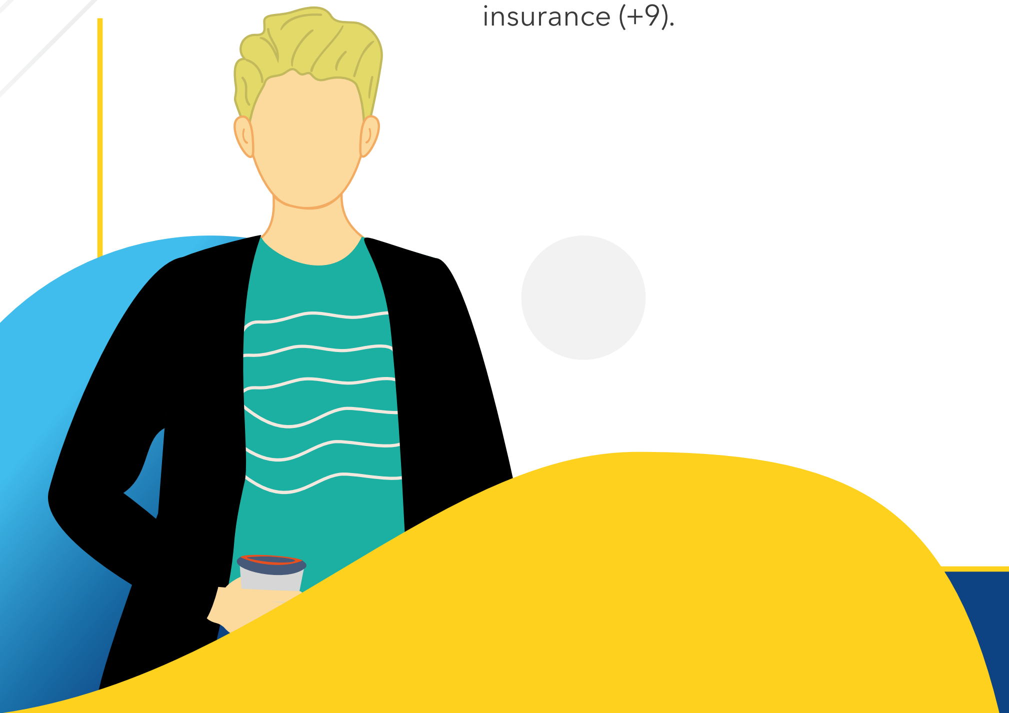
Negative Experience group is 2x as likely to say they don't discuss any of these topics today **(27%)** vs. total **(14%)**.

COSTS OF CANCER

In past surveys, the same physical, emotional, and financial issues have emerged as top concerns.

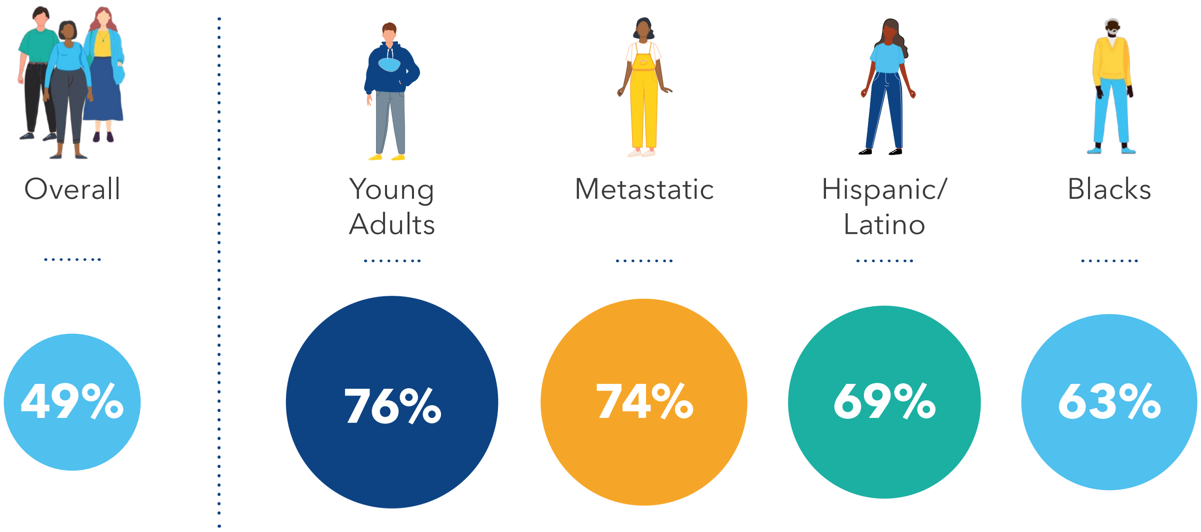
Overall, the top physical, financial, and mental health concerns this year include maintaining a healthy weight (61%), uncertainty about the future (60%), getting enough exercise (55%), the cost of medical care (55%), and being there for family and friends (55%). Among people living with metastatic cancer, emotionally preparing for end-of-life (62%), preparing to make/making end-of-life decisions (58%), and planning for end-of-life care (56%) were also top concerns. In all of these areas, the Negative Experience and Mixed Experience groups, as well as underserved populations, were more likely to say they experience these concerns.

While the same issues consistently rise to the top, more respondents are concerned about almost all of these issues in 2022, particularly financial concerns. Concerns that increased most significantly since last year's survey include the cost of non-medical expenses like food, housing, and transportation (+14 percentage points), the cost of prescriptions (+11), the cost of caregiving (+11), the cost of medical care (+9), and understanding insurance (+9).



Nearly half of respondents reported experiencing financial hardships and making employment and/or educational sacrifices because of their cancer care. This number is significantly higher among young adults, Blacks, Hispanics, and people living with metastatic cancer, as well as the Mixed Experience and Negative Experience groups that they are more likely to be a part of. For instance, 76% of young adults, 74% of people living with metastatic cancer, 69% of Hispanics, and 63% of Blacks said they were impacted financially. Further, 79% of Hispanics, 78% of young adults, and 77% of people living with metastatic cancer said they had to make employment and/or education sacrifices.

Experienced Financial Sacrifices



Cancer care also costs patients in terms of their time. Nearly one in four respondents have had to travel more than an hour from their home at least once to visit a health care provider to receive care. Approximately one-third of young adults, Blacks, Hispanics, individuals in the Negative Experience group, and patients in rural settings have had to travel to receive care. Notably, one-quarter of rural patients reported they had to travel over an hour away more than five times to receive care. Additionally, Hispanic patients who traveled for care had to travel an average of nearly three hours, while young adults and people living with metastatic cancer traveled an average of 2.5 hours from home.

CONCLUSION

Our 2022 State of Cancer Survivorship Survey provided us an invaluable opportunity to delve into the cancer survivorship journey from a range of perspectives and to better understand how NCCS can support our mission to advocate for quality care for all people touched by cancer.

This year, we were able to

Build upon and track our findings since 2021.

Measure satisfaction across different points in the cancer journey.

Better understand underserved 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, as well as explore trust in the care team.

Continue to explore the costs of cancer in terms of time, money, and physical and mental health.

The data showed

While on the surface most patients express a high degree of satisfaction with their cancer journey, there is a disconnect with the many problems they document once they begin to describe their journey.

Symptoms for some survivors persist after the conclusion of active treatment and are often left unaddressed with health care providers.

Significant disparities exist in the equity of and access to quality cancer care, with disproportionately negative experiences among people of color, young adults, women, and individuals with metastatic cancer.

The number of respondents who experienced physical, emotional, and financial issues has increased significantly, especially when it comes to financial concerns.

The rates of misdiagnosis are higher than they should be, and underserved populations wait longer and see more doctors before they receive a diagnosis.

Respondents who are connected to NCCS consistently had higher expectations in their assessments of quality care and were more likely to feel empowered to be active in their care.

The results of this year's survey demonstrate the importance of continuing our efforts to fulfill our mission. It is therefore critical that we continue to:

Advocate

for change in how the nation researches, regulates, finances, and delivers quality cancer care and work to pass the Cancer Care Planning and Communications Act.

Empower

cancer survivors and patient advocates through our publications, tools for self-advocacy, and programs, like the Survivorship Checklist, the Cancer Policy & Advocacy Team, and Elevating Survivorship.

Convene

advocates and cancer organizations to address nationwide public policy issues affecting cancer survivors.

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 Survey shows us where there are gaps in care and support, resulting in unequal outcomes for cancer survivors. Our work has never been more urgent.

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