

EXECUTIVE SUMMARY

BACKGROUND

The 2020 State of Cancer Survivorship Survey was designed to better understand the cancer patient and survivor journey from a range of perspectives. A total of 1,319 respondents participated in the nationwide survey fielded April 15 – May 1, 2020. The survey was first conducted among a sample of n=840 cancer patients, using an online panel provider. This survey used quota sampling to ensure it was representative of the adult US cancer population. To ensure statistical reliability, it included oversamples of African Americans, Hispanics, low-income cancer patients, and those over age 65. National sample respondents represent a range of cancer diagnoses, stages, and phases of treatment. A companion survey was also in the field at the same time among n=479 respondents invited from the NCCS database. All data is self-reported.

KEY FINDINGS

“DOCTOR KNOWS BEST” ABOUT TREATMENT IS THE PREVAILING MINDSET OF CANCER PATIENTS NATIONALLY.

- By almost a 3-to-1 margin, cancer survivors are more likely to rely on their doctor to tell them what treatment option was best (61%) versus being involved in the research and decision (22%).
- Groups that are more likely to rely on their doctor are: 65 years or older (66%), males (65%), lower income (63%), and have Medicare/Medicaid (63%).

FATIGUE AND MENTAL HEALTH ISSUES ARE THE MOST COMMON SIDE EFFECTS YET FEW FEEL THEIR HEALTH CARE PROVIDERS WERE VERY HELPFUL IN ADDRESSING DURING TREATMENT.

- Nationally, patients report a range of physical and emotional side effects experienced during or following treatment. Topping the list is: feeling overly tired (49%), depression and/or anxiety (30%), loss of appetite and/or taste (28%), muscle/joint pain (27%), and nausea/vomiting or diarrhea (27%). These five side effects are higher among females, African Americans, Hispanics, and chemotherapy patients.
- Less than half nationally say their doctor was helpful in addressing specific side effects during treatment, including the top four: feeling overly tired (just 35% of those who experienced say their doctor was very helpful), depression and/or anxiety (34%), loss of appetite and/or taste (34%), and muscle/joint pain (39%).
- During post-treatment visits, nearly half of patients discussed physical function (49%) and quality of life (47%) with doctors, but far fewer covered other aspects of functional status, including the most common side effects, i.e., depression and/or anxiety (only 29%) and fatigue (28%).

THOSE WHO REPORT BEING MORE INVOLVED IN INITIAL TREATMENT DECISIONS TEND TO HAVE MORE POSITIVE POST-TREATMENT EXPERIENCES.

- The survey suggests that initial involvement helps improve post-treatment care experiences. Patients who report being involved in treatment decisions felt better prepared for post-treatment (55%, vs. 50% who were not involved in initial treatment decision making), proactively spoke to their doctor about post-treatment care (53%, vs. 40%), and describe their post-treatment medical care as “excellent” (59%, vs. 50%).
- Majorities say they discussed what to expect post-treatment with their doctor (62%), but far fewer received additional information about exercise and nutrition (only 39%), long-term side effects (39%), nor mental health support (24%). Only 17% report getting a post-treatment survivorship plan.

SURVIVORS ARE CONCERNED ABOUT A RANGE OF PHYSICAL, EMOTIONAL, AND FINANCIAL ISSUES, YET THERE ARE MANY AREAS WHERE THEY DO NOT FEEL THEY RECEIVE OF SUPPORT FROM THEIR HEALTH CARE TEAM.

- Nationally, survivors’ top concerns are maintaining a healthy weight (64%), getting enough exercise (61%), being there for friends and family (57%), cost of medical care (56%), and having enough energy to make it through the day (56%).
- Few patients found their doctor was very helpful on any of these: maintaining a healthy weight (26% said their doctor was very helpful), getting enough exercise (24%), being there for family and friends (30%), cost of medical care (30%), and having the energy to make it through the day (25%).

POST-TREATMENT CONCERNS ARE GREATER: YOUNGER SURVIVORS, AFRICAN AMERICANS, HISPANICS, WOMEN, AND CHEMOTHERAPY PATIENTS.

- These audiences are more concerned about the range of issues mentioned above.

PATIENTS WHO ARE “CONNECTED” TO AN ADVOCACY GROUP HAVE HIGHER EXPECTATIONS OF CARE AND THEIR HEALTH CARE PROVIDERS.

- Some of these patients were involved in decision making from the beginning (35%), while others became interested and engaged in the process over time.
- The survey also shines a light on the fact that not every patient is willing to be a self-advocate or accept support. Half of survivors took advantage of any resource their health care team offered to help them through their cancer journey (53%) – but there are little differences by age, gender, race, income, or education level. Research reveals that this has less to do with patient demographics, and more to do with preferences, and how open a patient is to receiving help.

VISIT WWW.CANCERADVOCACY.ORG/SURVEY20 FOR ADDITIONAL RESOURCES.