

STATE OF SURVIVORSHIP

2024 SURVEY

EXECUTIVE SUMMARY

The 2024 State of Survivorship report from the National Coalition for Cancer Survivorship (NCCS) offers detailed insights into the experiences of cancer patients, survivors, and caregivers in the U.S., based on national surveys conducted between August and September 2024. With over 2,100 participants, including patients, caregivers, and an oversample of younger patients (aged 18-39), this report examines key areas such as treatment decision-making, post-treatment care, clinical trial participation, side effects, and financial burdens.

TREATMENT DECISION-MAKING



Patient and Caregiver Roles: Most cancer patients continue to rely on their doctors to choose the best treatment options for them, with 53% of patients deferring to their doctors. While overall, 27% of patients were actively involved in researching and deciding on treatment, some demographic groups report being very involved. Almost half of both younger and Hispanic patients report they were very involved in their treatment decisions.



Self-Advocacy: One-third of patients felt the need to advocate for themselves to receive the best treatment and care, particularly among Black patients (59%), younger patients (56%) and Hispanic patients (48%). These groups are less likely to rely solely on their doctors' recommendation.



Second Opinions: Only 29% of patients sought a second opinion during their cancer care. Younger patients (47%), Hispanic patients (43%), and LGBTQ+ patients (42%) were more likely to do so. Among those who did not seek a second opinion, the overwhelming reason is trust in their health care team (82%), followed by not wanting to wait to start treatment (26%).

CLINICAL TRIAL PARTICIPATION



Participation Rates and Barriers: Participation in clinical trials remains consistent, with key drivers being the doctor's recommendation (51%), wanting to contribute to science (41%), and the prospect of access to new treatments (28%). Among patients who did not participate in clinical trials, 74% of patients said that they were not asked, which is the largest barrier.



Reasons for Not Participating: Patients also cited concerns about side effects, treatment protocols, and location as secondary barriers, with these concerns being more prominent among younger patients and patients of color.



POST-TREATMENT CARE AND SURVIVORSHIP PLANS



Post-Treatment Care: Two-thirds of patients who are within five years of completing treatment report receiving post-treatment care. At the same time, majorities of those who are over 5 years out are not receiving post-treatment care, with most saying their doctor told them it was no longer needed.



Oncologists vs. PCP for Post-Treatment Care:

Most survivors see an oncologist (54%) or other specialist (26%) for post-treatment care. The share of patients seeing a primary care physician (PCP) for post-treatment care has dropped significantly in recent years, with only 19% reporting they are currently seeing a PCP, though 38% indicated they would consider it. Some have concerns about PCP's knowledge and ability to detect a recurrence.



Survivorship Plans: Less than half of the patients who completed treatment received a survivorship care plan. Among those who received a plan, most indicated it was provided through a verbal discussion (63%) or as a hard copy (63%). However, many patients desire more detailed information in their plans, including side effects and future screenings.

FINANCIAL IMPACTS OF CANCER



Financial Burdens: Over 40% of patients reported being financially impacted by their cancer diagnosis, with caregivers (69%), Black (55%), Hispanic (68%), people with Stage IV cancer (62%) and LGBTQ+ patients (69%) disproportionately affected. By far the most burdened by financial concerns are young adults, 90% of whom report at least one financial impact. These patients were more likely to have borrowed money, delayed significant life events, or applied for government assistance to cover costs.



Prescription Costs: On average, patients spent \$935 out-of-pocket on prescription drugs in the past year. Younger patients reported higher out-of-pocket costs at \$2,482, and over 70% of younger patients expressed interest in a monthly payment plan to spread the cost of their prescription medications.

SIDE EFFECTS AND QUALITY OF LIFE



Most Common Side Effects: Fatigue remains the most reported side effect (46%), followed by fear of recurrence (42%) and pain (37%). Mental health issues such as depression and anxiety are also prevalent, particularly among younger patients (57%), with nearly half (47%) of LGBTQ+ patients reporting mental health challenges during treatment.



Symptom Management: Despite 92% of patients reporting at least one side effect, the vast majority did not discontinue treatment because of them. Still, managing the impact of side effects on quality of life remains a significant concern.

EMPLOYMENT AND WORK IMPACT



Employment Challenges: Over half of the patients surveyed (51%) continued working during their treatment, with nearly a third indicating they felt they had no choice but to do so. This pressure was especially high among younger patients, 48% of whom felt obligated to keep working during their treatment.



Work Productivity: The cancer diagnosis significantly affected the productivity of both patients and caregivers. More than two-thirds of younger patients (67%) said their work or school productivity was "largely" or "completely" impacted. Patients reported missing an average of 21 hours per week of work, and caregivers missed an average of 15 hours per week.

NCCS represents more than 18 million Americans who share the survivorship experience – living with, through, and beyond a cancer diagnosis. Our 2024 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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