

The Costs of Colorectal Cancer



Cancer takes a huge physical toll on people facing the disease and comes with many costs. This fact sheet explores the costs of colorectal cancer (or where specifically noted, colon cancer).

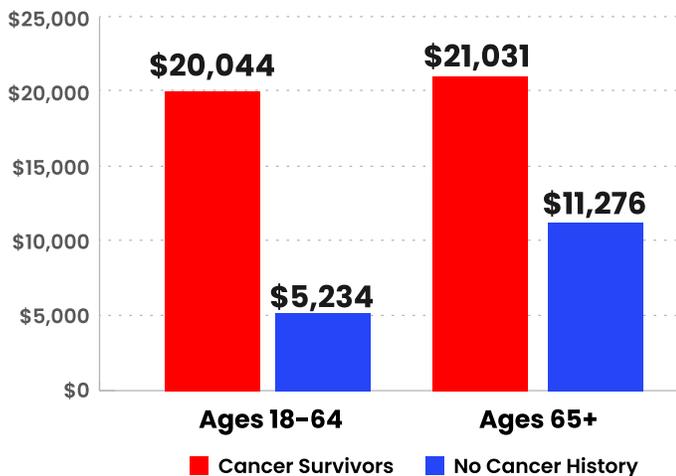
The financial costs of cancer do not impact all people with cancer equally. Evidence consistently shows that certain factors impact cancer diagnosis, treatment, survival and financial hardship experienced by people with a cancer history and their families:

- Age
- Race/ethnicity
- Sexual orientation
- Health insurance status
- Family income
- Where you live
- Cancer type

People with a history of colon cancer have higher health care expenses, out-of-pocket costs and rates of financial hardship compared to people who have never had cancer.

Overall, people with a history of colon cancer have almost two – to more than three – times the health care expenditures of those people who have not been diagnosed with cancer.^{1,2} Average expenses in the first year after diagnosis are significantly higher for people diagnosed with later-stage colorectal cancer than with earlier-stage disease.³

Annual Average Health Care Expenditures, 2018–2020



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018–2020. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp. July 2023.

All analyses incorporated complex survey design.

The Costs of Cancer in My Own Words

Peter Marinaro

New York



Peter Marinaro was 38 years old when he received news that he had cancer for the second time in his life. As a child, Peter underwent treatment

for an osteosarcoma. Over two decades later, Peter again faced cancer, but this time it was different; he was battling stage IV colorectal cancer as a husband, father of three girls and business owner.

Ahead of starting treatment, Peter switched insurance carriers, opting for a plan that would accept more doctors at more facilities. As a part-owner of his family business, Peter was grateful for the ability to change carriers and the flexibility this shift in coverage provided him. Peter wanted to ensure that he had the freedom to seek the best care. This new plan would afford him stronger-quality care, which included biomarker testing and a bowel resection surgery, as well as two separate courses of both chemotherapy and radiation therapy.

Throughout his treatment, Peter was forced to take time off work. But, thanks to the support of his family, he could do so without worrying about losing his job or health care coverage and could focus on his survivorship without sacrifice or stress.

Colorectal Cancer's Impact⁴

Colorectal cancer is estimated to have the second-highest number of deaths in 2023, after lung cancer. Despite overall declines in colorectal cancer the past decade, trends in new cases and deaths in individuals younger than 50 years of age continues to increase despite this group shrinking in overall population.

- ▶ In 2023, there are projected to be 153,020 new cases of colorectal cancer diagnosed in the U.S., and 52,550 people will die from the disease, including 19,550 diagnoses and 3,750 deaths in individuals younger than 50 years of age.
- ▶ The rate of new cases of colorectal cancer was 33% higher in men than in women during 2015-2019, and rates of new cases for advanced disease have increased by 3% annually in people 50-64 years of age since 2010.
- ▶ New cases of colorectal cancer in the U.S. are highest among people who are Alaska Native, American Indian or Black versus white; racial and ethnic disparities are similar for mortality.
- ▶ Despite overall declines in colorectal cancer during the past decade, the rate of new cases increased about 2% per year in those younger than 50 years of age. In 2019, 1 in 5 new cases of colorectal cancer were in people ages 54 years or younger, up from 11% in 1995.

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I am incredibly lucky to have an insurance plan that opened doors, instead of creating barriers to my care. Because of the robust coverage I received and the support my family provided me at home and work, I was able to focus fully on my recovery and avoid falling into debt. Though my world turned upside down when I received my stage IV diagnosis, my wife and I were determined to maintain stability for our girls. We wouldn't have been able to do so without strong support – from my provider, insurance carrier and family.

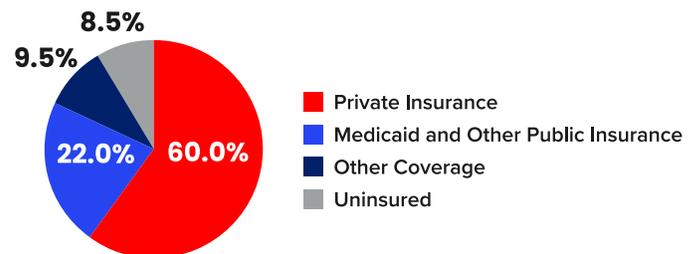
PETER MARINARO, NEW YORK

Health Insurance Coverage in People With Colorectal Cancer

The details of an individual's health insurance coverage – or lack thereof – have a huge impact on what that person pays for their cancer treatment.

- ▶ People with a history of colorectal cancer are more likely to be insured than those without a history of cancer.⁵
- ▶ For people with colorectal cancer who are insured, the type and details of their insurance coverage are an important determinant of their out-of-pocket costs. More than half of people with a history of colorectal cancer, ages 18-64 years, have private insurance.

Insurance Type, Colorectal Cancer Survivors, Ages 18-64



Source: National Center for Health Statistics: National Health Interview Survey, 2019-2022. Public-use data file and documentation. Retrieved from: <https://www.cdc.gov/nchs/nhis/data-questionnaires-documentation.htm>. July 2023.

All analyses incorporated complex survey design.

- ▶ More and more people are enrolled in lower-premium high deductible health plans (HDHPs), despite high up-front costs and mounting evidence that these plans cause them to delay important cancer care and have worse cancer outcomes.^{6,7,8} The majority (57%) of privately insured people with a colorectal cancer history have an HDHP.⁹

What People With Colorectal Cancer Pay Out of Pocket for Care

Cancer treatment is often complex, involves many services and is expensive. Research consistently shows that people who have been diagnosed with cancer have higher out-of-pocket costs than those without a cancer history.¹⁰ These increased costs often continue even years after the patient has finished active cancer treatment.

Younger people with a colon cancer history spend an average of \$2,123 every year on out-of-pocket medical expenses, which is almost three times that spent by those with no cancer history. And that doesn't even take into account monthly insurance premiums.^{11,12}

Average Annual Out-of-pocket Expenses, Ages 18-64, 2018-2020



Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018-2020. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp. July 2023.

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The Impacts of the Costs of Colorectal Cancer

The high costs of cancer have many adverse impacts. Research shows that among people ages 18-64 years with a history of colorectal cancer:¹³



27%

reported having problems paying medical bills in the past 12 months

VERSUS 12% OF PEOPLE WITHOUT A CANCER HISTORY



50%

reported worrying about paying future medical bills if they get sick or have an accident



12%

reported delaying medical care due to cost in the past 12 months



14%

reported skipping, taking less, delaying or not getting a medication due to cost in the past 12 months

VERSUS 7% OF PEOPLE WITHOUT A CANCER HISTORY



26%

experienced some level of food insecurity in the past 12 months

ACS CAN Supports Policies That Will Reduce the Costs of Colorectal Cancer

The American Cancer Society Cancer Action NetworkSM (ACS CAN) supports policies that will reduce the costs of cancer for people with a history of the disease. We want to make sure that everyone has a fair and just opportunity to prevent, detect, treat and survive cancer. To reduce the costs of cancer for people with a history of colorectal cancer, ACS CAN supports:

- ▶ **Maintaining funding for state and federal colorectal cancer screening and control programs.** Programs should raise public awareness about colorectal cancer screening and improve access to screening, including patient navigation and treatment services. Programs should use evidence-based patient and provider interventions to promote screening and reduce barriers to eligible adults. For example, the Centers for Disease Control and Prevention's (CDC) Colorectal Cancer Control Program (CRCCP) provides grant funding to 20 state health departments, eight universities, two tribal organizations and five other organizations to help prevent colorectal cancer.¹⁴ The goal of the CRCCP grant work is to increase colorectal cancer screening rates among high-need groups. Without a continued, dedicated federal investment in colorectal cancer prevention and early detection, the U.S. could experience a reduction in screening, leading to increases in preventable colorectal cancer cases and deaths. ACS CAN opposes any administrative or congressional efforts to cut or eliminate funding for programs like the CRCCP, which could reduce screening and add to the colorectal cancer burden in the U.S. and is an essential program in the fight against cancer, as it helps to reduce health inequities by serving those at most risk for the disease.
- ▶ **Ensuring insurers cover follow-up colonoscopies at no cost to the patient, including individuals insured by traditional Medicaid plans.** Guidance from the Tri-Agencies (Department of Labor, Department of Health and Human Services and Department of Treasury) clarifies that private insurance and Medicaid expansion plans are required to cover follow-up colonoscopies after a positive noninvasive stool test. Previously, colonoscopies after positive stool tests were often considered "diagnostic" and, therefore, not covered as a free preventive screening as required to be covered by the Affordable Care Act (ACA). While this new guidance will expand coverage of follow-up colonoscopies

The Costs of Cancer in My Own Words

Ken
Ohio



In 2014, Ken was diagnosed with colon cancer. That same year, they also found three cancerous tumors on his liver. Ken underwent several surgeries for

his colon and to have the tumors removed from his liver. Ken has never stopped working throughout his treatment because he can't risk losing his insurance, and his monthly bills don't stop. Even now, as Ken is getting chemo treatments every two weeks and often doesn't feel up to working after treatment, he has to go to work anyway. Ken has had to put his life on hold. He cut way back on going out and doing the activities he and his wife enjoy.

Ken has been told that he will likely be on chemo for the rest of his life, so this cycle will never end. Although Ken is thankful that the hospital is willing to work with him to make monthly payments toward his almost \$8,000 in medical debt, he still fears that one day he will have to file for bankruptcy.

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“I have been fighting cancer for eight years and that is hard enough, but the medical debt you acquire is almost too much. I have a \$5,600 out-of-pocket cost every year through this insurance. That means every January, I must find \$5,600. That is the cost of just my first chemo treatment that I need.”

KEN, OHIO

to many more individuals nationwide, it does not apply to traditional Medicaid and Medicare plans. The Medicare program adopted rules that would lower the minimum age of colorectal cancer screening to 45 and would cover with no cost sharing a follow-up screening colonoscopy after a Medicare-covered noninvasive stool-based colorectal cancer screening test returns a positive result. State Medicaid agencies are not required by federal law to cover colorectal cancer screenings. Coverage of these tests is an optional benefit and varies from state to state. ACS CAN promotes policies that will expand this coverage to traditional Medicaid and other non-ACA compliant plans to help ensure all individuals who need colorectal cancer screening are able to access testing.

► **Ensuring reasonable access to colonoscopies and colorectal cancer care.**

Health plan networks are required to meet certain network adequacy standards that include being geographically available to patients – so those people needing specific providers and testing services do not have to travel too far to access these services. Lack of access to in-network facilities can mean a person is less likely to get screened for cancer or receive care or risk being charged for out-

of-network care. ACS CAN advocates to ensure health insurance networks adequately provide all enrollees reasonable and timely access to an in-network facility that provides colonoscopies, follow-up colorectal cancer testing, high-quality treatment and appropriate health care providers.

- **Expanding Medicaid in the remaining states that have not done so.** Medicaid helps to improve cancer outcomes by offering access to prevention services and timely cancer screening and early detection services, as well as affordable treatment services and care. There are millions of people who fall into the “Medicaid coverage gap.” That gap refers to individuals who remain ineligible for Medicaid but earn too little to qualify for premium tax credits for qualified health plans in the marketplace. Medicaid is a lifeline for thousands of families that – without health insurance – would not have access to the screening, early detection treatment and follow-up care they need. ACS CAN advocates for all states to expand Medicaid and for Congress to close the coverage gap for lower-income Americans who live in states that have failed to expand to reduce cancer disparities.

In Their Own Words: Experience with Costs and Debt

The American Cancer Society Cancer Action Network (ACS CAN) gives voice to people impacted by cancer on critical public policy issues that affect their lives. In recent surveys about cost and debt issues, people with a colorectal cancer history told us they had problems affording treatment, dealing with worry and anxiety and medical debt.¹⁵

Problems affording treatment

It was difficult to afford my health care expenses.

40%

The cost of a treatment influences whether I get a treatment that my health care provider recommends.

34%

I delayed or did not pay other household expenses (like utility bills) to use the money for health care costs instead.

13%

Medical debt

I have current or past medical debt associated with my cancer care.

54%

- I have been contacted by a collections agency about debt related to my cancer care.

55%

(of those reporting current or past debt)

I declared bankruptcy due to health care costs or debts.

5%

Worry and anxiety

I am concerned about my ability to pay for current or future health care costs related to my cancer.

76%

I am concerned about incurring new debt for my cancer care.

65%



► **Increasing access to patient navigation services.** Patient navigation is an evidence-based intervention that eliminates health disparities across the cancer care continuum. Patient navigation services have been shown to help increase cancer screening rates among historically marginalized racial and ethnic populations by providing access to disease prevention education, conducting community outreach and facilitating public education campaigns.^{16, 17, 18} Patient navigation programs have shown improved quality of life and treatment adherence for Hispanic/Latino survivors of colorectal cancer who received patient navigation versus those who did not¹⁹ and have also improved guideline-concordant colorectal cancer screening. However, patient navigation is still absent or limited in many cancer programs and hospital settings due to a lack of long-term funding to pay for these services. ACS CAN advocates to ensure everyone at risk for – or diagnosed with – colorectal cancer can access patient navigation services.

► **Addressing patient costs to diversify participation in clinical trials.** Clinical trials are vital to advancing new and improved standards of care. Diverse representation in clinical trials helps to ensure that all populations can benefit from the improved outcomes achieved with new cancer therapies. However, individuals who belong to certain racial and ethnic groups are underrepresented in colorectal²⁰ cancer clinical trials, and those with limited incomes are less likely to participate.²¹ While patient willingness to enroll in clinical trials is high, some patients decline to participate due to costs. They are often responsible for non-medical costs, such as transportation and lodging associated with trial enrollment. These costs can occur when no local trials are available and patients have to travel to distant trial sites, or when there is a need for more frequent clinic visits for additional trial-related treatment or monitoring. To address this issue, the Diversifying Investigations Via Equitable Research Studies for Everyone (DIVERSE) Trials Act would allow clinical trial sponsors to provide financial support to trial participants and provide the technology needed to participate in trials remotely. Offering to reimburse patients for non-medical costs associated with trials such as transportation and lodging can increase overall enrollment and thereby help make it less costly for them to access new therapies through clinical trials during their cancer treatment. ACS CAN advocates for policies like the DIVERSE Trails Act, which can increase diversity in clinical trials and make it easier for all people with cancer to participate in clinical trials by reducing barriers to enrollment.

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About ACS CAN

The American Cancer Society Cancer Action Network (ACS CAN) advocates for evidence-based public policies to reduce the cancer burden for everyone. We engage our volunteers across the country to make their voices heard by policymakers at every level of government. We believe everyone should have a fair and just opportunity to prevent, detect, treat and survive cancer. Since 2001, as the American Cancer Society's nonprofit, nonpartisan advocacy affiliate, ACS CAN has successfully advocated for billions of dollars in cancer research funding, expanded access to quality affordable health care and advanced proven tobacco control measures. We stand with our volunteers, working to make cancer a top priority for policymakers in cities, states and our nation's capital.

Visit fightcancer.org to join the fight.