

The Costs of Cancer in People of Color



Cancer takes a huge physical toll on people facing the disease and comes with many costs. This fact sheet explores the costs of cancer in people of color, which includes all individuals identifying as non-White and non-Hispanic.

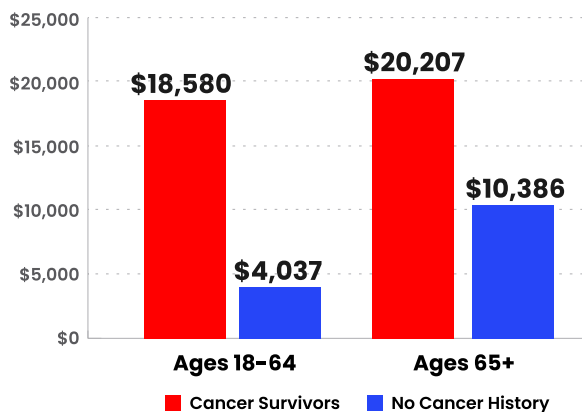
The financial costs of cancer do not impact all people with cancer equally. Evidence consistently shows that certain factors impact cancer diagnosis, treatment, survival and financial hardship experienced by people with a cancer history and their families:

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

People of color with a history of cancer pay more in out-of-pocket costs than people of color without a history of cancer, and are more likely to experience financial hardship than their White counterparts.

Overall, people of color with a cancer history have more than four times the annual health care expenses as people of color who have not been diagnosed with cancer among those ages 18-64 years.¹ For those ages 65+, people of color with a cancer history have nearly double the health care expenditures as people of color who have not been diagnosed with the disease.

Annual Average Health Care Expenditures for People of Color, 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

Valerie Taylor

Stone Mountain, Georgia



Valerie Taylor, 59, from Stone Mountain, Georgia, and was diagnosed with cancer after losing her job as a nurse. Without insurance and limited

income, she found herself in a financial crisis. While trying to focus on her diagnosis and treatment in the hospital, she had people from the business office visiting daily. She describes the experience akin to dealing with a credit collection agency.

Valerie's initial cancer treatment made working impossible. With \$240,000 in hospital debt, she was receiving charity care until she was able to get Medicaid coverage, which would only cover her hospital bills. The plan had a deductible that was difficult for Valerie to pay, given she had no income. As a result, her lifesaving stem cell transplant was postponed for nine months. Most recently, Valerie is fighting cancer again but may be forced into bill repayment if she loses her disability benefits. Since her diagnosis, Valerie has been buried under mounting credit card debt and sees very little relief in sight.

Cancer's Impact on People of Color²

Cancer greatly impacts people of color in the U.S. While inherited genetic factors contribute “minimally” to overall cancer disparities, racial and ethnic disparities in the cancer burden largely reflect “long-standing inequities in socioeconomic status and access to high-quality health care, which can be attributed to historical and persistent structural racism in the U.S. experienced by all people of color.”²

- ▶ Black men, along with American Indian and Alaska Native (AIAN) men, have the highest overall cancer mortality rate (216 per 100,000), which is 18% higher than White men. In particular, prostate cancer mortality among Black men is double that of men in most other groups.
- ▶ Black women have 40% higher breast cancer death rates than White women despite lower incidence rates – a disparity that peaked in 2011, and has since remained largely unchanged.
- ▶ The Alaska Native population has the highest colorectal cancer incidence in the U.S. – at least double the rates in American Indian, Black or White people.
- ▶ Kidney cancer incidence and death rates in the AIAN population are the highest among racial and ethnic groups.
- ▶ Despite the lowest rate for all cancers combined, Asian American Pacific Islander (AAPI) people have liver and stomach cancer rates that are about double those in White people.
- ▶ Among Hispanic people in the U.S., cancer was the leading cause of death prior to 2020, but was displaced by COVID-19 because of its disproportionate burden on this population. Compared to (non-Hispanic) White people, Hispanic people have lower overall rates for the most common cancers (female breast, colorectal, lung and prostate), but among the highest rates for cancers associated with infectious agents.

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I can't do cancer and finances at the same time. The hospital financial agency has representatives visiting my home daily. They are requesting financial information, including my checking account statements and retirement account balance – all while I am receiving chemotherapy in my hospital room.

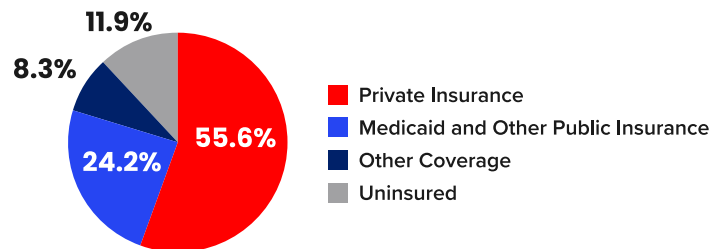
VALERIE TAYLOR, GEORGIA

Health Insurance Coverage in People of Color

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 of color with a history of cancer are more likely to be uninsured than non-Hispanic Whites with a history of cancer.³
- ▶ For insured people of color, the type and details of their insurance coverage are an important determinant of their out-of-pocket costs. Just over half of people of color with a history of cancer, ages 18-64 years, have private insurance, and another quarter have Medicaid.

Insurance Type, People of Color With a History of Cancer, 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.

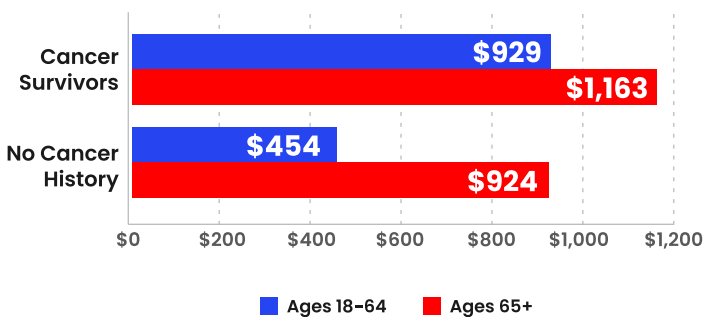
- ▶ More and more people are enrolled in lower-premium high-deductible health plans (HDHPs), despite high upfront costs and mounting evidence that these plans cause them to delay important cancer care and have worse cancer outcomes.^{4,5,6} The majority (56%) of privately insured people of color with a cancer history have an HDHP.⁷

What People of Color With a Cancer History 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.⁸ These increased costs often continue even years after the patient has finished active cancer treatment.

Younger people of color with a cancer history spend an average of \$929 every year on out-of-pocket medical expenses, which is more than double that of those without a cancer history. And that doesn't even take into account monthly insurance premiums.⁹ Older people of color with a cancer history spend more on out-of-pocket medical expenses.¹⁰

Average Annual Out-of-pocket Expenses, People of Color, 2018–2020

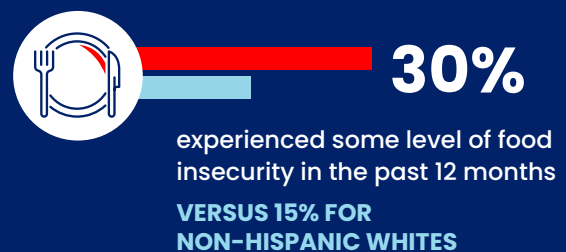
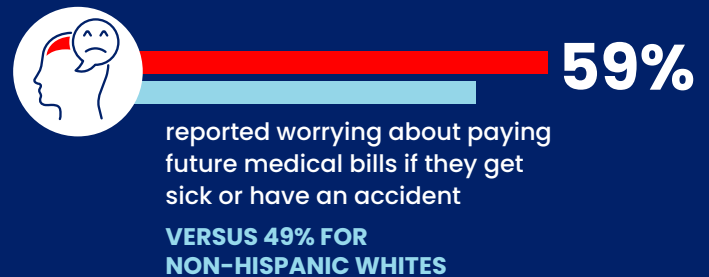
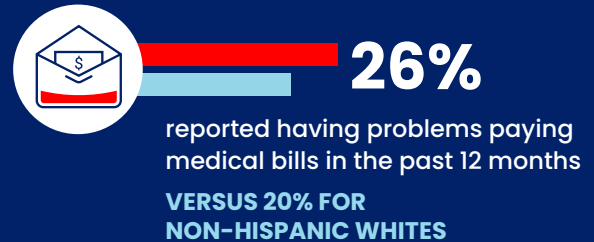


Source: Agency for Healthcare Research and Quality: Medical Expenditure Panel Survey, 2018–2020. Public-use data file and documentation. Retrieved from: https://meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp. July 2023.

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The Impacts of the Costs of Cancer on People of Color

The high costs of cancer have many adverse impacts. Research shows that among people of color ages 18–64 years with a history of cancer:¹¹



Note that these patterns are also seen in the ages 65+ population.

ACS CAN Supports Policies That Will Reduce the Costs of Cancer for People of Color

The American Cancer Society Cancer Action NetworkSM (ACS CAN) supports policies that will reduce the costs of cancer for people of color. 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 in people of color, ACS CAN supports:

- ▶ **Expanding access to care, including for those who are undocumented.** Access to care for those who are uninsured not only ensures that serious diseases like cancer can be detected and treated earlier, but also often means better patient outcomes and less costs to the individual and the larger health care system. The Affordable Care Act (ACA) expanded health insurance coverage to millions of Americans. However, despite these coverage gains, millions of people in the U.S. remain uninsured, with data showing that noncitizens are more likely to be uninsured. In 2021, 25% of lawfully present individuals and 46% of undocumented immigrants were uninsured, compared to only 8% of U.S. citizens.¹³ A critical factor for eliminating disparities and ensuring health equity is to guarantee that all individuals have access to affordable coverage, regardless of immigration status. By ensuring that everyone has access to care, serious diseases like cancer can be detected and treated earlier – often resulting in better outcomes and lower costs to the system. ACS CAN urges Congress to pass the Health Equity and Accountability Act (HEAA), which focuses on health inequalities, societal injustices and their intersection with immigration status, age, disability, sex, gender, sexual orientation and socioeconomic status.
- ▶ **Addressing patient costs to diversify participation in clinical trials.** Clinical trials are vital to advancing new and improved standards of care and give patients the opportunity to access the latest developments in treatment. 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. The additional costs can lead to unequal participation rates between high- and limited-income

people with cancer; the patients most impacted tend to be those traditionally underrepresented. For instance, women who belong to certain racial and ethnic groups¹⁴ are underrepresented in breast cancer clinical trials, and those with limited incomes are less likely to participate.¹⁵ 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 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.

- ▶ **Ensuring complete and timely collection and publication of demographic data that help identify disparities.** Ensuring detailed race and ethnicity data are available, as well as accurate, objective and impartial, is critical to evidence-based health equity work. ACS CAN supports funding and policies to promote timely collection and publication of demographic data that aid researchers, program managers and policymakers in identifying disparities to improve health equity in cancer prevention, detection and treatment. Separating out racial and ethnic information on certain groups would be helpful to target cancer prevention and control efforts – potentially helping health systems develop screening measures and prevention programs that would better identify diagnoses at earlier stages when less invasive and less costly treatment options are available to patients. Adding subgroups to the required minimum reporting categories can provide opportunities for improved reporting of information pertaining to the health of the nation's diverse population. When certain groups are underrepresented in survey data, such as the National Health Interview Survey (NHIS), it is difficult to identify widespread disparities that exist and can result in misleading data that fail to show striking differences in comorbidity burden and survival outcomes across different subgroups. Due to underrepresentation in the datasets used, some other historically underrepresented populations had to be excluded from these ACS CAN Costs of Cancer fact sheets, such as the Asian American and Pacific Islander community and the American Indian and Alaskan Native community.

► **Increasing access to patient navigation services.** Patient navigation is an evidence-based intervention that eliminates health disparities across the cancer care continuum. It has become increasingly recognized for improving patient outcomes, reducing unnecessary treatment costs and increasing patient satisfaction. Patient navigation services have also 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} ACS CAN supports increasing access to quality cancer care among communities that have been under-resourced by extending the reach of navigation services. The expansion and sustainability of patient navigation services will only be achieved through a reimbursement strategy to ensure everyone everywhere will have access to patient navigation services needed to ensure better patient experience and outcome due to a cancer diagnosis.

► **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; 60% of these uninsured individuals are people of color, and the vast majority live in the American South. 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 May 2022, we conducted a survey about cost and debt issues. Cancer survivors of color told us they had problems affording treatment, dealing with worry and anxiety and medical debt.¹²

Problems affording treatment

It was difficult to afford my health care expenses.

34%

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

52%

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

18%

Medical debt

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

67%

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

59%

(of those reporting current or past debt)

I declared bankruptcy due to health care costs or debts.

8%

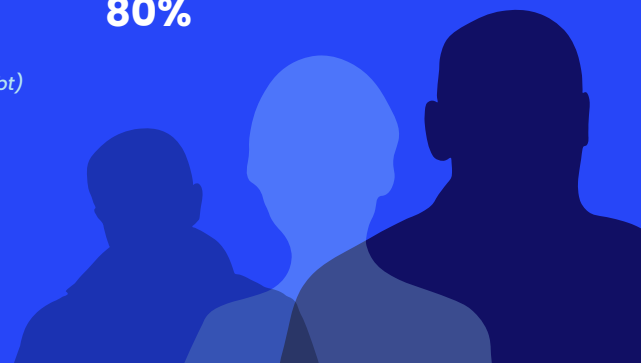
Worry and anxiety

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

82%

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

80%



► **Preventing medical debt and addressing its impact on cancer survivors.** Medical debt and the problems it causes are common among individuals with a cancer history. People with a history of cancer are significantly less likely to be homeowners and more likely to have negative net worth than those without a history of cancer. Medical debt impacts people with a cancer history in many ways: One study showed that those who incurred \$10,000 or more in debt were significantly more likely to report social and economic impacts, including housing concerns and strained relationships.¹⁹ ACS CAN's own survey data show that roughly half of those surveyed carried cancer-related medical debt, and African American respondents were more likely than Whites to incur such debt, which deepens existing health disparities.²⁰ We urge policymakers to enact policies that 1) prevent medical debt by providing all individuals access to affordable, comprehensive health insurance coverage; ensuring patients receive all the financial assistance they are eligible for; and resolving billing issues before they become medical debt; and 2) reduce the impact of already-incurred medical debt on patients' lives.

► **Eliminating tobacco²¹ use to address health disparities among people of color.** Tobacco use has been found to be one of the primary drivers of cancer-related health disparities because its use disproportionately impacts people based on race, ethnicity, sexual orientation, gender identity, disability status, mental health, income level, education level and geographic location.^{22, 23, 24} Eliminating health disparities depends heavily on eliminating tobacco use. The tobacco industry's aggressive marketing using advertising, price discounting and flavors to intentionally target African American people, Hispanic/Latinx people, Native Hawaiian or Pacific Islander people and American Indian or Alaska Native people has caused both disproportionate tobacco use and tobacco-related disparities among these populations.^{25, 26, 27, 28, 29, 30} ACS CAN will continue to advocate for comprehensive evidence-based policies at the local, state and federal levels that aim to reduce disparities and improve health outcomes for all individuals, including people of color. Effective policies known to prevent tobacco use and address tobacco-related disparities include adequately funding tobacco prevention and cessation programs; ensuring cessation services are comprehensive and accessible; increasing the price of tobacco products through regular and significant tax increases on all tobacco products; enacting comprehensive smoke-free laws that cover all workplaces, including restaurants, bars and gaming facilities; continuing to urge the Food and Drug Administration to use its full authority to regulate tobacco products and prohibit all flavored products, including menthol; and preserving local control of public health policies.

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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.