

The Costs of Cancer in the LGBTQ+ Community



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 the lesbian, gay, bisexual, transgender, queer/questioning (LGBTQ+) community. The + represents people who identify with the acronym, but don't necessarily identify with the specific ones listed.

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:

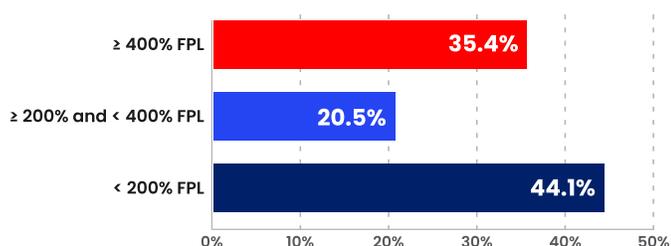
- Age
- Race/ethnicity
- Sexual orientation
- Health insurance status
- Family income
- Where you live
- Cancer type

Note that there are serious data limitations when studying cancer in this community. For example, many national datasets, including the National Health Interview Survey (NHIS), do not include a question about gender identity. Therefore, we are not able to include gender identity in the analyses below.

LGBTQ+ people with a cancer history are significantly more likely to experience financial hardship than non-LGBTQ+ people with a history of cancer.

According to analysis of the NHIS, 44% of LGBTQ+ people with a history of cancer (ages 18-64 years) have an income of less than 200% of the federal poverty level (FPL).¹ LGBTQ+ people with a cancer history are more likely to be in this lowest income bracket than LGBTQ+ people without a cancer history (31%) and straight people with a cancer history (27%).²

Income Distribution of LGBTQ+ Individuals with a History of Cancer, Ages 18-64



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.

Note: LGBTQ+ are those who are gay or lesbian, bisexual, or something else. Gender identity not available in this data.

All analyses incorporated complex survey design.

The Costs of Cancer in My Own Words

Corvus (he/him/his)

Pittsburgh, Pennsylvania

Corvus is a transmasculine 40-year-old from Pittsburgh, Pennsylvania. He is currently in treatment for breast cancer and has had thyroid cancer twice in the past. The threat of medical debt has been a critical aspect of Corvus' journey when attempting to find a doctor within his network who can meet his needs. He has struggled to find a doctor whose office was willing to accept his government insurance in order to get top surgery.

Corvus experienced discrimination, difficulty finding a provider and monthlong delays in accessing gender-affirming care. He was then called the day before his appointment and told that his provider was suddenly not in-network (despite confirming coverage ahead of time). Corvus gave up for years before finding another in-network surgeon who would provide gender-affirming care. It was during his third attempt with a new surgeon that they discovered breast cancer had developed. He received a call while at an oncology appointment that his top surgery was finally approved, but it was too late now as he had to get a cancer mastectomy.

These delays in care added further complications to his health care journey. Even medical staff oftentimes didn't know the answer to his questions about coverage or the unique care needs of LGBTQ+ cancer patients.

ACS CAN partnered with the National LGBT Cancer Network to showcase this patient story. Please note that Corvus is not the patient's real name and was used per the patient's request.

Cancer's Impact on the LGBTQ+ Community

Although cancer registries do not collect information on sexual orientation, research suggests that the LGBTQ+ community is likely at an increased risk for several cancers because of more exposure to risk factors.

- ▶ In 2021, 15.3% lesbian, gay or bisexual adults smoked cigarettes, compared to 11.4% of adults who were heterosexual.³ Research has also found that transgender and gender-diverse adults have a three times greater likelihood of current tobacco use compared to cisgender adults.⁴ Cigarette smoking is associated with a 25-fold increased risk of lung cancer,⁵ as well as higher risk for 11 other cancers.
- ▶ Lesbian, gay or bisexual adults are also more likely to report heavy alcohol use (8%-9% versus 6% in 2021),⁶ which increases the risk for cancers of the oral cavity, esophagus, liver, colorectum, female breast and stomach.⁷
- ▶ Gay and bisexual men, especially those who are HIV+, have a higher prevalence of HPV,⁸ the most important risk factor for anal cancer and several oral cancers.⁹
- ▶ Lesbian and bisexual women are more likely to be overweight or obese compared to their heterosexual counterparts,¹⁰ which increases the risk of many cancers, including uterus, liver, kidney, esophagus, stomach, pancreas and breast (postmenopausal).¹¹

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Without those programs, my medications alone are hundreds or thousands of dollars a month after insurance. I'd also owe 20% of everything in network if I lost Medicaid. I recently had Medicaid deny a mental health care need, and I decided to decline it because 20% of the treatment would cost me around \$500 per week. Fortunately, my hospital copays are small – at around \$5 a day. So, I'm still very lucky and fortunate. If I had to pay 20% of that, it would be an unpayable debt of about \$60,000 – about four times my yearly income – for the first 12 weeks of chemotherapy alone.

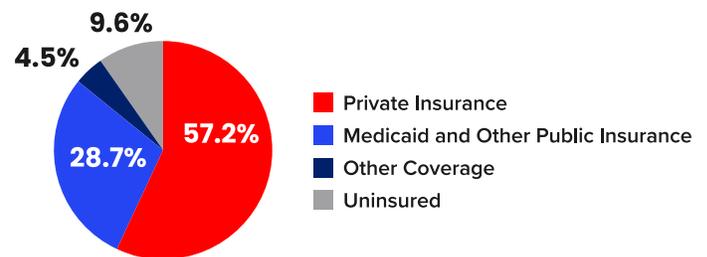
CORVUS, PENNSYLVANIA

Health Insurance Coverage in the LGBTQ+ Community

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

- ▶ For members of the LGBTQ+ community 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 LGBTQ+ people with a history of cancer, ages 18-64 years, have private insurance, and over a quarter have Medicaid.

Insurance Type, LGBTQ+ Individuals 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.

Note: LGBTQ+ are those who are gay or lesbian, bisexual, or something else. Gender identity not available in this data.

All analyses incorporated complex survey design.

- ▶ More and more people are enrolled in lower-premium high deductible health plans (HDHPs), despite the high up-front costs and mounting evidence that these plans cause them to delay important cancer care and have worse cancer outcomes.^{12, 13, 14} The majority (58%) of privately insured LGBTQ+ people with a cancer history have an HDHP.¹⁵

ACS CAN Supports Policies That Will Reduce the Costs of Cancer in the LGBTQ+ Community

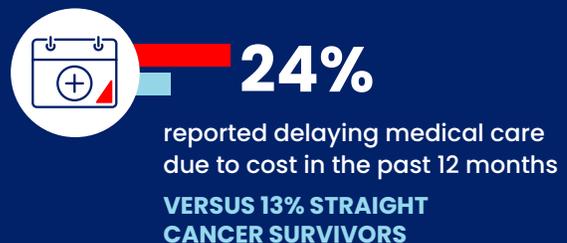
The American Cancer Society Cancer Action NetworkSM (ACS CAN) supports policies that will reduce the costs of cancer for the LGBTQ+ community. We want to make sure that everyone has a fair and just opportunity to prevent, detect, treat and survive cancer. To reduce the costs of cancer in the LGBTQ+ community,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

▶ **Safeguarding access to care through insurance protections.** ACS CAN is committed to removing any barrier to accessing affordable, quality health care that would threaten the fulfillment of our vision to end cancer as we know it, for everyone. Discrimination against the LGBTQ+ population that prevents the coverage for certain services creates disincentives for LGBTQ+ individuals to seek insurance coverage, thereby creating another barrier to accessing cancer care. ACS CAN continues to support protections under Section 1557 of the Affordable Care Act, which ensures broad protection against discrimination of LGBTQ+ individuals in health care services. We continue to oppose conscience and other discriminatory bills that threaten to deny cancer care and other health care services based on factors like religious beliefs.

▶ **Guaranteeing health insurance plan networks are adequate to ensure affordable and reasonable access to care.** Accessing health care services can be challenging for LGBTQ+ people generally and more specifically within their in-network contracted health plans. LGBTQ+ people with cancer may experience discrimination and be unable to obtain health care services when health systems, health plans or providers choose not to provide care because of their sexual orientation or gender identity. ACS CAN believes that in cases where an individual is not able to reasonably access covered health care services because of a provider's beliefs, the LGBTQ+ individual's network has failed to provide them with a provider that can meet their needs, is thus failing to meet the network adequacy of the plan and must provide the individual with reasonable access to other in-network providers that are available for care. ACS CAN aims to ensure health insurance networks adequately provide all enrollees reasonable and timely access to an in-network facility that provides cancer screenings, follow-up testing, high-quality treatment and appropriate health care providers.

Costs of Cancer on the LGBTQ+ Community

The high costs of cancer have many adverse impacts. Research shows that among LGBTQ+ people ages 18-64 years with a history of cancer:¹⁶



► **Eliminating tobacco¹⁷ use to address health disparities among the LGBTQ+ community.**

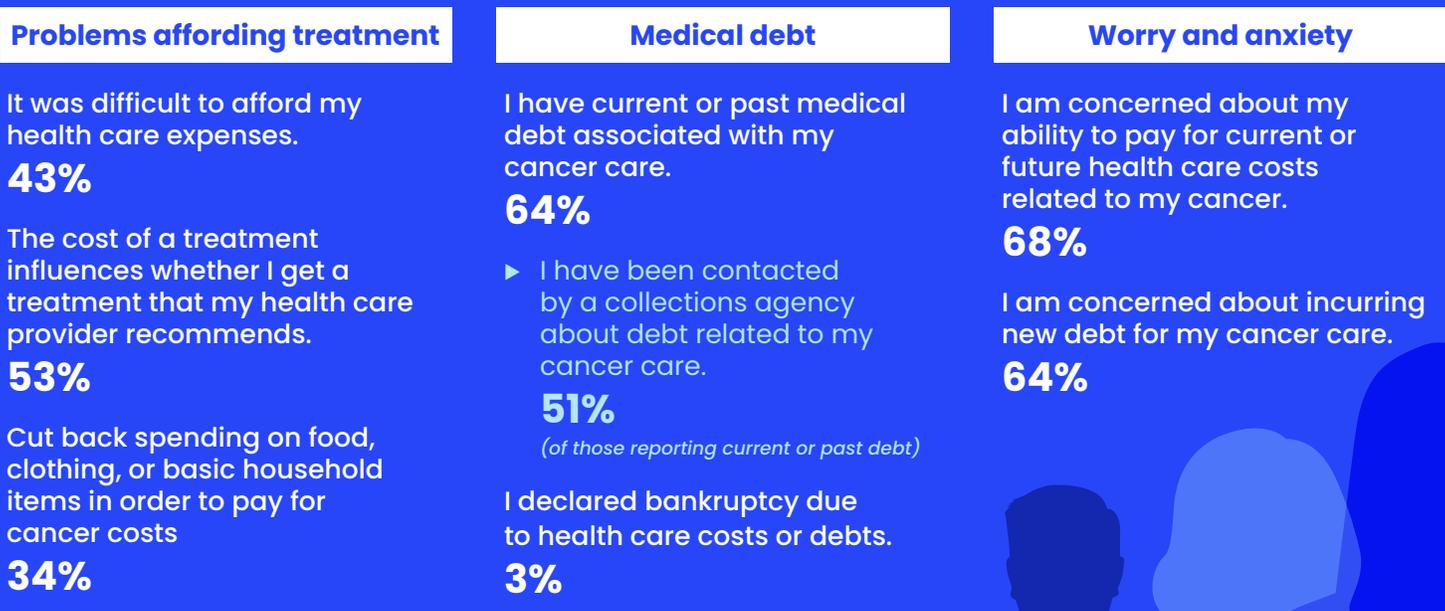
Tobacco use has been found to be one of the primary drivers of cancer-related health disparities because its use disproportionately impacts people based on race, ethnicity, sexual orientation, gender identity, disability status, mental health, income level, education level and geographic location.^{18,19,20} Eliminating health disparities depends heavily on eliminating tobacco use. The tobacco industry's aggressive marketing using advertising, price discounting and flavors to intentionally target LGBTQ+ people has caused both disproportionate tobacco use and tobacco-related disparities among this population.^{21,22,23} 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 the LGBTQ+ community. 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.

- **Increasing access to inclusive 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 populations by providing access to disease prevention education, conducting community outreach and facilitating public education campaigns.^{24,25} 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 – cancer can access patient navigation programs. Culturally competent and inclusive patient navigation services could help further ensure that LGBTQ+ patients and their families feel welcome and better understand cancer screening guidelines, diagnoses and treatment options.

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 2023, we conducted a survey about cost and debt issues. LGBTQ+ people with a cancer history told us they had problems affording treatment, dealing with worry and anxiety and medical debt.²⁶



► **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 currently fall into the Medicaid coverage gap – where individuals are ineligible for Medicaid but earn too little to qualify for premium tax credits for qualified health plans in the marketplace. Research shows that many LGBTQ+ individuals depend on Medicaid for health coverage, especially people of color and transgender individuals.²⁷ 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.

► **Increasing data collection of sexual orientation and gender identity data that help identify disparities.** Gaps in cancer information about the LGBTQ+ community are due to a persistent lack of sexual orientation and gender identity (SOGI) data collection. In addition, most medical intake forms do not encourage or allow disclosure of sexual orientation and/or gender identity.²⁸ ACS CAN supports legislative and regulatory proposals seeking to facilitate increased data collection of SOGI information that aids researchers and policymakers in identifying disparities to improve health equity in cancer prevention, detection and treatment - while also ensuring appropriate safeguards to protect the privacy of this health information. When certain groups are underrepresented in survey data, such as the NHIS, it is difficult to identify whether widespread disparities exist and can result in misleading data that fail to show differences in incidence, 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.

► **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. 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

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The commute to the surgeon I finally found was about 45 to 60 minutes each way. For weeks, I had to make that drive and travel another half hour into the city and pay the gas and for car upkeep. There's technically a medical assistance transportation program, but I stopped receiving reimbursements from the program and so I gave up on calling and submitting documents to them. They would cover \$14 per round trip, which does help. I did not have people to drive me after surgery, so at one point I had to travel by several buses, which took five hours.

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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 people most impacted tend to be those traditionally underrepresented. While there are gaps in cancer information about the LGBTQ+ community due to a persistent lack of sexual orientation and gender identity (SOGI) data collection²⁹, including data on LGBTQ+ representation in cancer clinical trials,³⁰ LGBTQ+ people face a disproportionate burden of some cancers and are also more likely to experience inequities, such as poverty, that can make access to health care a challenge.³¹ 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.

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Support for this project was provided by Bristol Myers Squibb.



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.