



The Costs of Cancer

2020 Edition





The American Cancer Society Cancer Action NetworkSM (ACS CAN) is making cancer—and the affordability of cancer care—a top priority for public officials and candidates at the federal, state and local levels.

ACS CAN is the American Cancer Society's nonprofit, nonpartisan advocacy affiliate. ACS CAN empowers advocates across the country to make their voices heard and influence evidence-based public policy change, as well as legislative and regulatory solutions that will reduce the cancer burden.

This ACS CAN report focuses specifically on the costs of cancer borne by patients in active cancer treatment as well as cancer survivors. It examines the factors contributing to the cost of cancer care, the types of direct costs patients face and the indirect costs associated with cancer. To more fully illustrate what people with cancer actually pay for care, the report also presents scenario models for several types of cancer and different types of insurance coverage. Finally, the report presents public policy recommendations for making cancer treatments more affordable for patients, survivors and the health care system as a whole.

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For more information regarding the methodology of the modeled patient cost scenarios in this report, and to view additional materials related to this report, please visit www.fightcancer.org/costsofcancer.

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Introduction

The American Cancer Society (ACS) estimates that roughly 1.8 million new cases of cancer will be diagnosed in the U.S. in 2020 and that more than 16.9 million Americans living today have a cancer history.¹ As a leading cause of death and disease in the U.S., not only does cancer take an enormous toll on the health of patients and survivors—it also has a tremendous financial impact.

Patient Costs are Unaffordable

For patients and their families, the costs associated with direct cancer care are staggering.

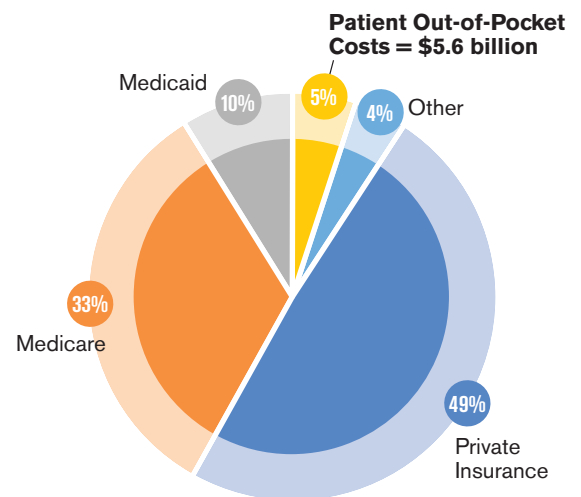
In 2018 cancer patients in the U.S. paid \$5.6 billion out of pocket for cancer treatments,² including surgical procedures, radiation treatments and chemotherapy drugs.

Overall Cancer Costs are Rising

Cancer also represents a significant portion of total U.S. health care spending. Approximately \$183 billion was spent in the U.S. on cancer-related health care in 2015, and this amount is projected to grow to \$246 billion by 2030—an increase of 34%.

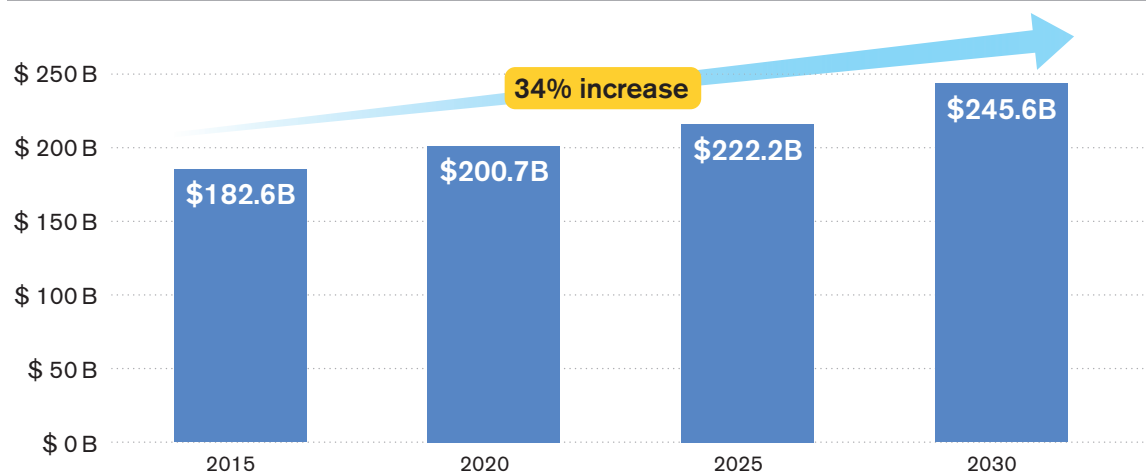
These high costs are paid by people with cancer and their families, employers, insurance companies and taxpayer-funded public programs like Medicare and Medicaid.

Everyone Pays the Costs of Cancer Treatment



Source: Data retrieved from the Agency for Healthcare Research and Quality, Medical Expenditure Panel Survey, 2018. <https://meps.ahrq.gov/mepsweb/>
 *See reference for category definitions.³ Percentages in chart have been rounded.

National Cancer Costs Projected to Increase Drastically by 2030



Spending on Cancer Care—in 2019 billions of dollars

Source: Mariotto AB, Enewold L, Zhao J, Zeruto CA, Yabroff KR. Medical Care Costs Associated with Cancer Survivorship in the United States. Cancer Epidemiol Biomarkers Prev June 10 2020 DOI: 10.1158/1055-9965.EPI-19-1534

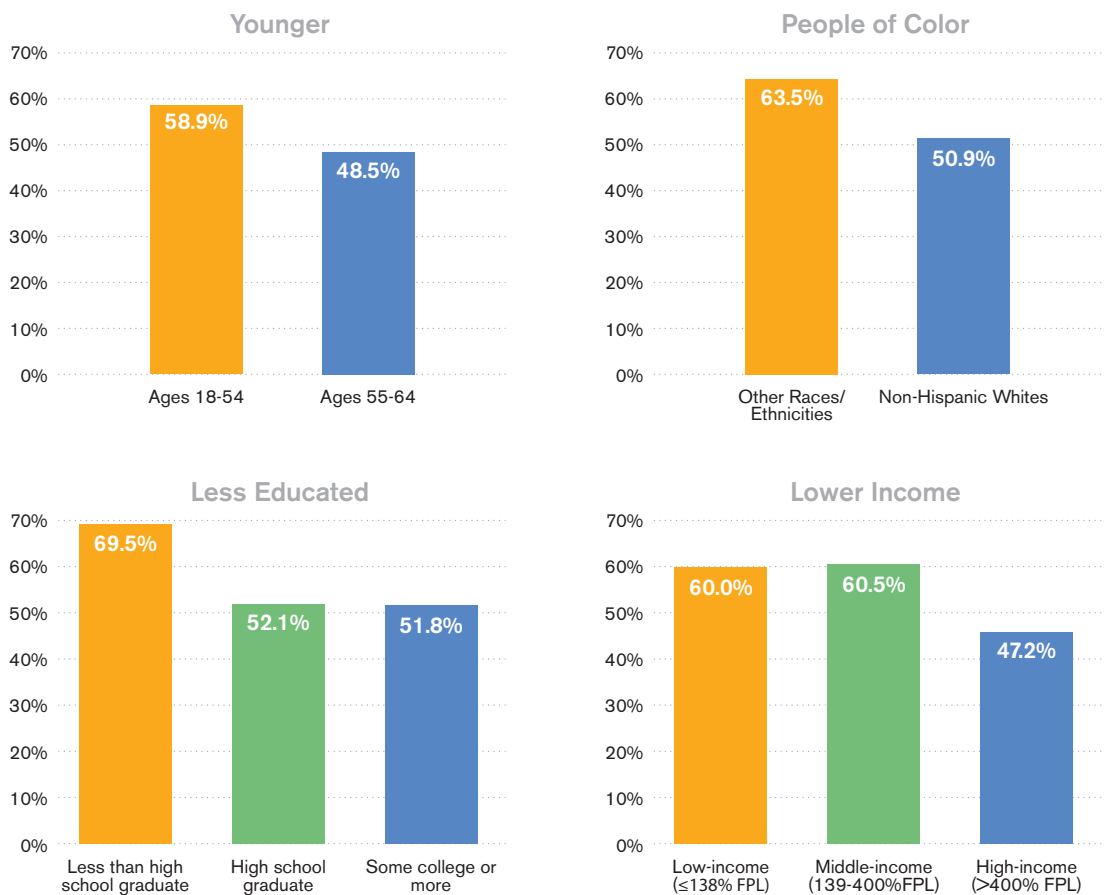
The Costs of Cancer Do Not Impact All Patients Equally

Because of high costs, many people with cancer and those who have survived cancer experience financial hardship, including problems paying bills, depletion of savings, delaying or skipping needed medical care, and potential bankruptcy. These costs and hardships do not impact all cancer patients equally—there are certain factors that make a patient more likely to experience financial hardship:

The Costs of Cancer Disparities

Cancer and its costs do not impact all individuals equally. Look for information about The Costs of Cancer Disparities throughout this report.

Cancer patients are more likely to experience financial hardship if they are:



% of Individuals with a History of Cancer Reporting at least 1 Type of Financial Hardship, Ages 18-64

*FPL = Federal Poverty Level

Source: Han X, Zhao J, Zheng Z, de Moor JS, Virgo KS, Yabroff KR. Medical Financial Hardship Intensity and Financial Sacrifice Associated with Cancer in the United States. *Cancer Epidemiol Biomarkers Prev.* 2020;29(2):308-317. doi:10.1158/1055-9965.EPI-19-0460

Note that similar patterns of disparities exist in the over-65 population.

Factors Contributing to the Costs of Cancer

With more than 200 different types of cancer, there is no “one size fits all” cancer treatment—and therefore the costs of cancer treatment vary significantly from patient to patient. However, there are several consistent factors that contribute to patients’ overall costs for their care.

Insurance Status/Type of Insurance Coverage:

Patients without health insurance are responsible for all of their treatment costs. Some uninsured patients may qualify for “charity care,” may be able to participate in drug discount programs to reduce their costs or may be able to negotiate discounts with providers. For patients with insurance, the kind of health insurance the patient has and the design of their plan are some of the most important factors in determining the ultimate costs for patients. Patient costs are often referred to as cost sharing or an out-of-pocket requirement. Following are some of the out-of-pocket components that determine what patients pay:

- **Premium:** The monthly amount the patient pays to stay covered by the insurance plan (in some cases an employer pays all or part of a patient’s premiums). Premiums are determined by a number of factors that differ depending on type of insurance and can include: age of the enrollee, where the enrollee lives, how generous the benefits are (including cost-sharing amounts listed below) and how much the plan anticipates it will pay in health care claims for enrollees. While many enrollees focus only on premium prices, the other out-of-pocket

costs listed below offer a more complete picture of what patients ultimately pay. For instance, enrollees who are high utilizers of care—including those with cancer—often face a trade-off of higher premiums for lower out-of-pocket costs and vice versa.

- **Deductible:** The amount the patient must first pay out of pocket for care before the insurance plan will start covering costs. Some plans have separate deductibles for medical services, drugs, and/or out-of-network services. High deductible health plans—defined in 2020 as

Survivor Views: The Costs of Cancer in Their Own Words

“I had good insurance through my husband’s work, but our deductibles were always high. We met our deductible twice with my cancers, we have never met it otherwise. The benefits after meeting the deductible were nice, but we had to put all of our bills on payment plans and most would go into collections even though we were paying them. When you are paying 8 different bills for thousands of dollars, and one person is working with the cost of living and food, there is little to go around.”

Ovarian Cancer Survivor, Ohio

plans with a deductible of \$1,400 or higher for individuals or \$2,800 for families—are becoming more prevalent in the U.S.⁴

- **Co-payment or Co-pay:** A flat fee patients pay per health care service, procedure or prescription.
- **Co-insurance:** A percentage patients pay of the total cost of a prescription, service or procedure. Co-insurance can be unpredictable because the patient often cannot determine the total cost of the treatment until arriving at the pharmacy or receiving a bill after the treatment.
- **Out-of-Pocket Maximum or Out-of-Pocket Cap:** The limit on what a patient must pay each year before the health plan starts to pay 100% for covered, in-network benefits. This amount excludes premiums. Current law establishes these caps in most private insurance plans. Caps provide a crucial protection to patients with high health care costs.
- **In-Network vs. Out-of-Network:** Many health insurance plans have “networks” of doctors, hospitals, and pharmacies. If a patient goes to an “in-network” provider, cost sharing is usually lower because the insurer has negotiated rates with the provider. Some insurance plans

Current law requires many private insurance plans to limit annual patient out-of-pocket spending. The 2020 limit is \$8,150 for an individual plan and \$16,300 for a family plan.

charge more cost sharing for “out-of-network” providers, while other plans do not cover out-of-network providers at all. Out-of-network costs do not always count towards the patient’s out-of-pocket maximums.

- **Balance Billing and Unexpected Costs:** Patients may also encounter unanticipated costs. Their plan may not cover a treatment they received, they may have used a provider who was not in-network, or their plan did not reimburse the provider for the full amount billed and the patient has to pay the difference (this is sometimes called “balance billing” or “surprise billing”). The amount of these surprise bills often does not count toward the patients’ out-of-pocket maximum.



Other factors contributing to costs variations are:

Treatment Plan: The type of treatment (surgery, radiation, chemotherapy, etc.) and how much treatment (duration, number of drugs, number of surgeries, etc.) the patient receives causes costs to vary significantly. Note that the stage at which a patient is diagnosed is an important factor in determining a patient's treatment plan, the potential outcome and the treatment costs. In some cases, doctors and patients have choices between treatment regimens and can consider costs in their decision. In other cases, there is only one treatment option.

Geographic Location: Costs vary based on where the patient lives and how many providers are available in that area. Areas that generally have high costs of living also tend to have higher treatment costs.

Treatment Setting: Treatment charges are based on many factors, and the costs to the patient may differ depending on whether care is delivered in a hospital, clinic or physician's office (for example, many hospitals charge facility fees that increase costs for patients). Sometimes patients may have a choice where they receive treatment, but other times they do not have a choice and must incur additional cost. Regardless of setting, it is difficult for patients to obtain price information in order to make comparisons.

Key Terms

- **Medical Benefit:** the benefits covered by a health plan. Generally, medical benefits include coverage for hospital visits, doctor visits and various kinds of tests. In some cases, a health plan has a separate pharmacy benefit that provides coverage for outpatient prescription drugs
- **Formulary:** the list of drugs and pharmacological therapies covered by a health plan. Formularies often sort drugs into tiers, which are groups of drugs assigned a certain co-pay or co-insurance.
- **Medicare:** the federal government program providing health coverage to Americans age 65 and older, as well as some individuals with disabilities. Medicare has several parts: Part A covers hospitalization, Part B covers physician and outpatient services (including physician-administered drugs), and Part D covers oral drugs. Part C offers private plans that cover hospitalizations, physician and outpatient services. Some individuals also have a Medigap plan (otherwise known as a Medicare Supplemental plan), which reduces cost sharing required in Parts A and B.
- **Medicaid:** Joint federal-state government program that provides health insurance coverage to qualifying people with low-incomes, people who are pregnant, children, seniors, and people with disabilities.
- **Employer-Sponsored Insurance:** Health insurance provided through an individual's employer. This type of insurance is also usually provided to the individual's spouse and/or dependents
- **Individual Marketplace Insurance:** Insurance purchased by individuals, not offered by employers or other groups. All individuals have access to either a state-based or federal Exchange that sells these plans which meet Affordable Care Act standards.
- **Short-Term, Limited-Duration Plan:** A private health insurance plan that provides coverage to policyholders for a period of as little as a month to as long as three years. These plans offer limited coverage and benefits and are not required to implement the same consumer protections as other plans.



Types of Cancer Treatment Costs

There are traditionally three primary approaches to treating cancer: surgery, radiation and pharmacological therapy (including chemotherapy, targeted therapy, hormone therapy and immunotherapy). Some patients receive all three treatment modalities, while others receive one or two types. Costs to the patient vary depending on the type and extent of the treatment.

Surgery: Surgery can be used to remove tumors, diagnose cancer and/or to find out how far a cancer has spread. Many people who have cancer have surgery at least once as part of their treatment. Surgery can involve multiple medical providers, hospitals or specialized facilities and other elements that result in multiple charges to patients and health insurers. Patients may be assessed additional facility and other fees associated with where the surgery is performed. If a provider is not in-network, a plan may not cover as much (or any) of the cost for the out-of-network provider or service. This can lead the patient to receive unexpected medical bills, sometimes known as “balance bills” or “surprise medical bills.” Some insurance plans may require the patient to pay co-insurance for each service or a bundle of services, and others have a flat co-pay per day or per hospital admission. Covered surgery and associated care are generally included under a plan’s medical benefit.

equipment and a team of health care providers. Treatment protocols vary, but some cancer patients receive radiation daily or several times a week for many weeks, which contributes to relatively high patient costs. Patients who have not yet met their out-of-pocket maximum will likely be required to pay co-pays per visit or co-insurance based on the total cost of treatment. Covered radiation is generally included under a plan’s medical benefit (or, in the case of Medicare, under Part B).

Pharmacological Therapy: Medication is a very common part of cancer treatment. This can include chemotherapy, targeted therapy, immunotherapy, hormone therapy and/or supportive care like pain or anti-nausea medication. Some of these drugs can be taken as pills obtained through mail-order or at a pharmacy, and some are administered intravenously (IV) in a doctor’s office, clinic or hospital. In most cases, covered IV drugs are included under a plan’s medical benefit; while covered drugs taken as pills or orally and obtained at a pharmacy are included under a plan’s pharmacy benefit. This difference is important because cost sharing is often different for these benefits, and some plans have separate medical and pharmacy deductibles. Co-pays and co-insurance are both common forms of patient cost sharing for drugs. These tiers are groupings of drugs—like “generic,” “preferred,” “non-preferred,” and “specialty,” and sometimes combinations thereof. Each tier has its own co-pay or co-insurance, which makes understanding patient out of pocket costs more complex. Covered pharmacological therapy is generally included in insurance policies as a separate pharmacy benefit.

New Therapies: Fortunately, oncology treatment is a very active area of research and development for government agencies—such as the National

“**Surprise medical billing**” or “balance billing” is when an insured patient is unknowingly treated by an out-of-network provider and is then billed the difference between what the provider charged and what the insurer paid. Surprise bills can be significantly higher than the consumer’s standard in-network cost sharing. They occur most often with ancillary providers—like anesthesiologists and emergency room physicians.

In an October 2019 survey, ACS CAN asked cancer patients and survivors about their experiences with surprise bills through its Survivor Views panel.⁵

- **24% of respondents reported having received a surprise bill** as a result of their cancer care.
- **28% of these surprise bills were for \$2,000 or higher.**

Radiation: Radiation therapy uses waves or high energy particles to destroy or damage cancer cells. Most patients who receive radiation treatments do so at a hospital or cancer treatment facility. Radiation treatment requires complex

Cancer Institute—as well as for academic and industry researchers. Decades of significant investment is resulting in a steady stream of new treatments becoming available to cancer patients and their providers. Many of these new treatments are pharmacological. Some innovations—like chimeric antigen receptor therapy (CAR-T), which takes a patient's own immune system cells and changes them in a laboratory to attack cancer cells before re-infusing them⁶—belong in their own unique category. Some new personalized therapies require biomarker testing (sometimes called “genomic testing”) to determine if the patient has the particular type of cancer the personalized therapy treats.

Because of the way industry recoups costs for research and development, a newer treatment is likely to be more expensive than when it has been used for many years and competitors have developed generic or biosimilar versions of the drug. This often results in higher out-of-pocket costs for a patient using a new treatment, especially if they must pay co-insurance, cannot use copay assistance, or are uninsured. Also, if a treatment is very new, a patient's insurance plan may not have added it as a covered benefit yet or may consider it ‘experimental.’ In these situations, a patient may be able to appeal to their insurance plan for coverage of the treatment—otherwise their out-of-pocket costs will likely be very high for an uncovered treatment or a patient may opt to go without the treatment.

Other Types of Cancer Care Costs: While surgery, radiation and pharmacological therapy are the three most common approaches to cancer treatment, patients may utilize other regimens like stem cell transplants, hyperthermia, photodynamic therapy and blood transfusions. Cancer patients also often need treatments such as supportive or palliative care, rehabilitative therapy, mental health services, nutrition counseling and cardiology consultations as a result of their cancer or treatments.⁷

It is also important to note that these various forms of treatment require multiple types of health care personnel. It is very common for people with cancer to see multiple health care providers during the course of their treatment, including primary care doctors, specialists for diseases and

side effects developed as a byproduct of cancer treatment (like cardiologists, neurologists and endocrinologists), medical oncologists, radiation oncologists, surgeons, palliative care specialists, rehabilitation specialists, physical therapists and nutritionists. The complexity of cancer treatment and the necessity of multiple specialists are large drivers of cancer patient costs. Many health

Survivor Views: The Costs of Cancer in Their Own Words

“One of the most surprising things is the cost of care AFTER active cancer treatment. I have lymphedema and the costs are significant, including various equipment, DME [durable medical equipment], compression clothing, and physical therapy. I didn't realize the costs would continue after active treatment.”

Breast Cancer Survivor, Arizona

insurance plans charge higher co-pays or co-insurance amounts for specialist visits compared to primary care. Additionally, very specialized providers are often in short supply, and patients are sometimes forced to go out-of-network to see a specialist. This is especially likely for patients who live in more rural areas.

Rural residents are more likely than their urban counterparts to have higher rates of unemployment and lack of health insurance.¹⁰

Survivorship Care Costs: It is also important to note that even when a person with cancer has completed their surgery, radiation and/or chemotherapy, the costs of care do not end immediately. Many cancer survivors deal with cancer symptoms and side effects of treatment months to years after finishing treatment—sometimes for the rest of their lives. Some cancer survivors also must take treatments long-term, like a 10-year regimen of hormone therapy to prevent breast cancer recurrence. This means many of the costs discussed in this section, including for seeing specialist providers like rehabilitation therapists and psychotherapists, can continue for years for cancer survivors. In fact, research shows that annual health care expenditures for cancer survivors are significantly higher than for individuals who have never had cancer.¹¹ Indirect costs of cancer—explored on the next page—also often continue into survivorship.

The Costs of Cancer Disparities

- Urban areas have approximately 5 times the number of oncologists compared to rural areas.⁸
- Rural patients have to travel nearly twice as long one-way as urban and suburban patients in order to see their cancer doctor.⁹

The Indirect Costs of Cancer

This report focuses on the direct costs of cancer—health care expenses directly for or related to cancer treatment—but there are other indirect costs that are just as significant and potentially problematic for people with cancer and their families.

As these are indirect costs, most of them are difficult to quantify and track. But these costs are significant for people with cancer and their families, adding to the overall costs of cancer care and also contributing to the “financial toxicity” of cancer.



Transportation

Some patients have to travel significant distances to medical appointments and the pharmacy



Lodging

Some cancer patients must travel to receive treatments, like specialized surgeries, and need a place to stay near their treatment site



Lost wages or income

Some cancer patients must stop working temporarily or permanently, or reduce their work schedules



Secondary Effects

Some patients must treat or deal with secondary effects of cancer or treatment, like fertility treatments, wigs and cosmetic items, or the cost of special food



Caregiving costs

Some patients may need to pay for help at home to care for themselves, or for their children

Survivor Views: The Costs of Cancer in Their Own Words


“Being diagnosed with cancer six years ago has caused me financial difficulties, stress, and anxiety. Although I am in remission, I continue to have adverse effects from my treatment. I spend 2-4 days per week in a doctor’s office and also had to be treated out of state twice in 2019. Each time I go out of state I am spending a minimum of \$1500. While we are fortunate my husband is well enough to work which helps pay for my medical bills and expenses, it’s still a financial strain on us. I am still not able to return to work so we are a one-income family. I don’t know how others who don’t have a moderate salary are able to afford it. If the ACA [Affordable Care Act] goes away, I will likely be penalized for my preexisting conditions. I am so nervous that my medications, physical therapy, treatments, and diabetic supplies will not be covered.”

Leukemia Survivor, Alaska

Patient Profiles: Cost Scenarios

Because of the complexity and variation in cancer treatment, it is difficult to predict the full costs for any individual with cancer at the time of diagnosis. The following illustrative patient profiles and associated data represent the typical costs for several cancer scenarios. The patients are hypothetical, but the treatment regimens are typical treatments for each specific cancer with the corresponding actual costs.

Tom—
Colorectal Cancer
Medicare



Carla—
Breast Cancer
Small Employer, High Deductible Health Plan



Franklin—
Prostate Cancer
Large Employer Plan



Shonda—
Pancreatic Cancer
Medicare



Kathy—
Lung Cancer
Individual Market Plan



Brian—
Lymphoma
Short-term Limited Duration Plan



Experts at ACS and ACS CAN constructed profiles of several typical cancer patients. The types, stages, and details of cancer represented in these profiles were chosen based on cancer incidence rates and the need to represent a diverse set of people with cancer and experiences. Clinical experts determined the usual course of treatment for these patients based on the National Comprehensive Cancer Network (NCCN) treatment guidelines for each of the cancers. Estimates for patient out-of-pocket costs for each of these patients were based on common insurance scenarios. Note that some patient profiles were used to run multiple insurance scenarios for comparison and analysis purposes—combinations of profiles and insurance design scenarios that are not reflected in this section will be discussed in future sections.

All prices and insurance designs are based on 2020 data. See methodology appendix for more details, published at www.fightcancer.org/CostsofCancer.

These patient profiles represent typical scenarios and timelines. They help illustrate the costs that cancer patients and health care payers incur for an individual's cancer treatments. Note that these scenarios do not include costs for other health care treatments unrelated to cancer (for example, if a patient has asthma, the costs to treat asthma are not included). Also note that these scenarios are unable to incorporate all the problems people with cancer face, including tests that have to be repeated and delayed timelines.

Case Study: Colorectal Cancer— Medicare Coverage



In January, Tom's **fecal immunochemical test (FIT)** test was positive indicating that he might have colon cancer. His primary care doctor sent him to a **gastroenterologist (GI) specialist**, who ordered a **colonoscopy**.

Tom received his **colonoscopy** at a hospital outpatient center. During the colonoscopy his doctors discovered **2 adenomatous polyps**, which were removed, and a **lesion suspicious for colon cancer**. The lesion was biopsied, and Tom was diagnosed with **Stage IIB colon cancer**.

In February, Tom had **blood tests** and a **CT scan** to check for possible spread of the disease.

In March, Tom had **colectomy surgery** to remove the lesion and surrounding tissue, and a **lymphadenectomy** to test if the cancer had spread. Tom's cancer tissue was also tested to see if he had any **biomarkers** that would point his doctors towards the right drug regimen.

In April and May, Tom received **chemotherapy** to treat his cancer and prevent reoccurrence, and **supportive care drugs**, like anti-nausea medication, to ease side effects.

Tom finished his treatments in May and began post-treatment follow-up, including **regular doctor's visits** and **blood tests**.

Throughout his treatment, Tom met with several practitioners and specialists, including his **primary care doctor**, a **GI specialist**, a **surgeon**, **oncologists**, and **oncology nurses**.

Tom—Colorectal Cancer Medicare

Tom had health insurance coverage through Medicare and Medigap. His premiums were:

Medicare Part A - **\$0/month**¹²

Medicare Part B - **\$145/month**¹³

Medigap (Policy G) - **\$236/month**

Medicare Part D - **\$25/month**

Tom's highest total spending came in April and May (\$767 in April and \$612 in May) when some of his chemotherapy and supportive care drugs were paid for through his Medicare Part D plan. Otherwise, Tom's Medigap plan protected him from high fluctuating out-of-pocket costs. In total Tom paid **\$405** in premiums every month. At the end of his plan year, he had paid a total of **\$4,864 in premiums** and **\$568 in cost-sharing—a total of \$5,432**—for his cancer care.*

The total health care costs for Tom's colorectal cancer treatment in 2020 were \$38,035. Medicare and Tom's Medigap and Part D plans paid the vast majority of these costs—**\$37,467**. If Tom had been uninsured, he would have been responsible for all of these costs,** and may have been required to pay them up-front before treatment.

Even though Tom is no longer in active treatment, he will still require regular follow-up visits with his oncologist and primary care physician which add to his costs in future years.

*Note that these costs only include cancer treatment, and do not include treatment for other conditions that may have developed as a result of the cancer treatments and/or any other treatments unrelated to cancer care or other preventive services.

**Costs for an uninsured patient may be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate. However, some uninsured patients are also able to receive charity care, which discounts or forgives certain treatment costs.

Case Study: Breast Cancer— Small Employer, High Deductible Health Plan

Year One: Carla has her first **mammogram** in January to screen for breast cancer. Her doctor sees something suspicious on the images and sends her for several follow-up tests including **blood tests**, a **breast MRI**, **CT scans of her chest and abdomen**, **ultrasounds of her breasts and lymph nodes**, and a **diagnostic mammogram**.

She then has a **core needle biopsy** in February, and is diagnosed with **stage III breast cancer**, with a large tumor and cancer present in her lymph nodes. Molecular tests reveal her cancer is **hormone receptor negative** and human epidermal growth factor receptor 2 (**HER2 positive**).

Carla's doctors recommend she start **neo-adjuvant** (before surgery) **chemotherapy** right away given the aggressive nature of her cancer. Before she starts this treatment, she consults with a **cardiologist** about the way her treatment can impact her heart and has a **chemotherapy port** installed.

Carla receives multiple cycles of chemotherapy from March through August, along with **supportive care drugs** to address symptoms and side effects like nausea. These treatments are successful in shrinking her tumors but do not fully eliminate them.

In September Carla has **local excision and lymphadenectomy surgery** to fully remove the tumors, and then begins **adjuvant** (post-surgery) **radiation therapy** to maximize local control of the cancer. In October she also continues her **HER2-targeted therapy infusions**, which started before surgery and will continue for one full year. During these treatments she continues to have **blood tests** and **visits with her oncologist** to monitor her treatment progress.

Year Two: January brings the one-year anniversary of the mammogram that caught her breast cancer—and Carla **continues to receive her HER2-targeted therapy treatments, monitoring blood tests, and visits with her oncologist**. She continues these treatments through June, when she completes a full year of post-surgery HER2-targeted therapy. In the remaining months of her second year, Carla is **tested for lymphedema**—a common side effect of breast cancer treatment—and continues to be **monitored by her oncologist**. Because Carla still has most of her breast tissue, she must still have a **mammogram** every year to look for cancer recurrence or new cancers.

Throughout her two years of cancer treatments, Carla met with several doctors and specialists, including her **primary care doctor**, a **medical oncologist**, **radiation oncologist**, **cardiologist**, and a **breast surgeon**.



Carla—Breast Cancer

Small Employer, High Deductible Health Plan

Carla is enrolled in a high-deductible health plan through her small employer. Carla pays **\$143 per month in premiums**. Note that Carla's employer does not offer an accompanying health savings account.

Carla is required to pay the full amount of her high deductible—\$6,000—and other cost-sharing in February, when she undergoes most of her diagnostic tests. Paying these big bills the same month she received a serious cancer diagnosis was a struggle. Fortunately, she hits her **maximum out-of-pocket limit of \$8,150** in February and her expenses level off. At the end of her first plan year, she had paid a total of **\$1,712 in premiums** and **\$8,150 in cost-sharing** for her cancer care: an **annual total of \$9,862**.*

Carla's costs continued in the second year after her diagnosis: in year two she once again paid a total of **\$1,712 in premiums** and **\$8,150 in cost-sharing** for her cancer care.

The total health care costs for Carla's breast cancer treatment were **\$222,981** (over two years). Carla's insurance plan paid the vast majority of these costs—**\$206,681**. If Carla had been uninsured, she would have been responsible for all of these costs,** and may have been required to pay them up-front before treatment.

* Note that these costs only include cancer treatment, and do not include treatment for other conditions that may have developed as a result of the cancer treatments and/or any other treatments unrelated to cancer care or other preventive services.

** Costs for an uninsured patient may be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate. However, some uninsured patients are also able to receive charity care, which discounts or forgives certain treatment costs.

Case Study: Prostate Cancer— Large Employer Plan



Franklin has a family history of prostate cancer. As part of his **annual physical** in January, Franklin receives a **digital rectal exam** and his primary care doctor orders a **PSA blood test**. Franklin's PSA score from this test is over 10, indicating possible prostate cancer. Franklin's doctor orders more **blood tests**, an **MRI**, **bone scan** and **CT scan**; and refers him to a **medical oncologist**.

After having a **core biopsy** in February, the tests determine that Franklin has **locally advanced prostate cancer**. Since Franklin has a life expectancy of more than 10 years, and he has an intermediate risk of his cancer growing quickly, Franklin chooses to have a **radical prostatectomy surgery** to remove his prostate and test his lymph nodes. The cancer is found in his lymph nodes, so his treatment continues with a goal of stopping its spread to other parts of his body.

In March he begins **androgen deprivation therapy** (ADT), or hormone therapy, which are pills he takes daily. Because Franklin also has diabetes, his doctor wanted to prescribe a certain drug for his treatment. However, Franklin's insurance coverage requires he try a different drug first.

In April he begins **radiation treatments**, and regular **PSA blood tests** and **doctor's visits** to monitor his progress.

After 4 months of these treatments, he has a new round of **blood tests** and a **bone scan**. These tests find that his PSA level has already doubled, indicating the treatments are not working, and Franklin is diagnosed with **'castration-resistant' prostate cancer**. In August he begins taking the **hormone therapy** his doctor originally wanted to prescribe, which stabilizes his cancer and he continues this therapy through the end of the year.

Throughout the course of his treatment, Franklin saw several doctors and specialists, including his **primary care doctor**, a **medical oncologist**, **surgical oncologist**, and a **radiation oncologist**.

Franklin—Prostate Cancer Large Employer Plan

Franklin is enrolled in health insurance through his large employer. Franklin's employer contributes **\$618 per month** towards the premium, and Franklin pays **\$169 per month**.

Franklin has a relatively **small deductible (\$500)** and **maximum out-of-pocket limit (\$3,000)**, and he reaches that limit by February, when his out-of-pocket costs level off. At the end of the year, he had paid a total of **\$2,030 in premiums** and **\$3,000 in cost-sharing** for his cancer care—for an **annual total of \$5,030***.

The total health care costs for Franklin's prostate cancer treatment were \$100,557.

Franklin's employer/insurance plan paid the vast majority of these costs—**\$97,557**. If Franklin had been uninsured, he would have been responsible for all of these costs,** and may have been required to pay them up-front before treatment.

By the end of the year, Franklin had found a treatment that seemed to be working to fight his prostate cancer. He will need to continue taking

this medicine for several years and monitoring his cancer with blood tests and extra doctor's visits. Franklin will continue to pay costs related to his prostate cancer for years to come.

*Note that these costs only include cancer treatment, and do not include treatment for other conditions that may have developed as a result of the cancer treatments and/or any other treatments unrelated to cancer care or other preventive services.

**Costs for an uninsured patient may be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate. However, some uninsured patients are also able to receive charity care, which discounts or forgives certain treatment costs.

The Costs of Cancer Disparities

Compared with white men, African American men are more likely to develop prostate cancer and are twice as likely to die from the disease.¹⁴

Case Study: Pancreatic Cancer— Medicare Coverage



Shonda is retired and lives in a rural area near her family. In January she has her annual Medicare **wellness exam** with her primary care doctor, where she shares that she has been having stomach pains and digestive issues. Her doctor recommends some **diet changes** and schedules a follow-up appointment in March to see if these changes help.

Unfortunately Shonda is still experiencing symptoms in March, so her doctor orders several **blood tests**, followed by a **CT scan of her pancreas**, an **endoscopic ultrasound**, and an **endoscopic retrograde cholangiopancreatography (ERCP) procedure**. The tests continue in April, when she has a **biopsy**, and **CT scans of her chest and pelvis**. After consulting with a **medical oncologist** and **gastroenterologist**, Shonda is diagnosed with **metastatic pancreatic cancer**. Surgery is not an option because the cancer has spread, so she prepares to start **systemic therapy**. Her tumors are **tested for biomarkers**, but none are found.

Her doctor tells her that she would be a good candidate for a clinical trial, which would be her choice for first-line treatment. However, the trial is only offered in a major city that is a 5-hour drive from her home, and her family is not able to travel that far and care for her while receiving treatment.

Shonda must choose a treatment that is available near her home, so she opts to receive chemotherapy from her local oncologist. In April she has a **port** installed and is tested for jaundice in preparation for her treatment. She also consults with a **palliative care specialist** to discuss her options for symptom and side effect control during her upcoming treatments.

In May Shonda begins her **chemotherapy** treatment at her local hospital that her children must drive her to a few times a month. Treatment includes **supportive care drugs**, **blood tests**, and **regular CT scans of her pancreas** to monitor progress. She also meets with her **oncologist** regularly.

After three months of chemotherapy, a scan shows that the treatment is not working to shrink her cancer. Shonda and her doctor decide to try another drug, so she begins a **2nd-line chemotherapy treatment**.

However, her cancer also does not respond to that treatment, and by November, Shonda's level of **pain** and **symptom burden** is increasing. She develops **blockages in her bile ducts and stomach**. In consultation with a **palliative care specialist** who has been monitoring her treatment, Shonda decides to choose care that is focused on her comfort, including regular doses of **pain medication** and the placement of a **gastrostomy tube** to allow her to receive nutrition directly.

The Costs of Cancer Disparities

African Americans are more likely to be diagnosed with cancer at an advanced stage compared to white Americans, and they also have lower survival within each stage—further reflecting inequalities in access to and receipt of high-quality cancer care.¹⁵

Shonda—Pancreatic Cancer Medicare

Shonda had health insurance coverage through Medicare and Medigap. Her

premiums for both were:

Medicare Part A - **\$0/month**¹⁶

Medicare Part B - **\$145/month**¹⁷

Medigap (Policy G) - **\$236/month**

Medicare Part D - **\$25/month**

Shonda's Medigap plan covered all of her cancer treatment expenses until May, when she began taking drugs covered through her Part D plan, which required cost-sharing. In total Shonda paid **\$405** in premiums every month. At the end of her plan year, she had paid a total of **\$4,864** in premiums and **\$1,767** in cost-sharing for her cancer care, for an **annual total cost of \$6,631**.*

The total health care costs for Shonda's pancreatic cancer treatment in 2020 were **\$27,911**. Medicare and Shonda's Medigap and Part D plans paid the vast majority of these costs—**\$26,144**. If Shonda had been uninsured, she would have been responsible for all of these costs,** and may have been required to pay them up-front before treatment.

She and her family may decide to move her to hospice care in the future—which will change how her cancer and supportive care are paid for.

*Note that these costs only include cancer treatment, and do not include treatment for other conditions that may have developed as a result of the cancer treatments and/or any other treatments unrelated to cancer care or other preventive services.

**Costs for an uninsured patient may be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate. However, some uninsured patients are also able to receive charity care, which discounts or forgives certain treatment costs.

Case Study: Lung Cancer— Individual Marketplace Plan

Kathy smoked previously and met high risk criteria for lung cancer, so she had an **annual low-dose CT scan** in January to screen for lung cancer. Her **primary care doctor** told her the scan was positive for a large mass in her left lung and referred her to a **pulmonologist**.



Her pulmonologist ordered a **CT scan** to confirm the first scan's results. In February, Kathy had several **blood tests** and a **lung function test**. She then had a **lung needle biopsy** to test cells from the mass in her lung, a **PET/CT scan**, a **brain MRI**, and was referred to a medical oncologist.

Kathy's oncologist diagnosed her with an **adenocarcinoma of the lung**. She was told the cancer was Stage IV, and it had metastasized to her bones. Because the cancer was too widespread, surgery and radiation were not treatment options. She also had special **biomarker tests** on her tumor which showed she was not a candidate to start with targeted therapy.

In March, Kathy began **chemotherapy with an immunotherapy treatment** at her doctor's office. She also had a consultation with a **palliative care specialist** to discuss her goals and treatment impact on her work and family and received **supportive care drugs** to ease side effects. She also began regular **PET scans** and **blood tests** to monitor the progress of the treatment.

In May, Kathy went to the **emergency room** and was hospitalized for trouble breathing. She stayed in the hospital for three days. Kathy and her doctor decided to try a second-line treatment, as her chemotherapy was not working.

In June, Kathy began receiving a **second immunotherapy treatment** at her doctor's office. She continued **PET scans** and **blood tests** to monitor progress. The immunotherapy worked to keep her cancer from spreading and maintained her quality of life, so Kathy continued the treatment and monitoring through the end of the year.

Throughout the course of her treatment, Kathy saw several doctors and specialists, including her **primary care doctor**, a **pulmonologist**, a **medical oncologist**, a **palliative care specialist**, and the doctors who treated her in the **emergency room**.

Kathy—Lung Cancer Individual Marketplace Plan

Kathy bought an individual health insurance plan through her state's marketplace,

which started in January. The premium for plan was **\$840 per month**, but she qualified for tax credits which helped reduce these costs. Kathy ended up paying **\$325 per month** in premiums.

Kathy finished paying her **high deductible (\$6,500)** in February and hit her **out-of-pocket maximum of \$8,150** in March. These costs were challenging to afford in the span of three months. Fortunately, after her maximum was met she only had to pay premiums for the rest of the year. At the end of her plan year, she had paid out-of-pocket **\$3,896 in premiums** and **\$8,150 in cost sharing** for her cancer care,* a **total of \$12,046**.

The total health care costs for Kathy's cancer treatment were \$140,247. Kathy's insurance plan paid the vast majority of these costs—**\$132,097**. Kathy's out-of-pocket costs

were significant but if she had been uninsured, she would have been responsible for all of these costs,** and may have been required to pay them up-front before treatment.

At the end of the year, Kathy had found an immunotherapy that had stabilized her cancer. Kathy will likely continue to take this treatment for several more months or years—however long it works—as well as being monitored for further cancer spread. Kathy will continue paying costs for cancer treatments into future years.

*Note that these costs only include cancer treatment, and do not include treatment for other conditions that may have developed as a result of the cancer treatments and/or any other treatments unrelated to cancer care or other preventive services.

**Costs for an uninsured patient may be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate. However, some uninsured patients are also able to receive charity care, which discounts or forgives certain treatment costs.

Case Study: Lymphoma— Short-term Limited Duration Plan



Brian works several part-time and freelance jobs and buys the cheapest plan he could find through an insurance broker website, not understanding that this short-term limited duration plan does not cover a comprehensive set of benefits or have to follow other patient protections.

Brian noticed that his lymph nodes were swollen and that he was frequently getting unexplained bruises. In January he went to his **primary care doctor**, and after ruling out an infection, his doctor ordered several **blood tests** followed by a **whole-body PET/CT scan**, and **CT scan of his chest, abdomen and pelvis**.

In February, Brian underwent a **bone marrow biopsy**, and was diagnosed with **Stage II diffuse large B-cell lymphoma**, which is a form of **Non-Hodgkin Lymphoma**. Because Brian may want to father children in the future, he opts to take **fertility preservation measures**, which are not covered by his insurance plan. He also has a **chemotherapy port** inserted to prepare for his treatments.

In March, Brian begins several cycles of **chemotherapy infusions**. He also receives **supportive care drugs** to treat side effects like nausea.

In April, after his 3rd cycle of chemotherapy, Brian has another **full body PET/CT scan** to check if the treatment is working. Fortunately, his cancer has shrunk, and he is able to complete treatment in June without incident and **does not require radiation**.

Follow-up blood tests show no evidence of cancer, but Brian and his doctors must continue to **monitor for cancer recurrence through imaging and blood tests** every 3-6 months for the next 5 years.

Throughout the course of his treatment, Brian saw several doctors and specialists, including his **primary care doctor**, a **medical oncologist**, a **hematologist**, and a **fertility specialist**.

Brian—Lymphoma Short-term Limited Duration Plan

Brian is enrolled in a short-term limited duration (STLD) plan that lasts 12 months. He pays **\$156 in premiums** every month for this non-comprehensive coverage. Note that his plan can also engage in post-claims underwriting, which means that once he is diagnosed with cancer, they will likely try to classify it as a pre-existing condition, not cover any of these costs, or rescind his coverage entirely.

Brian must pay an extremely high deductible (**\$12,500**—which he meets in February) before his plan will begin covering part of his cancer care costs. Once his plan begins covering some costs, he still must pay multiple thousands of dollars *every month* until he completes his active treatment in June. At the end of the year, he had paid a total of **\$1,878 in premiums** and **\$49,782 in cost sharing and costs for uncovered services**, for an annual total of **\$51,660**.*

The total health care costs for Brian's Non-Hodgkin's Lymphoma treatment were

\$97,849. While Brian's STLD plan did pay some of these costs, it did not cover nearly as many of the costs that a comprehensive, Affordable Care Act (ACA)-compliant plan would have paid. Despite being marketed as an insurance plan, STLD plans are not considered comprehensive insurance coverage, and **Brian was responsible for 51% of his cancer costs**.

While Brian has finished his active cancer treatment, he will continue to have tests and imaging for the next 5 years, so his out-of-pocket will likely continue to be higher than before he had cancer. If/when he chooses to have children, he will likely also have to pay out-of-pocket for fertility services because of his treatments.

*Note that these costs only include cancer treatment, and do not include treatment for other conditions that may have developed as a result of the cancer treatments and/or any other treatments unrelated to cancer care or other preventive services.

Data Analysis & Key Findings

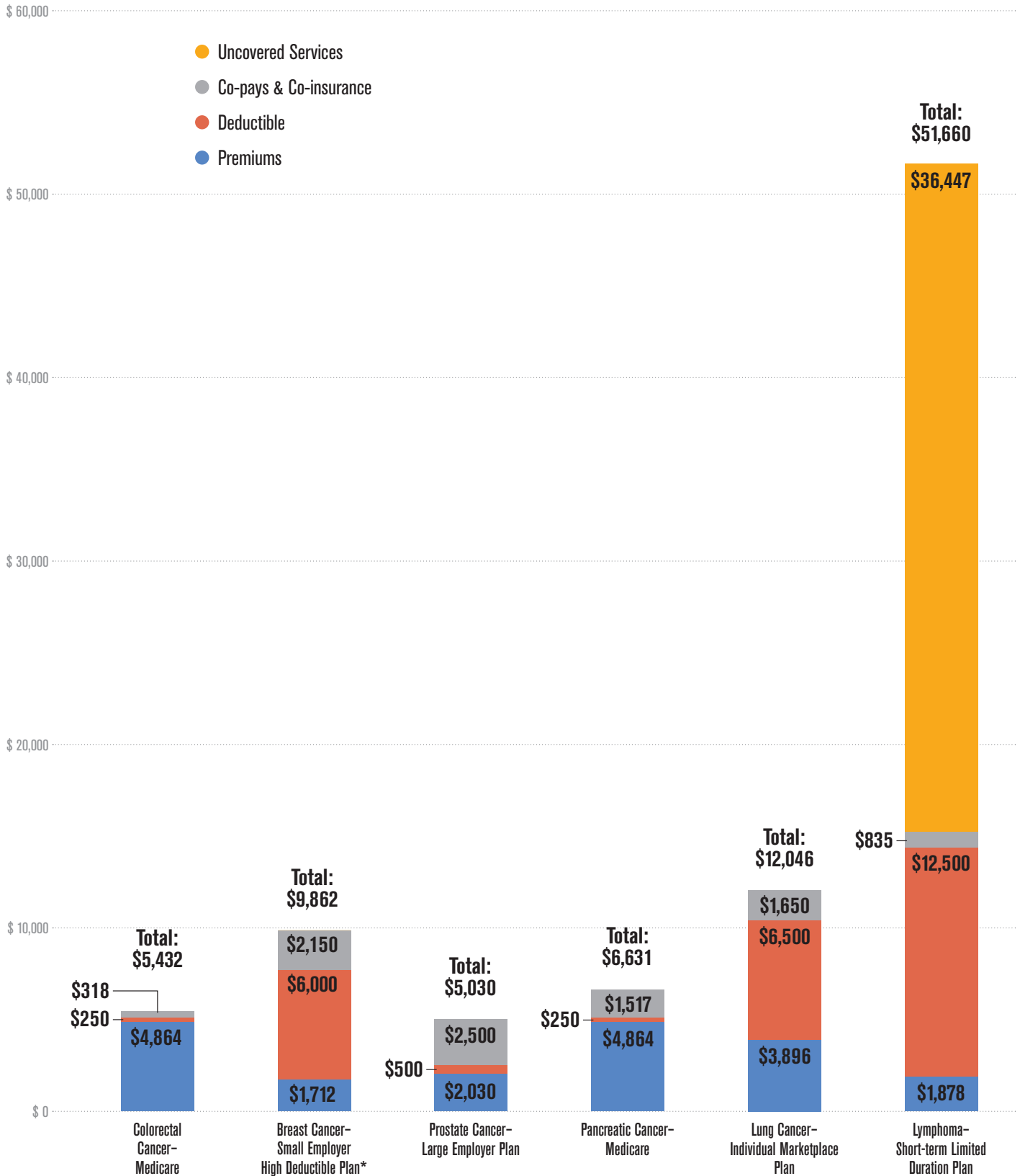
Comparing Patient Out-of-Pocket Costs—Key Findings

- **Insurance coverage is critical.** In each of the scenarios, patients paid a considerable sum out-of-pocket for their care but would have paid significantly higher amounts if they had not had insurance coverage.
- **The type of insurance a person with cancer has is an important factor in how much they will pay out-of-pocket.** The type of insurance a patient has, and that insurance benefit design, determines how much the patient pays, and in what form they pay it—e.g. in premiums that are a fixed monthly amount, in deductibles and cost sharing that are less predictable, or in uncovered costs that can be unlimited.
 - In these scenarios, the patient with the large employer plan pays the least out-of-pocket, with relatively affordable premiums and cost-sharing amounts, and a smaller out-of-pocket maximum that is met early in the year.
 - Patients with a small-employer, high deductible health plan or individual marketplace plan have much higher deductibles and maximum out-of-pocket limits and pay more overall.
 - Patients with Medicare (including Medigap coverage) pay a high amount every month in premiums, but lower amounts in co-pays and co-insurance. In these scenarios, the patients' supplemental Medigap plan requires the highest premiums, but also protects the patients from paying 20% co-insurance on many treatments. The majority of Medicare enrollees have similar supplemental coverage, but patients who do not have this coverage pay much higher cost-sharing amounts.
- The patient with a short-term limited duration (STLD) plan must pay a much higher deductible—almost twice as high as any other deductible in the model—and must pay the full price for many expenses that are not even covered by the insurance plan.
- **Out-of-pocket limits help protect cancer patients.** Cancer patients are super-utilizers of their insurance benefits, and each patient in the scenarios who had an out-of-pocket limit reached their maximum quickly. Once the maximum is reached, patients do not have to pay cost sharing for in-network, covered services. This is an important protection for many privately-insured patients.

The Dangers of Non-Comprehensive Coverage

Brian, who bought a short-term limited duration plan, paid over 4 times as much as any of the other cancer patients profiled in out-of-pocket costs. He did not realize that his plan had huge gaps in coverage (for instance it doesn't cover any prescription drugs) and now has to go into serious debt to pay for his cancer treatments.

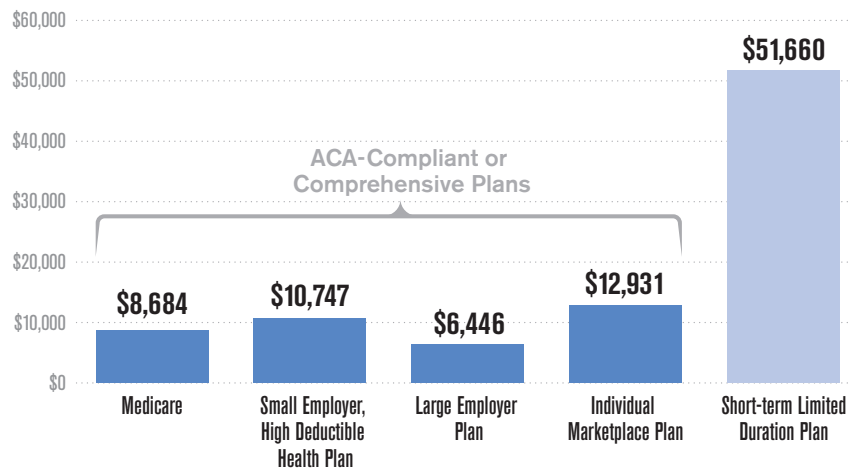
Patient Out-of-Pocket Costs Vary Widely, Particularly for Deductibles and Uncovered Services



*Annual costs for year 1 of breast cancer treatment

Patient Out-of-Pocket Costs Vary Widely, Even for the Same Patient

Total Annual Costs Paid by Brian, Lymphoma Patient in Each Plan Type



Brian's out-of-pocket costs vary from over \$6,000 to almost \$13,000 amongst the ACA-compliant plans we included in our analysis.

His out-of-pocket costs were over 4 times higher when he had a STLD plan that was not ACA-compliant.

Patient Costs Throughout the Year—Key Findings

- **Out-of-Pocket cancer costs spike quickly.**

Almost all of our cancer patients had to pay several thousands of dollars in the first one to three months after the first suspicion of cancer. Note that many of these costs were before the patient was officially diagnosed—as some diagnostic tests can be quite expensive. High amounts of spending are required until the cancer patient meets his or her deductible and maximum out-of-pocket limit (if applicable).

- **Costs spike higher for patients with higher deductibles and maximum out-of-pocket limits.**

Patients with a high deductible or maximum out-of-pocket limit experience higher spikes and more uneven month-to-month spending patterns because a higher amount of spending is required up-front before the plan begins covering expenses. This can cause significant financial hardship for patients who cannot afford to pay large medical bills all at once, and can also cause patients to delay tests or treatments.¹⁹

- **Medicare patients see different spending patterns.**

Because a majority of Medicare enrollees purchase supplemental coverage, most Medicare patients pay lower cost-sharing amounts. For the Medicare patients in our scenarios, their spending did not spike until they started taking pharmacy drugs—which are covered through Medicare Part D rather than their Medigap plan and require cost sharing, which can often be significant and is not capped.

- **STLD plans play by their own rules (or lack thereof).**

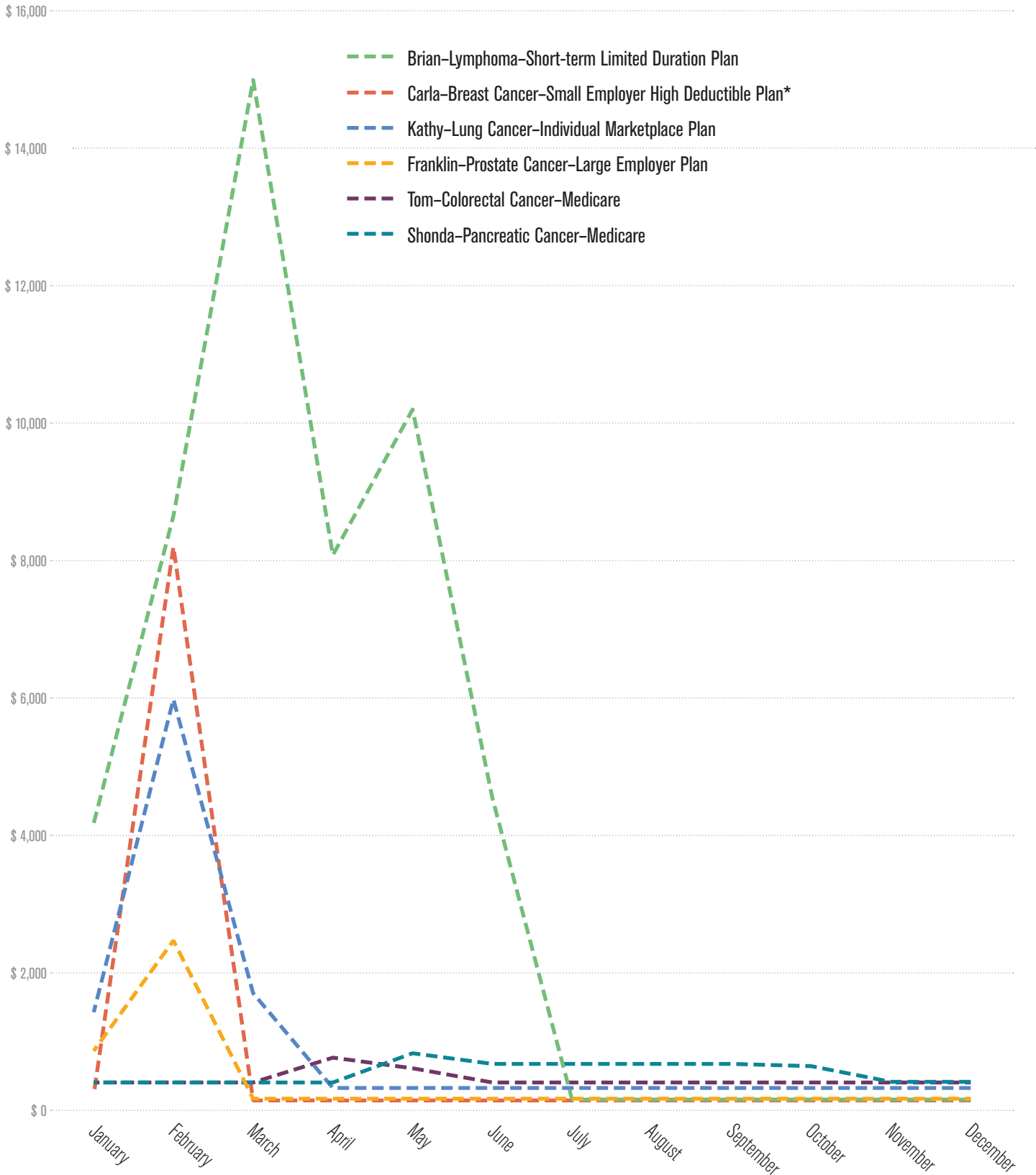
Because STLD plans are not required to have particular maximum out-of-pocket limits or cover specific services, the spending pattern under this plan is vastly different. Brian's spending spikes much higher, and for a longer amount of time, than the other patients. This is because his plan requires a very high deductible, has a high maximum out-of-pocket limit (note: some STLD plans do not have such a limit at all), and does not cover important services like prescription drugs. Therefore, Brian's high out-of-pocket costs never relent until he finishes his active cancer treatment in July.

The Costs of Cancer Disparities

Could YOUR monthly budget accommodate a \$5,000 (or higher) medical bill? These spending spikes are hard to afford even for middle- and high-income people with cancer.

An annual survey shows that 37% of Americans would NOT be able to cover a one-time unexpected expense of \$400 without borrowing money or using a credit card that is not paid off in full at the end of the month. The survey found that people of color and those with less education are more likely to have trouble covering an unexpected expense.¹⁸

Monthly Patient Out-of-Pocket Spending Spikes Within 1-3 Months of Diagnosis



*Monthly costs for year 1 of breast cancer treatment

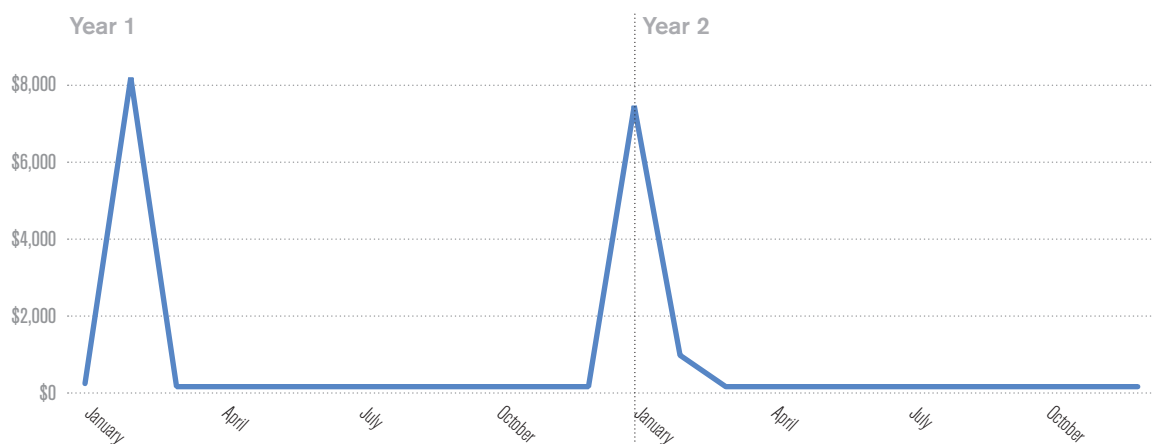
Patient Out-of-Pocket Spending Over Multiple Years—Key Findings

■ **The higher costs of cancer can span multiple years.** Carla had an aggressive form of breast cancer that required several months of chemotherapy before surgery, and many months of drug therapy after surgery. Her cancer experience—and therefore her spending on cancer treatments—did not fit neatly into a one-year timeline. Most patients' cancer treatments

cross plan years. Over the two years we tracked Carla's spending on cancer treatments, she paid her full maximum out-of-pocket amount twice—resulting in two spending spikes. As she continues to need follow-up care after her treatments, she will continue to pay higher costs for multiple years into survivorship.

When Cancer Treatments Span Multiple Years, Patient Out-of-Pocket Spending Spikes Multiple Times

Two Years of Monthly Out-of-Pocket Costs for Carla, Breast Cancer Patient



The Costs of Cancer Disparities

- Breast cancer is the most commonly diagnosed cancer in Hispanic women, and is also the leading cause of cancer death in this population.
- Breast cancer is less likely to be diagnosed at a local stage in Hispanic women compared to non-Hispanic white women. Lower rates of mammography screening and delayed follow-up on abnormal test results or self-discovered abnormalities likely contribute to this disparity.
- Hispanic women are less likely than non-Hispanic whites to receive appropriate and timely breast cancer treatment.

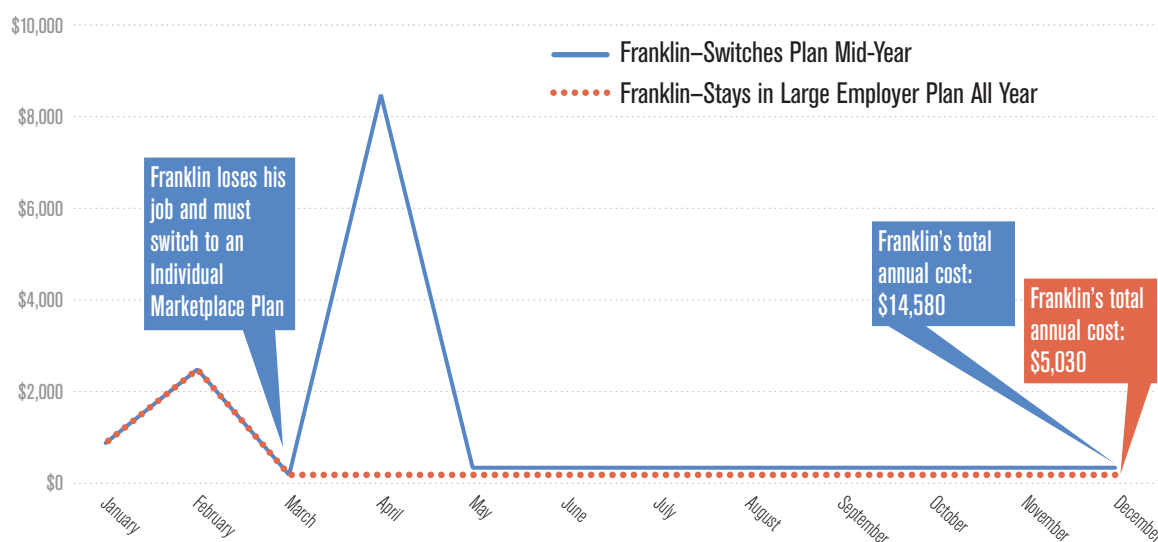
Source: American Cancer Society.²⁰

Insurance Coverage Transitions—Key Findings

- **Changing insurance plans mid-year or mid-treatment can cause spending spikes and higher total costs.** If a cancer patient must change insurance coverage mid-year or mid-treatment, they will likely be required to pay the new plan's deductible and maximum out-of-pocket amount—resulting in higher annual costs for the patient and multiple spikes in monthly spending. Higher costs also may result from the new plan covering different benefits and/or providers. A patient may have to change their insurance plan mid-year or mid-treatment if they have:
 - Changed jobs
 - Lost their job, or had to reduce hours to part-time because of their health, cancer treatments, or external factors
 - Moved to a new state, and did not have coverage that transferred to the new state or had providers located in the patient's new area
 - Were no longer able to afford paying premiums

Changing Insurance Mid-Year Causes Higher Costs and Multiple Spikes

Monthly Out-of-Pocket Costs for Franklin, Prostate Cancer Patient



The Costs of Cancer Disparities

What if Franklin wasn't able to afford to enroll in a marketplace plan right away after he lost his job and employer-sponsored insurance? A recent study²¹ showed:

Disruptions in insurance coverage are common among low-income populations.

Compared to people whose insurance coverage was continuous, those with disruptions were less likely to receive cancer prevention, screening, and treatment.

Types of Cancer Costs—Key Findings

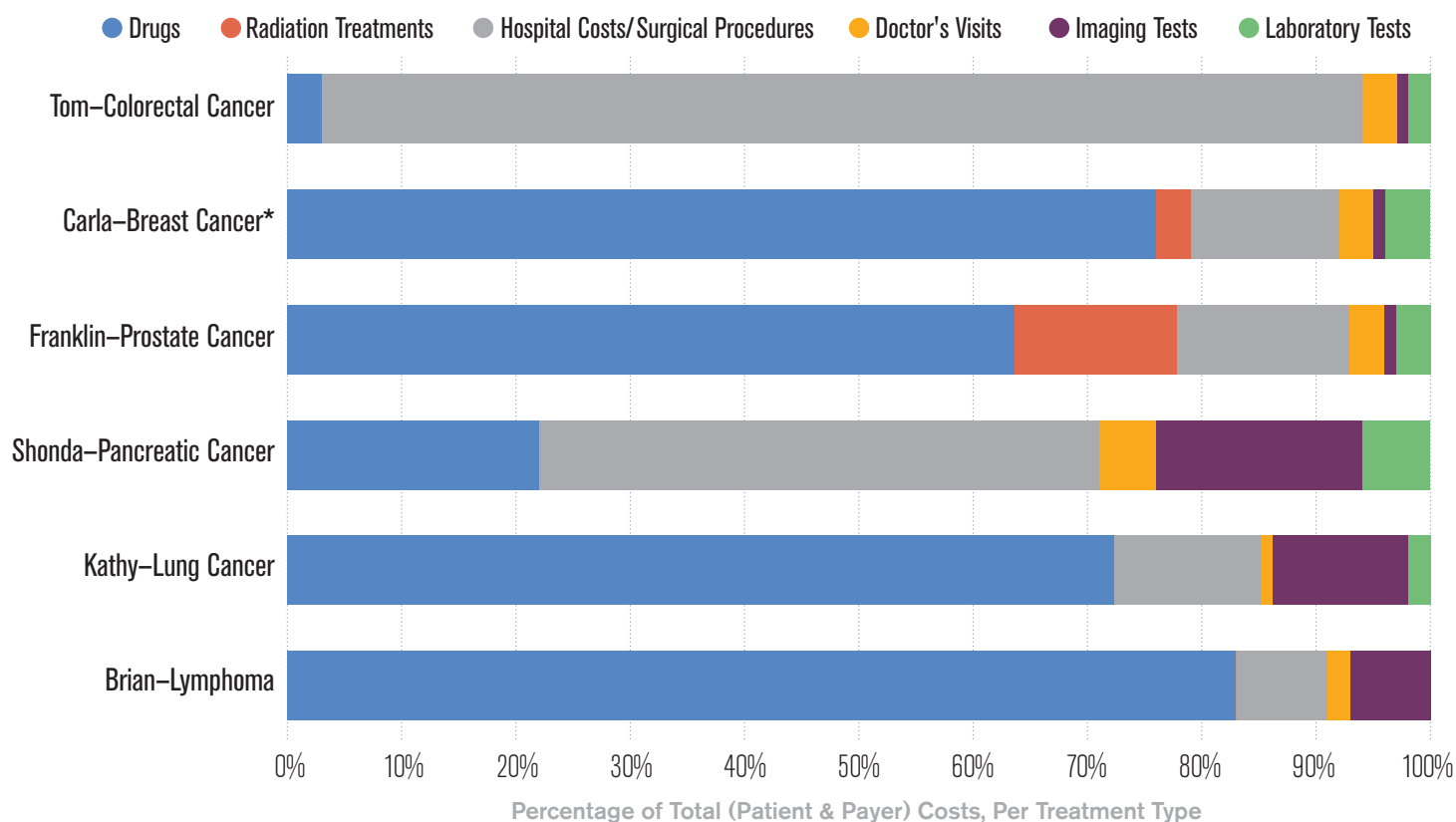
- **Type of cancer and treatment plan cause huge variation in the source of cancer costs.**

For all of the patients included in our analysis, the majority of their cancer treatment costs came from drugs, hospital costs, and/or surgical procedures. This amount varied, however, depending on the patient's treatment plan.

- **There are many drivers of the costs of cancer.**

While much attention tends to focus on drug costs, and whether they are rising, other types of treatments and services drive many of the costs for people with cancer.

The Drivers of Cancer Costs Vary Widely Among Patients



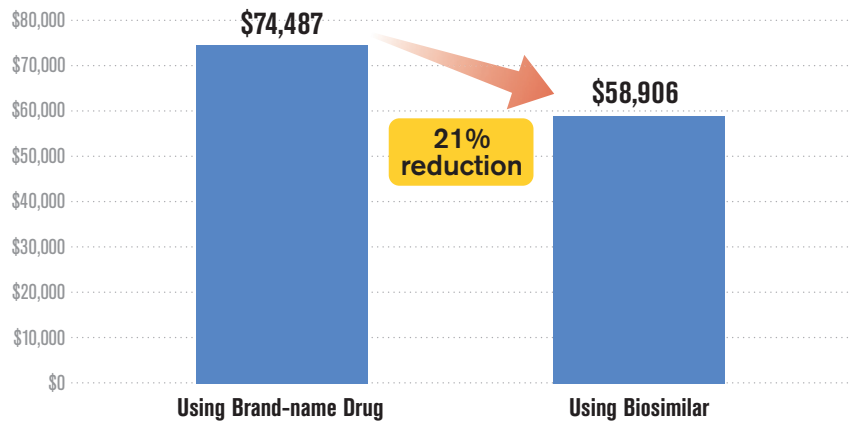
*Percentage of total costs for 2 years of breast cancer treatment

Spotlight on Drug Costs—Key Findings

- **Patients and payers can save when patients take biosimilars.** In our breast cancer scenario, Carla underwent drug therapy spanning multiple years. Under the scenario where she was able to substitute one of her main drugs for a biosimilar version, total spending on drugs was reduced by 21%.

Patients and Payers Save With the Use of Biosimilars

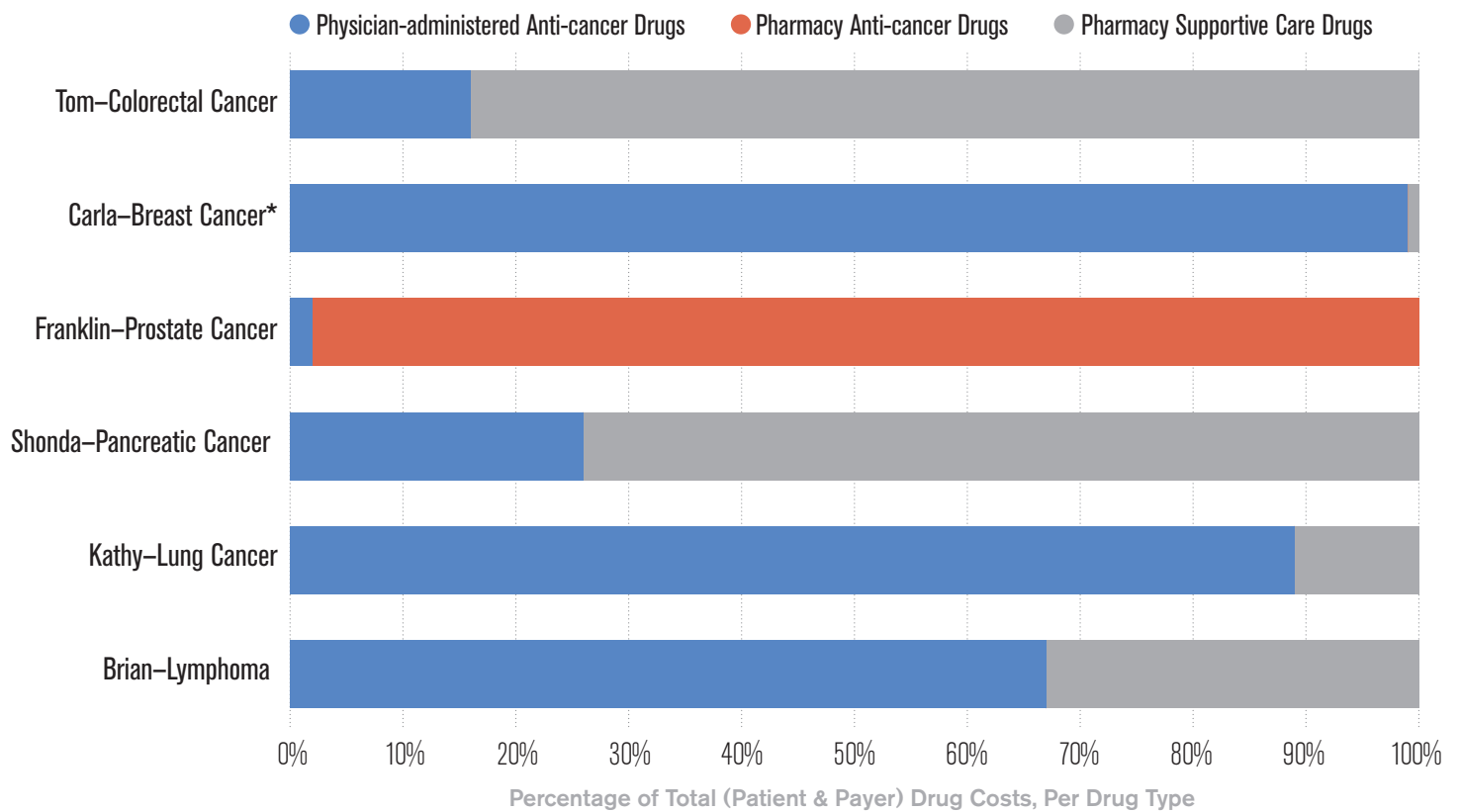
Carla, Breast Cancer: Total Expenditures Over 2 Years for Targeted Therapy



■ **The drivers of drug costs in cancer care vary widely based on the patient's treatment plan.** Anti-cancer drugs meant to kill cancer cells or keep them from returning—including chemotherapy, immunotherapy and hormone therapy drugs—can be delivered intravenously in a doctor's office, or via a pill obtained at the pharmacy. Supportive care drugs—intended

to help patients with side effects like nausea and pain—are also an important part of cancer drug treatment and can come in either form. Insurance plans often treat drugs differently—including placing them on different tiers and/or charging patients different amounts—depending on these distinctions.

Drivers of Drug Costs in Cancer Care Vary Widely



* Percentage of drug costs for 2 years of breast cancer treatment

Unexpected Problems that Add to Patient Out-of-Pocket Costs

In each of the modeled scenarios included in this report, analysts assumed that the cancer patients had no problems using their insurance benefits, and that each insurance plan covered every treatment.²² In reality, many people with cancer encounter problems that cause delays and complications and further increase their costs. Below are several common scenarios patients encounter that make their out-of-pocket costs higher than what was modeled in this report, or what the patient expected.

No Insurance Coverage

While each patient profiled in this report had insurance coverage (note: Brian's STLD plan—which left many treatments uncovered—is not considered comprehensive insurance), we know that millions of Americans are still uninsured.²³ Some of these Americans are diagnosed with cancer every year. While some uninsured cancer patients are able to negotiate discounts or qualify for charitable programs to help pay for their care, they are never guaranteed treatment. An uninsured cancer patient is responsible for all

costs of their treatment, and many forego care due to cost.

Example: what if Kathy didn't have insurance coverage?

In our scenario, Kathy has insurance coverage through her state's individual

marketplace. At the end of the year in which she is diagnosed with Stage IV lung cancer, she has paid over \$12,000 in premiums and cost-sharing—not a small amount. However, if Kathy were uninsured, she would be responsible for the entire cost of her cancer care—over \$140,000 (or likely higher because she would not benefit from a plan's negotiated rates). While she might be able to negotiate discounts with providers or receive some charity care, these costs and the uncertainty of how to pay them would likely to take a huge toll on Kathy's financial, emotional and physical quality of life.

Inadequate Coverage

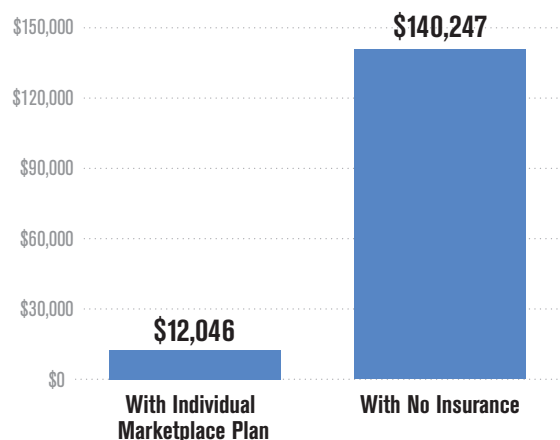
Some consumers struggle to afford health insurance premiums, and when shopping for cheaper premiums may unknowingly enroll in a plan that has inadequate coverage. Plans like short-term limited duration insurance—which despite the name, can last the same amount of time as other insurance plans—and Association Health Plans do not have to follow all of the requirements in the ACA and other regulations. These plans are missing comprehensive patient protections, and an enrollee who is diagnosed with a serious illness like cancer while enrolled in one of these plans will likely discover that it does not cover what they expected when purchasing the plan. Because of this, the patient pays catastrophically high costs.

The Costs of Cancer Disparities

- Most uninsured people are in low-income families and have at least one worker in the family.
- Adults are more likely to be uninsured than children.
- People of color are at higher risk of being uninsured than non-Hispanic Whites.²⁴

Costs are Much Higher for Uninsured Patients

Annual out-of-pocket costs for Kathy, lung cancer patient

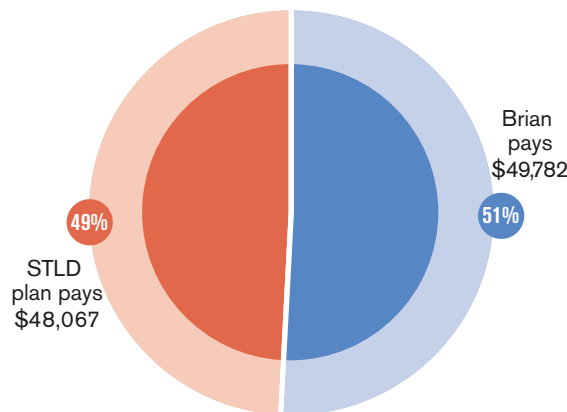


Example: Brian has a short-term limited duration plan.

As a young adult who works several part-time and freelance jobs, Brian was left to find health insurance on his own. He went online and bought the cheapest plan he could find through an insurance broker website, not understanding that this short-term plan does not cover a comprehensive set of benefits or have to follow other patient protections. He knew it had a high deductible, but he did not expect to need many health care services this year. Unfortunately, Brian is diagnosed with lymphoma and discovers that his plan's coverage is extremely limited. At the end of his year of cancer treatments, Brian's plan has covered less than half of his cancer treatment costs. Most significantly, Brian has to pay full price out-of-pocket for all of his prescription drugs, because his plan does not cover them. Brian will be in debt for many years to come because of this unexpected cancer diagnosis.

STLD Plans Cover Far Fewer Costs

Percentage of costs Brian's STLD plan covers compared to costs Brian pays for his lymphoma treatments



Non-Covered Treatments

Health insurance plans do not always cover every health care service or drug. When plans deny coverage of certain cancer treatments, patient out-of-pocket costs can increase considerably if the patient decides to proceed with their physician's recommended course of treatment. Costs for non-covered services do not count towards a patient's out-of-pocket maximum (where applicable), so patient costs for non-

covered treatments are unlimited and can add up quickly.

Example: what if Kathy's individual marketplace plan does not cover biomarker testing for her tumor?

When Kathy is diagnosed with lung cancer, her doctor wants to test her tumors for multiple biomarkers that could point them towards effective targeted therapy to treat her cancer. Thanks to recent therapeutic advances, several biomarkers are relevant to lung cancer treatment. However, Kathy's individual marketplace plan only covers a test that evaluates one biomarker. In order to get the full panel of recommended biomarker tests, Kathy must pay over \$1,500 out-of-pocket. Because these are charges for uncovered treatments, this amount also does not count towards Kathy's maximum out-of-pocket limit.

Large Deductibles

High deductible health plans (HDHPs) are becoming more prevalent as consumers seek to find plans with more affordable premiums, and employers—facing rising health care costs—want to have more predictability in what they spend on employee health care. While HDHPs are required to cover preventive services with no cost sharing, and some cover other routine services like primary care without applying the deductible, all of our scenarios show that once a patient is suspected to have cancer, the costs add up quickly and patients must pay their entire deductible. Often patients are not expecting these costs—because they did not expect a serious diagnosis, and/or they did not fully understand how their HDHP worked or may not have known the amount of their deductible.

Example: Carla has a small employer, high deductible health plan.

Carla's small employer only offers one option for health insurance, and it is a high-deductible health plan. While some employers offer their employees—or may help fund—a health savings account, Carla's employer does not. When her doctor sees a suspicious spot on her mammogram, Carla's doctor orders another imaging test. As it becomes clear that Carla has

an aggressive form of breast cancer, she is sent for several more scans and tests. Because she has a high deductible plan, she must pay full price for these tests out-of-pocket until she meets her \$6,000 deductible. Carla is very worried about a possible diagnosis of breast cancer, but she is also a working mother and cannot afford to pay \$6,000 within one month. She must choose between going into debt to pay these costs—if her credit card has a high enough limit or she can borrow from a friend—or delaying these tests and potentially letting the cancer get worse.



Unpredictable Co-insurance Costs

Once a patient meets their deductible for the year (as applicable), the primary cost sharing required are co-pays and co-insurance. Both are fees that the patient pays when health care services are delivered, or a prescription is filled. Co-pays are flat fees, usually defined clearly in a patient's insurance documents or formulary. Co-insurance, however, is a percentage of the total cost of the treatment or drug that the patient pays. Cancer patients often have trouble finding out what that total cost is ahead of time, and therefore cannot predict the amount of co-insurance they will owe. Health insurance plans often use co-insurance for certain types of treatment in their medical benefit, as well as in the most expensive upper tiers of their drug formularies.

Example: What if Shonda pays co-insurance for one of her drugs?

Shonda is dealing with a very serious diagnosis of pancreatic cancer, and her symptoms and quality

of life get worse throughout the year. Her doctor prescribes several pills to help with the nausea that her cancer and chemotherapy cause. One of these pills is not available as a generic, and Shonda's Part D plan charges 28% co-insurance. But Shonda does not know how much the drug costs. When her daughter drives to the pharmacy to pick up her prescription for her, Shonda does not know how much money to give her daughter to cover the cost of the drug.

	Shonda Pays...
If Shonda Paid a Co-Pay	\$47
If Shonda Paid Co-Insurance	28% of ??? = ???

Surprise Medical Bills

'Surprise medical bills' occur when an insured patient is unknowingly treated by an out-of-network provider and is then billed the difference between what the provider charged and what the insurer paid. This can happen when a patient receives emergency care at an out-of-network facility or non-emergency care at a facility that is in-network, but the doctor was out-of-network and the patient did not know. Surprise bills can be significantly higher than the consumer's standard in-network cost sharing, and they do not count towards a patient's maximum out-of-pocket limit (if applicable). They occur most often with ancillary providers—like anesthesiologists, assistant surgeons, and emergency room physicians.

Example: what if Franklin's anesthesiologist during his prostatectomy surgery was out-of-network?

After being diagnosed with advanced prostate cancer, Franklin's doctor recommends he have surgery to remove his prostate. Franklin chooses to have his surgery at a hospital that is considered in-network by his insurance plan. After his successful surgery, Franklin is surprised to receive a bill for over \$2,000 from the anesthesiologist who worked on his surgery. He is more surprised to learn that this doctor is out-of-network, even though his surgery was at an in-network hospital. Franklin's insurance plan will only pay the anesthesiologist its in-network rate, and the doctor has billed Franklin directly for the rest

of his fee. To add insult to injury, when Franklin pays this unexpected bill, the amount will not be counted towards his out-of-pocket maximum.

Unexpected Costs for Preventive/Screening Services

Almost all insurance plans are required to cover certain preventive and cancer screening services with no cost sharing for patients. Believing you will not need to pay for a service makes you more likely to seek out the service—and this is important for preventive services for which some patients need extra incentive. However, some patients encounter loopholes in these requirements that leave them with an unexpected bill for a service they thought would be free.

Example: what if Tom is charged for his colonoscopy?

Tom undergoes a screening colonoscopy. However, in the course of the procedure, polyps were discovered and removed. If Tom did not have a Medigap plan, Tom would be surprised to receive a bill for his colonoscopy because Medicare considers the removal of polyps to be a diagnostic procedure—regardless if the procedure began as a routine screening—because polyps were found and removed.²⁵ Tom would be charged 20% co-insurance (\$250 in this case) for the procedure, and he might struggle to pay the bill on his fixed income.

Problems Using Co-Pay Cards

Some people with cancer need the newest cancer treatments, and the drug their doctor prescribes is not yet available in a cheaper generic form. In most cases, their insurance plan will require much higher cost-sharing for the brand name drug that is medically indicated. Because of this, many drug manufacturers and patient assistance programs offer co-pay cards or discount programs that help patients in these situations pay their cost-sharing amounts and afford their drug treatment. However, Medicare patients are not eligible for these discounts because of current federal government policy. Recently, some private insurance policies have started to make it harder for patients to benefit from these discounts, by not applying the amount the card or assistance

program paid for the drug towards a patient's out-of-pocket maximum amount. This plan policy is known as an “accumulator” adjustment program.

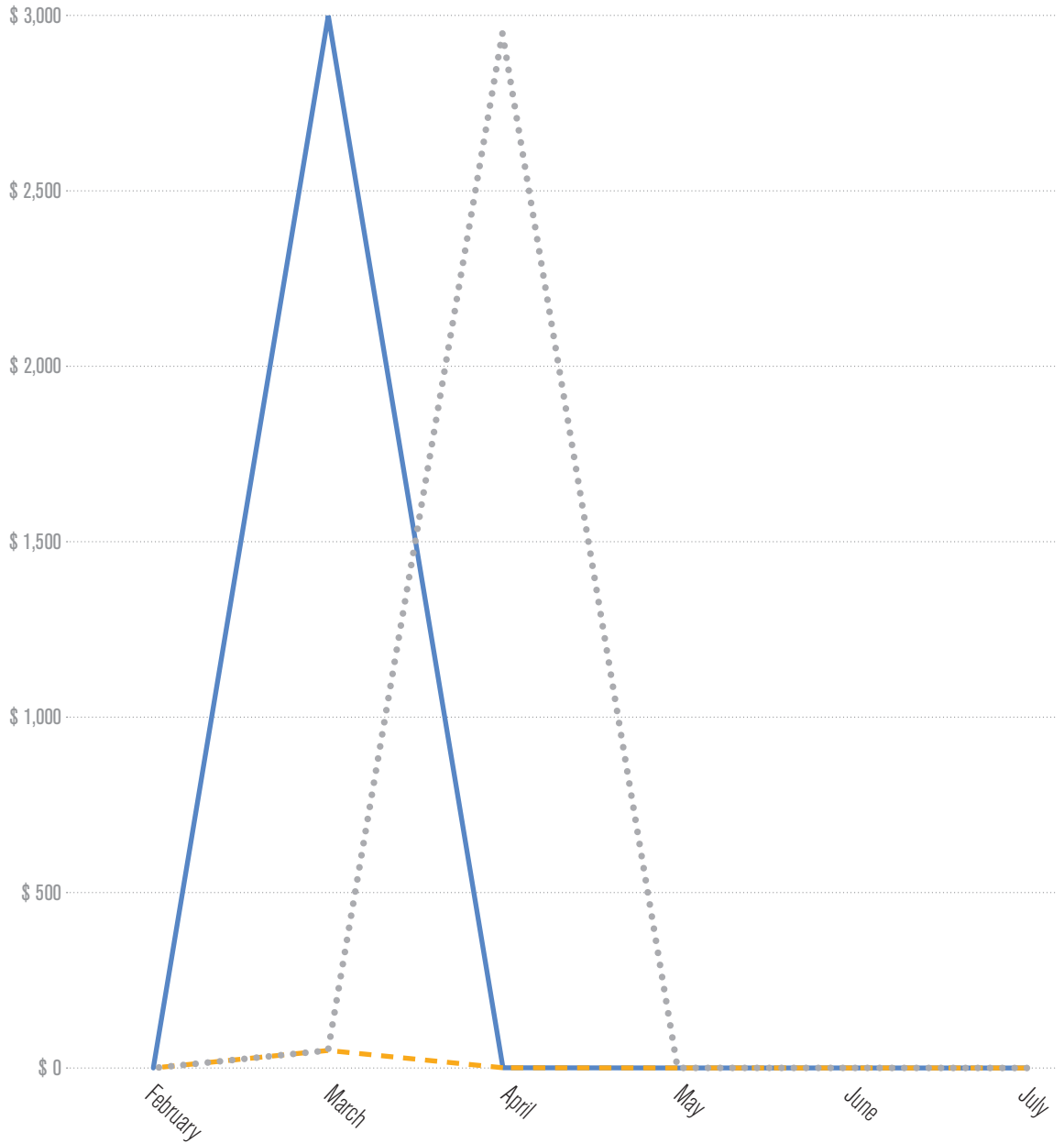
Example: what if Franklin needed to use a co-pay card for his hormone therapy drug?

When Franklin is diagnosed with advanced prostate cancer, he must take a hormone therapy drug for five months. This drug is not available in generic form, and costs over \$10,000 per month. His insurance plan considers it a specialty drug, and therefore requires him to pay 50% co-insurance for the drug until he meets his maximum out-of-pocket limit. Franklin's doctor tells him the drug manufacturer offers a co-pay card that can help with these costs. The card covers up to \$5,000 of cost-sharing expenses for patients in Franklin's situation, and allows Franklin to pay \$50 per month for the prescription, while the manufacturer covers the rest of his cost-sharing amount until he reaches his maximum.

Without the co-pay card, Franklin would be required to pay \$3,000 to fill his prescription in the first month—his entire maximum out-of-pocket amount. This huge up-front cost may be challenging for him to afford, and he may decide to delay or skip this treatment, which could mean his cancer gets worse. Using the manufacturer co-pay card, Franklin would only pay \$50 to fill his prescription. The manufacturer would cover the rest of his co-insurance amount up to his plan's \$3,000 maximum, and Franklin would not owe any more money for the prescription in the following months. However, if Franklin's plan uses an ‘accumulator’ adjustment program to discourage patients from using co-pay cards, the amount the manufacturer pays towards his prescription would not count towards his maximum out-of-pocket limit. This means Franklin would pay \$50 every month for his prescription until the co-pay card ran out of money in his second month of taking the drug—at which point he would have to cover the whole cost of the prescription.

Franklin's Costs are Most Affordable When He Can Use a Co-Pay Coupon as Intended

Franklin's Out-of-Pocket Spending on Hormone Therapy



— No Co-pay Card	\$0	\$3,000	\$0	\$0	\$0	\$0
- - - With Co-pay Card	\$0	\$50	\$0	\$0	\$0	\$0
..... With Co-pay Card in an Accumulator Plan	\$0	\$50	\$2,950	\$0	\$0	\$0

Spotlight in 2020: The Costs of Cancer and COVID-19

The worldwide COVID-19 pandemic has created an unprecedented set of circumstances and challenges for the U.S. health care system. These challenges are particularly acute for cancer patients, cancer survivors, and those at risk for cancer—and these challenges have already, or are likely to, impact the costs of cancer to patients and the health care system for years to come. The ultimate costs to cancer patients, cancer survivors, and the health care system of COVID-19 may likely include:

- **Additional costs associated with delayed or skipped cancer screenings.** Many individuals at risk for cancer have had their regular screenings delayed or missed because of facility closures, recommendations from health officials prioritizing urgent care and halting elective procedures, including cancer screenings, and patient and provider fears and confusion on the safety of screenings during a pandemic.^{26,27} These delays in screening can result in cancer that is detected at later stages, when it is harder and more expensive to treat.^{28,29,30}
- **Costs of postponed or missed cancer treatments.** For those who have already been diagnosed with cancer, delaying or skipping treatments can cause their cancer to progress and health outcomes to worsen^{31,32}—which may result in more costly care and more lives lost.
- **Costs of insurance coverage disruptions.** Huge upheavals to our country's economy caused by quarantines and other COVID-19 factors have caused many Americans to lose their jobs or be furloughed. As so many Americans receive their health insurance through an employer, this has definitely caused disruptions to insurance coverage.³³ The data show that gaps in insurance coverage cause people to miss screenings and be diagnosed with cancer at later stages when care is more expensive.³⁴ Additionally, individuals who must switch insurance plans because of these disruptions will have to pay new cost-sharing amounts, and their costs will likely rise.

The Costs of Cancer Disparities

People of color have been widely reported to be at increased risk for hospitalization and the related costs due to COVID-19,^{35,36} a disparity that is likely caused by disparate conditions that existed before COVID-19, like racial inequalities in insurance coverage and access to care. Additionally, data are showing that workers who are people of color are losing their jobs at higher rates than white workers; and because of these job losses, at least 1 million Asian, 2 million Black, and 3 million Hispanic people are likely to lose their employer-sponsored health insurance in 2020.³⁷ Consequently the increased costs discussed above will hit people of color more heavily and widen health disparities.

Financial Hardship—How High Costs Adversely Affect Cancer Patients, Survivors and their Families

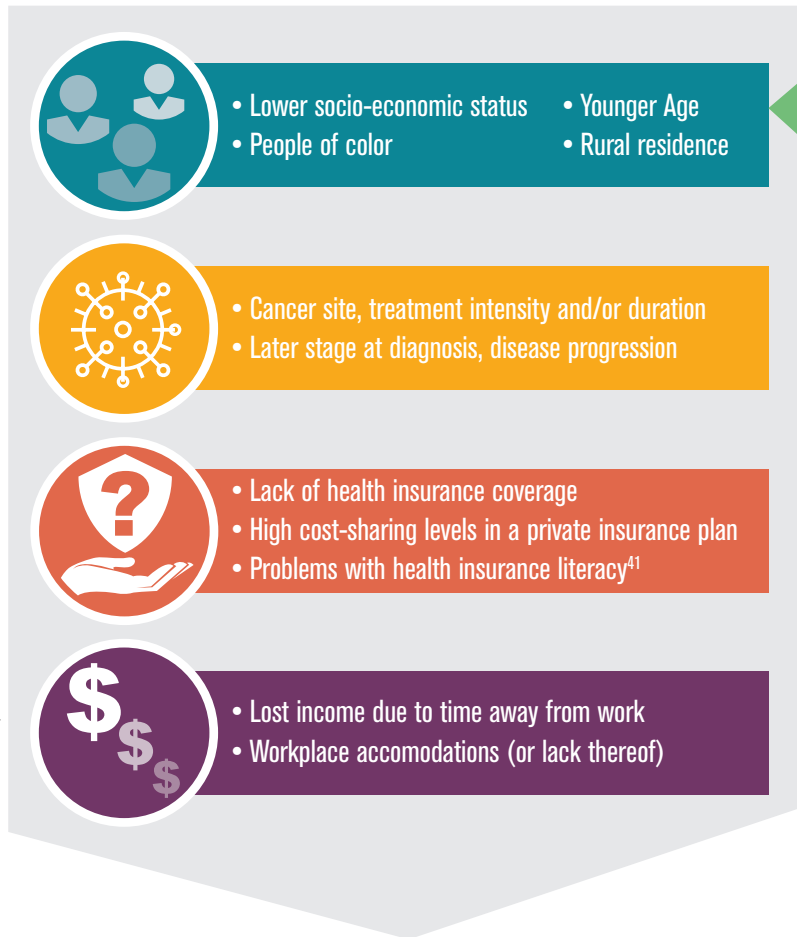
According to the National Cancer Institute, medical financial hardship is a term used to describe problems a patient has related to the costs of medical care.³⁸ Financial hardship is also often referred to as financial toxicity, distress, or burden. These kinds of problems happen often for cancer patients and survivors—research shows that individuals with a history of cancer are more likely to experience financial hardship than those with no cancer history.³⁹

There are three main types of medical financial hardship:⁴⁰



Cancer patient/survivor more likely to experience hardship if:

While financial toxicity or hardship is recognized as a medical, economic and societal problem; providers often find this toxicity harder to 'treat' or address than physical symptoms and side effects. As research continues to show how financial toxicity affects cancer patients and their families—and more innovative treatments become available with higher price tags—policymakers must address these problems through changes in policy. Lack of action will lead to wider disparities in cancer care and outcomes based on wealth and status.



Younger survivors are more likely to worry about:⁴²

- Monthly Bills
- Retirement
- Housing
- Standard of Living
- Food running out or not lasting
- Affording balanced meals



List of factors adapted from K. Robin Yabroff, Cathy Bradley, and Ya-Chen Tina Shih. Understanding Financial Hardship Among Cancer Survivors in the United States: Strategies for Prevention and Mitigation. Journal of Clinical Oncology 2020 38:4, 292-301.

Policy Solutions to Address the Costs of Cancer

The American Cancer Society Cancer Action Network (ACS CAN) works to ensure that all people with cancer can afford the right cancer therapy at the right time, as well as survivorship care, preventive services and all other required medical care. The affordability of cancer care—and health care in general—is a multi-faceted problem that requires multi-faceted solutions.

ACS CAN advocates for public policies that address the individual and systemic costs of cancer by:

- Ensuring access to affordable insurance coverage for all;
- Limiting costs by preventing cancer and detecting it early through the use of screening and preventive services;
- Ensuring access to health care services; and
- Reducing the overall financial impact of cancer for patients and their families.

Ensuring Access to Affordable Insurance Coverage

The single most important thing policymakers can do to help cancer patients afford the costs of cancer is to ensure that everyone has access to affordable comprehensive health insurance. American Cancer Society (ACS) research shows that individuals with health insurance are nearly

twice as likely as those without it to have access to critical early detection cancer procedures, and the uninsured are less likely to get screened for cancer, are more likely to be diagnosed with cancer at an advanced stage and are less likely to survive that diagnosis than their insured counterparts.^{47,48}

Survivor Views: The Costs of Cancer in Their Own Words

“My cancer care costs have completely depleted my savings. I am no longer able to buy a house because I cannot afford any down payment.”

Lymphoma Survivor, Oregon

Having access to insurance coverage means a patient is 1) not denied enrollment, 2) able to receive help when needed to understand the enrollment process and insurance coverage, and 3) able to afford the premiums and cost sharing.

Ensuring access to insurance coverage is not only an ACS CAN priority, but a priority of cancer patients and survivors. In a 2020 ACS

CAN Survivor Views survey,⁴⁹ respondents identified access to comprehensive and portable health insurance as a critical tool in supporting people with cancer. Over half of cancer patients and survivors (51%) indicated that ensuring health insurance covers all needed care was the priority that would have the greatest impact in helping people with cancer. The second most commonly prioritized issue was ensuring affordable health insurance is available regardless of job changes (20%).

The Costs of Cancer Disparities

Black and Hispanic individuals with cancer are more likely to be uninsured at diagnosis—although ACA implementation has reduced and even eliminated some of these disparities.⁵⁰

Spotlight on ACS CAN Policy Priorities:

Maintain Current Affordable Care Act (ACA) Patient Protections

All of the patients in our profiles benefited from ACA protections (except the patient who had a short-term limited duration plan, which does not have to follow ACA requirements—the allowance of which ACS CAN is challenging in the court system), including the ability to enroll in their insurance plans, the provision of comprehensive benefits and limits on their out-of-pocket spending. The ACA contains critical protections that provide an essential lifeline for millions who experience serious illnesses and conditions, like cancer. Prior to the ACA, individuals who most needed health insurance coverage—including those older and sicker who are not yet eligible for Medicare—often found it difficult, if not impossible, to obtain health insurance that covered necessary care at an affordable price.⁵¹ Uninsured patients are less likely to be screened for cancer and more likely to be diagnosed with

later stage disease which is harder to survive and more costly to treat.⁵²

Since the law went into effect, individuals with pre-existing conditions have been better able to access comprehensive health insurance. The uninsured rate among nonelderly patients with newly diagnosed cancer declined substantially, particularly among low-income people who resided in Medicaid expansion states—where it decreased six percent.⁵³ In addition, there is already a small but statistically significant shift that has been found toward early-stage diagnosis for colorectal, lung, breast and pancreatic cancer in states that have increased access to health care through Medicaid because of the ACA.⁵⁴

For all these reasons, ACS CAN strongly supports the continuation of the patient protections in the ACA. We strongly oppose any efforts to dismantle the legislation without replacing these protections, including the current efforts to invalidate the ACA through the California v. Texas litigation, currently pending at publication of this report and awaiting hearing from the Supreme Court of the United States.⁵⁵



Maintain and Expand Access to Medicaid

All of our patient profiles showed the high costs that an uninsured individual would face if diagnosed with cancer. However, individuals with very low incomes are less likely to be provided insurance coverage through their employer⁵⁶ (as applicable), and also are unlikely to be able to afford paying insurance premiums on their own. Medicaid is a lifeline for many of these low-income Americans and maintaining and expanding access to Medicaid significantly

reduces the costs of cancer for our country’s most vulnerable cancer patients. To date, 38 states and the District of Columbia have increased access to their Medicaid programs (or have passed policies requiring them to do so)⁵⁷, providing more than nine million individuals and families access to health care coverage and to lifesaving tests like mammograms, colonoscopies and other cancer screenings.

ACS CAN strongly supports and works towards the expansion of Medicaid eligibility up to 138% of the federal poverty level (FPL) in every state, as well as other efforts to ensure low-income Americans can access the health care they need through this safety net program. Furthermore, ACS CAN strongly opposes any efforts to restrict access to Medicaid or the benefits available to Medicaid enrollees, including state efforts to:

- Limit or restrict eligibility (through work or community engagement requirements, waiving retroactive eligibility or enrollment caps)
- Impose cost sharing (premiums, co-payments)
- Penalize enrollees for non-compliance with various program or wellness requirements
- Eliminate and/or restrict benefits/services
- Place limits on the length of program eligibility
- Change the financing structure (block grants or per-capita caps)

Data indicates that these policy proposals, especially those that limit or restrict eligibility, will significantly reduce enrollment in the Medicaid program and deny access to preventive and treatment services for individuals and families enrolled in the Medicaid program.^{58,59,60} Preservation of eligibility and access to health care coverage through state Medicaid programs is critical for continuing to make progress against cancer for those low-income Americans who depend on the program for cancer prevention, early detection, diagnostic, treatment and survivorship care services.

2020 Federal Poverty Level (FPL)		
	Individual	Family of 4
100%	\$12,760	\$26,200
138%	\$17,609	\$36,156
400%	\$51,040	\$104,800

Source: <https://www.healthcare.gov/glossary/federal-poverty-level-fpl/>

Expand Premium Subsidies for Marketplace Plans

Kathy, who had Stage IV lung cancer, was insured through the individual marketplace, and was fortunate to qualify for subsidies that partially paid her premiums and made insurance more affordable. Advanced Premium Tax Credits are available on a sliding scale for individuals and families earning between 100 and 400% FPL, and these subsidies allow many people in this income bracket to afford enrollment. However, individuals above 400% FPL and who enroll through the individual marketplace do not qualify for subsidies, and many of these individuals and families struggle to afford their premiums—or must forego enrollment altogether due to inability to pay. These middle-income individuals and families would greatly benefit from the expansion of these subsidies to include higher incomes.



Additionally, other families do not qualify for subsidies—and therefore may not be able to afford premiums—because of what is known as the “family glitch.” Under the ACA an individual is eligible for premium subsidies in the individual marketplace if the amount he/she would have to pay for their individual employer-sponsored coverage is more than 9.86% of their household income. Most employers subsidize the cost of their employee’s health insurance premiums. However, this subsidy may be less generous for family coverage. Even if the employee is paying a family premium, only the amount of the individual employee’s coverage is considered for purposes of calculating eligibility for subsidies. As a result, families who are paying insurance premiums in excess of 9.86% of their household income are ineligible for subsidies.

ACS CAN strongly supports expanding marketplace premium subsidies by fixing the family glitch, and by increasing the income range of individuals and families who are eligible for subsidies. Federal and/or state policymakers could create partial subsidies for individuals earning more than 400% FPL to make premiums more affordable for individuals who need to enroll through the individual marketplace.

Other Priorities to Ensure Access to Affordable Insurance Coverage:

- Funding outreach and enrollment programs, which help individuals and families make enrollment decisions, navigate the enrollment process, and make them aware of enrollment opportunities in the first place. Funding outreach and enrollment programs not only helps the individuals who need it—these programs also encourage more healthy individuals to enroll in insurance, improving the risk pool, lowering premiums for everyone and ensuring that everyone has access to a doctor or a hospital when they need it.
- The creation of reinsurance and risk corridor programs—at the state or federal level—that evenly distribute risk and keep premiums in the individual marketplace from rising.

In the current health care system, ensuring access to care means ensuring that everyone is able to enroll in a health insurance plan—whether it be through their employer, through a government program like Medicare or Medicaid or through the individual marketplace. Addressing the affordability of premiums for these types of plans is key, but so is taking other measures to make sure insurance enrollment is truly accessible.

Limiting Costs by Preventing Cancer and Detecting it Early Through the Use of Screening and Preventive Services

Some of the costs of cancer can be avoided before they ever occur by preventing cancers from developing in the first place or detecting cancer at early stages when it is easier to treat.

A substantial proportion of cancers are preventable,⁶¹ and much of ACS CAN’s work in prevention focuses on reducing the major risk

factors for cancer: tobacco use, excess weight/obesity, physical inactivity, poor nutrition and indoor tanning/sun exposure; as well as advocacy for critical cancer control programs and increased access to preventive and evidence-based screening services. ACS CAN advocates for evidence-based policies that address these risk factors and are proven to reduce cancer incidence and death. Preventing more cancers and detecting more cancers early requires changes to clinical settings and services, as well as to communities.

Spotlight on ACS CAN policy priorities:

Stop Unexpected Costs for Preventive and Screening Services

When Tom's FIT test was positive, indicating possible colorectal cancer, his doctor ordered a follow-up colonoscopy. During the colonoscopy doctors found and removed polyps that would have developed into cancer in the future. Tom's colonoscopy was a health care service that both prevented future cancer and screened for current cancer—and therefore should be provided with no cost sharing. Most insurance plans are currently required to cover preventive services and screenings with no cost sharing. However, Tom's scenario includes two loopholes in this policy: 1) his colonoscopy occurred after a FIT test, and some insurers apply cost sharing to the patient for a colonoscopy after a positive stool test; and 2) Tom's doctors removed polyps as part of the procedure, which changes the procedure from a preventive to a diagnostic procedure under Medicare policy—meaning Tom will likely wake up to an unexpected bill for the service. Other loopholes occur when a cancer survivor finishes his or her treatment and needs continued screening for possible cancer recurrence or secondary cancers, and the insurance policy considers these services to be diagnostic or follow-up care, instead of the preventive and screening services that they are.

ACS CAN supports fixing these loopholes in the coverage of preventive and screening services to ensure that all these services are truly provided to all patients with no cost sharing. Free comprehensive preventive and screening services will prevent patient and provider confusion, encourage patients to use preventive and screening services, and allow all patients to be able to afford these services.

Other priorities to limit costs by preventing cancer through the use of screening and preventive services:

- Funding that makes evidence-based prevention and early detection programs available to those who remain uninsured, including cancer screenings, HPV vaccines and tobacco cessation treatments. Targeting these programs to areas with higher needs or cancer rates is also crucial.
- Requiring all Medicaid programs to comprehensively cover all preventive and screening services given an 'A' or 'B' by the U.S. Preventive Services Task Force with no cost sharing.
- Reducing tobacco use and exposure to secondhand smoke through increasing the price



of tobacco products, implementing smoke-free policies, funding tobacco control programs and carefully regulating tobacco products.

- Promoting healthy eating and active living through adequately funding evidence-based programs and supporting strong nutrition standards and quality physical activity education in schools.
- Prohibiting minors' use of indoor tanning facilities and properly regulating such facilities.

While the preventive measures discussed above require some up-front investments, research shows that these interventions are cost-effective and that these investments pay off to prevent cancer and improve the health of communities.^{62, 63, 64, 65, 66, 67, 68} The best way to reduce the costs of cancer for any individual is to prevent them from developing cancer in the first place.

Ensuring Access to Health Care Services

Health insurance must provide true access to care by covering needed services at costs that are affordable to patients. Making care affordable includes addressing the underlying costs of treatments, as well as the cost sharing patients must pay to receive them.



Spotlight on ACS CAN Policy Priorities:

Address High-Deductible Health Plans (HDHPs)

Each patient in our scenarios who had a deductible had to pay it very quickly, and the higher their deductible, the more patient spending spiked at the beginning of the patient's year(s) in cancer treatment. The IRS defines an HDHP in 2020 as any plan with a deductible of at least \$1,400 for an individual or \$2,800 for a family,⁶⁹ and deductibles in the private insurance market can be much higher. The number of individuals who enroll in HDHPs also continues to rise⁷⁰—sometimes because it is their only choice. While HDHPs are required to cover preventive and screening services with no cost sharing pre-deductible, the deductible applies to most other services—like the diagnosis and treatment of cancer.

The evidence is mounting that high deductibles can cause serious problems if an enrollee is diagnosed with cancer. Studies show that HDHP enrollment is associated with a decrease in imaging tests⁷¹—the tests a patient needs if they have a positive screening test for suspected cancer—and that women who were switched to

an HDHP were more likely to experience delays in diagnostic breast imaging, breast biopsy, early-stage breast cancer diagnosis, and chemotherapy initiation.⁷² Among individuals with a history of cancer, HDHPs are associated with more delayed or foregone care, although these access to care problems are lessened somewhat if the patient has a health savings account (HSA).⁷³ Another study showed that breast cancer patients with HDHPs show such delays in care even when researchers divide patients by income level⁷⁴—meaning higher incomes do not insulate cancer patients from the effect of being required to pay large bills up front for cancer care. Additionally, having an HDHP has been shown to make a cancer survivor more likely to experience material, psychological and behavioral financial hardship⁷⁵—hardships that can have long and lasting effects on cancer patients and their families.

For all these reasons, ACS CAN has serious concerns about the proliferation of HDHPs—especially among enrollees who have low- and middle-incomes, may not fully understand the implications of a high deductible plan and therefore be ultimately ill-equipped to pay their deductible. These individuals and families are likely to experience problems accessing preventive care, cancer care and other health care services when they need them. To address these problems, ACS CAN supports policies that:

- Ensure that certain health care services are not subject to the deductible, and therefore are available for free or lower cost sharing so patients are not deterred from receiving them. This includes services that prevent disease, detect cancer early, and help maintain patient health.
- Increase enrollment assistance and financial navigation services so that potential and current enrollees can receive help understanding their insurance benefit and what they will have to pay up-front for health care services. These services should be targeted towards low- and middle-income individuals.
- Monitor and track the size of deductibles and study the impact of these deductibles on enrollees' access to care and health outcomes.

Prohibit Surprise Medical Billing

When Franklin had surgery to remove his prostate

and check his lymph nodes for cancer, he was surprised to learn that the anesthesiologist his in-network hospital provided was actually out-of-network—and wanted to bill Franklin for over \$2,000. Surprise billing affects millions of consumers each year, including people with cancer. In an ACS CAN survey of cancer survivors conducted in 2019, 24% reported having received a surprise bill as a result of their cancer care, and 27% of these bills were for amounts of over \$2,000. The most common services resulting in surprise bills were outpatient radiology and pathology.⁷⁶ Recent studies of other populations confirm that this problem is widespread,^{77,78,79} and amounts of these bills are increasing.⁸⁰

Survivor Views: The Costs of Cancer in Their Own Words

“Charges in the hospital are confusing. You are visited multiple times a day and night and you aren’t thinking “Will this person present a bill?” and “Is this person in my network?” Why would a hospital employ a provider that is not in the network? Am I expected to ask every time someone does a test or a room visit? That is unreasonable, especially when I was in ICU and pretty much out of it.”

Multiple Cancer Survivor, Indiana

ACS CAN supports legislative and regulatory policies at the state and federal level that prohibit patients from being surprise billed for unexpected out-of-network care and strongly urges Congress to pass federal legislation promptly so that patients across the country can benefit. Legislation addressing surprise billing should: 1) hold patients harmless, 2) apply protections to all insurance plans, 3) apply protections to all surprise bills, 4) apply protections to all care settings, 5) require transparency in addition to—and not instead of—surprise billing protections, 6) require additional research and data collection, and 7) strengthen state protections instead of weakening them.⁸¹

Stop the Proliferation of Non-Comprehensive Health Insurance Plans

When Brian, the lymphoma patient, had a short-term limited duration plan, he had to pay \$49,782 out-of-pocket for his treatments—this was by far the highest amount any of our patients had to pay

under any of the insurance designs we modeled. Short-term limited duration plans traditionally have low premiums but fail to provide the kind of comprehensive coverage an individual would need if they were diagnosed with a serious and unplanned disease such as cancer. Issuers offering short-term limited duration plans are permitted to engage in medical underwriting, meaning issuers can deny coverage to people with pre-existing conditions, charge more based on a person’s health status, or refuse to cover services related to an individual’s pre-existing conditions. They are also permitted to impose lifetime and annual limits on coverage and are not required to provide coverage of the ACA’s essential health benefits. Short-term limited duration plans often engage in post-claims underwriting (currently prohibited for ACA-compliant plans), meaning that once a person is enrolled in coverage if they submit claims for an expensive service, the issuer could undertake an investigation to determine whether the enrollee’s condition constituted a pre-existing condition. In addition, short-term limited duration policies can and will end coverage at the policy’s term, even if the policyholder has gotten sick and needs coverage to continue.⁸² For all of these reasons, patients enrolled in these non-comprehensive plans are left extremely vulnerable to what can be exorbitantly high out-of-pocket costs, and all the problems and financial toxicity such costs cause. Additionally, allowing these plans into a marketplace negatively impacts the risk pool and availability and affordability of ACA-compliant plans by siphoning off younger, healthier consumers who will be more likely to purchase cheaper, bare bones plans.⁸³

ACS CAN urges policymakers to consider prohibiting the sale, or at the very least limiting the availability of, short-term limited duration plans and other non-comprehensive plans. Since the administration expanded access to short-term limited duration plans in 2018, there has been a significant increase in the availability and coverage length for short-term limited duration plans. This can be confusing to consumers who may mistake these plans for comprehensive, ACA-compliant coverage. Policymakers could also consider requiring these non-comprehensive plans to follow the rules that ACA-compliant plans must follow.

Cap Patient Out-of-Pocket Expenses in Medicare

Our patient profiles showed that patients with Medicare sometimes have high out-of-pocket spending throughout the year, particularly individuals who lack supplemental coverage. Seniors and disabled Medicare beneficiaries are often on a fixed income and have trouble affording these high costs. If patients can't afford their cost-sharing, they may skip necessary doctor's visits or treatments, or split pills to save money. As health care costs continue to rise, patients need the protection of annual maximum out-of-pocket caps—and while most consumers have this protection in their employer-sponsored or private insurance plan, they lose this protection when they enroll in Medicare.

ACS CAN strongly supports efforts to cap patient out-of-pocket spending in Medicare. Several recent federal bills proposed such a cap in Medicare Part D, which would help many enrollees with cancer who have high and ongoing costs for prescription drugs—ensuring that they are able to take their drugs as needed, improving their cancer outcomes. ACS CAN encourages policymakers to enact this Part D cap and continue finding ways to limit total out-of-pocket spending for Medicare enrollees by considering caps in other parts of Medicare (e.g., Part A and B). This is especially important for those Medicare enrollees who do not have supplemental or Medigap coverage that protects them from high out-of-pocket expenses in Part B. Capping out-of-pocket spending in Medicare will reduce the financial toxicity of cancer for Medicare enrollees, and will give these enrollees more predictability in their annual expenses, which is especially helpful to those on fixed incomes.

Ensure Access to Biomarker Testing

Several patients in our profiles received biomarker testing to determine if certain targeted therapies would work to fight their cancers. Advances in precision medicine in cancer have led to targeted therapies that only work within populations of cancer patients with very specific biomarkers. Over the last several years, there has been a rapid increase in the development of new targeted therapies across cancer types and the diagnostics required to determine benefits from

specific therapies. Unfortunately, many patients who should be tested are not as testing rates lag behind clinical guideline recommendations, even years after new biomarkers are recognized and therapies are developed. In a 2020 ACS CAN survey, only 39% of cancer survivors reported having their tumor tested. About one in eight respondents indicated that biomarker testing was not covered by their insurance, and 15% of those who did receive biomarker testing reported paying more than \$500 out-of-pocket for the testing.⁸⁴



Insurer coverage is an important factor in provider uptake and patient access to biomarker testing. However, coverage of tests differs across health care payers. To ensure patients have access to appropriate biomarker testing ACS CAN supports policies that:

- Ensure coverage of FDA-cleared or -approved companion and complementary diagnostics and all National Comprehensive Cancer Network (NCCN) guideline-indicated biomarker tests as necessary to evaluate patient eligibility for a given targeted therapy.
- Ensure coverage for tumor-agnostic biomarker tests as medically appropriate.

As precision medicine shifts the way health care providers and patients think about cancer treatments, it will be important to identify barriers to biomarker testing. Addressing these barriers will require buy-in from diverse stakeholders across the health care system.⁸⁵

Ensure Working Cancer Patients, Survivors and Caregivers Have Paid Leave

Each cancer patient in our scenarios had to spend significant time at doctors' appointments

and for procedures—and most of them were working when they were diagnosed. The National Health Interview Survey (NHIS) indicates just over 6 million people with a cancer history were employed in the U.S. in 2018.⁸⁶ These individuals want to be productive employees during treatment and survivorship for many reasons—not the least of which are that working brings much needed income and often health insurance coverage. But cancer treatment is time consuming. Flexibility to balance cancer treatment and employment is essential. Additionally, many caregivers of cancer patients are working and need these accommodations as well. Studies show that cancer patients who have paid leave have higher rates of job retention and lower rates of financial burden.^{87,88} Yet not all cancer patients and survivors who work have access to paid leave. NHIS data show that only 58% of individuals with a cancer history over the age of 18 have access to paid sick leave.⁸⁹



ACS CAN supports policies at the national, state and local levels that increase access to job-protected paid family and medical leave that can be used for cancer treatments, survivorship care, and caregiving as well as other illnesses.

Increase Patient Access to and Use of Generic and Biosimilar Prescription Drugs

Patients and health care payers can save money when patients use a generic or biosimilar alternative to a branded drug. When Carla, the breast cancer patient in our scenario, used a biosimilar alternative to her targeted drug

The Costs of Cancer Disparities

For most racial/ethnic groups, female cancer survivors are more likely than males to report not adhering to prescribed medications for financial reasons. However, overall, Hispanics and African Americans of either sex are more likely to report medication non-adherence due to cost than other racial/ethnic groups.⁹¹

therapy, total expenditures for that drug (what Carla paid + what her insurer/employer paid) were decreased by 21%. Savings can be even bigger when generic alternatives to branded drugs are available—in fact, generics saved patients with cancers more than \$13 billion in 2019, and savings for the past 10 years total \$87.8 billion.⁹⁰

While it is important to continue to incentivize innovation through research that leads to development of new drug therapies, diagnostics and screenings; it is also important that patients have access to and are prescribed lower cost drug alternatives when they are available and medically appropriate for the individual. ACS CAN supports policy efforts to ensure that biosimilar and generic drugs are available to patients either through direct prescription or appropriate pharmacy substitution of interchangeable products. Further, ACS CAN encourages policymakers to explore policies that would increase access through reducing or eliminating cost-sharing for patients taking a biosimilar and incentivize biosimilar utilization through payment policies. Lastly, we support efforts that remove artificial barriers to the development and approval of generics and biosimilars.

Ensure Patients Can Use Co-pay Coupons and Discounts

In our patient scenarios, Franklin had to take a drug that did not have a lower cost generic or biosimilar alternative and used a co-pay coupon to help him pay the cost of the drug. These coupons, often distributed through patient assistance programs, can give patients access to a life-saving drug that they otherwise could not afford. Despite these benefits, because of federal anti-kickback rules, Medicare enrollees are not allowed to use these programs or coupons—leaving them vulnerable to high drug costs.

Additionally, some pharmacy benefit managers, insurers and/or employers are implementing “accumulator adjustment programs,” which prevent the costs that are covered by a patient assistance program or co-pay coupon from applying towards the patient’s deductible or out-of-pocket maximum.

A decision regarding oncology treatment should be a medical decision between a doctor and patient. Patient assistance programs help enrollees to have access to the most appropriate prescription drugs. Prohibiting the use of these programs or not counting their support toward out-of-pocket spending requirements could deny cancer patients access to medically necessary prescription drugs. At the same time, these programs should not be used to steer patients toward a higher-cost medication when a less expensive alternative is available, covered and medically appropriate for an enrollee. ACS CAN supports policies that ensure patients can use these coupons to help afford their drugs in situations where there is no clinically appropriate alternative.

Survivor Views: The Costs of Cancer in Their Own Words

“Even with what is considered decent insurance the financial impact of cancer is crippling. There is a never-ending series of doctor’s visits and test all adding up to out of pocket expenses that over multiple years completely drain you financially. You can’t even think about making a nonessential purchase out of fear of the next medical bill that will pop up.”

Breast Cancer Survivor, Michigan

Other priorities to ensuring access to care:

- Maintaining the Essential Health Benefit (EHB) coverage requirements for individual and small group marketplace health insurance plans
- Maintaining the ACA requirement that all private insurance plans have a maximum out-of-pocket limit for patient spending on in-network, covered services
- Maintaining the ACA prohibition on annual and lifetime limits in insurance plans
- Maintaining and strengthening insurance plan network adequacy standards so cancer patients

will have access to the providers they need in-network

- Requiring insurance plans to maintain robust formularies with utilization management practices that are based on clinical evidence and treatment guidelines and do not prohibit patients from taking the medication that their doctor has determined is the right choice for them. This includes standardizing plans’ prior authorization processes to 1) make them electronic, efficient, and easy for patients and providers to use, and 2) require specific response times on requests so patients have timely access to the treatments they need.
- Requiring that patients have access to an efficient and timely appeals process in cases where a cancer patient needs medications or services that are not covered or are subject to utilization management tools (such as prior authorization, step therapy, or quantity limits)
- Limiting the amount that patients must pay out-of-pocket for their drugs, including policies that encourage plans to use only co-pays on their formularies (which are more transparent and predictable than co-insurance), policies that cap cost-sharing amounts for drugs and policies that cap all out-of-pocket drug spending for the year
- Requiring plans to cover oral anti-cancer drugs with cost-sharing amounts that are comparable to their coverage of physician-administered anti-cancer drugs

Addressing the affordability of cancer care—including the base costs of treatments as well as the cost sharing and out-of-pocket expenses patients must pay—is paramount in ensuring true access to health care.

Reducing the Overall Financial Impact of Cancer for Patients and Their Families

Reducing the costs of cancer does not only mean reducing the actual out-of-pocket costs for patients—it also means addressing and preventing the long-term financial impact that high health care costs have on people with cancer and their families, and finding ways to help them plan for and afford the costs they have to pay.

Survivor Views: The Costs of Cancer in Their Own Words

“As a single mom, I rely on my employer’s health care plan for my children’s insurance and my own. This also means that any out-of-pocket costs (meeting deductibles, co-pays, etc.) are solely my responsibility... The financial toxicity brought on by cancer and the aftermath of its treatment is devastating--some months it can equal my mortgage payment.”

Breast Cancer Survivor, Michigan

Spotlight on ACS CAN Policy Priorities:

Help Patients “Smooth” Their High Out-of-Pocket Costs

Several patients in our profiles had large ‘spikes’ in their out-of-pocket spending in the 1-2 months after their first doctor’s visit that led to their cancer diagnosis. Cancer patients are especially vulnerable to these spikes because many cancer treatments and diagnostic tests are high-cost and scheduled within a short amount of time—requiring the patient to spend through their deductible and out-of-pocket maximum quickly. While many patients have challenges paying multiple thousands of dollars out-of-pocket over the course of a year, it is even more challenging when this amount of spending is required in a short time—monthly budgets simply can’t afford these large bills, especially at the same time as the family is dealing with a life-changing cancer diagnosis. Large spending spikes like these greatly contribute to the financial toxicity that people with cancer face. Many patients would benefit from having the option to “smooth” out their payments or spread them out over the course of the year—much like consumers have the option to pay for a new car in installments through a payment plan.

This concept of allowing patients to “smooth” their out-of-pocket costs has taken hold in the last few years in encouraging ways. Recent policy proposals to cap patient out-of-pocket expenses in Medicare Part D plans also included options to smooth these costs for Medicare patients that hit their cap. One way to accomplish this goal is to systematically identify Medicare patients who are going to reach the catastrophic drug out-of-pocket spending level (currently \$6,350) in the

span of one or two months, or with one or two fills of a prescription, and offer these patients the option to pay their expected annual cost in monthly, interest-free installments. This kind of policy could also be applied to other parts of Medicare, as well as in other types of insurance plans. Other policies that use ‘smoothing’ principles include policies that cap co-pays/co-insurance per monthly prescription for cancer drugs—a policy that has passed in several states. Additionally, some states have explored requiring plan issuers to offer a certain number of plan designs in their marketplaces that only use co-pays for prescription drugs, rather than co-insurance that leaves patients vulnerable to high and unexpected cost spikes. ACS CAN supports policies that will help patients with high costs avoid spikes, smooth their costs throughout the year and hopefully avoid the consequences of financial toxicity. However, we also note that most of these ‘smoothing’ solutions explored so far deal only with pharmacy drug costs. While this is one category of spending that tends to be high for cancer patients, it is not the only one. ACS CAN supports exploring smoothing solutions for all patient out-of-pocket costs.

Other priorities to reduce the overall financial impact of cancer:

- Requiring health care providers to give patients estimates of their costs for a procedure or treatment before that treatment occurs so patients can plan for expenses or ‘shop’ for providers that may perform the service at a lower cost
- Requiring insurance plans to be clear and transparent about what cost-sharing amounts are required for drugs—particularly translating co-insurance to dollar amounts for outpatient drugs and drugs covered under the medical benefit— so that patients are not surprised by charges when they arrive at the pharmacy/physician’s office
- Funding programs that provide patients with financial navigators who can help them determine how much treatments will cost, how to plan for these costs and how to best use their insurance benefits
- Requiring certain providers—like participants in the Oncology Care Model⁹²—to provide financial

navigation services to cancer patients

- Gathering more information on the options cancer patients are given to help pay large medical bills and potential problems—i.e. Are patients being required to pay high, or any, interest rates on payment plans? Are all patients offered these options equally? What happens when a patient is not able to pay on schedule?
- Finding ways to help people with cancer and their families who have significant medical debt because of their treatment, including ensuring medical debt does not factor into an individual's credit score and potentially creating debt forgiveness programs for cancer and other seriously ill patients

ACS CAN is committed to finding policy solutions that help address the long-term costs of cancer, and the huge impacts these costs can have all aspects of cancer patients' and their caregivers' lives.

Conclusion

For the millions of Americans diagnosed with cancer each year, the cost of treating the disease can be staggering. ACS CAN will continue to advocate for changes to the health care system that make care more affordable for cancer patients, survivors and those at risk for cancer.



Survivor Views: The Costs of Cancer in Their Own Words

“This treatment has saved my life but now I'm in debt \$365k +..my portion after insurance. I'll spend the rest of my life left paying this off.”

Survivor of Multiple Cancers, Colorado

Survivor Views: The Costs of Cancer in Their Own Words

“Cancer and/or the treatments caused me to have to leave my job permanently. Going from a double income home to single income was incredibly difficult on our family. No one should have to worry about how to pay for services or if they need to stay in a job they cannot perform any longer to pay for proper medical care. No one should have to deny a treatment for fear of debt. My diagnosis was 3 years ago and I am still paying. I am in collections. It is overwhelming and stressful at a time I need to reduce stress. Very afraid if ACA is repealed I will become a “pre-existing condition” and be denied insurance.”

Breast Cancer Survivor, Massachusetts

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