



The Costs of Cancer

Addressing Patient Costs

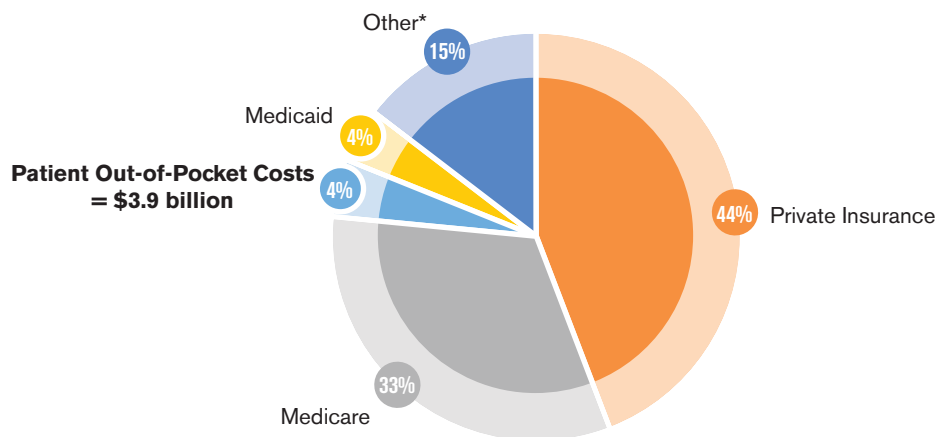


Introduction

Cancer is one of the leading causes of death and disease in the U.S. The American Cancer Society (ACS) estimates that roughly 1.7 million new cases of cancer will be diagnosed in the U.S. in 2017¹ and more than 15 million Americans living today have a cancer history.² Not only does cancer take an enormous toll on the health of patients and survivors—it also has a tremendous financial impact.

For patients and their families, the costs associated with direct cancer care are staggering. In 2014 cancer patients paid nearly \$4 billion out-of-pocket for cancer treatments. Cancer also represents a significant proportion of total U.S. health care spending. **Roughly \$87.8 billion was spent in 2014 in the U.S. on cancer-related health care.**³ These costs were paid by employers, insurance companies, and taxpayer-funded public programs like Medicare and Medicaid, as well as by cancer patients and their families.

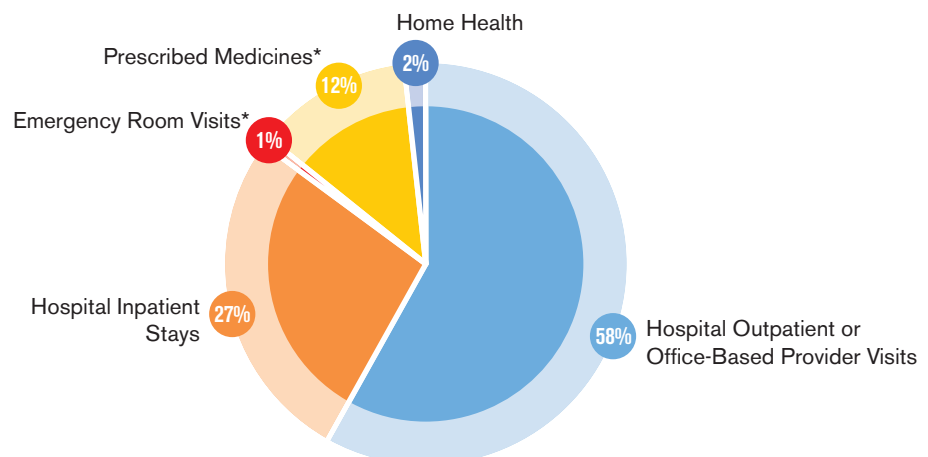
Total U.S. Expenditures for Cancer by Source of Payment—2014



Source: MEPS⁴

* The relative standard error for this category was greater than 30 percent. See reference for definition of "other."⁵

Total U.S. Expenditures for Cancer by Type of Service—2014



Source: MEPS⁶

* The relative standard error for this category was greater than 30 percent.

Note: the costs in this graph only include direct medical expenses, and do not include indirect costs such as transportation, lost wages, etc.

The American Cancer Society Cancer Action Network (ACS CAN), the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. This ACS CAN report focuses specifically on the costs of cancer borne by patients in active treatment as well as survivors. It examines the factors contributing to the cost of cancer care, the types of direct costs patients pay, and the indirect costs associated with cancer. To more fully illustrate what cancer patients actually pay for care the report also presents scenario models for three types of cancer: breast, colorectal, and lung cancer. It also presents three types of insurance coverage: employer-sponsored insurance, an individual market plan, and Medicare. Finally, the report presents public policy recommendations for making cancer treatments more affordable for patients and survivors.

Key Report Findings

- Access to quality health insurance is essential to making cancer care affordable for patients and survivors.
- A lower premium insurance plan may not actually save cancer patients money. Such plans often have high-cost sharing and cancer patients are high utilizers of care.
- Even with insurance, cancer patients often face unpredictable or unmanageable costs including high co-insurance, high deductibles, having to seek out-of-network care, and needing a treatment that is not covered by their plan.
- Newly diagnosed cancer patients often experience their highest out-of-pocket costs in the first two to three months following a positive screening or diagnosis until they meet their applicable deductible and out-of-pocket maximums.
- In each of the cancer scenarios included in the report, the patient with employer-sponsored insurance paid the least in premiums and cost-sharing and the patient with individual market insurance paid the most.
- Limits on out-of-pocket costs significantly lowered patients' expenses in two of the three insurance scenarios. Without these limits, patients' costs would have sky-rocketed.
- The profiles illustrate that without insurance coverage, cancer patients would likely face treatment costs totaling tens and possibly hundreds of thousands of dollars.

State and federal policymakers can address cancer patients' costs by:

- Ensuring cancer patients, survivors and those at risk for cancer have access to health insurance that is adequate, available, affordable and easy to understand
- Providing all Americans access to no cost prevention and early detection services—preventing cancer and diagnosing it earlier can reduce patient costs
- Passing public policies that prevent cancer and its costs to patients and society by reducing tobacco use and exposure to secondhand smoke, promoting healthy eating and active living, and protecting Americans from increased skin cancer risk associated with exposure to UV radiation emitted by indoor tanning devices

“Even as expensive as insurance has been and can be, the prospect of not being able to get insurance at all is terrifying. Currently, the medical bills received by my insurance carriers are close to \$1,000,000.”

Cindy Hinson, age 54 breast cancer survivor, Durham, NC

Factors Contributing to the Costs of Cancer

With more than 200 different types of cancer, there is no “one size fits all” cancer treatment, but 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 be able to negotiate discounts with providers, may qualify for “charity care” or may be able to participate in drug discount programs to reduce their costs.⁷ For patients with insurance, the kind of health insurance the patient has and the benefit structure 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 or other entity 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 cancer patients—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.
- **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 Cap:** The limit on what a patient must pay each year before the health plan starts to pay 100 percent for covered 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.

Current law requires most private insurance plans to limit annual patient out-of-pocket spending. The 2017 limit is \$7,150 for an individual plan and \$14,300 for a family plan.

- **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 cheaper because the insurer has negotiated rates with the provider. Some insurance plans charge more cost-sharing for “out-of-network” providers, while other plans do not cover out-of-network providers at all.
- **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 the plan did not reimburse the provider for the full billed amount and the patient has to pay the difference (this is sometimes called “balance billing”). The amount of these surprise bills often do not count toward the patients’ out-of-pocket maximum.



Other factors contributing to costs and causing variation 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. 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 considered to be the standard of care.

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. Sometimes patients may have a choice where they receive treatment, but other times the choice may be limited. Regardless of setting, it is still 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’s 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, and **Part D** covers drugs. **Part C** offers private plans that include Parts A and B, and sometimes Part D, coverage. Some individuals also have a **Medigap** plan (otherwise known as a **Medicare Supplemental** plan), which reduces cost-sharing required in Parts A and B in traditional Medicare
- **Employer-Sponsored Insurance:** Health insurance provided through an individual’s employer. This type of insurance is also sometimes provided to the individual’s spouse and/or dependents
- **Individual Market Insurance:** Insurance purchased by individuals, not offered by employers or other groups, through the private market

Types of Cancer Treatment Costs

There are three primary approaches to treating cancer: surgery, radiation, and pharmacological therapy (including chemotherapy, targeted therapy, hormone therapy and immunotherapy). Some patients receive all three modalities of treatment, 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 cancer patients 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.” Balance billing is more likely to occur with ancillary providers—like anesthesiologists and emergency room physicians—who are not employed by the facility and/or do not participate in a particular network. 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 is generally included under a plan’s medical benefit.

Radiation: Radiation therapy uses waves or high energy particles to destroy or damage cancer cells. Most patients receive radiation treatments at a hospital or cancer treatment facility. Radiation treatment requires complex 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 under Medicare 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 in a doctor’s office, clinic, or hospital. In most cases, covered intravenous (IV) drugs are included under a plan’s medical benefit; while covered drugs taken as pills



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 (fixed dollar amount) and co-insurance (percentage of cost) are both common forms of patient cost-sharing for drugs. The patient payment for a drug is often determined by the formulary tier on which the drug is placed. These tiers are groupings of drugs—like “preferred,” “non-preferred,” and “specialty”—for which the same co-pay or co-insurance applies. Covered pharmacological therapy is generally included in insurance policies as a separate pharmacy benefit.

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.⁸

It is also important to note that these various forms of treatment require multiple types of doctors and other health care personnel. It is very common for cancer patients to see multiple specialists 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, is a large driver of cancer patient costs. Many health insurance plans charge different cost-sharing for primary care doctor's visits versus specialists.



“My son Michael was diagnosed with Hodgkin's lymphoma when he was 22. He had tests, scans, surgery and 12 rounds of chemo. He had health insurance, but his plan had a \$10,000 deductible. There is no way he would have been able to pay that on his own—he was in college. As parents we were lucky to be able to help him, but two years later, we're still paying the bills from his deductible and other procedures that were not covered under his plan.”

Dona Wininsky, mother of Michael, age 23 Hodgkin's lymphoma survivor, Milwaukee, WI

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 problematic for cancer patients and their families.



The Indirect Costs of Cancer

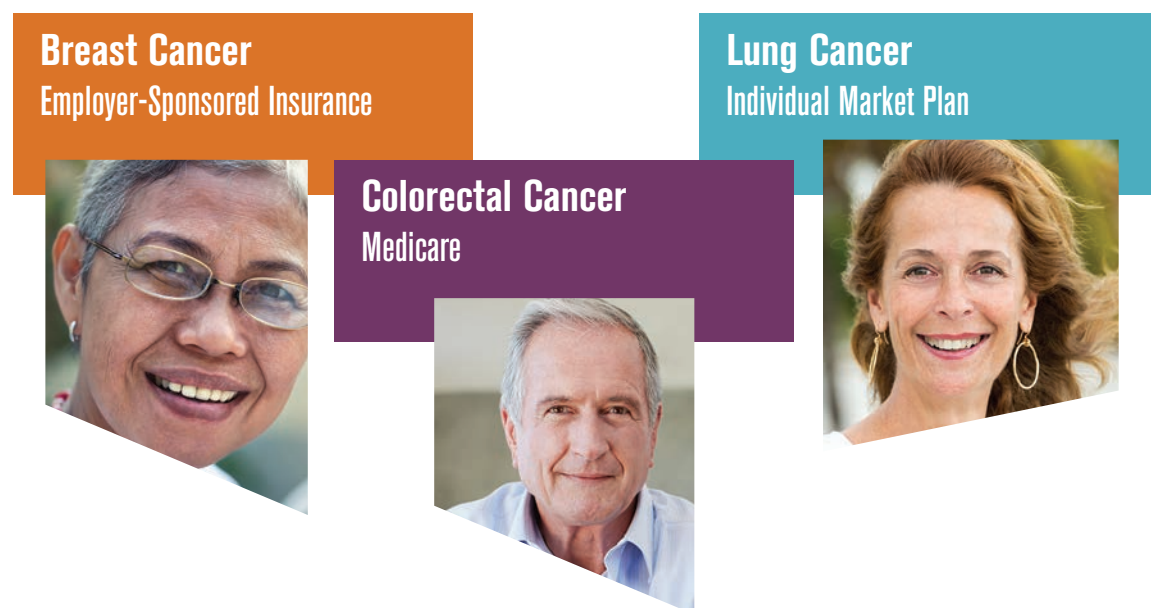
As these are indirect costs, most of them are difficult to quantify and track. But these costs are significant for cancer patients and families, and add to the overall costs of cancer care.

“Now that I am experiencing a recurrence, I don't know how tenable full-time work is. Doctors have a tendency to assume your health is your highest priority, so you missing work generally doesn't factor into their schedule or how long your appointment takes. Monitoring scans, chemo appointments—none of these things can be done on a lunch break. These are, in my experience, all morning or all afternoon affairs. I think cancer patients who have a long history with their company may be able to ask their boss for time off, but when you're a person entering the work force, telling your interviewer that you might need to take time off for chemo doesn't exactly increase your chances of getting the job . . . and the more time goes by that I don't have full time work, the more interest collects on my student loans.”

-Julienne Edwards, colon cancer survivor, Maryland

Patient Profiles: Cost Scenarios

Because of the complexity and variation in cancer treatment, it is difficult to predict the actual costs for any cancer patient at the time of diagnosis. The following patient profiles and associated data represent the typical costs for three hypothetical cancer patients with common cancers.



Experts at ACS and ACS CAN constructed profiles of three “typical” cancer patients, representing three of the most commonly diagnosed cancers: breast, colorectal and lung cancer. Experts determined the usual course of treatment for these patients based on National Comprehensive Cancer Network guidelines for each of the cancers. Analysts at Avalere Health, LLC estimated the patient out-of-pocket costs and total health care costs for each of these patients in three common insurance scenarios: Medicare, an employer-sponsored plan, and an individual market plan. All prices and insurance designs were based on 2016 data. See methodology appendix for more details, published at <https://www.acscan.org/policy-resources/costs-cancer>.

These patient profiles represent three “typical” scenarios. They help illustrate the costs that cancer patients and health care payers incur for their cancer treatments. Note that these scenarios do not include costs for other health care treatments not related to cancer (for example, if a patient had asthma, the costs to treat her asthma are not included).

Case Study



Mary had her regular **mammogram** in January, and her doctor told her the screening showed a lump suspected to be breast cancer. Mary had **blood tests**, an **ultrasound**, a **breast MRI**, and a **core needle biopsy**. She was diagnosed with **Stage I breast cancer**.

In March Mary had **lumpectomy** surgery to remove the tumor in her breast, and a sentinel lymph node **biopsy** to test if the cancer had spread. **Tests** determined that her cancer was hormone-receptive positive and HER2 negative.

In April and May, Mary underwent **chemotherapy** to attack any remaining cancer cells. Mary also received **supportive care drugs**, including anti-nausea medication, to ease side effects.

In June, Mary began **radiation**. She received radiation treatments 5 days a week for 6 weeks.

After finishing her radiation treatments in July, Mary began a multi-year regimen of daily **hormone therapy pills** to prevent her cancer from recurring. She also began regular check-ins with her **primary care doctor**.

Throughout her treatment, Mary saw several doctors and specialists, including her **primary care doctor**, her **oncologist**, a **radiation oncologist**, and a **breast surgeon**.

Breast Cancer Employer-Sponsored Insurance

Mary had health insurance through her employer. She paid **\$154** per month in health insurance premiums, and her employer paid **\$561**.

Mary's highest total spending was in **January (\$2,143)** and **February (\$1,765)** before her deductible and co-insurance out-of-pocket maximum were met. At the end of her plan year, she had paid a total of **\$1,844** in premiums and **\$3,975** in cost-sharing for her cancer care.*

The total health care costs for Mary's breast cancer treatment in 2016 were \$144,193.

Mary's insurance plan paid the vast majority of these costs—**\$140,218**. If Mary 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. Even though Mary is no longer in active treatment she will still require regular follow-up visits with her oncologist and primary care physician which will add to her 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 her cancer care, or other preventive services.

**Costs for an uninsured patient would likely be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate.

Case Study



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 is a high-risk patient, and he 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.

In April and May, Tom received **chemotherapy**, 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 doctors and specialists, including his **primary care doctor**, a **GI specialist**, a **surgeon**, and **oncologists**.

Colorectal Cancer Medicare

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

Medicare Part B—**\$122/month**

Medigap (Policy F)—**\$415/month**

Medicare Part D—**\$64/month**

Tom's highest total spending came in April and May (\$1,284 each) 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 or fluctuating out-of-pocket costs. In total Tom paid **\$600** in premiums every month. At the end of his plan year, he had paid a total of **\$7,205 in premiums** and **\$1,368 in cost-sharing** for his cancer care.*

The total health care costs for Tom's colorectal cancer treatment in 2016 were \$124,425. Medicare and Tom's Medigap and Part D plans paid the vast majority of these costs—**\$123,057**. 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 will 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 her cancer care, or other preventive services.

** Costs for an uninsured patient would likely be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate.

Case Study



Kathy had been a smoker and met high risk criteria for lung cancer, so she had her first **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**, 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 **genetic tests** on her tumor which showed she was not a candidate for targeted therapy or immunotherapy.

In March, Kathy began **chemotherapy** 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** 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 an **immunotherapy treatment** at her doctor's office. She continued **PET scans** 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.

Lung Cancer Individual Market Plan

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 bought an individual health insurance plan through her state's marketplace, which started in January. The premium for her plan was \$537 per month, but she qualified for tax credits which helped reduce these costs. Kathy ended up paying **\$272 per month** in premiums.

Kathy's highest costs were in **January (\$3,678)** and **February (\$3,716)** when she had multiple diagnostic tests and paid 40 percent co-insurance for imaging tests and scans, in addition to premiums. She met her maximum out-of-pocket limit in February—after that, no cost-sharing was required as long as she paid her premiums and received all her care in-network. At the end of her plan year, Kathy had paid a total of **\$3,264** in premiums and **\$6,850** in cost-sharing for her cancer care.*

The total health care costs for Kathy's lung cancer treatment in 2016 were \$210,067.

Kathy's insurance plan paid the vast majority of these costs—**\$203,217**. If Kathy 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.

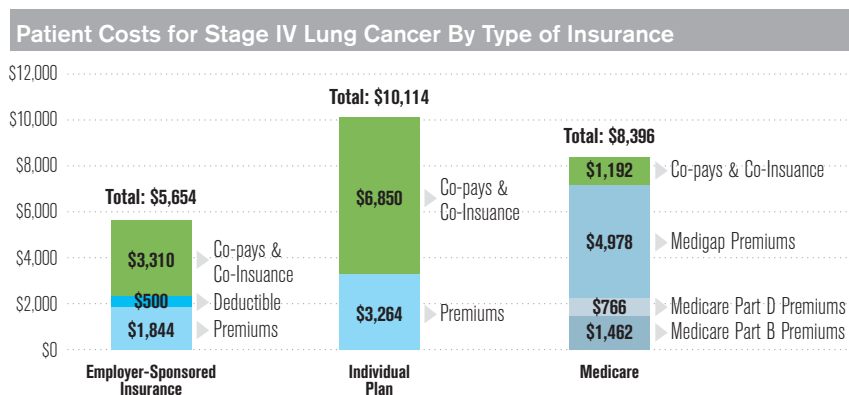
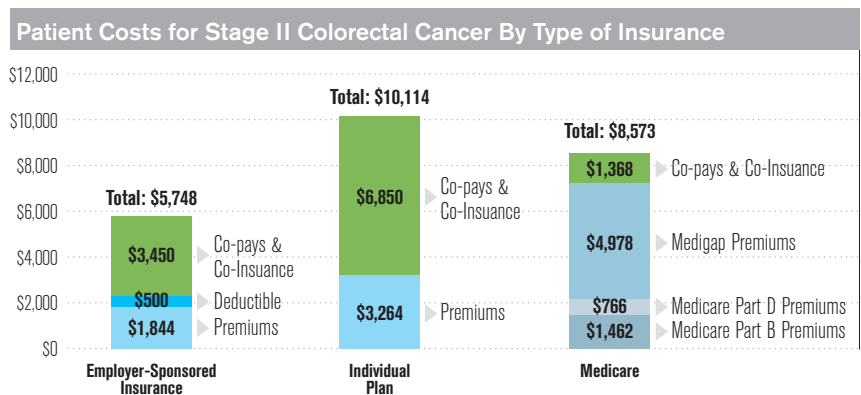
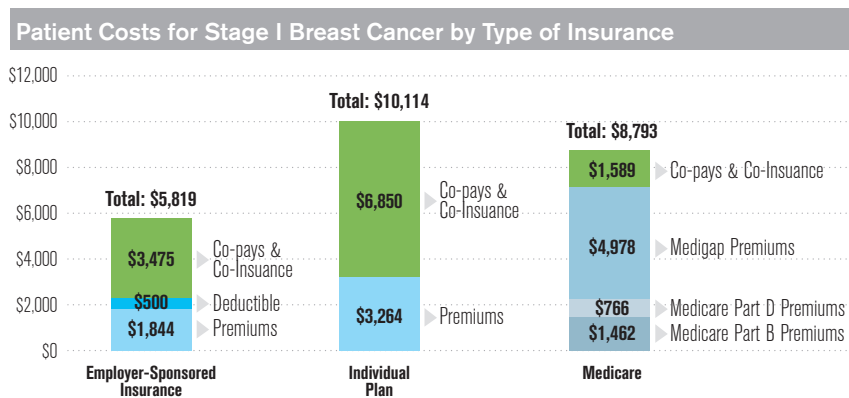
As Kathy remained in active treatment for her cancer at the end of 2016, her costs will continue into future years. When her new plan year began in January, she was once again responsible for paying cost-sharing until she meets her out-of-pocket maximum for the new year.

*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 her cancer care, or other preventive services.

**Costs for an uninsured patient would likely be higher than this estimate because uninsured patients do not benefit from a plan's negotiated discount rate.

Comparing Patient Out-of-Pocket Costs

As the three patient case studies illustrated, what patients pay for their cancer care varies greatly based on whether they have insurance and the scope of the policy. The following three graphs illustrate how patient costs for the treatment of each of the three cancers profiled—breast, colorectal, and lung—compare based on three different types of insurance coverage



*Note that in the Medicare scenario, the Medigap plan pays the patient's Medicare Part B deductible.
Source for all graphs on this page: Avalere Health LLC data analysis of 2016 plan year data. See methodology appendix for more information.

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.

Employer coverage tends to be more generous.

- In each modeled scenario, the cancer patient who had employer-sponsored insurance paid the lowest amount out-of-pocket, and the patient with an individual market plan paid the highest amount out-of-pocket.
- The cancer patient with employer-sponsored insurance paid the lowest in monthly premiums, and the Medicare patient paid the highest amount in premiums, due largely to the \$415 per month Medigap premium. However, while Medicare and Medigap premiums were high, they were offset by lower cost-sharing. This resulted in more consistent and predictable expenses throughout the year.

Out-of-pocket limits help protect patients.

While the patient with an individual market plan had the highest out-of-pocket costs in each scenario, the patient was protected from even higher overall costs by the maximum out-of-pocket limit. This is why these patients' out-of-pocket costs were the same in each scenario. The \$10,114 total patient obligation would still be challenging for many patients to afford, and in this particular scenario, represents 29 percent of total annual income.⁹

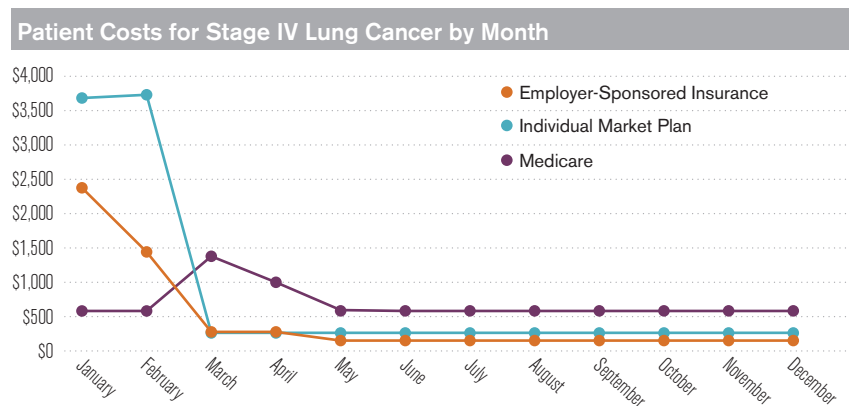
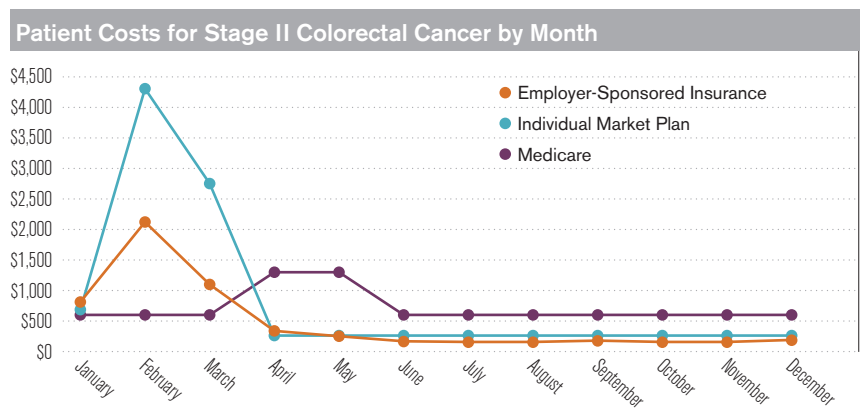
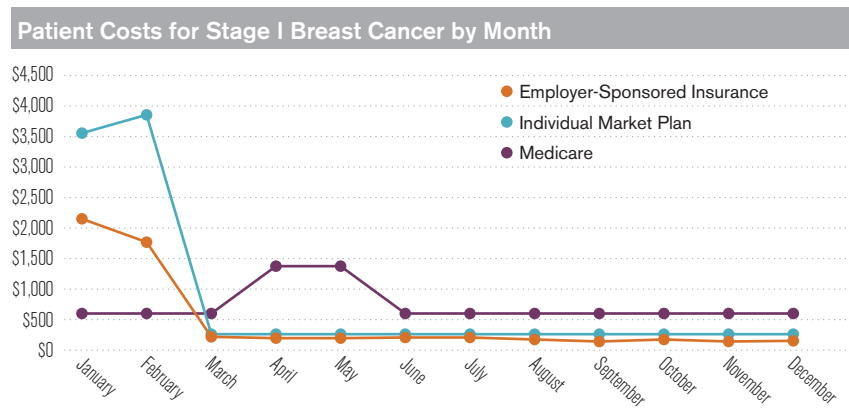
Drug costs vary greatly. Co-pay and co-insurance amounts fluctuated based on what type of treatments the patients received. The most important factor for these fluctuating costs was whether a treatment was covered under the medical or pharmacy benefit, particularly for drug costs:

- The patients with employer-sponsored insurance would have paid 20 percent co-insurance for drugs covered under the medical benefit, however, by the time they were treated with drugs they had reached their co-insurance maximum and did not have to pay anything out-of-pocket. For pharmacy benefit drugs, these patients paid co-pays ranging from \$5 to \$100 per drug per month.
- The patients with Medicare paid \$0 for drugs covered under the medical benefit because Medigap covered those costs. However, they paid co-pays (most often \$15) and co-insurance for drugs covered under Medicare Part D. Co-insurance percentages were 33 percent for specialty drugs and 40 percent for non-preferred brand drugs, and patient costs ranged from \$4 to \$760 per drug per month.
- The patients with individual market plans had all reached their out-of-pocket maximum by the time they were treated with drugs, so they did not pay anything out-of-pocket (note that all drugs were assumed to be covered by the plan in these scenarios, which is not always the case). Without this maximum in place, these patients would have paid 40 percent co-insurance for drugs covered under the medical benefit; and co-pays of \$35 or \$80 or 40 percent co-insurance for drugs covered under the pharmacy benefit.

Changes in Patient Costs Throughout the Year

Patient out-of-pocket expenses vary greatly month-to-month during active cancer treatment. The following three graphs represent out-of-pocket expenses by month for each of the cancer patients in each insurance scenario.

Note that each cancer patient was screened for cancer in January and diagnosed shortly thereafter. Also note each patient's insurance plan operated on a calendar year basis. This timeline was held the same across all patients for comparison purposes.



Source for all graphs on this page: Avalere Health LLC data analysis of 2016 plan year data. See methodology appendix for more information.

Key Findings

Cancer costs are front-loaded. In each cancer scenario, the patients with employer-sponsored insurance and individual market insurance experienced the highest out-of-pocket costs in the first 2-3 months after being screened and diagnosed with cancer. In each case, the cancer patients paid large amounts in applicable deductibles, co-pays and co-insurance in these months until they reached their co-insurance or out-of-pocket maximum. The patient with employer-sponsored insurance hit the \$3,000 co-insurance maximum and was only required to pay co-pays and premiums for the rest of the year. The patient with individual market insurance hit the \$6,850 out-of-pocket maximum and was only responsible for premiums for the rest of the year.¹⁰ It is important to note that these protective out-of-pocket maximums only last for one plan year, and in January the patients would once again be subject to cost-sharing.

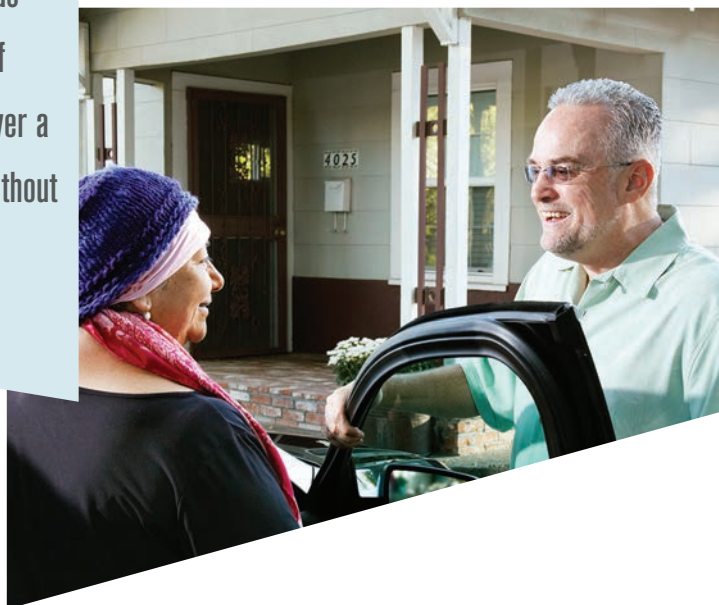
Medigap makes costs more consistent.

In each scenario the Medicare patient's costs followed a different pattern than that of the other two types of insurance. Because the Medicare patient had a Medigap plan, there was protection from co-insurance when utilizing the medical benefit. Therefore, the costs for the Medicare patient were more evenly distributed until the patient began using the Medicare Part D pharmacy benefit for oral drugs. This cost-sharing protection, however, came in exchange for significantly higher month-to-month premiums.

Timing of diagnosis and plan year matter.

Each of the cancer patients in these scenarios was diagnosed in January, which was also the start of their plan years. Certainly in most instances, cancer does not follow this timeline. Monthly medical expenses displayed in these graphs would look very different if the patients were diagnosed in different months, or if their plan years began in different months. Cancer patients should expect to pay a large amount of out-of-pocket costs leading up to and directly after a diagnosis, and they should be aware of their maximum out-of-pocket limits and deductibles.

According to a 2015 report on the economic wellbeing of U.S. households by the Federal Reserve, nearly half of Americans report being unable to cover a \$400 emergency medical expense without having to borrow or sell something.



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

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

Out-of-Network Charges

Insurance plans usually charge less cost-sharing if patients use health care providers, facilities or pharmacies that are in-network. Some plans do not cover any treatment out-of-network. In nearly every case, going out-of-network is going to increase costs for the patient. However, some circumstances may require that cancer patients seek care out of their plan's network.

Example—what if Mary's lumpectomy surgery was considered out-of-network?

Mary may have had to go out-of-network for several reasons:

- She lived in a rural area and an out-of-network surgeon was the only one she could see without traveling a significant distance
- Mary's breast cancer surgery was complicated, and she needed a surgeon with specific expertise that was not available in-network
- She was not aware that her surgeon was out-of-network because she did not understand the distinction, or because her plan's provider directory was outdated
- While Mary's surgeon was in-network; the anesthesiologist, radiologist or pathologist involved in her surgery were out-of-network providers

Mary's individual market plan did not cover health care services out-of-network. If Mary's surgery was performed at a hospital that was not in her plan's network she would have received a bill for the full amount of the surgery: \$46,400.¹¹

Payments for out-of-network services do not count towards her maximum out-of-pocket limit. Many cancer patients have problems paying these bills, particularly when they are unexpected.

Plans with Significant Upfront Costs—High Deductible Health Plans

A high deductible health plan (HDHP) is a plan that requires more payment "up-front" for health care by having a large deductible. The Internal Revenue Service (IRS) defines an HDHP as any plan with a deductible of at least \$1,300 for an individual or \$2,600 for a family,¹² but some HDHPs have even higher deductibles. For example, the most popular plan option in the Wisconsin Health Insurance Risk Sharing Plan (the state's pre-Affordable Care Act high risk pool, which is often considered one of the most successful programs of its kind) had a \$5,000 deductible.¹³ While in most cases HDHPs have lower premiums, and under current law they must cover in-network preventive services without cost-sharing pre-deductible—the up-front costs associated with HDHPs can prove very challenging for cancer patients. Some patients may delay or abandon follow-up tests or other care because they can't afford to meet their deductible. One recent study showed that HDHP enrollment was associated with a decrease in imaging tests,¹⁴ like tests each cancer patient analyzed in this report received.

Example—what if Kathy had an HDHP?

Kathy underwent two CT scans in January. The first was a lung cancer screening scan, which current law requires her plan to cover with no cost-sharing. However, her plan could charge cost-sharing for her second CT scan which was part of her evaluation and confirmed her test results. Kathy's radiologist charged her health plan \$8,611 for the second CT scan, which was the price negotiated by the plan and provider.¹⁵

If Kathy had an HDHP with a \$5,000 deductible, and she had not paid any other cost-sharing in January, she would be charged her full \$5,000 deductible in one bill. Kathy might have severely struggled to pay this bill. Furthermore, if Kathy knew her follow-up scan was going to cost her \$5,000, she might have delayed the scan, attempted to find a different facility or provider (though it can be very difficult to “comparison shop” for medical procedures), or decided not to get one at all. This would likely result in her lung cancer progressing even further before it was diagnosed.

Co-pays vs. Co-insurance

Once a patient meets his or her deductible for the year, the primary cost-sharing required are co-pays and co-insurance. Both are fees that the patient pays when a health care service is delivered or a prescription is filled. Co-pays are flat fees, usually defined clearly in a patient's insurance documents. 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 Mary had to pay co-insurance for a medication?

After her surgery, chemotherapy and radiation treatments for breast cancer, Mary's doctor prescribed her Letrozole, a pill that can reduce the risk of breast cancer recurrence. Mary is supposed to take Letrozole for five years after cancer treatment. The total cost of a month's supply of pills is \$426. This was the cost that Mary's health insurance plan paid the pharmacy for filling her prescription.

Mary's health insurance plan covered Letrozole but, in this example, placed it on the highest cost-sharing tier of its formulary. If Mary's plan required a \$50 co-pay for this tier of drugs, Mary knew she would have to pay \$50 every time she filled that prescription at the pharmacy for the next 5 years. But if her plan instead required a 30 percent co-insurance for tier 4 drugs, Mary would have to pay \$128 for her prescription, and she wouldn't know how much she owed until she got to the pharmacy for her first fill. Furthermore, if the price of the medication increased, Mary's costs would increase too because her co-insurance was based on the price of the drug. For the next five years Mary would always be uncertain of what she would owe for this medication.

Non-Covered Treatments

Health insurance plans do not always cover every health care service or drug. This is one way health insurance plans attempt to control their costs. When plans deny coverage of certain cancer treatments, patient out-of-pocket costs increase considerably if the patient decides to proceed with the 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 immunotherapy was not covered?

After her visit to the emergency room, Kathy and her doctor realized her chemotherapy was not working, and decided to use a new immunotherapy to try to stop her lung cancer from spreading. Nivolumab is a relatively new drug and is not yet available as a generic. One month’s worth of Nivolumab for Kathy’s immunotherapy treatments cost \$11,704.

Kathy’s individual market plan may not have covered this medication—it may have fallen outside their clinical protocols, they had yet to add it to their formulary, or it was simply not part of their benefit. Kathy could appeal the decision, and her doctor could argue that the medication was medically necessary and she had exhausted the use of covered drugs to treat her cancer. Some plans will cover this type of medication as a second-line treatment. If the plan continued to deny coverage, Kathy and her doctor could also go through an external appeals process.

However, if Kathy’s appeals did not succeed and the plan refused to cover her medication, Kathy would have been responsible for the full cost of her immunotherapy—\$11,704 every month. For most individuals, paying over ten thousand dollars every month for medication is impossible and would exhaust any financial reserves very quickly.

The Trade-Offs of Medigap Plans

While Medicare Parts A and B cover most Medicare enrollees’ hospital and physician services, traditional Medicare has relatively high deductibles and cost-sharing requirements and places no limits on patient out-of-pocket spending, leading 86 percent of Medicare enrollees to purchase some sort of supplemental coverage to help pay cost-sharing.¹⁶ This includes employer-sponsored supplemental coverage, Medicaid, Medigap or enrolling in a Medicare Advantage plan. The Medicare cancer patients in this report have enrolled in Medigap policy F, the most popular Medigap plan.

Example—What if Tom did not have a Medigap plan?

Tom’s Medigap plan paid 100 percent of his Medicare cost-sharing requirements for hospital and physician services (this does not include pharmacy costs). While this plan spared Tom from paying 20 percent co-insurance for most outpatient and physician services, it came with a high monthly premium. See examples below for Tom’s colon cancer treatments.

Tom’s Expenses WITH Medigap	Tom’s Expenses WITHOUT Medigap
Total premiums for the year: \$7,205	Total premiums for the year: \$2,227
Total cost-sharing for the year: \$1,368	Total cost-sharing for the year: \$14,165

For a cancer patient in active treatment, the protections against cost-sharing are an important consideration. However it is important to be aware of these trade-offs. Note that Tom would have been charged 20 percent co-insurance for his colonoscopy. Colonoscopies during which polyps are removed are considered diagnostic and not preventive under current Medicare policy. This often results in Medicare patients who do not have a Medigap plan getting a surprise bill for their colonoscopy.



Reducing Patients' Cancer Costs— Public Policy Options

Access to Health Insurance and Cancer Treatments

The single most important thing policymakers can do to help cancer patients deal with the costs of cancer is to ensure that all Americans—including cancer patients, survivors and everyone at risk for cancer—are able to enroll in comprehensive, affordable health insurance.

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.¹⁷ Uninsured Americans 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.¹⁸ Several other studies show that uninsured patients are more likely to be diagnosed with advanced-stage or metastasized cancer.^{19,20,21,22,23} Recent expansions in access to health insurance among young adults have been shown to increase the number of cancer cases diagnosed at early stages,²⁴ and increase initiation and completion of the human papillomavirus (HPV) vaccine that prevents cervical and other types of cancer.²⁵

Ensuring that all Americans are able to afford and enroll in quality health insurance coverage is not the only step in addressing patient costs. There are many other cost-related factors that affect cancer treatment, patient wellbeing, and health outcomes. Cancer patients need to have insurance plans that cover cancer treatments, be able to anticipate treatment costs, afford their cost-sharing, and have adequate access to in-network providers. Each of these factors influences the treatments cancer patients receive, and the costs they pay.

Many cancer patients have trouble affording their treatments, even when they are insured.²⁶ A 2016 survey by the Kaiser Family Foundation found about a quarter of adults aged 18-64 say they or someone in their household had problems paying or were unable to pay medical bills in the last 12 months. Sixty-two percent of these respondents were insured.²⁷ Fourteen percent of those who have had problems with medical bills cited cancer as the cause of the problems. Cancer is cited

more often than any other disease as the cause of such financial problems.²⁸ Another study found that economic hardship—including difficulty living on household income, inadequate housing, food or medical attention, or reducing living standards to the bare necessities of life—was evident in almost half of cancer survivors one year after their diagnosis.²⁹ Financial hardship can lead to lower quality of life, increased pain and greater symptom burden,^{30,31} as well as patients delaying or avoiding other necessary care like medications and mental health care.^{32,33} In these ways, financial hardships can lead to increasing health care costs as well as poorer health.

Transparency in what a health plan covers and how much it costs is essential for cancer patients. This clarity enables patients to select the right insurance coverage to meet their needs as well as plan for how to cover out-of-pocket costs. Knowing what and how a service or drug is covered is especially important for cancer patients as many cancer drugs are covered under a plan's medical rather than pharmaceutical benefit and are therefore not listed on formularies. Unlike formularies, medical benefit details can be challenging to access, particularly when it comes to drug coverage.³⁴ It is also important for other sources of health care such as hospitals, out-patient treatment centers, and health professionals to be transparent about what they charge for services.

Cancer patients also have difficulty navigating their plan's provider network. Several industry analysts and publications have noted a trend toward narrower provider networks, particularly in the individual insurance market.^{35,36,37} When plans include fewer providers in-network (thus, have a narrow network) consumers are more vulnerable to unexpected billing, and patients may

have trouble finding an accessible provider. This is especially true for cancer patients, as cancer treatment often involves several different types of specialists. A 2014 analysis by Milliman found that many individual market plans include only a limited number (if any) of National Cancer Institute-designated cancer centers or transplant centers in their networks.³⁸ More recent analyses confirm network adequacy is a problem in individual market plans for primary care³⁹ and oncology care.^{40,41,42}

ACS CAN supports policies that ensure all Americans—including cancer patients, survivors, and those at risk for cancer—have access to health insurance that is adequate, available, affordable and easy to understand. These policies include:⁴³

■ **Ensuring that health insurance is adequate**

- Requiring plans cover services essential to quality cancer care, including no-cost prevention and screening, hospitalization, specialty cancer care, physician services, prescription drugs, rehabilitative care, and mental health services
- Prohibiting annual and lifetime limits
- Requiring plans to cover routine care for patients enrolled in clinical trials
- Requiring plans to have adequate provider networks that include access to specialty care

■ **Ensuring that health insurance is available**

- Prohibiting pre-existing condition exclusions, including total denial of policies and excluding certain conditions from coverage
- Prohibiting insurance policy rescissions (cancellations)
- Ensuring patient protections discussed above are available to all Americans regardless of their income or the state they live in
- Providing special enrollment periods that allow Americans with a qualifying event to enroll in insurance outside of open enrollment

A 2012 survey of cancer survivors found that one-third of those surveyed had gone into debt. Of those who had gone into debt, 55 percent owed \$10,000 or more.

Source: Banegas M, Guy Jr. G, Yabroff K, et al. For Working-Age Cancer Survivors, Medical Debt And Bankruptcy Create Financial Hardships. *Health Affairs*. January 2016;35(1):54-61.

■ **Ensuring that health insurance is affordable**

- Prohibiting plans from using a patient's pre-existing conditions or health status to increase premium rates
- Providing tax subsidies or other mechanisms that make insurance affordable for lower-income Americans
- Instituting maximum out-of-pocket limits for all insurance plans
- Expanding eligibility to Medicaid based on income level
- Promoting competitive state insurance markets that incentivize low premiums
- Protecting patients from unexpected medical bills, otherwise known as “balance billing”

■ **Ensuring that health insurance is easy to understand**

- Providing Americans with an easily accessible method to shop for individual market coverage
- Increasing health plan transparency so patients are better able to choose the health plan that is right for them and plan for their costs
 - Requiring transparency in provider networks
 - Requiring transparency in formularies, including clear information about cost-sharing
 - Requiring transparency in drugs covered under a plan's medical benefit

Prevention and Early Detection

Preventing cancer in the first place or detecting it early is the best way to reduce many costs associated with cancer treatment—patient out-of-pocket costs, health care payer costs, and indirect costs.

A substantial proportion of cancers are preventable,⁴⁴ 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 funding that increase access to preventive services. ACS CAN advocates for evidence-based policies that address these risk factors and are proven to reduce cancer incidence and death.

While cancer prevention programs and strategies often involve up-front financial investments, research shows that these investments pay off. In the community setting, one report calculated that an investment of \$10 per person per year in community-based programs to increase physical activity, improve nutrition, and prevent tobacco use could save the country more than \$16 billion annually within five years. This is a return of \$5.60 for every \$1 invested.⁴⁵ Similar results are frequently proven in tobacco control programs,^{46,47,48} and evidence for these returns is emerging for community-based physical activity interventions.⁴⁹

Providing preventive services, such as tobacco cessation, and cancer screenings in the clinical setting is also crucial to preventing cancer and detecting it early. Analyses of these recommended services find that many are cost-effective and cost-saving.^{50,51} A 2012 analysis of the comprehensive tobacco cessation benefit provided to Massachusetts Medicaid enrollees showed that for every \$1 spent on the benefit, the state gained \$3.12 in medical cost savings.⁵² In addition, cancer screenings allow cancer to be caught at earlier stages (e.g., before symptoms appear), and earlier stage cancers are often easier and less costly to treat for patients and health care payers. Screening for colorectal cancer can actually prevent the disease by detecting and removing pre-cancerous growths.

ACS CAN advocates for cancer prevention and early detection policies to:

- **Ensure access to evidence-based prevention and early detection services, including cancer screenings and vaccines, and tobacco cessation**
 - Maintain requirements for coverage of all preventive services recommended with an 'A' or 'B' by the USPSTF with no cost-sharing, and extend these requirements to all plans, including Medicare and Medicaid
 - Pass the Removing Barriers to Colorectal Screening Act, which fixes a "glitch" in Medicare policy and removes patient cost-sharing for all colonoscopies
 - Adequately fund evidence-based federal and state cancer vaccination, screening, and control programs; including breast and cervical cancer early detection programs, colorectal cancer control programs, and comprehensive cancer control programs
- **Reduce tobacco use and exposure to secondhand smoke**
 - Increase the price of all tobacco products through significant and regular tobacco tax increases at the federal, state, and local levels
 - Implement comprehensive smoke-free policies nationwide, which includes ensuring communities are not precluded from passing their own, stricter provisions
 - Fully fund and sustain evidence-based federal and statewide tobacco prevention and cessation programs, including ensuring access to clinical cessation services
 - Work with the Food and Drug Administration to effectively implement the Family Smoking Prevention and Tobacco Control Act to comprehensively regulate tobacco products and marketing

- **Promote healthy eating and active living**

- Adequately fund evidence-based, federal and state programs and public health research to reduce overweight and obesity, improve nutrition, and increase physical activity
- Implement strong, evidence-based nutrition standards for all foods and beverages sold in schools and school-based programs and policies to improve nutrition education and promotion
- Increase the quantity and improve the quality of K-12 physical education and school-based physical activity

- Ensure that influential nutrition and physical activity guidelines reflect the current science with respect to diet, physical activity, body weight and cancer prevention and survivorship

- **Protect the public from increased skin cancer risk associated with exposure to UV radiation emitted by indoor tanning devices** by prohibiting minors' use of indoor tanning facilities, properly regulating tanning facilities, and informing consumers of the cancer risk associated with indoor tanning

Access to Palliative Care

Palliative care, or supportive care, helps to prevent and relieve suffering and maintain the best possible quality of life for patients and their families, regardless of the stage of the disease. Palliative care has also proven to reduce costs for patients and health care payers.

Patients receiving palliative care avoid crises; spend fewer days in the hospital, emergency department (ED), and intensive care unit (ICU); and need fewer re-admissions.⁵³ Palliative care achieves these outcomes at a lower cost than usual care by helping patients better understand their needs, choose the most effective treatments, and avoid unnecessary or unwanted hospitalizations and interventions. One study of adult patients with advanced cancer who were admitted to the hospital showed that having a palliative care consultation within 2 days of admission was associated with a reduction in costs up to 33 percent.⁵⁴

ACS CAN supports policies that increase patient access to palliative care in all stages of treatment starting at point of diagnosis and throughout the continuum of their care. Increasing access to palliative care increases cost-saving opportunities and augments a patient's quality of life. Specific and immediate policy solutions include:

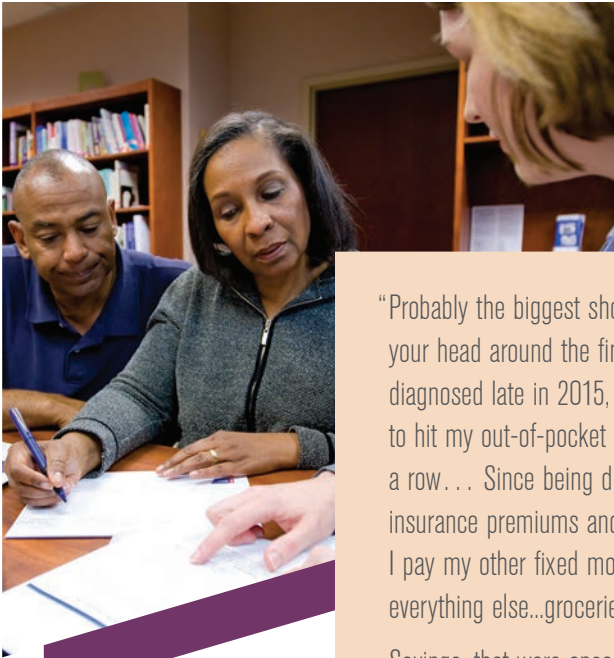
- **Enact and implement the Palliative Care and Hospice Education Training Act, which aims to increase education in, public awareness of, and research on palliative care.**
- **Remove patient cost-sharing for care coordination services in Medicare, and take other steps to increase care coordination**
- **Incentivize advance care planning**



Conclusion

For the millions of Americans diagnosed with cancer each year the cost of treating the disease can be staggering. Without comprehensive health insurance coverage, cancer patients' out-of-pocket costs would be even higher and millions would be unable to afford the care they need. As policy makers consider changes to the health care system, it is imperative that cancer patients, survivors, and those at risk of cancer continue to have access to adequate, affordable health insurance coverage.





“Probably the biggest shock after hearing you have cancer is wrapping your head around the financial impact of treating the disease. Having been diagnosed late in 2015, it became very clear very quickly that I was going to hit my out-of-pocket maximums with my insurance at least three years in a row. . . . Since being diagnosed, 28% of [my annual income] has gone to insurance premiums and annual deductibles/out-of-pocket max amounts. Once I pay my other fixed monthly bills, I have approximately \$25/day to pay for everything else...groceries, gasoline, car maintenance, clothing, pet care etc.

Savings, that were once used for unexpected/out of the ordinary expenses like new tires or custom orthotics needed for foot support due to weakening caused by chemo (which are not covered by insurance), has dwindled to almost nothing. Credit cards, which prior to cancer carried a zero balance, are now used instead. Every single expenditure is scrutinized as being a necessity or a luxury.”

**Cindy Hinson, age 54 breast cancer survivor
Durham, NC**

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For information regarding the methodology of the modeled patient cost scenario data in this report, please visit <https://www.acscan.org/policy-resources/costs-cancer>.

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American Cancer Society Cancer Action Network

ACS CAN, the nonprofit, nonpartisan advocacy affiliate of the American Cancer Society, supports evidence-based policy and legislative solutions designed to eliminate cancer as a major health problem. ACS CAN works to encourage elected officials and candidates to make cancer a top national priority. ACS CAN gives ordinary people extraordinary power to fight cancer with the training and tools they need to make their voices heard. For more information, visit <http://www.acscan.org/>.