MILLIMAN RESEARCH REPORT

# A Multi-Year Look at the Cost Burden of Cancer Care

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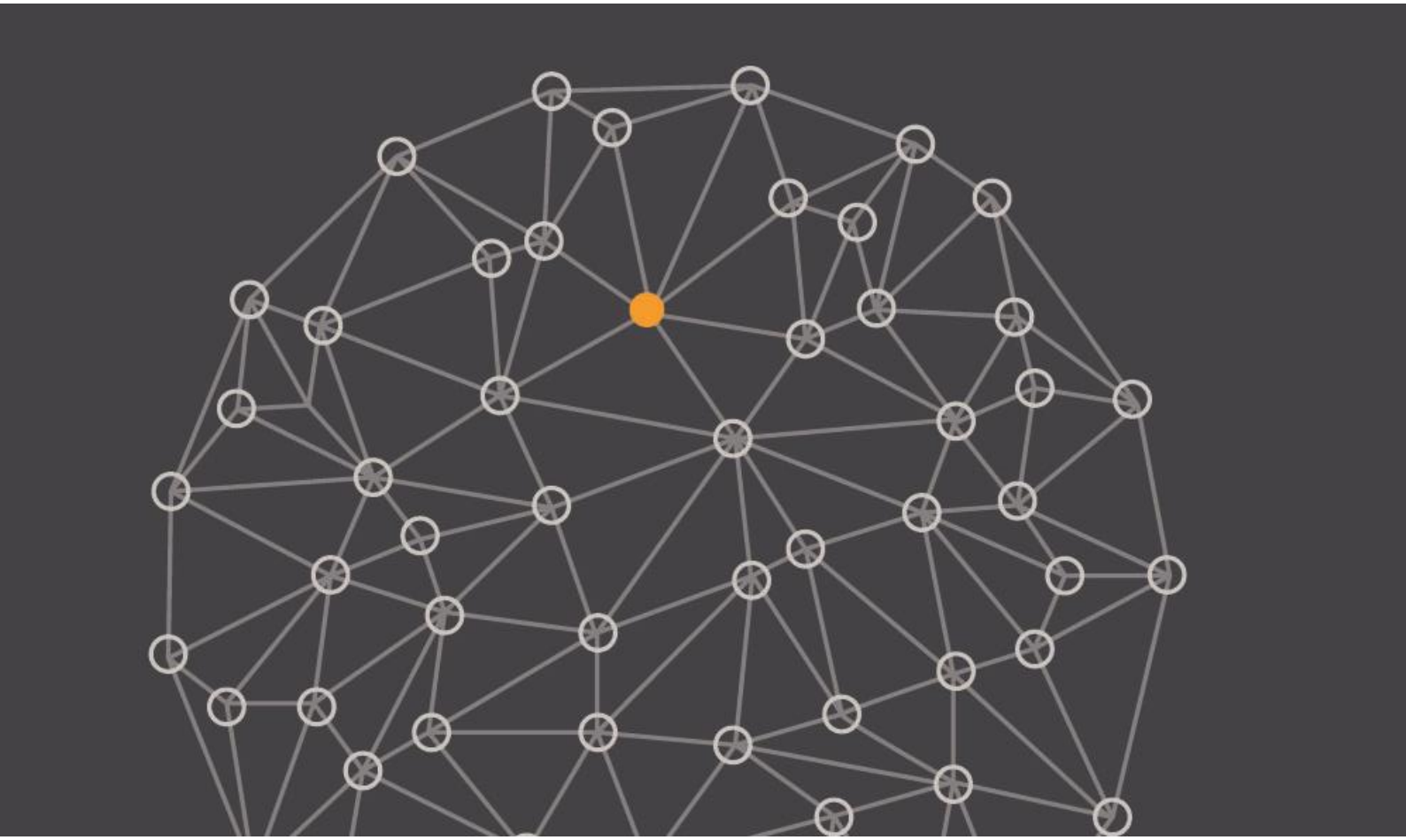
Commissioned by Pfizer, Inc.



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Of course, all errors and omissions are the authors' only.

# Executive Summary

This report characterizes the costs to cancer patients and their health plans for three cancers, breast, lung and colorectal to inform discussions related to the cost of cancer care. Together, these three cancers killed approximately 250,000 Americans in 2016, mostly from lung cancer.[1] We identified people with these three cancers in real-world claims data from people with employer-sponsored insurance (ESI). We tracked health plan spending and patient cost sharing starting with diagnosis in 2011 and followed people through 2014. We believe this is the first published study that follows cancer patients' costs and cost-sharing over multiple years using administrative claims data.

The context for this report is the widespread concern over healthcare spending in general and spending on cancer care. Total spending for cancer care in the US has been reported to be about 125 billion dollars in 2010 and is projected to increase between 27% and 39% by 2020.[2] [3] As cancer care spending grows, patient cost-sharing is also growing.[4] Out-of-pocket (OOP) costs by cancer patients has received much attention in medical journals and the general media.[5] [6]

We find in our analysis of real-world data that cancer patients can incur large OOP costs especially in the year of diagnosis, but also in following years. Patients diagnosed in 2011 incurred high costs, with average cumulative healthcare spending between $100,000 and $280,000 over the four years following diagnosis, depending on the cancer. For patients who survived and maintained their insurance coverage, the growth of cumulative total healthcare spending slowed after the second year, but spending and cost sharing never returned to their pre-diagnosis level.

We summarized the patients' experience from 2011, the year of diagnosis, through 2014 and examined both total healthcare spending and patient OOP costs. On average, total healthcare spending (the amounts paid against claims by the plan and the patient's responsibility) was highest immediately following a cancer diagnosis. Average healthcare spending per patient increased from less than $2,000 in the month preceding diagnosis to as high as $25,000 in the month of diagnosis. Average OOP costs also spiked dramatically immediately after diagnosis, averaging from $1800 to $2900 in the month of diagnosis alone. Total healthcare spending and OOP costs declined in the months following diagnosis, but high levels of total healthcare spending and OOP cost persisted well beyond the first few months after diagnosis. This finding suggests that, for some survivors, a diagnosis of cancer results in persistent healthcare spending.

Average OOP costs per patient showed a strong seasonal effect and spiked at the beginning of each calendar year, due to the need for patients to meet their deductible each annual benefit cycle. The average per-patient OOP costs in the first year after diagnosis were between $3,600 and $5,500, depending on the cancer type. These costs do not include premium contributions, non-emergency transportation or loss of income due to time off from work. Among members with the highest OOP costs, out-of-network (OON) services accounted for an important portion of OOP costs. Although the Affordable Care Act set annual OOP limits starting in 2014 ($6,350 in 2014),[7] for patients with income near or below the 2015 median household income of $55,775[8] these OOP costs could be a significant burden.

In summary, a cancer diagnosis translates into significant spending that may continue for years for both payers and patients. Our longitudinal perspective offers new information on the pattern and magnitude of the cost of cancer care that, we hope, will be useful to payers, patients, policy makers and patient advocates. We see relevance to the following broad health benefits questions:

- What are appropriate levels of out-of-pocket maximum and deductible?
- How should care coordination and financial counseling, assistance or HSAs be designed to best address the seasonal patterns of out-of-pocket cost for cancer patients?
- How do network composition, out-of-network benefits, cost-sharing, healthcare spending, balance billing and patient protection interact?
- The degree of importance to cancer patients of a comprehensive benefit package and thus potentially the pre-tax status of health benefits or an excise tax (aka "Cadillac Tax") tied to benefit expense

There are several limitations to the findings of our analysis. The patients in this study are covered by ESI, which provides relatively comprehensive coverage to over 145 million people.[9] Because ESI tends to offer more comprehensive benefits than the most popular plans sold in the small group or individual insurance markets, our findings may not apply completely to such programs. We present

national averages, but cost levels vary by payer and cost sharing varies with benefit program details, so our figures may not be appropriate for any particular individual. Healthcare costs and cancer treatments are changing, so our historical data from 2011-2014 may not be appropriate for other time periods.

This report was commissioned by Pfizer, Inc. The findings and conclusions reflect the opinion of the authors; Milliman does not endorse any policy. If this report is reproduced, we ask that it be reproduced in its entirety, as pieces taken out of context can be misleading. As with any economic or actuarial analysis, it is not possible to capture all factors that may be significant. Because we present national average data based on the 2010-2014 MarketScan, the findings should be interpreted carefully before they are applied to any particular situation. Findings for particular populations and for different time periods will vary from these findings. Bruce Pyenson and Gabriela Dieguez are members of the American Academy of Actuaries and meet its qualifications for this work.

# Background

Cancer imposes a financial burden on patients in many ways. One study found that patients with cancer were 2.5 times more likely to file for bankruptcy than those without cancer, and, in turn, patients who filed for bankruptcy were more likely to have received cancer treatment.[10] In a survey of patients diagnosed with Stage III colon cancer between 2008 and 2010, over a third of respondents reported one or more financial hardships despite having health insurance.[11] A 2012 survey indicated that socioeconomic status predicted preferences among efficacy, toxicity and cost in cancer treatment, with higher income patients more likely to focus on survival when making decisions, while lower-income patients were more likely to prefer avoiding costly treatment.[12]

Studies such as these raise questions about the effect of cost-sharing on income-based disparities in cancer care. But, there are significant gaps in understanding the total spending and cost-sharing on cancer patients today. Most of the recent literature on the impact of cost-sharing in cancer reports on the Medicare population.[13] [14] Furthermore, most studies are cross-sectional, examining relatively short time periods out of possibly multiyear cancer treatments. Finally, many published studies concentrate on pharmaceutical cost-sharing for specialty drug prescriptions.[15] [16] [17] This study presents real-world evidence of the costs experienced by patients with cancer and, in contrast to earlier studies, looks at the full scope of healthcare services over multiple years using longitudinal claims data for commercially-insured people.

As healthcare spending is consuming an ever greater portion of the national economic activity,[18] generating increasing scrutiny, a longitudinal look at total healthcare spending and cost-sharing paints a more complete picture than information obtained in a single year. This is especially true for conditions such as cancer, where treatment may ebb and flow over several years. The study's goal is to better understand the overall healthcare spending of cancer patients, including both the costs paid for by the insurance plan and those paid for by the patient (OOP) as well as the relative composition of those costs.

# Findings

This section presents two categories of finding from our five-year longitudinal study: total healthcare spending and patient OOP costs. Total healthcare spending reflects the fees negotiated between insurers and providers and includes patient OOP expenditures, while the OOP costs reflect the administration of benefit design cost-sharing terms, as well as OOP maximums. Costs reported exclude travel-related costs by patients and any productivity, income, or time loss, and are presented without trend for inflation. All patients were newly diagnosed in 2011.

Patient OOP costs reflect the administration of benefit design cost-sharing terms as well as OOP limits. OOP costs including deductibles, copays, and coinsurance but not premium contributions or services that are not covered by insurance.

## TOTAL HEALTHCARE SPENDING FOR CANCER PATIENTS

This section focuses on the total healthcare spending. In this report, total healthcare spending represents allowed (or negotiated) amounts for providers set by the insurer (or self-insured employer); this includes the amounts paid by the plan as well as patient cost-sharing, but excludes premiums and any non-covered services such as over-the-counter supplies. We include all covered medical services and drugs. For services performed by a provider outside the insurer's network (out-of-network provider), the allowed amounts in this report exclude "balance billing" to the patient for the difference between the provider's billed price and the amount allowed by the insurer.

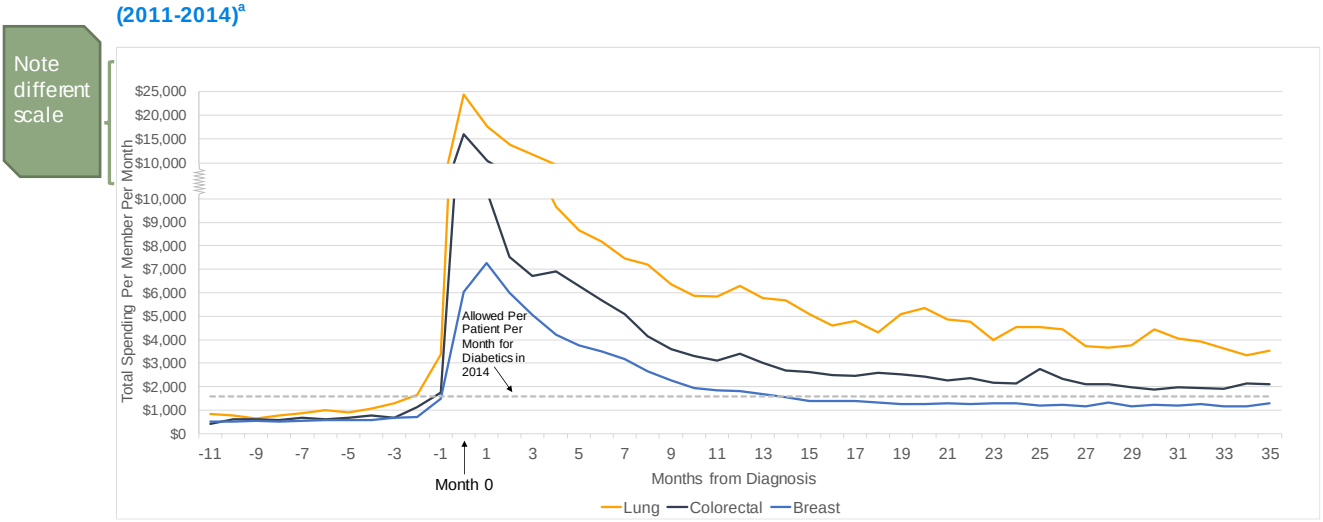
We present the monthly and cumulative spending for all services including treatment and ongoing maintenance, whether related to cancer or not.

### Monthly Total Healthcare Spending

Figure 1 presents total healthcare spending for cancer patients by month, before and after diagnosis (month 0). Until 2-3 months prior to diagnosis, the average total healthcare spending was under $1,000 per member per month. The average spending per patient increased just prior to diagnosis and spiked immediately following diagnosis: from less than $2,000 to as high as $25,000 in the month of diagnosis, which may include diagnostic expenses associated with the cancer. While spending declined over time after the initial spike, it did not return to the pre-diagnosis level during our study for any of the three cancers. Lung cancer had the highest spending levels post-diagnosis and throughout the study period; however, the three cancers studied exhibited a similar pattern. Each month's figures are averages for patients remaining in the database in that month.

The average monthly spending per patient spiked immediately following diagnosis: to as high as $25,000 in the month of diagnosis from less than $2,000 in prior months. Spending declined but did not return to the pre-diagnosis level in subsequent months.

**FIGURE 1: AVERAGE MONTHLY HEALTHCARE SPENDING BEFORE AND AFTER DIAGNOSIS, BY CANCER TYPE (2011-2014)[a]**




To put these figures in perspective, the average monthly healthcare spending for people in our data diagnosed with type 2 diabetes was about $1,600 in 2014.[19] Pre-diagnosis, cancer patients spent, on average, less than diabetes patients. The post-diagnosis monthly healthcare spending for the three cancers studied stabilized near or above the diabetes patient level after several months. This finding suggests that, for survivors, a diagnosis of cancer, like the diagnosis of a chronic condition, results in persistent healthcare spending.

## Total Healthcare Spending by Service Category

We analyzed the components of healthcare spending for cancer patients in Figures 2a-2c. The population of surviving cancer patients received care and access to an array of services in the four years after diagnosis:

- Hospital inpatient,
- Radiation therapy (including related outpatient and professional services),
- Chemotherapy, chemotherapy administration, and related drugs (including related outpatient and professional services),
- Other, non-chemotherapy, non-supportive drugs,
- Facility services other than inpatient (excluding professional, chemotherapy and radiation therapy), and
- Other professional services.

Please note that drug costs in this report capture both the cost of the drug and associated administration costs. A description of the specific services included in these categories is provided in the Appendix.

With some variation over time and across cancer types, care for the cancer population involves the six categories of services analyzed. The bars in Figures 2a-2c indicate that some patients had significant use of facility services in the year preceding the cancer diagnosis. For both colorectal and lung cancers, total spending on hospital inpatient increased as a percentage of total immediately following diagnosis. In all three cancers, the chemotherapy share of total spending increased rapidly in the first few months after diagnosis and, with the exception of breast cancer, continued at a fairly consistent level of around 20% of spending in subsequent years. Radiation therapy represented a small share of total spending except for breast cancer patients in the year following diagnosis.

As depicted by the line graph in each of the charts below, total healthcare spending on a per patient basis spikes in the month of diagnosis (month 0) for lung and colorectal cancer or the month following diagnosis (month 1) for breast cancer, and then steadily declines for months until leveling off after the first year. The observed increase before diagnosis is consistent with medical services leading to diagnosis.

The population of surviving cancer patients received care from an array of services in the four years after diagnosis.

**FIGURE 2A: DISTRIBUTION AND MAGNITUDE OF MONTHLY TOTAL HEALTHCARE SPENDING BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH LUNG CANCER (2011-2014)**

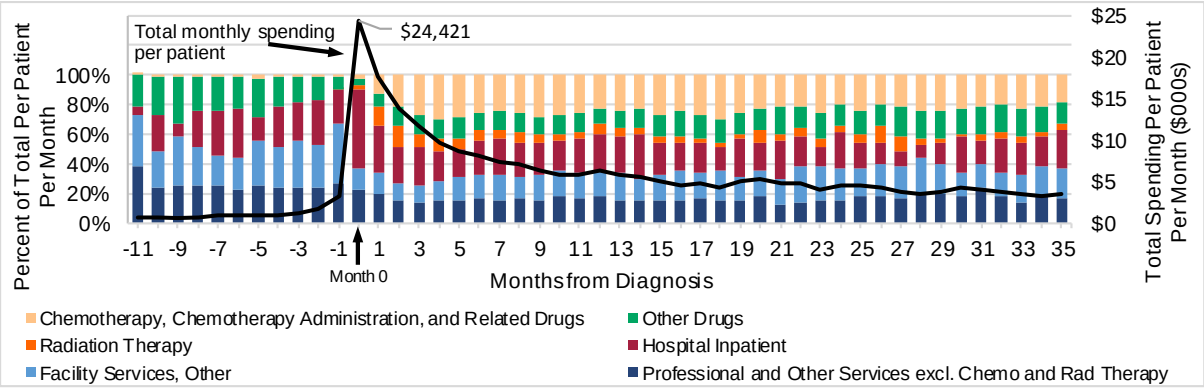



**FIGURE 2B: DISTRIBUTION AND MAGNITUDE OF MONTHLY TOTAL HEALTHCARE SPENDING BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH COLORECTAL CANCER (2011-2014)**

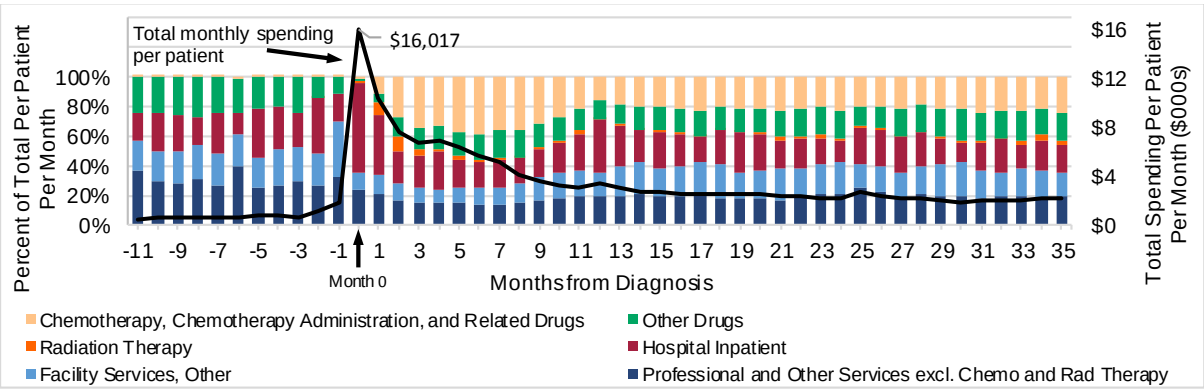
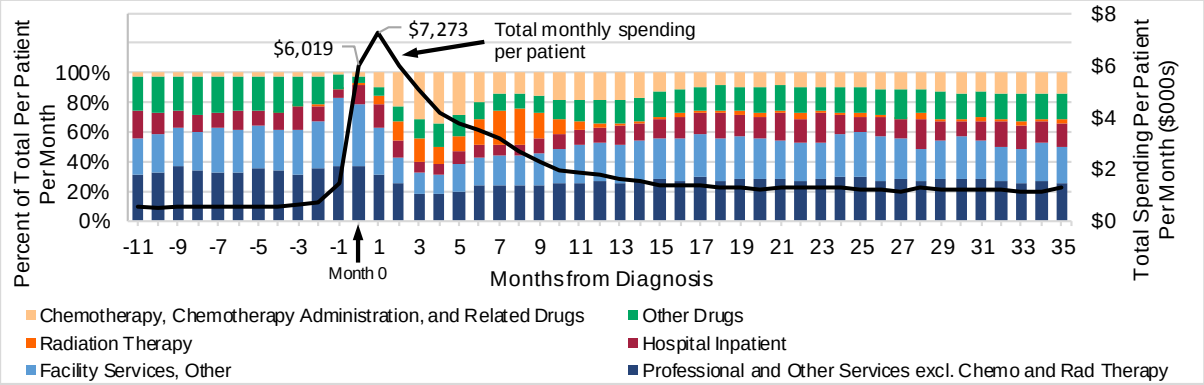


**FIGURE 2C: DISTRIBUTION AND MAGNITUDE OF MONTHLY TOTAL HEALTHCARE SPENDING BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH BREAST CANCER (2011-2014)**




Lung cancer and colorectal cancer patients had significant use of hospital inpatient services soon after diagnosis, which suggests that many patients underwent inpatient surgery in months 0 or 1. By contrast, breast cancer patients had less inpatient spending in months 0 and 1 and lower overall spending. The average monthly total healthcare spending started to drop two to three months after diagnosis. The mix of costs then became more consistently distributed across various service categories, which may reflect the varying approaches used to treat individual survivors. For example, by the time breast cancer patients reach the second month after diagnosis, the balance of services have shifted to chemotherapy and radiation therapy.

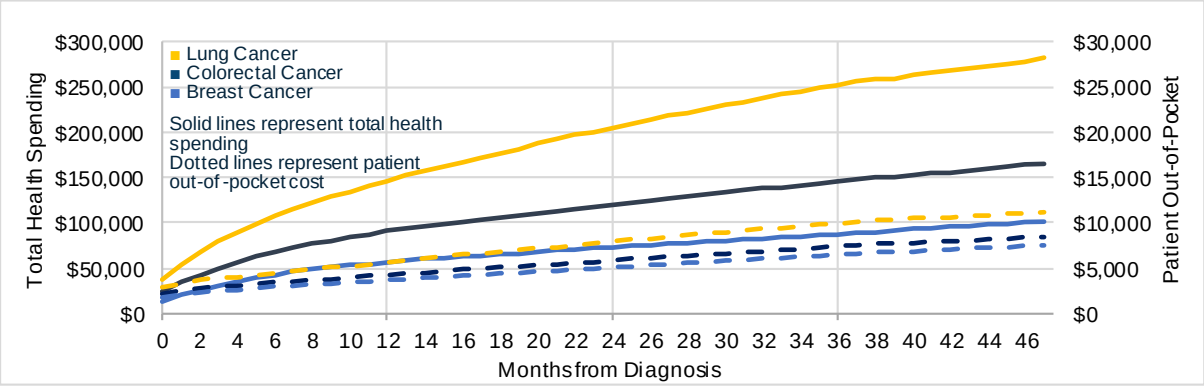
The pattern of spending by category shown in Figures 2a-2c illustrates an "aggregate" patient journey for these cancers—individual patients may not follow these patterns.

## Cumulative Total Health Spending and OOP Cost

Figure 3 presents a cumulative view of total healthcare spending for cancer patients. Over the 47-month period following diagnosis, patients who we could track had average cumulative total healthcare costs of $101,000 for breast cancer, $165,000 for colorectal cancer, and $282,000 for lung cancer. The cumulative figures by month since diagnosis are represented in the left axis using solid lines. Patient OOP costs are shown as dashed lines using the right axis. Relative to total average spending of $101,000 to $282,000 for the 4 year period, the patient OOP of $7,500 to $11,000 suggests that ESI provides substantial protection to many patients.

We note that patient contributions to premium would be in addition to the patient OOP costs. Premium contributions averaged approximately $1,100 per employee per year for single coverage, and over $5,000 for family coverage in 2016.[20] Patients may face other costs not reflected in these data such as travel expenses and loss of income.

**FIGURE 3: AVERAGE CUMULATIVE TOTAL HEALTHCARE SPENDING AND PATIENT OOP COSTS AFTER DIAGNOSIS, BY CANCER TYPE (2011-2014)**



| MONTHS FROM DIAGNOSIS | 0 | 5 | 11 | 17 | 23 | 29 | 35 | 41 | 47 |
|---|---|---|---|---|---|---|---|---|---|
| **CUMULATIVE TOTAL HEALTH SPENDING** | | | | | | | | | |
| LUNG CANCER | $37,621 | $99,062 | $139,958 | $172,213 | $200,580 | $225,270 | $248,163 | $265,725 | $282,147 |
| COLORECTAL CANCER | $24,555 | $62,355 | $87,316 | $103,993 | $118,372 | $131,762 | $143,722 | $154,450 | $165,080 |
| BREAST CANCER | $13,323 | $39,647 | $55,084 | $64,297 | $71,960 | $79,339 | $86,646 | $94,186 | $101,401 |
| **CUMULATIVE PATIENT OUT-OF-POCKET COST** | | | | | | | | | |
| LUNG CANCER | $2,918 | $4,299 | $5,489 | $6,648 | $7,747 | $8,848 | $9,794 | $10,588 | $11,180 |
| COLORECTAL CANCER | $2,180 | $3,273 | $4,113 | $4,973 | $5,744 | $6,534 | $7,274 | $7,938 | $8,442 |
| BREAST CANCER | $1,795 | $2,825 | $3,588 | $4,329 | $5,011 | $5,741 | $6,400 | $7,017 | $7,531 |

The table below Figure 3 presents the cumulative total healthcare spending and cumulative OOP costs at different times after diagnosis. The increase in cumulative spending and OOP costs slowed over time. For example, the average total spend per every 6 months was approximately $50,000 for the first two years following a lung cancer diagnosis (months 0 to 23), and then dropped to about $20,000 for subsequent six month periods.

## Cumulative Healthcare Spending by Service Category

Figures 4a-4c show the pattern of cumulative spending by category. In each of the charts below, the cumulative spending shows a stabilization of cost by service category after the first six to nine months after diagnosis. While all cancers stabilize during this time period, the percentages for each cancer differ with breast cancer patients spending a higher proportion of their total amount on non-inpatient facility services and lung and colorectal cancer patients spending a higher proportion of the total on inpatient services.

**FIGURE 4A: DISTRIBUTION OF CUMULATIVE TOTAL HEALTHCARE SPENDING BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH LUNG CANCER (2011-2014)**

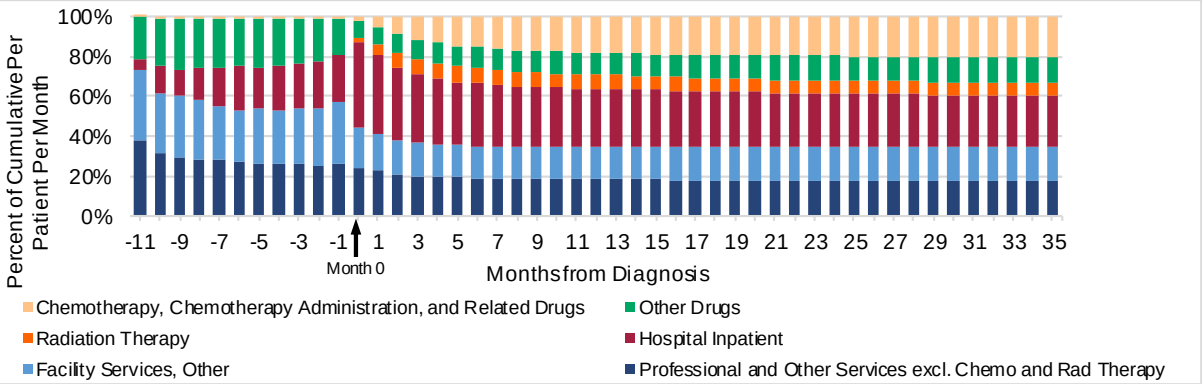


**FIGURE 4B: DISTRIBUTION OF CUMULATIVE TOTAL HEALTHCARE SPENDING BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH COLORECTAL CANCER (2011-2014)**

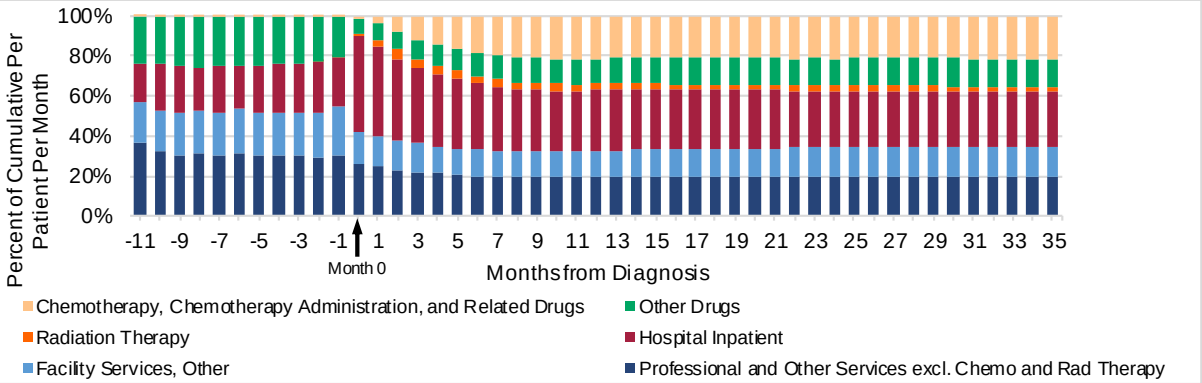
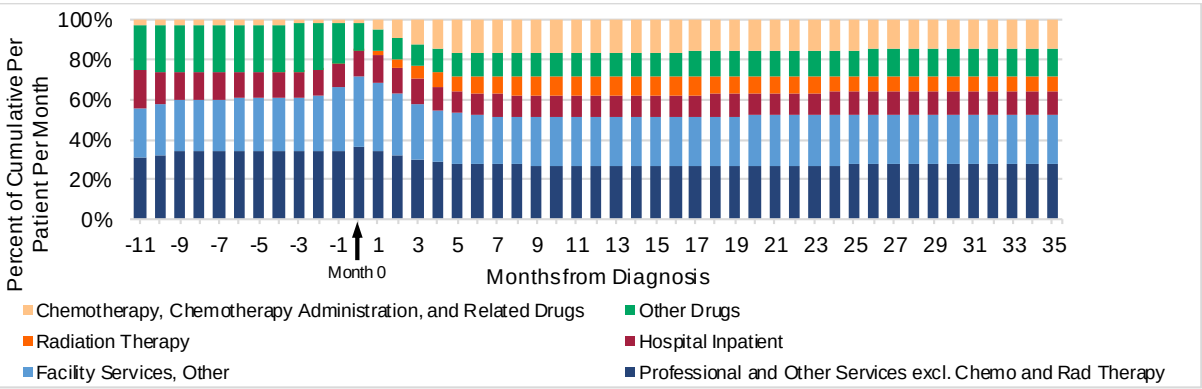



**FIGURE 4C: DISTRIBUTION OF CUMULATIVE TOTAL HEALTHCARE SPENDING BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH BREAST CANCER (2011-2014)**




## OUT-OF-POCKET COSTS OF CANCER PATIENTS

OOP limits offer patients important financial protections. Without such limits, what seem to be low cost-sharing amounts, such as 10%, could generate large patient liabilities when total healthcare spending reaches the six figure levels observed for the three cancers. In 2014, provisions of the Affordable Care Act (ACA) began requiring OOP limits for most ESI.† However, even before the ACA, most ESI offered OOP limits that were below the ACA requirements, and our data reflects OOP limits that are often at or below ACA requirements. The percentage of workers with ESI who either did not have an OOP limit or had an OOP limit above the ACA requirement was 14% in 2013 and 7% in 2014.[21]

The patients in this study are covered by ESI which provides relatively comprehensive coverage, with OOP maximums typically set at levels well below those required by the ACA.

### The Cyclical Nature of Patient Out-of-Pocket Costs

On a population basis, patient OOP costs followed a cyclical pattern, marked by the calendar-year nature of most ESI benefit plans. In 2011, the year of diagnosis, OOP costs were highest in the first two months following diagnosis (months 0 and 1). In the following years, OOP costs showed an annual pattern where monthly OOP costs peaked each January, as many patients faced calendar-year deductibles that must be met before insurance covers many benefits. After the first year, the

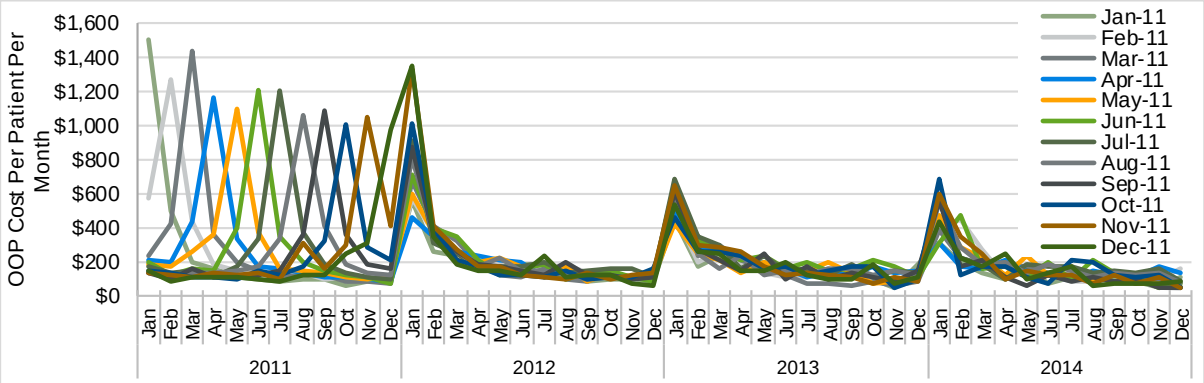
† Grandfathered health plans (those in existence as of 3/23/10) were exempt from these provisions.

month-to-month patient cost-sharing fell into this pattern regardless of the month of diagnosis. Figure 5 shows the OOP costs for the three cancers, which were quite similar in seasonal pattern.

The many spikes evident in 2011 in Figure 5 reflect the dramatic OOP cost increases experienced by members according to their month of diagnosis. However, after the year of diagnosis, all patients in this study incurred OOP costs with a peak in January. The fall-off after January each year means that, as the year progresses, more patients have met their deductible or have reached their OOP limit.

OOP costs per patient showed a strong seasonal effect. OOP costs peaked each January when many patients faced new calendar-year deductibles.

**FIGURE 5: AVERAGE PATIENT OUT-OF-POCKET COSTS IN THE BENEFIT YEAR, BY MONTH OF DIAGNOSIS – LUNG CANCER (2011-2014)**



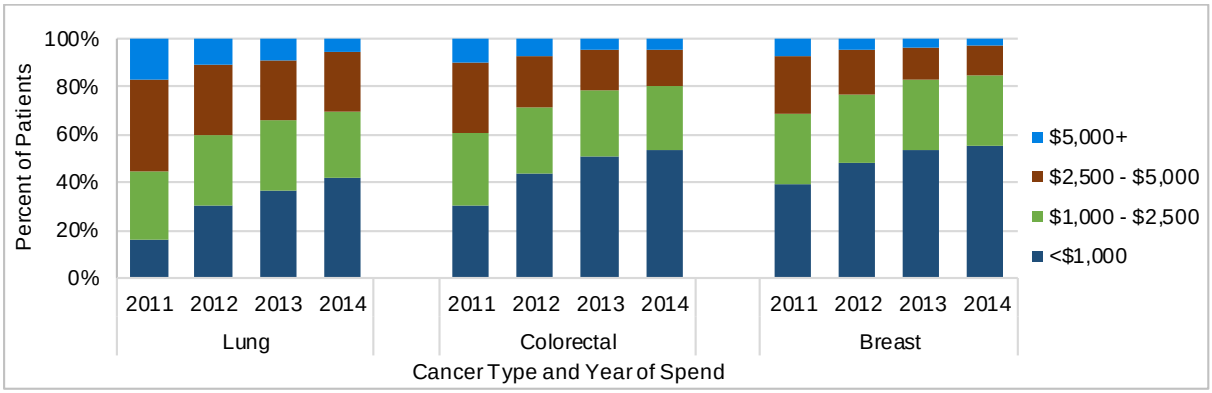

These patterns suggest an opportunity to better prepare patients for the significant financial strain they are about to incur for coverage-related OOP costs, in addition to non-care costs like transportation and loss of wages. The charts suggest the value of concentrating financial counseling and assistance resources around the time of initial diagnosis and also annually before the beginning of the calendar year. It may also be valuable to patients to develop benefits or financial instruments that allow costs to be spread more evenly throughout the year.

## Portion of Patients Attaining Different Levels of Out-of-Pocket Costs

The OOP average varies by cancer and, importantly, varies from patient to patient due to specific insurance coverage and treatment. Figure 6 illustrates the variability of cancer patient OOP costs in our study by year and cancer type. Depending on the cancer type, between a third and half of the patients had annual OOP costs in excess of $2,500 in the year of diagnosis. For about 10% to 20% of patients, OOP costs were in excess of $5,000 in the first year (year of diagnosis). In subsequent years, approximately half to two thirds of the surviving patients incurred over $1,000 in OOP costs, with about 20% to 40% bearing OOP costs above $2,500. Depending on the patient's income, these average OOP costs could become a significant burden.

Patient OOP costs vary by cancer and, importantly, vary from patient to patient due to specific insurance coverage and treatment.

**FIGURE 6: PATIENT DISTRIBUTION BY ANNUAL PATIENT OUT-OF-POCKET COST (2011-2014)**




## Patient Out-of-Pocket by Service Category

Figures 7a-7c present the components of OOP costs for cancer patients by month relative to their month of diagnosis. The bar graphs show that OOP costs are largely for physician and non-inpatient facility services, and, to a lesser extent, other drugs. OOP costs related to chemotherapy account for a small portion of the total patient OOP costs, except for the few months following diagnosis. It is worth noting that the line graph that represents the patient's per month OOP cost clearly shows a big spike for lung cancer and colorectal cancer around the time of diagnosis, likely associated with surgery.

**FIGURE 7A: DISTRIBUTION AND MAGNITUDE OF MONTHLY OOP COSTS BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH LUNG CANCER (2011-2014)**

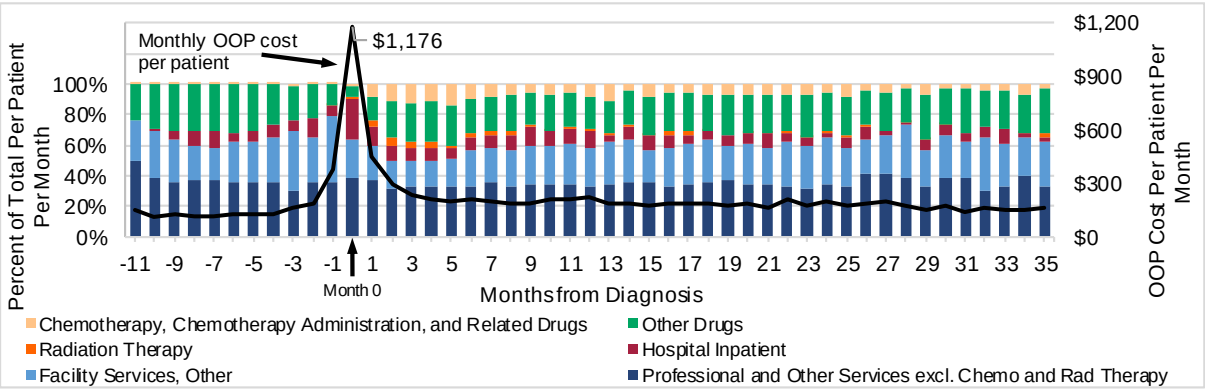



**FIGURE 7B: DISTRIBUTION AND MAGNITUDE OF MONTHLY OOP COSTS BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH COLORECTAL CANCER (2011-2014)**

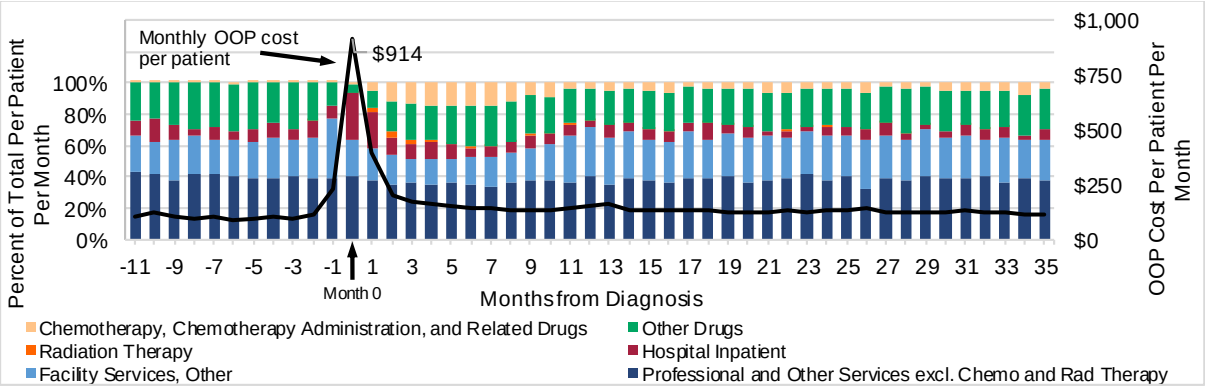
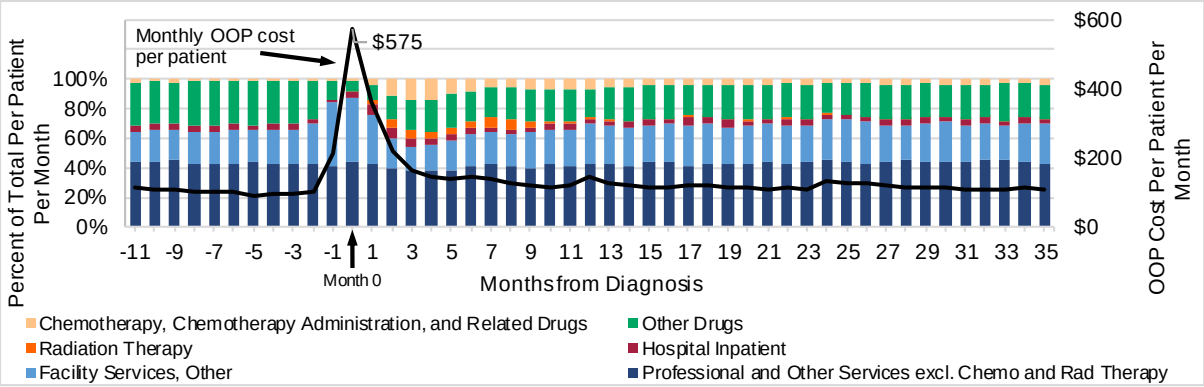


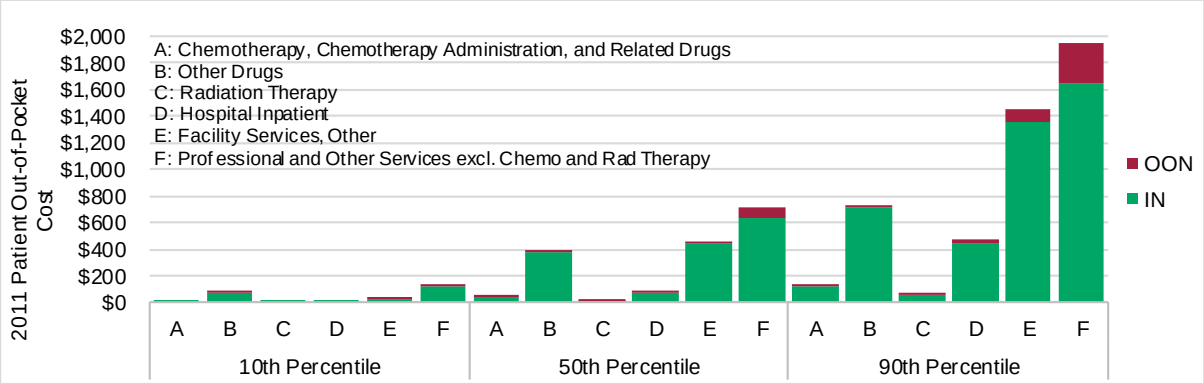
**FIGURE 7C: DISTRIBUTION AND MAGNITUDE OF MONTHLY OOP COSTS BY SERVICE CATEGORY BEFORE AND AFTER DIAGNOSIS, – PATIENTS DIAGNOSED WITH BREAST CANCER (2011-2014)**




## Out-of-Network Utilization and Cost Sharing

OOP costs in the year of diagnosis came mostly from professional and non-inpatient facility services. Figure 8 shows the level of OOP costs by percentile for all study cancers combined. In general, patient cost-sharing is higher for out-of-network services than in-network. Not surprisingly, cancer patients in the highest decile of OOP spending also incurred the highest portion of OOP costs for out-of-network providers; conversely, patients in the lowest decile incurred the lowest portion of OOP costs for out-of-network providers.

**FIGURE 8: OUT-OF-POCKET COSTS BY SERVICE CATEGORY, FOR SELECTED PERCENTILES – ALL CANCER PATIENTS (2011)**

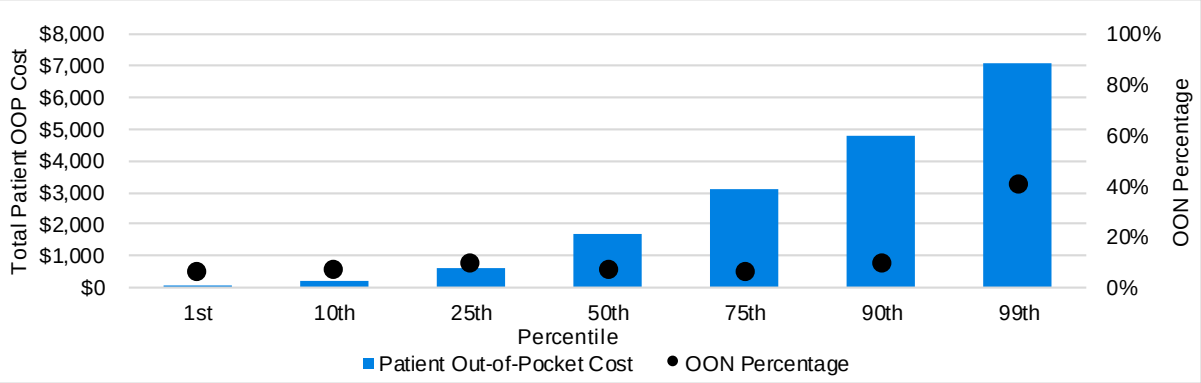



A patient's decision to use an OON provider selection may be intentional or accidental. Reasons patients may incur OON costs include patient preference for a particular provider or specialty care center that may be out of network, the lack of network providers with appropriate specialists, and the lack of awareness or transparency about which providers are in the patient's plan network. Common scenarios for accidental use of OON providers are emergency care or care from an OON provider working at an in-network hospital (e.g., radiologist, assistant surgeon, anesthesiologist).[22] [23]

Figure 9 suggests that there might be significant financial consequences to the patient going out of network, which could be exacerbated if health plans remove popular cancer providers from their networks. Figure 9 also provides information on the relationship between the OON percentage (right vertical axis--relative to total spending) and total patient cost-sharing (left vertical axis). While most patients in our study reported under 10% of all OOP cost in the year of diagnosis is spent on out-of-network providers, those in the highest percentile of OOP spending incurred as much as 40% of those costs out-of-network.

While most patients in our study reported under 10% of all OOP cost in the year of diagnosis is spent on out-of-network providers, those in the highest percentile of OOP spending incurred as much as 40% of those costs out-of-network.

**FIGURE 9: TOTAL PATIENT OUT-OF-POCKET COST AND OUT-OF-NETWORK PERCENTAGE (2011)**



## Conclusions and Limitations

This report presents, for the first time, longitudinal information about real world healthcare spending and patient OOP costs for cancer care. For three major cancers, lung, colorectal and breast, we followed patients covered by ESI for up to 4 years after their initial cancer diagnosis. We captured spending and cost-sharing for the full variety of services these cancer patients received.

With US spending on healthcare approaching 20% of gross domestic product, the cost of healthcare continues to face scrutiny. As spending on health benefits increases, many ESI programs have also increased patient cost-sharing and premium contributions. Significant patient protection for many patients comes from OOP limits in benefit plans. While the ACA mandated OOP limits, most employee benefit plans already provided limits that were below the ACA mandate. However, even with these limits, some individuals will face substantial OOP costs for care in the form of deductibles, coinsurance and copays. Higher spending on health benefits combined with an uncertain economy are likely to cause some employers to further increase patient cost-sharing and premium contributions.

Many surviving cancer patients face a highly seasonal pattern of peaks and ebbs in OOP costs. Some patients, depending on their benefit plan design and spending will reach the ACA's out-of-pocket limit of $7,150 in 2017; this cost-sharing is in the context of median family income that was about $55,775 in 2015. Patient costs can go even higher if the patient obtains out-of-network care, which may not be covered by an out-of-pocket limit. Patients have additional financial burdens not associated with cost-sharing, such as premium contributions and lost income from lost work-time, but we did not attempt to present those.

Information that might be valuable to cancer patients and their families include transparency about out-of-pocket costs and OON status before treatment is rendered and help with financial planning for cost-sharing in future years. Ways to smooth or finance on favorable terms the highly seasonal pattern of out-of-pocket costs may also be beneficial. An increase or elimination of out-of-pocket limits by some ESI plans would exacerbate the challenge of cost-sharing for cancer patients covered by these plans. As federal and state policy makers revisit ACA protections such as the Essential Health Benefit definitions and cost sharing limits, the findings of this report can serve to inform discussions about coverage adequacy and financial protections for people with cancer.

This report does point to the need for additional research. We did not split the ESI population between those covered by low cost-sharing and high cost-sharing plans (such as high-deductible plans). Such a split would likely show much higher cost-sharing for patients in high cost-sharing plans. In addition, research is needed on the migration of cancer patients among available choices of benefit plans; given a choice of options, cancer patients may migrate toward lower cost-sharing options (if available) during annual open enrollment periods. The reasons for use of OON services has been explored in the literature,[24] but further quantification of OON use by cancer patients would be useful. Additional financial burdens would emerge from balance billing for OON providers, and we did not quantify these amounts. While we identified patient cost-sharing, we could not tell whether these amounts were actually paid. It is possible that cost sharing (or balancing billing amounts) were uncollected and became bad debt for the providers, and may have contributed to patient bankruptcy. Such information would be helpful as policymakers at both the state and federal level consider patient protection rules.

As with any similar study, data and resource limitations may have affected our results, and we list the following cautions about interpreting our results:

- We report population averages for the 2010-2014 commercial population. Individual patients may have very different patterns from the population averages. Changes in treatment or technology occurring after our observation period could mean the relationships we observed will be different in the future
- We observed patients only while they were in the database, and we did not attempt to identify deaths. It is possible that people exited the databases in ways that biased our results.
- Regional and local care and spending vary significantly, so particular healthcare systems may exhibit patterns different than the national averages we report.
- Our database reflects the commercially-insured population. We would expect that other populations with other benefit structures, such as Medicare, could show different patterns. For

example, Medicare does not currently have OOP caps either for medical or pharmacy benefits, although the deductible structure for hospital inpatient care offers significant patient protection as do caps in Medicare Advantage plans.

# Sources and Methodology

## DATA

### Truven MarketScan® Commercial Claims Databases

MarketScan includes private sector health benefits claims and enrollment data from approximately 100 payers. The dataset contains more than 35 million commercially insured lives. The dataset consists of person-specific clinical utilization, expenditures and enrollment across inpatient, outpatient, prescription drug, and carve-out services from a selection of large employers, health plans, and government and public organizations. The MarketScan databases link paid claims and encounter data to detailed patient demographic information across sites and types of providers over time. We used years 2010-2014 for this analysis.

## METHODOLOGY

### Identification of study population

We identified patients with an initial cancer diagnosis in 2011. The date of service for the earliest identifying cancer claim in 2011 was designated the patient's DIAGNOSIS DATE. Cancer patients were excluded from the study if they met any of the following conditions:

- Missing date of birth or gender.
- Not an active employee (or a dependent of one) at time of diagnosis.
- Not 18-64 years of age at time of diagnosis.
- Enrolled in a capitated plan at any point.
- Did not have continuous medical and pharmacy coverage from date of diagnosis through departure from data set.
- Did not have an additional month of enrollment after date of diagnosis.
- Did not have continuous medical coverage for the 12 months prior to the diagnosis date.
- Reported cancer diagnosis, chemotherapy, or radiation treatment in lookback period.

Cancer patients were identified as individuals with cancer ICD-9 codes in any position on qualified claims, which are described in the table below. Patients were required to have a cancer ICD-9 code on one inpatient, or one observation, or two or more non-acute inpatient, outpatient, emergency department, or evaluation and management services that occur within 90 days of each other, and where the first of the two services (but not necessarily both) was incurred in 2011. Qualified claims were identified by the Current Procedural Terminology (CPT) or Revenue codes below:

| CLAIM TYPE | CPT CODES | REVENUE CODES |
|---|---|---|
| OUTPATIENT | 99201-99205, 99211-99215, 99241-99245, 99341-99345, 99347-99350, 99384-99387, 99394-99397, 99401-99404, 99411, 99412, 99420, 99429, 99455, 99456 | 051X, 0520-0523, 0526-0529, 057X-059X, 082X-085X, 088X, 0982, 0983 |
| NON-ACUTE INPATIENT | 99304-99310, 99315, 99316, 99318, 99324-99328, 99334-99337 | 0118, 0128, 0138, 0148, 0158, 019X, 0524, 0525, 055X, 066X |
| ACUTE INPATIENT | 99221-99223, 99231-99233, 99238, 99239, 99251, 99255, 99291 | 010X, 0110-0114, 0119, 0120-0124, 0129, 0130-0134, 0139, 0140-0144, 0149, 0150-0154, 0159, 016X, 020X, 021X, 072X, 080X, 0987 |
| OBSERVATION | 99217-99220, 99224-99226 | |
| EMERGENCY DEPARTMENT | 99281-99285 | 0450-0452, 0456, 0459, 0981 |

List of Cancer diagnosis codes for Cancer patient identification:

| DESCRIPTOR | ICD-9 CODES |
|---|---|
| PRIMARY MALIGNANT NEOPLASMS, NOT LYMPHATIC OR HEMATOPOIETIC | 140.XX-172.XX, 174.XX-195.XX |
| SECONDARY MALIGNANT NEOPLASMS (I.E. METASTATIC) | 196.XX-198.XX |
| MALIGNANT NEOPLASMS, UNKNOWN SITE | 199.00 |
| LEUKEMIAS AND LYMPHOMAS | 200.XX-208.XX |
| NEUROENDOCRINE TUMORS | 209.0X-209.3X |
| CARCINOMA IN SITU | 230.XX-234.XX |

Patients who reported any cancer diagnosis, physician-administered chemotherapy, or radiation therapy treatment in the 12 months preceding the date of diagnosis were removed from the analysis. Codes used to identify radiation therapy and physician-administered chemotherapy can be found in the Appendix.

Patients identified as having lung, colorectal, or breast cancer in 2011 are included in the study. Males with breast cancer were excluded. Some patients were identified as having multiple cancers. These patients were assigned according to the following hierarchy:

| CANCER | ICD-9 CODES |
|---|---|
| I. LUNG | 162.XX |
| II. PANCREATIC (EXCLUDED) | 157.XX |
| III. BLOOD (EXCLUDED) | 202.4X, 203.1X, 204.XX-208.XX |
| IV. NON-HODGKIN'S LYMPHOMA (EXCLUDED) | 200.XX, 202.0X-202.2X, 202.7X-202.8X |
| V. COLORECTAL | 153.XX, 154.0, 154.1 |
| VI. BREAST | 174.XX, 233.0 |

Patients were followed from 2010 through 2014 or until their departure from the data, whichever occurred first. Patients were followed for months of coverage under a COBRA or disabled status reported under the same membership ID. The data does not include a reason for disenrollment; patients could leave because of death, loss of subscriber's employment, change of plan (including entering Medicare), turning age 65, or long-term disability.

The table below details the study population identified by cancer and their annual population rate of survival-in-database for each of the three years of the study.

| | POPULATION SIZE (% OF PATIENTS) | | |
|---|---|---|---|
| | LUNG CANCER | COLORECTAL CANCER | BREAST CANCER |
| STUDY POPULATION (BEGINNING OF YEAR) | 3,425 (100%) | 4,680 (100%) | 26,755 (100%) |
| END OF YEAR 1 | 1,994 (57%) | 4,534 (77%) | 21,587 (81%) |
| END OF YEAR 2 | 996 (28%) | 2,730 (46%) | 14,193 (53%) |
| END OF YEAR 3 | 625 (18%) | 1,872 (32%) | 10,029 (37%) |

### Accounting for changes in mandated benefits

While many patients in the study were protected by OOP maximum features embedded in their insurance, for 2011-2013, we capped annual OOP costs at a maximum comparable to that set by the Affordable Care Act for 2014, when the OOP maximum first became mandatory.

# Appendix A: Service Category Descriptions

## Chemotherapy, Chemotherapy Administration, and Related Drugs

- Pharmacy-based oral chemotherapy prescriptions
- Physician-administered chemotherapy drugs
- Hematopoietic agents
- Chemotherapy adjuncts
- Anti-emetics
- Physician services associated with the delivery of the above drugs

## Other Drugs

- All pharmacy- and physician-administered drug claims that are not already classified under Chemotherapy, Chemotherapy Administration, and Related Drugs

## Radiation Therapy

- Radiation therapy treatments billed by facility and professionals. Codes used to identify radiation therapy can be found in Appendix B.

## Professional and Other Services Excluding Chemo and Rad Therapy

- All non-chemotherapy, non-radiation therapy services billed by medical professionals
  - Inpatient professional services
  - Emergency room professional services
  - Surgical and anesthesia services
  - Observation, urgent care, and office visits
  - Professional charges related to radiology (excl. radiation therapy), laboratory, and pathology services
  - Additional claims charged by professionals and Durable Medical Equipment, Prosthetics, Orthotics, and Supplies
  - Other: transportation, vaccinations, vision, dental, unknown

## Hospital Inpatient

- Acute inpatient admissions
  - Medical admissions
  - Surgical (cancer and non-cancer related) admissions
  - Radiation oncology services if administered as part of an inpatient stay
- Non-acute inpatient admissions
  - IRF, LTAC, and SNF stays
  - Radiation oncology services if administered as part of an inpatient stay

## Facility Services, Other Than Inpatient, Excluding Professional, Chemo and Rad Therapy

- All non-chemotherapy, non-radiation therapy related services billed by a hospital outpatient facility or ambulatory surgical center
  - Outpatient surgery (cancer and non-cancer related)
  - Emergency room (visits not resulting in an inpatient admission)
  - Radiology (excl. radiation therapy), lab, and pathology
  - All other facility or miscellaneous fees

# Appendix B: Code Set Detail

## Radiation Therapy

Outpatient facility and professional claims reporting a revenue code of 0333 or CPT codes listed below:

| CPT CODE | DESCRIPTION |
|---|---|
| 77261-77263 | THERAPEUTIC RADIOLOGY: TREATMENT PLANNING |
| 77280-77299 | RADIATION THERAPY SIMULATION |
| 77300-77370 | RADIATION PHYSICS SERVICES |
| 77371-77373 | STEREOTACTIC RADIOSURGERY (SRS) PLANNING AND DELIVERY |
| 77399 | UNLISTED PROCEDURE, MEDICAL RADIATION PHYSICS, DOSIMETRY AND TREATMENT DEVICES, AND SPECIAL SERVICES |
| 77401-77417 | RADIATION TREATMENT |
| 77418 | IMRT DELIVERY |
| 77421 | STEREOSCOPIC IMAGING GUIDANCE |
| 77422-77423 | NEUTRON THERAPY |
| 77427-77499 | RADIATION THERAPY MANAGEMENT |
| 77520-77525 | PROTON THERAPY |
| 77600-77620 | HYPERTHERMIA TREATMENT |
| 77750-77799 | BRACHYTHERAPY |
| 77424-77425 | INTRAOPERATIVE RADIATION TREATMENT DELIVERY |

## Physician-Administered Chemotherapy

| HCPCS | Description | HCPCS | Description | HCPCS | Description |
|---|---|---|---|---|---|
| A9543 | Y90 ibritumomab, rx | J9041 | Bortezomib injection | J9230 | Mechlorethamine hcl inj |
| A9545 | I131 tositumomab, rx | J9042 | Brentuximab vedotin inj | J9245 | Inj melphalan hydrochl 50 MG |
| C9021 | Injection, obinutuzumab, 10 mg | J9043 | Cabazitaxel injection | J9250 | Methotrexate sodium inj |
| C9025 | Injection, ramucirumab, 5 mg | J9045 | Carboplatin injection | J9260 | Methotrexate sodium inj |
| C9027 | Injection, pembrolizumab, 1 mg | J9047 | Injection, carfilzomib, 1 mg | J9261 | Nelarabine injection |
| C9131 | Injection, ado-trastuzumab emtansine, 1 mg | J9050 | Carmustine injection | J9262 | Inj, omacetaxine mep, 0.01mg |
| C9257 | Injection, bevacizumab, 0.25 mg | J9055 | Cetuximab injection | J9263 | Oxaliplatin |
| C9259 | Injection, pralatrexate, 1 mg | J9060 | Cisplatin 10 MG injection | J9264 | Paclitaxel protein bound |
| C9260 | Injection, ofatumumab, 10 mg | J9062 | Cisplatin 50 MG injection | J9265 | Paclitaxel injection |
| C9265 | Injection, romidepsin, 1 mg | J9065 | Inj cladribine per 1 MG | J9266 | Pegaspargase injection |
| C9273 | Sipuleucel-t, minimum of 50 million autologous cd54+ cells activated with pap-gm-csf, including leukapheresis and all other preparatory procedures, per infusion | J9070 | Cyclophosphamide 100 MG inj | J9267 | Injection, paclitaxel, 1 mg |
| C9276 | Injection, cabazitaxel, 1 mg | J9080 | Cyclophosphamide 200 MG inj | J9268 | Pentostatin injection |
| C9280 | Injection, eribulin mesylate, 1 mg | J9090 | Cyclophosphamide 500 MG inj | J9270 | Plicamycin (mithramycin) inj |
| C9284 | Injection, ipilimumab, 1 mg | J9091 | Cyclophosphamide 1.0 grm inj | J9271 | Injection, pembrolizumab, 1 mg |
| C9287 | Inj, brentuximab vedotin | J9092 | Cyclophosphamide 2.0 grm inj | J9280 | Mitomycin injection |
| C9289 | Inj, erwinia chrysanthemi | J9093 | Cyclophosphamide lyophilized | J9290 | Mitomycin 20 MG inj |
| C9292 | Injection, pertuzumab, 10 mg | J9094 | Cyclophosphamide lyophilized | J9291 | Mitomycin 40 MG inj |
| C9295 | Injection, carfilzomib, 1 mg | J9095 | Cyclophosphamide lyophilized | J9293 | Mitoxantrone hydrochl / 5 MG |

| | | | | | |
|---|---|---|---|---|---|
| C9296 | Injection, ziv-aflibercept, 1 mg | J9096 | Cyclophosphamide lyophilized | J9299 | Injection, nivolumab, 1 mg |
| C9297 | Omacetaxine mepesuccinate | J9097 | Cyclophosphamide lyophilized | J9300 | Gemtuzumab ozogamicin inj |
| C9442 | Injection, belinostat, 10 mg | J9098 | Cytarabine liposome inj | J9301 | Injection, obinutuzumab, 10 mg |
| C9449 | Injection, blinatumomab, 1 mcg | J9100 | Cytarabine hcl 100 MG inj | J9302 | Ofatumumab injection |
| C9453 | Injection, nivolumab, 1 mg | J9110 | Cytarabine hcl 500 MG inj | J9303 | Panitumumab injection |
| C9455 | Injection, siltuximab, 10 mg | J9120 | Dactinomycin injection | J9305 | Pemetrexed injection |
| J0202 | Injection, alemtuzumab | J9130 | Dacarbazine 100 mg inj | J9306 | Injection, pertuzumab, 1 mg |
| J0894 | Decitabine injection | J9140 | Dacarbazine 200 MG inj | J9307 | Pralatrexate injection |
| J9000 | Doxorubicin hcl injection | J9150 | Daunorubicin injection | J9308 | Injection, ramucirumab, 5 mg |
| J9001 | Doxorubicin hcl liposome inj | J9151 | Daunorubicin citrate inj | J9310 | Rituximab injection |
| J9002 | Doxil injection | J9155 | Degarelix injection | J9315 | Romidepsin injection |
| J9010 | Alemtuzumab injection | J9160 | Denileukin diftitox inj | J9320 | Streptozocin injection |
| J9015 | Aldesleukin injection | J9165 | Diethylstilbestrol injection | J9328 | Temozolomide injection |
| J9017 | Arsenic trioxide injection | J9170 | Docetaxel injection | J9330 | Temsirolimus injection |
| J9019 | Erwinaze injection | J9171 | Docetaxel injection | J9340 | Thiotepa injection |
| J9020 | Asparaginase, NOS | J9178 | Inj, epirubicin hcl, 2 mg | J9350 | Topotecan injection |
| J9025 | Azacitidine injection | J9179 | Eribulin mesylate injection | J9351 | Topotecan injection |
| J9027 | Clofarabine injection | J9181 | Etoposide injection | J9354 | Inj, ado-trastuzumab emt 1mg |
| J9031 | Bcg live intravesical vac | J9185 | Fludarabine phosphate inj | J9355 | Trastuzumab injection |
| J9032 | Injection, belinostat, 10 mg | J9190 | Fluorouracil injection | J9357 | Valrubicin injection |
| J9033 | Bendamustine injection | J9200 | Floxuridine injection | J9360 | Vinblastine sulfate inj |
| J9035 | Bevacizumab injection | J9201 | Gemcitabine hcl injection | J9370 | Vincristine sulfate 1 MG inj |
| J9039 | Injection, blinatumomab, 1 microgram | J9202 | Goserelin acetate implant | J9371 | Inj, vincristine sul lip 1mg |
| J9040 | Bleomycin sulfate injection | J9206 | Irinotecan injection | J9375 | Vincristine sulfate 2 MG inj |
| J9041 | Bortezomib injection | J9207 | Ixabepilone injection | J9380 | Vincristine sulfate 5 MG inj |
| J9042 | Brentuximab vedotin inj | J9208 | Ifosfamide injection | J9390 | Vinorelbine tartrate inj |
| J9043 | Cabazitaxel injection | J9211 | Idarubicin hcl injection | J9395 | Injection, Fulvestrant |
| J9045 | Carboplatin injection | J9212 | Interferon alfacon-1 inj | J9400 | Inj, ziv-aflibercept, 1mg |
| J9047 | Injection, carfilzomib, 1 mg | J9213 | Interferon alfa-2a inj | J9600 | Porfimer sodium injection |
| J9020 | Asparaginase, NOS | J9214 | Interferon alfa-2b inj | J9999 | Chemotherapy drug |
| J9025 | Azacitidine injection | J9215 | Interferon alfa-n3 inj | Q2017 | Teniposide, 50 mg |
| J9027 | Clofarabine injection | J9216 | Interferon gamma 1-b inj | Q2043 | Provenge, 50 million autologous CD54+ cells |
| J9031 | Bcg live intravesical vac | J9217 | Leuprolide acetate suspnsion | Q2048 | Doxil injection |
| J9032 | Injection, belinostat, 10 mg | J9218 | Leuprolide acetate injeciton | Q2049 | Lipodox 10 mg |
| J9033 | Bendamustine injection | J9219 | Leuprolide acetate implant | Q2050 | Doxil 10mg |
| J9035 | Bevacizumab injection | J9225 | Vantas implant | Q9979 | Injection, alemtuzumab |
| J9039 | Injection, blinatumomab, 1 microgram | J9226 | Supprelin LA implant | | |
| J9040 | Bleomycin sulfate injection | J9228 | Ipilimumab injection | | |

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