



ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces

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Executive Summary

In 2014 and 2015, the American Cancer Society Cancer Action Network (ACS CAN) analyzed coverage of cancer drugs in the health insurance marketplaces created by the Affordable Care Act (ACA). We found that high cost-sharing requirements and shortcomings in the transparency of drug formularies imposed significant barriers that could make it difficult for cancer patients to choose and enroll in the plan best suited to their needs. In this updated analysis, which examines 2017 formulary data in Alabama, California, Colorado, Nevada, New Jersey, and Texas, we found coverage transparency has improved since 2015. This is due to the use of integrated prescription drug formulary lookup tools on HealthCare.gov and in some state-run marketplaces. However, significant barriers remain for cancer patients, including:

- Plans continue to place most or all oral chemotherapy medications on the highest cost-sharing tier, creating transparency and cost barriers for patients.
- The two generic oral cancer drugs we studied regularly appeared on the most expensive tier (41 and 62 percent of the time). The effect may be to inappropriately discourage enrollment by cancer patients.
- Coverage and patient cost sharing information for intravenous medications cannot be reliably determined from the overwhelming number of plan formularies we studied.
- Roughly a quarter of the time, cost-sharing structures presented in plan formularies did not match those presented on marketplace websites, because the plan employed a five- or six-tier formulary.

To address these issues, we provide eight recommendations to states and the U.S. Department of Health and Human Services (HHS) to increase transparency of coverage and cost-sharing, ensure adequate access to medically necessary drugs via an exceptions process, make cost-sharing more predictable and affordable for patients, and monitor the marketplaces for evidence of discrimination against persons with high-cost conditions such as cancer. While we recognize the current political discussion could impact the future of the ACA and its health insurance

marketplaces, these policy recommendations transcend the ACA and would be pertinent in any health care system. The marketplace plans analyzed in this report represent plans commonly available in today's individual insurance market. These recommendations also are relevant to other health insurance types and other markets and could be adopted today by many insurance plans and/or employers, regardless of changes in federal legislation and policy. Moreover, we have seen states adopt legislation to implement some of the policy recommendations (for example, the recent Texas law providing disclosure of prescription drugs covered under the medical and prescription drug benefits) and encourage more states to enact patient protections as recommended in this report.

Background

In 2017, an estimated 1.7 million Americans will be diagnosed with cancer, and approximately 15.5 million Americans are cancer survivors.¹ In 2014, \$87.8 billion was spent on direct medical costs for cancer treatment in the United States, over \$12 billion* of which (about 14 percent) was spent on prescription medications.² Prescription drugs remain an important part of many cancer treatment protocols, and these drugs are increasingly targeted to specific molecules involved in the growth or spread of particular cancers; meaning drugs are not necessarily interchangeable, and most of these targeted medications are not yet available in generic form.³

The Affordable Care Act

The ACA increased health insurance coverage by expanding eligibility for Medicaid and by making it easier to access and afford private health insurance in the individual, or non-group, market. The law created marketplaces in each state where individuals can shop for health insurance and access federal financial assistance, in the form of premium and cost-sharing subsidies, to defray the costs of coverage. In mid-2016, about 10.5 million people were enrolled in coverage through the marketplaces,[†] with more expected to have chosen a plan by the end of the fourth enrollment period for plan year 2017.⁴ Large majorities of the currently enrolled report being satisfied with their marketplace coverage and many are using it to obtain care they would not have otherwise received.⁵

The ACA's essential health benefits rules require plans in the individual and small group markets to cover 10 enumerated categories of benefits, including prescription drugs. States help

* Note that the relative standard error for this number of dollars spent on prescribed medications is equal to or greater than 30 percent.

† As of the drafting of this paper, CMS has not released the final enrollment figures for the plan year 2017.

determine what specific benefits fall within these 10 categories by choosing an existing health plan to serve as a benefit benchmark.⁶ When developing their benefits packages, plans in the relevant markets must cover the same number of drugs in each United States Pharmacopeia (USP) category and class as does the state's benchmark plan, but in no event may a plan cover less than one drug per category and class.⁷ Cancer drugs are included in the category of “antineoplastic agents,” for which there are several subclasses.

The prescription drug benchmarks for the 2017 marketplace coverage year were chosen from health plans available in each state in 2014.⁸ Beginning in the 2017 coverage year, HHS is requiring each health plan's Pharmacy and Therapeutics (P&T) committee to review the prescription drug formulary to ensure coverage of a range of drugs across categories and classes to treat all disease states; to ensure the formulary does not discourage enrollment by particular groups; and to ensure access to drugs included in treatment guidelines.⁹ In addition, federal rules require health plans to comply with prescription drug formulary transparency requirements, including that formularies must list all drugs covered on its formulary drug list, be accessible to enrollees and potential enrollees, show tiering and limitations, and clearly indicate the plans to which the formulary applies.¹⁰

Research Focus

Though the ACA's consumer protections have improved coverage in the individual market, researchers and advocates have found that it remains difficult for many consumers to understand and compare plan benefits and have therefore identified coverage transparency as a key area for improvement.¹¹ In addition, because insurers retain significant flexibility to determine prescription drug coverage and the placement of specific drugs on their formulary tiers, concerns have been raised suggesting that some plans may not provide adequate or affordable coverage for certain diseases.¹²

ACS CAN analyzed coverage of cancer drugs for 2014 and 2015 in marketplace plans and found that coverage information—particularly for intravenous medications, and dollar cost-sharing requirements—could be challenging for cancer patients to find when trying to choose the best plan for their needs.¹³ These studies also showed plans tended to place most or all of their covered oral chemotherapy medications on the highest cost-sharing tier; a practice that may impose significant cost barriers for patients and could discourage the use of oral chemotherapy. Research on HIV medication coverage has found some plans place all HIV medications, including generics, on the highest cost-sharing tier, potentially as a way to discourage enrollment by HIV-positive patients.¹⁴ Other researchers have shown similar patterns for other complex

conditions, including cancer.¹⁵ Given concerns that these practices may have the effect of discriminating against cancer patients, and in light of previous reports showing significant variation in prescription drug coverage and formulary transparency, we updated our analyses for the 2017 plan year. This report thus considers the transparency of plan formularies, as well as coverage and cost of cancer drugs in 2017 marketplace plans, with a focus on the following research questions:

- Can consumers easily compare marketplace plans based on their coverage of cancer drugs?
- How often are specific cancer drugs excluded from coverage, and how often are coverage limitations used?
- Can consumers easily compare marketplace plans based on their likely out-of-pocket spending for cancer drugs?

Methods

We examined prescription drug formularies for all silver tier marketplace plans sold in six states: Alabama, California, Colorado, Nevada, New Jersey, and Texas. These states offer a geographically diverse sample and a mix of ACA marketplace models (California, Colorado, and Nevada operate their own marketplaces, while the marketplaces in Alabama, New Jersey, and Texas, are federally run). We also selected these states because of their population size and share of marketplace enrollment (the states accounted for 28 percent of marketplace enrollees as of March 31, 2016¹⁶) and the number of expected cancer diagnoses in 2016.¹⁷ In addition, two of these states, California and Texas, recently enacted legislation related to prescription drug cost-sharing and formulary transparency. ACS CAN also previously investigated coverage of cancer drugs by marketplace plans in California and Texas in 2014 and 2015, allowing us to compare trends in these states over time.¹⁸

We collected data for 22 unique cancer drugs from 33 silver plan formularies in the six study states using formulary links provided by the marketplaces.¹⁹ We assessed prescription drug coverage transparency based on the ease of access to the formulary, measured by whether the marketplace provided a direct hyperlink to the formulary and, if not, the number of clicks it took to reach the formulary from the marketplace-provided link; whether the cost-sharing tiers listed on the formulary matched the cost-sharing tiers presented on the marketplace website; whether formularies were searchable; and whether the information provided allowed a consumer to estimate any out-of-pocket costs.

We assessed cancer drug coverage by examining whether the cancer medications we selected were included on each formulary; their placement on cost-sharing tiers; and any limitations on coverage, such as prior authorization, quantity limits, or step therapy. Our examination focused on coverage of 22 brand-name drugs; however, in addition, we collected coverage data for the generic version of three of these drugs, bringing the total number of drugs for which we present data to 25.

Finally, we determined the applicable cost-sharing provisions to these drugs, including the number of drugs covered on the highest cost-sharing tier; and whether enrollees were required to pay coinsurance—a percentage of the cost of the drug rather than a flat copayment—on the highest cost-sharing tier; and where applicable, the median coinsurance rate or copayment for drugs on the most expensive tier.

The 22 cancer drugs we identified for investigation were drawn from several classes of anti-cancer medications on the USP. Fourteen of the selected drugs are available orally; eight are available exclusively through intravenous administration. A list of these drugs and their route of administration is available in Table 2.

We selected these drugs to provide analysis of coverage for a wide range of cancers, and to investigate a mix of oral and IV drugs and newly approved and older drugs. In general, intravenous drugs are frequently covered under a health plan's medical, rather than prescription drug benefit, meaning they are often unlisted on prescription drug formularies. Therefore, the absence of an intravenous drug on the prescription drug formulary does not necessarily indicate a lack of coverage, but rather that the coverage information is not available to consumers. Overall, 17 of the 22 drugs we investigated this year were the same as in our 2015 analysis.

Results

Marketplace Websites Have Improved Prescription Drug Coverage and Cost Transparency, Though Plan Formularies Often Require Multiple Steps to Access

All marketplaces in the six study states provide links to the prescription drug formularies of their participating plans, though the link locations vary across enrollment platforms. HealthCare.gov, the enrollment website for four of the six states (Alabama, Nevada, New Jersey, and Texas), allows consumers to access formulary links without creating an account as they browse and compare plans through the website's window shopping feature.²⁰ In California, formulary links are available to individuals without an account through a dedicated webpage that provides a

range of information about prescription drug benefits available through the marketplace; however, this page is separate from the website's window shopping experience, which does not include formulary links.²¹ Colorado's marketplace provides website visitors without an account, two ways to browse plans: one provides plan information with formulary links; the other offers consumers an integrated prescription drug search tool.²²

In an improvement since the 2015 formulary transparency analysis, two of the marketplace websites we assessed—Colorado and HealthCare.gov—now provide an integrated prescription drug formulary search tool. Consumers shopping through these websites can input specific prescription drugs and see, during window shopping, whether participating plans cover those medications. (The cost-sharing tier on which the drug has been placed is not indicated.) Enabling consumers to quickly and easily match the medications they are taking with the benefits health plans are offering can significantly help consumers determine which plan is right for them.

Similarly, the marketplaces in each of the six study states provide a tool that allows consumers to estimate the total cost of coverage—premium, minus subsidy, plus out-of-pocket expenses—that they may encounter under each plan option. Though the assumptions used to generate these estimates vary across marketplaces, each is in part based on the consumer's estimate of how much health care they expect to use in the coming year (e.g., low utilization, medium, or high). In the case of California and HealthCare.gov, these consumer usage estimates are defined, in part, by anticipated prescription drug use; however, neither marketplace's estimator examines specific prescription drugs costs.

Fewer than half (48 percent) of the plans we investigated provided a link on the marketplace website that connected consumers directly to that plan's formulary (Table 1). In some instances, the marketplace links directed consumers to a page on the insurer's website with links for a number of different formularies. This arrangement requires consumers to peruse the list for the specific formulary applicable to the insurer's marketplace plans. In a minority of cases (12 percent), the marketplace link was broken or missing. For the majority of insurers that did not provide a direct link or for which the link was broken or missing, it took an average of about 2.9 additional clicks to locate the formulary.

Table 1: Prescription Drug Formulary Transparency, by State

State	Number of formularies reviewed	Percent with direct link	Percent with broken or missing links	Average number of clicks for non-direct or broken links	Percent that are keyword searchable	Percent for which cost-sharing tiers listed on formulary do <u>not</u> match Marketplace website
Alabama	1	100%	0%	N/A	100%	100%
California	11	36%	0%	2.71	100%	9%
Colorado	6*	33%	17%	3	100%	33%
Nevada	3	100%	0%	N/A	100%	0%
New Jersey	2	0%	50%	4	100%	100%
Texas	10	60%	20%	2.5	100%	30%
Total	33	48%	12%	2.88	100%	27%

Source: Author’s analysis of 33 silver plan prescription drug formularies in six states.

* Although seven insurers are participating on the Colorado marketplace in 2017, the online formulary for one of them was not operational at the time of review and is therefore excluded from this analysis.

Notes: Clicks were counted from the link provided by the marketplace; if the link was broken (e.g., a link on a website that no longer works), clicks were counted from the insurer’s home page.

Once consumers find the formulary, it is critical that they be able to search for their prescription drugs and match the coverage tier listed on the formulary with the cost-sharing information provided on the marketplace website or in the plan’s Summary of Benefits and Coverage. All of the 33 formularies we reviewed were searchable. However, over a quarter (27 percent) of the corresponding plans used cost-sharing tiers that differed from the cost-sharing information provided on the marketplace website. The core of the discrepancy was that the marketplace websites displayed plan information through a template that assumes a prescription drug formulary with four cost-sharing tiers, but some plans use a benefit design with a different number of tiers. In three instances—one in California and two in New Jersey—plans used a three-tier design. More frequently, however, cost-sharing information did not align because the plan formulary had more than four tiers.

Though the vast majority of the plan formularies we studied did not include additional cost-sharing information beyond a general description of their tiering structure and an indication of each drug’s tier, a few health plans, mostly in Texas, went further and provided somewhat more detailed information regarding the price a consumer might expect to pay for a covered drug.

The additional information provided by the Texas plans may be the result of recent state legislation that sets new standards for drug formulary transparency.²³ Among the requirements, the Texas law obligates plans to disclose the cost-sharing amount for each covered drug through their formularies, including, as applicable, the dollar amount of a copayment or a dollar cost range for a drug subject to coinsurance. Implementing regulations permit insurers to provide this cost-sharing information via a web-based tool or a direct link which must be included on each page of the formulary itself.²⁴ These disclosures, which must be in place for non-group health plans in Texas beginning January 1, 2017, were not yet apparent in most of the formularies we investigated, during the first months of open enrollment in November and December 2016. However, we observed at least four insurers that were providing some additional cost-sharing data, including BlueCross BlueShield of Texas, which had made available a convenient web-based search tool. (Another insurer, Oscar, offered similar functionality for the then-current—2016—plan year but had not done so for 2017 coverage.)

Most of the Cancer Drugs Analyzed Are Covered by Most Plans

Of the 14 oral cancer drugs we reviewed, all were covered in their generic or brand form by at least 60 percent of plans (Table 2). Seven such drugs were covered by at least 90 percent of plans, while three—Revlimid, Sutent, and Tarceva—were covered by all of the formularies we analyzed. These three drugs had similarly broad coverage among our 2015 study sample.²⁵ However, another drug broadly covered in 2015, Gleevec, was among the oral chemotherapy drugs least likely to be covered in our 2017 sample. Sixty-four percent of plans covered the brand version of the drug, though more plans (79 percent) covered the recently FDA approved generic version (Imatinib Mesylate). Coverage levels across states generally did not vary dramatically. In only one instance was an oral drug on our list available in half or fewer of the plans in a given state. (Gilotrif was covered by three of six formularies in Colorado; coverage of Gleevec did vary widely and was below 50 percent in Colorado and Nevada, but a majority of plans in all six states covered its generic.)

Table 2: Coverage of Cancer Drugs in Marketplace Plan Formularies, Overall and by State

Name (Generic)	Name (Brand)	Oral/IV	Percent of formularies listing the drug as covered						
			Overall	AL	CA	CO	NV	NJ	TX
Ofatumumab	Arzerra	IV	24%	0%	9%	33%	33%	0%	40%
Bevacizumab	Avastin	IV	15%	0%	18%	33%	0%	0%	10%
Elotuzumab	Empliciti	IV	3%	0%	0%	17%	0%	0%	0%
Etoposide/ Etoposide Phosphate	Etopophos/ Toposar	Oral, IV	27%	0%	27%	50%	0%	0%	30%
Etoposide/ Etoposide Phosphate*	----	Oral, IV	97%	100%	91%	100%	100%	100%	100%
Afatinib Dimaleate	Gilotrif	Oral	79%	100%	73%	50%	100%	100%	90%
Imatinib Mesylate	Gleevec	Oral	64%	100%	64%	33%	33%	100%	80%
Imatinib Mesylate*	----	Oral	79%	100%	73%	100%	100%	100%	60%
Trastuzumab	Herceptin	IV	18%	0%	18%	33%	0%	0%	20%
Topotecan hcl	Hycamtin	Oral, IV	82%	100%	64%	83%	100%	100%	90%
Axitinib	Inlyta	Oral	76%	100%	64%	67%	100%	100%	80%
Pembrolizumab	Keytruda	IV	24%	0%	27%	17%	33%	0%	30%
Trametinib	Mekinist	Oral	82%	100%	73%	67%	100%	100%	90%
Nivolumab	Opdivo	IV	9%	0%	9%	17%	0%	0%	10%
Lenalidomide	Revlimid	Oral	100%	100%	100%	100%	100%	100%	100%
Rituximab	Rituxan	IV	64%	0%	82%	67%	67%	0%	60%
Sunitinib Malate	Sutent	Oral	100%	100%	100%	100%	100%	100%	100%
Erlotinib Hydrochloride	Tarceva	Oral	100%	100%	100%	100%	100%	100%	100%
Paclitaxel	Taxol	IV	0%	0%	0%	0%	0%	0%	0%
Paclitaxel*	----	IV	27%	0%	18%	50%	33%	0%	30%

Name (Generic)	Name (Brand)	Oral/IV	Percent of formularies listing the drug as covered						
			Overall	AL	CA	CO	NV	NJ	TX
Lapatinib Ditosylate	Tykerb	Oral	94%	100%	91%	83%	100%	100%	100%
Pazopanib Hydrochloride	Votrient	Oral	94%	100%	100%	67%	100%	100%	100%
Crizotinib	Xalkori	Oral	94%	100%	91%	83%	100%	100%	100%
Vemurafenib	Zelboraf	Oral	88%	100%	82%	83%	100%	100%	90%
Certinib	Zykadia	Oral	70%	100%	55%	67%	100%	100%	70%

Source: Author’s analysis of 33 silver plan prescription drug formularies in six states.

Notes: Except where noted, the table depicts the share of formularies covering the brand version of the drug. Rows denoted with an asterisk (*) provide the equivalent statistic for the generic version. For drugs available in IV form, absence from the formulary does not necessarily mean the drug is not covered by the plan. It could instead mean the drug is covered under the medical benefit. However, most plans do not provide a list of medical benefit drugs.

Coverage of IV Drugs Remains Difficult to Determine

Coverage for intravenously administered chemotherapy drugs remains difficult to determine based on plan formularies. This year’s analysis included eight drugs available exclusively by intravenous administration. Only one of these drugs, Rituxan, was covered on the formulary more than half of the time (64 percent). The remaining seven were covered much less frequently, appearing as part of a plan’s prescription drug benefit only in about a quarter of cases at most: the generic Paclitaxel was covered on 27 percent of formularies, while Arzerra and Keytruda were covered on one fewer formulary (24 percent overall). As we observed in our previous studies, physician-administered IV drugs are often made part of a health plan’s medical benefit, rather than its pharmacy benefit. Most formularies, in turn, do not systematically include such drugs, which makes it hard for patients that receive these medications to choose a health plan appropriate for their needs. Only one issuer among our study group, Rocky Mountain Health Plans, systematically listed drugs covered under its medical benefit on its formulary. Because it does, we know, for example, that it covers the IV drug Empliciti; it is the only plan among the 33 we studied to make clear on its formulary that it covers this newly approved medication.

To test whether a consumer could get information from a prospective health plan about whether a particular drug was covered under the plan’s medical benefit, we called the consumer toll-free lines in each of the states studied in this report. In a majority of the cases, the health plan failed to provide the caller with any information about whether the drugs were covered by the plan or required cost-sharing. The anecdotal data collected is illustrative of the challenges consumers face when trying to ascertain information about their plan’s coverage of drugs under the medical benefit.

Coverage Limits Remain Prevalent, but Their Potential Effect on Patients Is Unclear

As we found in our prior analyses, coverage limits—in particular, prior authorization and quantity limits—were applied frequently to the cancer drugs we studied, and information on the specific nature of those restrictions was often unavailable. Chemotherapy drugs are highly toxic, making prior authorization routine and a commonly understood practice for oncologists. Overall, nearly all of the formularies we reviewed required prior authorization (sometimes called prior review or prior notification) on multiple cancer drugs.

Most formularies also had quantity limits on cancer drugs, but relatively few clarified the specific number of refills or specific dosages that constituted these limits. For toxic drugs like chemotherapy, clinically-appropriate quantity limits likely do not represent a barrier to patients. However, requirements for more frequent refills (and associated cost-sharing) or quantity limits inconsistent with current on-label and off-label oncology practice could pose significant barriers to care. For example, in California and Texas, six local health plans placed quantity limits on several cancer drugs, allowing only two 15-day refills per month during the first three months of treatment.²⁶ No explanation for these limits was provided, and the formularies did not indicate whether copays or coinsurance must be paid for both refills in a given month.

Most of the Cancer Drugs Analyzed Are Placed on the Highest Cost-Sharing Tier and Usually Entail Significant Coinsurance Payments

Most of the oral cancer drugs we studied (12 of 14) were located on the highest cost-sharing tier in more than 80 percent of formularies (Table 3). The two exceptions, both generics, nevertheless carried significant cost-sharing obligations under many plans: Etoposide appeared on the highest tier 41 percent of the time (brand versions of the drug were on the top tier in 44 percent of formularies), while Imatinib Mesylate was on the most expensive tier in 62 percent of formularies (compared to 81 percent, for its brand version, Gleevec). Formularies in Texas were somewhat more likely to place oral cancer drugs on the top tier than were the other study states. Intravenous drugs, when they did appear on the formulary, also typically were placed on the most expensive tier, though with some greater variability than the oral medications.

Table 3: Percent of Formularies Placing Cancer Drugs on the Highest Cost-sharing Tier, Overall and by State

Name (Generic)	Name (Brand)	Oral/IV	Among formularies covering each drug, percent providing coverage on the highest cost-sharing tier						
			Overall	AL	CA	CO	NV	NJ	TX
Ofatumumab	Arzerra	IV	88%	N/A	100%	50%	100%	N/A	100%
Bevacizumab	Avastin	IV	80%	N/A	100%	50%	N/A	N/A	100%
Elotuzumab	Empliciti	IV	0%	N/A	N/A	0%	N/A	N/A	N/A
Etoposide/ Etoposide Phosphate	Etopophos/ Toposar	Oral, IV	44%	N/A	33%	33%	N/A	N/A	67%
Etoposide/ Etoposide Phosphate*	----	Oral, IV	41%	0%	50%	17%	33%	0%	60%
Afatinib Dimaleate	Gilotrif	Oral	81%	0%	75%	67%	100%	50%	100%
Imatinib Mesylate	Gleevec	Oral	81%	100%	57%	50%	100%	100%	100%
Imatinib Mesylate*	----	Oral	62%	0%	63%	50%	67%	0%	100%
Trastuzumab	Herceptin	IV	83%	N/A	100%	50%	N/A	N/A	100%
Topotecan hcl	Hycamtin	Oral, IV	85%	0%	86%	80%	100%	50%	100%
Axitinib	Inlyta	Oral	88%	0%	100%	75%	100%	50%	100%
Pembrolizumab	Keytruda	IV	88%	N/A	100%	0%	100%	N/A	100%
Trametinib	Mekinist	Oral	89%	0%	100%	75%	100%	50%	100%
Nivolumab	Opdivo	IV	67%	N/A	100%	0%	N/A	N/A	100%
Lenalidomide	Revlimid	Oral	85%	0%	82%	83%	100%	50%	100%
Rituximab	Rituxan	IV	62%	N/A	44%	75%	100%	N/A	67%
Sunitinib Malate	Sutent	Oral	91%	0%	100%	83%	100%	50%	100%
Erlotinib Hydrochloride	Tarceva	Oral	91%	0%	100%	83%	100%	50%	100%
Paclitaxel	Taxol	IV	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Name (Generic)	Name (Brand)	Oral/IV	Among formularies covering each drug, percent providing coverage on the highest cost-sharing tier						
			Overall	AL	CA	CO	NV	NJ	TX
Paclitaxel*	----	IV	44%	N/A	0%	33%	100%	N/A	67%
Lapatinib Ditosylate	Tykerb	Oral	87%	0%	90%	80%	100%	50%	100%
Pazopanib Hydrochloride	Votrient	Oral	90%	0%	100%	75%	100%	50%	100%
Crizotinib	Xalkori	Oral	90%	0%	100%	80%	100%	50%	100%
Vemurafenib	Zelboraf	Oral	90%	0%	100%	80%	100%	50%	100%
Certinib	Zykadia	Oral	87%	0%	100%	75%	100%	50%	100%

Source: Author’s analysis of 33 silver plan prescription drug formularies in six states.

Notes: Except where noted, the table depicts the share of formularies covering the brand version of the drug on the highest tier (among formularies covering the brand version as part of its prescription drug benefit). Rows denoted with an asterisk (*) provide the equivalent statistic for the generic version.

As we noted in our 2015 analysis, research suggests that placing all medications for a certain disease, including generics, on the highest cost-sharing tier may be evidence that insurers are attempting to discourage potentially high-cost patients from enrolling, an approach sometimes called “adverse tiering.”²⁷ The placement of all or nearly all cancer drugs on the highest cost-sharing tier, including generics, in many plans appears designed to extract the maximum patient cost-sharing for all cancer drugs rather than to encourage use of cheaper or more effective alternatives. However, unlike HIV, cancer treatment is often highly specialized to the unique genetics and site of tumors, and few generics are available. It is therefore more difficult to determine whether tier placement of particular cancer drugs may amount to discrimination.

Among the silver plan formularies we examined in the six study states, the vast majority required consumers to pay coinsurance for drugs placed on the highest cost-sharing tier (Table 4). For example, 82 percent of silver plan designs in Texas used coinsurance for the top tier, imposing a median coinsurance obligation of 38 percent. And all silver plans in New Jersey charged coinsurance, typically at a rate of 50 percent. Coinsurance is less transparent and predictable than copayments, since the underlying price information patients need in order to calculate the rate is rarely available. (In this regard, Texas’s new formulary transparency legislation may make it easier for consumers to know their coinsurance obligations, so long as insurers are diligent in maintaining the accuracy of their disclosures.) Coinsurance can also be extremely expensive for consumers: for example, coinsurance of 20 percent—a value lower than what we observed in

most plans—charged on a \$5,000-per-month drug would cost a cancer patient \$1,000 for each refill until the out-of-pocket cap is reached. Still, even in the few plans without coinsurance, consumers faced significant out-of-pocket costs: these plans were mostly high deductible health plans or else levied copayments of around \$500.

Table 4: Silver Plan Cost-sharing Designs, by State

State	Number of silver plan formularies investigated	Percent with fewer than 4 tiers	Percent with 4 tiers	Percent with more than 4 tiers	Percent of unique silver plan designs requiring coinsurance on highest tier	Median coinsurance percentage on highest tier (among plans using coinsurance)	Median copayment on highest tier (among plans using copayments)
Alabama	1	0%	0%	100%	100% (2 of 2)	30%	N/A
California	11	9%	91%	0%	100%*	20%	N/A
Colorado**	6	0%	67%	33%	Statewide data not available. See Denver and Grand Junction, below.		
<i>Denver</i>					62% (13 of 21)	40%	\$525
<i>Grand Junction</i>					25% (2 of 8)	37.5%	\$500
Nevada	3	0%	100%	0%	100% (18 of 18)	30%	N/A
New Jersey	2	100%	0%	0%	100% (9 of 9)	50%	N/A
Texas	10	0%	70%	30%	82% (28 of 34)	38%	N/A

Source: Author’s analysis of prescription drug formularies, as well as downloadable cost-sharing data for all silver plans available from HealthCare.gov.

* California requires a standardized silver plan design that uses 20 percent coinsurance, up to \$250 per prescription, for specialty drugs.

** Colorado does not use standardized plan designs or provide a downloadable dataset of cost-sharing designs for all silver plans, so we analyzed all silver plans available in Denver (zip code 80219) and Grand Junction (81501).

Note: For purposes of determining the number of tiers on a given formulary, we counted only those tiers that impose on the enrollee a cost-sharing obligation; tiers designating zero cost-sharing preventive drugs were excluded from the analysis.

Discussion

Since 2015, the marketplace shopping experience has improved for consumers looking for cancer drug coverage information, however challenges remain. For instance, the process of verifying oral medication coverage has gotten easier, thanks to new prescription drug lookup tools available on some marketplace websites, but because these tools are based on the underlying plan formularies, which often do not list physician-administered intravenous

medications, it remains virtually impossible to determine whether plans cover IV drugs. In addition, locating the formularies themselves still can be a circuitous process for many plans. Only about half of the formularies we investigated were available via a direct link from marketplace websites and Covered California continues to provide its formulary links on a standalone webpage which, though informative, is detached from the marketplace's window shopping experience. Perhaps most concerning, it can be difficult for consumers to discover even general information about their cost-sharing obligations—for example, more than a quarter of formularies had tiering structures that did not match the cost-sharing information provided by the marketplace websites—and it is usually impossible to determine such requirements in any detail. The exceptions were the few plans—mostly in Texas, following passage of a new state law—that offer ranges of expected cost-sharing for each covered drug or web-based tools that provide tailored estimates of out-of-pocket costs based on entered medications.

Overall, each of the 14 oral cancer drugs we investigated were covered in their generic or brand form by most plans. However, coverage was far from universal: only seven of the 14 oral drugs were covered by at least 90 percent of plans. In addition, only one formulary among those we studied systematically listed coverage of IV drugs, making it difficult to determine coverage levels for these drugs.

Comparing plans based on likely out-of-pocket costs for cancer drugs remains the most significant challenge facing consumers. Because many cancer drugs are extremely expensive, it is critical that consumers have ready access to clear and accurate information describing prescription drug cost-sharing before they enroll in a plan. Unfortunately, most plans place many, or even all, covered cancer drugs on the highest cost-sharing tier. Among the formularies we studied, even generic cancer drugs appeared on the most expensive tier with regularity (41 percent of the time in the case of Etoposide, and 61 percent for Imatinib Mesylate). Most of the time, the highest cost-sharing tier requires coinsurance rather than a flat copayment; but it is very difficult for consumers to manually estimate their coinsurance costs because the negotiated drug price on which coinsurance is based is not shown. As noted, a few plans have begun providing estimates of out-of-pocket costs, either on the formulary itself or via a web-based tool. Efforts should be made to refine these tools and policymakers may wish to encourage their broader adoption.

Policy Recommendations

ACS CAN strongly recommends that states and HHS pursue the following policy changes to ensure adequate, timely, and affordable access to prescription drugs to treat cancer:

- **Non-discriminatory tiering:** HHS and states should monitor prescription drug benefits closely for evidence of discrimination against patients with high-cost conditions like cancer. This includes monitoring the cost-sharing for generic and brand drugs used to treat high-cost conditions such as cancer, as well as monitoring coverage limits on these drugs.
- **Copays, not coinsurance:** HHS and states should encourage or require the use of copayments for prescription drugs rather than coinsurance. Coinsurance requirements are not transparent and prevent patients from adequately comparing plans. As a first step, states and HHS should require any plans using coinsurance to provide an estimate of out-of-pocket costs associated with all drugs covered using coinsurance. Legislation recently enacted in Texas, which requires plans to disclose through their formularies a cost range for all drugs subject to coinsurance, may serve as a model for other states.
- **Direct links to formularies:** HHS and state-based marketplaces should require insurers to provide direct links to searchable prescription drug formularies for each qualified health plan. HHS and states should have processes in place to verify the accuracy of the submitted links, and to allow insurers to provide updated links during the year if necessary.
- **Cost-sharing transparency:** All drugs listed in formularies should be clearly labeled with a cost-sharing tier that matches those displayed on the marketplace and in the Summary of Benefits and Coverage. HHS and state-based marketplaces should perform periodic checks to ensure that formulary links provided match prescription drug data submitted by qualified health plans and displayed on marketplace websites.
- **Complete tiering information on marketplaces and in the Summary of Benefits and Coverage:** Comparative information on HealthCare.gov and state-based marketplaces, as well as the standard Summary of Benefits and Coverage forms used nationwide, should be expanded as needed to include cost-sharing information for plans with five or more tiers in their prescription drug benefit.
- **Exceptions process:** HHS and states should strengthen and enforce the exceptions policy allowing enrollees access to non-covered drugs when medically necessary. The exceptions process could be strengthened through standardized cost-sharing requirements and standardized exceptions request forms, and by requiring plans to cover currently-used drugs for those changing plans as they pursue the exceptions process.

- **Coverage limits:** Quantity limits should be clearly described in formulary documents and consistent with clinically appropriate use. Quantity limits should not be used to place additional administrative or cost-sharing burdens on enrollees, such as requiring refills every 15 days. For patients changing plans, any step therapy requirements should be waived if the patient is already being successfully treated on a particular medication.
- **Consumer tools:** Marketplaces should continue to develop tools that allow consumers to search for plans that cover their prescription drugs. In addition, total cost estimator tools should be refined to account for consumers' specific prescription drug utilization.

¹ American Cancer Society. *Cancer Facts & Figures 2017*. Atlanta, GA: American Cancer Society; 2017.

² Agency for Healthcare Research and Quality. Total Expenses and Percent Distribution for Selected Conditions by Type of Service: United States, 2014. Medical Expenditure Panel Survey Household Component Data. Generated interactively. (December 29, 2016)

³ American Cancer Society. *Targeted Therapy*. Atlanta, GA: American Cancer Society; July 2013.

⁴ Centers for Medicare & Medicaid Services. *First Half of 2016 Effectuated Enrollment Snapshot*. Baltimore, MD: CMS; October 2016.

⁵ Collins, SR, Gunja, MZ, Doty, MM, Beutel, S. *Americans' Experiences with ACA Marketplace and Medicaid Coverage: Access to Care and Satisfaction*. New York: The Commonwealth Fund; May 2016; Government Accountability Office, *Most Enrollees Reported Satisfaction with Their Health Plans, Although Some Concerns Exist*. Washington, DC: GAO; September 2016.

⁶ Giovannelli, J, Lucia, K, Corlette, S. *Implementing the Affordable Care Act: Revisiting the ACA's Essential Health Benefits Requirements*. New York: The Commonwealth Fund; October 2014.

⁷ 45 C.F.R. §156.122.

⁸ Giovannelli, J, Volk, J, Lucia, K, Williams, A, Connor, K. *States Revisit Insurer Benefit Requirements, But Have Little Data on Consumers' Experiences*. New York: The Commonwealth Fund; October 2015.

⁹ 45 C.F.R. §156.122.

¹⁰ 45 C.F.R. §156.122.

¹¹ American Cancer Society Cancer Action Network. *Cancer Drug Coverage in Health Insurance Marketplace Plans*. Washington, DC: American Cancer Society Cancer Action Network; March 2014; Blumberg, LJ, Peters, R, Wengle, E, Arnesen, R. *Physician Network Transparency: How Easy Is It for Consumers to Know What They Are Buying?* Washington, DC: Urban Institute; August 2014; American Cancer Society Cancer Action Network. *Cancer Care and the Adequacy of Provider Networks Under the ACA Marketplace Plans*. Washington, DC: American Cancer Society Cancer Action Network; June 2014.

¹² American Cancer Society Cancer Action Network. *ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces*. Washington, DC: American Cancer Society Cancer Action Network; November 2015.

¹³ American Cancer Society Cancer Action Network. *Cancer Drug Coverage in Health Insurance Marketplace Plans*; November 2014; American Cancer Society Cancer Action Network. *ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces*; November 2015.

¹⁴ Jacobs, DB, Sommers, BD. Using Drugs to Discriminate – Adverse Selection in the Insurance Marketplace. *N Engl J Med* 2015; 372: 399-402.

¹⁵ Pearson, CF. *Avalere Analysis: Exchange Benefit Designs Increasingly Place All Medications for Some Conditions on Specialty Drug Tier*. Washington, DC: Avalere Health; February 2015.

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- ¹⁶ Centers for Medicare & Medicaid Services. *March 31, 2016 Effectuated Enrollment Snapshot*. Baltimore, MD: CMS; June 2016.
- ¹⁷ American Cancer Society. *Cancer Treatment & Survivorship Facts & Figures 2016-2017*. Atlanta, GA: American Cancer Society; 2016.
- ¹⁸ American Cancer Society Cancer Action Network. *Cancer Drug Coverage in Health Insurance Marketplace Plans*; November 2014; American Cancer Society Cancer Action Network. *ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces*; November 2015.
- ¹⁹ We obtained formulary links from the following sources: Centers for Medicare & Medicaid Services. *2017 Health Insurance Plans & Prices*; 2016; Covered California. *Prescription Drugs*; 2016; Connect for Health Colorado. *Individual and Families > Start your application for health coverage*; 2016.
- ²⁰ Centers for Medicare & Medicaid Services. *2017 Health Insurance Plans & Prices*; 2016.
- ²¹ Covered California. *Prescription Drugs*; 2016.
- ²² Website visitors that navigate to the first listed source can access an integrated prescription drug formulary lookup tool (but not hyperlinks to the formularies, themselves); visitors to the second-listed source can access hyperlinks to the formularies (but not the integrated search tool). Connect for Health Colorado. *Quick Cost and Plan Finder*; 2016; Connect for Health Colorado. *Individual and Families > Start your application for health coverage*; 2016.
- ²³ Texas House Bill 1624; 2015.
- ²⁴ Texas Department of Insurance. *Commissioner's Order No. 4605*. July 2016.
- ²⁵ American Cancer Society Cancer Action Network. *ACS CAN Examination of Cancer Drug Coverage and Transparency in the Health Insurance Marketplaces*; November 2015.
- ²⁶ These plans are, in California: Chinese Community Health Plan, L.A. Care Health Plan, and Valley Health Plan; and in Texas: Community Health Choice, Sendero Health Plans, and SHA (FirstCare Health Plans).
- ²⁷ Jacobs, DB, Sommers, BD. *Using Drugs to Discriminate – Adverse Selection in the Insurance Marketplace*; 2015.

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