

Drug Super Spenders: 2016 to 2018 Growth in Number of Members and Total Pharmacy Plus Medical Benefit Drug Cost for Members with Extremely High Annual Drug Cost in a 17 Million Member Commercially Insured Population

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BACKGROUND

- Advances in new innovative therapies — often priced in excess of over \$250,000 per year — are frequently for rare diseases. These have become an increasingly important health care cost-driver. Of 59 new drugs approved in 2018, 34 were for rare diseases.¹ In addition, one-time (e.g., gene) therapies are beginning to enter the market at a cost of over \$2.1 million.^{2,3}
- Utilizers of these extremely high cost drug therapies have prompted increasing use of the term “drug super spenders” to describe these insured members.
- Total drug management requires comprehensive medical and pharmacy benefit drug claims and cost data aggregation, at the member level, with drug super spenders identified by condition category.
- Health plans and pharmacy benefit managers need to understand the drug super spender growth rate and develop strategies that provide access to treatment while maintaining health insurance affordability. In addition, they need to ensure the drug therapy is priced proportionally to the value it provides, the lowest cost drug delivery channel is used, and most cost-effective drug therapy regimen is selected.

OBJECTIVE

- To categorize all members in a large commercially insured population by their total drug cost, defined as the combined cost from the pharmacy benefit and drugs covered by medical benefits, and to identify drug super spender members, defined as those with greater than \$250,000 in total drug cost per year.
- To determine overall drug super spender prevalence and aggregate cost trends by medical diagnosis condition categories.

METHODS

- We identified all members in a large, commercially insured population with any period of enrollment between January 2016 and December 2018.
- For each member for each calendar year with any enrollment:
 - The sum of allowed cost was determined for all pharmacy claims plus all medical benefit claim lines with a set of Healthcare Common Procedural Coding System (HCPCS) codes defined as drugs.
 - Medical drug claim lines included those with non-specific drug HCPCS codes, e.g., J3590 “unclassified biologics,” for which a specific HCPCS code had not yet been assigned at the time of billing. When provided on the medical claim, these drugs were specifically identified by National Drug Codes (NDC).
 - Cost was defined as the plan plus member cost share after network discounts with no further adjustment for drug manufacturer coupons or rebates.
- For drug super spender members (i.e., members with greater than \$250,000 in total drug cost in a calendar year):
 - Drug use for each member was further characterized by drug and drug categories using NDC codes on pharmacy claims and HCPCS codes +/- NDC codes on medical claims.
 - The clinical indication for high drug cost was deduced from a combination of information from the specific drugs accounting for most of the member’s drug expense and ICD-10 diagnosis codes on all medical claims incurred during the three years, 2016 to 2018.
- From preliminary exploratory analysis, for each clinical indication category, a set of specific drugs was identified that accounted for nearly all drug expense; these were defined as the “specified drugs” described in the results.
 - For some condition categories, only a single or a few drugs were defined as the specified specialty drugs. For example, the specified specialty drugs for spinal muscular atrophy, congenital hypophosphatasia, and cystinosis were, respectively, nusinersen (Spinraza®), asfotase alfa (Strensiq®) and cysteamine (Procysbi®, Cystaran®), Cystagon®).
 - For other condition categories, a larger set of specified drugs were defined. Examples: for cancer this included many different antineoplastic agents as well as G-CSF drugs such as pegfilgrastim (Neulasta®); for cystic fibrosis this included the specific disease-modifying agents ivacaftor (Kalydeco®), lumacaftor/ivacaftor (Orkambi®), and tezacaftor/ivacaftor (Symdeco®), as well as drugs primarily but not exclusively used for cystic fibrosis, such as inhaled anti-bacterials (e.g., Cayston®, Tobi®, Bethkis®), dornase alfa (Pulmozyme®) and pancreatic enzymes.
- Descriptive statistics were used to describe the growth in the number of super spenders and their aggregate expense, and to subcategorize these trends by clinical condition categories.

RESULTS

- The analytic population consisted of an average of 17.7 million unique members with any eligibility in each calendar year, 2016 to 2018. The analytic population had an average of 9.7 member-months per unique member with eligibility in the year.
- Table 1 and Table 2 and Figure 1 and Figure 2 show the numbers and aggregate drug cost for all members with any pharmacy plus medical benefit eligibility.
- Drug Super Spenders (members with > \$250,000 in a year of total drug cost from combined medical and pharmacy benefit drug claims)**
 - In 2016, there were 2,994 members (0.0169% of all members) accounting for \$1.324 billion (B) drug spend, which was 6.3% of all drug spend.
 - In 2018, there were 4,869 members (0.0275% of all members) accounting for \$2.119B drug spend, which was 8.6% of all drug spend.

2016 to 2018 Drug Super Spender Trends

- 63% increase in drug super spenders, 1,875 additional drug super spenders in 2018.
- 60% increase in drug super spenders costs, additional \$795M cost for drug super spenders in 2018.
- Of the \$795M increase from 2016 to 2018 in drug super spenders total drug expense:
 - Cancer condition categories accounted for \$378M (48%) of the total increase, with the largest increases for specified specialty drugs to treat breast, multiple myeloma, lung, kidney, colorectal, non-Hodgkin’s lymphoma and melanoma cancers.
 - Inherited single gene disorders accounted for \$243M (31%) of the total increase with the largest increases seen for hemophilia A and B, cystic fibrosis, spinal muscular atrophy, congenital hypophosphatasia, hereditary angioedema, cystinosis and Duchenne muscular dystrophy drug therapies.
 - The other categories accounting for nearly all the remainder increase in drug super spender expense from 2016 to 2018 were: the treatment conditions for eculizumab (Soliris®) including hemolytic-uremic syndrome, paroxysmal nocturnal hemoglobinuria, and myasthenia gravis; pulmonary hypertension; multiple sclerosis; and anti-inflammatory biologics.

Specified drugs together accounted for \$766M (96%) of the \$795M increase in total drug cost for drug super spenders shown in Table 3.

TABLE 1

Members and Cost by Drug Super Spender Cost Bands

Member annual drug spend cost band	Members		
	2016	2017	2018
≥ \$750K	256 (0.002%)	314 (0.002%)	354 (0.002%)
\$500K – < \$750K	421 (0.002%)	489 (0.003%)	701 (0.004%)
\$250K – < \$500K	2,317 (0.013%)	2,838 (0.016%)	3,814 (0.021%)
≥ \$250K	2,994 (0.017%)	3,641 (0.021%)	4,869 (0.027%)
Total membership	17,625,170	17,394,515	18,221,200

Cost Band = sum of total pharmacy claims plus total medical benefit drug claim lines expense for individual member; K = thousands of dollars; Member = distinct member with any pharmacy plus medical benefit eligibility during calendar year; Cost = plan plus member cost share after network discounts with no further adjustment for drug manufacturer coupons or rebates.

TABLE 2

Annual Drug Cost by Member Super Spender Drug Cost Bands

Member annual drug spend cost band	Cost in millions (M)		
	2016	2017	2018
≥ \$750K	\$297M (1.4%)	\$384M (1.8%)	\$417M (1.7%)
\$500K – < \$750K	\$254M (1.2%)	\$290M (1.3%)	\$422M (1.7%)
\$250K – < \$500K	\$773M (3.7%)	\$943M (4.3%)	\$1,280M (5.2%)
≥ \$250K	\$1,325M (6.3%)	\$1,617M (7.4%)	\$2,119M (8.6%)
Total drug cost	\$20,885M	\$21,972M	\$24,555M

Cost Band = sum of total pharmacy claims plus total medical benefit drug claim lines expense for individual member; K = thousands of dollars; Member = distinct member with any pharmacy plus medical benefit eligibility during calendar year; Cost = plan plus member cost share after network discounts with no further adjustment for drug manufacturer coupons or rebates.

FIGURE 1

Drug Super Spenders Trend, 2016 to 2018

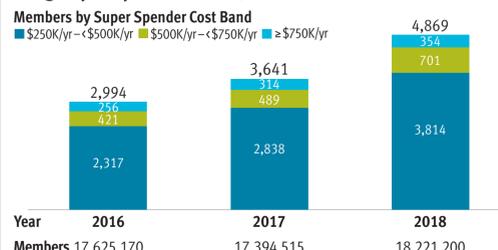
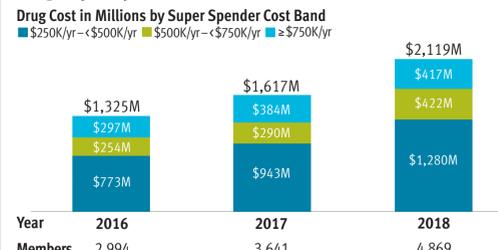


FIGURE 2

Drug Super Spenders Cost Trend, 2016 to 2018



Cost Band = sum of total pharmacy claims plus total medical benefit drug claim lines expense for individual member; K = thousands of dollars; Member = distinct member with any pharmacy plus medical benefit eligibility during calendar year; Cost = plan plus member cost share after network discounts with no further adjustment for drug manufacturer coupons or rebates.

TABLE 3

Drug Super Spenders and Cost from 2016 to 2018 by Drug Condition Categories

Drug indication category	Super spender members		Medical plus pharmacy claims cost for specified drugs (in millions)		
	Year 2016	Year 2018	Year 2016	Year 2018	Change '16 to '18
Cancer, total	1,141	2,167	\$431.6	\$809.7	\$378.0
Breast	259	476	\$96.8	\$182.2	\$85.4
Multiple myeloma	112	340	\$37.2	\$115.8	\$78.6
Lung	117	258	\$43.2	\$102.4	\$59.2
Melanoma	134	160	\$60.9	\$74.7	\$13.8
Colorectal	104	157	\$41.1	\$57.7	\$16.6
Non-Hodgkin’s lymphoma	76	126	\$27.4	\$45.9	\$18.5
Kidney	28	90	\$9.2	\$32.8	\$23.7
Acute lymphoblastic leukemia	51	68	\$26.9	\$31.5	\$4.6
Hodgkin’s disease	27	54	\$10.0	\$19.7	\$9.8
Prostate	35	71	\$9.5	\$18.5	\$9.0
Other cancer	198	367	\$69.4	\$128.4	\$58.9
Inherited single gene disorders, total	873	1,353	\$431.5	\$674.1	\$242.6
Hemophilia A and B	281	396	\$156.4	\$233.9	\$77.5
Cystic fibrosis	205	422	\$64.6	\$139.2	\$74.6
Hereditary angioedema	97	116	\$63.8	\$75.6	\$11.8
Spinal muscular atrophy	-	85	\$0.0	\$40.1	\$40.1
Congenital hypophosphatasia	13	26	\$10.1	\$26.2	\$16.1
Fabry’s disease	52	55	\$20.8	\$22.2	\$1.4
Pompe disease	22	21	\$18.4	\$17.5	-\$0.8
Gaucher’s disease	50	44	\$20.8	\$17.3	-\$3.5
Cystinosis	15	24	\$7.1	\$16.6	\$9.5
Urea cycle disorders	9	18	\$5.6	\$10.4	\$4.8
Chronic granulomatous disease	23	18	\$9.9	\$9.9	\$0.0
Wilson’s disease	25	21	\$9.5	\$6.7	-\$2.8
Duchenne muscular dystrophy	-	4	\$0.0	\$5.4	\$5.4
Alpha-1-antitrypsin deficiency	5	11	\$3.3	\$5.3	\$2.0
Coagulation factor 10 deficiency	2	3	\$2.7	\$4.6	\$1.8
Mucopolysaccharidoses	31	28	\$20.6	\$17.8	-\$2.7
Porphyria	1	7	\$0.5	\$3.2	\$2.6
Generalized lipodystrophy	3	4	\$1.7	\$2.7	\$1.0
Tuberous sclerosis	9	9	\$2.1	\$2.6	\$0.6
Coagulation factor 13 deficiency	5	7	\$2.0	\$2.6	\$0.6
Hereditary optic atrophy (gene therapy)	-	3	\$0.0	\$2.6	\$2.6
Amyotrophic lateral sclerosis	-	6	\$0.0	\$1.9	\$1.9
Tyrosinemia	1	4	\$0.4	\$1.8	\$1.4
Phenylketonuria	3	5	\$0.7	\$1.6	\$0.9
Other single gene disorders	21	16	\$10.5	\$6.4	-\$4.1
End-stage renal disease	370	407	\$143.0	\$154.8	\$11.8
aHUS/PNH/MG* (eculizumab [Soliris])	104	150	\$73.5	\$106.1	\$32.6
Immunoglobulins	112	172	\$41.5	\$60.3	\$18.8
Pulmonary hypertension	88	169	\$26.9	\$55.8	\$28.9
Multiple sclerosis	40	113	\$14.6	\$42.2	\$27.7
Anti-inflammatory biologics	65	142	\$23.5	\$46.0	\$22.5
Hepatitis c	76	3	\$22.5	\$0.4	-\$22.1
All others	125	193	\$38.6	\$63.6	\$24.9
Total specified specialty drugs	2,994	4,869	\$1,247.3	\$2,013.0	\$765.8
Total all medical plus pharmacy drugs	2,994	4,869	\$1,324.5	\$2,119.5	\$795.0

Drug Super Spenders = individual members with > \$250,000 in pharmacy plus medical drug cost per year; Cost = plan plus member cost share after network discounts with no further adjustment for drug manufacturer coupons or rebates; 2018–2016 = change in total cost from 2016 to 2018; Drug Condition Category = clinical condition for high drug cost deduced from a combination of information from the specific drugs accounting for most of the member’s drug expense and ICD-10 diagnosis codes on all medical claims incurred during the three years, 2016 to 2018; Specified Drugs = set of specific specialty drugs for each condition category derived from preliminary exploratory analysis; Mucopolysaccharidoses = Mucopolysaccharidosis I, II, III, and VI, combined; aHUS/PNH/MG* = atypical hemolytic-uremic syndrome, paroxysmal nocturnal hemoglobinuria, myasthenia gravis as conditions for eculizumab (Soliris®); Total all medical plus pharmacy drugs = sum of expense for Specified Specialty Drugs, see METHODS section, and all other drugs for super spenders.

LIMITATIONS

- Although this study was conducted using a large population, many of the individual conditions described are too rare to accurately estimate prevalence.
- These results represent commercially insured lives from many different clients of a national pharmacy benefit manager. The findings cannot be extrapolated to populations such as Medicare and Medicaid, and may differ from other commercially insured populations with different attributes.
- Extraordinarily high drug expense, i.e., drug super spending, for an individual member can result from a variety of different factors acting alone or in combination. Use of drugs for which manufacturers have set very high prices is a common factor. In addition, in some cases contractual agreements play a very important role, such as agreement by a health plan to pay a percentage of charges for medical claims by a facility combined with the facility’s decisions about what to charge.

CONCLUSIONS

- Pharmaceutical innovation is bringing needed therapies to market but driving more drug super spenders. In 2018, members with over \$250,000 a year in total drug costs account for 28 per 100,000 commercially insured. This small but fast-growing segment of insured members currently accounts for 8.6% of total drug expenditures through the medical and pharmacy benefit and Prime is forecasting it to be over 15% in the next 5 years.
- The 4,869 drug super spenders out of 17.7 million commercially insured members had over \$2 billion in total drug cost with a forecasted drug super spend cost of over \$4 billion in five years.
- Health plans need total drug cost management strategies for anticipating, tracking, and optimizing specialty drug and one-time (e.g., gene) therapy for these drug super spender members. These strategies are only possible when integrated medical and pharmacy benefit analytics, predictive modeling and clinical expertise can be combined with robust case management, innovative manufacturer contracting, e.g., value based contracting and fraud, waste and abuse capabilities.
- This study is part of the foundational work needed to develop a drug super spender comprehensive management approach.

REFERENCES

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