



Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017

January 2021

Revised March 2023

Suggested Citation: Wilson-Frederick, S., M. Hulihan, A. Mangum, T. Khan, M. Geibel, R. Malsberger, S. Verghese, R. Borck, R. Fox, and M. Rosenbach. "Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017." Baltimore, MD: Center for Medicaid and CHIP Services, Division of Quality and Health Outcomes, Centers for Medicare & Medicaid Services, 2021.



Contents

- Introduction 1
- Data Source 3
- Methods..... 4
- Key Findings 5
 - Beneficiary Characteristics..... 5
 - Recommended Care for Sickle Cell Disease 22
 - Health Care Utilization..... 29
 - Preventive Care..... 36
 - Health Conditions 39
- Concluding Remarks 43
 - For More Information 43

Tables

1	National and State-level Counts, State Distribution, and Prevalence of Sickle Cell Disease (SCD) per 100,000 Medicaid and CHIP Beneficiaries in 2017	7
2	Number of Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group and State.....	9
3	Demographic Characteristics of Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group.....	15
4	National and State-level Counts and Prevalence of Sickle Cell Disease (SCD) per 100,000 Medicaid and CHIP Beneficiaries in 2017, by Length of Coverage.....	18
5	Transcranial Doppler Ultrasound (TCD) Screenings among Medicaid and CHIP Beneficiaries Ages 3 to 16 with Sickle Cell Disease (SCD) in 2017, by Age Group.....	24
6	Hydroxyurea Use among Medicaid and CHIP Beneficiaries Age 21 Months and Older with Sickle Cell Disease (SCD) in 2017, by Age Group.....	25
7	Pneumococcal Vaccinations among Medicaid and CHIP Beneficiaries Under Age 2 with Sickle Cell Disease (SCD) in 2017	27
8	Antibiotic Prophylaxis among Medicaid and CHIP Beneficiaries Ages 15 Months to Age 4 with Sickle Cell Disease (SCD) in 2017	28
9	Emergency Department (ED) Use among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group.....	31
10	Number of Emergency Department (ED) Visits among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group	32
11	Inpatient Hospital Stays among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group.....	33
12	Number of Inpatient Hospital Stays among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group.....	34
13	Outpatient Visits among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group	35
14	Health Screenings among Medicaid and CHIP Beneficiaries Under Age 21 with and without Sickle Cell Disease (SCD) in 2017, by Age Group.....	37
15	Dental Examinations among Medicaid and CHIP Beneficiaries Ages 2 to 20 with and without Sickle Cell Disease (SCD) in 2017	38
16	Selected Diagnoses Among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group.....	40

Introduction

Sickle cell disease (SCD), the most prevalent lifelong inherited blood disorder in the United States, causes the body to produce red blood cells shaped like crescents or sickles rather than discs. These sickle-shaped blood cells tend to stick to vessel walls leading to blockage and impeding blood flow. When this occurs, oxygen is not delivered to body tissues, which ultimately leads to severe acute and chronic pain episodes known as crises.¹ SCD impacts all racial and ethnic groups. Of the approximate 100,000 people affected by SCD in the United States, Black and Hispanic populations are disproportionately impacted.² While medical advancements, such as newborn screening,³ penicillin prophylaxis,⁴ and [therapeutics](#) have transitioned SCD from a fatal childhood disease to a chronic condition, long-term [health complications](#) (for example, stroke, acute chest syndrome, and chronic end-organ damage) have been associated with increased morbidity and mortality among people with SCD compared to those without.⁵

Currently, a national SCD surveillance system does not exist. To address this gap in data availability and to improve the quality of care for people living with SCD, the Centers for Medicare & Medicaid Services (CMS) has developed several analytic products. In June 2019, CMS released a new claims-based SCD indicator that is available in the CMS Chronic Conditions Data Warehouse (CCW) (www.ccwdata.org) and released two data products on [Medicaid](#) and [Medicare Fee-for-Service](#) beneficiaries living with SCD. The previously released

CMS's Transformed Medicaid Statistical Information System (T-MSIS)

The Medicaid Statistical Information System (MSIS), used by CMS to create the MAX files, has been decommissioned and replaced by the [Transformed Medicaid Statistical Information System \(T-MSIS\)](#). In [November 2019](#), CMS released a series of robust data sets optimized for analytics, known as the T-MSIS Analytic Files (TAF). TAF data are an enhanced version of the T-MSIS data tailored to the research needs of those who use Medicaid and CHIP data. To support the use of TAF data, CMS has released several analytic resources including [TAF data quality reports](#), the [T-MSIS Substance Use Disorder \(SUD\) Data Book](#), and the [T-MSIS Data Quality \(DQ\) Atlas](#).

¹ Wilson-Frederick, S.M., M. Hulihan, and K.K. Anderson. "Prevalence of Sickle Cell Disease among Medicaid Beneficiaries in 2012. CMS Office of Minority Health Data Highlight, No. 16." Baltimore, MD: Centers for Medicare & Medicaid Services, 2019. Available at <https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-16-Sickle-Cell-Disease.pdf>.

² Hassell, K.L. "Population Estimates of Sickle Cell Disease in the U.S." *American Journal of Preventive Medicine*, vol. 38, no. 4, 2010, pp. S512–21. <https://doi.org/10.1016/j.amepre.2009.12.022>.

³ Vichinsky, E., D. Hurst, A. Earles, K. Kleman, and B. Lubin. "Newborn Screening for Sickle Cell Disease: Effect on Mortality." *Pediatrics*, vol. 81, no. 6, 1988, pp. 749–755.

⁴ Lin, K.W. "Screening for Sickle Cell Disease in Newborns." *American Family Physician*, vol. 79, no. 6, 2009, pp. 507–508.

⁵ Telen M.J. "Curative vs Targeted Therapy for SCD: Does it Make More Sense to Address the Root Cause Than Target Downstream Events?" *Blood Adv.*, vol. 4, no. 14, 2020, pp. 3457–3465. <https://doi.org/10.1182/bloodadvances.2020001469>.

Medicaid report on SCD used information from the 2012 [Medicaid Analytic eXtract \(MAX\)](#), the most current available data at the time.

In September 2020, to commemorate National SCD Awareness Month, CMS released the “*At a Glance: Medicaid and CHIP Beneficiaries with Sickle Cell Disease, T-MSIS Analytic Files (TAF) 2017*” ([SCD Infographic](#)). As a companion document to the SCD Infographic, CMS is releasing the “*Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017*” (SCD Report). For both the SCD Infographic and SCD Report, CMS used 2017 TAF data and applied a claims-based algorithm to identify Medicaid and Children’s Health Insurance Program (CHIP) beneficiaries with SCD.

The SCD Report includes detailed state-level analyses for demographic, health characteristics, and health care utilization patterns among Medicaid and CHIP beneficiaries who are under age 76 and living in the United States or in the territories of Puerto Rico and the U.S. Virgin Islands (USVI). To the extent possible, findings are reported for beneficiaries with and without SCD. The SCD Report also features information on recommended screenings and preventive care for children with and without SCD (including antibiotic prophylaxis, dental examinations, and pneumococcal vaccinations) to improve understanding of the diverse populations served by state Medicaid and CHIP programs and highlight opportunities for quality improvement.

The SCD Infographic and SCD Report are the first CMS-produced TAF data products to report on Medicaid and CHIP beneficiaries with SCD.

Data Source

State Medicaid and CHIP agencies collect enrollment and claims data for all persons enrolled in Medicaid and CHIP. Beginning in 1999, as required under the [Balanced Budget Act of 1997](#) (section 4753), all states and the District of Columbia began to submit their data to CMS using a standardized data format via the Medicaid Statistical Information System (MSIS). More recently, in an effort to enhance reporting for these programs, CMS replaced MSIS reporting with reporting in the Transformed Medicaid Statistical Information System (T-MSIS).

Through T-MSIS, each state reports data on Medicaid and CHIP enrollment, service utilization, payment, providers, and other information on a monthly basis. The size, complexity, and frequency of updates to T-MSIS data make the files very challenging to use for analytic purposes. In response to this, CMS created a series of data sets optimized for analytics and basic research known as the T-MSIS Analytic Files, or TAF. The analyses presented in the SCD Report are derived from five research-ready files in the 2017 version 4 (v4) TAF: Annual Demographic and Eligibility (DE), Inpatient (IP), Long-Term Care (LT), Other Services (OT), and Pharmacy (RX). The analyses aligned with the methods recommended in the set of TAF Data Quality Resources developed by CMS.⁶

Because the T-MSIS reporting system is relatively new, the TAF data were not fully robust in all states when the analytic work presented here was conducted in the summer of 2020.⁷ Most analyses include 49 states, the District of Columbia, Puerto Rico, and USVI. Due to concerns about data quality in the 2017 v4 TAF, results for Maryland are excluded from all tables in the SCD Report. Additional states are excluded from specific tables due to data quality concerns that only affected the analysis for that table; these additional exclusions are identified in the notes for each relevant table.

⁶ More information on TAF data quality is available at: <https://www.medicaid.gov/dq-atlas/welcome> and <https://www.resdac.org/taf-data-quality-resources>.

⁷ TAF data are continually updated as data quality issues emerge and are communicated back to states who respond by making corrections and improvements in their reporting and in refining their files.

Methods

Beneficiaries with SCD were identified using an adapted version of the CCW algorithm for identifying people with SCD using administrative data.^{8,9} The CCW algorithm uses diagnosis codes to identify SCD; more specifically, the algorithm classifies people as having SCD if they had at least three claims with a diagnosis of SCD over a five-year period.

For the purpose of this analysis, the CCW algorithm was adapted to include beneficiaries under age 76 who had 12 continuous months of enrollment with full Medicaid or CHIP benefits in 2017 and who had at least two claims with a diagnosis of SCD during the calendar year. Consistent with the CCW algorithm, beneficiaries with sickle cell trait were not included in the analysis. In addition, the analysis did not exclude beneficiaries in hospice, residents of long-term care facilities, or beneficiaries receiving palliative care. Due to the methods by which beneficiaries with SCD were identified, this analysis is unable to identify beneficiaries with SCD who did not seek care for this condition in 2017 or whose providers did not indicate a diagnosis of SCD when billing for the services provided.

Beneficiaries without SCD were defined as people under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and who had no claims or only one claim with a diagnosis of SCD during the calendar year. In all cases, age was assigned using each beneficiary's age as of December 31, 2017.

This analysis of the 2017 TAF data identified 41,995 people with SCD out of the almost 57 million beneficiaries under age 76 who had 12 continuous months of enrollment with full Medicaid or CHIP benefits in 2017. Other analyses using different data sources, methods, or time periods will produce different counts. For example, analyses using five years of data (recommended by the CCW algorithm) may identify more people with SCD compared to this analysis, which uses only one year of data. The Centers for Disease Control and Prevention (CDC) estimates that SCD affects approximately 100,000 people in the United States.

The next section contains the key findings and detailed data tables from each of the analyses conducted for the SCD Report. More information about the definitions used for each analysis is provided in the notes for each table. The key findings and results are shown in five sets of tables, with each set covering a specific aspect of beneficiaries with SCD: (1) demographic and geographic characteristics, (2) recommended care for SCD, (3) health care utilization, (4) preventive care, and (5) other health conditions.

⁸ More information on the CCW algorithm is available at: <https://www2.ccwdata.org/web/guest/condition-categories>.

⁹ Administrative data provide a rich, reliable source of information on the prevalence of various chronic conditions, but there are a few limitations. For example, the extent to which the data can be used to assess the duration or severity of these chronic conditions is limited. In addition, any undiagnosed conditions or covered services for which claims were not submitted would be missing from administrative data.

Key Findings

Beneficiary Characteristics

The tables in this section show the prevalence of SCD among Medicaid and CHIP beneficiaries nationally and in each state and describe the demographic characteristics of Medicaid and CHIP beneficiaries with and without SCD, including information about age, sex, dual eligibility, and geographic location.¹⁰ Key findings from each table are included below.

Table 1. National and State-level Counts, State Distribution, and Prevalence of Sickle Cell Disease (SCD) per 100,000 Medicaid and CHIP Beneficiaries in 2017

- Nationally, there were 41,995 Medicaid and CHIP beneficiaries with SCD in 2017. The national prevalence was 74 beneficiaries with SCD per 100,000 Medicaid and CHIP beneficiaries.
- The state prevalence of Medicaid and CHIP beneficiaries with SCD ranged from fewer than 50 per 100,000 beneficiaries in 24 states and Puerto Rico to 150 or more per 100,000 beneficiaries in 7 states (Alabama, Georgia, Louisiana, Mississippi, South Carolina, the District of Columbia, and USVI).
- More than half (53.5 percent) of Medicaid and CHIP beneficiaries with SCD lived in eight states (California, Florida, Georgia, Illinois, Louisiana, New York, North Carolina, and Texas).

Table 2. Number of Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group and State

- Nationally, 43.0 percent of Medicaid and CHIP beneficiaries with SCD were over age 20, compared to 44.2 percent of Medicaid and CHIP beneficiaries without SCD. The age distributions for the populations with and without SCD varied considerably across states, partly reflecting differences in Medicaid and CHIP eligibility criteria and enrollment rates as well as underlying population differences in the states.

Table 3. Demographic Characteristics of Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

- More than half of Medicaid and CHIP beneficiaries with and without SCD were female (53.5 percent and 53.7 percent, respectively). This percentage was higher (64.1 percent) among Medicaid and CHIP beneficiaries with SCD ages 46 to 75, compared to beneficiaries without SCD in this age group (56.5 percent).

¹⁰ Findings related to race and ethnicity are excluded from the SCD Report due to high levels of missing information about race/ethnicity in the 2017 v4 TAF.

- Three out of 10 (29.9 percent) Medicaid and CHIP beneficiaries with SCD who were ages 21 to 64 were dually eligible for Medicare benefits in 2017; this was double the percentage (14.6 percent) of beneficiaries without SCD in the same age group.
- A higher percentage of Medicaid and CHIP beneficiaries with SCD lived in an urban area in 2017 compared to those without SCD (91.2 percent versus 84.6 percent).
- Approximately 3 out of 10 (29.7 percent) Medicaid and CHIP beneficiaries with SCD lived in the South Atlantic Census Division, compared to 14.6 percent of beneficiaries without SCD. Conversely, 6.9 percent of Medicaid and CHIP beneficiaries with SCD lived in the Pacific Census Division, compared to 22.6 percent of beneficiaries without SCD.

Table 4. National and State-level Total Counts and Prevalence of Sickle Cell Disease (SCD) per 100,000 Medicaid and CHIP Beneficiaries in 2017, by Length of Coverage

- Nationally, there were 50,560 people with SCD who were enrolled in Medicaid or CHIP with full or comprehensive benefits for at least one month during 2017. Of these 50,560 beneficiaries, 16.9 percent (8,565 beneficiaries) were enrolled in Medicaid or CHIP for less than 12 months during the year while 83.1 percent (41,995 beneficiaries) were enrolled in Medicaid or CHIP for 12 continuous months in 2017. All other analyses in the SCD Report include the 41,995 beneficiaries with SCD who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017.

Table 1. National and State-level Counts, State Distribution, and Prevalence of Sickle Cell Disease (SCD) per 100,000 Medicaid and CHIP Beneficiaries in 2017

State	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	State percentage of total Medicaid and CHIP beneficiaries with SCD	Prevalence rate of SCD per 100,000 beneficiaries
United States	56,965,040	41,995	100.0%	73.7
Alabama	647,135	1,310	3.1%	202.4
Alaska	164,573	DS	0.0%	DS
Arizona	1,388,807	339	0.8%	24.4
Arkansas	762,208	608	1.4%	79.8
California	10,075,536	2,553	6.1%	25.3
Colorado	1,065,500	184	0.4%	17.3
Connecticut	644,995	500	1.2%	77.5
Delaware	165,198	226	0.5%	136.8
District of Columbia	216,044	367	0.9%	169.9
Florida	2,719,709	3,948	9.4%	145.2
Georgia	1,381,427	3,026	7.2%	219.0
Hawaii	289,799	DS	0.0%	DS
Idaho	232,171	DS	0.0%	DS
Illinois	2,486,608	1,988	4.7%	79.9
Indiana	1,010,562	622	1.5%	61.5
Iowa	489,395	155	0.4%	31.7
Kansas	312,621	143	0.3%	45.7
Kentucky	1,320,835	331	0.8%	25.1
Louisiana	1,246,227	2,084	5.0%	167.2
Maine	161,013	19	0.0%	11.8
Maryland	DQ	DQ	DQ	DQ
Massachusetts	1,314,584	907	2.2%	69.0
Michigan	1,841,836	1,368	3.3%	74.3
Minnesota	815,812	341	0.8%	41.8
Mississippi	482,743	1,099	2.6%	227.7
Missouri	849,314	750	1.8%	88.3
Montana	212,112	DS	0.0%	DS
Nebraska	35,192	18	0.0%	51.1
Nevada	440,538	282	0.7%	64.0

Table 1 (continued)

State	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	State percentage of total Medicaid and CHIP beneficiaries with SCD	Prevalence rate of SCD per 100,000 beneficiaries
New Hampshire	140,629	DS	0.0%	DS
New Jersey	1,237,634	1,043	2.5%	84.3
New Mexico	620,066	24	0.1%	3.9
New York	4,472,424	4,173	9.9%	93.3
North Carolina	1,604,805	2,082	5.0%	129.7
North Dakota	61,533	DS	0.0%	DS
Ohio	2,350,590	1,882	4.5%	80.1
Oklahoma	563,882	269	0.6%	47.7
Oregon	722,191	77	0.2%	10.7
Pennsylvania	2,000,086	1,567	3.7%	78.3
Puerto Rico	1,051,533	140	0.3%	13.3
Rhode Island	264,531	130	0.3%	49.1
South Carolina	863,892	1,659	4.0%	192.0
South Dakota	84,511	DS	0.0%	DS
Tennessee	1,223,217	1,118	2.7%	91.4
Texas	3,170,529	2,604	6.2%	82.1
USVI	14,916	31	0.1%	207.8
Utah	203,833	24	0.1%	11.8
Vermont	135,051	15	0.0%	11.1
Virginia	801,858	1,062	2.5%	132.4
Washington	1,393,183	224	0.5%	16.1
West Virginia	414,473	38	0.1%	9.2
Wisconsin	757,489	608	1.4%	80.3
Wyoming	39,690	DS	0.0%	DS

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 1 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

^a Results include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017.

^b Results include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

DQ = Not reported due to concerns about data quality in the 2017 v4 TAF.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Table 2. Number of Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group and State

State	Medicaid and CHIP beneficiaries with SCD ^a												
	Total number of beneficiaries with SCD	Number and percentage of beneficiaries, by age group ^c											
		Ages 0 to 5		Ages 6 to 12		Ages 13 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
		N	%	N	%	N	%	N	%	N	%	N	%
United States	41,995	7,637	18.2%	8,627	20.5%	7,691	18.3%	14,495	34.5%	3,305	7.9%	240	0.6%
Alabama	1,310	217	16.6%	264	20.2%	267	20.4%	452	34.5%	DS	DS	DS	DS
Alaska	DS	DS	DS	DS	DS	0	0.0%	DS	DS	DS	DS	0	0.0%
Arizona	339	48	14.2%	75	22.1%	68	20.1%	116	34.2%	DS	DS	DS	DS
Arkansas	608	121	19.9%	123	20.2%	108	17.8%	219	36.0%	DS	DS	DS	DS
California	2,553	357	14.0%	391	15.3%	394	15.4%	1,062	41.6%	325	12.7%	24	0.9%
Colorado	184	32	17.4%	DS	DS	45	24.5%	67	36.4%	DS	DS	0	0.0%
Connecticut	500	70	14.0%	113	22.6%	98	19.6%	179	35.8%	DS	DS	DS	DS
Delaware	226	63	27.9%	48	21.2%	43	19.0%	57	25.2%	DS	DS	DS	DS
District of Columbia	367	55	15.0%	86	23.4%	47	12.8%	147	40.1%	DS	DS	DS	DS
Florida	3,948	878	22.2%	916	23.2%	781	19.8%	1,158	29.3%	199	5.0%	16	0.4%
Georgia	3,026	579	19.1%	740	24.5%	603	19.9%	930	30.7%	160	5.3%	14	0.5%
Hawaii	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%
Idaho	DS	DS	DS	DS	DS	DS	DS	0	0.0%	DS	DS	0	0.0%
Illinois	1,988	325	16.3%	356	17.9%	357	18.0%	756	38.0%	179	9.0%	15	0.8%
Indiana	622	121	19.5%	142	22.8%	110	17.7%	205	33.0%	DS	DS	DS	DS
Iowa	155	34	21.9%	30	19.4%	25	16.1%	51	32.9%	DS	DS	DS	DS
Kansas	143	21	14.7%	30	21.0%	21	14.7%	58	40.6%	DS	DS	DS	DS
Kentucky	331	65	19.6%	62	18.7%	68	20.5%	109	32.9%	DS	DS	DS	DS

Table 2 (continued)

State	Medicaid and CHIP beneficiaries with SCD ^a												
	Total number of beneficiaries with SCD	Number and percentage of beneficiaries, by age group ^c											
		Ages 0 to 5		Ages 6 to 12		Ages 13 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
		N	%	N	%	N	%	N	%	N	%	N	%
Louisiana	2,084	405	19.4%	419	20.1%	455	21.8%	671	32.2%	DS	DS	DS	DS
Maine	19	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%	0	0.0%
Maryland	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ
Massachusetts	907	169	18.6%	183	20.2%	154	17.0%	313	34.5%	DS	DS	DS	DS
Michigan	1,368	209	15.3%	231	16.9%	236	17.3%	577	42.2%	DS	DS	DS	DS
Minnesota	341	65	19.1%	80	23.5%	76	22.3%	91	26.7%	DS	DS	DS	DS
Mississippi	1,099	274	24.9%	293	26.7%	226	20.6%	262	23.8%	44	4.0%	0	0.0%
Missouri	750	139	18.5%	166	22.1%	138	18.4%	238	31.7%	DS	DS	DS	DS
Montana	DS	0	0.0%	0	0.0%	0	0.0%	DS	DS	0	0.0%	0	0.0%
Nebraska	18	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%
Nevada	282	40	14.2%	52	18.4%	49	17.4%	117	41.5%	DS	DS	DS	DS
New Hampshire	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%	0	0.0%
New Jersey	1,043	159	15.2%	211	20.2%	174	16.7%	390	37.4%	98	9.4%	11	1.1%
New Mexico	24	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%
New York	4,173	684	16.4%	719	17.2%	722	17.3%	1,594	38.2%	428	10.3%	26	0.6%
North Carolina	2,082	367	17.6%	443	21.3%	402	19.3%	699	33.6%	158	7.6%	13	0.6%
North Dakota	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%	0	0.0%
Ohio	1,882	304	16.2%	352	18.7%	317	16.8%	716	38.0%	172	9.1%	21	1.1%
Oklahoma	269	59	21.9%	56	20.8%	43	16.0%	84	31.2%	DS	DS	DS	DS
Oregon	77	DS	DS	21	27.3%	13	16.9%	27	35.1%	DS	DS	DS	DS
Pennsylvania	1,567	273	17.4%	325	20.7%	288	18.4%	546	34.8%	DS	DS	DS	DS

Table 2 (continued)

State	Medicaid and CHIP beneficiaries with SCD ^a												
	Total number of beneficiaries with SCD	Number and percentage of beneficiaries, by age group ^c											
		Ages 0 to 5		Ages 6 to 12		Ages 13 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
		N	%	N	%	N	%	N	%	N	%	N	%
Puerto Rico	140	DS	DS	23	16.4%	30	21.4%	44	31.4%	21	15.0%	DS	DS
Rhode Island	130	29	22.3%	22	16.9%	22	16.9%	42	32.3%	15	11.5%	0	0.0%
South Carolina	1,659	301	18.1%	351	21.2%	277	16.7%	616	37.1%	DS	DS	DS	DS
South Dakota	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%	0	0.0%
Tennessee	1,118	184	16.5%	233	20.8%	223	19.9%	382	34.2%	DS	DS	DS	DS
Texas	2,604	580	22.3%	594	22.8%	459	17.6%	779	29.9%	DS	DS	DS	DS
USVI	31	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%
Utah	24	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%
Vermont	15	0	0.0%	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%
Virginia	1,062	192	18.1%	249	23.4%	196	18.5%	330	31.1%	DS	DS	DS	DS
Washington	224	48	21.4%	44	19.6%	36	16.1%	83	37.1%	DS	DS	DS	DS
West Virginia	38	DS	DS	DS	DS	DS	DS	23	60.5%	DS	DS	DS	DS
Wisconsin	608	94	15.5%	110	18.1%	85	14.0%	256	42.1%	DS	DS	DS	DS
Wyoming	DS	0	0.0%	DS	DS	0	0.0%	0	0.0%	0	0.0%	0	0.0%

Table 2 (continued)

State	Medicaid and CHIP beneficiaries without SCD ^b												
	Total number of beneficiaries without SCD	Number and percentage of beneficiaries, by age group ^c											
		Ages 0 to 5		Ages 6 to 12		Ages 13 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
		N	%	N	%	N	%	N	%	N	%	N	%
United States	56,923,045	10,326,625	18.1%	12,038,559	21.1%	9,369,898	16.5%	14,131,472	24.8%	8,707,127	15.3%	2,349,364	4.1%
Alabama	645,825	154,208	23.9%	178,689	27.7%	119,401	18.5%	88,004	13.6%	77,350	12.0%	28,173	4.4%
Alaska	DS	28,941	17.6%	31,037	18.9%	25,532	15.5%	48,252	29.3%	25,437	15.5%	DS	3.3%
Arizona	1,388,468	226,911	16.3%	267,152	19.2%	226,673	16.3%	387,881	27.9%	222,868	16.1%	56,983	4.1%
Arkansas	761,600	131,209	17.2%	146,560	19.2%	121,534	16.0%	229,943	30.2%	115,387	15.2%	16,967	2.2%
California	10,072,983	1,412,930	14.0%	1,768,577	17.6%	1,632,784	16.2%	2,855,505	28.3%	1,803,581	17.9%	599,606	6.0%
Colorado	1,065,316	177,600	16.7%	213,361	20.0%	172,308	16.2%	342,006	32.1%	149,462	14.0%	10,579	1.0%
Connecticut	644,495	84,538	13.1%	108,300	16.8%	100,995	15.7%	210,760	32.7%	121,595	18.9%	18,307	2.8%
Delaware	164,972	28,198	17.1%	34,006	20.6%	26,412	16.0%	46,723	28.3%	26,816	16.3%	2,817	1.7%
District of Columbia	215,677	28,184	13.1%	28,472	13.2%	24,652	11.4%	81,154	37.6%	46,943	21.8%	6,272	2.9%
Florida	2,715,761	682,249	25.1%	735,200	27.1%	512,500	18.9%	387,457	14.3%	239,973	8.8%	158,382	5.8%
Georgia	1,378,401	350,994	25.5%	415,399	30.1%	265,617	19.3%	183,853	13.3%	120,949	8.8%	41,589	3.0%
Hawaii	DS	42,711	14.7%	50,864	17.6%	44,598	15.4%	86,795	30.0%	52,030	18.0%	DS	4.4%
Idaho	DS	62,155	26.8%	73,745	31.8%	44,049	19.0%	29,767	12.8%	16,049	6.9%	DS	2.8%
Illinois	2,484,620	413,335	16.6%	500,039	20.1%	380,330	15.3%	714,507	28.8%	396,586	16.0%	79,823	3.2%
Indiana	1,009,940	212,695	21.1%	227,233	22.5%	165,985	16.4%	225,801	22.4%	150,815	14.9%	27,411	2.7%
Iowa	489,240	90,984	18.6%	105,436	21.6%	81,765	16.7%	126,612	25.9%	73,862	15.1%	10,581	2.2%
Kansas	312,478	81,900	26.2%	90,998	29.1%	56,240	18.0%	49,762	15.9%	25,482	8.2%	8,096	2.6%
Kentucky	1,320,504	192,770	14.6%	216,663	16.4%	200,214	15.2%	471,290	35.7%	212,841	16.1%	26,726	2.0%
Louisiana	1,244,143	229,239	18.4%	265,673	21.4%	220,725	17.7%	328,926	26.4%	171,894	13.8%	27,686	2.2%

Table 2 (continued)

State	Medicaid and CHIP beneficiaries without SCD ^b												
	Total number of beneficiaries without SCD	Number and percentage of beneficiaries, by age group ^c											
		Ages 0 to 5		Ages 6 to 12		Ages 13 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
		N	%	N	%	N	%	N	%	N	%	N	%
Maine	160,994	28,522	17.7%	36,129	22.4%	29,951	18.6%	41,420	25.7%	20,742	12.9%	4,230	2.6%
Maryland	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ
Massachusetts	1,313,677	175,051	13.3%	209,666	16.0%	193,847	14.8%	378,162	28.8%	284,734	21.7%	72,217	5.5%
Michigan	1,840,468	272,480	14.8%	312,549	17.0%	274,129	14.9%	572,092	31.1%	348,904	19.0%	60,314	3.3%
Minnesota	815,471	140,441	17.2%	157,267	19.3%	123,370	15.1%	230,453	28.3%	135,874	16.7%	28,066	3.4%
Mississippi	481,644	130,540	27.1%	162,045	33.6%	106,712	22.2%	54,401	11.3%	27,805	5.8%	141	0.0%
Missouri	848,564	205,208	24.2%	229,522	27.0%	149,318	17.6%	137,004	16.1%	97,354	11.5%	30,158	3.6%
Montana	DS	39,303	18.5%	44,534	21.0%	35,685	16.8%	57,507	27.1%	30,588	14.4%	DS	2.1%
Nebraska	35,174	7,160	20.4%	6,530	18.6%	4,097	11.6%	6,430	18.3%	6,658	18.9%	4,299	12.2%
Nevada	440,256	83,674	19.0%	94,241	21.4%	66,882	15.2%	118,982	27.0%	68,248	15.5%	8,229	1.9%
New Hampshire	DS	26,183	18.6%	31,714	22.6%	24,891	17.7%	34,773	24.7%	19,940	14.2%	DS	2.2%
New Jersey	1,236,591	211,855	17.1%	254,787	20.6%	199,279	16.1%	309,160	25.0%	206,441	16.7%	55,069	4.5%
New Mexico	620,042	99,217	16.0%	123,074	19.8%	102,915	16.6%	192,575	31.1%	90,786	14.6%	11,475	1.9%
New York	4,468,251	645,946	14.5%	760,534	17.0%	699,261	15.6%	1,250,467	28.0%	883,122	19.8%	228,921	5.1%
North Carolina	1,602,723	375,821	23.4%	434,927	27.1%	326,689	20.4%	249,147	15.5%	156,405	9.8%	59,734	3.7%
North Dakota	DS	12,753	20.7%	12,262	19.9%	8,451	13.7%	16,564	26.9%	9,449	15.4%	DS	3.3%
Ohio	2,348,708	370,878	15.8%	415,649	17.7%	349,028	14.9%	748,322	31.9%	400,666	17.1%	64,165	2.7%
Oklahoma	563,613	145,387	25.8%	167,867	29.8%	100,871	17.9%	67,305	11.9%	57,965	10.3%	24,218	4.3%
Oregon	722,114	115,230	16.0%	131,640	18.2%	109,002	15.1%	210,036	29.1%	134,024	18.6%	22,182	3.1%
Pennsylvania	1,998,519	309,998	15.5%	377,307	18.9%	319,454	16.0%	555,909	27.8%	365,243	18.3%	70,608	3.5%
Puerto Rico	1,051,393	95,642	9.1%	123,110	11.7%	140,792	13.4%	283,178	26.9%	263,683	25.1%	144,988	13.8%

Table 2 (continued)

State	Medicaid and CHIP beneficiaries without SCD ^b												
	Total number of beneficiaries without SCD	Number and percentage of beneficiaries, by age group ^c											
		Ages 0 to 5		Ages 6 to 12		Ages 13 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
		N	%	N	%	N	%	N	%	N	%	N	%
Rhode Island	264,401	36,777	13.9%	42,783	16.2%	40,357	15.3%	86,136	32.6%	49,157	18.6%	9,191	3.5%
South Carolina	862,233	192,555	22.3%	223,560	25.9%	152,512	17.7%	157,182	18.2%	94,958	11.0%	41,466	4.8%
South Dakota	DS	23,416	27.7%	26,301	31.1%	14,720	17.4%	10,727	12.7%	6,678	7.9%	DS	3.2%
Tennessee	1,222,099	247,314	20.2%	270,573	22.1%	218,067	17.8%	312,392	25.6%	140,098	11.5%	33,655	2.8%
Texas	3,167,925	975,515	30.8%	1,081,381	34.1%	556,834	17.6%	223,951	7.1%	214,932	6.8%	115,312	3.6%
USVI	14,885	2,615	17.6%	2,663	17.9%	2,127	14.3%	3,914	26.3%	2,630	17.7%	936	6.3%
Utah	203,809	54,223	26.6%	61,445	30.1%	33,346	16.4%	29,666	14.6%	17,680	8.7%	7,449	3.7%
Vermont	135,036	19,077	14.1%	23,398	17.3%	21,349	15.8%	41,030	30.4%	25,891	19.2%	4,291	3.2%
Virginia	800,796	199,224	24.9%	226,780	28.3%	140,051	17.5%	126,944	15.9%	75,883	9.5%	31,914	4.0%
Washington	1,392,959	251,281	18.0%	293,413	21.1%	223,302	16.0%	404,554	29.0%	203,117	14.6%	17,292	1.2%
West Virginia	414,435	56,267	13.6%	69,009	16.7%	59,014	14.2%	130,905	31.6%	86,121	20.8%	13,119	3.2%
Wisconsin	756,881	135,768	17.9%	163,415	21.6%	114,433	15.1%	188,090	24.9%	127,619	16.9%	27,556	3.6%
Wyoming	DS	9,553	24.1%	11,080	27.9%	6,848	17.3%	7,096	17.9%	3,812	9.6%	DS	3.3%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 2 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

^a Results include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^b Results include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

^c Age group is assigned using each beneficiary's age as of December 31, 2017.

DQ = Not reported due to concerns about data quality in the 2017 v4 TAF.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Table 3. Demographic Characteristics of Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

	Medicaid and CHIP beneficiaries with SCD ^a									
	Total number of beneficiaries with SCD		Number and percentage of beneficiaries, by age group ^c							
			Ages 0 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
	N	%	N	%	N	%	N	%	N	%
Sex										
Male	19,535	46.5%	12,125	50.6%	6,137	42.3%	1,204	36.4%	69	28.8%
Female	22,459	53.5%	11,829	49.4%	8,358	57.7%	2,101	63.6%	171	71.3%
Dual Eligible Status^d										
Dually Eligible	5,639	13.6%	181	0.8%	3,994	28.0%	1,256	38.4%	208	87.0%
Not Dually Eligible	35,736	86.4%	23,411	99.2%	10,282	72.0%	2,012	61.6%	31	13.0%
Geographic Area^e										
Urban	37,806	91.2%	21,496	91.1%	13,114	91.4%	2,986	91.2%	210	91.3%
Rural	3,643	8.8%	2,094	8.9%	1,241	8.6%	288	8.8%	20	8.7%
Census Division^f										
New England	1,579	3.8%	891	3.7%	543	3.8%	DS	DS	DS	DS
Middle Atlantic	6,783	16.2%	3,555	14.9%	2,530	17.5%	655	20.0%	43	18.7%
East North Central	6,468	15.5%	3,349	14.0%	2,510	17.4%	565	17.2%	44	19.1%
West North Central	1,420	3.4%	846	3.5%	446	3.1%	DS	DS	DS	DS
South Atlantic	12,408	29.7%	7,628	32.0%	3,960	27.4%	763	23.3%	57	24.8%
East South Central	3,858	9.2%	2,376	10.0%	1,205	8.3%	260	7.9%	17	7.4%
West South Central	5,565	13.3%	3,422	14.3%	1,753	12.1%	370	11.3%	20	8.7%
Mountain	867	2.1%	479	2.0%	318	2.2%	DS	DS	DS	DS
Pacific	2,876	6.9%	1,325	5.6%	1,177	8.1%	348	10.6%	26	11.3%

Table 3 (continued)

	Medicaid and CHIP beneficiaries without SCD ^b									
	Total number of beneficiaries without SCD		Number and percentage of beneficiaries, by age group ^c							
			Ages 0 to 20		Ages 21 to 45		Ages 46 to 64		Ages 65 to 75	
	N	%	N	%	N	%	N	%	N	%
Sex										
Male	26,327,890	46.3%	16,135,016	50.8%	5,379,570	38.1%	3,916,161	45.0%	897,143	38.2%
Female	30,594,259	53.7%	15,599,268	49.2%	8,751,862	61.9%	4,790,931	55.0%	1,452,198	61.8%
Dual Eligible Status^d										
Dually Eligible	5,437,079	9.7%	35,917	0.1%	1,042,035	7.5%	2,240,402	26.1%	2,118,725	91.1%
Not Dually Eligible	50,492,207	90.3%	31,119,913	99.9%	12,829,727	92.5%	6,335,289	73.9%	207,278	8.9%
Geographic Area^e										
Urban	46,924,897	84.6%	26,251,038	84.3%	11,668,116	84.9%	7,092,591	84.6%	1,913,152	87.2%
Rural	8,549,393	15.4%	4,894,969	15.7%	2,083,311	15.1%	1,290,901	15.4%	280,212	12.8%
Census Division^f										
New England	2,659,224	4.8%	1,233,528	3.9%	792,281	5.7%	522,059	6.2%	111,356	5.1%
Middle Atlantic	7,703,361	13.8%	3,778,421	12.0%	2,115,536	15.3%	1,454,806	17.2%	354,598	16.1%
East North Central	8,440,617	15.1%	4,307,946	13.7%	2,448,812	17.7%	1,424,590	16.9%	259,269	11.8%
West North Central	2,646,958	4.7%	1,628,139	5.2%	577,552	4.2%	355,357	4.2%	85,910	3.9%
South Atlantic	8,154,998	14.6%	5,588,292	17.8%	1,363,365	9.8%	848,048	10.0%	355,293	16.1%
East South Central	3,670,072	6.6%	2,197,196	7.0%	926,087	6.7%	458,094	5.4%	88,695	4.0%
West South Central	5,737,281	10.3%	4,142,795	13.2%	850,125	6.1%	560,178	6.6%	184,183	8.4%
Mountain	4,201,850	7.5%	2,329,974	7.4%	1,165,480	8.4%	599,493	7.1%	106,903	4.9%
Pacific	12,642,406	22.6%	6,161,842	19.6%	3,605,142	26.0%	2,218,189	26.3%	657,233	29.8%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Table 3 (continued)

Notes: Table 3 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF. Additional states are excluded from specific sections due to concerns about data quality; these additional exclusions are listed in the notes below. Slightly different totals across the sections are a function of these differences in the state exclusions.

^a Results include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^b Results include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

^c Age group is assigned using each beneficiary's age as of December 31, 2017.

^d People dually eligible for Medicare and Medicaid are also called dually eligible beneficiaries. Beneficiaries who were enrolled with dual eligibility for Medicaid and Medicare for at least 1 month in 2017 were classified as dually eligible for the purposes of this analysis. Results exclude Arkansas and Idaho due to concerns about data quality in the 2017 v4 TAF.

^e Beneficiaries are identified as living in an urban or rural location based on their most recent home address during the calendar year and the 2013 CDC Urban-Rural Classification Scheme for Counties: https://www.cdc.gov/nchs/data_access/urban_rural.htm. The urban classification combines the large central metro, large fringe metro, medium metro, and small metro categories; the rural classification combines the micropolitan and non-core categories. Results exclude Vermont and Wyoming due to concerns about data quality in the 2017 v4 TAF. Results also exclude Puerto Rico and USVI due to limitations in the CDC Urban-Rural Classification Scheme for Counties. Among the remaining states, there were 359 Medicaid and CHIP beneficiaries with an unknown geographic area.

^f Results exclude Puerto Rico and USVI because U.S. territories are not categorized into U.S. Census Divisions.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Table 4. National and State-level Counts and Prevalence of Sickle Cell Disease (SCD) per 100,000 Medicaid and CHIP Beneficiaries in 2017, by Length of Coverage

State	Beneficiaries with at least 1 month of Medicaid or CHIP enrollment in 2017			Beneficiaries with at least 6 months of Medicaid or CHIP enrollment in 2017			Beneficiaries with 12 months of Medicaid or CHIP enrollment in 2017		
	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries
United States	82,936,438	50,560	61.0	71,963,331	48,138	66.9	56,965,040	41,995	73.7
Alabama	1,090,330	1,559	143.0	894,618	1,482	165.7	647,135	1,310	202.4
Alaska	223,077	23	10.3	199,479	20	10.0	164,573	DS	DS
Arizona	2,041,569	420	20.6	1,797,815	399	22.2	1,388,807	339	24.4
Arkansas	1,076,990	682	63.3	935,785	670	71.6	762,208	608	79.8
California	13,781,278	2,977	21.6	12,077,405	2,812	23.3	10,075,536	2,553	25.3
Colorado	1,592,629	234	14.7	1,364,981	214	15.7	1,065,500	184	17.3
Connecticut	926,640	615	66.4	807,401	580	71.8	644,995	500	77.5
Delaware	254,373	277	108.9	218,441	268	122.7	165,198	226	136.8
District of Columbia	257,093	418	162.6	241,125	409	169.6	216,044	367	169.9
Florida	4,017,865	4,721	117.5	3,446,090	4,487	130.2	2,719,709	3,948	145.2
Georgia	2,120,110	3,557	167.8	1,826,401	3,393	185.8	1,381,427	3,026	219.0
Hawaii	391,107	15	3.8	346,589	14	4.0	289,799	DS	DS
Idaho	312,035	17	5.4	274,450	17	6.2	232,171	DS	DS
Illinois	3,427,597	2,365	69.0	3,015,147	2,265	75.1	2,486,608	1,988	79.9
Indiana	1,574,552	736	46.7	1,316,642	704	53.5	1,010,562	622	61.5
Iowa	747,611	206	27.6	641,806	197	30.7	489,395	155	31.7
Kansas	459,238	160	34.8	392,987	155	39.4	312,621	143	45.7

Table 4 (continued)

State	Beneficiaries with at least 1 month of Medicaid or CHIP enrollment in 2017			Beneficiaries with at least 6 months of Medicaid or CHIP enrollment in 2017			Beneficiaries with 12 months of Medicaid or CHIP enrollment in 2017		
	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries
Kentucky	1,517,521	363	23.9	1,417,627	354	25.0	1,320,835	331	25.1
Louisiana	1,652,792	2,338	141.5	1,489,815	2,265	152.0	1,246,227	2,084	167.2
Maine	242,105	31	12.8	208,416	24	11.5	161,013	19	11.8
Maryland	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ	DQ
Massachusetts	1,868,393	1,062	56.8	1,638,651	1,008	61.5	1,314,584	907	69.0
Michigan	2,736,285	1,663	60.8	2,382,214	1,595	67.0	1,841,836	1,368	74.3
Minnesota	1,247,330	458	36.7	1,069,545	431	40.3	815,812	341	41.8
Mississippi	652,339	1,228	188.2	586,920	1,197	203.9	482,743	1,099	227.7
Missouri	1,146,927	906	79.0	1,016,406	865	85.1	849,314	750	88.3
Montana	292,866	DS	DS	255,461	DS	DS	212,112	DS	DS
Nebraska	258,767	113	43.7	121,751	56	46.0	35,192	18	51.1
Nevada	783,686	380	48.5	638,786	349	54.6	440,538	282	64.0
New Hampshire	223,752	15	6.7	181,891	14	7.7	140,629	DS	DS
New Jersey	1,838,244	1,334	72.6	1,585,695	1,254	79.1	1,237,634	1,043	84.3
New Mexico	863,271	28	3.2	779,913	27	3.5	620,066	24	3.9
New York	7,029,327	5,321	75.7	5,940,126	5,006	84.3	4,472,424	4,173	93.3
North Carolina	2,105,269	2,372	112.7	1,886,899	2,272	120.4	1,604,805	2,082	129.7
North Dakota	114,229	12	10.5	90,837	DS	DS	61,533	DS	DS
Ohio	3,262,047	2,212	67.8	2,914,740	2,131	73.1	2,350,590	1,882	80.1

Table 4 (continued)

State	Beneficiaries with at least 1 month of Medicaid or CHIP enrollment in 2017			Beneficiaries with at least 6 months of Medicaid or CHIP enrollment in 2017			Beneficiaries with 12 months of Medicaid or CHIP enrollment in 2017		
	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries	Total number of Medicaid and CHIP beneficiaries ^a	Number of beneficiaries with SCD ^b	Prevalence rate of SCD per 100,000 beneficiaries
Oklahoma	901,769	332	36.8	771,627	312	40.4	563,882	269	47.7
Oregon	1,192,916	107	9.0	1,015,006	103	10.1	722,191	77	10.7
Pennsylvania	3,261,245	2,205	67.6	2,789,275	2,083	74.7	2,000,086	1,567	78.3
Puerto Rico	1,450,751	172	11.9	1,315,661	166	12.6	1,051,533	140	13.3
Rhode Island	337,520	149	44.1	312,412	142	45.5	264,531	130	49.1
South Carolina	1,169,115	1,870	160.0	1,039,871	1,807	173.8	863,892	1,659	192.0
South Dakota	131,923	DS	DS	111,187	DS	DS	84,511	DS	DS
Tennessee	1,612,696	1,257	77.9	1,397,090	1,201	86.0	1,223,217	1,118	91.4
Texas	5,087,102	3,229	63.5	4,341,925	3,068	70.7	3,170,529	2,604	82.1
USVI	28,090	40	142.4	21,057	38	180.5	14,916	31	207.8
Utah	380,355	34	8.9	300,638	33	11.0	203,833	24	11.8
Vermont	186,758	20	10.7	167,590	20	11.9	135,051	15	11.1
Virginia	1,145,798	1,268	110.7	995,447	1,219	122.5	801,858	1,062	132.4
Washington	2,005,312	282	14.1	1,742,204	261	15.0	1,393,183	224	16.1
West Virginia	625,158	51	8.2	546,410	48	8.8	414,473	38	9.2
Wisconsin	1,211,190	713	58.9	1,031,522	683	66.2	757,489	608	80.3
Wyoming	79,496	DS	DS	61,554	DS	DS	39,690	DS	DS

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 4 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

This table highlights how applying different criteria for the length of Medicaid or CHIP enrollment affects the number of beneficiaries with SCD and the prevalence rate of SCD per 100,000 beneficiaries.

Table 4 (continued)

Nationally, there were 50,560 people with SCD who were enrolled in Medicaid or CHIP with full or comprehensive benefits for at least one month during 2017. Of these 50,560 beneficiaries, 8,565 beneficiaries were enrolled in Medicaid or CHIP for less than 12 months during the year. These 8,565 beneficiaries are excluded from all other analyses in the SCD Report.

Beneficiaries with 12 continuous months of Medicaid or CHIP enrollment in 2017 are shown in the right panel of this table. All other analyses in the SCD Report include the 41,995 beneficiaries with SCD who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017.

^a Counts include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for the specified number of months in 2017.

^b Counts include beneficiaries under age 76 who were enrolled in Medicaid or CHIP with full or comprehensive benefits for the specified number of months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

DQ = Not reported due to concerns about data quality in the 2017 v4 TAF.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Recommended Care for Sickle Cell Disease

The tables in this section provide information about the receipt of recommended care for SCD among Medicaid and CHIP beneficiaries with SCD in 2017. SCD is a group of inherited red blood cell disorders and people who inherit two sickle cell genes (one from each parent) have a form of SCD commonly called sickle cell anemia (SCA).¹¹

Three of the four tables in this section reflect recommended care for people with SCA (a type of SCD that is usually one of the most severe and prevalent forms of the disease),¹² including Transcranial Doppler Ultrasound (TCD) screenings (Table 5), hydroxyurea use (Table 6), and antibiotic prophylaxis (Table 8). Previous studies suggest that claims data may not reliably identify SCD subtypes, such as SCA.¹³ Therefore, the data shown in Tables 5, 6, and 8 include information for people with any type of SCD. The data shown in Table 7 refer to pneumococcal vaccinations for children with any type of SCD. Key findings from each table are included below.

Table 5. Transcranial Doppler Ultrasound (TCD) Screenings among Medicaid and CHIP Beneficiaries Ages 3 to 16 with Sickle Cell Disease (SCD) in 2017, by Age Group

- TCD screenings are used to identify children who are at risk for stroke. The National Institutes of Health (NIH) recommends annual TCD screenings for children with SCA, a specific type of SCD, from ages 2 to 16. However, this analysis was not restricted to children with SCA due to concerns that claims data alone may not be reliable for identifying the subgroup of children with SCA.
- Fewer than 4 out of 10 (36.6 percent) Medicaid and CHIP beneficiaries ages 3 to 16 with SCD had at least one TCD screening in 2017. The percentage was higher among beneficiaries ages 3 to 5 (41.2 percent) and ages 6 to 12 (39.6 percent) than among beneficiaries ages 13 to 16 (26.3 percent).

Table 6. Hydroxyurea Use among Medicaid and CHIP Beneficiaries Age 21 Months and Older with Sickle Cell Disease (SCD) in 2017, by Age Group

- The National Institutes of Health (NIH) recommends hydroxyurea as a treatment for SCA, a specific type of SCD, for people age 9 months and older. However, this analysis

¹¹ U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. “What is Sickle Cell Disease?” Available from: <https://www.cdc.gov/ncbddd/sicklecell/facts.html>.

¹² Aluc, A., M. Zhou, S.T. Paulukonis, et al. “Using surveillance to determine the number of individuals with sickle cell disease in California and Georgia, 2005–2016.” *Pediatric Hematology and Oncology*, 2020. Available at: <https://doi.org/10.1080/08880018.2020.1779886>.

¹³ Grosse, S.D., N. Green, and S. Reeves. “Administrative data identify sickle cell disease: A critical review of approaches in U.S. health services research.” *Pediatric Blood & Cancer*, 2020, vol. 67, no. 12, pg. e28703. Available at: <https://doi.org/10.1002/pbc.28703>.

was not restricted to children with SCA due to concerns that claims data alone may not be reliable for identifying the subgroup of children with SCA.

- Just over one-third of Medicaid and CHIP beneficiaries with SCD had any days of hydroxyurea use in 2017 (37.1 percent of children and 34.5 percent of adults). Approximately 15.6 percent of children (ages 21 months to 20 years) and 9.6 percent of adults (ages 21 to 75) had more than 180 days of hydroxyurea use.

Table 7. Pneumococcal Vaccinations among Medicaid and CHIP Beneficiaries Under Age 2 with Sickle Cell Disease (SCD) in 2017

- The Advisory Committee on Immunization Practices recommends that children with SCD should receive four doses of the 13-valent conjugate pneumococcal vaccine before age 2.
- Approximately 6 out of 10 (59.1 percent) Medicaid and CHIP beneficiaries under age 2 with SCD received at least one pneumococcal vaccination in 2017.

Table 8. Antibiotic Prophylaxis among Medicaid and CHIP Beneficiaries Ages 15 Months to Age 4 with Sickle Cell Disease (SCD) in 2017

- Antibiotic prophylaxis is recommended for children under age 5 with SCA, a specific type of SCD, to decrease the risk of invasive pneumococcal disease. However, this analysis was not restricted to children with SCA due to concerns that claims data alone may not be reliable for identifying the subgroup of children with SCA.
- Just over 1 out of 10 (11.2 percent) Medicaid and CHIP beneficiaries ages 15 months to 4 years with SCD had 300 or more days of antibiotic prophylaxis in 2017. The median number of days of antibiotic prophylaxis during the year was 137 days.

Table 5. Transcranial Doppler Ultrasound (TCD) Screenings among Medicaid and CHIP Beneficiaries Ages 3 to 16 with Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Total number of beneficiaries with SCD ^b	Medicaid and CHIP beneficiaries with SCD			
		Beneficiaries with 0 TCD screenings		Beneficiaries with at least 1 TCD screening	
		N	%	N	%
Total	16,674	10,570	63.4%	6,104	36.6%
Ages 3 to 5	3,821	2,245	58.8%	1,576	41.2%
Ages 6 to 12	8,627	5,211	60.4%	3,416	39.6%
Ages 13 to 16	4,226	3,114	73.7%	1,112	26.3%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 5 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

TCD screenings are used to identify children who are at risk for stroke. The National Institutes of Health (NIH) recommends annual TCD screenings for children with sickle cell anemia (SCA), a specific type of SCD, from ages 2 to 16. Recommendation is available at: <https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease>. To align with the NIH recommendation for annual TCD screenings from ages 2 to 16, this analysis includes children who were at least age 2 but no older than age 16 for the entire calendar year. This analysis was not restricted to children with SCA due to concerns that claims data alone may not be reliable for identifying the subgroup of children with SCA. TCD screenings were identified using the procedure codes reported on claims.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

Table 6. Hydroxyurea Use among Medicaid and CHIP Beneficiaries Age 21 Months and Older with Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Total number of beneficiaries with SCD ^b	Percentage of beneficiaries with no hydroxyurea use	Percentage of beneficiaries with any hydroxyurea use	Number of days of hydroxyurea use among beneficiaries with SCD									
				0 days		1 to 90 days		91 to 180 days		181 to 270 days		More than 270 days	
				N	%	N	%	N	%	N	%	N	%
Total	34,508	63.8%	36.2%	22,017	63.8%	4,566	13.2%	3,264	9.5%	2,633	7.6%	2,028	5.9%
Total - Children (Ages 21 months to 20 years)	22,235	62.9%	37.1%	13,984	62.9%	2,490	11.2%	2,283	10.3%	1,967	8.8%	1,511	6.8%
Ages 21 months to 5 years	6,385	74.5%	25.5%	4,759	74.5%	454	7.1%	381	6.0%	358	5.6%	433	6.8%
Ages 6 to 12	8,475	59.1%	40.9%	5,008	59.1%	860	10.1%	958	11.3%	913	10.8%	736	8.7%
Ages 13 to 20	7,375	57.2%	42.8%	4,217	57.2%	1,176	15.9%	944	12.8%	696	9.4%	342	4.6%
Total - Adults (Ages 21 to 75)	12,273	65.5%	34.5%	8,033	65.5%	2,076	16.9%	981	8.0%	666	5.4%	517	4.2%
Ages 21 to 30	6,054	60.4%	39.6%	3,659	60.4%	1,292	21.3%	552	9.1%	334	5.5%	217	3.6%
Ages 31 to 45	4,193	67.6%	32.4%	2,833	67.6%	628	15.0%	310	7.4%	227	5.4%	195	4.7%
Ages 46 to 54	1,314	73.4%	26.6%	964	73.4%	116	8.8%	89	6.8%	72	5.5%	73	5.6%
Ages 55 to 64	686	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	32	4.7%
Ages 65 to 75	26	DS	DS	DS	DS	DS	DS	DS	DS	DS	DS	0	0.0%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 6 includes 47 states, the District of Columbia, and the U.S. Virgin Islands (USVI). Results for Arkansas, Idaho, Maryland, and Puerto Rico are excluded due to concerns about data quality in the 2017 v4 TAF. Dually eligible beneficiaries are excluded due to incomplete pharmacy claims for this population in the TAF. Beneficiaries who were enrolled with dual eligibility for Medicaid and Medicare for at least one month in 2017 were classified as dually eligible for the purposes of this analysis.

The National Institutes of Health (NIH) recommends hydroxyurea as a treatment for sickle cell anemia (SCA), a specific type of SCD, for people age 9 months and older. Recommendation is available at: <https://www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease>. To align with the NIH recommendation for hydroxyurea use for people age 9 months and older, this analysis includes people who were at least 9 months old for

Table 6 (continued)

the entire calendar year. This analysis was not restricted to people with SCA due to concerns that claims data alone may not be reliable for identifying the subgroup of people with SCA.

Hydroxyurea use was identified using the national drug codes reported on pharmacy claims. For this analysis, the number of days of hydroxyurea use reflects the number of calendar days in 2017 that a beneficiary was covered with a prescription for hydroxyurea.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Table 7. Pneumococcal Vaccinations among Medicaid and CHIP Beneficiaries Under Age 2 with Sickle Cell Disease (SCD) in 2017

Age group ^a	Total number of beneficiaries with SCD ^b	Medicaid and CHIP beneficiaries with SCD			
		Beneficiaries with 0 pneumococcal vaccinations during the year		Beneficiaries with at least 1 pneumococcal vaccination during the year	
		N	%	N	%
Under age 2	2,577	1,054	40.9%	1,523	59.1%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 7 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

Children should receive four doses of the 13-valent conjugate pneumococcal vaccine before age 2.

Recommendations from the Advisory Committee on Immunization Practices is available at:

<https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html>. This analysis used one year of data for calendar year 2017 and identified the percentage of children under age 2 who received at least one pneumococcal vaccination during the year. The one-year time period used for this analysis is not sufficient to determine the percentage of children who were up to date on recommended vaccinations in 2017.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

Table 8. Antibiotic Prophylaxis among Medicaid and CHIP Beneficiaries Ages 15 Months to Age 4 with Sickle Cell Disease (SCD) in 2017

Age group ^a	Medicaid and CHIP beneficiaries with SCD			
	Total number of beneficiaries with SCD ^b	Number of beneficiaries with at least 300 days of antibiotic prophylaxis	Percentage of beneficiaries with at least 300 days of antibiotic prophylaxis	Median number of days of antibiotic prophylaxis
Ages 15 months to 4 years	4,053	453	11.2%	137

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 8 includes 46 states, the District of Columbia, and the U.S. Virgin Islands (USVI). Results for Arkansas, Florida, Idaho, Maryland, and Puerto Rico are excluded due to concerns about data quality in the 2017 v4 TAF. Dually eligible beneficiaries are excluded due to incomplete pharmacy claims for this population in the TAF. Beneficiaries who were enrolled with dual eligibility for Medicaid and Medicare for at least one month in 2017 were classified as dually eligible for the purposes of this analysis.

Antibiotic prophylaxis is recommended for children under age 5 with sickle cell anemia (SCA) to decrease the risk of invasive pneumococcal disease. Additional information is available at: <https://pediatrics.aappublications.org/content/141/3/e20172182>. To align with the recommendation for antibiotic prophylaxis for children under age 5, this analysis includes people who were at least 3 months old but no older than age 4 for the entire calendar year. A lower age bound of 15 months, rather than 12 months, was used to allow for a 3-month lag in diagnosing children with SCD. This analysis was not restricted to people with SCA due to concerns that claims data alone may not be reliable for identifying the subgroup of people with SCA.

Antibiotic prophylaxis was identified using the national drug codes reported on pharmacy claims. For this analysis, the number of days of antibiotic prophylaxis reflects the number of calendar days in 2017 that a beneficiary was covered with a prescription for antibiotic prophylaxis.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

Health Care Utilization

The tables in this section show the patterns of specific types of health care utilization among Medicaid and CHIP beneficiaries with SCD compared to beneficiaries without SCD. These analyses examine emergency department (ED) use (Tables 9-10), inpatient hospital stays (Tables 11-12), and outpatient visits with any provider (Table 13). Key findings from each table are included below.

Emergency Department Use

Table 9. Emergency Department (ED) Use among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Table 10. Number of Emergency Department (ED) Visits among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

- Nearly 8 out of 10 (77.7 percent) Medicaid and CHIP beneficiaries with SCD had at least one ED visit, compared to 3 out of 10 (34.3 percent) beneficiaries without SCD.
- On average, Medicaid and CHIP beneficiaries with SCD had five times more ED visits than those without SCD in 2017.
- Approximately 30.4 percent of the ED visits for Medicaid and CHIP beneficiaries with SCD compared to 8.3 percent of ED visits among beneficiaries without SCD resulted in an inpatient hospital stay.
- More than 2 out of 10 (22.7 percent) Medicaid and CHIP beneficiaries with SCD had six or more ED visits during 2017, compared to 2.0 percent of beneficiaries without SCD.

Inpatient Hospital Stays

Table 11. Inpatient Hospital Stays among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Table 12. Number of Inpatient Hospital Stays among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

- Nearly half (48.6 percent) of Medicaid and CHIP beneficiaries with SCD had at least one inpatient hospital stay in 2017, compared to 6.3 percent of beneficiaries without SCD; 6.6 percent of beneficiaries with SCD had six or more stays during the year, compared to 0.1 percent for beneficiaries without SCD.
- Medicaid and CHIP beneficiaries with SCD had an average of 8.9 inpatient days in 2017, including an average of 4.7 days for beneficiaries up to age 20 and an average of 14.4 days for beneficiaries ages 21 to 75. Beneficiaries without SCD had an average of 0.6

inpatient days, including an average of 0.2 days for beneficiaries up to age 20 and an average of 1.0 days for beneficiaries ages 21 to 75.

Outpatient Visits

Table 13. Outpatient Visits among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

- Medicaid and CHIP beneficiaries with SCD had a median of 14 outpatient visits in 2017, which was nearly three times greater than beneficiaries without SCD, who had a median of 5 outpatient visits during the year.

Table 9. Emergency Department (ED) Use among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b				Medicaid and CHIP beneficiaries without SCD ^c			
	Total number of beneficiaries with SCD	Percentage of beneficiaries with at least 1 ED visit	Mean number of ED visits during the year	Percentage of ED visits that led to an inpatient hospital stay	Total number of beneficiaries without SCD	Percentage of beneficiaries with at least 1 ED visit	Mean number of ED visits during the year	Percentage of ED visits that led to an inpatient hospital stay
Total	41,995	77.7%	5.2	30.4%	56,923,045	34.3%	0.8	8.3%
Ages 0 to 5	7,637	76.9%	2.4	26.1%	10,326,625	39.4%	0.7	3.1%
Ages 6 to 12	8,627	67.5%	1.9	31.7%	12,038,559	25.3%	0.4	2.8%
Ages 13 to 20	7,691	74.6%	3.9	36.7%	9,369,898	30.0%	0.6	4.7%
Ages 21 to 30	7,949	88.5%	10.4	29.9%	6,521,897	40.1%	1.0	6.7%
Ages 31 to 45	6,546	83.4%	8.2	28.4%	7,609,575	40.1%	1.1	9.1%
Ages 46 to 54	2,106	78.4%	5.5	31.6%	4,216,465	39.1%	1.1	14.2%
Ages 55 to 64	1,199	73.9%	4.1	31.7%	4,490,662	36.2%	0.9	18.6%
Ages 65 to 75	240	69.6%	2.6	29.5%	2,349,364	29.2%	0.7	21.4%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 9 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

This analysis includes ED visits in which the beneficiary was treated and released as well as ED visits that resulted in a hospital admission. ED visits that resulted in a hospital admission are counted in the number of ED visits in Tables 9 and 10 as well as in the number of inpatient hospital stays in Tables 11 and 12.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

Table 10. Number of Emergency Department (ED) Visits among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b					Medicaid and CHIP beneficiaries without SCD ^c				
	Total number of beneficiaries with SCD	Number of ED visits during the year				Total number of beneficiaries without SCD	Number of ED visits during the year			
		0 ED visits	1 ED visit	2 to 5 ED visits	6 or more ED visits		0 ED visits	1 ED visit	2 to 5 ED visits	6 or more ED visits
Total	41,995	22.3%	18.5%	36.5%	22.7%	56,923,045	65.7%	18.4%	14.0%	2.0%
Ages 0 to 5	7,637	23.1%	22.7%	43.8%	10.4%	10,326,625	60.6%	21.8%	16.5%	1.1%
Ages 6 to 12	8,627	32.5%	24.1%	35.8%	7.6%	12,038,559	74.7%	17.0%	8.1%	0.3%
Ages 13 to 20	7,691	25.4%	18.3%	36.1%	20.2%	9,369,898	70.0%	17.6%	11.3%	1.1%
Ages 21 to 30	7,949	11.5%	12.3%	33.3%	42.8%	6,521,897	59.9%	18.5%	18.2%	3.4%
Ages 31 to 45	6,546	16.6%	13.8%	33.9%	35.7%	7,609,575	59.9%	18.6%	17.7%	3.7%
Ages 46 to 54	2,106	21.6%	18.4%	34.6%	25.4%	4,216,465	60.9%	18.1%	17.1%	3.9%
Ages 55 to 64	1,199	26.1%	19.7%	33.5%	20.7%	4,490,662	63.8%	17.5%	15.5%	3.2%
Ages 65 to 75	240	30.4%	19.2%	39.2%	11.3%	2,349,364	70.8%	15.1%	12.1%	2.0%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 10 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

This analysis includes ED visits in which the beneficiary was treated and released as well as ED visits that resulted in a hospital admission. ED visits that resulted in a hospital admission are counted in the number of ED visits in Tables 9 and 10 as well as in the number of inpatient hospital stays in Tables 11 and 12.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

Table 11. Inpatient Hospital Stays among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b			Medicaid and CHIP beneficiaries without SCD ^c		
	Total number of beneficiaries with SCD	Percentage of beneficiaries with at least 1 inpatient hospital stay	Mean number of hospital days during the year ^d	Total number of beneficiaries without SCD	Percentage of beneficiaries with at least 1 inpatient hospital stay	Mean number of hospital days during the year ^d
Total	41,995	48.6%	8.9	56,923,045	6.3%	0.6
Ages 0 to 20	23,955	40.3%	4.7	31,735,082	2.6%	0.2
Ages 21 to 75	18,040	59.7%	14.4	25,187,963	11.0%	1.0

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 11 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF. This analysis includes inpatient hospital stays in which the beneficiary was directly admitted to the hospital, as well as inpatient hospital stays in which the beneficiary was admitted to the hospital after being transferred from an ED or another facility. Inpatient hospital stays in which the beneficiary was admitted to the hospital after being transferred from an ED are counted in the number of inpatient hospital stays in Tables 11 and 12 as well as in the number of ED visits in Tables 9 and 10.

Inpatient hospital stays were identified using the methods recommended in the TAF technical documentation for claims files, available at: https://resdac.org/sites/datadocumentation.resdac.org/files/2021-08/TAF_TechGuide_Claims_Files.pdf

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

^d Mean number of hospital days during the year is calculated based on all Medicaid and CHIP beneficiaries, including those with 0 inpatient hospital stays during the year.

Table 12. Number of Inpatient Hospital Stays among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b					Medicaid and CHIP beneficiaries without SCD ^c				
	Total number of beneficiaries with SCD	Number of inpatient hospital stays during the year				Total number of beneficiaries without SCD	Number of inpatient hospital stays during the year			
		0 stays	1 stay	2 to 5 stays	6 or more stays		0 stays	1 stay	2 to 5 stays	6 or more stays
Total	41,995	51.4%	20.7%	21.3%	6.6%	56,923,045	93.7%	4.8%	1.4%	0.1%
Ages 0 to 5	7,637	60.1%	23.6%	15.3%	0.9%	10,326,625	96.8%	2.7%	0.4%	0.0%
Ages 6 to 12	8,627	65.7%	18.9%	14.0%	1.5%	12,038,559	98.8%	0.9%	0.2%	0.0%
Ages 13 to 20	7,691	52.5%	19.0%	22.0%	6.6%	9,369,898	96.2%	3.1%	0.6%	0.0%
Ages 21 to 30	7,949	35.0%	21.0%	29.2%	14.7%	6,521,897	88.5%	9.6%	1.8%	0.1%
Ages 31 to 45	6,546	42.5%	20.4%	26.6%	10.6%	7,609,575	90.9%	6.8%	2.1%	0.2%
Ages 46 to 54	2,106	47.8%	21.8%	23.5%	6.9%	4,216,465	89.2%	7.2%	3.2%	0.3%
Ages 55 to 64	1,199	49.0%	22.1%	DS	DS	4,490,662	87.3%	8.5%	3.9%	0.3%
Ages 65 to 75	240	50.4%	25.0%	DS	DS	2,349,364	87.6%	9.1%	3.2%	0.1%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 12 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

This analysis includes inpatient hospital stays in which the beneficiary was directly admitted to the hospital, as well as inpatient hospital stays in which the beneficiary was admitted to the hospital after being transferred from an ED or another facility. Inpatient hospital stays in which the beneficiary was admitted to the hospital after being transferred from an ED are counted in the number of inpatient hospital stays in Tables 11 and 12 as well as in the number of ED visits in Tables 9 and 10.

Inpatient hospital stays were identified using the methods recommended in the TAF technical documentation for claims files, available at: https://resdac.org/sites/datadocumentation.resdac.org/files/2021-08/TAF_TechGuide_Claims_Files.pdf.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Table 13. Outpatient Visits among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b				Medicaid and CHIP beneficiaries without SCD ^c			
	Total number of beneficiaries with SCD	Number of outpatient visits during the year	Median number of outpatient visits during the year	Mean number of outpatient visits during the year	Total number of beneficiaries without SCD	Number of outpatient visits during the year	Median number of outpatient visits during the year	Mean number of outpatient visits during the year
Total	41,995	1,025,436	14	24	56,923,045	776,723,116	5	14
Ages 0 to 5	7,637	118,134	11	15	10,326,625	97,708,264	6	9
Ages 6 to 12	8,627	151,604	11	18	12,038,559	121,243,681	5	10
Ages 13 to 20	7,691	150,372	13	20	9,369,898	91,739,835	4	10
Ages 21 to 30	7,949	235,431	18	30	6,521,897	85,394,065	4	13
Ages 31 to 45	6,546	221,899	20	34	7,609,575	122,765,401	6	16
Ages 46 to 54	2,106	82,760	23	39	4,216,465	88,232,970	9	21
Ages 55 to 64	1,199	51,998	25	43	4,490,662	105,405,112	10	23
Ages 65 to 75	240	13,238	25	55	2,349,364	64,233,788	8	27

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 13 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

This analysis includes visits with any provider in an outpatient setting, excluding claims for only laboratory, imaging, and transportation services. Professional claims for services provided in inpatient or long-term care settings are also excluded.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

Preventive Care

The tables in this section show the receipt of preventive care among Medicaid and CHIP beneficiaries with SCD compared to beneficiaries without SCD. For these analyses, recommended preventive care included routine health screenings (Table 14) and routine dental examinations (Table 15).¹⁴ Key findings from each table are included below.

Table 14. Health Screenings among Medicaid and CHIP Beneficiaries Under Age 21 with and without Sickle Cell Disease (SCD) in 2017, by Age Group

- The Bright Futures and American Academy of Pediatrics recommend that children age 3 and older should have one health screening per year. Children younger than age 3 should have more frequent screenings.
- Just over half (53.5 percent) of Medicaid and CHIP beneficiaries under age 21 with SCD had at least one health screening, which is slightly higher than rates among beneficiaries under age 21 without SCD (51.3 percent).
- The percentage of Medicaid and CHIP beneficiaries under age 21 with SCD who had at least one health screening decreased with age. Approximately 73.4 percent of children ages 0 to 5 had at least one screening, compared to 51.1 percent of beneficiaries ages 6 to 12 and 36.4 percent of beneficiaries ages 13 to 20.

Table 15. Dental Examinations among Medicaid and CHIP Beneficiaries Ages 2 to 20 with and without Sickle Cell Disease (SCD) in 2017

- The American Academy of Pediatric Dentistry (AAPD) recommends that children should have dental examinations every six months beginning no later than their first birthday.
- Just over half (54.1 percent) of Medicaid and CHIP beneficiaries ages 2 to 20 with SCD had at least one dental examination, which is similar to the rate among beneficiaries ages 2 to 20 without SCD (53.8 percent).
- The percentage of Medicaid and CHIP beneficiaries with SCD who had at least one dental examination was higher among beneficiaries ages 2 to 5 and ages 6 to 12 (58.1 and 60.3 percent, respectively) than among beneficiaries ages 13 to 20 (44.5 percent).

¹⁴ Both these services are covered by the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit, which provides comprehensive preventive health care services for children under age 21 who are enrolled in Medicaid. More information about the EPSDT benefit is available at:

<https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>.

Table 14. Health Screenings among Medicaid and CHIP Beneficiaries Under Age 21 with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b			Medicaid and CHIP beneficiaries without SCD ^c		
	Total number of beneficiaries with SCD	Number of beneficiaries with at least 1 health screening	Percentage of beneficiaries with at least 1 health screening	Total number of beneficiaries without SCD	Number of beneficiaries with at least 1 health screening	Percentage of beneficiaries with at least 1 health screening
Total	23,955	12,810	53.5%	31,735,082	16,280,499	51.3%
Ages 0 to 5	7,637	5,604	73.4%	10,326,625	7,049,870	68.3%
Ages 6 to 12	8,627	4,408	51.1%	12,038,559	5,750,451	47.8%
Ages 13 to 20	7,691	2,798	36.4%	9,369,898	3,480,178	37.1%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 14 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF. Health screenings are covered by the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. The Medicaid program provides the EPSDT benefit, which provides a comprehensive array of prevention, diagnostic, and treatment services for low-income infants, children, and adolescents under age 21, as specified in Section 1905(r) of the Social Security Act. Additional information on the EPSDT benefit is available at: <https://www.medicaid.gov/medicaid/benefits/early-and-periodic-screening-diagnostic-and-treatment/index.html>.

Children age 3 and older should have one health screening per year. Children younger than age 3 should have more frequent screenings. The Bright Futures and American Academy of Pediatrics recommendation is available at: https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf.

Health screenings were identified using the procedure codes and diagnosis codes reported on claims.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

Table 15. Dental Examinations among Medicaid and CHIP Beneficiaries Ages 2 to 20 with and without Sickle Cell Disease (SCD) in 2017

Age group ^a	Medicaid and CHIP beneficiaries with SCD ^b					Medicaid and CHIP beneficiaries without SCD ^c				
	Total number of beneficiaries with SCD	Beneficiaries with 0 dental exams		Beneficiaries with at least 1 dental exam		Total number of beneficiaries without SCD	Beneficiaries with 0 dental exams		Beneficiaries with at least 1 dental exam	
		N	%	N	%		N	%	N	%
Total	21,378	9,812	45.9%	11,566	54.1%	28,287,911	13,070,884	46.2%	15,217,027	53.8%
Ages 2 to 5	5,060	2,121	41.9%	2,939	58.1%	6,879,454	3,026,655	44.0%	3,852,799	56.0%
Ages 6 to 12	8,627	3,424	39.7%	5,203	60.3%	12,038,559	4,832,046	40.1%	7,206,513	59.9%
Ages 13 to 20	7,691	4,267	55.5%	3,424	44.5%	9,369,898	5,212,183	55.6%	4,157,715	44.4%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Notes: Table 15 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

Children should have dental examinations every six months beginning no later than the first birthday. The American Academy of Pediatric Dentistry (AAPD) recommendation is available at: https://www.aapd.org/globalassets/media/policies_guidelines/bp_recdentperiodschedule.pdf. To align with the AAPD recommendation for annual dental examinations beginning no later than the first birthday, this analysis includes children who were at least age 1 for the entire calendar year.

^a Age group is assigned using each beneficiary's age as of December 31, 2017.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^c Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

Health Conditions

The table in this section shows the prevalence of selected diagnoses among Medicaid and CHIP beneficiaries with SCD compared to beneficiaries without SCD in 2017. Diagnoses were identified using one year of claims data; this is not an indicator of whether an individual ever had the condition. The selected health conditions included in this analysis were: acute chest syndrome; anxiety disorders; asthma; chronic kidney disease; chronic obstructive pulmonary disease and bronchiectasis; depression; diabetes; epilepsy; fibromyalgia, chronic pain, and fatigue; heart failure; hyperlipidemia; hypertension; liver disease, cirrhosis, and other liver conditions; migraine and chronic headache; obesity; splenic sequestration; and stroke or transient ischemic attack.

Table 16. Selected Diagnoses Among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

- The five most common diagnoses among Medicaid and CHIP beneficiaries with SCD in 2017 were asthma (18.0 percent); acute chest syndrome (17.8 percent); fibromyalgia, chronic pain, and fatigue (15.5 percent); hypertension (12.9 percent); and depression (11.8 percent).
- The five most common diagnoses among Medicaid and CHIP beneficiaries without SCD in 2017 were depression (8.6 percent), hypertension (7.8 percent), anxiety disorders (5.9 percent), diabetes (5.2 percent), and hyperlipidemia (3.8 percent).
- The most common diagnoses by age group for Medicaid and CHIP beneficiaries with SCD were:
 - Ages 0 to 20: asthma (18.7 percent)
 - Ages 21 to 45: fibromyalgia, chronic pain, and fatigue (31.5 percent)
 - Ages 46 to 75: hypertension (50.2 percent)
- The most common diagnoses by age group for Medicaid and CHIP beneficiaries without SCD were:
 - Ages 0 to 20: asthma (3.9 percent)
 - Ages 21 to 45: depression (13.7 percent)
 - Ages 46 to 75: hypertension (30.9 percent)

Table 16. Selected Diagnoses Among Medicaid and CHIP Beneficiaries with and without Sickle Cell Disease (SCD) in 2017, by Age Group

Condition	Medicaid and CHIP beneficiaries with SCD ^a							
	Total		Ages 0 to 20		Ages 21 to 45		Ages 46 to 75	
	N	%	N	%	N	%	N	%
Total number of beneficiaries	41,995	100.0%	23,955	100.0%	14,495	100.0%	3,545	100.0%
Acute chest syndrome	7,472	17.8%	3,879	16.2%	3,206	22.1%	387	10.9%
Anxiety disorders	3,400	8.1%	870	3.6%	2,063	14.2%	467	13.2%
Asthma	7,580	18.0%	4,479	18.7%	2,653	18.3%	448	12.6%
Chronic kidney disease	3,453	8.2%	498	2.1%	1,846	12.7%	1,109	31.3%
Chronic obstructive pulmonary disease and bronchiectasis	1,480	3.5%	171	0.7%	731	5.0%	578	16.3%
Depression	4,947	11.8%	1,198	5.0%	2,995	20.7%	754	21.3%
Diabetes	1,503	3.6%	101	0.4%	761	5.3%	641	18.1%
Epilepsy	1,301	3.1%	307	1.3%	786	5.4%	208	5.9%
Fibromyalgia, chronic pain, and fatigue	6,515	15.5%	898	3.7%	4,564	31.5%	1,053	29.7%
Heart failure	1,747	4.2%	85	0.4%	1,003	6.9%	659	18.6%
Hyperlipidemia	851	2.0%	27	0.1%	382	2.6%	442	12.5%
Hypertension	5,417	12.9%	791	3.3%	2,845	19.6%	1,781	50.2%
Liver disease, cirrhosis, and other liver conditions	1,348	3.2%	347	1.4%	756	5.2%	245	6.9%
Migraine and chronic headache	1,762	4.2%	576	2.4%	1,030	7.1%	156	4.4%
Obesity	1,823	4.3%	365	1.5%	1,149	7.9%	309	8.7%
Splenic sequestration	1,141	2.7%	781	3.3%	309	2.1%	51	1.4%
Stroke or transient ischemic attack	1,100	2.6%	457	1.9%	464	3.2%	179	5.0%

Table 16 (continued)

Condition	Medicaid and CHIP beneficiaries without SCD ^b							
	Total		Ages 0 to 20		Ages 21 to 45		Ages 46 to 75	
	N	%	N	%	N	%	N	%
Total number of beneficiaries	56,923,045	100.0%	31,735,082	100.0%	14,131,472	100.0%	11,056,491	100.0%
Acute chest syndrome	223	0.0%	133	0.0%	46	0.0%	44	0.0%
Anxiety disorders	3,354,721	5.9%	892,009	2.8%	1,407,705	10.0%	1,055,007	9.5%
Asthma	2,130,751	3.7%	1,226,017	3.9%	477,096	3.4%	427,638	3.9%
Chronic kidney disease	1,760,488	3.1%	125,715	0.4%	385,765	2.7%	1,249,008	11.3%
Chronic obstructive pulmonary disease and bronchiectasis	1,162,153	2.0%	65,698	0.2%	149,622	1.1%	946,833	8.6%
Depression	4,867,150	8.6%	1,150,640	3.6%	1,930,912	13.7%	1,785,598	16.1%
Diabetes	2,972,146	5.2%	100,020	0.3%	597,789	4.2%	2,274,337	20.6%
Epilepsy	623,582	1.1%	180,558	0.6%	220,150	1.6%	222,874	2.0%
Fibromyalgia, chronic pain, and fatigue	1,775,738	3.1%	60,130	0.2%	643,661	4.6%	1,071,947	9.7%
Heart Failure	676,754	1.2%	11,786	0.0%	95,296	0.7%	569,672	5.2%
Hyperlipidemia	2,158,424	3.8%	74,916	0.2%	427,059	3.0%	1,656,449	15.0%
Hypertension	4,438,332	7.8%	71,003	0.2%	955,654	6.8%	3,411,675	30.9%
Liver disease, cirrhosis, and other liver conditions	426,963	0.8%	33,506	0.1%	123,303	0.9%	270,154	2.4%
Migraine and chronic headache	624,205	1.1%	140,141	0.4%	313,564	2.2%	170,500	1.5%
Obesity	1,653,946	2.9%	303,003	1.0%	717,448	5.1%	633,495	5.7%
Splenic sequestration	33	0.0%	15	0.0%	DS	DS	DS	DS
Stroke or transient ischemic attack	249,995	0.4%	7,417	0.0%	37,236	0.3%	205,342	1.9%

Source: Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF), 2017 v4.

Table 16 (continued)

Notes: Table 16 includes 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all analyses due to concerns about data quality in the 2017 v4 TAF.

This analysis used diagnosis codes and procedure codes to identify the select health conditions. The determination of whether a beneficiary met criteria for a specific health condition is described in the CMS Chronic Conditions Data Warehouse (CCW). These results indicate that the health condition could be identified based on claims data for 2017; it is not an indicator of whether an individual ever had the condition.

SCD is a chronic health condition that impacts all body systems and contributes to additional health challenges.

^a Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had at least two claims with a diagnosis of SCD during the calendar year.

^b Results include beneficiaries who were enrolled in Medicaid or CHIP with full or comprehensive benefits for 12 continuous months in 2017 and had zero or one claim with a diagnosis of SCD during the calendar year.

DS = Data suppressed because data cannot be displayed per the Centers for Medicare & Medicaid Services' cell-size suppression policy, which prohibits the direct reporting of data for beneficiary and record counts of 1 to 10 and values from which users can derive values of 1 to 10.

Concluding Remarks

The Medicaid and CHIP Sickle Cell Disease Report is the first-ever comprehensive national portrait of Medicaid and CHIP beneficiaries with sickle cell disease. The report highlights the characteristics of adults and children enrolled in Medicaid and CHIP with sickle cell disease and can be used to identify areas for improvement in access to and quality of care for beneficiaries. CMS also developed an [infographic](#) that shows key findings from the report.

The report is based on the 2017 [T-MSIS Analytic Files](#) (TAF), which is a new resource for analyzing characteristics, access, utilization, and costs among Medicaid and CHIP beneficiaries. As noted in the report, data quality was an issue for selected states for some analyses in the report. Over time, CMS expects [data quality](#) to improve, which may improve the completeness of data for future analyses. In addition, this analysis was based on one year of data. As additional years of data become available, CMS plans to conduct longitudinal analyses to better understand the health status and utilization patterns of those with sickle cell disease.

For More Information

If you have questions or comments about the Medicaid and CHIP Sickle Cell Disease Report, or would like to be added to our mailing list, please contact the TA mailbox at MACQualityTA@cms.hhs.gov. Please include “SCD Report” in the subject line.