



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

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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 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 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 5 states (Alabama, Georgia, Louisiana, Mississippi, and 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 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 | Percentage of Medicaid and CHIP beneficiaries with SCD in each state | 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 | Percentage of Medicaid and CHIP beneficiaries with SCD in each state | 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 Methodology Brief #5011, available at: https://www.resdac.org/sites/resdac.umn.edu/files/5011_Identifying_IP_Stays.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 Methodology Brief #5011, available at: https://www.resdac.org/sites/resdac.umn.edu/files/5011_Identifying_IP_Stays.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.