At a Glance: Medicaid and CHIP Beneficiaries with Sickle Cell Disease (SCD), T-MSIS Analytic Files (TAF) 2017

**KEY FACTS**

41,995 Medicaid and CHIP beneficiaries with SCD

74 per 100,000 National prevalence of SCD in the Medicaid and CHIP population per 100,000 beneficiaries

43% Medicaid and CHIP beneficiaries with SCD who were over age 20

30% Beneficiaries with SCD ages 21 to 64 who were dually eligible for Medicare and Medicaid

**CHARACTERISTICS OF BENEFICIARIES WITH SCD**

Geographic Variation in the Number of Medicaid and CHIP Beneficiaries with SCD Per 100,000 Beneficiaries in 2017

**RECOMMENDED CARE FOR SCD**

Transcranial Doppler Ultrasound (TCD) Screening

Children ages 2 to 16 with SCD who received a TCD screening in 2017

37%

Hydroxyurea Use among Children and Adults with SCD in 2017

Days of Hydroxyurea use

None 63% 1-180 Days 21% 181-365 Days 16%

Adults (21 to 75 years) 65% 25% 10%

Pneumococcal Vaccination

Children under age 2 with SCD who had at least 1 pneumococcal vaccination in 2017

59%

**DATA SOURCE AND METHODS**

This analysis used the Chronic Conditions Data Warehouse (CCW) algorithm for identifying people with SCD. The CCW algorithm classifies people as having SCD if they had at least 3 claims with a diagnosis of SCD over a 5-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 benefits in 2017 and who had at least 2 claims with a diagnosis of SCD during the year. The CCW algorithm can be found at: https://www2.ccwdata.org/web/guest/condition-categories.

Results include 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all exhibits due to concerns about data quality in the 2017 v4 TAF. Additional states are excluded from specific exhibits due to concerns about data quality; these additional exclusions are identified in the notes for each relevant exhibit.

This analysis used Transformed Medicaid Statistical Information System (T-MSIS) Analytic Files (TAF) 2017 version 4 (v4) data. TAF data include information for all Medicaid and Children’s Health Insurance Program (CHIP) beneficiaries, including person-level enrollment and service-level claims records, in a research-optimized format. For this analysis, beneficiaries with sickle cell disease (SCD) were identified using an adapted version of the Chronic Conditions Data Warehouse (CCW) algorithm for identifying people with SCD. The CCW algorithm classifies people as having SCD if they had at least 3 claims with a diagnosis of SCD over a 5-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 2 claims with a diagnosis of SCD during the year. The CCW algorithm can be found at: https://www2.ccwdata.org/web/guest/condition-categories. Results include 49 states, the District of Columbia, Puerto Rico, and the U.S. Virgin Islands (USVI). Results for Maryland are excluded from all exhibits due to concerns about data quality in the 2017 v4 TAF. Additional states are excluded from specific exhibits due to concerns about data quality; these additional exclusions are identified in the notes for each relevant exhibit.

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. Other analyses using different data sources, methods, or time periods will produce different counts. For example, analyses using 5 years of data, as recommended by the CCW algorithm, would identify more people with SCD. The Centers for Disease Control and Prevention (CDC) estimates that SCD affects about 100,000 people in the United States.

1. People dually eligible for Medicare and Medicaid are also called dually eligible beneficiaries. Results for Arkansas and Idaho are excluded due to concerns about data quality in the 2017 v4 TAF.
2. Results for Maryland are excluded due to concerns about data quality in the 2017 v4 TAF.
3. Beneficiaries are categorized as living in an urban or rural location based on the 2013 CDC Urban-Rural Classification Scheme for Counties: https://www.cdc.gov/nchs/data_access/urban_rural.htm. Results for Vermont, Wyoming, Puerto Rico, and USVI are excluded due to limitations in zip code information.
4. TCD screenings are used to identify children who are at risk for stroke. The National Institutes of Health recommends annual TCD screenings for children with sickle cell anemia (SCA), a specific type of SCD, from ages 2 to 16. Recommendations can be found at: https://www.ncbi.nlm.nih.gov/health-topics/evidence-based-management-sickle-cell-disease/. 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.
5. The National Institutes of Health recommends hydroxyurea as a treatment for SCA, a specific type of SCD: https://www.ncbi.nlm.nih.gov/health-topics/evidence-based-management-sickle-cell-disease/. 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. Results for Arkansas, Idaho, and Puerto Rico are excluded due to concerns about data quality in the 2017 v4 TAF. Dual eligible beneficiaries are excluded due to incomplete pharmacy claims for this population in the TAF.
6. Children should receive 4 doses of the 13-valent conjugate pneumococcal vaccine before age 2. Recommendations from the Advisory Committee on Immunization Practices can be found at: https://www.cdc.gov/vaccines/schedules/hcp/imz/child-adolescent.html. This analysis used 1 year of data for calendar year 2017 and included the percentage of children under age 2 who received at least 1 pneumococcal vaccination during the year. The 1-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.
### Emergency Department (ED) Visits in 2017

<table>
<thead>
<tr>
<th>Visits</th>
<th>Number of ED visits</th>
<th>Percentage of ED visits that led to an inpatient hospital stay</th>
<th>Mean number of ED visits during the year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficiaries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>with SCD</td>
<td>No visits</td>
<td>22%</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>1 visit</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2-5 visits</td>
<td>14%</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 or more visits</td>
<td>12%</td>
<td></td>
</tr>
<tr>
<td>without SCD</td>
<td></td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

**Beneficiaries with SCD:** 78% had at least 1 ED visit, compared to 34% of beneficiaries without SCD.

### Inpatient Hospital Stays in 2017

<table>
<thead>
<tr>
<th>Visits</th>
<th>Number of inpatient hospital stays</th>
<th>Mean number of hospital days during the year</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficiaries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with SCD</td>
<td>No stays</td>
<td>51%</td>
</tr>
<tr>
<td></td>
<td>1 stay</td>
<td>21%</td>
</tr>
<tr>
<td></td>
<td>2-5 stays</td>
<td>1%</td>
</tr>
<tr>
<td></td>
<td>6 or more stays</td>
<td>7%</td>
</tr>
<tr>
<td>without SCD</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Beneficiaries with SCD:** 49% had at least 1 inpatient hospital stay, compared to 6% of beneficiaries without SCD.

### Outpatient Visits in 2017

<table>
<thead>
<tr>
<th>Visits</th>
<th>Had at least 1 outpatient visit with any provider</th>
<th>Percentage with at least 1 health screening, by age</th>
<th>Percentage with at least 1 dental examination, by age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficiaries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>with SCD</td>
<td>99.8%</td>
<td>53%</td>
<td>54%</td>
</tr>
<tr>
<td>without SCD</td>
<td>87.1%</td>
<td>51%</td>
<td>54%</td>
</tr>
</tbody>
</table>

**Beneficiaries with SCD:** 99.8% had at least 1 outpatient visit with any provider, compared to 87.1% of beneficiaries without SCD.

### Selected Diagnoses among Beneficiaries with SCD in 2017

- **Asthma:** 18.0%
- **Acute Chest Syndrome:** 17.8%
- **Fibromyalgia, Chronic Pain & Fatigue:** 15.5%
- **Hypertension:** 12.9%
- **Depression:** 11.8%
- **Chronic Kidney Disease:** 8.2%
- **Anxiety Disorders:** 8.1%
- **Obesity:** 5.9%
- **Migraine & Chronic Headache:** 4.2%
- **Heart Failure:** 4.2%
- **Diabetes:** 3.6%
- **Chronic Obstructive Pulmonary Disease and Bronchiectasis:** 3.5%
- **Liver Disease, Cirrhosis & Other Liver Conditions:** 3.2%
- **Epilepsy:** 3.1%
- **Spleenic Sequestration:** 2.7%
- **Stroke or Transient Ischemic Attack:** 2.6%
- **Hyperlipidemia:** 2.0%

**Notes:**

7. This analysis includes ED visits in which the beneficiary was treated and then released from the ED, as well as ED visits that resulted in a hospital admission.

8. 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.

9. Children age 3 and older should have 1 health screening per year. Children younger than age 3 should have more frequent screenings. Recommendations from Bright Futures and the American Academy of Pediatrics can be found at: https://downloads.aap.org/AAP/PDF/periodicity_schedule.pdf.

10. Children should have dental examinations every 6 months beginning no later than the first birthday. Recommendations from the American Academy of Pediatric Dentistry can be found at: https://www.aapd.org/globalassets/media/policies_guidelines/bp_recdentperiodschedule.pdf.

Acknowledgment: The Centers for Medicare & Medicaid Services would like to thank CDC’s Division of Blood Disorders for sharing their understanding of data management practices to better understand sickle cell disease.