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DATA HIGHLIGHT
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Prevalence of Sickle Cell Disease among Medicaid Beneficiaries in 2012

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Introduction

Multiple medical advancements and health care interventions [1] have transformed sickle cell disease (SCD), a once fatal childhood disease, into a chronic condition. Previous studies have estimated that approximately 100,000 people are living with SCD in the United States [2]. Sickle cell disease, the most prevalent lifelong genetic blood disorder in the United States, causes the body to produce abnormal red blood cells shaped like sickles or crescents, which fail to properly deliver oxygen to body tissues. This shape change disrupts the normal flow of red blood cells through the blood vessels of the body, ultimately causing excruciating acute and chronic pain episodes (called pain crises). Sickle cell disease affects all racial and ethnic groups; however, in the United States, Black and Hispanic populations are disproportionately impacted. Despite the likelihood of people with SCD living longer, there are no national prevalence estimates on the Medicaid population living with SCD.

In 2004, an optional Medicaid benefit for SCD was included in the American Jobs Creation Act of 2004 (AJCA)[1] in order to provide a new optional benefit in the Medicaid program and to make available federal matching funds for education and outreach to Medicaid-eligible adults and children with SCD. Additionally, the Medicaid program's benefit for children and adolescents, known as Early and Periodic Screening, Diagnostic and Treatment services (EPSDT), provides a comprehensive array of prevention, diagnostic, and treatment services for low-income infants, children and adolescents under age 21[2], including care for SCD. The federal government continues to support and increase awareness of improving care for people living with SCD. In September 2018, the White House released a Presidential Message for National Sickle Cell Disease Awareness Month, and in December 2018, President Donald Trump signed the Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act, which reauthorizes a SCD prevention and treatment program and provides grants for research, surveillance, prevention, and treatment of heritable blood disorders.

Key Findings:

- 55,349 people who were covered by Medicaid were identified with SCD.
- The national prevalence of SCD in the Medicaid population, expressed as a rate per 1,000 beneficiaries, was 0.73.
- Mississippi (2.20) had the highest SCD prevalence rate, per 1,000 beneficiaries, followed by District of Columbia (1.93), South Carolina (1.77), Louisiana (1.77), and Georgia (1.71).
- New York (10.59%) and Florida (9.75%) had the two largest populations of Medicaid beneficiaries with SCD.
- More than one out of five (23.54%) Medicaid beneficiaries with SCD were between the ages of 19-30 years.

Data Source: Estimates were produced using the CMS CCW SCD Indicator and data from the 2012 Medicaid Analytic eXtract (MAX) files.

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[1] American Jobs Creation Act of 2004 (AJCA) (Pub. L. No. 108-357), which was signed by the President on October 22, 2004. Section 712 of the AJCA amends title XIX of the Social Security Act (the Act)

[2] The Early and Periodic Screening, Diagnostic and Treatment services (EPSDT) 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 (the Act)

In commemoration of World Sickle Cell Day, the Centers for Medicare & Medicaid Services (CMS) has released a new SCD indicator in the CMS Chronic Conditions Data Warehouse (CCW).[3] We hope that this indicator will facilitate analysis by internal and external CCW users of the Medicare and Medicaid population living with SCD.

Using the CCW SCD indicator, this data highlight provides the first national prevalence estimates on the Medicaid population with SCD in 2012. The estimates described herein were produced using the 2012 Medicaid Analytic eXtract (MAX) files, the most current comprehensive data available for this study. This information will be useful for health plans and care providers who aim to improve the quality of care delivered to patients with sickle cell disease. Understanding the unique health needs of this vulnerable federally insured population will inform the development of interventions to increase awareness and understanding of people living with SCD.

Methods

The CMS SCD indicator is available for internal and external researchers who use data stored in the CMS CCW. The CCW creates a unique beneficiary identifier that can be used to link individual level beneficiary information with multiple files across multiple years of data. Within the CCW environment, SAS Enterprise Guide (V.9.4; SAS, Cary, NC) was used to produce state-level estimates and the 'maptile' function in STATA 13 (College Station, TX) was used to create the maps. The details of the algorithm and the codes used to assign the indicator have been documented in the CCW (www.ccwdata.org) [3].

The CCW uses diagnosis codes to identify SCD. The algorithm requires three or more of any claim type (not including pharmacy claims) during a five calendar year "look-back" period (e.g., 2012 data would glean from claims data 2008 through 2012). Given that SCD is a chronic life-long health condition, a five-year look-back period was appropriate to best identify beneficiaries with SCD. Because individuals with SCD tend to have many encounters with the healthcare system, the algorithm required for claims to be separated by one day to account for multiple claims that may be associated with a single healthcare visit. There is evidence that claims-based algorithms are highly sensitive for SCD if three claims are required [4]. The diagnosis codes employed by this algorithm are consistent with the specifications employed by the CMS OMH [5] as well as other notable studies [4].

Using the SCD indicator in the CMS CCW, MAX data were pooled from 2008-2012 to identify beneficiaries with ICD-9 diagnosis codes for SCD. Individuals with sickle cell trait were excluded from the SCD indicator. These analyses included beneficiaries residing in the contiguous United States. Like all indicators in the CCW, the SCD indicator provides a standardized way to assess person-level research files indicating whether or not the given condition is present in our claims-based administrative database. This indicator along with its algorithm is designed to be flexible enough to facilitate a broad range of research studies, as well as to facilitate sickle-cell based exclusion criteria on studies of opioid use disorder. There are no restrictions or exclusions on these data for beneficiaries in hospice, residents of long-term care facilities, or beneficiaries receiving palliative care. In addition, for the algorithms to be flexible enough to meet different research needs, we did not build age constraints into the algorithms.

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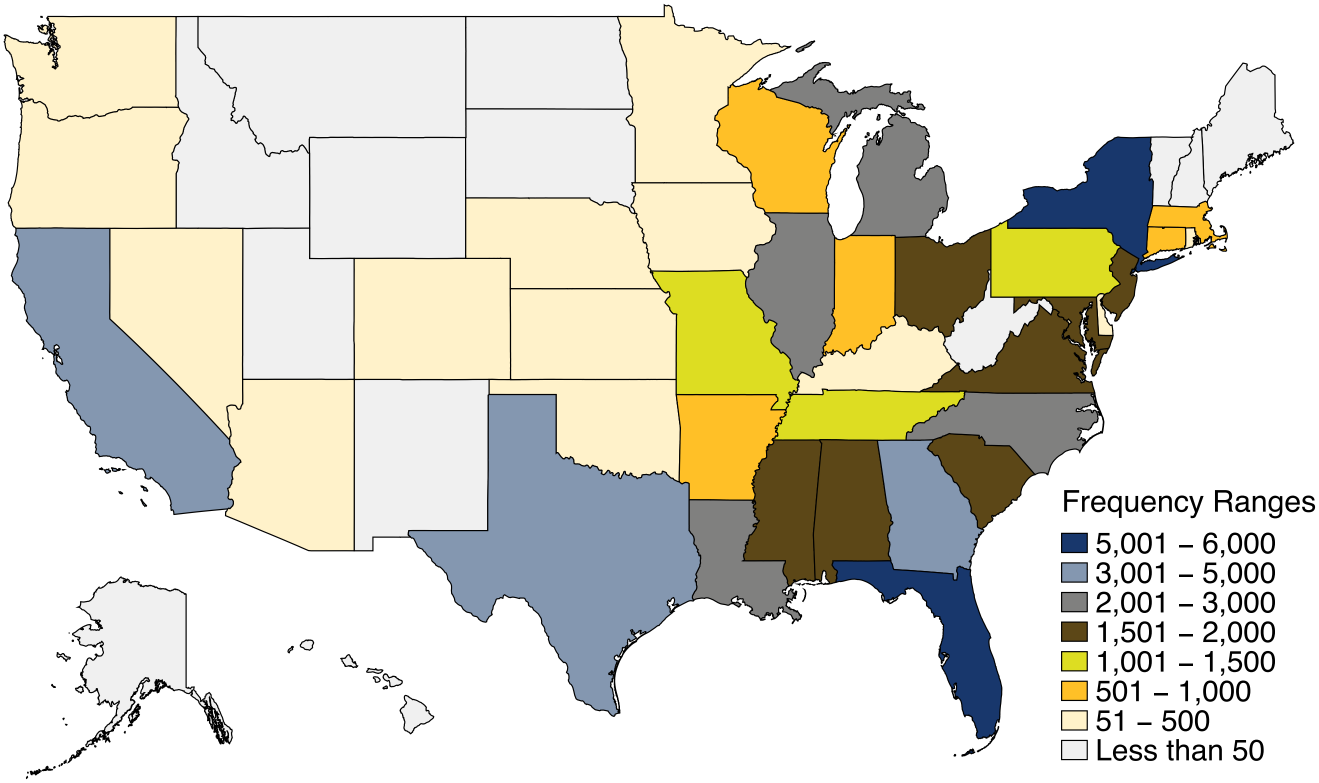
[3] More information on the SCD CCW indicator can be found at: https://www.ccwdata.org/web/guest/condition-categories

Results

Figure 1. Geographic Distribution of Medicaid Beneficiaries Living with Sickle Cell Disease in the United States in 2012



There was considerable representation of Medicaid beneficiaries living with SCD on the East Coast and in Southern states in 2012. Among Medicaid beneficiaries living with SCD, New York (n=5,863; 10.59% of Medicaid beneficiaries with SCD) and Florida (n=5,395; 9.75% of Medicaid beneficiaries with SCD) had the largest populations.

Figure 2. Prevalence Rates of Sickle Cell Disease, Per 1,000 Medicaid Beneficiaries, in 2012

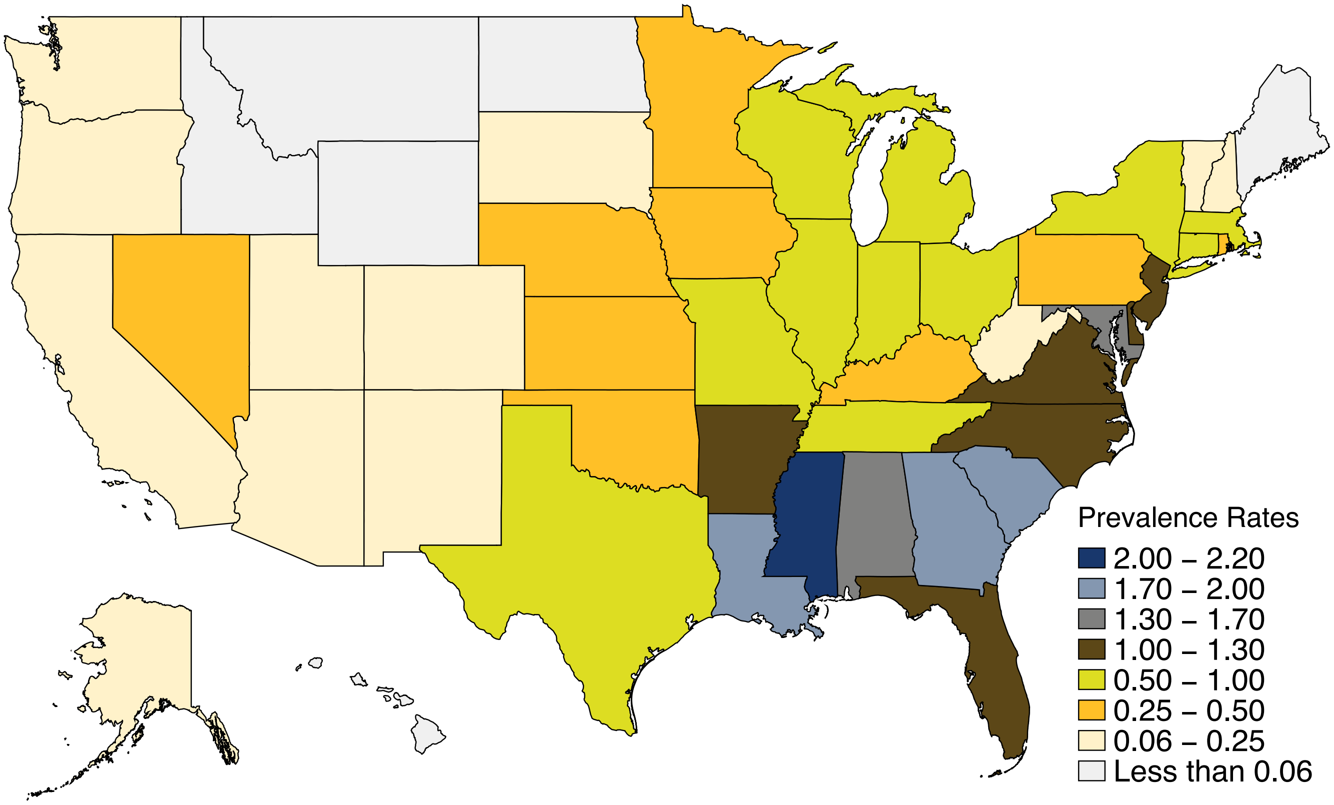


Figure 2 shows that Mississippi, with SCD prevalence rate of 2.20 per 1,000 Medicaid beneficiaries, was the only state with an SCD prevalence rate of 2.00 or greater in 2012. Several other states had SCD prevalence rates of 1.50 or greater: District of Columbia (1.93), South Carolina (1.77), Louisiana (1.77), Georgia (1.71), Alabama (1.61), and Maryland (1.53).

Table 1 shows that the prevalence of SCD in the Medicaid population, expressed as a rate per 1,000 beneficiaries, was 0.73 for the nation as a whole, in 2012. The following four states ranked within both the top ten states with the highest prevalence as well as the top ten states in terms of proportion of the SCD population: Georgia, Louisiana, North Carolina, and South Carolina.

Table 2 shows the state-level distribution of SCD among Medicaid beneficiaries by age. Among Medicaid beneficiaries with SCD the following age categories had the largest representation: 19-30 years (23.54%), 6-12 years (17.49%), ≤5 years (16.75%), and 31-45 years (15.95%).

Table 1. National and State-level Total Counts and Prevalence Rates of Sickle Cell Disease, Per 1,000 Medicaid Beneficiaries, in 2012

States	Number of Medicaid beneficiaries with SCD	Total number of Medicaid beneficiaries	Percent of all Medicaid beneficiaries with SCD	Prevalence rate of SCD Per 1,000 Medicaid beneficiaries
Alabama	1,754	1,087,010	3.17	1.61
Alaska	20	150,164	0.04	0.13
Arizona	320	1,725,214	0.58	0.19
Arkansas	812	787,503	1.47	1.03
California	3,015	13,374,370	5.45	0.23
Colorado	155	892,670	0.28	0.17
Connecticut	598	819,167	1.08	0.73
Delaware	276	256,188	0.50	1.08
District of Columbia	474	245,657	0.86	1.93
Florida	5,395	4,190,547	9.75	1.29
Georgia	3,752	2,191,946	6.78	1.71
Hawaii	11	332,913	0.02	0.03
Idaho	<11	302,709	*	*
Illinois	2,890	3,212,810	5.22	0.90
Indiana	789	1,304,423	1.43	0.60
Iowa	164	632,643	0.30	0.26
Kansas	220	439,698	0.40	0.50
Kentucky	372	1,007,306	0.67	0.37
Louisiana	2,559	1,445,249	4.62	1.77
Maine	13	383,602	0.02	0.03
Maryland	1,835	1,202,260	3.32	1.53
Massachusetts	877	1,651,901	1.58	0.53
Michigan	2,008	2,340,824	3.63	0.86
Minnesota	446	1,138,352	0.81	0.39
Mississippi	1,853	843,045	3.35	2.20
Missouri	1,134	1,208,261	2.05	0.94
Montana	<11	162,842	*	*
Nebraska	138	298,944	0.25	0.46
Nevada	186	389,816	0.34	0.48
New Hampshire	18	176,497	0.03	0.10
New Jersey	1,669	1,559,563	3.02	1.07
New Mexico	36	648,720	0.07	0.06
New York	5,863	6,013,629	10.59	0.97
North Carolina	2,667	2,116,498	4.82	1.26
North Dakota	<11	89,212	*	*
Ohio	1,900	2,687,125	3.43	0.71
Oklahoma	421	1,069,958	0.76	0.39

States	Number of Medicaid beneficiaries with SCD	Total number of Medicaid beneficiaries	Percent of all Medicaid beneficiaries with SCD	Prevalence rate of SCD Per 1,000 Medicaid beneficiaries
Oregon	79	809,796	0.14	*
Pennsylvania	1,162	2,559,639	2.10	0.45
Rhode Island	124	246,701	0.22	0.50
South Carolina	1,965	1,107,832	3.55	1.77
South Dakota	<11	143,989	*	*
Tennessee	1,388	1,566,821	2.51	0.89
Texas	3,314	5,922,736	5.99	0.56
Utah	39	420,302	0.07	0.09
Virginia	1,551	1,208,362	2.80	1.28
Vermont	18	204,146	0.03	0.09
Washington	234	1,438,670	0.42	0.16
Wisconsin	773	1,352,378	1.40	0.57
West Virginia	36	420,749	0.07	0.09
Wyoming	<11	84,334	*	*
Total	55,349	75,865,691	100	0.73

NOTE: Cells with <11 observations were censored.

Table 2: National and State-Level Distribution of Medicaid Beneficiaries Living with Sickle Cell Disease by Age in 2012

	Age Categories									Total Number of:	
States	≤5y	6-12y	13-18y	19-30y	31-45y	46-54y	55-64y	>65y	Unknown	Medicaid beneficiaries with SCD	Medicaid beneficiaries
Alabama	300	307	259	425	287	97	<11	<11	25	1,754	1,087,010
Alaska	<11	<11	<11	<11	<11	<11	<11	<11	<11	20	150,164
Arizona	45	53	45	64	58	27	<11	<11	15	320	1,725,214
Arkansas	137	148	132	163	131	43	<11	<11	30	812	787,503
California	439	435	359	708	578	244	118	44	90	3,015	13,374,370
Colorado	22	34	21	41	16	<11	<11	<11	11	155	892,670
Connecticut	103	92	77	151	96	38	<11	<11	15	598	819,167
Delaware	55	48	37	65	42	12	<11	<11	<11	276	256,188
District of Columbia	79	61	44	112	79	46	<11	<11	30	474	245,657
Florida	1,054	995	680	1,297	800	246	<11	<11	168	5,395	4,190,547
Georgia	702	714	527	817	537	174	<11	<11	158	3,752	2,191,946
Hawaii	<11	<11	<11	<11	<11	<11	<11	<11	<11	11	332,913
Idaho	<11	<11	<11	<11	<11	<11	<11	<11	<11	<11	302,709
Illinois	420	471	396	697	503	217	<11	<11	85	2,890	3,212,810
Indiana	146	145	109	165	112	53	<11	<11	32	789	1,304,423
Iowa	24	17	12	45	30	12	<11	<11	16	164	632,643
Kansas	39	31	18	47	25	11	<11	<11	42	220	439,698
Kentucky	80	65	44	85	54	23	<11	<11	<11	372	1,007,306
Louisiana	422	498	378	580	346	117	73	24	121	2,559	1,445,249
Maine	<11	<11	<11	<11	<11	<11	<11	<11	<11	13	383,602
Maryland	365	365	233	420	254	92	<11	<11	48	1,835	1,202,260
Massachusetts	156	156	119	194	158	51	<11	<11	17	877	1,651,901
Michigan	274	310	298	533	323	120	<11	<11	89	2,008	2,340,824
Minnesota	86	75	57	93	72	22	<11	<11	21	446	1,138,352
Mississippi	347	340	256	418	305	82	<11	<11	43	1,853	843,045
Missouri	138	213	135	257	188	91	<11	<11	33	1,134	1,208,261
Montana	<11	<11	<11	<11	<11	<11	<11	<11	<11	<11	162,842
Nebraska	30	33	15	29	18	<11	<11	<11	<11	138	298,944
Nevada	12	29	24	49	28	12	<11	<11	25	186	389,816
New Hampshire	<11	<11	<11	<11	<11	<11	<11	<11	<11	18	176,497
New Jersey	288	331	216	382	246	93	30	13	70	1,669	1,559,563
New Mexico	<11	<11	<11	<11	<11	<11	<11	<11	<11	36	648,720
New York	905	871	665	1,483	1,037	418	215	136	133	5,863	6,013,629
North Carolina	436	467	361	577	448	143	80	73	82	2,667	2,116,498
North Dakota	<11	<11	<11	<11	<11	<11	<11	<11	<11	<11	89,212

	Age Categories									Total Number of:	
States	≤5y	6-12y	13-18y	19-30y	31-45y	46-54y	55-64y	>65y	Unknown	Medicaid beneficiaries with SCD	Medicaid beneficiaries
Ohio	297	321	228	454	318	124	74	33	51	1,900	2,687,125
Oklahoma	72	72	68	81	64	24	<11	<11	20	421	1,069,958
Oregon	12	12	<11	25	<11	<11	<11	<11	<11	79	809,796
Pennsylvania	171	168	159	309	189	72	<11	<11	56	1,162	2,559,639
Rhode Island	13	29	19	24	26	<11	<11	<11	<11	124	246,701
South Carolina	314	359	268	498	318	96	53	15	44	1,965	1,107,832
South Dakota	<11	<11	<11	<11	<11	<11	<11	<11	<11	<11	143,989
Tennessee	255	259	192	340	207	55	<11	<11	41	1,388	1,566,821
Texas	606	682	469	771	454	149	<11	<11	108	3,314	5,922,736
Utah	<11	<11	<11	<11	<11	<11	<11	<11	<11	39	420,302
Vermont	<11	<11	<11	<11	<11	<11	<11	<11	49	1,551	204,146
Virginia	237	289	238	327	249	94	<11	<11	<11	18	1,208,362
Washington	43	37	27	60	45	<11	<11	<11	<11	234	1,438,670
West Virginia	<11	<11	<11	<11	<11	<11	<11	<11	<11	36	420,749
Wisconsin	119	105	86	204	148	54	<11	<11	33	773	1,352,378
Wyoming	<11	<11	<11	<11	<11	<11	<11	<11	<11	<11	84,334
Total	**9,273**	**9,680**	**7,300**	**13,013**	**8,830**	**3,193**	**1,555**	**623**	**1,864**	**55,349**	**73,865,691**
Percent of Medicaid beneficiaries with SCD[1]	**16.75**	**17.49**	**13.19**	**23.54**	**15.95**	**5.77**	**2.81**	**1.13**	**3.37**	**100**	

NOTE: Cells with <11 observations were censored.

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[1] Each column total was divided by the total number of Medicaid beneficiaries with SCD (55,349)

Conclusion

This study identified 55,349 Medicaid beneficiaries living with SCD in 2012, a majority of whom were non-elderly (less than 65 years of age). In 2012, the national prevalence of SCD in the Medicaid population, expressed as a rate per 1,000 beneficiaries, was 0.73, with the following states having the highest prevalence of SCD among Medicaid beneficiaries: Mississippi (2.20), District of Columbia (1.93), Louisiana (1.77), and South Carolina (1.77).

The data analyzed in this study are commonly referred to as healthcare services utilization data or claims data [6]. Derived from reimbursement information or the payment of bills, these data are clinically valid and include beneficiary level information for admission and discharge dates, diagnosis and procedure codes, source of care, and various demographic characteristics (race and ethnicity, age and place of residence) [6]. While claims data provide a rich source of information on the prevalence of various chronic conditions, these data do not reveal the duration of or the severity of a condition. Also, undiagnosed conditions do not appear in utilization files and claims do not provide information on the care needed. Covered services for which claims are not submitted (such as immunizations provided through a free clinic) are not included in these data. Despite these limitations, claims data provide a reliable source of information to study chronic conditions, such as SCD and allowed for reporting the prevalence rate for SCD among the Medicaid population in 2012.

CMS is committed to advancing equity for all beneficiaries including those with SCD [7]. The Pediatric Quality Measures Program (PQMP), established in 2011 by the Agency for Healthcare Research and Quality's (AHRQ) and CMS under Title IV the Children's Health Insurance Program Reauthorization Act of 2009 (CHIPRA), increased the portfolio of evidenced-based, consensus pediatric quality measures. Additionally, through the PQMP several Centers of Excellence have been funded to develop new and innovative pediatric measures for Transcranial Doppler, a known method for preventing strokes in children, and appropriate antibiotic prophylaxis for children diagnosed with SCD. In 2016, the CMS Quality Improvement Organization Program created Special Innovation Project to Quality Improvement Organizations (QIOs)[4] focused on improving care received in the emergency department and addressing acute pain management in SCD patients. With the release of the CCW SCD indicator, we hope that others will join us on the path to equity by improving care for all Medicaid beneficiaries, including those living with SCD.

Keywords

Medicaid, Sickle Cell Disease, Prevalence Rate, Administrative or Claims Data

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[4] In April 2019, atom Alliance, a CMS QIO, release the Sickle Cell Disease Resources for Providers and Patients and an overview highlighting the importance of the NHLBI Evidenced-Based Evidence-based Guidelines for Improving the Management of Sickle Cell Disease [3]. Recently, CMS funded the national expansion of an intervention developed by Qsource and atom Alliance that has improved acute pain management through patient education for 3,000 patients with SCD in Memphis, TN, and reduced hospital utilization resulting in an estimated savings of nearly $1.7M.

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