Quantitative Assessment of Sickle Cell Disease in Michigan

A Report from the MiSCDC Program

June 2025

MICHIGAN SICKLE CELL
DATA COLLECTION

Citation and Acknowledgements

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Michigan Sickle Cell Data Collection Program:

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List of Acronyms

CHEAR	Susan B. Meister Child Health Evaluation and Research Center
COVID-19	Coronavirus disease 2019
CSHCS	Children's Special Health Care Services
DTaP	Diphtheria, tetanus and acellular pertussis
ED	Emergency department
FDA	Food and Drug Administration
Hb	Hemoglobin
HCUP	Healthcare Cost and Utilization Project
HepB	Hepatitis B
Hib	Haemophilus influenzae type b
HSA	Health Status Assessment
ICD	International Classification of Diseases
IEP	Individualized Education Program
MCIR	Michigan Care Improvement Registry
MDHHS	Michigan Department of Health and Human Services
MiSCDC	Michigan Sickle Cell Data Collection program
MMR	Measles, mumps, rubella
PCV	Pneumococcal conjugate
PROPS	Penicillin Prophylaxis in Sickle Cell Disease
TCD	Transcranial Doppler
Title V	Title V of the Federal Social Security Act, focused on maternal and child health services
Title V/XIX	Integration of Title V and Title XIX of the Social Security Act (Medicaid) for comprehensive health services for children with special needs
SCD	Sickle cell disease
SCDC	Sickle Cell Data Collection program
SCDAA-MI	Sickle Cell Disease Association of America - Michigan Chapter
US	United States
VOC	Vaso-occlusive crisis

Executive Summary

The objective of this report is to support the development of the 2025 MDHHS strategic plan for SCD by providing a quantitative assessment of SCD in Michigan. The state of Michigan has a long-standing commitment to improving the lives of Michiganders with SCD. In 2021, $6.7 million dollars were appropriated to expand Children's Special Health Care Services (CSHCS) through the lifespan, provide grants to SCD clinics and support community-based organization initiatives through SCDAA-MI. Given the recent changes in SCD-related funding and the opportunity to significantly impact health outcomes and quality of life for individuals with SCD, MDHHS has embarked upon the development of a five-year strategic plan for SCD.

The data in this report is from the Michigan Sickle Cell Data Collection (MiSCDC) program, a longitudinal, population-based public health surveillance system funded by the Centers for Disease Control and Prevention (CDC) since 2020.[9-12] MiSCDC gathers health information about people living with SCD to inform policy and health care improvements. MiSCDC leverages numerous data sources to identify individuals with SCD in Michigan and evaluate health care utilization over time. Select findings from the time frame 2018-2022 are highlighted below.

- The average annual population of people with SCD in Michigan was 3,966 people of all ages, with most people living in southeast Michigan, including metro Detroit.
- The average age at time of death was 49.3 years. This varied by sex, with average age being 46.2 years for men and 51.7 years for women. The overall crude mortality rate among those with SCD during the same timeframe was 1.8 times more than the general Michigan population and 1.7 times more than the Black population in Michigan.
- Over half of people with SCD had at least one emergency department (ED) visit per year, averaging 2.6 ED visits per person, per year across all ages. People with SCD aged 30-39 years had the highest number and average of ED visits per person. In comparison, the average number of ED visits among the U.S. population aged 18-44 was 0.4 ED treat-and-release visits per person in 2022.
- The proportion of individuals with SCD enrolled in any Medicaid program was approximately 85%, with half enrolled in a full coverage plan for 12 months.
- Approximately three out of five people with SCD did not have a hematologist visit in a year. Individuals with SCD should have at least one visit with a hematologist every year; two or more hematologist visits in a year have been associated with higher uptake of life-saving preventive services.
- Among children with SCD, completion of the primary immunization series was over 80%, higher than the overall population average. However, rates of influenza and COVID-19 immunization among people with SCD are substantially lower compared to the overall population.
- Approximately one in five people with SCD had at least one filled prescription for hydroxyurea; among those with at least one filled prescription, the average annual days' supply covered half of the year.
- Less than 5% of people with SCD had any new disease modifying therapies (Endari, Oxbryta, Adakveo).

With these findings, gaps in services were identified and described to better understand and address the needs of the SCD population in Michigan. Further, with the recent introduction of new disease modifying and gene therapies, the health care landscape for SCD has fundamentally shifted. This necessitated exploration of the uptake and implementation of these new treatments. We anticipate this quantitative report will be used in conjunction with other efforts, such as focus groups and surveys, to support the centering of voices of individuals living with SCD in Michigan

and their families in strategic planning efforts. Through these actions, MiSCDC aims to provide the evidence necessary to support policies and programs that improve outcomes for all Michiganders with SCD.

Introduction

Hemoglobinopathies are a group of inherited disorders in which there is abnormal production or structure of the hemoglobin molecule.[13] This includes sickle cell disease (SCD), which is the most common inherited disorder in the US.[1] Approximately 100,000 people in the US are living with SCD. SCD primarily impacts populations with African/North African, Indian, Asian and Caribbean descent.[14] There are numerous subtypes of SCD, including Hemoglobin (Hb) SS, Hbβ^0thalassemia, HbSC and more than 40 other subtypes. Together, HbSS and Hbβ^0thalassemia are collectively referred to as the subtype sickle cell anemia.

SCD causes red blood cells to form an abnormal crescent shape that is rigid and sticky. These cells clump together more easily and block blood and oxygen from moving freely throughout the body, leading to substantial health-related impacts. Individuals with SCD are at a high risk of early mortality with a reduction in average life expectancy of more than 20 years compared to those without SCD. SCD is associated with substantial morbidity, such as severe pain crises, acute chest syndrome, stroke and infection, which leads to numerous health care encounters.[2-4] The burden of SCD is substantial, in terms of financial implications and quality of life.[5-7]

Approximately 90% of individuals with SCD in the U.S. are Black or Hispanic, groups that are underrepresented and experience resource gaps in the U.S. and in health care.[8] As such, individuals living with SCD are faced with structural racism and discrimination that also impacts health. For example, those living with SCD typically live in urban, low-income neighborhoods and are enrolled in Medicaid.[15] These social determinants of health can lead to lack of access to quality, comprehensive care and poor health outcomes.[16-18] As such, it is essential to identify opportunities to increase access to high-quality health care among people with SCD.

The state of Michigan has a long-standing commitment to improving the lives of Michigan residents with SCD. These efforts include the development and implementation of "A Public Health Strategic Plan to Address Sickle Cell Disease Across the Lifespan" in 2015 and participation in the Sickle Cell Data Collection (SCDC) program since 2020.[9, 19] Of particular importance, a recent initiative focused on SCD was included in the state budget signed by Gov. Gretchen Whitmer in October 2021. This funding supports expansion of CSHCS for people with SCD through the lifespan, grant support to enhance and expand SCD clinics, and funds to support community based activities through the SCDAA-MI.[20-22] Given the recent changes at the state level in SCD-related funding and the expansion of programmatic initiatives, MDHHS has embarked upon the development of a five-year strategic plan for SCD.

The objective of this report is to support the development of the 2025 MDHHS strategic plan for SCD by providing a quantitative assessment of SCD in Michigan. To do so, we leveraged multi-source data from Michigan Sickle Cell Data Collection (MiSCDC) program to describe the epidemiology and health care utilization of Michigan residents living with SCD. MiSCDC is a longitudinal, population-based public health surveillance system funded by the CDC since 2020.[9-12] The program is a collaborative effort between the Susan B. Meister Child Health Evaluation and Research (CHEAR) Center at the University of Michigan and MDHHS. The SCDC program is implemented in 16 states, including Michigan, and aims to improve quality of life for those with SCD by characterizing prevalence, health care utilization and health outcomes.[23] MiSCDC accomplishes this by linking, deduplicating and analyzing data from multiple sources, including newborn screening, vital records, Medicaid claims, discharge data and clinic data. Through this comprehensive approach, MiSCDC aims to identify everyone with SCD in Michigan and evaluate health care utilization and outcomes.

The topics covered in this report were selected and developed with input from MDHHS, the SCD Strategic Planning Executive Committee and the MiSCDC team. The findings allow for the identification and description of gaps in services, quality of care and opportunities for improvement for people with SCD in Michigan. This will help facilitate a better understanding of the needs of the SCD population in Michigan over the next five years. This report serves as a resource for policymakers, health care providers, insurers, researchers and community advocates to gain deeper insights into the needs of the SCD population in Michigan.

Methods

MiSCDC synthesizes data from multiple sources to understand trends in the population and health care utilization of people living with SCD in Michigan. Data collection for MiSCDC is conducted through a grant of public health authority from MDHHS to the University of Michigan, as well as data use agreements and Institutional Review Board approvals at multiple sites, including the University of Michigan, MDHHS, Henry Ford Health, Hurley Medical Center, and Bronson Healthcare.

Data Sources and Linkage

Data sources include Michigan newborn screening records, Michigan vital records (birth certificates; death certificates), administrative claims data from Michigan Medicaid and CSHCS, Michigan Inpatient Database, Michigan Outpatient Database, SCD clinics in Michigan (Hurley Medical System, Henry Ford Health, Bronson Healthcare, Michigan Medicine) and the Michigan Care Improvement Registry (**Table 1**). Each of the data sources are linked and deduplicated using linkage software to identify unique individuals with SCD living in the state. Linkage is performed using available variables within each dataset, such as name, date of birth and sex.

Table 1. Data sources included in MiSCDC

Data Source	Brief Description	Timeframe
Newborn screening records	The results of tests performed shortly after birth to identify hemoglobinopathy status (e.g., SCD).	1988-2022
Vital Records	Birth and death certificates.	1988-2022
Michigan Medicaid	Administrative claims from public insurance program providing medical coverage to eligible residents.	2010-2022
Children's Special Health Care Services	Condition-based program supporting medical care for children, including those with SCD.	2010-2022
Inpatient Database (Michigan Health and Hospital Association)	Records of hospitalizations across the state, irrespective of payer.	2016-2022
Outpatient Database (Michigan Health and Hospital Association)	Records of visits to outpatient facilities, including emergency, irrespective of payer.	2016-2022
SCD Clinics	Patient lists from Hurley, Henry Ford Health, Bronson Healthcare, Michigan Medicine.	Varies by clinic
Michigan Care Improvement Registry	Vaccination records for all administered doses.	All vaccinations

Identifying People with SCD in Michigan

To identify individuals with SCD, validated case definitions are applied to the data sources above.[24] Based on the case definition source, individuals with SCD are classified into the following categories:

- **Confirmed SCD:** Individual was identified using newborn screening records or SCD clinic data; has a confirmed genotype available from one of these sources.
- **Probable SCD:** Individual has no genotype available from newborn screening records or clinic data but has three or more SCD-related claims* in a five-year period across all datasets; or has a verified CSHCS diagnosis for SCD.
- **Possible SCD:** Individual has no genotype available from newborn screening records or clinic data but has one to two SCD-related claims* in a five-year period across all datasets.

- **Does not have SCD:** Individual has at least one SCD-related claim* in a five-year period across all administrative datasets and has a confirmed non-SCD genotype in newborn screening records or SCD clinic data (i.e., sickle cell trait, normal hemoglobin).

Individuals that are categorized as confirmed SCD and probable SCD were included in this report; those that were possible SCD or do not have SCD are excluded. Individuals living with SCD were characterized as living in the state of Michigan during a specific year by applying the following criteria sequentially: 1) born in the state during that year, or 2) enrolled in Medicaid or CSHCS during that year, or 3) received any health care within that year, broadly defined as having a record within Michigan Inpatient Database or Michigan Outpatient Database. Individuals with SCD were also characterized as living within the state during that specific year by applying criteria 2 or 3 for the year prior and the year after.

*International Classification of Diseases (ICD)-9 and ICD-10 diagnosis codes were used to identify all SCD-related claims (ICD-9: 282.X; ICD-10: D57.x). Sickle cell trait codes were excluded (ICD-9: 282.5; ICD-10: D57.3). All SCD-related claims were deduplicated by date.

Data Limitations

Newborn screening records: Only SCD cases identified through Michigan's Newborn Screening Program were included, so any cases not screened in Michigan due to refusal, miss or migration to Michigan after birth were not captured. Note that in 2022, 98.9% of infants born in Michigan had a completed newborn screen.[25]

Vital records/electronic birth certificates: It is possible that some newborn screening records were unable to be linked to electronic birth certificates (e.g., name changes; conflicting information); however, 98.5% of records were linked in 2022.[25]

Michigan Medicaid, CSHCS: These databases only represent services which were billed and paid for and will not include all services (e.g., medications provided during inpatient admissions).

Michigan Inpatient Database, Michigan Outpatient Database: Health care utilization records are provided to the Michigan Health and Hospital Association by hospitals across the state; however, submission is not mandatory. As such, there was annual variation in which hospitals submit individual-level utilization records. Consequently, utilization records may be incomplete.

Clinical data from SCD Clinics in Michigan: As of May 2025, MiSCDC had received data from Michigan Medicine, Hurley Medical Center, Henry Ford Health and Bronson Healthcare. Eligibility criteria for the patient populations were based upon clinic-specific criteria and may differ across health systems.

Michigan Care Improvement Registry (MCIR): The quality of the immunization information depends on consistent, accurate reporting by health care providers. While immunizations are encouraged to be reported to MCIR for all ages, reporting is only required for those under age 20. Not all MiSCDC records could be linked to MCIR records.

Generalizability of preventative services, hematology care and prescriptions: These measures were assessed among individuals enrolled in a full coverage Medicaid plan for 12 months with no other insurance in a calendar year. As such, these measures may not be generalized to those that do not meet these criteria (e.g., enrolled less than 12 months; other insurance).

The Population of People Living with Sickle Cell Disease in Michigan

An accurate understanding of the population of people living with SCD in Michigan can support health care providers and policy makers in planning and allocating health care resources for this population. As such, it is important to use multi-source public health surveillance data, such as MiSCDC, to assess the number, demographic characteristics and geographic location of people with SCD in the state. For example, use of Medicaid data alone resulted in an undercount of nearly half of individuals living with SCD in California and Georgia.[26] Comprehensive data collection efforts enable better targeting of resources and programs, resulting in improved health outcomes and diminished health disparities among this population.

Descriptive Summary: Using MiSCDC data, the number of people with SCD living in Michigan was identified from 2018-2022. Age, sex and geographic location, defined as the county of residence, were assessed in 2022 for individuals living in the state.

Findings:

- From 2018 to 2022, there were 4,648 unique individuals with SCD living in Michigan; the yearly average was 3,966 people across the five-year period.
- In 2022, 30.4% of individuals were under the age of 18 and 31.2% were ages 40+ (**Figure 1**); 42.0% were male.
- In 2022, nearly three out of every five Michigan residents with SCD resided in Wayne (46.4%), Oakland (9.7%), and Macomb (8.0%) counties; 51 out of 83 counties were home to someone living with SCD in Michigan (**Figure 2**).

Figure 1. Age and sex distribution of people with SCD, 2022 (N=3,905 people)

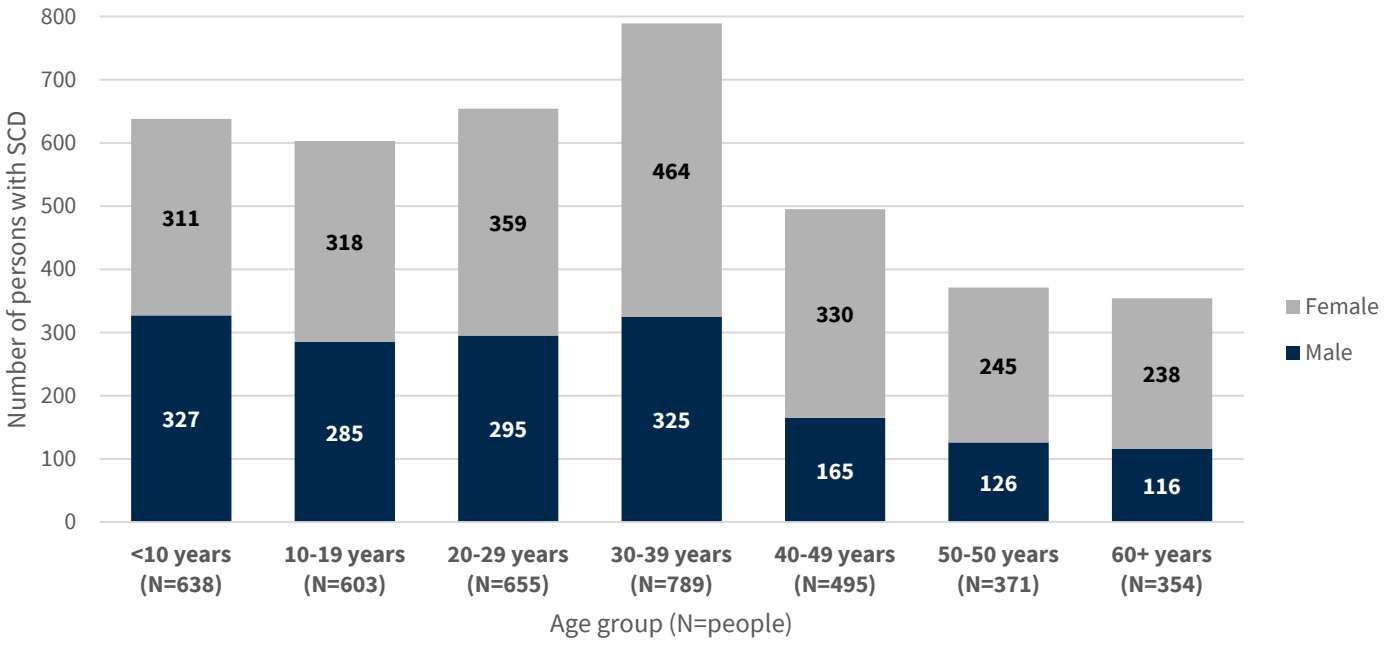
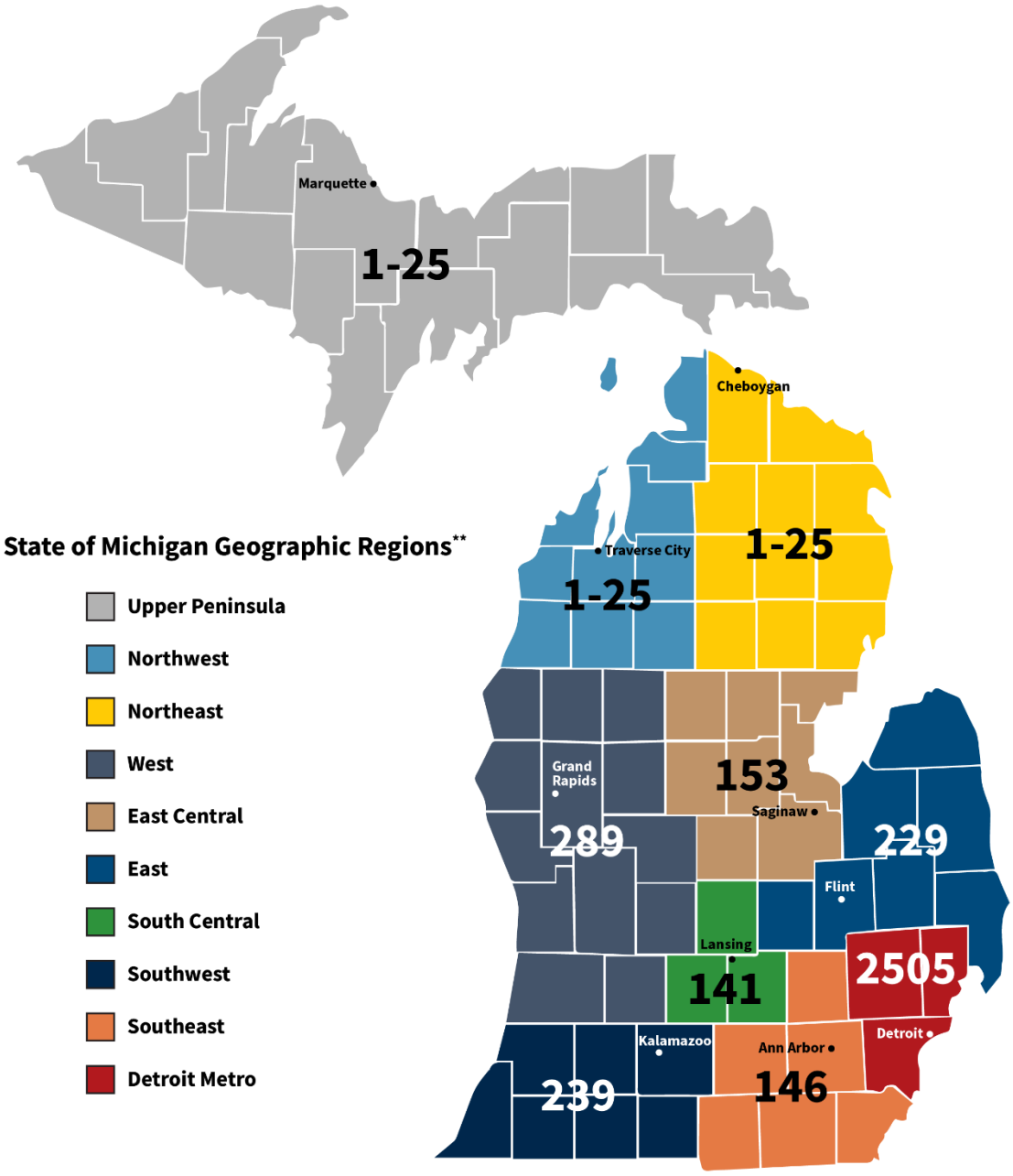


Figure 2. Geographic distribution of people with SCD, 2022 (N=3,905 people)*



*County unknown for 184 people

**Geographic regions are based on Michigan prosperity regions: https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder3/Folder39/Folder2/Folder139/Folder1/Folder239/Prosperity_Map1_430346_7.pdf?rev=4b907ee644814b6397163752b0c3807e

Sickle Cell Disease Births

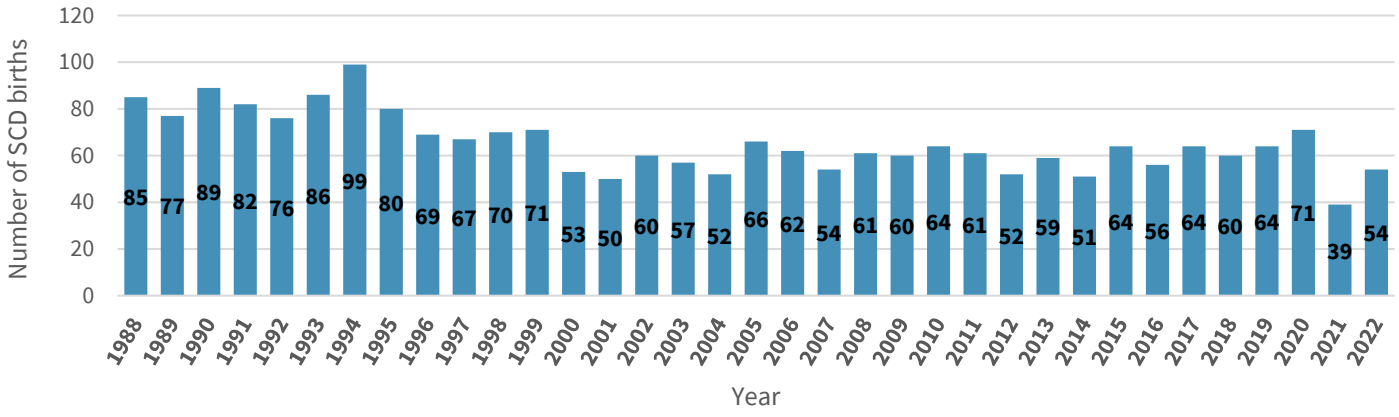
Newborn screening is a program that screens infants for serious but treatable congenital conditions.[27] Early identification of children with SCD through newborn screening enables establishment of essential comprehensive care, initiation of penicillin prophylaxis and integration into a community of support.[28] Since October 1987, MDHHS has been conducting newborn screening for SCD.[29] Infants that initially screen positive for SCD receive subsequent testing to confirm the SCD diagnosis.

Descriptive Summary: Newborn screening records from 1988-2022 were assessed to establish the number of infants that were confirmed to have SCD. SCD birth rate was calculated by dividing the number of infants with confirmed SCD by the total population of Michigan for each year and reported per 100,000 people. The SCD birth rate was compared to the overall Michigan birth rate calculated as number of live births by the total population of Michigan and reported per 100,000 people.[30] The frequency and percentage of infants with confirmed SCD by sex, race and subtype of SCD were calculated from newborn screening records linked to electronic birth certificates.

Findings:

- From 1988-2022, a total of 2,285 infants were confirmed to have SCD (**Figure 3**), corresponding to a birth rate of approximately 0.6 SCD births per 100,000 people. Yearly SCD birth rate stayed relatively similar over time as compared to the birth rate for the state of Michigan overall, which showed a decline (**Figure 4**).
- Among the confirmed SCD births, 50.2% were male, 91.8% were Black and 56.4% were the subtype sickle cell anemia (**Table 2**).

Figure 3. Confirmed SCD births, 1988-2022 (N=2,285 infants)



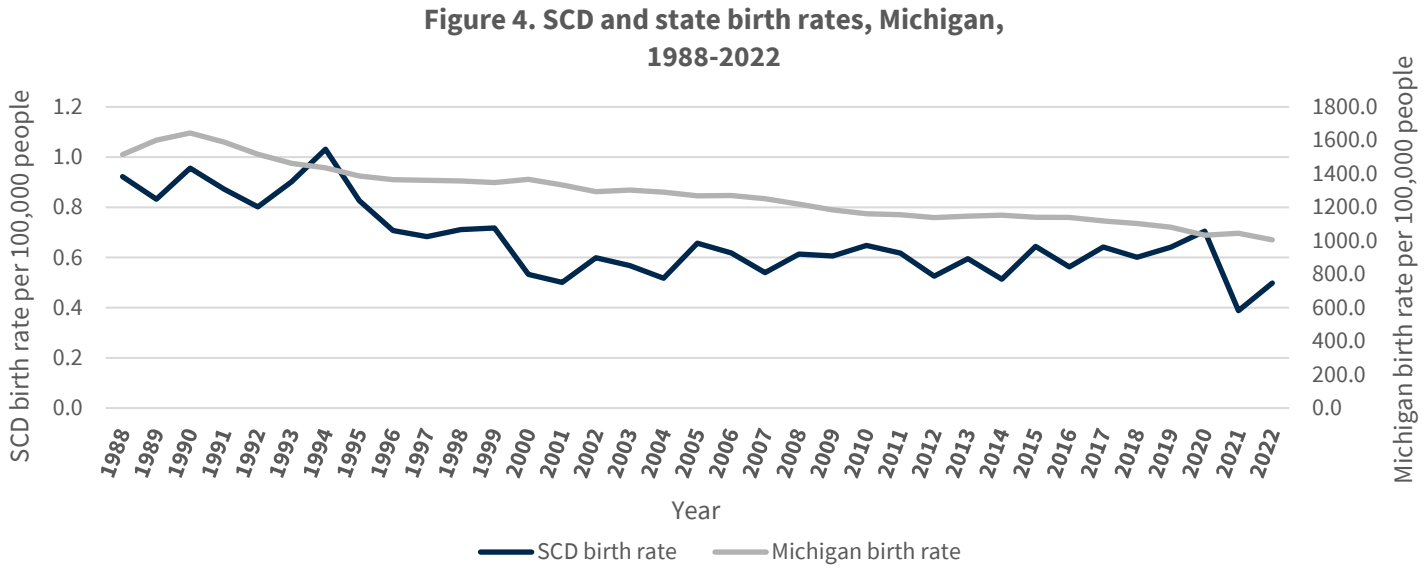


Table 2. Demographics and subtype of confirmed SCD births, 1988-2022 (N = 2,285 infants)

Subtype	**Number of births**	**% of births**
Sickle Cell Anemia (Hemoglobin (Hb) SS and HbSβ^0-thalassemia)	1,288	56.4
HbSC	759	33.2
HbSβ^+-thal	225	9.8
Other SCD (e.g., HbSE, HbSD)	13	0.6
Race	**Number of births**	**% of births**
Black	2097	91.8
Unknown	76	3.3
White	53	2.3
Multi-racial	35	1.5
Middle Eastern/Arab	21	0.9
Asian/Pacific Islander	<5	.
Sex	**Number of births**	**% of births**
Male	1147	50.2
Female	1112	48.7
Unknown	26	1.1

Sickle Cell Disease Mortality

Life expectancy among people with SCD began to increase in the U.S. in the 1980s, largely due to declines in childhood mortality. This is partially attributed to universal newborn screening, penicillin prophylaxis, and pneumococcal vaccinations.[31] However, there is still a demonstrated gap in age at mortality among those living with SCD compared to those that do not have SCD. It is estimated that the life expectancy of people with SCD is more than 20 years shorter than average; this gap is 10 years wider (30 years total) when considering quality adjusted life expectancy.[32, 33]

Descriptive Summary: MiSCDC data from 2018-2022 was used to identify deaths among people with SCD from 2018-2022. All individuals living with SCD in Michigan were included each year. The annual number of deaths and average age at time of death was calculated; this was further stratified by sex. The annual crude mortality rate was calculated overall by dividing the number of deaths by the number of people with SCD for each year, and reporting by 100,000 people. Five-year crude mortality rates by age were calculated for the timeframe from 2018-2022

For comparison, data on mortality among the general Michigan population was obtained from MDHHS Vital Statistics Mortality dashboard.[34]

Findings:

- Among the 4,648 people with SCD in Michigan from 2018-2022, there were 391 deaths during the same timeframe. The number of deaths ranged from a minimum of 54 in 2018 to a maximum of 97 in 2020 among the SCD population in Michigan. The number of deaths increased by 55% in 2020 during the COVID-19 pandemic compared to 2019 (**Table 3**).
- The average age at time of death across these five years was 49.3 years. This varied by sex, with average age being 46.2 years for men and 51.7 years for women.
- The crude mortality rate from 2018-2022 ranged from a minimum of 1,363 deaths per 100,000 people to a maximum of 2,445 deaths per 100,000 people in 2021 (**Figure 5**). The five-year crude mortality rate increased with age (**Table 4**).
    - In comparison, the overall crude mortality rate among those with SCD during the same timeframe was 1.8 times more than the general Michigan population and 1.7 times more than the Black population in Michigan.[34]

Table 3: Mortality among people with SCD, 2018-2022

Year	Number of people	Number of deaths	Average age at death in years
2018	3,961	54	44.6
2019	3,987	62	47.7
2020	4,010	96	50.5
2021	3,968	97	50.1
2022	3,905	82	51.1

Figure 5. SCD and state crude mortality rates, Michigan, 2018-2022

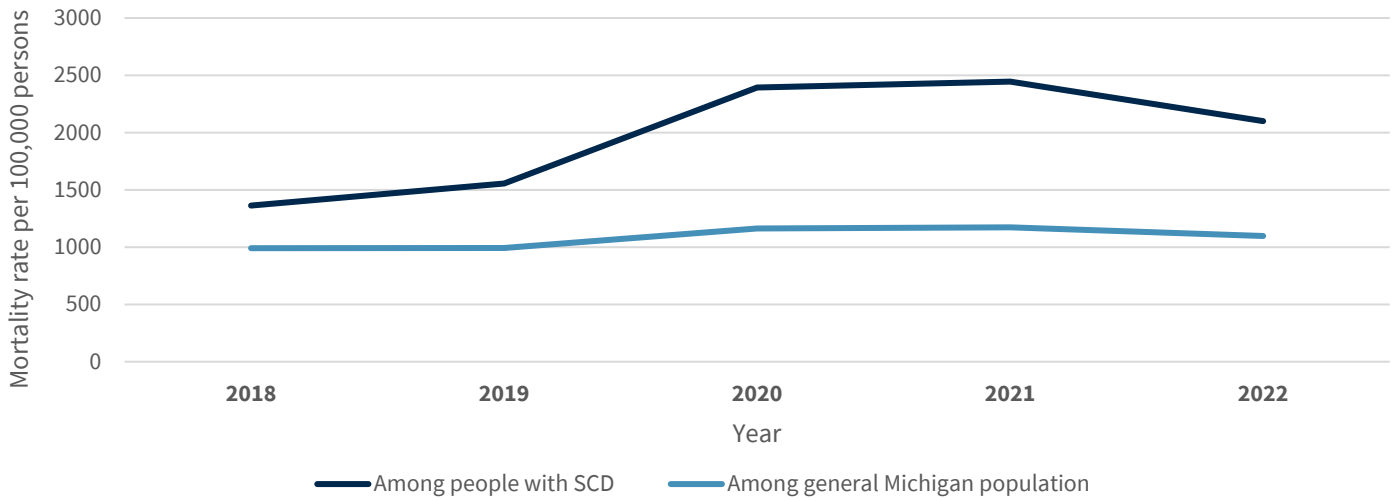


Table 4: SCD crude five-year mortality per 100,000 people by age group, 2018-2022

Age group	Crude 5-year mortality per 100,000 people
0 to 9	367.0
10 to 19	304.0
20 to 29	1210.2
30 to 39	1596.6
40 to 49	2427.4
50 to 59	4385.5
60+	7257.6
All ages	1971.7

Confirmatory Testing

Population-Based Measure

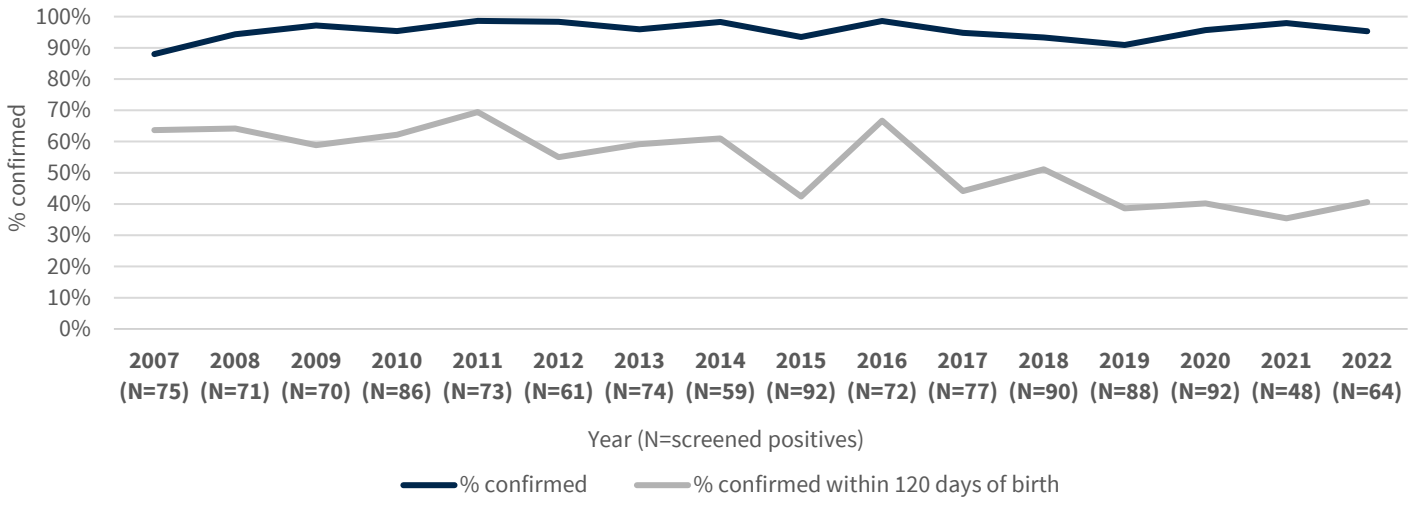
Infants who initially screen positive for SCD at newborn screening move onto confirmatory testing. In Michigan, the confirmatory testing for SCD is coordinated by the Sickle Cell Disease Association of America - Michigan Chapter (SCDAA-MI). SCDAA-MI reports the results of confirmatory testing (e.g., SCD, not SCD) back to the newborn screening program at MDHHS. For SCD, a goal of receiving confirmatory testing in 120 days is used at MDHHS given the timing of the switch between fetal and adult hemoglobin.[35]

Measure: Newborn screening records from 2007 to 2022 were assessed to establish the proportion of infants who screened positive for SCD at newborn screening and that received confirmatory testing. Among those, the proportion that received confirmatory testing within 120 days was calculated. This measure was calculated overall and by year.

Findings:

- From 2007-2022, a total of 1,192 newborns screened positive for SCD; 95.0% received a confirmatory diagnosis (i.e., SCD, not SCD). The percent that received a confirmatory diagnosis ranged from a minimum of 88.0% in 2007 to a maximum of 98.6% in 2011 (**Figure 6**).
- Among those who screened positive, 51.3% received a confirmatory diagnosis within 120 days (**Figure 6**). This decreased over time, from 69.4% in 2011 to 35.4% in 2021.

Figure 6. Confirmatory testing of newborns screened positive for SCD, 2007-2022 (N=1,192 screened positives)



Medicaid Enrollment

Population-Based Measure

Michigan Medicaid is a health care program for families and individuals who have low income. This includes families with children, pregnant women and people under the age of 21, as well as people with a disability or over the age of 65.[36] Medicaid offers a range of services, including doctor visits, hospital care, prescription medications and preventative services. Services covered by Medicaid are offered through what is called fee-for-service or through Medicaid Health Plans. Michigan Medicaid aims to improve access to quality health care, reduce financial barriers and enhance overall health outcomes for its beneficiaries. The program operates under various plans like the Healthy Michigan Plan, which expands coverage to eligible low-income adults.

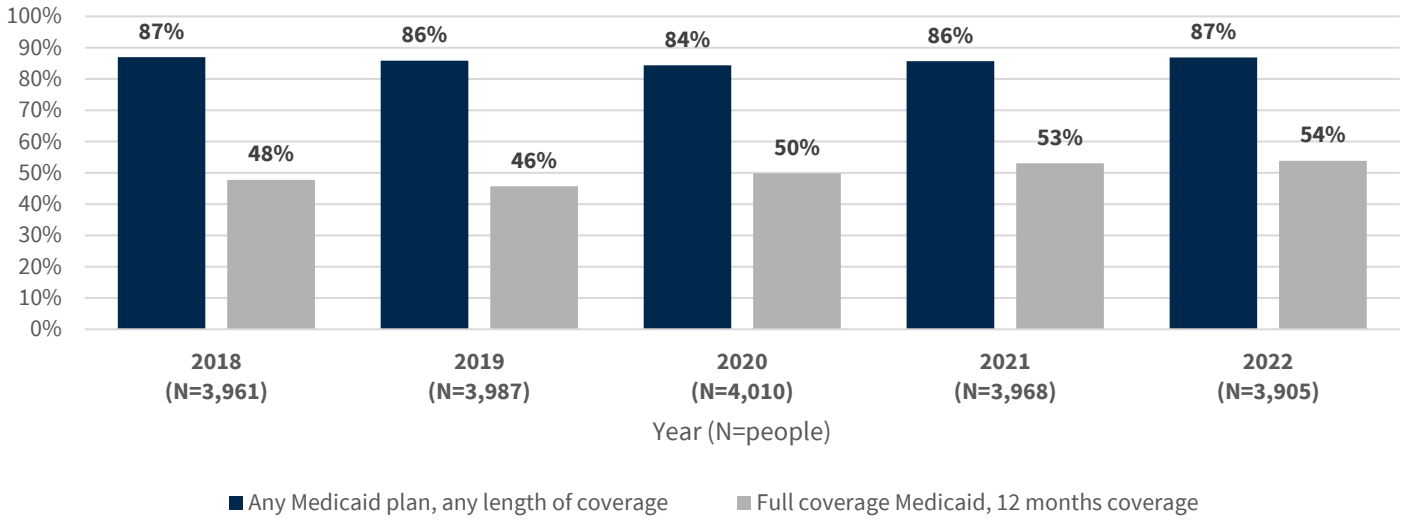
Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of Medicaid enrollment in Michigan among people with SCD. All individuals living with SCD in Michigan were included each year. Patterns included:

- Proportion of individuals with SCD enrolled at any time in any Medicaid plan (i.e., partial or full benefits).
- Among enrollees, the proportion enrolled for 12 months in full coverage Medicaid plans with no other forms of health insurance (i.e. no dual enrollment with Medicare or private insurance coverage).
    - Full coverage Medicaid health plans include: Medicaid – Managed Care/CSHCS Full Fee-for-Service Healthy Kids – Expansion, Full Fee-for-Service Medicaid, Freedom to Work, Healthy Michigan Plan, Healthy Michigan Plan – Managed Care, Medicaid – Managed Care, MIChild Program (CHIP) and Program All-Inclusive Care for Elderly.

Findings:

- The proportion of individuals with SCD enrolled in any Medicaid plan at any point during the year ranged from a maximum of 87.0% (2018, 2022) to 84.4% (2020), with nearly half enrolled in full coverage plans for 12 months with no other forms of insurance (**Figure 7**).
    - In 2022, among the enrollees with 12 months of continuous coverage, 38.5% were under 18 years old, 11.3% were 19-25 years old and 50.2% were over 25 years old. This corresponds to 68.2% of the total population under 18 years, 60.6% of all those aged 19-25 years and 45.4% of all people over 25 years.

Figure 7. Proportion of people with SCD enrolled in Michigan Medicaid, 2018-2022



Children's Special Health Care Services Enrollment

Population-Based Measure

CSHCS is a condition-based (i.e., not need-based) program which is part of the federal Title V Maternal and Child Health Services Block Grant. It offers supplemental coverage for individuals with private or public insurance, and primary coverage for the qualifying condition for those with no other coverage. CSHCS assists with payment for medical care and treatment, including co-pays, deductibles and transportation, and provides care coordination, case management and other support services. In October 2021, Michigan expanded CSHCS coverage to include people living with sickle cell disease over 21 years of age with the goal of improving health outcomes and reducing health disparities for this population.[20]

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of CSHCS enrollment in Michigan among people with SCD. Individuals under 21 years old living with SCD in Michigan were included each year for the first two measures while individuals age 21+ were included in the third measure. Patterns of enrollment included:

- Proportion of individuals with SCD who are enrolled in CSHCS that are Title V only, defined as individuals that are enrolled in CSHCS but not in a full coverage Medicaid plan.
- Proportion of individuals with SCD enrolled in CSHCS reported by Title V/XIX, defined as individuals who are enrolled in CSHCS and also full coverage Medicaid.
- Number of people 21+ years enrolled in CSHCS (i.e., Title V/XIX or Title V) at any point of the year in 2021 and 2022 (note: 21+ years were not eligible for enrollment in CSHCS until October 2021).

Findings

- Over half of individuals under 21 years with SCD were enrolled in Title V/XIX (i.e. full Medicaid with Title V benefits) at any point in the year from 2018-2022 while 11.3% (2020) to 6.9% (2021) of individuals under 21 years were enrolled in Title V only (**Figure 8**).
- CSHCS enrollment has increased among those age 21+ during these two years (**Table 5**).

Figure 8. Proportion of people with SCD enrolled in CSHCS under 21 years, 2018-2022

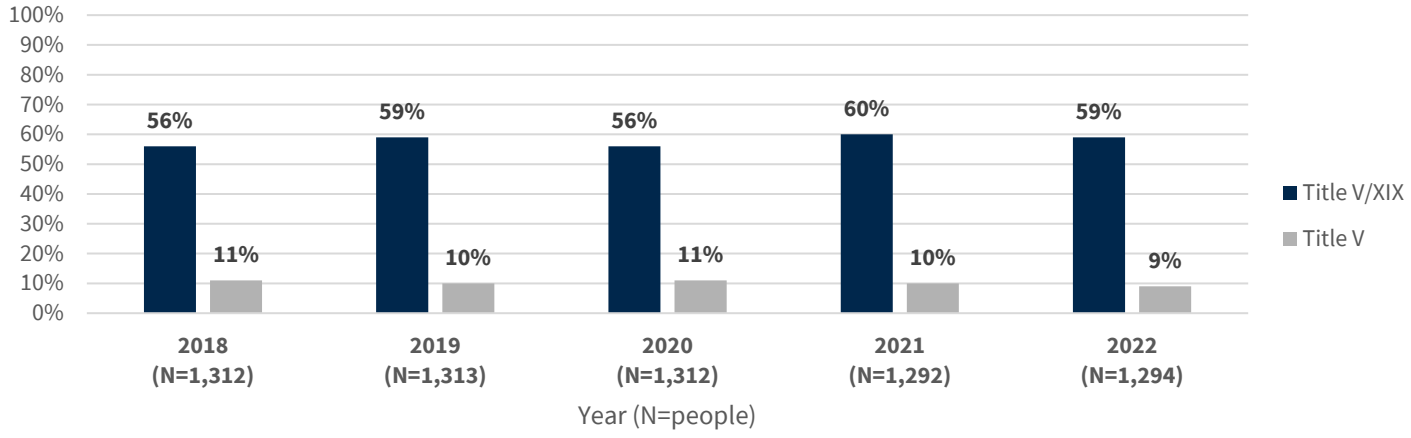


Table 5: CSHCS enrollment among people with SCD age 21+ years, 2021-2022

Year	Number of people enrolled in Title V	Number of people enrolled in Title V/XIX	Total number of people
2021	136	177	313
2022	224	253	477

Emergency Department Visits

Population-Based Measure

The complications caused by SCD often result in high rates of acute care utilization among individuals, such as emergency department (ED) visits. In the U.S., SCD-related ED visits cost more than $350 million annually, with studies indicating pain is the most frequent patient-cited reason for these visits.[37] Frequent ED visits among people with SCD may reflect a lack of access to comprehensive, high quality care and inadequate insurance coverage.[38, 39]

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of ED treat-and-release visits in Michigan among people with SCD (i.e., ED visit not resulting in inpatient admission). All individuals living with SCD in Michigan were included each year. Patterns included 1) annual number of visits; 2) average number of ED visits per person; and 3) percentage of people with SCD with at least one ED visit; these patterns were further stratified by age. The proportion of ED visits with a diagnosis code for SCD-specific complications was assessed using hospital discharge data from 2022.

For comparison, data on ED visits among the general U.S. population was obtained from the Healthcare Cost and Utilization Project (HCUP), a national database of hospital care data.[40]

Findings:

- In total, all individuals with SCD made an average of 10,412 ED treat-and-release visits per year (cumulatively, 52,063 visits from 2018-2022). The total number of ED visits per year ranged from a maximum of 11,520 in 2018 to a minimum of 9,499 in 2021.
- Individuals with SCD had an average of 2.6 ED visits per person per year. Across most years, the age group of 30-39 years had the highest total and average number of ED visits per person. In 2022, among the 789 individuals ages 30-39 years, there were 2,189 visits overall, with an average number of 3.3 ED visits per person (**Figure 9**).
    - In comparison, the average number of ED visits among the U.S. population aged 18-44 was 0.4 ED treat-and-release visits per person in 2022.[40]
- Annually, 51.0-59.0% of individuals with SCD had at least one ED visit across the five-year period. In 2022, the range of number of ED visits was 0 to 277 (**Table 6**).
    - In comparison, 31.2-37.8% of the U.S. general population had at least one ED treat-and-release visit between 2018-2022.[40]
- In 2022, 50.8% of ED visits had a diagnosis of acute vaso-occlusive crisis (VOC), 7.1% had a diagnosis of chronic kidney disease and 1.2% with a diagnosis of pulmonary hypertension (**Table 7**).

Figure 9. ED visits among people with SCD by age group, 2022 (N=3,905 people; 10,088 ED visits)

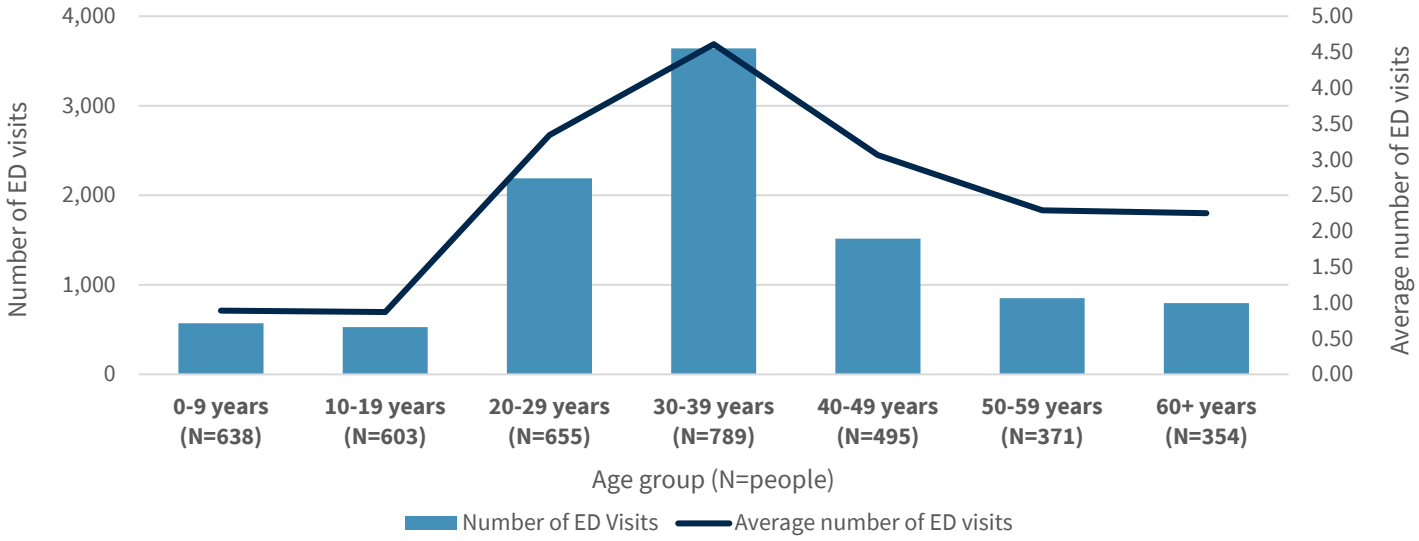


Table 6. Proportion of people with SCD by number of ED visits, 2022

Number of ED visits	Number of people	% of total people
0 visits	1,775	45.5
1-2 visits	1,309	33.5
3-5 visits	503	12.9
6-10 visits	185	4.7
11-19 visits	68	1.7
20-29 visits	15	0.4
30+ visits	50	1.3

Table 7. Proportion of ED visits with common SCD-associated complications, 2022

SCD-specific complication	Number of ED visits	% of ED visits
Acute vaso-occlusive crisis (VOC)	4025	50.8
Chronic kidney disease	563	7.1
Pulmonary hypertension	93	1.2
Priapism	73	1.0
Infection	60	0.8
Avascular necrosis	54	0.7
Pneumonia	52	0.7
Acute anemia	42	0.5
Stroke	35	0.4
Thrombosis	31	0.4
Acute chest syndrome	16	0.2
Splenic sequestration	14	0.2
Acute kidney disease	8	0.1
Retinopathy	<5	NA
Transient ischemic attack	<5	NA

Inpatient Admissions

Population-Based Measure

Given high rates of complications and ED visits, people with SCD are likely to have inpatient admissions more often than individuals without SCD. A study of pediatric SCD inpatient admissions indicated that $900 million was spent annually in associated health care expenditures.[41] Similar to ED visits, sickle cell VOCs are the leading cause of hospitalization among people with SCD in the U.S.[42] High inpatient hospitalization rates may indicate a significant burden of complications and limited access to high-quality care and preventive services.

Measure: MiSCDC data from 2018-2022 was used to assess annual patterns of inpatient admissions in Michigan among people with SCD. All individuals living with SCD in Michigan were included each year. Patterns included: 1) annual number of visits; 2) average number of inpatient admissions per person; 3) percentage of people with SCD with at least one inpatient admission; 4) average length of stay for inpatient admissions; and 5) percentage of inpatient admissions visits that were initiated in the emergency department. The proportion of inpatient admissions with a diagnosis code for SCD-specific complications was evaluated using hospital discharge data from 2022.

For comparison, data on inpatient admissions among the general U.S. population was obtained from HCUP.[43]

Findings:

- In total, all individuals with SCD had an average of 4,443 inpatient admissions per year (cumulatively, 22,218 inpatient admissions from 2018-2022). The total number of admissions per year ranged from a maximum of 4,992 in 2019 to a minimum of 4,098 in 2022.
- Individuals with SCD had an average of 1.1 inpatient visits per person per year. Like ED visits, the age group of 30-39 years had the highest total and average number of inpatient admissions per person. In 2022, among the 789 individuals ages 30-39 years, there were 1,209 admissions overall, with an average number of 1.5 admissions per person (**Figure 10**).
    - In comparison, the average number of inpatient admissions among the U.S. general population aged 18-44 years in 2021 was 0.1 inpatient admissions per person.[43]
- Annually, 38.4-45.0% of individuals with SCD had at least one annual inpatient admission (**Table 8**). The number of inpatient admissions in 2022 ranged from 0 to 46.
    - In comparison, 9.8-10.8% of people in the general U.S. population had at least one inpatient admission between 2018-2021.[43]
- The length of stay ranged from one to 275 days (6.7 days average) across the five-year period.
- Annually, 72.7-78.1% of annual inpatient admissions were initiated in the emergency department.
- In 2022, 66.6% of inpatient admissions had a diagnosis of acute VOC, 18.9% had a diagnosis of chronic kidney disease and 15.1% were infection-related (**Table 9**).

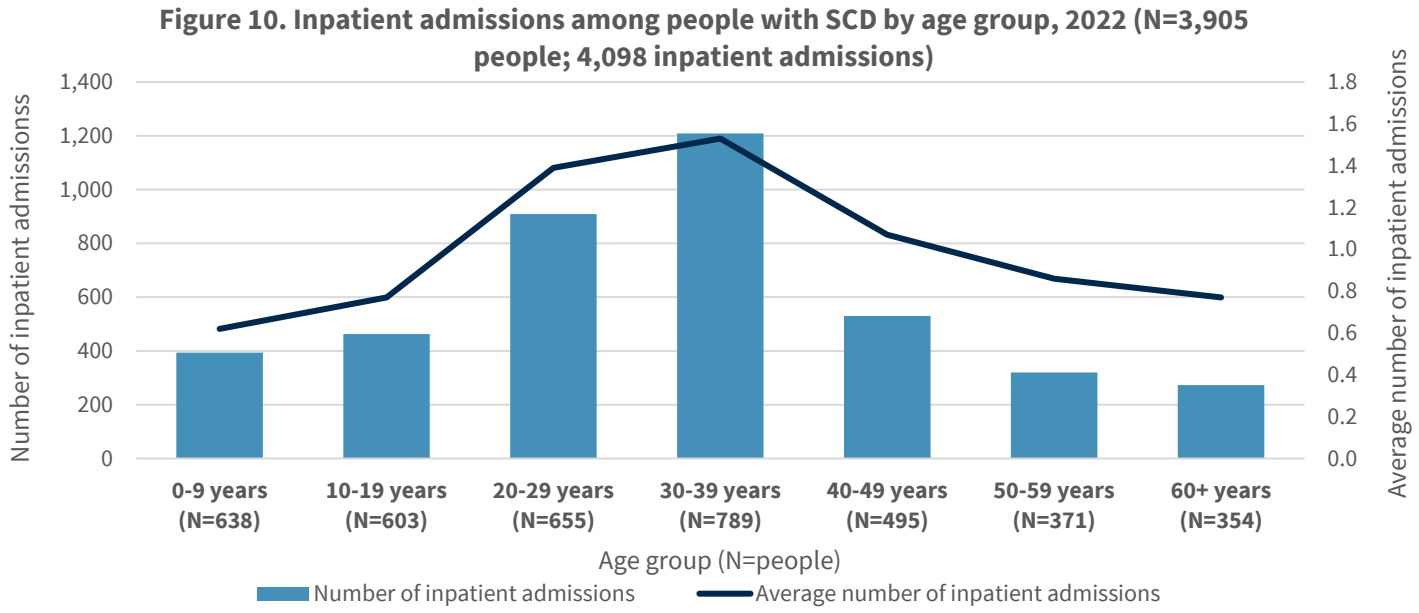


Table 8. Proportion of people with SCD by number of inpatient admissions, 2022

Number of inpatient admissions	Number of people	% of total people
0 admissions	2,405	61.6
1-2 admissions	1,016	26.0
3-5 admissions	336	8.6
6-10 admissions	89	2.3
11-19 admissions	51	1.3
20+ admissions	8	0.2

Table 9. Proportion of inpatient admissions with common SCD-associated complications, 2022

SCD-specific complication	Number of inpatient admissions	% of inpatient admissions
Acute vaso-occlusive crisis (VOC)	2509	66.6
Chronic kidney disease	711	18.9
Infection	568	15.1
Pneumonia	518	13.7
Pulmonary hypertension	363	9.6
Acute anemia	348	9.2
Acute chest syndrome	284	7.5
Avascular necrosis	236	6.3
Stroke	178	4.7
Thrombosis	162	4.3
Splenic sequestration	88	2.3
Priapism	62	1.6
Retinopathy	35	0.9
Acute kidney disease	8	0.2
Transient ischemic attack	5	0.1

Outpatient Visits

Medicaid-Only Measure

Children and adults with SCD have multiple interactions with the health care system each year, often in the form of outpatient visits. Periodic outpatient visits can improve the management of SCD and result in higher rates of preventive services. As such, national guidelines recommend that children and adults with SCD be seen regularly in outpatient settings by primary care providers, hematologists and other care providers as necessary.[44]

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of outpatient visits in Michigan among people with SCD. Individuals living with SCD in Michigan who were enrolled for 12 months in Medicaid were included each year. Patterns included 1) annual number of outpatient visits; 2) average number of outpatient visits per person; and 3) percentage of people with SCD with no outpatient visits; these patterns were further stratified by age.

Findings:

- In total, all individuals with SCD had an average of 14,934 outpatient visits per year (cumulatively, 74,671 visits from 2018-2022). The number of outpatient visits per year ranged from a maximum of 15,202 in 2022 to a minimum of 13,807 in 2020.
- Individuals with SCD had an average of 7.2 outpatient visits per person per year. Across years, either the age group of 50-59 or 60+ years had the highest total and average number of outpatient visits per person. In 2022, among the 57 individuals aged 60+ years, there were 798 visits overall, with an average number of 14.0 outpatient visits per person (**Figure 11**).
- Annually, the proportion of individuals with SCD that did not have one outpatient visit ranged from 9.4% to 12.8% (**Table 10**). In 2022, the range of number of outpatient visits was 0 to 164.

Figure 11. Outpatient visits among people with SCD by age group, Michigan Medicaid 2022
(N=2,102 people; 15,202 outpatient visits)

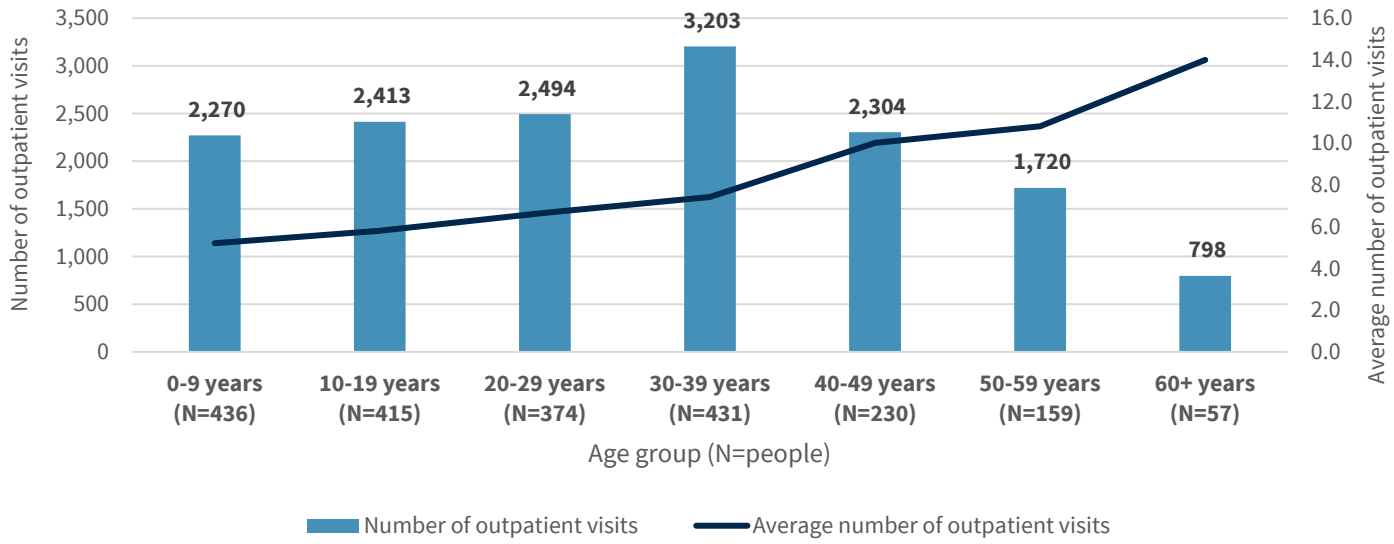


Table 10. Proportion of people with SCD by number of outpatient visits, Michigan Medicaid 2022

Number of outpatient visits	Number of people (N=2,102)	% of total people
0 visits	270	12.8
1-2 visits	366	17.4
3-5 visits	464	22.1
6-10 visits	471	22.4
11-19 visits	408	19.4
20-29 visits	92	4.4
30+ visits	31	1.5

Outpatient Hematology Visits

Medicaid-Only Measure

Hematologists, doctors who specialize in blood diseases, are the primary subspecialists caring for people with SCD. Individuals with SCD should have at least one visit with a hematologist every year.[44] Two or more hematologist visits in a year has been associated with higher uptake of life-saving preventive services, including antibiotic prophylaxis, immunizations and transcranial doppler screening, as compared to fewer visits.[45]

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of outpatient hematology visits among people with SCD. Individuals living with SCD in Michigan who were enrolled for 12 months in Medicaid were included each year. Among all outpatient visits, visits with a hematologist were identified using the National Provider Identifier and associated taxonomy codes. Patterns included 1) annual number of outpatient hematology visits; 2) average number of outpatient hematology visits per person; and 3) percentage of people with SCD with no outpatient hematology visits; these patterns were further stratified by age.

Findings:

- Individuals with SCD had an average of 3,266 outpatient hematology visits per year (cumulatively, 16,330 visits from 2018-2022). The number of outpatient hematology visits per year ranged from a maximum of 3,718 in 2022 to a minimum of 2,653 in 2018.
- Individuals with SCD had an average of 1.6 outpatient hematology visits per person per year. Across all years, the age group of 10-19 years had the highest total and average number of hematology visits per person. In 2022, among the 415 individuals ages 10-19 years, there were 927 hematology visits overall, with an average number of 2.2 hematology visits per person (**Figure 12**).
- Annually, the proportion of individuals with SCD who did not have any outpatient hematology visits ranged from 55.2% to 64.1% (**Table 11**). In 2022, the range of number of outpatient hematology visits was 0 to 45, with 46.7% of children under 18 years and 60.8% of adults 18 years and older having no hematologist visits.

Figure 12. Outpatient hematology visits among people with SCD by age group, Michigan Medicaid 2022 (N=2,102 people; 3,718 hematology visits)

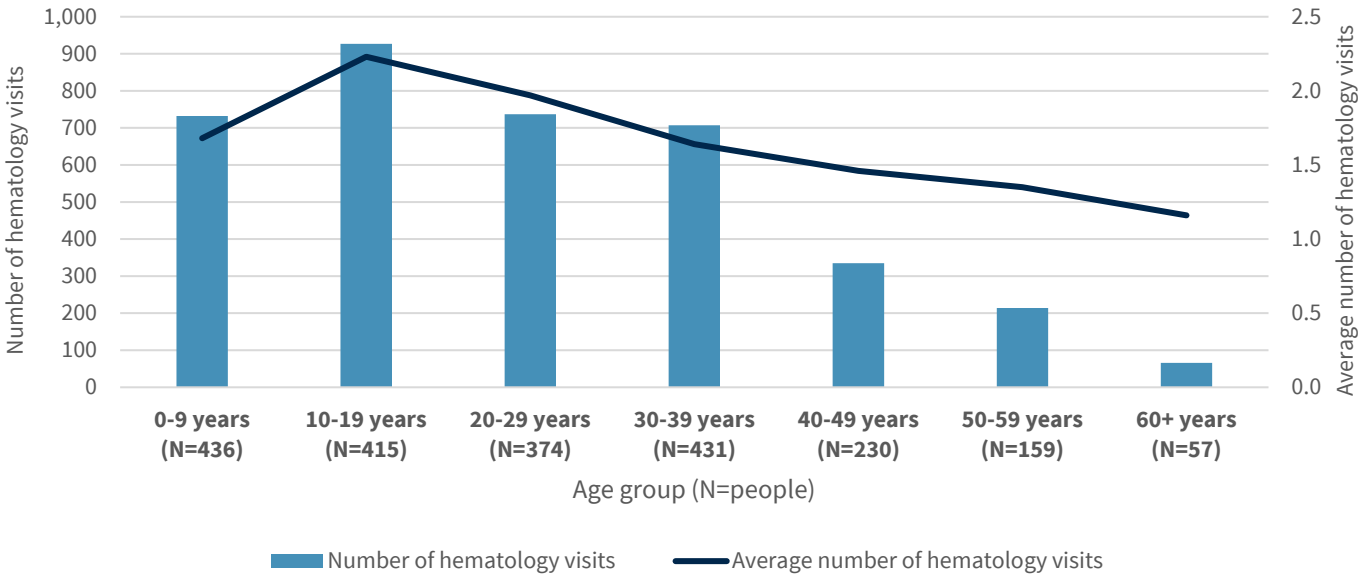


Table 11. Proportion of people with SCD by number of outpatient hematology visits, Michigan Medicaid 2022

Number of outpatient hematology visits	Number of people (N=2,102 people)	% of total people
0 visits	1,169	55.6
1-2 visits	430	20.5
3-5 visits	275	13.1
6-10 visits	179	8.5
11-19 visits	42	2.0
20+ visits	7	0.3

Immunizations

Population-Based Measure

Individuals with SCD are at an increased risk of infection due to reduced or absent splenic function.[46] As such, it is particularly important that people with SCD receive all immunizations recommended by the Advisory Committee on Immunization Practices.[47] These include the primary immunization series (i.e., four doses of Diphtheria, tetanus, and acellular pertussis (DTaP), three doses of Polio, one dose of Measles, mumps, rubella (MMR), three doses of Haemophilus influenzae type b (Hib), three doses of Hepatitis B (HepB), one dose of Varicella, four doses of Pneumococcal conjugate (PCV)), as well as immunizations for influenza and Coronavirus disease 2019 (COVID-19).[48]

Measure: MiSCDC data was used to identify all individuals living with SCD in Michigan from 2018-2022. Administered immunizations were acquired from MCIR. The following immunization patterns were evaluated each year among all individuals living with SCD:

- Completion of overall primary immunization series, among children with SCD ages three to <18 years annually from 2018 to 2022.
- Completion of individual immunizations within the primary series, among children with SCD ages three to <18 years in 2022.
- Receipt of at least one influenza vaccine annually (July 1-June 30), among people with SCD ages six months and older as of July 1 of each influenza season, July 2017- June 2022.
- Receipt of at least one COVID vaccine cumulatively from 2021-2022, among people with SCD aged six months and older as of January 1 of each year.

For comparison, immunization patterns among the general Michigan population were obtained from MDHHS and CDC vaccination reports. [49-51]

Findings:

- Most children with SCD aged three to <18 years completed their immunization series annually, with a minimum completion of 80.9% in 2019 to 83.5% in 2021 (**Figure 13**).
    - In comparison, from 2018-2022 the percent of Michigan children ages 19 to 35 months who had completed the primary immunization series ranged from 70.8% to 74.5%.[49]
- In 2022, completion rates varied by vaccine within the primary series. The vaccine with the highest rate of completion was MMR at 96.6%; the lowest was PCV at 84.1% (**Table 12**).
- Receipt of annual influenza vaccine among people with SCD ranged from a minimum of 26.4% in 2022 to a maximum of 31.9% in 2020 (**Figure 14**).
    - In comparison, annual influenza vaccine receipt among all people in Michigan six months and older ranged from a minimum of 39.5% in the 2018-2019 influenza season to a maximum of 55.7% in the 2021-2022 influenza season.[50]
- Among people with SCD, receipt of COVID-19 vaccine increased from 37.2% by the end of 2021 to 42.7% by the end of 2022, with substantial variation in receipt of vaccine by age (**Figure 15**). Individuals aged 60+ were most likely to have at least one COVID vaccine while those aged <10 years had the lowest receipt (**Table 13**).
    - In comparison, 63.4% of all Michigan residents have been vaccinated with at least one dose of COVID vaccine between December 2021 and March 2025.[51]

Figure 13. Primary series vaccine completion among children with SCD, 2018-2022

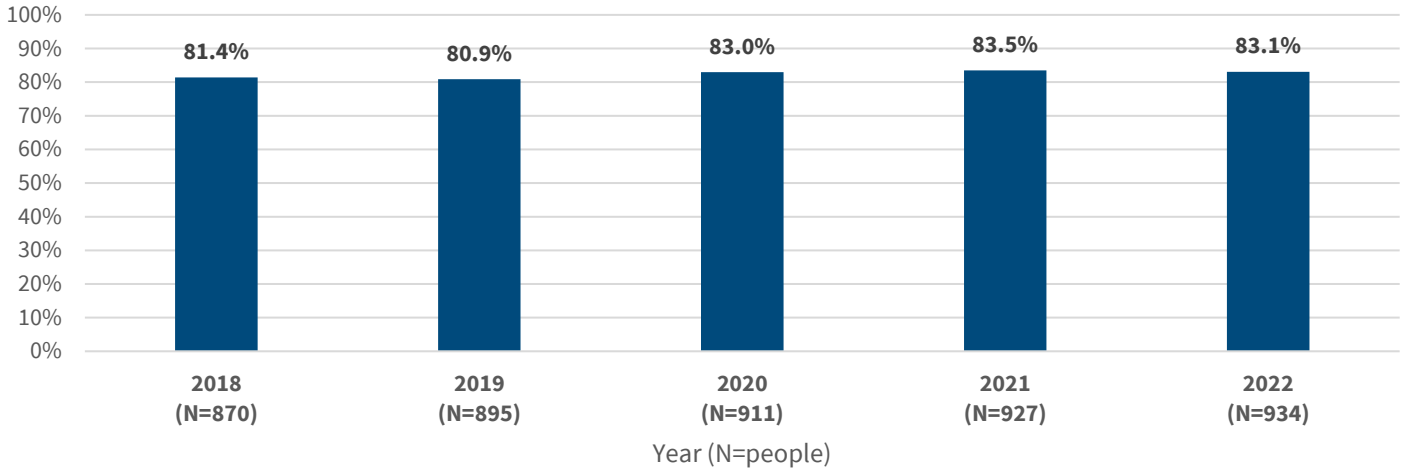


Table 12. Proportion of children with SCD who completed individual vaccines within primary series, 2022 (N=934 people)

Vaccine series	% of children that completed vaccine series
DTap	94.5
Polio	96.5
MMR	96.6
Hib	91.7
HepB	96.4
Varicella	96.3
PCV	84.1

Figure 14. Influenza vaccine receipt among people with SCD, 2018-2022

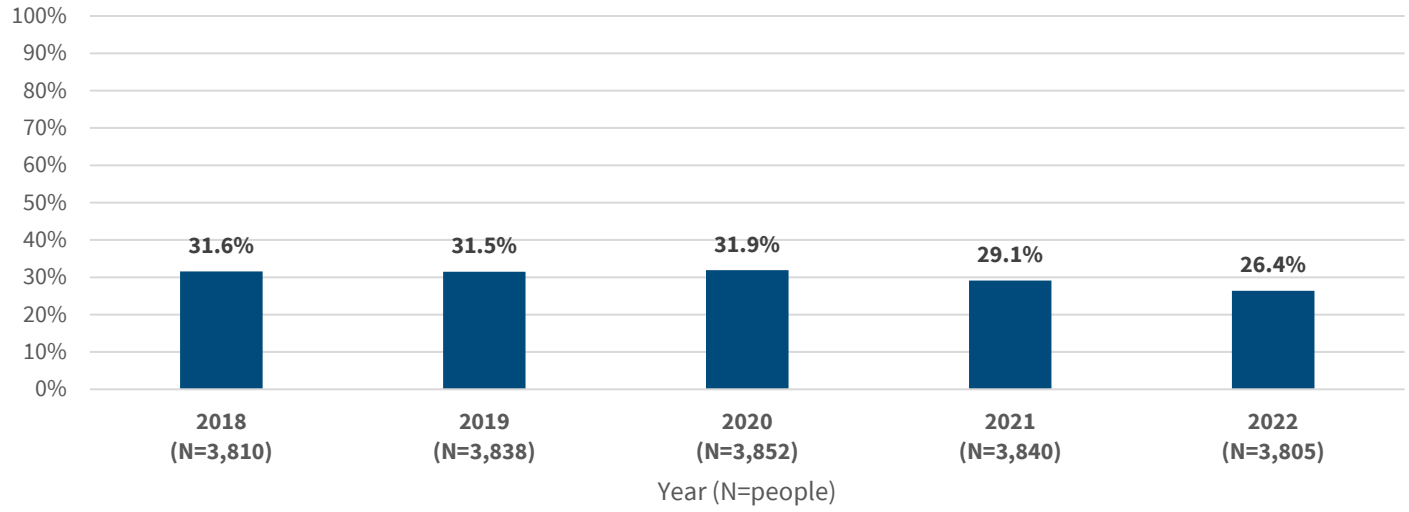


Figure 15. COVID vaccine receipt among people with SCD by age group, 2022

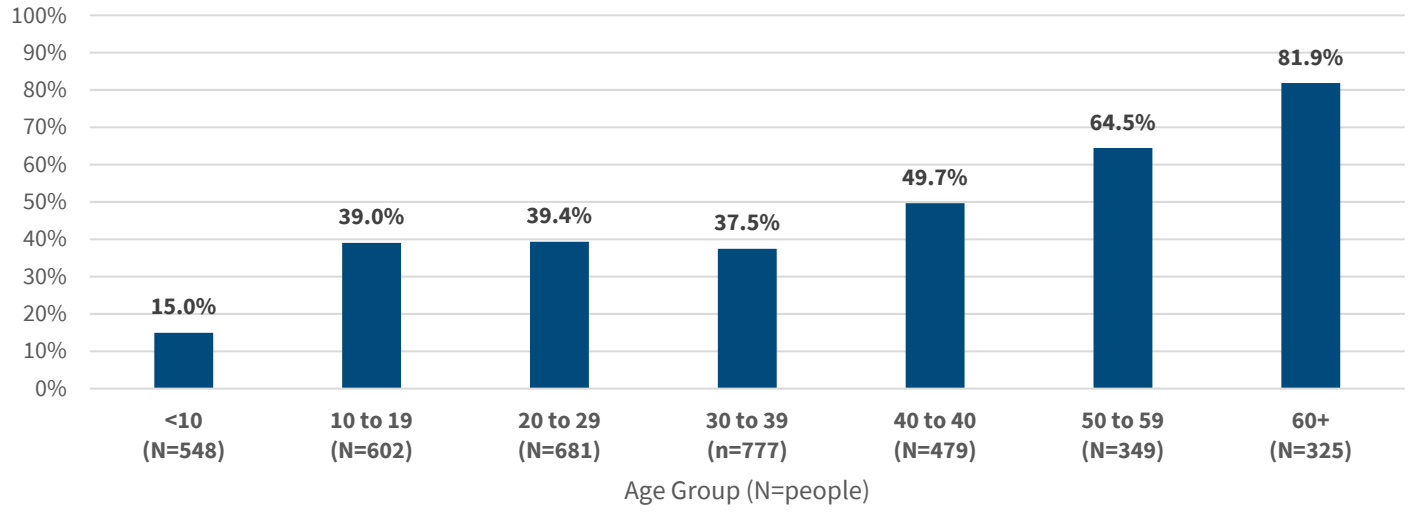


Table 13. Cumulative COVID vaccine receipt among people with SCD, 2021-2022

Year	Number of people	% of people with at least 1 COVID vaccine
2021	3,804	37.6
2022	3,761	42.7

Antibiotic Prophylaxis

Medicaid-Only Measure

Prior to antibiotic prophylaxis and pneumococcal vaccinations, young children with sickle cell anemia, a subtype of SCD, were 100 times more at risk of severe infection compared to children without sickle cell anemia.[52] In 1983, the Penicillin Prophylaxis in Sickle Cell Disease (PROPS) clinical trial demonstrated an 84% decrease in infections among children on twice daily penicillin relative to placebo.[53] As such, the National Heart, Lung, and Blood Institute strongly recommends young children with sickle cell anemia be initiated and maintained on a twice daily antibiotic prophylaxis regimen from birth to five years of age to decrease the risk of life-threatening infections.[54, 55]

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of filled antibiotic prophylaxis among children with sickle cell anemia. Individuals ages zero through five years living with SCD in Michigan who were enrolled for 12 months in Medicaid were included each year. Individuals with an identified subtype that was not sickle cell anemia or with an unknown subtype were excluded. Filled antibiotic prescriptions were identified using a validated list of National Drug Codes (NDCs). Patterns included 1) the proportion of children with at least one filled antibiotic prescription, 2) the proportion of children with at least 300 days of filled antibiotic prescriptions, and 3) average days of filled antibiotic prescriptions among children with at least one filled prescription for antibiotics.

Findings:

- Most children with sickle cell anemia had at least one filled prescription for antibiotics within the year. The proportion of children that did not have any antibiotic prescriptions in the year ranged from 10% to 15.9% (**Figure 16**).
- The proportion of children who had at least 300 days of filled antibiotics in the year ranged from a minimum of 5.3% in 2018 to a maximum of 16.2% in 2021 (**Figure 16**).
- Among children with at least one filled antibiotic prescription, average days' supply covered less than half of the year; across all years, the average was 160 days of filled antibiotics, with a range of one day to 459 days (**Table 14**).

Figure 16. Antibiotic prescriptions filled among children with sickle cell anemia, Michigan Medicaid 2018-2022

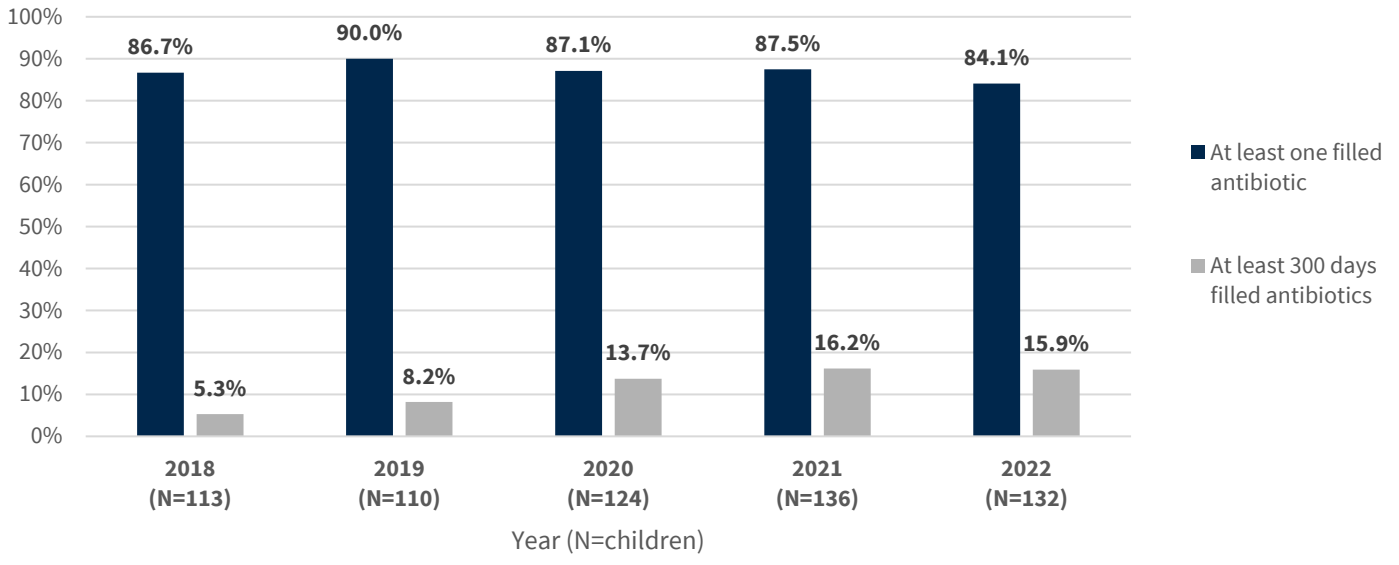


Table 14. Average days' supply of antibiotic prophylaxis filled among children with sickle cell anemia, Michigan Medicaid 2018-2022

Year	Number of children with at least one filled antibiotic prescription	Average days' supply (minimum to maximum)
2018	98	153 (14 to 388)
2019	99	145 (14 to 381)
2020	108	166 (10 to 420)
2021	119	170 (10 to 410)
2022	111	166 (1 to 459)

Transcranial Doppler Screening

Medicaid-Only Measure

Children with sickle cell anemia, a subtype of SCD, are at 300 times the risk of a stroke as compared to children without sickle cell anemia.[56, 57] Transcranial doppler (TCD) screening is used to assess stroke risk: for the three years following a high-risk reading, the risk of stroke is 40%.[58-60] Children at high risk of stroke should begin chronic blood transfusions, which reduce the risk of stroke by over 90%.[59, 60] As such, the National Heart, Lung, and Blood Institute strongly recommends children with sickle cell anemia have one TCD screen annually from ages two until 16 years.[54, 55]

Measure: MiSCDC data from 2018-2022 was used to analyze receipt of TCD screening among children and adolescents with sickle cell anemia. Individuals ages two through 15 years living with SCD in Michigan who were enrolled for 12 months in Medicaid were included each year. Individuals with an identified subtype that was not sickle cell anemia or with an unknown subtype were excluded. TCD screening was identified using Common Procedural Terminology (CPT) codes of 93886, 93888, 93890, 93892, 93893. The number and proportion of children with at least one TCD screen was calculated annually and additionally stratified by age (2-5 years; 6-11 years; 12 to 15 years).

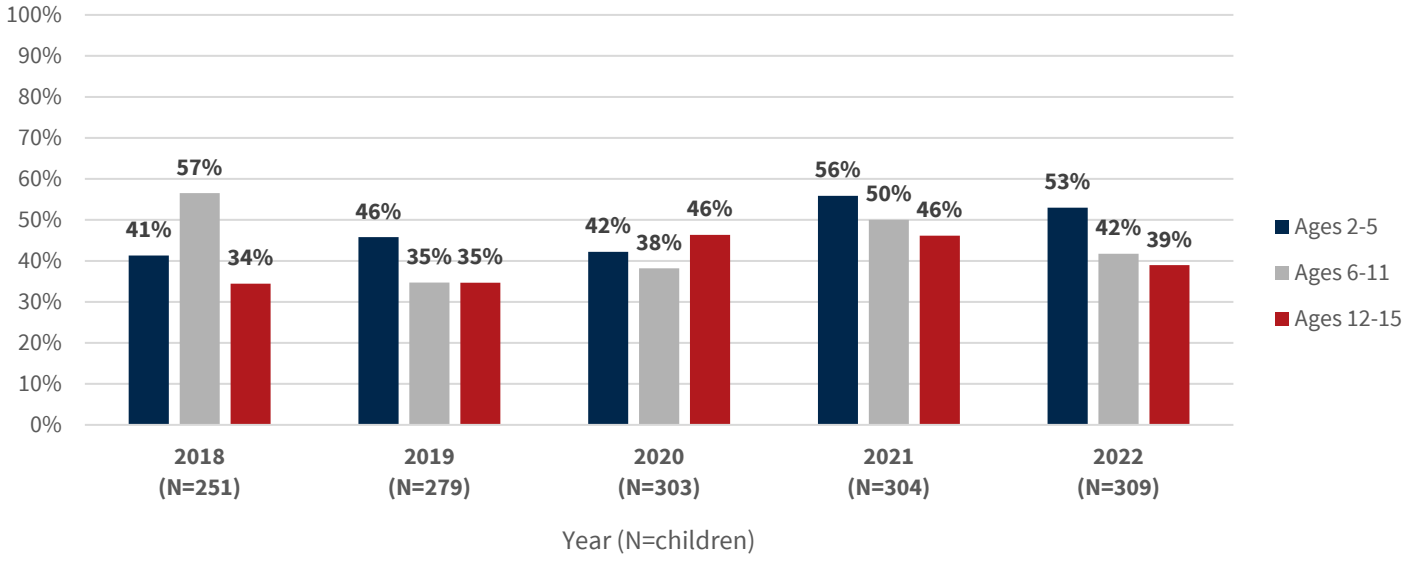
Findings:

- Less than half of children with sickle cell anemia received a TCD screen annually (**Table 15**); proportions ranged from a minimum of 38.0% in 2019 to a maximum of 51.0% in 2021.
- In general, children ages 12-15 were less likely to receive a TCD screen compared to other age groups, with an average percentage of 48.4% for two to five years, 44.1% for six to 11 years and 40.5% for 12-15 years (**Figure 17**).

Table 15. TCD screening among children with sickle cell anemia, Michigan Medicaid 2018-2022

Year	Total eligible children	Number of children with TCD screen	% of children with TCD screen
2018	251	117	46.6
2019	279	106	38.0
2020	303	126	41.6
2021	304	155	51.0
2022	309	140	45.3

Figure 17. TCD screening among children with sickle cell anemia by age, Michigan Medicaid 2018-2022



Hydroxyurea

Medicaid-Only Measure

Pain is the most common morbidity for people with SCD; it is persistent, unpredictable and recurrent.[61, 62] People with SCD experience pain through acute pain episodes (also known as VOCs) occurring periodically and ranging in frequency and severity. Chronic pain often develops during adolescence and persists throughout the lifespan. Among people with SCD, VOCs are associated with lower quality of life, inadequate sleep, increased school absences, chronic depression and impaired peer relationships.[6, 63-67] Importantly, receipt of the medication hydroxyurea reduces the incidence of pain crises and acute chest syndrome. Beginning in 2014, hydroxyurea was recommended by the National Heart, Lung, and Blood Institute to be offered to individuals with SCD beginning at nine months of age.[68]

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of filled hydroxyurea among individuals with SCD. Individuals aged one year or older living with SCD in Michigan who were enrolled for 12 months in Medicaid were included each year. Filled hydroxyurea prescriptions were identified using a validated list of NDCs. Patterns included 1) the proportion of individuals with at least one filled hydroxyurea prescription, 2) the proportion of individuals with at least 300 days of filled hydroxyurea, and 3) average days of filled hydroxyurea among people with at least one filled prescription for hydroxyurea. These patterns were further stratified by 10-year age groups using data from 2022.

Findings:

- Approximately one in five people with SCD had at least one filled prescription for hydroxyurea within each year. This increased over time from 18.4% in 2018 to 23.2% in 2022 (**Figure 18**).
- The proportion of people who had at least 300 days of filled hydroxyurea in the year ranged from a minimum of 3.4% in 2018 to a maximum of 5.3% in 2022 (**Figure 18**).
- Among people with at least one filled hydroxyurea prescription, average days' supply covered approximately half of the year; across all years, the average was 176 days of filled hydroxyurea, with a range of two days to 630 days (**Table 16**).
- In 2022, the proportion of people with at least one hydroxyurea prescription decreased across each 10-year age group. Children ages zero to nine years had the highest proportion of at least one filled hydroxyurea prescription (30.7%); people older than 50 years old had the lowest proportion (11.1%). This pattern also persisted when examining the proportion with at least 300 days of filled hydroxyurea (**Figure 19**).
- In 2022, among those with at least one filled hydroxyurea prescription, children ages zero to nine years had the highest average day supply (215 days); individuals ages 20-29 years had the lowest average day supply (160 days) (**Table 17**).

Figure 18. Hydroxyurea prescriptions filled among people with SCD, Michigan Medicaid 2018-2022

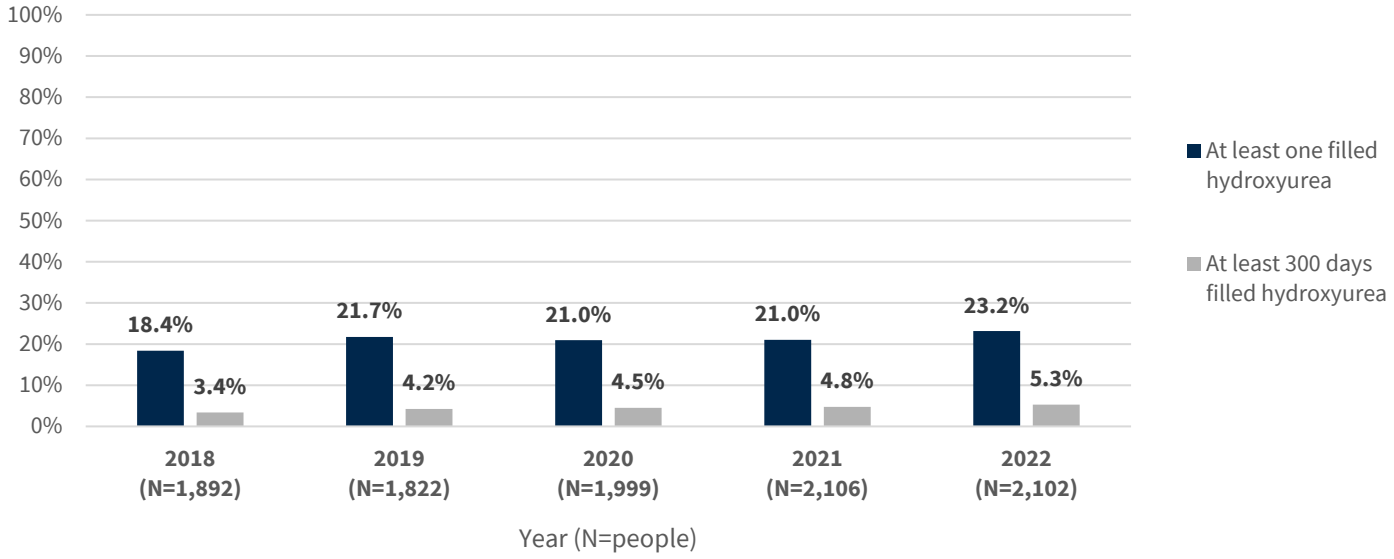


Table 16. Average days' supply of hydroxyurea filled among people with SCD, Michigan Medicaid 2018-2022

Year	Number of people with at least one filled hydroxyurea prescription	Average days' supply (minimum to maximum)
2018	348	174 (2 to 420)
2019	396	167 (10 to 494)
2020	419	177 (3 to 546)
2021	443	176 (6 to 450)
2022	487	184 (15 to 630)

Figure 19. Hydroxyurea prescriptions filled among people with SCD by age group, Michigan Medicaid 2022 (N=2,102 people)

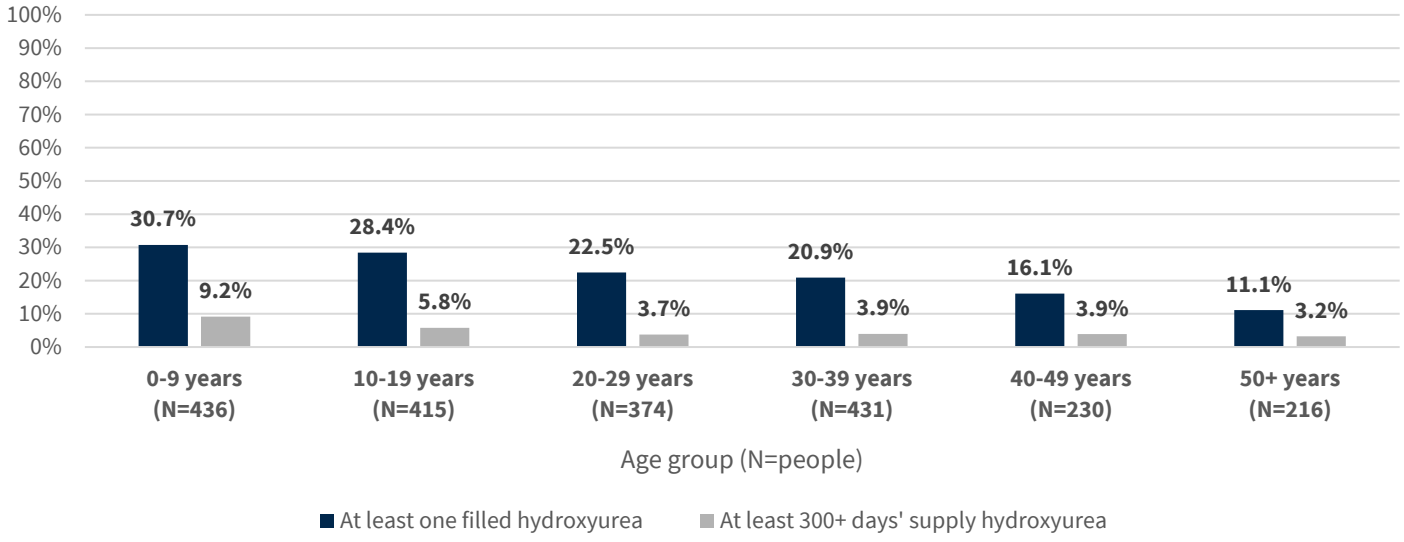


Table 17. Average days' supply of hydroxyurea filled among people with SCD by age group, Michigan Medicaid 2022

Age group	Number of people with at least one filled hydroxyurea prescription	Average days' supply of hydroxyurea (minimum to maximum)
0-9 years	134	215 (28 to 451)
10-19 years	118	167 (16 to 630)
20-29 years	84	161 (30 to 420)
30-39 years	90	170 (15 to 420)
40-49 years	37	200 (15 to 450)
50+ years	24	203 (30 to 390)

Disease Modifying Therapies

Medicaid-Only Measure

In the previous decade, three new disease-modifying therapies (e.g., medications) have been introduced for people living with SCD. These medications are brand names of Endari, Oxbryta and Adakveo. To date, there are no national recommendations for the use of these three medications.

- Endari (L-glutamine) is an oral, twice-daily medication that reduces severe complications associated with SCD, such as acute chest syndrome. Endari was approved by the Food and Drug Administration (FDA) in 2017 for individuals five years of age and older.
- Oxbryta (voxelotor) is an oral, once-daily medication approved by the FDA in November 2019 for people with SCD 12 years and older and for four years and older in 2021. Notably, Oxbryta was withdrawn from the market in October 2024 given risks for VOCs and death.
- Adakveo (crizanlizumab) reduces VOCs among people with SCD. It was approved by the FDA for people with SCD 16 years and older in November 2019. Adakveo is a 30-minute infusion given once a month after the second dose.

Measure: MiSCDC data from 2018-2022 was used to analyze annual patterns of Endari, Oxbryta and Adakveo among individuals with SCD. Individuals living with SCD in Michigan who were enrolled for 12 months in Medicaid were included each year. For each medication, the recommended age group and time of approval were included (i.e., Endari, individuals ages five and older in 2018; Oxbryta, individuals ages 12 and older in 2020 and four and older in 2021; Adakveo, individuals 16 and older in 2019). Filled prescriptions of Endari and Oxbryta were identified using NDCs. Adakveo was identified using CPT codes, J0791 and C9053, for the infusion. Patterns included the proportion of individuals with at least one filled prescription for Endari and Oxbryta; for Adakveo, at least one infusion. Among those with at least one filled prescription or infusion, days' filled supply and number of infusions was calculated in 2022.

Findings:

- The proportion of individuals with SCD with at least one filled Endari prescription increased from 0.7% in 2018 to 2.6% in 2022. In 2022, among individuals with at least one filled Endari prescription, the average days' supply was 140 days, with a range of 30 to 390 days (**Table 18**).
- The proportion of individuals with SCD with at least one filled Oxbryta prescription increased from 1.4% in 2018 to 4.6% in 2022. In 2022, among individuals with at least one filled Oxbryta prescription, the average days' supply was 122 days, with a range of 30 to 360 days (**Table 19**).
- The proportion of individuals with SCD receiving at least one Adakveo infusion from 2020-2022 is low; the percentage ranged from 0.3% in 2020 to 1.1% in 2022. In 2022, among individuals with at least one Adakveo infusion, the average number of infusions was six, with a range of one to 13 infusions (**Table 20**).

Table 18. Endari (L-glutamine) prescriptions filled among people with SCD, Michigan Medicaid 2018-2022

Year	Number of people	% of total people	Mean days' supply (minimum to maximum)
2018	1,705	0.7	98 (30 to 180)
2019	1,623	1.3	106 (30 to 210)
2020	1,778	1.2	124 (30 to 360)
2021	1,867	2.2	116 (30 to 390)
2022	1,890	2.6	140 (30 to 390)

Table 19. Oxbryta (voxelotor) prescriptions filled among people with SCD, Michigan Medicaid 2020-2022

Year	Number of people	% of total people	Mean days' supply (minimum to maximum)
2020	1,468	1.4 (age 12+)	77 (30 to 240)
2021	1,571	2.7 (age 4+)	99 (30 to 390)
2022	1,579	4.6 (age 4+)	122 (30 to 360)

Table 20. Adakveo (crizanlizumab) infusions among people with SCD, Michigan Medicaid 2020-2022

Year	Number of people	% of total people	Mean number of infusions (minimum to maximum)
2020	1,468	0.3	2 (1 to 4)
2021	1,571	1.0	5 (1 to 12)
2022	1,579	1.1	6 (1 to 13)

Next Steps

The objective of this report is to support the development of the 2025 MDHHS strategic plan for SCD by providing a quantitative assessment of SCD in Michigan. By leveraging multi-source data from MiSCDC, we described the epidemiology and health care utilization of Michiganders with SCD. We identified gaps in services, quality of care and opportunities for improvement, particularly in areas of preventive services, ED utilization and outpatient hematology visits. Further, with the recent introduction of new disease modifying and curative therapies, the health care landscape for SCD has fundamentally shifted; this report tracks the uptake and implementation of some of these new treatments. We anticipate that this quantitative report will be used in conjunction with other efforts, such as focus groups and surveys, to support the centering of voices of individuals living with SCD in Michigan and their families in strategic planning efforts.

The MiSCDC team plans to continue collaborating with MDHHS to support the robust monitoring and evaluation of the implementation of the strategic plan. This includes the development and tracking of short-term and long-term measures to assess progress toward the strategic plan objectives. For example, additional years of data will be available throughout the five-year implementation period of the strategic plan, which will be used to monitor trends. In addition, we will continue our work with SCD clinics to provide feedback on their own performance on measures. This will allow identification of opportunities for improvement, particularly when compared to results across Michigan. Further, additional measures such as use of telehealth, access to behavioral and mental health, and bone marrow transplants may be considered for inclusion in this report based upon identified priorities. Through these actions, MiSCDC aims to provide the evidence necessary to support policies and programs that improve outcomes for all Michigan residents with SCD.

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