CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
OFFICE OF MINORITY HEALTH

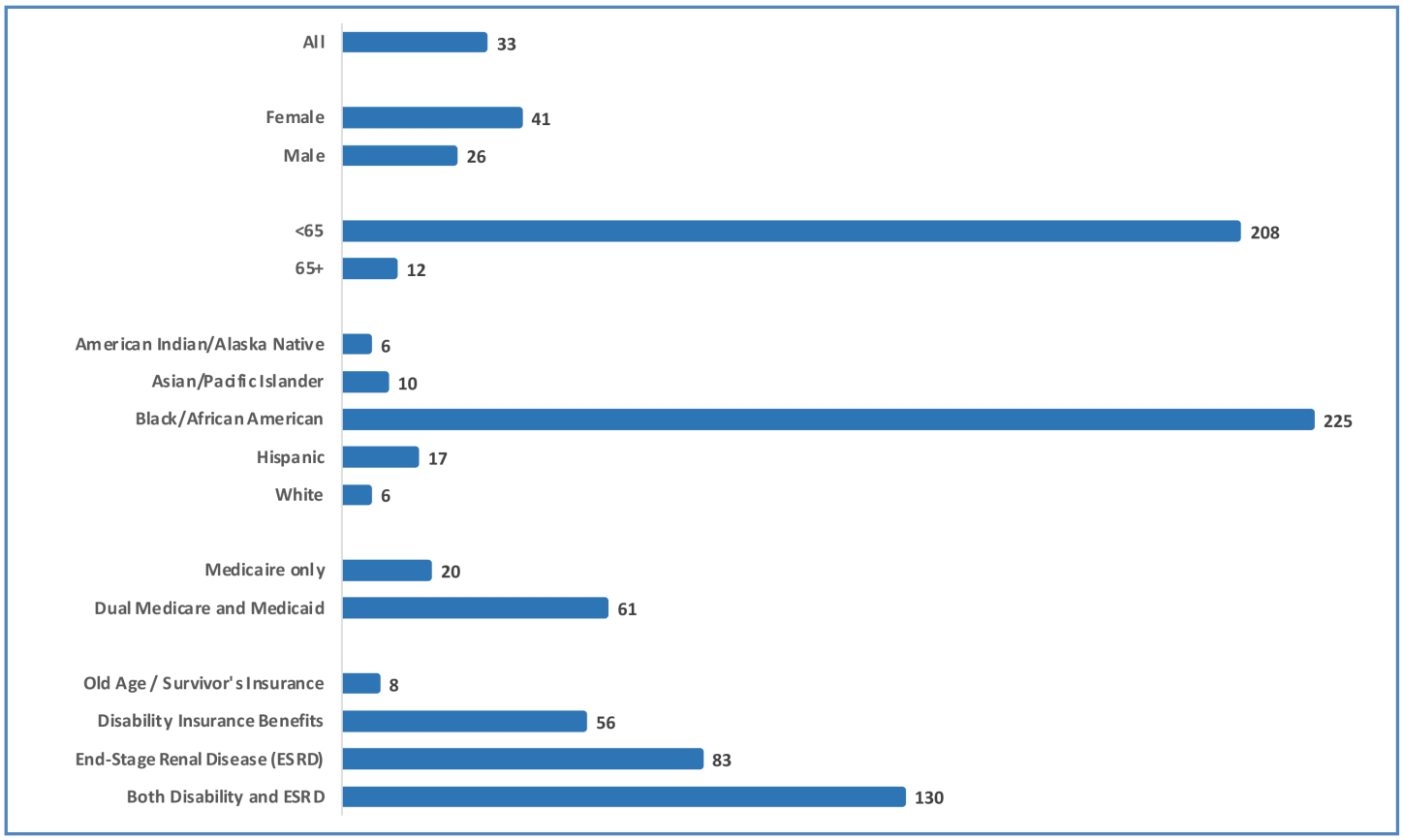
DATA SNAPSHOT
SEPTEMBER 2024

Sickle Cell Disease Disparities in People Enrolled in Medicare Fee-For-Service

Sickle cell disease (SCD) is a group of inherited disorders that affect hemoglobin, also called sickle cell anemia. SCD 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. SCD affects about 100,000 people from all racial and ethnic groups in the United States, but more than 90% are Black or African American, and 3% - 9% are Hispanic or Latino. Estimated life expectancy of those with SCD in the United States is more than 20 years shorter than the average expected.[1,2]

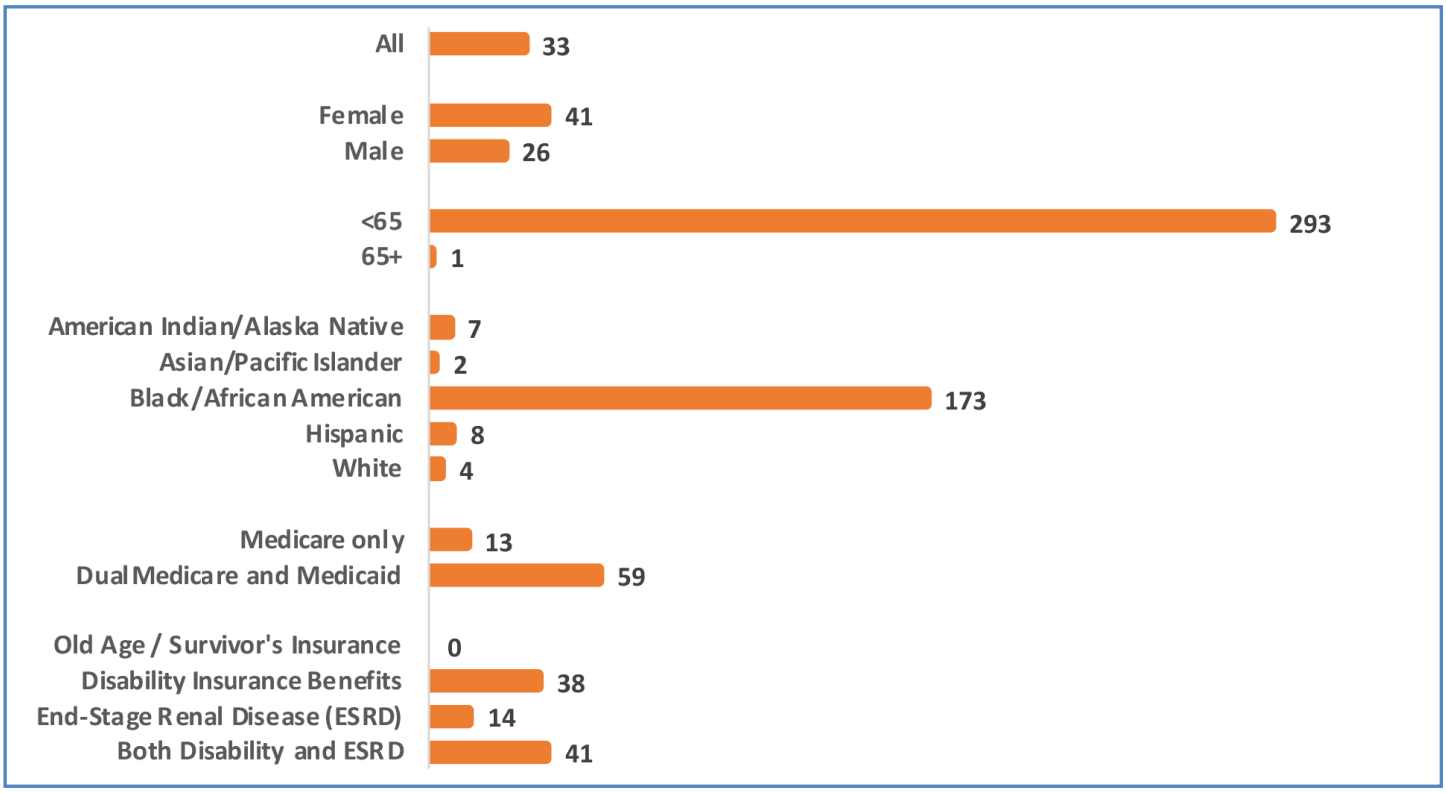
Approximately half of people affected by SCD are enrolled in Medicaid and 11% are enrolled in Medicare.[3,4,5] The national prevalence of SCD among people enrolled in Medicaid and CHIP was 74 per 100,000 enrollees in 2017.[6] The Mapping Medicare Disparities (MMD) Tool developed by the Centers for Medicare & Medicaid Services (CMS) indicates that 33 per 100,000 people enrolled in Medicare fee-for-service (FFS) had a diagnosis of SCD in 2022. The MMD Tool data shows the prevalence and hospitalization rates of SCD among Medicare FFS enrollees varied by sex, age, race and ethnicity, Medicare and Medicaid dual eligibility, original reason for entitlement, and geographic areas in 2022.[7]

Figure 1. Prevalence rate of SCD among People Enrolled in Medicare FFS by Enrollee Characteristics, 2022 (per 100,000 enrollees)



Note: Prevalence rate for sex, race and ethnicity, dual Medicare and Medicaid eligibility, and original reason for entitlement were age standardized rate.

Figure 2. Hospitalization rate of SCD among People Enrolled in Medicare FFS by Enrollee Characteristics, 2022 (per 100,000 enrollees)



Note: Hospitalization rate for sex, race and ethnicity, dual Medicare and Medicaid eligibility, and original reason for entitlement were age standardized rate.

As shown in Figure 1 and 2, the prevalence and hospitalization rates of SCD were higher among females (compared to males), people younger than 65 (compared to 65+), Blacks/African Americans (compared to American Indian/Alaska Native, Asian/Pacific Islander, Hispanic, and White enrollees), Medicare and Medicaid dual eligible enrollees (compared to the Medicare only enrollees), and those whose original reason for entitlement was Disability Insurance Benefits, End-Stage Renal Disease (ESRD) or Both Disability and ESRD (compared to Old Age/Survivor's Insurance).

Figure 3 and 4 shows the prevalence rate of SCD among people enrolled in FFS differed by state/territory in 2022. District of Columbia, U.S. Virgin Islands, Louisiana, Mississippi, Maryland, Alabama, Georgia, South Carolina, North Carolina, and Florida were the top 10 geographic areas with the highest prevalence rate of SCD at over 50/100,00 enrollees. SCD prevalence rate in American Samoa, Guam, Northern Marianas and North Dacota were 0 per 100,000 enrollees, and Montana and New Hampshire were 2 per 100,000 enrollees.

Figure 3. Map of SCD Prevalence among People Enrolled in Medicare FFS by State/Territory, 2022 (per 100,000 enrollees)

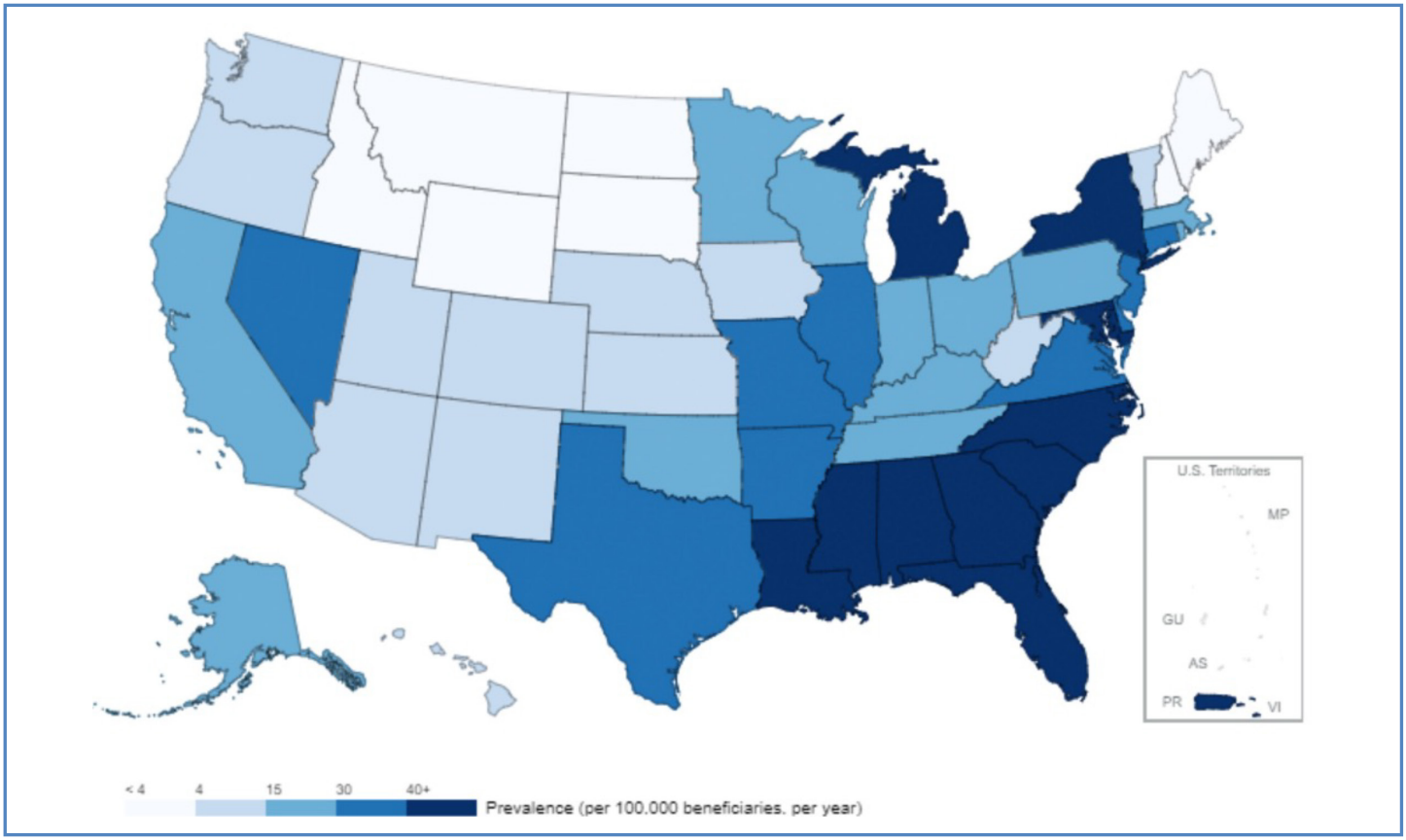
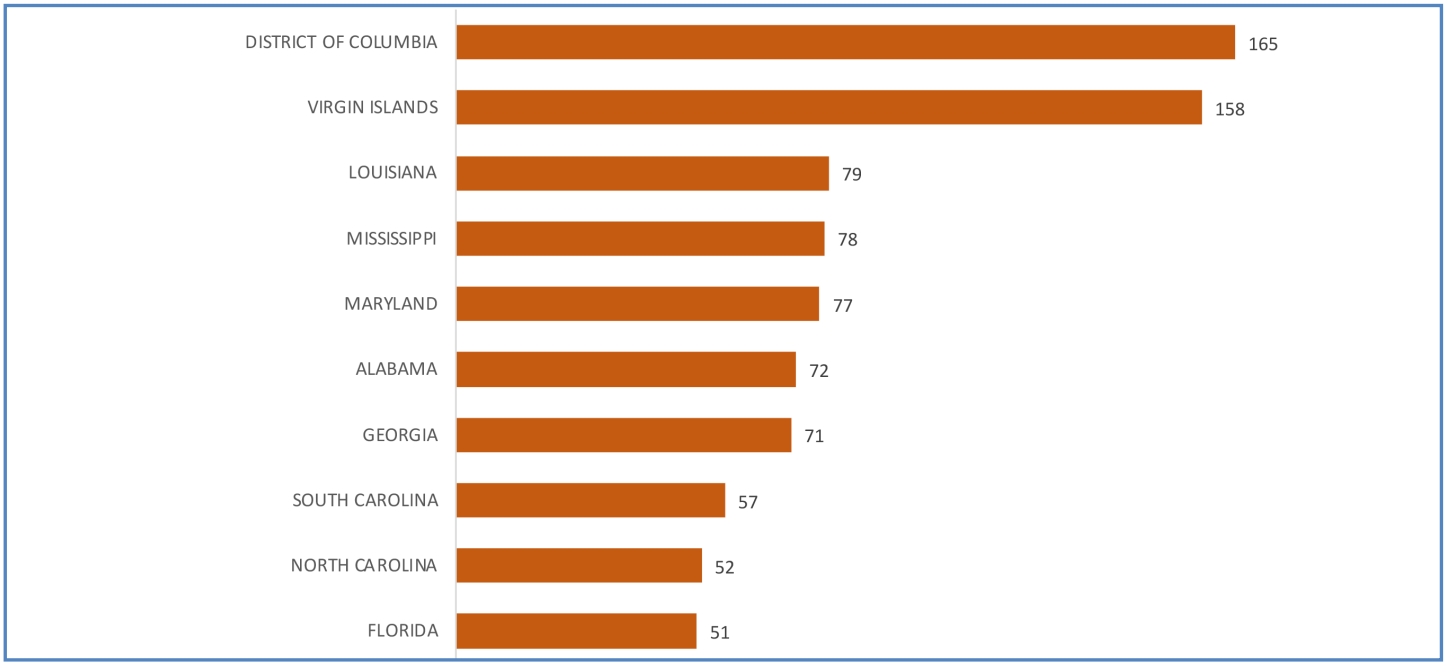


Figure 4. Top 10 State/Territory with the Highest Prevalence of SCD among People Enrolled in Medicare FFS, 2022 (per 100,000 enrollees)



CMS published data highlights and reports on the prevalence of SCD among people enrolled in Medicare FFS enrollees and Medicaid and CHIP. In 2023, CMS launched the Sickle Cell Disease Action Plan that outlines the efforts to eliminate barriers, reduce health disparities, and improve health outcomes for individuals with SCD. The Action Plan focuses on four key areas: (1) expanding coverage and access; (2) improving quality and the continuum of care; (3) advancing equity and engagement; and (4) examining data and analytics. The Cell and Gene Therapy (CGT) Access Model, a voluntary model, aims to increase access to potentially transformative treatments for people with Medicaid living with rare and severe diseases. Initially, the model will focus on access to gene therapy treatments for people living with SCD. All states and U.S. territories that participate in the Medicaid Drug Rebate Program (MDRP) are eligible to apply to participate in the model.

Enrollee Resources

- Sickle Cell Disease Fact Sheet
- Sickle Cell Disease: What You Need to Know (Video)
- Sickle Cell Has Many Faces (Video)
- CMS Sickle Cell Disease Action Plan
- At a Glance: Medicaid and CHIP Beneficiaries with Sickle Cell Disease
- ASH Center for Sickle Cell Disease Initiatives
- Cell and Gene Therapy (CGT) Access Model Overview Factsheet

Provider Resources

- The Invisible Crisis: Understanding Pain Management in Medicare Beneficiaries with Sickle Cell Disease
- Medicaid and CHIP Coverage of New Treatments and Opportunities to Improve Care for Sickle Cell Disease
- Steps to Better Health Toolkit
- Improved Access to Gene Therapy for Sickle Cell Disease
- Sickle Cell Disease: Milestones in Research and Clinical Progress Booklet
- Cell and Gene Therapy (CGT) Access Model

References/Sources

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2. Centers of Disease Control and Prevention. Data and Statistics on Sickle Cell Disease. https://www.cdc.gov/sickle-cell/data/index.html#:~:text=Key%20points,shorter%20than%20the%20average%20expected.
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5. Wilson-Frederick SM, Hulihan M, Blaz J, et al. Prevalence of Sickle Cell Disease among Medicare Fee-For-Service Beneficiaries, Age 18-75 Years, in 2016. CMS Data Highlight, No. 15. https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Data-Highlight-15-Sickle-Cell-Disease.pdf.
6. Wilson-Frederick S, Hulihan M, Mangum A, et al. Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017." Baltimore, MD: Center for Medicaid and CHIP Services. https://www.medicaid.gov/sites/default/files/2021-01/scd-rpt-jan-2021.pdf.
7. Centers for Medicare & Medicaid Services. Mapping Medicare Disparities Tool. https://data.cms.gov/mapping-medicare-disparities.

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