Living with Sickle Cell Disease

2026 Edition

A closer look at care through real-world data from the Data Hub

ASH RESEARCH COLLABORATIVE®

Dear Friends,

Welcome to the second ASH Research Collaborative® Living with Sickle Cell Disease Report. Last year, we shared the Data Hub story for the first time. This year, the story is bigger and tells us even more about the sickle cell disease (SCD) community.

The Data Hub continues to grow into a resource built *by* and *for* the SCD community. This report focuses on data collected in 2025, which includes 12,164 people living with SCD.

Like last year, this report looks at:

- Who is in the Data Hub
- The health problems people face
- Some medicines people take
- How often people visit the ER or stay in the hospital

This year, we also added a few new topics:

- The importance of evaluations for avascular necrosis and urine creatinine
- A first look at mental health in the SCD community

Thank you to everyone who makes this work possible, specifically the 2026 Report Working Group, the care teams who collect the data, and the community members who help guide us.

With gratitude,

Charles Abrams

Charles Abrams, MD

Chair, Sickle Cell Disease Research Network

ASH Research Collaborative

Titilope Fasipe

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Chair, Sickle Cell Disease National Community Advisory Board

ASH Research Collaborative

2026 Report Working Group

This report was shaped by a dedicated Working Group of community advisors, doctors, and ASH RC staff. We are so grateful for the time, care, and heart they brought to this work. Their voices helped us decide what to share and how to share it, and we thank them for trusting us with this work and for keeping the SCD community at the center of it.

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A full list of contributors and Data Hub sites appears at the end of this report.

Why the Data Hub Matters & Who is Included

Why is it important to have a Data Hub for Sickle Cell Disease?

Every person living with SCD has their own health story. The Data Hub brings thousands of those stories together in one place. By looking at the big picture, the SCD community, doctors, and researchers can ask better questions and look for solutions to improve the care and quality of life of people living with SCD.

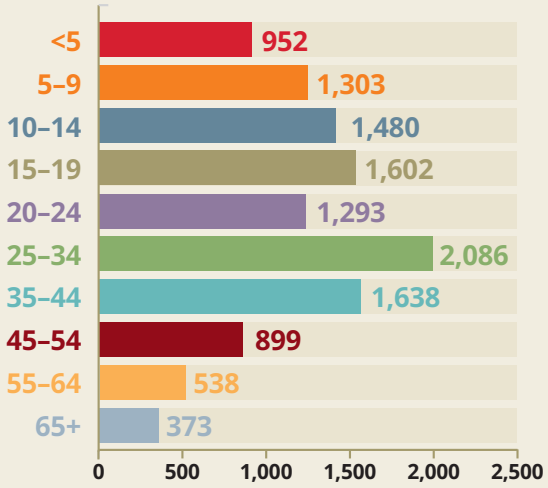
Who received care in 2025?

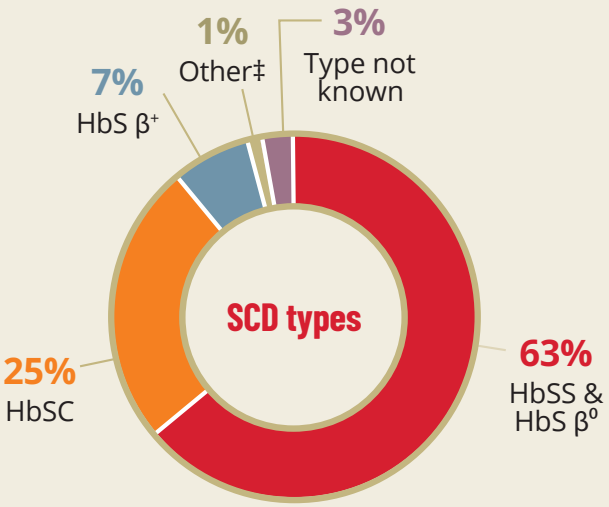
The data in this report represents 12,164 people who received care at a Data Hub participating site who had at least one clinic or hospital visit in 2025.

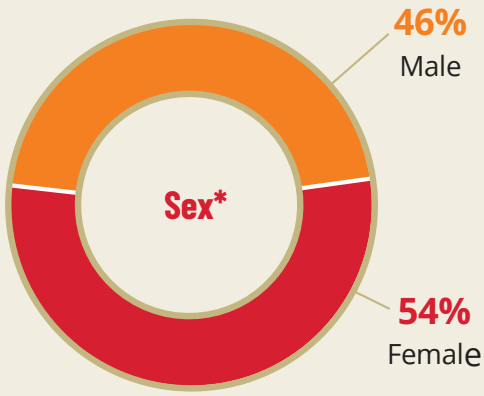
The Data Hub now includes data from 20 hospitals across 12 states.

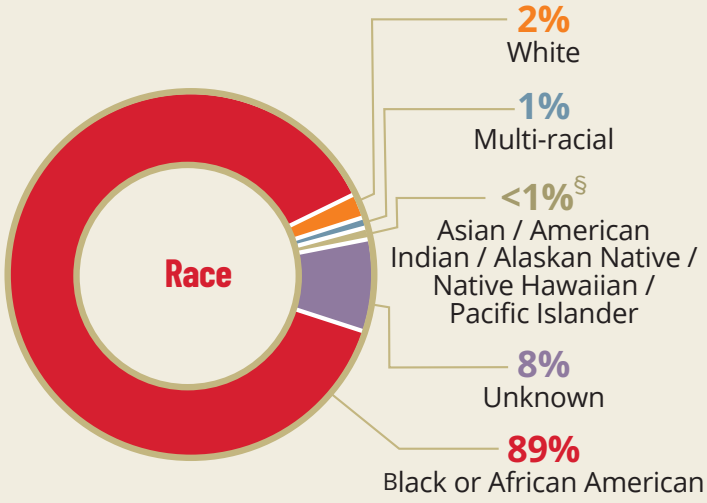
A bigger network means we see more of what life with SCD looks like at our participating hospitals across the country.

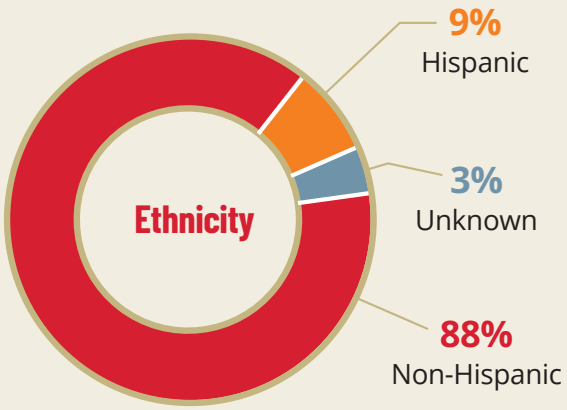
Age











Takeaway:

This report reflects the diversity of the SCD community represented in the Data Hub.

* The numbers in this report come from medical records that only use male and female categories. This limits how we can report data related to gender; however, we want to recognize and acknowledge the people living with SCD who do not identify as male or female.

§ The symbol "<" means "less than".

‡ HbS/Lepore, HBS/O Arab. HbS/Delta β0 thalassemia, HbSD, and HbSE

> “The ASH Research Collaborative Data Hub reflects the diversity of sickle cell and underscores why we must recognize the ‘typically atypical’ patient. By bringing together providers, researchers, patients, and caregivers, while also capturing varied genotypes, treatments, complications, and lived experiences, the Data Hub can help ensure that every person with sickle cell is represented and that equitable care remains at the forefront.”
>
> — JAIMEE ROQUE, MOM AND CAREGIVER TO TWO SICKLE CELL DISEASE WARRIORS, NCAB MEMBER

Health Problems Individuals with SCD Face

While pain caused by blocked blood vessels (vaso-occlusive crises) is the most reported complication, SCD affects almost every part of the body. The Data Hub collects information on health problems, such as high blood pressure (hypertension), stroke, and other complications.

By gathering this information in the Data Hub, we can see the bigger picture of how SCD affects people at every stage of life and across different sickle cell types. This information can help researchers and healthcare providers investigate how SCD care and treatments impact or prevent sickle cell complications. This information can also help identify areas where additional research and support are needed.

Health Conditions Recorded Among People Seen in 2025*

Health problem	<18 yo	18+ yo
Acute Chest Syndrome	14%	15%
Acute Kidney Injury	1%	6%
Avascular Necrosis	3%	14%
Chronic Kidney Disease	<1%	11%
Deep Vein Thrombosis	<1%	4%
Hypertension	2%	17%
Pulmonary Embolism	<1%	5%
Pulmonary Hypertension	<1%	7%
Priapism	1%	5%
Stroke	2%	3%
Vaso-Occlusive Crisis	38%	61%

* Does not include problems managed at home or at a hospital not participating in the Data Hub.

> “As both the parent of a sickle cell warrior and a clinical psychologist, I have seen the devastating impact of avascular necrosis (AVN) when it is diagnosed too late. National standards should require annual bone and joint assessments and evaluations following every vaso-occlusive crisis, along with patient education on the early signs of AVN. Earlier detection can prevent irreversible damage and preserve mobility, independence, and quality of life.”
>
> **– DEBRA BOND, PHD, MOTHER OF A SICKLE CELL WARRIOR**

Although, there are no current national standards for screening for AVN, clinicians and researchers are working to change this.

Catching Problems Early with Screening Tests

Many health problems caused by SCD do not show obvious symptoms right away. That is why routine screening tests are such an important part of care. Screenings help your care team catch issues early when they are easier to manage.

The Data Hub includes information about laboratory tests that are performed as part of SCD care. This information can be used to answer questions about the care individuals living with SCD receive and identify areas where improvement is needed. Other screening tests will be featured in future reports.

Percentage of People with Kidney Function Tests in 2025, by SCD Type

HbSS / HbS B^0	38%
HbSC	38%
HBS B+	34%
Other*	26%
Type not known	17%
Total	37%

*HbS/Lepore, HBS/O Arab. HbS/Delta β0 thalassemia, HbSD, and HbSE

Takeaway:

Going to clinic visits when you feel well is just as important as going when you feel sick. If you are not sure if you are due for a screening test, it is a great question to ask at your next appointment.

Understanding Infection Risks and Penicillin Protection

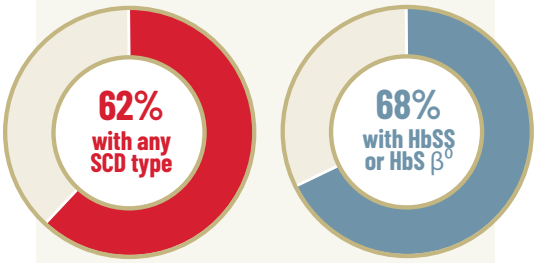
Data Hub prescription records can help show whether young children with SCD are being prescribed penicillin as recommended, and identify potential opportunities to strengthen preventive care. Over time, the Data Hub can help show which treatments individuals with SCD are receiving, whether recommended treatments are being prescribed, how treatments impact SCD complications and hospitalizations, and where there may be opportunities to improve care.

Looking at penicillin data is an example of how the Data Hub can help us learn more about whether individuals with SCD are receiving recommended treatments.

These data need to be interpreted carefully because prescription records may not include prescriptions filled at outside pharmacies and do not show whether a medication prescription was filled or taken. Even with these limits, tracking this information can help identify ways to improve preventive care for children living with SCD.

Prescriptions for Penicillin in 2025

Among children age 5 and younger:



Clinical guidelines are evidence-based recommendations that help health care teams provide consistent care. Current guidance recommends penicillin twice daily through age 5 for children with HbSS or HbSβ⁰-thalassemia to help prevent serious bacterial infections.

Takeaway:

Tracking these medicines can help us spot gaps in care. It also helps make sure these medicines reach everyone who could benefit.

Emergency Room and Hospital Care

How often are people visiting the hospitals that participate in the Data Hub?

*The numbers to the right show the average number of emergency room (ER) visits and hospital stays per person in 2025 for each age group.**

For many people with SCD, an ER visit or hospital stay is a stressful part of life. Vaso-occlusive crises and other health problems can come on quickly and need urgent medical care. The information collected in the Data Hub helps us learn more about how individuals living with SCD receive care in the ER and hospital setting.

Age in 2025	Average Emergency Room Visits	Average Inpatient Visits
<5	1.1	0.7
5–9	0.9	0.6
10–14	1	0.8
15–19	1.2	1.1
20–24	1.4	1.2
25–29	2.2	1.3
30–34	2.4	1.5
35–39	1.5	1.1
40–44	1.3	0.9
45–49**	1.4	1.1

**Adults age 50 and older are not shown because too few people were represented, and hospital visits outside of participating hospitals may be missing from the data.

*These numbers only capture if a patient was seen at a participating Data Hub hospital.

Takeaway:

Each ER visit and hospital stay matters. These visits affect how people feel, how they work or go to school, and how their families plan their lives. By tracking these visits over time, alongside medicine use and health problems, the Data Hub can help answer important questions.

Mental Health and SCD

The SCD community told us something clearly:
mental health is part of living with SCD,
but so often, it's not prioritized.

Unpredictable cycles of pain, fatigue, hospital stays, and the day-to-day weight of living with SCD can take a mental and emotional toll.

This year, we are starting to look at what the Data Hub can tell us about mental health in the SCD community. By looking at the mental health data collected in the Data Hub, we can ask questions and design research alongside our investigators to gain a better understanding of the relationship between mental health and SCD.

In 2025, these are the numbers of adults with SCD in the Data Hub who had either anxiety or depression documented in their medical record.

13% anxiety

12% depression

Takeaway:

These numbers likely undercount how many people are truly struggling, because mental health is not always talked about at clinic visits. Additionally, anxiety and depression do not encompass all mental health challenges experienced by individuals with SCD, including grief and post-traumatic stress disorder (PTSD).

Questions we are starting to ask:

How often are individuals with SCD being asked about their mental health?

Are we seeing more mental health diagnoses in certain age groups?

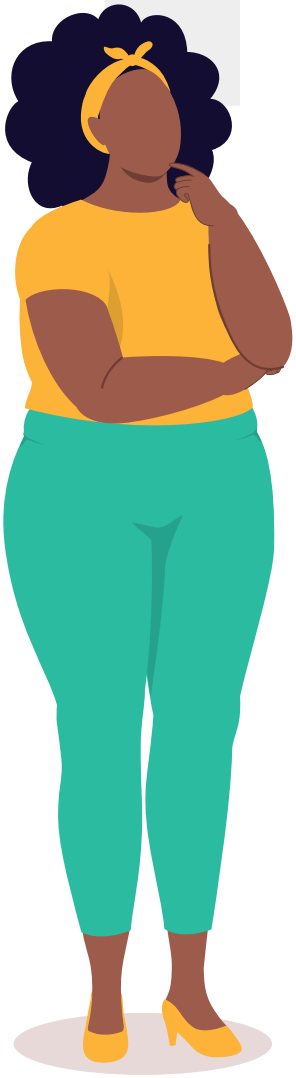
What medicines are being prescribed for mental health, and do they impact other health problems?

"The lived experience of sickle cell disease extends far beyond physical pain. Individuals often carry the cumulative burden of chronic stress, medical trauma, emotional fatigue, anxiety, depression, and the uncertainty that accompanies a lifelong condition. Mental health is not separate from sickle cell disease—it is an integral part of the disease experience. True comprehensive care requires recognizing that emotional well-being is just as important as physical health and ensuring that mental health support is treated as a standard component of care, not an afterthought."

– CLAYTON W. ANDREWS, LPC, CPCS, SICKLE CELL DISEASE WARRIOR AND NCAB MEMBER

What's Next?

Community feedback continues to inform the Data Hub research and reports. Your Voice Matters. Below are areas we hope to continue growing for next year and beyond.



More Hospitals, More Stories

With 20 hospitals this year and more on the way, the Data Hub keeps growing. The goal is to reflect the SCD community as closely as possible across the country.

Research in Motion

Many studies are underway right now that use Data Hub information to answer questions the community cares about, including new work on SCD medicines, health problems, and mental health. A special thank you to the NCAB members who helped prioritize projects that reflect what matters most to the community. A full list of projects can be found on our website: **www.ashresearchcollaborative.org/data-hub/research-and-analytics**.

Better Data, Deeper Insights

We're working to improve data quality, collect more complete transfusion information, and learn more about people who have received gene therapy. These efforts will help us better understand SCD care, treatments, and experiences.

Your Voice Matters

Community feedback led to the new mental health section in this report. Keep your ideas coming.

About the ASH Research Collaborative

The ASH Research Collaborative® (ASH RC) is a non-profit organization started by the American Society of Hematology (ASH) to improve the lives of people with blood diseases. It does this by building partnerships that speed up progress in research. The ASH RC runs Research Networks that use real-world data through a program called the Data Hub. The Data Hub collects HIPAA-compliant health data on people with SCD and is a modern, secure data-sharing system. The Data Hub combines this information so researchers can quickly answer research questions, create new treatments for blood diseases, and better understand how treatments work.

About the SCD Data Hub Program

The SCD Data Hub is a large, real-world data resource built to improve research and care for people living with SCD. By combining high-quality clinical data from many sources, the Data Hub supports testing research ideas, studying best practices, identifying important and measurable clinical trial outcomes, and describing the patient population included in the Data Hub. Through teamwork and collaboration, it is a key tool for developing better treatments for people living with SCD.

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Special Acknowledgements

The ASH RC extends its sincere appreciation to all members of its National Community Advisory Board (NCAB): **www.ashresearchcollaborative.org/about/sickle-cell-disease-scd-national-community-advisory-board**.

We are also grateful to the SCD Data Hub sites whose contributions of clinical data made this work possible:

- Baylor College of Medicine Texas Children's Hospital
- Boston Medical Center
- Children's Hospital of Philadelphia
- Children's Medical Center Dallas
- Cincinnati Children's Hospital Medical Center
- Emory University School of Medicine
- Johns Hopkins University Hospital
- Medical College of Wisconsin, Children's Hospital of Wisconsin
- Medical College of Wisconsin, Froedtert
- Montefiore Medical Center
- Nemours, Alfred I DuPont Hospital for Children
- NYC Health & Hospitals/Jacobi Medical Center
- Parkland Health and Hospital System
- The University of Chicago
- University of California, San Francisco Benioff Children's Hospital of Oakland
- University of Alabama at Birmingham
- University of California, Los Angeles
- University of Illinois at Chicago
- UT Southwestern Medical Center
- Washington University School of Medicine

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SCD Community Advisory Board
www.ashresearchcollaborative.org/sickle-cell-disease-research-network/sickle-cell-disease-community/community-advisory-boards/

ASH's 10 Years of SCD Progress
www.hematology.org/ash-center-for-sickle-cell-disease-initiatives

ASH Clinical Practice Guidelines
www.hematology.org/education/clinicians/guidelines-and-quality-care/clinical-practice-guidelines/sickle-cell-disease-guidelines

SCD Coalition
www.scdcoalition.org

NHLBI Guidelines
www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease

Sickle Cell Disease Association of America (SCDAA)
www.sicklecelldisease.org