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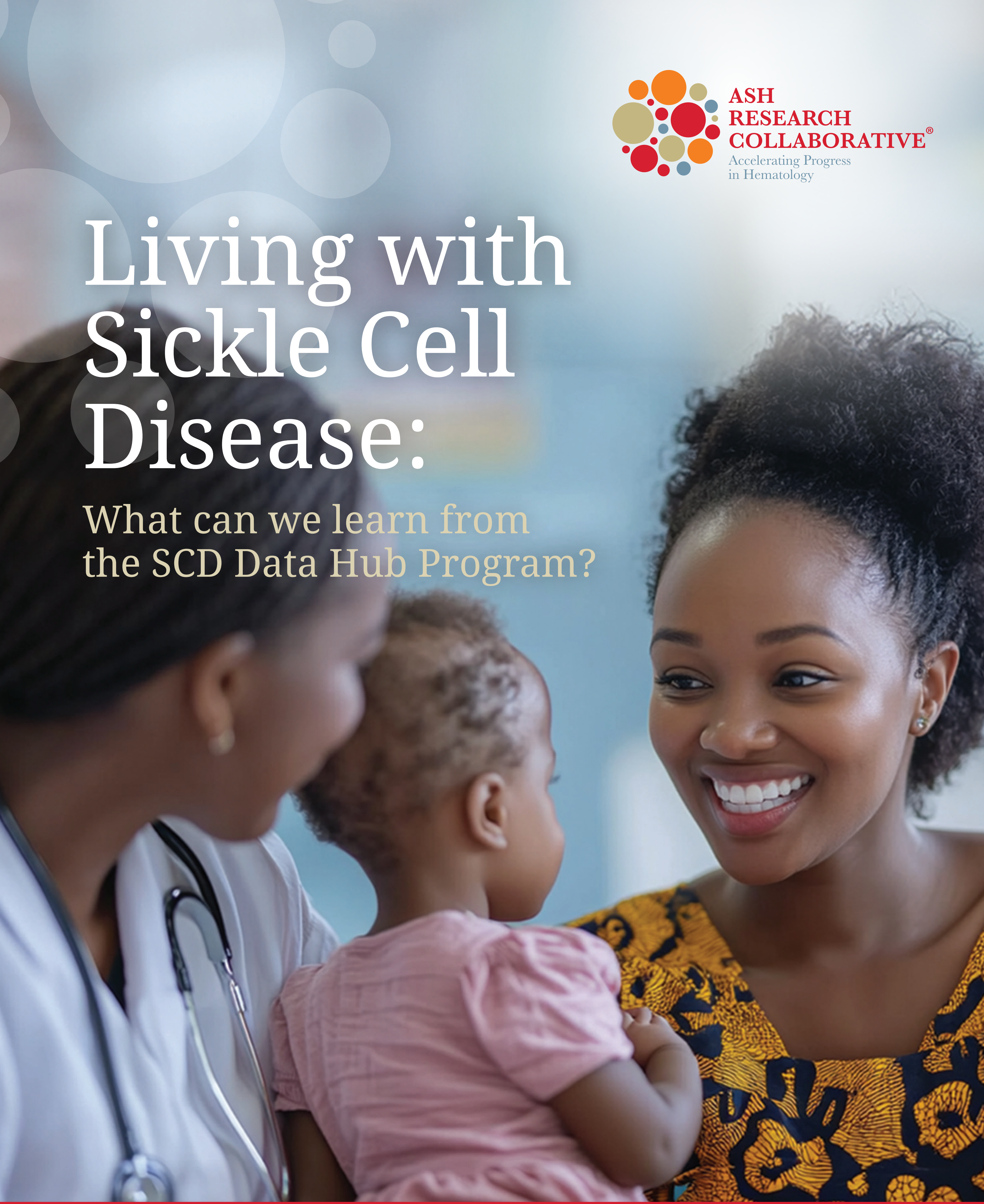
Accelerating Progress
in Hematology



Living with Sickle Cell Disease:

What can we learn from the SCD Data Hub Program?

2025

Dear Friends,

We are proud to share this inaugural ASH Research Collaborative Living with Sickle Cell Disease (SCD) Data Hub Report. This is the first Data Hub report built with real-world information about people living with SCD, **giving us some perspective of what life is like for people with data in the Data Hub from 2015–2024**.

The Data Hub brings together health information from thousands of people living with SCD from across the U.S. This gives us a big-picture view of how Data Hub data represents the SCD community's health, the challenges they face, the care they receive, and the progress being made.

This first report includes information from more than 13,000 people with SCD, collected from 17 hospitals between 2015 and 2024. It covers many parts of life with SCD, such as clinic visits, emergency room trips, hospital stays, lab results, medicines, and more.

Why does this matter? Because these data help us to understand:

- Patterns in care
- Common health problems
- How treatment can be better

This report is just the start. As the Data Hub receives more health information, it will continue to expand our understanding of the health challenges of SCD and provide insight on how to improve care and quality of life.

We are deeply thankful to everyone who helped create this report and for their trust in using the Data Hub to help shape a future that leads to healthier lives for people living with SCD.

With gratitude,

Charles Abrams, MD
Chair, Sickle Cell Disease Research Network
ASH Research Collaborative

Titilope Fasipe, MD, PhD
Chair, Sickle Cell Disease National Community Advisory Board
ASH Research Collaborative

Who we are

The ASH Research Collaborative (ASH RC) Data Hub is a program that's led by hematologists, researchers, and the sickle cell community to advance research and improve care for people living with SCD.

What we do

The Data Hub has collected information from medical records at 17 hospitals that care for people with SCD. **The data are kept private, secure, and follow all privacy laws to protect everyone's identify.**

Some examples of data in the Data Hub include:

- **visits** to the clinic, emergency room, and hospital stays
- **medications** that have been prescribed
- **procedures** and surgeries
- **lab tests**
- **medical complications**

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

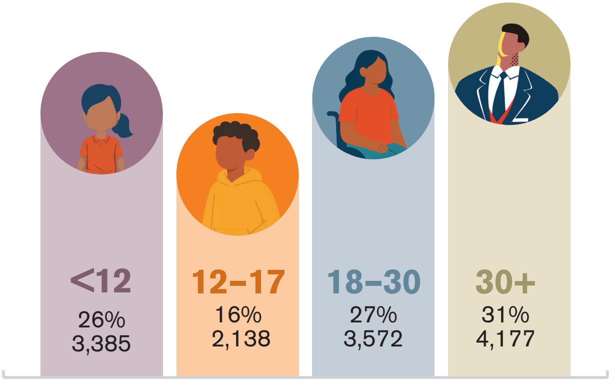
Everyone with SCD has their own story and health journey. The Data Hub brings together information from thousands of people with SCD to help us understand the community's real-world experiences, as determined from data in the Data Hub.

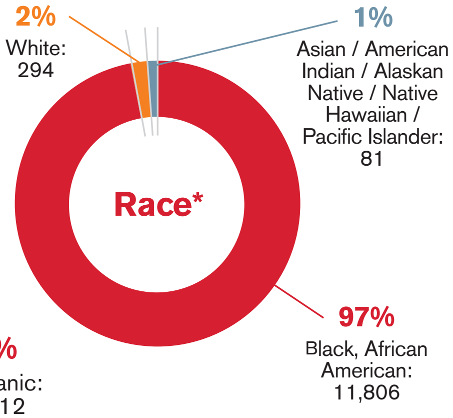
By looking at this data, doctors, researchers, and the SCD community can ask data driven questions to find new ways to improve care and support for people living with SCD.

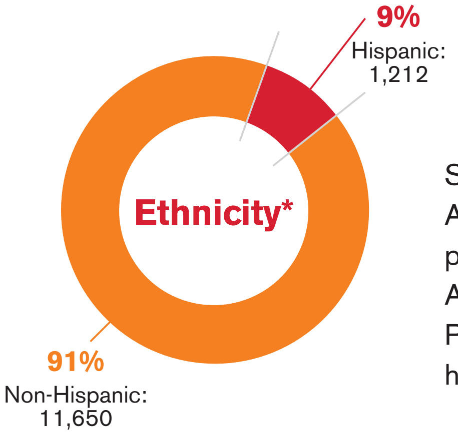
Who are the people currently included in the Data Hub?

13,272* people who have SCD

Age

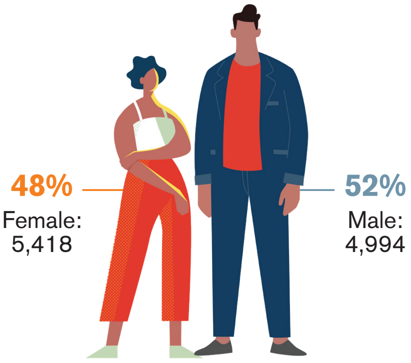




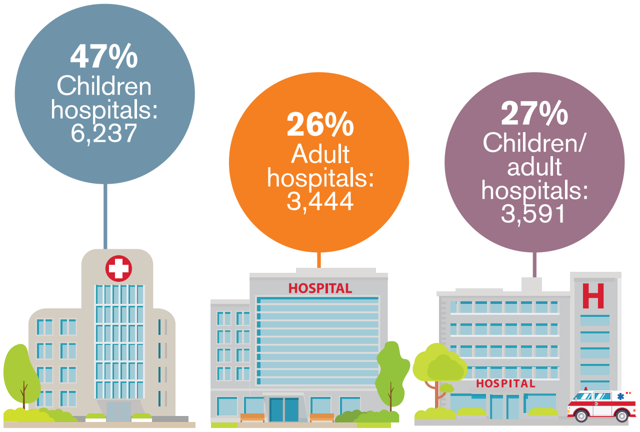


SCD mainly affects Black and African American people, but people from Hispanic, White, Asian, Native American, and Pacific Islander groups can have it too.

Sex



Where do people get care for their SCD?



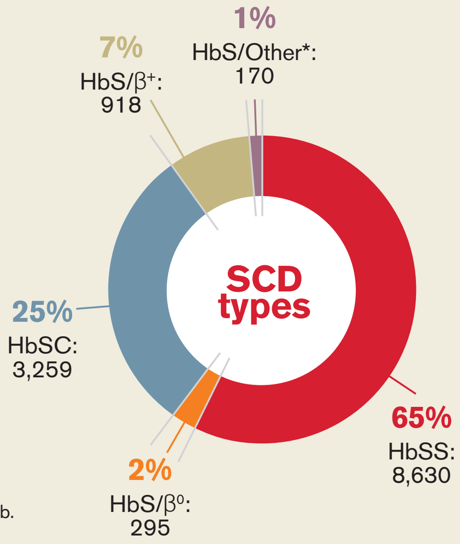
* Some information about race and ethnicity is missing from the Data Hub, so totals may not always add up to 13,272.

Who's in the Data Hub?

The sickle cell community includes people of all ages and with different types of SCD. The goal of the Data Hub is to represent and reflect the SCD community as closely as possible.

This growing dataset helps us ask better research questions and learn how SCD affects different groups, like older adults or children with less common SCD types.

Every journey with SCD is unique. The Data Hub unites them into one story by representing patients with different SCD types.



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

The Data Hub has collected information for 2015 to 2024

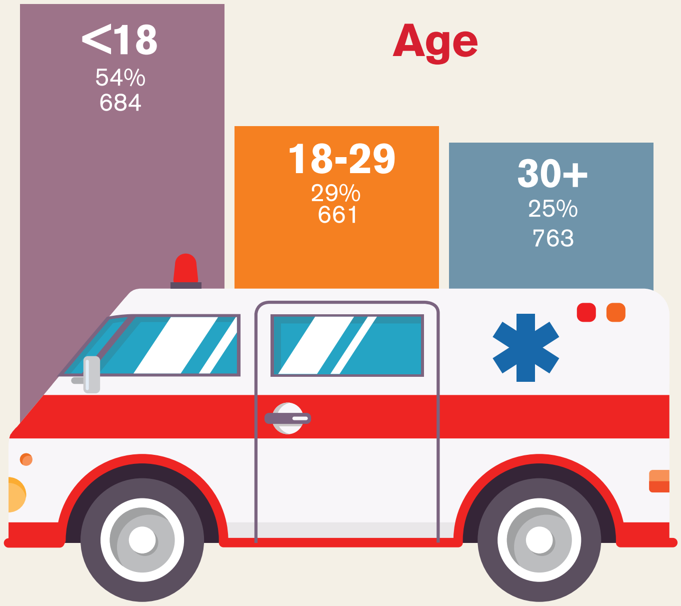
3+ million	records on hospital, emergency room, and clinic visits
8+ million	prescriptions
87+ million	records with lab results and health measurements

Who Went to the Emergency Room in 2024?

The Data Hub gives a big-picture view of people with SCD who go to the emergency room. In 2024, there were **3,108** records for an emergency room visit.

Why This Matters

The Data Hub shows that people with SCD of all ages visit the emergency room. Tracking this over time can help us find ways to reduce ER visits and improve care for the SCD community.



Better Data, Better Care: Improving Health and Reducing Health Problems

Working to make sure individuals living with SCD are receiving the recommended tests to monitor kidney, heart, and brain health can help reduce complications and improve overall health.

What kidney health tests were done in 2024?

By collecting information about laboratory tests, we can learn more about the healthcare people living with SCD receive and identify areas where improvement is needed.

Monitoring kidney health is an important part of SCD care.

37% had a record of a urine creatinine test: 3,031

29% had a record of a urine albumin test: 2,388

These tests help track kidney function and catch problems early.

What Kinds of Health Problems Do People with SCD Face?

The Data Hub tracks health problems related to SCD. Of people with data in the Data Hub, the percentage of people who experienced a health problem at least once between 2015 and 2024:

73%	Sickle Cell Pain Crisis: 9,468
38%	Acute Chest Syndrome: 5,164
11%	Chronic Kidney Disease: 1,165
9%	Priapism: 537 (Males only)
7%	Stroke: 934

This helps us understand how SCD impacts different groups and how treatments may help.

Who Is Prescribed Hydroxyurea?

The Data Hub includes information on over 5,857 people with SCD who have been prescribed hydroxyurea. Here's how hydroxyurea prescriptions break down by SCD type:

86%	HbSS and HbS/β^0: 5,032
10%	HbSC: 564
4%	HbS/β^+: 238
<1%	HbS/Other: 23

Looking at how medications like hydroxyurea, crizanlizumab, and L-glutamine are prescribed can help us explore connections between treatment, health problems, and ER visits or hospital stays.

This information can also help find ways to improve access to disease modifying therapies and support better health for people living with SCD.

What are the next steps with the Data Hub?

More Sites, More Stories, More Insight

As more hospitals join, the Data Hub will better reflect the full SCD community across the U.S.

Research Is Already Underway

Many projects using Data Hub information are underway to help us learn more about real-life experiences with SCD.

Your Voice Matters

We welcome ideas and feedback to help guide this work and ask the right questions.

About The ASH Research Collaborative

The ASH Research Collaborative® (ASH RC) is a non-profit group 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.

Suggested Citation

ASH Research Collaborative SCD Data Hub
2025 Data Hub Living with SCD Report
Washington, DC

Special Acknowledgements

The ASH RC extends its sincere appreciation to members of its National Community Advisory Board (NCAB): Naomi Bethel, MS, sickle cell patient; Rilwan O. Hollis; Jaimee Roque, sickle cell parent; Audrey Williams, sickle cell parent; Debra Bond, PhD, sickle cell parent; Clayton W. Andrews, LPC, CPCS, for their meaningful contributions to shaping this community-informed Data Hub report. Their feedback was essential in making the resource clear, accessible, and relevant to the SCD community.

We would also like to gratefully acknowledge the following individuals and institutions for their programmatic and statistical support: Hunter Carney, BS; Chris Dowd, MBA, Aliza Fink, DSc, MS; Justine Nicholas, MS; Susan Rogers, MSN, RN; Leslie Sanchez, MS; Emily Semmel, MS; and Kathleen Torres, DNP (formerly Hewitt).

We are especially 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 School of Medicine
- Medical College of Wisconsin Pediatric/Adult
- Montefiore Medical Center
- Parkland Health & Hospital System
- UCSF Benioff Children's Hospital of Oakland
- University of Alabama at Birmingham
- University of Illinois at Chicago
- University of Texas Southwestern Medical Center

For more information:

ASH Research Collaborative
ashrc.org

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

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

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

SCD Coalition
www.scdcoalition.org

National Heart, Lung, and Blood Institute (NIH) Guidelines
www.nhlbi.nih.gov/health-topics/evidence-based-management-sickle-cell-disease

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

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