

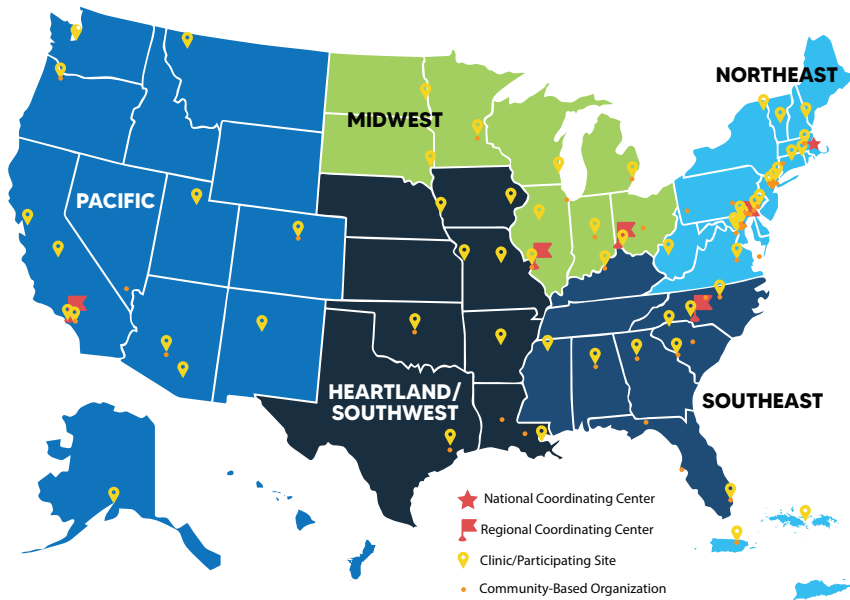
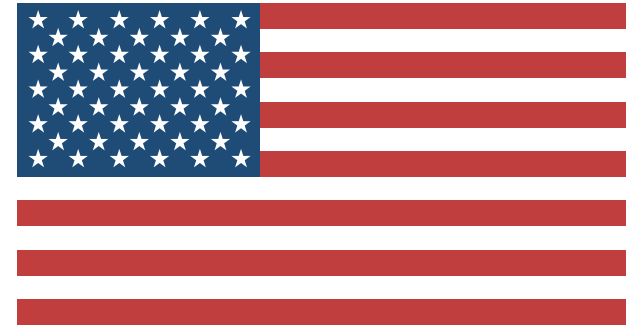
IMPACT STATEMENT

2017-2021

Operating years of the current Sickle Cell Disease Treatment Demonstration Regional Collaboratives Program, HRSA's fifth cycle of this demonstration program. NICHQ has served as the National Coordinating Center since 2010.

100,000

Approximate number of people in the U.S. living with sickle cell disease (SCD), a serious, debilitating, life-shortening, and often fatal condition. It's estimated that millions of people live with this disease worldwide. In the U.S., SCD is most common among African Americans. However other racial and ethnic groups are affected, including Latinos and people of Middle Eastern, Indian, Asian, and Mediterranean backgrounds. Sub-Saharan Africa has the greatest burden of disease.



2,000

Estimated number of children born each year in the U.S. with sickle cell disease (SCD). Despite the study of biological pathways for sickle cell disease for more than 100 years and the existence of innovative and effective treatments for this condition, there are still major gaps in accessible, quality care.



Additionally, comprehensive, national registries of children born with SCD and adults living with SCD are too few, resulting in inadequate data on the number of people who need care.

1 / 5 / 53 / 100+ Number of sickle disease centers, states, clinics, and local organizations in the Program that all partnered to improve and increase access

to care for people living with sickle cell disease: **1** National Coordinating Center: NICHQ, **5** Regional Coordinating Centers (RCCs) that cover **53** states and territories, and more than **100** participating health systems, clinics, and community-based organizations. These key partners worked together to improve programming and care for people with SCD.

>25,000

Number of people with sickle cell disease who were cared for in 2017-2021 by participating healthcare providers. The collaborative focused on:

☆ Increasing the number of providers using evidenced-based treatments for people living with SCD

☆ Enhancing and increasing provider-to-provider education and mentoring

☆ Improving access to quality care through strategies to engage patients and families

The Program focused on specific areas important to the pediatric population, including ensuring that young people with SCD transition safely from pediatric to adult care. Like the 3 areas noted above, ensuring safe and comprehensive transition from pediatric to adult care is important to ensuring quality care across the lifespan.

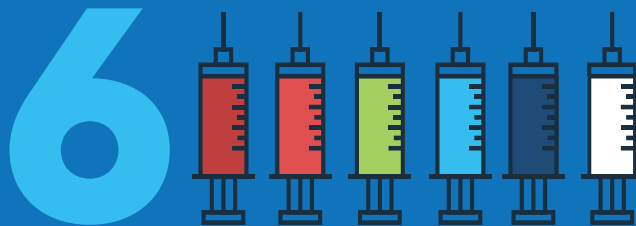
>1,200 Number of providers who cared for people with SCD during the work of this collaborative. These providers were able to prescribe medical treatment for sickle cell disease, making them essential to improving access and care.



70% of adults &
58% of children

Percent of eligible children and adults living with SCD, respectively, who received a prescription for hydroxyurea (HU) in this Program. HU can significantly reduce pain crises, episodes of Acute Chest Syndrome, the need for blood transfusions, and hospital stays. HU was approved for use in adults in 1998 and for children in 2017. Since 2010, its use has increased significantly.

Number of vaccines tracked by the Program. People living with SCD are considered immunocompromised, thus more susceptible to communicable diseases – and even worse – to the effects of invasive bacterial diseases. The Program focused on spreading improved vaccine practices, particularly pneumococcal and meningococcal, which are key to minimizing infection, sickness, and death related to these diseases.



Percent of 2-to-16-year-olds who received life-saving transcranial doppler screening in the Program, a painless, non-invasive procedure to help assess, predict, and manage risk for strokes, both “silent” ones and those with more obvious outward signs. This test is recommended for children between the ages of 2 and 16. Stroke is a leading cause of morbidity and mortality among children with SCD and is highly preventable using this screening test. Innovations in the Program increased screening rates to 80 and 90 percent in some sites. Stroke screening must be spread so that NO child with SCD goes without this lifesaving test.

66%

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National Institute for
Children's Health Quality

100% Percent of partners in the Program who were profoundly affected by the COVID-19 pandemic, whether a clinic, health center, emergency department, academic medical center, specialty site, primary care site, or community-based organization (CBO). People living with SCD are at high risk for life-threatening complications of COVID-19. Systems quickly adapted to help patients avoid unnecessary clinic and emergency department visits, even taking triage calls 24 hours a day so patients did not go to the hospital before speaking to someone on the SCD team. Clinics pivoted to implement telehealth solutions as healthcare workers and administrators raced to address the evolving changes happening in clinical care delivery.

51

Number of clinics providing multiple points of data in the comprehensive data system used by all five regions and developed by the National Coordinating Center (NICHQ). The NCC and RCCs collected important metrics of quality care in SCD from providers across the country through electronic medical chart review, provider surveys, and stakeholder interviews.

49 Number of community-based organizations that participated as partners in the Program. Building and maintaining authentic partnerships with patients, families, and caregivers – and the crucial role of community-based organizations (CBOs) in this process – is vital to providing comprehensive, holistic care. Growing these CBO partnerships was a specific focus of the Program. All five regions worked with a broad range of stakeholders to develop lasting partnerships to meet the needs of their patients.



14 to 50+

life expectancy for people living with SCD has risen from 14 years in the mid-1970s to 28 in 1979...to 43 years in 2017. Now, based on life expectancy modeling, babies born with SCD will live an average of more than 50 years. The interventions and treatments promoted by the Program have improved the lives of tens of thousands of people, mitigating some of the harsh effects of the condition, and increasing both length and quality of life.

1970 14 YEARS

0 50 100

1979 28 YEARS

0 50 100

2017 43 YEARS

0 50 100

100% of all people living with sickle cell disease in the United States and its territories can now potentially be reached by the Program. Four previously established regions were joined by the Southeast In 2017, the Southeast joined four previously established regions under a new funded mandate, resulting in the potential to reach all people living with SCD and their families throughout 50 states, the nation's capital, and its territories.

Read the Report
SCDTDRCP Report to Congress

Want to know more?
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National Institute for
Children's Health Quality