

Understanding Sickle Cell Disease: CDC's Role in Surveillance, Education and Awareness

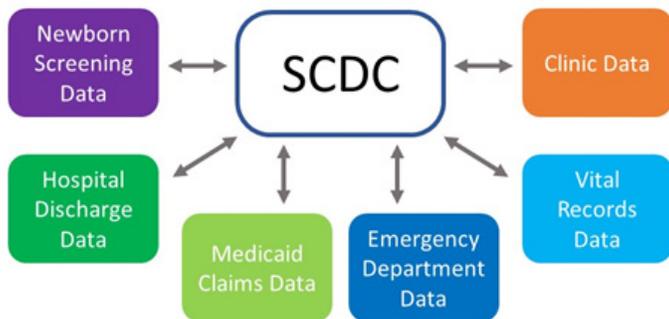


New, timely and national data are needed to better understand the state of sickle cell disease in the United States.

The Sickle Cell Data Collection (SCDC) program collects public health surveillance information about people with sickle cell disease to help them and communities, healthcare providers, policy makers, researchers, and federal, state, and local health agencies improve access to the healthcare system and overall health outcomes.

How does SCDC Work?

In two demonstration sites in California and Georgia, CDC works with grantees to collect and link data from several healthcare sources. Together, this information paints a picture of how an individual accesses healthcare; what are the indicators for poor outcomes; where patients are located; and more.



SCDC's data system gathers information from multiple sources to create a complete picture of sickle cell patients in GA and CA.

What is sickle cell disease?

Sickle cell disease is a group of inherited blood disorders that affects more than 100,000 Americans. Sickle cell disease causes the red blood cells to become hard and sticky and look like a C. These misshapen red blood cells get stuck and clog blood flow which may lead to severe pain, kidney disease, stroke and other serious health problems.

People with sickle cell disease still die more than 20 years before their peers, and often are unable to access the kind of quality healthcare that would help them live longer, healthier lives.

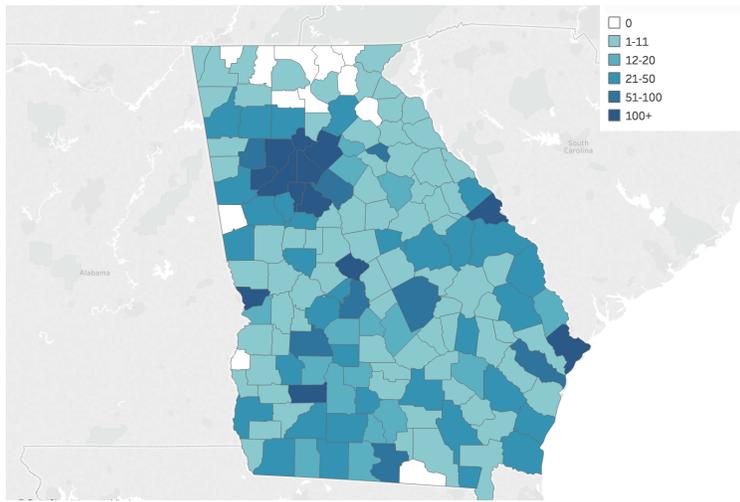
There are no federal resources for a national surveillance system to learn more about and address disparities for sickle cell patients. California and Georgia are funded to gather state-based data through a partnership with the CDC foundation.

Public health surveillance is essential for any disease because it helps:

- Healthcare providers understand how patients interact with the healthcare system and how these factors impact patient outcomes in the short and long term.
- Researchers know where to target activities and interventions that will result in improvement in healthcare, including better access to novel treatments or cures.
- Policymakers and administrators allocate resources and evaluate interventions to efficiently and effectively improve healthcare and health outcomes.

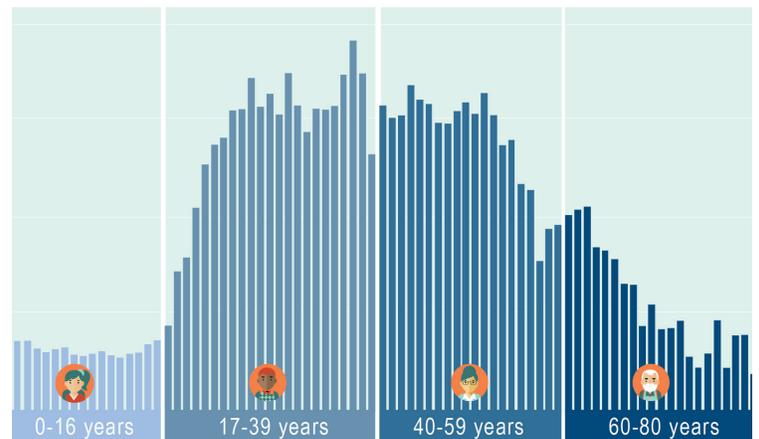
What has been learned from SCDC in California and Georgia?

- SCDC has identified more than 12,000 people with sickle cell disease in CA and GA. That's more than 10% of the estimated number of people with SCD in the US.
- SCDC has helped clinicians identify which healthcare practices help reduce how often patients require hospitalization and treatment.



Map of sickle cell patient density by County in Georgia, 2005

Georgia SCDC grantees are working with hospitals and health departments to identify areas with sickle cell patients but little to no specialist care. Specialists are working to provide training for care providers in these counties so they can better help and treat sickle cell patients in their towns and communities.



Emergency department visits among people with sickle cell in California, 2005-2014

California used SCDC data to understand how, when and where patients seek care in emergency departments in their state. How frequently a patient uses the ED indicates healthcare system factors, such as lack of access to health care, few SCD healthcare experts located nearby, or inadequate insurance coverage. Researchers can study these visits to better understand the changes in health care and policy that might lead to the improvement and extension of life for people with SCD.

If expanded to additional states, the SCDC program could be used in these ways and many more to reduce health disparities, prevent complications, and support the needs of our fellow federal partners who are researching new best practices, treatments and eventually a cure for sickle cell disease.