

CDC's Sickle Cell Data Collection (SCDC) Program



What is the SCDC Program?

The Centers for Disease Control and Prevention (CDC) estimates that sickle cell disease (SCD) affects more than 100,000 people in the United States, but the exact number of people with SCD is unknown. CDC's [Sickle Cell Data Collection \(SCDC\) program](#) gathers health information from multiple sources to determine how many people live with the disease in a particular state.

What is Sickle Cell Disease?

[SCD](#) is a genetic blood disorder passed from parents to children. People with SCD have abnormal red blood cells that prevent blood from getting to the body's tissues and organs, causing severe pain, infection, and in some cases, stroke and other serious [health problems](#). A severe form of SCD can shorten the lives of people with SCD by 20 to 30 years.

A Step in the Right Direction

The SCDC program helps to better understand:

Where people with SCD live

- ❑ SCDC can be used to develop maps that show where people with SCD live, and where healthcare providers or facilities are located. These maps can help people with SCD receive better healthcare services.

Transition from pediatric to adult care

- ❑ SCDC information can help to understand why people with SCD often have the most severe symptoms and use healthcare services most frequently when they shift from pediatric care to adult care.

Hispanic patients with SCD

- ❑ One in ten people with SCD in the United States are Hispanic. SCDC information can shed light on the challenges of identifying SCD among Hispanics, including Hispanics born outside the United States.

Older patients with SCD

- ❑ People with SCD are living longer, making it more important to use SCDC information to study common health problems—not just those related to SCD—that patients experience as they age.

The use of healthcare services

- ❑ SCDC information can identify how often people with SCD use healthcare services (for example, the emergency department) and what factors may lead to high use of these services.

Future Steps

As additional support becomes available, the SCDC program can include more states. An expanded SCD information system can determine how many people live with SCD in the United States, how SCD affects their health, and how researchers can improve medical treatments to extend and improve the lives of people with SCD.

For more information about SCD, visit:

www.cdc.gov/ncbddd/sicklecell

For more information about SCDC, visit:

www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html



SICKLE CELL DATA COLLECTION

CS287925 - June 12, 2018



Centers for Disease
Control and Prevention
National Center on Birth Defects
and Developmental Disabilities