Georgia Health Policy Center

Sickle Cell Data Collection

The goal of the Georgia Sickle Cell Data Collection (SCDC) Program is to improve the quality of life, life expectancy, and the health of individuals with sickle cell disease.

What is Included in SCDC Data?

As the data coordinating center for SCDC in Georgia, the Georgia Health Policy Center at Georgia State University maintains a comprehensive dataset that enables surveillance of sickle cell–related diagnosis and health care utilization for approximately 14,000 individuals living with sickle cell disease from 2004 to 2019. Data are collected from:

- Newborn screening results
- Death records
- Clinical records from the sickle cell treatment centers
- Administrative claims from Georgia's Medicaid, Children's Health Insurance Program, and the State Health Benefit Plan
- Hospital and emergency department discharge data

Why is SCDC Data Important?

SCDC data can help answer questions about access to care, health care utilization and costs, and quality of care, as well as how these patterns vary by age, sex, genotype, geography, and health insurance.

This information can help identify critical gaps in diagnosis, treatment, and access to care and can inform decision-makers about how these gaps can be filled through policy changes, improved health care practices, and education.

How is SCDC Data Used?

Educate — Shape individual or institutional practices or behaviors
Decide — Inform policy, service, and resource allocation decisions
Learn — Answer research questions to inform future actions
Target — Identify a population for interventions, services, or education

Who Uses SCDC Data?

- Health care providers
- Health services researchers
- Health systems
- Individuals living with sickle cell disease and their support circles
- Payers
- Policymakers

Topics Addressed with SCDC Data

- Aging sickle cell population
- COVID-19 and sickle cell disease
- Health care utilization
- Pain management
- Preventive care
- Social determinants of health and equity
- Transition from pediatric to adult care

SCDC Georgia

The Georgia Health Policy Center is the data-coordinating center for multi-institutional projects focused on surveillance of and health promotion for individuals with blood disorders, including sickle cell disease.

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