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Sickle Cell Disease Data Collection

Georgia Health Policy Center

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 (SCD).

SCDC

SICKLE CELL DATA COLLECTION

By collecting and analyzing health information from patients with SCD over time, SCDC can 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.

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Available SCDC data

As the data coordinating center for SCDC in Georgia, the Georgia Health Policy Center at Georgia State University is assembling a comprehensive dataset that enables surveillance of sickle cell–related diagnosis and health care utilization since 2004 for more than 10,000 patients. 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 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 assist in:

- Estimating the cost impacts of policy decisions
- Informing allocation of outpatient and telehealth services
- Targeting patient and family education materials and case management
- Focusing provider education and training

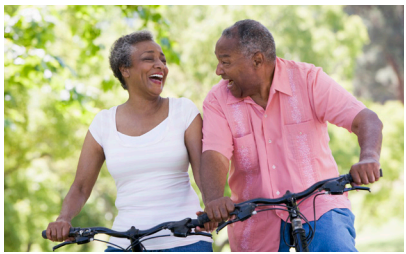
SCDC analysis can inform action:

- Educate — To shape individual or institutional practices or behaviors
- Decide — To inform policy, service, and resource allocation decisions
- Learn — To answer research questions to inform future actions
- Target — To identify a population for interventions, services, or education

Stakeholders who can drive action using SCDC data include:

- Patients and their support circles
- Individual health care providers
- Health systems
- Policymakers
- Payers

National SCDC priority areas:



- *Aging sickle cell population* — Documentation of complications, comorbidities, and outcomes over patients' life course can inform standards of care, interventions, reimbursement, and health care policy.
- *Geography of population* — Data can identify differences in access to care, health care utilization, and quality of care by patient location.
- *Hispanic population* — Data can better identify individuals with SCD born outside of the United States and estimate the prevalence in the Hispanic population.
- *Transition from pediatric to adult care* — Data enables examination of the factors that may be associated with increases in symptoms, complications, and poorer outcomes seen during the transition to adult care.
- *Utilization* — SCDC enables comparisons between low and high utilizers by diagnosis, procedure or intervention, and outcomes over time. Such analysis may inform clinical practice and patient self-care tied to better outcomes and lower costs.

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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 SCD.

Learn more: ghpc.gsu.edu/project/hemoglobin-disorders-data-coordinating-center/

Contact Angie Snyder (angiesnyder@gsu.edu) if you would like to use SCDC Georgia data for your research or planning.

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