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Sickle Cell Data Collection Program: Three-Year Dissemination and Analysis Plan for Georgia

Georgia Health Policy Center

GEORGIA
HEALTH POLICY CENTER



SICKLE CELL DATA COLLECTION PROGRAM:
THREE-YEAR DISSEMINATION AND ANALYSIS PLAN FOR GEORGIA

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Georgia Health Policy Center
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Table of Contents

Introduction

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 by developing and disseminating scientific evidence to inform policies and practices.

This longitudinal data-collection effort builds on five years of sickle cell disease surveillance in the state created under cooperative agreements with the U.S. Centers for Disease Control and Prevention (CDC) and the National Heart, Lung, and Blood Institute's Registry and Surveillance System for Hemoglobinopathies (RuSH) pilot project and the CDC's Public Health Research, Epidemiology, and Surveillance in Hemoglobinopathies (PHRESH) initiative.

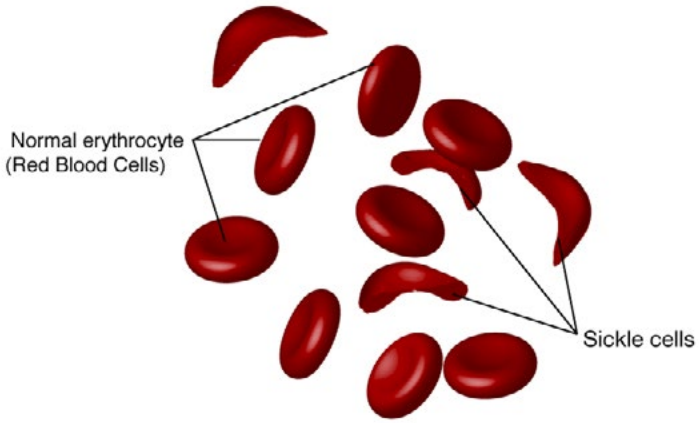
Georgia collected data (2004-2008) from the following sources to develop its surveillance system for hemoglobinopathies:[1]

- State newborn screening program (source: Georgia Department of Public Health);
- Death records (source: Georgia Department of Public Health);
- Clinical data from the three comprehensive sickle cell centers in the state (Augusta University, Grady Health System, and Children's Healthcare of Atlanta);
- Administrative claims data from Georgia's Medicaid, Children's Health Insurance Program, and the State Health Benefit Plan (source for all three: Georgia Department of Community Health); and
- Hospital and emergency department (ED) discharge data (source: Georgia Hospital Association under a data-sharing agreement with Georgia Department of Public Health).

The current goals are to continue using and improving upon developed methods and data sources for understanding sickle cell disease at the population level in Georgia, including extending the database to include longitudinal data through 2016 (or most recent year available). This unique data set enables examination of individual-level patient data for every health care system encounter for more than 10,000 patients over 13 years. The ability to collaborate with the SCDC project in California, and possibly other states in the future, brings additional power to the capabilities of the data set in its ability to identify trends and inform changes in both policy and practice.

The following plan represents our best-informed strategy for using the data over the next three years. It is based on substantial input from sickle cell disease stakeholders, including affected populations, policymakers, providers, and payers.

Sickle Cell Disease Overview



National Institutes of Health, National Human Genome Research Institute. Sickle cell disease [Photograph]. Talking Glossary of Genetic Terms. Retrieved from https://www.genome.gov/glossary/index.cfm?id=184

Sickle cell disease (SCD) describes a group of inherited blood disorders that affect hemoglobin, a protein in red blood cells that is responsible for carrying oxygen through the body. A single gene mutation causes people with SCD to have abnormal hemoglobin. Normal hemoglobin has a disc shape that is flexible and can move throughout the body's blood vessels to deliver oxygen. Instead of healthy, disc-shaped hemoglobin, those with SCD have sickle hemoglobin that forms stiff rods with a crescent shape. These sickle-shaped cells are not flexible and can stick to the walls of blood vessels, causing a blockage that slows or stops the flow of blood.[2] This blockage prevents oxygen from reaching tissues and organs. This can cause severe pain and fatigue, organ damage, strokes, and even death.

Distribution of sickle cell disease

Sickle cell is a rare disease, affecting approximately 100,000 people in the United States.[3] Overall, the prevalence of SCD has increased in the United States due to growth of at-risk populations, as well as improvements in patients' life expectancy.

In the United States, most people with SCD have African ancestry or identify themselves as black, but SCD also affects other groups, including those of Hispanic origin and people of Middle Eastern, Asian, Indian, and Mediterranean descent.[4]

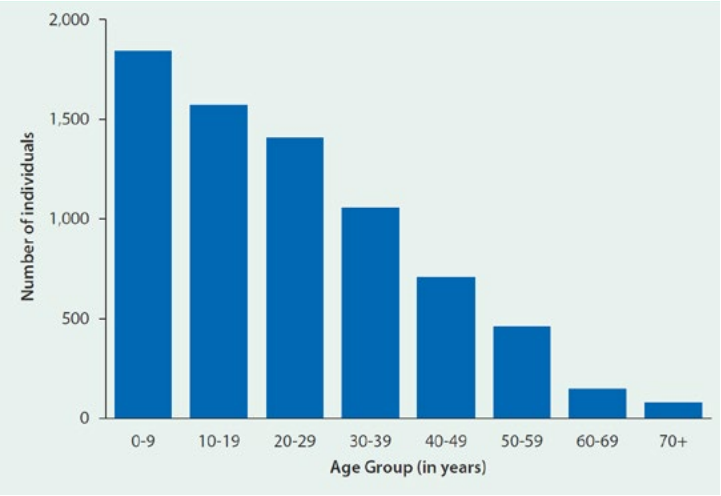
SCD occurs among approximately one of every 365 black or African-American births and in about one of every 16,300 Hispanic-American births.[3] Considerably more are born with sickle cell trait, meaning they are usually unaffected but could pass the condition to their offspring.[5]

Life expectancy

Once considered a childhood disease because of limited survival into adulthood, there has been great improvement in early SCD survival due to preventive care (e.g., prophylactic penicillin and vaccines), disease-remitting therapy (e.g., hydroxyurea), and use of comprehensive care models.[3, 6, 7, 8]

In 1973, the average life span of a person with SCD in the United States was only 14 years, with 20 percent of the deaths occurring in the first two years of life and one-third occurring before the fifth year of life.[9] More recently, population-based surveillance data from California and Georgia for years 2004 through 2008 show the all-cause mortality rate for the SCD population aged birth through 4 years was lower than the all-cause mortality rate among African-Americans and similar to the total population's all-cause mortality rates, but the rate was higher among those with SCD, compared to both the African-American and total population rates from ages 5 years through 74 years.[10]

Figure 1. Individuals with SCD in Georgia by Age



U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2013). Age distribution of individuals with SCD in Georgia identified by RuSH [Graph]. Sickle Cell Disease in Georgia. Retrieved from https://www.cdc.gov/ncbddd/sicklecell/documents/scd_in_ga_prov.pdf

The life expectancy of a person with SCD is now over 40 years.[10, 11] Among people with SCD, the average age of death was about 43 years for females and 41 years for males. About one in sixth deaths occurred in those under 25 years of age, and nearly half of all deaths occurred in those over 44 years of age.[10]

While comprehensive care for children with SCD has been linked to improved survival, the lack of comprehensive care for many adults with SCD may help explain the overall increased mortality rate for this population compared to the general U.S. population and African-American population.

Genetics of sickle cell disease

While SCD is a rare disease in the number of total people affected, it is one of the most common diseases caused by a single gene mutation. The most severe form of SCD, hemoglobin SS disease, occurs when the gene for sickle hemoglobin (hemoglobin S) is inherited from both parents. When only one hemoglobin S gene is inherited, the person is a carrier for SCD, or has sickle cell trait. While carriers can pass the hemoglobin S gene to their offspring, most with sickle cell trait are healthy and asymptomatic for SCD, although some complications have been documented.[12]

There are additional genetic forms of SCD, with varying severity:[13, 14, 15]

- Hemoglobin SC — A hemoglobin S gene is inherited from one parent along with another abnormal hemoglobin gene, hemoglobin C. Hemoglobin SC is usually a milder form of SCD.
- Hemoglobin Sβ-thalassemia — In this form of the disease a hemoglobin S gene is inherited from one parent, while a gene for β-thalassemia, another type of anemia, is inherited from the other parent. β-thalassemia has two forms, "0" and "+." Hemoglobin $S\beta^0$ thalassemia is a more severe form of SCD, while Hemoglobin $S\beta^+$ thalassemia is a milder form of SCD.
- Hemoglobin SD, SE, SO — These forms of SCD inherit one hemoglobin S gene as well as a gene for another abnormal type of hemoglobin (D, E, or O).

Diagnosis

SCD is diagnosed with a blood test. However, since young children with SCD are at an increased risk of health problems, even in infancy, early diagnosis and treatment are important. In the United States, SCD is most often diagnosed at birth during routine newborn screening at the hospital. Every state in the United States, the District of Columbia, and the U.S. territories requires that all newborn babies receive screening for SCD.[16] If a child has SCD, parents are notified immediately, before the child has symptoms.

Diagnosis in Georgia

The Georgia Newborn Screening Program ensures that as of January 1998 every newborn in Georgia is screened for 31 heritable disorders for prompt identification and treatment, including SCD.[17]

The Georgia Newborn Screening Program of the Georgia Department of Public Health is responsible for administering newborn screening, including the oversight of follow-up programs; monitoring and evaluating newborn screening practices; managing electronic data surveillance and tracking systems, including maintenance of long-term results; facilitating communication between practitioners, birth hospitals, laboratory personnel, and follow-up teams; providing ongoing education for practitioners; and reporting results to state and federal officials and to the public.

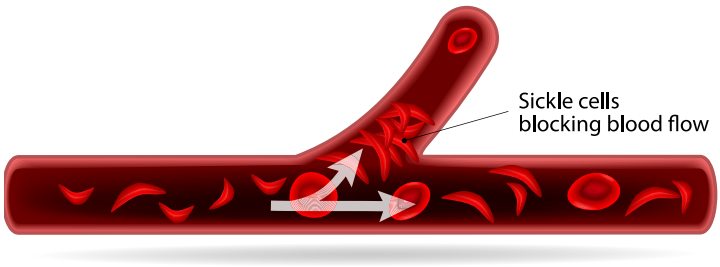
Following a positive hemoglobin screening result, the American Academy of Pediatrics recommends that positive screens be confirmed by 3 months of age, as early diagnosis of SCD is crucial in reducing the morbidity and premature death associated with the disease.[18] In Georgia, the newborn screening program contracts with three teams for follow-up of positive screens.[17] Children's Healthcare of Atlanta provides follow-up for positive results in the Metro Atlanta counties, while Augusta University provides follow-up for all other counties. The teams report abnormal results to the health care provider of record and parents, ensure timely confirmatory testing, and provide education and counseling to families. (Confirmatory testing and associated family studies for hemoglobinopathy are provided free of charge.) Confirmed cases are referred to the Children 1st program at the Georgia Department of Public Health for determination of eligibility for child health intervention services.

The Sickle Cell Foundation of Georgia is the third follow-up entity in Georgia, and it is responsible for follow-up of abnormal hemoglobin results that suggest a carrier or "trait" status as a result of inheriting a single hemoglobin S gene.

Complications

SCD is a lifelong illness. The severity of the disease varies widely from person to person and is not fully explained by genetics. Triggers for exacerbations and complications are also not fully understood, although certain self-care factors (e.g., hydration) and possibly some environmental factors (e.g., altitude, climate, and air quality) play a role.[19, 20, 21, 22, 23]

Most SCD-related complications result from the blockage of blood vessels from stuck, sickled hemoglobin S. The lack of oxygen can cause organ damage, commonly seen in the spleen, lungs, eyes, heart, kidney, liver, gallbladder, and joints.[13, 24] Increasingly, it is recognized that comprehensive care with a focus on preventive efforts can reduce complications.[13]



The most common complications include pain crises that often require hospitalization; debilitating chronic pain that also can lead to high health care utilization; anemia, often severe, due to the more frequent breakdown of fragile, sickled cells; life-threatening infections resulting from SCD-related spleen damage; and stroke, even in young children.[13, 25, 26, 27, 28, 29] Other complications can include delayed growth, pregnancy complications, cognitive problems, and mental health issues.[30]

Care and treatment

SCD patients are encouraged to see their SCD care providers regularly — every three to 12 months.[31] Routine visits can include examination and screening, prophylactic medicines and immunizations, diagnostic testing, and education of families about the disease and what to watch out for. Increased use of regular screenings and preventive measures have decreased infections, complications, and death.[13, 32, 33, 34, 35]

Measures that have become the standard of quality care include these:

- Prophylactic penicillin is recommended in children to decrease the rates of life-threatening infections.[36]
- Immunizations, including conjugated pneumococcal, meningitis, and influenza type B, also reduce serious infections.[7]
- Regular screening with transcranial Doppler (TCD) can identify stroke risk, particularly in children between the age of 2 and 16 years.[37, 38, 39, 40]
- Regular blood transfusions for those at risk of stroke have also decreased the rate of strokes and premature death.[33, 35]
- Treatment with hydroxyurea decreases the number and severity of pain episodes by increasing the amount of fetal hemoglobin (hemoglobin F) in the blood, providing some protection against the effects of hemoglobin S.[41, 42, 43, 44, 45]
- Stem cell transplants are the only cure for SCD, but they are limited in their use to certain targeted SCD populations.[46, 47]

Other examinations and screening, including eye examinations, pulmonary hypertension screening, and cognitive screening, can identify and treat SCD-related complications earlier.

Unfortunately, despite a growing body of evidence of the benefit of these care and treatment measures, they are not fully utilized.[32] Enhanced surveillance of utilization and quality practice can inform payers' and providers' efforts and ultimately yield enhanced outcomes for patients with SCD.

New treatments forthcoming
The landscape of care and treatment for those with SCD is poised to improve in the coming years. Pharmaceutical companies are currently testing dozens of compounds in clinical trials for SCD and related conditions. The SCD community is optimistic that these treatments will lead to increased life expectancy, lower health care costs, and improved quality of life.[49]

The compounds in development, as well as drugs originally developed for other purposes now being investigated in SCD, have multiple mechanisms of action. These include increasing production of hemoglobin F, targeting oxidative injuries and inflammation, and reducing cell adhesion among sickled cells.[13, 50] Longitudinal SCD data can better inform trials of these drugs by providing a baseline measure of SCD utilization and outcomes to which improved treatment-related outcomes can be compared.

Transitioning care
As noted, decades ago the most devastating consequences of SCD were experienced in childhood. Now, with advances in care, the deleterious effects of SCD are being borne most heavily by adolescents and young adults. Some of these ill effects are directly related to the disease — the longer one has lived with SCD, the more likely organ damage and additional disabilities have occurred. Additionally, adolescents and young adults are transitioning toward independence; this transition period has been shown to negatively affect self-management of the condition.

Rates of ED and hospital utilization are particularly high among adults with this disease. Availability of quality care, lack of insurance, and distance to care pose barriers to adult access to the comprehensive care models developed for the pediatric population.[51] These challenges are particularly profound during the transition years between pediatric and adult care, when increased rates of SCD-related complications and mortality have been seen among SCD patients.[51, 52] Throughout the nation there is a known shortage of hematologists trained and willing to care for adult SCD patients.[53]

Past Sickle Cell Disease Surveillance

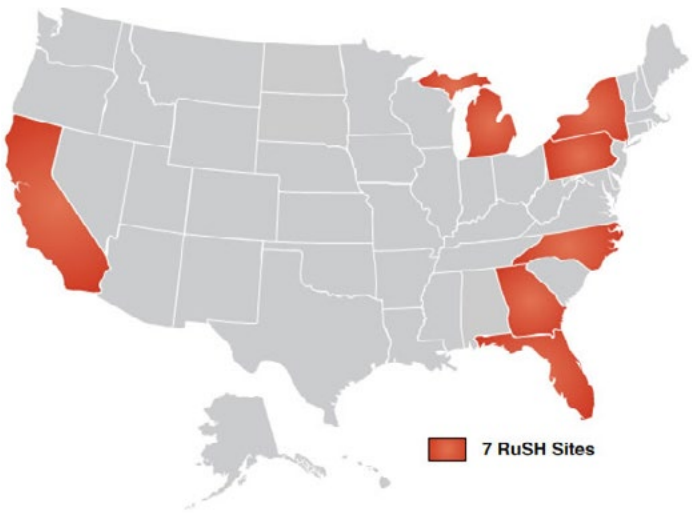
The only existing universal hemoglobinopathy screening and reporting activities in the United States are state-based newborn screening programs. Screening for SCD has been included on all 50 states' newborn screening panels since 2006. However, researchers note variability across newborn screening programs with regard to the states' public health role in follow-up for detected SCD, as well as use of reported data for statewide planning, quality assurance, and policy development functions.[54] Additionally, newborn screening does not capture those with SCD that move from another state, those born outside of the United States, or older individuals born prior to implementation of universal screening.

There have been calls for an improved system of data collection in order to accurately assess the number of individuals with SCD nationwide, understand the impact of SCD on the health care system, and strengthen development of comprehensive systems of care for those affected by SCD.[1, 3, 54] A comprehensive

understanding of the impact of hemoglobinopathies in the United States is important to health care providers, researchers, payers, and policymakers. Experts in SCD recognize that coordinated data collection has the potential to improve the understanding and treatment of SCD. Over the past several years, multiple stakeholders have identified the need for improved data collection as a priority.

In 2007, the American Society of Pediatric Hematology/Oncology Sickle Cell Summit identified population-based surveillance to measure outcomes as one of five major areas of opportunity for improving SCD care.[55] In 2008, the National Institutes of Health convened the Consensus Conference on Hydroxyurea Treatment for Sickle Cell Disease, which specifically called for an SCD surveillance system containing demographic, laboratory, clinical, treatment, and outcome information.[56] As a result of these meetings, the National Institutes of Health's National Heart, Lung, and Blood Institute and the Division of Blood Disorders at the CDC collaborated to work toward state-based surveillance for SCD and thalassemia.[1]

Figure 2. Map of RuSH Sites



U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2016). [Map of the U.S. showing 7 RuSH sites]. Registry and Surveillance System for Hemoglobinopathies (RuSH). Retrieved from https://www.cdc.gov/ncbddd/hemoglobinopathies/rush.htm

RuSH

The Registry and Surveillance System for Hemoglobinopathies (RuSH) began as a pilot project in 2010 under a cooperative agreement between CDC and the National Heart, Lung, and Blood Institute with seven states to develop and systematically test a multisource surveillance system. California, Florida, Georgia, Michigan, New York, North Carolina, and Pennsylvania participated. According to 2008 census data, these seven states combined represented approximately 38% of the total U.S. population, 42% of the black population, 54% of the Asian population, and 49% of the Hispanic population in the country.[1]

The overall purpose of RuSH was to collect state-specific, population-based data on people with SCD and thalassemia, with the long-term vision that the knowledge gained would result in a better understanding of the conditions and, ultimately, improve the lives of individuals with hemoglobinopathies. Specific objectives included:[57]

- Identifying all individuals in each state with an SCD or thalassemia diagnosis using pre-existing data sources;
- Determining how many people have SCD or thalassemia;
- Developing plans for a national surveillance system to gain a greater understanding of the health status and health practices of people living with SCD and thalassemia; and
- Creating and disseminating health education materials to increase knowledge and awareness about SCD and thalassemia among the general public.

Each state used a unique combination of data sources for the project, depending on the data sets they were able to access. Newborn screening records, hospital discharge data, ED records, death records, clinical records, and state Medicaid claims were used for case identification and/or as sources of demographic, clinical, and health care utilization data. While the original intent of RuSH was to devise a standardized data-collection protocol, the same methods could not be used by all states because of the varying availability of data sets and the identifying information contained within those data sets.

RuSH in Georgia

In Georgia, RuSH data-collection efforts were led by the Georgia Health Policy Center at Georgia State University on behalf of the Georgia Department of Public Health and in partnership with the Sickle Cell Disease Foundation of Georgia and the comprehensive sickle cell centers at Children's Healthcare of Atlanta, Grady Health System (Atlanta), and Augusta University Medical Center (formerly Georgia Regents University Medical Center).

Specific objectives in Georgia included determining the prevalence of hemoglobinopathies (SCD and thalassemia) across the life span in the state, calculating the annual incidence of hemoglobinopathies in Georgia, describing the demographics of the affected populations in Georgia, and developing and documenting the infrastructure and methodology for data collection to support possible continuation or expansion of surveillance efforts.

Georgia used data (2004-2008) from the following sources to develop its surveillance system for hemoglobinopathies:[1]

- State newborn screening program (source: Georgia Department of Public Health);
- Death records (source: Georgia Department of Public Health);
- Clinical data from the three comprehensive sickle cell centers in the state at Augusta University, Grady Health System, and Children's Healthcare of Atlanta;
- Administrative claims data from Georgia's Medicaid, Children's Health Insurance Program, and the State Health Benefit Plan (source for all three: Georgia Department of Community Health); and
- Hospital and ED discharge data (source: Georgia Hospital Association under a data-sharing agreement with Georgia Department of Public Health).

Identifiers are collected under the public health authority of the Georgia Department of Public Health and are used for matching and deduplication only. Few data sources included Social Security numbers or Medicaid identification numbers consistently. Therefore, deterministic matching of patients was not feasible for most data sets in Georgia.[1] Each data set was deduplicated and data sets were then matched, one at a time, using a probabilistic algorithm that assigned differing weights to identifying variables, such as date of birth, patient's name, mother's name (for children), sex, county, telephone number, and address.

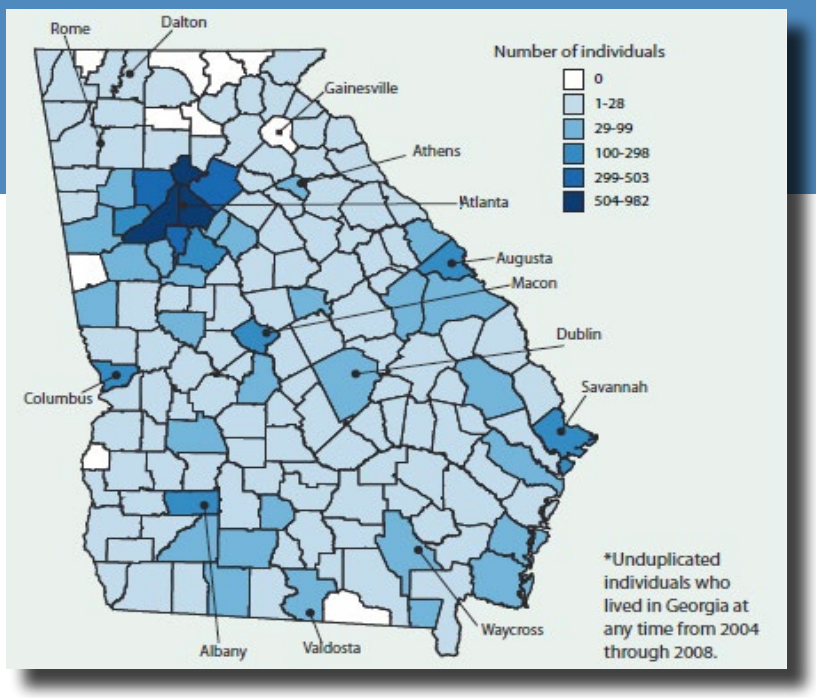
- Probable, or Level II, cases defined by administrative records of health care encounters consistent with SCD (two or more health care encounters with SCD ICD code plus one or more SCD-associated complication, treatment, or procedure within a five-year period). These probable cases included those with a positive newborn screening test but no confirmatory testing; clinical determination from an SCD comprehensive center; three or more SCD ICD codes from Medicaid, PeachCare, or the State Health Benefit Plan data; or three or more SCD ICD codes from hospital and ED discharge data.
- Possible, or Level III, cases involved a smaller number of health care encounters with SCD ICD codes — either sickle cell trait ICD code at two or more separate health care encounters plus one or more SCD-associated complications, treatments, or procedures, or a single health care encounter with an SCD ICD code.

Key Findings from RuSH Analysis:[1, 58]

Demographics

- **There are 7,299 people in Georgia living with SCD (confirmed and probable cases).**
- **People with SCD live in almost every county throughout Georgia.**
- **Those living with SCD in Georgia range in age from newborns to people over 70 years old.**
- **The vast majority (97% or more) of Georgia newborns with SCD are black or African-American, while approximately 2% are Hispanic.**
- **Roughly one out of every 295 black or African-American babies born in Georgia from 2004 through 2008 had some form of SCD.**

Figure 3. Number of Individuals with SCD by County

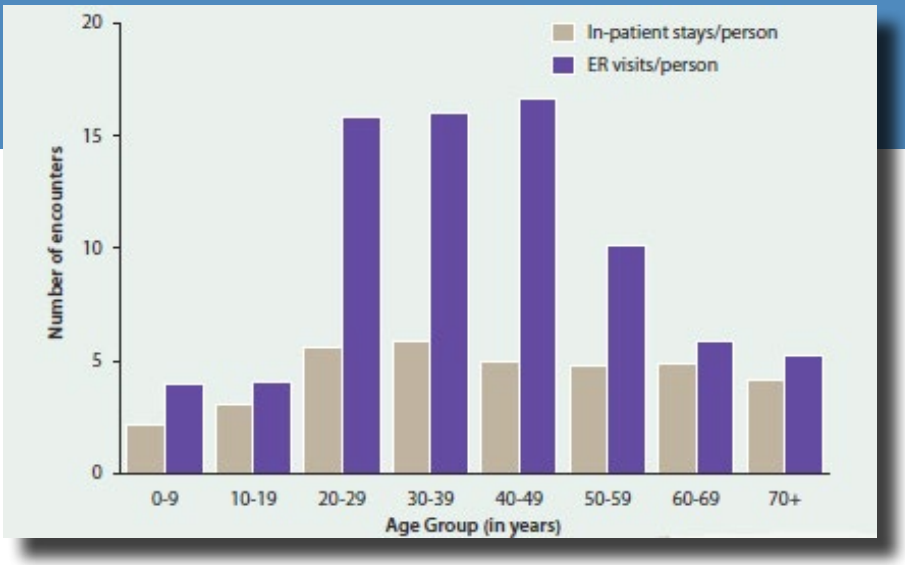


U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2013). Number of individuals with SCD in Georgia counties identified by surveillance [Graph]. Sickle Cell Disease in Georgia. Retrieved from https://www.cdc.gov/ncbddd/sicklecell/documents/scd_in_ga_prov.pdf

Health care utilization

- **There are documented health care visits for 94% of the identified 7,299 Georgia residents with SCD between 2004 and 2008.**
- **Of newborns with a positive screen for SCD from 2004 through 2008, 80% were later seen at one of Georgia's two pediatric sickle cell centers.**
- **For 26% of individuals with SCD, there were no hospitalizations during the five-year period, and 16% had no ED visits.**
- **Hospital visits, especially those to the ED, increased considerably after childhood. Children aged 0-19 years averaged four ED visits over the five years, while those aged 20-49 years had more than 15 emergency visits over the same period.**

Figure 4. Average Number of Hospital Encounters per Individual with SCD, by Age Group, 2004-2008



U.S. Department of Health and Human Services, Centers for Disease Control and Prevention. (2013). Average number of hospital encounters per individual with SCD, by age group, 2004-2008 [Graph]. Sickle Cell Disease in Georgia. https://www.cdc.gov/ncbddd/sicklecell/documents/scd_in_ga_prov.pdf

Case definition

RuSH established three levels of case definitions for SCD based on laboratory results and International Classification of Diseases, Clinical Modification, Ninth Revision (ICD-9-CM) codes.[1] Developing these case definitions was a key task and evolved as results were studied and definitions were validated:

- Confirmed, or Level I, cases defined by laboratory confirmation of SCD genotype. Laboratory results could be established either through confirmatory newborn screening testing or through genetic and laboratory testing at SCD comprehensive centers.

PHRESH

It was determined that the health care utilization and clinical data gathered during RuSH could serve as the foundation for the development of an ongoing, longitudinal SCD surveillance system. Expansion of the information collected during the RuSH project began in 2012 with the launch of the CDC-sponsored Public Health Research and Surveillance for Hemoglobinopathies (PHRESH) project. PHRESH focused on surveillance, as well as health promotion and prevention of complications in those with hemogloinopathies living in three partner states — California, Georgia, and Mississippi.

PHRESH's primary goals included:[59]

- Developing a monitoring program within a defined geographic area that provides accurate information on the burden of disease — how the disease impacts individuals and communities.
- Promoting health and preventing complications by improving the quality of care for people with hemoglobinopathies, with a particular focus on vaccinations, early and continuous screening (e.g., TCD screening), and the use of appropriate treatments (e.g., hydroxyurea). These focus areas align with three of Healthy People 2020's developmental objectives related to blood disorders.

Additionally, PHRESH sought to validate the RuSH methods and case definitions.

PHRESH in Georgia

Through its participation in PHRESH, Georgia extended its RuSH efforts of linking health care utilization to cases with confirmed SCD diagnosis. During PHRESH, Georgia performed validation studies of the SCD case definition developed during RuSH and examined the use of prevention strategies recommended for sickle cell patients. Specifically, Georgia sought to —

- Demonstrate the feasibility of a hemoglobinopathy surveillance program;
- Validate case definitions and methodologies for collection of surveillance data on persons with hemoglobinopathies;
- Derive baseline estimates of the demographics and health service utilization of persons with hemoglobinopathies, with priority attention to the Healthy People 2020 focus areas:
    - Determine the vaccination coverage and vaccine-preventable disease level in individuals with SCD;
    - Determine the proportion of children with Hb SS and Sβ° thalassemia screened by TCD ultrasonography for stroke risk; and
    - Determine the proportion of adults and children with Hb SS and Sβ° thalassemia receiving hydroxyurea treatment.
- Implement health promotion and prevention awareness strategies designed to improve patient care quality:
    - Develop and disseminate key health education materials for persons with hemoglobinopathies, their families, and health care providers; and
    - Conduct a needs assessment to identify gaps in knowledge and educational resources on appropriate vaccinations, early and continuous screening for complications, and disease-modifying therapies among patients and providers.

People with SCD are living longer, healthier lives, due in large part to advances in preventing disease-related complications. One of the goals of the PHRESH project was to find out how well these advances are reaching affected individuals in Georgia. Using the linked surveillance data, several briefs and academic papers were published validating the use of the surveillance data to identify individuals with SCD as well as their receipt of preventive therapies. Furthermore, educational materials highlighting prevention practices appropriate to those with SCD were also disseminated to providers caring for SCD patients in Georgia.

For the SCDC project, both Georgia and California updated their case definitions based on these findings.

Key Findings from Georgia PHRESH Work:[60]

Cases identified

- Across data sets, 4,288 Level 1 (confirmed), 3,011 Level 2 (probable), and 9,208 (possible) cases were identified in Georgia from 2004 through 2008.[1]
- The majority (88%) of the 828 newborns who screened positive for sickle cell disease from 2004 through 2008 had a documented confirmatory diagnosis at follow-up (Level 1 case). The remaining 98 cases with positive screens, but no confirmatory test, were categorized as Level 2.

Provider information[61]

Based on surveys completed with 100 primarily pediatric medical practices in 48 counties that, according to RuSH data, contain 85% of all confirmed SCD cases in Georgia:

- SCD patients were seen in 84 of 100 surveyed medical practices;
- Only seven practices had a sickle cell specialist on staff;
- Most respondents said they refer their patients with SCD to specialists to manage all aspects of sickle cell care; however
- Sixteen respondents said there was no such specialist within a one-hour drive, or they were not aware of one.

Health care utilization[32]

- Hydroxyurea was underutilized in Georgia from 2004 to 2008:
  - Among confirmed cases with SCD types for which hydroxyurea has demonstrated benefit, the portion meeting clinical criteria who received hydroxyurea was 38% (36% of children, 42% of adults); and
  - Overall, only 30% of individuals (29% of children, 32% of adults) who met the clinical criteria for hydroxyurea treatment filled a prescription.
- Initiation of TCD ultrasound screening and pneumococcal polysaccharide vaccination (PPV) in children from 2004 to 2008 is suboptimal in Georgia:
  - In a cohort of 125 Georgia toddlers with SCD, 77% received their first dose of PPV vaccine at 2 years of age; and
  - Only 23% of these same toddlers received their first TCD screening for stroke risk at 2 years of age, as recommended.

Validation studies[32]

- Claims data appears useful to track use of TCD in children and yields similar results to chart review.
- State-based immunization registries are the most complete source of tracking immunizations for individuals with SCD, better than chart review and claims data.
- Validation studies of the RuSH case definition found that a simpler definition of at least three SCD-coded encounters was just as effective as the original definition (two encounters with SCD diagnosis codes and at least one encounter with an SCD-associated treatment, procedure, or complication) in accurately identifing “probable cases” and reducing the number of missed cases.
- Based on a five-year surveillance period, using this updated case definition of at least three SCD-coded encounters to identify SCD in administrative data is 97% accurate in identifying true cases while only missing approximately 4% of cases.[62]

Sickle Cell Data Collection Program in Georgia

Data Collection

CDC is committed to continuing and expanding prior SCD surveillance activities. With donations from Pfizer Inc., Global Blood Therapeutics, and Bioverativ, the CDC Foundation has enabled CDC to partner with the California Rare Disease Surveillance Program and the Georgia Health Policy Center to revisit case definitions, update surveillance data sets for the two states, and plan and begin leveraging the data sets to improve policies and practices on behalf of the sickle cell patient population. As funds are available, CDC plans to support additional states' efforts. SCDC's overarching objective is to collect, synthesize, and disseminate multisource, population-based, longitudinal data on people with SCD.[63] Ultimately, this can enable efforts to:

- Establish a health profile of the SCD population;
- Track changes in SCD outcomes over time;
- Ensure that credible, scientifically sound information informs standards of care;
- Inform policy and health care practices; and
- Improve quality of life, life expectancy, and health among those living with SCD.

SCDC maintains the database and sources developed in RuSH but expands the years for which data is collected. Having data from 2004 through 2016, this data set enables longitudinal examination of individual-level patient data for every health care system encounter for more than 10,000 patients over 13 years.

While this unique data set is valuable to inform the above-stated goals, some limitations of the data should be noted. The majority of the data is from administrative data sources (linked hospital discharge, EDs, Medicaid claims, vital records, and newborn screening), rather than information collected directly from patients or health care providers. Furthermore, the database doesn't contain information from nonhealth agencies (e.g., school records), private data (nongovernment insurance claims or employment records), or patient-reported measures (e.g., quality of life surveys).

California and Georgia are the two states currently participating in SCDC. The participants, along with CDC, plan to expand dissemination of findings to date, including peer-reviewed publications, scientific presentations, and briefs for targeted audiences based upon possible output measures, including demographics, health system entry and exit points, health care utilization, complications, treatment, outcomes, and provider information. Additionally, with additional funding, the program would like to expand to include other states.

SCDC strives to improve health outcomes for people with SCD. By collecting and analyzing health information of patients with SCD over time, the program can identify critical gaps in diagnosis, treatment, and access to care for people with SCD. Backed by accurate, scientific information, the SCDC program can inform stakeholders about how these gaps can be filled through policy changes, improved health care practices, and new therapies. Stakeholders who can drive changes in action from knowledge gained from the SCDC data set include individual health care providers, health systems, policymakers, payers, and affected populations (patients and their support circles).

CDC, in partnership with stakeholders, established five priority areas for SCDC to address.[63]

Where people with SCD live
SCDC data shows where patients, health care providers, and health care facilities are geographically located and can help answer questions related to access, health care utilization, and quality of care.

The data allows examination of geographic challenges in gaining access to care, how far patients travel for treatment, whether they are seen at the closest facilities to their home, the ratio of identified patients to services or providers in a given region, and how these geographical factors may influence utilization by provider type (e.g., ED) and if local providers treat SCD patients according to best practices.

National SCDC Priority Areas

- Aging population
- Geography of population
- Hispanic SCD population
- Transition
- Utilization

Transition from pediatric to adult care
SCDC data includes information on utilization (i.e., how many times a patient visits specific types of providers or settings, treatments, and procedures) and health outcomes for most patients within a state, whether or not they are seen in an SCD clinic regularly.

Previous research has shown that the period of transition from pediatric to adult care coincides with the onset of the increasing symptom severity and high health care utilization, even for patients in regions with high-quality pediatric care. SCDC data enables examination of the factors (e.g., geography, access to care, insurance status, preventive care) that may be associated with increases in SCD symptoms and complications and poorer outcomes that surface during the transition to adult care.

Hispanic patients
SCDC data includes reliable information on ethnicity and race from patients with linked newborn screening and clinical case reports. Studies estimate that about 10% of patients with SCD in the United States are Hispanic.[64] SCDC enables analysis of variables (e.g., geography, utilization, and outcomes) through the lens of Hispanic ethnicity.

Older patients
SCDC data includes longitudinal data on middle-aged patients and can reliably determine SCD status even among patients who have relatively few SCD-related health system encounters. Additionally, SCDC data includes death records, with identified cause of death.

People with SCD are living longer, so we have the opportunity to study them as they become older adults.[10] Previous research has shown that in an SCD cohort, complications and comorbidities were common and included hypertension and diabetes, as well as early-onset complications, such as chronic renal disease, iron overload, and cardiovascular disease.[52] Additionally, the majority were not undergoing routine, recommended cancer screenings. SCDC data enables documentation of complications and outcomes during the life course, which can inform development of standards of care, interventions, and health care policy to serve this population.

Use of health care services
SCDC data includes longitudinal health care utilization information by patient and across patients. Utilization measures include counts of ED visits, outpatient visits (for those on Medicaid), visits by type of provider, and hospitalizations.

Previous research has been limited in its capacity to examine all forms of health care utilization. There have been some studies describing ED utilization (29% of SCD patients had no ED visits or hospitalizations while 16.9% had three or more per year), looking at age at time of heightened health care utilization (e.g., during transition between pediatric and adult care), and factors associated with higher utilization (e.g., age, disease severity, greater parental education, and psychiatric illness).[26, 51, 52, 65] SCDC data enables comparisons between low and high utilizers by diagnosis, procedure or intervention, and outcomes. It can also examine events or complications that precede periods of high utilization. Such analysis may inform practice behavior and patient self-care associated with improved outcomes at reduced costs.

Analysis And Dissemination Planning For Georgia

Guiding framework

The Georgia SCDC project set out to create a three-year plan for analysis and dissemination activities that was both stakeholder-informed and action-oriented. These principles help ensure the project's goal that use of this longitudinal data can inform changes in policies and practices that ultimately improve length and quality of life for SCD patients. We engaged a broad cross section of stakeholders in the planning process to provide as many perspectives and insights as possible into the potential for SCDC data to impact change and to build awareness and support for future analysis and dissemination activities. The identified stakeholders serve both as research design partners and audience for research outputs.

These guiding principles of having a stakeholder-informed and action-oriented plan aligned closely with those of the Patient-Centered Outcomes Research Institute (PCORI), so we developed a modified version of PCORI's Dissemination and Implementation Framework to guide our own work.[66]

PCORI's mission is to drive informed health care decisions and improve health care delivery and outcomes by producing and promoting high-integrity, evidence-based information.[67] Central to this mission is PCORI's tenent that those most likely to use the information should help guide the research process. To be effective, dissemination and implementation activities must reflect the needs and concerns of end users.

PCORI's Dissemination and Implementation Framework illustrates this commitment to increase the awareness of evidence and promote its integration into practice. The framework focuses on ways to enhance awareness and knowledge of useful and relevant information (dissemination) to help people and organizations make decisions and put it into practice (implementation).

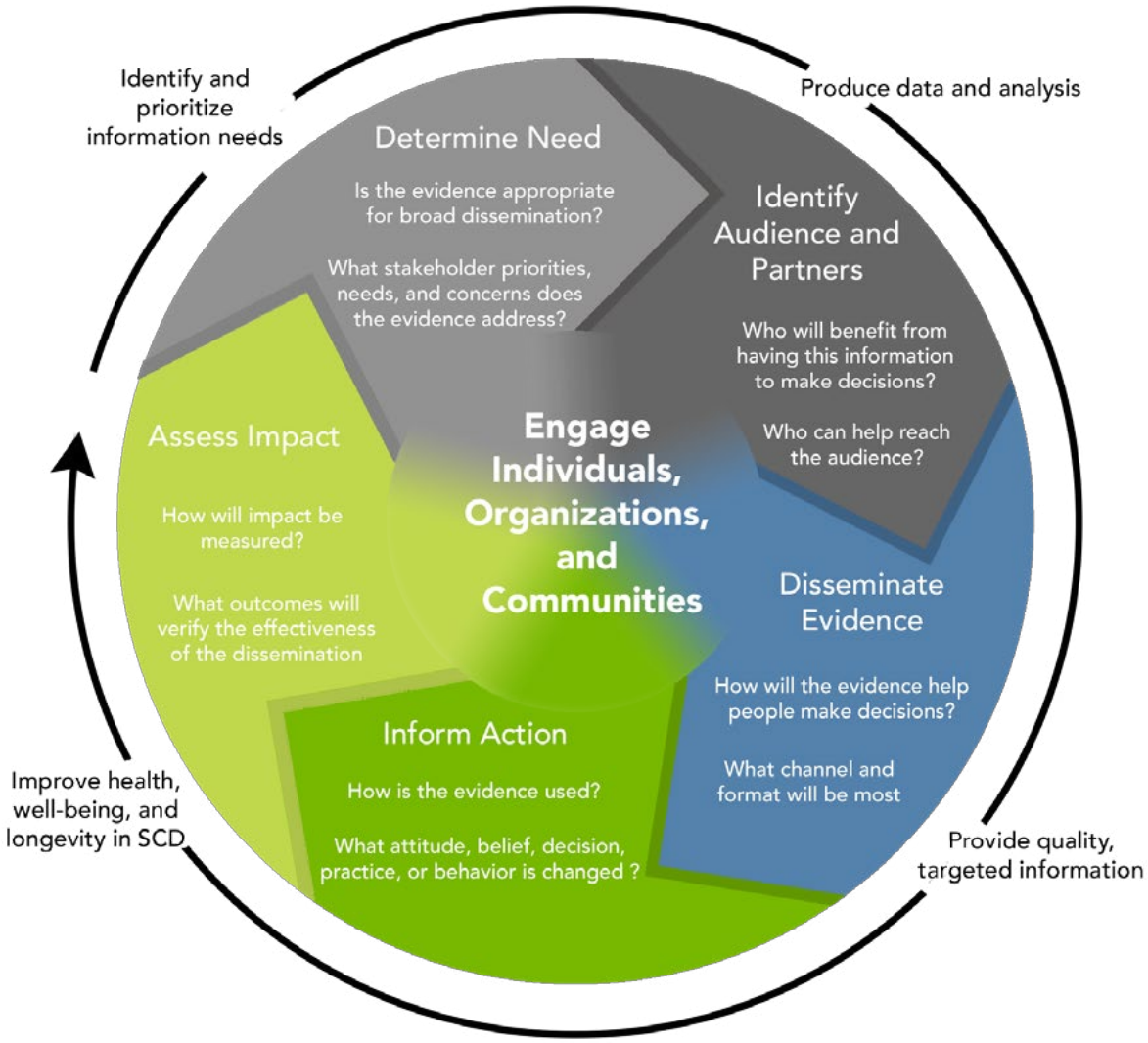
Effective knowledge-sharing starts at the point of research topic selection by recognizing the need to understand the priority questions that can inform practice and improve outcomes and to identify the audiences who will use this evidence to make relevant decisions. PCORI defines the key components of this cycle as:[66]

- Stakeholders — All people and organizations with a vested interest in increasing the quantity, quality, and timeliness of useful, trustworthy information to support health and health care decisions;
- Dissemination — The active process of identifying target audiences and tailoring communication strategies to increase awareness and understanding of evidence, and to motivate its use in policy, practice, and individual choices; and
- Implementation — The iterative process of integrating evidence into policy and practice through adapting evidence to different contexts and facilitating behavior change and decision making based on evidence among individuals, communities, and health care systems.

Georgia SCDC's modified version of the PCORI Dissemination Framework is shown in Figure 5.

The framework is presented as a set of concentric cycles, showing that the use of data to inform change is an iterative process that repeats as objectives are met, new findings emerge, or important contextual changes develop. The outer cycle reflects the overall steps: identify and prioritize information needs, produce the data and analysis, and provide quality, targeted information – ultimately to improve health, well-being, and longevity among people wih SCD. The inside cycle describes the steps in greater detail, with questions framing the objectives for each. "Engage individuals, organizations, and communities" is at the center, reflecting that stakeholders have roles throughout the cycle.

Figure 5. A Framework Linking Dissemination to Action and Results



Adapted from Esposito, D., Heeringa, J., Bradley, K., Croake, S., Kimmey, L. (2015). A framework linking dissemination to action and results [Flow Chart]. PCORI Dissemination & Implementation Framework. Retrieved from http://www.pcori.org/sites/default/files/PCORI-Dissemination-Implementation-Framework.pdf

Sickle cell stakeholder convening

Figure 6 illustrates the process the Georgia Health Policy Center used to develop the three-year dissemination and analysis plan for SCDC Georgia — determining needs, identifying audience and partners, and beginning to inform dissemination, action, and assessment.

The five topic areas identified as SCDC priorities nationally provided an initial foundation for the plan. Stakeholders were engaged at to help develop the three-year plan for Georgia through a smaller "design team" representing a microcosm of SCD stakeholders and in a day-long convening of diverse stakeholders (see Appendix A).

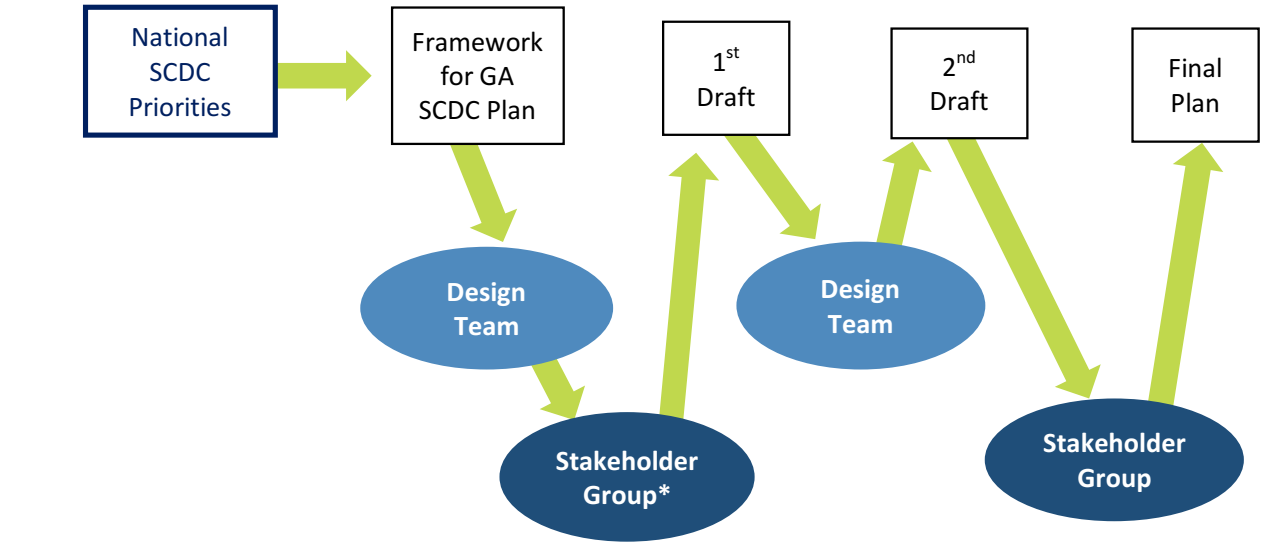
Design team members were recruited to help shape the convening and make sense of its results. In the months prior to the convening they met three times, providing insights, perspectives, and advice in response

to evolving drafts on the convening's purpose, intended outcomes, target stakeholder groups, invitation list, and agenda. The project team at the Georgia Health Policy Center incorporated input and arranged meeting logistics.

The meeting was designed to produce the following:

1. Stakeholder input for Georgia's three-year dissemination and analysis plan;
2. Increased awareness and understanding of Georgia's SCDC data set; and
3. New and stronger connections among SCD stakeholders in Georgia.

Figure 6. Development of Georgia SCDC Three-Year Analysis and Dissemination Plan



Stakeholder groups identified for engagement fell into three broad categories: those affected by SCD (e.g., patients, caregivers, community-based organization representatives); providers (e.g., outreach workers, clinic nurses, primary care and emergency physicians, pediatric and adult hematologists, pharmacists, and health system representatives); and decision makers/decision informers (e.g., elected officials and legislative staff, public and private payer representatives, public health personnel, health services researchers, research funders, pharmaceutical industry representatives, and health communicators).

A total of 49 individuals participated in the day-long convening, held outside of Atlanta, Ga. on May 11, 2017. Attendees' 24 organizational affiliations are listed in Appendix A). Participants included seven patients with SCD, four family members of SCD patients, 12 in public health, 13 clinicians, 17 researchers, nine from funding entities, three in public policy roles, three from the insurance industry, and six from the pharmaceutical industry.[1] Participants were assigned seats at tables designed to optimize the mix of perspectives. After a background presentation on SCD surveillance efforts and orientation to the SCDC data set, the remainder of the day was spent in focused table conversations or whole-room feedback and discussion. Input was captured on individual worksheets and table flip charts.

After the convening, Georgia Health Policy Center staff compiled and organized the output, identified themes, and developed a rough plan draft that was reflected back to the design team for input in a final meeting. That

feedback was then incorporated and a second draft shared with the full group of convening participants for final review and comment. What follows is the result of that process.

Georgia Priorities, 2017-2020

Definitions of key variables

Stakeholder groups

- Affected populations: Patients, caregivers, representative community-based organizations.
- Health systems: Organizations participating in the local system of care.
- Payers: Public and private entities responsible for paying for health care and defining enrollee benefits.
- Providers: Direct care providers, such as outreach workers, clinic nurses, primary care physicians, ED physicians, and hematologists.
- Policymakers: Those responsible for broad-level resource allocation decisions.

It should be noted that additional stakeholders (including research funding agencies, philanthropies, and pharmaceutical companies) may find SCDC data analysis useful. The five selected stakeholders reflect the broadest groups with the most widespread use for SCDC data analysis. However, partnerships with other groups would be valuable and welcome.

Actions that could be informed by SCDC analysis and dissemination

- Educate: To shape institutional or individual practices, behaviors, or attitudes.
- Decide: To inform policy or resource allocation decisions or plans.
- Learn: To answer research questions in order to inform future actions.
- Target: To define a population for receipt of interventions, services, or education.

Nationally identified SCD priority areas (previously defined in more detail on p. 18)

- Aging: Population of SCD patients reaching midlife and beyond.
- Geography: Demographic-related data, with a particular emphasis on location.
- Hispanic: Those with self-identified Hispanic ethnicity.
- High utilization: Those using higher levels of health care services.
- Transition: SCD patients moving from pediatric to adult services.

Fitting SCD priorities in the national health reform landscape

Efforts are underway locally, regionally, and nationally to transform the health care system to be more efficient,

equitable, and effective. The Triple Aim, as originally defined by the Institute for Healthcare Improvement in Cambridge, Mass., refers to the simultaneous pursuit of improving the patient experience of care (quality of care), improving the health of populations (overall outcomes), and reducing the per capita cost of health care. In recognition of these goals, Georgia SCDC mapped priorities to three key components of the Triple Aim: access, cost, and quality.

Access

Inherent in the pursuit of the Triple Aim is the assumption that patients are able to access health care. SCDC data includes measures of many components of access, including geography (the distribution of SCD patients in the state and distribution and types of SCD care providers throughout the state), and insurance status of patients. Other SCDC demographic data (e.g., age, race) may also be helpful in identifying any gaps in access to appropriate care.

Cost

Containing cost and increasing value is a pervasive theme of health care reform efforts. Public and private payers are in many cases tying reimbursement to the quality of care provided in order to ensure that care is effective, efficient, and coordinated. The focus on quality of care is placing more emphasis on evidence-based medicine and standardizing care as a way of enhancing quality and reducing disparities. As patients are footing an increasing share of health care bills, they too are starting to pay more attention to the cost of care.

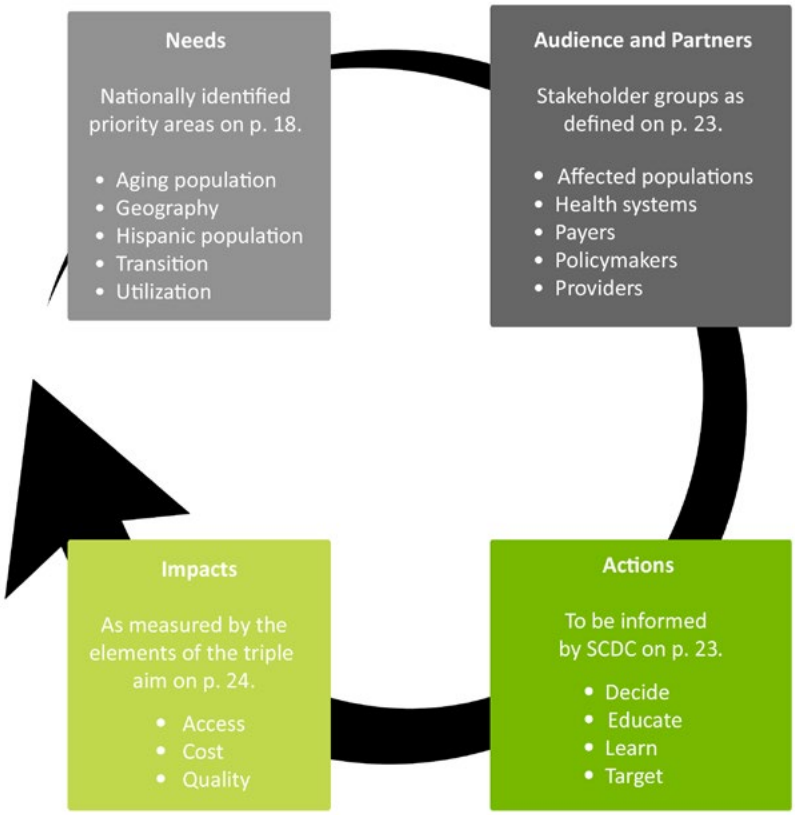
SCD care is costly and plagued with substantial practice variation.[32] Based on a multistate, multipayer patient sample, SCD-attributable medical expenditures in children were conservatively estimated in 2005 to cost $335 million.[68] Children with SCD incurred medical expenditures that were $9,369 and $13,469 higher than those of children without SCD enrolled in Medicaid and private insurance, respectively, or six and 11 times those of children without SCD enrolled in Medicaid and private insurance, respectively.[68] Care is even more costly in adults. Total health care costs with SCD rise with age, from $892 to $2,562 per patient-month in the 0-9–year and 50-64–year age groups, respectively.[69]

Extrapolated, the average lifetime of care for an SCD patient is $460,151. The same study showed that the majority of SCD-related health care costs (80.5%) are associated with inpatient hospitalizations. Stakeholders believe that interventions that can prevent SCD complications and hospitalizations have the potential to reduce the significant economic burden of the disease. Additionally, improving access to care and educating patients about appropriate care seeking (including self-care) based on symptoms also have the potential to cut SCD-related costs.

Quality

While the effectiveness of certain prophylactic treatments (hydroxyurea and penicillin) and screenings (TCD) have been documented in the literature, the adoption of these advances into routine clinical care is often lengthy.[70] Implementation of evidence-based practice standards has been shown to improve quality of care for patients with SCD, but, again, there are questions about whether this quality care is reaching all SCD patients.[71] Longitudinal SCDC data enables evaluation of the adoption of these promising practices in real-life settings, both in terms of provider behavior and impact on patient outcomes.

Figure 7. SCDC Georgia Plan Aligned With Dissemination Framework



The three-year analysis and dissemination plan for SCDC Georgia elaborates upon the elements of the Framework Linking Dissemination to Action and Results. The nationally identified SCDC priority areas served as a starting point for stakeholder-identified needs; the Design Team and the broader Stakeholder Group served as the audience and partners; the actions that can be informed by SCDC dissemination and analysis, as identified by the convening participants parallel actions; and the elements of the triple aim were selected as high-level parameters of impact.

Recommended dissemination activities

The convening yielded an extensive list of stakeholder-identified needs and potential actions that can be taken by multiple audiences as a result of SCDC data and analysis. The full list of Georgia SCDC priorities identified by convening attendees is displayed in Appendix B.

The Georgia SCDC team distilled the full list by:

- What is feasible with the data set;
- What is actionable by one or more stakeholder groups toward improving length or quality of life;
- The timeframe (short-term dissemination not requiring extensive analysis and longer-term, more complex research questions); and
- Priorities within the SCD community.

Table 1. Three-Year Dissemination Opportunities by Target Audience and Priority Area

Target Audience	Aging	Geography	Hispanic	Transition	Utilization
Affected Populations					
Target patient materials on SCD basics and appropriate use of health care through hospitals and emergency departments in parts of state with high utilization					
Target SCD patient and family education in parts of state with high SCD prevalence, high SCD-related mortality, high complication rates, or unusual utilization patterns					
Target high-incidence areas for trait education and screening					
Target culturally, linguistically, and topically appropriate patient outreach and education based on patient demographics by geography					
Health Systems					
Target outreach/case management capacity (and ultimately workforce/hiring decisions) based on areas of greatest service shortage, especially to ensure access to essential follow-up					
Decide allocation of outpatient resources/hours based on the most frequent presenting reasons for ED visits/hospitalizations					
Decide location and hours of specialty clinics and establishment of telehealth capabilities based on accessibility of care facilities across the acuity spectrum					
Payers					
Decide quality measures to reflect evidence-based practices					
Target transition-appropriate information on health, benefits, and referrals based on areas of highest transition-aged populations					
Target provider contracts to ensure in-network care options (or out-of-network coverage if no other option) for all ages, needs, acuities available within reasonable time and distance of patients					
Policymakers					
Decide resource allocation to make social services and supports accessible, based on distribution of births and transition-aged and aging populations					
Decide workforce development incentives to reduce provider-patient gaps by geography					
Target benefits counseling and referrals for parents of newborns, transition-age patients, and adult patients based on incidence/prevalence distributions by age					
Providers					
Target education of emergency physicians, primary care providers, OB/GYNs, and hospitalists in areas with high incidence, prevalence, mortality, or utilization					
Decide referral strategies based on location of specialists and SCD care providers					
Target culturally, linguistically, and topically appropriate provider education based on demographics by geography					

Table 1 reflects the top, short-term dissemination opportunities that can be completed using Georgia SCDC within a three-year timeframe. These prioritized dissemination needs are sorted by stakeholder audience and how they target national SCDC priorities.

The dissemination activities listed in Table 1 hinge on Georgia SCDC data outputs summarized in Table 2. Maps and tables of key variables by geography will be among the first products in the three-year plan, with additional variables by geography produced as requested by end users. Presenting reasons and quality-associated practice measures are targeted for Year 2. While the project team will proactively produce certain of these outputs and will solicit queries from and partner with stakeholder groups, those groups carry the primary responsibility for strategically disseminating the evidence provided and driving the desired actions.

Table 2. Three-Year Georgia SCDC Data Outputs

SCDC Data Outputs	Affected Population	Health System	Payers	Policymakers	Providers
Geography of patient demographics (age, race/ethnicity, language)	■		■	■	■
Geography of utilization (areas of high incidence, prevalence, mortality, and/or utilization)	■			■	■
Geography of providers (locations of SCD care providers and specialists; care facilities across the acuity spectrum)		■	■	■	■
Most frequent presenting reasons for emergency visits and hospitalizations		■	■	■	■
Quality measures for evidence-based practices	■	■	■		■

High-priority data analysis topics

Some of the needs and opportunities convening stakeholders identified require longer-term, more complex analysis of Georgia SCDC data. The Georgia SCDC team removed analysis requests that were not feasible with the data set and then worked with the design team to identify priority research questions — those of greatest immediate need and potential to impact change. Design team members also noted that priority should be given to questions that our longitudinal data is uniquely suited to answer, ones that have not been well studied to date, and ones that the patient/caregiver community has voiced as concerns.

The resulting priorities are grouped into three analysis topics: complications and utilization across the pediatric-to-adult transition, pain treatments and opioid usage, and complications and comorbidities in the aging population. Table 3 demonstrates how the analysis priorities can inform action and address the national SCDC priorities.

Initial studies in each of the three areas can begin in Year 1, with follow-up analysis in subsequent years determined according to availability of resources, evolving findings and new results in the field, and ongoing stakeholder input.

Table 3. Priority Analysis Topics by Action and Priority Area

Research Questions	Actions to Be Informed	Aging	Geography	Hispanic	Transition	Utilization
Complications and utilization across pediatric-to-adult transition: • What are the patterns in complications and health care utilization (e.g., transfusion frequency, prescription filling, outpatient visits, emergency department visits) across transition? • How do these patterns relate to insurance status, age, race/ethnicity, geography?	Decisions on health insurance coverage extensions for young adults and other transition-supportive policies and practices		■	■	■	■
Pain treatments and opioid usage: • Who is prescribing pain medicine for SCD patients? • Where and how often are these prescriptions being filled? • What treatments are associated with lower opioid prescribing? • Does mental health service consultation reduce opioid prescribing or use?	Policies and practices for patients, pharmacies, providers, and EDs.					■
Complications and comorbidities in the aging SCD population: • What are the patterns in complications and comorbidities in the aging SCD population by patient variables (e.g., genotype, race, geography)? • What complications are predictive of mortality in different age groups? • What complications are associated with pregnancy? • What are the patterns in complications for women from pre- to post-menopause?	Practice recommendations for primary and specialty care of adults	■	■	■	■	■

The convening stakeholders identified a wealth of relevant research questions that, given capacity and funding, Georgia SCDC would like to address. Analysis topics not put in the first tier for the three-year plan, but deemed important and doable with SCDC data, are listed below.

Utilization

- Are there patterns of complications associated with higher utilization/mortality? What factors are associated with hospital readmissions? What factors are associated with use of multiple emergency departments or multiple health systems? Are there early signs of complications that could inform patient self-care practices? Can we identify people who are at high risk for preventable, poor outcomes?

- What is the cost-effectiveness of treating SCD patients in a day hospital setting? Are there differences in morbidity/mortality by usual care setting or by access (cost/coverage) to specialists; to a comprehensive care center; to behavioral health care? Are there differences in utilization (ED, hospital, preventive services) by type of primary SCD provider (specialist or generalist)? Do those frequently using the ED have a primary source of SCD care?
- Are there differences in utilization types/frequencies by geographic distance? Does distance contribute to use of ED vs outpatient care? Are there SCD patients not seen regularly or unable to keep appointments for whom distance or transportation might be a key barrier?

Other

- Describe the overall cost burden of SCD. How does cost vary by patient demographics? What is the long-term cost-benefit of investment in preventive strategies? Describe ER cost-effectiveness to support the need for enhanced outpatient services. Can ED visits be mitigated through improved case management? Should payment be tied to outcomes?
- What are the trends over time in providers' adherence to recommended practices? Are there commonly used treatments that are not associated with better outcomes? Do new treatments have long-term implications for mortality and other outcomes?
- How is it best to manage the needs of dual beneficiaries?

Appendix A: Organizations Represented by Convening Attendees

A representative invitee list was initially developed by the design team. If invitations were declined, invitees were encouraged to refer others from their organization in order to achieve balance and ensure that representative stakeholders were present at each working table.

A total of 49 stakeholders, representing 24 different organizations, participated in the convening. Stakeholders attending the May 11, 2017, Sickle Cell Stakeholder Convening in Atlanta were roughly evenly representative of three broad categories: those directly affected by SCD (e.g., patients, caregivers, and representative community-based organizations), providers (e.g., outreach workers, clinic nurses, primary care, ED physicians, and pediatric and adult hematologists), and decision makers/decision informers (e.g., health services researchers, health communicators, public health personnel, payers, research funders, and legislators). The list of represented organizations follows.

- Alliant Quality
- Amerigroup/Anthem
- Association of University Centers on Disabilities
- Augusta University
- Bioverativ
- CDC
- CDC Foundation
- Children's Healthcare of Atlanta
- East Central Regional Hospital
- Emory University
- Georgia Department of Public Health
- Georgia Health Policy Center, Georgia State University
- Georgia House Budget and Research Office
- Georgia House of Representatives (Budget and Research Office)
- Georgia Southern University, College of Public Health
- Global Blood Therapeutics
- Grady Health System
- Medical College of Georgia, Augusta University
- Peach State Health Plan
- Pfizer
- Sickle Cell Awareness Ride
- Sickle Cell Community Consortium
- University of Maryland, School of Medicine
- WellCare of Georgia Inc.

Discussion at the convening surfaced additional stakeholders whose participation should be sought. These stakeholders categorically include:

- AARP
- American Society of Hematology
- Cultural liaisons
- Ga Department of Community Health
- Ga Department of Human Services
- Faith-based community
- Hospital association
- Immigrant and refugee community
- Legislators from the Health and Human Services and appropriations committees
- Media and celebrities
- Medical students and other emerging professionals
- Mental health community
- Palliative care community
- Patient advocacy (national representatives)
- Primary care
- Rural area representatives
- Social workers and case managers
- Sororities and fraternities

Appendix B: Undistilled Georgia SCDC Priorities Identified by Convening Attendees

	Geography	Health System Design	Insurance	Utilization	Appropriate level of care	Return on investment	Outcomes	Utilization	Recommendations	Opioid Rx	Disparity
	Access				Cost			Quality			
Affected Populations	Target: Education for patients/families on transition planning Target: Education of school nurses/university student health centers			Educate: About appropriate acuity of care to seek for various clinical scenarios Educate: About record-keeping and communicating with non-usual care physicians	Target: Materials/staff training for patients on SCD basics and appropriate use of health care at EDs where there is high utilization or a number of individual high-utilizers	Educate: On best practices for self-care and prevention Target: High-incidence areas for Trait education and screening Study: Biggest health concerns/lessons for transitioning youth to inform self-care practices	Study: Early signs of complications to inform patient self-care practices Study: Who is at high risk of preventable, poor outcomes to inform patient self-care practices		Decide: Self-care and self-advocacy practices based on what to expect - most common complications by age, sex, genotype		
Health Systems	Target: Workforce/hiring decisions based on ratio of patients to hematologists by geography Decide: Location and hours of clinics, referral strategies based on distance patients drive to access care in outpatient clinics	Decide: Inform location of specialty clinics and establishment of telehealth capabilities based on access to care facilities across the acuity spectrum Target: Outreach/case management capacity in areas of need/service shortage	Target: Transition-age patients with benefits counseling	Study: Do outcomes vary by setting of short-term crisis management?	Decide: Allocation of outpatient resources/hours based on the most frequent presenting reasons for ED visits/ hospitalizations		Decide: Case management based on most-preventable readmissions		Decide: Establish criteria for or use data to justify Center of Excellence status or other recognition for excellent SCD care	Study: Medication adherence	Decide: Resource allocation to address greatest disparities in outcomes - by race, geography, insurance, other

	Geography	Health System Design	Insurance	Utilization	Appropriate level of care	Return on investment	Outcomes	Utilization	Recommendations	Opioid Rx	Disparity
Payers	Target: Contracts to ensure in-network care options for all ages, needs, acuities are available within reasonable geographic distance	Target: Education of non-specialist providers, if specialists are not in close proximity	Target: Appropriate referrals and benefits counseling for transition-age patients	Decide: Need for enhanced outpatient services based on ER cost-effectiveness Target: Case management to those unable to access the appropriate acuity of care Target: Patients without usual care for referral, case management	Target: Education for providers whose patients are higher utilizers of emergency departments		Decide: Case management based on stats about preventable readmissions		Decide: Establish quality measures associated with evidence-based practice		
Policymakers	Decide: Planning and resource allocation based on prevalence distribution for different ages of SCD population. Do certain areas need to plan for transition-age, older SCD patients? Identify areas likely to need other social services, supports, outreach, transportation. Target: Outreach to cultural, language, and documentation status demographics	Decide: Incentivize workforce development based on provider/patient gaps	Decide: Over-age coverage extensions based on transition-age needs, outcomes, costs Target: Benefits counseling and referral for parents of newborns, transition-age patients and adult patients								

	Geography	Health System Design	Insurance	Utilization	Appropriate level of care	Return on investment	Outcomes	Utilization	Recommendations	Opioid Rx	Disparity
Providers	Target: Education of emergency physicians, primary care providers, ob/gyns in high-prevalence areas	Educate: Inform referral strategies. Where are specialist SCD care providers located?			Educate: Improve discharge/self-care planning with patients based on the most frequent presenting reasons for ED visits and hospitalizations Target: Education of providers in areas with more frequent ED utilizers	Educate: Improve uptake of best practices in preventive care, based on stats on preventive care and consequences Target: Education strategies based on areas of practice where standards are least followed					

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- Christine Grosso, M.S., public policy analyst, Association of University Centers on Disabilities (Silver Spring, Md.)
- Mandip Kaur, M.P.H., health communications specialist, CDC Foundation (Atlanta)
- Dena Smith, communications specialist, Center for Leadership in Disability, Georgia State University (Atlanta, Ga.)
- Angie Snyder, Ph.D., M.P.H., research assistant professor and director of health policy and financing, Georgia Health Policy Center (Atlanta, Ga.)

SCDC
Sickle Cell Data Collection

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