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

Georgia Health Policy Center

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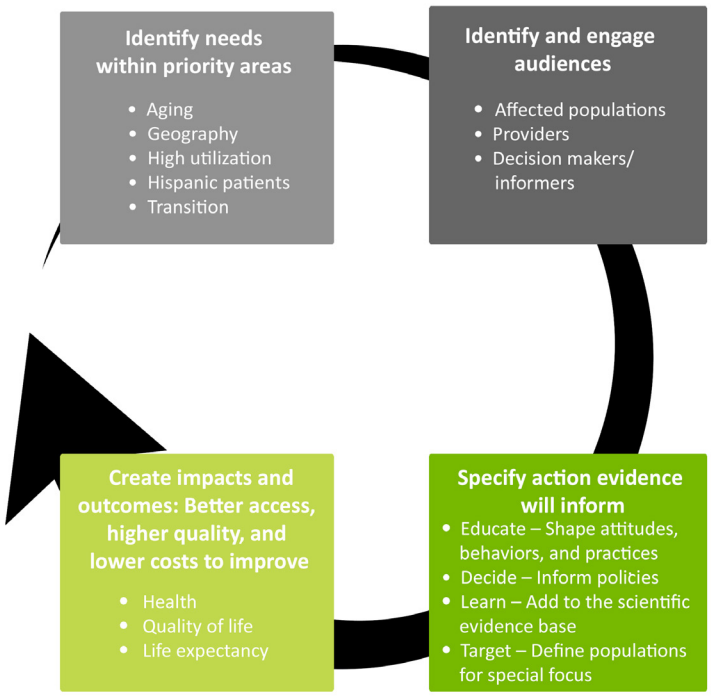
Three-Year Dissemination and Analysis Plan for Georgia

Sickle cell disease surveillance in Georgia

Over the past several years, Georgia has built a robust set of sickle cell disease (SCD) surveillance data for the purpose of developing and disseminating scientific evidence to inform policies and practices that will improve the health, quality of life, and life expectancy of individuals with SCD. This comprehensive dataset, which will soon include years 2004 through 2016, is built from newborn screening and vital records; Medicaid, Children's Health Insurance Program, and State Health Benefit Plan administrative claims; hospital and emergency department (ED) discharge records; and limited clinical variables from Georgia's three comprehensive SCD centers. This data enables detailed statistics and longitudinal, patient-level studies of diagnosis, demographic, geographic, and health care utilization for more than 10,000 patients over 13-plus years.

Three-year plan development

The Georgia Health Policy Center conducted a multistage process to develop a three-year analysis and dissemination plan to guide use of the SCD surveillance data (Figure 1). Priority areas identified by national stakeholders served as a starting point. A Design Team representing diverse SCD stakeholder groups — affected populations, providers, and decision makers/ informers — helped in planning a daylong convening. The 49 convening participants came from 24 different organizations across Georgia and beyond.



The convening produced an extensive array of potential study needs and dissemination actions. These were compiled and distilled with the help of the Design Team.

Priorities were selected as being feasible, high-leverage uses of the data, and actionable based on needed changes identified by the patient and provider communities.

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The tables below summarize the three-year plan. The full Sickle Cell Data Collection Program (SCDC) report is available at http://ghpc.gsu.edu/download/sickle-cell-data-collection-program-report/.

Dissemination opportunities by target audience and priority area Applications of Georgia SCDC data that are actionable and feasible in 2017-2020	Aging	Geography	Hispanic	Transition	Utilization
Affected Populations					
Target patient materials on use of health systems in regions with high utilization					
Target patient and family education in regions with high mortality or complications					
Target high-incidence areas for trait education and screening					
Target culturally, linguistically, and topically appropriate outreach based on demographics by region					
Health Systems					
Target outreach and case management capacity based on service shortage, especially to ensure follow-up					
Allocate outpatient resources and hours based on prevalent reasons for ED visits and hospitalizations					
Decide location and hours of clinics/telehealth based on accessibility of care across the acuity spectrum					
Payers					
Decide quality measures to reflect evidence-based practices					
Target transition outreach on healthy behaviors, insurance benefits, and referrals based on geography by age					
Ensure provider contracts create care options for all ages, needs, and acuities in reasonable time and distance					
Policymakers					
Allocate relevant social service to areas with high births, transition-age, and aging populations					
Decide provider workforce incentives to reduce provider-patient gaps by geography					
Target benefits counseling and referrals by geography of births, transition-age, and aging populations					
Providers					
Target ED, primary care, OB/GYN, and hospitalist education by geography of patient population and need					
Decide referral strategies based on location of specialists and SCD care providers					
Adapt culturally, linguistically, and topically appropriate provider education based on patient demographics					

Research Follow-up per findings, advances, resources, and stakeholder input	**Actions** Informed by findings				
Pediatric to adult transition: How complication and utilization patterns across transition relate to insurance status, age, race, and geography	Insurance and other transition-supportive policies				
Pain treatment and opioids: Prescribing and filling patterns; treatments associated with lower opioid prescribing; effect of mental health services	Policies and practices for patients, pharmacies, providers, EDs				
Aging: Complications and comorbidities by race, geography, genotype, pregnancy, menopause transition, and mortality by age group	Practice guidance for adult primary and specialty care				

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SCDC
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