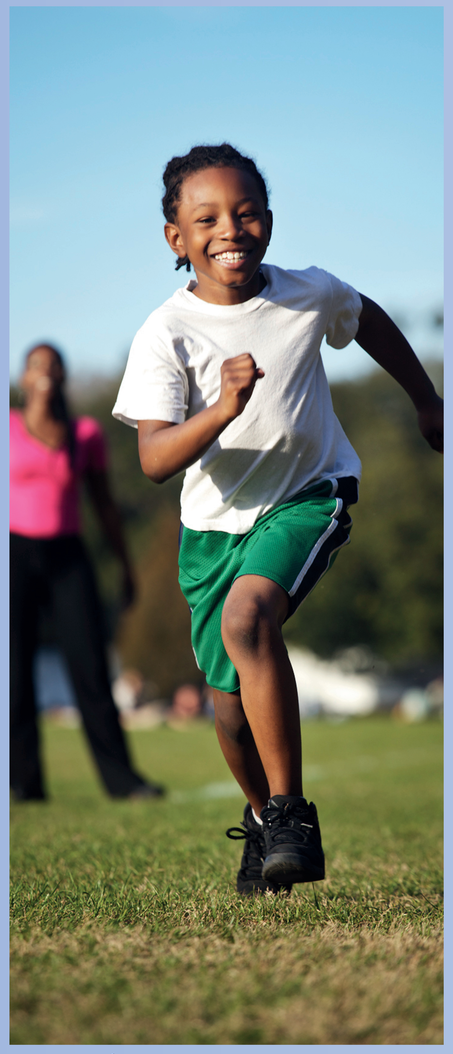
Constructing a Georgia Surveillance System for Hemoglobinopathies Using Multiple Data Sets: *The First Step towards a Comprehensive Prevention and Service Delivery Strategy*

*Angela Snyder, Ph.D., M.P.H ; Mei Zhou, M.S.; Jane Branscomb, M.P.H**

Georgia Health Policy Center



RESEARCH OBJECTIVE

To construct a hemoglobinopathy surveillance system to determine the annual incidence and five-year prevalence (2004-2008) of hemoglobinopathies in Georgia and to describe the demographics of the populations living with these disorders.

STUDY DESIGN

The surveillance system of hemoglobinopathy combines data from five data sources: (1)State Newborn Screening Program (NBS); (2)Georgia hospital discharge file, including most in-patient and emergency room visits in the state; (3) Grady, CHOA and GHSU health systems, including all outpatient visits; (4) State Medicaid and CHIP programs; and (5) State Health Benefit Plan (SHBP). Laboratory screening and confirmatory results, coupled with clinical expertise, are used to confirm cases from NBS, Grady, CHOA and GHSU data. ICD-9, CPT and NDC codes are used to identify probable and possible cases from additional administrative datasets.

A probabilistic matching method is adopted to merge all datasets and remove duplicate records. Each data source contains different data elements that can be used to link the records. Variables used in linking include but are not limited to patient's name, date of birth, sex, county, zip code, mother's name, phone number, and address. Records are compared on each of the specified variables and a weight is generated for each potential match to reflect the strength of agreement.

POPULATION STUDIED

Individuals with clinical or laboratory indication of sickle cell disease who lived in Georgia between 2004 and 2008.

PRINCIPAL FINDINGS

From 2004 through 2008, 829 newborns screened positive for a sickle cell disorder in Georgia with 85 percent of them having a confirmed diagnosis (Figure 1). Slightly over half of the newborns were diagnosed with SS or S Beta Zero Thalassemia and about one quarter Sickle C disease. Using newborn screening data from 2004 through 2008 (Figure 2), we identified the counties with the highest number of incident cases. Most cases are found in the five metro Atlanta counties (Fulton, DeKalb, Cobb, Gwinnett and Clayton) as well as the smaller metropolitan areas in South and Southeastern Georgia.

Figure 1: Incident cases of sickle cell disease by genotype

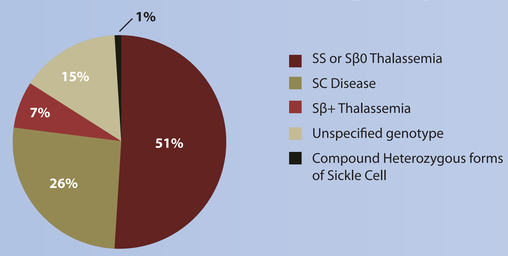
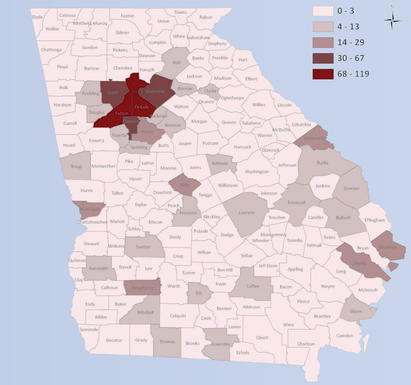
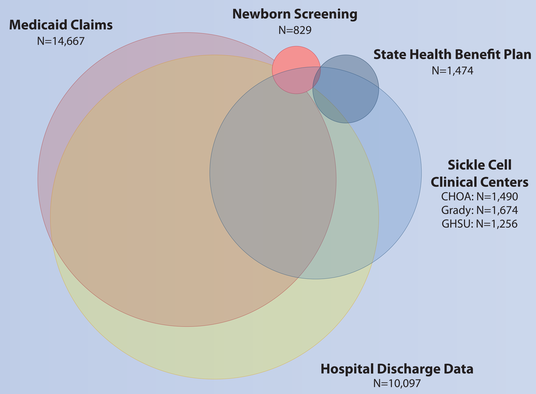


Figure 2: Georgia newborns screening positive for sickle cell disease, January 2004 through December 2008



During that same time period, CHOA treated approximately 1,490 pediatric patients with a hemoglobin disorder, and Grady and GHSU treated approximately 1,674 and 1,256 patients, respectively. Medicaid and CHIP programs paid claims for approximately 14,667 enrollees with a hemoglobinopathy-associated medical encounter, while the SHBP covered such services for 1,474 enrollees. Lastly, close to 10,097 individuals were treated in a Georgia emergency room or hospital for a hemoglobinopathy (Figure 3).

Figure 3: Overlap between health insurance claims data and Georgia hospital discharge data



We find 4,443 unique individuals (1,795 adults and 2,646 children) treated for a hemoglobinopathy in Georgia from 2004 through 2008 when merging all clinical and NBS data. More than 97 percent of these individuals have a confirmed diagnosis. We find 20,939 possible cases when merging the administrative datasets: Medicaid, SHBP, and Hospital discharge data with 36 percent of the Medicaid members overlapping with the hospital discharge file and 52 percent of the individuals identified through hospital discharge data overlapping with Medicaid. Twenty-one percent of the SHBP members were also found in the Hospital discharge file. While the next step is to merge and deduplicate the clinical and administrative data sets, we estimate that up to 47 percent of the individuals identified through state hospital discharge data may also be present in one of the three clinical systems.

CONCLUSIONS

The new surveillance system of hemoglobinopathies provides first hand estimates of the prevalence and geographic profile of the diseased population in Georgia. It can also be exploited to test the validity of using administrative data for health services research of sickle cell disease. This type of surveillance system is essential for the Georgia Department of Public Health to craft an effective service delivery strategy to a targeted population and prevent associated complications and healthcare utilization which may arise from unmanaged disease.

IMPLICATIONS FOR POLICY, DELIVERY OR PRACTICE

Early outcomes from this project have allowed us to identify areas to focus hemoglobinopathy prevention and outreach efforts. Further progress will allow us to answer programmatic, policy, and research questions specific to Georgia, and aid in the development of educational materials for providers, policy-makers and legislators. Lessons learned can be shared with other states interested in developing similar surveillance systems and shared with the health services research community who typically use administrative data for epidemiologic research.

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Georgia RuSH Collaborative:
Angela Snyder, PhD, MPH - Georgia Health Policy Center, Georgia State University
Sharon Quary, MS - Newborn Screening Unit, Georgia Department of Public Health
James Eckman, MD - Georgia Comprehensive Sickle Cell Clinic, Grady Memorial Hospital
Peter Lane, MD - Sickle Cell Disease Program, Children's Healthcare of Atlanta
Robert Gibson, PhD, MSOTR/L - School of Allied Health Sciences, Georgia Health Sciences University
Jackie George, MPH; Janeth Spurlin; Beverly Sinclair - Sickle Cell Foundation of Georgia, Inc.
Mei Zhou, MS; Holly Avey, PhD, MPH; Jane Branscomb, MPH; Lillian Haley, PhD, MSW - Georgia Health Policy Center, Georgia State University

For more information, contact the Georgia Health Policy Center at 404.413.0314 or visit us online at www.gsu.edu/ghpc.

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