

**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, 8,299 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 Sβ0 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 newborns identified as having Sickle C disease. This type of surveillance system is essential for the Georgia Department of Public Health to craft an effective service delivery system to target the population and prevent associated complications and healthcare utilization which may arise from unmanaged disease.

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