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Contributions to Surveillance by Dataset

Georgia Health Policy Center

Georgia PHRESH Findings

Public Health Research Evaluation and Surveillance for Hemoglobinopathies

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Contributions to Surveillance by Dataset

The first priority of the Registry and Surveillance for Hemoglobinopathies (RuSH) project was to determine the number of people with sickle cell disease living in Georgia during the five-year period, 2004-2008. To identify cases, we used data from seven sources: Georgia's Newborn Screening program; the comprehensive sickle cell centers at Georgia Regents University (GRU), Grady Health System, and Children's Healthcare of Atlanta (CHOA); and administrative claims data from Georgia's Medicaid/CHIP program, State Health Benefit Plan (SHBP), and the Georgia Hospital Association. Datasets were examined individually to identify cases, which were then matched against those identified from other sources for de-duplication and linking. This entailed numerous iterations and matching algorithms. Using CDC's RuSH case definition, we classified cases as Level 1 (confirmed), Level 2 (probable), or Level 3 (possible) sickle cell disease. The table below summarizes our results.

Sickle Cell Cases in Georgia Identified through RuSH, 2004-2008				
Data Set	Level 1	Level 2	Level 3	Level 1,2,3
Newborn Screening	730	98	0	828
GRU (clinic)	1,218	14	0	1,232
Grady (clinic)	1,661	2	0	1,663
CHOA (clinic)	1,908	242	427	2,577
Medicaid/CHIP	2,986	1,993	6,510	11,489
State Health Benefit Plan	209	215	598	1,022
Hosptial administrative data	3,339	2,147	3,230	8,716
De-duplicated Total	**4,288**	**3,011**	***9,208**	**16,507**

*Plus 77 vital records with an ICD-10 code of D57 included as an underlying cause of death.

Georgia requires all newborns in the state to be screened for sickle cell disease. Those with positive screening results are contacted for confirmatory testing. Eighty-eight percent of the 828 newborns who screened positive for sickle cell disease from 2004-2008 had a documented confirmatory diagnosis. These 730 newborns met the Level 1 case definition; while 98 with positive screens but no confirmatory test were categorized as Level 2. Case matching revealed that roughly 80 percent of newborns who screened positive for sickle cell disease were later seen at one of Georgia's two pediatric sickle cell centers.

The comprehensive sickle cell centers contributed the remainder of the Level 1 cases. Using patient registry data, Grady and GRU contributed 1,661 and 1,218 confirmed cases respectively. Additionally, Grady contributed two and GRU contributed 14 Level 2 cases of sickle cell disease with an unknown genotype. Using administrative data augmented by lab and patient records, CHOA identified 1,908 Level 1 cases. The remaining 242 Level 2 and 427 Level 3 cases came from administrative data collected from CHOA's clinic and hospital sites.

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Whereas the data sources described thus far provide excellent clinical and diagnostic information, administrative datasets offer abundant information on health care utilization, but less certainty regarding diagnosis. The Medicaid/CHIP, SHBP, and hospital discharge data alone can only add new cases in Levels 2 and 3. The final matched, merged, and de-duplicated dataset is rich with both diagnostic and health care utilization data, as roughly 70 percent of the 4,288 Level 1 cases were found in Medicaid/CHIP claims data; 78 percent in hospital/ER discharge data; and 5 percent in SHBP data.

The Medicaid/CHIP dataset added the largest number of Level 2 and 3 cases (1,993 and 6,510, respectively). To meet the Level 2 definition, cases must show repeated sickle cell disease diagnostic codes as well as health care utilization consistent with the disease. The Level 3 definition has a lower standard, including codes for sickle cell trait and health care utilization consistent with sickle cell disease. It is likely that most Level 3 cases indeed are sickle cell trait rather than disease, although there could be some miscoded cases here as well.

Hospital/ER discharge data added 2,147 Level 2 cases and 3,230 Level 3 cases to the surveillance dataset. Of Level 2 additions, 765 did not overlap with Medicaid/CHIP or SHBP, likely representing individuals who had emergency or inpatient encounters during the study period and were either uninsured or had private insurance or Medicare.

The SHBP data contributed another 215 Level 2 cases and 598 Level 3 cases. SHBP is this project's only source of health care utilization data for privately insured patients. As the state is one of the largest employers in Georgia with more than 600,000 covered lives in 2008, this data represents approximately 11 percent of the state's privately insured. From a comparison of SHBP to Medicaid/CHIP cases and a separate analysis of our Hospital/ER discharge data by payer, we estimate that close to two-thirds of those with sickle cell disease in Georgia received public coverage at some point during the study period.

In total, we identified 4,288 confirmed and 3,011 probable cases of sickle cell disease in Georgia from 2004-2008. This is consistent with previous estimates for Georgia, which range from 4,981 to 8,427 depending on the methodology.[1] Linking data from seven sources, we found an additional 9,208 cases categorized as possible sickle cell disease.

Georgia is extending RuSH efforts through the Public Health Research, Epidemiology, and Surveillance of Hemoglobinopathies (PHRESH) project by performing validation studies of the CDC case definition and examining the use of prevention strategies recommended for sickle cell patients. These investigations are possible using our unique dataset that links health care utilization variables to cases with confirmed sickle cell disease diagnosis.

[1]Hassell, K. L. (2010). Population estimates of sickle cell disease in the US. American Journal of Preventive Medicine, 38(4), S512-S521.

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