CDC's Sickle Cell Disease Surveillance History

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

Accessible version: https://www.cdc.gov/ncbddd/hemoglobinopathies/surveillance-history.html

The Centers for Disease Control and Prevention (CDC) and participating states began sickle cell disease (SCD) surveillance (monitoring) in 2010. SCD surveillance involves collecting information on diagnoses, treatment, and healthcare access for people with SCD in the United States. CDC and participating states developed many educational materials based on this information.

CDC coordinated these efforts as part of the two projects outlined below. Both used similar data sources, but each had a different funding source and amount. These differences influenced the number of participating states.

	Registry and Surveillance System for Hemoglobinopathies (RuSH)	Public Health Research, Epidemiology, and Surveillance for Hemoglobinopathies (PHRESH)
Duration	2010—2012	2012—2014
Participating states	CA, FL, GA, MI, NY, NC, and PA	CA, GA, and MS
Funding source	Interagency agreement between National Institutes of Health, National Health Lung, and Blood Institute, and CDC's Division of Blood Disorders	Various CDC funding sources
Funding amount	2 year project totals: $1,100,000 per state	2 year project totals: MS: $250,000 GA: $420,000 CA: $748,000
Purpose	To identify and collect data on people living with a SCD or thalassemia diagnosis in the participating states	CA and GA: To evaluate, validate, and release data collected during the RuSH project MS: To identify and collect data on people living with SCD in the state
Years of data	2004—2008	2004—2008
Data sources	• Newborn screening • Vital records (birth and death records) • Hospital discharge • Emergency room • Clinical records • State Medicaid claims	• Newborn screening • Vital records (birth and death records) • Hospital discharge • Emergency room • Clinical records • State Medicaid claims
Accomplishments	• Fact sheets for the public and health providers that increase knowledge about SCD, thalassemia, and the main findings of the RuSH project • Medscape Commentary • Strategies from the Field: Health Promotion • Strategies from the Field: Data Collection • Published peer-reviewed articles*	• Data Validation Report (available upon request) • Thalassemia fact sheet • Survey of Provider Information Needs • Sickle Cell Disease Treatment: Important Information for Patients and Health Care Providers • Hydroxyurea Use and Measurement • Published Peer-reviewed articles*

*See list of peer-reviewed articles on back.

Published peer-reviewed articles

RuSH

- Wang Y, Kennedy J, Caggana M, Zimmerman R, Thomas S, Berninger J, Harris K, Green NS, Oyeku S, Hulihan M, Grant AM, Grosse SD. Sickle cell disease incidence among newborns in New York State by maternal race/ethnicity and nativity. Genet Med. 2013 Mar;15(3):222–8.

- Paulukonis ST, Harris WT, Coates TD, Neumayr L, Treadwell M, Vichinsky E, Feuchtbaum LB. Population based surveillance in sickle cell disease: methods, findings and implications from the California registry and surveillance system in hemoglobinopathies project (RuSH). Pediatr Blood Cancer. 2014 Dec;61(12):2271–6.

- Hulihan MM, Feuchtbaum L, Jordan L, Kirby RS, Snyder A, Young W, Greene Y, Telfair J, Wang Y, Cramer W, Werner EM, Kenney K, Creary M, Grant AM. State-based surveillance for selected hemoglobinopathies. Genet Med. 2015 Feb;17(2):125–30.

- Wang Y, Liu G, Caggana M, Kennedy J, Zimmerman R, Oyeku SO, Werner EM, Grant AM, Green NS, Grosse SD. Mortality of New York children with sickle cell disease identified through newborn screening. Genet Med. 2015 Jun;17(6):452–9.

PHRESH

- Neunert CE, Gibson RW, Lane PA, Verma-Bhatnagar P, Barry V, Zhou M, Snyder A. Determining Adherence to Quality Indicators in Sickle Cell Anemia Using Multiple Data Sources. Am J Prev Med. 2016 Jul;51(1 Suppl 1):S24–30.