

## CDC's Sickle Cell Disease Surveillance: Overview

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### Gaps in Knowledge about SCD

- How many people have SCD in the US?
- Which doctors provide care for SCD?
- What does healthcare utilization for SCD look like?
- Does comprehensive healthcare improve health outcomes?
- What health issues are most common in adults with SCD?
- What are the causes of death for patients with SCD?



## Why are there Gaps in Knowledge?



Lack of national data collection



Clinic based



Administrative data based

## Past SCD surveillance programs



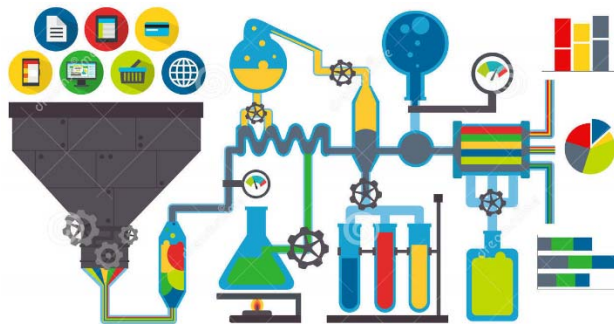
**PHRESH**  
PUBLIC HEALTH RESEARCH - EPIDEMIOLOGY - SURVEILLANCE  
OF HEMOGLOBINOPATHIES

## Current SCD surveillance program

- Sickle Cell Data Collection (SCDC)
- Objective: Collect, synthesize and disseminate multi-source, population-based, longitudinal data for people with sickle cell disease (SCD)
  - Establish a health profile of the SCD population
  - Track changes in SCD outcomes over time
  - Ensure credible, scientifically sound information to inform standards of care
  - Inform policy and health care practices
- Goal: Improve quality of life, life expectancy, and health among those living with SCD

## SCDC Data Sources

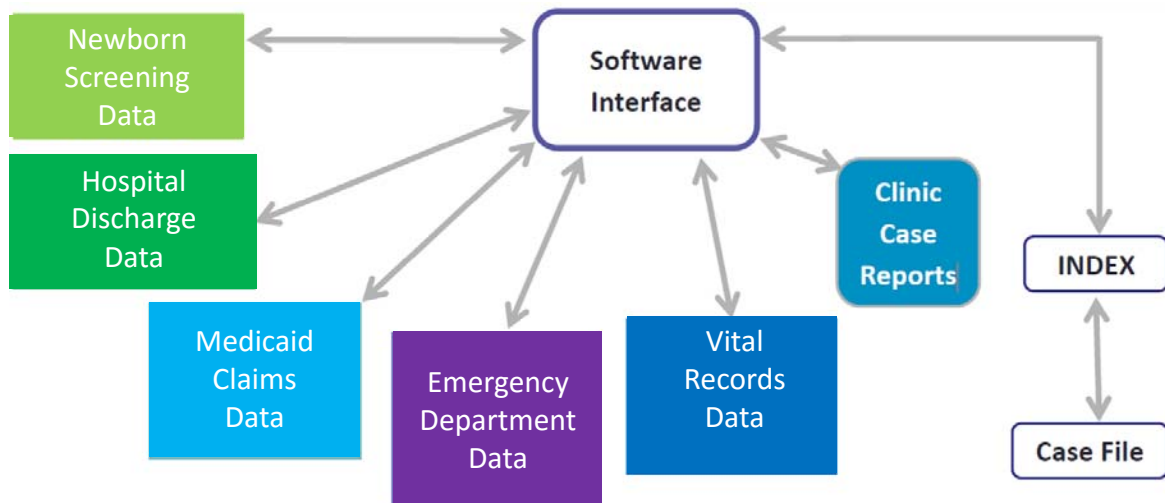
- Newborn screening
- Medicaid
- Death records
- Hospital discharge
- Emergency department
- Ambulatory surgery
- State Health Benefit Plan
- Immunization registry
- Cancer registry
- Community Based Organizations
- Clinical centers



## SCDC Case Definition

- Confirmed Cases
  - Laboratory confirmed SCD genotype
    - Newborn screening
    - Comprehensive sickle cell centers
- Probable Cases
  - Screening test or clinical determination only
    - Newborn screening
    - Comprehensive sickle cell centers
  - 3 or more healthcare encounters with SCD code in 5 years
    - Hospital/ER discharge data
    - Medicaid
- Possible Cases
  - 1 or more healthcare encounters with SCD code in 5 years

## SCDC Infrastructure



## SCDC Contents

- California and Georgia
- Statewide, population based, 2004-2016 data
- Individual level with identifiers
  - Collected and maintained by state partners
- ~12,000 – 15,000 patients = 12-15% of US SCD population

## What Happens to These Data?

- Our aims are to improve quality of care, health and life for those with SCD
- To accomplish that we support all who need it with useful information at an appropriate level of detail (for the audience, for privacy, etc.)
- We put out and amplify our useful information through:
  - Publication/Presentation
  - Health education
  - Outreach
  - Collaboration

## SCDC Stakeholders



## Health care providers, patients, public health

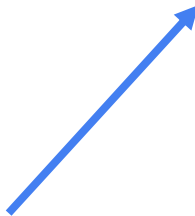


RESEARCH ARTICLE

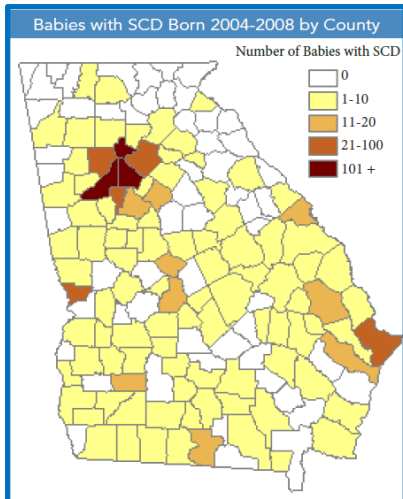
WILEY Pediatric Blood & Cancer aspho

Emergency department utilization by Californians with sickle cell disease, 2005–2014

Susan T. Paulukonis<sup>1</sup> | Lisa B. Feuchtbaum<sup>2</sup> | Thomas D. Coates<sup>3</sup> | Lynne D. Neumayr<sup>4</sup> |  
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## States, policy makers



### F.A.Q.

- How many people living with sickle cell disease are there in California?
- How many babies are born with sickle cell disease or sickle cell trait each year in California?
- Who cares for babies and children with sickle cell disease?
- Who cares for adults with sickle cell disease in California?
- What are the costs of care for sickle cell disease?

Send us your question.

Name

Email

Your Question \* (required)

## Researchers

**SCDC**

SICKLE CELL DATA COLLECTION

### Data Analysis Request

Name and Institute of person making request: Jane Smith

E-mail and phone number: Jane.Smith@anywhere.edu


Topic of Data Analysis: Uptake/Implementation of SCD Pediatric Standards of Care at the Institutional Level: Immunizations and Hydroxyurea

What is being requested? Analyses of CA Medicaid data to determine rates of Standards of Care Implementation by region and clinic type

How will these results be used? (choose all that apply)




- Peer-reviewed publication
- Legislative/policy activities
- Health education or communications materials
- Grant application or response to reviewers
- Abstract
- Information only
- Other (please specify) \_\_\_\_\_

**GEORGIA HEALTH POLICY CENTER**



**SICKLE CELL DATA COLLECTION PROGRAM: THREE-YEAR DISSEMINATION AND ANALYSIS PLAN FOR GEORGIA**

JUNE 2017

# Everyone

**Public Health Matters Blog**  
**Sickle Cell Disease Data Saves Lives**  
 Posted on October 10, 2017 by [Sally Hunsberger](#)

The American Medical Association (AMA) recently released a report of findings from a study of 1,000 patients with sickle cell disease (SCD) who were hospitalized in the United States. The study found that patients with SCD are hospitalized more often and for longer periods of time than other patients with chronic conditions. The study also found that patients with SCD are more likely to be hospitalized in the United States than in other countries. The study was conducted by researchers at the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH).

**What is sickle cell disease?**  
 Sickle cell disease is a genetic blood disorder that affects the shape of red blood cells. In people with SCD, the red blood cells are shaped like sickles instead of the smooth, round shape of normal red blood cells. Sickles do not flow smoothly through blood vessels. They can get stuck together and block blood flow, which can lead to pain, organ damage, and other complications.

**Identifying a Community Need**



How do the SCDC program begin and where is it located? ↗



What do we know about older patients living with SCD? ↗



Let's discuss experimental treatments for SCD anemia in clinical practice ↗



Important lessons to learn for people with SCD in acute dental care ↗



How can we get better on the SCD population to inform practice? ↗



How to select a new SCD clinic or care site in a new setting? ↗



What are the challenges related to recruiting a new team for the SCDC? ↗



How to reduce stress in a multi-specialist population for patients with SCD? ↗

### 5 FACTS YOU SHOULD KNOW ABOUT SICKLE CELL DISEASE

- A child gets sickle cell disease (SCD) when his or she receives two sickle cell genes\*—one from each parent.**  
 A child who inherits only one sickle cell gene has sickle cell trait (SCT). If both parents have either SCT or SCD, it is important for them to discuss this information with each other and with a doctor when making decisions about family planning.
- SCD has many faces.**  
 The disease affects millions of people worldwide and is especially common among people who come from and whose ancestors come from the following regions highlighted in red.
- SCD can be cured for certain patients.**  
 A bone marrow transplant, which involves replacing healthy cells from a donor whose immune system is stronger than the patient's, can cure SCD. However, a bone marrow transplant may not be the best choice for all patients because it comes with serious risks. A bone marrow transplant can also be performed on children, but it is a good choice for them.
- Anemia is a common effect of SCD, but it can be treated.**  
 Anemia occurs when there are not enough red blood cells in the body to carry enough oxygen throughout the body, causing anemia. Anemia or underdevelopment of the spleen, an organ that stores red blood cells, may make anemia worse. Blood transfusions are used to treat severe anemia.
- A person with SCD can live a long and high quality life.**  
 More than 90% of newborns with SCD in the United States will live to be adults. People with SCD can lower their chances of getting sick, live longer, and enjoy many normal activities by:
  - ✓ Getting regular checkups with their doctor.
  - ✓ Following treatment prescribed by their doctor, such as taking medication called hydroxyurea.
  - ✓ Following instructions by taking simple steps including washing their hands.
  - ✓ Practicing healthy habits like drinking 8 to 10 glasses of water per day and eating healthy food.

For more information about SCD, visit [www.cdc.gov/sicklecell](http://www.cdc.gov/sicklecell)

## SCDC Resources

- <https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html>
- <https://www.cdcfoundation.org/improving-lives-people-sickle-cell-disease>
- <http://casicklecell.org/index.php/Cadata/>
- <http://ghpc.gsu.edu/project/hemoglobin-disorders-data-coordinating-center/>



## SCDC Expansion

- Based on the Project ECHO model
- 2 year tele-mentoring based Training Institute
  - Led by CDC, Georgia, and California
  - Monthly didactic + information sharing sessions
  - Monthly homework and milestones
  - Bi-annual in-person meetings
- Ready to implement state-based SCD surveillance upon completion

## Proposed monthly sessions

- Building an SCDC team
- Partner identification and engagement
- SCDC data overview
- Data sources and data management
- Identifying and engaging with data source owners
- Working with Institutional Review Boards
- Data security
- Setting up data sharing agreements
- What does an SCDC data system look like?
- Data collection
- Data cleaning
- Linking across data sources
- De-duplicating
  - Within a single data source
  - Across multiple data sources
- Data warehousing
- Developing an SCDC data system

## Additional SCD Activities

- Understanding Transfusion Complications: <https://www.cdc.gov/ncbddd/hemoglobinopathies/blood-transfusions.html>
- CME/CNE Video Series: <http://ghpc.gsu.edu/cme/>
- Sickle Cell Trait Toolkit: <https://www.cdc.gov/ncbddd/sicklecell/toolkit.html>
- Personal Stories: <https://www.cdc.gov/ncbddd/sicklecell/stories.html>
- Factsheets and Infographics: <https://www.cdc.gov/ncbddd/sicklecell/materials/factsheets.html>
- National Resource Directory: <https://www.cdc.gov/ncbddd/sicklecell/map/map-nationalresourcedirectory.html>

**Thank you!**

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