National Center on Birth Defects and Developmental Disabilities

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

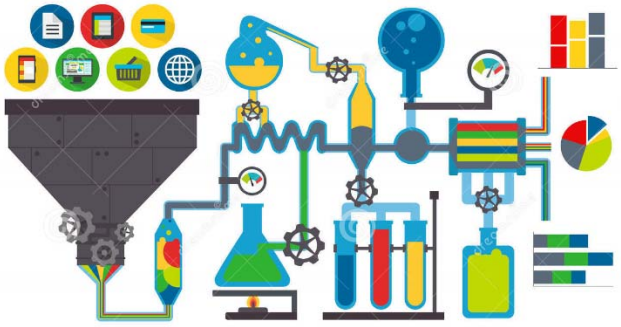
PUBLIC HEALTH RESEARCH • EPIDEMIOLOGY • SURVEILLANCE
OF HEMOGLOBINOPATHIES

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

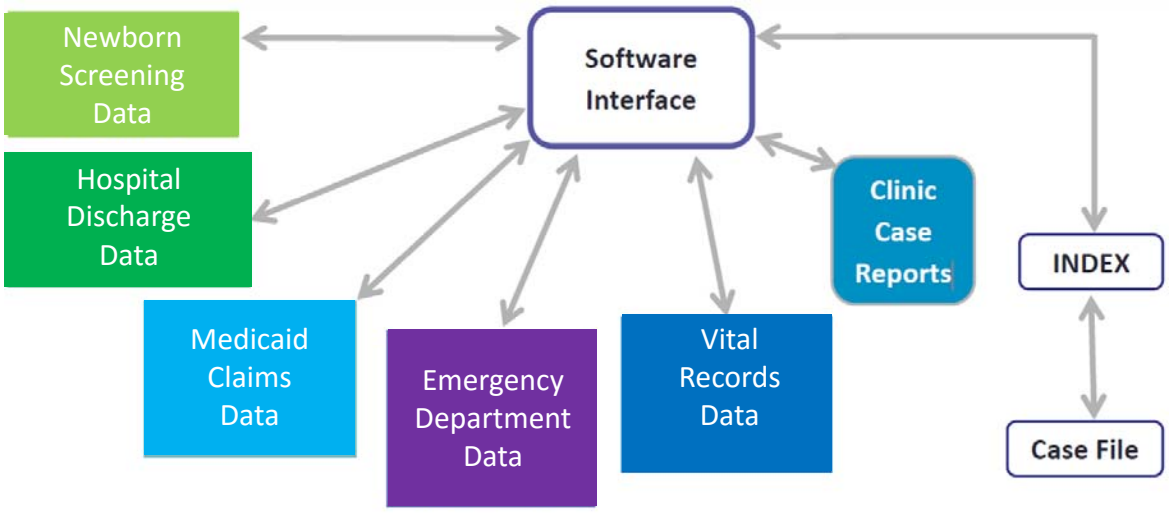
- Newborn screening
- Medicaid
- Death records
- Hospital discharge
- Emergency department
- Ambulatory surgery
- State Health Benefit Plan
- Immunization registry
- Cancer registry
- Community Based Organizations
- Clinical centers



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 Payers	States & Public Health	Health Care Providers
Researchers	Patients	Policy Makers
Federal Agencies	Foundations and Community Organizations	Private Partners

Health care providers, patients, public health

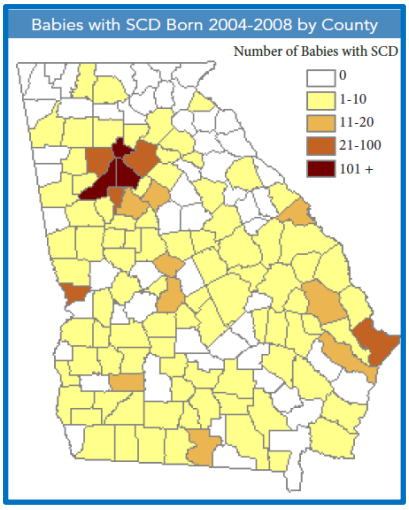
RESEARCH ARTICLE

WILEY Pediatric Blood & Cancer | aspho

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

Susan T. Paulukonis[1] | Lisa B. Feuchtbaum[2] | Thomas D. Coates[3] | Lynne D. Neumayr[4] | Marsha J. Treadwell[4] | Elliott P. Vichinsky[4] | Mary M. Hulihan[5]

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

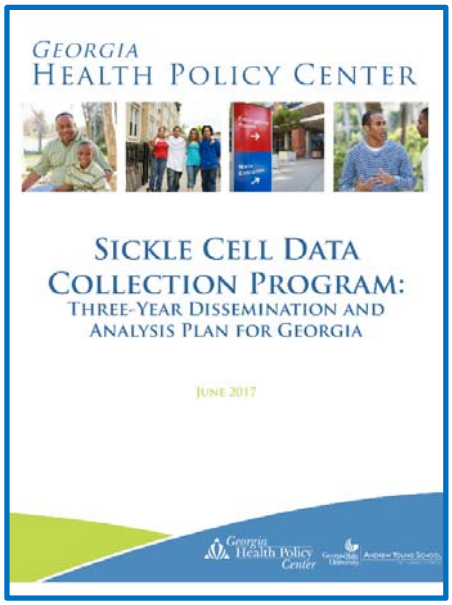
E-mail and phone number: Jane.Smith@anywhere.edu

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

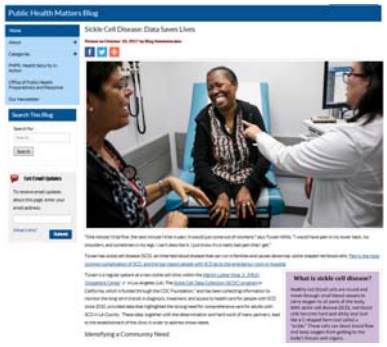
What is being requested? Analyses of CA Medicaid data to determine rates of Standards of Care implementation by region and clinic type

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) _____



Everyone



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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