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
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 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

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

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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

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

5 FACTS YOU SHOULD KNOW ABOUT SICKLE CELL DISEASE

A child gets sickle cell disease (SCD) when he or she receives two sickle cell genes—one from each parent.

A child who inherits only one sickle cell gene has sickle cell trait. Sickle cell trait does not cause any harm and is not a threat to the child’s health.

Sickle cell disease is a serious genetic disorder that affects the body’s ability to make healthy red blood cells.

Sickle cell disease can cause severe pain, weakness, fatigue, and organ damage, which can lead to complications such as strokes and organ failure.

Sickle cell disease affects millions of people worldwide and is especially common among people who come from and live in Africa and some other regions.

5 FACTS YOU SHOULD KNOW ABOUT SICKLE CELL DISEASE

Sickle cell disease can be cured for certain patients. A bone marrow transplant, which involves removing sickle cell disease from a donor and placing it into a sickle cell disease patient, can cure SCD. The procedure is risky and can have serious complications, but it can cure SCD for some patients.

Anemia is a common effect of SCD, but it can be treated. Its presence can cause early satiety and insufficient oxygen to reach the tissues throughout the body, making the person feel weakest.

A person with SCD can live a long and high-quality life. With proper care and management, people with SCD can live a full life, including attending school, participating in sports, and pursuing careers.

A person with SCD may need to live with pain, which can be managed with medications. It’s important for patients with SCD to work closely with their healthcare provider to find the right pain management plan.

Meeting the needs of people with SCD requires a multidisciplinary approach, including medical, psychological, and social support.

To learn more about sickle cell disease, visit SCDCinfo.org, which is designed to help people learn about sickle cell disease and its impact on patients and their families.
SCDC Resources

- https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html
- 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
Thank you!

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