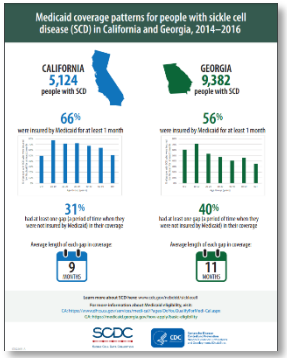
The Advisory Committee on Heritable Disorders in Newborns and Children

05/04/2023

Mary Hulihan, CDC/NCBDDD/DBD

SCDC Priorities



Data Collection

Policy

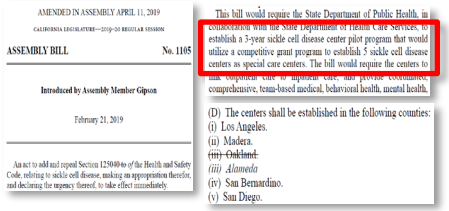
Data Use

SCDC

Sickle Cell Data Collection

Communications

Community Engagement



AMENDED IN ASSEMBLY APRIL 11, 2019

CALIFORNIA LEGISLATURE—2019–20 REGULAR SESSION

ASSEMBLY BILL No. 1105

Introduced by Assembly Member Gipson

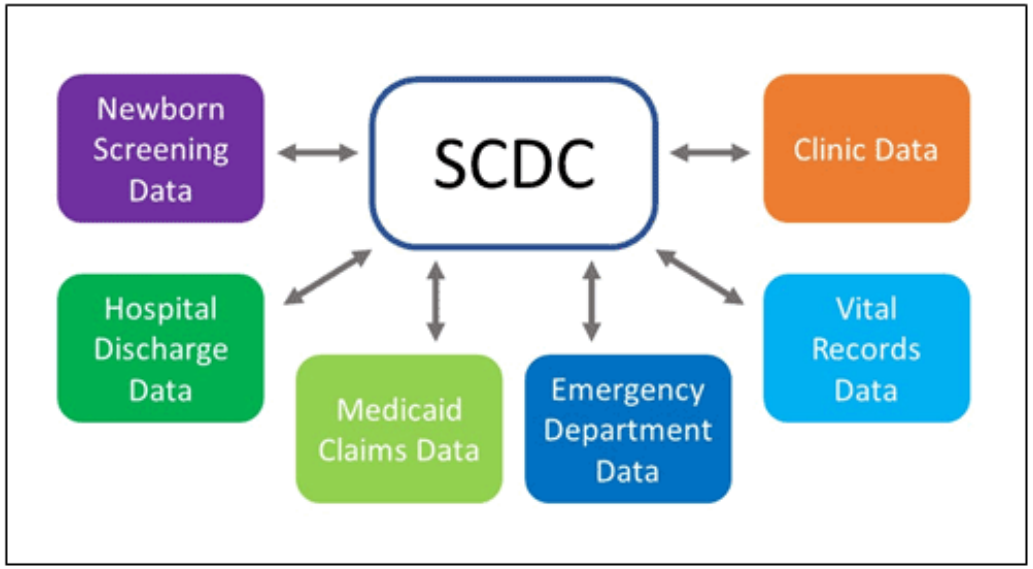
February 21, 2019

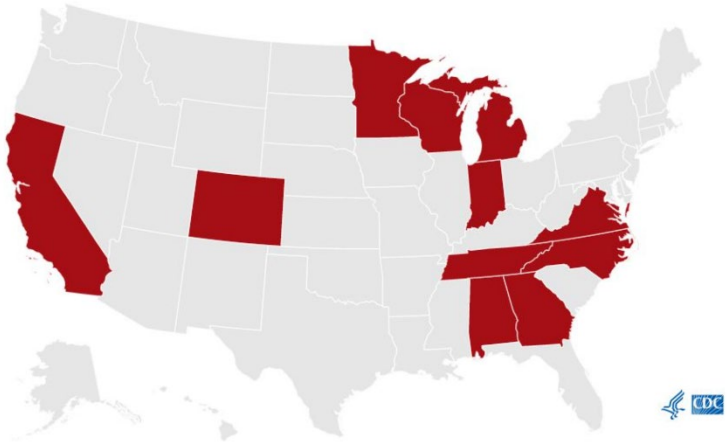
An act to add and repeal Section 125040 to of the Health and Safety Code, relating to sickle cell disease, making an appropriation therefor, and declaring the urgency thereof, to take effect immediately.

This bill would require the State Department of Public Health, in collaboration with the State Department of Health Care Services, to establish a 3-year sickle cell disease center pilot program that would utilize a competitive grant program to establish 5 sickle cell disease centers as special care centers. The bill would require the centers to link outpatient care to inpatient care, and provide coordinated, comprehensive, team-based medical, behavioral health, mental health,

(D) The centers shall be established in the following counties:
(i) Los Angeles.
(ii) Madera.
~~(iii) Oakland.~~
(iii) Alameda
(iv) San Bernardino.
(v) San Diego.

Current SCDC Data

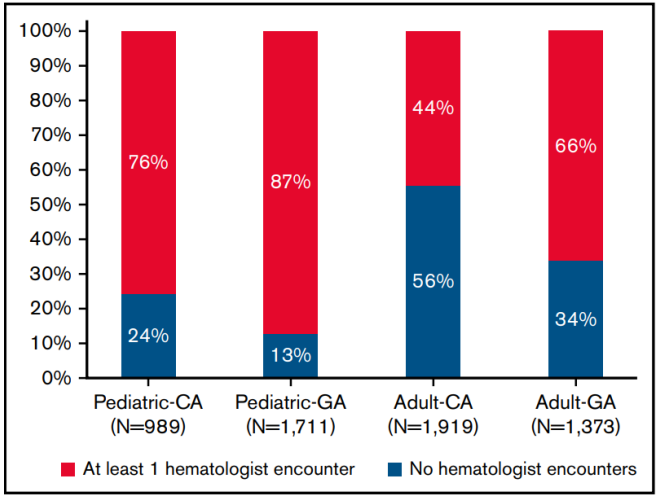




~36% of US SCD population

(based on US Census data)

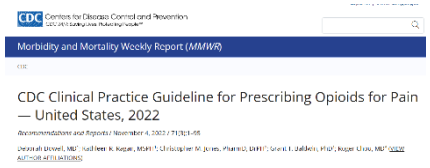
Why is Surveillance/Long Term Follow Up Important?



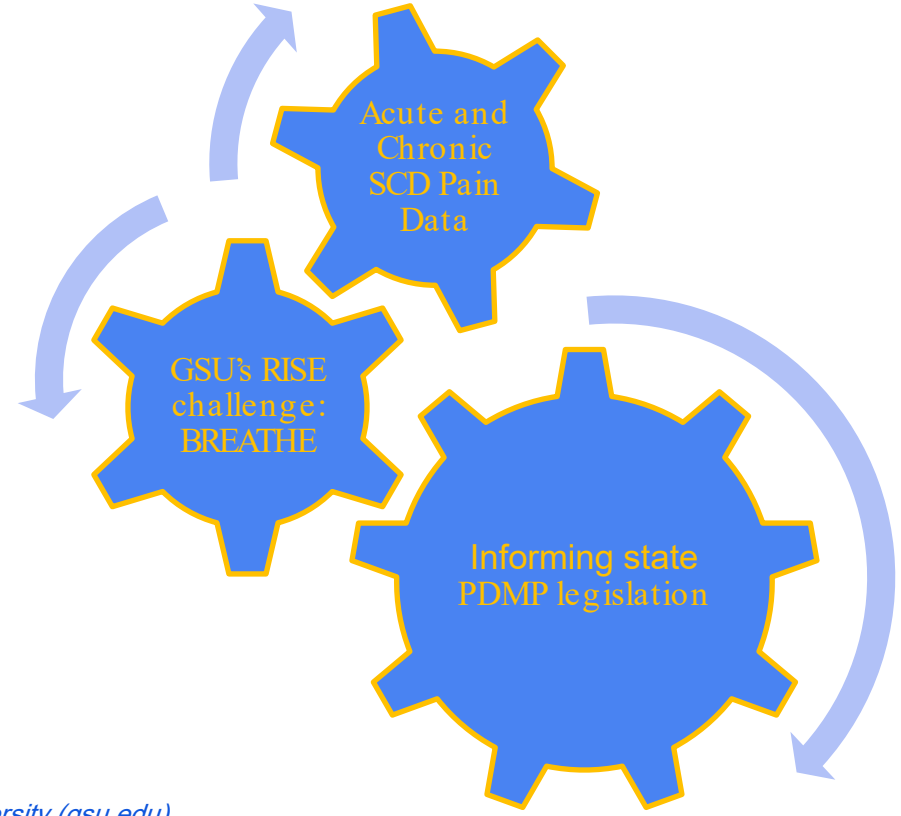
- Over a 3-year period:
  - 24% (CA) and 13% (GA) of pediatric patients had no hematology care
  - 56% (CA) and 34% (GA) of adult patients had no hematology care

Horiuchi et al, Blood Advances, 2022

SCDC Successes Example #1: Pain Management



"The recommendations do not apply to pain related to **sickle cell disease or cancer** or to patients receiving palliative or end-of-life care."



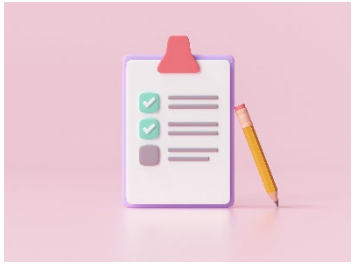
"The prescriber is not required to check the PDMP in these four situations:

*4) If the patient is receiving treatment for **cancer**."*

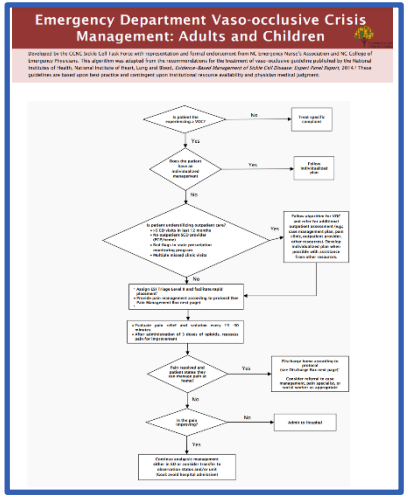
[Project RISEGeorgia State University (gsu.edu)]

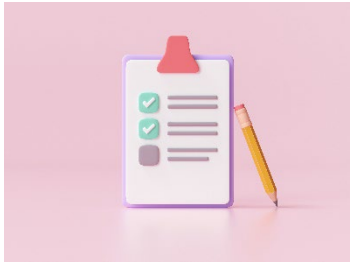
SCDC Successes Example #2: Emergency Department (ED) Education

Top 20 SCD EDs
1.
2.
3.
4.
5.
6.
7.



Pre-survey





Post-survey

SCDC Successes Example #3: Children's Special Health Care Services (CSHCS)

IHPI BRIEF

State-University Partnership to Enhance Outreach to Adults Living with Sickle Cell Disease in Michigan

INSTITUTE FOR HEALTHCARE POLICY & INNOVATION

Sickle cell disease is the most common inherited blood disorder in the U.S.

Sickle cell disease is associated with significant health complications across the life span, such as pain, stroke, and infection, as well as reduced average life expectancy of 45 years.[1,2] Access to consistent high-quality healthcare improves health outcomes among this population.[2] However, the risk for adverse outcomes is further heightened as over 90% of people with sickle cell disease in the U.S. are Black or Hispanic — racial and ethnic groups that have historically been economically and socially marginalized and often underserved in healthcare.[3]

There are over 4,000 individuals living with sickle cell disease in Michigan, the majority enrolled in Medicaid.[4] Historically, Michigan residents up to 21 years of age living with sickle cell disease were eligible to receive health coverage through Children's Special Health Care Services (CSHCS), a program within the Michigan Department of Health and Human Services (MDHHS) that serves children and some adults with special health care needs regardless of eligibility for other insurance coverage. The program is part of the federal Title V Maternal and Child Health Services Block Grant. CSHCS assists with reimbursement for medical care and treatment, including co-pays, deductibles, and transportation, and provides care coordination, case management, and other support services.

In October 2021, Michigan expanded CSHCS coverage to include people living with sickle cell disease over 21 years of age with the goal of improving health outcomes and reducing health disparities for this vulnerable population.[5]

In order to successfully implement this new expansion, the first step was to identify as many eligible people as possible. **MDHHS partnered with the Michigan Sickle Cell Data Collection (MiSCDC) program at the University of Michigan to identify adults with sickle cell disease who are newly eligible for CSHCS coverage.** The MiSCDC program uses multiple population-level data sources to identify people with sickle cell disease in Michigan (see page 2 for further details).[6]

Key outcomes of the state-university partnership

The collaboration between MDHHS and the MiSCDC program at the University of Michigan substantially increased identification of adults eligible to enroll in the CSHCS program expansion.

The partnership identified 2,569 adults living with sickle cell disease in Michigan who are eligible to enroll in the new CSHCS expansion.

- Initially, 400 eligible people were identified using CSHCS enrollment data.*
- An additional 2,169 eligible people were identified by leveraging the multi-source MiSCDC database.
- Of the additional people identified, 24% were adults who had been enrolled in CSHCS prior to 2015 and 76% were adults who had never been previously enrolled in CSHCS.

2,569 total adults identified

2,169 additional adults identified using the MiSCDC database

400 adults identified using recent CSHCS enrollment*

*CSHCS program enrollment data from 2016-2022 was used to identify people who had been unenrolled due to reaching the prior age cap of 21.

"The partnership between MDHHS and the University of Michigan allowed the MiSCDC team to leverage a multisource dataset to identify **five times** as many eligible people for the program expansion compared to relying on prior CSHCS enrollment data alone. This demonstrates the usefulness of state-university collaborations and creative strategies to improve the health and quality of life for populations that may be hard to reach.

Other states, particularly those who have Sickle Cell Data Collection (SCDC) programs, could consider using similar methodologies to identify individuals with sickle cell disease—or **other rare diseases**—who can be connected to resources and impacted by new policies and program expansions."

State-University Partnership to Enhance Outreach to Adults Living with Sickle Cell Disease in Michigan (umich.edu)

For More Information About SCDC:

- Webpages with state data, publications, fact sheets, and more
- MMWR article, *Surveillance for Sickle Cell Disease — Sickle Cell Data Collection Program, Two States, 2004–2018*, with information about the history of CDC's SCD surveillance programs, SCDC methods, and ways the data is resulting in active change in SCDC states
- Quarterly newsletter, *The Bloodline*, with updates about project-related activities in the SCDC states, including work with the SCD community and policy makers

Thank you!

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For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.