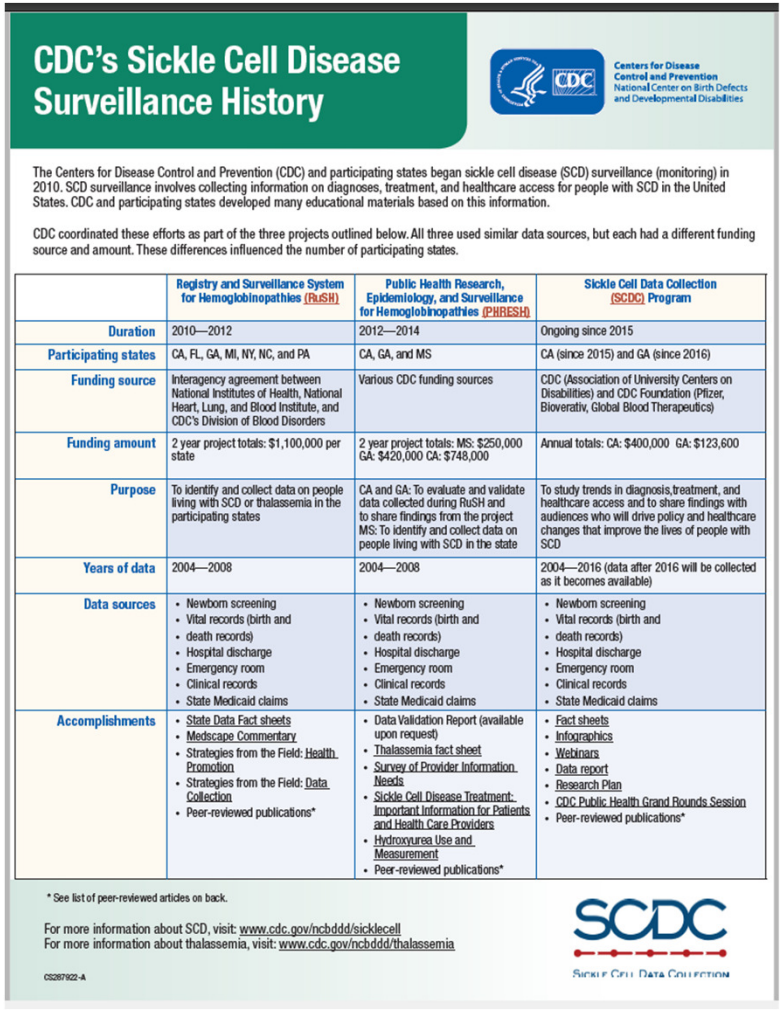
National Center on Birth Defects and Developmental Disabilities

DD19-1906 Capacity Building for Sickle Cell Disease Surveillance

Session 1: History of SCDC, SCDC Goal Setting, and Existing Infrastructure in Participating States

November 7, 2019



CDC's Sickle Cell Disease Surveillance History

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

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 three projects outlined below. All three 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)	Sickle Cell Data Collection (SCDC) Program
Duration	2010—2012	2012—2014	Ongoing since 2015
Participating states	CA, FL, GA, MI, NY, NC, and PA	CA, GA, and MS	CA (since 2015) and GA (since 2016)
Funding source	Interagency agreement between National Institutes of Health, National Heart, Lung, and Blood Institute, and CDC's Division of Blood Disorders	Various CDC funding sources	CDC (Association of University Centers on Disabilities) and CDC Foundation (Pfizer, Bioverativ, Global Blood Therapeutics)
Funding amount	2 year project totals: $1,100,000 per state	2 year project totals: MS: $250,000 GA: $420,000 CA: $748,000	Annual totals: CA: $400,000 GA: $123,600
Purpose	To identify and collect data on people living with SCD or thalassemia in the participating states	CA and GA: To evaluate and validate data collected during RuSH and to share findings from the project MS: To identify and collect data on people living with SCD in the state	To study trends in diagnosis,treatment, and healthcare access and to share findings with audiences who will drive policy and healthcare changes that improve the lives of people with SCD
Years of data	2004—2008	2004—2008	2004—2016 (data after 2016 will be collected as it becomes available)
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	• Newborn screening • Vital records (birth and • death records) • Hospital discharge • Emergency room • Clinical records • State Medicaid claims
Accomplishments	• State Data Fact sheets • Medscape Commentary • Strategies from the Field: Health Promotion • Strategies from the Field: Data Collection • Peer-reviewed publications*	• 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 • Peer-reviewed publications*	• Fact sheets • Infographics • Webinars • Data report • Research Plan • CDC Public Health Grand Rounds Session • Peer-reviewed publications*

* See list of peer-reviewed articles on back.

For more information about SCD, visit: www.cdc.gov/ncbddd/sicklecell
For more information about thalassemia, visit: www.cdc.gov/ncbddd/thalassemia

CS267922-A

SCDC
Sickle Cell Data Collection

- https://www.cdc.gov/ncbddd/hemoglobinopathies/surveillance-history.html
- https://www.cdc.gov/ncbddd/hemoglobinopathies/rush.html
- https://www.cdc.gov/ncbddd/hemoglobinopathies/phresh.html
- https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html

- Where do people with SCD live and receive their health care?
- What can we better understand about the transition from pediatric to adult care?
- Are there unique characteristics of Hispanic populations with SCD?
- What happens to people with SCD as they age?
- How, where, why, and when do people with SCD utilize healthcare services?

Goals and Objectives for SCD Surveillance

- Georgia's and California's Experience
  - Planned Outcomes
  - Unplanned Outcomes
- Developing Goals and Objectives

GA and CA Planned Outcomes

- RuSH (2010-2012)
  - Incidence
  - Prevalence
  - Healthcare utilization
  - Feasibility of surveillance (thalassemia and SCD)
  - Publications

GA and CA Unplanned Outcomes (1)

- Statewide collaboration with clinical providers/centers
  - Data collection
  - Analyses and publications
  - Grant proposals
- Collaboration and connection with state agencies
  - Data stewards
  - Medicaid
  - Newborn screening
  - Departments of Public Health

GA and CA Unplanned Outcomes (2)

- Improved infrastructure and access to care (CBOs, clinical care)
  - Grants to increase capacity, transportation, etc.
  - Attention to problems (with data)
  - Data to support new clinical sites (both states)
- State and Federal policy support and changes
  - CA AB 1105
  - Public Health Law 115-327 (SCD and Other Heritable Blood Disorders … Act of 2018)
  - Increased funding from other agencies

GA and CA Unplanned Outcomes (3)

- Health education
  - Capacity/resources to produce social media, webinars, training modules, Project ECHO implementation for clinicians
  - Videos for those living with SCD and clinicians
  - Outreach materials for distribution by CBOs and online
  - Patient resource tools and websites
- Publications and analyses
  - In collaboration with non-SCD, external researchers
  - Internal or multi-state

Input into Goals and Objectives

- Begin by collecting expertise and opinions
  - (But also begin by collecting data!)
- Broad-based expertise – People with knowledge about:
  - SCD (clinical, lived experience, CBOs)
  - Public health surveillance
  - Data stewards (what's feasible?)
  - Other disease areas with success (e.g., hemophilia, cystic fibrosis)
  - State agencies (what's already being done, e.g., newborn screening)

Building from Current Infrastructure

- Starting with What's in Place
  - Newborn screening
  - State registry system
  - Clinical registries
  - CBO registries or systems
  - Surveillance for other diseases (Reportable? Cancer registry?)

TRACKING CALIFORNIA

INFORMING ACTION FOR HEALTHIER COMMUNITIES

SCDC Capacity Building, November 7, 2019

California Surveillance Infrastructure

- 10 years of hemoglobinopathy surveillance
- Developed in Newborn Screening Program
- Data from multiple supportive state agencies
  - Administrative data (hospital discharge, ED)
  - Claims data (Medicaid)
  - Vital records (deaths)
  - Newborn screening (births w/SCD)
  - Clinical records (11 sites)
- Consistent staff/expertise over time
- Part of a larger team (Tracking California)
  - Within state department of public health

TRACKING CALIFORNIA
INFORMING ACTION FOR HEALTHIER COMMUNITIES

(Some) Collaboration Within State

- Community based organizations
  - SCDFC
  - Cayenne Wellness
  - Sickle Cell Advisory Council of Northern California
  - Sickle Cell Anemia Awareness of San Francisco
- Clinical collaborators
  - UCSF Benioff Children's Hospital Oakland
  - UCSF Zuckerberg General Hospital San Francisco
  - UCSD Rady Children's Hospital San Diego
  - UC Davis Medical Center
  - Children's Hospital Orange County
  - Loma Linda University Hospital
  - Children's Hospital Los Angeles
  - Center for Inherited Blood Disorders (Orange)
  - Stanford/Lucille Packard (Palo Alto)
  - Martin Luther King Jr. Medical Center (Los Angeles)
  - Valley Children's Hospital (Fresno)

TRACKING CALIFORNIA
INFORMING ACTION FOR HEALTHIER COMMUNITIES

Use of SCD Surveillance Data and Resources

- Expand SCD surveillance in California
  - New analyses and patient resources
  - Gather more data (Kaiser, Medicare)
- Improve access to care
  - New clinics based on data (with state funding)
  - Funded clinical grants based on pilot data
  - Identifying primary care givers w/SCD populations
  - Support CBOs in outreach and funding
- Health education
  - Materials for those with the disease and others
  - Transition videos
  - Annual reports
  - Webinar series
  - Social media

TRACKING CALIFORNIA
INFORMING ACTION FOR HEALTHIER COMMUNITIES

Use of SCD Surveillance Data and Resources

- Analyses and publications
  - Methodology
  - Mortality
  - Emergency department utilization
  - Maternal mortality
  - Cancer incidence
  - Periods of frequent emergency department utilization
  - End of life acute care utilization
  - Medicaid expansion impact for SCD (submitted)
  - Weather and VOC (in process)
  - Pediatric quality of care indicators (in process)

TRACKING CALIFORNIA
INFORMING ACTION FOR HEALTHIER COMMUNITIES

SCDC

Sickle Cell Data Collection

November 7, 2019

SUPPORT

This presentation was developed with support from the Centers for Disease Control and Prevention (1NU58DD000012). Its content is the responsibility of the authors and does not necessarily represent the official views of CDC or the Department of Health and Human Services.

Georgia's Sickle Cell Data Collection Program is supported by the CDC Foundation and CDC's Division of Blood Disorders, with additional funding from the Doris Duke Charitable Foundation, Global Blood Therapeutics, Pfizer, and Sanofi.

DATA SOURCES

- GA Department of Public Health (DUA, BAA)
  - Newborn screening
  - Death records
  - Hospital and Emergency Department discharge data (Ga. Hospital Association via GDPH)
- GA Department of Community Health (DUA)
  - Medicaid/PeachCare claims
  - State Health Benefit Plan claims
- Clinical case reports (under public health authority)
  - Grady Comprehensive Sickle Cell Program
  - Children's Healthcare of Atlanta Comprehensive Sickle Cell Program
- Clinical case reports (under DSA)
  - Augusta University Medical Center Comprehensive Sickle Cell Program
  - Memorial Children's Hospital Sickle Cell Program

CASES IDENTIFIED BY DATASET

Data Set	Confirmed Cases	Probable Cases
Newborn Screening	730	98
Augusta University (clinical)	1,218	14
Grady (clinical)	1,661	2
CHOA (clinical)	1,908	242
Medicaid/CHIP	2,986	1,993
State Health Benefit Plan	209	215
Hospital administrative data	3,339	2,147
De-duplicated Total	4,288	3,011

PAST & CURRENT USES

Validation Studies

- Case definition for SCD
- Accuracy of mortality data for SCD identification
- Best sources of data to monitor preventive services
- Identifying transfusions and transfusion reactions
- Multi-site transfusions & complication risk

Quality of Care/Outcomes

- Mortality
- Prescriptions filled for hydroxyurea
- Up-to-date immunizations
- Initiation of TCD screening
- Iron overload
- Use of iron chelators
- Comorbidities

Mary Hulihan (CDC): ibx5@cdc.gov
Susan Paulukonis (CA): Susan.Paulukonis@cdph.ca.gov
Angie Snyder (GA): angiesnyder@gsu.edu

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