Sickle Cell Data Collection (SCDC) Program: Today, Tomorrow, and Beyond

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Sickle Cell Data Collection (SCDC) program

- What is SCDC?
- What is SCDC doing today?
- What more could SCDC do tomorrow?
- What MORE could SCDC do in the future?
What is SCDC?
What is Public Health Surveillance?

- Definition: The ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice, closely integrated with the timely dissemination of these data to those responsible for prevention and control.

- Goal: To provide information that can be used for health action by public health personnel, government leaders, and the public to guide public health policy and programs.

"The reason for collecting, analyzing, and disseminating information on a disease is to control that disease. Collection and analysis should not be allowed to consume resources if action does not follow."

—William Foege, 1976

https://www.cdc.gov/publichealth101/surveillance.html
Systematic data collection: SCDC case definition

- Reported by the state newborn screening program with a confirmed diagnosis of sickle cell disease (SCD)
- Reported by one of the state’s hemoglobinopathy specialty treatment centers with a laboratory-confirmed diagnosis of SCD
- Three or more healthcare visits (hospital, emergency department, or outpatient) with an SCD ICD-9-CM or ICD-10-CM code over any 5-year period

Why do you need a case definition?

<table>
<thead>
<tr>
<th>Surveillance Period</th>
<th>SCD Case Definition</th>
<th>No. of SCD Cases Identified</th>
<th>No. of SCD Cases Confirmed</th>
<th>No. of SCD Cases Missed</th>
<th>No. of SCD Exclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 years</td>
<td>≥1 SCD ICD-9-CM code</td>
<td>1959</td>
<td>1763</td>
<td>0</td>
<td>196</td>
</tr>
<tr>
<td>5 years</td>
<td>≥2 SCD ICD-9-CM codes</td>
<td>1831</td>
<td>1735</td>
<td>27</td>
<td>100</td>
</tr>
<tr>
<td>5 years</td>
<td>≥2 SCD ICD-9-CM codes</td>
<td>1558</td>
<td>1512</td>
<td>251</td>
<td>155</td>
</tr>
<tr>
<td>5 years</td>
<td>≥3 SCD ICD-9-CM codes</td>
<td>1739</td>
<td>1693</td>
<td>70</td>
<td>150</td>
</tr>
<tr>
<td>5 years</td>
<td>≥5 SCD ICD-9-CM codes</td>
<td>1632</td>
<td>1612</td>
<td>151</td>
<td>176</td>
</tr>
<tr>
<td>5 years</td>
<td>≥6 SCD ICD-9-CM codes</td>
<td>1602</td>
<td>1586</td>
<td>177</td>
<td>180</td>
</tr>
<tr>
<td>Within 1 year</td>
<td>≥1 SCD ICD-9-CM code</td>
<td>1959</td>
<td>1763</td>
<td>0</td>
<td>196</td>
</tr>
<tr>
<td>Within 1 year</td>
<td>≥2 SCD ICD-9-CM codes</td>
<td>1827</td>
<td>1721</td>
<td>31</td>
<td>95</td>
</tr>
<tr>
<td>Within 1 year</td>
<td>≥3 SCD ICD-9-CM codes</td>
<td>1733</td>
<td>1678</td>
<td>85</td>
<td>45</td>
</tr>
<tr>
<td>Within 1 year</td>
<td>≥4 SCD ICD-9-CM codes</td>
<td>1636</td>
<td>1629</td>
<td>134</td>
<td>27</td>
</tr>
<tr>
<td>Within 1 year</td>
<td>≥5 SCD ICD-9-CM codes</td>
<td>1596</td>
<td>1589</td>
<td>183</td>
<td>16</td>
</tr>
<tr>
<td>Within 1 year</td>
<td>≥6 SCD ICD-9-CM codes</td>
<td>1544</td>
<td>1530</td>
<td>233</td>
<td>14</td>
</tr>
</tbody>
</table>

https://www.ccwdata.org/web/guest/home;
Systematic data collection: SCDC data sources
Why so many data sources?

<table>
<thead>
<tr>
<th>Data Source</th>
<th># of Individuals with SCD**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Newborn screening</td>
<td>900</td>
</tr>
<tr>
<td>Hospital discharge</td>
<td>1,800</td>
</tr>
<tr>
<td>Medicaid claims</td>
<td>3,900</td>
</tr>
<tr>
<td>Emergency department</td>
<td>3,400</td>
</tr>
<tr>
<td>Vital (death) records</td>
<td>650</td>
</tr>
<tr>
<td>Clinic 1</td>
<td>125</td>
</tr>
<tr>
<td>Clinic 2</td>
<td>75</td>
</tr>
<tr>
<td>Clinic 3</td>
<td>200</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>11,050</strong></td>
</tr>
<tr>
<td><strong>DEDUPLICATED TOTAL</strong></td>
<td><strong>7,250</strong></td>
</tr>
</tbody>
</table>

**Example data only**
What is SCDC doing today?
SCDC data from California and Georgia, 2004-2016

California, 2016
N=4,689

Georgia, 2005
N=6,935

Data analyses and publications

The accuracy of hospital ICD-9-CM codes for determining Sickle Cell Disease genotype
Angela B. Snyder1, Peter A. Lane2, Mei Zhou3, Susan T. Paulukonis4, and Mary M. Hulihan5

Determining Adherence to Quality Indicators in Sickle Cell Anemia Using Multiple Data Sources
Cindy E. Neunert, MD, MScS1, Robert Gibson, PhD, MSOTR(l,2, Peter A. Lane, MD3,4, Pragya Verma-Bhatnagar, MD, MPH5, Vaughn Barry, PhD, MPH3,4, Mei Zhou, MS, MA6, and Angela Snyder, PhD, MPH6,7

Emergency department utilization by Californians with sickle cell disease, 2005–2014
Susan T. Paulukonis1, Lisa B. Feuchtbaum2, Thomas D. Coates3, Lynne D. Neumayr4, Marsha J. Treadwell4, Elliot P. Vichinsky4, and Mary M. Hulihan5

Susan L. Podgornik, MA, RDH, B.J. Eron, MD1,2, J. Neumayr, MD1,2, N.H. Wang, RN1,3, W.H. Sherman, MD4, and R.S. Moses, PhD5

Figure 2: SCD Births in Georgia 2004-2016 by County of Residence (N = 2,019*)

Educational materials and outreach

How is SCDC helping the SCD community in California?

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.
(iv) Alameda.
(v) San Bernardino.
(vi) San Diego.

F.A.Q.

What counties have the highest numbers of people living with SCD?

<table>
<thead>
<tr>
<th>County</th>
<th>Adults age 21 or older</th>
<th>Children and young adults</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Los Angeles</td>
<td>590</td>
<td>490</td>
<td>1080</td>
</tr>
<tr>
<td>San Bernardino</td>
<td>260</td>
<td>162</td>
<td>422</td>
</tr>
<tr>
<td>Sacramento</td>
<td>290</td>
<td>15</td>
<td>345</td>
</tr>
<tr>
<td>Alameda</td>
<td>299</td>
<td>72</td>
<td>371</td>
</tr>
<tr>
<td>Riverside</td>
<td>212</td>
<td>97</td>
<td>309</td>
</tr>
<tr>
<td>San Diego</td>
<td>181</td>
<td>67</td>
<td>248</td>
</tr>
<tr>
<td>Contra Costa</td>
<td>168</td>
<td>68</td>
<td>236</td>
</tr>
<tr>
<td>San Joaquin</td>
<td>97</td>
<td>30</td>
<td>127</td>
</tr>
</tbody>
</table>
How is SCDC helping the SCD community in Georgia?

The MAVEN Project seeks to bring expert healthcare within everyone’s reach. We do this by connecting highly qualified volunteer physicians to underserved community clinics via telehealth technology.

SCDC data shows where patients, health care providers, and health care facilities are geographically located and can help answer questions related to access, health care utilization, and quality of care.

By overlaying SCD births in the state with pediatric SCD treatment centers, SCDC data highlights geographic challenges in gaining access to care, how far patients travel for treatment, whether they are seen at the closest facilities to their home, the rate of identified patients to services or providers in a given region, and how these geographical factors may influence utilization by provider type (e.g., emergency department).

For instance, there were 60 SCD births in Muscogee County (where Columbus is the county seat) from 2004 to 2016. But the Columbus area is nearly a two-hour drive to the pediatric comprehensive SCD treatment center in Atlanta and a four-hour drive to the pediatric comprehensive SCD treatment center in Augusta. To better serve SCD patients in the Columbus area, the Allegheny-Geneva Health System opened an outreach clinic in Columbus, with funding from the Piedmont Columbus Regional Foundation in March 2015.

At the time of writing, there are two comprehensive pediatric SCD programs in the state, with five associated pediatric outreach clinics in middle and south Georgia. There are two additional pediatric SCD treatment programs in the state. For more details, please visit the MAVEN Project website.

What more could SCDC do tomorrow?
More states: DD19-1906 and Public Law 115-327

More data analyses under consideration

- Palliative care model (accepted by J. of Palliative Care)
- Insurance coverage (abstracts for American Society of Hematology Conference)
- Older adults with SCD (abstracts for SCDAA Conference)
- Expand annual reports – births and deaths, other topics
- Causes of mortality
- Bone Marrow Transplant outcomes
- Applicability and feasibility of care models
- Disability eligibility
More collaborations under consideration

- Cure Sickle Cell Initiative
- Other Federal grants
  - HRSA’s Sickle Cell Disease Treatment Demonstration Program and Newborn Screening Program
  - NIH’s Sickle Cell Disease Implementation Consortium
- Longitudinal surveillance after new clinical care implementation
What MORE could SCDC do in the future?
Learn from and build upon other successful projects

Surveillance

- Natural history studies
- Pain and opioids
- Post-market follow-up of new treatments and cures
- Pharmacogenomics
- Development of new registries
  - Blood bank
- Connection to other registries
  - Cancer
  - Alzheimer’s
Thank you!

- California and Georgia SCDC teams
- CDC Foundation and private partners
  - Doris Duke Charitable Foundation
  - Global Blood Therapeutics
  - Pfizer
  - Sanofi
- CDC/DBD Policy and Communication
- SCD Community
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.

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For more information, contact CDC
1-800-CDC-INFO (232-4636)