California's Sickle Cell Data Collection Program

Public Health Surveillance for sickle cell disease (SCD) **did not exist** until 2010 - prior, the number of people living with the disease in California was **unknown**.

There was no clinical case data system that informed us of:

- What kind of care people living with SCD were getting
- Who was caring for people with SCD
- What was the health and mortality risks of those living with SCD

In 2010, the CDC began funding and supporting California and other states to develop systems to answer these questions.

About the data collected

The data came from sources that already exist:

- Insurance claims
- Vital records
- Hospital discharge records
- Newborn screening records
- Sickle cell center clinical case reports

California's SCDC program linked data sets so that we could look across many years at **patterns of healthcare, complications, and opportunities to improve health outcomes and quality of life for those with SCD**.

California's SCDC program is one of 15 states funded by the Center for Disease Control's National Sickle Cell Data Collection (SCDC) Program.

For more information about the national program, please visit: https://www.cdc.gov/ncbddd/hemoglobinopathies/scdc.html

Since 2010, data from California's SCDC program has made an impact in several ways

Identifying all Californians with SCD

- Identified the geographic location, healthcare utilization, and demographics of **over 8000 Californians living with SCD** - where previous estimates had been less than 5,000.
- Reported that **7% of Californians with SCD are Latinx,** with a high proportion of those being newborns and young children.

Helping identify the need for specialized and comprehensive care

- Found that most adults with SCD in California are **not in the regular care of a hematologist or SCD expert.**
- Determined that the risk of death for young adults (age 16) with SCD is higher than for the general population and that there is typically no clear warning signs - **every severe pain crisis needs to be treated very seriously.**

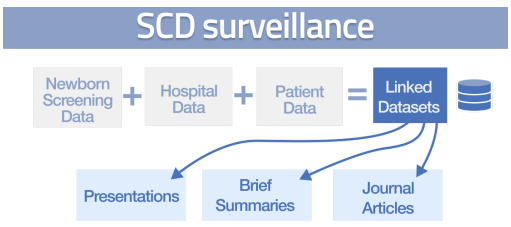
Deepening our understanding of healthcare utilization and treatment options

- Found that **high utilization of emergency room services in the adult population with SCD are not "chronic" but rather related to periods of poor health -** most folks with SCD are not frequent emergency department users for long periods of time.
- Researched the safety of deferasirox (Exjade) and found that when taken together with hyroxyurea**, this did not result in an increase in risk of adverse events.**

Advocating for funding support and the establishment of new SCD clinics

- Provided data to support the **establishment of the MLK Jr. SCD Clinic in South Central LA** as well as the CA legislative Black Caucus in support of funding and implementation of Networking California for Sickle Cell Care and the establishment of 12 new SCD clinics.

Training other states funded by SCDC to lead their own programs



- Along with partners at the Georgia Health Policy Center, **trained other states to implement their own SCDC programs.**

How can I get involved?

Sign up for newsletter updates

Attend our next webinar

Follow us on social media

	Share your thoughts with us
1	What are the biggest challenges for those living with SCD in CA?
2	What does change look like for you or the communities you work with?
3	What questions should we be answering with SCD data?
4	Is there anything else you'd like to share with us?

Please submit your responses to the above questions here: https://wkf.ms/44NXSRm

SCDC

Sickle Cell Data Collection

California's SCDC Program

For more information, please contact:

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