

California's Sickle Cell Data Collection (SCDC) Program

Data are often **siloed in different state-level entities**, making it hard for decision makers to answer important questions about persons living with Sickle Cell Disease (SCD) and their:

- population demographics and prevalence
- quality of life
- life expectancy
- health care utilization and accessibility
- preventive care and health outcomes
- additional needs

California's SCDC program *links existing data sets*, allowing us to look across years of health care patterns and complications.

Using these data sets, we can highlight interventions and policies that improve health.



We collect data on:

Population Demographics, Insurance Coverage, and SCD Prevalence

The impact and distribution of SCD in the state, including the prevalence within Latinx/Hispanic communities and patterns in Medi-Cal enrollment.

Health Care Utilization and Accessibility

The distance traveled for care; the frequency of Emergency Department visits, Outpatient Clinic appointments, or Telehealth services; and the factors that influence when and where patients seek healthcare; and their experience in receiving healthcare.

Preventive Care and Health Outcomes

Implementation of clinical guidelines for SCD, disparities in health outcomes within the SCD population, and the impact of air pollution on health outcomes.

Social Drivers of Health and Quality of Life

Key factors that impact the health and quality of life of the SCD population, such as transportation, housing, and access to healthy food.

Our program works to:



Connect and link existing state-level data



Improve and standardize data collection methods



Collaborate with partners and stakeholders to use data for policy change



About the data we collect

Data that we use has already been collected and validated by data partners. Data are governed by data use agreements that determine whether or not data can be shared, what is shared, and how it is shared. Only aggregated data about groups of people (not individual-level data) that meet our partners' privacy guidelines can be shared.

For more information or to request data on SCD in California, please contact scdc@trackingcalifornia.org.