SICKLE CELL DISEASE
PARTNERSHIP

A BLUEPRINT FOR ACTION:
Improving Access to Treatment and Community Services for Adults with Sickle Cell Disease

Establishing and developing a comprehensive care network for adults with Sickle Cell Disease, based on the Networking California for Sickle Cell Care Initiative.

www.SickleCellPartnership.org

Introduction

The Sickle Cell Disease Partnership (Partnership) recognizes that states are increasingly called upon to expand and strengthen health policies and programs in constrained fiscal environments. States must find innovative and efficient approaches to sustaining and enhancing services for their populations, including for individuals with Sickle Cell Disease (SCD). By highlighting state and federal models of care, the Partnership aims to document strategies that can help states to maximize impact, coordinate resources, and maintain continuity of care in an ever-shifting federal policy environment.

This Blueprint delineates the steps taken by California stakeholders to establish and develop the Networking California for Sickle Cell Care (NCSCC) Initiative. The goals of this resource are to (1) describe and highlight a model of care for SCD; (2) explain how the model advanced SCD policy in California; and (3) extract key steps and action items from the model that other states and stakeholders can leverage. Ultimately, the Blueprint can motivate further state action across the United States and better inform the development of federal programs and policies to support individuals living with SCD.

The Networking California for Sickle Cell Care (NCSCC) Initiative is a state-based treatment model for individuals living with SCD, projected by the Centers for Disease Control and Prevention's Tracking California to save the state over $100 million for every 2,500 patients served under the model. Developed through strategic advocacy, population data, and stakeholder engagement, NCSCC is one of the first networks of specialized clinics for adults living with SCD. Under the model, the treatment centers are each coupled with community-based ancillary and case management services.

SCD is a chronic, debilitating disease that is the most common inherited blood disorder in the United States. Although it is a rare disease, SCD affects approximately 100,000 Americans. Individuals living with SCD face severe health complications, including recurring and life-altering pain crises, repeat infection, acute chest syndrome, lung problems, severe and chronic pain, leg ulcers, organ damage, and stroke. Due to inadequacies in comprehensive care management, only about 1 in 4 patients with SCD receive the standard of care described in guidelines, resulting in individuals living with SCD needing to visit the emergency department far more often than the average population. These and other factors increase the cost of care for individuals living with SCD and on the health care system more generally. As a result of systemic inadequacies and the severity of the disease, individuals living with SCD have an estimated life expectancy that is dozens of years shorter than the average life expectancy in the nation.

Individuals living with SCD bring immense strength, resilience, and expertise to every part of their lives. Despite repeated encounters with pain, bias, and systemic barriers, they continue to advocate for themselves and for future generations. Their lived experiences are not only central to improving care — but they are the foundation on which impactful policy must be built.

Recognizing the severe, life-threatening, and high-cost nature of the disease, stakeholders, including state legislators, state health departments, payors, hospitals and health systems, industry, and professional organizations, are increasingly interested in providing better care and treatment for individuals living with SCD. NCSCC provides an example of how these stakeholders – alongside patients and their families, patient organizations, and Community-Based Organizations (CBOs) – can leverage the efficiencies directly stemming from a coordinated care system to improve health outcomes and lower health care costs for individuals living with SCD.

Methodology

In developing the background and analysis for this paper, the Partnership worked in close collaboration with NCSCC to accurately represent the model and the years of work NCSCC stakeholders have dedicated to improving the lives of those living with SCD. The Partnership is a public policy and advocacy collaboration of patient advocates, health care providers, biopharmaceutical manufacturers, and other health care stakeholders committed to advancing policies that will improve the lives of individuals living with SCD.

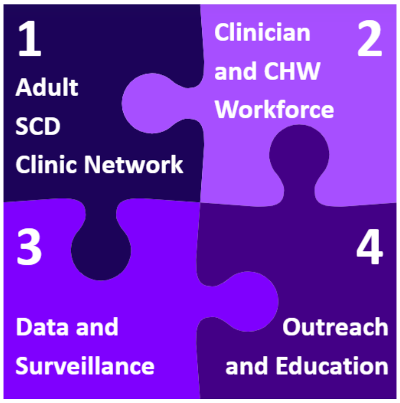
The Partnership closely evaluated the steps taken by NCSCC to develop its treatment model from the initial idea through present day implementation. In doing so, the Partnership reviewed published reports and data to piece together the model's development over time. The Partnership additionally conducted an interview with NCSCC's leadership, who described from their first-person perspective the strengths, challenges, and solutions developed in each piece of the model. To ensure the Blueprint is able to be generalized in different state environments and programs, as well as workable for a broad range stakeholders, the Partnership's members informed the Blueprint through their unique perspectives of the health care system and caring for individuals living with SCD.

Background: Networking California for Sickle Cell Care Initiative

NCSCC launched as the result of a successful advocacy effort that obtained state funding in 2019 to support a comprehensive care framework for adults with SCD. Started as a three-year initiative, NCSCC has now evolved and grown through its six-year history, with plans to expand in a manner that includes ongoing, sustainable funding.

The NCSCC is innovative in that it combines a broad range of services – both clinical and ancillary support services – under one organizational umbrella. Oftentimes, given the many valid considerations surrounding policy development, solutions tend to be piecemeal: individual puzzle pieces that are each valuable but do not necessarily fit together. NCSCC's approach is the opposite. NCSCC established, from the ground-up, the necessary elements of a successful SCD policy approach to be encapsulated in a single program. This holistic thinking permits NCSCC to coordinate case management and data tracking more thoroughly and efficiently, such that NCSCC can both (1) better identify those communities most in need of expanded services and target resources to them appropriately and (2) treat the entire person, from medical treatment to services targeting social determinants of health.

At its core, NCSCC has four essential elements:



1. **Clinical Network of Adult SCD Clinics:** Sustain a state network of adult SCD clinics by identifying, establishing, and supporting clinics aimed at providing evidence-based comprehensive care to individuals living with SCD.
2. **Knowledgeable SCD Clinician and Community Health Workforce:** Provide learning and development opportunities for medical students, graduates, and established providers.
3. **SCD Data and Surveillance:** Expand SCD data and surveillance efforts through multiple means, including the prevalence of disease, health outcomes, and ancillary services provided.
4. **Community Outreach and Education:** Strengthen core SCD outreach and education activities through partnerships with leading CBOs, public campaigns to increase awareness, and regular updates on activities.

Based on objective monitoring of emergency room data, hospital utilization, and shortened length of stay, NCSCC projects that its model has the potential of saving **over $100 million for every 2,500 adults with SCD**. At full capacity, NCSCC would be able to serve at least 4,000 of the 6,000 adults with SCD in California, which would amount to **$200 million in savings per year**. These savings projections are based on 2020 administrative data from the Centers for Disease Control and Prevention (CDC).

The breadth of services contributing to these costs savings is exemplified in the below data and throughout this Blueprint. By August 2024, the NCSCC:

- Established **12 clinics**, each coupled with the Sickle Cell Disease Foundation of California's ancillary and case management support services.
- Was **actively serving 960 patients** (about 14 percent of people living with SCD in California).
- Provided 2,573 units of **case management**, 2,218 units of **transportation services**, 1,236 units of **housing assistance**, 1,036 units of **social services support**, 888 units of **food assistance**, 735 units of SCD treatment **education**. Note each unit represents discrete individual services provided by SCDF Community Health Workers (CHWs).
- Provided Sickle Cell 101 **Bootcamps to 463 attendees**, including physicians, nurses, psychologists, social workers, and CHWs.
- From 2023-2024, worked with 62 graduate and medical students to complete a **SCD clinical rotation** for a cumulative **2,020 hours** of training in SCD.

The following sections outline the steps, approximate timeframes, recommended stakeholders, and action items California has taken – and other states should take – to improve health outcomes for individuals living with SCD. The overarching steps are as follows:

1. **Establish Initial Partnerships and Grants**
2. **Identify Current SCD Environment and Starting Priorities**
3. **Gather a Committee of SCD Stakeholders to Develop a State Action Plan**
4. **Release and Socialize State Action Plan**

5. **Draft State Legislation**
6. **State Lobbying to Cultivate New Financial Resources with Action Plan as Basis**
7. **Program Implementation**
8. **Continued Refinement and Expansion**

Step 1: Establish Initial Partnerships and Grants

Approximate Timeframe: 3 months
Identify initial SCD stakeholders to lead the state efforts.

RECOMMENDED STAKEHOLDERS ("Initial Leadership Group")

Individual Living with SCD
Community-Based Organization
SCD Treatment Center

ACTION ITEMS

- The Initial Leadership Group comprises the foundational stakeholders necessary to further build out the model. Each stakeholder should be an established leader in the SCD community in the state, with the knowledge and leadership capabilities necessary to lead the development of the model. Each stakeholder should be able to dedicate time towards the effort. It is essential to establish, especially at this early juncture, relationships between the patient community, CBOs, and treatment services. Therefore, the Initial Leadership Group represents each of these areas.
- Achieve agreement among identified stakeholders to pursue state legislative action to develop treatment centers.
- Acquire financial support or grant funding to support initial landscaping activities, such as from a regional sickle cell organization.

Step 2: Identify Current SCD Environment in the State and Starting Priorities

Approximate Timeframe: 3 months

Collect the available and pertinent data on SCD at the state-level and identify scope of clinical, ancillary, and community services currently available. Use this information to identify gaps in data and services and to inform starting priorities.

RECOMMENDED STAKEHOLDERS

Initial Leadership Group
Stakeholders as necessary to help inform the environment

ACTION ITEMS

- Compile the available data on the following pieces of information:
  - Prevalence
  - Life expectancy
  - Cost burden on the state
  - Availability of primary care providers and SCD specialists
  - Established SCD clinics or treatment centers
  - Pediatric to adult transition services
  - Reimbursement policies
  - Services addressing social determinants of health (transportation, homelessness, language barriers, racial bias, discrimination)
  - Provider knowledge and/or education programs on SCD and/or paint management
- To compile state-specific data on SCD, the Initial Leadership Group and other stakeholders can begin with the Centers for Disease Control and Prevention’s (CDC) Sickle Cell Data Collection program, state health departments, publicly available health databases, and other data sources as available. Because SCD surveillance varies by state, research spanning multiple sources is necessary. Stakeholders should also leverage their own professional networks to determine where state data is located.
- Collect information in one location. These initial data points will become the foundation for an Action Plan and further action.
- Begin to pinpoint the gaps in care, the breakdown of ancillary and community services, and opportunities for case management.

Step 3: Gather a Collaborative of SCD Stakeholders to Develop State Action Plan

Approximate Timeframe: 1 year
Establish a diverse committee – representing the full spectrum of SCD stakeholders – to meet, discuss, and compile State Action Plan.

RECOMMENDED STAKEHOLDERS ("SCD Stakeholder Collaborative")

Initial Leadership Group
Individuals Living with SCD
Family Members
Clinicians and Health Care Organizations
CBOs
Other Advocates

ACTION ITEMS

- The Health Resources and Services Administration's (HRSA) SCD Treatment Demonstration Program funded regional and state action plans that supported the goals, purpose, and requirements of the program. First confirm whether the respective state already has a state action plan. For example, the Pacific Sickle Cell Regional Collaborative led the development of state action plans for AZ, CA, CO, NV, OR, UT, and WA.
- If a state action plan is needed in the state, gather a SCD Stakeholder Collaborative comprised of individuals dedicated to improving SCD care and treatment in their individual and professional capacities.
- Consider federal and state funding sources to develop the state action plan.
- Achieve agreement on a regularly occurring meeting schedule, with opportunities for in-person working meetings at a central location in the state.
- Review Step 2 information and priorities and foster stakeholder input to further build out the foundational data.
- Once all available SCD data is compiled, establish recommendations and starting priorities.
- Compile report with stakeholder input:
    - Public health priorities
    - Key implementation agencies
    - Strategies to increase SCD as a state priority
    - Expanding health care services
    - Strengthening community awareness
    - Identify specific goals for comprehensive, patient-centered, coordinated, accessible, safe, and high-quality care.

Step 4: Release and Socialize State Action Plan

Recommended Timeframe: Until Next Legislative Session
Release State Action Plan and the Committee's goals on SCD to a broad audience.

RECOMMENDED STAKEHOLDERS

SCD Stakeholder Collaborative
Governor's Office
Legislature
State Agencies
Local Health Departments
Medical Community, Institutional Providers, Academic Medical Centers
Community-Based Organizations
Community Health Workers
Other SCD Champions in the State

ACTION ITEMS

- Widely circulate state action plan through multiple communication channels and stakeholders who will be involved in fulfilling the Action Plan's priorities. Expand the circle of those who have buy-in on the plan and ensure broad alignment on priorities amongst an array of stakeholders.
- Begin to identify possible forms of collaboration and partnerships across stakeholders and the appropriate and available forums for hosting the various needed capabilities identified in the Action Plan.
- Begin to identify champions at the state agency and legislative levels, using the Action Plan as a foundation and tool to demonstrate the basis and need for action – and to educate and garner interest in advancing policies for individuals living with SCD.

Step 5: Draft State Legislation

Recommended Timeframe: In Preparation for the Next Legislative Session
Develop state legislation, focused on the identified goals of the State Action Plan.

RECOMMENDED STAKEHOLDERS

SCD Stakeholder Committee
SCD Advocates
Individuals Living with SCD

ACTION ITEMS

- Model the proposed state legislation after California's successful legislation, AB-1105, adjusting to reflect specific state dynamics, the respective political environment, and specific findings from the Action Plan.
  - Determine political viability and appropriate framing for success. Generally, the bill should direct the legislature to appropriate an identified amount of financial resources to establish new or expand existing services for individuals living with SCD in the priority areas identified in the Action Plan.
  - Priority areas are likely to include:
    - Statewide network of adult SCD clinics and community organizations. Link outpatient care to inpatient services, and provide coordinated, comprehensive, team-based medical, behavioral, social support, and outcomes monitoring to adults with SCD.
    - Expansion and education of the SCD workforce, including clinical and allied health providers, through activities such as educational programming and continuing medical education credits and SCD-focused rotations for health professional students.
    - Multiple modes of surveillance and data collection, including the prevalence of disease, the volume of clinical and ancillary services provided, and pre-identified outcomes measures.
  - To realize the successes of the NCSCC initiative, it is imperative that funding is distributed to clinical services (network of treatment centers), social supports and case management (CBOs), *and* workforce development (initiatives led by both the treatment centers and CBOs). A focus on only one of these areas will not create lasing, system-level improvements.

Step 6: State Lobbying to Cultivate New Financial Resources with Action Plan as Basis

Recommended Timeframe: 3 months, or as legislative session dictates
Socialize legislation and the need for resources to support individuals living with SCD in the state.

RECOMMENDED STAKEHOLDERS

SCD Stakeholder Committee
Individuals living with SCD/Advocates
Governor's office
Department of Health/Public Health

Legislature, including:

- Health Committee
- Policy and Budget Staff
- Black Caucus, Latino Caucus
- Legislative Analyst

ACTION ITEMS

- Create advocacy materials for stakeholders in order to project a clear, unified, and amplified message.
  - For example, California's messaging: "Funding to support the development of a statewide clinical and community network of care for adults with SCD, as well as the expansion of clinical and community health workforce, enhancement of SCD surveillance, and strengthening of outreach and awareness."
- Prepare stakeholders to be ready to mobilize on short notice.
  - Develop talking points, advocacy trainings, and media trainings to enable stakeholders to present a confident and unified voice.
- Identify initial legislative and administrative champions, including legislators who might be interested in sponsoring the legislation.
- Hold meetings to educate state policymakers, key caucus chairs, legislature and budget staff, and state health department leaders on SCD needs and potential solutions.
- Finalize sponsors and introduce legislation.
- As a Committee, hold frequent legislative visits alongside patients and community stakeholders – garnering additional understanding of SCD and additional co-sponsors.
- Testify before appropriate committees and education on the importance of the introduced legislation.
- Pass legislation.

Step 7: Implementation

Recommended Timeframe: Ongoing
Secure funding and implement program.

RECOMMENDED STAKEHOLDERS

SCD Stakeholder Committee
Governor's Office
Legislature
State Agencies
Local Health Departments
Medical Community, Institutional Providers, Academic Medical Centers
Community-Based Organizations
Community Health Workers

ACTION ITEMS

- Implement the program and utilize funding as provided for in the legislation and as directed by the priorities first established in the Action Plan. The below delineated services encapsulate those services implemented in California and examples of programs and policies which could be replicated to advance SCD policy at the state and federal levels.
- Build a Network of SCD Clinics:
  - Establish clinical care sites.
  - Expand transitional wrap-around services for the pediatric to adult transition.
    - Facilitating a smooth transition.
    - Coordinating medical, psychosocial, and educational support services during the transitional period.
    - Empowering self-management skills.
    - Enhancing caregiver support during the transition.
    - Use established resources for the transition of care, including those from the American Society of Hematology and Got Transition.
- Institute Programs to Educate and Expand the Clinical Workforce:
  - Establish academic and institutional partners.
  - Develop SCD standard of care guidelines for providers in the state to ensure quality and reliable care across treatment sites.
    - California's standard of care guidelines can be found here.
  - Initiate a mini-credential for students in the health professions and/or SCD-specific clinical rotations implemented through partnerships with local degree programs.
  - Require patients co-develop curricula for clinical and Community Health Worker (CHW) programs
  - Provide continuing medical education credits.
- Include training expectations for implicit bias, trauma-informed emergency care, shared decision-making, and communication.

- Education format examples:
    - Short, intensive, on-site SCD 101 “boot camps”
    - Online clinics
    - Shadowing SCD clinics
    - Live tele-education with experts
- Expand the SCD Community Health Workforce:
    - Build out the role of CHWs to serve as bridges between communities and the health care system. CHWs should find, refer, and assist individuals living with SCD in enrollment and continued management of their care, with the ultimate goal of connecting a SCD patient with a hematologist with expertise in SCD. CHWs can help connect providers unfamiliar with SCD to best practices and educational resources.
    - Each established clinical site should be coupled with a CBO in the same geographic location. The CBO provides social support services, including care coordination and case management, transportation, housing translation, mental health services, and other services to support an individual living with SCD in achieving their personal goals and independence.
        - In California, the Sickle Cell Foundation established satellite offices in each country where a clinical site is located, facilitating convenient access to a range of service. Partner community sites are able to launch their own programs, such as adolescent transition programs.
    - Introduce an intensive training program for CHWs. California uses a 10-week course that introduces individuals to the philosophy and practice of community health program, uses student collaboration to strengthen leadership capabilities for facilitating sensitive dialogue, and strategies to actively foster collaboration among individuals, families, employees, and agencies.
- Grow SCD Data Capture and Surveillance Capabilities:
    - Implementation of a state-wide, multi-data source, longitudinal data collection system.
    - Characterize statewide trends and track financial savings, including with respect to (California uses the Tracking California Program and a contract with a health information exchange provider):
        - Health and health outcomes
        - Medicaid claims data
        - Access to quality care
        - Care utilization
        - Newborn screening case identification
        - Challenges
        - Reimbursement data through state- or locality-based MCOs.
    - Comprehensive case management system and database, to be used by the CBO and to track the following information:
        - Individual profile:

            - Demographic information, including past and present medical complications.
            - Data on SDOH, including unstable housing and food insecurity.
            - Used to design effective support strategies.
        - Case File
            - One or more individual profiles, to which a service program and primary care worker are assigned. Providers are able to access to learn from prior, similar cases.
        - Service File
            - To support care coordination, such as service booking and tracking of appointments and the specific service units provided to each individual.
- Community Outreach and Education
    - Award RFAs, with focuses in emergency room, pain management, and quality of life
    - Website to spread awareness about the ongoing projects within the treatment network.

Step 8: Continued Refinement and Sustainability

Recommended Timeframe: Ongoing
Examine methods to ensure ongoing sustainability of the model, tailored to the existing SCD policy infrastructure in the state.

RECOMMENDED STAKEHOLDERS

SCD Stakeholder Committee
Advocates
Governor's office
Department of Health/Public Health

Legislature, including:
- Health Committee
- Policy and Budget Staff
- Black Caucus, Latino Caucus
- Legislative Analyst

ACTION ITEMS

- Sustainability for such a SCD model is integral to ensuring the continued support of individuals living with SCD in the state. From the start of taking the actions delineated in this Blueprint, stakeholders should keep an eye towards long-term sustainability.
- Continue to expand individuals served and treatment and care capacity over time.
- Maintain long-term, strong connections with the legislature, governor, and state-based agencies.
    - Provide consistent updates on implementation and the successes and challenges of the program through in-person briefings, an annual report circulated broadly, and ad hoc updates as necessary.
- Using outcomes data, pinpoint needs for additional funding and activate an advocacy strategy, leveraging existing connections.
- Develop a plan and target model to ensure long-term sustainability, such as through contracts with local or state MCOs, in conjunction with the state Medicaid program, or through a standing line item in the state budget.
    - Leverage the savings produced throughout the model, paired with a patient-centric success metric.

Looking Beyond California

The Partnership encourages stakeholders, including state programs, health systems and SCD treatment centers, CBOs, biopharmaceutical advocates, health care providers, and SCD advocates to evaluate the NCSCC model and assess how the model may be tailored to better meet the needs of Americans with SCD in a particular state or locality. The catalyst for California's model was a small group of stakeholders, each representing a different part of the community, agreeing to collaborate to establish a system of care. Ultimately, the goal is to work together as one system, rather than in silos, from the point of care to community services. Therefore, when an individual with SCD is in need of care, the model enables them to receive coordinated and managed care through one efficient network.

The key ingredients necessary to the success of this model can be implemented in other states– connecting individuals with clinical care and community support under one overarching approach. The steps delineated in this Blueprint provide one successful example and a basis of core elements for doing so, and other states and treatment centers are taking similar steps to establish better comprehensive care for individuals living with SCD.

The Partnership recognizes that each state's existing infrastructure and needs are unique, meaning each model for comprehensive and coordinated care that may be inspired by this Blueprint will also be unique. Additionally, the feasibility of garnering political support and funding for SCD programs differs based on the state and the needs of individuals living with SCD in that community.

Regardless of the initially perceived feasibility, the Partnership encourages interested stakeholders to carefully evaluate the current SCD resources available in their respective communities and states and begin with building opportunities for collaboration and efficiencies between existing programs. From there, it becomes easier to envision the improved health outcomes of a broader, more holistic and collaborative approach, such as the NCSCC model.

California's NCSCC model produces significant cost savings and improved outcomes through its four foundational elements:

(1) a network of adult SCD clinics;

(2) a knowledgeable SCD workforce;

(3) data and surveillance; and

(4) community outreach and education.

CDC projected California will save $100 million for every 2,500 patients participating in the model. These savings are significant, and they should serve as leverage and a catalyst for stakeholders as they develop an Action Plan and pursue legislative opportunities: An investment in care *now* to extend the lifespans of those living with SCD and produce long-term cost savings for the state.

The Partnership further encourages stakeholders to be creative in their collaboration to improve the health and wellbeing of individuals living with SCD. Unique payment models, Medicaid policy strategy, value-based care models, and untraditional data sources should be considered for model sustainability.

Looking forward, the Partnership intends to further evaluate how the NCSCC model and subsequent state-specific outcomes using this Blueprint can help to inform and shape federal policy and programs. By identifying best practices, successful interventions, and measurable cost savings, the Partnership plans to consolidate such evidence to support federal policy innovation. These insights will be critical in shaping national programs and funding strategies that prioritize comprehensive care coordination and management for individuals living with SCD in the United States.

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- American Society of Hematology
- Beam Therapeutics
- Bluebird bio
- CSL Behring
- National Alliance of Sickle Cell Centers
- Novo Nordisk
- Pfizer
- Philip Sanders (patient advocate)
- Sick Cells
- Sickle Cell Community Consortium
- Sickle Cell Disease Association of America
- Sickle Cell Disease Foundation
- Vertex
- Wunmi Bakare (patient advocate)

Finally, this Blueprint exists because of the strength and guidance of individuals living with SCD, whose voices drive every recommendation herein.

* * *

For additional information, please contact the advisors to the Partnership, Josh Trent (Josh.Trent@LeavittPartners.com) and Tori Gemme (Victoria.Gemme@LeavittPartners.com).

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