

Understanding the Requirements for Sickle Cell Disease Comprehensive Systems of Care

May 14, 2026 | 2:00 PM to 3:30 PM ET

OMH
U.S. Department of Health and Human Services
Office of Minority Health



Welcome

CDR Matthew Johns, (Co-Moderator)

Strategic Partnerships and Sickle Cell Disease Team Lead, Office of Minority Health

U.S. Department of Health & Human Services

OMH
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Office of Minority Health

Understanding the Requirements for Sickle Cell Disease Comprehensive Systems of Care

- This convening is supported by the U.S. Department of Health and Human Services (HHS) Office of Minority Health (OMH).
- This presentation represents the personal opinions of the speakers and does not necessarily represent the views or policies of HHS or the Federal government.

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Email us at **MinorityHealthInfo@hhs.gov or scan our QR code** and let us know what part of today's session you found most useful and if you have ideas for how we can improve future events.



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Opening Remarks

CAPT Mahyar Mofidi

Deputy Assistant Secretary for Minority Health

Director, Office of Minority Health

U.S. Department of Health & Human Services

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Office of Minority Health

Vision and Mission

Vision

All individuals, families and communities are healthy and thriving.

Mission

To provide national leadership, resources, and coordination to improve the health of racial and ethnic minority populations and American Indians and Alaska Natives and eliminate health disparities.



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Run-of-Show & Housekeeping

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Agenda

Segment	Speaker
Welcome	**CDR Matthew Johns, (Co-Moderator)** Strategic Partnerships and Sickle Cell Disease Team Lead, HHS OMH
Opening Remarks	**CAPT Mahyar Mofidi** Deputy Assistant Secretary for Minority Health | Director, HHS OMH
Talk #1: Success stories and models of a comprehensive system of care for SCD	**Dr. Donnell Ivy, MD MPH** Chief Medical Officer, Sickle Cell Association of America
Talk #2: Current activities and policies related to comprehensive system of care for SCD	**Dr. Alexis Thompson, MD** Chair, ASH Sickle Cell Disease (SCD) Task Force Children's Hospital of Philadelphia
Question & Answer	**CDR Yvonne M. Santiago (Co-Moderator)** Senior Advisor, HHS OMH
Closing Remarks	**CAPT Mahyar Mofidi** Deputy Assistant Secretary for Minority Health | Director, HHS OMH

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Success Stories and Models of a Comprehensive System of Care for SCD

Dr. Donnell Ivy, MD

Chief Medical Officer, Sickle Cell Disease Association of America (SCDAA)

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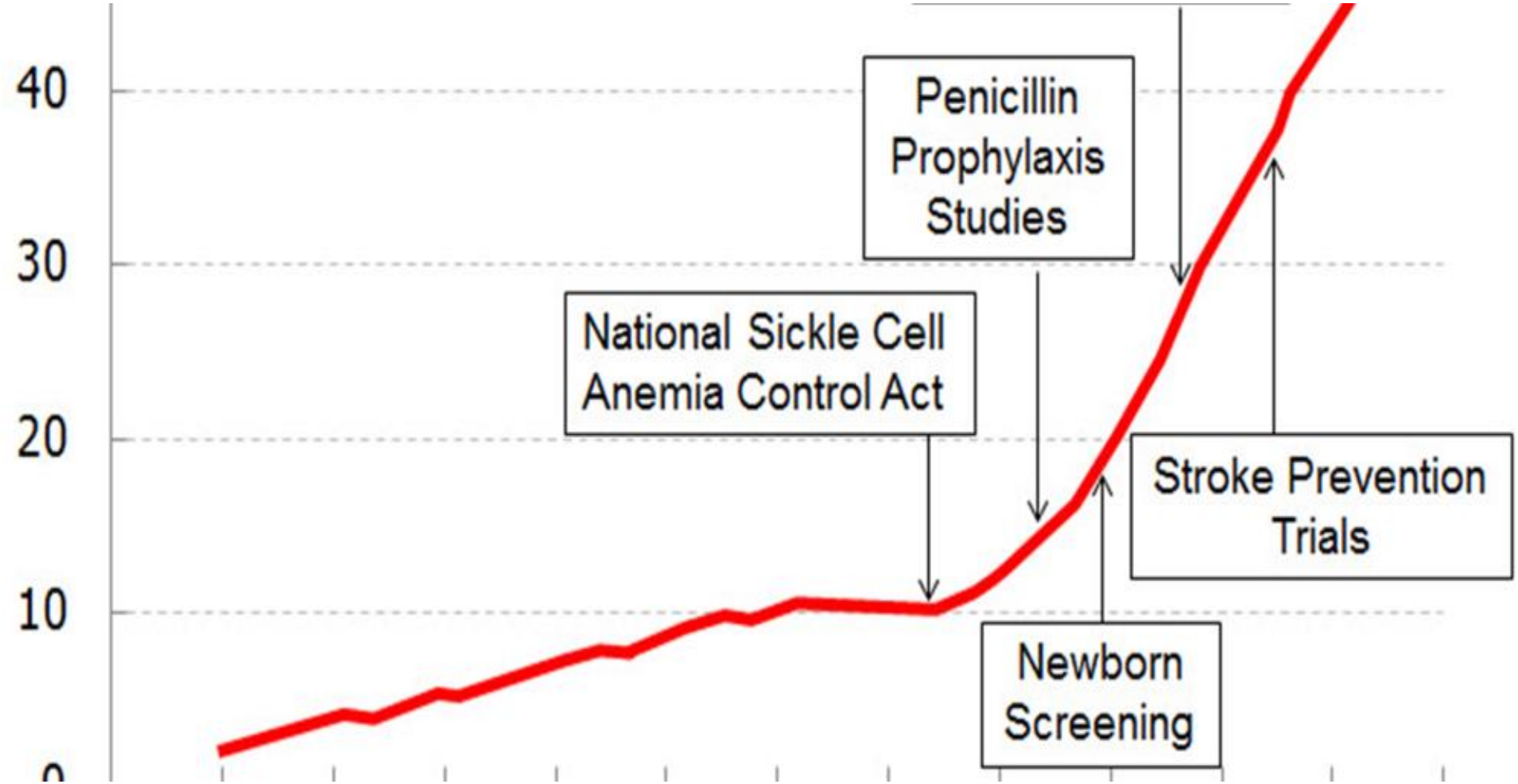
Sickle Cell Comprehensive Systems of Care

Edward Donnell Ivy, MD, MPH
Chief Medical Officer
Sickle Cell Disease Association of America

Disclaimer

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Life Expectancy of Patients with Sickle Cell Anemia has Increased



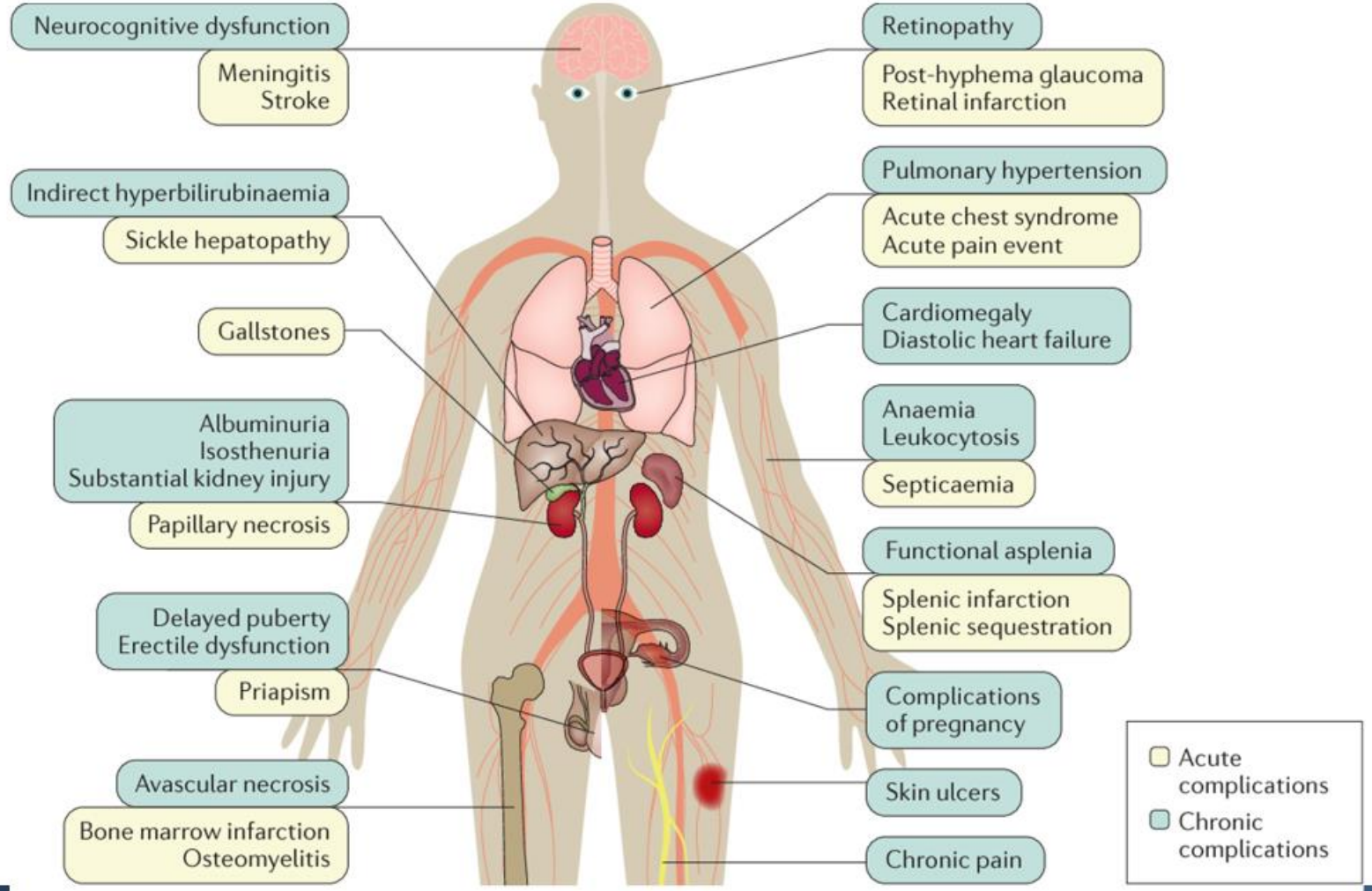
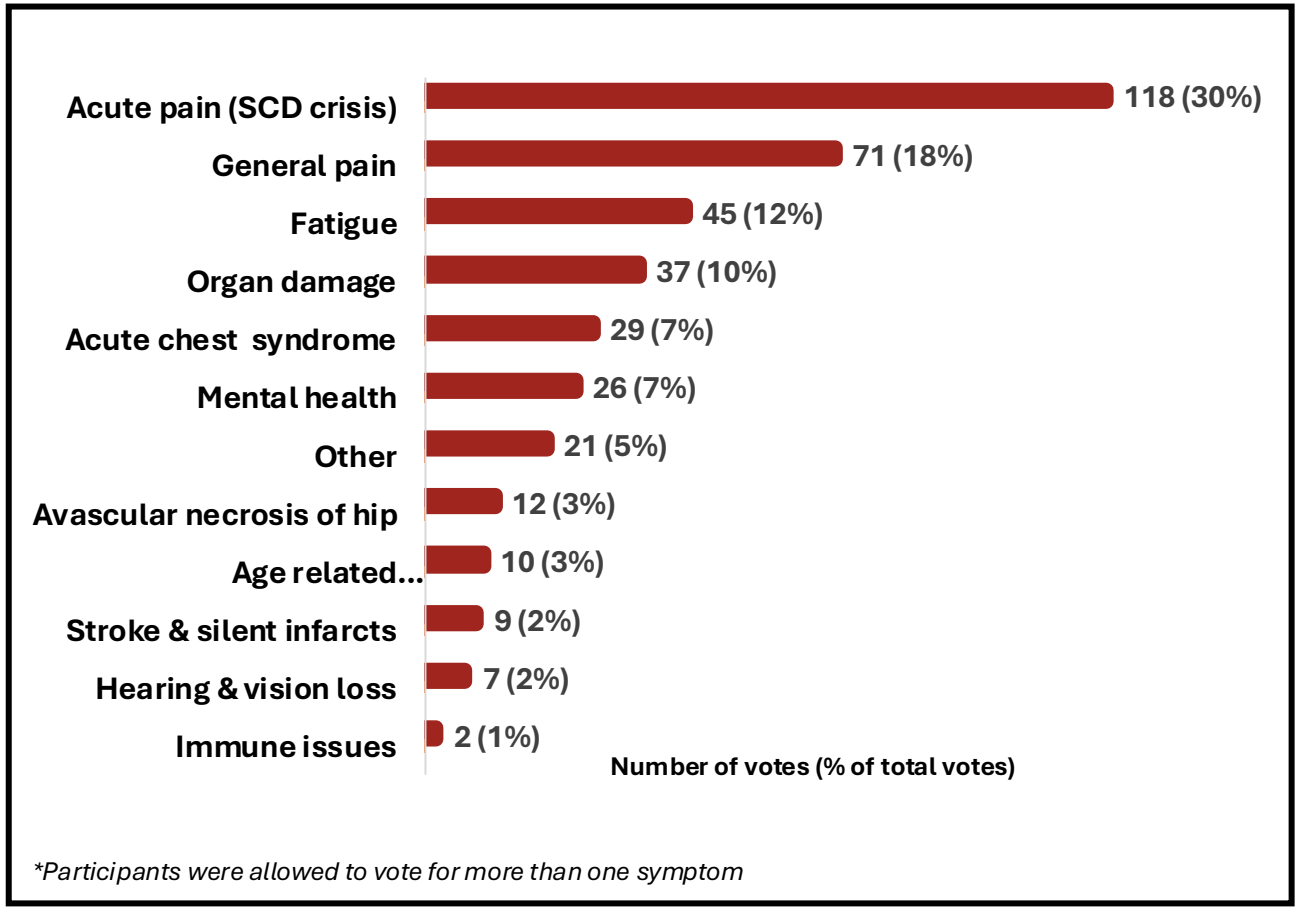


Figure 5 | **Sickle cell disease clinical complications.** Acute complications bring the individual with sickle cell disease

Impact of Sickle Cell Disease on Body Organs

Chronic Pain in Individuals With SCD

- Prevalence of chronic pain in adults with SCD is 60-70%
- Pain is a significant burden and cause of morbidity for people with SCD
- When exploring new therapies to treat SCD people living with the disease were asked to identify which disease-based symptoms should be targeted: 50% voted for pain



Blood Adv. 2021 Dec 14;5(23):53232-31.

Complications of sickle cell disease accumulate with increasing age



Infancy	Childhood	Adolescence	Young adulthood	Adulthood
• Dactylitis • Stroke • Sepsis • Splenic sequestration • Aplastic crises	• Stroke • Sepsis • Aplastic crises • Acute pain • Acute chest syndrome	• Aplastic crises • Acute pain • Acute chest syndrome • Osteonecrosis • Nephropathy • Cognitive dysfunction • Retinopathy • Gallstones	• Acute pain • Acute chest syndrome • Osteonecrosis • Nephropathy • Cognitive dysfunction • Retinopathy • Gallstones • Chronic pain • Pulmonary hypertension • Death	• Acute pain • Acute chest syndrome • Osteonecrosis • Nephropathy • Cognitive dysfunction • Retinopathy • Gallstones • Chronic pain • Pulmonary hypertension • High opioid use • Skin ulcers • Clots • Death

Acute and chronic complications

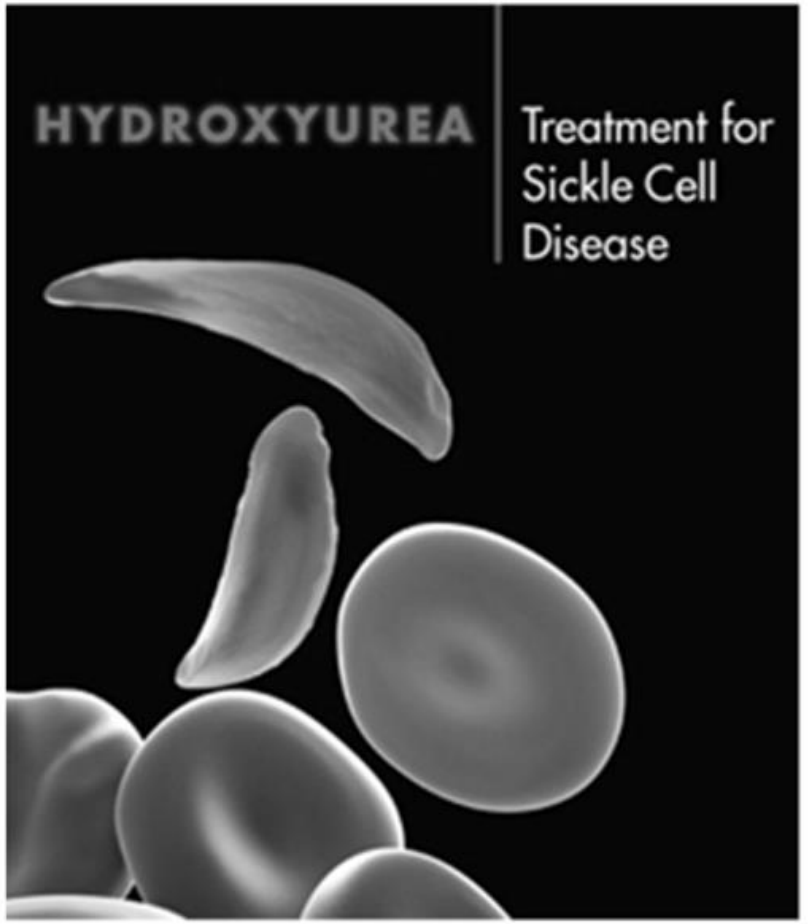
A Chronic Disease with Acute Symptoms

- Sickle cell disease is a chronic disease that has frequent acute complications, such as pain
- Sickle cell is a disorder that caused significant death in childhood, leading to focus on providing pediatric care
- Comprehensive care must include treatment of the chronic disease and not just the acute complications
- Every sickle cell patient should have a long-term sickle cell treatment plan that includes treatment of end organ damage
- Every sickle cell patient should have a hematologist involved in care and visit hematology team at least once a year

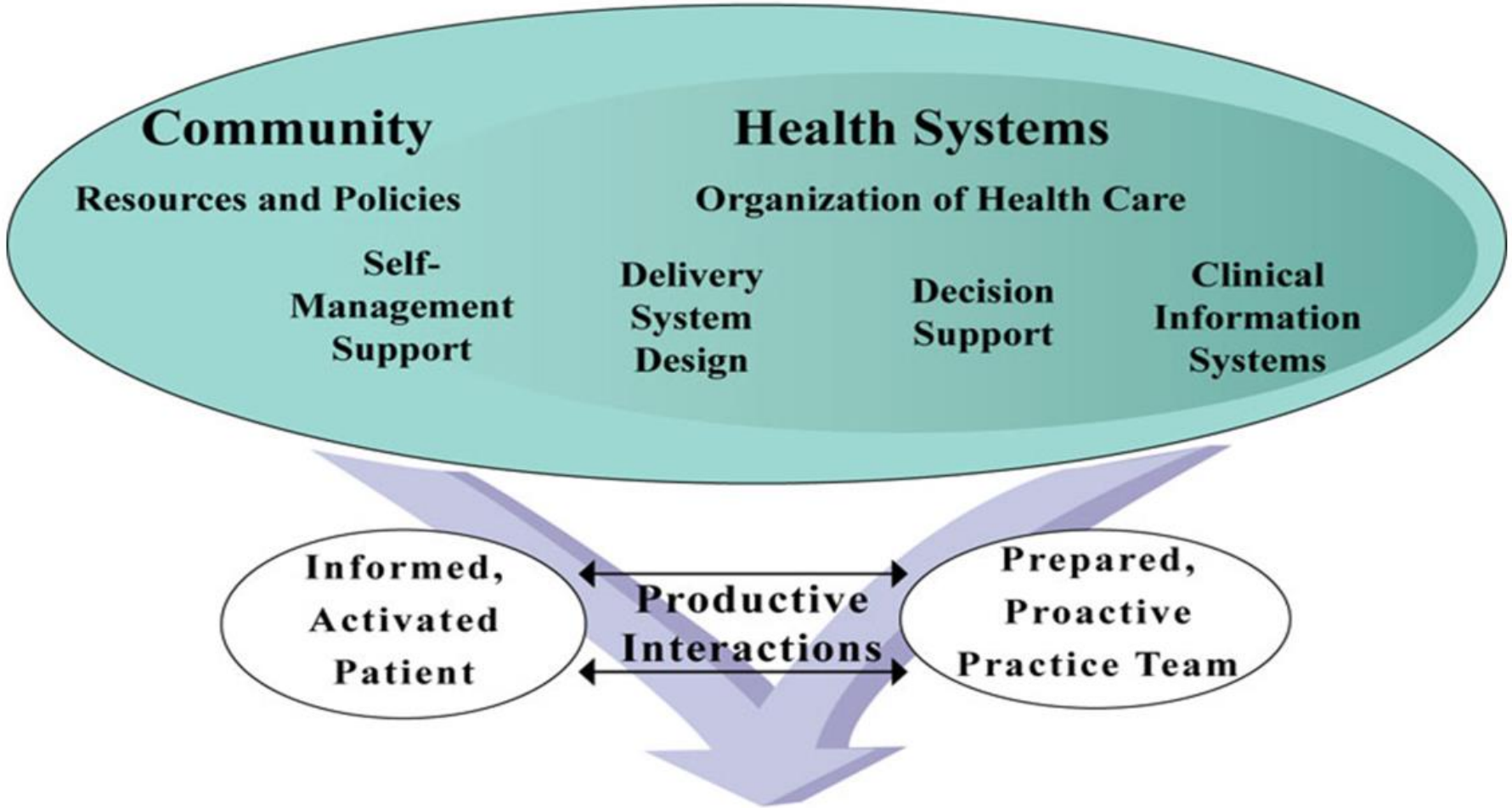


Barriers Beyond the Therapy

- Barriers were with both providers and patients
- Most patients were unaware
- Not a lot of doctors available to prescribe drug (only Hematologists)
- Patients and providers believed drug would cause cancer
- Drug requires frequent blood test to monitor
- Negative provider attitudes towards sickle cell patients
- Failure of providers to include patients in the decision making process



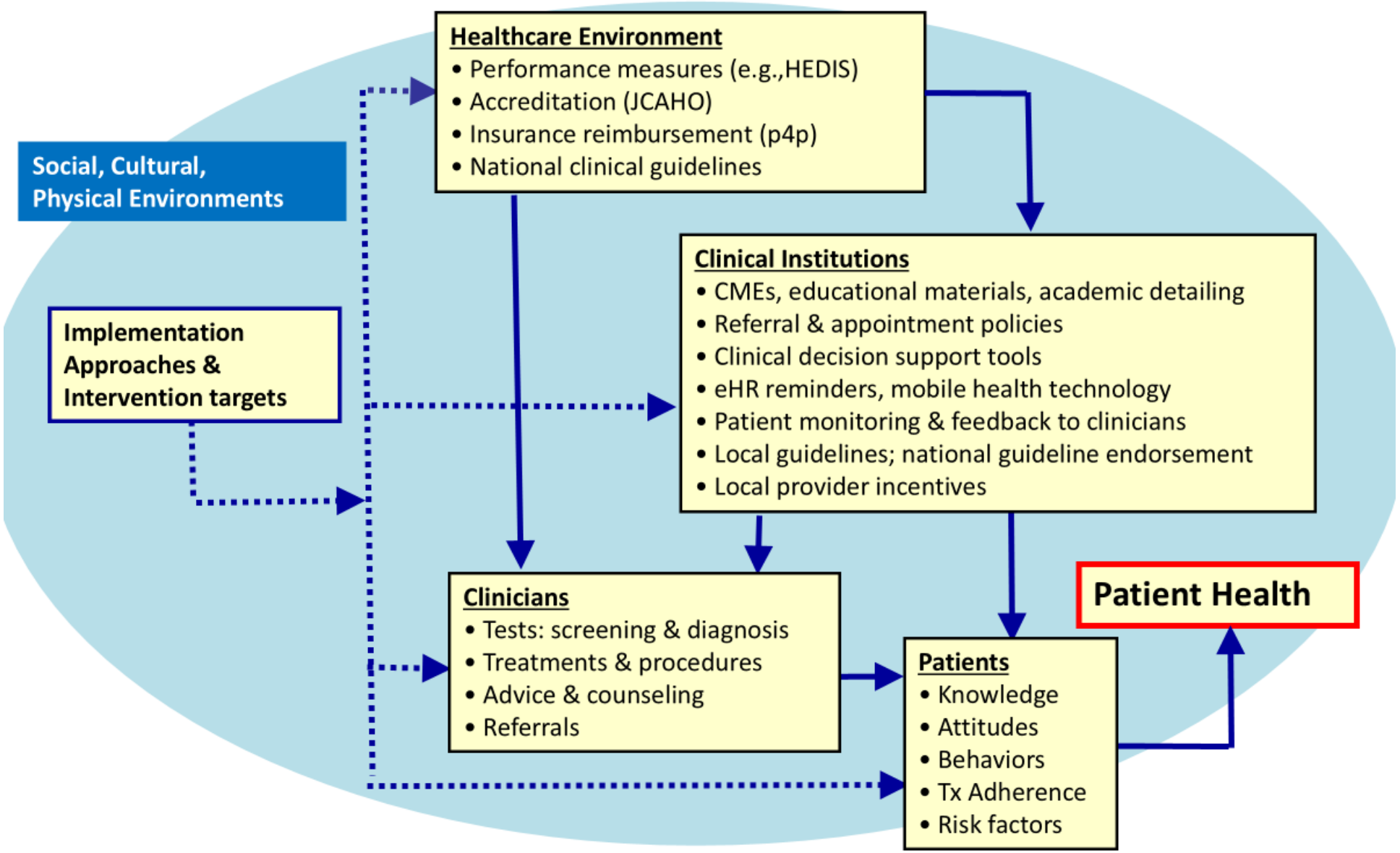
The Chronic Care Model



Improved Outcomes

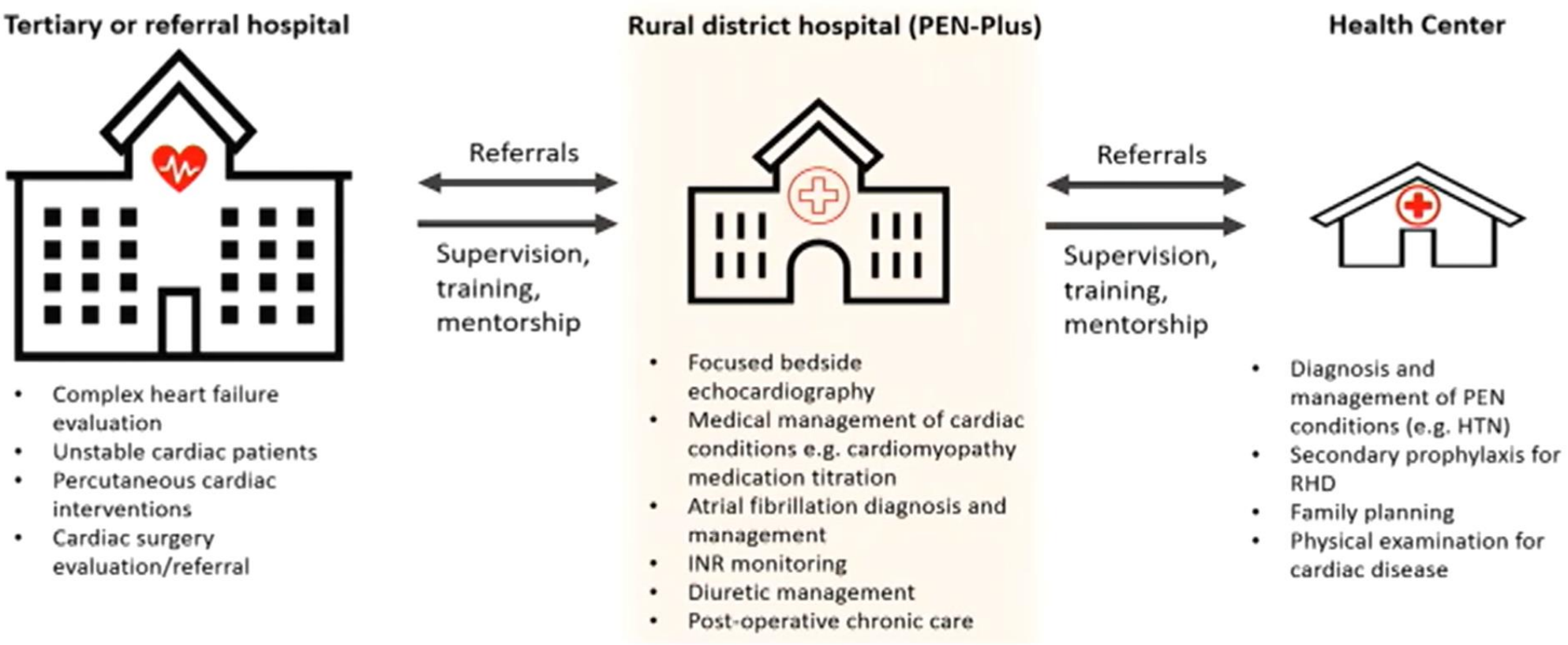
Developed by The MacColl Institute
® ACP-ASIM Journals and Books

Multi-level Model for Clinical Implementation



World Health Organization's Package of Essential Non-Communicable (PEN) Disease and PEN-Plus Models of Care

Originally designed for type-1 DM and cardiac conditions, including potentially complex ones, in low-income countries

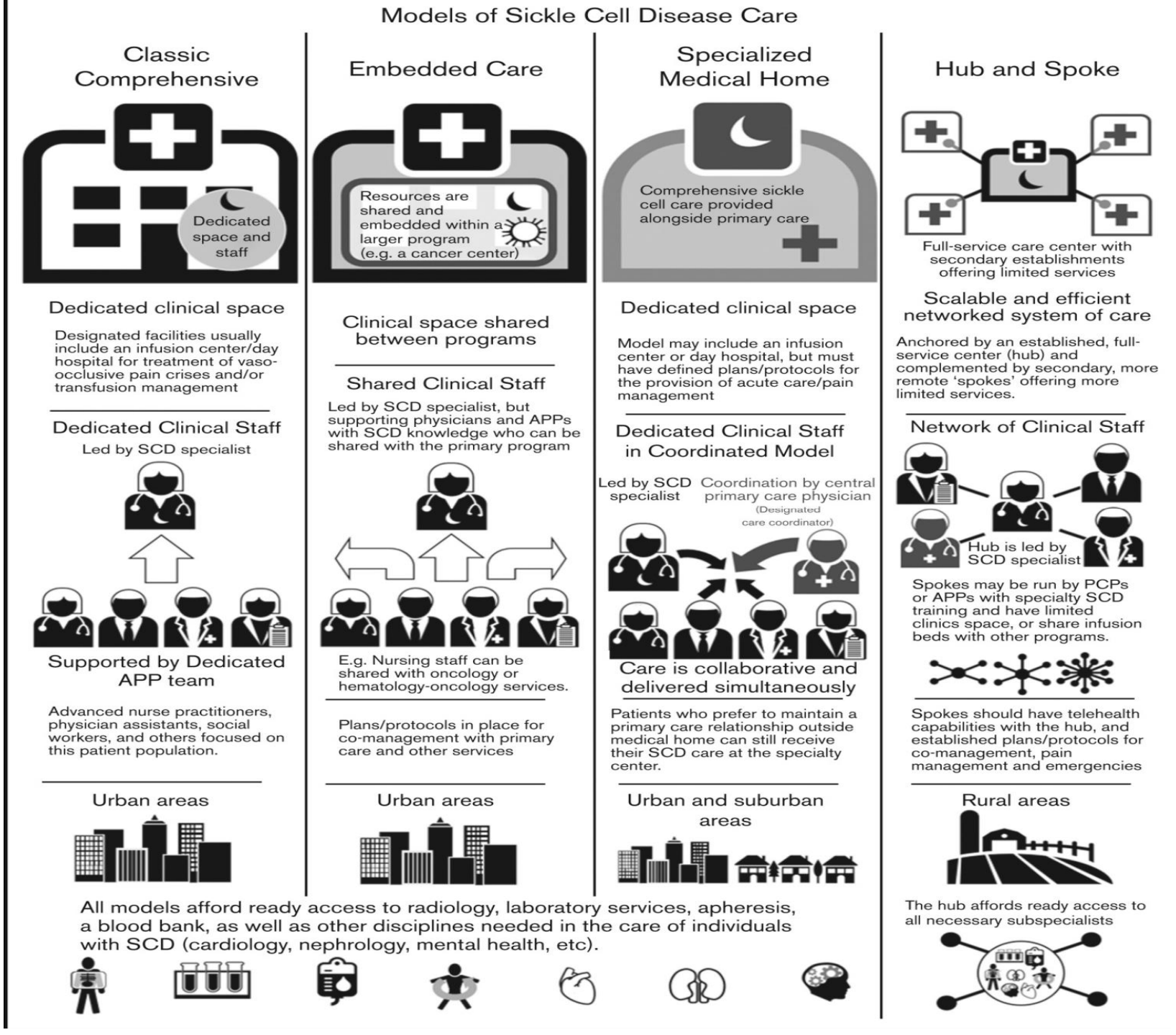


Buhkman *Lancet Diabet Endocrin* 2023;11:384; Klassen, *Global Heart* 2024;19:33

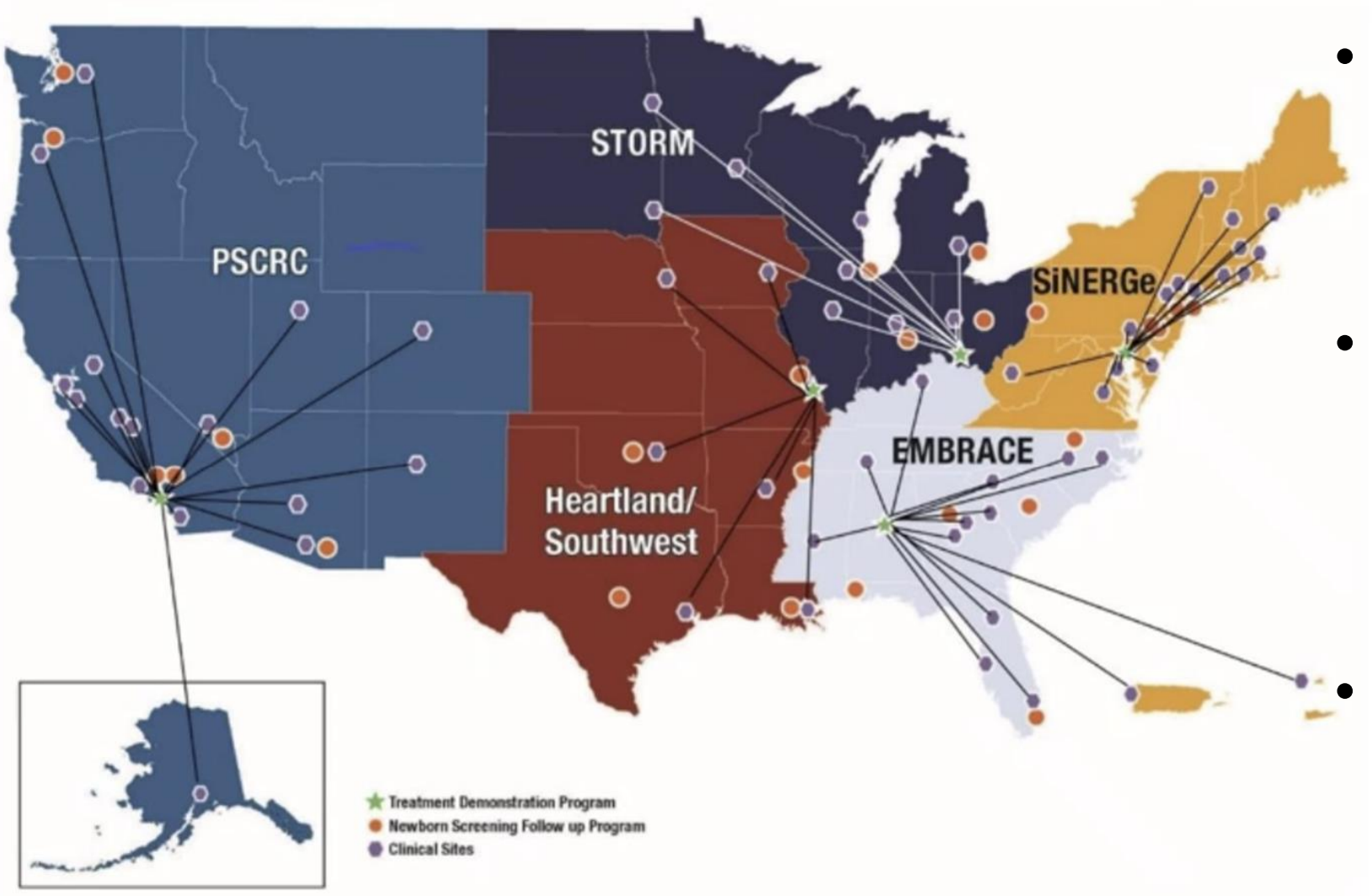
Building access to care in adult sickle cell disease: defining models of care, essential components, and economic aspects

Kanter, et al

https://www.sciencedirect.com/science/article/pii/S2473952920311393



HRSA SCDTDP – Building Clinical Capacity



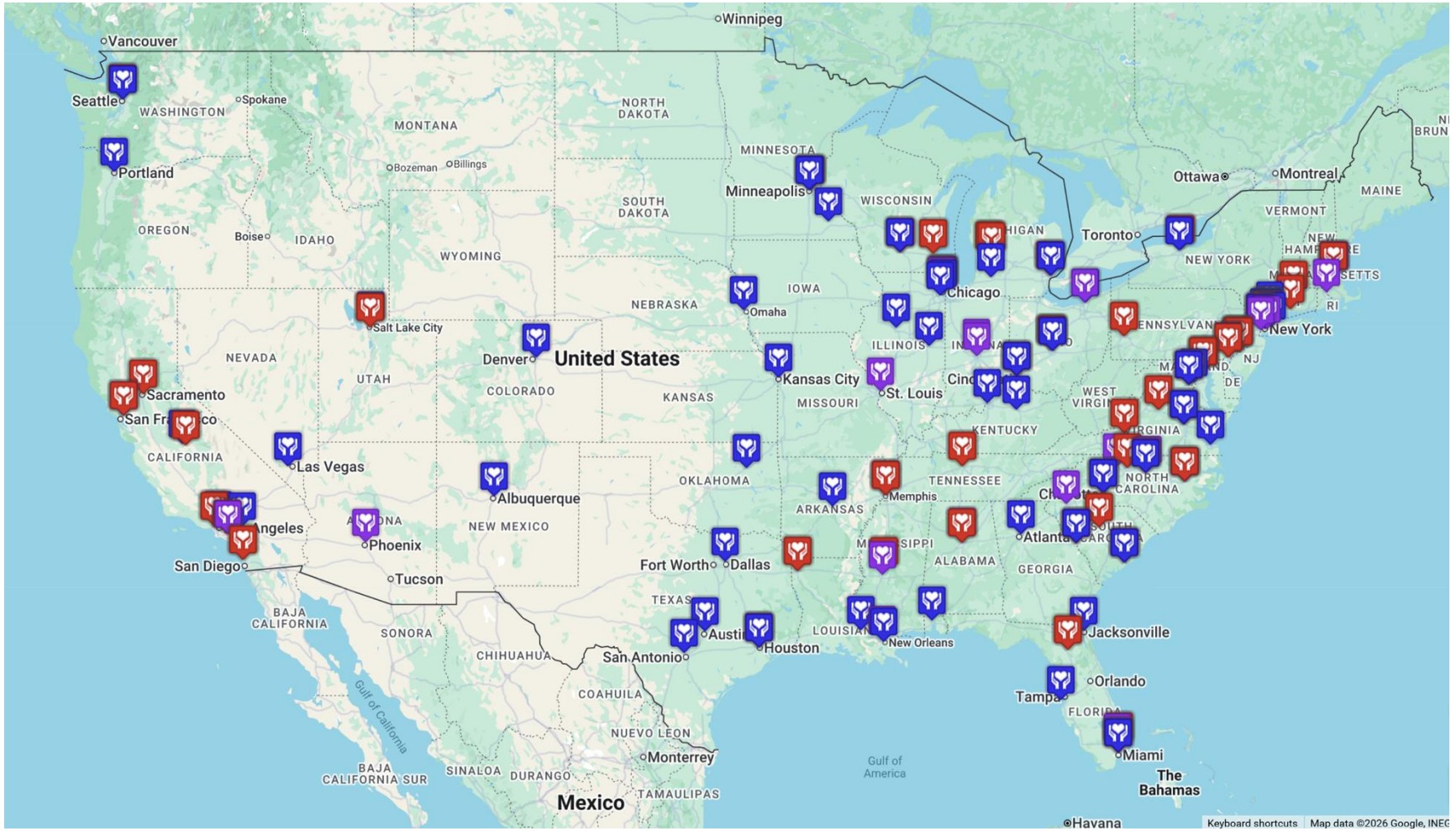
- 5 Regional Grantees funded to develop multi-state networks
- Grantees use Project ECHO to disseminate knowledge about sickle cell treatment
- State-level partners help lead state implementation efforts

National Alliance of Sickle Cell Centers

Adult Treatment Center

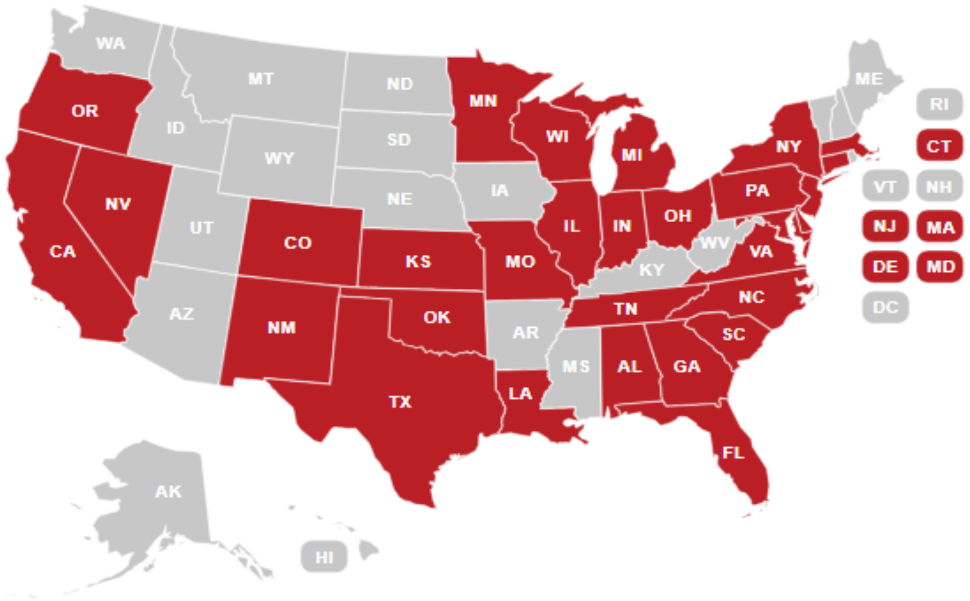
Pediatric Treatment Center

Whole Life Treatment Center



Sickle Cell Disease Association of America Community-based Organizations

SCDAA Chapters



SCDAA utilizes a network of CBOs and CHWs to engage the sickle cell community to ensure that Folia's HRO platform UX meets the needs and preferences of people from a range of backgrounds and experiences.

SCDAA CBOs and CHWs will encourage enrollment of members of the sickle cell community through outreach and awareness campaigns throughout its network. SCDAA will incentivize CBOs who generate high recruitment and participant completion numbers.

56 Community-based Organizations in 34 States and Territories



Community Health Workers

Role and Importance

Community health workers serve as vital links between healthcare services and local populations, providing education, support, and basic health services.

Core Responsibilities

They educate communities on health topics, assist with health screenings, and promote preventive care to improve overall public health.

Skills and Qualities

Effective communication, cultural competence, empathy, and adaptability are essential qualities for community health workers to succeed.

Community-based Organizations and Community Health Workers



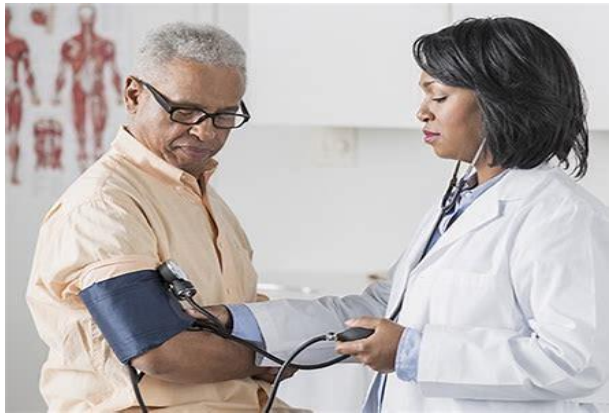
Building Capacity
through training & leadership development



Mobilizing Communities
toward an integrated and comprehensive approach to reducing the burden of CVD

Community Health Workers

Engaging Communities
Through partnership development & Community Participatory Planning



Systems Approach
Linking community education with clinical management



Sickle Cell Disease and Nutrition

- ↑ Resting energy expenditure
- Impaired growth and low lean mass
- Low bone mineral density
- Vitamin D insufficiency and zinc deficiency
- Social barriers to adequate food access



Adults with SCD: Both Ends of the Spectrum

Undernourished Adults

Some adults remain nutritionally depleted. Key priorities:

- Preserve lean mass
- Maintain micronutrient adequacy
- Address chronic appetite suppression

Overweight / Obese Adults

Broader population trends, hydroxyurea use, and survivorship contribute to weight gain. Address:

- Obesity and insulin resistance risk
- Hypertension and diet quality
- Cardiorenal nutritional alignment

Don’t assume all adults with SCD are underweight: **Nutritional counseling must be individualized**

Community Support for Education and Employment

Individuals with sickle cell disease can experience significant challenges with education	Limited employment opportunities can lead to poverty and reliance on public assistance for sickle cell patients	Mental health for adolescent and adult sickle cell patients to prevent loss to follow up and inappropriate use of healthcare
• Implement IEPs, 504 education plans		

NEW Passport to Care: Supporting Sickle Cell Patients in the ED

Passport to Care

For Patients Living With Sickle Cell Disease

Patient Name:

Date Issued:

Pain Medicine Name:	Dose Taken:

[Affix patient label here]



Passport to Care is your personal guide to managing pain crises and follow-up care. At each emergency visit, we will give you a new passport to replace the previous one.

- Keep the **most recent** passport with you **AT ALL TIMES**.
- Bring it to every follow-up appointment and emergency visit.

20010000039

Form # 005297 © 2025_09 www.hrh.

Care Instructions at Home

Manage Your Pain:

- Take the prescribed pain medicine exactly as directed.
- Use heat packs, warm baths, and gentle movements.
- Try relaxation techniques, such as deep breathing or meditation.
- If you cannot control your pain, return to the Emergency Department or call your healthcare provider.

Stay Hydrated:

- Drink plenty of fluids, such as water and electrolyte replacement drinks, every day (8 to 10 glasses for adults).

Note! If you have heart, kidney, or liver issues, speak to your healthcare provider about how you can keep hydrated.

Take Your Medicines:

- Take all medicines as prescribed:
  - ☐ Pain medicine ☐ Folic acid ☐ Laxative/stool softener
  - ☐ Hydroxyurea ☐ Antibiotic
- Do NOT stop taking any medicines without speaking to your healthcare provider.
- Carry your pain plan, if you have one.

Prevent Future Pain Crises:

- Avoid extreme temperatures (both hot and cold).
- Dress warmly in cold weather.
- Avoid dehydration, stress, and overexertion.
- Avoid smoking and drinking alcohol.
- Get enough sleep and rest (at least 7 hours a day for adults).

Safe Use of Opioids

If we prescribed opioids for your pain:

- Know the signs of an overdose
- Avoid alcohol and sedatives
- Never share your medicines.

We also offered you/your family a Naloxone kit.

Discharge Summary

At discharge: (check all that apply)

- ☐ My pain was adequately controlled
- ☐ I received the following prescriptions:
  - ☐ Pain medicine ☐ Folic acid ☐ Laxative/stool softener
  - ☐ Hydroxyurea ☐ Antibiotic
- ☐ I had all my questions and concerns addressed by the team
- ☐ I received instructions for signing onto My Humber Health
- ☐ I received a referral to see the Sickle Cell Awareness Group of Ontario's Patient Well-being Coordinator
- ☐ I received a Naloxone kit.

When to Seek Emergency Care

Go to the nearest Emergency Department if you have:

- A fever **over 38°C (100.4°F)**
- **Chest pain,** trouble breathing
- Pain that is severe or not improving with medicine
- Swelling, no urination, or **dark urine**
- Possible signs of **stroke** (confusion, slurred speech, or weakness)
- Possible signs of **opioid overdose** (slow breathing, confusion, unconsciousness).

Your Care Agreement

You have the right to:

- Be informed and involved in decisions about your care
- Ask questions and understand your condition and treatment options
- Create a care plan that reflects your goals and preferences
- Receive compassionate, safe, and respectful care
- Decline or stop treatments at any time.

Thank You

Thank you for trusting Humber River Health with your care.

We are committed to supporting you through every step of your journey with Sickle Cell Disease. Your wellbeing, dignity, and voice matter.

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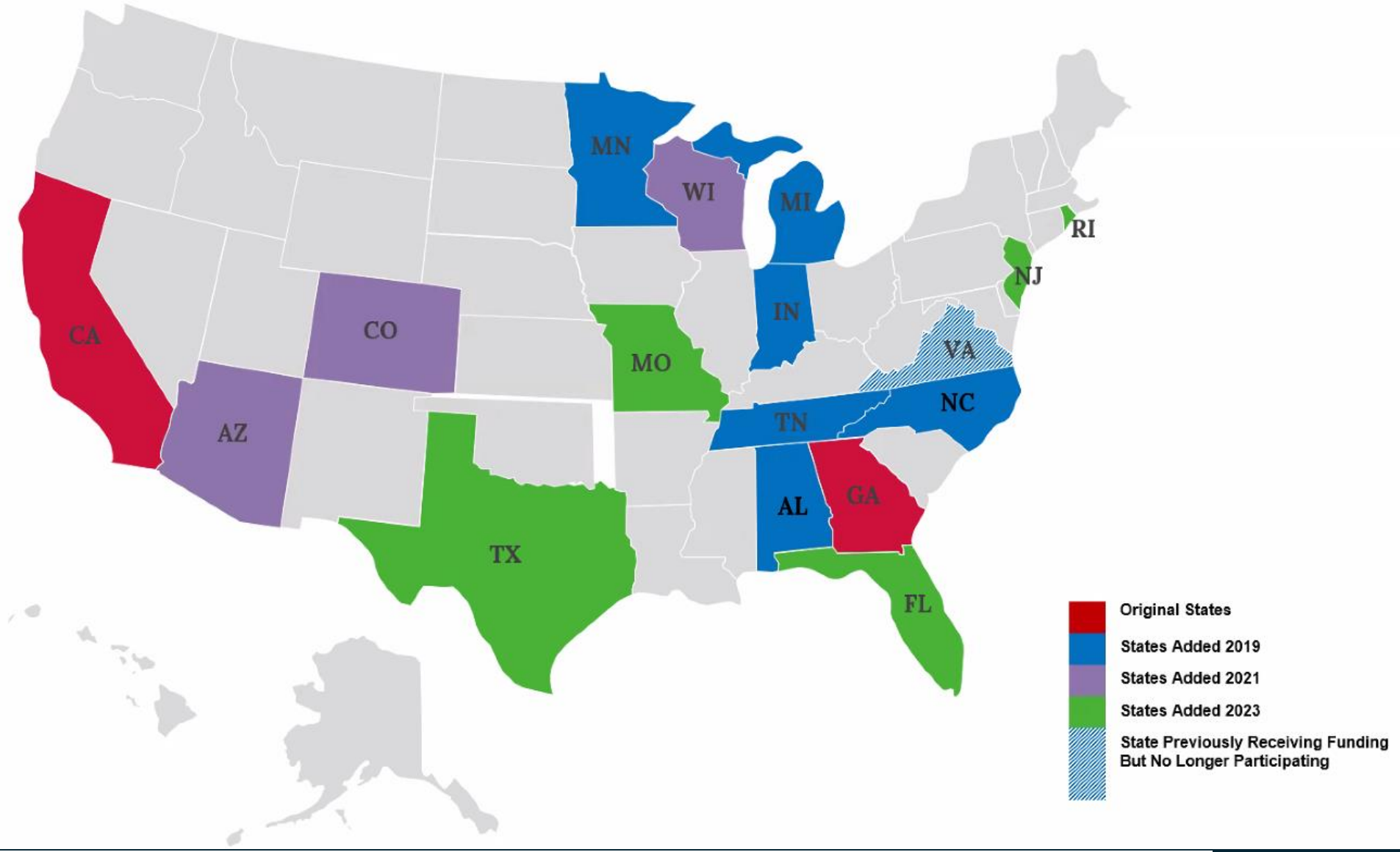
The information provided in this handout is for educational purposes. It does not replace the advice or specific instructions from your doctor, nurse, or other healthcare provider. Do not use this information to diagnose or treat. Please speak with your healthcare provider before making any changes to your medicines or treatment plan.

English: This information is important! If you have trouble reading this, ask someone to help you. **Italian:** Queste informazioni sono importanti! Se ha difficoltà a leggere questo, chieda aiuto a qualcuno. **Spanish:** ¡Esta información es importante! Si tiene dificultad en leer esto, pida que alguien le ayude.

Support CDC's Sickle Cell Data Collection Program

Current States:

1. Alabama
2. Arizona
3. California
4. Colorado
5. Florida
6. Georgia
7. Indiana
8. Michigan
9. Minnesota
10. Missouri
11. New Jersey
12. North Carolina
13. Rhode Island
14. Tennessee
15. Texas
16. Wisconsin



Importance of Data Collection cannot be overstated

Innovative Payment Models are Needed

Individuals with SCD are living longer, so it's no longer a disease of childhood (Need focus on improving adult care)

Strategies are needed to invest in long-term management instead of frequent acute care (Chronic Disease with Acute Complications)

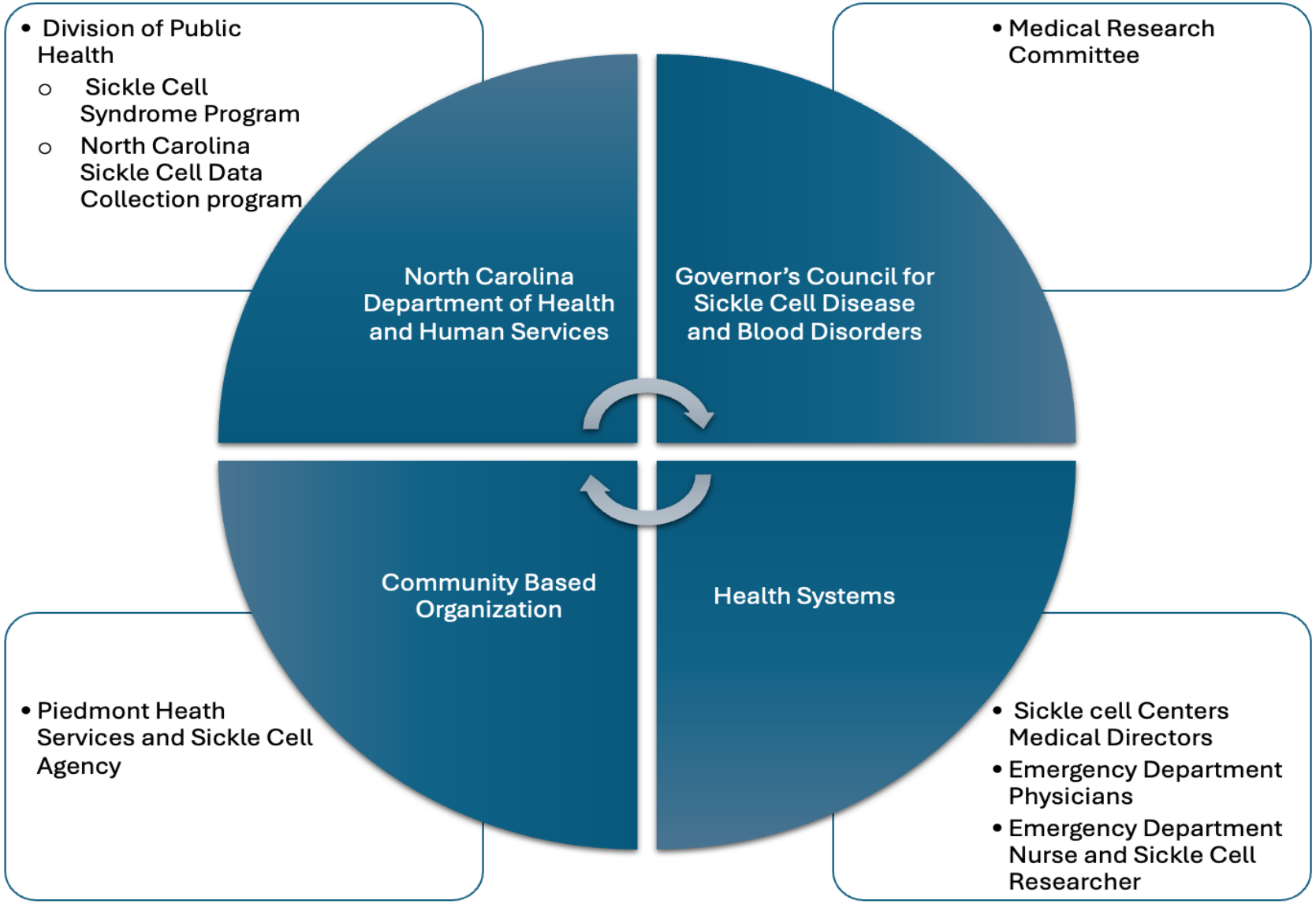
Payment models are needed to advance the use of new, innovative therapies that can be expensive (CMS Cell and Gene Therapy a great start)

Strategies need to engage stakeholders at multiple levels (federal payers, state-level payers, individuals and organizations)

Stakeholder Engagement to Build Infrastructure

- Federal Government
  - HRSA, CDC, NIH, CMS
- Academic Medical Centers
- Hematologists/Sickle Cell Experts
- National Profession Organizations
  - ASH, NASCC
- Patient Organizations
  - SCDAA, SC3, Sick Cells
- State Government
  - Health Departments, State Insurance, Newborn Screening
- Community Hospitals and FQHCs
- State Health Associations
- Community-based Organizations

NC Governor's Council for SCD and Blood Disorders

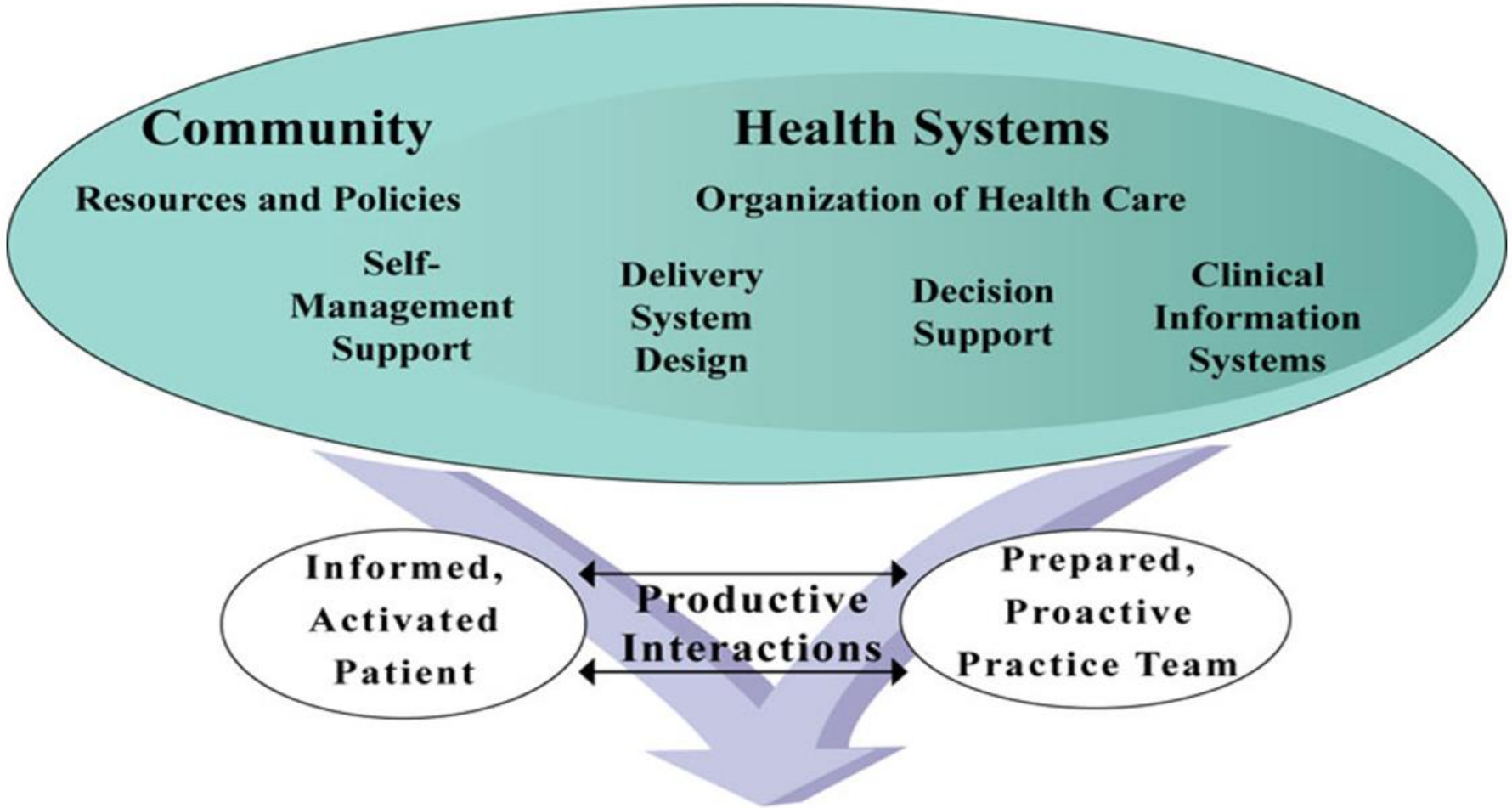


Interventions for High ED Use



- Committee is working on developing screening/referral criteria and interventions for high ED use
- Screening
  - # ED visits/year
    - Adults (age18+): High 10-32 and Super high: 33+ categories
    - Peds (ages 12-18) 4/year (uncomplicated VOE)
- Interventions
  - Will be based on engagement in out-patient care
- Referrals
  - Developed a policy to integrate and coordinate all health system, state and CBO resources

The Chronic Care Model



Improved Outcomes

Developed by The MacColl Institute
® ACP-ASIM Journals and Books

Elements of Comprehensive System of care for SCD

- Evidence-based recommendations on the management of SCD
- Prepared, Proactive Practice Teams which includes Hematologists
- Well funded Academic Medical Centers that can provide guidance on sickle cell care (Hubs)
- Informed, Activated Patients that are engaged in decision making
- Strong Community Support systems which utilize Community-based Organizations and Community Health Workers
- System for allowing patient input, including Community Advisory Boards on Research Projects
- Innovative payment models to finance care models
- Robust community programs to address education and employment, nutrition, exercise and activity support for patients



Current Activities and Policies Related to Comprehensive System of Care for SCD

Dr. Alexis Thompson, MD

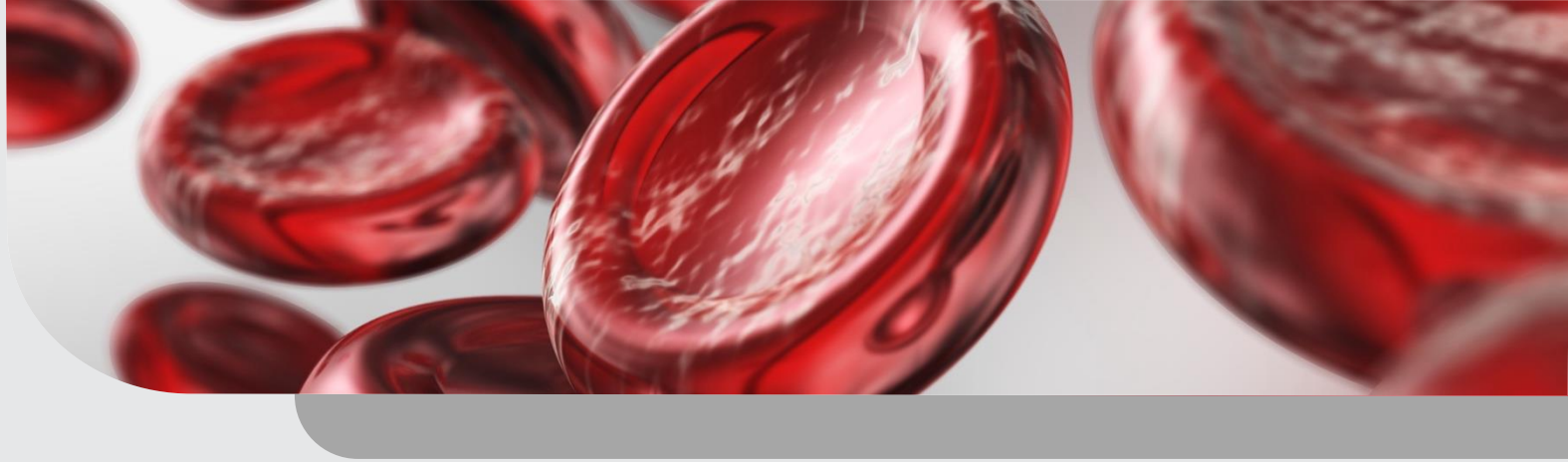
Chair, ASH Sickle Cell Disease (SCD) Task Force

Children's Hospital of Philadelphia

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Office of Minority Health

American Society of Hematology

Helping hematologists conquer blood diseases worldwide



Comprehensive Care for Sickle Cell Disease is Central & Vital

Alexis Thompson, MD, MPH

Chair, ASH Sickle Cell Disease (SCD) Task Force

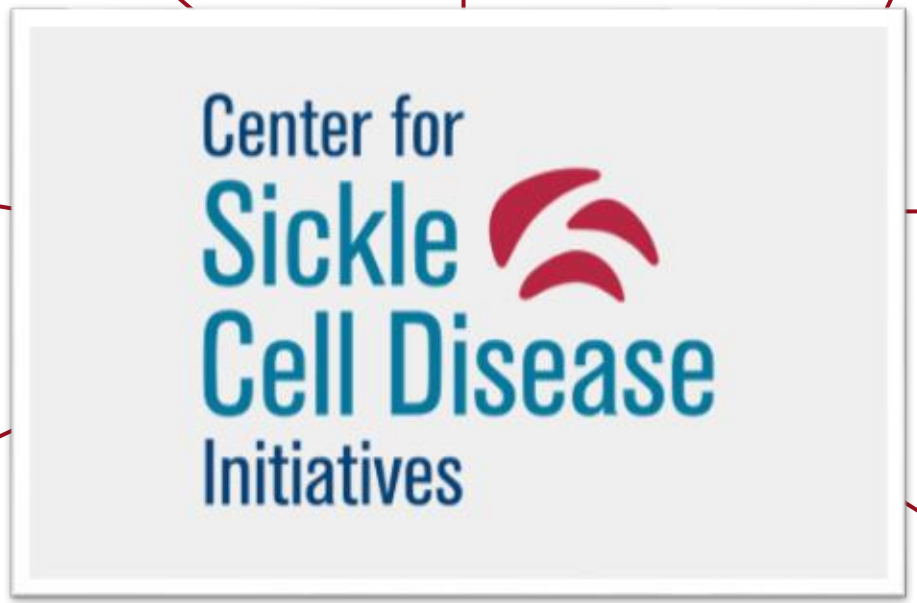
Children's Hospital of Philadelphia

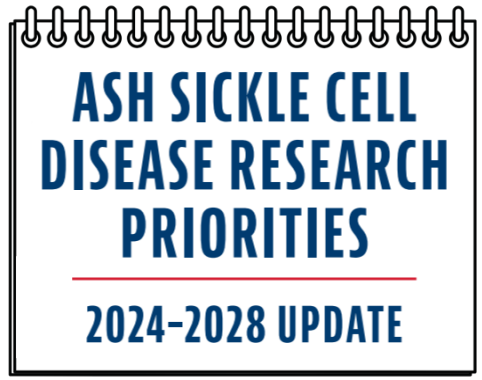

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PRIORITIES
2024-2028 UPDATE


consa
Consortium on Newborn
Screening in Africa for SCD


ASH Clinical
Practice Guidelines





By the Numbers: **A Decade of Impact**

6 **clinical guidelines published,** with **70,000+** implementation tools downloaded

160,000+ newborns screened and SCD care programs implemented in **7 Sub-Saharan countries**

130+ SCD-focused projects funded, totaling over **$18 million** in investment

Over 16,000 patient records collected through the **ASH Research Collaborative**

90+ organizations united to support **federal SCD legislation**

102 SCD Coalition members, **advancing a shared agenda** across disciplines

Four priorities guided ASH's investments from 2015 on, with advocacy supporting each area.



Access to Care

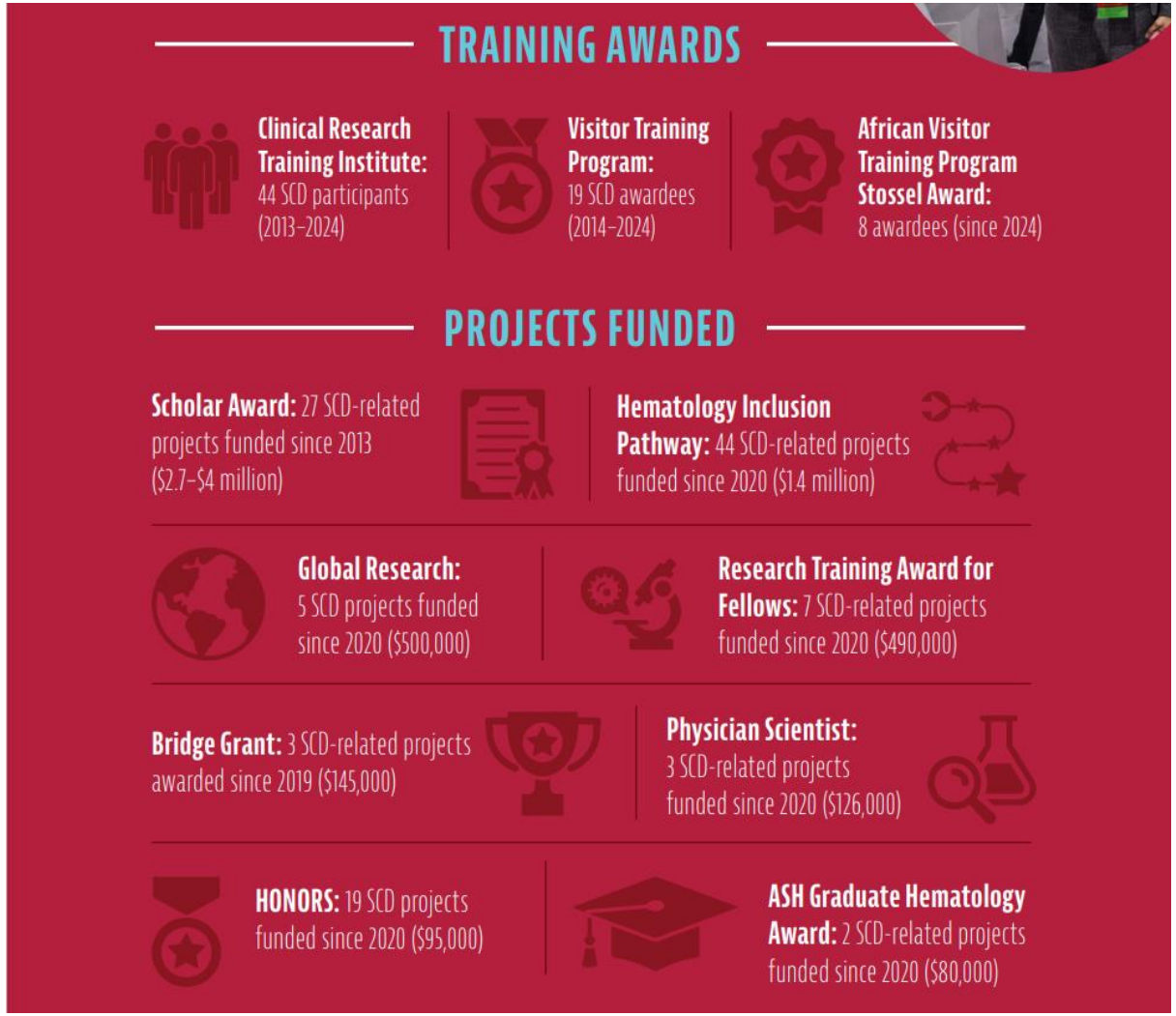
Guidelines Development

- Cerebrovascular Disease
- Cardiopulmonary & Kidney Disease
- Management of Acute and Chronic Pain
- Stem Cell Transplantation
- Transfusion Support
- Hydroxyurea Dosing & Monitoring
- Pregnancy (*in development*)

Quality Improvement

- Quality improvement measures on time to analgesic in ED developed and submitted to CMS
- ASH Quality Improvement Training Institute
- Learning community on transitions

Training and Professional Education





Advocacy

Advocacy is the throughline in all efforts, focused on:

- Raising SCD Awareness
- Enhancing Federal SCD Activities
- Protecting & Advancing Sickle Cell Research
- Improving Access to Comprehensive High-Quality Care
- Improving Reimbursement for SCD Care and Treatment



Strategic Priorities For SCD Moving Forward

Moving Forward:
Sickle Cell Disease Strategic Priorities at ASH

1. Enhance workforce development and capacity by cultivating and supporting providers' skills in SCD care and research

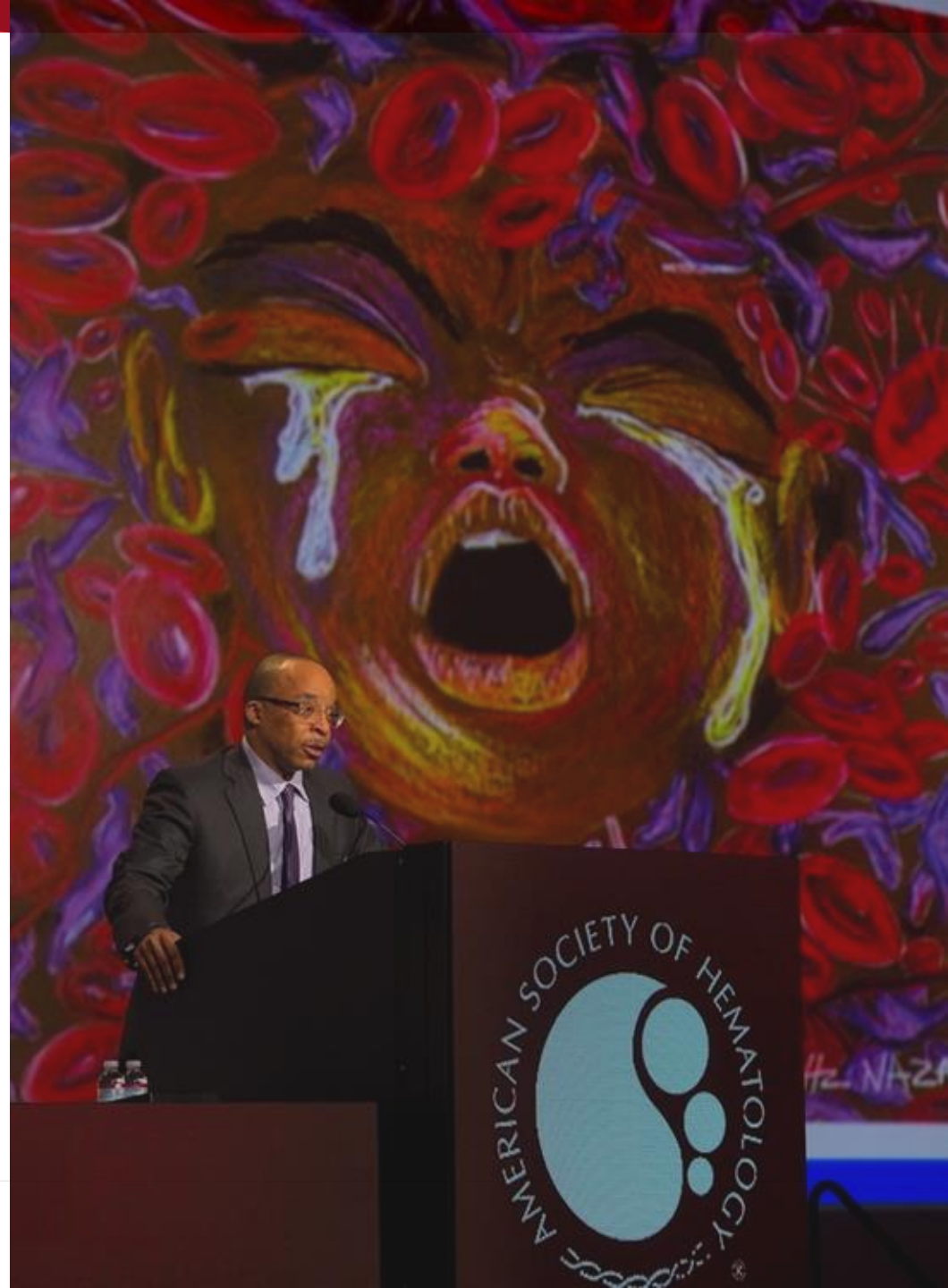
2. Advance and facilitate clinical and scientific research in SCD

3. Promote access to high quality care across an individual's lifespan

1: Workforce Development & Capacity Building (1 of 2)

Goal:

Robust, well-equipped workforce delivering high-quality SCD care and conducting innovative research



1: Workforce Development & Capacity Building (2 of 2)

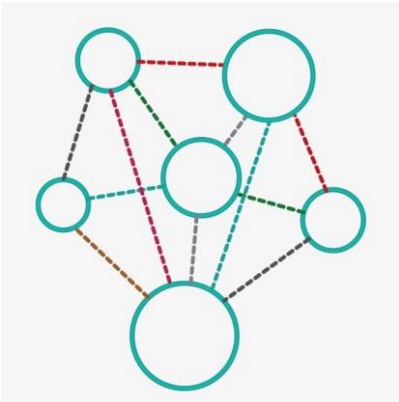
Key Initiative: SCD Education for Community Providers

→Audience: Primary care providers, non-specialist providers, non-SCD expert hematologists, allied health professionals, within the United States and globally

ASH Academy



ASH Connections



2: Advance and facilitate clinical and basic research in SCD (1 of 2)

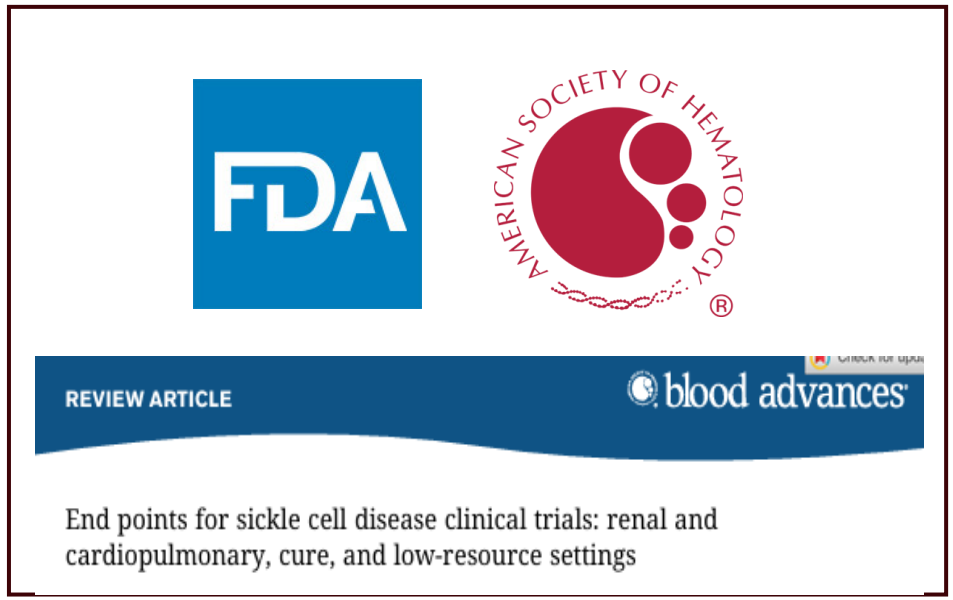
Goal:

Enable a supportive external ecosystem and internal infrastructure to drive progress on ASH's 2024 Research Priorities in SCD



2: Advance and facilitate clinical and basic research in SCD (2 of 2)

Key Initiative: Prioritize the key unanswered questions in SCD that would improve quality of life and advar





ASH Clinical Practice Guidelines

ASH RESEARCH COLLABORATIVE®
Accelerating Progress in Hematology

2: Advance and facilitate clinical and basic research in SCD



Key Initiative: Build capacity for the scientific community to work in partnership with lived experience community on research

- Collaborate with ASH RC on training site PIs and CAB members to conduct community-partnered research
- Leverage learnings from other ASH-led training programs (e.g., CRTI, Clinical Trials Learning Ecosystem)

3: Promote access to high quality care across the lifespan

Goal:

Support systems, practices, and partnerships that deliver high-quality, guidelines-based care across the lifespan, geographies, and settings



3: Promote access to high quality care across an individual's lifespan

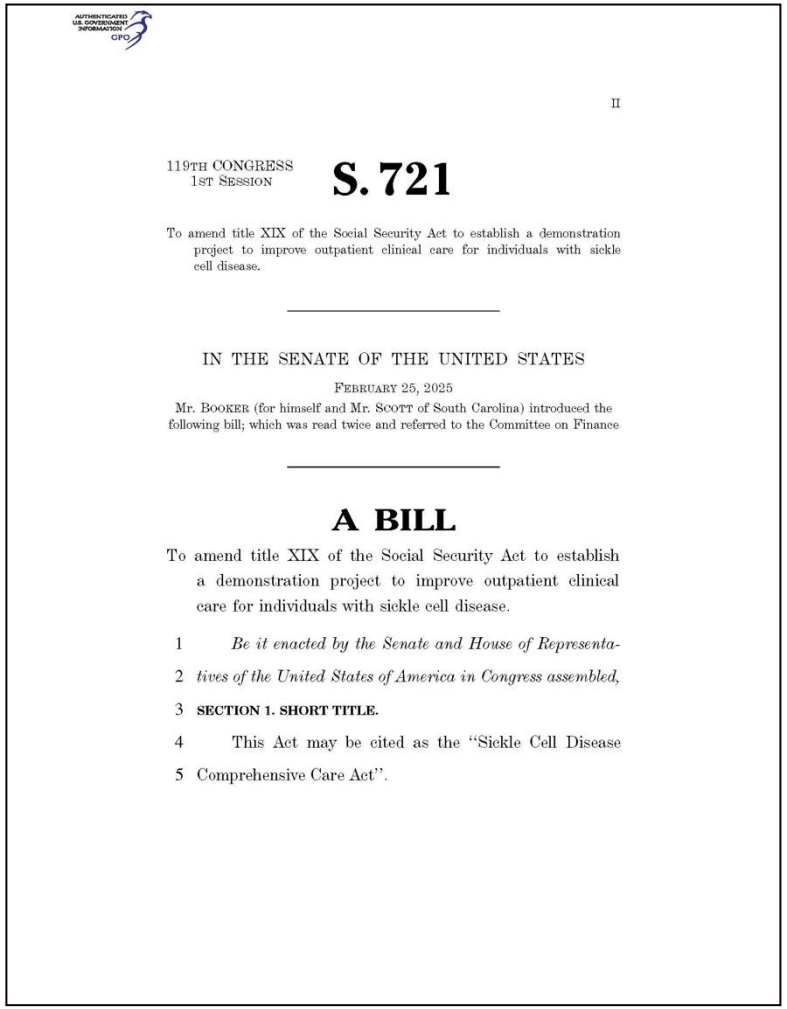
Key Initiative: Strengthen quality of SCD care through development of metrics and other implementation approaches that encourage use and uptake of guideline-based practices

→Assess the feasibility of creating quality metrics for SCD clinical practice guidelines

→Widely disseminate the 2026 Hydroxyurea Dosing and Monitoring Guidelines

→Ongoing collaborations with federal partners, community-based organizations and other medical societies

Sickle Cell Disease Comprehensive Care Act:
A Medicaid Health Home Model



II

119TH CONGRESS
1ST SESSION

S. 721

To amend title XIX of the Social Security Act to establish a demonstration project to improve outpatient clinical care for individuals with sickle cell disease.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 25, 2025

Mr. BOOKER (for himself and Mr. SCOTT of South Carolina) introduced the following bill; which was read twice and referred to the Committee on Finance

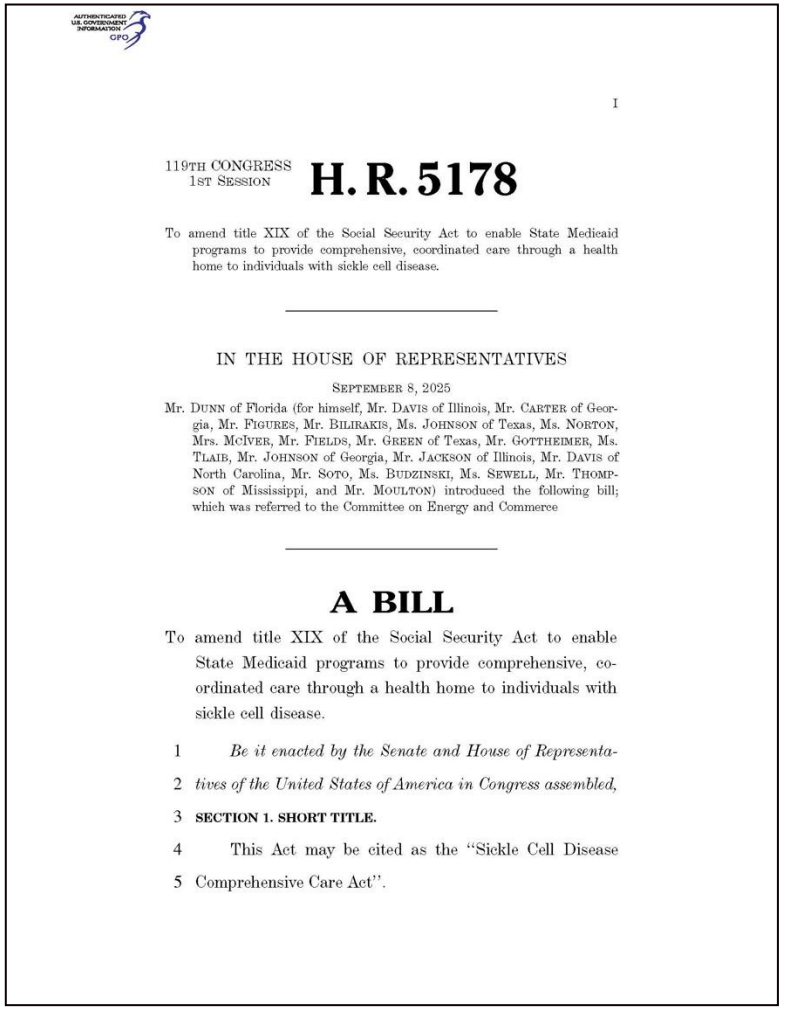
A BILL

To amend title XIX of the Social Security Act to establish a demonstration project to improve outpatient clinical care for individuals with sickle cell disease.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Sickle Cell Disease Comprehensive Care Act".



I

119TH CONGRESS
1ST SESSION

H. R. 5178

To amend title XIX of the Social Security Act to enable State Medicaid programs to provide comprehensive, coordinated care through a health home to individuals with sickle cell disease.

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 8, 2025

Mr. DUNN of Florida (for himself, Mr. DAVIS of Illinois, Mr. CARTER of Georgia, Mr. FIGURES, Mr. BILIRAKIS, Ms. JOHNSON of Texas, Ms. NORTON, Mrs. MCIVER, Mr. FIELDS, Mr. GREEN of Texas, Mr. GOTTHEIMER, Ms. TLAIB, Mr. JOHNSON of Georgia, Mr. JACKSON of Illinois, Mr. DAVIS of North Carolina, Mr. SOTO, Ms. BUDZINSKI, Ms. SEWELL, Mr. THOMPSON of Mississippi, and Mr. MOULTON) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend title XIX of the Social Security Act to enable State Medicaid programs to provide comprehensive, coordinated care through a health home to individuals with sickle cell disease.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Sickle Cell Disease Comprehensive Care Act".

Medicaid Health Home

- Authorized by the Patient Protection and Affordable Care Act
  - Pub. L. No. 111-148, 124 Stat. 119 (2010)
- Health Home models include an enhanced 90% Federal Match (FMAP) for the first eight quarters of the state's program
- States that elect to provide a Medicaid Health Home benefit will coordinate care for beneficiaries with chronic conditions. Services include:
  - Comprehensive clinical care management, including dental and vision
  - Care coordination
  - Health promotion
  - Comprehensive transitional care/follow-up
  - Patient & family support
  - Referral to community & social support services

Why a Health Home for Sickle Cell?



Medicaid is the major insurer for people living with SCD (approx. 50%)



Applies to all Medicaid beneficiaries regardless of age and would allow for a focus on the **transition from pediatric to adult care**



Allows for a **comprehensive care team approach;** Care coordination and comprehensive care shown to **save money and improve outcomes**

Sickle Cell Disease Comprehensive Care Act (S. 721/H.R. 5178)

Expands the existing Medicaid Health Home program to allow for a Health Home **with SCD as the single qualifying condition for eligibility**

Ensures individuals with SCD have **access to coordinated clinical, mental health, and ancillary services** to address their physical, mental, and social needs

Specifies **dental and vision benefits** as part of the included covered services in the Health Home

States that opt to establish a SCD Health Home will receive **federal medical assistance percentage (FMAP) equal to 90% for 8 fiscal quarters**

Physical activity and Nutrition in SCD

- Nutrition in SCD
  - Folic Acid: global standard of care
  - Vitamin D: improves bone health, muscle strength and quality of life
  - Zinc: may reduce pain, improve growth in children and boost immunity
- Exercise as Medicine in SCD
  - Gradual conditioning and moderate exercise are associated with reduction in chronic inflammation without triggering pain episodes
  - Weight training and core fitness improves fitness and possibly longevity in elderly patients with SCD



Question & Answers

CDR Yvonne M. Santiago (Co-Moderator)

Senior Advisor, Office of Minority Health

U.S. Department of Health & Human Services

OMH
U.S. Department of Health and Human Services
Office of Minority Health



Closing Remarks

CAPT Mahyar Mofidi

Deputy Assistant Secretary for Minority Health

Director, Office of Minority Health

U.S. Department of Health & Human Services

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WORLD SICKLE CELL DAY

SAVE THE DATE | June 18 | 2:00 to 3:30 pm EST

Part 2: Federal Resources and Efforts on Achieving Sickle Cell Disease Comprehensive Systems of Care

More information, including registration details, coming soon





New OMH Blog Post!
'Promoting Good Nutrition in People with Sickle Cell Disease'

In their latest blog post, written by CAPT Gayathri Kumar and CAPT Mahyar Mofidi, the HHS OMH highlights the unique nutritional needs of people with SCD and includes sample recipe ideas and tips on how to prepare healthy meals. It also describes actions health care providers and systems and communities can take to increase access to high-quality nutrition for people with SCD.

Visit minorityhealth.hhs.gov/news/promoting-good-nutrition-people-sickle-cell-disease to read the blog post today!

OMH
U.S. Department of Health and Human Services
Office of Minority Health



Hosted By: National Heart, Lung, and Blood Institute (NHLBI), in partnership with the Sickle Cell Disease Association of America (SCDAA)

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Thank You!

Follow **@MinorityHealth** on **X** and **YouTube**, and **@HealthGov** on **Facebook** and **Instagram**, to learn about new resources, initiatives, and events.

Visit **minorityhealth.hhs.gov** for health data and resources related to racial and ethnic minority populations and American Indians/Alaska Natives.

Email us at **MinorityHealthInfo@hhs.gov or scan our QR code** and let us know what part of today's session you found most useful and if you have ideas for how we can improve future events.

Email Us

