

COMPREHENSIVE SYSTEMS OF CARE FOR SICKLE CELL DISEASE ROUNDTABLE SERIES

Part 1: Understanding the Requirements for Sickle Cell Disease Comprehensive Systems of Care

Summary Report

May 14, 2026

U.S. Department of Health & Human Services (HHS)
Office of Minority Health (OMH)

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AGENDA

Roundtable Part 1: Understanding the Requirements for Sickle Cell Disease Comprehensive Systems of Care

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

Segment
Welcome Co-Moderator: CDR Matthew Johns *Strategic Partnerships and Sickle Cell Disease Team Lead, Office of Minority Health* *U.S. Department of Health & Human Services*
Opening Remarks CAPT Mahyar Mofidi *Deputy Assistant Secretary for Minority Health* *Director, Office of Minority Health* *U.S. Department of Health & Human Services*
Run-of-Show and Housekeeping Co-Moderator: CDR Matthew Johns *Strategic Partnerships and Sickle Cell Disease Team Lead, Office of Minority Health* *U.S. Department of Health & Human Services*
Presentation #1: Success Stories and Models of a Comprehensive System of Care for SCD Dr. Donnell Ivy, MD, MPH *Chief Medical Officer, Sickle Cell Disease Association of America (SCDAA)*
Presentation #2: Current Activities and Policies Related to Comprehensive System of Care for SCD Dr. Alexis Thompson, MD, MPH *Chair, American Society of Hematology (ASH) SCD Task Force* *Children's Hospital of Philadelphia*
Panel Discussion | Question & Answer Co-Moderator: CDR Yvonne M. Santiago *Senior Advisor, Office of Minority Health* *U.S. Department of Health & Human Services* Panelist: Dr. Donnell Ivy, MD *Chief Medical Officer, Sickle Cell Disease Association of America (SCDAA)* Panelist: Dr. Alexis Thompson, MD *Chair, American Society of Hematology (ASH) SCD Task Force* *Children's Hospital of Philadelphia*
Closing Remarks CAPT Mahyar Mofidi *Deputy Assistant Secretary for Minority Health* *Director, Office of Minority Health* *U.S. Department of Health & Human Services*

SUMMARY

BACKGROUND AND PURPOSE

Sickle cell disease (SCD) is a lifelong inherited blood disorder that requires coordinated, continuous, and patient-centered care across the lifespan. Although recent advances in treatment, including gene-based therapies and other emerging innovations, have created new possibilities for improving health outcomes, individuals living with SCD continue to face persistent challenges related to access, care coordination, pain management, and quality health. These challenges highlight the need for comprehensive systems of care that extend beyond individual therapies and address the full range of clinical, behavioral, social, and community-based supports.

To create a space for learning about a comprehensive system of care for SCD, the U.S. Department of Health & Human Services (HHS) Office of Minority Health (OMH) convened a two-part roundtable series that brought together SCD warriors, healthcare providers, community organizations, advocates, and federal partners. Part 1 of the webinar series, Understanding the Requirements for Sickle Cell Disease Comprehensive Systems of Care, explored the foundational components needed to strengthen care for people living with SCD. The discussion expanded the focus beyond treatment innovation alone to examine the broader elements required for a comprehensive SCD care model. The roundtable identified key system components, emphasized patient-centered approaches, and fostered dialogue on how federal partners, health care providers, community organizations, and other stakeholders can help to advance more coordinated and responsive care. Of the 729 individuals that registered for Part 1, 399 (54.7%) participated.

WELCOME



Commander (CDR) Matthew Johns

Strategic Partnerships and Sickle Cell Disease Team Lead,
Office of Minority Health
U.S. Department of Health & Human Services

CDR Matthew Johns served as the host and co-moderator alongside CDR Yvonne Santiago. He explained that the series was developed in response to themes that emerged during the September 2025 roundtable series on gene therapies for SCD which underscored the need for broader, holistic systems of care for individuals living with SCD.

OPENING REMARKS



Captain (CAPT) Mahyar Mofidi

Deputy Assistant Secretary for Minority Health
Director, Office of Minority Health
U.S. Department of Health & Human Services

CAPT Mahyar Mofidi reaffirmed HHS' and OMH's commitment to improving the lives of people with SCD, their families, and their communities. Highlighting OMH's SCD initiative as part of broader efforts to improve care and prevent the progression of chronic conditions among minority populations, he acknowledged the distinguished speakers, their work in advancing patient-centered solutions, and how their insights can help shape the discussion on what a comprehensive system of care should look like. He concluded by sharing that HHS is actively supporting SCD efforts across multiple agencies and that the Office of the Assistant Secretary for Health (OASH) and OMH will continue working closely with non-government stakeholders to help change the trajectory of SCD in the United States by transforming pain and stigma into resilience, hope, and health.

PRESENTATION #1: SUCCESS STORIES AND MODELS OF A COMPREHENSIVE SYSTEM OF CARE FOR SCD



Dr. Donnell Ivy, MD, MPH

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

Dr. Donnell Ivy's presentation focused on the need to build comprehensive, lifelong systems of care for individuals living with SCD. Dr. Ivy provided historical context, noting in the early 1970s, the average life expectancy for a person born with hemoglobin SS sickle cell disease was only 8 to 10 years. Today, however, advances in care – including penicillin prophylaxis and hydroxyurea therapy – have significantly improved survival, enabling many individuals with SCD to live well into adulthood. Despite this progress, he emphasized that pain remains the hallmark of SCD, with most individuals experiencing acute pain crises and many also facing chronic pain over time.

Dr. Ivy described SCD as a multisystem, lifelong disease, affecting the brain, lungs, kidneys, bones, joints, eyes, and other organs. Common complications discussed included stroke, sepsis, splenic sequestration, acute pain crises, kidney dysfunction, cognitive effects, retinopathy, fatigue, organ damage, and mental health concerns. Because these SCD-related complications accumulate across childhood, adolescence, and adulthood, Dr. Ivy stressed that SCD must be managed as a chronic, lifelong condition rather than solely through the lens of acute pain episodes. He noted that chronic pain is a major burden for adults with SCD, affecting an estimated 60–70% of this population and contributing substantially to morbidity and reduced quality of life. When individuals living with SCD were asked which disease-related symptoms new therapies should target, 50% identified pain, underscoring its crucial importance in treatment priorities.

Dr. Ivy identified several barriers to care, including lapse in SCD care as patients transition into adulthood, limited access to hematologists and other knowledgeable providers, inconsistent use of therapies such as hydroxyurea, patient concerns or misconceptions about treatment, and broader provider- and system-level challenges. Addressing these barriers requires coordinated, evidenced-based care; long-term treatment plans; annual hematology involvement; and systems that support both acute and chronic disease management.

Using the Chronic Care Model as a framework, Dr. Ivy emphasized that improved health outcomes for patients can be achieved when informed and activated patients work in partnership with prepared multidisciplinary care teams. He discussed models of SCD care such as comprehensive sickle cell centers, embedded care, specialized medical homes, hub-and-spoke systems, regional networks, and Project ECHO (Extension for Community Healthcare Outcomes)-style programs, as approaches to expanding reach and building clinical capacity by extending specialist expertise into community settings. He emphasized that every patient should have access to a hematologist and have an individualized long-term treatment plan, including pain and chronic disease management strategies.

Dr. Ivy emphasized that in addition to medical treatment, comprehensive care must address the whole person, including support for nutrition, education, mental health, and daily living needs. He highlighted the importance of educational accommodations for children and adolescents, such as individualized education plans (IEP) and Section 504 plans, which enable academic success. Dr. Ivy also discussed the need to address mental health for individuals with SCD, including self-esteem, coping skills, and overall psychosocial well-being. He highlighted the value of individualized care plans, including personalized pain management plans integrated into electronic health records and coordinated care between hematology and primary care providers to improve long-term outcomes.

The presentation also emphasized the importance of robust data collection and surveillance, which are essential in improving outcomes for individuals with SCD. Dr. Ivy noted that while the estimated number of people living with SCD in the United States has long remained approximately 100,000, more comprehensive data systems are needed to accurately identify where patients live, whether they receive high-quality care, and their clinical outcomes. He highlighted the importance of tracking indicators such as the use of individualized treatment and pain management plans, receipt of hydroxyurea therapy and transcranial doppler screening, and access to emerging therapies. He stated that continued support for initiatives, such as the CDC's Sickle Cell Data Collection Program, is critical to evaluating the effectiveness of interventions and identifying gaps in care.

Dr. Ivy underscored the need for innovative payment models to support access to new treatments, including new cell and gene therapies, while reducing reliance on emergency care. Dr. Ivy discussed the importance of partnerships among federal and state governments, insurers, healthcare systems, and community organizations to develop sustainable financing models that expand access while reducing long-term healthcare costs.

As an example of successful collaborations, Dr. Ivy highlighted North Carolina's statewide Sickle Cell Disease Program, which brings together government agencies, healthcare systems, academic institutions, and community organizations to improve care coordination, reduce preventable emergency department utilization, and develop targeted interventions for high-risk patients.

Dr. Ivy's concluded by outlining the key elements of a comprehensive system of care for SCD grounded in the Chronic Care Model. He emphasized that successful, patient-centered care requires informed and activated patients; proactive multidisciplinary care teams; evidence-based clinical practices; expert SCD care centers; strong community support systems; reliable data; sustainable payment models; and collaboration across federal, state, clinical, and community partners. He stressed that comprehensive care must extend beyond medical treatment to address education, nutrition, mental health, physical activity, and other drivers of health. By strengthening healthcare infrastructure and placing patients at the center of care, these coordinated strategies can achieve better long-term outcomes for individuals living with SCD.

PRESENTATION #2: CURRENT ACTIVITIES AND POLICIES RELATED TO COMPREHENSIVE SYSTEM OF CARE FOR SCD



Dr. Alexis Thompson, MD, MPH

Chair, American Society of Hematology (ASH) SCD Task Force

Children's Hospital of Philadelphia

Dr. Alexis Thompson provided an overview of the American Society of Hematology's (ASH) efforts to improve outcomes for individuals with SCD through comprehensive care, research, workforce development, education, and advocacy. She noted the expansion of ASH's work over the past decade, including the creation of the Center for Sickle Cell Disease Initiatives in December 2024 to better coordinate activities across ASH; these efforts include clinical guidance, policy advocacy, data development, global newborn screening, provider training, and support for the Sickle Cell Disease Coalition.

Dr. Thompson described ASH's major SCD priorities as access to care, global health, research and clinical trials, and training and professional education, all supported by advocacy. She emphasized that comprehensive care requires not only scientific discovery, but also implementation, quality improvement, and consistent use of evidence-informed practices. ASH has developed six clinical practice guidelines addressing major areas of SCD care, including cerebrovascular disease, cardiopulmonary and kidney disease, acute and chronic pain, stem cell transplantation, transfusion support, and hydroxyurea use. A seventh clinical practice guideline, related to pregnancy, is under development.

Dr. Thompson highlighted ASH's investment in strengthening the SCD workforce, with ASH investing over $18 million in training, early-career support, clinical research development, and global capacity building. ASH's strategic priorities for SCD moving forward are three-fold: 1) workforce development and capacity building, 2) advancing clinical and scientific research in SCD, and 3) promoting access to high-quality care across an individual's lifespan. A key initiative for workforce development is providing SCD education to community providers to increase the number of knowledgeable providers in the United States and globally. Dr. Thompson stressed that many patients receive care outside academic medical centers, making education for community providers, primary care physicians, and non-hematologists essential to improving the availability of knowledgeable SCD care.

For the research priority, Dr. Thompson described ASH's goal of advancing and facilitating clinical and basic research by supporting partnerships with federal agencies, including the CDC, NIH, and FDA, and by identifying clinical trial endpoints that matter to patients. She noted that this work includes research related to kidney disease, cardiopulmonary disease, potential cures, and SCD care in lower-resource settings. Dr. Thompson also emphasized that ASH's research activities are informed by patients, providers, advocates, and community advisory boards to ensure that priorities reflect the needs of those most affected by SCD.

For the priority focused on promoting the availability of high-quality comprehensive care, Dr. Thompson emphasized the need to support systems, practices, and partnerships that deliver high-quality care across geographies. She described quality metrics and implementation approaches as key tools for strengthening SCD care, such as working with the Centers for Medicare & Medicaid Services (CMS) and other entities to identify measures to evaluate hospitals and health care systems using guideline-based practices and ensuring the highest quality of care is provided. She believes partnerships with federal agencies, community-based organizations, and medical societies can help strengthen and improve SCD care.

Dr. Thompson underscored the importance of policy and legislative action to establish and sustain comprehensive systems of care for SCD. She highlighted the Sickle Cell Disease Comprehensive Care Act, a bipartisan bill currently before Congress, as an important policy effort to improve care for individuals with SCD. She explained that the bill would support a Medicaid Health Home model for SCD, building on provisions authorized under the Patient Protection and Affordable Care Act of 2010. This model would promote comprehensive care management, care coordination, health promotion, transitional care, patient and family support, and referrals to community-based services. As more than half of individuals with SCD rely on Medicaid, Dr. Thompson emphasized that this approach could have a significant impact on access, outcomes, and continuity of care across the lifespan, particularly during the transition from pediatric to adult care.

Dr. Thompson concluded by noting the importance of nutrition and physical activity in SCD care, including folic acid, vitamin D, zinc, and moderate exercise. She emphasized ASH's continued commitment to partnerships that expand comprehensive care, improve quality of life, and support better outcomes for individuals with SCD worldwide.

QUESTIONS & ANSWERS SESSION



CDR Yvonne M. Santiago
Senior Advisor, Office of Minority Health
U.S. Department of Health & Human Services

Panelists:

- Dr. Donnell Ivy, MD, Sickle Cell Disease Association of America (SCDAA)
- Dr. Alexis Thompson, MD, American Society of Hematology (ASH) SCD Task Force, Children's Hospital of Philadelphia

During the Question & Answer (Q&A) discussion, several key themes emerged regarding ways to improve care, access, and outcomes for people living with SCD.

One major focus was the need to improve how pain is understood and managed in healthcare settings. Speakers noted that many people with SCD receive care outside academic medical centers, particularly in emergency departments, federally qualified health centers, and primary care practices, where pain crises may be poorly understood or inconsistently treated. Panelists stressed the importance of provider education, evidence-informed tools, and better individualized pain management plans. They also highlighted the importance of empowering patients to advocate for themselves by maintaining access to their health information and care plans, including through mobile devices, that can be shared during treatment encounters. Speakers further discussed hub-and-spoke care models as a strategy of connecting community providers with SCD specialists and extending expertise into community settings.

Another major theme discussed during the Q&A centered on comprehensive, whole-person care. Speakers emphasized that adherence support, home-based services, psychosocial care, transportation assistance, and other wraparound supports should be viewed as essential components of care for people with SCD. The medical home model was discussed as one approach to address barriers that affect patients before, during, and beyond clinical visits across the lifespan. Questions from the attendees also underscored the impact of non-medical drivers of health, including food insecurity, transportation challenges, and limited access to services. Speakers highlighted the important role of community health workers and community-based organizations in identifying local barriers and connecting patients to practical resources and support.

The discussion also emphasized the importance of policy and systems-level changes to improve outcomes for people with SCD. Speakers pointed to the need for strong Medicaid programs, sustained federal partnerships, better data collection, quality-of-care standards, and greater investment in training more providers, including hematologists and primary care clinicians. They also stressed the importance of patient education and supports that promote long-term wellbeing for people with SCD. In response to questions about resources for identifying primary care providers caring

for people with SCD, speakers noted that the ASH is working to expand the network of knowledgeable providers and strengthen partnerships with other medical societies that serve communities affected by SCD. The discussion reinforced that high-quality primary care remains essential, as people with SCD also require routine preventive care and support for health issues unrelated to their disease.

The discussion concluded with a shared recognition that improving outcomes for people living with SCD will require coordinated action across clinical care, community support systems, and public policy. Speakers emphasized that comprehensive care must extend beyond acute treatment to include preventive services, psychosocial support, patient empowerment, and strong partnerships between specialists, primary care providers, community organizations, and federal agencies. The conversation reinforced the importance of building sustainable systems of care that are patient-centered, community-informed, and responsive to the evolving needs of individuals with SCD across the lifespan.

CLOSING REMARKS



CAPT Mahyar Mofidi

Deputy Assistant Secretary for Minority Health
Director, Office of Minority Health
U.S. Department of Health & Human Services

CAPT Mofidi closed Part 1 by thanking the speakers and facilitators for their thoughtful and comprehensive discussion on what is needed to build a sustainable system of care for the SCD community. His remarks emphasized that advancing care requires bridging clinical innovation with community-based support, ensuring that progress is grounded not only in medical advances but also in the lived needs of individuals and families affected by SCD. CAPT Mofidi reaffirmed OMH's continued commitment to fostering partnerships, supporting collective action, and working alongside federal, community, clinical, and advocacy partners to drive meaningful progress. He concluded by thanking all participants and organizations represented on the roundtable for their dedication to transforming the future of care for individuals living with SCD.

FOLLOW-UP EVENTS & INFORMATION



CDR Matthew Johns

Strategic Partnerships and Sickle Cell Disease Team Lead, Office of Minority Health
U.S. Department of Health & Human Services

CDR Johns shared several follow-up announcements with participants, including relevant upcoming events. He directed attendees to a newly published OMH blog post focused on nutrition, a topic briefly discussed during the session, and noted that the post is available through the OMH website. The session concluded with a reminder that slides would be made available, and participants could submit feedback or questions to minorityhealthinfo@HHS.gov.

APPENDIX

MEET THE PRESENTERS



CDR Matthew Johns (Co-Moderator)

Strategic Partnerships and Sickle Cell Disease Team Lead, Office of Minority Health
U.S. Department of Health & Human Services

Commander (CDR) Matthew Johns, MPH is the Regional Health Administrator for HHS Region 9 and a commissioned officer in the U.S. Public Health Service, serving as the senior federal public health official for the Office of the Assistant Secretary for Health. He also serves as Deputy for the Division of Preventive Medicine and Chief Epidemiologist for the PHS-2 Rapid Deployment Force.

CDR Johns has led and supported domestic and international public health emergency responses, including deployments for Ebola in Liberia, major hurricanes, COVID-19, and other disaster and humanitarian missions. His work spans global health security, emergency preparedness and response, epidemiology, and interagency coordination, including partnerships with FEMA to strengthen data-driven public health operations and community resilience.

Areas of expertise: Emerging infectious disease surveillance, epidemiology and response, and public health capacity building



CAPT Mahyar Mofidi, DMD, PhD

Deputy Assistant Secretary for Minority Health
Director, Office of Minority Health
U.S. Department of Health & Human Services

CAPT Mahyar Mofidi serves as the Deputy Assistant Secretary for Minority Health and Director of the HHS Office of Minority Health, where he leads national efforts to improve the health of racial and ethnic minority populations. He brings more than 25 years of public health experience across urban and rural settings, with a focus on serving underserved communities.

Prior to joining OMH, CAPT Mofidi spent over nine years at the Health Resources and Services Administration's HIV/AIDS Bureau, where he directed community HIV/AIDS programs, oversaw a $300 million portfolio supporting hundreds of community-based organizations, and advanced rural health and oral health initiatives. His earlier career includes academic and research roles at the University of North Carolina, with work focused on access to care for low-income and rural populations.

CAPT Mofidi holds a Doctor of Dental Medicine degree from the University of Louisville and a PhD in Health Behavior from the University of North Carolina.

Areas of expertise: Public health leadership, minority health policy, HIV/AIDS programs, community-based health systems, rural and underserved population health, federal health program administration

Dr. Donnell Ivy, MD, MPH

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



Dr. Ivy uses his personal and professional experiences to improve care for individuals with health conditions, including sickle cell disease, by working collaboratively to strengthen the public health infrastructure. Currently, Dr. Ivy serves as an education contractor for the Association of Black Cardiologists, Inc. (ABC). He is also currently serving as the Chief Medical Officer for the Sickle Cell Disease Association of America (SCDAA). Prior to joining the ABC and the SCDAA, Dr. Ivy worked in the USA federal government with the Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) as the Program Director of the Hemoglobinopathies Program, which included the Sickle Cell Disease Treatment Demonstration Program (SCDTDP), the Sickle Cell Disease Newborn Screening Program (SCDNBSP) and the Thalassemia Program. Dr. Ivy worked at the National Heart, Lung, and Blood Institute (NHLBI) of the National Institutes of Health where he was part of the team that developed the NHLBI Sickle Cell Disease Treatment Recommendations of 2014. Dr. Ivy completed his medical school training at East Carolina University School of Medicine. After starting a residency in Pediatrics, Dr. Ivy realized his interest in public health and attended the University of North Carolina at Chapel Hill School of Public Health where he received his master's in public health with honors.

Areas of expertise: SCD care; public health systems; hemoglobinopathies programs; federal health programs; health education and advocacy



Dr. Alexis Thompson, MD, MPH

Chair, American Society of Hematology (ASH) SCD Task Force
Children's Hospital of Philadelphia

Dr. Alexis Thompson is Professor of Pediatrics at the University of Pennsylvania Perelman School of Medicine and holds the Elias Schwartz MD Endowed Chair in Hematology. Her clinical interests include hemoglobinopathies (thalassemia and sickle cell disease), and stem cell transplantation, including gene therapy. Her most significant scientific contributions are clinical and translation studies to better understand and treat hemoglobinopathies. She has served on regional and national advisory committees for governmental agencies as well as non-profit organizations focused on improving healthcare access and reducing health disparities. As a leader of the American Society of Hematology (ASH), including ASH President in 2018, Dr. Thompson helped to develop a national sickle cell data collection platform and to implement newborn screening and early intervention efforts in sub-Saharan Africa, where the burden of SCD is profound. She is the Chair of the SCD Taskforce for the ASH Center for Sickle Cell Disease Initiatives and serves on the SCD Project Leadership Team for the ASH Research Collaborative. Dr. Thompson received the ASH Award for Leadership in Promoting Diversity in 2023 and was elected to the National Academy of Medicine in 2024.

Areas of expertise: SCD and hemoglobinopathies; Stem cell transplantation and gene therapy; hematology research; health quality and access to care; SCD policy and program leadership



CDR Yvonne M. Santiago

Senior Advisor, Office of Minority Health
U.S. Department of Health & Human Services

Commander (CDR) Yvonne M. Santiago serves as Senior Advisor with the Office of Minority Health. She has held a range of leadership and policy roles across the U.S. Department of Health and Human Services. Most recently, she served as Director of Operations in the Office of the Surgeon General.

CDR Santiago's HHS experience includes serving as Supervisory Policy Advisor at the Food and Drug Administration (FDA), Office of Minority Health and Health Equity and as a Commissioned Corps legislative liaison for both the Office of the Surgeon General and the U.S. Public Health Service Commissioned Corps. Her work spans regulatory policy, executive operations, legislative liaison support, and coordination across OASH program and regional offices, the Commissioned Corps, and external organizations, including prior service as Executive Assistant to the Principal Deputy Assistant Secretary for Health, Deputy Director of Operations in OSG, and Special Assistant to the Deputy Surgeon General.

CDR Santiago holds a Bachelor of Arts in Biological Sciences from The University of Chicago (2004), a Master of Arts in Biological and Environmental Sciences from Western Connecticut State University (2009), a Certificate in Public Health from New York University (2020), and a Certificate in Legislative Studies from Georgetown University Government Affairs Institute. She is currently enrolled in the Doctor of Public Health (DrPH) Leadership Program at the University of Illinois Chicago School of Public Health.

Areas of expertise: Health policy and federal affairs, public health leadership and executive operations, strategic planning and interagency coordination



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