

COMPREHENSIVE SYSTEMS OF CARE FOR SICKLE CELL DISEASE ROUNDTABLE SERIES

Part 2: Federal Resources and Efforts to Advance Sickle Cell Disease Comprehensive Systems of Care

Summary Report

June 18, 2026

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

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AGENDA

Roundtable Part 2: Federal Resources and Efforts to Advance Sickle Cell Disease Comprehensive Systems of Care

Thursday, June 18, 2026 | 2:00 PM - 3:30 PM ET

Segment
Welcome Co-Moderator: CAPT Gayathri Kumar *United States Public Health Service Commissioned Corps* *Chief Medical Officer, Office of Minority Health* *U.S. Department of Health & Human Services*
Opening Remarks ADM Brian Christine *Assistant Secretary for Health* *U.S. Department of Health & Human Services*
Run-of-Show and Housekeeping Co-Moderator: CAPT Gayathri Kumar *United States Public Health Service Commissioned Corps* *Chief Medical Officer, Office of Minority Health* *U.S. Department of Health & Human Services*
TALK #1: NIH Research and Programs Supporting Comprehensive Systems of Care for Sickle Cell Disease Griffin P. Rodgers, MD, MBA, MACP, FRCP (London) *Director, National Institute of Diabetes and Digestive and Kidney Diseases* *Chief, Molecular and Clinical Hematology Branch, National Heart, Lung, and Blood Institute*
TALK #2: Health Resources & Services Administration Sickle Cell Disease Programs **Mandy S. David, MPH, PA-C** *Team Lead & Sr. Public Health Analyst of Sickle Cell Programs* *Health Resources & Servies Administration*
TALK #3: Cell and Gene Therapy Access Model Abigale Sanft, MA *Director, Division of Drug Innovation* *Center for Medicare and Medicaid Innovation* *Centers for Medicare & Medicaid Services*
TALK #4: Advancing Sickle Cell Disease Data Exchange: The USCDI+ SCD Minimum Core Dataset LaVerne Perlie, MSN, BSN, RN *Nurse Consultant* *Office of Programs and Implementation* *Office of the National Coordinator for Health Information Technology*

Segment
Questions & Answers Co-Moderator: CDR Yvonne M. Santiago *Senior Advisor, Office of Minority Health* *U.S. Department of Health & Human Services* **Panelists:** • Griffin P. Rodgers, MD, MBA, MACP, FRCP (London) • Mandy S. David, MPH, PA-C • Abigale Sanft, MA • LaVerne Perlie, MSN, BSN, RN
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 complex inherited blood disorder that causes severe pain, organ complications, and reduced quality of life for affected individuals and their families. Although advances in treatment - including gene-based therapies and other emerging innovations - have expanded opportunities to improve outcomes, many people living with SCD continue to experience challenges receiving timely, coordinated, high-quality care. These ongoing challenges underscore the need for comprehensive systems of care that address clinical, behavioral, social, and community-based needs throughout the lifespan.

To advance understanding of these systems, the U.S. Department of Health & Human Services (HHS) Office of Minority Health (OMH) convened a two-part webinar series. Part 1 examined the foundational elements of comprehensive systems of care, while Part 2 focused on federal resources, implementation efforts, payment models, and data initiatives that support coordinated SCD care.

Held on June 18, one day before World Sickle Cell Day, the webinar brought together representatives from the National Institutes of Health (NIH), the Health Resources & Services Administration (HRSA), the Center for Medicare and Medicaid Innovation (CMMI), and the Office of the National Coordinator for Health Information Technology (ONC). Across the presentations, speakers emphasized that improving outcomes for people living with SCD requires coordinated clinical care, effective transitions across the lifespan, meaningful patient engagement, community partnerships, sustainable payment strategies, and interoperable data systems. Of the 718 individuals that registered for the roundtable session, 319 (44%) were in attendance.

WELCOME

Captain (CAPT) Gayathri Kumar

United States Public Health Service Commissioned Corps
Chief Medical Officer, Office of Minority Health
U.S. Department of Health & Human Services

CAPT Gayathri Kumar welcomed participants to the second roundtable discussion in the series and recognized World Sickle Cell Day as an opportunity to raise awareness of SCD, address persistent health disparities, and honor the resilience of individuals living with the disease, their families, and caregivers.

She explained that Part 1 of the series was focused on the core elements of comprehensive systems of care and the policies supporting their implementation, and that Part 2 will highlight federal programs and initiatives that are helping translate those principles into practice.

OPENING REMARKS



ADM Brian Christine

Assistant Secretary for Health (ASH)
Head, United States Public Health Service Commissioned Corps
U.S. Department of Health & Human Services

ADM Brian Christine reaffirmed HHS' commitment to improving the lives of individuals living with SCD and supporting their families and communities. He noted significant progress in treatment, including innovative therapies and models of care, and highlighted Secretary Kennedy's priority of expanding access to gene therapy.

He also highlighted the federal Medicaid pilot, the Cell and Gene Therapy (CGT) Access Model, which supports access to gene therapies for SCD; the model currently includes 33 states, the District of Columbia, and Puerto Rico, and serves approximately 84% of Medicaid beneficiaries living with the disease. He recognized OMH for its leadership in coordinating federal efforts and advancing partnerships that strengthen SCD care.

ADM Christine concluded by emphasizing that meaningful progress depends on collaboration across HHS agencies to improve care coordination, strengthen data and quality measurement, expand access to emerging therapies, and support better outcomes across the SCD care continuum.

TALK #1: NIH RESEARCH AND PROGRAMS SUPPORTING COMPREHENSIVE SYSTEMS OF CARE FOR SICKLE CELL DISEASE



Griffin P. Rodgers, MD, MBA, MACP, FRCP (London)

Director, National Institute of Diabetes and Digestive and Kidney Diseases

Chief, Molecular and Clinical Hematology Branch, National Heart, Lung, and Blood Institute

Dr. Griffin Rodgers described how NIH research and programs support comprehensive systems of care across the SCD continuum. Although advances in treatment have made SCD increasingly manageable - and in some cases curable - he noted that care delivery has not kept pace. In particular, he highlighted the persistent "care cliff" that many patients experience when transitioning from pediatric to adult care, where shortages of trained providers and fragmented services can disrupt treatment.

Dr. Rodgers emphasized that NIH's role extends beyond funding research to supporting the infrastructure needed to translate scientific discoveries into routine practice. NIH investments span therapeutic development, evidence-based clinical guidelines, implementation science, data infrastructure, workforce development, and community engagement.

Dr. Rodgers reviewed major therapeutic advances supported by NIH, including the development of hydroxyurea, evidence supporting chronic transfusion therapy, blood stem cell transplantation, and the scientific discoveries that ultimately led to the FDA approval of two gene therapies for SCD in 2023. He stressed that continued progress depends not only on new treatments but also on ensuring that evidence-based care is consistently implemented. To address this challenge, Dr. Rodgers highlighted the NHLBI's evidence-based clinical guidelines and the Sickle Cell Disease Implementation Consortium, which has enrolled more than 2,400 adolescents and adults across eight clinical centers. Findings from the consortium have identified patient-reported barriers such as negative health care experiences, cost, and unmet behavioral health needs, helping inform strategies to improve care delivery and support successful transition to adult care.

Dr. Rodgers also underscored the importance of standardized data systems, registries, and biospecimen resources that enable consistent measurement, data sharing, and continuous learning across health systems that ultimately supports better care decisions for patients. Dr. Rodgers concluded that scientific advances, implementation science, and strong data infrastructure must work together to ensure that curative therapies ultimately reach all people living with SCD.

TALK #2: HEALTH RESOURCES & SERVICES ADMINISTRATION SICKLE CELL DISEASE PROGRAMS



Mandy S. David, MPH, PA-C

Team Lead & Sr. Public Health Analyst of Sickle Cell Programs
Health Resources & Servies Administration

Mandy David described HRSA's efforts to strengthen coordinated care across the lifespan for individuals living with SCD. While survival has improved significantly over the past four decades, she noted that many individuals continue to encounter challenges obtaining specialty care, accessing emerging therapies, and transitioning from pediatric to adult services.

She emphasized that HRSA's longstanding investments are designed to strengthen care beginning with newborn screening and continuing through adulthood. The agency's portfolio includes the Sickle Cell Disease Treatment Demonstration Program, the SCD Newborn Screening Follow-up Program, and the Hemoglobinopathies National Coordinating Center, which together strengthen the system of care and support services by engaging regional clinical networks, community-based organizations, and other stakeholders to coordinate care, educate patients and their families, improve care quality, and develop the healthcare workforce.

Ms. David highlighted the critical role of community health workers and community-based organizations in connecting individuals and families to services, improving care coordination, and supporting successful transitions to adult care. She also noted that HRSA grantees provide patient and family education, provider training, and quality improvement initiatives to strengthen evidence-based care.

Fiscal year 2025 data demonstrated the reach of these investments. HRSA-supported SCD Treatment Demonstration Program sites served approximately 25,000 individuals with SCD, while community-based organizations funded by the SCD Newborn Screening Follow-up Program served approximately 12,000 people (an increase from about 8,000 the prior year). In addition, 77% of eligible patients receiving care through comprehensive clinics were prescribed disease-modifying therapies, although this measure did not yet include gene therapies.

Ms. David concluded by emphasizing that comprehensive SCD care requires a lifelong, coordinated approach, supported by integrated clinical services, strong community partnerships, data-informed quality improvement, and sustained support for patients and families from diagnosis through adulthood.

TALK #3: CELL AND GENE THERAPY ACCESS MODEL



Abigale Sanft, MA

Director, Division of Drug Innovation
Center for Medicare and Medicaid Innovation
Centers for Medicare & Medicaid Services

Abigale Sanft presented the Centers for Medicare & Medicaid Services (CMS) CGT Access Model, a voluntary Innovation Center initiative designed to improve access to gene therapies for individuals living with SCD while addressing affordability and payment challenges for state Medicaid programs. Although gene therapies offer transformative potential, their cost - often exceeding $2 million per treatment - and limited long-term outcomes data have created significant financial uncertainty for payers.

To address these challenges, the model enables CMS to negotiate pricing agreements with manufacturers on behalf of participating state Medicaid agencies. The agreements include standardized pricing, guaranteed discounts, and outcomes-based rebates when therapies do not achieve expected clinical results. Participating states agree to implement a common coverage approach while retaining responsibility for providing the therapies.

Ms. Sanft reported that CMS has negotiated agreements with manufacturers of FDA-approved gene therapies for SCD on behalf of states for outcomes-based agreements and that participating jurisdictions represent approximately 84% of Medicaid beneficiaries living with the disease. She described this broad participation as a significant milestone in expanding access while reducing financial risk for state Medicaid programs.

Recognizing that gene therapy extends well beyond the infusion itself, Ms. Sanft emphasized that the model also addresses the patient care journey. Patients often require months of evaluation, cell collection, conditioning, treatment, and recovery, creating logistical and financial challenges for families. The model supports transportation, lodging, meals, and other travel-related expenses and requires participating manufacturers to cover fertility preservation services because chemotherapy used during treatment may result in infertility.

Ms. Sanft concluded by noting that participating states have begun implementing the model with ongoing CMS technical assistance and cooperative agreement support. She added that CMS is monitoring the broader cell and gene therapy pipeline to determine whether similar outcomes-based payment models could be applied to additional diseases in the future.

TALK #4: ADVANCING SICKLE CELL DISEASE DATA EXCHANGE: THE USCDI+ SCD MINIMUM CORE DATASET



LaVerne Perlie, MSN, BSN, RN

Nurse Consultant
Office of Programs and Implementation
Office of the National Coordinator for Health Information Technology

LaVerne Perlie described how interoperable health data can improve care coordination and continuity for individuals living with SCD. She introduced the USCDI+ SCD Minimum Data Set Project, a collaboration among the ONC, the Office of the Assistant Secretary for Health (OASH), and the Assistant Secretary for Planning and Evaluation (ASPE) to establish standardized SCD data that can be shared across health care settings.

Although SCD-related information is collected by electronic health records, registries, payers, and public health programs, differences in data standards and system design often limit effective information exchange. To address these challenges, the project builds on the United States Core Data for Interoperability (USCDI) by developing SCD-specific extensions through the USCDI+ framework.

Development of the minimum data set has been guided by a multidisciplinary technical expert panel that includes individuals living with SCD, clinicians, researchers, state Medicaid leaders, advocacy organizations, federal partners, and health IT experts. A review of more than 34 SCD data systems identified inconsistent data capture, patient miscoding, incomplete clinical information when needed, and limited interoperability across systems.

Based on these findings, the panel identified two priority use cases - SCD diagnosis and emergency care - and developed a proposed minimum data set containing 45 standardized data elements, including 10 new draft elements. The data set is intended to support more accurate patient identification and improve the availability of critical clinical information during acute episodes.

Ms. Perlie concluded by encouraging public comment on the proposed data set and participation in pilot testing, emphasizing that standardized, interoperable data are essential to improving care coordination and creating a more connected system of care for people living with SCD.

QUESTION & ANSWER SESSION



Commander (CDR) Yvonne M. Santiago (Co-Moderator)

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

Panelists:

- Griffin P. Rodgers, MD, MBA, MACP, FRCP (London)
- Mandy S. David, MPH, PA-C
- Abigale Sanft, MA
- LaVerne Perlie, MSN, BSN, RN

The discussion reinforced several cross-cutting themes that emerged throughout the webinar, including sustained federal investment, implementation of emerging therapies, interoperable data, and the importance of patient and community engagement.

The panel also discussed implementation of emerging therapies and the broader systems needed to support their use. Ms. Sanft explained that although the current CMS model focuses on gene therapies for SCD, CMS is evaluating whether similar outcomes-based payment approaches could benefit other conditions and invited stakeholders to contact the CMS team with suggestions at cgtmodel@cms.hhs.gov with the subject line “Future Model Considerations.” Ms. Sanft also emphasized that successful implementation requires attention to the entire patient journey, including behavioral health, prolonged treatment timelines, travel, lodging, childcare, and other logistical needs. Complementing these efforts, Ms. David described HRSA's investments in workforce development, community health workers, care coordination, quality improvement, and partnerships between primary care providers and SCD specialists.

Several questions focused on clinical practice and health information exchange. Dr. Rodgers recommended NHLBI resources for providers, patients, and families seeking information about hydroxyurea and other evidence-based therapies. Ms. Perlie explained that the USCDI and USCDI+ initiatives build on established national standards - including SNOMED, LOINC, and ICD - to improve interoperability and support more consistent exchange of SCD information across health systems.

Panelists concluded by emphasizing the central role of individuals living with SCD and their communities in advancing care. Ms. David encouraged participants to engage through clinical programs, community-based organizations, telehealth ECHO programs, mentoring opportunities, and provider education. Dr. Rodgers underscored the principle of "nothing about us without us," encouraging patients and families to participate in research, advisory groups, and institutional review boards to ensure that research and policy reflect patient priorities. Ms. Perlie encouraged patients and families to actively access and share their electronic health information, particularly when receiving care across multiple health systems.

CLOSING REMARKS



CAPT Mahyar Mofidi

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

CAPT Mahyar Mofidi closed the webinar by recognizing World Sickle Cell Day and reaffirming HHS and the Office of Minority Health's commitment to improving the lives of people living with SCD and supporting their families and communities. He thanked presenters from NIH, HRSA, CMMI, and ONC for highlighting federal efforts to strengthen coordinated, patient-centered SCD care, as well as the OMH team for organizing the webinar series.

He concluded by emphasizing that continued progress will depend on sustained collaboration across federal agencies, health care providers, researchers, community organizations, and individuals living with SCD to advance comprehensive systems of care and improve health outcomes.

RESOURCES

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)

- CureSCi Metadata Catalog
- Cure Sickle Cell Initiative
- NHLBI Cure Sickle Cell Initiative Common Data Elements

Health Resources & Services Administration (HRSA)

- Sickle Cell Disease Programs | MCHB

Office of the National Coordinator for Health Information Technology (ONC)

- USCDI+ Platform
- Platform User Guides- Account Creation, Commenting, Site Navigation
- Overview Summary of the USCDI+ SCD Dataset and the Request for Public **Feedback**
- New Use Cases, Data Classes, and Specific Data Elements

Center for Medicare & Medicaid Innovation (CMMI)

- CGT (Cell and Gene Therapy Access) Model

APPENDIX

MEET THE PRESENTERS

CAPT Gayathri Kumar

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

CAPT Gayathri S. Kumar is the Chief Medical Officer of the HHS Office of Minority Health. In this role, she provides clinical expertise and insight for OMH programs and activities to help address health disparities and improve health outcomes for racial and ethnic minorities in the United States.

From 2021 to 2025, she served as the Acting Director and Deputy Director of the Division of Refugee Health (DRH) at the Office of Refugee Resettlement/Administration for Children and Families where she oversaw national refugee health benefits, health promotion, mental health, and survivors of torture programs. Prior to these roles, she also served as a Medical Officer in the Immigrant, Refugee, and Migrant Health Branch at the CDC; a CDC chronic disease epidemiology state assignee to the Georgia Department of Public Health; and as a CDC Epidemic Intelligence Service Officer in the fields of nutrition, physical activity, and obesity prevention.

She has provided healthcare for racial/ethnic minority communities—including limited English proficient communities—for the majority of her clinical career. She completed her internal medicine residency training at Emory University and her medical education at Indiana University School of Medicine.

Areas of expertise: Areas of expertise: Public health program development and clinical leadership, chronic disease prevention, minority health, population health, internal medicine



ADM Brian Christine

Assistant Secretary for Health (ASH)
Head, United States Public Health Service Commissioned Corps
U.S. Department of Health & Human Services

Admiral Brian Christine serves as the 18th Assistant Secretary for Health at the U.S. Department of Health and Human Services (HHS). In this role, he provides leadership on the nation's public health priorities, including chronic disease prevention and efforts to strengthen the nation's overall health.

ADM Christine also leads the U.S. Public Health Service Commissioned Corps, one of the nation's eight uniformed services, composed of more than 5,000 public health professionals dedicated to protecting, promoting, and advancing the health and safety of the nation.

President Donald Trump nominated ADM Christine for this position, and he was subsequently confirmed by the U.S. Senate.

As Assistant Secretary for Health, ADM Christine is focused on restoring trust in public health, radical transparency, and tackling the epidemic. His leadership emphasizes putting patients first, strengthening the integrity of public health institutions, and ensuring that every American has the opportunity to live a healthier, more fulfilling life. ADM Christine earned his Doctor of Medicine degree from Emory University and completed his residency in Urology at the University of Alabama at Birmingham. An internationally recognized leader in Men's Health, he established a practice regarded as a global Center of Excellence, treating patients from across the United States and abroad.

ADM Christine has published peer-reviewed research, lectured extensively, and trained surgeons around the world. He is a member of several leading professional organizations, including the American Urologic Association, the Sexual Medicine Society of North America, the International Society for Sexual Medicine, and the International Continence Society.

As a "Mainstreet Physician" treating the men, the women, and children of our republic, ADM Christine has demonstrated a deep commitment to service, innovation, and improving the health and well-being of all Americans.

Areas of expertise: Public health leadership, federal health policy, chronic disease prevention, healthcare system administration, men's health and urologic medicine



Griffin P. Rodgers, MD, MBA, MACP, FRCP (London)

Director, National Institute of Diabetes and Digestive and Kidney Diseases
Chief, Molecular and Clinical Hematology Branch, National Heart, Lung, and Blood Institute

Dr. Griffin P. Rodgers is Director of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health, a position he has held since 2007. In this role, he provides scientific leadership and strategic direction for one of NIH's largest institutes, overseeing a staff of more than 650 employees and a budget exceeding $2.3 billion.

Dr. Rodgers received his undergraduate, graduate, and medical degrees from Brown University, completed his residency at Barnes Hospital and Washington University School of Medicine, and pursued fellowship training in hematology through a joint NIH–George Washington University program. He subsequently earned an M.B.A. from the Johns Hopkins Carey Business School and a Master of Legal Studies.

As a physician-scientist, Dr. Rodgers is internationally recognized for pioneering work that led to hydroxyurea becoming the first FDA-approved therapy for sickle cell disease. More recently, he and his collaborators have reported a modified blood stem-cell transplant protocol with high efficacy and low toxicity in adults with sickle cell disease. He holds three patents, has published more than 250 peer-reviewed articles, and has edited five editions of the Bethesda Handbook of Clinical Hematology.

Dr. Rodgers is a member of the National Academy of Medicine, the American Academy of Arts and Sciences, and a Fellow of the Royal College of Physicians (London), among others. He has received honorary doctorates from Washington University, Meharry Medical College, and Albany Medical College, and is the 2026 recipient of the American College of Physicians' John Phillips Memorial Award.

Areas of expertise: Biomedical research leadership, diabetes and kidney disease research, sickle cell disease and hematology, clinical and translational research



Mandy S. David, MPH, PA-C

Team Lead & Sr. Public Health Analyst of Sickle Cell Programs
Health Resources & Servies Administration

Mandy S. David, MPH, PA-C is currently the Senior Public Health Analyst and Team Lead within the Genetic Blood Disorders Services Branch at the Health Resources and Services Administration. She currently manages the SCD Treatment Demonstration and SCD Newborn Screening Follow-Up Programs and leads the Hemophilia and Hereditary Hemorrhagic Telangiectasia teams. Ms. David completed her Master of Public Health degree with a concentration in global health and health disparities from the Johns Hopkins Bloomberg School of Public Health. Previously, she served as the Program Manager, Chief Physician Assistant, and Advanced Practice Provider Manager for the Sickle Cell Center for Adults at Johns Hopkins Hospital for over 15 years.

Areas of expertise: Sickle cell disease program leadership, genetic blood disorders, public health program management, health disparities, clinical care coordination



Abigale Sanft, MA

Director, Division of Drug Innovation
Center for Medicare and Medicaid Innovation
Centers for Medicare & Medicaid Services

Abigale R. Sanft, M.A., serves as the Director of the Division of Drug Innovation (DDI) at the Centers for Medicare & Medicaid Services (CMS), Center for Medicare and Medicaid Innovation (CMMI). In this capacity, she oversees the design, implementation, and oversight of innovative alternative payment models focused on prescription drug policy in Medicare Part B, Medicare Part D, and Medicaid.

Ms. Sanft's expertise lies at the intersection of drug pricing, payment policy, and healthcare delivery reform. At CMS, she has directed teams advancing Medicare and Medicaid drug models, advised senior CMS and HHS leadership, and collaborated with federal, state, and industry partners to align drug innovation with affordability and access. Her portfolio includes advancing model designs that address regulatory feasibility, operational integration, and consumer affordability while promoting value-based care in the pharmaceutical space.

Before joining CMS, Ms. Sanft was a Data and Policy Analyst at a consulting firm where she supported multiple federal health policy projects for HHS, focusing on Medicare and Medicaid prescription drug programs. Her work included data-driven evaluations of drug utilization, overdose risk factors, and reporting requirements. She also has research experience from the Dana-Farber Cancer Institute, where she contributed to translational research in chronic lymphocytic leukemia, supporting drug development and clinical trial policy efforts.

Ms. Sanft holds a Master of Arts in Public Management from Johns Hopkins University and an A.B. in Public Policy from Brown University, where she graduated with honors. She is also an alumna of CMS's Aspiring Leaders Program, reflecting her commitment to leadership and public service.

Areas of expertise: Prescription drug policy, Medicare and Medicaid payment innovation, value-based healthcare, pharmaceutical pricing and affordability, healthcare delivery reform



LaVerne Perlie, MSN, BSN, RN

Nurse Consultant
Office of Programs and Implementation
Office of the National Coordinator for Health Information Technology

LaVerne Perlie, MSN, BSN, RN, serves as a Nurse Consultant and Senior Clinical Advisor at the Office of the National Coordinator for Health Information Technology. She collaborates closely with federal partners and external stakeholders to advance health IT adoption, establish data standards, enhance patient safety, improve care coordination, and facilitate the implementation of health information exchange. She also provides health IT expertise for funding and technical assistance on interagency initiatives.

Currently, LaVerne is leading the development of the USCDI+ Sickle Cell Disease dataset. This important initiative, in collaboration with ASPE, aims to improve access to care by enabling the real-time exchange of health information for individuals living with Sickle Cell Disease. Prior to joining ONC, LaVerne Perlie served at the Centers for Medicare and Medicaid Services, contributing to the Center for Clinical Standards and Quality and the Office of Financial Management. Her nursing experience spans acute care, internal medicine, maternal health, utilization review, and quality improvement.

LaVerne holds a Bachelor of Science in Nursing from Coppin State University and a Master of Science in Nursing Informatics from Walden University.

Areas of expertise: Health information technology, nursing informatics, health data standards and interoperability, care coordination and health information exchange, quality improvement and patient safety



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



CAPT Mahyar Mofidi

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



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