SICKLE CELL DISEASE
PARTNERSHIP

PROGRESSING FORWARD:

Improvements to Access to Care and Treatment for Persons with Sickle Cell Disease

Assessing Progress From 2022 to 2024 Based on Recommendations in "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action" Issued by the National Academies in 2020

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SICKLE CELL DISEASE PARTNERSHIP

June 2024

In celebration of World Sickle Cell Day, on June 19, 2024, the Sickle Cell Disease Partnership is releasing this report. This report constitutes the Partnership's review of progress in federal legislative, regulatory, and administrative actions that respond to, and build on, the recommendations made by the National Academies of Science, Engineering, and Medicine's 2020 report, "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action."

The Sickle Cell Disease Partnership is a federal policy and advocacy alliance of health care organizations committed to advancing actionable federal health care policies that will improve the lives of patients living with Sickle Cell Disease (SCD). The Partnership was founded in Spring 2022 with an aspiration to complement the work of existing organizations in the SCD community by collaboratively working together to translate the recommendations of the National Academies' report into policy actions by the federal government. This assessment comes two years after the Partnership's founding and four years after the National Academies' report was released.

The Partnership is pleased to have played a role in advancing SCD policy and programs over the past two years. But more importantly than our role, we recognize and applaud that the progress to date is a direct result of the collaboration, hard work, creativity, and leadership of many individuals and organizations—including Partnership member organizations, organizations and leaders within the SCD community, and staff and policymakers in the federal government. Ultimately, progress is the fruit of collaboration and consensus-building amongst many different organizations and individuals.

At present, in many ways, the sense of progress in the federal policy community is real and energizing. By several metrics, the SCD health policy environment is improving. However, as this report shows, although much work has been undertaken, much work remains. There is still much that needs to be done to capitalize on the momentum, energy, and focus over the past two years. Legislation needs to be enacted. Care models need to be adopted. Access needs to be realized. Stigma needs to be addressed. Gaps in access to care and treatment in Medicaid need to be closed.

The Partnership's vision is a day when every individual with SCD in the United States lives to their fullest potential because the individual has timely, sustained access to high-quality, equitable, coordinated care and treatment. The vision of realizing that day is the inspiration and fuel that drives us forward in our work together.

We are progressing towards that day, but much work remains to be done. On World Sickle Cell Day 2024, we celebrate the successes, recognize the contributors, and rededicate ourselves to collaborating to advance our mission together.

METHODOLOGY

The Partnership assessed progress for each of the core strategic domains outlined in the National Academies' report. Given the ever-shifting policy environment and nature of the policy recommendations, this report assesses progress based on the general strategic domain and spirit of the overarching recommendations. This approach creates a framework that is grounded in the core strategic domains of the National Academies' report, yet flexible enough to consider a dynamic, evolving federal policy and program environment.

The report seeks to generally identify major accomplishments, activities, and actions taken by both the Administration and Congress within the National Academies' strategic domains. For purposes of this report, the Partnership adopts a ranking of outcomes for each of the strategic domains as follows:

- **Substantial Progress:** Significant and meaningful action has been taken towards fulfilling the recommendation.
- **Moderate Progress:** Material action has been taken towards fulfilling the recommendation; however, additional action is needed to fully realize it.
- **Limited Progress:** Some action has been taken towards fulfilling the recommendation; however, it is incomplete and/or does not specifically target SCD.
- **No Clear, Identifiable Progress:** No clear, identifiable action has been taken towards fulfilling the recommendation.

The Partnership recognizes that this report has two limitations. First, the work of the Partnership is focused on federal policy. As such, the report does not assess progress made through important work led by private sector organizations or work primarily effectuated at a state or local level as, given the scope of our work, it is beyond this report to focus on non-federal actions. Second, our assessment is based on our current understanding of federal policy actions. In some cases, there may be work behind the scenes that constitutes progress of which we are not yet fully aware.

Finally, it is important to note that the Partnership offers this assessment with an intent to celebrate the steps forward that have been taken—and to be clear-eyed about additional steps that remain to be taken. The Partnership recognizes and appreciates the dedicated professionals in the Administration and Congress who have been champions for developing and advancing policies to improve access to care and treatment for individuals with SCD. We count many staff and officials as collaborators in a common cause and look forward to continuing to work with them to move policies forward.

STRATEGY A

NASEM POLICY RECOMMENDATION:

Establish a national system to collect and link data to characterize the burden of disease, outcomes, and the needs of those with SCD across the life span.

ASSESSMENT

Administration: **Moderate Progress**

Congress: **Limited Progress**

ACTIONS TAKEN

- In 2021, CMS released a report sharing Medicaid and CHIP data about enrollees with SCD. The report included state-level analyses on demographics, health characteristics, and health care utilization patterns.
- In 2022, the Partnership released a Landscape Assessment of SCD Data Collection Efforts to assist federal policymakers, staff, and members of the policy community.
- In 2023, working with the American Society of Hematology (ASH), HHS hosted a series of three roundtables with select stakeholders to identify existing sources of data for SCD, especially disease registries.
- In each FY 2023 and FY 2024, Congress allocated $3 million to CDC for Sickle Cell Research, which supports CDC's Sickle Cell Data Collection Program. For FY 2025, the President's budget request asks for $6 million. This budget appropriation falls under CDC's birth defects, developmental disabilities, blood disorders, and disability and health programs, which promote health access for populations that have been disproportionately impacted in the United States and advance science to support those who have been historically marginalized.
    - With this allocation, 16 states receive funding under the Data Collection Program to gather health data about individuals with SCD to better understand how many people have SCD and potential policy solutions.
- In June 2024, in observance of World Sickle Cell Day, HHS held a virtual meeting: *"What's Data Got to Do With It? Perspectives on Federal Sickle Cell Disease Data Systems."* Hosted by the Office of the Assistant Secretary for Health, the Office of the National Coordinator for Health Information Technology, and the Office of Intergovernmental and External Affairs, the program explored processes to promote timely and interoperable sharing of SCD-related data, current data systems for SCD, and a new effort to develop an SCD minimum core data set across federal and non-federal programs.

2024 RECOMMENDATIONS

- In the wake of the HHS-ASH led SCD roundtables, HHS should finalize an intra-agency agreement for an Office of the National Coordinator project that came out of that initiative.
- HHS should evaluate and publicly report on the feasibility and any plans to facilitate or support additional data linkages to inform clinical care, research, development of care models, and other purposes.
- HHS should publish a follow-on report to the 2020 T-MSIS report that shares data about the characteristics of Medicaid and CHIP enrollees with SCD on a state-by-state basis.
- Congress should approve the President's $6 million budget request for an increase in funding to CDC's Sickle Cell Research budget item, which supports CDC's Sickle Cell Data Collection Program.

STRATEGY B

NASEM POLICY RECOMMENDATION:

Establish organized systems of care that ensure both clinical and nonclinical supportive services to all persons living with SCD.

ASSESSMENT

Administration: **Substantial Progress**

Congress: **Moderate Progress**

ACTIONS TAKEN

- In February 2022, CMS held a listening session on SCD with individuals with SCD and related stakeholder organizations. CMS staff heard personal stories and first-person perspectives that shed light on the diversity of challenges the SCD community faces. More than half the individuals who spoke stressed the need for CMS to use its guidance and regulatory authorities to strengthen Medicaid's role in helping improve care and treatment for individuals with SCD.
- In September 2023, to recognize SCD Awareness Month, the Partnership circulated to Congress and the Administration a video on SCD, challenges individuals with SCD face, and priorities for policy action. The video featured Dr. Lakiea Bailey, who is an SCD advocate, educator, and research scientist, as well as Executive Director of the Sickle Cell Consortium.
- In 2023, the House Energy and Commerce Committee and Senate HELP Committee passed legislation to reauthorize programs and activities under HRSA aimed to support research, prevention, and treatment for SCD for FY 2024-2028.
    - H.R. 3884/S. 1852, the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023*, would extend the authority of the HHS Secretary to award grants related to heritable blood disorders to collect and maintain data and/or to conduct public health activities on such disorders, including those that increase access to specialized care providers and knowledge of treatment options.
- In February 2024, Reps. Michael Burgess, M.D. (R-TX) and Danny Davis (D-IL) introduced H.R. 7432, an updated version of *The Sickle Cell Disease Comprehensive Care Act*. The legislation would incentivize state Medicaid programs to provide comprehensive, coordinated care through a Health Home model to individuals with SCD. The legislation was included in a hearing held by the Subcommittee on Health

in the House Energy & Commerce Committee on Rare Disease Day (February 29, 2024).

- In May 2024, the Social Security Administration held a listening session to hear from SCD stakeholders on their recommendations to improve the medical listings SSA uses to identify those individuals with SCD who quality for disability benefits.

2024 RECOMMENDATIONS

- In April 2024, the Partnership released new findings from its Medicaid & SCD Survey conducted of current and former Medicaid directors: "'Medicaid and Sickle Cell Disease' – Findings From A Survey of Medicaid Directors." The report contributed fresh insights on how Medicaid provides access to care and treatment for Americans with SCD, and it aimed to inform Congressional policymakers and CMS about additional opportunities to improve access to SCD care and treatment in Medicaid.
- CMS, specifically CMCS, should hold listening sessions with the SCD community twice a year. These listening sessions should include individuals with lived experience as a person with SCD, individuals who are caregivers and parents of persons with SCD, community-based organizations, and SCD policy stakeholders.
- The House Energy and Commerce Committee should include the bipartisan H.R. 7432, the *Sickle Cell Disease Comprehensive Care Act* in its next committee markup and advance the bill through the legislative process. In 2024, Congress should enact the legislation.
- Congress should, in 2024, enact H.R. 3884/S. 1852, the *Sickle Cell Disease and Other Heritable Blood Disorders Research, Surveillance, Prevention, and Treatment Act of 2023*. Without reauthorization, patient access to professionals trained to provide specialized care will be limited, potentially resulting in worse patient outcomes.
- The Social Security Administration (SSA) should use its existing authority to further evaluate its requirements under the Listing of Adult Disabling Impairments, which may inadvertently and inappropriately discriminate against some individuals with SCD who would otherwise qualify for Social Security Disability Insurance. SSA should evaluate to what extent it may be possible to update listings to achieve multiple important goals, such as: ensuring that one-size-fits-all criteria do not unduly discriminate against individuals with severe SCD, promoting participation in the workforce, and providing robust support for individuals with SCD who face severe and persistent limitations on their ability to participate in the workforce. The SSA should also consider to what extent it should broaden the criteria for individuals with SCD to include pain crises at the individual's home self-managed with oral opioids (rather than only parenteral narcotics) in the cases in which they are severe enough to hinder their ongoing employment or participation in the education system.

STRATEGY C

NASEM POLICY RECOMMENDATION:

Strengthen the evidence base for interventions and disease management and implement widespread efforts to monitor the quality of SCD care.

ASSESSMENT

Administration: **Limited Progress**

Congress: **No Clear, Identifiable Progress**

ACTIONS TAKEN

- In September 2023, CMS released an Action Plan on SCD, which delineates ways the agency is working to improve health outcomes and reduce health disparities for individuals with SCD.
    - The Action Plan highlighted many general policy initiatives which had some benefit for individuals with SCD.
    - Among the novel actions that were specifically focused on SCD, there were actions taken to address quality measures, including:
        - In 2022, the Core Quality Measures Collaborative, a public-private partnership with CMS, added two quality measures for children with SCD to the Consensus Core Set for pediatrics.
        - In 2023, CMS released a final rule that established requirements for mandatory annual state reporting of standardized quality measures in Medicaid and CHIP for an increasing number of measures over time. They are intended to identify gaps and health disparities among individuals with SCD enrolled in Medicaid and CHIP.
- NIH has been increasing its annual support level for SCD through its research grants, contracts, and other funding mechanisms. In 2022, NIH allocated $153 million to SCD-related research and $184 million in 2023, with an estimated $184 million in 2024 and $186 million in 2026. These amounts indicate a significant increase from $139 million in 2019. With this funding, in 2023, NIH supported 279 projects related to SCD and Sickle Cell Trait research across universities, medical centers, hospitals, life sciences companies, and on the NIH campus.
- NIH's National Heart, Lung, and Blood Institute (NHLBI) also included in its Congressional Justification SCD-related research programs and initiatives, including:
    - Blood Diseases and Resources, which includes the Cure Sickle Cell Initiative (CureSCi). Total program funding request for FY 2025: $491.9 million.

        - CureSCi identifies and supports promising gene therapies being tested in multicenter clinical research trials.
    - Division of Intramural Research, which includes the Intramural Sickle Cell Branch. Total NHLBI intramural research funding request for FY 2025: $266.8 million.
        - The program supports research to understand SCD and identify markers of disease severity. The Branch is also developing and improving treatments for severe pain episodes.

2024 RECOMMENDATIONS

- CMS should host a series of three workshops for state Medicaid programs that would disseminate research findings and highlight best practices regarding opportunities for adopting interventions and disease management strategies that monitor and improve the implement widespread efforts to monitor the quality of care for individuals with SCD. CMS should draw from high-quality, curated resources, as well as promising practices and best practices identified by the SCD community. Numerous practical ideas and recommendations are included in the 2024 Findings of the "Medicaid & Sickle Cell" Survey of Medicaid Directors that was conducted and disseminated by the Partnership.
- NIH should continue to support studies into SCD, and Congress should continue to increase NHLB's annual budget for NIH's SCD-related programs. The research and programs conducted by NIH are integral to advancing SCD treatments.

STRATEGY D

NASEM POLICY RECOMMENDATION:

Increase the number of qualified health professionals providing SCD care.

ASSESSMENT

Administration: **Limited Progress**

Congress: **Limited Progress**

ACTIONS TAKEN

- In May 2023, the *Sickle Cell Care Expansion Act* was reintroduced by Senators Chris Van Hollen (D-MD), Amy Klobuchar (D-MN), and Cory Booker (D-NJ) in the Senate (S. 1423) and by Reps. Barbara Lee (D-CA) and Danny Davis (D-IL) in the House (H.R. 3100). This bill requires HHS to:
    - Award grants to federally qualified health centers, community-based organizations, or other nonprofits that treat or otherwise support populations with sickle cell disease for education and advocacy programs concerning the disease;
    - Award grants to nonprofits that provide comprehensive care to populations with sickle cell disease for programs to support the transition from pediatric to adult care for patients with the disease; and
    - Establish a program to provide scholarships or student loan repayment awards to individuals who commit to engage in clinical practice or research related to sickle cell disease for a period of obligated service as physicians.

  Cosponsors in the House include Representatives Rep. Troy Carter (D-LA); Rep. Debbie Wasserman Schultz (D-FL); Rep. Alma Adams (D-NC); Rep. Terri Sewell (D-AL); Rep. Cori Bush (D-MO); and Rep. Jonathan Jackson (D-IL).
- Health Resources and Services Administration's (HRSA) Maternal and Child Health Bureau oversees the SCD Treatment Demonstration Program. Congressionally appropriated funds support five regional comprehensive SCD centers with a goal of ensuring individuals with SCD have access to an SCD-trained provider. The program aims to increase the number of clinicians or health professionals knowledgeable about SCD care; improve the quality of care provided to individuals with SCD; and improve care coordination.
    - In its FY 2025 budget request, HRSA requests $8.2 million for the program, which is the same funding amount as FY 2023 and FY 2024.

2024 RECOMMENDATIONS

- The Senate HELP Committee and the House Energy and Commerce Committee should hold hearings to consider S. 1423/H.R. 3100, the *Sickle Cell Care Expansion Act*, and committee staff should work to receive HHS' technical assistance on the legislation expeditiously.
- HRSA should make plans to expand the Sickle Cell Disease Treatment Demonstration program to increase its support for regional SCD infrastructure. As the program is currently structured, individuals with SCD may be limited in their participation in the program if they live far from the closest regional center.

STRATEGY E

NASEM POLICY RECOMMENDATION:

Improve SCD awareness and strengthen advocacy efforts through targeted education and strategic partnerships among HHS, health care providers, advocacy groups and community-based organizations, professional associations, and other key stakeholders (*e.g.*, media and state health departments).

ASSESSMENT

Administration: **Moderate Progress**

Congress: **No Clear, Identifiable Progress**

ACTIONS TAKEN

- In February 2024, CMS sent a slide deck to state Medicaid officials related to coverage of new treatments for SCD and opportunities to improve SCD care.
- In March 2024, Medicaid.gov released a new website with information on Medicaid and CHIP coverage of new treatments for SCD and opportunities for Medicaid programs to improve care for individuals with SCD. The website includes various materials that Medicaid and CHIP officials can use to ensure individuals with SCD are receiving optimal care, including reports on demographics, health, and healthcare of individuals with SCD, and quality improvement tools that states can use to improve care.
- In April 2024, the HHS Office of the Assistant Secretary for Health and the Office of Intergovernmental and External Affairs held a meeting in observance of National Minority History Month: "*SCD Past and Present: A Panel Discussion on Care Across the Lifespan*." The event recounted the advancements in SCD clinical care since SCD first received federal funding in 1972 and highlighted SCD trailblazers and individuals living with SCD.

2024 RECOMMENDATIONS

- CMS should continue to bolster the information available to state Medicaid officials so that these programs have easy-access resources to better implement care and coverage opportunities for individuals with SCD. CMS should be a persistent voice in encouraging Medicaid programs to expand their coverage for SCD treatments and ensure individuals with SCD who are covered by Medicaid are receiving coordinated and equitable health care services.

STRATEGY F

NASEM POLICY RECOMMENDATION:

Address barriers to accessing current and pipeline therapies for SCD.

ASSESSMENT

Administration: **Substantial Progress**

Congress: **Moderate Progress**

ACTIONS TAKEN

- In February 2023, HHS responded to President Biden's executive order that directed HHS Secretary Becerra to consider actions that would drive down prescription drug costs. Specifically, the executive order asked the Secretary to consider whether to select for testing by the CMS Innovation Center, new health care payment and delivery models that would lower drug costs and promote access to innovative drug therapies for Medicare and Medicaid beneficiaries. CMS announced that it selected three models, including the Cell and Gene Therapy Access Model.
    - In January 2024, CMS announced that the first focus of its new Cell and Gene Therapy Access Model would be SCD.
    - The Cell and Gene Therapy Access Model establishes a voluntary partnership among CMS, manufacturers, and state Medicaid programs to test a new approach for administering outcomes-based agreements to enhance access to new cell and gene therapies.
- In April 2023, Reps. Brett Guthrie (R-KY), Anna Eshoo (D-CA), John Joyce (R-PA), Jake Auchincloss (D-MA), Mariannette Miller-Meeks (R-IA), and Scott Peters (D-CA) introduced H.R. 2666, the MVP Act (*Medicaid Value Based Payments for Patients Act*). In May 2024, Senators Markwayne Mullin (R-OK), Kyrsten Sinema (I-AZ), Tim Scott (R-SC), and Margaret Wood Hassan (D-NH) introduced the MVP Act in the Senate as S. 4204.
    - The legislation would help improve access to care and life-changing therapies in Medicaid by allowing the use of varying best price points under value-based purchasing arrangements in the Medicaid Drug Rebate Program. The legislation would additional require CMS to establish a program under which state Medicaid programs may cover drugs in inpatient settings via value-based purchasing arrangements, which is critical to increase access to gene therapies for SCD.

- The MVP Act was considered and passed 31-19 at a May 2023 markup in the House Energy and Commerce Committee.
- The Partnership submitted a letter in support of the MVP Act.

- In December 2023, FDA approved the first two cell-based gene therapies for the treatment of SCD in patients 12 years and older, Casgevy and Lyfgenia. Director of FDA's Center for Biologics Evaluation and Research Peter Marks stated "These approvals represent an important medical advance with the use of innovative cell-based gene therapies to target potentially devastating diseases and improve public health…. Today's actions follow rigorous evaluations of the scientific and clinical data needed to support approval, reflecting FDA's commitment to facilitating development of safe and effective treatments for conditions with severe impacts on human health."
- In February of 2024, CMCS released a slide deck aimed at state Medicaid and CHIP programs that reviewed coverage for these new treatments under Medicaid and CHIP, including state opportunities in value-based purchasing, services related to gene therapy, and access to Out-of-State providers.
- In February 2024, House Energy and Commerce Committee Health Subcommittee Chairman Brett Guthrie (R-KY) released draft legislation seeking to clarify the exclusion of anti-kickback and other sanctions from certain travel and lodging arrangements between manufacturers of drugs and individuals being administered certain drugs. Since then, the Committee has been making refinements and improvements to the language based on feedback from stakeholders. While drug manufacturers participating in the CMS Innovation Center Access Model have the ability to provide access to transportation, lodging, and fertility preservation, Congress needs to act to clarify a safe harbor to the Anti-Kickback Statute and Stark Law regarding the ability of manufacturers to provide support for these activities associated with individuals who are receiving gene therapy.
- In April 2024, CMS released its proposed rule for hospital inpatient care, the Inpatient Prospective Payment System (IPPS) under Medicare Part A. In the proposed rule, the agency proposes to increase the New Technology Add-on Payment (NTAP) percentage for SCD gene therapies to 75 percent. This is a significant regulatory signal of support for access to therapies by the Administration, as the NTAP percentage is 65 percent for virtually all other products. In fact, only two other products have received a NTAP payment boost above 65 percent in the history of the program. The NTAP program was developed to help encourage hospitals to use new, costly technologies in the inpatient setting before the payment rate is updated to account for the cost of the new technology.

2024 RECOMMENDATIONS

- CMS and the CMS Innovation Center should continue to expeditiously advance the first Cell and Gene Therapy Access Model on SCD. In doing so, it should consider the Partnerships' recommendations, as outlined in an April 2024 letter, which include:
    - Remind states what they can be *currently* doing to ensure access to gene therapies under current law as the Access Model continues to be rolled out.
    - Ensure states participating in the Model adequately cover all additional clinical services need to make gene therapy successful.
    - Ask manufacturers to provide educational materials on cover fertility preservation services in the native language of the gene therapy recipient.
- Congress should enact H.R. 2666/S. 4204, the MVP Act, to expand value-based purchasing agreements in Medicaid.
- In 2024, the House and the Senate should advance thoughtful, targeted, bipartisan legislation to clarify a safe harbor to the Anti-Kickback Statute and Stark Law which allows biopharmaceutical manufacturers to provide transportation, lodging, and fertility preservation for individuals who are receiving gene therapy. The Partnership is appreciative of current bipartisan staff work to effectuate this aim and looks forward to being a resource in helping advance solid bipartisan legislation through the legislative process.
- In the final Medicare hospital payment rule (IPPS), CMS should include the proposed NTAP provision for SCD gene therapies. Despite the increased NTAP, the remaining costs are left unaddressed by the proposed change, and it does not impact Medicaid, which is the largest payer of care and treatments for Americans with SCD. Therefore, additional policies will need to be adopted in the future to address gaps more comprehensive in access to care and treatments.

STRATEGY G

NASEM POLICY RECOMMENDATION:

Implement efforts to advance the understanding of the full impact of sickle cell trait on individuals and society.

ASSESSMENT

Administration: **Limited Progress**

Congress: **Limited Progress**

ACTIONS TAKEN

- Congress continued funding, and HHS continued administering, the CDC's Sickle Cell Data Collection (SCDC) program, which gathers health information from multiple sources to determine how many people live with the disease in a particular state and to understand their health and health care needs. Each SCDC state collects and links data from several sources to develop a comprehensive health database to better understand the healthcare needs of people living with sickle cell disease in their state. SCDC data are helping states to better understand why people with SCD often have the most severe symptoms and use health care services most frequently when they shift from pediatric care to adult care.

RECOMMENDATIONS

- Congress should provide additional financial support so that the SCDC program can include more states. As HHS notes, "An expanded SCD information system can provide important new information on how many people live with SCD in the United States, how SCD affects their health, and how researchers can improve medical treatments to extend and improve the lives of people with SCD."
    - In August 2023, the Partnership sent a letter to Congressional Appropriations Committees on FY 2024 SCD funding in the Labor, Health and Human Services, Education, and Related Agencies appropriations bill. The Partnership urged the committees to invest in SCD research, data, and improvements to access to high-quality, comprehensive care.

STRATEGY H

NASEM POLICY RECOMMENDATION:

Establish and fund a research agenda to inform effective programs and policies across the life span.

Under this recommendation, the report's specific sub-recommendation focuses on collaboration between federal and private funders to develop a research agenda to address the intersection between SCD, race, and stigma.

ASSESSMENT

Administration: **Limited Progress**

Congress: **No Clear, Identifiable Progress**

ACTIONS TAKEN

- There is limited grant funding examining the role of stigma and bias play in the delivery of health care, especially for individuals with SCD.

RECOMMENDATIONS

- HHS should work with SCD stakeholders to identify priority areas for research into how stigma and bias may affect the care individuals with SCD receive.
- Based on gaps in current research, in 2024 HHS should, working through AHRQ, HRSA, or NIH, articulate a SCD-specific research agenda to inform effective programs and policies across the life span.

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