



# Medicaid & Sickle Cell Disease Survey

*A Survey of Medicaid Directors About The Critical Role Medicaid Plays In Helping Americans With Sickle Cell Disease*

2024 | The Sickle Cell Disease Partnership

[www.SickleCellPartnership.org](http://www.SickleCellPartnership.org)

## EXECUTIVE SUMMARY

On April 23, 2024, the [Sickle Cell Disease Partnership](#) released new findings from its *Medicaid & Sickle Cell Disease Survey* conducted of current and former Medicaid directors, contributing fresh insights about how Medicaid provides access to care and treatment for Americans with Sickle Cell Disease (SCD). About half of the estimated 100,000+ Americans with SCD are enrolled in Medicaid.

SCD is a [rare, genetic blood disorder](#) that primarily affects Black and Latino individuals in the United States. Individuals with SCD start to have signs of the disease during the first year of life. Individuals with SCD can experience different complications, but many of the common ones are very serious, including recurring pain crises, infection, acute chest syndrome, lung problems, severe and chronic pain, and stroke.

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](#). The Partnership aspires to work collaboratively across the federal policy community to translate the recommendations of a [National Academies report](#) into legislative and administrative actions in Congress and the Executive Branch.

The Partnership’s *Medicaid & Sickle Cell Disease Survey* includes qualitative perspectives from Medicaid directors on multiple aspects of sickle cell disease (SCD) and Medicaid. Key findings from the survey are below.

- 1. Medicaid Health Homes Are an Important Tool that Congress Should Tailor to Improve SCD Care.** Multiple respondents highlighted how a Medicaid Health Home model could be tailored to help ensure individuals with SCD get the services they need. Medicaid Health Homes providers will integrate and coordinate all primary, acute, behavioral health, and long-term services and supports to treat the whole person. As of [December 2023](#), about 20 states and the District of Columbia had [implemented](#) a total of 35 health home programs. CMS [found](#) that Health Homes reduced costs, improved quality and patient experience, and strengthened outcomes. Unfortunately, under current law, there are some limitations with regard to how individuals with SCD may be helped through a Medicaid Health Home.

**Why It Matters:** Survey respondents suggested adding SCD as a qualifying condition for Medicaid Health Homes and incentivizing states to create SCD-specific Health Homes. The Partnership strongly supports this approach and has endorsed bipartisan House legislation that would effectuate this approach.

[H.R.7432](#), *The Sickle Cell Disease Comprehensive Care Act*, sponsored by U.S. Reps. Burgess (R-TX, 26), Danny Davis (D-IL, 7), and Darren Soto (D-FL, 9) would incentivize state Medicaid programs to establish a Health Home to provide comprehensive, coordinated care for individuals with SCD enrolled in Medicaid, regardless of whether or not the state has a Health Home for another condition.

- 2. Getting Medicaid Utilization Management Right Is Critical to Enable Care for Individuals with SCD.** A majority of current and former Medicaid directors responding to the survey said it is “very important” or “important” that state Medicaid programs adopt approaches to utilization management and that their Pharmacy and Therapeutics (P&T) committees consider the specific and unique clinical needs and personal preferences of individuals living with rare diseases such as SCD.

**Why It Matters:** Individuals living with SCD often say Medicaid utilization management protocols make it harder to access timely, quality care.

- 3. Lived Experiences from Individuals with SCD Is Important for P&T Committees, And Evidence Is Critical.** Most respondents said patient advocate testimony in P&T committee meetings is “strongly considered” or “considered” when making subsequent P&T decisions. Respondents also highlighted a need to combine personal experiences with data and evidence to build the “business case” for Medicaid programs.

**Why It Matters:** In many states, the Medicaid Pharmacy and Therapeutics Committee is responsible for reviewing information on specific drugs and helping determine the use of medications in Medicaid, including the development and maintenance of a Medicaid drug formulary (including placement of drugs on a Preferred Drug List and utilization controls.) However, P&T committees without an understanding of the medical realities of SCD and lived experience of individuals with SCD are less well-informed to make important decisions that impact access to treatments in Medicaid.

- 4. Robust Provider Participation in Medicaid Is Critical for Timely Access, Especially Access to Specialists.** Most respondents noted that the most prominent challenge to sufficient participation of clinicians to treat individuals with SCD are low Medicaid reimbursement rates for physicians, especially with respect to specialists. To address this, a majority of respondents identified the importance of (1) strategies to engage specific providers and the broader care system to address the challenge of timely access to care; and (2) using specific contractual requirements with managed care organizations (MCOs) as an important way to address concerns about low reimbursement rates and low provider participation.

**Why It Matters:** Research and the lived experience of individuals with SCD show that timely access to the range of clinicians needed to treat SCD is inconsistent and often not timely or adequate.

- 5. The [Cell and Gene Therapy Access Model on SCD](#) from the CMS Innovation Center Must Address Cost Considerations, Patient Input, and Coverage of Support Services.** The vast majority of respondents said it is “very important/important” that the Model include support for medical follow-up care and ancillary services related to gene therapy treatment, as well as supportive social services to address needs like transportation, lodging, childcare, etc. A majority of respondents highlighted two dynamics that will be critical for success from a state Medicaid director perspective: (1) fundamental coverage and payment design considerations,

and (2) the input of the SCD community of patients, families, community-based organizations, and providers in a state seeking to participate in such Model, including patient testimony on the costs associated with SCD treatment.

**Why it Matters:** The Access Model is a novel utilization of Innovation Center authorities to help improve access to gene therapies approved to treat SCD. CMS is accepting state Medicaid applications to participate in the model as soon as January 2025.

- 6. Medicaid Programs Have Important Tools To Improve Health Equity.** A majority of respondents highlighted the importance of Medicaid managed care organizations in operationalizing opportunities to improve health equity and identified strategies to do so. A majority of respondents stressed the importance of partnerships with state and local organizations to improve health equity and identified related strategies to effectuate this priority.



## Methodology

On behalf of the Partnership, Leavitt Partners sent a survey to current and former Medicaid directors. Survey participants were informed that their name and state would be kept confidential, and responses would be deidentified.

No survey respondent was compensated for their participation; survey participants were informed that for each completed survey response a donation would be made to a non-profit SCD community-based organization.

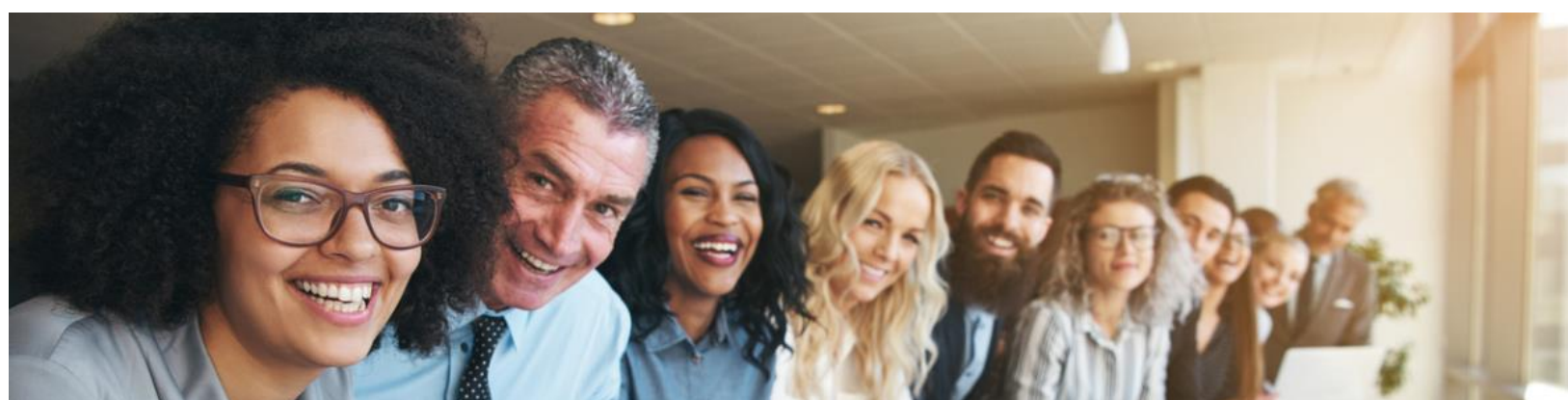
The survey received about a 20 percent response rate, including responses from both current and former state Medicaid directors. The survey responses present geographical diversity (e.g., the Partnership received responses from individuals representing small and large states, different regions of the United States, states with different political leadership, etc.). Additionally, the survey received responses from individuals with a wide range of familiarity regarding how Medicaid covers SCD-related services (ranging from “very familiar” to “unfamiliar”).

The survey was conducted over email and a web-based survey tool over a few week period. The survey was designed to provide timely, qualitative feedback on important federal and state policy issues related to SCD.

Survey limitations may include the length of the survey, the wording of specific questions, the duration of time in which the survey was open, etc. Additionally, in limited cases, updated contact information for Medicaid directors was not readily publicly available.

The timing of the survey presents potential limitations that should be acknowledged. For example, with regard to the CMS Innovation Center’s Cell and Gene Therapy Access Model, one survey limitation is that, at the time of the survey, relatively limited public information was available about the Model. Additionally, the survey was conducted on the heels of [FDA’s approval of two gene therapy treatments for SCD](#) - a time in which familiarity with these new treatments was likely much lower for respondents than it will be in coming months.

The survey was distributed to current and former Medicaid directors. In the future, a more comprehensive view of the Medicaid program could potentially be gained by also surveying Medicaid program staff and/or members of a state Medicaid P&T committee.



## **Domain 1 – Knowledge of SCD and Focus on SCD**

- **A majority of respondents were “very familiar/familiar/somewhat familiar” with how SCD is covered by Medicaid in their state, but indicated their state did not have any specialized programs or policies specifically designed to improve access to care and treatment for individuals with SCD.**
  
- **A minority of respondents highlighted some existing tailored approaches specifically designed to improve access to care and treatment for individuals with SCD, including states in which:**
  - Medicaid is required to conduct an annual review of treatments for individuals with SCD.
  - The Medicaid program puts out an annual SCD report.
  - The state has a focus for kids with SCD, including a transition program for young adults.
  - Medicaid has quality requirements for MCOs, including a disease management program for SCD.
  - The state’s MCOs have contracts and collaborate with specialized SCD providers and includes a focus on care coordination.
  
- **Respondents identified key policies and strategies that current Medicaid directors can use to improve access to care and treatment for individuals with SCD.** These strategies are identified below.
  - **Addressing Utilization Management.** A majority of respondents noted that states can design coverage policies for treatments to minimize barriers to care caused by imprecise utilization management, such as inappropriate prior authorization requirements. It was additionally noted that it would be useful to consider exemptions to drug lock-in programs.
  - **Harnessing Medicaid Health Homes.** Multiple respondents highlighted that Medicaid Health Homes (created under Section 1945 of the *Social Security Act*) can be utilized to help ensure individuals with SCD get the services they need.
  - **Optimizing Managed Care Organization (MCO) Strategies.** Respondents noted opportunities for leveraging MCOs to improve access to care and treatment, such as: including requirements in MCO contracts related to care management and uniform requirements regarding the placement of treatments for SCD on preferred drug lists; requiring MCOs to report certain measures; adding MCO risk mitigation strategies for costly SCD therapies to remove disincentives/adverse selection concerns; giving extra points in managed care procurements for specialized SCD programs, especially in regions with higher concentrations of beneficiaries with SCD; and monitoring MCO network adequacy requirements to ensure timely access to needed specialty care.
  - **Leveraging Available Data.** Respondents noted that states could integrate current, local, and reliable data to help build a holistic picture of the availability of care and gaps in care. States could publish information on the number of individuals with SCD served by Medicaid, which health plans they are enrolled in, which areas they live in, and what types of services they need.

- **Building State and Local Partnerships.** Respondents identified opportunities to partner with state and local entities. This includes opportunities like partnering with health care organizations (such as community health centers and hospitals) who are at the forefront of SCD care in the state. Another opportunity is empowering Medicaid directors with education on SCD and connecting directors with local community-based SCD organizations.
- **Utilizing Care Management Strategies.** Respondents highlighted opportunities states could take, such as implementing disease management programs, including targeted case management and medication management programs. States could also expand telemedicine policies to open access to specialty care consultation from home. Further, states can consider implementing the [interprofessional consultation program](#) now allowed by the Center for Medicaid and CHIP Services within the U.S. Department of Health and Human Services.



## **Domain 2 - Access to Current Treatments**

- **Respondents listed quantitative and qualitative data and perspectives that would be most helpful to inform state Medicaid directors to ensure that utilization management approaches are not across-the-board policies that inadvertently result in care delays for individuals with SCD.**

**Quantitative data examples that were identified are detailed below.**

- **Costs and outcomes data.** Multiple respondents suggested data explaining how the costs and outcomes related to SCD would justify some exception to normal protocols (e.g., how outcomes and costs are impacted if individuals with SCD do or do not get needed care).
- **Effect of barriers to care.** Multiple respondents suggested data explaining how individuals with SCD face specific barriers to care (including medical and care coordination, access to reliable transportation, etc.).
- **Prevalence, care utilization.** Respondents noted the importance of basic information regarding statistics on prevalence, information on the settings of care SCD patients utilize, and the types of clinicians they see.
- **Prior authorization.** Multiple respondents suggested data on prior authorizations would be helpful, including which specific prior authorizations tend to interfere with care, comparative data on patient experiences/cost/outcomes for individuals with treatments under prior authorization, and data on the many times prior authorizations are denied or approved (because a treatment consistently approved can have the prior authorization removed). It was also suggested to conduct a comparative analysis of relative savings from utilization management and the negative impact to patients (such as potential additional costs due to poor care management).
- **Other respondents suggested a range of data that could be impactful,** including: data on delays in receiving medication or treatment, and the effect the delays have on overall health and care; data on how treatment can improve length of life; estimates of intervention costs; data regarding which evidence-based practices can inform utilization management policies.

**Qualitative examples that were identified are detailed below.**

- **Multiple respondents highlighted the importance of speaking with patients and parents of patients,** including through fact-based, lived experience testimony to help program leaders know what living with SCD is like.
- **Medicaid managed care plans.** It was noted that Medicaid agencies should create specific access specifications in the MCO contracts. Such requirements could be measured and tracked publicly, which would create incentives for positive access and outcomes. One concern is the potential lack of specificity in requests related to prior authorization denials and appeals, saying that managed care plans would need to be given/request more information.



- **Other respondents suggested a range of approaches including:** a presentation from a neutral SCD expert (e.g., researcher unaffiliated with drug manufacturers) about the impacts of SCD on individuals and the benefits of appropriate treatment; articulating an approach to reforming utilization management policy that is generalizable and allows for appropriate variability to address negative impacts on individuals with rare diseases including, but not limited to, SCD; specific actions on how P&T committees can help; explaining why the risk of individuals with SCD seeking inappropriate care are low; work with Medicaid managed care plans and SCD specialty providers to minimize prior authorization requirements for patients of certain vetted providers.
- **Respondents listed quantitative and qualitative data and perspectives that are most helpful to improve a Medicaid Pharmacy and Therapeutics (P&T) committee’s understanding of, and responsiveness to, SCD in a manner that results in improved access to care and treatment for individuals with SCD.**

**Quantitative data examples that were identified are detailed below.**

- **Published research and literature.** Multiple respondents noted the importance of peer-reviewed studies on the efficacy of different treatments, noting the importance of “rely[ing] heavily on published literature.” Respondents noted the importance of evidence-based best practices and outcome data, as well as cost effectiveness data. They also emphasized the importance of highlighting any clinical data and guidelines for treatment that demonstrate that novel SCD therapies are unlikely to be misused.
- **P&T Committee metrics.** Stakeholders proposed metrics that P&T committees can track as a standing agenda item so the Committee can identify barriers and assess improvement over time.
- **Impacts on individuals’ lives.** Respondents noted the importance of data highlighting quality of life, length of life, and the ability to go to school and hold a job as a contributing member of society.

**Qualitative data examples that were identified by respondents are detailed below.**

- **Early engagement with clear education, evidence.** Respondents emphasized that stakeholders should help to educate the agency or support staff charged with the drafting of measures. They noted that it is often too late for advocacy efforts once a measure is up for a vote at a committee meeting. Stakeholders should also consider educational sessions with state Medicaid staff (clinical and financial leadership, and P&T committees), in which a neutral SCD expert (e.g., a researcher unaffiliated with drug manufacturers) gives a presentation about the impacts of SCD on individuals and the benefits of appropriate treatment. These stakeholders can also help to facilitate access to credible, distilled, and rigorous summaries of the timely evidence that should inform P&R deliberations around SCD policy.

- **Tailored care management.** Respondents explained that information can be provided to Medicaid directors to help establish tailored requirement of care plans and/or establish practices for chronic disease management. This could involve requiring certain staff to be trained in successful SCD pain management and/or requiring the P&T committee to review utilization data and prior authorization policies.
- **Personalized, localized.** Bring together stories from individuals in the state about living with SCD and the difficulties in accessing appropriate treatment.
- **Respondents assessed the extent to which it is important that state Medicaid programs adopt approaches to utilization management and P&T committees that take into account the clinical needs and personal preferences of individuals living with rare diseases such as SCD.**
  - Most respondents assessed this goal as “very important” or “important.”
- **Respondents relayed their sense of the extent to which patient advocate testimony in P&T Committee meetings is considered when making subsequent P&T decisions.**
  - Most respondents who had experiences with patient advocate testimony said such perspectives are “strongly considered,” “considered,” or “somewhat considered.”
  - Several respondents had not had experiences with patient advocate testimony in P&T meetings, so they felt they could not comment.
  - Two respondents said such perspectives were not considered.



## **Domain 3 - Health Care Providers**

**Respondents described the data, patient perspectives, policy strategies, program tools, and other authorities that are most helpful in ensuring that state programs have sufficient participation of clinicians for timely access to care, including needed primary care clinicians and specialty clinicians.** Responses are summarized below.

- **A majority of respondents noted that the most prominent challenges to sufficient participation of clinicians to treat individuals with SCD are low Medicaid reimbursement rates for physicians, especially specialists.** Low reimbursement rates discourage clinicians from participating in Medicaid or accepting many Medicaid enrollees. This can limit patients’ access to timely, needed care.
- **A majority of respondents identified the strategy of a state utilizing specific contractual requirements with MCOs** as an important way to address concerns about low reimbursement rates and low provider participation.
- **Many respondents identified specific tactics that could be useful in assessing timely access to care, such as:**
  - Reviewing contractual MCO requirements for network adequacy for both primary care and specialists by measuring time and distance to care for Medicaid enrollees using a geo-mapping network assessment tool.
  - Using “secret shoppers” to assess the availability and accuracy of network access for certain specialties.
  - Establishing Medicaid enrollee-to-provider ratios (especially for primary care).
  - Conducting annual appointment access surveys.
  - Utilizing surveys like Consumer Assessment of Healthcare Providers and Systems to help inform access considerations.
  - Reviewing provider survey results relating to specialty referrals.
  - Analyzing grievance and appeals data relating to access.
- **A majority of respondents identified the importance of utilizing strategies to engage specific providers and the broader care system to address the challenge of timely access to care.** Specific tactics identified included:
  - Creating a partnership with the specialists and children’s hospitals in the state to create a special funding pool.
  - Building alliances with secondary or tertiary care centers involved in providing SCD treatment.
  - Utilizing more structural extended tools like Project ECHO.
  - Working with Personal Care Attendants or other care connectors who are instrumental in providing or referring patients to care.

Other respondents cautioned that approaching provider engagement as an issue specific to SCD is unlikely to be successful and instead recommended strategic participation in broader advocacy efforts aimed at improving access to care in Medicaid.

- **Several respondents noted the critical role that telemedicine plays in improving timely access to care.** Telemedicine policies could allow for at-home telemedicine between providers and patients, and telehealth consults can be used to improve access to specialists, including special policies on telemedicine and out-of-state specialist enrollment (in limited cases).
- **Several respondents underscored the importance of data in helping to show the value of timely access to care,** including data focused on cost effectiveness, quality of life, impact to an individual’s life span, and impact on pain control. State Medicaid program staff and P&T committee members could be further educated about effective treatments, their benefits, and the costs of individuals with SCD *not* getting access to such care and treatments.

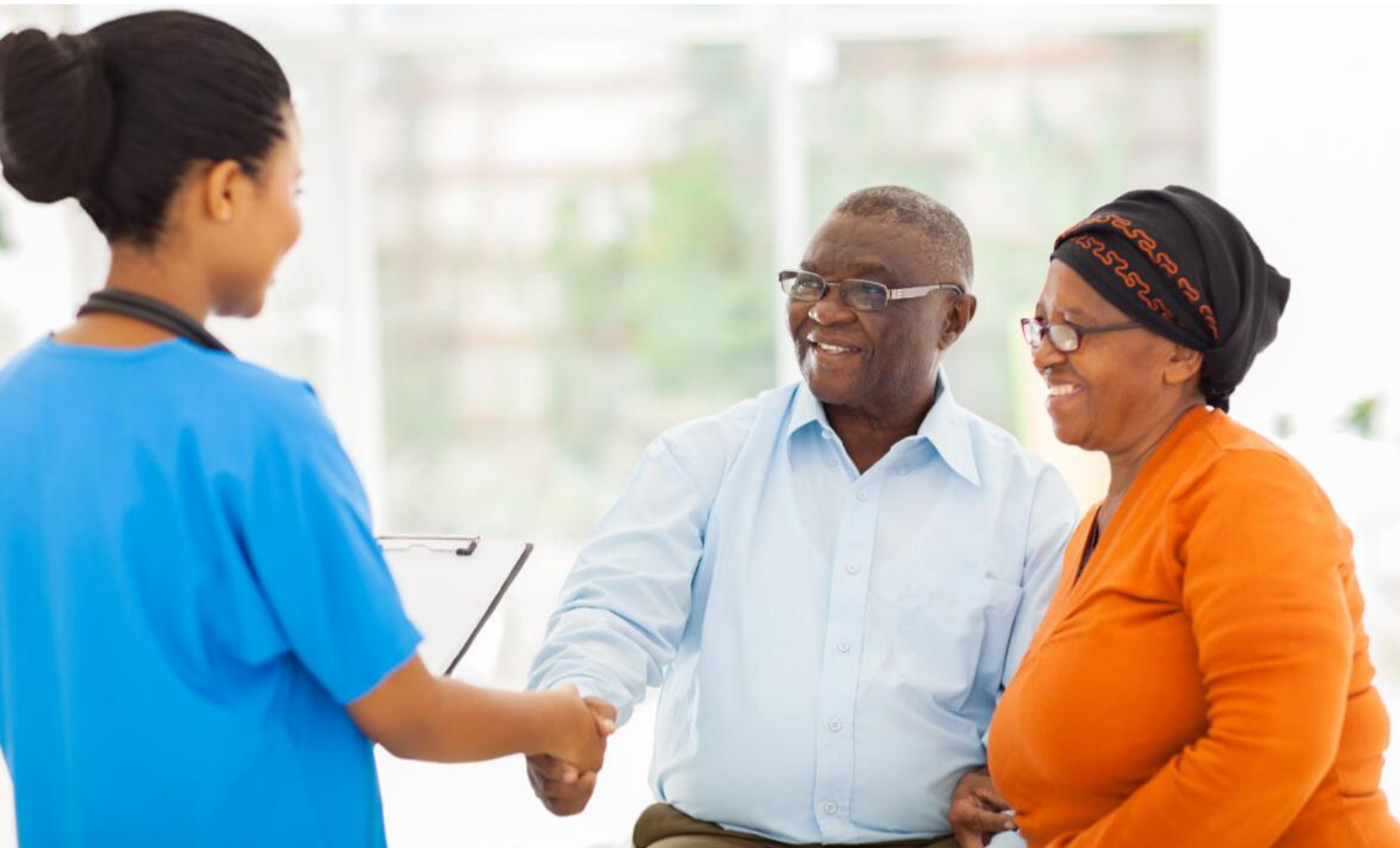


## **Domain 4 - Promoting Health Equity**

**Respondents identified the policy strategies, program tools, or other authorities that have been most effectively used in helping to reduce disparities, stigmatization, and provider bias for Medicaid patients. Responses are summarized below.**

- **A majority of respondents highlighted the importance of Medicaid managed care organizations in operationalizing opportunities to improve health equity.** Respondents noted that managed care has more tools to address bias and inequities in a way that fee-for-service Medicaid cannot. It was suggested that state programs prioritize foundational, actionable items (such as using health disparities to prove metrics with MCO contracts, ensuring accurate contact information for Medicaid enrollees) and then moving to more targeted items. Here are some examples of specific tactics identified:
  - States can create requirements for SCD-specific considerations to be included in MCO equity plans.
  - MCOs can operationalize evidence-based policies that can positively impact health equity in the context of improving health outcomes more broadly.
  - MCOs can be required to report on quality measures by race and ethnicity to develop interventions including provider and patient incentives to close measured gaps in access to high quality care. MCOs can also be required to achieve the NCQA Health Equity Accreditation and to evaluate any predictive analytic programs for potential selective biases often found in claims-based programs.
  - States can fund learning networks through MCOs and include ongoing training concerning diversity, equity, and inclusion in SCD networks.
  
- **A majority of respondents highlighted the importance of partnerships with state and local organizations to improve health equity,** emphasizing:
  - The power of partnering with other state agencies to help inform policy, such as maternal morbidity review committees, Quality Improvement Organizations, or Health Information Exchanges.
  - The utility of working with in-state medical schools and residency/GME programs to help address implicit biases in providers as they receive their medical training.
  - The importance of partnerships with provider organizations because provider education (especially for primary care providers and emergency department physicians) is integral to improving the health system for those with SCD.
  - The need for Medicaid policies to allow individuals with SCD to travel to centers of excellence if such care is not available inside a particular state.
  - Opportunities to learn from what is working in other states; the network of Medicaid medical directors, association of Medicaid directors, and other such affiliated groups or organizations can be beneficial points of engagement.

- **Multiple respondents highlighted specific strategies being utilized to improve health equity.** These included approaches such as:
  - Working to improve race, ethnicity, and language (REL) data (so that disparities can be identified in the first place).
  - Adding health equity officers either at the state or within a MCO.
  - Requiring MCOs to detail and adopt operational health equity plans.
  - Requiring or promoting health equity training for state staff, MCO staff and providers.
  - Examining data to determine the prevalence of delays in access to care for certain populations, including individuals with SCD.
- **Several respondents highlighted the health equity component of pain management for individuals with SCD, given that individuals with SCD are predominantly Black and Latino Americans.** It was noted that statewide preferred drug lists must highlight the need to consider individuals with SCD in prior authorizations for short and long-acting opioids. One example cited was working with their state’s department of health to develop pain management guidelines specific to individuals with SCD.



## **Domain 5 - CMS Innovation Center’s “Cell and Gene Therapy Access Model”**

**Background:** In February 2023, CMS [announced](#) the Innovation Center would develop a [Cell and Gene Therapy Access Model](#). According to CMS, this model would “establish a partnership among CMS, manufacturers and state Medicaid agencies, and it would test a new approach for administering outcomes-based agreements (OBAs) to help Medicaid beneficiaries gain access to potentially life changing, high-cost specialty drugs.” Under this Model, “in lieu of state Medicaid agencies pursuing manufacturer agreements individually, state Medicaid agencies would have the option of assigning CMS to structure and coordinate multi-state OBAs with participating manufacturers.” CMS said the agency “would also take on the responsibility of implementing, monitoring, reconciling, and evaluating the financial and clinical outcomes outlined in the OBAs.”

In January 2024, CMS [announced](#) that the first model will address SCD. In December 2023, the [FDA approved](#) two gene therapies for the treatment of SCD. While CMS originally “envisioned that this model would launch in 2026,” the agency [noted](#) that “to meet the imminent need expressed by states, the Innovation Center is accelerating model development and aiming for rolling launch dates with states joining the model throughout 2025.”

**Based on the information publicly available at the time of the survey, respondents identified model design features and processes for engaging the SCD community that should be included in the forthcoming CMS Innovation Center model to be attractive to state Medicaid directors in a manner that ultimately helps to effectuate timely access to any approved gene therapies for SCD. Responses are summarized below.**

- **A majority of respondents highlighted that coverage and payment design considerations are critical.** Suggestions relayed by respondents included:
  - Creating a payment model that simplifies reimbursement for providers and Medicaid agencies, including potentially a per-member, per-month (PMPM) amount. This could be paid by the agency or an MCO to a center delivering care and a state plan amendment template to make it easy to implement.
  - Addressing the fiscal impact of gene therapies, which several respondents stated is the most substantial challenge.
  - Ensuring value-based outcomes are transparent, clearly defined, and able to be measured without ambiguity.
  - Enabling a better understanding of payment, quality measures (inpatient measures that we normally use should be tailored), and eligibility.
  - Covering services such as peer supports, family supports, community health worker care, etc.
  - Ensuring states retain utilization management authority.

- **A majority of respondents highlighted that the input of the SCD community of patients, families, community-based organizations, and providers in a state will be important for success.** Other recommendations included:
  - Gather input and comments from the SCD community, as that work can be resource intensive for some states.
  - The SCD community and providers need to be actively engaged in reviewing the Model to ensure that any design elements do not lead to unintended barriers to access in states.
  - The evaluation component of the Model should be designed to incorporate feedback from actual Medicaid enrollees impacted by the model as well as SCD-related community-based organizations.
  - State Medicaid programs could form an advisory board of individuals with SCD, SCD care providers, and others to help inform state decisions.
  - Continue public testimony and comment are at applicable P&T, Drug Utilization Review, and Medical Assistance Advisory Council meetings as well as prior to posting of any final coverage bulletins.
  - The SCD community should attend budget hearings to advocate for the funds needed for treatment.
  
- **Several respondents highlighted some of the structural considerations states face with respect to Model participation, including:**
  - The structural differences of state governments’ annual budget cycles compared with federal multi-year policy visions and the resulting tension as to whether a federal solution fits into a state’s timing considerations.
  - Specialty models for rare disease may have limited appeal compared to other models that are targeted to broader-based diseases – despite the economic burden and impacts of the disease.
  - It will be important for CMS to allow for receiving comments and incorporating state feedback during the model design process.
  - Administrative barriers should be minimal if CMS wants states to adopt the model.
  - To build support for the Model, CMS should conduct advance work with larger MCOs and Medicaid Management Information System vendors in fee-for-service states.
  
- **The vast majority of respondents said it is “very important/important” to Medicaid directors that the forthcoming Innovation Center Model include support for medical follow-up care and ancillary services related to gene therapy treatment.** No respondents said this consideration was unimportant.
  
- **The vast majority of respondents said it is “very important/important” to Medicaid directors that the forthcoming Innovation Center Model include support for supportive social services to address needs like transportation, lodging, childcare, etc. for individuals receiving gene therapies.** Multiple respondents said it was “somewhat important.” It was also suggested that states adopt customized disease management or “navigation” services specific to SCD.





## **Domain 6 - Barriers and Challenges Federal Policymakers Could Address**

**Respondents identified potential actions CMS or Congress could take to modify federal policies, requirements, or rules in a targeted and thoughtful manner that would remove barriers to challenges state Medicaid directors face in ensuring Medicaid beneficiaries living with SCD have consistent high-quality, timely access to comprehensive care and treatment. Responses are summarized below.**

- **Multiple respondents identified affordability as something Congress or CMS could take actions to address to improve accessibility.** Respondents noted:
  - Medicaid programs face challenges in paying for treatments and services when an individual loses coverage but still needs care; continuous eligibility for a certain time period was one identified solution to this concern.
  - CMS should continue to pursue the “Cell and Gene Therapy Access Model,” especially to the degree that the state share of the risk involved in paying for these therapies may be mitigated.
  - Federal policymakers should consider creating new pathways to allow states additional flexibility to manage Medicaid costs, specifically those related to prescription drugs, if such flexibility could be demonstrated as improving access.
  
- **Respondents identified specific ways federal policymakers could help states in their efforts to ensure that individuals with SCD have timely access to high-quality care, such as:**
  - Explicitly add SCD as a qualifying condition for Medicaid Health Homes under Section 1945 of the *Social Security Act*.
  - Specifically allow directed payments for SCD treatment that could be easily added to an MCO capitation payment without additional burdensome review by CMS Center for Medicaid and CHIP Services or CMS Office of the Actuary.
  - CMS could publicize preapproved model contract language that states could adopt under MCO contracts.
  - CMS could promulgate a State Medicaid Director Letter or Informational Bulletin that outlines actions states could take to support SCD therapy (similar to past State Medicaid Director Letters on duals integration, value-based payment, and Home and Community Based Services).
  - CMS could improve education for medical providers about SCD, racial bias, and bias in health care delivery.
  - For states with fee-for-service delivery systems, create a mechanism for a per-member, per-month (PMPM) payment outside of complicated primary care case management (PCCM) structures.
  - Provide greater clarity on coverage, payment, and delivery regarding gene therapies, state Medicaid coverage of experimental therapies, and “Right to Try” products.
  - Create exceptions to the SUPPORT Act requirements for opioid management for children with SCD.

