

2022
COVERAGE
FOR SCD
SUMMIT



SESSION ONE:

THE STATE OF ACCESS IN MEDICAID

Speakers: Emma Andelson,
MPA

Date: August 31, 2022

Time: 12:30 – 12:55 PM EDT



Emma Andelson, MPA
Sick Cells

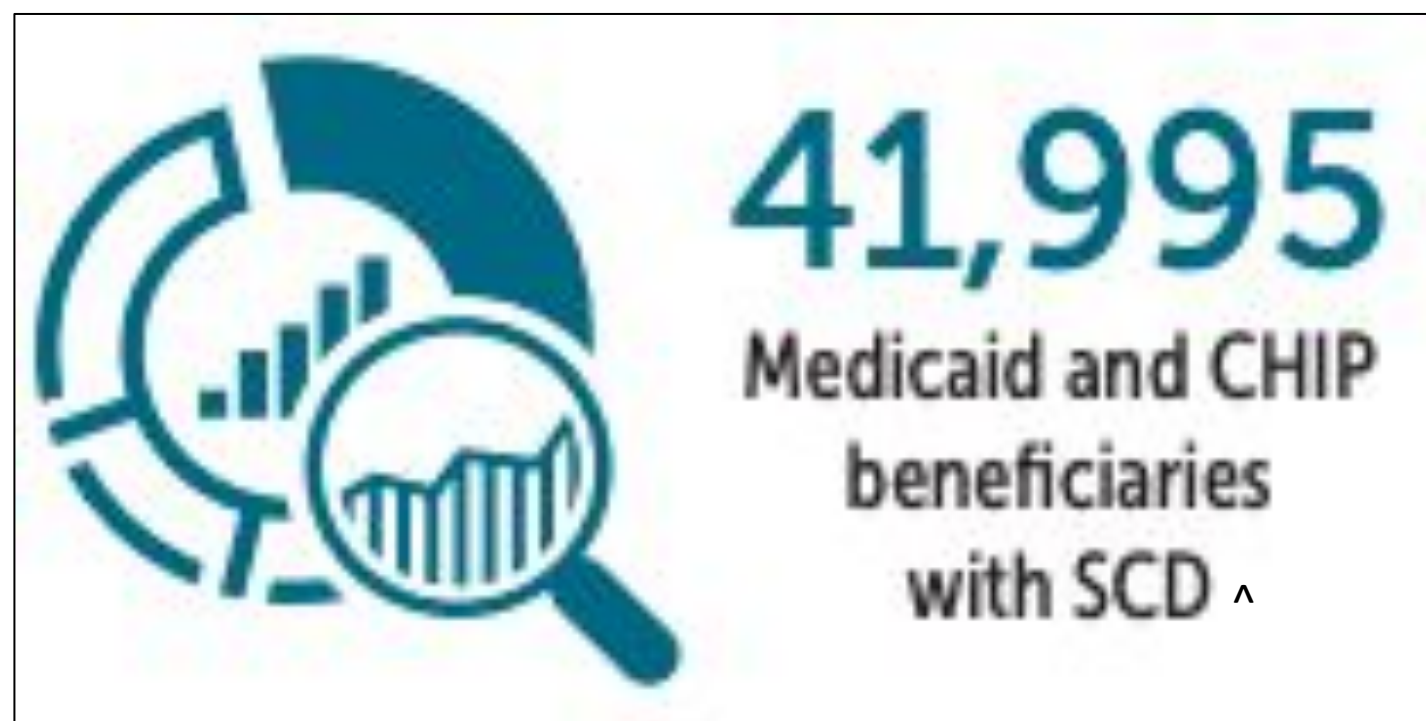




Background: Medicaid At A Glance

Beneficiaries with SCD

- Medicaid is been a key source of insurance coverage for individuals with sickle cell disease.
- **Disability** is a predominant pathway to Medicaid eligibility for those with SCD.* In turn, many of these individuals will receive Medicaid coverage on a **long-term basis**.



Up to **40%** of people with **SCD** meet the medical condition criteria for publicly funded **disability benefits**.^^

^Source: [CMS' Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files \(TAF\) 2017.](#)

^^Citation: Adams-Graves G. and Bronte-Jordan L. Recent Treatment Guidelines for Managing Adult Patients with Sickle Cell Disease: Challenges in Access to Care, Social Issues, and Adherence. Expert Review of Hematology; 2016. <https://pubmed.ncbi.nlm.nih.gov/27098013/>.

*Citation: Grady A, Fiori A, Patel D, Nysenbaum J (2021) Profile of Medicaid enrollees with sickle cell disease: A high need, high cost population. PLoS ONE 16(10): e0257796.

<https://doi.org/10.1371/journal.pone.0257796>

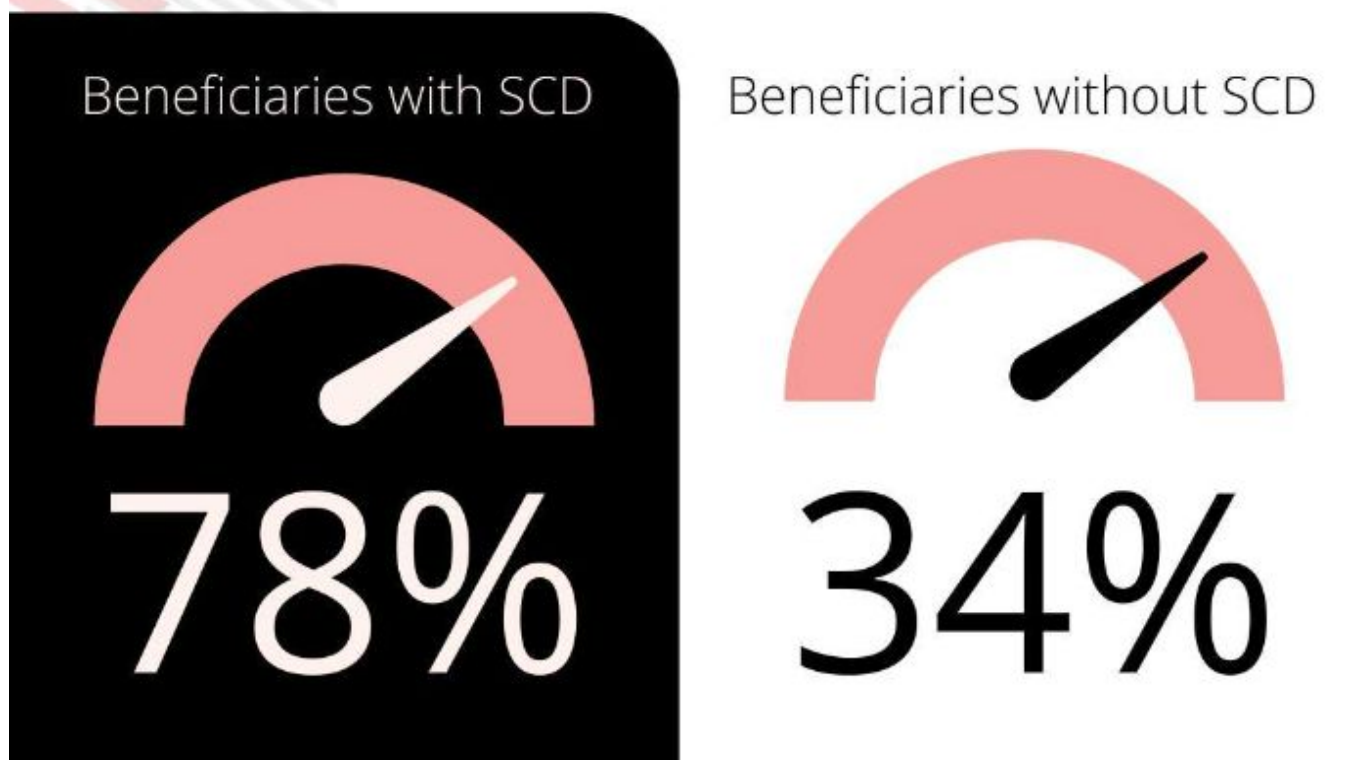


Background: Medicaid At A Glance

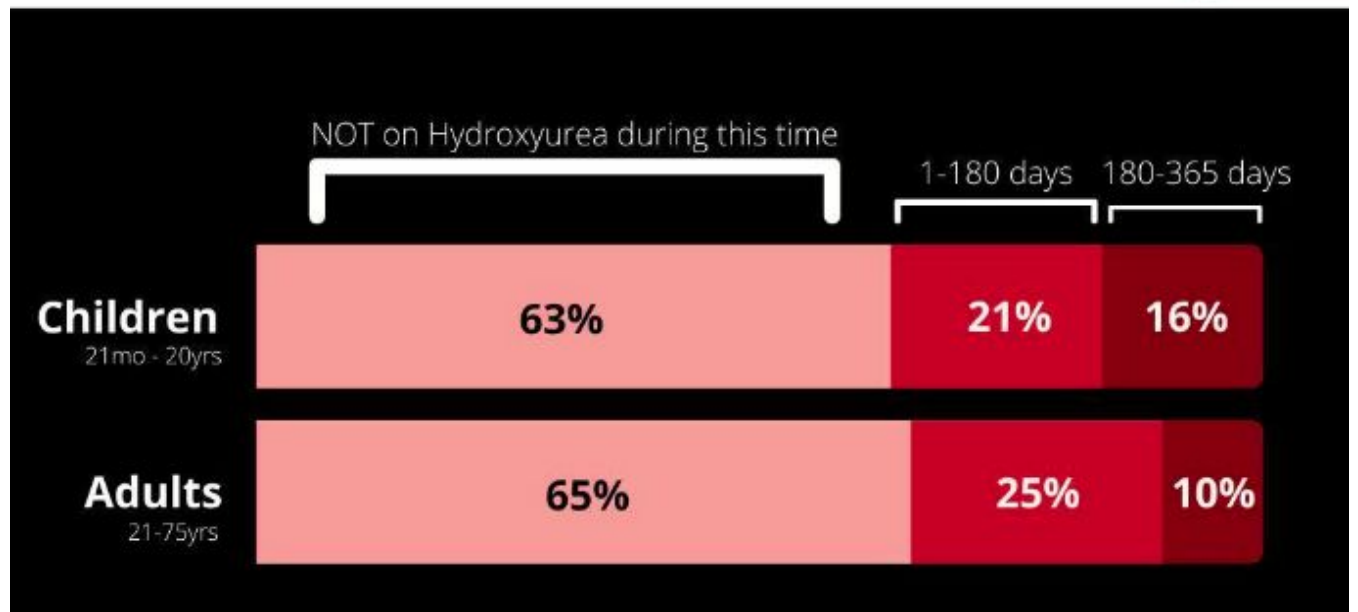
Medicaid and CHIP Report Card

- Understanding the role that Medicaid **plays in covering the needs of individuals** with SCD is increasingly important.
- Currently, a **national SCD surveillance system does not exist.**
- As new treatments emerge, questions of **appropriate coverage and reimbursement as well as expected outcomes** are at the forefront for Medicaid and other payers.

MEDICAID BENEFICIARIES WITH 1+ ED VISITS A YEAR



HOW MANY SCD WARRIORS ARE ON HYDROXYUREA?



Source: CMS' Medicaid and CHIP Sickle Cell Disease Report, T-MSIS Analytic Files (TAF) 2017.



Medicaid Access and Landscape Review

Project Overview

- In April 2022, Sick Cells conducted a **survey of decision makers at state Medicaid programs**.
- Survey findings were supplemented with **an environmental scan** to illuminate the state of access to SCD therapies in Medicaid.
- The report demonstrates **where there are challenges today** and **how access to therapies could be improved**.



Medicaid Landscape and Access Review for Prescription Drugs Treating Sickle Cell Disease. Sick Cells and Avalere Health; 2022

This effort was supported by contributions from the following companies. Contributing companies had no role in the design of the study, data collection, analysis, and interpretation, or writing of this report:





Methodology

Task 1: Environmental Scan Data

To examine drug access criteria, Avalere and Sick Cells identified 4 pharmacy benefit products

(Droxia[®], Endari, Oxbryta[®], and Siklos[®]) and 1 medical benefit product (Adakveo[®]).

- *Generic hydroxyurea is not analyzed in this report.*

We analyzed **preferred drug lists, prior authorization criteria summaries, and other coverage policies** as of June 2022 for state FFS programs and MCOs.

Table 1 – SCD Treatments Included in This Analysis

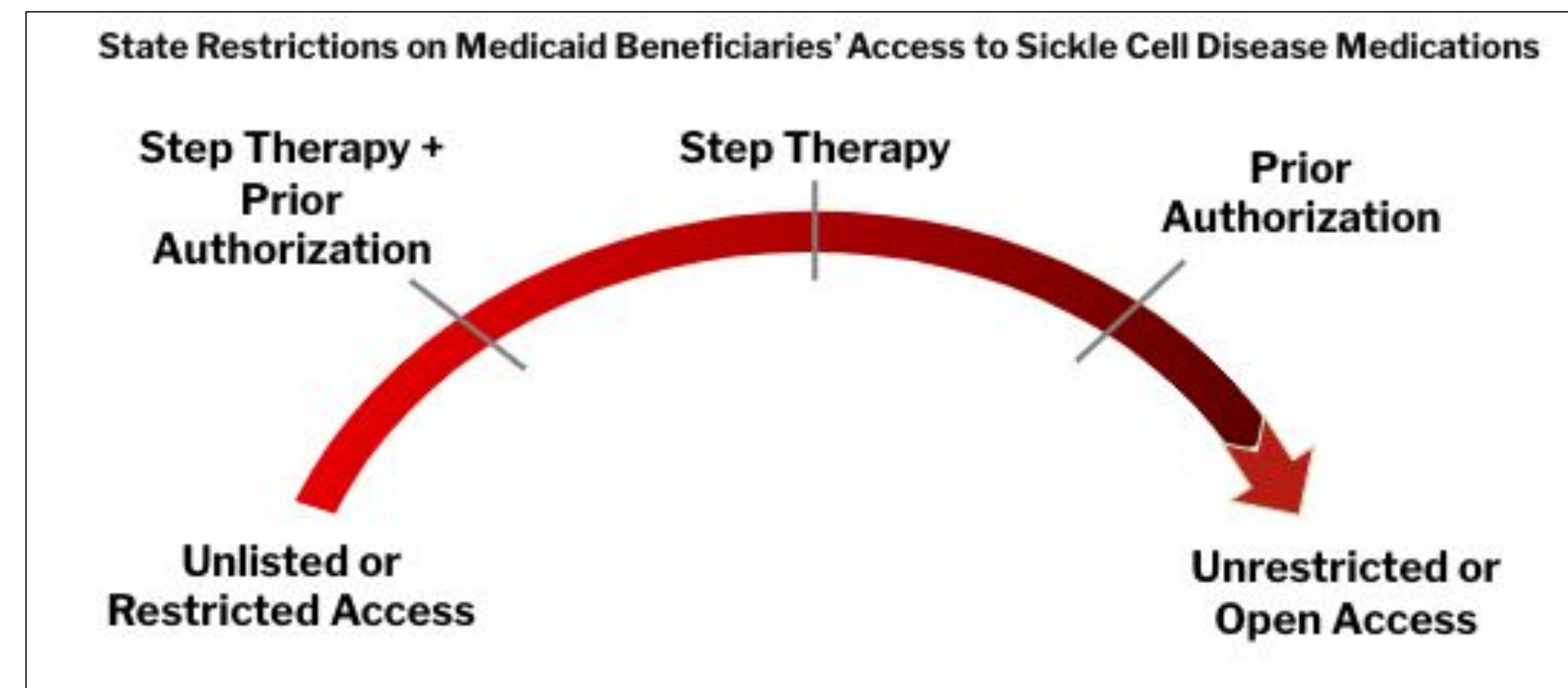
Trade Name	Product Name	Medical or Pharmacy Benefit	FDA Approval Date	Brand vs. Generic Status
Adakveo [®]	crizanlizumab	Medical	November 2019	Brand
Droxia [®]	hydroxyurea	Pharmacy	February 1998	Brand
Endari	L-glutamine	Pharmacy	July 2017	Brand
Oxbryta [®]	voxelotor	Pharmacy	November 2019 (Accelerated approval)	Brand
Siklos [®]	hydroxyurea	Pharmacy	December 2017	Brand



Methodology

Data Definitions

- **Not Listed:** Includes products not listed on the state or plan's PDL and products designated as Non Formulary/Exclusion.
- **Step Therapy and Prior Authorization:** Payer requires step therapy and prior authorization for the covered product.
- **Step Therapy:** Payer only requires the beneficiary or the beneficiary's physician to try and fail 1 or more preferred alternatives before the product is covered.
- **Prior Authorization:** Payer requires the beneficiary or the beneficiary's physician to get approval for the product.
- **Unrestricted (Open Access):** Plan does not require prior authorization or step therapy for the covered product.





Methodology

Task 2: Survey of Medicaid Decision-makers

To gain additional insights on the coverage and access landscape for SCD therapies, **two surveys were designed and administered:**

1. One survey was sent to current state Medicaid directors (Sick Cells conducted outreach)
2. Another was sent to broader group of relevant individuals at managed care organizations (MCOs) and individuals with prior state Medicaid experience (a survey firm conducted outreach)

Survey questions focused on the following domains:

- Coverage and care management for individuals with SCD
- Prescription drug management and access
- Health equity initiatives
- Stakeholder engagement

- Respondents responding for specific states represented (15):**

- Connecticut
- Kentucky
- Kansas
- Illinois
- Iowa
- Louisiana
- Massachusetts
- Missouri
- New York
- Pennsylvania
- Tennessee
- Texas
- Virginia
- Wyoming
- District of Columbia





Key Findings

- Across the environmental scan and survey, findings coalesced around **5 key topics**:

Prevalence of Utilization Management

Stakeholder & Contractor Engagement

Factors Influencing Decision Making

Role of MCOs

Health Equity Initiatives



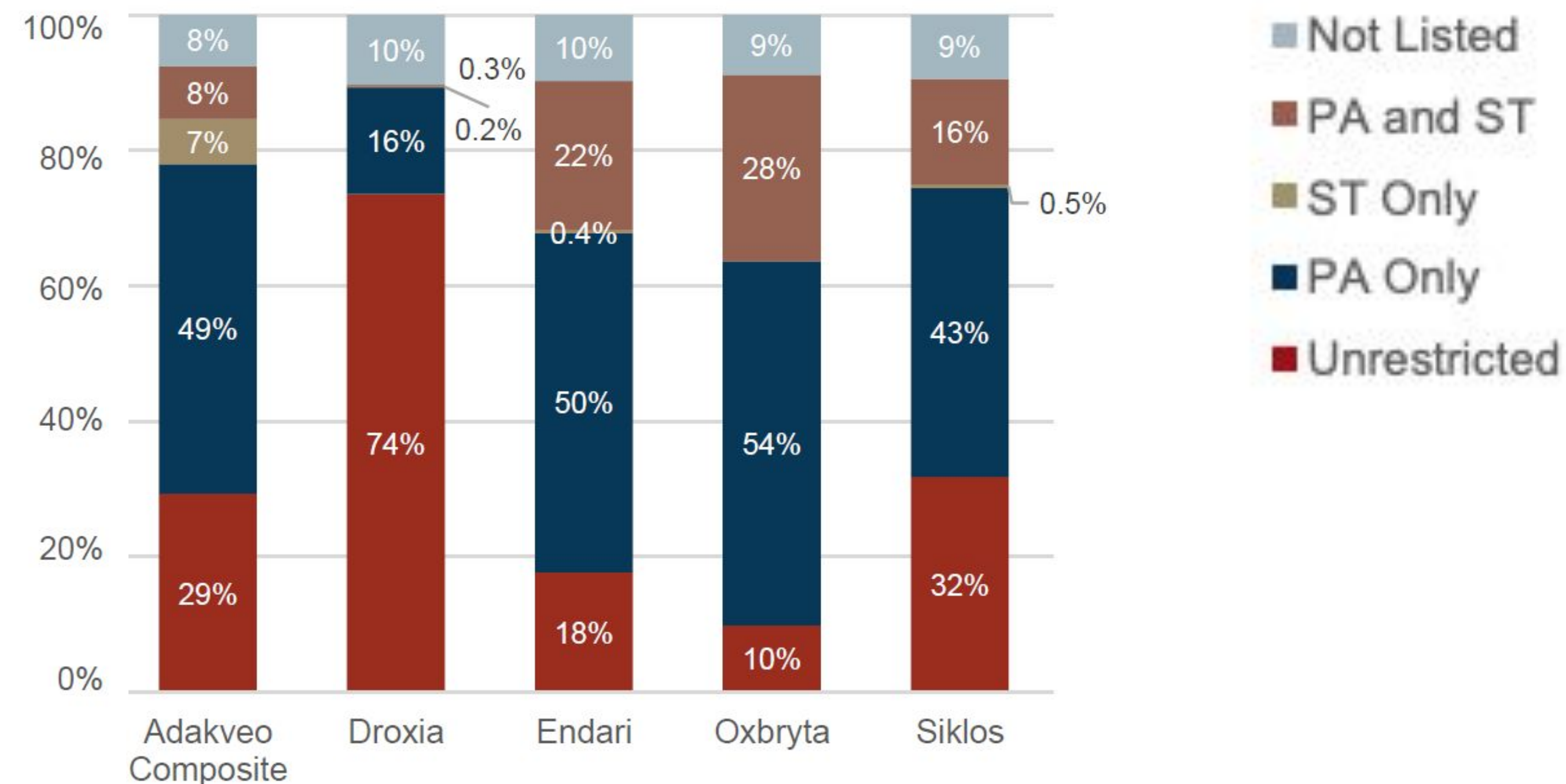
Key Findings

Prevalence of Utilization Management

Prevalence of Utilization Management

- State Medicaid programs and Medicaid MCOs use **utilization management techniques** to control drug cost and manage appropriate beneficiary access to therapies.
- The prevalence of **prior authorization and step therapy** is a key theme.

% of Time Medicaid Beneficiaries Experience Utilization Management Techniques Used For SCD Therapies Across All Medicaid





Key Findings

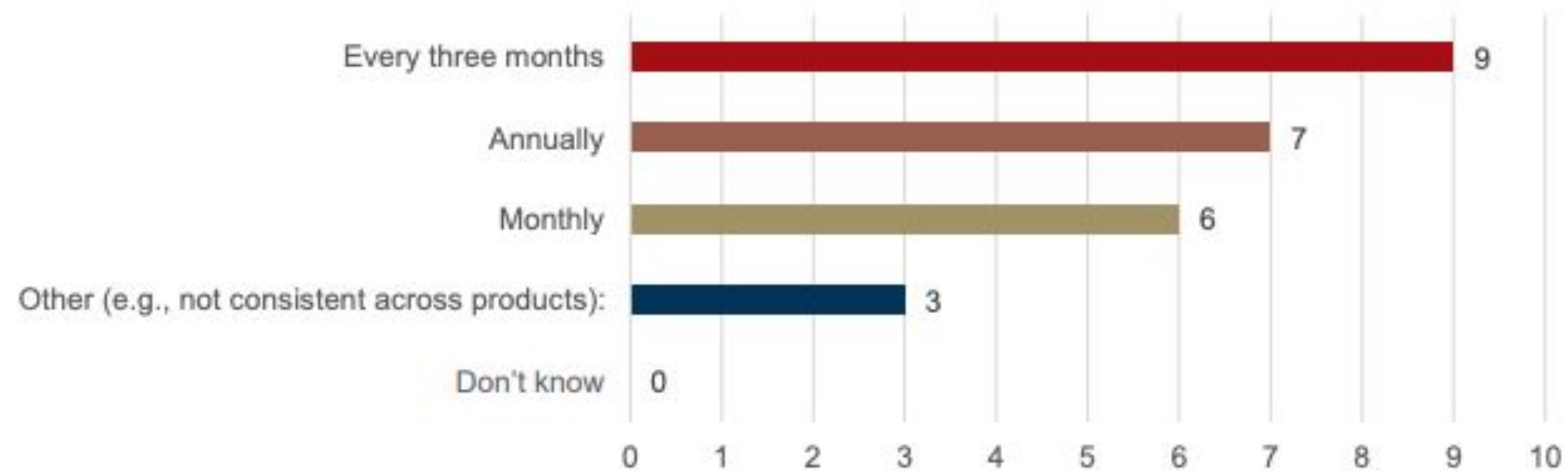
Prevalence of Utilization Management

Prevalence of Utilization Management

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- The prevalence of **prior authorization and step therapy** is a key theme.

Figure 7 – Reauthorization Frequency, Survey Counts

When a product that treats SCD has clinical prior authorization criteria, how frequently must a beneficiary's prescription be reauthorized?





Key Findings

Stakeholder & Contractor Engagement

- Survey respondents indicate that many decision makers consider **pharmacy benefit manager (PBM)** input in utilization management decisions. PBMs—some of which interact with many states and MCOs—play a key role alongside states and MCOs in determining access.
- However, stakeholders considered vary across FFS and MCOs. **MCOs look most frequently to input from PBMs**, whereas **states look most frequently to providers and clinical support vendors**.
- When decision makers are considering PDL placement and utilization controls, **patients and patient groups are the least consulted** stakeholders.



Key Findings

Factors Influencing Decision Making

- Most survey respondents reported using evidence of **comparative clinical effectiveness and established clinical benefits** in deciding whether to apply step therapy to SCD therapies.
- **Drugs' net prices** were also often cited as a factor in setting step therapy criteria. Medicaid net prices are complex and not available to the public.
- Preferences of **patients and statements from patient advocacy groups** are considered much less frequently than these other factors.



Key Findings

The Role of Managed Care Organizations (MCOs)

- Many Medicaid beneficiaries nationwide have their care managed by an MCO. This speaks to the power and influence MCOs can have on the Medicaid population.

Reflected in the survey, **35 of 40 survey respondents** reported some or all Medicaid beneficiaries with SCD in their state(s) of purview are enrolled in managed care.

- The survey revealed **the use of specialized MCOs for some beneficiaries with SCD** (11 respondents).



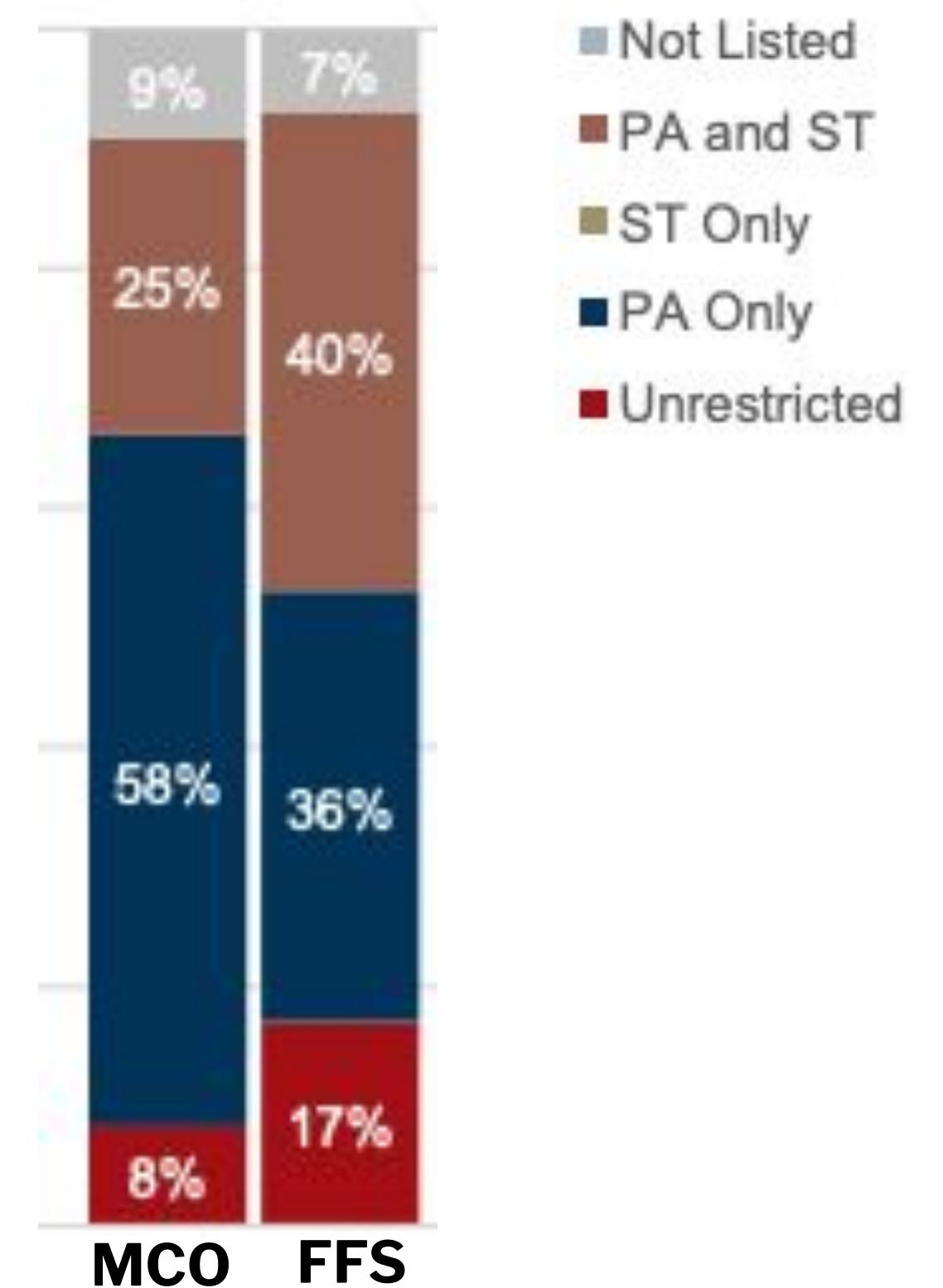
Key Findings

The Role of Managed Care Organizations (MCOs)

- MCOs used **prior authorization more often** than FFS programs do; however, MCOs generally apply **less step therapy**.
- **MCOs list their criteria more often.** Having access criteria documented on a PDL or other document is important to ensure beneficiaries and providers understand how therapies can be accessed.
- Some states with MCOs manage drugs through full drug carve outs or uniform preferred drug lists (PDLs), reducing the influence of their MCOs.

Role of MCOs

Oxbryta





Key Findings

Health Equity Initiatives

- State Medicaid programs are **taking steps to address health equity** and SDoH.
- States are **increasingly using their MCO contracts to screen for SDoH**, data collection, and data reporting to address health equity.
- Specific policies and programs designed to improve equity for individuals with SCD are still needed. Referrals to community organizations could be an important area for improved partnerships between community-based organizations (CBOs) and Medicaid.

Texas

- Collects race, gender & clinical risk group information. Texas External Quality Review Organization analyzes equity-focused data

Louisiana

- Have a Review, Advise & Inform Board of community members who advise their bureau

Kentucky

- Surveying providers & members to understand barriers to care access, including social & financial challenges



Conclusions & Recommendations

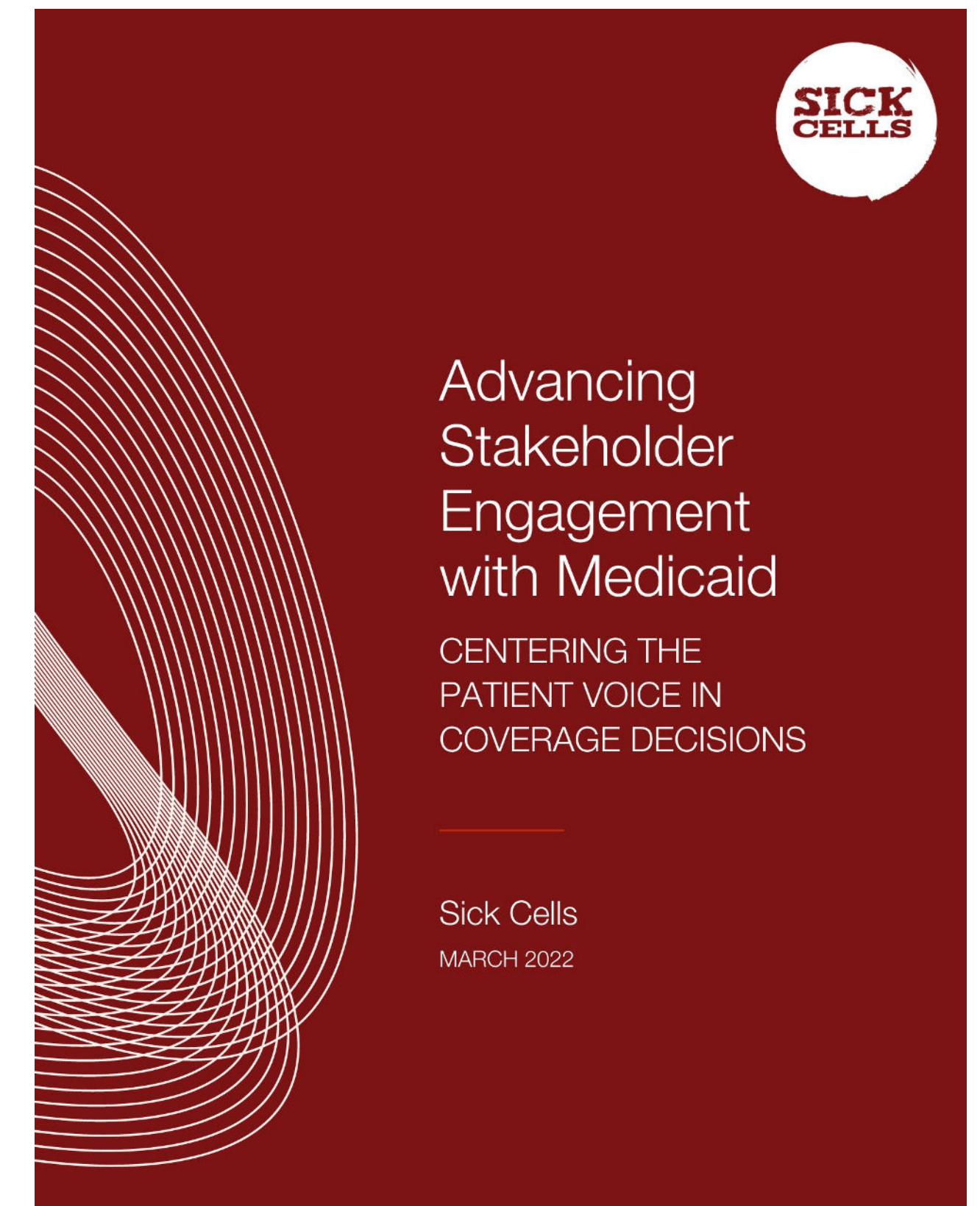
- Full conclusions & recommendations by theme in the report
- This presentation is to set the stage of today's conversations in the various sessions



ADVANCING STAKEHOLDER ENGAGEMENT WITH MEDICAID: Centering the Patient Voice in Coverage Decisions (White Paper)

Background

- Coverage for SCD treatments & therapies can vary by state & decisions are often made by an organized group of medical professionals on coverage decision committees (i.e. Drug Utilization Review Board (DUR Board) or Pharmacy & Therapeutics (P&T) committees). While members of these committees work hard to make informed decisions, **most are unfamiliar with SCD and therefore face challenges** when deciding access to and coverage of SCD treatments.
- To date, Sick Cells has **trained over 25 individuals** to advocate for sickle cell disease coverage in their state.



[READ THE PAPER](#)



Existing Barriers to Engagement

- Lack of specific expertise
- Restrictive public engagement procedures
- Limited transparency
- Insufficient use of existing expert groups

Case Studies

#1: Texas Medicaid DURB Meeting

- Highlights advocate experience with a receptive board, as well as the limitations around transparency.

#2: Missouri Prior Authorization Meeting

- Highlights lack of engagement with local expert groups

#3: Illinois D&T Meeting

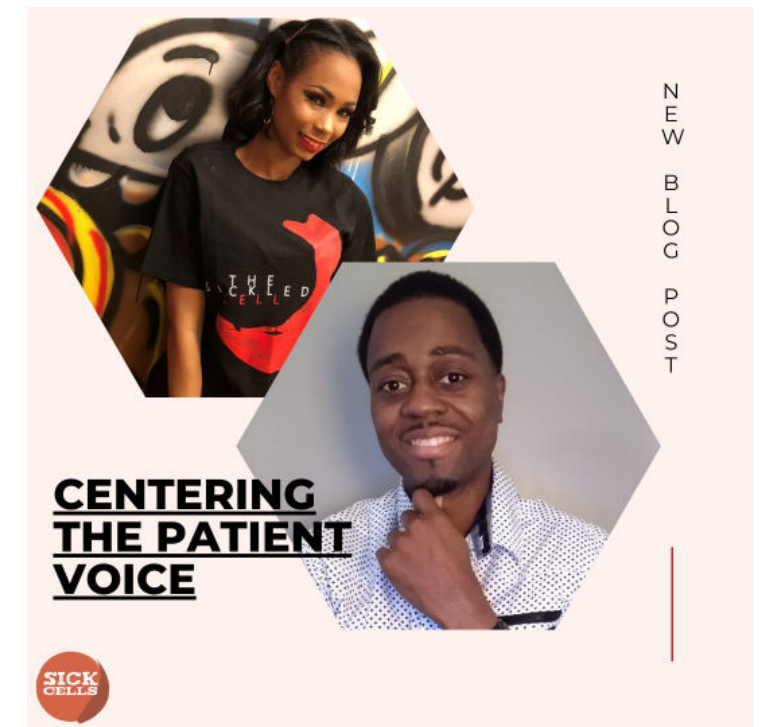
- Highlights the effectiveness of combined advocacy across stakeholder groups

#4: Wisconsin DURB Meeting

- Highlights the power of patient advocacy & an informed Board

Recommendations

- For the SCD Community: Recommendations focused on different ways to remain engaged with the Medicaid coverage process through direct involvement, letter writing, and legislative outreach.
- For state Medicaid programs: Recommendations focused on establishing direct outreach with the community, promoting transparency, and creating systems for involvement that are easy to navigate.



[READ THE BLOG](#)

Q&A Session

12:50 – 12:55 PM

This Q&A Session will last for about 5 minutes.

Please take a moment to submit your questions via the
“Q&A & Chat” box.



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