Advisory Board

STRATEGY REPORT

4 ways to improve site-of-care transitions for sickle cell patients

Optimizing inpatient to outpatient transitions of care for adults with sickle cell disease

Treating sickle cell disease (SCD) is both complex and challenging due to its chronic nature, the variability of symptoms, and the comprehensive management it requires. The condition's prevalence in underserved communities further complicates care, as these populations encounter substantial barriers to consistent, equitable treatment. Improving transitions of care from inpatient to outpatient settings for adults with sickle cell disease is crucial for reducing hospital stays, cutting unnecessary costs, and supporting the long-term health of individuals with SCD. Health system leaders can employ four key strategies to ensure more comprehensive and patient-centered transitions of care.

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Read time – 25 minutes

Audience

- Hospitals and health systems
- Physicians and medical groups

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The challenge

Sickle cell disease (SCD) is complex and requires continuous management across multiple care settings throughout a patient's life. As a result, treating SCD is particularly challenging for health systems, providers, and patients. While there are opportunities to improve many facets of SCD care, the transition of care between inpatient and outpatient settings is critical for reducing hospital length of stay, improving patient outcomes, and minimizing unnecessary costs to the health system. SCD is also prevalent among underserved communities that experience high barriers to receiving equitable care, which makes seamless, efficient transitions of care even more essential.

SCD places financial burden and capacity constraints on health systems

SCD contributes to increasing healthcare costs due to high ED use and inpatient admissions. Over the last 20 years, ED visits for SCD have risen by approximately 13%.[2] This increase can be linked to an aging SCD population, longer life spans, and a lack of coordinated access to primary and specialty care.[2] Consequently, patients may depend more on acute care services.

Patients with SCD frequently experience vaso-occlusive crises (VOCs) and other complications, leading to an average of five ED visits and three inpatient admissions per year.[3] This frequent reliance on acute care is not only disruptive for patients but also expensive. Notably, inpatient care accounts for 57% of SCD-associated costs, with about 30% of hospital stays resulting in a 30-day readmission.[4,5,6]

Despite the financial implications, health system leadership may lack understanding of the scope of problems associated with SCD care and question whether addressing a rare disease will align with broader system-wide priorities. Additionally, many regions face a shortage of outpatient services, clinics, and SCD-specific support, which hinders the delivery of effective care for this patient group.[7]

The challenge (cont.)

Complexity of SCD treatment leads to insufficient care and inequities

SCD affects about 100,000 individuals in the U.S., which is around 0.03% of the population.[8,9] It has a disproportionate impact on underserved communities, particularly among Black or African American individuals, with approximately 1 in 365 births, and, to a lesser extent, Latinos, with about 1 in 16,300 births.[8] Additionally, half of those living with SCD are Medicaid beneficiaries.[10]

SCD is a complex, lifelong condition that requires extensive, ongoing care. Patients with SCD face heightened infection risks and chronic organ damage, including cognitive impairment, acute chest syndrome, and renal disease. Lifelong management is essential to prevent these complications and involves regular blood transfusions, medication regimens for pain control, and infection prevention. Chronic conditions like SCD necessitate constant vigilance and frequent treatment adjustments, imposing physical, emotional, and financial burdens on patients and their families.

Furthermore, the current care process for SCD often overlooks the comprehensive needs of patients, many of whom face barriers to care. For example, 66% of SCD patients have at least one unmet socioeconomic need, such as food insecurity, difficulty finding housing, and a desire for more education.[11] In addition, many SCD patients often experience different biases based on race and socioeconomic status. This is particularly challenging as it relates to pain management, where some patients may even be seen by physicians as "drug seekers."[12]

> With SCD, health-related stigma can be compounded by racism (actual or perceived) and can pose significant barriers to getting appropriate care. For example, the standard of care for SCD patients with chronic or acute pain is to receive opioids. But some patients seeking medication for chronic or acute pain may be misperceived as drug addicts. Or people who need to rest from fatigue caused by SCD may be falsely thought of as malingers (those who pretend to be sick to get out of their responsibilities).[12]

Overcoming the Stigma of Sickle Cell Disease

The challenge (cont.)

Gaps in the SCD care journey exacerbate poor outcomes

Adult patients with SCD often encounter a fragmented health journey as they transition from the structured ED and inpatient environment to the relative autonomy of outpatient follow-up care.

Common phases of a SCD patient journey

Emergency department → Inpatient → Discharge planning → Discharge → Outpatient follow-up
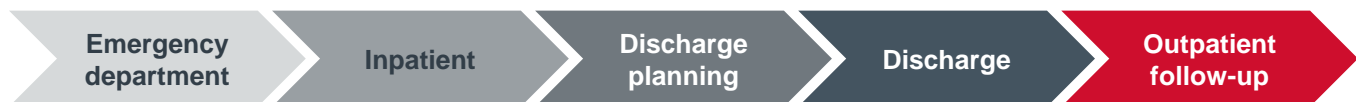
Specifically, adult patients are approximately three times more likely to face readmission within 30 days following discharge compared to admitted patients without SCD. Approximately 50% of patients with SCD fail to attend follow-up appointments.[13,14] This is frequently due to inadequate discharge planning and outpatient follow-up, a cycle that perpetuates high-cost care and hinders effective disease management.

A major contributing factor to poor SCD care navigation is that healthcare providers frequently feel discomfort and lack confidence in treating SCD. One survey of family physicians revealed that, of physicians who have one or more sickle cell patients, only 36% feel comfortable in their ability to manage the disease. Among the physicians who did not have any SCD patients, only 10% were comfortable managing the disease.[15]

Throughout the transition of care from inpatient to outpatient settings, patients often grapple with uncertainty. Unsure where to find reliable care post-discharge, many patients are left to navigate a healthcare landscape where SCD expertise is scarce. Even for physicians who are familiar with SCD, the practicalities of imparting extensive disease management education within the constraints of routine care remain challenging.

At the core of these issues lies a disconnect between the perceived value of improving SCD transitions of care and the incentives for providers, who may also harbor doubts about patient engagement and treatment adherence. Addressing these barriers goes beyond enhancing individual care touchpoints in the transition from inpatient to outpatient. Creating a seamless care continuum supports the long-term health and well-being of patients with SCD.

4 strategies to improve inpatient to outpatient transitions of care for adult patients with SCD

Focusing on the transition of care from inpatient to outpatient settings is a critical strategy for optimizing overall SCD management, improving health outcomes, and enhancing patient satisfaction. Health system leaders can implement four key strategies to streamline the transition from inpatient to outpatient, ensuring a more cohesive and patient-centric approach to managing SCD.

01   **Define and capture program ROI to secure ongoing system buy-in**

02   **Assemble a multidisciplinary care team to meet SCD-specific needs**

03   **Support and educate providers to bridge the SCD knowledge gap**

04   **Personalize the patient care journey to promote adherence and engagement**

01 Define and capture program ROI to secure ongoing system buy-in

To garner support from health system leadership and providers, SCD programs must define success metrics, collect data, and demonstrate benefits. Success metrics should be developed in collaboration with stakeholders, including clinicians, administrators, and patients. Health system leaders should also establish a robust data collection and analysis process to monitor program success and demonstrate its value to the system.

Quantitative and qualitative metrics of success may include:

- Reduced ED visits and readmission rates

- Improved patient satisfaction

- Cost savings

- Increased rates of outpatient follow-up

Moreover, aligning the program's benefits with system goals is key to gaining leadership and stakeholder support. Presenting cost savings and other advantages through compelling data helps to build a strong case for the SCD program. This evidence can help the C-suite and other key stakeholders understand the organizational imperative to improve SCD care.

Identify a program champion

Securing system-level support for a SCD program hinges on the presence of an influential and actively engaged program champion, such as a physician, nurse, or hospital administrator. Importantly, this individual should have both the respect of their peers and the passion to drive the SCD program forward.

Once identified, this champion should be equipped to advocate for the SCD program. It's the champion's responsibility to communicate the program's vision and the benefits it offers to patient care, aligning it with the organization's objectives. The champion's role also includes building trust by promoting transparency, engaging in ongoing dialogue to gather feedback, recognizing achievements, and addressing challenges head-on, demonstrating an unwavering commitment to transparency and continuous improvement.

For health systems that are just beginning to build a SCD program, start with a small pilot and scale up as resources grow.

❯ **Select a targeted patient population**

Choose a small, impactful subset from your SCD patient pool for a pilot. For example, select the top 10 highest-need patients or ED utilizers to show the pilot's potential effect.

❯ **Design a feasible pilot with specific, achievable goals**

Create a focused pilot with clear goals to test processes and collaboration effectively. Ensure goals are measurable and aligned with key SCD program objectives, like specific health outcomes, patient satisfaction, or reduced readmissions.

❯ **Evaluate and refine program objectives and practices**

Monitor and adjust the pilot using outcomes data and stakeholder feedback to enhance the program and identify best practices. Continuously collect data, solicit input, refine the program accordingly, and strategically resolve challenges.

❯ **Leverage pilot success to scale program**

Use the pilot as a success model, aligning with system-wide objectives to obtain resources for expansion. Perform a cost-benefit analysis to gauge the pilot's financial viability. Document and share pilot insights with key system players to guide wider SCD care improvements.

See how Virginia Commonwealth University used this strategy to start a small SCD Adult Medical Home Program and scale up over time.

Read now

Ways to expand your reach and impact

Grant funding can provide essential financial resources for starting and growing a sickle cell program. Collaboration with community organizations and other hospitals can strengthen grant proposals. Many grants favor projects that demonstrate community engagement and interinstitutional cooperation, as these are often seen as more sustainable and impactful.

02 Assemble a multidisciplinary care team to meet SCD-specific needs

Sickle cell disease is a rare, complex, and multifaceted disease. As such, it requires a wide array of expertise to properly address clinical and social elements of care. Given the scarcity of sickle cell expertise and funding challenges, healthcare systems must identify critical roles and responsibilities for an effective SCD program. Essential responsibilities include patient navigation, prior authorization, follow-up and lab coordination, medication management, and patient education. However, it is imperative that dedicated SCD professionals focused solely on this complex disease state fill these roles.

Nonnegotiable care team roles and responsibilities[1]

Program champion

- Functions as the central advocate and primary contact for leadership and external inquiries
- Builds on established trust with system leadership and respect in the field
- Coordinates overall strategy and makes final decisions
- Bridges interdisciplinary gaps, enhancing team-based SCD care and communication
- Ideal candidates for this role include community health workers, social workers, registered nurses, physicians, and system administrators with a passion for SCD

Dedicated coordinator or navigator

- Manages appointment scheduling and patient inquiries
- Implements standardized follow-up procedures predischarge
- Ensures follow-up adherence, addressing missed appointments and noncompliance
- Maintains consistent communication to prevent patient care lapses during transitions
- Ideal candidates for this role have a community health background

Social worker or community health worker

- Assesses patients' holistic social needs, including financial and psychosocial needs, transportation, housing, nutrition, and family care challenges
- Connects patients with social resources and advocates against biases
- Integrates social care management with clinical care to improve adherence

1. Some programs also include additional roles, such as a dedicated pharmacist, psychiatrist, hematologist, and infusion specialist. However, these specialized positions are not considered essential priorities to initially set up a program.

Once the system has established a multidisciplinary team, the next critical step is to institute a regular cadence for case review, best practice sharing, strategic planning, and problem-solving. This systematic approach is essential to guarantee effective communication and collaboration across the diverse specialties within the care team.

> **Intradepartmental collaboration:** Set regular SCD multidisciplinary team meetings to collaboratively review performance metrics, challenging cases, and strategic priorities. The presence of diverse multidisciplinary perspectives enriches the conversation, fostering innovative solutions and collaborative care approaches.

> **Interdepartmental collaboration:** Establish regular cross-departmental sessions between SCD and non-SCD teams to collaboratively refine best practices and share feedback, insights, challenges, and other suggestions to improve sickle cell care, fostering shared ownership and responsibility.

Ways to expand your reach and impact

To provide holistic patient care, identify areas where patients need extra support and partner with local organizations such as health systems, food banks, housing agencies, and mental health providers. These partnerships enable health systems to focus on their medical expertise while leveraging community resources for additional needs, enhancing patient outcomes, and conserving health system resources.

03 Support and educate providers to bridge the SCD knowledge gap

Effective management of SCD hinges on a well-informed multidisciplinary care team. It's crucial for healthcare systems to prioritize continuous education for every team member, from doctors to allied health professionals. Continuous education ensures everyone is equipped with the latest knowledge and techniques to provide empathetic, culturally sensitive, and bias-free care that fosters patient trust and improves outcomes.

Comprehensive training programs should cover up-to-date SCD treatment, pain management, and the unique challenges patients with SCD face. Consider making these programs interactive and include real patient experiences to humanize the training. Additionally, leveraging your program champion and leadership can help underscore the importance of this training to participants.

Standardized care protocols enhance comprehension and adherence

Electronic Medical Records (EMRs) are a central tool in managing patients with SCD across providers and care settings. They provide comprehensive and easily accessible records that are vital for connecting different health systems. Without interoperable EMRs, it's hard for providers to access patient records when they present in a different hospital or health system.

To optimize the use of EMRs for patient care, some healthcare organizations have embedded features such as pop-up reminders of care guidelines when a patient's profile is accessed. This requires providers to review and acknowledge the patient's care plan before proceeding, reinforcing adherence to existing treatment plans. Such enhancements in EMR functionality not only improve the quality of care but also contribute to a more informed and attentive healthcare environment for patients with SCD.

Implementing standardized care protocols for SCD ensures that healthcare providers and patients consistently understand and follow a care plan. To achieve this, healthcare systems should develop detailed order sets within the EMR. These sets should guide providers on various aspects of care, such as pain management plans, intake screening processes, emergency department orders, and discharge and follow-up procedures. The result is a more efficient transition between different care settings and a reduction in rehospitalization rates as patients receive standardized follow-up.

Ensure SCD expertise is accessible

To address the discomfort nonspecialized providers often feel when treating SCD, healthcare organizations must ensure SCD experts are readily accessible for consultation.[16] This support is crucial for delivering appropriate treatment and fostering confident care for patients with SCD. Additionally, clear and easy communication channels must be established within care teams and between departments, such as inpatient and emergency services, to ensure swift and effective collaboration.

The accessibility of the SCD team is fundamental to quality care. This multidisciplinary SCD team, comprised of hematologists, pain management experts, and nurse educators, should be available for consultations with non-SCD providers. Furthermore, secure and efficient communication processes are crucial for timely and comprehensive care. A hospital-wide messaging app coupled with dedicated phone lines can facilitate immediate dialogue among healthcare professionals, enabling them to make swift, coordinated decisions.

Ways to expand your reach and impact

To expand your reach, partner with local organizations and established SCD centers. Such collaborations could provide non-SCD providers with access to specialized knowledge via telehealth, joint clinics, or case discussions. These networks facilitate the sharing of treatment protocols and educational materials, bolstering SCD care effectiveness despite resource constraints.

04 Personalize the patient care journey to promote adherence and engagement

To ensure patients adhere to their care protocols, healthcare systems must overcome a history of mistrust and missed opportunities to improve care by making a concerted effort to build trust with SCD patients. This undertaking may require a substantial initial investment but is crucial for long-term patient outcomes. Healthcare providers can lay the foundation for trust by consistently demonstrating respect, reliability, and a genuine commitment to their patients' well-being.

Improving transparency in care processes is also important. Healthcare providers can dispel historical mistrust by keeping patients informed about their diagnosis, treatment options, and care plans. Some health systems, such as Medical University of South Carolina, encourage patients and caregivers to share their experiences with the wider medical community. By obtaining consent to share their stories at conferences or other events, patients and caregivers not only help center patients' experiences but also contribute to the improvement of SCD care across the community.

> " You can add on as many people as you want, but if the patients don't trust you, you won't see them. They have to know that you care.

Consuela Albright, CNP
Cleveland Clinic

Build trust between providers and patients with SCD

Empathetic communication is essential for building trust with patients. Healthcare providers should actively listen and validate patients' concerns through open, nonjudgmental dialogue. One effective method includes holding comprehensive care plan meetings with doctors, specialists, and family members. These meetings are aimed at empowering patients and fostering a trusting relationship by directly involving them in discussions about their care strategy.

Consistency in care is another key element. Employing consistent care teams and standardized protocols, especially for pain management, helps to build familiarity and trust for SCD patients, alleviating anxiety and tackling potential biases. This strategy shifts decision-making to established guidelines, instead of leaving care decisions to the sole discretion of individual providers, some of whom may not have formal SCD training or experience.

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Lastly, enhancing accessibility is important when fostering trust between patients and their care team. Providing SCD patients with direct phone lines, secure online portals, and after-hours services facilitates immediate contact with their care team during crises, empowering them to manage their health communication and records effectively. This level of accessibility not only fosters trust but also ensures that patients can reach out for assistance whenever necessary, thereby improving the overall quality and responsiveness of care.

Tailor care to individual patient needs to boost engagement and adherence

Personalized, multidisciplinary care plans that address unique medical and social needs are crucial for improving patient care and outcomes. Ensuring a seamless care experience involves integrating services from emergency visits through to outpatient follow-up, with careful management of transitions to eliminate gaps in care. Streamlining appointments into a single visit reduces the frequency of clinic trips, while care plan meetings with the team, patients, and caregivers support shared decision-making by offering multiple care options for a patient-centered strategy.

It's also important to foster patient engagement and autonomy by actively involving patients in shared decision-making. This empowers patients to make informed treatment choices and underscores their crucial role in self-managing their health. Care plans should be regularly reviewed and updated with direct patient input, reflecting changes in health status and personal preferences.

Finally, it's critical to offer an array of educational resources — such as brochures, videos, and apps — that cater to different learning styles and literacy levels, covering topics like treatment options, self-care techniques, and the care continuum. In practice, an effective patient education program provides extensive content and evolves based on patient feedback at multiple points of the care journey

For example, the Medical University of South Carolina hosts monthly town hall sessions where patients and caregivers can discuss relevant issues. This engagement refines educational materials to better align them with patient-identified priorities, covering subjects from new gene therapies to educational accommodations such as 504 plans and Individualized Education Programs (IEPs).

Ways to expand your reach and impact

Partnering closely with community organizations can help heath systems identify the needs of their patients. For example, a hospital's collaboration with a community sickle cell support group revealed insights into common barriers to accessing care, such as patients' concerns about long ED wait times due to acute pain. Other partnerships include local blood drives and gene therapy groups that aided in developing patient education for new treatments.

Conversations you should be having

Before launching or expanding a sickle cell program, it's important to address critical factors like the program's alignment with organizational goals, resource availability, and the potential for success with your health system's leadership.

Below are sample questions to guide your discussion with your leadership team:

- How do investments in a sickle cell disease program align with our health system's overall mission, vision, and strategic priorities?

- What are the specific needs of SCD patients that our program aims to address?

- What are the short-term and long-term goals for the SCD program, and how will we measure success?

- What resources (financial, human, infrastructure) are required to start, grow, or sustain an effective SCD program? How can we leverage our existing resources, and how will we secure the remained resources needed?

- What strategies will we employ to raise awareness about the program and educate the community, patients, and healthcare professionals about SCD?

- How will we involve patients and their families in the development and ongoing improvement of the SCD program and care plans to ensure their needs are met?

- Which community organizations, advocacy groups, or other healthcare institutions can we partner with to enhance the reach and effectiveness of our program?

Parting thoughts

Health systems need to consider adopting more holistic strategies for SCD that extend beyond improving transitions from inpatient to outpatient to effectively tackle broader challenges in the sickle cell care landscape.

Ensuring a smooth and effective transition from inpatient to outpatient SCD care is crucial to mitigate readmissions, reduce care costs, and engage patients in their care plans. However, optimizing this transition is just one aspect of the broader spectrum of challenges associated with caring for patients with SCD.

The transition of care from pediatric to adult transition, for example, is another critical juncture. As adolescents with SCD age out of pediatric care, they must navigate a healthcare system that may be less familiar with their individual needs and less equipped to provide the specialized care that SCD requires. This period is riddled with potential hurdles, including a shift in insurance coverage, a contrast in the healthcare delivery models of pediatric versus adult services, and an increased burden on the patients themselves to manage their health. Proactively addressing key aspects of adult sickle cell treatment during the pediatric to adult transition can improve patient outcomes. This can include prioritizing preventive care, coordinating specialist visits, and ensuring adherence to medication plans.

While improving transitions from inpatient to outpatient care for patients with SCD is a key imperative for health systems, this strategy must be considered as part of a larger framework for improving SCD care. By addressing these issues holistically, health systems leaders can build a stronger, more effective care continuum for patients with SCD.

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Endnotes

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