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CASE STUDY

How VCU built an ‘inescapable’ Adult Sickle Cell Medical Home to improve inpatient to outpatient transitions of care

Virginia Commonwealth University (VCU) Health launched the Adult Sickle Cell Medical Home Program in 2018 to address a sharp rise in readmission rates and ED visits for patients with Sickle Cell Disease (SCD).[1] This program delivers specialized, comprehensive treatment to almost 1,200 adult patients with SCD out of the total 5,000 patients across Virginia, marking a substantial growth in the patient population since the program’s inception. The program’s ‘inescapable’ structure ensures continuity in care and consistency in patient engagement, leaving little chance for patients to fall through the cracks in their transition from inpatient to outpatient care.[2] Through their work, VCU improved trust in the healthcare system and significantly reduced overall costs of care for SCD patients.

Published – April 2025

Read time – 15 min.

Audience

- Hospitals and health systems
- Physicians and medical groups

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Overview

The challenge

SCD readmissions data from VCU Health revealed concerning trends: the 30-day readmission rate for patients with SCD had spiked to 33.7% in 2016, up from 22.5% just two years earlier.[3] The average length of stay had increased by 2.5 days, and the number of emergency department (ED) visits was projected to double in 2017. VCU wanted to find a way to address the root causes of frequent ED visits among their patients with SCD, such as missed follow-up appointments, lack of provider expertise in SCD, funding challenges, and historic mistrust between patients and providers.

The organization

VCU Health is the medical campus of Virginia Commonwealth University, located in Richmond, VA. Under the direction of Dr. Wally Smith and Senior Program Manager Shirley Johnson, the Adult Sickle Cell Medical Home Program launched in 2018 to provide inpatient and outpatient treatment, research, and support for almost 1,200 adult patients with SCD out of the total 5,000 patients across Virginia.[1] The program is comprised of a 20-person care team that focuses on identifying and overcoming barriers to healthcare access for patients with SCD.

The approach

An analysis of National Hospital Ambulatory Medical Care Survey (NHAMCS) data for the years 1999 to 2007 revealed that patients with SCD nationwide commonly experienced a persistent cycle of ED reliance and prolonged hospital stays, prompting VCU Health to develop the specialized Medical Home to break this cycle by offering accessible and comprehensive care.[4] Led by SCD specialists and targeting the 50 highest utilizers based on the Centers for Medicare & Medicaid Services (CMS) guidelines, this initiative features a team-based approach with community health workers offering weekly individualized care management.[5] The Medical Home integrates primary care with structured protocols for acute care and pain management, all coordinated within a collaborative care framework. VCU Health’s strategy aims to tackle the root causes of frequent ED visits and enhance the overall continuity and quality of care for patients with SCD, thus ensuring patient engagement with an “inescapable” program and improving long-term health outcomes.

The result

VCU Health's specialized medical home approach for patients with SCD has yielded significant improvements across fiscal year 2019, with a 10% reduction in readmission rates and a decrease of 1,096 inpatient days across the 50 highest utilizers in VCU’s SCD population.[6] Additionally, the “inescapable” program has effectively lowered the average hospital stay by 0.86 days and reduced no-show rates, reflecting an enhanced trust between patients and the healthcare system. Moreover, the program averted $2.465 million in charges for its highest utilizers over two years.

01

Program overview: VCU's Adult Sickle Cell Medical Home

With a small staff accommodating a growing SCD patient population, the hospital's general care protocols weren't sufficient enough to address the specific needs of patients with SCD. Fragmented care teams operating in silos further exacerbated the challenge, as they were disconnected from the dedicated SCD care staff. Recognizing SCD as a primary driver of excessive hospital resource use and declining patient satisfaction, VCU sought out a new strategy to reduce costs and improve patient outcomes.[3]

In 2018, VCU launched the Adult Sickle Cell Medical Home Program. After evaluating different care models, VCU decided to pursue a specialized medical home model due to its collaborative, patient-centered nature (see supporting artifacts on page 13 for more information on care models). The program aimed to reduce readmissions and hospital stays, cut down on ED visits, and enhance the quality and outcomes of patient care. To deliver integrated and cohesive care, the program is structured around six core subservice committees, each fulfilling specific roles within the care continuum: inpatient, ED, ambulatory, behavioral health, evaluation, and clinician (see supporting artifacts on page 14 for more information on core subservice committees).

Effective communication is a cornerstone of this program. VCU holds weekly leadership oversight meetings to coordinate the activities across the program and to make informed adjustments based on collective feedback. Meanwhile, these committees individually convene on a regular basis to conduct a thorough review of policies, evaluate service designs, monitor performance metrics, and deliberate on individual patient treatment plans and more complex cases.

Additionally, a dedicated SCD clinical pager provides around-the-clock contact, operated by clinical providers on a rotating basis as determined by the inpatient nurse practitioner. This system is supplemented by regular communication through texts between clinical providers, case management team meetings, and committee discussions involving ED and inpatient hospitalists.

VCU’s Adult Sickle Cell Medical Home program has 2 main goals:

1. **Improve patient access and support**
    - A 24/7 text service provides patients with access to an on-call SCD provider.
    - Patient navigators conduct home, hospital, clinic, and telemedicine visits to assist with treatment plans and securing basic life necessities, while documenting interactions in case reports to track patient engagement and feedback.
    - Prior authorization specialists assist patients with insurance paperwork and medication refills, streamlining approvals to help prevent unnecessary ED visits and admissions.

2. **Promote patient engagement and responsibility**
    - The program sets clear expectations for patients to actively engage in their care and maintain open communication with their healthcare providers.
    - The “My VCU Health” patient portal provides easy access to medical information and improves communication with care teams.

02 How VCU funded their SCD program

Involve multidisciplinary stakeholders early on to ensure institutional buy-in and funding

Initially, ED and inpatient providers were skeptical about the need for integrating specialized SCD care into their routine practices. In response, the VCU team compiled a compelling case using hospital admissions data to show SCD as a top reason for hospitalizations and emphasized the potential financial benefits of a specialized care program. Drawing from evidence from other chronic conditions, they showcased how targeted SCD care could lead to lower readmission rates and healthcare costs.

Identifying early advocates, including Dr. Smith, within the healthcare system’s leadership proved instrumental in securing the buy-in needed to drive the program forward with the right momentum and resources. Involving these key advocates and stakeholders from the outset ensures alignment of goals, a clear understanding of the initiative, and fosters a sense of ownership that leads to active program promotion.

Conduct pilot program to demonstrate success and potential to scale

VCU launched a pilot program targeting the highest ED utilizers among patients with SCD, a decision dictated by both strategy and the constraints of limited funding and resources. The program's design, which focused on potential for significant health outcomes and cost savings, demonstrated cost savings of $333,000 in patient care costs over six months.[6]

Encouraged by these results, VCU invested $1 million to broaden the program's scope to include 50 additional high-utilization patients. Capitalizing on the pilot program's momentum, VCU expanded its reach, demonstrating that a larger patient base could benefit even more from the program's approach.

The program’s success began to attract national attention, bolstering its case for further support. Through workshops with the American Society for Hematology, along with other advocacy efforts, the program influenced broader educational initiatives and became a benchmark for data-driven healthcare improvement. By 2024, the continued expansion of VCU’s Adult Sickle Cell Medical Home Program affirmed its ongoing dedication to enhancing the quality of care for patients with SCD.

03

VCU’s 3 keys to program success

VCU’s Adult Sickle Cell Medical Home Program is grounded in three fundamental components: create trusting patient-provider relationships to ensure patient engagement, center a community health worker in the core leadership team, and establish SCD-specific standardized care protocols and order sets for adult patients in the electronic health record (EHR). These strategies were integral in improving the inpatient to outpatient transition of care for patients with SCD.

Key 1: Create trusting patient-provider relationships to ensure patient engagement

Recognizing the importance of trust in effectively managing the transition from inpatient to outpatient care, VCU matched the 50 highest utilizer patients with a patient navigator. This provided a consistent point of contact, offering stability and informed support throughout the patient's healthcare journey, from initial hospitalization to continuous outpatient care. These patient navigators established strong, trusting relationships by personally connecting with patients. For example, navigators have taken patients grocery and clothing shopping, invited them over for Saturday tea, and even responded to phone calls of patients at 3AM on their way to the ED.[1,7]

VCU also helped patients create adaptable treatment plans to address their changing health requirements. These plans went beyond medication and confronted any potential obstacles to care, including social drivers, memory issues, or the need for regular reminders. Involving patients in the decision-making process boosted their sense of autonomy and confidence in managing their disease. Additionally, VCU provided supportive resources, such as monthly support groups, which created a caring environment where patients could share their experiences and find encouragement.

To build lasting patient-provider trust and foster engagement, organizations should consider:

- Assigning the 50 highest utilizer patients to a patient navigator who remains involved across all stages of care, from hospital admission to post-discharge follow-up. This continuity ensures that patients have a stable point of contact who is familiar with their health journey and personal circumstances.
- Training patient navigators to develop deep, holistic understandings of their patients, including their medical history, social environment, and individual challenges. This comprehensive knowledge allows for personalized care that addresses more than just medical needs.
- Implementing a communication strategy that encourages regular, open dialogue between patients and their assigned patient navigators. This should include proactive outreach to patients, ensuring they understand their treatment plans, and providing support for medication adherence and appointment scheduling.
- Empowering patients by involving them in the development and ongoing refinement of their treatment plans. Engaged patients who feel a sense of ownership over their health outcomes are more likely to adhere to care recommendations.
- Connecting patients with resources that reinforce their self-management abilities, such as educational materials, support groups, and tools for self-monitoring. These resources should be tailored to address barriers related to social drivers of health, such as transportation, financial constraints, and health literacy.

Key 2: Involve community health workers[8] in program leadership and delivery

VCU’s program is grounded in a biopsychosocial model of care, which considers the biological, psychological, and social factors essential to patient health.[1,7] The key to its success is the formation of a care delivery team solely dedicated to patients with SCD, led by a program manager trained in social work.

In addition to a program manager, the care delivery team includes nurse practitioners, clinical social workers, and patient navigators who serve as primary points of contact for patients. Together, they provide comprehensive case management and coordinate closely with SCD providers to deliver holistic care. Meanwhile, an oversight team led by the senior program manager oversees the program's operations, focusing on smooth execution and enhancements through quality improvement initiatives, patient assessments, and analyses of data-driven outcomes.

In forming their SCD program care teams, organizations should consider:

- Ensuring each team includes a community health worker, a social worker, and a clinical social worker, supported by a multidisciplinary care team of hematologists, nurses, pain specialists, psychologists, and patient advocates. Establish clear roles and responsibilities that leverage the unique skills of each team member, promoting a holistic approach to care.
- Facilitating regular communication and collaborative planning among team members to develop a unified approach to care. For example, VCU implemented daily morning huddles and ongoing team chats to ensure consistent communication and teamwork within their SCD program's care teams.
- Prioritizing continuous education and training for the team on the latest SCD treatments, patient engagement strategies, and best practices in transitional care.
- Advocating for the inclusion of patients and their families in the care team, recognizing their insights as essential to tailoring the program to meet patient needs effectively.

Key 3: Establish SCD-specific standardized care protocols and order sets in the EHR

VCU developed standardized protocols for SCD management to provide consistency, quality, and safety across the entire care continuum. First, VCU identified areas for improvement. After examining established guidelines and expert recommendations, they identified and addressed gaps in their care model, including discharge planning. They shifted towards reliable resources and created an inpatient care protocol based on their findings, moving away from inconsistent patient assistance programs and support groups.

One of the pivotal elements of their inpatient care protocol is the inclusion of in-hospital consultations by a SCD nurse practitioner. This step was crucial, as SCD management is often in the hands of hospitalists, who may lack SCD training. Ensuring follow-up after hospital discharge was also a significant concern, as a lack of coordination often resulted in patients returning to the ED due to medication issues.

VCU also constructed a suite of order sets and treatment protocols tailored to various stages of the patient's journey, from the ED through to ongoing follow-ups after discharge. For example, they standardized their approach to pain management to include having a single opioid prescriber to maintain controlled medication management for patients. These protocols are categorized based on specific patient needs, such as whether the patient is new, requires an annual exam, is transitioning into adult care, or is considered a high utilizer of services.

In creating SCD-specific care protocols, organizations should consider these strategies:

- Begin by reviewing established guidelines and evidence-based recommendations to identify areas for improvement in the care of SCD patients. This process should involve identifying and addressing gaps in care, such as discharge planning, and integrating resources that are practical and effective for the specific population served.
- Develop comprehensive order sets and treatment protocols that span the entire patient journey, from the ED to outpatient care. VCU's protocols categorize patients based on factors such as recent admissions, opioid management, transition age, and utilization patterns, allowing for personalized care strategies.
- Maintain a regular cadence for assessing key quality metrics and care protocols. Employing criteria to evaluate patient engagement enables the team to proactively address areas in need of attention.

Results

How we know it’s working

In 2019, VCU’s Adult Sickle Cell Medical Home Program made remarkable strides in enhancing patient care and efficiency, leading to a notable 10% reduction in patient readmission rates.[6] This improvement not only reflects better quality of care but also contributes to significant cost savings, as proven by the program averting $2.465 million in charges during that same period.

The positive outcomes extended to the entire SCD patient population at VCU, with a substantial decrease of 1,096 inpatient days recorded in 2019. Additionally, the average hospital stay for patients with SCD was shortened by 0.86 days, indicating more efficient and effective patient care and management.

Patient engagement also improved, with the no-show rates dropping from 11% in 2019 to 6.8% in 2021.[7] This decrease in no-shows is indicative of a more trusting relationship between patients and the healthcare team. “For many of these patients, they have a trusting relationship with members of our team,” said Shirley Johnson, VCU’s program manager.[1] “They might not always like us, but they still trust us and they know that wherever they are, we will come and find them so they don’t fall through the cracks.”

Since its inception, the SCD program at VCU has played a pivotal role in standing up 50 adult sickle cell centers across the United States.[1] The program at VCU contributes extensively to the annual four-day Sickle Cell Care Coordination for Achieving Patient Empowerment (SCCAPE) Conference, which has been held since 2019.[7] The conference’s mission is to train professionals and family advocates in comprehensive assessment, care coordination, medical management, and patient-centered treatment adherence for SCD. To learn more about SCCAPE, please visit www.sccape.org.

In addition to training these 50 SCD programs, VCU consistently receives weekly inquiries for additional training and support materials. These requests underscore the critical need for continued investment in the educational development and support for SCD providers.

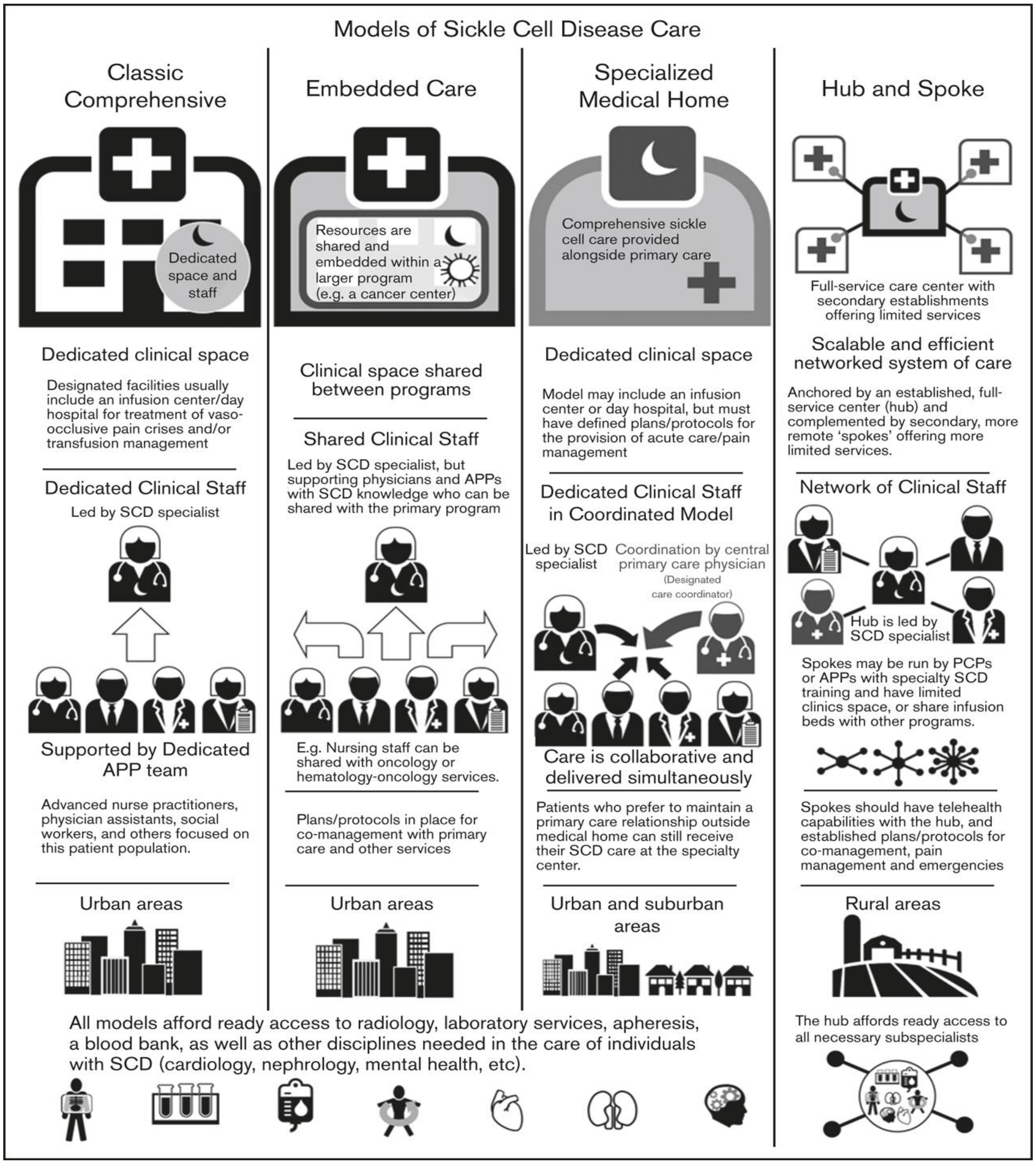
Future directions for VCU’s Adult Sickle Cell Medical Home Program

Looking forward, VCU is strategically positioning itself to engage with national collaboratives, with the aim of sharing and analyzing data in tandem with other leading adult SCD medical home programs throughout the nation.[7] This collaboration will allow VCU to benchmark and integrate best practices, optimizing care for SCD patients. Additionally, the quality improvement specialist at VCU has crafted surveys to capture patient experiences with their Sickle Cell Medical Home, specifically focusing on patient navigation, counseling services, and the prior authorization department. These surveys contribute to a deliberate effort to collect patient feedback and actively tackle care gaps. The team has also introduced a new metric to assess patient behavioral outcomes following navigation and community health worker interventions. This ongoing commitment to quality improvement underscores VCU’s dedication to advancing the standard of care for patients with SCD.

Supporting artifacts

The 4 SCD models of care[9]

The graphic below illustrates the models of SCD care that providers can use to establish adult sickle cell centers in their health systems and hospitals, aimed at improving care and reducing health disparities for patients.



Models of Sickle Cell Disease Care

Classic Comprehensive

Dedicated space and staff

Dedicated clinical space

Designated facilities usually include an infusion center/day hospital for treatment of vaso-occlusive pain crises and/or transfusion management

Dedicated Clinical Staff

Led by SCD specialist

Supported by Dedicated APP team

Advanced nurse practitioners, physician assistants, social workers, and others focused on this patient population.

Urban areas

Embedded Care

Resources are shared and embedded within a larger program (e.g. a cancer center)

Clinical space shared between programs

Shared Clinical Staff

Led by SCD specialist, but supporting physicians and APPs with SCD knowledge who can be shared with the primary program

E.g. Nursing staff can be shared with oncology or hematology-oncology services.

Plans/protocols in place for co-management with primary care and other services

Urban areas

Specialized Medical Home

Comprehensive sickle cell care provided alongside primary care

Dedicated clinical space

Model may include an infusion center or day hospital, but must have defined plans/protocols for the provision of acute care/pain management

Dedicated Clinical Staff in Coordinated Model

Led by SCD specialist

Coordination by central primary care physician (Designated care coordinator)

Care is collaborative and delivered simultaneously

Patients who prefer to maintain a primary care relationship outside medical home can still receive their SCD care at the specialty center.

Urban and suburban areas

Hub and Spoke

Full-service care center with secondary establishments offering limited services

Scalable and efficient networked system of care

Anchored by an established, full-service center (hub) and complemented by secondary, more remote 'spokes' offering more limited services.

Network of Clinical Staff

Hub is led by SCD specialist

Spokes may be run by PCPs or APPs with specialty SCD training and have limited clinics space, or share infusion beds with other programs.

Spokes should have telehealth capabilities with the hub, and established plans/protocols for co-management, pain management and emergencies

Rural areas

All models afford ready access to radiology, laboratory services, apheresis, a blood bank, as well as other disciplines needed in the care of individuals with SCD (cardiology, nephrology, mental health, etc).

The hub affords ready access to all necessary subspecialists

Supporting artifacts

VCU’s Adult Sickle Cell Medical Home Program: Core subservice committee descriptions

1. **Inpatient:** This team specializes in the care and management of SCD, focusing on innovative inpatient pain management and the improvement of vaso-occlusive crisis management. They collaborate with outpatient and ED teams to update treatment plans and aim to enhance inpatient care transitions.
2. **ED:** This team is focused on optimizing care for sickle cell patients in the emergency setting by creating triage pathways, standardizing treatment, aiming to decrease inpatient costs by managing more care within the ED, and leveraging data analysis to ensure their goals are achieved.
3. **Ambulatory:** This team focuses on enhancing the efficiency of clinic visits for patients by addressing issues like patient flow, scheduling, waiting times, appointment cancellations, prescription authorizations, and ambulatory transfusion processes. They meet monthly in the SCD clinic space to discuss and intervene on these operational concerns.
4. **Behavioral health:** This team provides emotional and behavioral support to adult SCD patients, focusing on skills to help patients manage their disease and life stressors more effectively. The team includes patient navigators, social workers, and other trained staff who offer case management and community support, with special attention given to high-risk patients.
5. **Evaluation:** This team is responsible for analyzing the program's performance and the health outcomes of SCD patients. While other teams are more involved in day-to-day patient interactions and care processes, the evaluation team takes a broader view by monitoring and assessing the program's outcomes to inform quality improvement and policy decisions.
6. **Clinician:** This team is directly responsible for the medical treatment and clinical management of SCD patients across various healthcare settings, including inpatient, outpatient, and infusion clinics. The clinician team is composed of medical professionals such as physicians, nurse practitioners, and nurses who make decisions regarding patient care plans, prescribe treatments, and manage acute medical needs.

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Endnotes

1. Note: Unless otherwise specified, all information in this case study came from Advisory Board interviews with contacts from VCU Health.
2. Note: SCD patients require care from a dedicated SCD provider and, as a result, the care they require from dedicated medical centers will not change. Therefore, the patient and the medical center need to continue to be committed to that care and the medical center cannot escape the commitment they need to provide to patients living with SCD, making them ‘inescapable.’
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6. Sickle Cell Disease Adult Medical Home Annual Report 2019. *VCU Health*. Accessed October 1, 2024.
7. Sickle Cell Disease Adult Medical Home Annual Report 2010-2022. *VCU Health*. Accessed October 1, 2024.
8. Note: Other organizations may refer to these roles as community health workers. At VCU, these professionals are designated as “patient navigators.”
9. Kanter J, et al. Building access to care in adult sickle cell disease: defining models of care, essential components, and economic aspects. *Blood Adv*. August 25, 2020.

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