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CASE STUDY

4 keys to success in the New England Sickle Cell Institute's outpatient program for adult sickle cell patients

UConn Health created the New England Sickle Cell Institute (NESCI) to improve access to high quality comprehensive care for adult patients with sickle cell disease (SCD) across the state.[1] Since its founding in 2009, the NESCI has expanded its patient base to over 400 patients. The program's comprehensive approach to sickle cell care has emphasized outpatient management and prevention of complications, which in turn has led to decreased hospitalizations and emergency visits among its patients. The development of this dedicated medical home has fostered trust among patients across the community. NESCI's success and continued growth has also led to the development of a new, larger facility that opened in 2025, further enhancing UConn Health's capacity to provide effective care for the SCD population.[1]

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Audience

- Hospitals and health systems
- Physicians and medical groups

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Methodology

This project details how UConn Health launched and scaled up their New England Sickle Cell Institute (NESCI). To achieve this, Advisory Board conducted two hour-long interviews with the Director of Operations for the NESCI. The team also reviewed several public-facing resources, such as news articles and pieces published on the UConn Health website and included these resources in the case study.

The following pages detail the key insights and analyses from the research team's comprehensive literature review and interviews with UConn Health. In this case study, Advisory Board outlined the challenge that served as the impetus for the new SCD program, UConn Health's approach to creating the SCD program, and the results of the SCD program to date. Advisory Board also detailed four keys to UConn Health's success based on the work achieved by UConn Health's NESCI program, evidence to support, and considerations for organizations looking to improve their SCD programs in those key areas.

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Overview

The challenge

In 2009, a UConn Health hematologist noticed that adults in the community with sickle cell disease (SCD) lacked access to a dedicated outpatient center that could provide appropriate care.[1] Not only were these community members not being engaged in proper chronic care management, but, once the patient population of UConn Health's SCD program grew, some patients were also frequently visiting the emergency department (ED) to manage their pain, which often led to extended hospital stays.[2]

The organization

UConn Health, a branch of the University of Connecticut, is an academic medical center located in Farmington, Connecticut. Founded in 2009, the New England Sickle Cell Institute (NESCI) is located within the Carole and Ray Neag Comprehensive Cancer Center at UConn Health's John Dempsey Hospital and is the only dedicated comprehensive outpatient center for patients with SCD in the region. With a dedicated team including hematologists, nurses, and social workers, the institute has expanded its patient base from a dozen to over 400 patients.[1,3]

The approach

Through grassroots efforts to identify adults in the community who were not receiving longitudinal sickle cell care elsewhere, the NESCI was created to engage patients in chronic care management and provide a dedicated outpatient center with infusion capabilities that patients can access for management of acute pain and other complications. For admitted patients, the outpatient center ensures robust ties with hospital services while focusing on effective pain management while serving as a reliable resource for patient inquiries and comprehensive care, including psychosocial support. The institute offers complete sickle cell care, from disease-modifying treatments, specialized transfusions, and specialty pharmacy services to clinical research opportunities, and tailors care plans to meet individual patient needs. Beyond its walls, NESCI collaborates with Connecticut Children's, their pediatric partner hospital located 10 miles away in Hartford, CT, to ensure smooth transitions from pediatric to adult care, and partners with other community entities to extend its reach.[1]

The result

As the patient base at NESCI has expanded, UConn Health has reduced hospital stays, decreased ED visits, and improved overall care for sickle cell patients. Their success has also contributed to the institution reaching its broader financial goals, securing support and investment from system leadership. Due to its success, the program expanded with a new, larger sickle cell center at UConn Health, equipped with additional examination and infusion rooms to accommodate more patients. This new center opened on Feb. 13, 2025.[1]

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Program overview: The New England Sickle Cell Institute at UConn Health

The NESCI was established with three main goals: to improve care and quality of life for adults with SCD, to decrease their dependence on the ED, and to improve pain management for patients with SCD within and beyond UConn Health.[1]

NESCI's impact grew significantly in 2016 with the opening of the region's first outpatient facility dedicated to sickle cell care.[1] It features private acute care suites, exam rooms, and blood transfusion rooms, all conveniently located next to critical care services. NESCI allows for both scheduled outpatient comprehensive care visits as well as same-day urgent care for management of SCD exacerbations.[1,2]

Program Statistics

- The NESCI has expanded from a dozen to over 400 patients since its inception in 2009.[1]
- The core team is comprised of several full-time employees: three nurse practitioners, one physician, one nurse coordinator, one medical assistant, two infusion nurses, and one social worker.[1]
- Over the program's lifespan, more than 120 patients have transitioned from Connecticut Children's to the NESCI.[1]

Since its inception in 2009, the NESCI has provided comprehensive care to hundreds of patients with SCD thanks to a highly dedicated, multidisciplinary leadership team and staff. The medical team and social worker gather to discuss patient concerns with health issues, medications, and treatment plans on a weekly basis. The research team conducting clinical trials is also present to discuss patient engagement and potential future studies.[1]

Beyond its core team, NESCI collaborates with external staff from Connecticut Children's, an independent nonprofit hospital located 10 miles away, to enhance the pediatric to adult transition of care process. The NESCI also partners with community groups such as Michelle's House, the first sickle cell community center in Connecticut, to support patient education and advocacy.[1]

The care journey is dependent on the patient's entry point into the system

Today, patients with SCD often arrive in the NESCI in several distinct ways. Adult patients who are new to UConn Health and/or who are experiencing an emergency pain event will often be admitted into the ED or inpatient facility. Here, UConn Health providers will assess their disease before ultimately referring them upon discharge to the NESCI clinic, which is conveniently located on the fourth floor of the hospital. Young adult patients at Connecticut Children's are directly transitioned into the NESCI through a process spanning more than five years that involves education, the development of self-management skills, and familiarity with the NESCI staff.[1]

Finally, patients in the community either self-refer or are referred to NESCI by community partners knowledgeable about NESCI or by physicians which often includes other hematologists.[1]

Patients with varying needs visit the NESCI clinic. Some come weekly for medication administration and evaluations, while others come as infrequently as every six months if they experience no complications and are stable on disease-modifying therapy. Every patient receives a personalized pain management plan based on their specific needs. A social worker makes daily rounds on NESCI patients who are hospitalized to meet each patient who is admitted in the hospital and assess their psychosocial needs, ensuring continuous support throughout their care journey. Alongside these daily rounds, NESCI staff remain on call for consultation in every care setting.[1]

At the point of discharge, the NESCI team takes steps to create a detailed care and pain management plan for the patient to use at home. They also schedule follow-up appointments and include information on their appointment date directly in the patient's discharge paperwork. Most patients are seen in the NESCI within three days of discharge.[1]

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UConn Health’s 4 keys to SCD program success

NESCI’s approach to effectively engaging patients in chronic care management is grounded in four fundamental keys to success:[1]

1. Foster connections with pediatric partners to build a strong foundation for adult sickle cell care.
2. Build allies across the system by articulating the clinical, financial, or workflow benefits of a robust adult sickle cell program.
3. Extend the reach of the multidisciplinary care team by supporting and educating non-SCD specialists within the broader health system.
4. Establish a balance between comprehensive patient support and individual patient autonomy to promote effective care management and patient engagement.

Key 1: Foster connections with pediatric partners to build a strong foundation for adult sickle cell care.

Establishing proper trust and patient engagement for adult patients is a process that takes time and multiple patient touchpoints. For many of their patients, NESCI begins this process while they are adolescents through their partnership with Connecticut Children’s, a pediatric acute care hospital 10 miles away in Hartford, CT. The partnership between NESCI and Connecticut Children's has become vital for transitioning adolescents with SCD into adult care. Over the NESCI’s lifespan, approximately 120 patients have transitioned from Connecticut Children's. The transition program introduces patients to the adult SCD staff and familiarizes them with the facility's layout, detailing where to go for specific services such as medical visits and lab tests, which can lead to a physical tour.[1]

The first in-person visit marks a significant step for patients, as they meet the complete adult care team face-to-face for their first routine appointment. A social worker conducts regular follow-up meetings to support patients in adapting to their new care environment. Additionally, NESCI collaborates with Connecticut Children's to participate in community events like the "Sickle Cell Walk." These gatherings allow pediatric patients of any age to connect with the adult care team in a nonclinical setting, easing the transition and strengthening the support network even before a patient approaches their age of transition.[1]

Building relationships with patients during their pediatric visits leads to easier transitions to adult care. Patients who intermittently seek care during severe pain episodes often struggle with consistent treatment adherence and establishing a good relationship with their care team. However, those who receive effective, comprehensive care for SCD in childhood are more likely to continue their care into adulthood.[4] The shift from pediatric to adult care offers a chance to strengthen trust, which is crucial for patients with SCD who may have faced challenges in receiving high-quality care.

In practice, trust is fostered through mutual respect between patients and providers, which promotes adherence to care plans and open communication about sensitive health issues. It's essential for patients to know their care team well, from doctors to social workers, and understand each member's role. This familiarity, developed during the pediatric-adult care transition, helps create a supportive environment that guides patients through their care journey with the necessary personal support.[1]

Key 2: Build allies across the system by articulating the clinical, financial, or workflow benefits of a robust adult sickle cell program.

Program champions were critical in building NESCI's respect and legitimacy. They encountered some instances of initial resistance from inpatient and ED staff who were hesitant to adopt the new care processes and protocols. In response, NESCI program leadership tailored NESCI's value proposition to the goals of each department they needed to work with.[1] Over time, they fostered new champions for the program across the leadership team, ED team, hospitalist team, and beyond.

For example, NESCI faced difficulties in securing treatment chairs in the cancer center due to the increase of SCD patients from the community. To secure funding for additional infusion chairs, NESCI program leaders collected data on visits for pain crises that unnecessarily resulted in patients being sent to the ED. The data included the timing, symptoms, and whether patients were admitted or sent home after each ED visit. Armed with this data, they demonstrated to senior leadership that the hospitalization rate for patients with SCD presenting with an acute pain episode could be cut from 30% to 9% with the addition of dedicated outpatient infusion chairs.[1] By linking this improvement to cutting costly and unnecessary hospital stays during which patients can experience additional complications, they secured a successful investment with small dedicated space in 2015 and the creation of long-term advocates within leadership.[1] This dedicated space had five infusion chairs and within one year of opening, the admission rate for patients treated there for an acute pain episode was less than 1%. Furthermore, the funding of dedicated nursing and social work positions for the NESCI program led to enhanced quality of care with an increase in outpatient visits per patient per year, a reduction in annual ED visits and hospitalizations, and improvements in average hospital length of stay by 50% and 30-day readmission rates by 33%.[1]

NESCI's success in connecting different parts of their healthcare system and securing resources hinges on the strong alliances they've built across the system. These champions can ensure that patients receive appropriate care and attention at each stage of their treatment. These relationships are also important to expand. After NESCI procured five initial dedicated SCD infusion chairs and small outpatient space with enhanced staffing, senior leadership recognized the value of their investment. Later, this support led to the creation of a new, fully equipped SCD facility in 2016 with expanded footprint and staff. Without such allies, achieving the necessary growth and resource allocation for patients with SCD would be a far greater challenge.[1]

Key 3: Extend the reach of the multidisciplinary care team by supporting and educating non-SCD specialists within the broader health system.

Since 2009, NESCI's patient population has grown to over 400. Despite its sizeable staff, NESCI often operates at full capacity and must rely on a broader network of support to provide adequate care. To bridge this gap, NESCI utilizes core members of their dedicated team alongside the electronic health record (EHR) to make it easier for UConn Health's non-SCD staff to provide quality care for patients with sickle cell disease.[1]

First, NESCI's social worker meets daily with the rotating inpatient hematology consultant and hospitalist team to coordinate patient care. In this way, the social worker acts as both the eyes and ears for the program's patients as well as the connective tissue between the inpatient site of care and the SCD outpatient clinic. Additionally, NESCI leaders run targeted SCD and bias trainings for staff across the health system, including those in UConn's nursing residency program, to broaden the base of competent care providers for patients with SCD without expanding the team. NESCI strengthens wider staff support by creating channels for continuous consultation and arranging extra SCD and bias training sessions.[1]

NESCI leaders have also incorporated processes into UConn Health's EPIC EHR system to expedite care for established patients with SCD. For example, they've created a sickle cell disease assessment tab that offers instant access to essential patient data such as test results, care plans, and medication specifics. This feature equips any physician to provide informed care to patients with SCD promptly. NESCI uses direct and secure messaging, phone calls, and emails for continuous communication, allowing non-SCD staff to consult the SCD team immediately in emergencies.[1]

To best support your core SCD team, consider providing targeted education and support strategies for the following non-SCD system staff:[1]

- Nursing staff, especially those within the inpatient facility and ED
- Emergency department providers
- Inpatient facility providers, including hospitalists, hematology consultants, and other specialists
- Members of your system's pharmacy team
- Members of other facilities or programs that may support or provide care for your patients with SCD, such as labor and delivery, the OR, or the blood bank

Key 4: Establish a balance between comprehensive patient support and individual patient autonomy to promote effective care management and patient engagement.

NESCI prioritizes a strong, standardized support infrastructure to strengthen care management. To achieve this, NESCI leaders have implemented several care protocols[1] :

- Outpatient follow-up appointments are automatically scheduled and detailed on patients' discharge papers for a clear post-discharge plan.
- Consistent individualized acute pain management protocols are available in the EHR for providers to use across all care settings.
- Routine tests, such as echocardiograms, eye exams, and urine tests, feature a simplified scheduling process.
- Existing patients experiencing acute SCD pain call to schedule same-day evaluation and treatment in outpatient SCD center.

During the course of care, NESCI providers engage patients by setting clear expectations for their treatment journey. This is necessary because, without proper patient accountability, there is a risk that patients will not fully engage in the essential continuum of care. For example, some patients assume they can receive some elements of their sickle cell care, such as medication infusions, and forego others, such as screenings for organ function, which not only undermines the program's effectiveness but also increases the risk of poor patient medical outcomes.[1]

To address this challenge, the SCD team makes it clear that following medical instruction and participating in each element of their comprehensive care plan is the means to receiving desired outcomes. For example, the team requires patients to annually sign and fully adhere to medication agreements, affirming proper medication use, and ensuring consistency in their pharmacy services. Education is the first tool NESCI employs, with ongoing discussions from the onset of care to reinforce the importance of adhering to their care plan.[1]

Further, as part of their comprehensive approach, the NESCI has curated a robust research arm. This clinical trial portfolio provides access to novel, and potentially transformative therapies with both investigator-initiated trials pharmaceutical company sponsored protocols. SCD patients have clear access to participate in these trials, if they choose to do so, which are offered by the trusted providers that they have partnered with throughout their disease management journey.[1]

Results

How we know it's working

NESCI monitors the success of its comprehensive SCD program using several metrics:

Length of stay and medication utilization

When the program began in 2009, the average length of stay was between 12 to 14 days. With the addition of five infusion chairs in the cancer center, this figure decreased between four and five days, which is below the national average.[1,5] There has also been a marked reduction in the number of SCD patient hospitalizations, ED visits, and the amount of pain medication used in these settings.[1]

Increased patient engagement with the program's core components

For NESCI leaders, increasing patient engagement is a major marker of a successful sickle cell treatment program. Considering that many patients with SCD have likely had a challenging relationship with the healthcare system, NESCI staff monitor numerous metrics to ensure their patients are engaged and adhering to their program plan.[1]

- The patient attends and persists with follow-up appointments at the outpatient facility.
- The patient chooses the outpatient facility for pain crises over the emergency department.
- The patient adheres to prescribed disease-modifying therapy and/or transfusions.
- The patient completes labs and exams as scheduled within the NESCI program.
- Patient attrition is reduced as they regularly return for care each year.

These metrics underscore the primary objectives of the SCD program: to ensure patients receive efficient and effective care and to minimize avoidable ED usage by patients with SCD.[1]

Looking ahead: NESCI's new sickle cell center

UConn Health expanded its program with the opening of a brand-new 12,000+ square foot dedicated sickle cell center on Feb. 13, 2025. This initiative not only reflects a growing patient population but also the institution's dedication to meeting their needs. The center houses six examination rooms and 10 infusion rooms, significantly enhancing patient care capabilities.[1] Active support from the senior leadership team has propelled this initiative forward, positioning UConn Health to provide even more effective and comprehensive care to its patients with SCD.

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Endnotes

1. Note: Unless otherwise specified, all information in this case study came from Advisory Board interviews with contacts from UConn Health.
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