Sickle Cell Disease in New York City

New York City Health Department

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Executive Summary

For thousands of New Yorkers living with sickle cell disease (SCD), New York City's healthcare infrastructure offers unique advantages that are undermined by fragmented systems, inconsistent care quality, and provider training gaps. Immediate investments in comprehensive care, enhanced provider training, and pathways to cures are required to meet the urgent need and address a legacy of historical neglect.

Strengths of New York City's Healthcare Landscape

The city offers significant advantages for SCD care, including comprehensive care centers, advanced treatments, clinical trial opportunities, an inclusive public hospital system, dedicated community-based organizations (CBOs), and an expansive public transit system that reduces geographical barriers. State-level policies like broad Medicaid eligibility further facilitate access.

Three Core Challenges

Despite the city's robust resources, New Yorkers living with SCD—particularly adults—struggle with substantial challenges across the continuum of care:

1. **Timely and Appropriate Pain Management (Chronic and Acute):** Across various settings, including urgent, emergency, and primary care, patients encounter provider biases. These include being mislabeled as drug-seekers, leading to inadequate pain treatment and undermining patient-trust. Insufficient awareness about pain management and evidence-based treatment guidelines further deteriorates care quality.
2. **Limited Access to SCD Specialists:** Despite the city's high physician density, there is a shortage of providers who are knowledgeable about SCD, which cascades into inadequate pain management, undermines other elements of care, and limits pathways to advanced therapies.
3. **Fragmented Care and Referral Pathways:** Care fragmentation is particularly pronounced during the critical pediatric-to-adult transition period. Care fragmentation leads to poor outcomes and ultimately harms timely access to basic and advanced therapeutics and cures.

Crucially, **these challenges stem primarily from issues within the healthcare system**, rather than factors that people living with SCD have significant control over. Centers of Excellence and other comprehensive care models have demonstrated success in addressing these challenges, yet they remain inaccessible for many due to persistent underinvestment. The lack of integration of trained Community Health Workers (CHWs) in hospital settings contributes to missed opportunities to provide support across multiple domains.

The Data Gap

The public health principle, "what is not counted doesn't count," captures significant shortcomings in SCD data infrastructure across the US and their consequences.

- **Absence of a Comprehensive Registry:** A comprehensive clinical patient registry—the gold standard for advancing rare disease understanding —remains absent for SCD at the national level. This leaves states and the medical community to implement their own painstaking efforts, resulting in fragmented, incomplete, and inefficient alternatives that prove to be unsustainable.

- **Limited State-Level Monitoring:** Past efforts by New York State have contributed valuable data on the prevalence and complications of SCD. However, the state is not currently participating in the Centers for Disease Control's (CDC) SCD Data Collection Program, which limits up-to-date knowledge.
- **Public Health Prioritization:** Public health continues to pay minimal attention to rare diseases, which are often viewed as outside the scope of the field's practice. However, important health outcomes such as hospital utilization due to SCD complications may be more common than for other conditions that benefit from greater attention and resources.

Root Causes

The challenges in SCD care stem from several interconnected factors: chronic underinvestment in monitoring, research, and health care capacity; outdated perceptions of SCD as primarily a pediatric disease; insufficient medical training; provider implicit bias; and structural racism. As noted by Power-Hays and McGann in the New England Journal of Medicine, "There may be no population of patients whose healthcare and outcomes are more affected by racism than those with sickle cell disease."[i]

Recommendations

The single biggest opportunity to address the core challenges in SCD care is to expand access to adult comprehensive care centers in New York City. However, since most non-specialized hospitals still see dozens to hundreds of SCD-related hospitalizations and emergency department visits annually, making improvements across all healthcare facilities is essential.

1. **Fund and Expand Access to Adult Comprehensive Care Centers.** Specialized comprehensive care is a successful model for SCD, with well-defined characteristics and proven effectiveness.[ii] However, there are notably fewer adult programs compared to the pediatric side to meet demand in New York City.
    a. **Sustainably fund existing and planned/developing centers:** These programs often struggle with various challenges, such as maintaining stable financial support for key personnel and addressing systemic issues like fragmentation of care. The annual cost of operating a comprehensive SCD care center serving 400 individuals is estimated to be roughly $6–9 million.
    b. **Advocate for sustainable funding for Centers of Excellence at the state level:** Passing S.1578/A.3676 ("Sickle Cell Treatment Act") would be an important first step towards establishing sustainable funding. This legislation designates five Centers for Sickle Cell Care Excellence to receive $400,000 annually towards research and provides $200,000 per year for ten Sickle Cell Outpatient Treatment Centers.
2. **Improve Clinical Care at All Facilities:**
    a. **Implement evidence-based pain management protocols:** Develop individualized pain protocols that can be widely accessed across different healthcare settings and establish ED/hospital workflows for treatment of vaso-occlusive events.
    b. **Educate providers** in primary care and other specialties involved in SCD care about pain management, implicit bias, and harmful attitudes. Utilize evidence-based guidelines from organizations like the American Society for Hematology (ASH). Examples of training materials may be found here.
    c. **Improve care coordination and establish robust referral pathways** to Centers of Excellence and other comprehensive care programs. **CBO-hospital partnerships** and CHW integration have proven effective in improving care continuity and SCD

outcomes.[iii] Given the urgent need for better coordination, these strategies warrant broader adoption and increased investment.

3. **Enhance Data Integration and Reporting Across Different Levels**
    a. **Implement an all-payer database (APD) at the state-level.** APD can provide valuable information on a population level, including the characterization of SCD prevalence and other basic epidemiology, disease management, healthcare utilization, and complications.
    b. **Participate in CDC's SCD Data Collection Program,** a multi-state effort to assess epidemiological trends and health care outcomes among people living with SCD across the US.
    c. At the city level, use existing data systems to monitor health care access and outcomes.
4. **Monitor Access for Cures and Advanced Treatments:**
    a. Track the landscape of advanced treatments for SCD, such as gene therapies, to ensure equitable access and explore long-term outcomes and trends.

Data

Sickle cell disease (SCD) represents an important but historically neglected public health challenge affecting thousands of individuals across the United States, with notable concentrations in metropolitan areas like New York City. Despite its significant prevalence, our understanding of SCD remains constrained by the absence of centralized data infrastructure for studying rare diseases and the lack of systematic public health surveillance. While progress at federal and state levels and by the medical community has yielded substantial contributions, overall efforts remain fragmented. This limits our ability to understand population trends, track health outcomes, develop evidence-based clinical recommendations, and address persistent inequities in care.

Background and Epidemiology

SCD is the most common inherited blood disorder and the most prevalent rare disease in the United States, affecting approximately 100,000 people. Impacting millions globally, SCD in the US is most commonly found among individuals of African ancestry, while people of Hispanic, Middle Eastern, South Asian, and Southern European ancestry are also affected. New York State is home to an estimated 10% of the US SCD population, with the majority of individuals residing in New York City, though areas like Albany and Buffalo upstate may also have significant populations. The majority of individuals living with SCD receive insurance coverage through Medicaid.

Sickle cell trait (SCT) is a benign genetic condition that occurs when a person inherits one copy of the sickle cell gene. Individuals with SCT are carriers— they do not have sickle cell disease and are not at risk of developing it. However, they can pass the gene to their children, which makes awareness and genetic counseling important. Most people who have SCT can lead healthy, normal lives. In rare cases, extreme conditions such as severe dehydration, high altitude, or intense physical exertion may lead to complications. In the US, an estimated 3 million people have SCT, including approximately 8-10% of Black Americans. Globally, over 100 million people are carriers of SCT. It is most common in regions where malaria is or was endemic, as SCT provides some protection against the disease.

Available Data for New York City

Most of what is known about SCD in New York City comes from state-level data sources and collaborations between the city and the state. Below is a summary of available information on SCD as well as a discussion of local data gaps.

Prevalence

Prevalence of SCD in New York City is currently unknown. Based on 2004-2008 data, the New York State Department of Health reported 8,374 individuals living with SCD in the state.[iv] More recent estimates are not available. Most people in the state who have SCD are believed to reside in the New York City area.

Newborns and Maternal Health

All newborns in the US are screened for both SCD and SCT. New York State has screened all newborns for SCD, SCT, and other genetic conditions since 1975 as part of its Newborn Screening Program. The program is celebrating its **50th anniversary** this year.

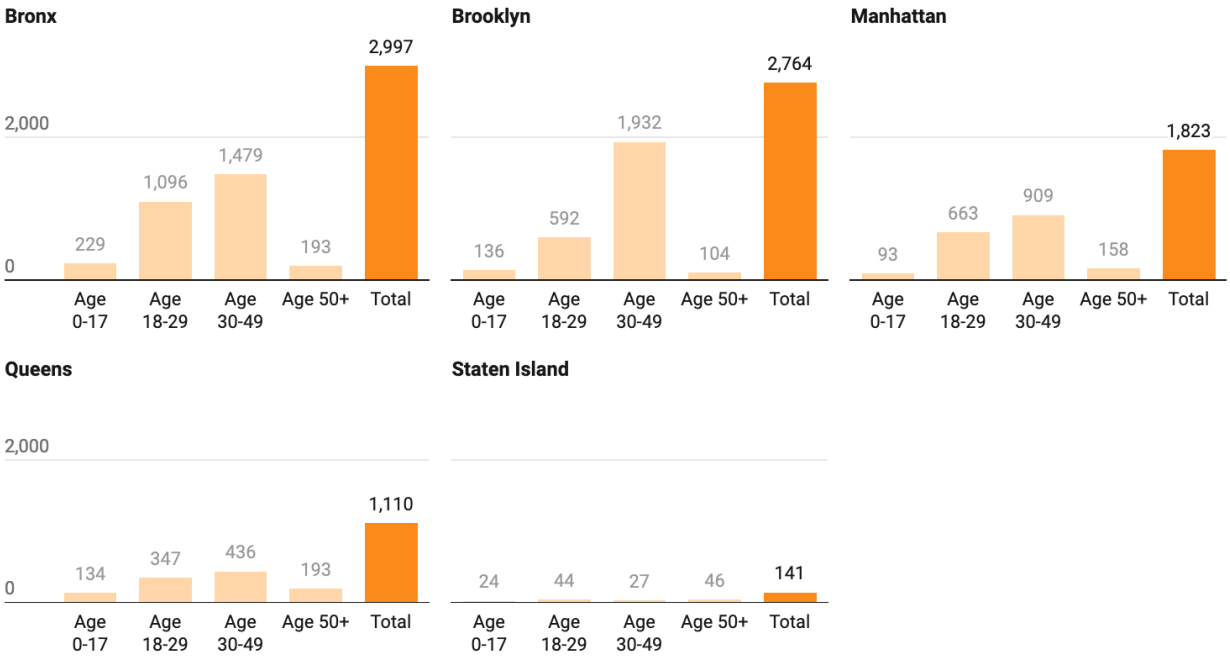
- **Newborns with SCD (2023):** About 100 babies were born with SCD in New York City. The Bronx (18) and Brooklyn (13) had the highest number of babies born with HbSS, the most severe form of the disease.
- **Newborns with SCT (2023):** 2,602 babies were born with sickle cell trait in New York City: 960 in the Bronx, 764 in Brooklyn, 317 in Manhattan, 481 in Queens, and 80 in Staten Island.
- In New York State, the **majority of newborns with SCD are born mothers who were born outside of the US.**[v]
- Analyses of national data report **excess risk of SCD pregnancy complications,** which also contributes to the black-white maternal morbidity and mortality inequities.[vi]

Hospital Utilization

There were about 9,000 treat and release emergency department visits and over 5,000 hospitalizations with a principal diagnosis of SCD across all age groups in New York City in 2023.

Emergency department visits for sickle cell disease in New York City (2023)

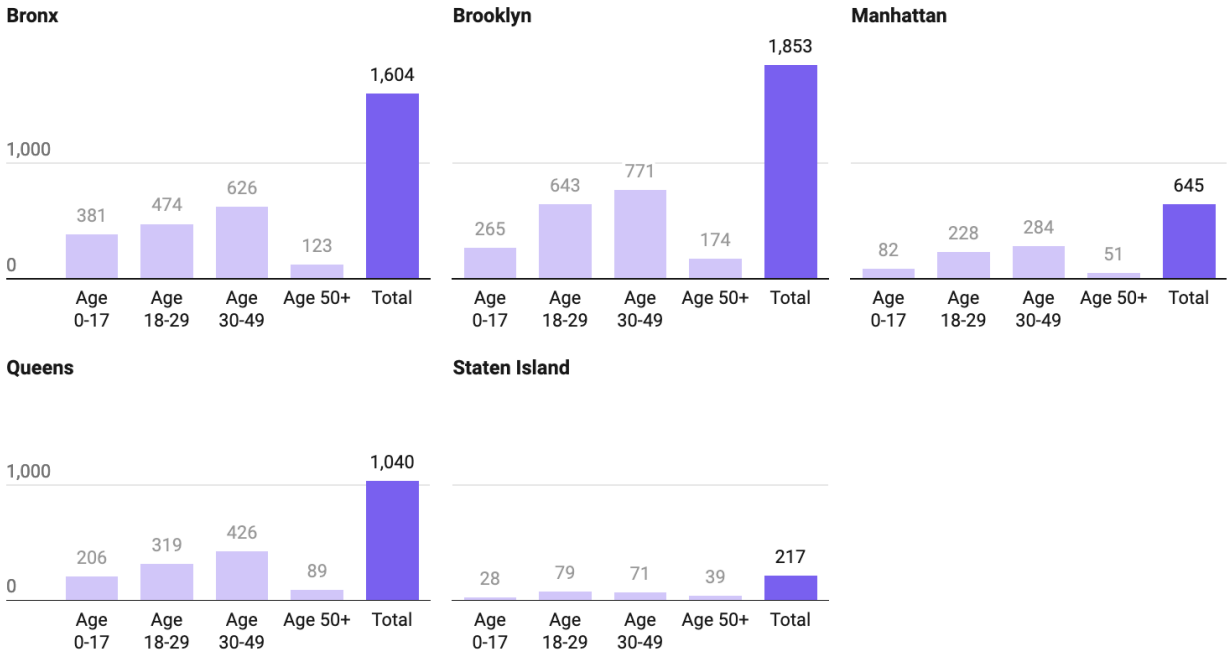
Number of treat and release visits



Source: New York State Department of Health, Statewide Planning and Research Cooperative System (SPARCS) • Created with Datawrapper

Hospitalizations for sickle cell disease in New York City (2023)

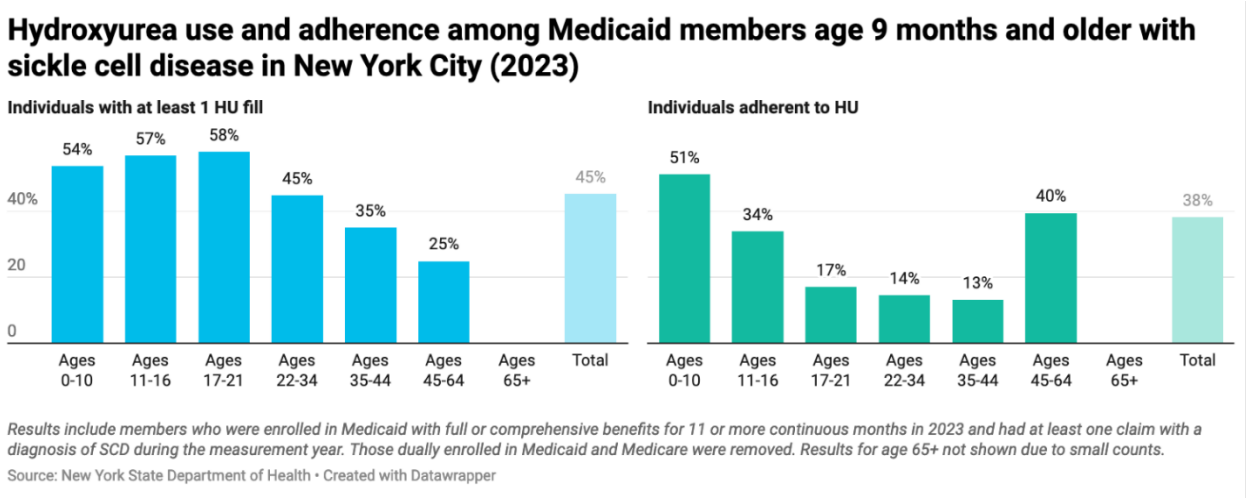
Number of hospitalizations



Source: New York State Department of Health, Statewide Planning and Research Cooperative System (SPARCS) • Created with Datawrapper

Disease Management – Hydroxyurea Use

Hydroxyurea (HU) is a commonly prescribed medication that reduces the frequency of painful vaso-occlusive events and decreases the need for blood transfusions. It is recommended as a standard disease-modifying therapy for most people living with SCD. However, uptake of HU remains suboptimal at **45%** across all age groups, likely related to issues in accessing SCD specialists. There is a sharp drop in hydroxyurea (HU) use and adherence beginning at the pediatric-adult care transition, likely resulting from the well-documented disruptions in continuity of care during this period.



Special Focus: Leave Against Medical Advice as a Signal of Unmet Care Needs in New York City Hospitals

Signals of unmet care needs in SCD are particularly evident in a hospital setting. In emergency departments, people who need care for SCD complications face significant inequities in pain management, wait times, and provider practice.[vii] These concerns extend to inpatient settings, where SCD has the highest 30-day readmission rate (37%) of any principal diagnosis (AHRQ 2024). National data demonstrate that SCD-related hospital stays result in leave against medical advice (LAMA) at a rate four times greater than non-SCD stays (AHRQ 2019).

Reasons for leaving against medical advice among the general hospitalized population may be wide-ranging. However, **for people hospitalized for SCD, leaving against medical advice may be a signal of unmet care needs,** such as inadequate or delayed pain management for vaso-occlusive events (Haywood 2010). Within the broader healthcare context, premature departures have serious consequences—18% of general patients who leave the emergency department without being seen return within 7 days, and leaving against medical advice is consistently associated with increased risk of 30-day hospital readmission and mortality (Evans 2025, Tan 2020).

Leave against medical advice rates for adult SCD hospitalizations exceed the NYC average (Table 1):

- **14%** of SCD hospitalizations result in LAMA, about triple the NYC average of **4.3%**
- SCD ranks **12th** among principal diagnoses resulting in LAMA by volume, despite comprising 0.5% of all adult hospitalizations
- Only alcohol-related disorders, drug poisoning, and opioid-related disorders have higher LAMA rates than SCD among the top 20 principal diagnoses.

Variation in rates of leave against medical advice in New York City hospitals is pronounced:
(Table 2):

- **Within the same hospital:** SCD LAMA rates consistently exceed overall LAMA rates
- **Across hospitals:**
  - Best-performing hospitals: **5-10%** of SCD hospitalizations result in LAMA
  - Worst-performing hospitals: **25-40%+** of SCD hospitalizations result in LAMA
- **Hospitals** with higher SCD patient volumes and comprehensive care programs demonstrate better performance on this metric.

Table 1

Top diagnoses of adult hospitalizations resulting in leave against medical advice (LAMA) in New York City hospitals (2022)

Ranked by # hospitalizations resulting in leave against medical advice

	Principal diagnosis	LAMA count	Total hospitalizations count	LAMA rate (%)	Total hospitalizations (%)
	NYC (Total)	32392	760676	4.3	100
1	Alcohol-related disorders	3,079	14,519	21.2%	1.9%
2	Septicemia	1,877	44,446	4.2%	5.8%
3	Diabetes mellitus with complication	1,416	18,494	7.7%	2.4%
4	Skin and subcutaneous tissue infections	1,320	9,361	14.1%	1.2%
5	Heart failure	1,290	22,286	5.8%	2.9%
6	Poisoning by drugs, initial encounter	1,080	4,914	22%	0.6%
7	Epilepsy; convulsions	830	8,813	9.4%	1.2%
8	COVID-19	774	18,059	4.3%	2.4%
9	Opioid-related disorders	742	2,226	33.3%	0.3%
10	Nonspecific chest pain	685	7,132	9.6%	0.9%
11	Chronic obstructive pulmonary disease and bronchiectasis	650	7,463	8.7%	1%
12	Sickle cell trait/anemia	585	4,170	14%	0.5%
13	Fluid and electrolyte disorders	584	7,539	7.7%	1%
14	Pancreatic disorders (excluding diabetes)	568	5,504	10.3%	0.7%
15	Acute and unspecified renal failure	507	9,130	5.6%	1.2%
16	Chronic kidney disease	494	7,255	6.8%	1%
17	Pneumonia (except that caused by tuberculosis)	481	7,315	6.6%	1%
18	Syncope	452	5,913	7.6%	0.8%
19	Cardiac dysrhythmias	420	12,263	3.4%	1.6%
20	Asthma	390	4,819	8.1%	0.6%

Source: Hospital Inpatient Discharges (SPARCS De-Identified): 2022 • Created with Datawrapper

Full table may be found at: https://www.datawrapper.de/_/epCkk/
Source (publicly available): New York State Department of Health, Hospital Inpatient Discharges (SPARCS De-Identified): 2022

Table 2

Adult hospitalizations for sickle cell disease resulting in leave against medical advice (LAMA) in New York City hospitals (2022)

Ranked by SCD LAMA rate (%)

	Hospital	System	SCD LAMA rate (%)	Overall LAMA rate (%)	SCD hospitalizations count
1	Mount Sinai Hospital - Mount Sinai Hospital of Queens	MOUNT SINAI HEALTH SYSTEM	42.9%	6.9%	50-99
2	Lenox Hill Hospital	NORTHWELL HEALTH	38.5%	2.4%	Less than 50
3	Harlem Hospital Center	NYC H+H	36.8%	10.0%	50-99
4	Bellevue Hospital Center	NYC H+H	36.7%	5.4%	100-199
5	North Central Bronx Hospital	NYC H+H	34.1%	8.8%	Less than 50
6	Metropolitan Hospital Center	NYC H+H	31.3%	6.6%	Less than 50
7	Jamaica Hospital Medical Center	MEDISYS HEALTH NETWORK	29.4%	4.9%	Less than 50
8	Mount Sinai West	MOUNT SINAI HEALTH SYSTEM	28.3%	5.8%	Less than 50
9	Wyckoff Heights Medical Center	INDEPENDENT	28.2%	9.3%	Less than 50
10	Mount Sinai Morningside	MOUNT SINAI HEALTH SYSTEM	27.4%	5.2%	50-99
11	New York-Presbyterian/Lower Manhattan Hospital	NEW YORK-PRESBYTERIAN HEALTHCARE SYSTEM	26.9%	2.8%	Less than 50
12	Jacobi Medical Center	NYC H+H	24.8%	6.8%	100-199
13	Mount Sinai Beth Israel	MOUNT SINAI HEALTH SYSTEM	23.1%	5.9%	Less than 50
14	Elmhurst Hospital Center	NYC H+H	23.1%	4.2%	Less than 50
15	Woodhull Medical & Mental Health Center	NYC H+H	21.1%	6.2%	Less than 50
16	Mount Sinai Brooklyn	MOUNT SINAI HEALTH SYSTEM	20.6%	3.9%	50-99
17	Lincoln Medical & Mental Health Center	NYC H+H	20%	10.4%	50-99
18	SBH Health System	INDEPENDENT	18.6%	11.5%	Less than 50
19	BronxCare Hospital Center	INDEPENDENT	18.5%	11.2%	100-199
20	Brookdale Hospital Medical Center	ONE BROOKLYN HEALTH SYSTEM	16.2%	11.3%	100-199

Additional 26 rows not shown.

Source: Hospital Inpatient Discharges (SPARCS De-Identified): 2022 • Created with Datawrapper

Full table may be found at:
https://www.datawrapper.de/_/mZXsI/
Source (publicly available): New York State Department of Health, Hospital Inpatient Discharges (SPARCS De-Identified): 2022

Patient Registries: The Gold Standard to Advance Understanding of Rare Diseases

Clinical patient registries represent the gold standard for data collection and reporting about rare conditions, which by definition affect small populations. Successful examples include the Cystic Fibrosis Foundation Patient Registry, TREAT-NMD Global Registries for neuromuscular diseases, and registries for bleeding disorders like hemophilia. Such registries feature standardized data collection protocols, comprehensive health outcomes reporting, robust data

governance with privacy protections, and sustainable funding. Clinical registries have significantly advanced understanding of disease progression, treatment development, clinical care guideline improvements, and patient access to clinical trials—achievements that would be difficult to replicate through fragmented data systems.

The Data Gap: Fragmentation Across US, State, and Local Levels

A 2020 National Academies report, "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action," identified the absence of a comprehensive SCD registry at the national level as a critical gap. As a result, SCD data collection remains fragmented across state, local, and healthcare facility levels—if it occurs at all.

Current efforts to address these data gaps indicate progress yet fall short in delivering timely, comprehensive information:

- **CDC's SCD data collection program** has advanced state-level initiatives, promoting better understanding and information exchange. However, the program has significant limitations: national coverage is constrained by voluntary state participation and resource-intensive local data integration, resulting in estimated coverage of under 40% of the U.S. population.
- **New York State** has made important contributions regarding SCD, but it does not currently participate in CDC's program. Understanding of basic epidemiology—such as the number of people living with SCD in New York— relies on estimates from 10-20 years ago.
- **Globin Regional Data and Discovery (GRNDaD) registry** – a multi-center effort by the medical community - represents a meaningful step forward, offering clinical trial facilitation, research support, and the ability to track health outcomes longitudinally. Though it currently captures a small proportion of patients and healthcare sites, such efforts are important to advance clinical care.

Recommendations

While action at the federal level is the most effective way to address gaps in SCD data, local and state governments can take the meaningful steps in the short-term. Namely:

1. Implement an **all-payer database (APD)** at the state-level. APD can provide valuable information on a population level, including the characterization of SCD prevalence and other basic epidemiology, disease management, healthcare utilization, and complications.
2. Participate in **CDC’s SCD Data Collection Program**, a multi-state effort to assess epidemiological trends and health care outcomes among people with SCD across the US.
3. At a city level, use readily available data sources to monitor health care access and outcomes, such as:
    a. Signals of unmet care needs, such as leave against medical advice in hospital settings.
    b. Access to advanced therapeutics.

Healthcare Access and Quality

Overview of the National Healthcare Landscape for Sickle Cell Disease

Effective management of SCD —a complex, multi-organ disorder marked by severe pain and life-threatening complications such as vaso-occlusive events—requires a well-resourced comprehensive care model. This includes specialized treatment centers, coordinated multidisciplinary teams that may include community-based organizations (CBOs), sustained research funding, and robust supporting infrastructure. This approach is regarded as the gold standard for managing other rare conditions such as hemophilia or cystic fibrosis. Despite the proven benefits of standardized treatment protocols and consistent research investment, SCD care, particularly for adults, remains fragmented and underfunded.[viii]

While there has been encouraging progress in recent years, the U.S. healthcare system continues to fall short in delivering accessible, equitable, and high-quality care for individuals with SCD. Many persistent challenges stem from insufficient funding, limited medical education on SCD, an outdated perception of SCD as primarily a childhood disease, and structural racism. Unstable and inadequate funding—often reliant on state and federal grants, institutional support, or philanthropy—restricts opportunities for research, clinical trials, healthcare capacity, service delivery, and effective tracking of health outcomes.

A notable funding gap exists between pediatric and adult care. For example, while the National Heart, Lung, and Blood Institute (NHLBI) previously funded pediatric comprehensive care centers, similar investments in adult care have been lacking, leaving a significant gap for older patients. Although care fragmentation is a widespread issue in the U.S. healthcare system, it alone does not fully explain the inequities in SCD care, particularly when compared to more successful rare disease care models.

Recent developments, such as the Cell and Gene Therapy Access Model introduced by the Centers for Medicare & Medicaid Services (CMS), offer promise for financing life-changing breakthrough treatments. However, ensuring equitable access will depend not only on health system capacity but also on providers' ability to navigate payment and financing challenges—considerations that have historically limited access to high-cost therapies.[ix]

For a summary of key challenges in SCD care across the US, please refer to Appendix 1.

New York City's Healthcare Landscape for Sickle Cell Disease: Advantages Amidst Wider Issues

New York City offers distinct advantages for sickle cell disease (SCD) care compared to the national landscape. The city benefits from a high concentration of dedicated programs, along with a relatively favorable public infrastructure and policy landscape. As a result, New Yorkers living with SCD have unique opportunities for care but still encounter challenges that reflect broader national trends.

Strengths of New York City's Healthcare Landscape

- **Comprehensive Care Centers:** The city has over ten comprehensive SCD care centers or programs within major health systems, offering pediatric, adult, or lifespan care. These include Montefiore Einstein in the Bronx, one of the largest SCD comprehensive care centers in the U.S. (serving both children and adults), and Mount Sinai in Manhattan, a high-volume center specializing in adult SCD care.
- **Inclusive Public Hospital System** New York City's Health + Hospitals system operates programs for SCD that deliver care regardless of an individual's ability to pay.
- **High Density of Physicians:** New York State has over 400 active physicians per 100,000 population compared to the US average of approximately 300, including 9 hematologists/oncologists per 100,000 versus 5 nationally.[x] While NYC-specific data is not available, many providers are concentrated in the city.
- **Policy Landscape:** New York State has broad eligibility for Medicaid, covering the vast majority of individuals who have SCD. Additionally, in 2022, SCD became a single-qualifying condition for the state-level Health Homes program, expanding access to care coordination for Medicaid members with SCD.
- **Community-Based Organizations (CBOs):** Several CBOs support individuals with SCD, helping them navigate the healthcare system and advocate for their needs.
- **High-Density Public Transit:** New York City's expansive public transportation system helps reduce geographical barriers to care compared to rural areas or less connected metropolitan areas.

Three Core Challenges

Despite numerous advantages of the city's healthcare landscape, New Yorkers living with SCD still encounter significant challenges in three core areas:

1. Timely and Appropriate Pain Management (Chronic and Acute):

- **Pain management in emergency departments and hospital settings remains a critical concern.** Although the American Society of Hematology has developed clinical guidelines and quality measures,[xi] implementation is often inconsistent. The consequences can be devastating, including prolonged wait times and a breakdown of trust between patients, providers, and healthcare institutions. For individuals experiencing vaso-occlusive events, timely and effective pain relief—along with appropriate medical treatment—is essential, as these episodes can be life-threatening. **People report experiencing the additional[xii] trauma of being perceived as drug-seeking while in severe pain—a persistent issue highlighted by community groups and healthcare providers.**[xiii]
- **Outpatient pain management** remain suboptimal. Effective pain management also depends on access to providers who are knowledgeable about SCD.

2. SCD Specialist Access

- NYC's high physician density does not necessarily translate into sufficient access to SCD specialists. Contributing factors include a shortage of adult benign hematology providers, discomfort among primary care providers with understanding of SCD, and insufficient medical education.

3. Fragmented Care and Referral Pathways:

- **Pediatric-to-adult transition** represents a high-risk period marked by disruptions in care. In New York City, pediatric programs often lack formal linkages to adult

comprehensive care programs. Additionally, many college students move to New York City for their education and may need to establish specialized care locally as they transition out of pediatric care.

- **Care coordination** is essential for people with complex health needs, but unstable funding for social workers often results in burnout and high turnover. At the state level, the **Health Homes** program was established to expand care coordination for Medicaid members, and SCD is a single-qualifying condition. Despite this, people with SCD and providers often lack awareness of the program's benefits or struggle with its integration into existing care systems. For additional information on barriers to wider adoption of Health Homes, see Appendix 2.
- **CBO-hospital partnerships and CHW integration into care teams** have demonstrated success in improving SCD outcomes through multi-faceted approaches like referral management, follow-ups, education, and supporting with social needs.[xiv] Despite their benefits, these resources remain underutilized and underfunded in hospital settings.

These challenges largely stem from healthcare system deficiencies rather than factors that people living with SCD have significant control over. Comprehensive care is a proven way to address many of these challenges simultaneously, yet it remains inaccessible for many people with SCD due to persistent underinvestment, particularly for adult services.

Special Focus: Adult Comprehensive Care

Comprehensive care centers have numerous advantages and are considered the ideal model of care for rare diseases like SCD. They provide specialized care such as individualized pain management (including opioid stewardship), monitoring organ function, guiding women through pregnancy, and enhanced psychosocial support. People who receive care at specialized centers have better outcomes including fewer complications and hospital admissions. [REF]

Elements of Adult Comprehensive Care The components of adult comprehensive care for SCD have been well-defined and include the following (Kanter 2020):

- **Essential Elements:** Lead SCD specialist supported by a multidisciplinary team (including social workers, care coordinators, and nurses), and adherence to clinical guidelines, particularly in pain management and transfusion protocols.
- **Optimal Elements:** Pediatric-to-adult transition programs, mental health support, dedicated infusion centers or day hospitals.
- **Adjunct Elements:** Integration with primary care services, physical therapist/occupational therapist, pharmacist, dental care, dedicated clinic space, SCD educator.

Challenges in Implementing Elements of Adult Comprehensive Care:

- **Insufficient capacity of existing centers:** The current number and capacity of existing centers is not enough to meet demand for adult services, limiting essential access to comprehensive care.
- **Existing adult comprehensive care centers face systemic issues** such as fragmentation of care and workforce shortages – all of which impact the centers' ability to implement essential and optimal components of care. For example, high social worker turnover compromises care coordination for complex patients.
- **Payment and financing:** Some comprehensive care centers offer advanced treatments such as bone marrow transplants, but high costs associated with these services can create financial pressures for Medicaid Managed Care plans, potentially impacting sustainability.

Estimated Cost of a Comprehensive Care Center

Costs associated with a comprehensive care center include startup costs, annual operational expenses, and staffing. While detailed breakdowns of all items are not available, staffing typically makes up the vast majority of annual costs. Below is an example of staffing costs, meant to serve as a starting point for a center that meets essential and optimal elements of an adult comprehensive care model. Estimates will vary depending on assumptions about staffing ratios and complexity of patient needs. Centers with higher patient volume will benefit from economies of scale, but staffing remains the biggest cost driver.

A starting point for estimating staffing and total annual costs for a SCD comprehensive care center:

Personnel Type	NYC Market Salary	200 Patients	400 Patients	1,000 Patients
SCD Specialist (Hematologist/Director)	$300K – $450K	1 staff (1:200)	2 staff (1:200)	5 staff (1:200)
Advanced Practice Providers (NP/PA)	$130K – $160K	2 staff (1:100)	4 staff (1:100)	10 staff (1:100)
Nurse Coordinators	$110K – $140K	2 staff (1:100)	4 staff (1:100)	10 staff (1:100)

Medical Assistants/Clinic Staff	$50K – $70K	2 staff (1:100)	4 staff (1:100)	10 staff (1:100)
Infusion Center Staff (RNs, Phlebotomists)	$100K – $150K	2 staff (1:100)	4 staff (1:100)	10 staff (1:100)
Pain Management Specialist	$250K – $350K	1 staff (1:200)	2 staff (1:200)	5 staff (1:200)
Pharmacist (SCD Specialized)	$140K – $180K	1 staff (1:200)	2 staff (1:200)	5 staff (1:200)
Social Workers	$80K – $100K	2 staff (1:100)	4 staff (1:100)	10 staff (1:100)
Administrative Leadership	$130K – $160K	1 staff	1 staff	3 staff
Mental Health Specialist	$90K – $140K	2 staff (1:100)	4 staff (1:100)	10 staff (1:100)
Physical Therapist	$80K – $120K	1 staff (1:200)	2 staff (1:200)	5 staff (1:200)
Transition Coordinator	$100K – $140K	1 staff (1:200)	2 staff (1:200)	5 staff (1:200)
Quality Improvement/Data	$100K – $140K	1 staff	1 staff	2 staff
Research Staff	$80K – $150K	1 staff	1 staff	3 staff
Patient Services Coordinators	$50K – $70K	1 staff (1:200)	2 staff (1:200)	5 staff (1:200)
Total Estimated Salary (in Millions)	**-**	**$2M-$3M**	**$4M – $6M**	**$11M – $15M**
Total Estimated Center Cost (in Millions)*	**-**	**$3M – $5M**	**$6M – $9M**	**$16M – $22M**

**Note: assumes staffing makes up approximately 70% of total center costs*

Current Efforts in New York City

Below is a snapshot of current efforts by health systems, community-based organizations, and other stakeholders in New York City related to SCD and SCT:

NYC Health + Hospitals is engaged in several initiatives to improve and expand access to care for individuals with SCD, as well as programs aimed at increasing awareness of SCT:

- Establishing three new adult SCD centers (Harlem, Kings County, and Queens locations) that will adopt the specialized medical home model—offering comprehensive care through coordinated collaboration between primary care providers and SCD specialists.
- Standardizing and enhancing counseling for families identified with SCT, including defining the role of pediatricians, developing educational materials, and addressing barriers to counseling.
- Implementing a successful pilot funded by the NYS Department of Health's Office of Minority Health (OMH) to improve hydroxyurea prescribing among pediatric providers.
- The intervention led to a rise in medication fill rates from approximately 60% to 80%—a significantly higher rate than among patients who did not see a participating provider.[xv] Components of the program included:
    - Provider incentives (for primary care, hematology, and emergency providers)
    - CME-eligible provider education
    - An EPIC-based documentation toolkit
    - Wrap-around support from a community-based organization (Candice's Sickle Cell Fund), addressing social needs, insurance navigation, education, and referral/follow-up support—often delivered in partnership with CHWs
    - Tracking quality metrics and evaluation of health outcomes.

Mount Sinai Health System is taking steps to address the needs of multi-visit patients to reduce leave against medical advice and hospital readmissions. High LAMA rates at certain MSHS sites were due to a small number of individuals who required multi-disciplinary, individualized care plan interventions.

Candice's Sickle Cell Fund is convening Project ECHO sessions to bring together representatives from comprehensive care centers, hospitals, community groups, and other stakeholders to educate providers and improve care in the emergency department.

Gene Therapies for SCD:

- As of early 2025, treatment programs offering gene therapies for SCD have been established at several medical centers in New York City, and more may be in the process of doing so. At least one individual has successfully undergone treatment.
- **The State Department of Health** submitted an application in March 2025 to participate in the Cell and Gene Therapy (CGT) Access Model. Under this pilot, New York's Medicaid program will adopt an outcomes-based payment agreement negotiated by the Centers for Medicare and Medicaid Services (CMS). Medicaid coverage for sickle cell gene therapies will be effective January 2026.

Recommendations

1. **Fund and Expand Adult Comprehensive Care Centers:**
   a. **Secure sustainable funding for both existing and developing centers:** Adequate resources are essential to ensure these centers can deliver comprehensive, high-quality SCD care and address systemic challenges such as fragmented care and payment/financing issues.
   b. **Support sustainable funding for Centers of Excellence at the state level.** S.1578/A.3676 ("Sickle Cell Treatment Act") designates $400,000 annually for five Sickle Cell Centers of Excellence and $200,000 annually for ten outpatient treatment centers.
2. **Improve Clinical Care at All Facilities:**
   a. **Implement Evidence-Based Pain Management Protocols:**
      - Develop individualized pain protocols in consultation with a hematologist or another provider knowledgeable about SCD.
      - Establish ED and inpatient workflows to ensure timely and consistent implementation of pain protocols.[xvi]
      - Educate providers across different settings (including primary care and ED) on SCD pain management and implicit bias.
      - Improve hydroxyurea uptake and adherence among children and adults
      - Monitor care quality in an outpatient and hospital setting:
        - Track hydroxyurea use and adherence
        - Measure time to analgesic administration for vaso-occlusive crises in emergency departments.[xvii]
        - Identify unmet care needs through indicators such as leaving against medical advice or 30-day readmission rates.
   b. **Expand SCD Specialist Workforce:**
      - Training for primary care providers in SCD management
   c. **Improve Care Coordination and Establish Robust Referral Pathways:**
      - Establish formal linkages between pediatric and adult comprehensive care programs (e.g., Centers of Excellence).
      - Invest in sustainable workforce of social workers to provide care coordination for people with complex health needs

- Increase awareness about Health Homes:
    - Educate providers on Health Home eligibility and benefits for people living with SCD.
    - Support outreach campaigns to communities with SCD, both through health care providers and patient advocacy groups, to raise awareness about Health Homes and other healthcare resources.
- Expand CBO-hospital partnerships and integrate CHWs into care teams. Given their contributions across multiple domains—including care navigation, patient advocacy and education, addressing social needs, and enhancing care continuity—these strategies warrant broader adoption and greater investment.

Recommendations Summary

The following recommendations aim to address three core challenges in SCD care: pain management, access to SCD specialists, and fragmented care. They are intended for local stakeholders—including New York City hospitals, health systems, community-based organizations, advocates, and city and state agencies—to guide partnerships and fostering collaboration to improve access to care and health outcomes for individuals living with SCD.

Immediate Actions:

Recommendation	Core Challenge Addressed	Impact	Effort
Develop individualized pain protocols with SCD specialists *	Pain Management (Chronic & Acute)	High	Medium
Implement ED & inpatient workflows for pain management *	Pain Management (Acute)	High	Low-Medium
Strengthen provider education on SCD pain & stigma (multiple specialties) *	Pain Management (Chronic & Acute)	High	Low-Medium
Sustainably fund social work & care coordination	Care Fragmentation	High	Medium
Establish formal pediatric-adult care linkages & strengthen referral pathways	Care Fragmentation	High	Medium
Advocate for state-level initiatives	Supporting Systems	Medium-High	Low
Monitor healthcare utilization, care quality, and developments in advanced treatments	Supporting Systems	Medium	Low-Medium

* = indicate highest priority recommendations

Medium to Long-Term Investments:

Recommendation	Core Challenge Addressed	Impact	Effort
Sustainably fund and expand access to adult comprehensive care (including Centers of Excellence) *	All Core Challenges	Very High	High
Specialized SCD training for PCPs *	Specialist Access, Pain management	High	Medium

* = indicate highest priority recommendations

Calendar Year 2024 Activities and Current Efforts

This section summarizes activities led by the New York City Health Department related to local law #163 of 2023 aimed at improving health outcomes for individuals living with SCD and to raise awareness about sickle cell trait (SCT). For current efforts led by health systems and community organizations, please refer to the Healthcare Access and Quality section.

Public Awareness:

- **Sickle Cell Disease and Sickle Cell Trait:** Webpage containing information about screening for sickle cell trait and resources for sickle cell disease https://www.nyc.gov/site/doh/health/health-topics/sickle-cell.page

Provider Education:

(In collaboration with NYC Health + Hospitals and Mount Sinai Health System)

- Health Advisory #15: **NYC Health Department Recommendations on Destigmatizing and Improving Provider Attitudes Towards Pain in Sickle Cell Disease** (May 17, 2024) https://www.nyc.gov/assets/doh/downloads/pdf/han/advisory/2024/han-advisory-15.pdf
- Continuing Medical Education (CME) Webinar: **Sickling Not Seeking: Uniting Patient and Provider Attitudes Toward Pain in Sickle Cell Disease** (June 21, 2024) https://ww2.highmarksce.com/nyh/Events/viewEnduring?attendeeID=-1&eventID=3195
    - Among the most popular provider webinars offered by the NYC Health Department
- Dear Colleague Letter: **Sickle Cell Trait** (September 30, 2024) https://www.nyc.gov/assets/doh/downloads/pdf/letters/2024/sct-dear-colleague-letter.pdf

Presentations and Publications:

- [Upcoming] **The Role of Municipal Department of Health in Advancing Sickle Cell Disease Care and Policy: Lessons from New York City.** Abstract accepted for an oral presentation at The Foundation for Sickle Cell Disease Research's (FSCDR) Annual Symposium in June 2025.
- **Leave against medical advice as a potential signal of unmet care needs in sickle cell disease hospitalizations in New York City.** Presentation for Metropolitan Hospital's Patient Safety Week, March 11, 2025.
- Seifu L, Sedlar S, Grant T, Faciano A, Ehrlich J. **Sickle Cell Disease and Lead Poisoning in New York City, 2005-2019**. Pediatrics. 2024 Oct 1;154(Suppl 2):e2024067808G. doi: 10.1542/peds.2024-067808G. PMID: 39352034.

Public Health Monitoring:

- Use of readily available data sources to examine SCD complications and signs of unmet care needs.

Community and Stakeholder Engagement:

- Engagement with community-based organizations such as Candice’s Sickle Cell Fund and Sickle Cell/Thalassemia Patients Network.

Conclusion

This report critically assesses sickle cell disease (SCD) care in New York City, highlighting both strengths and persistent barriers—including pain management, limited specialist access, and gaps in continuity of care—that undermine treatment and trust. Addressing these challenges may be done through a combination of immediate, low-resource interventions and sustained long-term investments. Comprehensive care centers offer a proven model to tackle multiple challenges of SCD care simultaneously.

Beyond expanding comprehensive care, system-wide initiatives are needed. Stakeholders have consistently raised several essential steps to make healthcare for SCD more accessible and consistent: standardizing pain management protocols, strengthening clinician education, streamlining data infrastructure at multiple levels, and integrating social work and community health workers. Indicators of care quality, while underdeveloped, provide vital feedback to track progress and inform meaningful improvements. As gene therapies and other emerging treatments advance, ongoing monitoring of access, cost, healthcare capacity, and insurance coverage will become important for ensuring equitable access. Together, these strategies can not only reduce health disparities but may ultimately improve quality of life and long-term outcomes for individuals living with SCD.

Appendix 1: SCD Care Challenges in the US

Comprehensive Care Centers

- Few dedicated SCD care centers across the US, especially for adults
- Limited access outside of urban areas

SCD Specialist Workforce

- Shortage of SCD specialists, particularly in adult benign hematology
- Low confidence among primary care providers in managing SCD
- Limited SCD training in medical education

Care Fragmentation

- Disruptions in care are frequently observed during the high-risk pediatric-adult transition period and are associated with increases in complications.
- Funding instability drives high turnover among social workers and strains care coordination.
- Limited integration of community health workers (CHWs) and CBOs results in missed opportunities across multiple domains, including referral management and facilitating care continuity.

Care Quality

- Care Delivery and Treatment:
    - Implicit bias and misperceptions of individuals with SCD as drug seekers—particularly in acute care settings—continue to undermine timely pain management, further compounded by the legacy of the opioid epidemic.
    - Inconsistent implementation of evidence-based clinical guidelines for pain management
- Clinical Standards:
    - Incomplete evidence to develop guidelines and inform clinical care in some domains
- Metrics and Evaluation:
    - Few endorsed care metrics (e.g., National Quality Forum), limiting quality monitoring
    - Hospitalizations for SCD have high rates of 30-day readmissions, but solutions are underdeveloped
    - Hospital ranking systems (e.g., U.S. News) may underweight SCD compared to other rare diseases, potentially affecting institutional priorities[xviii]

Research and Clinical Trials

- Suboptimal awareness and recruitment for clinical trials
- Research funding lags behind comparable conditions

Supporting Infrastructure

- Absence of a comprehensive clinical registry
- EMR tools: Limited adoption of decision-support tools for SCD care; lack of connectivity between different EMR platforms and hospital systems

- Telemedicine: Health system adoption falls short of patient demand, limiting potential to bridge geographic gaps and improve access

Appendix 2: Barriers to Wider Adoption of Medicaid's Health Homes Program

1. Awareness

- **Program Misperception**
  - Lack of awareness about SCD as a single qualifying condition: many participating organizations still list "two or more chronic medical conditions or a serious mental health condition" as eligibility criteria.
  - Confusion around the name "Health Homes" (mistaken for housing support)
- **Provider Knowledge Gaps**
  - Providers must be aware about and believe in the program's benefits for patients
  - Continuous education in academic medical settings is needed with rotating staff

2. Administrative and Operational

- **Documentation and Identification of Eligible Candidates**
  - No systematic method to screen and identify candidates.
  - Providers face significant pressure to prevent unnecessary enrollment and must meticulously screen for candidacy.
  - Documentation for enrollment and payment is administratively cumbersome.
- **Program Design and Eligibility**
  - Eligibility beyond SCD diagnosis (must need intensive coordination)
  - Program is designed to stabilize patients. "Graduation" model removes support once patients stabilize.

3. Financial

- **Funding Instability**
  - Health Homes funding significantly decreased while eligibility has expanded
  - As a budget line item, the program is easily targeted for cuts and has experienced multiple reductions.
  - Stagnant Medicaid reimbursement rates (unchanged since 2018)
  - Care management agencies discontinuing services due to cost concerns[1]

4. Patient Engagement

- **Program Intensity May Deter Some Participants**
  - Enrolled clients agree to substantial social worker involvement: frequent contact (approximately 4 times monthly) regarding disease management. Some patients may find the model invasive and may not want continuous Health Home Care Manager engagement.

[1] https://www.nysenate.gov/sites/default/files/admin/structure/media/manage/filefile/a/2025-02/cnyshh_nys-cm-coalition-written-testimony-2.11.25-joint-health-committee.pdf

Appendix 3: Jordan Neely Case and Sickle Cell Trait

Key Points

- Jordan Neely, a 30-year-old man experiencing homelessness known for his street performances, died on May 1, 2023, after being restrained in a chokehold by 26-year-old former U.S. Marine Daniel Penny on a New York City subway.
- A central debate at trial was whether Jordan Neely's underlying health conditions and other factors played a greater role in his death than the chokehold.
- Penny's defense argued he acted to protect other passengers and did not intend to kill Neely, and that Neely's death resulted from a combination of underlying health conditions, including sickle cell trait (a benign genetic condition that should not be confused with sickle cell disease,) and evidence of drug use.
- The prosecution argued that Penny used excessive force. In NYC Medical Examiner's Office testimony, Dr. Cynthia Harris unequivocally stated that the chokehold was the cause of Neely's death, countering assertions made by the defense. Dr. Harris' testimony was consistent with the medical consensus at the time, including statements made by the American Society of Hematology (ASH.)
- Admissibility of scientific evidence in the courtroom is governed by the *Frye* standard in NY State Courts and has been used to contest widely accepted theories in order to cast doubt on the credibility of the evidence presented to the jury.

Background

Jordan Neely, a 30-year-old man experiencing homelessness known for his street performances, died on May 1, 2023, after being restrained in a chokehold by 26-year-old former U.S. Marine Daniel Penny on a New York City subway. Witnesses reported that Neely had been shouting that he was hungry, thirsty, and ready to die or go to jail before Penny intervened and held him in a chokehold for about six minutes. Neely lost consciousness and was later pronounced dead. **The city's medical examiner ruled the death a homicide caused by "compression of the neck".** Penny was subsequently arrested and charged with second-degree manslaughter and criminally negligent homicide. The incident – also captured on video – sparked protests and rekindled public discussions about subway safety, mental health, and vigilantism, with additional scrutiny because Penny is White and Neely was Black.

Legal Proceedings

Legal proceedings unfolded over the following year. A Manhattan grand jury indicted Penny, and the case went to trial in late 2024. During the trial, Penny's defense argued he acted to protect other passengers and did not intend to kill Neely. The prosecution contended that Penny used excessive force. **A central debate at trial was whether Jordan Neely's underlying health conditions played a greater role in his death than the chokehold.** Defense attorneys argued that a combination of factors – sickle cell trait (SCT is a benign genetic condition and should not be confused with sickle cell disease), along with a history of schizophrenia and evidence of recent drug use (specifically synthetic cannabinoids) played a bigger role in his

death. **Expert witness for the defense, forensic pathologist Dr. Satish Chundru, asserted that if Neely was a completely healthy individual he would not have died of the chokehold.** After several days of deliberation, the jury was unable to reach consensus on the manslaughter charge (the more serious count), and the judge – at the prosecution's request – dismissed that charge, leaving only the lesser charge to consider. On December 9, 2024, Daniel Penny was acquitted of the lesser charge of criminally negligent homicide. Jury deliberations lasted five days and included requests to review definitions of criminal negligence and recklessness, as well as the Chief Medical Examiner's testimony—**indicating that medical evidence may have played a role in their deliberations.**

New York City Chief Medical Examiner's Testimony

Dr. Cynthia Harris of the Office of the Chief Medical Examiner performed Neely's autopsy and ruled the death a homicide caused by the asphyxiation of the neck (chokehold.) **Dr. Harris was unequivocal in her testimony, stating that the chokehold was the cause of Neely's death,** countering assertions made by the defense regarding the role of underlying health conditions and other factors like drug use. Below are excerpts of Dr. Harris's testimony, as reported by media outlets:

- Individuals with SCT almost never die suddenly unless severe stressors are present. Triggers like extreme dehydration, high heat, or intense over-exertion can precipitate a crisis, but those conditions were absent in Neely's case (for example, Neely's urine was light-colored, indicating he was not dehydrated)
- Dr. Harris explained that even in the unusual event of a sickle cell "crisis," death is typically not instantaneous – it can take hours or even a day for a crisis to become fatal, rather than the mere minutes in which Neely collapsed.
- Physical signs indicating that Neely died from asphyxiation (oxygen deprivation) due to neck compression. A bystander's video of the incident showed Neely's face turning purple and the veins on his forehead bulging – classic signs that blood flow was being impeded from the neck upwards
- Autopsy findings were diagnostic of Neely having been choked to death, not a spontaneous internal medical problem. Harris did acknowledge that she observed some sickled cells in Neely's blood during the autopsy, meaning a degree of sickling had occurred. However, she concluded that **any sickling was likely triggered by the chokehold itself** – in other words, the stress and lack of oxygen caused by strangulation could have caused some of Neely's red cells to sickle after the fatal sequence was already in motion. Crucially, Dr. Harris stated that Neely's cells would not have sickled at all "if Neely hadn't been placed in a chokehold." She firmly summarized the causal relationship as: **"That chokehold for that amount of time would have killed anyone."**
- Regarding other concerns raised by the defense, such as the presence of synthetic marijuana in Neely's blood, and a determination of the cause of death prior to receiving toxicology results, Dr. Harris said, **"he could have come back with enough fentanyl to put down an elephant" and her ruling [regarding the chokehold as the cause of death] would still be the same.**

New York Times Investigation and Subsequent Statements by the Medical Community

A 2021 investigation by the New York Times found over 40 instances over the preceding 25 years when sickle cell trait was used as a cause or major factor in deaths of Black people in policy custody, including 15 deaths since 2015. The death of George Floyd in 2020 is one such

instance, though in that case, assertions about the role of SCT did not persuade the jury, who found the accused police offer Derek Chauvin guilty of all counts, including murder.

Following these incidents and the New York Times investigation, the American Society of Hematology (ASH) released a statement in 2021 saying, "**Because of the rarity of sudden death in persons with sickle cell trait, cases where this is cited as the sole cause of death, or a major contributor must be viewed with profound skepticism**." ASH updated their position in January 2025, about two months after Daniel Penny's acquittal, releasing a stronger statement that "**Listing "sickle cell crisis" or "sickle cell trait" as a cause of death on an autopsy report for an individual with sickle cell trait is medically inaccurate.**"

Physicians representing several medical institutions in Minnesota and Michigan also raised issues with assertions by police departments about the role of SCT in custody deaths, writing in a letter in *The Lancet* that it is "**problematic that forensic pathologists continue to document sickle cell trait in cases of in-custody death. Such information does not elucidate the cause of death but rather creates plausible deniability for law enforcement officials.**"

Among the evidence cited in support of ASH position is a 2016 study published in the *New England Journal of Medicine* of about 50,000 black soldiers in the army who had undergone testing for HbAS and who were on active duty between 2011 and 2014. The study found no difference in mortality among soldiers with and without SCT, however they reported an increased risk of rhabdomyolysis.

Potential Role for NYC Health Department

- Educating providers and dispelling potential misunderstandings about SCT.
- Including information about SCT in public materials
- Communicating alignment with the medical community regarding the role of SCT (e.g. ASH position.)

Sources

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A 2017 analysis of the *Frye* standard to determine the admissibility of scientific evidence by the NY state bar association concluded that "recent case law suggests that litigants continue to devise new theories to challenge scientific techniques – even ones such as DNA testing which have gained nearly universal acceptance" https://nysba.org/NYSBA/Coursebooks/Spring%202017%20CLE%20Coursebooks/Commercial%20Litigation%20Academy%202017/7.A.%20Aguiar%20-%20An%20Analysis%20of%20the%20Frye%20Standard%20to%20Determine%20the%20Admissibility%20of%20Expert%20Trial%20Testimony%20in%20New%20York%20State%20Courts.pdf

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[viii] Farooq 2020; Martinez 2020
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[x] (AAMC 2024.)
[xi] ASH pain guideilnes, ASH Time to analgesic [REF ACEM/ASH)

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