

## Equity & Access Workgroup Project Summary

### Primary Equity & Access Workgroup (select one)

Workplace Diversity   
  Workplace Inclusion   
  Equity of Care   
  Monitoring & Evaluation

### Project Title

An Action Plan to End Healthcare Quality Inequities for Sickle Cell Disease (A Federally Recognized Disparity Disease)

### Description

*Describe what this project is about*

As healthcare professionals in a public hospital system, we are acutely aware of healthcare disparities. Probably no disease better exemplifies the devastating impact of systemic racism in medicine than sickle cell disease (SCD). The disparities in patient experience, quality of care health, and outcomes for SCD patients are unacceptable and the direct result from the low priority given to SCD compared to other similar conditions in the healthcare system.

Our proposed SCD Action Plan aims to eliminate healthcare inequities for sickle cell disease (SCD) patients by prioritizing SCD across the organization. The plan focuses on critical areas such as access to care, pain management, stigma, disease-modifying therapies, quality improvement, support for SCD community-based organizations, clinical trials, case management, and leveraging clinical data. By making SCD a priority, NYC Health and Hospitals has the potential to lead the way in eliminating SCD disparities, promoting wellness and improving the quality of life for SCD patients.

### Objective

*What do you plan to achieve by the end of this project?*

1. Utilization of Sickle Cell Disease Registry and EPIC Navigator across NYC H+H
2. Enhance Access to Comprehensive Adult SCD Care
3. Address the Transition and Transfer of Care from Pediatrics to Adult Care
4. Address Barriers to Obtaining Appropriate Pain Treatment
5. Mitigate the Negative Stigma of Individuals Affected by SCD
6. Address Insufficient Use of Disease-Modifying Therapies
7. Create a Structure for Robust Continuous Quality Improvement
8. Leverage Support From H+H & Legislators to Supplement Inadequately Resourced SCD Community-Based Organizations
9. Provide Access to Clinical Trials
10. Partner with Metro-Plus and Health Homes to Provide Case Management for High Utilizing Patients
11. Mitigate the Neurocognitive Effects of SCD on Mental Health and School Achievement/Performance
12. Leverage our Enterprise-wide Clinical Data to Inform Best Practices and Engage in Clinical Research/Publications/Presentations

### Background

*Describe the problem that this project seeks to resolve*

The mortality statistics for sickle cell disease is alarming. While the mortality rate for children with SCD has decreased, the overall mortality rate for this population is increasing, with emerging adults being the hardest hit. This reflects the lack of access to high-quality care for adults with SCD.

Despite being recognized by the federal government as a disparity disease, SCD often receives limited resources and attention compared to other healthcare priorities. This is largely due to two factors: 1) the small number of individuals affected by SCD, which makes the high per capita financial cost of this disease relatively insignificant compared to more prevalent chronic diseases, and 2) who it affects, minorities, people with low socio-economic status, and vulnerable, stigmatized groups. These inequalities are particularly pronounced when compared to less common genetic diseases that affect Caucasians (such as Cystic Fibrosis) or the general population (such as Hemophilia).

To address this social injustice, the Office of Minority Health commissioned the National Academy of Science, Engineering, and Medicine the 2020 report "Addressing Sickle Cell Disease: A Strategic Plan and Blueprint for Action," which provides specific guidance on how we as a nation can address these disparities. NYC Health + Hospitals gave the hospital stakeholder comments for the launch of this seminal report (<https://www.nationalacademies.org/our-work/addressing-sickle-cell-disease-a-strategic-plan-and-blueprint-for-action> ).

As one of the largest providers of sickle cell care in the nation, what we do will make a difference. We have begun to implement many of their recommendations at NYC Health and Hospitals (attachment – APHA poster). However, to eliminate these disparities, we need to make this an Enterprise-wide priority. We believe this aligns with our mission as a public hospital system. But it will take a concerted and organized effort to make this happen.

### Justification & Supporting Data

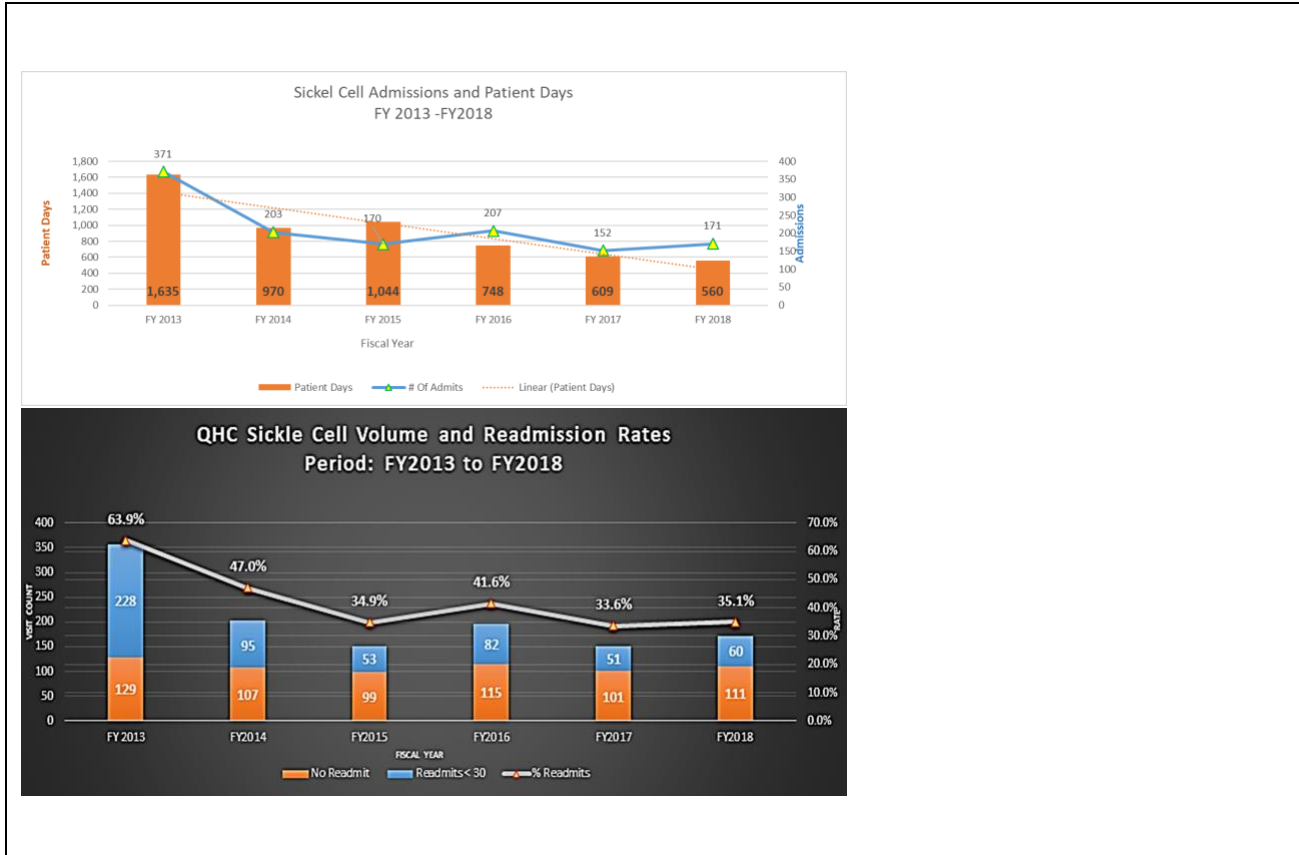
*Why is this important to NYC Health + Hospitals or how does it help improve Equity & Access to NYC H+H patients and staff? Include any data to support how the need was determined*

For the justification of NYC Health and Hospitals to be driving force for change, we need only look to our long and storied history in addressing the needs of SCD. Two of the first comprehensive sickle cell center in the nation were at Harlem and Kings County Hospitals. Our patients were involved in the multi-centered natural history SCD study, which led to sickle cell newborn screening.

Today, we are working to improve the care of our sickle cell patients through HHS Office of Minority Health SCD Programs, HRSA's Sickle Cell Treatment Demonstration Program, the American Society of Hematology (ASH) SCD-Clinical Trial Network, the ASH Adult SCD Workgroup, and the National Alliance of Sickle Cell Centers (NASCC). But more needs to be done to finally end healthcare quality inequities for SCD. Our action plan provides concrete steps to meet this goal, promoting wellness and improving healthcare quality across the lifespan for SCD patients.

Supporting data can be found in:

1. The number of patients we see:
  - a) In any given year, over one quarter of all individuals living with sickle cell disease in New York State are seen in one of our clinics, emergency departments, or hospitals.
  - b) In our clinics we follow about 1500 SCD patients/year
  - c) SCD patients have the highest per capital costs for Medicaid in NYS
  - d) National Medicaid costs per patient per year is about \$20,000
  - e) SCD patients have the highest 30 readmission rate
2. Queens Medical center documented an estimated 1.7 million dollar cost savings/year in decreased length of stay and 30 day hospital readmissions Queens Medical Center when they change from "clinic care" to comprehensive care through the addition of a single nurse practitioner.



**Success Criteria**

*What metrics will be used to track the success of this project?*

Process measures: eg SCD education, transition, TCD, immunizations, disease modifying therapy

Outcome measures:

Pain scores

Quality of life: changes in SCD QOL instruments

**Healthcare utilization: outpatient visits, ED visits, hospitalizations, length of stay, SCD complications**

Patient confidence they will be treated with dignity and respect.

Equity Lens:

Food insecurity, housing, language

**Setting:**

*Which facilities will be impacted?*

1. Wherever an individual with sickle cell disease touches our system
2. The six NYS designated pediatric sickle cell centers (Jacobi, Lincoln, Harlem, Met, Elmhurst, Kings)
3. One NYC H+H designated adult comprehensive sickle cell center in each borough

**Resources:**

*What resources are needed to execute this project?*

1. DNA data analyst to extract health care utilization across the enterprise
2. Creation of adult comprehensive sickle cell center will need dedicated NP and community health work and ideally a LCSW.
3. We have built a superb team to meet the deliverable of the HHS Office of Minority Health grant. This team has the skills to leverage our enterprise-wide clinical data to support grants, inform best practices and engage in clinical research. The team consists of study coordinator, data

analyst, research assistant, and community health worker. Their grant funded salaries will end 9/30/2024.

**Executive Sponsor and/or Site Champion:**

*Who are the executive sponsors or facility champions supporting this project?*

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**Project Team and Roles**

Name	Title	NYC H+H Facility	Project Role
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