



# Structurally Competent Care for Persons with Sickle Cell Disease

Mafudia A. Suaray, MD MPH; Associate Professor, Rutgers RWJMS

Project Sponsors: Dr. Sheraz Siddiqui, Division Chief for Hospital Medicine;

Mr. Franck Nelson, Asst VP, Office of Health Equity RWJBarnabas



## Abstract:

Sickle Cell disease (SCD) is a genetic disorder of red blood cells that is characterized by severe recurrent painful episodes, frequent infections, and premature death. Although a global disease, in the U.S over 90% of those affected are Black. Treatment options are limited and cure is still elusive. Persons with SCD experience significant health inequities and poor health outcomes among which is stigmatization and discrimination in health care settings. The effects of such stigma and discrimination have been shown to result in delay in seeking medical care, decreased trust in healthcare providers, decreased adherence to medical treatments, and increased stress and anxiety which in turn exacerbates the pain experience and increases utilization of acute care medical services. The goal of this project therefore is to create a multidisciplinary working group with the agency to design a culture change campaign and structurally competent care processes using the framework of the Quintuple Aim for Population Health Improvement for persons with SCD.

## Primary Stakeholders:

- Persons with SCD
- RWJBH Administration
- Clinicians –
  - hospital based
  - community based



Artist: Hertz Nazaire; a person with SCD

## Key Steps/Activities:

- 1-Create multidisciplinary working group
- 2- Design Individualized Care plans for patients with SCD
- 3- Develop and disseminate educational modules on structurally competent care for persons with SCD
- 4- Develop a SCD registry for institution

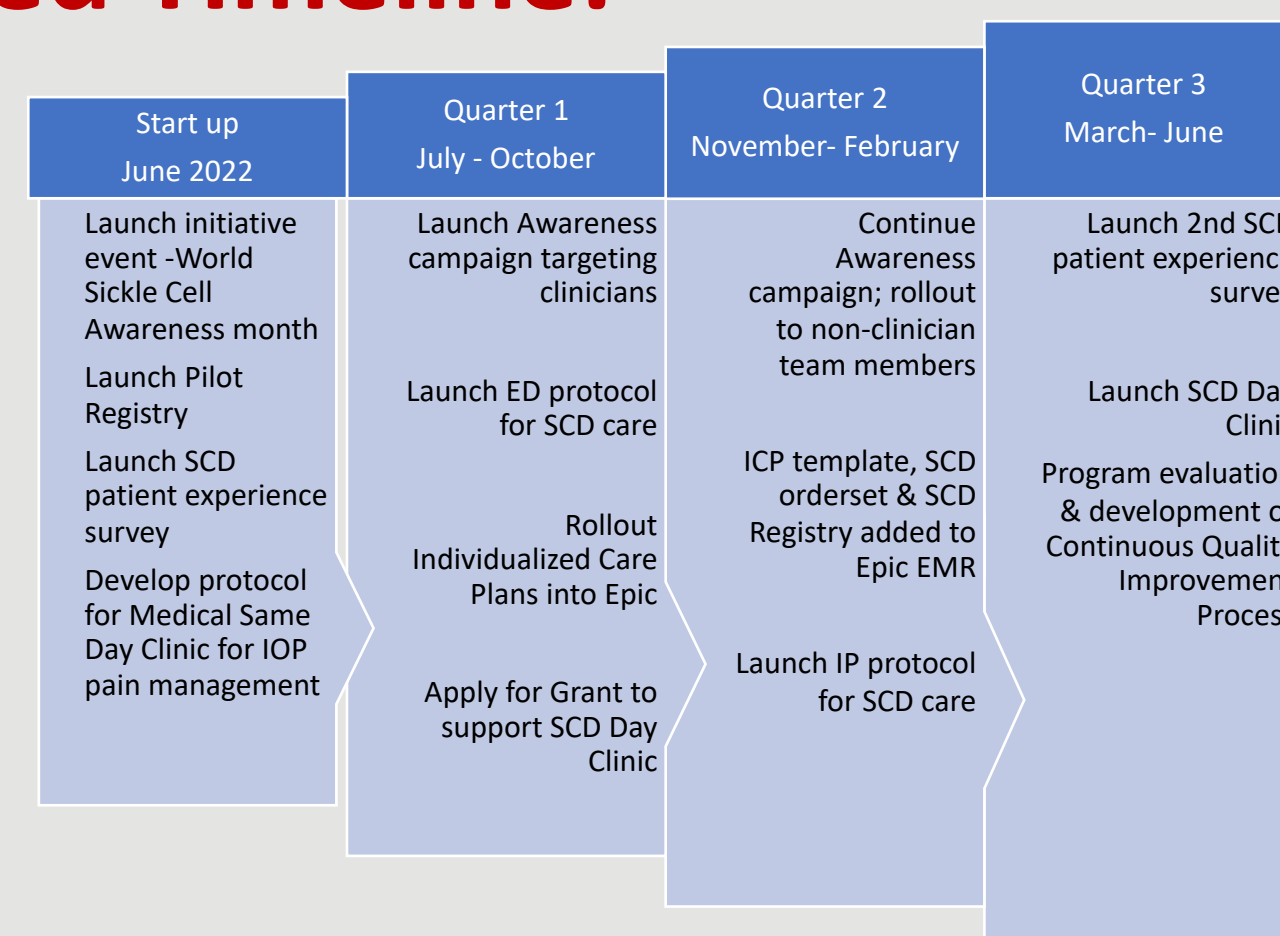
## Effectiveness Measures:

- 1) Incorporation of Individualized care plans into the electronic medical record
- 2) Incorporation of SCD management protocol into ED protocols and educational curriculum
- 3) Pre & Post surveys of clinicians exposed to the educational modules
- 4) Trend of utilization data for medical same day clinics, ER & hospitalizations
- 5) Patient surveys

## Communication/Engagement:

- Working Group:** regular meetings, emails
- Clinicians:** Launching event for initiative; educational modules; solicited feedback.
- Patients:** Periodic informant interviews of persons with SCD, patient surveys, newsletter.
- Community Partners-** Newsletter, targeted email communications

## Proposed Timeline:



## Current Status/Future Directions:

Working group is being formed, preliminary meetings held with key stakeholders. Individualized Care plans being prepared by Hematologists for SCDs patients currently actively engaged in care. Next steps will be to complete the working group and launch the initiative in earnest by June 2022.