What is Sickle Cell Disease (SCD)?

- SCD is a group of inherited conditions that affect hemoglobin, a protein that allows red blood cells to carry oxygen to all parts of the body.

- The most common types of SCD are:
  - **Hemoglobin SS Disease (HbSS)** - People who have this form of SCD inherit two sickle cell hemoglobin genes (“S”), one from each parent. This is commonly called sickle cell anemia and is usually the most severe form of the disease.
  - **Hemoglobin SC Disease (HbSC)** - People who have this form of SCD inherit a sickle cell hemoglobin gene (“S”) from one parent and from the other parent a gene for abnormal hemoglobin called “C”. This is usually a milder form of SCD.
  - **Hemoglobin S beta thalassemia (HbS beta thalassemia)** - People who have this form of SCD inherit one sickle cell hemoglobin gene (“S”) from one parent and one gene for beta thalassemia, another type of anemia, from the other parent. There are two types of beta thalassemia: “0” and “+”. Those with HbS beta^0-thalassemia usually have a more severe form of SCD. People with HbS beta^+ -thalassemia tend to have a milder form of SCD.
People with SCD in the 18-35 age group had the highest healthcare utilization.

Over 55% of people with SCD spent at least 1 day in the hospital during the 5 years.

Most of the babies born with SCD in North Carolina have Hemoglobin S/S disease or Hemoglobin S/Beta⁰-thalassemia.

Pneumonia/Acute Chest Syndrome (ACS) was the most common complication for people with SCD younger than 36 years.

Transcranial Doppler was the most common procedure for people with SCD younger than 18 years. RBC Transfusion was the most common procedure for people with SCD age 18 years and older.

This data was collected through the Registry and Surveillance System for Hemoglobinopathies (RuSH). RuSH was a pilot project that was implemented by the Centers for Disease Control and Prevention (CDC) in collaboration with the National Institutes for Health (NIH), National Heart, Lung, and Blood Institute (NHLBI).