National Institutes of Health (NIH)/National Human Genome Research Institute (NHGRI)

NHGRI studies how genes affect SCD, including why symptoms and complications vary from person to person. Researchers also study the associations between nutrition, diet and sickle cell related symptoms. In addition, NHGRI developed educational resources to help people living with SCD and their caregivers better understand their treatment options and make informed healthcare decisions. For more information visit: genome.gov

Populations Served



NIH/National Heart, Lung, and Blood Institute (NHLBI)/ Division of Blood Diseases and Resources (DBDR)

NHLBI's Division of Blood Diseases and Resources (DBDR) supports research to better understand, prevent, and treat blood diseases. It also helps ensure the safety and availability of the nation's blood supply and advances research on stem cells and gene and cell therapies, that may help repair or replace damaged tissues and organs. DBDR supports research on conditions such as SCD, anemia, hemophilia, blood clots, and other blood disorders that affect millions of people in United States. The division also trains future blood scientists, coordinate research efforts, and works with partners across the NHLBI, the NIH, and other federal agencies to promote and improve blood health. For more information visit: nhlbi.nih.gov/about/divisions/division-blood-diseases-and-resources

Populations Served



NHLBI/ Division of Intramural Research (DIR)/Hematology Branch

NHLBI's Hematology Branch, within DIR, conducts laboratory and clinical research on SCD and other blood disorders. The Sickle Cell Genetics and Pathophysiology Laboratory studies why SCD affects people differently and explores targeted treatments. The Cellular and Molecular Therapeutics Laboratory supports research to turn scientific discoveries into cures for SCD, including through stem cell transplantation, gene therapy, and other approaches. Together, these laboratories work to better understand SCD and translate research discoveries into improved treatments and patient care. For more information visit nhlbi.nih.gov/about/intramural-research/hematology

Populations Served



HHS Office of Minority Health (OMH)

HHS OMH leads federal collaboration to improve outcomes for people living with SCD. OMH raises awareness, develops and shares evidence-based educational resources, convenes partners across HHS and beyond, and fosters stakeholder engagement to strengthen coordination. Through these efforts, OMH helps reduce health disparities and enhance the quality of care, information, and support available to individuals and families affected by SCD. For more information visit: minorityhealth.hhs.gov/sickle-cell-disease

Populations Served



The Office of the National Coordinator for Health Information Technology (ONC)

ONC, with the Office of the Assistant Secretary for Planning and Evaluation (ASPE), is developing a United States Core Data for Interoperability Plus (USCDI+) SCD minimum core dataset of standardized data elements to enable consistent, interoperable exchange of SCD information across clinical, public health, and research settings. It improves diagnosis accuracy, emergency care access, surveillance, and data liquidity via strengthening care coordination and outcomes for people living with SCD. For more information visit: healthit.gov

Populations Served

