Populations Served

	Individuals Living with Sickle Cell Disease		Caregivers		Healthcare Professionals		Health System Administration
	Community-Based Organizations		Researchers		Policymakers		State and Local Governments

Centers for Disease Control and Prevention (CDC)

The CDC supports the Sickle Cell Data Collection (SCDC) program which collects health information about people with SCD to assess the long-term trends in diagnosis, treatment, and healthcare access for people with SCD in the United States. For more information visit: cdc.gov/sickle-cell/scdc/index.html

Populations Served

Centers for Medicare & Medicaid Services (CMS)/Center for Medicare and Medicaid Innovation (CMMI)

The CMMI Cell and Gene Therapy (CGT) Access Model is a multi-year, voluntary model for states and manufacturers to test whether a CMS-led approach to developing and administering outcomes-based agreements for CGTs increases Medicaid beneficiaries' access to innovative treatment, improves their health outcomes, and reduces health care costs and burden to state Medicaid programs. The initial focus of the model is on SCD. For more information visit: cms.gov/priorities/innovation/innovation-models/cgt

Populations Served

Food and Drug Administration (FDA)

The FDA's Division of Nonmalignant Hematology (DNH), within the Center for Drug Evaluation and Research (CDER), regulates treatments for non-cancerous blood disorders, reviewing Investigational New Drug applications (INDs), New Drug Applications (NDAs), and Biologics License Applications (BLAs). In parallel, the Center for Biologics Evaluation and Research (CBER), through its Office of Therapeutic Products (OTP), oversees the review and approval of gene therapies for SCD. Since 2018, six disease-modifying SCD therapies have been approved — including gene therapies regulated by CBER/OTP — with multiple clinical trials ongoing. Together, DNH and CBER/OTP actively engage patients, clinicians, and industry to advance safe and effective treatments for this serious condition. For more information visit: fda.gov/about-fda/cder-offices-and-divisions/office-cardiology-hematology-endocrinology-and-nephrology-division-non-malignant-hematology-dnh

Populations Served

Health Resources & Services Administration (HRSA)

HRSA's Sickle Cell Disease Program increases access to quality, coordinated, comprehensive care for individuals with SCD by: 1) increasing the number of clinicians or health professionals knowledgeable about the care of SCD, 2) improving the quality of care provided to individuals with SCD, and 3) improving care coordination with other providers. For more information visit: mchb.hrsa.gov/programs-impact/programs/sickle-cell

Populations Served