SCD Data Sources Inventory: Field Descriptions
This inventory includes data sources that can be used to conduct health outcomes research on SCD. The fields in the inventory that describe the data sources are detailed below.
Data Source Name – This includes the name of the data source and the link to its main webpage, if available.
Data Source Type – This indicates where the source's data is drawn from, such as the electronic health record, surveys, vital records, discharge data, newborn screening data. Note: "Electronic health record" encompasses clinical, laboratory, and pharmacy data.
Timespan of Data – This provides the timespan of the dataset and if data collection is ongoing.
Data Steward / Funder – This identifies the lead/funder of the dataset.
Does the Source Include International Data? – This indicates whether the source includes data from outside of the U.S.
Geographic Coverage of the Data in the U.S. – This indicates whether the source includes data from single states, multiple states, or all states (national).
Is the Data Representative at Its Unit of Geographic Scope? – This indicates whether data is representative of the geographical unit specified in the "Geographic Coverage of the Data in the U.S." field.
Developed Specifically for SCD? – This indicates whether the data source was developed specifically for the population with SCD.
Data Accessibility – This provides information on whether the data is publicly accessible or restricted use, and additional information on how to access the data.
Periodicity of Data Collection – This indicates how often the data source collects data (e.g., quarterly, annually).
Example Variables Pertinent to SCD-Focused Health Outcomes Research – This provides information on the types of variables relevant to SCD available in the dataset.
Patient-Reported Outcomes Included? – This indicates whether patient-reported outcomes (PROs) are available within the data source.
If Yes, Description of Patient-Reported Outcomes – If PROs are available, this specifies the types of such outcomes available in the data source.
Publications Related to SCD Health Outcomes Research – This includes citations of example publications that leveraged the data source.

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
Registries														
1	Arkansas Sickle Cell Disease Registry	Electronic health record (EHR) data Survey data	2015-2017	State of Arkansas	No	State (Arkansas)	No	Yes	Restricted use - Data requests can be made to University of Arkansas for Medical Sciences Adult Sickle Cell Clinical Program	Not specified	**Sociodemographic characteristics** Educational level Employment status Gender Insurance type State of birth **Risk factors and biomarkers** Comorbidities Genotype Laboratory test results (blood panel, urinalysis) **Health outcomes** Patient-reported outcomes (PROs) (quality of life [QoL]) Reproductive health and fertility outcomes **Treatments and therapies** Pharmacological therapy	Yes	QoL	None found
2	Center for International Blood and Marrow Transplant Research (CIBMTR) Database	EHR data Survey data	2008-ongoing	Medical College of Wisconsin and National Marrow Donor Program (NMDP)	No	Multistate (All states and Washington, D.C., except for Alaska, Maine, Wyoming)	No	No	Public and restricted use - Data requests can be made to CIBMTR	Annually	**Sociodemographic characteristics** Age Sex **Risk factors and biomarkers** Laboratory test results (Human leukocyte antigen typing, infectious disease markers) **Health outcomes** Mortality (cause of death) Organ function (immune reconstitution, infection, new malignancy) Transplant outcomes (survival, neutrophil and platelet engraftment, acute and chronic graft-versus-host disease [GVHD], relapse) **Treatments and therapies** Gene therapy (cellular therapy)	No	N/A	Taylor MR, Cole SW, Strom J, et al. Unfavorable transcriptome profiles and social disadvantage in hematopoietic cell transplantation: a CIBMTR analysis. Blood Adv. 2023;7(22):6830-6838. doi:10.1182/bloodadvances.2023010746 Arnold SD, Brazauskas R, He N, et al. Clinical risks and healthcare utilization of hematopoietic cell transplantation for sickle cell disease in the USA using merged databases. Haematologica. 2017;102(11):1823-1832. doi:10.3324/haematol.2017.169581

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
3.	Get Connected Registry	Survey data	2015-ongoing	Sickle Cell Disease Association of America (SCDAA)	No	Multistate	No	Yes	Restricted use - Data requests can be made by registered users	Not specified	**Sociodemographic characteristics** Ethnicity Geographic location Race **Risk factors and biomarkers** Genotype **Health outcomes** Not specified **Treatments and therapies** Not specified	No	N/A	National Academies of Sciences, Engineering, and Medicine. Addressing sickle cell disease: a strategic plan and blueprint for action. 2020. Washington, DC: The National Academies Press. https://doi.org/10.17226/25632
4	Global Sickle Cell Disease Registry	Not specified	2023-ongoing	The Global Action Network for Sickle Cell & Other Inherited Blood Disorders (GANSID)	Yes	Multistate	No	Yes	Restricted use - No link/email address for data access available	Not specified	Not specified	Not specified	Not specified	None found
5	Globin Research Network for Data and Discovery (GRNDaD) Registry	EHR data Survey data	2015-ongoing	Doris Duke Charitable Foundation	No	Multistate	No	Yes	Restricted use - Data requests can be made to GANSID	Not specified	**Sociodemographic characteristics** Age Gender **Risk factors and biomarkers** Imaging results **Health outcomes** Healthcare utilization (hospital admissions) Pain (severity) PROs (QoL, fatigue, pain) **Treatments and therapies** Not specified	Yes	Fatigue Health-related quality of life (HRQoL) Pain	Lanzkron S, Manwani D, Desai P, Kanter J, Little J. GRNDaD: big data and sickle cell disease. Blood Adv. 2022;6(3):1088. doi:10.1182/bloodadvances.2021005282 Kenney MO, Wilson S, Shah N, et al. Biopsychosocial factors associated with pain and pain-related outcomes in adults and children with sickle cell disease: a multivariable analysis of the GRNDaD multicenter registry. J Pain. 2024;25(1):153-164. doi:10.1016/j.jpain.2023.07.029

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
6	In-Epic Real-Time Registry for Children with Sickle Cell Disease	EHR data	2017-ongoing	Medical College of Wisconsin	No	State (Wisconsin, but data only from the city of Milwaukee)	No	Yes	Restricted use - No link/email address for data access available	Quarterly	**Sociodemographic characteristics** Age **Risk factors and biomarkers** Genotype Imaging results (transcranial doppler ultrasound) **Health outcomes** Healthcare utilization (acute care utilization) **Treatments and therapies** Blood transfusionsPharmacological therapy (hydroxyurea, pain medications)	No	N/A	Singh A, Danda V, Van Swol L, Scott JP, Brandow AM, Panepinto JA. Recommendation to reality: Closing the transcranial Doppler screening gap for children with sickle cell anemia. Pediatr Blood Cancer. 2021;68(2):e28831. doi:10.1002/pbc.28831 Singh A, Danda V, Panepinto JA. Real-time electronic health registry improves care for children with sickle cell disease. Blood. 2019;134:4673. https://doi.org/10.1182/blood-2019-123780.
7	Louisiana Sickle Cell Disease Registry	Hospital/ outpatient discharge data Vital records Newborn screening data Insurance claims data	2022-ongoing	State of Louisiana	No	State (Louisiana)	Yes	Yes	Restricted use - Data requests can be made to OPH-Bureau of Family Health Data	Annually	**Sociodemographic characteristics** Age Parish Race Sex **Risk factors and biomarkers** Not specified **Health outcomes** Healthcare costs (Medicaid) Healthcare utilization (hospital admissions, emergency room visits) Mortality **Treatments and therapies** Not specified	No	N/A	None found

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
8	Pediatric COVID-19 US Registry	Survey data	2020-not specified	St. Jude's Children's Research Hospital	No	Multistate	No	No	Restricted use - Data requests can be made to PIDTRAN Coordinators	Not specified	**Sociodemographic characteristics** Age Ethnicity Race Sex State of residence **Risk factors and biomarkers** Comorbidities (co-pathogens) Disease severity Genotype Imaging results Laboratory test results (absolute lymphocyte count, absolute neutrophil count) **Health outcomes** Healthcare utilization (hospital stay length) Organ function **Treatments and therapies** Transplant regimens (stem cell transplantation, hematopoietic cell transplantation [HCT], solid organ transplantation)	No	N/A	Dain AS, Diorio C, Fisher BT, Hankins JS, Witmer CM, Boustany M, Burton M, Ferrolino J, Sadaf S, Ross HS, Maron G; Pediatric COVID-19 US Registry. Description of a national, multi-center registry of patients with sickle cell disease and SARS-CoV-2 infection: data from the Pediatric COVID-19 United States Registry. Pediatr Blood Cancer. 2024 Jun;71(6):e30909. doi: 10.1002/pbc.30909. Epub 2024 Mar 12. PMID: 38469996; PMCID: PMC11039375.
9	Retrospective Registry of Transplants to Cure Sickle Cell Disease	EHR data	1993-2016	Sickle Cell Transplant Advocacy & Research Alliance (STAR)	No	Multistate	No	Yes	Restricted use - No link/email address for data access available	Not specified	**Sociodemographic characteristics** Age Sex **Risk factors and biomarkers** Comorbidities Genotype Laboratory test results Imaging results **Health outcomes** Comorbidities Mortality Organ function **Treatments and therapies** Transplant regimens	No	N/A	Stenger E, Xiang Y, Wetzel M, et al. Long-term organ function after HCT for SCD: a report from the Sickle Cell Transplant Advocacy and Research Alliance. Transplant Cell Ther. 2023;29(1):47.e1-47.e10. doi:10.1016/j.jtct.2022.10.012 Meier ER, Abraham AA, Ngwube A, Janson IA, Guilcher GM, Horan J, Kasow KA. Hematopoietic stem cell transplant referral patterns for children with sickle cell disease vary among pediatric hematologist/oncologists' practice focus: A Sickle Cell Transplant Advocacy and Research Alliance (STAR) study. Pediatric Blood & Cancer. 2021 Mar;68(3):e28861.

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
10	Sickle Cell Disease Implementation Consortium	EHR data Survey data	2014-ongoing	National Heart, Lung, and Blood Institute (NHLBI)	No	Multistate (Alabama, Arizona, California, Colorado, Florida, Georgia, Indiana, New Jersey, Michigan, Minnesota, Missouri, North Carolina, Rhode Island, Tennessee, Texas, Wisconsin)	No	Yes	Restricted use - Data requests can be made by registered users	Annually	**Sociodemographic characteristics** Age Gender **Risk factors and biomarkers** Genotype Comorbidities **Health outcomes** Medication adherence Mental health outcomes (depression) Pain PROs (Barriers to medical care, medication adherence, pain, social/mental health) **Treatments and therapies** Blood transfusions Pharmacologic therapy (hydroxyurea use)	Yes	Barriers to medical care Medication adherence Pain Social and mental health	Njoku F, Pugh N, Brambilla D, et al. Mortality in adults with sickle cell disease: results from the sickle cell disease implementation consortium (SCDIC) registry. Am J Hematol. 2024;99(5):900-909. doi:10.1002/ajh.27279 Glassberg JA, Linton EA, Burson K, et al. Publication of data collection forms from NHLBI funded sickle cell disease implementation consortium (SCDIC) registry. Orphanet J Rare Dis. 2020;15(1):178. Published 2020 Jul 7. doi:10.1186/s13023-020-01457-x
11	Scientific Registry of Transplant Recipients (SRTR)	Insurance claims data Vital records Survey data	1987-ongoing	Health Resources and Services Administration (HRSA)	No	National	Yes	No	Restricted use – Data requests can be made to SRTR	Monthly	**Sociodemographic characteristics** Age Sex Race Ethnicity Distance to transplant center **Risk factors and biomarkers** Not specified **Health outcomes** Transplant outcomes (graft survival/failure) **Treatments and therapies** Not specified	No	N/A	Hogen R, Kim M, Lee Y, et al. Liver transplantation in patients with sickle cell disease in the United States. J Surg Res. 2020;255:23-32. doi:10.1016/j.jss.2020.05.015 Bae S, Johnson M, Massie AB, et al. Mortality and access to kidney transplantation in patients with sickle cell disease-associated kidney failure. Clin J Am Soc Nephrol. 2021;16(3):407-414. doi:10.2215/CJN.02720320

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
12	SCCRIP: Sickle Cell Clinical Research and Intervention Program	EHR data Survey data	2014-ongoing	St. Jude's Children's Research Hospital	No	Multistate (Illinois, North Carolina, Tennessee, but only for select cities within each state)	No	Yes	Restricted use - Data requests can be made to SCCRIP	Not specified	**Sociodemographic characteristics** Age Educational level Gender Income level Marital status Race **Risk factors and biomarkers** Imaging results (transcranial doppler ultrasound) Laboratory test results (complete blood counts, comprehensive metabolic panel, hemoglobin fractionation, urinalysis) **Health outcomes** PROs (HRQoL) **Treatments and therapies** Blood transfusions Gene therapy Pharmacological therapy	Yes	HRQoL	Estepp JH, Cong Z, Agodoa I, et al. What drives transcranial Doppler velocity improvement in paediatric sickle cell anaemia: analysis from the Sickle Cell Clinical Research and Intervention Program (SCCRIP) longitudinal cohort study. Br J Haematol. 2021;194(2):463-468. doi:10.1111/bjh.1762 Hankins JS, Estepp JH, Hodges JR, et al. Sickle Cell Clinical Research and Intervention Program (SCCRIP): a lifespan cohort study for sickle cell disease progression from the pediatric stage into adulthood. Pediatr Blood Cancer. 2018;65(9):e27228. doi:10.1002/pbc.27228

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
13	The Sickle Cell Transplantation Evaluation of Long-Term and Late Effects Registry (STELLAR)	EHR data Survey data	2019-2022	National Heart, Lung, and Blood Institute (NHLBI)	Yes	Multistate (Georgia, Maryland, Missouri, New York, North Carolina, Texas, Washington, D.C.)	No	Yes	Restricted use - No link/email address for data access available	Not specified	**Sociodemographic characteristics** Employment history Insurance School history **Risk factors and biomarkers** Alcohol/substance abuse Brain and nervous system health Laboratory test results (metabolic screening, urinalysis, complete blood counts) **Health outcomes** Healthcare costs (financial hardship) Pain (pain intensity, muscle stiffness) PROs Fatigue, HRQoL, mental health outcomes, sexual function) Reproductive health and fertility outcomes (sexual function) **Treatments and therapies** Transplant regimens (bone marrow transplant outcomes, HCT outcomes)	Yes	Bone Marrow Transplant Survivor Study (BMTSS) surveys Chronic GVHD (via symptom scale survey) Daily pain (via electronic pain diary) Economic impact of HCT (via financial hardship survey) Health status and practices, HRQoL (via Patient-Reported Outcomes Measurement Information System [PROMIS] Pediatric Profile-25 or Pediatric Profile-29 survey) Sexual function (via PROMIS Sexual Function SexFSv2.0 survey)	Krishnamurti L, Arnold SD, Haight A, et al. Sickle Cell Transplantation Evaluation of Long-term and Late Effects Registry (STELLAR) to compare long-term outcomes after hematopoietic cell transplantation to those in siblings without sickle cell disease and in nontransplanted individuals with sickle cell disease: design and feasibility study. JMIR Res Protoc. 2022;11(7):e36780. Published 2022 Jul 6. doi:10.2196/36780 Arnold SD, Bakshi N, Ross D, et al. Long-term quality of life after hematopoietic cell transplant for sickle cell disease in childhood: A STELLAR interim analysis. Am J Hematol. 2024;99(10):2037-2040. doi:10.1002/ajh.27436

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
14	South Carolina Sickle Cell Disease Registry	Not specified	2023-ongoing	South Carolina Department of Public Health	No	State (South Carolina)	Yes	Yes	Restricted use - No link/email address for data access available	Not specified	Not specified	Not specified	Not specified	None found
15	Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE)-SCD Registry	EHR data	2020-2022	Medical College of Wisconsin	No	Multistate	No	Yes	Restricted use - No link/email address for data access available	Weekly	**Sociodemographic characteristics** Age Geographic distribution Sex **Risk factors and biomarkers** Comorbidities Genotype **Health outcomes** Comorbidity progression Mortality Pain **Treatments and therapies** Blood transfusions Pharmacological therapy	No	N/A	Mucalo L, Brandow AM, Singh A. A perspective on the sickle cell disease international COVID-19 registry. Best Pract Res Clin Haematol. 2022;35(3):101385. doi:10.1016/j.beha.2022.101385
Surveys														
16	Consumer Assessment of Healthcare Providers and Systems (CAHPS)	Survey data	1995-ongoing	Agency for Healthcare Research and Quality (AHRQ)	No	National	Yes	No	Restricted use - Data requests can be made to AHRQ	Annually	**Sociodemographic characteristics** Age Educational attainment Ethnicity Race Sex **Risk factors and biomarkers** Not specified **Health outcomes** Not specified **Treatments and therapies** Not specified **Patient experience measures** Access to care Communication with clinicians Comprehensiveness of care Coordination of care Courtesy and respect Information use Timeliness of care	Yes	All survey responses are patient-reported	Cronin RM, Yang M, Hankins JS, et al. Association between hospital admissions and healthcare provider communication for individuals with sickle cell disease. Hematology. 2020;25(1):229-240. doi:10.1080/16078454.2020.1780737 Kanter J, Gibson R, Lawrence RH, et al. Perceptions of US adolescents and adults with sickle cell disease on their quality of care. JAMA Netw Open. 2020;3(5):e206016. Published 2020 May 1. doi:10.1001/jamanetworkopen.2020.6016

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
17	Medical Expenditure Panel Survey (MEPS)	Survey data	1996-ongoing	Agency for Healthcare Research and Quality (AHRQ)	No	National	Yes	No	Public	Annually	**Sociodemographic variables** Age Education Level Employment status Ethnicity Insurance status Race Sex **Risk factors and biomarkers** Comorbidities **Health outcomes** Comorbidity progression Cost PROs (QoL) **Treatments and therapies** Non-pharmacological therapies Pharmacological therapy	Yes	All survey responses are patient-reported	Ojo VN. Health costs of sickle cell disease patients from the Medical Expenditures Panel Survey, 1996–1997, 2002–2003, 2007–2008. University of Missouri-Kansas City; 2012. Johnson KM, Jiao B, Ramsey SD, Bender MA, Devine B, Basu A. Lifetime medical costs attributable to sickle cell disease among nonelderly individuals with commercial insurance. Blood Adv. 2023;7(3):365-374. doi:10.1182/bloodadvances.2021006281
18	National Health Interview Survey (NHIS)	Survey data	1957-ongoing	Centers for Disease Control and Prevention (CDC)	No	National	Yes	No	Public	Annually	**Sociodemographic characteristics** Education level Household income Insurance Race **Risk factors and biomarkers** Comorbidities (developmental conditions) **Health outcomes** Accessibility (barriers to healthcare) Health status Healthcare utilization (primary and urgent care) PROs (QoL, functional status, mental health outcomes) **Treatments and therapies** Not specified	Yes	All survey responses are patient-reported	Gyamfi J, Tampubolon S, Lee JT, et al. Characterisation of medical conditions of children with sickle cell disease in the USA: findings from the 2007-2018 National Health Interview Survey (NHIS). BMJ Open. 2023;13(2):e069075. Published 2023 Feb 28. doi:10.1136/bmjopen-2022-069075 Peprah E, Gyamfi J, Lee JT, et al. Analysis of the 2007-2018 National Health Interview Survey (NHIS): examining neurological complications among children with sickle cell disease in the United States. Int J Environ Res Public Health. 2023;20(12):6137. Published 2023 Jun 15. doi:10.3390/ijerph20126137

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
Administrative Data														
19	Ad-Hoc Sickle Cell Disease Provisional Death Counts 2019-2021	Insurance claims data Vital records	2019-2021	Centers for Disease Control and Prevention (CDC)	No	National	Yes	Yes	Public	Ad-hoc Dataset is not updated routinely, but can be updated upon request	**Sociodemographic characteristics** Age group Ethnicity Race **Risk factors and biomarkers** Not specified **Health outcomes** Mortality (deaths with SCD listed as underlying cause of death, deaths with SCD listed as underlying or contributing cause of death, deaths with SCD and COVID-19) **Treatments and therapies** Not specified	No	N/A	None found
20	California Newborn Screening Disorders Dataset	Insurance claims data Vital records	2009-ongoing	State of California	No	State (California)	Yes	No	Public	Not specified	**Sociodemographic characteristics** County Race/ethnicity Region **Risk factors and biomarkers** Genotype **Health outcomes** Not specified **Treatments and therapies** Not specified	No	N/A	Snyder AB, Lakshmanan S, Hulihan MM, et al. Surveillance for sickle cell disease — Sickle Cell Data Collection Program, two states, 2004–2018. MMWR Surveill Summ 2022;71(No. SS-9):1–18. DOI: http://dx.doi.org/10.15585/mmwr.ss7109a1 Michlitsch J, Azimi M, Hoppe C, et al. Newborn screening for hemoglobinopathies in California. Pediatr Blood Cancer. 2009;52(4):486-490. doi:10.1002/pbc.21883

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
21	IBM MarketScan Multi-State Medicaid Database (MDCD)	Insurance claims data Hospital/ outpatient discharge data	1995-ongoing	IBM	No	National	No	No	Restricted use - Data requests can be made by registered users	Annually	**Sociodemographic characteristics** Age Ethnicity Gender Insurance Race **Risk factors and biomarkers** Not specified **Health outcomes** Healthcare costs Healthcare utilization (hospital admissions, emergency room visits) Mortality **Treatment and therapies** Pharmacological therapy	No	N/A	Schieve LA, Simmons GM, Payne AB, et al. Use of recommended health care measures to prevent selected complications of sickle cell anemia in children and adolescents — selected U.S. States, 2019. MMWR Morb Mortal Wkly Rep 2022;71:1241–1246. DOI: http://dx.doi.org/10.15585/mmwr.mm7139e1. Reeves SL, Ng S, Dombkowski KJ, Raphael JL, Chua KP. TCD screening and spending among children with sickle cell anemia. Am J Manag Care. 2023;29(3):e79-e84. Published 2023 Mar 1. doi:10.37765/ajmc.2023.89333
22	Medicare Part A, B, and D Data	Insurance claims data Hospital/ outpatient discharge data Pharmacy data	Medicare Part A & B: 1999-ongoing Medicare Part D: 2005-ongoing	Centers for Medicare & Medicaid Services (CMS)	No	National	Yes	No	Restricted use - Data requests can be made to CMS	Monthly	**Sociodemographic characteristics** Age Ethnicity Gender Insurance coverage Race **Risk factors and biomarkers** Not specified **Health outcomes** Healthcare utilization (outpatient medical services use, hospital stays) **Treatments and therapies** Pharmacological therapy	No	N/A	Agarwal S, Stanek JR, Vesely SK, et al. Pregnancy-related thromboembolism in women with sickle cell disease: an analysis of national Medicaid data. Am J Hematol. 2023;98(11):1677-1684. doi:10.1002/ajh.27045 Jiao B, Johnson KM, Ramsey SD, Bender MA, Devine B, Basu A. Long-term survival with sickle cell disease: a nationwide cohort study of Medicare and Medicaid beneficiaries. Blood Adv. 2023;7(13):3276-3283. doi:10.1182/bloodadvances.2022009202

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
23	Medicare Part C Data	Insurance claims data Hospital/ outpatient discharge data	2015-ongoing	Centers for Medicare & Medicaid Services (CMS)	No	National	Yes	No	Restricted use - Data requests can be made to CMS	Monthly	**Sociodemographic characteristics** Age Gender Ethnicity Insurance coverage Race **Risk factors and biomarkers** Not specified **Health outcomes** Healthcare utilization (healthcare encounters, inpatient care) **Treatments and therapies** Not specified	No	N/A	Mikosz CA, Zhang K, Haegerich T, et al. Indication-specific opioid prescribing for US patients with Medicaid or private insurance, 2017. JAMA Netw Open. 2020;3(5):e204514. Published 2020 May 1. doi:10.1001/jamanetworkopen.2020.4514
24	National Inpatient Sample	Hospital/ outpatient discharge data	1988-ongoing	Agency for Healthcare Research and Quality (AHRQ)	No	National	Yes	No	Restricted use - Data requests can be made to AHRQ	Quarterly	**Sociodemographic characteristics** Age Median household income for ZIP code Race Sex **Risk factors and biomarkers** Comorbidities Disease severity Genotype **Health outcomes** Healthcare costs (total charges) Healthcare utilization (hospital discharge status, length of hospital stay) **Treatments and therapies** Not specified	No	N/A	Cintron-Garcia J, Ajebo G, Kota V, Guddati AK. Mortality trends in sickle cell patients. Am J Blood Res. 2020;10(5):190-197. Published 2020 Oct 15. Nwogu-Onyemkpa E, Dongarwar D, Salihu HM, et al. Inpatient palliative care use by patients with sickle cell disease: a retrospective cross-sectional study. BMJ Open. 2022;12(8):e057361. Published 2022 Aug 16. doi:10.1136/bmjopen-2021-057361

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
25	Sickle Cell Data Collection Program Data	EHR data Vital records	2016-ongoing	CDC Foundation	No	Multistate (California, Georgia, Illinois, Maryland, Missouri, New York, North Carolina, Tennessee, South Carolina)	Yes	Yes	Public	Not specified	**Sociodemographic characteristics** Age County Ethnicity Insurance Race Sex **Risk factors and biomarkers** Newborn screening diagnosis **Health outcomes** Healthcare utilization (hospital admissions, emergency visits) Mortality (age at death) **Treatments and therapies** Not specified	No	N/A	Snyder AB, Lakshmanan S, Hulihan MM, et al. Surveillance for sickle cell disease - Sickle Cell Data Collection Program, two states, 2004-2018. MMWR Surveill Summ. 2022;71(9):1-18. Published 2022 Oct 7. doi:10.15585/mmwr.ss7109a1 Kayle M, Blewer AL, Pan W, et al. Birth prevalence of sickle cell disease and county-level social vulnerability - Sickle Cell Data Collection Program, 11 states, 2016-2020. MMWR Morb Mortal Wkly Rep. 2024;73(12):248-254. Published 2024 Mar 28. doi:10.15585/mmwr.mm7312a1
26	Transformed Medicaid Statistical Information System (T-MSIS)	Insurance claims data Hospital/ outpatient discharge data Pharmacy data	1999-ongoing	Centers for Medicare & Medicaid Services (CMS)	No	National	Yes	No	Restricted use - Data requests can be made to CMS	Monthly	**Sociodemographic characteristics** Age Ethnicity Geographic location Income Race **Risk factors and biomarkers** Not specified **Health outcomes** Healthcare costs Healthcare utilization **Treatments and therapies** Pharmacological therapy	No	N/A	Speller J, Rayel S, Hayashi K, et al. The highest-cost Medicaid enrollees with sickle cell disease had annual health care expenditures nearing $200 000. Health Aff Sch. 2024;2(4):qxae029. Published 2024 Mar 11. doi:10.1093/haschl/qxae029

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
Health Information Exchange (HIE) Organizations														
27	Chesapeake Regional Information System for our Patients (CRISP)	EHR data	2009-ongoing	Maryland Health Care Commission (MHCC)	No	State (Maryland)	Yes	No	Restricted use - Available to MD-based practices	Quarterly	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Genotype Imaging results Laboratory test results **Health outcomes** Healthcare utilization **Treatments and therapies** Non-pharmacological therapies Pharmacological therapy	No	N/A	None found
28	Indiana Network for Patient Care Research Database (INPCR)	EHR data	2004-ongoing	Indiana Health Information Exchange (IHIE)	No	State (Indiana)	Yes	No	Restricted use - Data requests can be made to Regenstrief Data Services	Not specified	**Sociodemographic characteristics** Not specified **Risk factors and biomarkers** Comorbidities Genotype Laboratory test results **Health outcomes** Comorbidity progression Medication adherence Mortality Organ function Reproductive health and fertility outcomes Transplant outcomes **Treatments and therapies** Blood transfusions Gene therapies Pharmacological therapy Transplant regimens	No	N/A	None found

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
29	PA Patient & Provider Network (P3N)	EHR data	2012-ongoing	Pennsylvania eHealth Partnership	No	State (Pennsylvania)	Yes	No	Restricted use - Available to PA-based practices	Not specified	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Genotype Imaging results Laboratory test results **Health outcomes** Healthcare utilization **Treatments and therapies** Non-pharmacological therapies Pharmacological therapy	No	N/A	None found
Other														
30	American Thrombosis and Hemostasis Network Dataset	EHR data	Not specified	American Thrombosis and Hemostasis Network (ATHN)	No	Multistate	No	No	Restricted use - Data requests can be made to ATHN	Not specified	**Sociodemographic characteristics** Age Education Level Employment Level Ethnicity Gender Race Sex **Risk factors and biomarkers** Comorbidities Imaging results Laboratory test results **Health outcomes** Comorbidity progression Healthcare utilization Mortality **Treatments and therapies** Gene therapy Non-pharmacological therapies Pharmacological therapy Transplant regimens	No	N/A	None found

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
31	ASH Research Collaborative® Data Hub	Insurance claims data EHR data Survey data	2015-ongoing	American Society of Hematology (ASH)	No	Multistate (Alabama, Arkansas, Connecticut, Florida, Illinois Iowa, Kansas, Louisiana, Massachusetts Maryland, Michigan, Missouri, Nebraska, New Jersey, New York, North Carolina, Ohio, Pennsylvania, Rhode Island, Texas, Virginia, Washington, D.C., Wisconsin)	No	Yes	Restricted use - Data requests can be made to ASH Research Collaborative Dashboard with aggregated summary data available	Quarterly	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Comorbidities Genotype Disease severity Environmental exposures Laboratory test results Pregnancy status **Health outcomes** Healthcare utilization (number of inpatient encounters, number of emergency room encounters, number of emergency room encounters) PROs **Treatments and therapies** Pharmacological therapy	Yes	Not specified	Wood WA, Marks P, Plovnick RM, et al. ASH Research Collaborative: a real-world data infrastructure to support real-world evidence development and learning healthcare systems in hematology. Blood Adv. 2021;5(23):5429-5438. doi:10.1182/bloodadvances.2021005902 Anderson AR, Strouse JJ, Manwani D, et al. COVID-19 mRNA vaccination responses in individuals with sickle cell disease: an ASH RC Sickle Cell Research Network Study. Blood Adv. 2024;8(17):4549-4553. doi:10.1182/bloodadvances.2024013878 ASH Research Collaborative. SCD data hub report 2025. Washington, DC: ASH Research Collaborative; 2025. Available from: https://www.ashresearchcollaborative.org/wp-content/uploads/2025/06/SCD-Data-Hub-Report-2025.pdf
32	Biologic and Data Repositories Information Coordinating Center (BioLINCC)	Based on study protocol	2008-ongoing	National Heart, Lung, and Blood Institute (NHLBI)	Based on study protocol	Based on study protocol	Based on study protocol	No	Public - Data requests can be made to BioLINCC	Based on study protocol	**Sociodemographic characteristics** Age Sex **Risk factors and biomarkers** Comorbidities Genotype Imaging results Laboratory test results **Health outcomes** Comorbidity progression Mortality Organ function **Treatments and therapies** Transplant regimens	Yes	Variable based on study	Nawaiseh M, Shaban A, Abualia M, Haddadin R, Nawaiseh Y, AlRyalat SA, Yassin A, Sultan I. Seizures risk factors in sickle cell disease. The cooperative study of sickle cell disease. Seizure 2021 Jul;89:107-113. Epub 2021 May 15. AlRyalat SA, Jaber BAM, Alzarea AA, Alzarea AA, Alosaimi WA, Al Saad M. Ocular manifestations of sickle cell disease in different genotypes. Ophthalmic Epidemiol 2021 Jun;28(3):185-190. Epub 2020 Aug 6.

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
33	Cooperative Study of Sickle Cell Disease	Laboratory results	1977-1995	National Heart, Lung, and Blood Institute (NHLBI)	No	Multistate (California, Connecticut, Georgia, Florida, Illinois, Massachusetts, Mississippi, Missouri, New York, North Carolina, Pennsylvania, Tennessee, Washington, D.C., but only for select cities within each state)	No	Yes	Public - Data requests can be made to BioData Catalyst	Not specified	**Sociodemographic characteristics** Age Sex **Risk factors and biomarkers** Genotype Psychological risk factors **Health outcomes** Comorbidity progression Healthcare utilization Organ function Pain **Treatments and therapies** Blood transfusions Non-pharmacological therapies Pharmacological therapy	No	N/A	Nawaiseh M, Roto A, Nawaiseh Y, et al. Risk factors associated with sickle cell retinopathy: findings from the Cooperative Study of Sickle Cell Disease. Int J Retina Vitreous. 2022;8(1):68. Published 2022 Sep 22. doi:10.1186/s40942-022-00419-8 Nawaiseh M, Shaban A, Abualia M, et al. Seizures risk factors in sickle cell disease. The cooperative study of sickle cell disease [published correction appears in Seizure. 2021 Oct;91:521-523. doi: 10.1016/j.seizure.2021.07.016.] Seizure. 2021;89:107-113. doi:10.1016/j.seizure.2021.05.009

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
34	Cure Sickle Cell Initiative (CureSCI) Metadata Catalog	Based on study protocol	Not specified	National Heart, Lung, and Blood Institute (NHLBI)	Based on study protocol	Based on study protocol	Based on study protocol	Yes	Public and restricted use - Data requests can be made to CureSCI	Based on study protocol	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Comorbidities (clinical status, medical events) Environmental risk factors Genotype Imaging results Laboratory test results Psychological risk factors (mental health, neurodevelopmental, neuropsychological) **Health outcomes** Accessibility (technology support) Healthcare utilization (hospitalization, acute care utilization) Mortality PROs (QoL, pain, functioning, quality of care, sleep) **Treatments and therapies** Blood transfusions Gene therapy Non-pharmacological therapies Pharmacological therapy Transplant regimens	Yes	Mental health euro-development Neuro-psychological Pain Psychosocial Physical function Quality of care Sleep Technology support	Pan H, Ives C, Mandal M, et al. CureSCi Metadata Catalog-making sickle cell studies findable. PLoS One. 2022;17(12):e0256248. Published 2022 Dec 12. doi:10.1371/journal.pone.0256248 Wu X, Stratford J, Kesler K, et al. CureSCi Metadata Catalog-finding and harmonizing studies for secondary analysis of hydroxyurea discontinuation in sickle cell disease. PLoS One. 2025;20(4):e0309572. Published 2025 Apr 23. doi:10.1371/journal.pone.0309572

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
35	The Database of Genotypes and Phenotypes (dbGaP)	Based on study protocol	Not specified	National Center for Biotechnology Information (NCBI)	Based on study protocol	Based on study protocol	Based on study protocol	No	Public and restricted use - Data requests can be made to the appropriate NIH Data Access Committee (DAC)	Based on study protocol	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Comorbidities Genotype Imaging results Laboratory test results **Health outcomes** Organ function Mortality PROs **Treatments and therapies** Not specified	Yes	Variable based on study	Lê BM, Hatch D, Yang Q, et al. Characterizing epigenetic aging in an adult sickle cell disease cohort. Blood Adv. 2024;8(1):47-55. doi:10.1182/bloodadvances.2023011188
36	Dissemination and Implementation of Stroke Prevention Looking at the Care Environment (DISPLACE) Study	EHR data	2012-2016	National Heart, Lung, and Blood Institute (NHLBI)	No	Multistate	Yes	Yes	Restricted use - No link/email address for data access available	Based on study protocol	**Sociodemographic characteristics** Not specified **Risk factors and biomarkers** Comorbidities Genotype Imaging results Laboratory test results **Health outcomes** Mortality Organ function **Treatments and therapies** Pharmacological therapy	No	N/A	Davidow KA, Miller RE, Phillips SM, Schlenz AM, Mueller M, Hulbert ML, Hsu LL, Bhasin N, Adams RJ, Kanter J. DISPLACE study shows poor quality of transcranial doppler ultrasound for stroke risk screening in sickle cell anemia. Blood advances. 2024 Jul 9;8(13):3444-52. Kanter J, Phillips S, Schlenz AM, Mueller M, Dooley M, Sirline L, Nickel R, Brown RC, Hilliard L, Melvin CL, Adams RJ. Transcranial Doppler screening in a current cohort of children with sickle cell anemia: results from the DISPLACE study. Journal of pediatric hematology/oncology. 2021 Nov 1;43(8):e1062-8.

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
37	Hydroxyurea to Prevent Organ Damage in Children with Sickle Cell Anemia (BABY HUG) Clinical Trial	EHR data	2000-2016	National Heart, Lung, and Blood Institute (NHLBI)	No	Multistate (Alabama, Florida, Georgia, Maryland, Michigan, Mississippi, New York, North Carolina, Pennsylvania, South Carolina, Tennessee, Texas, Washington, D.C.)	No	Yes	Public - Data requests can be made to BioLINCC	Based on study protocol	**Sociodemographic characteristics** Not specified **Risk factors and biomarkers** Comorbidities Genotype Imaging results Laboratory test results **Health outcomes** Comorbidity progression Mortality Organ function Pain Transplant outcomes **Treatments and therapies** Blood transfusions Transplant regimens	No	N/A	Alvarez O, Miller ST, Wang WC, Luo Z, McCarville MB, Schwartz GJ, Thompson B, Howard T, Iyer RV, Rana SR, Rogers ZR. Effect of hydroxyurea treatment on renal function parameters: results from the multi-center placebo-controlled BABY HUG clinical trial for infants with sickle cell anemia. Pediatric blood & cancer. 2012 Oct;59(4):668-74. Wang WC, Ware RE, Miller ST, Iyer RV, Casella JF, Minniti CP, Rana S, Thornburg CD, Rogers ZR, Kalpatthi RV, Barredo JC. Hydroxycarbamide in very young children with sickle-cell anaemia: a multicentre, randomised, controlled trial (BABY HUG). The Lancet. 2011 May 14;377(9778):1663-72.
38	NHLBI BioData Catalyst	Based on study protocol	2018-ongoing	National Heart, Lung, and Blood Institute (NHLBI)	Based on study protocol	Based on study protocol	Based on study protocol	No	Public - Data requests can be made to BioData Catalyst	Based on study protocol	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Comorbidities Genotype Imaging results Laboratory test results **Health outcomes** Mortality Organ function PROs **Treatments and therapies** Not specified	Yes	Variable based on study	Martin AS, Hebert K, Serret-Larmande A, Jouhet V, Hughes E, Stedman JP, DeSain T, Pillon D, Carpenter JL, Steinert P, Avillach P. Long-term survival and late death after hematopoietic cell transplant for patients with sickle cell disease surviving for at least two-years after transplantation. Blood. 2021 Nov 23;138:410.

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
39	OneFlorida Data Trust	Insurance claims data EHR data	2013-ongoing	University of Florida (UF), UF Health, and Patient-Centered Outcomes Research Institute (PCORI)	No	Multistate (Alabama, Florida, Georgia, but only for select cities within each state)	No	No	Restricted use - Data requests can be made to OneFlorida+ Clinical Research Network	Not specified	**Sociodemographic characteristics** Age Gender Insurance Race **Risk factors and biomarkers** Genotype Imaging results (radiologic assessments) Laboratory test results **Health outcomes** Healthcare utilization (acute care access) **Treatments and therapies** Pharmacological therapy (medications, prescription refill information)	No	N/A	Hogan WR, Shenkman EA, Robinson T, et al. The OneFlorida Data Trust: a centralized, translational research data infrastructure of statewide scope. J Am Med Inform Assoc. 2022;29(4):686-693. doi:10.1093/jamia/ocab221 Mainous AG 3rd, Rooks B, Tanner RJ, Carek PJ, Black V, Coates TD. Shared care for adults with sickle cell disease: an analysis of care from eight health systems. J Clin Med. 2019;8(8):1154. Published 2019 Aug 2. doi:10.3390/jcm8081154
40	Recipient Epidemiology and Donor Evaluation Study (REDS) Program	EHR data	1989-ongoing	National Heart, Lung, and Blood Institute (NHLBI)	No	Multistate (California, Connecticut, Massachusetts, Rhode Island, Wisconsin)	No	No	Public - Data requests can be made to BioLINCC	Not specified	**Sociodemographic variables** Age Ethnicity Race Sex **Risk factors and biomarkers** Laboratory test results **Health outcomes** Mortality **Treatments and therapies** Blood transfusions	No	N/A	Malta B, Cintho Ozahata M, Gomes Moura IC, et al. Clinics and genetics of hyperhemolysis syndrome in patients with sickle cell disease. Transfusion. Published online April 2, 2025. doi:10.1111/trf.18232 Josephson CD, Glynn S, Mathew S, et al. The Recipient Epidemiology and Donor Evaluation Study-IV-Pediatric (REDS-IV-P): a research program striving to improve blood donor safety and optimize transfusion outcomes across the lifespan. Transfusion. 2022;62(5):982-999. doi:10.1111/trf.16869

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
41	Science, Technology and Research partnership (STAR) Clinical Research Network (CRN) Data	Insurance claims data EHR data Survey data	2015-ongoing	Vanderbilt University Medical Center (VUMC) and Patient-Centered Outcomes Research Institute (PCORI)	No	Multistate (Arizona, California, Florida, Minnesota, North Carolina, North Dakota, South Carolina, Tennessee, Wisconsin)	No	No	Restricted use - Data requests can be made to STAR CRN	Quarterly	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Genotype Imaging results **Health outcomes** Healthcare utilization (hospital admissions, emergency room visits) **Treatments and therapies** Pharmacological therapy	Yes	Depressive symptoms Difficulty paying bills Hospital admissions Missed clinic appointments Spirituality	None found
42	Silent Cerebral Infarct Multi-Center Clinical Trial (SIT)	EHR data Survey data	2004-2013	National Institute of Neurological Disorders and Stroke (NINDS)	Yes	Multistate	No	Yes	Restricted use - No link/email address for data access available	Based on study protocol	**Sociodemographic characteristics** Not specified **Risk factors and biomarkers** Comorbidities Genotype Imaging results Psychological risk factors **Health outcomes** Comorbidity progression Mortality PROs (HRQoL) **Treatments and therapies** Blood transfusions	Yes	HRQoL Utility Assessment	Kawadler JM, Clark CA, McKinstry RC, Kirkham FJ. Brain atrophy in paediatric sickle cell anaemia: findings from the silent infarct transfusion (SIT) trial. British Journal of Haematology. 2017 Apr 1;177(1):151-3. Beverung LM, Strouse JJ, Hulbert ML, Neville K, Liem RI, Inusa B, Fuh B, King A, Meier ER, Casella J, DeBaun MR. Health-related quality of life in children with sickle cell anemia: impact of blood transfusion therapy. American journal of hematology. 2015 Feb;90(2):139-43.

Sr. No.	Data Source Name	Data Source Type	Timespan of Data	Data Steward / Funder	Does the Source Include International Data?	Geographic Coverage of the Data in the U.S.	Is the Data Representative at Its Unit of Geographic Scope?	Developed Specifically for SCD?	Data Accessibility	Periodicity of Data Collection	Example Variables Pertinent to SCD-Focused Health Outcomes Research	Patient-Reported Outcomes Included?	If Yes, Description of Patient-Reported Outcomes	Publications Related to SCD Health Outcomes Research
43	Trans-Omics for Precision Medicine (TOPMed)	Based on study protocol	Not specified	National Heart, Lung, and Blood Institute (NHLBI)	Based on study protocol	Based on study protocol	Based on study protocol	No	Public - Data requests can be made to BioData Catalyst	Based on study protocol	**Sociodemographic characteristics** Age Ethnicity Race Sex **Risk factors and biomarkers** Genotype Imaging results Laboratory test results **Health outcomes** Mortality PROs **Treatments and therapies** Not specified	Yes	Variable based on study	Cintho Ozahata M, Guo Y, Gomes I, et al. Genetic variants associated with white blood cell count amongst individuals with sickle cell disease. Br J Haematol. 2024;205(5):1974-1984. doi:10.1111/bjh.19758 Liggett LA, Cato LD, Weinstock JS, et al. Clonal hematopoiesis in sickle cell disease. J Clin Invest. 2022;132(4):e156060. doi:10.1172/JCI156060