

coreSCD Outcomes with Definitions

OUTCOME	DEFINITION
Acute sickle cell pain- frequency	How often the pain is experienced in a given time period. Acute sickle cell pain is pain directly related to sickle cell disease that is usually associated with vaso-occlusive crisis and may or may not result in an individual seeking medical care.
Stroke or cerebrovascular accident (CVA)	A traumatic complication of sickle cell disease, including ischemic and hemorrhagic stroke that is associated with intimal disease of the large cerebral arteries.
Acute chest syndrome (ACS)	A vaso-occlusive crisis of the pulmonary vasculature commonly seen in people with sickle cell anemia. This may include ACS incidence, ACS severity, ACS relapse rate, ACS duration.
Neurocognitive function	Cognitive functions associated with specific pathways or loci within the brain that are affected by different disease processes. Neurocognitive functions can be assessed by standard tests such as the Mini-Mental State Examination (MMSE) and the Montreal Cognitive Assessment (MoCA).
Health-related quality of life (HRQOL)	Patient's perception of the effect of their illness and its treatment on general well-being. HRQOL assessment for SCD should include measures of physical, social, and emotional functioning. Pain interference and fatigue should also be measured as part of HRQOL in SCD.
Ability to return to usual activities	Ability to carry out various activities such as going to work, doing housework, attending school, driving, shopping, etc.
Frequency of hospitalization	The number of admissions for a patient in a facility over a specified time period.
ED/acute care visit	The number of visits to the emergency department and/or SCD acute care center, where patients can receive timely treatment for urgent or extreme medical conditions.
Need for blood transfusion	This may include the number of transfusions, total units of transfusion, number of patients receiving transfusion.
Cause-specific survival/mortality	Impacts on survival/mortality caused by specific factors.
Event-free survival	The length of time after primary treatment for SCD ends that an individual remains alive and free of SCD symptoms.