

SickleInAfrica Core Data Elements

Please complete the survey below.

Thank you!

Consent

Has the patient consented? (SCDO:1000512)

- Yes
 No
 Refused
 Don't Know

Type(s) of informed consent obtained (SCDO:1000520)

- Study Enrollment Consent
 Specimen Storage Consent
 Genetic Material Storage Consent
 Broad Consent

Date subject signed consent (dd/mm/yyyy)
(SCDO:1000532)

Consented by: (SCDO:1000533)

(Who managed the consent process?)

Demographics

Visit date (dd/mm/yyyy) (SCDO:1000539)

Type of visit (SCDO:1000847)

- Routine
 Acute
 Review
 First visit

Site participant number (SCDO:1000542)

(Site-specific ID eg. GH20181234 for Ghana,
NG20184321 for Nigeria or TZ20180001 for Tanzania)

Medical record number (MRN) (SCDO:1000850)

Hospital name (SCDO:1000854)

First name (SCDO:1000856)

Middle Name (SCDO:1000857)

Last name (SCDO_1000862)

Date of birth (dd/mm/yyyy) (SCDO:1000543)

Calculated age (in months) (SCDO:1000734)

(Age on day of visit)

Self-reported age (in years) (SCDO:1000547)

(Age on day of visit)

Height/Length (SCDO:1000863)

(cm)

Weight (SCDO:1000866)

(kg)

Respondent's sex (SCDO:1000551)

- Male
- Female
- Intersex
- Refused

Current marital status (SCDO:1000548)

- Married
- Co-habiting
- Widowed
- Divorced
- Separated
- Never been married/Annulled

Ethnic group (SCDO:1000868)

Religion (SCDO:1000869)

Region (SCDO:1000870)

Street (SCDO:1000872)

Nearest landmark (SCDO:1000873)

Telephone 1 (SCDO:1000876)

Telephone 2 (SCDO:1000877)

Next of kin name (SCDO:1000878)

Next of kin telephone number (SCDO:1000879)

Relationship to participant (SCDO:1000880)

SCD Diagnosis Details

Is date of SCD diagnosis known? (SCDO:1000552) Yes
 No

Date of SCD diagnosis (dd/mm/yyyy) (SCDO:1000558)

SCD test result (SCDO:1000573) SS SBThal SC
 AS Other
(SS = Sickle Cell Disease-SS | SBThal = Sickle Beta
Thalassemia | SC = Sickle Cell Disease-SC | AS =
Sickle Cell Trait)

If other SCD test result, please specify:
(SCDO:1000578)

If other test, please specify: (SCDO:1000550)

ABO blood group (SCDO:1000579) A+
 A-
 B+
 B-
 O+
 O-
 AB+
 AB-

Type of test? (SCDO:1000575) HPLC
 HBE
 IEF
 Basique
 Acide
 Sickle SCAN rapid test
 Other
(HPLC = High-Performance Liquid Chromatography|
HBE = Hemoglobin Electrophoresis | IEF =
Isoelectric Focusing| Basique = Basique SCD Test |
Acide = Acide SCD Test)

Management Details

Using hydroxyurea (SCDO:1000591) Yes No

Date of initiation of hydroxyurea therapy (dd/mm/yyyy)
(SCDO:1000593)

Using penicillin V (prophylaxis) (SCDO:1000595) Yes No NA

Using malaria chemoprophylaxis (SCDO:1000600) Yes No NA
(Is any medication currently being taken to prevent
malaria infection?)

Using folic acid (SCDO:1000597) Yes No

Pneumococcal vaccination up to date (SCDO:1000601) Yes No

Blood transfusion (SCDO:1000886)

- Yes
 No
-

Date of blood transfusion (SCDO:1000549)

Units transfused (SCDO:1000887)

Vital Signs

Patient's body temperature (SCDO:1000711)

(degrees Celsius)

Type of body temperature taken (SCDO:1000759)

- Oral Temperature
 Tympanic (ear) Temperature
 Axillary (armpit) Temperature
 Rectal Temperature
-

Patient's respiratory rate (SCDO:1000714)

(breaths per minute)

Difficulty in breathing (SCDO:1000889)

- Yes
 No
-

Systolic blood pressure (SCDO:1000890)

(mmHg)

Diastolic blood pressure (SCDO:1000891)

(mmHg)

Priapism (SCDO:1000894)

- Yes
 No
-

Chest pain (SCDO:1000895)

- Yes
 No
-

Anaemia (SCDO:1000896)

- Yes
 No
-

Jaundice (SCDO:1000897)

- Yes
 No

Laboratory Results: Complete Blood Count (PhenX protocol PX220501 unless stated otherwise)

Red blood cell count (RBC) (SCDO:1000607)

(million cells/ μ L)

White blood cell count (WBC) (SCDO:1000611)

(1000 cells/ μ L)

Platelet count (SCDO:1000615)

(1000 cells/ μ L)

Hemoglobin (SCDO:1000619)

(g/dL)

Mean cell volume (MCV) (SCDO:1000621)

(fL)

Mean cell hemoglobin (MCH) (SCDO:1000627)

(pg)Mean cell hemoglobin concentration (MCHC)
(SCDO:1000630)

(g/dL)

Red cell distribution width (RDW) (SCDO:1000637)

(%)**Kidney Function Assay (Phenx protocols PX141401, PX141501 and PX141601 unless stated otherwise)**

Serum creatinine concentration (SCDO:1000645)

(mg/dL; PX141401)

Urea (SCDO:1000898)

(mmol/L)

Urinary albumin concentration (SCDO:1000510)

(μ g/mL; PX141501)

Urinary creatinine concentration (SCDO:1000650)

(mg/dL; PX141601)

Liver Function Assay (PhenX protocol PX190801 unless stated otherwise)

Alanine aminotransferase level (SCDO:1000657)

(IU/L)

Aspartate aminotransferase level (SCDO:1000660)

(IU/L)

Alkaline phosphatase level (SCDO:1000662)

(IU/L)**Laboratory Results: Bilirubin Level (PhenX protocol PX0810901 unless stated otherwise)**

Total bilirubin concentration (SCDO:1000680)

(mg/dL)**Laboratory Results: Lactate Dehydrogenase Level (PhenX protocol PX0811001 unless stated otherwise)**

Lactate dehydrogenase level (SCDO:1000682)

(IU/L)**Laboratory Results: Reticulocyte Count (PhenX protocol PX0810601 unless stated otherwise)**

Number of reticulocytes (SCDO:1000685)

(1000 cells/ μ L)**Laboratory Results: Hemoglobin Characterisation (PhenX protocol PX0830301 unless stated otherwise)**For which hemoglobins were assay results recorded? (SCDO:1000687)
(Select all relevant options)

- Hb A Hb F Hb S Hb C Hb E Hb A2 Hb D-Punjab Hb G-Philadelphia
 Hb O-Arab

Record the levels of Hb A if measured. (SCDO:1000691)

(%)

Record the levels of Hb F if measured. (SCDO:1000706)

(%)

Record the levels of Hb S if measured. (SCDO:1000693)

(%)

Record the levels of Hb C if measured. (SCDO:1000694)

(%)

Record the levels of Hb E if measured. (SCDO:1000696)

(%)

Record the levels of Hb A2 if measured. (SCDO:1000699)

(%)

Record the levels of Hb D-Punjab if measured.
(SCDO:1000700)

(%)

Record the levels of Hb G-Philadelphia if measured.
(SCDO:1000702)

(%)

Record the levels of Hb O-Arab if measured.
(SCDO:1000704)

(%)

Total hemoglobin (Hbtotal) (SCDO:1000751)

(g/dL)

Arterial blood gas - ABG (PhenX protocol PX090201 unless stated otherwise)

Partial pressure of carbon dioxide (PaCO₂)
(SCDO:1000717)

(mmHg)

Partial pressure of oxygen (PaO₂) (SCDO:1000722)

(mmHg)

Oxyhemoglobin saturation (HbO₂) (SCDO:1000724)

(%)

Carboxyhemoglobin (COHb) (SCDO:1000725)

(%)

Methemoglobin (MetHb) (SCDO:1000726)

(%)