

# Sickle In Africa Core Data elements

Research Subject ID Research ID

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## Consent

Has the patient consented?

- Yes  
 No  
 Refused  
 Don't Know

Type of informed consent

- Study enrollment  
 Specimen Storage Consent  
 Genetic Material Storage Consent  
 Broad consent

Date subject signed consent

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Consented by:

\_\_\_\_\_  
(Who managed the consent process?)

Upload the consent form

## Basic Demographics

Visit Date (dd/mm/yyyy)

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Participant Number

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

SCD Number

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Date of Birth (dd/mm/yyyy)

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Calculated age (in months)

\_\_\_\_\_  
(Age on day of Visit)

Self-reported age (in years)

\_\_\_\_\_  
(Age on day of Visit)

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Marital Status

- Married to a person of the opposite sex
- Married to a person of the same sex
- Not married but living together with a partner of the opposite sex
- Not married but living together with a partner of the same sex
- Widowed
- Divorced or annulled
- Separated
- Never been married
- Other

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If other marital status, please specify

\_\_\_\_\_

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Gender

- Male
- Female
- Refused
- Don't know

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**Diagnosis Details**

Is date of diagnosis known?

- Yes
- No

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Date of diagnosis

\_\_\_\_\_

Year of Diagnosis

- I don't know
- 1900
- 1901
- 1902
- 1903
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- 2014
- 2015
- 2016
- 2017
- 2018

Month of Diagnosis

I don't know  
 1  
 2  
 3  
 4  
 5  
 6  
 7  
 8  
 9  
 10  
 11  
 12

SCD Test Result

SS    SBThal    SC  
 AS

Type of test?

HPLC  
 HBE  
 IEF  
 Basique  
 Acide  
 Others

If other test, please specify:

\_\_\_\_\_

ABO Blood Group

A+  
 A-  
 B+  
 B-  
 O+  
 O-  
 AB+  
 AB-

### Management Details

Using Hydroxyurea

Yes    No

Date of Initiation of Hydroxyurea Therapy

\_\_\_\_\_

Penicillin V (prophylaxis)

Yes    No    NA

Folic Acid

Yes    No

Anti Malaria Prophylaxis

Yes    No    NA

Pneumococcal Vaccination up to date

Yes    No

Added by

\_\_\_\_\_

Add Date

\_\_\_\_\_

**Laboratory Results: Complete Blood Count**

Red blood cell count

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(million cells/uL)

White blood cell count (WBC)

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(1000 cells/uL)

Platelet count

---

  
(1000 cells/uL)

Hemoglobin

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(g/dL)

Mean cell volume

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(fL)

Mean cell hemoglobin

---

  
(pg)

Mean Cell Hb Concentration (MCHC)

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(g/dL)

Red cell distribution width (RDW)

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

Serum Creatinine Concentration

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(mg/dL; PX141401)

Urinary microalbumin concentration

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(PX141501)

Urinary Creatinine Concentration

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(PX141601)

**Liver Function Assay (PhenX protocol PX190801 unless otherwise stated)**

Results of alanine aminotransferase assay

\_\_\_\_\_  
(IU/L)

Results of aspartate aminotransferase assay

\_\_\_\_\_  
(IU/L)

Results of alkaline phosphatase assay

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

Results of bilirubin assay

\_\_\_\_\_  
(mg/dL)

Total bilirubin concentration

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

Lactate dehydrogenase level

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

Number of reticulocytes

\_\_\_\_\_  
(thousands/?L)**Laboratory Results: Hemoglobin Characterisation (PhenX protocol PX0830301 unless stated otherwise)**

Were the assay results recorded for the following hemoglobins?

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

Record the levels of HbA if measured.

\_\_\_\_\_

Record the levels of HbS if measured.

\_\_\_\_\_

Record the levels of HbC if measured.

\_\_\_\_\_

Record the levels of Hb E/A2 if measured.

\_\_\_\_\_

Record the levels of Hb D-Punjab if measured.

\_\_\_\_\_

Record the levels of Hb G-Philadelphia if measured.

\_\_\_\_\_

Record the levels of Hb O-Arab if measured.

\_\_\_\_\_

**Laboratory Results: Fetal hemoglobin/HbF**

What is the level of fetal hemoglobin

\_\_\_\_\_

**Pulse oximetry - rest (PhenX protocol PX091101 unless stated otherwise)**

Patient's Body Temperature (in degrees Celsius)

\_\_\_\_\_

(degrees Celsius)

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

Patient's Respiratory Rate

\_\_\_\_\_

Partial Pressure of Carbon Dioxide (PaCO2)

\_\_\_\_\_

Partial Pressure of Oxygen (PaO2)

\_\_\_\_\_

Total Hemoglobin (Hbtot)

\_\_\_\_\_

Oxyhemoglobin Saturation (HbO2)

\_\_\_\_\_

Carboxyhemoglobin (COHb)

\_\_\_\_\_

Methemoglobin (MetHb)

\_\_\_\_\_