

## ANNEX S1 - DATA COLLECTION TABLES IN THE REGISTRY FOR ADULT PATIENTS

### Adult database records

No.	FIELD
1	HOSPITAL NUMBER
2	SURNAME
3	FIRST NAME
4	OTHER NAME
5	DATE OF ENROLMENT
6	ADDRESS
7	NEAREST LANDMARK
8	PHONE NUMBER
9	NEXT OF KIN PHONE NUMBER
10	EMAIL
11	PATIENT'S OCCUPATION
12	LEVEL OF EDUCATION
13	FAMILY INCOME
14	PARENT/GUARDIAN OCCUPATION
15	DATE OF BIRTH
16	PLACE OF BIRTH
17	STATE OF ORIGIN
18	LOCAL GOVERNMENT
19	DIAGNOSIS
20	YEAR OF DIAGNOSIS
21	AGE AT DIAGNOSIS
22	Hb ELECTROPHORESIS DATE
23	HPLC DATE
24	PCR DATE
25	OTHERS DATE
26	GENDER
27	MARRITAL STATUS
28	MOTHERS TRIBE
29	FATHERS TRIBE
30	RELIGION
31	SCD SIBLINGS
32	BLOOD GROUP
33	EXTENDED PHENOTYPE
34	INSURANCE STATUS
35	TRANSFUSION (contained excel attachment for detail records of transfusion)

36	HISTORY SUMMARY
37	TREATMENT (contained excel attachment)
38	MAJOR FINDINGS AT VISIT (contained excel attachment)

### Visit details

S/NO	FIELDS
1	HOSPITAL NUMBER
2	DATE OF VIST
3	SYSTOLIC BLOOD PRESSURE
4	DIASTOLIC BLOOD PRESSURE
4	WEIGHT
5	HEIGHT
6	CLINICAL NOTES
7	LIVER SIZE
8	MCV
9	MCH
10	MCHC
11	RDW
12	RDW
13	RBC
14	PLATELETS
15	Hb
16	UNCORRECTED RETICS COUNT
17	WBC
18	OTHER RESULTS
19	TREATMENT
20	UREA
21	CREATININE
22	DIRECT BILIRUBIN
23	TOTAL BILIRUBIN
24	OTHER MEDICATIONS
25	USING HYDROXYUREA
26	PENICILIN PROPHYLAXIS
27	FOLIC ACID
28	PNEUMOCOCCAL VACCINE
29	PAIN
30	BLOOD TRANSFUSION
31	NUMBER OF UNITS TRANSFUSED
32	FREQUENCY OF TRANSFUSION IN THE LAST YEAR
33	DATE OF LAST TRANSFUSION

34	LEARNING DIFFICULTY
35	FREQUENCY OF CRISES PER YEAR
36	REMARK
37	SEIZURES
38	DACTYLITIS
39	BONE PAIN
40	HIP PAIN
41	CHEST PAIN
42	OTHER SIDE PAIN
43	DIFFICULTY IN WALKING
44	DIFFICULTY IN BREATHING
45	SWELLING
46	HOSPITALIZED IN PAST 30 DAYS PRIOR TO THIS VISIT
47	MALARIA
48	FEVER
49	ANAEMIA
50	LEG ULCER
51	ACUTE CHEST SYNDROME
52	STROKE
53	OSTEONECROSIS
54	AVASCULAR NECROSIS
55	RENAL COMPLICATIONS
56	PRIAPISM
57	PULMUNARY HYPERTENSION
58	JAUNDICE
59	ABNORMAL GAIT
60	EXERTIONAL DYSPNEA
61	DIZZINESS
62	HEADACHE
63	ABNORMAL APPETITE
64	STOOL FREQUENCY
65	NEXT APPOINTMENT
66	EXAMINER'S INITIALS

### Treatment

S/NO	FIELDS
1	ON FOLIC ACID
2	HOW REGULAR
3	ON PALUDRIN
4	HOW REGULAR

5	ON HYDROXY UREA
6	HOW REGULAR
7	ON PYRIMETHAMINE
8	HOW REGULAT
9	ON NAIDs
10	HOW REGULAR
11	NUMBER OF CRISES IN THE LAST 12 MONTHS
12	HISTORY OF SURGERIES
13	TYPES AND DATES

### Transfusion

S/NO	FIELDS
1	CLINICAL FEATURES (SUMMARY) AT FIRST VIST
2	INDICATION
3	DATE
4	BLOOD GROUP TRANSFUSED
5	NUMBER OF UNITS
6	REACTION
7	DATE OF FISRT TRANSFUSION
8	DATE OF LAST TRANSFUION
9	REACTION OF ANY
10	ANTIBODY SCREENED

### Major findings at visit

S/NO	FIELDS
1	TCD
2	USS
3	OPHTHALMOLOGY
4	ENT
5	DENTAL
6	URINALYSIS
7	U,E & CREATININE
8	ECHO
9	PELVIC X-RAY

## ANNEX S2: DATA COLLECTION TABLES IN THE REGISTRY FOR PAEDIATRIC PATIENTS

### Children database records

S/NO.	FIELDS
1	UNIT NUMBER
2	DATE OF BIRTH
3	DATE OF FIRST ATTENDANCE
4	ADDRESS
5	GENDER
6	RELIGION
7	TRIBE
8	FATHER'S OCCUPATION
9	MOTHER'S OCCUPATION
10	FATHER'S PHONE NUMBER
11	MOTHER'S PHONE NUMBER
12	BIRTH HISTORY
13	IMMUNIZATION
14	NUTRITION
15	DEVELOPMENT
16	MEDICAL HISTORY
17	BLOOD GROUP
18	ADMISSIONS
19	FAMILY AND SOCIAL HISTORY
20	COUNSELLING
21	FOLLOW UP DATE
22	HEIGHT
23	WEIGHT
24	OFC
25	SaO <sub>2</sub>
26	PALLOR
27	JAUNDICE
28	DACTYLISIS
29	TENDERNESS
30	CHEST FINDINGS
31	BLOOD PRESSURE
32	HEART SOUNDS
33	LIVER
34	SPLEEN
35	TARNER'S STAGE
36	OTHERS
37	Hb ELECTROPHORESIS

38	FULL BLOOD COUNTS AND RETIS (CONTAINED EXCEL ATTACHMENT)
39	TRANSCRANIAL DOPPLER (CONTAINED EXCEL ATTACHMENT)
40	LIVER FUNTION TEST AND CREATININE (CONTAIN EXCEL ATTACHMENT)
41	ECHO (CONTAINED EXCEL ATTACHMENT)
42	BLOOD GROUP
43	HBsAg
44	HCV
45	HIV
46	VISIT RECORDS (CONTAINED EXCEL ATTACHEMENT)
47	RESEARCH PARTICIPATION (CONTAINED EXCEL ATTACHMENT)
48	YEARLY REVIEW (CONTAINED EXCEL ATTACHMENT)

### Full blood count

S/NO	FIELDS
1	DATE
2	HOSPITAL NUMBER
3	PCV
4	Hb
5	WBC
6	MCH
7	MCHC
8	PLATELETS
9	RETICS %
10	GRANULOCYTE %
11	MID %
12	LYMPHOCYTE %
13	EOSINOPHILS %
14	MONOCYTES %
15	BLOOD FILM

### Transcranial Doppler

S/NO	FIELDS
1	DATE
2	HOSPITAL NUMBER
3	NORMAL SCAN
4	DATA
5	LOW CONDITIONAL
6	HIGH CONDITIONAL
7	ABNORMAL

8	HIGH ABNORMAL
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### Liver function test and Creatinine

S/NO	FIELDS
1	DATE
2	HOSPITAL NUMBER
3	UREA
4	SODIUM
5	POTTASIMUM
6	CHLORIDE
7	BICARBONATE
8	CREATININE
9	AST
10	ALT
11	TOTAL BILIRUBIN
12	UNCONJUGATED BILIRUBIN
13	ALBUMIN
14	GLOBULIN
15	CALCIUM
16	PHOSPHORUS
17	URIC ACID
18	AMYLASE
19	CSF CHEMISTRY
20	URINALYSIS

### Echo

S/NO	FIELDS
1	DATE
2	HOSPITAL NUMBER
3	REPORT

### Visit records

S/NO	FIELDS
1	DATE
2	HOSPITAL NUMBER
3	COMPLAIN
4	HEIGHT
5	WEIGHT
6	NUTRITION
7	DEVELOPMENT

8	CRISIS TYPE
9	PRESENT MEDICATION
10	ALLERGIES
11	HISTORY
12	DIAGNOSIS AND DATE
13	PALLOR
14	JAUNDICE
15	LIVER SIZE
16	SPLEEN
17	BLOOD PRESSURE
18	SaO2
19	PCV
20	WBC
21	RBC
22	MCH
23	MCHC
24	PLATELETS
25	RETICS
26	NEUTROPHILS
27	EOSINOPHILS
28	BASOPHILS
29	LYMPHOCYTES
30	MONOCYTES
31	BLOOD FILMS
32	COMMENTS

### Research participation

S/NO	FIELDS
1	DATE
2	HOSPITAL NUMBER
3	TYPE OF RESEARCH
4	OUTCOME

### Yearly review

S/NO	FIELDS
1	YEAR
2	NUMBER OF VISITS
3	NUMBER OF ADMISSIONS
4	NUMBER OF TRANSFUSIONS
5	COMPLICATIONS



6	COMORBIDITIES
7	PCV
8	CREATININE
9	ALP
10	BLOOD PRESSURE
11	URINALYSIS
12	TCD
13	HbsAg
14	HCV
15	HIV
16	MEAN WEIGHT
17	MEAN HEIGHT
18	MEAN LIVER SIZE
19	MEAN SPLEEN SIZE
20	MEDICATIONS