Questionnaire

Assessing the quality of wellbeing in patients with sickle cell disease taking Vs those not taking Hydroxurea.

STUDY SITE…………………………. **Study No.** | S |__|__|__|__|__| **Date** __/__/____

A) Personal information:

1. Patient name ---------------------------- Initials |__|__|__|

2. Date of Birth……………… Age………….. Sex: Male ☐ Female ☐

3. Tribe…………………………………………………………………

4. Address…………………………………………………………..

5. Religion

   1. Catholic ☐

   2. Protestant ☐

   3. Pentecostal ☐

   4 Muslim. ☐

   5. Others…………………………………………………………………….

B) Family history:

6. Do you have any other relatives with Sickle Cell Disease? Yes ☐ No ☐

7. How do children get sickle cell disease?

   1. Hereditary ☐

   2. Blood transfusion ☐

   3. Body contact ☐

   4. Not sure ☐

   5. Others………………………………………………………………………….

8. How many children do you have? …………………..…………………………………….

9. How many of them have sickle cell disease? ....

10. How many of them in your family have died of sickle cell disease? ……………………

11. At what age(s) did they die?

    1. < 5yrs ☐

    2. 5-18 ☐

    3. Above 18 ☐

12. How was the child diagnosed?

Sickling test ☐

Peripheral film Report ☐

Hb Electrophoresis ☐

Clinically ☐

C) Hydroxyurea Use:

13. Have you heard about a drug called HYDROXYUREA?   Yes ☐   No ☐

(If yes, answer 14)

14. What do you know about it?

1. Good drug ☐

2. Bad drug ☐

3. Expensive ☐

4. Not Sure ☐

15. Is/are the sickler(s) in your family using HYDROXYUREA?   Yes ☐   No ☐

(If yes, answer 16)

16. Where do you get it from?

1. Projects ☐

2. Government Hospitals ☐

3. Private clinic / Hospital ☐

4. Private Pharmacy ☐

17. How many admissions did the child have last year? ....

18. What were the illnesses in those admissions? *(tick all that apply):*

1. Fever ☐	8. Stroke ☐
2. Pains ☐	9. Swollen hands and feet ☐
3. Lack of blood ☐	10. Very large spleen ☐
4. Malaria ☐	11. Bleeding from the nose ☐
5. Pneumonia ☐	12. Painful hip ☐
6. Infection in the bone ☐	
7. Convulsions ☐	

13. *Others………………………………………………………………………………………*

19. Was the child transfused in those admissions?   Yes ☐   No ☐

(If yes, answer Question 20)

20. How many transfusions has the child gotten to date? ....

21. What drugs does the child take to prevent?

I. Malaria:

    1. Fansider ☐

    2. Chloroquine ☐

    3. Proguanil ☐

II. Bacterial infections:

    1. Pen V ☐

    2. Benzathine Pen ☐

22. Is this child immunized?

1. BCG ☐	3. PCV ☐	5. Measles ☐
2. Polio ☐	4. DPT ☐	

23. How often do you come to the sickle cell clinic? (*tick all that apply*)

1. Never ☐		4. Once a year ☐
2. Once every two weeks ☐		5. Once a month ☐
3. Once in three months ☐		6. Once in 6 months ☐

24. Is the child stigmatized?   Yes ☐   No ☐

    (If yes, answer Question 25)

25. Is the stigmatization at?

    Home ☐

    School ☐

    Community ☐

    Others; specify……………………………………………………………………………