

# **Pilot study to assess patients' and health workers' needs involved in Sickle Cell Disease management**

*(this document is produced in the framework of the ARISE project)*

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**FONDAZIONE PER LA RICERCA  
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## 1. Study general information

**Study Title:** Pilot study to assess patients and health workers needs involved in Sickle Cell Disease management

**Sponsor Name:** Not applicable.

**Full names, qualification and institutions of principal investigators:**

Full names	Qualification	Signature
Abubakar Abdulkareem	Masters in library and information science (with concentration in health information behaviour)  Investigator for Barau Dikko Teaching Hospital, Kaduna State University (BDTH) and study coordinating investigator	
Aliyu Mande	Health Information Management officer and Community Mobilizer  Investigator for Ahmadu Bello University Teaching Hospital Zaria (ABUTH)	
Halima Aliyu	Nurse officer  Investigator for Federal Medical Centre Katsina (FMC) and National Hospital Abuja (NHA)	

### Senior investigators

Full names	Qualification	Signature
Baba PD Inusa	Principal Investigator	
Fedele Bonifazi	ARISE Project coordinator	

The study protocol has been approved by all the concerned parties, as well as by the ARISE Ethics Advisor.

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**Summary:**

This pilot research aims at assessing the needs of patients and health workers involved in Sickle Cell Disease (SCD) management in Nigeria. To achieve this, a mixed methodology will be adopted and the research design to be adopted for this study will be case study. Data for this study will be collected using triangulation methods. A simple random and purposive sampling techniques will be used to select respondents for the study. The collected data for this study will be presented and analysed using SPSS and thematic analysis.

The primary objective of this study is to understand the needs of SCD patients and health workers involved in SCD management.

## 2. Background and rationale

Sickle cell disease (SCD) is a public health problem globally and presents major challenges to our health care systems. SCD is an inherited blood disorder caused by abnormal haemoglobin (Grosse, et al., 2011). Currently, approximately 250 million people worldwide carry the gene responsible for SCD and other haemoglobin disorders. Each year about 400,000 infants are born with a major haemoglobin disease worldwide. In Nigeria, the prevalence of SCD is 20-30/1000 live births annually (Ademola, 2015; WHO, 2006). SCD is associated with complications and most patients experience both chronic and episodic pain, and acute pain crisis is the most common reason for the emergency department use by patients with SCD (King et al., 2014).

Problems associated with SCD and complications have been adopted from different perspectives: genetic counseling, knowledge and awareness, pharmacological treatment like hydroxyurea, Patient and Physician Relationship, caregivers perspectives on the SCD treatment, socio-economic perspectives, etc (Galadanci, 2014; Ademola 2015; Green, et al., 2016; Makani et al., 2015; McGann, et al., 2015). However, while these perspectives have helped to better understand the problems, few studies are reported in literature to assess the needs of patients and in our knowledge none of them has been conducted in the centres concerned by this study.

## 3. Objectives

### 3.1. Primary objective

To assess the needs of SCD patients and health workers, with particular reference to the disease management in the clinical centre.

The study is intended as a pilot experience to verify the feasibility of the action through a structured survey. This is a descriptive, mixed method prospective questionnaire-based study. The study is intended as a pilot experience to verify the feasibility of the action through a structured survey.

### 3.2. Sample size determination

As pilot experience, the questionnaires will be administered to 30 SCD patients or parents/legally designated representatives of children affected by SCD and 30 Professionals working with SCD patients (mainly doctors and nurses) in each centre for a total of 120 patients and 120 health workers. A focus group discussion will be run with the SCD patients/parents. Following the pilot study, a wider survey will be launched involve patients, parents and healthcare professionals in the whole country and in other centres involved in the project.

### 3.3. Setting

The study will be conducted in the following four centres: Barau Dikko Teaching Hospital Kaduna State University (BDTH), Ahmadu Bello University Teaching Hospital Zaria (ABUTH), National Hospital Abuja (NHA), and Federal Medical Centre Katsina (FMC).

### 3.4. Sampling strategy

Random and purposive sampling technique.

## 4. Inclusion and exclusion criteria

The following inclusion criteria will apply for patients/parents:

- Aged  $\geq 18$
- Have SCD diagnosis or having a child with a SCD diagnosis
- Attending the centre from at least 6 months
- Nigerian nationality
- Informed Consent signed

The following inclusion criteria will apply for healthcare professionals:

- Working in a SCD clinic
- At least 5 years of experience with SCD patients
- Informed Consent signed

The following exclusion criteria will apply for all participants:

- Informed consent form withdrawal
- Illiterate subjects
- Any psychiatric conditions impairing the participation in this study.

## 5. Study procedure

### 5.1. Questionnaire completion

After obtaining the informed consent, subjects (patients, parents/legally designated representatives and healthcare professionals) will be asked to complete the questionnaire. Two questionnaires have been developed, one addressed to patients, parents, legally designated representatives (Annex I) and another one for healthcare professionals (Annex II)

The following measures will be adopted to reduce the interviewer effect:

- The investigator will give instructions to complete, but questionnaires will be self-completed.
- Participants will have time to complete the questionnaire in a private setting.
- Completed questionnaires will be blindly deposited in a closed box. This will be thus safeguarded by the investigators.
- Completed questionnaires will be returned to the coordinating investigator for analysis.

Questionnaires will be pseudonymised: an alphanumeric code will be indicated on each questionnaire and reported on the corresponding informed consent form.

All the study investigators are researchers/officers in the centres not involved in patients' clinical management. The veracity and consistency of responses are of paramount importance for the

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validity of the study and the improvement of the management of SCD patients: all the actions necessary to allow the participants to freely express themselves will be adopted.

Together with the questionnaire, participants will receive information about the time and venue for the focus group discussion (Annex III). For those who are willing, reminders about the focus group will be sent by e-mail/phone.

### **5.2. Focus group**

A 45-60 minutes discussion will be scheduled with patients and parents, according to details given in the attached guidance. The principal investigator of each centre will lead the focus group discussion, leaving the possibility to everyone to freely express his/herself.

### **5.3. Data collection**

Data will be collected and transcribed by the coordinating investigator in an Excel file that will be used for analysis.

### **5.4. Data analysis**

Data will be managed by the study investigator, his delegates and authorised people (e.g. the hosting institution staff, statisticians, IT people). Data will be analysed by the coordinating investigator. SPSS and Thematic Analysis will be performed.

## **6. Timeline and milestones**

### **6.1. Start of data collection**

March 2020

### **6.2. End of data collection**

September 2020

### **6.3. Final report of study results**

October 2020

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## 7. Ethics and data protection

This research is going to obtain approval from ethics committee, both NHREC and local. No invasive procedures will be performed. Personal data as well as special categories of personal data such as health data will be processed within this study. Specific consent will be got to use these data for research purposes. Aggregated data may be shared among institutions belonging to the ARISE Consortium after stipulating a Data Sharing Agreement (DSA). Data will be shared with academia and the broader community (e.g. conferences, articles, seminars, dissertation, reports) once anonymized. Data and recordings will be stored until December 2022,31<sup>st</sup> in Barau Dikko Teaching Hospital, Kaduna State University. At the end of the storage period data will be made anonymous and the recordings destroyed. After the end of the project, only anonymised data may be processed. Finally, a Data Protection Impact Assessment (DPIA) for the study was conducted under Article 35 of the European General Data Protection Regulation and was included as Annex in Deliverable 8.9 indicating that the processing activities do not result in a high risk for data subjects.

## 8. References

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## Annex I. QUESTIONNAIRE FOR NEED ASSESSMENT OF PATIENTS/PARENTS INVOLVED IN SICKLE CELL DISEASE MANAGEMENT

Questionnaire code: \_\_\_\_\_

### SECTION A

#### Bio Data

1. State \_\_\_\_\_
2. Local Government \_\_\_\_\_
3. Name of SCD Clinic/Hospital \_\_\_\_\_
4. Age \_\_\_\_\_
5. Gender Male [ ] Female [ ]
6. Education: University [ ], Secondary [ ], Primary [ ], Nursery [ ] Other (please specify) \_\_\_\_\_
7. Occupation: Business [ ], Civil Servant, [ ], Farmer [ ], Other (please specify) \_\_\_\_\_

### SECTION B

- 1. If you are a patient, what is your diagnosis? If you are a parent, what is the diagnosis of your child?**
  - A. Sickle cell disease [ ]
  - B. Sickle cell/b-thal [ ]
  - C. Sickle Beta-Plus Thalassemia [ ]
  - D. Other (please specify) \_\_\_\_\_
- 2. How is your/your child current transfusion regime?**
  - A. I am not transfused [ ]
  - B. I am regularly transfused [ ]
  - C. I am occasionally transfused [ ]
  - D. Other (please specify) \_\_\_\_\_
- 3. Where do you usually get information about Sickle Cell Disease?**
  - A. Websites
  - B. Social Networks
  - C. Scientific journals
  - D. TV
  - E. Radio
  - F. Leaflets/booklets
  - G. Doctor/nurse
  - H. Other patients
  - I. Relatives/friends
  - J. Religious leaders
  - K. Other (please specify) \_\_\_\_\_

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**4. Please, indicate your main information source:** \_\_\_\_\_

**5. How satisfied are you with the communication about Sickle Cell Disease and its treatment?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**6. Following your/your child Sickle Cell Disease diagnosis, who did you/your child get support from to deal with the disease?**

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**7. How satisfied are you with the support you/your child received at the time of the diagnosis?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**8. How satisfied are you with your involvement by doctor in the decisions that affect your/your child disease?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**9. How satisfied are you with the instruction given by doctor about pain control?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**10. How satisfied are you about the waiting times to see doctors in the clinic?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

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**11. How short or long on the next clinic appointment giving by the doctors?**

- A. Very short [ ]
- B. Short [ ]
- C. Neither short Nor long [ ]
- D. Long [ ]
- E. Very long [ ]

**12. How satisfied are you about the services provided in the lab?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**13. How satisfied are you during or when communicating with lab technicians?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**14. How satisfied are you about the waiting times in the lab?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**15. How satisfied are you with the nursing care in clinic?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**16. How satisfied are you during or when communicating with nurses?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

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**17. How satisfied are you with your/your child SCD current treatment and management for SCD (e.g. Hydroxyurea, blood transfusion, pain medications, vaccination, surgeries etc.)?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied Nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**18. How expensive about the cost of treatment in the hospital?**

- A. Very expensive [ ]
- B. Expensive [ ]
- C. Neither expensive Nor inexpensive [ ]
- D. Cheap [ ]
- E. Very cheap [ ]

**19. How good about the about the overall service quality?**

- A. Very good [ ]
- B. Good [ ]
- C. Neither good Nor poor [ ]
- D. Poor [ ]
- E. Very poor [ ]

**20. How would you rate access to the treatment centre (in terms of distance, cost etc.)?**

- A. Very easy [ ]
- B. Easy [ ]
- C. Neither easy nor difficult [ ]
- D. Difficult [ ]
- E. Very difficult [ ]

**21. Who pays for your treatment? (tick all that apply)**

- A. My self/my family [ ]
- B. Health insurance (private) mine [ ]
- C. Health insurance (private) my employer's [ ]
- D. State goverment provide free healthcare [ ]
- E. Other (please specify) \_\_\_\_\_

**22. Do you need to move to other centres to perform one of the following?**

- A. Periodical visit [ ]
- B. Specialist visit [ ]
- C. Special examination [ ]

D. Laboratory analysis [ ]  
E. Other (please specify) \_\_\_\_\_

**23. If yes, how far are the centres from your home?**

A. 5-10km [ ]  
B. 10-30km [ ]  
C. 30-50km [ ]  
D. 50-60km [ ]  
E. 60-70km [ ]

**24. Are there facilities for psychological support in this hospital?**

A. Yes [ ]  
B. No [ ]

**25. How satisfied are you with the support received from the psychological support facilities?**

A. Very satisfied [ ]  
B. Satisfied [ ]  
C. Neither satisfied Nor dissatisfied [ ]  
D. Dissatisfied [ ]  
E. Very Dissatisfied [ ]

**26. How can you recommend this hospital to relatives and friends?**

A. Definitely no [ ]  
B. Probably no [ ]  
C. Definitely yes [ ]  
D. Probably yes [ ]

**27. How would you describe your/your child current health?**

E. Very poor [ ]  
F. Neither poor nor good [ ]  
G. Good [ ]  
H. Excellent [ ]

**Is there any additional aspect you would like to propose to improve the management of SCD?**

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## Annex II. QUESTIONNAIRE FOR NEED ASSESSMENT OF HEALTH WORKERS INVOLVED IN SICKLE CELL DISEASE MANAGEMENT

Questionnaire code: \_\_\_\_\_

### SECTION A - Bio Data

1. State \_\_\_\_\_

2. Local Government \_\_\_\_\_

3. Name of SCD Clinic/Hospital \_\_\_\_\_

4. Age \_\_\_\_\_

5. Gender Male [ ] Female [ ]

6. Please indicate your area of specialization

- A. Medical Doctor [ ]
- B. Nurse [ ]
- C. Laboratory technology [ ]
- D. Pharmacist [ ]
- E. Others (please specify) \_\_\_\_\_

7. Average weekly effective working hours \_\_\_\_\_

### SECTION B

**1. Which of the following additional training did you receive on Sickle Cell Disease management in the past three months?**

- A. Seminar [ ]
- B. Conference [ ]
- C. Workshop [ ]
- D. Training [ ]
- E. None of the above [ ]
- F. Other (please specify) \_\_\_\_\_

**2. How often do you see or attended to Sickle Cell Disease patients?**

- A. Once in a week [ ]
- B. Twice in a week [ ]
- C. Once in a month [ ]
- D. Twice in a month [ ]
- E. Other (please specify) \_\_\_\_\_

**3. How many Sickle Cell Disease patients do you see or attend in the clinic?**

- A. 5-10 [ ]

B. 10-15 [ ]  
C. 15-20 [ ]  
D. Other (please specify) \_\_\_\_\_

**4. How many SCD patients do you think is adequate for you to see or attend?**

A. 5-10 [ ]  
B. 10-15 [ ]  
C. 15-20 [ ]  
D. Other (please specify) \_\_\_\_\_

**5. How satisfied are you with the relationship you have with the patients?**

A. Very satisfied [ ]  
B. Satisfied [ ]  
C. Neither satisfied Nor dissatisfied [ ]  
D. Dissatisfied [ ]  
E. Very Dissatisfied [ ]

**6. At the clinic, do you educate patients with SCD on self-management aspect of their disease? If yes, what type of information do you give them?**

A. Information about how to avoid complication [ ]  
B. Information about pain management [ ]  
C. Information about symptom [ ]  
D. Other (please specify) \_\_\_\_\_

**7. How adequate are the number of facilities in the clinic/lab?**

A. Very adequate [ ]  
B. Adequate [ ]  
C. Neither adequate nor inadequate [ ]  
D. Inadequate [ ]  
E. Very inadequate [ ]

**8. How good are the facilities provided to manage SCD patients?**

A. Very good [ ]  
B. Good [ ]  
C. Neither good nor poor [ ]  
D. Poor [ ]  
E. Very poor [ ]

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**9. If the facilities have any problems, please state them below**

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**10. How satisfied are you with the management of your clinic?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**11. Do you feel protected from injuries and professional risks?**

- A. Very good [ ]
- B. Good [ ]
- C. Neither good nor poor [ ]
- D. Poor [ ]
- E. Very poor [ ]

**12. How do you judge your involvement in the decision-making process of your centre?**

- A. Very good [ ]
- B. Good [ ]
- C. Neither good nor poor [ ]
- D. Poor [ ]
- E. Very poor [ ]

**13. How satisfied are you with your career advancement (if you are willing to)?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**14. How satisfied are you with the level of responsibility you have?**

- A. Very satisfied [ ]
- B. Satisfied [ ]
- C. Neither satisfied nor dissatisfied [ ]
- D. Dissatisfied [ ]
- E. Very Dissatisfied [ ]

**15. How satisfied are you with on the decision-making autonomy you have?**

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A. Very satisfied [ ]  
B. Satisfied [ ]  
C. Very Dissatisfied [ ]  
D. Dissatisfied [ ]  
E. Neither satisfied nor dissatisfied [ ]

**16. How do you judge the level of appreciation of your work?**

A. Very good [ ]  
B. Good [ ]  
C. Neither good nor poor [ ]  
D. Poor [ ]  
E. Very poor [ ]

**17. In general, are you satisfied with your work with SCD patients?**

A. Yes  
B. No

**If not, please indicate the reason:**

A. Poor collaboration from colleagues and other staff [ ]  
B. Poor collaboration from patients [ ]  
C. Work overload [ ]  
D. Poor training [ ]  
E. Poor equipments [ ]  
F. Poor organisation [ ]  
G. Poor career possibility [ ]  
H. No social/psychological support [ ]  
I. Inadequate economic renumeration [ ]  
J. Other (please specify) \_\_\_\_\_

**18. In general, what do you think is more important to improve your work?**

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### Annex III. FOCUS GROUP INTERVIEW GUIDE

**Topic: Needs Assessment of patients and health workers involved in SCD management.**

**Introduction:**

Hello and welcome to our session. My name is Abubakar Abdulkareem, a researcher from **“African Research and Innovative initiative for Sickle cell Education: Improving Research Capacity for Service Improvement” (ARISE)** project, assisting me is .....

Thank you for taking your time to join us to talk about the needs assessment of patients involved in SCD management.

The aim of this discussion is to understand the needs of patients involved in SCD management. We will be discussing on your perceptions and understanding. The discussion will last from 45 minutes to one hour.

As part of the focus group, facilitators will ask questions related to your own perception on health workers and the facilities involved in SCD management. In order to have a fruitful discussion, participants are encouraged to speak one person at a time. Please you are to keep in mind that there are no “negative or positive” comments to any question that will be asked. The purpose is to stimulate conversation and hear the opinion of everyone in this room. I hope you will be comfortable speaking honestly and sharing your ideas with us.

Please note that this session will be recorded, and notes will be taken during the focus group to ensure that we don't miss any of your comments due to their importance. Unfortunately, we can't write fast enough to get them all down that is why we must record them. However, the comment from the focus group will remain confidential and your name will not be attached to any comment. Do you have any question before we begin? Thank you.

1. Please share with me your perception of the health workers in this clinic.
2. Please share with me your perception of the services provided in this clinic.
3. Please share with me your perception of the facilities both in the clinic and lab (e.g. adequacy and functioning).
4. What do you perceive as major need concerning the management of your disease in the clinic?
5. What is the most satisfactory aspect of the management of your disease in the clinic?
6. Is there anything we haven't discussed that you think is important regarding the needs of patients involved in SCD management?