



Milestone n. 3

“First version of the context analysis on healthcare policies and centres organisation”

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FARMACOLOGICA GIANNI
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1. Summary

This report describes the preliminary results from the context analysis on healthcare policies and centres organisation performed within the ARISE task 2.2 “Healthcare policies and centres organisation analysis”. A cross-sectional, web-based pilot survey was designed to map and assess the organisation of selected Nigerian clinical centres managing Sickle Cell Disease (SCD) patients.

Reference persons for each centre were invited to join an electronic survey aimed to collect information such as:

- General information (no. beds, staff, yearly admissions, etc.)
- Availability of clinical, diagnostic and laboratory services

Moreover, information related to the SCD management, screening and prevention were collected and mapped (e.g. presence of patient registries, types of treatments available, relevant medical facilities available, adoption of national guidelines and the provision of genetic counselling).

This is geared towards the collection of data to support the implementation of the management of SCD patients including of a Newborn screening (NBS) program in Nigeria.

The study was conducted in collaboration with the Nigerian researchers carrying out their secondments at Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus (FGB) that leads this task. This study was designed as a pilot to be extended, during the project, to the whole Nigerian country, Kenya and Lebanon. The collection of data will continue until the end of the project with the aim to obtain the full maps of the 3 countries. Therefore, this report will be amended as additional data become available.

2. Context analysis on healthcare policies and centres organisation in Nigeria

The ARISE task 2.2 “Healthcare policies and centres organisation analysis” aims to map and assess the organisation of centres managing SCD patients in order to support the implementation of the management of SCD patients including of a Newborn screening (NBS) program in Nigeria, Kenya and Lebanon.

To this end, a cross-sectional, web-based pilot study was designed to map and assess the organisation of selected Nigerian clinical centres managing SCD patients.

The study was conducted in collaboration with the researchers, Ashel Dache Sunday, from Barau Dikko Teaching Hospital (BDTH) and Aliyu Mande from Ahmadu Bello University Teaching Hospital (ABUTH), carrying out their secondments at Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus (FGB) that leads this task. This study was designed as a pilot study to be extended, during the project, to the whole Nigerian country, Kenya and Lebanon.

Lack of data and government/policy makers commitment have greatly affected NBS implementation in African countries, so the data gathered will help in identifying gaps and best way to implement NBS in Nigeria. As shown from other programs, publicly funded data becomes publicly assessed, usable and reusable¹, for successful implementation of NBS program in Africa, nutrition and nutrition education needs to be integrated. So, this will be captured by this study and included in the research as appropriate. As stated by the World Health Organisation (WHO), the burden of SCD in sub Saharan Africa is increasing with the increase in population². This has major public health and socioeconomic implications.

In order to reduce the burden of SCD, the Nigerian Federal Ministry of Health released in 2014 the “National Guideline for the Control and Management of Sickle Cell Disease”³. The publication of this guideline shows the government’s continuous commitment to guarantee appropriate clinical interventions for patients suffering from SCD in all the healthcare facilities nationwide.

Despite interest in SCD, including commitment from some African First Ladies and the adoption of a United Nations (UN) resolution recognizing SCD as a public health problem, the investment in SCD prevention and management using effective primary prevention measures remains inadequate. For a successful SCD NBS, the WHO has stated several guiding principles which include country ownership (which includes having a national guideline), leadership fairness and community participation to own the program in the implementation of the regional strategy. Effective, cost effective and accessible care for SCD should be made available especially for rural dwellers and the poor².

Also integrated and evidence-based interventions and prevention focused population-based approach should be followed for a step by step implementation of priority intervention as part of the national health plan. Partnership, team building, coordination, strengthening health systems, cultural sensitivity and

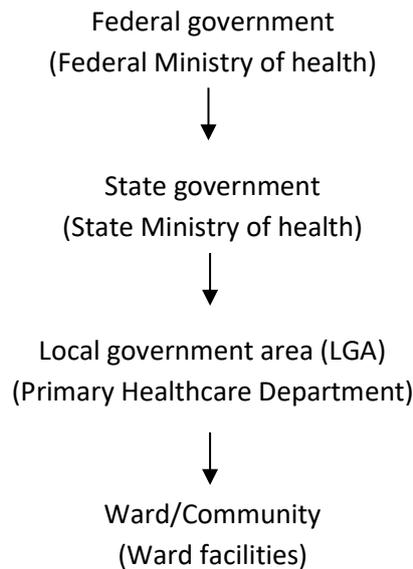
¹ Lewis Hsu, Obiageli E. Nnodu, Biobele J. Brown et al. White Paper: Pathways to Progress in Newborn Screening for Sickle Cell Disease in Sub-Saharan Africa. *J Trop Dis Public Health*. 2018;6(2):260.

² World Health Organisation. Sickle cell disease: A strategy for the WHO African Region. Malabo, Equatorial Guinea. 2010. Available from: <https://apps.who.int/iris/bitstream/handle/10665/1682/AFR-RC60-8.pdf?sequence=1&isAllowed=y> (last access 18/02/2020)

³ Federal Ministry of Health. National Guideline for the Control and Management of Sickle Cell Disease. 2014. Available from: <https://www.medbox.org/ng-guidelines-others/nigeria-national-guideline-for-the-control-and-management-of-sickle-cell-disease/preview?q=>(last access 18/02/2020)

accountability are crucial to successfully implement the NBS program. In addition, advocacy, partnership, social impact and genetic counselling should be considered². A lot of pilot studies have been done in Africa on SCD, like in Tanzania for example. The main aim is to have a health policy which will aid in having a cost-effective intervention. Grants have been assessed to pilot research on NBS, an example is the welcome trust project grant (nutrition and physiology in SCD), though grants are recommendable, but they are not sustainable.

The Nigerian healthcare system is organised according to the following structure:



At federal level, the Ministry has several departments specializing in different aspects of health care. In each State is appointed a commissioner of health. The State is divided into several Local Government Areas (LGAs) coordinated by a director; each LGA consists of different wards where a ward local person is appointed. LGAs are responsible for primary healthcare; the State Governments are responsible for providing secondary care while the Federal Government is responsible for policy development, regulation, overall stewardship and providing tertiary care.

The Nigerian healthcare system is organised according to tertiary, secondary and primary healthcare levels, described as follows:

- Tertiary facilities at national level (Teaching hospitals, federal medical centres, training centres, comprehensive health centres)
- Secondary facilities at State level (General hospitals, specialist hospitals, rural hospitals)
- Primary facilities at local level (Health centres, health clinics, Dispensary & health posts)

2.1. Methodology

A cross-sectional, web-based pilot study was designed, in collaboration with the ARISE Steering Committee, to map and assess the organisation of Nigerian clinical centres managing SCD patients.

Reference persons for each centre were invited to join an electronic survey aimed to collect information such as:

- General information (no. beds, staff, yearly admissions, etc.)
- Availability of clinical, diagnostic and laboratory services

Moreover, information related to the SCD management, screening and prevention were collected and mapped (e.g. presence of patient registries, types of treatments available, relevant medical facilities available, adoption of national guidelines and the provision of genetic counselling).

2.1.1. Questionnaire

The questionnaire (Annex 1) was developed in English and adapted according to the National Guideline for the Control and Management of Sickle Cell Disease released by the Nigerian Federal Ministry of Health in 2014³. It investigated facilities' features including SCD management, screening services, counselling and education. Administrative data were required in order to provide with relevant information on demographic gaps in care for patients with SCD in rural and urban settings. Either primary, secondary or tertiary health facilities managing SCD were included in the study. An online system (Limesurvey) was used to administer the questionnaires to the selected reference persons however a printed form was used as needed.

2.1.2. Study population

Clinical centres partners of the project or from direct contact with project partners was considered. Moreover, the following sources were consulted to identify additional reference centres:

- Lists of centres that participate in similar research, like the research on current SCD management practices in Nigeria conducted by Galadanci N et al. in 2014⁴
- Official guidelines or lists issued by the government authorities
- Identification of health facilities involved with SCD on the web

Sixteen clinical centres were selected from 5 Nigerian States namely Kaduna, Katsina and Federal Capital Territory - FTC Abuja, Lagos and Ilorin Kwara were assessed in this pilot phase (table 1).

The percentage of the States to be included will be increased by about 70% coverage of the Nigerian States in the next phase of the analysis.

NAME OF FACILITY	TYPE OF CLINIC
Kaduna State	
Ahmadu Bello Teaching Hospital Zaria	Adults and Paediatrics
Barau Dikko Teaching Hospital Kaduna	Adults and Paediatrics
General Hospital Kafanchan	Adults and Paediatrics
Katsina State	
Federal Medical Center Katsina	Adults and Paediatrics
FTC Abuja	
National Hospital Abuja	Paediatrics
University of Abuja Teaching Hospital Gwagwalada	Adults and Paediatrics

⁴ Galadanci N1, Wudil BJ, Balogun TM et al. Current sickle cell disease management practices in Nigeria. *Int Health*. 2014 Mar;6(1):23-8

Zankli Medical Centre Abuja	Paediatrics
Lagos State	
Lagos State Teaching Hospital	Adults and Paediatrics
Ilorin Kwara State	
University of Ilorin Teaching Hospital	Adults and Paediatrics

Table 1. Selected Nigeria clinical centres

2.1.3. Ethics and data protection

The study protocol and the questionnaire were revised and approved by the Ethics Advisor.

Moreover, the study obtained the approval from the National Health Research Ethics Committee of Nigeria (NHREC) (NHREC/01/01/2007-27/07/2020) on 27 July 2020.

The study does not foresee the processing⁵ of personal data, unless the specific contacts (Name and email address) of those invited to complete the survey. These data were processed in compliance with the European General Data Protection Regulation (GDPR)⁶ and the Nigerian Data Protection Regulation, issued by the National Information Technology Development Agency (NITDA) in 2019⁷.

3. Data analysis and results

IBM® SPSS® Statistics 19⁸ was used for the analysis.

10 answers were received, from 2 secondary and 8 tertiary care facilities. They include University of Abuja Teaching Hospital (UATH), University of Ilorin Teaching Hospital (UIH) and both adults and paediatrics facilities from Ahmadu Bello Teaching Hospital (ABUTH), Barau Dikko Teaching Hospital (BDTH) General Hospital Kafanchan (GHK), Federal Medical Centre, Katsina (FMC Katsina) (Table 2).

Facilities	Type of facilities
Kaduna State	
Ahmadu Bello Teaching Hospital Zaria	Adults and Paediatrics
Barau Dikko Teaching Hospital Kaduna	Adults and Paediatrics
General Hospital Kafanchan	Adults and Paediatrics

⁵GDPR - Article 4: 'processing' means any operation or set of operations which is performed on personal data or on sets of personal data, whether or not by automated means, such as collection, recording, organisation, structuring, storage, adaptation or alteration, retrieval, consultation, use, disclosure by transmission, dissemination or otherwise making available, alignment or combination, restriction, erasure or destruction.

⁶European Parliament and Council of European Union (2016) Regulation (EU) 2016/679. Available from: <https://eur-lex.europa.eu/eli/reg/2016/679/oj> (last access 18/02/2020)

⁷National Information Technology Development Agency. Nigeria Data Protection Regulation. 2019. Available from: <https://nitda.gov.ng/wp-content/uploads/2019/01/Nigeria%20Data%20Protection%20Regulation.pdf> (last access 25/11/2020)

⁸IBM® SPSS® Statistics 19. Available at <https://www.ibm.com/products/spss-statistics> (last access 25/11/2020)

Katsina State	
Federal Medical Center Katsina	Adults and Paediatrics
FTC Abuja	
University of Abuja Teaching Hospital Gwagwalada	Paediatrics
Ilorin Kwara State	
University of Ilorin Teaching Hospital	Adults

Table 2. Facilities included in the analysis

Preliminary results were presented during the Annual Conference Academy for Sickle Cell and Thalassaemia - ASCAT in October 2020 (Annex 2) and published on the HemaSphere journal⁹.

They show that:

- there is no online SCD patient registry at the investigated facilities
- all the facilities perform basic laboratory tests on SCD patients
- most of facilities (9/10) adopt the National Guidelines for the control and management of SCD patients

The percentage of coverage of individuals screened receiving follow up education/counselling/treatment ranges from 45% to 56%, mostly adults.

Moreover, screening services are paid out of pocket by the patients in 8 facilities or sponsored by other non-government organisations in 2.

Concerning test type for SCD screening, all facilities perform Alkaline Gel Electrophoresis, while more than one half perform blood film test. More details in the table 2.

Screening test Facilities	Sickling test	Haemoglobin Solubility Test/ Sickledex	Alkaline Gel EF	Acid gel EF	Blood film	HPLC	IEF
UATH	-	-	+	-	+	-	-
UITH	-	-	+	-	-	-	-
ABUTH (adult)	-	-	+	-	+	-	-
ABUTH (paed)	-	-	+	-	+	+	-
BDTH (adult)	-	-	+	-	+	-	-
BDTH (paed)	-	-	+	-	-	-	-
GHK (adult)	-	-	+	-	-	-	-
GHK (paed)	-	-	+	-	-	-	-
FMC (adult)	+	+	+	-	+	-	-
FMC (paed)	-	-	+	-	+	-	-

Table 2. Diagnostic tests performed in the interviewed facilities

⁹A.D. Sunday, A. Didio, L. Ruggieri, F. Bonifazi, A. Landi, B. Inusa, L. Dogara. Analysis of the organisation of the healthcare centres managing sickle cell disease in Nigeria, HemaSphere, 2020;4:S3, 15th Annual Sickle Cell and Thalassaemia, 1st EHA European Sickle Cell Conference, and 60th Anniversary of BSH Abstract Book, DOI: <http://dx.doi.org/10.1097/HS9.0000000000000498>

Only 1 of these 10 centres of excellence has SCD screening services delivered by a community staff. 5 centres delivered SCD screening services as part of special campaigns and 6 as part of maternal and child health care services (fig. 1).

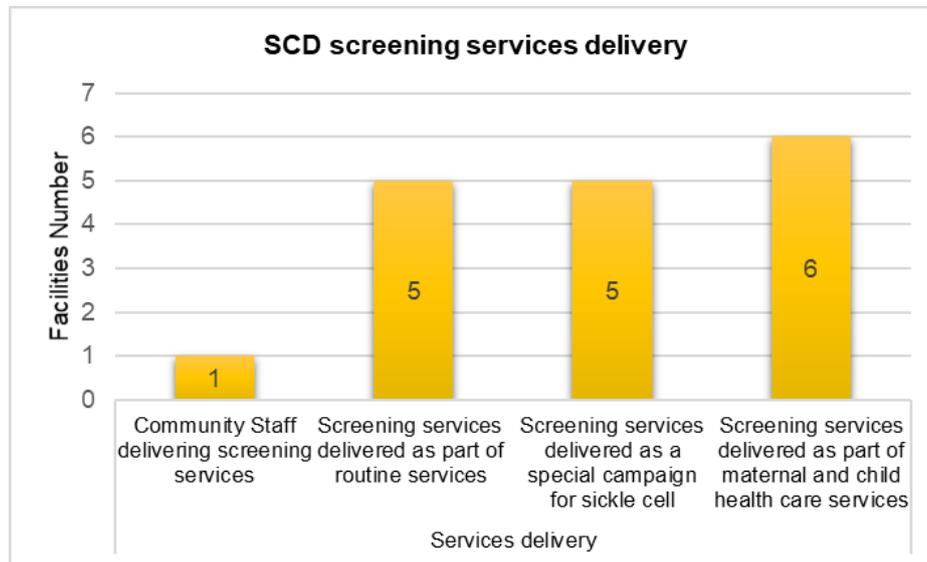


Fig. 1 SCD screening service delivery

4. Conclusions and next steps

This pilot study investigated the organisation of 10 facilities managing both paediatric and adult patients with SCD in Nigeria. General features related to the management of patients in the clinic have been analysed as well as the available screening services have been explored.

From the preliminary analysis emerges that there is a potential for an excellent management of SCD patients in Nigeria.

Moreover, improvements are possible, especially in terms of online registries to assess data for planning and research, health insurance and good policy to encourage patients to attend the clinics.

Additional results will be included as they become available.

After this initial pilot testing, some specific questionnaire adjustments can be made in order to enhance the data collection in the other centres. The study will be extended to cover the whole Nigerian country.

The same initiative will be performed also in Kenya and Lebanon. Virtual interactions have been established with the ARISE partners from these two countries in order to finalised the study protocols and identify all the ethical and regulatory requirements to be fulfilled in order to proceed with the data collection.

5. Annexes

5.1. Annex 1 – Invitation message and study questionnaire

Dear Colleague,

I hope this email finds you well.

We are contacting you in the framework of the activities of the “African Research and Innovative Initiative for Sickle Cell Education: improving Research Capacity for Service Improvement - ARISE” project (GA 824021— H2020-MSCA-RISE-2018).

We are performing a study to collect information on clinical centres managing Sickle Cell Disease (SCD) and the availability of clinical, diagnostic and laboratory services. It has been approved by the National Health Research Ethics Committee, Federal Ministry of Health <PLEASE INCLUDE REFERENCE AND DATE>

We need your collaboration as healthcare professional to complete the following survey: (*individual link to complete*), aimed at mapping and analysing the healthcare centres managing SCD in Nigeria.

The link to the questionnaire is strictly personal and can be used for only one online submission. It is possible to save data and complete the questionnaire later.

Please take your time to provide as much relevant and accurate information to each of the questions where possible.

In order to proceed with the analyses and next steps of the activity, we would kindly ask you to complete the assessment survey by (*2 weeks from the receipt*)

The information you should provide includes personal data limited to your contact details. Personal data will be collected to allow us to contact you for further details on your centre. In addition, you can also opt-in to authorise your contact details used for further purposes: you can be contacted to work on other collaborative research projects or to receive ARISE communications (e.g. periodic newsletters).

Personal data will be disclosed only to authorised people, bound by professional secrecy. All the collected data will be kept confidential within the ARISE consortium and will be stored for the duration of the activities of the ARISE project (expected to end in December 2022). After the end of the storage period, personal data will be destroyed, and questionnaires made anonymous.

All the information will be made available to authorised third parties in an aggregated manner (e.g. cumulative data and statistics).

The results of this survey will be used for the ARISE purposes only and may be shared within the ARISE Consortium. The summary of the study results will be made publicly accessible through the ARISE web portal. You have the right to request access to and rectification or erasure of your personal data or restriction of processing concerning your personal data or to object to processing as well as the right to data portability.

If you have any question on the survey or you want to exercise your rights and for any technical enquiry, please contact: survey@benzifoundation.org.

The ARISE Consortium, represented by Fondazione per la RicercaFarmacologica Gianni Benzi Onlus (Via Abate Eustasio, 30 70100 Valenzano BA – info@benzifoundation.org) is responsible for the treatment of personal data. All the data will be processed in compliance with the European General Data Protection Regulation (GDPR), Regulation (EU) 2016/679 and the 2019 Nigeria Data Protection Regulation. For more details, you can refer to the Fondazione per la RicercaFarmacologica Gianni Benzi Onlus Data Protection Policy.

Thank you for your collaboration!

STUDY PRINCIPAL INVESTIGATOR

ARISE PROJECT COORDINATOR

ARISE SCIENTIFIC COORDINATOR

Mr Ashel Dache Sunday

Mr Fedele Bonifazi

Dr Baba Inusa

Declaration

I have read the above information and

I authorise the treatment of personal data, in compliance with the General Data Protection Regulation, Regulation (EU) 2016/679 and the 2019 Nigeria Data Protection Regulation for the specific purpose they are collected (any communication of personal data to private or public subject will be allowed only for the specific purpose they are collected).

We need your consent to the treatment of personal data to proceed with survey completion.

I authorise to be contacted for involvement in future collaborative initiatives, which might fall within the scope of my research activity.

I authorise to be contacted for dissemination and communication activities (e.g. newsletters, invitations to meetings).

A. General Information

1. What kind of health provider are you?

- General Haematologist
- Paediatric Haematologist
- Paediatrician
- Trainee doctor
- General medical practitioner/Family physician
- Nurse
- Community Health Care Provider
- Other (Please Specify _____)

2. What type of health care facility do you provide care in?

- Tertiary Care Facility
- Secondary Care Facility
- Primary Care Facility
- Private Care Facility
- Other (Please Specify _____)

a. What is the name of the health care facility, centre or hospital where you provide health care services?

b. What is the total number of yearly admissions in the last year? _____

3. What is the staff strength (no. of doctors, nurses and other medical staffs) at the SCD clinic?

- 0-50

-
- 51-100
- 101-200
- 201-500
- >200
4. What is the number of beds for SCD patients?
- 0-50
- 51-100
- 101-200
- 201-500
- >500
5. What are the numbers of admissions in the last year? _____
6. Is there a SCD patient registry in your facility? YES NO
7. If YES, is the registry online or offline? _____
- a. Website address of the registry (if any) _____
8. How many SCD patients are on treatment in your facility currently? _____
9. What is the age range of SCD patients managed in your facility? _____
10. Do you have the equipment/instruments to perform the following tests/examinations in SCD patients?
- Hb/PCV, WBC**, Platelet and Reticulocyte counts, ESR
- Examination of Blood Film (especially for malaria parasites)
- Plasma Bilirubin Level (total & conjugated)
- Serum Urea, Electrolytes, Creatinine & C-Reactive Protein (CRP)
- Infection Screening (blood, urine, stool, sputum etc) as necessary
- Abdominopelvic ultrasound scan as necessary

-
- Chest X-Ray
 - Pulse Oximetry (Arterial Blood Gases if SaO₂ <92%)*
 - Transcranial Doppler Ultrasonography (TCD USS)
 - Computerized Axial Tomography (CAT)
 - MRI/PET

Any note to be added on this: _____

B. Screening diagnosis and management services for Sickle Cell Disease

1. How are screening services for sickle cell currently being delivered?

- As part of routine services delivery
- As part of maternal and child health care services
- As a special campaign for sickle cell
- Community Staff
- Other (please specify _____)

2. Who is sponsoring screening services in your centre?

- Federal Government
- State Government
- Non-Government Organizations
- Other (please specify _____)

3. What screening tests are used in your centre?

- Sickling test
- Haemoglobin Solubility Test / Sickledex
- Alkaline Gel Electrophoresis (cellulose acetate)

-
- Acid gel Electrophoresis (agar)
- Blood film
- High-Performance Liquid Chromatography (HPLC)
- Isoelectric Focusing (IEF)
- DNA or Molecular Testing
- Other (please specify _____)
4. Do you follow a standardised algorithm/pathway for laboratory diagnosis of SCD?
- YES
- NO
- If yes, algorithm/pathway origin (e.g. hospital standards, national/international guidelines, etc) ...
5. In what setting are the specimens taken for screening?
- Blood sample taken by midwife
- Blood sample taken from immunization clinics / well-baby clinics
- Traditional birth assistants
- Others (Please specify _____)
6. Is training provided to staff involved in taking blood samples for sickle cell disease screening in your healthcare facility? YES NO
- a) Is this mandatory? YES NO
- b) How often is this training made accessible to staff responsible for collecting blood spots?
- 6 monthlies
- Yearly
- 2-yearly
- Never planned
- Others specify

C. SCD management

1. Who provides the treatment / advice at your facility?

- Doctors
- Nurses
- Health care assistants
- Community extension workers
- Parents/patients with SCD
- Others, please specify

2. Do you have enough supplies for treatment at your facility?

- YES
- NO

3. Who pays for treatments at your facility?

- Families out of pocket
- Health Insurance
- Free medical provision
- Children are exempted from paying
- Others, please specify

4. What routine tests do you offer at your facility?

	In adults	In children
Blood Pressure		
Eye examinations/ Vision		
Haemoglobin screening		
Kidney Screening		
Learning assessments		

Malaria screening		
Psychological screening		
Stroke screening		

Other (Please specify) _____

5. Do you manage acute and chronic complications in your facility? (e.g. acute and chronic pain, infections).

Only acute complications

Only chronic complications

Both

6. Which treatment options are available at your facility?

Hydroxyurea

Folic acid

Infection prophylaxis

Transfusion

Other (Please specify) _____

7. Do you perform microbiological testing to optimise infection treatment? YES NO

8. What type of blood transfusion do you provide at your facility?

Simple (Top-Up) Blood Transfusion

Exchange Blood Transfusion

9. Which infection prophylaxis is available at your facility?

Pneumococcal Vaccination

Meningococcal Vaccination

Antimalarials / Mosquito nets

Other (Please specify) _____

10. Do you manage pregnant women with sickle cell disease at your facility?

Yes

No

11. If yes, how many pregnant women do you manage every year? About _____

12. Is your facility equipped to perform the following pre-natal diagnosis techniques?

Chorionic villous sampling (CVS)

DNA analysis

Pre-implantation genetic diagnosis (PGD) after in-vitro fertilization

Detection of foetal biomarkers in maternal blood

Other, please specify

D. Program Management: Coverage and Surveillance

1. Approximately, what is the screening coverage in your facility, if any (newborns, children and adults screened with the recommended interval)?

Newborns and Infants (0-6 months)

Young Children (7 months- 5 years)

Primary school age (6- 10 years)

Junior secondary (11-14 years)

Senior secondary school (15-17 years)

Adults (18 years and older)

DON'T KNOW

2. Of the individuals who are screened in your centre, how many receive follow-up education/counselling/treatment (please indicate the percentage)?

Newborns and Infants (0-6 months) _____

Young Children (7 months- 5 years) _____

Primary school age (6- 10 years) _____

Junior secondary (11-14 years) _____

Senior secondary school (15-17 years) _____

Adults (18 years and older) _____

3. (a). Is there a functioning system to track patients who require follow-up care and to reduce the number of patients lost to follow-up?

YES (If yes please list the name of the system used to track patients who require follow-up care _____)

NO

(b). if YES, by what means _____

4. How often do patients in steady state have regular clinical assessment?

Assessment	5-6 times/year	3-4 times/year	Twice year	Annually	Bi-Annually	Other
History indicative of specific features of sickle cell disease						
Physical examination and vital signs						
Complete/Full Blood Count						
Liver Function Tests						
Total plasma protein with albumin globulin fraction						
Kidney Function Test						

Echocardiography to detect pulmonary hypertension						
Ophthalmology review						
Dental review						
Ear Nose Throat review						
Transcranial Doppler Ultrasonography						
Other, please specify						

E. Counselling and Education

1. Do you conduct education/counselling for the following subjects?

Parents of SCD children found to have SCD?	YES	NO
School aged children found to have SCD?	YES	NO
Adults found to be carriers of SCD trait?	YES	NO
Adults who have SCD?	YES	NO

2. Which type(s) of education/counselling are offered to the following subjects categories?
(Check all that apply)

	Diagnosis and Genetic Counselling	How to identify important or serious symptoms	Ongoing Treatment and Health Care Management	Psychosocial coping related to illness	Other	No education/counselling is recommended in existing guidelines
--	-----------------------------------	---	--	--	-------	--

Parents of SCD children found to have SCD							
School aged children found to have SCD							
Adults found to be carriers of SCD trait							
Adults who have SCD							

3. Who provides education/ counselling to the following subjects categories? (Check all that apply)

	Primary Care Provider	Screening Doctor	Genetic Counsellor	Community Health Worker	Village Health Council Member	Religious Leader	Family Member (Please Specify)	Other (Please specify)
Parents of SCD children found to have SCD								
School aged children found to have SCD								
Adults found to be								

carriers of SCD trait								
Adults who have SCD								

11. Do you educate your patients with SCD on self-management aspects of their disease (e.g. recognition of early features of crises, information about how to avoid vaso-occlusive complications, pain treatment)?

YES

NO

12. Do you educate the SCD patients in steady state to have regular clinical assessment at the out-patient clinic?

YES

NO

13. Do you educate parents of children with SCD on what to expect as normal occurrences in patients with SCD and how to look for signs of more serious events?

YES

NO

14. Who of the two parents of children with SCD is more frequently involved in education/counselling activities?

The mother

The father

Both

F. SCD GUIDELINES

1. Do you know and adopt the *National Guideline for the Control and Management of Sickle Cell Disease released by the Nigerian Federal Ministry of Health in 2014?*

-
- I know and I use them
 - I know them but I do not use them
 - I don't know them

2. Please list or link all the other clinical guidelines you follow in your centre for the management of Sickle Cell Disease patients (provide a link, where available)

3. What are the main burdens limiting adherence to the guidelines?

- Poor equipment/resources
- Time constraints
- No proper training received
- Not relevant for our setting
- Other, please specify _____

G. FINAL COMMENTS

How do you find this questionnaire?

- Easy to complete
- Neither easy, nor difficult to complete
- Too much detailed to be completed

The compilation of this questionnaire involved (n) ____ persons to be involved in my centre and took me around (time estimate) _____ to be completed.

What would you like to add as item to be investigated? _____

What would you like to modify as item to be investigated? _____

5.2. Annex 2 – Poster on *Analysis of the organisation of healthcare centres managing Sickle Cell Disease in Nigeria*

Analysis of the organisation of healthcare centres managing Sickle Cell Disease in Nigeria

A.D. Sunday¹, A.Didio², L. Ruggieri², F. Bonifazi², A. Landi², L.Dogara^{3*}, PDB Inusa⁴

¹ Pediatrics Department, Barau Dikko Teaching Hospital, Kaduna State University, Kaduna State, Nigeria.

² Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus, Via Abate Eustasio, 30 – 70010 Valenzano (BA), Italy

^{3*} Department of Haematology and Blood Transfusion, Faculty of Basic Clinical Sciences, Kaduna State University College of Medicine

⁴ Evelina London children's hospital, Guys's and St Thomas NHS Foundation trust

Background

In the framework of the European research project "African Research and Innovative initiative for Sickle cell Education: Improving Research Capacity for Service Improvement" – ARISE project, a **cross-sectional, web-based pilot survey was designed to map and assess the organisation of Nigerian centres managing Sickle Cell Disease (SCD) patients**. To achieve effective NBS, it is essential to describe the state of SCD centres that will provide ongoing care for infants diagnosed with SCD

Methods

The questionnaire for the online survey was developed in collaboration with the ARISE Steering Committee in line with published criteria for comprehensive SCD management. It investigated facilities' characteristics including SCD management, screening services, counselling and education. Questionnaire was administered to selected facilities (16, including paediatrics and adults' services) using an online system (Limesurvey). SPSS software was used for the analysis.

National Health Research Ethics Committee of Nigeria
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Results

10 answers were received, from 2 secondary and 8 tertiary care facilities. They include University of Abuja Teaching Hospital (UATH), University of Ilorin Teaching Hospital (UIH).and both adults and paediatrics facilities from Ahmadu Bello Teaching Hospital (ABUTH), Barau Dikko Teaching Hospital (BDTH) General Hospital Kafanchan (GHK), Federal Medical Centre, Katsina (FMC Katsina).

Results show that:

- there is *no online SCD patient registry* at the investigated facilities
- all the facilities perform *basic laboratory tests on SCD patients*
- most of facilities (9/10) adopt the *National Guidelines* for the control and management of SCD patients
- The percentage of coverage of individuals screened receiving follow up education/counseling/treatment ranges from 45% to 56%, mostly adults.

Screening services are paid out of pocket by the patients in 8 facilities or sponsored by other non-government organisations in 2.

Concerning test type for SCD screening, all facilities perform Alkaline Gel Electrophoresis, more than one half blood film. Full details of test type is available in fig.2

Screening test Facilities	Sickling test	Haemoglobin Solubility Test/ Sickledex	Alkaline Gel EF	Acid gel EF	Blood film	HPLC	IEF
UATH	-	-	+	-	+	-	-
UIH	-	-	+	-	-	-	-
ABUTH (adult)	-	-	+	-	+	-	-
ABUTH (paed)	-	-	+	-	+	+	-
BDTH (adult)	-	-	+	-	+	-	-
BDTH (paed)	-	-	+	-	-	-	-
GHK (adult)	-	-	+	-	-	-	-
GHK (paed)	-	-	+	-	-	-	-
FMC (adult)	+	+	+	-	+	-	-
FMC (paed)	-	-	+	-	+	-	-

Fig. 2 type of tests performed in the investigated facilities

Only 1 of these 10 centres of excellence has SCD screening services delivered by a community staff. 5 centres delivered SCD screening services as part of special campaigns and 6 as part of maternal and child health care services (fig. 1)

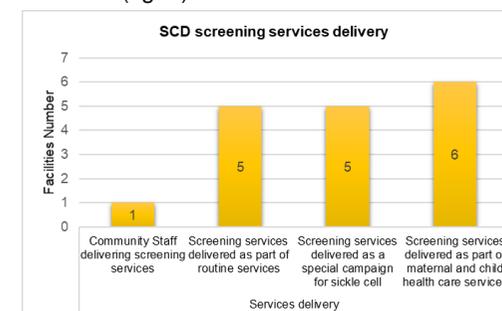


Fig. 1 SCD screening services delivery

Conclusion and next steps

There is potential for an excellent management of SCD patients in Nigeria.

Improvements are possible, especially in terms of online registries to assess data for planning and research, health insurance and good policy to encourage patients to attend the clinics.. After this initial pilot testing, the survey will be reviewed and extended to cover around 70% of Nigerian centres managing SCD patients