



ARISE

African Research And Innovative
Initiative For Sickle Cell Education

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

The ARISE project is an EU funded four year programme aimed at creating an interagency and multidisciplinary staff exchange programme between researchers, early start investigators and other relevant staff members of the partner institutions to share best practices in Newborn Screening, diagnosis and treatment of SCD, leading to improvement in overall disease outcome. A large secondment plan between EU and non-EU countries will enable collaborative research and training initiatives, covering the following topics: Sickle Cell Disease (SCD) prevalence, genotypes and phenotypes, existing “best practices” for Newborn Screening and early diagnosis, engagement with patients, families and policy makers to determine barriers to Newborn Screening, lab diagnosis and quality assurance systems for population screening and treatment protocols for the management of common SCD complications and transition from paediatric to adult care and health promotion strategies and nutrition. These topics of the project are set out to be achieved under the expertise and management of eight work packages.

The ARISE Project consortium is composed of twenty-three partner organisations from EU (Italy, France, UK and Cyprus) and non-EU countries (Nigeria, Lebanon, Kenya and USA). The project governance includes a Project Management Team who oversee the day-to-day management of the project. Whist the Steering Committee provide Strategic direction and support to the Project Management Team.

Learn more about the project by visiting our [website](#), and or join us on Twitter @_Project_ARISE or LinkedIn ARISE initiative

MEET OUR TEAM

Project Management

Professor Baba Inusa, Project Scientific Coordinator
Fedele (Duccio) Bonifazi, Project Coordinator
Serena Ottomano, Project Manager
Raleen Fernandes, Scientific Programme Manger
Stephanie Quirk, Project Management Team member
Lucia Ruggieri, Project Management Team member
Antonella Didio, Project Management Team member

Steering Committee

1. F. Bonifazi (FGB) - as Project Coordinator
2. S. Ottomano (FGB) - WP1 Leader
3. L. Ruggieri (FGB) - as WP2 Leader
4. J. Elion (INSERM) - WP3 Leader
5. B. Inusa (GSTT) - as Project Scientific Coordinator and WP4 Leader
6. M. Kleanthous (CING) - as WP5 Leader
7. P. Milligan (LSHTM) - as WP6 Leader
8. S. Quirk (GSTT) - as WP7 Leader
9. V. Giannuzzi (FGB) - as WP8 Leader
10. L. Hsu (UIC) US representative
11. B. Ogutu (SU) Kenya representative
12. M. Abboud (AUB) Lebanon representative
13. J. Olu Funke Lawson (UA) Nigeria representative
14. S. Scott (LSHTM), UK Representative
15. R. Yalma (UA), Nigeria Representative

The Partner Organisations

Guy's and St Thomas' NHS Foundation Trust (UK)
Fondazione per la Ricerca Farmacologica Gianni Benzi onlus (Italy)
Lagos State University (Nigeria)
University of Abuja (Nigeria)
University of Ilorin (Nigeria)
International Foundation Against Infectious Diseases in Nigeria – IFAIN
(Nigeria)
Zankli Medical Centre (Nigeria)
Sickle Cell Cohort Research – Score Foundation (Nigeria)
Azienda Ospedaliera
American University of Beirut (Lebanon)
Institut National de la Sante et de la Recherche Medicale (France)
The Cyprus Foundation for Muscular Dystrophy Research (Cyprus)
University College London (UK)
The Royal College of Pathologists (UK)
University of Illinois at Chicago (USA)
London School of Hygiene & Tropical Medicine (UK)
Strathmore University (Kenya)
Ahmadu Bello University (Nigeria)
Kaduna State University (Nigeria)
Kaduna State Assembly (Nigeria)
PANAF schools (Nigeria)
Barau Dikko Teaching Hospital (Nigeria)



ARISE TRAIN-THE-TRAINER WORKSHOP

ABUJA, NIGERIA

SEPTEMBER 11TH – 13TH 2019



WORKING ALONE MAY GET YOU TO YOUR DESTINATION FASTER

BUT WORKING TOGETHER AS A TEAM GETS YOU FURTHER.

- **WORKSHOP DELEGATE**

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

INDEX

1. WORKSHOP EXECUTIVE SUMMARY
2. WORKSHOP PROGRAMME
3. SESSION SUMMARY
 - a. DAY1
 - b. DAY 2
 - c. DAY 3
4. APPENDICES
 - a. LIST OF DELEGATES
 - b. LINKS TO VIDEOS
 - c. COPY OF DAY 3 GROUP ACTIVITY
 - d. COPY OF CERTIFICATE OF PARTICIPATION
 - e. COPY OF BLANK EVALUATION FORM & SUMMARY
 - f. WP3 OBJECTIVES
 - g. WP4 OBJECTIVES

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

1. Workshop Executive Summary

As part of the programme work package (wp) 3 & 4 objectives, the African Research and Innovative Initiative Education for Sickle Cell (ARISE) project management team along with Guy's & St Thomas' NHS Foundation Trust, INSERM & the Royal College of Pathologists (RCPATH), Partner organisations and Work Package leaders delivered their first train-the-trainer workshop in Abuja, Nigeria focusing on enhancing knowledge and skills of professionals including Laboratory Scientists, Nurses, Medical Doctors, Community Workers and Traditional Birth Assistants (TBAs). The main workshop venue was the Reiz Continental Hotel and the Laboratory practical sessions were held at the International Foundation against Infectious Disease in Nigeria (IFAIN) Laboratory. A total of 50 delegates were nominated by their institutional leads to attend the workshop (**Appendix 1**). The workshop faculty included a total of 27 experienced and knowledgeable speakers who are experts in the field of SCD, and are known for their contribution to making lives better for patients living with the condition.

Ahead of the workshop there was a survey conducted which helped identify gaps in current practice. The survey focused on 12 key areas which included Laboratory type, level & affiliation, staffing, location & population served, tests, quality systems & accreditation, areas for improvement, sample processing, quality assurance, staff, communication, management and networking. A total of 7 professionals, which included Head of departments/laboratories and Laboratory scientists completed the survey. The results demonstrated the presence of a mixture of urban & rural provision and a communication strategy with primary health care systems. Currently there is a wide range of tests carried out with basic infrastructure. Key strengths is an existing defined leadership structure and existing good procedures for dealing with emergency specimens. There is room for protocol developments and strict adherence to standard operating procedures (SOP). Furthermore the key areas for improvement included laboratory expansion possibilities, developing a robust staff management system including personal development plans & human resources, initiatives to maintain version control of SOPs, how to barcode samples for easy tracking, identifying different laboratory analysers, how to improve average turn around for laboratory results, developing laboratory staff training manuals, conducting regular staff improvement surveys, developing a well-defined sample processing and handling pathway.

The gap analysis results helped in outlining the overarching topics of the training which included; an overview of New Born Screening and Sickle Cell Disease, insight into other sickle cell related projects, counselling, sample collections & transportation, laboratory skills, information & data management, comprehensive care & follow-up clinics and essential skills.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

The content of the workshop tied in well with the key objectives of WP 3 & 4. For wp 3 which is a) To develop and implement a comprehensive programme in population screening management approached including techniques for haematological analysis, with emphasis on identification of SCD carriers and propose a prevention program of affected births where suitable and/or acceptable (tasks 3.1, 3.2). b) To improve the quality and capacity of laboratory diagnostic testing services in relation to the diagnosis, treatment and monitoring of SCD through baseline assessment, training and mentoring of laboratory health workers, managers and other allied staff. For wp 4 which is to determine the feasibility of implementing a Newborn SCD Screening Programme that is sustainable in African countries to be achieved by providing training about the UK NBS database, training in management of SCD, development of protocols and cognitive screening.

In summary, the workshop served as one of the first successes in the journey of implementing a robust NBS pathway in Nigeria. It was an opportunity which brought together professionals and provided them with a platform to brainstorm and learn.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

2. Workshop Programme

WELCOME	09.00 – 09.15	Welcome Professor Baba Inusa
	09.15 – 09.30	House keeping Ms. Raleen Fernandes & Ms. Kelley Price
	09.30 – 10.00	Recent studies in Africa – REACH & NoHARM Professor Kolade Ernest
		Overview of structure of healthcare in Nigeria and newborn screening - Why undertake an historical perspective Dr. Jonathan Gajere
	11.00 – 11.20	Morning break
	11.20 – 11.50	What can we learn from other programmes? Professor Jacques Elion
SESSION 2 INSIGHT INTO OTHER SICKLE CELL RELATED PROJECTS Opportunities for partnerships, networking and collaboration, learning from other organisations	11.50 – 12.20	ARISE, ASH consortium, SPARCO, SAdACC, SickleGenAfrica, REDAC (generic) SPAN (SICKLE PAN AFRICAN NETWORK) & sickle cell coalition Dr. Livingstone Dogra & Mr. Augustine Kwabena Asubonteng
	12.20 – 12.50	Existing programmes to enhance newborn screening for Sickle Cell disease in Africa Professor Obiageli Nnodu
SESSION 3 COUNSELLING, SAMPLE COLLECTION & TRANSPORTATION Opportunity to broaden skills on genetic counselling and learn about sample collection, logistics and ethics.	12.50 – 13.20	Group discussion about morning activities. What have we learnt? Dr. Wale Atoyebi
	13.20 – 14.20	Lunch
	14.20 – 14.50	Other NGO's e.g. Safiya, gender awareness trust / Nursing / CHEWS Professor John Dada & Miss. N'zallah Zamani

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	14.50 – 15.20	Logistics including forms, sampling, demographics, transportation & storage Miss. Gloria Bahago, Mr. Augustine Kwabena Asuboteng & Mrs. Grace Olanipekun
	14.50 – 15.20	Confidentiality, breaking bad news and counselling Mrs. Nkechi Anyanwu
	15.20 – 15.40	Afternoon break
SESSION 4	15.40 – 16.10	Newborn screening App & database development Mr. Augustine Kwabena Asuboteng
INFORMATION & DATA MANAGEMENT	16.10 – 16.40	Database development – registries Ms. Robyn O'Loughlin
Agreed data entry platform, GDPR overview and reach a point where there is a single lead for each lab.	16.40 – 17.10	Haemoglobinopathy Registries / Dashboards Dr. Wale Atoyebi & Professor Jacques Elion
	17.10 – 17.40	What can we learn from other programmes? Miss Gloria Bahago
	17.40 – 17.50	Day 1 summary discussion group Dr. Wale Atoyebi
	17.50 – 18.00	Day 1 Close Professor Baba Inusa

DAY 2 – DOCTORS, NURSES, COMMUNITY HEALTH WORKERS & TBAs

WELCOME	08.00 – 09.00	Breakfast & day 2 registration
	09.00 – 09.15	Welcome Professor Baba Inusa
SESSION 5	09.15 – 9.45	Registering patients University of Abuja – Professor UCHE Unne-Agwumadu
COMPREHENSIVE CARE & FOLLOW-UP CARE CLINICS	9.45 – 10.15	Primary health care first initial assessment and counselling - infrastructure already in place. General hospital. Specialist hospital

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

90% of babies' effective treatment of diagnosed patients.		once a year. How the three tiers can be linked together. Dr Oluseyi Oniyangi
	10.15 – 10.45	Routine screening of children. Training someone to do Transcranial Doppler (TCD) Dr E. David
	10.45 - 11.00	Break
	11.00 – 11.30	Monitoring & Evaluation Ms. Kelley Price & Ms. Raleen Fernandes
	11.30 – 12.00	Kaduna NBS programme and history Prof Stephen Obaro
	12.00 – 13.00	Lunch
	13.00 – 14.00	Management protocols Dr Olu Funke Juliana Lawson, & Professor Hafsah Ahmad
SESSION 6	14.00 – 14.30	Retention Strategies for Life Course Studies of Sickle Cell Disease in Nigeria Dr Ramsey Yalma
ESSENTIAL SKILLS	14.30 – 15.30	Communications Mrs Nasara D. Ifere, Mr Aliyu Mande & Ms Esther Gani
Enhancing communication skills & gaining a deeper understanding for roles and responsibilities	15.30 – 16.00	Roles & responsibilities Professor Abdulaziz Hassan & Dr Wale Atoyebi
	16.00 – 16.50	Day 2 summary discussion group Professor Baba Inusa
	17.00	Day 2 close Professor Baba Inusa

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

DAY 2 – LABORATORY STAFF ONLY

WELCOME	08.00 – 09.00	Breakfast & day 2 registration
SESSION 7	10.00 – 10.30	Laboratory staff only - transfers from hotel to laboratory
	10.30 – 11.00	Principles of IEF for newborn screening /protocols Oluwadamilola Fakolujo & Professor Jacques Elion
	11.00 – 11.30	Quality control, good laboratory practice/ SOP development (generic) Mrs Grace Olanipekun
	11.30 – 11.45	Break
	11.45 – 12.15	Accreditation Dr Wale Atoyebi
	12.15 – 12.45	Automation Abbas Adam
	12.45 – 13.15	Feedback on the laboratory gap assessment survey June 2019 Dr Wale Atoyebi
	13.15 – 14.15	Lunch
	SESSION 8	14.15 – 15.15
15.15 – 16.15		Demonstration of the newborn IEF procedure / NEQAS morphology slides assessment exercise All (facilitated by Dr Wale Atoyebi)
16.15 – 17.00		Summary, close & transfers from the laboratory to the hotel (join the main group for remaining talks and activities, refer back to the schedule for doctors, nurses, CHEWS & TBAs)

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	Dr Wale Atoyebi	
--	-----------------	--

DAY 3 – ALL PARTICIPANTS

WELCOME	08.00 – 09.00	Breakfast & day 3 registration
	09.00 – 09.15	Welcome Professor Baba Inusa
SESSION 9 Interactive actives to consolidate learning over the last two days.	09.15 – 10.15	E-Learning & Inspirational clips
	10.15 – 12.00	Interactive learning group activity - part 1 Ms Kelley Price & Mrs Raleen Fernandes
	12.00 – 12.40	Summary Professor Baba Inusa
	12.40 – 13.40	Lunch
Presentation Ceremony	13.40 – 15.00	Presentation of certificates Professor Baba Inusa Dr Wale Atoyebi Professor Jacques Elion

3. Session Summary - Day 1

SESSION 1	
	<p>Welcome Professor Baba Inusa welcomed delegates & faculty and opened the workshop. It was exciting to see the enthusiasm and dedication of all participants. Professor Inusa provided a brief overview of the African Research and Innovative Initiative Education for Sickle Cell (ARISE) programme.</p> <p>House keeping Ms. Raleen Fernandes & Ms. Kelley Price provided an overview of the day and covered key house keeping issues.</p> <p>Overview of structure of healthcare in Nigeria and newborn screening - Why undertake an historical perspective Dr. Jonathan Gajere provided a historical perspective of the structure of healthcare in Nigeria & new born screening. His presentation covered some key topics which included</p>

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	<p>Introduction on population facts and figures, levels of health care deliveries, healthcare financing, health management information system (HMIS), newborn screening and challenges faced.</p>
	<p>What can we learn from other programmes? Professor Jacques Elion provided a detailed insight on other African programmes which was a fantastic opportunity to learn and understand the project focus areas and achievements.</p>

SESSION 2

INSIGHT INTO OTHER SICKLE CELL RELATED PROJECTS

Opportunities for partnerships, networking and collaboration, learning from other organisations



ARISE, ASH consortium, Sparaco, SADaCC, SickleGenAfrica, REDAC (generic) SPAN (SICKLE PAN AFRICAN NETWORK) & sickle cell coalition

Dr. Livingstone Dogara discussed the opportunity that ARISE project offers through collaboration with other sickle cell initiatives ongoing within consortium partners including Stroke Prevention in Nigeria (SPIN), The Sickle Pan-African Research Consortium (Sparaco), American Society of Haematology (ASH), Kaduna State Newborn Screening of Sickle Cell Disease (KD-NBS) and African Research Innovative Initiative for Sickle Cell Education (ARISE). The challenge is on achieving the balance in making this a joint up approach for the benefit of the clients with sickle cell disease and system He reported on the progress being made in getting Kaduna State on board the ARISE project and other associated programmes.

Existing programmes to enhance Newborn screening for Sickle Cell disease in Africa

Professor Obiageli Nnodu, Nigeria’s lead for SPARCO spoke about barriers to NBS for SCD in African countries and her topics included inadequate laboratory infrastructure, transport systems and trained health care workers. With newer point of care test kits, screening can be undertaken on existing public health programs to detect babies with SCD in resource limited settings. The Newborn Screening Translational Research Network, The National NBS and Global Resource Centre have developed resources and support systems for NBS which can be utilized by all countries. Knowledge of available resources will help to deploy them in NBS and early intervention programs to reduce the burden of SCD globally.

SESSION 3

COUNSELLING, SAMPLE COLLECTION & TRANSPORTATION

Opportunity to broaden skills on genetic counselling and learn about sample collection, logistics and ethics.

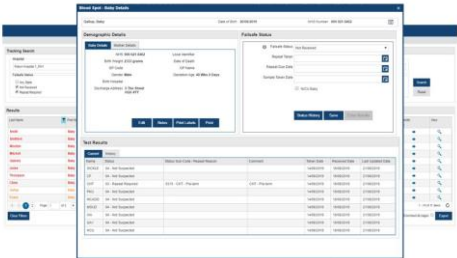
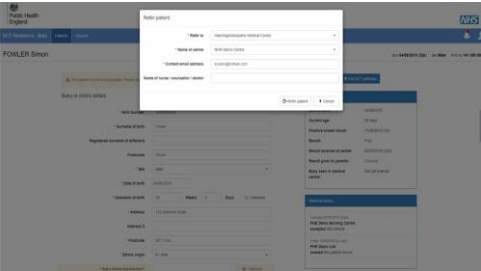
Recent studies in Africa – REACH & NoHARM

	<p>Professor Kolade Ernest gave the group a detailed insight on the difficulties faced in Africa, he reported the varying incidence of SCD in Nigeria ranging from 1.7 to 2.7% from different pilot studies in the country, and most recent from North West Nigeria 1.7% . He then gave detailed information on the REACH & NoHARM projects and shared the conclusion of each project. NOHARM conclusions indicated that Hydroxyurea (hydroxycarbamide) provided significant clinical and laboratory benefits which suggested that it would be safe and effective across sub Saharan Africa. Hydroxyurea did not increase the incidence or severity of malaria events in sub Saharan Africa. REACH conclusions suggested Hydroxyurea treatment was feasible and safe in children with Sickle Cell Anaemia in Sub Saharan Africa. Hydroxyurea reduced clinical events and is recommended for wider access and use especially in sub Saharan Africa.</p> <p>Other NGO's e.g. Safiya, gender awareness trust / Nursing / CHEWs (Community Health Extension Workers)</p> <p>Miss. N'zallah Zamani delivered a lively and energetic presentation highlighting the work and achievements of her organisation. N'zallah gave a passionate presentation on the need for patient advocacy and shared personal anecdotes by the Safiya foundation and made appeal for support. .</p> <p>Logistics including forms, sampling, demographics, transportation & storage</p> <p>Miss. Gloria Bahago a Nurse at the Sickle Cell Research Unit in Barau Dikko Teaching Hospital (BDTH) provided an overview of Dry Blood Spot (DBS) testing and her topics covered the process and protocol of sample transportation, associated documentation, result to end user patient tracking and lost to follow up, registration in to routine clinic, follow up, transition through youth and adolescent clinic and finally lessons and challenges.</p> <p>Mrs. Grace Olanipekun, Laboratory Manager at the International Foundation Against Infectious Disease in Nigeria Laboratories gave a detailed presentation covering logistics around DBS which included collection and transportation of dried blood spot cards, pre collection and</p>
--	--

	<p>collection process, temporary storage, transportation and transmittal forms.</p> <p>Confidentiality, breaking bad news and counselling</p> <p>Mrs. Nkechi Anyanwu delivered an interactive session educating the group about the importance of confidentiality & counselling. Mrs. Anyanwu who is a Community Matron at Guy’s & St Thomas’ NHS Foundation Trust shared with the group processes followed in the UK. From feedback received the session was immensely helpful to delegates in understanding the importance of counselling and the impact it has if done in an effective & structured way. Mrs Anyanwu discussed case scenarios in order to relay the message effectively to the community health workers in the audience. The counselling programme may be led in a number sites by CHEWs.</p>
--	---

**SESSION 4
INFORMATION & DATA MANAGEMENT**

Agreed data entry platform, General Data Protection Regulation (GDPR) overview and reach a point where there is a single lead for each lab.

<p style="text-align: center;">The failsafe System</p>  	<p>Newborn screening App & database development</p> <p>Ms. Robyn O’Loughlin demonstrated the failsafe system used to capture the results of the heel prick test, which screens for 9 serious conditions. The test is offered to every baby born in the UK, ideally when they are 5 days old. The session also covered the main aims, functions and benefits of a new system developed for roll out across England. The new system has been designed in order to facilitate the referral process when babies test positive for sickle cell or thalassaemia. Moreover, it was explained how the new system links with the National Haemoglobinopathy Registry (NHR), a consented register of all patients with haemoglobinopathies in the UK. The talk also emphasised how these processes assimilate in order to provide important and valuable insights into the effectiveness of the NHS sickle and thalassaemia SCT screening programme in England.</p>
	<p>Database development – registries</p> <p>Mr. Augustine Kwabena Asuboteng delivered an informative session on the app currently being used in Ghana to capture Newborn screening results. Mr. Asubonteng even delivered a live presentation of the working of the app and the entire</p>

New Born Screening App



Newborn Screening Program App Manual



Overview

This manual belongs to

Facility: _____
 Focal Person: _____
 Public Health Nurse: _____

This manual will teach you:

1. The basics of your phone
2. What CommCare is
3. How to use CommCare
4. How to use the Newborn Screen Program App
5. Troubleshooting with common problems

In case of general problems, please contact:

In case of technical problems, please contact:

The CommCare System

CommCare is a mobile application that sends information to other phones and to the web. Only people with passwords can access this data.



process of creating a record, capturing data and saving information.

Day 1 summary discussion group

Dr. Wale Atoyebi summarised the day's talks and captured all key topics covered.

Day 1 Close

Professor Baba Inusa thanked faculty and delegates for their contribution to the days' events and closed the session.

3. Session Summary

b. Day 2

The format for day two saw doctors, nurses, and traditional birth attendants (TBAs) stay at the main venue for a series of talks. Whilst the laboratory staff, joined in a practical isoelectric focusing (IEF) demonstration, which took place in the Foundation Against Infectious Disease in Nigeria (IFAIN) laboratory.

<p>SESSION 5 COMPREHENSIVE CARE & FOLLOW-UP CARE CLINICS 90% of babies' effective treatment of diagnosed patients.</p>	
	<p>Welcome</p> <p>Professor Baba Inusa gave an opening speech and the Vice Chancellor of the University of Abuja who arrived earlier than scheduled. Later in the morning The Nigerian television Authority (NTA) came to interview Professor Baba Inusa and other key members of the ARISE consortium.</p>
	<p>Registering patients</p> <p>Professor Uche Unne-Agwumadu, Head of Paediatric Unit at the University of Abuja Teaching Hospital (UATH) provided some useful background information on the Sickle Cell Unit at the hospital. She then spoke about the patient recruitment process and shared some key patient statistics. The importance of collaboration was emphasised, this would enhance effective strengthening of systems.</p> <p>Professor Unne-Agwumadu then provided an overview of the care process and shared interesting pictures of leaflets used in clinics.</p>
	<p>Primary health care first initial assessment and counselling - infrastructure already in place. General hospital. Specialist hospital once a year. How the three tiers can be linked together.</p> <p>Dr Oluseyi Oniyangi delivered an engaging talk covering the role of Primary Health Care (PHC). SCD related counselling and education, SCD related assessments, linkages to other levels of care and overcoming the challenges. Dr Oniyangi effectively ran a question and answer session, this was well received and generated practical points for practitioners including CHEWs, Nurses and Doctors.</p>
	<p>Sickle Cell Disease: Routine screening of children including Transcranial Doppler (TCD)</p> <p>Dr Ekaete David's talk explored the different laboratory techniques carried out on patient specimens with the aim of diagnosing SCD. Also focused on</p>

	<p>Transcranial Doppler (TCD) Scans, which are most useful for children aged 14 years and below as a predictor of the risk of stroke.</p>
	<p>The Long Road to “ARISE” from Nigeria Professor Stephen Obaro, MD, FRCPCH, PhD Trustee, IFAIN. Professor of Paediatrics and Infectious Diseases, University of Nebraska Medical Centre, Omaha. NE, USA. Delivered a detailed history of the joint efforts he was involved in with Prof Inusa, Mrs Bola Ojo and Dr Olufunke Lawson with others from 2009 through Abuja, Kaduna state and Katsina state leading to the application for this EU grant on the compounds of SETRACO Nig Ltd. This has been a collaborative effort between individuals and intuitions in Nigeria, U.K.USA and evidence of persistence.</p>
	<p>Management protocols Dr Olu Funke Juliana Lawson, & Professor Hafsah Ahmad talks addressed this topic by sharing their experience and knowledge of the protocols in place at their organisations. Dr Juliana Olufunke Lawson, Paediatrician at Zankli Medical Centre, Abuja. Dr Lawson’s talk incorporated the organisation of clinical care, how to prevent infection, genetic and reproductive counselling, nutrition and monitoring of growth, development in children and transition to adult care. Furthermore, screening of specific complications of SCD and management of complications of SCD were included. Professor Hafsah Rufai Ahmad, Paediatrician at Ahmadu Bello University/Teaching Hospital Zaria spoke about vaso-occlusive crises, acute anaemia, infections, malaria, acute chest syndrome and acute splenic sequestration, and other acute complications of SCD.</p>
	<p>Retention Strategies for Life Course Studies of Sickle Cell Disease in Nigeria Dr Ramsey Yalma, Lecturer/Consultant Public Health Physician, at the Department of Community Medicine, at the University of Abuja. The objectives of the discussion Dr Yalma led were to enable participants to describe the retention strategies of newborn babies in prospective longitudinal studies to decide the retention strategies that may be effective in the proposed ARISE project Newborn Screening (NBS) and life course study in the Nigerian setting and to have some understanding of some of the contextual issues including the sociodemographic and characteristics.</p>
	<p>Communications Mrs. Nasara Danmaida Ifere, Director/School Administrator, Panaf schools, Barnawa, Kaduna, shared her knowledge and first-hand experience of SCD, the society and, education as a tool. Showing a teacher’s approach to</p>


ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	<p>enlightening and educating children between the ages of 5-10 and teenagers into young adults with the aim of prevention.</p> <p>Mr Aliyu Mande who is a Health Information Management Officer and community mobilizer provided a brief introduction on communication and dissemination plan for implementation. Mr. Mande spoke about Target/Identified resources for implementation of African Research and Innovative Initiative Education for Sickle Cell (ARISE) project. He also showcased the Information, Education and Communication (IEC) materials for implementation of ARISE project.</p>
<p>SESSION 6 ESSENTIAL SKILLS Enhancing communication skills & gaining a deeper understanding for roles and responsibilities.</p>	
	<p>Roles & Responsibilities in Achieving Effective Teamwork in the Laboratory</p> <p>Professor Abdulaziz Hassan, Ahmadu Bello University (ABUTH), Nigeria. Professor Hassan, in a very interactive and informative presentation, defined a laboratory and clinical laboratory. He discussed the different categories of staff who work in a haematology laboratory and clearly explained the difference between roles versus responsibilities. He concluded by showing each party is key to the success of a well-run programme. Delegates were also given a detailed talk on a laboratory workflow and the importance of a team working together.</p> <p>Day 2 summary discussion group</p> <p>Professor Baba Inusa facilitated a conversation that encouraged audience discussion and questions about the day's programme of talks.</p>

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

Laboratory staff

Please note, 21 participants were split into two groups due to the capacity of the laboratory. These sessions involved purely practical activity.

SESSION 7	
	<p>Isoelectric focusing (IEF) demonstration</p> <p>A demonstration of the isoelectric focusing (IEF) method was demonstrated by Mr Abbas Adam. The demonstration included DBS card punching, handling and loading the samples on the IEF gel, running the electrophoretic separation, to final drying of gel, hands on practice questions and answers with additional participation of Mr. Augustine Kwabena Asuboteng, Mrs Grace Olanipekun, Dr Wale Atoyebi and Prof Jacques Elion.</p>

3. Session Summary

Day 3

The format for day three provided a practical focus for doctors, nurses, Chew's and TBAs . Where the programme for laboratory focused on theoretical basis of the practical demonstration in the laboratory during day two. Therefore, the programme which comes first outlines the activities organised for all participants apart from laboratory staff, their programme of activity follows.

SESSION 8	
Interactive actives to consolidate learning over the last two days.	
	<p>Welcome</p> <p>Professor Baba Inusa gave a welcoming open to the third day and showed some Inspirational video clips to provide the group with some eLearning (Appendix 5).</p>
	<p>Interactive learning group activity</p> <p>Ms. Kelley Price & Ms. Raleen Fernandes set out a group activity with the overall objective being for each group to create an action plan, considering all that they had learnt from the previous two days, with an added focus of transitioning a patient from paediatric to adult care (Appendix 6). Participants apart from laboratory staff were divided into four groups by state, Abuja, Kaduna, Ilorin and Traditional Birthing Assistants and some community health workers. The three-part activity included a thirty-minute discussion, an hour for establishing their action plans and finally ten minutes to present back to the wider group in the room the plan that had been created. Professor Baba Inusa facilitated a panel type discussion after each presentation and the audience were</p>

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	<p>encouraged to ask questions to those that had presented their work. Please see below for some of the action points that came from one of the groups.</p>
<p>DISCUSSION 1</p>	<p>PLAN</p> <ul style="list-style-type: none"> • Identify community stakeholders with the help of residents in an area of interest. • Identification of traditional and religious leaders, again with the help of residents and paying advocacy visits to them. • Identify major gatekeepers of the community and train them in preparation to share important messages and educate individuals and groups within the community. They hope to involve the local chairman and engage his wife as part of this action. • Sensitisation of the community on SCD and NBS can then be carried out for the community, either in communal space, door-to-door depending on the human resource available. • Management of SCD after NBS and counselling of patients and caregivers by trained medical doctors, TBAs, PHC workers and other relevant trained persons. <p>DATA COLLECTION</p> <ul style="list-style-type: none"> • We will begin to collect data from the community engagement register which is already in existence. <p>FEEDBACK AND FOLLOW-UP</p> <ul style="list-style-type: none"> • Selected members of the team will follow up on enrolment of identified sufferers of SCD and assess how dedicated they are following their treatment plans. The persons nominated to carry out these follow-up visits will then report to higher authorities so that developments, challenges and other important issues will be captured and can be addressed accordingly.
<p>DISCUSSION 2</p>	<p>IN THE SHORT-TERM</p> <ul style="list-style-type: none"> • We are currently on the strategizing and re-strategizing stage to see what is working and what is not and where improvements can be made. • We must first establish the passion and commitment of individual members of the team to the cause • Need resources – awareness materials soft and hard

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	<ul style="list-style-type: none"> • In 1-2 months, team coordination made up of CHEWs, TBAs, CHOs and other community workers. <p>CHALLENGES</p> <ul style="list-style-type: none"> • Resistance from locals due to social resistance and to cultural sentiments; lack of aligned human resources because of differences in day to day activities of parties and involvement. <p>OVERCOMING CHALLENGES</p> <ul style="list-style-type: none"> • Establishing and maintaining a good relationship with gatekeepers and the community. Training up more people in the community to do what we do, this way we will have people on the ground at any given time. This will also promote stepdown training and mentoring for generations to come. <p>Please note: All these actions will require money to be implemented and as such we would appreciate financial support where possible.</p>
<p>RECOMMENDATIONS</p>	<ul style="list-style-type: none"> • Steering committees, if not already done so are created. • Appoint specific roles and responsibilities, so that willing individuals become accountable for certain tasks within the action plan being completed and to keep things moving. • Regular meetings to ensure that team things are on track and any issues or challenges that they may encounter can be addressed as a team. • The ARISE team should have follow-up calls to stay in-touch with progress being made and offer help and support where needed and to share relevant and important updates.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

SESSION 9	
LABOATORY SKILLS THEORETICAL SESSION	
	<p>Principles of isoelectric focusing (IEF) for newborn screening</p> <p>Mrs Grace Olanipekun’s talk explained the definition of how Isoelectric focusing is the electrophoretic method that separates proteins (haemoglobins) according to the isoelectric points and the principles and purpose behind it and why it is the most appropriate to use in the neonatal period.</p>
	<p>Quality assurance and, good laboratory practice</p> <p>Mrs Damilolia Fakolujo talked on standard operating procedures (SOP) and principles giving a step-by-step guide to quality assurance and good laboratory practice and standard operation procedures when using the isoelectric focusing (IEF) and the advantages of it.</p>
PLAN OF ACTION	<ul style="list-style-type: none"> • Feedback on the laboratory gap assessment survey June 2019 • Dr Wale Atoyebi used the Gap analysis report that was compiled in June from the results of the surveys that were completed by 6 laboratories. From this they prioritised the areas that needed to be addressed and agreed to focus efforts on making these changes first, which are as follows: <ul style="list-style-type: none"> • Lack of documentation – Kafanchan lab has examples of good documentation, such as SOPs. • Poor access to training opportunities – encourage use of online learning resources. • Lack of access to external quality assurance • Achieve full laboratory accreditation • A WhatsApp group has been set up between this group and is proving to be helpful in sharing of information
RECOMMENDATIONS	<ul style="list-style-type: none"> • Engage ASH and ask for their support in providing online learning resources. • Investigate whether NEQAS in the UK is able to support working towards laboratory accreditation in some way, as well as ASH. (Kafanchan and ABU already do some forms of NEQAS) • Aim to achieve full laboratory accreditation – Explore Nigerian Medical Laboratory Council.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	<p>Certificates of attendance</p> <p>Participants were awarded certificates recognising their contributions and attendance at the event. The certificates were signed by Professor Baba Inusa, ARISE Scientific Coordinator, Dr Wale Atoyebi, ARISE Clinical Lead on behalf of the Royal College of Pathologists and Professor Jacques Elion, Work package 3 lead (Appendix 7).</p> <p>Participants and faculty also completed an evaluation form, 59 forms were completed and returned to us (Appendix 8).</p>
	<p>Day 3 close</p> <p>Professor Baba Inusa thanked all faculty and participants for their contributions and engagement during the workshop.</p>

Workshop faculty



PROFESSOR BABA INUSA, UK

Lead Consultant Haemoglobinopathies,

Lead consultant haemoglobinopathies at Evelina London, a trustee of the UK Forum on haemoglobin disorders (2016< formerly National Secretary (2005-2016) and Convenor of Academy for sickle cell and thalassaemia (ASCAT) now in the 14th year. Founder of Sickle cell Cohort Research Foundation (SCORE), Nigeria (from 2010) to strengthen capacity building in Africa. Steering committee member of 6 New Drug Trials in SCD in the UK and co-chair SCD treatment, American Society of Hematology (ASH) sickle cell initiative for Africa since 2014.

Graduated MBBS, ABU Zaria Nigeria, 1984, Postgraduate fellowship, 1992, Postgraduate diploma, haematology, RPMS, UK, 1993, MRCP, 1995, Consultant shared care oncology, East and North Herts (1997-2002).

Main Research: SCD-Newborn screening and chronic organ damage.

Principal investigator 'African Research and Innovation Initiative for Sickle cell disease education –improving research capacity for service improvement.



ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

DR WALE ATOYEBI, UK
Consultant Haematologist

Dr Wale Atoyebi is lead for red cell disorders at the Oxford University Hospitals NHS Foundation Trust, Oxford and honorary senior clinical lecturer at Oxford University. Trained in medicine in Nigeria, he underwent his haematology training in Oxford. His main interests are haemoglobinopathies and disorders of iron metabolism including diagnostics utilising an Oxford NGS iron regulatory panel. He is member of the NHS England, Clinical Reference Group for Haemoglobinopathies and on the editorial board of the 2018 Standards for The Clinical Care Of Adults With SCD in the UK. He is also involved in collaborative research focused on strengthening healthcare systems by improving best practice in the diagnostics and management of SCD in sub-Saharan Africa. Recently appointed Royal College of Pathologists (UK) - clinical lead for the EU - H2020-MSCA-RISE-2018 (ARISE) program.



PROFESSOR JACQUES ELION, FRANCE
Université de Paris – Medical School

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

INSERM (National Institute of Health and Medical Research)

INTS (National Institute of Blood Transfusion)

Professor Elion received his MD from Paris Descartes and a PhD from Paris Diderot Universities. He was a Research Assistant at the Mayo Graduate School of Medicine, University of Minnesota and a Fogarty Scientist at NIH, Bethesda. Dr Elion is Professor of Molecular Genetics (Université de Paris) and Visiting Professor (Universidade de São Paulo). He is the former Director of the Department of Medical Genetics at the Robert Debré Pediatric Hospital.

Dr Elion's research is focused on pathophysiology, prevention and global care of SCD and conducted at the INSERM Unit 1134 (National Institute of Blood Transfusion, Paris, and University Hospital of Guadeloupe). The Unit is part of the French Laboratory of Excellence on the Red Cell (GR-Ex). Dr Elion has developed extensive international collaborations notably in sub-Saharan Africa, India, the Caribbean and Brazil.



Dr. ABDULAZZIZ HASSAN, NIGERIA

Consultant Haematologist

Dr. Abdulaziz. Hassan graduated from Ahmadu Bello University (ABU) Zaria Nigeria with an M.B,B.S degree in 2000. Training in Haematology at the Ahmadu Bello University Teaching

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

Hospital (ABUTH) and a fellow (FMCPATH) of the National Postgraduate Medical College of Nigeria (NPMCN) in 2008 before obtaining a Doctor of Medicine (MD) in 2016.

Since 2009 he has been working as a Consultant Haematologist at the ABU Teaching Hospital and lectures at the ABU and is involved in the management and care of sickle cell disease and other haematological disorders. Dr. Abdulaziz Hassan has been an Associate Professor since 2014. Moreover, he is the North-West coordinator for the Sickle Cell Support Society of Nigeria and Secretary of the Nigerian Society for Haematology and Blood Transfusion (NSHBT) 2017-2019.



AUGUSTINE KWABENA ASUBONTENG B.A (Hon), GHANA
Research Officer IT

Augustine Kwabena Asubonteng graduated from the University of Ghana with B.A Sociology and Linguistics in the year 2014. He has also undertaken courses like; CommCare Application Building for Public Health Students, CommCare Fundamentals and Application Building at the Dimagi Academy.

He is currently the Research Officer IT at the Foundation under the National Newborn Screening Program for Sickle Cell Disease. He plays a key role in the creation and management of the Newborn Screening Application.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

He assisted in the recently published article “Relation Between Religious Perspectives and Views on Sickle Cell Disease Research and Associated Public Health Interventions in Ghana” in the Journal of Genetic Counselling.



MRS NKECHI ANYANWU (BSC HONS, RGN, RM), UK
Service Manager & Clinical Lead

Nkechi Anyanwu is a Service Manager and Clinical Lead for South East London Community Sickle and Thalassaemia services, for Guy’s and St Thomas’ NHS Trust and the Vice chair for Sickle Cell and Thalassaemia Association of Nurses, Midwives and Allied Professionals (STANMAP); as well as the co-lead for Nursing in the South Thames Sickle Cell and Thalassaemia Network (STSTN).

She has also been the senior haemoglobinopathy counsellor with clients, families and carers with Sickle Cell and Thalassaemia, since 1998. Providing management, professional and clinical leadership to a team of specialist haemoglobinopathy nurses delivering an integrated community based nursing service. Dedicated to increasing patients coping strategies in the community.



DR LIVINGSTONE GAYUS DOGARA, NIGERIA

Lecturer and Research Coordinator

Dr Livingstone Gayus Dogara, MBBS, FMCPATH, ORCID 0000-0002-9603-6512, is a faculty member (Consultant Haematologist) at Kaduna State University, Barau Dikko Teaching Hospital. He completed specialty training in Haematology and Blood Transfusion at National Postgraduate Medical College of Nigeria, Lagos in 2015 and additional fellowship at Charlotte Maxeke Johannesburg Academic Hospital in South Africa in Haemophilia Care in 2016. Dr Dogara currently coordinates activities for the Nationwide multi-centre study of transition to adult centered sickle cell disease care in Nigeria (LREC/06/10/875), and the NIH funded “The Sickle Pan-African Research Consortium-SPARCO” (NHREC/01/01/2007-24/11/2017) and Additionally the ASH Africa (American Society of Hematology) initiative programme for newborn screening of sickle cell disease in Africa. Additionally, he is in mentorship training with Prof Johnny Mahlangu of the School of Pathology, University of the Witwatersrand.



PROFESSOR S KOLADE EARNEST

Professor of Paediatrics & Child Health

S Kolade Ernest is a Fellow and Facilitator of the West African College of Physician, a Fellow of the Royal College of Paediatrics and Child Health, a Faculty of the College of Health Sciences, University of Ilorin with more than 20 years of unbroken experience in Paediatric Haematology, Infectious diseases, International Child Health and Training consultancy. A Professor of Paediatrics & Child Health, University of Ilorin, well published with more than ninety publications. He is the Chairperson for the National Institute of Health (NIH), USA, Remote Site in University of Ilorin and University of Ilorin Teaching Hospital. For almost two decades had led the team caring for children in the University of Ilorin Teaching Hospital. The success of his efforts was heightened and maximized with his introduction of the use of Hydroxyurea in the care of children with SCD.



DR JONATHAN GYAWIYA GAJERE, NIGERIA
Director in the Ministry of Health in Kaduna State

Dr. Gajere Gyawiya Jonathan is currently a Director in the Ministry of Health in Kaduna State Ministry of Health overseeing clinical activities the tertiary, secondary and primary Health care facilities.

In addition to which he is a trainer on Emergency Obstetrics care, Lifesaving skill, Maternal Perinatal death review and surveillance, Interpersonal communications, Counselling in prevention of mother to child transmission of HIV, Post abortion care and newborn screening.

Dr Gajere did his National Youth Service (NYSC) at Cottage Hospital, Doma, Nasarawa State. Worked in General Hospital Lafia, 1992 to 1996 and studied at the faculty of Medicine, (1985 to 1990), masters in public health, Department of Community Medicine, Ahmadu Bello University, Zaria (2007).



PROFESSOR STEPHEN OBARO, USA

Professor of Pediatrics, Director of International Pediatric Research Program and Adjunct Professor with the Department of Microbiology and Pathology

Stephen is Professor of Pediatrics, Director of International Pediatric Research Program and Adjunct Professor with the Department of Microbiology and Pathology at the University of Nebraska Medical Center. Trained in Pediatrics, Immunology and Infectious diseases, he has over the past couple of decades acquired clinical and research experience across the continents of Africa, Europe and the North America.

He is a trustee and co-founder of International Foundation against Infectious Diseases in Nigeria (IFAIN), a non-governmental, not-for-profit organization that has established a platform for multidisciplinary research projects in infectious disease and training for graduate and postgraduate students. The IFAIN laboratory network also supports research projects in Liberia, Ghana through the Joint West Africa Research Group (JWARG) and Rwanda.



PROFESSOR Nnodu E. OBIAGELI, NIGERIA

Professor of Haematology and Blood Transfusion, Director, Centre of Excellence for Sickle Cell Disease Research and Training

Obiageli E. Nnodu is Professor of Haematology and Blood Transfusion, Director, Centre of Excellence for Sickle Cell Disease Research and Training, University of Abuja (CESRTA), Honorary Consultant Haematologist, University of Abuja Teaching Hospital Gwagwalada, Abuja, Nigeria. She is a founding member of Sickle CHARTA and Vice Chair of the Nigerian Sickle Cell Support Society (SCSSN) which works with the government and professional groups for the control of SCD in Nigeria. She serves on technical committees of the government on non-communicable diseases and has completed several national assignments related to SCD.

Professor Nnodu has NIH-funded clinical trial trainings and has participated in various clinical trials in haematology as Co- investigator, Principal Investigator and National –PI.

She is Nigeria PI for the Sickle Pan African Research Consortium (SPARCO), a Site Coordinator for the H3Africa SickleGenAfrica Consortium and the national coordinator of the American Society of Hematology African New-born Screening and Early Intervention Consortium. Professor Nnodu, a Chevening Scholar and alumnus of Imperial College, London is Chair Advocacy, Sickle Pan African Network (SPAN).

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT



GLORIA YIMI BAHAGO, NIGERIA

Nurse

Gloria Bahago has a special interest in Sickle cell disease. Her professional objective is to contribute to the development, efficient utilisation of resources and effective provision of nursing care to people, especially those living with sickle cell. With a focus on improving their quality of life.

Gloria is also currently involved in Stroke Prevention in the Nigeria (SPRING) trial, which is an NIH funded, multi-centre partial double blind randomised clinical trial in collaboration with Vanderbilt University Medical Centre, Nashville Tennessee on behalf of the Kaduna site.



GRACE M OLANIPEKUN, NIGERIA

Laboratory Manager

Mrs Grace Olanipekun currently serves as Senior Laboratory Scientist with IFAIN. She has experience in co-ordinating and implementing protocols and processes in infectious disease research. Earning her first degree in Medical Laboratory science at Ambrose Ali University Ekpoma and a master's degree in public health at the Ladoke Akintola University of Technology, Nigeria. Prior to her current role at IFAIN, She worked as an intern at the National Hospital, Abuja and as Assistant Manager in Health First Diagnostic center, a privately run laboratory service in Abuja. Since joining IFAIN, Mrs Olanipekun has served in various capacities supporting programmes in community awareness on Sickle Cell Disease, specimen collection and laboratory screening of samples using the HPLC-based BD Variant.



MS. ROBYN O'LOUGHLIN, UK
Project and Implementation Lead

Robyn works in the Antenatal and Newborn Screening team at Public Health England. For the past 18 months, she has been involved in developing and implementing the Sickle Cell and Thalassaemia Newborn Outcomes System nationally. She has recently started a new role leading on the Newborn Blood Spot Failsafe Solution, which serves to ensure that all newborn babies in England are screened and that results are recorded for all the 9 conditions screened for; this includes Sickle Cell Disease.



Dr. OLUSEYI ONIYANGI, NIGERIA

Consultant Paediatrician

Dr Oluseyi Oniyangi is a Consultant Paediatrician at the National Hospital, Abuja Nigeria. She holds an MBBS from Ahmadu Bello University Zaria, Nigeria, and Fellowship of West African College of Physicians (FWACP Paed), and International Paediatric Nephrology Association (IPNA).

She's a specialist in the care of children in general and those with sickle cell disease (SCD) in particular. She organized the sickle cell clinic of the National Hospital Abuja and is a resource person for trainings and community outreaches on SCD. She was a member of the editorial team that produced the SCD Policy and guidelines of care for Nigeria, has published academic articles on the subject, peer-reviewed same for publications in scientific journals, and participated in related research and clinical trials.



DR RAMSEY MSHELIZA YALMA, NIGERIA

Lecturer, Consultant & Public Health Physician

Ramsey is a Senior lecturer and consultant public health physician at the University of Abuja/Teaching Hospital, Nigeria. He is Medical graduate of the University of Nigeria and a Fellow of the National Postgraduate Medical College of Nigeria. Ramsey's areas of professional interest include Epidemiology, Biostatistics and Primary Health Care. He believes that one should not only work hard but also work smart and remain focused on one's set life and career goals. He thinks that in all the pursuit of knowledge and career one should not lose health and family.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

4. Appendices

A. LIST OF DELEGATES

Org	No.	Background
UATH	1	Lab Scientist
	2	Lab Scientist
	3	Medic
	4	Medic
	5	Nurse
Safiya Sickle Cell Foundation	1	Community
	2	Community
	3	Community
Zankli Medical Centre	1	Lab Scientist
	2	Lab Scientist
Fatsaam	1	Community
	2	Community
	3	Community
ABUTH	1	Lab Scientist
	2	Lab Scientist
	3	Medic
	4	Medic
	5	Nurse
	6	Nurse
BDTH	1	Lab Scientist
	2	Lab Scientist
	3	Medic
	4	Medic
	5	Nurse
	6	Nurse
Kafanchan	1	Lab Scientist
	2	Lab Scientist
	3	Medic
	4	Medic
	5	Nurse
	6	Nurse
	7	Nurse
Community Workers	1	Community
	2	Community
	3	Community
	4	Community
	5	Community
	6	Community
Traditional Birthing Assistants	1	TBA
	2	TBA
	3	TBA

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

	4	TBA
	5	TBA
IFAIN	1	Medic
University of Ilorin Teaching Hospital	1	Lab Scientist
	2	Lab Scientist
	3	Medic
	4	Medic
	5	Nurse
Ministry of health	1	Medic
Total	50	

B. VIDEOS FROM THE MORNING OF DAY 3

Please follow the link to the ARISE website where the videos shown on the morning of day 3 can be accessed.

<https://www.ariseinitiative.org/>

C. COPY OF THE PRACTICAL GROUP ACTIVITY FROM DAY 3

PUTTING LEARNING INTO PRACTICE

INSERT DATE HERE

We invite you to work together to see how much you've learnt in the last **INSERT NUMBER OF DAYS HERE** and to put your learning into practice. The exercise is in three parts and suggested timings for each section can be found next to the sub-headings. Please read this guidance document before you begin.

Discussion (30 minutes)

1. Reflecting and discussing as a group what you have all learnt and experienced over the last **INSERT NUMBER OF DAYS HERE** days. How will you take your learning to improve processes and ways of working within your organisation? In your group discussions consider:

TRANSITION

- At what age does a Sickle Cell patient transition from Paediatric to adult care?
- How far in advance do Paediatric and adult teams begin communications prior to a patient's transition?
- How do the Paediatric and adult teams communicate before, during and after the transition of a patient?
- What guidelines policies are in place around the transition of a Sickle Cell Patient?
- Your roles and responsibilities as an individual.
- Your work as a team.
- The institution as a whole.
- Collaboration beyond your organization.

Create a plan of action (1 hour)

2. Demonstrating how you will implement a practical short-term, mid-term improvements that came out of your group discussion. The plan should include 3-5 action points. All of the following should be considered:
 - Where are you currently at with making these improvements?
 - What steps need to be taken in order for each of them to happen?
 - What resources, time and human resources do you need to achieve this?
 - What challenges might be faced and how can these be overcome?
 - When in the next twelve months will you commit to making each of these improvements?
3. **Presenting your action plan (10 minutes)**

Nominate someone from your group to present your action plan to the whole room. You may decide to co-present, or take a section each.

D. COPY OF CERTIFICATE OF PARTICIPATION

I



CERTIFICATE
of
PARTICIPATION

AWARDED TO

Ado Maryam Saad

FOR ATTENDANCE AT THE EVENT

**ARISE Work package 3 improving laboratory diagnosis and quality assurance systems
for population screening**

11th to 13th September 2019

ORGANISED BY

ARISE Partners

Professor Baba Inusa, Project Scientific Coordinator

Dr Wale Atoyebi, Work Package 3 Clinical Lead, UK

Professor Jacques Elion, Work Package 3 Clinical Lead, France

E. COPY OF EVALUATION FORM



We value your opinion and would appreciate your feedback on the workshop. This will enable us to improve the work we are doing and enable us to continue where possible supporting you on the ARISE project.

Instructions on completing this form

Please indicate your level of agreement with the statements from 1- 7 listed below. There is also space further down to give written responses.

Once the form is complete please return it Kelley or Raleen.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. Expectations of the overall workshop have been met.				
2. The presenters were engaging.				
3. The presentation materials were relevant.				
4. The faculty were well prepared and able to answer any questions.				
5. The group activities and practical sessions were relevant and engaging.				
6. The length of the talks and group activities were appropriate.				
7. The pace of the talks and group activities was appropriate to the content and provided a quality learning experience.				

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

8. What have you most enjoyed about the three-day training workshop?

9. What have been your most valuable learnings and how will you apply it to your work?

10. What other topics would have been beneficial?

11. What other improvements could be made to the workshop?

12. What further support related to the project objectives would you like from the ARISE team after today?

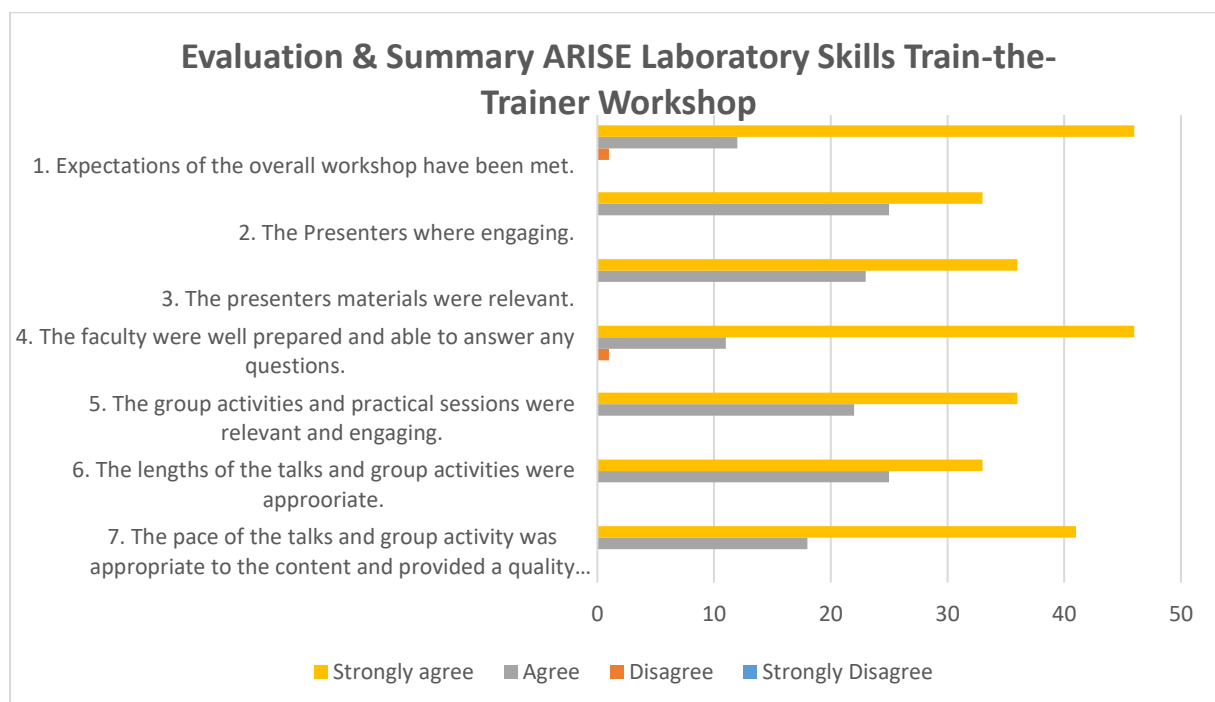
13. Any other comments...

THANK YOU FOR COMPLETING THIS EVALUATION FORM.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

Summary of Evaluation form

On the third day of the workshop delegates and faculty were provided with evaluation forms to complete (**Appendix 2**). Key feedback points captured are as follows;



Most Enjoyable Aspect of the workshop

Overall people enjoyed the presentations, discussions and engagement with colleagues from different backgrounds and organisations. General feedback about the planning of the workshop logistics, such as time management of talks, the quality of the workshop content, food and accommodation has been excellent.

Most valuable learning & further implementation

Delegates found the practical sessions using the isoelectric focusing (IEF) machine very helpful. It has enhanced their laboratory knowledge for newborn screening (NBS)

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

Delegates commented on training their colleagues back in their workplace and putting into practice what they have learnt. Participants found the session on counselling and breaking bad news highly useful. Data collection and management emerged from the feedback as another element in the workshop that people found immensely valuable, including HbSS patients tracking. Furthermore, people commented on how sharing of case studies and personal experiences assists in reaching out to communities and rural areas, as it enables understanding and empathy of the challenges faced from a grassroots level.

Topic suggestion for future training events

Many additional topics were suggested, however the ones that reoccurred most were: tackling cultural beliefs and barriers, e.g. the secrecy gap that can impact the flow of information and community penetration, such as at grassroots level. Some feedback responses said it is key to involve religious leaders and well-respected people in the community, even those retired from the health services should be offered the chance to be involved in getting vital messages out into the community. Pre-marital counselling in addition was recommended. Topics offering practical methods for disclosing patient's results were also raised. Stem cell transplantation, data analysis, quality management were other topics highlighted.

Suggested improvements

Presentations made available in hard copy ahead of the talks, more practical interactive and intimate sessions. Additional time factored in for group discussions. Furthermore, information to be provided on transportation and expenses to and from the venue. More collaboration with sister organisations within research, community and engagement. Inclusion of O&G nurses and doctors so newborns can be screened soon after birth. Be more mindful of the diversity of participants and potential language barriers.

Support from the African Research and Innovative Initiative Education for Sickle Cell (ARISE)

Provision of equipment to continue training and promoting the work of African Research and Innovative Initiative Education for Sickle Cell (ARISE) such as banners. People called for infrastructure support for implementing equipment in centres. There was suggestion to support free testing especially in rural areas just like HIV testing because even after being educated and informed people may not have the money to visit hospitals for testing. There have been many requests for the project team to keep everyone informed about what's happening and progress being made in the African Research and Innovative Initiative Education for Sickle Cell (ARISE) program.

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

Additional Comments

Overall the workshop was described as a fruitful learning and awareness campaign that was well organised. And many gave a big thank you to the African Research and Innovative Initiative Education for Sickle Cell (ARISE) project team.

F. WP3 OBJECTIVES

Work Package Number	3	Start Month 1 – End Month 48
Work Package Title	Improving laboratory diagnostics and quality assurance systems for population screening	
Lead Beneficiary	INSERM	
<p>Objectives</p> <p>This work package aims to:</p> <ol style="list-style-type: none"> a) Develop and implement a comprehensive education programme in population screening management approaches including techniques for haematological analysis, with emphasis on identification of SCD carriers and propose a prevention program of affected births where suitable and / or acceptable (tasks 3.1, 3.2). b) Improve the quality and capacity of laboratory diagnostic testing services in relation to the diagnosis, treatment and monitoring of SCD through baseline assessment, training and mentoring of laboratory health workers, managers and other allied staff. 		
<p>Description of work and role of partners</p> <p>Task 3.1. Design of national prevention policies (M7-M48). Task Leader: INSERM Participants: AOPD, RCPATH in collaboration with partner organisations from TC.</p> <p>Prevention policies will be designed, based on the very successful and efficient Greek National Prevention Program of affected births from Thalassaemia/SCD, bearing in mind the local needs and acceptability. An indicative management protocol for SCD prevention includes strategies – and related education and training – for:</p> <ol style="list-style-type: none"> 1. Public awareness and education through multimedia, social media or other strategies according to the local stakeholders 2. Awareness & education of scientific personnel with the aid of Universities / Ministry of health, through special events/seminars/workshops 3. Identification of disease burden across the country (in case that it is unknown). This task consists of two distinct parts i) Identification of patient numbers and distribution in the country through national registries (in collaboration with WP2) and ii) identification of carriers and their distribution in the country. In cases where this information is unclear, mobile units (possibly supported also by the international/local volunteers) will perform blood sampling from all over the country, especially from areas with high population density. Samples will be subsequently analysed by HPLC in one/few central haematological labs and the results will be assessed in order to calculate the disease endemics in the country. Data will be compared with the patient's burden (registries run in parallel) and the total disease prevalence will be estimated and mapped on the country. 4. Establishment of local population screening units in areas with high incidence with the aim of the population screening during reproductive period. 		

5. Identification of couples at risk and genetic counselling (WP5). In case where both partners are carriers of Sickle Cell Disease (SCD), trained nurses/genetic counsellors will provide adequate information to the couple in order to decide the management of an existing or a future pregnancy. Choices available should be: i) prenatal testing, ii) pre-implantation testing where applicable, iii) newborn screening (WP4)
6. Molecular analysis of underlying mutations (WP5). Laboratory Scientists will be trained in analysis of alpha and beta globin gene mutations, based on the haematological parameters.
7. Prenatal testing (WP5).
8. Post-Prenatal testing genetic counselling (WP5) when required aims in explaining possibilities for pregnancy therapeutic abortion where selected with emphasis in non-directive counselling.

During the whole project, policies and protocols will be continuously updated according to their impact once implemented and to any new emerging issue.

Task 3.2 Laboratory protocols for haemoglobin analysis and SCD diagnosis (M7-M36). Task leader INSERM and RCPATH. Participants: AOPD in collaboration with partner organisations from TC.

Laboratory scientists will be trained in haemoglobin (Hb) analysis by HPLC followed by sickling test to confirm diagnosis or capillary electrophoresis. Education and training on laboratory diagnosis will include:

- I. the principle of Hb analysis and parameters affecting measured values like temperature etc.
- II. choice of the most suitable HPLC program for Hb analysis
- III. evaluation of Hb analysis results and choice of confirmation approach in case of positive results
- IV. the principle of haematological indices analysis and parameters affecting values
- V. evaluation of the results in combination with Hb analysis results
- VI. written report syntax
- VII. External and internal quality assurance of the diagnostic and testing process.
- VIII. Development of Standard Operating Procedures (SOPs).

Training will be accredited by The Royal College of Pathologists (RCPATH)

The RCPATH will also recruit and deploy experienced volunteer haematologist and senior laboratory scientists from the UK and Europe to deliver on-site (in-country) training and mentoring to the laboratories and health workers. This will ensure that training and mentoring are made locally accessible to those laboratory staff who are unable to travel.

A comprehensive protocol in the form of guidelines will be created in order to spread the education in a wider basis on African countries laboratories. The training in the management protocol described is expected to significantly confer to assist in the organization and performance of an effective prevention program in the SSA countries and in Lebanon that are willing to accept it, aiming in the significant reduction of SCD affected births in the African continent and worldwide (population motilities).

Local stakeholders (including scientific associations and government) will be assisted to organize the best suited approach to their home countries according to the local needs identified with the aim to prevent affected births, where this concept is socially and ethically acceptable. Moreover, the established network created for the needs of this project will continue co-operation and educational / scientific support of the participating colleagues and after the end of the project

aiming in continuous development of a more concrete and expanded network efficient in managing SCD.

Task 3.3 Laboratory Accreditation & External Quality Assurance (EQA) M1-M48. Task leader RCPATH. Participants: AOPD, INSERM, in collaboration with partner organisations from TC.

- a) Conduct a gap analysis/ baseline assessment survey of (i) the laboratories and (ii) laboratory staff in terms of capacity, standards and diagnostic testing/ quality. The gap analysis will be measured against the WHO-AFRO SLIPTA Checklist and ISO 15189 Accreditation Framework.
- b) Produce a laboratory capacity development plan for each laboratory, including Laboratory Improvement Plans addressing the gaps and weaknesses identified in the baseline assessment. Work with laboratory health workers to devise individualized Personal Development Action Plans (PDAP).
- c) Deploy RCPATH volunteer mentors and trainers to deliver on-site/in-country training, mentoring and capacity building. This will also include the development and delivery of at least 4 Laboratory Improvement Projects, which will require the laboratories to collaborate with each other – building research capacity as well as improvement actions.
- d) Establish an External Quality Assurance (EQA) scheme to measure the impact of the training and mentoring actions as well as measure/ monitor the improvements being made in diagnostic testing quality and accuracy.

List of Deliverables

D3.1. EQA Scheme assignments & results of the evaluation Linked to tasks 3.3 (M48)

G. WP4 OBJECTIVES

Work Package Number	4	Start Month 7 – End Month 48
Work Package Title	Newborn SCD screening, screening for neurocognitive complications, clinical care and antibiotic prophylaxis	
Lead Beneficiary	GSTT	
Objectives		
<p>The main objective of WP4 is to determine the feasibility for implementing a Newborn SCD Screening Programme that is sustainable in African countries. While the majority of patients with SCD are born in SSA (>80%) the mortality remains unacceptably high with less than 50% of babies surviving beyond 10 years compared to over 95% reaching adulthood in the UK. There is also a substantial neurocognitive burden, including a high risk of stroke as well as slow processing speed, which reduces life chances. The goal for visitors to learn from the expertise developed over the years from the UK universal screening programme that was implemented in 2004. The comprehensive approach that involved training for all professionals involved in the management of SCD, protocols for laboratory scientists, clinicians, development of public engagement programme to mobilise the community and families to achieve a high level of public awareness which is essential for policy-makers to institute the appropriate environment for incorporation with the health systems.</p> <p>In addition, the feasibility of preventing neurocognitive deficits by screening for risk of stroke and cognitive decline will be explored.</p>		

Essential Background

Effective management of SCD should incorporate the provision of early diagnosis followed by the institution of appropriate intervention that includes antibiotic prophylaxis, malarial prevention in SSA, health promotion activity and continuous reassessment of national policy. To achieve a sustainable programme, it is important for policy-makers to adopt the relevant strategy to address the cost of services and support a community-based work force that is competent in recognising sick patients, parental education, counselling and family support

Description of work and role of partners

Task 4 1. Public Patient Involvement (PPI) and Community engagement (M7-M48). Task leader GSTT. Participants: CING, UIC, FGB in collaboration with partner organisations from TC. Total number of Person Months allocated = 28

a) The main objectives for this task is to engage the community, policymakers, and healthcare providers early to determine potential barriers and to adopt strategies for the development and implementation of a Newborn screening programme at state and national level and to determine the feasibility of establishing SCD Newborn screening programme within primary care and community settings in order to achieve develop a sustainable initiative b) Implementation Science training in SCD—Core reading on implementation science. Read and discuss landmark articles on the challenges of SCD implementing guidelines. Observe the activities of the NIH-funded SCD Implementation

Consortium, including stakeholder engagement through Advisory Committees and individual advisors, and synthesis by the Steering Committee and Working Groups. The use of graphics and design principles for healthcare communication will be incorporated. Weekly discussion will simulate stakeholder motivation and capacity with a set of scenarios of SCD complications that Dr. Hsu (UIC) has prepared for training.

Task 4.2. Design clinical management Protocols (M7-M36). Task leader AOPD. Participants: GSTT, UCL, INSERM, UIC in collaboration with partner organisations from TC. Total number of Person Months allocated = 13. Clinical management protocols for Doctors, Nurses and health care workers, including screening for risk of stroke and cognitive decline with oximetry, TCD and simple cognitive tests, will be designed. Training in neurological examination, pulse oximetry, TCD and neurocognitive testing will also be available from Dr. Kirkham and her team at UCL Great Ormond Street Institute of Child Health in London:

a) Blood spot collection, transportation to the laboratory

b) Breaking News for affected families, counselling of families through face to face contacts. To highlight the multidisciplinary nature of professionals involved in diagnosis and treatment of SCD. The urgency for result disclosure, ensuring that all diagnosed infants are linked with care services. This would involve developing a care pathway that is effective in closing any gaps, a robust audit process that assess the completeness of patient treatment including antibiotic prophylaxis, immunisations, surveillance for organ damage such as stroke screening, renal function and other patient related outcomes.

c) - Training for clinicians - The clinical program includes daily inpatient ward rounds on all sickle cell Paediatric patients and attending Paediatric and adult sickle cell clinics. During clinics and

ward rounds, the ARISE exchange clinical staff member will be expected to discuss management plans and options for the patient in a comprehensive manner. The ARISE exchange staff member is expected to attend general Paediatrics grand rounds once a week, during which Haematology/Oncology problems are often presented and discussed. Weekly discussion will simulate clinical decision-making with a set of scenarios of Paediatric sickle cell complications that Drs. Hsu and Inusa have prepared for training of healthcare providers. Unscheduled time could include examining inpatients and reviewing charts in quality assessment/ quality improvement projects.

Task 4.3. Community Health Worker programme for SCD (M7-M48). Task leader GSTT.

Participants: UIC, FGB in collaboration with partner organisations from TC. Total number of Person Months allocated = 28

By working with the CHW programme for SCD at UIC, and comparison with SCD CHW programmes in Europe, plus CHW for other diseases in Chicago.

a) community engagement, quality improvement measures, and innovative programs in the Comprehensive Sickle Cell Center might overcome social barriers and healthcare disparities

b) ARISE exchange staff can note the roles of Community Health Workers for SCD in the day-to-day care and quality improvement projects. Weekly discussions will use scenarios of clinical contributions from CHW home visits and CHW embedded in clinics to illustrate the benefits of CHW. Discussion of the features of the SCD CHW program and manual-based training curriculum for SCD, and the rationale for each feature, will facilitate adaptation CHW to another locale. They can participate in a 12-hour training session for CHW to learn about SCD. Participants will also study the features of the SCD CHW programmes in UK, to analyse the key features of CHW programmes that can be adapted to other settings in Africa and Europe. Evaluation and sustainability of CHW will be discussed with managers of CHW programmes for asthma and diabetes in other sites in Chicago, to provide insights on evaluation, sustainability, and utility of implementation science approaches.

Task 4.4. Institution of appropriate treatment protocols (M37-M48). Task leader UCL.

Participants: CING, AOPD, GSTT, INSERM, UIC, FGB in collaboration with partner organisations from TC. Total number of Person Months allocated = 14

a) The outcome of SCD diagnosis is dependent on the institution and adherence with appropriate prophylaxis with penicillin V administration, immunisation against bacterial infection and for SSA prevention of malaria infection through the use of insecticide treated bed nets (ITN). To investigate the appropriateness of malaria chemoprophylaxis, adherence to the chosen national malaria policy. To determine the utilisation of hydroxyurea and review the possibility for developing a national policy

b) Treatment protocols for acute complications such as multi-modal pain management, acute chest syndrome, stroke screening using TCD and neurocognitive assessment.

Task 4.5. Evaluation of the outcome of Infants Diagnosed with SCD. (M37-M48). Task leader GSTT.

Participants: CING, AOPD, UCL, INSERM, UIC, FGB in collaboration with partner organisations from TC. Total number of Person Months allocated = 28

ARISE TRAIN THE TRAINER WORKSHOP NIGERIA SEPTEMBER 2019 SUMMARY REPORT

To establish care pathways that ensures the majority of those confirmed with SCD are referred to clinics, are receiving penicillin prophylaxis and are registered in databases (Task 6.2) and patient registries (Task 2.6). Specific actions are:

- a) To investigate the impact of the introduction of Newborn Screening on the survival of infants and children with SCD;
- b) To assess the proportion of infants with SCD who are successfully registered in treatment centres (see Work package 3 and 6);
- c) To determine common morbidity and mortality pattern of patients with SCD.

List of Deliverables

D4.1: Community health worker programme in TCs sites. Linked to Task 4.3 (M48)

D4.2: Report investigating the impact of the treatment protocols. Linked to Task 4.5 (M48)

ACKNOWLEDGEMENTS

We take this opportunity to thank everyone who contributed to the organisation and delivery of the Train-the-Trainer workshop in Abuja in September 2019.

From the positive feedback and the appreciative comments we received, it's with confidence we can say it was a fruitful and successful event. This was a big achievement for us all as it marks the first ARISE train-the-trainer workshop.