# MSCA STAFF EXCHANGE EXPERIENCE

African Research and Innovative Initiative for Sickle cell Education (ARISE): Improving Research Capacity for Service Improvement

# THE ARISE PROJECT

ARISE is a research project funded by the EU in the framework of the H2020-MSCA-RISE-2018 programme Led by Fondazione Gianni Benzi and the Guys and St Thomas' NHS Foundation Trust in London. It is established as an inter-agency and multidisciplinary staff exchange programme within the EU institutions (Italy, France, UK and Cyprus) and non-EU (Nigeria, Lebanon, Kenya, Angola, Zambia and USA) countries to share best practices in newborn screening, diagnosis and treatment of sickle cell disease (SCD)

**WP2 – Implementing eHealth technologies to support a Newborn screening programme in African countries and Lebanon**

The main objective is to facilitate the implementation of the project through eHealth technologies.

**WP3 – Improving laboratory diagnostics and quality assurance systems for population screening**

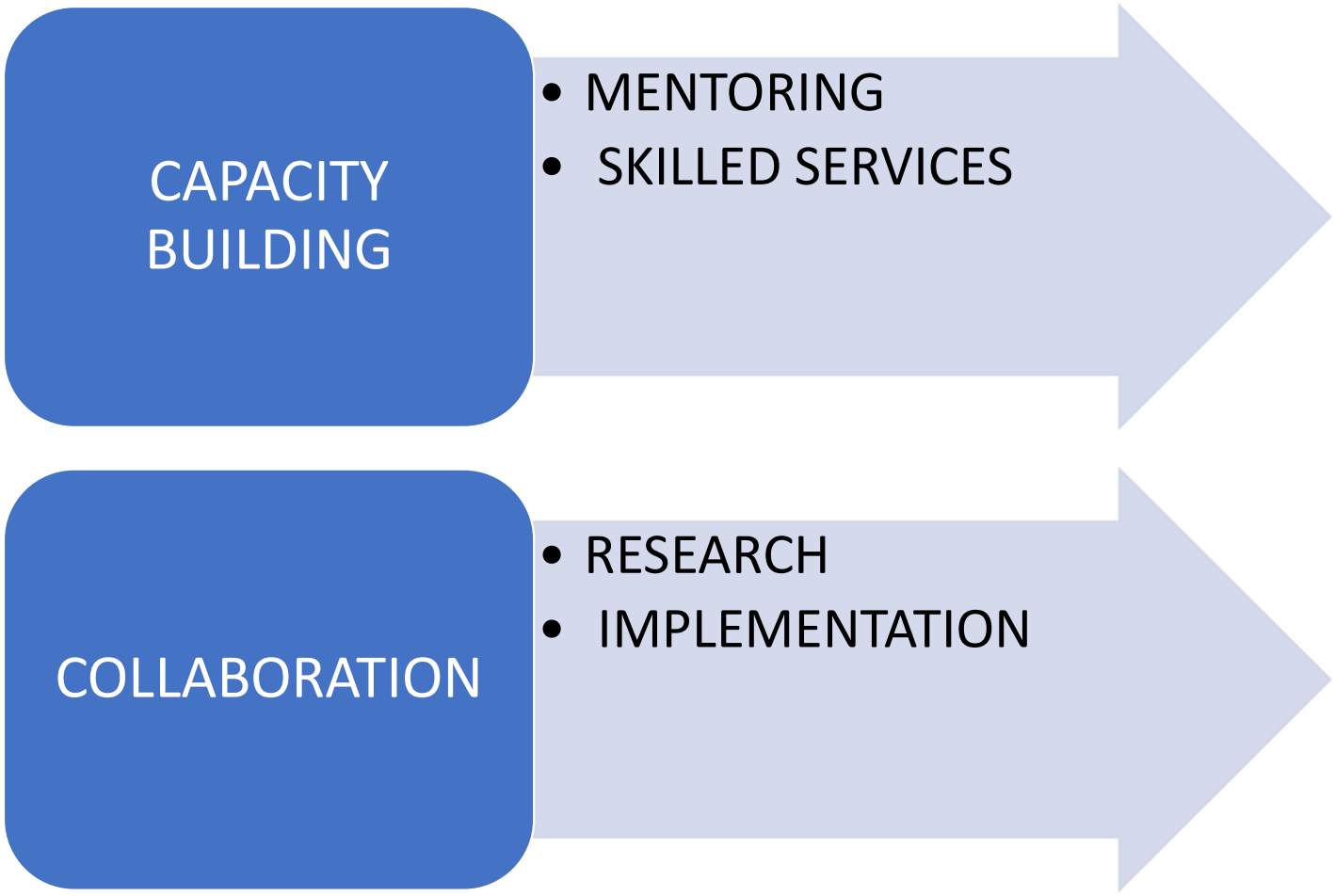
The main objective is to improve the quality and capacity of laboratory diagnostic testing services in relation to the diagnosis, treatment and monitoring of SCD.

# AHMADU BELLO UNIVERSITY (ABU) AS PARTICIPATING INSTITUTION

ABU is the pioneer and the largest university in northern Nigeria and it is among the 5 universities that participated in the ARISE project.

- location
- patient's population
- specialist medical care
- research activities
- SCD service delivery
- training

# STAFF BENEFITS



# INSTITUTIONAL BENEFITS

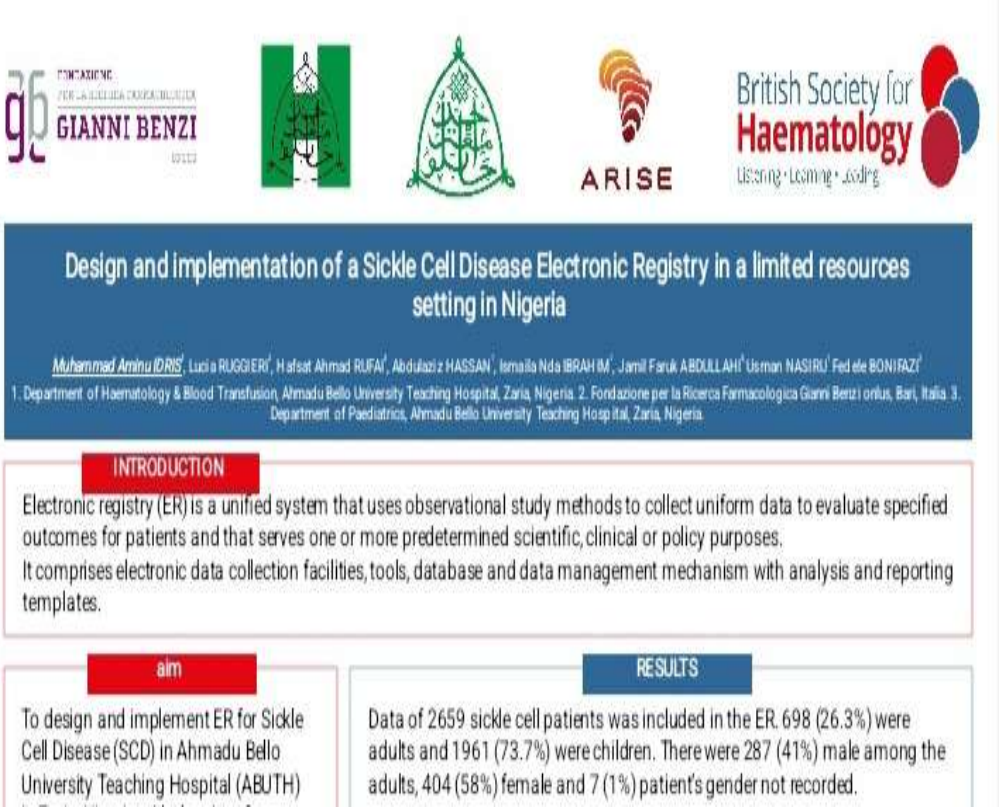
**TECHNOLOGICAL INNOVATIONS**

- SCD REGISTRY

**QUALITY IMPROVEMENT PROJECTS**

- EFFECTIVE SERVICE DELIVERY

# RESEARCH WORK 1



Design and implementation of a Sickle Cell Disease Electronic Registry in a limited resources setting in Nigeria

Muhammad Aminu IDRIS[1], Lucia RUGGIERI[2], Hafsat Ahmad RUFAI[1], Abdulaziz HASSAN[1], Ismaila Nda IBRAHIM[1], Jamil Faruk ABDULLAHI[1] Usman NASIRU[1] Fedele BONIFAZI[3]

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INTRODUCTION

Electronic registry (ER) is a unified system that uses observational study methods to collect uniform data to evaluate specified outcomes for patients and that serves one or more predetermined scientific, clinical or policy purposes.
It comprises electronic data collection facilities, tools, database and data management mechanism with analysis and reporting templates.

aim

To design and implement ER for Sickle Cell Disease (SCD) in Ahmadu Bello University Teaching Hospital (ABUTH)

RESULTS

Data of 2659 sickle cell patients was included in the ER. 698 (26.3%) were adults and 1961 (73.7%) were children. There were 287 (41%) male among the adults, 404 (58%) female and 7 (1%) patient's gender not recorded.

Open Access Article

# Design and Implementation of a Sickle Cell Disease Electronic Registry in Resource Limited Setting in Nigeria—A Pilot Study

by Muhammad Aminu Idris [1,*], Lucia Ruggieri [2], Hafsat Rufai Ahmad [3], Abdulaziz Hassan [1], Ismaila Nda Ibrahim [1], Faruk Jamil Adullahi [1], Sani Awwalu [1], Usman Nasiru [1], Fedele Bonifazi [2] and Baba P. D. Inusa [4]

# RESEARCH WORK 2

19th Annual Sickle Cell & Thalassaemia Conference

ASCAT

Achieving Equitable Progress:
A Call for Collaborative Action
in a World of Growing Disparities



ASCAT Academy For Sickle Cell & Thalassaemia

British Society for Haematology

eha

## PATTERN OF INFECTIONS REPORTED AMONG PAEDIATRIC SICKLE CELL PATIENTS ATTENDING A TERTIARY HOSPITAL IN NIGERIA

Muhammad Aminu Idris,
Medical Laboratory Scientist, Ahmadu Bello University Teaching Hospital, Zaria, Nigeria

Open Access Article

## Pattern of Reported Infections Among Paediatric Patients with Sickle Cell Disease: A Single-Centre Cohort Study in Nigeria

by Muhammad Aminu Idris [1,2,*], Lucia Ruggieri [3,*], Hafsat Rufai Ahmad [2,4], Abdulaziz Hassan [1,2], Ismaila Nda Ibrahim [1,2], Jamil Abdullahi Faruk [2,4], Niyi Mustapha Adebiyi [4], Sani Awwalu [1,2], Nasiru Usman [1,2], Rabiu Wada [5], Musa Muhammad [2,6], Saidu Abdulkadir [1,7], Fedele Bonifazi [3], Wale Atoyebi [8] and Baba Psalm Duniya Inusa [9,10]

# RESEARCH WORK 3

## LOW USE OF HYDROXYUREA AMONG CHILDREN LIVING WITH SICKLE CELL DISEASE IN A TERTIARY HOSPITAL IN NORTHERN NIGERIA


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### BACKGROUND

Use of Hydroxyurea (HU) can improve the health condition of about 300,000 individuals born each year with sickle cell disease (SCD) in sub-Saharan Africa, particularly in Nigeria which has the largest population of people living with SCD. This study was conducted during an African Research and Innovative initiative for Sickle cell Education (ARISE, EC GA No 824021) staff exchange programme.

### AIMS

To determine the use of HU among paediatric SCD patients reported at clinic visits at Ahmadu Bello University Teaching Hospital, Zaria, Nigeria from 2014 to 2022.


### KEY WORDS

Use of Hydroxyurea, sickle cell disease.


### METHODS

We reviewed records of paediatric SCD patients in our paediatric registry and extracted the records of HU usage among paediatric SCD patients reported at clinic visits using structural query searching.

### RESULTS

Data of 1961 SCD paediatric patients was retrieved from the registry.1041 (53.1%) were male children, 906 (46.2%) female and 14 (0.7%) gender not recorded. 280 (14.3%) children were using HU and 1248 (63.6 %) not using it. There was no record about using it or not among 433 (22.1%) of the children.

### CONCLUSION

There is low use of HU among paediatric SCD patients in our institution despite its importance in improving the health condition of SCD patients. We do not know whether the low use of it is due to lack of availability, affordability, accessibility and adherence, hence the need for more studies to determine the cause.


*This study has been conducted within the African Research and Innovative initiative for Sickle cell Education (ARISE) that has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No 824021.*


### REFERENCES


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FONDAZIONE PER LA RICERCA FARMACOLOGICA GIANNI BENZI

ARISE

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# CONCLUSION

Clinicians, scientists and patient advocates are working day and night with collaboration, communication and commitment to see that people living with SCD have the quality of care they deserve, such that they can have quality of life, ARISE has empowered us with knowledge and skills to properly manage SCD in different capacities, this would not have been possible without MSCA.