ARISE

African Research And Innovative Initiative For Sickle Cell Education

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

webinar “Iron overload: an elusive complication in sickle cell disease and thalassaemia”

13 Sept. 2023

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021

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

ARISE project coordinators

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Fondazione per la Ricerca Farmacologica Gianni Benzi Onlus

Baba Inusa
Guy's & St. Thomas' Hospital NHS Foundation Trust

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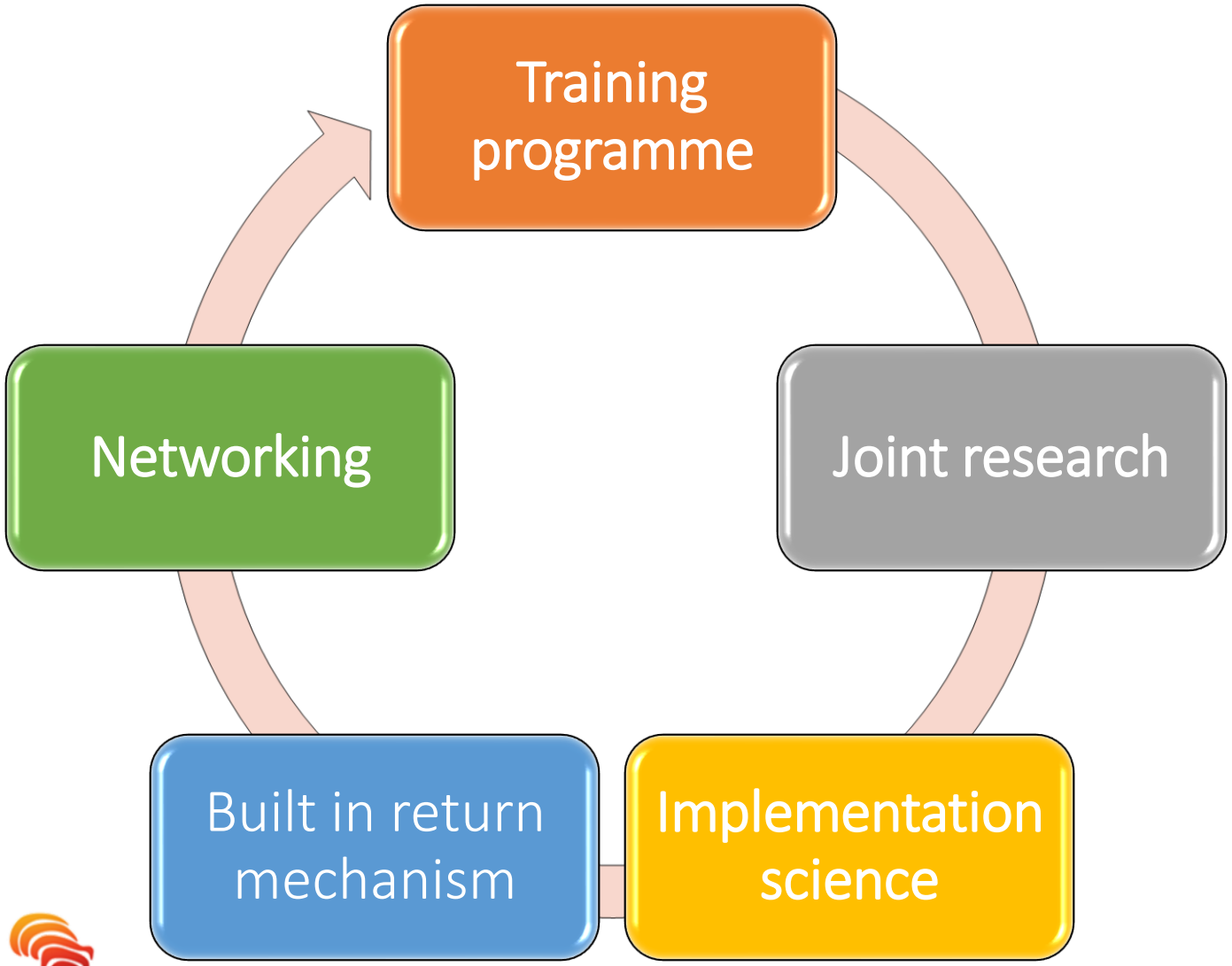
Agenda

- **Introductory remarks** - Baba Inusa
- **ARISE project** – F. Duccio Bonifazi
- **Iron overload: an elusive complication in sickle cell disease and thalassaemia** - Tim St Pierre
- **Q&A session**
- **Final remarks**

Domains of the ARISE action and main aims



An EU funded project launched in 2019 with the aims:

- *to have a **universal newborn screening and early infant diagnosis programme** successfully implemented and effectively embedded within regional and national policies in SSA*
- *to **build capacity of personnel** to achieve excellence in clinical practice and research using SCD projects as learning laboratories*

ARISE project

Specific objectives

- ✓ To evaluate the prevalence of SCD in target countries
- ✓ To establish laboratory diagnosis and quality assurance systems
- ✓ To test the feasibility for establishing newborn and early infant screening for SCD
- ✓ To develop best practices in clinical management for acute and chronic complications in SCD

Work Programme

Scientific coordination and project management [FGB]

eHealth technologies to support a Newborn screening programme [FGB]

Improving laboratory diagnostics and quality assurance systems for population screening [RCPath]

Newborn SCD screening, screening for neurocognitive complications, clinical care and antibiotic prophylaxis [GSTT]

Training in molecular diagnostic and genetic counselling and conducting epidemiological and genetic research [CING]

Training and support for clinical research [LSHTM]

Dissemination and Communication [GSTT]

Ethics requirements [FGB]

Output

160 staff members with improved ability:

- ✓ implementation science
- ✓ laboratory skills
- ✓ epidemiology and statistics
- ✓ clinical management of SCD
- ✓ genetic counselling
- ✓ TCD
- ✓ research protocols development
- ✓ communication

The partnership

Baba Inusa

F. Duccio Bonifazi

Paul Milligan

Maddalena Casale

Fenella Kirkham

Marina Kleanthous

Raffaella Colombatti

Jaques Elion, Mariane de Montalembert

Miguel Brito

Wale Atoyebi

Paola Cogo

Jocelyne Neto de Vasconcelos

Ramsey Yalma

Moses Mamman

Benhards Ogutu

Miguel Abboud

Ijeoma Diaku-Akinwumi

Catherine Chunda

Lewis Hsu

19 Institutions from 11 countries

Staff exchange program

458 exchange months by Oct. 2024

- ✓ Visa
- ✓ Travel plan
- ✓ Accommodation
- ✓ Activity program

- Early-stage/experienced researchers
- Technical and administrative staff

Health technologies to manage SCD complications – questionnaire for healthcare facilities

Joint research

Questionnaire-based study, developed in Task 2.2 ***Healthcare policies and centres organisation analysis*** *designed by Kaduna State University (ARISE fellow A. Sunday) and Benzi Foundation in collaboration with the Consortium for Advancement of MRI Education and Research (CAMERA)*

1. To **map and analyse the organisation of healthcare centres managing SCD** in African countries and Lebanon in terms of **accessibility** and **readiness of health technologies**

2. To help providing educational and training resources and context related information to support the adoption of **best practices in SCD management**

3. **3 ad hoc online questionnaires** developed according to the WHO Service Availability and Readiness Assessment (SARA) approach

- **Blood transfusion**
- **Magnetic Resonance Imaging**
- **Transcranial Doppler**

Topics		Parameters/Tracer indicators
Access	Availability	• Facility information • Technology description • Technology density
	Affordability	• Funding to sustain the technology costs
Readiness		• Specialised health workers density • Usage, indication and frequency • Maintenance, servicing access and frequency • Basic amenities • Equipment & supplies • Personnel Training and education • Standard precautions
Research Translation		• Capacity for use of technologies in clinical trials and large population studies • Networking and access to research networks

WHO *Service availability and readiness assessment (SARA). https://www.who.int/data/data-collection-tools/service-availability-and-readiness-assessment-(sara)*

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LimeSurvey

4

4 reference centres in Nigeria volunteered for a **pilot phase** to test the feasibility of the surveys

State	City	Institution
Kaduna	Kaduna	Kaduna State University
Kaduna	Zaria	Ahmadu Bello University Teaching Hospital
Lagos	Ikeja	Lagos State University Teaching Hospital
Federal Capital Territory	Abuja	Abuja University Hospital

5

Surveys will be sent to **reference persons** with request to complete (or forward to the most appropriate colleagues)

6

Extension to all the ARISE and CAMERA countries

START: Autumn 2023

END: Summer 2024

today's webinar

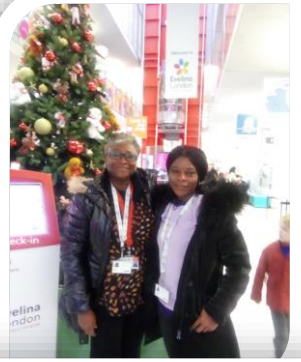
- **Iron overload: an elusive complication in sickle cell disease and thalassaemia**
- **Professor Tim St Pierre** is a biomedical physicist who has a strong research interest in the form and properties of iron in the human body and has helped develop diagnostic tools for the non-invasive measurement of iron levels in human tissues.
- He is a Senior Honorary Research Fellow at The University of Western Australia and has a part time position as Chief Research Scientist at Resonance Health Analysis Services Pty Ltd

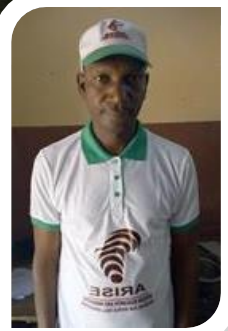
next webinar

28th September 2023 at **3:00pm** Nigerian time - **GMT +1**

MRI diagnostics of iron overload using the affordable, AI-trained method FerriSmart - Tim St Pierre

Thanks a lot!





www.ariseinitiative.org, arise@benzifoundation.org

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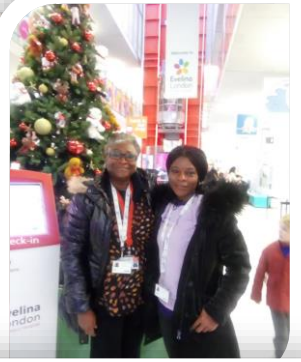
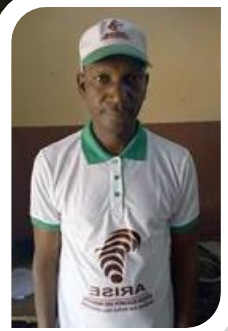
Thanks a lot!





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