



ARISE

African Research And Innovative
Initiative For Sickle Cell Education

Train-the-Trainer Workshop

Abuja, Nigeria

11th – 13th September 2019

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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



- Stroke Prevention in Nigeria (**SPRING**)
- The Sickle Pan-African Research Consortium (**SPARCO**)
- American Society of Hematology (**ASH**)
- Kaduna State Newborn Screening of Sickle Cell Disease (**KD-NBS**)
- African Research Innovative Initiative for Sickle Cell Education (**ARISE**)



Nigeria Demography



Population Est. 200.96m (2019 proj.)

Population Growth Rate: 2.6% (2017 est.)

Birth Rate: 38.89 births/1000 births

SCD births: >150,000/year in Nigeria

Death Rate: 12.4 deaths/1,000 population (2017 est.)

Inusa, et al., Pediat Therapeut 2015, 5:3 DOI: 10.4172/2161-0665.1000262

<https://nigerianstat.gov.ng> › download



Kaduna Demography



Population Est. 8.9m (2019 proj.)

Population Growth Rate: 2.6% (2017 est.)

Birth Rate: 38.89 births/1000 births

Delivery by health professionals: 40.4%

Delivery without assistance: 28.8%

Facility based delivery rate: 32.4%

**Antenatal visit attendance: 30% (2008),
43.8% (2017)**

Kaduna Pilot NBS (2010-2011): 4000 babies

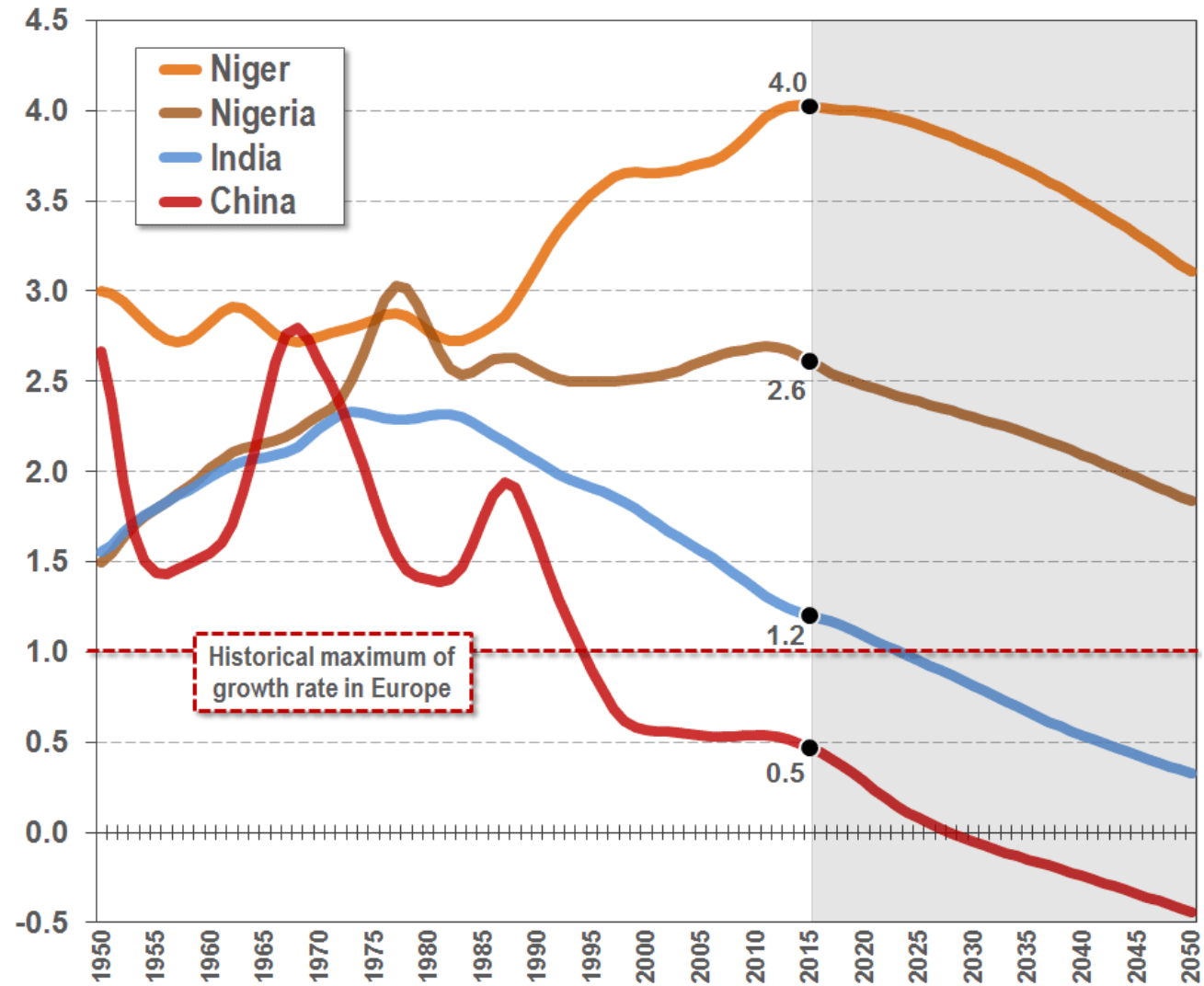
Inusa, et al., Pediat Therapeut 2015, 5:3 DOI: 10.4172/2161-0665.1000262

<https://kdbs.ng/app/uploads/2019/06/KADUNA-STATE-SDGs-WATCH-1.pdf>

<https://nigerianstat.gov.ng/download>



Growth Rate

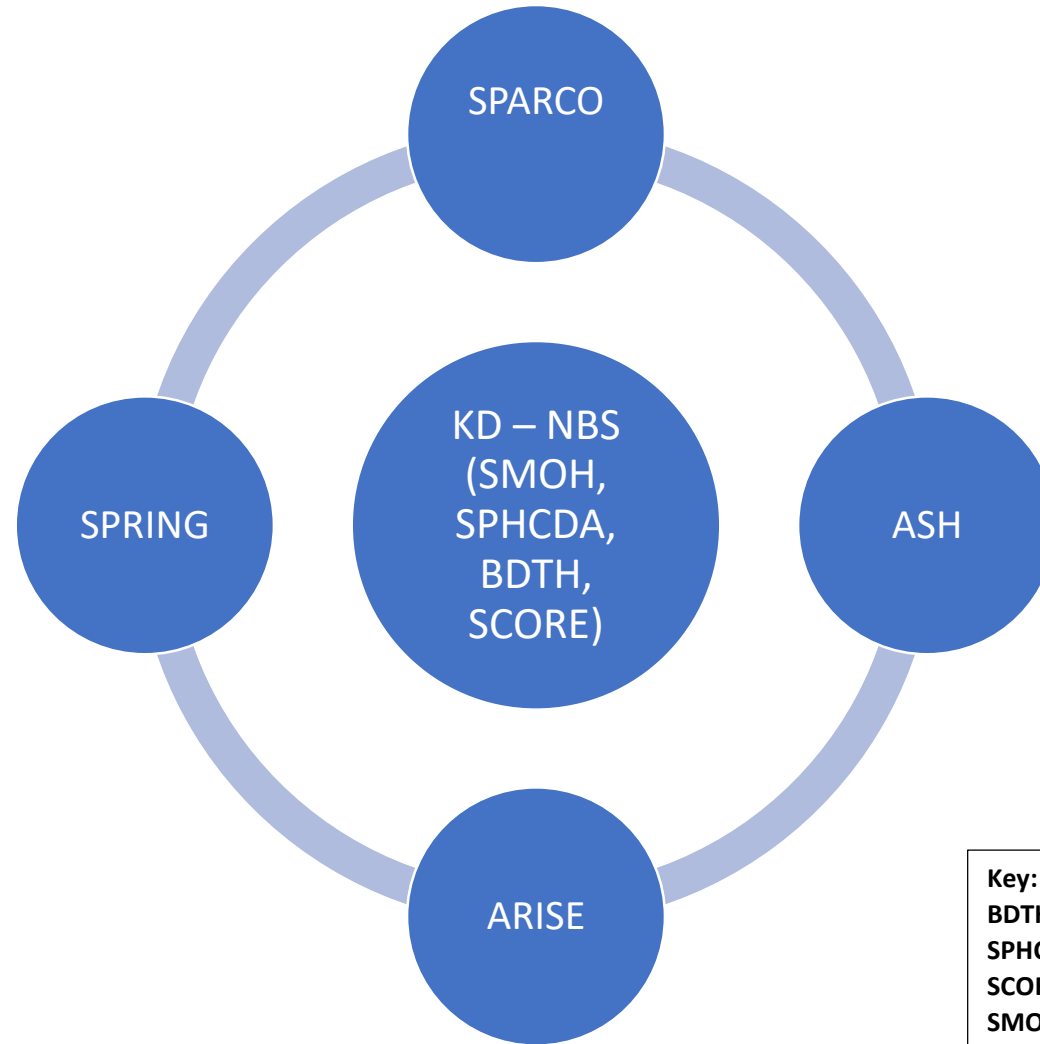


Niger, Nigeria, India, China: Average annual growth rates of the population (in percent), 1950-2050. Source: UN WPP2015.

www.demographics.a



How and Why They Need to Relate



Key:

BDTH – Barau Dikko Teaching Hospital

SPHCDA – State Primary Health Care Development Agency

SCORE – Sickle Cell Cohort Research Foundation

SMOH – State Ministry of Health



SPARCO: BDTH in a nutshell

Learning points from SPARCO

KD – NBS hub at BDTH

Areas that are critical in building this infrastructure are SCD database, standards of care, training and planning for future research

SickleGenAfrica (Sickle Cell Disease Genomics in Africa)

To develop prognostic biomarkers of organ damage through the discovery of key genetic modifying factors and cognate mechanisms
Build capacity and career pipelines in Africa to support patient-centered research
To advance the development of innovative therapy for SCD

SPAN (Sickle Pan-African Network) involving 20 sites in 15 countries

Develop a sickle cell disease (SCD) database (SCD registry)
Establish standards of care
Strengthen skills and plan research
Implementation studies (newborn screening, infection prevention and Hydroxyurea)


SADaCC (Sickle Africa Data Coordinating Centre)

Support the activities of a companion SCD Network in Africa
Provision of support and maintenance of a centralized e record of sickle Haemoglobinopathies for research and improve clinical care

Outcome - BDTH

Data – SMOH/Fantsuam
Standard of Care – SPRING, ASH, SPHCDA, ARISE, MDTs
EMR – BDTH HIMMS
Awareness – SPRING, SSCF

Paediatric enrolment clinic
Registered 73 so far
Adult enrolment clinic
Registered 150 so far



Enrolment Clinic
Genetic Counseling
Sickle health education
MDTs
Community awareness
Adherence counseling
Research
Transition
web-based database



Database development: Process

Policies

- There are already policies and procedures that have been developed for disease specific registries
- Electronic data sharing – policy not in place
- Committee for set up of BDTH EMR

Draw back

- Due to the selection bias of hospital-based, disease registries
- Paper base hospital records
- Poor record keeping and storage facilities
- DHIS not elaborate

Expected outcome

- the SCD registry will link into demographic and health surveillance systems such as INDEPTH data repository
- These will lead to establishment of a population based SCD registry
- Development of a bio-repository



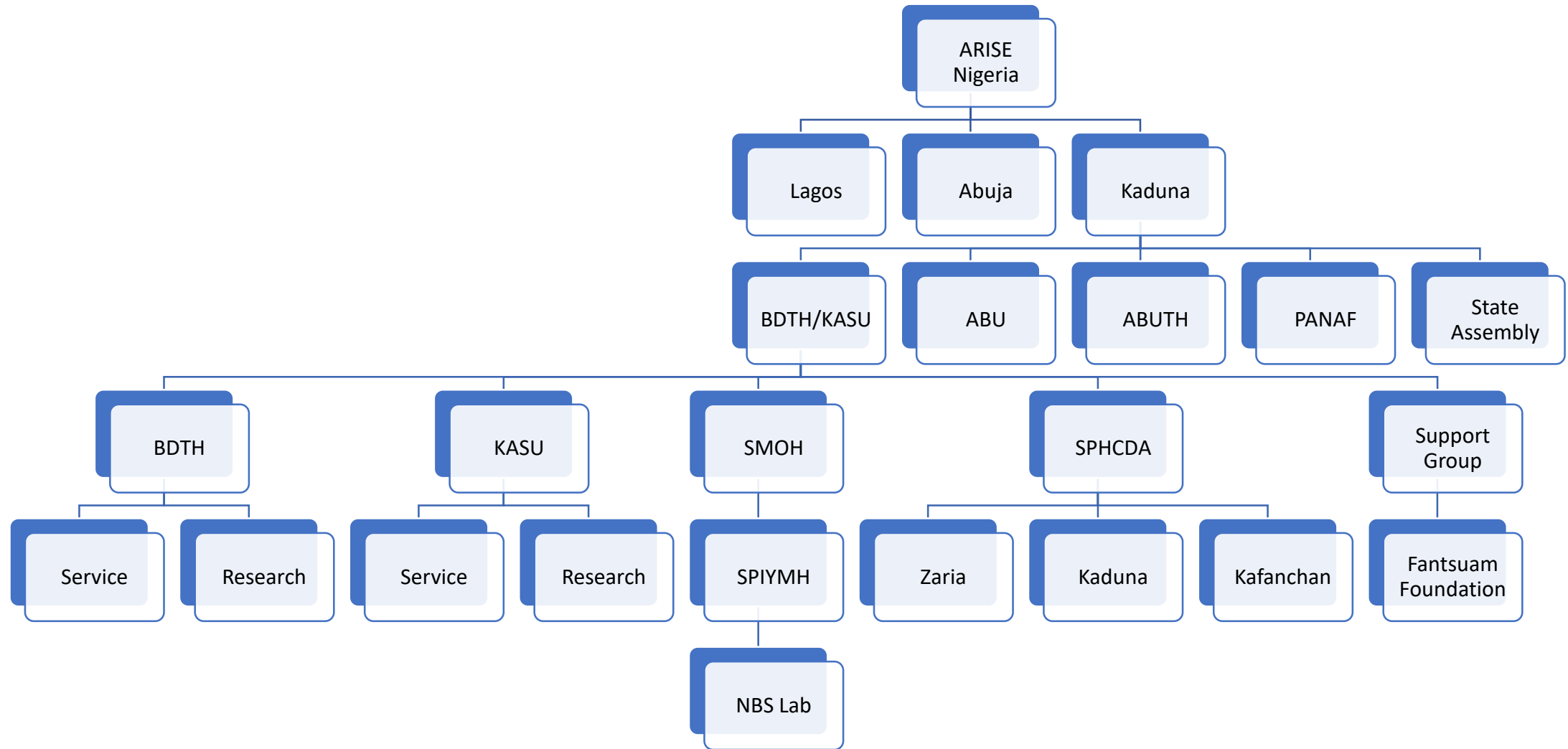
ARISE Project : Acronym: ARISE

- Title: African Research and Innovative Initiative for Sickle cell Education: Improving Research Capacity for Service Improvement (ARISE):
 - Project Number:824021:
- Consortium of 15 institutions
- Africa, Europe, and the US

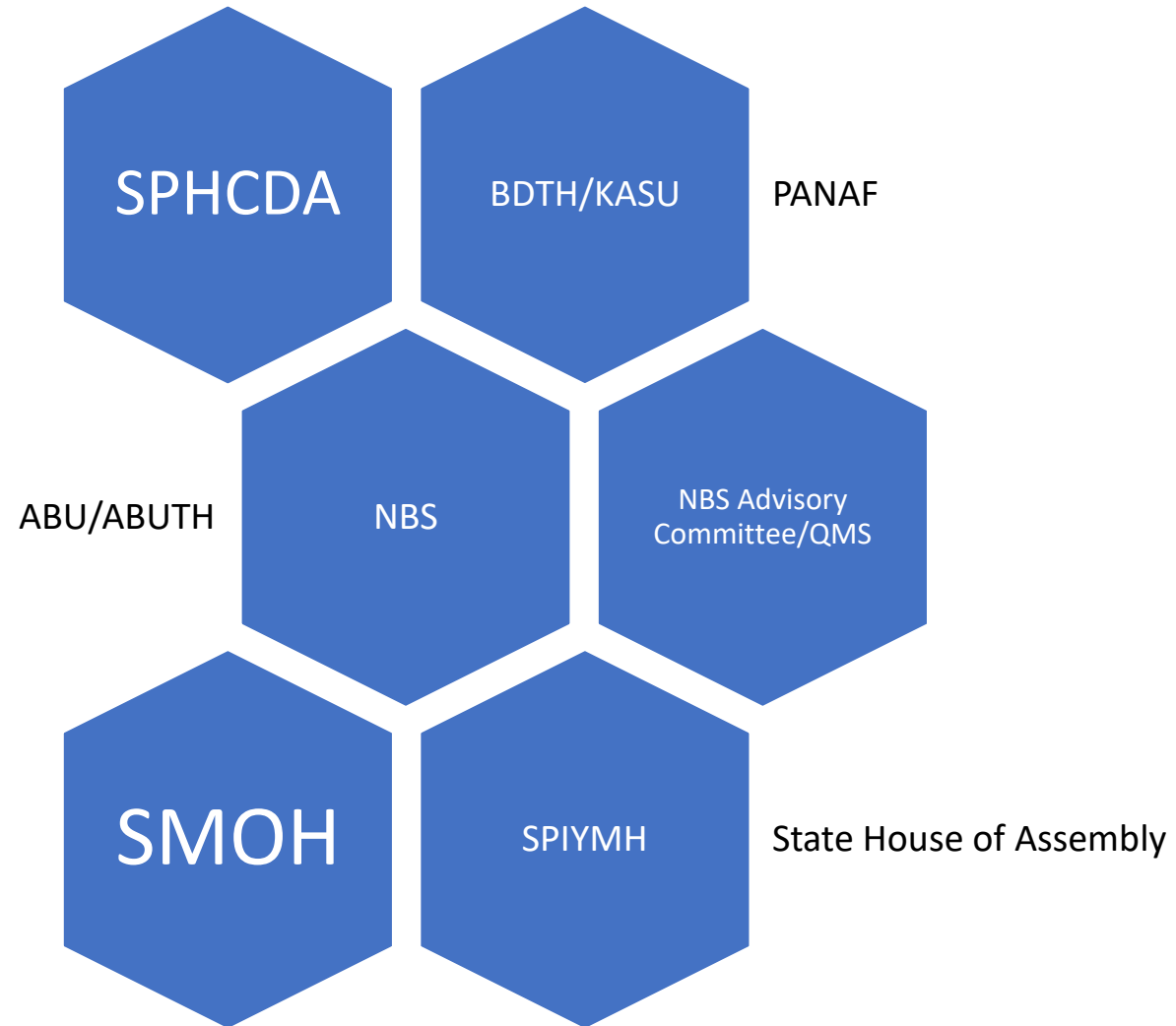
H2020-MSCA-RISE-2018, <https://www.kcl.ac.uk/archive/news/solcs/2018/king's-and-evelina-collaboration>



Kaduna ARISE



ARISE through Kaduna NBS



Impact on BDTH - KASU

- On-going exchange
- BDTH/KASU to FGB (Fondazione Gianni Benzi Onlus | Gianni Benzi Foundation)
 - 2
- Planned last quota 2019 exchange
 - BDTH/KASU to Royal College of Pathologists (UK)
 - 2
 - KASU to Guys and St. Thomas' (London)
 - 3



ARISE leadership mix in BDTH

- Clinicians (Paediatricians, Haematologists and Obstetrician and Gynaecologists)
- Basic clinical researchers
- Implementation scientists
- Public health specialist
- Administrators
- Social Scientists
- Educationists



SPRING: Primary Prevention of Stroke in Children With Sickle Cell Disease in Sub-Saharan Africa II

- NIH/NINDS funded
- Study type: Interventional (Phase III Clinical Trial) multi-centre (Kano and Kaduna, Vanderbilt University as Coordinating Centre)
- Estimated enrolment: 400 participants
- Allocation: Randomized
- Intervention Model: Single Group Assignment
- Masking: Double (Investigator, Outcomes Assessor)
- Primary Purpose: Prevention

<https://clinicaltrials.gov › show › NCT02560935>



Delivery

- Target age: 5-12yrs
- Labs – CBC, Urea, electrolytes, creatinine, urinalysis, HPLC
- TCD
- Hydroxyurea
- Media – Radio jingles
- Community based organizations – Sickle Cell Patient Health Promotion, Sickle Cell Aid Foundation (SCAF)



Benefit/outcome

- Abnormal TCD on hydroxyurea - 50
- Conditional – monitored
 - High – 2 weekly
 - Low – 3 months
- Institution of standard of care model
 - Regular routine labs – every 3 months
 - Penicillin
 - Improved hydroxyurea uptake
 - Supplements: Vitamins, Folic acid
 - Malaria prophylaxis
 - Health education
- Commitment of government to procure hydroxyurea for confirmed abnormal TCD not in the study
- Training for TCD
- Capacity building in research for the team



ASH Sickle Cell Disease Initiative

- multifaceted initiative to address the burden of sickle cell disease (SCD)
- In 2016, the [Sickle Cell Disease Coalition](http://scdcoalition.org/global) (SCDC)
 - Improve outcomes for individuals with SCD
 - Facilitate innovative approaches to clinical trials research
 - Expedite drug development

<http://scdcoalition.org/global>

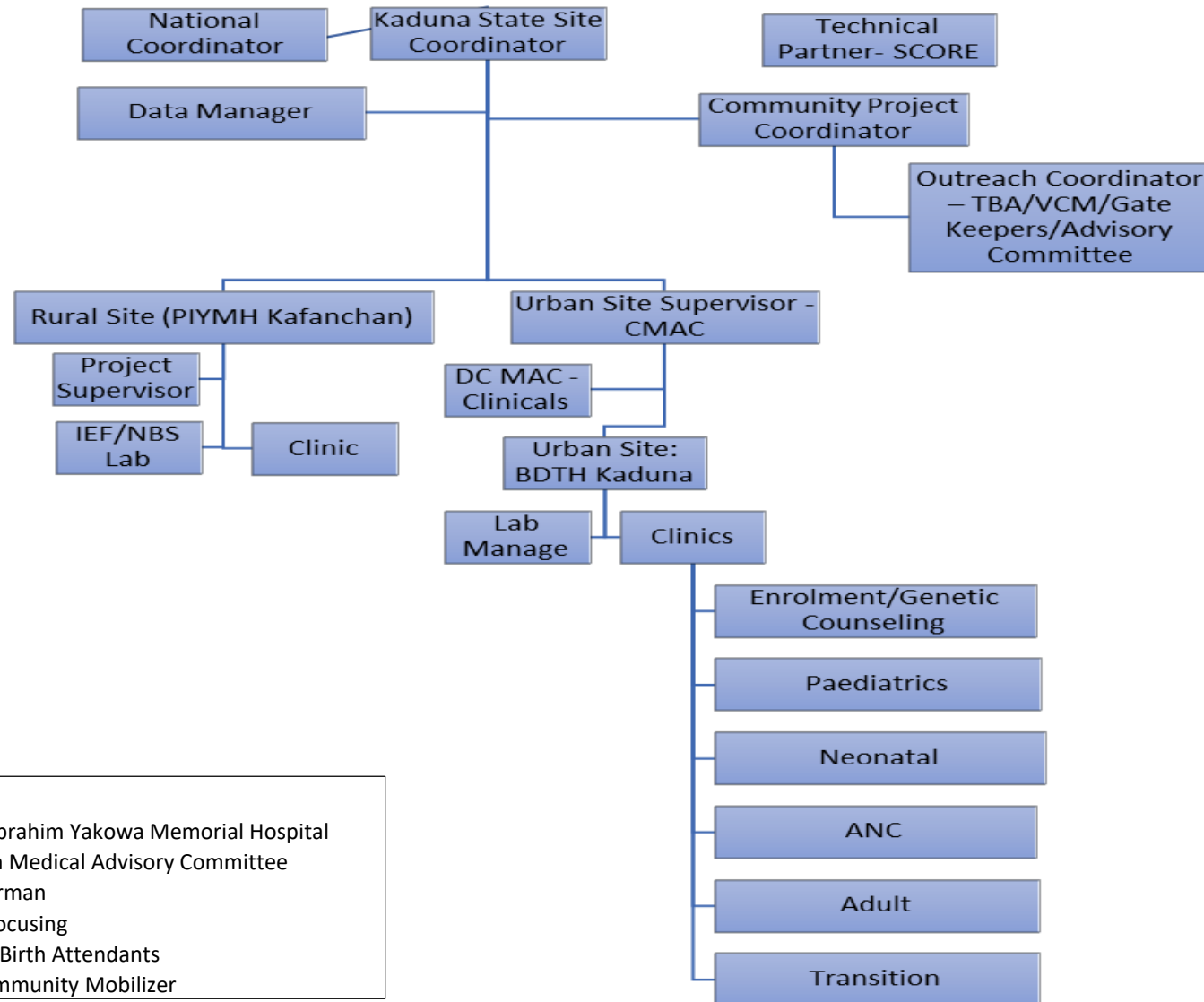


ASH: African Newborn Screening and Early Intervention Consortium

- Background
- Consortium of sub-Saharan African countries
 - Nigeria (2 sites, Kaduna, Abuja)
 - Tanzania
 - Zambia
 - Ghana
 - Kenya
- to address newborn screening for sickle cell disease (SCD)
- introduce standard-of-care practices for screening and early intervention therapies
- goal of decreasing childhood mortality rates for SCD



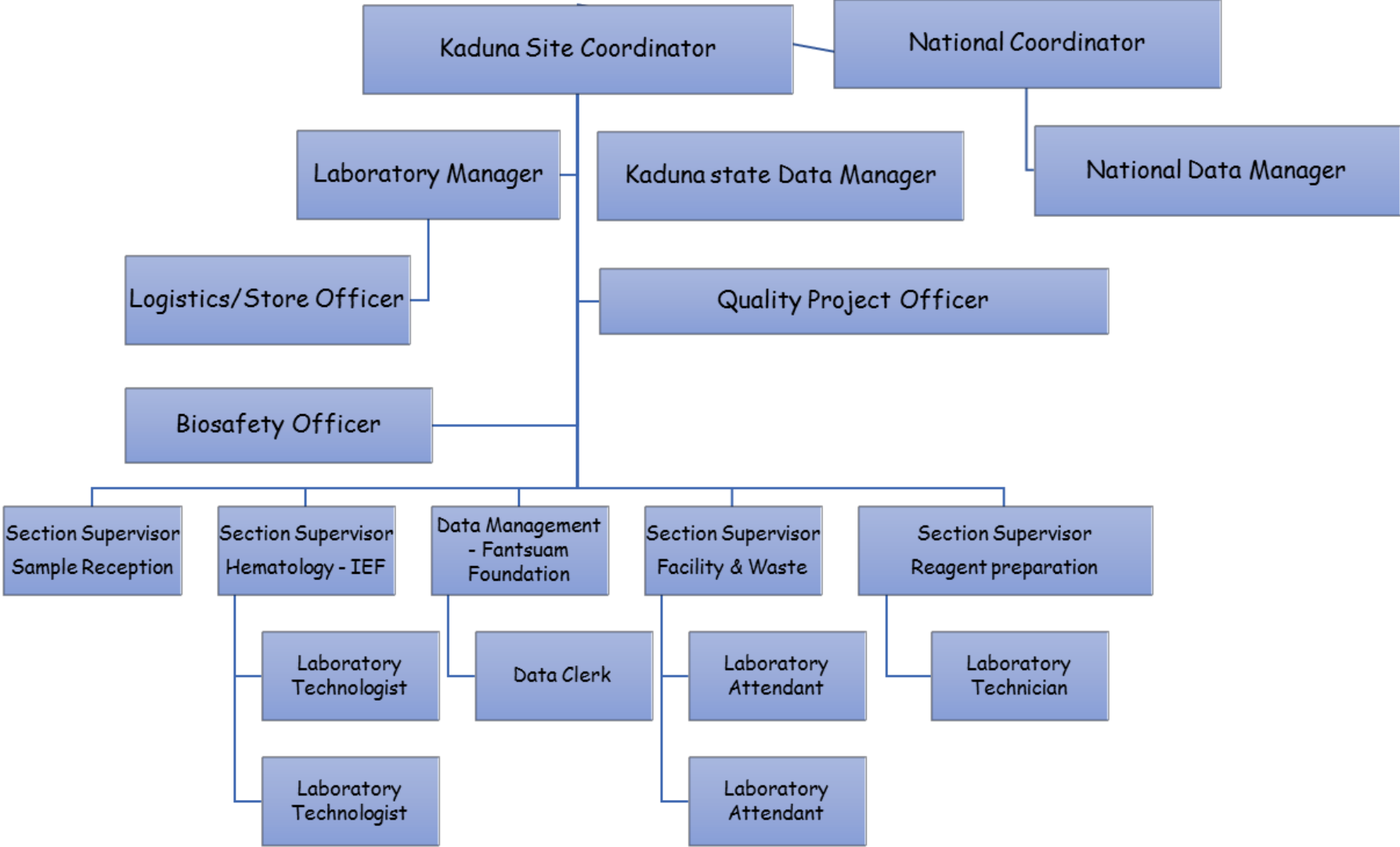
ASH SCD Consortium: Structure and Governance



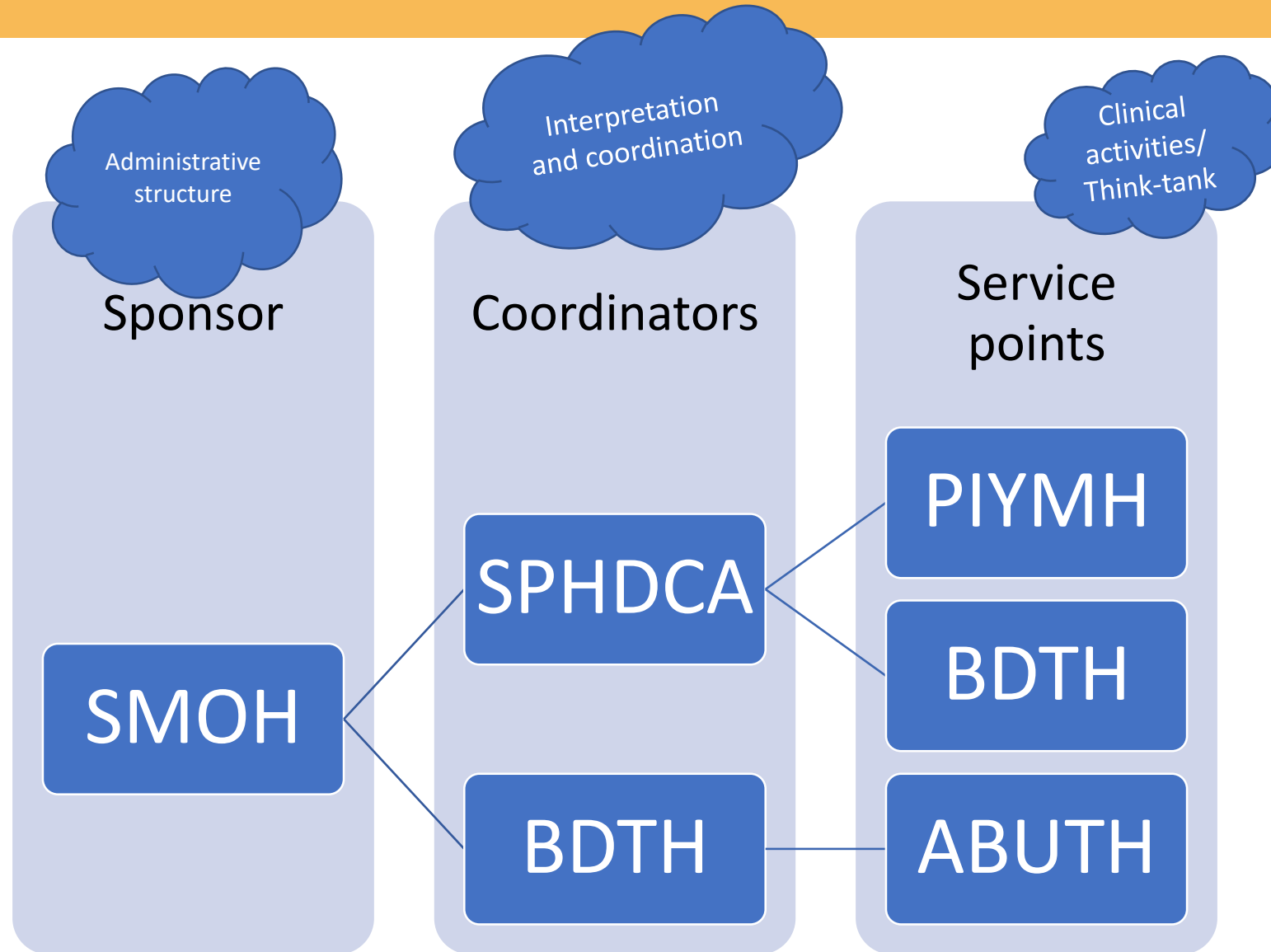
Key:
PIYMH – Patrick Ibrahim Yakowa Memorial Hospital
CMAC – Chairman Medical Advisory Committee
DC – Deputy Chairman
IEF – Isoelectric Focusing
TBA – Traditional Birth Attendants
VCM – Village Community Mobilizer



ASH SCD Consortium: Lab Organogram for Kaduna Site



Kaduna NBS Structure and Governance



Impact of the Collaborations

- Established protocol for standard of care
- Multidisciplinary teams (MDTs)
- Increase hydroxyurea uptake
- Improved community awareness
 - Media
 - Students
- independent and inter-dependent approach to collaboration
- Program linkage through a fulcrum
- Role definition and ease of operation by team capacity building
 - Research nurses
 - Genetic counselling team
 - Hydroxyurea counselling and monitoring
 - Patient support group
 - Ease of patient recruitment and tracking



Acknowledgements

- SickleGen Africa
- The Sickle Pan-African Network (SPAN)
- Baba Inusa, ARISE PI
- Obiageli Nnodu, SPARCO PI
- HB Manga, SPRING BDTH Kaduna PI
- KDBS GHS 2015 & 2017, DHS 2013 & 2015, NNHS 2015, WHO
- NBS-Multiple Indicator Cluster Survey (MICS 2016/17)
- Haematology Department, Barau Dikko Teaching Hospital (BDTH) & Kaduna State University (KASU), Kaduna



Thanks for Listening



Thank You
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This presentation reflects only the author(s)'s view and the EU Research Executive Agency (REA) is not responsible for any use that may be made of the information it contains.



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