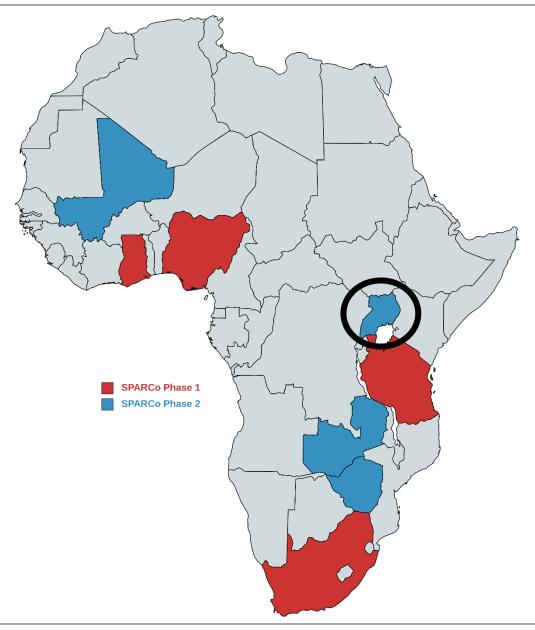


SickleInAfrica Consortium Meeting 10 11 – 15 October 2023



Kampala, Uganda Lake Victoria Serena Resort











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Introduction

It is a great pleasure to welcome you all to the 10th SickleInAfrica Consortium Meeting. SickleInAfrica has successfully conducted nine (9) SickleInAfrica Consortium Meetings since 2017.

The NHLBI funded the establishment of a multinational Sickle Pan-African Research Consortium (SPARCO) which is supported by the Sickle Africa Data Coordinating Center (SADaCC) and the SPARCO Clinical Coordinating Center (CCC). The first phase of this grant focused mainly on research capacity development with an emphasis on establishing a patient disease registry. The second phase of this grant is focusing on implementing research studies that could change the quality of care and life for Sickle Cell Disease patients in Africa.

Main aim of the 10th SickleInAfrica Consortium Meeting: To optimize the implementation plans, impact and sustainability of the Newborn Screening and the Malaria Chemoprophylaxis cross-consortium research studies.

The consortium meeting will be pre-empted by a 2-day Writing Workshop that will focus on further development of Research Fellows' writing skills. The aim is to also finalise papers and reviews that were initiated during the Fellows' training sessions over the last few months. These workshop sessions are open to all meeting attendees.

Summary of Meeting Activities

Day 1: Writing Workshop
Day 2: Writing Workshop
Day 3: Consortium Meeting Opening: Progress Reports – Newborn Screening
Day 4: Consortium Meeting: Progress Reports – Malaria Chemoprophylaxis
Day 5: Consortium Meeting: Data Quality and Research Processes



Agenda

Day 1	11 Oct 2023	Writing Workshop	
Facilitator(s)	Time (EAT)	Title	Speaker
	08:00 - 08:30	Welcome	SADaCC
	08:30 - 09:00	Writing Skills Workshop Session 1: <i>Providing and receiving</i> <i>constructive feedback</i>	Ms Taahira Goolam Hoosen
	09:00 - 09:30	Systematic Review Presentations & Expected Outputs	SickleInAfrica Fellows
	09:30 - 11:00	Cross-consortium manuscripts presentations & Expected Outputs	ТВА
Coordinator	11:00 - 11:15	Tea Break	
ocoramator	11:15 - 12:15	Writing Sessions	
	12:15 - 13:00	Writing Sessions	
	13:00 - 14:00	Lunch Break	
	14:00 - 14:30	Presentation	
	14:30 - 15:30	Peer-to-Peer Reviews	
	15:30 - 16:00	Tea Break	
	16:00 - 17:00	00 Peer-to-Peer Reviews	
	<mark>17:00 - 17:30</mark>	0 Report-backs	

Day 2	12 Oct 2023	Writing Workshop	
Facilitator	Time (EAT)	Title	Speaker
	08:00 - 08:30	Welcome	SADaCC
Coordinator: Mali	08:30 - 09:00	Writing Skills Session 2: Strengthening your academic voice	Ms Taahira Goolam Hoosen
	09:30 - 11:00	Writing Session	
	11:00 - 11:15	Tea Break	
	11:15 - 12:00	Writing Sessions	
	12:00 - 13:00	Writing Session	
	13:00 - 14:00	Lunch Break	
	14:00 - 14:30	Writing Session	
	14:30 - 15:30	Writing Session	
	15:30 - 16:00	Tea Break	
Coordinator: Nigeria	16:00 - 17:00	Writing Session	
Nigeria	17:00 - 17:30	Report-backs	



Day 3	13 Oct 2023	Welcome and Progress Reports: NBS	
Facilitator	Time (EAT)	Title	Speaker
	08:30 - 09:00	SickleInAfrica Video and Infographic Videos Playing Testing of sound for online presence	
	09:00 - 09:30	Welcome and Introductions	Prof Léon Tshilolo & Prof Sarah Kiguli
	09:30 - 10:00	SADaCC	Prof Ambroise Wonkam & Prof Nicola Mulder
Prof Ambroise	mbroise 10:00 - 10:30 SPARCo CCC		Prof Julie Makani, Dr Irene Minja & Prof Emmanuel Balandya
Wonkam	10:30 - 11:00	Ghana	Prof Fred Sarfo
& Prof Julie	10:30 - 11:00	Tea Break	
Makani	11:30 - 12:00	Nigeria	Prof Obiageli Nnodu
	12:00 - 12:30	Tanzania	Prof Emmanuel Balandya
	12:30 - 13:00	Mali	Prof Aldiouma Guindo
	13:00 - 14:00	0 Lunch Break	
	14:00 - 14:30	Uganda	Prof Sarah Kiguli
	14:30 - 15:00	Zimbabwe/ Zambia	Dr Patience Kuona
		Reflections and Discussions	
Prof	15:30 - 16:00	Tea Break	
Emmanuel Balandya	16:00 – 17:30	NBS: Overall progress discussions	Prof Obiageli Nnodu



Day 4	14 Oct 2023	Welcome and Progress Reports - MCP		
Facilitator	Time (EAT)	Title	Speaker	
	08:30 - 09:30	SickleInAfrica Video and Infographic Videos Playing Testing of sound for online presence		
Dr Patience Kuona & Prof Fred	09:30 - 10:00	SADaCC	Prof Ambroise Wonkam & Prof Nicola Mulder	
Sarfo	10:00 - 10:30	SPARCo CCC	Prof Julie Makani, Dr Irene Minja & Prof Emmanuel Balandya	
	10:30 - 11:00	Ghana	Prof Fred Sarfo	
	11:00 - 11:30	Tea Break		
	11:30 - 12:00	Nigeria	Prof Obiageli Nnodu	
Prof Leon	Prof Leon 12:00 - 13:00 Tanzania Prof Emmanuel Ba		Prof Emmanuel Balandya	
Tshilolo &	12:30 - 13:00	Mali Prof Aldiouma Guindo		
Prof Fumni	13:00 - 14:00	Lunch Break		
Olopade	14:00 - 14:30	Uganda	Prof Sarah Kiguli	
	14:30 - 15:00	Zimbabwe/ Zambia	Dr Patience Kuona	
	Reflections and Discussions			
	15:30 - 16:00	Tea Break		
	16:00 – 17:00	MCP Overall progress discussions	Prof Guindo	
	17:00 – 18:00	Presentations and Recommendations	Prof Steven Taylor and Dr Ndunjuna	



Day 5	15 Oct 2023	Data Quality and Research Processes		
Facilitator	Time (EAT)	Title	Speaker	
	08:00 - 08:20	SickleInAfrica Ontology - Application for Research Studies	Ms Jade Hotchkiss	
	08:20 - 08:40	SickleInAfrica Biorepository for Research Studies	Ms Chandré Oosterwyk	
Prof Nicola	08:40 - 09:00	SickleInAfrica	Mr Mario Jonas	
Mulder	09:00 - 09:20	Standard of Care Guidelines	Dr Vivian Painstil	
	09:20 - 09:40	ELSI	Dr Nchangwi Munung	
	09:40 - 10:00	SickleInAfrica Training	Dr Irene Minja	
	10:00 - 11:00	Reflections and General Discussions		
	11:00 - 11:15	Tea-break		
	11:15 – 13:00	Data Coordination	SADaCC	
	13:00 - 14:00	Lunchbreak		
Prof	Ethics Worksho Agenda Devel CCC	hop: elopment: Dr Syntia Nchangwi Munung supported by SADaCC and		
Raphael Sangeda	14:00 - 14:30	Welcome; Advantages of Conducting Clinical Multi-country Projects for SCD (Case studies)	Prof Tshilolo	
	14:30 – 15:00	Advantages of Data-Driven Multi-country Projects	Prof Nicola Mulder	
	15:00 – 15:30	Challenges in Obtaining Ethical Approval for Multi-country and NIH funded Research Projects	Prof Guindo and Prof Obiageli	
	15:30 - 16:00	Tea-break		
	15:30 – 17:30	 Talks about IRB Requirements from each country 1. Ethics requirements from each country 2. Administrative approvals: what each country requires. They will be asked to focus on: Clinical studies Data driven studies Secondary research Considerations for multi-country 		
	17:30 - 18:00	Remarks from CCC on IRB issues		



SickleInAfrica Consortium Co-Chairs



Prof Leon Tshilolo

Professor of Pediatrics and Haematology at Ufficial University of Mbujimayi (UOM) in DRC and Visitor at University of Kinshasa and University of Lubumbashi, DRC Director of Research in the Institut de Recherche Biomédicale et Drépanocytose associated to Monkole Hospital. Kinshasa, DRC. (since 2020) Paediatric haematologist in Centre Hospitalier Monkole (1998-2020) Expert of ITHANET-HVP Global Globin Panel (since 2016) DRC leader Investigator of REACH-Realizing

Effectiveness Across Continents with Hydroxyurea (since 2013) Co-Chair in SickleinAfrica Consortium. President and co-fondator of REDAC, a network of SCD Research in Central Africa. Member of the Académie de Médecine de France and the Académie Congolaise des Sciences (ACCOS).



Prof Olufunmilayo Olopade

Professor Olufunmilayo is the Walter L. Palmer Distinguished Service Professor of Medicine and Human Genetics, Dean for Global Health, and Director of the Center for Innovation in Global Health at the University of Chicago. Professor Olopade develops innovative strategies for comprehensive cancer risk assessment and prevention based on evolving understanding of genetic and nongenetic factors in individual patients, with a focus on women of African ancestry across the Diaspora.

She has received numerous honors and awards, including honorary degrees from North Central, Dominican, Bowdoin, and Princeton Universities; MacArthur Foundation Fellowship; Doris Duke Distinguished Clinical Scientist and Exceptional Mentor Award; American Cancer Society Clinical Research Professorship; Officer of the Order of the Niger Award; and the Franklin D. Roosevelt Freedom from Want Award. She is an elected member of the Association of American Physicians, National Academy of Medicine, American Academy of Arts and Sciences, and the American Philosophical Society, and currently serves on the board of directors for Susan G. Komen, Cancer IQ, Lyric Opera of Chicago, and MacArthur Foundation.

Principal Investigators



Prof. Ambroise Wonkam (Principal Investigator and Director, SADaCC)

Professor Wonkam is a professor of medical genetics, Director of GeneMAP (Genetic Medicine of African Populations), and immediate past Deputy Dean Research at the Faculty of Health Sciences, University of Cape Town, South Africa. In addition to his current UCT appointment, that allow him to continue ongoing research activities in Africa, he was recently appointed Professor and Director, of the McKusick-Nathans Institute, and Department of Genetic Medicine, Johns Hopkins University, School of Medicine Baltimore, USA.

After a MD training from the Faculty of Medicine and Biomedical Sciences, University of Yaound I (Cameroon), he completed a thesis in Cell Biology in the department of Morphology, and a specialist training as medical geneticist at University of Geneva (Switzerland) and a PhD in Human Genetics

(University of Cape Town, South Africa). His research interests and international recognition by the academic community are reflected in > 200 peer-reviewed publications.



Prof. Wonkam has been investigating numerous monogenic conditions of High burden in Africa, e.g. Sickle cell disease and inheritable hearing Impairment in Africa with focus on the use of genetics in public health intervention. He has a traceable record of studying genomic factors that affect the SCD phenotype, specifically studying HbF-promoting loci and co-inheritance of SCD and alpha-thalassemia in Cameroon and genomic variants affecting Kidney Dysfunctions. Moreover, his research has emphasized the huge genetic and locus heterogeneity in rare diseases in Africa including congenital hearing loss, and particularly genes variants, and novel genes, as well as innovative finding in the genetic architecture that will inform the pathobiology globally. In this application, he will build of what is presumed to be the World's largest collection of Whole Exome Sequencing Data of individual living with Hearing impairment, with African ancestry.

He has successfully advocated for more focus on Intellectual (syndromic and non-syndromic) by contributing to establish a section on Case report in Diverse Population in the American Journal of Medical Genetics (PMC7255818).Dr Wonkam was the principal investigator (PI) of a NIH funded H3Africa grant aiming to examine ethical issues relating to sickle cell genomics research in Cameroon, Tanzania and Ghana. Since 2017, He established the Sickle Africa Data Coordinating Center (SADaCC) to support the activities of the Sickle Pan African Research Consortium (SPARCo) site in Tanzania, Nigeria, Mali, Uganda, Zimbabwe, Zambia and Ghana (https://www.sickleinafrica.org/)



Prof. Nicola Mulder (Co-Principal Investigator, SADaCC)

Professor Mulder heads the Computational Biology Division at the University of Cape Town (UCT) and is a full member of the Institute of Infectious Disease and Molecular Medicine. She leads H3ABioNet, a Pan African Bioinformatics Network of 28 institutions in 17 countries, which is developing bioinformatics capacity to enable genomic data analysis through an extensive training program for African researchers.

She also co-leads a Sickle Cell Disease Data Coordinating Centre and a Wellcome Trust Centre Data Integration Platform at UCT and is PI of the new DS-I Africa Open Data Science Platform. She received her PhD in Medical Microbiology from the University of Cape Town and then worked for 8.5 years at the European Bioinformatics Institute in Cambridge, as a Team Leader. At UCT her research focuses on genetic determinants of susceptibility to disease, African genome variation, and microbial genomics and infectious diseases from both the host and pathogen perspectives. Her group provides bioinformatics services and training and develops new algorithms and resources for the analysis of complex African genetic data. Prof Mulder is actively involved in capacity development, including training, education and curriculum development in Bioinformatics. She also sits on a number of international scientific advisory boards.





Prof. Julie Makani (Principal Investigator, SPARCo CCC)

Professor Makani is a Physician Scientist in the Department of Haematology and Blood Transfusion at Muhimbili University of Health and Allied Sciences (MUHAS) www.muhas.ac.tz and Provost Visiting Professor at Imperial College London, UK. Tanzania established one of the world's largest single-center study cohorts for sickle cell disease. She serves as Principal Investigator of the Sickle Cell programme in MUHAS and Sickle Pan African Research Consortium (SPARCO) Clinical Coordinating Centre (CCC) within <u>SickleInAfrica network</u>. Site Principal Investigator for MUHAS for

<u>H3ABioNet</u>; Co- Principal Investigator <u>SickleGenAfrica</u>. This work aims to use sickle cell disease as a model to establish scientific and healthcare solutions in Africa, that are locally relevant and globally significant. The approach integrates public health interventions with genomics including gene therapy to improve health and cure sickle cell disease.

Prof. Fred Sarfo (Principal Investigator, SPARCo Ghana)

Professor Sarfo is a researcher, a clinician and an educator. He practiced as a Neurologist from 2010 to date and holds 2 doctoral degrees in Epidemiology and Molecular Medicine from Durham University UK and the Kwame Nkrumah University of Science & Technology (KNUST) respectively. In 2010, he started a Neurology clinic at KATH in Kumasi where he led in providing services for a population of 12 million Ghanaians in the middle and northern sectors of the country as the only practicing

neurologist for this sector of Ghana. He is passionate about context-specific research as a way of fashioning out locally relevant solutions to the health challenges of my society. His research focus is on Stroke in the sub-Saharan African context.

Prof. Sarfo is currently the Kumasi site lead-Investigator on the SIREN (Systemic Investigative Research and Education Network) project which is the biggest study on stroke in sub-Saharan Africa investigating the traditional and emerging risk factors of stroke as well as characterizing the genetic markers of stroke. Understanding the incidence prevalence determinants and risk modifiers of stroke occurrence among individuals with Sickle Cell Disease has received little attention in Sub-Saharan Africa. Ghana SPARCO sites therefore seek to characterize the determinants etiologic subtypes outcomes and sequelae (functional status cognitive impairment quality of life) of incident and recurrent strokes across the lifespan of patients with SCD.

This sub-aim is embedded in our overall goal of to establish a prospective cohort of 6 000 individuals living with SCD across the lifespan with a dual purpose of understanding the determinants of the protean manifestations of acute and chronic complications of SCD in a resource-limited setting while conducting implementation research to address " surmount & integrate the best resource-based standards of clinical care for SCD with a vision towards establishing hubs of excellence for research and care for SCD in Ghana.





Prof. Aldiouma Guindo (Principal Investigator, SPARCo Mali)

Professor Guindo is a Professor of Hematology at the University of Bamako, and in addition to the PharmD degree, he obtained a PhD from the University of London, did post-doctoral training in the NIAID Laboratory of Malaria and Vector Research under Dr Thomas E. Wellems. He is a member of French society of hematology and an allied member of American society of hematology. In his current role he leads all operations of the CRLD and also serves as an advocate for sickle cell disease care, research and education to the national government.

He has a broad background in hematology, with specific training and expertise in red blood cell disorders and screening research and data analysis on sickle cell disease. His research includes sickle cell disease, G6PD deficiency and infections. The purpose of this grant is to improve the quality and duration of life of African people living with sickle cell disease. Prof. Guindo 's early publications directly addressed the afforded protection of sickle cell gene, hemoglobin C and G6PD deficiency against severe malaria and the mechanism by which that protection occurs. These publications found that sickle cell gene and HbC are associated with high protection against severe malaria by reducing infected erythrocytes cytoadherence to the vascular endothelium and the abnormal display of knobs on erythrocyte containing HbC. These results of natural protection against malaria have changed the design of any malaria vaccine trials.

In addition to the contributions described above, with a team of collaborators, he directly documented the issue of the physiopathology of sickle cell disease, transfusion safety, infection in sickle cell disease and the referral values in hematology in Mali. This work allowed us to shed light on the field of research in hematology as well as in improving the quality of care.



Prof. Obiageli Nnodu (Principal Investigator, SPARCo Nigeria)

Professor Nnodu is Professor of Haematology and Blood Transfusion and Director, Centre of Excellence for Sickle Cell Disease Research and Training at University of Abuja (CESRTA), the National Coordinator of the American Society of Hematology Consortium for Newborn Screening in Africa (CONSA), the Nigerian Principal Investigator for SPARCO, Abuja Coordinator for SickleGenAfrica and Co-PI for the UK NIHR Patient centred management of sickle cell disease in Sub Saharan Africa.

Prof Nnodu is a UK Foreign Office Chevening Scholar. She has carried out many multi-institutional, multinational research projects including a multilateral DFID DELPhe Project. She serves as expert on technical committees on non-communicable diseases with the Nigerian government and as consultant for international agencies including the WHO AFRO. Between 2018-2019, she carried out an assessment of the level of implementation of the WHO AFRO Strategy in SCD in sub Saharan Africa high burden countries and the findings highlighted the need for increased global funding for SCD. In partnership with Silver Lake Laboratories, she led a successful application for the inclusion of point of care tests for sickle cell disease in the essential diagnostics list of the WHO - EDL3.

Prof Nnodu is Chair of the largest network of SCD in Africa, the Sickle Cell Support Society of Nigeria and a Fellow of the Nigerian Academy of Medicine.





Prof. Emmanuel Balandya (Principal Investigator, SPARCo Tanzania)

Professor Emmanuel Balandya is a physician-scientist with expertise in biomedical sciences, encompassing Physiology, Haematology and Immunology. He obtained his Medical Degree at the University of Dar-es-salaam, Tanzania (2005); Doctorate Degree at Dartmouth College, USA (2012) and post-doctoral fellowship at Harvard Medical School, USA (2014).

Following his return to Tanzania, he has researched on immunity and infections in Sickle Cell Disease (through the NIH-FIC/NHLBI/UCSF Global Health Fellowship) and is currently PI of the NIH/NHLBI-funded U01 HL156853 grant titled Sickle Pan-African Research Consortium (SPARCO)-Tanzania and Interim PI of SPARCO Clinical Coordinating Centre U24 HL135881, part of the larger SickleInAfrica Consortium involving Tanzania, Nigeria, Ghana, Mali, Uganda, Zimbabwe, Zambia and South Africa. In He is co-Investigator in several ongoing health research and education capacity building projects at MUHAS.

He is published and has presented his work at national and international platforms. Prof. Balandya is also Member of the Organizing Committees for the MUHAS Scientific Conference and National NCD Scientific Conference in Tanzania; is Acting Deputy Vice Chancellor-Academic at MUHAS; Board Member of Young Scientists Tanzania (YST), a nation-wide Science Outreach Programme, and consults with the National Institute for Medical Research (NIMR) and Tanzania Commission for Universities (TCU) on matters related to health research and education. He is a scientific reviewer for Tanzania Journal of Health Research (TJHR), Allergologia et Immunopathologia, Journal of Community Genetics, PLOS ONE, Lancet Haematology and PNAS.



Prof. Sarah Kiguli (Principal Investigator, SPARCo Uganda)

Professor Kiguli (MBCHB, M.MED (MAK), MHPE (Maastricht)) is a Paediatrician and Health Profession Educationalist. She is the Principal Investigator of the NIH funded Sickle Pan-African Research Consortium (SPARCO) Uganda Project and the HEPI project: Health professions education and training for strengthening the health system and services in Uganda. She is a Professor and Past Head of Department of Paediatrics & Child Health, and Past Chairperson of the Teaching and Learning Committee of the Makerere University College of Health Sciences.

Prof Kiguli was a Council Member Makerere University, Representing Senate (2010-18).

She is a Fellow of the Foundation for the Advancement of International Medical Education and Research (FAIMER) Institute, President of the East African Health Professionals Educators (EAHPE) Association, Member, Uganda National Immunization Technical Advisory Group, Past Member of the Executive Committee of the Network-Towards Unity for Health (Network-TUFH) representing the Sub-Saharan Region, Women and Health Task Force of the Network-TUFH, and served as Global Faculty Advisor for the FAIMER Institute, and Faculty for the Southern Africa Foundation of Advancement of International Medical Education and Research (SAFRI) and sits on several National and International Boards.

In addition, she is a Founder Member of Women and Health: Together for the Future organization. Prof Kiguli is a Past President of the Association of Uganda Women Medical Doctors (2018-2020). She served in the same position for 4 years (2003-2007; 2028-2020). She is also a member of the Uganda Medical

& Dental Practitioners Council.

During the last 20 years, she has focused on advancement of Health Professions Education, Paediatrics



Clinical Research and Services. Her main research areas have included Emergency Peadiatrics, Child Health, Childhood Tuberculosis, Sickle Cell Anaemia and Health Professions' Education. She has been involved in Clinical Trials involving Fluid Resuscitation, Blood Transfusion and Children's Oxygen Administration Strategies in severely sick children in low resource settings. She has more than 70 publications in peer reviewed journals.



Dr Patience Kuona (Principal Investigator, SPARCo Zimbabwe)

Dr Kuona (PhD) is a Paediatric Haemato-Oncologist and Senior Lecturer in the Child and Adolescent Health Unit at the University of Zimbabwe Faculty of Medicine and Health Sciences where she has taught and researched for the past 13 years. She is the principal investigator of the Sickle Haemoglobinopathy research programme in Zimbabwe and Zambia (SHAZ).

She is a clinician with a passion for patient-centred care who established the Harare SCD cohort at the SCD clinic at Parirenyatwa Teaching Hospital in 2018 as a MEPI Junior Faculty scholar in 2016-2018. She was also an ICOHRTA/FIC/NIH research fellow in 2007-2008 during her Masters in medicine (Paediatrics) programme.

Attendees: Ghana

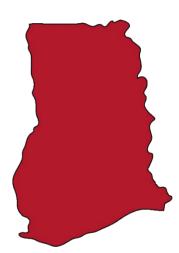


Dr Vivian Paintsil

Dr Paintsil has over 21 years of Medical practice. She is a Senior Lecturer at the Department of Child Health, School of Medicine and Dentistry, Kwame Nkrumah University of Science and Technology (KNUST), Kumasi, Ghana and a Senior Specialist Paediatrician working at the Komfo

Anokye Teaching Hospital (KATH) in Kumasi. She holds a Bachelor of Medicine and Surgery (MB ChB) from the School of Medical Sciences,

KNUST and a postgraduate training in paediatrics from the West African College of Physician. She is a Fellow of the West Africa College of Physician Paediatrics and the Ghana College of Physicians and Surgeons. She also holds a certificate in paediatric haem/oncology. Her work involves clinical care of paediatric cancer patients and others with haematological problems, especially haemophilia and sickle cell disease at KATH. She has been involved with the newborn screening program for SCD in Kumasi. Over the last Fifteen years, she has gained extensive experience in undergraduate and postgraduate teaching and in research in Ghana. She is currently heading the Paediatric haem/oncology unit. She is involved with the SCD newborn screening project and the ORDISS project. She was the co-PI for SPARCO I for the Ghana site and in the SickleGen Africa project. She is also involved in ongoing clinical trials at KATH. She is the PI for the SIOP Wilms Tumour Africa Project at the Kumasi Site and part of the CANCaRe Africa consortium for paediatric oncology lead for the Kumasi City C/Can project.







Mr Evans Xorse Amuzu

Mr Xorse Amuzu is a Health Research Officer with experience in managing hospitalbased and community based observational and interventional studies. He currently coordinates SCD clinical research studies/trials in the Komfo Anokye Teaching Hospital. He also provides research design and management support to staff in their research projects and also training of other junior officers in research skills. Evans also has a special interest in Health Informatics and has designed and currently manages numerous databases being used in the collection of both cross-sectional and

longitudinal studies cutting across several medical specialties. He is currently pursuing an MPhil in Epidemiology and Applied Biostatistics in the Kwame Nkrumah University of Science and Technology (KNUST)



Dr Eunice Agyeman Ahmed

Dr. Agyeman Ahmed is an adult haematologist working at the Komfo Anokye Teaching Hospital in Kumasi-Ghana. She obtained her medical degree at the Kwame Nkrumah University of Science and Technology, Kumasi, and post-graduate training at the Ghana College Of Physicians and Surgeons in Accra. She has a keen interest in sickle cell disease and blood transfusion. She strives to make a huge contribution to sickle cell disease care in Ghana and the whole of Africa. She loves to spend time with her family, playing tennis and sightseeing.



Dr Lawrence Osei-Tutu

Dr. Osei-Tutu is a specialist clinical paediatric haematologist-oncologist at the Komfo Anokye Teaching Hospital (KATH) in Kumasi, Ghana. He specializes in treating children, adolescents and adults with sickle cell disease and other benign and malignant haematological disorders with clinical and research experience in rural and urban Ghana. He led the comprehensive sickle cell clinic team to develop and implement hydroxyurea therapy as a standard of care at KATH He is currently the Sickle Pan African Research Consortium (SPARCo) Ghana site's representative

in the SickleInAfrica Ethical Legal and Social Issues (ELSI) working group.

As the head of the Paediatrics department from April 2018 to May 2021 at the Presbyterian Hospital, Agogo, on secondment from KATH, he has established a sickle cell clinic that offers hydroxyurea therapy to more than 120 children, adolescents, and adults, under the Ghana-Novartis Hydroxyurea for Sickle Cell (Ahodwo) programme. In 2020, Dr. Osei-Tutu was a recipient of the American Society of Hematology (ASH) Visitor Training Program (VTP). He completed his post-graduate fellowship training in clinical Paediatric Haematology and Oncology in 2017 at the University of Cape Town (UCT), South Africa to earn a post-graduate diploma in clinical Paediatric Haematology and Oncology (awarded on December 14, 2018). Affectionately known to many as "*Dr. O.T*", he is a passionate advocate for patient/family-centered holistic sickle cell care for all affected persons everywhere.





Dr. Ruth Owusu-Antwi

"...I am a Fellow of the Ghana College of Physicians and Surgeons. I hold an MBChB and an MSc.Global Mental health from the Kwame Nkrumah University of Science and Technology (KNUST). I am a Lecturer at Department of Behavioural Sciences at the School of Medicine and Dentistry and serves on the KNUST Committee on Human Research Publications and Ethics (CHRPE). I also practice in Komfo Anokye Teaching Hospital (KATH) as a senior specialist and the current head of the Psychiatry Unit. I am prolific conference speaker and a critical researcher with many publications and books

to my credit. My research interest is in Gender-based violence, women mental health and child Psychiatry. I have won many awards in my field of practice, including the 2019 international fellow of the Association of Women Psychiatrists in San Francisco, U.S, in recognition of my work towards women mental health. I have recently been recognized by the sitting president of Ghana, His Excellency, Nana Akufo-Addo, in my role as the Ashanti Regional Lead for Psychosocial support during the Covid Pandemic. I am the current President of Psychiatric Association of Ghana (PAG)..."



Mr Suraj Yawnumah Ababakar

"...I am a Research Officer with the Sickle Cell Unit of Komfo Anokye Teaching Hospital (KATH) where I have developed skills in research and administrative procedures and also assist in both clinical and non-clinical research in the Hospital. I hold a Bachelor of Science (Biochemistry) from Ghana. I provide technical assistance to staff of KATH in their research projects and also training of other junior officers in research skills. I also have a

special interest in Bioinformatics. I have an appreciable knowledge in Microsoft Office Suite, Stata, Epi-Info, REDcap, and Open Data Kit software..."



Attendees: Mali

Dr Touré Boubacar Ali

Hematologist at Centre de Recherche et de Lutte contre la Dr panocytos, Assistant professor at the Faculty of Medecine and Stomatology, Head of consultation-Hospitalzation unit, Mali Sparco team member, Mali NBS protocol coordinator.



Dr Yeya Dit Sadio Sarro

"...I am Epidemiologist in Sickle cell disease

center at Bamako and associate senior scientist in UCRC-SEREFO laboratory and Associate professor in Epidemiology at the faculty of medicine and Dentistry (FMOS). I have been in this NIAID/NIH program more than 15 years and have done many tuberculosis project. This program have a state of art immunology laboratory where we run assay exploring the immune system. This equipment is required for any

vaccine trial. I have leaded this core Immunology from 2003 to 2017 and have conducted complex tuberculosis immunological assay. Beside this immunological skill I have more than 10-years experiences in data management..."





Dr Sekou Kene

Clinical Haematologist at the Centre de Recherche et de Lutte contre la Dr panocytose (CRLD). In charge of the transfusion unit and transcranial doppler. Focal person for malaria chemoprophylaxis (SPARCO-Mali).



Dr Abdulmalik Koya

Abdulmalik (He/Him) is a fully supported SaDaCC research fellow (Mali Site). In 2018 he was awarded the Tu Youyou National Chinese Medicine Communication Media Award. Subsequently, he worked briefly as a clinician during the COVID-19 pandemic and left to pursue the interest of aspiring physician-scientist. He is currently a Ph.D. student at the cardiovascular unit at Glenfield Hospitals affiliated with the University of Leicester, UK. His research focuses on the 1. sudden cardiac death. 2. Psychosocial influence on

potential use of drug of abuse among people living with sickle cell disease. In his spare time, he learns how to fly a plane, run marathons, read autobiographies, and chinwag.



Dr Dolo Housseini

Attendees: Nigeria



Prof Maxwell Nwegbu

Maxwell Nwegbu is a Professor of Chemical Pathology and the Head. Department of Chemical Pathology, College of Health Sciences, University of Abuja, as well as a Consultant Chemical Pathologist, University of Abuja Teaching Hospital (UATH). An alumnus of the College of Medicine, University of

Nigeria, his post-graduate/specialist training was in laboratory medicine (Chemical Pathology sub-speciality), at University College Hospital, Ibadan, Oyo state, Nigeria.



He is the recipient of the 2007 Awoonor-Reiner prize for best graduating Fellow (Laboratory Medicine), West African College of Physicians, Fellow of the Open Medical Institute, Austrian-American Foundation in Pathology and Global Health Fellow, Novartis Institute of Biomedical Research (NIBR), Cambridge, Massachusetts. He leads the skills development working group in SPARC-NEt and is currently the



laboratory manager at the Centre of Excellence for Sickle Cell Disease Research and Training (CESRTA), University of Abuja. Prof Nwegbu is a sub-Investigator (laboratory) in a number of clinical trials, a research team member of the International Hemoglobinopathy Research Network (INHERENT) and laboratory coordinator in number of NIH-funded projects including the Men of African Descent and Carcinoma of the Prostate (MADCaP) consortium. He is a member of the Health Research Ethics Committee (HREC) of UATH, and the North-Central Zonal coordinator of the Continuing -Professional Development/Medical Education (CPD/CME) of the Nigerian Medical Association.



Prof Anazoeze Madu

Prof Madu is a Haematology specialist with a 15 year experience in managing people living with sickle cell. He works with the University of Nigeria where he does clinical and research work in sickle cell and other hematological conditions. He also engages in academic training at postgraduate and undergraduate levels in the University. He has published more than 70 peer-reviewed works in sickle cell and other hematological disorders. He has been a member of Skills and Research Working Group of SPARCo Nigeria since it's inception and is the Country lead in the Malaria Chemoprophylaxis Study



Dr Patrick Ohiani Moru

Dr Moru is a Medical Doctor and a Research Fellow at the Centre of Excellence for Sickle Cell Disease Research and Training (CESRTA) University of Abuja, with certifications and trainings in; Project Management, Leadership and Management in Global Health and Human Clinical and Health Research ethics, he facilitates training, coordinates and support ongoing research projects/programs, capacity building for Sickle Cell Disease (SCD) patients/Caregivers, research protocol implementation and implementation of

Evidence Based Health Interventions in the Management of SCD.



Mr Ikechukwu Chianumba

Mr Reuben Chianumba is a valued member of the Data Management team at SPARC-NEt Nigeria. He plays a crucial role in facilitating research endeavors at CESRTA, University of Abuja, FCT Nigeria. With a strong commitment to data governance and ethics, he has undergone extensive training in these domains, including Best Practices in Sharing Individual-Level Research Data and Data Management for Clinical Research Studies.

Reuben is well-versed in utilizing various data management tools for comprehensive data analysis. In addition to his primary responsibilities, he also provides valuable support for various ongoing research initiatives at CESRTA, contributing to their success.



Ms Onyinye Udeozo

"...I am a recent graduate of Electronics and Computer Engineering from Nnamdi Azikiwe University, Awka, Anambra State. I have a passion for technology and creativity, which led me to excel in front-end web development. Currently, I am contributing my skills as a diligent data clerk at CESRTA (Centre of Excellence for Sickle Cell Research and Training) in Abuja, Nigeria. In my work, I adhere to a simple but profound philosophy: delivering my utmost best and paying attention to details. I don't consider a task complete until it's in its finest form. I hold a belief in the power of technology to bring about positive change and transformation. With a strong foundation in electronics and computer engineering,

I am committed to contributing to this change.

Beyond my professional pursuits, I find joy in the rhythm of music and dance. I spend most of my off-work hours finetuning my skills with new courses, but I could make out time for a good book or movie, if it offers



me hearty laughter as a reward ... "

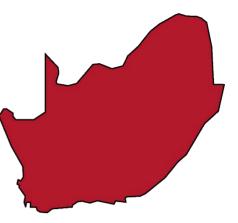
Attendees: South Africa



Dr Victoria Nembaware

Dr Nembaware was officially appointed as the Project Manager for SADaCC in November 2017 and is the outgoing training coordinator for H3Africa. She earned her first degree in Chemistry and Microbiology from the University of Cape Town and then graduated Cum Laude for her Hons and MSc degrees from

the University of Western Cape (South African Bioinformatics Institute). Vicky was awarded a PhD in Bioinformatics in 2008 from the



University of Cape Town. In addition to her didactic training in Bioinformatics and Monitoring and Evaluation, Vicky has research experience in Bioinformatics and in the Public Health field. She also has experience in designing, monitoring and evaluation of projects in the Information Communication Technology field (particularly in mHealth). Vicky has conducted numerous mHealth projects which include a public participatory project in the development of the South African National Strategic Plan on AIDS, TB and HIV (2012-2015). To this end, "…I was developing a mobile phone app in collaboration with members of the H3Africa consortium which is aimed primarily to train researchers how to engage and educate the general public on heredity and health in Africa. I am passionate about evidence-based training and mentoring of the next generation of African health researchers…"



Dr Syntia Munung Nchangwi

Dr Nchangwi is a Bioethics Researcher



Mrs Jade Hotchkiss

Mrs Hotchkiss is the lead developer and curator for the Sickle Cell Disease Ontology (SCDO), amongst performing other tasks as an employee of the Sickle Africa Data Coordinating Centre (SADaCC), based at the University of Cape Town (UCT) in South Africa. She works remotely from her home in Kloof (KZN, South Africa) and travels for work as necessary. Her undergraduate background is in biochemistry and physiology. She has qualifications and work experience related to high school teaching and programming and research in the bioinformatics field. She also has

work experience in software development quality control, documentation creation and editing, website development and maintenance, and graphic design. She is an avid learner of new skills, both professionally and as hobbies, and is interested in many different topics.





Mr Mario Jonas

Mr. Jonas' background in Bioinformatics, multi-disciplinary in nature, serves him well in supporting the research and functioning of SADaCC in particular and the SickleInAfrica Consortium in general. He finds satisfaction in enabling his colleagues to focus on their areas of expertise and he is passionate about capacity building and teaching.



Ms Zimkita Magangana

"...I am an assistant administrator at the University of Cape Town, under the Human Genetics Division. I have an honours degree in Environmental Sciences from Walter Sisulu University..."



Ms Chandre Oosterwyk

Ms Oosterwyk received her BSc in Medical Bioscience and microbiology at the University of the Western Cape in 2018. In 2018 she completed her Honours degree in Human Genetics. Chandré completed her MSc (Human genetics) in 2023 and is currently working as a laboratory technician and coordinator for SADaCC.

Attendees: Tanzania

Dr Agnes Jonathan



Dr Jonathan is a physician, Public Health Specialist and a Master of Business Administration (MBA) candidate at Mzumbe University. She holds a Master of Public Health at Muhimbili University of Health and Allied Science (MUHAS) and a Degree of Medicine from Kilimanjaro Christian Medical University College

(KCMUCo). She is currently serving as a Programme Manager for Sickle Pan African Research Consortium



(SPARCO) CCC and Sickle Cell Programme, Project Coordinator for Consortium (SPARCO)-Tanzania at Muhimbili University of Health and Allied Science (MUHAS). In this position, she contributes greatly in project management aspects, administration, finance, research, standard of care, skills, team building and increasing the number of registered patients in the database (currently over 6000 patients). She contributed in grant writing for SPARCO-Tanzania and secured funding from NIH. In scientific writing, she has contributed in 13 peer-reviewed scientific publications as lead and/or co-author. She formulated policy brief which has been disseminated to policy makers and other stakeholders. She is also working with the Ministry of Health, SCD Taskforce in developing SCD 5 years Strategic Plan, practice notes for SCD and other SCD-related activities. Dr. Agnes has experience in coordinating national stakeholders? meetings, including the multi-stakeholder meeting during 7th MUHAS

University-wide Dissemination Symposium, which had great achievements including enhanced



Hydroxyurea access to patients enrolled in all National Health Insurance Fund (NHIF) schemes. She is also a technical lead for PEN-Plus Sickle Cell Disease Expert Group in the NCDI Poverty Network. Dr. Agnes is a member of Project Management Institute, PMI-Global and Tanzania Chapter, a member of SickleInAfrica and a member of the Institute of Directors in Tanzania (IoDT).



Dr Siana Nkya

"...I am a biomedical scientist specialized in molecular biology and human genetics. My research goal is utilize human molecular and genomics skills includes disease prevention and diagnosis, understanding disease mechanisms, interventions discovery and development (drugs and gene based therapies) and monitor treatment outcomes (pharmacogenomics). I have primarily applied my skills in malaria and sickle cell disease (SCD).

During my early training I conducted research in malaria focusing on molecular resistant markers of drug resistance in P. falciparum. For the PhD training, I have conducted research in Sickle Cell Disease (SCD). For the past 15 years I have focused my research on genomics of SCD, particularly genetic determinants of fetal hemoglobin and pharmacogenomics of fetal hemoglobin interventions such as Hydroxyurea. In 2014, we were able to establish a genetic database of more than 1700 individuals with SCD with well described SCD phenotypes, among the first in Africa. This data is available for investigation of genetic variants associated with SCD phenotypes, disease and intervention outcomes. During my career, I have worked closely with the Molecular hematology department, Kings college London led by Professor Thein, now based at NHLBI , the medical genetics group at Wellcome Trust Sanger Institute (WTSI), Professor Vijay Sankaran and his team based at the Division of Hematology/Oncology, Boston Children's Hospital and Dr Emile Chimusa who is a Professor of Bioinformatics in the department of Department of Applied Sciences, University of Northumbria . I have gathered basic knowledge and built networks that support SCD genetic studies in our country.

In 2015, I was part of a team which initiated the establishment of newborn screening programme for sickle cell disease in Tanzania and I have gained experience in setting up a laboratory for screening of SCD. Although newborn screening is a healthcare programme but it provides opportunities to study and set up preventive interventions including genetic diagnosis of SCD disease modifiers at birth and plan for curative therapies such as bone marrow transplant and gene therapy. I have received various research support including; I) NIH; the Fogarty global health fellowship (2016) and the Emerging Global Leader Award (K43, 2019-2024) to continue work on SCD genomics and to establish a birth cohort as a platform for studying determinants of fetal hemoglobin decline ii) American Society of Hematology (ASH); Global Research Award (2018) to conduct a study on pharmacogenomics of hydroxyurea in individuals with SCD in Tanzania iii) Novartis global health; investigators initiated trial (2022) to scale up the pharmacogenomics of hydroxyurea study to Ghana, and Nigeria iv) Early Career Women Scientist award by the Organization for Women in Science for the Developing World (OWSD)(2018-2020), to develop a minION DNA diagnostic technology for hemoglobinopathies in collaboration with Professor Anna Schuh of the University of Oxford, UK.

Due to my passion and work in human genetics, in 2017, I co-founded the Tanzania Human Genetics Organisation (THGO) and currently serve as the first President..."





Dr Ritah Mutagonda

Dr. Mutagonda is a clinical pharmacologist currently working as an academician and a researcher at the Department of Clinical Pharmacy and Pharmacology, School of Pharmacy at the Muhimbili University of Health and Allied Sciences (MUHAS). MUHAS is the main clinical, academic, and medical research center in Tanzania. Dr. Mutagonda's specific research interests include but are not limited to infectious disease prevention and management, such as malaria and HIV. She did her MSc by research, aiming to assess the implementation of the national policy for the

prevention and treatment of malaria in pregnant women in Tanzania. This study assessed malaria treatment guideline implementation challenges contributed by pregnant women, health care providers, and the health care system in general. After completion of her MSc, she was funded by the Swedish International Development Cooperation Agency (SIDA) under the MUHAS reproductive and child health sub-program to pursue her Ph.D. studies.

Her Ph.D. thesis is titled "Factors Affecting Malaria Treatment Outcome in Pregnant Women Treated with Artemether-Lumefantrine: A Study of Genetics and Day 7 Lumefantrine Plasma Concentration". We prospectively recruited 205 malaria-positive pregnant women and 72 malaria-positive non-pregnant women. The study has provided insight into how pregnancy changes can affect drug metabolism, affecting malaria treatment outcomes. Since completing her Ph.D. in December 2019, she has received several grants to conduct research, either as a principal or co-investigator. She is a member of the Sickle Pan-African Research Consortium (SPARCO) - Tanzania and the country's lead investigator for multicounty malaria chemoprophylaxis in sickle cell disease patients study. She is actively involved in research and has published more than 50 papers in internationally peer-reviewed journals. She supervises a number of undergraduate and postgraduate students' research projects.



Dr George Judicate Ndossi

Dr. Judicate is a medical doctor, researcher and lecturer at the Muhimbili University of Health and Allied Sciences (MUHAS). He has a medical degree from MUHAS, Tanzania and a PhD in Medical Sciences from Kumamoto University, Japan. After returning from his studies, he joined the Department of Microbiology and Immunology and the Sickle Cell Program at MUHAS, where he had the opportunity to learn and was also given a chance to contribute to the Sickle Cell Program. He is currently working as a focal person in a project titled "SickleInAfrica Proposal for

Clinical and Implementation Research in Newborn Screening for Sickle Cell Disease Using Dried Blood Spots for Point of Care Tests". Also, he is interested in understanding infections in sickle cell disease (SCD), SCD immunology and the immunological aspect of advanced therapies for sickle cell disease patients



Dr Thuwein Said Dr Said works as hematologist at Mnazimmoja refferal hospital





Dr Mbonea Yonazi

Dr Yonazi is a senior haematologist working at Muhimbili National Hospital (MNH), Tanzania. He has played a significant role in modernising the haematology care and practice at Muhimbili National Hospital. Through his practice and skills, he has been resourceful in the formulation of plans and procedures for the management of haematological conditions at MNH and in the national capacity. The latter is through being a sitting member of the national sickle cell disease technical working group.

Mbonea trained for his Degree in Medicine at the University of Dar es Salaam (Muhimbili) and proceeded with a Master of Medicine Degree in Haematology and Blood Transfusion from Muhimbili University of Health and Allied Sciences. He has benefited vastly from short-term training in management, transplantation science and research methods. He is currently a member of the executive management of the Muhimbili National Hospital, serving as the Director of Clinical Support Services.



Ms Josephine Mgaya

Ms. Mgaya, a Microbiology and Chemistry graduate from UDSM, specializes in Sickle Cell Disease (SCD) with Postgraduate Diploma in Hemoglobinopathy and is pursuing an MSc at MUHAS. She has over 10 years of experience as a Laboratory Scientist, managing personnel and quality assurance activities with extensive experience in SCD clinics, including spending time at NIH/NHLBI laboratory of Early Sickle Mortality Prevention studying the biochemical impact of Hydroxyurea therapy in SCD patients. Her focus is on early detection and management of complications associated with HU

therapy to improve care standards. She has also contributed to the development of SCD management and Newborn Screening guidelines and is currently coordinating Standards of Care and Skills development activities for the SPARCO CCC and consortium.



Dr Heriud Martin

"...I am a medical officer in department of Paediatrics and Child health at Bugando Medical Centre, BMC but also I am SPARCo Tanzania Research Fellow based at BMC located in Mwanza, Tanzania..."



Ms Gloria Minja

Ms Minja has been working with MUHAS Sponsored research projects as an accontant for the past 9 years where she has been participating in preparation of project budgets and budget justifications. She is also working in the post award management of projects in areas regarding finance. She is responsible for day-to-day financial transactions for the project. She has been managing received funds, prepares payments, prepares statutory deductions and ensuring compliance. Gloria has experience in financial reporting with various templates and financial presentation. Gloria is currently working with several Federal awarded grants as an accountant. She

is responsible for Payment Management System and submission of Federal Financial Reports.





Ms Janeth Manongi

Ms Manongi is the Head of Project Administration, Finance, and Operations at Sickle Pan African Research Consortium Clinical Coordinating Center (https://www.sickleinafrica.org/) She holds a bachelor's degree in International Relations and also possesses a Master?s degree in Public Administration. She has over five years of experience in project coordination. She has worked with various institutions including Government and the Public. within the Sickle Cell Programme,

she also serves as the programme officer and has been instrumental in facilitating partners' engagement at both the national and global stages. Her commitment to both work and patient advocacy has made her an invaluable member of the team.



Ms Upendo Masamu

Upendo Masamu is a holder of Msc in Statistics from the Katholieke Universiteit Leuven in Belgium and Bachelor of Computer Science from the University of Dar es Salaam. She currently work as research and data coordinator for the SPARCo Clinical Coordinating Center.



Dr Bruno Mmbando

Dr Mmbando is a Principal Research Scientist at the National Institute for Medical Research, Tanzania since June 2000, currently stationed at Tanga Centre. He also works with the Muhimbili Sickle Cell Programme (MSP) affiliated to the Muhimbili University of Health Sciences as a Statistician since 2012. Dr Mmbando has mainly worked on epidemiology of malaria, HIV, Population studies, sickle cell disease, onchocerciasis and epilepsy, and clinical trials. Currently, he is a PI in a surveillance studies aimed at

assessing factors associated persistence of onchocerciasis and associated epilepsy in onchocerciasis endemic areas, and a co-investigator in trials assessing the effectiveness of seasonal malaria chemoprophylaxis in children below five years, and assessing the impact of intermittent preventive treatment for malaria in school aged children in Tanzania. In SPARCO consortium, work as statistician and one of experts in cohort consortium studies. He has supervised several MSc and PhD students, and has authored about 95 publications in peer reviewed Journals.

Attendees: Uganda



Dr Deogratias Munube Paediatric Haematologist-Oncologist ,Co-PI for the Uganda SPARCO site.







Mrs Anna Namazzi

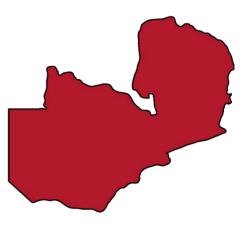
"...I graduated with a bachelors degree in human resource management from Makerere University Business School. I am currently the project administrator for SPARCO Uganda I see myself attaining a Masters in business administration five years from now with an aim of improving my administrative and project management skills.

Attendees: Zambia



Dr Catherine Chunda Liyoka

Consultant Paediatrician; SCD Focal Person; National Coordinator SCD-NBS/EID; Vice Chair Paeds NCD National TWG; In-Country PI: SHAZ, PACTS, CONSA, ARISE; Ministry of Health (MOH), University Teaching Hospitals - Children's Hospital, (UTHs-CH)Lusaka, Zambia; Honorary Lecturer: University of Zambia, School of Medicine (UNZA-



SOM); Lusaka Apex Medical University ((LAMU)



Dr Natasha Mupeta Kaweme

Dr. Kaweme (MBBS, MMED) is a specialist registrar in the haematology department of the University of Zambia Teaching Hospital. She is experienced in clinical haematology, haematology pathology, and has received conceptual training in genomics and genomic techniques. Dr. Kaweme is an accomplished medical practitioner and a research fellow for the SPARCo Zambia site. Her interest in research stems from the desire to resolve complex scientific questions and make a

meaningful contribution to the lives of many. Dr. Kaweme aims to understand the molecular and genomic aspects of haematological malignancies and hemoglobinopathies, particularly

sickle cell disease. Among her accomplishments in her current role has been the development of training materials for the Gazelle device in qualitative and quantitative measurement of haemoglobin, facilitation of training, and coordination of outreach activities. Dr. Kaweme has also authored peer-reviewed articles and continues to broaden her research by exploring the molecular genomics of disease through advanced techniques such as DNA sequencing and the application of bioinformatics to analyse genomic data.



Mrs Cynthia Phiri

Mrs Phiri is a Social Scientist with 8 years of experience in clinical and community research. She possesses a particular proficiency in qualitative research, adeptly crafting research designs, and demonstrating exceptional project management skills. Currently, she holds the role of Research Coordinator/Assistant within the esteemed SickleInAfrica consortium, operating under the banner of the Sickle

Hemoglobinopathy Research in Zimbabwe and Zambia (SHAZ). This consortium maintains a close affiliation with the University Teaching Hospitals-Children's Hospitals (UTHs-CH), with a dedicated mission to enhance the quality of care available to individuals with sickle cell disease. Within her

capacity, Cynthia serves as a pivotal figure, adeptly managing the intricate administrative aspects of



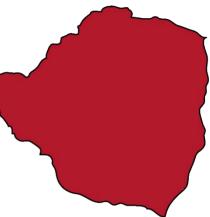
numerous projects dedicated to advancing the field of sickle cell disease at the University Teaching Hospital-Children's Hospital (UTHs-CH). Noteworthy among these initiatives are the Consortium on Newborn Screening in Africa for Sickle Cell Disease (CONSA), the Patient-Centered Sickle Cell Disease Management in Sub-Saharan Africa (PACTS), and the Global Blood Therapeutics (GBT) project.

Attendees: Zimbabwe



Dr Takudzwa Chagumaira

Dr Takudzwa is a Medical Research Scientist with more 17 years' experience in laboratory diagnostics, quality systems management, medical research, project management and coordination with cumulative expertise in setting up organisational systems and operational procedures. Her work has transitioned through



fulltime clinical laboratory practice to clinical research and implementation science. Dr. Takudzwa holds a BSc in Medical Laboratory Sciences, an MSc in Medical Microbiology from the UZ, Masters in Public Health from Maseno University, Masters in Business Administration. and a PhD in Translational Medicine. Prior to joining the university in 2015, She worked at the National Microbiology Reference Laboratory, Ministry of Health and Child Care in Zimbabwe, and she has significant experience in developing project protocols and implementation tools. Her main role in SHAZ is to provide overall day-to-day management and ensure successful study implementation.



Dr Ian Ruredzo

Dr Ian Ruredzo is a Senior Lecturer and current Chairman in the Department of Laboratory Diagnostic and Investigative Sciences, University of Zimbabwe. He teaches Clinical Biochemistry, his research interest is in Non-communicable diseases and Health Systems Strengthening. He is a founding member and current Chairman of the PublicHealth.Africa and Africa Consortium on Laboratory Systems Strengthening.



Dr Lawson Takawira Chikara

I am a specialist paediatrician working as a lecturer at The University of Zimbabwe. Currently, i am also a research fellow with The Sickle Pan-African Research Consortium (SPARCO). My research area of interest is Mendelian disorders including sickle cell disease in children."



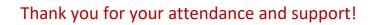


Dr Pamela Chidawanyika

She is a lecturer in the Internal Medicine Unit - Faculty of Medicine and Health Sciences with the University of Zimbabwe. Her research interests are in HIV related malignancies and frailty. She is currently a PhD candidate with the University of Zimbabwe.









Sickle Pan-African Research Consortium









