Sickle Cell Disease Research, Support and Clinical Initiatives in Africa

By Linia Zambezi; CEO and Co-founder of Afromics

Introduction

Sickle cell disease (SCD) represents one of the most significant genetic disorders affecting sub-Saharan Africa, with an estimated 85% of the projected 400,000 annual newborns with SCD expected to be born in this region by 2050 (Piel *et al.,* 2013). This analysis provides a comprehensive assessment of current research initiatives, clinical programs, and advocacy efforts across the African continent.

The establishment of large-scale research consortiums, implementation of newborn screening programs, and advancement of genomic medicine approaches have transformed the SCD research landscape in Africa. Understanding the scope and interconnections of these initiatives is crucial for assessing current progress and identifying future research priorities.

Major Research Consortiums, Networks, Support and Advocacy groups and NPO's in Sickle cell disease

The SickleInAfrica Consortium

The SickleInAfrica consortium represents the largest coordinated SCD research initiative in Africa, encompassing three complementary components: the Sickle Pan-African Research Consortium (SPARCO), the Sickle Africa Data Coordinating Center (SADaCC), and the Sickle Pan African Network (SPAN) (SickleInAfrica, 2025). The consortium is led by Professor Ambroise Wonkam, Professor Nicola Mulder, and Professor Andre Pascal Kengne. The SickleInAfrica consortium has established one of the largest multinational SCD registries globally, with 13,403 patients enrolled from 2017-2021 across 31 facilities in Ghana, Nigeria, and Tanzania (Morrice *et al.,* 2025). Analysis of this registry reveals significant variations in care delivery, with average age at diagnosis of 3 months in Ghana, 19 months in Nigeria, and 3 years in Tanzania, reflecting differences in country-specific newborn screening programs and policies.

Analysis of the SickleInAfrica registry reveals significant disparities in SCD care across African countries (Makani *et al.,* 2020). Hydroxyurea utilization varies substantially, with Ghana demonstrating highest adoption (21%), followed by Nigeria (12%) and Tanzania (6%). Notable sex differences in SCD management have been observed, with males more likely to receive

hydroxyurea and blood transfusions. At the consortium level, hydroxyurea initiation correlates with enrollment age rather than age at diagnosis, highlighting the need for earlier intervention strategies. These findings emphasize the potential of large-scale registries for enhancing understanding of regional disparities in SCD care and identifying potential gender inequalities in treatment access (Morrice *et al.,* 2025).

Sickle Pan-African Research Consortium (SPARCO)

SPARCO emerged from a 2015 National Heart, Lung, and Blood Institute (NHLBI) request for applications, resulting in a multinational collaboration among Muhimbili University of Health and Allied Sciences (MUHAS) in Tanzania as the coordinating hub, with additional sites at the University of Abuja, Nigeria, and Kwame Nkrumah University of Science and Technology (KNUST), Ghana (Paintsil *et al.,* 2022).

The consortium's primary objectives include the formation of a centralized, electronic, patient-consented sickle hemoglobinopathy database facilitating registration and follow-up of SCD patients, creation of shared database elements and harmonized SCD phenotype definitions, and development of SCD standards of care appropriate to regional resource availability and clinical needs (SickleInAfrica, 2025).

Sickle Africa Data Coordinating Center (SADaCC)

Based at the University of Cape Town, South Africa, and led by Professor Nicola Mulder, SADaCC serves as the administrative, data standardization, and coordinating center for SCD research. The centre’s mandate focuses on supporting and coordinating data and communications for the SPARCO research network, with plans for expansion to support additional research groups within the broader SPAN network (SickleInAfrica, 2025).

A significant contribution of SADaCC is the development of the Sickle Cell Disease Ontology (SCDO) project, originally a collaboration between H3ABioNet and SPAN, now maintained by SADaCC (Sickle Cell Disease Ontology Project, 2025). The SCDO aims to establish community standardized SCD terms and descriptions, create canonical and hierarchical representation of SCD knowledge, and link to other ontologies including DO, PhenX, MeSH, ICD, NCI's thesaurus, SNOMED, and OMIM.

Centre of Excellence for Sickle Cell Disease Research and Training (CESRTA)

Located at the University of Abuja, Nigeria, and led by Professor Obiageli Nnodu, CESRTA represents a multidisciplinary research centre bringing together faculty from health, social, computer sciences, education, and mass communication (CESRTA, 2025). The centre coordinates several major research initiatives spanning clinical care, screening, and training

programs. These include the ACCELERATE Project, CONSA and PACTS and SPARC-Ner-CESRTA

The ACCELERATE Project

The ACCELERATE Project (U01HL156942) represents an NIH-funded research study conducted collaboratively between CESRTA and the ISEE Lab at New York University School of Global Public Health (ACCELERATE Project Team, 2025; ISEE Lab, 2025). The study evaluates whether training healthcare providers in hydroxyurea adoption improves SCD management outcomes.

Consortium on Newborn Screening in Africa (CONSA)

CONSA has achieved significant milestones in newborn screening implementation, with 158,013 babies receiving SCD screening results as of 2025. The program has identified 2,278 babies with SCD and 28,117 babies with sickle cell trait, demonstrating the substantial impact of systematic screening programs (CESRTA, 2025).

Patient-Centered Sickle Cell Disease Management (PACTS)

PACTS represents a research collaboration between Liverpool School of Tropical Medicine, University of Abuja, University of Zambia, Kwame Nkrumah University of Science and Technology, Syracuse University, and Imperial College London. Led by Professor Imelda Bates from Liverpool School of Tropical Medicine and Professor Obiageli Nnodu from the University of Abuja, the initiative focuses on implementing evidence-based clinical interventions and improving SCD detection through patient-centered approaches (CESRTA, 2025).

Sickle Pan-Africa Research Consortium Nigeria Network (SPARC-Net)

The **Sickle Pan-Africa Research Consortium Nigeria Network (SPARC-Net)**, under the broader SPARCO initiative, plays a critical role in advancing sickle cell disease (SCD) research and care across sub-Saharan Africa. One of its primary objectives is the development of a centralized, ethically and legally approved, web-based database containing health and research data from 15,818 pediatric and adult SCD patients—distributed across Nigeria (8,818), Tanzania (4,000), and Ghana (3,000). SPARC-Net also focuses on standardizing SCD care through the creation, implementation, and evaluation of resource-based, multi-level clinical guidelines tailored for the sub-Saharan African context. In addition, the network is committed to capacity building by organizing short-, medium-, and long-term training programs aimed at strengthening healthcare and research skills related to SCD. Finally, SPARC-Net seeks to establish robust SCD cohorts across the region to support future

epidemiologic, translational, and clinical research, thereby laying the groundwork for sustainable advancements in SCD management and treatment (SPARC-Net, 2025).

Ghana-Novartis Public-Private Partnership in Sickle Cell Disease

Ghana has established innovative public-private partnerships, notably the Ghana-Novartis Public-Private Partnership in Sickle Cell Disease. This collaboration involves the Sickle Cell Foundation of Ghana, Ministry of Health, and Ghana Health Service, demonstrating comprehensive industry engagement in SCD care improvement (Nyonator *et al.,* 2023).

Sickle Cell Foundation of Ghana (SCFG)

The Sickle Cell Foundation of Ghana (SCFG), established in 2004 and previously led by Professor Kwaku Ohene-Frempong (who passed away) and now led by Professor Solomon Ofori-Acquah, serves as a non-governmental organization with the mission to support resource and service development for improving health and quality of life of people with SCD. The organization functions as an agency of the Ministry of Health and maintains strong connections with the Ghana Health Service (Dimagi, 2024)

Sickle Life

Sickle Life, founded by Dr. Enam Sefakor Bankas in 2013 and incorporated in 2016, has become one of Ghana's leading SCD advocacy organizations, focusing on public education and patient empowerment (Sickle Life, 2025).

Envision Sickle Cell Ghana

Another key player is Envision Sickle Cell Ghana, a volunteer-driven initiative spanning Ghana, Germany, and the UK. The organization aims to empower individuals with SCD to live fulfilling lives by promoting awareness, preventing complications—particularly vision loss—and providing support through screening and surgical interventions (Envision Sickle Cell Ghana, 2025).

Sickle CHARTA

Adding to the collaborative landscape is Sickle CHARTA (Coordination, Health, Advocacy, Research, Training in Africa), which works with researchers, healthcare providers, and patient advocates to strengthen partnerships and advance therapies for SCD across the continent (Sickle CHARTA, 2025).

International Sickle Cell Centre (ISSC)

Further contributing to this ecosystem is the International Sickle Cell Centre (ISSC), a non-profit organization founded in 2021 by Dr. Mary Dede Ansong and Pharm Martha Wiafe in

Ghana. ISSC is committed to increasing global awareness and support for SCD, offering early diagnosis and genetic counseling, delivering comprehensive healthcare, and conducting translational research for both SCD and sickle cell trait. The organization's mission is to reduce the global burden of SCD through the development of low-cost preventive strategies and universally accessible, cost-effective treatments (International Sickle Cell Centre, 2025).

Clinton Health Access Initiative (CHAI)

In addition, the **Clinton Health Access Initiative (CHAI)** has played a pivotal role in advancing SCD care across Africa. In partnership with Ghana's Ministry of Health, CHAI has supported the implementation of a national newborn screening program (Clinton Health Access Initiative, 2025). The organization leverages geospatial tools to map new screening and treatment delivery sites, facilitating the expansion of services to previously underserved regions. In May 2025, CHAI announced a landmark agreement to provide affordable access to SCD diagnostics in low- and middle-income countries, significantly reducing costs and enabling global scale-up of early detection for a disease that, without proper care, claims the lives of up to 90% of affected children before the age of five (Clinton Health Access Initiative, 2025).

The Sickle Cell Programme and the Sickle Pan-African consortium registry in Tanzania

The Sickle Cell Programme at Muhimbili University of Health and Allied Sciences has established the Muhimbili Sickle Cohort (MSC), representing one of the largest SCD patient cohorts globally with 5,476 patients. Originally established in 2011 as a Wellcome Trust-funded research project, the program has expanded to operate seven specialized SCD clinics by May 2021, with five in the Dar es Salaam region, one in Pwani region, and one in the Mwanza region. Despite the substantial patient population, Tanzania demonstrates challenges in treatment adoption, with the lowest hydroxyurea utilization rates (6%) among major African programs and later average age at diagnosis (3 years) compared to other countries (Makani *et al.,* 2018; Kandonga *et al.,* 2023).

Tanzania has signed a research and development agreement with Novartis Institute for BioMedical Research to develop gene therapy in Tanzania, which is a positive step forwards (Moshi, Sheehan, and Makani, 2022).

Nigerian Sickle Cell Support Society (SCSSN)

Founded by Professor Obiageli Nnodu in 2010 and registered in 2014, SCSSN serves as an umbrella organization bringing together Nigerian doctors, scientists, NGOs, and patients with SCD interests (SickleInAfrica, 2025). The society maintains a network of collaborators across 37 clinical centers throughout Nigeria, engaging in clinical research, capacity building, and

advocacy while working closely with government entities for SCD control (Sickle Cell Support Society of Nigeria, 2025).

The Sickle Hemoglobinopathy research in Zimbabwe and Zambia (SHAZ)

The Sickle Hemoglobinopathy research in Zimbabwe and Zambia (SHAZ) study represents an emerging regional program led by researchers at the University of Zimbabwe, with objectives to develop and manage an electronic SCD registry with standardized clinical follow-up, targeting recruitment of at least 4,000 participants over five years (Mujuru et al., 2025). The program aims to establish consistent standards of care for SCD patients in both countries while building research capacity and improving biobanking capabilities (Kuona *et al.,* 2025).

Genomic Research Initiatives

West African Genetic Medicine Centre (WAGMC)

WAGMC coordinates the Sickle Cell Disease Genomics Network of Africa (SickleGenAfrica), a comprehensive genomic research program spanning Ghana, Nigeria, and Tanzania. The network includes sites at the University of Ghana (Accra and Kumasi), Bayero University (Kano), and Muhimbili University (Dar es Salaam). The program is led by Professor Solomon Ofori-Acquah (founding director), Professor Gordon Awandare, and Professor Julie Makani, who also serve on the steering committee of the H3Africa Consortium (SickleGenAfrica, 2025).

The program's primary objectives include developing prognostic biomarkers of organ damage through discovery of key genetic modifying factors and cognate mechanisms, and building capacity and career pipelines in Africa to support patient-centered research advancing innovative SCD therapy development (H3Africa, 2025).

Preliminary results from SickleGenAfrica have identified quantitative differences in key haemolysis defence proteins influencing end-organ damage development in SCD . The network is currently validating these findings through studies of the largest global SCD patient cohort and animal models to better understand their effects in disease processes (H3Africa, 2025).

Pharmacogenomic Research Programs

Next-Generation Sequencing Panel Development

Complementary work in Tanzania led by researchers at Muhimbili University has developed a tailored next-generation sequencing panel for hydroxyurea pharmacogenomics research (Nkya *et al.,* 2024). The custom-designed Illumina (MiSeq) panel provides extensive coverage

and high sequencing depth, creating a robust platform for studying genetic variations associated with hydroxyurea response and HbF changes.

Hydroxyurea Pharmacogenomics in Tanzania

Recent research led by Siana Nkya and colleagues at Muhimbili University of Health and Allied Sciences has explored genetic predictors of hydroxyurea response in Tanzanian SCD patients (Nkya *et al.,* 2025). The study investigated genetic determinants of hydroxyurea treatment response, identifying associated genetic variants in *CYP2C9, KLF10, BCL11A, ARG2, HBG1, SAR1A, MYB,* and *NOS1* as potential predictors of treatment response.

A particularly significant finding demonstrates that fetal hemoglobin (HbF) loci influence hydroxyurea response, with treatment response notably affected by baseline HbF levels influenced by genetic factors across multiple loci. The research investigated genetic variants at 13 loci: two associated with hydroxyurea metabolism (*CYP2C9* and *CYP2E1*) and eleven associated with HbF induction (Nkya *et al.,* 2025).

Pain Management Pharmacogenetics

Research in Zimbabwe led by investigators at the University of Zimbabwe has evaluated the role of pharmacogenetics in SCD pain management, specifically examining variability in codeine, tramadol, and morphine clinical effects during vaso-occlusive pain crises (Ndamba *et al.,* 2023). The study focused on gene candidates based on published CIPIC guidelines on drug-enzyme interactions for which there is strong clinical evidence of association, particularly *UGT2B7* rs73823859 interactions with morphine and how it could be useful for pharmacogenetic-guided dosing even though it lacks strong clinical evidence association.

The iPROTECTA Program

The Implementing Pharmacogenomics Testing for Effective Care and Treatment in Africa (iPROTECTA) program represents a pioneering initiative in Nigerian SCD care. Phase 1 of the program determined *CYP2D6* allele and phenotype frequencies while evaluating the feasibility of implementing pre-emptive pharmacogenomic testing to guide opioid therapy for SCD patients (Adeagbo *et al.,* 2025).

A notable innovation of this program is the development of personalized pharmacogenetic cards for each patient, providing pre-emptive pharmacogenetic reports to guide individualized treatment decisions (Adeagbo *et al.,* 2025).

Policy Frameworks and Global Initiatives

The Lancet Haematology Commission on Sickle Cell Disease (2023)

A landmark initiative in global SCD policy development was the publication of the Lancet Haematology Commission in 2023, led by an independent group of experts along with patients and activists including Professor Frédéric Piel, Professor David Rees, Professor Michael DeBaun, Professor Obiageli Nnodu, and Professor Brigitte Ranque (Piel *et al.,* 2024). The Commission aims to seize current opportunities to make the world a better place for all people with sickle cell disease by defining priorities and setting short-term, mid-term, and long-term recommendations to guide public health policies and investments. Their ambition is to monitor and document progress towards these recommendations and to evaluate achievements and shortfalls within the next decade, while curative treatments continue to be developed in parallel.

WHO Package of Interventions (2024)

Building on the momentum from the Lancet Commission, the World Health Organization published a comprehensive Package of Interventions for Sickle Cell Disease Management in 2024 (Sickle Cell Disease Association of America, 2024). This document represents the first standardized global framework for SCD care delivery, with particular relevance for resource-limited settings in Africa.

Conclusion: How Afromics will fit in

The extensive body of work analysed demonstrates the remarkable progress being made across multiple fronts in sickle cell disease research and care in Africa. From groundbreaking genomic research and advocacy efforts to the establishment of disease registries, newborn screening programs, and pharmacogenomic initiatives, the scientific and clinical community has laid a strong foundation for understanding and addressing sickle cell disease. This collective effort represents years of dedicated work to improve the outcomes of people with sickle cell disease across the continent.

Building upon this solid foundation, research findings present an unprecedented opportunity for comprehensive genomic studies in African populations with sickle cell disease. Current evidence reveals gaps that large-scale African genomic initiatives can address: over 80% of gene variants accounting for enhanced HbF expression remain unknown in African

populations, existing HbF-modulating genes explain merely 16% of expression variability, and our capacity to predict disease severity remains low (Piel *et al*., 2023; Wonkam *et al.,* 2024).

Enriched loss-of-function variants in African stroke survivors and long-term survivors over 40 years old illuminate the untapped potential within African genomic diversity (Wonkam *et al.,* 2024). Expanding this research using whole-genome sequencing will leverage the vast African genomic diversity to identify rare coding, non-coding, and structural variants in nuclear genomes, epigenetic signatures, and variations in mitochondrial DNA, and their associations with sickle cell disease phenotypes (Wonkam *et al.,* 2024).

Adult mortality from sickle cell disease has remained unchanged over four decades in high-resource settings like the USA, while childhood mortality has dramatically decreased through screening and comprehensive care. This highlights an urgent need to identify the full spectrum of genetic variants that modify clinical complications of SCD, including variants associated with long survivors, i.e. ≥40 years, living in unfavourable environments of Africa (Wonkam, 2023). With 7-8 million people worldwide projected to live with sickle cell disease, the majority of African ancestry, the genomic insights locked within African genetic diversity represent the key to unlocking novel therapeutic targets and developing effective risk stratification models (Commissioners S.C.D., 2023).

Afromics emerges at this pivotal moment as a driver of inclusive precision medicine. By building a comprehensive biobank of people of African ancestry with sickle cell disease, Afromics will generate whole genome sequences with comprehensive functional analysis. This initiative will enable clinical trials to be conducted on the African continent and provide participants with actionable pharmacogenetic insights to optimise their care. It will facilitate longitudinal studies that track disease progression and treatment responses over time, while creating opportunities for international research collaborations through shared, standardised data. By providing pharmaceutical companies with representative African genomic data, it will accelerate drug discovery and support the development of treatments that work effectively and are accessible and affordable in African populations. The biobank will enable the creation of genetic risk models to predict SCD complications and stratify patients, and the development of robust pharmacogenomic panels specifically tailored to African genetic diversity. It will advance gene therapy approaches through a better understanding of African genomic contexts and open the door to discovering novel pain management targets by identifying African-specific variants in pain pathway genes. Furthermore, it will support the development of African-specific reference genomes to improve diagnostic accuracy and fundamentally transform our understanding of sickle cell disease, from a monogenic disorder of mysterious variability into a characterised condition with targeted therapeutic pathways.

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