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The SickleGenAfrica Network

In 2012, the US National Institutes of Health and the UK-based Wellcome Trust funded a US$76 million initiative called Human Heredity and Health in Africa (H3Africa), in partnership with the African Society of Human Genetics. Grants were awarded directly to African institutions to support their faculties in directing their own research, fostering collaborations, and building infrastructure in bioinformatics and genomics.[1] H3Africa was founded on the belief that researchers and research participants in Africa are best positioned to work together to study diseases that exact a heavy burden on the continent. The first phase of 5-year funding supported five collaborative centres, seven research projects, four pilot biorepositories, one bioinformatics network, and one ethical legal and social implications project. Researchers planned to analyse samples from more than 50 000 participants to study the microbiome, kidney disease, HIV, tuberculosis, stroke, cardiometabolic disorders including obesity, schizophrenia, and febrile illness among Africans. They generated de-novo DNA sequence data from thousands of Africans, some of which were used midway through the first phase to develop the H3Africa single nucleotide polymorphism array. At the end of the first phase, in 2017, the consortium had developed world-class biorepositories in Abuja, Nigeria; Cape Town and Johannesburg, South Africa; and Kampala, Uganda, produced several policy documents to guide genomics research, and made major scientific contributions to advance understanding of the genomics of Ebola, Lassa fever, and other diseases relevant to Africa.

Notwithstanding the remarkable success of H3Africa, the first phase did not include a genomics research project on sickle cell disease, the first requisite of genomic medicine and the prototypical monogenic human disorder. Africa is home to the largest number of people with sickle cell disease; nearly 2% of livebirths in West Africa are affected by sickle cell disease,[2] and the majority of children die within 5-years.[3] End-stage organ damage is a major clinical problem in sickle cell disease globally, with its effects on the cardiovascular, respiratory, and genitourinary systems accounting for more than 75% of deaths among sickle cell disease patients in the USA.[4] Genetic medicine interventions involving predictive medicine and personalised medicine offer a promising opportunity to overcome end-stage organ damage and other challenges of sickle cell disease. However, the genomics of sickle cell disease remain understudied despite decades of shrinking costs for genome sequencing, partly because genomics technology has been concentrated in high-income countries, whereas the largest sickle cell disease cohorts exist in Africa. We sought to address this knowledge gap by leveraging a longitudinal cohort study of sickle cell disease in Ghana called ORDISS to develop a continent-wide genomics network, when the second phase funding of H3Africa was announced in late 2016.[5]

We launched the Sickle Cell Disease Genomics of Africa (SickleGenAfrica) Network in April 2018 in Accra, Ghana, with a vision of aligning the survival of individuals who have sickle cell disease in Africa with national norms. The network is organised into three research projects and multiple cores working from universities and hospitals in Ghana, Nigeria, Tanzania, and South Africa in collaboration with the University of Pittsburgh, to test the overarching hypothesis that genetic variation affects the body's defence against intravascular haemolysis and the development of organ damage in sickle cell disease (appendix p 2). Acute haemolysis releases alarmins, such as extracellular haem, into the blood circulation, causing vascular injury.[6] Chronic intravascular haemolysis promotes cardiovascular dysfunctions, including pulmonary hypertension, that lead to right ventricular dysfunction, and sudden death.[7,8] Additionally, haemolysis is associated with higher rates of death among patients with sickle cell disease and acute malaria infections,[9] and it contributes to the pathophysiology of severe sepsis and many iatrogenic conditions.[10] Africans might harbour genetic variants that mitigate the hazards of intravascular haemolysis, because of the endemicity of sickle cell disease and malaria on the continent. Such variants are likely present in genes that encode cytoprotective proteins that scavenge (eg, haemopexin), degrade (eg, haem oxygenase-1), and sequester (eg, ferritin) haemolysis alarmins, and therefore this group of genes is the initial focus of the genomic studies of SickleGenAfrica.

SickleGenAfrica is now the largest cohort study of sickle cell disease in the world. We recruited

See Online for appendix

6200 participants (88% of our target of 7000), before COVID-19 lockdowns in participating institutions in March, 2020, forced the network to suspend enrolment. Patients are recruited with broad consent that will allow the sharing of their samples, and clinical, phenotypic, and molecular data with the global scientific community. These resources will serve as a unique reference for future translational studies. Our infrastructure is paving the way for the introduction of new postgraduate programmes in genetics in Africa, including in genetic counselling. Ultimately, SickleGenAfrica will not only tether sickle cell disease to the genomics revolution taking place in Africa, but will also help overcome the developmental challenge in human genetic disorders in the region by improving access to genetic health.

I declare no competing interests.

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