WORLD SICKLE CELL DAY 2026

Voices of Resilience - 19th June 2026

From Voices to Discovery:

Why the Future of Sickle Cell Innovation Depends on Representation

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For patients, advocates, clinicians, data partners, donors, investors, governments, and policymakers

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Introduction

Every year on 19th June, communities across six continents pause to mark World Sickle Cell Day. There are candles, vigils, social media campaigns, and events in hospital halls and community centres where patients, families, and healthcare workers gather to bear witness to a disease that affects more than 300 million people worldwide. This year's theme, **Voices of Resilience**, honours the extraordinary courage of those who live with sickle cell - the children who manage crises before they can fully name them, the parents who learn to read pain scales like a second language, the adults who have built entire lives in the shadow of a condition that remains poorly understood, under-resourced, and, in too many parts of the world, inadequately treated.

Resilience is real. It deserves to be honoured. But resilience, by definition, describes how people endure systems that have failed them. It is a response to absence - absence of early diagnosis, of equitable access to treatment, of research that reflects the populations most affected. When we celebrate resilience alone, we risk making

peace with the conditions that make it necessary. The work of this moment is not simply to honour those who persist through hardship; it is to build the infrastructure, the datasets, the partnerships, and the policy environments that make such heroic persistence unnecessary.

Forty-eight hours after this event, patients and families will return home. Clinicians will return to wards. Advocates will begin drafting the next campaign. Policymakers will face the same constrained budgets and competing priorities they faced before the event. What will have changed? What must change? And what role does data - specifically, representative genomic and clinical data - play in the future of sickle cell innovation?

This essay is an attempt to answer those questions honestly, and to make a case that the future of sickle cell care will not be determined solely by the therapies we develop, but by **whose lives, whose voices, and whose data are represented in the discovery process.**

Section 1: The Progress We Have Made

It is important to begin with honesty about progress. In many parts of the world, the story of sickle cell disease in the past five decades is genuinely one of hard-won advances, and those who have driven that progress - patients, clinicians, researchers, and advocates - deserve recognition.

New-born screening programmes, first established in the United States in the 1970s and subsequently expanded across much of the developed world, transformed the survival prospects of children born with sickle cell disease. Before universal screening, a significant proportion of children with sickle cell anaemia in sub-Saharan Africa did not survive beyond age five. The simple act of identifying a child at birth and initiating prophylactic penicillin changed those odds dramatically.

Hydroxyurea, first approved for sickle cell disease by the US Food and Drug Administration in 1998, remains one of the most important interventions available. By inducing foetal haemoglobin production, it reduces the frequency of painful vaso-occlusive crises, lowers the risk of stroke, and improves overall survival. It is inexpensive, generically available, and has decades of safety data behind it. Yet its uptake in low- and middle-income countries remains disappointingly low - a gap that speaks less to the science than to the systems that translate science into care.

The establishment of specialist sickle cell centres in the United Kingdom, the United States, and parts of West Africa has created pockets of genuine excellence.

Comprehensive care models that integrate haematology, psychology, social work, and patient education have improved quality of life and reduced emergency department usage. The UK's NHS has made notable strides, including through the National Haemoglobinopathy Registry, which provides the kind of longitudinal clinical data that is essential for monitoring treatment outcomes at a population level.

Most significantly, the past five years have seen the arrival of gene therapies - Casgevy and Lyfgenia - that offer, for some patients, the prospect of a functional cure. These treatments represent a scientific triumph of the highest order, drawing on decades of basic research in genetics, molecular biology, and cell therapy. They are a demonstration of what is possible when research investment is sustained and scientific ambition is matched by regulatory pathway.

We have come further than many realise. But the distance we have travelled must not obscure the distance that remains.

> ***"We have come further than many realise - but that progress has been uneven, incomplete, and has not yet reached those who need it most."***

Section 2: The Discovery Gap

Sickle cell disease is the world's most common serious monogenic disorder, yet it remains one of the most under-researched relative to its global burden. The numbers are stark: of the approximately 515,000 children born with sickle cell disease each year, roughly 80 percent are born in sub-Saharan Africa. Nigeria alone accounts for around 100,000 new cases annually. Yet the overwhelming majority of research publications, clinical trial participants, and genomic datasets originate from North America, Europe, and, to a lesser extent, the Caribbean.

This mismatch between disease burden and research representation is not merely an ethical problem - it is a scientific one. When our understanding of a disease is built primarily on data from a minority of those affected, we cannot claim to understand the disease. We can claim to understand its expression in specific populations, in specific healthcare environments, with specific historical exposures to particular interventions. But generalising those findings to the 240,000 children born with sickle cell disease in West Africa each year, or to families navigating the disease in Sudan, Tanzania, or India, requires assumptions we cannot currently validate.

The Data Fragmentation Problem

Even within well-resourced research environments, data about sickle cell disease is fragmented. Electronic health records capture clinical events but rarely with the granularity needed for precision medicine research. Biobank samples are frequently collected without the long-term follow-up data that allows researchers to link genotype to phenotype across the disease course. International collaboration is hampered by inconsistent data standards, differing consent frameworks, and institutional reluctance to share proprietary datasets.

In Africa, where the unmet need is greatest, the infrastructure to generate, store, link, and analyse clinical and genomic data at scale is still nascent. There are notable exceptions - H3Africa, the African Genome Variation Project, and a small number of pioneering biobanks in Ghana, Nigeria, and Kenya have demonstrated what is possible. But these initiatives remain fragmented and underfunded relative to their counterparts in the global north.

What We Still Cannot Answer

Consider the questions that matter most to a clinician treating a twelve-year-old with sickle cell anaemia in Lagos or Accra: Why do two children with the same HbSS genotype experience such dramatically different disease severity? Which child is at elevated risk of silent cerebral infarction? Which patient will respond well to hydroxyurea, and which will not? What are the long-term effects of the chronic anaemia and inflammation that accompany sickle cell disease on organ function, cognitive development, and fertility?

We cannot yet answer these questions with confidence, in part because the genomic and longitudinal clinical datasets needed to answer them - at scale, in African populations, with appropriate controls - do not yet exist. This is the discovery gap. And it is a gap that no amount of therapeutic innovation can bridge on its own.

> ***"We still cannot answer many of the questions that matter most - because we are missing the data, the infrastructure, and the representation to ask them properly."***

Section 3: Why Representation Matters

The case for representation in sickle cell research is sometimes framed primarily as a question of fairness: patients from high-burden communities deserve to be included in the research that shapes their care. That framing is correct, but it undersells the argument. Representation in biomedical research is not merely a fairness issue - it is a **scientific necessity.**

Precision medicine, the emerging paradigm in which treatments are tailored to the genetic, environmental, and biological characteristics of individual patients, depends on datasets that capture the full spectrum of human variation. If those datasets are built predominantly from patients of European ancestry, as many current biobanks are, then precision medicine algorithms trained on those datasets will systematically underperform in patients of African, South Asian, or Middle Eastern ancestry - precisely the populations most affected by sickle cell disease.

Genetic Modifiers and Treatment Response

Sickle cell disease is a monogenic condition - it is caused by a single point mutation in the HBB gene - but its clinical presentation is shaped by a complex array of genetic modifiers. Alpha-thalassaemia co-inheritance, variants in the BCL11A gene that influence foetal haemoglobin production, and polymorphisms affecting nitric oxide metabolism, coagulation, and inflammatory pathways all influence how the disease manifests and how individuals respond to treatment.

Many of these genetic modifiers show significant population-level variation. Some protective variants are far more common in West African populations than in the populations that have historically been the subjects of most research. Without large-scale genomic studies that include patients from high-burden African populations, we risk developing precision medicine tools that are specifically optimised for the minority of patients who already benefit from the best-resourced healthcare systems.

Treatment response is similarly heterogeneous and population-specific. The pharmacogenomics of hydroxyurea - why some patients respond dramatically and others show minimal benefit - is still incompletely understood. Gene therapy approaches being developed today will need to navigate the specific genetic backgrounds of African patients if they are to be truly universally applicable. None of this is possible without representative data.

Disease Severity and the Missing Middle

Research on sickle cell disease has tended to be concentrated at two ends of the clinical spectrum: the most severely affected patients presenting at specialist centres in high-income settings, and, increasingly, participants in clinical trials for novel therapeutics. The ‘missing middle’ - the vast majority of patients in low- and middle-income countries who manage the disease without specialist care, often without

hydroxyurea, and in healthcare environments where pain management options are severely constrained - is almost entirely absent from the research literature.

Understanding this missing middle is not only a matter of scientific completeness. It is essential for global health policy. The interventions that work for a highly selected patient population in a tertiary academic medical centre may not be the same interventions that can be delivered at scale in district hospitals in Ghana or community health facilities in northern Nigeria. Representation in research means research that informs decisions across the full range of healthcare contexts where sickle cell disease is managed.

> ***"Representation is not a fairness issue alone - it is a scientific necessity. Without it, precision medicine risks becoming precision exclusion."***

Section 4: From Patients to Partners

The history of medical research in Africa is not, unfortunately, a history that inspires automatic trust. Communities across the continent have experienced research extraction: samples taken, data collected, papers published, and careers built in the global north - with little benefit returning to the communities from which the data originated. This history is not ancient. It is within living memory. And its effects on community willingness to participate in research are real and rational.

Any serious effort to build representative research infrastructure for sickle cell disease in Africa must begin by acknowledging this history honestly, and by committing to a different model: one in which patients and communities are not subjects of research but active partners in it.

Community Participation and Trust

Community participation in research is not simply about consent - though informed, ongoing, and genuinely voluntary consent is non-negotiable. It is about co-design: ensuring that the research questions being asked reflect the priorities of those most affected, that the methods used are appropriate to the cultural and social contexts in which data is collected, and that the benefits of research - in the form of improved clinical care, trained local researchers, and functional health infrastructure - are demonstrably returned to participating communities.

The sickle cell patient community, globally and in Africa specifically, includes individuals and organisations with extraordinary expertise: lived experience of managing a complex chronic condition, deep knowledge of local healthcare environments, and a sophisticated understanding of the research landscape. These are not passive beneficiaries of research. They are potential co-investigators, community advisory board members, data stewards, and advocates for the policy changes that will be needed to sustain research infrastructure over the long term.

Governance and Ethical Stewardship

Trust cannot be built without robust governance. Data governance frameworks for sickle cell biobanks and registries must be designed to protect participants, ensure community benefit, and prevent extractive use of data. This means clear policies on data ownership, access, and benefit sharing; independent ethics oversight with meaningful community representation; and transparent reporting on how data has been used and what benefits have accrued to participating communities.

In an era of increasing commercial interest in genomic data, these governance questions are not academic. The genomic data of African populations is enormously scientifically valuable - precisely because of its diversity and its underrepresentation in existing databases. That value must translate into tangible benefit for the communities from which it originates, not primarily into commercial returns for data platforms operating in the global north.

> ***"Research should be built with communities, not extracted from them. Trust is not a soft metric - it is the foundation on which representative science depends."***

Section 5: The Infrastructure Imperative

Good intentions, community trust, and scientific ambition are necessary conditions for progress in sickle cell research - but they are not sufficient. Discovery requires infrastructure. And in much of the world where sickle cell disease is most prevalent, that infrastructure is still being built.

Registries and Biobanks

Patient registries - structured databases that capture clinical, demographic, and outcomes data on individuals with a specific condition over time - are foundational research tools. They allow researchers to track disease trajectories, identify risk

factors, evaluate treatment effectiveness in real-world settings, and generate hypotheses for prospective studies. For sickle cell disease, registries that span multiple countries and are linked to biological sample collections create the longitudinal genomic datasets that precision medicine research requires.

Building these registries in Africa is technically feasible today in ways that would not have been possible a decade ago. Mobile data collection tools, electronic health record systems adapted for low-resource environments, cloud-based data storage with appropriate security controls, and increasingly affordable genotyping and sequencing technologies all reduce the barriers to building high-quality research infrastructure at scale.

Data Standards and Interoperability

The value of any individual registry or biobank is multiplied many times over when it can be linked with other datasets. A patient's genomic data from a biobank sample becomes far more powerful when linked with their longitudinal clinical record, their treatment history, their complication events, and, eventually, their outcomes data over decades. Achieving this linkage requires common data standards: agreed definitions for clinical variables, consistent coding systems, harmonised consent frameworks, and interoperable data architectures.

The development and adoption of such standards is unglamorous, technically demanding work. It rarely attracts philanthropic funding or political attention. But it is the kind of work that determines whether the individual investments in data collection made by hospitals, research groups, and biobanks across Africa can eventually be combined into datasets large enough to answer the questions that matter most.

Cross-Border Collaboration

Sickle cell disease does not respect national borders. A child born in Senegal whose family later moves to France, or a patient from Ghana receiving treatment in the United Kingdom, generates data across multiple healthcare systems. Cross-border data sharing, governed by appropriate frameworks, could enormously expand the scale and diversity of available research data. It also creates new opportunities for scientific partnership between African and European or North American research institutions - partnerships in which African researchers lead, not merely participate.

The African Continental Free Trade Area and the African Union's Continental Health Architecture provide political frameworks within which pan-African data infrastructure for health research could be developed. The science is ready. The technology is increasingly available. What is needed is political will, sustained

funding, and the kind of institutional coordination that only comes when multiple stakeholders commit to a shared vision.

> ***"Discovery requires infrastructure. And infrastructure requires sustained investment, political will, and a long-term commitment to scientific capability that outlasts individual grants and government cycles."***

Section 6: Africa's Opportunity

For too long, the narrative of Africa in global health research has been one of burden and deficit: the continent bears the greatest disease burden, has the weakest health systems, and receives the least research investment. That narrative is not without foundation. But it is dangerously incomplete, because it obscures a set of structural advantages that make Africa uniquely positioned to contribute to - not merely benefit from - the next generation of sickle cell research.

Population Scale and Diversity

Africa's demographic profile is extraordinary from a research perspective. With a population of 1.4 billion people growing rapidly toward 2.5 billion by 2050, and a median age below 20, the continent offers unparalleled opportunities for longitudinal research in young, large, genetically diverse populations. For sickle cell disease specifically, the concentration of affected individuals in West and Central Africa - combined with the genetic diversity of African populations, which far exceeds that of any other region on Earth - means that African genomic data is not merely large in quantity but uniquely rich in scientific information content.

Growing Scientific Capacity

Africa's scientific talent base is growing rapidly. A generation of African researchers trained at leading global institutions is returning to the continent or maintaining active research collaborations from diaspora positions. Pan-African research networks such as H3Africa have built capacity in genomics, bioethics, and data management. Universities in Nigeria, Ghana, Kenya, South Africa, and Uganda are developing research programmes of genuine international quality.

The question is not whether Africa has the scientific talent to lead sickle cell research - it does. The question is whether the funding models, publication systems, and institutional structures of global science will evolve quickly enough to let that talent

flourish on its own terms, rather than as a junior partner in research agendas set elsewhere.

Emerging Research Ecosystems

Across the continent, research ecosystems are taking shape that offer new models for how science and health systems can develop together. Nigeria's Genomics Research Hub, Ghana's Kintampo Health Research Centre, the East African Consortium for Clinical Research, and a range of smaller initiatives are demonstrating that high-quality research can be done in African settings with African leadership. What these initiatives need is not merely technical assistance from the global north - they need sustained funding, institutional recognition, and the political support of African governments who understand that scientific capability is a component of national development strategy.

Africa does not need to wait for the global research community to include it. Africa can lead. But leadership requires investment: in people, in infrastructure, in governance, and in the long-term institutional relationships between research organisations, health systems, patient communities, and governments that make sustained scientific progress possible.

> ***"Africa can become a contributor to global discovery, not merely a recipient of its benefits. The science is ready. The talent is here. The question is whether the systems and resources will follow."***

Section 7: A Call for Collective Action

The gap between what we know and what we need to know about sickle cell disease will not be closed by any single actor. It requires a coordinated effort across multiple sectors, each bringing its specific capacities to a shared challenge. What follows is a set of concrete calls to action, addressed to each of the communities whose engagement is essential.

For Patients and Patient Organisations

- Engage with research as partners, not merely participants. Advocate for community advisory structures in any research programme that involves your community's data.
- Champion biobank participation within your networks, while holding researchers accountable for clear benefit-sharing commitments.
- Demand transparency from institutions and governments about how patient data is used, who benefits, and what governance structures are in place.
- Connect globally. The sickle cell patient community spans six continents. Shared advocacy, coordinated campaigns, and mutual support across national contexts amplifies collective influence.

For Clinicians and Healthcare Providers

- Treat data collection as part of clinical care, not an add-on. Every patient encounter is an opportunity to contribute to the evidence base that will improve care for future patients.
- Support the development of common data standards and advocate for electronic health record systems that can feed into research registries with appropriate patient consent.
- Engage in cross-border professional networks to share clinical expertise, align treatment protocols, and identify opportunities for collaborative research.
- Advocate loudly for equitable access to existing treatments, including hydroxyurea, in low-resource settings. Scientific progress that does not reach patients is not progress.

For Researchers and Academic Institutions

- Design research programmes that prioritise representativeness from the outset, not as an afterthought. Diversity in research cohorts is a methodological requirement, not a political preference.
- Build genuine co-investigator relationships with African research institutions and researchers. Authorship, intellectual property, and career development pathways must reflect these partnerships.
- Invest in the ‘boring infrastructure’ of research: data standards, consent frameworks, data governance models, and long-term sample storage. These are the foundations on which transformative science is built.
- Publish not only results but negative findings, methodological innovations, and lessons from failed approaches. The research community learns from failures, but only if they are shared.

For Governments and Policymakers

- Mandate newborn screening for sickle cell disease nationally, and fund the clinical infrastructure needed to act on screening results - not just the screening itself.
- Invest in national research registries and biobanks as public health infrastructure, with the same long-term commitment given to roads, schools, and hospitals.
- Develop regulatory frameworks that enable cross-border data sharing while protecting participant rights - and engage actively in the development of pan-African data governance standards.
- Fund African research institutions to lead, not merely participate in, international research programmes on sickle cell disease. Scientific sovereignty is a component of national sovereignty.

For Industry and Biotechnology

- Develop equitable access strategies for sickle cell therapies at the earliest stage of drug development, not as a regulatory afterthought. A gene therapy priced at over two million dollars per patient is not a solution for the populations most affected by the disease.
- Invest in research and development partnerships with African research institutions, bringing manufacturing, clinical trial, and regulatory expertise to the continent.
- Support open-data initiatives and data standards development as pre-competitive infrastructure from which the entire field benefits.
- Engage with patient communities as strategic partners in trial design, outcome measure selection, and post-approval access planning.

For Philanthropists and Funding Bodies

- Commit to long-term research funding. Infrastructure, capacity building, and longitudinal data collection cannot be achieved through two-year grants. The time horizons of sickle cell research require the time horizons of institutional endowments.
- Fund the ‘unfundable’: data standards, governance development, community engagement capacity, and the salaries of local researchers who might otherwise be lost to brain drain.
- Prioritise African-led research initiatives and resist the temptation to channel funding through global north intermediaries who extract administrative overhead without adding proportionate scientific value.
- Develop explicit impact metrics that include equity and representativeness - not just publication counts, citation indices, or patent applications.

Conclusion: The Future of Sickle Cell Discovery

Two days ago, in London and in cities around the world, people came together to mark World Sickle Cell Day under the banner of *Voices of Resilience*. They shared stories of pain endured and crises survived, of families holding together under enormous strain, of patients who have outlived the prognoses that once defined their possible futures. Those voices are real, and they matter.

But if we are serious - if those events are more than commemoration, if they are the starting point for sustained, collective action - then the voices we heard on 19th June must translate into something more durable than goodwill. They must translate into research programmes that are built on those communities' data and designed to answer those communities' most urgent questions. They must translate into biobanks and registries that are governed by the communities whose samples they hold. They must translate into African scientific leadership that is recognised, resourced, and respected.

The gene therapies developed in the past five years demonstrate what is achievable when scientific ambition, sustained funding, and rigorous research infrastructure align. They are a glimpse of what is possible for sickle cell disease. But they are also, for the moment, accessible only to a small minority of the patients who could benefit from them - those who happen to have been born in high-income countries with healthcare systems capable of delivering cell therapies at extraordinary cost. The scientific triumph is real. The equity failure is equally real.

Closing that gap requires everything this essay has argued for: representative data, African research leadership, community partnership, robust governance, sustained infrastructure investment, and a willingness by governments, philanthropists, and industry to make long-term commitments that extend beyond individual project cycles or political terms. None of this is easy. All of it is possible.

The future of sickle cell care will not be determined solely by the therapies we develop. It will be determined by whose lives, whose voices, and whose data are represented in the discovery process. That is both the challenge and the opportunity before us.

About Afromics

Afromics is a UK and Africa-based genomics biobank and research platform focused on sickle cell disease and other haemoglobinopathies affecting populations of African descent. Our mission is to build the representative genomic and clinical data infrastructure needed to power the next generation of sickle cell discoveries - with

African communities as partners, not subjects. For more information, visit afromics.org.

Hashtags: #WorldSickleCellDay • #VoicesOfResilience • #SickleCellResearch • #Afromics • #FromVoicesToDiscovery