Investing in Access: Sickle Cell Care as an Entry Point for Blood-Health Systems in Africa

Komla Amega[1] **| Larry Ajuwon**[2]

1 School of Business and Law, University of Brighton, Brighton, United Kingdom
2 Founder and Director, RHIEOS Ventures

Abstract

Sickle cell disease is one of Africa's highest-burden inherited conditions, yet access to early diagnosis, essential treatment, blood services and follow-up remains uneven. Financing is fragmented, and households often incur substantial out-of-pocket costs. This policy and thought-leadership paper reframes the problem as a financing and delivery gap. It argues that sickle cell disease can serve as a practical starting point for strengthening wider blood-health systems, and that observed spending can understate true need when people delay or forgo care.

The term access intelligence is used to describe the combination of registry, service, patient, and cost data to identify where care is missed and what requires financing or strengthening. Building on existing African programmes and financing approaches, the paper outlines a staged model: foundational public functions, shared infrastructure, and specialised capabilities added only when basic services are working reliably. ReachOne for sickle cell disease is presented as a bounded Nigerian implementation and learning platform, not a substitute for public financing or existing programmes. Screening prices have fallen sharply, but cost per child in continuing care is set by linkage and retention, not the price of a test. Three steps follow: access measures with published baselines; funded baseline establishment in one high-burden country; and matching diaspora financing mechanisms to a defined pathway and registry.

Keywords: sickle cell disease; Africa; health financing; access; blood health; registries; remittances.

1. Overview of Sickle Cell Disease in Africa

Sickle cell disease (SCD) is an inherited blood disorder in which abnormal haemoglobin alters the shape and function of red blood cells (Integrated African Health Observatory & World Health Organization, 2024). In this paper, SCD is treated not only as an urgent disease burden but also as a practical starting point for strengthening broader blood health systems. Many of the capabilities needed for dependable SCD care – screening and diagnostics, laboratories, blood services, medicines, trained staff, referral and follow-up – are also foundations for maternal and child health, chronic care, and future advanced therapies. Globally, about 54,000 deaths of all ages in 2023 were attributed to SCD as the underlying cause, up from about 45,600 in 2000 (Naghavi et al., 2025). That count understates the burden. Where SCD is counted as a contributing cause rather than a single underlying one, global SCD-related deaths in 2021 were estimated at 376,000 (95% Confidence Interval [CI]: 303,000-467,000), including 81,100 in children under five (Thomson et al., 2023). The measurement problem that hides these deaths also hides unmet need, and it recurs throughout this paper.

Africa bears a disproportionate share of the burden, and 6.4% of under-five mortality in Africa is attributable to SCD (Integrated African Health Observatory & World Health Organization, 2024). Estimates of early mortality vary widely by method. Older survey data suggested that

between 50% and 90% of children born with SCD in SSA died before age five (Grosse et al., 2011). More recent studies report lower figures: 36.4% (95% CI: 33.4-39.4) across five countries in the MIDAS study (Ranque et al., 2022), 49% (95% CI: 24-70) in a model-based analysis of Nigerian survey data (Nnodu et al., 2021), and 29% in a Kenyan birth cohort (Uyoga et al., 2019). Survival is improving, but the width of that range reflects a measurement gap rather than a settled finding (Ranque et al., 2026; World Health Organization, 2026a).

Country- and subregional data remain incomplete (Jonani et al., 2025; Ranque et al., 2026). The Global Burden of Disease Study, based on limited data, estimates that approximately 405,000 (95% CI: 343,000-478,000) babies were born with sickle cell anaemia (SCA) in Sub-Saharan Africa (SSA) in 2021, an increase of 27.2% on the 2000 figure (Thomson et al., 2023). However, heterogeneity remains substantial. A meta-analysis of African studies reports pooled SCA prevalence of about 2.0% in Central Africa, 1.7% in North Africa, 1.4% in East Africa, 1.1% in West Africa and 0.6% in Southern Africa. The confidence intervals around these estimates overlap almost entirely, and the North African figure rests on very few studies, so they indicate orders of magnitude rather than a ranking (Jonani et al., 2025). By country, Equatorial Guinea, Benin, Burkina Faso, Nigeria, Sierra Leone and Togo had estimated birth prevalence above 2%, while the Democratic Republic of Congo (DRC), Sao Tome and Principe, Ghana, Guinea, Angola, Niger and Kenya recorded between 1% and 2% (Thomson et al., 2023). Variation within countries can be as large as variation between them. Newborn screening in the DRC found 0.2% in Butembo and Beni against 2.2% in Kisangani (Ranque et al., 2026). The variation within and between regions underscores the need for country-specific strategies rather than a single continental model.

Whatever the local prevalence, mortality at these levels is not inevitable. In the Kilifi birth cohort, children with SCD who attended a clinic offering folic acid, penicillin prophylaxis and malaria prophylaxis had a mortality rate of 2.9 per 100 person-years, against 10.4 among those who did not (Uyoga et al., 2019). The binding constraint is that most children are never diagnosed, and most of those who are diagnosed do not stay in care.

2. Financing Reliable Sickle Cell Access in Africa

SCD imposes substantial costs on families through medical expenses - including diagnosis, hospitalisation, transfusions and medicines - as well as lost income for patients, parents and carers (Amarachukwu et al., 2022; Kamya et al., 2025; Olatunya et al., 2015). Yet the financing problem is not simply the amount of money available. Funding comes from households, national budgets, donors, philanthropy, research funders, and private-sector partnerships, often through separate, time-limited streams. External support can also remain project-based, with sustainability weakened when programmes are not integrated into national financing and delivery systems (Archer et al., 2022; Brito et al., 2025). The central question is how these resources can support reliable care over time and strengthen the systems that enable access.

Out-of-pocket spending remains a major source of both general health and SCD expenditure (Amarachukwu et al., 2022). The World Bank estimates that the share of current health expenditure paid out of pocket in SSA averaged 30.4% in 2023 (World Bank, 2026). However, this share could be as high as 71.9% in Nigeria, 66% in Equatorial Guinea and 64.3% in Togo, and as low as 4.1% in Rwanda, 4.3% in Botswana and 7.5% in Namibia over the same period (World Bank, 2026). The burden is especially acute for low-income households in Nigeria. In

one tertiary-care study, about 61% of the poorest group incurred SCD-related expenditure exceeding 40% of household non-food expenditure (Amarachukwu et al., 2022). These costs can push families into financial distress and poverty.

Observed spending is therefore an incomplete measure of need. When families delay clinic visits, self-medicate, seek alternative care, or forgo tests and medicines because of cost, little or no formal expenditure may be recorded even though the health need remains. Recent qualitative evidence from Ghana identifies financial barriers, transport and time constraints, self-medication, and alternative care as barriers to formal SCD care (Ohemeng-Tinyase et al., 2025). For planning and financing, current expenditure should therefore be considered alongside unmet clinical need and missed or delayed care. Therefore, this paper reframes sustainable SCD financing as the financing of access – not merely of isolated activities, but of the people, services, infrastructure, and information required to make care reliable and sustainable. It examines how unmet needs can be made visible, how funding can be directed towards identified gaps, and how SCD can serve as a practical entry point for strengthening broader blood-health system capacity.

The price of screening is now low and falling. A ceiling price of US$1.00 per point-of-care test was agreed for low- and middle-income countries in May 2025 (Clinton Health Access Initiative, 2025), against US$3.67–5.88 per child for the laboratory method it displaces (Mvundura et al., 2019). The most systematic multi-country costing remains Kuznik et al. (2016), which modelled screening with a prophylactic package across 47 SSA countries at about US$9.94 per newborn screened and US$58 per child a year; those figures are in 2014 dollars and predate point-of-care testing, and no updated analysis has been published. What this means for financing is the point. Screening is paid on every newborn tested, not on the cases found, so the cost per child in continuing care is set less by the price of the test than by whether that child reaches a clinic and stays in it. Halving the price of a test moves a budget line but it does not by itself change how many children are still in care a year later.

3. Barriers to Effective SCD Care in Africa

The literature identifies five connected barriers to effective SCD care: awareness, screening and early diagnosis; treatment and operations; socio-cultural and psychological factors; policy and structural constraints; and financing (Figure 1) (Dei-Adomakoh et al., 2026; Munung et al., 2026; Obeagu & John, 2025).

3.1. Barriers to Awareness, Screening and Early Diagnosis

Genotype screening and genetic counselling before pregnancy can support informed reproductive choices (Bindhani et al., 2020; Kisanga et al., 2021). Access to accurate genotype information and non-directive counselling should not be limited to marriage (Peter & Makeri, 2024). Barriers to early diagnosis include limited diagnostic equipment, weak laboratory capacity and gaps in newborn screening (Dei-Adomakoh et al., 2026; Munung et al., 2026). Newborn screening is feasible in Africa, but its sustainability depends on integration into routine health systems, government ownership and financing (Archer et al., 2022). Nonetheless, efforts to standardise screening and early intervention are underway in several high-burden countries (Integrated African Health Observatory & World Health Organization, 2024).

3.2. Treatment and Operational Barriers

Treatment barriers include limited clinician training, uneven access to hydroxyurea and pain medicines, and weak supply and laboratory systems (Dei-Adomakoh et al., 2026; Munung et al., 2026). Local hydroxyurea production is emerging in some African countries, yet availability and affordability remain uneven (Dei-Adomakoh et al., 2026). Specialist treatment and transplant capacity remain concentrated in a small number of countries (Esoh et al., 2021). Workforce shortages, long travel and waiting times, and weak referral pathways further disrupt care, while primary care remains underused (Integrated African Health Observatory & World Health Organization, 2024; Munung et al., 2026).

3.3. Socio-Cultural and Psychological Challenges

SCD imposes a substantial psychosocial burden, including fear, anxiety, distress, isolation and treatment fatigue (Dei-Adomakoh et al., 2026; Munung et al., 2026). Depression, anxiety and post-traumatic stress disorder are reported more frequently among people living with SCD than in the general population (Mishkin et al., 2023). Stigma and discrimination can erode trust, worsen pain management and limit access to care (Obeagu & John, 2025). Mental health assessment and support should therefore be integrated into routine SCD care (Adeyokunnu et al., 2025).

3.4. Policy and Structural Barriers

Structural barriers include low policy priority, inadequate resource allocation, weak pharmaceutical supply chains, and limited research and data capacity (Dei-Adomakoh et al., 2026; Munung et al., 2026). SCD receives less policy attention than several other high-burden diseases in Africa (Integrated African Health Observatory & World Health Organization, 2024). African participation in SCD clinical research also remains disproportionately low: in an analysis of 156 industry-sponsored SCD drug trials registered between 1990 and 30 June 2024, only 7.9% of enrolling centres were in Africa (Costa et al., 2025). Sustained implementation also requires ownership beyond health ministries, particularly among finance and planning institutions that shape national priorities and budgets.

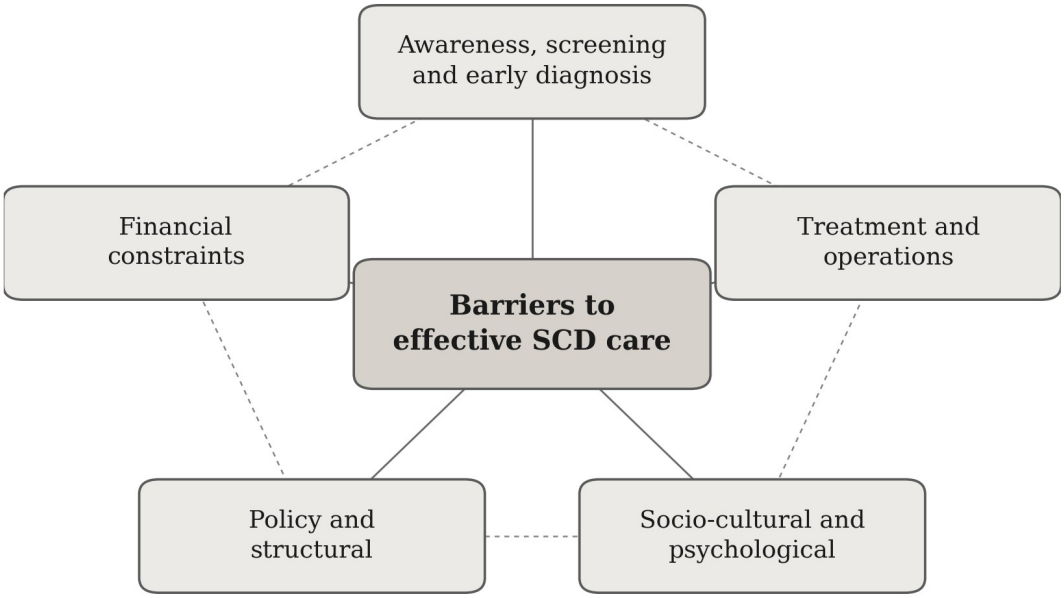
3.5. Financial Constraints

Financial barriers are a major driver of inequitable SCD care, through both direct out-of-pocket costs and indirect costs, such as lost income (Mensah et al., 2026; Ryan et al., 2020). Where insurance or public subsidy is limited, households bear much of the cost of care. In Nigeria, catastrophic expenditure has been reported across socioeconomic groups, with the poorest households most affected (Amarachukwu et al., 2022). A 2025 prospective study of 723 children in Uganda and Malawi likewise found substantial household costs and frequent catastrophic expenditure, particularly among poorer families (Kamya et al., 2025). For a lifelong condition, sustained household financing can deepen poverty and contribute to treatment interruption or abandonment (Brito et al., 2025).

The financing gap is therefore not a stand-alone problem; it is a financing-and-delivery gap. Screening, diagnostics, laboratories, medicines, blood services, workforce capacity, referral systems and patient follow-up all require sustained investment. The policy challenge is to connect public, philanthropic, private and household resources to what needs to be built or strengthened, in ways that are predictable, accountable and aligned with national priorities. Registries and outcome data can help, but their value is greater when combined with

information on patient journeys, service use, costs, delayed or missed care, and local service capacity. We use the term access intelligence to describe this combined view: evidence showing where people are missing care, which proven interventions are underused, and what needs financing or strengthening. This builds on established work on effective coverage and unmet need, but it is assembled to inform financing decisions, so each gap it identifies is linked to the investment that would close it. Sustainable SCD financing should be judged not only by the amount of money mobilised, but also by the access and patient outcomes it creates.

Figure 1. Challenges Associated with Sickle Cell Disease Management



4. Building on Existing Efforts

Africa's SCD response is not starting from zero. Governments, patient organisations, clinical networks, researchers, philanthropies and private-sector partners have already built important capabilities across advocacy, research, care delivery and financing (Table 1). These are building blocks for stronger access systems, not a blank landscape. The remaining gap is often the connection between evidence, financing priorities and day-to-day delivery. WHO's June 2026 technical consultation on newborn screening recommends starting with one or a few priority conditions and linking screening to diagnosis, treatment, referral, follow-up and long-term care within national health systems, supported by practical data systems and sustainable financing (World Health Organization, 2026b). This direction aligns with parts of the access framing used in this paper, which asks how data and financing can be organised around what needs strengthening for reliable SCD access.

Ghana's hydroxyurea programme merits more detail, as it both illustrates the sequence argued for here and complicates it. The programme began in 2019 as a public-private partnership to expand access to a single medicine. It did not wait for registries, newborn screening or laboratory capacity to be in place. What made it durable was what followed. In 2022, the government adopted hydroxyurea into the National Health Insurance Scheme, shifting costs from households and donors to a national financing mechanism. Elements of the programme are now informing work elsewhere in Africa (Nyonator et al., 2023). Access nonetheless remains uneven. Providers in Ghana report ongoing supply, adherence and cost barriers that a listing decision alone does not resolve (Mensah et al., 2026). Two lessons follow. A specific, well-defined intervention can build the political case for financing reform more quickly than system-building alone. However, a financing decision becomes access only when supply,

workforce, and follow-up hold – which the layered approach described later in the paper is intended to address.

Table 1. Relevant Models, Institutions and Enabling Approaches

Actor/source	**Unique contribution**	**What it contributes to reliable access**
Sickle Cell Foundation Nigeria	Locally led, end-to-end SCD service delivery in a high-burden, resource-constrained setting	Shows how locally led services can reduce direct costs and improve continuity of care
SickleInAfrica Consortium	Pan-African research, registry and data infrastructure	Provides registry and data infrastructure that can help map need, monitor outcomes and inform financing priorities
Foundation Pierre Fabre	Combines multi-country programme funding, support for clinical and data infrastructure, and catalytic grants for digital health and for civil society	Shows how multi-country funding can support clinical, data and civil-society infrastructure
TY Danjuma Foundation	African philanthropic capital and local grant-making	Example of domestic philanthropic capital supporting public-interest health priorities
Glory Healthcare	COMESO payment application, developed from the dedicated health account concept in Amega (2023)	Working implementation of the remittance-linked health account concept, showing how digital payment infrastructure can collect and disburse earmarked health funds
WHO-African Region	Macro framework for diversifying African health revenues	Provides regional policy guidance within which SCD access and financing can be aligned
Amega (2023)	Concept of a dedicated health account funded through remittances	Conceptual model for channelling remittances through a dedicated health account
RemitAid; HealthBridge	AU-endorsed remittance match-funding mechanism; pooled diaspora health-protection platform	Established routes for converting remittance flows into structured, pooled health financing

Actor/source	Unique contribution	What it contributes to reliable access
Brikci (2024)	Evidence on feasibility and implementation of innovative domestic finance	Evidence on innovative domestic financing mechanisms and their implementation constraints in Africa
Mobile money models	Digital collection and disbursement of health funds	Transactional infrastructure that could support voluntary, transparent health contributions
Africa Centres for Disease Control and Prevention	Continental health agency supporting health initiatives and institutional responses	Continental policy and institutional platform for health-system strengthening and financing

5. Where ReachOne and HEMA-Global Fit

ReachOne aims to deliver better access now; HEMA-Global sets out what can be built over time.

5.1. Definitions and Key Concepts

Key terms

Blood health: The wider system for preventing, diagnosing and treating blood-related conditions and for providing safe, reliable blood services. SCD is used here as the starting point, not the full scope.

Access intelligence: The combined use of registry, service, patient and cost data to show where people are missing care, which proven interventions are underused, and what needs to be financed or strengthened.

Foundational public functions (often called public goods in the health financing literature): Functions that benefit the wider health system and are difficult to sustain through patient payments alone. These include screening, registries, data standards, workforce training, clinical standards, referral pathways, and blood-system resilience. Most of these are not classified as public goods in the strict economic sense. What they share is a significant positive externality and a limited private incentive to supply them.

Shared infrastructure: This comprises laboratories, diagnostics, blood hubs, clinics and supply systems, and digital records that support multiple services.

Specialised capabilities: It entails adding more advanced services where basic care and supporting systems are working reliably, such as advanced diagnostics, specialist centres, selected manufacturing and future therapies.

5.2. The Programme in Practice

Financing, data and delivery sit in separate projects, with limited continuity across the patient pathway, making fragmentation the main constraint.

SCD is a practical starting point for stronger blood-health and chronic-care systems (RHIEOS Ventures, 2026). Reach One for Sickle Cell, launched on World Sickle Cell Day in June 2026 as a HEMA-Global campaign by RHIEOS Ventures in partnership with Sickle Cell Foundation Nigeria (SCFN), translates that framing into a concrete implementation and learning programme. The campaign uses SCD as a focused starting point within the wider blood-health proposition: improving access for people living with SCD now while learning how financing, data, and delivery can connect more reliably. It does not replace public financing, insurance, existing SCD programmes, or research networks; instead, it seeks to connect action around defined access outcomes (RHIEOS Ventures / HEMA-Global, 2026).

The first application is deliberately concrete. RHIEOS Ventures and SCFN launched the Sickle Cell Disorder Registry Nigeria (SCDRN) in 2019. The registry currently includes 1,915 patients, with a target of 5,000 within three to five years. ReachOne links that expansion to newborn screening, earlier diagnosis, patient follow-up, training for genetic counsellors, and a comprehensive cohort study. As the registry and linked work mature, the aim is to move beyond counting patients to combining clinical, follow-up, service-use and cost information to show where care is missed, which interventions are underused and where financing or delivery needs strengthening. This is the practical access-intelligence role described above. However, the scale should be stated clearly. Nigeria has an estimated 150,000 SCA births each year, and the SickleInAfrica registry network has already enrolled more than 30,000 patients across several countries (Ranque et al., 2026). A cohort of 5,000 patients in one country will not measure national access and is not intended to do so. Instead, it can test whether linked clinical, follow-up, and cost data change financing decisions and whether the measures set out below can be collected reliably. The intention is to report participation, learning, and outcomes publicly as the programme develops (RHIEOS Ventures / HEMA-Global, 2026).

This poses a real-world test of a broader financing question: can fragmented sources of support be organised around the care pathway rather than isolated activities? ReachOne is exploring grant, match-funding, philanthropic, community, diaspora, private-sector and institutional participation. Diaspora-supported health spending is not new. Remittances to African countries reached over US$55 billion in 2023, around 3% of the continent's gross national income, and part of this already pays for care (Iyahen et al., 2025). Evidence across Africa suggests remittances can improve health outcomes, but they do not substitute for government health spending or financial protection (Chen & Ajide, 2026). The limitation is structural rather than a matter of volume. These transfers arrive after the shock rather than before it, without pooling, prepayment or regulatory protection. Mechanisms are being built to change that: RemitAid, adopted by the African Union Executive Council in 2022 and launched at the Fourth International Conference on Financing for Development in July 2025 (RemitAid, 2025), and HealthBridge, which proposes pooled diaspora contributions and prepaid access to a defined benefit package (Iyahen et al., 2025; Nwuneli & Iyahen, 2026).

5.3. The Framework

HEMA-Global provides the longer-term access and investment architecture. It is a framework for what needs to be built and in what order. It is not a financing mechanism, nor is it an extension of any single programme. It distinguishes three layers. First are foundational public functions, such as screening, registries and data, workforce training, clinical standards, referral pathways, and blood-system resilience. Second is shared infrastructure, including laboratories, diagnostics, blood services, clinic and supply systems, and digital records. Third are specialised capabilities, including advanced diagnostics, selected manufacturing, specialist centres, and future advanced therapies. Different layers require different combinations of government funding, philanthropy, private investment and other capital. Mechanisms such as remittance-linked accounts and pooled diaspora insurance map onto specific layers rather than across all of them. The principle is simple: strengthen the basics first, then add more complex services only when they can be reliably supported.

This sequencing is a working assumption rather than a settled principle, and evidence challenges it. For instance, Ghana's hydroxyurea programme, set out above, began with treatment rather than with foundational systems, and the treatment drove the policy and financing changes that followed. Additionally, vertical disease programmes have at times built laboratory, supply, and workforce capacity that outlasted them. There is also a practical risk that prioritising the basics first becomes an indefinite deferral of anything more ambitious. The layers are therefore best read as a way of matching the type of funding to what is being built, rather than as a fixed order of construction.

Making the scale of the opportunity visible also requires looking beyond current spending. A practical estimate of the funding and investment required for access would combine observed healthcare expenditure with unmet clinical need, care forgone because of cost or distance, underuse of proven interventions, and the system investments needed for reliable delivery. Because several of these elements are poorly measured, early estimates should be presented as ranges and scenarios rather than as a single market-size figure. The purpose is not to inflate the market, but to make the true scale of need and the financing required to address it more visible.

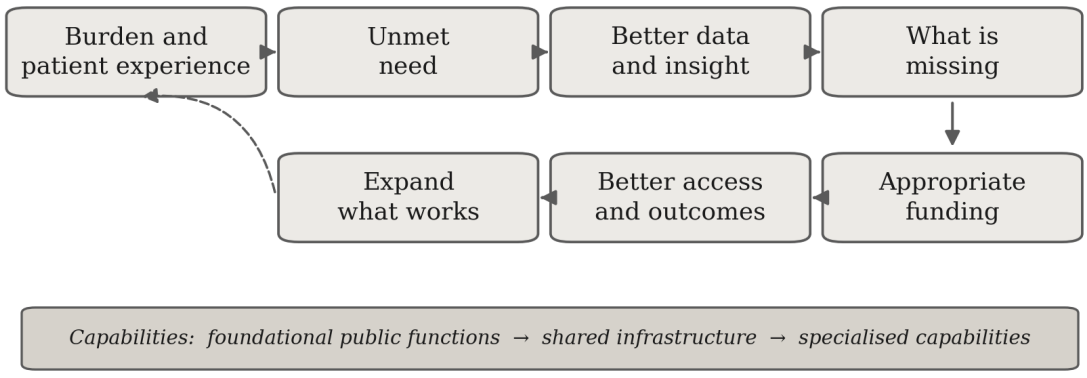


Figure 2. From hidden need to reliable access: a practical financing pathway

The engagement structure should follow the same logic. ReachOne should not become another large SCD consortium. Instead, it can contribute a focused workstream covering access,

financing, and outcomes within existing country and African-led structures. A small core group can align a limited set of priorities, assign clear responsibilities, coordinate funding, and report against common measures, while wider partners contribute through defined workstreams in policy, evidence, delivery, supply, financing, or technology. Scale should follow demonstrated delivery, not participation alone.

Success should be measurable. For the first phase, we propose five measures, each with a stated baseline: registry enrolment against the 5,000-patient target; the proportion of enrolled patients completing a scheduled follow-up visit within the defined interval; pain crises and crisis-related admissions per patient-year; age at first diagnosis, and the proportion of newly enrolled patients diagnosed before their first birthday; and the proportion of patients with uninterrupted access to hydroxyurea over twelve months. Two baselines are now established. Registry enrolment stood at 1,915 against the 5,000-patient target in April 2026, and the mean age at first diagnosis was 45 months across 1,373 patients at the March 2024 data cut (Sickle Cell Disorder Registry Nigeria, 2024, 2026). Where investments strengthen laboratories, blood services, data or the workforce, their wider benefits beyond SCD should also be measured. The aim is to move from emergency giving to sustained systems, from fragmented projects to coordinated investment, and from activity counts to outcomes that matter to patients.

6. Conclusion

The argument of this paper is straightforward: SCD access cannot be solved by financing alone, but it cannot be solved without financing designed around delivery. SCD should also be seen as a strategic starting point for stronger blood health systems in Africa. The same foundations needed for reliable SCD care – early diagnosis, laboratories, blood services, medicines, data, workforce and referral – can strengthen wider services when built as part of national systems.

This narrative redefines what innovative financing should mean. The goal is not financial novelty for its own sake, nor is it to shift responsibility to families or diaspora communities. The task is to make unmet need visible, identify what is missing for reliable access, and match funding to what needs to be built. Public responsibility remains central; philanthropy, diaspora participation, private capability and institutional capital can complement it where they add clear value and leave durable capacity behind.

ReachOne offers a bounded setting to test this logic in Nigeria: expand the registry and screening pathway, strengthen follow-up and the workforce, use linked data to improve understanding of access gaps, generate evidence, and make outcomes visible. The longer-term HEMA-Global proposition is to use learning from SCD to inform a staged blood-health access and investment model: strengthen foundational public functions, build shared infrastructure, and add specialised services only when the basics are working reliably.

The practical test is whether this approach can make earlier diagnosis, essential treatment, follow-up, and referral reliable for more people, reduce avoidable financial burdens on families, and clarify where future investment should be directed. If so, SCD can be both an urgent health priority and a practical entry point for more durable approaches to blood health and access to care.

On that basis we propose three steps. First, national SCD strategies and newborn screening plans should adopt a small set of access measures with published baselines – diagnosis before

the first birthday, completion of scheduled follow-up, and uninterrupted access to hydroxyurea rather than counting activities alone. Second, at least one high-burden country should fund the establishment of those baselines as a costed first-phase deliverable. Third, the mechanisms now being built for diaspora and pooled contributions, including RemitAid and HealthBridge, should be matched to a defined clinical pathway and a registry able to report against it, so that a benefit package can be priced and held to account. ReachOne offers one place to test all three; each can also be taken up independently by any government, funder, patient organisation or diaspora partner already working in this field.

Declarations

Conflicts of interest. LA is Founder and Director of RHIEOS Ventures, which convenes the HEMA-Global proposition and, together with Sickle Cell Foundation Nigeria, operates the Sickle Cell Disorder Registry Nigeria and the Reach One for Sickle Cell campaign described in this paper. KA is the author of Amega (2023), a dedicated health account concept on which parts of the financing argument are based. Neither author receives any personal financial benefit from the programmes discussed. The authors declare no other competing interests.

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Author contributions

Conceptualisation, LA and KA; Methodology, KA; Investigation, LA; Writing - original draft, KA; Writing - review and editing, KA and LA; Resources, LA; Project administration, LA.

Data availability

This paper presents no new primary data. All referenced figures are extracted from previously published sources listed in the references section. The registry figures for the Sickle Cell Disorder Registry Nigeria are reported as of April 2026.

Ethics approval

Not applicable. This paper involves no research with human participants.

Use of AI tools

Generative AI tools were used to prepare this manuscript, including verifying cited evidence, supporting structural and critical analysis, and assisting with drafting. The authors reviewed and verified all content and take full responsibility for the accuracy and integrity of the work.

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