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# INHERITED BLOOD DISORDERS LEADERSHIP FORUM REPORT

STRENGTHENING BLOOD DISORDERS CARE  
IN NIGERIA THROUGH COLLABORATIVE  
PARTNERSHIPS AND SUSTAINABLE INVESTMENT



11-12 FEBRUARY 2026

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## ***Executive Summary***

That inherited blood disorders are preventable, manageable, and cost-effective to treat when addressed through well-coordinated systems of care was the central message of the Inherited Blood Disorders Leadership Forum, held in Abuja, Nigeria, on 11–12 February 2026. Translating this principle into measurable progress will require deliberate collaboration, effective national and sub-national coordination, and sustained commitment from all stakeholders. In Nigeria, that alignment has been the missing piece.

Nigeria bears a significant burden of inherited blood disorders, with sickle cell disease and haemophilia among the most prominent. Yet efforts to address this burden have remained fragmented with clinicians working within hospitals, advocates mobilising in communities, and policymakers operating from government offices - each confronting the same crisis from different angles, rarely in the same room. The Inherited Blood Disorders Leadership Forum sought to change that. For the first time in Nigeria, those with the authority to transform the national response - health policymakers, clinicians, researchers, patient advocates, development partners, and faith and community leaders - gathered in Abuja to deliberate on "Strengthening Blood Disorders Care in Nigeria Through Collaborative Partnerships and Sustainable Investment."

Organised by the Nigerian Society of Haematology and Blood Transfusion (NSHBT Haemophilia Care Team) in collaboration with the National Blood Service Agency (NBSA) and the Novo Nordisk Haemophilia & Haemoglobinopathies Foundation (NNHF), and chaired by Professor Wuraola Shokunbi, the Forum was convened with a clear objective: to reposition haemophilia and sickle cell disease within Nigeria's public health and development agenda.

The Forum was attended by 74 participants comprising federal and state directors of hospital services, key opinion leaders in the management of haemophilia and sickle cell disease, international partners, and patient member organisations. Financial support was provided by the Novo Nordisk Haemophilia and Haemoglobinopathies Foundation.

Access to care for inherited blood disorders in Nigeria remains highly centralised. The country's 17 haemophilia treatment centres operate exclusively within tertiary hospitals, limiting access to care for patients in rural and underserved communities. This is not an isolated issue but part of a wider set of system constraints. While Nigeria has reported notable achievements, including pioneering stem cell transplant for sickle cell disease in Sub-Saharan Africa and establishing national registry systems, these gains have yet to translate into consistent, accessible care.

largely due to weak policy integration, insufficient domestic financing, and fragmented implementation. Gaps in care are particularly evident in areas that receive less attention. Mental health morbidity among people living with sickle cell disease was reported at up to 84% in some clinical settings, yet mental health services remain absent from standard care protocols.

Over two days of keynote and guest presentations, panel discussions, and interactive sessions, participants reviewed the current state of inherited blood disorders care in Nigeria. Discussions focused on inequities in access to care, diagnostic capacity gaps, human resources for health limitations, unsustainable financing mechanisms, uneven decentralisation of services, and the psychosocial and economic impact of inherited blood disorders on patients and their families. The Forum also identified practical steps towards stronger government ownership, including policy reform, dedicated budgetary allocations, and strengthened institutional coordination.



## Key Highlights

The Inherited Blood Disorders Leadership Forum 2026 was the first convening of its kind in Nigeria bringing together clinicians, policymakers, patient advocates, researchers, development partners, faith leaders, and persons living with the conditions themselves.

Nigeria bears the world's highest burden of sickle cell disease, with significant child mortality and limited survival into mid-adulthood. Haemophilia remains underdiagnosed, with only a small fraction of estimated patients formally identified. There is no government funding for haemophilia treatment and access to standard care is limited. Only a small proportion of registered sickle cell patients receive hydroxyurea, haemophilia services are concentrated in tertiary hospitals, and confirmatory diagnostics are largely unavailable. Newborn screening systems are underfunded and weak, while a growing shortage of trained health personnel further strains an already fragile system.

Testimonies documented the physical, emotional, and financial devastation of living with these conditions without adequate care. Patients described relying on painkillers, and in some cases non-medical substances, in the absence of appropriate treatment.

Tanzania moved from zero haemophilia infrastructure in 2020 to 14 functioning treatment centres, a bone marrow transplant programme, Ministry of Health coordination, and full national insurance integration - within four years - by securing government co-ownership before a single clinic was established. Nigeria itself has performed the first stem cell transplant for sickle cell disease in Sub-Saharan Africa and now operates two functioning transplant centres.

Few countries receiving humanitarian donations have developed domestic financing for treatment. Every future programme must embed defined pathways to government ownership and domestic financing from inception.

## Key Challenges Identified

### 1. Sickle Cell Disease

- High disease burden with significant contribution to childhood mortality.
- Limited neonatal screening capacity and weak follow-up systems.
- Predominantly out-of-pocket financing and limited insurance coverage.
- Urban concentration of services with poor rural access.
- Low uptake of disease-modifying therapy such as hydroxyurea.
- Insufficient attention to psychosocial and mental health needs.
- Lack of nationwide data infrastructure.

### 2. Haemophilia and Other Bleeding Disorder

- Only 17 Haemophilia Treatment Centres serve a population of over 200 million with restricted diagnostic capacity and very few centres able to perform factor assays.
- Dependence on humanitarian donations from the WFH for clotting factor concentrates, with inconsistent supply due to logistical and regulatory barriers.
- Unsafe traditional practices and delayed presentation in some parts of the country.
- Inadequate blood product infrastructure and skilled workforce.

### Recommendations

The Forum produced recommendations across several key pillars of action:

- The Federal Government must create dedicated budget lines for haemophilia and sickle cell disease (SCD), gazette and implement the National Haemophilia Guidelines, include factor concentrates and hydroxyurea on the National Essential Medicines List, and establish a national haemophilia registry while strengthening the existing sickle cell registry.
- The National Health Insurance Authority (NHIA) must provide comprehensive coverage across the care continuum - including diagnostics, treatment, mental health services, and genetic counselling - and enforce compliance among Health Maintenance Organisations.
- Federal and State authorities must decentralise SCD and haemophilia services beyond tertiary hospitals to secondary and primary levels.

- Newborn screening infrastructure should be expanded, supported by structured task-shifting and telemedicine integration to improve access in underserved areas.
- Shift advocacy from awareness-focused campaigns to evidence-driven engagement.
- Engage faith-based organisations, traditional leaders, and the media to address stigma and misinformation.
- Embed sustainability clauses, exit strategies, and government co-investment requirements in all donor-supported programmes.
- Establish a national consortium to unify stakeholders under a single, accountable governance platform.

## Background

Inherited blood disorders remain among the most significant yet neglected public health challenges in Nigeria. Among these, sickle cell disease and haemophilia carry the heaviest burden, affecting thousands of families and imposing substantial human, social, and economic costs.

The Inherited Blood Disorders Leadership Forum 2026 opened not with epidemiological data or policy arguments, but with recorded testimonies from individuals and families living with haemophilia and sickle cell disease, setting a solemn and urgent tone for deliberations.

Angela described a life constrained by avascular necrosis, arthritis, and chronic pain: “Even to socialise, to go out, to mingle with friends and do all the things I need to do to make myself happy, I cannot.”

Gabriel James spoke of wounds he chose not to show on camera, mindful of viewers’ mental health, noting that the condition “affects us mentally, emotionally, and socially.”

Fatima Farouk, a mother of four children living with sickle cell disease, reflected on twenty-two years of caregiving: “All my life, it's about hospital - in and out of hospital. Sometimes I feel like giving up. But when I give up on them, who will be there for them?”

David Aremu, a 25-year-old living with severe haemophilia A, spoke of irreversible joint damage and unaffordable treatment, but also of completing a degree in computer science and his hope that future generations will not endure similar hardship.

Ebenezer Matthew, who underwent a stem cell transplant in 2013 and has since lived free of crises, described the transformative impact of accessible care: “I've been living my life free, without crisis, without pain,” he said. “Being a sickle cell is not funny. I've lived a life of being a sickle cell, and I'm living a life of being AA — and there's a big difference.”



In her opening remarks, Professor Omolade Awodu, Professor of Haematology, Team Lead for Strengthening Haemophilia Care in Nigeria and Co-Host of the Forum, acknowledged Nigeria's position as the country with the highest global burden of sickle cell disease. She noted that haemophilia, though less prevalent, exerts a profound toll on affected individuals and families. The core challenge, she stated, is not a lack of technical expertise or professional commitment, but "limited policy integration, weak domestic financing, and insufficient coordination across sectors." Addressing these systemic constraints, she emphasised, will require a deliberate shift toward nationally owned, sustainably financed solutions that reduce long-term dependence on external support.

Recognising the contributions of partners such as the Novo Nordisk Haemophilia & Haemoglobinopathies Foundation and the World Federation of Haemophilia, Dr Awodu described humanitarian support as "lifesaving" for many patients. However, she stressed that the Forum was convened to chart a path that "progressively moves Nigeria towards self-sufficiency with minimal dependence on international humanitarian donations."

Reflecting on decades of clinical practice, Professor Wuraola Shokunbi, Professor of Haematology and Blood Transfusion and Chairman of the Forum, noted that while awareness of sickle cell disease has grown considerably, haemophilia remains profoundly under-recognised, a gap she described as her "soft spot." Drawing on the examples of countries where people living with inherited blood disorders are treated free of charge, "Many countries have budgets for sickle cell disorders. Many countries have budgets for haemophilia care," She challenged participants to hold their own government to the same standard.

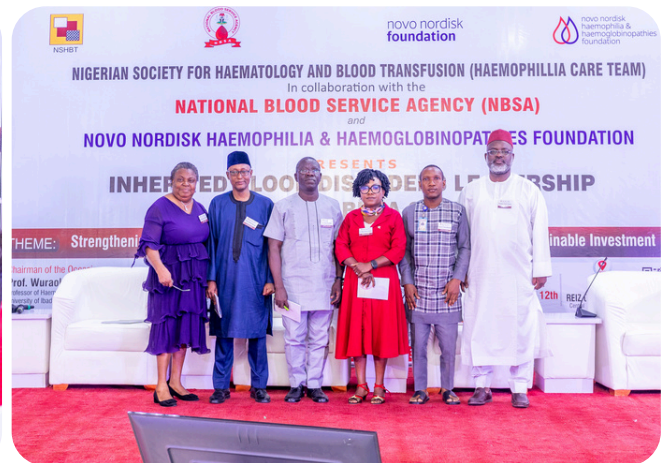


The keynote address was delivered by Professor Alani Akanmu, Professor of Haematology and Blood Transfusion, University of Lagos, who presented a clinical and structural case for decisive, systemic reform. Tracing the history of haemophilia care in Nigeria from its earliest documented cases to the present, he argued that the knowledge and tools to manage both conditions effectively already exist in Nigeria. The barrier is access, cost, and political will. "No one today should die," he said. "What people will die of is lack of access to the current state of knowledge with respect to care of haemophilia."

On sickle cell disease, Dr Akanmu explained the evolutionary relationship between the sickle gene and malaria endemicity and affirmed that while gene therapy represents the horizon of curative care, stem cell transplantation is today's most effective option. He concluded with a framework for the collaborative partnerships he argued are indispensable to progress: government-to-government financing, national insurance integration, hub-and-spoke health system design, civil society advocacy, faith-based community engagement, and pharmaceutical partnership - not donation.

Denise Brændgård, General Manager of the Novo Nordisk Haemophilia & Haemoglobinopathies Foundation, affirmed her organisation's commitment to a partnership model defined by Nigerian stakeholders rather than external agendas. "Our role is to listen, to partner, and to help catalyse the solutions defined by you," she said. Ms Brændgård identified three principles, which she called "the three 'Cs'", as the foundation of meaningful progress: collaboration, coordination and commitment from

## Policy and Systems



While Nigeria has made formal policy commitments, including the incorporation of haemophilia into the National NCD Policy and the passage of the Sickle Cell Bill in 2021, significant gaps remain in implementation, particularly in prevention and control. These gaps are especially reflected in service delivery constraints. All 17 haemophilia treatment centres currently operate exclusively within tertiary hospitals, limiting equitable access to care.

The evidence base for effective intervention is well established: early screening, hydroxyurea therapy, prophylactic factor replacement, and coordinated multidisciplinary care significantly reduce morbidity and mortality. The central challenge for Nigeria lies in translating policy commitments into funded, implemented, and monitored programmes anchored in genuine government ownership and sustained domestic financing. It is against this backdrop that the Inherited Blood Disorders Leadership Forum, Abuja 2026, was convened.

## *Understanding the Burden of Haemophilia and Sickle Cell Disease in Nigeria*

### Sickle Cell Disease in Nigeria



**Professor Obiageli Nnodu,**  
Director, Centre for Sickle Cell Disease  
Research and Training, University of Abuja

Sickle cell disease is a multi-organ condition caused by abnormal haemoglobin that distorts red blood cells and blocks blood vessels, depriving tissues of oxygen. The consequences are severe and lifelong: recurrent painful crises, acute chest syndrome, childhood stroke, avascular necrosis, chronic leg ulcers, kidney damage, splenic crises in young children, and priapism, which can lead to permanent complications. Without preventive treatment and surveillance, many of these complications occur early and carry significant disability and mortality risk.

Nigeria's most reliable national data on Sickle Cell disease (SCD) comes from the 2018 National Demographic and Health Survey, the first to include SCD testing following sustained advocacy. Presented by Professor Obiageli Nnodu, Director, Centre for Sickle Cell Disease Research and Training, University of Abuja, the findings showed a national prevalence of 1.3 percent among children under five, with regional variation reaching up to four percent in some zones. Given Nigeria's population size, this translates into hundreds of thousands of affected children, who face a mortality risk four times higher than their peers, largely due to gaps in diagnosis and treatment. Although hydroxyurea is proven to reduce complications and improve survival, only 13 percent of patients in the national registry receive it, reflecting systemic barriers in access and continuity of care. Available data further indicate that sickle cell disease accounts for approximately 4.2 percent of infant mortality in Nigeria, emphasising its substantial but under-prioritised public health impact.

## The SPARCO Registry and What It Reveals

The Sickle Cell Patients Outcome Registry in Nigeria (SPARCO) was built over eight years by a consortium of researchers and clinicians working across twenty-five sites throughout the country. It holds records for over 10,700 patients, making it the largest sickle cell disease registry in Africa. As a research instrument and an advocacy resource, it is invaluable. But as Professor Nnodu observed during her presentation, "If you look at the age category, you will see that most of our patients are young, very young. We have very few who are over the age of forty-five."

This demographic slant is not a reflection of the age structure of Nigeria's general population. It is a reflection of premature death. People living with sickle cell disease who do not have access to the proper treatment do not routinely survive to middle age in Nigeria. Professor Shokunbi offered a different perspective, recalling a 72-year-old patient who lived for decades with the condition. "We do not celebrate the long survivors of sickle cell disorder," she said, urging greater attention to those who reach adulthood and beyond. Their survival, she argued, deserves to be studied as closely as mortality.

SPARCO also reveals significant gaps in treatment access. Registry data show that only 13 percent of registered patients are receiving hydroxyurea. The data further indicate that most patients present in crisis rather than for routine care, pointing to a system that remains reactive rather than preventive. The registry therefore serves not only as a documentation tool, but as a mechanism for tracking whether this pattern changes over time.

The Sickle Cell Patients  
Outcome Registry in Nigeria

**HOLDS RECORDS FOR  
OVER**



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Sickle cell patients

**13%**  
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*"If you look at the age  
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**>Age 45**

## The Hidden Mental Health Crisis

Presenting findings from a mental health study conducted with researchers at the University of Chicago and embedded within Nigeria's national sickle cell cohort, Professor Nnodu reported that 84 percent of the 241 patients studied were living with significant mental health challenges, including severe anxiety and depression. Some had developed dependence on analgesics to manage chronic pain, and repeated hospitalisations were linked to trauma responses. The findings indicated that the burden of sickle cell disease extends far beyond physical symptoms, yet mental health care remains largely absent from routine treatment pathways.

For many in the room, this was confirmation rather than revelation. Hauwa Audu described the adult experience: "The adult sickle cell warrior is going through a lot. Apart from the normal limitations of adult life, you still have to worry about the limitations posed by sickle cell disorder. At thirty, I never married because I was looking for an AA man."

Josephine Olunaike, who has run a sickle cell welfare clinic in Abuja for seven years, made a direct appeal: "I think the mental health issue is so common with the adults, the teenagers living with sickle cell. We want to plead with the leaders in this forum that every sickle cell centre should have a genetic counselling space — not just for genetics, but for the adults, young adults, people in their menopausal stage, and the mental problems that they have.

## Prevention, Newborn Screening, and the Ethics of Knowledge

The Forum examined strategies for reducing the number of children born with the sickle cell gene, beginning with the biological reality that the gene persists in the population because individuals with the AS genotype have a survival advantage in malaria-endemic settings.

Professor Nnodu cautioned against encouraging individuals with the AS genotype to choose only AA partners. "We need natural selection, not selective mating... And if we do selective mating, eventually you'll find that you have a lot more AS in the population and there are no more AAs to marry." Professor Akanmu reinforced this point, noting that at population level, any meaningful reduction in sickle cell prevalence ultimately depends on sustained malaria control and eventual eradication.

Professor Nora Akinola, Retired Professor of Haematology and Sickle Cell Disease Care Advocate, opened the session on Strengthening Newborn Screening and Early Diagnosis for Sickle Cell Disease in Nigeria with a practical exercise simulating inheritance outcome through a dice roll. She was clear about the ethical boundaries of counselling. “Counselling is non-directional. You are not to judge your clients. You are not to give your own opinion. At the end of the day, if they are both AS, you are not to tell them not to marry.” She added, “We are not marriage counsellors. We are haemoglobinopathy counsellors - giving information and giving them the right to decide for themselves. That is informed consent.”

Subsequent discussions on newborn screening and early diagnosis highlighted both measurable progress and persistent gaps. The Consortium for Newborn Screening in Africa (CONSAR) has screened more than 51,000 newborns in the Federal Capital territory (FCT) and Kaduna State, making it the country’s most structured large-scale screening initiative. However, between 60 to 80 percent of infants diagnosed with sickle cell disease are lost to follow-up due to distance, health system limitations, and parental barriers. Although validated point-of-care testing presents a scalable and reliable pathway for expansion, the growing presence of unregulated testing kits in the market raises serious quality concerns, reinforcing the need for stronger regulatory oversight.

**60 to 80%**

of infants diagnosed with sickle cell disease are **lost to follow-up** due to distance,



**>51,000**

newborns in the Federal Capital territory (FCT) and Kaduna State

**Screened for Sickle Cell Disease**



## The Economic and Productivity Burden

Sickle cell disease imposes significant economic strain not only on individuals, but on entire households. Families frequently incur catastrophic and recurring out-of-pocket expenses for hospitalisations, medications, transfusions, and laboratory tests, often pushing them into financial distress or poverty. As Gabriel James noted, “It’s not easy accessing care because it’s expensive, and it’s more tough on some of us whose families are financially incapacitated.”

Beyond the financial burden, the disease disrupts education, employment, and long-term workforce participation. As Hauwa Audu reflected, “The average warrior needs to thrive, not just survive. We are just like anybody else. We need to live. We need to thrive. But then the pains and limitations are still holding us back.”

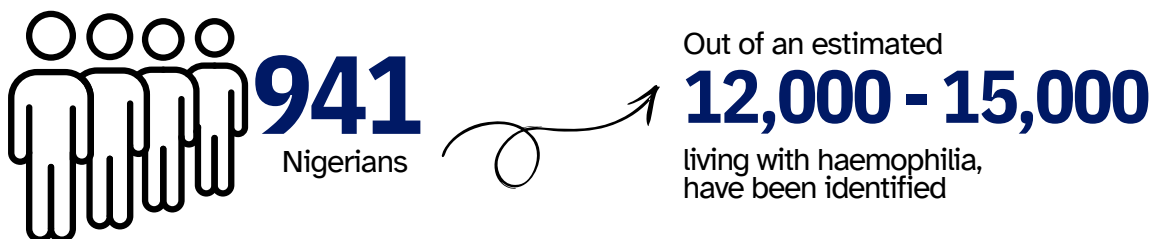
## Haemophilia in Nigeria

Haemophilia is an inherited bleeding disorder caused by the deficiency or dysfunction of specific clotting factors within the coagulation cascade. The most debilitating complication of untreated severe haemophilia is recurrent joint bleeding, known as hemarthrosis. Without prophylactic treatment to prevent these bleeds, a child with severe haemophilia will typically develop permanent, progressive joint disease in multiple joints before the age of ten.



Professor Akanmu described this trajectory, "By the time a haemophilic person is getting to age eight, nine, or ten, he's already crippled because of the recurrent hemarthrosis." However, with prophylactic factor replacement therapy - administered two or three times weekly to maintain circulating factor levels above the threshold of spontaneous bleeding, a child with severe haemophilia can live a near-normal life. He noted that with consistent prophylaxis, "people with haemophilia can actually play football."

Of the two conditions at the centre of this Forum's deliberations, haemophilia remains largely unseen in Nigeria. Not because it is rare, but because, as Professor Titi Adeyemo, Director, Haemophilia Treatment Centre, Lagos, noted, of an estimated 12,000 to 15,000 Nigerians with haemophilia, only about 941 have been identified and registered. This represents a diagnosis rate of approximately six percent, a fraction of the eighty-one percent diagnosis rate achieved in high-income countries. This gap represents thousands of individuals living with an undiagnosed and unmanaged bleeding disorder.



## The Cost of Treatment

The cost of haemophilia treatment in Nigeria is, by any measure, catastrophic for individual families. A single dose of Factor VIII concentrate for an average adult Nigerian with severe haemophilia costs approximately ₦2.8 million. Prophylactic treatment, which prevents rather than manages acute bleeds, requires administration of factor concentrate two to three times per week and costs an estimated US\$620,000 per patient annually at international prices. Even the "demand therapy" model in which bleeds are treated as they occur, runs into hundreds of millions of naira per patient each year at unsubsidised rates.

Every unit of factor concentrate currently reaching patients in Nigeria is supplied through a donation from the World Federation of Haemophilia (WFH). The country does not allocate domestic funding for the treatment of haemophilia. Speaking on what this means in the long-term, Thomas Gowa, Regional Manager, WFH said, "Aid, by its very nature, creates dependency. And humanitarian aid is also guilty of that. Because, in all the countries that we've been providing humanitarian aid, we are not seeing local procurement." In December 2025, that dependency translated into near-complete stockouts across treatment centres nationwide.

## The Diagnosis Gap

### 01

The first gap is awareness at the level of the community, the family, and the clinical workforce. Haemophilia receives little attention in many medical training programmes. Professor Akanmu described reviewing the curricula of several medical schools and finding no mention of the condition. Dr. Odunbvu, Associate Professor and Consultant in Paediatric Haematology, recounted the experience of a relative whose bleeding disorder had been attributed to witchcraft for years and remained undiagnosed until a medically trained family member recognised the signs.

### 02

The second gap is diagnostic infrastructure. Confirming haemophilia requires a factor assay, a laboratory test that measures the level of Factor VIII or Factor IX in the blood. Such testing is not available in many of Nigeria's teaching hospitals and is largely absent from general hospitals and primary care facilities. Over the past three years, the Novo Nordisk Haemophilia & Haemoglobinopathies Foundation's programme has supported the establishment of diagnostic capacity in seven treatment centres. However, in a country of over 240 million people, seven centres represent access for only a small fraction of those in need.

03

The third gap is geographic access. Nigeria has seventeen functioning haemophilia treatment centres; all located in tertiary hospitals. This means that for most Nigerians with haemophilia, particularly in rural areas, there is no accessible treatment centre at all.

04

The fourth gap is cultural context. In parts of Northern Nigeria, the practice of uvulectomy - the removal of the uvula during naming ceremonies, performed by traditional healers - poses a significant risk for children with undiagnosed haemophilia. Circumcision presents similar danger. Boys with severe, undiagnosed haemophilia may experience catastrophic bleeding following these procedures and die before the underlying cause is identified. As Professor Gwarzo, Associate Professor and Consultant Haematologist, stated: "Whether we agree or not, those patients that we are not seeing, the unidentified numbers are likely dying somewhere in the places of the traditional healers."

### The Diagnosis Gap

The ninety-four percent undiagnosed rate for haemophilia in Nigeria indicates points to systemic failures across the entire diagnostic pathway.



Professor Akanmu

01

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## The Haemophilia Foundation of Nigeria and the WFH Partnership

Haemophilia care in Nigeria has been sustained largely through the efforts of the Haemophilia Foundation of Nigeria (HFN), established in 2005, and its long-standing partnership with the World Federation of Hemophilia (WFH). In the absence of structured government programmes, the Foundation supported the establishment of treatment centres, developed a patient registry of 941 diagnosed individuals, and led advocacy, training, and community support initiatives.



Illustrating the life-saving impact of donated treatment, Megan Adediran, Executive Director of HFN, recounted holding her son - a child with haemophilia - and praying for death to end his suffering before donated factor concentrate arrived and changed his prognosis. She also spoke of the broader social consequences: "I have a lot of mothers who are single mothers today just because they have sons with haemophilia. Their families have driven them out." The consequences of unmanaged haemophilia extend beyond

clinical complications; they fracture marriages, destabilise households, and impose profound economic hardship, often borne disproportionately by women.

Since 2006, the WFH partnership has played a significant role in sustaining haemophilia care in Nigeria, expanding access to donated factor concentrates, strengthening diagnostic and clinical capacity, and providing ongoing technical support and professional training. As Professor Gwarzo acknowledged, "We cannot discuss haemophilia in Nigeria in reality without appreciating the Haemophilia Foundation of Nigeria and the WFH. They have been doing a lot. Without them, I don't know where we would have been."

However, the humanitarian model was never designed to be permanent. As Thomas Gowa made clear, the objective is transition to government ownership through domestic systems and sustainable financing - a shift that has yet to happen.

The question of ownership surfaced repeatedly throughout the Forum. In her presentation on "The Past, Present and Future Direction of Haemophilia in Nigeria," Professor Adeyemo addressed it directly: "Our major problem, particularly with haemophilia, is failure of recognition of this disease. It has no mother. It has no father. And the government needs to come and adopt the programme. We can't treat them. And they are dying right in front of us."

## **Systemic Failures: The Gap Between Need and Response**

Delegates at the Forum brought together a combined depth of clinical expertise, research leadership, patient experience, and institutional knowledge. Nigerian haematologists trained internationally; researchers whose work had been published in leading international journals, transplant physicians who pioneered procedures in Africa and patient advocates who built organisations, trained counsellors, and sustained community clinics for decades. Clearly, the scientific and clinical capacity to manage inherited blood disorders in Nigeria is not the problem. The challenge is in establishing the systems and structures required to translate that expertise into accessible, equitable care.

At the centre of this challenge is a governance gap. No government body currently holds a clear mandate, authority, and resources to coordinate the national response to inherited blood disorders. Although haemophilia was included in the 2021 National NCD Policy, implementation has stalled. There is no federal budget line for haemophilia treatment, no finalised national clinical guideline in effect, and no designated coordinating unit within the Ministry with primary responsibility for haemophilia.



**Dr. Alayo Sopekan**

Director and National Coordinator of Non-Communicable Diseases (NCDs), Federal Ministry of Health

Dr. Alayo Sopekan, Director and National Coordinator of Non-Communicable Diseases (NCDs) at the Federal Ministry of Health, stated that the Ministry has developed a national policy on haemophilia and inherited bleeding disorders. The clinical guideline remains in draft form, though he committed to finalising it in 2026.

Sickle cell disease has greater policy visibility - reflected in its inclusion in the NDHS, research investment, and national health strategy documents - but policy recognition has not translated into effective programme management. The Forum repeatedly highlighted the wide gap between well-designed national policies and weak implementation. Dr. Sopekan acknowledged this, noting that without state-level ownership, budget allocations, designated desk officers, and accountability mechanisms, national guidelines remain documents rather than functioning programmes.

## The Financing Architecture and Its Failures

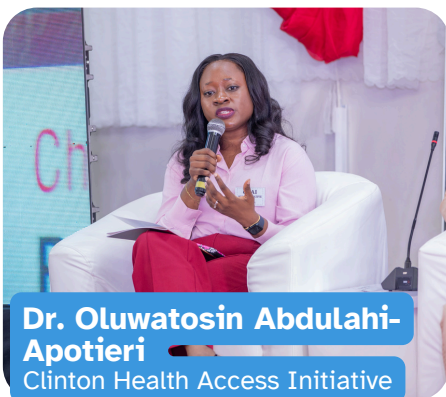
Funding remains a major challenge in inherited blood disorder care in Nigeria. There is no government contribution to haemophilia treatment. For sickle cell disease, care relies on a combination of donor-supported programmes, ad hoc state-level allocations, and an inconsistent national health insurance framework.

Although the National Health Insurance Authority (NHIA) benefit package technically covers enrolled beneficiaries at accredited facilities, significant coverage gaps exist in practice. Essential components of comprehensive sickle cell care, including hydroxyurea monitoring tests, appropriate analgesics, clinically indicated transfusions, and extended admissions during severe crises, are often limited, capped, or denied. Annual admission caps leave patients financially exposed once defined limits are exceeded, while formulary restrictions exclude medications prescribed by specialist haematologists. In addition, mechanisms that allow Health Maintenance Organisations to avoid enrolling chronically ill patients undermine equitable access.



**Dr. Oche Otalú**  
Director, NHIA

As Dr. Oche Otalú, Director, NHIA, acknowledged, “As long as there is out-of-pocket expenditure, there is a gap. Every crisis is a reminder of gaps in coverage, not gaps in medicine.” While the NHIA benefit package is “almost comprehensive” on paper, he noted that it remains misaligned with the chronic, predictable, and high-frequency care needs of people living with sickle cell disease.



**Dr. Oluwatosin Abdulahi-Apotieri**  
Clinton Health Access Initiative

Dr. Oluwatosin Abdulahi-Apotieri of the Clinton Health Access Initiative highlighted a further constraint: the absence of reliable nationwide data. “When we even want to make a case to fund us, to support or provide funding for these programmes, it's very difficult with weak surveillance systems.” Without accurate data on prevalence, service utilisation, per-patient costs, and the economic value of preventive care, neither the NHIA nor the federal government can design an actuarially sound benefit package or justify sustained budget allocations.

Physical infrastructure deficits compound these governance and financing failures. Nigeria's clinical capacity for inherited blood disorders is severely inadequate at all levels of the health system.

For haemophilia, there are only seventeen treatment centres nationwide, all located in Teaching hospitals in major cities. There is no treatment capacity at state General hospital level. For a condition requiring regular factor administration under cold chain conditions, laboratory monitoring, physiotherapy, and orthopaedic support, this concentration amounts to structural exclusion. As Professor Gwarzo observed: "You can imagine somebody moving from Asaba to Benin is a problem. And then when you go to those states that have treatment centres, the treatment centres are all located in the teaching hospitals. For you to travel from one village to another to the Teaching hospital is a problem."

Blood transfusion services in many general hospitals cannot produce cryoprecipitate - the minimum bridge therapy when factor concentrate is unavailable. Kano, a state of eighteen million people, has only one facility capable of producing it. Factor assay testing, required for definitive diagnosis and treatment monitoring, is absent from most teaching hospitals. Professor Shokunbi expressed great distress at the fact that a "Teaching hospital in Nigeria cannot do a coagulation factor assay."

For sickle cell disease, transcranial Doppler (TCD) machines used for stroke surveillance are available in only a limited number of centres. The Novo Nordisk Haemophilia & Haemoglobinopathies Foundation's three-year capacity-building programme equipped seven treatment centres with diagnostic infrastructure. Beyond these sites, significant diagnostic gaps persist.

## **The Workforce Crisis: Three 'R's**

The clinical management of inherited blood disorders depends on a specialised workforce that Nigeria does not currently have in sufficient numbers or equitable distribution. The Forum identified three dimensions of this challenge, summarised by Professor Gwarzo as the three Rs: recruit, retrain, and retain. Each presents a distinct challenge, and weaknesses in one area reinforce failures in the others.

### **Recruitment**

Recruitment into haematology remains constrained by the perception that it is a resource-intensive specialty practiced within a resource-limited system - one in which clinicians can diagnose the problem, understand the appropriate treatment, yet lack the means to deliver it. The psychological toll of witnessing preventable deaths influences both entry into the specialty and long-term commitment to it.

### **Retraining**

Retraining was the dimension of workforce development that the forum addressed most specifically. Nigeria's national task-shifting and task-sharing policy formally endorses expanding the scope of practice for nurses, community health officers, medical officers, and community health extension workers to perform tasks traditionally reserved for specialist haematologists. However, a policy endorsement without a training programme remains a paper commitment. The Forum called on professional bodies, including the Nigerian Society for Haematology and Blood Transfusion (NSHBT), to lead the design and delivery of task-shifting curricula. Professor Gwarzo and other senior clinicians signalled their willingness to contribute without financial compensation if necessary: "We can train most of these people without being paid. But you need to take the lead. You need to identify the manpower."

### **Retention**

Retention remains equally critical. Professor Bazuaye described his experience: "I've trained several doctors in the acts of transplant, but I still remain alone in Nigeria. Because once I finish training, they take off." The Forum therefore called for structured retention packages, protected research time, and sustained investment in centres of excellence to address what must be treated as a national human resource crisis.

These workforce constraints are compounded by a profound subnational gap. Inherited blood disorder care in Nigeria is concentrated almost entirely at the tertiary level. State and local health systems, including general hospitals and primary health centres, where most Nigerians seek care, are largely unable to manage sickle cell disease or haemophilia.

In many rural communities, patients cannot reliably access hydroxyurea, laboratory monitoring, TCD screening, or specialist consultation at local facilities. Many facilities lack physicians and even basic laboratory capacity. According to Dr. Oluwatosin, a Clinton Health Access Initiative (CHAI) assessment conducted in two states found that between seventy and ninety percent of health facilities had no doctor at all, and most were unable to perform a complete blood count.

Alongside the subnational gap, a recurring theme throughout the Forum was what Professor Gwarzo described as fragmentation: the proliferation of NGOs, pilot projects, advocacy initiatives, and community programmes, each undertaking valuable work but without unified governance or a shared national strategy. As one patient advocate observed, “As 100 or 200 NGOs, we cannot be knocking on the government door one after the other. But when we go as a unified voice, we will be listened to.”

This fragmentation extends beyond civil society to the clinical and research community, across hospitals and academic institutions. The absence of shared registries, harmonised training curricula, and a consolidated advocacy platform weakens collective policy influence.

Accordingly, participants called for the establishment of a national consortium grounded in collaboration, coordination, and commitment. As Ms. Braendgaard noted, “If you can come together with a united voice - this is also part of the selection criteria that our council applies when we receive grant applications.”

## ***The Donor Dependency Trap***

Several speakers noted that humanitarian aid, while lifesaving, can inadvertently create conditions for government inaction by substituting for investments that should be domestically financed. Thomas Gowa stated that “Aid, by its very nature, creates dependency. Humanitarian aid is also guilty of that. Because we see in all the countries that we've been providing humanitarian aid, we are not seeing local procurement.” As long as factor concentrate is supplied through the WFH humanitarian programme, there is limited fiscal incentive for government to allocate domestic resources for procurement.

Ms. Braendgaard cautioned against replicating this pattern in sickle cell programming: “There needs to be a way that the countries continue supplying these medications and point-of-care tests when the donations from outside stop.”

Participants proposed that all donor arrangements include clearly defined, time-bound transition plans to domestic financing, supported by accountability mechanisms to ensure follow-through.

## ***The Data Vacuum: You Cannot Manage What You Do Not Measure***

Nigeria lacks the data infrastructure required to manage inherited blood disorders effectively. As Professor Akanmu stated, “What is not counted is never prioritised.” Without a national haemophilia registry, there is no authoritative dataset to guide planning, resource allocation, or financing decisions, leaving advocacy reliant on estimates that policymakers can easily dismiss.

Data systems for sickle cell disease are more advanced through SPARCO and CONSAR, but they remain institution-based and fragmented. There is no fully integrated, real-time national database accessible to policy and decision makers.

The Forum therefore called for the establishment of a government-owned national haemophilia registry, alongside the strengthening and national integration of the SPARCO sickle cell registry under formal government stewardship. Participants pointed to international examples where robust national registries have enabled sustained public investment and improved continuity of care.

## **Lessons From East Africa – The Tanzania Transformation**

When Dr. Stella Rwezaula, Head of the Haematology Unit at Muhimbili National Hospital, Tanzania, and Chair of the Haemophilia Society of Tanzania, described how her country moved from zero to 14 haemophilia treatment centres in four years, established the first bone marrow transplant programme in East and Central Africa, and transitioned from total donor dependence to full government ownership within the lifespan of the initiating grant, it marked a defining moment at the Forum.



**Dr. Stella Rwezaula,**  
Head of the Haematology Unit at  
Muhimbili National Hospital, Tanzania

In 2020, Tanzania had no haemophilia treatment centres and only sixteen registered patients. Suspected bleeding disorder samples were sent abroad for diagnosis, often with fatal delays. There was no national programme, no coordination mechanism, no structured training pipeline, and no system linking specialist care to regional diagnosis and follow-up.

Although sickle cell infrastructure was relatively more developed due to higher prevalence, Tanzania had no coordinated national programme. There was no government ownership, no hub-and-spoke referral network, no structured sub-specialist training, and no system for engaging traditional healers, leaving many patients undiagnosed and outside the formal health system.

In 2021, a grant from the Novo Nordisk Haemophilia & Haemoglobinopathies Foundation launched Tanzania's haemophilia programme. However, the decisive factor was early and deliberate government involvement. As Dr. Rwezaula stated, "From day one we started establishing this treatment centre, we have been involving the government, especially the Ministry of Health." Government officials were embedded in stakeholder meetings and clinic launches, and equipment procurement decisions were made jointly with the Ministry. "We didn't buy any equipment for those centres without involving government. The aim was that the government has the Ministry of Health, so they advised us which machine should we donate to the regional hospital." This approach ensured continuity, when the grant ended, the programme continued.

Muhimbili National Hospital served as the national hub, with regional centres functioning as spokes. Regional clinics focused on services that could be delivered locally - screening, basic diagnosis, follow-up of stable patients, and referral of complications.

Dr. Rwezaula noted that training was the enabling mechanism. “When we launch these clinics, we usually train healthcare providers from district and regional hospitals surrounding that hospital, whether they have capacity to do that or not. So, we train them. They know what to do even if they don't have the machine.” She added that Tanzania trained more than 1,000 healthcare providers across cadres and deliberately engaged traditional healers as referral partners.

By 2025, Tanzania reported fourteen haemophilia treatment centres established within four years and an increase in registered haemophilia patients from sixteen in 2020 to 473. Haemophilia care was incorporated into the national insurance scheme and essential medicines list. A national stakeholder accountability structure was established, bringing together the Ministry of Health, Parliament, the national insurance fund, NGOs, and patient organisations.

At Muhimbili, a functioning bone marrow transplant programme was operational, including twenty-five allogeneic transplants for sickle cell disease and twenty-one autologous transplants. Crucially, government funding and ownership were secured within the lifespan of the initiating grant. Tanzania also entered regional bulk procurement arrangements with Kenya, Uganda, and Rwanda to reduce costs.

Dr. Rwezaula's message to Nigeria was direct: “You have to have a technical working group in the Ministry to make sure that these things are moving at high speed. The government should prioritise blood disorders as a national health agency and stop the reliance on donors. If we work together as Africa, it will help us a lot not to be dependent on the donors.”

As one participant reflected, “In life, at times, things don't become obviously possible until you see somebody do it... I marvel at what we could do that we have not done... what leadership that has the will, the political will, can achieve.”

“

***If we work together as Africa, it will help us a lot not to be dependent on the donors.”***

”

## Collaborative Innovation and Sustainable Partnership

Mr Llyord Mwaniki, Project Coordinator, Africa, Novo Nordisk Haemophilia & Haemoglobinopathies Foundation, reflecting on nearly fourteen years of support for haemophilia care in Nigeria, argued that the most impactful gains over that period have been structural rather than technological - and that sustainable progress depends on system design and domestic ownership rather than isolated projects.

Drawing from continental experience, he highlighted family tree tracing as a practical, scalable case-finding strategy. In Tanzania, structured family tracing significantly accelerated identification, increasing registered haemophilia patients to 472 within three years. The implication for Nigeria was clear: closing the diagnosis gap does not always require expensive population screening; it requires deliberate, systematised identification.

He also pointed to laboratory innovation in low-resource settings, noting how semi-automated coagulation machines and basic factor assays have been deployed effectively elsewhere to expand screening capacity using available infrastructure. Innovation, in this context, means working strategically with existing tools to expand reach.

Beyond technical adaptation, Mr Mwaniki emphasised policy innovation. Sustainable solutions, he noted, must be “home-driven” and anchored in government ownership rather than externally defined models. Welcoming the Forum’s shift toward sustainability, he stated: “We are very happy that the conversation around sustainability has begun. That is the area we would want to play in.”

He reaffirmed continued partnership in active follow-up with Ministries of Health and high-level decision-makers, support for decentralising care, and expansion of programme focus to include sickle cell disease through a structured, nationally aligned initiative. Data systems were identified as central to this effort. “Without good data, we are not able to make the right investment decisions to accelerate care,” he observed, aligning with repeated calls for a government-owned registry infrastructure.

## *Curative Therapies – Bone Marrow Transplant and Gene Therapy In Nigeria*

For decades, care for sickle cell disease in Nigeria focused on managing crises and preventing complications. That paradigm is shifting. Bone marrow transplantation is now practised in Africa, and gene therapy has received regulatory approval in the United States and Europe. The scientific barrier to cure has been crossed. The remaining barriers are structural: financing, infrastructure, workforce capacity, and government ownership.

Nigeria's first stem cell transplant for sickle cell disease was performed in 2011 at the University of Benin Teaching Hospital by Professor G. Nosa Bazuaye. Between 2011 and 2024, fewer than twenty transplants were completed - not because of lack of demand, but because of systemic constraints.

"I was an orphan between 2011 and 2024," Professor Bazuaye stated, describing years without national programme support. "Each one of them was like taking the head of a camel through the eye of a needle."

Although additional centres have since emerged, Nigeria still lacks a national transplant programme, a dedicated public financing mechanism, and a coordinated referral system. As Professor Bazuaye observed, "In a private setting, within five years I've done almost about twenty transplants. In a teaching hospital setup over four years, I could only do three."

He identified the principal barriers to scaling curative therapy: transplants are not covered by national insurance; specialist workforce capacity is limited; infrastructure – including reliable power supply - remains inconsistent; and retention of trained specialists is poor. "I have trained several doctors in the acts of transplant, but I still remain alone in Nigeria." Nigeria now has three transplant centres emerging, preparations for gene therapy are underway, and plasma manufacturing initiatives have begun. The scientific foundation exists.

As Professor Bazuaye concluded: "It has been a long journey, but I think we are making progress... steadily we are getting to our finish line." What remains is political infrastructure: government ownership, national insurance coverage, coordinated referral systems, workforce retention, and sustained financing. Without these, curative therapy will remain isolated excellence.

## Community, Culture, And Stigma – The Invisible Barriers to Care

The session on 'Community Engagement and Advocacy Strategies: Tackling Myths and Stigma' examined how stigma operates through discrimination, exclusion and poor attitudes. Socially, inherited blood disorders may be framed as curses or punishment. Economically, stigma contributes to discrimination in employment and marriage. Within health facilities, patients may encounter poor attitudes and diminished dignity. These dynamics directly affect health-seeking behaviour and treatment adherence.



Ms. Josephine Olunaïke, a genetic counsellor, founder of the Bula Sickle Cell Foundation, and herself a person living with sickle cell disease, identified three myths she has found most damaging in her community work: the belief that people living with sickle cell disease do not live long and cannot expect a meaningful quality of life; the social assumption that they should not expect agency in relationships or marriage; and the persistent spiritualisation of the condition.



Florence Olukokun, a nurse with the Haemophilia Foundation of Nigeria, described how haemophilia is similarly filtered through cultural and religious interpretations - frequently attributed to witchcraft or framed as a spiritual test of fate. These beliefs, she noted, directly delay diagnosis and access to treatment, often until complications become severe. In some households, particularly in polygamous settings, maternal blame becomes entrenched when male children die after circumcision, further compounding stigma and social isolation.

The Forum recognised that harmful interpretations do not exist in isolation - they are reinforced in spaces of trust. Faith institutions, in particular, have a reach the formal health system often does not.



Professor Samson Fatokun underscored the need to address spiritualisation and blame narratives directly from those trusted platforms: "Pastors need to come up on the pulpit and educate the church members very well and let them know that this thing has a natural cause." Structured seminars, collaboration with health professionals embedded in churches and mosques, and consistent evidence-based messaging were proposed.

as scalable channels to reduce stigma and encourage timely care-seeking, correcting misinformation without alienating the communities the health system most needs to reach.

Three approaches emerged as consistently effective in community engagement. The first was lived-experience advocacy: when individuals living well with sickle cell disease or haemophilia speak publicly, they disrupt fatalistic narratives and restore possibility. The second was endorsement by community leaders. As one participant observed, "If we enter a community and we get the aid of that leader, you can be sure that everybody will be around for that talk." The third was patient inclusion in programme design. Florence invoked the principle that "there is nothing about us without us", emphasising the inclusion of patients and caregivers in governance, education, and advocacy.

## **Women and the Social Burden**

Women bear a disproportionate share of the social burden - as caregivers of children with sickle cell disease, as mothers blamed for haemophilia, and as adults navigating stigma in marriage and reproductive decision-making. Fatima Farouk, caring for four children living with sickle cell disease, expressed the emotional toll:

"Sometimes I feel like giving up. But when I give up on them, who will be there for them?"

Her statement underscored a broader reality: caregiving, stigma management, and economic survival often converge on women. The Forum stressed that genetic counselling and psychosocial support must address these lived realities comprehensively - extending beyond reproductive decisions to encompass mental health, social stability, dignity in care, and sustained caregiver support.

Patients who never present for care, whose families interpret illness through spiritual frameworks, or who avoid diagnosis because of shame cannot be reached by clinical services alone. A national response that fails to integrate community actors - faith leaders, traditional authorities, patient advocates, caregivers, and trained peer counsellors - will leave structural gaps unaddressed.

## **Early Diagnosis and Continuous Care: From Identification to Outcome**

If community engagement determines whether patients present for care, diagnosis determines whether they survive. As Dr. Christiana Udo stated, “The management of any disease starts with the diagnosis. Because if you don’t know what you want to treat, how can you treat it?” Effective care begins with accurate diagnosis linked to a functioning referral pathway. Yet in Nigeria, this foundational step fails at scale - and when diagnosis succeeds, continuity often breaks down.



**Dr. Christiana Udo**

## **Newborn Screening: Progress Without Coverage**

Newborn screening for sickle cell disease is one of the most established life-saving interventions in paediatric haematology. Early identification enables penicillin prophylaxis, immunisation, parental education, and structured enrolment into care. Nigeria has invested in screening infrastructure and implementation efforts. However, coverage remains limited, and retention is weak: only an estimated 20–40% of diagnosed infants are successfully enrolled into ongoing care.

For haemophilia, population-level newborn screening is not yet feasible. Immediate priorities are pragmatic case-finding strategies: structured bleeding history before circumcision, training birth attendants to recognise abnormal post-circumcision bleeding, and systematic family tracing from confirmed cases. The Forum’s conclusion was unequivocal: diagnosis without retention is failure.

Screening and diagnosis must be matched by primary healthcare capacity. Nigeria’s task-shifting framework assigns sickle cell services to primary healthcare facilities, but operational capacity remains limited. A CHAI assessment in two states found that 70–90% of PHC facilities had no doctor, most could not perform a full blood count, and 60% of secondary facilities did not provide sickle cell services.

Participants agreed that PHC integration must be realistic and phased. A defined minimum service package - combined with reliable referral pathways - is more viable than assuming comprehensive care can be delivered everywhere without the necessary workforce and diagnostic capacity.

## **Policy And Financing Architecture: Building What Must Last**

Inherited blood disorders sit across three national levels: the NCD framework, the NHIA benefit package, and the Essential Medicines List (EML). While each provides policy recognition, none has been fully activated as an operational instrument. The 2021 NCD Policy recognises haemophilia. The next step is not further recognition, but enforceable instruments. The Forum identified three immediate national deliverables: finalisation and gazetting of the national haemophilia guideline, currently in draft; a national sickle cell standards-of-care document defining minimum service packages at each level of the health system; and a formal national programme structure with a named government lead, a dedicated budget line, and an annual public performance report.

Dr. Alayo Sopekan, National NCD Coordinator, committed publicly to advancing these actions, including finalising the haemophilia guideline, pursuing EML inclusion for hydroxyurea and factor concentrates, and expanding NHIA coverage. EML inclusion is particularly consequential - it shifts medicines from discretionary procurement to system obligation, enabling routine budgeting and NHIA reimbursement.



A recurring theme was that implementation accelerates when demands are framed in quantifiable terms. As Professor Akanmu stated, "numbers talk more than emotions" and "what is not counted is never prioritised." The Forum prioritised development of a government-owned haemophilia registry, designed to integrate over time with existing sickle cell data platforms - not as a research exercise, but as the foundation for planning, budgeting, and financing negotiations.

It enables the economic case government responds to: the cost of unmanaged disease compared with the cost of systematic care. The Forum urged production of policy-ready evidence - disease burden, outcomes under standard interventions, operational bottlenecks, and cost-effectiveness data - positioning inherited blood disorders as financeable programmes with measurable returns.

On financing, the Forum identified NHIA reform as the fastest national lever for reducing catastrophic out-of-pocket spending and standardising access. A proposed model would generate a unique NHIA identifier at diagnosis, allowing patients to access a defined package of services at any accredited facility without repetitive authorisation barriers. For sickle cell disease, the minimum package discussed included

hydroxyurea, monitoring tests, immunisations, transfusions, emergency care, TCD screening, counselling, and transplant eligibility where appropriate. For haemophilia, factor concentrate coverage is essential - without it, haemophilia care remains structurally excluded. Participants highlighted persistent implementation barriers: HMO avoidance of high-cost patients, restrictive formularies, and illegal out-of-pocket charges for covered services. The Forum endorsed strategic purchasing - contracting facilities for comprehensive packages and paying for quality and outcomes rather than fragmented transactions - and called for NHIA to convene a technical working group within six months to define, cost, and implement the benefit package.

Because service delivery is largely state-driven, states must be visibly embedded in the response. The Forum's minimum expectations were straightforward: designate a desk officer, create a budget line, and domesticate the national benefit package through state insurance or equivalent mechanisms. Kano State's AbbaCare programme was presented as operational proof - defined budget support, trained primary healthcare workers, uninterrupted hydroxyurea procurement, and expanding comprehensive services. The Forum's conclusion was that Kano's progress reflects prioritisation and system design, not exceptional wealth. The Nigerian Governors' Forum was identified as the platform for structured best-practice exchange, beginning with budget line creation and formal programme designation in each state.

Dr. Amina Abubakar, representative from Nigeria Governor's Forum provided practical insight into how state-level financing decisions are unlocked. Large, open-ended funding requests tend to fail; structured matching contributions alter the political calculus entirely:

***"When we send a letter saying please release 150 million naira for this project, I promise you they will refuse. But when you send a letter saying this is a 500 million project, partners are providing 420 million, and we are requesting your matching contribution of 80 million - from then, he started releasing the funds."***

She added a reminder that sits beneath all the data: "Beyond statistics, the fundamental thing is that they are human beings first before they are a number." The Governors' Forum signalled readiness to carry the agenda forward - "we have convening power; whatever comes out of this, we are more than willing to take it up there" - and the Forum concluded that this offer should be translated into a structured engagement package combining evidence briefs, costed models, case studies, and selected patient testimonies.

International partners were welcomed, but dependency was firmly rejected. Ms. Braendgaard emphasised coordination and sustainability as grant conditions, noting that fragmented actors are less likely to attract sustained support. Thomas Gowa warned that "we are not seeing local procurement in any of the countries we've been providing humanitarian aid." The Forum proposed a structured transition

mechanism for haemophilia care, including formal timelines for shifting from donated to domestically procured factor concentrate, with local manufacturing - as already demonstrated with hydroxyurea - identified as the long-term sustainability pathway. To address fragmentation, the Forum endorsed the creation of a Nigerian Inherited Blood Disorders Consortium linking government agencies, clinicians, patient organisations, insurers, states, and partners under a unified agenda. Core functions would include a multisector steering structure with government co-chairing; technical working groups delivering defined outputs within six months across clinical standards, benefit design, screening, workforce, and community strategy; biannual stakeholder review meetings; and a shared national data infrastructure anchored in a government-owned registry. A dedicated secretariat, proposed within NBSA, would coordinate implementation and track commitments.

The Forum's final message was direct: coordination must move from endorsement to action immediately. Secretariat designation, steering appointments, and working group activation are the first visible steps. Without them, the agenda risks dissolving into good intentions.

## Recommendations

The Forum concluded that Nigeria's next phase in inherited blood disorder care must move decisively from dialogue to disciplined execution. The following recommendations represent the structural priorities required to translate policy recognition into measurable outcomes.

### 01 Operationalise Government Ownership within the National NCD Framework

Haemophilia and sickle cell disease (SCD) must be fully operationalised through enforceable instruments, not policy recognition alone. This includes gazetting the National Haemophilia Guidelines, publishing a national SCD standards-of-care document, appointing dedicated desk officers at federal and state levels, and instituting annual public performance reporting with measurable targets.

### 02 Strengthen Medicines Governance Through Essential Medicines List Inclusion

Hydroxyurea and clotting factor concentrates must be formally included on the National Essential Medicines List to enable routine procurement, NHIA reimbursement, and structured state-level budgeting.

**03****Establish Ring-Fenced Domestic Financing**

Federal and state governments must create dedicated budget lines for haemophilia and SCD. State-level models such as Kano's AbbaCare programme demonstrate that structured financing and uninterrupted medicine procurement are achievable where political prioritisation exists.

**04****Transition from Donor Dependence to Domestic Procurement**

Nigeria must implement a time-bound transition framework from humanitarian donations to domestically financed procurement of essential medicines and clotting factors. All donor-supported programmes should include sustainability clauses, exit strategies, and government co-investment requirements. Investment in local manufacturing of plasma-derived products and essential medicines should be prioritised.

**05****Expand and Reform Insurance Coverage**

Comprehensive care, including diagnostics, disease-modifying therapy, emergency services, transfusion support, physiotherapy, genetic counselling, and mental health services, must be explicitly defined and funded within NHIA and state insurance benefit packages.

NHIA should guarantee portability of care, enforce compliance among HMOs, prevent discriminatory enrolment practices, and adopt strategic purchasing mechanisms that reward continuity of care and improved outcomes.

**06****Decentralise Service Delivery and Reduce Inequity**

Care must expand beyond federal tertiary hospitals to zonal, state, and secondary facilities. Primary healthcare centres should provide a defined minimum package of SCD services, including newborn screening linkage, hydroxyurea initiation where appropriate, crisis stabilisation, and structured referral pathways.

Structured haemophilia identification pathways, including family tracing and bleeding risk recognition, should be integrated into maternal and child health services. Geographic inequity in access must be treated as a national policy priority.

**07****Strengthen Workforce Capacity and Protect Specialist Investment**

Task-shifting frameworks should extend defined responsibilities to trained primary and secondary healthcare workers, supported by telemedicine and specialist oversight.

Blood disorders nursing should be designated as a recognised specialist area with sustained domestic training provision. Retention strategies are required to protect investments in specialist training and prevent repeated disruption of patient care.

**08****Scale Early Diagnosis and Build a National Data Backbone**

Universal newborn screening for SCD should be scaled nationally, with robust follow-up systems to ensure enrolment in care.

A government-owned national haemophilia registry should be established and integrated with a strengthened SCD registry to support planning, financing, monitoring, and accountability. Advocacy should be evidence-driven, recognising that “what is not counted is never prioritised.”

**09****Integrate Mental Health, Genetic Counselling, and Structured Community Engagement**

Mental health and psychosocial services must be incorporated into comprehensive care and insurance coverage. Every sickle cell centre should include a dedicated genetic counselling space capable of addressing adult mental health, social, and relationship challenges — not solely reproductive counselling.

Adult patients should be trained and incorporated as peer counsellors and programme participants, in line with the principle that “nothing about us without us.” Long-term survivors should be visibly engaged to counter fatalistic narratives.

Formal partnerships with faith bodies, traditional leaders, and community structures should deliver standardised education at scale. Engagement of traditional healers in high-risk settings should be linked to formal referral pathways. Social media strategies should support existing patient-led communities.

**10****Establish a National Coordination and Governance Architecture**

A Nigerian Inherited Blood Disorders Consortium should unify government agencies, professional societies, patient organisations, state governments, insurers, and partners under a shared governance framework with government co-chairing.

Technical working groups should deliver defined outputs within six months across clinical standards, insurance benefit design, screening scale-up, workforce development, and community strategy. A dedicated secretariat anchored within the National Blood Service Agency should coordinate implementation and publicly track commitments.

Expansion of bone marrow transplantation and emerging curative therapies should proceed within sustainable financing structures and be anchored in strong primary care and referral systems.

**11****Strengthen Blood Transfusion Infrastructure**

Blood transfusion infrastructure must be strengthened to enable the provision of cryoprecipitate across facilities as a bridge therapy when clotting factor concentrate is unavailable. The National Blood Service Agency should collaborate with state health authorities to ensure equitable distribution of blood products and standardise the availability of minimum blood components at all levels of the health system.

**Implementation  
Roadmap**

The following phased roadmap sets out the sequence of priority actions required to translate Forum commitments into measurable progress, with implementation tracked through periodic stakeholder review:

- Establish a national technical working group and define timelines for all priority actions.
- Create dedicated budget lines and integrate inherited blood disorder services into national and state insurance packages.
- Pilot decentralised care models in selected states, using task-shifting frameworks and hub-and-spoke referral structures.
- Develop a National Registry for haemophilia and sickle cell disease integrated with a coordinated research agenda to generate policy-ready evidence.
- Monitor progress through periodic stakeholder reviews with public reporting against defined targets.

## Conclusion

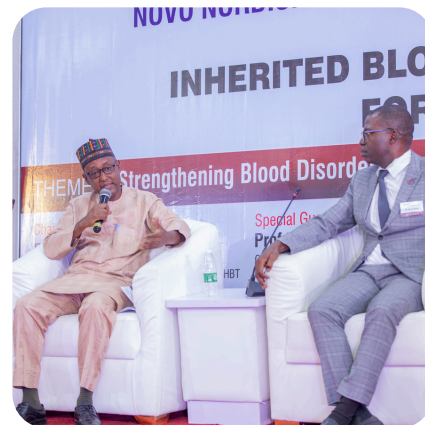
The Forum concluded that Nigeria's challenge is not awareness, but execution. Professor Dalha Gwarzo described the convergence of the "four Ps" - patients, professionals, policymakers, and partners - as a rare alignment that creates a real opportunity for progress, provided efforts remain coordinated. Speakers stressed that progress will depend not only on technical solutions but on how the issue is positioned within political decision-making.

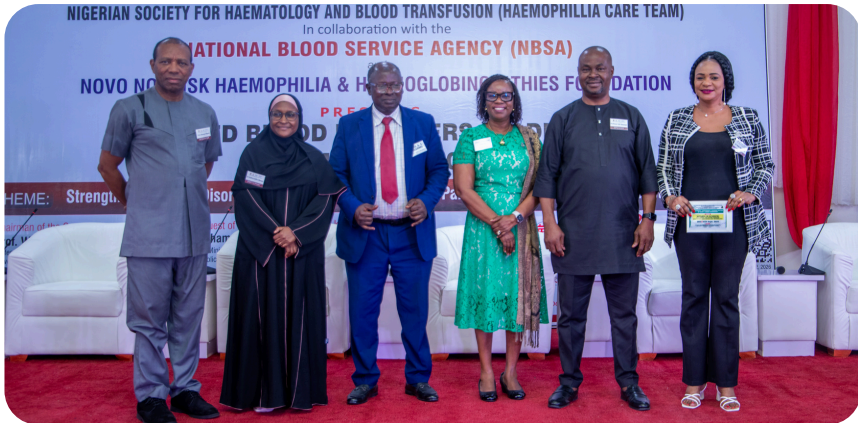


Denise Brændgård and Mr Llyord Mwaniki reinforced the need for a coordinated consortium model and a “united voice” to sustain momentum and partnership. From the Nigerian Governors’ Forum, Dr. Amina Abubakar offered practical guidance on effective subnational engagement. She stressed that advocacy must be “concise and very straight to the point,” noting that funding requests succeed when they are specific, costed, and framed as shared investments. She also emphasised the importance of reliable data, reminding participants that “we can’t manage what we don’t measure.” The Governors’ Forum signalled readiness to elevate the issue nationally, stating that it is willing to take forward structured proposals emerging from the Forum.

Three commitments emerged from the closing session: establishing the National Inherited Blood Disorders Consortium with government co-chairing and active technical working groups; launching the national haemophilia registry as the data foundation for planning and financing decisions; and converting Forum outcomes into enforceable policy instruments backed by budget lines.

The Forum therefore closed with a clear direction to translate these commitments into enforceable programmes and budget lines, strengthen national data systems to support advocacy and financing, and institutionalise coordination so that collaboration extends beyond the Forum itself.





## Communiqué

At the close of the Forum, participants issued the following communiqué outlining the shared principles and institutional commitments of the meeting.

### **Inherited Blood Disorders Leadership Forum | Abuja, Nigeria | 2026**

ORGANISED BY THE NIGERIAN SOCIETY OF HAEMATOLOGY AND BLOOD TRANSFUSION (NSHBT) AND THE HAEMOPHILIA FOUNDATION OF NIGERIA (HFN)  
IN COLLABORATION WITH THE NATIONAL BLOOD SERVICE AGENCY AND THE NOVO NORDISK HAEMOPHILIA & HAEMOGLOBINOPATHIES FOUNDATION

**Theme:** Strengthening Blood Disorder Care Through Collaboration, Partnership, and Sustainable Investment

#### Preamble

Participants at the Inherited Blood Disorders Leadership Forum convened in Abuja over two days in 2026, bringing together representatives from federal and state government institutions, clinicians, researchers, patient advocates, development partners, and community organisations. This communiqué records the key findings, shared principles, and institutional commitments that emerged from the meeting.

Nigeria bears the world's highest burden of sickle cell disease, with an average prevalence of 1.3 percent among children nationwide and up to four percent in some regions. Haemophilia affects an estimated 12,000 to 15,000 Nigerians, yet fewer than six percent have been diagnosed. Both conditions continue to impose a significant burden of illness and preventable deaths. Yet both are preventable, manageable, and cost-effective to treat when supported by functioning health systems.

This forum marks the first time in Nigeria that stakeholders working on sickle cell disease and haemophilia - from government, clinical, research, patient, and philanthropic sectors - have come together to examine the national situation and commit to a coordinated response.

## Consensus Principles

Participants reached consensus on several guiding principles for strengthening inherited blood disorder care in Nigeria:

### **Inherited blood disorders are treatable conditions.**

With early diagnosis, appropriate treatment, and structured systems of care, people living with these conditions can live full and productive lives.

### **Collaboration is essential.**

No single institution or sector can address these challenges alone. Progress will require coordinated action across government, healthcare institutions, civil society, patient organisations, and development partners.

### **National coordination is required.**

Participants recognised the need for a coordinated national platform to align government agencies, clinicians, patient organisations, and partners. Establishing a Nigerian Inherited Blood Disorders Consortium was identified as a mechanism to strengthen collaboration, support policy implementation, and sustain accountability across stakeholders.

### **Sustainable investment is critical.**

Humanitarian support has saved lives, but long-term progress will depend on government ownership, domestic procurement of essential medicines, and institutionalised public financing.

### **Subnational governments are central to implementation.**

Much of Nigeria's health spending occurs at the state level. Federal policy must therefore be matched by state-level commitment, including budget allocations and programme implementation.

### **Data must guide decision-making.**

Reliable registries, surveillance systems, and locally generated evidence are essential for planning services, mobilising financing, and sustaining government commitment.

### **Patients must remain at the centre of the response.**

People living with inherited blood disorders and their representative organisations must be actively involved in designing and implementing programmes that affect their lives.

### **Regional experience demonstrates what is possible.**

Experience from Tanzania demonstrates that rapid progress, establishing haemophilia treatment centres, strengthening sickle cell services, and securing government ownership can be achieved when strong political commitment is combined with coordinated implementation.

## ***Specific Commitments Recorded at this Forum***

The following commitments were publicly made during the Forum and are recorded here to support accountability:



### **Federal Ministry of Health** (Dr Alayo Sopekan, Director, NCDs)

Clinical Guidelines for Inherited Bleeding Disorders will be finalised in 2026. Haemophilia will be integrated into the National NCD Programme, and a dedicated NCD desk officer for inherited blood disorders will be established within the Ministry.



### **National Blood Service Agency** (Prof Saleh Yuguda, Director General)

The Agency reaffirmed its commitment to supporting haemophilia and sickle cell disease care through its mandate, including advocating for budget allocation for factor concentrates and cryoprecipitate, and supporting registry development and service coordination.



**Novo Nordisk Haemophilia & Haemoglobinopathies Foundation**  
(Denise Brændgård, General Manager)

The Foundation will expand its support to include a sickle cell disease programme in Nigeria, developed in partnership with Nigerian stakeholders. All programming will incorporate government co-ownership and a transition to domestic sustainability from inception.



**Nigerian Governors' Forum**

Dr Amina Abubakar. Representative from Nigeria Governor's Forum

The Forum will use its convening platform to take forward the recommendations of this communiqué to state governors, advocating for dedicated budget lines and ring-fenced allocations for sickle cell disease and haemophilia.



**Forum Organising Committee**  
(Prof Dalha Gwarzo)

Action points emerging from the Forum will be itemised, assigned timelines, and tracked through a monitoring framework designed to measure progress against the commitments made.



## Closing Declaration

Participants concluded the Forum with a shared commitment to sustain the urgency and momentum generated by the meeting.

### **We reaffirm that:**

- Every Nigerian living with sickle cell disease or haemophilia deserves dignity, access to care, and the opportunity to live a full life.
- The knowledge, technology, and expertise required to manage these conditions already exist. What has been lacking is coordinated and sustained national commitment.
- Inherited blood disorders must no longer remain invisible in policy discussions, absent from public budgets, or neglected within the health system.



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