THE REPUBLIC OF UGANDA
MINISTRY OF HEALTH

TERUMO
BLOOD AND CELL
TECHNOLOGIES

JCRC
Joint Clinical Research Centre

imara
Sickle Cell Framework

IMARA 2026:

FROM AWARENESS TO ACTION

IN SICKLE CELL DISEASE CARE

20th July 2026:



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Executive Summary

A Proven Foundation for Scale

Sickle cell disease (SCD) is a major inherited blood disorder and a persistent public health challenge across sub-Saharan Africa. The IMARA Programme, supported by Terumo Blood and Cell Technologies, is demonstrating how an integrated, multi-stakeholder approach can strengthen SCD systems across countries while adapting implementation to national and local contexts.

The Challenge

The challenge is not the absence of effective interventions. SCD can be identified early and managed effectively. The fundamental challenge is fragmentation. Screening may occur without reliable linkage to care. Diagnosed patients may face barriers to medicines. Facilities may lack laboratory and blood transfusion capacity. At the community level, limited awareness delays diagnosis and care-seeking. At system level, insufficient data and coordination make it difficult for governments and partners to plan, finance, and scale effective responses.

The Response

IMARA was created to change this paradigm. It is a multi-country initiative designed to elevate SCD as a public health priority and demonstrate how a comprehensive care pathway can be integrated within existing health systems. Initially implemented in Uganda, Kenya, and Côte d'Ivoire, the programme brings together Ministries of Health, healthcare providers, laboratories, blood services, patient organizations, researchers, and implementation partners around a shared vision.

Early Results (2026)

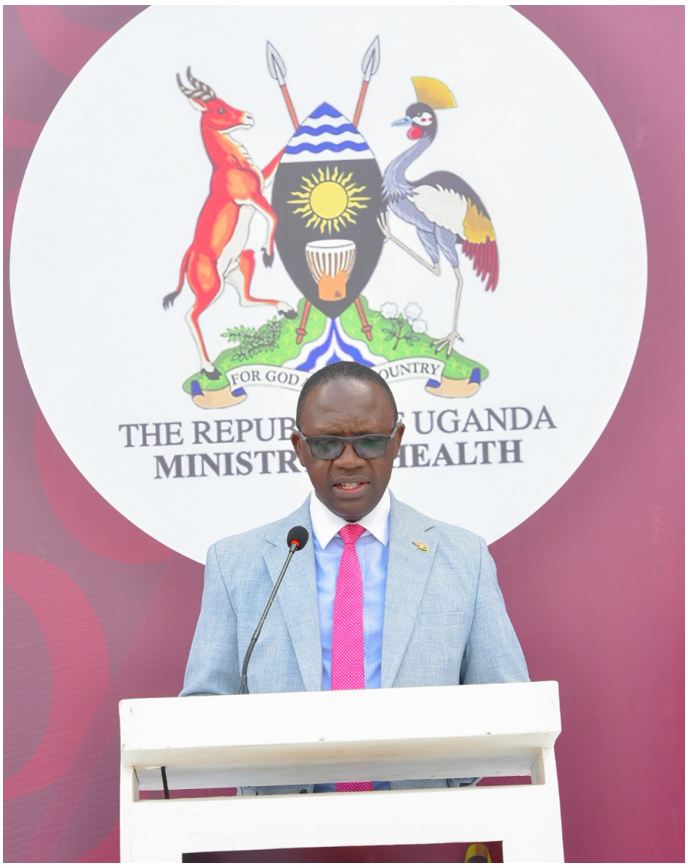
In 2026, IMARA generated early evidence from Uganda and Kenya. The programme combined community awareness, screening, identification of people living with SCD and sickle cell trait, linkage to care, treatment continuity, blood-system strengthening, scientific engagement, and policy partnership.

Across both countries, IMARA demonstrated that SCD interventions can be delivered through schools, technical institutions, markets, churches, and health facilities creating multiple entry points for underserved populations.

The Opportunity

The next investment opportunity is to move from successful campaigns to sustained, decentralized, and nationally scalable SCD systems. This includes expanding early and newborn screening, strengthening diagnostic and laboratory systems, improving linkage and retention in care, increasing access to hydroxyurea and advanced therapies, strengthening blood availability, building data and learning systems, and institutionalizing community engagement and patient-centered care.

The evidence generated in Uganda and Kenya provides a strong foundation for this next phase of regional scale-up.



Dr. Daniel Kyabayinze (Guest of Honor)
At World Sickle Cell Day Celebrations

Why Imara Matters

The Sickle Cell Disease Challenge

Sickle Cell Disease (SCD) is one of Africa's most significant inherited health challenges and one of its most under-recognized public health priorities. Sub-Saharan Africa carries the greatest global burden of SCD, with hundreds of thousands of children born with the disease each year. Yet in many countries, SCD remains inadequately integrated into national health priorities, financing and service delivery. The result is a persistent burden of preventable pain, severe anaemia, infections, stroke, organ damage, recurrent hospitalization and premature death among children and adults living with the disease.

The challenge is not the absence of effective interventions. SCD can be identified early and managed effectively when people have access to timely diagnosis, comprehensive care and essential medicines and services. Newborn and community screening can identify affected individuals before severe complications develop. Early linkage to care enables prevention, routine monitoring and timely treatment. Hydroxyurea and other disease-modifying approaches can reduce complications and improve quality of life. Reliable blood supplies are essential for patients requiring transfusion, while laboratory and diagnostic capacity, genetic counselling, patient education and effective referral systems are critical to lifelong care.

The fundamental challenge is fragmentation. The solutions exist but often not connected. Screening may occur without reliable linkage to care; diagnosed patients may face barriers to medicines; facilities may lack laboratory and blood transfusion capacity; and patients with complex complications may have limited access to specialized services. At the community level, limited awareness further delays diagnosis and care-seeking. At system level, insufficient data and coordination make it difficult for governments and partners to plan, finance and scale effective SCD responses.

IMARA Programme: was created to change this paradigm.

IMARA is a multi-country initiative designed to elevate SCD as a public health priority and demonstrate how a comprehensive SCD care pathway can be integrated within existing health systems. Initially implemented in Uganda, Kenya and Côte d'Ivoire, the programme brings together Ministries of Health, healthcare providers, laboratories, blood services, patient and community organizations, researchers, implementation partners and other stakeholders around a shared vision for transforming SCD care.

At inception, memorandums of understanding were signed with participating countries Ministries of health.

Rather than creating parallel structures, IMARA strengthens and connects existing systems. Its approach brings together community awareness and engagement, newborn and population screening, early diagnosis and linkage to care, routine clinical management, diagnostics, hydroxyurea and other essential medicines, safe blood and transfusion services, referral and specialized care, data systems, research, advocacy and policy engagement as components of one integrated patient pathway.

The programme operates across primary, secondary and tertiary levels of care, bringing prevention and early detection closer to communities, strengthening routine management at appropriate health facilities, and improving referral for complex disease. Cross-cutting investments in workforce capacity, diagnostics, commodities, blood systems, data, stakeholder coordination and financial governance are intended to create sustainable capabilities within national health systems.

The 2026 implementation period marks an important transition from strategy to action. Across the programme countries, IMARA is translating the framework into tangible interventions, including community awareness, population and facility-based screening, linkage to care, hydroxyurea access, blood donation and transfusion-system strengthening, diagnostic capacity and multi-stakeholder engagement. These early achievements

demonstrate the potential of coordinated action to bring SCD services closer to communities and strengthen continuity of care.

IMARA is therefore more than a disease-specific project. It is a platform for health-system strengthening, evidence generation, coordinated investment and national scale-up. With sustained support from governments, international partners, foundations and the private sector, IMARA can build on its early successes to expand access, strengthen national systems and generate evidence for wider African adoption helping ensure that SCD is identified earlier, treated more effectively and no longer remains a neglected cause of preventable death and disability.

The Multi-Country Initiative: MOU signing with the partner Countries



JCRC Uganda, Terumo sign MOU.



Uganda Advisory Board Meeting



Terumo, Ministry of Health Côte d'Ivoire sign MOU.



Terumo, Ministry of Health Kenya sign MOU.

IMARA Programme: From Campaign to System

The formal launch of the IMARA Programme in June 2026 marked an important transition from episodic sickle cell disease (SCD) campaigns toward a coordinated, systems-based response across Uganda, Kenya and Côte d'Ivoire.

IMARA brings together early identification, community engagement, linkage to care, treatment continuity, blood-system strengthening, evidence generation and multi-stakeholder partnership connecting activities that are often delivered separately into a more integrated continuum of SCD care.

2026 AT A GLANCE

16,000
People screened in Uganda

205
HbSS cases identified in Uganda

2407
People screened in Kenya

2, 176
Infants screened across Uganda (634), Kenya (1542)

776
Hydroxyurea refills provided across three major Uganda facilities

738
Blood units mobilised across Uganda (91) and Kenya (647)

1,986
Registrations for the Uganda scientific symposium

During the WSCD Commemoration in Kenya, registration with the Social Health Insurance Fund (SHIF) was carried out to foster financial protection, of which 32 people living with SCD were registered

WHAT THE 2026 PROGRAM DEMONSTRATED

EARLY IDENTIFICATION

In Uganda, 16,000 people were screened, with 205 HbSS cases identified. In Kenya, 2361 people were screened, identifying 110 HbSS/probable HbSS cases, 258 with sickle cell trait (AS) and 03 with AC genotype.

COMMUNITY DEMAND AND ENGAGEMENT

Uganda reached communities through 20+ outreaches, media engagement, VHTs, schools, faith-based and market structures. Kenya extended engagement to institutional and community settings including Bunyala TVET,Mombasa,Nairobi, USIU-Africa,Taita Taveta and Kilifi counties.

INFANT SCREENING

2219 infants were screened in Uganda and Kenya, demonstrating the potential to embed early-life identification within routine health-system approaches.

TREATMENT CONTINUITY

Uganda provided 776 hydroxyurea refills across three major facilities, demonstrating the importance of linking identification with continued access to disease-modifying treatment.

FACILITY-BASED CARE AND LINKAGE

Screening was integrated with hospitals and HC IVs, with referral and linkage pathways designed to connect individuals identified through community and facility activities to appropriate SCD care.

BLOOD-SYSTEM STRENGTHENING

Uganda mobilized 91 blood units through a targeted drive with Uganda Blood Transfusion Services (UBTS), while Kenya collected an additional 647 units, demonstrating the programme's regional contribution to strengthening blood availability for people living with SCD.

SCD IDENTIFICATION AND SOCIAL PROTECTION

During the WSCD Commemoration in Kenya, registration with the Social Health Insurance Fund (SHIF) was carried out to foster financial protection, of which 32 people living with SCD were registered

EVIDENCE AND LEARNING

The Uganda programme convened a scientific symposium with 1,986 registrations and 592 attendees, creating a platform for evidence sharing, professional learning and dialogue on strengthening SCD services.

PARTNERSHIP AND POLICY ENGAGEMENT

Both Uganda and Kenya launches were led by the Ministries of Health, bringing together government, clinical, private-sector and civil-society partners.

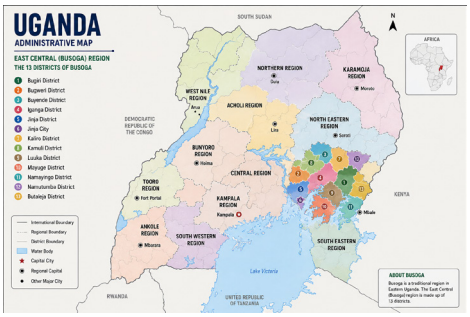
The value of IMARA is therefore not simply the number of people screened. Its distinctive contribution is the architecture created around those individuals connecting community awareness and case-finding to confirmatory diagnosis, counselling, registration, linkage to care, treatment, blood support, health financing and longer-term follow-up.

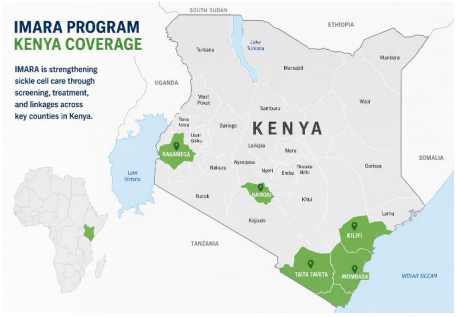
The 2026 results from Uganda and Kenya demonstrate the potential of this model to move SCD programming beyond isolated campaigns toward a sustainable continuum of care embedded within national health systems. By combining community-level demand generation with facility strengthening, blood-system interventions, treatment continuity, social protection, evidence generation and government leadership, IMARA provides a platform for scaling equitable SCD services across participating countries.

The programme's emerging regional experience also creates an opportunity to generate cross-country evidence on what works, where implementation gaps remain, and how proven approaches can be institutionalised and financed for long-term impact.

Geographical reach of IMARA Programme







Community Awareness and Demand Generation

Community awareness was deliberately designed as a multi-channel intervention. Radio was the principal mass communication platform, complemented by television, Village Health Teams, religious leaders, market leaders, school administrations, district leadership and community structures.

Key messages emphasized knowing one's SCD status, availability of free screening, benefits of early diagnosis, linkage to treatment and follow-up, trust in the health system and early health-seeking behaviour.

This approach helped generate demand before services arrived. It also created community ownership: schools mobilized learners, VHTs mobilized households, faith leaders supported participation, and district structures coordinated implementation. For scale-up, this demand-generation architecture offers an immediately adaptable model for integrating SCD into routine community health systems.

Awareness / mobilization channel	Documented output
Radio talk shows	3 KBS shows in Kamuli; 2 Bridge FM shows in Jinja; Eye Radio engagement in Iganga
Television	Baaba TV and NBS National TV coverage
Community structures	VHTs, religious leaders, market leaders and school administrations engaged
Geographic reach	9 districts
Community outreach platforms/ Markets, places of worship	20+
Schools	15+



IMARA Program team, local district authorities, and the Central Public Health Laboratory (CPHL), Ministry of Health, during a sensitisation campaign.



Community Awareness Campaign In Jinja City On Sickle Cell Disease

Community and School-Based Screening

School-based screening was a central pillar of the IMARA. It enabled the programme to identify individuals at risk of sickle cell disease (SCD) and sickle cell trait outside conventional health-facility settings. In Uganda, 16,000 individuals were screened, with school-based outreac h accounting for the largest proportion 10,784 people (67.4%). The approach leveraged school assemblies, coordinated mobilization and existing education structures to reach large numbers of adolescents efficiently. ti-channel intervention. Radio was the principal mass communication platform, complemented by television, Village Health Teams, religious leaders, market leaders, school administrations, district leadership and community structures.



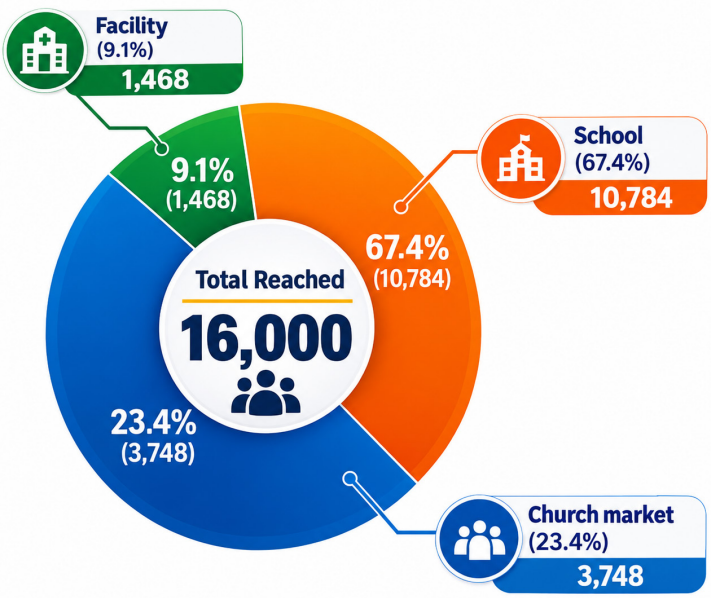


SCD screening at school premises.

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Schools reached included Iganga High School, Nakavule SS, Bukoyo SS, Jinja SS, PMM Girls, Mother Kevin SS, Iganga Town View, Iganga Progressive School, Iganga Parents School, Top Care SS, Alhijr School, Bukembe Islamic SS, Jinja Vocational, St Eliza, Mpumude High School and others.



Community, Market and Faith-Based Screening

In Uganda, 3,552 people (23.4%) of all individuals screened) were reached through church, market and community-based platforms. These approaches extended screening beyond formal institutions and enabled the programme to reach traders, working adults, mobile populations and other individuals who may not routinely access health facilities.

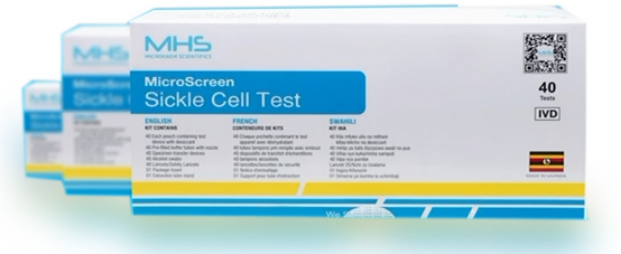


SCD screening in Iganga Market.

Kenya further expanded the community-based screening model through strategic partnerships and institutional outreach. The Bunyala TVET screening in Busia County reached 221 individuals, while the three-day USIU-Africa campaign reached 296 individuals and 265 reached in Kakamega. To support the early identification of SCD, the Africa Sicke cell Organisation (ASCO) screened 1579 individuals of which 1542 were infacts and newborns. This was made possible through procurement of 2000 test kits distributed across facilities in Taita Taveta and Kilifi counties.

Importantly, the Kenya activities demonstrated that screening can serve as an entry point not only for determining sickle cell status but also for identifying people who already know they are living with SCD and connecting them to health and social protection systems.

Taken together, the Uganda and Kenya experiences show that the IMARA model is adaptable across diverse community contexts where people live, learn, worship, work and gather. This diversification reduces dependence on facility-based services and increases the probability of reaching underserved and previously untested populations.



In Uganda,the MicroScreen test kits were used for community screening.

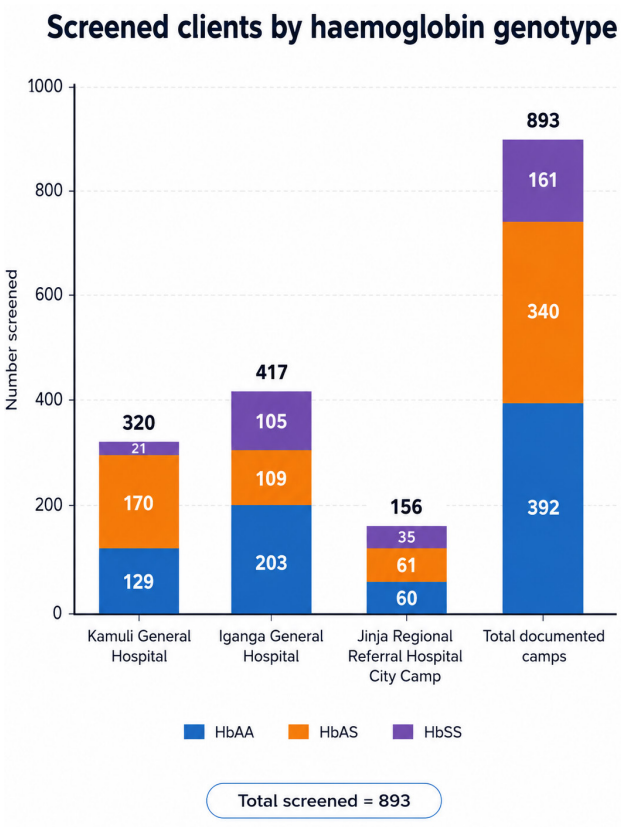


Community activities ongoing in Kenya.

Facility-Based Screening and Medical Camps

Facility-based screening complemented community outreach. It created a direct bridge from diagnosis to clinical care. Across the major facility camps at Kamuli General Hospital, Iganga General Hospital and Jinja City in Uganda, 896 people were screened.

The facility camps showed particularly high diagnostic yield among care-seeking populations. Importantly, screening was not separated from care: individuals with SCD were counselled and linked into established clinical pathways, while known patients received treatment refills.







Participants waiting in the tent to be served at the Kamuli camp.

Infant Screening: Building the Earliest Entry Point

Infant screening is central to changing the natural history of SCD because it identifies affected infants before severe complications develop. The campaign generated practical implementation evidence that newborn screening can be integrated into existing facility service points.

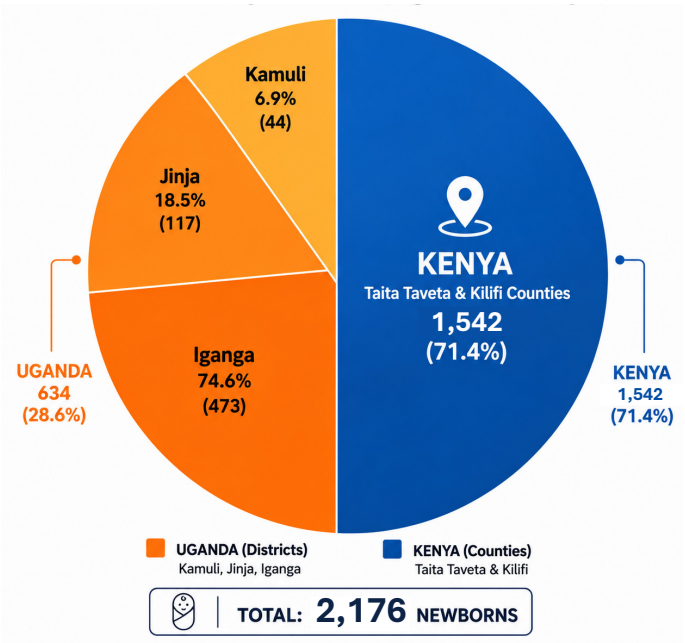
The component was integrated into facility-based services, particularly in high-volume facilities where maternal, neonatal and child health contacts already exist. This provides an important platform for future national scale-up.

In Uganda, a Gazelle diagnostic machine was donated to Iganga Hospital by Raising Hope International to support continuity of the screening initiative. The experience reinforces a key IMARA principle: investment in equipment is most valuable when paired with trained teams, commodities, referral pathways, data systems and routine service integration.



Gazelle machine used during the campaign

Newborn screening represents one of the clearest opportunities to generate long-term population health impact because it shifts the response from late diagnosis to prevention of avoidable complications from infancy.





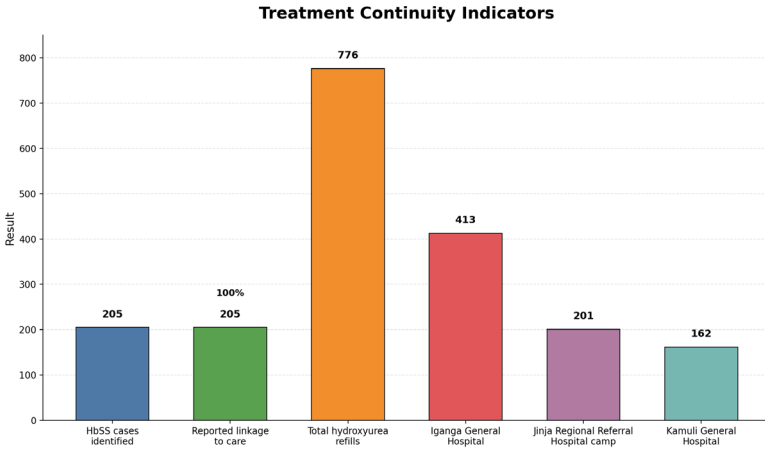
Infant screening during a facility based camp in Uganda



Infant SCD screening during a community outreach in Kenya

Linkage to Care and Hydroxyurea Continuity

The campaign deliberately connected screening with care. All 205 HbSS cases identified through the campaign were reported as successfully linked to care through established facility networks. Facility-based screening achieved near-complete immediate enrolment because diagnosis occurred at clinical service points.





The 776 refills represented two-month supply cycles and helped protect continuity for patients already enrolled in chronic care. The scale of demand illustrates both the value of hydroxyurea and the importance of reliable procurement and decentralized distribution.

The IMARA opportunity is to institutionalize this cascade: identify early, confirm diagnosis, counsel, enroll, initiate or continue hydroxyurea where indicated, monitor, prevent complications,and retain in lifelong care.

Blood Systems Strengthening: Mobilizing Blood for SCD Care

Blood transfusion is an essential component of comprehensive SCD management, particularly for individuals experiencing severe anaemia and other complications requiring transfusion. Under IMARA, blood-donation activities in Uganda and Kenya demonstrate the programme's ability to link community engagement with practical strengthening of blood availability.



In Uganda, a targeted blood donation drive was conducted at Jinja College in June 2026, in collaboration with Uganda Blood Transfusion Services (UBTS), generating 91 units of blood. In Kenya, IMARA-supported blood donation activities generated an additional 647successful blood units 56 pints collected during the 19 June Busia activity and 160 units collected during the July USIU-Africa campaign. In Taita Taveta and Kilifi, 431 units were also collected.

> ***"Combined Uganda–Kenya output: 738 blood units mobilized/collected."***

The blood-donation component demonstrates how a single community engagement platform can simultaneously increase SCD awareness, facilitate screening and generate urgently needed blood supplies. The Kenya experience further demonstrates the potential for multi-stakeholder and youth-focused donor mobilization, while the Uganda experience illustrates integration with the national blood-transfusion system
For future IMARA investment, the blood component provides an opportunity to move beyond episodic blood drives toward sustainable regional blood-system strengthening, including voluntary donor mobilization and retention, improved availability and distribution of blood, transfusion safety, strengthened links between SCD services and blood-transfusion services, and, where appropriate, development of capacity for advanced transfusion services such as red-cell exchange for people living with severe SCD complications.



Blood donation drive at United states International University (USIU Africa) conducted by Children Sickle Cell Foundation.

Scientific Symposium: Evidence Driving Action

Symposium metric	Result
Registrations	1,986
Physical attendance	53
Unique virtual Zoom viewers	539
Total attendance	592
Countries represented	**Uganda, Kenya, Tanzania & other international participants**

The Sickle Cell Scientific Symposium was held on 16 June 2026 in Kampala as a major pre-commemoration event. It created a bridge between research evidence, clinical practice, policy and programme implementation.

Four thematic sessions addressed epidemiology and basic science; treatment advances; testing, care and policy; and the cure agenda. The symposium highlighted evidence on hydroxyurea, newborn screening, blood safety, AI-enabled screening, district-level care, community advocacy and future advanced therapies.

The meeting generated ten strategic priorities for 2026–2030: univer sal newborn screening; universal hydroxyurea access; decentralized comprehensive care; strengthened blood services; infection prevention; brain health and stroke prevention; registry and surveillance; sustainabl e financing; research and innovation; and future readiness for advanced therapies.

This evidence to-action platform is a critical part of IMARA because sustainable scale requires more than service delivery it requires learning, policy influence and a pipeline of locally generated evidence.



The Director General officially opened the symposium, framing it as a critical pre-activity leading to World Sickle Cell Day on June 19, 2026.



Presenters and participants who attended physically pose for a photo at the symposium



Dr. Ssali Francis giving a presentation on red blood cell exchange at the scientific symposium



Physical attendance at the scientific symposium

Ministry of Health Leadership and Multi-Stakeholder Partnership

IMARA's early achievements were enabled by an unusually broad partnership architecture. The Kenya and Uganda Ministries of Health provided national leadership, policy guidance and oversight, while district health offices and local governments coordinated implementation. The JCRC provided programme coordination and technical leadership.

Partner group	Contribution
Ministry of Health	National leadership, policy alignment and strategic oversight
JCRC	Technical leadership, programme coordination, implementation and data stewardship
Terumo Blood Cell Technologies	Technical, logistical and supplementary support
District Health Offices / Local Governments/ County departments of Health	Planning, coordination and community mobilization
Jinja RRH, Iganga GH, Kamuli GH and other facilities	Clinical services, screening and linkage
Central Public Health Laboratories (CPHL)	Laboratory support, quality assurance and commodities
Clinton Health Access Initiative (CHAI)	Logistic and Technical support to scientific symposium
Baylor Uganda	Hydroxyurea supply and treatment continuity support
Micro Heam	Provision of community testing kits
Nicosam	Provision of sickle cell disease testing during blood drives and facility confirmation testing
Uganda Blood Transfusion Services and Kenya Tissue and Transplant Authority (KTTA)	Blood donation coordination and supply strengthening
Raising Hope International	Community mobilization, advocacy and screening support
Private-sector diagnostic partners	Testing commodities, technologies and laboratory innovation
Civil society / patient groups such as, Sickle Cell Alliance Uganda,Don Amolo Memorial Kids Ark (DAMKA). The Africa Sickle cell Organisation (ASCO) and Children Sickle Cell Foundation (CSCF).	Advocacy, lived experience and community accountability
Busoga Health forum	Community awareness and Health care provider capacity building
Busoga kingdom	Community mobilization and awareness

World Sickle Cell Day and Official IMARA Launch

The World Sickle Cell Day commemoration brought together 133 officially registered participants and more than 700 students, demonstrating broad stakeholder ownership. Representation included MOH, district leadership, referral facilities, implementing partners, private-sector companies, UBTS, academic groups, patient advocates, cultural and religious leaders and media.



Dr. Andrew Balyeku, Busoga kingdom Minister oF Health delivering a speech at WSCD

The significance of the launch is strategic: it provides a recognized framework around which international donors, private-sector partners, government and implementing organizations can align investment rather than supporting fragmented activities.





Dr Daniel Kyabayinze,Ministry of Health Uganda deiivering a speech at the Commemoration.

The programme highlighted lived experiences of people affected by SCD, cultural performances, technical presentations, partner exhibitions and public education. The IMARA launch positioned SCD as a shared national development challenge requiring government leadership and sustained partnership.



Kenya launches the IMARA Framework Kenya in Busia during the WSCD Commemoration on June 19 2026







Uganda launches the IMARA Framework in Jinja during the WSCD Commemoration on June 19 2026



Warriors performing at the world sickle cell day



Guests touring the exhibitors.



JCRC and Terumo team at the Exhibition booth



Microheam team show casing their SCD Kits.



Don Amolo Memorial Kids Ark commemorated WSCD at Mumias Hospital in collaboration with Kakamega County Department of Health



Civil society organisations at the world sickle cell day.



Nicosam Health Care Limited showcasing a Gazelle



Uganda Protestant Medical Bureau at the event.



Sickle cell Alliance Uganda at the event.



Exhibitor's Stalls



Other coaliations l aunched during the events.

Post IMARA Launch

5th Annual Uganda Sickle Cell Convention

The IMARA project team participated in the th annual Uganda sickle cell Convention two weeks after the offical IMARA launch on 3 July 2026 at Makere university.

The convention brought,together government representatives, healthcare professionals, researchers, development partners, civil society organisations, people living with sickle cell disease (SCD), caregivers and other stakeholders.

The Convention was organised by Raising Hope International Friends (RHIF) in collaboration with the Ministry of Health (MoH), Uganda, as part of efforts to strengthen national action on sickle cell disease. The 2026 Convention placed particular emphasis on strengthening early identification and diagnosis of SCD, with the Ministry of Health reiterating the importance of early screening as a foundation for timely care and improved outcomes.



JCRC and Terumo repesentstives at the event.



National Programme Sickle Cell Coordinator Uganda submitting at the event.



Audience at the 5th Annual Convetion.



IMARA senior team repesentstives during a panel dicussion at the event.

Conclusion: From Early Results to Sustainable Scale

The 2026 IMARA experience in Uganda and Kenya provides a strong foundation. It shows how sickle cell disease can move from a fragmented health challenge into a coordinated, sustainable continuum of care. More importantly, IMARA has demonstrated that scale is achievable through partnership. Governments, health facilities, communities, schools, blood services, civil society, researchers, private-sector partners and patient organizations can work together around a common SCD agenda. The experience in Uganda and Kenya also shows that the model can be adapted to different health-system and community contexts while maintaining a consistent focus on early identification, comprehensive care and equity.

The next phase is therefore an opportunity to move from demonstrated delivery to sustained national and regional scale expanding newborn and community screening, strengthening diagnostics and data systems, ensuring reliable access to hydroxyurea and other essential therapies, improving blood availability, strengthening linkage and retention in care, and generating evidence to guide policy and investment.

IMARA has established the platform. The opportunity now is to invest in its scale, institutionalization and long-term sustainability so that every child and adult at risk of SCD can be identified early, connected to quality care and supported to live a longer, healthier and more productive life.


COMMEMORATING
WORLD SICKLE
COMMITMENT TO SUPPORT
SCD In Uganda
JINJA, UGANDA


JCRC
TERUMO

