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Imara Seeks to Transform Sickle Cell Care from Fragmented Interventions to Lifelong Support

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Eyong Ebai, General Manager, Africa, Terumo Blood and Cell Technologies, discusses how the Imara model is connecting governments, clinicians, blood services and patient organisations to build coordinated sickle cell care pathways across Africa.

Africa carries the majority of the global sickle cell disease burden, yet care across many health systems remains fragmented, with gaps between early diagnosis, treatment, blood services and long-term patient management. Imara is seeking to change this by building a more connected model of care that supports patients throughout their lives.

In this interview with ***BioSpectrum Asia*, Eyong Ebai, General Manager, Africa, Terumo Blood and Cell Technologies,** explains how Imara is working with governments and the World Coalition on Sickle Cell Disease to strengthen existing healthcare ecosystems in Uganda, Kenya and Côte d'Ivoire. He also discusses the importance of continuity of care, multi-stakeholder collaboration and infrastructure investment, and how lessons from the initiative could help shape more sustainable approaches to managing sickle cell disease and other complex chronic conditions across emerging health systems.

Africa accounts for the majority of the global sickle cell disease burden. What are the most critical gaps in the current care pathway that Imara aims to address across Uganda, Kenya and Côte d'Ivoire?

The biggest challenge isn't a lack of commitment or even a lack of solutions. Across Africa, there are many dedicated organizations working on screening, diagnosis, treatment, advocacy and community outreach. The challenge is connecting those efforts into a sickle cell disease care pathway that works consistently for patients throughout their lives.

What we're trying to address is fragmentation. A child doesn't experience healthcare in pieces; they need care that works as a connected system from diagnosis through adulthood. That's why Imara focuses on strengthening the entire patient journey, linking early detection, routine care, blood services, complication management, ensuring that referral pathways are in place, healthcare financing, data systems and program coordination into a more integrated approach.

Importantly, this isn't about replacing existing programs. It's about helping connect and strengthen what's already there. The World Coalition on Sickle Cell Disease has played a critical role in bringing stakeholders together around that shared vision, while governments lead implementation based on local priorities and needs.

The model places significant emphasis on continuity of care rather than individual interventions. Why is coordinated, lifelong patient management becoming increasingly important in improving outcomes for people living with sickle cell disease?

Sickle cell disease is a lifelong condition, so improving outcomes requires more than a single intervention at a single point in time.

A newborn screening program is important, but its value is limited if patients aren't connected to ongoing care. Access to treatment matters, but patients also need monitoring, follow-up, safe high quality blood components & services when needed, and support in managing complications throughout their lives. We know what many of the individual solutions are. The challenge is ensuring they work together in a way that's consistent and sustainable for patients and families

We've seen globally that outcomes improve when care is coordinated across the full patient journey. That's why our focus is helping health systems move from a reactive model, such as responding when patients are already in crisis, to a more proactive approach that emphasizes early diagnosis, continuity of care and long-term management.

Success isn't measured by the number of interventions available. It's measured by whether patients receive the right care, at the right time, throughout their lives.

Imara brings together governments, clinicians, patient organizations, blood services and implementation partners. What lessons have emerged from building this multi-stakeholder coalition, and how do you ensure alignment among such diverse participants?

One of the most important lessons is that no single organization can solve the sickle cell challenge alone. Sustainable progress requires governments, healthcare providers, patient advocates, blood services, funders and implementation partners working toward a shared goal.

We've also learned that alignment becomes much easier when conversations start with the patient journey instead of individual organizational priorities. Stakeholders may bring different expertise and perspectives, but everyone agrees that people living with sickle cell disease deserve better outcomes.

The World Coalition on Sickle Cell Disease has been instrumental in making that alignment possible. The Coalition helped develop the model through a multi-stakeholder consensus process and continues to play a leading role in advocacy, stakeholder engagement and mobilizing support behind comprehensive sickle cell care. When people ask what comprehensive sickle cell care should look like in practice, this work helps translate that vision into action.

Governments remain the primary owners of implementation, but the Coalition helps ensure that partners are pulling in the same direction.

That collaborative approach is critical because our goal isn't to create another standalone initiative. It's to connect and strengthen existing efforts so they can have greater impact for patients.

Healthcare infrastructure is often discussed in the context of hospitals and equipment. From your perspective, what infrastructure investments will have the greatest impact on sickle cell diagnosis, treatment access and long-term disease management over the next five years?

When people hear the word infrastructure, they often think about buildings and equipment. Those investments matter, but for sickle cell disease, infrastructure is much broader than that.

The greatest impact will come from strengthening the systems that connect patients to care over time. That includes early diagnosis and screening programs, access to routine treatment and monitoring, safe and reliable blood components, healthcare financing mechanisms, data systems that support patient follow-up, and training for healthcare professionals.

I'd also highlight care coordination. Patients shouldn't have to navigate a fragmented healthcare system on their own. That means building stronger referral pathways, information systems, workforce capacity and financing mechanisms that connect services together so they don’t stop at diagnosis.

The encouraging part is that many countries already have valuable assets in place, from community health workers to hospitals, national blood services and public health programs. The opportunity is to build on those foundations and strengthen the connections between them, rather than creating parallel systems.

Terumo Blood and Cell Technologies has extensive experience supporting blood and cell therapy ecosystems globally. How can innovations in blood management, diagnostics and healthcare delivery help strengthen sickle cell care in emerging markets?

Innovation can be transformative, but technology alone doesn't improve outcomes. What matters is whether innovation reaches patients and becomes part of sustainable care delivery.

In emerging markets, some of the greatest opportunities are in helping patients be identified earlier, ensuring they can access appropriate care more consistently, and strengthening the systems that support long-term disease management. Diagnostics, blood services, digital health tools and new care delivery approaches can all contribute to that goal. But they are most effective when they're integrated into a broader healthcare ecosystem.

One lesson we've learned from supporting healthcare systems around the world is that innovation works best when it's paired with training, financing, policy support, strong referral pathways and local capacity building. In that sense, the challenge isn't simply introducing new solutions. It's creating the conditions that allow those solutions to deliver real and lasting value for patients.

That's why we see system strengthening and innovation as complementary, not separate conversations.

Looking beyond the initial implementation countries, what does success for Imara look like over the next three to five years, and how could the model be adapted by other countries facing a high sickle cell disease burden?

Success starts with stronger health systems and better patient outcomes. Over the next three to five years, we'd like to see more people diagnosed early, more patients connected to ongoing care, and stronger national capacity to manage sickle cell disease across the full patient journey. Achieving that will require continued investment across the care ecosystem, including stronger diagnostics, high quality blood components and services, workforce training and other innovations that help improve access to quality care.

Beyond those outcomes, I'd also like to see proof that this approach can help countries move from fragmented activities toward a more coordinated model of care. Every country starts from a different place. Some may prioritize screening, others treatment access, financing or data systems. The principle remains the same: connect the pieces so patients experience care as a continuum rather than a series of isolated interventions.

That's why I believe the model has relevance beyond the initial countries and even beyond Africa. Many health systems face similar challenges when managing complex chronic diseases. While the specific solutions may differ, the need for coordination, continuity and partnership is universal. While this work is focused on sickle cell disease, the lessons around care coordination, continuity of care and multi-stakeholder collaboration are relevant to many chronic diseases in emerging health systems.

The World Coalition on Sickle Cell Disease and Terumo BCT have important roles to play in advancing that vision by helping build awareness, political commitment and collaboration so that successful approaches can be adapted and scaled where they're needed most.

Many health systems already have dedicated people, valuable programs and effective interventions in place. The challenge isn't a lack of solutions. It's connecting those solutions into a care system that works consistently for patients throughout their lives. If this work can help countries do that, whether in Africa or elsewhere, we'll consider it a success.