imara
Sickle Cell Framework

Coordinating Comprehensive, Multidimensional Sickle Cell Disease Care in Africa

From fragmented efforts to integrated impact

Sickle cell disease (SCD) is one of Africa's most significant, yet neglected, public health challenges. Many dedicated stakeholders across Africa are doing vital work, whether through screening programs, treatment initiatives, or community outreach. But significant challenges remain, including:

- Fragmented efforts operating in silos
- Fragile patient care pathways
- Inconsistent and disconnected data systems

Now, there is a way forward.

5.7 million people in Africa are living with SCD, accounting for 74% of the global SCD population[1]

515,000 babies were born with SCD in 2021, primarily in sub-Saharan Africa[2]

50% to 90% of children with SCD die before age 5 without coordinated care[3]

The Imara approach: Integration across existing health systems

In collaboration with like-minded partners and thanks to a consensus of more than 35 experts across Kenya, Uganda, and Ivory Coast, the Imara Sickle Cell Framework was developed to provide a comprehensive and integrated approach to improve and manage SCD care in Africa.

Critically, the Imara framework builds on existing systems and resources, such as community health workers, immunization programs, and hospitals, to strengthen the patient journey.

Imara also encourages public-private-donor partnerships to collaborate on policymaking, funding, supplies, and scale-up needs — because no single organization can solve the SCD challenge alone.

The goal: Progress for patients and population-level impact.

At a glance: The Imara Sickle Cell Framework

10 activities across all health system levels of care

Care referral pathway

Tertiary interventions

Specialized and complex care

Focus on strengthening existing healthcare capacity to provide specialized and complex care, leveraging trained healthcare specialists.

7. Complication management (acute and chronic care)

Secondary interventions

Routine care provision

Focus on strengthening existing healthcare capacity to provide routine care while ensuring availability of diagnostics, medicines, and blood with local, trained healthcare professionals.

6. Availability of safe and adequate blood components
5. Laboratory and imaging diagnostics
4. Routine medical management

Primary interventions

Leveraging community engagement

Focus on community engagement, early disease identification, and early linkage to care.

3. Sustainable linkage to care
2. Newborn, early infant, and family screening
1. Community awareness

Cross-cutting engagements

Monitoring progress, supporting access, and driving execution

Focus on information systems to maximize patient management and public health assessment, healthcare financing, and overall program management.

8. SCD data management system
9. Healthcare financing
10. Program management

Imara is the Swahili word for “firm” or "strong" — a fitting reflection of our commitment to strengthening health systems, building sustainable partnerships, and empowering communities to change the trajectory of sickle cell disease. It also personifies the resilience of people living with SCD.

Join a coalition in motion

For more information on the Imara Sickle Cell Framework, please contact the Joint Clinical Research Centre (JCRC) at **jcrc@jcrc.org.ug**.

[1]Njuguna F, Kilach C, Njuguna C, et al. Building a comprehensive sickle cell disease program in Western Kenya: A decade of experience and growth. *Ann Glob Health*. 2026;92(1):7.

[2]World Health Organization. Sickle-cell disease. Published August 6, 2025. Accessed June 8, 2026. https://www.who.int/news-room/fact-sheets/detail/sickle-cell-disease.

[3]Uyoga S, Macharia AW, Mochamah G, et al. The epidemiology of sickle cell disease in children recruited in infancy in Kilifi, Kenya: A prospective cohort study. *Lancet Glob Health*. 2019;7(10):e1458-e1466.