2024

A BLUEPRINT FOR CHANGE:

UGANDA'S APPROACH TO SICKLE CELL DISEASE MANAGEMENT

WORLD COALITION ON SICKLE CELL DISEASE

INTRODUCTION

Overview of Sickle Cell Disease (SCD)

Sickle Cell Disease (SCD) is a significant global health concern, affecting 7.74 million people worldwide, with the highest prevalence in Sub-Saharan Africa.[I] The disease is caused by a gene mutation affecting hemoglobin, crucial for oxygen transport, leading to rigid, crescent-shaped red blood cells. These malformed cells block capillaries and restrict oxygen delivery to tissues. Patients with SCD manifest a plethora of symptoms, primarily acute pain crises, anemia, increased susceptibility to infections,[II] and over time, potential organ damage.[III]

Importance of Early Detection and Intervention in SCD Management

In the fight against SCD, newborn and infant screening is vital, enabling early intervention like penicillin prophylaxis and pneumococcal vaccinations. Indeed, prophylactic penicillin, started in the first few weeks of life and continued until at least age five, has been shown to significantly reduce the risk of infections; a landmark U.S. study reported an 84% infection reduction for young children receiving penicillin prophylaxis[IV] . Pneumococcal vaccination, too, can prevent infant deaths from bacterial sepsis or severe anemia.[V]

Without screening, diagnosis of SCD might be delayed until a child presents with symptoms or experiences disease-related complications; these delays in turn can lead to severe health consequences, including death.[VI] Tragically, many children in high-burden areas do not survive to adulthood, with over 500 succumbing daily due to inadequate newborn screening and limited treatment access.[VII]

Future Challenges

The challenges posed by SCD could increase in the next decades if no action is taken, thus hindering progress toward achieving SDG3. By 2050, the number of newborns with the hemoglobinopathy is expected to rise by 30% globally.[VIII] Economic and geopolitical crises, coupled with climate change pressures, will likely increase migration flows.[IX] As a result, SCD prevalence is likely to shift and increase across geographies.

Global and Regional Challenges in SCD Screening and Treatment

While states like the US, along with Malta or Spain in Europe, carry out universal screening for SCD,[x] [xi] many nations struggle to incorporate these screenings into regular care processes.[xii] The disparity in care between developed and developing nations will further exacerbate the challenges associated with managing the disease. For instance, hydroxyurea has seen limited adoption in sub-Saharan Africa, driven by a lack of medical professionals in rural areas, inadequate equipment for regular blood checks, and higher acquisition and administration costs.[xiii]

Nevertheless, hope is on the horizon. While no country in Africa has yet fully implemented universal screening programs for Sickle Cell Disease,[xiv] some nations like Benin and Ghana have implemented robust screening initiatives.[xv] Uganda, too, has made great strides in addressing SCD with evidence-based decision-making.

Uganda's Journey: A Model for Tackling SCD

Uganda, situated in East Africa, provides a compelling case study for addressing SCD, particularly due to its significant burden of the condition, ranking fifth highest in Africa.[xvi] Its efforts are also remarkable in light of its tumultuous past.

Historically, Uganda developed from the ancient Buganda kingdom, coming under formal British control in the late nineteenth century.[xvii] Despite gaining independence in 1962, the nation grappled with ongoing political instability, ethnic tensions, human rights violations, and economic challenges.[xviii] In addition, during the 1980s, Uganda experienced the emergence of a severe HIV/AIDS epidemic, compounding the nation's already dire social and economic challenges.[xix]

Both Sickle cell disease (SCD) and noncommunicable diseases (NCDs) exert significant influence on mortality rates in the region, with an estimated 20,000 babies born with SCD annually[xx] and NCDs accounting for 33% of total deaths.[xxi] In addition, the risk of premature death from an NCD is 22% for every Ugandan citizen.[xxii]

Recognizing the critical nature of addressing SCD, in 2013, the Ugandan Ministry of Health undertook a rigorous epidemiological study, the Uganda Sickle Surveillance Study (US3) to gauge the prevalence of Sickle Cell Trait (SCT) and disease within its population.[xxiii]

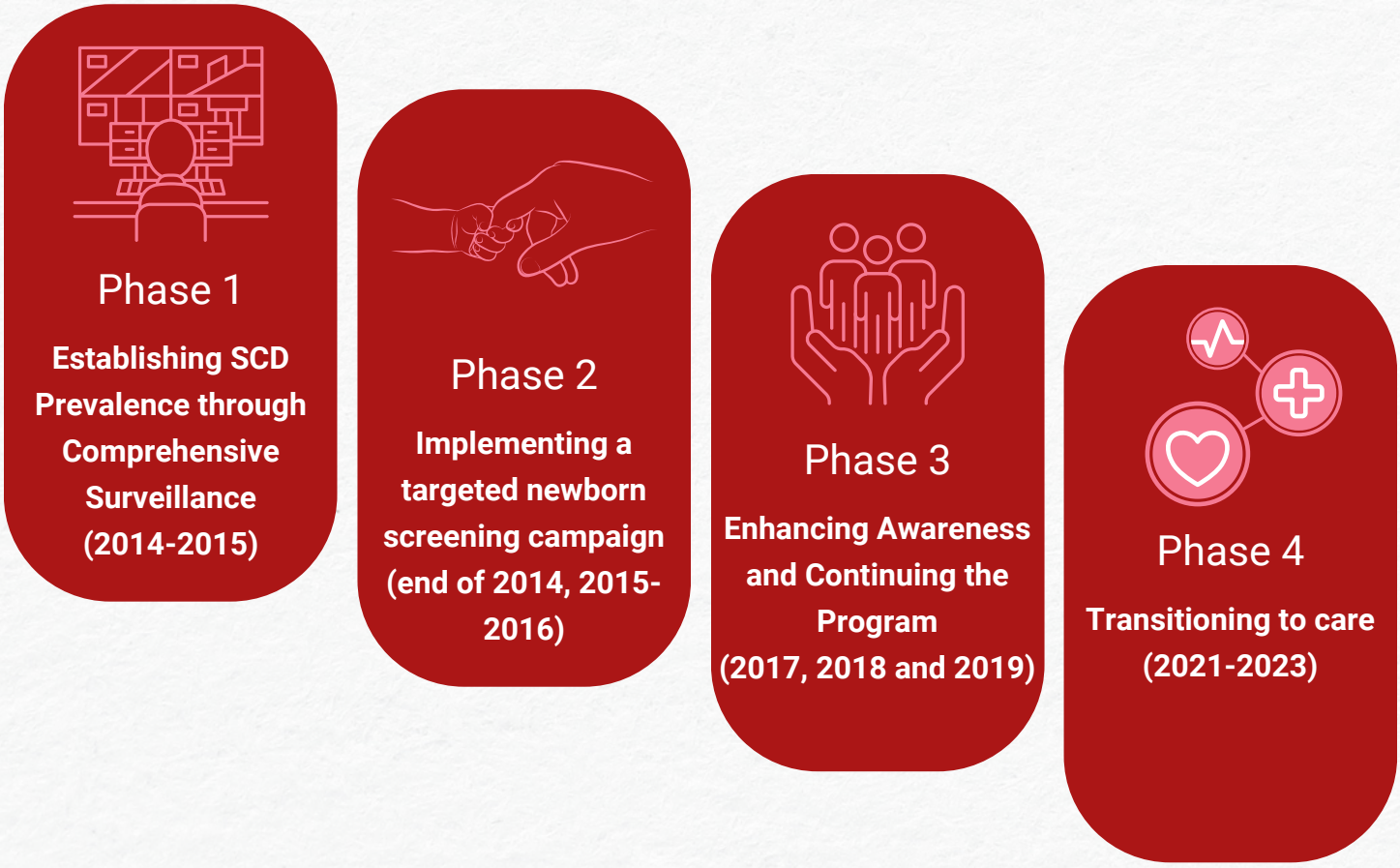
In response to the insights gained, Uganda initiated a newborn screening program, focusing on high-burden counties, that tested more than 179,620 infants for sickle cell trait and disease in the four years following its initial US3 study, which lasted between February 2014 and March 2019.[xxiv] In parallel, Uganda developed a multi-pronged strategy including

community outreach, capacity building in healthcare facilities, and increased public awareness campaigns.

The international community, including the World Bank and Novartis, a pharmaceutical company, recognized Uganda's determined efforts, providing substantial grants and forming partnerships to bolster these initiatives, respectively. Through collaborative efforts, Uganda was able to transition from a research-based survey to a comprehensive public health strategy that integrated screening, awareness, and treatment initiatives. Uganda now boasts 23 Centers of Excellence providing newborn screening and genetic counseling; 10 within the public system and 13 within the private not for profit (PNFP) system.[xxv] These Centers of Excellence are complemented by 85 satellite clinics offering care and management to children affected by SCD.[xxvi]

In an effort to provide a blueprint for other high-burden countries grappling with SCD, this case study sheds light on Uganda's journey. Based on interviews with key government officials and desk research, it outlines the phases of Uganda's disease management and shares lessons that other countries can emulate. The study also acknowledges the challenges remaining, as identified by the Ugandan government.

CASE STUDY: UGANDA'S FIGHT AGAINST SCD



Phase 1:
Establishing SCD Prevalence through Comprehensive Surveillance (2014-2015)

Call to Action

Uganda's efforts were catalyzed by the 2006 World Health Organization (WHO) report, "Sickle-cell anaemia", which highlighted the global prevalence of sickle-cell anemia and offered recommendations for its care and management.[xxvii] More specifically, the report called for research and monitoring of the disease to develop appropriate models of care, and underscored the importance of surveillance in prioritizing resources in LMICs.[xxviii]

Responding to Global Health Priorities

Answering WHO's call, the Uganda Ministry of Health decided to launch US3 in 2013. This pivotal study, a collaborative effort between the Ministry of Health, Cincinnati Children's Hospital, and Makerere University, aimed to collect crucial data to assess the prevalence of sickle cell trait and disease across the nation.[xxix] [xxx] As part of an active program for prevention of mother-to-child transmission of HIV, around 100 000 HIV-exposed infants are tested each year through the Early Infant Diagnosis programme.[xxxi] Dried blood spots (DBS) are collected around the country and shipped to the Central Public Health Laboratories in Kampala.[xxxii] Leveraging the existing DBS samples, US3 tested 99,243 dried blood spot samples from infants in all 112 districts of Uganda from February 2014 to March 2015.[xxxiii]

Analyzing Data to Inform Health Strategies

The findings were significant, revealing an average disease prevalence of 0.7% for SCD in the cohort studied, with sickle cell trait present in every district.[xxxiv] More importantly, the study revealed the uneven distribution of sickle cell trait. The

prevalence was notably lower in the South Western region, where it was below 5% in nine districts and under 3% in two.[xxxv] Conversely, 8 districts exhibited a prevalence exceeding 20%, with Alebtong in the Northern Region recording the highest at 23.9%.[xxxvi]

Interestingly, the data also revealed a significant correlation between the prevalence of sickle cell trait and malaria, with a correlation coefficient of 0.69 and a p-value of 0.026.[xxxvii] These results bolstered earlier studies showing an association between malaria and sickle cell trait at the global level.[xxxviii] In addition, they showed that malaria control strategies may want to take into account the distribution of sickle cell trait.[xxxix]

Securing Alignment from Internal Stakeholders

How did such a nationwide effort gain the momentum it needed to succeed? The study received robust support within the Ministry from its inception, notably from the Director General of Health Services at the time, Dr. Jane Ruth Aceng, who was also a senior author of the study.[xl] The US3 launch event testified to the momentous political will behind the study. The Honorable Minister of Health (PHC) Sarah Opendi, was present, as well as members of Parliament, Ministry of Health staff, Directors from Regional Referral Hospitals, District Health Officials, representatives from Civil Societies, representatives from Cincinnati Children's Hospital in the US, along with members of the media.[xli]

Soliciting Support from External Partners

Beyond securing wide support internally, several external partners were engaged in the US3 efforts. First, the Makerere University College of Health Sciences played a pivotal role in supporting US3. It served as an academic base, ensuring all necessary local institutional review board approvals were obtained.[xlii] It also facilitated the results announcements and spearheaded educational training in districts with a high prevalence of sickle cell disease.[xliii]

Thanks to the partnership with Cincinnati Hospital, in turn, a laboratory was built, containing Isoelectric focusing (IEF) equipment.[xliv] Beyond the purchase of equipment, the Cincinnati Children's Hospital Medical Center provided training and expertise in testing methodologies, as well as remote observation and examination of outcomes. [xlv]

Paving the Way Forward

Ultimately, the insights from US3 not only provided vital epidemiological data, but they also provided a roadmap to inform next steps for policymakers. By highlighting the unevenness of the sickle cell burden nationally, US3 underscored the importance of targeting screening efforts in regions with the highest burden of the disease.[xlvi]

Phase 2:
Implementing a targeted newborn screening campaign (end of 2014, 2015-2016)

Initiating the Sickle Cell Screening Campaign

Following the US3 study, targeted newborn screening efforts began in the districts with the highest prevalence of SCT and SCD. The Gulu and Lira districts were initiated in October 2014, followed by the Dokolo, Jinja, Kampala, Kitgum, Oyam and Tororo districts in April-May 2015.[xlvii] A third wave was initiated in July-August 2016, which included Alebtong, Agago, Amolatar, Apac, Bundibugyo, Lamwo, Luwero, Mityana, Mubende, and Pader districts.[xlviii]

While the US3 study focused on existing dried blood spots, the subsequent screening program covered all newly collected samples specifically requested for sickle cell analysis, identified through various methods.[xlix] Healthcare providers could request either exclusively sickle cell testing or combined sickle cell and HIV testing from any region. Concurrently, the Central Public Health Laboratory (CPHL) implemented an automatic process for scheduling sickle cell tests for samples from high-incidence areas, irrespective of the initial request being solely for sickle cell, both sickle cell and HIV, or only HIV testing. Additionally, any sample testing positive for HIV was automatically processed for sickle cell testing.[l]

Follow-Up Measures Post-Screening

From 2014 to 2019, the sickle/HIV co-testing cohort was found to have an overall sickle cell trait prevalence of 14.4% and disease prevalence of 0.9% - thus mirroring the results of US3.[li] Conversely, the sickle-specific cohort found a rise in disease prevalence after year 1, rising to 9.7%.[lii] This suggests increased recognition of sickle

cell by healthcare providers over time, and thus, successful education and training.[liii]

Targeted newborn screening was coupled with comprehensive education and training for healthcare providers on sickle cell diagnostics and the new CPHL screening programs. While the affected children were referred to local district hospitals for specialized care,[liv] "the inability to ensure that all children identified with sickle cell disease in the study have received their result and have been entered into medical care" was listed as one of the drawbacks of Uganda's newborn screening strategy.[lv] Nevertheless, the screening program significantly advanced Uganda's progress towards achieving universal newborn screening.

Addressing Challenges in the Newborn Screening Pilot Program

The targeted newborn screening program was not without challenges. The CPHL laboratory ran at only one-fourth of its capacity due to a lack of reagents and up-to-date HCP knowledge.[lvi] Additionally, an internal Ministry of Health document highlighted the operational challenges of the burgeoning newborn screening program. This included the challenges of managing busy maternity wards and resistance to change among some healthcare workers.[lvii] Finally, the need for recurrent training became apparent to ensure ongoing compliance with standards and achieve the program objectives.[lviii] Ultimately, these hurdles pointed to the "growing pains" associated with transitioning from a small-scaled project to a fully-fledged national program, one where newborn screening becomes an integral part of routine healthcare.

Phase 3:
Enhancing Awareness and Continuing the Program (2017, 2018 and 2019)

Continuing Programmatic Efforts

Screening efforts continued over the years. In the 2017/2018 fiscal year, the CPHL conducted 60,293 sickle cell tests using hemoglobin electrophoresis. These samples were collected from health facilities nationwide, indicating a comprehensive approach to understanding the prevalence and spread of the disease.[lix]

In the following years, the Ministry continued its screening efforts. In 2018, 69’511 newborns and infants were screened, and over 40’000 in 2019, culminating in over 300’000 children aged 0-24 months being screened for sickle cell trait and disease between February 2014 and March 2019.[lx]

Complementing these efforts, the Ministry of Health took decisive steps to enhance the handling of SCD. A notable development was the establishment of a national sickle cell technical working group. This body was appointed and launched by the Minister of Health to provide expert support and guidance in addressing the complexities of SCD management and care.[lxi]

While the pandemic slowed the programmatic activities, 2020 nevertheless saw the launch of the first-ever sickle cell disease treatment guidelines by the Ministry of Health. This initiative aimed to standardize care for patients across the country.[lxii] The guidelines provide a detailed list of medications, their usage intervals, and procedures for referrals to more advanced care facilities. Additionally, the Ministry worked towards including hydroxyurea, a key medication in SCD management, in the essential medicines list. This was part of a broader partnership with Novartis, illustrating the Ministry's dedication to improving access to effective SCD treatments.[lxiii]

These concerted efforts by the Ministry of Health reflected a comprehensive strategy to combat sickle cell disease in Uganda and were accompanied by widespread community outreach.

Boosting SCD Awareness and Combating Stigma

In parallel to newborn screening, the Ministry of Health undertook significant efforts to educate and destigmatize SCD among the population. This initiative was particularly crucial in light of a 2019 study conducted in a rural district of Uganda, which revealed that misconceptions and discriminatory attitudes towards SCD were prevalent. The study found that 56% of secondary school students surveyed held the view that individuals with SCD should be restricted from socializing, underscoring the need for widespread educational and awareness efforts.[lxiv]

A pivotal component of these sensitization efforts involved a partnership with the Buganda Kingdom, an influential cultural group in Uganda.[lxv] This collaboration was particularly strategic given the Kingdom's substantial influence and reach. The partnership's highlight was the birthday run of the King, or Kabaka, a significant event where SCD was the main theme for three consecutive years (2017-2019).

The 2019 Buganda Kingdom run was a landmark event, attracting 50,000 participants and raising 494 million Ugandan Shillings for SCD test kits.[lxvi] These kits were then disseminated across health facilities nationwide, forming a part of a broader strategy that included health camps and media campaigns to bolster SCD awareness.[lxvii]

The efficacy of this partnership in raising awareness about SCD was significant. Dr. Susan Nabadda, the Commissioner of National Health Laboratory and Diagnosis Services, attributed the increase in mass awareness of SCD from a mere 2% to a remarkable 30-40% to the robust collaboration with the Buganda Kingdom.[lxviii]

In addition to the Kabaka Run, specific efforts were also made to engage cultural and religious leaders.[lxix] The Ministry of Health also involved herbalists, since herbalists were accused of peddling false cures for sickle cell.[lxx] By providing two training sessions to herbalist committees, the Ministry of Health ensured buy-in from key stakeholders in raising awareness.

Phase 4:
Transitioning to Care (2021-2023)

Solidifying Partnerships

Following the continuation of newborn screening and awareness-raising activities, with 42,611and 48,496 infants screened in 2022 and 2023 respectively,[lxxi] the post-COVID period was marked by an increased focus on treatment and care. Following the 2020 Memorandum of Understanding[lxxii] with Novartis and the registration of hydroxyurea,[lxxiii] the Ministry of Health continued on its path of collaboration. In 2022, through its partnership with the American Society of Hematology (ASH), Novartis facilitated the expansion of an app's use to Uganda, an app initially pioneered in Ghana for tracking babies diagnosed with Sickle Cell Disease (SCD).[lxxiv] Uganda also received a one-time bridging stock of hydroxyurea from Novartis to supplement the government's efforts in ensuring access to treatment, as well as support in areas of screening and health system strengthening,[lxxv] that enabled the government to set up SCD Centers of Excellence and treatment centers in high-burden areas.[lxxvi]

Beyond private sector institutions, international organizations also took note of Uganda's efforts. Two World Bank donations of over 100'000 USD each were used to procure more hydroxyurea.[lxxvii] Today, Uganda continues its advocacy efforts vis-à-vis global financiers, evolving from an approach centered on newborn screening to one focused on continuity of care for SCD patients.

LESSONS LEARNED AND THE WAY FORWARD

The journey of Uganda in managing SCD provides valuable lessons for other resource-constrained settings, highlighting the significant opportunities that come with strategic planning and collaboration.

1. Data-driven approach: The US3 study was pivotal, providing a comprehensive national picture of SCD burden. This data-driven approach enabled informed decision-making and resource allocation, setting a precedent for other countries facing similar challenges. It enabled the government to set priorities and focus its subsequent actions on counties with the highest burden – thus maximizing effectiveness.

2. System integration and innovation: The innovative integration of SCD screening within existing HIV detection frameworks demonstrated a resource-efficient approach, capitalizing on established healthcare systems. This model can be replicated in LMICs for various public health interventions.

3. Community engagement and cultural sensitivity: Engaging major community figures, including cultural leaders like the Buganda king, was crucial. Tailoring strategies to the local context facilitated wider acceptance and effectiveness of the programs.

4. Capacity building and training: Collaborating with the Cincinnati Children's Hospital and American Society of Hematology for capacity building improved testing reliability and fostered local expertise, which has been hailed as a key component to fighting SDC in sub-Saharan Africa.[lxxviii] This facilitates ownership and sustainability of such programs.

5. Partnerships for success: The success of Uganda's approach to SCD management was bolstered by its ability to forge multifaceted partnerships. These collaborations – across sectors and continents – enhanced the scope and sustainability of its programs.

- Government and political support: The Ministry of Health's leadership, notably from figures like pediatrician and current Minister of Health Dr Jane Ruth Aceng, was instrumental.[lxxix] Her commitment provided the necessary political will to ensure that SCD remained a national health priority. This support facilitated the allocation of resources, policy formulation, and implementation of nationwide programs.

- International collaborations: Partnering with the Cincinnati Children's Hospital not only provided financial support, but also technical expertise and capacity building, thus increasing the sustainability of the screening program.

- Public-private partnerships: Public private partnerships focused on sustainability and policy change lead to long term improvements in health care for patients. Uganda's holistic approach and investment in education, training, and advocacy ensured that the treatment centers and screening activities were part of a sustainable ecosystem.

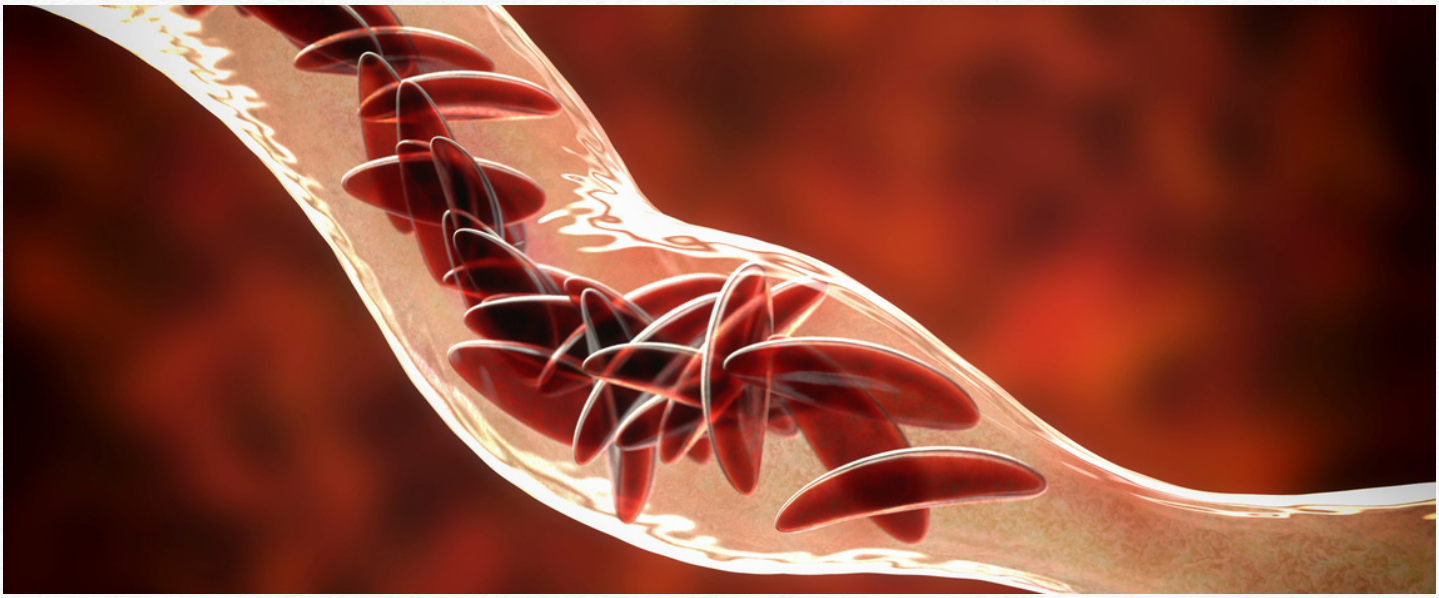
- Sharpening local capacity: Industry, for example Novartis through its Africa Program, centered on hydroxyurea dosing[lxxx] or the Cincinnati Hospital training laboratory technicians on testing methodologies,[lxxxi] developed local capacity and know-how, ensuring long-term success.

- Academic and research institutions: Ties with academic institutions further anchored screening efforts within the country and aided with evidence-based decision-making by providing robust methodologies.

- International funding agencies: Financial support from international agencies like the World Bank was a critical aspect of Uganda's SCD management. Thanks to Uganda's efforts to prioritize and invest in the full continuum of care, they were able to evolve from data generation to a comprehensive program with screening, follow up and treatment.

- Global advocacy: the Ugandan government has actively promoted its approach to SCD management across various global platforms, from networking informally at the 61st ASH Annual Meeting in Orlando to making a formal speech at the Coalition's launch during the World Health Assembly 2023 in Geneva[lxxxii] – thus successfully advocating for its interests with international institutions.

6. Transparent acknowledgment of challenges: The Ugandan government has readily and openly acknowledged the challenges in combating SCD, such as variable awareness rates across regions, and laboratory processing delays.[lxxxiii] This candidness signals honesty and a commitment to continuous improvement – two qualities highly valued in international partnerships. It also allows for continuous learning and adaptation, demonstrating the resilience and flexibility required for complex health issues like SCD.



Ultimately, the synergy between various sectors – healthcare, government, private, and non-profit – created a robust framework for tackling SCD. Multidisciplinary partnerships, in fact, have been hailed as a key component to improving the diagnosis and treatment of SCD.[lxxxiv]

CONCLUSION

Moving forward, Uganda aims to further enhance its SCD management strategies . Key focus areas include:[lxxxv]

- Accessing child-friendly formulation of hydroxyurea.
- Advanced diagnostic tools: implementing point-of-care devices in primary care settings to enable swift screening.
- Decentralization of laboratory services: to expedite test results and improve access to diagnostics.
- Facilitate curative approaches: Uganda established a legal framework for organ transplant, which will facilitate the bone marrow transplant required for sickle cell sufferers.

By addressing these areas, Uganda can solidify the gains made in SCD management and build a resilient health system capable of advancing despite potential challenges. This approach not only prevents backsliding but also positions Uganda as a leader in SCD management, offering valuable lessons for other countries facing similar health challenges. Ultimately, Uganda's journey in managing SCD testifies to the power of comprehensive, multi-faceted approaches. It serves as an inspiring model for other nations grappling with similar health challenges, illustrating the power of data-driven decision-making, community engagement, capacity building, and strong multi-sectoral partnerships.

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