# **BMJ Global Health**

# Strengthening global partnerships for sustainable sickle cell disease care: insights from SickleInAfrica at the 77th United Nations General Assembly and the US-Africa Leaders' Summit

Irene Kida Minja , ¹ Siana Nkya,² Daima Bukini , ³ Nesia Mahenge,⁴ Upendo Masamu,⁵ Janeth Manongi,⁶ Josephine Mgaya,⁶ Frank Mtiiye,⁵ Malula Nkanyemka,⁶ Eka Patricia Kisali,² Isihaka Mwinchande Mahawi , ⁶ Aisha Rifai,³ Agnes Jonathan,⁶ Victoria Nembaware,⁶ Mario Jonas,⁶ Nicola Mulder,⁶ Ruth Namazi,¹¹ Deogratius Munube,¹¹ Vivian Paintsil,¹² Raphael Zozimus Sangeda , ¹³ Hans Ackerman,¹⁴ Ruhl Parker,¹⁵ Fred Stephan Sarfo,¹⁶ Aldiouma Guindo,¹ሾ Obiageli Eunice Nnodu , ¹ጾ,¹⁰ Emmanuel Balandya,³ Sarah Kiguli,²⁰ Catherine Chunda-Liyoka,²¹ Patience Kuona,²² Emmanuel Peprah,²³ Appolinary Kamuhabwa,²⁴ Julie Makani³

**To cite:** Minja IK, Nkya S, Bukini D, *et al.* Strengthening global partnerships for sustainable sickle cell disease care: insights from SickleInAfrica at the 77th United Nations General Assembly and the US-Africa Leaders' Summit. *BMJ Glob Health* 2025;**10**:e017154. doi:10.1136/ bmjgh-2024-017154

**Handling editor** Naomi Clare Lee

Received 12 August 2024 Accepted 25 February 2025



© Author(s) (or their employer(s)) 2025. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ Group.

For numbered affiliations see end of article.

**Correspondence to** Dr Irene Kida Minja; ikminja@blood.ac.tz

## **ABSTRACT**

**Background** Addressing sickle cell disease (SCD) is crucial for achieving health-related Sustainable Development Goals, particularly in Africa. The region is significantly affected, with 78.7% of patients with SCD residing in sub-Saharan Africa and over 515 000 newborns diagnosed annually. Historically, African health systems have struggled to provide optimal care for patients with SCD, resulting in high under-5 mortality and severe childhood morbidity. Scientific innovations and stakeholder engagement offer hope for improving SCD outcomes. **Objective** To explore the role of high-level partnerships and scientific innovation in advancing SCD care and research in Africa, focusing on the contributions and strategic engagements of the SickleInAfrica, as highlighted at the 77th United Nations General Assembly (UNGA) and the US-Africa Leaders' Summit.

**Approach** SickleInAfrica, comprising eight countries, leverages a robust infrastructure for SCD research and care. The consortium has established a comprehensive SCD database and a patient registry in each of the consortium sites that includes demographic details, clinical diagnosis, management details and follow-ups/visits. Currently, over 34 000 patients with SCD are enrolled, making it the largest globally. It has also contextually adapted clinical guidelines for managing SCD for all levels of care. The high-level engagements at the 77th UNGA held in September 2022 in New York and the US-Africa Leaders' Summit held in December 2022 in Washington DC promoted SCD awareness and partnerships. The UNGA session emphasised biomedical science, implementation research and partnerships in therapeutic development, while the US-Africa Leaders' Summit session focused on Global Partnerships for SCD: Advancing Science and Technology for Health in Africa.

## **SUMMARY BOX**

- ⇒ For sustainability, governments in countries with a high burden of sickle cell disease (SCD) play a key role in developing policies that favour access to comprehensive care for SCD, including integration of SCD care into existing healthcare systems.
- ⇒ The need to seek bilateral and multilateral partners for the entire chain of SCD comprehensive care, from newborn screening to curative therapies for SCD in the region is of paramount importance.
- ⇒ There is a compelling need for the establishment of SCD Centres of Excellence in Africa to build capacities for cell and gene therapy facilities, bone marrow transplant and provide a platform to conduct cutting-edge research and training on SCD.

Conclusions High-level engagements facilitate crossborder dialogues, underscoring the importance of partnerships from grassroots to global alliances. Key outcomes include increased awareness, policy advocacy and the establishment of SCD Centres of Excellence and genomics capacity-building initiatives. Sustainable efforts require robust partnerships, government involvement, community awareness and equitable access to advanced therapies.

# **BACKGROUND**

Achieving the Sustainable Development Goals (SDGs) for health in many countries in Africa will include addressing non-communicable diseases (NCDs) including sickle cell disease



(SCD). Africa is the epicentre of the disease burden with an estimated 78.7% of patients living in sub-Saharan Africa and more than 515000 (425 000–614 000) newborns are diagnosed with SCD each year. Historically, health systems in many regions have been ill equipped to provide optimal preventative and therapeutic health-care over the life course of patients with SCD. The result has been high rates of under-5 mortality and severe morbidity beginning in early childhood. In this context, the current era of scientific innovation holds promise for helping patients through engagement with policy-makers and other stakeholders to make a sustained impact on SCD population health. <sup>34</sup>

In moving the global health agenda forward to improve health outcomes for individuals living with SCD in lowincome and middle-income countries, it is imperative to strategically engage with different stakeholders at various levels, from individual, national, regional governments and philanthropies, to high-level engagement.<sup>3</sup> There are examples where high-level advocacy engagement in global health has succeeded in improving population health. For example, the Bill & Melinda Gates Foundation has played a pivotal role in pushing the agenda for SDGs in the Global South, specifically for HIV.<sup>5</sup> Development of health programmes in the Global South is implemented with dependency on resource mobilisation from the Global North. Extending implementation efforts beyond the funding period is mostly left to the recipient country, which is often challenging due to a lack of resources, expertise and funding, among other limitations. In view of that, the SickleInAfrica consortium mainstreamed the sustainability plans through its working groups at the inception stage of funding.

A group of eight African countries formed SickleInAfrica, a consortium that includes a Clinical Coordinating Centre in Tanzania, a Data Coordinating Centre in South Africa and study sites in Ghana, Nigeria, Mali, Uganda, Zimbabwe, Zambia and Tanzania. SickleInAfrica aims to reduce the burden of SCD in Africa while establishing the capacity for research that will contribute to scientific knowledge to improve health outcomes and find a cure for SCD. SickleInAfrica, which started with three countries, has expanded to eight countries.<sup>6</sup> The consortium has established an infrastructure for research in SCD to understand SCD in Africa and guide locally appropriate interventions. SickleInAfrica has established an ethically and legally approved SCD database registry, with more than 13000 participants enrolled. Patients with SCD enrolled and attending clinics in these facilities are being managed by care providers using contextually adapted clinical guidelines developed by the Standards of Care group of the consortium.<sup>8</sup> By the end of 2026, more than 34 000 patients with SCD will be enrolled in the database, making it one of the largest databases of SCD on the globe. This practice paper specifically shares the efforts forged by the SickleInAfrica consortium through the clinical coordinating centre in Tanzania to engage and build high-level partnerships aiming at sustaining efforts

to improve the overall health of people living with SCD in Africa.

# **APPROACH AND OUTCOMES**

The SickleInAfrica, MUHAS and the Tanzanian Embassy to the USA in partnership with the Tanzania Ministry of Health and ISC Intelligence in Science conducted two hybrid scientific sessions to address SCD. Two platforms were identified: the 77th United Nations General Assembly (UNGA) in September 2022 and the US-Africa Leaders' Summit in December 2022.

The United Nations organisation comprises the UNGA, a core policy-making organisation that hosts about 193 member states. The meeting provided an avenue where international issues in the UN Charter are discussed and approved at a high level. Furthermore, the assembly involves stakeholders, partners, funders and philanthropies. Therefore, SickleInAfrica set out to use this platform through the Science Summit to conduct its first session. The theme of the session was formulated to capture the current efforts in addressing SCD in Africa and the other advanced SCD care opportunities available globally. The session was titled Scientific Innovation to Address Sickle Cell Disease: From Newborn Screening to Curative Gene Therapy in Africa. Participants included different partners involved in addressing SCD at country, regional and global levels, such as patient advocates, healthcare providers, policy-makers and other government officials, researchers, industry, non-governmental organisations, philanthropies and multilateral health and research organisations. Thematic sessions focused on three critical areas of scientific contributions: (1) Biomedical Science aimed at advancing the understanding of SCD in African patients, with a focus on the genetic factors influencing disease pathophysiology. (2) Implementation Research aimed at improving the delivery of life-saving interventions, including newborn screening, community mobilisation and access to existing medicines. (3) Research and Development of Partnerships—Facilitating the development and accessibility of new SCD therapeutics, particularly gene therapy. Table 1 outlines the specific topics discussed, the countries represented by presenters and key recommendations.

The US-Africa Leaders' Summit is held to showcase the US ongoing commitment to Africa and emphasise the importance of US-Africa relations and enhanced cooperation on shared global priorities. Organised by the US head of state, the summit has only been held twice, in 2014 and 2022, with the most recent gathering bringing together 49 African leaders. It serves as a crucial platform for African heads of state to engage in dialogue with the US head of state and other stakeholders. SickleInAfrica used this opportunity to host a science session on SCD as a side event. This session built on previous discussion during UNGA and the Tanzania-US Partnership for Health and Health Services. The session, aligned with the aforementioned theme 3 of the critical areas of



|       | s discussed during the first science see                              | Topic (presenter country/   |   |
|-------|---|---|---|
| S/No. | Thematic area   | countries)  | Recommendations   |
| 1.    | Setting the Stage and Biomedical Sciences                             | <ul> <li>a. The Importance of Centres of Excellence in Sickle Cell Disease (Mali)</li> <li>b. NCDI Poverty Network— PEN-PLUS building on WHO-PEN (USA)</li> <li>c. SickleInAfrica—Uganda site (Uganda)</li> <li>d. Biomedical sciences— Access to gene therapy for SCD (Tanzania)</li> <li>e. Biomedical sciences— Gene therapy experience (France)</li> <li>f. Innovation—Gene editing (USA).</li> </ul> | build human resource capacity, and pioneer policy changes that will lead to reduced SCD in Africa.  ► Increase accessibility to care for SCD patients in Africa.  ► Involvement of policy-makers on issues pertaining to SCD in Africa.  ► Develop policies to increase access to care for SCD  ► There is a need to initiate access to advanced therapy in Africa where                    |
| 2.    | Implementation Science  | Newborn Screening<br>and Hydroxyurea (HU)<br>treatment. (Tanzania)  | <ul> <li>Integration of newborn screening into the healthcare system in Africa</li> <li>Increase access to HU for SCD patients in Africa.</li> <li>Involve policy-makers in Africa and African diaspora for capacity building.</li> <li>Important to involve policy-makers and PPP for sustainability.</li> </ul>   |
| 3.    | Partnerships for Scientific<br>Discovery, including gene<br>therapies | <ul> <li>a. Overview of<br/>SickleInAfrica (Tanzania).</li> <li>b. Novartis Africa<br/>Programmes<br/>(Switzerland).</li> <li>c. The Worldwide SCD<br/>global coalition (USA).</li> <li>d. Advanced therapies and<br/>technology for disease,<br/>including SCD (USA).</li> </ul>   | <ul> <li>Partnerships with governments are important at all levels for the sustainability of health intervention programmes.</li> <li>Advocate for curative options for SCD, such as gene therapy</li> <li>Launching gene therapy trials in SSA is important.</li> <li>Important to introduce available drugs, such as crizanlizumab.</li> <li>It is important to have concerted</li> </ul> |

NCDI, Non-Communicable Disease and Injury; PPP, public-private partnership; SSA, sub-Saharan Africa; UNGA, United Nations General Assembly.

scientific contributions, was held during the Summit in Washington, D.C., on 13 December 2022, titled: *Global Partnerships for Sickle Cell Disease: Advancing Science and Technology in Health in Africa.* The session focused on building a global partnership for SCD with the goal of advancing science and discovery to facilitate the accessibility of advanced therapies for SCD in Africa, as shown in table 2.

# **DISCUSSION**

SickleInAfrica's proactive engagement in high-level meetings, such as those in collaboration with MUHAS, the Tanzanian Embassy to the USA and ISC Intelligence in Science (ISC), has effectively underscored the critical importance of merging fundamental research with the delivery of state-of-the-art care for individuals affected by SCD. These

efforts in reducing the burden of SCD in Africa and globally



 Table 2
 Topics discussed during the second science session on sickle cell disease (SCD) during the US-Africa Leaders'

 Summit

| S/No. | Thematic area   | Topic (presenter country/ countries)   | Recommendations   |
|-------|---|--|---|
| 1.    | Partnerships in health, research<br>and training to advance<br>knowledge and care for SCD   | <ul> <li>a. NIH funding for Biomedical research. (USA)</li> <li>b. NIH-funded SickleInAfrica consortium. (USA).</li> <li>c. Overview of MUHAS plans to become a training Hub for postgraduate and superspeciality programmes. (Tanzania)</li> <li>d. SCD Programmes Novartis (USA)</li> </ul>  | <ul> <li>There is a need for support from governments in Africa to ensure sustainable and equitable access to facilitate translation of research to healthcare.</li> <li>There is a need to establish SCD Centres of Excellence.</li> <li>There is a need for partnership in training and research in SCD.</li> <li>Develop advanced therapies in Africa.</li> <li>Expand NIBR Scientific fellowships for capacity building.</li> </ul> |
| 2.    | Inclusive Policies for SCD to reduce costs and support comprehensive patient care   | <ul> <li>a. Ministry of Health strategy to address SCD (Tanzania).</li> <li>b. Overview of Sickle Cell Disease Association of America. (USA)</li> <li>c. SCD patient experiences (Tanzania).</li> </ul>  | <ul> <li>There is potential for collaboration in health, training, research and advocacy.</li> <li>Global collaboration is needed to address SCD.</li> <li>There is a need to address access to SCD care</li> <li>There is a need for advanced therapies and community outreach programmes.</li> </ul>  |
| 3.    | Financing and Investments in research to ensure sustainable advances in SCD   | <ul> <li>a. The role of Centres of Excellence in Sciences in Africa. (Tanzania).</li> <li>b. NCDI Poverty network and Pen Plus initiatives (USA).</li> <li>c. Curative care for SCD in Africa (Tanzania).</li> <li>d. Gene therapy for SCD (USA).</li> </ul>   | <ul> <li>Investments, integration and partnership in health are essential in addressing SCD.</li> <li>The need to expand integrated care for chronic diseases, including SCD,</li> <li>Strengthen comprehensive basic care in tandem with curative advanced therapies, through partnerships at different levels.</li> <li>Apply for funding opportunities such as the African Genomics Center of Excellence.</li> </ul>                 |
| 4.    | Manufacturing in Africa to increase access and reduce financial costs for essential medicines and novel therapies including gene and cell therapy | <ul> <li>a. Cost analysis and investment required for gene therapy programmes in low-resource settings. (Singapore).</li> <li>b. overview of the current development of gene therapy products for HIV/SCD (Uganda).</li> <li>c. Gene and Cell therapy in LMICs. (U.S.A)</li> <li>d. In vivo and Ex vivo gene therapies. (USA).</li> <li>e. Opportunities for investment in Africa (Tanzania).</li> <li>f. Lessons from the COVID-19 pandemic (Nigeria).</li> </ul> | <ul> <li>Develop a model for implementing gene therapies in Africa. Enhance the use of MRNA technology (lesson from COVID-19). Strengthen partnerships in Africa for funding applications. Enhance efforts to make gene therapy affordable. Encourage the production of products in the African region—lower the cost.</li> <li>Make use of the available opportunities for investment in the region.</li> </ul>                        |



strategic gatherings provided a global platform for exchanging knowledge and ideas, amplifying the urgency of addressing SCD globally based on the three thematic areas of scientific contribution. By fostering a dialogue which transcends borders, they have heightened awareness and accelerated the drive to bridge the gap between research and practical solutions for patients with SCD.

For example, these meetings begin to address three thematic areas of scientific contribution for SCD in Africa. Moreover, these meetings have illuminated the central role of partnerships at every level of engagement, encompassing a diverse range of stakeholders as recognised in theme 3 (tables 1 and 2). These partnerships extend from the grassroots level, involving patient communities, to institutional collaborations and even extend to national, regional and global alliances. The participation of the private sector and pharmaceutical companies, such as the Novartis-Tanzania partnership, highlights the comprehensive approach taken to sustain the activities implemented to combat SCD (table 1). Moreover, these strategies uphold the United Nations objective of supporting public–private partnerships (PPPs) to achieve SDG. 11 Through these multifaceted partnerships, the viability and effectiveness of SCD initiatives are ensured, cementing their significance in the global healthcare landscape.

Governments have been observed to play a substantial role in strengthening partnerships and shaping policies that favour access to comprehensive care for SCD. This underscores the importance of these collaborations and ensures more equitable access to services for communities in need according to theme 2 (table 1). The WHO package for essential NCDs (PEN) is an example of a comparable government partnership that is now in existence. Building the capacity of mid-level providers in rural and semiurban facilities to provide patient care for NCDs such as type I diabetes, cardiac disease and SCD is the initiative's main goal, under the Non-Communicable Disease and Injury Poverty Network/Outcomes. These efforts have been initiated in some SickleInAfrica countries, with more regions showing the need for expansion.

To further support research and scientific discovery aimed at improving patient care, institutions in the region require administrative and infrastructure support. According to theme 1, the available evidence-based interventions, for instance, newborn screening and hydroxyurea use need to be upscaled and integrated into healthcare systems in countries with the highest burden of disease. Hence, the value of involving policy makers on issues pertaining to SCD in these countries. This entails partnerships that address critical areas such as improving digital health and disease registries integration into National Census Programmes (theme 2). Additionally, the establishment of SCD Centres of Excellence is vital. These centres will serve as hubs or a one-stop shop to provide a platform to conduct cutting-edge research, involving local participants, to be translated into practice

(theme 1); and training on SCD comprehensive clinical care, cell and gene therapy, and the like (tables 1 and 2). An important development on the horizon is the potential to establish Centres of Excellence in Genomics, with the African Genomics Center of Excellence. This effort will significantly enhance genomic capacity in addressing SCD and other infectious diseases such as HIV/TB, further solidifying the commitment to advancing healthcare in the region. The plan is to raise funds to establish eight Genomics Centres of Excellence across Africa has been discussed to address the burden of diseases including SCD in Africa.<sup>12</sup> The strategy is to have a coordinating hub with the eight centres. For sustainability purposes, these centres should be leveraged by local academics and other public health institutions. Another development was the establishment of the Lancet Haematology Commission, 'Defining global strategies to improve outcomes in SCD: a Lancet Haematology Commission'. The commission involved bringing together different initiatives in the region from a group of experts in SCD, patients and activists to push the SCD agenda. The commission emphasised collaboration of different stakeholders for these initiatives to materialise and finally agreed on recommendations of priority for access to curative services by 2040. 13

# **CONCLUSIONS**

In conclusion, the sustainability of the different efforts globally to address SCD will require robust and multifaceted global partnerships. First, there is a need to involve governments to ensure SCD comprehensive care, for example, to make mandatory early diagnosis for SCD and making hydroxyurea medication available. Early diagnosis is crucial as it allows for timely intervention, which can significantly improve patient health outcomes. Second, investing in raising general awareness of SCD in communities is vital. This includes educational campaigns to inform the public about the disease, its symptoms and the importance of early diagnosis and treatment. Such awareness initiatives can lead to increased community support and reduce stigma associated with the condition. Third, equitable access to advanced therapy services must also be a priority. Communities in need, particularly those in high prevalence areas such as Africa, should have access to the latest treatments and care options. This should include medication and curative therapies such as bone marrow transplants and gene therapy, which have the potential to offer a cure for SCD. Finally, involvement of diverse stakeholders is crucial for the success of these initiatives. PPP and philanthropists can play a significant role in expanding and strengthening SCD care and improving health outcomes. From scaling up newborn screening programmes to strengthening comprehensive care services to equitable access to curative therapies for SCD on the African continent.

In high-burden areas like Africa, such collaborations can make a profound difference. By pooling resources,



expertise and effort, PPPs can help bridge the gap in healthcare services, ensuring that individuals with SCD receive the care they need to lead healthy and productive lives. Ultimately, the fight against SCD requires a united and coordinated effort. By leveraging global partnerships, engaging governments, raising community awareness and ensuring equitable access to advanced therapies, we can make significant strides in improving the lives of those affected by SCD and move closer to eradicating this debilitating disease.

### **Author affiliations**

- <sup>1</sup>Restorative Dentistry, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of
- <sup>2</sup>Department of Biochemistry and Molecular Biology, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of
- <sup>3</sup>Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of
- <sup>4</sup>Christoffel-Blindenmission Deutschland eV, Bensheim, Germany
- <sup>5</sup>Department of Hematology and Blood Transfusion, Muhimbili University of Healthy and Allies Science, Dar es salaam, Tanzania, United Republic of
- <sup>6</sup>Sickle Cell Program, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of
- <sup>7</sup>Radboud Universiteit, Nijmegen, Netherlands
- <sup>8</sup>University of Cape Town, Rondebosch, Western Cape, South Africa
- <sup>9</sup>University of Cape Town, Rondebosch, South Africa
- <sup>10</sup>Department of Paediatrics, Makerere University, Kampala, Uganda
- <sup>11</sup>Paediatrics and Child Health, Makerere University, Kampala, Uganda
- <sup>12</sup>Komfo Anokve Teaching Hospital, Kumasi, Ashanti, Ghana
- <sup>13</sup>Department of Pharmaceutical Microbiology, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of
- <sup>14</sup>Physiology Unit, NIH, Bethesda, Maryland, USA
- <sup>15</sup>NIH, Bethesda, Maryland, USA
- <sup>16</sup>Department of Medicine, Kwame Nkrumah University of Science and Technology, Kumasi, Ashanti, Ghana
- <sup>17</sup>Department of Hematology, University of Bamako, Bamako, Mali
- <sup>18</sup>Haematology and Blood Transfusion, University of Abuja College of Health Sciences, Abuja, Nigeria
- <sup>19</sup>Haematology and Blood Transfusion, University of Abuja Teaching Hospital, Gwagwalada, Nigeria
- <sup>20</sup>Makerere University College of Health Sciences, Kampala, Uganda
- <sup>21</sup>Department of Paediatrics and Child Health, University Teaching Hospital, Lusaka, Zambia
- <sup>22</sup>Department of Pediatrics, University of Zimbabwe, Harare, Zimbabwe
- <sup>23</sup>School of Global Health, New York University, New York, New York, USA
- <sup>24</sup>Vice Chancellor, Muhimbili University of Health and Allied Sciences, Dar es Salaam, Tanzania, United Republic of
- X Raphael Zozimus Sangeda @rsangeda and Obiageli Eunice Nnodu @oennodu

Acknowledgements We would like to acknowledge Professor Funmi Olopade and Professor Leon Tshilolo—SickleInAfrca Co-Chairs, Professor Ambroise Wonkam, PI—SADaCC and Dr. Bruno Mmbando—Investigator, SPARCo—CCC. We also wish to thank the following who made these efforts possible: Mr. Declan Kirane—ISC-Intelligence in Science, the NYU School of Global Public Health, the Permanent Mission of the United Republic of Tanzania (U.R.T) to the United Nations, the Embassy of the United Republic of Tanzania in the USA, the U.R.T—Ministry for Health and the U.R.T—Ministry of Foreign Affairs.

**Contributors** IKM, SN, DB, NMa, UM, JMan, JMga, FM, MN, EPK, IMM, AR, AJ, VN, MJ, NMu, RN, DM, VP, RZS, HA, AR, FSS, AG, OEN, EB, SK, CC-L, PK, EP, AK and JMak all contributed to the coordination of the meeting, drafting of the manuscript

and review of its content. All authors reviewed and approved the final version of the manuscript.

**Funding** Sickle Pan African Research Consortium—Clinical Coordinating Center (SPARCO-CCC) is funded by the National Heart, Lung and Blood Institute of the National Institutes of Health under Award Number U24 HL135881.

**Disclaimer** The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

Competing interests None declared.

Patient consent for publication Not applicable.

Provenance and peer review Not commissioned; externally peer reviewed.

**Data availability statement** Data sharing not applicable as no datasets generated and/or analysed for this study.

**Open access** This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

### **ORCID** iDs

Irene Kida Minja http://orcid.org/0000-0002-5508-119X
Daima Bukini http://orcid.org/0000-0002-1376-4654
Isihaka Mwinchande Mahawi http://orcid.org/0009-0001-5378-553X
Raphael Zozimus Sangeda http://orcid.org/0000-0002-6574-5308
Obiageli Eunice Nnodu http://orcid.org/0000-0002-4801-3156

### REFERENCES

- 1 Thomson AM, McHugh TA, Oron AP, et al. Global, regional, and national prevalence and mortality burden of sickle cell disease, 2000–2021: a systematic analysis from the Global Burden of Disease Study 2021. Lancet Haematol 2023;10:e585–99.
- 2 Piel FB, Hay SI, Gupta S, et al. Global burden of sickle cell anaemia in children under five, 2010-2050: modelling based on demographics, excess mortality, and interventions. PLoS Med 2013;10:e1001484.
- 3 Bragge P, Waddell A, Kellner P, et al. Characteristics of successful government-led interventions to support healthier populations: a starting portfolio of positive outlier examples. BMJ Glob Health 2023;8:e011683.
- 4 Lo YR, Chu C, Ananworanich J, et al. Stakeholder Engagement in HIV Cure Research: Lessons Learned from Other HIV Interventions and the Way Forward. AIDS Patient Care STDS 2015;29:389–99.
- 5 Bhandari N. Integrating non-hiv services into hiv programs, nairobi. 2024. Available: www.cquin.icap.columbia.edu
- 6 Nkya S, Masamu U, Kuona P, et al. Update on SickleInAfrica: a collaborative and multidimensional approach to conduct research and improve health. Lancet Haematol 2024;11:e565–6.
- 7 Makani J, Sangeda RZ, Nnodu O, et al. SicklelnAfrica. Lancet Haematol 2020;7:e98–9.
- 8 Paintsil V, Ally M, Isa H, et al. Development of multi-level standards of care recommendations for sickle cell disease: Experience from SickleInAfrica. Front Genet 2022;13:1052179.
- 9 United States Department of State. U.S.-Africa leaders summit. 2021-2025 Available: https://2021-2025.state.gov/africasummit/
- 10 Thigo P. Tanzania-us partnership for health and health services health and health care roundtable. 2021.
- 11 UNECE. Public-private partnerships (ppps) for the SDGs. 2025 Available: https://unece.org/pppFebruary12
- 12 Caelers D. Plan for network of Genomics Centres of Excellence across Africa. Nat Africa 2023.
- 13 Piel FB, Rees DC, DeBaun MR, et al. Defining global strategies to improve outcomes in sickle cell disease: a Lancet Haematology Commission. Lancet Haematol 2023;10:e633–86.