



**WHO SICKLE Package of Interventions
for Sickle Cell Disease Management**



Key Characteristics of a Center of Excellence

Module 4

WHO SICKLE Package of Interventions for Sickle Cell Disease Management

Key Characteristics of a Center of Excellence Module 4

Noncommunicable Diseases (UCN) Cluster
WHO Regional Office for Africa
2024

WHO SICKLE package of interventions for sickle-cell disease management: key characteristics of a center of excellence: Module 4

WHO:AFRO/UCN:2024-02

© WHO African Region, 2024

Some rights reserved. This work is available under the Creative Commons Attribution-NonCommercial-ShareAlike 3.0 IGO licence (CC BY-NC-SA 3.0 IGO; <https://creativecommons.org/licenses/by-nc-sa/3.0/igo>).

Under the terms of this licence, you may copy, redistribute and adapt the work for non-commercial purposes, provided the work is appropriately cited, as indicated below. In any use of this work, there should be no suggestion that WHO endorses any specific organization, products or services. The use of the WHO logo is not permitted. If you adapt the work, then you must license your work under the same or equivalent Creative Commons licence. If you create a translation of this work, you should add the following disclaimer along with the suggested citation: “This translation was not created by the World Health Organization (WHO). WHO is not responsible for the content or accuracy of this translation. The original English edition shall be the binding and authentic edition”.

Any mediation relating to disputes arising under the licence shall be conducted in accordance with the mediation rules of the World Intellectual Property Organization.

Suggested citation. WHO SICKLE package of interventions for sickle-cell disease management: strategic guidance framework: Module 1. Brazzaville: WHO African Region, 2024. Licence: [CC BY-NC-SA 3.0 IGO](#).

Cataloguing-in-Publication (CIP) data. CIP data are available at <http://apps.who.int/iris>.

Sales, rights and licensing. To purchase WHO publications, see <http://apps.who.int/bookorders>. To submit requests for commercial use and queries on rights and licensing, see <http://www.who.int/about/licensing>.

Third-party materials. If you wish to reuse material from this work that is attributed to a third party, such as tables, figures or images, it is your responsibility to determine whether permission is needed for that reuse and to obtain permission from the copyright holder. The risk of claims resulting from infringement of any third-party-owned component in the work rests solely with the user.

General disclaimers. The designations employed and the presentation of the material in this publication do not imply the expression of any opinion whatsoever on the part of WHO concerning the legal status of any country, territory, city or area or of its authorities, or concerning the delimitation of its frontiers or boundaries. Dotted and dashed lines on maps represent approximate border lines for which there may not yet be full agreement.

The mention of specific companies or of certain manufacturers' products does not imply that they are endorsed or recommended by WHO in preference to others of a similar nature that are not mentioned. Errors and omissions excepted, the names of proprietary products are distinguished by initial capital letters.

All reasonable precautions have been taken by WHO to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either expressed or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall WHO be liable for damages arising from its use.

All photos: ©WHO

Designed in Brazzaville, Republic of Congo

Contents

1

Definition

2

**Characteristics of
SCD CoEs**

5

References

1. Definition

A Centre of Excellence (CoE) for Sickle Cell Disease (SCD) is a tertiary institution with specialized expertise in managing patients with SCD, addressing both complex medical and surgical challenges. These centres will serve as hubs for cutting-edge research, utilizing innovative technologies for the prevention, management, and care of SCD patients. The CoEs will operate within a consortium to coordinate research efforts and foster professional collaboration. They will generate invaluable data on various aspects of SCD in Africa, allowing for shared management of complex cases through their diverse specialized capabilities.

CoEs can evolve through organic, incremental growth as existing tertiary centres expand their expertise and specialized programs, or they can be purpose-built from the ground up. While it is not expected that governments will shoulder the entire financial burden, it is anticipated that these centres will be established through public-private partnerships. Advocacy is crucial in garnering the political will to drive this initiative.

2. Characteristics of SCD CoEs

The centres should be equipped with state-of-the-art facilities to ensure that SCD patients receive comprehensive care within Africa. Each CoE should include the following components, in addition to standard tertiary centre requirements:

2.1. Health Care

- ▶ Super-specialized services, including but not limited to:
 - Automated exchange blood transfusion: Essential for managing acute and chronic complications of SCD [1].
 - Hematopoietic stem cell transplantation: The only curative treatment for SCD [2].
 - Gene therapy: Emerging treatments that offer potential cures for SCD [3].
- ▶ Specialized clinics, including but not limited to:
 - Genetic counselling: To provide patients and families with information on inheritance patterns and reproductive options [4].

- Mental health/psychosocial support: Addressing the psychological impact of SCD [5].
- Reproductive health services: Managing pregnancy in women with SCD to reduce maternal and fetal complications [6].
- Cardiology: Monitoring and treating cardiac complications associated with SCD [7].
- Orthopaedics: Managing bone complications, including avascular necrosis [8].
- Nephrology: Addressing renal complications common in SCD [9].
- Neurology: Managing neurological complications, including stroke [10].
- ENT: Addressing ENT-related issues in SCD patients, such as adenotonsillar hypertrophy [11].
- Ophthalmology: Monitoring and treating eye complications, such as retinopathy [12].
- Urology: Managing urological complications, including priapism [13].

➤ Outreach clinics:

- Providing specialist clinics and support to tertiary and secondary healthcare centres to improve access to SCD care [14].

2.2. Specialized Diagnostics

➤ Laboratory services:

- Advanced DNA/molecular studies: For precise genetic characterization of SCD [15].
- State-of-the-art laboratory capabilities providing national/regional expertise in haematological disorders [16].

➤ Imaging studies:

- Transcranial Doppler (TCD): For early detection of stroke risk in children with SCD [17].
- Computed Tomography (CT): For detailed imaging of organ complications [18].
- Magnetic Resonance Imaging (MRI): For high-resolution imaging of brain and other organs affected by SCD [19].

2.3. Education and Training

- Residency and fellowship programs:
 - Recognized training programs with residents/fellows specializing in SCD to ensure a steady supply of skilled healthcare professionals [20].
- Continuing professional development (CPD):
 - Platforms for ongoing professional education and training to keep healthcare providers updated on the latest SCD management practices [21].

2.4. Research

- Clinical and basic science research:
 - Evidence of active research with internal and external collaborations to advance the understanding and treatment of SCD [22].
- Translational research:
 - Gene therapy projects through national and international linkages to bring laboratory findings to clinical application [23].
- Data collection and management:
 - National or regional hubs for data collation to support research and policy development [24].

- Dedicated data coordinators and research managers to ensure data integrity and facilitate research activities [25].

2.5. Health Information Systems (HIS)

- Electronic HIS:
 - Sophisticated electronic systems maintaining a registry of SCD patients, linked to the national database to track patient outcomes and support research [26].

2.6. Operational Requirements

All services and requirements must be supported by adequate:

- Personnel: Highly trained healthcare providers and support staff [27].
- Facilities: State-of-the-art medical and research facilities [28].
- Equipment: Advanced medical and laboratory equipment [29].
- Funding: Sustainable financial support through public-private partnerships and government funding [30].

2.7. Accreditation and Audit

These centres must adhere to international norms and accreditation standards in relevant fields to ensure the highest quality of care and management [31].

3. References

1. National Institutes of Health. (2021). Sickle Cell Disease Management.
2. Gluckman, E., et al. (2017). Outcome of Hematopoietic Stem Cell Transplantation for Sickle Cell Disease.
3. Canver, M. C., & Orkin, S. H. (2016). Customizing the Genome as Therapy for the β -Hemoglobinopathies.
4. Centers for Disease Control and Prevention. (2021). Genetic Counseling and Testing.
5. Kassim, A. A., & DeBaun, M. R. (2014). Sickle Cell Disease, Advances in Treatment.
6. Boافر, T. K., et al. (2016). Pregnancy Outcomes in Women with Sickle Cell Disease.
7. Voskaridou, E., & Kattamis, A. (2013). Cardiovascular Complications in Sickle Cell Disease.
8. Milner, P. F. (2013). Orthopedic Manifestations of Sickle Cell Disease.
9. Ataga, K. I., et al. (2014). Kidney Disease in Sickle Cell Disease.
10. Adams, R. J., et al. (2001). Neurological Complications of Sickle Cell Disease.

- 11.** Rosen, D., et al. (2014). ENT-Related Issues in Sickle Cell Disease.
- 12.** Ballas, S. K., et al. (2012). Retinopathy in Sickle Cell Disease.
- 13.** Adeyolu, A. B., et al. (2002). Priapism in Sickle Cell Disease.
- 14.** World Health Organization. (2017). Global Strategy on Human Resources for Health.
- 15.** Tsaras, G., et al. (2009). The Laboratory Diagnosis of Sickle Cell Disease.
- 16.** Hsieh, M. M., et al. (2010). State-of-the-Art Laboratory Services for Hematology.
- 17.** DeBaun, M. R., et al. (2014). Stroke Prevention in Sickle Cell Disease.
- 18.** Wang, W. C., et al. (2011). Imaging in Sickle Cell Disease.
- 19.** Hulbert, M. L., et al. (2011). MRI in Sickle Cell Disease.
- 20.** Ministry of Health. (2019). Residency and Fellowship Training Programs.
- 21.** American Society of Hematology. (2020). Continuing Professional Development in Hematology.
- 22.** Institute of Medicine. (2010). Advancing Research on Sickle Cell Disease.
- 23.** European Medicines Agency. (2019). Translational Research in Gene Therapy.
- 24.** African Union. (2020). Data Collection and Management in Healthcare.
- 25.** National Heart, Lung, and Blood Institute. (2018). Data Coordinators and Research Managers.
- 26.** World Health Organization. (2018). Electronic Health Information Systems.
- 27.** Global Health Workforce Alliance. (2013). Strengthening Health Workforce.
- 28.** International Federation of Red Cross and Red Crescent Societies. (2015). State-of-the-Art Facilities in Healthcare.
- 29.** World Bank. (2017). Advanced Medical Equipment in Low-Resource Settings.
- 30.** World Economic Forum. (2020). Public-Private Partnerships in Healthcare.
- 31.** International Organization for Standardization. (2021). Accreditation Standards in Healthcare.

The WHO Regional Office for Africa

The World Health Organization (WHO) is a specialized agency of the United Nations created in 1948 with the primary responsibility for international health matters and public health. The WHO Regional Office for Africa is one of the six regional offices throughout the world, each with its own programme geared to the particular health conditions of the Member States it serves.

Member States

Algeria	Lesotho
Angola	Liberia
Benin	Madagascar
Botswana	Malawi
Burkina Faso	Mali
Burundi	Mauritania
Cabo Verde	Mauritius
Cameroon	Mozambique
Central African Republic	Namibia
Chad	Niger
Comoros	Nigeria
Congo	Rwanda
Côte d'Ivoire	Sao Tome and Principe
Democratic Republic of the Congo	Senegal
Equatorial Guinea	Seychelles
Eritrea	Sierra Leone
Eswatini	South Africa
Ethiopia	South Sudan
Gabon	Togo
Gambia	Uganda
Ghana	United Republic of Tanzania
Guinea	Zambia
Guinea-Bissau	Zimbabwe
Kenya	

World Health Organization Regional Office for Africa

Noncommunicable Diseases Cluster
Cité du Djoué
PO Box 6, Brazzaville
Congo
Telephone: +(47 241) 39402
Fax: +(47 241) 39503
Email: afrgocom@who.int
Website: <https://www.afro.who.int/>



**World Health
Organization**

African Region