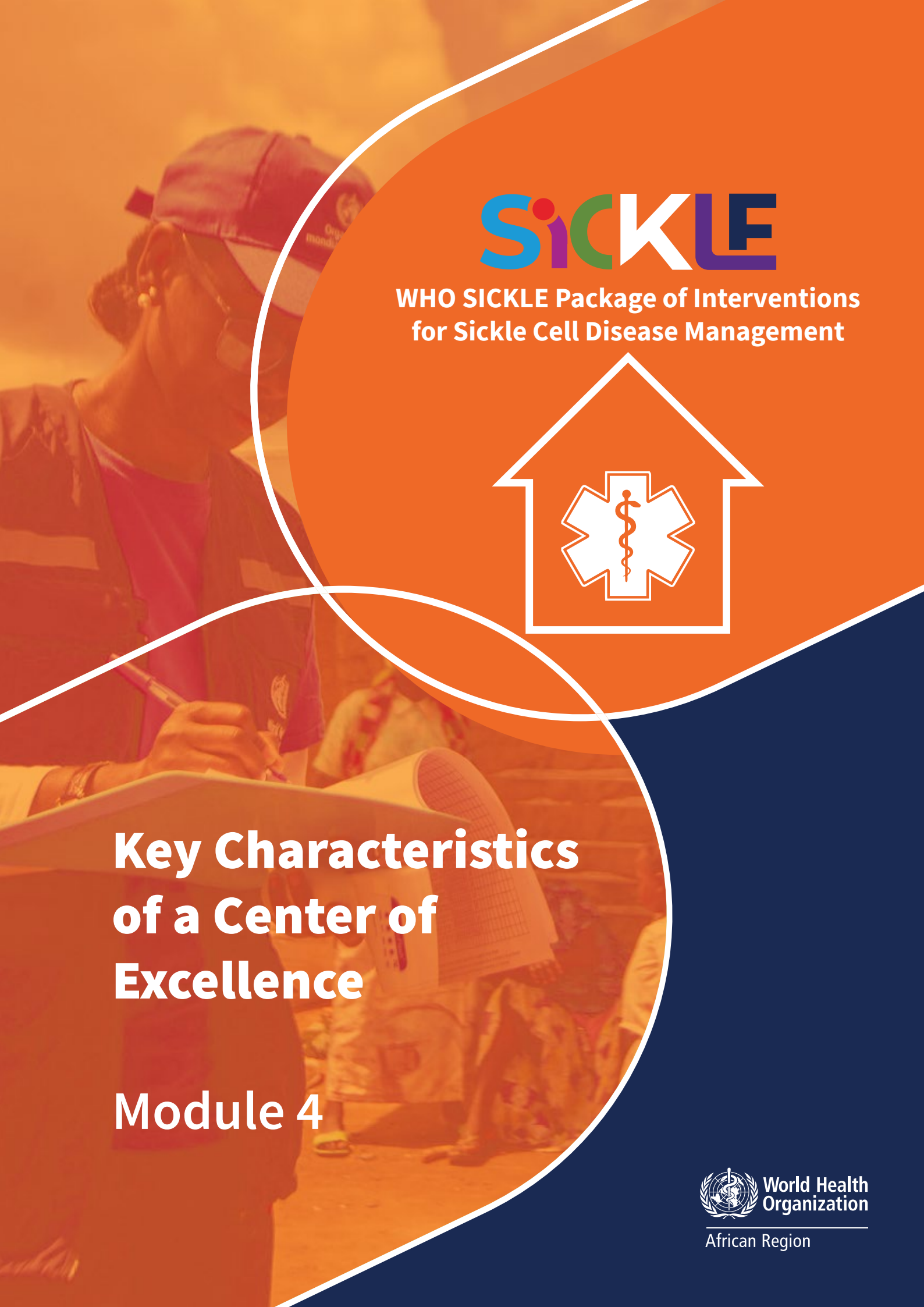

SICKLE

WHO SICKLE Package of Interventions for Sickle Cell Disease Management

Key Characteristics of a Center of Excellence

Module 4

World Health Organization
African Region

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

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.

Designed in Brazzaville, Republic of Congo

Contents

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

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