



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



# **Key Characteristics of a Center of Excellence**

## **Module 4**

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## **Key Characteristics of a Center of Excellence Module 4**

Noncommunicable Diseases (UCN) Cluster  
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## WHO SICKLE package of interventions for sickle-cell disease management: key characteristics of a center of excellence: Module 4

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# 1. Definition

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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

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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].



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