

SICKLE CELL DISEASE ERADICATION INITIATIVE

(SCDEI)

STRATEGIC PLAN

FOR THE PERIOD

2021 -2026

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FOREWORD

Sickle cell disease has been largely an invisible global health issue, especially in regions of high incidence mainly due to lack of awareness among both the local health policy makers and the public. Sickle cell disease is by far the commonest inherited disorder in the world with 75% of cases occurring in Africa. Nigeria contributes about half of the estimated 300,000 newborns with Sickle cell disorder annually, this causes immense suffering to patients, their families and caregivers. However, Yobe State of Nigeria has a recent prevalence of 32.6% - the highest in the country. This inherited disorder can be completely eradicated when necessary policies on premarital genotype counselling and testing, public health interventions such as screening of newborns and awareness raising on Sickle Cell Disease are put in place.

These challenges necessitated the formation of Sickle Cell Disease Eradication Initiative (SCDEI), a Community Based Organisation (CBO) registered in Damaturu Yobe-State with the aim of eradicating Sickle Cell Disease in Yobe-State, Northeastern Nigeria, Nigeria, Africa and the world at large.

This strategic plan is intended to guide Sickle Cell Disease Eradication Initiative (SCDEI) in achieving her strategic objectives.

Sickle Cell Disease Eradication Initiative (SCDEI) has been opened to real challenges facing communities and the result of which, have partly helped inform our plans. Among the challenges is the socio-cultural beliefs, insecurity, conflicts and displacement food insecurity and poor economic status among others. Amidst these challenges, strategic intervention necessitated continuity to balancing our resource allocation to programme areas of awareness raising, care and support and livelihood. With the focus of building and strengthening the capacity of health educators, improve patients care and empower family and caregivers with vocational skills and financial literacy support is the SCDEI's goal for the next 5 years.

To achieve this goal, Sickle Cell Disease Eradication Initiative (SCDEI) implementation strategy of its activities shall be carried out in a systematic manner using responsible speed.

First, our intervention shall be based on researched facts and information, Organisation Capacity Assessment (OCA), and Sickle Cell Disease control programs.

Our organisation development strategy in the strengthening of health educators shall focus on ensuring that they have the required competencies, systems and resource mobilisation strategies to deliver premarital genotype counselling and testing. The improved sickle cell disease patients' care shall focus on the provision of accessible blood bank and transfusion services and affordable or free treatment services through policy advocacy and strategic partnerships with key stakeholders. While the livelihood strategy shall focus on the provision of sustainable vocational skills, entrepreneurship skills and enhance accessibility to credit and financial support to the family and caregivers.

In the implementation of the plan, Sickle Cell Disease Eradication Initiative (SCDEI) will promote the strategy advocacy on policy influence, strategic partnerships with key stakeholders like local, state and federal governments, donor agencies and relevant networks. Exposure visits of communities shall be promoted to enhance learning and sharing from one another.

I would like to thank the various stakeholders who contributed to the development of this strategic plan through sharing their ideas with us. Hope to continue learning and sharing from one another in order to attain excellence.

I thank the executives and all the members for their creativity and willingness to critic their methods of work and above all for their tireless commitment during the strategic planning process.

I am confident of their continued commitment in the implementation this plan.

Yours,

Dr Aliyu Usman Muhammad (RN, MBChB, MPH)

Executive Director

SCDEI

LIST OF ACRONYMS

CBO	-	Community Based Organisation
CSO	-	Civil Society Organisations
GBV	-	Gender Based Violence
GDP	-	Gross Domestic Product
IEC	-	Information, Education and Communication
LG	-	Local Governments
LSMS	-	Living Standards Measurement Study
NBS	-	New Born Screening
NBS	-	National Bureau of Statistics
NGO	-	Non-Governmental Organisation
NLSS	-	Nigerian Living Standards Survey
OCA	-	Organisation Capacity Assessment
OVI	-	Objectively Verifiable Indicators
SCA	-	Sickle Cell Anaemia
SCD	-	Sickle Cell Disease
SCDEI	-	Sickle Cell Disease Eradication Initiative
SOCP	-	Standard-Of-Care Practices
SWOT	-	Strength, Weakness, Opportunities, Threats
ToTs	-	Training of Trainees
WHO	-	World Health Organisation

1.0 EXECUTIVE SUMMARY

This is the first strategic plan of Sickle Cell Disease Eradication Initiative (SCDEI). SCDEI was founded in 2020 and became a legal entity in 2021 as a Community Based Organisation (CBO) registered in Yobe-State Nigeria. The organization's main aim is to eradicate Sickle Cell Disease, improve the quality of care for sickle cell disease patients and improve on the livelihood of patients, their families and caregivers through awareness raising on premarital genotype counselling and testing, provision of accessible blood bank and transfusion services entrepreneurship and mentorship among others. SCDEI currently operates in Yobe-State Nigeria in areas of public health awareness, patient care support, vocational training and entrepreneurship skills among others.

This document highlights the plan of sickle cell disease eradication initiative (SCDEI) for the next five years. We intend to implement activities following this plan; the activities and budget are herein attached. The documents further show the methodology used to develop this plan, the SWOT analysis, and the background information of SCDEI, objectives, mission statement, mandates and core functions, the organization structure, implementation, monitoring, evaluation and control.

This strategic plan aims at contributing to empower the sickle cell disease patients, their families, caregivers and other community members with knowledge and support through skills and resources for self-sustenance in order to improve their livelihood and achieve community development & peaceful co-existence. The community will be empowered and engaged in decision making processes to address their strategic needs. This will be done in 3 thematic areas i.e. Awareness raising, Patient's care support and livelihoods improvement through skills and entrepreneurship.

SCDEI's strategic approach involves the following; working in consortiums of regional and national organizations, dialogues, ICT platform, IEC materials, Advocacy and lobbying, ToTs, use of existing religious and government structures, knowledge structure and strategic partnerships.

Vision:

An empowered society free of Sickle Cell Disease.

Mission:

To empower Sickle Cell Disease warriors and the community with knowledge, services and skills for self-sustenance in order to achieve community development & peaceful co-existence.

Objectives:

1. To provide health education and raise awareness on Sickle Cell Diseases (SCD) within the community.
2. To encourage Pre-marital counselling and testing for Sickle Cell Diseases (SCD) using HB Genotype or any other recommended test for SCD
3. To promote early screening for SCD amongst children at six (6) months of age, for timely management of affected children.
4. To carry out routine meetings with parent, caregivers, patients and care providers for updates and experience sharing for effective management of SCD patients.
5. To provide unique identification to registered members for easy access to emergency healthcare services.
6. To establish special blood bank for SCD patients in collaboration with government and development partners.
7. To advocate and champion the establishment of special clinics for SCD patient across the state for effective management and follow-up.
8. To advocate and lobby through relevant stakeholders, the provision of SUBSIDIZED or FREE testing and treatment for SCD Patients.
9. To establish a trust fund to support and empower members affected by SCD.
10. To develop and promote eradication strategies for SCD in the community.
11. To advocate and promote for the permanent treatment of SCD using Stem Cell Therapy and other effective treatment modalities, both within and outside Nigeria.

12. To advocate and lobby for legislative laws on compulsory pre-marital testing for SCD and banning marriages between high risk spouses such as; AS and AS, SS and AS, SS and SS etc.
13. To sensitize communities and the community populace through drama, radio jingles and sharing of posters and other Information, Education and Communication (IEC) materials on the need to eradicate SCD.
14. To establish a secure and credible database for SCD patients using standard and approved methods of data collection and storage.

Core values:

- A. Transparency: Ensuring good governance and accountability.
- B. Team work: Achieving success through collective efforts.
- C. Open mindedness: Willing to listen & share new ideas and respecting other people's opinions.
- D. Exemplary: Being inspirational to society.
- E. Excellence: Striving for the best in everything.

1.1 Organisation structure

- a. Advisory Board
- b. Sickle Cell Disease Eradication Initiative Project (SCDEI) Management Committee.
- c. SCDEI Project Coordinator.
- d. SCDEI Assistant Coordinator.
- e. SCDEI Volunteers

a. The Advisory Board

The members of the Board shall oversee the running of the CBO.

b. The Management Committee.

- To supervise the day to day running of the SCDEI
- Handle financial transactions involving SCDEI.
- Arrange routine meetings with the personnel who manage the project.

c. SCDEI Coordinator

- Direct the implementation of the Project
- Coordinate trainings for the different groups of stakeholders.
- Supervise organisational programs and liaise with relevant stakeholders towards successful implementation of SCDEI's activities.

- Giving accountability to the management committee.

d. SCDEI Assistant Coordinator.

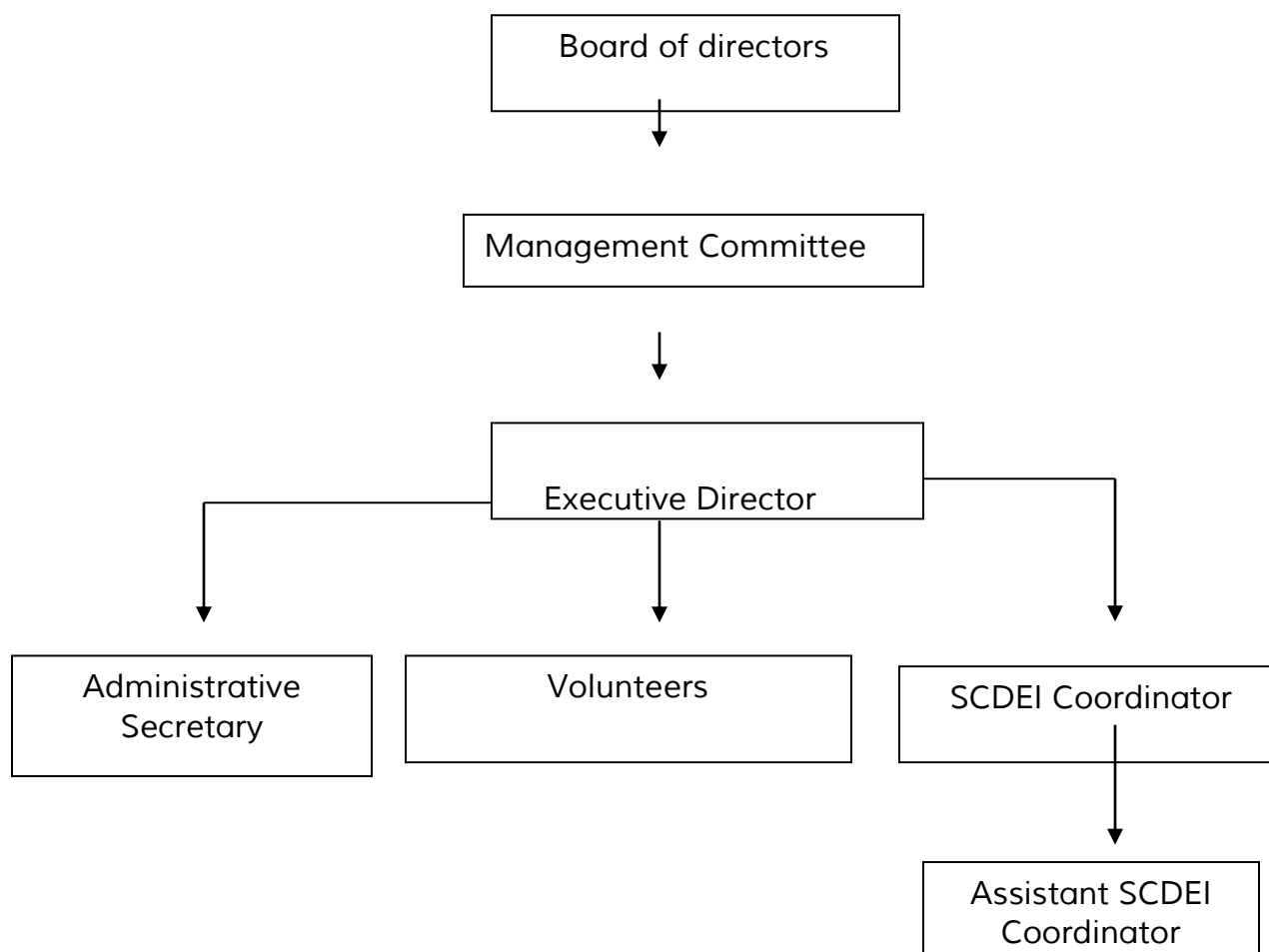
- Supports the Coordinator
- Oversee the experts and instructors carrying out different activities of the organisation.
- Handling registration of members
- Organizing and keeping project files.
- Other responsibilities assigned by the coordinator.

e. Volunteers.

- Do Community Sensitization.
- Engage in health education and training.
- Carryout Community outreach programs.

1.2 The Organogram

Organogram of Sickle Cell Disease Eradication Initiative (SCDEI)



1.3 Aims of the strategic plan.

The aim of this strategic plan is to enable Sickle Cell Disease Eradication Initiative (SCDEI) have a systematic way of implementing what has been planned in order to achieve its objectives in the next five years.

To facilitate the achievement of its strategic agenda, SWOT analysis for Sickle Cell Disease Eradication Initiative (SCDEI) was carried out. This involved identifying key strengths, weaknesses, opportunities and threats, which constitute the internal and external operational environment.

The review exercise was intended to critically examine the current operations of Sickle Cell Disease Eradication Initiative (SCDEI) to identify gaps and develop strategies that would enhance its operation on accessing the most grassroots communities in the state and country at large. The strategic plan will be operational for the next 5 years up to 2026.

2.0 Methodology.

To solicit for the input of primary stakeholders, a one-day strategic plan workshop comprising representatives of the executive board members, sickle cell disease eradication initiative (SCDEI) secretariat staff and some representatives of the local community members was held on 10th and 4^h September, 2020.

A participatory, flexible and interactive approach was employed throughout the planning process. The method was most appropriate particularly because the stakeholders would be the implementers of the plan and their interest would be catered for. Therefore, their full participation in the planning process was necessary to ensure ownership of the plan. The plan 2021-2026 is based on information collected from various sources. Basically the field walks and consultative meetings held in 2020, the baseline survey and needs assessment conducted in March 2020. World Health Organisation (WHO) Sickle-Cell Disease Strategy for the African Region, Civil Society Organisation (CSO)'s strategy documents, Research and scientific findings, recommendations and key lessons learnt from implemented projects, staff and stakeholders' discussions, organization assessment report, consultation of local and state government officials.

2.1 situational analysis

Yobe is located in northeast Nigeria and borders four Nigerian states as well as the Republic of Niger. It has a population of 3.4 million. Its economy is mainly based on agriculture which is greatly affected by the ongoing humanitarian crises due to the Boko Haram war currently ongoing in the region. Thus, the burden of SCD (32.6% prevalence) further worsens the economy of the people as their main source of livelihood (agriculture) was significantly disrupted by insecurity in the region.

In 2006, the World Health Organization (WHO) acknowledged SCD as a disease with high global impact and a remarkable public health significance in Africa with a greater need for attention to improve the overall child survival rate. Sickle cell disease (SCD) is a more common and severe disease in Africa. Nigeria the most populous black nation in Africa has the largest number of Sickle Cell Anaemia (SCA).

In Nigeria, the prevalence of sickle cell trait is about 23.7%, while the frequency of sickle cell disease is about 20 per 1000 births resulting in about 150,000 babies being born annually with SCD. This figure ranks Nigeria, a country with the largest burden of SCD globally with about 2.69–5% of the population being affected. (SCA). Borno and Yobe States have the largest number of sickle cell trait in Nigeria with prevalence of 27.9% and 32.6% respectively (above the National figure of 23.7%). The WHO estimates that 70% of SCD deaths in Africa are preventable with simple, cost-effective interventions such as early identification of SCD patients by Newborn Screening (NBS) and subsequent provision of comprehensive care

Socio-cultural situation;

Yobe state is predominantly Muslim society where intermarriages between first cousins and other distant relatives is acceptable, hence aiding the occurrence of hereditary diseases like Sickle Cell Disease within the community. More so, the cultural norms and values do not enforce premarital genetic counselling and testing on intending couples who often know their genotype retrospectively after giving birth to SCD child. Due to these factors cultural and religious institutions are very key in reaching out to the community.

The medical care support situation;

Although Nigeria has the highest burden of sickle cell disease (SCD) worldwide, there is still variable and poor utilisation of Standard-Of-Care Practices (SOCP) for SCD patients in the country. The care available for SCD in Nigeria is still suboptimal and there is an urgent need for concerted effort to tackle the problem, but to make a significant impact on the burden of the disease would require more focus at the primary care level. The key to successful management of SCD patient include health education, access to blood transfusion services, availability and affordability of routine medications in addition to family care and support. Therefore, provision of efficient blood bank and transfusion services, advocating for policies that could offer free or subsidize laboratory and medical services to SCD patients could significantly improve the lives of SCD warriors or survivors.

The economic situation;

Nigeria's real Gross Domestic Product (GDP) growth was estimated at 2.3% in 2019, marginally higher than 1.9% in 2018. Growth was mainly in transport, an improved oil sector, and information and communications technology. Agriculture was hurt by sporadic flooding and by conflicts between herdsmen and local farmers. The economic downturn in Nigeria was triggered by a combination of declining oil price and spillovers from the Covid-19 outbreak, which not only led to a fall in the demand for oil products but also stopped economic activities from taking place when social distancing policies were enforced. In 2020, the Nigerian economy retracted due to the COVID-19 outbreak, reporting a negative growth balance of 4.3%, compared to 2.2% in 2019. According to the IMF's October 2020 forecast, growth is expected to resume in 2021, estimated at 1.7% of GDP, and stabilise in 2022 at 2.5%.

Therefore, there is need to keenly address the economic question by ensuring zero tolerance to corruption, pursuing sound macro and microeconomic policies and ensuring equity in distribution of the economic gains across all regions. This will cater for all SCD patients, their families and ensures emancipation and economic revitalization of the grass root communities.

The livelihood situation;

Nigeria is classified among the developing countries in the world with a high degree of economic vulnerability and one of most highly populated countries with a population growth of 2.6% with a total fertility rate of 5.3%. The country's rural communities mainly depends on agriculture whose GDP has reduced to 21.9%. Rising level of insecurity, economic recession and political unrest in some parts of the country further worsens the livelihood situation of the common citizen. Furthermore, the northeast Nigeria's source of livelihood is majorly agriculture which is significantly affected by the current regional war by Boko Haram. At community level there is need to create awareness and build community capacities to respond to realities of the cash economy so they can shift focus from the traditional systems of production to market oriented ones. This is often

impossible due to lack of appropriate skills, poor attitude towards hard work, and lack of incentives for innovation, lack of capital inputs, poor roads, markets, and electricity among others.

In summary, the situation reveal that the people are among the poorest of the poor who lack a secure and sustainable livelihood.

2.2 The SWOT Analysis.

In order to set the future direction of Sickle Cell Disease Eradication Initiative (SCDEI) in terms of vision, mission, objectives and goals, a full understanding of the internal and external environment is of paramount importance. This is intended to realise the direction and actualise the set strategies in the uncertain environment. The following were established as key strength, weakness, opportunities and threats to Sickle Cell Disease Eradication Initiative (SCDEI)

2.2.1 Internal assessment

Strength

- a. Sickle Cell Disease Eradication Initiative (SCDEI)'s registration with the Yobe State Government enables it to operate legally.
- b. Sickle Cell Disease Eradication Initiative (SCDEI) has active members who voluntarily support the organisation with finances and technical expertise.
- c. Well-articulated core programme activities.
- d. A clear structure with well-defined roles & responsibilities.
- e. Good working relationship and strong partnerships with local authorities, Non-Governmental Organisations and other development partners.
- f. Working with Interfaith organisations dealing with all religious sects for peace, harmony, tolerance and community development.

Weakness

- a. Lack of funds / permanent funds to implement our strategic plan.
- b. Lack of permanent premises for the Sickle Cell Disease Eradication Initiative secretariat, which affects the effective running of the organisation.
- c. Reliance on external consultants in capacity building initiatives

- d. Under staffing at the secretariat compared to the existing workload.

2.2.2 External assessment

Opportunities

- a. Growth in membership.
- b. Enabling political environment in Yobe state, which enables Sickle Cell Disease Eradication Initiative conduct its activities with ease.
- c. The Sickle Cell Disease Eradication Initiative structure allows a bottom-up flow of ideas and information.
- d. Recognition of Sickle Cell Disease Eradication Initiative by the relevant authorities- in areas where it operates.
- e. Partnership with local CSOs and other International development partners- networks.

Threats

- a. The current policies of the Nigerian Government on Aid in the Northeast region does not favour effective operation of CBOs like SCDEI.
- b. Over reliance on donors, this is likely to cause donor fatigue.
- c. High expectations and demands of members and the entire community.

Sickle cell disease eradication initiative (SCDEI) should consolidate the strength while exploiting the opportunity to their advantage. It should also capitalize on its strength to take advantage of the opportunities. However, weaknesses should be examined strongly and threats minimized.

This way Sickle Cell Disease Eradication Initiative will be able to realize its set mission and objectives.

2.3 goal, objective and strategies

Goal.

The broad goal for this strategic plan is to strengthen the capacity of health educators and policy influencers in the community towards eradication of Sickle Cell Disease, through awareness raising, medical care support and improving the source of community livelihoods.

Objectives

To realise the above broad goal, the following objectives are enlisted;

- a) To provide health education and raise awareness on Sickle Cell Diseases (SCD) within the community.
- b) To encourage Pre-marital counselling and testing for Sickle Cell Diseases (SCD) using HB Genotype or any other recommended test for SCD
- c) To promote early screening for SCD amongst children at six (6) months of age, for timely management of affected children.
- d) To carry out routine meetings with parent, caregivers, patients and care providers for updates and experience sharing for effective management of SCD patients.
- e) To provide unique identification to registered members for easy access to emergency healthcare services.
- f) To establish special blood bank for SCD patients in collaboration with government and development partners.
- g) To advocate and champion the establishment of special clinics for SCD patient across the state for effective management and follow-up.
- h) To advocate and lobby through relevant stakeholders, the provision of SUBSIDIZED or FREE testing and treatment for SCD Patients.
- i) To establish a trust fund to support and empower members affected by SCD.
- j) To develop and promote eradication strategies for SCD in the community.
- k) To advocate and promote for the permanent treatment of SCD using Stem Cell Therapy and other effective treatment modalities, both within and outside Nigeria.

- l) To advocate and lobby for legislative laws on compulsory pre-marital testing for SCD and banning marriages between high risk spouses such as; AS and AS, SS and AS, SS and SS etc.
- m) To sensitize communities and the community populace through drama, radio jingles and sharing of posters and other Information, Education and Communication (IEC) materials on the need to eradicate SCD.
- n) To establish a secure and credible database for SCD patients using standard and approved methods of data collection and storage.
- o) To strengthen the institutional capacity of SCDEI and its members in order to enable them deliver on their commitment with strategic partners.

Strategic approaches

1. Religious seminars /workshops
2. Training of Trainers (ToTs) - SCDEI shall work through carefully identified individuals and CBOs.
3. Use of IEC materials for information dissemination.
4. Use of media- electronic, social, print, TV stations and radios.
5. Use of existing Government and informal structures
6. Strategic partnerships: for purposes of resource mobilization, learning, information sharing among others.
7. Knowledge transfer
8. Monitoring and reporting on service delivery
9. Dialogue
10. Advocacy and lobbying

2.4 implementation strategies

SCDEI acknowledges the need to define and constantly follow a clear set of approaches if it is to achieve its goal by the end of the five-years. Below are strategies to be undertaken for the organization to achieve her goal and objectives.

- a) SCDEI will aim at mutual recognition and respect for one another's capacity as it works with the partners/stakeholders. Clear roles and responsibility will be reviewed to enhance partnership and mutual accountability.
- b) The organization shall strengthen its systems and procedures to enhance proper functioning. These include records, accounts, finance and administrative systems. Relevant manuals already developed to guide its operations.
- c) SCDEI secretariat provides a supportive role to the community as a facilitator, a conduit and a referral for member organizations. The organization shall concentrate effort to areas such as resource mobilisation, linking SCDEI to opportunities for capacity building and building systems for information management.
- d) SCDEI will adopt and or develop common guidelines and standards on best practice to the community where the activities are implemented.

2.5 outcomes for each objective

3.0 sustainability plan.

For SCDEI to effectively and efficiently implement this strategic plan it requires sustainable resource mobilization and institutional capacity building. This will call for using various fundraising mechanisms including project proposal writing to the various donors, starting up income generating activities, capacity building for members on various aspects in order to deliver on its mandate and mainstreaming the strategic plan in other programs.