A Comparative Study of Existing Sickle Cell Laws in Four States of Nigeria

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nguvu COLLECTIVE

Executive Summary

In Nigeria, the National Assembly is currently deliberating a National Law aimed at addressing the high prevalence of Sickle Cell Disease, while since 2017, four states have proactively introduced legislation at different times, requiring premarital genotype testing to help reduce the incidence of the disease.

This comparative study examines current pre-marital genotype screening laws in four Nigerian states: Kano, Anambra, Kaduna, and Abia, as well as a landscape analysis of the Sickle Cell Disease (SCD) burden in the country. This report examines how numerous elements of the State Laws handle sickle cell disease prevention, control, and management.

According to the World Health Organisation, Nigeria has the world's highest burden of SCD, with an estimated 150,000 births recorded per year. As a result, attempts to reduce the occurrence of SCD at the state level through the incorporation of premarital genotype screening as a preventive measure have increased across different governance structures (state, culture, and religion) in the country.

This study details the immense public health burden that SCD poses in Nigeria, where four to six million people carry the sickle cell trait, leading to SCD being listed as one of the top non-communicable diseases in the country. Though the Federal Government has made some interventions in the form of newborn screening programs and the establishment of SCD management centres, the success rate of these interventions is debatable, especially given Nigeria's low life expectancy for those with SCD (21 years) in comparison to global statistics (53.6 years) using the United States of America as a reference point.

The legal frameworks in Kaduna, Anambra, Kano, and Abia states are being examined to assess the role of premarital genotype screening as a preventive measure to tackle SCD in those states. Premarital genotype tests are generally voluntary; these laws were established to reduce the risk of SCD in future generations. **This comparative analysis encompasses an evaluation of the main provisions of the respective state laws, reviews the state of public awareness about these laws, enforcement procedures and penalties stipulated, as well as samples the thoughts of the key stakeholders involved in improving implementation in the respective states.**

The analysis further revealed common themes in these State Laws focused on promoting informed life-long decisions like marriage, public health awareness of SCD, care procedures for sickle cell patients, and reducing stigmatisation towards people with genetic disorders.

Challenges that have been noted throughout the research in the 4 states are:

- Inconsistent implementation: Enforcement of the law across the different states varies; some areas are not even aware of the existence of the law or its implementation, while others have limited implementation.
- Public awareness of the law: Awareness of these laws varied across the states.The level of awareness in Anambra is quite high. The Law is well known to the citizenry due to the active nature of advocacy efforts, especially by CSOs, spread across the state. The laws in other states, however, remained largely unknown except when discussed in policy online groups.
- Non-Standardised Framework: A standard legal framework does not exist at the national or sub-national level in the country. This poses differing ways to prevent SCD in these states and, hence, inconsistencies in policy implementation.
- Penalties and Restrictions: Penalties within the law seem to neglect certain conditions that might limit the implementation as they border on other rights that patients are entitled to. The analysis of the ethical and legal framework extensively covers these challenges.

While there are laws governing premarital genotype screening, the wide adoption of the screening programs and the understanding or knowledge of genetic blood disorders in the country are hindered by several challenges listed below:

- Rural Areas Left Behind: Awareness varies across the length and breadth of Nigeria, with urban areas having better access to information compared to their rural counterparts. Even among literate populations, knowledge of this disease remains very limited and scarce.
- Myths & Misconceptions: Common misconceptions about SCD persist, and among those, very little is often mentioned regarding the long-term implications of the disease. Poor advocacy efforts and general mutedness over the subject aggravate this condition.
- Accessibility & Cost: There are challenges concerning accessibility and cost that are significant, especially for the expense of the available genotype screening services, especially in rural areas. Primary Health Care (PHC) centres' resources are limited, and the expenses are therefore substantial, resulting in low participation in genotype screening.
- Infrastructure & Budgets: The Nigerian health system is characterised by the limited infrastructure and budgetary funds needed to provide essential care to SCD patients. Most states lack the facilities and equipment to allow for early detection and management, which forms the reason for late treatment with poor outcomes. It is equally expensive, hence the additional burden on the patients, their families, and the healthcare system.
- Socio-cultural and religious beliefs: These influence attitudes towards SCD and genotype screening. Marriage and family lineages are emphasised over genetic compatibility in many cultural norms. Though religious leaders provide counselling for screening, they face resistance from couples with incompatible genotypes who still want to intermarry. When met with the consequences, the culture of silence and stigmatisation by which SCD is characterised erodes trust and open communication.
- Legal and ethical considerations: Mandatory genotype screening laws, aimed at reducing SCD incidence and promoting public health, raise concerns about human rights and potential discrimination. There is a delicate balance between public health goals and individual freedoms, with debates ongoing about the best approach to implementing these laws without infringing on human rights.

Recommendations from the study include:

- Targeted public awareness campaigns;
- Stakeholder capacity development;
- Investments in research;
- Sharing of firsthand accounts of people living with SCD;
- Expanded access to affordable genotype screening services.

All of these can be done to reduce the incidence of SCD, respect individual rights, and solve the socio-cultural challenges of Nigeria.

Acknowledgement

This report is the brainchild of Nguvu Change Leader Onor-Obassi Egim Tawo, a survivor of Sickle Cell Disease from Cross-river State, who lost her brother to the disease. Onor, a lawyer, has been advocating for a national framework to address Sickle Cell Disease in Nigeria. In June 2024, she set out on a journey to assess the existing legal provisions on Sickle Cell in 4 states of Nigeria to inform the National Bill that was reintroduced in the Senate in May 2024. Onor's comparative study is supported by Nguvu Collective's staff in Nigeria.

The authors wish to express their deepest gratitude to the interviewees who generously shared their personal experiences and insights. Their willingness to engage in this study has provided invaluable contributions, bringing depth and authenticity to our findings.

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Also to all stakeholders who supported this project in providing insights, your contributions, no matter how small, have been instrumental in bringing this project to fruition. We hope that the insights gained from this research will contribute meaningfully to ongoing efforts in the field and inspire further collaboration and action.

About Nguvu Collective
Nguvu Collective, an international non-profit organisation dedicated to empowering women leaders from marginalised communities. We work with individuals who have lived experiences of injustice to drive social and political change by enhancing their capacities to champion issues through narrative campaigns, organising, and mobilising support.

At Nguvu Collective, we provide resources, expertise, and support to these women to help them advocate effectively for their rights and causes. Our approach includes developing strategies, facilitating connections with key stakeholders, offering training and tools for campaign execution, and amplifying their campaign messages.

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Abbreviation

FMoH	Federal Ministry of Health
IDI	In-depth Interviews
SCD	Sickle Cell Disease
HbSS	Homozygous Sickle Cell Disease
HPCL	High-Performance Liquid Chromatography
HIV	Human Immunodeficiency Virus
NASS	National Assembly of Nigeria
NCD	Non-Communicable Diseases
SOPs	Standard Operating Procedures
WHO	World Health Organisation

Onor Obassi Tawo at one of her grassroots interventions on Sickle Cell.
Image Credit: Okares Sickle Cell Foundation

Introduction

According to the World Health Organisation, Nigeria is home to one of the highest burdens of Sickle Cell Disease (SCD) globally, with an estimated 150,000 children born each year with this genetic disorder. Sickle Cell Disease is a condition characterised by the production of abnormally shaped red blood cells that can lead to severe pain, organ damage, and reduced life expectancy if not managed effectively. Advocacy efforts led by Nguvu Change Leader, Onor-Obassi Egim Tawo, and various organisations persist in pushing for a national framework on sickle cell awareness, screening for prevention, and early diagnosis.

To grasp the existing disparities in sickle cell prevention and control regulations across the four states of Kano, Anambra, Kaduna, and Abia, Nguvu Change Leader Onor-Obassi Egim Tawo from Cross River State, with support from fellow Change Leader Mariya Bagudo supported by Nguvu Collective's Nigeria team, presents a comprehensive analysis of enacted laws and their implementation.

This comparative examination of sub-national laws intends to:

1. Shed light on policy formulation and implementation, encompassing legal frameworks, enforcement mechanisms, screening service accessibility, and public awareness endeavours.
2. Enable a deeper understanding of the gaps in the formulation and implementation of state laws that need resolution, and inform the Sickle Cell Anaemia (Prevention, Control, and Management) Bill, 2022 introduced in the Senate on critical aspects that will enhance the effectiveness of policy and law implementation.

Methodology

This research employed a qualitative approach to review legal frameworks and assess public perceptions of premarital genotype screening laws across four Nigerian states. The methodology was divided into three main components:

Legal Framework Analysis:

- Document Review: State laws and policies were reviewed through government websites and online databases. Relevant documents were examined to understand the legal context.
- Expert Consultation: Insights were sought from a legal expert to ensure a thorough interpretation of the data.
- Data Categorisation: The data were categorised based on policy comprehensiveness,enforcement mechanisms, and penalties.

Stakeholder Engagement:

- In-depth Interviews (IDIs): Detailed interviews were conducted with healthcare workers, clerics, policymakers, and community leaders. These interviews were conducted both online and through in-person meetings
- The aim was to explore stakeholders' experiences and challenges with premarital genotype screening laws, to identify barriers to policy implementation, and to gather suggestions for improvement.
- Online IDIs were carried out via Google Meet, with recordings and transcriptions managed by Fireflies.

Social media Listening:

- A social media listening approach was employed to gauge public sentiment. This method was used to measure public discourse and complement the insights gained from interviews.

Respondent Demography

The respondents for this study were strategically chosen to capture diverse perspectives within the sickle cell ecosystem across four states, ensuring a comprehensive understanding of the issues related to its prevention, management, and advocacy. A total of 15 respondents participated in the interview drawn from the following sub-groups.

- Medical Practitioners: Key healthcare professionals, including medical doctors, nurses, and paediatricians, were selected for their expertise in diagnosing and managing sickle cell disease. Their insights are vital in identifying healthcare challenges, evaluating current protocols, and assessing the feasibility of interventions like premarital genetic screening.
- Clerics: Religious leaders, who influence community beliefs and decisions, were included due to their role in counselling couples on genetic compatibility. Their perspectives help us understand the cultural and religious factors that could impact the acceptance of health initiatives such as premarital screening.
- Sickle Cell Advocates: Advocacy groups were chosen for their role in raising awareness and pushing for policy changes surrounding SCD. Their input highlights the challenges and opportunities in ongoing efforts to support individuals living with sickle cell disease and the need for effective advocacy.
- Individuals Living with Sickle Cell Disease (Sickle Cell Warriors): Individuals living with SCD provide firsthand accounts of the challenges they face. Their experiences are crucial for understanding the personal impact of the disease and the effectiveness of current healthcare practices.

Limitations of the Research

The study is a descriptive analysis of the existing legislation on the management, prevention, and care of Sickle Cell Disease in Nigeria. However, due to the limited availability of some policy documents and the lack of information on the implementation of the Laws in some states, the research team leveraged policy discussion, social media listening, and expert consultations as an avenue to attain an understanding of the contents of the laws that were not publicly available.

Photo Credit: The New York Times. Family in Kano who lost 3 children to SCD in Nigeria

Background

Sickle Cell Disease (SCD) is an inherited blood disorder that is said to mainly affect people of African descent, earning it the reference "the black man's disease."[1]. The disorder is identified by the body's production of abnormal haemoglobin, which causes the red blood cells to take on a sickle shape, leading to a host of medical complications such as anaemia, pain, and organ damage. If not properly managed or controlled, it can result in mortality. Globally, the disorder presents a critical distress point for global public health, as the World Health Organisation (WHO) estimated that more than 300,000[2] children are born annually with a severe form of the disease. Most of such births occur in low- and middle-income countries, with the highest burden in Africa, with Nigeria as the epicentre.

In Nigeria, about four to six million people are carriers of SCD, listing the disorder among the top ten priority Non-Communicable Diseases (NCDs) in the country and significantly contributing to both child and adult morbidity and mortality rates[3]. Despite the severity of the disease, some interventions have been developed by the government to enable the reduction of the burden on the country and the healthcare system. For example, the Federal Ministry of Health (FMoH) has:

Nguvu Changeleaders with the Department of Non-Communicable Disease, Federal Ministry of Health Abuja

- Developed a National Desk Guide and Standard Operating Procedures (SOPs) to provide step-by-step instruction for healthcare workers to perform newborn and infant screening for SCD and also to ensure quality outcomes for Universal Newborn and Infant Screening Programme for SCD in Nigeria;

1 Black People and Sickle Cell Anaemia
2 Over 300 000 babies with severe haemoglobin disorders are born each year.
3 Nigerian 'sickle cell warriors' face new foe: climate change

- Established (6) centres of excellence for the control and management of SCD across Nigeria, one in each geo-political zone with each equipped with HPLC and other complementary equipment and staff to serve as a hub for newborn screening[4].

The success of these interventions is still a matter of debate, particularly as individuals affected by SCD still exhibit a lower life expectancy when compared to the general population in the country. In Nigeria, the average life expectancy for individuals with SCD is estimated to be around 21 years,[5] which is significantly lower than the national average of approximately 54 years for the general population. However, on a global scale, the median life expectancy for individuals with SCD is around 52.6 years.[6] In contrast, the national average life expectancy for the general population is 73.5 years, with the United States of America serving as a reference point.

Premarital Genotype Screening For Prevention of SCD

To combat the rising number of Sickle Cell Disease (SCD) cases, the global health community is placing greater emphasis on the implementation of preventive measures. This includes advocating for voluntary pre-marital screening tests that incorporate genotype testing and counselling for prospective couples. There is a need for greater education and sensitisation of sickle cell disease and pre-marital genotype screening in Nigeria, and several organisations including the Coalition of Sickle Cell NGOs, Samira Sanusi Sickle Cell Foundation, Okares Sickle Cell Foundation, and the Sickle Cell Aid Foundation have been actively involved in raising awareness and educating the public about all aspects of SCD through various channels, including campaigns, town hall meetings, and social media outreach efforts.

Religious bodies and traditional leaders (chieftains) equally play a very vital role in these efforts. Recognising the influential sway they have within various communities, faith-based organisations are becoming more and more supportive of their members undergoing genotype testing before marriage. They extend post-test support and counselling, enabling people to cope with the emotional and social impacts of the test results and decisions made. This involvement of religious institutions and traditional leaders is pivotal in normalising genotype screening within society and ensuring that the practice is embraced across different demographic groups.

A laboratory scientist screening women and a child during a voluntary genotype testing- Photo Credit: Samira Sanusi Sickle Cell Foundation

At the sub-national level, a few states within Nigeria have even taken proactive steps in this regard with policy formulations that guarantee that genotype screening tests are run even before marriages, institutionalising such practices, and making the exercise mandatory as a convention during premarital stages. Although attitudes towards screening are positive, genotype screening can be a bit tricky. There's significance and importance in raising awareness and informing the general populace about genotype screening. It remains a fact that a considerable number of people have little knowledge about SCD or the role of genotype screening in reducing its transmission.

Hence, it calls for concerted efforts from governmental agencies, NGOs, health care providers, faith-based organisations, and religious and community leaders to provide proper information and ensure full public participation in pre-marital screening programs.

4 Sickle2024 World Sickle-Cell Day; FG institutes policies and several strategic interventions to address the challenges of the disease.
5 Autopsy findings and pattern of mortality in Nigeria sickle cell disease patients
6 Quantifying the Life Expectancy Gap for People Living with Sickle Cell Disease

Photo credit: The New York Times 2021: Sadiya Haruna, a SCD patient from Kano State, Nigeria

Comparative Analysis of the Enacted Laws in Nigerian States on Premarital Genotype Screening

Global Trends

Globally, premarital genotype screening for sickle cell traits before marriage and reproducing has proven to be an effective preventive measure for reducing the burden of SCD on public health systems and families. There has been a significant decline in the number of newborns with SCD, as evidenced by countries like Saudi Arabia and Cyprus, which achieved this through the mandated or strong encouragement of premarital screening, which included genotype testing. In Saudi Arabia, the government instituted mandatory premarital screening in 2004, and in more than a decade, at-risk marriages have decreased by 60%, while SCD births have decreased by nearly 90%[7]. Likewise, in Cyprus, a national screening program was instituted in the 1970s, and today, the rate of incidence of SCD is close to zero from the previous 1 in 158 births. The high levels of knowledge and awareness of SCD and its effects have contributed to the success of these strategies. It has enabled people to make proper decisions about marriage and childbirth, thus reducing pressure on the public health system and the family system as a whole.

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7 Premarital Screening and Genetic Counseling Program, Sickle Cell Anaemia, and Thalassemia in Saudi Arabia

State Laws

Four states in Nigeria - Kano, Kaduna, Anambra and Abia - have passed Laws on premarital screening for intending couples. This shows growing attempts at actualising premarital screening at the subnational level. Among the four state laws, the Kaduna and Kano laws focus on premarital screening, which is recognised as a public health measure to reduce the prevalence of a range of diseases like HIV, HPV, Hepatitis B, and sickle cell. The other two laws in Abia and Anambra states focus specifically on genotype screening to curb the widespread SCD within the states.

Overview of the Existing Laws in Nigeria

The following section will involve an examination of the legislations of four Nigerian states, with a focus on the provisions, restrictions, and penalties, the challenges encountered, and the extent to which it has been adopted within the individual states.

1. Kaduna State Premarital Medical Examination Law, 2017

The Kaduna State Premarital Medical Law 2017 mandates premarital screening and other medical tests covering HIV, Hepatitis B, and genotype screening before marriage. While voluntary testing has been practised in the state, this law has made these screenings a compulsory requirement for couples intending to marry in the state. The overall purpose of this Law is to promote informed health decisions and reduce the spread of infectious diseases and genetic disorders.

Restrictions & Penalties outlined within the Kaduna State Premarital Examination Law

- No person is to formalise any marriage contract without a medical certificate issued by a medical doctor
- A fine of ₦ 100,000 or six months jail time or both to couples who do not comply.
- Any health worker or health facility who issues false results is liable to ₦ 200,000 for imprisonment of not less than a year

Key Provisions within the Kaduna State Premarital Examination Law

- Any person who intends to marry shall submit a genotype in a sample of blood.
- Medical test examination shall be conducted twice: three months before marriage and two weeks before the marriage.
- The examination shall be conducted by both parties.
- The medical examination shall be done in an approved health facility.
- The results of the medical tests will be explained to the two parties by the medicaldoctor, who must issue them certificates.
- The certificate should be signed by qualified medical doctors with their full names, qualifications, and work.

Role of Key Stakeholders defined in the law

- State health agencies are to monitor and ensure compliance with the law
- Village heads and wards shall enforce the compliance

2. Anambra State Sickle Cell Disease Control and Eradication Law, 2019

Anambra State Sickle Cell Disease Control and Eradication Law, 2019 is a preventive measure by the state to help reduce the incidence of Sickle Cell Disease within the state by curtailing marriages between persons with incompatible genotypes. The principal purpose of the law, in essence, is to help control and, over the years, reduce the incidence of SCD in the state. The legislation ensures, through genotype testing before marriage, the reduction of neglect and prevalence of the disease—all in a bid to reduce marriages that could make a transfer of the condition.

Restrictions & Penalties outlined within Anambra Sickle Cell Disease Control and Eradication Law

- Any person who contravenes the provisions of this section shall be guilty of an offence and is liable on conviction to the fine of ₦ 500,000 or imprisonment to a term of 5 (five) years or both.
- There cannot be a marriage of persons with unqualified SCS certificates within the State. The law defined what an unqualified SCS certificate means as opposed to a qualified SCS certificate. (Qualified - AA & AA, AA & AS, AA & SS - Unqualified- AS & AS, SS & SS, SS & AS.)

Key Provisions within the Anambra Sickle Cell Disease Control and Eradication Law

- As of the commencement of this law, persons with verification of unqualified Sickle Cell Status Certificate shall not be married as husband and wife.
- No parent, guardian, person or group of persons shall give out a woman in marriage without verification of a qualified SCS certificate of the couple.
- No religious body or registry shall wed any person(s) without verification of a qualified SCS certificate of the couple.
- The sickle cell status certificate shall be issued by a qualified and licensed medical laboratory scientist.
- Verification shall be done by parents/guardians, person or group of persons, religious body or registry within the State
- The sickle cell status certificate shall be issued by a qualified and licensed medical laboratory scientist.

3. Abia State Blood Group and Genotype Law: Abia State Law of No. 5, 2018

The Abia State law was passed in 2018 as a way of reducing the incidence of Sickle Cell Disease by mandating that citizens conduct a sickle cell test and insert their blood group and genotype on their identity cards, as well as ensuring they must know their genotype before marriage including the widespread awareness and informed decision-making, particularly concerning marriage and family planning[8]. In 2023, the Abia State Ministry of Health announced a mass genotype screening for all residents within the state in line with the provisions of the law.[9]

Key Provisions within the Abia State Blood Group and Genotype Law, 2018

- No institution or registry of the State shall perform any marriage ceremony for couples without ascertaining their genotype compatibility or blood group.

8 It is important to know that they state has now conducted a mass blood group and genotype testing on all residents of the state
9 https://dailypost.ng/2023/05/07/abia-govt-to-conduct-mass-blood-group-genotype-tests-on-residents/

4. Kano State Pre-Marital Health Screening Law:

In Kano State, mandatory testing was passed in May 2024 for HIV/AIDS, Hepatitis B, genotype testing, and other relevant examinations before marriage. It also prohibits any discrimination or stigmatisation against individuals living with HIV/AIDS, sickle cell anaemia, hepatitis, and related conditions. The Kano Law has not been gazetted and therefore is not available in the public domain when this report was published, but the available provisions were gleaned from news articles examining the details of the law.

Restrictions & Penalties outlined within the Kano State Pre_marital Health Screening Law

- Any individual found in violation of its provisions commits an offence and, upon conviction, may face a fine of up to ₦ 500,000 or a minimum of five years imprisonment, or both.
- Prohibits any discrimination or stigmatisation against individuals living with HIV/AIDS, sickle cell anaemia, hepatitis, and related conditions.

Key Provisions within the Kano State Pre-marital Health Screening Laws

- Any individual intending to marry must undergo testing for HIV, Hepatitis B and C, genotype, and any other relevant tests before marriage.
- No formalisation of any marriage contract for individuals planning to marry without presenting a test certificate from a government-approved health facility.

The primary objective of premarital genotype screening is for individuals to understand their genetic compatibility with potential partners, further reducing the risk of having children with SCD. This screening aims to empower couples to make informed choices and contribute to public health by potentially reducing the long-term healthcare burden associated with managing SCD. Against this backdrop, four states (Kano, Kaduna, Anambra, and Abia) enacted laws on premarital health, including premarital genotype testing, since 2017. Religious bodies have also adopted this screening requirement for marriage solemnisation.

Common Themes Across the Enacted Policy Frameworks

The premarital screening laws focus on preventing genetic disorders like Sickle Cell Disease and curbing the spread of infectious diseases such as HIV/AIDS and hepatitis. They promote informed marital decisions, public health awareness, and reduce stigmatisation of those with chronic conditions, ultimately aiming to enhance public health through early detection, awareness, and prevention.

However, several challenges persist across the states of Kano, Kaduna, Abia, and Anambra in terms of awareness and implementation of the Laws for Sickle Cell Prevention and Control. The comparative analysis highlights these ongoing challenges with the laws, providing valuable insights into the areas where improvements are needed to enhance the effectiveness of these regulations.

- **Inconsistent Implementation**: In the states where the laws have been enacted, stakeholders have demonstrated varying degrees of implementation. Despite the existence of these policies, the actual enforcement and execution of the laws remain inconsistent across these regions.
- **Public Awareness:** There exists a significant variation in awareness regarding state laws related to premarital screening across different regions. For example, in Kaduna State, respondents displayed a notable lack of awareness about the mandatory premarital screening law. This indicates a potential gap in the dissemination and implementation of the legislation within the state, while in

Anambra State, there is considerable awareness of the state law on genotype screening, attributed to ongoing advocacy efforts by the SCD community (including NGOs). This continuous engagement has effectively kept the public informed about the legislation.

- **Lack of a Standardised Framework:** The absence of a standardised legal framework has led to differing approaches and varying levels of enforcement across the states where this law has been enacted. There is a need for a unified framework that can be utilised across different states while still containing the contextual nuances of that state.
- **Accessibility and Cost:** The accessibility of genotype screening services is a major concern, especially in remote areas where access to healthcare resources is limited.
- One argument is that not all health centres are equipped to conduct the HB electrophoresis test, and the need for a confirmation test further adds to the expense, potentially leading to lower uptake of screening services. While there are six dedicated centres for managing sickle cell diseases (SCDs), concerns have been raised regarding the geographical accessibility, capacity of staff, and overall operational effectiveness of these centres. This also affects the implementation of the laws in some of the states.

Comparative Analysis Summary

While these enacted laws have in one way or another created some elbow room towards solving the sickle cell burden in their various states, gaps still exist in ensuring that a comprehensive and inclusive law is formulated for the people living with sickle cell. Below are some of the gaps that have been identified:

- Most of these laws have focused on pre-marital screening and associated processes, while there are still gaps with regard to patient care for those already with the trait or living with the disease. Though care for those living with SCD is covered in the proposed national bill, this cannot be said of the state laws, which is non-inclusive.
- There's a need to classify the genetic disorders within the law, as it only states one form of sickle cell disorder: haemoglobin SS. It does not mention other SCD carrier traits equally prevalent in Nigeria (e.g., AC, SC, etc.).
- Mandatory tests implemented in some states have also raised ethical questions regarding the laws, their enforcement, and infringements on human rights. Some of the participants reacted with ethical questions that bordered on privacy, potential discrimination, and the likelihood that an individual would suffer from social stigmatisation based on the outcome of the screenings.
- There is no provision for the development of support systems for SCD patients to help build a sense of belonging and be able to connect with people on a much deeper level.
- Some laws mandate the production or provision of an SCS certificate, verifiable by the accredited institutions; however, those pose further questions for forgery or falsification of their results, if production is stunted, undermining trust in the system.

Landscape Assessment of Sickle Cell Disease in Nigeria

This section explores the attitude of society, cultural beliefs, and public awareness about SCD in Nigeria, informed by interviews with key stakeholders. From the analysis of these factors, we aim to identify the gaps and misconceptions riddling the management, prevention, and control of SCD. These insights guide and inform more effective strategies for education, advocacy, and policy decisions to help stem the rising incidence of SCD within the country.

Perception, Awareness and Knowledge about SCD

In Nigeria, awareness about SCD varies significantly across socio-economic classes. Urban areas generally have higher awareness due to accessibility to information sources (e.g. hospitals, campaigns, access to the internet, and other relevant information sources). In contrast, rural areas often rely on secondary sources of information (e.g. community leaders and religious figures). However, the information transmitted through these secondary channels may be diluted or simplified, leading to a less comprehensive understanding of SCD. Overall, knowledge about SCD remains limited across both urban and rural areas in Nigeria.

"We have muted awareness among the literate about Sickle Cell Disease and premarital genotype screening."- Public Health Specialist, Female, FCT Abuja

The current advocacy efforts by public health institutions do not sufficiently highlight the severity and risks associated with Sickle Cell Diseases (SCDs) and the importance of pre-marital genotype screening. This could be due to a lack of understanding about the impact of SCDs on their lives and that of their unborn child. As a result, couples intending to marry may greatly underestimate the potential consequences of their genetic compatibility and rely on their ability to handle any challenges that may arise.

Onor and volunteers from Okares Sickle Cell Foundation during a sickle cell advocacy outreach

"People always want to gamble. People gamble with their own lives. So why do you think they will not gamble with a child they have not yet brought forth?" - Church Marriage Counsellor, Female, FCT Abuja

Many individuals, regardless of their educational background, have misconceptions about Sickle Cell Disease (SCD). Carriers of the sickle cell strain believe they can effectively manage the challenges of raising a child with SCD, while others think careful planning will prevent having children with the disorder altogether. These misconceptions often lead couples to make significant decisions without a full understanding of the long-term consequences.

Managing the care of a child with HbSS (Homozygous Sickle Cell Disease) often called Sickle Cell Anaemia, a genetic condition where a child inherits sickle cell genetic strains, from both parents. This causes their red blood cells to become stiff and sickle-shaped instead of being round and flexible. Children with SCD are usually sufferers of chronic pain, sickle crises, anaemia, increased infection risks, organ damage, etc., which can severely impact their mental and physical well-being and can cause profound emotional and financial challenges for their caregivers and/or parents.

Without a comprehensive understanding of SCD, these decisions can have serious repercussions, further intensifying the difficulties for both the children and their caregivers and affecting their overall quality of life. Institutions view this practice as essential for making well-informed decisions and effectively planning for the future. Despite its importance, there is a prevalent misconception that genotype screening can hinder individuals from reaching important life milestones such as marriage, starting a family, or engaging with others.

"Due to a lack of knowledge about Sickle Cell Disease, and an unwillingness to undergo premarital screening, the prevalence of the disease might be on the increase." - Registered Nurse, Female, Kaduna State

Universal Health Care Access and Infrastructure for Sickle Cell Disease Management in Nigeria.

The current health system faces major challenges with budget allocation that further hinder SCD patients from accessing necessary and adequate care. Patients with SCD require continuous and comprehensive care to manage health crises like pain and leg ulcers. This level of care demands specialised doctors, subsidised medications, ongoing support and mental health counselling. However, such resources are largely absent in most states, with Anambra being an exception due to its state health insurance for SCD patients.

A key issue is the lack of adequate facilities and equipment for the identification and management of SCD, which fails to meet the growing demand. For example, many health facilities lack advanced screening technology for early SCD detection at birth, leading to delayed treatment and an increased risk of frequent crises and potential mortality. **The six existing SCD centres are not widely known among stakeholders, and their services are often underutilised.** This situation impedes early identification of the genetic trait and the timely initiation of treatment, exacerbating the challenges faced by patients.

"The healthcare system is not well equipped with the sophistication to manage sickle cell carriers." - Medical Doctor, Male, Anambra State

Most healthcare professionals interviewed recommend not relying solely on initial genotype test results. They advise conducting a confirmatory test at a different facility to ensure accuracy, as incorrect diagnoses can devastate intending couples. The use of a second test is considered an accepted and alternative solution; however, there are concerns about the potential for increased costs and the overall reliability of the HB Electrophoresis test.

"The margin of false negatives of genotype tests is usually as high as 30%, and that in itself is problematic." Medical Doctor, Male, Anambra State

In light of the current economic conditions, the accessibility of social and medical services has presented increasingly formidable challenges for individuals afflicted with sickle cell anaemia (HbSS). For example, the expense incurred for conducting genotype tests in rural areas, such as PHCs and private laboratories, ranges from two thousand naira (₦ 2,000) to three thousand naira (₦ 3,000). Conversely, teaching hospital costs can escalate to as much as sixteen thousand naira (₦16,000) per test. There's also the cost of managing their health, as the cost of medication, transfusions, and other procedures for sickle cell management is excessively high and they often require more advanced and specialised drugs to manage their crises.

The lack of subsidised health plans (i.e. State or National Health insurance) that can help SCD patients to access medication, and consultations and tackle costs contributes to

these challenges which place a heavier burden on both the patients and their caregivers and further strain the healthcare system[10]. Finally, sickle cell patients often struggle to access mental health support due to the scarcity of dedicated services within health facilities. Health-related stigma within healthcare settings where health officers undermine or ignore the severity of sickle cell patients can further hinder their access to care, further highlighted by the lack of appropriate infrastructure[11].

Socio-cultural and Religious influences on Sickle Cell Disease and Pre-marital genotype screening in Nigeria

Nigeria is a multi-cultural and multi-religious country, which has greatly shaped the approach to SCD and pre-marital genotype screening. Culturally, there is an emphasis on the continuity of lineage and societal pressure to marry within one's community or marry more than one wife, which can often overshadow the potential genetic risks associated with SCD. Religiously, many couples consult faith-based leaders for guidance on marriage and rely on their faith for miraculous healing from the disease. This sheds light on a lack of knowledge of SCD as a hereditary disease.

The faith-based leaders who responded to this Study said that individuals often seek guidance from their cultural and/or religious leaders regarding marriage. It is important to recognize that these leaders may not always possess sufficient knowledge about genetic compatibility and genetic conditions such as Sickle Cell Disease to provide comprehensive advice, as these topics are not usually discussed in those spheres. Despite this limitation, the Study reveals that clerics have played a crucial role in promoting pre-marital genotype screening among their followers, empowering them to make well-informed decisions about their future marriages.

"The main reason we encourage them to take this test is they need to make informed decisions before going into marriage and for the best decision for their new home." - Cleric, Male, Kaduna State

Nevertheless, the clerics who responded to the Study said they often encounter challenges when couples with incompatible genotypes still express a strong desire to proceed with their matrimonial plans with the belief that God can change their genotypes.

In certain situations, couples may choose to prioritise their current emotional connection and the time invested in building their relationship over potential genetic compatibility concerns when deciding whether to marry. This decision may stem from their desire to continue nurturing their established bond rather than seeking a genetically compatible partner. In cases like these, these leaders usually consider other factors for marriage (e.g. the couple coming from a good home) and an undertaking absolving the institution from any blowback that comes from taking such decisions. Intending couples may also express their willingness and ability to care for a child with HbSS if they were to have one. In such cases, the cultural or religious leader may proceed with officiating their marriage.

"Many Christians have abused their so-called faith in God. They believe that faith in God is enough to overlook the need to undergo the screening test."- Cleric, Female, FCT Abuja

In some instances, respondents said incompatible couples intending to marry are advised against it by their religious leader due to genetic compatibility concerns. As a result, they may choose to falsify their genotype results, and/ or seek out a different religious leader who is more likely to officiate the

10 Nigerian Sickle cell patients face N1 million a month bill as hospital admissions rises
11 Psychosocial challenges of persons with sickle cell anemia: A narrative review

marriage, potentially with biased or self-centred motivations.

Respondents also highlighted that some couples with sickle cell strain decide to marry, driven by deep love and unwavering commitment, believing their bond can overcome the challenges ahead. However, others marry due to inaccurate test results, unknowingly facing significant risks.

"Some sickle cell carriers choose to marry, believing that their love for each other outweighs the potential risks and challenges they may face." Medical Doctor, Female, Abia State

However, the decision to enter into a marriage or a long-term relationship has significant implications, particularly when it involves bringing a child into the world who may inherit SCD. This can present challenges for both the child and the parents as they struggle to adapt to the new circumstances. It also underscores the lack of awareness and knowledge among carriers of the genetic disorder about sickle cell disease.

Culturally, there's a culture of silence with SCD which can be based on a lack of understanding of the severity of the disorder. This culture of silence has pushed many who have been afflicted or have experienced talk about it to the public or amongst their circles due to the perceived notions around SCD leading to stigmatisation or discrimination.

Policy Implementation and Framework

The respondents are still uncertain about how effective the implementation of the state laws has been, together with the follow-up of compliance. They feel that existing feedback mechanisms may not ensure the needed robustness in adherence.

While the existing state laws do not aim to prevent marriages they provide important information that may influence a person's decisions. They, therefore, attempt to ensure that couples know and are informed of the genetic risks accompanying sickle cell disease before the marriage, hoping that such risks would influence one to go back on their decision to marry the other.
The implementation of the state laws, however, raises several issues. There's an interwoven moral concern—does this law strip them of the freedom to marry, and what does breaking the law imply?

I have concerns about what happens after the test is mandated. Does it stop the couples from getting married? - Cleric, Male, Zaria

For example, some respondents expressed concerns about the legal charges faced by parents who knowingly have a child with sickle cell disease (SCD) with or without undergoing the mandated premarital screening. This raises questions about the moral responsibility towards the child, especially when the parents are imprisoned and the care of the child falls on others. Many respondents believe applying these laws should go together with the proper observance of human rights, specifically the right to marriage and association and the right of the child.

Legal and Ethical Considerations and Implications

The issue of mandating the premarital genotype screening law has raised serious concerns in terms of ethics and legality. There are concerns about a possible violation of basic human rights to marry and find a family, those of the child, and the right to care without discrimination. One of the respondents - a cleric in Kaduna State - who counselled an intending couple, was told that:

"While compulsory screening legislation might seem effective in reducing incidents of Sickle Cell Disease (SCD), it raises concerns about personal freedoms. Couples with the AS genotype may feel pressured into avoiding marriage, despite their right to make informed decisions about the possibility of having children with SCD."- Cleric, Male, Kaduna State.

Also, information about the genotype status of an SCD patient that is made publicly available to other members of society leads to potential discrimination and stigmatisation, through withdrawal of association with SCD patients, either relational or in the workplace.

Mandating laws for genotype screening could impose an equal burden on some other already vulnerable populations, in regions especially where access to healthcare, and genetic counselling, would be diminished. This could result in unequal access and inequity in care, introducing further wrinkles into the ethical landscape. This is confirmed in a report by the World Health Organisation[12] (WHO) that stated public health interventions "including those concerning pre-marital genotype screening may be beneficial, it must, however, be developed, adopted and applied with due caution to avoid infringing on the rights of the target population.

While these legislations are designed to help lessen the enormous burden of SCD, they have also created conversations on the need for complementary measures, such as programs which allow screening voluntarily, public health education, and accessible genetic counselling services, to ensure that the needs of the individuals are met. Indeed, this forms the major point of challenge in the discourse on pre-marital genotype screening both within and outside Nigeria: trying to balance the clarion call for public health intervention and protection of individual rights.

They also highlight the need for a more holistic approach towards control and prevention of Sickle Cell Disease, through a unified, national framework that could potentially address the systemic issues affecting the country.

12 WHO Sickle Package of Interventions for Sickle Cell Disease Management: Strategic Guidance Framework - Module 1

The Sickle Cell Anaemia (Prevention, Control, and Management) Bill, 2022 [National Bill]

In Nigeria, the Sickle Cell Anaemia (Prevention, Control, and Management) Bill, 2022, is a national policy framework aimed at addressing the prevention, control, and management of Sickle Cell Disorder (SCD) along with providing patient care for those already affected by the disease. Initially introduced by Senator Sam Egwu during the 8th Assembly (2015-2019) and later by Senator Ibrahim Yahaya Oloriegbe in the 9th Assembly (2019-2022), the bill successfully passed its third reading in the Senate. However, it did not proceed to a concurrent reading in the House of Assembly. The Bill was designed to establish a legal framework to ensure access to affordable healthcare and insurance and to establish a comprehensive policy on SCD that encompasses primary, secondary, and tertiary prevention strategies.

Following its re-introduction in 2022, key stakeholders called for a review of the bill to revisit its core principles, particularly focusing on the human rights aspect of individuals living with or affected by SCD. This review aimed to avoid duplication of existing efforts and instead concentrate on enhancing current infrastructure, improving access to the Sickle Cell Excellence Centres across the country, and addressing the stigmatisation and discrimination faced by those living with SCD. However, the deliberations on the National Bill went silent.

In 2024, the Bill is currently witnessing a third attempt at being reintroduced by Senator Zam, Titus Tartenger for an Assembly Debate, and this could come as a ray of hope for the Sickle Cell Community in Nigeria.

At the time of this report, the "Sickle Cell Anaemia (Prevention, Control, and Management) Bill, 2024, was docked on the Bill Projection Chart/tracker of the National Assembly and passed its first reading on May 8, 2024, sponsored by Senator Zam, Titus Tartenger.13

Key Provisions within the Sickle Cell Anemia (Prevention, Control, and Management Bill, 2022

- Government to prevent, control and manage SCD - S. 1, 2 and 3 of the Bill.
- The Ministry (of Health) representing the government may accredit public and private hospitals, organizations and bodies (as partners) to prevent, control and manage SCD.
- Receiving donations for the prevention, control and management of SCD, directive on the use of such funds and punishment for misappropriation of such funds- s. 6,7,8,9 & 10.

Restrictions & Penalties outlined within Sickle Cell Anemia (Prevention, Control, and Management Bill, 2022

- The Bill in S.11(3) provides that the Ministry shall NOT, (unless the National Assembly directs it to), assign tasks to its agents without a report/complaint from a certain part of the Federation concerning a peculiar trend of occurrence, SPREAD, or effect of the disease.
- S. 7 provides for restrictions on donations; to test the drugs and verify the literature to ascertain their relevance, and to refuse funds that are ill-gotten or illegally sourced.
- S. 12(2a) of the Bill is restrictive to intending couples of incompatible genotypes when it provides that they should NOT marry.
- S. 12(4) of the Bill provides penalties for erring parents and the child born to their union as explained in number 2 under "Rights

of Individuals involved and Implications"
- The second penalties in the Bill are for the offences of diverting or converting donated or available funds, or funds meant for donations. These offences in prescribing punitive measures of imprisonment OR a fine of N500,000, N800,000 and N1,000,000 is subtly making an offer to commit the offences.
- S.13 provides for withdrawal/cancellation of accreditation of any of the Ministry's agents in the circumstance provided thereunder.
- S. 14 provides for forfeiture of diverted funds etc to the government who will send it back to the Ministry

Key Stakeholders Defined in the Policy Framework
- The Federal Ministry of Health [FMoH]
- Accredited Hospitals and Clinics in all the states
- Accredited Organizations and bodies [e.g. Foreign and Local NGOs and Private Organizations] in all the states.

This is a critical moment for lawmakers to collaborate and establish national policies that reflect best practices and lessons learned from state-level initiatives, leading to improved public health outcomes and informed decision-making for individuals and families nationwide.

Recommendations

Having reviewed the legal framework at the national and subnational levels addressing sickle cell disease in Nigeria, and speaking to key stakeholders in the sickle cell landscape to understand their thoughts on how to combat the disease, we make the following recommendations based on our analysis.

1. Develop Targeted Public Awareness Campaigns: It is imperative to increase awareness and knowledge of SCD and the value of pre-marital genotype screening through targeted campaigns and education. This can be achieved by taking a logical approach to ensuring that all information on SCD is publicly available and accessible. Messaging should be straightforward, human-centric, and available in its simplest form to avoid breeding misconceptions. Leverage existing avenues (i.e. religious & cultural leaders, health talks etc.) for sharing information to get messages to the hard-to-reach areas.

2. Tell Real Life Stories: Many SCD carriers have shown reluctance in telling their story because they fear stigmatisation and discrimination but that could also be the reason why there is mutedness and limited knowledge on SCD in Nigeria. Engaging sickle cell warriors to confidently and without bias share their stories could be beneficial to building awareness and education on the topic

3. Invest in More Research on Sickle Cell Disease: Existing knowledge of SCD, especially in Nigeria, many participants confirmed, was very limited and grossly out of date. The need to carry out more research that documents details of the burden of the disease could be very important and timely. Detailed research would deconstruct the current information at hand, especially on contextual nuances and how they might add to the spread of the disease and provide more clarity on handling and management.

4. Enhance the Capacity of Stakeholders: Stakeholders in this ecosystem need to be equipped with more than enough knowledge to be able to either adequately inform people about SCD or implement the guiding principles to reduce the incidence of SCD.e.g. religious and cultural leaders need to know enough about SCD to be able to counsel their members to take the pre-marital genotype test before marriage and provide support and care for that post-decision, provide anonymity etc.

5. Improved Accessibility: To improve healthcare accessibility, there needs to be a focus on expanding access to affordable genotype screening services, such as the Sickle Cell Rapid Test kit, especially in underserved regions where access to healthcare is limited.

6. Establish Public-Private Partnerships (PPPs): Establishing public-private partnerships and collaborations will be essential in achieving a wider uptake of screening, as they can bring together resources, expertise, and funding to support the implementation of affordable screening services in these underserved areas.

7. Ethical Guidelines: In the discussions surrounding the implementation of a national law that may encroach upon individuals' rights, it is important to consider the development and enforcement of a comprehensive set of ethical guidelines. These guidelines would serve to safeguard individuals from discrimination and uphold the confidentiality of information throughout the screening process.

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